Parenting practices and experiences in families of children with and without autism spectrum disorder, cerebral palsy or Down syndrome: A mixed-methods inquiry

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FACULTY OF PSYCHOLOGY
AND EDUCATIONAL SCIENCES

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A dissertation submitted to Ghent University in partial
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Academic year 2020–2021

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Orthopedagogische reeks Gent, n°64, 2020.

Cover design in cooperation with Julie and Michel Burez. Printing by Mirto Print.

Je bent mooi
niet mooier
je bent anders
mooi

Je bent lief
niet liever
je bent anders
lief

Je bent zacht
niet zachter
je bent anders
zacht

Je bent wijs
niet wijzer
je bent anders
mooi
lief
zacht
weet

'k hou van jou

Herman Van Veen
Anders Anders

Dankwoord

Het schrijven van dit doctoraat is een uitdagend en leerrijk traject geweest. Nu de eindmeet in zicht is, kijk ik terug met grote dankbaarheid. Dankbaarheid voor de kansen die ik gekregen heb, maar vooral voor de warme mensen die me omringd hebben.

Die dankbaarheid start bij de mensen die dit alles mogelijk hebben gemaakt, namelijk de ouders en kinderen die deelgenomen hebben aan dit onderzoek. Zonder jullie was dit onderzoek er simpelweg niet geweest. We hebben veel van jullie gevraagd en jullie hebben ontzettend veel teruggegeven. Bedankt om tijd te maken, om me binnen te laten in jullie thuis, jullie verhaal te delen en om jullie open en kwetsbaar te durven opstellen. Jullie enthousiasme voor het onderzoek, de telefoontjes, de kaartjes tijdens de feestdagen en zoveel meer hebben mij geraakt en verwarmd. Ik hoop oprecht dat dit onderzoek voor jullie een meerwaarde kan betekenen en een erkenning kan zijn voor jullie verhaal en doorzetting. Veel dank aan alle voorzieningen, scholen en beheerders van sociale netwerksites om ons in contact te brengen met deze ouders: Sint-Lievenspoort, Tanderuis, De Kangoeroe, Autisme Centraal, de Vlaamse Vereniging voor Autisme, vzw Victor, vzw Het Raster, vzw Stijn, Dominiek Savio, ’t Spoor, Sint-Gerardus, vzw Windekind, dvc Sint-Jozef, Sint-Gregorius, Ten Dries, Sint-Lodewijk, Downsyndroom Vlaanderen. Dankzij jullie vertrouwen, interesse, en betrokkenheid is dit project tot stand kunnen komen.

Sarah, dankzij jouw promotorschap is dit uitdagende traject kunnen starten. We leerden elkaar kennen toen je volop je onderzoekslijn aan het uitbouwen was en jouw enthousiasme en passie om bij te dragen aan het leven van ouders van kinderen met special needs werkte aanstekelijk. Ook je gedrevenheid om zaken in de diepte uit te werken, je leergierigheid, detailgerichtheid, oog voor nuance en ruim gamma aan theoretische bagage is erg inspirerend geweest doorheen dit traject. Steeds opnieuw bracht je kleur, reliëf en helderheid in de manuscripten van dit doctoraat en ondersteunde je mij om het verhaal scherper en to-the-point te brengen. Ik zie jou als een bruggenbouwer, tussen onderzoek en praktijk, tussen de orthopedagogiek en de ontwikkelingspsychologie, en tussen ‘zwart’ en ‘wit’ door het benadrukken van nuance en complexiteit. Je vertrouwen en steun zorgden er voor dat ik mijn eigen bruggen kon bouwen. Bedankt om naast je professionele, ook een heel persoonlijke, warme en menselijke kant te laten zien.

Bart, ik prijs me gelukkig dat je dit onderzoekstraject van dichtbij mee hebt opgevolgd. Tijdens overleg bracht je steeds duidelijkheid en houvast en gaf je me energie om verder aan de slag te gaan. Jouw wijde expertise, analytische geest en kunde om beslissingen weloverwogen en helder af te wegen, hebben dit project naar een hoger niveau getild. Je fijn gevoel voor humor zorgde voor een luchtige toets tijdens overlegmomenten. Jouw rustige en betrokken houding maakte het ontzettend aangenaam om met jou samen te werken.

Peter, het is mooi om te zien hoe je dit project een warm hart toedraagt en je je optimaal inzet om de afstand tussen onderzoek en praktijk te verkleinen. Dankzij jou hebben we vele ouders van kinderen met cerebrale parese kunnen enthousiasmeren om deel te nemen aan het onderzoek. Jouw heldere en constructieve feedback zette me telkens weer op weg. Waar het kon, greep je ook de kans om positieve ontwikkelingen in het onderzoek te belichten. Die schouderklopjes deden ontzettend deugd.

Petra en Els, ik waardeer jullie betrokkenheid bij dit project en waardevolle feedback tijdens de begeleidingscommissies. Jullie expertise en visie vormden een echte verrijking voor dit doctoraat. Petra, jouw constructieve kritische ingesteldheid lokte erg waardevolle reflecties uit, wat doorschijnt in de discussie van het vijfde hoofdstuk. Je ging steeds mee op zoek naar een heldere vertaalslag van de onderzoeksvragen naar de praktijk. Els, bedankt om jouw enthousiaste praktijkbril binnen te brengen in dit onderzoek en me kansen te bieden om de bevindingen terug te koppelen naar de praktijk.

Hartelijk dank aan de leden van de examencommissie prof. dr. Carlo Schuengel, prof. dr. Ilse Noens, dr. Elien Mabbe, prof. dr. Stijn Vandevelde en voorzitter prof. dr. Reitske Meganck voor jullie interesse en tijd die jullie investeerden om dit werk te lezen en te evalueren.

Aan de fantastische ‘nalees-crew’, starring Sara, Lana, Aline, Anne, Florien, Clara, en Lore, jullie gedetailleerd naleeswerk en vele (virtuele) duwtjes in de rug tijdens de laatste weken hebben voor mij enorm veel betekend.

De vakgroep Orthopedagogiek, een warm en geëngageerd nest, gedragen door betrokken, gedreven en mooie mensen. Het is een plezier geweest om jullie de voorbije jaren mijn collega’s te noemen. Jullie hebben me toegejuicht en uitgedaagd om het beste van mezelf te geven bij zowel onderzoek, onderwijs, dienstverlening als daarbuiten. Ik heb zo ontzettend veel van jullie geleerd! Een grote dankjewel aan: Delphine, Athina, Olivier, Cédric, Marieke, Silke, Elisabeth, de Inge’s, Geert, Matthias, Evelien, Hanne, Gert, Annelore, Anne DG., Yasmine, Claudia, Didier, Jan, Jentel, Femke, Katrien, Lien, en voorbije collega’s Julie, buurvrouw Natalie, Orphée, Marjolein, Tina, Sven, Mieke, de collega’s van ONT en steunpunt Ouders voor Inclusie. Wouter en Stijn, bij de projecten die dit traject voorafgingen was het heel aangenaam en verrijkend om met jullie samen te werken. Stijn, ik heb genoten van de leuke spontane babbeltjes en je humor heeft me vaak aan het lachen gebracht. Ik bewonder je goedhartigheid, zorgzaamheid en doorzetting om ‘ergens een verschil te maken’.

De trofee voor beste meter van het jaar werd vier jaar op rij in de wacht gesleept door Anne. Lieve Anne, ik leerde je kennen als mijn stagementor, nadien als collega en sportcoach, maar vooral als hartverwarmende verbinder en stevige lijm tussen mensen en projecten op de vakgroep. Je bent er eentje uit de duizend en kan als het geen ander mensen motiveren en coachen. Dankjewel, voor je ontelbare duwtjes in de rug (ook na je vertrek op de vakgroep), voor het delen van plezier en je onuitputtelijke interesse in zoveel zaken, op en naast het werk. Je hebt zo ongelofelijk veel betekend voor mij in dit traject.
Ook dank aan je lieve mama voor het vergemakkelijken van het post-gewijs contact met onze noorderburen.

Lieve buurvrouw, Clara, ook al zaten we in het nieuwe gebouw niet meer naast elkaar, we wisten elkaar wel te vinden. Je stond altijd klaar, voor de grote en de kleine dingen. Niets is jou te veel. Je bood steeds een klare kijk op de dingen en gaf duidelijkheid en geruststelling wanneer ik het nodig had. Ik heb enorm veel waardering voor hoe je zo kwalitatief en efficiënt te werk gaat, een geboren onderzoeker lijkt me. En naast die onderzoeker, gewoon een top madam.

Aline, onze opgewekte patrijs, wat straal jij warmte en gezelligheid uit. Jouw oprechte interesse in anderen, gedrevenheid en speelse persoonlijkheid maakte het een plezier om jouw collega te zijn. Je stond steeds paraat om samen de kleine en grote successen te vieren. Ik heb me ongelofelijk geamuseerd om samen met jou en de andere feestcomité-collega’s leuke activiteiten te bedenken. Dankzij jou is de pp10 een nog warmer nest geworden.

Florien, wat heb ik genoten van onze verdiepende gesprekken. Vaak op vrijdagavond (want wat doet een doctoraatsonderzoeker anders op vrijdagavond), maar oh zo ondersteunend. Wat hoop ik dat we deze vrijdagavondgesprekken nog lang zullen verderzetten. Als het gaat om echt luisteren, dan weet jij als geen ander hoe dat gaat. Je bent enorm gedreven in je onderzoeks- en onderwijstaken en dit straalt ook uit naar de mensen rondom jou. Je onderzoek wordt ongetwijfeld een ontzettend waardevol werk voor vele gezinnen en praktijkwerkers.

Lore B., je hebt me zo vaak doen reflecteren door je ontwapenende kijk op de wereld. Merci voor je openheid en (soms komische) eerlijkheid over het leven, daar kan ik nog veel van leren.

Lana, mijn naamgenootje, ik kan me geen betere reiscompagnon voorstellen om Athene mee te verkennen. Wat heb ik genoten van je vrolijke aanwezigheid, je humor, je praktische tante-Kaat-tips en groene vingers (die blijkbaar besmettelijk zijn).

Sara, ik heb veel respect voor alles wat je doet op de vakgroep en hoe je dit alles zo kwalitatief opvolgt. Merci voor je zoete tussendoortjes en om vaak je betrokkenheid te uiten door te vragen: 'En hoe ist nog?'

Lore VD., van de GI tot GLM, je bracht me je passie voor onderzoek bij. Ik kijk nog steeds met bewondering terug op je doorzetting en wilskracht om je te smijten voor de dingen die je belangrijk vindt. Ik wens je het allerbeste toe in je nieuwe stekje.

Chris, bij jou heb ik het gevoel dat we over alles kunnen praten en lachen, en dat de tijd dan ook veel te snel vooruit gaat. Jouw reflectieve en praktijkgerichte blik heeft het zesde hoofdstuk ongetwijfeld meer diepgang gegeven.

Didier, jouw vele gedichten, foto's, en tekeningen de afgelopen jaren brachten telkens weer een glimlach op mijn gezicht en zorgden voor een warm gevoel vanbinnen.

Julie Schamp, ik weet nog dat ik in het begin van mijn traject ongelofelijk onder de indruk was van een Engelstalig praatje dat je hield op een congres in Brussel, en dat de moed me in de schoenen zonk toen ik er aan dacht dat het ooit mijn beurt zou zijn. Je verzekerde me dat dat tijd nodig heeft en dat je daarin groeit. Dankjewel voor je vertrouwen en lieve aanpak.

Gert, Annelore, Florien, jullie waren fantastische metgezellen om Berlijn mee te ontdekken. Jullie zorgden voor een onvergetelijke studiereis. Gert, van karaoke met de studenten tot salsa les en lange wandelingen in Potsdam, het was een plezier om je beter te leren kennen.

Deborah, I wonder whether I should still address you in English, because with your work ethic you probably already get the hang off our Dutch language. Thank you for the pleasant chats, your refreshing and funny look on 'the Belgian' culture – but most of all – your engaging and warm personality.

David, thank you for the wonderful moments we shared, from the flea market to the 'resto', for your inspiring view on the world, your support when starting this project, and your *" 't goa ol goe komn"*-mentality. Your beautiful giraffe artwork found a nice place in our new – and your old – hometown Gentbrugge. Our door will always be open for you.

Aan alle masterproefstudenten die betrokken waren bij dit project, ook al waren jullie met velen, het was een plezier om jullie doorheen jullie masterproef en ruimere reflecties te gidsen. Bedankt om uitdagende vragen te stellen en betekenis en kleur te geven aan complexe onderzoeksvragen. Ik wens jullie het allerbeste toe, zowel binnen de wereld van de orthopedagogiek als daarbuiten.

Marijke, met jouw lange praktijkervaring bracht je de complexiteit van de dagelijkse praktijk binnen in dit onderzoek. Ik hecht veel waarde aan je diepgaande reflecties en je on-ontspoorbare blik op de personen om wie het echt gaat: de kinderen.

Mijn waardering gaat ook uit naar de collega's van de vakgroep ontwikkelingspsychologie. Het was ontzettend boeiend om bruggen met jullie te slaan en elkaars onderzoek te verrijken. Lisa, ik had het geluk om mijn eerste stappen in de dataverzameling te zetten met jou aan mijn zijde. Jouw doctoraatstraject zette de weg uit en gaf me houvast. Jouw heldere communicatie, planmatige aanpak en gedrevenheid maakten het leuk om met jou samen te werken. Je gaf jouw onderzoekskriebels door.

Jolene, dankzij jou leerde ik de wondere (maar best wel uitdagende) wereld van Mplus kennen. Je zette me steeds op weg wanneer ik dreigde vast te lopen. Geen enkele moeilijkheid was onoverkomelijk en je bleef steeds rustig, positief en vol vertrouwen in het onderzoek. Ook naast je ruime waaier aan academische kennis en kunde, heb ik bewondering voor jouw moed, zin voor avontuur en hoe je je rijke gezinsleven combineert met een gevuld takenpakket. Hopelijk kruisen onze wegen in de nabije toekomst in Noorwegen of België.

Aan de andere pp07-collega's, Joachim (wat een top idee was CaviR), Gert-jan, de Nele's, Charlotte, Branko en Michiel, jullie zorgden voor fijn gezelschap tijdens intellectueel uitdagende (zoals presentaties) en – iets minder intellectueel uitdagende – congresmomenten (zoals genieten van Partie Party) in Athene, Egmond aan Zee en onze lieflijke thuisstad Gent. Wim, bedankt voor je statistische ondersteuning bij het vierde hoofdstuk.

Dominiek, dankzij jou bleef ik elke woensdagavond met mijn beide voeten in de praktijk staan. En wat heb ik de voorbije jaren veel van je geleerd, onder andere, wat het echt betekent om te luisteren, om te werken 'op het tempo van' en het ongelofelijke belang van een goeie knuffel (zeker in deze corona tijden). Je bent een netwerker als geen ander, je gaat volop voor je dromen en je loopt over van de goeie ideeën. Er zouden wel wat meer Dominieken mogen rond lopen op deze wereld. Evelien, Elien, Laure, en Kimberly merci voor de mooie momenten, van de netwerkvergaderingen tot in het 'brobbelbad', jullie waren/zijn topcollega's.

Aan ouders, 'plus' ouders en schoonfamilie, dankjewel om van veraf of dichtbij betrokken te zijn. Jullie zorgden voor gezelligheid, een gevoel van rust en thuis komen. Mama en papa, als ik het zo bekijk, lijkt dit traject een combinatie van jullie beiden. Het sociaal geëngageerde van de sociaal werker en het creatief onderwijzende van de leerkracht plastische opvoeding. Ik waardeer jullie onvoorwaardelijke steun, fierheid en emotionele schouderklopjes enorm. Mama, je hebt ongetwijfeld een grote impact gehad op mijn keuze om de orthopedagogische weg in te slaag. Je passie voor je werk, jouw verhalen aan de keukentafel en de inspirerende geest van Eric Broekaert heb ik van kleins af aan meegekregen. Je bleef steeds in me geloven en gaf me vertrouwen dat het goed ging komen. Papa, je unieke kijk op de wereld en verwondering naar de mooie dingen in het leven zijn inspirerend. Ik heb genoten van onze uitwaaimomentjes aan zee. Marc en Chris, twee trouwe supporters. Bedankt voor jullie care packages, in de vorm van eten aan huis of gezelligheid rond de keukentafel. Geertrui en Michel, jullie zorgden er voor dat Evergem de voorbije jaren ook als een thuis aanvoelde voor mij. Jullie zijn twee fantastische schoonouders, steeds met een luisterend oor en warme schouder klaar. Julie, doorheen dit traject zag ik jou en Tom een fantastisch kindje opvoeden. En als er iemand daarvoor geboren lijkt te zijn, dan ben jij het wel. Bedankt voor jouw oprechte interesse en om jouw creativiteit samen met je papa te delen op de cover van dit boek.

Jarne, dat we als tweeling tot ons 18 jaar samen in de klas zouden zitten, vind ik al indrukwekkend, maar dat we allebei voor een doctoraatstraject gingen, had ik nooit gedacht. Ik bewonder je doorzettingsvermogen en gedrevenheid in je werk, maar ook naast je knappe kopje, ben ik ontzettend fier op wie je bent. Bedankt lieve broer, voor je zachte betrokkenheid en me het gevoel te geven dat ik steeds op je kan rekenen. Twinzies for life! Elien, wat ben ik blij dat ik je mijn schoonzus mag noemen. Het is zo mooi om je inzet voor je job te zien, waarbij je op een empathische manier oog hebt voor de sterktes en uitdagingen bij elk kind in je klas. Jouw inspirerende houding heeft me ongetwijfeld gestimuleerd om verder te reflecteren over de bevindingen in dit werk.

Merci lieve nichten, neven, tantes en nonkels voor de gezelligheid en fijne familiemomenten. Een speciale dankjewel aan de ‘wenduinebuddies’ voor de ontelbare mooie momenten. Meme, de warme sfeer die je creëerde in Serskamp heeft vertrouwen gegeven dat ik dit kon. Lieve grootouders, ongelofelijk bedankt voor alles wat jullie deden, wat mis ik jullie.

Merci lieve vrienden van de oudejaargroep om voor heerlijke verstrooiing te zorgen met verkleedfeestjes, cafébezoekjes, een boek- en wijn club (maar vooral wijn) en zoveel meer. Een extra dankjewel aan Simon, voor de steun en zorgzaamheid in de aanloop naar dit traject, aan Jan-de-man-die-alles-kan-Frederik, voor je oprechte interesse en betrokkenheid, en aan Lorrie, voor je ongeziene lindy hop moves en zo veel meer.

Lieve Maren, van tennissen, koken, dansen tot de academische wereld, je blijft steeds naast me staan en ik kan bij jou met alles terecht. Ik heb zo ontzettend genoten van de talloze mooie momenten die we de afgelopen jaren beleefden en ik ben er van overtuigd dat er nog vele komen.

Liesbeth, merci om samen de mooie momenten te vieren. Dankjewel voor je luisterend oor, de wandelingen, de attente geschenkjes, maar vooral voor de mooie persoon die je bent. Wat mis ik je Liesbeth-knuffels.

Sofie, mijn metgezel in de ‘ups and downs' van de academische wereld. Merci voor je grote interesse en inspirerende manuscripten, waaruit ik graag een stukje citeer: ‘Gigi forever!’ (Boterberg, 2020).
Lieve Liselot, bij jou voelt het steeds vertrouwd aan. Zowel de vele lachmomenten, maar ook de kwetsbare momenten mogen er zijn. Op jou kan ik steeds rekenen. Barbara, Paul, Krystle en Nils, van kampeermomenten in de bossen tot creatieve quarantaine-quizzen, ik prijs me erg gelukkig met zo’n topvrienden. Niels en Giselle, Gentbrugge zou maar half zo plezant zijn zonder jullie. Bedankt om te zijn wie jullie zijn, authentiek en integer. Ik hoop oprecht dat we nog heel lang vrienden blijven. ‘De orthootjes’, Steffi, Ellen en Jasmine, mijn maatjes tijdens de opleiding en daarna. Onze afspraakjes gaven me steeds weer voeling met de praktijk en een duwtje in de rug. Laura en Rachida, twee knappe onderzoekers en lieve supporters. Er ligt ongetwijfeld een mooie toekomst op jullie te wachten, welke weg jullie ook inslaan. Merci sportieve schermers, Haeike en Maxime, Robin en Iris, Laurent en Jonathan, voor jullie vriendschap, de gezellige spelletjesnamiddagen en heerlijke bbq-momenten.

Lieve vrienden, wat kijk ik er naar uit om jullie na deze coronaperiode te omhelzen!

Olivier, mijn pateke, wat een geluk heb ik gehad om jou naast mijn zijde te hebben tijdens dit traject. Je kent me beter dan wie ook en liet me zijn wie ik ben. Enthousiast en opgewekt als het goed ging, maar ook de moeilijkere momenten mochten er zijn. Je beschreef het zelf eens als ‘need-supportive boyfriending’, de nagel op de kop. Bij deze een term die we samen kunnen lanceren in de literatuur, zeker onderzoekswaardig. Maar ook naast jouw fijne humor, toonde je steeds vertrouwen, deelde je je positieve ingesteldheid en bood je een luisterend oor. Je laat me zoveel lachen, kortom, genieten van het leven. Bedankt, lieve schat, gewoon om te zijn wie je bent. Wat hou ik er van om elke dag bij jou thuis te komen.

Lana,
december 2020

Prologue

This dissertation aims to increase our understanding of parenting practices and experiences, and children’s psychosocial development across families raising a child with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

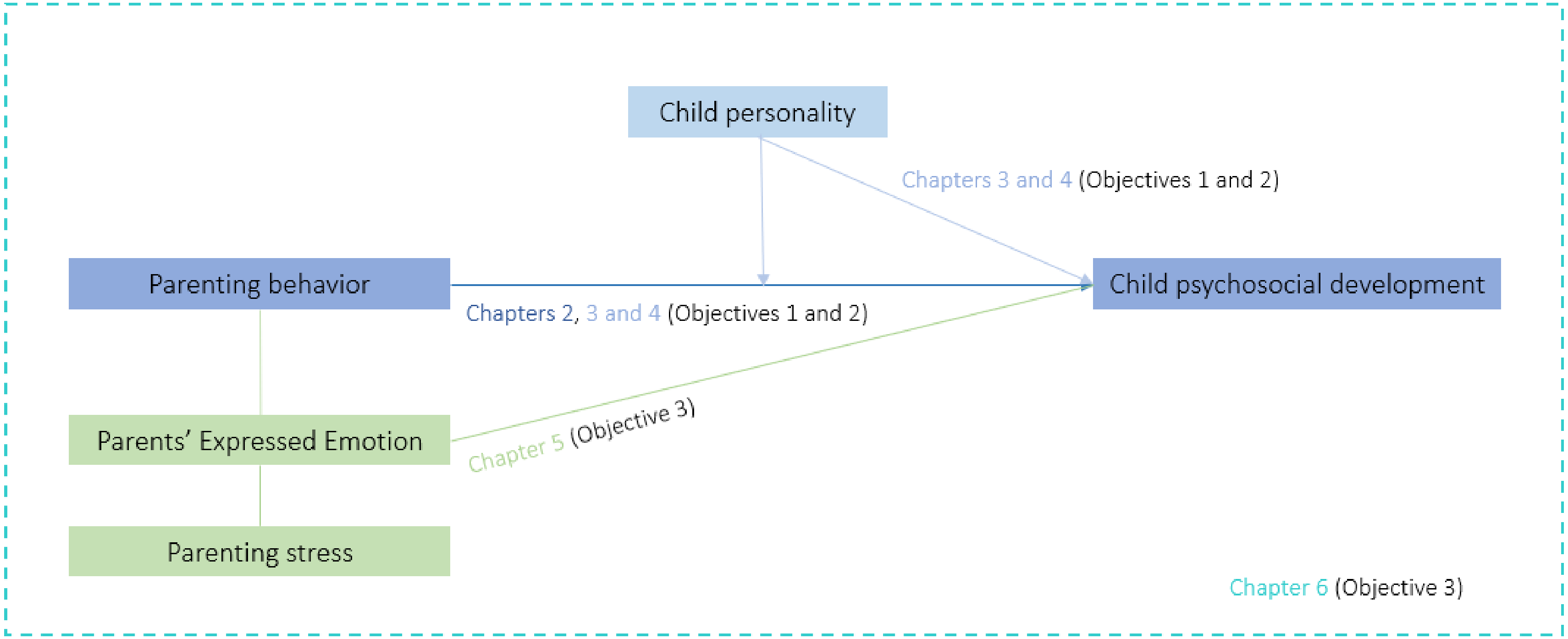
This research encompasses three research objectives, examined in five empirical chapters (see Figure 1).

First, we examine group differences and change in the psychosocial development of children with and without autism spectrum disorder, cerebral palsy, or Down syndrome (Chapters 1, 2, and 3).

Second, we investigate the role of parenting behaviors and child personality as modifiers of this psychosocial development in children with and without autism spectrum disorder, cerebral palsy, or Down syndrome (Chapters 1, 2, and 3).

Third, we explore the emotional climate within these families, while examining parents’ affective well-being, and need-related experiences (Chapters 4 and 5).

Figure 1. Graphical representation of the empirical chapters



Objective 1: To examine group differences and change in the psychosocial development of children with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

Objective 2: To investigate the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

Objective 3: To explore the emotional climate, parents' affective well-being, and parents' need-related experiences among families raising a child with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

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Chapter 1

General introduction

Abstract

This general introduction gives an overview of the literature and empirical studies included in this dissertation, focusing on parenting practices and experiences in families raising a child with and without autism spectrum disorder, cerebral palsy, or Down syndrome. First, we start with describing the state-of-the-art of research on parenting children with a neurodevelopmental disability. Second, we elaborate on the value of a cross-disability design to study parenting practices and experiences across multiple disability groups. Third, we introduce parenting and child personality as important modifiers of the psychosocial development in children with and without autism spectrum disorder, cerebral palsy, or Down syndrome. The conceptualization of parenting and its association with children's psychosocial development is discussed within the overarching theoretical framework of this dissertation: i.e., Self-Determination Theory (Deci & Ryan, 1985; Deci & Ryan, 2000). Child personality-adjustment associations are discussed from the Five-Factor framework of child personality, while also describing the personality-by-parenting interplay. Fourth, we introduce two research avenues that provide possibilities to deepen our understanding of the complex reality of raising a child with a neurodevelopmental disability: the family emotional climate and a multi-group qualitative approach. Fifth, we describe how the research themes outlined in this introduction relate to the context of this dissertation, by setting out the three main research objectives and the methodological designs of the five empirical chapters included in this work. Finally, we reflect from an orthopedagogical point of view on the research process and the objectives of this dissertation.

1.1 Parenting and the development of children with a neurodevelopmental disability

> *Each day, more than three-quarters of a million adults around the world experience the rewards*
> *and challenges, as well as the joys and heartaches, of becoming parents.*
> *The human race succeeds because of parenting. From the start, parenting is a '24/7' job.*
> *Parenting formally begins during pregnancy and continues throughout the life-span:*
> *Practically speaking for most, once a parent, always a parent.*
> *—Marc H. Bornstein*

In the field of psychology, education, sociology, and philosophy, parenting is considered as one of the most vital factors in a child's development (Bornstein, 2015; Hoghughi & Long, 2004). For each parent, raising a child can be considered an emotionally powerful and complex undertaking, bringing new opportunities, challenges, and responsibilities (Bornstein, 2015; Heward, 2013; Nelson et al., 2014; Nomaguchi & Milkie, 2020). However, when a child is growing up with a social, physical, or intellectual disability, due to *a neurodevelopmental disability* (NDD) (i.e., an impairment in the functioning of the brain that affects a child's behavior, memory, or ability to learn; WHO, 2011) parents face additional challenges in the process of raising their child (Resch et al., 2010; Van Riper, 2007). Next to more generic parenting tasks, these parents face supplementary challenges to provide the needed care for their child and to stimulate their child's development. For instance, parents of children with a NDD are required to make adjustments to their daily life but also need to adjust their expectations towards their own parental role, aspirations, and future life. Also, many of these parents are obliged to organize specialized care, face financial worries, and uncertainties about their child's development and future (De Belie & Van Hove, 2005; Resch et al., 2010).

Contemporary research on family processes among NDD-populations mainly examines how parents adjust to these challenges, and more specifically how raising a child with a NDD impacts parents' well-being and psychological functioning (e.g., Abbeduto et al., 2004; Hayes & Watson, 2013; Singer & Floyd, 2006; Valicenti-McDermott et al., 2015). From a more critical point of view, it can be noted that the majority of this research focuses on capturing the increased levels of 'stress' and 'burden' of these families (Deater-Deckard, 1998; Hayes & Watson, 2013). Next to what parents *feel* (i.e., parenting stress), in this dissertation, we focus on what parents *do* in the interaction with their child, namely parenting behaviors and practices. Moreover, we aim to provide a more balanced view, also attending to the many strengths and capabilities of these children and their families.

1.1.1 A prevailing focus on parenting stress among families raising a child with a neurodevelopmental disability

Of the various paradigms in family research that aimed to capture parents' experiences, the most widely investigated topic is that of *parental stress* (e.g., Gupta, 2007; Hayes & Watson, 2013; Valicenti-McDermott et al., 2015; Watson et al., 2011). In its simplest definition, parental stress is described as the experience of distress or discomfort resulting from an imbalance between, on the one hand, demands associated with the parental role and, on the other hand, the availability of resources (both at the psychological or practical level) to address these demands (Deater-Deckard, 1998; Hayes & Watson, 2013). When confronted with an imbalance, parents mobilize coping mechanisms to restore their functioning. However, when parents' coping mechanisms cannot meet the new demands, the outcome might be stress. A vast amount of research among parents of children with a NDD convincingly demonstrates that these parents share an increased vulnerability to experience higher levels of parental stress and lower levels of well-being within diverse life domains (e.g., emotional, physical, social, financial) compared to parents of children with no disability (Abbeduto et al., 2004; Glenn et al., 2009; Gupta, 2007; Hayes & Watson, 2013; Hodapp, 2007; Pousada et al., 2013; Reilly et al., 2012; Rentinck et al., 2007; Singer & Floyd, 2006; Sipal et al., 2010; Valicenti-McDermott et al., 2015; Vargus-Adams, 2011; Yorke et al., 2018). Moreover, this vulnerability is not related to a specific developmental period (e.g., after receiving the diagnosis) but remains present throughout the lifespan of the child, from infancy to adulthood (Cadman et al., 2012; Davis et al., 2010; Reichman et al., 2008).

Additionally, several studies suggest that parenting stress is particularly prevalent among parents raising a child with autism spectrum disorder. These studies demonstrate that parents of children with autism spectrum disorder experience higher levels of parenting stress compared to parents raising a child with no disability, but also compared to parents raising a child with a developmental disability other than autism spectrum disorder (e.g., Gupta, 2007; Hayes & Watson, 2013; Huang et al., 2014; Valicenti-McDermott et al., 2015; Yorke et al., 2018).

1.1.2 Increased attention for research on parenting processes among families raising a child with a neurodevelopmental disability

In contrast to the huge amount of studies that focus on how parents of a child with a NDD *feel*, research on what parents actually *do* in their parenting (i.e., parenting behaviors/strategies/ practices) is much more limited to date. This relative paucity of research is partly related to historical controversial theories on the role of parents in the etiology and course of a NDD, such as autism spectrum disorder. In early accounts of parenting research in autism, researchers such as Leo Kanner (1943) and Bruno Bettelheim (1972) postulated that parents' lack of warmth and/or mechanical approach towards their child plays a causal role in the etiology of autism. This misinformed 'parent-blaming hypothesis' has made big wounds to the autism research community, which significantly forestalled research on parenting and family processes in families raising a child with autism spectrum disorder. To date, however, there is accumulating evidence that family processes and parenting behaviors are important factors to better understand the large variation in prognosis and life outcomes in children with a NDD (e.g., McCauley et al., 2019; Power et al., 2019). Moreover, in recent years, a growing number of studies convincingly illustrate that parenting behaviors are important antecedents or correlates of the development and well-being of children with a NDD (e.g., Dieleman et al., 2020; Lambrechts et al., 2011; Phillips et al., 2017). Aran et al. (2007), for example, demonstrate that parenting behavior relates strongly to the child's psychosocial quality of life, even exceeding the role of the severity of physical limitations.

In this field of research, one of the main questions remains to what extent parenting behaviors differ between parents of children raising a child with a NDD and parents raising a child without any known disability. Overall, multiple group comparison studies suggest that parents of children with a NDD are at risk to more frequently adopt pressuring or dysfunctional parenting strategies compared to parents raising a child with no disability (Heinonen & Ellonen, 2013; Hibbard & Desch, 2007; Myers et al., 2009; Pinquart, 2013; Sikora et al., 2013; Totsika et al., 2014), even though these findings remain subject to debate. For example, several studies demonstrate that parents of children with a NDD rely on more overprotective parenting behavior compared to parents of children without a NDD (Heinonen & Ellonen, 2013; Hibbard & Desch, 2007; Pinquart, 2013; Sikora et al., 2013; Totsika et al., 2014). To interpret this finding, it has been hypothesized that these parents' stimulation of their child's development (e.g., to take on challenges, trying new things) is hampered by feelings of indispensability for their child's support needs and the uncertainty about their child's abilities (e.g., Gau et al., 2008; Gau et al., 2010; Ho et al., 2008; Holmbeck et al., 2002).

Alternatively, however, other scholars suggest that the higher levels of parental involvement or overprotection are simply adaptive responses to the child's abilities and hence should be considered as crucial to accommodate the child's well-being (Hodapp et al., 2019; Power et al., 2019). In that case, supporting the needs of a child with a NDD requires a greater level of parental oversight and involvement than would otherwise be necessary for the child's level of development (Power et al., 2019). Notably, research on this issue is not conclusive. One study found that mothers of children with Down syndrome used less verbal hostility (related to psychological control) and less reasoning/inductive parenting (related to autonomy-supportive parenting) compared to mothers of children without a disability (Phillips et al., 2017). Also, other group comparison studies contradict the hypothesis of clear group differences and found no or minor differences in parenting behaviors between parents of children with and without a disability (Lambrechts et al., 2011; Ventola et al., 2017).

It is important to emphasize that – up till now – conclusions on parenting differences across NDDs are hampered by the use of diverse instruments and theoretical frameworks to assess parenting behaviors across studies. Also, the majority of these studies rely on one group of parents raising a child with a specific NDD compared to parents raising a child without any known disability, with little input from other NDDs. One interesting exception is the study of Blacher and colleagues (2013), examining longitudinal observations of parenting behavior across mothers of young children with autism spectrum disorder (*n* = 12), cerebral palsy (*n* = 9), Down syndrome (*n* = 10), an undifferentiated developmental delay (*n* = 37), and without any known disability (*n* = 115). This study reports that levels of negative parenting are higher in mothers of preschoolers from the disability-groups, yet also retrieves the highest levels of positive parenting behaviors (including aspects of autonomy-supportive and responsive parenting) in mothers raising a child with Down syndrome. Although this study highlights some interesting group differences, the authors also suggest that future research would benefit from considering other modalities, such as questionnaires, across a longer time period, and with larger samples in order to better understand the family context of specific disabilities (Blacher et al., 2013).

This dissertation aims to complement the current parenting literature in NDD-populations by investigating *specific parenting behaviors* in and across multiple NDD-groups, while also including a reference group of children without any known disability. More specifically, this dissertation examines the relation between parenting behaviors and other child (i.e., child psychosocial development, child personality) and parental factors (i.e., parenting stress, Expressed Emotion, need-related experiences), while relying on a validated theoretical framework on parenting (i.e., Self-Determination Theory; Deci & Ryan, 1985; Deci & Ryan, 2000). By doing so, we aim to inform family support and interventions that foster high-quality parent-child relationships.

1.1.3 Rethinking parenting research among families raising a child with a neurodevelopmental disability, adopting a balanced approach

In the past decades, the growing awareness of the shortcomings of the medical-psychiatric discourse (e.g., putting children's and parents' 'inabilities' and 'vulnerability' at focus), the rise of the socio-cultural disability paradigm, and the emergence of positive psychology resulted in a renewed thinking about family research in NDD-populations (De Belie & Van Hove, 2005; Wehmeyer et al., 2017). Within this thinking, disability is not attributed or reduced to the child nor its environment. Instead, disability lies in the interaction, the gap, the mismatch, between personal capacity on the one hand, and the demands of the environment on the other (De Belie & Van Hove, 2005; Wehmeyer et al., 2017). This view does not deny the reality of disability nor its impact on the individual and its family, but it does challenge the physical, attitudinal, communicative, and social environment to accommodate disability as an expected incident of human diversity. Stemming from this perspective, research on parents' adaption, coping, and resilience found its way in the literature, and strengths and capabilities of families and children with disabilities became increasingly emphasized (De Belie & Van Hove, 2005).

These lines of research demonstrate that there exists wide variability in parents' adaptation to raising a child with a NDD, and that most parents cope relatively well in handling daily challenges and hassles (Bayat, 2007; Heward, 2013; Whittingham et al., 2013; Ylvén et al., 2006). The majority of these parents not only cope successfully with the challenges posed by raising a child with a NDD but also experience benefits to the family life (Blacher & Baker, 2007; Nurullah, 2013; Van Riper, 2007). Nurullah (2013), for example, concludes that parents of children with a NDD often describe their experiences as *"a roller coaster",* indicating that raising their child is both challenging yet also rewarding, depending on the circumstances they face during a particular day.

Although this renewed thinking on parenting research encompasses a more positive and nuanced perspective on the reality of raising a child with a NDD, the prevailing research still tends to examine parenting practices and experiences from a one-sided view, either negative or positive. While the large majority of studies still focuses on dysfunctional processes (e.g., controlling parenting behaviors, parental stress, ill-being, and child problem behavior), a minority now starts to focus on 'positive' processes and opportunities among parents' affective functioning (e.g., coping, resilience, and adaption), yet disregarding the challenges of parenting in these families.

Therefore, this dissertation strives towards a more *balanced perspective* on parenting, building upon the idea that children with a NDD and their parents are both vulnerable and resilient (De Belie & Van Hove, 2005). More specifically, the five studies in this dissertation attend towards the variability in the ‘challenging’ (e.g., need-thwarting parenting behaviors and experiences, emotional and behavioral problems in children, parenting stress) as well as the more ‘positive’ (e.g., need-supportive parenting behaviors and experiences, psychosocial strengths in children, positive family climates) aspects of parenting practices and experiences, and children’s psychosocial development. This balanced yet strengths-oriented approach (Peer & Hillman, 2014) aims to provide a fuller understanding of the complex reality of raising a child with a NDD. On the one hand, by increasing our understanding of how negative parenting practices and experiences can be moderated and, on the other hand, by understanding how resilience, well-being, and positive family functioning can be facilitated and strengthened. By doing so, this dissertation also aligns with calls of scholars (e.g., Guyard et al., 2017; Peer & Hillman, 2014; Van Riper, 2007), national (cf., ‘contextgericht- en versterkend werken’ in Dutch; Visiedocument voor de jeugdhulp in 2020, 2012) and international policy guidelines (e.g., World Health Organization), and current multidimensional models of disability (e.g., American Association of Intellectual and Developmental Disabilities-model, International Classification of Functioning, Disability and Health-model) to devote more attention to positive aspects of raising a child with a NDD, and to focus on vulnerabilities as well as strengths in these families.

1.2 Towards a better understanding of parenting practices and experiences among parents raising a child with a neurodevelopmental disability: A cross-disability approach

As noted above, the current empirical research on parenting practices and experiences among parents raising a child with a NDD mostly focuses on one single NDD, with little input from similar research on another NDD. Yet, to understand whether the dynamics of parenting behaviors or parent-child interactions are specific to one disability, or instead generalize across disabilities, we believe it is important to explore these constructs and their relations across multiple NDD-groups (e.g., Laghezza et al., 2010; Lindsay, 2018a; McCauley et al., 2019; Sher-Censor, 2015). Moreover, it has been suggested that a multi-group design can benefit our understanding of parental experiences and processes as a whole (Morse, 2004), while simultaneously highlighting how these processes might vary between groups (Lindsay, 2018b; Ritchie, Lewis, Nicholls, & Ormston, 2003). Hence, contrasting these groups with one another, while also including a reference group without any known disability, provides a unique paradigm to unravel the syndrome-(a)specificity of parenting and child effects.

1.2.1 A cross-disability approach including parents of children with ASD, CP, DS, and without any known disability

This dissertation adopts such a cross-disability approach by evaluating parenting practices and experiences within and across three NDDs: autism spectrum disorder, cerebral palsy, and Down syndrome, while also including a reference group of children without any known disability. The choice of these NDD-groups enables a comparison of children comprising developmental challenges characterized by a delay or disturbance in the acquisition of skills in three main developmental domains, including social-communication, motor functioning, and cognition (APA, 2013). Also, these NDDs comprise three of the most prevalent NDDs among children in Western society (Elsabbagh et al., 2012; Irving et al., 2008; Oskoui et al., 2013).

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental brain disorder caused by a complex multifactorial gene-environment interplay (Mandy & Lai, 2016). The global prevalence of ASD is currently estimated at a median of 62 per 10.000 (0.62%) children, which is characterized by difficulties to socialize, communicate, or relate to others (Elsabbagh et al., 2012). Following the DSM-5 criteria, children can be diagnosed with ASD based on two main criteria: (1) persistent difficulties in social communication and interaction across multiple contexts, and (2) the presence of restricted and repetitive patterns of behavior, interests, or activities (APA, 2013). Of children meeting criteria for ASD, the male-to-female ratio was often assumed to be 4:1 (Elsabbagh et al., 2012), but a more recent meta-analysis estimates the gender ratio closer to 3:1 (Loomes et al., 2017). There appears to be a diagnostic gender bias, meaning that females with ASD are more likely to be missed by current diagnostic criteria (Loomes et al., 2017). Although children with ASD share these two main criteria, they also vary widely in the nature and severity of the symptoms (Masi et al., 2017).

Cerebral palsy (CP) is one of the most common developmental disabilities with an estimated prevalence of 21 per 10.000 (0.21%) live births (Oskoui et al., 2013). Children with CP experience difficulties in movement and posture attributed to neuromuscular non-progressive disturbances in the fetus or infant brain that occurred during the pre-, peri-, or postnatal period (Rosenbaum et al., 2007). This brain lesion has a higher incidence in males than females with a gender ratio of 1.3 to 1.4:1 (Romeo et al., 2016; Rosenbaum et al., 2007; Stanley et al., 2000). Most commonly, CP is classified based on the involved body parts (i.e., monoplegia, diplegia, hemiplegia or hemiparesis, bilateral palsy, or quadriplegia) or the motor type reflecting anomalies in different parts of the brain (i.e., spastic, ataxic, dyskinetic, or mixed type). Due to differences in type, location, and size of the brain lesion, the presentation of CP is very heterogeneous. Therefore, also children with CP can differ a lot in the severity and type of limitations in activity and participation they experience (Rosenbaum et al., 2007).

Down syndrome (DS) is the most commonly identified genetic cause of intellectual disability (Bittles et al., 2006). In 2015, DS occurred in around 23 of 10.000 (0.23%) live births in European countries (Lanzoni et al., 2019). In 95% of the cases, DS finds its etiology in the presence of all or part of the third copy of chromosome 21. Therefore, DS is also referred to as trisomy 21, indicating the presence of 47 chromosomes in each body cell instead of 46 (Sherman, Allen, Bean & Freeman, 2007). For most individuals, DS is characterized by intellectual disability and additional medical and phenotypic characteristics, such as physical growth delays, a flatted nose, and slanted eyes (Bittles et al., 2006; Irving et al., 2008). Among children with DS, the male-to-female ratio is estimated at 1.31:1 (Kovaleva, 2002). Important to mention is that, at the societal level, the arrival and implementation of non-invasive prenatal tests (NIPT) to detect genetic abnormalities, such as trisomy-21, are currently heavily influencing the experiences of parents raising a child with DS (Allyse et al., 2015). Even though this ethical debate will not be touched upon in the empirical chapters of this dissertation, it is important to remark that the NIPT-policy might influence the future prevalence of DS drastically, and therefore also family research and practices.

Within this dissertation, these three groups of NDDs are supplemented with a reference group comprising parents raising a child *without any known disability*. This reference group includes parents who participate in a longitudinal Flemish Study on Temperament and Personality across Childhood (FSTPC; De Pauw, 2010). During each assessment period, these parents indicated that their child never received a clinical diagnosis (e.g., psychiatric diagnosis or NDD diagnosis).

This dissertation is unique in applying this innovative *cross-disability approach* and investigating parenting practices and experiences across multiple child disabilities, while also including a reference group of parents raising a child without any known disability. This approach provides possibilities to illuminate overarching parenting processes that generalize across groups, as well as disability-sensitivities, which are specific for the context of raising a child with ASD, CP, DS, or without any known disability. By increasing our understanding of the overarching (i.e., disability a-specific) and specific (i.e., disability-specific) processes that facilitate and challenge the reality of raising a child with a NDD, we aim to better inform guidelines to support these families.

1.2.2 A challenging psychosocial development: A shared commonality among children with ASD, CP, and DS

To date, the large heterogeneity in the psychosocial development is an eminent feature of children with a NDD (Arim et al., 2015; Hodapp et al., 2019; McCauley et al., 2019; Power et al., 2019). Studies demonstrate that children with ASD, CP, or DS are not only fairly different in disability-specificities (i.e., social-communication in ASD, motor in CP, and cognition in DS) but also in the diversity of their behavioral and emotional development (Brossard-Racine, Waknin, et al., 2012; Hodapp, 2007; Hodapp et al., 2019; McCauley et al., 2019; Vrijmoeth et al., 2012). Nevertheless, studies emphasize a shared commonality since – as a group – these children are at much higher risk (on average, a two to four-fold increase) to *develop behavioral or emotional difficulties* compared to peers without a disability (Arim et al., 2015; Bjorgaas et al., 2012; De Pauw et al., 2011; Dykens, 2007; Dykens et al., 2002; Emerson & Hatton, 2007; Hayes & Watson, 2013; Kanne & Mazurek, 2011; Maljaars et al., 2014; Munir, 2016; van Gameren-Oosterom et al., 2011). Scholars demonstrate that these behavioral and emotional difficulties have a strong impact. They not only hinder children's participation in daily activities, compromising their quality of life (Bjorgaas et al., 2012; Brossard-Racine, Hall, et al., 2012; Parkes et al., 2008; Sigurdardottir et al., 2010; Vrijmoeth et al., 2012), but also strongly impact their caregivers' well-being (Majnemer et al., 2007; Romeo et al., 2010). Longitudinal studies highlight that many of these behavioral and emotional difficulties continue into adolescence and emerging adulthood (e.g., Dykens et al., 2002; Sipal et al., 2010; Taylor & Seltzer, 2010).

Although the variation in the psychosocial development among children with a NDD is widely acknowledged, still many questions linger about the risk and resilience factors underlying this wide heterogeneity. Although a significant part of the children with a NDD develop emotional or behavioral difficulties, many of these children attain qualitative levels of adaptive functioning (e.g., positive relations, vitality, well-being) (Hodapp et al., 2019; McCauley et al., 2019; Tan et al., 2014; Vrijmoeth et al., 2012). To better comprehend this vulnerability or resilience towards emotional or behavioral problems, theorists now advocate that researchers should go beyond the inquiry of 'disability-specific sources' (e.g., nature and degree of symptoms). Instead, they call for research on 'non-syndrome-specific' or 'transdiagnostic' factors that naturally vary among all children (Aran et al., 2007; Chetcuti et al., 2019; McCauley et al., 2019). Especially in the context of ASD-research, this rationale is operationalized in the Modifier Model of Autism (McCauley et al., 2019; Mundy et al., 2007). According to this model, non-syndrome-specific processes (i.e., modifier processes) are important moderators of the course and outcome of ASD, in addition to more syndrome-specific biological etiological processes (i.e., initial causal processes*)*. Also in the context of CP-research, there is growing recognition that developmental outcomes are closely related to children's general psychological characteristics and psychosocial family variables, instead of exclusively being determined by disability-specific characteristics (Cohen et al., 2008; Majnemer & Mazer, 2004). In particular, theorists now have nominated both *parenting behavior* and *child personality* as potential 'non-syndrome-specific' factors that may provide a richer understanding of the psychosocial heterogeneity in NDD-samples, including youth with ASD, CP, or DS (Aran et al., 2007; De Pauw, 2017; McCauley et al., 2019; Mundy et al., 2007).

Hence, this dissertation examines both parenting behaviors and child personality in relation to children's psychosocial outcomes among families raising a child with a NDD. Scholars suggest that further unraveling the marked heterogeneity in these children's psychosocial development is important to provide additional tools to support assessment, research, as well as treatment in families of children with ASD (Burrows et al., 2016; De Pauw et al., 2011; Maljaars et al., 2014; Mundy et al., 2007), CP (Parkes et al., 2008; Vrijmoeth et al., 2012), and DS (Stoneman, 2007).

1.3 Parenting and child personality as modifiers of the psychosocial development in children with and without ASD, CP, or DS

As noted, children with ASD, CP, and DS share a heterogeneous psychosocial development, characterized by an increased risk to develop behavioral or emotional difficulties compared to peers without a disability (e.g., Arim et al., 2015; Hayes & Watson, 2013). To provide a richer understanding of this heterogeneity, both parenting behavior and child personality have now been nominated as valuable modifiers of the psychosocial development in children with ASD, CP, and DS (Aran et al., 2007; De Pauw, 2017; McCauley et al., 2019; Mundy et al., 2007). To conceptualize both parenting and child personality, however, a wide ocean of theories, measures and frameworks exist. To address parenting, this dissertation adopts Self-Determination Theory (SDT; Deci & Ryan, 1985; Deci & Ryan, 2000), a widely validated metatheory on human behavior and motivation, and increasingly applied to parenting, to advance our understanding of parenting-adjustment associations among both neurotypical and NDD-populations (e.g., Soenens et al., 2017). To address child personality and its interplay with parenting, this dissertation builds upon the Five-Factor framework of child personality. First, we elaborate on the vital role of parenting in children's development from an SDT-perspective. Second, we focus on the unique and interactive role of child personality and its interplay with parenting in the psychosocial development of children with NDDs.

1.3.1 The vital role of parenting in children's development

In the past decades, substantial effort has been directed towards unraveling the vital role of parenting in supporting children's social, emotional, and behavioral development (Kiff et al., 2011). Throughout this history of parenting research, there has been growing consensus about the conceptualization and understanding of three key parenting dimensions. This converging evidence is aligned with the shift from a configurational approach (e.g., the parenting styles as described by Baumrind (1967)) to a more dimensional approach to parenting. Whereas a configurational approach attempts to identify particular types or styles of parenting that are defined by certain constellations of parenting characteristics (e.g., a group of parents who are high on warmth, and low on behavioral control and psychological control; a group who are high on warmth and behavioral control, and low on psychological control, etc.), a dimensional approach on parenting attempts to separate various aspects of parenting from one another to better understand their independent relations to child outcomes (Barber et al., 2005; Darling & Steinberg, 1993). Within a dimensional approach, three key dimensions have been described: (1) *parental support* (i.e., parents' expression of their love, affection, and appreciation towards their child, the degree to which they are involved in their child's life, and the extent to which they offer support and care), (2) *behavioral control* (i.e., clear communication and monitoring of rules, but also the use of harsh punishment and hostility), and (3) *psychological control* (i.e., intrusive and manipulative behaviors aiming to dominate the child's thought and feelings by using insidious strategies such as guilt-induction, ignoring, love withdrawal, and shaming) (Barber et al., 2005; Locke & Prinz, 2002; Prinzie et al., 2009; Skinner et al., 2005; Soenens & Vansteenkiste, 2010).

The Self-Determination Theory perspective on parenting

However, regardless of the consensus on these three 'classic' parenting dimensions, there remain some issues concerning the conceptual clarity of the dimensions, especially concerning behavioral and psychological control. To address these conceptual issues, a theory-driven approach originated from the framework of SDT (Deci & Ryan, 1985; Deci & Ryan, 2000). In addition to providing conceptual clarity, the SDT-perspective on parenting applies a balanced point of view on parenting, attending to both the 'bright' (i.e., associations between need-supportive parenting and child adjustment) and 'dark' (i.e., associations between need-thwarting parenting and maladjustment) sides of parenting, while providing clear predictions concerning the impact on children's development (Soenens et al., 2017).

SDT can be described as an ‘organismic-dialectic’ metatheory on human development and motivation (Deci & Ryan, 1985; Deci & Ryan, 2000). ‘Organismic’ relates to SDT’s central tenet that each individual, from birth on, is equipped with three basic psychological needs, that inquire fulfillment to incite personal growth and well-being. These three needs are considered to be innate and universal for all human beings and are identified as *autonomy* (i.e., feeling able to give direction to your actions), *relatedness* (i.e., feeling connected with and loved by others), and *competence* (i.e., feeling competent in what you do) (Deci & Ryan, 2000; Ryan & Deci, 2017). When these needs are satisfied, the development and personal growth of a person is stimulated, providing energy, vitality, and feelings of self-development. Conversely, when these needs are actively thwarted, frustrated, or suppressed, a person’s psychological well-being and growth get forestalled, which is hence associated with an increased risk for maladjustment and diverse unfavorable outcomes (Deci & Ryan, 2000; Veronneau et al., 2005).

‘Dialectic’ relates to the second central tenet of SDT, stating that the interaction with the socialization context is crucial to attaining fulfillment of the three basic psychological needs. A substantial body of work in neurotypical populations convincingly demonstrates that socialization by parenting is a vital factor in child development (Soenens & Vansteenkiste, 2010). In this regard, parenting strategies can be regarded as adequate in supporting the child’s fundamental psychological needs (i.e., need-supportive parenting behavior), or in contracts as less adequate (i.e., need-thwarting parenting behavior) (Soenens & Vansteenkiste, 2010). When a child experiences need-supportive parenting behaviors, the child’s adjustment, feelings of well-being, and psychological growth is promoted. In contrast, need-thwarting behaviors may lead to more adjustment difficulties, such as internalizing or externalizing behaviors of the child (Soenens et al., 2017).

The first dimension of need-supportive parenting is *autonomy-supportive parenting*, which closely relates to ‘parental support’ and opposites ‘psychological control’ from the classic dimensional approach to parenting. Autonomy-supportive parenting involves being empathic towards the child’s frame of reference, attuning to the pace and rhythm of a child’s development, and encouraging initiative, for example by providing choice or stimulating dialogue and participation (Joussemet et al., 2008). When parents act in an autonomy-supportive way, they try to connect with their child's individuality, showing curiosity, openness, and trust towards their child’s opinions and perspectives (Soenens et al., 2017). Autonomy-supportive parents also use inviting language (e.g., “*You can try to …”*) and minimize their use of controlling language (e.g., “*You have to …”*) (Ryan & Deci, 2017; Soenens et al., 2017). Whereas autonomy-supportive parenting enhances children’s volitional functioning, *controlling parenting* refers to intrusive, manipulative, and domineering parenting behavior. These behaviors thwart the need for autonomy and pressure children to think, feel, or act in a way that is not congruent with their own interests, goals, or values (Grolnick, 2003; Grolnick & Pomerantz, 2009). Depending on whether the source of the pressure is internal or external, SDT differentiates between psychologically controlling parenting and externally controlling parenting (Grolnick, 2003; Soenens & Vansteenkiste, 2010). When parents rely on psychologically controlling behaviors, by inducing guilt, shame, or love-withdrawal, they activate internal pressuring forces in children (e.g., self-criticism, guilt, shame) which regulates children's behavior from the 'inside out'. When parents rely on externally controlling parenting (also described as behavioral control), by using (corporal) punishment, verbal or physical coercion, or threats, children feel forced to direct their behaviors to meet external requirements (Soenens & Vansteenkiste, 2010). Thus, the concept of controlling parenting in SDT encompasses both subtle, insidious, and internally pressuring strategies and more blunt externally pressuring parental behaviors (Soenens et al., 2019).

The second dimension of need-supportive parenting is *relatedness-supportive parenting*, also described as warmth or responsiveness (cf., 'parental support' in the classic dimensional approach to parenting). Responsive parenting can be described as a warm, kind, sensitive and loving approach towards the child, where parents convey their desire to support and nurture their child and offer comfort and adequate support when the child needs it (Davidov & Grusec, 2006). This approach can be conveyed emotionally and physically, by for example proactively considering the impact of situations on the feelings of a child or by giving hugs and kisses (Davidov & Grusec, 2006; Soenens et al., 2017). This parenting dimension also entails that parents are both physically and mentally present, which means that parents spend a sufficient amount of time interacting with their child but also pay attention to the child's mental world and mentally engage with their child (Davidov & Grusec, 2006; Soenens et al., 2017). *Unresponsive parenting behavior*, in contrast, refers to a parental attitude characterized by distance and cold. These behaviors express parents' indifference or even hostility or rejection towards the child (Skinner et al., 2005).

The third dimension of need-supportive parenting refers to parenting behavior that nurtures and fosters the child's sense of competence and can be described as *structure* (cf., 'behavioral control' in the classic dimensional approach to parenting; Soenens et al., 2017). Structure refers to parenting behavior that aims to regulate and monitor children's behaviors by providing clear communication and consistent guidelines and rules (Grolnick et al., 1997). Parents can also provide structure by scaffolding their support, the environment, and their expectations of children's capacities and needs (Grolnick et al., 1997). Furthermore, structuring parents also assist children with setting goals, provide informational feedback on this process, and encourage the child to reflect on his/her performance and learning process (Soenens et al., 2019). Conversely, *chaotic parenting* refers to parenting behavior that undermines children's sense of competence due to its inconsistent, unpredictable, and arbitrary nature (Skinner et al., 2005). Chaotic parents do not provide clear guidelines or apply them inconsistently, do not scaffold their help to their child's capacities or needs, provide irrelevant feedback, and may even use expressions of criticism concerning the child's performance or accomplishments (Soenens et al., 2017; Soenens et al., 2019).

The parenting-child interplay: Associations between need-supportive and need-thwarting parenting behaviors and children's psychosocial development

In the past two decades, the SDT-framework has been widely applied and validated to better understand the impact of parenting on child behavioral outcomes (Deci & Ryan, 2000; Soenens et al., 2017). Especially among neurotypical populations, a substantial body of work convincingly demonstrates that the SDT-framework can help to better understand how socialization by parenting impacts behavioral outcomes in children and adolescents, via the mediating mechanism of need-support versus need frustration (Soenens & Vansteenkiste, 2010).

Autonomy-supportive parenting plays a prominent role in SDT-based research on parenting and child development (Ryan & Deci, 2017) because this type of parenting is found to highly foster all three basic psychological needs in children (Grolnick et al., 2018; Soenens et al., 2007). A vast amount of research has now linked autonomy-supportive parenting behavior to various adaptive developmental child outcomes, such as better social functioning (Roth, 2008), emotion regulation (Bindman et al., 2015; Brenning et al., 2015), and school functioning (Soenens & Vansteenkiste, 2005).

Autonomy-thwarting parenting is often studied alongside the effect of autonomy-supportive parenting (Mabbe et al., 2018) as both dimensions appear to be only moderately and negatively correlated (Costa et al., 2016). Moreover, the presence of autonomy-thwarting or controlling parenting does not simply involve an absence of autonomy-supportive parenting (Silk et al., 2003). These dimensions retain their own uniqueness since controlling parenting has a more active and undermining effect on children's needs compared to the absence of autonomy-supportive parenting, and results not only in feelings of low need satisfaction but also in feelings of need frustration (Mabbe et al., 2018). To date, a large body of research (including cross-sectional, longitudinal, diary, and experimental studies) demonstrates that controlling parenting strongly relates to children's and adolescents' internalizing and externalizing problems (e.g., Pinquart, 2017a; Pinquart, 2017b).

Responsive parenting is also extensively studied in the 'classic' parenting literature and many studies show that this type of parenting is centrally important for a child's healthy development in order to attain secure attachment (Stern et al., 2015), self-esteem (Brummelman et al., 2015), and executive functioning skills (Merz et al., 2017). SDT-inspired research now adds to this 'classic' literature that responsive parenting not only strongly nurtures a child's need for relatedness but also fosters a child's need for autonomy and competence (Breiner et al., 2016).

Parental structure is examined mainly in the academic domain, with studies showing that structure positively relates to children's experiences of competence, academic engagement, and performance in school (Farkas & Grolnick, 2010; Grolnick et al., 2015) and even plays a protective role when children are confronted with academic failure (Raftery-Helmer & Grolnick, 2016). Moreover, other studies demonstrate that parents' provision of structure is also relevant in other life domains, especially in life domains and activities that are relatively new or unfamiliar to children and adolescents, such as parent-child conversations about new and sensitive topics (Mauras et al., 2013) or when learning to drive a car (Laird, 2014).

Self-Determination Theory in the disability field

As early as in 1986, Deci and Chandler wrote a progressive essay on how SDT-principles can help to foster motivation in youth with learning disabilities and emotional-behavioral disorders (Deci & Chandler, 1986). However, currently, research has only begun to empirically inquire the applicability of SDT in NDD-groups. This is surprising, as SDT claims to be universally applicable, which implies that *"children with and without special needs have the same basic needs to feel competent, to feel autonomous, and to feel loved"* (Deci & Chandler, 1986, p. 592). Some indirect evidence, however, stems from a few empirical studies evaluating SDT-premises in special educational settings. These few studies, for example, demonstrate the positive impact of autonomy-supportive behaviors on the autonomous motivation and school achievement in children and/or adolescents with ASD (Shea et al., 2013), intellectual disabilities (Katz & Cohen, 2014), and learning disabilities (Deci et al., 1992).

Another set of indirect evidence for the SDT-tenets stems from studies among youth with ASD, CP, or DS based upon 'classic' parenting measures in these groups. These study findings are based upon a wide myriad of parenting instruments and constructs, and have predominantly focused on associations with negative yet limited positive child outcomes. For instance, among families of children with ASD, some studies examining associations between controlling parenting and externalizing child problem behavior, document positive associations among cross-sectional (Boonen et al., 2014; Maljaars et al., 2014; Ventola et al., 2017) as well as longitudinal designs (Bader & Barry, 2014; Baker et al., 2011; Dieleman et al., 2017; Greenberg et al., 2006). In the literature on children with CP, one research group (Aran et al., 2007; Cohen et al., 2008) shows that autonomy-supportive and accepting parenting cross-sectionally relate to better mental health, higher self-esteem, and less social and emotional difficulties among children. Another study demonstrates that parental sensitivity, structuring, and non-intrusiveness associates with fewer peer problems among youth with CP (Barfoot et al., 2017). Furthermore, one research group evaluating parenting practices among parents of children with DS, report consistent positive associations between autonomy-supportive or 'less detached' parenting and positive child characteristics. By contrast, less autonomy support and more detachment in parent-child interactions associates with more negative, socially undesirable child behaviors (Gilmore & Cuskelly, 2012; Gilmore et al., 2009; Gilmore et al., 2016).

In sum, also parenting research among NDD-populations starts to recognize the important role of need-supportive parenting for children's adaptive development and to replicate the association between need-thwarting parenting and maladaptive developmental outcomes. However, no studies to date consistently examined these associations among families raising a child with ASD, CP, or DS from an SDT-perspective. **This dissertation examines both cross-sectional and longitudinal associations between need-supportive and -thwarting parenting behaviors and children's emotional and behavioral difficulties as well as their psychosocial strengths among families raising a child with and without ASD, CP, or DS.**

1.3.2 The unique and interactive role of child personality in children's psychosocial development

It goes without saying that each child is unique and has a unique way to think, feel, behave, and interact with his/her environment. Especially within neurotypical populations, these individual differences between children, captured by the construct of *child personality*, are considered one of the most significant contributors to children's psychosocial development (Caspi & Shiner, 2006; De Pauw, 2017; De Pauw et al., 2009). A very fruitful research tradition has now shown that a child's personality plays an important role in how a child is affected by, responds to, or interprets certain parenting behaviors (e.g., Caspi & Shiner, 2006; Tackett, 2006). Hence, associations between parenting and child behavior might not apply to all children equally, but might differ according to a child's personality. To date, this research avenue receives little attention among NDD-populations. Therefore, in this section, we describe the current literature on personality-adjustment associations and the personality-by-parenting interplay among neurotypical populations, while also describing its plausible value in NDD-populations.

Associations between child personality and child behavior

Personality refers to individual tendencies to behave, think, and feel in certain consistent ways, that surface early in life and that are relatively stable across situations and time (Caspi & Shiner, 2006; Shiner, 1998; Shiner & Caspi, 2003). To assess and theorize differences in adult personality, the Big Five or Five-Factor Model of personality is generally considered one of the most comprehensive and well-validated models of individual differences in personality (e.g., Caspi & Shiner, 2006; John et al., 2008; McCrae & John, 1992; Shiner & DeYoung, 2013). Within childhood, the Five-Factor Model of personality also distinguishes five major personality dimensions, which are similar yet not entirely identical to their adult counterparts: Extraversion, Benevolence (close to Agreeableness), Conscientiousness, Emotional Stability, and Imagination (related to the adult Openness to Experience) (see for reviews: De Pauw, 2017; Mervielde et al., 2009; Tackett, 2006). Extraversion refers to behaviors, thoughts, and feelings that can be described as sociable, expressive, lively, and energetic. Children with high levels of Benevolence are considered warm, kind, considerate, empathic, generous, gentle, and protective of others. Conscientiousness refers to children who can be described as responsible, attentive, persistent, orderly, and think before they act. Emotional Stability refers to overall positive emotional adjustment, characterized by self-confidence and low anxiety. Children with high levels of Imagination can be described as eager and quick to learn, knowledgeable, perceptive, imaginative, curious, and original (Mervielde et al., 2009; Shiner & Caspi, 2003; Tackett, 2006).

Within neurotypical and clinical populations, personality differences in terms of the Big Five/Five-Factor Model have been extensively studied to better understand the onset, development, and severity of various emotional, behavioral, and psychiatric difficulties among children (De Pauw, 2010; Shiner & Caspi, 2003; Tackett, 2006). More specifically, these studies convincingly demonstrate associations between specific personality domains and children's internalizing or externalizing behaviors (e.g., Caspi & Shiner, 2006; De Pauw, 2017). While lower levels of Benevolence and Conscientiousness put children at risk of externalizing problem behavior, lower levels of Emotional Stability or Extraversion consistently relate to more internalizing problem behavior (e.g., De Pauw, 2010; Mervielde et al., 2005; Millikan et al., 2002; Prinzie et al., 2003;

Prinzie et al., 2014; Van Leeuwen et al., 2004). Multiple longitudinal studies also demonstrate the predictive role of child personality for a child's development over time. In neurotypical populations, a decline in Emotional Stability or Extraversion relates to more internalizing problem behavior, whereas a decline in Emotional Stability, Benevolence, or Conscientiousness, or an increase in Extraversion associates with more externalizing problems (e.g., Klein et al., 2011; Prinzie et al., 2010; Van den Akker et al., 2013).

Over the past years, several models have tried to clarify how we can understand child personality in the context of child mental health problems, and whether the relation between child personality and problem behavior or clinical symptoms is similar for neurotypical children and children with a clinical diagnosis (Caspi & Shiner, 2006; Tackett, 2006). To better understand these associations, four theoretical models have been put forward: (1) the *vulnerability model*, proposing that personality can put children at risk for the development of problems, (2) the *spectrum model*, proposing that personality and problems are manifestations of the same construct; (3) the *pathoplasty model*, proposing that personality can affect the manifestation of problems; (4) and *the scar model*, proposing that the development of problems affects personality (Shiner & Caspi, 2003; Tackett, 2006). To date, all these models received some empirical support (e.g., De Bolle et al., 2012; Klimstra et al., 2010; Mervielde et al., 2005). Moreover, the idea grows that these models are not mutually exclusive but that each model can help to explain a part of the association between child personality and emotional or behavioral difficulties (De Pauw & Mervielde, 2010).

Although these models have been extensively studied in neurotypical populations and among children with behavioral, emotional, or psychiatric disorders, studies on trait-adjustment associations in children with a NDD are still in their infancy. Yet, especially in the field of ASD, there is growing attention to examining the construct of child personality, as several studies point out that such research may provide valuable keys to better grasp the wide behavioral variability demonstrated by individuals with ASD (Burrows et al., 2016; De Pauw et al., 2011; Mundy et al., 2007; Schwartz et al., 2009). For instance, De Pauw and colleagues (2011) examined the spectrum hypothesis within the context of ASD, postulating that differences in personality and problem behaviors between clinical (a low-symptom and a high-symptom ASD-group) and non-clinical samples (comparison group of children with no ASD) are primarily differentiated by mean-level differences. In general, the association patterns between child personality and problem behavior showed to be strongly similar across both ASD and non-ASD children, but these relationships appeared stronger and more specific in the ASD-group. The authors concluded that differences in the association between child personality and problem behavior between children with ASD and without ASD could be regarded as rather quantitative (i.e., the strength of the association), than qualitative. In CP-research, studies on the relation between child personality and adjustment are again very limited. One relevant study (Vrijmoeth et al., 2012) examined cross-sectional relations between maladjustment and maladaptive personality traits as measured by the Dimensional Personality Symptom Item Pool (De Clercq et al., 2003) in 101 youth with motor and intellectual disabilities (including 45 children with CP). This study demonstrates generally similar findings as reported in neurotypical populations, illustrating that higher scores on Disagreeableness (a proxy of lower Benevolence) and lower scores on Emotional Stability relate to behavior problems (Vrijmoeth et al., 2012).

In sum, more research is needed to unravel the role of child personality in the psychosocial development of children with a NDD. **Therefore, this dissertation evaluates associations between child personality and psychosocial outcomes in two longitudinal studies of families raising a child with ASD or CP.** We also worked on a longitudinal study of children wth DS during the process of this dissertation, yet the sample size was not sufficient to allow longitudinal analyses using structural equation modeling.

The role of personality-by-parenting interplay in children's psychosocial development

SDT's universal framework purports that need-supportive parenting is universally important for each child's well-being and growth, whereas need-thwarting parenting universally hinders personal growth and development (Deci & Ryan, 2000; Soenens et al., 2017). However, this claim may seem very strong and might raise the intriguing question of whether all children are equally sensitive to the effects of need-supportive or need-thwarting parenting. In other words, is it plausible that the associations between parenting and child behavior are similar for each child (i.e., universal perspective), or do they differ according to the child's unique personality (i.e., relativistic perspective)?

This intriguing question was already embedded in the historical concept of 'goodness-of-fit' by Thomas and Chess (1977). These developmental 'pioneers' in the temperament/personality field postulated that positive child adjustment can be regarded as the result of a good fit between a child's characteristics and the demands of the context, whereas a poor fit – or mismatch between child and context – might lead to child maladjustment (Kiff et al., 2011; Lengua et al., 2019; Lerner & Lerner, 1994). Building further upon the goodness-of-fit framework, other theories suggest that children might have an increased sensitivity to either stressful (cf., diathesis-stress model; Monroe & Simons, 1991), supportive (cf., vantage-sensitivity model; Pluess & Belsky, 2013), or both stressful and supportive environments (cf., differential-susceptibility model; Belsky et al., 2007; Belsky &

Pluess, 2016) depending on their personality. According to the diathesis-stress model, more challenging personality traits render a child more vulnerable to develop difficulties when exposed to a stressful environment with punitive or controlling parenting disciplines (Dubas et al., 2002; Lengua et al., 2000; Van Leeuwen et al., 2004). More recently, the vantage-sensitivity model suggests that also the child's sensitivity towards a supportive environment depends upon personality traits (Pluess & Belsky, 2013). This idea is also implemented in the differential-susceptibility theory, which postulates that children who are highly susceptible to stressful environmental conditions might also be the ones who are more susceptible to supportive contexts, displaying a 'for-better-and-for-worse' pattern in their adjustment. Other children might – based upon their constitutional make-up (expressed by more 'even-tempered', moderate personality traits) – experience only limited impact of either positive or negative environmental conditions (Belsky et al., 2007; Belsky & Pluess, 2016; Roisman et al., 2012). In a recent meta-analysis, Slagt, Dubas, Deković, et al. (2016) document some support for this differential susceptibility model in neurotypical populations, showing that children with higher levels of negative emotionality (a proxy of low Emotional Stability) are indeed more vulnerable to the effect of negative parenting, but also benefit more from positive parenting compared to children with lower or more moderate levels of negative emotionality.

Over the past decades, the diathesis-stress model was mostly investigated since research primarily looked at child maladjustment as outcomes. These studies demonstrate that children with more challenging personality traits (i.e., low Benevolence, Conscientiousness, Emotional Stability) are particularly vulnerable to develop behavioral problems when exposed to controlling parenting behaviors (Bates & Pettit, 2015; de Haan et al., 2010; Kiff et al., 2011; Meunier et al., 2011; Prinzie et al., 2003; Van Leeuwen et al., 2007). In a longitudinal study, Prinzie, Van Harten, Dekovíc, Van den Akker, and Shiner (2014), even illustrate that the relation between overreactive parenting and internalizing child problems is influenced by children's scores on facets of Benevolence (i.e., Irritability and Compliance) but also of Extraversion (i.e., Shyness) during the transition from childhood to adolescence.

Examining the moderating role of individual differences yields a new and challenging way to test SDT's claims about the universal importance of need-supportive and -thwarting parenting in children's psychosocial development. However, to date, this line of research is mainly limited to neurotypical populations and is still in its infancy among NDD-populations. To our knowledge, no study so far has empirically addressed the joint value of personality and parenting variables in relation to emotional and behavioral problems and strengths in youth with a NDD. This is surprising as evaluating the association between personality and parenting is considered one of the most fruitful approaches to better understand the psychosocial development in neurotypical populations (Bates & Pettit, 2015; Kiff et al., 2011; Slagt, Dubas, & van Aken, 2016). Both theoretical and empirical work now suggest that – at least for ASD – fundamentally similar processes operate in children with and without a NDD, so that these groups may differ in degree of these processes but not in kind (Burrows et al., 2016; Coghill & Sonuga-Barke, 2012; De Pauw et al., 2011; Mundy et al., 2007; Schwartz et al., 2009). **This dissertation evaluates the role of the personality-by-parenting interplay in children's psychosocial development using longitudinal data from families raising a child with ASD and CP**. By examining which children could be less or more sensitive to the benefits associated with autonomy-supportive parenting or the costs associated with controlling parenting, we aim to inform practical guidelines for a more optimal parent support.

1.4 The family environment: The emotional climate and parents' perspectives in raising a child with ASD, CP, or DS

All children are nested in a complex network of interconnected systems (Bronfenbrenner, 1986; Sameroff, 2009). Moreover, parenting behaviors and feelings can be regarded as only one – yet a fundamental – aspect of this complex network (Belsky, 1984; Breiner et al., 2016). When a child is growing up with a socio-communicative, physical, or cognitive disability, due to a NDD, this also influences the broader family climate (Resch et al., 2010; Van Riper, 2007). Studies indicated that these family environments might be more stressed-out due to the additional challenges that parents of children with a NDD face, such as organizing specialized care, financial worries, uncertainties about specialized support, or experiences of inequality and stigma (De Belie & Van Hove, 2005; Green, 2003; Resch et al., 2010). This section elaborates on the construct of Expressed Emotion, which is regarded as an indicator of this emotional family climate, and the need for more qualitative research to examine parents' personal perspectives on this climate.

1.4.1 Expressed Emotion: An indicator of the emotional family climate

In recent years, the construct of Expressed Emotion (EE) has been widely examined as an indicator of the emotional quality of a family subsystem, among neurotypical populations (Rea et al., 2020; Sher-Censor, 2015) and – to a lesser extent – also among populations with developmental disabilities (Laghezza et al., 2010; Thompson et al., 2018). The most widely used approach to assess this construct of EE is the Five Minute Speech Sample (FMSS) method (Magaña-Amato et al., 1986) in which parents are asked to spontaneously speak for five uninterrupted minutes about their child and the relationship with their child (Magaña-Amato, 1993).

The construct of Expressed Emotion and its assessment through care givers' spontaneous speech samples

The construct of EE stems from adult psychiatry literature and was originally developed to assess caregivers' attitudes and emotions toward their relative with psychological support needs, and schizophrenia in particular (Brown et al., 1972; Brown & Rutter, 1966; Butzlaff & Hooley, 1998; Gottschalk & Gleser, 1969). The caregivers' expressions about this relative and the intensity and regulation of these emotions in their expressions (i.e., EE) have consistently been found to be vital indicators for the recovery process (i.e., decrease the change of relapse) and the well-being of the relative (Butzlaff & Hooley, 1998; Gottschalk & Gleser, 1969). High EE among caregivers (i.e., the excessive presence or intensity of emotions, often beyond the control of the caregiver) has been associated with a less positive prognosis and has been regarded a potential risk factor for developing more psychological difficulties in the relative. By contrast, low EE among caregivers (i.e., well-modulated and balanced level of communicated emotion) has been regarded a protective factor, associated with better prognosis and life outcomes (Asarnow et al., 2001; Brown et al., 1972). To assess EE, Brown and Rutter developed the Camberwell Family Interview (CFI; Brown & Rutter, 1966; Rutter & Brown, 1966). Although the CFI showed to be a well-established index of the family environment of adults with psychiatric disorders, the administration and scoring of the CFI was very time-consuming and costly. To address these practical limitations, Magaña-Amato and colleagues developed the FMSS-EE measure (Magaña-Amato, 1993; Magaña-Amato et al., 1986), which has been validated in developmental research (see for reviews: Rea et al., 2020; Sher-Censor, 2015).

Within the FMSS-method, a caregiver is asked to speak for five uninterrupted minutes about what kind of person the relative is and about how they get along together (Magaña-Amato, 1993; Magaña-Amato et al., 1986). Thereafter, the audio-recorded sample is transcribed and coded based on the content and emotional tone of emotions, feelings, and attitudes expressed in the monologue, following a structured coding scheme (Magaña-Amato et al., 1986). Within this coding scheme two main domains are assessed: attitudes reflecting *Emotional Over-involvement* (i.e., expressions of over-protectiveness, self-sacrificing behavior, or excessive use of praise or blame towards the child) and *Criticism* (i.e., expressions of dissatisfaction about the child or the caregiver-child relationship). Both components are subsumed under the more general categories of High EE and Low EE. The FMSS is scored as High EE if it meets the criteria for High Emotional Over-involvement and/or High Criticism. A Low EE classification is given when the caregiver's FMSS reflects Low Emotional Over-involvement and Low Criticism, or meets criteria for Borderline

Criticism and/or Borderline Emotional Over-involvement classifications (i.e., indications of Criticism or Emotional Over-involvement but not sufficient to code high EE).

Expressed Emotion in the field of developmental psychology

In developmental psychology, the FMSS-method has now been increasingly applied to examine EE of parents towards their child. Across a variety of age periods (i.e., ranging from unborn babies in pregnant woman to adolescents) and settings (i.e., ranging from community to clinical settings), parents' EE showed to be a valuable indicator of the quality of a family's emotional climate, and by extension the well-being and development of children (e.g., Greenberg et al., 2006; Peris & Baker, 2000; Peris & Miklowitz, 2015; Sher-Censor, 2015).

To provide more fine-grained assessments in the context of parent-child interactions, scholars now also score the construct of parental *Warmth*, in addition to the standard EE-domains of Emotional Over-involvement and Criticism (Narayan et al., 2012; Orsmond et al., 2006; Romero-Gonzalez et al., 2018). Parental Warmth can be coded within the FMSS based on parents' expressions of interest, sympathy, concern, and empathy towards their child. Especially within the context of raising a child with increased support needs, scholars have argued that parental Warmth is a valuable construct to increase our understanding of the emotional quality within a family unit (Hickey et al., 2019; Kubicek et al., 2013).

In the broader field of developmental psychology among neurotypical populations, parents' EE has now also been examined in association with parenting-related concepts, such as parenting stress and parenting behavior (e.g., Sher-Censor, 2015; Weston et al., 2017). These studies demonstrate that especially high levels of parental Emotional Over-involvement and Criticism and low levels of parental Warmth relate to more conflict in the family and lower quality in marital relationships (Boger et al., 2008; Delvecchio et al., 2014; Narayan et al., 2012). Also, high parental Criticism and low Warmth have been associated with diverse negative parenting behaviors and observed parent-child interactions, such as less skill encouragement, less responsive parenting, and more harsh or coercive parenting (Cruise et al., 2011; Kim Park et al., 2008; McCarty et al., 2004; Narayan et al., 2015).

Expressed Emotion in the field of disability studies

In recent years, the construct of EE also receives increasing attention capturing the emotional quality of a family subsystem in families of children with a NDD. A first research avenue within this research field examines whether parents of children with a NDD exhibit similar levels of EE compared to neurotypical populations. A recent (yet limited) meta-analysis of seven studies reports that approximately 40% of parents raising a child with a developmental disability exhibits high EE (Thompson et al., 2018). Since point estimates of high EE among neurotypical populations tend to vary from to 13 to 23% (Griffith et al., 2015; Hibbs et al., 1991; Stubbe et al., 1993), this report concludes that a sizable proportion of families with a child with a developmental disability raise their child in a stressed-out emotional climate (Thompson et al., 2018).

A second research avenue lies in the examination of the conceptual meaning of this EE-construct within NDD-populations (Rea et al., 2020; Sher-Censor, 2015). Notably, some authors have questioned the validity of the EE-domain ‘Emotional Over-involvement’ in these populations. Although Emotional Over-involvement is historically regarded as a marker of a more dysfunctional family climate (Magaña-Amato et al., 1986), some scholars examining EE in NDD-populations argue that Emotional Over-involvement can be considered a more normative or even an adaptive aspect of raising a child with a disability. They suggest that Emotional Over-involvement might rather indicate parents’ commitment towards their child instead of indicating overidentification with the child or overly protective behavior (Kubicek et al., 2013; Laghezza et al., 2010; Wamboldt et al., 2000).

To better understand the conceptual meaning of the EE-concept in NDD-populations, scholars now call out for more research examining how EE maps onto other more established constructs for assessing parent-child dynamics, such as parenting stress and parenting behaviors (Hastings & Lloyd, 2007; Hickey et al., 2020; Laghezza et al., 2010; Sher-Censor, 2015). To date, however, the large majority of EE-research among parents of children with disabilities relies on small sample sizes (Laghezza et al., 2010) and primarily examines associations between parents’ EE and child behavioral difficulties. Especially in ASD-research, strong associations between higher levels of parental Criticism and lower levels of parental Warmth, on the one hand, and externalizing child behavior, on the other hand, are reported (see for reviews: McCauley et al., 2019; Romero-Gonzalez et al., 2018). Two studies did demonstrate significant positive associations between higher levels of EE and parenting stress among parents of children with ASD (Hickey et al., 2020) and CP (Yığman et al., 2020), but no study evaluated associations between EE and parenting behaviors among these populations. Also, no study evaluated EE among families of children with DS, yet a handful of studies did use the FMSS-method in parents of children with ID, sometimes including children with DS (see for reviews: Laghezza et al., 2010; Thompson et al., 2018).

In sum, the FMSS-method is regarded as a promising rich and innovative method to assess the emotional quality within a family unit in neurotypical and, to some extent, NDD-populations

(Laghezza et al., 2010; Sher-Censor, 2015; Thompson et al., 2018). However, further research is needed to clarify whether stressed-out family climates (indicated by high EE) are more prevalent among parents of children with a NDD, and how these climates might impact parents' feelings of stress and interaction with their child. **This dissertation examines these two research avenues among parents raising a child with ASD, CP, DS, and without any known disability.**

1.4.2 Parents' perspectives in raising a child with a neurodevelopmental disability: The need for a mixed-methods inquiry

In the current parenting literature, parent-report questionnaires are the first and preferred method to quantitatively evaluate parental experiences. However, it becomes widely acknowledged that qualitative studies of parents' perspectives are needed to grasp and deepen the complex reality of raising a child with a NDD. Because parenting can be seen as a deeply personal process, qualitative research provides unique possibilities to complement and unravel the unicity and complexity of these experiences. Hence, parents' opportunities and challenges in their interaction with their child can be identified, providing insight for future support (Dieleman et al., 2018; Dieleman et al., 2019).

Moreover, SDT-based (Dieleman et al., 2018; Dieleman et al., 2019) and SDT-related research (e.g., Alaee et al., 2015; Farkas et al., 2018; Meirsschaut et al., 2010) demonstrates that the framework of SDT is a valuable tool to integrate and synthesize the qualitative findings of parents' experiences in terms of need satisfaction and need frustration. More specifically, the SDT-approach shows to provide a balanced and differentiated insight into the experiences of parents raising a child with a NDD, by highlighting both frustrating and satisfying experiences in parents' needs for autonomy, relatedness, and competence (Dieleman et al., 2018; Dieleman et al., 2019). For instance, in ASD-research, parents describe autonomy frustration when they experience a lack of time or possibilities to develop their own interests (DePape & Lindsay, 2014) but also autonomy satisfaction when they find a new direction in life (Dieleman et al., 2018). Parents of children with CP report relatedness frustration when they experience limited time to spend as a couple or lack time and energy to maintain social contacts (Alaee et al., 2015; Davis et al., 2010; Dieleman et al., 2019), yet also relatedness satisfaction when they experience an intense parent-child relationship, strong family cohesion, or establish new social networks (Björquist et al., 2016; LaForme Fiss et al., 2014). Parents of children with DS mention competence frustration, such as struggling to get access to services or feeling uncertain to make decisions regarding their child's education (Farkas et al., 2018; Povee et al., 2012) but also competence satisfaction when their child acquires new skills that maximizes their child's independence (Gilmore et al., 2016).

To date, the large majority of qualitative designs in parenting research relies on interview guidelines (e.g., (semi-)structured or in-depth interviews), which might bias or steer participants into a certain direction or might elicit social desirability (Ritchie et al., 2003). To overcome this challenge, we chose to qualitatively examine the rich material obtained by the FMSS-method (Magaña-Amato, 1993; Magaña-Amato et al., 1986). Also other authors have used a more qualitative approach to FMSSs, showing that this approach captures spontaneous and naturalistic family life experiences and provides a more ecological look into individuals' experiences. For instance, three studies demonstrate that this approach provides unique opportunities to gain more insight into parents' thoughts, feelings, and attitudes towards their child with selective mutism (Kovac, 2018), early signs of ADHD (Perez et al., 2014), or antisocial behavior difficulties (Caspi et al., 2004).

As noted in the context of the quantitative research questions in this dissertation, the available qualitative studies examining experiences among parents raising a child with a NDD also mainly rely on one specific group, with little input from similar research on another NDD. To enable our understanding of parental experiences as a whole, while also illustrating context-specific idiosyncrasies, we chose to adopt a multi-group comparison qualitative design (Lindsay, 2018b; Moola, 2012; Morse, 2004; Ritchie et al., 2003). Within this design, the perspectives of diverse groups of parents raising children with varied conditions are simultaneously examined (Lindsay, 2018a, 2018b; Morse, 2004, 2015). To date, the value of this approach is illustrated in research examining the overarching and disability-specific experiences of parents raising a child with ASD (Dickie et al., 2009), an intellectual disability (Makela et al., 2009), and cystic fibrosis or congenital heart disease (Moola, 2012) compared to parents of children with other disabilities and/or neurotypical children.

To further deepen our understanding of the complex and balanced reality of raising a child with a NDD, **this dissertation qualitatively examines parents' spontaneous speech samples from the theoretical lens of SDT using a multi-group qualitative design**.

1.5 Research objectives and methodological design of the studies

Building upon this literature background, the identified themes, and the needs in the literature, the overall aim of this dissertation is to deepen our understanding of parenting practices and experiences when raising a child with ASD, CP, or DS and to improve our insights into the wide heterogeneity in the psychosocial development of these children. This dissertation includes five empirical chapters, steered by three research objectives. Table 1 provides a schematic outline of these chapters and their methodological designs. Figure 1 illustrates the process of data collection.

1.5.1 Research objectives

Objective 1: To examine group differences and change in the psychosocial development of children with and without ASD, CP, or DS

Although several studies indicate that children with a NDD are at increased risk to develop emotional or behavioral difficulties compared to their peers without a disability (e.g., Arim et al., 2015; Hodapp et al., 2019), few studies relied on multiple NDD-conditions and a reference group. Also, most studies have focused on children's behavioral difficulties, whereas children's psychosocial strengths are often overlooked. The few studies who did address strengths among children with NDDs, for instance, have mainly focused on normative aspects of child strength, such as adaptive or prosocial behavior (e.g., Chiarello et al., 2009; Iizuka et al., 2010), or self-esteem (e.g., Schuengel et al., 2006). However, more research is needed to examine psychosocial strengths, such as interpersonal strengths or family involvement, among these children to highlight a balanced and strengths-based approach to child development (Buntinx & Schalock, 2010).

As a first objective, this dissertation examines children's psychosocial development during their transition from childhood to adolescence (range child age = 10.1 - 19 years old). This dissertation starts by examining group differences in emotional and behavioral difficulties as well as psychosocial strengths among children with ASD, CP, DS and without any known disability (***Research question 1.1***). We evaluate these associations using Kruskal-Wallis H tests in a multigroup quantitative design (**Chapter 2**). Next, we examine how these emotional and behavioral difficulties, and psychosocial strengths develop from childhood into adolescence and (emerging) adulthood (***Research question 1.2***). This research question is evaluated over a nine-year period in the context of ASD (**Chapter 3**) and over a two-year period in the context of CP (**Chapter 4**) by applying structural equation modeling (SEM), and more specifically latent change modeling.

The transition to adolescence and emerging adulthood is particularly interesting because it brings new challenges for all children and their parents (Soenens et al., 2019). Yet, this transition might be especially challenging for youth with a NDD since normative challenges can be exacerbated by the child's social-communicative, motor, or intellectual disability (e.g., Björquist et al., 2016; Brossard-Racine, Hall, et al., 2012; Taylor & Seltzer, 2010). By focusing on this age-specific period throughout the different studies, we aim to better understand children's and parents' functioning within a specific context typical to the child's age and living environment.

Objective 2: To investigate the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without ASD, CP, or DS

Although the developmental variance in the psychosocial development of children with a NDD is widely acknowledged (e.g., Arim et al., 2015; Hodapp et al., 2019), very little is known about the underlying risk and resilience factors that can help to explain this heterogeneity. To better comprehend this vulnerability or resilience towards emotional or behavioral problems, scholars called out for research on 'non-syndrome-specific' factors, more particularly, parenting behavior and child personality (Aran et al., 2007; Chetcuti et al., 2019; De Pauw, 2017; McCauley et al., 2019; Mundy et al., 2007).

Therefore, as a second main objective, this dissertation examines the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without ASD, CP, or DS. To evaluate what parents do in their relation with their child, we examine specific parenting behaviors among parents raising a child with ASD, CP, DS, and without any known disability, and how these behaviors might differ across groups (***Research question 2.1***). This research question is evaluated in two cross-sectional multi-group studies using Kruskal-Wallis H tests (**Chapter 2**) and multivariate analysis of variance (MANOVA) (**Chapter 5**). Also, from a longitudinal perspective, we examine whether these behaviors among parents raising a child with ASD (**Chapter 3**) and CP (**Chapter 4**) change over time while their child develops from childhood into adolescence and (emerging) adulthood (***Research question 2.2***) using latent change modeling.

Next, to better understand how these parenting behaviors relate to children's psychosocial development, we examine associations between parenting behaviors and children's psychosocial development (i.e., internalizing problems, externalizing problems, and psychosocial strengths) (***Research question 2.3***) by conducting one cross-sectional (**Chapter 2**) and two longitudinal studies (**Chapters 3 and 4**). More specifically, in **Chapter 2**, we explore whether the alleged universal basic psychological needs of SDT operate in similar ways among children with and without a NDD. In other words, we inquire to what extent we can corroborate the strong and differential paths between, on the one hand, need-supportive parenting and positive psychosocial development (as expressed in greater psychosocial strengths) and, on the other hand, need-thwarting parenting behaviors and negative behavioral outcomes (as expressed in more emotional and behavioral

Table 1. Overview of empirical studies

Ch.	Sample characteristics					Study design	Analytical technique	Measures of parental factors	Measures of child factors	Objective (Research questions)[1]
	Population	*n*	M_{age} child (years)	% boys	% mothers					
2	ASD, CP, DS, RG	409	11.5	62.5	94.3	Cross-sectional questionnaire data	Multi-group SEM	Parenting behavior: AS, RESP, CON	Child behavior: INT, EXT, STR	1 (1.1) 2 (2.1, 2.3)
3	ASD	141	10.1-16.0-19.0	83.0	98.6	Longitudinal three-wave (nine years) questionnaire data	SEM - latent change modeling	Parenting behavior: CON	Child behavior: INT, EXT, STR Child personality	1 (1.2) 2 (2.2, 2.3, 2.4, 2.5)
4	CP	118	10.9-12.1-12.9	64.4	88.1	Longitudinal three-wave (two years) questionnaire data	SEM - latent change modeling	Parenting behavior: AS, CON	Child behavior: INT, EXT, STR Child personality	1 (1.2) 2 (2.2, 2.3, 2.4, 2.5)
5	ASD, CP, DS, RG	447	12.3	64.7	92.8	Cross-sectional spontaneous speech sample data	Contingency table analysis and MAN(C)OVA	Parenting behavior: AS, RESP, CON, OVER Expressed Emotion Parenting Stress	Child behavior: EXT	2 (2.1) 3 (3.1, 3.2)
6	ASD, CP, DS, RG	160	13.1	67.5	87.5	Multi-group qualitative design of spontaneous speech samples	Thematic analysis	Open questions	Open questions	3 (3.3)

Note. Ch. Chapter, *ASD* autism spectrum disorder, *CP* cerebral palsy, *DS* Down syndrome, *RG* reference group of children without any known disability, *SEM* structural equation modeling, *AS* autonomy-supportive parenting, *RESP* responsive parenting, *CON* controlling parenting (i.e., psychologically controlling parenting in Chapters 2 and 5; externally controlling parenting in Chapters 3 and 4), *OVER* overreactive parenting, *INT* internalizing child behavior, *EXT* externalizing child behavior, *STR* psychosocial strengths.

[1] 1.1: Are their group differences in children's psychosocial development?, 1.2: How does children's psychosocial development change over time?
2.1: Are there group differences in parenting behaviors?, 2.2: How does parenting behavior change over time?, 2.3: How do parenting and children's psychosocial development relate?, 2.4: How does child personality relate to children's psychosocial development?, 2.5: Is there a moderating role of child personality in parenting-child (mal)adjustment associations?
3.1: Are their group differences in point estimates of Expressed Emotion?, 3.2: How do parenting stress, parenting behavior, and Expressed Emotion relate?, 3.3: Which need-related challenges and opportunities do parents experience when raising their child, and do they differ across groups?

problems) in and across four groups (i.e., ASD, CP, DS, and without any known disability). These pathways are cross-sectionally examined using multi-group SEM. Based on SDT's universally applicable framework, we hypothesize that similar pathways will occur across groups. In **Chapters 3 and 4**, we use a more developmental approach and examine these parenting-child (mal)adjustment associations using latent change modeling in two longitudinal designs.

In addition to these parenting behaviors, we also examine the unique role of child personality in the psychosocial development of children with ASD (**Chapter 3**) and CP (**Chapter 4**) within two longitudinal studies using latent change modeling (***Research question 2.4***). Also, we examine whether children with ASD (**Chapter 3**) and CP (**Chapter 4**) are more sensitive to the effects of certain parenting behaviors based on their personality (***Research question 2.5***). Doing so, we investigate whether children's psychosocial development is supported or thwarted by parenting behaviors in a similar way for each child or whether some children are more sensitive towards the impact of certain parenting behaviors based upon their unique personality. We hypothesize that the effects of the personality-by-parenting interplay will be highly similar to the well-studied effects among neurotypical populations. In other words, we expect these effects to be largely non-syndrome-specific, even though the strength of these relations may vary across the different NDDs.

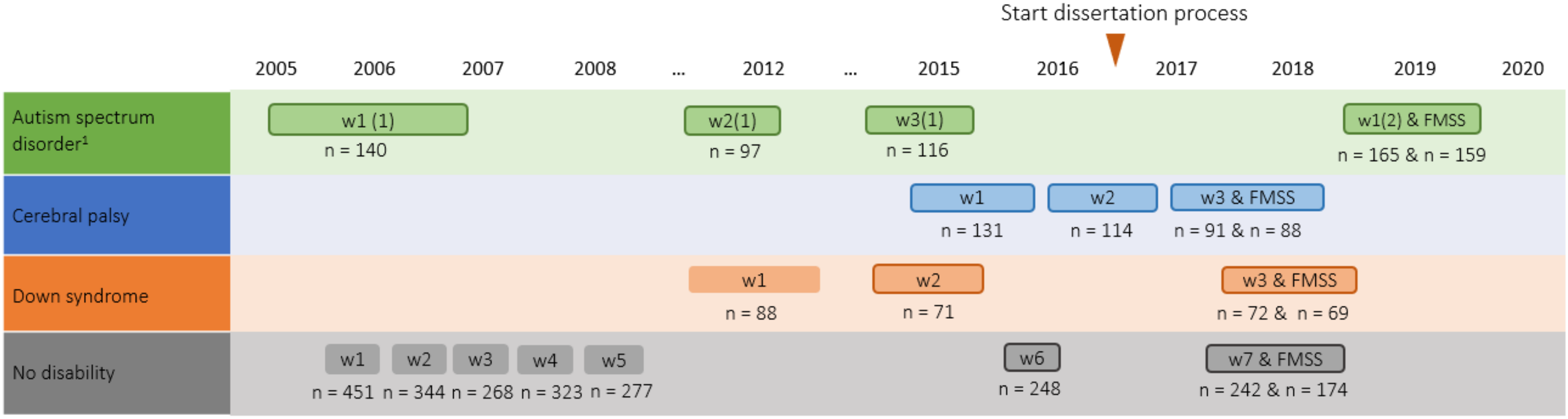
Objective 3: To explore the emotional climate, parents' affective well-being, and need-related experiences among families raising a child with and without ASD, CP, or DS

To capture naturalistic family life experiences and to provide a more ecological look into parents' experiences, we examine spontaneous speech samples of parents describing their child, the relationship with their child, (and their parental experiences) both quantitatively (**Chapter 5**) and qualitatively (**Chapter 6**). Although a strong line of quantitative research shows that parents raising a child with a NDD are prone to experience more stress and challenges in their parenthood (e.g., Gupta, 2007; Hayes & Watson, 2013), few studies examine the underlying mechanisms. Analyzing parents' speech samples can offer a more profound and balanced insight into both challenging and satisfying experiences among these parents.

In **Chapter 5**, we explore the construct of EE, assessed by the FMSS-method (Magaña-Amato, 1993; Magaña-Amato et al., 1986), in the context of raising a child with or without ASD, CP, and DS to better understand parental attitudes and family interaction patterns within these families. First, we examine group differences in point estimates of EE and levels of parenting stress, using contingency table analysis and MANOVA (***Research question 3.1***). We expect higher levels of EE and parenting stress among parents of children with a NDD compared to the groups of parents raising a child with no disability. Additionally, **Chapter 5** aims to get a better understanding of the conceptual meaning and value of EE in the context of raising a child with a NDD. Therefore, we explore whether the associations between EE, on the one hand, and parenting stress and behavior, on the other hand, are similar across groups (***Research question 3.2***) using multivariate analysis of covariance (MANCOVA). We expect highly similar associations between the NDD-populations and the neurotypical population. More specifically, we hypothesize that a more positive emotional climate in the family, indicated by low EE, would be associated with lower levels of parenting stress and more need-supportive parenting behaviors and that a more stressed-out family climate would be associated with higher levels of parenting stress and more need-thwarting parenting behaviors, in each group alike.

Finally, to gain a nuanced understanding of the complex reality of raising a child with a NDD, and to supplement the previous quantitative studies, **Chapter 6** encompasses a content-analysis of a selection of the FMSSs included in **Chapter 5**. More specifically, this chapter aims to deepen our understanding of the opportunities and challenges that parents of children with and without ASD, CP, or DS experience in their need for autonomy, relatedness, and competence (***Research question 3.3***). Within **Chapter 6**, we analyze parents' speech samples derived from the FMSS-method (i.e., *Can you tell me about the kind of person your child is an how you get along?)* and their responses to an additional question concerning their parental experiences (i.e., *Can you tell me about your experiences as a parent of [child name]?).* Forty interviews from each group were randomly selected from the larger dataset on FMSSs (**Chapter 5**), reflecting similar sociodemographic characteristics across groups (e.g., child age, gender, living situation, mother: father ratio, parents' age, educational level, and marital status). Parents' experiences were analyzed using thematic analysis in NVivo. We incorporated a deductive approach and structured parents' experiences based upon the SDT-framework. By relying on this framework and by using a multi-group comparison design, we aim to illuminate both general and disability-(a)specific themes that might provide insight into the factors that make raising a child with a certain NDD potentially stressful, but also into those factors that create possibilities for positive need-satisfying experiences. Although we assume that the parental experiences would be, at a fundamental level, similar among all parents based on SDT's universality claim (Deci & Ryan, 2000), we also expect disability-specific diversity in parents' need-related experiences.

Figure 1. Process of data collection



Note. Data from the assessment periods without a frame were not included in this dissertation.

[1] Parents of children with ASD participated in a longitudinal three-wave study from 2005 to 2015 (i.e., ASD-study (1)). In 2019, we started a new ASD-cohort (i.e., ASD-study (2)).

Chapter 2 includes data from the second and third assessment periods from the ASD (1)-, CP-, and DS-study, and from the sixth and seventh assessment periods from the study among parents of children without any known disability (participants were included based on child age). Chapter 3 incorporates data from the three assessment periods from the ASD-study (1). Chapter 4 includes data from the three assessment periods from the CP-study. Chapters 5 and 6 incorporate data from the first assessment period from the ASD-study (2), the third assessment period from the CP- and DS-study, and the seventh assessment period from the study among parents of children without any known disability (during these assessment periods we conducted Five Minute Speech Samples).

1.5.2 Methodological design

This dissertation encompasses both *cross-sectional* (**Chapters 2, 5, and 6**) and *longitudinal* quantitative studies (**Chapters 3 and 4**) to gain a better insight into both the short-term and long-term development of children with a NDD and their families. Even though cross-sectional designs can be considered as first stepping stones in establishing associations, they do not allow to examine change over time and the direction of effects. To date, the lack of longitudinal studies among families raising a child with a NDD stands in sharp contrast to the very rich and fruitful longitudinal research tradition in neurotypical populations (Bates & Pettit, 2015; Bornstein, 2015; Taraban & Shaw, 2018). This dissertation adopts a longitudinal perspective when examining change in both parenting behaviors and children's psychosocial development, and when investigating the unique and interactive effects of parenting practices and child personality on the psychosocial development of children with ASD (**Chapter 3**) and CP (**Chapter 4**).

Within three quantitative studies (**Chapters 2, 3, and 4**), we applied *Structural Equation Modeling* (SEM) in Mplus 8.3 (Muthén & Muthén, 1998–2012) to model associations between parenting behaviors (and child personality) and children's psychosocial development. SEM can be described as a confirmatory technique, which allows to test whether a model adequately fits the data (Byrne, 2012), and incorporates some advantages compared to traditional multivariate techniques. Whereas more traditional multivariate techniques do not incorporate or model measurement error, SEM explicitly assesses measurement error by estimating error variance parameters for both independent and dependent variables. Also, SEM allows to estimate latent (unobserved) variables from observed variables by the creation of composites and allows to evaluate whether the sample data fits the proposed conceptual or theoretical model (Kaplan, 2008). In **Chapter 2**, we use cross-sectional multi-group SEM to examine whether the structural paths between parenting and child behavior are similar between groups. In the longitudinal study designs (**Chapters 3 and 4**), we apply latent change modeling (LCM), a specific technique within SEM. LCM provides a unique possibility to study (nonlinear) change trajectories and to examine *inter-individual differences in change* (Zhang & Liu, 2018). More specifically, LCM allows to examine processes of change at the level of a family unit. This type of change is highly relevant from a practical point of view since absolute change at the within-family level is assessed (e.g., whether an effect is significant relative to the individual's own average), rather than relative change between families (e.g., whether an effect is significant relative to other individuals in the study). For example, we examine whether changes across the years in the parents' behavior (relative to the parents' own general score across all waves) relate to changes in the child's psychosocial development (relative to the child's own general score across all waves). This level of analysis is particularly valuable in the application of parenting research because this is the level where real changes (through interventions and parent support) can take place (Keijsers et al., 2016). Moreover, analyses at the within-person level can be particularly valuable as the findings at the within-level of analysis might differ, and even be opposite of the findings at the between-level of analysis. This paradox has been described as the Simpson's paradox (Keijsers et al., 2016), demonstrating that, for example, two variables might be correlated positively across a population of individuals yet negatively within each individual over time (Dietvorst et al., 2018; Kievit et al., 2013).

Within these longitudinal studies (**Chapters 3 and 4**), we examine personality-by-parenting interaction effects using the Johnson-Neyman technique. This technique allows to indicate the specific value along the continuum of the personality trait at which the relation between parenting and child behavior is significant (i.e., regions of significance; Del Giudice, 2017).

Next to these quantitative studies (**Chapters 2-5**), we apply a qualitative study design to deepen our understanding of and to give more color and nuance to parents' perspectives raising a child with ASD, CP, DS, and without any known disability in **Chapter 6**. More specifically, we apply a multi-group comparison qualitative design, providing the opportunity to examine parents' experiences as a whole, while also shedding light on group-specificities (Lindsay, 2018b; Morse, 2004; Ritchie et al., 2003). Also, it has been argued that incorporating a *mixed-methods approach* in research, which involves the integration of qualitative and quantitative findings at some or multiple stages of the research process (Kroll & Neri, 2009; Östlund et al., 2011), can be particularly useful since a broader range of perspectives of 'different ways of knowing' can do more justice to the complexity of the phenomena studied. Whereas quantitative designs are valuable to map processes, to follow up, to standardize, to generalize, and to study phenomena on a broad level, qualitative designs have the potential to bring more nuance into a story or reality and to dive into the experience of individuals in their natural context (Malterud, 2001). Moreover, a combination of qualitative and quantitative data could strengthen the validity of research findings by ensuring that the limitations of one type of data are balanced by the strengths of another (Östlund et al., 2011). Within this dissertation, the data collection, analysis, and interpretation of the quantitative studies (**Chapters 2 - 5**) and qualitative study (**Chapter 6**) ran in parallel, allowing both approaches to influence each other along the way.

1.6 Orthopedagogical approach to the study

This dissertation is situated within the field of 'orthopedagogics', which focuses on the improvement of the participation, quality of life, and living situations of people in vulnerable situations in a systematic and meaningful way by gaining insight in both the strengths and the (support) needs of the people we work with (Vanderplasschen et al., 2015). In this section, we highlight four aspects that illustrate the orthopedagogical nature of this dissertation.

First, the study of parenting and educational situations among children in 'vulnerable situations' has been a main pillar throughout the history of orthopedagogical research (Kok, 1991; Vandevelde et al., 2017). By focusing on parenting and child-parent interactions, we examine *everyday environments and natural networks,* supporting the idea that individuals are not individual islands in society but are inherently part of complex systems of interactions and relationships (Vanderplasschen et al., 2015; Vandevelde et al., 2017). Following a transactional and dynamic perspective, we examine children's and parents' functioning as processes that mutually influence each other (McCauley et al., 2019).

Second, this dissertation attempts to apply an orthopedagogical view on the framing of disability. Throughout the diverse studies, we acknowledge a person-environment fit model, stating that disability lies in the gap between personal capacity and the demands of the environment (Wehmeyer et al., 2017), instead of attributing or reducing the disability to the individual child or environment (Nunkoosing & Haydon-Laurelut, 2011). Following this vision, we aim to defy a deficit thinking by putting the opportunities and challenges that lie within the alignment and *interaction between the individual and its environment* forward. For instance, the study of personality-by-parenting interactions provides opportunities to frame a child's development as an interpretation of the interaction between the child's unique personality and the socializing context (i.e., parenting behaviors). Also, we aim to look beyond the child's disability or 'clinical' diagnosis by focusing on *'non-syndrome specific factors'*, that naturally vary among all children and their families, i.e., parenting behavior and child personality. Examining both constructs among NDD-populations supports the idea that developmental outcomes of these children depend on both family variables and children's psychological characteristics, instead of being determined only by disability-specific characteristics (Aran et al., 2007; Cohen et al., 2008; Majnemer & Mazer, 2004; McCauley et al., 2019; Mundy et al., 2007).

Third, this person-environment fit model of disability opens the door for strengths-based approaches to disability (Wehmeyer et al., 2017). Although it is not always easy to search for and acknowledge strengths since we have the natural tendency to 'fix' things that we perceive as ‘broken’, ‘inappropriate’ or ‘maladaptive’, the continuous attempt to map out more than just ‘the problematic aspect’ illustrates the identity of orthopedagogics (Vanderplasschen et al., 2015). Following a *balanced strengths-orientated approach*, underlining the idea that within each child and context limitations coexist with strengths (Buntinx & Schalock, 2010; Seligman & Csikszentmihalyi, 2000; Wehmeyer et al., 2017), we assess both ‘positive’ and ‘challenging’ aspects of parental processes (i.e., need-supportive and need-thwarting parenting behavior, positive family emotional climates and parenting stress, need-satisfying and need-frustrating experiences) and children’s psychosocial development (i.e., psychosocial strengths, and internalizing and externalizing problems). Since family functioning is a complex system and a child’s disability can impact families in different ways, many researchers argue that the examination of families’ true experiences should also include these positive factors (e.g., Blacher & Baker, 2007; Hastings et al., 2002; Hastings et al., 2005; Seligman & Darling, 2007; Taunt & Hastings, 2002).

Fourth, an essential characteristic of orthopedagogics is that *different paradigms and methods* can go together alternately (Broekaert et al., 2004). Holistic orthopedagogics even prefers to look at ‘a reality’ through as many ‘glasses’ or frameworks as possible (Broekaert, 1988; Vandevelde et al., 2017). To do so on a theoretical level, we aim to build bridges between theories and frameworks in the field of disability studies and different branches of psychology (e.g., developmental, motivational, personality, and clinical psychology). We believe that an interdisciplinary approach can cause cross-pollination and deepen our understanding of certain research constructs. For instance, we examine the applicability and value of well-validated and widely-documented theories and constructs from the field of developmental and personality psychology, such as SDT, EE, and personality-by-parenting processes, in the context of raising a child with a NDD. Furthermore, we aim to incorporate a holistic and biopsychosocial view on disability by reflecting its complexity in the interaction of biological (i.e., brain functioning, genetics), psychological (i.e., child behavior, child personality, stress), and sociological factors (i.e., parenting behavior, EE). On a more methodological level, this dissertation applies a *mixed-methods design* by including both quantitative and qualitative studies. We support the idea that both methods are equally valuable and can complement each other to provide a broader perspective on the complexity of a studied phenomenon (Broekaert et al., 2004; Vandevelde et al., 2017). Nevertheless, it remains important to notice that orthopedagogical concepts are difficult to grasp and cannot be pinned down in one single reality, neither with quantitative nor qualitative methods.

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Chapter 2

Need-supportive parenting and psychosocial development in youth with and without autism spectrum disorder, cerebral palsy, or Down syndrome: A cross-disability comparison

Based on De Clercq, L., Van der Kaap-Deeder, J., Dieleman, L. M., Soenens, B., Prinzie, P., & De Pauw, S. S. W. (2019). Parenting and psychosocial development in youth with and without autism spectrum disorder, cerebral palsy, and Down syndrome: A cross-disability comparison. *Advances in Neurodevelopmental Disorders*, *3*(2), 220-234. https://doi.org/10.1007/s41252-019-00112-2

Abstract

Parents play an important role in supporting their child's social, behavioral, and emotional development. In the past decade, research on parenting in neurotypical populations increasingly relied on Self-Determination Theory (SDT) to better understand the association between parenting behaviors and child behavioral outcomes. In populations of children with a neurodevelopmental disability, however, very little research has examined parenting behaviors from an SDT-perspective. This study examines associations between parenting dimensions (responsive parenting, autonomy-supportive parenting, and psychological control) and children's psychosocial outcomes (behavioral and emotional problems, and psychosocial strengths) in and across four specific groups. Parents of children between 7 and 15 years old with autism spectrum disorder (*n* = 95), cerebral palsy (*n* = 121), Down syndrome (*n* = 73), and without any known disability (*n* = 120) rated their parenting and their child's behaviors. Group comparisons indicated that mean levels of parenting did not vary widely across groups. By contrast, salient differences in children's behavioral presentations were observed, with parents of children with autism spectrum disorder reporting the most emotional and behavioral problems and the lowest scores on psychosocial strengths. Multi-group structural equation models revealed similar, SDT-predicted relations between parenting dimensions and psychosocial development in each group. Three structural effects were found: whereas higher levels of psychologically controlling parenting related to more externalizing problems, higher levels of responsive as well as autonomy-supportive parenting were associated with more psychosocial strengths. These results indicate that need-supportive parenting is related to beneficial outcomes and that need-thwarting socialization is related to maladaptive development in and across youth growing up with and without a neurodevelopmental disability.

2.1 Introduction

In developmental psychology, a long and fruitful research tradition has addressed the role of parenting in supporting children's social, emotional, and behavioral development (Collins et al., 2000). In the past two decades, this research tradition has witnessed a growing interest in applying Self-Determination Theory (SDT) to better understand the relation between parenting and child behavioral outcomes (Deci & Ryan, 2000; Soenens et al., 2017). A central tenet in SDT is that each individual, from birth on, is equipped with three basic psychological needs, that require fulfillment in order to incite personal growth and well-being. These three needs are considered to be innate and universal for all human beings and are identified as autonomy (i.e., feeling psychological freedom and authenticity), relatedness (i.e., feeling connected with and loved by others), and competence (i.e., feeling able to reach personal goals) (Deci & Ryan, 2000; Ryan & Deci, 2017). When these needs are satisfied, the development and personal growth of a person is stimulated, providing energy, vitality, feelings of wellness, and higher levels of self-development. Conversely, when these needs are not adequately satisfied or even actively frustrated, a person's psychological well-being and growth gets forestalled, which may result in more unfavorable outcomes (Deci & Ryan, 2000; Vansteenkiste & Ryan, 2013). According to SDT, the socialization environment is crucial to attaining either fulfillment or frustration of these three basic psychological needs. Socializing agents (e.g., caregivers, teachers) can be actively fostering, indifferent to, or antagonistic toward a person's satisfaction of needs (Vansteenkiste & Ryan, 2013).

In the past two decades, a substantial body of work in neurotypical populations has convincingly demonstrated that this SDT-framework helps to better understand how parenting is related to behavioral outcomes in children and adolescents, via the mediating role of need satisfaction versus need frustration (Soenens & Vansteenkiste, 2010). Parenting strategies can be regarded as more or less adequate in supporting the child's fundamental psychological needs. When a child experiences need-supportive parenting, this will promote the child's adjustment, by strengthening the inner resources of the child and by nurturing feelings of well-being and psychological growth. Other parenting behaviors are more need-thwarting in nature and relate to more adjustment difficulties in the child, such as internalizing or externalizing problems (Joussemet et al., 2008; Soenens et al., 2017).

In this study, we focus on two central dimensions of need-supportive parenting, that is, responsive and autonomy-supportive parenting (Mabbe et al., 2018; Ryan & Deci, 2017). First, responsive parenting is characteristic of parents who are warm, sensitive, and affectionate towards the child and who are physically and mentally present (Davidov & Grusec, 2006). In doing so, parents primarily support children's need for relatedness. Many studies have shown that responsive parenting is related to children's better psychosocial development (Prinzie et al., 2009; Stern et al., 2015).

Second, parental support for autonomy involves being empathic towards the child's frame of reference, attuning to the pace and rhythm of a child's development, and encouraging a child's initiative (Joussemet et al., 2008). This type of parenting nurtures all three basic psychological needs in children (Grolnick et al., 2018; Soenens et al., 2007; Vansteenkiste & Ryan, 2013) and is related to various adaptive developmental outcomes, such as better social functioning (Roth, 2008) and emotion regulation (Brenning et al., 2015).

In contrast to these dimensions of need-supportive parenting, psychologically controlling parenting is an intensively studied dimension of need-thwarting parenting (Soenens & Vansteenkiste, 2010). Psychological control refers to an intrusive type of control, manifested in the use of manipulative tactics such as guilt induction, shaming, love withdrawal, and controlling language (Barber, 1996). In SDT-based research, this type of autonomy-thwarting parenting is often studied alongside the effect of autonomy-supportive parenting (e.g., Mabbe et al., 2018) as these two dimensions are only moderately and negatively correlated (Costa et al., 2016). In this regard, it has been shown that psychologically controlling parenting has a more actively undermining effect on children's needs, resulting in feelings of need frustration whereas the absence of autonomy support primarily results in feelings of low need satisfaction (Mabbe et al., 2018). To date, a large body of research, including cross-sectional, longitudinal, diary, and experimental designs, has convincingly demonstrated that psychological control strongly relates to both internalizing and externalizing problems in childhood and adolescence (Pinquart, 2017a, 2017b).

How do need-supportive and need-thwarting parenting behaviors relate to behavioral and emotional problems and psychosocial strengths in youth with and without a neurodevelopmental disability?

While the relations between these three parenting dimensions and aspects of child development have been extensively studied in neurotypical populations, there is a paucity of research evaluating these relations in youth with a neurodevelopmental disability (NDD). Even though the interest in family dynamics in these groups is currently growing, the majority of studies to date has focused on elevated levels of stress or mental health problems in parents of a child with a NDD (Hayes & Watson, 2013; Yorke et al., 2018), and less on specific parenting behaviors (Dieleman et al., 2017; Maljaars et al., 2014; Phillips et al., 2017). Therefore, this paper aims to examine associations between these three parenting dimensions (i.e., responsive parenting, autonomy-supportive parenting, and psychological control) and children's psychosocial adjustment, in and across four groups: parents raising a child with autism spectrum disorder (ASD), cerebral palsy (CP), and Down syndrome (DS), and a reference group (RG) of parents raising a child without any known disability. These three parenting dimensions will be studied in relation to two types of child behavioral outcomes: internalizing-externalizing problems and psychosocial strengths.

To date, there is a substantial body of research evaluating internalizing and externalizing behaviors in youth with ASD, CP, and DS. These pieces of literature demonstrate that children growing up with these NDDs are at increased risk to develop behavioral, emotional, or psychiatric difficulties compared to their peers without a disability. The highest risks apply to youth with ASD (e.g., De Pauw et al., 2011; Maljaars et al., 2014) but research also indicates that youth with CP and DS are at increased risk to develop emotional and behavioral problems (e.g., Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; Vrijmoeth et al., 2012). At the same time, research in youth with ASD, CP, as well as DS highlights large inter-individual variation in the manifestation of these behavioral difficulties (Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; Vrijmoeth et al., 2012; Yorke et al., 2018).

This study supplements the focus on problem behaviors by also evaluating psychosocial strengths in youth with ASD, CP, and DS compared to peers without any known disability. In a study of children with DS, problem behaviors and psychosocial strengths showed to be related, yet distinct constructs (Dieleman, De Pauw, Soenens, Van Hove, et al., 2018). Psychosocial strengths, as defined by Epstein and Sharma (1998) and Epstein (2004), denote specific child behaviors and skills that create a sense of satisfaction, foster relationships, strengthen abilities to cope with adversity, and generally promote well-being and development. Two examples are the degree to which a child can express affection in close relationships or respond adaptively to distress in others by expressing concern or offering comfort. Recent studies suggested that the BERS-2 (Epstein, 2004) is a promising instrument to assess psychosocial strengths in children with heterogeneous disabilities, including those with DS (e.g., Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; Sointu et al., 2012). Notably, this budding research also highlighted important variation in the presentation of psychosocial strengths among children with and without a NDD (e.g., Dieleman, De Pauw, Soenens, Van Hove, et al., 2018).

Previous research demonstrated that youth with a NDD are at increased risk to develop behavioral or emotional problems (Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; Vrijmoeth et al., 2012; Yorke et al., 2018). However, still very little is known about factors involved in the heterogeneity of problems and strengths displayed by youth with a NDD. Quality of parenting may be one such factor that can clarify (at least partly) why some children develop more problems whereas other children attain high levels of adaptive functioning (e.g., positive relations, vitality, well-being).

A cross-disability examination of Self-Determination Theory's universality claim

As research has only begun to inquire the applicability of SDT in special needs groups empirically, it remains a vital question to what extent this SDT-model can be applied to children with or without a NDD. Therefore, this study focuses on three of the most prevalent NDDs: ASD, CP, and DS. The choice of these three conditions enables a cross-disability comparison of children experiencing difficulties in at least one of three domains of functioning: i.e., psychosocial, physical, and/or cognitive.

There are two main sets of arguments to assume that there will be fundamental similarities in these relationships across parents raising a child without a disability and parents raising a child with ASD, CP, and DS. The first set of arguments is theoretical. SDT claims to be universally applicable, postulating that *"all humans are active, growth-oriented organisms with innate psychological nutriments that are essential for ongoing psychological growth, integrity, and well-being"* (Deci & Ryan, 2000, p. 229). This universality claim implies that children with and without special needs have the same basic needs. In 1986, Deci and Chandler wrote a progressive essay on how SDT-principles can help to foster motivation in youth with learning disabilities. In this review, they stated that self-determined functioning should be a goal of all education, including special education. In this context, they stated that *"all children need to feel competent, to feel autonomous, and to feel loved"* (Deci & Chandler, 1986, p. 592). No study to date has addressed this universality claim in the context of parenting a child with a NDD but some indirect evidence stems from the few studies evaluating SDT-premises in special educational settings. For instance, Deci et al. (1992) reported that when parents and teachers provided more autonomy support and involvement, youth with learning disabilities displayed more internal motivation, achievement, and adjustment at school. Shea et al. (2013) evaluated the self-ratings of 26 adolescents with high-functioning ASD and found that perceived autonomy support by teachers was related to more intrinsic motives for doing schoolwork and academic self-regulation. A similar finding was reported by Katz and Cohen (2014) in a study on 88 students with an intellectual disability (ID), where student-perceived teacher autonomy correlated significantly with more autonomous motivation for school.

The second set of arguments stems from the limited empirical research evaluating associations between parenting and developmental outcomes in youth with ASD, CP, and DS, even though these studies used various parenting instruments and predominantly focused on associations with negative but not positive child outcomes. In families of children with ASD (*n* = 48), Ventola et al. (2017) recently reported a moderate association between the use of parental psychological control and externalizing problems. Other studies (Boonen et al., 2014; Maljaars et al., 2014) found only weak correlations between parenting and problem behaviors in children with ASD, with some support indicating that demanding, controlling parenting is associated with more externalizing behavior. A few longitudinal studies also hint that externally controlling parenting relates to more externalizing problems later in development in youth with ASD (Dieleman et al., 2017; Greenberg et al., 2006). Notably, some studies evaluated the relationship between a more general composite score of positive parenting, on the one hand, and both problems and prosocial behaviors, on the other, but did not find significant effects (Boonen et al., 2014; Dieleman et al., 2017; Maljaars et al., 2014).

In the literature on children with CP, a few studies showed associations between need-supportive and need-thwarting parenting behaviors and children's behavioral problems and well-being. One research group (Aran et al., 2007; Cohen et al., 2008) found that in a subset of 39 children with CP, autonomy-supportive and accepting parenting related to better mental health, higher self-esteem, and less social and emotional difficulties. In this small group of children, parenting was reported to have the only significant effect on psychosocial functioning, even exceeding any effect of physical disability. Another study showed that parental sensitivity, structuring, and non-intrusiveness were associated with fewer peer problems in 23 children with CP (Barfoot et al., 2017).

Research on relations between parenting and child behaviors among families of children with DS is even more limited. To the best of our knowledge, only one research project has evaluated associations between parenting practices and child behavior in the context of DS (Gilmore & Cuskelly, 2012; Gilmore et al., 2009; Gilmore et al., 2016). This research longitudinally followed 25 mothers of a child with DS and 43 mothers of matched controls. Mothers whose young child with DS displayed many positive characteristics tended to be more autonomy-supportive, more consistent, and less detached in their parenting. By contrast, mothers whose child displayed many negative, socially undesirable behaviors were less likely to support their child's autonomy and were more detached in their parenting as they avoided or withdrew more often from their child (Gilmore & Cuskelly, 2012).

In sum, research has begun to demonstrate associations between important dimensions of parenting and the psychosocial development of children with a NDD. Because the relationship between parenting and children's psychosocial development is inherently reciprocal in nature (Collins et al., 2000; Pinquart, 2017a), these associations need to be interpreted bidirectionally:

children's problems are likely to elicit less need-supportive and more psychologically controlling parenting, with such parental behavior further reinforcing developmental difficulties in children. Importantly, while research has begun to examine the role of parenting in the context of specific disabilities, only a few studies have formally examined similarities and differences in associations between parenting and child behavior across different NDDs.

The present study

This study complements the limited empirical research on the association between parenting and psychosocial functioning in youth with and without a NDD by addressing these relations across four groups, including children with ASD, CP, DS, and without any known disability. To date, research has mostly focused on a single condition, with little input from similar research on another disability, precluding the evaluation of disability-(a)specific relationships. Prior to examining associations between parenting and child outcomes across the four groups of children, for descriptive purposes, we will first explore mean-level group differences, applying a balanced perspective that focuses on both positive and negative dimensions of parenting (responsive parenting, autonomy-supportive parenting, psychological control) as well as positive and negative behavioral outcomes (internalizing-externalizing problems and psychosocial strengths). To date, only a few studies have examined mean-level differences in parental behaviors across disabilities. In one relevant study, Blacher et al. (2013) compared longitudinal observations of parenting behaviors across mothers of 12 young children with ASD, 9 with CP, 10 with DS, and 37 with an undifferentiated developmental delay to mothers of 115 preschoolers without any disability. This study reported that observed negative parenting behavior was higher in mothers of preschoolers with a disability. Notably, they reported that observed positive parenting behaviors (including aspects of both responsive and autonomy-supportive parenting) were highest in mothers raising a child with DS. Phillips et al. (2017) compared self-reports of parenting in 35 mothers of school-aged children with DS to 47 mothers of children without a disability. They found that mothers of children with DS used less verbal hostility (related to psychological control) and less reasoning/inductive parenting (related to autonomy-supportive parenting) than mothers of children without a disability.

The second and primary aim of this study is to address group differences in parenting-(mal)adjustment associations, thereby examining the hypothesis that need-supportive socialization (i.e., responsive and autonomy-supportive parenting) will be associated with more positive outcomes (i.e., psychosocial strengths) and that need-thwarting socialization (i.e., psychological control) will be related to more behavioral difficulties (i.e., both internalizing and externalizing problems). Based on SDT's universality claim and research in neurotypical populations, we hypothesize that these relations will generally be similar across all groups.

2.2 Methods

Participants

Overall, 409 parents participated in this study: 95 parents had a child with ASD (*M*age = 12.5 years old), 121 parents had a child with CP (*M*age = 10.9 years old), 73 parents had a child with DS (*M*age = 10.6 years old) and 120 parents had a child without any known disability (*M*age = 11.8 years old). Across all groups, children were on average 11.5 years old (SD = 2.1, age range = 7 - 15), and children from the ASD- and reference group were on average slightly older than the children from the CP- or DS-group. All groups included more boys than girls, but this gender imbalance was less pronounced in the DS- and reference group (53% and 54% boys) than in the CP- and ASD-group (66% and 77% boys). Mothers were the main informants in this study (overall = 94%). They were on average 42.5 years old (SD = 5.0 years old), while fathers were on average 45.0 years old (SD = 5.9 years old). Mothers of the DS-group were, on average, older than mothers of the ASD- ($p = .02$), CP- ($p < .001$) and the reference group ($p < .001$). The majority of the participants has a Belgian nationality (overall = 90.7%), 6.6% a European non-Belgian nationality, and 2.7% a non-European nationality. In line with the recruitment procedure, significantly more parents had a European non-Belgian (i.e., Dutch) nationality in the DS-group compared to the other groups ($\chi^2(6) = 73.66$, $p < .001$). The majority of parents obtained a degree in higher education (overall = 61.9%), varying from 55.1% in the CP-group to 69.7% in the DS-group. No significant differences were found in parents' educational level across groups ($\chi^2(6) = 6.82$, $p = .34$). Neither parents' nationality nor their educational level was related to child or parental behavior (all *p*s > .05).

In each NDD-group, there was large variability in the severity of disability symptoms. In the ASD-group, parents reported on the Social Responsiveness Scale (SRS; Constantino & Gruber, 2005) to identify the presence and extent of social difficulties in their child. The reports showed an average total score of 98.42 (SD = 27.9, range = 50 - 168), indicating that the large majority of the children experienced moderate (14.0%, 61 < T-score < 75) or serious (76.7%, T-score > 75) difficulties in social responsiveness. In the CP-group, children's level of motor functioning was retrieved from medical files and, if needed, supplemented with parent report on the Gross Motor Function Classification System (GMFCS; Palisano et al., 2008; Palisano et al., 1997), indicating that 22.2% of the children functioned at level I (i.e., the child can walk without restrictions but has limitations in more advanced motor skills), 37.6% at level II, 17.9% at level III, 9.4% at level IV, and 12.8% at level V (i.e., the child has very limited motor abilities). In the DS-group, 34.7% of the parents reported that their child had a mild ID (IQ-range = 50 - 69), while 25.3% were diagnosed with a moderate ID (IQ-range = 36 - 49), and 14.6% were reported to have a profound ID (IQ-range = 20 - 35). For the remaining 25.4%, parents reported they did not know the ID-classification of their child with DS. In the ASD-group, 64.2% of the parents provided reports on the intellectual functioning of their child, of which 8.2% (*n* = 5) indicated that their child had an ID (IQ-score < 70). Among parents of children with CP, 66.1% of the parents gave information about the intellectual functioning of their child, where a third (33.8%, *n* = 27) of the parents indicated that their child had an ID. Table 1 shows the demographic characteristics of the overall sample by group status.

Table 1. Demographic characteristics by group (total *n* = 409)

	Autism spectrum disorder (*n* = 95)	Cerebral palsy (*n* = 121)	Down syndrome (*n* = 73)	Without any known disability (*n* = 120)
Child				
Mean age (SD)	12.5 (2.4)	10.9 (2.3)	10.6 (2.2)	11.8 (0.8)
Gender (% boys)	76.8	66.1	53.4	54.2
School: regular (%)	43.2	24.8	26.0	97.5
special (%)	45.3	71.1	56.2	1.7
other or missing (%)	11.6	4.1	17.8	0.8
Informant				
Mother (%)	100.0	86.8	90.4	100.0
Father (%)	0.0	11.6	9.6	0.0
Other (aunt, grandmother) (%)	0.0	1.7	0.0	0.0
Mean age mother (SD)	42.7 (4.7)	41.6 (5.5)	44.7 (5.2)	42.0 (4.2)
father (SD)	46.2 (6.9)	43.0 (5.1)	46.7 (5.8)	44.8 (5.3)
Education level: primary school	4.2	3.3	0.0	2.5
secondary school	29.5	40.5	27.4	35.0
higher education	62.1	53.7	63.0	61.7
missing	4.2	2.5	9.6	0.8

Procedure

This study uses data from an ongoing larger longitudinal project on psychosocial development in children with and without a NDD in Flanders, Belgium. The ASD-group was identified through the registries of four governmental centers, providing at-home support and/or counseling to families of a child with ASD, and by placing announcements on websites regarding ASD. Parents of children with CP were recruited through seven Flemish service centers for children with physical disabilities. The DS-group included parents of a child with DS, who responded to announcements for this research distributed by the major Flemish family organizations for DS and by specified centers, schools, and support services. Additionally, invitations were also sent via a Facebook group of Belgian and Dutch parents of children with DS. The reference group included parents of children without any known disability, who participated in the Flemish Study on Temperament and Personality across Childhood (FSTPC; De Pauw, 2010), a longitudinal study periodically following the development of a cohort of children born in 2004-2005. This sample was used as a reference group, even though the age range in this group was narrower than in the NDD-groups. The study received ethical approval from the Institutional Review Board of the host University and written informed consent was obtained from all participants.

Measures

Responsive parenting. Parents rated their responsiveness towards their child using the corresponding scale from the Child Report of Parenting Behavior Inventory (CRPBI; Schaefer, 1965). This scale consists of seven items (e.g., *"I give my son or daughter a lot of care and attention"*) rated on a five-point Likert scale, ranging from 1 (*Completely not true*) to 5 (*Completely true*). The CRPBI is a well-validated instrument in neurotypical populations (e.g., Pinquart, 2017a) and also showed good reliability in youth with CP (Cohen et al., 2008). Cronbach α's ranged from .63 (DS) to .80 (ASD).

Autonomy-supportive parenting. Parents were administered a reduced version of the well-validated Autonomy Support Scale of the Perceptions of Parents Scale (POPS; Grolnick et al., 1991). Two items of the original seven-items scale, which have to be reverse-scored according to the scoring instruction, were excluded as they tap into controlling parenting rather than into autonomy-supportive parenting (e.g., *"I insist to do everything my way."*). This version includes five items (e.g., *"I am usually willing to consider things from my child's point of view"*), which were scored on a five-point Likert scale ranging from 1 (*Completely not true*) to 5 (*Completely true*). The POPS has been validated for use in parents of children with and without a NDD (Dieleman, De Pauw, Soenens, Mabbe, et al., 2018; Soenens et al., 2007). Cronbach α's ranged from .60 (ASD) to .77 (RG).

Psychologically controlling parenting. Parents filled out the eight items of the Psychological Control Scale (PCS; Barber, 1996), which addresses several key aspects of psychologically controlling parenting, including guilt-induction (e.g., *"I blame my child for other family members'* *problems"*), intrusiveness (e.g., *"I try to change how my child feels or thinks about things"*), and love withdrawal (e.g., *"I am less friendly with my child when s/he does not see things my way"*). Items are scored on a five-point Likert scale, ranging from 1 (*Completely not true*) to 5 (*Completely true*). This instrument has been validated and frequently used in past research among children with and without a NDD (Dieleman, De Pauw, Soenens, Mabbe, et al., 2018; Mabbe et al., 2016). Cronbach α's ranged from .62 (DS) to .79 (CP).

Internalizing and externalizing problems. Emotional and behavioral problems were assessed with the Child Behavior Checklist/6-18 (CBCL; Achenbach, 2001). Using a three-point Likert scale, parents indicated how often a child displayed specific behavior over the past six months, ranging from 0 (*Never*) to 2 (*Often*). The broadband scale internalizing problems comprised two scales: anxious/depressed (13 items; e.g., *"Cries a lot"*) and withdrawn/depressed (8 items; e.g., *"Enjoys little"*). We did not include somatic complaints, as we considered that, given to the specific nature of the NDD-groups, medical problems could falsely overestimate this internalizing score, especially within the CP- and DS-group. The broadband scale externalizing problems included two scales: rule-breaking (17 items; e.g., *"Lies and cheats"*) and aggressive behavior (18 items; e.g., *"Destroys things belonging to others"*). The CBCL previously showed to be adequate for examining emotional and behavioral problems in youth with and without a disability (e.g., Holtmann et al., 2007; van Gameren-Oosterom et al., 2011). In this study, Cronbach α's ranged from .80 (DS) to .89 (ASD) for internalizing and from .83 (RG) to .92 (ASD) for externalizing problems.

Child psychosocial strengths. Parents rated their child's psychosocial strengths using the Behavioral and Emotional Rating Scale-2 (BERS-2; Epstein, 2004), a strengths-based assessment scale specifically designed for addressing positive behavioral qualities of children in vulnerable situations. Each item is rated on a five-point Likert scale, ranging from 1 (*Completely not true*) to 5 (*Completely true*). The overall strengths index comprises four subscales: interpersonal strengths (15 items; e.g., *"Admits mistakes"*), family involvement (10 items; *"Trusts a significant person with his/her life"*), intrapersonal strengths (11 items; *"Demonstrates a sense of humor"*), and affective strengths (7 items; *"Expresses affection for others"*). The BERS-2 was developed to be broadly applicable and recently scholars have successfully used this questionnaire in research on children with a disability (e.g., Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; Sointu et al., 2012). Cronbach α's ranged from .92 (ASD) to .96 (RG).

Data analysis

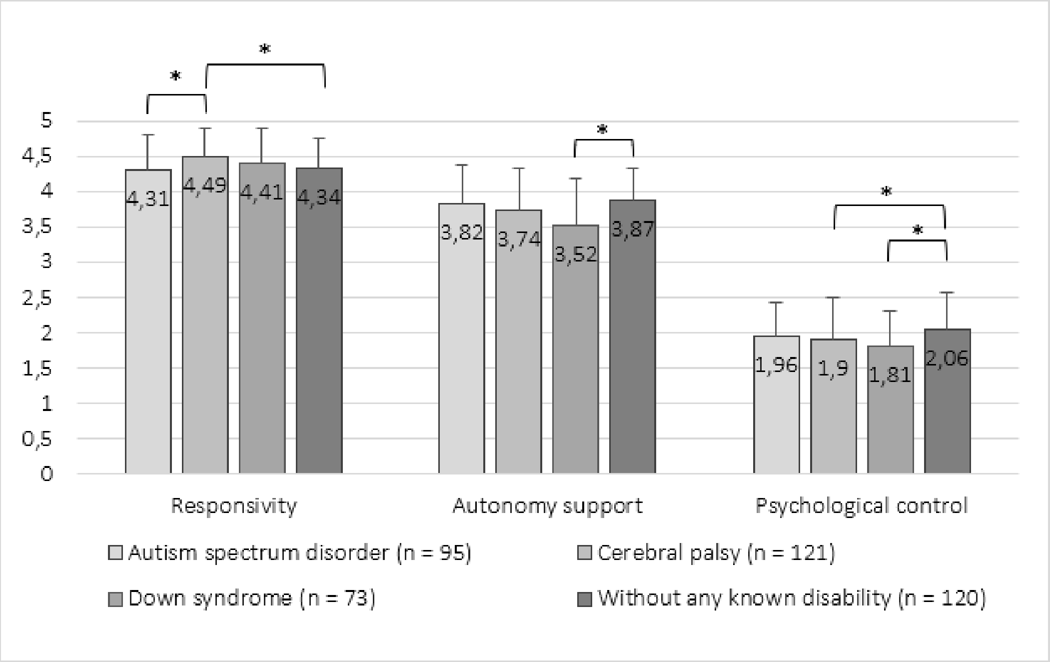
Given the non-normal distribution of problem behaviors in each group, Kruskal-Wallis H tests were conducted to examine group differences in both parenting and psychosocial behavioral outcomes. The associations between parenting, on the one hand, and emotional and behavioral problems and psychosocial strengths, on the other hand, were examined by bivariate correlation analyses within each group. Multi-group structural equation modeling (SEM) using Mplus 8.3 (Muthén & Muthén, 1998–2012) was performed to evaluate the SDT-based premises that need-supportive parenting is associated with psychosocial strengths, whereas need-thwarting parenting is linked with behavioral difficulties in and across all groups. Missing values were missing completely at random, as the normed χ^2/df (4489.10/3525) was 1.27 (i.e., smaller than the recommended cut-off of 2; Ullman, 2001). Hence, model parameters were estimated using the full information maximum likelihood procedure (Schafer & Graham, 2002). When conducting χ^2-difference tests using the MLR estimator, χ^2 was adjusted using the Satorra-Bentler scaling correction (Satorra & Bentler, 1994). An item-to-construct balance method was used for constructing parcels with regard to the three parenting constructs. Within this method, an item with the highest item-scale correlation is paired with the item with the lowest item-scale correlation. Subsequently, the next highest and next lowest items were paired in a second parcel, and so on (Landis et al., 2000). This method was also used with regard to emotional and behavioral problems since the model did not converge using the CBCL-subscales as parcels and more than two indicators are recommended per construct (Little, 2013). This item-to-construct balance method at the item-level resulted in three parcels for each parenting scale and in five parcels for internalizing and for externalizing problems. Two CBCL-items (*"Sets fires"*, *"Uses drugs for nonmedical purposes"*) were excluded from the analyses, as no parent endorsed these items. As the conceptual construct of psychosocial strengths is multidimensional in nature, we used the internal-consistency approach (Kishton & Widaman, 1994), using the four BERS-subscales as indicators of the latent factor for psychosocial strengths (see Figure 3).

2.3 Results

Group differences in parenting, problem behaviors, and psychosocial strengths

Kruskal-Wallis H tests were conducted to examine group differences in both parenting dimensions and psychosocial behavioral outcomes (Table 2). In all groups, we found relatively high and comparable levels of responsive and autonomy-supportive parenting as well as low levels of psychologically controlling parenting. These analyses revealed five significant, yet modest group differences (Figure 1). Levels of responsive parenting were highest in parents of a child with CP, and significantly higher than reported by parents from the reference ($d_{\text{CP-RG}}$ = .35) and ASD-group ($d_{\text{CP-ASD}}$ = .39). Levels of autonomy support were highest in parents from the reference group but they were only slightly higher than in parents raising a child with ASD or CP. Only parents of a child with DS provided significantly less autonomy support than parents from the reference group ($d_{\text{RG-DS}}$ = .60). Levels of psychologically controlling parenting were markedly lower than need-supportive parenting behaviors. Again, these levels were highest in parents from the reference group, followed by parents raising a child with ASD, CP, and DS. Notably, differences were only statistically significant between parents from the reference group and parents raising a child with CP ($d_{\text{RG-CP}}$ = .29) or DS ($d_{\text{RG-DS}}$ = .50).

Figure 1. Group differences in need-supportive and need-thwarting parenting behaviors

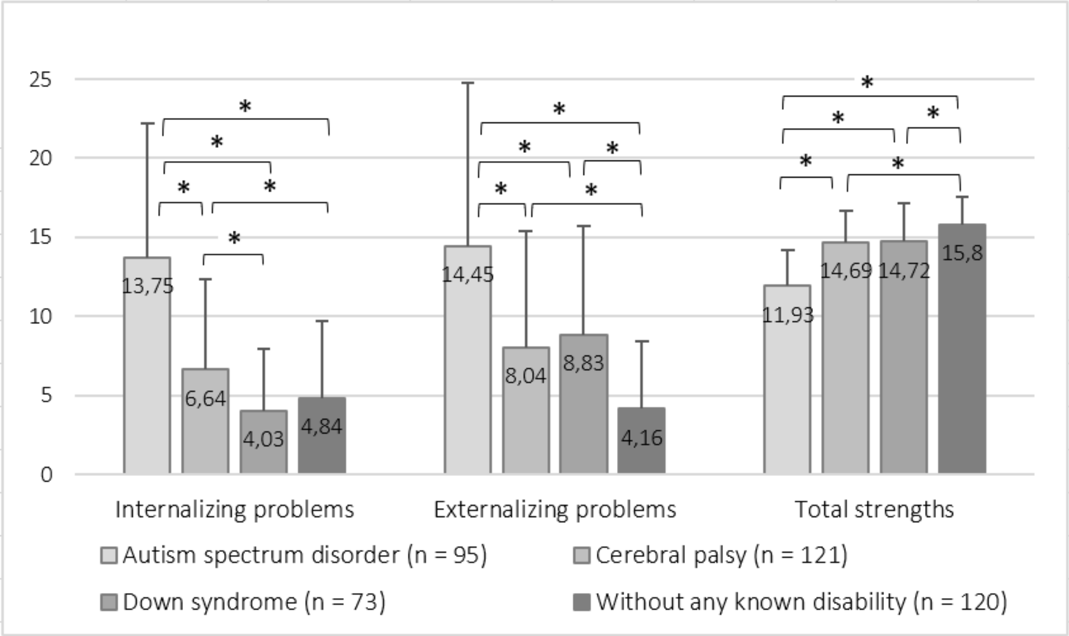


Note. $^{*}p < .05$.

In contrast to the modest mean-level differences in parenting, analyses revealed striking group differences in psychosocial outcomes: five of six pairwise group comparisons were significant for children's internalizing and externalizing problems, as well as for psychosocial strengths (Figure 2). As anticipated, children with ASD showed the most challenging profile, with on average the highest levels of internalizing and externalizing problems and the lowest levels of psychosocial strengths across the four groups. Effect sizes were large to very large in magnitude for internalizing

(d_{ASD-CP} = .99, d_{ASD-DS} = 1.48, d_{ASD-RG} = 1.29), moderate to very large for externalizing problems (d_{ASD-DS} = .64, d_{ASD-CP} = .70, d_{ASD-RG} = 1.31), and very large for psychosocial strengths (d_{ASD-RG} = 1.92, d_{ASD-CP} = 1.30, d_{ASD-DS} = 1.20). Children without any known disability showed, as expected, the least externalizing problems and the most psychosocial strengths. Interestingly, parents of children with DS reported the lowest internalizing problems, but this was not significantly lower than in the reference group. Children with CP, however, showed a higher risk to develop internalizing problems than the reference (d_{CP-RG} = .34) and DS-group (d_{CP-DS} = .53). Both children with DS (d_{DS-RG} = .81) and with CP (d_{CP-RG} = .65) had comparable yet elevated levels of externalizing problems. Children with DS and CP also had comparable levels of psychosocial strengths, which were only moderately lower than children without any known disability (d_{DS-RG} = -.51, d_{CP-RG} = -.59).

Figure 2. Group differences in internalizing and externalizing problems and psychosocial strengths



Note. $^{*}p < .05$

Associations between parenting and psychosocial outcomes across groups

As Kruskal Wallis H and Chi-square tests identified group differences in child age ($H(3) = 41.87$, $p < .001$), child gender ($\chi^2(3) = 16.44$, $p < .001$) and the age of the informant ($H(3) = 26.02$, $p < .001$), correlations were controlled for these demographic differences. Differences between groups were evaluated by pairwise comparisons of the magnitude of the correlations, after Fisher *r*-to-*z*-transformation. None of the 90 possible bivariate pairwise comparisons reached statistical

Table 2. Parenting behaviors, emotional and behavioral problems, and psychosocial strengths across groups (*n* = 409)

	Autism spectrum disorder (*n* = 95)			Cerebral palsy (*n* = 121)			Down syndrome (*n* = 73)			Without any known disability (*n* = 120)		
	M	*(SD)*	α	M	*(SD)*	α	*M*	*(SD)*	α	*M*	*(SD)*	α
Parenting												
Responsive	4.31^{a}	(0.49)	.80	4.49^{b}	(0.42)	.77	$4.41^{a,b}$	(0.48)	.63	4.34^{a}	(0.43)	.76
Autonomy-supportive	$3.82^{a,b}$	(0.55)	.60	$3.74^{a,b}$	(0.60)	.69	3.52^{a}	(0.68)	.64	3.87^{b}	(0.47)	.77
Psychological control	$1.96^{a,b}$	(0.46)	.66	1.90^{a}	(0.60)	.79	1.81^{a}	(0.50)	.62	2.06^{b}	(0.51)	.74
Problem behavior												
Internalizing	13.75^{a}	(8.44)	.89	6.64^{b}	(5.71)	.87	4.03^{c}	(3.91)	.80	4.84^{c}	(4.87)	.83
Externalizing	14.45^{a}	(10.30)	.92	8.04^{b}	(7.33)	.90	8.83^{b}	(6.92)	.87	4.16^{c}	(4.26)	.83
Psychosocial strengths												
Total strengths	11.93^{a}	(2.25)	.92	14.69^{b}	(2.00)	.95	14.72^{b}	(2.41)	.95	15.80^{c}	(1.76)	.96

Note. *M* Means of sum scores, *SD* Standard deviation, *α* Cronbach alphas. Values with different superscripts indicate significant differences (*p* < .05) between groups tested with the Kruskal-Wallis H test, adjusted by the Bonferroni correction for multiple tests.

significance ($p < .001$). This finding indicated a rather consistent pattern of covariation across the four groups (Table 3).

Table 3. Partial correlations between parenting behaviors, emotional and behavioral problems, and psychosocial strengths within the four study groups, while controlling for child age, child gender, and informant age (n = 409)

	Autism spectrum disorder (n = 95)					Cerebral palsy (n = 121)				
	1	2	3	4	5	1	2	3	4	5
1. Responsive										
2. Autonomy-supportive	0.42^{***}					0.33^{**}				
3. Psychological control	-0.09	-0.15				-0.36^{***}	-0.16			
4. Internalizing problems	0.01	0.25^{*}	0.04			-0.13	-0.01	0.18		
5. Externalizing problems	-0.15	-0.08	0.23^{*}	0.36^{**}		-0.12	-0.03	0.28^{**}	0.65^{***}	
6. Psychosocial strengths	0.26^{*}	0.15	-0.02	-0.33^{**}	-0.53^{***}	0.28^{**}	0.23^{*}	-0.13	-0.41^{***}	-0.45^{***}
	Down syndrome (n = 73)					Without any known disability (n = 120)				
1. Responsive										
2. Autonomy-supportive	0.39^{**}					0.36^{***}				
3. Psychological control	-0.31^{*}	0.06				-0.46^{***}	-0.30^{**}			
4. Internalizing problems	-0.04	-0.11	0.07			-0.14	-0.05	0.13		
5. Externalizing problems	-0.03	-0.08	0.45^{***}	0.43^{**}		-0.16	-0.23^{*}	0.24^{*}	0.38^{***}	
6. Psychosocial strengths	0.18	0.40^{**}	-0.01	-0.46^{***}	-0.48^{***}	0.47^{***}	0.32^{**}	-0.36	-0.47^{***}	-0.45^{***}

Note. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

In each group, sizeable yet moderate correlations between responsive and autonomy-supportive parenting were found. Psychological control was negatively and moderately related to responsive parenting in each group, but surprisingly not to autonomy support in the three NDD-groups. In the reference group, there was a moderate negative correlation (r = -.30). As anticipated, sizeable positive correlations between the two problem scales and negative correlations between behavioral problems and psychosocial strengths were found in each group. Regarding parenting-adjustment associations, evidence for differential relations was found in each group, yielding modest to moderate correlations. In all groups, psychologically controlling parenting was associated with more externalizing problems (rs ranging from .23 in children with ASD to .45 in children with DS). In children with CP and children without any known disability, both responsive and autonomy-supportive parenting were related to more psychosocial strengths. In children with DS, a sizeable association (r = .40) between autonomy support and psychosocial strengths was replicated, but the correlation with responsive parenting did not reach significance. In children with

ASD, we found that responsive parenting but not autonomy support was associated with more strengths. Notably, internalizing problems were not associated with any of the parenting dimensions, except for a modest relation in the ASD-group, where more autonomy-supportive parenting was related to more internalizing problems (r = .25).

Structural relations between parenting behavior and psychosocial outcomes across groups

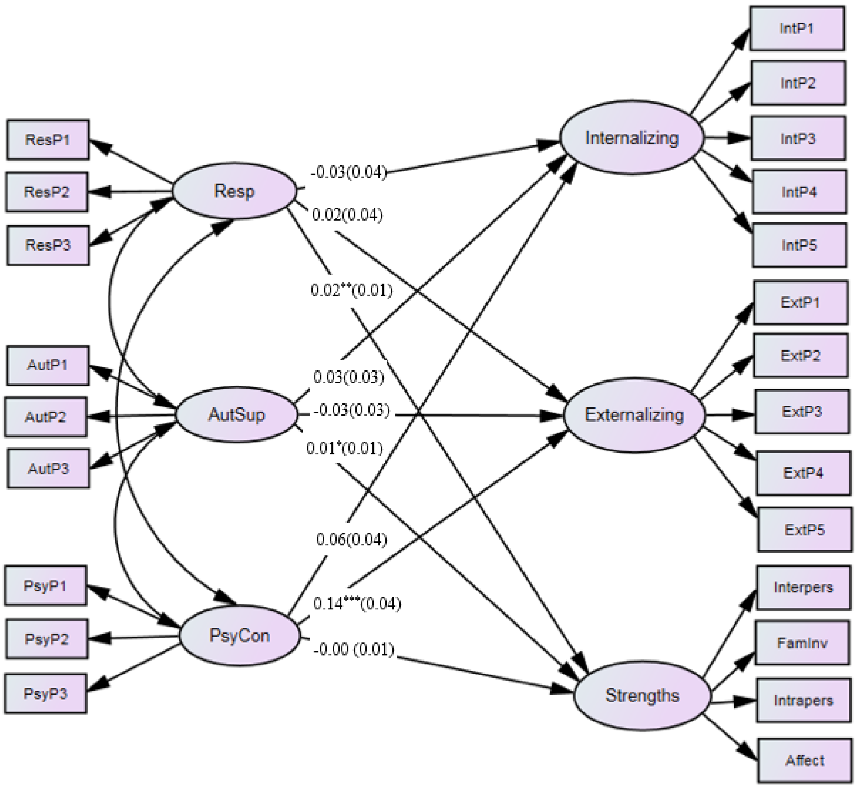
In a first step, we examined measurement equivalence of the scales across the four groups, creating two separate measurement models: one for the parenting variables and one for the behavioral variables. In the first measurement model on parenting, a fully unconstrained model where all factor loadings were allowed to vary between groups was compared to a constrained model where the factor loadings were fixed to be equal across the groups. Results showed that the constrained model fitted the data equally well as the unconstrained model (ΔSBS-$\chi^2(18) = 20.09$, $p = .33$), indicating factorial invariance (Meredith, 1993) of the three parenting scales across groups. In the second measurement model on the behavioral variables, the fully unconstrained model fitted the data better than the model with constrained factor loadings (ΔSBS-$\chi^2(33) = 89.24$, $p < .001$). Further analyses determined which loadings differed across groups. Three factor loadings differed significantly between groups: internalizing problems on the third and fifth parcel, and externalizing problems on the second parcel. Hence, the final measurement model consisted of constrained factor loadings for the parenting variables and three freely estimated factor loadings for the behavior variables.

In a second step, the structural model was tested, comparing constrained models to unconstrained models for each behavioral variable separately, in order to not overload the model. These analyses indicated no significant differences in the behavioral variables. The partially constrained model with unconstrained correlations between the latent variables had a significantly better fit than the constrained model with constrained paths between the latent variables (ΔSBS-$\chi^2(18) = 51.21$, $p < .001$). Further analyses indicated that this difference was due to a significantly stronger correlation between internalizing and externalizing problems in the CP-group compared to the other groups (ΔSBS-$\chi^2(3) = 15.60$, $p < .001$) and a significantly stronger correlation between externalizing behavior and psychosocial strengths in the ASD-group compared to the other groups (ΔSBS-$\chi^2(3) = 17.58$, $p < .001$). Additionally, interaction effects between the parenting domains were explored across and within the study groups, but no significant interactions were found.

In a final step, we also controlled for the influence of the demographic variables child age, child gender, and informant age. Only child age had a significant effect on the behavioral variables.

Overall, older children with CP and DS showed more psychosocial strengths, and older children with CP and ASD scored lower on externalizing problems than younger children. Older children with CP also showed more internalizing problems. No age effect was found in the reference group. Results from the final model, in which we controlled for these effects ($\chi^2(1199) = 1863.14$, $p < .001$; CFI = 0.852, SRMR = 0.108, TLI = 0.841, RMSEA = 0.077) are shown in Figure 3. This final model (Figure 3) identified three significant associations that held across all four groups. The first relationship indicated that, in all groups, higher levels of psychologically controlling parenting were positively related to externalizing problems. A relationship between parenting and internalizing problems did not emerge. The second and third significant relationship showed that higher levels of responsive parenting as well as higher levels of autonomy support related to more psychosocial strengths in all groups. Hence, this model supports the SDT-based premises in all groups. Only the anticipated relationship between need-thwarting parenting and internalizing problems was not corroborated.

Figure 3. Final structural model depicting the relation between parenting behaviors and children's psychosocial development



Note. Resp Responsive parenting, *AutSup* Autonomy-supportive parenting, *PsyCon* Psychologically controlling parenting. Unstandardized coefficients (standard errors) are reported on the arrows that indicate direct effects between parenting behavior and psychosocial outcomes. The six latent variables and their indicators, displayed by three, four or five parcels, are represented in respectively oval and square boxes. We estimated the correlations between the latent variables in the model but these are not presented for reasons of parsimony. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

2.4 Discussion

Although associations between parenting and behavioral child outcomes have been extensively studied in neurotypical populations, research on these relations in children with a NDD, such as ASD, CP, and DS, is still in its infancy. The last decade has witnessed a growing interest in family dynamics in these groups, yet most studies have focused on the elevated levels of stress in parents of children with a NDD (e.g., Hayes & Watson, 2013; Pinquart, 2013; Yorke et al., 2018) and not on parenting behaviors (Dieleman et al., 2017; Maljaars et al., 2014; Phillips et al., 2017). Moreover, the limited, available empirical research has mostly focused on one specific disability, thereby limiting the possibilities to identify potential disability-specific parenting dynamics. Also, these few studies commonly relied on small to modest sample sizes (e.g., Blacher et al., 2013; Phillips et al., 2017; Ventola et al., 2017).

Exploring differences across groups

The first aim of this study was to explore mean-level differences in parenting, emotional and behavioral problems, and psychosocial strengths across the four study groups. All included instruments were originally developed for neurotypical populations of children and adolescents but acceptable to excellent internal consistencies were found for all scales in this study, warranting their use in research with NDD-populations. Strikingly, levels of parenting behaviors did not vary widely between groups. In each group, parents reported high levels of responsive and autonomy-supportive parenting and low levels of psychologically controlling parenting. Nevertheless, some small to modest group differences were found, yielding intriguing indications on disability-specific aspects of parenting. First, parents of children with CP reported significantly more responsive parenting than parents of children without any known disability or children with ASD. Even though these effects were small, they mesh with observations that children with CP often develop intense and close relations with their parents, so that parents are strongly attuned to their child's needs for both physical and emotional support (Whittingham et al., 2013). Parents of children with DS also reported high levels of responsive parenting, but these were not significantly different than in other groups. Hence, this study (based on self-report) does not confirm Blacher et al.'s (2013) suggestion (based on observations) that children with DS may evoke more positive parenting behaviors than children with other disabilities, such as ASD, given the presumed more positive personality characteristics in DS (i.e., being cheerful and friendly).

Second, parents in the DS-group reported significantly lower levels of autonomy support than parents in the reference group. This moderate effect is in line with suggestions emerging from earlier studies showing that parents of young children with DS tend to be more directive than parents whose children are developing without disabilities (de Falco et al., 2011; Glenn et al., 2001). However, this is not a consistent finding as some studies found no significant group differences in directiveness and autonomy-supportive parenting (e.g., Gilmore et al., 2009). A more in-depth examination with qualitative interviews clarified that even though mothers of children with DS reported that they held strong aspirations for their child's future autonomy and independence, they often felt that their capacity to promote autonomy was constrained by a range of child and family factors, such as concerns about the child's safety, difficulties with communication, competing family responsibilities, sensory issues or sibling influences (Gilmore et al., 2016). Future research should further replicate and evaluate these potential barriers for autonomy support towards children with DS, in comparison to other disability conditions. In this regard, this study found no differences in autonomy support between the ASD-, CP- and reference group, even though parents raising a child with ASD or CP might face diverse challenges in promoting their child's autonomy.

Third, parents in both the CP- and the DS-group reported lower levels of psychological control than parents in the reference group. Interestingly, the finding for DS corroborates a study by Phillips et al. (2017) who observed less verbal hostility in mother-child interactions in families raising a child with DS compared to a reference group. These authors related this finding to the presumed more characteristically pleasant personalities of the child with DS, even hypothesizing that this unique phenotype in DS may lead to the use of less coercion in these families, compared to children with other disabilities. Again, this intriguing hypothesis warrants further inquiry, preferably by studies addressing both quantitative and qualitative differences in parenting and simultaneously evaluating these processes in and across multiple disabilities.

Although not a central aim of this study, our findings further confirmed that mean levels of both internalizing, externalizing, and psychosocial strengths strongly varied across groups, a finding contrasting sharply with the minor mean-level differences in parenting. In line with previous research (De Pauw et al., 2011; Maljaars et al., 2014), children with ASD were rated with the most challenging behavioral profile, showing the most internalizing and externalizing problems and the lowest scores on psychosocial strengths. These large group differences partly reflect diagnostic features of ASD (e.g., lower interpersonal skills), yet also corroborate the finding that children with ASD are at increased risk to developing more anxious, withdrawn, depressive as well as more rule-breaking and aggressive behaviors (De Pauw et al., 2011; Maljaars et al., 2014). However, the large variances in these emotional and behavioral scales suggest that it would be unwarranted to create stereotypes of children with ASD based on their mean-level profile. Instead, these large variances call for a consideration of the unique psychosocial difficulties and strengths of each individual with ASD.

The mean-level differences in emotional and behavioral problems also corroborate previous findings that children with CP show elevated levels of externalizing and – to a lesser extent – internalizing problems compared to controls (Parkes et al., 2008; Vrijmoeth et al., 2012). Our cross-disability comparison also revealed that children with DS were rated with the lowest levels of internalizing problems of all groups, which is also in line with prior findings (van Gameren-Oosterom et al., 2011). This lower score might reflect true differences, but an alternative explanation might be that children with DS have fewer abilities to express these feelings and experiences, which makes it more difficult for parents to recognize these symptoms. Notably, the mean score on externalizing problems in children with DS was (just as in children with CP) more than twice as high than the mean score in the reference group. This finding confirms that also children with DS are at increased risk to develop behavioral difficulties (Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; van Gameren-Oosterom et al., 2011). Yet, also in these groups, there was a large variation in parents' reports of difficulties.

In addition to its focus on behavioral and emotional problems, this study addressed psychosocial strengths in and across the four groups. We found that in all four groups, parents reported relatively high levels of psychosocial strengths in their children despite relatively large group differences. Children from the reference group scored only about 0.52 SD higher than children with DS and CP, but 1.51 SD higher than children with ASD. This research provides additional support that addressing a child's strengths is important in both research and practice, as it might provide crucial keys to support children and their families. Focusing on a child's strengths, as well as his/her behavioral or emotional difficulties, not only provides a more holistic view of the child but can also facilitate feelings of empowerment and positivity in support interventions (Dieleman, De Pauw, Soenens, Van Hove, et al., 2018).

Testing a Self-Determination Theory-based model of parenting-adjustment associations

The second, and most important aim of this study was to address SDT-based premises on how the three parenting dimensions relate to problem behaviors and postulated strengths, in and across the four groups. Based upon SDT's universality claim, we expected the emergence of two differential pathways in all four groups: a 'bright' pathway indicating that need-supportive parenting is associated with more psychosocial strengths, versus a 'dark' pathway showing that need-thwarting parenting is associated with more problem behaviors (Soenens et al., 2017; Vansteenkiste & Ryan, 2013).

Overall, based upon both correlational analyses and multi-group SEM, this study provides cross-disability support for these two differential paths. Pairwise comparisons of correlations across groups yielded no significant differences, providing the first evidence for similarity in the pattern of parenting-adjustment associations across groups. Multi-group SEM-analyses further supported measurement invariance for both parenting and behavioral variables. These multi-group SEM-analyses revealed three significant paths, uncovering a ‘bright’ and ‘dark’ pathway. In all groups, both indicators of contextual need-support (i.e., responsive and autonomy-supportive parenting) related to more psychosocial strengths, whereas the indicator for need-thwarting parenting, psychological control, was associated with more externalizing problems in the child. In contrast to other studies (Barber & Harmon, 2002; Pinquart, 2017b), this study did not find a significant association between parenting and internalizing problems, except for a small and counter-intuitive correlation in the ASD-group, where more autonomy support related to more internalizing problems. Previous research on the association between parental control and child outcomes in children with developmental delays showed mixed findings (Green et al., 2014). These mixed findings may be partially accounted by the potential differences between types of parental control (Grolnick & Pomerantz, 2009). On the one hand, constructive control, which is described as ‘structure’ in SDT literature, is related to the child’s current focus or goal (Soenens et al., 2017). This type of control is suggested to be beneficial, especially for children who need structure, prompting, and direction because of their disability. On the other hand, intrusive or interfering control, which is unrelated to the child’s goal, is suggested to be detrimental (Green et al., 2014). The counterintuitive correlation in the ASD-group might be related to a disability-specific effect, where parenting behavior that might be considered developmentally appropriate for most children, might be experienced as less supportive for a child with ASD. For instance, autonomy-supportive parenting behavior that encourages initiative, by providing choice and stimulating dialogue, might be experienced as more stress-inducing for a child with ASD, who is likely to need more structure and direction. Nonetheless, more research is needed to replicate and unravel the meaning of this relation in raising a child with ASD. Furthermore, associations between parenting and internalizing problems might be underestimated when relying only on parent reports, because internalizing problems sometimes remain unnoticed by parents (Kolko & Kazdin, 1993; van de Looij-Jansen et al., 2010). Therefore, future research would do well to include also child reports of parenting and child behavior.

Overall, this study corroborates associations between need-supportive parenting and beneficial outcomes and associations of need-thwarting parenting with behavioral problems in all children, regardless of the diagnostic group. Consequently, this study provides unique, yet cross-sectional evidence for the universality claim of SDT in the context of parenting a child with a NDD. As such, it complements the few conceptual and empirical SDT-based studies on the benefits of basic need satisfaction in special education settings (Deci & Chandler, 1986; Deci et al., 1992; Katz & Cohen, 2014; Shea et al., 2013). Importantly, the associations obtained in this study need to be interpreted from a transactional perspective on parenting. That is, need-supportive parenting is likely to not only foster children's psychosocial strengths but also to be affected by these strengths. It seems likely that it is easier for parents to be patient and attuned to their child's needs when their child is socially competent and emotionally stable. Similarly, psychologically controlling parenting and externalizing problems are likely to mutually reinforce one another in a vicious negative cycle (Pinquart, 2017a). Taken together, this study adds cross-disability evidence for a 'dark' pathway, revealing that guilt induction, shaming, and love withdrawal strongly relate to behavioral problems in all groups. Also, it sheds light on a 'bright' pathway in and across children with and without ASD, CP, and DS, indicating that sensitive, warm parents who seek to attune their parenting to the developmental needs of their child and actively search for opportunities to promote autonomy, also recognize and/or reinforce more psychosocial strengths in their child.

These findings have both theoretical and practical relevance, as they identify SDT as a valuable theory to further examine motivational dynamics to promote the well-being and quality of life of both children with a NDD and their families. As SDT-based interventions in neurotypical populations now suggest that encouraging parents to engage in need-supportive parenting is beneficial for both parents' and children's mental health (Allen et al., 2019; Joussemet et al., 2014) these interventions might be beneficial for families raising a child with a NDD as well. Additionally, these findings underscore the importance for parents of children with a NDD to be responsive and autonomy-supportive towards their child, even though they are frequently challenged to cope with difficult child behavior. In order to better understand these findings, future research could examine more in-depth how parents' expectations of their child and coping strategies relate to their parenting behaviors (Heiman, 2002).

Limitations and future directions

When interpreting the current results, some limitations need to be taken into account. First, the generalizability of the findings is limited by the specific choice of parenting and behavior parent-report instruments and by relying on mothers as the primary source of information. Future research should replicate whether these relations also generalize across alternative measures of parenting, such as observations, and other indicators of behaviors and well-being. Also, future research could benefit from including multiple informants, especially fathers, as prior research highlighted the significant impact of paternal parenting on child development (Prinzie et al., 2009). Furthermore, the majority of participating parents had a Belgian nationality, were highly educated, and participated voluntarily, which might impact the generalizability of the findings as well. For instance, because financially well-resourced parents generally face fewer stressors, it might be easier for them to display stably high levels of warm parenting (Taraban & Shaw, 2018). Hence, future research should attempt to collect more diverse samples of parents.

Second, this study did not formally tap into the mediating mechanism of basic psychological need satisfaction/frustration in the relation between socialization contexts and behavioral outcomes. Future studies should assess such experiences of need satisfaction or need frustration in children with a NDD. Recently, a self-report questionnaire operationalizing satisfaction and frustration with the three basic SDT-needs has become available for adults with mild ID (Frielink et al., 2019), yet more work is needed to address need satisfaction in younger age groups with disabilities.

Third, it could be interesting to further explore the impact of other factors that previously have been shown to regulate or moderate differences in how parenting behavior relates to children's psychosocial development, such as child temperament and personality (De Pauw et al., 2011; Mabbe et al., 2016), parental personality (Prinzie et al., 2009), parental psychological functioning, stress, and support (Taraban & Shaw, 2018). Given the elevated levels of parental stress among parents of children with a NDD (e.g., Hayes & Watson, 2013; Phillips et al., 2017; Pinquart, 2013), parental stress might be a particularly important mediator in the relation between parenting and child behavior within these families (Dieleman, De Pauw, Soenens, Mabbe, et al., 2018; Yorke et al., 2018). Also the role of children's intellectual functioning was not comprehensively addressed in this study, as we primarily relied upon parent reports and not all parents provided IQ information of their child. In future research, more objective assessments of intellectual functioning should be included.

Finally, the cross-sectional design of this study allowed no causal interpretations of the relations between parenting and child behavior. Most likely, these relations are bidirectional in nature, with parenting not only affecting children's development but also with children's behavior eliciting specific parental behaviors. Future research with prospective longitudinal designs should evaluate this fundamental issue of transactional developmental effects in and across children with and without a NDD. Previous research confirmed the bidirectional relationships between SDT-based parenting practices and child behavior problems in youth with ASD (Dieleman et al., 2017), but no study to date explored these processes in families of children with CP or DS.

2.5 Conclusion

This study showed that parenting is associated with behavioral outcomes in large samples of children with and without ASD, CP, and DS. Our analyses revealed only minor mean-level differences in parenting behaviors across the study groups, despite large differences in children's behavioral presentations. In addition, our findings provide cross-disability support for the similarity of parenting-adjustment associations across children with and without ASD, CP, or DS. In all groups, two differential paths emerged: need-supportive parenting (responsive and autonomy-supportive parenting) was associated with more positive outcomes (psychosocial strengths) and need-thwarting parenting (psychological control) was related to more behavior difficulties (externalizing, but not internalizing problems). Overall, this study suggests that SDT may be a valuable framework to study parenting dynamics in families raising a child with a NDD. Corroborating the beneficial links of need-supportive parenting and the detrimental association of need-thwarting parenting with children's psychosocial development, this study provides initial support to SDT's universality claim that *"all children need to feel competent, autonomous, and loved"* (Deci et al., 1992), including those growing up with special needs.

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Chapter 3

Parenting and child personality as modifiers of the psychosocial development in youth with autism spectrum disorder: A nine-year longitudinal study at the level of within-person change

Based on De Clercq, L., Dieleman, L. M., Van der Kaap-Deeder, J., Soenens, B., Prinzie, P., & De Pauw, S. S. W. (2020). Negative controlling parenting and child personality as modifiers of psychosocial development in youth with autism spectrum disorder: A 9-year longitudinal study at the level of within-person change. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04761-4

Abstract

This nine-year longitudinal study addresses the joint contribution of parent-rated externally controlling parenting and child personality on psychosocial outcomes in 141 families of children with autism spectrum disorder (83% boys, mean age Time 1 = 10.1 years old). Latent change modeling revealed substantial variation in within-person change in parenting and psychosocial outcomes across a six- and three-year interval. Over time, externally controlling parenting and child personality were consistently related to externalizing problems, whereas personality was differentially related to internalizing problems and psychosocial strengths. Three personality-by-parenting interactions were significant, suggesting that children with less mature personality traits show more externalizing behaviors in the presence of externally controlling parenting. Overall, this study identified both parenting and child personality as important modifiers of developmental outcomes in youth with autism spectrum disorder.

3.1 Introduction

The past decades have witnessed an increasing interest in studying psychosocial development in youth with autism spectrum disorder (ASD) across adolescence and emerging adulthood. Studies focusing on the development of ASD core symptoms in this age period documented a general, yet modest, improvement in social communication and adaptation across adolescence (e.g., Gray et al., 2012; McGovern & Sigman, 2005; Taylor & Seltzer, 2010; Woodman et al., 2015). However, adolescence is quite a challenging period for youth with ASD, even more than is the case for their peers without ASD. During adolescence, the increasing emphasis on social interactions outside the family, including peer relationships, accentuates the social challenges of youth with ASD. Also, the demands for increasingly mature roles and responsibilities might be more difficult to accommodate for youth with ASD (e.g., McCauley et al., 2019). Importantly, these studies emphasized remarkable behavioral heterogeneity in psychosocial developmental outcomes in this age period, both across and within samples of youth with ASD.

To better comprehend this wide variation in the psychosocial development of children with ASD, Chetcuti et al. (2019) recently advocated that researchers should go beyond the inquiry of ‘ASD-specific sources’. In particular, they nominated parenting factors and child personality differences as potential ‘transdiagnostic’ or ‘non-syndrome-specific’ factors, standing poised to provide a richer understanding of heterogeneity in ASD. Their suggestion is consistent with the *Modifier Model of Autism* (McCauley et al., 2019; Mundy et al., 2007). This model postulates that the large heterogeneity within the behavioral phenotype of children and adolescents with ASD arises from at least two sources: *syndrome-specific Initial Causal Processes* (ICPs) and *non-syndrome-specific Modifier Processes* (MPs). According to this model, varied constellations of genetic and neurodevelopmental ICPs contribute to differences in ASD expression at different ages. In addition to these more biological etiological interactions, this model proposes that processes *not specific* to the biological etiology of ASD may also be considered as important non-etiological moderators of the course and outcome of ASD across youth. Specifically, this model identifies both *parenting* and *personality trait variation* as two non-syndrome-specific moderators that may contribute to a better understanding of the wide heterogeneity in ASD (McCauley et al., 2019; Mundy et al., 2007).

The current study builds upon these theoretical suggestions in four important ways. First, this study focuses on *externally controlling parenting* as a first potential transdiagnostic contextual influence on the psychosocial development of adolescents with ASD. In the broader developmental literature, many studies demonstrated that externally controlling parenting behaviors, such as overreactivity, coercive, or harsh discipline, or psychological control are systematically related to behavioral and/or emotional problems (Pinquart, 2017a, 2017b; Soenens et al., 2019). To date, a handful of studies observed cross-sectional associations between parent-rated controlling parenting and behavioral problems in samples of youth with ASD (Boonen et al., 2014; De Clercq et al., 2019; O'Nions et al., 2019; Ventola et al., 2017). Also, a few short-term longitudinal studies supported these associations in the context of ASD. For example, Lindsey et al. (2020) demonstrated that parent-rated controlling behavior predicted unique variance in child externalizing and internalizing behaviors one year later. Similar results were found by Bader and Barry (2014), showing that higher levels of parental criticism, rated in parents' five-minute speech samples, predicted higher levels of child externalizing behaviors two years later. Additionally, a series of studies following 170 families of adolescents and adults with ASD (aged 11 - 44 years old) showed that higher levels of maternal criticism towards their child with ASD, again rated in parents' five-minute speech samples, were bidirectionally related to elevated internalizing, externalizing, and asocial behavioral problems across an 18-month interval (Greenberg et al., 2006) and even a seven-year interval (Baker et al., 2011). Similarly, Dieleman et al. (2017) retrieved bidirectional associations between questionnaire-rated externally controlling parenting and externalizing problems across a nine-year interval. However, the statistical approach used in these longitudinal studies (i.e., regressions and cross-lagged panel models) focused on rank-order changes in adolescents' adjustment rather than on within-person change. Thus, it remains to be examined whether within-family fluctuations in externally controlling parenting also relate to within-person fluctuations in (mal)adjustment in youth with ASD.

Second, this study considers the role of *personality variation* as a second potential transdiagnostic factor. In non-ASD populations, individual differences in personality, i.e. constitutionally-based tendencies in thoughts, behaviors, and emotions that surface early in life and are relatively stable across situations and time (Caspi & Shiner, 2006), are well-studied contributors to social development. In autism, however, research is more limited and confined to cross-sectional evidence. To date, three studies demonstrated similar relations between personality dimensions on the one hand, and adjustment difficulties on the other, across youth with and without ASD, using both parent- and self-ratings (Burrows et al., 2016; De Pauw et al., 2011; Schwartz et al., 2009). Overall, these studies uncovered that – for youth with and without ASD alike –, children with lower scores on Emotional Stability and Extraversion had more internalizing problems, whereas children with lower scores on Benevolence and Conscientiousness had more externalizing problems. No study to date, however, evaluated the longitudinal associations of these personality traits on changes in psychosocial outcomes in ASD. Also, the impact of child personality on more adaptive behavioral outcomes, such as psychosocial strengths (e.g., showing positive interactions and family involvement), has not been studied. One criticism sometimes levelled against research on trait-psychopathology associations is that there is conceptual confounding between child personality and behavior problems as well as a risk for item-overlap in the assessment of both types of constructs (De Pauw et al., 2009; Rothbart & Bates, 2006). Some conceptual overlap between these constructs is theoretically to be expected because personality contributes to the development of behavior problems (Bates, 1990). However, findings indicated that the amount of item contamination is rather limited and that child personality and behavioral problems are conceptually more different than alike (De Pauw et al., 2009; Lengua et al., 1998; Prinzie et al., 2005).

Third, this study goes beyond the search for additive effects, by also evaluating the influence of the personality-by-parenting interplay on psychosocial outcomes. Specifically, we address whether the influence of parenting in youth with ASD varies as a function of children's unique personality traits. Previous research in neurotypical and clinical populations other than ASD demonstrated that individual trait differences can affect a child's vulnerability to negative environmental influences (Kiff et al., 2011; Lengua et al., 2019; Mabbe et al., 2019). More specifically, research suggested that especially children with more challenging personality traits, such as lower Emotional Stability/higher Negative Affect, lower Benevolence, lower Conscientiousness/Effortful Control, are particularly vulnerable to develop behavioral problems when also exposed to controlling parenting (Bates & Pettit, 2015; Kiff et al., 2011; Van Leeuwen et al., 2007). To our knowledge, however, no research addressed personality-by-parenting interactions in the prediction of social development outcomes in the context of ASD to date.

Finally, this study examines the unique and interactive roles of both parenting and child personality in the psychosocial adjustment in youth with ASD by using latent change modeling (LCM). This technique allows to model change at the within-person level (i.e., the level of a family unit), which is important because this type of change is most salient and personally meaningful to families. Also, prevention and intervention efforts predominantly target this level of change (Keijsers et al., 2016).

In sum, the present study aims to achieve a more comprehensive account of the contribution of externally controlling parenting and child personality to psychosocial outcomes in youth with ASD. As a first research aim, we explore continuity and change in internalizing and externalizing behaviors, psychosocial strengths and externally controlling parenting across a nine-year interval. As a second research aim, we investigate the additive and interactive effects of externally controlling parenting and child personality on behavioral problems and psychosocial strengths in youth with ASD. Given that personality factors are by definition characterized by substantial continuity and long-term stability (Caspi & Shiner, 2006), only baseline assessments of personality are included in these analyses.

3.2 Methods

Participants

Parents of 141 children with ASD reported on their family background, their child's personality, emotional and behavioral problems, psychosocial strengths, and their own parenting behavior, as part of a long-term longitudinal study on the psychosocial development of youth with ASD (De Pauw et al., 2011; Dieleman et al., 2017). At Time 1 (T1), children with ASD were on average 10.1 years old (SD = 2.4, range = 5.1 - 16.2), at Time 2 (T2) the mean age was 16.0 years old (SD = 2.3, range = 11.6 - 22.6) and at Time 3 (T3), the mean age was 19.0 years old (SD = 2.3, range = 14.4 - 23.9). The mean time interval between T1 and T2 was 6.18 years old (SD = .38, range = 5.51 - 7.01) and 2.70 years old between T2 and T3 (SD = .09, range = 2.17 - 3.00). The children and adolescents were predominantly male (83.0%). The majority of the children with ASD were reported to have one or more comorbid diagnoses (53.9% at T1), of which ADHD (19.1%), motor disorder (15.6%), and language development disorder (10.6%) were most prevalent. 75.2% of the parents (*n* = 106) also reported on their child's intellectual functioning, indicating that 12.3% (*n* = 13) of these children had an intellectual disability (IQ < 70). Informants were mainly mothers (98.6% at T1) with an average age of 39.9 years old (SD = 4.9) at T1. The majority of parents were married (80.7% at T1) and employed (75.7% of mothers and 90.7% of fathers at T1). At T1, 87.9% of the participating families reported that their child or family received some kind of counseling or treatment, of which home counseling (24.3%), support from a functional rehabilitation center (9.3%) or integrated education support (7.1%) were most frequently reported. At T2 and T3, respectively 59.8% and 56.9% of the families reported to still receive one or more of these services. Table 1 presents additional demographic characteristics. The study received ethical approval from the Institutional Review Board of the host University and all participants filled out an informed consent at each assessment.

Procedure

Seventy-five percent of the parents were recruited through the registries of four care centers providing home support and counseling to families of persons with ASD (based on DSM-IV-TR criteria) in Flanders, Belgium. Other participants were addressed through teachers and announcements on websites regarding ASD. Kruskal-Wallis tests revealed no differences in study variables according to the recruitment strategy (all *p*s > .05). Primary inclusion criteria for the participants were: the child (a) had received a formal diagnosis of autistic disorder, Asperger syndrome, or pervasive developmental disorder not otherwise specified based on DSM-IV-TR or ICD-10 criteria and (b) was at least four years old. The ASD diagnosis was verified by a written parent report and confirmed by verbal communication with a research assistant. Parents also clarified when and by whom the formal ASD diagnosis was made. To evaluate associations over time, we

Table 1. Descriptive data on the participating children and their parents in the study

	T1 (*n* = 140)		T2 (*n* = 97)		T3 (*n* = 116)	
	n	%	*n*	%	*n*	%
Type of education child						
Kindergarten	6	4.3	0	0.0	0	0.0
Regular primary education	60	42.9	3	3.1	0	0.0
Special primary education	37	26.4	11	11.3	1	0.9
Regular secondary education	23	16.4	38	39.2	35	30.2
Special secondary education	7	5.0	32	33.0	30	25.9
Higher education	0	0.0	7	7.2	20	17.2
Other	7	5.0	6	6.2	14	12.1
Missing	0	0.0	0	0.0	16	13.8
Living situation child[1]						
At home with parent(s)	-	-	75	77.3	91	78.4
During week at boarding school, weekend at home	-	-	16	16.5	2	1.7
During week in dorms, weekend at home	-	-	3	3.1	11	9.5
Living independently	-	-	0	0.0	4	3.4
Living in an institution[2]	-	-	0	0.0	3	2.6
Other	-	-	3	3.1	5	4.3
Nationality parents (mother/father)[3]						
Belgian	126/124	90.0/88.6	-	-	-	-
Other European nationality	13/10	9.3/7.1	-	-	-	-
Non-European	0/1	0.0/0.7	-	-	-	-
Missing	1/5	0.7/3.6	-	-	-	-
Education level parents (mother/father)[3]						
Primary school	3/7	2.1/5.0	-	-	-	-
Secondary school	57/62	40.7/44.3	-	-	-	-
Higher education (college or university)	74/57	52.9/40.7	-	-	-	-
Missing	6/14	4.3/10.0	-	-	-	-

Note. *T1* Time 1, *T2* Time 2, *T3* Time 3. [1] Only measured at T2 and T3. [2] The child lives permanently or two-thirds of the time in an institution. [3] Only measured at T1.

only included the 141 families who participated at least two out of three times. Mann–Whitney tests revealed no significant differences between participants who participated once (*n* = 69) and participants who participated two (*n* = 70) or three times (*n* = 71) in terms of demographic characteristics and study variables (all *p*s > .05).

Measures

Child behavior problems. At each of the three assessment points, parents rated their child's emotional and behavioral problems using the Dutch version of the parent-report Child Behavior Checklist/4-18 (CBCL; Achenbach, 1991) on a three-point Likert scale ranging from (0) *not at all* to (2) *clearly or often*. These items were clustered into two broadband factors: internalizing problems (32 items, comprising anxious/depressive behavior, withdrawn/depressive behavior, and somatic complaints) and externalizing problems (33 items, comprising delinquent behavior and aggressive behavior). Parents also completed this questionnaire at T3, as this study aims to examine longitudinal relations in this construct and previous studies confirmed the applicability of this instrument in adolescents and young adults with ASD (Holtmann et al., 2007). Raw scores were used in all analyses, except to examine clinical levels of emotional and behavioral problems where raw scores were converted into T-scores. Clinical scores (T-scores above 63) were calculated based on American norms for the CBCL 4/18 (Achenbach, 1991) to optimize comparability with previous research. Cronbach α's ranged from .87 (internalizing problems at T1) to .93 (externalizing problems at T3).

Child psychosocial strengths. At T2 and T3, parents rated their child's positive emotions, behaviors, and life aspects on the Behavioral and Emotional Rating Scale (BERS-2; Epstein et al., 2004). The questionnaire comprises 43 items rated on a five-point Likert scale, ranging from (1) *completely not true* to (5) *completely true*. The items were clustered into three subscales: interpersonal strengths (15 items; e.g., *"Accepts responsibility for his/her behavior"*), family involvement (10 items; e.g., *"Shows a sense of commitment towards the family"*) and intrapersonal-affective strengths (18 items; e.g., *"Accepts closeness and intimacy from others"*). Even though this instrument has not been used in autism research before, it has been used in diverse other clinical samples (including Down syndrome; Dieleman, De Pauw, Soenens, Van Hove, et al., 2018). Cronbach α's ranged from .78 (intrapersonal-affective strengths at T2) to .89 (interpersonal strengths at T3).

Externally controlling parenting. At each assessment point, parents completed the negative control scale from the Parental Behavior Scale (PBS; Van Leeuwen & Vermulst, 2004). This scale taps into punitive parenting (6 items, e.g., *"If my child contradicts, lies or argues, I give him/her a punishment"*) and harsh punishment (5 items, e.g., *"I hit my child if he/she does not keep to what has been agreed"*). These 11 items were rated on a five-point Likert scale, ranging from (1) *never* to (5) *always.* The PBS has been recently validated in parents of children and adolescents with ASD (Lambrechts et al., 2011; Maljaars et al., 2014; van Esch et al., 2018). In this study, Cronbach α's ranged from .79 (T1 and T3) to .81 (T2).

*Child Personality***.** At T1 and T2, parents rated their child's personality using the Hierarchical Personality Inventory for Children (HiPIC; Mervielde & De Fruyt, 2002), an empirically derived questionnaire in the lexical tradition based on an extensive analysis of parental free descriptions of their child. Parents indicated how characteristic 144 statements were for their child on a five-point Likert scale, ranging from (1) *hardly characteristic* to (5) *very characteristic*. The 144 items represent 18 underlying facets, which can be grouped into five higher-order factors: Emotional Stability is represented by the facets of Anxiety (reversed) and Self-Confidence; Benevolence includes the facets Altruism, Dominance (reversed), Egocentrism (reversed), Compliance and Irritability (reversed); Conscientiousness is represented by the facets Concentration, Perseverance, Orderliness and Achievement Motivation; Imagination encompasses the facets Creativity, Intellect and Curiosity; and Extraversion includes the facets Energy, Expressivity, Optimism and Shyness (reversed). Cronbach α's ranged from .83 (Imagination at T1) to .93 (Benevolence at T2).

Autism severity. Parents rated their child's ASD symptom severity on the Social Communication Questionnaire Current Version (SCQ-Current; Rutter et al., 2003; Warreyn et al., 2004) at T1 and the Social Responsiveness Scale (SRS) (Constantino & Gruber, 2005; Roeyers et al., 2011) at T2 and T3. The SCQ consists of 40 yes-or-no questions and covers symptoms (as displayed within the past three months) in the domains of language/communication, social functioning, and repetitive/stereotyped behaviors. The SRS consists of 65 items on a four-point Likert scale ranging from (1) *not true* to (4) *almost always true,* where parents reported on their child's ASD symptoms (i.e., social awareness, social information processing, capacity for reciprocal social communication, social anxiety/avoidance, and autistic preoccupations) displayed over the past six months. Parents rated the SCQ at T1 (2005-2006) because at that time there was no validated Dutch version of the SRS available. The Cronbach α was .82 for the SCQ, .95 for the SRS at T2, and .93 for the SRS at T3.

Data analysis

LCM was used to model change at the within-person level (i.e., within a family unit) in parenting and psychosocial outcomes across a nine-year interval. LCMs use latent variables for intercepts (i.e., level) and slopes (i.e., change over time) to estimate within-person change between two adjacent assessment points. Between-person differences in within-person change are indicated by variance in the slope (Beyers & Goossens, 2008). We tested these models using Mplus 8.3 (Muthén & Muthén, 1998–2012) with robust maximum likelihood as estimator since missing data were missing completely at random (Little's missing completely at random test: χ^2 (229) = 228.46, p = .50) (Usami et al., 2019). Model fit was evaluated according to fit criteria suggested by Hu and Bentler (1999), with an acceptable fit being indicated by a Root Mean Square Error of Approximation (RMSEA) and Standardized Root Mean Square Residual (SRMR) of 0.08 or below, and a Comparative Fit Index (CFI) of 0.90 or above (Kline, 2005).

Change in the study variables was modeled in two separate models, from T1-to-T2 (first time period) and from T2-to-T3 (second time period). The decision to separate these periods (rather than to model change across three assessment points simultaneously) was motivated by two arguments. First, the interval between the assessment moments varied, with T1-to-T2 spanning six years and with T2-to-T3 spanning three years. Second, the nature of the transition from T1-to-T2 might be qualitatively different from the nature of the transition from T2-to-T3.

The measurement model described the latent level and change factors for each latent variable. Because behavior problems, psychosocial strengths, and child personality were measured as multidimensional constructs, the corresponding subscales were used as indicators for their latent factors (i.e., the internal-consistency approach; Kishton & Widaman, 1994). Regarding children's psychosocial strengths, we used the family involvement, interpersonal, and intrapersonal-affective strengths subscales as three indicators for their latent factor. The 18 facets of the HiPIC were used as indicators of the five higher-order latent factors. Since externally controlling parenting can be regarded as a unidimensional construct, we employed the recommended item-to-construct balance method (Landis et al., 2000), where stronger loading items were combined with weaker loading items, to create two parcels. The measurement model for each study variable showed adequate fit with an average fit of RMSEA = 0.06, CFI = 0.94, and SRMR = 0.08.

Next, the measurement models were supplemented with a structural model that specified how these level and change factors were interrelated. Within these models, initial levels of, and change in, the outcome variables were predicted simultaneously by initial levels of, and change in, externally controlling parenting and by one personality domain. Ten models were tested in the first time period (i.e., five personality domains and two outcome variables), and fifteen models in the second time period (i.e., five personality domains and three outcome variables, including psychosocial strengths) (Figure 1). To counteract multiple testing, we only focus on findings that remained significant after Bonferroni correction (*p* < .002).

Furthermore, we added the interaction term between the personality dimension and externally controlling parenting in separate analyses to examine the moderating role of child personality in effects of externally controlling parenting on behavioral outcomes. For probing interactions, we followed the Johnson-Neyman technique, which allows to indicate the specific value along the continuum of the personality trait at which the relation between parenting and child behavior was significant (i.e., regions of significance; Del Giudice, 2017). For reasons of parsimony, the interaction effects are not presented in Figure 1, but significant interactions were visually illustrated using plots in SPSS 26.0 (IBM Corporation, Armonk, NY, USA).

3.3 Results

Preliminary analyses

Means, standard deviations, minimum and maximum scores, and correlations between the study variables are presented in Table 2. Based on the American norms for the CBCL 4/18 (Achenbach, 1991), 69.6 % (T1), 44.8% (T2), and 41.8% (T3) of the children exhibited clinical levels for internalizing problems, while 61.6% (T1), 35.5% (T2), and 21.1% (T3) of the children scored in the clinical range for externalizing problems.

Prior to the main analyses, we examined relations between several demographic characteristics (i.e., child age, child gender, the child's intellectual functioning, ASD symptom severity, and parental age) and the variables of interest. Correlational analyses indicated that children's age related to fewer externalizing problems at T1 (*r* = -.22, *p* = .01). At T2, child age related to fewer internalizing problems (*r* = -.22, *p* = .03), fewer externalizing problems (*r* = -.36, *p* < .001), more psychosocial strengths (*r* = .25, *p* = .02), and less externally controlling parenting (*r* = -.24, *p* = .02). Parents of older children also perceived their children to be higher in Benevolence (*r* = .24, *p* = .02 at T2) and Conscientiousness (*r* = .21, *p* = .02 at T2), and lower in Extraversion (*r* = -.17, *p* = .04 at T1). Gender differences were only found for internalizing problems and personality. Girls scored significantly higher on internalizing problems (*U* = 339.50, z = -2.44, *p* = .02 at T2; *U* = 462.00, z = -3.83, *p* < .001 at T3) and lower in Emotional Stability (*U* = 913.00, z = -2.65, *p* = .01 at

T1; *U* = 533.00, z = -3.72, *p* < .001 at T3), whereas boys had higher scores for Imagination (*U* = 954.00, z = -2.42, *p* = .02 at T1; *U* = 300.00, z = -2.89, *p* < .01 at T2) and Extraversion (*U* = 997.50, z = -2.18, *p* = .03 at T1). We observed no significant differences in children's psychosocial functioning, nor in externally controlling parenting between children with an intellectual disability (IQ < 70) compared to children with no intellectual disability (IQ > 70) (all *p*s > .05). Only Imagination at T1, which includes the facet 'Intellect', was significantly higher in children without an intellectual disability compared to children with an intellectual disability (*F*(1,95) = 15.05, *p* < .001).

To examine the role of ASD symptom severity, we used the SCQ total score at T1 and only the SRS total score at T2 in further analyses, given the high correlation between the SRS total score at T2 and T3 (*r* = .75, *p* < .001). These indicators of ASD symptom severity correlated significantly with each other (r SCQ_{T1} - SRS_{T2} = .45, *p* < .001) and with the variables of interest. Specifically, the SCQ total score at T1 related significantly to more internalizing problems at T1 (*r* = .19, *p* = .03), more externalizing problems at T1 (*r* = .19, *p* = .02), fewer psychosocial strengths at T2 (*r* = -.39, *p* < .001) and T3 (*r* = -.26, *p* = .01), less Benevolence at T2 (*r* = -.23, *p* = .02), and less Extraversion at T1 (*r* = -.18, *p* = .03). The SRS total score at T2 significantly correlated with internalizing problems at T2 (*r* = .44, *p* < .001) and T3 (*r* = .37, *p* < .01), externalizing problems at T1 (*r* = .38, *p* < .001), T2 (*r* = .57, *p* < .001) and T3 (*r* = .45, *p* < .001), psychosocial strengths at T2 (*r* = -.62, *p* < .001) and T3 (*r* = -.48, *p* < .001), externally controlling parenting at T2 (*r* = .33, *p* < .01) and T3 (*r* = .30, *p* = .01), Emotional Stability at T2 (*r* = -.28, *p* = .01) and T3 (*r* = -.26, *p* = .03), Benevolence at T1 (*r* = -.35, *p* < .01), T2 (*r* = -.52, *p* < .001) and T3 (*r* = -.45, *p* < .001), Conscientiousness at T1 (*r* = -.28, *p* = .01), T2 (*r* = -.31, *p* < .01) and T3 (*r* = -.23, *p* = .04), and Imagination at T1 (*r* = -.22, *p* = .03), T2 (*r* = -.39, *p* < .001) and T3 (*r* = -.27, *p* = .02). Higher parental age related significantly to fewer externalizing problems in the child (*r* = -.27, *p* < .01 at T1) and less externally controlling parenting (*r* = -.20, *p* = .04 at T3). In each LCM, we controlled for child age, child gender, ASD symptom severity and parental age. We included the SCQ total score at T1 as a covariate in the univariate LCM and the LCMs concerning the first time period and the SRS total score at T2 was included as a covariate in the LCMs concerning the second time period.

Table 2. Means, standard deviations, minimum and maximum scores, and correlations between the study variables

	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.	18.	19.	20.	21.
T1																					
1. Internalizing																					
2. Externalizing	.38***																				
3. External control	.05	.27**																			
4. Emotional Stability	-.70***	-.17*	.09																		
5. Benevolence	-.25**	-.76***	-.12	.18*																	
6. Conscientiousness	.08	-.23**	-.21*	-.17*	.19*																
7. Imagination	.05	.19*	-.02	-.01	-.11	.11															
8. Extraversion	-.31***	.37***	.08	.32***	-.19*	-.12	.45***														
T2																					
9. Internalizing	.48***	.27**	.11	.40***	-.22*	.16	-.10	-.09													
10. Externalizing	.13	.72**	.25*	.04	-.58***	-.18	.07	.38***	.46***												
11. Strengths	-.01	-.32**	-.23*	.04	.34***	.30**	.20*	.04	-.27**	-.53***											
12. External control	.07	.39***	.53***	-.12	-.22*	-.16	-.11	.12	.15	.46***	-.33***										
13. Emotional Stability	-.40***	-.31**	-.10	-.51***	.31**	-.18	.06	.05	-.67***	-.33**	.16	-.11									
14. Benevolence	-.04	-.64***	-.14	.08	.72***	.16	-.07	-.28**	-.19	-.77***	.61***	-.43***	.19								
15. Conscientiousness	.17	-.25*	-.25*	.20	.19	.71***	-.04	-.27**	.13	-.34***	.54***	-.35***	-.17	.36***							
16. Imagination	.04	.09	-.25*	.09	-.08	.21*	.59***	.25*	-.15	-.10	.45***	-.17	.01	.11	.26*						
17. Extraversion	-.27**	.27**	-.13	-.26**	-.14	.01	.17	.55***	-.32**	.25*	.26**	.04	.18	-.18	-.03	.42***					
T3																					
18. Internalizing	.54***	.16	.13	.36***	-.07	.21*	.11	-.20*	.75***	.37**	-.15	.14	-.53***	-.06	.19	-.13	-.30*				
19. Externalizing	.22*	.55***	.22*	.09	-.44***	-.05	.10	.26**	.35**	.82***	-.45***	.48***	.24*	-.57***	-.36**	-.03	.33**	.37***			
20. Strengths	-.18	-.35***	-.17	-.04	.37***	.18	-.15	-.07	-.21	-.37**	.69***	-.28*	.15	.43***	.44***	.23	.18	-.35***	-.45***		
21. External control	.05	.40***	.52***	.03	-.27**	-.16	-.11	-.04	.21	.36**	-.12	.73***	-.20	-.20	-.15	-.04	-.01	.08	.34***	-.21*	
Mean[1]	16.70	18.58	2.30	2.67	2.91	2.74	2.89	2.77	13.31	11.51	130.43	2.05	2.69	3.05	2.91	2.94	2.78	12.52	8.33	139.53	1.76
SD	9.33	10.24	0.47	0.76	0.64	0.60	0.68	0.64	10.30	10.30	24.14	0.54	0.76	0.64	0.69	0.62	0.56	10.34	9.10	25.83	0.51
Minimum	0.00	0.00	1.00	1.63	1.23	1.09	1.38	1.50	0.00	0.00	70.00	1.00	1.13	1.50	1.38	1.42	1.38	0.00	0.00	43.00	1.00
Maximum	46.0	49.0	3.50	4.94	4.20	4.31	4.54	4.63	53.00	46.00	192.00	3.45	4.44	4.55	4.88	4.33	4.38	49.00	61.00	199.00	3.18

Note. T1 Time 1, *T2* Time 2, *T3* Time 3. [1] To enhance comparability with previous studies, we report raw scores for the CBCL (Achenbach, 1991) and BERS-2 (Epstein, 2004) and mean scores for the Parental Behavior Scale (Van Leeuwen & Vermulst, 2004) and HiPIC (Gray et al., 2012; Mervielde & De Fruyt, 2002). $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

Main analyses

Research Question 1: Do internalizing and externalizing behaviors, psychosocial strengths, and parenting change across time?

Univariate LCMs were estimated to investigate mean-level change and variability in change in internalizing and externalizing behavior, psychosocial strengths, and externally controlling parenting. Results indicated that from T1-to-T2, mean levels of internalizing problems remained stable, whereas externalizing problems decreased. Notably, from T2-to-T3, mean levels of emotional and behavioral problems remained stable but children's psychosocial strengths increased. There were no mean-level changes across time in externally controlling parenting. Interestingly, the results indicated significant variances in the slope for all latent variables, suggesting substantial between-person differences in how child behavior and parenting changed over time. An overview of the parameter estimates and fit indices for each study variable is provided in Table 3. All univariate LCMs fitted the data well with the average fit being RMSEA = 0.06, CFI = 0.98, and SRMR = 0.05.

Research Question 2: What are the additive and interactive effects of externally controlling parenting and child personality on behavioral outcomes?

Main effects of externally controlling parenting and child personality

Main effects of externally controlling parenting and child personality on internalizing and externalizing problems, and psychosocial strengths are shown in Figure 1. The findings demonstrated no significant associations between initial levels of externally controlling parenting and initial levels of internalizing problems or psychosocial strengths. Nevertheless, initial levels of externally controlling parenting were positively associated with initial levels of externalizing problems (in 3 out of 5 models examining T1-to-T2, and 1 out of 5 models examining T2-to-T3). There were no significant associations between the slopes, suggesting that change in externally controlling parenting did not systematically relate to an increase or decrease in emotional or behavioral problems or psychosocial strengths.

Table 3. Parameter estimates and fit indices of the univariate latent change model

	Parameter estimates						Fit indices		
	Level		Change T1-to-T2		Change T2-to-T3				
	M	s^2	*M*	s^2	*M*	s^2	RMSEA	CFI	SRMR
Internalizing problems	2.98 **	0.82***	0.12	0.81***	-0.42	0.99***	0.05	0.93	0.07
Externalizing problems	3.58 ***	0.90***	-2.19*	0.83***	-0.46	0.91***	0.08	0.96	0.06
Psychosocial strengths[1]	4.43 ***	0.77***	-	-	2.42*	0.88***	0.07	0.92	0.07
External control	3.32 ***	0.96***	-1.65	0.84***	-1.37	0.96***	0.05	0.98	0.03

Note. T1 Time 1, *T2* Time 2, *T3* Time 3, *RMSEA* Root mean square error of approximation, *CFI* Comparative fit index, *SRMR* Standardized root mean square residual.

[1] The BERS-2 was not assessed at T1. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

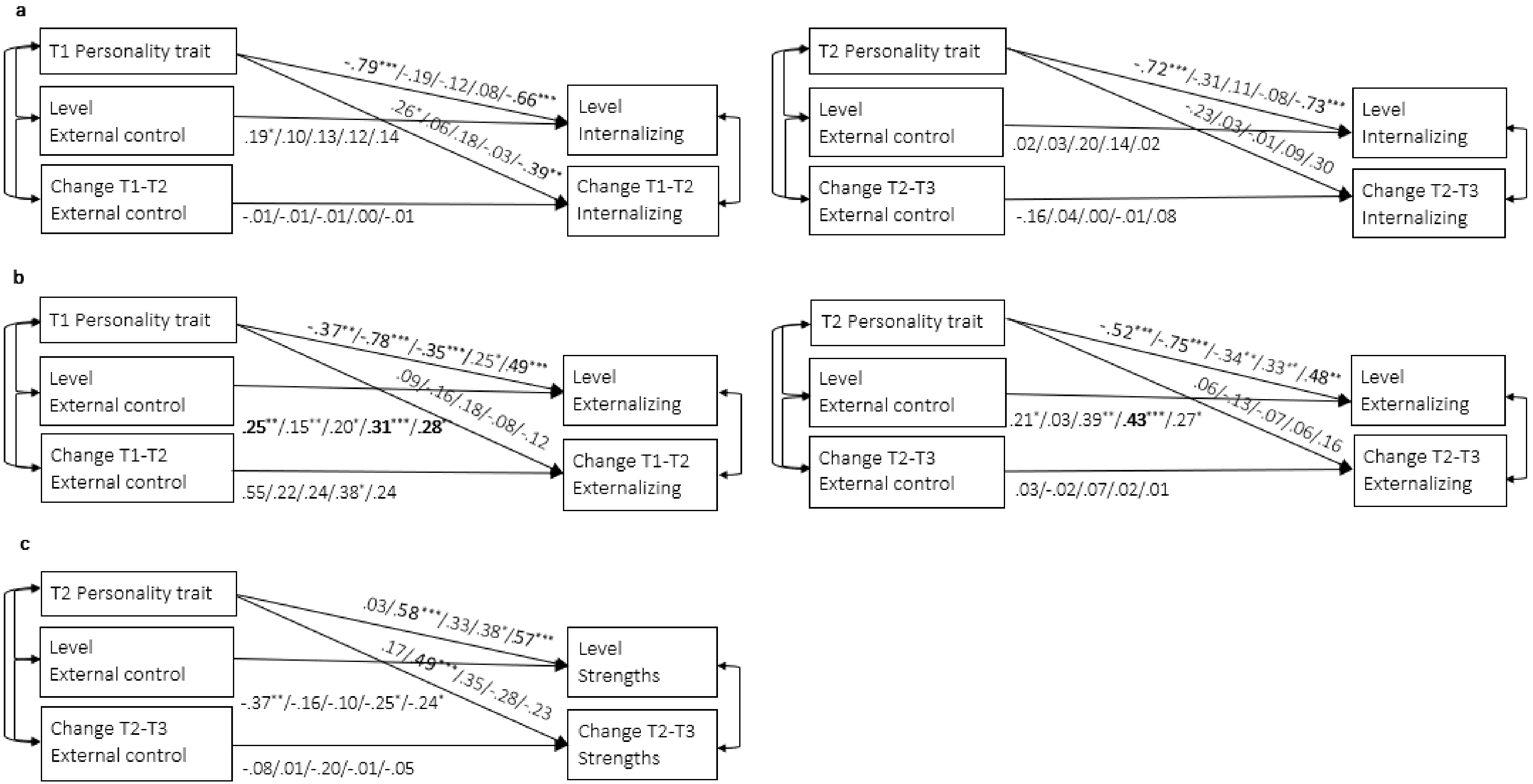
Across both time periods, low Emotional Stability and low Extraversion related significantly to higher initial levels of internalizing problems (in 2 out of 2 models examining T1-to-T2, and 2 out of 2 models examining T2-to-T3). In addition, Extraversion was related negatively to the change factor (T1-T2) of internalizing problems, indicating that higher Extraversion related to a decrease in internalizing problems during the first time period. Across both time periods, low Emotional Stability, low Benevolence, and high Extraversion yielded a significant association with higher initial levels of externalizing problems (in 3 out of 3 models examining T1-to-T2, and 3 out of 3 models examining T2-to-T3). Additionally, low Conscientiousness related significantly to initial levels of externalizing problems in the first time period. No further significant effects were found concerning change in the outcome factor.

Benevolence and Extraversion related positively to initial levels of psychosocial strengths in the second time period (in 2 out of 2 models examining T2-to-T3). Moreover, a second significant effect emerged concerning change in the outcome factor, as high Benevolence related to an increase in psychosocial strengths in the second time period.

The moderating role of child personality

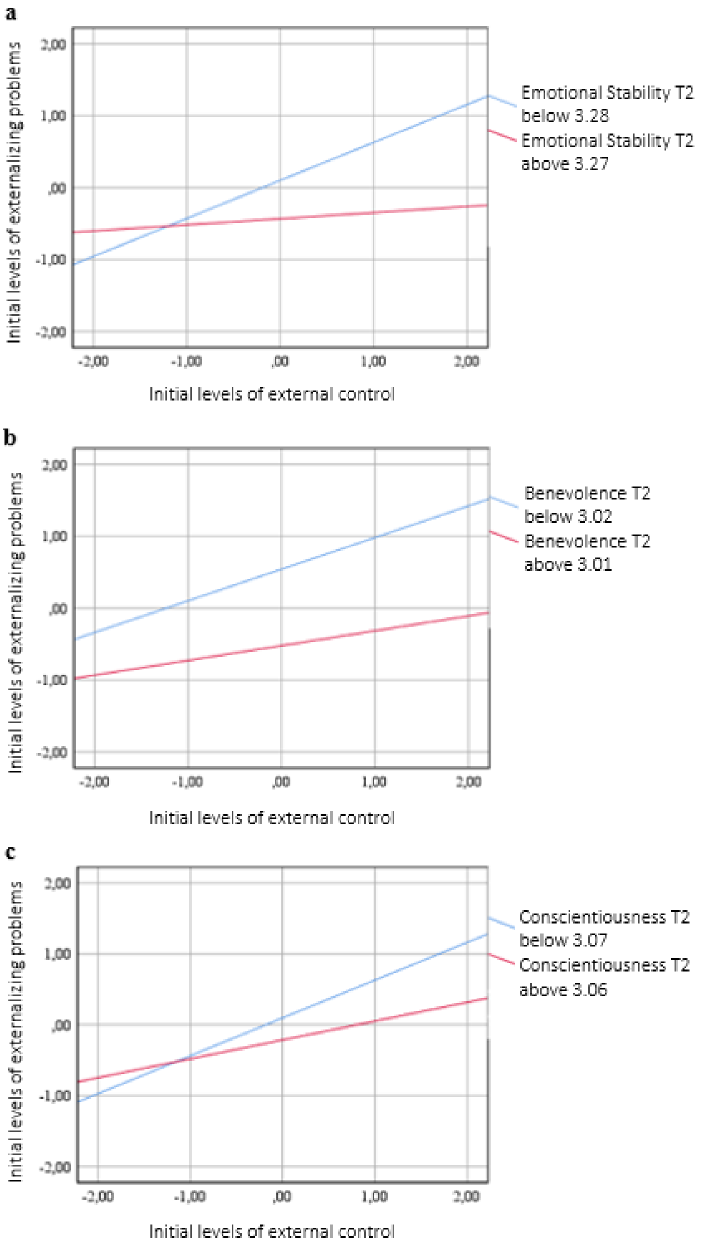
Three interaction effects (out of 25 tested interactions) were significant, demonstrating that the relation between initial levels of externally controlling parenting and initial levels of externalizing behavior were significant for children with less adaptive personality traits at T2, yet not significant for children with more adaptive personality traits at T2. These effects were not found in the first time period, with personality at T1 as a predictor. More specifically, children with lower scores on Emotional Stability ($t(93) = -1.57$, $p = .02$, b = -0.39), Benevolence ($t(93) = -3.03$, $p < .01$, b = -0.33), and Conscientiousness at T2 ($t(93) = -2.18$, $p = .04$, b = -0.36) showed elevated initial levels of externalizing problems when exposed to externally controlling parenting. Furthermore, the Johnson-Neyman technique indicated the specific value along the continuum of the personality trait at which the relation between parenting and child behavior was significant. This technique demonstrated that the relation between initial levels of externally controlling parenting and initial levels of externalizing problems was significant for children with a score lower than 3.28 on Emotional Stability (74.2% of the children), a score lower than 3.02 on Benevolence (48.5% of the children), or a score lower than 3.07 on Conscientiousness (60.3% of the children), but not for children with higher scores on these personality domains (Figure 2).

Figure 1. Latent change model on the relation between externally controlling parenting and child behavior (**a** internalizing problems, **b** externalizing problems, and **c** psychosocial strengths) for the first (T1-T2) and second time period (T2-T3)



Note. Path coefficients refer to the models including the following personality traits: Emotional Stability/Benevolence/Conscientiousness/Imagination/Extraversion. *** *p <.001,* ** *p <.01,* * *p < .05.* Coefficients in bold remain significant after Bonferroni correction (*p* < .002).

Figure 2. Interaction between child personality at T2 (**a** Emotional Stability, **b** Benevolence, and **c** Conscientiousness) and initial levels of externally controlling parenting on initial levels of externalizing problems



3.4 Discussion

Scholars increasingly advocated that researchers should go beyond the inquiry of ASD-specific sources of heterogeneity and investigate 'non-syndrome-specific' factors to better understand the diverse behavioral presentations and developmental outcomes in youth with ASD (Chetcuti et al., 2019; McCauley et al., 2019; Mundy et al., 2007). In particular, theorists increasingly nominated child personality and parenting as two potential 'spearhead' transdiagnostic factors. Yet, to date, only a handful of studies empirically evaluated the impact of personality or parenting variability to (mal)adjustment in children with autism. These few studies have now uncovered important, yet mainly cross-sectional, relations between *either* personality *or* parenting and psychosocial development in youth with ASD. To our knowledge, this study is one of the first to address the *joint* value of child personality and parenting in relation to emotional and behavioral problems as well as psychosocial strengths in youth with ASD from a nine-year longitudinal perspective.

The transition to adolescence and emerging adulthood can be considered as a pivotal period of change for all children, and it can be particularly challenging for youth with ASD since adolescence is characterized by an increased emphasis on social interactions, changes in demands, and challenges to establish and maintain peer relationships (McCauley et al., 2019). However, as only limited longer-term longitudinal research on the psychosocial development of adolescents with ASD is available (Gray et al., 2012; Greenberg et al., 2006; McGovern & Sigman, 2005; Taylor & Seltzer, 2010; Woodman et al., 2015), this study provides unique longitudinal information on continuity and change across a nine-year interval. Given that the three assessment points were six and three years apart, we adopted a LCM approach, allowing a unique examination of within-person processes.

Change in children's psychosocial development and stability in externally controlling parenting

The first aim of this study was to explore continuity and change in internalizing and externalizing behaviors, psychosocial strengths, and externally controlling parenting across three assessment points, spanning a nine-year interval. Concerning emotional and behavioral problems, our findings indicated that at all assessment points, a large percentage of youth with ASD demonstrated clinically significant levels of both internalizing and externalizing problems. Yet, large standard deviations indicated large variability at all three assessment points. Univariate LCMs indicated no significant mean-level change in internalizing problems, yet a significant mean-level decrease in externalizing problems during the first time period. Although some studies examined within-person change in behavioral or emotional problems among youth with ASD (Gray et al., 2012; Taylor &

Seltzer, 2011; Woodman et al., 2015), no study to date evaluated this research question applying the Child Behavior Checklist (Achenbach, 1991; Achenbach & Rescorla, 2001). The stability of clinically significant levels of internalizing problems corroborates research in neurotypical and ASD-populations, indicating that many youth struggle with feelings of anxiety, uncertainty, or low self-worth throughout puberty (McCauley et al., 2019; Robins & Trzesniewski, 2005). The decrease in externalizing problems during the first time period is in line with longitudinal studies among youth with ASD, demonstrating a general pattern of improvement in maladaptive behaviors (Gray et al., 2012; Taylor & Seltzer, 2010; Woodman et al., 2015). However, these studies relied on broad age ranges and used other instruments and analytical methods to assess change in child behavior, which hampers comparability between study findings.

At the second and third assessment point, we also evaluated psychosocial strengths using the Behavioral and Emotion Rating Scale (Epstein et al., 2004) to attain a more balanced perspective on children's adjustment. The univariate LCM indicated that psychosocial strengths showed a significant, yet modest increase in the second time period. To the best of our knowledge, no study reported on the intra-individual change in psychosocial strengths in youth with ASD yet. Nonetheless, this increase in strengths is consistent with the small body of literature uncovering modest improvements in social communication and adaptation across adolescence and emerging adulthood among youth with ASD (Gray et al., 2012; McGovern & Sigman, 2005; Taylor & Seltzer, 2010; Woodman et al., 2015).

Regarding externally controlling parenting, the univariate LCM showed a slight decline across the three measurements, but these within-person decreases were not significant. This finding is somewhat surprising as the broader developmental literature demonstrates that externally controlling parenting tends to decline across adolescence and emerging adulthood (Desjardins & Leadbeater, 2016). Nonetheless, this finding corroborates previous short-term longitudinal studies (of one-two years) in parents of children with ASD, demonstrating that indicators of externally controlling parenting (i.e., Expressed Emotion) showed considerable stability when assessed with repeated measurements (Greenberg, et al., 2006; Bader and Barry, 2014). Nonetheless, further investigations are needed to replicate this finding and to further unravel reasons for the relatively high stability in externally controlling parenting in youth with ASD. Notwithstanding this high degree of mean-level stability in external parental control, there was substantial variation in within-person change in both external parental control and child behavior. These findings suggest that both parents and children differ in the degree to which their use of external control or their psychosocial development change across time.

Effects of externally controlling parenting and child personality on psychosocial problems and strengths

The second and most important aim of this study was to address the additive and interactive effects of externally controlling parenting and child personality on psychosocial problems and strengths in youth with ASD. Findings showed that both parenting behavior and personality variation uniquely related to children with ASD's emotional or behavioral problems as well as their psychosocial strengths, generally following the relations that are well-documented in the broader developmental literature. This provides support for theoretical claims that parenting and personality are vital for the psychosocial development of *all* children, including those with ASD (Chetcuti et al., 2019; McCauley et al., 2019; Mundy et al., 2007). Three important findings require further discussion.

Effects of externally controlling parenting

First, this study adds empirical support that externally controlling parenting, with high levels of punitive and harsh disciplining, relates to higher levels of externalizing problems in youth with ASD. As such, this association supports previous cross-sectional (Bader et al., 2014; Boonen et al., 2014; De Clercq et al., 2019; Maljaars et al., 2014; Ventola et al., 2017) and longitudinal work (Bader & Barry, 2014; Greenberg et al., 2006; Lindsey et al., 2020) demonstrating the positive association between externally controlling parenting and maladaptive behaviors in children with ASD. However, it is important to notice that the LCMs used in this study could not address the direction of effects. As relations between child and parenting behavior are fundamentally transactional in neurotypical and ASD-populations (Dieleman et al., 2017; Taraban & Shaw, 2018), this finding also suggests that parents of children with more externalizing behaviors tend to rely on more controlling parenting behaviors as a response to more frequent externalizing behaviors.

Notably, this study did not reveal a significant association between externally controlling parenting and internalizing problems in youth with ASD, which corroborates previous findings in families with children with ASD (e.g., Boonen et al., 2014), but contrasts findings in neurotypical populations (Pinquart, 2017b). This lack of relation might be due to the use of parent report for both constructs, as internalizing problems often remain less noticed by parents (van de Looij-Jansen et al., 2010). Also, there is some evidence that other parenting variables, such as psychologically controlling parenting or conditional parental regard, may be more strongly related to internalizing problems than externally controlling parenting. These more subtle and covert types of parental control may create more inner conflicts and distress (Soenens & Vansteenkiste, 2010) than the blunt and more overt type of external control measured in this study. Surprisingly, the present study also found no significant associations between changes in externally controlling parenting and changes in internalizing or externalizing behaviors. This may be related to the relatively long time intervals between measurements. Possibly, more associations could have been detected when shorter time intervals were used, for instance on an annual, monthly, or even daily basis (Dieleman et al., 2019; Mabbe et al., 2018). This idea was supported in a two-year longitudinal study in children with ASD, where higher levels of parental criticism in parents' five-minute speech samples, predicted an increase in child externalizing behaviors two years later (using hierarchical regression analyses) (Bader & Barry, 2014). Future research should study these relationships over different time intervals, including shorter intervals.

Effects of child personality

Second, our study is one of the first to empirically uncover that child personality is differentially related to both negative and positive behavioral outcomes among youth with ASD across a nine-year interval. Notably, this study revealed similar associations as in youth without ASD (De Pauw & Mervielde, 2010; Prinzie et al., 2010): lower scores on Emotional Stability and Extraversion were associated with internalizing problems whereas lower scores on Emotional Stability and Benevolence, and higher scores on Extraversion were consistently associated with externalizing problems across the two time periods. Hence, these results corroborate that personality variation can be regarded as a 'transdiagnostic' or 'non-syndrome-specific' modifier (Chetcuti et al., 2019; Mundy et al., 2007). Additionally, we found one time-specific association. In line with research in neurotypical populations, we found that lower scores on Conscientiousness related to more externalizing problems (De Pauw & Mervielde, 2010; Mervielde et al., 2006), but only in the first time period. Furthermore, the documented trait-adjustment relations not only provided tools for identifying children with ASD at risk for developing emotional or behavioral problems, but also identified several 'resilience processes'. More specifically, higher scores on Benevolence and Extraversion were significantly related to higher levels of psychosocial strengths in children with ASD. These findings corroborate previous findings in non-ASD populations where high Benevolence and Extraversion related to more adaptive outcomes, such as health and well-being (Hill & Roberts, 2016). Two time-specific significant associations were found between child personality and change in the outcome variable. Lower scores on Extraversion at T1 related to an increase in internalizing problems in the first time period, whereas higher scores on Benevolence at T2 were associated with an increase in psychosocial strengths in the second time period. The case of Extraversion illustrates how fine-grained trait information might be useful to further detect and describe different trajectories of children with ASD across different time points. Higher scores on Extraversion at a mean age of 10 related to fewer internalizing problems and even a decrease in these problems during the first time period, but also to more externalizing problems. Higher scores on Extraversion at a mean age of 16 were associated with fewer internalizing problems and more psychosocial strengths at a mean age of 19, yet also related to more externalizing problems.

Although the content-overlap between child personality and behavioral problems has been extensively discussed in previous research (Shiner & Caspi, 2003), findings generally support the idea that child personality and behavioral problems are conceptually more different than alike (De Pauw et al., 2009; Prinzie et al., 2005). Moreover, our own findings demonstrated a number of unique associations between personality and emotional or behavioral problems not previously documented in neurotypical populations. If associations between these constructs would be driven entirely by item-overlap, such unique associations would be unlikely to occur. For example, the significant associations between Extraversion and more externalizing problems, on the one hand, but also the associations between Extraversion and fewer internalizing problems and more psychosocial strengths, on the other hand, provide unique information that might be ASD-specific.

Personality-by-parenting interplay

Third, three interesting interaction effects were significant in this study, indicating that children with less mature personality traits (i.e., low Emotional Stability, Benevolence, or Conscientiousness) show more externalizing problem behaviors in the presence of externally controlling parenting compared to children with higher scores on these personality traits. On the one hand, the number of significant interactions (3 out of 25 tested interactions) is limited and the effect did not replicate across time. Therefore, the moderating role of these personality traits should be considered as relatively modest and further replication is warranted. However, on the other hand, these three effects proved to be significant despite the limited sample size (and corresponding limited power). Intriguingly, these interactions corroborate previous research in non-ASD populations, uncovering that effects of controlling parenting are more pronounced among children who are rated as less resilient or less agreeable in personality (Mabbe et al., 2016; Meunier et al., 2011; Van Leeuwen et al., 2004). These findings might suggest that children with ASD with lower scores on these traits have fewer abilities to cope effectively with an environment that is experienced as controlling or pressuring. Another interpretation here is that for these children, parents are more likely to address high levels of externalizing problems with controlling parenting as they have more concern about their child and feel a stronger need to control their child's behavior. Alternatively, it is also possible that children with higher scores on these traits have more positive interactions with others that further diminishes the unfavorable effect of externally controlling parenting (Prinzie et al., 2003) or these children might be less likely to interpret a potentially controlling environment as intrusive or pressuring (Mabbe et al., 2016).

Practical implications

Several findings of this study have practical implications. First, the positive associations between externally controlling parenting and externalizing problems in the two time periods highlight the important role of parenting in the life of youth with ASD. Therefore, family interventions could aim to support parents to engage in parenting practices that are related to more adaptive child outcomes, such as autonomy-supportive and responsive parenting behavior, and to avoid controlling practices when confronted with externalizing child behaviors (Allen et al., 2019; De Clercq et al., 2019; Joussemet et al., 2018).

Second, this study shows that certain personality traits render children with ASD either more vulnerable or more resilient to developing emotional and/or behavioral problems. As the current diagnostic classification system is less focused on individual differences among individuals with ASD (Beauchaine, 2003), applying a non-pathologizing language to talk about individual differences, captured by personality traits, might be especially valuable. Interventions might, for example, specifically target personality characteristics that are related to psychosocial strengths in children (i.e., high Benevolence and Extraversion) in order to recognize and reinforce them. Moreover, it might be more stimulating and energizing for parents to recognize and acknowledge positive child characteristics and behaviors, instead of focusing on decreasing behavioral problems.

Third, the three significant personality-by-parenting interactions suggest that child personality plays a moderating role in the relation between parenting behaviors and children's psychosocial development. A better understanding of this complex and transactional interplay can help parents, relatives, and care providers to acknowledge the role of a child's individuality in how children respond to or interpret certain parenting behaviors. Consequently, research and practice could further reflect on accommodating interventions and parental strategies to the unique strengths and challenges in each child's personality. Eventually, attuning to a child's unique personality can result in a better goodness-of-fit and hence better psychosocial outcomes and higher quality parent-child relationships (Stoltz et al., 2013).

Limitations and directions for future research

First, the generalizability of the present findings is limited by the sample characteristics. This study only relies on parent reports (primarily mothers), which might increase the likelihood of finding significant results due to (mono-)rater bias (Bauer et al., 2013). For example, it is possible that some parents generally appraise their child's behavior and their own parenting more positively (or more negatively), even when children objectively have more positive (or negative) characteristics. Also, participating parents were mainly recruited from autism-service centers. Therefore, we were not able to examine whether participating families encountered more challenges in parenting and child behavior than parents who received no parental guidance or support. Although we controlled for child age in the analyses, we acknowledge that the children's age range was rather broad and overlapped between time periods. Therefore, we could not formulate time-specific findings related to children's developmental phases. Future research should include multiple informants such as mothers, fathers, and other important caregivers, and should also apply more diverse recruitment strategies to reach a more heterogeneous group of parents. Such a more heterogeneous sample may also allow to examine with greater precision the moderating role of socio-demographic variables, including the role of socio-economic status.

Second, the generalizability of the findings is also limited by the specific choice of parenting, personality, and (mal)adjustment instruments. Future research could benefit from applying alternative measures and assessment methods (e.g., observational designs; Taraban & Shaw, 2018). Further work could also map a broader spectrum of parenting behaviors, including both dysfunctional as well as more constructive parenting practices. Attention to more positive parenting behaviors, such as autonomy-supportive and responsive parenting, is especially welcome in future research, as it seems plausible that positive parenting might play a more prominent role in fostering positive outcomes rather than in protecting against maladaptive outcomes (Vansteenkiste & Ryan, 2013). This idea was recently supported by a cross-sectional multi-group study, where higher levels of both responsive and autonomy-supportive parenting related significantly to more psychosocial strengths in children with and without a neurodevelopmental disability, including youth with ASD (De Clercq et al., 2019).

Third, it is important to further examine the impact of other factors that may influence the association between parenting behavior and children's psychosocial development in families with ASD. Both child (e.g., ASD symptom severity, intellectual functioning), as well as parental factors (e.g., personality, feelings of need frustration or parenting stress, social support, marital relationship quality), might be plausible mediators in the relation between parenting and child behavior (e.g., Dieleman, De Pauw, Soenens, Mabbe, et al., 2018; Hayes & Watson, 2013). Future research should especially address possible confounding in the conceptualization and measurement of child personality and the severity of core and noncore/associated ASD features more thoroughly (Chetcuti et al., 2019).

Finally, we fully acknowledge the transactional and complex interplay between the child (i.e., personality) and its environment (i.e., parenting) in the psychosocial development of youth with ASD (e.g., Van den Akker et al., 2013; Van Heel et al., 2019). The choice for LCM in this study did not allow to address transactional processes fully, yet this choice was motivated by the restricted sample size and the inclusion of only three measurement occasions. Ideally, new prospective longitudinal studies, including larger sample sizes and more measurement occasions, but also multiple informants, can further disentangle the complex transactional nature of the interplay between parenting and personality across the psychosocial development in youth with ASD.

3.5 Conclusion

This study shows that both externally controlling parenting and child personality are related to the psychosocial development of youth with ASD in unique and interactive ways. Across a nine-year interval, externally controlling parenting, low Emotional Stability, low Benevolence, and high Extraversion consistently related to higher initial levels of externalizing problems, whereas low Emotional Stability and Extraversion were associated with higher initial levels of internalizing problems. Additionally, higher scores on Benevolence or Extraversion related to higher initial levels of psychosocial strengths in the second time period. A limited set of personality-by-parenting interactions provided evidence for moderator effects, where children with lower scores on Emotional Stability, Benevolence, or Conscientiousness showed more externalizing behaviors in the presence of externally controlling parenting.

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Chapter 4

Parenting and child personality as modifiers of the psychosocial development in youth with cerebral palsy: A two-year longitudinal study at the level of within-person change

Based on De Clercq, L., Soenens, B., Dieleman, L. M., Prinzie, P., Van der Kaap-Deeder, J., Beyers, W., & De Pauw, S. S. W. (2020). Parenting and child personality as modifiers of the psychosocial development of youth with cerebral palsy. *Child Psychiatry & Human Development*. https://doi.org/10.1007/s10578-020-01106-1.

Abstract

This two-year longitudinal study addresses the joint contribution of parent-rated parenting behaviors and child personality on psychosocial outcomes in 118 families of children with cerebral palsy (M age Time 1 = 10.9 years old, 64.4% boys). Latent change modeling revealed intra-individual changes in children's psychosocial development as internalizing and externalizing behaviors increased from the first to the second assessment and psychosocial strengths increased from the second to the third assessment, whereas externally controlling and autonomy-supportive parenting behavior remained stable over time. Externally controlling parenting related to higher levels of, and increases in behavioral problems, with these associations being most pronounced among children low in Extraversion, Conscientiousness, or Imagination. Autonomy-supportive parenting related to higher levels of psychosocial strengths, with this association being most pronounced among children high in Emotional Stability.

4.1 Introduction

Cerebral palsy (CP) is the most common cause of physical disability in childhood, characterized by difficulties in movement and posture attributed to neuromuscular non-progressive disturbances in the fetus or infant brain (Rosenbaum et al., 2007). Heterogeneity is an eminent feature of CP, as reflected in the wide variety in motor functioning among children with CP (Monbaliu et al., 2017), but also in the diversity of behavioral and emotional functioning (Brossard-Racine et al., 2012; Vrijmoeth et al., 2012). Studies addressing the psychosocial development of children with CP show that these children, on average, are at increased risk to develop behavioral or emotional problems compared to their peers without a disability (e.g., Parkes et al., 2008; Sipal et al., 2010). These psychosocial problems not only jeopardize the children's quality of life and participation in life situations, but also their caregivers' well-being (Majnemer et al., 2007; Romeo et al., 2010). A longitudinal study among children with CP has also indicated that these behavioral and psychological problems persist into adolescence (Brossard-Racine et al., 2012). Nevertheless, very little is known about the underlying risk and resilience factors that can help to explain this developmental variance (Tan et al., 2014; Vrijmoeth et al., 2012).

To better understand why some youth with CP are more vulnerable or resilient to develop behavioral problems, scholars increasingly argue that it is important to go beyond the examination of 'disability-specific sources'. Instead, they call for research on 'non-syndrome-specific' factors that naturally vary among all children (Aran et al., 2007; Chetcuti et al., 2019). Indeed, there is growing recognition that developmental outcomes for children with CP essentially depend on children's general psychological characteristics and psychosocial family variables, instead of being determined only by disability-specific medical or physical functioning (Cohen et al., 2008; Majnemer & Mazer, 2004). In particular, researchers nominated both parenting behavior and child personality as potential 'non-syndrome-specific' factors that may provide a richer understanding of the psychosocial heterogeneity in clinical samples, including youth with CP (Aran et al., 2007; De Clercq et al., 2019; De Pauw, 2017). Building on this literature, the current study aims to examine the role of parenting and child personality, as well as their interplay, in the psychosocial development of children with CP.

The importance of parenting for the psychosocial development of children with cerebral palsy

Research increasingly points towards the importance of *parenting behavior* in the psychosocial development of children with CP (e.g., Aran et al., 2007). Indeed, a recent meta-analysis showed that both dysfunctional and constructive parenting behaviors were systematically related to the well-being of children with a chronic physical condition (Crandell et al., 2018). One dimension of parenting with particular relevance to children with CP is parental autonomy support. As conceptualized in Self-Determination Theory (SDT; Deci & Ryan, 2000), a macro-theory on human socialization, *autonomy-supportive parenting* is characteristic of parents who promote their child's volitional functioning by offering choice, supporting exploration, and trying to understand the child's point of view. Such parenting contributes to feelings of authenticity, self-direction, and psychological freedom in the child (Soenens et al., 2017). Autonomy-supportive parenting can be contrasted with autonomy-thwarting parenting, which involves intrusive and domineering attempts to pressure a child to think, act, and feel in parent-imposed ways (Grolnick, 2003; Grolnick & Pomerantz, 2009). One specific type of autonomy-thwarting parenting is *externally controlling parenting*, which involves punitive and disciplining behaviors such as (corporal) punishment, verbal or physical coercion, or threats (Soenens & Vansteenkiste, 2010). Research in the neurotypical population has shown that, whereas autonomy-supportive parenting is related to beneficial developmental outcomes such as adaptive social functioning (Roth, 2008) and emotion regulation (Brenning et al., 2015), autonomy-thwarting parenting is systematically related to maladaptive outcomes, such as behavioral and/or emotional problems (Mabbe et al., 2016; Pinquart, 2017a, 2017b; Soenens et al., 2019).

In the past two decades, research has also begun to examine the role of autonomy-supportive parenting among children with a neurodevelopmental disability. In CP-research, a number of studies have demonstrated cross-sectional associations between autonomy-supportive parenting and better psychosocial outcomes, such as better mental health, higher self-esteem, better academic functioning, more psychosocial strengths, and less social and emotional problems (Aran et al., 2007; Cohen et al., 2008; De Clercq et al., 2019; Elad et al., 2018). In contrast, autonomy-thwarting parenting was found to relate to maladaptive outcomes. In a recent meta-analysis among children with a chronic physical condition, Crandell et al. (2018) found that parental coercion (which involves forceful and threatening parenting practices) related to child depression, poorer quality of life, poorer physical function, and more internalizing problems. Although few studies looked into the role of externally controlling parenting (i.e., punitive and disciplining behavior) specifically, studies in CP-populations did demonstrate the detrimental effects of various other autonomy-thwarting parenting practices. For example, psychologically controlling parenting (which involves manipulative and insidious practices such as guilt-induction and love withdrawal) related to more externalizing problems in children with three types of neurodevelopmental disabilities, including 121 children with CP (De Clercq et al., 2019). Furthermore, overprotective parenting (which conceptually also involves overbearing, autonomy-suppressing behaviors) related to lower self-esteem and more feelings of anxiety among youth with CP (Ho et al., 2008; Manuel et al., 2003).

The importance of child personality for the psychosocial development of children with cerebral palsy

Besides parenting, children's unique individuality in how they behave, think, and feel, plays an important role in the development of emotional or behavioral problems as well as psychosocial strengths. These individual tendencies that surface early in life and that are relatively stable across situations and time are commonly described as *personality* (Caspi & Shiner, 2006). Research among children without developmental difficulties has consistently shown that personality differences significantly influence children's development (De Pauw, 2017; De Pauw & Mervielde, 2010; Shiner & Caspi, 2003). These studies generally relied on the well-validated Five-Factor Model of personality, which in childhood distinguishes among five major personality dimensions: Extraversion, Benevolence, Conscientiousness, Emotional Stability, and Openness-to-experience/Imagination (De Pauw, 2017; Tackett, 2006).

Focusing on specific personality traits, both cross-sectional and longitudinal research in neurotypical populations identified robust relations between high Extraversion and low Benevolence, Conscientiousness, and Emotional Stability, on the one hand, and emotional or behavioral problems on the other hand (e.g., De Pauw & Mervielde, 2010; Prinzie et al., 2003; Prinzie et al., 2014; Van Leeuwen et al., 2004). In CP-research, however, studies on the relationship between personality and child adjustment are more limited and confined to cross-sectional evidence. Vrijmoeth et al. (2012) examined maladaptive, pathological personality traits measured by the Dimensional Personality Symptom Item Pool (De Clercq et al., 2003) among 101 youth with motor and intellectual disabilities, including 45 children with CP. Results showed that higher scores on Disagreeableness (a proxy of low Benevolence) and lower scores on Emotional Stability and Compulsivity (a proxy of extreme Conscientiousness) were related to behavior problems. However, no study to date has evaluated longitudinal associations of personality traits with psychosocial outcomes in CP. Also, associations between personality and more positive behavioral outcomes, such as psychosocial strengths, have not been studied to date.

The interplay between child personality and parenting

In addition to the recognition that both child personality and parenting are implicated in children's psychological functioning, there is increasing attention for the interplay between these two major factors (Lengua et al., 2019). That is, based upon their personality make-up, children differ in how sensitive they are to their social environment and specifically to parenting practices. Children might have an increased sensitivity to either stressful (cf., diathesis-stress model; Monroe & Simons, 1991), supportive (cf., vantage-sensitivity model; Pluess & Belsky, 2013), or both stressful and supportive environments (cf., differential-susceptibility model; Belsky et al., 2007; Belsky & Pluess, 2016) depending on their personality make-up.

Studies among neurotypical populations and families of children with behavioral difficulties have provided most support for the diathesis-stress model, indicating that children with more challenging personality traits (i.e., lower Benevolence, Conscientiousness, Emotional Stability) are particularly vulnerable to develop behavioral problems when exposed to autonomy-thwarting parenting (Bates & Pettit, 2015; Kiff et al., 2011; Prinzie et al., 2003; Van Leeuwen et al., 2007). Furthermore, a meta-analysis on temperament-by-parenting interactions in neurotypical populations showed that children with a more challenging temperament (compared to those with an 'easier' temperament) were more vulnerable to negative parenting, but also found evidence for the differential susceptibility model, as these same children were also more sensitive to the beneficial effects of positive parenting (Slagt et al., 2016). To our knowledge, no study to date has evaluated this personality-by-parenting interplay among families of children with CP.

The present study

This longitudinal study with three annual waves aims (1) to map out intra-individual changes in children's psychosocial development and parenting behavior across a two-year period and (2) to examine the additive and interactive effects of both parenting and child personality in the psychosocial development of youth with CP. This study contributes to the literature in three innovative ways. First, research in neurotypical populations addressing the roles of personality and parenting, as well as personality-by-parenting interactions, has increased our understanding of heterogeneity in children's psychosocial development. However, among families of children with motor disabilities, this research avenue is still in its infancy and confined to cross-sectional evidence. To our knowledge, this is the first study to address these processes from a longitudinal perspective in families of children with CP. Second, developmental literature on CP has been primarily focusing on children's behavioral problems and dysfunctional parenting behavior, which provides a limited and one-sided view on children's development and parenting quality. This study complements this vulnerability-oriented approach with a strengths-oriented approach by addressing the role of both autonomy-thwarting and -supportive parenting behavior, and their relations with negative as well as positive child outcomes. Doing so, this study aims to uncover keys to promote constructive parenting and child behavior. Third, this study uses latent change modeling (LCM) to examine the unique and interactive roles of both parenting and child personality in children's psychosocial development. This technique allows to model absolute change at the within-person level, which provides insight into processes of change within a family unit, rather than processes of relative change among the sample group as a whole. Studies at the level of a family unit are particularly valuable for the application of parenting research in practice because the examination of processes at this level are most salient and meaningful to individuals with CP and their families. Moreover, the family unit is the place where real changes through interventions and parent support can take place (Keijsers et al., 2016).

4.2 Methods

Participants

Participants were parents of 118 children with CP (64.4% boys). The sample consisted of 104 mothers, 12 fathers, and two legal guardians with an average age of 41.4 years old at Time 1 (T1) (*SD* = 5.4, range = 30.1 - 65.4). Most participants were married or lived with their partner (78.8% at T1) and were employed (82.9% mothers and 90.4% fathers at T1). At T1, children were on average 10.9 years old (*SD* = 2.9, range = 4.6 - 17.0, age range = 7 - 15 years old for 86.4% of the children). At Time 2 (T2), the mean age was 12.1 years old (*SD* = 2.9, range = 5.8 - 18.3) and at Time 3 (T3) the children had an average age of 12.9 years old (*SD* = 2.9, range = 6.7 - 19.3). The majority of the children were reported to have spastic CP (72.9%), followed by 11.9% with a mixed type of CP, 7.6% with dyskinetic CP, and 1.7% with ataxic CP. For 5.9% of the participants, the type of CP was unknown. Reports on the Gross Motor Function Classification System (GMFCS; Palisano et al., 2008; Palisano et al., 1997) indicated that 21.2% of the children functioned at level I (i.e., the child can walk without restrictions but has limitations in more advanced motor skills), 39.0% at level II, 17.8% at level III, 8.5% at level IV, and 13.6% of the children functioned at level V (i.e., the child has very limited motor abilities). Table 1 provides additional demographic information of the participants.

Procedure

Primary caregivers of children with CP were recruited through seven service centers for children with physical disabilities in Belgium. Primary inclusion criteria for the participants were: being a primary caregiver of a child that (a) received a formal diagnosis of CP and (b) was aged between 4 and 18 years old. At the beginning of the study and during each follow-up, each participant was contacted by telephone by a researcher from the research team. During this telephone conversation, the researcher not only explained the aim and the course of the study but also discussed the participant's relationship with the child and tried to get a clearer view on whether the participant was aware of the child's daily life experiences and could provide insight into the child's development. From these conversations, it became clear that the participant was a main caregiver for the child. Participants were asked to report on family background information, their perceptions of their child's emotional and behavioral problems, psychosocial strengths, personality, and their own parenting behavior through paper questionnaires that were sent to the family home. All participants who indicated that they wanted to participate in a longitudinal study during the baseline assessment were re-invited in the first and second follow-up study by telephone. To evaluate associations over time, we included the 118 participants (i.e., 104 biological mothers, 12 biological fathers, and two legal guardians) who participated three (n = 92) or two (n = 26) times. ANOVAs and Chi-square tests revealed no significant differences between the participants who participated once (n = 13) and the participants who participated two or three times (n = 118) in terms of demographic characteristics and study variables (all ps > 0.05). The study received ethical approval from the Institutional Review Board of the host University and informed consent was obtained from all individual participants included in the study at each assessment.

Measures

Child behavior problems. Parents assessed their child's emotional and behavioral problems with the Dutch version of the parent-report Child Behavior Checklist/6-18 (CBCL; Achenbach & Rescorla, 2001) on a three-point Likert scale ranging from (0) *not applicable* to (2) *often applicable*. Internalizing problems comprised the subscales for anxious/depressive (13 items) and withdrawn/depressive behavior (8 items). The subscales for aggressive (18 items) and rule-breaking behavior (17 items) represented externalizing problems. Cronbach α's ranged from .86 (internalizing problems at T2) to .92 (externalizing problems at T3).

Table 1. Descriptive data on the participating children and their parents (*n* = 118)

	n	%
Child characteristics		
GMFCS[a]		
I	25	21.2
II	46	39.0
III	21	17.8
IV	10	8.5
V	16	13.6
CFCS[b]		
I	51	43.2
II	22	18.6
III	24	20.3
IV	7	5.9
V	1	0.8
Unknown	13	11.0
Intellectual functioning[c]		
Intellectual disability (IQ < 70)	31	26.3
No intellectual disability (IQ > 69)	50	42.4
Unknown	37	31.4
Comorbid diagnose[d]		
Epilepsy	38	32.2
Autism spectrum disorder	26	22.0
Cerebral visual impairment	32	27.1
Other[e]	45	38.1
Type of education		
Special kindergarten	3	2.5
Regular primary education	17	14.4
Special primary education	66	55.9
Regular secondary education	10	8.5
Special secondary education	14	11.9
Unknown	8	7.0
Living situation		
At home with parents	92	78.0
Part-time at home, part-time at school	13	11.0
During the week at school, in the weekend at home	7	5.9
Unknown	6	5.1
Parent characteristics		
Marital status		
Married or living with partner	93	78.8
Living without partner (single, divorced, widow)	10	8.5
Unknown	15	12.7
Degree of education		
Primary school	2	1.7
Secondary school	49	41.5
Higher education	64	54.2
Unknown	3	2.5

Note. [a] Scores on the GMFCS (Palisano et al., 2008; Palisano et al., 1997) retrieved from the medical file at T1. If the GMFCS scores were not found at T1, scores were based on parent report at T2 or T3. [b] At T2 and T3 parents were asked to rate their child's ability to communicate on the Communication Function Classification System (Hidecker et al., 2011). Scores are based on parent reports at T2 and, if needed, supplemented with parent report at T3. [c] Retrieved from the medical file at T1. [d] Based on information from the medical file and parent report at T2 and T3. Parents could indicate several comorbid diagnoses. [e] Specific learning disorder, AD(H)D, and behavioral disorder were most prevalent.

Child psychosocial strengths. Parents rated their child's psychosocial strengths on the Behavioral and Emotional Rating Scale (BERS-2; Epstein, 2004) on a five-point Likert scale ranging from (1) *completely not true* to (5) *completely true*. The questionnaire comprises three types of strengths: interpersonal strengths (15 items, e.g., *"Accepts responsibility for his/her behavior"*), family involvement (10 items, e.g., *"Shows a sense of commitment towards the family"*), and intrapersonal-affective strengths (18 items, e.g., *"Accepts closeness and intimacy from others"*). Cronbach α's ranged from .75 (family involvement at T2) to .93 (interpersonal strengths at T3).

Externally controlling parenting. Parents' use of coercion and physical punishment was assessed with the negative control scale from the Ghent Parental Behavior Scale (PBS; Van Leeuwen & Vermulst, 2004). This scale taps into punitive parenting (6 items, e.g., *"If my child does something that is not allowed, I give him/her a punishment"*) and harsh punishment (5 items, e.g., *"I spank my child when he/she is disobedient"*) (r = .32 at T1, r = .41 at T2, r = .27 at T3) rated on a five-point Likert scale, ranging from (1) *never* to (5) *always.* Cronbach α's ranged from .83 (T1) to .85 (T2).

Autonomy-supportive parenting. Parents rated their autonomy-supportive parenting using a reduced version of the Autonomy Support Scale of the Perceptions of Parents Scale (POPS; Grolnick et al., 1991; Soenens et al., 2007). The seven items were scored on a five-point Likert scale, ranging from (1) *not applicable* to (5) *fully applicable* (e.g., *"I am usually willing to consider things from my child's point of view"*). Cronbach α's ranged from .75 (T1) to .80 (T2).

Child personality. Given that personality factors are characterized by substantial continuity and long-term stability (Caspi & Shiner, 2006), parents assessed their child's personality only during the baseline assessment, at T1, using the Hierarchical Personality Inventory for Children (HiPIC; Mervielde & De Fruyt, 2002). In this questionnaire, parents indicated how characteristic 144 statements were for their child's behavior on a five-point Likert scale, ranging from (1) *hardly characteristic* to (5) *very characteristic*. The 144 items represent 18 underlying facets, which can be grouped into five higher-order factors: Extraversion is represented by the facets Energy, Expressivity, Optimism and Shyness (reversed); Benevolence includes the facets Altruism, Dominance (reversed), Egocentrism (reversed), Compliance and Irritability (reversed); Conscientiousness is represented by the facets Concentration, Perseverance, Orderliness and Achievement Motivation; Emotional Stability encompasses the facets of Anxiety (reversed) and Self-Confidence; Imagination includes the facets Creativity, Intellect and Curiosity. Cronbach α's ranged from .86 (Benevolence) to .96 (Conscientiousness).

These questionnaires were all developed to be broadly applicable and were successfully used in research among children with special needs, including youth with CP (De Clercq et al., 2019; De Pauw et al., 2011; Dieleman et al., 2020; Sointu et al., 2012).

Data analysis

LCM was used to model change at the within-person level (i.e., within a family unit) in parenting and psychosocial outcomes across a two-year interval. The LCMs were estimated using Mplus 8.3 (Muthén & Muthén, 1998–2012) with robust maximum likelihood as estimator because missing data were missing completely at random (Little's missing completely at random test: χ^2 (254) = 235.50, p = .79) (Usami et al., 2019). To gain acceptable statistical power to analyze the models, we modeled change across the three waves in two separate models: T1-to-T2 (first time period) and T2-to-T3 (second time period). This decision was also informed by latent growth curve analyses (McArdle, 2009) performed initially on these data, which indicated no significant mean slope nor variance in the slope of the outcome variables when change was modeled across three assessment points simultaneously. However, when change was modeled in a more fine-grained fashion between two one-year intervals using LCM, we did find significant variance in the growth parameters predicting the initial level and change in the outcome variables. Acceptable model fit was evaluated according to: a Root Mean Square Error of Approximation (RMSEA) and Standardized Root Mean Square Residual (SRMR) of 0.08 or below, and a Comparative Fit Index (CFI) of 0.90 or above (Hu & Bentler, 1999).

The measurement model described the latent level and change factors for each latent variable. Concerning the parenting behaviors, two parcels were created for each parenting construct applying the item-to-construct balance method, where stronger loading items are combined with weaker loading items (Landis et al., 2000). As child behavior problems, psychosocial strengths, and personality are considered to be multidimensional in nature, their subscales were used as indicators for their latent factors (cf., the internal-consistency approach; Kishton & Widaman, 1994). The measurement model for each study variable showed adequate fit, with the average fit being: RMSEA = 0.05, CFI = 0.99, and SRMR = 0.04.

Next, the measurement models were supplemented with a structural model that specified how these level and change factors were interrelated. Within each of the structural models, the level of, and change in, an outcome variable was predicted simultaneously by one personality domain (measured at baseline) and the level of, and change in, one parenting construct. Given the three outcome variables and the five personality domains, this resulted in 15 models regarding externally controlling parenting and 15 models regarding autonomy-supportive parenting (Figure 1). All models showed adequate fit with an average fit of RMSEA = 0.05, CFI = 0.97, and SRMR = 0.06.

Furthermore, we tested the moderating role of child personality by adding interaction terms between a child personality domain and the level of, and change in, parenting behavior to the models. For each personality domain, three interaction terms were created (i.e., between child personality, on the one hand, and the level of, change from T1-to-T2, and change from T2-to-T3 in parenting behavior, on the other hand), which simultaneously predicted the level of, and change in, the outcome variables. This approach resulted in 30 tested interaction terms (i.e., five personality domains, two parenting variables, and three outcome variables). For probing interactions, we followed the Johnson-Neyman technique, which allowed to indicate the specific value along the continuum of the personality trait at which the relation between parenting and child behavior was significant (i.e., regions of significance; Del Giudice, 2017). The interaction effects are not presented in Figure 1 for reasons of parsimony, but significant interactions are visually illustrated using plots in SPSS 26.0 (IBM Corporation, Armonk, NY, USA).

4.3 Results

Preliminary analyses

Before addressing the main research questions, the associations between several demographic characteristics and the variables of interest were examined. A MANCOVA was conducted with child gender, type of CP, CP symptom severity (i.e., GMFCS-level), and the informant's educational level as fixed variables, with the child's and informant's age as covariates, and with all study variables as dependent variables. Within these analyses, yearly-assessed variables were aggregated across the three assessment points. The findings revealed no overall multivariate effects for the child's age, type of CP, level of physical functioning (i.e., CP symptom severity based on GMFCS-level), and the informant's educational level or age (all *p*s > .05). An additional MANCOVA including the available information on children's cognitive functioning (*n* = 81), demonstrated that the child's intellectual functioning also did not have a significant effect on the study variables (all *p*s > .05). However, the multivariate effect of child gender was significant (Wilk's λ = .70, *F*(10,51) = 2.24, *p* = .03), indicating that parents of girls reported more internalizing problems (*F*(1,115) = 4.54; *p* = .04) and less Emotional Stability (*F*(1,116) = 4.62; *p* = .03) compared to parents of boys. Looking more closely into the effect of child age in each assessment period, correlation analyses indicated that child age was associated with more internalizing problems at T1 (*r* = .20, *p* = .03), more Benevolence (*r* = .24, *p* = .01) and less Extraversion (*r* = -.35, *p* < .001). Therefore, all LCMs controlled for child age and child gender. Means, standard deviations, and correlations between the study variables are presented in Table 2.

Main analyses

Research question 1: Do problem behaviors, psychosocial strengths, and parenting change over time in children with cerebral palsy?

Mean-level changes in children's psychosocial development and parenting behavior were estimated using univariate LCM. Results indicated a significant mean-level increase in both internalizing and externalizing problems from T1-to-T2 and no significant change thereafter. Psychosocial strengths remained stable in the first time period but increased significantly from T2-to-T3. Both externally controlling parenting as well as autonomy-supportive parenting showed mean-level stability across the two-year period. The models showed significant variances in the slope for all latent variables, suggesting substantial individual differences in how child behavior and parenting behavior changed over time. Parameter estimates and fit indices of the univariate LCMs are provided in Table 3.

Research question 2: What are the additive and interactive effects of parenting and child personality on behavioral outcomes in children with cerebral palsy?

Main effects of parenting and child personality

First, the main effects of parenting and child personality on behavioral outcomes were examined (Figure 1). Concerning parenting behavior, the findings showed that both the level of, and change in, externally controlling parenting related positively to higher levels of, and change in, externalizing child behavior (at both time periods). Moreover, change in externally controlling parenting also related positively to change in internalizing problems (in the first time period). Furthermore, the level of autonomy-supportive parenting related positively to the level of psychosocial strengths. Concerning child personality, less Extraversion, Benevolence, and Emotional Stability related to higher levels of internalizing problems, and less Benevolence, Conscientiousness, and Emotional Stability were associated with higher levels of externalizing problems. Higher scores on all

Table 2. Means, standard deviations, and correlations between the study variables (n = 118)

	Mean	SD	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.	15.	16.	17.	18.	19.	20.
GMFCS^{a}	-	-	-.16	-.04	.07	-.11	.21	.16	.06	.10	.18	.19	-.18	-.02	-.01	-.15	.01	-.10	.00	-.05	-.14	-.07
T1																						
1. Internalizing	6.47	5.88																				
2. Externalizing	8.14	7.36	.63***																			
3. Strengths	3.64	0.52	-.39***	-.54***																		
4. External control	3.90	1.10	.06	.14	-.03																	
5. Autonomy support	3.86	0.56	-.05	-.07	.34***	.12																
6. Extraversion	3.44	0.61	-.43***	-.08	.49***	.03	.33***															
7. Benevolence	3.26	0.60	-.36***	-.74***	.64***	.00	.00	.03														
8. Conscientiousness	2.99	0.59	-.11	-.39***	.46***	.04	.24**	.08	.50***													
9. Emotional Stability	2.91	0.66	-.64***	-.43***	.23*	-.10	-.07	.34***	.27**	-.08												
10. Imagination	3.20	0.73	-.17	-.12	.41***	.05	.45***	.61***	.08	.38***	.11											
T2																						
11. Internalizing	7.32	5.94	.70***	.46***	-.29**	-.12	.03	-.38***	-.27**	-.01	-.57***	-.06										
12. Externalizing	8.59	7.78	.53***	.80***	-.43***	.03	.01	-.01	-.69***	-.31***	-.40***	.01	.57***									
13. Strengths	3.68	0.54	-.31***	-.48***	.70***	.07	.31***	.45***	.55***	.29**	.27**	.34***	-.38***	-.51***								
14. External control	3.92	1.11	.01	.17	-.16	.66***	-.09	-.05	-.08	-.12	-.06	-.04	.02	.17	.03							
15. Autonomy support	3.90	0.58	-.14	-.08	.26**	.08	.50***	.23*	.07	.31***	-.02	.27**	-.01	-.11	.34***	.05						
T3																						
16. Internalizing	7.44	6.61	.71***	.54***	-.32**	-.01	-.14	-.35***	-.32**	-.05	-.57***	-.03	.80***	.64***	.43***	.07	-.19					
17. Externalizing	8.85	8.01	.55***	.81***	-.37***	.08	-.04	-.01	-.66***	-.20	-.45***	.08	.52***	.88***	.47***	.15	-.11	.66***				
18. Strengths	3.68	0.51	-.38***	-.52***	.73***	.03	.44***	.41***	.52***	.29**	.33**	.41***	-.39***	-.53***	.79***	.16	.39***	-.47***	-.57***			
19. External control	3.85	1.08	.16	.11	-.10	.75***	-.06	-.13	.05	-.04	-.20	-.02	.06	.01	.09	.72***	.10	.02	.08	.08		
20. Autonomy support	3.82	0.55	-.07	.01	.43***	.03	.55***	.30**	.01	.24*	-.03	.34**	-.06	-.03	.46***	.18	.56***	-.16	-.01	.50***	.07	

Note. SD Standard deviation. ^{a} Scores on the Gross Motor Function Classification System (Palisano et al., 2008; Palisano et al., 1997), *Mode* = 2.00, range = 1.00 to 5.00.
$^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

personality traits related positively to the level of psychosocial strengths. One significant association was observed between child personality and change in the outcome variables, where high Conscientiousness related to an increase in psychosocial strengths in the first time period.

The moderating role of child personality

Second, interaction terms were added, examining whether the nature and/or relation between the level of, or change in, parenting behavior and the level of, or change in, children's psychosocial development varied as a function of child personality. Nine out of 30 tested interactions were significant: six with the level of psychosocial development as an outcome (Figure 2), and three with change in psychosocial development as an outcome (Figure 3).

First, concerning the level of internalizing problems as an outcome, the findings indicated that the relationship between the level of externally controlling parenting and the level of internalizing problems was only significant for children with lower scores on Extraversion ($t(113) = -2.03$, $p = .04$, $b = -1.33$). The Johnson-Neyman technique indicated that when Extraversion was below 2.44 (6.8% of the children), the relationship between the level of externally controlling parenting and the level of internalizing problems became statistically and positively significant (Figure 2a).

Second, three significant interaction effects were found concerning the level of externalizing problems as an outcome. The relation between the level of externally controlling parenting and the level of externalizing problems was only significant among children with lower scores on Extraversion ($t(113) = -2.24$, $p = .03$, $b = -1.43$), Conscientiousness ($t(113) = -2.45$, $p = .02$, $b = -1.38$), or Imagination $t(113) = -2.32$, $p = .02$, $b = -1.15$). The relation became statistically and positively significant when Extraversion was lower than 3.40 (43.2% of the children), when Conscientiousness was lower than 3.02 (45.8% of the children), or when Imagination was lower than 3.09 (44.9% of the children) (Figure 2b).

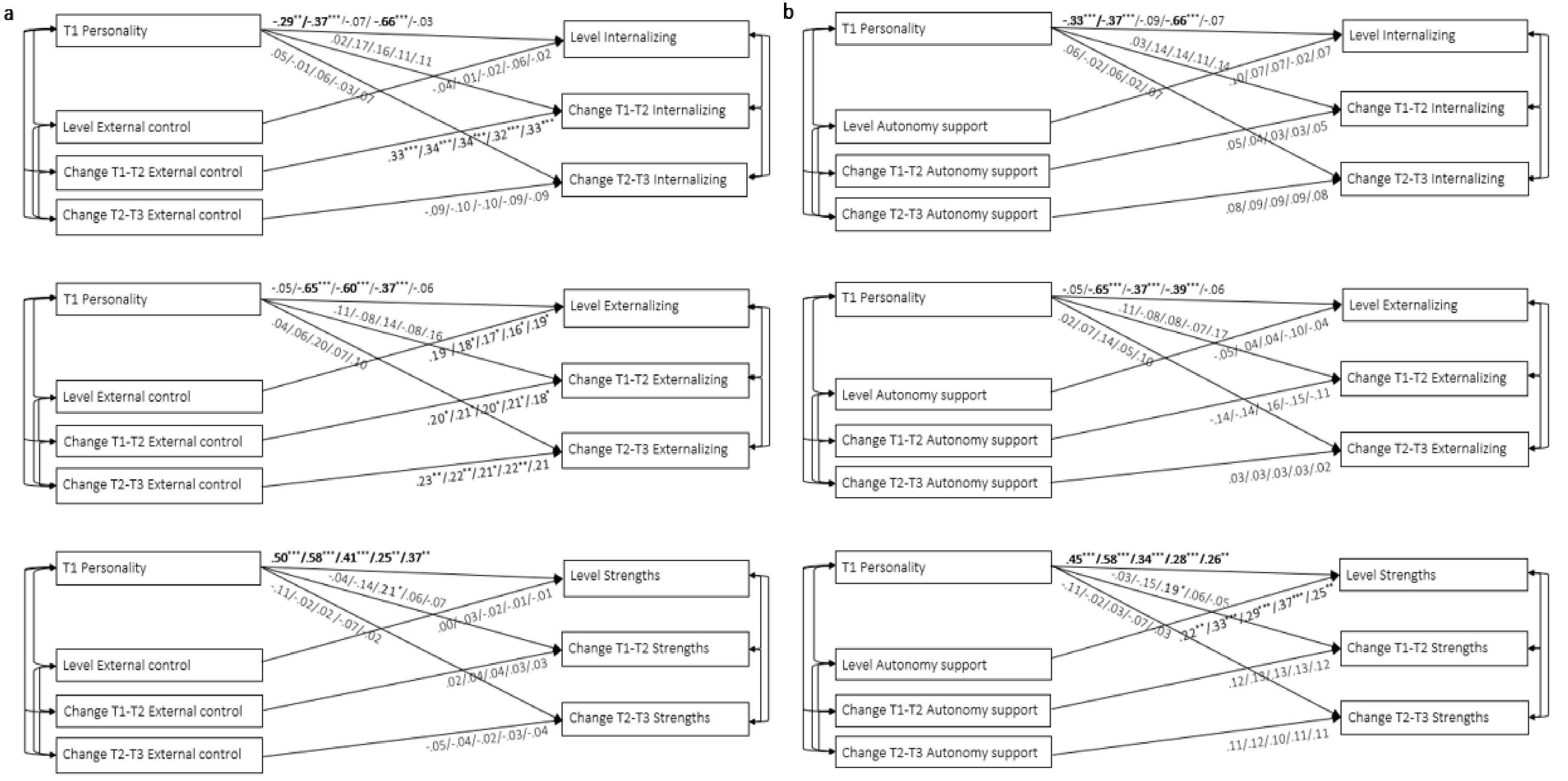
Third, two significant effects were found concerning the level of psychosocial strengths as an outcome. When Extraversion was lower than 2.60 (8.5% of the children) or when Imagination was lower than 2.06 (6.8% of the children), the relation between the level of externally controlling parenting and the level of psychosocial strengths became statistically and negatively significant ($t(113) = 2.17$, $p = .03$, $b = 0.30$; $t(113) = 2.14$, $p = .03$, $b = 0.25$, respectively) (Figure 2c).

Table 3. Parameter estimates and fit indices of the univariate latent change model, controlling for child age and gender (n = 118)

	Level		Change T1-to-T2		Change T2-to-T3		Correlation (level, Change12)		Correlation (level, Change23)		Correlation (Cha12, Change23)		Fit indices		
	M	s^2	*M*	s^2	*M*	s^2	Est	SE	Est	SE	Est	SE	RMSEA	CFI	SRMR
Internalizing problems	1.09*	2.80**	0.27*	0.95*	0.22	0.98***	-0.38	0.13**	-0.09	0.16	-0.15	0.38	0.07	0.96	0.08
Externalizing problems	1.75***	3.22***	0.42*	1.08***	0.47	0.70**	-0.11	0.14	0.00	0.15	-0.51	0.21*	0.07	0.98	0.06
Psychosocial strengths	3.40***	0.19***	-0.09	0.11***	0.12**	0.06***	-0.36	0.01***	0.05	0.15	-0.65	0.12***	0.08	0.97	0.11
External control	2.34***	0.27***	0.12	0.19**	-0.12	0.13**	-0.30	0.13*	0.19	0.22	-0.68	0.15***	0.07	0.98	0.04
Autonomy support	3.83***	0.24***	0.04	0.22***	-0.10	0.19***	-0.40	0.11***	0.16	0.14	-0.70	0.12***	0.05	0.99	0.08

Note. The table reports unstandardized means and variances of the level and change in the study variables and standardized correlations between the level and change in the study variables. *RMSEA* Root Mean Square Error of Approximation, *CFI* Comparative Fit Index, *SRMR* Standardized Root Mean Square Residual. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

Figure 1. Latent change model on the relation between child personality and parenting behavior (**a** externally controlling parenting, **b** autonomy-supportive parenting) on children's internalizing problems, externalizing problems, and psychosocial strengths



Note. Path coefficients refer to the models including the following personality traits: Extraversion/Benevolence/Conscientiousness/Emotional Stability/Imagination. Significant effects are indicated in bold. *** p <.001, ** p < .01, * p < .05.

Furthermore, we observed three significant interaction effects concerning change in all outcome factors. First, the association between change in externally controlling parenting and change in internalizing problems in the second time period was significantly negative among children with a score lower than 2.61 on Emotional Stability (31.4% of the children), yet not significant among children with higher scores (t(113) = 3.72, *p* < .001, *b* = 1.22) (Figure 3a). Second, the previously reported interaction between Conscientiousness and externally controlling parenting was replicated when change in externalizing problems in the first time period was modeled as an outcome (*t*(113) = -2.40, *p* = .02, *b* = -0.80). More specifically, when children scored lower than 2.89 on Conscientiousness (39.0% of the children), change in externally controlling parenting related positively to change in externalizing problems (Figure 3b). One interaction effect was observed concerning autonomy-supportive parenting. Whereas the relation between change in autonomy-supportive parenting and change in psychosocial strengths in the first time period was significant among children with a score of 2.90 or higher on Emotional Stability (50.0% of the children), this effect was not significant for children with lower scores (*t*(113) = 2.03, *p* = .04, *b* = 0.26) (Figure 3c). A similar effect was observed when the level of, and change in, psychosocial strengths at the second time period were modeled as outcome factors, but these effects did not reach significance (both *p*s = .09).

After Bonferroni-correction (*p* < .002 in the structural model), only one interaction effect remained significant, concerning the effect between Emotional Stability and change in externally controlling parenting on change in internalizing problems in the second time period (Figure 3a) (*β* = .42, *p* < .001 in the structural model). Since the personality-by-parenting interplay has never been documented among youth with CP and because Bonferroni correction is quite rigorous to uncover interaction effects (Blake & Gangestad, 2020), we described all significant interactions (*p* < .05 in the structural model).

Figure 2. Interaction between child personality and parenting on the level of psychosocial development (**a** internalizing problems, **b** externalizing problems, and **c** psychosocial strengths)

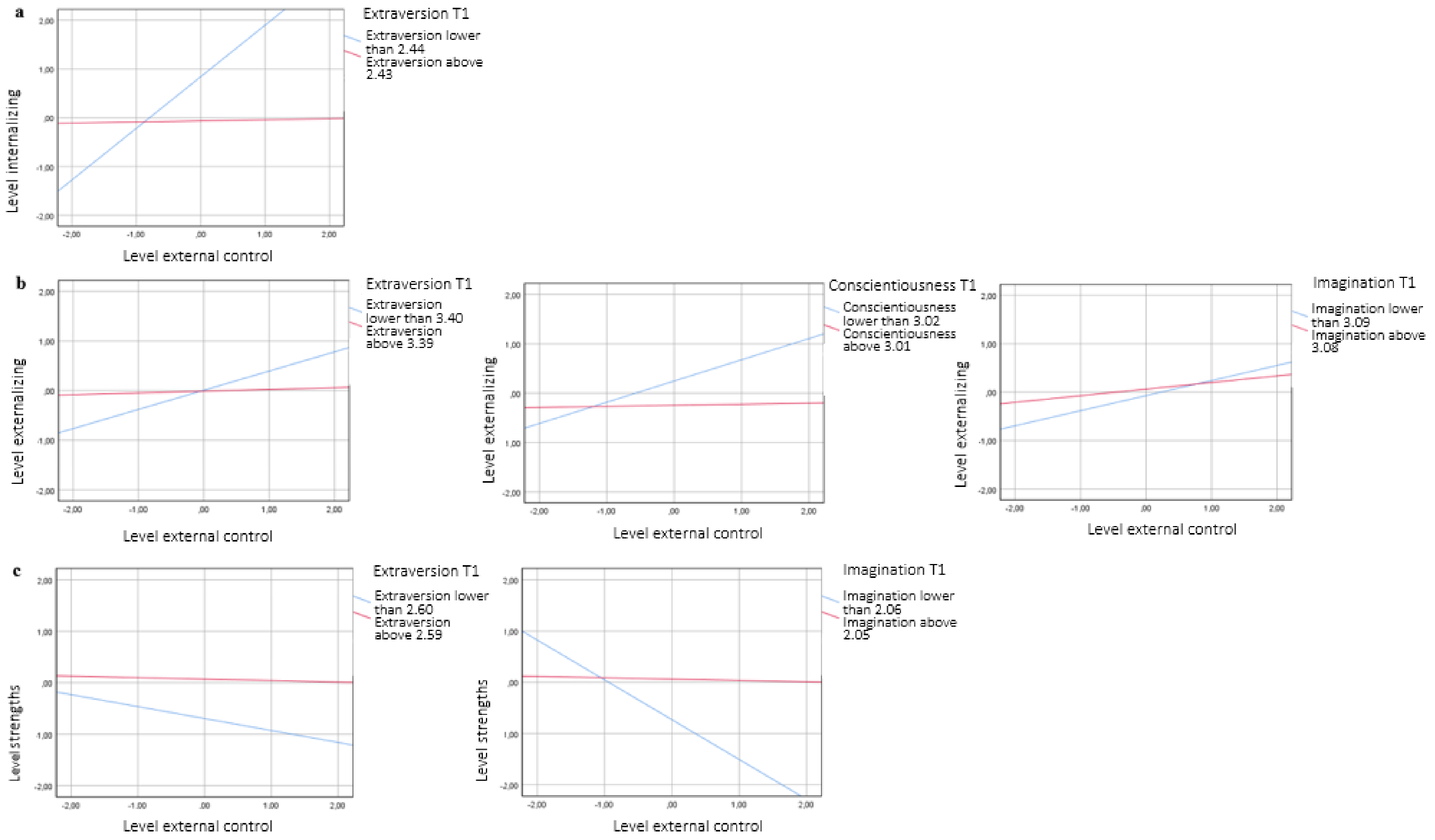
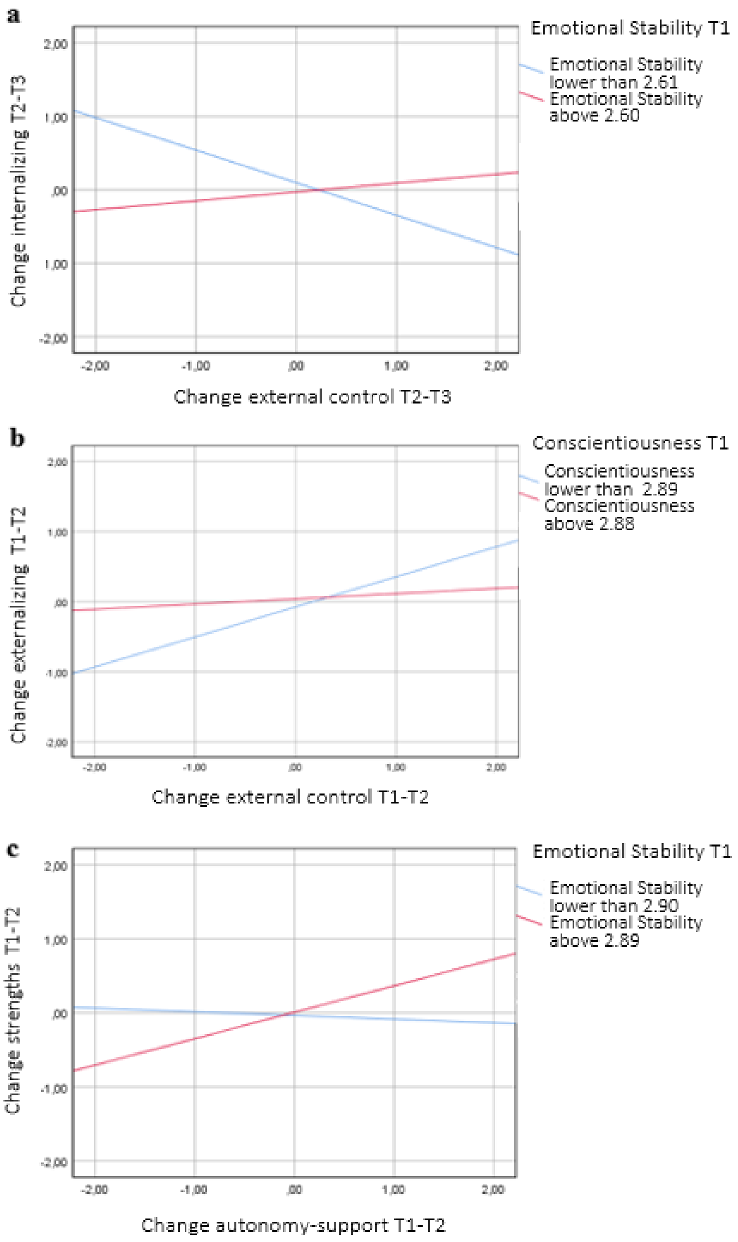


Figure 3. Interaction between child personality and parenting on change in psychosocial development (**a** internalizing problems, **b** externalizing problems, and **c** psychosocial strengths)



4.4 Discussion

Given that children with CP vary widely in their psychosocial adjustment, it is essential to understand the underlying factors that help to explain why some children experience many behavioral or emotional problems whereas others report high levels of psychosocial well-being (Novak et al., 2012; Vrijmoeth et al., 2012). Researchers advocated to go beyond the inquiry of ‘disability-specific sources’ and encouraged studies examining ‘non-syndrome-specific’ factors. This study aims to advance the understanding of the psychosocial development of children with CP by examining the joint value of parenting behavior and child personality in relation to emotional and behavioral problems and psychosocial strengths, from a two-year longitudinal perspective.

Continuity and change in children's psychosocial development and parenting behavior

As a first research aim, we explored continuity and change in psychosocial development and parenting behavior over time. Univariate LCMs indicated a significant increase in both internalizing and externalizing problems during the first time period, and a significant increase in psychosocial strengths during the second time period. To our knowledge, no study to date has reported on intra-individual changes in emotional or behavioral problems and psychosocial strengths in youth with CP, assessed with the CBCL (Achenbach & Rescorla, 2001) and BERS-2 (Epstein, 2004). These findings are generally consistent with the small body of longitudinal research demonstrating that behavior problems persist and social strengths, such as social participation, tend to moderately improve when children with CP develop into young adolescents (Brossard-Racine et al., 2012; Tan et al., 2014). The significant increase in both internalizing and externalizing problems may be indicative of the new challenges puberty presents to children with CP and their families. During puberty, demands for more maturity and responsibility increase, peers become more important and youth tend to struggle more often with their self-worth (Soenens et al., 2019). Among youth with CP these normative challenges can be exacerbated by the child's motor disability. Therefore, puberty can be an especially challenging period for youth with CP as they tend to compare themselves more often with their peers and become more aware and reflective of their own capabilities and limitations (Brossard-Racine et al., 2012; Parkes et al., 2008).

Further, our findings indicated no significant change in parenting behavior across time, suggesting that parents are, on average, quite stable in the way they interact with their child. This finding is consistent with findings obtained in the neurotypical population (Barber et al., 2005). Importantly, however, we found substantial variation in intra-individual changes in parenting, indicating that parents differ in how their parenting behavior changes across time. In general, the substantial variation in within-person change in each study variable suggested that children and parents differed in the degree to which their psychosocial development or use of parenting behaviors changed across time. These findings across a two-year interval complement a recent diary study among children with CP, showing that the degree to which parents are autonomy-supportive and controlling can considerably vary from one day to the other during one week (Dieleman et al., 2020).

Effects of parenting and child personality on children's psychosocial development

As a second research aim, we investigated additive and interactive effects of parenting behavior and child personality on emotional or behavioral problems and psychosocial strengths in youth with CP. Overall, this study showed that parenting as well as child personality act as important and unique precursors of the psychosocial development of children with CP. More specifically, three important findings illustrated that these 'non-syndrome-specific' factors might act as risk-factors leading to behavioral problems as well as protective factors enhancing psychosocial strengths.

Effects of parenting

First, corroborating previous research, autonomy-supportive parenting behavior related uniquely and substantially to the psychosocial development of youth with CP (Aran et al., 2007). In line with hypotheses derived from SDT, externally controlling parenting consistently related to emotional and behavioral problems, whereas autonomy-supportive parenting was associated with beneficial outcomes (Deci & Ryan, 2000). Both high levels of, and change in, externally controlling parenting were associated with more externalizing problems in youth with CP. This finding supports previous cross-sectional work among CP-populations (De Clercq et al., 2019) and longitudinal work among neurotypical populations (Pinquart, 2017a). Moreover, it suggests that children are more likely to engage in aggressive or rule-breaking behavior when parents rely on harsh disciplining or pressuring behaviors. Previous studies have also indicated consistent associations between externally controlling parenting and internalizing problems among neurotypical (Pinquart, 2017b) and CP-populations (Crandell et al., 2018). Although this study did not identify a significant association between the level of externally controlling parenting and the level of internalizing problems, change in both factors during the first time period were significantly associated. This finding meshes with previous findings among neurotypical populations, illustrating that changes in controlling parenting are positively tied to changes in children's internalizing problems (Mabbe et al., 2019; Pinquart, 2017b).

Further, the level of autonomy-supportive parenting consistently related to higher levels of psychosocial strengths, a finding consistent with previous studies demonstrating associations between autonomy-supportive parenting and better outcomes in the psychosocial development of children with CP (e.g., Crandell et al., 2018; Elad et al., 2018). Since we found no significant association between autonomy-supportive parenting and emotional or behavioral problems, this study supports the idea that positive parenting might play a more prominent role in fostering positive outcomes rather than in protecting against maladaptive outcomes (Vansteenkiste & Ryan, 2013).

Effects of child personality

Second, this study is one of the first to demonstrate that individual differences in personality relate uniquely to both negative and positive behavioral outcomes in youth with CP. Our findings generally confirmed well-documented associations obtained in the broader developmental literature (De Pauw & Mervielde, 2010) and prior research among children with CP (Vrijmoeth et al., 2012). Lower levels of Extraversion, Benevolence, and Emotional Stability were associated with higher levels of internalizing problems, and lower levels of Benevolence, Conscientiousness and Emotional Stability related to higher levels of externalizing problems. Furthermore, child personality predicted children's psychosocial strengths, indicating that personality can also function as a source of resilience. All personality domains consistently related to the level of parent-reported psychosocial strengths, and Conscientiousness even positively related to increases in psychosocial strengths in the first time period. Higher scores on Benevolence, Conscientiousness and Emotional Stability have been previously related to more adaptive outcomes in neurotypical populations (e.g., Anglim et al., 2020), but the association with Extraversion and Imagination might be more CP-specific. Perhaps, expressions of energy, expressivity, and optimism in children with CP (i.e., more Extraversion) might relate to the child's motor and speech abilities to communicate and express thoughts and feelings towards others, which facilitates the possibility to show affect or involvement towards others. Additionally, children with CP who display more curiosity and creativity (i.e., more Imagination) might immerse themselves more strongly in interpersonal relationships, which may lead to the development of stronger affective and interpersonal skills.

Personality-by-parenting interplay

Third, this study identified nine significant interaction effects out of 30 tested interactions. Since the number of interaction effects is limited and only one interaction effect remained after Bonferroni correction, the role of these interactions should be interpreted with caution and further replication is warranted. Nevertheless, these interactions proved to be significant despite the limited sample size, and suggest a fairly robust moderating effect of child personality in the relation between parenting and child behavior. The findings mainly supported the idea that children with CP with a more vulnerable personality might have an increased sensitivity to dysfunctional parenting (cf., diathesis-stress model). One interaction was consistent with the notion that adaptive personality increases sensitivity to supportive parenting (cf., vantage-sensitivity model). No evidence was found supporting the differential-susceptibility model in this study.

In line with the diathesis-stress model (Monroe & Simons, 1991), extensive research on personality-by-parenting interactions in neurotypical populations identified strong support for the idea that especially children with lower Emotional Stability or lower Conscientiousness are at increased risk to develop behavioral problems when exposed to negative parenting practices (Bates & Pettit, 2015). Whereas this study showed that the interaction effect concerning Conscientiousness also applies to youth with CP, other significant interactions might be more CP-specific.

Consistent with previous studies, lower Conscientiousness served as a vulnerability factor, associated with elevated levels of externalizing behavior when parents are more controlling (Prinzie et al., 2003; Van Leeuwen et al., 2007). Similar findings were observed concerning lower Extraversion and Imagination. Children with lower scores on Extraversion exhibited higher levels of internalizing and externalizing problems, as well as lower levels of psychosocial strengths when exposed to externally controlling parenting. Although significant interaction effects with the personality domain Extraversion are rare in the extant literature, our finding is consistent with at least one previous study suggesting that Shyness (a facet of Extraversion) plays a role in the development of internalizing problems, but only in the context of high or average levels of overreactive parenting (Prinzie et al., 2014). Furthermore, children with lower scores on Imagination exhibited higher levels of externalizing problems, as well as lower levels of psychosocial strengths when exposed to externally controlling parenting. Because interaction effects with Imagination are rarely documented among neurotypical populations, Imagination might play a unique role among youth with CP. Furthermore, our findings supported the notion that children lower in Emotional Stability are more sensitive to the effects of their environment compared to children higher in Emotional Stability (Bates & Pettit, 2015). Whereas change in externally controlling parenting in the second time period was negatively associated with change in internalizing problems among children with lower Emotional Stability, this association was not significant among youth with higher Emotional Stability. This interaction could be interpreted as an effect of child behavior on parents. When children go through a period in which they temporarily exhibit more internalizing problems than usual, parents might be less controlling, especially when children are more vulnerable. These parents may have already experienced that in times of internalizing problems, these vulnerable children do not benefit from increasing the pressure, and so they might give their child some breathing space. Aunola et al. (2013) observed a similar effect on a daily level in the neurotypical population, where parents reduced their use of psychological control when their child showed more depressive symptoms than usual.

One interaction was consistent with the vantage-sensitivity model, which involves that children with a more adaptive or mature personality might have an increased sensitivity to a supportive environment (Pluess & Belsky, 2013). In this study, the psychosocial strengths of children with higher scores on Emotional Stability increased during the first time period when exposed to more autonomy-supportive parenting, whereas children with lower Emotional Stability did not seem to experience this beneficial effect. This finding might suggest that when a child shows that he/she can handle adversity or is self-confident, it is easier for parents to recognize strengths and be patient and attuned to their child's needs. Similar results have been found in neurotypical populations, where children with low levels of fear and distress were positively affected by supportive parenting behavior, such as maternal sensitivity, whereas fearful children were more likely to experience equal or even elevated levels of behavioral problems (Davis et al., 2015; Hartz & Williford, 2015).

The findings indicated no significant interaction effects including Benevolence. This is somewhat surprising as previous research in neurotypical populations identified Benevolence as a meaningful moderator in the relation between child behavior and parenting (Prinzie et al., 2014; Van Leeuwen et al., 2007). Overall, future studies on the unique and interactive effects of child personality and parenting behavior on the psychosocial development in youth with CP are needed to further unravel the meaning of these findings.

Practical implications

This study has multiple practical implications. First, the vast majority of studies on CP and interventions for children with CP draw from a medical point of view, focusing primarily on the child's medical and physical functioning related to the disability. However, the current findings support the growing recognition of the importance of psychosocial characteristics and family variables for the well-being of children with CP (e.g., Aran et al., 2007). Therefore, we encourage clinicians and researchers to attend to the psychological, emotional and social well-being of these children, in addition to their physical development. Moreover, the increase of emotional and behavioral problems during the first time period indicated that the beginning of puberty might be a challenging period for both children with CP and their context. During this transition, the relationship with caregivers changes, and growth and puberty interact with the disability (Colver & Dickinson, 2010). Therefore, we encourage caregivers to be open, alert, and responsive towards questions and uncertainties related to this stage of life, involving peer relationships- and acceptance, self-worth, body image, and emerging sexuality.

Second, the longitudinal associations between parenting and child psychosocial development highlight that autonomy-thwarting and autonomy-supportive parenting behaviors play important roles in the development of youth with CP. Therefore, family interventions should pay attention to controlling behaviors, but also recognize parents’ autonomy-supportive behaviors and reinforce them. Interventions could provide strategies and rationales for their importance, even when the child’s motor functioning or behavioral problems challenge parents’ coping strategies or opportunities to rely on autonomy-supportive strategies. Previous intervention studies among neurotypical populations have indeed supported the beneficial impact of an autonomy-supportive parenting program for children's mental health (Allen et al., 2019; Joussemet et al., 2018). Moreover, it might be more stimulating and energizing for both parents and care providers to recognize and to acknowledge autonomy-supportive behaviors, rather than to focus on ways to avoid controlling parenting (Dieleman et al., 2019).

Third, the findings revealed that certain personality traits rendered children with CP either more vulnerable or resilient to develop emotional and/or behavioral problems, and at the same time increased or decreased their sensitivity towards their environment. To date, interventions are less focused on individual differences among children with CP. Therefore, applying a non-pathologizing language to talk about individual differences as captured by personality traits, might be especially valuable to accommodate interventions and parental strategies to the unique strengths and challenges in each child’s personality. Attuning to a child’s unique personality can result in better behavioral outcomes and higher quality parent-child relationships (Stoltz et al., 2013).

Limitations and directions for future research

When interpreting the findings of the current study, some limitations should be kept in mind. First, the generalizability of the present findings is limited by several factors: the specific choice of instruments and parenting dimensions, the reliance on mothers as the primary source of information (i.e., mono-rater bias), and the specific recruitment strategies. Future research could benefit from applying alternative measures and assessment methods (e.g., observational designs; Taraban & Shaw, 2018), including multiple informants and more diverse recruitment strategies (e.g., social media, inclusive education). Future research would also do well to examine broader conceptualizations of parenting (Grolnick, 2003), for instance, by including a measure of parental structure. This can allow to examine combinations of structure and autonomy-support, and to investigate whether the effects of these combinations are also moderated by the personality of the child.

Second, we acknowledge that other factors influence the association between parenting behavior and psychosocial development in families with CP. Diverse child factors (e.g., feelings of pain, comorbid diagnosis) or contextual factors (e.g., parents' personality, feelings of stress, motivation to take care of the child, marital relationship, social support) might play a role in the relation between parenting and child behavior (Brossard-Racine et al., 2012; Colver & Dickinson, 2010; Sipal et al., 2010; Vrijmoeth et al., 2012). Although this study corroborates previous findings by demonstrating no significant associations between the severity of the child's physical functioning or intellectual functioning and parenting behaviors (Barfoot et al., 2017; Cohen et al., 2008; Ho et al., 2008), future research should assess the role of symptom severity and other comorbid disorders (e.g., Tan et al., 2014) more extensively. A comprehensive examination could, for instance, include the child's language ability and should also use measures that are reliable and validated within a CP-population, such as standardized intelligence tests for children with motor disabilities (Yin Foo et al., 2013). Additionally, based on Attachment Theory, it could be particularly valuable to assess parent-child attachment, parents' resolution towards their child's diagnosis, and how these factors influence parents' behaviors and children's psychosocial development. Although the large majority of parents raising a child with CP seems to have resolved their reactions to their child's diagnosis (Schuengel et al., 2009), unresolved reactions have been associated with less parental sensitivity and emotional availability, and more disorganized parent-child attachments (Howe, 2006; Marvin & Pianta, 1996; Quinn & Gordon, 2011). More generally, future research would do well to combine insights from SDT and Attachment Theory, in order to gain more complete insight into the quality of attachment relationships between parents and children with CP. While Attachment Theory emphasizes the importance of parental warmth and responsive parenting (i.e., sensitivity, which provides children with a sense of a safe haven), SDT places more emphasis on the importance of autonomy support, where parents encourage initiative and thus facilitate the function of a secure base. Research among parents of children without any known disability shows that both parenting dimensions are important in the development of secure attachment and related developmental outcomes (e.g., Bernier et al., 2014; Whipple et al., 2011). However, these unique effects have not yet been demonstrated in the context of CP, which could be valuable for future research.

Third, the data-analyses did not fully account for transactional processes between the child (i.e., behavior and personality) and its environment (i.e., parenting behavior). Several studies among neurotypical populations have convincingly shown that child behavior, child personality, and parenting behavior reciprocally affect each other throughout time (e.g., Lengua et al., 2019; Van Heel et al., 2019). Although studies examining these bidirectional effects are currently lacking in the CP-literature, we assume that similar bidirectional processes operate in this population. For instance, the significant association between externally controlling parenting and externalizing child behavior also suggests that parents of children with more externalizing behaviors might rely on more controlling parenting behaviors as a response to more frequent externalizing behaviors. Also, we acknowledge that the sample size was relatively small for the modeling method used, which might have resulted in a lack of power for some of the analyses. Moreover, the large number of analyses might have resulted in an increased risk for Type I errors. However, an a-priori sample size calculation for structural equation modeling (SEM) demonstrated that our sample size was sufficient to detect effects (Soper, 2020). Also, two approaches for power analysis within SEM, namely a power analysis based on RMSEA by MacCallum et al. (1996) and a power analysis using Satorra and Saris’ (1985) method based on the Chi-square test indicated sufficient power for the different models (power values ranging from 0.78 to .87, and from 0.85 to 0.93 in the two approaches, respectively). Nevertheless, future prospective longitudinal studies with larger sample sizes, multiple informants, and more assessment moments are needed to replicate the current results and to further disentangle the transactional child-parent interplay among families of youth with CP.

4.5 Conclusion

This study shows that parenting behavior and child personality are important and unique modifiers of the psychosocial development in children with CP. Across two years, children’s psychosocial development showed substantial change, whereas parenting behavior remained stable. Both parenting behavior and child personality functioned as risk-factors leading to emotional and/or behavioral problems and as protective factors enhancing psychosocial strengths. Externally controlling parenting related to more maladaptive outcomes, with increased vulnerability among children with low Extraversion, Conscientiousness, or Imagination. Autonomy-supportive parenting related to more adaptive outcomes, with more beneficial effects among children with high Emotional Stability. Therefore, this study provides empirical support for the theoretical claim that examining the personality-by-parenting interplay is vital for the psychosocial development of *all* children, including those with CP.

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Chapter 5

Expressed Emotion in families of children with and without autism spectrum disorder, cerebral palsy, or Down syndrome: Relations with parenting stress and parenting behaviors

Based on De Clercq, L., Prinzie, P., Warreyn, P., Soenens, B., Dieleman, L. M., & De Pauw, S. S. W. (2020). Expressed Emotion in families of children with and without autism spectrum disorder, cerebral palsy and Down syndrome: Relations with parenting stress and parenting behaviors. *Journal of Autism and Developmental Disorders.* Manuscript under review.

Abstract

This study examined the family emotional climate as assessed by Five Minute Speech Samples and the relation with parenting stress and parenting behaviors among parents of children (6 - 17 years old, 64.7% boys) with autism spectrum disorder, cerebral palsy, Down syndrome, and without any known disability (*n* = 447). In general, the findings indicated that the large majority of parents (79%) expressed low levels of Expressed Emotion, an indicator of a positive emotional family climate. In all groups, more Emotional Over-involvement, more Criticism, and fewer expressions of Warmth were associated with higher levels of parenting stress. Across groups, Emotional Over-involvement was related to more autonomy-supportive parenting, Criticism to more psychologically controlling and overreactive parenting, and Warmth was associated with more responsive and less psychologically controlling and overreactive parenting.

5.1 Introduction

In both neurotypical populations (Sher-Censor, 2015) and populations of children with a disability (Thompson et al., 2018), the construct of Expressed Emotion (EE) receives increasing attention to capture the emotional quality within a family subsystem. More specifically, there is a growing interest in using the Five Minute Speech Sample (FMSS) method to capture EE of parents towards their child (Magaña-Amato, 1993). Currently, two research avenues are pursued in EE-literature among families of children with a disability: evaluating the 'point estimates' of how many parents of children with a disability exhibit high EE, and less pursued, the evaluation of the nomological network (i.e., how EE maps onto other more established constructs for assessing parent-child dynamics). Notably, the accumulation of study findings on the impact of EE is hampered by two important limitations. First, current studies among parents raising a child with a disability are based on small sample sizes, rely on one specific disability with little input from similar research on another disability, and include no comparison group (Laghezza et al., 2010; Sher-Censor, 2015; Thompson et al., 2018). Second, very few studies evaluated the conceptual meaning of EE among parents raising a child with a disability by examining its nomological network. The current study addresses these limitations by (1) examining group differences in EE-point estimates, parenting stress, and parenting behaviors and (2) exploring relations between EE and parenting stress, on the one hand, and relations between EE and parenting behaviors, on the other hand, in and across three groups of parents raising a child with diverse neurodevelopmental disabilities (NDDs), namely autism spectrum disorder (ASD), cerebral palsy (CP), and Down syndrome (DS), and one reference group of children without any known disability.

The growing interest in what parents of children with a disability 'feel, do, and say'

The past decades have witnessed a growing interest in studying the reality of raising a child with a NDD. To date, the majority of these studies have focused on the construct of parenting stress with many studies pointing out that, as a group, parents of children with a NDD are likely to experience more parenting stress than parents of children without a disability (Hodapp et al., 2019; Peer & Hillman, 2014; Pinquart, 2018; Yorke et al., 2018). Also, accumulated research now suggests that parents of children with ASD report the highest levels of parenting stress compared to other types of NDDs, even though group differences are generally small to moderate in effect size and depend on the specific nature of the comparison group (Hayes & Watson, 2013; Valicenti-McDermott et al., 2015).

In addition to the vast parenting stress literature, recent research also started to evaluate specific parenting behaviors in parents raising a child with a disability (Boonen et al., 2015; Dieleman et al., 2017; Dieleman, De Pauw, et al., 2018; Dieleman et al., 2020; Maljaars et al., 2014; Phillips et al., 2017). To do so, some studies adopted the framework of Self-Determination Theory (SDT; Ryan & Deci, 2017), a motivational theory on human socialization, which is prominent in research on parenting within neurotypical populations and claims to be universally applicable (Deci & Ryan, 2000; Soenens et al., 2017). Within this framework, both need-supportive parenting (i.e., parenting behaviors that satisfy children’s needs for autonomy, relatedness, and competence) and need-thwarting parenting behaviors (i.e., parenting behaviors that impede children’s psychological needs) are examined. Although this body of research is quite limited in NDD-populations (Dieleman et al., 2017; Dieleman, De Pauw, et al., 2018; Dieleman et al., 2020), it has been suggested that parents of children with a NDD might rely more on need-thwarting parenting (i.e., psychologically controlling or overreactive parenting) and less need-supportive parenting (i.e., autonomy-supportive or responsive parenting) due to the increased levels of parenting stress or need-frustrating experiences these parents face when raising their child (Hodapp et al., 2019; McCauley et al., 2019).

Next to examining what parents *feel* (i.e., feelings of parenting stress) or *do* (i.e., parenting behaviors) in their relationship with their child, there is a growing interest to capture parents’ thoughts and feelings about their child and their parent-child relationship relying on what they *say* in free speech samples (McCauley et al., 2019). Within these studies, the FMSS-method (Magaña-Amato, 1993) is increasingly being used to assess the emotional quality within a family relationship. Within the FMSS-method, parents are asked to speak for five uninterrupted minutes about their child and the relationship with their child. By doing so, parents’ EE can be assessed, which has been described as the attitude of a parent towards their child represented by expressions about the child, and the intensity and regulation of emotion in these expressions (Sher-Censor, 2015). Parents’ responses are transcribed and coded to capture an overall rating of high EE (i.e., excessive presence or intensity of emotions, often beyond the control of the parent) or low EE (i.e., well-modulated and balanced level of communicated emotion), and specific domains of EE. These EE-domains encompass the parents’ level of *Emotional Over-involvement* (EOI) (i.e., parental expressions of over-protectiveness and/or self-sacrificing behavior or excessive use of praise or blame towards the child), *Criticism* (i.e., expressions of dissatisfaction about the child or the parent-child relationship), and *Warmth* (i.e., expressions of interest, sympathy, concern, and empathy towards the child) (Hickey et al., 2019; Magaña-Amato, 1993; Rea et al., 2020).

Research avenue 1: A cross-disability perspective on Expressed Emotion, parenting stress, and parenting behaviors

One major study objective in the research on EE in NDD-populations is to address ‘how many’ parents express higher levels of EE compared to parents raising neurotypically developing peers (Thompson et al., 2018). To date, a conclusive estimate is lacking due to the large heterogeneity across studies, and because results heavily depend upon the nature of the control group. Currently, two studies evaluated EE in the context of differential parenting, comparing speech samples of parents on their child with a disability and their sibling without a disability. Parents showed to express substantially more Criticism and less Warmth towards their child with ASD (Griffith et al., 2015) or higher levels of EE towards their child with an intellectual disability (ID) (Beck et al., 2004) than towards their child without a disability.

A recent meta-analysis (Thompson et al., 2018) identified seven studies providing point estimates of the proportion of parents exhibiting high EE towards their child (or adolescent) with a developmental disability (i.e., two studies on ASD, three studies on ID, one on Fragile X-syndrome, and one cross-disability study). Based upon a fixed-effects meta-analysis, effect sizes across studies varied from .19 to .61, with an overall pooled proportion of .39. Therefore, this study suggests that approximately 40% of parents raising a child with a developmental disability exhibits high EE (Thompson et al., 2018). However, the results of this small meta-analysis should be interpreted with caution as the included studies are limited, have widely varying sample sizes (ranging from 33 to 202), often do not control for the impact of sociodemographic factors (such as child age, parental age, socio-economic status), and the use of fixed-effects modeling might cause an overestimation of point estimates (Borenstein et al., 2007). Nevertheless, this report suggests that a sizable proportion of parents raising a child with a developmental disability raise their child in a stressed-out emotional family climate.

Notably, in this literature on point estimates of high EE in families of children with a disability, the current practice is to focus on only one, single disability (Thompson et al., 2018). Scholars increasingly argue that our understanding of the construct of EE in NDD-groups would benefit from a cross-disability perspective, in which EE is evaluated across multiple groups of children with a NDD (Hastings & Lloyd, 2007; Laghezza et al., 2010; Sher-Censor, 2015). Therefore, the current study evaluates group differences in point estimates of EE (percentages of high EE and EE-domains), parenting stress, and parenting behaviors across three groups of parents raising a child with a NDD: ASD, CP, and DS. These three groups resemble three of the most prevalent NDDs and include difficulties in at least one of the three main domains of functioning: psychosocial (ASD), physical (CP), and/or cognitive (DS). Additionally, we include a reference group of parents raising a child without any known disability. Based upon the available literature (e.g., Thompson et al., 2018; Valicenti-McDermott et al., 2015), we hypothesize that higher levels of EE (especially high Criticism), parenting stress, and need-thwarting parenting behaviors will be more present among parents of children with a NDD compared to parents of children without any known disability. Moreover, we expect the highest levels of parenting stress among parents of children with ASD (Hayes & Watson, 2013).

Research avenue 2: In search for the nomological network: relations between Expressed Emotion, parenting stress, and parenting behaviors

In addition to research on addressing 'how many' parents exhibit high EE, an even more important research question is to better understand the conceptual meaning of EE in developmental studies (Rea et al., 2020; Sher-Censor, 2015). Recently, scholars called out for more research examining how EE maps onto other more established constructs for assessing parent-child dynamics. More specifically, parenting stress and parenting behaviors have been put forward as two especially relevant constructs to evaluate in this nomological network (Hastings & Lloyd, 2007; Hickey et al., 2020; Laghezza et al., 2010; Sher-Censor, 2015). To date, however, the large majority of EE-research among parents of children with a disability mainly examines direct associations between parents' EE and child adjustment outcomes, with very few studies evaluating concurrent relations with parenting stress and parenting behaviors. Especially in ASD-research, EE-studies consistently demonstrated strong associations between higher levels of parental Criticism and lower levels of parental Warmth, on the one hand, and externalizing child behavior on the other hand (see for reviews: McCauley et al., 2019; Romero-Gonzalez et al., 2018).

Another lingering issue in EE-research among NDD-populations is the validity and conceptual meaning of the EE-domain EOI. Historically, EOI has been conceptualized as a marker of a dysfunctional emotional family climate, characterized by parental self-sacrificing or overprotective behavior and/or excessive praise or blame towards the child (Magaña-Amato et al., 1986). However, scholars examining EE in special needs populations suggested that EOI might be a more normative or even an adaptive aspect of raising a child with a disability. These authors stated that EOI might rather indicate parents' commitment towards their child instead of referring to overidentification with the child or overly protective behavior (Wamboldt et al., 2000; Kubicek et al. 2013; Laghezza et al., 2010).

Current studies on the nomological network between what parents of children with a neurodevelopmental disability 'feel, do and say'

Even though the current interest in EE among families of children with a NDD is growing, a literature search identified few studies examining relations between EE and parenting stress, and even fewer studies investigating relations between EE and parenting behaviors in special needs groups. Also, the handful of existing studies applied diverse methods and theoretical concepts to assess parenting stress and parenting behaviors (Sher-Censor, 2015), which hampers the integration of existing research findings.

In ASD-research, one recent study addressed the relation between parenting stress and both maternal and paternal EE in 150 families of children with ASD (aged 5 - 12 years old). Both mothers' and fathers' levels of parenting stress predicted higher levels of Criticism toward their child with ASD 12 months later, in mothers as well as fathers. Parenting stress also predicted lower levels of maternal Warmth 12 months later, but this relation was not observed for fathers (Hickey et al., 2020). To date, no study evaluated associations between EE and parenting behaviors among ASD-populations.

In CP-research, we retrieved one relevant study where an indicator of parenting stress was related to EE, yet assessed by a questionnaire instead of the FMSS-method. This study observed a moderate correlation between parents' feelings of caregiver burden and the EE-questionnaire among 144 caregivers of children with CP (Yığman et al., 2020).

We found no specific study on EE in parents of children with DS, even though a handful of studies have used the FMSS-method in parents of children with ID, sometimes including DS (see for reviews: Laghezza et al., 2010; Thompson et al., 2018). These studies mostly relied on small sample sizes and have reported mixed results. On the one hand, high EE predicted more feelings of burden among 31 parents of children with ID (Datta et al., 2002) and was longitudinally associated with higher stress levels in parents of youth and adults with ID (also including youth with ASD) (Greenberg et al., 2006; Hastings et al., 2006; Orsmond et al., 2006). In contrast, a study among 33 mothers raising a child with ID (including 18 with DS) observed that mothers with high EE also report more feelings of parenting satisfaction (i.e., an affective dimension reflecting parenting satisfaction, anxiety, and motivation) (Beck et al., 2004).

One study adopted a cross-disability perspective evaluating associations between EE and observed parent-child interactions (Kubicek et al., 2013). Although this study suggested that the FMSS-method is a viable measure for assessing the emotional quality of a parent-child relationship among families of young children with special needs, the study findings lack generalizability due to the limited study sample (*n* = 38), the young age of the children (aged 6 to 34 months), and the wide range of disabilities (including general developmental delays, delays in speech/language, vision impairments, hearing loss, ASD, CP, and DS).

Towards a better understanding of the nomological network of Expressed Emotion through the lens of Self-Determination Theory

In pondering the nomological network of the EE-construct with parenting stress and parenting behaviors, it is important to consider that the FMSS-method has been developed from bottom-up analyses and is not grounded in a firm theoretical framework (Magaña-Amato et al., 1986; Sher-Censor, 2015). To better understand the conceptual nature of the EE-construct through its nomological network we adopt the well-validated SDT-framework (Deci & Ryan, 2000). Studies following this framework consistently demonstrated that positive parent-child interactions relate to parental feelings of need satisfaction (i.e., less parenting stress) and more need-supportive parenting. Conversely, greater parent-child conflict has been associated with feelings of need frustration and more need-thwarting parenting (Ryan & Deci, 2017; Vansteenkiste & Ryan, 2013). Although SDT-research within NDD-populations is limited, we assume similar relations in families of children with and without ASD, CP, or DS based on SDT's universality claim (Deci & Ryan, 2000). We hypothesize that, across all groups, positive emotional family climates (indicated by low EE) will be associated with less feelings of parenting stress and more need-supportive parenting behaviors, and that more stressed-out emotional family climates (especially indicated by high levels of parental Criticism) will relate to more parenting stress and more need-thwarting parenting. Based upon the conceptual ambiguity of the EOI-domain (see above, Wamboldt et al., 2000; Kubicek et al., 2013), we expect that the relations between EOI and parenting stress and parenting behaviors will be less clear.

The present study

The first aim of this study is to examine group differences in EE-point estimates, parenting stress, and parenting behaviors among parents of children with ASD, CP, DS, and without any known disability. The second aim of this study is to address the nomological network associated with EE through the examination of associations between EE and parenting stress and parenting behaviors within and across groups. This cross-disability approach allows to explore disability-(a)specific parent-child processes. Furthermore, given that previous studies highlighted strong relations between parental Criticism and children's externalizing behavior (Greenberg et al., 2006; Rea et al., 2020), we additionally analyzed whether significant relations between EE and the parental factors remained while controlling for externalizing child behavior.

5.2 Methods

Participants

Speech samples and questionnaire data were gathered from 447 parents, of which 159 parents had a child with ASD (*M*age = 10.80 years old, *SD*age = 2.80 years, 77.4% boys), 67 parents raised a child

Table 1. Demographic characteristics of the study sample (*n* = 447)

	Autism spectrum disorder (*n* = 159)	Cerebral palsy (*n* = 67)	Down syndrome (*n* = 54)	Reference group (*n* = 167)
Child				
Age				
Mean (SD)	10.80 (2.80)	12.44 (2.67)	13.12 (2.57)	13.31 (0.45)
Range	6.18 - 16.60	6.70 - 17.97	6.07 - 17.63	12.35 - 14.73
Gender				
Boys (%)	123 (77.4)	43 (64.2)	26 (48.1)	97 (58.1)
Main living situation				
At home during week and weekends (%)	137 (86.2)	58 (86.6)	43 (79.6)	139 (83.2)
Co-parenting[1] (%)	17 (10.7)	5 (7.5)	8 (14.8)	23 (13.8)
Care facility/boarding school[2] (%)	4 (2.5)	3 (4.5)	2 (3.7)	0 (0.0)
Missing (%)	1 (0.6)	1 (1.5)	1 (1.9)	5 (3.0)
School				
Regular (%)	107 (67.3)	14 (20.9)	15 (27.8)	161 (96.4)
Special (%)	49 (30.8)	51 (76.1)	38 (70.4)	1 (0.6)
Other or missing (%)	3 (1.9)	2 (3.0)	1 (1.9)	5 (3.0)
Informant				
Relation with child				
Mother (%)	150 (94.3)	60 (89.6)	42 (77.8)	163 (97.6)
Father (%)	9 (5.7)	6 (9.0)	10 (18.5)	4 (2.4)
Other (aunt, grandmother) (%)	0 (0.0)	1 (1.5)	2 (3.7)	0 (0.0)
Mean age				
Mean age mother (SD)	40.24 (5.43)	43.38 (5.16)	48.04 (4.73)	43.92 (4.14)
Mean age father (SD)	43.06 (5.54)	44.87 (4.95)	50.11 (5.12)	46.01 (4.44)
Education level				
Primary school (%)	3 (1.9)	0 (0.0)	1 (1.9)	1 (0.6)
Secondary school (%)	39 (24.5)	27 (40.3)	14 (25.9)	27 (16.2)
Higher education (%)	117 (73.6)	36 (53.7)	35 (64.8)	137 (82.0)
Missing (%)	0 (0.0)	4 (6.0)	4 (7.4)	2 (1.2)

Note. [1] Parenting of the child is shared between the informant and another adult not living with the informant, mostly the other adult is the biological parent of the child (92%) or an aunt/grandparent/sister (8%). [2] During three or more days a week.

with CP (*M*age = 12.44 years old, *SD*age = 2.67 years, 64.2% boys), 54 parents had a child with DS (*M*age = 13.12 years old, *SD*age = 2.57 years, 48.1% boys), and 167 parents raised a child without any known disability (*M*age = 13.31 years old, *SD*age = 0.45 years, 58.1% boys).

Overall, children were on average 12.25 years old (SD = 2.45, range = 6.07 - 17.97) and 64.7% of the children were boys. Mothers were the main informants in this study (*n* = 415, 92.8%), with an average age of 42.90 years old (SD = 5.49). The majority of the participants (87.4%) were married or lived together with the biological parent of the child. Additional demographic characteristics of the participants are described in Table 1.

The severity of the child's disability varied largely in each NDD-group. In the ASD-group, parents reported an average total T-score of 90.03 (SD = 15.30, range = 43 - 131) on the Social Responsiveness Scale (SRS; Constantino & Gruber, 2005; Roeyers et al., 2011), indicating that the large majority of the children experienced serious (85.0%, T-score > 75) or moderate (13.3%, 61 < T-score < 75) difficulties in social responsiveness compared to the neurotypical populations. In the CP-group, reports on the Gross Motor Function Classification System (GMFCS; Palisano et al., 2008; Palisano et al., 1997) indicated that 24.6% of the children functioned at level I (i.e., the child can walk without restrictions but has limitations in more advanced motor skills), 36.9% at level II, 15.4% at level III, 7.7% at level IV and 15.4% of the children functioned at level V (i.e., the child has very limited motor abilities). The majority of the children had spastic CP (78.8%), 9.1% had dyskinetic CP, 3% ataxic CP, and 9.1% a mixed type of CP. In the DS-group, approximately half of the children (51.0%) had a mild ID (IQ-range = 50 - 69). A quarter of the parents (24.5%) reported that their child had a moderate ID (IQ-range = 36 - 49), 10.2% were reported to have a profound ID (IQ-range = 20 - 35), and 14.3% of the parents did not know the ID-classification of their child. Also in the ASD- and CP-group, respectively 73.0% (*n* = 116) and 74.6% (*n* = 50) of the parents provided reports on the intellectual functioning of their child, of which respectively 4.3% (*n* = 5) and 40.0% (*n* = 20) of the parents indicated that their child had an ID (IQ-score < 70) (APA, 2000).

Procedure

This study is part of an ongoing larger longitudinal project on psychosocial development in children with and without a NDD in Flanders, Belgium. Parents raising a child with a NDD were included in this study if their child: (1) had received an official diagnosis of ASD, DS, or CP based on the DSM-IV-TR or DSM-5 criteria, and (2) was between 6 and 17 years old. To verify the ASD diagnoses, several parents provided the diagnostic reports and all parents clarified when and by whom the diagnosis was made, and which instruments were used. Parents of children with ASD were contacted through autism-service centers, schools, and online groups that provide support to families of a child with ASD. The CP-group was identified through seven Flemish service centers for children with physical disabilities. Parents of children with DS were recruited with the support of Flemish family organizations for DS, specified centers, schools, and an online support group for Belgian and Dutch parents of children with DS. Parents of children without any known disability (i.e., reference group) were included from the Flemish Study on Temperament and Personality across Childhood (FSTPC; De Pauw, 2010). In the reference group, parents reported on possible diagnoses, and children with any known disability were omitted.

Data on sociodemographic factors, parenting stress and behaviors, and child behavior were gathered through parent-report questionnaires, which were sent by post to the family home of the participant (cf., phone FMSS-administration) or delivered during a home visit (cf., in-person FMSS-administration). Speech samples were administered in the family home or through telephone since previous research described an excellent agreement between both procedures (Beck et al., 2004). All speech samples were audiotaped and transcribed to facilitate subsequent coding. Each sample was coded by the first author, who followed the official training program by Magaña-Amato (Magaña-Amato, 1993), and one or two research assistants, who were trained by the first author, relying on the official FMSS-EE coding scheme (Appendix 1; Magaña-Amato, 1993). This training included a detailed review of the manual, memorization of the coding rules and definitions, practice coding, and discussion of results. Inconsistencies in codings were discussed within the research team. The coders reached substantial interrater reliability, with Cohen's kappa (κ) = .76 for EE-overall, κ = .74 for EOI, κ = .73 for Criticism, and κ = .66 for Warmth (all *p*s < .001) (Landis & Koch, 1977). Written informed consent was obtained from all participants and the study received ethical approval from the Institutional Review Board of the host University.

Measures

Expressed Emotion. Parents were given the standard FMSS-instruction: *"I'd like to hear your thoughts and feelings about (relative's name), in your own words and without my interrupting with any questions or comments. When I ask you to begin I'd like you to speak for five minutes, telling me what kind of person (relative's name) is and how the two of you get along together. After you begin to speak, I prefer not to answer any questions until after the five minutes are over. Do you have any questions you would like to ask before we begin? Please begin"* (FMSS-manual p.3; Magaña-Amato, 1993). When the parent stopped talking before the end of the proposed five minutes, the interviewer waited for 20-30 seconds and if the parent did not continue talking, the interviewer said: *"Please tell me anything about (child's name) for a few more minutes"* (cf., FMSS-manual p.5; Magaña-Amato 1993).

Parents' EE was examined using the whole EE-construct (i.e., EE-overall) and its underlying domains (i.e., EOI, Criticism, Warmth). Following Magaña-Amato's FMSS coding protocol (Magaña-Amato, 1993), EE-overall was coded as either low (i.e., low/borderline coding for EOI and low/borderline coding for Criticism) or high (i.e., high coding for EOI and/or high coding for Criticism) depending on the ordinal coding of the EE-domains EOI and Criticism.

EOI and Criticism were coded based on the content and tone of parents' spontaneous speech samples (Magaña-Amato, 1993). EOI-coding relied on the parent's: (a) expression of self-sacrificing and/or overprotective behavior (e.g., *"I give up everything for her"*), (b) emotional display of intense emotions (e.g., crying), (c) descriptions of excessive detail about the past, (d) statements of strong feelings of love for the child or willingness to do anything for the child, and (e) excessive praise (i.e., more than five positive comments). Criticism was coded based on the parent's: (a) initial statement, (b) description of the quality of the parent-child relationship, and (c) expressions of critical remarks (e.g., *"He is incredibly annoying"*). In line with previous research on EE, EOI and Criticism were given an ordinal ranking: 0 (low), 1 (borderline), or 2 (high) (e.g., Kubicek et al., 2013; Greenberg et al., 2006).

Parental Warmth was coded based on early EE-rating systems (Vaughn and Leff, 1976; Hickey et al., 2019) and expressions of Warmth and tone of voice during the speech samples (e.g., *"He is also good at basketball, whenever he has a match, I try to be there")*. More specifically, the ordinal Warmth rating was based on the parent's: (a) tone of voice, (b) spontaneity of expression of sympathy, concern, and empathy, and (c) expression of interest in the child, and was globally considered across the entire speech sample as 'low' (0), 'medium' (1), or 'high'(2) (Vaughn and Leff, 1976; Magaña-Amato, 1986).

Parenting stress. Parents rated their feelings of stress in the parent-child system on 40 items of the Dutch version of the Parenting Stress Index (PSI; Abidin, 1986; NOSI; De Brock et al., 1992). Five subscales from the PSI were included in this study, rated on a six-point Likert scale, ranging from (1) *totally disagree* to (6) *totally agree*. Three stress domains particularly related to the frustration of parents' own psychological needs: role restriction (i.e., autonomy frustration; e.g., *"I often have the feeling that the wishes and needs of my child control my life"*), attachment stress (i.e., frustration in relatedness; e.g., *"It bothers me that my feelings towards my child are less close and warm than I expected"*), and stress related to parental competence (i.e., competence frustration; e.g., *"I often have the feeling that I can't handle things very well"*). Two domains of stress related to feelings of frustration in the social context: marital stress (e.g., *"Raising this child* *has caused more problems in the relationship with my partner than I had expected"*) and social isolation (e.g., *"Since I have children, I have much less opportunity to see my friends and/or make new friends"*). Cronbach α's ranged from .70 (attachment stress in the DS-group) to .90 (role restriction in the CP-group).

Autonomy-supportive parenting. Parents rated their autonomy-supportive parenting behavior using a reduced version of the well-validated Autonomy Support Scale of the Perceptions of Parents Scale (POPS; Grolnick et al., 1991). This version includes seven items (e.g., *"I allow my child to decide things for himself"*), scored on a five-point Likert scale ranging from (1) *completely not true* to (5) *completely true*. Cronbach α's ranged from .76 (ASD-group) to .86 (DS-group).

Responsive parenting. Parents' responsive parenting towards their child was assessed using the responsivity scale from the Child Report of Parenting Behavior Inventory (CRPBI; Schaefer, 1965). This scale consists of seven items (e.g., *"I find it important to show my child that I love him/her"*) rated on a five-point Likert scale, ranging from (1) *completely not true* to (5) *completely true*. Cronbach α's ranged from .74 (DS-group) to .82 (reference group).

Psychological control. Parents filled out the parent version of the Psychological Control Scale (PCS; Barber, 1996; Soenens et al., 2006), to examine key aspects of psychologically controlling parenting, such as guilt induction, shaming, love withdrawal, and the use of controlling language (e.g., *"I blame my child for other family members' problems").* The eight items were scored on a five-point Likert scale, ranging from (1) *completely not true* to (5) *completely true*. Cronbach α's ranged from .69 (ASD-group) to .79 (CP-group).

Overreactive parenting. Parents completed the overreactivity scale from the Parenting Scale (PS; Arnold et al., 1993; Prinzie et al., 2007) to assess the extent to which they respond with irritation, anger, frustration, or impatience towards their child. This scale consists of seven items (e.g., *"When I am angry or tensed, I constantly criticize my child"*) rated on a five-point Likert scale ranging from (1) *(almost) never* to (5) *(almost) always*. Cronbach α's ranged from .78 (ASD-group) to .95 (DS-group).

Externalizing child behavior. Children's externalizing behavior was assessed using the broadband scale externalizing problems of the Child Behavior Checklist/6-18 (CBCL; Achenbach, 2001). Parents indicated how often their child displayed rule-breaking (17 items; e.g., *"Lies and cheats"*) or aggressive behavior (18 items; e.g., *"Destroys things belonging to others"*) over the past six months on a three-point Likert scale, ranging from (0) *never* to (2) *often*. Cronbach α's ranged from .88 (reference group) to .92 (CP-group).

Data analysis

In the preliminary analyses, we explored group differences in demographic factors, and whether these factors and children's disability severity significantly related to EE. Subsequently, to examine the first study objective, we investigated group differences in EE (i.e., EE-overall, EOI, Criticism, and Warmth) using post-hoc contingency table analysis (Beasley & Schumacker, 1995). Group differences in parenting stress and parenting behaviors were examined with two MANOVAs, given the high correlation between the parenting stress domains (*r* varying from .38 to .73) and the parenting variables (*r* varying from -.22 to .58) (Table 2). As a second study objective, we examined associations between the EE-domains and the parenting factors (i.e., parenting stress and parenting behaviors) and whether these relations differed across groups. Therefore, two-way MANCOVAs with Sum of Squares Type III, accounting for unequal sample sizes were performed, which controlled for the child's and informant's age (see preliminary analyses). 'Group' (i.e., ASD, CP, DS, reference group) and EE-domains (i.e., EOI, Criticism, Warmth) were included as independent factors, and all parenting stress domains or parenting behavior scales were simultaneously included as dependent variables (Table 3). Additionally, we added child externalizing behavior as a control variable in a MANCOVA, to investigate the robustness of the associations among EE and parenting stress and behaviors.

5.3 Results

Preliminary analyses

Analyses examining group differences in demographic factors indicated that children without any known disability and with DS were significantly older compared to children with ASD ($F(3,443) = 39.94$, $p < .001$). Corroborating previous research (Loane et al., 2013), informants of children with DS were significantly older compared to the informants of other groups ($F(3,443) = 37.64$, $p < .001$). In line with prevalence studies (Loomes et al., 2017; Stanley et al., 2000), significantly more boys were present in the ASD- and CP-group, compared to the DS- and reference group ($\chi^2(3) = 20.83$, $p < .001$). More children with a NDD attained special education compared to the reference group ($\chi^2(3) = 176.56$, $p < .001$), but there was no group difference concerning the child's living situation ($p > .05$). More fathers participated in the DS-group ($\chi^2(6) = 29.26$, $p < .001$) and more higher educated informants participated in the ASD- and reference group ($\chi^2(6) = 19.93$, $p < .05$) compared to the other groups. Group analysis also indicated that children with ASD exhibited significantly more externalizing behaviors (*M* = 15.16, *SD* = 8.38) compared to the CP- (*M* = 7.95, *SD* = 7.11), DS- (*M* = 7.12, *SD* = 7.02), and reference group (*M* = 4.10, *SD* = 5.15) (*F*(3,443) = 68.62, *p* < .001).

Furthermore, we examined associations between these demographic factors and EE. EE was only significantly related to the child's and the informant's age, but not to the other demographic factors (*p* > .05). Parents of older children from the reference group expressed more Criticism compared to parents of younger children (*F*(2,164) = 4.83, *p* = .01), and older parents of children with ASD expressed less Criticism (*F*(2,156) = 4.45, *p* = .01) compared to younger parents. Therefore, the child's and informant's age were added as control variables in further analyses. EE only related to the child's disability in the ASD-group, where parents who expressed more thoughts and feelings of EOI reported more difficulties in social responsiveness, measured with the SRS (Constantino & Gruber, 2005; Roeyers et al., 2011) (*F*(2,156) = 4.75, *p* = .01). EE did not significantly relate to the degree of motor problems in the CP-group (assessed with the GMFCS; Palisano et al., 2008; Palisano et al., 1997), nor with the IQ-score or classification of intellectual functioning in the DS-group (all *ps* > .05).

Research Question 1: How similar and different are Expressed Emotion, parenting stress, and parenting behaviors across groups?

EE-point estimates

One-fifth of the participating parents (*n* = 92, 20.6%) received an overall high rating on EE, of which 47 parents (51.1%) were rated high only on EOI, 35 parents (38.0%) received a high rating only on Criticism, and 10 parents (10.9%) received a high rating on both domains. Descriptive analyses indicated that the majority of parents expressed low levels of EOI (48.3%), low levels of Criticism (57.9%), and/or high levels of Warmth (59.1%). Contingency table analyses indicated salient group differences regarding EE-overall, Criticism, and Warmth. Parents of children with ASD and CP expressed more high EE compared to the reference group. Moreover, parents of children with ASD expressed more Criticism compared to the reference group, and less Warmth compared to the other groups (all *p*s < .05). No group differences were found regarding EOI (Table 2 and Figure 1).

Parenting stress

A two-way MANOVA indicated that all scores on the parenting stress domains differed significantly between groups. Parents of children with ASD reported substantially more role restriction and marital stress compared to parents of children with CP and DS, who in turn reported higher levels on these domains compared to parents of children without any known disability. Parents in the ASD-group also reported slightly more attachment stress and moderately more competence stress compared to all other groups. Parents of children with a NDD reported substantially more feelings of social isolation compared to parents of children from the reference group (all *p*s < .05).

Parenting behavior

Results revealed significant group differences in all parenting behaviors. Parents of children with ASD or without any known disability reported moderately more autonomy-supportive parenting behavior compared to parents of children with CP or DS. A small group difference was observed concerning responsive parenting behavior, where parents of children with a NDD reported higher levels compared to the reference group. Parents of children with ASD or without any known disability reported slightly more psychologically controlling parenting compared to parents of children with CP or DS. Notably, larger group differences were observed concerning overreactive parenting. Parents in the ASD-group reported substantially more overreactive parenting compared to the other groups, and the reference group also reported more overreactive parenting compared to the CP- and DS-group (all *ps* < .05) (Table 2).

Research Question 2a: How does Expressed Emotion relate to parenting stress within and across groups?

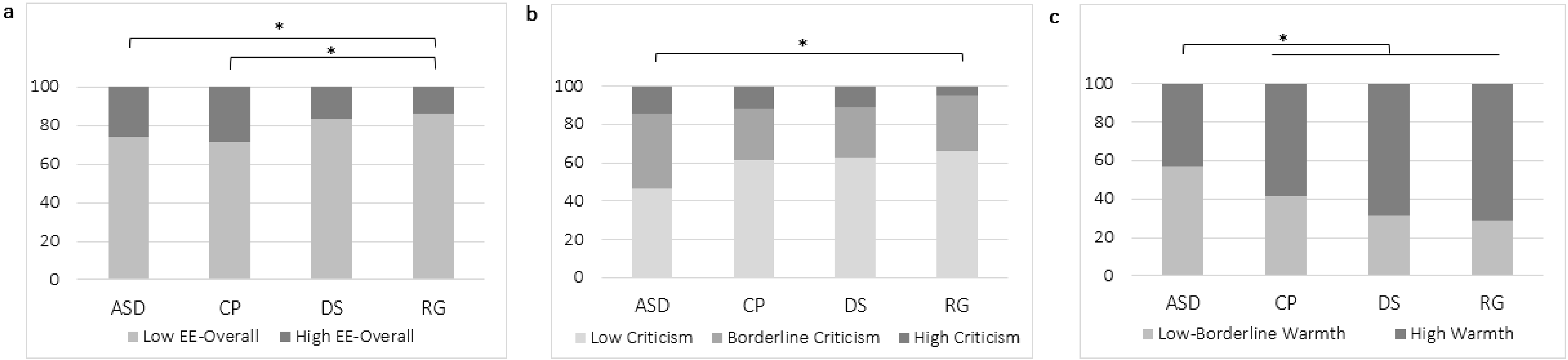
A two-way MANCOVA was used to identify significant associations between the EE-domains and parenting stress, and whether these associations differed across groups (Table 3a). Concerning EOI, one significant association was observed, indicating that marital stress was significantly lower among parents coded low on EOI compared to parents coded borderline (*p* = .02) or high on EOI (*p* = .03). Expressions of Criticism were significantly associated with diverse parenting stress domains. Parents with a higher coding on Criticism reported more feelings of attachment and competence stress (all *p*s < .05). Moreover, parents who expressed borderline or high expressions of Criticism reported significantly more feelings of role restriction and marital stress compared to parents with low expressions of Criticism (all *p*s < .05). One significant interaction effect was observed, indicating that the relation between parental Criticism and social isolation differed across groups (*p* < .05). Whereas parents of children with DS who expressed high Criticism reported more feelings of social isolation compared to parents with a low or borderline coding, this association was not significant in the ASD-, CP-, or reference group (*p* > .05) (Figure 2a). Furthermore, parents exhibiting high Warmth reported significantly less feelings of role restriction, attachment stress, competence

Table 2. Descriptives and group differences in Expressed Emotion, parenting stress, and parenting behaviors

		Autism spectrum disorder (n = 159)	Cerebral palsy (n = 67)	Down syndrome (n = 54)	Reference group (n = 167)	Total (n = 447)		
		% (n)	% (n)	% (n)	% (n)	% (n)	χ^2	
EE-overall	Low	74.2^{a} (118)	71.6^{a} (48)	83.3^{a,b} (45)	86.2^{b} (144)	79.4 (355)	10.36*	
	High	25.8^{a} (41)	28.4^{a} (19)	16.7^{a,b} (9)	13.8^{b} (23)	20.6 (92)		
EE-EOI	Low	49.7^{a} (79)	47.8^{a} (32)	48.1^{a} (26)	47.3^{a} (79)	48.3 (216)	5.61	
	Borderline	34.6^{a} (55)	35.8^{a} (24)	42.6^{a} (23)	43.1^{a} (72)	38.9 (174)		
	High	15.7^{a} (25)	16.4^{a} (11)	9.3^{a} (5)	9.6^{a} (16)	12.8 (57)		
EE-Criticism	Low	46.5^{a} (74)	61.2^{a,b} (41)	63.0^{a,b} (34)	65.9^{b} (110)	57.9 (259)	17.68**	
	Borderline	39.0^{a} (62)	26.9^{a,b} (18)	25.9^{a,b} (14)	29.3^{b} (49)	32.0 (143)		
	High	14.5^{a} (23)	11.9^{a,b} (8)	11.1^{a,b} (6)	4.8^{b} (8)	10.1 (45)		
EE-Warmth^{1}	Low-Borderline	56.6^{a} (90)	41.8^{b} (28)	31.5^{b} (17)	28.7^{b} (48)	40.9 (183)	28.43***	
	High	43.4^{a} (69)	58.2^{b} (39)	68.5^{b} (37)	71.3^{b} (119)	59.1 (264)		
		M (SD)	*M* (SD)	*M* (SD)	*M* (SD)	*M* (SD)	*F*	η^2
Parenting stress	Role restriction	3.47^{a} (1.09)	3.03^{b} (1.18)	2.91^{b} (1.04)	2.07^{c} (0.64)	2.81 (1.13)	59.55***	.26
	Attachment stress	2.02^{a} (0.79)	1.67^{b} (0.59)	1.75^{b} (0.69)	1.66^{b} (0.46)	1.80 (0.66)	9.91***	.04
	Competence stress	2.64^{a} (0.79)	2.11^{b} (0.71)	2.08^{b} (0.72)	2.03^{b} (0.58)	2.26 (0.75)	24.05***	.08
	Marital stress	3.32^{a} (1.26)	2.48^{b} (1.17)	2.29^{b} (1.00)	1.92^{c} (0.68)	2.55 (1.19)	52.26***	.24
	Social isolation	2.71^{a} (0.94)	2.21^{a} (1.04)	2.30^{a} (1.19)	1.71^{b} (0.59)	2.21 (0.98)	35.59***	.16
Parenting behavior	Autonomy support	4.14^{a} (0.49)	3.83^{b} (0.53)	3.86^{b} (0.61)	3.99^{a} (0.47)	3.99 (0.51)	8.05***	.07
	Responsive	4.43^{a} (0.44)	4.45^{a} (0.41)	4.47^{a} (0.44)	4.29^{b} (0.49)	4.39 (0.46)	4.25**	.02
	Psychological control	2.03^{a} (0.52)	1.79^{b} (0.47)	1.81^{b} (0.50)	2.08^{a} (0.49)	1.99 (0.51)	8.11***	.05
	Overreactive	2.70^{a} (0.73)	2.08^{b} (0.64)	2.02^{b} (0.57)	2.36^{c} (0.55)	2.40 (0.68)	23.52***	.16

Note. EE Expressed Emotion, *EOI* Emotional Over-involvement, *M* Mean, *SD* Standard deviation, η^2 Partial eta squared (.01 = small, .06 = medium, .14 = large). ^{1}Since only two FMSS (0.004%) were coded low on Warmth, the low and borderline categories were merged and coded as (2) *Low-Borderline*. Values with different superscripts indicate significant differences between groups. $^{*}p < .05$, $^{**}p < .01$, $^{***}p < .001$.

Figure 1. Group differences in Expressed Emotion (**a** EE-overall, **b** Criticism, **c** Warmth)



Note. EE Expressed Emotion, *ASD* Autism spectrum disorder, *CP* Cerebral palsy, *DS* Down syndrome, *RG* Reference group. $^{*}p < .05$

stress, and marital stress compared to parents with a low or borderline coding (all *p*s < .05). One interaction effect was significant (*p* = .02), indicating that only parents of children with ASD who received a high coding on Warmth reported more feelings of social isolation compared to parents with a low-borderline coding (Figure 2a).

Research question 2b: How does Expressed Emotion relate to parenting behaviors within and across groups?

Furthermore, we examined the relations between EE-domains and parenting behaviors, and whether these differed across groups (Table 3b). Parents with a high coding on EOI reported more autonomy-supportive parenting behavior compared to parents with a low (*p* < .05) or borderline coding (*p* = .03). Concerning parental Criticism, parents low on Criticism reported less psychologically controlling and less overreactive parenting compared to parents coded borderline (*p* < .05 and *p* < .001, respectively) or high on Criticism (*p* = .01 and *p* < .001, respectively). Two significant interaction effects indicated that the association between Criticism and the need-supportive parenting behaviors differed across groups. Whereas parents from the reference group who expressed low or borderline Criticism engaged in more autonomy-supportive and responsive parenting compared to parents with a high Criticism coding (all *p*s < .05), these associations were not significant among the NDD-groups (*p* > .05). Parents with a high coding on Warmth reported significantly more responsive parenting (*p* < .05), less psychologically controlling (*p* < .001), and less overreactive parenting (*p* < .001) compared to parents with a low-borderline coding. One interaction effect was significant, indicating that whereas parents of children with DS and without any known disability who expressed high Warmth reported more autonomy-supportive parenting compared to parents with a low-borderline coding (all *p*s < .01), this association was not found among the ASD- or CP-group (*p* > .05) (Figure 2b).

Additionally, we tested whether the relations between EE and the parental factors remained after controlling for child externalizing behavior problems. Partial Spearman rank-order correlations between parental Criticism and externalizing child behavior indicated significant associations in each group, ranging from *r* = .27 (*p* = .02) in the ASD-group to *r* = .47 (*p* < .001) in the DS-group. After repeating the same analyses while controlling for externalizing child behavior, parental Criticism was no longer significantly related to marital stress (*p* = .30), autonomy-supportive parenting (*p* = .37), and psychologically controlling parenting (*p* = .55). Also, the relation between parental Warmth and role restriction (*p* = .42), marital stress (*p* = .17), responsive parenting (*p* = .29), and overreactive parenting (*p* = .26) became insignificant. However, all other main and interaction effects were replicated.

Table 3. Group differences in the relation between the Expressed Emotion-domains and the parental factors (**a** parenting stress, **b** parenting behaviors) (total *n* = 447)

a Parenting stress

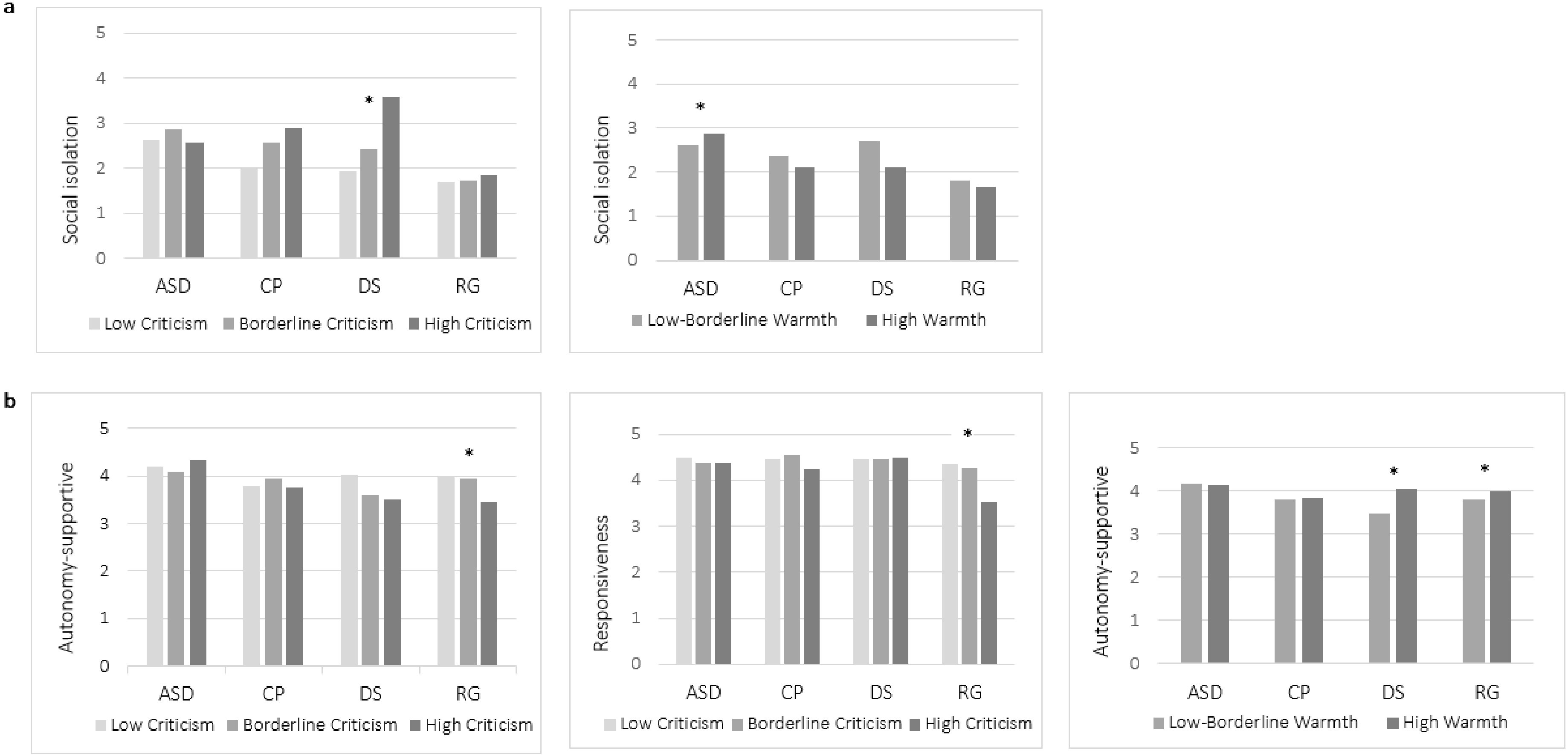
	Emotional Over-involvement							Criticism							Warmth				
	Low	Bord.	High	F$_{EOI}$	η^2	F$_{GroupxEOI}$	η^2	Low	Bord.	High	F$_{CRIT}$	η^2	F$_{GroupxCRIT}$	η^2	Low-Bord.	High	F$_{WARMTH}$	η^2	F$_{GroupxWarmth}$	η^2
	M *(SE)*	*M* *(SE)*	*M* *(SE)*					*M* *(SE)*	*M* *(SE)*	*M* *(SE)*					*M* *(SE)*	*M* *(SE)*				
Role restriction	2.77^a	2.90^a	3.06^a	1.85	.01	0.69	.01	2.68^a	3.05^b	3.29^b	9.31***	.04	1.94	.03	3.04^a	2.76^b	6.69*	.02	1.28	.01
	(.07)	(.08)	(.15)					(.07)	(.10)	(.16)					(.09)	(.07)				
Attachment stress	1.82^a	1.72^a	1.83^a	1.10	.01	1.14	.02	1.63^a	1.94^b	2.24^c	19.61***	.08	0.69	.01	1.99^a	1.67^b	21.50***	.05	1.93	.01
	(.05)	(.06)	(.10)					(.04)	(.06)	(.10)					(.06)	(.04)				
Competence stress	2.21^a	2.21^a	2.38^a	1.06	.01	1.07	.01	2.09^a	2.39^b	2.65^c	14.62***	.06	1.30	.02	2.45^a	2.11^b	19.89***	.04	1.09	.01
	(.05)	(.06)	(.11)					(.05)	(.07)	(.11)					(.06)	(.05)				
Marital stress	2.34^a	2.60^b	2.68^b	3.16*	.01	1.71	.02	2.32^a	2.70^b	2.83^b	6.98**	.03	1.16	.02	2.72^a	2.34^b	10.63**	.02	0.50	.00
	(.08)	(.09)	(.16)					(.07)	(.10)	(.17)					(.09)	(.07)				
Social isolation	2.18^a	2.26^a	2.35^a	0.73	.00	0.55	.01	2.08^a	2.36^b	2.72^c	10.04***	.04	3.30**	.04	2.37^a	2.19^a	3.48	.01	3.77*	.03
	(.07)	(.08)	(.14)					(.06)	(.09)	(.15)					(.08)	(.06)				

b Parenting behaviors

	Emotional Over-involvement							Criticism							Warmth				
	Low	Bord.	High	F$_{EOI}$	η^2	F$_{GroupxEOI}$	η^2	Low	Bord.	High	F$_{CRIT}$	η^2	F$_{GroupxCRIT}$	η^2	Low-Bord.	High	F$_{WARMTH}$	η^2	F$_{GroupxWarmth}$	η^2
	M *(SE)*	*M* *(SE)*	*M* *(SE)*					*M* *(SE)*	*M* *(SE)*	*M* *(SE)*					*M* *(SE)*	*M* *(SE)*				
Autonomy support	3.89^a	3.97^a	4.15^b	4.89**	.02	1.60	.02	3.99^a	3.90^{a,b}	3.76^b	3.92*	.02	3.16*	.05	3.82^a	4.00^b	10.74***	.07	5.43**	.04
	(.04)	(.04)	(.08)					(.03)	(.05)	(.08)					(.04)	(.03)				
Responsive	4.34^a	4.42^a	4.46^a	2.21	.01	0.80	.01	4.45^a	4.42^a	4.16^b	6.00**	.03	2.74*	.04	4.35^a	4.46^b	4.52**	.03	0.48	.00
	(.03)	(.04)	(.06)					(.03)	(.05)	(.08)					(.04)	(.03)				
Psychol. control	1.95^a	1.92^a	1.88^a	0.44	.00	0.77	.01	1.87^a	2.01^b	2.09^b	4.97**	.02	1.13	.02	1.96^a	1.92^b	7.49***	.05	0.65	.01
	(.04)	(.04)	(.08)					(.03)	(.05)	(.08)					(.05)	(.04)				
Overreactive	2.37^a	2.24^a	2.25^a	1.57	.01	1.16	.02	2.17^a	2.46^b	2.63^b	12.76***	.06	1.41	.02	2.44^a	2.23^b	11.85***	.08	0.60	.00
	(.05)	(.06)	(.10)					(.04)	(.06)	(.10)					(.06)	(.04)				

Note. Bord Borderline, *Psychol. control* Psychological control*,* *M* Mean, *SE* Standard Error, η^2 Partial eta squared (.01 = small, .06 = medium, .14 = large). Values with different superscripts indicate significant differences between groups. $^*p < .05$, $^{**}p < .01$, $^{***}p < .001$.

Figure 2. Interaction between group and Expressed Emotion-domain on parenting factors (**a** parenting stress, **b** parenting behaviors)



Note. ASD Autism spectrum disorder, *CP* Cerebral palsy, *DS* Down syndrome, *RG* Reference group. $^{*}p < .05$

5.4 Discussion

Although there is substantial evidence that the construct of EE is a meaningful indicator of the emotional quality of a parent-child relationship, which is a crucial determinant for child and parental well-being, research on EE among children with special needs is limited (Rea et al., 2020; Sher-Censor, 2015; Thompson et al., 2018). Moreover, point estimates of high EE among parents raising a child with a NDD and the conceptual meaning of the EE-construct among these populations need further attention. This study examined group differences in EE-point estimates, parenting stress, and parenting behaviors, and their mutual relationships, across four study groups: parents of children with ASD, CP, DS, and without any known disability.

Group differences in Expressed Emotion, parenting stress, and parenting behaviors

The large majority of parents expressed low levels of EE (*n* = 355, 79.4%), which highlights overall positive family climates. The point estimates of high EE among the ASD- (25.8%) and reference group (13.8%) corroborate previous ratings among parents of children with ASD (21.5 - 27.5%) (Greenberg et al., 2006) and parents of children with ASD expressing EE towards their child with no ASD (10.5%) (Griffith et al., 2015). Although we found no studies directly evaluating EE among children with CP and DS, the point estimates of high EE among the CP- (28.4%) and DS-group (16.7%) tend to be lower than previously reported among parents of children with asthma (43%) (Wamboldt et al., 2000) or more general ID (30 - 60%) (Laghezza et al., 2010). It is plausible that parents of children with asthma exhibit more 'high EE' because these parents regularly face acute situations, which elicit over-concern, whereas parents of children with CP might face more continuous concerns about the care of their child. Additionally, parents of children with DS might exhibit less high EE due to more positive personality traits and fewer maladaptive behaviors in children with DS, which results in less parenting stress and higher levels of well-being compared to parents of children with other intellectual or developmental disabilities (Beck et al., 2004; Stoneman, 2007).

Across groups, the large majority of parents expressed low levels of EE (*n* = 355, 79.4%). Therefore, the findings suggest that the vast majority of parents raising a child with (*M* = 75.4% low EE) or without a developmental disability (86.2% low EE), raise their child in a positive emotional family climate characterized by warmth and positive parent-child interactions. Moreover, this finding suggests that most parents of children with ASD, CP, or DS have a positive attitude towards their child and their parent-child relationship and that these parents effectively regulate their emotions during spontaneous speech samples. Despite these positive findings, our results also support Thompson et al. (2018)'s research indicating that parents of children with developmental disabilities are more vulnerable to exhibit elevated levels of high EE. More specifically, our findings illustrated that the emotional family climates among families of children with ASD (25.8% high EE) and – to a lesser extent – also families of children with CP (28.4% high EE) might be more stressed-out and require further attention. Parents of children with DS exhibited similar levels of high EE (16.7%) compared to the reference group (13.8%), which corroborates previous descriptions of emotional family climates among families of children with DS as warm, close and harmonious (Skotko et al., 2011; Hodapp, 2007).

Looking more closely into the different EE-domains, expressions of EOI showed to be equally distributed across groups. This finding corroborates previous studies showing no significant differences in EOI expressed by parents towards their child with ASD and their brother or sister without ASD (Griffith et al., 2015). More generally, this finding also challenges the perception that parents of children with a disability might express more thoughts and feelings of overprotectiveness or overidentification with the child (e.g., Holmbeck et al., 2002). Instead, the findings suggest that the parents in this study express EOI in a similar way, regardless of the presence or type of their child's disability. Furthermore, parents of children with ASD expressed more Criticism compared to the reference group and less Warmth compared to the other groups, which might be related to both child and parental characteristics. On the one hand, the elevated levels of emotional and behavioral difficulties among these children with ASD might be frustrating for parents to manage (Baker et al., 2011; Griffith et al., 2015; Greenberg et al., 2006), or ASD-characteristics might challenge parents to understand their child's feelings and emotional state (Dieleman, Moyson, et al., 2018). On the other hand, some of these parents might also face additional difficulties to express sympathy, concern, and empathy during the speech samples because they also exhibit autism-related traits (cf., broader autism phenotype) (Hickey et al., 2019).

Furthermore, the study findings indicated that raising a child with a NDD impacts parents' feelings of stress and well-being in different life domains (Peer & Hillman, 2014). Group differences with large effect sizes (η^2 = .16 to .26) indicated that parents across all NDD-groups report substantially higher levels of stress in their personal freedom (i.e., more role restriction), partner relation (i.e., more martial stress), and relatedness with their social network (i.e., more social isolation) compared to parents of children without any known disability. Moreover, parents of children with ASD experienced the highest levels of parenting stress in all domains, except for the domain of social isolation. This finding corroborates previous research, indicating that parenting stress in families raising a child with ASD tends to be higher compared to other types of NDDs, and therefore warrants attention and intervention (Hayes & Watson, 2013; Seltzer et al., 2000; Valicenti-McDermott et al., 2015).

Small to medium group differences were found concerning parenting behaviors, except for overreactive parenting. Parents of children with a NDD reported more responsive parenting compared to the reference group, which might relate to previous findings indicating that parent-child relationships among families of children with a NDD are often described as close and intense since parents strongly attune to their child's needs for both physical and emotional support (Whittingham et al., 2013). Additionally, parents of children with ASD or without any known disability reported more autonomy-supportive parenting behavior, psychologically controlling, and overreactive parenting compared to parents of children with CP or DS. Regarding autonomy-supportive parenting, it has been suggested that parents of children with DS tend to be more directive in their interactions with their children than parents whose children are developing without disabilities (de Falco et al., 2011; Glenn et al., 2001). Also, parents of children with CP might face additional challenges to support their child's autonomy due to their child's physical limitations and dependency on parental support (Dieleman et al., 2019). Furthermore, parents of children with ASD might be more inclined to use disciplining techniques or respond with frustration, anger, or impatience towards their child when they are struggling to manage or understand their child's behavior (Dieleman et al., 2017; Dieleman, Moyson, et al., 2018). Although parents of children with ASD – as a group – reported large elevated levels of overreactive parenting (η^2 = .16), the levels of psychologically controlling parenting and autonomy-supportive parenting were similar compared to the reference group. Overall, these findings warrant further inquiry, preferably by studies addressing both quantitative and qualitative differences in parenting using alternative measures of parenting, such as interviews and observations.

Similar associations between Expressed Emotion, parenting stress, and parenting behaviors across groups

In line with previous studies investigating EE and parenting stress in one single disability (Hastings et al., 2006; Hickey et al., 2020; Yığman et al., 2020), our findings support the idea that the nomological network of EE-parenting stress is highly similar across youth with and without a NDD. Across all groups, parents who expressed more Criticism or less Warmth towards their child reported more feelings of frustration in all three psychological needs: autonomy (i.e., role restriction), relatedness (i.e., attachment stress), and competence (i.e., competence stress). Moreover, in each group, more expressions of Criticism and EOI, and fewer expressions of Warmth significantly related to feelings of stress beyond the parents' own psychological needs, into the parent-couple relationship (i.e., marital stress). This finding corroborated previous research among parents of children with ASD, suggesting that emotionally challenging parent-child relationships might have a spillover effect on the parent-couple relationship (Hickey et al., 2019). Furthermore, a significant interaction effect indicated that a sense of social isolation related to more expressions of Criticism in each group, but only significantly in the DS-group. This sense of social isolation was also related to fewer expressions of Warmth among the CP-, DS-, and reference group, and contra-intuitively, with more Warmth in the ASD-group. Although more research is needed to replicate this finding, it might be plausible that parents of children with ASD who express a lot of concern and empathy towards their child might also feel isolated from their social context. On the one hand, these parents might experience their child's need for their parent to be emotionally and physically present as an expression of love and connectedness, but on the other hand, this intense parent-child dynamic might limit their freedom to meet with friends and family (Dieleman, Moyson, et al., 2018).

Subsequently, the limited group-specific associations between EE and parenting behaviors also suggest that the nomological network between EE and certain parenting behaviors (i.e., responsive parenting, psychologically controlling, and overreactive parenting) is highly similar across families of children with and without a NDD. In line with the SDT-framework (Deci & Ryan, 2000), our findings demonstrated that need-supportive parenting behaviors related to more qualitative parent-child relationships, and therefore lower levels of EE, whereas need-thwarting parenting behaviors related to more parent-child conflicts, indicated by higher levels of EE.

EOI was only related to need-supportive parenting behavior, more specifically autonomy-supportive parenting, and no significant associations were found with need-thwarting parenting. Next to the finding that EOI only significantly related to marital stress, these associations support the idea that EOI may be a normative and even adaptive part of caring for a child (with a disability), instead of being an indicator for a dysfunctional emotional family climate (Kubicek et al., 2013; Wamboldt et al., 2000). Therefore, we support previous recommendations stating that researchers should primarily focus on the EOI-subdomain 'self-sacrificing and/or overprotective behavior', rather than the EOI-domain as a whole when they aim to capture the accurate meaning of EOI (i.e., overidentification with the child or overly protective behavior) (Rea et al., 2020; Sher-Censor, 2015).

Furthermore, parental Criticism was significantly associated with higher levels of need-thwarting parenting behavior (i.e., psychologically controlling and overreactive parenting) in each group. Although to date, no study examined these associations in neurotypical and NDD-populations, these findings are in line with previous research demonstrating that dysfunctional parent-child relationships are associated with more controlling parenting behaviors (Cruise et al., 2011; Kim Park et al., 2008). Furthermore, autonomy-supportive and responsive parenting behaviors were only significantly associated with fewer expressions of Criticism in the reference group but showed similar patterns in the other groups.

In each group, parental Warmth showed significant associations with parenting behaviors that support children’s well-being: more responsive parenting, less psychologically controlling parenting, and less overreactive parenting. Autonomy-supportive parenting was also associated with higher levels of Warmth, but only in the DS- and reference group. It might be plausible that these relations were not observed among parents of children with ASD and CP because these parents might experience more obstacles, and therefore frustrations, to support their child’s autonomy due to disability-specificities (i.e., limited motor functioning, need for routine and predictability) (Dieleman, Moyson, et al., 2018; Dieleman et al., 2019). Although parents of children with ASD significantly reported more autonomy-supportive parenting behavior compared to parents of children with CP, this parenting behavior might require more energy and persistence from both parents of children with ASD and CP due to these obstacles, which in turn might influence these parents’ expressions of Warmth. However, it should be noted that the interpretation of this – and the previously described interaction effects – should be interpreted with caution. Moreover, replication is warranted to further clarify the meaning of these group-specific findings. Nonetheless, the strong associations between parental Warmth, on the one hand, and parenting stress and parenting behaviors, on the other hand, supports previous statements that parental Warmth might be an especially valuable EE-domain in NDD-populations, possibly even more valuable than the EOI-domain (Smith et al., 2008; Woodman et al., 2015).

The finding that the majority of the relations between EE and the parental factors remained while controlling for externalizing child behavior provided additional support for the robustness of these associations. Nonetheless, some relations became insignificant. For example, parental Criticism remained significantly associated with responsive parenting and overreactive parenting but was no longer associated with autonomy-supportive parenting and psychologically controlling parenting. Therefore, it seems plausible that child characteristics, such as child behavior, play a moderating role in the association between parents’ EE and their feelings of stress and parenting behaviors. As suggested by the theoretical process model of Belsky (1984), parents’ behavior is shaped by (the interplay of) parental characteristics, as well as child characteristics, and contextual sources of stress and support. Following this model, parental Criticism might reflect a parent’s negative or insensitive thoughts and feelings towards the child that might exacerbate behavioral problems, and/or expressions of Criticism might be a reaction to challenging child behavior or stressful events, which parents might find hard to manage (Hastings & Lloyd, 2007; McCarty et al., 2004).

Relevance for practice and research

Several findings of this study have practical and theoretical implications. First, the study findings demonstrated that, across groups, the large majority of parents expressed thoughts and feelings related to a positive emotional family climate characterized by parental love, pride, and appreciation for the intrinsic worth of their child. Although parents of children with a disability generally experience more obstacles, the majority of parents raising a child with a disability in this study also expressed love and value towards their child and significant benefits in the experience of raising their child. In other words, these parents, while likely to report feeling stressed, are also likely to feel emotionally rewarded, rather than saddened by their parenting experiences (Green, 2007). Therefore, this finding asks for a critical rethinking of the perception that families raising a child with a disability are automatically characterized by subjective burden or vulnerability. Future research should not solely focus on parents' emotional distress or subjective burden, but should aim to unravel the broad complexity of factors that impact parents' thoughts and feelings towards their child, including meaningful positive experiences and broader socio-cultural factors, such as stigma and the organization of specialized care (Green, 2007). In practice, it might be interesting to further investigate which factors (e.g., parents' coping strategy, attribution style, support network) contribute to these positive emotional family climates and how these may increase parents' emotional and cognitive resources.

Nonetheless, the findings also illustrated that especially families of children with ASD, and to a lesser extent families of children with CP, might be at risk for stressed-out emotional family climates. However, since parental EE can be best conceptualized as a parent's attitude and (emotional and cognitive) regulation of emotions towards the child, which are shaped by parent-child interactions (Greenberg et al., 2006), assessment of the emotional quality of a parent-child relationship can also create possibilities for change and intervention. In this regard, psychoeducation has shown to be a valuable platform for changing parental attributions or interaction patterns (e.g., Smith et al., 2014). Previous research indicated that high EE especially occurs when parents perceive their child to have control over his or her symptoms and behaviors (Lancaster et al., 2014), instead of acknowledging the factors that lie beyond the child's control, such as birth complications, genetics or environmental toxins (Greenberg et al., 2006). Therefore, it might be interesting to thoroughly explore how and why parents perceive their child's behavior in a certain way. To further support a positive emotional family climate, psychoeducation should be accompanied by skills training, addressing problem-solving and communication techniques (Peris and Miklowitz, 2015). Furthermore, family interventions addressing emotional arousal or emotion regulation, such as cognitive training or self-soothing strategies, also have proven to decrease the impact of negative interactions or communication on the emotional family climate (Peris and Piacentini, 2013). However, further research is needed to develop and evaluate the effects of similar interventions among families of children with ASD, CP, and DS.

Second, the unique assessment method (i.e., free speech) has the advantage of reducing response bias by eliciting spontaneous open-ended responses, rather than asking questions that might prompt parents' responses or might trigger social desirability. Therefore, the FMSS-method provides opportunities to reveal parents' thoughts and feelings that might have not been exposed during a structured interview. For example, whereas several speech samples reflected parents' warmth, affect, and engagement towards their child and their family life, others revealed red flags for parental burnout, such as emotional exhaustion or detachment from the child.

Third, the study findings support the idea that the FMSS-method can be used as a robust method across a wide variety of populations. Few significant relations were observed between parents' EE and the child's disability severity or other sociodemographic factors, corroborating previous research (e.g., Boger et al., 2008; Delvecchio et al., 2014; Smith et al., 2008). Also, the method has some additional practical benefits for use in practice and research since FMSSs can be effectively administered over the phone, without the presence of a trained coder, and a limited amount of time is needed to administer or code the FMSS (e.g., Beck et al., 2004).

Limitations and suggestions for future research

The current study has some limitations. First, although we did control for significant demographic variables (i.e., the child's and informant's age) and participants' ethnicity and level of education were representative compared to the Flemish population (Statistics Belgium, 2018), our group samples were fairly heterogeneous within and across groups. For example, we did not assess information on household income, job security, or the number of children (with special needs) within a family unit, which might differ across groups. Although so far, studies among special needs populations showed no association between parents' level of EE and parents' education level (Peris and Hinshaw, 2003) or the number of children with a disability or psychiatric diagnosis in the family unit (Hickey et al., 2019), more research is needed to examine how these sociodemographic factors might influence the emotional family climate and/or parents' feelings of stress. Furthermore, only one informant from the family unit participated in the study, of which the majority were mothers (92.8%). The underrepresentation of fathers might influence our findings since previous research among parents of children with ASD indicated that mothers expressed more Criticism (Hickey et al., 2019) and experienced elevated levels of parenting stress (Foody et al., 2015) compared to fathers. Future research could benefit from including more homogeneous groups and multiple informants to investigate both parent-child relationships as well as possible spillover effects to the parent-couple relationship (Hickey et al., 2019). Moreover, future studies could rely on alternative measures of parenting behaviors, such as observations, and should additionally include measures of child behavior to further disentangle the conceptual meaning of the EE-construct in NDD-populations. Second, Benson and colleagues have adapted the original FMSS-method (Magaña-Amato et al., 1986) for use specifically with caregivers of children with ASD (Benson et al., 2010), addressing certain considerations related to the expression of Criticism and the addition of an explicit global code for Warmth (Daley & Benson, 2008). Although we did not apply the adapted coding scheme in the ASD-group, driven by a cross-disability perspective, we examined parental Warmth as an important construct, next to EOI and Criticism, in line with early EE-rating systems (Vaughn & Leff, 1976). Third, the cross-sectional design of this study does not allow to explore directions of effects. Therefore, for example, it remains unclear whether parenting stress drives EE or whether EE is a determinant of parenting stress and consequently mediates the effect of the child's disability on feelings of parenting stress (Beck et al., 2004). Future longitudinal research is needed to explore directions of effects, but also to determine the stability of the EE-domains over time.

5.5 Conclusion

This study aimed to provide insight into EE and its relationship with parenting stress and parenting behaviors among parents of children with and without a NDD. The study findings indicated that 79.4% of parents expressed low levels of EE, suggesting that the large majority of parents raise their child in a positive emotional family climate characterized by warmth and positive parent-child interactions. Within each group, a stressed-out family climate, especially indicated by more parental expressions of Criticism and fewer of Warmth, related to higher levels of parenting stress and need-thwarting parenting behaviors. These findings suggest that the FMSS-method holds strong potential as a brief but richly informative tool for indexing parent-child dynamics in both practice and developmental research, and to identify parent-child dyads whose relationships are at risk and in need of intervention.

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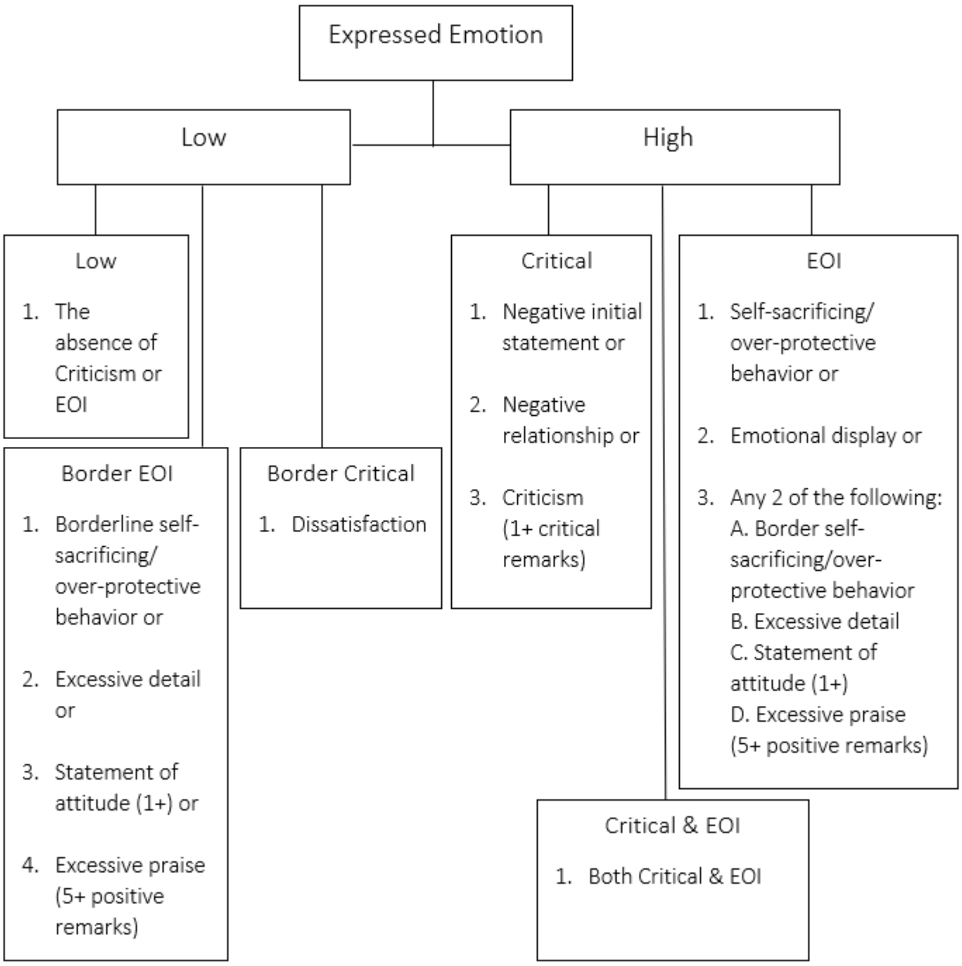
Appendix 1. Expressed Emotion coding scheme



Note. EOI Emotional Over-involvement. Coding scheme retrieved from the 'Manual for Coding Expressed Emotion from the Five Minute Speech Sample' (p. 40) developed by Magaña-Amato and colleagues (Magaña-Amato, 1993; Magaña-Amato et al., 1986).

Chapter 6

“Tell me about your child, the relationship with your child and your parental experiences”: A qualitative study of spontaneous speech samples among parents raising a child with and without autism spectrum disorder, cerebral palsy, or Down syndrome

Based on De Clercq, L., Prinzie, P., Swerts, C., Ortibus, E., & De Pauw, S. S. W. (2020). "Tell me about your child, the relationship with your child and your parental experiences”: A qualitative study of spontaneous speech samples among parents raising a child with and without autism spectrum disorder, cerebral palsy or Down syndrome. *Journal of Developmental and Physical Disabilities*. Manuscript under review.

Abstract

Ample quantitative studies have shown that parents raising children with neurodevelopmental disabilities are prone to experience more stress and challenges in their parenthood. Notwithstanding the strength of this line of research, qualitative studies are crucial to grasp the complex reality of these parenting experiences. This qualitative study adopted Self-Determination Theory to analyze parents' described experiences, appraising both challenges and opportunities in parents' psychological need for autonomy, relatedness, and competence. A multi-group comparative design is adopted to examine similarities and differences in the perspectives of 160 parents raising an adolescent with autism spectrum disorder, cerebral palsy, Down syndrome, or without a disability (*M* age child = 13.09 years, 67.5% boys). Parents' perspectives were examined through speech samples probing parents to talk spontaneously about their child, their relationship with the child, and their parental experiences. Forty samples in each group were randomly chosen from a larger dataset and were analyzed using deductive thematic analysis. Parents of children with a disability described more need-frustrating but also more autonomy-satisfying experiences compared to parents of children without a disability. Parents of children with autism spectrum disorder reported the most challenges concerning their relatedness with their child and their own parental competence. Parents raising a child with cerebral palsy expressed the most worries about their child's future and continuity of care. Parents of a child with Down syndrome described the most need-satisfying experiences related to their self-development and family life. This study offers a more balanced view on the realm of parenting a child with a neurodevelopmental disability.

6.1 Introduction

Parenting is an emotionally powerful and complex undertaking, which strongly affects parents' well-being (Nomaguchi & Milkie, 2020). When a child is growing up with a social, physical, or intellectual disability, due to a neurodevelopmental disability (NDD) such as autism spectrum disorder (ASD), cerebral palsy (CP), or Down syndrome (DS), parents face additional challenges in providing their child with the needed care. These parents are required to make adjustments to their daily life, but they also need to adjust their expectations towards their own parental role, aspirations, and future life (Reichman et al., 2008; Resch et al., 2010). Over the past decades, research into the experiences of parents raising a child with a disability in general – and children with a NDD more specifically – has predominantly focused on the rather 'negative' impact of a child's disability on parents' well-being and functioning. Within this line of research, ample quantitative studies have demonstrated that parents of children with a NDD share an increased vulnerability to experience higher levels of parenting stress and lower levels of well-being compared to parents of children with no disability (Gupta, 2007; Hayes & Watson, 2013; Singer & Floyd, 2006). However, this research focusing on parental stress provides a rather one-sided view on the reality of raising a child with a NDD, losing sight of parents' positive or satisfying experiences.

Self-Determination Theory: Towards a more balanced view on parenting a child with a neurodevelopmental disability

To offer a more profound and balanced insight into both challenging and satisfying experiences when parenting a child with a NDD, this study puts forward the widely-validated theoretical framework of Self-Determination Theory (SDT; Deci & Ryan, 2000; Soenens et al., 2017). According to this theory, the development and growth of an individual largely depends on the extent to which a social environment supports or frustrates three innate basic psychological needs: the need for *autonomy* (i.e., to feel psychological freedom and authentic), *relatedness* (i.e., to feel connected with and loved by others), and *competence* (i.e., to feel able and effective to reach personal goals) (Deci & Ryan, 2000; Ryan & Deci, 2017). Especially among neurotypical populations, the SDT-framework is a prominent theory to unravel how parents' *need-frustrating* (e.g., feelings of pressure, social alienation, and personal failure) and *need-satisfying* experiences (e.g., experiences of authenticity, reciprocal care, and personal effectiveness) impact parents' well-being, vitality, and self-development (e.g., Soenens et al., 2017; Soenens et al., 2019; Vansteenkiste & Ryan, 2013).

Inspired by the assumption that SDT has universally applicable tenets (Deci & Ryan, 2000), there is now growing interest to use this theory to better understand the complex realm of parents raising a child with a disability, both using quantitative (e.g., Dieleman et al., 2020; Gilmore & Cuskelly, 2012) and qualitative methodologies (Dieleman, Moyson, et al., 2018; Dieleman, Van Vlaenderen, et al., 2019; Gilmore et al., 2016). Interestingly, SDT's distinction between two pathways of *need satisfaction* versus *need frustration*, may help to capture the phenomenon of 'silver linings' (Bultas & Pohlman, 2014). A few qualitative studies of parents raising a child with a disability now indicate that, despite frequent obstacles, parenting is not always doom and gloom but also entails enriching need-satisfying experiences (e.g., Dieleman, Moyson, et al., 2018; Gilmore et al., 2016). To date, research evaluating SDT in disabilities has mostly focused on one single NDD, with little input from similar research on another NDD. Therefore, this study examines the need-related experiences of parents raising a child in and across three diverse NDDs, namely ASD, CP, and DS. We selected these NDDs because of their high prevalence (Elsabbagh et al., 2012; Irving et al., 2008; Oskoui et al., 2013) but also based on the diversity of the developmental domain in which limitations occur (i.e., social-communicative in ASD, physical in CP, and cognitive in DS).

Self-Determination Theory as a lens to synthesize the experiences of parents raising a child with a neurodevelopmental disability

The current, blossoming literature to validate SDT-premises in studies on parenting a child with a disability primarily builds upon two classic research methodologies: i.e. questionnaires and interviews. The current study introduces a third, innovative design and evaluates the potential of SDT to synthesize naturalistic, spontaneous speech samples of parents.

Questionnaire data: Evaluating parental stress as psychological need frustration

To date, parent-report questionnaires are the first and preferred method to *quantitatively* evaluate parental experiences. A handful of studies now explicitly used SDT to better understand the a-theoretical construct of 'parental stress' in terms of frustration of parental needs for autonomy, relatedness, and competence (e.g., de Haan et al., 2013). Within NDD-populations, these studies demonstrated that parents of children with ASD (Dieleman, De Pauw, et al., 2018; Dieleman, Soenens, et al., 2019), CP (Dieleman et al., 2020), and DS (Gilmore & Cuskelly, 2012) are more vulnerable to experience elevated levels of parental need frustration (De Clercq et al., 2020). Moreover, these elevated levels of need frustration have been empirically linked with dysfunctional parenting behaviors in both long-term (Dieleman et al., 2017) and diary studies (Dieleman et al., 2020; Dieleman, Soenens, et al., 2019) among families raising a child with ASD or CP. In turn, these dysfunctional parenting behaviors have been associated with more externalizing problems and fewer psychosocial strengths across children with and without ASD, CP, and DS (De Clercq et al., 2019).

In-depth interviews: Unraveling complexity

The past decade has witnessed a growing body of qualitative work on experiences of parents raising a child with ASD, CP, and DS (e.g., Alaee et al., 2015; Farkas et al., 2018; Meirsschaut et al., 2010), including two recent, SDT-based studies in ASD (Dieleman, Moyson, et al., 2018) and CP (Dieleman, Van Vlaenderen, et al., 2019). These studies are mainly based on in-depth or (semi-)structured interviews and demonstrated that the SDT-lens is a valuable tool to integrate qualitative findings of parents' experiences in terms of need satisfaction and need frustration.

For instance, in ASD-research, parents describe *need frustration* when they experience a lack of time or possibilities to develop their own interests (i.e., autonomy frustration) or strain in their relationship with their partner and friends (i.e., relatedness frustration) (Dieleman, Moyson, et al., 2018). Parents of children with ASD also report frustration in their need for parental competence when they struggle to find the right approach to manage challenging child behaviors (Dieleman, Moyson, et al., 2018; Meirsschaut et al., 2010; Myers et al., 2009; Woodgate et al., 2008). In CP-research, parents also report autonomy frustration when they experience restrictions to develop their own interests or when they must give up their professional aspirations. When these parents experience limited time to spend as a couple or lack time and energy to maintain social contacts, this can be interpreted as frustrations in their need for relatedness (Alaee et al., 2015; Davis et al., 2010; Dieleman, Van Vlaenderen, et al., 2019). Parents of children with CP also report competence frustration regarding the difficulties they face to provide and organize specialized care or to interpret their child's needs (Dieleman, Van Vlaenderen, et al., 2019; Huang et al., 2010). Similarly, research among parents of children with DS also identifies multiple examples of autonomy frustration, such as the feeling that they need to invest too much of their free time to organize medical and therapeutic support (Povee et al., 2012). Parents of children with DS also mention relatedness frustration, such as a lack of social acceptance or support from their family or friends, or competence frustration, such as struggling to get access to services or feeling uncertain to make decisions regarding their child's education (Farkas et al., 2018; Povee et al., 2012).

Evaluating existent qualitative studies through an SDT-lens also illuminates positive *need-satisfying experiences*. For instance, parents of children with ASD report opportunities for need satisfaction, such as finding a new direction in life (i.e., autonomy satisfaction), growing closer together as a family (i.e., relatedness satisfaction), or feeling proud when their child achieves certain goals (i.e., competence satisfaction) (DePape & Lindsay, 2014; Dieleman, Moyson, et al., 2018). Studies among parents raising a child with CP highlight relatedness satisfaction when they mention intense parent-child relationships, new social networks, or strong family cohesion (Björquist et al., 2016; LaForme Fiss et al., 2014). Parents of children with CP report that they especially feel competent when their child reaches an unexpected goal or when specialized healthcare professionals recognize the positive evolutions of their child (Davis et al., 2010; Dieleman, Van Vlaenderen, et al., 2019). Additionally, parents raising a child with DS report experiences of autonomy satisfaction when their child enhances their self-development or shapes their philosophy of life (e.g., by appreciating diversity, learning to be more patient and flexible) (Povee et al., 2012). These parents also report relatedness satisfaction describing how their child facilitates new friendships (Farkas et al., 2018) and competence satisfaction when their child acquires new skills that maximize the child's independence (Gilmore et al., 2016).

Spontaneous speech samples: Exploring naturalistic experiences

In addition to the more traditional methodologies of questionnaires and in-depth interviews, this study adopts SDT as a lens to synthesize spontaneous, *free speech samples* of parents describing their child, the relationship with their child, and their parental experiences. In recent years, the interest in the free speech sample method has gradually grown to capture more naturalistic family life experiences, both quantitively and qualitatively. In parenting and broader developmental research, the Five Minute Speech Sample (FMSS) (Magaña-Amato et al., 1986) became a widely-validated operationalization of this method (Sher-Censor, 2015; Thompson et al., 2018). Within this method, parents are asked to speak spontaneously for five minutes about what kind of person their child is and how they experience the relationship with their child, without being interrupted by interview questions (Magaña-Amato, 1993).

The FMSS-method is traditionally used in quantitative studies to measure parents' levels of Expressed Emotion (i.e., low or high intensity and regulation of emotion in parents' expressions) through a structured coding scheme (Magaña-Amato, 1993). In both neurotypical (Sher-Censor, 2015) and NDD-populations (e.g., Hastings et al., 2006; Hickey et al., 2020; Yığman et al., 2020), scholars now argue that high levels of parental Expressed Emotion can be interpreted as an indicator of a stressed-out family climate, where parents' experiences of stress are elevated. Notably, a few studies explored the rich, naturalistic information embedded in these parents' spontaneous speech samples. These studies qualitatively examined speech samples among caregivers of children with a disability (Kovac 2018; Perez et al. 2014), behavioral difficulties (Caspi et al. 2004), or children growing up in precarious living situations and poverty (de Wit 2018) using diverse qualitative techniques, such as computer-based linguistic analysis, thematic, or content analysis. Two studies applied a qualitative analysis of FMSSs to evaluate whether caregivers' perceptions and attitudes towards the child and their relationship with the child positively evolved after an intervention or parenting program (de Wit 2018; Kovac 2018). Similarly, Caspi et al. (2004) and Perez et al. (2014) suggested that the FMSS-method is a useful tool to examine parents' perceptions and attitudes towards their child's behavior in general, and diagnosis in particular (e.g., ADHD or antisocial behavior). Moreover, a better understanding of these perceptions and attitudes provided guidelines to increase the quality of parent-child relationships and to maximize the relevancy and effectiveness of parenting interventions (Caspi et al. 2004; Perez et al. 2014). For instance, the qualitative examination of parents' narratives showed that parenting interventions should not only include techniques to improve effective behavior management and communication skills but should also include strategies that focus on promoting affectionate parent-child relationships, positive perceptions, and activities that facilitate enjoyment and positive mood within the family context (Perez et al. 2014).

The present study

This qualitative study aims to provide a deeper understanding of the perspectives of parents raising an adolescent with ASD, CP, DS, and a reference group of parents raising a child without any known disability (i.e., reference group). The inclusion of these four groups allows a multi-group qualitative comparative design, providing the opportunity to examine parents' experiences as a whole, while also shedding light on group-specificities (Lindsay, 2018; Morse, 2004; Ritchie et al., 2003). In other words, this design permits to examine general overarching parental experiences, generalizing across groups, while also exploring differences across groups. These group differences might provide valuable insight into the factors that make raising a child with a certain NDD potentially stressful, but also into those factors that create possibilities for positive need-satisfying experiences. This study examined parents' perspectives through spontaneous descriptions, where parents were asked to talk about what kind of person their child is, how they get along with their child (i.e., FMSS-method instruction), and their parenting experiences. Whereas interviews tend to follow a certain interview guideline that might bias or steer participants into a certain direction or might elicit social desirability (Ritchie et al., 2003), spontaneous speech samples ought to provide a more ecological look into people's experiences. The SDT-framework was applied to structure these spontaneous speech samples in order to provide a more balanced view on parents' perspectives regarding their need for autonomy, relatedness, and competence.

6.2 Methods

Participants

As part of an ongoing longitudinal project, 489 speech samples of parents raising a child with ASD (*n* = 159), CP (*n* = 88), DS (*n* = 69), and without any known disability (*n* = 174) were collected (De Clercq et al., 2020). Forty interviews from each group (total *n* = 160) were randomly selected to reflect similar socio-demographic characteristics across groups, while also ensuring sufficient sample sizes to reflect diversity and to retain in-depth coverage and thematic saturation (Lindsay, 2018; Ritchie et al., 2003). More specifically, the four parent groups were closely distributed based on: the child's gender (2:3, boys:girls), age (ranging from 10 to 15 years old), and living situation (overall, 85.0% of the children lived at home during the week and weekends), and the informants' relation towards the child (35:5, mother:father), age (overall, *M*age mother = 44.36 years old, overall *M*age father = 46.44 years old), educational level (overall, 68.8% higher education), and marital status (overall, 77.5% living together/married). Additional sample characteristics by group are presented in Table 1.

Procedure

Parents were eligible to participate in the longitudinal project if their child (1) had an official ASD, CP, or DS diagnosis and (2) was between 6 and 17 years old. Parents of children with a NDD provided information on their child's diagnostic process and were asked to verify their child's diagnosis through additional reports. These parents were recruited via specialized care facilities, schools, and online parent groups. Parents from the reference group raised a child between 6 and 17 years old, who did not receive a clinical diagnosis. These parents were included from the Flemish Study on Temperament and Personality across Childhood (De Pauw, 2010).

At the beginning of the interview, parents were asked to provide some general demographic information about their child and family (Table 1). Parents' perspectives were administered through short interviews, either in the family home or through telephone. Both approaches showed to have good validity to assess spontaneous, free speech samples (Beck et al., 2004). The data collection consisted of two structured open-ended questions (i.e., *Could you tell me about the kind of person your child is and how you get along? Could you tell me about your experiences as a parent of [name child]?*) to explore the same issues across samples (Ritchie et al., 2003). The first question is the official instruction of the FMSS-method, where parents are asked to

Table 1. Demographic characteristics by group (total *n* = 160)

	Autism spectrum disorder (*n* = 40)	Cerebral palsy (*n* = 40)	Down syndrome (*n* = 40)	Reference group (*n* = 40)	Total (*n* = 160)
Child					
Gender[1]					
Boys (%)	27 (67.5)	27 (67.5)	27 (67.5)	27 (67.5)	108 (67.5)
Age					
Mean (SD)	12.85 (1.31)	13.04 (1.53)	12.83 (1.59)	13.64 (0.52)	13.09 (1.34)
Range	10.02-15.82	10.07-15.50	10.01-15.72	12.90-14.73	10.01-15.82
Main living situation					
At home (%)	36 (90.0)	32 (80.0)	32 (80.0)	36 (90.0)	136 (85.0)
Co-parenting[2] (%)	4 (10.0)	5 (12.5)	7 (17.5)	4 (10.0)	20 (12.5)
Care facility /boarding school[3] (%)	0 (0.0)	3 (7.5)	1 (2.5)	0 (0.0)	4 (2.5)
School					
Regular (%)	35 (87.5)	9 (22.5)	13 (32.5)	40 (100.0)	97 (60.6)
Special (%)	5 (12.5)	31 (77.5)	27 (67.5)	0 (0.0)	63 (39.4)
Disability severity[4]					
Mild (%)	1 (2.5)	10 (25.0)	20 (50.0)	-	-
Moderate (%)	5 (12.5)	23 (57.5)	10 (25.0)	-	-
Severe (%)	34 (85.0)	7 (17.5)	5 (12.5)	-	-
Informant					
Relation to child					
Mother (%)	35 (87.5)	35 (87.5)	35 (87.5)	35 (87.5)	140(87.5)
Father (%)	5 (12.5)	5 (12.5)	5 (12.5)	5 (12.5)	20(12.5)
Age					
Mean age Mother (SD)	41.90 (5.00)	43.81 (4.79)	47.84 (5.05)	43.88 (4.37)	44.36 (5.24)
Mean age Father (SD)	44.67 (6.34)	44.85 (4.85)	49.84 (5.56)	46.41 (4.07)	46.44 (5.62)
Education level					
Primary school (%)	1 (2.5)	0 (0.0)	1 (2.5)	0 (0.0)	2 (1.3)
Secondary school (%)	11 (27.5)	15 (37.5)	12 (30.0)	10 (25.0)	48 (30.0)
Higher education (%)	28 (70.0)	25 (62.5)	27 (67.5)	30 (75.0)	110 (68.8)
Marital status					
Living together/married	32 (80.0)	29 (72.5)	31 (77.5)	32 (80.0)	124 (77.5)
Newly assembled family	3 (7.5)	6 (15.0)	5 (12.5)	6 (15.0)	20 (12.5)
Single	5 (12.5)	5 (12.5)	4 (10.0)	2 (5.0)	16 (10.0)

Note. [1]Child gender ratio was distributed in line with prevalence rates among children with ASD and CP. [2]Parenting of the child is shared between the informant and another adult not living with the informant, mostly the other biological parent of the child (92%). [3]During three or more days a week. [4]In the ASD-group, parents filled out the Social Responsiveness Scale (Constantino & Gruber, 2005; Roeyers et al., 2011) to indicate mild (T-score < 62), moderate (61 < T-score < 75), or serious (T-score > 75) difficulties in social responsiveness among their child. In the CP-group, parent reports on the Gross Motor Function Classification System (Palisano et al., 2008; Palisano et al., 1997) indicated mild (level I), moderate (level II and III), or severe (level IV and V) impairments in motor functioning. The majority of the children had spastic CP (82.5%), 7.5% had dyskinetic CP, 5.0% ataxic CP and 5.0% a mixed type of CP. In the DS-group, parent indicated whether their child had a mild (IQ-range = 50 - 69), moderate (IQ-range = 36 - 49), or profound intellectual disability (IQ-range = 20 - 35). 12.5% (*n* = 5) of these parents did not provide IQ information.

speak (at least) for five uninterrupted minutes about what kind of person their child is and how they get along together (Magaña-Amato et al., 1986). Concerning the second question, parents were encouraged to spontaneously speak about their experiences as a parent, for at least three minutes. The interviewer did not say anything while the respondent was speaking, which meant that the interviewer did not provide any comments, verbal affirmations, or leading prompts that could direct the conversation. When the parent stopped talking before the end of the proposed amount of minutes, the interviewer waited for 20-30 seconds, and if the parent did not continue talking, the interviewer repeated the interview instruction (cf., FMSS-method instruction; Magaña-Amato, 1993). Parents' speech samples ranged from 8.33 to 19.05 minutes (*M* = 11.19). Written informed consent was obtained from all parents and the study received ethical approval from the Ethics Committee of the Faculty of Psychology and Educational Sciences at Ghent University, in accordance with internationally accepted criteria for research.

Data analysis

All interviews were recorded, transcribed verbatim, and analyzed using the qualitative software program NVivo (QSR International, 2012). The data analysis followed the principles of thematic analysis (Braun & Clarke, 2006). Because parents' perspectives were analyzed using the SDT-framework (i.e., need for autonomy, relatedness, and competence), a deductive theory-driven thematic approach was used. The data-analytic process started with data familiarization and noting initial comments about meaningful information across groups to get a sense of the whole, before comparing similarities and differences across groups (Lindsay, 2018). Next, initial codes were generated through line-by-line coding and organized into potential (sub)themes. The coding process followed a specific sequence, where the coding of ten samples from a specific group was followed by the coding of ten samples from another group, and so on, until all data of 40 samples within each group were coded. This approach allowed to minimize possible group-bias effect (Lindsay, 2018). Further, all (sub)themes were critically appraised on whether they formed a coherent pattern and if they accurately represented parents' perspectives. Next, (sub)themes were reconsidered and reflected upon by multiple researchers of the research team to increase credibility and to limit personal bias (Shenton, 2004). Finally, each theme was defined within the research team and associated quotes were discussed to identify a selection of descriptions reflecting the overarching topic. Irrespective of the steps described, the analytic process was not linear, but involved loops going back and forth between the different steps (Howitt, 2016).

6.3 Results

Parents' perspectives were structured within the framework of SDT and categorized as need-frustrating or need-satisfying experiences in parents' needs for autonomy, relatedness, or competence. Overall, parents of children with ASD, CP, and DS described more need-frustrating experiences in all three psychological needs compared to parents of children with no disability. Interestingly, parents raising a child with DS described a similar – and regarding autonomy and relatedness even a higher – amount of need-satisfying experiences compared to parents of the reference group. An overview of these themes and their frequency in each group, is presented in Table 2. Figure 1 visually represents the count of challenges and/or opportunities that parents described in their need for autonomy, relatedness, and competence.

Frustration and satisfaction in the need for autonomy

Within descriptions of parents' need for autonomy, two salient themes emerged: self-development and family life. Notably, only parents of children with a NDD spontaneously described autonomy-frustrating experiences related to their self-development and family life, whereas all parents mentioned autonomy-satisfying feelings of enrichment or family cohesion.

Self-development: Role restriction versus Enrichment

Role restriction. Challenges for self-development only emerged in the spontaneous speech samples of parents of children with a NDD. Several parents of children with ASD felt forced to be near their child all the time or to *"stick with old patterns or activities".* According to these parents, these experiences related to their child's anxiety to rely on others or to do things alone, their child's need for predictability, or adversity towards new stimuli. Many parents of children with CP also mentioned role restriction because their child needed a lot of practical support (e.g., eating, washing, clothing), emphasizing that the management of specialized care was time-consuming.

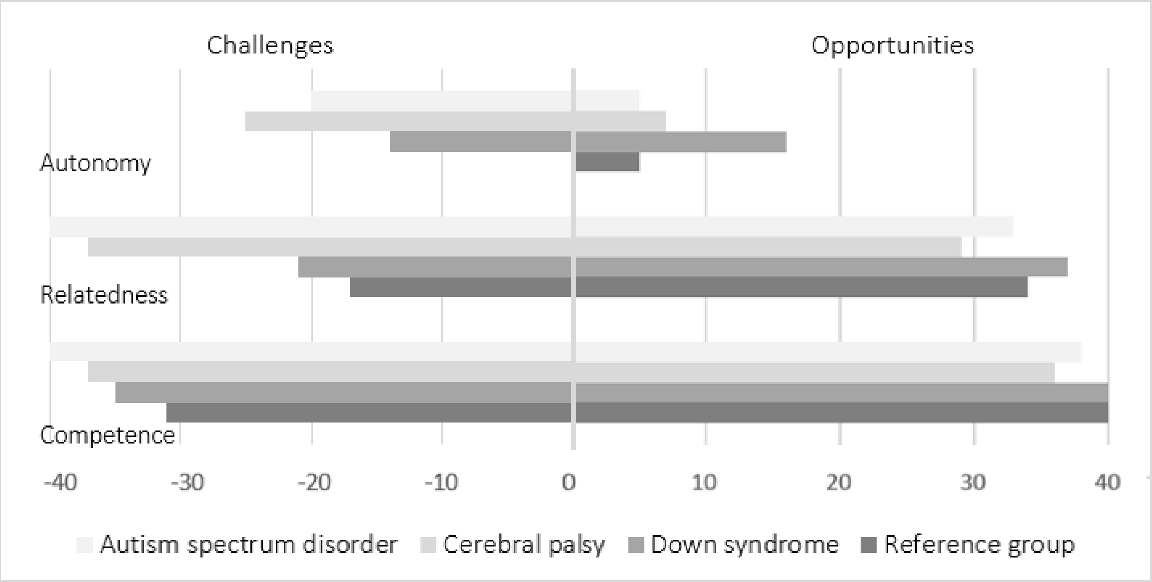
> *"You sacrifice a part of your own life, a part of your own life is lost. You have less freedom. You have less free time to do the things you used to do, but you learn to live with it."* (Mother of J., boy with CP)

Table 2. Content and frequency of the (sub)themes in the four comparison groups (total *n* = 160)

			Autism spectrum disorder (*n* = 40)				Cerebral palsy (*n* = 40)				Down syndrome (*n* = 40)				Reference group (*n* = 40)			
Themes	Subthemes		Opportunities		Challenges		Opportunities		Challenges		Opportunities		Challenges		Opportunities		Challenges	
			n int.	*n* ref.	*n* int.	*n* ref.	*n* int.	*n* ref.	*n* int.	*n* ref.	*n* int.	*n* ref.	*n* int.	*n* ref.	*n* int.	*n* ref.	*n* int.	*n* ref.
Autonomy	Self-development		5	8	11	14	7	7	16	21	12	14	11	17	2	3	0	0
	Family life		0	0	10	14	0	0	12	19	6	6	3	4	3	4	0	0
	Total		5	8	20	28	7	7	25	40	16	20	14	21	5	7	0	0
Relatedness	Child		30	42	38	52	22	27	22	27	32	47	13	16	29	40	9	16
	Sibling		1	1	20	21	5	11	10	18	15	24	3	6	12	16	9	10
	Social network	Partner	4	4	6	6	3	4	4	5	1	1	2	2	2	3	2	2
		Family and friends	4	4	7	9	5	6	7	9	3	3	4	4	3	3	0	0
		Unacquainted	1	1	9	11	3	3	7	10	5	6	9	12	0	0	0	0
		Care providers	2	2	6	10	2	2	5	9	4	4	1	1	0	0	0	0
	Total		33	54	40	109	29	53	37	78	37	85	21	41	34	62	17	28
Competence	Parenting	Autonomy support	27	49	38	80	18	26	9	9	14	16	10	12	34	55	11	17
		Responsive	20	36	17	29	17	23	12	17	22	30	7	13	38	53	20	23
		Competence support	18	39	31	40	11	14	16	25	24	37	10	16	36	81	21	39
	Parental identity		14	22	10	12	18	27	8	10	18	23	4	4	4	6	0	0
	External support		21	35	16	42	14	20	11	16	13	15	5	6	3	3	2	3
	The future		3	3	16	25	3	5	22	34	6	7	7	7	14	16	5	5
	Total		38	184	40	228	36	115	37	111	40	128	35	58	40	214	31	87

Note. n int. The number of interviews in which the (sub)theme was identified, *n ref.* The total number of references to the (sub)theme.

Figure 1. Visual representation of the number of interviews in which parents described opportunities and challenges in their need for autonomy, relatedness, and competence



Several parents of children with DS described that their personal time was limited because their child needed a lot of proximity and supervision during activities, or needed a lot of stimulation to do things alone. This, however, required a lot of explanation, probing, control, and repetition. Therefore, some of these parents found it difficult to leave their child alone at home, which further hindered their possibilities to go out. Some parents of children with a NDD also mentioned restrictions in their chances to pursue a professional career. Eight parents spontaneously mentioned they decided to work less and three parents gave up their professional ambitions. Whereas half of these parents experienced feelings of regret to do so, others mentioned that this decision allowed them to provide the needed care for their child and to arrange the household. Especially parents of children with CP cut back a few steps in their professional career quite early to keep up with the appointments with doctors and therapists.

> *"It is not always easy to keep a job while raising a child with a disability... you have to go to hospitals a lot, see doctors, all that. Colleagues do not really understand that."*
> (Mother of B., girl with CP)

Enrichment. In all groups, there were many expressions of parents indicating that raising their child is a positive and rewarding experience, enhancing their self-development and changing their perspective on life. Especially parents of children with DS mentioned that they became more reflective, creative, or resilient when handling challenges, or developed a more down-to-earth view on life (e.g., putting things in perspective, living in the moment, enjoying *"the little things"*).

> *"I learned a lot from A. She can be so satisfied and happy with small things. I really try to think about that regularly. Given our society's emphasis on accomplishments, that's not always evident. I think we always want more, and bigger and better, but for A., good is good enough."* (Mother of A., girl with DS)

Multiple parents of children with a NDD even described feelings of empowerment when they responded with resilience towards barriers and confrontations, such as legal care provisions or stigmatization. Some of these parents saw it as their duty to take an active role in fighting for their child's participation and inclusion, or to be an advocate for their child, for example, by organizing inclusive schooling or leisure activities, or by coaching care providers.

> *"Many care providers think in a restrictive way and assume she is not able to do things, and then I find that I must take action. I really learned to be assertive and to be more provocative, in a friendly and respectful manner of course. I try to coach care providers in how you can support her and stimulate her the most."* (Mother of N., girl with DS)

Some parents of children with DS even felt they had to *"claim a secure place in society"* for their child. They questioned the current view on prenatal screening and took an active role in defending the right to live for people with DS. Parents hoped that in the future, medical staff would engage more often in an open and balanced dialogue about these screenings, which reflected the positive side of raising a child with DS. Also, several parents of children with a NDD mentioned that changes in child (e.g., increased independence) or contextual factors (e.g., different care providers located in the same care facility instead of scattered) could increase their opportunities for self-development.

Family life: Challenging family activities versus Intensified family cohesion

Challenging family activities. Parents of children with a NDD mentioned multiple challenges to commit to or adjust family and holiday activities. Especially parents of children with ASD mentioned that they had to restructure or cancel family activities due to the child's need for structure and predictability, or because social events caused over-stimulation (e.g., too crowded, noisy, other food). Particularly parents of children with ASD and CP mentioned limitations related to family holidays. Whereas some parents of children with ASD were not able to go on a family holiday because it was too stressful or exhausting to provide enough structure and predictability, parents of children with CP were confronted with the inaccessibility of locations or activities, which could also create tensions with siblings.

> *"Going somewhere, does it work or not? We never know in advance. Looking ahead or planning, that doesn't exist for us. So, life is quite difficult. When we want to go somewhere, we are always stressed because we don't know if it will work out. (…). A normal school day is already difficult, let alone a holiday where nothing is planned."* (Mother of V., boy with ASD)

> *"Of course, everything depends on him, we can't just go on vacation anywhere. We have to see whether it is accessible... and even then, it is always a bit of a compromise."* (Mother of F., boy with CP)

Intensified family cohesion. Parents of children with DS and from the reference group also spontaneously mentioned many autonomy-satisfying experiences related to their family life. Whereas several of these parents described that they felt unrestricted and happy to bring their child to family activities or social events, other parents mentioned that their child enriched their family life because the child created or enhanced a positive atmosphere in the family unit.

Frustration and satisfaction in the need for relatedness

Parents from each group spontaneously described many challenges and opportunities in their need for relatedness with their child and other siblings, and their social network (i.e., partner, family, friends, unacquainted people, and care providers). Notably, only parents of children with a NDD mentioned relatedness frustration beyond the parent-child relationship into their relation with their social network and care providers.

Relatedness with the child: Intensity versus Indispensability

Intensity. All parents mentioned different challenges in relatedness with their child, yet their content differed substantially across groups. Parents from the reference group especially described difficulties in the context of puberty, noting that their child *"pushed them away"* to be more independent, showed more rebellious behavior (e.g., not adhere to rules and agreements, offer a rebuttal), was more talkative towards their friends instead of their parents, or liked to be in the spotlight all the time. Among parents of children with ASD, the parent-child relationship was often described as *"challenging"* characterized by conflicting signals. These parents struggled to reach reciprocity due to their child's communication difficulties or preference to be alone. Several of these parents felt pressured or dissatisfied when their child too strongly relied on them to fill in their free time, to *"translate"* social interactions, to provide structure and predictability, or when they were confronted with physical aggression and tantrums. Many parents of children with CP described their parent-child relationship as *"intense"*, characterized by enduring care and demanding support needs (e.g., clothing, eating, washing, putting on aids, going to therapies and hospitals) and dependence, which sometimes felt strenuous and exhausting. Some of these parents even indicated that their relationship with their child felt more stressful during puberty, as the child wanted to dismiss itself from the parent but also unwillingly had to depend on the parent's care for everyday things.

> *"At the moment, my relationship with him is more difficult. I think he is in puberty, but not physically though. He can really push me away and say: "Leave me alone, I don't need you."* (Mother of S., boy with CP)

Several parents of children with DS mentioned that their parent-child relationship was often under strain since their child required a lot of affection, proximity, and/or supervision, which could feel very tiring for some parents.

> *"Right now, he has been mom-oriented for months, and then it is always mom who has to do it. Nobody else can do anything. Mommy has to wash him, has to dress him, has to give him food, has to go to bed with him. It's all mommy mommy mommy and that requires a lot from a person."* (Mother of I., boy with DS)

Indispensability. Across all groups, many parents spontaneously mentioned need-satisfying experiences in their parent-child relationship, characterized by a unique connection or understanding. Many parents from the reference group described their parent-child relationship as *"open"*, referring to a relationship where the child spontaneously shared his or her thoughts and feelings, and showed affection towards the parent. Parents of children with ASD mentioned that over time they better understood their child's thought processes and support needs, and were able to recognize more subtle signs of relatedness. Some of these parents described themselves as *"interpreters"* or *"soundboards"* as they were often the ones translating their child's thoughts and feelings to the outside world and the other way around. Other parents of children with ASD used the term *"emotional resting places"* to describe themselves as a place where the child felt comfortable and understood. Parents of children with CP especially mentioned that due to the large amount of time they spent together with their child and due to the intensive practical and emotional support, parents felt indispensable for their child, which created a unique and close parent-child relationship. Several parents of children with DS described their parent-child relationship as *"warm"*, characterized by a lot of physical affection, open communication, and humor. According to these parents, this warm relationship was facilitated due to the fact that their child liked social moments, easily picked up other people's feelings, expressed their love very expressively, or often showed gratitude.

Relatedness with siblings: Distributing attention versus Nurturing sibling relationships

Distributing attention. In each group, several parents (with multiple children) struggled to provide equal attention to each of their children and to build qualitative relationships with each child. Whereas some parents from the reference group struggled to do so in the context of a newly assembled family, parents of children with a NDD felt uncertain about how far the adaption of rules and expectations towards their children could go in order to meet each child's needs. Sometimes siblings reacted frustrated because they felt treated unequally (e.g., less parental attention, more chores in the household, more parental demands to be more flexible) or the child with a NDD felt jealous towards the sibling because s/he was not able or allowed to participate in a similar activity (e.g., meeting alone with friends, going to a party).

> *"His brother feels depressed that his oldest brother is autistic and requires so much attention. He feels neglected, less worthy. So it's a bit of a hassle to pay equal attention to the children."* (Mother of X., boy with ASD)

*Nurturing sibling relationships***.** Across groups, parents mentioned relatedness satisfaction when their children got along well. Some parents of children with CP and DS stated that having a child with a disability brought the family closer together or made the sibling more caring towards others. Especially when the developmental age of a child with DS matches that of a (younger) sibling, this relationship seems to be facilitated.

Relatedness with social network: Feeling misunderstood versus Feeling supported

Feeling misunderstood. Parents mentioned relatedness frustration when they felt misunderstood by important others. Whereas parents from each group mentioned frustrating experiences in their partner relationship, only parents of children raising a child with a NDD mentioned these experiences concerning their relationship with their family, friends, unacquainted people, and care providers.

Concerning the partner relationship, several parents felt frustrated when they had limited time to spend as a couple due to all the parenting tasks or when they disagreed on how to handle certain parenting situations. For parents of a child with a NDD, these disagreements often related to discussions about the practical organization of care tasks or setting similar expectations for the child with a NDD and the sibling(s). Furthermore, only parents of children with a NDD mentioned relatedness-frustrating experiences with family or friends, particularly when family and friends did not understand or minimized the impact of raising a child with a disability. Especially parents of children with ASD felt misunderstood when family or friends stated that certain difficulties (e.g., not wanting to do schoolwork, aggression) could be ‘fixed’ by parenting differently (e.g., being stricter). Some parents of children with a NDD lost friends due to a lack of time or energy to participate in social activities or because joined activities with other families mismatched their child’s needs (e.g., too many stimuli, required walking skills).

> *“A family with a child with a disability is a restricted family. That is very clear. So this makes it really difficult. Especially towards social contacts, you become somewhat isolated. Your friends stay away a bit, you have less energy, and if you go somewhere, you don’t know if it will work out.”* (Father of F., boy with DS)

Furthermore, the physical (in)visibility of the child’s NDD played a salient factor in parents’ relatedness frustration with unacquainted people. For example, parents of children with ASD felt that unacquainted people were less understanding or reacted irately when their child behaved ‘inappropriately’, urging parents to constantly justify their child’s behavior. Also, according to parents of children with DS, the stereotypical idea about DS (i.e., being kind, loving, affectionate) did not always match their child’s needs or personality, and even felt as an underestimation of their struggles as a parent. Several parents of children with a NDD also mentioned painful experiences, such as being stared or laughed at, or when receiving pitying or indignant looks. Although their child was often not aware of these experiences, they had a strong impact on parents and made them feel sad, angry or ‘different’.

> *"When I get into the (public) swimming pool with her, you always have people going out of the pool. Then I always feel like saying: "It's not contagious!". But yes, that affects me. Why do they do that, or why do they look that way, why do they react like that? I think about that."* (Mother of A., girl with DS)

Parents of children with a NDD also mentioned intense and long-lasting contacts with a broad group of care providers. They discussed elements of need frustration when care providers did not take their concerns seriously, only focused on their child impairments, underestimated their child's abilities, or instead asked too much of the child (and themselves).

> *"Those doctors keep saying what to do, but in the meantime, it's very hard for us to do everything the right way. (…) My child has to do so much more than another child. It is very difficult because every specialist tells him what to do. And if you want to follow up all that, the poor child has no time for himself and neither do we."* (Mother of M., boy with CP)

Feeling supported. Across each group, several parents mentioned relatedness satisfaction in the relationship with their partner when they worked together as a team to overcome challenges, pursued similar parenting goals, or supported each other in their parenting style. Some parents of children with a NDD even mentioned that their partner relationship became more intense after their child with a disability was born. They pointed out that it was essential to respect each other's way of dealing with their child's diagnosis, and to support and comfort each other during the acceptance process and when going through difficult moments. In each group, family and friends were salient sources of support for both practical (e.g., taking care of the child once and a while) and emotional reasons (e.g., exchanging parental experiences, listening to concerns). Parents of children with a NDD especially experienced renewed energy when family or friends attentively listened to uncertainties or frustrations, recognized their parental efforts, or noticed small acts of progress in their child's development. Friendships that endured became extra meaningful and valuable, and new friendships with other parents of children with disabilities (for example through parenting groups) were treasured as these parents understood their situation and provided useful tips to handle challenges. In their interaction with unacquainted people, some parents of children with ASD also valued the invisibility of their child's disability because it caused less stigmatization. By contrast, some parents of children with CP and DS valued the visibility of their child's disability because the environment could immediately adjust to their child's abilities. In relation to care providers, parents felt connected when care providers noticed and valued the strengths of their child, collectively searched for solutions, acknowledged parents' hard work, or motivated parents to continue.

Frustration and satisfaction in the need for competence

In each group, many parental remarks were allocated as competence-related experiences, which were mainly related to feeling (less) competent in parental practices and skills. Parents of children with a NDD described more competence-frustrating experiences concerning their parental identity, the provision of external support, and their child's future. Whereas competence-satisfying experiences encompassed an affective component of pride and relief, competence-frustrating experiences included feelings of exhaustion, powerlessness, or misunderstanding.

Parenting: Struggling to support child needs versus Relying on need-supportive parenting behaviors

Across groups, parents' competence-related experiences were primarily and bi-directionally related to their own parenting behaviors and more specifically, the extent to which they felt they struggled or, conversely, adequately responded towards their child's need for autonomy, relatedness, and competence (i.e., need-supportive parenting).

Struggling to support child needs. In all groups, parents described feelings of uncertainty while struggling to support their child's need for *autonomy*. Especially parents from the reference group described struggles to find a balance between allowing more freedom (e.g., going to a party, staying home alone) and providing enough boundaries. Some parents of children with ASD spontaneously mentioned to use autonomy-thwarting parenting behaviors, such as harsh disciplining techniques or punishment, as a response towards challenging child behavior or because they felt stressed-out. However, these parents also mentioned that they realized that these techniques often had the opposite effect and resulted in more behavior problems, because their child was not able to link the punishment to its actions or because the behavior was not intentional. Parents of children with ASD also described unsuccessful experiences when stimulating their child's social development (e.g., inviting peers at home, encouraging their child to start a new hobby), because their child felt overstimulated, misunderstood, or got into a conflict. Some parents of children with CP also described feeling frustrated or tired to motivate their child to engage in therapy, to do (daily) exercises, or to use assistive devices or night orthoses because their child found it monotonous, redundant, or even painful. Parents of children with DS especially felt uncertain to give their child more independence because they worried that something might happen to their child.

Within each group, parents also described struggles to be *responsive* towards their child's needs. For parents from the reference group, these struggles especially occurred when their child did not open up about peer-related issues that made the child feel sad or excluded (e.g., feeling insecure, an unanswered crush, bullying).

> *"As a parent, I find that very hard to deal with. Because you know, adolescents, adolescent girls, they can be very hard on each other. She has to solve those things for herself, while I try to give a little guidance, but it's very difficult to get a grip on that."* (Mother of J., girl without any known disability)

Several parents of children with a NDD felt uncertain or powerless in how they could support their child in the process of accepting their disability and its consequences. These parents stated that their children became more aware of their own disability during puberty, as they increasingly started to compare themselves with peers and started questioning why they needed additional support or a specialized school trajectory. A number of parents found it difficult to deal with their child's feelings of *"not wanting to be different"*, which sometimes resulted in depressive feelings or protest against additional support (e.g., not wanting to wear visual supports such as splits, refusing to participate in therapy). Some parents of children with ASD hypothesized that their child had a great awareness of 'being different' because their child's intellectual functioning matched that of peers without ASD or because their child is highly intelligent. Several parents of children with ASD also mentioned struggles to act responsively when they were confronted with challenging child behavior (e.g., aggression or withdrawal) or felt uncertain about whether their child's behavior related to the child's personality or was rather disability-specific.

> *"Sometimes it's difficult to distinguish: "Is this about the character? Is it autism? Is it about temperament?" A mixture, I think, as within every person, and hence also in children with autism."* (Mother of B., boy with ASD)

Some parents of children with CP and DS found it especially hard to be responsive towards their child's feelings and thoughts when their child was limited in their verbal and/or nonverbal communication.

Concerning *competence-supportive parenting behaviors*, several parents in each group reported challenges in setting clear and attainable boundaries. For parents from the reference and the ASD-group, this was mainly related to activities such as doing homework or using electronic devices. More specifically, whereas many parents from the reference group struggled to limit the use of mobile devices and social media, parents of children with ASD worried about their child's excessive gaming behavior. Additionally, parents of children with DS described struggles relating to their child's 'excessive' social behavior. For example, some parents talked about worries they had about their child interacting 'inappropriately' towards strangers. Parents of children with a NDD described additional challenges in being stringent since they acknowledged their child's daily and intensive efforts to keep up with the demands of society. For instance, many parents of children with ASD indicated that their child often felt overstimulated or frustrated after a day at school, because he/she pushed him/herself to act 'socially-desirable' (e.g., being social, achieve high grades) or to prevent exhibiting stereotype behaviors. Consequently, some parents 'allowed' their child to release their tensions in a safe home environment, through tantrums or 'wild' behavior. Similarly, some parents of children with CP mentioned they sometimes *"took over"* to offer their child some breathing space although they knew their child was able to do a certain task independently.

Relying on need-supportive parenting behaviors. Across groups, many parents described competence-satisfying experiences when they were able to encourage their child's *autonomy*, by creating an open atmosphere, fostering their child's skills, or including their child in decision making. For many parents of children with ASD, it was vital to offer their child a meaningful rationale (e.g., explaining the causes and consequences of people's actions, clarifying social rules) to facilitate their child's understanding of the world and to lower barriers for interaction with others.

Across all groups, parents tried to support their child's need for *relatedness* by making their child feel secure and loved. To do so, they offered warmth, tried to be emotionally and physically present, or responsive towards their child's feelings. Several parents indicated that, over time, they felt more competent because they were able to better read their child's emotional state, recognized subtle indications of relatedness, or found other successful ways to communicate with their child (e.g., through body language, gestures, visualizations).

> *"I think he understands that I understand him. We have like an unspoken bond, he doesn't have to explain things in so many words. I will notice if something is wrong."*
> (Mother of S., boy without any known disability)

Several parents of children with a NDD also intentionally payed more attention towards their child's socio-emotional functioning, instead of their child's chronological age to better tailor to their child's needs and living environment. Parents of children with ASD even proactively tried to avoid stressful situations or reactively stayed calm to regulate their child's emotions, for example with emotion thermometers or visualizations, when their child felt overstimulated. Some parents of children with ASD also intentionally underlined their child's positive behavior, regardless of how small these positive actions appeared to be, since their child already faced a lot of remarks during the day due to non-intentional negative or 'inappropriate' behaviors. For parents of children with DS, being patient was a vital factor in their life as they acknowledged that their child needed more time and repetition to understand things or to reach certain milestones.

Across all groups, many parents tried to support their child's need for *competence* by providing structure, clear communication and rules, and creating a context in which their child had possibilities to experience success. Several parents from the reference group felt proud and respected when they were able to set clear rules and their child adhered to it. For many parents of children with ASD, it was especially important to provide structure and predictability, through clear daily routines, visualization, time schemes, and consistent rules, to relieve stress in their child and to facilitate smooth family functioning. Parents of children with a NDD also consciously formulated achievable goals or adjusted tasks according to their child's abilities so that it was more feasible for the child to meet them. As several parents of children with CP often received a negative or uncertain prognosis about their child's developmental possibilities, certain successes or achievements (e.g., being able to ride a bike, talking clearly) felt very rewarding and strengthened the parents' belief in themselves and their child.

Integration of the parental role: Struggling to accept versus Adjusting aspirations

Across groups, parents' perspectives indicated that becoming a parent changes one's identity. For many parents of children with a NDD, *"the process of accepting being a parent of a child with a disability"* affected their feelings of competence. Whereas some parents were confronted with ongoing struggles in their new parental role, many parents described feeling satisfied about the new objectives they had about themselves, their child, and family life.

Struggling to accept. Some parents of children with a NDD reported ongoing difficulties in accepting their parental role because they felt guilty (e.g., due to difficulties during the delivery process) or sad about giving up future aspirations for themselves (e.g., traveling, professional career) or their child (e.g., living independently, having a family). Some of these parents even felt disenfranchised because they were *"stuck"* or *"forced"* into a certain parenting role, which they did not want or which felt unnaturally (e.g., providing lifelong intensive care, being very structured, overprotective, disciplining).

> *"He makes me being a mom that I actually don't want to be. I have to keep setting boundaries all the time and play the referee in different situations. It made me change as a person (...) I dreamed of a harmonious family. For a long time, I have blamed him a bit for the fact that he is what he is, which kept my life from going the way I wanted it to."* (Mother of J., boy with ASD)

> *"Saying goodbye to a future perspective is the hardest part. My son is going to make his way, he will get married, have children, will be able to live alone. With her, I had the same hopes until she was 5 to 6 years old, but then, every day again you think "that is no longer possible, and that is no longer possible, and that won't be the case either". Every time it's just saying goodbye to ordinary things."* (Mother of J., girl with CP)

Adjusting aspirations. The majority of parents raising a child with a NDD mentioned they were able to let go of certain aspirations and created adjusted expectations for themselves and their family life. Consequently, they felt more confident about their role as a parent and their parenting processes. Several parents of children with a NDD mentioned that the time and context where they received their child's diagnosis played a vital role in doing so. For many parents of children with ASD, the diagnostic process was complex, emotionally exhausting, and time-consuming, and encompassed feelings of not being heard or taken seriously. For several of these parents, the ASD diagnosis felt as a relief, strengthening their position as a parent since it provided an *"explanation"* or *"guide"* for the experienced difficulties and how to handle them, and assured an *"entrance ticket"* for professional support.

> *"Our eyes really opened up because of that diagnosis and by actually delving into it. Doing so, we understand how he thinks and why he thinks like that. And that is very instructive."* (Mother of S., boy with ASD)

Parents of children with CP and DS mentioned that their acceptance process started quite early as the diagnosis was often given quite shortly after their child's birth, which gave them more time to process their living situation (up to the time of the interview). Parents who consciously chose to raise a child with DS after prenatal screening results, described less feelings of loss and less clear expectations about their parental role or future objectives.

External support: Facing versus Overcoming barriers

Although parents from each group described competence-related experiences regarding the provision of external support, this theme was more prominent among parents raising a child with a NDD.

Facing barriers. Especially parents of children with a NDD described practical (e.g., transportation, combination with other tasks), financial (e.g., expensive consultations), and structural barriers (e.g., waiting lists, exclusive school trajectories) in providing support tailored to their child, which made them question their competence as a parent. Some parents specifically described feelings of stress and uncertainty about choosing 'the right' school trajectory (e.g., regular or specialized) or finding solutions for their child's enduring medical or emotional problems (e.g., eating, sleeping, anxiety problems). Some parents of children with CP even felt powerlessness or guilty when they were not able to ameliorate the physical and emotional pain of their child after medical procedures or while wearing devices such as splints.

> *"I still feel 'if only I could take over'. Very often I would shed a tear. Why did that have to happen to her? I would have preferred it to happen to me, but unfortunately, we cannot change that."* (Mother of L., girl with CP)

Overcoming barriers. In each group, several parents described feeling competent when the support they organized paid off and helped their child move forward in life. Whereas parents from the reference group especially appreciated the support from school or youth movements, parents of children with a NDD mainly described competence-satisfying experiences concerning professional care providers. For many of these parents, different kinds of external support not only stimulated their child's development but also – and many parents emphasized this as most importantly – it gave them some time to breathe. Parents of children with ASD especially felt strengthened when at-home counseling helped them to creatively look for solutions or to better understand challenging child behaviors.

The future: Uncertainty versus Confidence

Although especially parents of children with a NDD described feelings of uncertainty about their child's future, in each group, several parents also mentioned feeling confident and positive about the future of their child.

Uncertainty about the future. Whereas parents from the reference group especially worried about their child’s schooling and ability to stand up for themselves, parents of children with a NDD expressed uncertainties in diverse domains, such as their future supporting power (e.g., whether they would keep up taking care of their child), their child’s social-communicative or physical development (e.g., making friends, taking public transportation independently), social relations (e.g., having a partner or family of their own), future career (e.g., having a job), and the management and continuity of adjusted care for their child (e.g., housing, education, financial support) especially when the parent would pass away. Parents of children with CP expressed the most worries about the future and six parents even described *“the lifelong uncertainty and its responsibility”* as the greatest challenges in raising their child.

Confidence in the future. Notably, in each group, several parents were convinced that their child would find his/her way in life. Most of these parents tried to live in the moment (e.g., to take every day as it comes) and avoided worrying too much. Although this theme was mentioned in each group, it was more prevalent among parents from the reference group.

6.4 Discussion

The current qualitative study examined the experiences of parents raising a child with ASD, CP, DS, and without any known disability, analyzing parents’ spontaneous responses to two open questions. The SDT-framework (Deci & Ryan, 2000) was applied to structure parents’ perceived challenges and opportunities in their need for autonomy, relatedness, and competence. By differentiating between these three needs in each group, we aimed to identify both overarching and group-specific (sub)themes in order to provide guidelines for parenting support and to enhance parents’ well-being. Moreover, the innovative comparative design allowed us to process and compare a large amount of data in a similar way, and to compare parents’ perspectives across three diverse NDDs and a reference group. However, these group differences must be interpreted carefully and, above all, must be regarded as tentative since the qualitative comparison is confined to the interpretations of the research theme. Nevertheless, the prominence and saliency of themes seemed to differ across groups.

Similar experiences across groups

In line with SDT’s universality claim (Deci & Ryan, 2000), all parents stated that raising a child entails both challenges and opportunities with regard to their need for autonomy, relatedness, and competence. Importantly, the different groups reported a similar amount of need-satisfying experiences. This observation highlights that although parents of children with a NDD face regular challenges, they also experience a broad array of meaningful positive experiences. Moreover, parents showed to be eager to mobilize resources to help their child, and resilient to adjust their hopes and aspirations for themselves and their family (Van Riper, 2007). Also relatedness-satisfying experiences regarding the parent-child relationship were equally distributed across groups. This finding corroborates with previous research indicating that the challenges associated with a child’s disability can also make the parent and child grow closer to each other (Björquist et al., 2016; Ooi et al., 2016). Despite studies suggesting that partner relationships among families of children with a disability can be more strained (Davis et al., 2010; DePape & Lindsay, 2014; Myers et al., 2009), the findings in this study revealed no clear group differences in relatedness frustration regarding the partner relationship. With regard to parents’ need for competence, parents from each group mentioned feeling proud or strengthened when their parenting behaviors matched their child’s needs, indicating that parents' competence-related experiences and parenting behaviors are highly intertwined (Dieleman, Moyson, et al., 2018; Dieleman, Van Vlaenderen, et al., 2019). Interestingly, parents’ spontaneous speech samples demonstrated that parents from each group relied on similar parenting behaviors to support their child’s needs. For instance, in each group several parents tried to support their child’s need for relatedness by offering warmth, showing empathy, and being emotionally and physically present. This finding corroborates with the results from a recent quantitative multi-group study among parents raising a child with ASD, CP, DS, and without any known disability, demonstrating minor differences in parent-report parenting behaviors across groups (De Clercq et al., 2019).

Group-specific findings

In addition to the shared experiences across groups, this study sheds light on three themes for which parents’ need-related experiences varied according to the presence or type of the child’s disability.

Unique and changing parent-child relationships

While the study findings support the idea that parents of children with a NDD experience more challenges in accomplishing reciprocal parent-child relationships (Van Riper, 2007; Watson et al., 2011), these challenges appeared to differ in content and intensity according to the child’s type of disability. The challenging parent-child relationship within the ASD-group corroborates Myers et al.'s (2009) qualitative study where parents of children with ASD described the impact of their child's disability on their own and families' life as *"my greatest joy and my greatest heartache"*. In other words, whereas many parents acknowledged the challenges of raising a child with ASD (e.g., stress, dealing with behavior problems, social isolation), many also found positive meaning in life (Myers et al., 2009). The intense parent-child relationship among CP-populations has been related to the rigorous support and adaptions these parents have to make, which felt intense but also caused parents to spend a lot of time with their child and to feel highly involved and important in their child's life (Dieleman, Van Vlaenderen, et al., 2019; Huang et al., 2010). The observation that many parents of children with DS described their parent-child relationship as warm and the finding that parents from the DS-group reported less need-frustrating experiences compared to the other NDD-groups might tentatively relate to what has been described as the 'Down syndrome advantage' (Skotko et al., 2011; Stoneman, 2007). Following this idea, these parents' reports of less need-frustrating experiences could be attributed to more positive personality traits and fewer maladaptive behaviors among children with DS compared to children with other developmental disabilities (Stoneman, 2007). Moreover, the positive stigma about children with DS (e.g., kind, loving, affectionate), might facilitate parents' experiences with the environment (Hodapp et al., 2019). However, both this study and previous research emphasize that the struggles of these parents should not be underestimated, as these parents also clearly describe challenges related to their personal and social life, and the broader environment (Povee et al., 2012).

Furthermore, since the study included parents of children with a specific age range (i.e., emerging adolescence), the findings revealed some development-specific experiences. For instance, parents' experiences demonstrated a dynamic character, showing that parents' perspectives are strongly embedded in a specific time frame of changing parent-child relationships. Among parents raising a child with a NDD, the child's transition into adolescence encompassed additional challenges as the child's social-communicative, physical, or cognitive abilities hindered opportunities to disclose changes that the adolescent encountered or to solicit advice, information, and comfort from their parents. Especially within families raising an adolescent with CP, the adolescent's increased strive for independence showed incompatibility with the strong physical dependency and hence might complicate their child's adherence to therapy and daily exercises (Holmbeck et al., 2002). In line with previous research, our findings demonstrated that during the transition from childhood to adolescence, parents of children with a NDD might experience more feelings of grief because they realize that certain milestones will not be reached or because it is hard to support their child in dealing with 'being different' (Hamilton et al., 2015).

Facing barriers to belong

In line with previous studies (e.g., Altiere & von Kluge, 2009; Cuskelly & Gunn, 2003; Dieleman, Van Vlaenderen, et al., 2019; Myers et al., 2009; Sipal et al., 2010; Skotko et al., 2011), our findings indicated that raising a child with or without a NDD impacts parents' relationship with significant others, namely the child's sibling(s), their partner, friends and family, and the broader society in both positive and negative ways. Although parents' perspectives were quite similar concerning the sibling and partner relationship across groups, parents of children with a NDD mentioned consistently more relatedness-frustrating experiences regarding their social context or relationship with care providers. In line with previous studies, especially parents of children with ASD and CP mentioned they lacked social contacts due to the intense care for their child and practical difficulties limiting their possibilities to join activities with friends or families (Alaee et al., 2015; Davis et al., 2010). Whereas these social contacts were additionally hampered due to disagreements about how to deal with challenging behavior in children with ASD (Myers et al., 2009; Woodgate et al., 2008), parents of children with CP were confronted with more structural difficulties (e.g., social events that are not wheelchair-accessible) (Dehghan et al., 2015).

Also, the (in)visibility of the child's disability played a vital role in parents' and children's interactions with the broader environment. Although experiences of social exclusion or stigmatization differed according to the child's type of NDD, parents from each NDD-group described painful experiences (e.g., being stared at, pitying looks, whisperings, or laughter) indicating that these families often have to deal with judgments from others (Lalvani, 2015; Ludlow et al., 2011). These experiences also corroborate previous research among parents raising a child with ASD (Gray, 2002), indicating that the majority of these parents experience both felt stigma (i.e., feelings of shame or the fear of rejection) and enacted stigma (i.e., instances of overt rejection or discrimination experienced by stigmatized individuals). It is also interesting to notice that although parents of children with a NDD described more empowering experiences than parents from the reference group, these experiences might be particularly motivated by confrontations with societal boundaries or deficit discourses (e.g., exclusion, injustice, stigma, accessibility, ethics of prenatal screening), instead of being volitionally motivated. Within these confrontations, parents take on a 'battler role', fighting for equal rights regarding diversity and support (Altiere & von Kluge, 2009; Van Hove et al., 2009).

"Being a parent": A transformative process

Parents' perspectives highlighted that parents grow and evolve in their position as a parent. For parents of children with a disability, this transformation could not be reduced to *"learning to live with it"*, but included a set of experiences and conditions. According to Isarin (2004), conditions for such a transformation are: the ability to accept the child as it is while intending to make the best of it, the conviction that this parenthood is meaningful, building up confidence, and the ability to live with uncertainty. Our findings align with these conditions and even indicated that this process of transformation also varies depending on the specific disability of the child, the time and circumstances of the diagnosis, and the support from family, friends, and care providers (Isarin, 2004; Schuengel et al., 2009). Moreover, this process of transformation showed to be highly intertwined with how parents perceived their parental role and identity. Several parents seemed to internalize their parental role as parents' values, beliefs, commitments, and behaviors became personally endorsed and aligned with the self (Soenens & Vansteenkiste, 2011). In NDD-research, this process has been related to Bowlbys (1980) concept of resolution, since a child's NDD-diagnose may pose similar challenges of reorganization and integration for parents as experiences of loss or other psychological trauma. In line with previous research among parents of children with CP (Schuengel et al., 2009), our findings suggested that many parents resolved their reactions to their child's diagnosis at the time when their child reached adolescence, while others still expressed unresolved reactions indicated by dissatisfaction about their current life or retainment to unfulfilled dreams.

Implications for research and practice

The comparative design of this qualitative study provides a more nuanced and contextualized perspective on parents' experiences, hence enhancing rigor, credibility, and reliability of the findings (Morse, 2015). Using SDT as a theoretical framework also contributed to a systematical comparison of experiences across diverse groups, while also taking into account a more balanced approach on parenting (i.e., examining both challenging and rewarding experiences). Additionally, our findings support that the collection of spontaneous speech samples holds potential as a brief, time-efficient, yet rich informative tool for indexing naturalistic parental experiences in both research and practice (Sher-Censor, 2015). Also, since the method can be effectively administered over the phone and a limited amount of time is needed to administer the speech samples, the FMSS-method encompasses some practical benefits to quickly assess where the greatest needs and strengths are situated within a family. Moreover, the findings based on this innovative method are similar to findings that emerge from small-scaled in-depth interview studies, but allow to meaningfully integrate information from much larger samples.

In addition to research implications, this study implies multiple lessons on how practitioners and policymakers can help to better support parents' needs for autonomy, relatedness, and competence while raising a child with a disability. First, the prominence of autonomy-satisfying experiences among parents raising a child with a NDD supports an approach in practice where parents' positive experiences and the 'things that go well' are explicitly acknowledged and reinforced. Moreover, these experiences can provide valuable insight into the factors that enhance but also impede parents' resilience. For instance, when parents indicate a need to invest more time in their own interests and needs, care providers could organize (specialized) respite care, after-school care, or at-home support to give parents more 'breathing space' (Guyard et al., 2017).

Second, parents felt especially connected with care providers who treated them as equals and when care providers were attentive and non-judgmental, noticed and valued the strengths of their child, and were genuinely interested in the well-being of the child (Frye, 2016). During the whole process of diagnosis, assessment, and rehabilitation, care providers must recognize parents as valuable contributors. Moreover, they should ensure transparent and open communication since these experiences form parents' trust and confidence in professional support after the diagnostic process (Boshoff et al., 2019). Furthermore, it seems important to 'zoom out' during parent support and acknowledge the value of parents' relationships with important others: their partner, other children, friends, relatives, and the broader society. Previous studies also demonstrated that for parents raising a child with a disability, the amount of support from others, such as relatives, friends, neighbors, and care providers, is crucial for their family quality of life (Brown et al., 2003; Steel et al., 2011). When parents need a new source of relatedness, care providers could, for instance, facilitate contact with parent-to-parent peer support groups, which might also increase parents' coping abilities and decrease parental stress (Bray et al., 2017).

Third, to increase parents' feelings of competence, care providers should acknowledge parents' efforts and perseverance, their expert position about their child, and should provide information and guidance for navigating the complexity of care trajectories (De Belie & Van Hove, 2005; Frye, 2016). Setting clear boundaries regarding the use of electronic devices might also be an important theme in parent support. Especially among children with ASD, excessive gaming behavior and the many concerns of parents related to this topic requires further attention (Mazurek & Wenstrup, 2013).

Moreover, this study highlighted unique insights into the challenges that parents of children with a NDD face while supporting their child's needs. For instance, although parents of children with a disability wanted to be need-supportive, the child's attention span, communication, motor, or sensory difficulties, or 'reduced readability' (i.e., the child shows less initiative to signalize needs or to engage in social relationships) might interfere to do so (Gilmore et al., 2016; Hodapp et al., 2019). Therefore, parents might struggle to estimate the time, amount, and specificity of support their child needs or might feel they have to be more directive or constantly supervising to guarantee their child's safety (Gilmore et al., 2016). Also, as several parents indicated they struggled to interpret their child's behavior, it might be valuable to support parents to understand the functionality of their child's behavior and reflect on their own attribution style. In their book 'Positive discipline for children with special needs', Nelsen and colleagues (2011) even argued that parents should be supported to distinguish 'innocent' behaviors associated with the child's disability from deliberately 'misbehaving', as the misinterpretation of 'innocent' behaviors may elicit new challenging behaviors.

Limitations and directions for future research

Several limitations should be taken into consideration. First, our findings might be limited due to some sample characteristics as few fathers (5%) participated, plausibly only parents participated who acknowledged their child's diagnosis, and because many parents already received a form of professional care. Future research should aim to include an equal amount of fathers compared to mothers while also trying to better understand how certain socio-demographic factors (e.g., amount of support, family socio-economic status, amount of children (with a disability) in the family unit) might influence parents' perspectives. Second, we acknowledge that the current qualitative comparative design still remains a reduction of the complexity of parents' perspectives. Since every parent and every child is unique, it is highly plausible that the experiences of parents within the same group may differ more than represented. Third, it might be interesting to examine parents' perspectives from another theoretical framework than SDT. It might be particularly valuable to use a framework that comprises more societal-ecological experiences since the SDT-lens primarily operates at a micro- and meso-level. For example, future studies could apply the Health Stigma and Discrimination Framework as this framework encompasses a holistic and socio-ecological view, which includes individuals' experiences on an individual (e.g., attitudes, skills), interpersonal (e.g., family, friends, social networks), organizational (e.g., social institutions, workplaces), and policy level (e.g., national and local laws and policies) (Stangl et al. 2019). Perhaps, this framework might uncover more parental experiences with broader systems of inequality or power structures.

6.5 Conclusion

We used the lens of Self-Determination Theory to capture and compare the richness of 160 parental spontaneous speech samples about raising an adolescent with and without ASD, CP, and DS. This comparative framework allowed to meaningfully describe these 'spontaneous snapshots' in terms of need-satisfying and -frustrating experiences, illuminating overarching as well as disability-specific themes. Notably, all parents spontaneously endorsed both pains and pleasures in parenting. Even though raising a child with a NDD, such as ASD, CP, or DS, is accompanied by particular risks for frustration of parents' needs for autonomy, relatedness, and competence, many opportunities for need-satisfying experiences are uncovered. Overall, this study offers a more balanced view on the realm of parenting children with ASD, CP, and DS, highlighting the importance of parents' own psychological basic needs.

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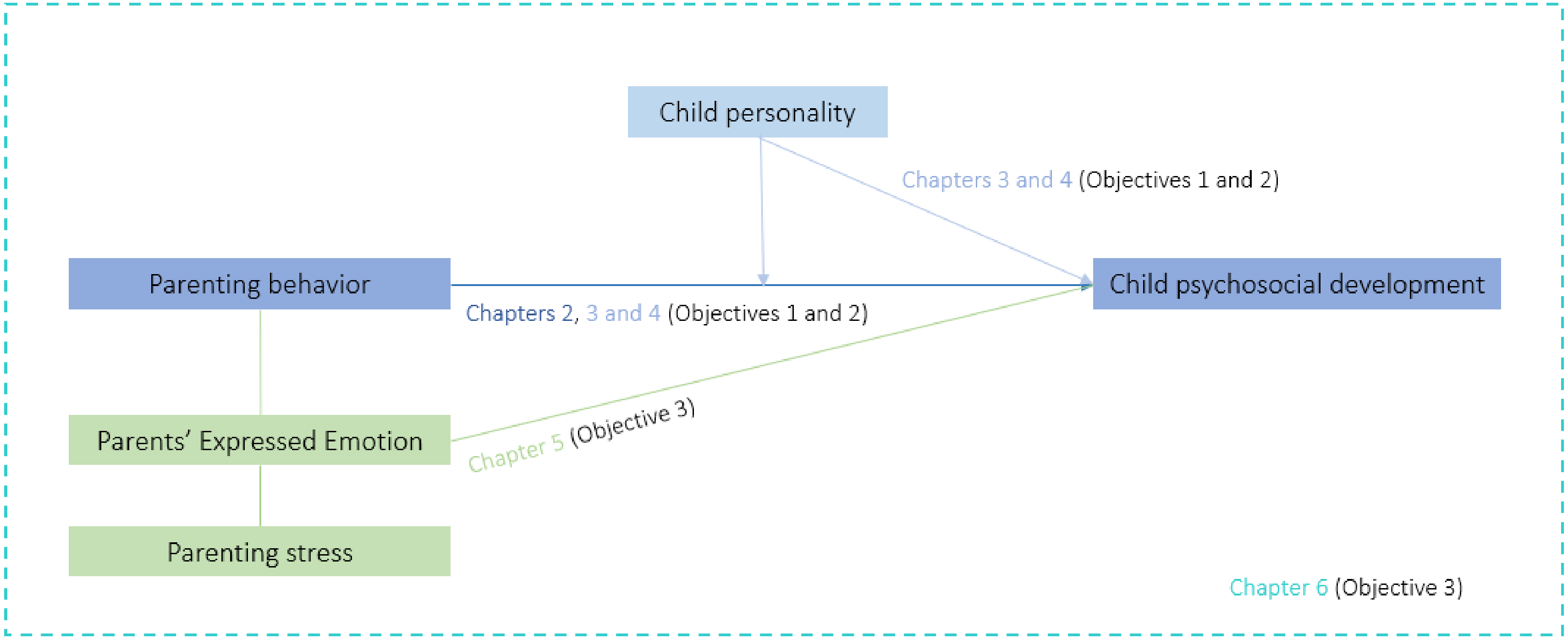
Chapter 7

General discussion

Abstract

The overall aim of this dissertation is to examine parenting practices and experiences, and children's psychosocial development across families raising a child with autism spectrum disorder (ASD), cerebral palsy (CP), Down syndrome (DS), and without any known disability (reference group). This general discussion summarizes the most salient insights from the different studies and reflects on their implications for practice, research, and policy. First, we provide an overview of the research findings based on this dissertation's three main objectives (Figure 1), while discussing the overarching findings across parent-groups. Second, we highlight some disability-sensitivities, illuminating that parents and children encounter several unique challenges and opportunities depending on the type of the child's disability. Third, we provide an outline of how the findings of this research can inform guidelines for practitioners and parents in order to enhance parents' and children's well-being. Fourth, we describe some theoretical considerations on the added value of Self-Determination Theory (Deci & Ryan, 1985; Deci & Ryan, 2000) for research on parents raising a child with a neurodevelopmental disability (NDD). Fifth, we zoom out to a macro-position and reflect on the position of parents raising a child with a NDD in a broader societal context. The final part of this discussion describes some study limitations and suggestions for future research among families raising a child with a NDD. An epilogue concludes with a more personal reflection on the research process.

Figure 1. Graphical representation of the empirical chapters



Objective 1: To examine group differences and change in the psychosocial development of children with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

Objective 2: To investigate the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

Objective 3: To explore the emotional climate, parents' affective well-being, and need-related experiences among families raising a child with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

7.1 An overview of the research findings

This section provides an overview of the main research findings and highlights the links between the findings across the different chapters. First, we summarize the findings on children's psychosocial development and look into the specific time-frame of adolescence and emerging adulthood (Objective 1). Second, we describe the unique role of parenting behaviors and child personality in the psychosocial development of children with a NDD, while also evaluating the role of the personality-by-parenting interplay (Objective 2). Third, we explore the emotional climate, parents' affective well-being, and need-related experiences, by relying on parents' spontaneous descriptions about their child, their parent-child relationship, and parental experiences (Objective 3). Throughout this section, we build a case for adopting a more balanced approach, combining both a vulnerability-based and strengths-based approach, to deepen our understanding of parenting practices and experiences and child development in families raising a child with a NDD.

7.1.1 Objective 1: Examining group differences and change in the psychosocial development of children with and without ASD, CP, or DS

The psychosocial development of children with a neurodevelopmental disability: Shared commonalities and disability-sensitivities

In general, the examination of group differences in the psychosocial development of children with ASD, CP, DS, and no disability (Chapter 2), demonstrated that children with a NDD share common vulnerabilities, but also unique behavioral and emotional profiles.

Challenging psychosocial profiles. The findings illustrated that, as a group, children and adolescents growing up with a NDD are at much higher risk to develop emotional or behavioral difficulties compared to neurotypical populations, as documented by parent reports. These findings mainly corroborate previous research on single disability groups (e.g., Bjorgaas et al., 2012; De Pauw et al., 2011; Dykens, 2007; Emerson & Hatton, 2007; Kanne & Mazurek, 2011; Maljaars et al., 2014; Munir, 2016; van Gameren-Oosterom et al., 2011). Moreover, the cross-disability approach uncovered salient differences across NDD-groups (Chapter 2). Notably, children with ASD exhibited the most challenging behavioral profile of all groups, indicated by the highest levels of internalizing and externalizing problems and the lowest scores on psychosocial strengths. This behavioral profile partly reflects diagnostic features of ASD (e.g., lower interpersonal skills), but also supports findings that children with ASD are at increased risk of developing more anxious, withdrawn, depressive as well as more rule-breaking and aggressive behaviors (De Pauw et al., 2011; Maljaars et al., 2014). In line with previous research (Parkes et al., 2008; Vrijmoeth et al., 2012), children with CP are also rated with elevated group levels of externalizing and – to a lesser extent – internalizing problems compared to children from the reference group. Also in children with DS, we found that the mean score on externalizing problems was more than twice as high compared to the reference group. Additionally, children with DS were rated with the lowest levels of internalizing problems of all four groups. These lower levels of internalizing problems among children with DS have also been reported in group comparisons with neurotypical peers (van Gameren-Oosterom et al., 2011). These may reflect a true group difference for the DS-group, but might alternatively reflect these children's challenges to express feelings of anxiety or sadness, which makes it more difficult for parents to recognize them. Notably, the retrieved behavioral profile among children with DS demonstrates that children with DS are also at increased risk to develop behavioral difficulties (Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; van Gameren-Oosterom et al., 2011), challenging the 'Down syndrome advantage' hypothesis that has long lingered in the literature and popular media on DS (e.g., Esbensen & Seltzer, 2011).

Multiple, meaningful psychosocial strengths. In addition to behavioral and emotional difficulties, Chapter 2 also addressed children's psychosocial strengths (i.e., interpersonal strengths, family involvement, intrapersonal strengths, and affective strengths) across the four groups. The findings illustrated that, in each group, parents report relatively high levels of psychosocial strengths in their children, even though relatively large group differences were found. Whereas parents of children from the reference group reported the highest levels of psychosocial strengths, parents of children with CP and DS reported similar levels, which were significantly higher compared to parents of children with ASD. Interestingly, the findings also support the value of assessing psychosocial strengths in NDD-populations by applying the BERS-2 (Epstein, 2004). Therefore, we support future studies examining psychosocial strengths, and – more broadly – to highlight strengths and resilience within these groups.

Heterogeneity in children's psychosocial functioning and parenting behaviors. In addition to the described group differences, another salient aspect of all four groups is the large variance in parents' reports of their child's psychosocial functioning. The importance of this wide diversity within each group cannot be overemphasized. It warns against creating stereotypes of children with a NDD solely based on these children's psychosocial profiles or behavioral phenotypes. Instead, from an orthopedagogical point of view, these large variances call for a consideration of the unique profile of behavioral difficulties and strengths of each child when tailoring support and interventions (Broekaert et al., 2004). The importance of acknowledging individual variance will also be further discussed when examining the personality-by-parenting interplay (Objective 2).

The transition from childhood into adolescence and (emerging) adulthood: A period that warrants attention

Furthermore, from a more longitudinal perspective, we examined whether the challenging psychosocial profile among children with ASD (Chapter 3) and CP (Chapter 4) continued over time, more specifically when children reached adolescence or (emerging) adulthood. In general, the two longitudinal studies indicated that whereas the increased behavioral and emotional difficulties among children with ASD (Chapter 3) and CP (Chapter 4) tended to continue, psychosocial strengths tended to increase, from childhood into adolescence and emerging adulthood.

Improvement in children's psychosocial development, but still elevated levels of behavioral or emotional difficulties over time. Chapter 3 evaluated the psychosocial development of children with ASD across a nine-year interval. This study generally corroborated the small body of literature, uncovering modest improvements in social communication and adaptation among youth with ASD across adolescence and emerging adulthood (Gray et al., 2012; McGovern & Sigman, 2005; Taylor & Seltzer, 2010; Woodman et al., 2015). Whereas the elevated levels of internalizing problems remained stable over the nine-year period, externalizing problems decreased in the first time period (10.1 to 16.0 years old) while psychosocial strengths increased in the second time period (16.0 to 19.0 years old). Although these findings might demonstrate a hopeful picture (i.e., fewer externalizing problems and more psychosocial strengths over time), it remains important to notice that the clinical levels of both internalizing (69.6 % at T1, 44.8% at T2, and 41.8% at T3) and externalizing difficulties (61.6% at T1, 35.5% at T2, and 21.1% at T3) remained high throughout childhood and emerging adulthood. Chapter 4 evaluated longitudinal relationships in children with CP across three waves over a two-year interval. Even though the time frame of this study was much more limited than in the ASD-group, this study also demonstrated that the levels of emotional and behavioral difficulties among children with CP changes over time, where strengths tend to moderately improve when children with CP develop into young adolescents (Brossard-Racine, Waknin, et al., 2012; Tan et al., 2014). Both internalizing and externalizing problems increased during the first time period (10.9 to 12.1 years old) and psychosocial strengths significantly increased during the second time period (12.1 to 12.9 years old).

Disability might exacerbate normative challenges during puberty. Overall, both our cross-sectional (Chapter 2) and longitudinal findings (Chapters 3 and 4) demonstrate that the age period between childhood and emerging adulthood can be considered as a pivotal period of change for both children with a NDD and their families. Although it is widely understood that puberty brings new challenges for each child (Soenens et al., 2019), our findings tend to suggest that normative challenges can be exacerbated by a child's social-communicative, motor, or intellectual disability. Interestingly, the qualitative study examining parents' perspectives (Chapter 6) gave more color and depth to these developmental pathways. For instance, for many parents raising a child with a NDD, one of the most prevailing challenges in adolescence encompasses the delicate balance between the child's strive for independence and the need for support. Attaining this balance appeared to be particularly difficult for parents raising a child with CP. During the transition from childhood to adolescence, also adolescents with CP are marked by an increased strive for independence, yet parents are used to being needed and relied upon. Searching for a new equilibrium in this phase was reported to even complicate their child's adherence to therapy and daily exercises, corroborating previous research (Holmbeck et al., 2002). Some parents reported that this difficult balance strained the parent-child relationship because the child wanted to dismiss itself from the parent but also unwillingly had to depend on the parent's care for everyday things.

Another challenge for parents raising a child with a NDD during puberty and adolescence lies within the child's increasing awareness of 'being different'. In line with previous findings, parents in our studies mentioned that – during puberty – their child tended to compare themselves more often with their peers and hence became more aware and reflective of their own capabilities and limitations (Björquist et al., 2016; Brossard-Racine, Hall, et al., 2012; Dykens et al., 2002; Parkes et al., 2008; Taylor & Seltzer, 2010). Not wanting to 'be different' often resulted in depressive feelings or protest against additional or specialized support (e.g., refusing to participate in therapy or a specialized school trajectory, not wanting to wear splits). Consequently, several parents described feelings of powerlessness and uncertainty in how they could soothe and support their child to accept their disability and its consequences during this developmental phase (Hamilton et al., 2015).

7.1.2 Objective 2: Investigating the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without ASD, CP, or DS

To better comprehend the wide variation in emotional or behavioral difficulties among children with NDDs, scholars increasingly advocate that researchers should go beyond the inquiry of 'disability-specific sources'. Instead, they call for research on 'non-syndrome-specific' or ‘transdiagnostic’ factors that naturally vary among all children (Aran et al., 2007; Chetcuti et al., 2019; McCauley et al., 2019). In particular, *parenting behavior* and *child personality* have been nominated as potential ‘non-syndrome-specific’ factors that may provide a richer understanding of the psychosocial heterogeneity in clinical samples, including youth with ASD (De Pauw, 2017; McCauley et al., 2019; Mundy et al., 2007) or CP (Aran et al., 2007).

This dissertation is one of the first to examine the role of specific parenting behaviors in addition to child personality traits in the psychosocial development of children with ASD, CP, DS, and without any known disability. This section starts by reflecting on group differences in parenting behaviors, the longitudinal continuity and change of parenting behaviors (in ASD and CP), its associations with child behavior, and the added value of Self-Determination Theory (SDT; Deci & Ryan, 1985; Deci & Ryan, 2000) in the context of parenting a child with a NDD. Next, we describe the unique role of child personality and its interactive effect with parenting behaviors in children’s psychosocial development among families raising a child with ASD and CP.

Group differences and similarities in parenting behaviors

In Chapters 2 and 5 we examined group differences in both need-thwarting and need-supportive parenting behaviors across parents raising a child with ASD, CP, DS, and without any known disability. Interestingly, the large majority of group differences in parenting can be interpreted as small to modest (except for overreactive parenting in Chapter 5, where we observed large group differences). Nevertheless, the results also suggested intriguing disability-specific aspects of parenting. In the following paragraphs, we describe this dissertation’s findings concerning three SDT-based parenting practices, namely need-thwarting, autonomy-supportive, and responsive parenting.

Need-thwarting parenting. Overall, levels of need-thwarting parenting were generally low in all groups. Parents of children with ASD or without any known disability reported the highest levels of need-thwarting parenting behaviors (i.e., psychological control, overreactive parenting), which were significantly higher than those reported by parents raising a child with CP or DS. The levels of overreactive parenting were significantly higher among parents of children with ASD compared to the reference group. Plausibly, parents of children with ASD might be more inclined to use disciplining techniques or respond with frustration, anger, or impatience towards their child because they are more frequently confronted with challenging child behavior, which might be difficult to manage (Dieleman et al., 2017; Dieleman, De Pauw, Soenens, Mabbe, et al., 2018; Dieleman, Moyson, et al., 2018). The findings concerning the DS-group corroborated previous research that observed less verbal hostility in mother-child interactions in families with a child with DS compared to a neurotypical reference group (Phillips et al., 2017). The authors related this finding to the presumed characteristic personalities among children with DS (i.e., kind, loving, affectionate). Regarding the CP-population, we found a similar observation where parents of children with CP reported significantly lower levels of need-thwarting parenting behavior compared to parents from the ASD- or reference group. Although these findings require further replication, it is also interesting to notice the variance in these parenting behaviors, indicating that parents from the same group might substantially differ in how much they rely on need-thwarting parenting behaviors, which might also vary from day to day (Dieleman, Soenens, et al., 2019).

Autonomy-supportive parenting. Parents of children with ASD and of those without any known disability reported significantly higher levels of autonomy-supportive parenting compared to parents of children with DS and – to a lesser extent – also compared to parents of children with CP. Although there is limited cross-disability research available to compare our results with, this finding could be interpreted as in line with suggestions emerging from other studies showing that parents of young children with DS tend to be more directive than parents whose children are developing without disabilities (de Falco et al., 2011; Glenn et al., 2001). However, these findings have also been contradicted as other studies found no significant differences in directiveness and autonomy-supportive parenting between parents of children with DS and a neurotypical group (Gilmore et al., 2009). Interestingly, the findings of the qualitative study (Chapter 6) shed some light on plausible hypotheses related to this finding. In line with another in-depth examination of parents' experiences (Gilmore et al., 2016), parents' spontaneous descriptions demonstrate that even though parents of children with DS held strong aspirations for their child's autonomy and independence, they often feel constrained to do so, for instance, due to concerns about their child's safety or their child's difficulties with communication or sensory issues. Also, parents of children with CP face additional challenges to support their child's autonomy, which plausibly relates to the child's physical limitations and dependency on parental support (Dieleman, Van Vlaenderen, et al., 2019).

Responsive parenting. Notably, parents of children with CP and DS reported more responsive parenting compared to parents of children with ASD and without any known disability. However, in Chapter 5 parents of children with ASD also reported significantly more responsive parenting compared to the reference group. These elevated levels of responsive parenting among NDD-populations might relate to previous findings indicating that parent-child relationships among families of children with a NDD are often described as close and intense since parents strongly attune to their child's needs for both physical and emotional support (Dieleman, Van Vlaenderen, et al., 2019; Whittingham et al., 2013). The qualitative findings in Chapter 6 lend support to this hypothesis, for instance, since parents of children with CP mentioned that the large amount of time they spend together with their child, due to the enduring intensive practical and emotional support, brought them closer together and created a feeling of indispensableness. The higher levels of responsive parenting in the DS-group corroborates Blacher et al.'s (2013) suggestion that children with DS may evoke more positive parenting behaviors than children with other disabilities given the presumed more positive personality characteristics in DS (i.e., being cheerful and friendly), yet this hypothesis was not confirmed in our results regarding autonomy-supportive parenting. However, it should be noted that Blacher et al.'s (2013) study was based on a more limited sample of ten mothers of children with DS.

To date, the general parenting research supports the rather one-sided understanding that, as a group, parents of children with a NDD are at risk to adopt more frequently pressuring or dysfunctional (i.e., need-thwarting) parenting strategies compared to neurotypical populations (Dieleman et al., 2017; Heinonen & Ellonen, 2013; Hibbard & Desch, 2007; Myers et al., 2009; Sikora et al., 2013; Totsika et al., 2014). However, our multi-group and more balanced design highlights a more nuanced and differentiated picture illustrating that parents of children with a NDD also intensively and persistently engage in need-supportive parenting behaviors despite the challenges they face.

Continuity and change in parenting behaviors

To date, very limited longitudinal evidence is available on parenting in NDD-groups. The longitudinal examination of parenting behaviors among parents of children with ASD (Chapter 3) and CP (Chapter 4) uncovered no significant within-person change across time, suggesting that parents show, on average, relative stability in the way they interact with their child.

Few changes in parenting behaviors. More specifically, externally controlling parenting among parents of children with ASD and CP, and autonomy-supportive parenting among parents of children with CP remained stable across a nine-year and two-year period, respectively. Although these findings are in line with few studies in ASD-populations (based upon the FMSS-proxy of Expressed Emotion; Bader & Barry, 2014; Greenberg et al., 2006), the broader developmental literature suggests that controlling parenting across adolescence and emerging adulthood tends to – at least slightly – decline (Desjardins & Leadbeater, 2016). It remains plausible that the current methodological design did not have sufficient power to tap into more fine-grained developmental changes.

Substantial intra-individual differences. Importantly, however, the two longitudinal studies in ASD and CP emphasize the substantial variation in intra-individual changes in parenting behaviors, indicating that parents differ in how their parenting behavior changes across time. These long-term longitudinal findings also parallel recent diary findings (hence on a shorter term) among parents of children with CP. In this study, it was found that the degree to which parents are autonomy-supportive and controlling towards their child can vary considerably on a short time interval, that is from one day to the other (Dieleman et al., 2020). Notably, several SDT-grounded diary studies suggested that this daily variation in controlling or autonomy-supportive behaviors among parents raising a child without any known disability (Mabbe, Soenens, et al., 2018; Van der Kaap-Deeder et al., 2017), ASD (Dieleman, Soenens, et al., 2019), or CP (Dieleman et al., 2020) was nurtured by parents' own frustration or satisfaction in their needs for autonomy, relatedness, and competence. Accordingly, these findings pointed to the underlying mechanisms of experienced vitality and stress as important sources of daily variation in parenting (Dieleman et al., 2020; Van Der Kaap-Deeder et al., 2019).

Associations between parenting behaviors and children's psychosocial development

In this dissertation, we additionally examined how these need-thwarting and need-supportive parenting behaviors related to child psychosocial outcomes. These associations were both studied cross-sectionally among parents raising a child with ASD, CP, DS, and without any known disability (Chapter 2) and longitudinally among parents raising a child with ASD (Chapter 3) and CP (Chapter 4). In line with hypotheses derived from SDT (Deci & Ryan, 2000), both the cross-sectional study and longitudinal work tend to support two pathways: an unfavorable association between need-thwarting parenting and maladaptive outcomes on the one hand, and a beneficial link between need-supportive parenting and beneficial outcomes on the other hand.

Need-thwarting parenting-maladjustment associations. Regarding the first pathway, the multi-group, cross-sectional approach in Chapter 2 illustrates that parenting-maladjustment associations not only occur in neurotypical populations, but also apply to the context of raising a child with ASD, CP, or DS. More specifically, the findings show that psychologically controlling parenting was related to more externalizing child behaviors in each group. Interestingly, this need-thwarting parenting-maladjustment association is also replicated in the longitudinal associations among families of children with ASD and CP. Both studies demonstrate that initial levels of need-thwarting parenting (i.e., externally controlling parenting in Chapters 3 and 4) relate to initial levels of externalizing child behavior across a nine-year period in youth with ASD and across a two-year period in youth with CP (note, however, that this relation did not remain significant after Bonferroni-correction in the CP-sample). In line with previous cross-sectional and longitudinal work among ASD-populations (e.g., Boonen et al., 2014; Lindsey et al., 2020; Maljaars et al., 2014; Ventola et al., 2017) and neurotypical populations (Pinquart, 2017a), this association signifies that also children with a NDD are more likely to engage in aggressive or rule-breaking behavior when parents rely on harsh disciplining or pressuring behaviors. However, it is also important to mention that the statistical designs included in these longitudinal studies (i.e., latent change modeling) cannot address the direction of these effects. As relations between child and parenting behavior are fundamentally transactional in nature (Dieleman et al., 2017; Taraban & Shaw, 2018), these findings may alternatively suggest that parents of children with more externalizing behaviors tend to rely on more controlling parenting behaviors as a response to more frequent externalizing behaviors. Although these longitudinal associations were not examined within the DS-population due to sample and time constraints, we expect similar associations based upon the cross-sectional data. Based upon these findings, we suggest that need-thwarting parenting might be regarded as threatening for all children's psychosocial well-being and/or that externalizing child behavior might be regarded as threatening for parents' need-supportive behaviors, irrespective of the presence or specificity of a child's disability.

Furthermore, the longitudinal findings also demonstrated that change in parenting behavior relates to change in children's psychosocial development. More specifically, change in externally controlling parenting was positively associated with change in externalizing problems among youth with CP (Chapter 3), which remained significant after Bonferroni-correction in the second time period, but not in the first time period. This association was not observed in the ASD-population, which encompassed a six-and a three-year interval (Chapter 2). Possibly, this association could have been detected when a shorter time interval was used, for instance on an annual, monthly, or even daily basis (Dieleman, Soenens, et al., 2019; Mabbe, Vansteenkiste, et al., 2018). To our knowledge, one study provided some support for this hypothesis in ASD-families, relying upon the FMSS proxy of Expressed Emotion, documenting that higher levels of parental Criticism (i.e., expressions of dissatisfaction about the child or the parent-child relationship) predicted an increase in children's externalizing behaviors two years later (Bader & Barry, 2014).

Notably, only the longitudinal study among families of children with CP (Chapter 3) showed associations between need-thwarting parenting behaviors and internalizing child problems, where change in externally controlling parenting was positively associated with change in internalizing problems during the first time period. This finding corroborates previously documented associations between controlling parenting and internalizing child behavior in CP-populations

(Crandell et al., 2018) and neurotypical populations (Mabbe et al., 2019; Pinquart, 2017b). However, since the initial levels of these constructs were not significantly related, the findings suggest that especially an increase – rather than high initial levels – of externally controlling parenting behavior are associated with more internalizing problems in youth with CP. In light of these findings, it is somewhat surprising that the cross-sectional study in Chapter 2 did not retrieve a significant relation between psychological controlling parenting and internalizing problems. Particularly since it has been suggested that more subtle and covert types of parental control (Chapter 2), instead of the blunt and more overt type of external control (Chapter 3), may more strongly relate to internalizing problems since these parenting behaviors create more inner conflicts and distress (Soenens & Vansteenkiste, 2010). Perhaps this lack of replication might be due to the use of parent report for both constructs, given that internalizing problems sometimes remain less noticed by parents (van de Looij-Jansen et al., 2010).

Need-satisfying parenting-adjustment associations. Regarding the second pathway, the multi-group, cross-sectional approach in Chapter 2 also illustrates that parenting-adjustment associations not only occur in neurotypical populations, but also apply to the context of raising a child with ASD, CP, or DS. More specifically, the findings showed that both autonomy-supportive and responsive parenting are associated with more psychosocial strengths in each group. This parenting-adjustment pathway was also examined longitudinally among youth with CP in Chapter 4 (but not among children with ASD in Chapter 3) and retrieved findings corroborating SDT-premises and previous suggestions among CP-populations (Aran et al., 2007; Crandell et al., 2018; Deci & Ryan, 2000; Elad et al., 2018). More specifically, initial levels of autonomy-supportive parenting related substantially to initial levels of children's psychosocial strengths. Taken together, these findings suggest that children feel more encouraged to show and develop their psychosocial strengths when parents stimulate their child, stay attuned to their child, and respond in a warm and sensitive way. Also, the recognition of the child's psychosocial strengths might in turn provide parents with positive and energizing feelings to further engage in need-supportive parenting. This hypothesis is further supported by the qualitative findings of this dissertation (Chapter 6) suggesting that the positive effects of parents' need-supportive behaviors not only strengthen the parents' belief in their competence as a parent but also foster a more positive parent-child relationship. Interestingly, neither the cross-sectional nor the longitudinal designs found significant associations between need-supportive parenting behaviors on the one hand, and behavioral or emotional problems on the other hand. Therefore, our findings support the idea that positive parenting might play a more prominent role in fostering positive outcomes rather than in protecting against maladaptive outcomes (Vansteenkiste & Ryan, 2013). Also, from a more transactional point of view, it might be plausible that behavioral or emotional problems especially trigger need frustration in parents, causing them to more easily rely on need-thwarting behaviors, rather than to adopt less need-supportive behaviors.

In sum, this dissertation's cross-sectional and longitudinal findings provide unique evidence for SDT's universality claim, stating that *"all children need to feel competent, autonomous, and loved"* (Deci et al., 1992), including children growing up with special needs. More specifically, the cross-sectional and longitudinal associations indicate that whereas need-thwarting parenting relates to unfavorable outcomes, need-supportive parenting associates with more beneficial outcomes, for children with ASD, CP, DS, and without any known disability alike.

Associations between child personality and child behavior

In addition to parenting behavior, child personality is increasingly nominated as a potential 'non-syndrome-specific' factor that may provide a richer understanding of the psychosocial heterogeneity among youth with a NDD (De Pauw, 2017; McCauley et al., 2019; Mundy et al., 2007). In Chapters 3 and 4, we also examined the unique and additive role of child personality in the psychosocial development of youth with ASD and CP. Overall, these findings illustrated that children's unique individuality in how they behave, think and feel, plays an important role in the development of behavioral or emotional problems as well as psychosocial strengths in both youth with ASD and CP.

Child personality – maladjustment associations. Lower Extraversion and Emotional Stability were associated with higher initial levels of internalizing problems, and lower Benevolence and Emotional Stability were associated with higher initial levels of externalizing problems in both youth with ASD and CP. These findings are in line with the well-documented associations in the broader developmental literature (De Pauw & Mervielde, 2010; Prinzie et al., 2010) and also support prior research findings among children with ASD (McCauley et al., 2019) and CP (Vrijmoeth et al., 2012). In other words, the findings revealed that also children with ASD or CP who have lower self-confidence or are more easily upset (i.e., lower Emotional Stability) might be more at risk for anxiety problems or withdrawal but also to exhibit aggressive or rule-breaking behavior. Also, children who can be described as less sociable, expressive, and energetic (i.e., lower Extraversion) might be more at risk to experience more anxiety and withdrawal, and children who can be described as less kind, considerate, empathic, generous, and protective of others (i.e., lower Benevolence) are more likely to exhibit aggressive and rule-breaking behavior. Interestingly, among youth with CP, lower Benevolence was also related to higher initial levels of internalizing problems, and lower

Conscientiousness was related to higher initial levels of externalizing problems. This latter association was also observed in the first time period in the ASD-population, and corroborates previous research in neurotypical associations (De Pauw & Mervielde, 2010; Mervielde et al., 2006; Prinzie et al., 2004). In line with studies among neurotypical populations (e.g., Prinzie et al., 2004; Slobodskaya & Akhmetova, 2010), higher Extraversion among youth with ASD was also associated with higher initial levels of externalizing problems.

Child personality – adjustment associations. Notably, child personality was also associated with more child psychosocial strengths in both the ASD- and CP-population, indicating that personality can also function as a source of resilience. In both populations, higher scores on Benevolence and Extraversion were significantly related to higher initial levels of psychosocial strengths (yet only in the transition from 16 to 19 years old in the ASD-population), which is in line with previous findings in neurotypical populations where both personality traits have been associated with more adaptive outcomes, such as health and well-being (Anglim et al., 2020; Hill & Roberts, 2016). Moreover, in the CP-population, also higher scores on Conscientiousness, Imagination, and Emotional Stability related to higher initial levels of psychosocial strengths. Whereas the association with Conscientiousness and Emotional Stability has been previously reported in neurotypical populations (Anglim et al., 2020), the association with Imagination might be more CP-specific. Perhaps, children with CP who display more curiosity and creativity (i.e., higher Imagination) might immerse themselves more strongly in interpersonal relationships, which may lead to the development of stronger affective and interpersonal skills. Within the ASD-population, we also found two time-specific significant associations between child personality and change in the outcome variable. More specifically, higher scores on Extraversion at the mean age of 10 years old related to a decrease in internalizing problems during their transition to 16 years old, and children with higher scores on Benevolence at the mean age of 16 years old experienced an increase in their psychosocial strengths during their transition to 19 years old. Within the CP-population, we found no significant associations between child personality and change in the outcome variable (after Bonferroni-correction), which might be related to the shorter time interval (i.e., two-year interval).

Taken together, the similar personality-(mal)adjustment associations between the NDD-groups and neurotypical populations can be interpreted as lending support to the theory that personality variation can be regarded as a ‘transdiagnostic’ or ‘non-syndrome-specific’ modifier (Chetcuti et al., 2019; Mundy et al., 2007). Moreover, these findings indicate that personality-(mal)adjustment associations cannot only provide tools for identifying children with ASD or CP at risk for developing emotional or behavioral problems but is also valuable to identify ‘resilience processes'. Simultaneously, however, our findings also illustrate some unique personality-(mal)adjustment associations, which were not previously documented in neurotypical populations. Consequently, these findings provide a reply to the criticism sometimes leveled against research on personality-psychopathology associations. This criticism is based on the assumption that there is conceptual confounding between child personality and behavior problems as well as a risk for item-overlap in the assessment of both types of constructs (De Pauw et al., 2009; Rothbart & Bates, 2006). Although some conceptual overlap between these constructs is theoretically to be expected because personality contributes to the development of behavior problems (Bates, 1990), our findings support the idea that these constructs are conceptually more different than alike (De Pauw et al., 2009; Lengua et al., 1998; Prinzie et al., 2005; Shiner & Caspi, 2003). If associations between these constructs would be driven entirely by item-overlap, unique associations related to the ASD- or CP-group would be unlikely to occur. Consequently, our results suggest that the examination of personality-(mal)adjustment associations might provide interesting insight into the psychosocial development of children, including children with a NDD.

The role of personality-by-parenting interactions on children's psychosocial development

In addition to the recognition that both child personality and parenting are implicated in children's psychological functioning, there is also increasing attention to examine the interplay between these two 'spearhead domains' (Lengua et al., 2019). More specifically, it has been suggested that children differ in how sensitive they are to their social environment, and specifically to parenting practices, based upon their constitutional make-up (e.g., in their personality). Although this research avenue on personality-by-parenting interactions has been intensively studied among neurotypical populations in the past decades, little attention has been paid towards these processes among children with NDDs. In Chapters 3 and 4, we therefore examined the role of personality-by-parenting interactions on the psychosocial development of children with ASD and CP.

Child personality moderates parenting-child adjustment associations. In the ASD-population, we identified three interaction effects, indicating that children with less mature personality traits (i.e., lower Emotional Stability, Benevolence, or Conscientiousness) show more externalizing problem behaviors in the presence of externally controlling parenting compared to children with higher scores on these personality traits. These interactions corroborate previous research in non-ASD populations, uncovering that effects of controlling parenting are more pronounced among children who are rated as less resilient or less agreeable in personality (Mabbe et al., 2016; Meunier et al., 2011; Van Leeuwen et al., 2004). On the one hand, these findings might suggest that children with ASD with lower scores on these traits have fewer abilities to cope effectively with an environment that is experienced as controlling or pressuring. On the other hand, these findings might also illustrate that parents are more likely to address high levels of externalizing problems with controlling parenting as they might experience more concerns about their child or feel a stronger need to control their child's behavior. Alternatively, it is also possible that children with higher scores on these traits have more positive interactions with others that further diminishes the unfavorable effect of externally controlling parenting (Prinzie et al., 2003) or that these children might be less likely to interpret a potentially controlling environment as intrusive or pressuring (Mabbe et al., 2016). In the CP-population, one interaction effect remained after Bonferroni correction, corroborating previous research indicating that children lower in Emotional Stability are more sensitive to the effects of their environment compared to children higher in Emotional Stability (Bates & Pettit, 2015). More specifically, among children who can be described as anxious or have lower self-confidence (i.e., lower Emotional Stability) change in externally controlling parenting was negatively associated with change in internalizing problems in the second time period, but this association was not significant among youth with higher Emotional Stability. This finding suggests that when children go through a period in which they temporarily exhibit more internalizing problems than usual, parents might be less controlling, especially when children are more vulnerable. Plausibly, these parents may have already experienced that in times of internalizing problems, children with lower Emotional Stability do not benefit from increasing the pressure, and so they might give their child some breathing space. Aunola et al. (2013) observed a similar effect on a daily level among parents raising a child without a disability, where parents reduced their use of psychological control when their child showed more depressive symptoms than usual, as reported in a diary study.

Evidence for both the vulnerability and resilience model. Taken together, our findings can be interpreted as providing evidence for both the vulnerability and resilience model (Caspi & Shiner, 2006). While lower Emotional Stability, Benevolence, and Conscientiousness seem to indicate vulnerability and heightened sensitivity, higher Emotional Stability, Benevolence, and Conscientiousness might be regarded as resilience factors against externalizing behaviors in the presence of controlling parenting among children with ASD. However, in the CP-population, the findings are less straightforward. The puzzling findings indicated that although children with CP and lower Emotional Stability seem to be at risk to experience elevated levels of both internalizing and externalizing problem behaviors, parents of those children also tend to be less controlling when their child temporarily exhibits more internalizing problems than usual. In line with previous findings among neurotypical populations (Belsky & Pluess, 2016; Slagt et al., 2016) and the general literature on sensory processing sensitivity (Aron & Aron, 1997; Greven et al., 2019), our findings suggest that especially the personality trait Emotional Stability might be an important individual characteristic that influences a child's sensitivity towards the environment. More specifically, our findings suggest that children with ASD or CP, who score lower on self-confidence, often doubt their abilities, or tend to feel anxious and tense (i.e., lower Emotional Stability), might be more sensitive towards the effects of parental behaviors. A controlling environment might awaken the affective distress to which children lower in Emotional Stability are more susceptible. In contrast, children scoring higher in Emotional Stability might be less susceptible to a controlling parenting context because of their internal sense of security and resilience (De Pauw, 2017). Alternatively, it is also possible that children with higher scores on this trait have more positive interactions with others that further diminish the unfavorable effect of controlling environments (Prinzie et al., 2003) or that these children might be less likely to interpret a potentially controlling environment as intrusive or pressuring (Mabbe et al., 2016).

Nonetheless, these findings and interpretations require further replication and should be interpreted very carefully due to our single-informant approach, our varied time intervals, and since the chosen analytical methods did not allow to examine directions of effects.

7.1.3 Objective 3: Exploring the emotional climate, parents' affective well-being, and need-related experiences among families raising a child with and without ASD, CP, or DS

To evaluate parenting practices and experiences in a more naturalistic and spontaneous way, this dissertation examines what parents say in spontaneous speech samples, relying on the Five Minute Speech Sample-method (FMSS-method; Magaña-Amato, 1993; Magaña-Amato et al., 1986).

Two multi-group comparison studies evaluated parents' spontaneous speech samples in both a quantitative (Chapter 5) and qualitative manner (Chapter 6). More specifically, in Chapter 5, we examined levels of Expressed Emotion (EE) and their association with parenting stress and parenting behaviors across families raising a child with ASD, CP, DS, and without any known disability. In Chapter 6, we analyzed a subset of the spontaneous speech samples included in Chapter 5 qualitatively, to explore parents' need-related experiences when raising their child in-depth. In this section, we integrate the findings from Chapters 5 and 6 to gain a deeper understanding of parents' affective well-being and the emotional climate among families raising a child with a NDD (Objective 3).

The family climate and parents' affective functioning: Areas that require further attention and contextualization in NDD-populations

Overall, both the cross-disability quantitative (Chapter 5) and qualitative analysis (Chapter 6) of parents' spontaneous speech samples indicated that parents of children with a NDD are at increased risk for stressed-out family climates, reporting elevated levels of parenting stress, and mentioning more need-frustrating experiences. However, both chapters simultaneously highlight that these parents also mentioned many need-satisfying experiences, emphasizing that raising a child with a NDD entails challenging, but also rewarding experiences.

Elevated levels of EE, parenting stress, and need-frustrating experiences. Results from Chapter 5 indicated that – across groups – the large majority of parents expressed low levels of EE (79.4%), which points to overall positive family climates. Nevertheless, high EE, which refers to a more stressed-out family climate, was much more prevalent among families of children with ASD (25.8%) and CP (28.4%) compared to families of children with DS (16.7%) or without any known disability (13.8%). Also, parents of children with ASD expressed much more Criticism compared to parents from the reference group and less Warmth compared to the other groups.

These group differences in EE are also in line with parents' reports of stress in diverse life domains (Chapter 5) and with their spontaneous descriptions of need-frustrating experiences (Chapter 6). Overall, parents from each NDD-group reported substantially higher levels of stress in their personal freedom (i.e., more role restriction), partner relation (i.e., more marital stress), and relatedness with their social network (i.e., more social isolation) compared to parents of children without any known disability (Chapter 5). This finding supports previous studies suggesting that raising a child with a NDD impacts parents' feelings of stress and well-being in different life domains (Peer & Hillman, 2014) and that these parents experience sufficient higher levels of parental stress compared to neurotypical populations (e.g., Gupta, 2007; Hayes & Watson, 2013).

Interestingly, the qualitative analysis of parents' spontaneous speech samples gave more color and depth to these quantitative, questionnaire-based findings of 'elevated stress'. For instance, only parents of children with a NDD spontaneously mentioned autonomy-frustrating experiences (e.g., role restriction). These experiences primarily related to restriction in these parents' self-development (e.g., parents felt restrictions to invest time in their hobbies, interest, or to pursue a professional career) and family life (e.g., parents mentioned multiple challenges to commit to or adjust family and holiday activities). Also feelings of social isolation or challenges 'to belong' were prevailing themes in parents' spontaneous speech samples. These parents particularly mentioned relatedness-frustrating experiences with family or friends when family or friends did not understand or minimized the impact of raising a child with a disability. Especially parents of children with ASD felt misunderstood when other family members or friends stated that certain difficulties (e.g., not wanting to do schoolwork, aggression) could be easily 'fixed' by parenting differently (e.g., just being stricter). Only parents of children with a NDD mentioned stigmatizing and painful experiences with unacquainted people, such as being stared or laughed at or receiving pitying or indignant looks, which increased feelings of 'being different' and feeling socially isolated.

Many challenging, yet also various meaningful positive experiences. As noted, the qualitative findings complement the previous focus on (family) stress, by illuminating that parents of children with a NDD also experience a rich scale of meaningful positive interactions with their child and environment. For instance, in each group, parents indicated that raising their child is a positive and rewarding experience, enhancing their self-development and changing their perspective on life. Especially parents of children with DS mentioned that they became more reflective, creative, or resilient when handling challenges, or developed a more down-to-earth view on life (e.g., putting things in perspective, living in the moment, enjoying *"the little things"*). Corroborating previous research, the qualitative analyses bears witness of many parents who developed close and warm relationships with their child and other members of the family unit (Björquist et al., 2016; Ooi et al., 2016; Schippers et al., 2020). Moreover, these parents seemed eager to mobilize resources to help their child and showed resilience to adapt their hopes and aspirations for themselves and their family (Van Riper, 2007).

How can we understand the construct of Expressed Emotion in the context of raising a child with a neurodevelopmental disability?

An important question in this dissertation is how we can understand the conceptual meaning of EE within NDD-populations. Therefore, we examined how EE mapped onto other, more established, constructs for assessing parent-child dynamics, such as parenting stress and behaviors (Chapter 5).

In general, our findings support the idea that the nomological network of EE-parenting stress relations is highly similar across youth with and without a disability. In each group of parents, stressed-out family climates (indicated by more parental Criticism and/or less Warmth) related to more feelings of role restriction, attachment stress, competence stress, and marital stress. Also, the associations between EE and parenting behaviors suggest that the nomological network between EE and certain parenting behaviors is highly similar across families of children with and without a disability. More specifically, positive climates were associated with more need-supportive parenting (i.e., responsive parenting), whereas stressed-out climates related to more need-thwarting parenting behaviors (i.e., psychologically controlling, and overreactive parenting) in each group.

These similar associations between EE, parenting stress, and parenting behaviors across the parent groups might tentatively suggest an explanatory mechanism that operates in a similar way within both families of children with and without a NDD. It might be plausible that parents' need frustration acts as an energetic basis for parenting stress, which feeds more need-thwarting and less need-supportive behaviors and hence cultivates a stressed-out family climate. In other words, parenting stress might be an explanatory mechanism in the association between parents' need frustration and the family climate. A similar mechanism has been described in a diary study where parental need frustration related to less daily psychological availability and more stress, which in turn related to more psychologically controlling parenting (Van Der Kaap-Deeder et al., 2019). The significant association between EE and marital stress in each group could even suggest that emotionally challenging parent-child relationships might have a spillover effect on the parent-couple relationship (Hickey et al., 2019). This effect might also act in the opposite direction, where interparental conflict might impact parents' interaction style, attitude, and emotional availability towards their child (van Eldik et al., 2020). However, it is important to mention that these are tentative suggestions, which require further research.

Taken together, we suggest that EE within NDD-populations is best conceptualized from a transactional point of view, namely that the emotional quality of a family climate is shaped by the interplay of parental characteristics, child characteristics, as well as contextual sources of stress and support (Belsky & Jaffee, 2006; Sameroff, 2009). On the one hand, elevated levels of EE could be understood in relation to child characteristics as parents might feel frustrated to cope with and manage the elevated levels of emotional and behavioral difficulties among their child (Baker et al., 2011; Greenberg et al., 2006; Griffith et al., 2015). However, the source of elevated EE might also lie within the broader social environment. For instance, the qualitative findings (Chapter 6) indicated that parents of children with a NDD more often face a lack of support, stigmatizing experiences, and structural barriers to provide adequate support for their child. Consequently, parents' might feel frustrated or misunderstood, which might impact their ability to mentalize or to be emotionally present for their child.

Therefore, in our opinion, parents' EE could be interpreted and acknowledged as parents' thoughts, feelings, and attitudes towards their child but also as parents' reflections on how child, parental, and societal factors interact with each other and shape one another. Consequently, high levels of parental Criticism can be interpreted as a parent's representation of the mismatch in the interaction between child (e.g., challenging behavior), parent (e.g., critical thinking as a response to challenging behavior, a crash of the parent's mentalizing ability), and/or societal factors (e.g., lack of support). Within practice, it might be valuable to unravel these underlying factors when parents express their thoughts and feelings towards their child and to explore how these factors impact parents' affective functioning (see further 7.3.2).

Supporting a more balanced perspective in parenting research

In general, the overarching findings of this dissertation support a more balanced perspective, illustrating that parents of children with a NDD and their children indeed encompass both aspects of 'vulnerability' and 'resilience' (De Belie & Van Hove, 2005). From an orthopedagogical point of view, the findings ask for a reconsideration of the one-sided and long-prevailing medical-psychiatric approach on individuals with a disability, where disabilities are framed as an individual problem and the 'defects' of the child and the 'inability' of the parents to cope with their life circumstances are at the forefront (De Belie & Van Hove, 2005; Nunkoosing & Haydon-Laurelut, 2011). Contrasting this belief, the current findings support a more positive and holistic perspective, in which the strengths and capabilities of children with a disability and their parents are also acknowledged (De Belie & Van Hove, 2005). For instance, in line with other research, our findings highlight that most parents of children with a NDD raise their child in a positive family climate, hence suggesting that the majority of these parents cope relatively well in handling daily challenges (Bayat, 2007; Heward, 2013; Whittingham et al., 2013; Ylvén et al., 2006), and even experience benefits to their family life (Blacher & Baker, 2007; Nurullah, 2013; Van Riper, 2007). Parents of children with a NDD did not place themselves – as in earlier versions of the labeling theory (Link et al., 1989) – in a passive 'victim position', feeling they cannot compete with the people who attach a label to their children (Van Hove et al., 2009). On the contrary, several parents of children with a NDD even used the special situation of their child to coach caregivers in a strengths-based approach of care or actively advocated for equal rights of people with a disability in society. A mother of a child with DS illustrates this as follows:

> *"Parents of children who have a disability fight for the emancipation of their child on two levels: in the positive and in the vulnerable. Positive when they stand up for the rights of their child and when they emphasize their child's capabilities. But also in their vulnerability, because they know their child needs extra care and support. You can't ignore that. It's also their right."*

Therefore, we encourage further research and practices that encompass this balanced approach illuminating both the challenges and opportunities that parents of children with NDDs experience. This balanced approach is needed to better understand the complex but fascinating reality of raising a child with a NDD. Moreover, it is needed to critically reflect on the current societal beliefs and framing about disability, since these beliefs can implicitly influence parents' well-being and how they engage with their child (Woolfson, 2004).

7.2 Disability-specificities in the research findings

Although the aforementioned study findings highlighted several similarities and specificities between families raising a child with ASD, CP, or DS, this section reflects more thoroughly on some group-specificities, that might be particularly relevant when working with children with a specific NDD, such as ASD, CP, or DS, in research and practice. Some suggestions for future research are also provided, which are further described in more detail (section 7.3).

7.2.1 Sensitivities in raising a child with autism spectrum disorder

Across the diverse study concepts, our findings consistently demonstrate that parents of children with ASD are in a particularly challenging position. Compared to the other NDD-groups, parents of children with ASD face the highest levels of emotional or behavioral child problems (Chapter 2), report the most parenting stress, express the most Criticism and least Warmth in spontaneous speech samples (Chapter 5), and describe the most relatedness- and competence-frustrating experiences (Chapter 6). Therefore, our findings validate other family research among ASD-populations, where it has become commonplace to introduce articles by stating that parents of children with ASD experience elevated levels of parenting stress (Gupta, 2007; Hayes & Watson, 2013; Valicenti-McDermott et al., 2015; Yorke et al., 2018), less overall well-being and more daily hassles compared to parents of neurotypical children or parents of children with other NDDs (Hamlyn-Wright et al., 2007; Quintero & McIntyre, 2010). However, these studies provided limited information on the underlying factors that might explain these processes. This dissertation's cross-disability and mixed-methods approach provided opportunities to advance insights into the multilayered complexity of these realities.

Parents' spontaneous speech samples (Chapter 6) indicated that many parents of children with ASD describe their parent-child relationship as challenging. Many of these parents mentioned they struggled to understand their child's thoughts and feelings (e.g., because the child preferred to be alone or showed little reciprocity in interaction with others). These experiences suggest that one of the key diagnostic aspects of ASD, namely impairments in social communication, is particularly stressful for parents to understand and handle (Davis & Carter, 2008). More specifically, parents' qualitative experiences reflected previous findings that children with ASD do not employ as much attention to caregivers or social partners as do children with other NDDs or neurotypical children (Dawson et al., 2004; Klin et al., 2002; McCauley et al., 2019). This developmental difficulty can be related to – among other social-communicative difficulties – less 'joint attention', hampering children's adaption or recognition of a common perspective or point of focus with other people (Dawson et al., 2004; Mundy et al., 2009). Consequently, our findings demonstrate that these social-communicative difficulties impact the parent-child interaction as children with ASD less spontaneously share experiences with their parents and because parents might find it difficult to engage with their child or teach new skills. Nevertheless, like all aspects of the phenotype, it is important to notice that children with ASD vary in the growth and development of these social-communicative difficulties, such as joint attention and other mentalizing capacities (McCauley et al., 2019).

Next to this specific feature related to the ASD-phenotype, our findings illustrate that the reaction and understanding of the broader social environment concerning this ASD-phenotype also plays an important role in parents' as well as children's well-being. A unique characteristic of ASD, which is clearly different from children with CP or DS, is the *invisibility of the disability*. In line with previous research, parents' experiences (Chapter 6) clearly illustrate that parents of children with ASD are often subject to stigma by the general public due to the disruptive nature of ASD-symptoms and the environment's limited understanding of ASD (Cheung et al., 2019; Dieleman, Moyson, et al., 2018; McCauley et al., 2019). Moreover, these parents feel that the environment attributes the child's display of ASD-symptoms as parents' incompetence in adequate parenting and behavioral discipline. This experience refers to what has been described as 'felt stigma', where individuals experience feelings of shame or the fear of rejection (Gray, 2002). Gray (2002) also demonstrated that these experiences of stigma were more prevalent among parents with ASD whose child exhibited more aggressive behavior. Since children with ASD exhibited the most externalizing difficulties across NDD-groups (Chapter 2), these stigmatizing experiences might be particularly prevalent amongst these families. Unfortunately, these experiences sometimes lead to negative self-evaluation or feelings of guilt in parents, which might even result in the internalization of these stigmatizing experiences. This phenomenon has been described as 'affiliated stigma' (i.e., parents negatively evaluate themselves as socially undesirable) (Corrigan & Shapiro, 2010; Mak & Cheung, 2012), which not only occurs among parents raising a child with ASD (Mak & Kwok, 2010) but has also been observed among parents of children with other NDDs (Green, 2003). Mak and Cheung (2012), for instance, warrant for the detrimental effect of these experiences for parents' well-being and feelings of competence and called out for more research on studies and practices combating stigma. To decrease the impact of affiliated stigma, it might be valuable to support parents to reduce self-blame by cognitive restructuring or psychoeducation about the negative consequences of self-blame, to establish empowering parent support groups, and to increase the awareness of ASD in society by public education and exposure to ASD (Mak & Kwok, 2010).

7.2.2 Sensitivities in raising a child with cerebral palsy

Although the majority of CP-research focuses on medical and physical progress, this dissertation's findings emphasize the importance of examining these children's psychosocial development. Moreover, the findings indicated that parenting – an understudied concept in CP-literature – is a vital factor in the lives and development of children with CP. Additionally, our findings highlighted some specific challenges that parents of children with CP have to cope with.

One of these challenges relates to the theme *'uncertainty'* (Chapter 6), which has been previously identified as a salient theme throughout the lives of children with CP and their families (Alaee et al., 2015; Björquist et al., 2016; Dieleman, Van Vlaenderen, et al., 2019). Beginning from the birth of their child, many parents of children with CP receive uncertain messages about the development and progress of their child (Huang et al., 2010). Stern (1995) described this experience as a 'representational vacuum', referring to a vacuum that exists when parents know nothing about the future of their newborn and cannot make a representation about their child's future. Even to the date of our studies, when children had reached adolescence, many of these parents described (Chapter 6) that they still continued to worry. They worried about their child's future social-communicative or physical development, social relations, future career (e.g., having a job), and/or the availability and continuity of care services, especially when the parent would pass away.

Next to these emotionally stressful experiences of uncertainty, these parents also described intensive and time-consuming practical support (e.g., washing, eating, clothing of the child, the management of healthcare and therapies), which largely impacted parents' personal need for autonomy. Perhaps, the combination of this prevailing impact of uncertainty, the adaptions that go with them (e.g., letting go of certain aspirations and ambitions), and the intensive practical support might explain why parents of children with CP described the highest levels of Criticism during the spontaneous speech samples (Chapter 5).

Another challenge that emerged as more specific to the context of raising a child with CP, is the *impact of pain* (McKinnon et al., 2019; Power et al., 2019). Children with CP frequently have to undergo medical procedures that can be very frightening and painful for the child but also can upset parents. The qualitative findings in Chapter 6 demonstrate that several parents of children with CP struggle to find a 'suitable' way to cope with their child's chronic or recurrent pain experiences. Some parents mention they provide special attention, sympathy, and comfort when their child is in pain and also allow their child to avoid strenuous activities, such as chores. Some authors refer to this later pattern of parenting behavior as 'protective', in the sense that the parent strives to protect the child from physical pain and emotional distress (Power et al., 2019; Simons et al., 2008). However, we found no support for this hypothesis as Chapter 5 did not reveal group differences in Emotional Over-involvement, an indicator of over-protective parenting (see critical comments on Emotional Over-involvement in the context of raising a child with a NDD). Nonetheless, the elevated levels of responsive parenting and lower levels of autonomy-supportive parenting among parents of children with CP (Chapters 2 and 5) might illustrate these parents' struggle to find a good balance: i.e., a delicate balance between, on the one hand, relieving stress and discomfort and, on the other hand, supporting the independence and development of their child (e.g., performing tasks and activities of daily living despite experiencing pain).

Interestingly, the study findings of Chapter 4 did not demonstrate significant associations between the type of CP (i.e., spastic, mixed, ataxic, or unknown) or symptom severity of CP (i.e., levels on the Gross Motor Function Classification System), and other variables of interest (i.e., child behavior, child personality, parenting behaviors). On the one hand, these results confirm previous findings retrieving no significant associations between the severity of the child's physical functioning and parenting behaviors (Barfoot et al., 2017; Cohen et al., 2008; Ho et al., 2008). On the other hand, however, the lack of findings might alternatively relate to the specific choice of measurements and informants in our studies. Hence, future research should further address the role of symptom severity and type of CP in parenting processes and children's psychosocial development more comprehensively. A comprehensive examination should, for instance, include the child's language and cognitive abilities and other comorbid problems, such as epilepsy or cerebral visual impairment, and could also use other measures that are reliable and validated within a CP-population (Tan et al., 2014; Yin Foo et al., 2013).

7.2.3 Sensitivities in raising a child with Down syndrome

Among DS-research, the hypothesis of the 'Down syndrome advantage' has historically received much attention. Following this hypothesis, children with DS ought to be easier to raise compared to children with other developmental disabilities due to the more positive personality traits (e.g., loving, kind, affectionate) and fewer maladaptive behaviors in DS (Corrice & Glidden, 2009; Esbensen & Seltzer, 2011; Skotko et al., 2011; Stoneman, 2007). Due to this 'advantage', parents of children with DS would tend to experience less parental stress (Boström et al., 2010; Ricci & Hodapp, 2003), higher levels of well-being, and lower levels of coping difficulties compared to parents of children with other developmental disabilities (e.g., Hodapp et al., 2001; Ricci & Hodapp, 2003; Stoneman, 2007). Notably, this 'advantage' has also been critiqued based on its stigmatizing effect and the risk of ignoring that also parents of children with DS experience elevated levels of parenting stress (Abbeduto et al., 2004) and have to cope with more behavioral and/or emotional child difficulties compared to parents of neurotypical peers (van Gameren-Oosterom et al., 2011). Moreover, this 'Down syndrome advantage hypothesis' fosters the many popular stereotypic views of DS, ignoring the large variability between persons with DS.

This dissertation's findings supports a more *nuanced stance on this 'Down syndrome advantage hypothesis'*. On the one hand, we found relative consistent support that parents of children with DS report less emotional child problems (Chapter 2), exhibit less high EE (Chapter 5), mention less need-frustrating experiences, and more need-satisfying experiences (Chapter 6) compared to parents of children with other developmental disabilities, in this case, ASD and CP. Autonomy-satisfying experiences were even the most prevalent among parents of children with DS as these parents described many opportunities for their self-development (e.g., becoming more reflective, creative or resilient when handling challenges, developing a more down-to-earth view on life) and family life (e.g., the child with DS created or enhanced a positive atmosphere in the family unit) (Chapter 6).

On the other hand, our findings also support the critique because parents of children with DS also reported elevated levels of externalizing child behaviors (Chapter 2) and parenting stress (Chapter 5), which were quite similar compared to the levels reported by parents of children with CP. Moreover, large variances in these reports suggest that the psychosocial profile and affective well-being among these parents tend to vary widely. Therefore, we follow the idea that the hypothesis of the 'Down syndrome advantage' must be addressed with absolute caution. We believe that this hypothesis might underestimate the struggles that parents of children with DS face and might even stigmatize the complexity and unicity of raising a child with DS. Also, some studies indicated that family income might be a more important factor than child etiology in predicting these parent outcomes. More specifically, a slightly higher socioeconomic status in families with DS might underlie this 'advantage' since parents of children with DS tend to be older when receiving the child and consequently have spent more years in the labor market (Corrice & Glidden, 2009; Esbensen & Seltzer, 2011; Stoneman, 2007).

Furthermore, the practices and experiences of parents raising a child with DS are situated within a unique, socio-ecological environmental context, where *prenatal screening* for DS is currently becoming common practice. During parents' free speech samples, some parents of children with DS spontaneously mentioned the impact of the current societal view on prenatal screening. More specifically, they critiqued the limited debate about the impact of prenatal screening and how it impacts our perception of normality and the 'perfect society'. Some of these parents hoped that in the future, medical staff would engage more often in an open and balanced dialogue about prenatal screening, which encompasses transparent information about both the challenges and opportunities of raising a child with DS. In doing so, future parents could make more educated and informed choices, which showed to be the key point of reproductive autonomy (Kater-Kuipers et al., 2018). Looking through an orthopedagogical lens, some of these parents seemed to take on an active 'battler' role, fighting for equal rights regarding diversity and support (Altiere & von Kluge, 2009; Van Hove et al., 2009). These parents felt they had to *"claim a secure place in society"* for their child.

7.3 Translating the research findings into practice

This dissertation's cross-disability and mixed-methods approach provides multiple opportunities to formulate both overarching and disability-specific guidelines for practice. First, we describe some guidelines stemming from the framework of SDT. Second, we provide some guidelines to better understand challenging child behavior, diminish parental stress, and foster a positive family climate among families raising a child with or without ASD, CP, or DS. Although these guidelines might provide some guidance in working with these families, it is important to notice that a 'one-size-fits-all approach' will not suffice in supporting these heterogeneous groups of families. Therefore, when working with these families, it remains essential to continuously pay attention to and acknowledge the particular and changing strengths, concerns, and vulnerabilities of each unique child, parent, and their context.

7.3.1 The added value of Self-Determination Theory in practice

In this dissertation, we adopted SDT as theoretical framework. Our findings suggest, as one of the first, that SDT is not only a valuable and rich framework to apply to parenting in neurotypical populations, but also in NDD-populations. Based upon this SDT-framework and the results of this dissertation, we here describe some guidelines for practitioners, parents, and other support figures to rely on SDT-based premises when working with families of children with ASD, CP, or DS.

A need-supportive practitioner: How to support parents' psychological needs?

Parents' spontaneous speech samples (Chapter 5 and 6) indicated that parents of children with a NDD have long-term and intensive contact with a diversity of care providers, such as doctors, therapists, educators, and at-home counselors. Therefore, care providers are in a unique and valuable position to enhance parents' well-being and growth by actively supporting or acknowledging parents' needs for autonomy, relatedness, and competence. Although many practitioners already adhere to these need-supportive elements intuitively, the framework of SDT might allow them to incorporate these elements more consciously when conducting or developing parent support or parent interventions.

Support parents' need for autonomy. Several parents of children with a NDD mentioned they feel a sense of loss or grief because they are not able to pursue certain dreams or aspirations related to their career, hobbies, or family life due to the intensive care for their child. To support parents' need for autonomy, it might be valuable for care providers to acknowledge the impact of a child's NDD on the volitional functioning of parents and to leave room for feelings of loss or grief. To foster parents' need for autonomy, caregivers could support parents to identify factors that enhance or impede their resilience and could help to organize (specialized) care (e.g., respite care, after-school care, at-home support) to give parents more 'breathing space' and room to invest in their own interests and needs (Guyard et al., 2017; Peer & Hillman, 2014; van der Pas; 2017).

Support parents' need for relatedness. To support parents' need for relatedness, care providers could adopt a warm, positive, and empathic attitude by genuinely listening to the concerns of parents, acknowledging and valuing the child's possibilities, and showing sincere interest in the well-being of the child and parents (Frye, 2016). During parent support meetings, it might also be valuable to 'zoom out' and to acknowledge the value of parents' relationship with important others: their partner, other children, friends, relatives, and the broader society. When parents need a new source of relatedness, care providers could, for instance, facilitate contact with parent-to-parent peer support groups. These groups have shown to increase coping abilities and parental stress in parents raising a child with a disability (Bray et al., 2017).

Support parents' need for competence. As parents of children with a NDD face a lot of uncertainties and challenges, one of the main competence-supportive experiences for parents may lie in the acknowledgment of uncertainty, their struggles, and worries. Practitioners should acknowledge that because of their child's disability, parents are in a vulnerable position (Resch et al., 2010). Our findings demonstrate that parents experience a multitude of pressures, coming from within (e.g., feelings of failure, grief, loss) and without (e.g., aggressive child behavior, organization of care, stigma), that regulate the way they interact with their child. By noticing the vast impact of these factors, parents might feel recognized for their perseverance and efforts that they undertake to offer their child the best possible care. Moreover, care providers could consciously focus on *"the things that are going well"*, and stress the potential progress concerning the child's functioning but also concerning the parent's efforts. Parents' need for competence might be especially strengthened when care providers do not position themselves as 'the professional' but instead acknowledge the parents as an equal partner and as the experts of their own child (cf., acknowledging parents' 'eigen-wijsheid'; Isarin, 2004). Since many parents of children with a NDD also face difficulties to navigate through the complex care system, care providers could also provide information about the possibilities of different care trajectories and actively guide parents to manage and continue these trajectories. In this regard, one area of caution is to avoid slipping into a neoliberal notion of care, where all responsibility is placed in the hands of parents as individual care users who ought to fully manage their child's support trajectory (see further section 7.5.2). To date, continuity of care is a hard objective to attain in the current context of limited financial means. However, from our results we derive that longer-term parent-professional relationships are important tools for parent support. These long-term relationships can avoid that parents have to constantly repeat their story, and can facilitate care trajectories where professionals experience and assess the long-term development of a child.

Be attentive towards parents' affective experiences and promote self-care. Our research urges practitioners to listen attentively to what parents express, also in the tone and descriptions of their parent-child relationship or how they cope with parenting challenges. SDT provides a helpful structuring framework to pick up parents' need-supportive and need-frustrating experiences and to further explore them. When parents indicate that they experience little need satisfaction and/or often experience need frustration, practitioners could support parents to identify and invest in moments in which they experience (or used to experience) psychological freedom and authenticity, reciprocal care, and personal efficacy (Sheldon et al., 2010). Similarly, practitioners could support parents in detecting need-thwarting situations and to diminish the negative effects of need frustration by promoting effective ways to cope with need-frustrating experiences.

Also, since parents raising a child with a NDD tend to sometimes (partially) give up on their own aspirations or put their own psychological needs to the background in order to take care of their child's needs, it is essential that parents realize the value of need-based self-care. It might even be recommended to start parent support or family interventions by encouraging parents to be sensitive to and take care of their own psychological needs or 'emotional household', before advising parents in more need-supportive parenting practices. It seems plausible that parents' own needs have to be fulfilled in order to have sufficient energy to be emotionally available and to engage in need-supportive parenting practices. Ryan et al. (2010) demonstrated that parent interventions that target parents' psychological needs not only strengthen the relation and collaboration between practitioners and parents but also increase the effectiveness in promoting need-supportive behaviors towards the child. Also, interventions based on Acceptance and Commitment Therapy, which stresses the importance of self-care, have been found to effectively reduce symptoms of stress and depression in parents of children with ASD and CP (Blackledge & Hayes, 2006; Whittingham et al., 2016).

A need-supportive parent: How to support children's psychological needs?

This section provides some practical guidelines for parents or other caregivers to support children's psychological basic needs. Additionally, we highlight some disability-specific elements to consider when supporting the needs of children with ASD, CP, or DS.

Engage in need-supportive parenting. The findings across the different chapters illustrate that need-supportive parenting behaviors (i.e., autonomy-supportive and responsive parenting) relate to more adaptive outcomes (i.e., child psychosocial strengths and positive family climates), whereas need-thwarting parenting behaviors (i.e., psychologically and externally controlling parenting) associate with more maladaptive outcomes (i.e., externalizing child behavior and stressed-out family climates). Moreover, these associations seem to generalize across groups and therefore ought to be applicable for children with ASD, CP, DS, and without any known disability. Even though the current findings did not allow to determine the direction of effects, we reason – based upon SDT and more 'classic' parenting intervention rationale – that increasing and promoting the repertoire of need-supportive parenting practices might be associated with more positive outcomes. In line with these findings, in Table 1 we provide some specific guidelines, that parents and other caregivers can use, to engage in autonomy-supportive parenting, to avoid autonomy-thwarting parenting, and to rely on responsive parenting (Davidov & Grusec, 2006; Joussemet et al., 2008; Ryan & Deci, 2017; Soenens et al., 2017).

Given that autonomy-supportive parenting involves more than the absence of controlling parenting (Vansteenkiste & Ryan, 2013), family interventions and parent support should recognize and reinforce parents' autonomy-supportive behaviors while also trying to diminish controlling behaviors. Interventions should provide strategies and rationales for the importance of autonomy-supportive behavior, even when the child's socio-communicative, motor, or cognitive functioning, or behavioral difficulties challenge parents' opportunities to be autonomy-supportive. Since previous intervention studies among neurotypical populations supported the beneficial impact of an autonomy-supportive parenting program for children's mental health (Allen et al., 2019; Joussemet et al., 2018), more practice-based research should inquire to what extent these interventions can also be applied among families raising a child with a NDD and to what extent practical suggestions should be adapted to accommodate the specific needs of a child with a NDD (Whittingham et al., 2011). Our results hint that the rationale underlying these guidelines is fairly similar across groups. Notably, it might also be more stimulating and energizing for all parents and caregivers to focus on augmenting autonomy-supportive behaviors, rather than solely focusing on ways to avoid controlling parenting (Dieleman, Van Vlaenderen, et al., 2019).

Apply need-supportive language. Next to concrete behaviors, parents and other caregivers should also be attentive towards the language they use in interaction with a child, since specific communication skills and techniques showed to be supportive or either thwarting for children's psychological needs (Wuyts et al., 2018). For instance, to support a child's need for autonomy in a conversation, it is important to give the child a choice about the topic of conversation, to listen reflectively, to ask questions about the child's experiences, and to show authentic interest and empathic understanding (Wuyts et al., 2018). Conversely, controlling behavior in a conversation is characterized by the use of closed questions, controlling language, commands, unsolicited advice, interruption, and intrusive questions where parents tend to show disappointment, envy, mistrust, or induce guilt (Wuyts et al., 2018). Although – to date – the role of need-supportive language has not been explicitly examined in NDD-populations, we believe in its importance for both neurotypical and special needs populations.

Table 1. Basic guidelines to support children's basic psychological needs

Supporting children's need for autonomy		Supporting children's need for relatedness
Engage in autonomy-supportive parenting	Avoid or decrease controlling parenting	Engage in responsive parenting
Nurture/respect the child's inner motivation sources.	Avoid relying on external motivators (rewarding).	Be physically (spending time together, doing joint activities) and emotionally present (being mentally engaged).
Encourage initiative, for example by providing choice and stimulating and participation.	Avoid ignoring the child's input and choice.	Show involvement in the child's life. Pay attention to the child's mental world.
Provide a meaningful rationale/explanation when you expect something from the child.	Avoid a lack of a rationale or self-oriented rational.	Offer comfort and adequate support when the child needs it.
Patiently follow and attune to the rhythm and pace of the child. Try to connect with the child's individuality, by showing curiosity, openness, and trust towards the child's opinions and perspectives.	Avoid ignoring the rhythm of the child and imposing your own rhythm.	Adapt an affectionate, warm, and kind attitude when interacting with the child in a physical (giving hugs, kisses) and/or emotional way (kindness).
Recognize the child's negative feelings and resistance by being curious.	Avoid ignoring, minimizing, suppressing, or denying negative feelings and resistance.	
Use inviting language (e.g., *"You can try to…"*) and informative language.	Avoid the use of controlling and threatening language (e.g., *"You have to…"*).	

Note. Basic guidelines based on research from Davidov and Grusec (2006), Joussemet et al. (2008), Ryan and Deci (2017), and Soenens et al. (2017).

Acknowledge disability-specific sensitivities in autonomy support. This dissertation uncovers that encouraging the autonomy of a child with a NDD might encompass certain disability-specific challenges. For instance, in the case of ASD, we found a counterintuitive positive correlation between autonomy-supportive parenting and internalizing problems (Chapter 2). Plausibly, parenting behavior that encourages initiative, by providing choice and stimulating dialogue might be experienced as stress-inducing by some children with ASD, who likely need more structure and direction. The qualitative findings from Chapter 6 support this explanation. Some parents of children with ASD indicated that autonomy-supportive parenting is not easy to convey because their child adheres to certain routines, schemes, and consistent rules. Moreover, a parent's negative experiences of child distress due to unclarity or unpredictability might cause the belief that children with ASD have more difficulties coping with autonomy. Nevertheless, we would like to stress that supporting a child's autonomy does not exclude the provision of structure, but can go together. For instance, the provision of choice (a facet of autonomy-supportive parenting) can take place within a highly structured context, where choice options and their consequences are clearly described or visualized within a schedule.

Searching for possibilities to increase a child's sense of ownership or autonomy about a certain activity might also be a valuable strategy to manage challenging child behavior, which parents of children with a NDD are often confronted with. In this context, Vansteenkiste and Ryan (2013) argue that 'revolting behavior' is often not driven by the child's unwillingness to do a certain activity, yet in many cases, the child wants to do that activity differently. To increase a child's ownership over an activity, the activity can be altered in different ways by adapting the moment, context, manner, or amount in which choice is provided (Vansteenkiste & Ryan, 2013). For example, when a parent wants to stimulate his/her child to play outside more often instead of playing computer games, the parent can provide choice in the moment (e.g., *"I want to play outside, but not immediately"*), the context (e.g., *"I want to play outside, but not in this park"*), the nature or manner (e.g., *"I want to play outside, but not with a ball"*), or amount (e.g., *"I want to play outside, but only for 20 minutes"*). For parents, it might be valuable to experiment and be creative with different approaches to provide choice in order to find the approach that matches their child's needs.

However, these general guidelines might need some tailoring or adjustment to meet the specific needs of a child with a NDD. Therefore, it is interesting to further elaborate on the concepts of 'autonomy-as-independence' and 'autonomy-as-volition' and its distinction when promoting autonomy in a child with a disability. According to Wehmeyer and Shogren (2020), promoting autonomy or ownership in a child with a disability should not be confined to autonomy-as-independence (i.e., acting independently) but should be broadened to autonomy-as-volition (i.e., acting based upon our preferences and interests and in the pursuit of goals that are of value to us and enhance our quality of life). Moreover, they suggest that autonomy-as-volition might be particularly important for children with a disability, who may need external support to perform preferred activities. Wehmeyer and Shogren (2020) described the following illustration to clarify how autonomy-as-volition for a person with a physical disability might look like:

> "*So, if a person with a physical disability wants to prepare dinner, but requires assistance to get ingredients together, mix and stir recipe ingredients, put the dish into the oven, and so*

> *forth, it is not important that the person did not perform these tasks alone and without assistance (e.g., autonomy-as-independence) but that the person chose what to eat and that the meal preparation process was carried out according to that person's preferences and desires (e.g., autonomy-as-volition)."*

Tune into a child's individuality. Next to these more generic SDT-based guidelines, the findings from Chapters 3 and 4 demonstrate that it is essential to acknowledge a child's unique individuality, strengths, and vulnerabilities (which is also an essential part of autonomy-supportive parenting, e.g., follow and attune to the rhythm of the child). The exploration of a child's personality and an elaborated understanding of the personality-by-parenting interplay can help parents to more effectively tune into their child's individual differences, and might even help caregivers to tailor parenting advice and interventions to children's unique personality (Huntington & Simeonsson, 1993). This tailor-made approach, for instance, proved to yield larger effects in a school-based intervention for preventing externalizing child behavior in neurotypical groups (Stoltz et al., 2013). Since our findings particularly indicate the sensitivity of children with lower Emotional Stability towards the effects of parenting, parents and other care providers could be especially attentive to the interactive effect between their parenting behaviors and these children's development, while also searching for possibilities to enhance these children's self-confidence and their abilities to withstand difficult situations or handle adversity. For instance, Rettew (2013) encourages parents of more inhibited and/or anxious children to slightly push the child's boundaries and to not give in to their anxieties in a loving, accepting yet consistent manner. Parent support and intervention programs may also attend more strongly to the children that are less sensitive to the benefits associated with need-supportive parenting and more sensitive to the costs associated with need-thwarting parenting (Mabbe et al., 2019). Overall, this 'non-syndrome-specific' or 'who is this unique child'-focused approach, can also support parents and caregivers to look beyond a child's diagnosis and to defy a deficit-thinking solely focusing on children's limitations. This is in line with an orthopedagogical approach, which strives towards the acceptance and appreciation of diversity, and receptivity towards differences (De Schauwer et al., 2017). However, more research is needed on personality-by-parenting interactions in NDD-populations and how these interactions might guide parent support and interventions among families raising a child with a NDD.

A need-supportive society

Interestingly, one of the key strengths of the SDT-framework is that a diversity of socializing contexts, other than the parenting context, play a crucial role in the development and growth of children (Deci & Ryan, 2000; Ryan & Deci, 2017). Therefore, a need-supportive context is not confined to the parent-child dyad, but can be elaborated into other socializing contexts, such as schooling, sports, social activities, residential youth care facilities, and so forth (e.g., Banack et al., 2011; Deci & Ryan, 2000; Haakma et al., 2016; van der Helm et al., 2018). Consequently, not only parents or caregivers but also other important actors in a child's life, such as friends, grandparents, teachers, trainers, and members of a youth movement can be valuable need-supportive individuals for a child with a NDD. For instance, a study on need-supportive teaching among students with visual or hearing impairments or deaf blindness demonstrated that the provision of structure in lessons (i.e., supporting children's need for competence) had a positive impact on students' motivation, engagement, and educational outcomes (Haakma et al., 2016). Consequently, the aforementioned guidelines to support children's basic psychological needs also apply to important others in the lives of children with a NDD. Feeling autonomous, related, and competent is not only crucial within a family context, but in all contexts.

7.3.2 Understanding challenging child behavior, diminishing parental stress, and fostering a positive family climate

In our studies, we found consistent associations between need-thwarting parenting, stressed-out family climates, parenting stress, and externalizing child behaviors across the four groups. Conversely, we also observed similar relations between need-supportive parenting, positive family climates, and children's psychosocial strengths in each group. We interpret these findings from a transactional point of view (Sameroff, 2009), acknowledging that parenting behaviors, child behavior, and parents' need-related experiences and well-being may simultaneously influence each other and might even reinforce each other. In this section, we provide some guidelines to (1) manage and understand challenging child behavior, (2) diminish parental stress, and (3) foster a positive family climate, informed by this research.

Understanding challenging child behavior

Try to understand challenging child behavior. In order to support parents to manage and understand challenging child behaviors, it is important to acknowledge that challenging child behavior might be triggered by a diversity of reasons, which are possibly and frequently outside parents' (sphere of) control. Therefore, practitioners could search, together with parents, for possible triggers of this behavior (e.g., too much noise or stimuli, pain, feeling misunderstood) and support them in understanding and interpreting what is behind their child's behavior, in other words, the functionality of their child's behavior (e.g., challenging behavior as a survival mechanism, a way to escape a stressful situation, an expression of feeling misunderstood) (Lucyshyn et al., 2007; Power et al., 2019; Reese et al., 2005).

In this context, it might be especially valuable to examine how parents perceive and appraise their child's behavior, that is, their attribution style. Parents can attribute their child's behavior based on location (i.e., internal or external factors), dispositionality (i.e., situational or dispositional), intentionality (i.e., intentional or not deliberate), controllability (i.e., controllable or uncontrollable), and stability (i.e., stable/fixed or unstable/growth) (e.g., Del Vecchio & O'Leary, 2008; Lancaster et al., 2014; Leung & Slep, 2006). Studies demonstrated that parents who attributed their child's problem behavior as intentional and within the child's control (e.g., a fixed problem about which parents can do nothing) described more feelings of anger and depression and relied on more controlling and unresponsive parenting behaviors compared to parents who attribute their child's behavior as unintentional and outside the child's control (e.g., challenging behavior as a developmental learning task that children can work through with parental support) (Lancaster et al., 2014; Park et al., 2018; Wilson et al., 2006). Moreover, Nelsen et al. (2011) even argued that behaviors that are associated with the child's disability should be considered as 'innocent' behaviors since the misinterpretation of 'innocent' behaviors as deliberately 'misbehaving' can elicit new challenging behavior. In that respect, Whittingham et al. (2009) demonstrated that parents of children with ASD, who attribute ASD-symptoms as uncontrollable or unintentional by the child, protect them from feeling less competent or from feeling alienated from their child. This finding verifies parents' experiences in Chapter 6, where parents diminished their use of disciplining techniques or punishment to teach their child that a certain behavior was not appropriate, as it often had the opposite effect and even caused more behavior problems. Over the years, these parents realized that this maladaptive process related to the fact that their child could not link the punishment to their own actions because, in many cases, their behavior was unintentional.

Recognize puberty as a challenging transition period. Both quantitative (Chapters 2, 3, and 4) and qualitative findings (Chapter 6) demonstrate that the transition to adolescence and emerging adulthood might be challenging for both children and their parents. For instance, the findings illuminated that, during this period, parents of children with a NDD struggle with the delicate balance between the child's strive for independence and the need for support, and feelings of 'being different'. To support families, it might be valuable to provide parents and children with information about the physical, emotional, and behavioral changes of a child during puberty through psycho-education, with a specific focus on how these changes might interact with functional aspects of the child's disability. Furthermore, caregivers should be attentive to increased feelings of 'being different' or 'otherness' (i.e., the degree to which a person feels that he/she varies from a socially-constructed 'norm'; Murdick et al., 2004) among children and their parents. The findings from Chapter 6 and previous research indicated that, especially during this phase of transition, both children and parents might experience more feelings of grief or sadness because they feel 'different' or realize that certain milestones will not be reached, such as living independently or having a family of their own (Bruce & Schultz, 2001; Hamilton et al., 2015).

Diminishing parental stress

Invest in emotion regulation strategies. Even though studies open up a more balanced perspective, many parents raising a child with a NDD experience elevated levels of stress. It is hence important that parent support workers actively reflect on how stress in the parental role (or broader: more generic need frustration) can be diminished. For instance, to support parents to regulate the frequent challenges they face and to provide them with more 'breathing space', the theoretical framework of the 'window of tolerance' might be particularly interesting to work with (Ogden et al., 2006; Siegel, 1999). This model is now commonly used to understand and describe brain and body reactions in response to adversity. According to the model, individuals have an optimal arousal level when they are functioning within the window of tolerance that allows for the ebbs and flows, the ups and downs of emotions. However, when individuals experience hurt, trauma, anxiety, pain, or anger, these experiences bring us close to the edges of the window, which might lead to hyper- or hypo-arousal (Ogden et al., 2006). In practice, the window of tolerance might be a valuable framework to help parents, but also children, reflect on their needs, to express feelings of tension, and to understand what is needed to effectively shift their emotional state within the optimal arousal level when needed. This framework could also encourage parents and children to focus mindfully on how they feel, how their body feels, but also teach them strategies to regulate their own emotional state as well as those of others (Corrigan et al., 2010).

Practice mindful parenting and acceptance. Furthermore, scholars suggested that interventions that focus on parental psychological processes of mindfulness and acceptance might be especially fruitful among families raising a child with a disability (Whittingham, 2014). Moreover, scholars highlight the value of increasing mindful parenting skills to decrease stress in the parental role (e.g., Duncan et al., 2009; Gouveia et al., 2016). Mindful parenting is characterized by an open receptive awareness and acceptance of what is happening in the parent-child interaction (Duncan et al., 2009). During parent-child interactions, mindful parents listen to their child with full attention, thereby showing high levels of awareness of their own and child's feelings. They try to identify their own and their child's emotions, instead of reacting automatically to them, and adopt a non-judgmental attitude of empathy, compassion, and forgiveness towards themselves and the child (Duncan et al., 2009; Gouveia et al., 2016). This is also conceptually close to what is framed by SDT as autonomy-supportive parenting. Within NDD-populations, several studies now demonstrate the potential benefits of incorporating mindfulness within parenting interventions (Beer et al., 2013; Dieleman et al., 2020; Jones et al., 2014; MacDonald & Hastings, 2010; Whittingham, 2014; Whittingham et al., 2016). Also, since parents of children with NDDs are more vulnerable to experience parental burnout, these parents might especially benefit from mindfulness-inspired interventions that target emotional exhaustion and support parents' emotional competence and resilience (Basaran et al., 2013; Mikolajczak et al., 2018).

Moreover, since a child's NDD-diagnose may pose similar challenges of reorganization and integration for parents as experiences of loss or other psychological trauma (Bowlby, 1980), investing in acceptance and mindful parenting might also help parents to accept their reactions to their child's diagnosis. Although many parents of children with a NDD seemed to accept their reactions to their child's diagnosis at the time when their child reached adolescence, others expressed dissatisfaction about their current life or retainment to unfulfilled dreams (Chapters 5 and 6). Since parents may follow different routes in their acceptation and grief processes, parent support should also be flexible and should individualize the support to parents' unique experiences of adaptation and grief (Schuengel et al., 2009). According to Manu Keirse, a Belgian grief expert, parents raising a child with a (severe) disability live with a 'living loss' (cf., 'levend verlies' in Dutch). With this term he proposes the idea that these parents deal with challenges throughout their life, accompanied by a sense of loss, that never pass. According to Keirse, care providers should therefore support parents to accept their child, their child with a disability, rather that accepting the limitations where their child has to live with, and to 'survive' or 'learn to live with', rather than 'coming to terms with' feelings of loss and grief (Keirse, 2020).

Although these psychological processes of mindfulness and acceptance might be valuable to provide parents with more 'breathing space', we also believe that more 'material' buffers, such as respite care and high-quality care and education facilities, are equally important and might even be essential prerequisites for parents to be able to invest in these psychological processes.

Fostering a positive family climate

Acknowledge both the parent's and child's perspective. Although interventions or therapy for children with a NDD mainly focus on the benefits for the child (Da Paz & Wallander, 2017), our findings also support the orthopedagogical and contextual concept of 'multidirected partiality' (Boszormenyi-Nagy, 1987). Multidirected partiality refers to a caregiver's basic attitude where the caregiver hears and acknowledges each actor involved and searches together for mutual connection. Therefore, during parent-child support, both the parent's and child's perspective should be equally adhered to. For example, regarding the consistent associations between controlling parenting behaviors and externalizing child problems (Chapters 1, 2, and 3), practitioners could discuss with children how they experience their parents' controlling behavior and support them to seek adaptive ways to express their need frustration. Similarly, practitioners could discuss with parents how they experience and respond to aggressive and rule-breaking behaviors and support them to seek more adaptive ways to respond to these behaviors.

Recognize and strengthen the positive. Next to diminishing deconstructive processes, this dissertation's findings also illustrate the need for a more positive and strength-based approach in family support, where parents' need-supportive parenting behaviors, competence, and children's psychosocial strengths are acknowledged and strengthened. For instance, during parent support, parents can be advised to recognize and to acknowledge their child's positive behavior, rather than to focus only on difficult behavior. It seems likely that parents find it easier or more energizing to respond in need-supportive ways when they notice more positive child behaviors, and children might also feel more encouraged to develop and thrive when parents support their needs. Focusing on both challenging and positive processes not only provides a more orthopedagogical holistic approach in family support but also facilitates feelings of empowerment and positivity in interventions (Dieleman, De Pauw, Soenens, Van Hove, et al., 2018; Wehmeyer et al., 2017). We recognize the rationale of such an approach, for instance, within the 'Positive Behavior Support Plan', which showed positive results among a family of a girl with ASD and severe problem behaviors (Lucyshyn et al., 2007).

The findings in Chapter 6 also illustrate that intentionally underscoring positive child behavior, even within a crisis situation, resulted in more positive outcomes instead of becoming angry or upset. Phrasing positive child behaviors could feel especially supportive for a child with ASD, as these children already face a lot of remarks during the day due to non-intentional negative or 'inappropriate' behaviors. Interestingly, such parental behaviors can also be related to the framework of 'nonviolent communication' (Rosenberg, 2004), which highlights the importance of respectful and compassionate communication even when things are getting out of hand. In response to challenging behavior, the framework advises parents to express feelings of responsivity and compassion (e.g., *"I am here for you, I will not let go"*), instead of responding with irritation, anger, impatience, control, or punishment (Rosenberg, 2004). Although the framework of nonviolent communication is not widely studied among NDD-populations, one study demonstrated that a 'nonviolent communication program training' also benefited the parent-child interaction among mothers of children with an intellectual disability (Rezaei et al., 2019).

7.4 The theoretical value of incorporating Self-Determination Theory in parenting research among families raising a child with a neurodevelopmental disability

This dissertation's incorporation of the SDT-framework on parenting among ASD-, CP-, and DS-groups includes three main theoretical implications, in addition to the described practical implications. Furthermore, given that the study findings support SDT's universality claim, stating that need-supportive parenting is universally adaptive and that controlling parenting is universally maladaptive, one could argue that these processes apply to all children, leaving limited place for the effect of child personality. In that respect, we further elaborate on a universalistic versus relativistic perspective on parenting.

7.4.1 Three main theoretical implications

Incorporating the SDT-framework in NDD-populations includes three main theoretical implications: the SDT-framework (a) provides possibilities to uncover overarching processes as well as subtle differences in disability-specific processes, (b) allows to understand parents' experiences in a more complete, nuanced, and balanced way, and (c) offers a more in-depth and differentiated insight into what makes raising a child with a NDD more challenging or potentially stressful. These theoretical implications are discussed in more detail below.

First, and perhaps most importantly, SDT shows to be valuable and applicable in both neurotypical and special needs populations. The results in Chapter 2 specifically demonstrate similar pathways between need-supportive parenting and positive child outcomes, on the one hand, and between need-thwarting parenting and maladaptive outcomes, on the other hand, across groups, which supports SDT's universality claim (Deci & Ryan, 2000; Ryan & Deci, 2017). This is especially valuable since theoretical frameworks that apply to both neurotypical and special needs populations are scarce. Because of SDT's universality claim, we were able to map out overarching processes as well as disability-specific processes. Therefore, the framework provided opportunities to highlight that raising a child with a NDD shares many similarities with raising a child without a disability but encompasses also unique challenges and opportunities depending on the child's disability.

Second, previous research on parenting practices and experiences in the context of ASD, CP, or DS tells a rather one-sided story strongly focusing on parental ill-being and parenting stress (e.g., Gupta, 2007; Hayes & Watson, 2013). Exploring parents' behaviors and experiences within the SDT-framework offered a balanced and nuanced insight into parents' rich and complex experiences. Although both quantitative and qualitative multi-group comparisons indeed support previous findings indicating that parents of children with NDDs experience more challenges compared to parents of children without any known disability (e.g., Gupta, 2007; Hayes & Watson, 2013; Kubicek et al., 2013; Resch et al., 2010), the current findings also reveal opportunities and positive parental experiences (e.g., feeling enriched, close family relations). For instance, Chapter 6 demonstrated that the frequency of the described need-satisfying experiences is similar between parents from the NDD-groups and the neurotypical group. Thus, although raising a child with ASD, CP, or DS might entail unique challenges or require specific adaptations, structuring parental processes within the three SDT-needs allowed us to also get a better understanding of the opportunities that a child's NDD creates for positive need-satisfying experiences. In general, this balanced approach unraveled that raising a child with a NDD is indeed not all doom and gloom, but is accompanied by both challenging and rewarding experiences, comparable to each parent-child relationship (Nurullah, 2013).

Third, the framework of the three psychological needs offered a profound and differentiated insight into the reality of raising a child with a NDD. Whereas many studies report elevated levels of challenging experiences among parents raising a child with a NDD (e.g., Gupta, 2007; Valicenti-McDermott et al., 2015), these studies do not provide much information about the sources of these experiences. Therefore, the differentiation between the three needs allowed us to get a better understand of the underlying sources of what makes raising a child with ASD, CP, or DS challenging and rewarding. For instance, the quantitative findings from Chapters 1, 2, and 3, indicate that especially controlling parenting behaviors, which thwart children's need for autonomy, relate to more maladaptive child outcomes. Also, the findings from Chapter 5 indicate that parents of children with a NDD report the highest levels of stress concerning their need for autonomy (i.e., role restriction), which indicates that many of these parents feel constrained by their responsibilities as a parent (e.g., *"I often feel that my child's needs and wishes control my life"*, *"In order to meet my child's needs, I have to sacrifice more of my life than I expected"*). These findings relate to previously reported experiences of parents raising a child with a disability describing themselves as *“managers”* (e.g., managing and organizing specialized care, finding a way in the landscape of care facilities, balancing work and life) at the expense of *“just being a parent”* (Van Hove et al., 2009). Taken together, these findings complement suggestions that the need for autonomy might be the most vital psychological need in order to thrive and feel good as a human being (Grolnick et al., 2018; Soenens et al., 2007; Vansteenkiste & Ryan, 2013). However, in Chapter 6 competence-related experiences were most prevalent among these parents, which also suggests that *“feeling competent”* and worrying about *“doing the right thing”* are central and vital themes for these parents’ well-being and vitality.

7.4.2 The universality claim of Self-Determination Theory and the role of child personality: A complementary approach

When SDT would be interpreted from an extreme universalistic perspective, there would be no room for moderation by personality differences. In other words, all children would be assumed to benefit from need-supportive parenting to the same degree and need-thwarting parenting would have similar costs for each child. In contrast, an extreme relativistic position on parenting would suggest that the effects of need-supportive and thwarting parenting are fully dependent upon individual differences in children. Therefore, it would be hard to define what constructive parenting involves since the effects of parenting should always be contextualized. Moreover, an extreme stance of this relativistic perspective could state that some children even benefit from a controlling approach and suffer from need-supportive parenting (Mabbe, 2018).

Importantly, SDT does not represent a strict universalistic perspective but advocates a more moderate viewpoint on universalism (Soenens et al., 2015). According to SDT’s perspective on parenting, individual differences may alter the strength of the association between parenting and developmental outcomes but not the presence or absence of these associations (Deci & Ryan, 1987). More specifically, SDT states that the role of individual differences may surface in three different ways. That is, individual differences in children can (a) affect the strength of the association between socialization and outcomes (i.e., gradation), (b) impact how children interpret parenting behaviors and socialization (i.e., interpretation), and (c) influence how the benefits and costs of socialization manifest (i.e., manifestation) (Mabbe et al., 2016; Mabbe et al., 2019). In other words, individual differences can alter a child's sensitivity and appraisal of potentially need-supportive or thwarting parenting practices, and might also influence the way they cope with these practices (Mabbe et al., 2019; Soenens et al., 2015). Since this theory is built upon research in neurotypical children, further research is needed to better understand how these processes may operate in children with a NDD.

7.5 Zooming out: Parenting a child with a neurodevelopmental disability in a broader societal context

Although the SDT-framework provides many benefits on the practical and theoretical level, these benefits are mainly restricted to the microsystem of parent-child dyads. Nonetheless, this dissertation's findings also illustrate the importance of situating parenting and children's development in a broader ecological context. Following Bronfenbrenner (1986), the family unit must be viewed as a microsystem within a larger ecological framework of nested systems including relatives, friends, and neighbors, which are also embedded in larger social units, such as school, work, the local community, and wider society. In this section, we zoom out and reflect on the position of parents raising a child with a NDD in today's societal context.

7.5.1 The importance of social support for parents' and children's well-being

Although our research aims were primarily confined to the micro-level (e.g., psychological needs, well-being, stress, parent-child interactions), this dissertation's findings corroborate previous studies illustrating that parents' and children's functioning and well-being exceeds these levels and also relates to the extent to which socio-contextual factors facilitate or impede parents' and children's functioning and well-being (Grolnick et al., 1996; Taraban & Shaw, 2018). Especially the different life domains in which parents experience stress (Chapter 5) and parents' spontaneous speech samples (Chapter 6) illuminate that socio-contextual factors can, on the one hand, support parents and children to overcome challenges but, on the other hand, can also further exacerbate the challenges they were already confronted with.

First, concerning positive experiences, parents of children with a NDD primarily describe support from their close environment, including their partner, family, friends, and professional care providers. In their interaction with unacquainted people, few positive experiences were spontaneously mentioned. However, some parents hinted that they appreciated others who tried to adjust to their child's abilities, acknowledged and reinforced their child's strengths, or tried to enable inclusive contexts. In sum, the findings validate previous studies showing that social support is crucial for families' quality of life (Brown et al., 2003; Steel et al., 2011) and might even be more important for these parents' well-being compared to parents in the neurotypical population (Bray et al., 2017; Dieleman, Van Vlaenderen, et al., 2019). Peer and Hillman (2014) even identified social support (both formal and informal), next to parental coping and optimism, as a key buffer against stress and a strong predictor of resilience among parents raising a child with an intellectual or developmental disability.

Second, the findings also illustrate parents' challenges within a broader societal context. For instance, parents across all NDD-groups reported substantially higher levels of stress in their relatedness with their social network (i.e., more social isolation) compared to parents of children with no disability (Chapter 5) and mentioned several confrontations with societal boundaries or deficit discourses, in the form of exclusion, injustice, inequality, expensive care, stigma, accessibility, and ethics of prenatal screening (Chapter 6). For instance, several parents of children with a NDD mentioned painful experiences of being stared at or laughed at by unacquainted people, which left painful scars and made them wonder about their place in society and how children with a NDD are welcomed in this world. This quote from a mother of a boy with ASD painfully illustrates how, for some parents, the challenges they face might primarily lie in the misunderstanding and miscomprehension of society:

> *"You encounter a lot of misunderstandings. I have a very hard time when people stare at us when A. is having a hard time. Then, I feel like they are making it all worse. I feel frustrated, my child feels ten times more frustrated and all that unsolicited advice leads to the utmost frustration. So that, we both… When I get frustrated, A. gets ten times more frustrated of course. Yes, I think I mainly have problems with society. That society and the schools perceive autism as behavior that probably results from the house they grew up in, that the parenting is probably not that good. While in fact, A. is a very sweet boy, very caring, very helpful, but he has communication difficulties that can over-stimulate him."*

Incorporating the role of the social-cultural context can also be valuable within parent support since experiences of stigma, exclusion, and inequality have been found to increase the risk for dysfunctional parenting or parenting stress (Blacher & Hatton, 2001; Bøe et al., 2014; Lalvani, 2015; McCauley et al., 2019; Wuyts et al., 2015). When parents are confronted with adverse social contexts, well-intended goals of parent support interventions may be short-lived. Contextual adversity might deplete parents' energy to engage in need-supportive parenting and might even diminish parents' belief in an inclusive society or their possibilities to seek need-satisfying experiences. Parents may then first need tangible support to overcome these socio-cultural barriers before interventions are implemented to strengthen parenting skills and psychological resilience.

To overcome these barriers and to increase parents' resilience, care providers could encourage parents to use resources in their social environment, which should be broadly interpreted (e.g., family, friends, local residents, people from the church or mosque, (former) classmates, teachers, colleagues, volunteers). Van der Zijden and Diephuis (2011) stated that support from the social network could be particularly valuable as this form of support is more sustainable than support from care facilities, which encompasses financial, legal, or practical restraints.

7.5.2 Towards shared responsibility and an open dialogue about ethical debates

However, support from the close social environment might not be sufficient for parents. According to van der Zijden and Diephuis (2011), another crucial factor to overcome parental barriers is the feeling of co-responsibility. Moreover, a supportive and involved social network that feels co-responsible for the well-being and upbringing of a child can be a major protective factor, especially within families facing many challenges (van der Zijden & Diephuis, 2011). However, to date, within a prevailing neoliberal political context, parenting is mainly seen as an individual matter building on individual responsibility, putting parents as the main – and sometimes only – responsible person for a child's development and well-being. To decrease this societal pressure on parents, it could be helpful to take parenting more out of the individual context and to see parenting as a shared responsibility of both the parent and the wider society (cf., *"It takes a village to raise a child"*). This implies a broader responsibility for parents' network, communities, care providers, and policymakers, in sum, each citizen.

As such, 'good enough' parenting or a child's adaptive functioning should not be interpreted within a vacuum but as a result of a complex interplay of numerous factors (e.g., the child, the family situation, the social network, the professional support, and the social-cultural context). According to de Vries et al. (2005), this 'good enough' parenting can only take place when a number of socio-cultural conditions are met. For instance, society must provide sufficient opportunities and facilities to support parents in their parenting task (e.g., adequate (specialized) care and schooling) and must create an environment where everybody feels welcome (Isarin, 2004; van der Pas, 2017). Belgium endorsed this responsibility by ratifying the UN-Conventions on 'the rights of the child' and 'the rights of persons with disabilities', which stipulates that the government, among other things, must provide sufficient and equal opportunities to educate each child according to their abilities and needs, and must provide quality care and support so that full participation in society can be guaranteed for each citizen (Foreign Affairs, Foreign Trade and Development Cooperation, 2016). Unfortunately, to date, the waiting lists and support budgets for individuals with a disability are major obstacles (Vandelanotte, 2020). For instance, according to the most recent figures (31/12/2019), 1.038 Flemish children with a disability currently have a 'personal assistance budget' (cf., 'persoonlijk assistentiebudget' in Dutch), which finances at-home support. However, more than 1.769 other children who are also entitled to this financing are on the waiting list (VAPH, 2019). This waiting list is growing every day.

Although this issue primarily relates to financial matters, the government and its citizens also have a bigger responsibility. Namely, to convey models of inclusion, where disability is part of 'the norm' and where every citizen feels safe, welcome, and supported. To facilitate and sustain such an inclusive society and mindset, tolerance, appreciation, and respect for diversity are crucial. Education plays a critical role in this area, as it provides opportunities to install values of appreciation, respect for diversity and dialogue, and a critical reflection on exclusion and stigma (DESA, 2009). Also popular media can play an important role in increasing a socially inclusive discourse. For instance, by creating positive and nuanced narratives about disability, underlying the notion that individuals with a disability are different but not 'abnormal' and by decreasing the stigma of those categorized as disabled as 'other' (Goethals et al., 2020). Taken together, an inclusive society is about creating solidarity, about the realization that even though there are differences, we are all human beings. It is about encouraging the acceptance of others and interconnectedness, and sharing a sense of belonging as well as a sense of responsibility (DESA, 2009).

In line with this discussion on shared responsibility and the government's influence in the micro-context of parenting, the debate about prenatal screening, specifically in the context of DS, is interesting to further elaborate on. Since 2011, noninvasive prenatal genetic testing (NIPT), which detects fetal chromosomal aneuploidies in the blood of a pregnant woman, has changed the field of prenatal screening and has quickly spread across the globe (Allyse et al., 2015). In Belgium, the NIPT is used to detect DS and since 2017 the test is almost entirely refunded by the Belgian government. Philosopher Devisch (2017) states that, from a democratic point of view, it is positive that the test is accessible to everyone since an individual's income should not play a role in the accessibility of medical care. However, it presents new moral dilemmas because the availability of the test could increase the pressure on individuals to carry out the test, and here the 'right to' risks to transition into a 'duty to' (Devisch, 2017). Consequently, also the accountability shifts from the government and companies, who provide a certain 'care', to the individual, who has to justify their (non-)usage of the available 'care'. Devisch (2017) warrants that we are often not aware of the subtle play of social pressure that arises from social norms and its influence on individual decisions. When parents have to decide about conducting the NIPT, do we still speak of freedom? When DS is discovered in the fetus, is it still possible to speak of free choice, or does it push parents towards a certain decision?

This medical progress and the policy about NIPT inevitably impact the experiences of parents currently raising a child with DS. In parents' speech samples (Chapter 6), some parents of children with DS mentioned the current reality about prenatal screening and how they felt about it. Several of these parents felt misunderstood and advocated for a critical debate on this matter and plead for an open dialogue, where possible test outcomes and parents' attitudes, values, and concerns about prenatal screening are openly discussed. Also Sally, a mother of a boy with DS who made the BBC documentary *"A world without Down syndrome"*, posed the intriguing question of whether parents will consciously choose for a child with DS if society does not seem to welcome diversity (Gee, 2016). Another father of a daughter with DS questioned what freedom of choice really means if one considers that the continuation of the pregnancy after a positive NIPT hits sky-high barriers when the child is born, such as struggles with inclusive education or a personal assistance budget (Lebeer, 2017).

Although it cannot be denied that raising a child with a disability, or DS specifically, can be challenging, it should not impede a critical stance on the current impact of medical progress. Therefore, the debate on prenatal screening should be broadened, thinking critically about the society we want to live in and how we value and perceive diversity. A society that opens up comprehensive technological possibilities should also create ethical and emotional guidance to take these decisions (Devisch, 2017). Here, the discussion is related to the context of DS but this discussion can elaborate into debates on each form of prenatal screening or genetic manipulations of 'diseases' and disabilities. As more and more 'diseases' become treatable and genes can be adjusted, we might already know what our society could look like in the future and the 'perfect society' might no longer seem like a utopia. Therefore, the key questions remain: What kind of society do we want to live in? How do we view life and what value do we assign to it (Devisch, 2017)? These are interesting but difficult questions, that ask for continued reflection, without only considering the economic or medical side but – most importantly – the human and ethical side of the story.

I believe Down syndrome is a life worth saying yes to.
Every life matters regardless of the number of chromosomes we have.
- Karen Gaffney-

7.6 Limitations and directions for future research

When interpreting this dissertation's findings, some general limitations need to be taken into account. To overcome some of these limitations and to further deepen our understanding of parenting practices and experiences among parents raising a child with a NDD, this section also formulates suggestions for future research.

Sample and design characteristics

The generalizability of the presented findings is limited and associated with multiple choices on design, methodology, theoretical considerations and data-analyses. Here, we highlight five sample and design characteristics that may have influenced this dissertation's findings.

First, regarding the samples characteristics of the parents, one of the main limitations is that mothers were the main participant throughout the different studies and *fathers* only represented a minority of the participants. To date, the large majority of parenting research focuses on mothers, which can be partly explained by theoretical (e.g., attachment theory), practical (e.g., fathers might have fewer possibilities to work halftime) as well as socio-cultural reasons (e.g., parental roles and expectations). During the recruitment of participants, it became clear that some fathers strongly adhered to the idea of 'the mother as the main care figure', as they instantly called out for their partner when we told them the research focused on parenting. Future research needs to make efforts to recruit more fathers in parenting research as *"dads kind of get forgotten"* (Schippers et al., 2020; Seymour et al., 2020). To do so, it might be necessary to use more active strategies that specifically target fathers and to convince fathers they have an equal voice in parenting research as mothers.

Second, our study findings might be limited by the homogeneity in *parents' socio-economic status*. Although we assessed and controlled for parents' level of education, which might be regarded as a proxy, we did not assess parents' socio-economic status directly. Future research should include this factor, as the family's socio-economic status showed to be an important factor in the relation between child and parenting behavior (Bøe et al., 2014; Taraban & Shaw, 2018). Additionally, parents were mainly *recruited via care facilities*, such as specialized care centers, specialized schools, at-home counseling services, and online support groups for parents of children with ASD, CP, or DS. Therefore, it might be plausible that the study findings were somewhat biased based upon the type and intensity of the support parents received. Plausibly, we did not include parents who were not connected to service centers in any kind of way or who did not acknowledge their child's diagnosis. Future research could apply a more diverse recruitment strategy and should examine the role of professional support more directly, for example, by conducting action research or more participatory observations.

Third, the generalizability of the presented findings is also limited due to certain sample characteristics of the children. The children included in the different studies *varied relatively widely in age*, ranging from childhood to adolescence, and some age-ranges in the longitudinal studies showed overlap. Although we controlled for the plausible effect of child age in the data analysis, this approach might have masked some age-specific effects. Therefore, we could not make firm conclusions about the age-specificity of certain findings. To address these limitations, future work should target more specific age groups or recruit larger samples which makes it possible to explore age effects more in-depth.

Fourth, we also acknowledge that the use of a multi-group approach (Chapters 2, 5 and 6) limited the possibility to highlight the *heterogeneity between children with the same diagnosis*. Although children with a certain 'label' are all mutually different in their psychosocial development but also in other developmental areas and the context they grew up in, we examined group similarities and differences solely based on the presence or type of a child's diagnosis. Although comparing multiple groups based on a diagnosis provides several benefits (Dykens & Hodapp, 2001; Hayes & Watson, 2013), this approach may also miss key elements in the lives of children with a disability and their parents (Gupta, 2007). To highlight the heterogeneity between children with a certain disability and their parents and to better map out individual development trajectories (cf., Chapters 3 and 4), future research could apply in-depth interviews or thoroughly examine case studies (n = 1 studies).

Fifth, the studied 'groups' might not be entirely representative of that specific group. For instance, in Chapter 5, only 4.3% of the parents of children with ASD indicated their child had an intellectual disability (IQ-score > 70) and 9.5% of these parents indicated subnormal intellectual functioning (IQ-score = 70-85) (APA, 2000). As the current global prevalence of intellectual disability among the ASD-population is estimated at approximately 50% (Russell et al., 2019), our findings might not generalize to the broader ASD-population. Future research should aim to recruit a sample of children that is representative of that specific population, taking into account diverse child factors such as intellectual functioning but also symptom severity. Also, shared child characteristics between the disability groups might have biased the findings. Previous studies, for example, indicated that also children with CP or DS have elevated levels of ASD-symptoms (Delobel-Ayoub et al., 2017; Reilly, 2009). Therefore, 'disability-specific characteristics' in a certain group might be more common in other NDD-groups than assumed, which challenges group comparison designs

(Seltzer et al., 2004). As suggested by Seltzer et al. (2004), future studies should either attempt to match participants by behavioral phenotypes or control for these effects statistically.

Methodological decisions

Further, we highlight three general methodological decisions that might confine this dissertation's findings.

First, the different studies only relied on parent reports of *single informants* (mainly mothers), which might have contributed to shared method variance and rater bias causing associations to inflate (Bauer et al., 2013; Williams & Brown, 1994). For instance, parents might generally appraise their child's behavior and their own parenting more positively (or more negatively), even when children objectively have more positive (or negative) characteristics. To overcome these challenges, future research should include multiple informants. For instance, children could report about their parents' behaviors, and significant others, such as siblings, grandparents, or teachers, could report on the child's behavior. Especially including children's own perspectives remains an important, yet challenging undertaking for future family research in NDD-populations (McCauley et al., 2019). To do so, a critical view towards a vulnerability-oriented approach, where children with a disability are framed as 'dependent', 'helpless' or 'to be protected', is needed (Daelman et al., 2020). Moreover, creative research techniques, such as ethnographic approaches, photovoice projects, theatre, and involving significant others as experts by experience, might be valuable ways to conduct inclusive research where the voices of individuals with a disability are heard (Maes et al., 2020). Including children's perspectives in parenting research, can provide valuable information about what 'good enough' parenting means for them and how practitioners can support positive family climates. Perhaps, the association between need-thwarting parenting and internalizing child problems, which are more difficult for parents to notice (van de Looij-Jansen et al., 2010), would remain less undetected when relying on child reports.

Second, when using parental self-reports, *social desirability* may also have been a potential problem (Sessa et al., 2001), for instance, causing parents to underreport controlling parenting and overreport autonomy support (Korelitz & Garber, 2016). To overcome difficulties with social desirability, future research could rely on *alternative measures and assessment methods*, such as observational studies (McCauley et al., 2019; van Esch et al., 2018; Wuyts et al., 2017). Moreover, these observational studies might also provide opportunities to further disentangle the effects of what parents actually do and say from how children interpret, perceive, or cope with these parental behaviors (Mabbe, 2018). Ideally, these observational studies should take place in a natural environment.

Third, the findings may be confined due to the specific *choice of questionnaires* to assess parenting behaviors, child (mal)adjustment, and child personality. For instance, in the longitudinal ASD-study (Chapter 3), we only assessed dysfunctional parenting behaviors, which provides a rather one-sided view on parenting practices. Also, the comparison of findings between the cross-sectional (Chapters 2 and 5) and the longitudinal studies (Chapters 3 and 4) is limited by the use of diverse measures of need-thwarting parenting, namely psychologically and externally controlling parenting, respectively. Although both parenting behaviors refer to intrusive, manipulative, and domineering parenting behaviors that thwart children's need for autonomy, they refer to different sources of pressure, namely internal or external (Grolnick, 2003; Grolnick & Pomerantz, 2009; Soenens & Vansteenkiste, 2010).

Also, to capture how parents of children with a NDD adjust their parenting behaviors to their child's disability-related vulnerabilities and needs, future research might need to rely on *more specific measures of parenting behavior* rather than the general questionnaires that were applied in this dissertation. For example, in ASD-research, the Parental Behavior Scale-ASD (PBS-A) (Lambrechts et al., 2011; Van Leeuwen & Noens, 2013) was developed to assess both general parenting behaviors and parenting behaviors that reflect specific adaptations of parents to their child's disability. In addition to the generic PBS-measures, the PBS-A includes two ASD-specific scales examining the degree to which parents stimulate the development of their child (e.g., by enhancing their child's theory of mind) and the degree to which they adapt the environment to their child (e.g., by adjusting their communication style). To the best of our knowledge, no comparable adapted parenting measures have been developed for parents of children with CP or DS yet. Future parenting research might consider an in-depth exploration of these parents' specific behavioral adaptations in the context of ASD, CP, and DS.

Another example is that we chose to examine child personality as a marker of individual differences between children even though a vast amount of research, especially in neurotypical populations, demonstrated that the construct of child temperament is equally valuable to capture these individual differences (De Pauw, 2017; Shiner, 1998; Shiner & Caspi, 2003). Moreover, scholars suggested that temperament and personality are neither entirely distinct nor completely redundant but should rather be conceptualized as two unique and complementary concepts (e.g., De Pauw, 2017; De Pauw & Mervielde, 2010; De Pauw et al., 2009; Shiner & DeYoung, 2013). Future research could assess both temperament and personality domains in NDD-populations to provide a more comprehensive picture of individual differences and to examine whether the current findings replicate.

Data-analytic decisions

This dissertation's insight into parenting practices and experiences may also be confined by our selection and choices of *data-analytic methods*.

For instance, whereas the majority of the studies presented in this dissertation focus on the effects of parenting on children's psychosocial development, the opposite direction of the effects seems equally plausible (e.g., Taraban & Shaw, 2018; Van den Akker et al., 2013; Van Heel et al., 2019). Notably, we used multi-group structural equation modeling (SEM) (Chapter 2) and latent change modeling (Chapters 3 and 4), to analyze parent to child effects yet these techniques did not address *bidirectionality*. It is important that future research searches for strategies to better capture the reciprocal interplay between parenting-(mal)adjustment associations in order to better understand its transactional nature.

Also, since SEM requires a *sufficient sample size* to provide a good model fit and statistical power (Kaplan, 2008), we were not able to examine longitudinal associations in the DS-group similar to the longitudinal study in the ASD- (Chapter 3) and CP-group (Chapter 4). It would be good if future research could rely on larger samples, particularly to study personality-by-parenting interactions as these effects are notoriously difficult to find, due to statistical reasons related to effect and sample size. Studying these interactions in the context of raising a child with DS might be particularly interesting to further unravel the meaning of the 'Down syndrome advantage', which states that children with DS might be easier to raise due to their personality profile (e.g., Stoneman, 2007).

Although the moderating role of child personality should be interpreted as modest and time-specific since the number of significant interactions is limited and some of the effects did not replicate across time (Chapters 3 and 4), the observed significant effects could be considered as a starting point for future studies on personality-by-parenting interactions among NDD-populations. Also, more intervention-based research is needed to investigate how parents can attune their parenting behavior to their child's personality in order to inform further guidelines for tailor-made support in families raising a child with a NDD.

Theoretical considerations

In addition to the many benefits, the choice for the theoretical framework of SDT also encompasses some limitations. Furthermore, we suggest some theoretical avenues that may be interesting for further examination, especially within these NDD-populations.

For instance, the SDT-framework mainly operates at the intra- and inter-individual level, which might have overshadowed broader ecological and socio-contextual processes. Future research could ponder on complementary or integrative theoretical frameworks that encompass more clearly how parenting is affected by socio-contextual factors, such as exclusion, stigma, equality, and power structures.

Another theoretical appealing avenue for future research is to further explore the construct of EE (Chapter 5) from a more longitudinal perspective. Within a longitudinal design, the stability of EE and its predictive value for the psychosocial development of children with a NDD can be evaluated. To also broaden our understanding of personality-by-parenting interplay models, it would be interesting to examine whether children are more vulnerable or susceptible to the effects of a stressed-out family environment (i.e., high EE) based upon their personality. Plausibly, EE may act as an environmental stressor that plays an important role in the development of behavioral or emotional child difficulties. Another interesting avenue regarding EE-research would be to further explore how EE relates to the construct of parental burnout in parents raising a child with a NDD. In neurotypical populations, there is now increasing recognition that extreme parental stress can result in parental burnout, characterized by feelings of physical and emotional exhaustion, incompetence in the parental role, and detachment of the child (Mikolajczak et al., 2018). It would be interesting to inquire to what extent high EE is related to feelings of parental burnout, both cross-sectionally and longitudinally.

Also the framework of attachment theory might be particularly interesting to further investigate in order to better understand the complexity of raising a child with a NDD. Studies applying attachment theory to special needs populations suggest that child disability should be understood as a ‘child factor’ that influences attachment, parent-child relationships, and the quality of caregiving (e.g., Howe, 2006; Janssen et al., 2002; Quinn & Gordon, 2011; Vandesande et al., 2019; Williamson et al., 2002). Especially since a child’s diagnosis can be experienced as *“traumatic”* or as *“a sense of loss”* for parents, attachment might play a particularly imperative role in the context of raising a child with a NDD from early age on. Moreover, these early experiences have been shown to impact parents’ sensitivity and emotional availability towards their child and the parent-child relationship throughout life (Howe, 2006; Marvin & Pianta, 1996; Quinn & Gordon, 2011; Schuengel et al., 2009). Perhaps this issue is extra salient in the context of CP, where the child's birth is often accompanied by traumatic experiences with intensive neonatal care and parents' fear of losing their child. Also research shows that the child's brain lesions could affect the development of brain connections related to emotion processing and regulation, which in turn directly affect attachment (Quinn & Gordon, 2011; Williamson et al., 2002).

Expanding the view to include broader factors

Finally, future research could also benefit from examining other child (e.g., comorbidity, symptom severity, the timing and process of the diagnosis, attachment), parental (e.g., personality, employment status, mindful parenting, resilience), and societal factors (e.g., the availability of services and support, the attitude of professionals or the community towards disability) that already have been identified as important sources of influence in children's psychosocial development or parent-child relationships (e.g., Gupta, 2007; Hayes & Watson, 2013; McCauley et al., 2019; Prinzie et al., 2009).

For instance, concerning children's additional difficulties, previous studies suggested to pay particular attention to the impact of regulatory problems (e.g., difficulties with eating and sleeping) in children with ASD (e.g., Davis & Carter, 2008), epilepsy, cerebral visual impairment, and ASD-symptoms in children with CP (Delobel-Ayoub et al., 2017; Novak et al., 2012; Philip et al., 2020), and heart diseases and ASD-symptoms in children with DS (Reilly, 2009). These additional difficulties might not only impact children's psychosocial development but also parents' experiences and behaviors.

As a second example, symptom severity might be an important moderator in parent-child interactions, requiring further in-depth research. For instance, in the longitudinal ASD-study (Chapter 3), the severity of ASD-symptoms was consistently associated with child personality and behavior. By statistically controlling for ASD-symptom severity in this study, the variation in emotional and behavioral problems and psychosocial strengths might have been reduced, limiting the chances to find significant parent-child associations. Hence, future research should explore the role of symptom severity more in-depth, for instance, by including symptom severity (e.g., ASD-symptoms in the ASD-group, GMFCS-scores in the CP-group, and intellectual functioning in the DS-group) as a moderator in the analyses and by relying upon a professional assessment of symptom severity (rather than parent report).

Also, more research is needed to examine positive family processes and its underlying dynamics in NDD-populations (Hayes & Watson, 2013; Van Riper, 2007; Whittingham et al., 2013;

Ylvén et al., 2006). Ideally, these positive family processes should be examined next to challenging processes and interactions, in order to provide more balanced views on family functioning within NDD-populations.

7.7 Epilogue: Personal reflections on the research process

In addition to these methodological, theoretical, and ethical reflections, in this section, I share some personal reflections on my position as a researcher and the struggles, uncertainties, and searches for balance and complexity I encountered during this research process.

A balance between complexity and generalizability. One of the main challenges I came across early in this research process was the struggle to capture the full complexity of what it means to raise a child with a NDD. As I started with the plan to explore a multitude of factors – derived from an orthopedagogical holistic point of view (Broekaert et al., 2004) and Belsky's process model on parenting (Belsky & Jaffee, 2006; Taraban & Shaw, 2018) – I realized its impossibility along the way. Moreover, I realized that parenting can be best interpreted as a multi-determined phenomenon shaped by child, parent, as well as social factors (Belsky, 1984; Belsky & Jaffee, 2006; Taraban & Shaw, 2018) and as a deeply personal process. Therefore, parents of children with a NDD cannot be pinned down to a single position. Accordingly, the research process became a search for balance. A balance between, on the one hand, aiming to encompass 'enough' complexity and, on the other hand, embracing the belief that the reality cannot be fully grasped while coming to terms with the feasibility of theoretical and statistical possibilities.

Thinking about diversity and labeling. Throughout the research process, I also struggled to find a balance between acknowledging the value of labels and providing enough room to disrupt these labels and to highlight children's and parents' individuality. On the one hand, the value and importance of labels became clear throughout the research process. In line with previous research, our findings demonstrate that a child's diagnosis can provide clarity and comfort, give parents access to appropriate support and interventions, and give them knowledge about their child's vulnerabilities and needs and how they can support them (Mulligan et al., 2012; Watson et al., 2011). Moreover, labels can be a useful tool as they provide a common language to work with in research and practice. For parents of children with ASD, the diagnosis could even feel apologetic, as parents realized that their child's difficulties did not originate from their own parental approach. Therefore, denying or questioning the label could also be experienced as hurtful.

On the other hand, labeling often also encompasses the unfavorable effects of reduction, stigmatization, categorization, and exclusion. To disrupt these processes, we also searched for possibilities to question well-defined boxes and labels on different levels. First, we tried to disrupt the framing of disability as an individual problem (Nunkoosing & Haydon-Laurelut, 2011) by examining the construct within its natural context (i.e., parent-child dyad), and leaving opportunities to elaborate on socio-cultural factors that position the construct of disability and parenting in a wider ecological framework. Second, we tried to illuminate the heterogeneity among children with and without ASD, CP, DS, and their parents by applying data-analytic methods which allowed us to examine processes at the level of the family unit (i.e., within-person level) (Keijsers et al., 2016). Third, this dissertation includes the examination of non-syndrome-specific factors (i.e., parenting and child personality), that vary within each individual, to encounter diversity between individuals, and to highlight the unicity of children with ASD, CP, and DS. Fourth, the inclusion of a reference group of children without any known disability enabled the identification of similar themes and processes across groups. These similarities provided opportunities to question and reflect on predetermined ideas about raising a child with a NDD and to question and disrupt certain dichotomies, such as disability-ability, abnormal-normal, healthy-sick, etc. In this line of thinking, De Schauwer et al. (2017) call out for an approach to disability, where all human beings, notwithstanding the processes of categorization, are seen as multiple and intra-active, and as always ‘becoming’ in intra-action with others.

In sum, I believe that the use of labels or diagnoses encompasses benefits but that we must be reflective and attentive of its improper use. It remains important to recognize the versatility of labels, which includes biological, psychological, and social components. Good diagnostics and support should take these three components into account and explore how these components might complicate someone's life or act as levers for resilience. I believe that the main message is not to reduce an individual to their label and to be continuously critical about the label’s impact on the individual and their environment. After all, a person is more than the generic name with which he/she is often referred to (Vanderplasschen et al., 2015). Following Hens (2019), labels should be approached as a concept with many meanings: as a diagnosis that is given based on criteria from a manual but also as a phenomenon that is inextricably linked to today's demanding society. For instance, ASD should not be regarded as a static fact but as a dynamic phenomenon that arises in interaction with the context, as a meaningful response to certain environments (Hens, 2019). Furthermore, labels and differences between individuals should be valued and perceived as a natural component of human life, rather than something that should be normalized or problematized. I believe that regular encounters with ‘the other’, for instance during schooling or leisure activities, a nuanced but also positive imaging of disability in the media, and a critical stance towards neoliberal political contexts are three examples of practices that can promote these goals.

Also, valuing diversity and disability requires action, responsibility, and continued critical reflection of all individuals on how practices or structures related to diversity or disability often result in stigma or exclusion.

Power disparities in the use of language. In line with this reflection on labeling, I became more reflective about the impact of language and its underlying power mechanisms during the research process. Following Lacan, language can invert and distort the discourse of 'the other' (Feldstein, 1995). Labeling people or defining 'groups' of people (with or without a disability) always entails a form of inclusion and exclusion. For instance, for me, it was a struggle to apply a 'suitable' term to describe the 'reference group', referring to the children without any known disability. Fluctuating between terms as 'children without a disability', 'typical children', the 'general population', the 'mainstream population', the 'no-disability group', and the 'no-NDD group', I realized there is no term which transcends the 'us-them thinking' and also fully captures the heterogeneity and complexity of the individuals that comprise a certain 'group'. Although this search ended up in the use of the terms 'reference group' and 'neurotypical population' – stemming from ASD-self-advocacy movements – I also acknowledge these terms' restrictions. For instance, 'neurotypical' still confines the complexity of a certain 'group' to a neurological level and even encompasses a sense of exclusion by the dichotomy between the 'typical' and 'atypical' ones. Stemming from the idea that every individual is unique and has his/her own strengths and vulnerabilities, I wonder what defines 'being typical' and who decides which individual is typical or not. In the light of this reflection, I would like to mention the release of the Maori glossary in June 2017, entitled 'The language of Enrichment'. The Maori glossary provides translations of existing words as well as the creation of new words to provide a common and non-judgmental language that increases individuals' understanding about the field of mental health, addiction, and support for individuals with a disability. Within this glossary, autism is translated as "*Takiwatanga*", which means "*In his/her own time and space*", a nonjudgmental representation that is based on the strength and ability of people (Cao, 2018).

The value of a mixed-methods approach. Although quantitative and qualitative research might seem quite different in nature, Broekaert (1988) states that quantitative and qualitative research approaches and methods are not contradictory but can go together alternatingly. Throughout this research process, I became convinced that both designs have their strengths and pitfalls and can complement each other to grasp a fuller picture of reality. Moreover, I believe this approach enriched the interpretation of the study findings but also deepened my own theoretical and reflective thinking.

More specifically, on the one hand, the quantitative results helped to structure the qualitative findings. For instance, the findings of Chapter 2 highlighted the applicability and usefulness of SDT's framework in NDD-populations, which strengthened our decision to structure parents' speech samples relying on SDT's framework (Chapter 6). Furthermore, the statistical analyses enabled us to illuminate patterns and associations and to formulate more 'generalizable' guidelines for practice. Although these guidelines provide a general basis, a common ground, an outline for practitioners, they also need to be adapted and differentiated along the way to meet the individuality of the child, parent, and their context. On the other hand, the qualitative findings also helped to interpret the findings from the quantitative studies, as they highlighted diversity and the need for nuance and contextualization. For example, the quantitative findings indicated that parents of children with a NDD, and CP more specifically, relied more on responsive parenting compared to the other parent-groups (Chapters 2 and 5). Based on parents' speech samples (Chapter 6), we were able to better understand that these findings seem to relate to the intense parent-child relationships in families of children with CP. More specifically, these parents mentioned they knew their child very well because they spent a huge amount of time with their child (e.g., going to therapies, doctor appointments) and had to be physically and mentally present due to the intense support needs of their child. By doing so, these parents conveyed their desire to support and nurture their child and to offer comfort and adequate support when their child needed it.

Even more importantly, the qualitative research approach in Chapter 6 enabled me to deepen the connection with the respondents and to better understand the complexity of parents' living situation. This connection is perceived as a prerequisite to enable meaningful action and to improve people's lives within orthopedagogical research (Broekaert et al., 2004). Whereas the initial contact with parents started through email, the connection with parents grew by contacting parents via telephone, for instance, to provide information about the research project and when inviting them to continue their participation in a follow-up study. This connection was especially strengthened when parents were also willing to participate in the spontaneous, free speech samples (Chapters 5 and 6), which were conducted through telephone or in parents' home environments. These personal contacts motivated me to continue the project in the best way possible and gave me a better understanding of parents' living situations. Hearing the struggles and perseverance in their voices, seeing their living environments (and how it was adapted to meet their child's needs), meeting their children, or looking through family photo books, gave a deeper meaning to parents' stories. Also, parents' engagement and enthusiasm to participate, their openness to share their stories, and generosity to invite an unfamiliar researcher into their homes filled – and still fills – me with great gratitude.

7.8 General conclusion

This dissertation aims to gain a deeper understanding of the complex reality of raising a child with a NDD, more specifically children with autism spectrum disorder, cerebral palsy, or Down syndrome. Therefore, we apply a balanced and cross-disability approach, examining both maladaptive and adaptive child and parenting factors across multiple child conditions and a reference group of children without any known disability. Quantitative and qualitative designs supplement one another, providing a fuller and nuanced perspective on parenting practices and experiences, and children's psychosocial development.

This dissertation's findings indicate that children with a NDD are at increased risk to demonstrate behavioral and emotional difficulties, where adolescence can be considered as an especially challenging period for both children and parents. We found evidence that both parenting behaviors and child personality are unique and important modifiers of this psychosocial development. Whereas need-supportive parenting behaviors strengthen a child's development, need-thwarting parenting behaviors hamper a child's development, for children with and without NDDs alike. Specific personality traits among children with a NDD were found to act as a risk or resilience factor in children's psychosocial development and a few personality-by-parenting interactions even suggested that some children might be more susceptible to the impact of parenting processes than others based upon their personality. For the majority of families raising a child with a NDD, these processes evolved in a positive emotional family climate, characterized by warmth and appreciation. However, compared to parents raising a child without any known disability, parents of children with a NDD reported more stress in diverse life domains and described more stressed-out family climates. Nonetheless, parents' spontaneous descriptions about their child, their parent-child relationship, and their experiences as a parent also illustrated that these parents experience many need-satisfying experiences when raising their child, for instance, as reflected in increased self-development and intense parent-child relationships. Overall, this dissertation's findings suggest that while raising a child with a NDD, for most parents, life is more intense, but at the same time also fascinating.

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Appendix I

English summary

Parenting practices and experiences in families of children with and without autism spectrum disorder, cerebral palsy or Down syndrome: A mixed-methods inquiry

Introduction

This dissertation aims to contribute to the current literature on parenting practices and experiences, and children's psychosocial development among families raising a child with and without a neurodevelopmental disability (NDD) by applying three innovative approaches. First, by examining what parents *do* in the interaction with their child (i.e., *specific parenting behaviors*), rather than the widely examined research avenues that study how parents *feel* (i.e., parental stress and well-being). Second, this dissertation aims to provide a *balanced perspective* on the complex reality of raising a child with a NDD by attending to the variability in the 'challenging' (e.g., need-thwarting parenting behaviors and experiences, emotional and behavioral problems in children, parenting stress) as well as the 'positive' (e.g., need-supportive parenting behaviors and experiences, psychosocial strengths in children, positive family climates) aspects of parenting practices and experiences, and children's psychosocial development. Third, this dissertation includes three diverse groups of parents raising a child with a NDD and a reference group of parents raising a child without any known disability, enabling a *cross-disability approach*. This approach provides possibilities to illuminate general parenting practices and experiences that generalize across groups, as well as disability-sensitivities, which are specific for the context of raising a child with a particular NDD. Also, within this dissertation, quantitative and qualitative designs supplement one another, providing a fuller and nuanced perspective on parenting practices and experiences, and children's psychosocial development.

Parenting and the development of children with a neurodevelopmental disability

For each parent, raising a child can be considered an emotionally powerful and complex undertaking that brings new opportunities, challenges, and responsibilities (Bornstein, 2015; Nelson et al., 2014; Nomaguchi & Milkie, 2020). However, when a child is growing up with a social, physical, or intellectual disability, due to a NDD, parents face additional challenges in the process of raising their child, such as providing the needed care for their child, financial worries, and uncertainties about their child's development and future (De Belie & Van Hove, 2005; Resch et al., 2010). Of the various paradigms in family research that aim to capture the experiences of parents raising a child with a NDD, the most widely investigated topic is that of *parental stress.* This research avenue consistently demonstrated that these parents share an increased vulnerability to experience higher levels of parental stress and lower levels of well-being within diverse life domains compared to parents of children with no disability (e.g., Gupta, 2007; Hayes & Watson, 2013; Valicenti-McDermott et al., 2015; Watson et al., 2011). Although these studies on parenting stress increased our understanding of how parents of children with a NDD *feel*, only limited research examined what parents actually *do* in the interaction with their child, more specifically *parenting behaviors*. This is unfortunate since the available studies acknowledge the vital role of parenting behaviors in the development and well-being of children with a NDD (e.g., Aran et al., 2007; Hodapp et al., 2019; McCauley et al., 2019; Power et al., 2019).

Towards a better understanding of parenting practices and experiences among parents raising a child with a neurodevelopmental disability: A cross-disability approach

In order to effectively support parents raising a child with a NDD, it is crucial to understand which overarching (i.e., disability-a specific) and specific (i.e., disability-specific) processes facilitate and challenge the reality of raising a child with a NDD. To do so, scholars called out for studies examining the dynamics of parenting behaviors and parent-child interactions across multiple NDD-groups (e.g., Laghezza et al., 2010; Lindsay, 2018; McCauley et al., 2019; Sher-Censor, 2015). This dissertation adopts a cross-disability approach by evaluating parenting practices and experiences within and across three NDDs: autism spectrum disorder (ASD), cerebral palsy (CP), and Down syndrome (DS), while also including a reference group of children without any known disability. The choice of these NDD-groups enables a comparison of three of the most prevalent NDDs among children in industrialized countries (Elsabbagh et al., 2012; Irving et al., 2008; Oskoui et al., 2013). Also, these three NDD-groups comprise children encountering developmental challenges (characterized by a delay or disturbance in the acquisition of skills) in three main developmental domains, including social-communication, motor functioning, and/or cognition (APA, 2013).

Studies among these populations have emphasized one striking similarity in the development of these children, that is the higher risk (on average, a two- to four-fold increase) to *develop behavioral or emotional difficulties* compared to peers without a disability (e.g., Arim et al., 2015; Bjorgaas et al., 2012; Dykens, 2007; Emerson & Hatton, 2007; Maljaars et al., 2014; Munir, 2016; van Gameren-Oosterom et al., 2011). Longitudinal studies even demonstrated that these behavioral and emotional difficulties continue into adolescence and emerging adulthood (e.g., Dykens et al., 2002; Sipal et al., 2010; Taylor & Seltzer, 2010). Although this developmental risk is widely acknowledged, very little is known about the underlying factors that can help to explain why some of these children develop additional behavioral or emotional difficulties, while others do not (Hodapp et al., 2019; McCauley et al., 2019; Tan et al., 2014; Vrijmoeth et al., 2012).

To better comprehend this vulnerability or resilience towards behavioral or emotional problems, scholars advocated that researchers should go beyond the inquiry of 'disability-specific sources'. Instead, they call for research on 'non-syndrome-specific' or 'transdiagnostic' factors that naturally vary among all children (Aran et al., 2007; Chetcuti et al., 2019; McCauley et al., 2019). Especially in the context of ASD-research, this reasoning is operationalized in the Modifier Model of Autism (McCauley et al., 2019; Mundy et al., 2007) stating that 'non-syndrome-specific' processes (i.e., modifier processes) are important moderators of the course and outcome of ASD, in addition to more 'syndrome-specific' biological etiological processes (i.e., initial causal processes). In particular, these lines of research nominated both *parenting behavior* and *child personality* as potential 'non-syndrome-specific' factors that may provide a richer understanding of the psychosocial heterogeneity in clinical samples, including youth with ASD, CP, or DS (Aran et al., 2007; De Pauw, 2017; McCauley et al., 2019; Mundy et al., 2007).

Parenting and child personality as valuable modifiers of the psychosocial development in children with a neurodevelopmental disability

To evaluate associations between *parenting behavior* and child outcomes, the framework of Self-Determination Theory (SDT), a macro-theory on human socialization, has been widely applied and validated in neurotypical populations (Deci & Ryan, 2000; Soenens et al., 2017). According to SDT, every individual is equipped with three basic psychological needs, that require fulfillment in order to incite personal growth and well-being: the need for autonomy (i.e., the need for self-direction), relatedness (i.e., the need for reciprocal care), and competence (i.e., the need to feel effective) (Deci & Ryan, 2000). As stated in SDT, the socialization environment is crucial to attaining either fulfillment or frustration of these three basic psychological needs. Consequently, parenting strategies can be regarded as more (i.e., need-supportive parenting) or less adequate (i.e., need-thwarting parenting) in supporting the child's fundamental psychological needs (Deci & Ryan, 2000; Vansteenkiste & Ryan, 2013).

In this dissertation, we primarily focus on two central dimensions of need-supportive parenting, that is autonomy-supportive and responsive parenting, and two dimensions of need-thwarting parenting, namely psychologically and externally controlling parenting (Soenens & Vansteenkiste, 2010). To date, a large body of research among neurotypical populations has convincingly demonstrated strong and differential paths between, on the one hand, need-supportive parenting and positive psychosocial development and, on the other hand, need-thwarting parenting and negative behavioral outcomes (Pinquart, 2017a, 2017b). However, research has only begun to empirically inquire the applicability of SDT in NDD-groups. This is surprising, as SDT claims to be universally applicable, which implies that *"children with and without* *special needs have the same basic needs to feel competent, to feel autonomous, and to feel loved”* (Deci & Chandler, 1986, p. 592).

Next to parenting behaviors, the study of individual differences between children, theoretically captured by the construct of *child personality*, is considered as one of the most significant contributors to children’s psychosocial development (Caspi & Shiner, 2006; De Pauw, 2017; De Pauw et al., 2009). More specifically, both cross-sectional and longitudinal studies consistently associated lower levels of Emotional Stability or Extraversion with more internalizing problem behavior, while lower levels of Benevolence and Conscientiousness showed to put children at risk of externalizing problem behavior (e.g., Prinzie et al., 2010; Prinzie et al., 2014; Van Leeuwen et al., 2004). However, these pathways have been mainly studied in neurotypical populations and among children with a behavioral, emotional, or psychiatric diagnosis. Although, especially within the field of ASD, there is growing attention to examine the construct of child personality to better grasp the wide behavioral variability demonstrated by individuals with ASD (Burrows et al., 2016; De Pauw et al., 2011; Mundy et al., 2007; Schwartz et al., 2009), the examination of personality-(mal)adjustment pathways is still in its infancy among children with a NDD.

Moreover, research suggested that a child’s personality also plays an important role in how a child is affected by, responds to, or interprets certain parenting behaviors. In the past decades, the most consistent support was found for the diathesis-stress model, indicating that children with more challenging personality traits (i.e., lower Benevolence, Conscientiousness, Emotional Stability) are particularly vulnerable to develop behavioral or emotional problems when exposed to controlling parenting behaviors (e.g., Bates & Pettit, 2015; de Haan et al., 2010; Kiff et al., 2011; Meunier et al., 2011). However, to date, no study has empirically addressed the joint value of child personality and parenting variables in relation to emotional and behavioral problems and psychosocial strengths in youth with a NDD. This is unfortunate since the identification of children, who might be less or more sensitive to the benefits associated with need-supportive parenting or the costs associated with controlling parenting, might provide valuable opportunities for tailored family support (Mabbe et al., 2019).

The family climate within families raising a child with a neurodevelopmental disability: Examining the construct of Expressed Emotion

When a child is growing up with a socio-communicative, physical, or cognitive disability, due to a NDD, this also influences the family climate (Resch et al., 2010; Van Riper, 2007). To examine these environments, the construct of *Expressed Emotion* (EE) has been widely applied as an indicator of the emotional quality of a family subsystem, among neurotypical populations (Rea et al., 2020; Sher-Censor, 2015) and – to a lesser extent also – among populations with developmental disabilities (Laghezza et al., 2010; Thompson et al., 2018). EE refers to a caregiver's spontaneous expressions about a relative and the intensity and regulation of emotions in those expressions. These expressions are captured by the Five Minute Speech Sample (FMSS) method, where a caregiver is asked to speak for five uninterrupted minutes about what kind of person the relative is and about how they get along together (i.e., spontaneous speech sample; Magaña-Amato, 1993; Magaña-Amato et al., 1986). In developmental research, high levels of a parent's EE towards their child, characterized by an excessive presence or intensity of emotions, have been associated with more conflict in the family but also with less favorable parenting behaviors (e.g., Cruise et al., 2011; Delvecchio et al., 2014; Kim Park et al., 2008; Narayan et al., 2015). Also in NDD-populations, the construct of EE is now receiving increasing attention to capture the emotional quality of a family subsystem. Although a small meta-analysis of seven studies demonstrated that significantly more parents raising a child with a developmental disability exhibit high EE compared to neurotypical populations (Thompson et al., 2018), more studies examining point estimates of EE and the conceptual meaning of EE in NDD-populations are needed (Kubicek et al., 2013; Laghezza et al., 2010).

Next to this quantitative approach to parents' EE (using a structured coding system), this dissertation also submitted parents' spontaneous speech samples to a *qualitative analysis*. These analyses aimed to capture naturalistic family life experiences and to provide a more ecological look into parents' experiences, instead of the more traditional qualitative approaches, such as (semi-)structured or in-depth interviews, which might bias or steer parents into a certain direction or might elicit social desirability (Ritchie et al., 2003). Moreover, previous qualitative analyses of parents' spontaneous speech samples demonstrated that this approach provides unique opportunities to gain more insight into parents' thoughts, feelings, and attitudes towards their child with a disability (Caspi et al., 2004; Kovac, 2018; Perez et al., 2014). Since parenting can be seen as a deeply personal process, more qualitative research is needed to unravel the complex reality of raising a child with a NDD. By doing so, parents' opportunities and challenges in their interaction with their child can be identified, providing insight for future support (Dieleman, Moyson, et al., 2018; Dieleman et al., 2019).

Research objectives

This dissertation includes five empirical chapters, steered by three research objectives (Figure 1).

Objective 1: To examine group differences and change in the psychosocial development of children with and without ASD, CP, or DS

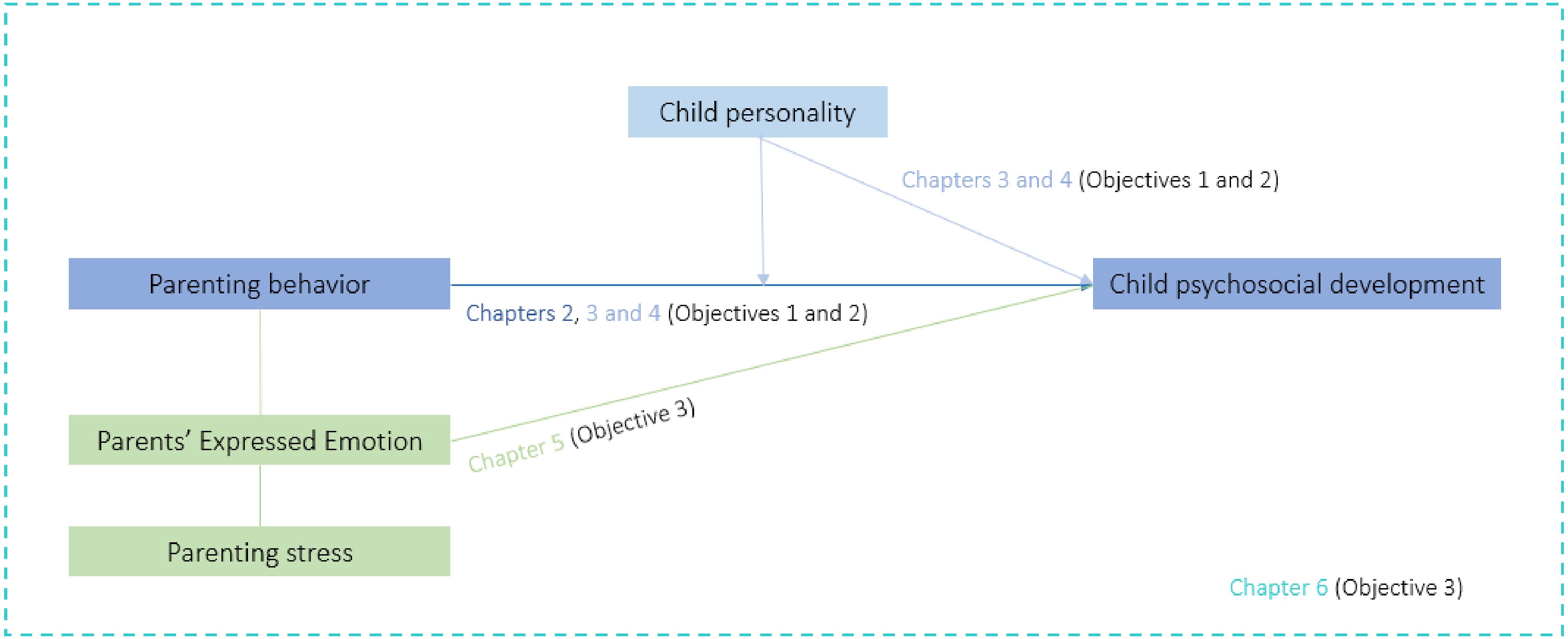
This dissertation starts by examining group differences in emotional and behavioral difficulties as well as psychosocial strengths among children with ASD, CP, DS, and without any known disability (**Research question 1.1**), by conducting Kruskal-Wallis H tests within a multigroup cross-sectional quantitative study (Chapter 2). Next, we aim to examine how these emotional and behavioral difficulties, and psychosocial strengths develop from childhood into adolescence and (emerging) adulthood (**Research question 1.2**), by testing latent change models within two longitudinal studies among children with ASD across a nine-year period (Chapter 3) and children with CP across a two-year period (Chapter 4).

Objective 2: To investigate the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without ASD, CP, or DS

As a second objective, this dissertation examines the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without ASD, CP, or DS.

First, to examine what parents do in their relation with their child, we examine need-supportive and -thwarting parenting behaviors among parents raising a child with ASD, CP, DS, and without any known disability, and how these behaviors might differ across groups (**Research question 2.1**). Group differences are examined within two cross-sectional multi-group studies using Kruskal-Wallis H tests (Chapter 2) and multivariate analysis of variance (MANOVA) (Chapter 5). Second, from a longitudinal perspective, we apply latent change modeling to examine whether parenting behaviors among parents raising a child with ASD (Chapter 3) or CP (Chapter 4) change over time, when their child develops from childhood into adolescence or (emerging) adulthood (**Research question 2.2**). Third, to better understand parenting-(mal)adjustment associations, we examine associations between parenting behaviors and children's psychosocial development (**Research question 2.3**). This research question is evaluated within a cross-sectional design using multi-group structural equation modeling (Chapter 2) and two longitudinal designs using latent change modeling (Chapters 3 and 4). Fourth, we also examine the unique role of child personality

Figure 1. Graphical representation of the empirical chapters



Objective 1: To examine group differences and change in the psychosocial development of children with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

Objective 2: To investigate the role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

Objective 3: To explore the emotional climate, parents' affective well-being, and parents' need-related experiences among families raising a child with and without autism spectrum disorder, cerebral palsy, or Down syndrome.

in children's psychosocial development among children with ASD (Chapter 3) and CP (Chapter 4) using latent change models (**Research question 2.4**), and whether these children are more sensitive to the effects of certain parenting behaviors based upon their personality (**Research question 2.5**). These personality-by-parenting interaction effects are examined using the Johnson-Neyman technique (Del Giudice, 2017).

Objective 3: To explore the emotional climate, parents' affective well-being, and need-related experiences among families raising a child with and without ASD, CP, or DS

To explore the third research objective, we conduct a quantitative (Chapter 5) and qualitative analysis (Chapter 6) of speech samples among parents spontaneously describing their child, the relationship with their child and – in Chapter 6 also – their parental experiences.

First, we examine point estimates and group differences of EE and levels of parenting stress among parents raising a child with ASD, CP, DS, and without any known disability using contingency table analysis and MANOVA (**Research question 3.1**). Next, to increase our understanding of the conceptual meaning of EE in the context of raising a child with a NDD (**Research question 3.2**), we explore whether the associations between EE, on the one hand, and parenting stress and behaviors, on the other hand, are similar across groups using multivariate analysis of covariance (MANCOVA) (Chapter 5). Finally, we qualitatively examine spontaneous speech samples among parents raising a child with ASD, CP, DS, and without any known disability. Relying on the SDT-framework, we explore possible group differences in these parents' spontaneously described need-frustrating and -satisfying experiences (**Research question 3.3**) within a multi-group qualitative comparison study using a deductive thematic analysis in NVivo (Chapter 6).

Results and discussion

Group differences and change in the psychosocial development of children with and without ASD, CP, or DS (Objective 1)

As a first research question, we examined group differences in the psychosocial development of children with and without ASD, CP, or DS (**Research question 1.1**). The study findings demonstrated that children with a NDD share a common vulnerability, that is, an increased risk to develop behavioral and/or emotional difficulties compared to children without a disability but the results also uncovered disability-sensitivities. More specifically, children with ASD exhibited the most challenging behavioral profile, indicated by the highest levels of internalizing and externalizing problems and the lowest levels of psychosocial strengths. Also children with CP showed elevated levels of externalizing and – to a lesser extent – also elevated levels of internalizing problems compared to children from the reference group. Among children with DS, the mean score on externalizing problems was more than twice as high compared to the reference group, yet these children demonstrated the lowest levels of internalizing problems of all groups. Although the findings among children with ASD and CP supplement previous findings (e.g., De Pauw et al., 2011; Maljaars et al., 2014; Parkes et al., 2008; Vrijmoeth et al., 2012), the results among children with DS support – less acknowledged – assumptions demonstrating that children with DS are also at increased risk to develop behavioral difficulties (Dieleman, De Pauw, et al., 2018; van Gameren-Oosterom et al., 2011). Concerning children's psychosocial strengths, the parents in each group reported relatively high levels of psychosocial strengths, yet demonstrating clear group differences. Whereas parents of children from the reference group reported the highest levels of psychosocial strengths, parents of children with CP and DS reported similar levels, which were significantly higher compared to parents of children with ASD.

Additionally, the longitudinal results indicated change in these psychosocial profiles in the transition from childhood into adolescence and emerging adulthood (**Research question 1.2**) among children with ASD (Chapter 3) and CP (Chapter 4). More specifically, among children with ASD, the elevated levels of internalizing problems remained stable over a nine-year period, externalizing problems decreased in the first time period (10.1 to 16.0 years old), and psychosocial strengths increased in the second time period (16.0 to 19.0 years old). Among children with CP, both internalizing and externalizing problems increased during the first time period (10.9 to 12.1 years old), yet psychosocial strengths significantly increased during the second time period (12.1 to 12.9 years old). Also the qualitative findings (Chapter 6) validated that the transition from childhood into adolescence can be a particularly challenging period for both parents and children as parents mentioned that they struggled with the delicate balance between the child's strive for independence and their child's need for support.

The role of parenting behaviors and child personality as modifiers of the psychosocial development in children with and without ASD, CP, or DS (Objective 2)

Interestingly, the examination of group differences in both need-thwarting and need-supportive parenting behaviors across parents raising a child with ASD, CP, DS, and without any known disability (Chapters 2 and 5) revealed overall small to modest differences (**Research question 2.1**). Concerning need-thwarting parenting, parents of children with ASD and parents of children with no disability reported higher levels of psychological control and overreactive parenting compared to parents raising a child with CP or DS. Parents of children with ASD and without any known disability also reported higher levels of autonomy-supportive parenting, yet lower levels of responsive parenting, compared to parents of children with CP and DS.

Taken together, although the general parenting research supports the idea that parents of children with a NDD are at risk to adopt more frequently pressuring or dysfunctional parenting strategies compared to neurotypical populations (Dieleman et al., 2017; Myers et al., 2009; Totsika et al., 2014), our results illustrate a more nuanced and differentiated perspective. More specifically, our findings show that parents of children with a NDD intensively and persistently engage in need-supportive parenting behaviors despite the frequent challenges they face.

Also the longitudinal analyses of parenting behaviors demonstrated no significant change in autonomy-supportive and controlling parenting behaviors (**Research question 2.2**) among parents of children with ASD (Chapter 3) or CP (Chapter 4) across time. Importantly, both studies demonstrated substantial variation in intra-individual changes in parenting behaviors, indicating that parents differ in how their parenting behaviors change across time.

Subsequently, we examined how these need-thwarting and need-supportive parenting behaviors related to child outcomes (**Research question 2.3**). In line with hypotheses derived from SDT (Deci & Ryan, 2000), both cross-sectional (Chapter 2) and longitudinal studies (Chapter 3 and 4) demonstrated two pathways, namely the unfavorable association between need-thwarting parenting and maladaptive outcomes, and the beneficial link between need-supportive parenting and beneficial outcomes.

Concerning the first pathway, the multi-group approach in Chapter 2 illustrated that psychologically controlling parenting was related to more externalizing child behaviors across children with ASD, CP, DS, and without any known disability. This parenting-maladjustment association was also replicated in longitudinal associations, where initial levels of need-thwarting parenting (i.e., externally controlling parenting in Chapters 3 and 4) related to initial levels of externalizing child behavior across a nine-year period in youth with ASD and across a two-year period in youth with CP. These associations suggest that children, with and without a NDD, are more likely to engage in aggressive or rule-breaking behavior when parents rely on harsh disciplining or pressuring behaviors. However, as relations between child and parenting behavior are fundamentally transactional (Dieleman et al., 2017; Taraban & Shaw, 2018), these findings may also suggest that parents of children with more externalizing behaviors tend to rely on more controlling parenting behaviors as a response to more frequent externalizing behaviors.

Concerning the second pathway, the multi-group approach in Chapter 2 also illustrated a positive parenting-adjustment pathway, as both autonomy-supportive and responsive parenting were associated with more psychosocial strengths in each group. This pathway was also examined and replicated longitudinally among youth with CP (Chapter 4), demonstrating that initial levels of autonomy-supportive parenting related significantly to initial levels of psychosocial strengths. These findings suggest that children might feel more encouraged to show and develop their psychosocial strengths when parents stimulate the child, stay attuned to the child, and respond in a warm and sensitive way. Also, the recognition of the child's psychosocial strengths might in turn provide parents with positive and energizing feelings to further engage in need-supportive parenting. Interestingly, the cross-sectional nor longitudinal designs found significant negative associations between need-supportive parenting and behavioral or emotional problems. Therefore, our findings support the idea that positive parenting might play a more prominent role in fostering positive outcomes rather than in protecting against maladaptive outcomes (Vansteenkiste & Ryan, 2013).

Next to parenting behaviors, the findings illustrated that also children's unique personality plays an important role in the development of emotional or behavioral problems as well as psychosocial strengths in both youth with ASD (Chapter 3) and CP (Chapter 4) (**Research question 2.4**). Regarding personality-maladjustment associations, the findings revealed similar associations as the well-documented associations in the broader developmental literature (e.g., De Pauw & Mervielde, 2010; Prinzie et al., 2010), where lower Extraversion and Emotional Stability were associated with higher initial levels of internalizing problems, and lower Benevolence and Emotional Stability were associated with higher initial levels of externalizing problems in both youth with ASD and CP. Among youth with CP, lower Benevolence was also related to higher initial levels of internalizing problems, and low Conscientiousness related to higher initial levels of externalizing problems. This latter association was also observed in the transition from 10 to 16 years old in the ASD-population, where higher Extraversion was also associated with higher initial levels of externalizing problems.

Additionally, child personality was also associated with more positive child outcomes, since higher scores on Benevolence and Extraversion were significantly related to higher initial levels of psychosocial strengths among both youth with ASD (only in the transition from 16 to 19 years old) and CP. Whereas these associations mainly corroborate previous findings in neurotypical populations (Anglim et al., 2020; Hill & Roberts, 2016), the association between other personality domains (i.e., higher Conscientiousness, Imagination, or Emotional Stability) and higher initial levels of psychosocial strengths among the CP-population might be more disability-specific. Within the

ASD-population, we also found two time-specific significant associations between child personality and change in the outcome variable, where higher Extraversion at the mean age of 10 years old related to a decrease in internalizing problems during the transition to 16 years old. Also, children with ASD with higher Benevolence at the mean age of 16 years old experienced an increase in their psychosocial strengths during their transition to 19 years old. Within the CP-population we found no significant associations between child personality and change in the outcome variable, which might be related to the shorter time interval in the CP-study.

Additionally, we examined the role of personality-by-parenting interactions on the psychosocial development of children with ASD and CP in these longitudinal studies (**Research question 2.5**). While lower Emotional Stability, Benevolence, and Conscientiousness seemed to indicate vulnerability and heightened sensitivity, higher Emotional Stability, Benevolence, and Conscientiousness served as resilience factors against externalizing behaviors in the presence of controlling parenting among children with ASD. In the CP-population, children with lower Emotional Stability also showed to be at risk to experience elevated initial levels of both internalizing and externalizing problem behaviors, yet parents also tended to be less controlling when these children temporarily exhibited more internalizing problems than usual.

Although these findings warrant further replication, they do support the idea that also children with a NDD might be more sensitive to the effects of parenting based upon their personality. Moreover, the findings corroborate previous research avenues among neurotypical populations suggesting that especially the personality trait Emotional Stability can be regarded as an important individual characteristic that influences a child's sensitivity towards the environment (Belsky & Pluess, 2016; Slagt et al., 2016).

The emotional climate, parents' affective well-being, and need-related experiences among families raising a child with and without ASD, CP, or DS (Objective 3)

The examination of group difference in point estimates of EE (**Research question 3.1**) revealed that the large majority of parents expressed low levels of EE (79.4%), yet high EE, which refers to a stressed-out family climate, was more prevalent among families of children with ASD (25.8%) and CP (28.4%) compared to families of children with DS (16.7%) or without any known disability (13.8%). Moreover, parents of children with ASD expressed more Criticism compared to parents from the reference group and less Warmth compared to the other groups. These group differences in EE were also reflected in parents' reports of stress, where parents of each NDD-group reported substantially higher levels of stress in their personal freedom, partner relation, and relatedness with their social network compared to parents of children without any known disability. These findings corroborate previous studies indicating that raising a child with a NDD impacts parents' well-being in different life domains (Peer & Hillman, 2014) and that these parents experience sufficient higher levels of parental stress compared to neurotypical populations (e.g., Gupta, 2007; Hayes & Watson, 2013).

Furthermore, our findings suggest that the nomological network of EE-parenting stress and EE-parenting behavior associations is highly similar across families raising a child with or without a disability (**Research question 3.2**). In each group of parents, stressed-out family climates (indicated by more parental Criticism and/or less Warmth) related to more feelings of role restriction, attachment stress, competence stress, and marital stress. Also, positive climates were associated with more need-supportive parenting (i.e., responsive parenting), whereas stressed-out climates related to more need-thwarting parenting behaviors (i.e., psychologically controlling and overreactive parenting) in each group. These similar associations across groups suggest that for families raising a child with or without a NDD, parents' need frustration might act as an energetic basis for parenting stress, which feeds less need-supportive and more need-thwarting behaviors and cultivates a stressed-out family climate. Moreover, our findings support the idea that the emotional quality of a family climate is shaped by the interplay of parental characteristics, child characteristics, and contextual sources of stress and support (Belsky & Jaffee, 2006; Sameroff, 2009).

Also the qualitative analysis of parents' spontaneous speech samples about their child, the relationship with their child, and their parenting experiences, revealed that parental, child, and societal factors (e.g., support from the environment, feelings of stigma and/or exclusion) shape parents' perspectives about raising their child. Moreover, the group differences in parents' need-related experiences (**Research question 3.3**) indicated that, in general, parents of children with a NDD describe more need-frustrating but also many autonomy-satisfying experiences (e.g., becoming more creative or resilient when handling challenges, developing a down-to-earth view on life), compared to parents of children without a disability. Moreover, the findings revealed disability-specificities. Whereas parents of children with ASD reported the most challenges concerning their relatedness with their child and their own parental competence, parents of children with CP expressed the most worries about their child's future and continuity of care, and parents of children with DS described the most need-satisfying experiences related to their self-development and family life.

Overall, the qualitative study findings offered a more balanced view on the realm of parenting a child with a NDD. Although raising a child with ASD, CP, or DS might entail unique challenges or require specific adaptations, structuring parental processes within the three SDT-needs also allowed us to get a better understanding of the opportunities that a child's NDD creates for positive need-satisfying experiences. This balanced approach unraveled that raising a child with a NDD is indeed not all doom and gloom, and is accompanied by both challenging and rewarding experiences, such as each parent-child relationship (Dieleman, Moyson, et al., 2018; Dieleman et al., 2019; Nurullah, 2013).

Practical implications

Regarding the psychosocial development of children with a NDD (Objective 1), the findings demonstrate that the psychosocial development of children with ASD, CP, and DS warrants further attention. Although it is widely understood that the transition from childhood to (emerging) adulthood brings new challenges for each child (Soenens et al., 2019), the study findings indicate that this transition can be considered as a pivotal period of change for both children with a NDD and their families. To support families during this transition period, it might be valuable to provide parents and children with information about the physical, emotional, and behavioral changes of a child during puberty through psycho-education, with a specific focus on how these changes might interact with the child's disability. Care providers should also be attentive to the well-being and feelings of 'being different' or 'otherness' (Murdick et al., 2004) among children and their parents during this phase of transition. To counteract feelings of 'otherness', caregivers, but also important others, should convey models of inclusion, where diversity is part of 'the norm', respected, and valued.

Furthermore, this dissertation's findings show that both parenting behaviors and child personality are unique modifiers of the psychosocial development in children with a NDD (Objective 2). Regarding parenting, this dissertation provided unique evidence for SDT's universality claim that *"all children need to feel competent, autonomous, and loved"* (Deci et al., 1992), including children growing up with special needs. More specifically, whereas need-thwarting parenting showed to be associated with unfavorable outcomes, need-supportive parenting was related to beneficial outcomes, for children with ASD, CP, DS, and without any known disability alike. Therefore, family interventions and parent support should try to diminish controlling parenting behaviors and challenging child behaviors, while also acknowledging and reinforcing parents' need-supportive behaviors and children's psychosocial strengths. Since previous SDT-based intervention studies among neurotypical populations supported the beneficial impact of an autonomy-supportive parenting program for children's mental health (Allen et al., 2019; Joussemet et al., 2018), we believe that these interventions could also be applied among families raising a child with a NDD. Moreover, the findings point towards the importance of applying a strength-based approach in parenting research and practice, where both parents' and children's strengths and efforts are acknowledged and reinforced, instead of solely focusing on ways to avoid or diminish controlling parenting or behavioral child problems (Dieleman et al., 2019).

Notwithstanding that these SDT-based guidelines might provide some general guidance in practice, this dissertation's findings also show that it is important to tune into a child's unique personality. Therefore, the exploration of a child's personality, its accompanying sensitivity towards the environment, and an elaborated understanding of the personality-by-parenting interplay can help parents and caregivers to more effectively tune into a child's unique personality (Huntington & Simeonsson, 1993). Parent support and intervention programs may then, for instance, attend more strongly to the children that are less sensitive to the benefits associated with need-supportive parenting and more sensitive to the costs associated with need-thwarting parenting (Mabbe et al., 2019).

Finally, future research and practice could pay particular attention to the emotional quality within a family subsystem of families raising a child with a NDD, as these climates might be more stressed-out, encompassed by more parenting stress in diverse life domains and more deconstructive parenting behaviors (Objective 3). Therefore, it seems important to 'zoom out' during parent support and to acknowledge the value of parents' relationships with important others, such as their partner, other children, friends, relatives, but also broader society. Especially reflecting on the position of these parents in a broader societal context might increase caregivers' awareness of important processes of stigmatization, individualized responsibility, and inequality. Also, combining quantitative (Chapters 2-5) and qualitative research designs (Chapters 6) in a mixed-methods inquiry, provided the possibility to grasp a fuller and nuanced perspective on the complex reality of raising a child with a NDD. Together, the findings illuminated that raising a child with a NDD encompasses both challenges as well as many need-satisfying opportunities. Therefore, we encourage further research and practices, where parents and children are met in their 'vulnerability' but – more importantly – also in their 'resilience'.

Conclusion

This dissertation aimed to gain a deeper understanding of the complex reality of raising a child with a NDD, more specifically children with ASD, CP, and DS. The findings indicated that parenting practices and experiences among these families are challenged, partially due to children's increased risk to demonstrate behavioral and/or emotional difficulties, where adolescence can be considered as an especially challenging period for both children and parents. We found evidence that both parenting behaviors and child personality are unique and important modifiers of this psychosocial development. Whereas need-supportive parenting behaviors strengthened a child's development, need-thwarting parenting behaviors hampered a child's development, for children with and without NDDs alike. Specific personality traits among children with a NDD were found to act as a risk or resilience factor in children's psychosocial development and a few personality-by-parenting interactions even suggested that some children might be more susceptible to the impact of parenting processes than others based upon their personality. For the majority of families raising a child with a NDD, these processes evolved in a positive emotional family climate, characterized by warmth and appreciation. However, compared to parents raising a child without any known disability, parents of children with a NDD reported more stress in diverse life domains and described more stressed-out family climates. Nonetheless, parents' spontaneous descriptions about their child, their parent-child relationship, and their experiences as a parent also illustrated that these parents experience many need-satisfying experiences when raising their child, for instance, as reflected in increased self-development and intense parent-child relationships. Overall, this dissertation's findings suggest that while raising a child with a NDD, for most parents, life is more intense, but at the same time also fascinating.

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Appendix II

Nederlandstalige samenvatting

Ouderschapspraktijken en ervaringen in gezinnen van kinderen met en zonder een autismespectrumstoornis, cerebrale parese of downsyndroom: Een mixed-methods onderzoek

Introductie

Dit proefschrift focust op de complexe realiteit van het opvoeden van een kind met een neurologische ontwikkelingsproblematiek zoals een autismespectrumstoornis, cerebrale parese en downsyndroom. Het proefschrift heeft als doel om ouderschapspraktijken en ervaringen in deze gezinnen beter begrijpen en meer inzicht te verwerven in de grote variatie van de psychosociale ontwikkeling bij de kinderen in deze gezinnen. Hiervoor steunt dit proefschrift op drie innovatieve benaderingen. Ten eerste, verbreden we in dit proefschrift de focus op hoe ouders zich *voelen* (d.w.z., ouderlijke stress en welzijn), door ook te onderzoeken wat ouders *doen* in de interactie met hun kind (d.w.z., specifiek opvoedingsgedrag). Ten tweede hanteert dit proefschrift een *evenwichtiger perspectief* om de complexe realiteit van het opvoeden van een kind met een neurologische ontwikkelingsproblematiek in kaart te brengen. Dit doen we door de aandacht te richten op de variatie in zowel 'uitdagende' (bijv., nood-ondermijnend opvoedingsgedrag, gedrags- en emotionele problemen bij kinderen, ouderlijke stress, ervaringen van nood-frustratie) als 'positieve' aspecten (bijv., nood-ondersteunend opvoedingsgedrag, psychosociale sterktes bij kinderen, positief gezinsklimaat, ervaringen van nood-satisfactie) van de ouderschapsbeleving en de psychosociale ontwikkeling van kinderen. Ten derde baseert dit proefschrift zich op een innovatieve 'cross-disability' benadering. Ouderschapsbeleving en de psychosociale ontwikkeling worden namelijk over vier groepen ouders heen in kaart gebracht: ouders van kinderen met drie diverse en frequent voorkomende neurologische ontwikkelingsproblematieken, namelijk autismespectrumstoornis, cerebrale parese en downsyndroom, en een referentiegroep van ouders die een kind opvoeden zonder een beperking. De vergelijking van opvoedingsprocessen in en over deze groepen heen biedt mogelijkheden om belangrijke generieke opvoedingsprocessen te identificeren, maar laat daarnaast ook ruimte om meer beperking-specifieke gevoeligheden te belichten, die specifiek zijn voor de context van het opvoeden van een kind met een bepaalde ontwikkelingsproblematiek. In dit proefschrift vullen kwantitatieve en kwalitatieve analysemethoden elkaar aan om een vollediger en genuanceerder perspectief te bieden op ouderschapspraktijken en ervaringen en de psychosociale ontwikkeling van kinderen met en zonder een neurologische ontwikkelingsproblematiek (hierna verkort naar ontwikkelingsproblematiek).

Ouderschap en de ontwikkeling van kinderen met een ontwikkelingsproblematiek

Voor zo goed als elke ouder betekent het opvoeden van een kind een emotioneel intense en complexe onderneming die nieuwe kansen, uitdagingen en verantwoordelijkheden met zich meebrengt (Bornstein, 2015; Nelson et al., 2014; Nomaguchi & Milkie, 2020). Wanneer een kind echter opgroeit met een sociale, fysieke of verstandelijke beperking als gevolg van een ontwikkelingsproblematiek, worden ouders geconfronteerd met extra uitdagingen bij de opvoeding, zoals het bieden van de aangepaste zorg, financiële bekommernissen en onzekerheden over de ontwikkeling en toekomst van hun kind (De Belie & Van Hove, 2005; Resch et al., 2010). Het is dan ook niet verwonderlijk dat het huidige familieonderzoek bij ouders die een kind opvoeden met een ontwikkelingsproblematiek vooral focust op het thema van *ouderlijke stress*. Deze onderzoekslijn toont consequent aan dat ouders van een kind met een beperking een grotere kwetsbaarheid delen om hogere niveaus van ouderlijke stress en lagere niveaus van welzijn in diverse levensdomeinen te ervaren in vergelijking met ouders van kinderen zonder een beperking (bijv., Gupta, 2007; Hayes & Watson, 2013; Valicenti-McDermott et al., 2015; Watson et al., 2011). Hoewel deze onderzoeken naar ouderlijke stress ons begrip vergroten over hoe ouders van kinderen met een beperking zich *voelen*, is er slechts beperkt onderzoek naar de rol van wat ouders feitelijk *doen* in de interactie met hun kind, meer bepaald hun opvoedingsgedrag. Dit is jammer, omdat de evidentie groeit dat opvoedingsgedrag een vitale rol speelt in de ontwikkeling en het welzijn van kinderen met een ontwikkelingsproblematiek (bijv., Aran et al., 2007; Hodapp et al., 2019; McCauley et al., 2019; Power et al., 2019).

Naar een beter begrip van ouderschapspraktijken en ervaringen van ouders die een kind opvoeden met een ontwikkelingsproblematiek: Een ‘cross-disability’ benadering

Als we ouders beter willen ondersteunen in de opvoeding, is het cruciaal om te begrijpen welke generieke (d.w.z., beperking-aspecifieke) en specifieke (d.w.z., beperking-specifieke) processen het opvoeden van een kind met een ontwikkelingsproblematiek faciliteren of net uitdagen. Om dit te doen, roepen academici op om de dynamieken van opvoedingsgedrag en ouder-kind interacties in meerdere groepen van kinderen met een ontwikkelingsproblematiek te onderzoeken (bijv., Laghezza et al., 2010; Lindsay, 2018; McCauley et al., 2019; Sher-Censor, 2015). Dit proefschrift hanteert een ‘cross-disability’ benadering door ouderschapspraktijken en ervaringen binnen en tussen drie ontwikkelingsproblematieken te bestuderen, namelijk bij ouders van kinderen met een autismespectrumstoornis (ASS), cerebrale parese (CP) of downsyndroom (DS), en door ook een referentiegroep te betrekken van kinderen zonder een beperking. De keuze van deze groepen maakt een vergelijking mogelijk tussen drie van de meest voorkomende ontwikkelingsproblematieken bij kinderen in geïndustrialiseerde landen (Elsabbagh et al., 2012; Irving et al., 2008; Oskoui et al., 2013). Bovendien omvatten deze drie groepen ook kinderen die geconfronteerd worden met ontwikkelingsmoeilijkheden (gekenmerkt door een vertraging of verstoring in het verwerven van vaardigheden) in drie belangrijke ontwikkelingsdomeinen, namelijk sociale-communicatie, motoriek en/of cognitie (APA, 2013).

Studies bij deze populaties benadrukken één opvallende overeenkomst in de ontwikkeling van deze kinderen, namelijk het verhoogde risico (gemiddeld twee- tot viermaal zoveel) om *gedrags- of emotionele problemen te ontwikkelen* in vergelijking met leeftijdsgenoten zonder een beperking (bijv., Arim et al., 2015; Bjorgaas et al., 2012; Dykens, 2007; Emerson & Hatton, 2007; Maljaars et al., 2014; Munir, 2016; van Gameren-Oosterom et al., 2011). Longitudinale studies hebben zelfs aangetoond dat deze gedrags- en emotionele problemen aanwezig blijven in de adolescentie en jongvolwassenheid (bijv., Dykens et al., 2002; Sipal et al., 2010; Taylor & Seltzer, 2010). Hoewel dit ontwikkelingsrisico algemeen wordt erkend, is er beperkte kennis over de onderliggende factoren die kunnen verklaren waarom sommige van deze kinderen bijkomende gedrags- of emotionele problemen ontwikkelen en andere niet (Hodapp et al., 2019; McCauley et al., 2019; Tan et al., 2014; Vrijmoeth et al., 2012).

Om deze kwetsbaarheid of veerkracht ten opzichte van gedrags- of emotionele problemen beter te begrijpen, moedigen academici onderzoekers aan om verder te gaan dan louter het bestuderen van ‘beperking-specifieke’ factoren. In plaats daarvan pleiten ze voor onderzoek naar ‘niet-syndroom-specifieke’ of ‘transdiagnostische’ factoren, die van nature verschillen tussen alle kinderen (Aran et al., 2007; Chetcuti et al., 2019; McCauley et al., 2019). Voornamelijk in de context van ASS-onderzoek wordt deze redenering geoperationaliseerd in het ‘Modifier Model of Autism’ (McCauley et al., 2019; Mundy et al., 2007) waarin wordt gesteld dat ‘niet-syndroom-specifieke’ processen (d.w.z., ‘modifier’ processen) belangrijke beïnvloedende factoren zijn in het ontwikkelingsbeloop en de ontwikkelingsuitkomsten bij kinderen met een ASS, naast meer ‘syndroom-specifieke’ biologische etiologische processen (d.w.z., initiële causale processen). In het bijzonder stellen deze onderzoekslijnen onderzoek voorop naar zowel het *opvoedingsgedrag* als de *persoonlijkheid van het kind*, aangezien deze potentiële 'niet-syndroom-specifieke' factoren een beter begrip kunnen geven van de psychosociale heterogeniteit in klinische groepen, waaronder jongeren met een ASS, CP of DS (Aran et al., 2007; De Pauw, 2017; McCauley et al., 2019; Mundy et al., 2007).

Opvoedingsgedrag en de persoonlijkheid van het kind als waardevolle beïnvloedende factoren in de psychosociale ontwikkeling van kinderen met een ontwikkelingsproblematiek

Om verbanden tussen *opvoedingsgedrag* en uitkomsten in de ontwikkeling van kinderen te evalueren, werd het theoretisch kader van de Zelf-Determinatie Theorie (ZDT), een macrotheorie over menselijke socialisatie, op grote schaal toegepast en gevalideerd in neurotypische populaties

(Deci & Ryan, 2000; Soenens et al., 2017). Volgens de ZDT heeft elk individu drie psychologische basisnoden die satisfactie vereisen om persoonlijke groei en welzijn te stimuleren: de nood aan autonomie (d.w.z., de nood aan psychologische vrijheid), verbondenheid (d.w.z., de nood aan een warme en hechte band met anderen) en competentie (d.w.z., de nood om zich bekwaam te voelen) (Deci & Ryan, 2000). Bovendien stelt de ZDT dat de socialisatiecontext cruciaal is voor het bereiken van satisfactie of frustratie van deze drie psychologische basisnoden. Bijgevolg kunnen opvoedingsstrategieën worden beschouwd als meer (d.w.z., nood-ondersteunend opvoedingsgedrag) of minder adequaat (d.w.z., nood-ondermijnend opvoedingsgedrag) in het ondersteunen van de fundamentele psychologische noden van een kind (Deci & Ryan, 2000; Vansteenkiste & Ryan, 2013).

In dit proefschrift richten we ons voornamelijk op twee centrale dimensies van nood-ondersteunend opvoedingsgedrag, namelijk autonomie-ondersteunend en responsief opvoedingsgedrag, en twee dimensies van nood-ondermijnend opvoedingsgedrag, namelijk psychologisch en extern controlerend opvoedingsgedrag (Soenens & Vansteenkiste, 2010). In de laatste decennia, hebben een groot aantal studies bij neurotypische populaties overtuigend aangetoond dat er sterke en differentiële associaties zijn tussen enerzijds nood-ondersteunend opvoedingsgedrag en positieve ontwikkelingsuitkomsten bij kinderen en anderzijds tussen nood-ondermijnend opvoedingsgedrag en gedragsmoeilijkheden bij kinderen (Pinquart, 2017a, 2017b). Echter, er is maar heel weinig onderzoek dat deze associaties in gezinnen van kinderen met een ontwikkelingsproblematiek onderzoekt. Dit is enigszins verrassend omdat de ZDT beweert ‘universeel toepasbaar’ te zijn, wat impliceert dat *"kinderen met en zonder specifieke ondersteuningsnoden dezelfde basisnoden hebben om zich competent, autonoom en geliefd te voelen"* (Deci & Chandler, 1986, p. 592).

Naast opvoedingsgedrag, wordt de studie van individuele verschillen tussen kinderen, dat theoretisch gevat wordt in het concept van *persoonlijkheid*, beschouwd als een van de belangrijkste factoren in de psychosociale ontwikkeling van kinderen (Caspi & Shiner, 2006; De Pauw, 2017; De Pauw et al., 2009). Meer specifiek, tonen zowel cross-sectionele als longitudinale studies consequente associaties aan tussen lagere niveaus van Emotionele Stabiliteit of Extraversie en meer internaliserend probleemgedrag, terwijl lage niveaus van Welwillendheid en Consciëntieusheid geassocieerd worden met meer externaliserend probleemgedrag (bijv., Prinzie et al., 2010; Prinzie et al., 2014; Van Leeuwen et al., 2004). Deze associaties zijn echter voornamelijk bestudeerd bij neurotypische populaties en bij kinderen met gedrags-, emotionele- of psychiatrische moeilijkheden. De laatste jaren is er vooral in ASS-onderzoek steeds meer aandacht voor het bestuderen van de persoonlijkheid van het kind om de brede gedragsvariabiliteit bij personen met een ASS beter te begrijpen (Burrows et al., 2016; De Pauw et al., 2011; Mundy et al., 2011; al., 2007; Schwartz et al., 2009). Echter, algemeen gezien, staat het onderzoek naar de associaties tussen persoonlijkheid en (mal)adaptieve ontwikkelingstrajecten nog in de kinderschoenen bij kinderen met een ontwikkelingsproblematiek.

Bovendien toont onderzoek aan dat de persoonlijkheid van een kind ook een belangrijke rol speelt in de manier waarop een kind wordt beïnvloed door, reageert op, of bepaald opvoedingsgedrag interpreteert. In de afgelopen decennia werd de meest consistente evidentie gevonden voor het diathese-stressmodel, wat veronderstelt dat kinderen met meer uitdagende persoonlijkheidskenmerken (d.w.z., lagere Welwillendheid, Consciëntieusheid, Emotionele Stabiliteit) kwetsbaarder zijn voor het ontwikkelen van gedrags- of emotionele moeilijkheden wanneer ze worden blootgesteld aan controlerend opvoedingsgedrag (bijv., Bates & Pettit, 2015; de Haan et al., 2010; Kiff et al., 2011; Meunier et al., 2011). Tot op heden heeft echter geen enkele studie empirisch de waarde van het samenspel tussen persoonlijkheids- en opvoedingsvariabelen in relatie tot gedragsproblemen en psychosociale sterktes bij jongeren met een ontwikkelingsproblematiek onderzocht. Dit is jammer, omdat de identificatie van kinderen, die mogelijk minder of meer gevoelig zijn voor de voordelen van nood-ondersteunend opvoedingsgedrag of de nadelen van controlerend opvoedingsgedrag, waardevolle kansen kan bieden voor gezinsondersteuning op maat (Mabbe et al., 2019).

Het gezinsklimaat binnen gezinnen die een kind opvoeden met een ontwikkelingsproblematiek: Onderzoek naar het concept van Expressed Emotion

Wanneer een kind opgroeit met een sociaal-communicatieve, motorische of cognitieve beperking, door een ontwikkelingsproblematiek, heeft dit ook invloed op het gezinsklimaat (Resch et al., 2010; Van Riper, 2007). Om deze contexten te bestuderen, werd het construct van 'Expressed Emotion' (EE) reeds frequent bij neurotypische populaties (Rea et al., 2020; Sher-Censor, 2015) onderzocht als indicator voor de emotionele kwaliteit van een familiesubsysteem. Een veel beperktere set aan studies evalueerde het EE-construct ook bij populaties met een kind met een ontwikkelingsproblematiek (Laghezza et al., 2010; Thompson et al., 2018). Het construct EE verwijst specifiek naar de uitdrukkingen van een zorgverlener over een bepaald familielid en de intensiteit en regulering van emoties die het familielid hierbij uitdrukt. Deze uitdrukkingen worden in onderzoek frequent vastgelegd door de 'Five Minute Speech Sample' (FMSS)-methode, waarbij een zorgverlener wordt gevraagd om gedurende vijf minuten ononderbroken te vertellen over wat voor persoon het familielid is en hoe ze overeenkomen (cf., spontane spraaksamples; Magaña-Amato, 1993; Magaña-Amato et al., 1986). In ontwikkelingsgericht onderzoek werden hoge niveaus van ouderlijke EE naar het kind - gekenmerkt door een overmatige aanwezigheid of intensiteit van emoties - relatief consistent in verband gebracht met meer conflicten in het gezin, maar ook met minder gunstig opvoedingsgedrag (bijv., Cruise et al., 2011; Delvecchio et al., 2014; Kim Park et al., 2008; Narayan et al., 2015). Ook in populaties met kinderen met een ontwikkelingsproblematiek krijgt het construct van EE nu steeds meer aandacht om de emotionele kwaliteit van een gezinsklimaat beter te begrijpen. Hoewel een kleine meta-analyse van zeven studies aantoonde dat significant meer ouders die een kind met een ontwikkelingsproblematiek opvoeden hoge EE vertonen in vergelijking met neurotypische populaties (Thompson et al., 2018), zijn er meer studies nodig die het voorkomen van hoge EE en de conceptuele betekenis van EE in deze populaties onderzoeken (Kubicek et al., 2013; Laghezza et al., 2010).

Naast deze kwantitatieve benadering van EE (met behulp van een gestructureerd coderingssysteem), omvat dit proefschrift ook een *kwalitatieve analyse* van deze spontane spraaksamples van ouders. Deze kwalitatieve analyses trachten om meer naturalistische ervaringen in het gezinsleven te vatten en om een meer ecologische kijk te geven op de ervaringen van ouders. Dit om onder meer tegemoet te komen aan meer traditionele kwalitatieve benaderingen, zoals (semi-) gestructureerde of diepte-interviews, die ouders in een bepaalde richting kunnen sturen of meer sociale wenselijkheid kunnen oproepen (Ritchie et al., 2003). Bovendien toonden eerdere kwalitatieve analyses van spontane spraaksamples van ouders aan dat deze benadering unieke kansen biedt om meer inzicht te krijgen in de gedachten, gevoelens en attitudes van ouders ten opzichte van hun kind met een beperking (Caspi et al., 2004; Kovac, 2018; Perez et al., 2004; al., 2014). Omdat ouderschap kan worden gezien als een zeer persoonlijk proces, is meer kwalitatief onderzoek nodig om de complexe realiteit van het opvoeden van een kind met een ontwikkelingsproblematiek te ontrafelen. Door dit te doen, kunnen de kansen en uitdagingen van ouders in hun interactie met hun kind worden geïdentificeerd, wat ook nieuwe inzichten kan bieden voor toekomstige ondersteuning (Dieleman, Moyson, et al., 2018; Dieleman et al., 2019).

Onderzoeksdoelstellingen

Dit proefschrift omvat vijf empirische hoofdstukken, waarin drie grote onderzoeksdoelstellingen beantwoord worden (Figuur 1).

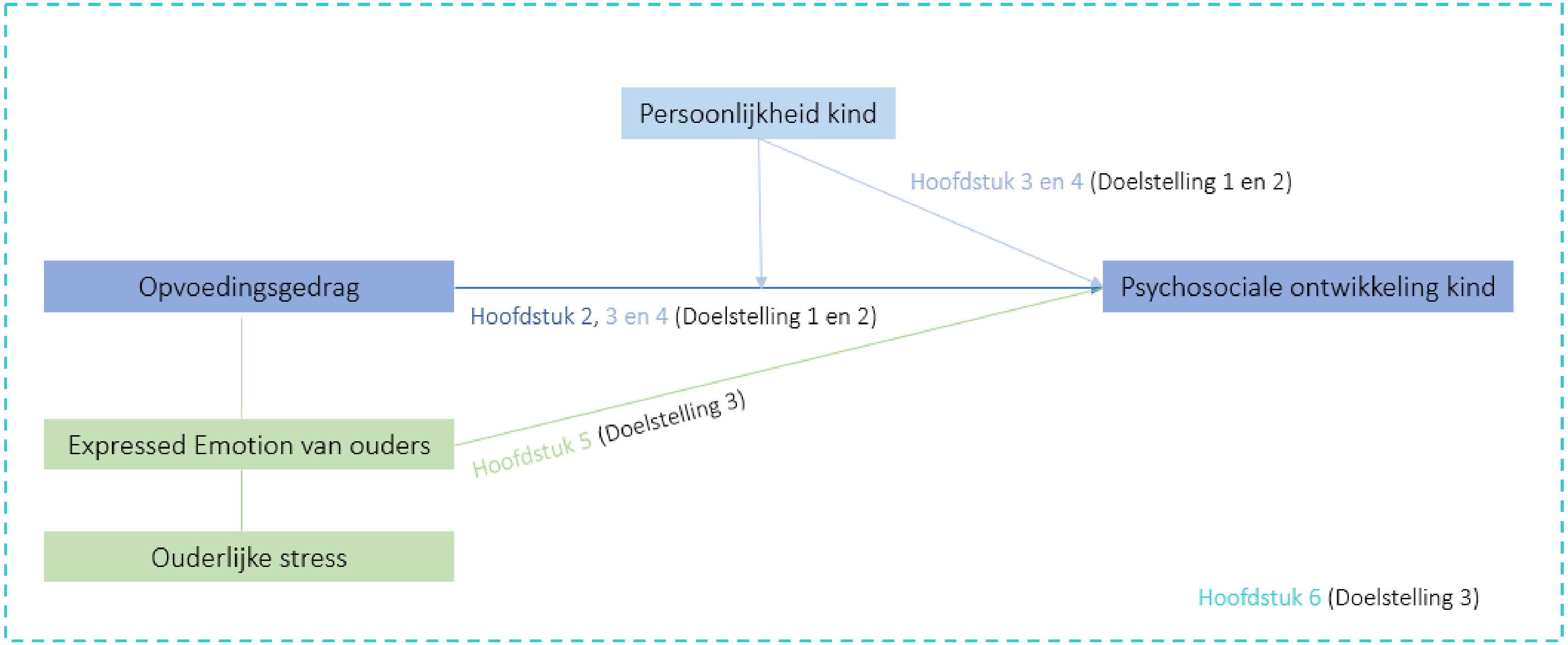
Doelstelling 1: Het onderzoeken van groepsverschillen en veranderingen in de psychosociale ontwikkeling van kinderen met en zonder ASS, CP of DS

Dit proefschrift begint met het onderzoeken van groepsverschillen in gedrags- en emotionele problemen en psychosociale sterktes bij kinderen met een ASS, CP, DS en zonder een beperking (**Onderzoeksvraag 1.1**) door Kruskal-Wallis H-tests uit te voeren in een cross-sectionele multi-groep studie (Hoofdstuk 2). Vervolgens onderzoeken we hoe deze gedrags- en emotionele problemen en psychosociale sterktes zich ontwikkelen van de kindertijd tot de adolescentie en (jong) volwassenheid (**Onderzoeksvraag 1.2**). Deze onderzoeksvraag wordt onderzocht door latente veranderingsmodellen te testen in twee longitudinale studies bij kinderen met een ASS over een periode van negen jaar (Hoofdstuk 3) en bij kinderen met CP over een periode van twee jaar (Hoofdstuk 4).

Doelstelling 2: Het bestuderen van de rol van opvoedingsgedrag en de persoonlijkheid van het kind als beïnvloedende factoren in de psychosociale ontwikkeling van kinderen met en zonder ASS, CP of DS

Als tweede doelstelling onderzoekt dit proefschrift de rol van opvoedingsgedrag en de persoonlijkheid van het kind als beïnvloedende factoren in de psychosociale ontwikkeling van kinderen met en zonder ASS, CP of DS. Om te bestuderen wat ouders doen in hun relatie met hun kind, onderzoeken we eerst nood-ondersteunend en -ondermijnend opvoedingsgedrag van ouders die een kind opvoeden met een ASS, CP, DS of zonder een beperking, en hoe dit gedrag mogelijks verschilt tussen groepen (**Onderzoeksvraag 2.1**). Groepsverschillen worden onderzocht in twee cross-sectionele multi-groep studies met behulp van Kruskal-Wallis H-tests (Hoofdstuk 2) en multivariate variantieanalyse (MANOVA) (Hoofdstuk 5). Ten tweede passen we latente veranderingsmodellen toe om vanuit een longitudinaal perspectief te onderzoeken of het opvoedingsgedrag van ouders die een kind met een ASS (Hoofdstuk 3) of CP (Hoofdstuk 4) opvoeden verandert over de tijd, wanneer hun kind zich ontwikkelt van de kindertijd tot de adolescentie of (jong) volwassenheid (**Onderzoeksvraag 2.2**). Ten derde onderzoeken we associaties tussen opvoedingsgedrag en (mal)adaptieve uitkomsten in de psychosociale ontwikkeling van kinderen (**Onderzoeksvraag 2.3**). Deze onderzoeksvraag wordt geëvalueerd in een cross-sectioneel design met behulp van multi-groep structurele vergelijkingsmodellen (Hoofdstuk 2) en in twee longitudinale designs met behulp van latente veranderingsmodellen (Hoofdstuk 3 en 4). Ten vierde onderzoeken we ook de unieke rol van de persoonlijkheid van het kind in de psychosociale ontwikkeling van kinderen met een ASS (Hoofdstuk 3) en CP (Hoofdstuk 4) met behulp van latente veranderingsmodellen (**Onderzoeksvraag 2.4**) en of deze kinderen gevoeliger

Figuur 1. Grafische weergave van de empirische hoofdstukken



Doelstelling 1: Het onderzoeken van groepsverschillen en veranderingen in de psychosociale ontwikkeling van kinderen met en zonder een autismespectrumstoornis, cerebrale parese of downsyndroom.

Doelstelling 2: Het bestuderen van de rol van opvoedingsgedrag en de persoonlijkheid van het kind als beïnvloedende factoren in de psychosociale ontwikkeling van kinderen met en zonder een autismespectrumstoornis, cerebrale parese of downsyndroom.

Doelstelling 3: Het exploreren van het emotionele klimaat, het affectieve welzijn en de nood-gerelateerde ervaringen van ouders die een kind opvoeden met en zonder een autismespectrumstoornis, cerebrale parese of downsyndroom.

zijn voor de effecten van bepaald opvoedingsgedrag op basis van hun persoonlijkheid (**Onderzoeksvraag 2.5**). Om de interactie-effecten tussen de persoonlijkheid van het kind en opvoedingsgedrag door de ouder na te gaan in de associatie met de psychosociale ontwikkeling van kinderen met een ASS (Hoofdstuk 3) en CP (Hoofdstuk 4) gebruiken we de Johnson-Neyman-techniek (Del Giudice, 2017).

Doelstelling 3: Het exploreren van het emotionele klimaat, het affectieve welzijn en de nood-gerelateerde ervaringen van ouders die een kind opvoeden met en zonder ASS, CP of DS

Om de derde onderzoeksdoelstelling te bestuderen, voeren we een kwantitatieve (Hoofdstuk 5) en kwalitatieve analyse (Hoofdstuk 6) uit van spraaksamples van ouders die spontaan vertellen over hun kind, de relatie met hun kind en - in Hoofdstuk 6 ook – over hun ouderlijke ervaringen.

Eerst onderzoeken we het voorkomen van de diverse EE-domeinen, groepsverschillen van EE en niveaus van ouderlijke stress bij ouders die een kind opvoeden met of zonder een ASS, CP of DS, met behulp van kruistabelanalyse en MANOVA (**Onderzoeksvraag 3.1**). Ten tweede, trachten we om het begrip van de conceptuele betekenis van EE in de context van het opvoeden van een kind met een ontwikkelingsproblematiek te vergroten (**Onderzoeksvraag 3.2**). Om deze onderzoeksvraag te beantwoorden, gaan we na of de associaties tussen EE, enerzijds, en ouderlijke stress en opvoedingsgedrag, anderzijds, vergelijkbaar zijn tussen de groepen met behulp van multivariate covariantie-analyse (MANCOVA) (Hoofdstuk 5). Ten slotte analyseren we op een kwalitatieve manier spontane spraaksamples van ouders die een kind opvoeden met een ASS, CP, DS en zonder een beperking. Met de ZDT als structurerend kader, gaan we na of er bij deze samples groepsverschillen zijn in ouderlijke ervaringen van nood-frustratie en -satisfactie (**Onderzoeksvraag 3.3**). Deze onderzoeksvraag bestuderen we binnen een kwalitatieve vergelijkingsstudie met behulp van deductieve thematische analyse in NVivo (Hoofdstuk 6).

Resultaten en discussie

Groepsverschillen en verandering in de psychosociale ontwikkeling van kinderen met en zonder ASS, CP of DS (Doelstelling 1)

Als eerste onderzoeksvraag onderzochten we groepsverschillen in de psychosociale ontwikkeling van kinderen met en zonder ASS, CP of DS (**Onderzoeksvraag 1.1**). De bevindingen van het onderzoek toonden aan dat kinderen met een ontwikkelingsproblematiek een gemeenschappelijke kwetsbaarheid delen, namelijk een verhoogd risico op het ontwikkelen van gedrags- en/of emotionele problemen in vergelijking met kinderen zonder een beperking. Bovendien brachten de resultaten ook beperking-specifieke gevoeligheden aan het licht. Meer specifiek vertoonden kinderen met een ASS het meest uitdagende gedragsprofiel, gekenmerkt door de hoogste niveaus van internaliserende en externaliserende problemen en de laagste niveaus van psychosociale sterktes. Ook kinderen met CP vertoonden verhoogde niveaus van externaliserende en – in mindere mate – ook verhoogde niveaus van internaliserende problemen in vergelijking met kinderen uit de referentiegroep. Ook bij kinderen met DS was de gemiddelde score op externaliserende problemen meer dan twee keer zo hoog als in de referentiegroep. Opmerkelijk is dat deze kinderen de laagste niveaus van internaliserende problemen van alle groepen vertoonden. Hoewel de bevindingen bij kinderen met een ASS en CP in lijn liggen met eerder onderzoek (bijv., De Pauw et al., 2011; Maljaars et al., 2014; Parkes et al., 2008; Vrijmoeth et al., 2012), ondersteunen ze ook – minder (h)erkend – onderzoek dat aantoont dat kinderen met DS ook een verhoogd risico lopen op het ontwikkelen van gedragsproblemen (Dieleman, De Pauw, et al., 2018; van Gameren-Oosterom et al., 2011). Wat betreft de psychosociale sterktes van kinderen, rapporteerden de ouders in elke groep relatief hoge niveaus van psychosociale sterktes, maar toonden de bevindingen ook duidelijke groepsverschillen. Terwijl ouders van kinderen uit de referentiegroep de hoogste niveaus van psychosociale sterktes rapporteerden, was het niveau van deze sterktes vergelijkbaar tussen kinderen met CP en DS, die op hun beurt significant hoger waren dan bij kinderen met een ASS.

Bovendien wezen de longitudinale resultaten op significante verandering in deze psychosociale profielen in de overgang van de kindertijd naar de adolescentie en (vroege) volwassenheid (**Onderzoeksvraag 1.2**) bij kinderen met een ASS (Hoofdstuk 3) en CP (Hoofdstuk 4). Meer specifiek, bij kinderen met een ASS bleven de verhoogde niveaus van internaliserende problemen stabiel over een periode van negen jaar, namen externaliserende problemen af in de eerste tijdsperiode (10.1 tot 16.0 jaar oud) en namen psychosociale sterktes toe in de tweede tijdsperiode (16.0 tot 19.0 jaar oud). Bij kinderen met CP namen zowel internaliserende als externaliserende problemen toe tijdens de eerste tijdsperiode (10.9 tot 12.1 jaar oud), maar psychosociale sterktes namen ook significant toe tijdens de tweede tijdsperiode (12.1 tot 12.9 jaar oud). Ook de kwalitatieve bevindingen (Hoofdstuk 6) belichtten dat de overgang naar (vroege) volwassenheid een bijzonder uitdagende periode kan zijn voor zowel ouders als kinderen, aangezien ouders aangaven dat ze tijdens deze periode worstelden met het delicate evenwicht tussen, enerzijds, het streven van het kind naar onafhankelijkheid en, anderzijds, de blijvende nood aan ondersteuning.

De rol van opvoedingsgedrag en de persoonlijkheid van het kind als beïnvloedende factoren in de psychosociale ontwikkeling van kinderen met en zonder ASS, CP of DS (Doelstelling 2)

Het bestuderen van mogelijke groepsverschillen in zowel nood-ondermijnend als -ondersteunend opvoedingsgedrag tussen ouders die een kind opvoeden met een ASS, CP, DS en zonder een beperking (Hoofdstuk 2 en 5) brachten algemeen kleine tot matige verschillen aan het licht (**Onderzoeksvraag 2.1**). Wat betreft nood-ondermijnend opvoedingsgedrag, rapporteerden ouders van kinderen met een ASS en ouders van kinderen zonder een beperking hogere niveaus van psychologische controle en overreactief opvoedingsgedrag in vergelijking met ouders die een kind opvoeden met CP of DS. Ouders van kinderen met een ASS en zonder een beperking rapporteerden ook hogere niveaus van autonomie-ondersteunend opvoedingsgedrag, maar lagere niveaus in responsief opvoeden in vergelijking met ouders van kinderen met CP en DS.

Hoewel eerder opvoedingsonderzoek het idee ondersteunt dat ouders van kinderen met een ontwikkelingsproblematiek het risico lopen om vaker controlerende of minder gunstige opvoedingsstrategieën te hanteren in vergelijking met neurotypische populaties (Dieleman et al., 2017; Myers et al., 2009; Totsika et al., 2014), illustreren onze resultaten een meer genuanceerd en gedifferentieerd perspectief. Meer specifiek suggereren onze bevindingen dat ouders van kinderen met een ontwikkelingsproblematiek zich met veel doorzetting en volhouding inzetten om nood-ondersteunend opvoedingsgedrag te hanteren ondanks de vele uitdagingen waarmee ze worden geconfronteerd.

De longitudinale analyses van opvoedingsgedrag lieten geen significante verandering zien in autonomie-ondersteunend en -controlerend opvoedingsgedrag (**Onderzoeksvraag 2.2**) bij ouders van kinderen met een ASS (Hoofdstuk 3) of CP (Hoofdstuk 4) doorheen de tijd. Beide studies toonden wel substantiële variatie in intra-individuele veranderingen in opvoedingsgedrag, wat suggereert dat ouders verschillen in de manier waarop hun opvoedingsgedrag in de loop van de tijd verandert.

Vervolgens onderzochten we hoe nood-ondermijnend en -ondersteunend opvoedingsgedrag zich verhouden tot de psychosociale ontwikkelingsuitkomsten bij het kind (**Onderzoeksvraag 2.3**). Zowel de cross-sectionele studie (Hoofdstuk 2) als de longitudinale studies (Hoofdstuk 3 en 4) toonden twee paden aan in overeenstemming met ZDT-gebaseerde hypothesen (Deci & Ryan, 2000), namelijk het ongunstige pad tussen nood-ondermijnend opvoedingsgedrag en maladaptieve uitkomsten en het gunstige pad tussen nood-ondersteunend opvoedingsgedrag en adaptieve uitkomsten.

Wat het eerste pad betreft, illustreerde de multi-groep benadering in Hoofdstuk 2 dat psychologisch controlerend opvoedingsgedrag significant geassocieerd is met meer externaliserend kindgedrag bij zowel kinderen met een ASS, CP, DS en zonder een beperking. Dit verband tussen opvoedingsgedrag en gedragsmoeilijkheden bij kinderen werd ook gerepliceerd in de longitudinale studies, waar initiële niveaus van nood-ondermijnend opvoedingsgedrag (d.w.z., extern controlerend opvoedingsgedrag in Hoofdstuk 3 en 4) gerelateerd werden aan initiële niveaus van externaliserend kindgedrag over een periode van negen jaar bij jongeren met een ASS en een periode van twee jaar bij jongeren met CP. Deze associaties suggereren dat kinderen, met en zonder een ontwikkelingsproblematiek, meer risico hebben om agressief of regeloverschrijdend gedrag te vertonen wanneer ouders streng disciplinerende of controlerende strategieën gebruiken. Aangezien de relatie tussen kind- en opvoedingsgedrag echter fundamenteel transactioneel is (Dieleman et al., 2017; Taraban & Shaw, 2018), suggereren deze bevindingen ook dat ouders van kinderen die meer externaliserend gedrag vertonen de neiging hebben om meer controlerend opvoedingsgedrag te gebruiken als reactie op dit externaliserend gedrag.

Wat het tweede pad betreft, illustreerde de multi-groep benadering in Hoofdstuk 2 ook een gunstiger pad, aangezien zowel autonomie-ondersteunend als responsief opvoedingsgedrag significant geassocieerd werden met meer psychosociale sterktes in elke groep. Dit pad werd ook longitudinaal onderzocht én gerepliceerd bij jongeren met CP (Hoofdstuk 4), waarbij initiële niveaus van autonomie-ondersteunend opvoedingsgedrag significant geassocieerd bleken te zijn met initiële niveaus van psychosociale sterktes. Deze bevindingen suggereren dat kinderen zich meer aangemoedigd voelen om hun psychosociale sterktes te tonen en verder te ontwikkelen wanneer ouders het kind stimuleren, zich afstemmen op het kind en op een warme en gevoelige manier reageren. Bovendien is het ook mogelijk dat wanneer ouders de psychosociale sterktes van hun kind meer erkennen, dit ouders op een positieve manier stimuleert om verder in te zetten op nood-ondersteunende opvoedingsgedragingen. Het is daarnaast interessant om op te merken dat noch de cross-sectionele studie noch de longitudinale studies significante negatieve associaties vonden tussen nood-ondersteunend opvoedingsgedrag en gedrags- of emotionele problemen. Daardoor ondersteunen onze bevindingen het idee dat positief opvoedingsgedrag een meer prominente rol zou kunnen spelen bij het bevorderen van adaptieve ontwikkelingsuitkomsten dan in het beschermen tegen maladaptieve ontwikkelingsuitkomsten (Vansteenkiste & Ryan, 2013).

Naast opvoedingsgedrag, lieten onze resultaten ook zien dat de unieke persoonlijkheid van kinderen een belangrijke rol speelt bij de ontwikkeling van gedrags- of emotionele problemen en psychosociale sterktes bij zowel jongeren met een ASS (Hoofdstuk 3) als CP (Hoofdstuk 4) (**Onderzoeksvraag 2.4**). De associaties tussen persoonlijkheid en maladaptieve ontwikkelingstuitkomsten waren vergelijkbaar met de goed gedocumenteerde associaties bij neurotypische populaties (bijv., De Pauw & Mervielde, 2010; Prinzie et al., 2010). Namelijk, lagere Extraversie en Emotionele Stabiliteit waren significant geassocieerd met hogere initiële niveaus van internaliserende problemen en lagere Welwillendheid en Emotionele Stabiliteit werden geassocieerd met hogere initiële niveaus van externaliserende problemen, bij zowel jongeren met een ASS als CP. Bij jongeren met CP werd lagere Welwillendheid ook gerelateerd met hogere initiële niveaus van internaliserende problemen en lagere Consciëntieusheid geassocieerd met hogere initiële niveaus van externaliserende problemen. Dit laatste verband werd ook waargenomen bij de overgang van 10 naar 16 jaar in de ASS-populatie, waar hogere Extraversie ook samenhing met hogere initiële niveaus van externaliserende problemen.

Bovendien werd de persoonlijkheid van het kind ook significant geassocieerd met positievere adaptieve ontwikkelingsuitkomsten. Zo hingen hogere scores op Welwillendheid en Extraversie samen met hogere initiële niveaus van psychosociale sterktes bij zowel jongeren met een ASS (alleen in de overgang van 16 naar 19 jaar) als CP. Terwijl deze associaties eerdere bevindingen in neurotypische populaties bevestigen (Anglim et al., 2020; Hill & Roberts, 2016), is de associatie tussen bepaalde persoonlijkheidsdomeinen (bijv., hogere Consciëntieusheid, Vindingrijkheid of Emotionele Stabiliteit) en hogere initiële niveaus van psychosociale sterktes bij de CP-populatie mogelijks meer beperking-specifiek. In de ASS-populatie vonden we ook twee tijd-specifieke significante associaties tussen de persoonlijkheid van het kind en verandering in de uitkomstvariabele, waarbij hogere Extraversie op de gemiddelde leeftijd van 10 jaar gerelateerd werd aan een afname van internaliserende problemen tijdens de overgang naar 16 jaar oud. Ook kinderen met een ASS met hogere Welwillendheid op de gemiddelde leeftijd van 16 jaar toonden een toename in psychosociale sterktes tijdens de overgang naar 19 jaar. In de CP-populatie vonden we geen significante associaties tussen de persoonlijkheid van het kind en verandering in de uitkomstvariabelen, wat mogelijks verband kan houden met het kortere tijdsinterval in de CP-studie.

Daarnaast onderzochten we in deze longitudinale studies ook mogelijke interacties tussen persoonlijkheid en opvoedingsgedrag in de associatie met de psychosociale ontwikkeling van kinderen met een ASS en CP (**Onderzoeksvraag 2.5**). Terwijl lagere Emotionele Stabiliteit, Welwillendheid en Consciëntieusheid leken te duiden op een bepaalde kwetsbaarheid en verhoogde gevoeligheid, bleken hogere waardes van deze persoonlijkheidstrekken op te treden als veerkrachtige factoren bij het uiten van externaliserend gedrag in de aanwezigheid van controlerend opvoedingsgedrag bij kinderen met een ASS. In de CP-populatie bleken kinderen met een lagere Emotionele Stabiliteit ook het risico te lopen om verhoogde initiële niveaus van zowel internaliserend als externaliserend probleemgedrag te ervaren, maar ouders hadden ook de neiging om minder controlerend op te voeden wanneer deze kinderen tijdelijk meer internaliserende problemen vertoonden dan normaal.

Hoewel replicatie van deze bevindingen zeker nodig is, ondersteunen ze het idee dat ook kinderen met een ontwikkelingsproblematiek (namelijk ASS en CP) gevoeliger kunnen zijn voor de effecten van opvoedingsgedrag op basis van hun persoonlijkheid. Bovendien liggen deze bevindingen in lijn van eerder onderzoek bij neurotypische populaties, die aantoonden dat vooral de persoonlijkheidstrek Emotionele Stabiliteit kan worden beschouwd als een belangrijk individueel verschil dat de gevoeligheid van een kind voor de omgeving beïnvloedt (Belsky & Pluess, 2016; Slagt et al., 2016).

Het emotionele klimaat, het affectieve welzijn van de ouders en nood-gerelateerde ervaringen bij gezinnen die een kind opvoeden met en zonder ASS, CP of DS (Doelstelling 3)

De studie naar mogelijke groepsverschillen in het voorkomen van de EE-domeinen (**Onderzoeksvraag 3.1**) onthulde dat de grote meerderheid van alle ouders lage EE uitten (79.4%). Echter, hoge EE, wat wijst op een gespannen gezinsklimaat, kwam beduidend vaker voor bij gezinnen met kinderen met een ASS (25.8%) en CP (28.4%) vergeleken met gezinnen met kinderen met DS (16.7%) of zonder een beperking (13.8%). Bovendien uitten ouders van kinderen met een ASS meer Criticisme in vergelijking met ouders uit de referentiegroep en minder Warmte in vergelijking met de andere groepen. Deze groepsverschillen in EE kwamen ook tot uiting in de gerapporteerde ouderlijke stress van ouders. Zowel ouders van kinderen met een ASS, CP en DS rapporteerden namelijk aanzienlijk hogere niveaus van stress in hun persoonlijke vrijheid, partnerrelatie en verbondenheid met hun sociale netwerk in vergelijking met ouders van kinderen zonder een beperking. Deze bevindingen bevestigen eerdere studies die aangeven dat het opvoeden van een kind met een ontwikkelingsproblematiek invloed heeft op het welzijn van ouders in verschillende levensdomeinen (Peer & Hillman, 2014) en dat deze ouders heel wat meer ouderlijke stress ervaren in vergelijking met neurotypische populaties (bijv., Gupta, 2007; Hayes & Watson, 2013).

Bovendien suggereren onze bevindingen dat het nomologisch netwerk tussen EE en ouderlijke stress, enerzijds, en tussen EE en opvoedingsgedrag, anderzijds, sterk vergelijkbaar is tussen gezinnen die een kind opvoeden met of zonder een beperking (**Onderzoeksvraag 3.2**). In elke groep ouders werden namelijk meer gespannen gezinsklimaten (gekenmerkt door meer Criticisme en/of minder geuite Warmte door ouders) gerelateerd aan meer gevoelens van rolrestrictie, hechtingsstress, competentiestress en stress in de partnerrelatie. Positievere gezinsklimaten, daarentegen, werden geassocieerd met meer nood-ondersteunend opvoedingsgedrag (d.w.z., responsief opvoeden), terwijl gespannen gezinsklimaten verband hielden met meer nood-ondermijnende opvoedingsgedrag (d.w.z., psychologisch controlerend en overreactief opvoedingsgedrag) in elke groep. Hoewel verdere toetsing noodzakelijk is, kunnen deze vergelijkbare associaties over groepen heen suggereren dat zowel voor gezinnen met als zonder een kind met een ontwikkelingsproblematiek, de nood-frustratie van ouders kan fungeren als een energetische basis voor ouderlijke stress, die op zijn beurt minder nood-ondersteunend en meer nood-ondermijnend opvoedingsgedrag voedt, en daardoor een meer gespannen gezinsklimaat cultiveert. Bovendien lijken onze bevindingen de idee te ondersteunen dat de emotionele kwaliteit van een gezinsklimaat wordt gevormd door het samenspel tussen zowel ouder- en kind-kenmerken als meer contextuele bronnen van stress en steun (Belsky & Jaffee, 2006; Sameroff, 2009).

Ook uit de kwalitatieve analyse van de spontane spraaksamples door ouders over hun kind, de relatie met hun kind en hun opvoedingservaringen, bleek dat zowel ouder-, kind- als maatschappelijke factoren (bijv., ondersteuning van de omgeving, gevoelens van stigma en uitsluiting) mee de ervaringen van ouders over het opvoeden van hun kind bepalen. Bovendien suggereren de groepsverschillen in nood-gerelateerde ervaringen van ouders (**Onderzoeksvraag 3.3**) dat ouders van kinderen met een ontwikkelingsproblematiek in het algemeen meer nood-frustrerende ervaringen beschrijven, maar verrassend ook meer autonomie-satisfactie (bijv., creatiever of veerkrachtiger omgaan met uitdagingen, het ontwikkelen van een nuchtere kijk op het leven), vergeleken met ouders van kinderen zonder een beperking. Bovendien belichtten de kwalitatieve bevindingen ook meer beperking-specifieke ervaringen. Terwijl ouders van kinderen met een ASS de meeste uitdagingen rapporteerden in de verbondenheid met hun kind en hun ouderlijke competentie, vermeldden ouders van kinderen met CP de meeste zorgen over de toekomst en continuïteit van de zorg voor hun kind. Ouders van kinderen met DS beschreven dan weer de meeste ervaringen gerelateerd aan nood-satisfactie in hun zelfontplooiing en gezinsleven.

Over het algemeen hielpen de kwalitatieve onderzoeksresultaten om evenwichtiger te kijken naar ouderschap bij een kind met een ontwikkelingsproblematiek. Hoewel het opvoeden van een kind met een ASS, CP of DS unieke uitdagingen met zich meebrengt en specifieke aanpassingen vereist, bood het structureren van ouderlijke ervaringen binnen de drie ZDT-noden ook een beter begrip van de positieve ervaringen die zorgen voor nood-satisfactie binnen deze gezinnen. Deze gebalanceerde benadering ontrafelde bovenal dat het opvoeden van een kind met een ontwikkelingsproblematiek niet allemaal kommer en kwel is, maar gepaard gaat met zowel uitdagende als dankbare ervaringen, zoals in elke ouder-kindrelatie (Dieleman, Moyson, et al., 2018; Dieleman et al., 2019; Nurullah, 2013).

Praktische implicaties

Op vlak van de psychosociale ontwikkeling van kinderen met een ontwikkelingsproblematiek (Doelstelling 1), laten de bevindingen zien dat de psychosociale ontwikkeling van kinderen met een ASS, CP en DS verdere aandacht verdient. Hoewel algemeen wordt aangenomen dat de overgang van de kindertijd naar (vroege) volwassenheid voor elk kind nieuwe uitdagingen met zich meebrengt (Soenens et al., 2019), geven de onderzoeksresultaten aan dat deze overgang kan worden beschouwd als een cruciale overgangsperiode voor zowel kinderen met een ontwikkelingsproblematiek als hun families. Om gezinnen tijdens deze overgangsperiode te ondersteunen, kan het waardevol zijn om ouders en kinderen door middel van psycho-educatie informatie te verstrekken over de fysieke, gedragsmatige en emotionele veranderingen van een kind tijdens de puberteit, met een specifieke focus op hoe deze veranderingen kunnen interageren met de beperking van het kind. Zorgverleners kunnen tijdens deze periode ook extra aandachtig zijn voor het welzijn en het gevoel van 'anders zijn' (Murdick et al., 2004) bij kinderen en hun ouders. Om deze gevoelens van ‘anders zijn’ tegen te gaan, lijkt het belangrijk dat zorgverleners, maar ook significante anderen, modellen van inclusie installeren, waarbij diversiteit deel uitmaakt van ‘de norm’ en wordt gerespecteerd en gewaardeerd.

Bovendien laten de bevindingen van dit proefschrift zien dat zowel het opvoedingsgedrag als de persoonlijkheid van het kind belangrijke beïnvloedende factoren zijn in de psychosociale ontwikkeling van kinderen met een ontwikkelingsproblematiek (Doelstelling 2). Met betrekking tot opvoedingsgedrag leverde dit proefschrift unieke ondersteuning voor de universele bewering van de ZDT dat *"alle kinderen de nood hebben om zich competent, autonoom en geliefd te voelen"* (Deci et al., 1992), inclusief kinderen die opgroeien met specifieke ondersteuningsnoden. Meer specifiek toonden onze resultaten aan dat terwijl nood-ondermijnend opvoedingsgedrag samenhangt met maladaptieve uitkomsten, nood-ondersteunend opvoedingsgedrag gerelateerd is aan adaptieve uitkomsten, voor zowel kinderen met een ASS, CP, DS, als zonder een beperking. Daarom zouden gezinsinterventies en ouderondersteuning zich kunnen richten op het verminderen van controlerend opvoedingsgedrag en uitdagend kindgedrag, maar ook op het erkennen en versterken van nood-ondersteunend opvoedingsgedrag en de psychosociale sterktes van kinderen. Aangezien eerdere ZDT-gebaseerde interventiestudies bij neurotypische populaties de gunstige impact van autonomie-ondersteunende ouderschapsprogramma’s op het welzijn van kinderen aantoonden

(Allen et al., 2019; Joussemet et al., 2018), zijn we van mening dat deze interventies ook een meerwaarde kunnen bieden bij gezinnen die een kind opvoeden met een ontwikkelingsproblematiek. Bovendien wijzen de bevindingen op het belang van een sterktegerichte benadering in ouderschapsonderzoek en -praktijken, waarbij de sterktes en inspanningen van zowel ouders als kinderen worden erkend en versterkt, in plaats van louter te focussen op manieren die controlerend opvoedingsgedrag of uitdagend kindgedrag kunnen verminderen (Dieleman et al., 2019).

Hoewel deze ZDT-gebaseerde richtlijnen enige houvast kunnen bieden in de praktijk, toonden de bevindingen van dit proefschrift ook aan dat het belangrijk is om af te stemmen op de unieke persoonlijkheidskenmerken van een kind. Bijgevolg kan de exploratie van de persoonlijkheid van een kind, de bijbehorende sensitiviteit naar de omgeving en de interactie tussen persoonlijkheid en opvoedingsgedrag, ouders en zorgverleners begeleiden om hun ondersteuning verder af te stemmen op de unieke persoonlijkheid van een kind (Huntington & Simeonsson, 1993). Ouderschapsondersteuning en -interventies kunnen dan bijvoorbeeld meer aandacht besteden aan de kinderen die minder gevoelig zijn voor de voordelen van nood-ondersteunend opvoedingsgedrag en gevoeliger zijn voor de nadelen die samenhangen met nood-ondermijnend opvoedingsgedrag (Mabbe et al., 2019).

Ten slotte zou toekomstig onderzoek én praktijk bijzondere aandacht kunnen besteden aan de emotionele kwaliteit van een gezinsklimaat bij gezinnen die een kind opvoeden met een ontwikkelingsproblematiek, aangezien deze klimaten mogelijks meer gespannen zijn en gepaard kunnen gaan met meer ouderlijke stress in diverse levensdomeinen en minder gunstig opvoedingsgedrag (Doelstelling 3). Daarom lijkt het ook belangrijk om 'uit te zoomen' tijdens ouderondersteuning en de waarde te erkennen van de relaties die ouders hebben met diverse belangrijke anderen, zoals hun partner, hun andere kinderen, vrienden, familieleden, maar ook de bredere samenleving. Vooral door te reflecteren over de positie van deze ouders in een bredere maatschappelijke context kan het bewustzijn van zorgverleners rond de impact van stigmatisering, geïndividualiseerde verantwoordelijkheid en ongelijkheid toenemen. Daarnaast biedt de combinatie van kwantitatieve (Hoofdstuk 2-5) en kwalitatieve onderzoeksmethoden (Hoofdstuk 6) in dit proefschrift handvaten om tot een vollediger en genuanceerder perspectief te komen op de complexe realiteit van het opvoeden van een kind met een ontwikkelingsproblematiek. Samen laten de bevindingen zien dat het opvoeden van een kind met een ontwikkelingsproblematiek zowel uitdagingen als veel kansen voor nood-satisfactie met zich meebrengt. Daarom moedigen we verder onderzoek en praktijken aan, waarbij ouders en kinderen worden ontmoet in hun ‘kwetsbaarheid’ maar – belangrijker nog – ook in hun ‘veerkracht’.

Conclusie

Dit proefschrift had tot doel een dieper inzicht te verkrijgen in de complexe realiteit van het opvoeden van een kind met een ontwikkelingsproblematiek, meer bepaald kinderen met een ASS, CP en DS. De bevindingen gaven aan dat ouderschapspraktijken en ervaringen in deze gezinnen op de proef worden gesteld, onder meer vanwege het verhoogde risico op gedrags- en/of emotionele problemen bij deze kinderen, waarbij de adolescentie kan worden beschouwd als een bijzonder uitdagende periode voor zowel kinderen als ouders. We vonden evidentie dat zowel het opvoedingsgedrag van de ouder als de persoonlijkheid van het kind unieke en belangrijke beïnvloedende processen zijn in deze psychosociale ontwikkeling. Terwijl nood-ondersteunend opvoedingsgedrag de ontwikkeling van een kind voedt, belemmert nood-ondermijnend opvoedingsgedrag de ontwikkeling van een kind, zowel voor kinderen met als zonder een ontwikkelingsproblematiek. Specifieke persoonlijkheidskenmerken bij kinderen met een ontwikkelingsproblematiek bleken ook te fungeren als een risico- of veerkrachtfactor in de psychosociale ontwikkeling van deze kinderen. Een paar significante interacties tussen persoonlijkheid en opvoedingsgedrag suggereerden zelfs dat sommige kinderen vatbaarder zijn voor de impact van ouderschapsprocessen dan andere, gebaseerd op hun persoonlijkheid. Voor de meeste gezinnen die een kind met een ontwikkelingsproblematiek opvoeden, vonden deze processen plaats in een positief emotioneel gezinsklimaat, gekenmerkt door veel warmte en waardering. In vergelijking met ouders die een kind opvoeden zonder een beperking, rapporteerden ouders van kinderen met een ontwikkelingsproblematiek echter meer stress in diverse levensdomeinen en beschreven ze meer gespannen gezinsklimaten. Echter, illustreerden de spontane beschrijvingen van ouders over hun kind, hun ouder-kindrelatie en hun ervaringen als ouder ook dat deze ouders veel nood-satisfactie ervaren bij het opvoeden van hun kind, zoals blijkt uit een verhoogde zelfontplooiing en intense ouder-kindrelaties. Over het algemeen tonen de bevindingen van dit proefschrift aan dat wanneer men een kind opvoedt met een ontwikkelingsproblematiek, het leven voor de meeste ouders (veel) intenser is, maar tegelijk ook fascinerend is.

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Appendix III

Data storage fact sheets

Data Storage Fact Sheet 1

Name/identifier study: Chapter 2 – ANDI_2019
Date: 26 October 2020

1. Contact details

1a. Main researcher

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2. Information about the datasets to which this sheet applies

- Reference of the publication in which the datasets are reported:

De Clercq, L., Van der Kaap-Deeder, J., Dieleman, L. M., Soenens, B., Prinzie, P., & De Pauw, S. S. W. (2019). Parenting and psychosocial development in youth with and without autism spectrum disorder, cerebral palsy, and Down syndrome: A cross-disability comparison. *Advances in Neurodevelopmental Disorders*, *3*(2), 220-234. https://doi.org/10.1007/s41252-019-00112-2

- Which datasets in that publication does this sheet apply to?: This data fact sheet applies to the data in the corresponding article and chapter.

3. Information about the files that have been stored

3a. Raw data

- Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

- On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [X] other (specify): All questionnaire data in paper version are stored in a locked cupboard in the office of the main researcher and responsible ZAP at

the Department of Special Needs Education (Henri Dunantlaan 1, 9000 Ghent)

- Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [X] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

3b. Other files

- Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: SPSS syntax file for transition raw data in used variables and parcels
- [X] file(s) containing processed data. Specify: .dat file for Mplus data
- [X] file(s) containing analyses. Specify: SPSS syntax files for preliminary analyses
- [ ] files(s) containing information about informed consent:
- [ ] a file specifying legal and ethical provisions:
- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: Word files describing which questionnaires and variables are included in the study.
- [X] other files. Specify: Excel files with respondent contact information, and information linking respondents to ID-codes.

- On which platform are these other files stored?

- [X] individual PC
- [X] research group file server
- [] other:

- Who has direct access to these other files (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

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- Address:
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Data Storage Fact Sheet 2

Name/identifier study: Chapter 3 – JADD_2020
Date: 26 October 2020

1. Contact details

1a. Main researcher

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

- Reference of the publication in which the datasets are reported:

De Clercq, L., Dieleman, L. M., Van der Kaap-Deeder, J., Soenens, B., Prinzie, P., & De Pauw, S. S. W. (2020). Negative controlling parenting and child personality as modifiers of psychosocial development in youth with autism spectrum disorder: A 9-year longitudinal study at the level of within-person change. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04761-4

- Which datasets in that publication does this sheet apply to?: This data fact sheet applies to the data in the corresponding article and chapter.

3. Information about the files that have been stored

3a. Raw data

- Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

- On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [X] other (specify): All questionnaire data in paper version are stored in a locked cupboard in the office of the main researcher and responsible ZAP at

the Department of Special Needs Education (Henri Dunantlaan 1, 9000 Ghent)

- Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [X] all members of the research group
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- [ ] other (specify): ...

3b. Other files

- Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: SPSS syntax file for transition raw data in used variables and parcels
- [X] file(s) containing processed data. Specify: .dat file for Mplus data
- [X] file(s) containing analyses. Specify: SPSS syntax files for preliminary analyses
- [ ] files(s) containing information about informed consent:
- [ ] a file specifying legal and ethical provisions:
- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: Word files describing which questionnaires and variables are included in the study.
- [X] other files. Specify: Excel files with respondent contact information, and information linking respondents to ID-codes.

- On which platform are these other files stored?

- [X] individual PC
- [X] research group file server
- [] other:

- Who has direct access to these other files (i.e., without intervention of another person)?

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- [X] responsible ZAP
- [ ] all members of the research group
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Data Storage Fact Sheet 3

Name/identifier study: Chapter 4 – CHUD_2020
Date: 26 October 2020

1. Contact details

1a. Main researcher

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

- Reference of the publication in which the datasets are reported:

  De Clercq, L., Soenens, B., Dieleman, L., Prinzie, P., Van der Kaap-Deeder, J., Beyers, W., & De Pauw, S. S. W. (2020). Parenting and child personality as modifiers of the psychosocial development of youth with cerebral palsy. *Child Psychiatry & Human Development*. https://doi.org/10.1007/s10578-020-01106-1.

  - Which datasets in that publication does this sheet apply to?: This data fact sheet applies to the data in the corresponding article and chapter.

3. Information about the files that have been stored

3a. Raw data

- Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

- On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [X] other (specify): All questionnaire data in paper version are stored in a locked cupboard in the office of the main researcher and responsible ZAP at the Department of Special Needs Education (Henri Dunantlaan 1, 9000 Ghent)

- Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [X] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

3b. Other files

- Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: SPSS syntax file for transition raw data in used variables and parcels
- [X] file(s) containing processed data. Specify: .dat file for Mplus data
- [X] file(s) containing analyses. Specify: SPSS syntax files for preliminary analyses
- [ ] files(s) containing information about informed consent:
- [ ] a file specifying legal and ethical provisions:
- [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: Word files describing which questionnaires and variables are included in the study.
- [X] other files. Specify: Excel files with respondent contact information, and information linking respondents to ID-codes.

- On which platform are these other files stored?

- [X] individual PC
- [X] research group file server
- [] other:

- Who has direct access to these other files (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [ ] all members of the research group
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- [ ] other (specify): ...

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Data Storage Fact Sheet 4

Name/identifier study: Chapter 5 – JADD_2020
Date: 26 October 2020

1. Contact details

1a. Main researcher

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1b. Responsible Staff Member (ZAP)

Name: Sarah De Pauw
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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

- Reference of the publication in which the datasets are reported:

De Clercq, L., Prinzie, P., Warreyn, P., Soenens, B., Dieleman, L. M., & De Pauw, S. S. W. (2020). Expressed Emotion in families of children with and without autism spectrum disorder, cerebral palsy and Down syndrome: Relations with parenting stress and parenting behaviors. *Journal of Autism and Developmental Disorders.* Manuscript under review.

- Which datasets in that publication does this sheet apply to?: This data fact sheet applies to the data in the corresponding article and chapter.

3. Information about the files that have been stored

3a. Raw data

- Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

- On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [X] other (specify): All questionnaire data in paper version are stored in a locked cupboard in the office of the main researcher and responsible ZAP at the Department of Special Needs Education (Henri Dunantlaan 1, 9000 Ghent)

- Who has direct access to the raw data (i.e., without intervention of another person)?

  - [X] main researcher
  - [X] responsible ZAP
  - [X] all members of the research group
  - [ ] all members of UGent
  - [ ] other (specify): ...

3b. Other files

- Which other files have been stored?

  - [X] file(s) describing the transition from raw data to reported results. Specify: SPSS syntax file for transition raw data in used variables and parcels.
  - [] file(s) containing processed data.
  - [X] file(s) containing analyses. Specify: SPSS syntax files for main and preliminary analyses
  - [ ] files(s) containing information about informed consent:
  - [ ] a file specifying legal and ethical provisions:
  - [X] file(s) that describe the content of the stored files and how this content should be interpreted. Specify: Word files describing which questionnaires and variables are included in the study.
  - [X] other files. Specify: Excel files with respondent contact information, and information linking respondents to ID-codes. Anonymized audio files and transcripts of participants' spontaneous speech samples.

- On which platform are these other files stored?

  - [X] individual PC
  - [X] research group file server
  - [] other:

- Who has direct access to these other files (i.e., without intervention of another person)?

  - [X] main researcher
  - [X] responsible ZAP
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Data Storage Fact Sheet 5

Name/identifier study: Chapter 6 – JODD_2020
Date: 26 October 2020

1. Contact details

1a. Main researcher

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If a response is not received when using the above contact details, please send an email to data.pp@ugent.be or contact Data Management, Faculty of Psychology and Educational Sciences, Henri Dunantlaan 2, 9000 Ghent, Belgium.

2. Information about the datasets to which this sheet applies

- Reference of the publication in which the datasets are reported:

De Clercq, L., Prinzie, P., Swerts, C., Ortibus, E., De Pauw, S. S. W. (2020). "Tell me about your child, the relationship with your child and your parental experiences": A qualitative study of spontaneous speech samples among parents raising a child with and without autism spectrum disorder, cerebral palsy or Down syndrome. *Journal of Developmental and Physical Disabilities.* Manuscript under review.

- Which datasets in that publication does this sheet apply to?: This data fact sheet applies to the data in the corresponding article and chapter.

3. Information about the files that have been stored

3a. Raw data

- Have the raw data been stored by the main researcher? [X] YES / [ ] NO
  If NO, please justify:

- On which platform are the raw data stored?
  - [X] researcher PC
  - [X] research group file server
  - [] other (specify):

- Who has direct access to the raw data (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [X] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

3b. Other files

- Which other files have been stored?

- [X] file(s) describing the transition from raw data to reported results. Specify: SPSS syntax file for transition raw data in variables providing background information.
- [] file(s) containing processed data.
- [X] file(s) containing analyses. Specify: NVivo file with coded data.
- [ ] files(s) containing information about informed consent:
- [ ] a file specifying legal and ethical provisions:
- [] file(s) that describe the content of the stored files and how this content should be interpreted.
- [X] other files. Specify: Excel files with respondent contact information, and information linking respondents to ID-codes. Anonymized audio files and transcripts of participants' spontaneous speech samples.

- On which platform are these other files stored?

- [X] individual PC
- [X] research group file server
- [] other:

- Who has direct access to these other files (i.e., without intervention of another person)?

- [X] main researcher
- [X] responsible ZAP
- [ ] all members of the research group
- [ ] all members of UGent
- [ ] other (specify): ...

4. Reproduction

- Have the results been reproduced independently?: [ ] YES / [X] NO

- If yes, by whom (add if multiple):

- Name:
- Address:
- Affiliation:
- E-mail:

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