From the Department of Women’s and Children’s Health
Karolinska Institutet, Stockholm, Sweden

TRANSITION-AGED AUTISTIC YOUTH – FUNCTIONING, QUALITY OF LIFE, AND INTERNET-DELIVERED PSYCHOEDUCATION

Anna Backman

Stockholm 2023

All previously published papers were reproduced with permission from the publisher.
Published by Karolinska Institutet.
Printed by Universitetsservice US-AB, 2023

ISBN 978-91-8017-057-4
Cover illustration: The SCOPE logo was designed by Gullers Grupp and Galleri Inuti, used with permission from Habilitering & Hälsa, Stockholm Region

TRANSITION AGED AUTISTIC YOUTH – FUNCTIONING, QUALITY OF LIFE, AND INTERNET-DELIVERED PSYCHOEDUCATION

Thesis for Doctoral Degree (Ph.D.)

By

Anna Backman

The thesis will be defended in public at KIND/BUP FOU centrum, Gävlegatan 22B, Stockholm, on the 29th of September at 09.00

Principal Supervisor:
Tatja Hirvikoski, PhD, Associate Professor
Karolinska Institutet
Department of Women's and Children's Health
Division of Neuropsychiatry

Co-supervisor(s):
Sarah Vigerland, PhD
Karolinska Institutet
Department of Clinical Neuroscience
Centre for Psychiatry Research

Lise Roll-Pettersson, PhD, Professor
Stockholm University
Department of Special Education

Eric Zander, PhD
Karolinska Institutet
Department of Women's and Children's Health
Division of Neuropsychiatry

Opponent:
Peik Gustafsson, PhD, Professor
Lund University
Department of Clinical Sciences

Examination Board:
Daiva Daukantaitė, PhD, Associate Professor
Lund University
Department of Psychology

Jonas Ramnerö, PhD, Associate Professor
Karolinska Institutet
Department of Clinical Neuroscience
Centre for Psychiatry Research

Kari Trost, PhD, Associate Professor
Stockholm University
Department of Special Education

Till minne av pappa Stig

Popular science summary of the thesis

The transition from childhood to adulthood, from about 16 years to 25 years, presents unique challenges for many autistic individuals. According to their parents, transition-aged autistic youth experience difficulties in functioning and have a low quality of life. Structured interventions, such as psychoeducation, can help ease the transition into adulthood. Psychoeducation aims to increase autism knowledge and self-awareness. The psychoeducative programme SCOPE was developed together with emerging autistic adults. It is an eight-week internet-based psychoeducation program that is therapist-guided and features texts, video vignettes, and self-reflection assignments.

In **study I**, we investigated how autistic transition-aged youth (16-25 years old) report their functioning and quality of life, as well as which factors influence these outcomes. Amongst the 140 newly diagnosed transition-aged autistic youth, we found that their self-reported overall functioning and quality of life were low. Autism traits and mental health problems contributed to difficulties in functioning. While mainly mental health problems and not having friends contributed to lower quality of life. Therefore, designing interventions that promote mental health and support autistic individuals in their daily life may improve functioning and quality of life.

In **study II**, we focused on the feasibility of SCOPE, through investigating treatment completion, technical usability, treatment credibility and satisfaction. We included 28 participants to take SCOPE and measured their responses on several outcomes before and after SCOPE. Most participants completed SCOPE and could use it online without problems. Participants liked the contents of SCOPE and believed it could be beneficial to them and others. According to the preliminary findings, SCOPE could educate transition-aged autistic youth about autism without harming their mental health.

In **study III**, we compared the effects of SCOPE on autism knowledge, symptoms of mental health, and quality of life to those of self-study and services as usual. One hundred and forty-one autistic transition-aged youth were randomly selected to undergo either SCOPE (n = 75), self-study consisting of eight weekly website links (n = 37), or receive services as usual (n = 29). SCOPE participants and those who self-studied improved their autism knowledge after the eight weeks, unlike participants who used services as usual. However, only SCOPE participants kept their knowledge three months after program completion, and the self-study participants did not. No group had an increase in anxiety or depression symptoms. In addition, quality of life increased for the SCOPE participants but not for the self-study participants or those who obtained services as usual. In sum, SCOPE teaches autistic transition-age youth about autism and increases their quality of life.

Abstract

Background

Transition-aged autistic youth, ranging from 16 to 25 years of age, often experience challenges in functioning and have a diminished quality of life (QoL). Several factors have been reported to be associated with these outcomes. However, limited studies have examined the self-reporting of transition-aged autistic youth regarding these outcomes, and few have analysed the specific impact of autistic traits and mental health problems on functioning and QoL. To enhance autism knowledge, promote active participation in healthcare, and improve QoL, psychoeducation is commonly recommended as an initial intervention following an autism diagnosis.

Aims

The aim of **study I** was to investigate self-reported functioning and QoL in transition-aged autistic youth and to analyse the relative importance of associated factors on the two outcomes. The aims of **studies II** and **III** were to evaluate a new internet-delivered psychoeducative intervention (SCOPE) by investigating (1) feasibility, evaluating intervention completion, credibility and satisfaction (**study II**); and (2) the pragmatic effectiveness of SCOPE (**study III**).

Methods

In **study I,** 140 transition-aged autistic youth were interviewed about their functioning and provided self-rating questionnaires about QoL. In addition, participants rated their autism symptom severity, symptoms of mental ill-health and answered a questionnaire on demographic details. We analysed functioning and QoL scores using descriptive statistics. We analysed associations between all variables, followed by entering the significant associations as independent variables into a linear regression model with either functioning or QoL as the dependent variable. In **studies II** and **III,** we evaluated SCOPE – containing eight autism-themed modules with weekly digital therapist support. For **study II**, we recruited n = 28 participants, aged 16-25 years. We evaluated feasibility through intervention completion rates, credibility using a self-report scale and satisfaction using module evaluations. We analysed preliminary effects regarding autism knowledge, symptoms of mental ill-health, life satisfaction and acceptance of diagnosis, collected at pre-, post-intervention and three-month follow-up. In **study III** we included n = 141 participants, aged 16-25 years, to be randomised according to 2:1:1 to SCOPE, self-study online of informative autism websites, or treatment as usual (TAU). The primary outcome of autism knowledge, and the secondary outcomes of symptoms of mental ill-health, QoL and acceptance of diagnosis were assessed at pre, post and follow-up.

Results

In **study I**, participants reported low functioning, on the 90th percentile compared to general population norms, indicating significant disability, and rated low overall QoL. The predictors that contributed the most to functioning were autism symptom severity and symptoms of anxiety, followed by gender and ADHD-diagnosis. Meanwhile, higher QoL was predicted by fewer anxiety and depression symptoms, as well as having friendships but not by autism symptom severity. **In study II** we observed 79% completers, as well as good treatment credibility and treatment satisfaction. Additionally, autism knowledge was increased post-intervention. These results were supported by findings in **study III**, where we found that SCOPE and self-study, but not TAU, increased autism knowledge post-intervention (primary outcome). However, the self-study participants' knowledge scores returned to baseline at the three-month follow-up. SCOPE participants had increased autism knowledge at follow-up compared to self-study and TAU, and the increase in knowledge was not coupled with significant changes in mental health problems. SCOPE participants reported improved QoL (secondary outcome) at post-intervention and three-month follow-up compared to both control conditions.

Conclusions

We highlight that functioning and QoL are predicted by several factors, necessitating a comprehensive assessment of transition-aged autistic youth, including information about autism traits and mental health problems, to plan tangible interventions. The SCOPE trials suggest that the internet-delivered psychoeducational intervention SCOPE is a feasible first-line intervention in terms of treatment completion. Further, SCOPE could increase youths’ autism knowledge and improve QoL.

Sammanfattning

Bakgrund

Äldre tonåringar och unga vuxna autister, 16–25 år, har rapporterade svårigheter med funktion och nedsatt livskvalitet, och flera faktorer är associerade med båda utfallen. Det finns få studier som har låtit dem själva rapportera, och ännu färre som har undersökt den relativa vikten av de olika associerade faktorerna. Specifika interventioner bör utvecklas för denna åldersgrupp. Psykoedukation för unga vuxna autister kan vara en lämplig första insats efter diagnos, eftersom den ger de unga bättre kunskaper om autism och om sig själva, vilket kan bidra till att de känner sig stärkta och i kontroll över sitt liv. Insatser som tar hänsyn till autisters kommunikationsstil och använder ett medskaparperspektiv är att föredra.

Syfte

Ett delsyfte med avhandlingsarbetet var att undersöka den självrapporterade funktionsnivån och livskvalitén hos äldre tonåringar och unga vuxna med autism, samt att analysera vilka associerade faktorer som har störst inverkan på utfallen (**delstudie I**). Ett ytterligare syfte var att utvärdera en ny internet-baserad psykoedukativ insats (SCOPE) genom att undersöka (1) genomförbarheten, tilltron till insatsen och nöjdhet (**delstudie II**) samt (2) de pragmatiska effekterna av interventionen (**delstudie III**).

Metod

I **delstudie I** intervjuade vi 140 äldre tonåringar och unga vuxna med autism angående deras funktionsnivå och de fick skatta livskvalité genom frågeformulär. De skattade även sina autismsymptom, symptom på psykisk ohälsa och besvarade frågeformulär om ett stort antal demografiska faktorer. Vi använde deskriptiv statistik för att analysera funktionsnivå och för livskvalité, och analyserade sedan associationer mellan samtliga variabler. De signifikanta associationerna användes sedan som oberoende variabler i en linjär regressionsanalys med antingen funktionsnivå eller livskvalité som beroende variabler. I **delstudierna II** och **III** utvärderades SCOPE. Insatsen har åtta autism-relaterade teman som presenteras ett i taget i åtta veckor, med veckovis digital handledarkontakt. För **delstudie II** rekryterade vi 28 deltagare i åldrarna 16–25 år för att genomgå SCOPE. Vi följde upp genomförbarhet, tilltro och nöjdhet, samt preliminära effekter (autismkunskap, symptom på psykisk ohälsa, livskvalité och

diagnosacceptans) innan och efter insatsen, samt vid tre-månaders uppföljning. I **delstudie III** rekryterade vi 141 deltagare (16–25 år) som randomiserades enligt en 2:1:1 fördelning till SCOPE, självstudier av informativa webbplatser om autism, eller sedvanlig behandling. Även dessa deltagare fick fylla i skattningsskalor (autismkunskap, symptom på psykisk ohälsa, livskvalité och diagnosacceptans) innan, efter och vid tre-månaders uppföljning.

Resultat

Ur **delstudie I**, rapporterade deltagarna låg funktionsnivå, i linje med 90e percentilen i jämförelse med denna allmänna befolkningen – vilket innebär att de hade en funktionsnivå som motsvarade de 10 % av befolkningen som har lägst funktion. Därtill var livskvalitén under det rekommenderade värdet för god livskvalitet. Funktionsnivå predicerades till störst del av autismsymptom och ångestsymptom, samt även av könstillhörighet och ADHD-diagnos. Medan högre livskvalité predicerades av både lägre ångest- och depressionssymptom samt vänskaper, men inte av autismsymptom. I **delstudie II** kunde vi visa på god genomförbarhet hos SCOPE genom högt deltagande samt nöjdhet med och tilltro till behandlingen. Vi såg även en signifikant förbättring av autismkunskapen efter SCOPE. Dessa resultat bekräftades i **delstudie III** som visade att SCOPE-deltagare och självstudie-deltagarna ökade sin autismkunskap efter 8 veckors intervention, men endast SCOPE-deltagarna behöll sin kunskap vid tre månaders-uppföljningen. Dessutom hade endast SCOPE-deltagarna signifikant högre livskvalité vid eftermätningen och vid tremånaders-uppföljningen.

Slutsatser

Vi betonar att funktionsnivå och livskvalité hos unga med autism är relaterade till flera faktorer. Detta innebär att breda utredningar som inkluderar information om både autismsymptom och psykisk ohälsa är nödvändiga för att kunna planera och erbjuda adekvata insatser för denna målgrupp. SCOPE-studierna indikerar att insatsen är genomförbar, uppskattad och kan förbättra ungdomarnas autismkunskaper och livskvalité, samt därigenom förhoppningsvis stärka individernas delaktighet i sin vård.

List of scientific papers

I. **Backman, A.**, Zander, E., Vigerland, S., Roll-Pettersson, L., Hirvikoski, T. (2023) Functioning and quality of life in transition-aged youth on the autism spectrum – associations with autism symptom severity and mental health problems. *Research in Autism Spectrum Disorder*: 104: online first

II. **Backman, A.**, Mellblom, A., Norman-Claesson, E., Keith-Bodros, G., Frostvittra, M., Bölte, S., Hirvikoski, T. (2018) Internet-delivered psychoeducation for older adolescents and young adults with autism spectrum disorder SCOPE: An open feasibility study. *Research in Autism Spectrum Disorder*: 51-64

III. **Backman, A.,** Mellblom, A., Norman-Claesson, E., Sundqvist, E., Roll-Pettersson, L., Zander, E., Vigerland, S., Hirvikoski, T. (*under review*) SCOPE internet-delivered psychoeducation for transition aged autistic youth: A Pragmatic Randomized Controlled Trial.

List of scientific papers not included in the thesis

I. Sjöwall, D., **Backman A.**, Thorell, L.B. (2015). Neuropsychological heterogeneity in preschool ADHD: Investigating the interplay between cognitive, affective, and motivation-based forms of regulation. *Journal of Abnormal Child Psychology,* Volume 43 (4): 669-680

II. Renhorn, E., Nytell. C., **Backman, A.**, Ekstrand, C., Hirvikoski, T. (2019). Mothers Navigating the Complex Landscape of ADHD Services: Analysis of Calls to ADHD Helpline. *Scandinavian Journal of Child and Adolescent Psychiatry*, Volume 7: 88-91

III. Agius, H., Luoto, A-K., **Backman, A.**, Eriksdotter, C., Jayaram-Lindström, N., Bölte, S., Hirvikoski, T. (2023). Mindfulness-based Stress Reduction for Autistic Adults – a Feasibility Study in an Outpatient Context. *Autism*, *Online first*

Contents

List of abbreviations

AB	Adaptive Behavior
ADHD	Attention-Deficit/Hyperactivity Disorder
AF	Adaptive Function
ASD	Autism Spectrum Disorder
CI	Confidence Interval
DV	Dependent Variable
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5th edition
EF	Executive Function
ES	Effect Size
FSIQ	Full-scale IQ
ICD-10	International Classification of Diseases, 10th edition
ICD-11	International Classification of Diseases, 11th edition
ICF	International Classification of Functioning
ID	Intellectual Disability
IQ	Intelligence Quotient
IVs	Independent Variables
NDD	Neurodevelopmental Disorder
QoL	Quality of Life
RCT	Randomized Controlled Trial
rmANOVAs	repeated measures Analysis of Variances
SCOPE	Spectrum COmputerized PsychoEducation
SD	Standard Deviation
SoB	Stöd och Behandling: Swedish national internet platform for e-health services
SS	Self-study
TAU	Treatment as Usual
WHODAS 2.0	World Health Organization Disability Assessment Schedule 2.0

Introduction

While pursuing my clinical license, I was inspired to work on the projects within this thesis. As a clinician, I witnessed first-hand the transformative power of self-knowledge. I observed how gaining knowledge about neurodevelopmental disorders helped transition-aged youth, parents, and close relatives improve their quality of life and self-sufficiency. This process was particularly delicate for individuals in the transitional period between childhood and adulthood. Understanding one's difficulties and strengths is crucial for successful transitioning into adulthood, especially for those who are neuro-divergent. Psychoeducation plays a pivotal role in achieving this.

As psychologists working with neuro-developmental disorders, we aim to improve the life circumstances of individuals and their families. Our work involves setting flexible yet essential life goals such as enhancing functioning, increasing quality of life, and reducing mental health problems. To achieve these goals, we must communicate directly with the neuro-divergent individuals and identify what they feel is not working, and what they want to change. We adopt an identity-first perspective in providing healthcare and aim to involve autistic individuals in all aspects of our work. This approach is important because it promotes autonomy, self-determination, and empowerment.

Collaboration is a critical component of efficient interventions. Working together as healthcare professionals with neuro-divergent individuals, and their families can lead to the development of effective interventions and ensure that all parties involved have a shared understanding of the goals. It fosters a sense of teamwork and ensures that the interventions are consistent with the individual's needs and preferences. Additionally, it is important to maintain a strengths-based approach to interventions, recognising and building on the individual's unique abilities, and interests. By doing so, we can help neuro-divergent individuals develop the skills and confidence needed to thrive and lead fulfilling lives.

This thesis includes an evaluation of an internet-delivered psychoeducational intervention for transition-aged autistic youth. The intervention – SCOPE – was initially designed by professionals working at Habilitering & Hälsa in Region Stockholm, who drafted the written contents based on the typically reported difficulties associated with autism: social interaction, behaviours and interests, Theory of Mind, central coherence, executive functions, intelligence and memory functions, and finally perception. This first version of SCOPE (or *Koll på Asperger* as it was first named) was then tried, tested and later co-developed with members of the autism community. Their feedback and impressions meant that the version of SCOPE that we evaluated had a much more strength-based perspective and a more careful approach to phrasing.

1 Literature review

1.1 Autism

Autism spectrum disorder (henceforth, autism) is a neurodevelopmental disorder (NDD), characterised by difficulties with social interaction and communication, as well as by repetitive behaviours and interests. NDD means that the onset of symptoms or behaviours is during early development (Ismail & Shapiro, 2019; Morris-Rosendahl & Crocq, 2020) and can affect the course of typical developmental milestones. The categorisation of autism as an NDD was introduced in the Diagnostic and Statistical Manual, fifth edition (DSM-5: APA, 2013), grouped with other NDDs such as Attention-Deficit/Hyperactivity Disorder (ADHD) and Intellectual Disability (ID) (Morris-Rosendahl & Crocq, 2020). Similarly, the International Classification of Diseases 11th edition has placed autism in its NDD section (ICD-11: WHO, 2019). Autism is now the single diagnostic label for what had been overlapping and similarly defined subtypes in previous versions of the diagnostic systems (i.e., the DSM and the ICD), such as Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS). Similar to other NDDs, autism is commonly diagnosed in childhood, although many individuals are not recognized until later in life (Bishop & Seltzer, 2012; Crane et al., 2021a; Lai & Baron-Cohen, 2015). Moreover, the autism traits and difficulties seen in childhood persist into adulthood for the majority of autistic individuals (Helles et al., 2015). Transitioning from childhood into adulthood significantly impacts autistic individuals (Bennett et al., 2018; Anderson et al., 2018; Thompson et al., 2018), also for those with an IQ in the broader average range (i.e., full-scale IQ >70), which will be further explored in this literature review.

1.1.1 Aetiology and prevalence

The aetiology of autism is primarily related to genetic factors, with an estimated heritability between 64–93 % (Tick et al., 2016; Thapar & Rutter, 2021; Taylor et al., 2020). Autism-related genes are pleiotropic (i.e., one gene with several phenotypic presentations), explaining the genetic overlap between autism, ADHD, intellectual disability and bipolar disease (Havdahl et al., 2021; Morris-Rosendahl & Crocq, 2020). These genes and their presentation occur in the context of potential environmental risks and through the gene-environment interplay (Thapar & Rutter, 2021). Environmental factors, such as older parental age and aspects of the foetal environment, contribute to the likelihood of autism

(Bölte et al., 2019). Furthermore, parental psychopathology is strongly associated with autism aetiology (Amiri et al., 2020). Additionally, as revealed in a large twin cohort study revealed that genetic markers have a larger impact than environmental factors on clinical autism, broader phenotypical autism and autistic traits in general (Taylor et al., 2020).

The current world-wide prevalence of autism in children is about 1.5 % (Christensen et al., 2018), with averaged global prevalence of 1% (Zeidan et al., 2022), and a male-to-female ratio of 4.2:1. For adults Brugha et al. (2016) reports a prevalence of 1.7%. In Stockholm, Sweden, the latest prevalence rate for transition-aged autistic youth is 2.4 % (ages 18-24 years) (Kosidou et al., 2017). The Swedish rates are comparable to those in other countries, such as 2.8% in Denmark (Schendel & Thorsteinsson, 2018), 2.6% in South Korea (Young Shin Kim et al., 2011), and 3.6% in New Jersey, USA (Shenouda et al., 2022). In the past two decades, a 3.5-fold increase in prevalence rates has been reported (Idring et al., 2015; Lyall et al., 2017; Maenner et al., 2023). The large increases in the prevalence and incidence of autism diagnoses have led to wide-spread speculation and are subject to scientific discussion (Taylor et al., 2020; Russell et al., 2022). The prevalence increase may be related to the fact that adults and females are now recognized to a much larger degree (Russell et al., 2022; Jensen et al., 2014) and to the more abstract description of autism criteria in DSM-5 leading to wider heterogeneity of registered diagnoses (Rabot et al., 2023). However, there is still no consensus as to the cause of the increase.

1.1.2 Autism traits and symptoms

Autism is characterised by two main areas of symptoms and behaviours: social communication and social interaction, as well as restricted, repetitive behaviours and interests. According to the ICD, published by the World Health Organization (WHO, 2019) and the DSM-5 (APA, 2013), these core symptoms and behaviours must be persistent and observable across many contexts and should cause significant impairment in several life domains and essential areas of functioning. Additionally, the symptoms must be evaluated with the individual's sociocultural context in mind and considered with age-related norms to determine whether the behaviour differs from peers in their specific context.

The first area – social communication and social interaction – contains three symptoms. Firstly, the symptom of social and emotional reciprocity pertains to the limited reaction to and recognition of the behavioural and emotional responses of others. Secondly, the symptom of non-verbal communication can present as having neutral facial expressions, atypical eye contact, and limited body language. The non-verbal difficulties are typically noticeable both in the neutral expression and in the misinterpretation of others' non-verbal communication. Thirdly, there are difficulties and differences in developing and maintaining social relationships, regardless of how socially motivated the individual is. For some, there may be a lack of interest in social relationships.

The second diagnostic area describes restrictive and repetitive behaviours that set autistic individuals apart from their peers. Firstly, there may be expressions of stereotypical and repetitive motor movements, such as rocking back and forth, flapping hands, or symmetrical finger and hand movements (popularly referred to as “stimming”). Secondly, there is typically an insistence on sameness and rigidity regarding routines, schedules, and everyday activities – which cause distress if deviated from. Thirdly, and commonly described, there may be specific interests, that can lead to an intense focus on a chosen subject matter. The specific interests lead to functional issues if they exclude the individual from social or educational settings. Fourthly, there may be a distinct sensory hyper- or hyposensitivity, which may lead to sensory interests, or it may lead to adverse reactions to sensory stimuli.

Additionally, the concept of autism ‘traits’ is frequently used (Constantino et al., 2003; Constantino & Todd, 2003; Taylor et al., 2020). In contrast to the more clinical concept of ‘autism symptoms’ described above, autism traits encompass a diverse range of characteristics. Some of these characteristics are examples from the symptom areas described above, e.g., avoiding eye contact, or having unusual eye contact. While other autism traits are characteristics that are common in autism but do not correspond directly with the symptom areas, e.g., is easily frustrated when trying to make themselves understood in conversations. Moreover, autism trait severity can be seen as the extent that these characteristics relate to autism as a diagnosis or to the specific symptom areas described above.

1.1.3 Associated cognitive difficulties

Available evidence suggests that autism may be associated with various cognitive characteristics that affect an individual’s presentation and functioning. According to a recent literature review conducted by Rezayi et al. (2023), five areas of cognitive functioning that appear particularly affected in autistic children are highlighted: executive functions (EF), social cognition and emotion, attention, learning and memory, as well as language. Although these associated difficulties are fairly well studied in autistic children, their salience in the transitioning years and early adulthood remains to be known.

Executive dysfunction may contribute to the explicit behavioural and social interaction difficulties seen in autism, according to meta-analyses that included autistic adults (Demetriou et al., 2018; Xie et al., 2020). Specifically, autistic adults exhibit difficulties with facets of EF: cognitive flexibility, inhibition, planning, working memory, and fluency (Kiep & Spek, 2017; Xie et al., 2020), which may affect how an individual interacts with their environment, whether social or otherwise.

Additionally, difficulties with social cognition, particularly theory of mind (ToM), have been widely studied as a cognitive trait associated with autism (Happé et al., 2006). These difficulties can present as issues with joint attention, eye contact in autistic children (Ioannou et al., 2020), and emotion perception and recognition in adolescents and young adults (Bölte et al., 2015). However, it is important to note that autistic individuals with an average intellectual capacity (i.e., IQ > 70) can perform well on ToM tasks, indicating their capacity to understand and reason about others' behaviours and reactions (Gernsbacher & Yergeau, 2019).

Moreover, autistic individuals often excel at processing details and exhibit local coherence rather than forming quick global impressions (Happé et al., 2016; Happé & Frith, 2006). This attention to detail is associated with strengths in information processing across various modalities including visual, auditory, and sensory modalities (Happé & Frith, 2006; Neufeld et al., 2020), and may also affect more complex situations such as a conversation (Beckerson et al., 2022). Meanwhile, flexibility, problem-solving, planning, and organising are typically defined as EF and simultaneously related to central coherence (Beckerson et al., 2022; Pellicano, 2012). Indeed, there is no conceptual consensus of what central coherence is; e.g., is it a limitation in global processing, a heightened ability to process locally, or to some extent both as discussed by Bojda et al. (2021)?

Learning and memory are reportedly affected in autistic individuals, with variations in the type and amount of information retained compared to non-autistic peers (Boucher & Anns, 2018). Specifically, difficulty with episodic memory, free recall and short-term memory tasks have been observed (Boucher

& Anns, 2018; Desaunay et al., 2020). Interestingly, compensatory mechanisms have been noted, with autistic individuals relying more on their semantic and procedural memory systems to aid in learning (Boucher & Anns, 2018). In addition, while some studies suggest difficulties in recalling specific autobiographical memories (Crane et al., 2012; Goddard et al., 2014), others have found that autistic individuals may have more vivid and detailed perceptual memories, including noticing sensory information missed non-autistic individuals (Crane et al., 2013; Williams et al., 2006).

Historically, attempts to provide a unified explanation of autism and its associated behaviours have been made by theorists (Happé et al., 2006). However, empirical evidence has found stronger support for the multiple pathway theories and keeping a developmental perspective that recognises the "knock-on" effects of missed or delayed developmental milestones (Jones et al., 2018; Pellicano, 2012). While no single cognitive feature fully explains autism, educating autistic individuals about features associated with autism may improve self-understanding and reduce stigma. Importantly, the core symptoms of autism along with the associated cognitive features have a significant bearing on functioning difficulties that persist into adulthood for most autistic individuals (Xie et al., 2020; Helles et al., 2015; Howlin, 2021).

1.1.4 Co-occurring mental health conditions

Autistic individuals are prone to co-occurring psychiatric conditions that significantly impact their mental health. Indeed, the prevalence of poor mental health amongst autistic individuals is staggering, with rapid increases in prevalence during the transitioning period, going from about 70% in childhood (Rosen et al., 2018) to 95% in autistic adults (Hossain et al., 2020). Unfortunately, there is a lack of appropriate services for autistic individuals with mental health problems, which in itself has been described as a crisis (Mandy, 2022).

Among autistic individuals, the most common co-occurring condition is ADHD (Lai et al., 2019). Other prevalent NDDs are specific language disorders (63.4 %), sensory integration disorders (15.7%), and specific learning disorders (6.3%) (Levy et al., 2010). Additionally, population-based studies have shown that the criteria for Intellectual Disability, i.e. having an IQ below 70 and corresponding impairments in adaptive behaviours are met in 30-50% of autistic children (Etyemez et al., 2022; Katusic et al., 2021).

As for other psychiatric co-occurrences, sleep disorders, depression and anxiety are the most frequently reported conditions in autistic adults (Hollocks et al., 2019; Lai et al., 2019; Hossain et al., 2020). In addition, consequences of mental health problems and psychiatric co-occurrence include an elevated risk of suicidal behaviour, including suicide attempts and suicide (Hirvikoski et al., 2020), especially among autistic women. Moreover, autistic women have a higher relative risk for psychiatric co-occurrence compared to autistic men (Martini et al., 2022; Vannucchi et al., 2014).

While the co-occurrence of psychiatric conditions is clear, their temporality in relation to autism is a discussed issue (Rubenstein & Bishop-Fitzpatrick, 2019). The concerns relate to whether the psychiatric conditions are truly co-morbid or instead be secondary to the core autism symptoms (Rubenstein & Bishop-Fitzpatrick, 2019; Lai et al., 2019), or perhaps related to contextual factors such as stigma, social exclusion and poor person-environment fit. Simultaneously, diagnostic overshadowing is a concern, a phenomenon where any co-occurring condition may be assessed as integral to autism and not as separately treatable conditions, as seen in two studies on comorbidities and associations between conditions in autistic children and adolescents (Kerns et al., 2014; Rodriguez-Seijas et al., 2020). The consequences of disregarding mental health problems or labelling them as an integral part of autism has meant that autistic individuals miss out on crucial interventions as seen in a qualitative survey study with autistic adults (Camm-Crosbie et al., 2019). Additionally, regardless of the temporality of the mental health problems and symptoms, such as anxiety or depression, in autistic adults, they may contribute independently to deficits in functioning (Kraper et al., 2017; Zukerman et al., 2019) and to QoL (Oakley et al., 2021; Knuppel et al., 2018; Lin & Huang, 2019). However, studies focusing on the transition-aged population are scarce and the relative contribution of mental health problems with other clinical factors remains unclear.

1.2 The impact of autism

To explore the impact of autism, it is necessary to disentangle the related but distinct concepts of functioning, quality of life (QoL), and stigma. While functioning entails the ability to perform activities and daily tasks in important life areas, that in turn contribute to an individual's health and well-being (Naughton & Shumaker, 2003; Leidy, 1994; WHO, 2002), QoL encompasses the subjective appraisal of physical, psychological, social, and spiritual well-being

(Whitcomb, 2011; Schalock, 2004). Whitcomb (2011) points out that QoL and functioning are not interchangeable, one does not fully determine the other. These concepts are interconnected, and their relationships are influenced by multiple factors. Additionally, stigma can have a significant impact on different aspects of functioning (Sickel et al., 2014), and on QoL (Rosenfield, 1997; Sickel et al., 2014). In the realm of intervention research, it is generally recommendation for psychiatric services to target both symptom reduction and improvements in QoL (Cuijpers, 2019). Indeed, interventions should focus on domains with low functioning (Whitcomb, 2011). To achieve these goals, clinicians and researchers need to have a comprehensive understanding of the specific factors that influence functioning and QoL in the sensitive time between childhood and adulthood.

1.2.1 Functioning

Firstly, an understanding of the term "functioning" is needed. According to Leidy (1994), the conceptual framework for functioning includes four dimensions: functional capacity, functional performance, functional reserve, and functional capacity utilisation in one's performance of life activities. Though there is no broad consensus regarding a definition, functioning can be specified as a multi-dimensional concept describing the individual's ability to carry out daily activities, participate in social interactions and maintain a sense of well-being (encompassing the physical, psychological, cognitive and social factors of influence on performance) (Üstün & Kennedy, 2009; WHO, 2002; Leidy, 1994). Importantly, there is a dynamic aspect to functioning, where an individual seeks to adapt to circumstances and challenges (external or internal) that arise across the lifespan.

According to the DSM-5 (APA, 2013), the deficits and associated behaviours of autism should: "… cause clinically significant impairment in… important areas of current functioning." (pp. 50). Functional impairment is contextual, requiring clinicians to consider the interplay between individual characteristics and their environment. In addition, the history of the term 'functioning' in autism has perhaps been misused (e.g., 'high functioning autism') and has not been an informative label of life circumstances (Alvares et al., 2020). The misnomer of using high or low-functioning autism was not related to autism severity, nor did it describe the individual's everyday life. Therefore, to recapture the importance of the functioning concept, one should consider 'functioning' a neutral term that informs autistic individuals in their self-knowledge and aids healthcare services in services development (Bölte, 2023).

Meanwhile, the most frequently used term in autism research is not functioning, but rather adaptive behaviour (AB), or as it is also referred to, adaptive functioning (AF). The primary perspective in AF is on the skills necessary for functioning within several life areas and situations as well as the ability to adapt and cope with the demands of the environment (Wehmeyer, 1999; Sparrow, 2005). Meanwhile, the WHO (2002) defines functioning, through its work with ICF (WHO, 2013), as a broader concept that includes an individual's ability to perform activities within important areas of life, which affect physical, psychological, and social functioning. Environmental factors, societal attitudes, and the physical and cultural environment can all affect this ability. In contrast to the AF approach, the ICF embraces a more holistic view of the individual, including areas of performance difficulty, environmental barriers, and information about the individual's strengths (Bölte, 2023; Mahdi, Albertowski, et al., 2018).

Regardless of the conceptual framework, there is an apparent discrepancy between the functioning and the intellectual development of autistic individuals (de Schipper et al., 2016; Kanne et al., 2011; Mahdi, Viljoen, et al., 2018; Tillmann et al., 2019; Zimmerman et al., 2018). Studies have found that socialization, communication, and daily living skills are affected in adolescents (Kanne et al., 2011; Duncan & Bishop, 2013), transition-aged autistic youth (Matthews et al., 2015) and emerging adults (Kraper et al., 2017). These studies typically use parent or proxy ratings to assess AF. Similarly, when using self-rated methods, such as the ICF-based WHO Disability Assessment Schedule 2.0 (WHODAS 2.0), comparable domains are rated as distinctly affected in autistic individuals, i.e., cognition, getting along with others, life activities, and participation in society (Park, Demetriou, et al., 2019; Schmidt et al., 2015).

Furthermore, functioning in autism is influenced by various individual characteristics, such as autism severity (Tillmann et al., 2019; Kraper et al., 2017); mental health problems such as symptoms of psychiatric co-occurrence (Kraper et al., 2017; Zukerman et al., 2019; Joshi et al., 2013); stress (Park, Song, et al., 2019), negative thinking and maladaptive coping (Zimmerman et al., 2018). However, few studies elucidate the relative contribution of different individual characteristics on functioning in transition-aged autistic youth.

1.2.2 Quality of life

Secondly, QoL refers to how an individual perceives or 'feels' about their overall well-being and satisfaction within various life domains. Several definitions of QoL exist, for example, the WHO defines it as an individual's subjective perception of their position in their life, contextualized by culture and local values and with the individual's environment (WHO, 1998). In comparison, Schalock (2004) defines it as an overarching phenomenon including subjective and objective aspects of well-being in numerous more or less abstract domains: relationships, social inclusion, personal development, physical well-being, self-determination, material well-being, emotional well-being, and personal rights. Moreover, others have simplified the concept into an overall subjective life satisfaction with several concrete indicators: leisure time, view on life, creativity, learning, friends, friendship, and view of self (Lindner et al., 2016). Schalock (2004) and Cuijpers (2019) focus on the subjective QoL, pointing out that it has become a vital intervention outcome and is now a frequent focus for clinical change in psychological treatments and psychiatric services. Similarly, within the autism field, there are ambitions of designing QoL-targeted interventions and, at the very least, using it as a salient outcome in intervention trials (Ayres et al., 2017; Sáez-Suanes & Álvarez-Couto, 2022).

Autistic individuals are consistently reported to have lower QoL compared to their peers (Mason et al., 2018; Ayres et al., 2017; Billstedt et al., 2011; Egilson et al., 2017; Oakley et al., 2021). This is particularly evident in autistic adults (Ayres et al., 2017; Moss et al., 2017) and among transition-aged autistic youth (Biggs & Carter, 2016; Billstedt et al., 2011), where self-rated QoL is especially reduced in domains related to social inclusion and interaction. Although there may be a correlation between low QoL and autism trait severity for autistic individuals of varying ages (Khanna et al., 2014; van Heijst & Geurts, 2015; Knuppel et al., 2018), a meta-regression of 17 studies did not find a significant contribution of this association to QoL in autistic adults (Kim & Bottema-Beutel, 2019). Instead, social functioning and social support (Kim & Bottema-Beutel, 2019; Mason et al., 2018; Moss et al., 2017; Khanna et al., 2014), as well as mental health problems such as depression in autistic adolescents (Oakley et al., 2021; Knuppel et al., 2018) and stress (Hong et al., 2016), were identified as significant predictors of QoL. Additionally, a cross-sectional study found that lower scores on a measure of self-determination, which includes the concept of self-empowerment, were associated with lower QoL scores in autistic young adults (White et al., 2018). An important finding to consider is that self-report consistently generates higher QoL estimates than those by parents or other proxies across multiple studies and reviews (Ayres et al., 2017; Sáez-Suanes & Álvarez-Couto, 2022; Knuppel et al., 2018), but is rated lower than among non-autistic peers (Khanna et al., 2014; Ayres et al., 2017).

1.2.3 Acceptance of Diagnosis and Stigma

Thirdly, an exploration of what stigma may mean is needed. Erving Goffman (1963) defined stigma as a social process, through which a negative label is placed on an individual based on “discrediting” characteristics or “attributes.” Inspired by Goffman, Han et al. (2022) describe stigma as being reduced as a person and discounted because of one’s inherent characteristics. Goffman and Han, home in on an individual’s traits or characteristics and judgements made of them, and that those traits are subjected to negative stereotypes and prejudices. For autistic individuals, issues of identity and the self-perception of autism (acceptance of diagnosis) are closely linked to stigma (Botha et al., 2022). The concept of stigma and autism was first described by Gray (1993), in which the diverse social behaviours of autistic individuals, in combination with the absence of noticeable physical features and the lack of autism knowledge, leads to stigmatisation. Moreover, autism stigma remains an issue among the public (Kitchin & Karlin, 2022; Turnock et al., 2022), service providers (Nicolaidis et al., 2015; Malik-Soni et al., 2022), and, most saliently, autistic individuals themselves (Han et al., 2022).

Meanwhile, a recent systematic review indicated that stigma is declining amongst autistic adults compared to individuals with other mental disorders (Han et al., 2022), corroborated by a cross-sectional study asking autistic adults to rate internalised stigma (Bachmann et al., 2019). In contrast, 15% in Bachmann et al. (2019) reported ‘severe’ autism stigma, as did 31.2% of participants from a large cross-sectional study on autistic adults in outpatient psychiatric services (Dubreucq et al., 2020). In addition, recent qualitative accounts of self-perception and stigma in autistic adults, report consistently negative and self-deprecating labelling by autistic adults (Botha et al., 2022; Leedham et al., 2020). There are associations between increased autism knowledge and reduced stigma seen among autistic adults in an online survey study (Bury, Jellett, et al., 2022) and similarly among the wider public (Kitchin & Karlin, 2022). However, learning about autism from traditional sources such as healthcare providers may be associated with more internalized stigma than reading about personal accounts from blogs or social media (Bury, Haschek, et al., 2022). This raises questions about how information is presented and what type of information is beneficial to reducing stigma, increasing diagnosis acceptance, and any other potential gains.

Additionally, improved self-identity and positive remarks regarding autism are seen amongst autistic individuals that have reframed and reconstructed the public's prejudiced perception of autism, as seen in Han et al. (2022)'s systematic review of autistic people's experiences of stigma. Similarly, having a positive autism identity may be linked to better mental health from a cross-sectional survey study with a large sample of autistic adults (Cooper et al., 2017). Indeed, Cooper et al. compared autistic individuals with typically developing peers and found a positive association between self-esteem and participants' autism identification. Similarly, Cage et al. (2018) saw an association between not identifying as autistic and having higher rates of anxiety and depression symptoms among autistic adults. Disclosing and talking about identity-related issues seems to improve one's self-perception of autism, as well as reframing and being given positive examples about autism (Han et al., 2022). Moreover, Pellicano et al. (2020)'s mixed-methods study combines findings from a cross-sectional study exploring adaptive functioning in autistic adults with emergent themes from interviews with the same participants, revealing a discrepancy between autism severity and the aspirations of the individuals as well as their perception of 'being autistic.' Moreover, forming one's identity is at the core of the psychological development processes during the transitioning period, for all individuals (Arnett, 2007).

1.3 Transition-Aged Autistic Youth

Entering adulthood can be challenging as it involves simultaneously navigating psychological changes and societal demands. This transition usually occurs between late adolescence of about 16 years to mid-to-late 20's (Arnett, 2007). For individuals in 'high-income countries,' this period is defined by specific occasions of seeking independence, attaining education and establishment within the workforce, all the while developing and practising decision-making skills. However, for autistic individuals, the transitioning period is especially challenging as achieving independence can be slower and more complicated. In addition, autistic adults may not meet expected milestones in social relationships, education, or employment, as shown by both cross-sectional studies (Jonsson et al., 2019; Matthews et al., 2015; Thompson et al., 2018) and qualitative studies (Anderson et al., 2018; Cheak-Zamora & Teti, 2014; Cribb et al., 2019). Nevertheless, an interview study with autistic adults who had been followed since childhood, describe being hopeful about their future (Cribb et al., 2019) and reported gained confidence and self-assurance when entering adulthood. Critique suggests that applying normative expectations to their transition may not be appropriate, as they may have a unique trajectory and different outcomes compared to non-autistic individuals (Cribb et al., 2019; Pellicano et al., 2020; Lounds Taylor, 2017). While much has been reported about the challenges faced by the transition-aged autistic youth (Howlin, 2021; Howlin & Magiati, 2017), Lounds Taylor (2017) asked the crucial question: What outcomes are good for autistic individuals? Similarly, Cribb et al. (2019) argue that conventional outcome markers are not reliable even for typically developing individuals, and consequently inappropriate for autistic individuals. In addition, there has been profound criticism towards the normative perspective on outcomes, even by Howlin and Magiati (2017), in that it assumes the same type of outcomes suit and are wanted by all individuals in the transition age-group. Autistic individuals have unique strengths and challenges, interventions that fail to account for this diversity may miss important opportunities for growth and development among autistic individuals.

1.3.1 Transition needs

To achieve a successful transition into adulthood for autistic individuals, both quantitative (Howlin et al., 2004; Howlin & Magiati, 2017; Volkmar et al., 2017) and qualitative studies (Cribb et al., 2019; Sosnowy et al., 2017; Thompson et al., 2018) show a need for assistance in major life areas. Indeed, facilitating occupational opportunities, helping with maintaining social relationships and assisting with living independently, all serve to retain and build upon the positive experiences of becoming an adult asked for by transition-aged autistic youth and their parents (Cheak-Zamora & Teti, 2014; Cribb et al., 2019; Thompson et al., 2018). Unfortunately, the challenges with transitioning described in the literature coincide with a loss of services when becoming an adult, referred to as "dropping off a cliff," rendering many autistic individuals and their families without support from services (Bennett et al., 2018; Taylor & Henninger, 2015). Moreover, the transition into adulthood could be helped by increased self-awareness of difficulties and strengths, as well as through knowledge about accessible support (Lee et al., 2020; Thompson et al., 2018).

1.3.2 Lived Experience of transition-aged autistic youth

In the past decade, there has been growing interest to explore the lived experiences of transition-aged autistic youth. Several qualitative studies have attempted to describe the subjective experience of transition-aged autistic youth, providing valuable insights into their aspirations and struggles. For example, studies have reported the importance of finding an appropriate person-environment fit in employment and educational settings (Anderson 2018), and the desire for independence and autonomy in daily living skills, managing finances, and job training (Sosnowy et al., 2017). Through a study using survey responses from transition-aged youth and their parents, Sosnowy et al. (2017) point out that transition-aged autistic youth say that striving for independence is a chance to achieve autonomy while recognising that there will be difficulties along the way. Similarly, Cheak-Zamora and Teti (2014) describe health-related issues for transition-aged autistic youth in that they actively think about (and struggle with) healthcare-related independence issues; needing to remember appointments, going to appointments on their own and then independently adhering to the recommendations or treatment plans provided. A later study by Cheak-Zamora et al. (2021) confirmed earlier findings that transition-aged autistic youth expressed a desire to understand health-care processes and to be independent in the usage of services. In a recent qualitative interview study from Sweden, Lothberg et al. (2023) et al. note that housing support workers servicing transition-aged autistic youth convey a need to balance between providing support and letting the youth be independent. However, this study did not report on the perspectives of emerging adults themselves.

Moreover, transition-aged autistic youth report that they feel more in control of their lives when they have opportunities to develop their skills through mainstream schooling, work, and college (Pellicano et al., 2020). Some also report that developing an autistic identity (be it embracing it or deeming it no longer a big problem and now being “mildly” autistic) increases their sense of control (ibid.). These youths describe valuing deeper social relationships, wanting true friendships of ‘high’ quality and not necessarily many friends. A study by Tesfaye et al. (2022) with autistic adolescents, identified similar themes, such as seeking social connections, establishing autonomy, and complex thoughts about their autism identity. Additionally, providing a forum to develop these perspectives within themselves, for example through an approachable intervention, may be a way to ameliorate the challenges associated with transitioning to adulthood as an autistic individual.

1.4 Interventions for transition-aged autistic youth

Transition-aged autistic youth need support that intends to alleviate inherent difficulties associated with core symptoms and the functional impairments of autism (Cribb et al., 2019; Thompson et al., 2018). For example, they may need to build upon previous knowledge in new situations, as well as help with generalizing information between contexts (Volkmar et al., 2017; Lee et al., 2023). In addition, they need help developing their decision-making skills to reach independence (Arnett, 2007) and seek to improve their health-care competence (Cheak-Zamora et al., 2021). Typically, transition-aged autistic youth do not receive sufficient interventions and support to make a harmonious entry into adulthood (Burke et al., 2018; Cheak-Zamora et al., 2014). They are largely left to navigate life on their own without the support of disability services or accommodated mental health services, as such treatment as usual (TAU) for this age group is severely lacking (Cheak-Zamora et al., 2017; Malik-Soni et al., 2022; Robert A. Nathenson & Benjamin Zablotsky, 2017).

Recent reviews of interventions for transition-aged autistic youth reveal that the few group interventions focusing on social skills and cognitive behavioural therapies are effective in improving both core symptoms of autism and associated comorbidities (Chancel et al., 2022; Bottema-Beutel et al., 2022). In addition, the authors recommend psychoeducational interventions, but too few were available for in-depth analyses. Additionally, Bottema-Beutel et al. (2022), identified promising interventions, including vocational training programs, peer mentoring programs, and social skills interventions, but noted that most studies had a high risk of bias. Of the extant interventions for transition-aged youth several target employment or vocational aspects of adult life (employment training interventions), some focus on general issues about the transition between childhood and adulthood (Hatfield et al., 2017; Jonsson et al., 2019), but few deal with self-knowledge or identity-related issues.

Additionally, few interventions convey a stepped-care approach (i.e., providing low-intensity interventions to all, and adding other interventions case-by-case as needed) to providing services (Burke et al., 2018), nor target the expressed need for suitable communication styles (e.g., digital communication) of young autistic adults (Lounds Taylor et al., 2012; Gillespie-Lynch et al., 2014). The scarcity of evidence-based interventions for transition-aged autistic youth (Bottema-Beutel et al., 2022; Lamash et al., 2022; Pallathra et al., 2019), in combination with a lack of access to health care services usage in the transitioning and adult ages (Bennett et al., 2018; Adams & Young, 2021; Maddox et al., 2020), could contribute to the mental-health care crisis among autistic adults (Mandy, 2022).

1.4.1 Adopting a co-development approach

The autism community has consistently called for the inclusion of autistic individuals in the development and research of autism interventions, as highlighted in seminal papers (Lai et al., 2020; Pellicano et al., 2014). A co-development approach, as described by Grindell et al. (2022), involves collaborative and participatory processes in which diverse stakeholders, community members and researchers work together to co-develop solutions to complex problems. This approach aims to mobilise knowledge and expertise and to create a shared understanding of a problem and its potential solutions. In addition, they emphasize that while the co-development approach can be a useful way to understand and support different conditions, there are limitations to its effectiveness, e.g., insufficient descriptions of the specific methods used to achieve co-development, and that the effects of co-development can be difficult to measure and evaluate, which make it challenging to demonstrate its impact. Despite these limitations, Grindell et al. (2022) argue that the co-development approach can be a powerful tool for promoting knowledge mobilisation.

Moreover, Burke et al. (2018) argue that interventions need to be co-developed, enabling a better match to the needs of transition-aged autistic youth. A flexible approach to the development of the intervention and the research itself is recommended, including considering the timing of the intervention, mode of delivery, measurable outcomes, and who the intervention targets. In a report on autism services in the UK, Beresford et al. (2020) found that users (i.e., autistic patients) emphasised the importance of the scope and access of interventions (often psychoeducation), the mode of delivery, and the availability of alternatives to group-settings when receiving care. A review by Anderson et al. (2018) on the conveyed healthcare needs of transition-aged autistic youth wanted interventions that aid independence in healthcare and interventions that focus on individualised support and environmental modification rather than behavioural change. By prioritising the voices of autistic individuals and using a flexible co-developed approach to intervention development, interventions can better serve the needs of this population.

1.4.2 Stepped care model

Designing interventions using stepped care models may increase treatment approachability and accessibility. Stepped care models are systematic and flexible approaches for delivering healthcare services that are tailored to the patient's specific needs. They consist of a hierarchy of interventions, with less intensive and less demanding interventions at the first steps, and more intensive and individualised interventions at the subsequent steps (Ip et al., 2019; Bennett et al., 2022). The goal of stepped-care models is to match the patient's level of need with the appropriate level of intervention, so that the patient receives the most effective treatment while minimizing the burden on the patient and the healthcare system (Trudgeon & Carr, 2007). In mental health settings, the stepped-care approach provides both an economical (Rodgers et al., 2012; Bennett et al., 2022) and clinical effectiveness (Bennett et al., 2022). In autism care in the UK and Sweden, guidelines have been developed (Wilson et al., 2014; Ip et al., 2019; Axén, 2010) describing a stepped-care approach to providing interventions for NDDs, focusing on first-line interventions that are easily delivered and accessed. These guidelines typically describe providing information about autism (e.g. through psychoeducation) as one of the first-line interventions provided, and then further services as required. By providing fewer intensive and less resource-demanding interventions first and then escalating the level of care only as necessary, the stepped-care model can help ensure that patients receive the most effective and efficient care possible.

1.4.3 Psychoeducation

An often recommended, low-intensity first-line intervention, following a confirmed autism diagnosis is psychoeducation (Axén, 2010; Wilson et al., 2014; Beresford et al., 2020). It integrates educational, didactic methods with psychotherapeutic strategies to promote condition-specific knowledge, self-awareness, and increased self-management (Beresford et al., 2020; Motlova et al., 2017). Psychoeducation as a treatment concept originates from work with schizophrenic patients and their families (Murray-Swank & Dixon, 2004; Zhao et al., 2015; Hayes & Gantt, 1992), intending to manage their care and help with adherence to treatment plans. In other areas of the healthcare system, structured psychoeducation has become a staple of physicians, psychologists, and other professionals to enable a better understanding of the condition of a relative or oneself (Motlova et al., 2017). As such, psychoeducation is now a well-established, evidence-based intervention for several psychiatric disorders (Lyman et al., 2014; Higgins et al., 2020), intended to empower patients by building self-awareness and self-acceptance through condition-specific knowledge (Hayes & Gantt, 1992; Higgins et al., 2020; Lyman et al., 2014; Zhao et al., 2015), most often provided in group-settings.

Over time, psychoeducational interventions have transformed their targets. Initially, psychoeducation primarily focused on practical aspects such as medication adherence and informing families about symptoms and condition progression. However, the scope of psychoeducation has expanded to encompass broader objectives, including enhancing overall well-being by fostering self-understanding and providing factual information about various conditions. For example, in group-based psychoeducative interventions, hearing about the experiences of peers is seen as helpful for accepting one's condition, both across different mental health conditions (Higgins et al., 2020) and specifically in the context of autism (Beresford et al., 2020; Crane et al., 2021b). Moreover, core targets for most modern psychoeducative interventions are understanding critical features of one's condition (including positive aspects) and learning specific coping techniques that may lead to increased functioning and improved mental well-being. In addition, most studied interventions are aimed at families and in a group setting, but there is a burgeoning evidence base for individual (also referred to as consumer-directed) patient-directed psychoeducation according to a large review of psychoeducational interventions for patients with schizophrenia, psychosis, bipolar disorder and depressive disorders (Lyman et al., 2014).

Focusing on psychoeducation for autistic adults, it is evident that several "in-house" initiatives have not been scientifically evaluated (Beresford et al., 2020), although several evaluated programmes for parents or carers of autistic children exist (Morsa et al., 2022). Furthermore, most trialled programmes were group-based for parents of autistic children (Morsa et al., 2022) and one for adolescents with autism and their parents (Gordon et al., 2015; Oshima et al., 2020). With only one for autistic adults and their close relations (Hidalgo et al., 2022) and one for their parents (Smith et al., 2012). Hence, for transition-aged adults on the autism spectrum, the field of psychoeducational interventions is still in its infancy, with very few studies of sufficient methodological rigour

(Chancel et al., 2022). Nonetheless, of the programmes mentioned earlier, many were effective in increasing autism knowledge (Morsa et al., 2022), as well as increasing self-esteem or a sense of self-awareness (Gordon et al., 2015; Morsa et al., 2022).

Crane et al. (2021b) conducted a qualitative interview study of an autistic-led psychoeducational programme – where participants appreciated the peer-led modality, appreciated the diversity (heterogeneity) of autistic individuals, and the positive information about autism. Interestingly, in several studies described in a scoping review on psychoeducation for mental health conditions in general, a common barrier to service utilisation was to be in a group-setting (Higgins et al., 2020), which was echoed in the report on services use for autistic patients in the UK (Beresford et al., 2020).

1.4.4 Internet-delivered and technology-based interventions

Internet-delivered treatment options for transition-aged autistic individuals are few, but there are a few internet-based or computer-aided interventions for autistic individuals in general. Reviews on computer-mediated interventions for autism have provided support for the continuing development and clinical use of this mode of intervention, although most studies lack scientific rigor and had limited sample sizes for the intended analyses (Fletcher-Watson & Fletcher-Watson, 2014; Grynszpan et al., 2014; Lamash et al., 2022). Nonetheless, among the few recent internet-delivered interventions for autistic (emerging) adults, a small open pilot trial and an RCT, the authors found improved mental health and self-esteem following an online chat-based coaching programme, as well as being a feasible alternative to face-to-face health care services (Sehlin et al., 2020; Wentz et al., 2012). Additionally, Tang et al. (2021) created a digital intervention for social-emotional understanding in autistic adults; participants who received both programmes showed larger improvements in distant generalisation skills (of social cognition) and higher self-efficacy scores than controls. Additionally, Bross et al. (2021) showed that their small group of young autistic adults appreciated the technology-based components of an online intervention to increase planning skills and participation in social activities.

Although there is great interest in technology-based interventions, including internet-delivered ones, there is considerable work to be done in terms of understanding the effects, benefits and potential limitations (Lamash et al., 2022; Grynszpan et al., 2014; Valencia et al., 2019). Concerns exist regarding accessibility, in that, not all autistic individuals have equal access to the internet and computers or are equally computer literate, which may create disparities in the ability to benefit from digital communication, as noted by two reviews of technology-based interventions for autistic individuals (McGhee Hassrick et al., 2021; Lamash et al., 2022). Another concern is that some individuals may prefer face-to-face interactions and may not find internet-based interventions as effective, as has been shown in mental health services in Sweden for adults (Wallin et al., 2016).

Nonetheless, from a qualitative account of internet-delivered interventions for transition-aged autistic youth, Sehlin et al. (2018) reported the online coaching participants showed appreciation of the text-based mode of communication, being at home, as well as the immediacy of the intervention. Similarly, Westerberg et al. (2021) noted that participants of an internet-delivered cognitive behavioural therapy (ICBT) for autism, appreciated the written communication and found the digital format acceptable and the intervention as an overall positive experience.

1.5 Summary

Autism presents numerous challenges for young adults, especially during the transition into adulthood, and is linked to adverse outcomes in various life areas. Social outcomes, such as relationships, occupation, and independence, are the most reported challenges. Additionally, mental health is significantly impacted during the transition years and later in adulthood, with several studies reporting low functioning and quality of life in this age group. The factors associated with functioning and QoL and their relative importance on the outcomes are not yet fully understood. While there are available interventions for skills enhancement and stress reduction, they are typically only accessible through specialized healthcare services and not easily accessed by autistic emerging adults. Additionally, while internet-delivered options are growing in popularity, research on interventions for transition-aged autistic youth is limited, with heterogeneous outcomes. Few studies have examined the efficacy of commonly provided psychoeducational interventions for transition-aged autistic youth, and none have investigated the effects of delivering psychoeducation in an unstructured and ad hoc way. This thesis addresses the concepts of self-reported functioning and quality of life and evaluates an internet-delivered psychoeducative intervention for transition-aged autistic youth aimed at improving their autism knowledge, self-acceptance and quality of life.

2 Research aims

The overarching aim of this doctoral thesis is to advance the understanding of transition-aged autistic individuals by expanding the knowledge base in areas such as functioning, reduced quality of life, and about an internet-based psychoeducational intervention about autism. The studies within this thesis include a cross-sectional clinical cohort study and two treatment trials. The cross-sectional study (**study I**) focused on factors predicting self-reported functioning and QoL in transition-aged autistic youth. The two treatment trials evaluated the internet-delivered psychoeducational intervention SCOPE (Spectrum COmputerized PsychoEducation) through, firstly, a feasibility study (**study II**) with an open design; and secondly, a pragmatic randomised controlled trial (**study III**) evaluating the effectiveness of SCOPE.

2.1 Study I: Cross-sectional analysis of functioning and quality of life

The aim of **study I** was to describe to what extent autism symptom severity and mental health problems are associated with self-reported functioning and QoL in treatment-seeking transition-aged autistic youth. With the following research questions:

(1) How do transition-aged autistic youth report their experiences of functioning and QoL?
(2) Is the relative importance of mental health problems and autism symptom severity different for functioning versus QoL?

2.2 Study II: Feasibility pilot study of SCOPE

The aim of **study II** was to evaluate the feasibility of SCOPE, in older adolescents and young adults with autism, aged 16–25 and with average range intellectual functioning. Feasibility was evaluated through analysis of completion rates, treatment credibility and treatment satisfaction following SCOPE, as well as its content and user-friendliness from both participant and professional perspectives. Additionally, preliminary efficacy in terms of autism knowledge, and changes in mental health were analysed.

2.3 Study III: Randomised effectiveness study of SCOPE

The aim of **study III** was to evaluate the effectiveness of SCOPE – therapist supported internet-delivered psychoeducative program using a pragmatic randomized controlled design. Study III tested the following hypotheses:

(1) The effectiveness of SCOPE on autism knowledge is superior to passive treatment as usual (TAU) and active self-study comparators in a clinical outpatient setting.
(2) Symptoms of depression and anxiety do not increase following SCOPE participation compared to control conditions TAU and self-study.
(3) Acceptance of Diagnosis and QoL will increase at follow-up in participants of SCOPE compared to TAU and self-study.

3 The empirical studies

3.1 The research setting

All three studies were conducted in cooperation between Habilitation & Health, Stockholm Region outpatient disability healthcare services and the Center of Neurodevelopmental Disorders at Karolinska Institutet (KIND). Habilitation & Health provides interventions for individuals with NDDs and their network, whereas KIND is dedicated to research, development of novel methods and interventions, and education about NDDs. See table 1 for an overview of the studies.

Table 1. Study overview with study aims, number of participants, research design and data collection timeline.

Study	Aims	Participant numbers (N)	Research design	Data collection timeline
I	To describe self-reported functioning and QoL in transition-aged autistic youth, and analyse the relative contribution of associated factors.	140 Sourced from study III.	Cross-sectional	2016-2020
II	To evaluate the feasibility and preliminary efficacy of SCOPE	28	Feasibility pilot, open trial	2015-2016
III	To evaluate the effectiveness of SCOPE	144	Pragmatic randomised controlled trial	2016-2022

3.2 The intervention

The intervention in focus is the SCOPE programme: containing eight weekly psychoeducational modules about autism, delivered online. SCOPE was accessed through the Swedish national e-health platform Stöd och Behandling (SoB: in English, it reads, Support and Treatment platform). In pre-trial development, an older version of SCOPE was used by autistic young adults to evaluate and experience all parts of SCOPE and to provide comments on content, design, and user-friendliness. The results and feedback from the target-group were considered when completing the design and content of the SCOPE-version trialled in **study II**. Further amendments of wording to emphasise the concept of neuro-diversity, as well as the addition of positive information about autism, were made after the feasibility study and before the subsequent RCT (i.e., between **study II** and **study III**). In addition, we employed neuro-diverse designers from a daily activity centre to do some of the artwork in SCOPE. In the end, SCOPE's eight autism-related topics, one per module (see figure 1 and Table 2), each contains (1) a text describing the module topic, (2) four video vignettes with recurring fictional transition-aged autistic youth who speak about their lives and perspectives on the module topic, (3) a bullet-point list of non-autistic characteristics related to the module's topic, (4) self-reflection using three or four questions related to the module topic, answered by multiple choice suggestions and a voluntary written comment. SCOPE contains wording and examples which intend to contextualise information about autism and related themes, as well as features to empower the participant; see table 2 for examples from each module.

Across both intervention trials, participants had a therapist allocated to them in the first module who wrote instructions for how to use SCOPE, checked participants' answers and progress, responded to comments, and offered further insights into the module theme. Therapists were health professionals, including clinical psychologists, special educators, social workers, and occupational therapists working in specialised habilitation service units for autistic older adolescents and young adults. These therapists were already experts in their fields but had to undergo SCOPE-specific training to become SCOPE-therapists. The SCOPE developers conducted digital training of SCOPE with all therapists, which included a thorough review of each module and module components in the SoB platform, instructions about the platform usage; and instructions about how to write responses, including a phrase bank in the manual. All new SCOPE therapists were supervised during their first two participants with recurring weekly supervision sessions as well as supervisors surveying responses to participants.

Figure 1. Picture from the SCOPE index page (in Swedish) depicting the eight autism themed modules and contents.

Table 2. Content description of SCOPE modules and positive aspects of autism.

Modules	Content description	Excerpts of positive aspects
1. Introduction to the history of autism.	Text about the history of autism, and information about the diagnosis in broad terms. Specific skills are described as “Aspie superpowers.”	Accuracy and precision are strengths that many autistic individuals have in common.
2. Social functioning and communication	Specifically describing the diagnostic criteria related to social skills and communication. E.g., the tacit rules of social interaction.	Autistic individuals often describe themselves as loyal friends who are reliable and keep their promises.
3. Behaviours and interests	Specifically describing the diagnostic criteria regarding behaviours and interests. Examples of positive aspects of behaviours and interests. E.g., the joy of intense interests.	Having a good memory, a strong ability to notice details, and a capacity to collect and categorize information enable many autistic individuals to delve deeply into their interests.
4. Theory of Mind	Definition of the term, as well as how it is related to autism. E.g., awareness of the thoughts and motivations of others.	From a video vignette: “I observe people quite a lot. I can sense when someone is not happy, even if they don't say anything…”
5. Central Coherence	Definition of the term, as well as how it is related to autism. Information about detail focus, context blindness, and complications in social interaction.	A well-developed sense of detail can also be a fantastic asset. Notably, it can be enriching to notice things that most others overlook.
6. Executive functions	Definition of the term, as well as how they are related to autism. Information regarding what EF is; about planning, structuring, and guiding one-self.	From a video vignette: "I have a need for things to turn out as I have envisioned. In the morning, I carefully think through everything I have to do from morning until evening."
7. Intelligence and Memory	Definition of the terms, as well as how they are related to autism. Differences in memory functions, and description of unevenness IQ.	An autistic person can possess an impressive ability for detailed memory and achieve good results on memory tests.
8. Perception	Definition of the terms, as well as how they are related to autism. E.g., coping strategies for hyper- and hyposensitivity. Description of filtering issues, as well as gross and fine motor skills.	Having sharp senses is valuable. Some autistic individuals may be skilled artists, demonstrating a superior sense of detail in their drawings or paintings.

3.3 Study I

3.3.1 Methods

The first study is a descriptive cross-sectional study. We included n = 140 participants (drawn from **study III**), aged 16-25 years, with community-based autism diagnoses, i.e., diagnosed by clinicians in the public or private healthcare system. We confirmed autism diagnoses by reviewing medical records (i.e., diagnostic assessment reports stating their diagnosis, patient record entries, or psychiatrist notes). In addition, we validated the autism diagnoses by asking about autism traits and symptoms using the semi-structured diagnostic interviews, the Ohio State University Global Severity Scale for Autism (OARS-4: Choque Olsson & Bölte, 2014; OSU, 2005).

Four self-rating instruments were used to assess functioning, QoL, autism symptom severity, and mental health problems. The first instrument, the World Health Organisation Disability Assessment Schedule 2.0 (WHODAS 2.0 36-item interview) was administered to assess functioning in six life domains: cognition, mobility, self-care, getting along, life activities, and participation (WHODAS 2.0: Üstün, 2010). The WHODAS 2.0 manual uses population-wide norms presented as percentiles to assess the level of disability, higher percentiles indicate more disability. WHODAS 2.0 has been validated for autistic adults with an IQ in the average range (i.e., FSIQ ≥ 70), with satisfactory psychometric properties (Park, Demetriou, et al., 2019). In our data, the internal consistency of responses was established using Cronbach's alpha, with $\alpha = 0.95$, which indicates excellent reliability of obtained scores.

Brunnsviken Brief Quality of Life Scale was used to assess QoL (BBQ: Lindner et al., 2016). The BBQ has good psychometric properties in two sample populations (non-clinical: $\alpha = 0.69$; clinical [patients seeking treatment for social anxiety disorder]: $\alpha = 0.71$) and could ascertain lower scores for the clinical sample (Lindner et al., 2016). Our data had Cronbach's $\alpha = 0.75$, which is acceptable internal consistency.

The Social Responsiveness Scale, Second Edition (SRS-2) was used to assess autism symptom severity (Constantino & Gruber, 2012); it is especially suitable for detecting individuals who have milder presentations of autism traits (Constantino, 2021). The Swedish version was used and has reported excellent reliability at Cronbach's $\alpha = 0.95 - 0.97$ (Constantino, 2019). Our data had Cronbach's $\alpha = 0.88$, which is very good internal consistency.

The Hospital Anxiety and Depression Scale was used to assess anxiety and depression symptoms (HADS: Bjelland et al., 2002; Snaith, 2003). HADS consists of 14 items evenly distributed into two subscales: anxiety (HADS-A) and depression (HADS-D), rated on a Likert scale from 0 (never) to 3 (often). A cut-off of 8 for each subscale defines a clinically significant level of anxiety and depression symptoms (Bjelland et al., 2002). HADS has been validated for autistic transition-aged individuals, with good psychometric properties for the Anxiety (HADS-A) subscale, with Cronbach's $\alpha = 0.83$ and acceptable reliability for the Depression (HADS-D) subscale at $\alpha = 0.65$ (Uljarević et al., 2018). Our data had very good reliability for both subscales with Cronbach's $\alpha = 0.86$ for HADS-A and $\alpha = 0.87$ for HADS-D.

In addition, to assess other markers of psychiatric co-occurrence and mental health problems, we had access to medical records, diagnostic assessment reports, and a self-report form stating all current diagnoses, current treatments, and background demographic information. The background demographic information was collected via an extensive questionnaire about relationships with friends, family, the living situation in terms of independence and type of housing, the highest level of educational attainment, current occupation, financial situation, and leisure activities. Participants self-reported by choosing provided categorical options.

3.3.1.1 Statistical analyses

Functioning, assessed by WHODAS 2.0 and QoL by BBQ, was analysed using descriptive statistics.

Spearman's correlation was used to analyse associations between potential predictor variables, i.e., autism symptom severity (SRS-2), mental health problems (anxiety and depression symptoms [HADS-A and -D], co-occurring self-reported ADHD self-reported diagnosis), demographic variables (age, gender, years since autism diagnosis, current occupation, friendships, independence in living) and outcomes, i.e., functioning (WHODAS 2.0 summary score) and QoL (BBQ total score). Following the correlation analysis, all significant associations were used as potential predictors of the outcomes (functioning; QoL), using multiple linear regression. This approach of first assessing associations between variables to reduce the number of independent variables (IVs) to later be used in a regression model is described by Tabachnick and Fidell (2018). By including all significant predictors simultaneously as independent variables, the analysis can identify the combined influence of these factors on the outcomes of interest functioning and QoL). The predictors are presented in the form of Standardised Coefficient Beta, interpreted according to

(Cohen, 1988), whereby a standardized coefficient of 0.50 or higher represents a large effect, 0.30–0.49 represents a moderate effect, and 0.10–0.29 represents a small effect. The regression was performed on z-score transformed values and bootstrapped n = 1000 for confidence intervals. All statistical analyses were conducted using SPSS 26.0, with an α-level of 0.05.

3.3.2 Main results

The average overall functioning in our sample was 34.4 (out of 100) WHODAS 2.0 summary score – which corresponds to the 90th percentile (compared to population norms). WHODAS 2.0 measures the *level of disability*, meaning that the 90th percentile indicates distinct difficulties in the measured domains. There were differences in functioning between domains (or level of disability); two domains (i.e., *mobility* and *self-care)* had close-to-average levels of functioning (compared to population norms) while the remaining domains had distinctly low functioning scores, i.e., *Cognition*, *Life Activities*, *Participation,* and *Getting along with others*. For more details, see Table 3.

Quality of life, as measured by the aggregated BBQ score, had a mean score of 43.19 (SD = 19.43), which is lower than the general population mean, as well as lower than the clinical cut-off indicating low QoL than in the general population and in a clinical population.

From the next step in the analysis, we found several significant associations between IVs and functioning (as the dependent variable [DV]). We found that functioning was associated with several potential predictors: SRS-2 scores (r = .61; p < .001), HADS-A (r = .41; p < .001), HADS-D (r = .29; p = .001), gender (r = .32; p < .001), and co-occurring ADHD (r = .30; p < .001). In the regression analysis, after controlling for gender (which had a significant impact on functioning scores, $\beta = .14$; p = .04) it was the self-reported autism traits (SRS-2), anxiety symptoms (HADS-A) and self-reported ADHD that contributed significantly to the model $F(5,134) = 25.10$, p < .001, with an adjusted R^2 0.46 (i.e., the IVs in the model predicted 46% of functioning scores).

Table 3. Descriptive statistics of overall functioning, domain scores (Backman et al., 2023).

n = 140	**Mean**	**SD**
WHODAS 2.0 Summary score	34.42	11.23
WHODAS 2.0 Domains:		
Cognition	41.84	16.30
Self-care	18.75	16.43
Getting along	47.72	16.83
Life activities	45.53	21.17
Participation	43.25	17.37
Mobility[a]	5	65
BBQ total score	43.19	19.43

*Note: ***p < .001; **p <.01; *p <.05; WHODAS 2.0: World Health Organization Disability Assessment Schedule 2.0; [a]median (IQR: Inter-Quartile Range); BBQ: Brunnsviken Brief Quality of Life Scale*

The β-coefficients represent the strength and direction of the associations between the IVs and functioning scores within the regression model, the significant β-coefficient for autism traits was .51 ($p < .001$); .17 ($p = .03$) for anxiety symptoms and .13 ($p = .05$) for self-reported ADHD-diagnosis. Depression symptoms did not contribute independently to the model ($\beta = .05$; $p = .51$), i.e., they were not significantly associated with functioning scores after accounting for the other variables in the model.

Several associations between QoL as the DV and IVs were found. QoL scores had a small association with SRS-2 scores at $r = -.23$; $p = .006$; a large association with HADS-A ($r = -.50$; $p < .001$), and with HADS-D ($r = -.62$; $p < .001$), and a small association with having active friendships ($r = .20$; $p = .02$). Therefore, we included these variables in the regression model for QoL (DV). The regression model was significant at $F\ (5{,}133) = 21.37$, $p < .001$, with $R^2 = .45$. The adjusted R^2 indicates that the model predicted 43% of QoL scores. Symptoms of depression ($\beta = -.45$; $p < .001$) contributed relatively the most to the regression model, this indicates a strong negative association between depression symptoms and QoL scores, with higher levels of depression symptoms associated with lower QoL scores. Whereas symptoms of anxiety ($\beta = -.25$; $p = .001$) and having active friendships ($\beta = .13$; $p = .05$) to a lesser extent, i.e., having more anxiety symptoms and fewer friendships was associated with lower QoL scores. In contrast, there was no significant independent contribution from autism symptom severity (SRS-2) ($\beta = -.07$; $p = .34$) when accounting for the other variables in the model.

In sum, the results indicate that autism symptom severity, anxiety symptoms and having an ADHD-diagnosis have a significant negative impact on functioning scores, while depression symptoms did not. Additionally, symptoms of depression and anxiety have a significant negative impact on QoL scores, while having active friendships has a modest positive association with QoL scores.

3.4 Study II

3.4.1 Methods

The feasibility of the internet-delivered intervention, SCOPE, was evaluated from 2015 to 2016 as an open within-group trial. Twenty-nine transition-aged autistic youth were included in the study, and 28 individuals underwent the intervention. Five participants did not complete the intervention; see Figure 2. for a flow chart of participants.

Participants were 16-25 years, diagnosed with autism spectrum disorder (community diagnosis), had Full-scale IQ >70 (not meeting criteria for ID), and were cable of using an internet-based platform and reading Swedish proficiently to engage with a psychoeducative program, with numerous written components. Participants were excluded if they met the criteria for substance use disorder; had acute severe suicidal behaviours; were diagnosed with traumatic brain injury (e.g., stroke), other severe psychiatric disorders (e.g., psychosis) or had psychosocial circumstances that would render participation unlikely or impossible. Ongoing pharmacological or other treatments were not reasons for exclusion.

The main aim of this study was to investigate the feasibility of SCOPE, as such, feasibility was assessed through a pre-defined benchmark of > 75% completers (with at least five out of eight completed modules). In addition, we used the Treatment Credibility Scale to assess treatment credibility and expectations (TCS: Borkovec & Nau, 1972) and module evaluations to assess satisfaction with each module. Reliability for TCS, in our data, was deemed very good at Cronbach's $\alpha = 0.85$. The therapists also completed the TCS, including the same items as those completed by the participants, but adjusted to assess the coaches' experience of SCOPE. At post-intervention, all therapists and course co-ordinators involved were asked eight open-ended questions about their views on the coach training, the SCOPE manual, and the intervention itself.

For preliminary efficacy, we used a knowledge quiz created for the study, using similar quizzes as a template (Bramham et al., 2009; Hirvikoski et al., 2017; Hirvikoski et al., 2015). The reliability through internal consistency analysis, measured using Kuder-Richardson 20 (KR_{20}), was 0.68 ($n = 28$), which is acceptable according to (Cohen, 2005).

We assessed mental health problems using HADS (Snaith, 2003). In this data set, we had Cronbach's $\alpha = 0.82$ for HADS-A, and Cronbach's $\alpha = 0.86$ for the HADS.D, which are both indicative of very good reliability.

Acceptance of diagnosis was measured using a modified version of The Acceptance and Action Questionnaire 2 (AAQ-II: Bond et al., 2011). We modified the questions to reflect the acceptance of diagnosis. Questions were (1) "My diagnosis makes it difficult for me to lead a life I could value"; (2) "I am afraid of my diagnosis"; (3) "I worry about not being able to control my worries and my feelings regarding my diagnosis"; (4) "My diagnosis prevents me from leading a fulfilling life"; (5) "My diagnosis creates problems in my life"; (6) "I feel uncomfortable with my diagnosis"; (7) "My diagnosis gets in the way of my success" ours. Our data had Cronbach's $\alpha = 0.84$, which indicates very good internal consistency.

QoL was assessed using the Satisfaction with Life Scale (SWLS: Pavot et al., 1991), which is a brief measure with questions asking for a subjective appraisal of life satisfaction. Our data had very good reliability: Cronbach's $\alpha = 0.87$.

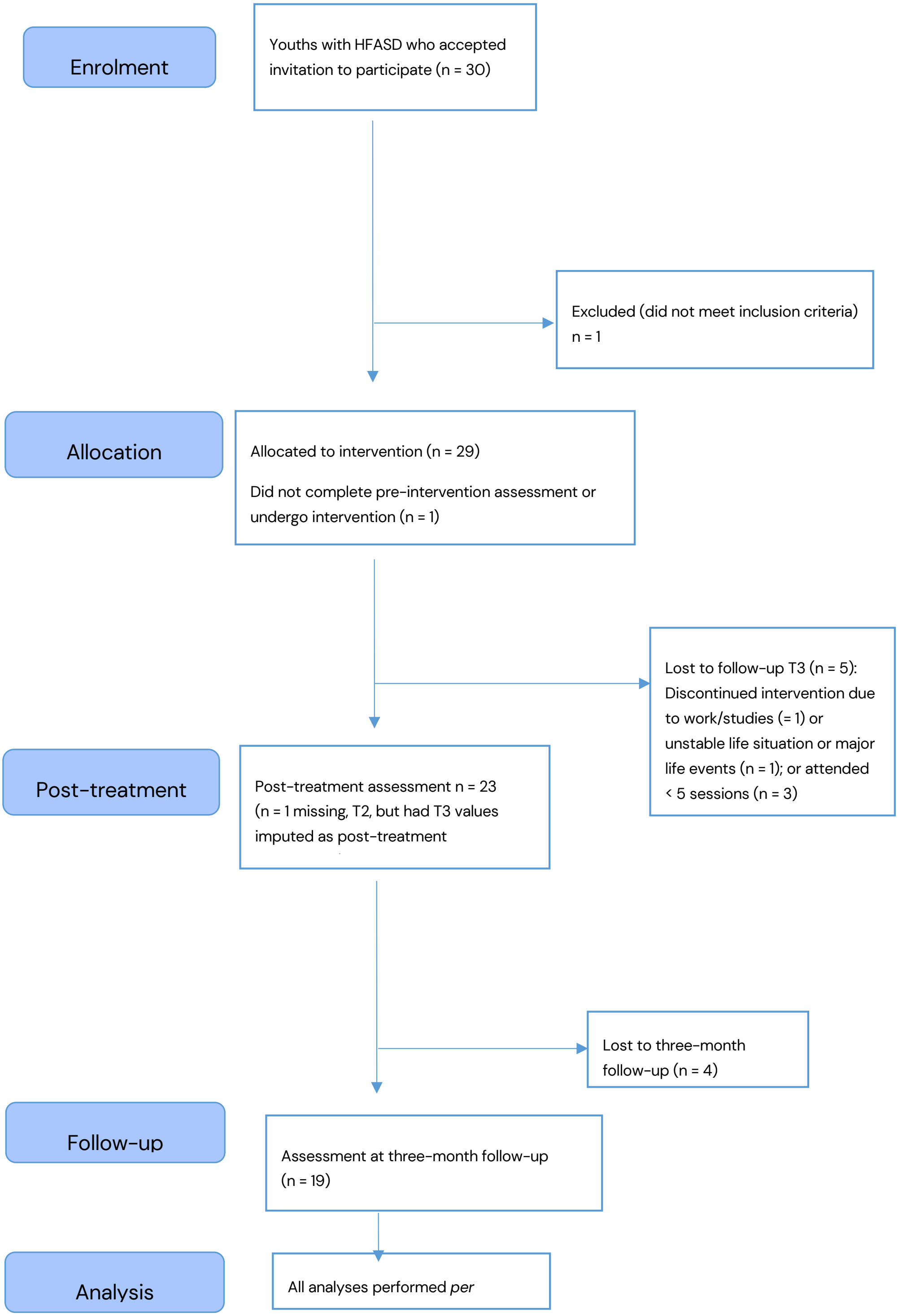

Figure 2. Participant flow-chart SCOPE feasibility study (Backman et al., 2018)

3.4.1.1 Statistical and qualitative analyses

The feasibility measures were analysed using descriptive statistics and ANOVA to analyse treatment credibility. The efficacy-related measures were analysed using a series of repeated measures ANOVAs (rmANOVAs), with a baseline score and post-intervention score (imputed from follow-up score if missing) as a within-subjects repeated measure factor. The main statistical analyses were performed per protocol on all participants who (1) completed the intervention, i.e., participated in at least five out of eight modules and (2) had post-intervention or follow-up data. The effect sizes were expressed as partial eta squared (η^2) for efficacy-related measures and interpreted using the guidelines proposed by Cohen, i.e., 0.01 = small effect size, 0.06 = moderate effect size, and 0.14 = large effect size (Cohen, 1988). The α -levels were set at $p < 0.05$.

For the qualitative analysis of data, the participants' and therapists' written responses were analysed thematically by content and grouped into emergent themes. The initial analysis was conducted by a research assistant (psychology student) and then confirmed by two project members following a discussion regarding the content validity of the themes and sub-categories.

3.4.2 Main results

Twenty-three out of the 29 included participants (79%) completed the intervention. The participants' experience of treatment credibility (TCS) was increased following SCOPE participation, yielding a large effect size $\eta^2 = 0.30$ ($p = 0.007$). In addition, overall satisfaction (module evaluations) with the treatment was high, $M = 3.5$ (out of 5); $SD = 0.75$. The therapists reported high treatment credibility and good clinical feasibility.

In addition, the participants' autism knowledge increased significantly from pre- to post-intervention and the increases were maintained at follow-up. The increased autism knowledge was not associated with negative effects on mental health problems (i.e., increased anxiety and depression symptoms), changes in acceptance of diagnosis or life satisfaction scores.

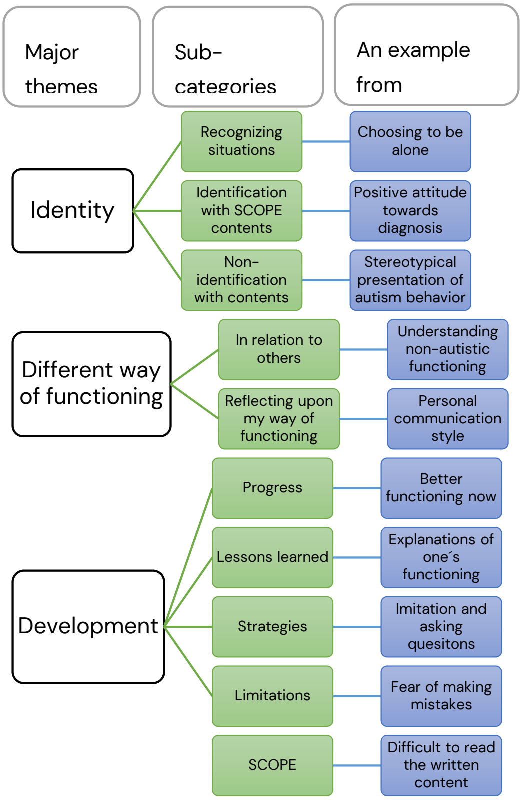

Figure 3. Qualitative analysis of participant comments – major themes, sub-categories and examples from comments.

The thematic analysis showed the following main themes: *Identity*; *Different way of functioning;* and *Development*. Several sub-themes were categorised, see figure 3. for sub-categories and participant comments.

3.5 Study III

3.5.1 Methods

Study III is a three-armed pragmatic randomized controlled trial (RCT) evaluating the effectiveness of SCOPE. We have defined the trial as a pragmatic RCT (Patsopoulos, 2011) due to its assessment of effectiveness and that the trial was conducted with existing clinical staff from Habilitation & Health, trained in the SCOPE method.

Participants (n = 145; 16 – 25 years old) were enrolled in blocks between 2016 - 2021. Following Patsopoulos (2011) we had broad inclusion criteria (1) diagnosed autism spectrum disorder (in accordance with DSM-IV, -V or ICD-10 diagnostic manuals) through community diagnosis and with IQ in the broader average range (i.e., Full-Scale IQ > 70); (2) sufficient Swedish language proficiency; (3) ability to log on and utilize the internet-based platform. Exclusion criteria were few, being diagnosed with acquired brain injury, current problematic substance use, severe suicidal ideation, and other severe psychiatric disorders that were not under stable medical treatment. (e.g., psychosis or bipolar disorder), or adverse psychosocial circumstances (e.g., being homeless).

Participants were randomized to one of three conditions, by 2:1:1 to SCOPE, TAU, or self-study (SS) of internet-based autism information (i.e., informative websites from stakeholder organisations, universities, and healthcare providers), see Fig. 4 for a CONSORT flow chart of SCOPE RCT participation. We achieved 16 blocks with a minimum of 4 and a maximum of 13 participants. The discrepancy in participant numbers per randomised block was dictated by the slow recruitment rate and by clinic-related resources, e.g., availability of therapists.

The primary outcome was autism knowledge, measured using the same knowledge quiz as in **study II**. The ASD Quiz consists of 16 'autism facts,' with three answer options (true; not true; unsure). The KR_{20} coefficient α was 0.57 ($n = 141$) in pre-intervention, 0.63 ($n = 108$) at post-intervention and 0.59 ($n = 98$) at follow-up. The secondary outcomes were symptoms of depression and anxiety, using HADS (Snaith, 2003); acceptance of diagnosis using the modified AAQ-II (Bond et al., 2011); quality of life using BBQ (Lindner et al., 2016), for psychometric properties of the secondary outcome measure, please refer to the description under **study I**. In addition, we measured treatment credibility in SCOPE participants and the self-study controls, using the TCS (Borkovec & Nau, 1972).

3.5.1.1 Statistical Analyses

All statistical analyses were planned *a priori,* and α was set at $p < .05$.

All variables were screened for violations of normality and sphericity; outcome data were approximately normally distributed. Statistical outliers for all outcome measures were screened using boxplots in SPSS, and the few ($n = 7$) extreme outliers (defined as 1st or 3rd Quartile ± 1.5) were corrected by moving them to the closest whisker (i.e., to the 1st or 3rd Quartiles).

Differences between the treatment arms (SCOPE vs. Self-study vs. TAU) from pre-post and pre-to-follow-up were determined using linear mixed models

(Gueorguieva & Krystal, 2004). The models included random intercept, random time (slope), and other covariance structures; the model with the best fit was established using the log-likelihood ratio test. For outcomes where the slopes between self-study and TAU did not differ (four out of five outcomes), the control groups were collapsed into one to increase power. For the ASD Quiz, the slopes of self-study and TAU differed significantly, post hoc tests were conducted to analyse the slopes of SCOPE against self-study and TAU, respectively. Between-group effect sizes, presented as Cohen's *d*, were calculated by dividing the above-described coefficients of time * group interaction effect by the observed pre-treatment pooled standard deviation (Feingold, 2009). Effect sizes were interpreted as, 0.2 = small, 0.5 = medium, and 0.8 = large (Cohen, 2005).

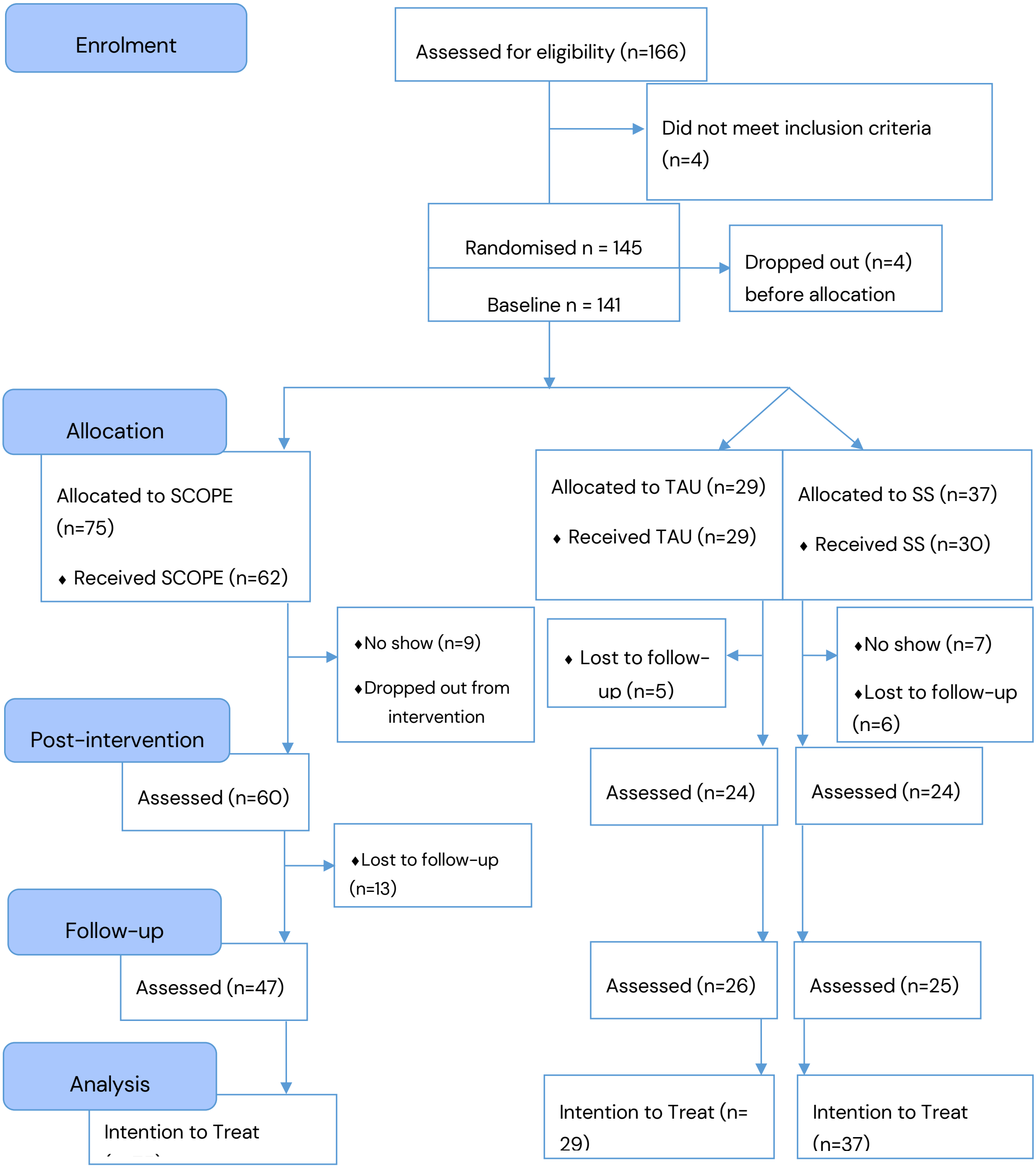

Figure 4. CONSORT flow chart of participants.

3.5.2 Main results

We found that SCOPE and self-studies, but not TAU, increased autism knowledge from baseline to post-treatment, see figure 5 for a graph with observed values. In the intention-to-treat analysis at post-treatment of SCOPE, participants compared to TAU showed estimated mean difference of 1.03 (95% CI 0.04 to 2.02, *p* = .04). Compared to the self-study participants there was no significant difference in scores, with estimated mean difference at -0.18 (95% CI -1.18-0.83, *p*= .73) However, the self-study participants' knowledge scores returned to baseline at the three-month follow-up and SCOPE participants had further increased autism knowledge at follow-up compared to self-study (estimated mean difference 1.27; 95% CI 0.25 – 2.30, *p* = .02) and treatment as usual (estimated mean difference 1.15; 95% CI 0.15 – 2.15, *p* = .02), with small to medium effect sizes.

The increases in autism knowledge were not associated with significant changes in mental health problems at post-treatment or 3-month follow-up. Moreover, SCOPE participants reported improved QoL with a mean score difference of 7.21 (95% CI 1.79 – 12.62, *p* = .02) at post-intervention and a mean score difference of 11.33 (95% CI 5.70 – 16.97, *p* = .001) at three-month follow-up compared to both control conditions, with small to medium effect sizes.

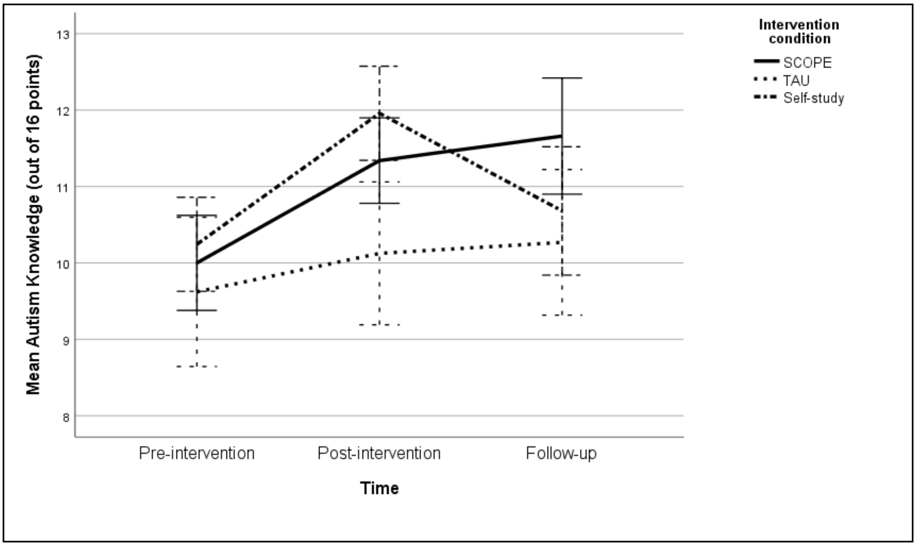

Figure 5. Multiple line graph of observed Autism Knowledge means at pre-intervention, post-intervention, and follow-up by intervention condition, with 95 % CI error bars (Backman, et al., *submitted).*

3.6 Ethical considerations

Ethical considerations in healthcare research are crucial for ensuring ethical conduct. The central ethical permit (EPN: 2014/1868-31/5) in this thesis reflects adherence to key ethical principles of autonomy, non-maleficence, beneficence, and justice (Varkey, 2021). These principles guide clinicians and researchers in intervention studies, using research setting specifications from Saks et al. (2002) on consent, confidentiality, and the risk-benefit ratio to analyse the trials in this thesis. Furthermore, the Helsinki Declaration (WMA, 2013) emphasizes respect, professionalism, and participant autonomy in research.

The principles of autonomy are rooted in the belief that all individuals have an intrinsic worth (Varkey, 2021), expressed through the ethical considerations of consent and confidentiality (Saks et al., 2002), and can be referred to as 'person-oriented research ethics' recommended for autism research (Cascio & Racine, 2018). For example, consent requires that the risk-benefit conditions be relayed to participants. In control conditions of RCTs, the potential benefit of an intervention is delayed due to the research design, therefore participants need to be informed about these parameters, as well as how randomisation will occur and potentially affect them. In **study III**, participants were not blinded to the allocated intervention condition and were given verbal and written information about the project parameters. In addition, written informed consent was collected for all participants in **studies I-III**, and the written information was supplemented with verbal information when conducting the intake interviews. Despite these efforts, a number of participants randomised to the self-study condition thought they had received SCOPE. In future studies, more consideration of the cognitive requirements associated with autism may increase the individual's understanding of the information provided. Moreover, with respect to autonomy, participants signed informed consent, which was a prerequisite for the intake interview and was explicitly informed that they had complete participation autonomy and could discontinue participation at any time without any negative consequences with their regular healthcare.

Autonomy and confidentiality were upheld through adherence to Swedish patient confidentiality laws (Patientsäkerhetslagen [2010:659]) and the EU Act General Data Protection Regulation Services from 2018 onwards (GDPR: Wolford, 2021). In addition, autonomy was encouraged in participants younger than 18 years (the legal age of adulthood in Sweden) to make informed consent and exercise their autonomy to receive an intervention. In all three studies, participants between 16 and 18 years could independently access the studies and the interventions. It was explicitly stated that caregivers and parents could not enter the study on behalf of the older adolescents, but to aid accessibility, they could help with the intake procedure in compliance with study parameters (i.e., accessing SoB, opening modules, and filling out questionnaires at the specified timepoints).

Non-maleficence in clinical settings involves relieving patient suffering (Varkey, 2021), while in research settings, it relates to the risk-benefit ratio (Saks et al., 2002). **Study III** randomised participants to intervention conditions, potentially causing temporary discomfort, but randomization is a recommended method to assess intervention efficacy. Logistical challenges in **study III**, such as delays between inclusion and baseline measures, were addressed to minimise risk and ensure participants had access to healthcare services. In the intervention trials (**studies II** and **III**), non-maleficence considerations included addressing potential participant fatigue and stress from self-rating scales. The studies were conducted in a clinical setting with experienced therapists who were prepared to deal with any negative consequences. We used standardized and established instruments to assess symptoms of anxiety and depression, enabling us to monitor mood changes and referrals to further interventions if needed.

Beneficence, i.e., promoting well-being, is intertwined with all other ethical principles. In the context of this thesis, promoting the well-being of autistic individuals involved evaluating an innovative intervention modality (internet-delivered) and investigating the effects of psychoeducation on the strengths and difficulties associated with autism. In **studies II** and **III**, the inclusion procedures required self-referral, emphasising empowerment in decision-making (Cascio & Racine, 2018). This approach was chosen to make sure that the individuals accessing the projects within this thesis had control over their participation. Beneficence is also associated with social justice in disability research, by addressing health disparities and ensuring that underserved populations have access to high-quality care. In line with this, **study I** aimed to highlight issues of diagnostic overshadowing in transition-aged autistic youth to enable better care and services.

Justice in healthcare settings involves fair resource distribution and evaluating interventions for improved accessibility. In autism research it is related to the type of research conducted; Pellicano and Stears (2011) suggest that it may be appropriate to consider the subjective perspectives of autistic individuals and prioritize research areas proposed by themselves, as further elaborated by Poulsen et al.'s (2022) paper on ethics in autism research. **Study II** utilized thematic analysis to explore SCOPE participation, following these recommendations. Similarly, **study I** focused on self-reported functioning and quality of life, addressing the lack of self-reported information, particularly for females. Analysing the importance of clinical characteristics contributes to justice in healthcare and service settings. Additionally, adopting a co-development approach represents justice for autistic individuals through their inclusion in research ventures (Cascio & Racine, 2018).

4 Discussion

The overall aims of this thesis were to gain knowledge about self-reported functioning and QoL in transition-aged youth on the autism spectrum and to evaluate the feasibility and effectiveness of an internet-delivered psychoeducative intervention. Findings from the first study confirm the relative importance of mental health above and beyond autism traits on functioning and QoL in this age group. In addition, this thesis provides new evidence that internet-delivered, therapist-guided psychoeducation for transition-aged autistic youth is feasible and effective, and among this cohort more effective in regard to increased autism knowledge at follow-up compared to self-study. The following sections discuss the results in detail.

4.1 Factors of importance for functioning and QoL

In **Study I,** we actively sought to use self-reported information and aimed to disentangle the relative importance of different predictors on functioning and QoL. The current sample was self-referred, treatment-seeking, transition-aged autistic youth, who is a reportedly marginalised population on account of often falling between healthcare and services systems (Burke et al., 2018; Ames et al., 2022; Malik-Soni et al., 2022), while simultaneously needing to navigate adulthood and fending for themselves (Ames et al., 2022; Wisner-Carlson et al., 2020; Cribb et al., 2019). However, it is important to point out that our cohorts were not representative of being underserviced by healthcare and social services, as shown in supplementary Table I for **study I**. In, we analysed the influence of gender on the outcomes, which is often raised as important (de Schipper et al., 2016; Lai et al., 2015; Lundin Remnélius, 2023), but has not been sufficiently studied (Halladay et al., 2015).

Consistent with previous literature, the results from **study I** confirm the link between mental health problems and poorer functioning (Joshi et al., 2010; Joshi et al., 2013; Park, Song, et al., 2019; Zukerman et al., 2019), as well as with lower QoL in autistic individuals (Hong et al., 2016; Klang et al., 2022; Mason et al., 2018; Oakley et al., 2021; Park, Song, et al., 2019). However, previous studies have not specified the relative and independent contribution of these factors on the outcomes. In **study, I**, autism symptom severity, anxiety, having an ADHD diagnosis, and gender had a significant impact on functioning scores, whereas symptoms of depression did not. Furthermore, although autism severity correlated with QoL, the association disappeared when considering mental health problems and having a friend in the regression analysis. This suggests that mental health problems have a greater impact on both functioning and QoL than the other investigated factors. Therefore, a comprehensive assessment, recognition and treatment of mental health problems are especially important for autistic individuals, as they are still overlooked due to diagnostic overshadowing (Pezzimenti et al., 2019) and frequently left untreated (Lai et al., 2020; Mandy, 2022). By further elucidating the relative importance of different aspects of mental health problems, such as parsing out different symptoms and problem areas, and aiming to explicitly improve a sense of empowerment and self-determination hopefully leads to improved functioning and QoL. These strategies align with the goal of providing evidence-based interventions for autistic youth (Burke et al., 2018; Mandy, 2022).

Even so, autism symptom severity is the main feature of both prevalent diagnostic systems (APA, 2013; WHO, 2019), and as such needs to be carefully considered. Assessing the severity of autism symptoms and traits plays a crucial role in determining the appropriate level of intervention and support needed for individuals on the autism spectrum. In previous work on autistic adults, higher autism trait severity was associated with various aspects of daily functioning (Tillmann et al., 2019), as well as with mental health problems such as self-perceived stress (Hirvikoski & Blomqvist, 2015), higher rates of depression (Gotham et al., 2015), increased sexual anxiety (Byers et al., 2012), and poor healthcare independence (Cheak-Zamora et al., 2021). However, concerning QoL, some studies suggest autism severity as predictive of QoL in autistic adults (Mason et al., 2018; Lin & Huang, 2019; Khanna et al., 2014) – but had not explored the relative contribution of autism symptoms in relation to other predictors on QoL. In contrast, a large review (Chiang & Wineman, 2014) and a meta-regression (Kim & Bottema-Beutel, 2019) on predictors of QoL in autistic adults did not find support for autism trait severity being a predictor of QoL, in line with results from the **study I**. The discrepancy between the importance of autism traits on functioning versus on QoL has not been explored and could be the focus of future work. Understanding the role of autism traits on these two intertwined outcomes may further our knowledge about treatment targets.

Another key finding of **study I** is that the use of self-reported assessment for functioning and QoL in the transitioning age group seems to capture similar perspectives as proxy assessments shown in other studies with autistic adults (Oakley et al., 2021; Tillmann et al., 2019); where QoL and functioning were clearly lower across domains than in the comparison population. It is an important finding and aligns with attempts to compare self-report by autistic individuals to those of proxies, often parents (Egilson et al., 2017; Hong et al., 2016; Sandercock et al., 2020). Moreover, it challenges the historical view that autistic individuals are incapable of reflecting upon and rating their own experiences, feelings and traits (Botha et al., 2022; Milton et al., 2022). Instead, **study I** shows that autistic transition-aged youth are able and willing to both rate and reason about themselves. In the long run, subjective self-reported information may enable a more active participation in healthcare and service encounters for individuals on the autism spectrum (Howlin, 2021; Sandercock et al., 2020). By recognising and valuing the perspectives and insights of autistic individuals, healthcare and support services can better tailor their approaches and provide more effective interventions.

Regarding the known predictors of functioning and QoL, findings from **study I** suggest that the variables chosen can predict functioning and QoL to some extent, but a significant portion of the variance is still unexplained. It is crucial to consider the impact of individual characteristics on mental health, functioning, and QoL, as they vary significantly among individuals. Each autistic individual has unique strengths, challenges, as well as support needs. Factors other than those measured in **study I** and similar studies, such as individual differences in cognition, environmental factors, or the complex nature of autism itself, likely contribute to the variability in these outcomes (Mahdi, Albertowski, et al., 2018; Mahdi, Viljoen, et al., 2018). Therefore, a more comprehensive understanding of the individual's profile through information about autism trait severity, mental health problems, as well as demographic and contextual factors should enable tailored interventions that promote positive mental health outcomes, enhance functioning, and improve quality of life.

4.2 The feasibility of SCOPE

The SCOPE programme was designed to serve as an option for first-line post-diagnostic interventions, with high intervention accessibility for individuals who do not typically use traditional face-to-face services (Cheak-Zamora et al., 2014; Taylor & Henninger, 2015) and prefer digital communications and interventions (Gillespie-Lynch et al., 2014; Grynszpan et al., 2014; Lamash et al., 2022). Additionally, SCOPE was developed to address the lack of interventions designed for transition-aged autistic youth, as observed in two recent reviews (Bottema-Beutel et al., 2022; Chancel et al., 2022). This novel intervention modality necessitated a co-development approach and to first trial feasibility aspects of the intervention.

Concerning co-development, we use the definition put forth by Grindell et al. (2022), in that knowledge needs to be mobilised from different sources (e.g. clinicians and autistic individuals), and through different means, e.g., through iterative development, with workshops and focus-group interviews. Within autism research there have been calls for the inclusion of autistic individuals in the description of research targets (Poulsen et al., 2022; Pellicano & Stears, 2011), in the development and design of interventions (Gillespie-Lynch et al., 2017), as well as moving towards intervention research targeting the transition period (Ames et al., 2022; Burke et al., 2018). In relation to the projects within this thesis, several versions (iterations) of SCOPE were tried in a workshop setting with emerging autistic adults giving feedback on all aspects of the intervention. In addition, SCOPE contents include information about the strengths associated with an autistic cognitive style (see table 2), explicitly asked for by members of the autistic community (Lee et al., 2020; Thompson et al., 2018). Indeed, the qualitative analysis of SCOPE participation in **study II** provided comments about SCOPE being the first time the transition-aged youth had read positively worded information about autism. However, the majority of information in SCOPE and the module themes draw from a deficit-based perspective on autism (see Table 2), which is in contrast to what transition-aged autistic youth say the need and want (Crane et al., 2021b; Lee et al., 2020; Lee et al., 2023), emphasising a need for peer-led and peer-developed programs that focus on strengths and supportive solutions. In line with the iterative aspects of co-development a version of SCOPE was evaluated for technical functionality, feasibility in a clinical context, treatment satisfaction and credibility, the trial ran from 2015 to 2016 (Backman et al., 2018), subsequently modified in a later version (**study III**).

Furthermore, in keeping with the conceptual framework of feasibility trials (Eldridge et al., 2016), the SCOPE feasibility pilot (**study II**) addressed whether SCOPE “could be done”, and if we should “proceed” with SCOPE. Firstly, the technical functionality of SCOPE worked, participants were able to log on and utilise the program as it was intended. Participants could access the contents from wherever they chose to be. In addition, SCOPE is entirely internet-based and therefore suitable for those who do not want to be in a group setting and those who are facilitated by the multi-media learning components, such as the films, and the possibility for repetition of the written content. Secondly, in terms of clinical feasibility completers in **study II** were 79%, and as such good, given that psychiatric intervention trials typically have completion rates between 26% to 82% (Mazzotti & Barbaranelli, 2012). Although no meta-analysis of attrition-rates on interventions for autistic individuals exists, our study's completion rates were comparable to those reported in other autism psychoeducative interventions (Gordon et al., 2015; Hidalgo et al., 2022), as well as an internet-delivered coaching involving chat sessions for autistic adults (Sehlin et al., 2020). We speculate that the internet-delivery, weekly therapist support and thoroughly vetted contents of SCOPE contributed to the intervention completion. Finally, further trials are needed to analyse the active intervention components to better encapsulate the feasible aspects of this type of intervention.

Another aspect of an intervention's feasibility is how approachable it seems to the intended audience, for example, witnessed in the recruitment pace of potential participants. In **study III,** the slow recruitment suggests a low level of face validity of SCOPE. Although completion rates were high for **studies II** and **III**, recruitment was slow especially for **study III**, with approximately thirty participants included every year (2016 to 2020). The recruitment pace could suggest that the study did not reach the intended target audience, possibly because the intervention was perceived as too time-consuming, somehow unappealing to transition-aged autistic youth, or the mode of study entry was cumbersome (application through the study website using e-identification). Given the apparent willingness of autistic transition-age participants to receive interventions (Bennett et al., 2018; Burke et al., 2018; Volkmar et al., 2017), we expected a higher flow of participants to **study III**. It raises the question of how to reach individuals with less healthcare and support services usage. Unfortunately, this study was unable to identify the complex reasons for participant recruitment difficulties in these trials.

In addition, feasibility was analysed in terms of treatment satisfaction – which in this case was high and similar to other psychoeducational trials for autistic adolescents (Gordon et al., 2015) and adults (Hidalgo et al., 2022). Unfortunately, no quantitative feasibility assessment of comparable internet-delivered interventions for autistic adults has been made. Similarly, to the acceptable treatment satisfaction, the treatment credibility of SCOPE was initially high and increased following the intervention. The increased treatment credibility could be due to SCOPE's digital communication, preferred by autistic individuals'

(Nicolaidis et al., 2015; Gillespie-Lynch et al., 2014), or positively framed autism information and the use of inclusive language. In other internet-delivered interventions, a connection between high treatment credibility and low attrition has been found (Alfonsson et al., 2016), perhaps explaining the relatively low attrition in **studies II** and **III**. Moreover, the approach of pre-post assessment of treatment credibility was chosen in light of documented negative expectations and experiences of interventions and services by autistic adults (Maddox et al., 2020; Adams & Young, 2021), which is also seen among clinicians responsible for providing care (Malik-Soni et al., 2022; Maddox et al., 2020). Therefore, in **study II**, the significantly increased treatment credibility amongst participants, as well as the high treatment credibility by therapists following SCOPE, indicates a potential for strong adherence to and acceptability of SCOPE. These findings highlight an important aspect of feasibility and indicate that the SCOPE intervention was well-received by both participants and therapists.

4.3 The effectiveness of SCOPE

Following the promising results of the feasibility study (**study II**), we initiated a pragmatic RCT to evaluate the effectiveness of SCOPE. Conducting research with patients as participants in their regular clinical setting has several real-world advantages (Barnish & Turner, 2017; Patsopoulos, 2011). Firstly, it enables direct implementation as staff and logistical aspects of the intervention are already set up and tried. Secondly, it ensures that the intervention is tried on typical patients and that the effects seen will be of higher external validity than if they were an overly controlled participant category (e.g., with many exclusion criteria). Finally, it is beneficial to the patient to receive a new intervention in a safe and existing setting that the patient naturally is a part of.

The results of **study III** were in favour of SCOPE over the control conditions. Previous research on psychoeducation for autistic adolescents and adults (Gordon et al., 2015; Hidalgo et al., 2022) and parents of autistic adults (Hidalgo et al., 2022; Smith et al., 2012) show similar autism knowledge gains as **study III**. It is important to note that in absolute numbers, the ASD Quiz score changes, were small for participants in the SCOPE condition as well as for self-study participants at post-treatment and at follow-up. Nonetheless, several key factors set **study III** apart from previous psychoeducational intervention research in general, and for autistic individuals specifically.

A main difference to the broader field of psychoeducative intervention research is using an active comparator to psychoeducation, which has not been mentioned in research overviews (Higgins et al., 2020; Lyman et al., 2014; Zhao et al., 2015). Nor has it been tried in the few psychoeducational initiatives studied for autistic individuals. In **study III**, we used the commonly practised self-study of informative websites, similar to how bibliotherapy is used (Jack & Ronan, 2008), as an active comparator to SCOPE. Self-study options, such as informative websites, have previously been reported to be potentially negative for autistic individuals (Beresford et al., 2020), and are usually of insufficient quality (Grant et al., 2015). Moreover, Beresford et al. (2020) noted that individuals who engaged in self-study did not follow through with other recommended services compared to those who received in-house psychoeducational interventions at autism services across the UK. In **study III**, the self-study participants initially learnt as much about autism as SCOPE participants. However, they did not retain the information three months after the intervention ended, nor did any improvements in QoL occur. These findings suggest that SCOPE possessed more effective qualities for information dissemination compared to self-study.

In addition, the SCOPE participants, in contrast to the self-study participants and TAU, had significantly increased QoL scores post-intervention as well as at follow-up – implying that the components of SCOPE were more beneficial when compared to studying websites (self-study comparator) and to TAU. The focus on QoL as an important outcome in mental health interventions, including psychoeducation, is recommended by Cuijpers (2019) and is rooted in its connection with identity and stigma (Sickel et al., 2014). Moreover, research has shown that positive reframing and self-identification with autism can contribute to well-being and improved mental health in autistic individuals (Han et al., 2022; Cooper et al., 2017), which aligns with the aims of psychoeducation in general and specifically with how SCOPE was designed. Participants in the SCOPE feasibility study (**study II**) reported positive attitudes towards having an autism diagnosis, and that the positive perspective on autism conveyed in SCOPE was enjoyable. However, in **study III** we saw no effects on our measure of autism acceptance. So far, no qualitative analysis of the RCT participant responses has been made, but there is reason to believe that similar perspectives can be found amongst the RCT participants due to more information on positive autism features and traits added to the final version of SCOPE.

While psychoeducation is generally considered a helpful and effective form of treatment for a variety of mental health conditions, there are potential negative side effects, such as increased stigma (Bury, Haschek, et al., 2022), and emotional distress (Jutel & Nettleton, 2011). Specifically, a qualitative survey study on autism identity and stigma reported that autism information from healthcare professionals or parents, as opposed to peer-disseminated information, may lead to higher rates of self-stigmatisation and a negative autism identity (Bury, Haschek, et al., 2022), suggesting a need for a critical examination of how autism information is delivered by healthcare professionals. In contrast, it has been reported that the absence of psychoeducation following a diagnosis may lead to the deterioration of mental health in autistic adults (Beresford et al., 2020). In **study III**, we observed that the autism knowledge gains made by SCOPE and self-study participants were not associated with negative effects on mental health symptoms, but also no changes in acceptance of diagnosis. Our findings are in line with the other psychoeducational interventions tailored to autistic individuals, which noted an absence of negative mental health consequences following structured psychoeducational interventions (Gordon et al., 2015; Hidalgo et al., 2022; Crane et al., 2021b).

There is a dearth of qualitative and quantitative research describing that transition-aged autistic youth feel optimistic about the future but lack information, sufficient support, and effective interventions (Cribb et al., 2019; Lee et al., 2020; Thompson et al., 2018; Volkmar et al., 2017). In line with these statements, SCOPE aimed to impart psychoeducation designed with autistic transition-aged youth in mind. Findings from **studies II** and **III**, together with other interventions for the transitioning age (Hatfield et al., 2017; Jonsson et al., 2019), show participant appreciation for interventions designed for transition-aged autistic youth, hereby contributing to the evidence base of interventions for this age group. Additionally, it is important to understand the implications of intervention timing and level of intervention (i.e. intervention intensity and scope of aims) when providing healthcare services for transition-aged autistic youth (Burke et al., 2018); psychoeducation is meant as a first-line intervention, with many individuals' needing further services and care according to the severity of symptoms and difficulties.

4.4 Limitations

The studies within this thesis have several limitations which affect generalisability, interpretation of effects as well as issues regarding information bias.

4.4.1 Sample issues

Firstly, there were several issues regarding our samples. For all three studies, our samples were participants who were treatment seeking, and as can be judged by participant characteristics active recipients of healthcare and other services (see supplementary Table I for **study I**). This is in stark contrast to what has been described as a population "falling off a cliff " and lacking viable services (Bennett et al., 2018), therefore limiting generalisability to other transition-aged autistic individuals.

In addition, the current sample had lower self-rated autism traits, as measured by the SRS-2, than the recommended clinical cut-off for autism (Bezemer et al., 2021). This suggests that the participants in our study may have had fewer or less severe autism traits compared to previous studies that used the same measure. The implications of this discrepancy are hard to discern, particularly concerning its association with functioning in autistic individuals (Tillmann et al., 2019) and with QoL in emerging adults (Oakley et al., 2021). The lower self-rated autism traits could be indicative of selection bias for our samples. Nonetheless, it is important to note that all participants had their community diagnoses validated by experienced clinicians and rated their functioning as low in comparison to population norms – therefore meeting formal criteria for autism. Additionally, in line with previous studies of this population (Bennett et al., 2018; Chang et al., 2021; Davignon et al., 2018; Friedman et al., 2013; Kraper et al., 2017), our participants shared similar life circumstances (i.e. regarding independence, educational attainment, etc.) and had many co-occurring psychiatric conditions.

Moreover, the sample size was limited in all three studies when trying to detect small effects. In **study I**, the required sample to detect small effects as defined by Cohen (1988), would have been more than 800 participants, which would have been unattainable given our recruitment rates and timeframes. Nonetheless, we did see both small as well as medium effects of predictors on functioning and QoL. In **study II**, the final sample sizes at post-intervention and more so at follow-up limited our ability to detect effects. Finally, in **study III**, we were perhaps underpowered to fully detect all effects.

Furthermore, in contrast to many autism cohorts, our cohorts comprised a majority of female participants. While this may limit generalisability to male autistic participants, it begs questions related to what motivated participants to seek out our trials. The female majority may be reflective of findings maintaining that autistic females obtain their diagnosis later than males (Bargiela et al., 2016; Rutherford et al., 2016), which may explain the over-sampling of females in this type of intervention study (i.e., geared toward a newly diagnosed target group). Moreover, autistic females also report higher rates of mental health problems (Sedgewick et al., 2020), perhaps contributing to more treatment-seeking behaviour in general. In addition, the study participants had intellectual capacity in the broad average range; hence, the results from the current studies cannot be generalised to autistic individuals with lower intellectual capacity (i.e., those with Intellectual Disability). An intervention such as SCOPE is not considered accessible to individuals with autism and ID, due to the need for verbal comprehension in the average range, as well as an ability to access the technology used independently (with e-identification in the inclusion procedure as well as in the intervention).

4.4.2 Methodological considerations

Secondly, a central limitation for **studies II** and **III,** is that the chosen measures are all self-reported, as such no independent, objectively observed or assessed outcomes were used. Self-report may increase information bias, potentially leading to either over- or underestimating individual progress.

Furthermore, for **studies II** and **III**, several outcome measures used were not validated for autistic populations. This poses a potential issue in terms of reliability and validity, as there may be cognitive and communication issues limiting the accessibility of the questionnaires. Autistic individuals may need careful phrasing and specific additional questions to fully represent their perspectives on a given outcome. For example, an alternative, and more appropriate QoL measure would have been the WHOQoL-BREF with their autism add-ons (McConachie et al., 2018), which is widely used and recommended. However, at the time of study conception, it had not yet been validated for autistic individuals, nor did a Swedish language version exist; with autism validation being published in 2018 (McConachie et al., 2018), while the Swedish validation study was published in 2023 (Ramji et al., 2023). Instead, in **studies I** and **III** we chose a brief Swedish measure (BBQ) tried on the general population as well as on a clinical population with social anxiety (Lindner et al., 2016), due to its favourable psychometric properties and brief format.

To assess distal outcomes of psychoeducation (i.e., assessing other outcomes than the condition-specific knowledge), we tried to assess the acceptance of diagnosis (AAQ: Bond et al., 2011) as a proxy for self-stigma – we adapted a measure of psychological inflexibility and experiential avoidance to instead ask about having a diagnosis. In this case, there is a main factor that could contribute to information bias; the measure has not been psychometrically evaluated. However, our data (**studies II** and **III**) showed adequate reliability in terms of internal consistency. Nonetheless, it remains unclear if the measure is inherently valid or relevant to the underlying construct we aimed to measure – the tentative psychometry may be redundant. Similar issues regarding our ASD Quiz exist. In **study II**, we saw adequate reliability through KR_{20} alpha, whereas in **study III** we did not. In a review of autism knowledge assessments, Harrison et al. (2017) highlight the inadequacy of most autism knowledge measures, and of the acceptable ones, none were geared towards our target population nor were available in Swedish at the time of study conception. Nonetheless, we used the ASD Quiz as our primary outcome measure because we needed to test the specific contents of SCOPE and developed the quiz accordingly.

5 Conclusions

Study I showed that using self-reported assessment of functioning and QoL in the transitioning age group seems to capture similar perspectives as proxy assessments. Additionally, the key finding is the predictive value of autism trait severity and mental health problems on functioning, and the independent contribution that mental health has on QoL. We found that autism trait severity and anxiety symptoms, and to some extent gender and having an ADHD diagnosis, explained almost half of the variance in overall functioning. Symptoms of anxiety and depression, and to a lesser extent, active friendship, explained a large portion of the variance in QoL.

Study II findings supported the notion that an internet-delivered intervention such as SCOPE is feasible for autistic participants, with high completion rates. Participants completed the intended number of modules and expressed appreciation for SCOPE. Additionally, participants considered SCOPE to be significantly more credible upon intervention completion than beforehand. From qualitative analyses, the transition-aged autistic participants enjoyed the positively worded autism information, liked the contextualising information and focus on neuro-diversity, but also commented on some components being stereotypical of autism and not always recognising the information given. Building on these results and feedback from participants a subsequent version of SCOPE was trialled in a RCT.

The findings of **study III** demonstrate the effectiveness of a structured internet-delivered psychoeducation within an outpatient setting, for autistic emerging adults. Specifically, the SCOPE program outperformed self-study active controls and treatment as usual in maintaining autism knowledge and elevating the quality of life. Moreover, these positive outcomes were sustained or even further improved at the three-month follow-up assessment. The knowledge gains did not coincide with increased symptoms of mental health problems but also did not increase acceptance of diagnosis.

6 Points of Perspective

6.1 Clinical implications

6.1.1 Embracing a strength-based approach

The concept of functioning, especially when examined through the lens of the ICF, provides a framework for understanding an individual's abilities, difficulties, and participation in various aspects of life. However, we should bear in mind the limitations of a generic normative paradigm when assessing the functioning of autistic individuals. The limitations of using generic frameworks are that the point of reference is neurotypical development and that anything (and anyone) who diverges from this is seen as being ‘in deficit’ or ‘disabled.’ While functioning frameworks like the ICF offer insights into overall well-being and participation, they may not fully capture the unique strengths and challenges experienced by autistic individuals, at least not through the WHODAS 2.0, the instrument used in this thesis. Autistic individuals may exhibit excellent functioning within a context adjusted to their needs and in areas aligned with their strengths, but their abilities may not translate to general norms or societal expectations. Moreover, the limits of a generic perspective on functioning pinpoints the importance of incorporating a strength-based approach when analysing the situations and life circumstances of autistic individuals, perhaps through adding questions not only on ‘disability’ but also on ‘abilities.’ A strength-based approach identifies the unique strengths, talents, and abilities of individuals rather than solely focusing on deficits or areas of impairment. By recognising and valuing the divergent strengths of autistic individuals, it becomes possible to better understand their functioning within their own personal and social contexts.

Furthermore, strength-focused interventions for transition-aged autistic youth have garnered increased attention in recent years due to their potential to promote positive outcomes during this life period. Instead of focusing on deficits, autistic challenges and what to do about them, strength-focused interventions identify and build upon the strengths and talents of autistic individuals. This approach promotes self-esteem, self-awareness, and self-advocacy by emphasising existing abilities and interests. Additionally, by recognising the strengths of autistic youth, such as their attention to detail, creativity, or specialised knowledge, strengths-based interventions can promote engagement, and motivation during the transition period. Although SCOPE was created with information based on the conceptualisation of specific deficits and associated difficulties, parts of each module attempt to ameliorate negative perceptions of autism by incorporating information about neuro-diversity and giving examples of autism strengths. Future programs should have a more explicit strength-based approach, to promote empowerment and self-determination.

6.1.2 Reframing quality of life assessment

Similarly, when assessing the quality of life in autistic individuals' there are limitations when relying solely on proxy reports or societal perceptions of what constitutes high QoL (e.g., through generic QoL measures). Since autistic individuals report better QoL than what may be captured through proxy assessments, the subjective experience and individual perspectives of autistic emerging adults play an important role in determining their quality of life. Autistic individuals may find fulfilment and satisfaction in areas that differ from societal expectations, and different from the previously conceptualised aspects of QoL. Factors such as autonomy, acceptance, meaningful relationships, and engagement in activities matched to their interests and strengths possibly contribute to their perceived quality of life. To address the potential disparity caused by inaccurate assessment, it is crucial to prioritise the self-report of autistic individuals when assessing their quality of life. Equally important is to not only use rating-scales of QoL but also assess it through interviews where the individual can expand and explain what matters to them. By valuing their self-perceived and described QoL, interventions and support services can be tailored to address their unique needs and enhance their overall satisfaction and fulfilment.

6.1.3 Enhancing access and suitability of online interventions

Pertaining to **study II** primarily, but noticeable in **study III**, the question of needing tailored and accessible interventions is in focus. While the autistic participants who entered the studies may have cognitive abilities that helped them access the study and the intervention itself, it is important to examine whether SCOPE or similar online interventions are suitable and effective for a group of autistic individuals in need of more support, and of a different cognitive profile (e.g. those with lower IQ). When considering the applicability of internet-delivered interventions like SCOPE, several factors come into play, such as assessing the accessibility and usability of online platforms. Careful consideration of digital accessibility in interventions ensures that individuals with varying levels of cognitive abilities, communication skills, and technological proficiency can engage with the intervention effectively. Additionally, assessing the level of support needed to enable access to psychoeducation should be of general concern to professionals working with assessments and in the disability services clinics (i.e., Habiliteringen). Accommodations may be necessary to address potential barriers and provide appropriate support to facilitate internet-based participation.

In addition, the majority of participant recruitment occurred before the Covid-19 pandemic, as such the acceptability and approachability of internet-delivered interventions may have since changed. The technological proficiency familiarity of the wider population, as well as among autistic individuals probably increased during and following the pandemic. The increased technological proficiency among this population, driven by the need to adapt to remote learning, telehealth, and virtual social interactions, has likely enhanced their ability to navigate and utilise online platforms with greater ease. Furthermore, the pandemic necessitated the development and improvement of telehealth infrastructure, making internet-delivered interventions more accessible and widely available. Considering the changes in healthcare delivery and the increased technological proficiency among autistic individuals, it is important to explore the acceptability, feasibility, and effectiveness of internet-delivered interventions in the post-pandemic era.

6.1.4 Examining the active components of internet-delivered psychoeducation

Active components in psychoeducation have been investigated in several studies, but it remains unclear which specific elements contribute to its effectiveness. Psychoeducation typically includes condition-relevant information (i.e., facts) presented in a structured and pedagogical way; examples from peers; may include problem-solving strategies; information about accessing further support and services; and features that promote self-sufficiency and empowerment. The findings of **study III** indicate that the SCOPE-specific components as seen in the differences between the SCOPE and self-study participants, have an impact on retained knowledge and quality of life outcomes, even though it is modest. In contrast, offering reading materials without proper support or control over their presentation and interpretation could be ineffective (with knowledge being lost and no discernible effects) and may yield side-effects. This raises concerns about the widespread clinical practice of providing written psychoeducation through pamphlets or instructions to read a website without structure or sufficient therapist involvement. Moreover, in the context of psychoeducation about autism – the active and efficacious ingredients are unknown. The typical features of psychoeducation should be tried separately to establish which features are needed for the different recipients of psychoeducation, i.e. what is needed for caregivers or parents, and what are essential components for consumer-directed psychoeducation.

6.2 Future research

Considering the mental health problems of this population, and the difficulties in functioning as well as reduced QoL, a more complete picture of predictors of outcomes is needed. Similar, if not identical studies have been conducted in the past decade, underscoring the need for new research aims that delve into specific factors contributing to the unexplained variance in functioning and quality of life. This could mean investigating potential mediators or moderators of the relationship between mental health problems and outcomes. Additionally, exploring the predictive capacity of environmental factors, or examining the effectiveness of individually tailored interventions for improving functioning and QoL in autistic individuals will move the field of intervention targets forward.

Equally important, is to conduct further research and evaluation of online interventions like SCOPE for autistic individuals, to determine the effectiveness and acceptability for individuals of varying levels of cognitive capacity as well as for individuals with diverse cultural and ethnic backgrounds. Rigorous assessment of outcomes, participant feedback, and the level of support required should be the focus of future trials, perhaps achievable through qualitative interview studies. Moreover, it is necessary to make informed decisions about the viability and potential benefits of internet-delivered interventions for different subgroups within the autistic population. Additionally, the support needed by transition-aged autistic individuals to approach healthcare services in general, and specifically to access and adhere to technology-based interventions needs to be further elucidated.

7 Acknowledgements

First and foremost, I would like to express my gratitude to all the participants in the three studies, who generously dedicated their time and efforts to further knowledge about autism in transition-aged youth. We are indebted to each and every one of you.

My *main supervisor* **Tatja**, has been steadfast, dedicated and thorough. You have given me so much of your time and I have amassed a wealth of knowledge and experiences throughout our nine (!) years of collaboration. Thank you!

My *co-supervisors*: **Sarah**, you are an impressive woman of science! A true voice of reason, providing me with balance, and you have served as a role model for leadership and supervision. I admire your fearlessness and commitment to academic integrity. **Lise**, thank you for your insightful thoughts and reflections on autism and on how to conduct qualitative trials. Your positive spirit has helped me progress and not to give up. **Eric**, your vast knowledge and attention to detail have given me a sense of security in our final products. The dedication you had during my second paper was pivotal.

I would also like to acknowledge the support provided by the Dept. of Women's and Children's Health, particularly through conversations with **Professor Angelica Hirschberg Lindén**, **Caroline Rådestad** and **Johanna Ahlström** during challenging times.

From my early days as a clinical psychologist, I have been fortunate to have the support of strong female leaders. **Agneta Hellström**, I sincerely believe I wouldn't be writing these words without your unwavering belief in me and the many amazing mentoring conversations we have had over the course of 15 years. Thank you to **Camilla Ekstrand** and **Pernilla Lindén Röjdmark** for being amazing leaders and supporters of my endeavours – I cannot thank you enough for all that you have enabled. **Dr. MaiBritt Giacobini**, my PhD mentor, we have had many inspirational conversations about being a clinician in an academic setting. Your perspectives on my work from an external standpoint have been invaluable.

I have had the great fortune of working alongside brilliantly intelligent and interesting colleagues, who have become dear friends. At *Habilitering och Hälsa*, **Are Mellblom** and **Elisabeth Norman Claesson**, without the two of you – none of this would have been possible. We wouldn't have SCOPE, and wouldn't have recruited our participants. I am deeply grateful to both of you. **Emma Sundquist**, thank you for your clinical work in our projects, and **Maj Frostvittra**, you were an exceptional research assistant for so many years. **Lena Westholm** my first supervisor! **Linda Maurin, Corinna Von Holst, Susanne Wallin, Anna Högfeldt, Sahar Gaveli, Kalle Nytell,** and **Sofia Buddgård**: so many laughs and so many insights! *Inside Team,* what a gang of professional and fun psychologists and psychiatrists: **Sofia Scherfors, Sara Möller, Ulrika Friberg, Åsa Palmqvist, Caroline Englund, Erik Rehnberg, Christina Tysk, Carl Engström, Emma Supanich, Sylwia Czarnocka, Annika Nelson, Anne Gutschy, Hjalmar Nowak** and **Niclas Tindberg!**

My PhD buddies at *KIND*: **Therese**, I cannot thank you enough for all of our conversations, sending articles, talking about science and navigating the academic world together. You are so impressive, kind, knowledgeable, and a fellow GBG: are. As is **Hanna**, our wonderful and powerful psychiatrist supernova. Thank you to **Tiina**, **Hanna A** and **Elina** for your support and for contributing to a great setting to work within. I also express my gratitude to **Dr. Douglas Sjöwall** for many years of support and fun conversations. Of course, a huge thank you to all of my wonderfully smart and empathetic colleagues at KIND: **Anna Fridell**, **Dr. Melissa Black**, **Dr. Karl Lundin Remnélius**, **Dr. John Hasslinger**, and **Dr. Elisabeth Nilsson Jobs**, **Christina Coco, Dr. Janina Neufeld, Dr. Soheil Mahdi** and many more throughout the years.

I have been lucky to meet and get to know many interesting and helpful academics: **Dr. Jacqueline Borg**, **Dr. Lars Klintwall** (my book buddy), **Dr. Lisa Thorell**, and **Nathaniel Hidalgo**. I have made great friends through *Forskarskolan för kliniker*, **Dr. Kristina Aspvall** and **Dr. Essi Heinonen Whaites**. **Filippa Hall**, so thankful for your specialist paper, we saw some important things because of it, and now we read and read and read together.

My patient and wonderful friends, the memories we have created together and the many, many words of support and encouragement from you all: **Dr Helen Rix Runting**, **Anna Brantmark**, **Karin Ringqvist**, **Karin Matz**, **Nina Marklund**, **Anna Forsberg**, **Kajsa Westling**, **Anna Roxvall**, and **Caroline Mellstrand** - I love you all! **Christian Tsangarides** and **Rutger Sjögrim**, you have made me lose my composure whilst discussing psychiatry and psychology, I will never forget it, I promise…

My мамочка **Natalja**, my brother **Alexander** (the older), and my aunt **Berit**: endless love and support. And thank you to my accomplished and inspiring cousins **Dr. Birthe Anderssohn** and **Dr. Maike Anderssohn**. Thank you to my mother-in-law **Inger** and father-in-law **Professor Henry Engler** for your support and love! And to the extended **Pahnke** and **Carlsson** families for their kindness and hugs.

Finally, my beloved husband, **Dr. Johan Pahnke**. We wouldn't have met without the projects within this thesis, and so much of my work is thanks to you. And to our amazing and funny son **Alexander** (the younger) who provides a great contrast to academic life.

Acknowledgement and gratitude for financial support for the projects within this thesis by the following **foundations**: Stiftelsen Promobilia for a four-year doctoral grant; as well as by Region Stockholm funding for medical training and research (PPG/ALF), Jerringfonden, Stiftelsen L.J. Boëthius, Sällskapet Barnavård, and Sunnerdahls Handikappfond.

8 References

Adams, D., & Young, K. (2021). A Systematic Review of the Perceived Barriers and Facilitators to Accessing Psychological Treatment for Mental Health Problems in Individuals on the Autism Spectrum. *Review Journal of Autism and Developmental Disorders*, *8*(4), 436-453. https://doi.org/10.1007/s40489-020-00226-7

Alfonsson, S., Olsson, E., & Hursti, T. (2016). Motivation and Treatment Credibility Predicts Dropout, Treatment Adherence, and Clinical Outcomes in an Internet-Based Cognitive Behavioral Relaxation Program: A Randomized Controlled Trial. *Journal of Medical Internet Research*, *18*(3). https://doi.org/ARTN e5210.2196/jmir.5352

Alvares, G. A., Bebbington, K., Cleary, D., Evans, K., Glasson, E. J., Maybery, M. T., . . . Whitehouse, A. J. O. (2020). The misnomer of 'high functioning autism': Intelligence is an imprecise predictor of functional abilities at diagnosis [Article]. *Autism*, *24*(1), 221-232. https://doi.org/10.1177/1362361319852831

Ames, J. L., Mahajan, A., Davignon, M. N., Massolo, M. L., & Croen, L. A. (2022). Opportunities for Inclusion and Engagement in the Transition of Autistic Youth from Pediatric to Adult Healthcare: A Qualitative Study. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-022-05476-4

Amiri, M., Lamballais, S., Geenjaar, E., Blanken, L. M. E., El Marroun, H., Tiemeier, H., & White, T. (2020). Environment-Wide Association Study (EnWAS) of Prenatal and Perinatal Factors Associated With Autistic Traits: A Population-Based Study. *Autism Research*, *13*(9), 1582-1600. https://doi.org/https://doi.org/10.1002/aur.2372

Anderson, K. A., Sosnowy, C., Kuo, A. A., & Shattuck, P. T. (2018). Transition of Individuals With Autism to Adulthood: A Review of Qualitative Studies. *Pediatrics*, *141*(Supplement 4), S318. https://doi.org/10.1542/peds.2016-4300I

APA. (2013). *Diagnostic and statistical manual of mental disorders (5th ed.)*. American Psychiatric Association. https://doi.org/http://dx.doi.org/10.1176/appi.books.9780890425596.CautionaryStatement

Arnett, J. J. (2007). Emerging Adulthood: What Is It, and What Is It Good For? *Child Development Perspectives*, *1*(2), 68-73. https://doi.org/10.1111/j.1750-8606.2007.00016.x

Axén, M., Brar, A., Huslid, E., Nordin, V., Nylander, L., Walch, M. . (2010). *Regionalt Vårdprogram: ADHD, lindrig utvecklingsstörning och autismspektrumtillstånd hos barn, ungdomar och vuxna*. SLL

Ayres, M., Parr, J. R., Rodgers, J., Mason, D., Avery, L., & Flynn, D. (2017). A systematic review of quality of life of adults on the autism spectrum. *Autism*, *22*(7), 774-783. https://doi.org/10.1177/1362361317714988

Bachmann, C. J., Hofer, J., Kamp-Becker, I., Kupper, C., Poustka, L., Roepke, S., . . . Hoffmann, F. (2019). Internalised stigma in adults with autism: A German multi-center survey. *Psychiatry Research*, *276*, 94-99. https://doi.org/10.1016/j.psychres.2019.04.023

Backman, A., Mellblom, A., Norman-Claesson, E., Keith-Bodros, G., Frostvittra, M., Bolte, S., & Hirvikoski, T. (2018). Internet-delivered psychoeducation for older adolescents and young adults with autism spectrum disorder (SCOPE): An open feasibility study. *Research in Autism Spectrum Disorders*, *54*, 51-64. https://doi.org/10.1016/j.rasd.2018.07.001

Backman, A., Zander, E., Roll-Pettersson, L., Vigerland, S., & Hirvikoski, T. (2023). Functioning and quality of life in transition-aged youth on the autism spectrum – associations with autism symptom severity and mental health problems. *Research in Autism Spectrum Disorders*, *104*, 102168. https://doi.org/https://doi.org/10.1016/j.rasd.2023.102168

Bargiela, S., Steward, R., & Mandy, W. (2016). The Experiences of Late-diagnosed Women with Autism Spectrum Conditions: An Investigation of the Female Autism Phenotype. *J Autism Dev Disord*, *46*(10), 3281-3294. https://doi.org/10.1007/s10803-016-2872-8

Barnish, M. S., & Turner, S. W. (2017). The value of pragmatic and observational studies in health care and public health. *Pragmatic and Observational Research*, *8*, 49 - 55.

Beckerson, M. E., May, K. E., & Kana, R. K. (2022). Chapter 4 - Social, cognitive, perceptual, and other models of autism spectrum disorder. In R. K. Kana (Ed.), *The Neuroscience of Autism* (pp. 65-85). Academic Press. https://doi.org/https://doi.org/10.1016/B978-0-12-816393-1.00005-1

Bennett, A. E., Miller, J. S., Stollon, N., Prasad, R., & Blum, N. J. (2018). Autism Spectrum Disorder and Transition-Aged Youth. *Current psychiatry reports*, *20*(11), 103. https://doi.org/10.1007/s11920-018-0967-y

Bennett, S. D., Myles-Hooton, P., Schleider, J. L., & Shafran, R. (2022). *Oxford Guide to Brief and low intensity interventions for children and young people*. Oxford University Press. https://doi.org/10.1093/med-psych/9780198867791.001.0001

Beresford, B., Mukherjee, S., Mayhew, E., Heavey, E., Park, A.-L., Stuttard, L., & al., e. (2020). Evaluating specialist autism teams' provision of care and support for autistic adults without learning disabilities: the SHAPE mixed-methods study. *Health Service Delivery Research*, *8*(48).

Bezemer, M. L., Blijd-Hoogewys, E. M. A., & Meek-Heekelaar, M. (2021). The Predictive Value of the AQ and the SRS-A in the Diagnosis of ASD in Adults in Clinical Practice. *Journal of Autism and Developmental Disorders*, *51*(7), 2402-2415. https://doi.org/10.1007/s10803-020-04699-7

Biggs, E. E., & Carter, E. W. (2016). Quality of Life for Transition-Age Youth with Autism or Intellectual Disability. *Journal of Autism and Developmental Disorders*, *46*(1), 190-204. https://doi.org/10.1007/s10803-015-2563-x

Billstedt, E., Gillberg, I. C., & Gillberg, C. (2011). Aspects of quality of life in adults diagnosed with autism in childhood:A population-based study. *Autism*, *15*(1), 7-20. https://doi.org/10.1177/1362361309346066

Bishop, S. L., & Seltzer, M. M. (2012). Self-reported autism symptoms in adults with autism spectrum disorders. *J Autism Dev Disord*, *42*(11), 2354-2363. https://doi.org/10.1007/s10803-012-1483-2

Bjelland, I., Dahl, A. A., Haug, T. T., & Neckelmann, D. (2002). The validity of the Hospital Anxiety and Depression Scale. An updated literature review. *J Psychosom Res*, *52*(2), 69-77. https://doi.org/10.1016/s0022-3999(01)00296-3

Bojda, A., Srebnicki, T., Konowałek, Ł., & Bryńska, A. (2021). Weak central coherence - construct conception, development, research methods. *Psychiatr Pol*, *55*(6), 1373-1386. https://doi.org/10.12740/PP/OnlineFirst/120931 (Słaba centralna koherencja – rozwój i koncepcja konstruktu, metody badania.)

Bond, F. W., Hayes, S. C., Baer, R. A., Carpenter, K. M., Guenole, N., Orcutt, H. K., . . . Zettle, R. D. (2011). Preliminary psychometric properties of the Acceptance and Action Questionnaire-II: a revised measure of psychological inflexibility and experiential avoidance. *Behav Ther*, *42*(4), 676-688. https://doi.org/10.1016/j.beth.2011.03.007

Borkovec, T. D., & Nau, S. D. (1972). Credibility of analogue therapy rationales. *Journal of Behavior Therapy and Experimental Psychiatry*, *3*(4), 257-260. https://doi.org/http://dx.doi.org/10.1016/0005-7916(72)90045-6

Botha, M., Dibb, B., & Frost, D. M. (2022). "Autism is me": an investigation of how autistic individuals make sense of autism and stigma. *Disability & Society*, *37*(3), 427-453. https://doi.org/10.1080/09687599.2020.1822782

Bottema-Beutel, K., LaPoint, S. C., Kim, S. Y., Mohiuddin, S., Yu, Q., & McKinnon, R. (2022). An evaluation of intervention research for transition-age autistic youth. *Autism*. https://doi.org/10.1177/13623613221128761

Boucher, J., & Anns, S. (2018). Memory, learning and language in autism spectrum disorder. *Autism & developmental language impairments*, *3*, 239694151774207. https://doi.org/10.1177/2396941517742078

Bramham, J., Young, S., Bickerdike, A., Spain, D., McCartan, D., & Xenitidis, K. (2009). Evaluation of Group Cognitive Behavioral Therapy for Adults With ADHD. *Journal of Attention Disorders*, *12*(5), 434-441. https://doi.org/10.1177/1087054708314596

Bross, L. A., Huffman, J. M., Watson, E. K., Wills, H. P., & Mason, R. A. (2021). Social Skills Instruction, Online Modules, and Telecoaching to Develop Planning Skills of Young Adults With Autism. *Journal of Special Education Technology*, *36*(4), 297-310. https://doi.org/10.1177/0162643420924188

Brugha, T. S., Spiers, N., Bankart, J., Cooper, S.-A., McManus, S., Scott, F. J., . . . Tyrer, F. (2016). Epidemiology of autism in adults across age groups and ability levels. *British Journal of Psychiatry*, *209*(6), 498-503. https://doi.org/10.1192/bjp.bp.115.174649

Burke, M. M., Waitz-Kudla, S. N., Rabideau, C., Taylor, J. L., & Hodapp, R. M. (2018). Pulling back the curtain: Issues in conducting an intervention study with transition-aged youth with autism spectrum disorder and their families. *Autism*, *23*(2), 514-523. https://doi.org/10.1177/1362361317753016

Bury, S. M., Haschek, A., Wenzel, M., Spoor, J. R., & Hedley, D. (2022). Brief Report: Learning About Autism: Is the Source of Autism Knowledge Associated with Differences in Autism Knowledge, Autism Identity, and Experiences of Stigma. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-022-05823-5

Bury, S. M., Jellett, R., Haschek, A., Wenzel, M., Hedley, D., & Spoor, J. R. (2022). Understanding language preference: Autism knowledge, experience of stigma and autism identity. *Autism*. https://doi.org/10.1177/13623613221142383

Byers, E. S., Nichols, S., Voyer, S. D., & Reilly, G. (2012). Sexual well-being of a community sample of high-functioning adults on the autism spectrum who have been in a romantic relationship. *Autism*, *17*(4), 418-433. https://doi.org/10.1177/1362361311431950

Bölte, S. (2023). A more holistic approach to autism using the International Classification of Functioning: The why, what, and how of functioning. *Autism*, *27*(1), 3-6. https://doi.org/https://doi.org/10.1177/13623613221136444

Bölte, S., Ciaramidaro, A., Schlitt, S., Hainz, D., Kliemann, D., Beyer, A., . . . Walter, H. (2015). Training-induced plasticity of the social brain in autism spectrum disorder. *British Journal of Psychiatry*, *207*(2), 149-157. https://doi.org/10.1192/bjp.bp.113.143784

Bölte, S., Girdler, S., & Marschik, P. B. (2019). The contribution of environmental exposure to the etiology of autism spectrum disorder. *Cellular and Molecular Life Sciences*, *76*(7), 1275-1297. https://doi.org/10.1007/s00018-018-2988-4

Cage, E., Di Monaco, J., & Newell, V. (2018). Experiences of Autism Acceptance and Mental Health in Autistic Adults. *Journal of Autism and Developmental Disorders*, *48*(2), 473-484. https://doi.org/10.1007/s10803-017-3342-7

Camm-Crosbie, L., Bradley, L., Shaw, R., Baron-Cohen, S., & Cassidy, S. (2019). 'People like me don't get support': Autistic adults' experiences of support and treatment for mental health difficulties, self-injury and suicidality. *Autism*, *23*(6), 1431-1441. https://doi.org/10.1177/1362361318816053

Cascio, M. A., & Racine, E. (2018). Person-oriented research ethics: integrating relational and everyday ethics in research. *Accountability in Research*, *25*(3), 170-197. https://doi.org/10.1080/08989621.2018.1442218

Chancel, R., Miot, S., Dellapiazza, F., & Baghdadli, A. (2022). Group-based educational interventions in adolescents and young adults with ASD without ID: a systematic review focusing on the transition to adulthood. *European Child & Adolescent Psychiatry*, *31*(7), 1-21. https://doi.org/10.1007/s00787-020-01609-1

Chang, J. C., Lai, M. C., Tai, Y. M., & Gau, S. S. F. (2021). Mental health correlates and potential childhood predictors for the wish to be of the opposite sex in young autistic adults [Article; Early Access]. *Autism*, 14, Article 13623613211024098. https://doi.org/10.1177/13623613211024098

Cheak-Zamora, N. C., Farmer, J. E., Mayfield, W. A., Clark, M. J., Marvin, A. R., Law, J. K., & Law, P. A. (2014). Health Care Transition Services for Youth With Autism Spectrum Disorders. *Rehabilitation Psychology*, *59*(3), 340-348. https://doi.org/10.1037/a0036725

Cheak-Zamora, N. C., Nowell, K., Helterbrand, E., & Tait, A. (2021). Investigating health-related knowledge and independence for physical and mental health conditions in young adults with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *85*, 101801. https://doi.org/https://doi.org/10.1016/j.rasd.2021.101801

Cheak-Zamora, N. C., & Teti, M. (2014). “You think it’s hard now … It gets much harder for our children”: Youth with autism and their caregiver’s perspectives of health care transition services. *Autism*, *19*(8), 992-1001. https://doi.org/10.1177/1362361314558279

Cheak-Zamora, N. C., Teti, M., Maurer-Batjer, A., & Koegler, E. (2017). Exploration and Comparison of Adolescents With Autism Spectrum Disorder and Their Caregiver’s Perspectives on Transitioning to Adult Health Care and Adulthood. *Journal of Pediatric Psychology*, *42*(9), 1028-1039. https://doi.org/10.1093/jpepsy/jsx075

Chiang, H. M., & Wineman, I. (2014). Factors associated with quality of life in individuals with autism spectrum disorders: A review of literature. *Research in Autism Spectrum Disorders*, *8*(8), 974-986. https://doi.org/10.1016/j.rasd.2014.05.003

Choque Olsson, N., & Bölte, S. (2014). Brief Report: "Quick and (not so) Dirty" Assessment of Change in Autism: Cross-Cultural Reliability of the Developmental Disabilities CGAS and the OSU Autism CGI [Article]. *Journal of Autism and Developmental Disorders*, *44*(7), 1773-1778.

Christensen, D. L., Braun, K. V. N., Baio, J., Bilder, D., Charles, J., Constantino, J. N., . . . Kurzius-Spencer, M. (2018). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—autism and developmental disabilities monitoring network, 11 sites, United States, 2012. *MMWR Surveillance Summaries*, *65*(13), 1.

Cohen, J. (1988). *Statistical Power Analysis for the Behavioral Sciences*. Routledge. https://doi.org/10.4324/9780203771587

Cohen, R. J., Swerdlik, M. E. (2005). *Psychological testing and assessment: An introduction to tests and measurement* (6 ed.). MacGraw-Hill.

Constantino, J. N. (2021). Social Responsiveness Scale. In F. R. Volkmar (Ed.), *Encyclopedia of Autism Spectrum Disorders* (pp. 4457-4467). Springer International Publishing. https://doi.org/10.1007/978-3-319-91280-6_296

Constantino, J. N., Davis, S. A., Todd, R. D., Schindler, M. K., Gross, M. M., Brophy, S. L., . . . Reich, W. (2003). Validation of a brief quantitative measure of autistic traits: Comparison of the social responsiveness scale with the autism diagnostic interview-revised. *Journal of Autism and Developmental Disorders*, *33*(4), 427-433. https://doi.org/Doi 10.1023/A:1025014929212

Constantino, J. N., & Gruber, C. (2012). *Social Responsiveness Scale, Second Edition (SRS-2)*. Western Psychological Services.

Constantino, J. N., Gruber, C. P. (2019). *Social Responsiveness Scale, Second Edition - Swedish Version*. Hogrefe.

Constantino, J. N., & Todd, R. D. (2003). Autistic traits in the general population - A twin study. *Archives of General Psychiatry*, *60*(5), 524-530. https://doi.org/10.1001/archpsyc.60.5.524

Cooper, K., Smith, L. G. E., & Russell, A. (2017). Social identity, self-esteem, and mental health in autism [Article]. *European Journal of Social Psychology*, *47*(7), 844-854. https://doi.org/10.1002/ejsp.2297

Crane, L., Goddard, L., & Pring, L. (2013). Autobiographical memory in adults with autism spectrum disorder: The role of depressed mood, rumination, working memory and theory of mind. *Autism*, *17*(2), 205-219. https://doi.org/10.1177/1362361311418690

Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021a). Supporting Newly Identified or Diagnosed Autistic Adults: An Initial Evaluation of an Autistic-Led Programme. *J Autism Dev Disord*, *51*(3), 892-905. https://doi.org/10.1007/s10803-020-04486-4

Crane, L., Hearst, C., Ashworth, M., Davies, J., & Hill, E. L. (2021b). Supporting newly identified or diagnosed autistic adults: An initial evaluation of an autistic-led programme. *Journal of Autism and Developmental Disorders*, *51*(3), 892-905.

Crane, L., Pring, L., Jukes, K., & Goddard, L. (2012). Patterns of Autobiographical Memory in Adults with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, *42*(10), 2100-2112. https://doi.org/10.1007/s10803-012-1459-2

Cribb, S., Kenny, L., & Pellicano, E. (2019). 'I definitely feel more in control of my life': The perspectives of young autistic people and their parents on emerging adulthood. *Autism*, *23*(7), 1765-1781. https://doi.org/10.1177/1362361319830029

Cuijpers, P. (2019). Targets and outcomes of psychotherapies for mental disorders: an overview. *World Psychiatry*, *18*(3), 276-285. https://doi.org/https://doi.org/10.1002/wps.20661

Davignon, M. N., Qian, Y., Massolo, M., & Croen, L. A. (2018). Psychiatric and Medical Conditions in Transition-Aged Individuals With ASD. *Pediatrics*, *141*(Supplement 4), S335-S345. https://doi.org/10.1542/peds.2016-4300K

de Schipper, E., Mahdi, S., de Vries, P., Granlund, M., Holtmann, M., Karande, S., . . . Bolte, S. (2016). Functioning and disability in autism spectrum disorder: A worldwide survey of experts. *Autism Res*, *9*(9), 959-969. https://doi.org/10.1002/aur.1592

Demetriou, E. A., Lampit, A., Quintana, D. S., Naismith, S. L., Song, Y. J. C., Pye, J. E., . . . Guastella, A. J. (2018). Autism spectrum disorders: a meta-analysis of executive function. *Molecular Psychiatry*, *23*(5), 1198-1204. https://doi.org/10.1038/mp.2017.75

Desaunay, P., Briant, A. R., Bowler, D. M., Ring, M., Gérardin, P., Baleyte, J.-M., . . . Guillery-Girard, B. (2020). Memory in autism spectrum disorder: A meta-analysis of experimental studies. *Psychological Bulletin*, *146*, 377-410. https://doi.org/10.1037/bul0000225

Dubreucq, J., Plasse, J., Gabayet, F., Faraldo, M., Blanc, O., Chereau, I., . . . Franck, N. (2020). Self-stigma in serious mental illness and autism spectrum disorder: Results from the REHABase national psychiatric rehabilitation cohort. *European Psychiatry*, *63*(1), e13, Article e13. https://doi.org/10.1192/j.eurpsy.2019.12

Duncan, A. W., & Bishop, S. L. (2013). Understanding the gap between cognitive abilities and daily living skills in adolescents with autism spectrum disorders with average intelligence. *Autism*, *19*(1), 64-72. https://doi.org/10.1177/1362361313510068

Egilson, S. T., Olafsdottir, L. B., Leosdottir, T., & Saemundsen, E. (2017). Quality of life of high-functioning children and youth with autism spectrum disorder and typically developing peers: Self- and proxy-reports. *Autism*, *21*(2), 133-141. https://doi.org/10.1177/1362361316630881

Eldridge, S. M., Lancaster, G. A., Campbell, M. J., Thabane, L., Hopewell, S., Coleman, C. L., & Bond, C. M. (2016). Defining Feasibility and Pilot Studies in

Preparation for Randomised Controlled Trials: Development of a Conceptual Framework. *Plos One*, *11*(3). https://doi.org/10.1371/journal.pone.0150205

Etyemez, S., Esler, A., Kini, A., Tsai, P.-C., DiRienzo, M., Maenner, M., & Lee, L.-C. (2022). The role of intellectual disability with autism spectrum disorder and the documented cooccurring conditions: A population-based study. *Autism Research*, *15*(12), 2399-2408. https://doi.org/https://doi.org/10.1002/aur.2831

Feingold, A. (2009). Effect sizes for growth-modeling analysis for controlled clinical trials in the same metric as for classical analysis. *Psychol Methods*, *14*(1), 43-53. https://doi.org/10.1037/a0014699

Fletcher-Watson, S., & Fletcher-Watson, S. (2014). A Targeted Review of Computer-Assisted Learning for People with Autism Spectrum Disorder: Towards a Consistent Methodology. *Review Journal of Autism and Developmental Disorders*, *1*(2), 87-100. https://doi.org/10.1007/s40489-013-0003-4

Friedman, N. D. B., Warfield, M. E., & Parish, S. L. (2013). Transition to adulthood for individuals with autism spectrum disorder: current issues and future perspectives. *Neuropsychiatry*, *3*(2), 181-192. https://doi.org/10.2217/Npy.13.13

Gernsbacher, M. A., & Yergeau, M. (2019). Empirical failures of the claim that autistic people lack a theory of mind. *Archives of Scientific Psychology*, *7*, 102-118. https://doi.org/10.1037/arc0000067

Gillespie-Lynch, K., Kapp, S. K., Brooks, P. J., Pickens, J., & Schwartzman, B. (2017). Whose Expertise Is It? Evidence for Autistic Adults as Critical Autism Experts. *Front Psychol*, *8*. https://doi.org/43810.3389/fpsyg.2017.00438

Gillespie-Lynch, K., Kapp, S. K., Shane-Simpson, C., Smith, D. S., & Hutman, T. (2014). Intersections between the autism spectrum and the internet: perceived benefits and preferred functions of computer-mediated communication. *Intellect Dev Disabil*, *52*(6), 456-469. https://doi.org/10.1352/1934-9556-52.6.456

Goddard, L., Dritschel, B., Robinson, S., & Howlin, P. (2014). Development of autobiographical memory in children with autism spectrum disorders: Deficits, gains, and predictors of performance. *Development and Psychopathology*, *26*(1), 215-228. https://doi.org/10.1017/s0954579413000904

Goffman, E. (1963). *Stigma; notes on the management of spoiled identity*. Prentice-Hall.

Gordon, K., Murin, M., Baykaner, O., Roughan, L., Livermore-Hardy, V., Skuse, D., & Mandy, W. (2015). A randomised controlled trial of PEGASUS, a psychoeducational programme for young people with high-functioning autism spectrum disorder. *Journal of Child Psychology and Psychiatry*, *56*(4), 468-476. https://doi.org/10.1111/jcpp.12304

Gotham, K., Marvin, A. R., Taylor, J. L., Warren, Z., Anderson, C. M., Law, P. A., . . . Lipkin, P. H. (2015). Characterizing the daily life, needs, and priorities of adults with autism spectrum disorder from Interactive Autism Network data. *Autism*, *19*(7), 794-804. https://doi.org/10.1177/1362361315583818

Grant, N., Rodger, S. A., & Hoffmann, T. C. (2015). Evaluation of Autism-Related Health Information on the Web. *Journal of applied research in intellectual disabilities : JARID*, *28 4*, 276-282.

Gray, D. E. (1993). Perceptions of Stigma - the Parents of Autistic-Children. *Sociology of Health & Illness*, *15*(1), 102-120. https://doi.org/10.1111/1467-9566.ep11343802

Grindell, C., Coates, E., Croot, L., & O'Cathain, A. (2022). The use of co-production, co-design and co-creation to mobilise knowledge in the management of health conditions: a systematic review. *BMC Health Services Research*, *22*(1), 877. https://doi.org/10.1186/s12913-022-08079-y

Grynszpan, O., Weiss, P. L., Perez-Diaz, F., & Gal, E. (2014). Innovative technology-based interventions for autism spectrum disorders: a meta-analysis. *Autism*, *18*(4), 346-361. https://doi.org/10.1177/1362361313476767

Gueorguieva, R., & Krystal, J. H. (2004). Move Over ANOVA: Progress in Analyzing Repeated-Measures Data andIts Reflection in Papers Published in the Archives of General Psychiatry. *Archives of General Psychiatry*, *61*(3), 310-317. https://doi.org/10.1001/archpsyc.61.3.310

Halladay, A. K., Bishop, S., Constantino, J. N., Daniels, A. M., Koenig, K., Palmer, K., . . . Szatmari, P. (2015). Sex and gender differences in autism spectrum disorder: summarizing evidence gaps and identifying emerging areas of priority [journal article]. *Molecular Autism*, *6*(1), 36. https://doi.org/10.1186/s13229-015-0019-y

Han, E., Scior, K., Avramides, K., & Crane, L. (2022). A systematic review on autistic people's experiences of stigma and coping strategies. *Autism Research*, *15*(1), 12-26. https://doi.org/10.1002/aur.2652

Happé, F., & Frith, U. (2006). The Weak Coherence Account: Detail-focused Cognitive Style in Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, *36*(1), 5-25. https://doi.org/10.1007/s10803-005-0039-0

Happé, F., Ronald, A., & Plomin, R. (2006). Time to give up on a single explanation for autism. *Nature Neuroscience*, *9*(10), 1218-1220. https://doi.org/10.1038/nn1770

Happé, F. G., Mansour, H., Barrett, P., Brown, T., Abbott, P., & Charlton, R. A. (2016). Demographic and Cognitive Profile of Individuals Seeking a Diagnosis of Autism Spectrum Disorder in Adulthood [journal article]. *Journal of Autism* *and Developmental Disorders*, *46*(11), 3469-3480. https://doi.org/10.1007/s10803-016-2886-2

Harrison, A. J., Slane, M. M., Hoang, L., & Campbell, J. M. (2017). An international review of autism knowledge assessment measures. *Autism*, *21*(3), 262-275. https://doi.org/10.1177/1362361316638786

Hatfield, M., Falkmer, M., Falkmer, T., & Ciccarelli, M. (2017). Effectiveness of the BOOST-A™ online transition planning program for adolescents on the autism spectrum: a quasi-randomized controlled trial. *Child and Adolescent Psychiatry and Mental Health*, *11*(1), 54. https://doi.org/10.1186/s13034-017-0191-2

Havdahl, A., Niarchou, M., Starnawska, A., Uddin, M., van der Merwe, C., & Warrier, V. (2021). Genetic contributions to autism spectrum disorder. *Psychological Medicine*, *51*(13), 2260-2273. https://doi.org/10.1017/S0033291721000192

Hayes, R., & Gantt, A. (1992). Patient Psychoeducation - the Therapeutic Use of Knowledge for the Mentally-Ill. *Social Work in Health Care*, *17*(1), 53-67. https://doi.org/10.1300/J010v17n01_04

Helles, A., Gillberg, C. I., Gillberg, C., & Billstedt, E. (2015). Asperger syndrome in males over two decades: stability and predictors of diagnosis. *Journal of Child Psychology and Psychiatry*, *56*(6), 711-718. https://doi.org/10.1111/jcpp.12334

Hidalgo, N., Sjöwall, D., Agius, H., Byström, C., Brar, A., Borg, J., & Hirvikoski, T. (2022). Psychoeducational group intervention for intellectually able adults with autism and their close relations (Prisma) – an open feasibility study. *BMC psychiatry*, *22*(1), 556. https://doi.org/10.1186/s12888-022-04134-4

Higgins, A., Murphy, R., Barry, J., Eustace-Cook, J., Monahan, M., Kroll, T., . . . Gibbons, P. (2020). Scoping review of factors influencing the implementation of group psychoeducational initiatives for people experiencing mental health difficulties and their families. *Journal of Mental Health*, 1-14. https://doi.org/10.1080/09638237.2020.1714002

Hirvikoski, T., & Blomqvist, M. (2015). High self-perceived stress and poor coping in intellectually able adults with autism spectrum disorder. *Autism*, *19*(6), 752-757. https://doi.org/10.1177/1362361314543530

Hirvikoski, T., Boman, M., Chen, Q., D'Onofrio, B. M., Mittendorfer-Rutz, E., Lichtenstein, P., . . . Larsson, H. (2020). Individual risk and familial liability for suicide attempt and suicide in autism: a population-based study. *Psychol Med*, *50*(9), 1463-1474. https://doi.org/10.1017/S0033291719001405

Hirvikoski, T., Lindstrom, T., Carlsson, J., Waaler, E., Jokinen, J., & Bolte, S. (2017). Psychoeducational groups for adults with ADHD and their significant others (PEGASUS): A pragmatic multicenter and randomized controlled trial. *Eur Psychiatry*, *44*, 141-152. https://doi.org/10.1016/j.eurpsy.2017.04.005

Hirvikoski, T., Waaler, E., Lindström, T., Bölte, S., & Jokinen, J. (2015). Cognitive behavior therapy-based psychoeducational groups for adults with ADHD and their significant others (PEGASUS): an open clinical feasibility trial. *Atten Defic Hyperact Disord*, *7*(1), 89-99. https://doi.org/10.1007/s12402-014-0141-2

Hollocks, M. J., Lerh, J. W., Magiati, I., Meiser-Stedman, R., & Brugha, T. S. (2019). Anxiety and depression in adults with autism spectrum disorder: a systematic review and meta-analysis. *Psychological Medicine*, *49*(4), 559-572. https://doi.org/10.1017/S0033291718002283

Hong, J., Bishop-Fitzpatrick, L., Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2016). Factors Associated with Subjective Quality of Life of Adults with Autism Spectrum Disorder: Self-Report Versus Maternal Reports. *Journal of Autism and Developmental Disorders*, *46*(4), 1368-1378. https://doi.org/10.1007/s10803-015-2678-0

Hossain, M. M., Khan, N., Sultana, A., Ma, P., McKyer, E. Lisako J., Ahmed, H. U., & Purohit, N. (2020). Prevalence of comorbid psychiatric disorders among people with autism spectrum disorder: An umbrella review of systematic reviews and meta-analyses. *Psychiatry Research*, *287*, 112922. https://doi.org/https://doi.org/10.1016/j.psychres.2020.112922

Howlin, P. (2021). Adults with Autism: Changes in Understanding Since DSM-111. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-020-04847-z

Howlin, P., Goode, S., Hutton, J., & Rutter, M. (2004). Adult outcome for children with autism. *Journal of Child Psychology and Psychiatry*, *45*(2), 212-229. https://doi.org/10.1111/j.1469-7610.2004.00215.x

Howlin, P., & Magiati, I. (2017). Autism spectrum disorder: outcomes in adulthood. *Curr Opin Psychiatry*, *30*(2), 69-76. https://doi.org/10.1097/YCO.0000000000000308

Idring, S., Lundberg, M., Sturm, H., Dalman, C., Gumpert, C., Rai, D., . . . Magnusson, C. (2015). Changes in prevalence of autism spectrum disorders in 2001-2011: findings from the Stockholm youth cohort. *J Autism Dev Disord*, *45*(6), 1766-1773. https://doi.org/10.1007/s10803-014-2336-y

Ioannou, C., Seernani, D., Stefanou, M. E., Riedel, A., Tebartz van Elst, L., Smyrnis, N., . . . Klein, C. (2020). Comorbidity Matters: Social Visual Attention in a Comparative Study of Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder and Their Comorbidity. *Frontiers in psychiatry*, *11*, 545567. https://doi.org/10.3389/fpsyt.2020.545567

Ip, A., Zwaigenbaum, L., Brian, J. A., Society, C. P., & Force, A. S. D. G. T. (2019). *Post-diagnostic management and follow-up care for autism spectrum disorder*. https://cps.ca/en/documents/position/asd-post-diagnostic-management: Canadian Paediatric Society Retrieved from https://cps.ca/en/documents/position/asd-post-diagnostic-management

Ismail, F. Y., & Shapiro, B. K. (2019). What are neurodevelopmental disorders? *Current Opinion in Neurology*, *32*(4), 611-616. https://doi.org/10.1097/wco.0000000000000710

Jack, S. J., & Ronan, K. R. (2008). Bibliotherapy: Practice and research. *School psychology international*, *29*(2), 161-182.

Jensen, C. M., Steinhausen, H.-C., & Lauritsen, M. B. (2014). Time Trends Over 16 Years in Incidence-Rates of Autism Spectrum Disorders Across the Lifespan Based on Nationwide Danish Register Data [journal article]. *Journal of Autism and Developmental Disorders*, *44*(8), 1808-1818. https://doi.org/10.1007/s10803-014-2053-6

Jones, C. R. G., Simonoff, E., Baird, G., Pickles, A., Marsden, A. J. S., Tregay, J., . . . Charman, T. (2018). The association between theory of mind, executive function, and the symptoms of autism spectrum disorder. *Autism Research*, *11*(1), 95-109. https://doi.org/https://doi.org/10.1002/aur.1873

Jonsson, U., Coco, C., Fridell, A., Brown, S., Berggren, S., Hirvikoski, T., & Bölte, S. (2019). Proof of concept: the TRANSITION program for young adults with autism spectrum disorder and/or attention deficit hyperactivity disorder. *Scandinavian Journal of Occupational Therapy*. https://doi.org/10.1080/11038128.2019.1695933

Joshi, G., Wozniak, J., Petty, C., Martelon, M. K., Fried, R., Bolfek, A., . . . Biederman, J. (2013). Psychiatric comorbidity and functioning in a clinically referred population of adults with autism spectrum disorders: a comparative study. *J Autism Dev Disord*, *43*(6), 1314-1325. https://doi.org/10.1007/s10803-012-1679-5

Jutel, A., & Nettleton, S. (2011). Towards a sociology of diagnosis: reflections and opportunities. *Social Science & Medicine*, *73*(6), 793-800. https://doi.org/10.1016/j.socscimed.2011.07.014

Kanne, S. M., Gerber, A. J., Quirmbach, L. M., Sparrow, S. S., Cicchetti, D. V., & Saulnier, C. A. (2011). The Role of Adaptive Behavior in Autism Spectrum Disorders: Implications for Functional Outcome. *Journal of Autism and Developmental Disorders*, *41*(8), 1007-1018. https://doi.org/10.1007/s10803-010-1126-4

Katusic, M. Z., Myers, S. M., Weaver, A. L., & Voigt, R. G. (2021). IQ in Autism Spectrum Disorder: A Population-Based Birth Cohort Study. *Pediatrics*, *148*(6), Article e2020049899. https://doi.org/10.1542/peds.2020-049899

Kerns, C. M., Kendall, P. C., Zickgraf, H., Franklin, M. E., Miller, J., & Herrington, J. (2014). Not to Be Overshadowed or Overlooked: Functional Impairments Associated With Comorbid Anxiety Disorders in Youth With ASD. *Behavior therapy*, *46*(1), 29-39. https://doi.org/10.1016/j.beth.2014.03.005

Khanna, R., Jariwala-Parikh, K., West-Strum, D., & Mahabaleshwarkar, R. (2014). Health-related quality of life and its determinants among adults with autism. *Research in Autism Spectrum Disorders*, *8*(3), 157-167. https://doi.org/https://doi.org/10.1016/j.rasd.2013.11.003

Kiep, M., & Spek, A. A. (2017). Executive functioning in men and women with an autism spectrum disorder. *Autism Research*, *10*(5), 940-948. https://doi.org/10.1002/aur.1721

Kim, S. Y., & Bottema-Beutel, K. (2019). A meta regression analysis of quality of life correlates in adults with ASD. *Research in Autism Spectrum Disorders*, *63*, 23-33. https://doi.org/https://doi.org/10.1016/j.rasd.2018.11.004

Kitchin, J. L., & Karlin, N. J. (2022). Awareness and Stigma of Autism Spectrum Disorders in Undergraduate Students. *Psychological Reports*, *125*(4), 2069-2087, Article 00332941211014144. https://doi.org/10.1177/00332941211014144

Knuppel, A., Telleus, G. K., Jakobsen, H., & Lauritsen, M. B. (2018). Quality of life in adolescents and adults with autism spectrum disorder: Results from a nationwide Danish survey using self reports and parental proxy-reports. *Research in Developmental Disabilities*, *83*, 247-259. https://doi.org/10.1016/j.ridd.2018.09.004

Kosidou, K., Edwin, V., Magnusson, C., & Dalman, C. (2017). *Autismspektrumtillstånd och ADHD bland barn och unga i Stockholms län: Förekomst i befolkningen samt vårdsökande under åren 2011 till 2016* (CES Faktablad 2017:1, Issue. SLL.

Kraper, C. K., Kenworthy, L., Popal, H., Martin, A., & Wallace, G. L. (2017). The Gap Between Adaptive Behavior and Intelligence in Autism Persists into Young Adulthood and is Linked to Psychiatric Co-morbidities. *Journal of Autism and Developmental Disorders*, *47*(10), 3007-3017. https://doi.org/10.1007/s10803-017-3213-2

Lai, M.-C., Anagnostou, E., Wiznitzer, M., Allison, C., & Baron-Cohen, S. (2020). Evidence-based support for autistic people across the lifespan: maximising potential, minimising barriers, and optimising the person–environment fit. *The Lancet Neurology*, *19*(5), 434-451. https://doi.org/https://doi.org/10.1016/S1474-4422(20)30034-X

Lai, M.-C., & Baron-Cohen, S. (2015). Identifying the lost generation of adults with autism spectrum conditions. *The Lancet Psychiatry*, *2*(11), 1013-1027. https://doi.org/https://doi.org/10.1016/S2215-0366(15)00277-1

Lai, M. C., Kassee, C., Besney, R., Bonato, S., Hull, L., Mandy, W., . . . Ameis, S. (2019). Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysis. *The Lancet Psychiatry*, *6*(10), 819-829. https://doi.org/https://doi.org/10.1016/S2215-0366(19)30289-5

Lai, M. C., Lombardo, M. V., Auyeung, B., Chakrabarti, B., & Baron-Cohen, S. (2015). Sex/Gender Differences and Autism: Setting the Scene for Future Research. *Journal of the American Academy of Child and Adolescent Psychiatry*, *54*(1), 11-24. https://doi.org/10.1016/j.jaac.2014.10.003

Lamash, L., Little, L., & Hen-Herbst, L. (2022). Telehealth Interventions to Promote Health and Behavior-Related Outcomes in Adolescents with Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-022-05440-2

Lee, E. A. L., Black, M. H., Falkmer, M., Tan, T., Sheehy, L., Bolte, S., & Girdler, S. (2020). "We Can See a Bright Future": Parents' Perceptions of the Outcomes of Participating in a Strengths-Based Program for Adolescents with Autism Spectrum Disorder. *J Autism Dev Disord*, *50*(9), 3179-3194. https://doi.org/10.1007/s10803-020-04411-9

Lee, E. A. L., Scott, M., Black, M. H., D'Arcy, E., Tan, T. L., Sheehy, L., . . . Girdler, S. (2023). "He Sees his Autism as a Strength, Not a Deficit Now": A Repeated Cross-Sectional Study Investigating the Impact of Strengths-Based Programs on Autistic Adolescents. *Journal of Autism and Developmental Disorders*. https://doi.org/10.1007/s10803-022-05881-9

Leedham, A., Thompson, A. R., Smith, R., & Freeth, M. (2020). 'I was exhausted trying to figure it out': The experiences of females receiving an autism diagnosis in middle to late adulthood. *Autism*, *24*(1), 135-146. https://doi.org/10.1177/1362361319853442

Leidy, N. K. (1994). Functional Status and the Forward Progress of Merry-Go-Rounds: Toward a Coherent Analytical Framework. *Nursing Research*, *43*(4), 196-202. https://journals.lww.com/nursingresearchonline/Fulltext/1994/07000/Functional_Status_and_the_Forward_Progress_of.2.aspx

Levy, S. E., Giarelli, E., Lee, L.-C., Schieve, L. A., Kirby, R. S., Cunniff, C., . . . Rice, C. E. (2010). Autism Spectrum Disorder and Co-occurring Developmental, Psychiatric, and Medical Conditions Among Children in Multiple Populations of the United States. *Journal of Developmental & Behavioral Pediatrics*, *31*(4), 267-275. https://doi.org/10.1097/DBP.0b013e3181d5d03b

Lin, L.-Y., & Huang, P.-C. (2019). Quality of life and its related factors for adults with autism spectrum disorder. *Disability and Rehabilitation*, *41*(8), 896-903. https://doi.org/10.1080/09638288.2017.1414887

Lindner, P., Frykheden, O., Forsstrom, D., Andersson, E., Ljotsson, B., Hedman, E., . . . Carlbring, P. (2016). The Brunnsviken Brief Quality of Life Scale (BBQ): Development and Psychometric Evaluation. *Cognitive Behaviour Therapy*, *45*(3), 182-195. https://doi.org/10.1080/16506073.2016.1143526

Lothberg, M., Hirvikoski, T., Girdler, S., Bolte, S., & Jonsson, U. (2023). Support in Daily Living for Young Adults with Neurodevelopmental Conditions in Sweden: A Qualitative Description of Current Practice. *Journal of Autism* *and Developmental Disorders*. https://doi.org/10.1007/s10803-023-06014-6

Lounds Taylor, J. (2017). When is a good outcome actually good? *Autism*, *21*(8), 918-919. https://doi.org/10.1177/1362361317728821

Lounds Taylor, J., Dove, D., Veenstra-VanderWeele, J., Sathe, N. A., McPheeters, M. L., Jerome, R. N., & Warren, Z. (2012). AHRQ Comparative Effectiveness Reviews. In *Interventions for Adolescents and Young Adults With Autism Spectrum Disorders*. Agency for Healthcare Research and Quality (US).

Lundin Remnélius, K. (2023). *Female Autism Phenotypes: Sex/Gender Differences in Functioning, Camouflaging, and Eating Problems* [Compilation, Karolinska Institutet]. Stockholm.

Lyall, K., Croen, L., Newschaffer, C., Lyall, K., Croen, L., Daniels, J., . . . Newschaffer, C. (2017). The Changing Epidemiology of Autism Spectrum Disorders. *Annual Review of Public Health*, *38*(1), 81-102. https://doi.org/10.1146/annurev-publhealth-031816-044318

Lyman, D. R., Braude, L., George, P., Dougherty, R. H., Daniels, A. S., Ghose, S. S., & Delphin-Rittmon, M. E. (2014). Consumer and family psychoeducation: Assessing the evidence. *Psychiatric Services*, *65*(4), 416-428.

Maddox, B. B., Crabbe, S., Beidas, R. S., Brookman-Frazee, L., Cannuscio, C. C., Miller, J. S., . . . Mandell, D. S. (2020). “I wouldn’t know where to start”: Perspectives from clinicians, agency leaders, and autistic adults on improving community mental health services for autistic adults. *Autism*, *24*(4), 919-930.

Maenner, M., Warren, Z., AR, W., & al., e. (2023). *Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2020.*: Centers for Disease Control and Prevention

Mahdi, S., Albertowski, K., Almodayfer, O., Arsenopoulou, V., Carucci, S., Dias, J. C., . . . Bolte, S. (2018). An International Clinical Study of Ability and Disability in Autism Spectrum Disorder Using the WHO-ICF Framework. *J Autism Dev Disord*, *48*(6), 2148-2163. https://doi.org/10.1007/s10803-018-3482-4

Mahdi, S., Viljoen, M., Yee, T., Selb, M., Singhal, N., Almodayfer, O., . . . Bolte, S. (2018). An international qualitative study of functioning in autism spectrum disorder using the World Health Organization international classification of functioning, disability and health framework. *Autism Res*, *11*(3), 463-475. https://doi.org/10.1002/aur.1905

Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., . . . Frazier, T. W. (2022). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. *Pediatric Research*, *91*(5), 1028-1035. https://doi.org/10.1038/s41390-021-01465-y

Mandy, W. (2022). Six ideas about how to address the autism mental health crisis. *Autism*, *26*(2), 289-292. https://doi.org/10.1177/13623613211067928

Martini, M. I., Kuja-Halkola, R., Butwicka, A., Du Rietz, E., D'Onofrio, B. M., Happé, F., . . . Taylor, M. J. (2022). Sex Differences in Mental Health Problems and Psychiatric Hospitalization in Autistic Young Adults. *JAMA Psychiatry*. https://doi.org/10.1001/jamapsychiatry.2022.3475

Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Res*, *11*(8), 1138-1147. https://doi.org/10.1002/aur.1965

Matthews, N. L., Smith, C. J., Pollard, E., Ober-Reynolds, S., Kirwan, J., & Malligo, A. (2015). Adaptive Functioning in Autism Spectrum Disorder During the Transition to Adulthood. *Journal of Autism and Developmental Disorders*, *45*(8), 2349-2360. https://doi.org/10.1007/s10803-015-2400-2

Mazzotti, E., & Barbaranelli, C. (2012). Dropping out of psychiatric treatment: a methodological contribution. *Acta Psychiatr Scand*, *126*(6), 426-433. https://doi.org/10.1111/j.1600-0447.2012.01872.x

McConachie, H., Mason, D., Parr, J. R., Garland, D., Wilson, C., & Rodgers, J. (2018). Enhancing the Validity of a Quality of Life Measure for Autistic People. *Journal of Autism and Developmental Disorders*, *48*(5), 1596-1611. https://doi.org/10.1007/s10803-017-3402-z

McGhee Hassrick, E., Holmes, L. G., Sosnowy, C., Walton, J., & Carley, K. (2021). Benefits and Risks: A Systematic Review of Information and Communication Technology Use by Autistic People. *Autism in Adulthood*, *3*(1), 72-84. https://doi.org/10.1089/aut.2020.0048

Milton, D., Gurbuz, E., & López, B. (2022). The 'double empathy problem': Ten years on. *Autism*, *26*(8), 1901-1903.

Morris-Rosendahl, D. J., & Crocq, M.-A. (2020). Neurodevelopmental disorders—the history and future of a diagnostic concept *Dialogues in clinical neuroscience*, *22*(1), 65-72. https://doi.org/10.31887/DCNS.2020.22.1/macrocq

Morsa, M., De Andrade, V., Alcaraz, C., De La Tribonnière, X., Rattaz, C., & Baghdadli, A. (2022). A scoping review of education and training interventions in Autism Spectrum Disorder. *Patient Education and Counseling*, *105*(9), 2850-2859. https://doi.org/https://doi.org/10.1016/j.pec.2022.05.012

Moss, P., Mandy, W., & Howlin, P. (2017). Child and Adult Factors Related to Quality of Life in Adults with Autism. *Journal of Autism and Developmental Disorders*, *47*(6), 1830-1837. https://doi.org/10.1007/s10803-017-3105-5

Motlova, L. B., Balon, R., Beresin, E. V., Brenner, A. M., Coverdale, J. H., Guerrero, A. P. S., . . . Roberts, L. W. (2017). Psychoeducation as an Opportunity for Patients, Psychiatrists, and Psychiatric Educators: Why Do We Ignore It?

Academic Psychiatry, *41*(4), 447-451. https://doi.org/10.1007/s40596-017-0728-y

Murray-Swank, A. B., & Dixon, L. (2004). Family psychoeducation as an evidence-based practice. *CNS Spectr*, *9*(12), 905-912. http://www.ncbi.nlm.nih.gov/pubmed/15616476

Naughton, M. J., & Shumaker, S. A. (2003). The case for domains of function in quality of life assessment. *Quality of Life Research*, *12*, 73-80. https://doi.org/Doi 10.1023/A:1023585707046

Neufeld, J., Hagström, A., Van't Westeinde, A., Lundin, K., Cauvet, É., Willfors, C., . . . Bölte, S. (2020). Global and local visual processing in autism – a co-twin-control study. *Journal of Child Psychology and Psychiatry*, *61*(4), 470-479. https://doi.org/https://doi.org/10.1111/jcpp.13120

Nicolaidis, C., Raymaker, D. M., Ashkenazy, E., McDonald, K. E., Dern, S., Baggs, A. E., . . . Boisclair, W. C. (2015). "Respect the way I need to communicate with you": Healthcare experiences of adults on the autism spectrum. *Autism*, *19*(7), 824-831.

Oakley, B. F. M., Tillmann, J., Ahmad, J., Crawley, D., Caceres, A. S. J., Holt, R., . . . Loth, E. (2021). How do core autism traits and associated symptoms relate to quality of life? Findings from the Longitudinal European Autism Project [Article]. *Autism*, *25*(2), 389-404, Article 1362361320959959. https://doi.org/10.1177/1362361320959959

OSU, O. R. U. (2005). OSU Autism CGI. In. Colombus, OH: OSU Research Unit on Pediatric Psychopharmacology.

Pallathra, A. A., Cordero, L., Wong, K., & Brodkin, E. S. (2019). Psychosocial Interventions Targeting Social Functioning in Adults on the Autism Spectrum: a Literature Review. *Current psychiatry reports*, *21*(1). https://doi.org/10.1007/s11920-019-0989-0

Park, S. H., Demetriou, E. A., Pepper, K. L., Song, Y. J. C., Thomas, E. E., Hickie, I. B., . . . Guastella, A. J. (2019). Validation of the 36-item and 12-item self-report World Health Organization Disability Assessment Schedule II (WHODAS-II) in individuals with autism spectrum disorder. *Autism Research*, *12*(7), 1101-1111. https://doi.org/10.1002/aur.2115

Park, S. H., Song, Y. J. C., Demetriou, E. A., Pepper, K. L., Norton, A., Thomas, E. E., . . . Guastella, A. J. (2019). Disability, functioning, and quality of life among treatment-seeking young autistic adults and its relation to depression, anxiety, and stress. *Autism*, *23*(7), 1675-1686. https://doi.org/10.1177/1362361318823925

Patsopoulos, N. A. (2011). A pragmatic view on pragmatic trials. *Dialogues in clinical neuroscience*, *13*(2), 217-224. https://doi.org/10.31887/DCNS.2011.13.2/npatsopoulos

Pavot, W., Diener, E., Colvin, C. R., & Sandvik, E. (1991). Further validation of the Satisfaction with Life Scale: evidence for the cross-method convergence of well-being measures. *Journal of Personality Assessment*, *57*(1), 149-161. https://doi.org/10.1207/s15327752jpa5701_17

Pellicano, E. (2012). The Development of Executive Function in Autism. *Autism Research and Treatment*, *2012*, 146132. https://doi.org/10.1155/2012/146132

Pellicano, E., Cribb, S., & Kenny, L. (2020). Patterns of Continuity and Change in the Psychosocial Outcomes of Young Autistic People: a Mixed-Methods Study. *Journal of Abnormal Child Psychology*, *48*(2), 301-313. https://doi.org/10.1007/s10802-019-00602-w

Pellicano, E., Dinsmore, A., & Charman, T. (2014). Views on Researcher-Community Engagement in Autism Research in the United Kingdom: A Mixed-Methods Study. *Plos One*, *9*(10). https://doi.org/ARTN e10994610.1371/journal.pone.0109946

Pellicano, E., & Stears, M. (2011). Bridging autism, science and society: moving toward an ethically informed approach to autism research. *Autism Research*, *4*(4), 271-282. https://doi.org/https://doi.org/10.1002/aur.201

Pezzimenti, F., Han, G. T., Vasa, R. A., & Gotham, K. (2019). Depression in Youth with Autism Spectrum Disorder. *Child and Adolescent Psychiatric Clinics of North America*, *28*(3), 397-+. https://doi.org/10.1016/j.chc.2019.02.009

Poulsen, R., Brownlow, C., Lawson, W., & Pellicano, E. (2022). Meaningful research for autistic people? Ask autistics! *Autism*, *26*(1), 3-5. https://doi.org/10.1177/13623613211064421

Rabot, J., Rødgaard, E.-M., Joober, R., Dumas, G., Bzdok, D., Bernhardt, B., . . . Mottron, L. (2023). Genesis, modelling and methodological remedies to autism heterogeneity. *Neuroscience & Biobehavioral Reviews*, *150*, 105201. https://doi.org/https://doi.org/10.1016/j.neubiorev.2023.105201

Ramji, R., Rämgård, M., & Kottorp, A. (2023). Psychometric properties of the WHOQOL-BREF in citizens from a disadvantaged neighborhood in Southern Sweden. *Front Psychol*, *14*, 1118575. https://doi.org/10.3389/fpsyg.2023.1118575

Rezayi, S., Tehrani-Doost, M., & Shahmoradi, L. (2023). Features and effects of computer-based games on cognitive impairments in children with autism spectrum disorder: an evidence-based systematic literature review. *BMC psychiatry*, *23*(1), 2. https://doi.org/10.1186/s12888-022-04501-1

Robert A. Nathenson, Ph.D., M.S.E. , and, & Benjamin Zablotsky, Ph.D. (2017). The Transition to the Adult Health Care System Among Youths With Autism Spectrum Disorder. *Psychiatric Services*, *68*(7), 735-738. https://doi.org/10.1176/appi.ps.201600239

Rodgers, M., Asaria, M., Walker, S., McMillan, D., Lucock, M., Harden, M., . . . Eastwood, A. (2012). The clinical effectiveness and cost-effectiveness of low-intensity psychological interventions for the secondary prevention of relapse after depression: a systematic review. *Health Technol Assess*, *16*(28), 1-130. https://doi.org/10.3310/hta16280

Rodriguez-Seijas, C., Gadow, K. D., Rosen, T. E., Kim, H., Lerner, M. D., & Eaton, N. R. (2020). A transdiagnostic model of psychiatric symptom co-occurrence and autism spectrum disorder. *Autism Research*, *13*(4), 579-590. https://doi.org/https://doi.org/10.1002/aur.2228

Rosen, T. E., Mazefsky, C. A., Vasa, R. A., & Lerner, M. D. (2018). Co-occurring psychiatric conditions in autism spectrum disorder. *International Review of Psychiatry*, *30*(1), 40-61. https://doi.org/10.1080/09540261.2018.1450229

Rosenfield, S. (1997). Labeling mental illness: The effects of received services and perceived stigma on life satisfaction. *American Sociological Review*, *62*(4), 660-672. https://doi.org/Doi 10.2307/2657432

Rubenstein, E., & Bishop-Fitzpatrick, L. (2019). A matter of time: The necessity of temporal language in research on health conditions that present with autism spectrum disorder. *Autism Research*, *12*(1), 20-25. https://doi.org/https://doi.org/10.1002/aur.2010

Russell, G., Stapley, S., Newlove-Delgado, T., Salmon, A., White, R., Warren, F., . . . Ford, T. (2022). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. *J Child Psychol Psychiatry*, *63*(6), 674-682. https://doi.org/10.1111/jcpp.13505

Rutherford, M., McKenzie, K., Johnson, T., Catchpole, C., O'Hare, A., McClure, I., . . . Murray, A. (2016). Gender ratio in a clinical population sample, age of diagnosis and duration of assessment in children and adults with autism spectrum disorder. *Autism*, *20*(5), 628-634. https://doi.org/10.1177/1362361315617879

Sáez-Suanes, G. P., & Álvarez-Couto, M. (2022). Factors Associated with Quality of Life in Adults with Autism Spectrum Disorder: A Systematic Review. *Review Journal of Autism and Developmental Disorders*, *9*(3), 307-319. https://doi.org/10.1007/s40489-021-00254-x

Saks, E. R., Jeste, D. V., Granholm, E., Palmer, B. W., & Schneiderman, L. (2002). Ethical Issues in Psychosocial Interventions Research Involving Controls. *Ethics & Behavior*, *12*(1), 87-101. https://doi.org/10.1207/S15327019EB1201_6

Sandercock, R. K., Lamarche, E. M., Klinger, M. R., & Klinger, L. G. (2020). Assessing the convergence of self-report and informant measures for adults with autism spectrum disorder. *Autism*, *24*(8), 2256-2268. https://doi.org/10.1177/1362361320942981

Schalock, R. L. (2004). The concept of quality of life: what we know and do not know. *J Intellect Disabil Res*, *48*(Pt 3), 203-216. https://doi.org/10.1111/j.1365-2788.2003.00558.x

Schendel, D. E., & Thorsteinsson, E. (2018). Cumulative Incidence of Autism Into Adulthood for Birth Cohorts in Denmark, 1980-2012. *JAMA*, *320*(17), 1811-1813. https://doi.org/10.1001/jama.2018.11328

Schmidt, L., Kirchner, J., Strunz, S., Broźus, J., Ritter, K., Roepke, S., & Dziobek, I. (2015). Psychosocial Functioning and Life Satisfaction in Adults With Autism Spectrum Disorder Without Intellectual Impairment. *Journal of Clinical Psychology*, *71*(12), 1259-1268. https://doi.org/10.1002/jclp.22225

Sedgewick, F., Leppanen, J., & Tchanturia, K. (2020). Gender differences in mental health prevalence in autism. *Advances in Autism*. https://doi.org/10.1108/aia-01-2020-0007

Sehlin, H., Hedman Ahlström, B., Andersson, G., & Wentz, E. (2018). Experiences of an internet-based support and coaching model for adolescents and young adults with ADHD and autism spectrum disorder –a qualitative study. *BMC psychiatry*, *18*(1), 15. https://doi.org/10.1186/s12888-018-1599-9

Sehlin, H., Hedman Ahlström, B., Bertilsson, I., Andersson, G., & Wentz, E. (2020). Internet-Based Support and Coaching With Complementary Clinic Visits for Young People With Attention-Deficit/Hyperactivity Disorder and Autism: Controlled Feasibility Study [Original Paper]. *J Med Internet Res*, *22*(12), e19658. https://doi.org/10.2196/19658

Shenouda, J., Barrett, E., Davidow, A. L., Halperin, W., Silenzio, V. M. B., & Zahorodny, W. (2022). Prevalence of autism spectrum disorder in a large, diverse metropolitan area: Variation by sociodemographic factors. *Autism Research*, *15*(1), 146-155. https://doi.org/https://doi.org/10.1002/aur.2628

Sickel, A. E., Seacat, J. D., & Nabors, N. A. (2014). Mental health stigma update: A review of consequences. *Advances in Mental Health*, *12*(3), 202-215. https://doi.org/10.1080/18374905.2014.11081898

Smith, L. E., Greenberg, J. S., & Mailick, M. R. (2012). Adults with autism: Outcomes, family effects, and the multi-family group psychoeducation model. *Current psychiatry reports*, *14*, 732-738.

Snaith, R. P. (2003). The Hospital Anxiety And Depression Scale. *Health Qual Life Outcomes*, *1*, 29. https://doi.org/10.1186/1477-7525-1-29

Sosnowy, C., Silverman, C., & Shattuck, P. (2017). Parents' and young adults' perspectives on transition outcomes for young adults with autism. *Autism*, *22*(1), 29-39. https://doi.org/10.1177/1362361317699585

Sparrow, S., Cichetti, D. V., & Balla, D. A. . (2005). *Vineland-II. Vineland Adaptive Behavior Scales* (2 ed.). AGS Publishing.

Tabachnick, B., & Fidell, L. (2018). *Using Multivariate Statistics*. Pearson. https://books.google.se/books?id=cev2swEACAAJ

Tang, J. S. Y., Falkmer, M., Chen, N. T. M., Bölte, S., & Girdler, S. (2021). Development and Feasibility of MindChip: A Social Emotional Telehealth Intervention for

Autistic Adults. *J Autism Dev Disord*, *51*(4), 1107-1130. https://doi.org/10.1007/s10803-020-04592-3

Taylor, J. L., & Henninger, N. A. (2015). Frequency and Correlates of Service Access Among Youth with Autism Transitioning to Adulthood. *Journal of Autism and Developmental Disorders*, *45*(1), 179-191. https://doi.org/10.1007/s10803-014-2203-x

Taylor, M. J., Rosenqvist, M. A., Larsson, H., Gillberg, C., D'Onofrio, B. M., Lichtenstein, P., & Lundström, S. (2020). Etiology of Autism Spectrum Disorders and Autistic Traits Over Time. *JAMA Psychiatry*, *77*(9), 936-943. https://doi.org/10.1001/jamapsychiatry.2020.0680

Tesfaye, R., Courchesne, V., Mirenda, P., Mitchell, W., Nicholas, D., Singh, I., . . . Elsabbagh, M. (2022). Autism voices: Perspectives of the needs, challenges, and hopes for the future of autistic youth. *Autism*. https://doi.org/10.1177/13623613221132108

Thapar, A., & Rutter, M. (2021). Genetic Advances in Autism. *Journal of Autism and Developmental Disorders*, *51*(12), 4321-4332. https://doi.org/10.1007/s10803-020-04685-z

Thompson, C., Bölte, S., Falkmer, T., & Girdler, S. (2018). To be understood: Transitioning to adult life for people with Autism Spectrum Disorder. *Plos One*, *13*(3), e0194758. https://doi.org/10.1371/journal.pone.0194758

Tick, B., Bolton, P., Happé, F., Rutter, M., & Rijsdijk, F. (2016). Heritability of autism spectrum disorders: a meta-analysis of twin studies. *Journal of Child Psychology and Psychiatry*, *57*(5), 585-595. https://doi.org/https://doi.org/10.1111/jcpp.12499

Tillmann, J., San José Cáceres, A., Chatham, C. H., Crawley, D., Holt, R., Oakley, B., . . . group, t. E.-A. L. (2019). Investigating the factors underlying adaptive functioning in autism in the EU-AIMS Longitudinal European Autism Project. *Autism Research*, *12*(4), 645-657. https://doi.org/https://doi.org/10.1002/aur.2081

Trudgeon, C., & Carr, D. (2007). The impacts of home-based early behavioural intervention programmes on families of children with autism. *Journal of Applied Research in Intellectual Disabilities*, *20*(4), 285-296. https://doi.org/10.1111/j.1468-3148.2006.00331.x

Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding Stigma in Autism: A Narrative Review and Theoretical Model. *Autism in Adulthood*, *4*(1), 76-91. https://doi.org/10.1089/aut.2021.0005

Uljarević, M., Richdale, A. L., McConachie, H., Hedley, D., Cai, R. Y., Merrick, H., . . . Le Couteur, A. (2018). The Hospital Anxiety and Depression scale: Factor structure and psychometric properties in older adolescents and young adults with autism spectrum disorder. *Autism Research*, *11*(2), 258-269. https://doi.org/https://doi.org/10.1002/aur.1872

Valencia, K., Rusu, C., Quiñones, D., & Jamet, E. (2019). The Impact of Technology on People with Autism Spectrum Disorder: A Systematic Literature Review. *Sensors*, *19*(20), 4485. https://www.mdpi.com/1424-8220/19/20/4485

van Heijst, B. F. C., & Geurts, H. M. (2015). Quality of life in autism across the lifespan: A meta-analysis. *Autism*, *19*(2), 158-167. https://doi.org/10.1177/1362361313517053

Vannucchi, G., Masi, G., Toni, C., Dell'Osso, L., Marazziti, D., & Perugi, G. (2014). Clinical features, developmental course, and psychiatric comorbidity of adult autism spectrum disorders. *CNS Spectrums*, *19*(2), 157-164. https://doi.org/10.1017/S1092852913000941

Varkey, B. (2021). Principles of Clinical Ethics and Their Application to Practice. *Medical Principles and Practice*, *30*(1), 17-28. https://doi.org/10.1159/000509119

Volkmar, F. R., Jackson, S. L. J., & Hart, L. (2017). Transition Issues and Challenges for Youth with Autism Spectrum Disorders. *Pediatr Ann*, *46*(6), e219-e223. https://doi.org/10.3928/19382359-20170519-03

Wallin, E. E. K., Mattsson, S., & Olsson, E. M. G. (2016). The Preference for Internet-Based Psychological Interventions by Individuals Without Past or Current Use of Mental Health Treatment Delivered Online: A Survey Study With Mixed-Methods Analysis [Original Paper]. *JMIR Ment Health*, *3*(2), e25. https://doi.org/10.2196/mental.5324

Wehmeyer, M. L. (1999). A functional model of self-determination: Describing development and implementing instruction. *Focus on Autism and Other Developmental Disabilities*, *14*(1), 53-61.

Wentz, E., Nyden, A., & Krevers, B. (2012). Development of an internet-based support and coaching model for adolescents and young adults with ADHD and autism spectrum disorders: a pilot study. *European Child & Adolescent Psychiatry*, *21*(11), 611-622. https://doi.org/10.1007/s00787-012-0297-2

Westerberg, B., Bäärnhielm, S., Giles, C., Hylén, U., Holländare, F., & Bejerot, S. (2021). An Internet Based Intervention for Adults With Autism Spectrum Disorder-A Qualitative Study of Participants Experiences. *Frontiers in psychiatry*, *12*, 789663-789663. https://doi.org/10.3389/fpsyt.2021.789663

Whitcomb, J. J. (2011). Functional Status Versus Quality of Life Where Does the Evidence Lead Us? *Advances in Nursing Science*, *34*(2), 97-105. https://doi.org/10.1097/ANS.0b013e3182139683

White, K., Flanagan, T. D., & Nadig, A. (2018). Examining the Relationship Between Self-Determination and Quality of Life in Young Adults with Autism

Spectrum Disorder. *Journal of Developmental and Physical Disabilities*, *30*(6), 735-754. https://doi.org/10.1007/s10882-018-9616-y

WHO, W. G. (1998). Development of the World Health Organization WHOQOL-BREF quality of life assessment. The WHOQOL Group. *Psychol Med*, *28*(3), 551-558. https://doi.org/10.1017/s0033291798006667

WHO, W. H. O. (2002). *Towards a Common LanguageforFunctioning, Disability and Health:ICFThe International Classificationof Functioning, Disability and Health*. WHO. Retrieved 2020-12-11 from https://www.who.int/classifications/icf/icfbeginnersguide.pdf

WHO, W. H. O. (2013). How to use the ICF: A practical manual for using the International Classification of Functioning, Disability and Health (ICF). Exposure draft for comment. In. Geneva: WHO.

ICD-11: International classification of diseases 11th revision, (2019). https://icd.who.int

Williams, D. L., Goldstein, G., & Minshew, N. J. (2006). The profile of memory function in children with autism. *Neuropsychology*, *20*(1), 21-29. https://doi.org/10.1037/0894-4105.20.1.21

Wilson, E. C., Roberts, G., Gillan, N., Ohlsen, C., Robertson, D., & Zinkstok, J. (2014). The NICE guideline on recognition, referral, diagnosis and management of adults on the autism spectrum. *Advances in Mental Health and Intellectual Disabilities*, *8*(1), 3-14. https://doi.org/10.1108/AMHID-05-2013-0035

Wisner-Carlson, R., Uram, S., & Flis, T. (2020). The Transition to Adulthood for Young People with Autism Spectrum Disorder. *Psychiatric Clinics of North America*, *43*(4), 673-686. https://doi.org/https://doi.org/10.1016/j.psc.2020.08.005

WMA, W. M. A. (2013). World medical association declaration of helsinki: Ethical principles for medical research involving human subjects. *JAMA*, *310*(20), 2191-2194. https://doi.org/10.1001/jama.2013.281053

Xie, R., Sun, X., Yang, L., & Guo, Y. (2020). Characteristic Executive Dysfunction for High-Functioning Autism Sustained to Adulthood. *Autism Research*, *13*(12), 2102-2121. https://doi.org/https://doi.org/10.1002/aur.2304

Young Shin Kim, M.D., Ph.D. „ Bennett L. Leventhal, M.D. „ Yun-Joo Koh, Ph.D. „ Eric Fombonne, M.D. „ Eugene Laska, Ph.D. „ Eun-Chung Lim, M.A. „ . . . Roy Richard Grinker, Ph.D. (2011). Prevalence of Autism Spectrum Disorders in a Total Population Sample. *American Journal of Psychiatry*, *168*(9), 904-912. https://doi.org/10.1176/appi.ajp.2011.10101532

Üstün, B., & Kennedy, C. (2009). What is "functional impairment"? Disentangling disability from clinical significance. *World psychiatry : official journal of the World Psychiatric Association (WPA)*, *8*(2), 82-85. https://doi.org/10.1002/j.2051-5545.2009.tb00219.x

Üstün, T. K., N.; Chatterji, S; Rehm, J. . (2010). *Measuring Health and Disability: Manual for WHO Disability Assessment Schedule (WHODAS 2.0)*. Geneva: WHO Press

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., . . . Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *15*(5), 778-790. https://doi.org/https://doi.org/10.1002/aur.2696

Zhao, S., Sampson, S., Xia, J., & Jayaram, M. B. (2015). Psychoeducation (brief) for people with serious mental illness. *Cochrane Database of Systematic Reviews*(4). https://doi.org/10.1002/14651858.CD010823.pub2

Zimmerman, D., Ownsworth, T., O'Donovan, A., Roberts, J., & Gullo, M. J. (2018). High-functioning autism spectrum disorder in adulthood: A systematic review of factors related to psychosocial outcomes. *Journal of Intellectual & Developmental Disability*, *43*(1), 2-19. https://doi.org/10.3109/13668250.2016.1262010

Zukerman, G., Yahav, G., & Ben-Itzchak, E. (2019). Increased psychiatric symptoms in university students with autism spectrum disorder are associated with reduced adaptive behavior. *Psychiatry Research*, *273*, 732-738. https://doi.org/https://doi.org/10.1016/j.psychres.2019.01.098