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Access to Early Support for Children with Developmental Disabilities and their Families

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Thesis submitted in fulfilment of the requirements for the degree of Doctor of Philosophy in Education and Psychology

University of Warwick
Centre for Educational Development, Appraisal and Research (CEDAR)
December 2021

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List of Abbreviations[1]

AAP	American Academy of Pediatrics
AB	Assembly Bill
ABA	Applied Behaviour Analysis
ADHD	Attention Deficit Hyperactivity Disorder
ALN	Additional Learning Needs
APA	American Psychiatric Association
ASN	Additional Support Needs
ASQ®	Ages and Stages Questionnaires®
CBF	Challenging Behaviour Foundation
CDC	Centers for Disease Control and Prevention
CEDAR	Centre for Educational Development, Appraisal and Research
DEC	Division for Early Childhood
DfE	Department for Education
DH	Department of Health
DHSC	Department of Health and Social Care
DSM-5®	Diagnostic and Statistical Manual of Mental Disorders 5th edition®
EHCP	Education Health and Care Plan
EIF	Early Intervention Foundation
E-PAtS	Early Positive Approaches to Support
ESDM	Early Start Denver Model
GP	General Practitioner
ICD-11	International Classification of Diseases 11th revision
IDEA	Individuals with Disabilities Education Act
IEP	Individualised Education Plan
IFSP	Individualised Family Support Plan
IMD	Indices of Multiple Deprivation
IPSEA	Independent Provider of Special Education Advice
IQ	Intelligence Quotient
ITCA	IDEA Infant and Toddler Coordinators Association
LA	Local Authority
MP	Member of Parliament

[1]For ease of reading, abbreviations are written out in full the first time they appear in any chapter.

NDIS	National Disability Insurance Scheme
NHS	National Health Service
NICE	National Institute for Health and Care Excellence
OECD	Organisation for Economic Co-operation and Development
ONS	Office for National Statistics
OR	Odds Ratio
PACT	Paediatric/Pre-school Autism Communication Therapy
PECS®	Picture Exchange Communication System®
PEDS	Parents' Evaluations of Developmental Status
PRT	Pivotal Response Treatment
RR	Rate Ratio
SCERTS®	Social Communication Emotional Regulation and Transactional Support®
SD	Standard Deviation
SEN	Special Educational Needs
SEND	Special Educational Needs and Disabilities
TEACCH®	Treatment and Education of Autistic and related Communications Handicapped Children®
UK	United Kingdom
UN	United Nations
USA	United States of America
WHO	World Health Organization

Acknowledgements

I am extremely fortunate and grateful for the incredible support I have received from various individuals and organisations throughout my PhD studies. Firstly, I am thankful to Cerebra, Mencap, and the University of Warwick Collaborative Postgraduate Research Scholarship for funding my PhD research.

I am exceptionally grateful for the dedicated, patient, and encouraging support of my fantastic supervisors, Doctor Vaso Totsika and Professor Richard Hastings. It would not have been possible for me to complete my PhD without their ongoing knowledgeable and empathetic support, which has been invaluable for my research and personal development throughout my PhD studies.

The support from Cerebra, Mencap, and Ambitious about Autism has been particularly valuable throughout my PhD studies. Their support has certainly enhanced the quality of my research, especially considering real-world impact and ways to improve access to early support for children with developmental disabilities and their families.

I am thankful to those who supported with the development of the Support in the Early Years survey, particularly Caitlin Murray, Cerebra, Mencap, Ambitious about Autism, the Challenging Behaviour Foundation, and the parental caregivers who piloted the survey and provided invaluable feedback. I would also like to thank everyone who supported with participant recruitment for the Support in the Early Years study (too many to name!), but especially Caitlin Murray, Cerebra, Mencap (in England, Northern Ireland, and Cymru), and Ambitious about Autism. I would also like to thank all of the parental caregivers who shared their experiences of access to early support for the purposes of this research. In addition, I am grateful to Catherine Stanford for their contribution to the qualitative analysis of barriers and facilitators of access to support.

I am also grateful to fellow students and staff at the Centre for Educational Development, Appraisal and Research (CEDAR) at the University of Warwick for their support, in particular Caitlin Murray, Nikita Hayden, Magda Apanasionok, Mairi Ann Cullen, Samantha Flynn, Louise Denne, Alison Baker, and Diana Smith.

Prior to my PhD, I was fortunate to work with some remarkable individuals who share my passion and commitment to improving the lives of people with developmental disabilities and their families. As I may have not embarked on this PhD without their insightful support, I would like to express my gratitude to these

individuals – Louise Denne and Richard Hastings (CEDAR, University of Warwick), Jacqui Shurlock, Viv Cooper, and Holly Young (Challenging Behaviour Foundation), Nick Gore and Jill Bradshaw (Tizard Centre, University of Kent), and Louise Lombardi (Surrey County Council).

I also feel extremely privileged to have worked with Embracing Complexity on a cross-sector placement funded by Emerging Minds towards the end of my PhD. It was fantastic to work with the insightful Georgia Harper (Embracing Complexity lead) and various organisations involved in the coalition throughout the project.

I am enormously fortunate to have received exceptional mentoring during my PhD studies from the wonderful Emma Foottit, which has undoubtedly been a great source of support, especially during difficult times. I am also thankful to Miriam Reidy and Jina Tanton for their wellbeing support.

Finally, I would like to thank my amazing family and friends for their loving and patient support during my PhD studies – especially my husband, Luke Sapiets, my mother, Angie Norris, and my closest friend, Zaila Monroe. I am also grateful for my incredible siblings, Aimee, Becca, and Matthew, who motivated me to conduct research on this topic. I would also like to thank other family members for their active support throughout my PhD studies: my stepfather, David, my mother-in-law, Beth, my stepmother-in-law, Molly, my father-in-law, George, my sister-in-law, Mel, and my two rescue cats, Sunny and Molly.

Declarations

This thesis is submitted to the University of Warwick in support of my application for the degree of Doctor of Philosophy. It has been composed by myself and has not been submitted in any previous application for any degree or award at another university or institution. Where material has been derived from other sources, full bibliographical information has been provided. The work presented (including data generated and data analysis) was carried out by myself under the supervision of Doctor Vasiliki Totsika and Professor Richard Hastings except in the cases outlined below.

For Chapters 3 and 4, I worked collaboratively with Caitlin Murray to design the survey (see Appendix 2) and recruit participants. I led the development of the section on access to early support for my PhD research and Caitlin Murray led the development of the section on parental and family wellbeing for their PhD research. We developed the section on child and family characteristics together. Additional input was sought from a group of key stakeholders, including parental caregivers of children with developmental disabilities, early support professionals, and charity organisations that work with families (Cerebra, Mencap, Ambitious about Autism, and the Challenging Behaviour Foundation). For Chapter 3, Catherine Stanford provided additional support with the qualitative analysis of barriers and facilitators of access to early support.

Parts of this thesis have been published (or submitted for publication):

Chapter 2: Sapiets, S. J., Totsika, V. & Hastings, R. P. (2021). Factors influencing access to early intervention for families of children with developmental disabilities: A narrative review. Journal of Applied Research in Intellectual Disabilities, 34(3), 695-711. https://doi.org/10.1111/jar.12852.

Chapter 3: Sapiets, S. J., Hastings, R. P., Stanford, C. & Totsika, V. (2022a). Families' access to early intervention and support for children with developmental disabilities. Journal of Early Intervention. https://doi.org/10.1177/10538151221083984

Chapter 4: Sapiets, S. J., Totsika, V. & Hastings, R. P. (2022b). Predictors of access to early support and unmet need for early support in families of children with developmental disabilities in the UK. Manuscript submitted for publication.

Abstract

Early support constitutes a range of support provided during early childhood (0-6 years), including specific interventions and programmes to improve child and family outcomes, and contact with services across education, health, and social care. While it is important to ensure families of children with suspected or diagnosed developmental disabilities (e.g., developmental delay, intellectual disability, autism) are able to access early support, research indicates disparities in access. This thesis sought to examine access to early support for children with developmental disabilities and their families. In Chapter 2, a conceptual framework mapping the process of access to early support across three key phases (recognition of potential need, identification or diagnosis, and early support receipt) was proposed. A narrative review identified several factors that affect access to early support for each phase across multiple factor levels (family, service, intersection, and contextual). In Chapter 3, data from a UK survey of parental caregivers (N = 673) of children with developmental disabilities was presented, providing a comprehensive description of participants' access to early support (professionals, services, intervention programmes), in addition to perceived of ease of access to early support, unmet need for early support, and barriers and facilitators of access to early support. In Chapter 4, multiple regression analyses were conducted to identify predictors of access to (and perceived unmet need for) early support. Cumulatively, this research has led to substantial increased understanding of the complex multifactorial nature of access to early support for families of children with developmental disabilities. Key selected factors include family socioeconomic status, nature and severity of need, formal identification of need, service coordination and collaboration, and the nature of service delivery in relation to family factors. The contribution of this research is invaluable for identifying potential policy and practice investments and directions for future research to improve access to early support.

Chapter 1: An Introduction on Access to Early Support for Children with Developmental Disabilities and their Families

Brief Overview

Early support, commonly referred to as early intervention, is the provision of support to ensure optimal child development during early childhood (i.e., 0-6 years), including specific interventions and programmes to improve child and family outcomes, and contact with various support services across education, health, social care, and other service sectors in the early years (Akhmetzyanova, 2016; Dunst, 2007; Harbin et al., 2000; McWilliam, 2016). The provision of early support for families who have children with developmental disabilities (e.g., developmental delay, intellectual disability, autism) is especially important due to the presence of early developmental delay (American Psychiatric Association [APA], 2013; Salvador-Carulla et al., 2011; McDonald et al., 2006).

Access to early support is currently set as a global research priority for developmental disabilities (Tomlinson et al., 2014). Early support has also frequently been identified as a priority for research in consultations with various stakeholder groups, including people with developmental disabilities, parents, families, carers, professionals across various disciplines, and researchers (e.g., Autistica, 2016; Gotham et al., 2015; Finlay-Jones et al., 2020; Fletcher-Watson et al., 2017; Frazier et al., 2018; Lim et al., 2019; McIntyre et al., 2010; Morris et al., 2015; Ontario Brain Institute, 2018; Pellicano et al., 2014; Royal College of Speech and Language Therapists, 2019a, 2019b; Sinclair et al., 2019; Tomlinson et al., 2014). It is important to ensure children with developmental disabilities and their families are able to access support in the early years. The focus of this thesis is, therefore, on *access* to early support for children with developmental disabilities and their families.

Terminology and Language

Throughout this thesis, I use the term *early support* rather than *early intervention* in attempt to: (a) adequately reflect the broad range of supports that fit under this umbrella term (e.g., support from a range of professionals or services, receipt of specific support approaches, programmes, interventions, and/or early intervention curriculum); and (b) to highlight the emphasis is on *supporting* children with developmental disabilities and their families, rather than *intervening* to change, fix, or cure children with developmental disabilities, which has negative

connotations and perpetuates ableist ideologies (Bottema-Beutel et al., 2021). Similarly, I use the term *autism* rather than *autism spectrum disorder/condition* to avoid pathologizing autism. With regard to autism, I also use *identity-first* (i.e., "autistic person" or "on the autism spectrum") rather than *person-first* language (i.e., "person with autism" or "person with autism spectrum disorder/condition"), as literature indicates these person-first terms are the least preferred, and considered the most offensive, by autistic people (Botha et al., 2021; Bottema-Beutel et al., 2021).

In the absence of extensive research on language preferences both for developmental disabilities as a collective group and for developmental disabilities other than autism (e.g., developmental delay, intellectual disability), in the current thesis I use *person-first* (i.e., people-first) language to describe these. This is because existing literature suggests person-first is preferable for developmental disabilities, primarily intellectual disability, related to the disability rights movement (Branca, 2016; Crocker & Smith, 2019; Down Syndrome Ireland, 2021; Liebowitz, 2015; McDonald, 2012; Rea-Keywood & Brill, 2018). Furthermore, the use of person-first language for developmental disabilities is consistent with recently published research (e.g., Aishworiya & Kang, 2021; Bailey et al., 2021; Botha et al., 2021; Buckley et al., 2020; Eapen et al., 2021; Govender et al., 2021; Jeste et al., 2020; Mimmo et al., 2020; Neece et al., 2020; Smythe et al., 2021; Totsika et al., 2020; Tromans et al., 2020). For example, Botha et al. (2021) use person-first language to describe learning disabilities[2]. However, it is important to highlight that this language may not be preferred by everyone represented in this research, and there is a need to continually consider the use of language related to developmental disabilities, to ensure it is not stigmatising.

While *autism* is predominately used in the current thesis to refer to all autism diagnostic labels, equivalent to the use of *autism spectrum disorder* as an all-encompassing autism diagnosis in the Diagnostic and Statistical Manual of Mental Disorders fifth edition (DSM-5®; APA, 2013), I sometimes refer to previously used autism diagnostic labels (e.g., Asperger syndrome, pervasive developmental disorder not otherwise specified, rett syndrome, autistic traits) to describe studies completed

[2]The use of the term *learning disabilities* in Botha et al. (2021) is synonymous with *intellectual disabilities*, as this terminology is commonly used within services and research in the UK.

prior to the DSM-5® and in instances where diagnostic label is pertinent to the findings (see Chapter 2).

A Brief Introduction to Developmental Disabilities and Early Support

What are Developmental Disabilities?

Developmental disabilities is an umbrella term used to refer to a collection of neurodevelopmental conditions characterised by neurological and developmental differences, such as developmental delay, intellectual disability, autism, developmental coordination disorder, attention deficit hyperactivity disorder, Down syndrome, and foetal alcohol syndrome, to name but a few (APA, 2016; Dyck & Russell, 2020; Gallagher et al., 2020; Odom et al., 2009). Although developmental disabilities are diverse, they often share common characteristics, such as difficulties (or differences) related to general development, cognitive and adaptive skills, communication and language, social interaction, motor coordination, sensory perception and responsiveness, attention, behaviour, and sleep (Gillberg, 2010; Odom et al., 2009; Thapar et al., 2017; Watson et al., 2011). Below I will define the terms developmental delay, intellectual disability, and autism, as the focus of my thesis is primarily on these. In addition, I will describe related terms, such as special educational needs and disabilities (SEND), to contextualise these within the broader policy, practice, and research landscape.

Developmental delay refers to a significant delay (i.e., more than two standard deviations below the mean) in one or more developmental domains (Battaglia & Carey, 2003). A specific developmental delay is focused around one domain of development, whereas a global developmental delay affects at least two of five developmental domains: gross and fine motor, speech and language, cognition, personal and social development, and/or activities of daily living (McDonald et al., 2006). As a term, developmental delay is often used to describe children whose difficulties are apparent early in childhood where a cause is not yet established, and when standardised assessment is not possible (Walters, 2010).

Intellectual disability, also referred to as intellectual developmental disorders by the World Health Organization (WHO), is defined as ‘a group of developmental conditions characterised by significant impairment of cognitive functions, which are associated with limitations of learning, adaptive behaviour and skills’ (Salvador-Carulla et al., 2011, p.177). In the United Kingdom (UK), the term learning disability is commonly used to refer to intellectual disability within services,

policies, and some research (Cluley, 2018). In the United States of America (USA), the term learning disabilities is not interchangeable with the term intellectual disabilities, instead it is used to refer to specific learning disorders (e.g., dyslexia, dysgraphia, dyscalculia; APA, 2013, 2021), which are commonly referred to as learning difficulties (or specific learning difficulties) in the UK.

Autism is a neurodevelopmental condition characterised by persistent "deficits" (or differences) in social communication and social interaction, and "restricted" patterns of repetitive behaviours, interests, or activities (APA, 2013). As a diagnostic term in the DSM fifth edition® and the International Classification of Diseases eleventh revision (ICD-11), "autism spectrum disorder" encompasses all forms of autism, including previously used autism diagnostic labels, such as Asperger syndrome and pervasive developmental disorders (APA, 2013; WHO, 2018).

In the UK, special educational needs (SEN), SEND, additional learning needs (ALN), additional support needs (ASN), and other terms are sometimes used to describe developmental disabilities within educational services and policies (e.g., ALN and Education Tribunal (Wales) Act, 2018; ALN Code for Wales, 2021; Children and Families Act, 2014; National Audit Office, 2019; Education (Additional Support for Learning) (Scotland) Act, 2004; Scottish Government, 2017; SEND Act (Northern Ireland), 2016; SEND Code of Practice, 2014), though, as terms, they refer to a broader group of children. In addition to developmental disabilities, these terms (SEN, SEND, ASN, ALN) can also refer to children who have difficulty learning for different reasons, such as 'disadvantages in physical, behavioural, intellectual, emotional and social capacities' (UNESCO Institute for Statistics, 2012, p.83).

Prevalence of Developmental Disabilities. In 2016, it was estimated that, globally, there were 52.9 million children with developmental disabilities aged under 5 years (Olusanya et al., 2018). Recent estimates in the USA indicate the prevalence of developmental disabilities is 17.8% of children aged 3-17 years (Zablotsky, 2019). Rates for specific developmental disabilities vary, both across and within specific developmental disabilities. The international prevalence of intellectual disability is estimated to be 10.37/1,000 of the general population (around 1% worldwide), with higher rates of 18.3/1,000 among child and adolescent populations (Maulik et al., 2011). Intellectual disability prevalence rates are higher in low- and middle-income

countries, with rates almost double the rates in high-income countries (Maulik et al., 2011). In 2017, Olusanya et al. (2020) estimated the global prevalence of intellectual disability to be 3.2% of children aged <20 years. Global cases of intellectual disability were reported to be 3318/100,000 of children aged 1-4 years, accounting for over 18 million children aged 1-4 years worldwide (Olusanya et al., 2020). Recent census data from Scotland found 1.6% of children and young people aged 0-24 years were autistic and 0.6% had an intellectual disability (Kinnear et al. 2019). Within this sample there was co-occurrence of intellectual disability and autism, 15.0% of autistic children and young people additionally had an intellectual disability, and 40.0% of the children and young people with an intellectual disability were also autistic. This is consistent with other research indicating overlap between developmental disabilities (Bitsko et al., 2009, Boulet et al., 2009; Levy et al., 2010; Pauc, 2005).

Shifts in Understanding of Developmental Disabilities and Neurodevelopment. Increasingly, neurodevelopmental conditions (including developmental disabilities) are being understood as 'an inherent and valuable part of the range of human variation, rather than a pathological form of difference' (Dyck & Russell, 2020, p.170), challenging traditional medical-model frameworks that have pathologized neurodevelopmental conditions and viewed them as deficits, disorders, or diseases in relation to a 'normal/abnormal binary' (Bottema-Beutel et al., 2021, p.21). This is related to the social model of disability, which posits that individuals are disabled due to the inaccessible set up of society (see Anastasiou & Kauffman, 2013). For example, Oliver (1996, p.32) states 'it is not individual limitations, of whatever kind, which are the cause of the problem but society's failure to provide appropriate services and adequately'. It is clear people with developmental disabilities experience several challenges and inequalities, which may be reduced or removed by ensuring adequate access to support from an early age, consistent with the social model of disability.

These shifts in our understanding of neurodevelopment are welcomed, especially by neurodivergent advocates (e.g., den Houting, 2019), as it is imperative we as a society value human diversity and challenge deficit-based models of developmental disabilities (Robertson, 2009). However, it can pose challenges for (or appear at odds with) existing services, systems, and policies that are based on medical-model frameworks. For example, several support services require formal

identification of need in order to provide support to children and their families, yet formal identification of developmental disabilities is often based on evidence of "difficulties", "deficits", or "impairments" (e.g., APA, 2013; Crane et al., 2016; WHO, 2018, 2021).

Why is Early Support Important for Developmental Disabilities?

Before defining early support, I will outline why early support is important for children with developmental disabilities and their families. Firstly, as developmental disabilities typically emerge during early childhood and last throughout an individual's lifetime (APA, 2000, 2013; Patel & Merrick, 2011; WHO, 2018, 2021), it is important to consider the provision of early support to enable children and families to benefit from support at the earliest possible stage regarding any needs that arise (either as a result of developmental disabilities or living in a world that is not always appropriate or inclusive for people with developmental disabilities and their families).

Early Inequalities. In addition to neurological and developmental differences which are present by definition, children with developmental disabilities and their families often also experience a range of physical health, mental health, and social inequalities. These inequalities can emerge in the early years and persist into adulthood. For instance, there is an increased risk of co-occurring health conditions in children with developmental disabilities (e.g., epilepsy, obesity, osteoporosis, congenital heart defects, thyroid disorders, asthma, diabetes, allergies; Gurney et al., 2006; Kinnear et al. 2019; Liao et al., 2021; Oeseburg et al., 2011; Reddihough et al., 2021; Schieve et al., 2012), and this increased risk persists into adolescence and adulthood (Bishop-Fitzpatrick & Rubenstein, 2019; Havercamp & Scott, 2015; Hirvikoski et al., 2016; Kinnear et al. 2019; Liao et al., 2021; Oeseburg et al., 2010; Rydzewska et al., 2018). Despite this, research has identified disparities in both access to and quality of healthcare for children with developmental disabilities, in addition to unmet healthcare needs (Bitsko et al., 2009; Cheak-Zamora & Thullen, 2017; Kogan et al., 2008; Reddihough et al., 2021; Schieve et al., 2012).

Children and adults with developmental disabilities are also at increased risk of co-occurring mental health conditions (e.g., anxiety, depression, obsessive compulsive disorder, psychosis; Bakken et al., 2010; Bishop-Fitzpatrick & Rubenstein, 2019; Buckley et al., 2020; Emerson, 2003; Einfeld & Tonge, 1996; Eyre et al., 2019; Gurney et al., 2006; Kinnear et al. 2019; Merrell & Holland, 1997;

Rzepecka et al., 2011; Strømme & Diseth, 2000). Despite the high prevalence of mental health conditions in children and adolescents with intellectual disabilities, low rates of access to specialist mental health services are reported for this group (Munir, 2016; Toms et al., 2015). Children with developmental disabilities are also at increased risk of exposure to traumatic experiences, such as abuse and maltreatment (Berg et al., 2016; Jones et al., 2012; McDonnell et al., 2019).

Children with developmental disabilities are more likely to display behaviour that challenges, such as self-injury, aggression, running away, property damage, "inappropriate" behaviour in public, and persistent non-compliance (Bailey et al., 2019; Baker et al., 2002, 2003; Eisenhower et al., 2005; Emerson, 2003; Emerson & Brigham, 2014; Gore et al., 2014; Gray et al., 2012; Gurney et al., 2006; Nicholls et al., 2020; O'Nions et al., 2018; Rzepecka et al., 2011; Totsika et al., 2011; Tonge & Einfeld, 2000). The presence of behaviour that challenges increases the likelihood of individuals with developmental disabilities being subjected to restrictive practices (e.g., physical restraint, seclusion, medication; Allen et al., 2009; Bowring et al., 2017; Male, 2003). In Bowring et al. (2017), for example, the presence of behaviour that challenges was a significant predictor of psychotropic medication use in adults with an intellectual disability. The presence of behaviour that challenges in children with developmental disabilities is also associated with increased parental stress (Hastings, 2002).

Sleep problems, such as difficulty initiating or maintaining sleep, early morning waking, excessive sleepiness during the day, and parasomnias (i.e., events that interrupt sleep, e.g., teeth grinding, enuresis, nightmares, sleepwalking) are also prevalent in children with developmental disabilities (Agar et al., 2021; Bissell et al., 2021; Bonuck, & Grant, 2012; Didden & Sigafoos, 2001; Halstead et al., 2021; Rzepecka et al., 2011; Surtees et al., 2018, 2019). For example, in their meta-analysis, Surtees et al. (2018) found poorer sleep quality and reduced sleep duration amongst people with intellectual disabilities, compared to people without intellectual disabilities. In addition, they found no evidence of sleep differences reducing during adulthood. Sleep problems in children with developmental disabilities are also related to other inequalities, including pain and co-occurring health conditions (Breau & Camfield, 2011; Trickett et al., 2018; Ghanizadeh & Faghih, 2011), the presence of behaviour that challenges (Cohen et al., 2018), and parental stress (Richdale et al., 2000).

Parents of children with developmental disabilities can also experience several inequalities, such as increased stress, poorer wellbeing and quality of life, and increased risk of mental health problems (Baker et al., 2002, 2003, 2005; Eisenhower et al., 2005; Gupta, 2007; Herring et al., 2006; Singer, 2006; Vasilopoulou & Nisbet, 2016). For example, in their meta-analysis, Singer (2006) found elevated level of depression in mothers of children with developmental disabilities compared to mothers of children without developmental disabilities. Furthermore, family carers of children and adults with developmental disabilities report experiencing psychological trauma, often as a result of ineffective and support systems (e.g., Challenging Behaviour Foundation [CBF], 2020; Clements & Aiello, 2021).

The presence of early inequalities for children with developmental disabilities and their families means it is critical to consider the provision of early support, especially as early support can prevent or reduce these inequalities. For example, if prevented or adequately addressed upon emergence, behaviour that challenges can be prevented or reduced (Emerson & Brigham, 2014; Einfeld et al., 2013; Skotarczak & Lee, 2015).

Early Years Development. Another consideration for the provision of early support for children with developmental disabilities is the potentially critical nature of the early year period for maximising development (e.g., Inguaggiato et al., 2017). Regarding early support for children with developmental disabilities, Smythe et al. (2021, p.222) states ‘A focus on supporting children with [developmental] disabilities to thrive during their early years is important, as this period is critical for maximising their development’, emphasising how early support can help children with developmental disabilities to ‘achieve their full potential’. Research indicates the provision of early support can significantly alter the developmental trajectory of developmental disabilities (e.g., Fuller & Kaiser, 2020; Ho et al., 2021; Inguaggiato et al., 2017; Lai et al., 2014; Webb et al., 2014). Furthermore, developmental disabilities are increasingly being identified earlier (e.g., autism; Volkmar & Klin, 2005), thus increasing the opportunities for the provision of early support.

What is Early Support?

Definitions of Early Support. Broadly, early support (see page 1) is an umbrella term which constitutes a range of different supports to ensure optimal child development, such as services or interventions provided to families early in their

child's life (i.e., preventative or proactive), or early in response to the emergence of a need (i.e., reactive or responsive). Early support has been conceptualised differently in literature across various fields (e.g., Powell et al., 2021), perhaps reflecting the range of groups targeted and multiple supports available (i.e., various specific interventions and programmes, contact with various services across education, health, social care, and other support systems). As stated in Powell et al. (2021, p.5) 'The common thread between different definitions is their focus on the importance of early support for children and their families, to improve children's later life chances, health and wellbeing'.

Early support can be universal or targeted at groups with increased likelihood of needing support or developing problems, such as babies born with extremely low birth weight (e.g., Brooks-Gunn et al, 1994), children and families experiencing socioeconomic disadvantage (e.g., Casey et al., 2017; Gwynne et al., 2009), or people at risk for developing mental health conditions (e.g., Fusar-Poli et al., 2017). Early support can also be provided following the identification of a need, such as after the identification of developmental disabilities (e.g., Ip et al., 2019), carer's needs (e.g., Hibbs et al., 2015; Pickard et al., 2015), or mental health conditions (e.g., Fusar-Poli et al., 2017).

Sharp and Filmer-Sankey (2010, p.2) define early support as 'Intervening early and as soon as possible to tackle problems emerging for children, young people and their families or with a population most at risk of developing problems'. With a disability focus, Dunst (2007, p.162) define early support as 'the experiences and opportunities afforded infants and toddlers with disabilities by the children's parents and other primary caregivers that are intended to promote the children's acquisition and use of behavioural competencies to shape and influence their prosocial interactions with people and objects'.

Dunst's definition describes the outcomes of early support, but emphasises the key role of the child's caregivers, rather than support systems and services. The integration, collaboration, and coordination of services features in some definitions of early support. For example, the Early Intervention Foundation (EIF, 2018) states early support 'requires a multilevel, holistic approach' and Akhmetzyanova (2016, p.1) describes early support as 'a system of coordinated services designed to promote the development of children with impairments or at risk of emerging disabilities and support their parents'. Brito and Lindsay (2015, p.3) describe early support as 'the

intervention of professionals, aiming to enhance the development of children up to six years in a situation of established, biological or environmental risk'. Describing early support in the context of autism, Lipinska-Loks and Stein-Szala (2015, p.131) also highlight the multifaceted nature of early support, stating 'The assistance should cover all developmental spheres, and its impact should be administered everywhere where the child resides'. In addition, they emphasise the need for early support to be individualised according to the child's needs and characteristics, due to the heterogeneity (i.e., diverse nature) of autism.

Munro (2011, p.69) highlight that definitions of early support can be ambiguous 'referring both to help in the early years of a child or young person's life and early in the emergence of a problem at any stage in their lives'. With the exception of Dunst's definition, the majority of early support conceptualisations refer to early support as being delivered and led by services, purporting the view that professionals (or those responsible for administering early support) are the "experts". However, there is a shift towards the inclusion of caregivers as important partners to enhance outcomes in early identification and support, and utilising family-centred, rather than child- or professional-centred, approaches in early support (Brooks-Gunn et al., 2000; García-Grau et al., 2019; Russell, 2008; WHO & Unicef, 2012).

A recent definition of early support by Powell et al. (2021, p.4) highlights the broad public policy approach of early support across the UK: '[early support] is a public policy approach to identify and support children and their families at an early stage, to prevent problems developing later in life, such as poor physical and mental health, low educational attainment, crime and anti-social behaviour'. The EIF (2018, p.5) notes that policies in this area can take many different forms: 'from home visiting to support vulnerable parents, to activities to support children's early language development, to school-based programmes to improve children's social and emotional skills, to family therapy to improve children's behavioural development'.

Conceptualisation of Early Support for the Present Thesis. In the present thesis, I conceptualise early support as all formal support accessed by families of children with developmental disabilities in relation to the child's developmental disability, including support that is preventative and following the emergence of a child or family need. This incorporates support provided in the early years, and in the early stages of a need (or "problem") as proposed by Munro (2011), but I focus on support during early childhood (i.e., 0-6 years) rather than at any age (cf. Brito &

Lindsay, 2015; Powell et al., 2021). Preventative support may be universal (e.g., developmental screening for all children) or targeted (e.g., developmental screening for children with an increased likelihood of developmental disabilities). Reactive support refers to services provided following the identification of a need, such as diagnosis of a developmental disability or identification of another child or family need (e.g., child communication need, child sleep problem, parental need for information, parental mental health).

As a result of the variety of areas with which children and families may need support, families can come into contact with a range of professionals and services as part of early support for developmental disabilities. This may include professionals and services across education, health, social care, voluntary, community, and other service sectors. In addition to general contact with professionals and support services, early support also encapsulates packaged intervention programmes targeting specific needs, such as parenting programmes to increase caregiver's understanding of developmental disabilities and parenting confidence, interventions to develop children's and caregiver's communication, and interventions to reduce self-injurious behaviour. Early support can be mainstream (i.e., universal service provision for the general population, e.g., general practice health service) or specialist (i.e., specialist service provision for people with a specific need, e.g., child and adolescent mental health services). The funding of services also varies, including public, private, and third-sector services.

Akhmetzyanova's (2016) definition of early support encompasses support for parents as well as children. In my conceptualisation, early support includes support for the family as a system, which can be provided to the child, parental caregivers, siblings, other family members, or a combination of these. It is widely accepted that child development does not occur in isolation; rather it is influenced by various systems in the child's environment and interactions within and between systems (e.g., ecological systems theory, family systems theory, developmental systems model; Bronfenbrenner, 1979; Dunst, & Trivette, 2009; Guralnick, 2001). For example, Bronfenbrenner's ecological systems theory hypothesised that, in addition to the child's individual characteristics, child development is influenced by five environmental systems: micro, meso, exo, macro and chrono systems (Bronfenbrenner, 1979; Rosa & Tudge, 2013). Micro-systems are the child's direct environment for interaction (e.g., with family, friends, professionals supporting

them), meso-systems are interactions between two micro-systems (e.g., interactions between parents and professionals), exo-systems are indirect environments that influence child development (e.g., a parent's workplace, local government), macro-systems are attitudes and beliefs within the culture and society, and chrono-systems are interactions between the various systems and their influence on each other over time (Rosa & Tudge, 2013). Therefore, the provision of early support solely to the child may not be as effective (or sustainable) at improving child development. Furthermore, the provision of early support for the family as a system has been shown to facilitate a range of outcomes, including child development, parental wellbeing, parental self-efficacy, and parent-child interactions (Trivette et al., 2010).

Why Focus on Access to Early Support?

It is clearly important to ensure *all* people with developmental disabilities are able to access support throughout their lifetime across different stages, including the early years. In the present thesis, I chose to focus on access to support in the early years (0-6 years) for several reasons. Firstly, if we are able to identify disparities of access to support in the early years, there is potential to address these issues at the earliest point of families' contact with support systems. It is possible this could ameliorate psychological trauma experienced by families due to negative experiences with service systems in attempt to obtain support (e.g., CBF, 2020; Wigham & Emerson, 2015). In addition, there is a considerable diverse body of evidence indicating a range of improved child and family outcomes following support provided within the early years (e.g., Bernstock et al., 2019; Emerson & Brigham, 2014; Einfeld et al., 2013; Essex County Council & OPM Group, 2017; Fuller & Kaiser, 2020; Ho et al., 2021; Inguaggiato et al., 2017; Lai et al., 2014; National Children's Bureau et al., 2021; Powell & Gheera, 2021; Skotarczak & Lee, 2015; Webb et al., 2014). Furthermore, there is evidence in support of the assumption 'the earlier the better', whereby the provision of support earlier within a child's development (i.e., during the early childhood developmental period) is more effective at improving outcomes (Fenske et al., 1985; Fuller & Kaiser, 2020; Heckman, 2015; National Children's Bureau et al., 2021; Powell & Gheera, 2021; Schweinhart, 2018; Smith et al., 2015; van IJzendoorn et al., 2021). This suggests receiving support at a younger age can significantly improve outcomes for children with developmental disabilities and their families, thus highlighting the importance of conducting research examining access to support in the early years.

The decision to focus on the early years was also partly due to methodological considerations, in order to narrow the scope of an already broad research topic (i.e., access to support across developmental disabilities). While some conceptualisations of early support focus on a more limited age range (i.e., 0-2 years, see Powell & Gheera, 2021), I decided to focus on children aged 0-6 years to include children whose developmental disability was recognised following contact with statutory educational services (see What is Early Support). Despite the decision to focus on the early years for this research, as access to a broad range of supports (e.g., general contact with services across support systems, in addition to specific interventions and programmes to improve child and family outcomes) is explored in my research, it is likely the findings will be applicable to access to support for people with developmental disabilities in other age groups (e.g., access to healthcare for autistic adults, see Doherty et al., 2022; Weir et al., 2022). Furthermore, there are many people with developmental disabilities who receive a diagnosis in later childhood, adolescence, or adulthood (e.g., Huang et al., 2020), for which the findings may also be applicable to.

The Current Context

Research on Early Support for Developmental Disabilities

Overall, research shows early support is effective for improving outcomes for children without developmental disabilities and their families (e.g., Englund et al., 2014). Therefore, it is reasonable to expect early support may be effective for children with developmental disabilities and their families.

Child and Family Outcomes. Research suggests early identification of developmental disabilities and the provision of support at the earliest possible age can improve several outcomes, including improved child development and adaptive skills (e.g., Dyches et al., 2012; Fuller & Kaiser, 2020; Fuller et al., 2020; Grindle et al., 2009, 2012, 2013, 2021; Ho et al., 2021; Lai et al., 2014; Majnemer, 1998; McManus et al., 2019; Ryberg, 2015; Smith et al., 2015), reduced child behaviour and sleep problems (e.g., Einfeld et al., 2013; Leung et al., 2013; Roberts et al., 2003; Singer et al., 2007; Skotarczak & Lee, 2015; Wiggs & Stores, 2001), and improved parental mental health, wellbeing, and parenting self-efficacy (e.g., Bristol et al., 1993; Grindle et al., 2009; Herman, & Marcenko, 1997; Leung et al., 2013; Sofronoff & Farbotko, 2002). As a result, early support has the potential to increase quality of life for families and their children with developmental disabilities, through

both improving outcomes and preventing or reducing problems from developing (e.g., parental stress, child behaviour that challenges).

The timeliness of access to support may also be critical. Research indicates receiving support at a younger age improves outcomes for children with developmental disabilities (Fenske et al., 1985; Fuller & Kaiser, 2020; Smith et al., 2015). For example, in a recently published meta-analysis examining the effect of early support programmes on social communication outcomes for young autistic children (aged <8 years), Fuller and Kaiser (2020) found significantly greater improvements on social communication measures for children who received early support compared to children in control groups. The age of participants (both mean and quadratic age, i.e., age squared) was also significantly related to treatment effect size for social communication outcomes. While older mean child age was associated with larger outcomes, the relationship between quadratic age and outcomes was in the opposite direction, indicating the benefit of age diminished as the children approached 8 years, with optimal outcomes occurring at age 3.8 years (Fuller & Kaiser, 2020). Similarly, another meta-analysis examining the effects of an early support programme for autistic children, namely the Early Start Denver Model (ESDM), Fuller et al. (2020) found statistically significant improvements (of moderate effect size) for both cognition and language were amongst autistic children aged <5 years who received EDSM.

Societal Economic Impact. In addition to improving child and family outcomes, timely provision of early support has potential economic benefits by reducing the economic cost of providing services later in life (e.g., Chasson et al., 2007; Einfeld et al., 2010; Motiwala et al., 2006; Peters-Scheffer et al., 2012; Piccininni et al., 2017). Significantly higher costs are associated with supporting adults compared to children with developmental disabilities, therefore, early support may have economic benefits, however, further research is needed to ascertain the potential cost savings of early support for developmental disabilities (Knapp et al., 2009; Romeo & Molosankwe, 2010). Increased costs for supporting adults with developmental disabilities may be due to systematic failures of society to accommodate and support people with developmental disabilities (Bottema-Beutel et al., 2021), therefore the provision of appropriate, inclusive early support may, in part, result in decreased costs for support in adulthood. Despite this, economic impact and cost-effectiveness should not *solely* drive decisions regarding support

provision, as this risks not valuing people as individuals, and as it is inequitable to determine worth based on the cost of needed support for people living in a society that is not set-up to be inclusive and accessible for them.

Critique of the Evidence Base for Early Support. While there is a significant amount of research indicating early support can improve a range of child and family outcomes (as described above), there are some limitations with the present evidence base on early support. One key challenge for this evidence base is the lack of a universal definition of early support, in terms of research, policy, and practice (National Children's Bureau et al., 2021). Furthermore, early support is not straightforward to evaluate, due to the broad scope of early support included and the substantial range of factors involved in child and family outcomes (see National Children's Bureau et al., 2021). Due to this complexity, single and meta-analytic studies are often focused on a specific early support provision (e.g., targeted intervention programme, contact with a specific service), subsequently examining a set of outcomes logically connected to the provision being assessed, rather than a broader approach across provisions and outcomes. In addition, studies are often focused on 'short-term, individualised and manualised forms of support with clearly defined and measurable outcomes' which 'greatly outnumber studies that engage with long-term, community-led, and flexible forms of support with large numbers of envisaged outcomes' (National Children's Bureau et al., 2021, p.8). While there is promising evidence that early support improves outcomes for children and families, stronger evidence is needed, particularly longitudinal studies evaluating long-term outcomes and studies across different early support provisions, such as studies to identify the most effective types of early support.

Policy and Practice Landscape

International. Internationally, the provision of early support for children with developmental disabilities is a key area of interest for policy, and early support is advocated for in multiple policy, practice, and guidance documents worldwide (e.g., Division for Early Childhood [DEC], 2014; Collins et al., 2017; Individuals with Disabilities Education Act [IDEA], 2004; National Disability Insurance Scheme [NDIS] Act, 2013; National Institute for Health and Care Excellence [NICE], 2018; United Nations [UN] Convention on the Rights of the Child, 1989; UN Sustainable Development Goals, 2015; WHO & Unicef, 2012; WHO Regional Office for Europe, 2014; WHO & World Bank, 2011). For example, the UN Convention on the

Rights of the Child sets out the rights *all children everywhere* are entitled to in 54 linked articles, and states how governments must work together to ensure these rights are upheld (UN, 1989). Within this, the right to early support is highlighted for all children, including those with developmental disabilities, especially in articles 6 (life, survival and development), 18 (parental responsibilities and state assistance), 23 (children with a disability), 24 (health and health services), 26 (social security), and 28 (right to education; see Unicef UK, n.d.).

Early support is also highlighted in the UN Sustainable Development Goals (UN, 2015), particularly in goals 1 (end poverty, e.g., 1.2), 2 (end hunger, e.g., 2.2.), 3 (healthy lives and wellbeing, e.g., 3.2, 3.8), and 4 (inclusive and equitable quality education, e.g., 4.5). Below I will provide an overview of the policy and practice landscape relevant to early support for developmental disabilities within the UK, due to this being the context primary data was collected for as part of this thesis (see Chapters 3 and 4). Furthermore, as several studies included in my literature review (see Chapter 2) were conducted in the USA, I will also provide a brief overview of relevant policy and practice in the USA.

United Kingdom. In the UK, early support is acknowledged and promoted in several governmental policies, commissioned reviews, and guidance documents spanning across health, education, and social care (e.g., Allen, 2011; Children and Families Act, 2014; Children and Families Act 2014 Commencement (Wales) Order, 2015; Department for Education [DfE], 2011, 2012, 2013, 2021; DfE & Department of Health and Social Care [DHSC], 2014; Department of Health [DH], 2010, 2013; DH Northern Ireland, 2009; DHSC, 2009, 2013, 2015, 2018, 2021; EIF, 2018; Field, 2010; Education (Additional Support for Learning) (Scotland) Act, 2004; Equality Act, 2014; Health and Social Care Committee, 2019; Munro, 2011; Office for Disability Issues & Department for Work and Pensions, 2013; Public Health England, 2016a, 2016b; Science and Technology Committee, 2018, 2019; Scottish Government, 2015, 2019; SEND Act, 2001; Tickell, 2011; Welsh Government, 2016).

The Marmot Review ‘Fair Society, Healthy Lives’ (DH, 2010) was a key policy development for early support within the past decade, focused on addressing the social determinants of health inequalities across England. This was followed by a broader review of early support by Allen (2011), which proposed a pathway to achieve a long-term culture of early support in the UK. Subsequent educational

policies followed, outlining the provision of early support for all young children from birth to five years of age (DfE, 2012) and those with SEND (DfE, 2012). The latter set out a vision of a 'new system' for SEN provision in the UK, emphasising earlier identification of children's needs, and the routine, rapid provision of early support. Understandably, this included ensuring 'staff have the knowledge, understanding and skills' to be able to provide the 'right support' for children with SEN (DfE, 2012, p.4). It also included the integration of SEN support into a single education, health, and care plan (EHCP), envisaged to make the process of accessing support from various service systems easier for families, and giving parents greater control over the services their family use (e.g., personal budgets).

This was followed by the Children and Families Act (2014), a key piece of legislation influencing support provision for children and young people, including those with SEND (e.g., part 3). The Act set out to transform the system of provision for SEN as described in DfE (2012), including coordinated assessment and support plans, improved integration of health, education, and social care services, and greater choice and control for families over their support. The SEND Code of Practice (2014) further describes the requirements of local government authorities regarding SEN provision. A number of subsequent policies and practice guidance documents relating to the needs of children with SEND have been published across the four nations of the UK (e.g., Children and Families Act 2014 Commencement (Wales) Order, 2015; ALN and Education Tribunal (Wales) Act, 2018; ALN Code for Wales, 2021; Scottish Government, 2017; SEND Act (Northern Ireland), 2016).

One crucial element of the SEND reforms related to early support was the timely assessment of SEN and coordinated support plans (referred to as an EHCP, an individual development plan, a coordinated support plan, or a statement of SEN, dependent on the terminology used in the UK nation). These plans are legally enforceable, documenting the child's entitlements to specific packages of support across education, health, and social care. The plan is a formal recognition of the child's SEN, but specifically for the purposes of educational service provision. Another key aspect was the requirement for all local authorities to publish a local offer, detailing the range of services that are available in their area for children and young people with SEND, including those with and without a plan. In addition to a range of service systems involved in early support for children with SEN, there is

also a range governing bodies and stakeholders involved in the process (e.g., see National Audit Office, 2019, p.21).

The health system also plays a key role in early support in the UK, mainly through universally free services provided by the National Health Service (NHS). Perhaps most notable are child health programmes (e.g., DH Northern Ireland, 2009; DHSC, 2009; NHS Education for Scotland, 2018; Scottish Government, 2015, 2019; Welsh Government, 2016). For example, the healthy child programme (DHSC, 2009) in England set out universal provision for all families (e.g., health and development reviews, screening, promotion of health and wellbeing) and additional provision for children and families "at-risk" (e.g., additional support and monitoring for infants with health or developmental "problems", parenting support programmes, high intensity-based intervention, referral for specialist input).

Health visitors are key professionals involved in child health programmes across the UK, generally responsible for supporting children aged 0-5 years and their families (Royal College of Nursing, 2020). Health visitors work with families to identify needs as early as possible, prevent health problems, and improve health and wellbeing. Health visiting is particularly relevant to early support for developmental disabilities, as it includes developmental surveillance and screening, providing routine opportunities for the recognition of potential developmental disabilities among other child and family needs.

In addition to policy, service and professional guidelines are also pertinent for early support in the UK. These can be from broad agencies, such as NICE, or specific professional organisations governing practice (e.g., Royal College of Nursing, Royal College of Speech and Language Therapists, Royal College of Psychiatrists, British Psychological Society). NICE provide guidance regarding the provision of support services in the UK. NICE guidance is comprised of 'Evidence-based recommendations developed by independent committees, including professionals and lay members, and consulted on by stakeholders' (NICE, 2021). NICE guidance relevant to early support for children with developmental disabilities and their families include, for example, developmental follow-up of children born preterm (NICE, 2017), autism diagnosis (NICE, 2011), autism support (NICE, 2013) intellectual disabilities and challenging behaviour (NICE, 2015, 2018), and mental health problems in people with intellectual disabilities (NICE, 2016).

United States of America. Several policy and practice guidance documents highlight the importance of early support in the USA (e.g., Houtrow et al., 2019; Hyman et al. 2020; IDEA, 2004; Lipkin et al., 2020; Moeschler et al., 2014). One key policy related to early support for developmental disabilities is the 'Individuals with Disabilities Education Act' (IDEA, 2004). Subchapter 3 (referred to as Part C) of IDEA relates to supporting 'infants and toddlers with disabilities', namely children from birth to 2 years of age with (or at increased likelihood of) developmental delays and disabilities (US Department of Education, 2016). Within Part C, states are granted funds to implement state-wide 'systems of coordinated, comprehensive, multidisciplinary, interagency programs [programmes]' and ensuring early support services are available to all eligible children and their families (US Department of Education, 2016). Subchapter 2 (referred to as Part B) of IDEA relates to special education and related services for children aged 3-21 years with disabilities. Similar to statutory plans in the UK, in the USA an individual family service plan (IFSP) documents support provided under Part C of IDEA, and an individualised education plan (IEP) documents support provided under Part B of IDEA.

The set-up of services in the USA is different to the UK, one major difference is that the USA does not have a universally free health system. Despite this, there are publicly funded early support services for children aged 0-3 years across the USA, which provide services for free or at reduced cost for eligible children (Centers for Disease Control and Prevention [CDC], 2019). Furthermore, disability evaluation (i.e., assessment) and early support services are often provided under Part B and C of IDEA.

In the USA, developmental surveillance and screening is generally carried out by paediatricians at well child visits, based on recommendations from the American Academy of Pediatrics (AAP; e.g., Committee on Practice and Ambulatory Medicine & Bright Futures Steering Committee, 2007; Bright Futures Steering Committee & Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2006). The AAP recommends universal screening and developmental surveillance for all children, including screening for developmental delays and autism (Lipkin et al., 2020). Similar to NICE in the UK, the AAP also publishes policy and guidance related to early support for developmental disabilities, including evaluation of developmental delay or intellectual disability (Moeschler et

al., 2014), autism diagnosis and support (Hyman et al. 2020), and therapy services for children with disabilities (Houtrow et al., 2019).

Research on Access to Early Support for Developmental Disabilities

Despite the strong case for the provision of early support for children with developmental disabilities and their families, international research indicates the level of access to early support does not always match the level of need for children with developmental disabilities and their families (e.g., Betz et al., 2004; Crane et al., 2016; Gobrial, 2012; Grant & Isakson, 2013; McManus et al., 2014a, 2014b; Roberts et al., 2008; Rosenberg et al., 2008; Stevens, 2006; see Chapter 2 for further details). The issue of inequitable access to early support, including unmet need for early support, will be discussed in subsequent chapters, as the overall aim of my thesis is to examine access to early support for children with developmental disabilities and their families. This includes examining levels of access to early support, identifying factors that influence access to early support, and considering ways to improve access to early support.

My Personal Interest in Early Support and Developmental Disabilities

Before providing an overview of the subsequent chapters in my thesis, I will reflect on my personal interest and motivation to conduct research on access to early support for children with developmental disabilities and their families. Reflecting on my personal interest to conduct this research is an important aspect of my PhD, due to the inevitable influence of personal interests, experiences, and values on research.

My primary motivation for researching early support arose from my experience working at a specialist inpatient mental health hospital for children and young people with developmental disabilities and co-occurring mental health conditions. In this environment, there was a significant lack of understanding of the needs of people with developmental disabilities, resulting in a lack of appropriate support and considerable use of restrictive practices (e.g., restraint, seclusion, segregation, medication), which even feature within clinical guidance (e.g., NICE, 2015). Many children in these institutions are also miles away from home and their families (e.g., Allen, 2008; Emerson & Robertson, 2008; Mencap, 2020). While I am committed to supporting children and young people in the best way possible, within such an overtly restrictive setting, providing person-centred, values-based support appeared impossible. It was restrictive both in terms of the physical set-up and organisational structures. For example, it was located in an extremely rural area,

surrounded by fields, miles away from the closest villages and transportation links. The outer buildings are gated, and the inner buildings, used as wards, are guarded by tall metal fences. Staff all receive mandatory training in physical restraint techniques as part of general induction, yet almost nothing in relation to understanding and meeting the needs of children with developmental disabilities and co-occurring mental health conditions. Frequent staff shortages and high staff turnover due to the stressful environment contributed to the restrictive environment, as the priority was keeping the children safe, rather than providing individualised therapeutic support for their mental health conditions.

My subsequent experiences and learning about developmental disabilities have furthered my anger towards this type of institution, and my sense of injustice for the children that are locked away in these places. To me, it seems as if children and their families are punished simply for being different, for living in a society that does not value diversity, and for not being granted access to support to let them live their life. After I stopped working at the hospital, I worked in a range of services and learnt about supporting people with developmental disabilities, including using evidence-based support approaches for people with developmental disabilities, such as augmentative and alternative communication strategies. This enabled me to see first-hand the outcomes of evidence-based supports for people with developmental disabilities. I also learnt about the trauma children and families face in their attempts to access appropriate support (e.g., CBF, 2020; Wigham & Emerson, 2015). Early support in the community and proactive service systems is often recognised as being vital for preventing admissions to inpatient hospitals for children and young people with developmental disabilities (e.g., CBF, 2021; NHS, 2019; Reid et al., 2013; Sholl et al., 2014). Therefore, it seemed logical to expand current knowledge on access to early support, as a starting point to improve current systems and support for children with developmental disabilities and their families.

I also have personal reasons for my interest in early support for developmental disabilities; I have two younger autistic siblings, who received their diagnoses at age 9 and 12, one older sibling diagnosed with attention deficit hyperactivity disorder at age 26, and I was recently diagnosed with autism at age 26 (during my PhD research). While the earlier diagnosis for my younger siblings meant they have been able to access *some* support during childhood, accessing support from a younger age might have prevented some of the challenges they have

experienced (e.g., anxiety, self-harm, school refusal). Similarly, early support may have prevented myself and my older sibling from experiencing several challenges throughout our childhood and later in life (e.g., depression, anxiety, self-harm, suicidal behaviour, substance abuse, domestic abuse).

The difference in timing of diagnoses may reflect ongoing improvements in recognising and identifying developmental disabilities (e.g., NICE, 2018, 2019; Palmer et al., 2011). It may also reflect different family environments or early childhood experiences. Myself and my older sibling grew up in poverty, primarily in a single-parent family, and were exposed to ongoing regular domestic abuse from one of our parents, who is not related to (and has no contact with) our younger siblings. Our younger siblings grew up with economic stability, in a supportive two-parent family, which may have enabled earlier diagnosis, and access to support at an earlier age. Irrespective of my personal interest in this topic, I am dedicated to generating understanding about access to early support for children with developmental disabilities through my PhD research, to add to the existing research literature.

Overview of Subsequent Chapters

In Chapter 2, I propose a conceptual framework to map the process of access to early support and use this framework to synthesise factors that might influence the process of access to early support for children with developmental disabilities and their families, based on a narrative review of international research evidence.

In Chapter 3, I present data on access to early support for children with developmental disabilities and their families in the UK, based on a survey of parental caregivers (N = 673) of children aged 0-6 years with suspected or diagnosed developmental disabilities, conducted between September 2018 and May 2019. Within this chapter, I provide a comprehensive description of participants' access to various early support provisions (e.g., professionals, services, intervention programmes) and investigate perceived ease of access to early support, unmet need for early support, and barriers and facilitators of access to early support.

In Chapter 4, I examine predictors of access to early support and unmet need for early support for children with developmental disabilities and their families in the UK. Using data collected from the aforementioned survey of parental caregivers of children with suspected or diagnosed developmental disabilities, multiple regression

models were fitted for access to early support and perceived unmet need for early support.

Lastly, in Chapter 5, I consider ways to improve access to early support for children with developmental disabilities and their families based on the additional knowledge and understanding gained from this research.

Chapter 2 (Study 1): Narrative Review of Factors Influencing Access to Early Support for Children with Developmental Disabilities and their Families[3]

Abstract

Early support can improve a range of outcomes for families of children with developmental disabilities. However, research indicates the level of access to early support does not always match the level of need. To address disparities, it is essential to identify factors influencing access to early support. In this chapter, I propose a framework where access to early support is conceptualised as a process that includes three main phases. A narrative review examined potential barriers, facilitators, and modifiers of access for each phase. The process of access to early support includes: (1) recognition of need, (2) identification or diagnosis, and (3) early support receipt or provision. Several factors affecting access to early support for each phase were identified across multiple levels, including family factors, service factors, the intersection between family and service factors, and contextual factors. A broad range of factors appear to influence the process of access to early support for this population. My framework can be used in future research investigating access to early support. Broad implications for policy, practice, and future research to improve access to early support are discussed.

[3]A shorter version of this chapter has been published in the *Journal of Applied Research in Intellectual Disabilities* as follows: Sapiets, S. J., Totsika, V. & Hastings, R. P. (2021). Factors influencing access to early intervention for families of children with developmental disabilities: A narrative review, *Journal of Applied Research in Intellectual Disabilities, 34*(3), 695-711. https://doi.org/10.1111/jar.12852. The terminology and language used in this chapter varies from the published paper, as discussed in Chapter 1 (see p.1-2).

Introduction

Despite the strong case for early support (see Chapter 1), international research indicates the level of access to early support does not always match the level of need for children with developmental disabilities and their families (e.g., Betz et al., 2004; Bowker et al., 2011; Crane et al., 2016; Gobrial, 2012; Grant & Isakson, 2013; McManus et al., 2014a, 2014b; Roberts et al., 2008; Rosenberg et al., 2008; Ruble et al., 2005; Stevens, 2006). For example, in Ruble et al. (2005), the use of Medicaid services for autistic children in the United States of America (USA) was only 10% of the numbers expected from autism prevalence rates. Furthermore, in a study of 1,047 parents in the United Kingdom (UK), during or following the autism diagnostic process, only 21% were directly offered support, 38% were signposted to advice or help, and 35% were not offered any help or assistance at all (Crane et al., 2016). It is therefore not surprising that many parents express dissatisfaction with support accessed post-diagnosis (Crane et al., 2016; Howlin & Moore, 1997; Siklos & Kerns, 2007).

The timeliness of access to early support is also an issue, as earlier support can significantly alter the developmental trajectory of children with (or at increased likelihood of) developmental disabilities (see Webb et al., 2014). However, low rates of access to early support have been found for very young children (i.e., <3 years of age) with developmental disabilities (Grant & Isakson, 2013; McManus et al., 2014a, 2014b; Roberts et al., 2008; Rosenberg et al., 2008). For example, Rosenberg et al. (2008) found only 10% of children with developmental delays received early support at age two, despite being eligible under Part C of the Individuals with Disabilities Education Act (IDEA), a federal law that mandates early support services in the USA (IDEA, 2004). Notably, lower rates were found in Grant and Isakson (2013). Across the USA, only 2.7% of age-eligible children (birth through to 35 months of age) received early support under Part C of IDEA, with a range of 1.2-6.5% for specific states, suggesting there is a significant group of children who need but do not receive early support (Grant & Isakson, 2013). Similar findings were reported in a study on preterm children; children with more severe disabilities were more likely to receive early support, but almost 50% of children with moderate to severe disabilities (defined as moderate to severe intellectual impairment, moderate to severe cerebral palsy, blindness, or deafness) and 72% of children with mild

disabilities (defined as mild intellectual impairment or mild cerebral palsy) did not receive services at age two (Roberts et al., 2008). Furthermore, in a sample of 965 children under three years of age with a range of developmental disabilities, McManus et al. (2014a) found less than half (45.7%) accessed early support.

Delays in diagnosis receipt may also be long, especially for autism (Crane et al., 2016; Daley, 2004; Howlin & Moore, 1997; Siklos & Kerns, 2007; Wiggins et al., 2006), which may also delay access to early support. For example, delays of up to 3.8 years from first contact with a professional regarding a developmental concern and receipt of a formal diagnosis of autism, as reported by parental caregivers (Crane et al., 2016; Daley, 2004; Howlin & Moore, 1997; Siklos & Kerns, 2007; Wiggins et al., 2006). This is concerning, considering delays in the identification of developmental disabilities can delay access to early support and increase parental stress. There are also widespread concerns regarding the under-recognition (and subsequent reduced access to support) amongst autistic females (Hull et al., 2020; Mandy et al., 2012). Furthermore, delays in the identification of (and provision of support for) special educational needs (SEN) are implied by the rates of parental appeals, which inevitably slow the process of accessing support. For example, a review of SEN and disability disagreement resolution procedures in the UK found varied rates of appeals at different stages: 7% of parents appealed following an assessment refusal, 12% appealed the service's refusal to issue a formal statement of need following assessment, and 6% appealed the content of the plan (Cullen et al., 2017). The age range for SEN identification and support, however, extends the early years (i.e., <25 years).

Families may also experience difficulties in the identification of (and access to support for) other child and family needs. For example, compared to children without developmental disabilities, children with developmental disabilities have a greater risk of developing mental health problems and displaying behaviour that challenges (e.g., self-injury, aggression, destruction to property), however, limited access to support for these needs has been reported (Betz et al., 2004; Bromley et al., 2004; Davies & Oliver, 2016; Emerson, 2003; Emerson & Hatton, 2007a; Raghavan & Waseem, 2007). In Betz et al. (2004), while 88 of 102 parents of children with developmental disabilities reported having "unaddressed concerns" relating to their child's behaviour, of these only 12 children were referred to behaviour or

counselling services. The two most frequently identified barriers to child behavioural needs being addressed were a lack of available services and information (Betz et al., 2004). This is problematic, as the presence of behaviour that challenges can limit the family's ability to access a range of services. For example, children with developmental disabilities have been excluded from respite care services due to displaying behaviour that challenges (McGill et al., 2006). An overlap between mental health problems and behaviour that challenges, or limited understanding of the nature and presentation of mental health problems in children with developmental disabilities may account for issues in detection, diagnosis, and access to support for mental health problems for children with developmental disabilities (Raghavan & Waseem, 2007). Diagnostic overshadowing (i.e., the attribution of symptoms being part of the child's developmental disability rather than another need, such as a co-occurring physical or mental health condition) may also contribute to difficulties in the identification of other support needs (Reiss et al., 1982).

Furthermore, a lack of support to meet the needs of parents and siblings of children with developmental disabilities has also been reported (Bromley et al., 2004; Burke & Montgomery, 2000). For example, in Bromley et al.'s (2004) study of 68 mothers of autistic children in the UK, several unmet needs highlighted by participants were related to parental and other family support, such as 'To do things parent enjoys' (91%), 'Break from caring for child' (87%), 'Someone to talk to' (85%) and 'To enable parent to spend more time with other children' (63%). This is concerning, especially as Bromley et al. (2004) found low levels of family support were associated with increased significant parental psychological distress. Sibling support is a potentially overlooked area of early support, as the majority of early support provision is targeted at the child with a developmental disability and/or parental caregivers. Research suggests the impact of having a sibling with developmental disabilities is variable, reporting both positive and negative impacts to emotional, behavioural, and relationship adjustment (Bågenholm & Gillberg, 1991; Kaminsky & Dewey, 2001; Petalas et al., 2009; Taunt & Hastings, 2002). This highlights a potential need for supporting siblings within the provision of early support. Current research evidence on access to sibling support is limited, but the absence of support for siblings of children with developmental and other disabilities

has been reported by practitioners as part of the rationale to develop sibling support groups (e.g., Burke & Montgomery, 2000; Evans et al., 2001).

Inequities in access to early support have also been identified. For example, disproportionately low rates of access to developmental surveillance and diagnosis of developmental disabilities are found in families from ethnic minority groups in the USA and Australia (Mandell et al., 2009; Overs et al., 2017). Furthermore, in a study of 2,068 parents of children aged 4-35 months with low, medium, or high increased likelihood of developmental delay, Stevens (2006) found children with more risk factors for poor health (i.e., ethnic minority, poverty, lower maternal educational attainment, lack of child health insurance, and poorer maternal mental health) were less likely to access early support. Similarly, Roberts et al. (2008) found children in families with higher "social risk" were less likely to receive early support, after adjusting for disability type (moderate to severe disability, mild disability, or no disability). In the study, social risk was measured as composite of six aspects of social status: family structure, primary caregiver educational attainment, primary caregiver occupation type, employment status of primary income earner, language spoken at home, and maternal age at birth. While research indicates there are inequities in access to early support, at present (to my knowledge), no comprehensive review has been conducted on factors influencing access to early support for children with developmental disabilities and their families.

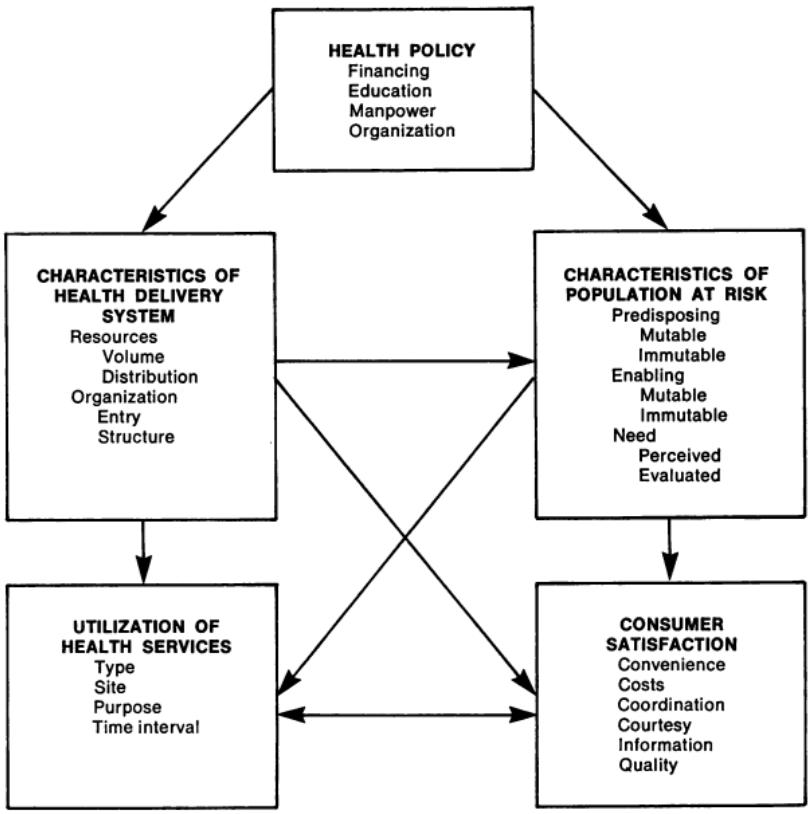
Due to the diverse nature of the needs of children with developmental disabilities and their families, early support covers a broad range of supports, including a variety of specific support approaches, programmes, and targeted interventions, in addition to general support from health, education, social care, voluntary, community, and other service sectors. For example, a broad range of support approaches are identified for children with autism alone (Denne et al., 2018; Goin-Kochel et al., 2007). At present, there is a lack of precise standards across disciplines and diagnoses for developmental disabilities (Magnusson et al., 2016). Furthermore, accessing early support for developmental disabilities is not straightforward, as it covers 'primary, secondary and tertiary levels of care in both acute and community sectors of the health service, various sections of the education department, social services, and community and voluntary agencies' (Bernard & Turk, 2009, p.25). It is therefore not surprising that both professionals and parental

caregivers report early support is difficult to navigate and access (Bernard & Turk, 2009; Kohler, 1999; Vohra et al., 2014). To improve outcomes for children with developmental disabilities and their families (see Chapter 1), it is essential to first develop a comprehensive understanding of factors related to access to early support for this group.

Conceptual Models and Theoretical Frameworks of Access to Support

In addition to child development and family systems theories discussed in Chapter 1, highlighting the various systems influencing child development (e.g., Bronfenbrenner, 1979; Dunst & Trivette, 2009; Guralnick, 2001), conceptual models and theoretical frameworks aiming to describe differences in access to support are informative for understanding access (or non-access) to early support for children with developmental disabilities and their families. Aday and Andersen's framework of access to healthcare is one example, in which access is conceptualised as 'proceeding from health policy objectives through the characteristics of the health care system and of the populations at risk (inputs) to the outcomes or outputs *actual utilization* [utilisation] of health care services and consumer satisfaction with these services' (Aday & Anderson, 1974, p.211-212, see Figure 2.1).

Figure 2.1 Framework for the study of access (Aday & Anderson, 1974, p.212)



In the context of early support for developmental disabilities, within this model, children with developmental disabilities and their families are considered as the 'population at risk' (i.e., at risk of not accessing early support) and service systems related to early support are the 'health delivery system'. Based on this model, factors directly related to service utilisation can be understood as child and family characteristics (predisposing, enabling, and need factors), service system characteristics (resources, organisation), and satisfaction with services (convenience, costs, coordination, courtesy, information, and quality). In the model, (health) policy factors are directly related to service system and family characteristics; however, they are not directly related to service utilisation (see Figure 2.1).

While Andersen's model of service use has been widely used to investigate access to health services, the type and categorisation of variables examined in studies has varied considerably, with the same variable being categorised both as 'predisposing' or 'enabling' population factors (Babitsch et al., 2012). This model has previously been used to examine service use amongst people with developmental

disabilities and their families, primarily exploring access to specific services, including health services, mental health services, emergency services, and social services (Balogh et al., 2013; Kalb et al., 2016; Lunsky et al., 2015; Narendorf et al., 2011; Olsson et al., 2020; Pruchno & McMullen, 2004; Rast et al., 2018; Shattuck et al., 2020; Willet et al., 2018). In addition, the model has been used to examine access to multiple supports or service systems for people with developmental disabilities, however, this is limited (Ishler et al., 2021; Kang & Harrington, 2008; Magaña et al., 2002; Thomas et al., 2007). Studies using this model for developmental disabilities have predominantly focused on access to support in middle- to late- childhood or adulthood, which does not capture access to early support, with the exception of Thomas et al. (2007) and Kang and Harrington (2008), as they additionally included young children (<6 years).

There are a few theoretical frameworks specifically aiming to describe differences in access to early support, however, these have primarily focused on the family seeking or accepting support (Arcia et al., 1993; Birkin et al., 2008). For example, Arcia et al.'s (1993) model of the process that gives rise to families' willingness to seek services suggested families' willingness to seek and enter early support is influenced by predisposing family factors, perception of the "problem" (i.e., the need for support), and enabling factors (i.e., the intersection of family factors and early support, such as finances and time available/required; see Figure 2.2). Birkin et al.'s (2008) model of factors which influence the uptake of interventions by families of children with a disability additionally included factors related to early support provision, such as clinical relevance, cultural relevance, and accessibility (see Figure 2.3), similar to system and policy factors in Andersen's model.

Figure 2.2 Process that gives rise to families' willingness to seek services (Arcia et al., 1993, p.285)

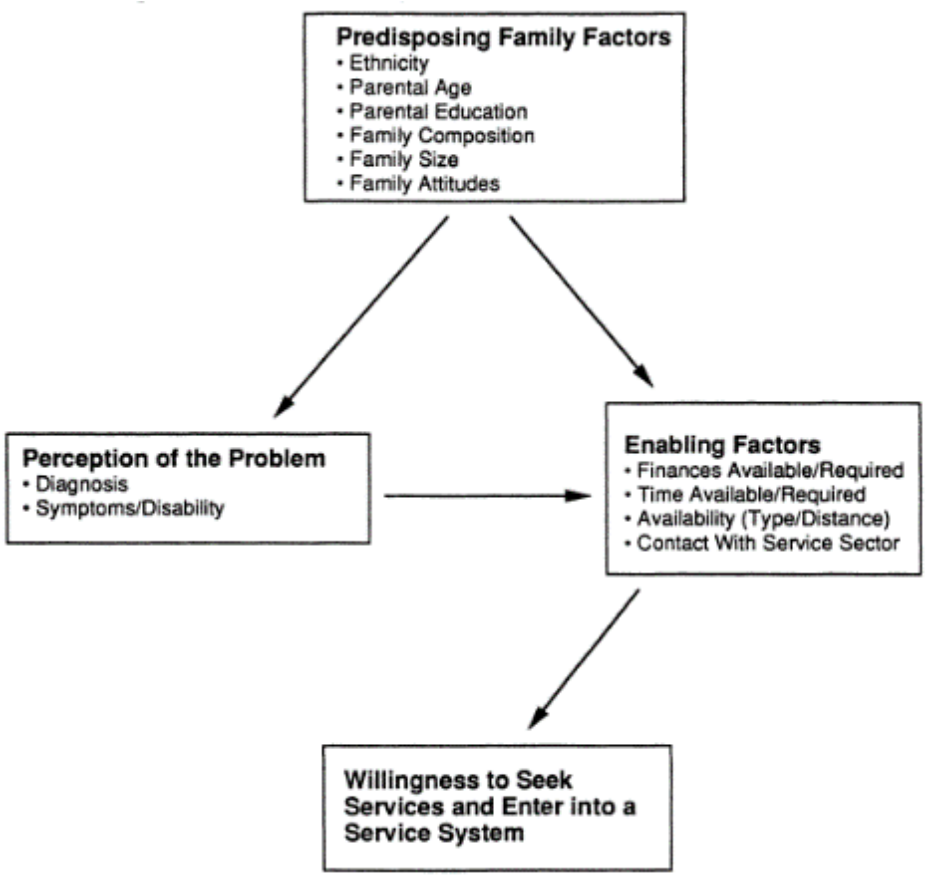
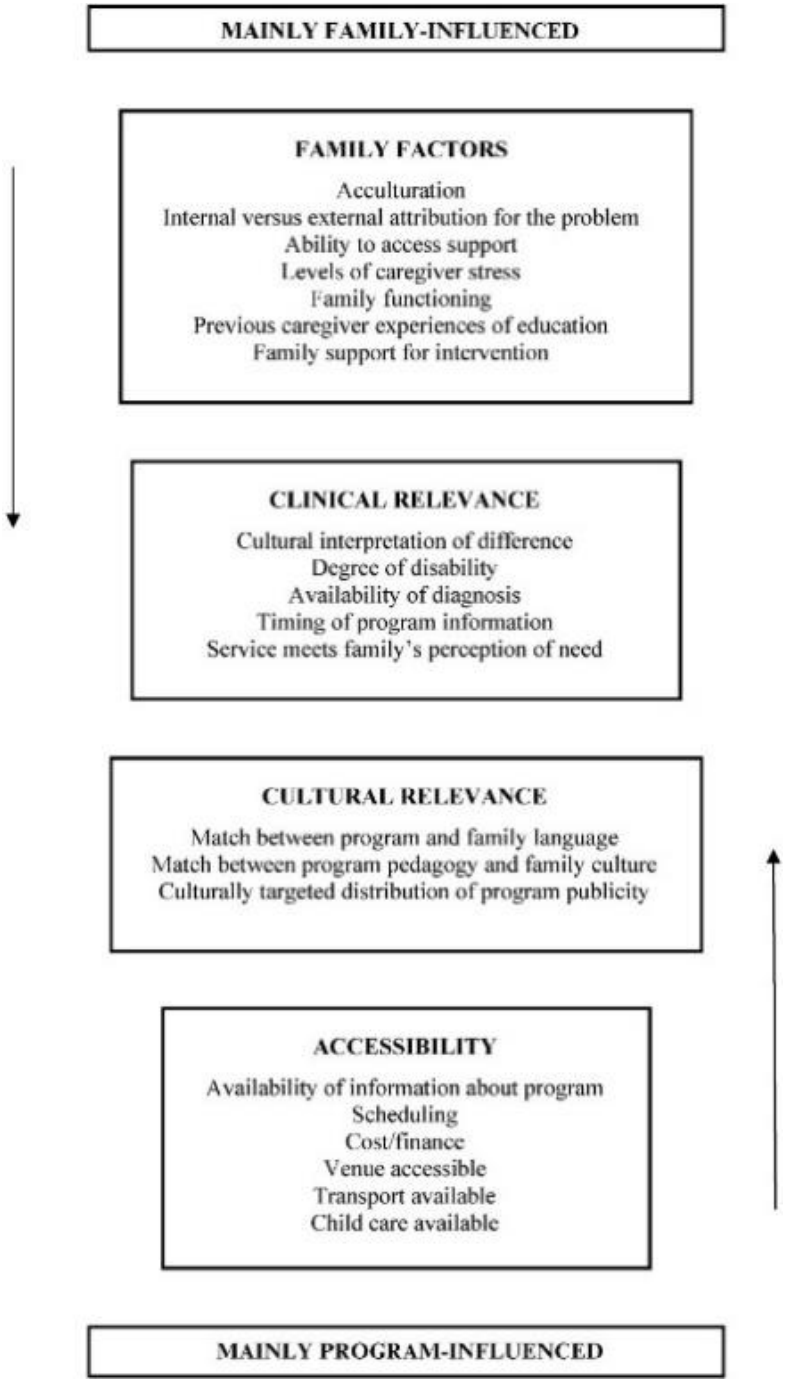


Figure 2.3 A model of factors which influence the uptake of interventions by families of children with a disability (Birkin et al., 2008, p.115)



Other relevant models include the developmental systems model for early intervention and models of help-seeking and referral pathways. The developmental systems model for early intervention (Guralnick, 2001) is a comprehensive system of the application of community-based services for vulnerable children and their families. It has various components detailing the process access to early support

should take, starting with screening or referral. Models of help-seeking (e.g., Pavuluri et al., 1996) and referral pathways (e.g., Verhulst & Koot, 1992) consider prior steps, such as parental recognition of a "problem", consideration of seeking help, and crossing perceived barriers to seeking help (Douma, 2006). Furthermore, Powell et al. (2007) synthesised knowledge related to the process of identification and access to services for children with behaviour that challenge (not specifically those with developmental disabilities) and their families by describing federal programmes and funding streams that provide pathways to services and associated mandates relating to cross-system convergence, along with (limited) empirical data related to implementation, utilisation, and effectiveness.

While these models are informative, access to early support is a process that spans across various systems (the family system, the system of service provision, etc.) and requires a framework that can encompass this complexity. Furthermore, factors related to accessing early support may operate differently across steps or stages of the process. In the absence of a suitable existing framework, below I propose a framework to map the process of access to early support. Under this framework, in the present narrative review I aim to synthesise research evidence on barriers and facilitators of access to early support for families of young children with suspected or diagnosed developmental disabilities. Therefore, in the present chapter I aim to: (a) propose a conceptual framework that maps the process of access to early support, and (b) use this framework to synthesise an overview of factors that might influence the process of access to early support for children with developmental disabilities and their families based on international research evidence.

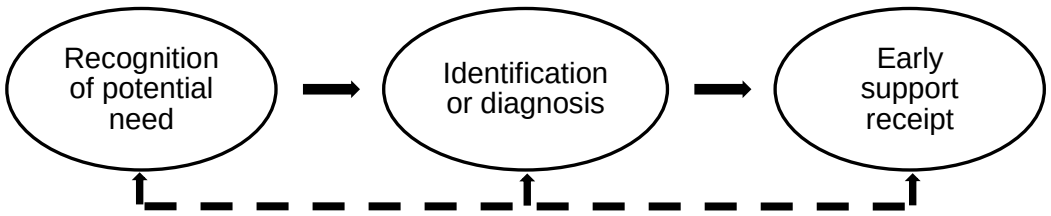
Pathway of Access to Early Support

Access to early support is a *process*, as opposed to a time-specific phenomenon. I propose that this process might be summarised by Figure 2.4, represented as a general pathway of access to early support. This framework shows the temporal sequence of steps required for access to early support children with developmental disabilities and their families, divided into three key phases: (1) recognition of potential need, (2) identification or diagnosis of need, and (3) early support receipt. Although various steps may occur within each family's journey to accessing early support, the process generally follows the sequence of recognising a potential need, identifying or clarifying it, and accessing support for it. This

proposed pathway is intentionally generic to enable the exploration of access to different services and supports in various contexts. It also enables the consideration of actions instigated by different systems, such as families, professionals, services, or governing systems; each of which has an important role in the process and need to be considered to understand the factors contributing to early support access. Furthermore, this process can happen at different time points in the lifecycle of a family and multiple times in a response to different needs or different support provisions (i.e., child or family focused early support). The process may, therefore, be cyclical and potentially bidirectional, also indicated in Figure 2.4. The development of this framework was informed by other models and frameworks described above, including frameworks of access to early support (Arcia et al., 1993; Birkin et al., 2008), the developmental systems model (Guralnick, 2001), and help-seeking and referral pathways (Douma, 2006; Pavuluri et al.,1996; Verhulst & Koot, 1992).

https://www.draw.io/?page-id=2O-rJ-umTS1FV3CuCT9x&scale=auto -G1ZQ8NknJjgw93O9mv-7kvvmt3zHPrXsJg

Figure 2.4 Pathway of access to early support



The first phase of the pathway of access to early support is the recognition of a potential need in the family system (referred to hereafter as ‘recognition’). The ‘need’ can relate to a number of different areas, such as a need to support the child (e.g., developmental, physical or mental health, educational), parents and carers in their role supporting the child (e.g., educational, psychological, social, mental health), other family members (e.g., sibling support) or other family life domains (e.g., housing, monetary support, transport). Initial recognition can be made by a parent, other family member, someone in the family's network, a professional working with the family, or through universal monitoring and screening systems

(e.g., health and development reviews, health visitor checks, well-child visits; Centers for Disease Control and Prevention [CDC], 2021; National Health Service [NHS], 2020). For example, in a study exploring parental experiences of intellectual disability and autism diagnosis in Scotland, 60% of parents reported they had raised initial concerns about their child's development, whereas 40% reported they were made aware of the concern by others (Pankaj, 2015). This phase may relate to the recognition of other needs within the family system, such as a need for parental or sibling support (Dyke et al., 2009; Siklos & Kerns, 2006). To progress through phases, the potential need recognised will need to be shared with another party (a parent, professional, or service). If recognition of potential need is not shared, or the need is resolved, the process might stop at this phase.

The second phase covers the formal identification or diagnosis of need (referred to hereafter as ‘identification’), which may involve a referral for screening or assessment of the need, the screening or assessment itself, and the formal identification or diagnosis of the need and associated supports. Whilst this predominantly relates to the identification of developmental disabilities and special educational needs, it also encapsulates the identification of other family needs, such as the identification of parental needs via a carer's assessment (McCafferty & McCutcheon, 2020). If a need is not formally identified, the process may stop at this phase, or a plan may be put in place to monitor and review the area of need, as proposed in the developmental systems model (Guralnick, 2001). Once a need is formally identified, the next steps are planning appropriate support and putting it in place. Families should be offered some formal support whilst waiting for screening or assessment of needs, as waiting times may delay access to support considerably and recommendations stipulate that access should begin as soon as a developmental disability is suspected (National Research Council, 2001).

The final phase is early support receipt, which may include the provision of information and advice, signposting to services, or receipt of support from a range of professionals, services, or intervention programmes (see Chapter 1). The support provided will vary depending on the need identified and the associated impact on the child and family. Accessing support may not be the end of the process; families may return to an earlier point in the pathway for a number of reasons, such as requiring

further support to meet the need, a change in the family's situation, or to access support for a different need within the family system.

Various factors might influence the process of access to early support, and the way these factors operate may vary for the three different phases. Using my framework depicting the pathway of access to early support (Figure 2.4) might be a useful starting point to identify factors that influence access to early support for families of children with developmental disabilities, to develop understanding of why some families are not accessing early support.

Factors Influencing Access to Early Support

To gain a comprehensive picture of potential factors associated with access to early support for children with developmental disabilities and their families, I conducted a narrative review (see Ferrari, 2015) of international research evidence. Evidence across broad fields (e.g., paediatrics, diagnostic services, healthcare, education, social care, family support, community services) and various developmental conditions within developmental disabilities (e.g., developmental delay, intellectual disability, autism) were considered, rather than focusing on a specific early support or developmental disability, such as autism.

To ensure a minimum level of quality of the evidence included, only evidence from papers published in peer-reviewed academic journals were considered. To ensure a good match to the research question, studies whose definition of early support was synonymous and consistent with my conceptualisation of early support (i.e., any formal support provided to families of children with suspected or diagnosed developmental disabilities in early childhood, 0-6 years of age, see Chapter 1) was considered. In this broad field of investigation, factors associated with access to early support have been investigated in quantitative and qualitative studies with children, families, and various professionals involved in early support. Overall, evidence was obtained from 85 peer-reviewed papers. The majority of research evidence included was from the USA or UK, with the rest from various other countries, such as Australia, Canada, China, New Zealand, Taiwan, India, Bangladesh, Singapore, Turkey, and several European countries.

Below, I organise the description of factors according to the phases of the pathway of access to early support (recognition, identification, and early support receipt; see Figure 2.4) and their effect (i.e., barrier, facilitator, or modifier). By

definition, barriers have a detrimental effect on a process, such as factors that prevent a process from starting, impede or interrupt a process, or result in early termination of a process (Hicks et al., 2007). For example, the Social Care Institute for Excellence (2017, p.7) describe barriers as '*obstacles* to accessing social care'. For my review, barriers were defined as factors that had a detrimental effect on the process, such as factors that prevented, challenged, or stopped something within the pathway of access to early support. Facilitators are the opposite; they have an enabling effect and motivate, sustain, or enhance a process, making it easier or faster (Hicks et al., 2007). For my review, facilitators were defined as factors that had an enabling effect, such as factors that sustained, enhanced, supported, and/or allowed movement across the pathway of access to early support. Lastly, modifiers were defined as factors that are related to the process but did not have a direct impact on it, including factors that altered the relationship between another factor and its effect on the pathway of access to early support; for example, parental education might affect parental awareness of services and language proficiency, which in turn affect access to early support (Bailey et al., 1999; Vande Wydeven et al., 2012).

Based on other models of access to early support (Arcia et al., 1993; Birkin et al., 2008), factors were organised into the following categories: family factors (i.e., factors related to the child or family, including factors that are intrinsic or amenable to change, such as skills, knowledge, and perceptions); service factors (i.e., factors related to professionals, services, or governing systems); intersection factors (i.e., the intersection between family and service factors); and contextual factors (i.e., broader structural factors). These factor categories also map onto the various systems influencing child development identified in Bronfenbrenner's ecological systems theory, such as individual characteristics, micro systems, meso systems, exo systems, macro systems, and chrono systems (Bronfenbrenner, 1979; Rosa & Tudge, 2013; see Chapter 1).

A variety of factors influencing the pathway of access to early support were identified through my narrative review (see Figure 2.5 for an overview). Several factors operated at all three or across two phases of the pathway of access to early support, whereas other factors appeared unique to one part of the process. An overview of the phases at which each factor operated is presented in Table 2.1. A full list of references for each factor identified in my review is provided in Table 2.2.

Figure 2.5 Factors influencing access to early support for families of children with developmental disabilities

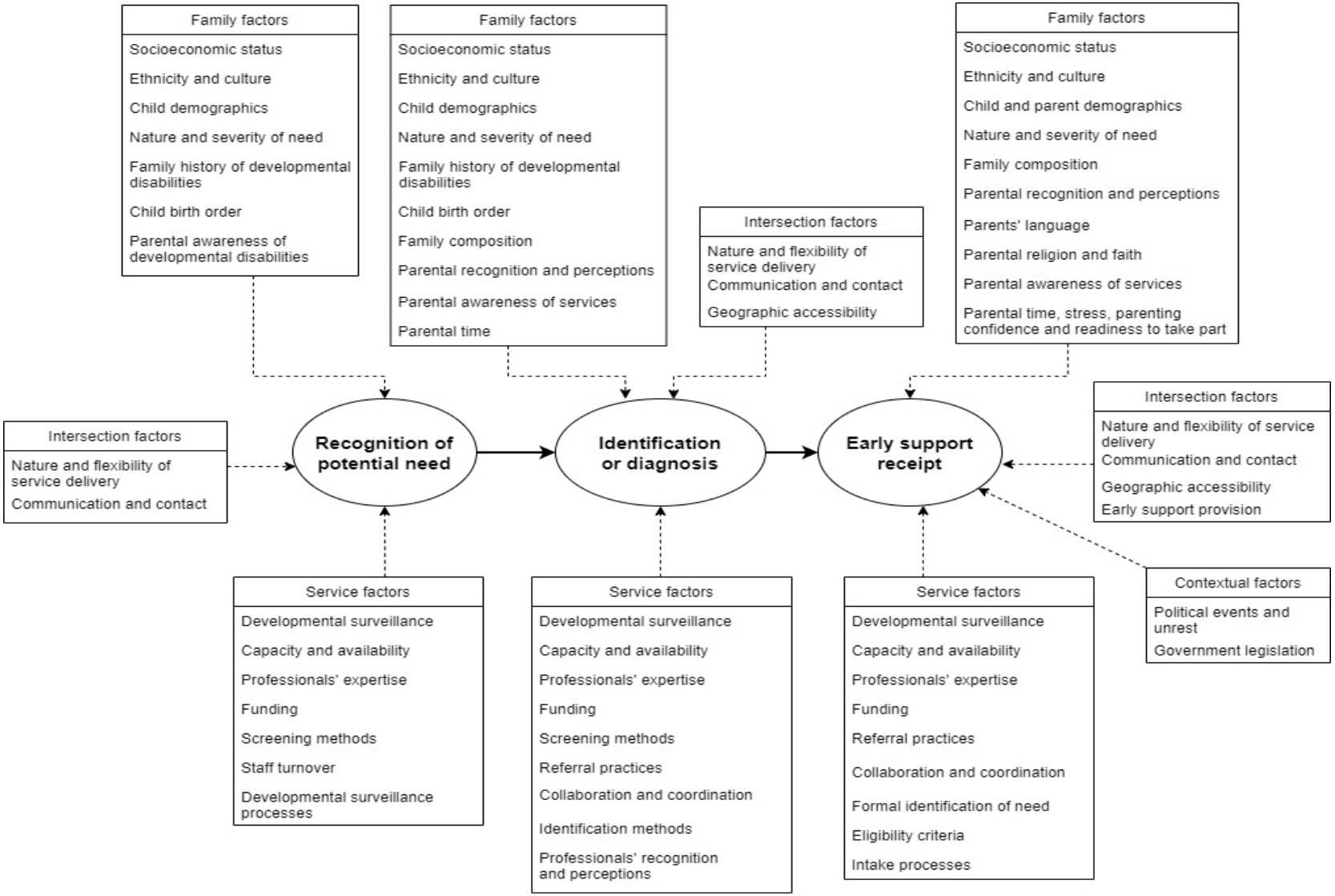


Table 2.1 Factors influencing the pathway of access to early support

	Pathway phases influenced[1]		
Factors	1	2	3
Family factors			
Socioeconomic status	✓	✓	✓
Ethnicity and culture	✓	✓	✓
Child demographics	✓	✓	✓
Nature and severity of need	✓	✓	✓
Family history of developmental disabilities	✓	✓	
Child birth order	✓	✓	
Parental recognition and perceptions		✓	✓
Parental awareness of services		✓	✓
Family composition		✓	✓
Parental time		✓	✓
Parental awareness of developmental disabilities	✓		
Parenting confidence			✓
Parental readiness to take part			✓
Parents' language			✓
Parental gender			✓
Parental religion and faith			✓
Parental stress			✓
Service factors			
Developmental surveillance	✓	✓	✓
Service capacity and availability	✓	✓	✓
Funding	✓	✓	✓
Professionals' expertise	✓	✓	✓
Screening methods	✓	✓	
Collaboration and coordination		✓	✓
Referral practices		✓	✓
Staff turnover	✓		
Developmental surveillance processes	✓		
Identification methods		✓	
Professionals' recognition and perceptions		✓	
Formal identification of need			✓
Eligibility criteria			✓
Intake processes			✓
Intersection factors			
Nature and flexibility of service delivery	✓	✓	✓
Communication and contact	✓	✓	✓
Geographical accessibility		✓	✓
Early support provision			✓
Contextual factors			
Political events and unrest			✓
Government legislation			✓

Note. [1]Phases of the pathway of access to early support include: (1) recognition of potential need, (2) identification or diagnosis, and (3) early support receipt.

Table 2.2 References for factors influencing access to early support

Factor	References
	Family factors
Parental socioeconomic status	Bickel et al., 2015; Brett et al., 2016; Chauhan et al., 2017; Fountain et al., 2011; Howlin & Moore, 1997; Hudson et al., 2008; Jimenez et al., 2012, 2014; Keenan et al., 2010; Leininger & Levy 2015; Mackintosh et al., 2012; Mandell et al., 2009; Marshall et al., 2015; McConachie et al., 2001; Moh & Magiati, 2012; Payakachat et al., 2017; Rosenberg et al., 2008; Salomone et al., 2016; Thomas et al., 2012a, 2012b; Vande Wydeven et al., 2012
Ethnicity and culture	Birkin et al., 2008; Dababnah et al., 2018; Evans et al., 2016; Fountain et al., 2011; Hussein et al., 2019; Jimenez et al., 2012; Magaña et al., 2013; Mandell et al., 2002, 2009; Matheis & Matson, 2015; Moh & Magiati, 2012; Payakachat et al., 2017; Rosenberg et al., 2008, 2011; Thomas et al., 2012b
Child demographics	Begeer et al., 2013; Brett et al., 2016; Chen et al., 2008; Jimenez et al., 2012, 2014; King et al., 2010; Mandell et al., 2009; Mandy et al., 2012; Marshall et al., 2015; Matheis & Matson, 2015; McConachie et al., 2001; Payakachat et al., 2017; Rynkiewicz et al., 2016; Salomone et al., 2016; Shattuck et al., 2009; Siklos & Kerns, 2007
Nature and severity of need	Adams et al. 2016; Bickel et al., 2015; Bowker et al., 2011; Brett et al., 2016; Chadwick et al., 2002; Crane et al., 2016; Howlin et al., 1995; Jimenez et al., 2012, 2014; King et al., 2010; Maenner et al., 2013; Mandell et al., 2005, 2009; Marshall et al., 2015; Matheis & Matson, 2015; Mayes & Calhoun, 2003; McGill et al., 2006; Moh & Magiati, 2012; Oswald et al., 2017; Payakachat et al., 2017; Rosenberg et al., 2008, 2011; Salomone et al., 2014, 2016; Shevell et al., 2001; Twardzik et al., 2017; Zuckerman et al., 2015
Family history of developmental disabilities	Bickel et al., 2015; Matheis & Matson, 2015
Child birth order	Bickel et al., 2015; Rosenberg et al., 2011
Parental recognition and perceptions	Bickel et al., 2015; Birkin et al., 2008; Chauhan et al., 2017; Evans et al., 2016; Hussein et al., 2019; Jimenez et al., 2012, 2014; McConachie et al., 2001; McIntyre, 2008b; Miller-Gairy & Mofya 2015; Salomone et al., 2014; Shyu et al., 2010; Vande Wydeven et al., 2012
Parental awareness of services	Birkin et al., 2008; Chadwick et al., 2002; Howlin &Moore, 1997; Jimenez et al., 2012, 2014; Keenan et al., 2010; Ludlow et al., 2012; Marshall et al., 2015; Vande Wydeven et al., 2012
Family composition	Bickel et al., 2015; Chadwick et al., 2002; Chauhan et al., 2017; Jimenez et al., 2014

Parental time	Chauhan et al., 2017; Evans et al., 2016; Jimenez et al., 2012; Ludlow et al., 2012; Marshall et al., 2015; McConachie et al., 2001; McIntyre, 2008a, 2008b; Montes & Halterman, 2008
Parental awareness of developmental disabilities	Birkin et al., 2008; Hussein et al. 2019; Miller-Gairy & Mofya, 2015
Parenting confidence	McConachie et al., 2001
Parental readiness to take part	Birkin et al., 2008
Parents' language	Bailey et al., 1999; Marshall et al., 2015
Parental gender	Evans et al., 2016; Herbert & Carpenter, 1994; Kayfitz et al., 2010; Ly & Goldberg, 2014; Ridding & Williams, 2019
Parental religion and faith	Dababnah et al., 2019; Evans et al., 2016; Hussein et al., 2019; McConachie et al., 2001
Parental stress	Mackintosh et al., 2012; McConachie et al., 2001; Thomas et al., 2007
	Service factors
Developmental surveillance	Dosreis et al., 2006; King et al., 2010; Nygren et al., 2012
Service capacity and availability	Birkin et al., 2008; Dosreis et al., 2006; George et al., 2014; Karim et al., 2012; King et al. 2010; Mackintosh et al., 2012; Marshall et al., 2015; McGill et al., 2006; Rosenberg et al., 2008; Roux et al., 2012; Sices et al., 2003
Funding	Brookman-Frazee et al, 2012a, 2012b; Hudson et al., 2008; Karim et al., 2012; King et al. 2010; Marchbank, 2017; Mathews et al., 2018; Ridding & Williams, 2019
Professionals' expertise	Brookman-Frazee et al., 2012a, 2012b; Chen et al., 2008; Dosreis et al., 2006; Hudson et al., 2008; Kalkbrenner et al., 2011; Ludlow et al., 2012; Shevell et al., 2001; Vande Wydeven et al., 2012
Screening methods	King et al., 2010; Marshall et al., 2015; Roux et al., 2012; Sices et al., 2009
Collaboration and coordination	Cassidy et al., 2008; Carr & Lord, 2016; Jimenez et al., 2012; Mathews et al., 2018; Vande Wydeven et al., 2012
Referral practices	Carr & Lord, 2016; Crane et al., 2016; Howlin & Moore, 1997; Jimenez et al., 2012, 2014; King et al., 2010; Marchbank, 2017; Oswald et al., 2017; Shevell et al., 2001; Vande Wydeven et al., 2012; Zuckerman et al., 2015
Staff turnover	King et al., 2010
Developmental surveillance processes	King et al., 2010; Nygren et al., 2012

Identification methods	Howlin & Moore, 1997; Jimenez et al., 2014; Karim et al., 2012; Moh & Magiati, 2012; Wiggins et al., 2006
Professionals' recognition and perceptions	Begeer et al., 2009; Burke et al., 2015, 2016; Crane et al., 2016; Cuccaro et al., 1996; Howlin & Moore, 1997; Karim et al., 2012; Oswald et al., 2017; Vande Wydeven et al., 2012; Zuckerman et al., 2015
Formal identification of need	Bowker et al., 2011; Chen et al., 2008; Payakachat et al., 2017
Eligibility criteria	Birkin et al., 2008; Mackintosh et al., 2012; Twardzik et al., 2017
Intake processes	Marchbank, 2017
	Intersection factors
Nature and flexibility of service delivery	Birkin et al., 2008; Carr & Lord, 2016; Chadwick et al., 2002; Chauhan et al., 2017; Dababnah et al., 2019; Howlin & Moore, 1997; Hudson et al., 2008; Jimenez et al., 2012, 2014; Kong & Au, 2018; Mathews et al., 2018; McIntyre 2008a; Phaneuf & McIntyre, 2011; Roux et al., 2012
Communication and contact	Birkin et al., 2008; Carr & Lord, 2016; Chadwick et al., 2002; Crane et al., 2016; Howlin & Moore, 1997; Jimenez et al., 2012, 2014; Keenan et al., 2010; Ludlow et al., 2012; Mackintosh et al., 2012; Marshall et al., 2015; McConachie et al., 2001; Moh & Magiati, 2012; Oswald et al., 2017; Roux et al., 2012; Vande Wydeven et al., 2012; Zuckerman et al., 2015
Geographic accessibility	Birkin et al., 2008; Chen et al., 2008; Howlin & Moore, 1997; Kalkbrenner et al., 2011; Keenan et al., 2010; Marshall et al., 2015; McConachie et al., 2001; Moh & Magiati, 2012; Ridding & Williams, 2019; Rosenberg et al., 2011; Salomone et al., 2016; Twardzik et al., 2017
Early support provision	Chauhan et al., 2017; Dababnah et al., 2019; Kong & Au, 2018; Magaña et al., 2017; McConachie et al., 2001; McIntyre, 2008a; 2008b
	Contextual factors
Political events and unrest	Dababnah et al., 2019
Government legislation	Brookman-Frazee et al., 2012a, 2012b

Factors Influencing Recognition

Family Factors. Family factors that influenced the first phase, recognition, were parental socioeconomic status (including economic status and educational level), ethnicity and culture, parental awareness of developmental disabilities, family history of developmental disabilities, child birth order, nature and severity of need, and child demographics.

Parental Socioeconomic Status. Generally, higher parental socioeconomic status facilitated recognition and lower socioeconomic status was a barrier (Leininger & Levy, 2015; Moh & Magiati, 2012). For example, in Moh and Magiati's (2012) study of autism diagnosis in Singapore, parents with higher educational qualifications and income recognised potential child developmental needs earlier than parents with lower educational qualifications and income, regardless of the severity of their child's developmental disability. In contrast, Rosenberg et al. (2011) found no association between maternal education and the age of child development concerns.

The impact of parental socioeconomic status on recognition might be magnified in contexts without a universally free healthcare system, especially in cases where the need is recognised by a professional. For example, in the USA, where access to healthcare is not universally free, an associated decrease in access to well-child visits has been found for each month a child is without health insurance (Leininger & Levy, 2015), potentially obstructing recognition. Developmental surveillance (i.e., the routine monitoring of child development), defined as 'a flexible, continuous process whereby knowledgeable professionals perform skilled observations of children during the provision of health care' (American Academy of Pediatrics [AAP] Committee on Children with Disabilities, 2001, p.192), is routinely implemented at well-child visits. Developmental surveillance tasks can include a health professional maintaining a developmental history of the child, eliciting and attending to parental concerns, conducting observations, completing developmental checklists, recording developmental milestones, and sharing opinions or concerns with other professionals (AAP Committee on Children with Disabilities, 2001). Therefore, families in the USA with low socioeconomic status might be more likely to experience barriers to recognition, as decreased access to well-child visits reduces the child's receipt of professional developmental surveillance.

Ethnicity, Culture and Parental Awareness of Developmental Disabilities. Being part of an ethnic minority group was a barrier to the recognition of potential developmental disabilities (Matheis & Matson, 2015; Rosenberg et al., 2011). For example, parents of children belonging to ethnic minority groups in the USA reported a later age of child development concerns (Rosenberg et al., 2011). Furthermore, Matheis and Matson (2015) found caregivers of African American children in the USA were more likely to refuse the offer of free routine autism screening, which is a 'brief assessment procedure designed to identify children who should receive more intensive diagnosis or assessment' (AAP, 2001, p.192), which can be carried out for a range of developmental, health, or other needs.

Findings from Moh and Magiati (2012) suggest cultural differences may exist in the recognition of developmental disabilities, as the child's age when parents first became concerned about their child's development varied across countries. Culture also modified factors directly related to recognition, such as parental awareness of developmental disabilities. For example, low parental awareness of autism was a barrier to recognition, which appeared more prominent in non-Western cultures, such as Pasifika and Maori families in New Zealand (Birkin et al., 2008) and Somali families in the UK (Hussein et al., 2019).

Parental Recognition of Need. Parents recognised potential developmental delays significantly earlier than school-based professionals, at 4.8 years and 5.3 years, respectively (Burke et al., 2015). Rosenberg et al. (2011) found a cumulative variation of child and family factors contributed to the age of initial parental concern, rather than one single modifiable factor, indicating various family factors contribute to variation in parental recognition of needs. Several studies have found a delay between the time parents first became concerned about their child's development and the time they consulted a professional (Crane et al., 2016; Howlin & Moore, 1997; Moh & Magiati, 2012), however, reasons for this delay are not clear.

Family History of Developmental Disabilities and Child Birth Order. Having a family member with developmental disabilities facilitated recognition (Matheis & Matson, 2015). Matheis and Matson (2015) found parents in the USA were more than twice as likely to accept routine autism screening if their child had an autistic family member (suspected or diagnosed). Another study in the USA found later birth order (i.e., child was second-born or later, as opposed to first-born)

also facilitated recognition of autism, whereas being first-born was a barrier (Bickel et al., 2015). Similarly, Rosenberg et al. (2011) found a later age of child development concern was associated with first-born children. This may also be related to parental awareness of developmental disabilities, or child development in general.

Nature and Severity of Need. The nature (i.e., type) and severity of need (or needs) also influenced recognition (Matheis & Matson, 2015; Oswald et al., 2017; Rosenberg et al., 2011; Zuckerman et al., 2015). For example, a younger age of developmental concern was found in parents of autistic children compared to parents of children with intellectual and other developmental disabilities in the USA (Oswald et al., 2017; Zuckerman et al., 2015). Increased severity or increased number of needs (i.e., higher level or complexity of need, or the presence of co-occurring needs) also facilitated recognition. For example, a younger age of first developmental concern was found in parents of autistic children with co-occurring intellectual disabilities, compared to parents of children with autism or intellectual disability only (Zuckerman et al., 2015). Similarly, Rosenberg et al. (2011) found earlier developmental concern amongst parents of autistic children with co-occurring health problems, and "high medical risk" was the single largest correlate for earlier age of developmental concern.

In contrast, prior identification of other needs was sometimes a barrier to recognition. For example, in Matheis and Matson (2015), parents of children with an already identified developmental disability, such as Down syndrome or cerebral palsy, were more likely to refuse routine autism screening, whereas parents of children born with higher birthweight (i.e., less likely to be born prematurely) were less likely to refuse routine autism screening.

Child Demographics. Findings suggest that younger child age and female gender are barriers to recognition. For example, in Matheis and Matson (2015), parents of younger children and female children were more likely to refuse routine autism screening.

Service Factors. Service factors that influenced recognition were the implementation of developmental surveillance (including screening methods and developmental surveillance processes), professionals' expertise, service capacity, staff turnover, and funding.

Developmental Surveillance, Screening Methods and Professionals' Expertise. The implementation of developmental surveillance was a facilitator of recognition, modified by the nature of the need and professionals' experience (Dosreis et al., 2006; King et al., 2010; Nygren et al., 2012). For example, rates of routine screening were significantly lower for autism compared to other developmental disabilities, with 8% compared to 82%, respectively (Dosreis et al., 2006). Disparate rates of routine screening for autism compared to other developmental disabilities were reported as being related to professionals' expertise, a lack of familiarity with autism screening tools, and limited capacity (Dosreis et al., 2006).

The methods and tools utilised for routine developmental surveillance and screening were not always effective at detecting potential developmental disabilities, which was a barrier to professionals' recognition (King et al., 2010; Marshall et al., 2015). For example, several parents in Marshall et al. (2015) reported receiving a false-negative prenatal screen for Down syndrome, delaying recognition. Furthermore, in King et al. (2010), the rates of recognition of potential developmental disability through routine screening varied based on the screening tool utilised, perhaps indicative of the tools' efficiency to detect potential delays.

Utilising non-traditional surveillance methods to contact a wider population (e.g., conducting telephone screening) facilitated the recognition of developmental delay and autism (Roux et al., 2012). Furthermore, utilising system-wide processes for developmental surveillance, dividing staff responsibilities at multiple levels, and adjusting implementation systems based on active monitoring of implementation, facilitated recognition (King et al., 2010; Nygren et al., 2012).

Service Capacity, Staff Turnover and Funding. Limited capacity of services, especially during busy periods, was a barrier to the recognition of developmental disabilities through developmental surveillance (Dosreis et al., 2006; King et al., 2010; Roux et al., 2012). Increased staff turnover, especially losing staff in managerial positions, and a lack of clarity around financial reimbursement were also barriers to the recognition of developmental disabilities through developmental surveillance (King et al., 2010).

Other Service Factors. Delays were initially recognised by school professionals in approximately one fifth of children with developmental disabilities,

and recognition was more frequent in primary, followed by pre and secondary school (Burke et al., 2015). This may be due to various reasons, such as variation amongst professionals' knowledge and awareness of developmental disabilities (e.g., Dosreis et al., 2006), or because developmental disabilities are more apparent in primary school activities as compared to pre-school.

Intersection Factors. Factors at the intersection of family and services that influenced recognition were the nature and flexibility of service delivery in relation to family factors, and communication between services and families. A good match between service delivery and family factors, and the ability to be flexible in service delivery, facilitated recognition. For example, Roux et al. (2012) facilitated recognition of developmental delay and autism for families with low socioeconomic status from ethnic minority groups by implementing developmental surveillance remotely. Furthermore, employing professionals fluent in an array of languages also facilitated recognition, by reducing communication barriers (Roux et al., 2012). The adaptions provided by Roux et al. (2012) may have reduced specific barriers of access to standard services experienced by this group, as the majority did not have access to a car, had limited economic resources, and spoke different languages.

Factors Influencing Identification

Family Factors. Family factors that influenced the second phase, identification, were parental socioeconomic status, ethnicity, parental recognition and perception of need, parental awareness of services, parental time, family history of developmental disabilities, family composition, child birth order, nature and severity of need, and child demographics.

Parental Socioeconomic Status. Similar to recognition, higher parental socioeconomic status (i.e., increased economic resources and education level) was generally a facilitator and lower socioeconomic status was a barrier to identification (Chauhan et al., 2017; Fountain et al., 2011; Jimenez et al., 2012; Keenan et al., 2010; Thomas et al., 2012a). The financial set-up of service systems modified the relationship between socioeconomic status and identification. For example, in contexts without a universally free service system, such as the USA, socioeconomic status barriers reduced or disappeared when costs were removed or heavily subsidised (Jimenez et al., 2014), whereas low socioeconomic status appeared to

facilitate recognition in contexts with a universally free service system, such as the UK (Brett et al., 2016).

In the USA, a persistent gap in the age of developmental disability diagnosis between children from families with high versus low socioeconomic status has been found, whereas the gap has diminished for parental education (Fountain et al., 2011). In contrast, Bickel et al. (2015) found the child's insurance type (i.e., private or public insurance coverage) did not predict the age of diagnosis in an autism centre in Boston, suggesting socioeconomic status may not be a barrier in all services within a non-universal system. Furthermore, when developmental assessment was provided universally free under government schemes, such as Part C of IDEA in the USA, low socioeconomic status was not always a barrier. In Jimenez et al.'s (2012) study on developmental assessment under Part C of IDEA, low socioeconomic status appeared to be a barrier, as a higher percentage of children whose parents had a low income did not receive a developmental assessment. However, in a later study with a larger sample size, socioeconomic status was not significantly associated with referral to or receipt of developmental assessment, after controlling for other variables (Jimenez et al., 2014). Parents of autistic children in the USA reported financial barriers influenced their ability obtain a genetics assessment in Vande Wydeven et al. (2012). In the same study, parental education was higher amongst families who accessed a genetics assessment; however, this did not reach statistical significance (Vande Wydeven et al., 2012).

As briefly described above, in contexts with a universally free service system, such as the UK, low socioeconomic status appeared to facilitate identification. Brett et al. (2016) found an association between higher family deprivation and earlier autism diagnosis, indicating universally-free services lessen the impact of socioeconomic status on identification. However, despite the universally-free service system in the UK, some parents report having to pay privately for an autism diagnostic assessment (Howlin & Moore, 1997). Furthermore, in Northern Ireland and the Republic of Ireland, a shorter autism diagnostic period was experienced by parents' who were able to pay for private services compared to parents' dependant on public services (Keenan et al., 2010), indicating disparities of access based on parental socioeconomic status. This

indicates other factors may influence access, such as the availability, capacity, and geographical spread of universally-free services, or parental choice.

No association between socioeconomic status and identification was reported in a study conducted in Singapore (Moh & Magiati, 2012), which has a mixed healthcare system. As services in Singapore are part funded by families' mandatory savings and government subsidies, out-of-pocket costs for parents are reduced, perhaps reducing economic barriers. In India, which also has a mixed healthcare system, the cost of various assessments was reported as a barrier by families (Chauhan et al., 2017). Access to public services is free for families living in poverty in India. However there is a lack of public services available, especially in rural areas where many families in poverty live, meaning families may need to travel long distances to access services or pay for private healthcare and/or insurance.

Ethnicity. The child or a parental caregiver belonging to an ethnic minority group was a barrier to the identification of developmental disabilities (Dababnah et al., 2018; Fountain et al., 2011; Jimenez et al., 2012; Magaña et al., 2013; Rosenberg et al., 2011). For example, Rosenberg et al. (2011) found being part of an ethnic minority group was a risk factor for delayed autism diagnosis in the USA, such as multiracial or Black/African American ethnicity. Similarly, Fountain et al. (2011) found the age of diagnosis increased for ethnic minority groups and children whose mother was born outside the USA, though the effect of the latter disappeared over time. Magaña et al. (2013) found the age of autism diagnosis was significantly higher for Latino children compared to White children. In Jimenez et al. (2012), children with parents from ethnic minority groups were less likely to receive developmental assessment, however, no association between parental ethnicity and developmental assessment receipt was found in a later study with a larger sample size (Jimenez et al., 2014).

Mandell et al. (2002) found children from ethnic minority groups both entered autism assessment services and received diagnoses at later ages compared to children from ethnic majority groups. After controlling for other factors, children from ethnic minority groups had a longer duration of diagnostic assessment, which suggests ethnicity might influence professionals' abilities to identify autism. Mandell et al. (2009) examined the prevalence of autism in a group of children based on records meeting the case definition for autism. Although they found no differences

of ethnicity and autism prevalence in the sample, children from ethnic minority groups were less likely to have a formal diagnosis than children from non-minority ethnic groups, indicating that ethnicity influences the identification of autism (Mandell et al., 2009). Furthermore, whilst children with an intellectual disability were more likely to receive a diagnosis of autism, children with an intellectual disability from ethnic minority groups were less likely to receive a diagnosis (Mandell et al., 2009). This suggests ethnicity might indirectly influence the identification of developmental disabilities through other factors.

Whilst socioeconomic status accounted for some ethnicity disparities in the identification of developmental disabilities, due to an overrepresentation of families from ethnic minority groups in low-income communities (Thomas et al., 2012a, 2012b), Dababnah et al. (2018) found being part of an ethnic minority group persisted as a barrier regardless of socioeconomic status for Black/African American parents of autistic children in the USA.

Parental Recognition and Perceptions of Need. Parental recognition of potential child need (e.g., developmental delay, intellectual disability, autism) facilitated identification, whereas parents' non-recognition or ambivalence of child need was a barrier (Bickel et al., 2015; Jimenez et al., 2012; Vande Wydeven et al., 2012). Certain parental beliefs about the aetiology of developmental disabilities were barriers to identification, such as that developmental disability is caused by parenting style or is a punishment for the past behaviour of the family (Birkin et al., 2008). Parental beliefs about the causes of developmental disabilities were partly modified by religion and culture. For example, varied beliefs about the causes of autism are documented across cultures, such as Maori, Pasifika, Korean, Somali, and Taiwanese families (Birkin et al., 2008; Hussein et al., 2019; Shyu et al., 2010). For example, if a child is recognised as "different" within the Maori culture, they are more likely to be nurtured rather than labelled: '…they wouldn't have had a diagnosis for autism back in the day, it would have just been ''he's special''' (Birkin et al., 2008, p.112).

Greater parental concern appeared to correspond with an earlier diagnosis of developmental disability (Bickel et al., 2015). Parents' perceptions of the need appeared to modify professionals' decisions on whether to refer the child for assessment; professionals reported they were more likely to refer a child whose parents expressed concern and, conversely, delay a referral if parents did not desire

one, regardless of the outcome of developmental screening (Jimenez et al., 2014). Professionals in this study reported this decision was related to respecting parental desires, whilst also putting in place more active monitoring of the need: 'I shorten the time to next visit and I make a plan… if he's doing x by then, great, if he's still not doing y, then let's refer, and they [parents] usually are on board with that. So that's when I tend not to refer' (Jimenez et al., 2014, p.321).

Some parents expressed a preference to wait for the concern to resolve or to work with their child on their own before seeking support, but if the problem persisted only some parents sought help (Jimenez et al., 2012). Professionals reported parental perceptions of need influenced their motivation to overcome barriers in the assessment process (i.e., parents who were ambivalent about developmental concerns were viewed as being more vulnerable to practical barriers, e.g., time constraints, contact issues, not understanding the referral process) compared to parents who were concerned about their child's development (Jimenez et al., 2012). Parents also reported that it was ultimately their choice whether to follow through with a developmental assessment or not, as they were the expert on their child's development: 'I thought it was my choice, it was my responsibility, it was my choice to contact [early support service] if I felt that he needed services or not' (Jimenez et al., 2012, p.554).

Parental Awareness of Services and Time. Limited parental awareness of services (including service systems and processes) was a barrier to identification (Jimenez et al., 2014; Vande Wydeven et al., 2012). Many parents who had not accessed a genetics assessment in Vande Wydeven et al. (2012) reported a lack of awareness of the availability of genetics evaluations for autistic children. For example, one parent said: 'I never even thought of it, I figured it is what it is, why bother. But knowing what I know now […] I would do it at a moment's notice' (Vande Wydeven et al., 2012, p.807). Parental time constraints was also a barrier to the identification of developmental delay (Jimenez et al., 2012).

Family Composition, History of Developmental Disabilities and Child Birth Order. Family composition, family history of developmental disabilities, and child birth order were related to the age of diagnosis. In Bickel et al. (2015), significant predictors of an earlier age of autism diagnosis were fewer children living in the household, a later child birth order (i.e., child was second-born, third-born or greater,

as opposed to first-born), and having an autistic sibling. In a sub-group analysis of children aged <36 months, having an autistic sibling was the only significant predictor (Bickel et al., 2015). In contrast, having an extended autistic family member was not a significant predictor of the age of autism diagnosis (Bickel et al., 2015). No association was found between other family compositional factors (e.g., single-parent household) and identification were found in Jimenez et al. (2014).

Nature and Severity of Need. Nature and severity of need (or needs) inevitably influenced identification (Bickel et al., 2015; Brett et al., 2016; Crane et al., 2016; Jimenez et al., 2014; King et al., 2010; Maenner et al., 2013; Mandell et al., 2005; Shevell et al., 2001). For example, in Crane et al.'s (2016) UK study, children with Asperger syndrome experienced longer diagnostic delays and later age of diagnosis compared to children diagnosed with other autism diagnostic labels (e.g., autism, pervasive developmental disorder not otherwise specified, rett syndrome, autistic traits). In the USA, children with special health needs or communication delays (compared to delays in other developmental domains) were more likely to be referred for developmental assessment, thus facilitating identification (Jimenez et al., 2014; King et al., 2010). Furthermore, greater severity of observed developmental delay was a facilitator to being referred for developmental assessment in Canada, whereas lower severity of observed developmental delay was a barrier (Shevell et al., 2001).

In Moh and Magiati (2012), increased autism severity was related to consulting fewer professionals during the diagnostic process, but did not appear to influence the duration or age of diagnosis. It is possible children with more complex needs were referred to highly specialised professionals who may have had longer waiting lists. In contrast, a higher frequency of documented autism behavioural features was associated with an earlier age of autism diagnosis in Maenner et al. (2013), indicating increased severity of external autism presentation facilitated earlier diagnosis.

Across studies, earlier age of autism diagnosis was found to be associated with lower receptive and expressive language abilities, language delay or regression, non-verbal communication impairments, inflexible routines, repetitive motor behaviours, atypical behaviours (i.e., hand-flapping, toe walking, sustained "odd" play), higher level of support needs, impairments in pretend play, and a diagnosis of

autism compared to other autism diagnostic labels (Bickel et al., 2015; Brett et al., 2016; Mandell et al., 2005; Maenner et al., 2013). Later age of autism diagnosis was associated with oversensitivity to pain, hearing impairments, and difficulties in peer relations, conversational ability, and idiosyncratic speech (Mandell et al., 2005; Maenner et al., 2013). These findings indicate certain needs or presentations might facilitate or obstruct the identification of developmental disabilities. Furthermore, professionals reported "complex cases" prolonged diagnostic processes (Moh & Magiati, 2012). It is possible that multifaceted needs without biological markers (e.g., autism) complicate and delay identification, as they may require multidisciplinary input or additional "tests" to rule out other causes of needs (genetic causes, visual or hearing impairments, etc.).

An increased number of needs appeared to facilitate identification. For example, in Jimenez et al. (2014), children were more likely to receive a developmental assessment if concerns spanned more than one developmental domain. Furthermore, the identification of autism was facilitated by the presence of co-occurring intellectual disability (Rosenberg et al., 2011; Zuckerman et al., 2015). Similarly, Mandell et al. (2009) found autistic children were more likely to be diagnosed if they had a cognitive impairment (measured as an intelligence quotient [IQ] of <70, suggesting the presence of a co-occurring intellectual disability), or if their IQ was unknown. This may explain why children diagnosed with Asperger syndrome experienced longer diagnostic delays and were diagnosed at later ages than children diagnosed with other autism diagnostic labels in Crane et al. (2016), as previously the diagnostic criterion for Asperger syndrome was the absence of a clinically significant cognitive impairment (e.g., American Psychiatric Association [APA], 2013; Mayes & Calhoun, 2003). Furthermore, autism "symptom severity" decreases as IQ increases, and autistic children with higher IQ are more likely to be diagnosed later due to displaying "milder symptoms" compared to those with a lower IQ (for further information see Mayes & Calhoun, 2003, p.21).

In contrast, Bickel et al. (2015) found higher cognitive and adaptive functioning predicted earlier autism diagnosis in children aged <36 months. Furthermore, Howlin et al. (1995) raised concerns regarding autism diagnosis in children with Down syndrome due to diagnostic shadowing, whereby autism symptoms are attributed to cognitive delays related to Down syndrome, obstructing

the identification of autism. The contradictory findings on IQ and age of autism diagnosis may be due to differences in the IQ measures or sample age. Bickel et al. (2015), for example, measured non-verbal, rather than standard IQ, and found cognitive functioning did not predict the age of diagnosis receipt when the analysis included children aged >36 months.

Child Demographics. Older child age appeared to be a barrier to identification (Jimenez et al., 2014; King et al., 2010). Compared to younger children, Jimenez et al. (2014) found children aged >24 months were less likely to be referred to and receive a developmental assessment. However, after controlling for other variables, the only family factors associated with developmental referral or assessment receipt were the nature of the need and child gender (Jimenez et al., 2014). It is possible child age might modify other factors. For example, King et al. (2010) found child age influenced professionals' decisions to refer a child for developmental assessment or not.

Male child gender was a facilitator of identification, whereas female gender was a barrier to both accessing a diagnostic assessment and receiving a developmental disability diagnosis, especially autism (Begeer et al., 2013; Brett et al., 2016; Jimenez et al., 2014; Mandell et al., 2009; Shattuck et al., 2009; Siklos & Kerns, 2007). In contrast, Bickel et al. (2015) found child gender was not predictive of the age of autism diagnosis receipt. Gender differences in autism diagnosis may also be linked to the nature of the need. For example, in Begeer et al. (2013), Asperger syndrome was the only autism diagnostic label for which females were identified later than males. Furthermore, differential presentation of autism between females and males can mask diagnostic features of autism in females, obstructing identification (Rynkiewicz et al., 2016). In Rynkiewicz et al. (2016), autistic females presented "better" on non-verbal communication (e.g., gestures) aspects of autism assessment compared to autistic males, which may in part explain the finding of delayed identification of autism in females.

Service Factors. Service factors that influenced identification were the implementation of developmental surveillance, screening methods, referral practices, professionals' recognition and perception of need, identification (i.e., assessment and diagnostic) methods, professionals' expertise, service capacity and availability, funding, and collaboration.

Developmental Surveillance and Screening. Similar to recognition, developmental surveillance facilitated the number of children subsequently identified with developmental disabilities (King et al., 2010; Nygren et al., 2012). Furthermore, the methods and tools utilised for non-routine developmental screening impacted identification as either a barrier or facilitator (King et al., 2010; Marshall et al., 2015; Roux et al., 2012). For example, Sices et al. (2009) found significant discordance between the outcomes of two commonly used developmental screening tools: Parents' Evaluations of Developmental Status (PEDS; Bricker & Squires, 1995) and the Ages & Stages Questionnaires® (ASQ®; Glascoe, 1997). The tools did not detect potential delays in the same children, with 33% of children being identified with a likely developmental disability through only one instrument (Sices et al., 2009).

Referral Practices. Referral practices inevitably influenced identification. Professionals' proactive response to parental concerns and sending referrals directly to assessment services facilitated identification, whereas passive or reassuring responses to parental concerns, placing responsibility or onus on parents to contact services, and complex referral systems were barriers to the identification of developmental delay or autism (Crane et al., 2016; Howlin & Moore, 1997; Jimenez et al., 2014; Zuckerman et al., 2015).

Referral practice was modified by the nature of the need, professionals' recognition or perception of need, parental concerns or desire for referral, and screening tools utilised (Jimenez et al., 2014; King et al., 2010; Zuckerman et al., 2015). For example, in Vande Wydeven et al. (2012) parents of autistic children were more likely to see a genetics professional if their child's doctor suggested a genetics evaluation, if they specifically requested to see a genetics professional, and/or if they received a genetics referral from their child's doctor. Of the parents who received a referral, the majority had previously asked for this referral (Vande Wydeven et al., 2012). Several parents reported the primary reason for not seeing a genetics professional was because their child's doctor had not referred them or suggested it, for example one parent said: '[My child] is currently being treated by Dr. [X] I will do whatever he recommends', and another said: 'We have not been referred and did not know how to go about getting into a genetics professional. I spent 4 years fighting' (Vande Wydeven et al., 2012, p.807).

Furthermore, parents of autistic children were more likely to receive passive or reassuring responses to their concerns and less likely to receive proactive responses compared to parents of children with other developmental disabilities (Oswald et al., 2017; Zuckerman et al., 2015). Shorter diagnostic delays were observed when professionals' responses to parental concerns were proactive rather than reassuring or passive (Zuckerman et al., 2015). Paediatricians were more likely to refer a child for speciality assessment compared to other professionals (e.g., general or family practice physicians, specialist physicians), perhaps indicative that experience and knowledge influences professionals' perception of need, or that certain professionals are not given adequate training to identify developmental disabilities (Shevell et al., 2001). Furthermore, professionals reported deferring or foregoing an assessment referral if they thought parents misunderstood screening questions, for example: 'I think [the questions] are written well for the most part, but I definitely absolutely have families who are at a low enough cognitive level that they don't understand' (Jimenez et al., 2014, p.321).

While the AAP policy statement recommends every child whose screen identifies a potential developmental disability should be referred for assessment (Council on Children With Disabilities et al., 2006), in King et al. (2010), services referred only 61% of children following a screen identifying potential developmental disability. Variation in referral rates may be linked to the screening tool used, perhaps indicative of differences in the way professionals utilised and/or perceived a screening tool's sensitivity (King et al., 2010). Referral rates were lower when the 10-item PEDS screening scale was used compared to the 30-item ASQ®, with 43% and 72% referral rates, respectively (King et al., 2010). This is concerning, considering twice as many children received a screen indicating potential developmental disability when PEDS was used rather than the ASQ® (King et al., 2010). Since widespread implementation of developmental surveillance, the rates of non-referral following screening indicating a potential delay have increased (King et al., 2010). This suggests the need for two distinct systems for screening and referral, as screening rates increased over time, but referral rates decreased, perhaps due to the fact services are largely focused on screening (King et al., 2010).

Professionals' Recognition and Perceptions of Need. Professionals' recognition of need facilitated identification (e.g., conducted assessment, referred to

another professional), whereas non-recognition of need was a barrier (e.g., told parent there was no problem, reassured parent) (Crane et al., 2016; Zuckerman et al., 2015). Professionals' perception of need was modified by their occupational role, nature and severity of the need, child age, ethnicity, and socioeconomic status. For example, professionals' perception of developmental disabilities in an artificial vignette varied dependent on their occupational role: psychiatrists more frequently identified autism, and speech and language practitioners more frequently identified language disorder (Cuccaro et al., 1996). Whilst this might indicate professionals' experience influences their perception of need, professionals' identification was not related to their years of work experience, experience with developmental disabilities, or experience working with children from ethnic minority groups (Begeer et al., 2009; Burke et al., 2015).

The frequency of developmental disability symptoms also influenced professionals' perception of need, as identification was higher when more developmental disability symptoms were present (Begeer et al., 2009; Burke et al., 2015; Cuccaro et al., 1996). Professionals less frequently identified autism in artificial vignettes describing children from low socioeconomic status backgrounds or ethnic minority groups (Begeer et al., 2009; Cuccaro et al., 1996). Potential socioeconomic status and ethnicity biases in perceptions of developmental disabilities were challenged in Burke et al. (2016), who found socioeconomic status and ethnicity did not influence the identification of developmental disabilities in artificial vignettes, rather the number of symptoms and child age did (e.g., identification of developmental disabilities increased when the vignette had higher developmental disability symptoms and decreased child age). The authors suggested previous findings may be due to a lack of tight controls for other factors (Burke et al., 2016), although it is possible biases are reducing over time. These findings should be interpreted with caution, however, as they are based on experimental situations and therefore may not represent real-life biases.

Professionals' perception of parental response to diagnosis also modified identification. For example, in Karim et al. (2012), professionals in the UK reported diagnosing children with Asperger syndrome, over another autism diagnostic label, if they thought parents "would respond better" to this label.

Professionals' Expertise. A study in the USA indicated a higher level of specialisation amongst professionals (measured by occupational role, for example specialist neurologists and psychiatrists) facilitated the identification of autism, whereas less expertise (e.g., primary care physicians) was a barrier to identification (Kalkbrenner et al., 2011).

Identification Methods. Assessment and diagnostic processes that were long, complex, and placed the onus on parents to obtain referrals and contact services, were barriers to the identification of autism in the UK (Howlin & Moore, 1997) and developmental delay in the USA (Jimenez et al., 2014). One parent commented: 'The time waiting for screening and diagnoses was a year, a long time spent wondering what could be wrong' (Crane et al., 2016, p.160), and a professional stated: 'we relied on the parents to make the first contact, that wasn't working because the parents would either forget or [the assessment service] was so busy they would tell them to call back...' (Jimenez et al., 2014, p.321). Similarly, Howlin and Moore (1997) reported that parents needed to be persistent to obtain an autism diagnosis, indicative of services over-reliance on parents to seek assessment and overcome barriers, placing the responsibility with families and not services and systems.

As there are no biological markers for autism, it has been proposed that the "gold-standard" diagnostic method is best-estimate clinical diagnosis (see Kuriakose & Shalev, 2016), which can be assisted by various diagnostic tools. The use of standardised diagnostic tools (e.g., diagnostic instruments, manuals) reportedly facilitated the identification of autism (Moh & Magiati, 2012). However, professionals did not always use diagnostic tools, reporting a preference for professional judgement, as tools were perceived as being complex, time-consuming, and/or not effective (Karim et al., 2012; Wiggins et al., 2006). For example, in Karim et al. (2012), while 58% of professionals reported using diagnostic manuals to facilitate the identification of autism, 42% of professionals reported not using diagnostic manuals and instead relied on their professional judgement. A preference to rely on professional judgement may act as a barrier to the identification of autism (Karim et al., 2012).

Although multidisciplinary assessments are recommended for the identification of multifaceted needs, including developmental disabilities (e.g., see

National Research Council, 2001; Penner et al., 2017), utilising a multidisciplinary approach was reported as being helpful to identify autism, but also increased the assessment duration and occasionally led to conflicts of opinion (Moh & Magiati, 2012). For example, a professional stated: 'it's part of our service policy if we suspect that a child has an autistic spectrum disorder we must set up a multi-agency team […] You could sometimes get into a disagreement with those professionals because they felt their professional view was being challenged…' (Karim et al., 2012, p.119).

Service Capacity and Funding. Limited capacity and availability of services and professionals were barriers to identification, including extensive waiting lists for autism diagnostic assessment and a lack of specialists (Karim et al., 2012). For example, one professional stated: 'I must admit the time slots that the children have in the clinic is probably not adequate to assess [autism]' (Karim et al., 2012, p.117).

Limited funding and resources within the system were also barriers to identification, modified by budget allocation. For example, Karim et al. (2012) found UK government funding cuts to services increased barriers to autism diagnosis. In contrast, the development of a robust funding and business model, to sustain service provision through ongoing acquisition of local and federal grants, facilitated autism identification in the USA (Mathews et al., 2018).

Collaboration. Poor communication and collaboration between services and professionals were barriers to the identification of developmental delay and autism (Jimenez et al., 2012; Mathews et al., 2018). For example, in Jimenez et al. (2012), professionals reported difficulties contacting other professionals (specifically paediatricians), was a barrier to the diagnosis of developmental disabilities.

Intersection Factors. Intersection factors that influenced identification were the nature and flexibility of service delivery in relation to family factors, communication between services and families, and geographical accessibility (i.e., the geographical intersection of services and families, such as geographical spread, proximity, and urbanicity).

Nature and Flexibility of Service Delivery. The intersection between service delivery (e.g., costs, services provided, location, flexibility) and family factors (e.g., economic resources, nature of the need, proximity to services, ability to travel) influenced identification. A good match between service delivery and family factors,

and flexibility in service delivery, was a facilitator of identification (Carr & Lord, 2016; Roux et al., 2012). For example, delivering assessments in the family home rather than at a clinic, and providing support with transport, facilitated autism identification amongst families with low socioeconomic status in the USA (Carr & Lord, 2016). As previously mentioned, Roux et al. (2012) found implementing screening via telephone calls in different languages appeared to facilitate the identification of needs for families with low socioeconomic status from ethnic minority groups, perhaps as these methods reduced barriers experienced by this group.

Communication and Contact. Communication barriers that influenced identification included a loss of contact between services and families for various reasons (e.g., staff turnover, family moving), professionals "not listening" to parents or addressing their perspectives, divergence in perceptions regarding needs, a lack of involvement of parents as partners, and linguistic barriers (e.g., Howlin & Moore, 1997; Jimenez et al., 2012; Roux et al., 2012). If a professional initiated the conversation about child developmental concerns, the child was less likely to receive a formal assessment (Jimenez et al., 2012), perhaps indicating the parent did not share the same concerns or that the professional did not explain the reasons they thought the child needed an assessment. Professionals not addressing parents' perspectives in relation to their child's development (i.e., when parents did not perceive a delay) was a barrier, which was perceived as being related to parental motivation to seek assessment and ability to overcome practical barriers (Jimenez et al., 2012). Unsurprisingly, limited parental knowledge or understanding of assessment services and referral systems were barriers that arose when parents were not given sufficient information from professionals (Jimenez et al., 2012, 2014).

The majority of both parents and professionals reported that increased support and guidance should be in place for families during identification (Keenan et al., 2010). Parental dissatisfaction with the identification of need was related to both a lack of involvement with parents as partners and disagreement with the outcome (i.e., the need identified): 'It was not a true overall result, professionals gave the impression they knew all the right questions to ask. But they never asked me what I knew about my child, considering mother always knows best' (Keenan et al., 2010, p.393). Howlin and Moore (1997) found, in addition to disagreement with the

outcome of diagnostic assessment, parents who were dissatisfied with the diagnostic process were more likely to seek further referrals, extending the process of identification.

Geographical Accessibility. The geographical proximity between services and families influenced identification. Inevitably, there are regional differences in services available, which might account for some of the variation in the age of diagnosis, and the duration of the diagnostic period (Howlin & Moore, 1997; Keenan et al., 2010; Moh & Magiati, 2012). A general lack of services where families lived was a barrier to identification (Howlin & Moore, 1997).

Increased urbanicity (indexed with indicators including population density, education level, occupation, age, and rate of physicians per population) was a facilitator of identification, whereas lower urbanicity was a barrier, modified by the nature of the need (Chen et al., 2008; Kalkbrenner et al., 2011; Rosenberg et al., 2011). For example, in the USA, Kalkbrenner et al. (2011) found a younger age of autism diagnosis in areas with a higher concentration of specialist neurologists and psychiatrists, and Rosenberg et al. (2011) found a later age of autism diagnosis in rural areas. Whilst Chen et al. (2008) found living in rural areas was a barrier to obtaining an autism diagnosis, they found no urbanicity differences were present in the diagnosis of other developmental disabilities in Taiwan.

Factors Influencing Early Support Receipt

Family Factors. Family factors that influenced the third phase, early support receipt, were parental socioeconomic status, ethnicity and culture, parental perceptions, parental awareness of services, parents' time resources, parenting confidence, parental readiness to take part, parents' language, parental gender, parental religion and faith, parental stress, family composition, nature and severity of need, and child demographics.

Parental Socioeconomic Status. Again, similar to recognition and identification, higher parental socioeconomic status (i.e., increased education and financial resources) was a facilitator and lower socioeconomic status was a barrier of early support receipt, modified by the financial set-up of services (Chauhan et al., 2017; Hudson et al., 2008; Jimenez et al., 2014; Mackintosh et al., 2012; Marshall et al., 2015; Payakachat et al., 2017; McConachie et al., 2001; Salomone et al., 2016).

The majority of studies that found economic resources or insurance coverage influenced early support receipt were conducted in countries without a universally free healthcare system, such as the USA and Bangladesh (Mackintosh et al., 2012; Marshall et al., 2015; McConachie et al., 2001; Payakachat et al., 2017).In these contexts, early support receipt varied depending on health insurance status and coverage (Marshall et al., 2015; Payakachat et al., 2017). For example, parents of children with limited or no insurance coverage experienced barriers of access to early support, due to the limited availability and capacity of services available for families with low socioeconomic status, such those provided as part of Medicaid (Marshall et al., 2015).

Parents who did not meet the criteria to receive economic support also experienced barriers of access to early support: 'I am having a very hard time getting help. We aren't poor enough for gov [government] assistance and our ins. [insurance] won't pay. Public school is all we have' (Mackintosh et al., 2012, p.57). As families with private insurance reported struggling to cover the cost of early support, this indicates either limited or no insurance coverage for early support, for example: 'We had [insurance] copays to pay but you know that twice a week $50 dollars each time […] it adds up' (Marshall et al., 2015, p.368) and: 'We use no treatments. Our insurance pays for nothing' (Mackintosh et al., 2012, p.57).

In addition to being a barrier of early support receipt, lower economic resources also influenced families' ability to access information about services (e.g., via the internet) and their capacity to travel to services (Marshall et al., 2015). Whilst economic barriers influenced early support receipt for families living in urban or rural areas of Bangladesh, some parents reported they had moved from urban to rural areas due to the cost of living in urban areas, which subsequently had implications on early support receipt, in relation to their proximity to services and travel costs (McConachie et al., 2001).

Rosenberg et al. (2008) found no association between poverty, health insurance and early support receipt in the USA. Whilst those in poverty were more likely to have a child with a developmental delay, there was no association between poverty and early support receipt (Rosenberg et al., 2008). Furthermore, whilst there were more children with health insurance that received early support than those without (2.9% versus 0.8% respectively), health insurance was not significantly

associated with early support receipt (Rosenberg et al., 2008). The lack of association between poverty, health insurance and early support receipt might be because Rosenberg et al. (2008) explored access to services under Part C of IDEA, which although are not universally free (unlike developmental assessments described above), the government states "inability to pay" will not result in the delay or denial of early support services. It is also possible that economic reimbursement for providers delivering early support services for families living in poverty also influences the relationship between socioeconomic status and early support receipt. For example, families who lived in states with higher Medicaid reimbursement rates in the USA were less likely to experience barriers of access to early support (Thomas et al., 2012b). Therefore, when Medicaid services are provided for families living in poverty, reimbursement rates appeared to modify the influence of socioeconomic status (particularly economic resources) on early support receipt (i.e., stopping lower socioeconomic status from being a barrier).

Parental economic resources also influenced early support receipt in countries with mixed service systems, which provide some universally-free services, such as India. The economic costs of services was reported as a barrier of early support receipt in India, with some parents also describing experiencing a dilemma in the allocation of their limited financial resources to meet the needs of all their children, not just their child with developmental disabilities (Chauhan et al., 2017). In India, public healthcare services are provided free to families living in poverty, however, it is reported that public services vary in quality and availability, with a shortage of services in rural areas where families in poverty are more likely to live. As a result, families may need to travel long distances to public services or pay for private services, which may explain why the economic cost of services was a barrier of early support receipt in Chauhan et al. (2017). Therefore, the issue of service availability and the availability of a skilled workforce appears to be a barrier regardless of whether the health system is universally free or not.

Economic barriers also prevented early support receipt for some families in countries with a universally free healthcare system, such as Australia and Canada. Although some universal coverage is provided for 'medically necessary [healthcare] services' in countries with a universally free service system (e.g., Government of Canada, 2016), early support for developmental disabilities is not always defined as

a “medical necessity”, which may explain the influence of socioeconomic status on early support receipt. Furthermore, families with lower income might struggle to pay for childcare or transportation to enable them to access early support. Hudson et al. (2008) mitigated this by providing economic support for childcare and transportation for families who needed it to access early support.

Generally, increased parental educational level or attainment was a facilitator of early support receipt. Salomone et al. (2016) found higher parental education level predicted early support receipt in Europe, which appeared to be modified by the geographical region and the type of early support services. Analyses of specific European regions found parental education level predicted specific early support receipt in East and South regions, but not in North and West regions (Salomone et al., 2016). Furthermore, lower parental education level was more frequent in families without any early support provision (Salomone et al., 2016). In a study by Payakachat et al. (2017) in the USA, higher maternal education level was associated with both increased number of early support services and hours of early support received per week.

In contrast, Bailey et al. (1999) found parental education level did not account for variance in early support receipt amongst Latino families in the USA. However, parental education level was associated with English language proficiency, which did account for variance in early support receipt (see below). This suggests, whilst parental education level was not directly related to early support receipt, it modified early support receipt via English language proficiency in this sample.

Ethnicity. Being part of an ethnic minority group was a barrier to early support receipt; children from ethnic minority groups were less likely to receive early support or received less early support provision compared to children from ethnic majority groups (Magaña et al., 2013; Rosenberg et al., 2008; Payakachat et al., 2017). For example, in their study of access to services under Part C of IDEA in the USA, Rosenberg et al. (2008) found children from White ethnicity groups were more than twice as likely as children from Black ethnicity groups to receive early support. In Magaña et al. (2013), Latino children were less likely than White children to receive speciality autism services, such as Applied Behavioural Analysis (ABA). One study found ethnicity did not influence early support receipt access (Adams et al., 2016), though this discrepancy might be due to methodological

differences, as it had a small sample size, wider age range, and investigated access to universally free healthcare services.

As rates of identification of developmental disabilities were differentiated across ethnicity groups, with children from ethnic minority groups less likely to be identified with developmental disabilities (e.g., Mandell et al., 2009, see earlier), reduced early support receipt amongst ethnic minority groups might be attributed to the differential identification or prevalence of developmental disabilities. Furthermore, children from ethnic minority groups were diagnosed at later ages (e.g., Mandell et al., 2002, see earlier), which might negatively impact early support service eligibility. The relationship between ethnicity and early support receipt may also be influenced by socioeconomic status, as families belonging to ethnic minority groups were more likely to live in areas with higher levels of deprivation (e.g., Thomas et al., 2012a, see earlier). Furthermore, parental perceptions of developmental disabilities and services appear to be differentiated by ethnicity and culture (e.g., Evans et al., 2016, see below), which may also account for some variation in early support receipt amongst ethnicity groups.

Parental Perceptions and Culture. Parental perceptions of developmental disabilities, their child's needs, and services influenced early support receipt, partly modified by culture, parental faith, and gender (Birkin et al., 2008; Chauhan et al., 2017; Evans et al., 2016; Jimenez et al., 2012, 2014; McConachie et al., 2001; McIntyre, 2008b; Salomone et al., 2014; Shyu et al., 2010). For example, in a study conducted in Taiwan, parents' attributions of the causes of autism influenced their decisions about early support (Shyu et al., 2010). In Birkin et al. (2008) and Jimenez et al. (2012), some parents did not receive early support because they expressed a desire to wait before accepting support, wanting to work with their child alone, or because they did not want support. For example, one parent said 'I would rather work with my child, before someone on the outside will work with them… But if when you work with them and if that doesn't work then yeah, I will talk to [early support services]' (Jimenez et al., 2012, p.554).

In a study exploring early support for families of children with developmental delays in India, Chauhan et al. (2017) found parents who perceived their child as physically weak often sought massage and medical services rather than educational services, associated with cultural perceptions of child development. In

addition, parents in the study generally perceived their children needed support for physical development (e.g., using their limbs) prior to support for speech development, which was reflected in increased access to physiotherapy compared to speech therapy in the sample (Chauhan et al., 2017). A minimal perceived benefit of special education in relation to cultural traditions and expectations was a barrier to early support receipt, for example: 'What's the use of spending money [on special education] now if she cannot be married in a good family' (Chauhan et al., 2017, p.54). The authors described this as parental inability to accept a realistic future goal for their child (e.g., achieving maximum functioning rather than a "cure" for developmental disabilities). This may be influenced by the previously described resource allocation dilemma, as parents had limited financial resources to meet the needs of the whole family (Chauhan et al., 2017).

Parental perceptions of developmental disabilities and services were also modified by parental faith and gender. For example, in Evans et al. (2016) qualitative study, positive faith and spiritual connection was a contributor to positive attitudes and perceptions of developmental disabilities and early support services amongst African American parents, which was as a facilitator of early support receipt.

Parental Awareness of Services. Limited parental awareness of services, systems, and processes was a barrier to early support receipt, modified by contact with professionals and the provision of information (Birkin et al., 2008; Chadwick et al., 2002). For example, in a study of parents of children with severe intellectual disabilities in the UK, low parental awareness of respite services was associated with a lack of contact with social workers (Chadwick et al., 2002).

Parenting Confidence and Readiness to Take Part. In a Bangladesh study of parents of children with cerebral palsy, McConachie et al. (2001) found mothers with lower parenting confidence (i.e., in their ability to provide adaptations to match their child's needs) were more likely to receive early support, compared to mothers with higher parenting confidence. Parental readiness to take part in early support also influenced early support receipt. In Birkin et al. (2008), parents reported their readiness to take part in early support influenced their participation in early support. Specifically, low parental readiness to take part (when early support was offered) was as barrier to early support receipt.

Parental Language. Parental language influenced early support receipt (Bailey et al., 1999; Marshall et al., 2015). In families whose primary language differed from that of the primary language spoken in their area of residence, language barriers were reported to make it difficult to access information about early support (Marshall et al., 2015). In Bailey et al. (1999), increased English language proficiency was associated with early support receipt and (as described above) parental education level modified language proficiency, as higher English language proficiency was associated with increased educational level in the sample.

Parental Gender. Being a father, as opposed to a mother, was a barrier to early support receipt, modified by perceptions of parental roles, cultural norms, societal expectations, work schedules, and the timing of early support (Evans et al., 2016; Herbert & Carpenter, 1994; Ridding & Williams, 2019). For example, in a UK study, Herbert and Carpenter (1994) reported no early support was directly offered to fathers, as early support was focused on support for the mother and child with Down syndrome. Similarly, a perceived disregard of fathers in terms of service provision (e.g., location, focus, timing of support), which was viewed as being more mother-orientated, was identified as a barrier of early support receipt by fathers of children with Down syndrome in the UK (Ridding & Williams, 2019).

Parental gender also appeared to modify perceptions of services. Mothers of children with a range of developmental disabilities and needs (developmental delay, cerebral palsy, behavioural needs, epilepsy) in Evans et al.'s (2016) study in the USA reported that fathers felt "uncomfortable" interacting with professionals, deferring care to mothers. In the study, mothers also reported fathers were more concerned with financially supporting the family and paying for early support, rather than participating in it. Limited time and work schedules were specific barriers to fathers' early support receipt (Evans et al., 2016; Herbert & Carpenter, 1994; Ridding & Williams, 2019).

Parental Religion and Faith. Parental religion and faith also influenced early support receipt (Dababnah et al., 2019; Hussein et al., 2019; McConachie et al., 2001). For example, some parents expressed a preference to access support from a religious healer rather than formal early support services, such as educational, medical, or social services (Hussein et al., 2019; McConachie et al., 2001). In their small qualitative study of Somali parents in the UK, Hussein et al. (2019) reported a

shift towards accessing both religious and formal early support, indicated in the following parent's quote: 'I think there has to be a balance, prayers are important but so is medical help' (Hussein et al., 2019, p.1414). Parental faith was also a modifier of parental perceptions of developmental disabilities and services (see above).

Parental Stress. Parents experiencing higher levels of stress were more likely to receive early support services, suggesting increased parental stress facilitated early support receipt (Thomas et al., 2007). Parental stress did not predict early support receipt in McConachie et al. (2011), however, higher levels of parental stress increased the likelihood of continued early support attendance. Difficulties obtaining early support was reported as a unique source of stress for parents, and so increased parental stress may be a result of navigating complex systems to in order to access early support (Mackintosh et al., 2012; McConachie et al., 2001). For example, one parent said: 'I'm like a deer standing in the middle of the highway with headlights shining in my eyes. I feel paralyzed [paralysed] not knowing which way to turn first in getting her help. I've exhausted most of my resources on her twin brother's therapies (he was diagnosed 1.5 years ago), and I'm not getting as much support for her. His needs were more obviously sensory and easier to diagnose. She is just miserable 95% of the time and states that she wants to die at 6 years old' (Mackintosh et al., 2012, p.58).

Family Composition. Family composition influenced early support receipt, modified by the type of early support and informal support available (Chadwick et al., 2002; Chauhan et al., 2017). For example, early support receipt was enhanced for some families living in multi-generational households in India, as they received additional childcare support, but for others this reduced their control over early support decisions (Chauhan et al., 2017). The number of children in the household also influenced early support receipt; parents with only one child with developmental delay, or two-three grown up children in addition to their child with developmental delay, accessed more early support than parents with two young children (Chauhan et al., 2017). In the study, parents with grown up children (especially daughters) received support with caring and household duties, parents with one child were able to focus their time on them, whereas parents with two children (one with developmental delay), reported early support receipt was a challenge due to time: 'I am always busy with either the household work or taking care of my disabled child.

My other child is getting very aggressive and does not behave with me properly' (Chauhan et al., 2017, p.53).

Parental Time. Parental time constraints were barriers to early support receipt, modified by family composition, employment status, work schedules, caring responsibilities, household duties, and other time commitments (Chauhan et al., 2017; Birkin et al., 2008; Evans et al., 2016; Marshall et al., 2015; McConachie et al., 2001; McIntyre, 2008a, 2008b). The time barrier was greater for families in cultures that place traditional expectations on mothers with regards to caring and household duties (Birkin et al., 2008). In addition, due to the time required to navigate service systems and access early support (and difficulty or inability to access childcare), many parents reduced their working hours or left employment to care for their child with a developmental disability, which subsequently reduced their economic resources and affected their health insurance status (e.g., Marshall et al., 2015; Montes & Halterman, 2008).

Nature and Severity of Need. The nature and severity of the need(s) influenced early support receipt. For example, Bowker et al. (2011) found reduced early support receipt amongst children with Asperger syndrome compared to children with other autism diagnostic labels. Generally, greater severity of need facilitated early support receipt, whereas lower severity was a barrier. For example, children with a greater likelihood of developmental disabilities or increased severity of developmental delay accessed more early support (Jimenez et al., 2014; Payakachat et al., 2017; Salomone et al., 2016; Twardzik et al., 2017), whereas children with a lower likelihood of developmental disabilities or milder developmental delay accessed less early support (Jimenez et al., 2014; Twardzik et al., 2017).

In contrast, increased complexity of behavioural needs acted as a facilitator or barrier of early support receipt (Payakachat et al., 2017; Salomone et al., 2014). In Salomone et al. (2014), children with higher levels of emotional and behavioural needs were more likely to access early support. Whilst behavioural needs did not influence the overall number of early support professionals accessed in Adams et al. (2016), the cost of services for children who displayed behaviours described as "destruction to the environment" or "aggression" were higher, indicating children with these needs accessed early support services at an increased frequency or

intensity. In Payakachat et al. (2017), however, children with higher levels of behavioural needs were less likely to access early support. Furthermore, some parents in McGill et al. (2006) reported their child was excluded from respite due to the presence of "challenging behaviour". Therefore, this may be due to limited availability or capacity of services with the appropriate skills or speciality to support children with behaviours that challenge.

The type of early support received varied according to the nature of the need (Chadwick et al., 2002; Marshall et al., 2015; Salomone et al., 2014). For example, an increased use of respite care was associated with having a larger family and parents' having less access to informal support from family and friends (Chadwick et al., 2002), both of which indicate a greater need for respite.

Whilst a trickle-down effect of delayed recognition or identification of developmental disabilities may in part explain the relationship between the nature of the need and early support receipt, it also appeared to be modified by other factors, such as service intake or eligibility criteria (Birkin et al., 2008; Twardzik et al., 2017).

Child Demographics. Although older child age appeared to be a barrier to early support receipt (Marshall et al., 2015), the type and amount of early support accessed varied dependent on child age (Payakachat et al., 2017; Salomone et al., 2016). For example, whilst younger autistic children (aged <3 years) accessed more hours of early support services, older autistic children (aged 3-6 years) accessed more early support services overall (Payakachat et al., 2017). Salomone et al. (2016) found certain child ages were associated with higher rates of contact with specific professionals or interventions; for example, younger child age predicted an increased use of behavioural, developmental, and relationship based early support.

Female child gender was a barrier to early support receipt and male child gender was a facilitator (Chen et al., 2008; McConachie et al., 2001; Payakachat et al., 2017). For example, female autistic children received less early support than males (Payakachat et al., 2017), which may be attributed to barriers in the preceding steps of the pathway subsequently influencing early support receipt (e.g., delayed recognition or identification). In contrast, some studies reported no evidence of gender differences and early support receipt (Adams et al., 2016; Salomone et al., 2016).

Service Factors. Service factors that influenced early support receipt were the implementation of developmental surveillance, referral practices, eligibility criteria, intake processes, formal identification of need, professionals' expertise, service capacity, availability, funding, collaboration, and coordination.

Developmental Surveillance and Referral Practices. Similar to preceding phases, the implementation of developmental surveillance facilitated early support receipt for children with developmental delays, as it increased the number of children who received early support (King et al., 2010). Referral practices that facilitated early support receipt included prompt follow-up post-diagnosis, sending referrals directly to services, and actively supporting families to enrol in early support (Carr & Lord, 2016; Jimenez et al., 2014). Carr and Lord (2016) facilitated early support receipt by actively supporting families to enrol in early support services, such as by contacting services (e.g., phone calls, emails) and completing application forms. Providing informational support to families, such as practical information and advice on early support services available in the area, also facilitated early support receipt (Carr & Lord, 2016). In contrast, complex referral systems and placing responsibility on parents to contact services were barriers to early support receipt (Jimenez et al., 2014).

Eligibility Criteria. Strict eligibility criteria (service level or regionally) were a barrier, and broad eligibility criteria were a facilitator of early support receipt (Birkin et al., 2008; Twardzik et al., 2017). For example, Twardzik et al. (2017) found higher early support receipt amongst children with developmental delays in states with a broad eligibility policy compared to states with a narrow eligibility policy in the USA. Furthermore, families reported being denied early support if they did not meet specific eligibility criteria, such as if their child was "too young" or "too old" (Birkin et al., 2008; Mackintosh et al., 2012).

Intake Processes. Service intake procedures also influenced early support receipt (Marchbank, 2017). For example, in Marchbank (2017), low levels of early support receipt following the rollout of the National Disability Insurance Scheme (NDIS, 2013; Australian Government, 2018) in Australia was attributed to "broken down" intake procedures before the NDIS became operational.

Formal Identification of Need. Formal identification of need (i.e., receipt of a diagnosis or label from a professional) generally facilitated early support receipt

(Chen et al., 2008; Jimenez et al., 2014; Payakachat et al., 2017). However, formal identification of a developmental delay did not *always* result in early support receipt for children and their families (Jimenez et al., 2014). Early support receipt was also facilitated by a younger age of diagnosis receipt and increased time passed since diagnosis receipt (Chen et al., 2008; Jimenez et al., 2014; Payakachat et al., 2017). The diagnostic label given also influenced early support receipt, potentially related to the type or level of support needs (e.g., Bowker et al., 2011; Chen et al., 2008; Payakachat et al., 2017; see above).

Professionals' Expertise. Increased professionals' expertise (i.e., higher levels of training and training in developmental disabilities) facilitated early support receipt, whereas lower expertise was a barrier (Brookman-Frazee et al., 2012a, 2012b; Chen et al., 2008; Hudson et al., 2008; Ludlow et al., 2012). Chen et al. (2008) found an associated increase in early support receipt amongst children who were diagnosed by a service or professional with increased expertise in developmental disabilities (e.g., metropolitan compared to local hospital, psychiatrist compared to less specialised professional).

Both parents and providers reported limited professionals' expertise in developmental disabilities, related to their access to training, was a barrier of early support receipt (Brookman-Frazee et al., 2012a). Furthermore, parents in Ludlow et al. (2012) reported it was difficult to find professionals that were "experienced enough" to support their child's needs, particularly childminders and respite carers, due to a perceived lack of training. In some cases, inability to access support led to parents leaving employment to care for their child full time (Ludlow et al., 2012; see above). In Brookman-Frazee et al. (2012b), therapists reported they lacked the "tools" needed to support autistic children and expressed "desperation" for autism training, indicating a lack of autism expertise.

In contrast, the provision of support to develop professionals' expertise in developmental disabilities was a facilitator of early support receipt, such as providing mandatory and supplementary training, opportunities to work alongside experienced practitioners, and networking meetings (Hudson et al., 2008). As a result, various practitioners developed the knowledge, skills and experience needed to deliver an early support programme and continued to deliver it 6 months after the trial ended (Hudson et al., 2008).

Capacity and Availability. Limited capacity and availability of services and professionals were barriers to early support receipt, including waiting lists, systemic issues of the delivery of local services, and a lack of specialists (Birkin et al., 2008; Mackintosh et al., 2012). For example: 'the worst dislike is the length of time spent on waiting lists for treatment [early support]' and 'My state does not offer enough services. I think the therapy they provide is a joke' (Mackintosh et al., 2012, p.57). Although roughly half of the parents in Birkin et al. (2008) reported they were either satisfied with the waiting time for early support or "didn't notice it", others said it "could have been better" or were very frustrated by it. As a result of dissatisfaction with waiting time, a small number of parents dropped out of the study (Birkin et al., 2008).

Service capacity issues have also resulted in some families not being able to access early support, where delays in obtaining a diagnosis resulted in the child exceeding eligibility criteria (Birkin et al., 2008). Rosenberg et al.'s (2008) findings indicate the capacity of early support services were insufficient to serve the estimated prevalence of children with developmental disabilities. Service constraints also have a negative impact on the number of sessions early support services were able to provide (George et al., 2014). McGill et al. (2006) suggest inequalities of access to family support is inevitable when there is limited proactive service provision, and it is likely only families who "make a nuisance" will receive support, potentially those with more financial, educational, and psychological resources.

Funding. Funding barriers also obstructed early support receipt, such as limited funding and resources within the system and unclear funding streams, modified by government legislation and budget allocation (Brookman-Frazee et al., 2012a, 2012b; Marchbank, 2017; Ridding & Williams, 2019). For example, legislation that stipulated funding for early support reduced barriers (see contextual factors later, e.g., Brookman-Frazee et al., 2012a, 2012b), whereas budget cuts increased barriers (Marchbank, 2017; Ridding & Williams, 2019). Changes in funding streams and a reduction in funding negatively impacted professionals' ability to provide early support in Marchbank (2017), resulting in a reduction in early support hours provided to families.

In Mathews et al. (2018), the development of a robust funding and business model to sustain service provision facilitated early support receipt, in addition to

identification; within the first 28 months all early support was universally free, after which a mandate was used so that those with insurance paid for early support through their insurance, and those without insurance were funded through scholarships and grants. This enabled Mathews et al. (2018) to meet their aim of providing early support for children without insurance or benefits. Similarly, the provision of grants to enable services to fund early support and to cover costs related to early support (e.g., travel, childcare) for families "in need" facilitated early support receipt in the USA (Hudson et al., 2008). In Brookman-Frazee et al. (2012a, 2012b), the special education system was the primary funding (and referral) source for community mental health services for autistic children, indicating the potential importance of special education funding in the USA.

Collaboration and Coordination. Poor collaboration and communication between services and professionals and a lack of coordination across services were barriers to early support receipt (Cassidy et al., 2008; Mathews et al., 2018). For example, families in Cassidy et al. (2008) reported a need for increased coordination, collaboration, and communication amongst early support services. Establishing and maintaining partnerships and links between organisations facilitated early support receipt, as it enabled collaboration and the opportunity to share resources (Carr & Lord, 2016). Furthermore, having a service or professional to act as a liaison between families and early support providers (e.g., by attending meetings) also facilitated early support receipt in Carr and Lord (2016).

Intersection Factors. Intersection factors that influenced early support receipt included the nature and flexibility of service delivery in relation to family factors, communication and contact between services and families, geographical accessibility, and the intersection of early support provision and family factors.

Nature and Flexibility of Service Delivery. A good match between service delivery factors (services provided, costs, etc.) and family factors (nature of need, available resources, etc.) facilitated early support receipt, whereas a poor match was inevitably a barrier (Birkin et al., 2008; Chadwick et al., 2002). When aspects of service delivery did not align with family factors, this presented difficulties and was a barrier of early support receipt. For example, despite reporting a need for respite provision, some parents of children aged <8 years denied respite care offered to them, as it was only offered as an overnight placement away from home, which was

perceived as not being appropriate for their needs and therefore not acceptable (Chadwick et al., 2002). Furthermore, parents were sometimes unable to access early support because the sessions required too much time commitment which did not fit around their existing commitments, sessions were not offered at times that were convenient for them, or the location was inaccessible to them (Birkin et al., 2008; Chauhan et al., 2017).

A poor fit between the nature of service delivery methods and families' culture (such as the use of video, large group sessions, and time commitments not matching parental obligations) was a barrier for some families (Birkin et al., 2008). For example, families from Māori and Pasifika cultures struggled in relation to videotaping, observation, and criticism: 'People are not too happy with the idea of videotaping. They wouldn't want to have a tape of their child being shown to a new group of people' and: 'I know that there is the observation aspect where you have to take video and then everyone has to critique that and for me that, I don't know, I think that as a family we would find that really hard. To be critiqued about different things. No matter how constructive it is it would be easier if that information could come from a kaumatua [elder]' (Birkin et al., 2008, p.113). Furthermore, one professional stated: '[Group participation] with other parents, that could be perceived as quite an anxiety-provoking thing for Korean parents because of language barriers and because they are not very used to speaking out in a group setting' (Birkin et al., 2008, p.113), indicating differences in the language of service delivery and the predominant language spoken by families may also be related to this (see below).

The ability of services to be flexible and adapt to meet the needs of families facilitated early support receipt. Flexibility and adaptability included, for example, providing services in accessible locations (e.g., local community centre, family home) or remotely (e.g., telephone, internet), delivering multiple services within a single location, providing early support in multiple delivery modes (e.g., reading, individual or group sessions), and offering services at times that are suitable for families (Carr & Lord, 2016; Chauhan et al., 2017; Hudson et al., 2008; Mathews et al., 2018; McIntyre 2008a; Phaneuf & McIntyre, 2011). For example, Phaneuf and McIntyre (2011) found using a three-tier model of early support delivery (e.g., self-administered, group or individual sessions) facilitated early support receipt, perhaps as it allowed for flexibility in the way early support was delivered to families. Fewer

parents accessed early support via self-administered delivery (where parents were given material to read at home) compared to group and individual sessions (in both, parents received material in sessions led by a professional) (Phaneuf & McIntyre, 2011).

Communication and Contact. Providing parents with practical information about local services and actively supporting their contact with other services facilitated early support receipt (Carr & Lord, 2016). Conversely, communication barriers between professionals and families obstructed early support receipt, such as lack of information and guidance provided to families and language barriers (Birkin et al., 2008; Carr & Lord, 2016; Howlin & Moore, 1997; Marshall et al., 2015). For example, some parents reported receiving no information or being given limited information that was out-of-date or overly generic (Birkin et al., 2008; Marshall et al., 2015). Parents highlighted that it would have been beneficial to have been provided with information early on, with regards to different services, benefits, and the roles and responsibilities of different professionals. For example, one parent in Howlin and Moore (1997, p.160) said: 'It would have helped us considerably if we had been provided, from the start, with a set of leaflets explaining the basic things parents need to know about […] It took us a long time to find out this sort of information, much of which was gleaned from other parents who had also found things out the hard way'. Another parent said: 'we didn't have any information, we didn't know we could actually go for a statement through the GP [general practitioner] or anything. There is no, there's no information at all. You, it's all down to you' (Ludlow et al., 2012, p.705). Both quotes perpetuate a sense that the responsibility of early support receipt fell on parents, and that parents need to be persistent and exert pressure on professionals and services in order to access early support (similar to identification, see above).

As described above, low parental awareness of available respite services was a barrier of respite receipt, which was strongly associated with families' lack of contact with social workers (Chadwick et al., 2002). It is possible contact with a social worker was a gateway to respite care receipt, as social workers are part of social services in the UK, which assess families' need for respite care. Parents' awareness of respite services also varied depending on which borough of London

they lived in, suggesting services in certain areas may be more effective in informing parents (Chadwick et al., 2002).

Language differences between services and families (i.e., a mismatch between the language of early support professionals or services and the language of families) was a barrier of early support receipt (Birkin et al., 2008; Carr & Lord, 2016). One parent in Birkin et al. (2008, p.113) said: '…most people can't speak the language. Language is a problem'.

Geographic Accessibility. Similar to identification, geographical proximity between families and services influenced early support receipt (Birkin et al., 2008; Chen et al., 2008; Howlin & Moore, 1997; Marshall et al., 2015; McConachie et al., 2001; Twardzik et al., 2017). For example, geographical proximity between families and services influenced early support receipt in New Zealand (Birkin et al., 2008). A lack of services where families lived was reported as a barrier to early support receipt in the UK and access was described as being subject to a "postal [zip] code lottery" (i.e., dependant on services available in the catchment area, rather than need) (Howlin & Moore, 1997; Ridding & Williams, 2019). For example, one parent in Howlin & Moore (1997, p.160) said: 'There is practically no support for parents here, save the odd bit of respite care. I have contact with a social worker once a year when they do a review of my son to see if he still has a need for respite'.

Urbanicity also appeared to influence the type of early support families received (Chen et al., 2008; McConachie et al., 2001). For example, Chen et al. (2008) found families living in urban areas of Taiwan received more psychiatric services, whereas families living in non-urban areas of Taiwan received services with specialities other than psychiatry.

Early Support Provision. A poor match between the early support provision (i.e., early support type or content) and family factors was a barrier, whereas a good match was a facilitator (Chauhan et al., 2017; Dababnah et al., 2019; McConachie et al., 2001). As previously described, parents generally sought early support that aligned with their perceptions of developmental disabilities or their child's needs (e.g., Chauhan et al., 2017; McConachie et al., 2001; Shyu et al., 2010). For example, parents of autistic children who perceived behavioural-based early support was important for their child appeared to be motivated to participate in a trial of behavioural-based early support (McIntyre, 2008b, p.10): 'several families of

children with autism reported to me that they were searching for behavioural strategies to use with their children and, given the emphasis placed on principles of applied behaviour analysis, volunteered for the study'.

Consideration of the cultural and contextual background of families in the development of early support facilitated access for "hard-to-reach" families, such as families including refugees or from ethnic minority groups (Dababnah et al., 2019; Magaña et al., 2017). For example, in Magaña et al. (2017), an ecological validity framework was used to develop a culturally sensitive and informed early support programme for Latino parents of autistic children. One critical element was the use of a community health worker model ("promotoro de salud model"), whereby early support was delivered by a lay health educator or peer leader indigenous to the Latino community, with training to provide education and encourage behavioural change in a culturally informed way. This was especially important due to a history of mistrust of medical professionals amongst this community. They also ensured the "promotoro" was a parent of an autistic child.

Modifications to increase the relevance of the early support for families also facilitated access (Kong & Au, 2018; McIntyre, 2008a). For example, McIntyre (2008a) modified a universal parenting programme, Incredible Years® Parent Training, to increase its relevance for parents of children with developmental disabilities (e.g., additional content on functional assessment of behaviour), which facilitated early support receipt. Kong and Au (2018) further modified the Incredible Years® Parent Training programme to increase its cultural relevance and accommodate the needs of dual-career Chinese parents (e.g., reducing the time commitment required, using the "growth mindset" concept to encourage praise and break challenging tasks into smaller parts; see Dweck, 2006), which also facilitated early support receipt.

Contextual Factors. Political events, political unrest, and government legislation influenced early support receipt. For example, during an early support trial for Syrian refugees in Turkey, a terrorist attack and an attempted government coup (which increased animosity towards refugees) were barriers to early support receipt, as they reduced the security and safety of families in their community (Dababnah et al., 2019).

The absence of government legislation requiring insurance companies to fund early support was reported as a barrier, whereas government legislation stipulating funding for early support facilitated early support receipt in the USA, such as the California Assembly Bill (AB2726, 1996; AB3632, 1984), which allocates funding for students with "mental health problems that interfere with their academic functioning" (Brookman-Frazee et al., 2012a, 2012b).

Discussion

In this chapter, I described a framework depicting the pathway of access to early support across three key phases (recognition of potential need, identification or diagnosis, and early support receipt) and provided an overview of factors identified in the research literature found to influence access to early support across this pathway for families of children with suspected or diagnosed developmental disabilities. Whilst some factors operated similarly across the pathway, others appeared to operate differently across phases, and the impact a factor had was context dependent. For example, whilst older child age facilitated recognition and identification of autism in children without intellectual disabilities, older child age was a barrier of early support receipt. The information brought together in my framework and narrative review is a useful starting point to consider potential implications for policy, practice, and future research, in relation to targeting investments to improve access to early support for families of children with developmental disabilities. Investments (financial or otherwise) to improve access to early support might have the most impact if targeted at factors which operate across multiple parts of the process. Conversely, factors which operate at only one phase might be useful for targeting individual or service level change.

Although I found that some factors influenced only one or two phases of the pathway of access to early support, it is likely that some influenced other phases but this evidence is simply not available due to gaps in the research evidence. For example, whilst the effect of staff turnover was only apparent at recognition, no studies included in this review examined the influence of staff turnover on identification or early support receipt. Similarly, although parental language proficiency (in relation to the prominent language spoken in their area of residence) emerged as influential to early support receipt, language barriers are likely to also influence recognition and identification. The influence of a factor at a specific phase

may also trickle down to subsequent phases. Whilst this phenomenon was clearly demonstrated for developmental surveillance (the implementation of developmental surveillance facilitated recognition, which in turn increased the number of children with needs formally identified and receiving early support as a result), other factors may also influence the process of access to early support in similar ways. Further, although in my narrative review factors are primarily described individually in terms of their influence on the process of access to early support, it is very likely that the factors are not independent. Rather, several factors are likely to co-occur and their influence on access to early support is interrelated, such as nature and severity of need, ethnicity, culture, language, and socioeconomic status (e.g., Rosenberg et al., 2011).

Implications

My overview of factors influencing access to early support (Figure 2.5) can be used to inform the development of future research investigating rates of access to early support, in addition to barriers, facilitators, and modifiers of access. Although I broadly discuss the implications of these findings below, access is context-specific, and the complex relationship between various factors may vary accordingly. My framework (Figure 2.5) can be applied to various contexts to develop a comprehensive understanding of access for a specific context. Several broad implications for policy and practice in relation to potential investments to increase access to early support emerged in my narrative review. In addition, my review suggests much needed research to explore gaps in the literature, develop this body of knowledge, and explore ways to improve access to early support.

First, policies to reduce poverty (or the effect of poverty on access to services) have the potential to facilitate earlier recognition and identification of needs, in addition to early support receipt. Reducing poverty has also been identified as the top priority and greatest global challenge in the Sustainable Development Goals (United Nations [UN], 2015). Whilst the specific steps required to reduce poverty or its impact on early support access will vary greatly across contexts (wealth of country, financial set-up of service systems, etc.), policies could target poverty directly or focus on either subsidising service costs or providing universal free access to education, health, and social services. The provision of universally free services has the potential to influence the entire early support access pathway, as

increasing contact with services increases the opportunities for professionals to recognise potential needs, in addition to increasing families' ability to access services to identify and meet needs. As families of children with developmental disabilities are more likely to experience poverty (Rosenberg et al., 2008), initiatives to remove or reduce economic barriers may be especially important to improve access to early support for this group. My findings also highlighted the need to increase the capacity and availability of services that are universally free or heavily subsidised, and to ensure services are available in areas with high deprivation. Where this is not possible, such as in areas with limited or no public services, providing support with transport or remote access (e.g., telehealth), may reduce barriers.

As parents usually were the first to recognise potential delays or needs, investments to raise parental awareness of developmental disabilities and other family needs could be beneficial, paired with practical advice on what to do if they recognise a potential need. Future research should explore the time delay between initial parental concerns and seeking support, as further understanding can help identify strategies to reduce this. As parents with higher socioeconomic status recognised needs earlier, interventions to increase awareness and knowledge could be most impactful if targeted at parents with lower socioeconomic status. Although belonging to certain cultural and ethnicity groups appeared to operate as a barrier to accessing formal early support, aspects of culture and ethnicity may act as protective factors for parental wellbeing (Akbar & Woods, 2019). Due to the clear influence of cultural and contextual factors on perceptions of developmental disabilities and help-seeking, factors identified in de Leeuw's et al. (2020) review on autism, which also included non-autism literature, could be useful for designing research to understand access in non-Western, low- and middle-income countries. Key factors include cultural norms, beliefs and attitudes, mental health and child development literacy, goals of seeking clinical help and transference of information towards the clinician (de Leeuw et al., 2020). It would also be beneficial to raise awareness of developmental disabilities amongst various professionals who work with children and families. Investment to increase the skill and capacity of the workforce is vital to improve early support access and requires multifaceted approaches to recruitment, retention, and the provision of adequate training and support for professionals. Training should cover recognising various needs, screening methods, referral

processes, diagnostic methods and early supports (Kuriakose & Shalev, 2016), as well as communicating with and building partnership with families.

Increasing professionals' awareness of children and families who are most at-risk of delays to recognition and identification (e.g., lower socioeconomic status, ethnic minority groups, female gender) may also improve early support access (Kuriakose & Shalev, 2016). Exploration of research into the recognition or identification of developmental disabilities in middle-late childhood or adulthood, including research on masking or camouflaging, may also be important for understanding and addressing these barriers earlier (e.g., Bargiela et al., 2016; Dean et al., 2016; Huang et al., 2020; Lai et al., 2017). For example, gender differences in autism symptomology and presentation, diagnostic criteria, assessment instruments (e.g., developed predominately on male populations), and societal gender biases might account for gender differences in autism identification (e.g., Mandy et al., 2012).

My findings highlight the need for further research in differential symptom presentation, professionals' knowledge of developmental disabilities, and the sensitivity of screening tools may facilitate progression from recognition to identification. Investment to roll out developmental surveillance and screening for all young children could improve access across recognition, identification, and early support receipt phases. Whilst this is particularly important for countries without universal screening systems, enhancing screening processes and methods is important for countries that implement universal screening. Universal screening may not be appropriate for different developmental disabilities. For example, there has been debate over the implementation of universal autism screening, citing the potential benefits of early identification and support, whilst raising concerns regarding the efficiency of screening tools (Mandell & Mandy, 2015). Therefore, a two-pronged approach to surveillance is needed, implementing universal developmental screening in addition to improving the effectiveness and practicality of screening tools. It is crucial to provide training and support in the use of screening tools for professionals. To enable professionals to select the most appropriate methods, the suitability and effectiveness of screening (and diagnostic) tools at detecting developmental disabilities in different groups of children (e.g., gender, culture, ethnicity) and different contexts should be reviewed. A useful example is a

recently published review of screening tools for developmental disabilities in the context of low- and middle-income countries (Marlow et al., 2019).

Conducting surveillance and screening for other family needs (e.g., parenting support, parental stress, mental health, behaviours that challenge, sibling adjustment) as part of routine monitoring may also be beneficial, especially for facilitating access to early support. This is key in a system designed to serve families, rather than just the child. Currently, early support mostly focuses on child needs, but as the family system influences child development and other early support outcomes (e.g., Totsika et al., 2020), the orientation of early support should focus on supporting the family system, as this is crucial for sustaining child outcomes (Brooks-Gunn et al., 2000). Therefore, the success of early support should be defined by both child and family-level outcomes (Bailey et al., 2008).

Assessment and diagnostic pathways need to be simplified with clear, transparent processes, referral practices, and criteria. Services and families should be involved in the development of local services pathways, with incentives to increase collaboration and partnership in the process, and to agree the responsibilities of each service. Right from the start, professionals should clearly explain to families the reasons for assessment referral, what they can expect from the process, and the potential benefits of early identification and support. Reducing reliance on families to navigate the system is vital. Monitoring the implementation of assessment pathways is crucial, to ensure they are fit-for-purpose and followed by professionals.

Although there is a significant amount of research into families' experiences across recognition to identification or diagnosis of developmental disabilities, especially autism, there is a paucity of research that captures families' experiences across all phases of the process. Whilst more comprehensive research is needed, following the identification of need, providing families with follow-up sessions to ensure they have the opportunity to discuss needs with professionals and to provide them with useful information (e.g., about the need, benefits and goals of early support, how to access services, eligibility, financial supports), may be critical to improve access from identification to early support receipt. Professionals and services should also provide families with practical support with access to early support (e.g., completing forms, emails, phone calls) and share up-to-date resources.

Investments to improve the intersection between service and family factors are also key to improving early support access. For example, providing multiple services in a single location with appointments coordinated across services could reduce the impact of several practical barriers of access (e.g., time, cost, travel). Employing culturally and linguistically diverse staff teams and ensuring the content of early support provision is culturally appropriate could reduce cultural barriers. The issue of limited service capacity in relation to need has to be addressed to increase the number of families served and reduce unacceptably long waiting times. Some actions to increase service capacity might be to: increase government funding for services, increase the size of the workforce with the skills to support families via training programmes and incentives, or to employ professionals to assess needs within existing services (e.g., specific to resource-constrained settings, such as establishing small-scale multidisciplinary teams and early support delivery by non-specialists, see Divan et al., 2015, 2019; Khan et al., 2018).

There is a need to develop an understanding in local areas of families of children with developmental disabilities in terms of prevalence, geographical spread, and demographics, to understand the match between the availability of services and local need. Considering the match between family factors, services provided (e.g., type of support, content of early support provision) and service delivery factors (e.g., location, costs, time, delivery method) may be invaluable to increasing access. Subsequent plans to reduce barriers can be instigated, such as ensuring services are provided at accessible locations (including the family home or virtually, where appropriate), the types and intensity of supports match the varied needs of families, information about early support is accessible to different groups, and the content of early support is appropriate matched to needs. Tools are available to help services review and increase their accessibility for various families, such as the model of risk, disability, and hard-to-reach families (Phoenix & Rosenbaum, 2019). It is vital that families are consulted with regard to the development and/or improvement of early support services.

Finally, investments to improve communication and partnership between services and families have great potential to facilitate access to early support. Communication barriers were prominent across the research evidence reviewed and had a detrimental impact on the process of access to early support, especially with

regard to professionals' responses to parental concerns. There is also emerging evidence that getting communication right is crucial to parents feeling that they are getting "good" support (Stanford et al., 2020). As parents were usually the first to recognise developmental delays (and were generally right in their assessment, e.g., Bellman et al., 2013), ensuring professionals respond effectively to parental concerns is key to facilitating timely identification and early support receipt. Increasing partnership between families and professionals may also be beneficial, especially in contexts with limited or reduced funding for services, such as the recent implementation of austerity by the UK government (Karim et al., 2012).

Limitations

Whilst my conceptual framework of access to early support (Figure 2.4) was simple so as to be inclusive of all services and provisions within early support, different factors influencing access may have been identified if a model of access to specific services was used, such as a framework of access specifically to healthcare services (Meade et al., 2015). I also acknowledge that my review may not reflect all available research evidence, as it was not a systematic review. However, it was intended as a starting point to conceptualise the process of access to early support and capture a diverse body of literature on factors that might influence this process for families of children with developmental disabilities.

Whilst conclusions drawn from the present review need to be considered within the context of the narrative review methodology, there is now room for empirical research and systematic reviews (with a clear pre-registered protocol, systematic inclusion and exclusion criteria, and quality assessment of the included literature) to rigorously investigate more focused questions on early support access for families of children with developmental disabilities.

Conclusion

In conclusion, several factors influence the process of access to early support across three key phases: (1) recognition of need, (2) identification or diagnosis, and (3) early support receipt or provision. Factors influencing access to early support spanned multiple levels (family, service, intersection, context) and operated as barriers, facilitators, or modifiers of the process. These findings are useful for targeting policy and practice investments to improve access to early support. My framework can also be used in future research investigating access to early support.

Chapter 3 (Study 2): Parental Caregiver Survey Examining Families' Access to Early Support for Children with Developmental Disabilities in the UK[4]

Abstract

The provision of early support is critical for families who have children with developmental disabilities, but existing evidence suggests access to early support is not always straightforward. The purpose of this study was to provide a comprehensive description of access to various early support provisions (e.g., professionals, services, interventions) for families of young children with suspected or diagnosed developmental disabilities across the United Kingdom (UK), and to investigate parental caregivers' perceived ease of access to early support, unmet need for early support, and barriers and facilitators of access to early support. A total of 673 parental caregivers of children aged 0-6 years with suspected or diagnosed developmental disabilities (developmental delay, intellectual disability, autism) completed my survey anonymously. Across education, health, and social care, services accessed the most were: paediatrics (*N* = 569, 84.5%), speech and language (*N* = 567, 84.2%), and general medical practitioners (*N* = 530, 78.8%). However, only 18.9% (*N* = 127) accessed packaged intervention programmes. More than three-quarters (*N* = 508, 75.5%) reported unmet need for early support, indicating a mismatch between the availability and capacity of services and demand for supports. Parental caregivers also reported common barriers (e.g., obstructive services, unhelpful professionals) and facilitators (e.g., supportive and competent professionals, enabling parent factors) of access to early support. Implications for policy, practice, and research are discussed.

[4]A version of this chapter has been published in the *Journal of Early Intervention* as follows: Sapiets, S. J., Hastings, R. P., Stanford, C. & Totsika, V. (2022). Families' access to early intervention and supports for children with developmental disabilities. *Journal of Early Intervention*. https://doi.org/10.1177/10538151221083984. The terminology and language used in this chapter varies from the published paper, as discussed in Chapter 1 (see p.1-2).

Introduction

The provision of early support for young children (i.e., 0-6 years) with developmental disabilities and their families is important, due to delays in cognitive and adaptive skills (American Psychiatric Association [APA], 2013; McDonald et al., 2006; Salvador-Carulla et al., 2011) and the presence of health and social inequalities (e.g., increased risk of co-occurring physical and mental health conditions, increased risk of exposure to traumatic experiences; see Chapter 1). However, as described in Chapter 2, data from several research studies indicate low levels of access to early support for children with developmental disabilities and their families, with access rates as low as 5% of young children with suspected or identified developmental disabilities (Betz et al., 2004; Birkin et al., 2008; Bromley et al., 2004; McManus et al., 2014a, 2014b, 2020; Feinberg et al., 2011; Rosenberg et al., 2008; Ruble et al., 2005; Salomone et al., 2016; Thomas et al., 2007; Wei et al., 2014; Zimmer & Panko, 2006; see Chapter 2). There is also variability in rates of access to early support. For example, Yingling and Bell (2020) found that 75.7% of 1,968 autistic children had accessed a state early support programme and 71.0% had accessed speech-language, occupational, or physical therapies (respectively 65.8%, 33.4% and 18.4%). In contrast, while examining access to early support under Part C of the Individuals with Disabilities Education Act (IDEA, 2004), a federal law that mandates early support services in the USA, Grant and Isakson (2013) found only 2.7% of age-eligible children across the USA accessed early support, with a range of 1.2-6.5% for specific states.

There may be a significant proportion of children with developmental disabilities who need but do not receive early support, indicating potential unmet need for various early support provisions. Furthermore, difficulties accessing early support (or services across childhood) are reported by parents of children with developmental disabilities, including difficulties contacting services, limited availability or a lack of services, waiting times, cultural, financial, and geographical barriers, to name a few (Betz et al., 2004; Birkin et al., 2008; Crane et al., 2016; Dababnah & Bulson, 2015; Hussain & Taint, 2015; Khanlou et al., 2017; Kohler, 1999; Zuckerman et al., 2015).

As described in Chapter 2, several factors can influence access to early support for families of children with developmental disabilities as barriers, facilitators, or modifiers of the process of access to early support. These factors can

be organised into four factor levels: (1) family, (2) service, (3) intersection, and (4) contextual. Barriers of access to early support include, for example, lower parental socioeconomic status, complex referral systems, limited funding for early support, and a poor match between family and service factors (see Chapter 2). In contrast, facilitators of access to early support include, for example, higher parental socioeconomic status, wide service eligibility criteria, consideration of families' cultural and contextual background during the development of early support provision, and government legislation stipulating funding for early support (see Chapter 2).

Current literature on families' access to early support is fragmented. Previous studies typically focused on one aspect of early support provision within the broad scope of early support, such as specific services or interventions (e.g., Birkin et al., 2008; Feinberg et al., 2011; Grant & Isakson, 2013; Karpur et al., 2019), or one developmental condition within developmental disabilities, such as autism (e.g., Birkin et al., 2008; Thomas et al., 2007; Wei et al., 2014). Whilst the findings of these studies are informative at highlighting potential gaps in families' access to early support, such as mental health services (Wei et al., 2014), there is a lack of research capturing access to a diverse range of early support provisions across education, health, and social care service systems for families of children with developmental disabilities broadly. In addition, a large proportion of available research data on access to early support is outdated or retrospective, limiting the practical applicability of the findings (e.g., Betz et al., 2004; Birkin et al 2008; Kohler, 1999; McManus et al., 2020). Research in this area is further limited in scope due to small and potentially unrepresentative sample sizes, especially for young children (e.g., Bromley et al., 2004; Dababnah & Bulson, 2015; Kohler, 1999; Toms et al., 2015).

Ensuring families who have children with developmental disabilities are able to access early support is clearly important. To inform ways to improve access to early support, it is first crucial to explore what early support provisions families are currently accessing or not accessing, unmet need for early support, and barriers and facilitators of access to early support. The main aim of the present study was to address gaps in the research by recruiting a large sample of families who have young children with suspected or diagnosed developmental disabilities across the UK. My research questions were: (a) What early support provisions do families of young

children with suspected or diagnosed developmental disabilities across the UK currently access (i.e., types of early support provisions, proportion of access, and waitlist to access)? (b) How easy do parental caregivers find accessing early support provisions? (c) What early support provisions do parental caregivers perceive as an unmet need? and (d) What are the main barriers and facilitators of access to early support perceived by parental caregivers?

Method

Participants

Overall, 673 parental caregivers of children with diagnosed or suspected developmental disabilities completed my survey (see Table 3.1 for key participant characteristics). The majority of respondents (referred to hereafter as parents') were the child's biological mother (*N* = 613, 91.1%), though a few were biological fathers (*N* = 28, 4.2%), adoptive mothers (*N* = 13, 1.9%), grandmothers (*N* = 10, 1.5%), or other caregivers (*N* = 5, 0.7%). The majority of participants lived in England (*N* = 505, 75.0%).

Child Characteristics. The majority of the children were male (*N* = 481, 71.5%) and the mean child age was 4.8 years (*SD* = 1.5, range 1 month to 6 years 10 months). A variety of developmental disability labels were reported (Table 3.2). The most common was autism (*N* = 524, 77.9%), followed by special educational needs (SEN) (*N* = 390, 57.9%), intellectual disability (*N* = 328, 48.7%), and developmental delay (*N* = 317, 47.1%). More than half of the children also had a physical health condition (*N* = 446, 66.3%), such as a mobility problem, visual impairment, hearing impairment, or epileptic seizures. Over half of the children (*N* = 338, 50.2%) had a statutory statement (termed education, health and care plan, individual development plan, coordinated support plan, or statement of SEN) that is a legally enforceable document detailing the child's education, health and social care needs and additional support the local government authority must procure to meet these. It is important to note that not all children with SEN will have had these needs recognised through a statutory statement. Over half of the children (*N* = 378, 56.2%) attended a mainstream educational setting (i.e., school, pre-school, nursery).

Parent and Family Characteristics. The majority of parents were female (*N* = 633, 94.1%) and the mean age of parents was 36.5 years (*SD* = 6.6, range 22-72). The majority of parents identified their ethnicity group as White (*N* = 618, 91.8%) and lived with a partner (*N* = 536, 79.6%). In approximately half of the families, at

least one caregiver was educated to degree level or higher (*N* = 339, 50.4%), and in more than three-quarters at least one caregiver was in full or part-time employment (*N* = 545, 81.0%). Over half of participants' equivalised household income was below the poverty line (*N* = 393, 58.4%), based on the Organisation for Economic Co-operation and Development (OECD, n.d.) poverty indicator (see below, Measures). Around one fifth of participants lived in the 20% most deprived neighbourhood areas (*N* = 137, 20.4%), based on the UK Indices of Multiple Deprivation (IMD; see below, Measures).

Table 3.1 Participant characteristics

Participant characteristics	Total *N* (%) or *M* (*SD*) range
Country of residence	505 (75.0) England
	71 (10.5) Northern Ireland
	66 (9.8) Wales
	31 (4.6) Scotland
Child age (years)	4.8 (1.5) 0.1-6.9
Child gender	481 (71.5) male
	189 (28.1) female
Child physical health	446 (66.3) ≥1 physical health problem
	227 (33.7) <1 physical health problem
Child statutory statement of SEN	338 (50.2) with statutory statement
	134 (19.9) with statement being developed
	31 (4.6) applied for but not received statement
	120 (17.8) not applied for statement
Child adaptive skills (GO4KIDDS)	21.4 (7.6) range 8-39
Child educational setting	378 (56.2) mainstream
	45 (6.7) mainstream in SEN unit
	179 (26.6) specialist
	14 (2.1) home
	55 (8.2) none
Parent age (years)	36.5 (6.7) 22-72
Parent gender	633 (94.1) female
	30 (4.5) male
	2 (0.3) other
Parent ethnicity group	618 (91.8) White
	24 (3.6) Asian/Asian British
	8 (1.2) Mixed/Multiple ethnicity groups
	5 (0.7) Black/African/Caribbean/Black British
	3 (0.4) Other ethnicity group
Parent marital status and living arrangement	536 (79.6) living with partner
	132 (19.6) not living with partner or single
Household education	338 (50.2) ≥1 caregiver educated to at least degree level
	310 (46.1) <1 caregiver educated to degree level
Household employment	543 (80.7) ≥1 caregiver in employment
	124 (18.4) <1 caregiver in employment
Household income poverty (OECD)	393 (58.4) ≤ poverty line
	195 (29.0) > poverty line
Area-level deprivation (IMD)	137 (20.4) ≤2 deciles (most deprived 20%)
	407 (60.5) >3 deciles
Other children with disabilities in household	189 (28.1) ≥1 other children with disabilities
	477 (70.9) <1 other children with disabilities

Notes. OECD = Organisation for Economic Co-operation and Development poverty indicator. IMD = Indices of Multiple Deprivation. SEN = special educational needs.

Table 3.2 Child developmental disability label and identification stage

Developmental disability label	Children with label[1] (*N* = 673)		Identification stage[2]					
			Diagnosed		Assessment		Waitlist	
	N	%	*N*	%	*N*	%	*N*	%
Intellectual disability	328	48.7	225	68.6	46	14.0	57	17.4
Autism	524	77.9	340	64.9	81	15.5	103	19.7
Developmental delay	317	47.1	252	79.5	38	12.0	27	8.5
Social communication disorder	214	31.8	115	53.7	43	20.1	56	26.2
Dyspraxia	121	18.0	39	32.2	29	24.0	53	43.8
Cerebral palsy	29	4.3	25	86.2	1	3.4	3	10.3
Down syndrome	54	8.0	54	100.0	0	0.0	0	0.0
Williams syndrome	5	0.7	3	60.0	1	20.0	1	20.0
Fragile X syndrome	7	1.0	4	57.1	2	28.5	1	14.3
ADHD	123	18.3	22	17.9	28	22.8	73	59.3
Complex needs	116	17.2	101	87.1	7	6.0	8	6.9
SEN, ALN or ASN	390	57.9	296	75.9	57	14.6	37	9.5
Other diagnosis	167	24.8	135	80.8	24	14.4	8	4.8

Notes. ADHD = attention deficit hyperactivity disorder ALN = additional learning needs. ASN = additional support needs. SEN = special educational needs.

[1]This includes all children with or suspected to have the respective developmental disability label (diagnosed, assessment, and waitlist).

[2]For identification stage, percentages in the table are proportions of children at each stage for the respective label. For example, 328 children had suspected or diagnosed intellectual disability, among those, 68.6% (225/328=0.6859) were diagnosed, 14.0% (46/328=0.1402) were in assessment, and 17.4% (57/328=0.1737) were on a waitlist.

Procedure

Ethical approval was granted by the University of Warwick's Humanities and Social Sciences Research Ethics Committee (reference 57/17-18, see Appendix 1 for ethical approval letters). Between September 2018 and May 2019, parental caregivers in the UK with a child aged 0-6 years (from birth until the day before their 7th birthday) with suspected or diagnosed developmental delay, intellectual disability, and/or autism were invited to complete the survey anonymously (see Appendix 2 for survey documentation, including the webpage, advert, participant information sheet, consent form, survey, and end of survey information sheet).

As there can be long delays to receipt of developmental disability diagnosis, especially diagnosis of autism (e.g., Crane et al., 2016), parental caregivers of children with *suspected* developmental disabilities were included. Furthermore, prior research indicates parents were often the first to identify developmental delays and were generally right in their assessment (e.g., Bellman et al., 2013). The child age range of 0-6 years was selected in line with my conceptualisation of early support as the provision of formal support across education, health, social care, and other service systems during early childhood (i.e., 0-6 years) (see Chapter 1). Furthermore, this age-range captures children whose developmental disability was recognised following contact with education services, as in the UK it is only compulsory for children to begin full-time education following their 5th birthday.

Participants were recruited via social media and distribution via several organisations that worked with families of young children with developmental disabilities in the UK, such as charities, independent service providers, and specialist schools. The survey took approximately 30 minutes to complete and was available to complete online (hosted by Snap™ Surveys) or by surface mail, based on participant preference. All survey questions were optional, except for 'child age' on the online survey. The survey was available in the English language only. As the survey was shared widely (social media, various organisations) and participation was both anonymous and voluntary, it was not possible to ascertain survey response rate. Participation was anonymous to reduce any potential concerns regarding participation impacting access to support from services. No incentives were provided for participation or survey completion.

Survey Development and Measures

For the purposes of this study, data on access to early support and a range of child and family characteristics were collected in the survey (see Appendix 2). The survey was developed with input from a group of key stakeholders, including parental caregivers of children with developmental disabilities, early support professionals, and charity organisations that work with families. Prior to distribution, the survey was piloted with four parental caregivers of children with developmental disabilities and adapted based on their feedback (e.g., terminology used, clarity of questions, length). Parental caregivers who piloted the survey were specifically recruited for this purpose through partner charity organisations as they had young children with developmental disabilities and experience of early support provision in the UK.

Access to Early Support. Access to early support was measured in several ways to capture access to various early support provisions (professionals, services, interventions). A comprehensive list of 49 early support sources was included in the survey. The list was developed with input from a group of parental caregivers and professionals to describe professionals and support services in the current UK context. Early support sources were presented in three groups: (a) 27 key professionals across education, health, and social care services (e.g., school staff, occupational therapist, social worker, respite carer, general practitioner; see Table 3.4), (b) 10 health specialists (e.g., neurologist, ophthalmologist, podiatrist; see Table 3.5), and (c) 12 other supports (e.g., parent groups, telephone helplines, websites, children's centres; see Table 3.5). For the 27 key professionals, participants were asked to report their contact with each (yes/no/on a waitlist/not sure) in the preceding 12 months. For the other supports listed, participants were asked to report any they had been in contact with in the preceding 12 months.

If a participant reported they *had not* accessed support from any one of the 27 key professionals, they were asked if they had wanted to access support from that professional (yes/no). Unmet need was defined as not access to a particular professional in the past 12 months **and** wanting to access this professional (i.e., support wanted but not accessed). A total count of unmet need for early support (possible range 0-27) was calculated as the sum of professionals' participants reported they wanted to access but had not accessed in the past 12 months.

Participants who indicated they *had* accessed support from professionals were then asked to rate: how easy it was to access the professional on a 5-point Likert-type scale, with 1 being 'very difficult' and 5 being 'very easy'.

Participants were also asked whether, in the preceding 12 months, either their child had received any interventions to support their development, or they had received any interventions to support them in their role as parental caregiver (yes/no). To help participants complete the question, a few interventions were listed as examples, such as Applied Behaviour Analysis (ABA), Hanen®, Early Bird, Triple P™, Incredible Years®, Social Communication Emotional Regulation and Transactional Support® (SCERTS®), Treatment and Education of Autistic and related Communications® (TEACCH®), therapy, and counselling. If a participant responded 'yes' they were asked to list the interventions or support approaches received in a free response text box. These responses were analysed to identify access to packaged intervention programmes, additional to the 49 early support sources covered in the quantitative part of the survey (see below, Analysis).

Participants were also asked to describe up to three things that made it difficult for their family to access support from professionals or services (i.e., barriers), and up to three things that helped their family to access support from professionals or services (i.e., facilitators). These responses were analysed to identify barriers and facilitators of access to early support (see below, Analysis).

Child and Family Characteristics. Data were gathered in the survey on the variables reported in Table 3.1. For child developmental disability, participants identified any developmental disability labels professionals had told them their child had (or might have had) from a list of 12 provided in the survey with a space for participants to write any other additional diagnoses or genetic syndromes (see Table 3.2). Participants selected the identification stage of applicable developmental disability labels from the following three options: waiting for an assessment, currently going through assessment, has received this diagnosis.

A self-identification measure of ethnicity recommended by the UK Office for National Statistics (ONS) was used, that comprised 18 responses across five ethnicity groups: Asian, Black/African/Caribbean, Mixed/Multiple ethnicity groups, White, and Other ethnicity group (Potter-Collins, 2011). Family income was equivalised using the modified OECD (n.d.) scale. Income poverty was measured using the OECD's definition; families with an income below 60% the UK median

equivalised income, £28,400 at the time of data collection (ONS, 2019), were classified as living in poverty. Using postal (i.e., zip) codes, neighbourhood deprivation was ascertained from UK IMD scores which incorporate seven domains: income, employment, education, health, crime, housing, and living environment (UK Government, 2019). Neighbourhood deprivation was dichotomised to identify participants living in the 20% most deprived neighbourhoods of their UK country (e.g., IMD deciles 1-2) versus participants living in less deprived neighbourhoods (e.g., IMD deciles 3-10).

To measure child adaptive skills, participants with children aged <2 years were asked 13 child development questions used in the Millennium Cohort Study, which comprised 8 items from the Denver Developmental Screening Test (Frankenburger et al., 1974) and 5 items from a UK adaptation of the MacArthur Communicative Development Inventories (Fenson et al., 1994). The questions measured three child development areas: (1) communicative gestures (e.g., 'S/he smiles when you smile at him/her'), (2) gross motor (e.g., 'S/he can sit up without being supported'), and (3) fine motor (e.g., 'S/he puts his or her hands together'). For each item, participants were asked to indicate how often their child demonstrates the behaviour on a 3-point scale (often/once or twice/not yet), with lower scores indicating fewer developmental skills. A summed score provided an overall development index (range 0-26).

For children aged >2 years, child adaptive skills were measured using the GO4KIDDS Brief Adaptive Behaviour Scale (Perry et al., 2015), modified to reflect UK terminology. Parents were asked eight questions measuring: (1) support needs, e.g., 'What level of support is needed for your child (e.g., toileting, dressing, eating)', (2) communication, e.g., 'How much does your child use spoken language to communicate', (3) socialisation, e.g., 'How much does your child engage in social interactions with familiar adults', and (4) self-help skills, e.g., parent is asked to select the most accurate description of child's eating skills. Items are rated on a 5-point scale (customised responses for each question), with higher scores indicating greater skill level and independence. I added an additional question to measure communication using augmentative and alternative methods, such as signing and symbol systems, e.g., 'How much does your child use alternative methods of communication to communicate'. For the GO4KIDDS Brief Adaptive Behaviour Scale, a total adaptive score is calculated by the sum of the 8 standard items (range

8-40). I made a small adjustment to this scoring method to better reflect the level of adaptive skills children had. The highest score for either the standard expressive communication item or the item on alternative methods of communication was identified and combined with the seven remaining items to create a total summed score. A total score was not calculated when participants had more than one missing item.

Analysis

Data from online and hard copy surveys were collated into a single database. Descriptive statistics were calculated for quantitative data. Text responses on interventions accessed were analysed to identify access to packaged intervention programmes, defined as multi-sessional support packages. Inclusion criteria for responses to be coded as a packaged intervention programme were: (1) Specific intervention programme named (e.g., *"Triple P Stepping Stones" "SCERTS" "Currently attending the Incredible Years Course once a week" "ABA 12 week programme" "funded and did the TEACCH train programme myself, I have also funded PECS"*), or (2) Clear indication of multiple-session supports additional to those covered in the quantitative part of the survey (e.g., *"Play therapy sessions once a week" "art therapy" "Counselling for Carers…10 sessions of counselling" "Two sessions with a family therapist"*).

Exclusion criteria were: (1) Multiple-session supports covered in the quantitative part of the survey, with no indication of an additional packaged intervention programme (e.g., *"Speech and language therapy" "Portage" "Physio Therapy" "Occupational therapy" "Sure start"*), (2) Single session or one-off supports (e.g., *"EHCP Workshop, Sleep Training Study day, Sensory Workshop" "Specialist teacher came in to give advice about what to put in place for her"*), (3) Supports provided without the mediation or involvement of a service or professional (e.g., *"I did a lot of work unsupported by professionals by reading books and watching videos online and then used this to help my daughter… Hanen's Talkability for Verbal Autistic Children"*), and (4) No intervention programme named or vague response (e.g., *"At school only" "Behaviour support"*).

Framework analysis (Ritchie & Spencer, 1994; Ward et al., 2013) was used to explore barriers and facilitators of access. Framework analysis is a rigorous and systematic qualitative analysis approach comprised of several distinct but inter-related stages (i.e., familiarisation, identifying a framework, indexing and charting

data, mapping, and interpretation). The first step, familiarisation with the data, involved reading all responses. Next, a framework is identified or developed to organise the data in a meaningful and manageable way, which I based on my framework of factors influencing access to early support for families of children with developmental disabilities (see Chapter 2). Subsequently, data were charted according to this framework based on: (a) the type of effect: barrier or facilitator, and (b) the factor level: family, service, intersection, or contextual. Prior to analysis, I developed a comprehensive a priori coding scheme based on the framework of factors influencing access to early support to identify barriers and facilitators of access across the four factor levels (family, services, intersection, and contextual). A bottom-up approach was then used to code the charted data; I delineated prominent barriers and facilitators that emerged from the data. During data analysis, the coding scheme was iteratively reviewed and revised. Where similar barriers or facilitators emerged, codes were merged into overarching barriers or facilitators where appropriate. For example, 'knowledgeable professionals' and 'positive engagement with professionals' codes were integrated to an overarching 'supportive and competent professionals' facilitator code.

I report the count of the frequency of mentions of barrier or facilitator codes by participants rather than the frequency of participants who reported the code, as this captured when participants described multiple things that impacted their access relating to one overarching barrier or facilitator code. For example, one participant reported *"Waiting lists"* and *"Long forms to fill in"* made accessing support difficult for their family, both of which were coded as service-level barriers, reflecting two mentions of this barrier. However, if a participant reported the exact same barrier or facilitator multiple times, this was only counted once. For example, one participant reported access to support was difficult because there were *"No groups for her [my daughter] to go to"* twice, which was coded as service-level barriers once, reflecting one mention of this barrier.

Furthermore, reporting the count of participants that reported a barrier or facilitator would not adequately reflect the data, as not all participants provided data in this section due to the survey questions being voluntary. Also, although participants were asked to provide up to three barriers and up to three facilitators, as responses were collected via free response text boxes, participants were able to report as many as they wanted, not a fixed number. Therefore, to reflect more

accurately the relative importance of a barrier or facilitator, I counted the frequency it was reported among those who provided data in this section.

A subset of the data (*N* = 80 participants, 11.9%) was independently coded by a Research Assistant, Catherine Stanford, and interrater reliability was calculated based on the percentage of agreement for codes identified and Cohen's Kappa (Cohen, 1960). There was substantial interrater reliability agreement for the codes identified (mean agreement 87.2%, range 84.5-90.3%, mean Kappa = 0.74, range 0.49–0.93).

Results

Access to Early Support

All participants' provided data on their family's access to a range of early support sources, including access to professionals, services, and interventions.

Access to Packaged Intervention Programmes. Less than one third of participants (*N* = 197, 29.3%) reported they or their child had received a specific intervention in the preceding 12 months, either to support child development or the participant in their role as parental caregiver. Using my coding scheme (see above, Analysis), free-text responses from less than one fifth of participants (*N* = 127, 18.9%) described access to a packaged intervention programme, supplemental to contact with the 49 early support sources (i.e., professionals, services) described below. A wide range of packaged intervention programmes were accessed by participants, the most frequently reported were Early Bird, ABA, Hanen® programmes, Triple P™ parenting programmes, TEACCH®, Incredible Years®, See and Learn®, SCERTS®, and talking therapy or counselling (see Table 3.3).

Access Professionals and Services. Of the 49 early support sources listed in the survey (i.e., professionals, services), supports accessed by the highest proportion of participants were: paediatrician (*N* = 569, 84.5% of participants accessed), speech and language therapist (*N* = 567, 84.2%), general practitioner (*N* = 530, 78.8%), dentist (*N* = 511, 75.9%), and school staff (*N* = 482, 71.6%). Supports accessed by the smallest proportion of participants were: foster carer (*N* = 7, 1.0%), podiatrist (*N* = 26, 3.9%), endocrinologist (*N* = 26, 3.9%), support to manage direct payments independent from the local authority (*N* = 38, 5.6%), and independent support advisor (*N* = 40, 5.9%). Data on participants' access to the 49 early support sources are presented in full in Tables 3.4 and 3.5.

Waitlist. Approximately one third of participants (*N* = 221, 32.8%) were on a waitlist for at least one of the 27 key professionals (*M* = 0.6 key professionals, *SD* = 1.1, range 0-11; Table 3.4). With the exception of foster carer, advocate, and independent support advisor (no participants reported being on a waitlist to access each of these), between 0.1% (*N* = 1) and 7.0% (*N* = 47) of participants were on a waitlist for each support source. Professionals with the highest proportion of participants on a waitlist to access were: occupational therapist (*N* = 47, 7.0% of participants on a waitlist), educational psychologist (*N* = 46, 6.8%), staff from the local authority or health team responsible for assessing SEN (*N* = 30, 4.5%), mental health professional (*N* = 30, 4.5%), and sleep practitioner (*N* = 23, 3.4%).

Unsure of Access. Almost one quarter of participants (*N* = 162, 24.1%) were "not sure" if they had accessed support from at least one of the 27 key professionals. For each of the 27 key professionals, a small group of participants (0.2-4.2%) were "not sure" if they had accessed support. Professionals with the highest proportion of participants unsure of access were: family support worker (*N* = 28, 4.2% of participants not sure of access), staff from the local authority or health team responsible for assessing SEN (*N* = 27, 4.0%), behaviour specialist (*N* = 27, 4.0%), advocate (*N* = 21, 3.1%), and independent support advisor (*N* = 21, 3.1%).

Unmet Need for Early Support

More than three-quarters of participants (*N* = 508, 75.5%) reported a perceived unmet need for at least one of the 27 key professionals (*M* = 3.2 key professionals, *SD* = 3.2, range 0-17; Table 3.4). Professionals with the highest perceived levels of unmet need (of participants who had not accessed the respective professional, not total sample) were: occupational therapist (*N* = 136, 52.9% of participants who had not accessed an occupational therapist), educational psychologist (*N* = 131, 52.8%), staff from the local authority or health team responsible for assessing SEN (*N* = 83, 52.2%), behaviour specialist (*N* = 232, 43.0%), and paediatrician (*N* = 28, 40.0%).

Ease of Access to Early Support

Mean ease of access ratings for the 27 key professionals were between 2.3 and 3.8 (possible range 1 to 5; Table 3.4). Supports with the highest ease of access ratings were: foster carer (*M* = 3.8, *SD* = 1.0), dentist (*M* = 3.8, *SD* = 1.0), charity worker (*M* = 3.7, *SD* = 1.1), optician (*M* = 3.7, *SD* = 1.0), and advocate (*M* = 3.6, *SD* = 1.2). Supports rated the least easy to access were mental health professional (*M* =

2.3, *SD* = 1.3), social worker (*M* =2.4, *SD* = 1.3), staff from the local authority or health team responsible for assessing SEN (*M* = 2.6, *SD* = 1.2), home support staff (*M* = 2.6, *SD* = 1.3), and behaviour specialist (*M* = 2.6, *SD* = 1.3).

Table 3.3 Packaged intervention programmes reported by participants

Packaged intervention programmes[1]	Participants[2]	
	N	%
Early Bird	26	3.9
Applied Behaviour Analysis	17	2.5
Hanen® programmes	16	2.4
Triple P™ / Stepping Stones™	13	1.9
TEACCH®	13	1.9
Incredible Years®	10	1.5
See and Learn®	6	0.9
SCERTS®	5	0.7
Talking therapy or counselling	5	0.7
Other parenting courses (e.g., autism and ADHD parenting courses, communication courses, sleep training, Theraplay training, sensory processing training)	16	2.4
Other interventions[3] (e.g., Cygnets, play therapy, Lego® therapy, PACT, PECS®, attention autism, Intensive Interaction®, family therapy, music therapy, E-PAtS, sensory integration therapy, PRT, Son Rise® programme, reading interventions, sleep therapy)	43	6.4

Notes. ADHD = Attention Deficit Hyperactivity Disorder. E-PAtS = Early Positive Approaches to Support. PACT = Paediatric/Pre-school Autism Communication Therapy. PECS® = Picture Exchange Communication System®. PRT = Pivotal Response Treatment. SCERTS® = Social Communication, Emotional Regulation and Transactional Support®. TEACCH® = Treatment and Education of Autistic and related Communications Handicapped Children®.

[1]Packaged interventions were identified by analysing participants' text responses on interventions accessed using my coding scheme (see Analysis).

[2]Participants were able to report multiple interventions, therefore the number reported in this table exceeds the number of participants whose text responses were coded as access to packaged interventions (*N* = 127, 18.9%).

[3]Specific interventions were reported by <4 participants.

Table 3.4 Access to key early support sources, unmet need, and ease of access ratings

Support source	Access to support (*N* = 673)				Unmet need[1]		Ease of access ratings[2]	
	Accessed		*Waitlist*					
	N	%	*N*	%	*N*	%	*M*	*SD*
Education and social care professionals								
Childminder or nanny	91	13.5	2	0.3	47	8.4	3.5	1.3
Social worker	157	23.3	15	2.2	63	13.0	2.4	1.3
Respite or short break worker	82	12.2	15	2.2	156	27.9	2.8	1.2
Foster carer	7	1.0	0	0.0	4	0.6	3.8	1.0
Home support staff	77	11.4	7	1.0	118	21.0	2.6	1.3
Staff at nursery, pre-school or crèche	442	65.7	3	0.4	3	1.4	3.5	1.2
Staff at school	482	71.6	9	1.3	12	8.1	3.4	1.3
Portage worker	143	21.2	10	1.5	118	23.8	3.3	1.2
Staff from the LA or health team that assess SEN	451	67.0	30	4.5	83	52.2	2.6	1.2
Behavior specialist	79	11.7	21	3.1	232	43.0	2.6	1.3
Charity worker	281	41.8	6	0.9	75	20.7	3.7	1.1
Advocate	56	8.3	0	0.0	100	17.0	3.6	1.1
Independent support advisor	40	5.9	0	0.0	51	8.6	3.3	1.2
Family support worker	129	19.2	5	0.7	133	26.6	3.2	1.2
Healthcare professionals								
Educational psychologist	361	53.6	46	6.8	131	52.8	2.8	1.1
Speech and language therapist	567	84.2	21	3.1	29	39.7	3.0	1.2
Occupational therapist	348	51.7	47	7.0	136	52.9	2.8	1.3
General practitioner[3]	530	78.8	2	0.3	6	4.9	3.4	1.1
Health visitor	413	61.4	1	0.1	35	14.4	3.5	1.2
Paediatrician	569	84.5	19	2.8	28	40.0	2.9	1.2
Geneticist	152	22.6	16	2.4	76	16.2	2.9	1.1
Dietician	196	29.1	22	3.3	103	24.5	3.3	1.1

Sleep practitioner	106	15.8	23	3.4	181	34.8	3.2	1.2
Physiotherapist	240	35.7	12	1.8	54	13.7	3.4	1.2
Optician	361	53.6	10	1.5	26	9.4	3.7	1.0
Dentist	511	75.9	12	1.8	44	33.3	3.8	1.0
Mental health professional	97	14.4	30	4.5	112	21.7	2.3	1.3

Note. LA = local authority. SEN = special educational needs.

[1]Unmet need: For professionals' participants had not accessed (excluding waitlist), participants were asked if they had wanted support from the professional, a response of 'yes' was categorised as unmet need. Percentages in the table are the proportions of participants that reported unmet need among those who had not accessed the professional. For example, 561 participants had not accessed a childminder, among those, 8.4% (47/561=0.0838) reported an unmet need for access to a childminder.

[2] Ease of access: For professionals' participants had accessed, participants were asked to rate the ease of access on a 5-point scale. Higher scores indicate the professional was rated easier access.

[3]A general practitioner is a community based medical doctor that treats common medical conditions in the UK.

Table 3.5 Access to other early support sources

Support source	Access to support (N = 673)	
	Accessed	
	N	*%*
Health specialists[1]		
Audiologist	237	35.2
Neurologist	123	18.3
Cardiologist	80	11.9
Endocrinologist	26	3.9
Respiratory	49	7.3
Ophthalmologist	165	24.5
Gastroenterologist	43	6.4
Continence specialist	93	13.8
Podiatrist	26	3.9
Orthotist	97	14.4
Other services and supports		
Telephone helpline	96	14.3
Parent or self-help group	303	45.0
Interactive website	453	67.3
Non-interactive website	172	25.6
SEND information advice and support service	208	30.9
Specialist services for child's needs	161	23.9
School transport department	123	18.3
LA housing department	56	8.3
Benefit or financial advice	114	16.9
Support to manage direct payments independent from the LA	38	5.6
Children's centre	154	22.9
Carer's centre	44	6.5

Note. SEND = special educational needs and disabilities. LA = local authority.
[1]In addition, 9.8% of participants reported access to health specialists not listed in the survey (e.g., otorhinolaryngology, orthopaedics, optometry, orthoptics, rheumatology, dermatology, diabetology, nephrology, chiropractic, immunology).

Barriers and Facilitators of Access to Early Support

Barriers of access to early support were identified from participants' descriptions of what made accessing support difficult for their family. Facilitators of access to early support were identified from participants' descriptions of what helped their family access support.

Barriers of Access to Early Support. Six overarching barriers emerged (see Table 3.6), primarily covering service, family, and intersection factors. Barriers with the highest count of mentions by participants were: service-level barriers (insufficient resources and capacity, adverse or inflexible service features, lack of

continuity; *N* = 711 mentions), unhelpful professionals (negative engagement styles, obstructive actions, limited knowledge; *N* = 225), parental caregiver barriers (limited knowledge, other responsibilities, time constraints, lack of resources and support from family or peers; *N* = 133), and an absence of services (*N* = 108; Table 3.6). A small group of participants (*N* = 64, 9.5%) reported no barriers.

Facilitators of Access to Early Support. Seven overarching facilitators emerged (see Table 3.7), primarily covering service, family, and intersection factors. Facilitators with the highest count of mentions by participants were: supportive and competent professionals (positive attitudes and engagement styles, proactive support, knowledgeable; *N* = 151 mentions), followed by empowered parental caregivers (resources, skills, proactive behaviours, knowledge; *N* = 133), peer and family support (*N* = 127), and accessible services (features of service delivery, flexibility, provision of resources, availability, continuity; *N* = 119; Table 3.7). Over one-fifth of participants (*N* = 154, 22.9%) did not identify anything that facilitated their access to early support.

Table 3.6 Barriers of access to early support

Barrier code	Total *N*[1]	Description	Examples
Service-level barriers	711	Obstructive service-level factors, such as limited service capacity, under-resourced services, adverse or inflexible service features (e.g., entry criteria, admin, location, time), and a lack of continuity of support.	'Government funding cuts' 'services oversubscribed' 'Cost associated with equipment' 'support only during working hours' 'Need diagnosis to access help' 'early discharge when still a need'
Unhelpful professionals	225	Unhelpful elements of how professionals engage with parents (e.g., negative attitudes, not listening, being dismissive or obstructive, not providing information) and limited knowledge of developmental disabilities and services.	'Difficult people who don't help unlock other services' 'Professionals that have no empathy' 'Rudeness of staff' 'professionals not knowing if your child is eligible for services' 'not recognising autism in girls'
Complex service system	190	Obstructive aspects of a complex service system and system-level factors, such as a lack of service coordination or collaboration, absence of information on services, and a lack of accountability for access.	'Confusing system' 'Lack of transparent, clearly defined care Pathway' 'No joined up approach. Each service seems to act solely independently' 'Batted from one to another so not taking responsibility'
Parental caregiver barriers	133	Obstructive parent factors, such as limited knowledge of services or developmental disabilities, other responsibilities, time constraints, lack of resources and support from family or peers, and parent attributes.	'Had no idea how the system worked' 'Difficult to access when you also have a younger child' 'work commitments' 'Lack of transport' 'Separated from husband and he is unsupportive' 'my own anxiety'
Absence of services	108	Absence of general or specific support services and practitioners (e.g., post-diagnostic support, parental support, specialist support).	'No groups for her to go to' 'Lack of respite provision' 'No provisions after diagnosis' 'no occupational therapy available' 'Specialist settings not available'
Nature and presentation of child needs	50	Child needs that are either: a) less severe or less visible based on external presentation, or b) more severe or complex, including the presence of multiple needs.	'Non-visible symptoms' 'child masking' 'autism isn't "severe" enough' 'told he's too severe' 'complex conditions' 'multiple diagnoses'

Notes. [1]Total reflects the count of mentions of barrier codes across participants, not the frequency of participants who reported each barrier, to capture when participants described multiple things that impacted their access related to one overarching barrier.

Table 3.7 Facilitators of access to early support

Facilitator code	Total *N*[1]	Description	Example
Supportive and competent professionals	151	Supportive elements of how professionals engage with families (positive attitudes, engagement style, actions, proactive support) and their knowledge.	'Attitude and willingness to help' 'Compassionate and knowledgeable professionals' 'Empathy' 'A professional who listens and reads medical notes or care plans'
Empowered parental caregivers	133	Enabling parent factors, such as parents' resources (financial, travel), attributes, skills, proactive behaviours, and knowledge of services and developmental disabilities.	'My determination' 'Ability to pay' 'Being able to drive' 'not taking no for an answer' 'Going to MP' 'Knowing what to say/ask for' 'Awareness of what is available'
Peer and family support	127	Support from other parents, family members, friends, or colleagues, including informational and practical support.	'The prior knowledge of other parents who 'know the system' more than I do' 'Help making calls from parent group' 'Help with paperwork from friends'
Accessible services	119	Accessible features of service delivery (criteria, location, contact), flexibility, provision of resources (benefits, childcare), financial set-up (free, low-cost), availability and capacity, and continuity.	'Direct contact telephone numbers' 'drop-in session at Children's Centre' 'Short waiting time' 'Longer/double appointments' 'Bursaries (travel, childcare for my other children when we go to appointments)'
Professionals' acknowledgement of need	79	Professionals' acknowledgement of need, such as recognition, assessment, or formal identification of need (e.g., diagnosis, support plan, report), and making referrals to other professionals or services.	'carers assessment' 'General Practitioner advising to see the Paediatrician because of autistic traits' 'developmental assessment' 'Getting a diagnosis' 'Paediatrician reports' 'Having an EHCP in place' 'Health visitor referral to sure start'
Information and advice	77	Service information, advice and signposting, including general and access-specific information.	'portage particularly helpful at signposting' 'IPSEAS website for their valuable tools in applying for an EHCP'
Service collaboration	21	Collaboration between services and professionals, including collaboration with the family.	'Having a multi-disciplinary team who will meet together' 'Communication between professionals'

Notes. MP = Member of Parliament. EHCP = Education Health and Care Plan. IPSEA = Independent Provider of Special Education Advice. [1]Total reflects the count of mentions of facilitator codes across participants, not the frequency of participants (see Analysis).

Discussion

In this chapter I provided comprehensive data on current access levels to early support among a large sample of families of young children with (suspected or diagnosed) developmental disabilities in the UK. My findings show families of young children with developmental disabilities access support from a diverse array of professionals and services across education, health, and social care (similar to Maltais et al., 2020). However, only a small proportion of families access packaged intervention programmes that are generally considered internationally to constitute "early intervention", and there was variation in families' access to early support.

Access to primary healthcare services (i.e., general practitioner, health visitor, dentist, optician) was high, with a low proportion on a waitlist and low levels of unmet need. Primary health services were also rated easy to access. These findings may reflect that primary health services are universally free for children in the UK, are designed to serve the UK population, do not require a referral to access, and are community based (i.e., local settings, including home). High levels of primary health access may also reflect the increased prevalence of health conditions among children with developmental disabilities (Allerton et al., 2011). However, primary health services in the UK are a gateway to more specialist services, as referrals from primary care are often required to access such services. Therefore, repeated contact with primary care services may be a necessity for families to obtain referrals to diagnostic or other specialised services (e.g., Crane et al., 2016; Zuckerman et al., 2015).

Access to specialised healthcare services was less straightforward, perhaps reflecting the diverse range of specialised supports covered in my survey, which can be delivered in the community, hospitals, or specialist centres. Paediatrics and speech and language were accessed by the highest proportion of families, likely due to these professionals' key roles in developmental disability assessment and early support provision. Previous research indicates communication development concerns facilitate parental support seeking and professional referral to early support (see Chapter 2), which may explain the high proportion of access to speech and language in my study. This may also be due to the high proportion of children with (suspected or diagnosed) autism in the sample, as speech and language therapy is one of the most common intervention approaches for children with autism in the UK (Denne et

al., 2018). Furthermore, several packaged interventions reported by participants in the present study predominantly focused on communication supports (e.g., Early Bird, Hanen® programmes, TEACCH®, See and Learn®, SCERTS®, Makaton courses for caregivers, PACT, PECS®). Despite high access, paediatrics and speech and language were rated as being relatively difficult to access, potentially reflective of the high demand for these services or the difficulty obtaining a referral. The importance of speech and language emerged in participants' free-text responses, several reported paying for private access or access through other services (e.g., children's centre, school). In addition, limited capacity (or a complete absence) of publicly funded speech and language services was perceived as a barrier, which may be suggestive of variation in public service provision across the UK.

Educational psychology and occupational therapy were accessed by around half the families, with a high waitlist in comparison to other supports and high levels of unmet need. Educational psychologists generally assess children's learning and development using psychological approaches and techniques, in addition to supporting children, their families, and schools to promote children's emotional and social wellbeing. The role of educational psychologists is similar to that of school psychologists in other countries, but they are not typically school based in the UK, instead they are positioned at the level of the local educational authority, requiring a referral to access. It is likely these supports are in high demand for families of children with developmental disabilities due to the nature of the difficulties associated with developmental disabilities (see Chapter 1), however, my findings highlight failures across service delivery to meet these needs. Similar to speech and language, limited capacity (or absence) of publicly funded educational psychology or occupational therapy was perceived as a barrier by participants, along with difficulties obtaining referrals and inflexible entry criteria (e.g., age, diagnosis, catchment area). In contrast, parents' ability to fund private services was thought to facilitate access.

Access to mental health and sleep practitioners was low, with a moderately high waitlist and relatively high levels of unmet need, consistent with previous research (Bromley et al., 2004; Toms et al., 2015). Mental health professionals were rated the most difficult to access of all early support professionals in the survey. Difficulties accessing these services may reflect the complex, multifactorial nature of

mental health and sleep disorders in children with developmental disabilities, and a general lack of knowledge amongst professionals regarding such needs and services, further confounded by a limited capacity of specialist services (Read & Schofield, 2010; Royal College of Psychiatrists, 2016; Sutton et al., 2019). Previous research demonstrates an inadequate capacity of mental health services to serve children with or without developmental disabilities (Crenna-Jennings & Hutchinson, 2020; Toms et al., 2015). In the UK, children may be excluded from mainstream mental health services due to the presence of developmental disabilities or behaviour that challenges; or excluded from developmental disability services if they do not have the "right" diagnosis (Royal College of Psychiatrists, 2016). Conflict between services regarding criteria, terminology, or provision can result in 'families being left stranded between services' (Royal College of Psychiatrists, 2016, p.14). Participants in the study reported unhelpful professionals was a barrier of access to mental health and sleep services, due to a lack of knowledge and professionals being dismissive of their concerns (e.g., one parent commented "*Clinical Overshadowing everything was put down to ASD [autism]"*).

Physiotherapists, dieticians, and geneticists were each accessed by around one quarter of participants, but had relatively low levels of unmet need, indicating a closer match between service availability and demand for these compared to other health specialists, or that families experience fewer obstacles accessing them.

Access to education was generally high, with low levels of unmet need or participants on a waitlist. It is, therefore, unsurprising that education services were rated as being easy to access. This likely reflects the organisation of education services across the UK: education provision is universally free for children from age 3 (at least part-time), with full time education provision universally free and compulsory from age 5. Equally, access to teams that assess SEN was high, but also had a high proportion on a waitlist and high levels of unmet need. Formal identification of SEN is often a requirement to access specialist early support, therefore, these services are crucial. Participants' free-text responses indicated barriers to accessing teams that assess SEN were insufficiently resourced services, complex process, extensive delays and waiting times, unsupportive or obstructive professionals, and having to "fight" to access support (e.g., parents' commented: *"Cuts in SEN" "waiting times for the EHC [education, health and care needs]*

assessment and draft and communication from the LA [local authority] is appalling" "EHCP [education, health and care plan] writing is very behind, the 20 week plan. This is very distressing"). Whilst some families who had accessed a SEN assessment or statutory statement perceived it as a facilitator, for other families barriers persisted, with SEN support not being provided primarily due to unsupportive professionals, a lack of understanding of developmental disabilities and limited resources in education services (e.g. one parent commented: *"My son has missed 15 months of compulsory schooling due to failure to implement EHCP properly and train staff in medical needs currently waiting a tribunal date"* and another stated *"Funding allocated to him was withdrawn to fund school deficit by head"*). Similar barriers accessing SEN assessment and subsequent provision in England were found in Cullen and Lindsay (2019).

In the USA, early childhood special education is a key aspect of early support provision (Reichow et al., 2016). While some educational supports in the UK are similar (e.g., portage, specialist educational provision, educational psychology, educational interventions), there is no direct comparison. Therefore, there may be scope to expand on early childhood special education for early support in the UK. The majority of children in the present study attended a mainstream educational setting, rather than a specialist school or a SEN unit within a mainstream school. While this is promising in terms of inclusion, it may indicate limited educational support if the mainstream provision has insufficient resources or expertise (e.g., parents' reported: *"Lack of funding at schools to provide additional support whilst waiting for a diagnosis" "Lack of understanding at first mainstream primary school"*). Participants' free-text responses on interventions accessed indicated several children accessed these at school (e.g., *"School do TEACCH and other specialist interventions"* "*ABA therapy, speech therapy and play therapy - all at special school"* "*We managed to get our child in a school that has taken on the Hanen method, is also taking on SCERTS"*). While this demonstrates the potential importance of school for access to early support, it also indicates a potential gap in early support provision for younger children. However, as participants were not directly asked to specify where early support sources were accessed, this needs to be interpreted with caution.

Family-directed services appeared to be a challenge to access, perhaps representing a key gap in provision compared to child-directed services (cf. Turnbull et al., 2007). Access to home support, respite, and family support workers was low, and around one fifth of the total sample perceived these as unmet needs. This is likely an underrepresentation of this need, as families are often not aware of the availability or importance of family-directed supports in comparison to child-directed supports (Harbin et al., 2000; Turnbull et al., 2007). As social workers typically link families to these services (or act as gatekeepers), these findings may in part be explained by the low rate of access to (and reported difficulty of accessing) social workers in the sample. This is supported by previous evidence of an association between a lack of contact with a social worker and lower awareness of respite services amongst parental caregivers of children with intellectual disabilities in the UK (Chadwick et al., 2002, see Chapter 2).

Similarly, access to social work for families of children with developmental disabilities has been reported as problematic by practitioners (Okumura et al., 2018). Limited capacity and increasing thresholds to access family-directed supports also emerged in the study (e.g., one parent reported *"Told we didn't need [respite and personal budget] as we are not in crisis and doing very well"*), contradicting the very principles of early, preventative support and intervention. Low rates of access to family-directed early supports are especially concerning, considering the provision of only child-directed supports may not be as effective at improving child development.

Access to interventions, especially packaged intervention programmes, was considerably low and there was substantial variation in the interventions reported, covering a range of child-directed (e.g., ABA, SCERTS®), parental caregiver-directed (e.g., parenting courses, counselling), and family-directed (e.g., Hanen® programmes, family therapy) supports. This may partly be due to the broad question used to capture participants' access to interventions. The question was intentionally broad to capture the wide range of interventions that may be provided to children with developmental disabilities and their families. My findings may not thoroughly reflect participants' levels of access to packaged intervention programmes, as participants were required to name interventions their family had accessed in a free-text response box. This relied on participants' being aware of (and able to recall) the

interventions. Eight of the most frequently reported packaged interventions were included as examples listed in the question (Early Bird, ABA, Hanen® programmes, Triple P™, TEACCH®, Incredible Years®, SCERTS®, and talking therapy or counselling), whereas other examples listed were not reported by any participants (Early Intensive Behavioural Intervention, Parents Plus Early Years Programme, CANparent). Nonetheless, a considerable number of additional packaged intervention programmes were reported by participants (e.g., See and Learn®, Cygnets, Paediatric/Pre-school Autism Communication Therapy).

Significant levels of unmet need for support in the early years are highlighted in my findings, with over three-quarters of families perceiving an unmet need for at least one key professional. Prominent areas of perceived unmet need included: (1) assessment and/or provision of support for developmental disabilities and associated needs (e.g., occupational therapy, educational psychology, SEN assessment, behaviour support, speech and language therapy, sleep support); (2) provision of family-directed supports (e.g., respite, family support work); and (3) general health services (e.g., paediatrics, dental). My findings indicate a potential mismatch between the availability and capacity of services to support children with developmental disabilities and the demand for support (i.e., number of families perceiving the need for support), perhaps related to austerity, and higher prevalence of some developmental disability diagnoses (e.g., autism; Chiarotti & Venerosi, 2020). It is not unusual for families to report wanting more services than they receive (e.g., Harbin et al., 2000), especially if they perceive access to more specialised support will lead to better child outcomes (McWilliam et al., 1995). However, as access to more services or professionals can be negative for families (McWilliam, 2016), perceived unmet need for support from specialised services may instead reflect a lack of understanding or expertise of developmental disabilities in non-specialised services. This may also reflect very few services come under non-specialist primary care provision in the UK (e.g., general practitioner, dentist, teacher), as most services have moved under specialist care.

A crucial finding in this study is the identification of the complexity of the early support system in the UK as a barrier, along with a disjointed approach to the provision of support across services. Similarly, parents reported that collaboration and communication between early support professionals and services facilitated

access (cf. Atkins et al., 2020). Over the past four decades there have been significant developments moving away from fragmented service systems, with multiple agencies working autonomously, towards achieving a more comprehensive and coordinated service system for early support in the USA (Harbin et al., 2000). Despite progress towards this goal, Harbin et al. (2000) highlight interagency coordination is complex and nuanced, with service delivery models being influenced by an ecological cluster of interacting factors, and 'the enactment of legislation and the implementation of that legislation are very different processes' (p.387). While similar efforts have also been made in the UK, for example the Children and Families Act (2014) and the SEND Code of Practice (2014), it is clear there is still a long way to go to providing a cohesive service delivery system for families. There was also a recurring rhetoric of families having to "fight" to access various supports (cf. McWilliam et al., 1995), at least in part due to the inadequate capacity of specialist services to serve families. This suggests access is based on parent ability to advocate to access support, which raises concerns regarding equity.

Implications

A number of implications can be drawn these findings which should be beneficial to inform initiatives to improve access to early support for families of children with developmental disabilities.

Implications for Policy and Practice. It is important for policy and public health to acknowledge and address the high levels of unmet needs. In terms of practical implications, improving professionals' engagement styles and understanding of family needs and available services is key to facilitating access, enabling professionals' to effectively support families. There also needs to be change on a wider systemic level, such as simplifying processes, coordinating support services, examining service coverage and requirements (i.e., age, diagnosis), to ensure no families fall through the net, in addition to increased government investment in early support services.

Existing initiatives to improve the provision of early support in other contexts could be adapted to improve access to early support in the UK, such as service coordination under Part C of IDEA (McWilliam, 2016; Harbin et al., 2000). This is a coordinated approach to provision across a comprehensive service system, incorporating individualisation, family-centred focus, integration of therapies, and

inclusion (see McWilliam, 2016; Harbin et al., 2000). As these characteristics appear congruent with the barriers and facilitators of access to early support raised by families in the present study, implementation of service coordination for early support in the UK context may be beneficial. It may also be beneficial to draw on National Health Service (NHS) England's keyworker pilot, currently targeting children and young people with intellectual disabilities and/or autism who are inpatients in, or at risk of being admitted to, a mental health hospital (NHS England, n.d.). If successful, the keyworker model could be expanded to support all children with suspected or diagnosed developmental disabilities and their families, rather than just to those with 'the most complex needs', ensuring a more proactive approach to supporting children and families to 'get the right support at the right time' (NHS England, n.d.).

Implications for Future Research. Future research on families' access to early support will be beneficial, especially studies utilising population-based samples. The development of comprehensive quantitative measures of access to intervention programmes will also be advantageous. In addition to the areas covered in the present study, collecting data on: (a) the location of early support provision (e.g., family home, community service, school, hospital), (b) their funding (public, private, or other), (c) the focus of supports (child, parental caregiver, or family directed), (d) resources required for families to access (e.g., service costs, travel, time), and the flexibility of the supports (i.e., ability to tailor to individual and family needs or highly specified curriculum to follow) will be helpful to further understand families' experiences of access to early support. In addition, future research should capture data from a range of early support stakeholders (children with developmental disabilities, parental caregivers, professionals working across education, health, social care and other services, service providers, commissioners, etc.). Last but not least, to ensure equitable access to early support for all families, future research should identify interacting factors linked to variation in levels of access across families.

Limitations

Although these findings highlight key issues regarding access to early support, as I used a convenience sample there is potential risk of bias and therefore generalisability to all families with children with developmental disabilities in the

UK is limited. Participants were recruited primarily through third-sector developmental disability organisations and social media. Consequently, families not in contact with these networks or social media platforms may be underrepresented in the sample. A few autism-focused charities supported with recruitment, which may explain the high proportion of children with (suspected or diagnosed) autism in the sample.

While the study included a diverse sample in relation to socioeconomic indicators, for example, income poverty (58.4% of participants, compared to 32% of UK households in 2020; Department for Work and Pensions, 2021) and unemployment (18.4% of participants, compared to 13.4% of UK households in 2021; ONS, 2021), there was an overrepresentation of participants who identified their ethnicity group as White and an underrepresentation of participants from other ethnicity groups. Compared to census data for England and Wales in 2011 (ONS, 2018), the sample had overrepresentation of participants that identified their ethnicity group as White (N = 618, 91.8% of participants; 86.0% of census) and an underrepresentation of parental caregivers that identified their ethnicity group as Asian (N = 24, 3.6% of participants; 7.5% of census), Black (N = 5, 0.7% of participants; 3.3% of census), Mixed/Multiple (N = 8, 1.2% of participants; 2.2% of census) and other ethnicity groups (N = 3, 0.4% of participants; 1.0% of census). Future research could address this by designing accessible studies (culturally, linguistically, etc.) and targeting recruitment to promote participation from families typically underrepresented in research. Despite these limitations, reasonable confidence can be placed in the descriptive statistics reported due to the large sample size (N = 673).

As my measurement of unmet need for early support was based on parents' perspectives of "wanted support" from professionals they had not accessed, it is possible participants may not have known what support other professionals provide or if their family needed those services. However, it does provide insight into parents' perspectives of unmet need for early support that is part of the standard health and social care system across the UK. Whilst parents' experiences and perceptions of access to early support are extremely informative, my study lacked perspectives of professionals and services within the early support system. However, similar findings have emerged in studies of professionals within the early support

system. For example, in Mazurek et al. (2020), primary care providers reported their lack of knowledge and insufficient resources were barriers to the provision of support for families of children with developmental disabilities.

Conclusion

The findings of this study clearly indicate access to early support is not straightforward for families who have a young child with suspected or diagnosed developmental disabilities in the UK, and there are several common barriers and facilitators of access to early support.

Chapter 4 (Study 3): Predictors of Access to and Unmet Need for Early Support in Families of Children with Developmental Disabilities in the UK

Abstract

It is important to ensure families of children with developmental disabilities can access early support. Current research on access to early support is limited, especially during the early years (0-6 years) and in the United Kingdom (UK). This study aimed to examine predictors of access to early support, including access to interventions, access to early support sources, and unmet need for early support in families of young children with suspected or diagnosed developmental disabilities in the UK. I designed and conducted a survey of parental caregivers (N = 673) and fitted multiple regression models for intervention access, access to early support sources (professionals and services across education, health, social care, and other services), and unmet need for early support. Receipt of a developmental disability diagnosis and increased caregiver educational level were associated both with a higher likelihood of accessing intervention and increased access to early support sources. Increased access to early support sources was also associated with receipt of a statutory statement, a higher number of child physical health conditions, lower adaptive skills, caregiver White ethnic majority group, and an increased informal support. Increased family economic deprivation, one (rather than two) caregivers in the family household, less informal support, and lower helpfulness of informal support were associated with increased unmet need for early support. Multiple factors influence access to early support in families of young children with suspected or diagnosed developmental disabilities in the UK. Key implications to address disparities include the provision of more accessible services and enhancing the flexibility of service systems to respond to the individual needs of families during the early years.

Introduction

Early identification of developmental disabilities (e.g., developmental delay, intellectual disability, autism) and the provision of support during the early years (0-6 years of age) can improve a range of child and family outcomes and potentially reduce the likelihood of health and social inequalities (e.g., physical and mental health disparities, poorer caregiver wellbeing; see Chapter 1). The importance of early support for children with developmental disabilities and their families is also highlighted in policy and guidance documents worldwide (see Chapter 1).

Despite this recognition, comparatively little evidence is available on accessing early support during the crucial early years of development. Overall, research suggests that levels of service access are low for families of children with developmental disabilities and families report experiencing difficulties accessing support (Betz et al., 2004; Crane et al., 2016; Dababnah & Bulson, 2015; Hodgetts et al., 2015; Hussain & Taint, 2015; Khanlou et al., 2017; Ruble et al., 2005; Vohra et al., 2014). However, most of the evidence considers early years, middle childhood, and early adulthood together. In Chapter 3 (Study 2), I investigated rates of access to support specifically during the early years in the UK. In this study, I found variable rates of access to early support sources, with rates of accessing statutory services being higher than rates of accessing packaged intervention programmes. Given the importance of the early developmental period for several child outcomes (e.g., Guralnick, 2005; Inguaggiato et al., 2017; Ismail et al., 2017; Webb et al., 2014), research is needed to investigate factors that facilitate or impede access to early support during the early years of development.

Predictors of Access to Early Support

Existing research suggests several factors influence access to early support for children with developmental disabilities and their families (see Chapter 2). Factors predicting access to early support include (for example) caregiver ethnicity, educational attainment, and economic resources, the primary language spoken at home, and child age, gender, ethnicity, and individual needs (Kasilingam et al., 2019; Khetani et al., 2017; Marshall et al., 2016; McIntyre & Zemantic, 2017; McManus et al., 2014b, 2019; Nguyen et al., 2016; Roberts et al., 2008; Rosenberg et al., 2008). Although the findings of these studies are informative, current research evidence on this topic is limited. There are also challenges and limitations in the existing evidence base.

First, different measurements of access to early support have been used across studies, often related to specific interventions and therapies (e.g., Kasilingam et al., 2019; McIntyre & Zemantic, 2017; Nygren et al., 2016), rather than overall contact with health, education, social care, and other service systems that can provide support to families during the early years. Furthermore, broad or general dichotomous measurements of support access have been used, such as receipt of an individualised family support plan (IFSP), individualised education plan (IEP), receipt of Part C early support services, or caregiver report of qualification for the use of special therapies (e.g., Marshall et al., 2016; McManus et al., 2014b; Roberts et al., 2008; Rosenberg et al., 2008). It is possible these broad measurements do not fully capture variation in access to early support. Some studies examined variation in access to early support, such as the timeliness, intensity, and discipline of services received (e.g., Khetani et al., 2017; McManus et al., 2019). However, this was amongst families of children who had either been referred to or received early support. Therefore, this may not fully reflect the experiences of families who do not receive early support.

Second, the samples of several studies have consisted of children who have already obtained a diagnosis of developmental disability, primarily autism (Kasilingam et al., 2019; McIntyre & Zemantic, 2017; Nygren et al., 2016). Therefore, their findings might not account for factors impacting access to support in families whose children have not yet received a formal diagnosis or label of developmental disability. Considering one of the main aims of early support is prevention, such as early identification of developmental disabilities and reduction of the risk of secondary health and psychosocial difficulties experienced by children and families (e.g., Royal Australasian College of Physicians, 2013), it is important to investigate access among everyone, not just those with established diagnoses.

Last, I could find no studies in the UK context about access to early support for families of children with developmental disabilities. As the set-up of service systems varies across countries, inevitably impacting access to support (see Chapter 2), research in the UK would inform the development of strategies to improve access to early support for families specific to the UK context.

Predictors of Unmet Need for Early Support

In addition to exploring levels of access to support, it is also important to understand predictors of unmet need for early support, as unmet need can represent

non access (or non-receipt) of support. Unmet need for support has been defined as 'myriad situations in which children and their families are *unable to access* needed health [and other] services for the child (e.g., prescription medication, therapy services) or the family (e.g., respite care, family mental healthcare)' (Lindly et al., 2017, p.713).

Unmet need for support is typically measured by parental caregiver report of support needed but not accessed, based on their perceptions. Other measures of unmet need include estimating families likely to need support, professional judgment (e.g., direct clinical examination or record review), or comparing service utilisation to existing professional standards (Magnusson et al., 2016). However, these measures are costly for large-scale studies and are not always appropriate for developmental disabilities, given varying service needs and 'the lack of precise therapeutic standards across disciplines and diagnoses' (Magnusson et al., 2016, p.145). While parents might underreport unmet need (Magnusson et al., 2016) as their perceptions can be influenced by various factors, in general this measure is the most straightforward, cost-effective way to obtain insight into unmet need, especially when conducting research with families that are not in contact with support services.

There is a paucity of research examining predictors of unmet need for support in the early years (0-6 years) only. Despite considering predictors of unmet need across childhood (0-17 years), in McManus et al.'s (2016) study, parents of children aged 3-5 years reported the highest unmet need for therapy (physical, occupational, speech therapy) and mobility aids across all childhood age groups, demonstrating the significance of unmet need in the early years. Research specific to the early years for families of children with developmental disabilities suggests unmet need for early support is predicted by families' access to services (developmental or health services), elements of family-centred healthcare provision, caregiver educational attainment, and child age, ethnicity group, expressive language skills, and health needs (Kasilingam et al., 2019; Magnusson et al., 2016; Magnusson & Mistry, 2017). However, at present, there is limited research on predictors of unmet need for early support amongst families of children with developmental disabilities. In addition, there are some limitations with the measurement of unmet need for early support in these studies.

Similar to measurements of access to early support, varied measures of unmet need for early support are used across studies. These primarily focus on unmet need

for specific supports, such as unmet need for physical, occupational, or speech therapy (Magnusson et al., 2016; Magnusson & Mistry, 2017) or early educational interventions (Kasilingam et al., 2019), rather than unmet need across early support sources (i.e., professionals and services that provide early support to families). Furthermore, dichotomous variables of unmet need are used (Magnusson et al., 2016; Magnusson & Mistry, 2017), which may not account sufficiently for variation in unmet need. In contrast, Kasilingam et al. (2019) accounted for variation in unmet need by counting parent-reported unmet needs. Lastly, there have been no studies on unmet need in the UK, therefore it is unknown what factors predict unmet need for early support in the UK service system context.

The Present Study

For the present study, a parental caregiver survey was designed (see Chapter 3) to collect cross-sectional data on several factors within child, family, and service domains that have been found in the literature to be related to access and utilisation of early support (see Chapter 2). Utilising this comparatively large dataset, I examined predictors of three measures of access to early support (intervention access, access to early support sources, and unmet need for early support) in families of young children (aged 0-6 years) with suspected or diagnosed developmental disabilities across the UK.

This study addresses limitations of previous research on early years support by utilising comprehensive measurements of access to early support, such as access to interventions, access to various support sources (professionals and services across education, health, social care, and other support services in the early years) and unmet need for early support. In addition, I focus explicitly on the early years, include families of children with suspected developmental disabilities and those not presently in contact with services or receiving early support, and provide UK specific evidence to add to the international literature.

Method

For this study, a parental caregiver survey was designed to collect cross-sectional data on access to early support and a range of child, family, and service factors (see Chapter 3 and Appendix 2). Ethical approval was granted by the University of Warwick's Humanities and Social Sciences Research Ethics Committee (reference 57/17-18, see Appendix 1).

Participants

Overall, 673 parental caregivers of children with diagnosed or suspected developmental disabilities in the UK completed the survey (see Table 4.1 for selected participant characteristics). The majority of participants lived in England (*N* = 505, 75.0%), 10.5% (*N* = 71) lived in Northern Ireland, 9.8% (*N* = 66) lived in Wales, and 4.6% (*N* = 3) lived in Scotland. Overall, most of the children had received at least one developmental disability diagnosis (*N* = 561, 83.4%), primarily a diagnosis of autism (*N* = 340, 50.5% of children), followed by developmental delay (*N* = 252, 37.4%), intellectual disability (*N* = 225, 33.4%), and social communication disorder (*N* = 115, 17.1%). Other frequently reported developmental disability diagnoses included Down syndrome (*N* = 54, 8.0%), dyspraxia (*N* = 39, 5.8%), cerebral palsy (*N* = 25, 3.7%), attention deficit hyperactivity disorder (*N* = 22, 3.3%), Fragile X syndrome (*N* = 4, 0.6%), Williams syndrome (*N* = 3, 0.4%), developmental language disorder (*N* = 2, 0.3%), foetal alcohol syndrome, (*N* = 1, 0.1%), 22q11 duplication syndrome (*N* = 1, 0.1%), missing chromosome (*N* = 1, 0.1%), and hydrocephalus (*N* = 1, 0.1%).

Around one sixth of the children had no diagnosed developmental disability (*N* = 112, 16.6%). The majority were suspected to have autism (*N* = 104, 15.5%), social communication disorder (*N* = 53, 7.9%), intellectual disability (*N* = 47, 7.0%), attention deficit hyperactivity disorder (*N* = 42, 6.2%), developmental delay (*N* = 40, 5.9%), dyspraxia (*N* = 25, 3.7%), Williams syndrome (*N* = 2, 0.3%), Fragile X syndrome (*N* = 1, 0.1%), cerebral palsy (*N* = 1, 0.1%), and chromosome microdeletion 15q25.2 (*N* = 1, 0.1%).

Respondent caregivers had a mean age of 36.5 years (*SD* = 6.7, range 22-72 years) and were mostly female (*N* = 633, 94.1% female; *N* = 30, 4.5% male; *N* = 2, 0.3% other gender). The majority of respondent caregivers rated their overall health as ‘good’ or ‘very good’ (*N* = 390, 57.9%), 31.9% (*N* = 215) rated it as ‘fair’, and 9.8% (*N* = 66) rated it as ‘bad’ or ‘very bad’.

Table 4.1 Participant characteristics

Participant characteristics (*N* = 673)	Total N (%) *or* Mean (SD)
	Predictor variables
Child factors	
Child age (years)	4.8 (1.5) range 0.1-6.9
Child sex	481 (71.5) male
	189 (28.1) female
Child health conditions	1.4 (1.3) range 0-5
Child adaptive skills (GO4KIDDS)	21.4 (7.6) range 8-39
Family factors	
Caregiver ethnicity group	98 (14.6) ethnic minority group
	560 (83.2) non ethnic minority group
Caregiver disability	260 (38.6) disability
	410 (60.9) no disability
Caregivers in the household	132 (19.6) one caregiver
	536 (79.6) two caregivers
Caregivers' educational level	338 (50.2) ≥1 caregiver educated to degree level or higher
	310 (46.1) <1 caregiver educated to degree level
Family economic deprivation	1.5 (1.1); range 0-4
Caregivers' employment[1]	543 (80.7) ≥1 caregiver in employment
	124 (18.4) <1 caregiver in employment
Income poverty[1]	195 (29.0) > poverty line
	393 (58.4) ≤ poverty line
Subjective poverty[1]	557 (82.8) managing financially
	105 (15.6) not managing financially
Ability to raise money[1]	261 (38.8) could raise money
	405 (60.2) would struggle to raise money
Other disabled children in the family	189 (28.1) ≥1 other children with disabilities
	477 (70.9) <1 other children with disabilities
Informal support sources	3.6 (2.4) range 0-12
Helpfulness of informal support	3.7 (0.8) range 1.3-5.0
Service factors	
Developmental disability diagnosis	112 (16.6) no diagnosed developmental disability
	561 (83.4) at least 1 diagnosed developmental disability
Statutory statement of SEN	332 (49.3) no statutory statement
	338 (50.2) statutory statement
	Outcome variables
Intervention access	127 (18.9) intervention access
	545 (81.0) no intervention access
Access to early support sources	14.6 (5.7) range 0-32
Unmet need for early support	3.2 (3.2) range 0-17

Notes. SEN = special educational needs.
[1]Variable used in family economic deprivation composite.

Procedure

Between September 2018 and May 2019, parental caregivers of children aged 0-6 years with diagnosed or suspected developmental disabilities in the UK, were invited to complete a survey anonymously. Participants were recruited via social media and distribution via several organisations that work with families of young children with developmental disabilities in the UK (e.g., charities, independent service providers, specialist schools). The survey took approximately 30 minutes to complete and was available to complete online (hosted by Snap™ Surveys) or by surface mail, based on participant preference. All survey questions were optional, except for 'child age' on the online survey.

Measures

Access to Early Support. Data on access to support covered intervention access, access to early support sources, and unmet need for early support sources.

Intervention Access. To measure intervention access, participants were asked whether, in the preceding 12 months, either their child had received any interventions to support their development, or they had received any interventions to support them in their role as parental caregiver. To help participants complete the question, a few interventions and support approaches were listed as examples (e.g., Applied Behaviour Analysis (ABA), Hanen®, Early Bird, Incredible Years®, Social Communication Emotional Regulation and Transactional Support® (SCERTS®), Treatment and Education of Autistic and related Communications® (TEACCH®), Triple P™, therapy, counselling). If a participant responded 'yes' they were asked to list the interventions or support approaches their family had received in a free response text box. Text responses were coded against a pre-specified definition of packaged intervention programmes as a specific, named intervention or programme (e.g., Incredible Years®, TEACCH®, ABA) or a multi-sessional support programme (e.g., art therapy, family therapy, counselling), unless explicitly covered in the measure of access to early support sources described below (e.g., occupational therapy, respite) (see Chapter 3 for further details). From this, a binary variable was created to identify if the participant had (or had not) accessed a packaged intervention programme.

Access to Early Support Sources. A comprehensive list of 49 early support sources was included in the survey to measure access to early support sources. As described in Chapter 3, the list was developed with input from a group of parental

caregivers and professionals to describe early support services in the current UK context. Early support sources were presented in three groups: (a) 27 key professionals across education, health, and social care (e.g., nursery and school staff, general practitioner, occupational therapist, speech and language therapist, social worker, respite, home support, charity worker), (b) 10 additional health specialists (e.g., neurologist, ophthalmologist, podiatrist), and (c) 12 other supports (e.g., parent groups, telephone helplines, websites, children's centres). For the 27 key professionals, participants were asked to report their contact with each (yes, no, not sure; or being on a waitlist for support) in the preceding 12 months. For the other support sources listed, participants were only asked to indicate any they had been in contact with in the preceding 12 months. From the 49 early support sources, a variable was created to count the total number of early support sources accessed.

Unmet Need for Early Support. The third measure of access to early support covered unmet need for early support sources, as this represents a way of determining non receipt of early support based on parental caregivers' perspectives of wanted support. If a participant reported they *had not* accessed support from any of the 27 key professionals (excluding those on a waitlist or unsure of access), they were asked to indicate if they wanted to access support from that professional. For those participants, a response of 'yes' was classified as an unmet need (i.e., support wanted but not accessed). A variable was created to count participants' unmet need for early support across the 27 key professionals.

Child, Family and Service Factors. Data were gathered in the survey on the variables reported in Table 4.1 (also see Participants). For the purposes of this study, these are organised into child, family, and service factors.

Child Factors. Child factors included child demographics (age, sex), adaptive skills (e.g., communication, social, motor, and functional skills), and physical health conditions. Regarding physical health conditions, participants were asked to indicate if their child had: (1) a visual impairment, (2) a hearing impairment, (3) epileptic seizures (current or in the past), (4) mobility problems, and/or (5) other physical health problems. From these, a variable was created to count the number of physical health conditions the child had.

For children aged <2 years, adaptive skills was measured using the GO4KIDDS Brief Adaptive Behaviour Scale (Perry et al., 2015), modified to reflect UK terminology. Parents were asked eight questions measuring: (1) support needs,

(2) communication, (3) socialisation, and (4) self-help skills. An additional question on using augmentative and alternative methods of communication was included in the survey. The highest score for either the standard expressive communication item or the item on alternative methods of communication was identified and summed with the remaining items to create a total adaptive score (range 8-40).

Family Factors. Family factors included respondent caregiver ethnicity group and disability, number of caregivers in the household, caregivers' educational level, family economic deprivation (caregivers' unemployment, income poverty, subjective poverty, and perceived inability to raise money), other disabled children in the household, and informal support.

A self-identification measure of ethnicity recommended by the UK Office for National Statistics (ONS) was used to measure caregiver ethnicity, which was comprised of 18 responses across five ethnicity groups: Asian, Black, Mixed/Multiple, White, and Other (Potter-Collins, 2011). Caregiver ethnicity was coded as a binary variable to identify whether the respondent caregiver belonged to an ethnic minority group (e.g., all ethnicity responses except White English/Welsh/Scottish/Northern Irish/British). Participants were also asked to indicate if they had a disability, longstanding illness, or infirmity (yes/no). This question was used to create a binary variable to identify if the caregiver had a disability or longstanding illness.

Participants were asked to indicate their marital status and living arrangement with one of three responses: (1) married/civil partnership and living with spouse/civil partner, (2) living with partner, or (3) divorced/separated/single/widowed/not currently living with partner. From this, a binary variable was created to identify if there were one or two caregivers living in the household. Participants were also asked to indicate if any other children in the family or household had disabilities (yes/no) and a binary variable was created to identify if there were other disabled children in the household.

Regarding caregivers' educational level, participants were asked to indicate their (and their partner's, if living with a partner) highest level of educational qualifications. A binary variable was created from this to identify households with at least one caregiver educated to degree level or higher. To ascertain caregivers' employment, participants were asked to indicate their (and their partner's, if living

with a partner) work status and a binary variable was created to identify households with at least one caregiver in employment (either full or part-time).

In addition to caregivers' (un)employment, three other measures were used to ascertain economic deprivation (income poverty, subjective poverty, and perceived inability to raise money). Income poverty was calculated based on participants weekly household income and family composition. Family income was equivalised using the modified Organisation for Economic Co-operation and Development (OECD, n.d.) scale, accounting for the number of children and adults living in the household. Income poverty was measured using the OECD's definition; families with an income below 60% the UK median equivalised income, £28,400 at the time of data collection (ONS, 2019), were classified as living in poverty.

Subjective poverty was measured by asking participants to indicate their current financial management as: (1) living comfortably, (2) doing alright, (3) just about getting by, (4) finding it quite difficult, or (5) finding it very difficult. A variable was created to dichotomise responses 1-3 as 'managing financially' and 4-5 as 'struggling financially'. Participants were also asked about their perceived ability to raise £2,000 for a hypothetical emergency as: (1) I could easily raise the money, (2) I could raise the money, but it would involve some sacrifices (e.g., reduced spending, selling a possession), (3) I would have to do something drastic to raise the money (e.g., selling an important possession), or (4) I don't think I could raise the money. A variable was created to dichotomise responses 1-2 as 'could raise the money' and 3-4 as 'would struggle to raise the money'.

A composite variable of family economic deprivation was created by combining the dichotomised variables for caregivers' unemployment, income poverty, subjective poverty, and perceived inability to raise money, to provide an overall deprivation score of 0-4 (with higher scores indicating higher economic deprivation). Participants with missing data on two or more of these variables were not included in the composite.

A list of 12 informal support sources was included in the survey (e.g., my parents, my partner, my friends, my other children, other parents, co-workers; see Appendix 2.5). The list was developed by adapting the Family Support Scale (Dunst et al., 1984). Participants were asked to indicate any informal support sources they had received support from in the preceding 12 months. From this, a variable was created to count the total number of informal support sources. For any informal

support sources the participant indicated they had accessed, they were asked to rate how helpful the support was for themselves and their family on a 5-point Likert-type scale (with 1 being ‘not at all helpful’ and 5 being ‘extremely helpful’). A mean helpfulness rating was calculated for informal support sources.

Service Factors. Service factors included receipt of developmental disability diagnosis and statutory statement, both as indicators of formal identification of need. A list of 10 developmental disability labels was provided in the survey (intellectual disability, autism, social communication disorder, developmental delay, dyspraxia, cerebral palsy, Down’s syndrome, Williams syndrome, Fragile X syndrome, and attention deficit hyperactivity disorder) with a space for participants to write any other additional diagnoses or genetic syndromes. This was used to create a binary variable to identify if the child had received a formal diagnosis *of at least one* developmental disability, which indicates a formal recognition of the child’s developmental disability. For those who had not received a diagnosis from the developmental disabilities listed in the survey, text responses on other diagnoses were analysed to identify other developmental disabilities. Responses were manually coded as ‘diagnosed developmental disability’ if a developmental disability was named by the participant as diagnosed (e.g., developmental language disorder, foetal alcohol syndrome, 22q11 duplication syndrome, hydrocephalus).

Participants were also asked to indicate if their child had a received a statutory statement identifying their child’s needs, such as a statement of special educational needs, an education, health and care plan, an individual development plan, or a coordinated support plan (the terminology used varies across the UK). A binary variable was created to identify if the child had received a statutory statement of their needs, which indicates a formal recognition of the child’s needs for the purposes of service provision across education, health, and social care systems.

Analysis

Multiple regression models were fitted for the three outcome variables: (1) intervention access, (2) access to early support sources, and (3) unmet need for early support. The type of model used reflected the type and distribution of the outcome variable: binary logistic regression for intervention access (binary variable: intervention access/no intervention access), multiple linear regression for access to early support sources (count variable but distributed fairly normally), and negative

binomial regression for unmet need for early support (count variable with overdisperson, see Table 4.1).

Potential predictors in the dataset were selected based on factors identified as influencing access to early support in my narrative review (see Chapter 2). Predictor variables included: (1) child age (years), (2) child sex (male/female), (3) child adaptive skills (total GO4KIDDS adaptive behaviour score), (4) number of child physical health conditions, (5) caregiver ethnicity group (ethnic minority group/non ethnic minority group), (6) caregiver disability (caregiver disability yes/no), (7) caregivers in household (one caregiver in household/two caregivers in household), (8) caregivers' educational level (at least one caregiver in household educated to degree level or higher/no caregiver in household educated to degree level), (9) family economic deprivation (economic deprivation composite score), (10) other disabled children in family (other disabled children/no other disabled children), (11) number of informal support sources, (12) helpfulness of informal support (mean helpfulness rating of informal support sources), (13) receipt of developmental disability diagnosis (at least one diagnosed developmental disability/no diagnosed developmental disability), and (14) receipt of statutory statement (statutory statement/no statutory statement).

Participants with missing data for any of the outcome or predictor variables were excluded from analyses, this included: intervention access (N = 1 participant with missing data, 0.1% of participants), child age (N = 2, 0.3%), child sex (N = 3, 0.4%), child adaptive skills (N = 31, 4.6%), caregiver ethnicity group (N = 15, 2.2%), caregiver disability (N = 3, 0.4%), caregivers in household (N = 5, 0.7%), caregivers' educational level (N = 29, 4.3%), family economic deprivation (N = 11, 1.6%), other disabled children in family (N = 7, 1.0%), helpfulness of informal support (N = 27, 4.0%), and receipt of statutory statement (N = 3, 0.4%). Overall, 107 participants (15.9%) were not included in the analysis for intervention access and 106 participants (15.8%) were not included in the analyses for access to early support sources and unmet need for early support.

Results

Intervention Access

Table 4.2 reports the results of the binary logistic regression model for intervention access. Caregivers' educational level (b = -0.617, OR = 0.539, p = .008) was a significant independent predictor of intervention access, as was receipt of a

developmental disability diagnosis (*b* = 1.027, *OR* = 2.792, *p* = .013). A lower likelihood of intervention access was found in households without a caregiver educated to degree level or higher and for families who had a child who had not received a developmental disability diagnosis.

Table 4.2 Binary logistic regression model of intervention access

Predictor variables [reference group]	*B*	Sig.	*OR*	95% CI for *OR* Lower	Upper
Child age	0. 057	. 594	1.059	0. 858	1. 307
Child sex [male]	0. 119	.629	1.127	0.695	1.827
Child adaptive skills	-0.015	.401	0.985	0.952	1.020
Child health conditions	-0.113	.224	0.893	0.744	1.072
Caregiver ethnicity group [ethnic minority group]	0.198	.520	1.219	0.667	2.231
Caregiver disability [no disability]	0.160	.492	1.174	0.743	1.855
Caregivers in household [1 caregiver]	0.398	.214	1.489	0.795	2.790
Caregivers' educational level [≥1 caregiver educated to degree level or higher]	-0.617	.008*	0.539	0.341	0.853
Family economic deprivation	0.127	.260	1.135	0.910	1.416
Other disabled children [no other disabled children]	0.176	.482	1.192	0.730	1.947
Informal support sources	0.031	.546	1.031	0.933	1.139
Helpfulness of informal support	-0.238	.078	0.788	0.605	1.027
Diagnosed developmental disability [no diagnosis]	1.027	.013*	2.792	1.247	6.250
Statutory statement [no statement]	0.089	.722	1.093	0.668	1.789

Notes. CI = Confidence Interval. OR = Odds Ratio. * p = < .05

Access to Early Support Sources

Table 4.3 reports the results of the multiple linear regression model for access to early support sources. The number of child health conditions was a significant independent predictor of access to early support sources(*b* = 1.780, β = 0.400, *p* < .001), as were: child adaptive skills (*b* = -0.110, β = -0.150, *p* < .001), caregiver ethnicity group (*b* = -1.275, β = -0.081, *p* = .016), caregivers' educational level (*b* = -0.812, β = -0.072, *p* = .048), and the number of informal support sources (*b* = 0.428, β = 0.170, *p* < .001), receipt of a developmental disability diagnosis (*b* = 1.306, β = 0.084, *p* = .019), and receipt of a statutory statement (*b* = 2.469, β = 0.218, *p* < .001). Increased access to early support sources was found for families who had a child

with a higher number of physical health conditions, lower adaptive skills, a diagnosed developmental disability, and a statutory statement. Increased access to early support sources was also found for families who had a primary caregiver from a White ethnic majority group, with one or more caregivers educated to degree level or higher, and who had a higher number of informal support sources.

Table 4.3 Multiple linear regression model of access to early support sources

Predictor variables [reference group]	*B*	Sig.	β	95% CI for β Lower	Upper
Child age	-0.118	.525	-0.027	-0.484	0.247
Child sex [male]	0.802	.064	0.062	-0.048	1.652
Child adaptive skills	-0.110	< .001**	-0.150	-0.171	-0.050
Child health conditions	1.780	< .001**	0.400	1.467	2.092
Caregiver ethnicity group [ethnic minority group]	-1.275	.016*	-0.081	-2.314	-0.235
Caregiver disability [no disability]	0.290	.474	0.025	-0.506	1.087
Caregivers in household [1 caregiver]	-0.335	.512	-0.023	-1.339	0.669
Caregivers' educational level [≥1 caregiver educated to degree level or higher]	-0.812	.048*	-0.072	-1.617	-0.007
Family economic deprivation	-0.121	.515	-0.025	-0.487	0.244
Other disabled children [no other disabled children]	0.576	.190	0.046	-0.287	1.439
Informal support sources	0.428	< .001**	0.170	0.247	0.610
Helpfulness of informal support	-0.010	.965	-0.002	-0.472	0.451
Developmental disability diagnosis [no diagnosis]	1.306	.019*	0.084	0.214	2.397
Statutory statement [no statement]	2.469	< .001**	0.218	1.601	3.336

Notes. CI = Confidence Interval. * p = < .05 ** p < .001

Unmet Need for Early Support

Table 4.4 reports the results of the negative binomial regression model for unmet need for early support. The number of caregivers in the household was a significant independent predictor of unmet need for early support (*b* = -0.366, *RR* = 0.693, *p* = .007), as were: family economic deprivation (*b* = 0.101, *RR* = 1.107, *p* = .033), the number of informal support sources (*b* = -0.084, *RR* = 0.920, *p* = .001), and the helpfulness of informal support sources (*b* = -0.140, *RR* = 0.870, *p* = .023).

Increased unmet need for early support was found in families with one caregiver in the household (rather than two caregivers), increased family economic deprivation, fewer informal support sources, and lower helpfulness of informal support sources.

Table 4.4 Negative binominal regression model of unmet need for early support

Predictor variables [reference group]	*B*	Sig.	*RR*	95% CI for *RR* Lower	Upper
Child age	0.089	.067	1.094	0.994	1.204
Child sex [male]	0.158	.173	1.171	0.933	1.468
Child adaptive skills	-0.014	.090	0.986	0.971	1.002
Child health conditions	-0.004	.919	0.996	0.916	1.082
Caregiver ethnicity group [ethnic minority group]	0.039	.783	1.039	0.789	1.369
Caregiver disability [no disability]	-0.038	.723	0.963	0.780	1.188
Caregivers in household [1 caregiver]	-0.366	.007*	0.693	0.531	0.906
Caregivers' educational level [≥1 caregiver educated to degree level or higher]	0.140	.188	1.151	0.934	1.418
Family economic deprivation	0.101	.033*	1.107	1.008	1.215
Other disabled children [no other disabled children]	-0.219	.051	0.804	0.645	1.001
Informal support sources	-0.084	.001**	0.920	0.877	0.965
Helpfulness of informal support	-0.140	.023*	0.870	0.771	0.981
Developmental disability diagnosis [no diagnosis]	0.104	.465	1.109	0.840	1.464
Statutory statement [no statement]	0.142	.216	1.152	0.921	1.442

Notes. CI = Confidence Interval. RR = Rate Ratio. Dispersion parameter = 1 (negative binomial dispersion parameter set by SPSS). * p = < .05 ** p < .001

Discussion

In this study I examined predictors of access to early support, including intervention access, access to early support sources, and perceived unmet need for early support among a comparatively large sample (N = 673) of families who have a young child with a suspected or diagnosed developmental disability in the UK.

Child Factors and Access to Early Support

Lower levels of child adaptive skills and a higher number of child physical health conditions were significant independent predictors of access to early support sources, though not packaged, intervention programmes. This indicates access to early support is partly based on a higher level of child need (e.g., developmental,

health), which is consistent with previous literature indicating access to early support is influenced by the nature (i.e., type) and severity of child needs (see Chapter 2). These findings are also in line with the findings of several other studies on predictors of access to early support (Khetani et al., 2017; Marshall et al., 2016; McIntyre & Zemantic, 2017; McManus et al., 2014b, 2019).

Household Factors and Access to Early Years Support

Caregiver education level was an independent predictor of access to interventions and early support sources. It is possible caregivers with higher educational attainment are more likely to access interventions and early support sources due to an increased awareness of the need for, and potential benefit from, early support (Nguyen et al., 2016). Increased educational level may also improve caregivers' abilities to navigate complex service systems and advocate for their family in order to obtain early support. Mixed findings are reported in previous studies; while some studies have also found increased caregiver educational level predicts access to early support (Khetani et al., 2017; Nguyen et al., 2016), other studies have not found an association between caregiver educational level and access to early support (Kasilingam et al., 2019; McIntyre & Zemantic, 2017). Both studies reporting no association between caregiver educational level and access to early support had small sample sizes (≤65 participants) and consisted only of children who had obtained an autism diagnosis, which may account for the difference in findings.

In my study, caregiver ethnicity group predicted access to early support sources, but not interventions, with increased access to early support sources found for households with a respondent caregiver identifying as belonging to a White ethnic majority group, compared to households with a respondent caregiver identifying as belonging to an ethnic minority group. This indicates disparities of access to early support based on ethnicity, which is consistent with the findings of earlier studies (Khetani et al., 2017; Marshall et al., 2016; McManus et al., 2019; Nygren et al., 2016; Rosenberg et al., 2008). However, the association between ethnicity and access to support is likely more complex than the findings of this study suggests, as my prior research indicates access varies according to specific ethnicity group, rather than simply minority versus non-minority status (Chapter 2). The wider social context may also account for ethnicity disparities in access to early support, such as structural racism, discrimination, and marginalisation of people from ethnic minority groups, which contribute to barriers of accessing services for people from

ethnic minority groups (e.g., Čolić et al., 2021; Barnard-Brak et al., 2021). Further, a lack of culturally appropriate services may in part explain the ethnicity disparity found in this study, as previous research has highlighted the importance of culturally and contextually appropriate supports (Čolić et al., 2021; de Leeuw et al., 2020; also see Chapter 2).

The number of informal support sources (e.g., partners, relatives, friends, other parents) predicted access to early support sources, but not interventions. Increased access to early support sources was found for caregivers who reported a higher number of informal support sources. At present, there is limited research on the relationship between informal support and access to formal early support, though this appears to be related to family composition (i.e., the number of children and adults in the household) and the availability of informal childcare support (Chapter 2). The findings of this study indicate increased informal support facilitates access to early support, perhaps due to practical, informational, emotional, or other support provided by informal sources. Informal support may be directly related to accessing formal support (e.g., help contacting, travelling to, or paying for services) or indirectly related (e.g., helping with caregiving and other responsibilities, enabling the caregiver more time to navigate formal support systems). As the helpfulness of informal support did not predict access to interventions or early support sources, this suggests the quantity, rather than quality, of informal support is associated with access to early support.

Service Factors and Access to Early Support

A crucial finding of the study is that services' formal identification of child need (i.e., receipt of developmental disability diagnosis and/or statutory statement) predicted access to early support. Developmental disability diagnosis status (diagnosed versus suspected developmental disability) was a significant independent predictor of access to both interventions and early support sources, indicating that having a formal diagnosis is an important predictor of access to early support. The presence of a statutory statement was also a significant independent predictor of access to early support sources, though not intervention access. These findings indicate that, in addition to the nature and severity of child needs (see above), access to early support is also partly related to services' formal identification of child needs (e.g., receipt of developmental disability diagnosis and/or statutory statement). This

is consistent with previous literature indicating access to early support is influenced by formal identification of developmental disabilities (see Chapter 2).

It is promising that receipt of a statutory statement predicted access to early support sources, indicating related legislation across UK governments may contribute to promoting access to early support for this group (e.g., Special Educational Needs and Disability Act, 2001; Children and Families Act, 2014; Special Educational Needs and Disability Code of Practice, 2014; Education (Additional Support for Learning) (Scotland) Act, 2004; Children and Families Act 2014 Commencement (Wales) Order, 2015; Special Educational Needs and Disability Act (Northern Ireland), 2016; Additional Learning Needs and Education Tribunal (Wales) Act, 2018). It is interesting, however, that receipt of a statutory statement did not predict intervention access. This might be as my measure of early support sources included several provisions typically stipulated in statutory statements (i.e., education, health, and social care services), whereas my measure of intervention access was based on participants' free-text responses, capturing access to specific packaged interventions or multi-sessional supports not listed in the quantitative measure of early support sources. In addition, my measure of intervention access included interventions to support the child *or* parental caregiver, and statutory statements only include child-directed supports. Furthermore, it is possible interventions accessed by participants were provided by non-statutory services, such as community-based organisations or charities, which may have less strict entry criteria.

Unmet Need for Early Support

Perceived unmet need for early support represents a way of perceiving non-access to wanted early support sources, based on parents' perspectives. Both the number of informal support sources and the helpfulness of informal support predicted unmet need for early support, with increased unmet need amongst caregivers who reported fewer informal support sources and lower helpfulness of informal support. This suggests both the quantity and quality of informal support influences caregivers' perceptions of support needed in the early years. It is possible families receiving an increased number of informal support sources and more helpful informal support are less likely to perceive an unmet need for early support from sources they have not accessed, especially the social care supports listed in the survey (e.g., home support staff, respite care or short breaks, childminder or nanny,

family support worker). These supports were accessed by a relatively small proportion of participants (between 11.4-19.2% of participants, *N* = 82-129 participants; Chapter 3) and were individually reported as an unmet need by a considerable group of participants (between 8.4-27.9% of participants that had not accessed the support source, *N* = 47-156 participants; see Chapter 3). Yet, this measure included health, education, and social care services, suggesting informal support also relates to perceptions of unmet need for early support across these systems.

Similarly, the number of caregivers in the household also predicted unmet need for early support, with increased unmet need reported in families with one caregiver compared to two caregivers in the household. This might be related to increased caregiving and household responsibilities for caregivers in one-parent households, leading to caregivers perceiving (and likely needing) more early support. Interestingly, the number of caregivers in the household did not predict access to early support sources or interventions, nor did the helpfulness of informal support, indicating these factors are not directly related to access to early support, but they are related to perceived unmet need for early support.

Family economic deprivation (comprised of caregivers' unemployment, income poverty, subjective poverty, and perceived inability to raise money) predicted perceived unmet need for early support. This highlights potential limitations of the UK's universally free service system, as families experiencing higher levels of economic deprivation reported increased unmet need for early support across health, education, and social care services. In addition to direct economic costs (e.g., cost of private services), this might be due to indirect economic costs associated with access to support (e.g., cost of travel to public or private services, costs of childcare for parent-only supports).

I expected, but did not find, that family economic deprivation would predict access to intervention and early support sources. Differences in the financial set-up of service systems likely account for this lack of association; previous research has largely focused on contexts without a universally free service system (Khetani et al., 2017; Marshall et al., 2016; McIntyre & Zemantic, 2017; McManus et al., 2019; Nguyen et al., 2016), whereas the UK has a universally free service system for health, education, and social care provision. Despite this, families in the UK (including those in the present sample) have reported difficulties accessing public

services, with some paying to access private services, in part related to government funding cuts for public services (Howlin & Moore, 1997; Karim et al., 2012; Keenan et al., 2010; also see Chapters 2 and 3). Similar to the current study, Rosenberg et al. (2008) found poverty and insurance status were not associated with access to early support in the USA, after controlling for developmental delay status and ethnicity, which were associated with access to early support services.

Unrelated Factors

A few factors examined in the study were not found to predict any of the early support access outcomes (intervention access, access to early support sources, unmet need for early support): these were child age, child sex, caregiver disability, and other disabled children in the family. Mixed findings are reported on the relationship between child demographics (age, sex) and access to early support; some literature indicates child age or sex influences access to support (Marshall et al., 2016; McIntyre & Zemantic, 2017; see Chapter 2), whereas other literature has not found a relationship between child demographics and access to early support (Kasilingam et al., 2019; McManus et al., 2019; see Chapter 2). The lack of relationship between child demographics and access to early support in the present study is promising, as it suggests a lack of age and gender disparities in access to early support, especially as my sample included a high proportion of suspected or diagnosed autistic children, for which gender disparities are commonly reported (Begeer et al., 2013; Payakachat et al., 2017; see Chapter 2). The lack of association between child age and access to early support may, however, be due to the exclusion of children aged <2 years (N = 24, 3.6%) from the analyses, as the child adaptive skills measure used (GO4KIDDS) was not appropriate for children aged <2 years.

It is also promising that parental disability did not appear to be related to access to early support in the current study. I expected parent disability might influence access to early support due to an increase in family needs. However, I did not ask participants to specify caregiver disability or longstanding illness, which may have influenced my findings. At present, there is a lack of research on access to early support for families who have children with developmental disabilities *and* parental caregiver(s) with developmental or other disabilities. Yet, given the genetic link of autism, for example, it is likely a considerable proportion of autistic children have an autistic parent or parents (Rubenstein & Chawla, 2018), therefore autistic parents may be represented within existing research. There is also emerging research

exploring the experiences of autistic parents who have autistic children, demonstrating distinctions between parenting experiences of autistic and non-autistic parents (e.g., Dugdale et al., 2021; Crane et al., 2021; Pohl et al., 2020). These include parenting experiences directly related to access to early support, such as communicating with professionals, advocating on behalf of their autistic child, and battling for the right support (Dugdale et al., 2021; Pohl et al., 2020). Further consideration of parent developmental and other disabilities in future research examining access to early support is warranted.

Lastly, I expected, but did not find, that having other disabled children in the household would be related to access to early support for the youngest child with a suspected or diagnosed developmental disability. This was due to previous research indicating having a family member with developmental disabilities, particularly an older sibling, facilitates the recognition and identification of developmental disability (see Chapter 2). It is possible this did not influence access to support in the present study, as participants were not asked to specify disability type. Therefore, this may include children with disabilities distinct to developmental disabilities (e.g., physical disabilities, mental health conditions) with different support and service needs. Yet, in free-text response, one participant indicated intervention access was related to having an older child with developmental disabilities, for example: *"Cerebra help for sleep (mostly for eldest child but looked at youngest who's in this questionnaire)"*.

Implications for Policy, Practice and Future Research

The findings of this study can be useful to inform future policy and practice regarding the provision of early support for families of children with suspected or diagnosed developmental disabilities across UK services and support systems. In addition, there are implications for future research on access to early support.

Formal Identification of Need. First, as developmental disability diagnosis and statutory statement receipt were associated with increased access to early support, one key implication is to enhance processes for formal identification of need in the early years (i.e., developmental disability diagnosis, statutory statement). Although these pathways of access to early support are clearly important, formal identification of need does not guarantee access. As such, other strategies also need to be considered. In addition, it is problematic if access to early support is dependent *only* on formal identification of need, due to disparities in developmental disability

diagnosis receipt, especially for autism (e.g., Crane et al., 2016). As highlighted in Chapter 2, a myriad of factors appear to influence formal identification of developmental disabilities (e.g., family socioeconomic status, child gender, professionals' perceptions of child need, availability and capacity of services), which can delay or prevent diagnosis receipt, potentially acting as a barrier of access to early support. Similarly, considerable issues with the process of obtaining a statutory statement have been reported (Cullen & Lindsay, 2019; Lamb, 2019). Thus, examining and addressing barriers to formal identification of need should be a priority. Another potential implication is to reconsider service eligibility criteria regarding receipt of developmental disability diagnosis or statutory statement. Ensuring families are able to access support regardless of receipt of a developmental disability diagnosis or statutory statement may be the single most straightforward action that has potential to facilitate service access.

Economic Status. Second, it is also clear further action is needed to address disparities of access to early support based on parental caregivers' economic status (e.g., income poverty, unemployment). Policies and investments to reduce poverty have the potential to reduce perceived unmet need for early support and improve access to early support. Disability increases the risk of poverty, both broadly and for developmental disabilities (e.g., Blackburn et al., 2010; Emerson, 2004, 2012; Emerson et al., 2010), related to direct costs associated with disability (e.g., paying for specialist equipment, out-of-pocket costs associated with service access) and indirect costs (e.g., caregivers reducing or leaving employment due to caregiving responsibilities) (Cleaton et al., 2020; Dillenburger et al., 2015). Furthermore, adverse outcomes may also, in part, be attributed to increased risk of economic disadvantage, such as poorer health (Emerson & Hatton, 2007b; Totsika et al., 2021; Hayden et al., 2022). Therefore, reducing economic disadvantage has greater implications than just for improving access to early support amongst children with developmental disabilities.

Accessible Services. Caregiver educational attainment was also predictive of access to intervention and early support sources in this study. Broadly speaking, reducing inequalities of access to education, particularly higher education, has potential implications for improving access to early support. Targeted interventions to improve caregivers' knowledge and skills specific to accessing early support may also reduce disparities of access. However, ensuring services are more accessible is

likely the most efficient action in terms of facilitating access to early support. Making services more accessible might include, for example, ensuring accessible information is available for families, accepting referrals from families in addition to professionals and services, and utilising a range of communication methods.

There is a clear need for more accessible services and flexible service systems that respond to the individual needs of families. This might include a professional that coordinates support across services for families, and flexibility regarding the location, timing, format, and content of provision. Further research is needed in order to understand inequality of access on the basis of parental ethnicity and other related factors (e.g., socio-economic deprivation, parental perceptions of developmental disabilities). However, services can take active steps in attempt to reduce these and provide culturally appropriate support, such as increasing their cultural competence to reduce inadvertent discrimination, increasing professionals' knowledge of culture and their cultural skills, employing diverse and bilingual staff, and actively tackling racism (e.g., Doody, & Doody, 2012; Heer et al., 2015; Magaña et al., 2021; Mir, 2010; Perepa, 2007).

Models of Care. A broader perspective across education, health, social care, and other support systems for children and their families may also be beneficial to improve access to early support. Drawing existing on models of care from other contexts might be useful, such as the "medical home" in the USA (e.g., Medical Home Initiatives for Children With Special Needs Project Advisory Committee, 2002). The medical home is an organised approach to provision across the broad healthcare system, comprised of six key characteristics: accessible, family-centred, continuous, comprehensive, coordinated, compassionate, and culturally effective. The application of this model within the context of health, education, and social care services in the UK may be beneficial. Data management tools (e.g., Hafidh et al., 2020) may be key to enabling a broader perspective across service systems for children and their families. Another implication for improving early support is to enhance and develop families' informal support networks, adjunctive to the provision of formal supports, such as establishing peer networks, informal parent groups, or circles of support for parental caregivers. Exploration of existing models of care that integrate both formal and informal support may be beneficial to consider for the context of service provision in the UK.

Limitations

There are several limitations to this study. Firstly, other factors might influence access to early support which were not examined in this study, either due to being out of the scope or due to characteristics of the sample. For example, previous research indicates primary language predicts access to early support (Khetani et al., 2017; Marshall et al., 2016; Nguyen et al., 2016; Roberts et al., 2008; also see Chapter 2). However, language was not examined in this study, as only a small proportion of families reported they only spoke a language different to English at home (N = 6 participants, 0.9%), limiting the statistical power of including this variable in regression analyses. There are also other variables that need to be explored in relation to access to early support that were not captured in the present study, such as the implementation of developmental surveillance, service capacity, availability, and funding, professionals' expertise, and government legislation (see Chapter 2).

Secondly, as cross-sectional data was utilised, it is not possible to ascertain causal relationships between the factors examined. However, the findings provide a useful insight into outcomes of interest (measures of access to early support) and multiple variables associated with them, at a specific point in time. Future studies on access to early support, especially prospective longitudinal studies, will be useful.

Lastly, due to utilising a convenience sample, there is potential risk of bias in the sample. Recruitment methods may have missed "hard to reach" families, including families not in contact with services or the organisations that supported with recruitment, those not wanting support, or those unaware of (potential) child developmental disability. While the study included a diverse sample in relation to socioeconomic indicators, for example income poverty (defined as 60% of UK median equivalised income: 58.4% of participants, compared to 32% of UK households in 2020; Department for Work and Pensions, 2021) and unemployment (18.4% of participants, compared to 13.4% of UK households in 2021; ONS, 2021), there was an underrepresentation of participants from ethnic minority groups (14.6% of participants, compared to 19.4% of the population of England and Wales in 2011; ONS, 2018). Future research could address this by designing accessible studies (culturally, linguistically, etc.) and targeting recruitment to promote participation from families typically underrepresented in research.

Conclusion

Multiple factors influence access to early support for families of young children with suspected or diagnosed developmental disabilities across the UK. Efforts to improve access need to be multi-pronged to reflect this, such as enhancing processes for formal identification of need, ensuring access is not solely dependent on formal identification of need, addressing socioeconomic disparities by reducing poverty and increasing funding for services, empowering families with information and practical support, enhancing the accessibility of services, drawing on other models of care, and enhancing families' informal support networks. Future research is needed to further develop our understanding of factors influencing access to early support and ways to facilitate access to early support for families across education, health, social care, and other service systems in the UK.

Chapter 5: Discussion of Research and Improving Access to Early Support for Children with Developmental Disabilities and their Families

Summary of Research

Research Aims

The overall aim of my PhD research, as stated in Chapter 1, was to examine access to early support for children with developmental disabilities and their families, including examining levels of access to early support, identifying factors that influence access to early support, and considering ways to improve access to early support. This research contributes to developing an understanding of disparities in access to early support for children with developmental disabilities and their families. My first study was a narrative review of international research evidence (Chapter 2), in which I identified several family, service, intersection, and broader contextual factors that influence the process of access to early support (i.e., recognition, identification, and early support receipt) for families who have children with suspected or diagnosed developmental disabilities. For my second study (Chapter 3), I designed and conducted a comprehensive survey examining families' access to a range of early support provisions (e.g., professionals, services, interventions) in the UK. In addition, I examined parental caregivers' perceptions of ease of access to early support, unmet need for early support, and barriers and facilitators of access to early support. Using data from this survey, in my third study I identified predictors of access to early support sources (professionals, services), intervention access, and perceived unmet need for early support, based on quantitative analyses of family and service level factors (Chapter 4). Throughout these chapters, I have described implications of the findings of my research, specifically in relation to policy, practice, and future research to improve access to early support for children with developmental disabilities and their families. This discussion will also be continued in this final chapter (see below).

Research Contribution

This research has led to substantial increased understanding of the complex and multifactorial nature of access to early support for children with developmental disabilities and their families (Chapters 2, 3 and 4). Multiple family, service, intersection, and wider contextual factors have been identified throughout my research, either acting as barriers, facilitators, or modifiers (and sometimes a mixture of these) of the process of access to early support. In addition, my empirical research

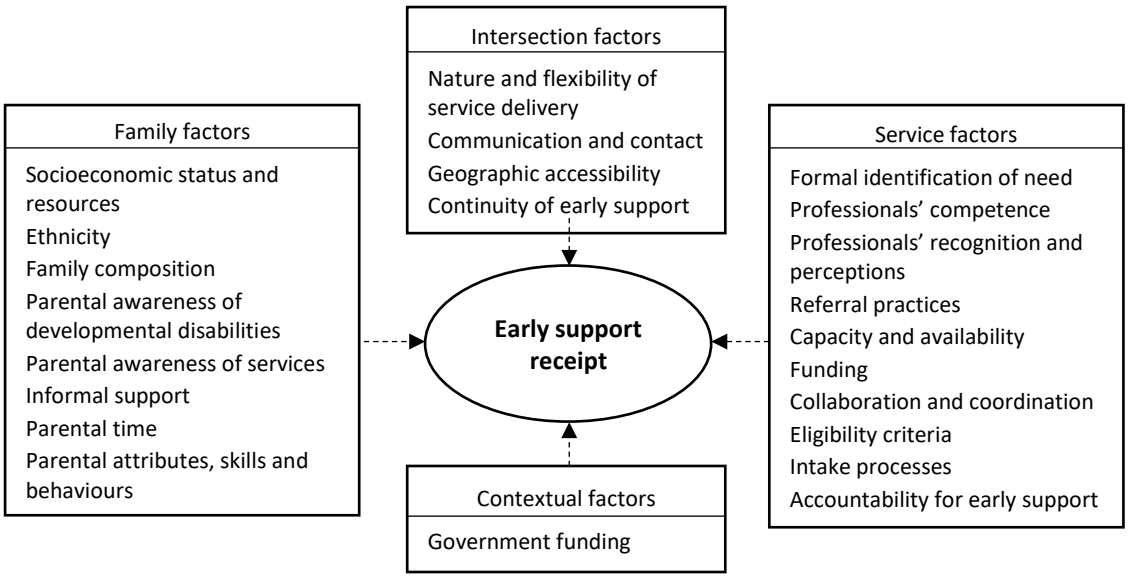
(i.e., the two studies based on my parental caregiver survey of access to early support) has provided insightful and comprehensive data on families' access to early support in a large sample across the UK (Chapters 3 and 4). This has enhanced current understanding of the experiences of families in the UK context regarding access to (and unmet need for) early support, in addition to barriers and facilitators of access. Data collected via the survey enabled rigorous examination of multiple factors within a single statistical model to determine factors that are independently related to families' access to (and unmet need for) early support (Chapter 4). This adds to the extremely limited research literature on access to support focused on the critical early years developmental period (i.e., 0-6 years).

Key Findings

The populated pathway of access to early support from my narrative review of international research evidence (Figure 2.5, Chapter 2) demonstrates the complex nature of access to early support for families of children with developmental disabilities, with various factors influencing access across the pathway. This framework can also be used to present findings from my empirical research studies (Chapter 3 and 4) on access to early support for families of young children with suspected or diagnosed developmental disabilities in the UK (see Figure 5.1). As data collected via my survey predominantly focused on the third phase of the pathway of access to early support (i.e., early support receipt or provision), Figure 5.1 is focused on this phase. This is beneficial to identify overlaps in findings across my narrative review and empirical research. For example, several perceived barriers and facilitators of access to early support reported by parental caregivers (Chapter 3, Study 2) mapped onto factors (family, service, intersection) identified in the review (Chapter 2, Study 1), such as parental socioeconomic status (primarily economic resources), parental awareness of developmental disabilities and services, service capacity and availability, service funding, professionals' expertise/competence, and geographical accessibility, to name a few. Furthermore, significant independent predictors of access to early support sources, access to intervention programmes, and perceived unmet need for early support (Chapter 4, Study 3) also mapped onto factors identified in the review (Chapter 2, Study 1) and/or perceived barriers and facilitators of access (Chapter 3, Study 2). These factors include, for example, socioeconomic status (family economic resources and parental educational attainment), nature and severity of need, ethnicity, family composition, and formal

identification of need. An overview of evidence sources for each factor identified across my research is presented in Table 5.1. This is also useful to identify overlaps across my studies, in addition to identifying gaps that may warrant future research.

Figure 5.1 Factors influencing early support receipt for families of young children with suspected or diagnosed developmental disabilities in the UK



Note. This figure includes factors identified in my empirical research only, including parental caregivers perceived barriers and facilitators of access to early support (Study 2, Chapter 3) and significant independent predictors of access to early support sources, intervention access, and unmet need for early support (Study 3, Chapter 4).

Table 5.1 Factors influencing access to early support across my research

Factors	Study 1	Study 2	Study 3
Family factors			
Socioeconomic status	✓	✓	✓A, B, C
Ethnicity and culture	✓		✓ A
Child demographics	✓		
Nature and severity of need	✓	✓	✓ A
Family history of developmental disabilities	✓		
Child birth order	✓		
Parental recognition and perceptions	✓	✓	
Parental awareness of services	✓	✓	
Family composition	✓		✓ C
Parental time	✓	✓	
Parental awareness of developmental disabilities	✓	✓	
Parenting confidence	✓		
Parental readiness to take part	✓		
Parents' language	✓		
Parental gender	✓		
Parental religion and faith	✓		
Parental stress	✓		
Parental attributes, skills and behaviour		✓	
Informal support	✓	✓	✓ A, C
Service factors			
Developmental surveillance	✓		
Capacity and availability	✓	✓	
Funding	✓	✓	
Professionals' expertise and competence	✓	✓	
Screening methods	✓		
Collaboration and coordination	✓	✓	
Referral practices	✓	✓	
Staff turnover	✓		
Developmental surveillance processes	✓		
Identification methods	✓		
Professionals' recognition and perceptions	✓	✓	
Formal identification of need	✓	✓	✓ A, B
Eligibility criteria	✓	✓	
Intake processes	✓	✓	
Continuity of early support		✓	
Accountability for early support		✓	
Intersection factors			
Nature and flexibility of service delivery	✓	✓	
Communication and contact	✓	✓	
Geographical accessibility	✓	✓	
Early support provision	✓		
Contextual factors			
Political events and unrest	✓		
Government legislation	✓		
Government funding		✓	

Notes. Study 1 = Narrative review of international research (Chapter 2). Study 2 = Parental caregivers perceived barriers and facilitators of access to early support (Chapter 3). Study 3 = Predictors of access to early support sources, access to intervention programmes, and perceived unmet need for early support (Chapter 4).
[A] Significant independent predictor of access to early support sources.
[B] Significant independent predictor of access to intervention programmes.
[C] Significant independent predictor of perceived unmet need for early support.

Key Factors Influencing Access to Early Support

While several factors related to the process of access to early support were identified in my research (see Table 5.1), in this section I will describe key *selected* factors. Of the 42 factors identified across my research, four were identified in all three of my studies, 17 were identified in two of my studies, and 21 were identified in only one study (Table 5.1).

Family Socioeconomic Status. Across all three studies, family socioeconomic status (e.g., family economic resources, parental educational level) influenced access to early support for families of children with developmental disabilities. In my narrative review (Chapter 2), family socioeconomic status influenced all three phases of the process of access to early support. Family socioeconomic status was also identified in my empirical studies (Chapters 3 and 4), in parental caregivers' descriptions of barriers and facilitators of access to early support (specifically their economic resources) and in regression models, as a significant independent predictor of access to early support sources (caregivers' educational level), access to intervention programmes (caregivers' educational level), and perceived unmet need for early support (family economic deprivation). Generally, higher socioeconomic status (i.e., increased economic resources and/or parental educational level) facilitated access to early support, whereas lower socioeconomic status was a barrier. The influence of economic resources on access to early support was modified by the financial set-up of service systems, whereby economic barriers were reduced (but not completely removed) in contexts with a universally free service system, such as the UK. It is likely other factors influencing access to early support (as identified in my research) are related to this, for example the availability and capacity (or absence) of universally free services and referral practices.

Nature and Severity of Need. The nature and severity of need was another key factor identified in all three of my PhD studies. Generally, a higher level of child

need (e.g., developmental, health), including the presence of multiple or co-occurring needs (e.g., autism and intellectual disability, co-occurring physical health conditions), facilitated access to early support, whereas less severe (or less visible, based on external presentation) child need was a barrier (Chapters 2, 3 and 4). However, more severe or more complex child need, including the presence of multiple or co-occurring needs, was sometimes identified as a barrier (Chapter 2 and 3). This might be related to siloed approaches to supporting needs in the current set-up of services and systems, such as the presence of distinct systems for health, education, and social care, and separate services for different developmental disabilities, such as the presence of autism and intellectual disability specific services.

While most research was focused on child rather than parental or other family needs, reduced informal support from family and friends (which arguably demonstrates an increased need for family and social care support) emerged in each study as being related to early support. Reduced informal support was a facilitator of access to early support (specifically respite care) in the review (Chapter 2), was perceived as a barrier of access by parental caregivers in the survey (Chapter 3) and, alongside reduced helpfulness of informal support, was also a significant independent predictor of unmet need for early support (Chapter 4).

Formal Identification of Need. The third and final factor identified in all three of my studies was formal identification of need (e.g., receipt of developmental disability diagnosis, receipt of statutory statement of needs), which facilitated access to early support (Chapters 2, 3 and 4). Early support receipt also appeared to be influenced by the type of formal identification (e.g., diagnosis or statutory statement) and type of need (e.g., developmental disability), potentially related to the nature and severity of need and the different sources of early support examined in the research (e.g., professionals, services, intervention programmes).

Intersection Between Service Factors and Family Factors. Three key interrelated intersection level factors (nature and flexibility of service delivery, communication and contact, and geographical accessibility) were identified in two of my studies, specifically the review (Chapter 2) and in barriers and facilitators of access reported by parental caregivers in the survey (Chapter 3). Firstly, a good match between service delivery factors (services provided, costs, location of provision, etc.) and family factors (nature and perception of need, economic

resources, location of residence, ability to travel, etc.) facilitated access, whereas a poor match was a barrier. Furthermore, flexible features of service delivery (i.e., services' ability to adapt service delivery according to family need or preferences) facilitated access to early support, while inflexible service delivery was a barrier. Relatedly, increased geographical proximity between services and families facilitated access to early support and decreased geographical proximity was a barrier. This was related to urbanicity, families' ability to travel, and features of service delivery, such as catchment area, entry criteria, and the location support is provided (e.g., community or clinical service, family home, remote). Communication and contact between services or professionals and families was also crucial for access to early support. The provision of information and supportive engagement (e.g., professionals' positive attitudes, engagement style, their actions, proactive support) facilitated access to early support, whereas an absence of service information, unhelpful engagement (e.g., professionals' negative attitudes, not listening, being dismissive or obstructive), communication differences (e.g., language, modes of communication) and loss of contact were barriers.

Service Collaboration and Coordination. Service collaboration and coordination was identified in two studies, the narrative review (Chapter 2) and in barriers and facilitators of access reported by parental caregivers (Chapter 3). Ultimately, a lack of (or poor) service coordination and collaboration were barriers of access to early support, including poor communication between services and professionals. Parental caregivers highlighted an absence of a joined-up approach in the UK, for example: *"No joined up approach. Each service seems to act solely independently"* (Chapter 3). In contrast, increased coordination and collaboration between services and professionals facilitated access.

Professionals' Expertise and Competence. The last key factor I will describe is professionals' expertise and competence (in part related to professionals' recognition and perceptions of need and referral practices), identified in the narrative review (Chapter 2) and in barriers and facilitators of access reported by parental caregivers (Chapter 3). Limited professional expertise and competence, particularly in relation to developmental disabilities, was a barrier of access to early support, as it prevented recognition of need (e.g., professionals not conducting routine autism screening due to a lack of familiarity with autism screening tools), prevented or delayed identification of need (e.g., passive or reassuring responses to parental

concerns, not making referrals), and reduced early support receipt (e.g., not referring or signposting to services). Increased professionals' expertise and competence, including higher levels of training broadly and specific to developmental disabilities, facilitated access to early support.

Limitations of Research

As with all research, my research is not without some limitations. Firstly, it is possible my conceptualisation of early support may be criticised for being too broad, potentially limiting the applicability of findings to specific contexts. My conceptualisation of early support incorporated all formal support accessed by children and families in relation to suspected or diagnosed developmental disabilities during early childhood (0-6 years) for a range of child and family needs, including preventative and reactive support, in addition to universal, targeted, and specialist support from statutory and non-statutory services, across health, education, social care, voluntary, and community sectors. However, this broad conceptualisation arguably makes the findings relevant to a range of supports for children with developmental disabilities and their families. Furthermore, this broad conceptualisation enabled the exploration of access to early support across different services and settings, including the identification of factors related to access across services and systems (e.g., the influence of service coordination and collaboration, see above).

My research was also limited in respect to co-production (i.e., participatory research, patient and public involvement), which is increasingly being recognised as essential for high quality, impactful research (e.g., Beighton, et al., 2019; Ogourtsova et al., 2021). Although I consulted with some professionals and parental caregivers of children with developmental disabilities with respect to the design and development of my research (both for the review and the survey), this was restricted to a relatively small group and primarily during the design rather than across different stages of the research process (e.g., analysis, publication, dissemination). Furthermore, consultation is the lowest form of participatory research, due to power over decisions being held by the researcher. Nevertheless, three developmental disability charities (Cerebra, Mencap, and Ambitious about Autism) were actively involved across the research process (e.g., design, analysis, publication, dissemination). Increased co-production and collaboration would undoubtedly have enhanced the quality of my research, however, it is important to recognise additional

resources are essential. In addition to collaborating with parental caregivers, it is also be important to directly involve children with developmental disabilities in research on access to early support.

The explicit focus on English language across my research studies is another limitation, primarily due to my language abilities (i.e., only proficient in English). This may have impacted the findings, due to potentially excluding or missing the experiences and perspectives of families who do not speak English, who speak English as a second or other language, or who are not proficient in English. In my narrative review, only research papers published in English language were considered and included. As such, this may have overlooked relevant research published in other languages. Despite the exclusion of research published in languages other than English, parents' language was identified as influencing access to early support in the review, related to ethnicity. However, evidence on language was limited to only two studies, perhaps due to the focus on research published in English. Unfortunately, it is not uncommon for studies published in languages other than English to be excluded from reviews, due to a dominance of researchers from English-speaking countries, and a lack of funding, time, and language resources (e.g., professional translators) in research (Rasmussen & Montgomery, 2018). Furthermore, my survey was only available in English. Charities involved in the research offered to support parental caregivers to complete the survey in other languages, however, the survey not being available in multiple languages clearly limited participation from those who do not speak English, speak English as a second or other language, and/or have limited English-language proficiency. The majority of participants in the survey (N = 604, 89.7%) only spoke English at home, a small proportion (N = 62, 9.2%) spoke English and another language at home, and a very small proportion (N = 6, 0.9%) only spoke another language at home. Language was not examined in regression models, primarily due to the small proportion of families who reported they only spoke a language different to English at home, as this limited the statistical power of including this variable in the analyses. Furthermore, due to the way language was measured (i.e., asking participants about language(s) spoken in their household), comparing those who spoke English only with those who spoke English and another language was unlikely to represent language differences, as it did not capture English language proficiency. In an adult sample, Chee and de Vries (2021) found discrepant responses on the

autism spectrum quotient (measure of autistic traits) according to the language it was completed in (e.g., English, Mandarin), in part related to language proficiency. It is possible this is also related to factors identified in my research on access to early support, such as screening and identification methods, ethnicity and culture, and communication between services and families. Therefore, research comparing the influence of language across the pathway of access may be fruitful, especially those also considering the influence of potentially related factors (ethnicity, culture, screening and identification methods). Future research on access to early support should address the English-language bias, by researching the experiences of families who speak diverse languages, especially those who do not speak English or have limited English-language proficiency. It would be beneficial for diverse research teams (e.g., language, ethnicity, culture) to conduct this research through co-production.

Regarding my narrative review, the key methodological challenge was that the review was not systematic. Initially, I considered conducting a systematic or realist review to identify barriers and facilitators of access to early support for children with developmental disabilities and their families, with an accompanying UK policy review. To determine the most appropriate methodology, I conducted a non-systematic scoping exercise of literature on barriers and facilitators of access to early support, to get a sense of the literature available (e.g., scope, sample, methodology, types of data relevant to my research questions). In addition to general searches, I explored several lines of enquiry in search of relevant literature, such as general evaluations of early support policies or entitlement (e.g., Part C of the Individuals with Disabilities Education Act [IDEA], the National Disability Insurance Scheme [NDIS], Sure Start), evaluations and reviews of early support for children with developmental disabilities and their families (e.g., programmes, input from various professionals or services across education, health, social care, and other sectors), national datasets with rates of access and non-access to early support, and experiences of professionals working in early support. A large body of relevant literature was identified (academic and non-academic) with a diverse range of focus and type of evidence (e.g., qualitative data from parental caregivers' and professionals, quantitative data on access and non-access, and reflection of potential barriers or facilitators).

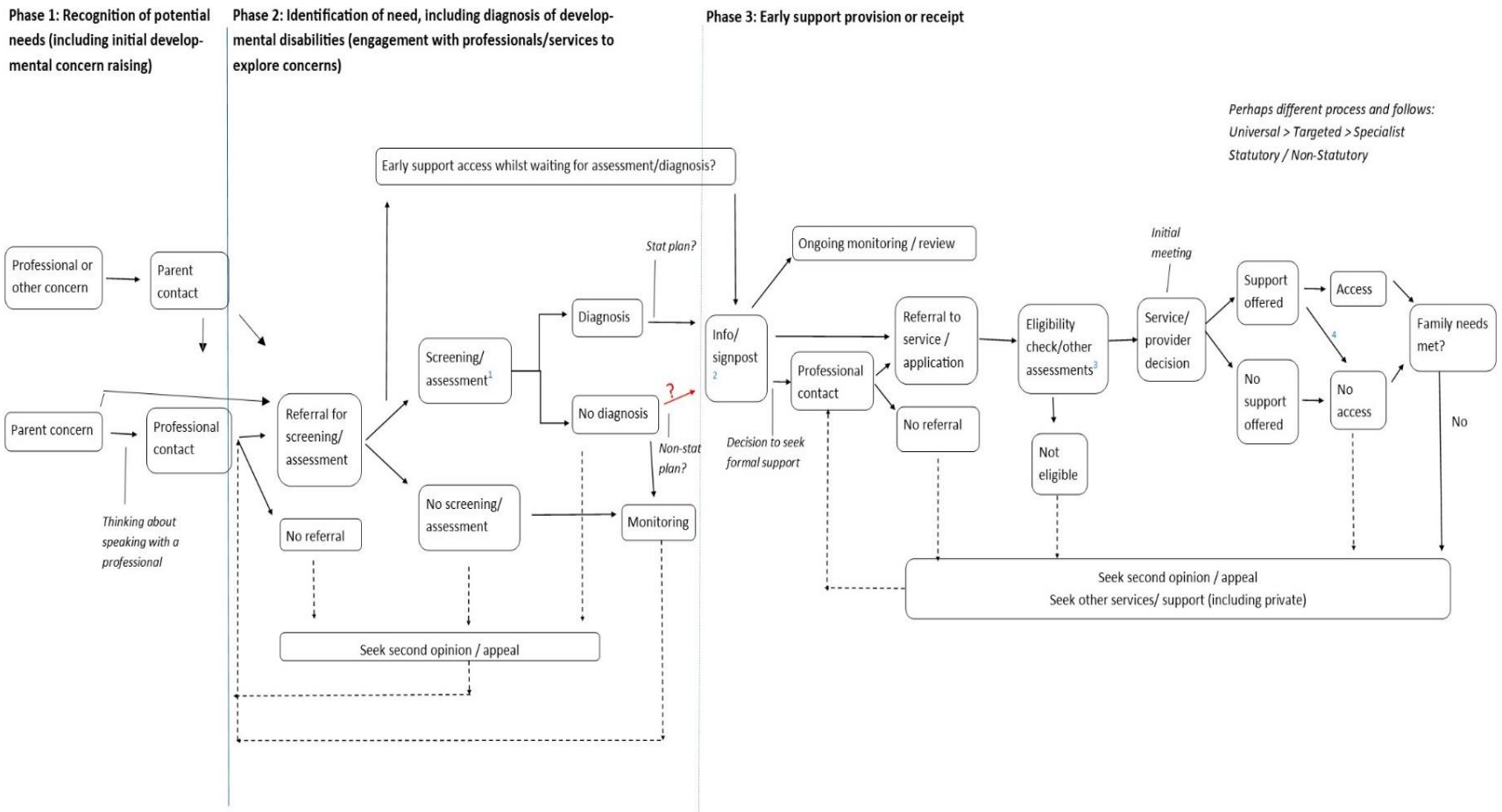
While a systematic review of early support evaluations may have been sufficient to answer some part of my research question, utilising this methodology would have required the scope of the review to be significantly narrowed, excluding a large proportion of relevant literature and evidence on factors related to access. Furthermore, factors influencing access may be different depending on the type of support (e.g., respite versus parent training) which poses an issue for early supports without published evaluations. A realist review is a theory-driven review methodology for complex interventions or programmes, which seek to explain why and how interventions work, synthesising data through a "realist lens" based on context-mechanism-outcome configurations (Greenhalgh et al., 2011, 2012; Kirst & O'Campo, 2012; Pawson et al., 2005; Wong et al., 2014). While some aspects of this methodology appeared appropriate and beneficial for this study (e.g., realism philosophy, engaging with the "messiness" of the real-world context, ability to incorporate a range of data and sources, solution-focus), I ultimately decided it was not appropriate and practical, primarily as early support encapsulates a range of supports across multiple systems, rather than a single (albeit complex) programme. Furthermore, realist reviews typically focus on why and how programmes work (or don't work), which did not directly map on to my research questions. In addition, this approach requires a significant and broad range of data on a specific programme to examine context-mechanism-outcome configurations and identify and test theories, which was not practical for the study.

As a result of the broad nature of the research available on factors influencing access to early support (e.g., minimal research explicitly focused on access across various early support provisions, with relevant research split across diverse research disciplines), I decided to conduct a narrative review. Therefore, the evidence on factors identified may not reflect all available evidence, and there may be other factors related to access to early support that were not included. However, my narrative review was intended as a starting point to develop understanding of disparities in access to early support and future research can and should build on this. To develop the evidence base, systematic reviews could be conducted with a narrower scope, such as examining specific factors or components identified in my review or examining specific early support provisions or developmental disability labels. Furthermore, while non-systematic reviews have been criticised for an increased likelihood of bias (e.g., Petticrew & Roberts, 2006; Tranfield et al., 2003),

as I utilised a bottom-up approach to identify factors based on the research evidence rather than a top-down approach based on my ideas or assumptions, potential bias in the selection and analysis of the literature was reduced. Furthermore, systematic reviews can also be subject to biases (e.g., Jansen, 2017; Massaro et al., 2016). I also acknowledge that my review is situated within the literature review continuum (see Massaro et al., 2016) and that future research is needed to develop the evidence-base to understand the complex issue of access to early support.

Another potential limitation of my review is the use of a simple framework of access to early support (Figure 2.4, Chapter 2). Due to the broad scope of my review, I explored various conceptual models and theoretical frameworks to use in order to structure the review (e.g., models of access to support, help-seeking and referral pathways, developmental systems model, ecological systems theory; see Chapter 2). In the absence of a suitable existing framework, I drafted a framework identifying potential steps involved in the process of accessing early support for families of children with developmental disabilities (Figure 5.2). Due to variation in the process dependent on the type of need or early support, various potential steps were highlighted. I therefore condensed these into three key phases in an attempt to capture the main phases of the process of access to early support across different needs and early support provisions. By definition, the model was simple so as to be inclusive. It is possible utilising other frameworks or models (e.g., models focused on specific supports, such as access to healthcare) might have identified different factors influencing access to early support, therefore this may be useful to consider in future research.

Figure 5.2 Draft framework – Pathway of access to early support for families of children with developmental disabilities



In addition to the theoretical and conceptual frameworks examined as part of my research, other frameworks may also be beneficial to understand access to early support for developmental disabilities. For example, a conceptual framework for public mental health in England has recently been developed, bringing together evidence (research, reports, policies, consultations) to map factors affecting mental health across all stages of a person's life (Public Mental Health Programme, 2021). Within the framework, factors are organised into four broad categories and further divided into sub-categories: (1) individual (trauma and adversity, physical and psychological health, life experiences and opportunities, identity, personal traits, sociodemographic), (2) family (family dynamics and family structure), (3) community (systems and services, social environment, geographic and physical environment), and (4) structural (broad factors, industry, norms and rights, government and political). While this framework is not explicitly focused on access to support or developmental disabilities, several factors appear congruent with those identified to influence access to early support across my research. Factors also related to access to early support for developmental disabilities include, for example, ethnicity and culture (identity, individual), gender and sex (identity, individual), caring responsibilities (family structure, family), household composition (family structure, family), health and social care (systems and services, community), public and community services (systems and services, community), social support and networks (social environment, community), urbanicity differences (geographic and physical environment, community), cultural and social norms (norms and rights, structural), and government policies and legislation (government and political, structural).

The evidence reviewed came from diverse studies with different methodological approaches (e.g., different methodologies, sample sizes, sample recruitment, sample characteristics). Some of the discrepancies identified in the evidence may be due to methodological differences. To mitigate this, key methodological or contextual differences are noted in the description of the review findings. The majority of the studies were limited in scope, exploring specific: (1) developmental disabilities, (2) early support provisions, (3) factors, and/or (4) phases of the pathway of access. However, drawing from a range of literature enabled me to explore the overall picture, which can inform the design of future research studies to investigate the impact of various factors on access to early support. In addition, the

majority of research included in my review was focused on access to early support specific to the child's developmental needs. As such, the process of recognising, identifying, and receiving early support for other child and family needs (e.g., parent or child mental health, parent support needs, sibling support) was limited and not explored in depth. Therefore, it may be beneficial to conduct future research explicitly examining access to early support for other child and family needs.

A limitation of my survey is the primary focus on the third (and final) phase of the pathway of access to early support (early support receipt or provision). The reason for this is as the development of the survey took place before the pathway of access to early support was developed for the review, to enable sufficient time for ethical approval and data collection whilst conducting the review concurrently. However, some questions related to earlier phases of the pathway of access (e.g., questions on developmental disability diagnosis and identification stage). Furthermore, several participants' responses to open-ended questions on barriers and facilitators of access to support covered recognition of potential needs (phase one) and identification or diagnosis of needs (phase two). However, it was not possible to accurately unpick these in the qualitative analysis across all responses, especially as the question focused on receipt of early support, rather than explicitly asking participants about recognition and/or identification of need. It would be beneficial for future empirical research to directly examine factors influencing access to support across the three phases.

The design of the survey was impeded by the lack of a standardised definition of early support (or other similar terms). As described above, based on a range of different definitions and descriptions of early support (and other terms used for similar purposes, e.g., early intervention), I adopted a broad conceptualisation of early support. While I consulted with a small group of professionals and parental caregivers in the design of the survey to ensure I measured a broad range of early support provisions specific to the UK context, a different conceptualisation of early support would have led to different support provisions being measured in the survey, which may have influenced the findings (e.g., rates of access to early support, barriers and facilitators of access, and predictors of access). For example, a narrower conceptualisation of early support focused on targeted intervention programmes may have led to the measurement of access to a range of intervention programmes and the exclusion of access to professionals and services. Different uses of the same terms,

and the use of different terms, are key limitations of research on this topic, as it leads to fragmented research. As described in Chapter 2, it can be challenging to bring together and synthesise research that is fragmented and siloed, partly due to differences in terminology and language used, for example ‘Across research silos (conditions or disciplines), there is a broad range of language and terminology used, varying interpretation of language, and varying use of the same terms (i.e., the same term used to mean something different)’ (Sapiets, 2021, p.29). Furthermore, as discussed in Chapter 1, the use of language needs to reflect the preferences of the community (such as people with developmental disabilities, their families, professionals, policymakers) in addition to researchers. Therefore, the development (and widespread dissemination) of a standardised definition of early support for children with developmental disabilities and their families would be beneficial for future research.

The use of only parental report for primary data collected for my research is another potential limitation, as it relies on their memory and may be subject to recall bias, for example. Regarding questions on access to support, participants were asked to consider the preceding 12 months, this timeframe may be difficult to recall, however, due to variable and potentially infrequent contact with support sources listed, this timeframe was considered critical to capture families’ experiences of access to a range of early support provisions. It would have also been beneficial to ask families what support they had accessed in the preceding three or six months, as this may have yielded different results. Reliance on parental report is especially an issue in relation to the measurement of intervention programmes, as this was based on an open-ended question, rather than including a list for participants to select from. While a few examples of interventions were provided in the survey, it is possible participants were not aware of interventions accessed, potentially skewing responses towards non-access. Furthermore, participants’ free-text responses were analysed to identify access to intervention defined as multi-sessional support packages, if a specific intervention or programme was named, or if there was a clear indication of multiple-session support not covered in the quantitative part of the survey. This reduced the number of participants in the intervention access group from less than one third (N = 197, 29.3%) to less than one fifth (N = 127, 18.7%), which may be due to participants’ not writing the name of an intervention or multi-sessional support package, rather than reflecting non-access. Therefore, it may be beneficial

for future research to include a list of different interventions programmes for participants to select from, as this may yield different results. Furthermore, there is clearly a need for further research on the experiences and perspectives of professionals and service providers involved in early support provision, and pooling data on access from service records, in order to triangulate data. Nevertheless, the perspectives of parental caregivers was and is essential for this research topic, and (as described earlier), many of the barriers and facilitators of access to early support reported by parental caregivers directly corresponded with factors identified in the narrative review, which incorporated evidence from different data sources (e.g., professionals, service providers, service records).

The use of a convenience sample was another limitation of my survey, due to convenience sampling bias, meaning generalisability may be limited (e.g., Jager et al., 2017). Relatedly, the recruitment methods used (primarily through third-sector developmental disability organisations and social media) may have missed certain groups (e.g., families not in contact with services or the organisations that supported with recruitment, those not wanting support, those unaware of child developmental disability, or those not using social media platforms), which may have skewed the findings. While the sample obtained was diverse in relation to socioeconomic indicators (e.g., income poverty, unemployment), there was an underrepresentation of participants from ethnic minority groups (see Chapters 3 and 4). The sample had limited representation of parental caregivers that were not the child's biological mother, particularly fathers, which is a common limitation of developmental disability research (e.g., Langley et al., 2020). Furthermore, there was limited representation of families who primarily spoke languages other than English (see above), from UK countries other than England (Wales, Scotland, Northern Ireland), and who had younger children (e.g., N = 83, 12.3% had children aged <3 years, and N = 185, 27.5% had children aged <4 years). Despite limitations, reasonable confidence can be placed in the descriptive findings due to the large sample size (N = 673), though future research using population-based samples would largely address these limitations. Another way this could be addressed in future research is through designing more accessible studies (culturally, linguistically, etc.) and targeting recruitment to promote participation from families and/or group underrepresented in research.

The cross-sectional nature of the data and analyses was a limitation of my third study, as this meant that it was not possible to ascertain causal relationships. However, the findings can be used to inform measures of interest for future prospective longitudinal studies on access to early support for children with developmental disabilities and their families, which would enable examination of casual relationships. Researchers based in Canada have developed a questionnaire assessing service trajectories in developmental disabilities from the families' perspective (see Rivard et al., 2020, 2021), this tool may be beneficial to adapt and use in UK longitudinal studies families of young children with developmental disabilities.

While I was able to incorporate a range of child, family, and service level factors within the regression models, my narrative review clearly highlighted several other factors which may influence access to early support that were not included in my analyses. This is a key limitation, as the inclusion of other factors may have impacted the findings. For example, my review indicated the financial set up of service systems or individual services modified the relationship between family socioeconomic status (particularly economic resources) and access. While the research was conducted in the UK, which has a universally free service system, the inclusion of a variable related to service funding (i.e., public, private, voluntary) may have influenced the relationship between socioeconomic status and access to (or unmet need for) early support. Furthermore, the predictor variables included were primarily child and family related (excluding formal identification of need via receipt of a developmental disability diagnosis and/or statutory statement), primarily as data was only collected from parental caregivers. As described above, it would be beneficial for future research to be conducted to gather the experiences and perspectives of professionals and service providers. In addition, collecting and triangulating a range of data sources (e.g., parental caregiver report, professional report, examining service records) would be beneficial, but likely time-consuming and expensive. If future parental caregiver surveys are conducted, additional questions could be incorporated to additionally examine service level factors, such as funding (e.g., public, private, voluntary), referral method (e.g., self-referral, referral from professional/service), or speciality level (e.g., universal, specialist) of services accessed.

Implications for Improving Access to Early Support

Policy and Practice Implications

The knowledge gained from my research is especially useful for considering policy and practice investments to improve access to early support for children with developmental disabilities and their families. Due to the broad and extensive findings of my PhD research (i.e., the identification of multiple family, service, intersection, and contextual factors influencing access to early support), much of this section will focus on implications related to key selected factors, rather than describing all potential implications related to each factor identified. However, while we need to address disparities of access based on specific factors identified in my research, it is important to highlight the need to take a broader intersectional approach across factors. In addition to the identification of various factors influencing access to early support across families, my research also highlighted variability within each family's needs, characteristics, and experiences of access to early support. Thus, a broader intersectional approach, looking at the bigger picture (i.e., considering various factors potentially influencing access for children and their families) rather than focusing on specific factors, may be essential to achieving equitable access. There is a need for services to embrace diversity and consider how services and systems can be more flexible and accommodating, rather than trying to fit all children and families into a service or system that results in inequitable access. This needs to also be practical and manageable, therefore increased capacity and resources for professionals and services will be needed to be able to achieve this. Investments to improve access to early support are most likely to be effective if they are system-wide across early support provision, in addition to addressing multiple factors influencing access. Nonetheless, there are investments that can be made at an individual service or professional level to improve access to early support for families, such as improving professionals' engagement styles and developing clear information regarding how families can access the service (e.g., referral processes, eligibility criteria). There are also actions across services on a smaller scale that can improve access, such as enhancing collaboration between professionals and services within a specific area. Below I will discuss crucial implications based on key selected factors identified in my research, primarily focused on modifiable factors (i.e., those that are amendable to change).

Family Socioeconomic Deprivation. Firstly, there is a clear need to reduce economic deprivation experienced by families of children with developmental disabilities, in addition to reducing the impact of socioeconomic status on access to early support. Alarmingly, more than half of survey participants' equivalised income was on or below the poverty line (N = 393, 58.4%), demonstrating considerable economic deprivation experienced by families. This may also be underrepresented, as measures of equivalised income do not take into consideration disability, and disability increases the risk of poverty (see Chapter 4). While reducing economic deprivation may lead to improved access to early support, it is likely such investments will have greater implications, as adverse outcomes are, in part, attributed to increased risk of socioeconomic disadvantage (Emerson & Hatton, 2007b; Hayden et al., 2022; Totsika et al., 2021). In addition to directly targeting poverty, improving the availability and capacity of universally free (i.e., public) services may also facilitate access to early support, which relates to the survey participants' most frequently reported barrier of access to support (N = 711 mentions; Chapter 3). It is also imperative to ensure services are available for families experiencing economic deprivation, including families living in areas with high deprivation.

Cross-government programmes targeting multiple levels of inequalities are likely needed to transform service systems, focusing on long-term organisational change to ensure equity and prioritising 'the fundamental redistribution of resources, funding, workforce, services and power' (Ford et al., 2021, p.1). Promising results were demonstrated by prior implementation of cross-government strategies to prevent health inequalities for people living in deprived areas of the UK between 2000 and 2010 (Ford et al., 2021). However, since the end of the strategy and the UK government's implementation of austerity, there is evidence of increasing health inequalities, related to child poverty (Ford et al., 2021; Flynn, 2019). It is therefore unsurprising that cuts in early years services appear to disproportionately impact children and families living in the most deprived areas (Smith et al., 2018). The reduction in funding for the Sure Start children's centre programme, which brought together services for young children and their families and acted as a gateway for more specialised provision (Smith et al., 2018), may, to some extent, explain why I found families with higher economic deprivation perceived increased unmet need for early support (Chapter 4). Therefore, reinvestment in early support at the national

level, such as for Sure Start, and reversing funding cuts for local authorities, is essential to strengthen early years provision.

Employment is another component of socioeconomic deprivation that warrants further attention. In my survey, 18.4% of participants (*N* = 124) reported no caregiver in the household was in employment (either full or part-time, including those on long term leave). There was a considerable group of employed respondent caregivers (*N* = 185, 27.5% of participants) and partners living in the household (*N* = 33, 4.9%) that were employed part-time rather than full-time, which has direct implications for their economic resources. Perhaps unsurprisingly, the majority of unemployed respondent caregivers were full-time carers (*N* = 271, 40.3%), as were unemployed partners living in the household (*N* = 45, 6.7%). This is consistent with research indicating many parents reduce their working hours or leave employment to care for their child with developmental disabilities, related to issues accessing childcare and the time required to navigate service systems and obtain support (see Chapter 2). This may also be related to a lack of workplace support or adjustments for employees who have children with developmental disabilities, which have been demonstrated in recent research (Stefanidis & Strogilos, 2020; Stefanidis et al., 2020).

The household unemployment aspect of the economic deprivation composite likely accounts for some of the variation in unmet need for early support found in my third study (Chapter 4). In addition to being related to economic deprivation, unemployment may account for increased perceived unmet needs for support due to a potentially reduced social network supporting the family (e.g., direct support with childcare, indirect support regarding information on services). In contrast, being a professional (especially within education, health, or social care services) may reduce the likelihood of unmet needs due to an increased knowledge or awareness of their entitlement for support or how to obtain support from service systems. Further, it may be related to the clout associated with their professional role (in)advertently influencing responses from services or professionals when they seek support for their child and family. Investment to ensure caregivers of children with developmental disabilities are adequately supported to remain (or return to) employment, if they choose to do so, is warranted (e.g., Stefanidis & Strogilos, 2020; Stefanidis et al., 2020).

Service Coordination and Collaboration. Another key area in need of investment relates to the coordination of support across services and collaboration between services, which was a key factor influencing access to early support. Ideally, support should be coordinated across services and systems, but this is often not the case in practice. There is no single "point of entry" or "pathway" into early support. In the UK there is no one organisation or department "in charge" of early support, as it spans across multiple sectors, agencies, services, and systems. Different professionals and services will have different governance regarding their support provision (including internal and external policies) and there can be fragmentation of supports. Early support is, therefore, a complex system, often with professionals and services working individually rather than providing joined-up support across the whole system. Enhancing collaboration between different professionals and services may have significant utility, such as designated liaison professionals (e.g., Manohar et al., 2019).

While previous policy and practice investments have sought to improve collaboration across supports for people with developmental disabilities in the UK (e.g., Children and Families Act, 2014; see Chapter 1), this has clearly not been enough. Therefore, further investment to bring different parts of the system to work together for families would be beneficial. Policies and models of service coordination in the USA (e.g., Dunst & Bruder, 2006; Harbin et al., 2000, 2004; Division for Early Childhood [DEC] & IDEA Infant and Toddler Coordinators Association [ITCA], 2020) may have utility for the UK context. Ensuring families have support from a coordinating professional to guide them through the 'complex service system' (see Chapter 3) could improve families' experiences of access to support, related to other factors identified in my research (e.g., parental awareness of services, communication and contact, referral practices). However, it is vital that professionals working as service coordinators are competent and adequately supported to provide support to children and families, including consideration of 'the complexity of the work and the specialised knowledge and skill set necessary to support the unique population of families of infants and toddlers with delays or disabilities' (DEC & ITCA, 2020, p.2). The use of technology to support coordination across services may also be advantageous, such as the School Care Coordination System (Hafidh et al., 2019, 2020).

The Children's Commissioner for Wales (2020) report 'No wrong door: Bringing services together to meet children's needs' highlights key investments needed to improve services in relation to a lack of service coordination across complicated systems. While focused on Wales, the learning and recommendations are pertinent to UK-wide policy and practice. Key recommendations include moving towards a "no wrong door" approach (e.g., early help panels or hub models, provision of specialist support in the community), increased government investment to support regions to achieve "transformation" of services (e.g., supporting projects, sharing learning, providing longer-term financial support), regions working with children and families to re-shape service provision, and "whole-region" funding and resources, rather than funding being seen as the property of local authorities or health boards (Children's Commissioner for Wales, 2020).

In addition, establishing Family Hubs may be an effective model to improve service collaboration and provide a single point of entry to early support. A Family Hub is 'a system-wide model of providing high-quality, joined-up, whole-family support service' (Anna Freud Centre, 2021b). While each Family Hub is bespoke to the local community it serves, there are three underlying key delivery principles: (1) access (i.e., having a clear and simple way for families to access help and support), (2) connection (i.e., services and professionals working together for families with a universal "front door", shared outcomes, and effective governance), and (3) relationships (i.e., prioritising strengthening relationships and building on family strengths; Anna Freud Centre, 2021b). Recently an implementation toolkit for Family Hubs was launched, a collection of co-produced resources aimed at supporting local authorities, health, education, voluntary, and community sector teams to implement Family Hubs in their local area (Anna Freud Centre, 2021a).

Supportive Professionals. Enhancing professionals' ability to be supportive, particularly regarding their engagement with families, is another key investment area for policy and practice. Specific education and training to improve professionals' communication skills and engagement styles with families may, therefore, be beneficial (e.g., Kemper et al., 2008; Meyer et al., 2009; Nair, 2019). Communication training for professionals should also incorporate understanding and supporting communication styles and preferences across families, especially with respect to developmental disabilities and cultural diversity. The ability of professionals to be supportive is closely linked to their competence (i.e., expertise,

skills), recognition and perceptions of need, and actions (e.g., referral practices). Therefore, additional training to upskill professionals regarding developmental disabilities and early support for families will have benefit. Furthermore, it will be beneficial for training across the range of different professionals involved in early support for developmental disabilities, in addition to being across professional levels.

In addition to training, ensuring professionals have adequate time to listen, respond to, and engage with families is a crucial element of improving their engagement with families. Relatedly, consideration of wider service, system, and contextual issues (e.g., service funding, capacity and availability, government funding for services) is needed with regard to enhancing professionals' ability to be supportive, as professional education alone is likely to be ineffective. We need to recognise and attend to the demands and pressures of professionals experience (e.g., increasing demands, high staff turnover, burnout), to ensure they are able to support children and families.

Parental Awareness and Knowledge. Improving parents' awareness and knowledge, both of developmental disabilities and early support, is another key policy and practice investment area to improve access to early support. Improving parents' awareness and knowledge of developmental disabilities via educational campaigns is a potential investment for improving access to early support, which is likely to be most effective through a public health approach (i.e., disseminating information about developmental disabilities to *all* parents of young children). Information for families will need to be culturally and linguistically diverse and address potential misconceptions of developmental disabilities (e.g., Alsehemi et al., 2017; Sun et al., 2013).

Further investment is needed to ensure parents are aware of early support available and how to access it. However, following the Children and Families Act (2014), local authorities in England have had a statutory duty to develop and publish a 'local offer', detailing education, health, and social care provision available for children and young people with special educational needs or disabilities in their area. An early evaluation by Spivack et al. (2014) highlighted variable accessibility of local offers, including variation in the quality and quantity of information. Therefore, developing and publishing information on provision available may not be enough. A recently published toolkit for parents on accessing public services (Cerebra, 2021)

suggests strategies for families encountering difficulties with statutory agencies in relation to education, health, and social care provision, based on different categories of dispute. In addition, the charity run free workshops ‘to help parents and carers, and the professionals who support them, to access the services that their children need’ (Cerebra, 2021). Therefore, multi-pronged approaches to inform and guide parents regarding early support may be beneficial, such as providing information in varied formats and providing practical support for families regarding service access (see Carr & Lord, 2016).

Perhaps due to the considerable difficulties families face in obtaining access to early support, several early intervention programmes explicitly cover accessing services and supports (e.g., Coulman et al., 2020). This information inevitably needs tailoring according to the supports and services available for families in the local area. Ensuring families have access to such information and support early on could have positive implications for their access to health, education, social care, and other services. Open referrals for such programmes, enabling families to self-refer and for various professionals to refer families from the very point developmental disability is first suspected, would be invaluable.

Nature and Flexibility of Services. The last key implication area for policy and practice I will discuss is the nature and flexibility of service delivery. There is a clear need for services to provide family-centred support and adapt their provision to ensure accessibility for *all* families. Flexible service systems that respond to the individual needs of families can improve access for all, not just families of children with suspected or diagnosed developmental disabilities, or those experiencing specific barriers of access (e.g., socioeconomic deprivation, ethnic minority). Flexible service provision includes, for example, being flexible with the location of service delivery (e.g., hospital or clinic, community, family home, remote), the timing of provision, and the format (e.g., group, individual, phone call, video call, email). Furthermore, individual services and wider service systems desperately need to ensure provision is culturally accessible (e.g., de Leeuw et al., 2020; Magaña et al., 2021; Stahmer et al., 2019).

There is a clear case for remote delivery mechanisms to facilitate access to support, especially given the impact of the Covid-19 pandemic on service delivery and families’ support needs (cf. Asbury et al., 2021; Bailey et al., 2021; Neece et al., 2020; Toseeb et al., 2020; Zaagsma et al., 2021). Flexibility of service provision

remains of vital importance, however, given differences in families' resources and preferences (e.g., internet/telephone access, ability to travel, communication preferences). Furthermore, investments to improve access to early support should consider the potential impacts of wider contextual factors on families' access to early support, namely the Covid-19 pandemic, austerity, Brexit, and the social care recruitment crisis (e.g., Ameis et al., 2020; Asbury et al., 2021; Bailey et al., 2021; de Maeseneer, 2021; Forrester-Jones et al., 2021; Gahwi & Walton-Roberts, 2021; Hallett, 2021; Neece et al., 2020; Spain et al., 2021).

Research Implications

In addition to the policy and practice implications discussed above, my research also points to implications for future research on access to early support for children with developmental disabilities and their families, broadly split into two key areas: (a) expanding our understanding of factors influencing access to early support, and (b) developing and testing ways to enhance access to early support.

Firstly, there is a need for future research to further develop our understanding of factors influencing access to early support for children with developmental disabilities and their families. Future in-depth research examining the influence of specific factors on access to early support based on factors identified in my research (Table 5.1) will be beneficial, such as systematic reviews of the influence of socioeconomic status, ethnicity or culture on access to early support, robust examination of the influence of screening and/or identification methods, or exploratory qualitative research on less commonly researched factors, such as parenting confidence. In addition to research focused on specific factors, research examining the influence of (and relationships between) multiple factors on access to early support will be vital to unpick the complex multifactorial nature of access to early support. The pathway of access to early support (Figure 2.4, Chapter 2) may be a helpful framework for researchers to consider in future research on access to early support, with regard to examining all three key phases of access to early support. In addition to Table 5.1, frameworks displaying findings from my PhD research (Figure 2.5, Chapter 2; Figure 5.1) will be useful for the design and development of future studies, as they demonstrate the various factors influencing access to early support. Primarily, these will be useful for considering topics to focus future research efforts on, such as key converging factors (see above) and potential gaps warranting additional research attention (e.g., UK based empirical research on service and

contextual level factors). Furthermore, they may be helpful for consideration of different areas to measure in future research on access to early support (i.e., capturing different factors influencing access) and to organise and synthesise future research on access to early support.

The second key implication area for future research is developing and testing ways to enhance access to early support for children with developmental disabilities and their families. Based on the findings of my research, it will be beneficial for future research to examine and test ways to improve access to early support, perhaps through targeting key modifiable factors described above. It is possible interventions to enhance access to early support will achieve maximum benefit when targeting multiple factors across systems, though future research should seek to ascertain how to effectively maximise access to early support. As mentioned above, it is important for future research to be conducted with participatory methods, to ensure the voice of children and families is central to future efforts improving access to early support.

Impact of Research

My research is useful and will move the field forward in several ways. Specifically regarding Chapter 2, to my knowledge, no other existing review has brought together such a broad scope of diverse research evidence across multiple disciplines in attempt to generate in-depth understanding of access to early support across developmental disabilities. My review appears to be of interest to other researchers in the field of early support and developmental disabilities. Following a successful symposium submission, I delivered a presentation on my review at the International Association for the Scientific Study of Intellectual and Developmental Disabilities World Congress in 2019 (Scott et al., 2019). Furthermore, a manuscript of the review was published in the Journal of Applied Research in Intellectual Disabilities (Sapiets et al., 2021) and has subsequently been cited by other researchers (Coulman et al., 2021; Gore, 2021; Gore et al., 2022; Hassanein et al., 2021; Heyns & Roestenburg, 2021; Mabaso, 2020; Olusanya et al., 2022; Reitzel et al., 2021). In addition, as part of their Accessible Academia series, the charity Autistic Nottingham prepared a series of infographics on the review which they shared via social media (Autistic Nottingham, 2021).

Findings from my survey also appear to be of interest to researchers in the field. In 2019 I delivered a presentation on the preliminary descriptive findings at the Seattle Club Conference. I also led a successful symposium submission for the

Gatlinburg Conference in 2020 which included a presentation on these findings, however, the conference was cancelled due to the Covid-19 pandemic. Following peer review, a manuscript on this has been published in the Journal of Early Intervention (Sapiets et al., 2022a). In addition, I recently submitted a manuscript on the predictors of access to (and unmet need for) early support for publication (Sapiets et al., 2022b). My research has also contributed to other projects. For instance, my findings contributed Ambitious about Autism's "Right from the Start" project, focused on supporting parents and carers of autistic children to access professional support in the early years (Stanford et al., 2019).

Most importantly, the findings of my research have the potential to impact the day-to-day lives of children with developmental disabilities and their families, through enhancing access to early support – primarily via targeted recommendations for policy, practice, and future research to reduce inequalities of access to early support. For example, the research findings will be utilised by charity partners (Cerebra, Mencap, Ambitious about Autism) in their campaigning and policy influencing work. In addition to the dissemination activities described above, the knowledge generated from my research will be widely disseminated to relevant stakeholders (people with developmental disabilities, families, carers, various professionals, service providers, third sector organisations, policy makers, researchers, etc.) via presentations, publications, lay summaries, infographics, and social media posts. It will also inform future research applications to develop ways to improve access to support.

Conclusion

In conclusion, my research has led to substantial increased understanding of the complex and multifactorial nature of access to early support for children with developmental disabilities and their families. Factors influencing access span across family, service, intersection, and contextual levels. Key selected factors identified include family socioeconomic status, nature and severity of need, formal identification of need, nature and flexibility of service delivery in relation to family factors, communication and contact between services and families, service coordination and collaboration, and professionals' competence. There is a clear need to address disparities of access and to improve access to early support for children with developmental disabilities and their families, to ensure they are able to access support from an early age. Efforts should be intersectional, targeting multiple factors

identified in my research, and participatory, ensuring the voice of children with developmental disabilities and families is central. Future research will be beneficial to further develop our understanding of factors influencing access to early support, in addition to developing and testing ways to improve access to early support for children with developmental disabilities and their families.

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Appendices

Appendix 1: Ethical Approval for Support in the Early Years

1.1: Conditional Approval Letter

Humanities and Social Sciences Research Ethics Committee
Kirby Corner Road
Coventry
CV4 8UW

Wednesday, 31 January 2018

Suzi Scott and Caitlin Murray
CEDAR
University of Warwick
Coventry
CV4 7AL

Dear Suzi and Caitlin,

Ethical Application Reference: 57/17-18
Title: Support in the Early Years

Thank you for submitting your project to the Humanities and Social Sciences Research Ethics Sub-Committee for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, conditional approval for your project is hereby granted.
Please respond to the comments below within 21 days to enable full approval to be granted.

1. Poster: Suggest amend the first sentence to "If so, you are invited to take part …"
2. Participant Information Sheet:
    a. *Will my taking part be kept confidential?* Given the Data Protection Act will be replaced in May of this year, it is advised that the reference to the DPA is removed. It is sufficient to end the sentence after the reference to training.
3. Consent Form:
    a. Statement 3: The reference to accessing records is normally seen in consent forms for clinical research, as such we suggest replacing records with information.

Please submit any responses and amended documentation, with changes clearly highlighted, to hssrec@warwick.ac.uk.

Before conducting your research it is strongly recommended that you complete the on-line ethics course: https://www2.warwick.ac.uk/services/ldc/researchers/opportunities/development_support/research_integrity/
Support is available from your Departmental contact in Research & Impact Services.

Any material changes to any aspect of the project will require further consideration by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

1.2: Full Approval Letter

Humanities and Social Sciences Research Ethics Committee
Kirby Corner Road
Coventry
CV4 8UW

Tuesday, 06 February 2018

Suzi Scott and Caitlin Murray
CEDAR
University of Warwick
Coventry
CV4 7AL

Dear Suzi and Caitlin,

Ethical Application Reference: 57/17-18
Title: Support in the Early Years

Thank you for submitting your updated ethics application to the Humanities and Social Sciences Research Ethics Sub-Committee, following the letter of conditional approval on **31 January 2018**. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full approval for your project is hereby granted for the duration of the study.

Before conducting your research it is strongly recommended that you complete the on-line ethics course:
https://www2.warwick.ac.uk/services/ldc/researchers/opportunities/development_support/research_integrity/
Support is available from your Departmental contact in Research & Impact Services

Any material changes to any aspect of the project will require further consideration by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

[redacted]

Dr Fiona MacCallum
Chair, Humanities and Social Sciences Research Ethics Sub-Committee

1.3: Amendment Approval Letter

Humanities and Social Sciences Research Ethics Committee
Kirby Corner Road
Coventry
CV4 8UW

Friday, 11 May 2018

Suzi Scott and Caitlin Murray
CEDAR
University of Warwick
Coventry
CV4 7AL

Dear Suzi and Caitlin,

Ethical Application Reference: 57/17-18
Amendment number: 1
Title: Support in the Early Years

Thank you for submitting your project amendments to the Humanities and Social Sciences Research Ethics Sub-Committee for consideration. We are pleased to advise you that, under the authority delegated to us by the University of Warwick Research Governance and Ethics Committee, full approval for your project is hereby granted.

Before conducting your research it is strongly recommended that you complete the on-line ethics course: www.warwick.ac.uk/ritraining. Support is available from your Departmental contact in Research & Impact Services.

Any material changes to any aspect of the project will require further consideration by the Committee and the PI is required to notify the Committee as early as possible should they wish to make any such changes.

May I take this opportunity to wish you the very best of luck with this study.

Yours sincerely

[redacted]

Dr Fiona MacCallum
Chair, Humanities and Social Sciences Research Ethics Sub-Committee

Appendix 2: Support in the Early Years Documentation

2.1: Study Webpage

Support in the Early Years

The Family Research Group at the University of Warwick are working with the charities Cerebra, Mencap, Ambitious about Autism and ENABLE Scotland on a new study called **Support in the Early Years**, to explore the experiences of families of young children with a diagnosed or suspected learning disability and/or autism in the UK. The study will focus on the use of and access to support in the early years, as well as family and parental wellbeing.

This study will further our understanding of what support families access in the early years, what may prevent them from accessing services, and what could help to improve access to early years support. This research will also help us to develop ways to increase access to early intervention and support for families of children with learning disabilities and/or autism in the UK in future research projects.

Are you the parent or parental caregiver of a child aged 0-6 years old (from birth until the day before their 7th birthday) with a diagnosed or suspected learning disability and/or autism and live in the UK? If you are interested in taking part, please click here.

Why is this research important?

Suzi Scott, PhD student in CEDAR at the University of Warwick, said:

> *"It's crucial that families who have a child with a learning disability and/or autism are able to access the support they need when their child is young. The purpose of my PhD research is to improve access to early intervention and early years support for young children with learning disabilities and/or autism.*
>
> *"Our 'Support in the Early Years' study is a key part of my research and will help develop understanding of the experiences of families across the UK. It is an honor to be conducting this research in partnership with such*

fantastic charities – Cerebra, Mencap, Ambitious about Autism and ENABLE Scotland, each bringing their invaluable experience working with families.

"The Family Research Group at the University of Warwick is part of CEDAR, an internationally acknowledged research centre carrying out research on a range of educational and psychological issues. CEDAR's research focuses on special educational needs and inclusion, disability across the lifespan (especially learning disability and autism), and parenting and families research."

Tracy Elliott, Head of Research and Information at Cerebra, said:

"Cerebra is the charity that works with families who include children with brain conditions. By listening to families we know that it can be difficult for them to access the support they need and are entitled to in the early years.

"This research project will explore the current levels of access to early years support across the UK and what factors/things are related to families accessing (or not accessing) support in these early years. The evidence gathered in this study will be the foundation for future research aiming to develop ways to improve access to early years support for families who have a young child with a developmental disability."

Margaret Kelly, Strategic Lead for Early Intervention at Mencap, said:

"We are delighted to be a key partner with the University of Warwick and other charities in this research project exploring access to early intervention and early years support for families who have a young child with a learning disability and/or autism.

"There are currently around 119,000 children under the age of 7 who have a learning disability in England, Wales and Northern Ireland, and we believe every young child with a learning disability should have access to early intervention services that support their development from birth."

At Mencap, we are committed to ensuring children with a learning disability and their families have access to effective early intervention services and approaches and we believe hearing from parents and caregivers themselves is vital to both understand how they access support and how we can increase their access to support."

Alison Worsley, Director of External Affairs at Ambitious about Autism, said:

"Ambitious about Autism is a national charity for children and young people with autism. We provide services, raise awareness and understanding, and campaign for change. Our ambition is to make the ordinary possible for more children and young people with autism.

"Early intervention and support are critical if children and young people with autism are to learn, thrive and achieve – but we know many families face a struggle to access the help they need. This important research will help us identify and better understand those challenges – in turn helping parents to better support their children during crucial early years."

ENABLE Scotland, said:

"ENABLE Scotland is a charity founded in 1954 by the parents of children who had learning disabilities. For over sixty years, we've campaigned for every child who has a learning disability to have the same opportunities in life as every other child in Scotland.

"The experience of our members and our own research has revealed the challenges faced by parents in the early years, especially around obtaining a diagnosis of a learning disability or autism and accessing appropriate support. We are excited to be involved in this important research and look forward to using the findings to inform our continuing work to deliver an equal society for every person who has a learning disability in Scotland."

Want to find out more or receive updates about our study?

If you have any questions or would like to know more about the study, please contact the research team at familyresearch@warwick.ac.uk or 024 7657 5866.

We will provide updates on the research here on our website as well as through our social media pages. You can follow us on Twitter (@Family_RG1) and/or Facebook (www.facebook.com/FamilyRG1) to keep up-to-date with the research.

Family_RG1

You can also sign up for our Family Research newsletter below. This mainly focuses on our Cerebra 1,000 Families study but also covers findings and updates from other family research from CEDAR.

facebook.com/FamilyRG1

Find out more about taking part in the study

Click here to take part in the study

- Subscribe to our newsletter
- Link to our Newsletter – May 2019
- Link to our Newsletter - May 2018
- Link to our Newsletter - May 2017

To learn more about the Family Research Group and our partners, please visit our websites:

The Family Research Group

WARWICK
THE UNIVERSITY OF WARWICK

Cerebra

CEREBRA
Working wonders for children with brain conditions

Mencap

Mencap Northern Ireland

Mencap Cymru

mencap
The voice of learning disability

Ambitious about Autism

Ambitious about Autism

ENABLE Scotland

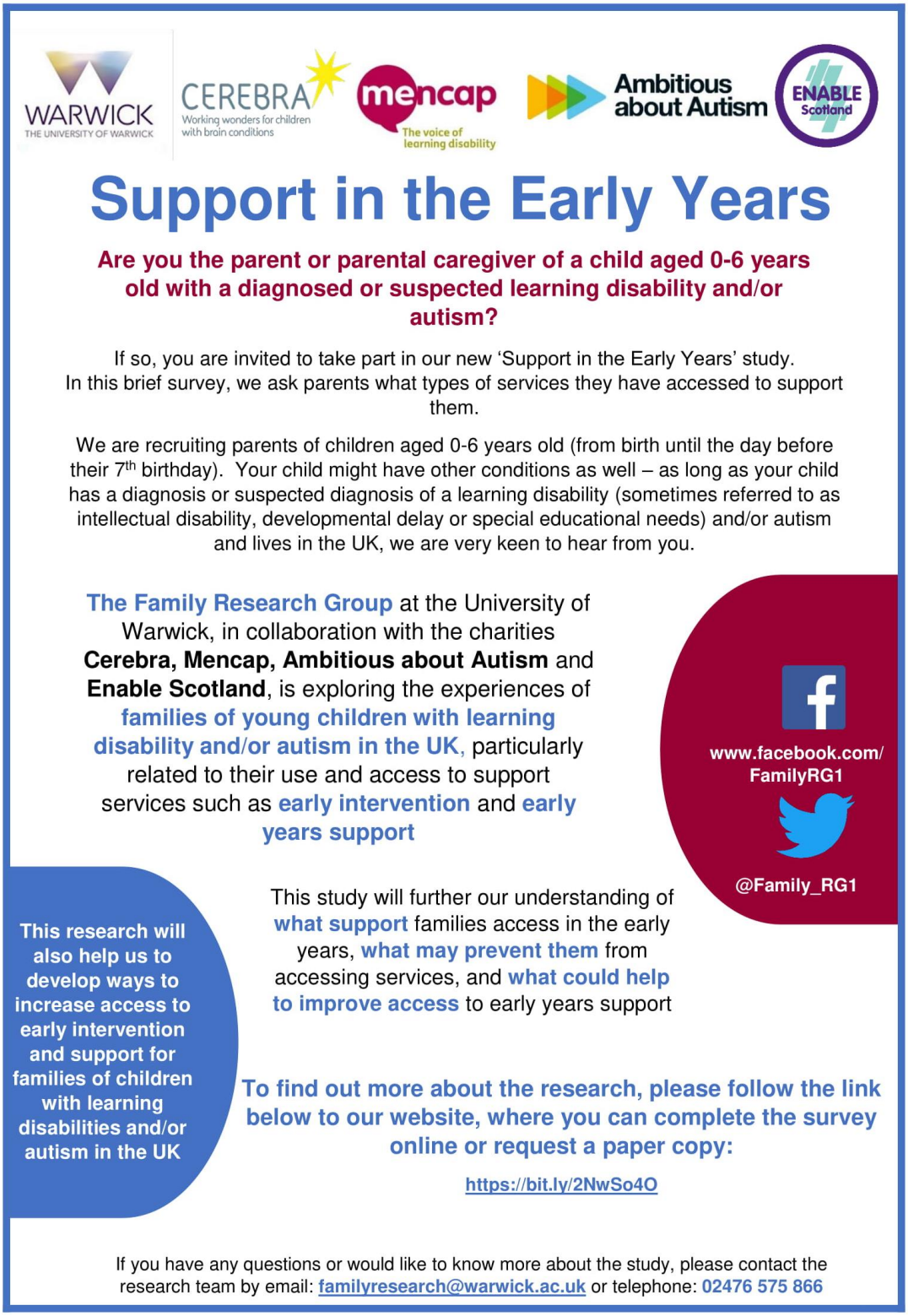
- Advert (PDF)
- Information Sheet (PDF)

Centre for Educational Development, Appraisal and Research (CEDAR)
University of Warwick, Coventry, CV4 8UW, United Kingdom
Tel: +44 (0)24 7652 3638 · Fax: +44 (0)24 7652 4472
View our location on Westwood Campus

Page contact: Alison Baker
Last revised: Wed 5 Jun 2019
Powered by Sitebuilder | © MMXXII | Terms | Privacy | Cookies | Accessibility

Coronavirus (Covid-19): Latest updates and information

2.2: Advert


WARWICK
THE UNIVERSITY OF WARWICK
CEREBRA
Working wonders for children with brain conditions
mencap
The voice of learning disability
Ambitious about Autism
ENABLE Scotland
Support in the Early Years
Are you the parent or parental caregiver of a child aged 0-6 years old with a diagnosed or suspected learning disability and/or autism?
If so, you are invited to take part in our new 'Support in the Early Years' study.
In this brief survey, we ask parents what types of services they have accessed to support them.
We are recruiting parents of children aged 0-6 years old (from birth until the day before their 7th birthday). Your child might have other conditions as well – as long as your child has a diagnosis or suspected diagnosis of a learning disability (sometimes referred to as intellectual disability, developmental delay or special educational needs) and/or autism and lives in the UK, we are very keen to hear from you.
The Family Research Group at the University of Warwick, in collaboration with the charities Cerebra, Mencap, Ambitious about Autism and Enable Scotland, is exploring the experiences of families of young children with learning disability and/or autism in the UK, particularly related to their use and access to support services such as early intervention and early years support
www.facebook.com/FamilyRG1
@Family_RG1
This research will also help us to develop ways to increase access to early intervention and support for families of children with learning disabilities and/or autism in the UK
This study will further our understanding of what support families access in the early years, what may prevent them from accessing services, and what could help to improve access to early years support
To find out more about the research, please follow the link below to our website, where you can complete the survey online or request a paper copy:
https://bit.ly/2NwSo4O
If you have any questions or would like to know more about the study, please contact the research team by email: familyresearch@warwick.ac.uk or telephone: 02476 575 866

2.3: Participant Information Sheet

Support in the Early Years

PARTICIPANT INFORMATION SHEET

Version 1.3, 22/06/18

Title of Project: Support in the Early Years

Name of researcher(s): Suzi Scott, Caitlin Murray, Dr Vaso Totsika, and Professor Richard Hastings

Introduction

We would like to invite you to take part in a research study. Before you decide, you need to understand why the research is being done and what it would involve for you. Please take the time to read the following information carefully. You can talk to others about the study before you decide whether to take part.
Please ask us if there is anything that is not clear, or if you would like more information. Take time to decide whether you wish to take part.

PART 1

What is the study about?

This study aims to understand the experiences of parents/caregivers and families of young children aged 0-6 years old with diagnosed or suspected learning disabilities (sometimes referred to as intellectual disabilities, developmental delays) and/or autism, in the UK.

We want to find out what support families and children are currently receiving in the early years, such as support from professionals, early years services, and early intervention services. We are also interested in what helps families access support and what makes it difficult for families to access support.

We will also explore parent and family wellbeing for families during the early years. The early years are an important time, and this research aims to further understand how families are doing and how access to services, or lack of services, can impact the family.

Who can take part in this study?

We would like to invite parent/caregivers of a child aged 0-6 years old with a diagnosed or suspected learning disability and/or diagnosed or suspected autism to take part in this study. A learning disability may also be referred to as “intellectual disability” or “developmental delay”. Your child with a learning disability and/or autism might also have other diagnosed conditions such as Down’s syndrome, or other genetic syndromes. Your family must currently live somewhere in the UK to participate.

Do I have to take part?

No. It is entirely up to you to decide.

Once you have read this information sheet, we will ask you to either tick boxes on a paper consent form or complete the form on the online survey to confirm that you have agreed to take part. You will be free to withdraw at any time, without giving a reason and this will not affect you or your circumstances in any way. **You do not need to answer any questions that you are uncomfortable answering.**

What will happen to me if I take part?
You will be asked to answer some questions about your child with a learning disability and/or autism and your family using an online survey. If you would prefer to complete a paper questionnaire, this can be requested on our website.

The survey takes about 30 minutes to complete. You will be asked for some anonymised information about you and your family, your child's skills and development, any disability diagnoses your child has been given, you and your family's wellbeing, what type of support you currently receive from services, how difficult you have found it to access services, as well as anything that has helped you with access to services.

What are the possible disadvantages of taking part in this study?
We do not anticipate any risks to parents or their children as part of this research. We will not be asking for your name, to protect your anonymity. Most questions that we are asking have been used in several research studies before. However, it is possible that you will find some of the questions to be upsetting because we do ask about your wellbeing and some of the challenges faced by you, your family and your child with a learning disability and/or autism. If you are upset by any of the questions, you do not have to respond to them and you are under no obligation to continue with the survey.

If any of the survey or interview questions make you concerned for yourself or another family member's wellbeing, we recommend that you make contact with your General Practitioner (GP) or one of the helplines listed below:

Mencap: 0808 808 1111, Contact a Family: 01332 557 975, KIDS: 0207 359 3635

In addition, a factsheet on emotional wellbeing for parents/carers of children with a learning disability can be found at www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-emotional-well/.

What are the possible benefits of taking part in this study?
Involvement in this research provides an opportunity to share you and your family's experiences during the early years, as well as contribute to a greater understanding of access to early intervention and support for families of children with a learning disability and/or autism. It is planned that this research will lead to developing ways to increase access to early intervention and support for families of children with a learning disability and/or autism. The information you provide will help us to understand more about families like yours, to share this information, and to inform ways to better support families.

What if there is a problem?

If you have a concern about any aspect of this study, you can speak to someone from the research team who will do their best to answer your questions (contact details on the next page). If you remain unhappy and wish to complain formally, please contact the University of Warwick (contact details can be found below in Part 2).

This concludes Part 1.

If the information in Part 1 has interested you and you are considering participation, please read the additional information in Part 2 before making any decision.

PART 2

Who is organising and funding the study?

The University of Warwick is responsible for this research. The research project is funded by the University of Warwick, and the charities Cerebra and Mencap. Ambitious about Autism and ENABLE Scotland are partners in the project but have not directly provided funding.

What will happen if I don't want to carry on being part of the study?

You can withdraw from the study at any time, without giving a reason, and without affecting you in any way. Please note, that if you participate in the survey and later change your mind, we will only be able to remove your data if you decide to give us your full postcode. Otherwise, we will not be able to identify who you are.

Who should I contact if I wish to make a complaint?

Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance
Post: Research & Impact Services, University House, University of Warwick, Coventry, CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Will my taking part be kept confidential?

Yes, all information about you will be handled in confidence and all information will be kept securely (in locked cabinets, or secure password protected computers) in an anonymised form. Information from the study will only be seen by the research team. Names and addresses used to send out paper versions of the survey will be deleted or shredded and no record of this will be kept. The survey asks you to provide your postcode. We would like this information because we can then get other information from the UK Census about the area in which you live. You do not have to provide this information. Postcodes will be kept separate from all other data and protected on an encrypted University of Warwick server.

Only members of the research team will have access to data. However, in some instances, officials from regulatory authorities may need to access data for checking the quality of the research. All members of the research team and regulatory bodies are trained in data protection issues. Study information will be kept securely for up to 10 years in line with the University of Warwick's policies.

What will happen to the results of the study?
We will publish reports and give presentations about the results of the study. Once the research study is complete, we will provide information about the results of the research on our website https://warwick.ac.uk/fac/soc/cedar/familyresearch/supportearlyyears/ as well as through our social media pages. You may opt to follow us on Twitter (@Family_RG1) and/or Facebook (www.facebook.com/FamilyRG1) to keep up-to-date with the research.

Who has reviewed the study?
This study has been reviewed and given favourable opinion by the University of Warwick's Humanities and Social Science Research Ethics Committee (HSSREC): 57/17-18

What if I want more information about the study?
If you would like to ask questions before deciding whether to participate, please contact a member of the research team (Tel: 02476 524 139, Email: familyresearch@warwick.ac.uk).

You can also contact Suzi Scott (Email: S.Scott.8@warwick.ac.uk, Tel: 02476 575 866) or Caitlin Murray (Email: C.Murray.7@warwick.ac.uk, Tel: 02476 575 866) directly if you would prefer.

Thank you for taking the time to read this Participant Information Sheet

2.4: Consent Form

Support in the Early Years

CONSENT FORM

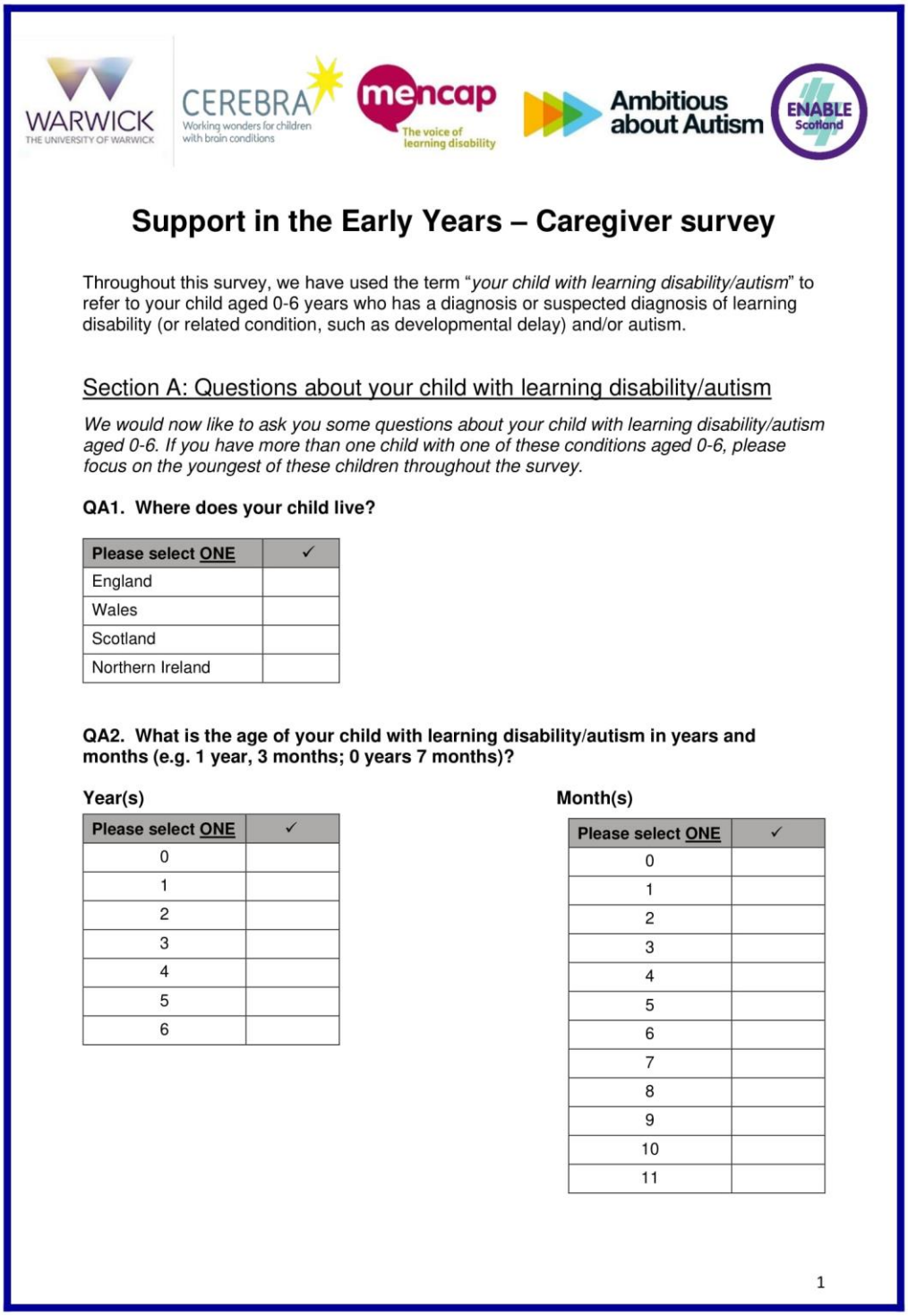
Title of Project: *Support in the Early Years*

Name of researcher(s): *Suzi Scott, Caitlin Murray, Dr Vaso Totsika, and Professor Richard Hastings*

Please read the statements below carefully. If you agree with these statements then tick in the corresponding box. ***Unfortunately, if you do not consent to all the statements we cannot use your survey responses.***

		Please tick box
1.	I have read and understood the information sheet (*version 1.3, 22/06/18*) provided for the above study. I have asked any questions I wanted to ask.	☐
2.	I understand that my participation is voluntary and that I am free to withdraw at any time without giving any reason.	☐
3.	I understand that the data from this study will be used in a non-identifiable way in publications (e.g., journal articles, conference presentations). I agree that my anonymised data can be used in this way.	☐
4.	I understand that my data will be securely stored for a minimum of 10 years, in line with the University of Warwick's Research Data Management Policy.	☐
5.	I agree to take part in the above study.	☐

2.5: Survey



Support in the Early Years – Caregiver survey

Throughout this survey, we have used the term "*your child with learning disability/autism*" to refer to your child aged 0-6 years who has a diagnosis or suspected diagnosis of learning disability (or related condition, such as developmental delay) and/or autism.

Section A: Questions about your child with learning disability/autism

We would now like to ask you some questions about your child with learning disability/autism aged 0-6. If you have more than one child with one of these conditions aged 0-6, please focus on the youngest of these children throughout the survey.

QA1. Where does your child live?

Please select ONE	✓
England	
Wales	
Scotland	
Northern Ireland	

QA2. What is the age of your child with learning disability/autism in years and months (e.g. 1 year, 3 months; 0 years 7 months)?

Year(s)

Please select ONE	✓
0	
1	
2	
3	
4	
5	
6	

Month(s)

Please select ONE	✓
0	
1	
2	
3	
4	
5	
6	
7	
8	
9	
10	
11	

QA3. Is your child with learning disability/autism male or female?

Please select ONE	✓
Male	
Female	
Prefer not to say	
Other (please specify)	

QA4. Has any professional (e.g., GP, paediatrician, psychologist, doctor) ever told you your child has (or might have) any of the conditions below?

Please indicate whether your child is awaiting further assessment (e.g., on waiting list), is going through assessment or has already been diagnosed.

Select ALL that apply for your child and leave blank for those that do not apply	Has received this diagnosis	Currently going through assessment	Waiting for an assessment
Learning disability /learning difficulty (or suspected learning disability/difficulty) – may also be called intellectual disability			
Autism /Autistic Spectrum Disorder /Autistic Spectrum Condition /Asperger's Syndrome (or suspected autism)			
Social Communication Disorder			
Developmental Delay /Global Developmental delay (or suspected developmental delay)			
Dyspraxia /Developmental co-ordination disorder			
Cerebral palsy			
Down's syndrome			
Williams syndrome			
Fragile X syndrome			
Attention Deficit Hyperactivity Disorder (ADHD)			
Complex needs			
Special educational needs/additional learning needs/additional support needs			
Other diagnosis/genetic syndrome (please describe below)			

QA5. Has a professional told you, or do you think, that your child with learning disability/autism has a visual impairment?

Please select ONE	✓
Yes	
No	

QA6. Has a professional told you, or do you think, that your child with learning disability/autism has a hearing impairment?

Please select ONE	✓
Yes	
No	

QA7. Does your child with learning disability/autism currently have epileptic seizures?

Please select ONE	✓
Yes (Please go to QA9)	
No (Please go to QA8)	

QA8. Has your child with learning disability/autism ever had an epileptic seizure in the past?

Please select ONE	✓
Yes	
No	

QA9. Does your child with learning disability/autism have any mobility problems?

Please select ONE	✓
Yes	
No	

QA10. Does your child with learning disability/autism have any other physical health problems?

Please select ONE	✓
Yes	
No	

QA11a. Does your child with learning disability/autism normally…

Please select ONE	✓
Live with you full-time? (Please go to QA12)	
Live with you part-time? (Please got to QA11b)	

QA11b. Please state the approximate number of days that your child with learning disability/autism lives with you on a weekly basis

QA12. Which of the following does your child with learning disability/autism usually attend?

Please select ONE	✓
Not currently in school or pre-school/nursery	
Mainstream school	
Mainstream school in a Special Education Needs (SEN) unit or similar *(e.g. Enhanced Learning Provision (ELP) unit)*	
Mainstream preschool or nursery	
Mainstream preschool or nursery in a Special Education Needs (SEN) unit or similar	
Special school	
Special preschool or nursery	
Home schooled	

Section B: Questions about support for your child with learning disability/autism and family

QB1. Listed below are people that are often helpful to caregivers and families of a child with learning disability/autism. In the past 12 months, have you received support from any of the following people? Please select ALL that apply.

For each person you have received support from, please circle the appropriate number to indicate how helpful they have been.

	Please select ALL that apply ✓	***If yes:* How helpful have these people been to you and your family?**				
		Not at all Helpful	A little Helpful	Generally Helpful	Very Helpful	Extremely Helpful
My parent(s)		1	2	3	4	5
My partner		1	2	3	4	5
My partner's parent(s)		1	2	3	4	5
My other relatives		1	2	3	4	5
My partner's other relatives		1	2	3	4	5
My friends		1	2	3	4	5
My partner's friends		1	2	3	4	5
My other children		1	2	3	4	5
Other parents		1	2	3	4	5
Co-workers		1	2	3	4	5
People from social groups/clubs		1	2	3	4	5
Religious leaders/ people from a religious group		1	2	3	4	5

5

QB2. Listed below are professionals that some families may consult with for advice or support for their child. In the <u>past 12 months</u>, have you or your child with learning disability/autism been in contact with any of the professionals below about your child's needs?

For each professional you respond 'no', please answer the question in column A.
For each professional you respond 'yes', please answer the questions in columns B and C.

If you are not aware of or been in contact with any of the professionals listed below please do not worry. It is likely families will not have come into contact with all of the professionals in the list about support for their child and may not know what some of these professionals do.

		Column A	***Column B***	***Column C***
Please circle the appropriate response	**Have you or your child been in contact with this professional?**	***If no:*** **Is this a professional you have wanted contact with but have not had contact with?**	***If yes:*** **How helpful has this professional been to you and your family?** *Responses:* *1. Not at all helpful* *2. A little helpful* *3. Generally helpful* *4. Very helpful* *5. Extremely helpful*	***If yes:*** **How easy was it to access support from this professional?** *Responses:* *1. Very Difficult* *2. Difficult* *3. Neither easy nor difficult* *4. Easy* *5. Very easy*
Education and Social Care Professionals				
Child Minder or Nanny	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Social Worker	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Respite or short break workers	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Foster carers	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Home support staff *(e.g. Support/ Care Worker/ Personal Assistant)*	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Staff at nursery, pre-school or crèche	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Staff at school	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Portage Worker *(home-based teaching for babies and young children)*	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*

QB2 (continued).

Please circle the appropriate response	**Have you or your child been in contact with this professional?**	***Column A*** ***If no:*** **Is this a professional you have wanted contact with but have not had contact with?**	***Column B*** ***If yes:*** **How helpful has this professional been to you and your family?** *Responses:* *1. Not at all helpful* *2. A little helpful* *3. Generally helpful* *4. Very helpful* *5. Extremely helpful*	***Column C*** ***If yes:*** **How easy was it to access support from this professional?** *Responses:* *1. Very Difficult* *2. Difficult* *3. Neither easy nor difficult* *4. Easy* *5. Very easy*
Education and Social Care Professionals (continued)				
Someone from the Local Authority or health team responsible for assessing Special Educational Needs (SEN), Additional Learning Needs (ALN) or Additional Support Needs (ASN)	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Behaviour specialist	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Someone working for a charity	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Advocate *(A person who speaks on behalf of or in support of another person. They can help people say what they want and make sure their voice is listened to and answered. They help ensure everyone has equal rights and support people to make choices)*	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Independent Support Advisor *(including Independent Mediation Advisor)*	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Family Support Worker	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*

QB2 (continued).

Please circle the appropriate response	**Have you or your child been in contact with this professional?**	***Column A*** ***If no:*** **Is this a professional you have wanted contact with but have not had contact with?**	***Column B*** ***If yes:*** **How helpful has this professional been to you and your family?** *Responses:* *1.Not at all helpful* *2. A little helpful* *3. Generally helpful* *4. Very helpful* *5. Extremely helpful*	***Column C*** ***If yes:*** **How easy was it to access support from this professional?** *Responses:* *1. Very Difficult* *2. Difficult* *3. Neither easy nor difficult* *4. Easy* *5. Very easy*
Health Professionals				
Educational Psychologist	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Speech and Language Therapist	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Occupational Therapist	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
GP or Nurse	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Health Visitor	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Paediatrician *(hospital or community)*	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Geneticist	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Dietician	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Sleep practitioner	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Physiotherapist	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Optician	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Dentist	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*
Mental health professional for your child *(e.g. Counsellor, Therapist, Psychiatrist, Psychologist, other Child and Adolescent Mental Health Services (CAMHS) professional)*	*Yes / No / Not sure / Waiting list*	*Yes / No*	*1 2 3 4 5*	*1 2 3 4 5*

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QB3. Please select any other health professionals you have consulted with for advice or support for your child in the past 12 months below.

Please select ALL that apply	✓
Audiologist	
Neurologist	
Cardiologist	
Endocrinologist	
Respiratory Consultant	
Ophthalmologist	
Gastroenterologist	
Continence specialist	
Podiatrist	
Orthotist	
Other (please specify)	

QB4. Listed below are other services families may consult with for advice or support when they have a child with learning disability/autism. In the past 12 months have you been in contact with any of the services below for support with your child with learning disability/autism? Please select ALL that apply.

If you are not aware of or been in contact with any of the services listed below please do not worry. It is likely that many families will not have come into contact with some or all of the services and may not know what some of these services do.

For each service you have received support from, please circle the appropriate number to indicate how helpful the service has been.

	Please select ALL that apply ✓	***If yes:* How helpful has this service been to you and your family?**				
		Not at all Helpful	A little Helpful	Generally Helpful	Very Helpful	Extremely Helpful
Telephone helpline		1	2	3	4	5
Parent group or self-help group		1	2	3	4	5
Interactive website *(e.g. Facebook, Twitter, Forums)*		1	2	3	4	5
Other website that is not interactive		1	2	3	4	5
Special Educational Needs and Disabilities (SEND) Information Advice and Support Service, Parent Partnership Service, Scottish Advice Service for Additional Support for Learning (Enquire), or Special Educational Needs Advice Centre (SENAC)		1	2	3	4	5
Specialist services to meet your child's needs *(e.g. specialist teachers, behavioural support teams)*		1	2	3	4	5
School transport department		1	2	3	4	5
Local Authority housing department		1	2	3	4	5
Benefit or financial advice		1	2	3	4	5
Support to manage Direct Payments *(independent to the Local Authority)*		1	2	3	4	5
Children's centre *(Sure Start children's centre, family centre services, child development centre etc.)*		1	2	3	4	5
Carer's centre		1	2	3	4	5

QB5. Within the <u>past 12 months</u> have either:

- **<u>Your child</u> with learning disability/autism received any interventions or approaches to support their development?**
- **<u>You</u> received any interventions to support you in your role as a parent/caregiver to your child with learning disability/autism?**

For example, Applied Behaviour Analysis (ABA) programmes, Early Intensive Behavioural Intervention (EIBI), Early Start Denver Model, Early Bird, Triple P, Incredible Years, Sure Start, Son Rise, SCERTS, TEACCH, Parents Plus Early Years Programme, CANparent, Stepping Stones, Hanen Programme, therapy and/or counselling etc.

Please select <u>ONE</u>	✓
No	
Yes (Please list all interventions received in the past 12 months below)	

QB6. What has been particularly helpful for your family when accessing support from professionals or services for your child with learning disability/autism?
Please list <u>up to 3</u> things that have been the most helpful in accessing support.

If there has been nothing that has helped please write "none".

	Please write <u>up to 3</u> things that have <u>helped</u> your family access support
1	
2	
3	

QB7. What has been particularly difficult for your family when accessing support from professionals or services for your child with learning disability/autism? Please list up to 3 of the main things that have made it difficult to access support.

If there has been nothing that has made it difficult please write "none"

	Please write up to 3 things that have made it difficult to access support
1	
2	
3	

QB8. Does your child with learning disability/autism have one of the following?

- Education, Health and Care (EHC) plan
- Individual Development Plan (IDP)
- Co-ordinated support plan (CSP)
- Statement of Special Educational Needs (SEN)

Please select ONE	✓
Yes	
In the process of being developed	
Applied for but did not receive one	
Have not applied for one	
Don't know	

Section C – The development and adaptive skills of your child with learning disability/autism

This section is split into two parts:

- Complete section C1 if your child is **under 2 years of age (page 13)**
- Complete section C2 if your child is aged **2 years or above (page 14-15)**

When you have completed C1 or C2 please complete section D, which starts on page 16.

Section C1: Children under 2 years

QC1. All children develop differently and at their own pace. The following questions cover a range of behaviours, and we would like you to indicate how often your child with learning disability/autism demonstrates the behaviours listed below.

Please select ONE answer per statement	Often	Once or twice	Not yet
S/he smiles when you smile at him/her			
S/he can sit up without being supported			
S/he can stand up while holding onto something such as furniture			
S/he puts his or her hands together			
S/he grabs objects using the whole hand			
S/he can pick up a small object using forefinger and thumb only			
S/he passes a toy back and forth from one hand to another			
S/he can walk a few steps on his or her own			
S/he reaches out and gives you a toy or some other object that s/he is holding			
S/he waves bye-bye on his or her own when someone leaves			
S/he extends his or her arms to show s/he wants to be picked up			
S/he nods his/her head for 'yes'			
If you put your child down on the floor, can s/he move about from one place to another?			

Section C2: Children 2 years old and above

The following questions ask about your child's adaptive skills, which includes their support needs, communication, social and self-help skills. Please choose the response that best matches your child with learning disability/autism's current day-to-day skills.

QC2a. What level of help or support is needed for your child (e.g. toileting, dressing, eating?)

Please select ONE	✓
Requires support for almost all aspects of life	
Requires support for most, but not all, aspects of life	
Requires support for some aspects of life	
Requires support for only a few aspects of life	
Does not require support	

QC2b. How much does your child understand spoken language?

Please select ONE	✓
Able to understand very little spoken language	
Able to understand some basic language and simple instructions in familiar contexts (e.g. sit down)	
Able to understand most basic instructions and questions	
Able to understand most routine everyday language	
Able to understand complex language about a wide range of topics	

QC2c. How much does your child use spoken language to communicate?

Please select ONE	✓
Able to use very little meaningful speech	
Able to communicate basic needs and wants	
Able to communicate needs, wants and some ideas	
Able to communicate about a limited range of topics in a meaningful way	
Able to communicate about a wide variety of topics in a meaningful way	

QC2d. How much does your child use alternative methods of communication (e.g., signing, Makaton, symbol systems, PECS) to communicate?

Please select ONE	✓
Does not use alternative means of communication	
Able to communicate very little by using alternative means of communication	
Able to communicate basic needs and wants by using alternative means of communication	
Able to communicate needs, wants and some ideas by using alternative means of communication	
Able to communicate about a limited range of topics in a meaningful way by using alternative means of communication	
Able to communicate about a wide variety of topics in a meaningful way by using alternative means of communication	

QC2e. How much does your child engage in social interactions with familiar adults?

Please select ONE	✓
Shows little or no interest in social interactions with familiar adults	
Shows limited social interest but will sometimes respond to familiar adults	
Shows some interest, responds to others, but does not initiate social interactions with familiar adults	
Shows clear social interest, responds to others, and sometimes initiates social interactions with familiar adults	
Engages in a wide range of social interactions involving both responding and initiating social contact with familiar adults	

QC2f. How much does your child engage in social interactions with other children?

Please select ONE	✓
Shows little or no interest in social interactions with other children	
Shows limited social interest but will sometimes respond to other children	
Shows some interest, responds to others, but does not initiate social interactions with other children	
Shows clear social interest, responds to others, and sometimes initiates social interactions with other children	
Engages in a wide range of social interactions involving both responding and initiating social contact with other children	

QC2g. Please select the most accurate description of your child's skills in eating:

Please select ONE	✓
Needs complete assistance with eating	
Eats with fingers	
Can use spoon but may be messy	
Uses spoon and fork	
Eats completely independently with proper use of all cutlery	

QC2h. Please select the most accurate description of your child's skills in toileting:

Please select ONE	✓
Wears nappy day and night	
Wears nappy but indicates when needs changing	
Indicates or asks to use toilet, but does not go independently	
Toilet trained in daytime (occasional accidents); wears nappy or pull-up at night	
Completely toilet trained day and night	

QC2i. Please select the most accurate description of your child's skills in dressing:

Please select ONE	✓
Needs complete assistance dressing and undressing	
Cooperates with dressing (e.g. raising arms)	
Can remove or pull on/up clothes	
Can dress self quite well but needs help with buttons, zips, etc.	
Can dress and undress self completely	

Source: Adapted from Perry, A., Taheri, A., Ting, V., & Weiss, J. (2015).. Journal of Applied Research in Intellectual Disabilities, 28(6), 594–597. https://doi.org/10.1111/jar.12143

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Section D: Questions about your feelings and wellbeing

The following questions ask about how you have been feeling during the past 30 days.

QD1. For each question, please select the response that best describes how often you had this feeling. Please select ONE answer per statement.

During the past 30 days, about how often do you feel…

	All of the time	Most of the time	Some of the time	A little of the time	None of the time
…nervous?					
…hopeless?					
…restless or fidgety?					
…so depressed that nothing could cheer you up?					
…that everything was an effort?					
…worthless?					

Source: Kessler 6 Scale as found in Kessler, R.C., Barker, P.R., Colpe, L.J., Epstein, J.F., Gfroerer, J.C., Hiripi, E., Howes, M.J., Normand, S.L.T., Manderscheid, R.W., Walters, E.E., Zaslavsky, A.M. (2003). Archives of General Psychiatry. 60(2):184-9.

The following statements are about your feelings and thoughts.

QD2. Please select the response best describes your experience over the last 2 weeks.

Please select ONE answer per statement	None of the time	Rarely	Some of the time	Often	All of the time
I've been feeling optimistic about the future					
I've been feeling useful					
I've been feeling relaxed					
I've been feeling interested in other people					
I've had energy to spare					
I've been dealing with problems well					
I've been thinking clearly					
I've been feeling good about myself					
I've been feeling close to other people					
I've been feeling confident					
I've been able to make up my own mind about things					
I've been feeling loved					
I've been interested in new things					
I've been feeling cheerful					

Source: Warwick-Edinburgh Mental Well-being Scale (WEMWBS) © NHS Health Scotland, University of Warwick and University of Edinburgh, 2006, all rights reserved.

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Section E: Questions about your life and family satisfaction

We are now going to ask you about your satisfaction with life.

QE1. Here is a scale from 1-10 where '1' means that you are completely dissatisfied and '10' means that you are completely satisfied. All things considered, please could you circle the number which corresponds with how satisfied or dissatisfied you are about the way your life has turned out so far.

Completely dissatisfied									Completely satisfied
1	2	3	4	5	6	7	8	9	10

We would now like to ask you about how satisfied you are with family life.

QE2. Please read the following statements and select what best applies to you.

Please select ONE answer per statement	Almost always	Some of the time	Hardly ever
I am satisfied that I can turn to my family for help when something is troubling me			
I am satisfied with the way my family talks over things with me and shares problems with me			
I am satisfied that my family accepts and supports my wishes to take on new activities or directions			
I am satisfied with the way my family expresses affection and responds to my emotions, such as anger, sorrow and love			
I am satisfied with the way my family and I share time together			

Source: Smilkstein G. (1978). Journal of Family Practice, 6, 1231–1239.

Section F: Questions about you

QF1. Please indicate your relationship to the child with learning disability/autism.

Please select ONE	✓
Biological mother	
Biological father	
Adoptive mother	
Adoptive father	
Stepmother	
Stepfather	
Foster mother	
Foster father	
Grandmother	
Grandfather	
Other (please describe)	

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QF2. Your postcode

We would like this information to be able to access UK national data based on the 2011 Census about the neighbourhood in which you live. Once we have done this, we will delete your postcode information.

QF3. How do you identify your gender?

Please select ONE	✓
Male	
Female	
Prefer not to answer	
Other (please specify)	

QF4. How would you describe your ethnicity?

Please select ONE	✓
Asian/Asian British: Indian	
Asian/Asian British: Pakistani	
Asian/Asian British: Bangladeshi	
Asian/Asian British: Chinese	
Asian other (please describe below)	
Black/African/Black British: African	
Black/African/Black British: Caribbean	
Black other (please describe below)	
Mixed/multiple ethnic groups: White and Black Caribbean	
Mixed/multiple ethnic groups: White and Black African	
Mixed/multiple ethnic groups: White and Asian	
Mixed other (please describe below)	
White: English/Welsh/Scottish/Northern Irish/British	
White: Irish	
White: Travelling community	
White: Other (please describe below)	
Other Ethnic group: Arab	
Any other ethnic background (please describe below)	
Prefer not to answer	

QF5. How old are you in years?

QF6. Please select the highest level of your educational qualifications

Please select ONE	✓
No qualifications	
Some GCSEs passes or equivalent	
5 or more GCSEs at A*-C or equivalent	
5 A/AS Levels or equivalent	
Higher Education but below degree level	
Degree (e.g. BA, BSc, MA)	
Don't know	

QF7. What is your current work status?

Please select ONE	✓
Employed or self-employed full time (30+ hours/week)	
Employed or self-employed part-time (or unknown hours)	
Employed or self-employed but on long-term leave (e.g. maternity, paternity, sick)	
Full time carer	
Not working and looking for work	
Not working and not looking for work	

QF8. How is your health in general?

Please select ONE	✓
Very good	
Good	
Fair	
Bad	
Very bad	

QF9. Do you have a longstanding illness, disability or infirmity? By longstanding we mean anything that has troubled you over a period of time or is likely to affect you over a period of time?

Please select ONE	✓
No	
Yes	

Section G: Questions about your household

Data from research with families with a family member with a disability has shown that a family's financial resources are important in understanding family member's views and experiences. With this in mind, we would be grateful if you could answer the additional question below. We are not interested in exactly what your family income is, but we would like to be able to look at whether people with different levels of financial resources have different experiences.

QG1. What is your total weekly household income (after any deductions e.g. income tax), including income from paid work, pension, Social Services Benefits (e.g. Job Seekers Allowance, DLA, Carers' Allowance, Attendance Allowance, Tax Credits, Housing Benefits, Pension Credits) etc.?

Please select ONE	✓
£200 or less	
Between £201 and £300	
Between £301 and £400	
Between £401 and £500	
Between £501 and £600	
Between £601 and £700	
Between £701 and £800	
Between £801 and £900	
Between £901 and £1000	
Over £1000	

QG2. How well would you say you [and your husband/wife/partner] are managing financially these days?

Would you say you are...

Please select ONE	✓
living comfortably?	
doing alright?	
just about getting by?	
finding it quite difficult?	
finding it very difficult?	

G3. Suppose you only had one week to raise £2000 for an emergency, which of the following best describes how hard it would be for you to get that money?

Please select ONE	✓
I could easily raise the money	
I could raise the money, but it would involve some sacrifices (e.g. reduced spending, selling a possession)	
I would have to do something drastic to raise the money (e.g. selling an important possession)	
I don't think I could raise the money	

QG4a. What is your current marital status?

Please select ONE	✓
Married/civil partnership and living with spouse/civil partner	
Living with partner	
Divorced /Separated /Single /Widowed /Not currently living with partner	

If you indicated that you are currently living with a spouse or partner, please answer the questions QG4b and QG4c about your partner:

QG4b. Please select the highest level of your partner's educational qualifications

Please select ONE	✓
No qualifications	
Some GCSEs passes or equivalent	
5 or more GCSEs at A*-C or equivalent	
5 A/AS Levels or equivalent	
Higher Education but below degree level	
Degree (e.g. BA, BSC, MA)	
Don't know	

QG4c. What is your partner's current work status?

Please select ONE	✓
Employed or self-employed full time (30+ hours/week)	
Employed or self-employed part-time (or unknown hours)	
Employed or self-employed but on long-term leave (e.g. maternity, paternity, sick)	
Full time carer	
Not working and looking for work	
Not working and not looking for work	

QG5. In total, how many people currently live in your home (including yourself and your child with learning disability/autism)?

Please indicate the number of:

Individuals aged 14 years and above ☐

Individuals below the age of 14 ☐

QG6a. Do any of the other children in the family/household have disabilities?

Please select ONE	✓
I do not have other children	
None of my other children have disabilities	
I have one or more children with disabilities	

QG6b. If yes, please indicate how many of your other children have a learning disability and/or autism.

QG7. What is the primary language spoken at home?

Please select ONE	✓
English only	
English and another language	
Another language only (please indicate):	

You have now reached the end of the survey.
Thank you very much for your participation in this study.

Please return your completed survey and the consent form in the prepaid envelope in your pack.

If you have any questions please contact a member of the research team (Tel: 02476 575 866, Email: familyresearch@warwick.ac.uk).

If you are interested in finding out more, please read the separate sheet with further information.

2.6 End of Survey Information Sheet

Support in the Early Years Further Information

Please read on if you would like to know more about the research after completing the survey.

The aim of this study was to understand the experiences of parents/caregivers and families of young children aged 0-6 years old with a diagnosed or suspected learning disability and/or autism, in the UK.

We want to find out what support families and children are currently receiving in the early years, such as support from professionals, early years services, and early intervention services. We are interested in what helps families access support and what makes it difficult for families to access support. We will also explore parent and family wellbeing for families during the early years.

Resources

We realise that some of questions may be upsetting for some people, as we asked about your wellbeing and some of the challenges faced by you, your family and your child with a learning disability and/or autism. If any of the survey or interview questions made you concerned for yourself or another family member's wellbeing, we recommend that you contact your General Practitioner (GP) or one of the helplines listed below:

Mencap: 0808 808 1111, Contact a Family: 01332 557 975, KIDS: 0207 359 3635

In addition, a factsheet on emotional wellbeing for parents/carers of children with a learning disability can be found at http://www.cerebra.org.uk/help-and-information/guides-for-parents/factsheet-emotional-well/

Finding Out More

Once the research study is complete, we will provide information about the results of the research on our website: (https://warwick.ac.uk/fac/soc/cedar/familyresearch/supportearlyyears), as well as through our social media pages. You may opt to follow us on Twitter (@Family_RG1) and/or Facebook (www.facebook.com/FamilyRG1) to keep up-to-date with the research.

Questions and Concerns

If you would like to ask any questions about the study, please contact a member of the research team (Tel: 02476 524 139,
Email: familyresearch@warwick.ac.uk).

You can also contact Suzi Scott (Email: S.Scott.8@warwick.ac.uk, Tel: 02476 575 866) or Caitlin Murray (Email: C.Murray.7@warwick.ac.uk, Tel: 02476 575 866) directly if you would prefer.

If you have any concerns about your treatment during this research please use the contact details below. Any complaint about the way you have been dealt with during the study or any possible harm you might have suffered will be addressed. Please address your complaint to the person below, who is a senior University of Warwick official entirely independent of this study:

Head of Research Governance
Post: Research & Impact Services, University House, University of Warwick, Coventry, CV4 8UW
Email: researchgovernance@warwick.ac.uk
Tel: 024 76 522746

Thank you very much for taking part in this research.