

**Right from the Start:
Early Years' Support for Families of Children
with Autism**

Final Research Report

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1. Executive Summary

1.1 Research Purpose

The purpose of this report is to provide evidence to inform the **Right from the Start: Early Years' support for families of children with autism** project. The information in this report will describe parents' experiences of early years' service access of their young child with autism. The report focuses on what services are accessed during these early years, as well as when, whilst also identifying factors which may act to facilitate entry to, or act as barriers to, service access. The information within this report is informed by two research studies: a survey including 405 parents of children with diagnosed or suspected autism (aged 0-6 years old), and interviews with 18 mothers reflecting on their experience of service access during their child's early years.

1.2 Key Findings

Whilst parents were able to access many mainstream services for their children during the early years (such as a paediatrician, GP, or dentist), parents wanted access to further specialised services, such as behaviour or sleep specialists. There was also significant variability in services accessed by parents during the early years. Approximately one third of survey respondents indicated they had received an intervention for either themselves or their child over the past twelve months. The minority who had accessed an intervention had typically accessed parental education or intervention for their child's communication skills.

Facilitators to service access reported across both research studies included: useful information, parents' own knowledge, determination or financial resources, supportive attitudes of professionals, ease of access to services, support from peers, recognition of need, and getting a referral. Parents also reported several barriers. Across both research studies, the most frequent barriers were: a general lack of services or acceptable provision, a lack of recognition of their child's needs, poor communication by services and professionals, families not meeting service's criteria to access support, and long waiting times across all stages of accessing support (from first referral to receipt of support).

The mothers interviewed identified good practice in terms of: courteous, knowledgeable, and empathetic professionals, who were able to both effectively listen to and communicate with parents, whilst also building rapport and a growing relationship with their child. Professionals' personal experiences of autism, and going "above and beyond" for families were also valued. Services were considered to demonstrate good practice through being considerate and respectful when working

with families, being consistent and dependable, and being easily accessible and adaptable around the needs of children. Services were valued when they provided speedy or informative responses, and engaged in practical work which focused on the child.

1.3 Recommendations

1. Universal health services have very high levels of access during children's early years (0-5, e.g. GP, dentist, and paediatrician). Similarly high levels of access can be seen for some specialist services, notably speech and language therapy. Access to speech and language therapy may be a strength in service provision given the centrality of communication problems in autism. More specialist services such as occupational therapy, and support for behaviour or sleep problems, were accessed by fewer parents but a large number of parents would have liked to have accessed such services. These findings suggest an unmet need in these areas of provision. Given the high prevalence of behaviour problems and sleep difficulties in children with autism, early intervention needs to include support for behaviour problems and sleep difficulties.
2. Mental health services, social care, and local authority services were perceived by parents to be the least easy to access and the least helpful services. While reasons behind these perceptions were not included in this research, frequently identified barriers were lack of services, long waiting times, and unhelpful communication with service providers or professionals. Addressing all or some of these barriers is likely to increase access, and improve parents' perceptions of the helpfulness of mental health and social care services.
3. The proportion of respondents who reported accessing any intervention during the previous 12 months was only about one third of participants. While education about autism and support for communication were the main two areas where intervention was provided, comprehensive early intervention seem to be accessed by a very low number of parents (22% of those who accessed any intervention). Researchers and service providers need to work together to determine factors needed for take up and sustained implementation of comprehensive early intervention models across the country.
4. Good practice and good access start with timely identification of need. Timely identification of need might involve better education of both expectant parents and professionals who monitor development (i.e. health visitors). Parents and health visitors could be equipped to identify deviations from typical child development more successfully, be empowered to voice

any concerns they may have, and to be empathetic in communication with each other (e.g. 'really listening' to parental concerns).

5. Empathetic communication is a key attribute of good practice. Empathetic communication can be developed as part of professional practice across a wide range of service providers who come into contact with parents.
6. Professionals who are knowledgeable, empathetic, and keen to build rapport with the child are those who parents value most.
7. Problems with structural characteristics of service provision (e.g. where no services are available, services with too restrictive inclusion criteria, long waiting times, not enough specialist staff, and poor communication systems) need to be addressed urgently. Resources may not be the only solution to addressing structural barriers. Service development requires an inclusive ethos: services need to be made available to address *need* in the population (as opposed to gatekeeping using age or diagnostic labels as barriers); to work collaboratively with parents, and empower them to navigate the system of service provision. At the heart of a well-resourced service with an inclusive ethos is empathetic communication between professionals and parents, where the child's development and family's well-being is placed at the heart of conversations.

2. Early Years' Survey on Access to Early Intervention for Children with Autism

2.1 Introduction

The information presented in this section of the report reflects findings from an early years' survey for caregivers of children who had a suspected or diagnosed developmental disorder or learning disability (aged 0-6 years old). The data presented in this report primarily reflect the information collected by parents of children with either a diagnosis or suspected diagnosis of autism spectrum disorder (ASD), living in England (N=405). Participants were recruited through social media advertising. Data was collected between September 2018 and April 2019. A description of the sample is presented in Table 2.1 below.

Table 2.1. Demographic information about survey respondents

Child Gender	308 male (76%), 96 female (24%)
Child Age	Mean = 5.13 years (S.D.=1.25), Range 8 months -7 years
Parent/Caregiver Gender	20 male (5%), 397 female (94%)
Parent/Caregiver Age	Mean = 36.50 years (S.D.=7.25, Range 22-72 years)
Work	163 full-time carers (40%)
Education	168 degree level (41%)
Parent Health	181 in "good" overall health (45%)
Income (<£200 - £1000+)	64 earning £501 to £600 p/w (16%)
Marital Status	238 married/living with/civil partnership (59%)
Additional Children	193 have no other children with disabilities (48%)

2.2 Professional support services families accessed in the past 12 months

Participants were asked to indicate the early intervention (EI) services they had accessed over the past 12 months. Participants were asked to select services from a list of professional services that spanned education, health, and social care. The top three most accessed services included a paediatrician (84%), speech and language therapist (82%), and school staff (78%). The least accessed services were home support staff (8%), an advocate (8%), and a foster carer (1%). The services which were highlighted as having the most children or families on a waitlist were for an occupational therapist (27 on a waitlist; 6% of respondents), educational psychologist (22 on a waitlist; 5%), and for a mental health professional (18 on a waitlist; 4%). Table 2.2 below indicates the number and percentage of study participants who accessed these services.

Table 2.2. Professional support services accessed in the past 12 months

Service	Accessed Service	On Waiting List for Service
Paediatrician	339 (84%)	7 (2%)
Speech and language therapist	332 (82%)	16 (4%)
School staff	317 (78%)	3 (1%)
GP	302 (75%)	2 (1%)
Dentist	302 (75%)	8 (2%)
Local authority	272 (67%)	14 (3%)
Staff at nursery	266 (66%)	0
Health visitor	229 (57%)	0
Educational psychologist	209 (52%)	22 (5%)
Occupational therapist	187 (46%)	27 (6%)
Optician	181 (45%)	8 (2%)
Charities	151 (37%)	3 (1%)
Dietician	102 (25%)	14 (3%)
Physiotherapist	100 (25%)	6 (1%)
Family support worker	83 (21%)	1 (1%)
Portage worker	76 (19%)	5 (1%)
Social worker	74 (18%)	6 (1%)
Mental health professional	74 (18%)	18 (4%)
Geneticist	61 (15%)	7 (2%)
Sleep practitioner	60 (15%)	11 (3%)
Behaviour specialist	52 (13%)	8 (2%)
Respite	49 (12%)	10 (3%)
Childminder	48 (12%)	1 (1%)
Independent support advisor	35 (9%)	0
Home support staff	34 (8%)	2 (1%)
Advocate	32 (8%)	0
Foster carer	2 (1%)	0

2.3 Helpfulness and ease of access of services families accessed in the past 12 months

Respondents rated both helpfulness and ease of access of professional support services using a five point scale ranging from 1 (not very helpful) to 5 (extremely helpful). The top three most helpful services were home support staff (helpfulness score 3.88, accessed by 8% of respondents), advocacy (3.81, accessed by 8% of respondents), and portage (3.71, accessed by 19% of respondents). For full information on helpfulness of all professional services, please refer to Table 2.3 below.

Table 2.3. Helpfulness rating (5=extremely helpful) of accessed professional support services

Service	Mean (S.D.)	N who accessed (% of sample)
Home support staff	3.88 (1.19)	34 (8%)
Advocate	3.81 (.97)	32 (8%)
Portage	3.71 (1.39)	76 (19%)
Charities	3.66 (1.13)	151 (37%)
Optician	3.39 (1.15)	181 (45%)
Staff at nursery	3.39 (1.27)	266 (66%)
Dentist	3.38 (1.14)	302 (75%)
Paediatrician	3.32 (1.26)	339 (84%)
Independent support advisor	3.26 (1.42)	35 (9%)
Occupational therapist	3.21 (1.29)	187 (46%)
School staff	3.20 (1.28)	317 (78%)
Childminder	3.16 (1.36)	48 (12%)
Educational psychologist	3.11 (1.23)	209 (52%)
Family support worker	3.10 (1.37)	83 (21%)
Physiotherapist	3.09 (1.19)	100 (25%)
Speech and language therapist	3.08 (1.28)	332 (82%)
Respite	3.02 (1.20)	49 (12%)
Behaviour specialist	3.00 (1.28)	52 (13%)
Geneticist	3.00 (1.37)	61 (15%)
Health visitor	2.81 (1.50)	229 (57%)
Sleep practitioner	2.88 (1.30)	60 (15%)
Dietician	2.74 (1.50)	102 (25%)
Mental health professional	2.72 (1.36)	74 (18%)
Local authority	2.67 (1.22)	272 (67%)
GP	2.62 (1.17)	302 (75%)
Foster carer	2.50 (2.12)	2 (1%)
Social worker	2.45 (1.25)	74 (18%)

In relation to ease of access, respondents rated services on a five point scale ranging from 1 (very difficult) to 5 (very easy). The three services rated easiest to access were dentist (ease of access score 3.73, accessed by 75% of respondents), an optician (3.73, accessed by 45% of respondents), and charities (3.65, accessed by 37% of respondents). For full information on ease of access of services, please refer to Table 2.3.1 below.

Table 2.3.1 Ease of access rating (5=very easy) of professional support services

Service	Mean (S.D.)	N who accessed (% of sample)
Dentist	3.73 (1.00)	302 (75%)
Optician	3.73 (1.03)	181 (45%)
Charities	3.65 (1.05)	151 (37%)
Advocate	3.63 (1.03)	32 (8%)
Staff at nursery	3.55 (1.22)	266 (66%)
Health visitor	3.45 (1.16)	229 (57%)
Childminder	3.30 (1.39)	48 (12%)
Portage	3.29 (1.23)	76 (19%)
GP	3.28 (1.13)	302 (75%)
School staff	3.28 (1.26)	317 (78%)
Independent support advisor	3.26 (1.16)	35 (9%)
Physiotherapist	3.24 (1.06)	100 (25%)
Family support worker	3.19 (1.09)	83 (21%)
Sleep practitioner	3.18 (1.18)	60 (15%)
Dietician	3.10 (1.17)	102 (25%)
Foster carer	3.00 (0)	2 (1%)
Geneticist	2.92 (1.25)	61 (15%)
Speech and language therapist	2.90 (1.25)	332 (82%)
Home support staff	2.88 (1.34)	34 (8%)
Educational psychologist	2.78 (1.15)	209 (52%)
Respite	2.78 (1.21)	49 (12%)
Paediatrician	2.69 (1.24)	339 (84%)
Occupational therapist	2.61 (1.24)	187 (46%)
Behaviour specialist	2.59 (1.35)	52 (13%)
Local authority	2.52 (1.22)	272 (67%)
Social worker	2.52 (1.35)	74 (18%)
Mental health professional	2.29 (1.36)	74 (18%)

It is important to highlight that five services appeared within the **top** ten highest rated services for **both** helpfulness and ease of access. These were: advocacy, portage, charities, an optician, staff at nursery, and dentist. There were also three services rated in the **bottom** five of all services in terms of both helpfulness and ease of access (lowest five rated services). These were: mental health professionals, local authority, and social workers.

2.4 Services wanted by families

If a respondent did *not* access a service, they were asked to indicate if this was a service that they **would have** wanted to access. The top three professional support services that respondents would have wanted to access were a behaviour specialist (39%), a sleep practitioner (30%), and an occupational therapist (24%). The three least wanted services reported by respondents were a general practitioner (2%), a foster carer (1%), and staff at nursery (1%). For further information on which services were reported as wanted by respondents, refer to Table 2.4 below.

Table 2.4. Services that participants would have wanted to access in the past 12 months

Service	Total	Percentage
Behaviour specialist	158	39%
Sleep practitioner	120	30%
Occupational therapist	97	24%
Respite	94	23%
Educational psychologist	91	23%
Family support worker	78	19%
Mental health professional	77	19%
Portage	74	18%
Dietician	71	18%
Home support staff	70	17%
Advocate	64	16%
Local authority	58	14%
Geneticist	48	12%
Charities	43	11%
Dentist	36	9%
Social worker	33	8%
Physiotherapist	33	8%
Independent support advisor	28	7%
Childminder	23	6%
Speech and language therapist	20	5%
Optician	19	5%
School staff	9	2%
GP	6	2%
Foster carer	3	1%
Staff at nursery	3	1%

It is important to note that Table 2.4 reflects the number of participants who identified they *would have wanted* to have access to specific services in the past 12 months, who have **not** already accessed said service

2.5 Other services families accessed in the past 12 months

In addition to a list of professional services, participants were asked to indicate other services they had accessed over the past 12 months. Among those other services (Table 2.5), the only service to have been accessed by over half of respondents were interactive websites (70% of respondents). Otherwise the two most accessed services were parent or self-help groups (47% of respondents) and SEND information (35% of respondents). The three least accessed services were local authority housing departments (8% of respondents), carers' centres (7% of respondents), and support to manage direct payments (4% of respondents). For full information access please refer to Table 2.5 below.

Table 2.5. Other services accessed

Service	Total	Percentage
Interactive website e.g. Facebook	283	70%
Parent or self-help group	191	47%
SEND information	140	35%
Other non-interactive website	115	28%
Specialist services	96	24%
Children's centre	88	22%
Benefit or financial advice	73	18%
Telephone helpline	65	16%
Transport	64	16%
Local authority housing department	34	8%
Carers' centre	28	7%
Support to manage direct payments	16	4%

2.6 Helpfulness of other services families accessed in the past 12 months

As well as being the most accessed other service, interactive websites were also rated as the most helpful (helpfulness score 3.54, accessed by 70% of respondents). However, it is important to note that this service was still rated as less helpful than home support, advocacy, portage, and charities (see Table 2.6). Parent self-help groups were also reported to be the second most helpful other service accessed (3.54). However, specialist services were reported as the third most helpful (score 3.52, accessed by 24% of respondents). The three least helpful other services were reported to be transport (2.97, accessed by 16% of respondents), support to manage direct payments (2.88, accessed by 4% of respondents), and the local authority housing department (1.97, accessed by 8% of respondents). For full information on helpfulness of other services, refer to Table 2.6 below.

Table 2.6. Mean rating of helpfulness of other services

Service	Mean (S.D.)	N who accessed (% of sample)
Interactive website e.g. Facebook	3.54 (1.06)	70%
Parent or self-help group	3.54 (1.15)	47%
Specialist services	3.52 (1.10)	24%
Telephone helpline	3.31 (1.15)	16%
Children's centre	3.31 (1.18)	22%
Other non-interactive website	3.25 (.95)	28%
SEND information	3.19 (1.25)	35%
Benefit or financial advice	3.14 (1.34)	18%
Carer's centre	3.04 (1.32)	7%
Transport	2.97 (1.35)	16%
Support to manage direct payments	2.88 (1.15)	4%
Local authority housing department	1.97 (1.36)	8%

2.7 Interventions accessed in the past 12 months, for their child or their role as a carer

In addition to the structured list of professional or other services accessed, we asked participants to indicate what other interventions they may have accessed for themselves or their child over the same time period. We provided descriptions of what was meant by interventions, and parents were asked to write in their own words the interventions they accessed. We coded responses among the first 300 survey participants. Among respondents, only 93 (31%) indicated they had received *any* intervention in the last 12 months. The most often received intervention reported was grouped as 'education for a parent', such as Early Bird, or another autism awareness course (31% of those who accessed an intervention). The second most accessed related to 'communication training' for their child, such as a Makaton or PECS course (30%). The third most accessed intervention related to 'comprehensive early intervention', intervention targeting multiple child outcomes (e.g. "Applied Behaviour Analysis" or "Pivotal Response Training", 22%).

A key point regarding interventions accessed by families in the last 12 months relates to the overall small proportion of respondents who indicated they had received any intervention; approximately one third. This raises questions as to whether this reflects a general lack of intervention access, or whether parents are not identifying input they have received as "intervention". The current survey findings also indicate very few parents are accessing any of kind of intervention for to support their own needs or their own well-being (see Table 2.7). For full information as to descriptions of types of interventions accessed, and the proportion of those who did access different interventions, refer to Table 2.7.

Table 2.7. Interventions accessed in the past 12 months

<p>Within the <u>past 12 months</u> have either:</p> <ul style="list-style-type: none"> • <u>Your child</u> with 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 autism? <p>If yes please list all interventions received in the last 12 months</p>		
Code	Explanation	Total (%/93)
Education for parent	Any course (or receipt of information in a less structured manner) that aims to increase the parents understanding of the DD or an aspect of it. These include psychoeducational programmes e.g. . Early Bird, autism awareness courses	29 (31%)
Communication training	Any training or intervention which aims to increase the child’s level of receptive or expressive communication (e.g. any SLT input, Hanen, Makaton courses, PECS)	28 (30%)
Comprehensive early intervention	Any training which encompasses a range of child outcomes (such as cognitive skills, adaptive functioning, social skills) e.g.. ABA, TEACCH, PRT	20 (22%)
Parent training	Any intervention whereby parents are trained to manage their child’s challenging behaviour. The main aim is to help the parent better manage their child’s behaviour through changes in their own behaviour (parent) e.g. 123 Magic, Incredible Years, Triple P	15 (16%)
Intervention for sensory issues or physical needs	Any intervention or training which is focused on sensory concerns or physical needs i.e. sensory integration therapy, physiotherapy	7 (8%)
Social skills training	Any intervention aimed at increasing children’s social skills e.g. Lego therapy, SCERTS	7 (8%)
Psychological therapy	Any psychological therapy e.g. CBT, counselling, family therapy	6 (6%)
Occupational therapy	Any mention of occupational therapy input	6 (6%)
Specific child skill training	Any training aimed at addressing a specific challenge for children e.g. toilet training, tooth brushing	3 (3%)
Movement and music-based approaches	Any process engaged with to aid relaxation or physical activity e.g.. yoga, music therapy	2 (2%)

2.8 Perceived facilitators of accessing professional support

To gain a comprehensive view of factors that make it easier for parents to access EI services (i.e., facilitators of service access), participants were asked to describe in three open-ended responses ‘what has been particularly helpful for your family when accessing support from professionals or support services for your child?’ As previously, we coded responses among the first 300 participants (i.e. potentially, 900 responses). Table 2.8 contains a full summary of facilitators reported, and we also describe the findings below.

Named services were the most often reported facilitator for professional support access (69% of respondents). This primarily consists of parents reporting the service with no additional comments, and so by nature of the question can only be classed as a helpful named service. These included health professionals, educational settings, interventions or courses, charities, and the local authority.

Just under a quarter of respondents (23%) indicated that *nothing* was helpful to them when trying to access professional services.

Information was also reported as helpful, primarily using online resources and professionals guiding them to services or resources (18% of respondents). Similarly, the same percentage of respondents (18%) described their own assets as facilitators: their own knowledge, determination and persistence, or financial resources.

Certain types of service practice were also highlighted as helpful: the attitudes of professionals or services (e.g. willingness and openness), and services’ ease of access (e.g. good communication and ability to access services at different times). We coded this as ‘good practice’ and it was reported by 16% of participants.

Peer support was also highlighted as helpful (15% of respondents). This included both formal support options i.e. formalised parent groups, or informal support e.g. getting to know other local families.

Recognition of need was also reported as a facilitator (11% of respondents). This included the recognition of the child’s needs by professionals, or parents’ concerns being listened to by services. Finally, getting a referral was also highlighted as helpful when accessing professional support (3% of respondents).

Table 2.8 What has been particularly helpful for your family when accessing support from professionals or services for your child with autism? Please list up to 3 things that have been the most helpful in accessing support.

Code	Sub-Code	Sub-Code	Totals	Explanation	Overall (%/300)
Named Services	Health Professionals	Health Visitor	15	Helpful named services which are under the remit of health or social care Specific services that parents identified as helpful which are under the remit of education	72
		SALT	11		
		Paediatrician	15		
		Other	31		
	Education	Portage	9	Specific services that parents identified as helpful which are under the remit of education	68
		Nursery	17		
		School	30		
		Other	12		
	Interventions		30	Interventions, courses, or programmes mentioned by parents	30
	Charities		26	Helpful named charities	26
Local Authority/Gov		10	Helpful named local authority of wider government services	10	
Nothing			124	Nothing was stated to be helpful to these parents; 70 'none' codes listed under helpful 1	124 (41%)
Information		Online	32	Information which was described as helpful primarily falling into three categories: information obtained using online sources, information provided or directed to by professionals, and other	55 (18%)
		Professional Given/Guided	18		
		General/Other Modalities	5		
Parental Assets		Knowledge	13	Helpful aspects for parents which are driven by their own assets, be that their own knowledge of autism or systems, their own psychological skillsets, or their monetary funds	54 (18%)
		Determination	24		
		Financial Resources	17		
Good Practice		Attitudes of Professionals	22	Helpful elements of good practice described by parents surrounding a) attitudes of professionals (proactive, willing, non-judgemental) and ease of access (able to communicate easily, attend sessions easily)	47 (16%)
		Ease of Access	22		
		General	3		
Peer Support		Formal	24	Support from peers identified by parents as helpful. This is presented as formalised support settings focused on peer support, and informal support	45 (15%)
		Informal	21		
Recognition of need		Parental concerns	9	Recognition identified as helpful by professionals in terms of a) recognising parental concerns about their child and b) being knowledgeable enough to recognise children's needs	34 (11%)
		Children's needs	25		
Getting a Referral			11	Helpful to get a referral for diagnosis and to receive further services	11 (3%)

2.9 Perceived barriers to accessing professional support

To gain a comprehensive view of factors that make service access more difficult (i.e., barriers), respondents were given the opportunity to report three open-ended responses to the question 'what has been particularly difficult for your family when accessing support from professionals or support services for your child?' Table 2.9 contains a full summary of facilitators reported, and this is also summarised in the following paragraphs.

Lack of services was reported as the main barrier to professional support by half of respondents (50%). This barrier includes responses indicating that services were not available at all, or not available in the local community, or a lack of funding to allow an adequate level of services, or services not being easy to access (because of inclusion/exclusion criteria).

Long waiting times were also mentioned as a barrier to professional support (by 40% of respondents) across all stages of EI access, for example from diagnosis, to EI appointments, to slow service response.

Low standards of services were identified as a barrier by 19% of respondents. This code encompassed both professional approach and standard of care. Lack of recognition of need was explicitly named as a barrier (18% of respondents).

Poor communication was another reported barrier to accessing professional services (16% of respondents). This primarily reflected communication between services and parents, but also encompassed services communicating with other services. Learning to navigate the complex systems surrounding various professional support and services was also highlighted as a barrier (15% of respondents), including the information they had available to do this with.

Narrow criteria was also reported as a barrier to professional support and service access (13% of respondents). This includes for example narrow criteria surrounding symptom severity when trying to access services or professional support. Named services were again highlighted, but in this case as barriers (11% of respondents). This again was where services were simply named, with no mention as to why they were considered 'difficult'.

Getting a referral was again highlighted, this time as a barrier to professional support, primarily in preventing diagnosis and service access (10% of respondents). The same proportion of respondents (10%) also referred to parents needing to assume responsibility for roles services should provide when accessing professional support, for example chasing services or paying for support.

Table 2.9. What has been particularly difficult for your family when accessing support from professionals or services for your child with autism? Please list up to 3 things that have been the most helpful in accessing support.

Code	Sub-Code	Totals	Explanation	Overall (%/300)
Lack of services	Services not available	55	Difficulties with services not being available. Four key areas: support is not available, support is not available locally, funding limits support, services cannot be accessed (either due to barriers such as childcare, or not to the level parents feel is required)	151 (50%)
	Lack of local services	16		
	Funding limits services	28		
	Services not able to be accessed	42		
Long waiting times	Diagnosis/initial access	28	Difficulties due to having to wait at all stages of services access. Four key areas: diagnosis/initial access, appointments, slow service response, general comments	121 (40%)
	Appointments	11		
	Slow service response	10		
	General	72		
Low standard of services		56	Parents describe concerns due to professionals approach i.e. manner, service provision, standard of care	56 (19%)
Lack of recognition of need		53	Parents reported that the child's needs are not properly recognised either because professionals do not take parental concerns seriously or because they do not have the skills and knowledge to recognise the child's needs. In a small number of cases, the child's needs were not being recognised by the other parent	53 (18%)
Poor communication	Service to service	13	Difficulties which arise due to communication issues between: services and other services, services and parents, and parents to parent. Primarily codes relating to services and parents i.e. parents cannot contact services to begin communication, whilst services perceived to not engage in effective communication	49 (16%)
	Service to parent	35		
	Parent to parent	1		
No barriers		49	Parents reported no difficulties; 26 codes under difficult 1	49 (16%)
Learning to navigate complex systems		45	Parents reported struggling to understand the system of service provision which they perceived as complex, and the lack of information they have to do so	45 (15%)
Narrow service access criteria		40	Difficulties whereby children are not eligible to access a service because their characteristics place them outside of the service's eligibility criteria (e.g., age, severity of need, family functioning)	40 (13%)
Named services		33	Names of services without further comments to aid classification as to why parents perceived them as 'difficult' when accessing services or professionals, most referenced being Occupational Therapist (6 codes)	33 (11%)
Getting a referral		30	Parents reported that a barrier to accessing support for their children was not getting a referral i.e. for diagnosis, or for service access	30 (10%)
Parents assuming responsibility		29	Difficulties where parents felt the needed to take on the responsibility to fight, chase, or pay for support or service access, which they feel should have been organised or provided by services	29 (10%)

3. Families’ experiences of accessing early intervention services in the early years: a qualitative study

3.1 Introduction

Interviews were conducted with mothers of children with a diagnosis of autism, currently aged between 5 years and 10 years old, who lived in England. The primary purpose of these interviews for this report was to describe the experiences of parents trying to access services and professional support during their child’s early years of life (0 to 5 years old). Eighteen interviews were conducted, all with mothers of children with an autism diagnosis (1 PDA diagnosis). Although we invited family carers to take part in the research, only mothers responded to the invitation and agreed to be interviewed. Sample characteristics are described below in Table 3.1.

Table 3.1. Demographic information regarding children reported in interviews

		Participants
Child Gender		4 Female (20%), 14 Male (80%)
Child Age		Mean age = 7.16 years; Range = 5 to 10 years
Location of Family		7 (39%) South East, 7 (39%) Midlands, 1 (6%) North West, 1 (6%) South West, 2 (11%) undisclosed
Number of Services Accessed	Birth to Nursery	Mean = 3.22 services; Range = 0 to 8
	Nursery to School	Mean = 5.94 services; Range = 0 to 14
	Early School years	Mean = 3.33 services; Range = 1 to 10
	Total	Mean = 12.5 services; Range = 3 to 24
Diagnosis Age		Mean age = 4.28 years; Range = 2 to 8 years
Additional Diagnoses		Sensory issues (2), global developmental delay (1), hypermobility (1), hypertonicity (1), developmental coordination disorder (1), verbal dyspraxia (1), selective mutism (1)

3.2 Key points in a young child’s life where services were mostly needed and contacted

As well as the mean number of services accessed before 5 years old, as summarised in Table 3.1, further analysis examined service use by the period services were accessed. These were subdivided into age periods via typical progression through services. These were: 1. Birth to nursery (0-2 years), 2. Nursery to school (2-4 years), 3. Early school years (4-5 years). Service access numbers were counted as the first instance a service was accessed, and were not re-counted in following periods unless the service had been re-accessed. Similarly, different services accessed within broader services are additionally included. For example if a parent referenced a SENCO and school, as the SENCO

individually represents an additional element of support provided to the parent within that environment both were counted separately. As seen in Table 3.1, the highest mean number of services accessed occurred during the nursery period (2 to 4 years old). This is not a surprising finding considering the mean age of diagnosis (4.28 years) likely coincided with this period of increased service access.

3.3 Main barriers to service access

Main barriers identified by mothers as to why they felt unable to access various professional services or supports were coded into themes. For the purposes of this report a ‘theme’ is considered to be pertinent if there were at least **five parents** who contributed to that theme (approximately 25% of the sample).

3.3.1 Barriers relating to mothers

Lack of Recognition of Need (6 mothers)

This theme encompasses mothers’ comments relating to being unaware of traits or behaviours related to autism, due to a lack of awareness around autism and child development. Responses ranged from parents being completely unaware of any concerns relating to their child’s behaviour (***“we weren’t concerned about her behaviour or anything as parents we just thought she was a spirited little girl who liked to run away a lot”***), to pushing off concerns due to a lack of awareness (***“when we started getting more worried about certain things about him we sort of put it on, sort of subconsciously put it off because all babies are different but in hindsight there were some things that really warranted seeing a health visitor”***).

Mothers indicated they felt unable to identify traits which they could have raised with services due to not previously having raised a child:

“Both me and my husband didn’t have that experience of raising children before so we wasn’t really sure of key milestones [...] [child] had an issue about food and we put that down to the fact he had issues with his tonsils [...] but things like getting dressed it was such a massive struggle and we didn’t realise that it shouldn’t be. We assumed... it was just our normal [...] it wasn’t until we sat around the table doing the questionnaires that me and my husband thought “oh my gosh we didn’t realise that this was actually an issue”. It was just like our normal and we had nothing to benchmark it against. So we never really spoke to anybody about it because he was our only child and so forth”.

Similarly, mothers commented on comparing their child to other ‘easier’ children (***“I just kind of thought well I’m used to a really easy girl and I’ve got two other children so of course it’s hard”***), as well as a lack of awareness with autism meaning they did not understand concerns raised (***“for me it***

was all new I had never been around anyone who had autism so I had no idea so I felt that my child was a naughty child is that what they are trying to say”).

3.3.2 Barriers relating to services

Poor Communication (5 mothers)

This theme describes mothers’ difficulties accessing services due to a lack of communication from services and professionals. This relates to parents finding it difficult to contact services, as well as services then not being effective with their communication to parents:

“The whole local authority thing with the EHCP¹ process you have to email and email and ring, ring and ring just for somebody to call you back”.

“Sometimes when he had a few violent outbursts and stuff at home I would ring and leave messages and nobody would ring me back”.

“You sort of have a meeting or you get some information from someone and then it sort of disappears and you don’t know if it’s being acted on or not”.

Lack of Understanding of Child Behaviours or Needs by professionals (5 mothers)

This theme reflects mothers’ comments whereby service providers appeared to not understand children’s behaviour, thus making it difficult for them to access services. Mothers reported that professionals expected children to behave a certain way during sessions, not recognising when or why children failed to conform: *“And we took him there [monkey music], he was not interested and then they kept telling him off and making him sit down, and they were obviously used to neurotypical children. And they were telling him off, making him sit down, getting me to hold him down and I was like no I’m not doing that, and they in the end we were asked to leave, we were asked to leave monkey music, we were asked to leave the football one”.*

Similarly, mothers also reported that services did not arrange their provision in a way that made it accessible to children with autism, showing a lack of understanding of child behaviour or needs: *“They say you can take your kids to events but I’ve never wanted to take my kids to it because it’s a massive event with noise, lights, smells and all sorts and who would want to take a child that struggles in those environments”.*

¹ Education, Health and Care Plan

Services Trying to Refuse Parents (9 mothers)

This theme encompasses strong negative views from mothers, whereby they felt services were actively trying to refuse children's access to services:

"It's like CAMHS they bounced us away twice".

"Because at first despite all the evidence from the assessments and from school and from myself, they refused to assess him [...] so I actually had to have a meeting with the head of Suffolk Special Educational Needs department in the council, and I actually had to have a mediation session and just plead my case. And she just kept saying no, no, he's not getting an assessment and this went on for about 45 minutes to an hour, and then finally in the end she said ok we'll do the assessment".

"The ABA consultant told me, the specialist ABA tutor [...] go in for like 5, 6 hours a week maybe, just to support him to settle down at school. But again the school, mainstream school, they refused to let anyone go into their school, or have reports privately, or have anyone talk about my son with professionals involved".

"Things didn't get any better because at that point when he got diagnosed the school he was at (which was a private school for boys) they basically started making all measures to get rid of us. Which I don't think is unusual in a private school they do try and get rid of kids who they know aren't going to do anything for their grades and things".

Limited Provision (9 mothers)

This theme encapsulates mothers' descriptions of barriers to service in relation to services existing or not being able to provide support to a level parents feel is appropriate or necessary: ***"and it's quite far spaced apart – so it's not like it's a regular thing".***

This theme also covers mothers' concerns at not being able to access service because it was not currently available although normally provided (***"but the Cygnet course wasn't running so we ended up doing it through the charity"***), comparison of the limited service provision provided by the community compared to others (***"and then I've finally found the one that the local provider community provides which is an hour [laughs] so it's nothing like a ten week course, you can't learn so much in an hour to me"***), or a lack of provision due to service demands (***"everywhere they passed his paperwork to, all the local specialist schools were full, and the not so local specialist schools were full"***).

Limited Service Resources (9 mothers)

This theme encompasses comments by mothers whereby resources of services are deemed to be a barrier to access or provision. This includes funding being removed, not enough staff in services, and a limited number of appointments with services:

“You know you’ve got lovely staff at the children’s centre it gets shut down, you’ve got lovely staff they go somewhere the pay’s better, you know just you can see the money’s being leeches out of the system at every point and I wouldn’t recommend any of it because it doesn’t function as a whole”.

“But our council’s decided to completely de-fund them so they’re all going now. They’ve been, the service they’re able to provide now compared to what it was like when he was little is just a shadow of its former self unfortunately”.

“But there were quite a lot of kids with additional needs in that pre-school so I think there were a lot of kids there as well [...] so she possibly might have not observed him as much as I wanted her too”.

Narrow Service Criteria (10 mothers)

Mothers reported not meeting service inclusion criteria as being a key barrier to accessing services. One reason children were reported not to meet criteria to access services, especially diagnostic services, was age:

“And the GP said [...] “there’s nothing we can do wait until he’s about four”.

“The reasoning they gave us originally was because they said he was too young. They basically said to us any EHCP review that comes in for anyone aged under five they will decline straight away”.

Other barriers reported by mothers were their child not having a severe enough language impairment to allow support from services, having or not having a diagnosis blocking access to different services, and not being a “troubled family” blocking access to services:

“But we ended up getting discharged out of speech and language therapy, not because he didn’t need support but because of the funding situation that they were only funded for tier three and four kids. So really significant speech and language issues and not kids like my son where there was a level of difficulty in delay but not in terms of how they would definite it in their criteria”.

“We were told he couldn’t access any speech and language therapy because his speech was ok, we were told we couldn’t access any occupational therapy because he was able to do buttons and his physical fine motor skills were okay, even though he had quite a few sensory issues”.

“One may say try this service and you ask them for help and you say well he’s got this diagnosis, oh you know we can’t help you but it’s like he’s got these symptoms, you were saying if he had these symptoms but without this label you could help him and they say yeah”.

“You know you get told oh well we want to help you but you don’t need the right things, or that you don’t qualify for help because you’re too capable or well-spoken you know, or you know they’re bringing in this troubled families approach where you have to have like truancy, and drugs, and crime in your family in order to access support so you know if you’re relatively holding it together in some ways, and you’re not just you know it’s not all completely falling apart”.

Services Withdrawing (10 mothers)

Mothers reported a key barrier to service contact was withdrawing once they had been accessed. This is differentiated from refusal of services, due to these services having already been accessed:

“But she has been seeing an OT, she has been seeing an OT on an ongoing basis, she keeps on getting discharged and I have to keep going back and saying actually no we haven’t resolved the issues”.

“We also got the private speech therapist as well at that point, because after the six weeks of the video therapy that I mentioned it [speech and language therapy] sort of tailed off, [child] wasn’t really getting any professional speech and language therapy”.

“Physio were good they would give her exercises [...] they were very good to start with [...] but then basically they tailed off as well”.

“I just think we went in after it stopped and said ‘please could it continue’ [LEGO therapy] but it wasn’t [...] also we wanted a social skills group, so we asked about the social skills group but they said they didn’t do that anymore”.

Transition of Service Provision (10 mothers)

Transition of service provision was a key barrier identified by mothers to service access. This includes transition of service provision across local areas, provision for different age groups, and transition from private to public services:

“But as willing as they were they said their hands were tied [speech and language] to do anything because the pre-school was not on the border it was within Rochdale so, if it had been on the border they might have had a case for being able to step over it kind of thing, but because I had to drive into, and it’s really silly because it’s only about three miles”.

“Like I say the Portage was very helpful, that was stopped because she was doing too many sessions at pre-school, Speech and Language stopped coming round because that was basically passed on to be done in school so it didn’t really, there wasn’t any sort of consistency”.

“Then he ended up leaving nursery and the childminder because it was the summer holidays, and then he started pre-school and then nothing, no sort of dots ever get joined up from that and then obviously he was in a completely different setting and nothing, no I never really saw another person after that”.

“I think the problem is I didn’t go through the NHS community in my local area [...] so I don’t think there is massive support once you get diagnosed from the community but at least you’re known to them, whereas where I’m trying to ring and I’ve got a diagnosis from somewhere else [out of borough] their like oh we don’t know [child] and I’m like no you won’t because I’ve had it done privately”.

Long Waiting Times (13 mothers)

Another consistently reported barrier related to the amount of time spent waiting to access services: *“so the waiting list make services meaningless because it doesn’t happen in a timely manner, that’s my experience generally”.* Comments under this theme refer predominantly to waiting lists for services:

“And the waiting list is massive. I reapplied for a playgroup when [child] was two when they were considering his diagnosis, he was referred to a playgroup, we actually got a phone call when he was five saying that a space had become available”.

“I called them [occupational therapy] [...] and they said that they had a chronically long waiting list and currently the waiting list is twelve months plus and I should hear from them about an appointment after that day”.

“I asked the paediatrician to do a referral to the OT and he said that he would do one but it would be months and months down the line because there was only a certain amount of occupational therapists in South Birmingham that could actually do a Sensory Diet and what I wanted”.

Lack of Recognition of Need (14 mothers)

This theme primarily encapsulates mothers' comments about services not recognising the needs of their child prior to diagnosis, which either delayed or prevented their access to initial services:

“Again we went to the midwife and we went to the doctors and bear in mind at this point our oldest child had been diagnosed with autism. So we were kind of thinking is something going on here does she need to see somebody. We just go “oh no, she’s just delayed, its fine”.

“We saw a community paediatrician in Solihull and she dismissed all concerns with [child], even the speech, she said oh she’ll grow out of it, she’ll be ok, there are no concerns and I remember she dismissed the fussiness with food, the walking on tiptoes, the [child] always liked to just wear her pyjamas out”.

“Just literally on the sixteen month mark, and, you know, in the Dr’s office she was saying he looks too... I don’t know whether it’s her perception of autism... because I said, ‘I think he might be autistic’, she said ‘no he looks too... along the lines of the traits he is showing now it is definitely not autism, it may be that there is some speech delay”.

Mothers also reported a lack of recognition of need from one service impacting on their ability to access other services (***“and the ASD assessment service still refused to see her because school were saying “oh no, no everything is fine”***). Mothers also commented that as well as implying children would “catch-up” professionals also believed that many of the traits being shown by children instead reflecting behaviours of autism, were simply the product of parenting:

“[Child] sort of did things like climbed on cupboards in the kitchen, and the health visitor just thought we lacked discipline and weren’t actually managing very well as parents and that it was our fault”.

“She said to me [nursery] “it could be something like family issues at home” and I was “we don’t have family issues”.

3.4 Main facilitators of service access

Alongside barriers, facilitators were also grouped into themes. Similarly, a ‘theme’ is considered to be pertinent if it was reported by at least **five** parents (just under 25% of the sample). In contrast to the numerous barriers to services identified by mothers, only two facilitators were identified by parents:

3.4.1 Facilitators relating to mothers

Financial Resources to Access Services (7 mothers)

A consistent facilitator reported by mothers was having their own financial resources to access services. As well as commenting on having the financial resources to access a specific service, mothers also commented on the importance of having accessed this service:

“So I thought maybe ok getting EHC plan is very important and I focus on those reports and I paid like nearly £10,000 just to get the EHC plan sorted”.

“Privately, I would say, every private person we saw was fantastic, in their job, was very good”.

“But if I didn’t have the money, I wouldn’t have my son now”.

“We made the decision to go private in early June and we saw the consultant within two weeks [...] we saw the psychologist two weeks later so I think about and then the consultant again in two weeks so yeah the whole process was probably seven weeks I think from first contact with the paediatrician to the diagnosis, which is incredible like, the power of money for something that would have taken 18 months at least”.

Maternal Characteristics (8 mothers)

This theme encapsulates the various attributes of mothers which they felt facilitated their service access. These include being determined, persistent and pushing for services:

“I was on a waiting list to see the paediatrician and I rang and got a cancellation, I kept ring [sic] every day and said have you got a cancellation, have you got a cancellation, have you got a cancellation because I know that if you just wait for them to come to you, you are waiting for a long time. So I just kept pushing and eventually I got a cancellation”.

“So you can see that the service he’s been involved in are the ones that he has been involved in are basically because I pushed for them because I know that if you don’t push for them you don’t get them and that’s a big problem in Birmingham. That’s the way I think”.

“I went away that day and booked an appointment to see somebody else and said, ‘I’m not leaving until you do refer us, I do want some answers, I want to know if there’s something wrong”.

“And I spent hours on the internet researching what needs to go in the EHC plan, what I needed to do, and to this day I still do the same”.

3.4.2 Facilitators relating to services

Easily Accessible (5 mothers)

Mothers reported a key facilitator of service access was ease of access of services. Many of these references also highlight that ease of access equates to having a free service provided:

“Some of the agencies I do a lot more with they do a lot online and do a lot of support in closed Facebook groups. If you can message somebody and somebody will message you back and all things like that for me helped, fitted in with my needs around accessibility”.

“you know just to have somewhere to go, because unless you pay for like expensive soft play and both were too little for play barn, there’s not many places in the middle of the countryside that you can go with a little baby and so to be able to drop into one of those [playgroups] most of the days of the week it was just sanity saving”.

3.5 Examples of Good Practice

The following section examines elements of good practice noted within these interviews. Initially, three general descriptions of good practice by professionals or services reported by mothers will be provided, before detailed themes will be considered in-depth.

Example 1

“Again like I said with the Speech and Language person she was really positive and she offered sort of lots of sort of acknowledgement that we’re doing the right thing and she gave us feedback about stuff that said we’d tried to do and, you know just an approachable, personable person who seemed to be on our wavelength, and not preachy you know, there was no doubt there not one even tiny bit of doubt which surprised me because I think a lot of places you go now you see a doctor or even an appointment at a hospital or anything, you always need to prove it in some way that what you’re saying is true, she literally took our word for everything, did a bit of observing with him and she’d really diagnosed him within an hour”

Example 2

“The private paediatrician [...] just, her knowledge, experience, and although because she’s private but she used to work for the NHS it means the NHS professionals that now we see and are in contact with do take her seriously and listen to her, because I’m aware sometimes a private diagnosis can be ignored or dismissed, but it was her reputation that really mean it gets taken seriously. She’s very sort of no nonsense and again straight talking, very good with both the children [...] she’s good at

building rapport with them. Very human, you know I remember her saying to both of them you can call me [name], which was unusual for a paediatrician to say that really. Again, just not too clinical...

You could tell that she had children with disabilities as well, that empathy again”

Example 3

“Her knowledge [nursery key-worker] she knew what we needed to do, she talked through any paperwork that we needed to fill out so we understood what we needed to do. He would go to pre-school two or three times a week and every time we picked him up they would talk us through his day so we knew exactly what he had done, things that went well, things that didn’t go well.

Encouraged us to do particular things at home to see how they worked for him. Just communication really as well, we always had that communication with them and their advice and their knowledge that helped us with all the paperwork that we had to do and what to expect from the paediatrician or going to speech therapy appointments and all things like that. So that’s what they did really well”

3.6 Good Practice Themes

Good practice themes were drawn out of these broader examples of good practice relating to services and professionals. It is important to note that mothers were specifically asked about services, professionals, individuals or processes which they deemed to be most helpful, very good, or supportive. Themes here are included if they were contributed to by **five or more mothers** (just over 25% of all interviewees). These are sub-divided into characteristics described for ‘professionals’ and ‘services’, although these are sometimes arbitrary divisions with many themes transcending across both.

3.6.1 Professional Characteristics

Receptive to Parents (5 mothers)

One element mothers reported as denoting good practice, was when professionals were prepared to listen to, believe or trust parents’ opinions, as previously mentioned in Example 1. Other examples related to this theme include:

“The paediatrician for actually taking everything on-board and actually listening”.

“Sort of made lots of notes, and she took us seriously really, she wasn’t quick to dismiss us altogether or blame us as parents”.

Open and Flowing Communication (5 mothers)

Mothers also appreciated and noted clear communication as being an element of good practice, whether that was in relation to communication with a professional or the delivery of written or other forms of communication:

“I’m going to send you a letter with all the details there’s no point in keeping you any longer [...] but you will get more information in the post”. He was brilliant! It was a short appointment but it was so short because he was so professional and concise, he explained what was going to happen and it happened”.

“And she was again, very straight talking, explained things properly”.

“He would go to pre-school two or three times a week and every time we picked him up they would talk us through his day so we knew exactly what he had done, things that went well, things that didn’t go well”.

Professionals’ Personal Experiences (6 mothers)

Mothers identified that individual professionals’ experiences with autism or disabilities made them more relatable, and increased their understanding:

“Yes the paediatrician himself has a very close link with autism. So he understood the way things happen and the reasons why things happen and he could read in-between the lines quite easily on the situations that happened”.

“She [consultant] was also a parent of a child with special needs herself so she really understood exactly what I was saying, she was very good at listening and open to what I was saying”.

Emotional Understanding (7 mothers)

Good practice was also commented to be related to the emotional understanding displayed by professionals. This related to professionals showing empathy, but also being supportive and non-judgemental:

“And she kept telling me that I know it’s difficult”.

“She’s just been very sup, she’s been very supportive”.

“But the way they interact and talk to you about it, even when you break down and say there, there”.

Knowledge (8 mothers) (sub-theme, Navigating Complex Systems, 6 mothers)

Broadly, mothers mentioned they had found professionals knowledge most helpful or very good. This refers to many factors of professional knowledge, be that about autism, strategies for intervention, or medical information:

“Yeah she was an excellent, experienced SENCO. She knew exactly what she was talking about in regards to Asperger’s syndrome”.

“She was very, very she was very knowledgeable I would say [CAMHS staff] [...] she wasn’t another typical TA telling them to do this do that, she had education she has been educated regarding autism, she was a specialist so she knew exactly what she had to do with my son or what support he needs so... her knowledge helped us”.

“He was a newly qualified GP so he was quite young and obviously not long having qualified and so was more up to date on stuff”.

“So I think in terms of the therapy because they know what they’re talking about they’ve [occupational therapist] made some recommendations that have really helped and they understand it and they get it”.

More specifically, many mothers reported that professionals knowledge and expertise in knowing how to navigating the complex systems of support for children were helpful and an element of good practice:

“well I think perhaps she was aware of these services that we could access and the forms we needed to do [...] so she was like ok there is something we can do let’s try this, she knew how to access the forms because a lot of these processes now are done online as well, and she also knew how to word things how to put things down as well, in order for to try and access the help. So I think obviously her skills being a headmistress and doing a lot of form filling and red tape and stuff all these years”.

Overall Positive View of Professional (8 mothers)

Mothers made reference to various general aspects of professionals’ manner that they found most helpful, good or supportive. Professionals were described as approachable, friendly, relatable, and a great attitude:

“And, you know just an approachable, personable person who seemed to be on our wavelength, and not preachy you know”.

“Just really friendly and really approachable and no but nothing else in particular”.

Rapport and Relationship Building (11 mothers)

Mothers also reported valuing the rapport professionals were able to build with their child, for example they valued professionals taking the time to engage with their child when accessing services, as well as adapting their behaviour to build relationships with children:

“When he saw [child] his mannerism with [child] was brilliant in terms of he said his name, he acknowledged him, he spoke to him, his interaction with [child] was great and we were in and out of that appointment in like fifteen, twenty minutes not because we got rushed but because he was brilliant with children in general regardless of their neurodiversity”.

“She’s good at building rapport with them. Very human, you know I remember her saying to both of them you can call me [name], which was unusual for a paediatrician to say that really”.

Mothers also made comments regarding valuing the continued rapport and relationships built by professionals over time, and the benefit this relationship has to their child:

“The members of children’s centre staff just being really engaged with the kids, I mean you know making relationships with them week on week and you know, really getting to know them and offering advice based on how they’d got to know the child”.

“She [child] had a really good relationship with he [keyworker], and that was pivotal for [child] as well that”.

Beyond Role Requirements (11 mothers)

Mothers also made comments where they felt professionals had gone the ‘extra mile’ when working with their children. Some of these comments related to going the extra mile within their job role: ***“but she has gone above and beyond you know this woman [headmistress] has sat in her lunch break eating her lunch, helping us fill out like CAS forms or any other forms that needed to be done, so she has been really helpful.***

Other mothers mentioned professionals going above and beyond by maintaining in contact during transitions between services, maintaining contact and interest in their child, and even assisting outside of their role requirements:

“She [community coordinator] was really lovely and I ended up phoning her a few times because

every time he passed an age where someone said ‘oh there’s not really much you know we, he’s not really early years anymore he’s this or we only do nursery, and there was a little grey area of a few months where I thought I have a few concerns and I didn’t know who, I didn’t know who the point of contact was so I phoned her and she actually said he’s actually gone past the age that we, that was when he had already joined school, and she said we’re pure like early years, before school years, but she spent hours on the phone with me anyway, just out of kindness”.

“Even now we still talk [key workers] and they genuinely cared about him”.

“And would go the extra mile if needed [childminder]. For example, if [child] had a sports day or afternoon and I couldn’t go, she would go for me”.

3.6.2 Service Characteristics

Considerate Processes (5 mothers)

Another example of good practice identified by mothers was when services engaged in considerate processes with families, by clarity of process and allowing parents time and ability to understand and prepare to engage with services:

“I would say [name] speech and language therapy services, she was really nice she was professional and contacted us and said the school had invited her to come and assess [child] and she would like to speak to the parents there if that was possible and she was... she was really professional and she met us before she assessed [child] and then she contacted us again and said she had assessed [child] and said can I send you out the report and the report was really clear and really concise”.

“It was really good to have somebody tell you in advance that they wanted to see you at the school so that we were able to make arrangements for my daughter, she doesn’t do pre-school so I was able to make arrangements for someone to be with my daughter which meant me and my husband were able to speak to this lady. She could have turned up and then said can I have a minute to speak to you and it would have been productive”.

Personalised Adaptations (5 mothers)

It was highlighted that being adaptable in terms of service provision was another element of good practice. This relates to services making small adjustments, such as where a child may sit in assembly:

“I can go in and say, oh [child] seems to be struggling and he doesn’t like assembly because

everyone's in the hall and it's so many people, for him he struggles with that, so their like right ok so we'll move him right to the back and to the end so he's not like in and surrounded by children, just that kind of, just little things that really will make a difference to him".

However, this also related to the larger adaptable nature of services, to change their ways of working to allow the inclusion of children:

"The people who make a difference to us and to [child] are the people who are prepared to accept that things can be a bit different. So I was looking for a dance class for him last year or the year [...] and the place we go now is incredible, he spent the first three months crying [...] and the they supported him through that and he ended up as position of 'Head Wolf' in their annual performance last year [...] we talk about reasonable adjustment don't we, and it is that bit of reasonable adjustment that makes such a big difference".

Easily, Consistently Accessible (5 mothers)

Mothers commented on accessibility of services in relation to good practice. This included there being multiple groups to access, services which were affordable, and at practical times of the day for working parents:

"You could still go out everyday to the children's centre and take part in a nice activity [...] you know just to have somewhere to go, because unless you pay for like expensive soft play [...] there's not many places in the middle of the countryside".

"The one that was particularly helpful the one with the information... arranging the evening [...] I was never able to access that [other early intervention service] because it was always a daytime thing, so I never went for any of those ones. So things they put on in the evening I find that really helpful for me as a parent".

Rapid Response (5 mothers)

Mothers valued services acting with speed, be that for a referral, service access, or diagnosis:

"It's just the fact that obviously it was quick to diagnosis".

"And the health visitor ladies because they just kind of ran when I called in a sense and really were able to do that [...] when I phoned up in a crisis the kind of duty health visitor phoned back within 45 minutes".

“They made the referral immediately with you know letters coming through within day [...] but with her [health visitor] everything happened instantly”.

“But school [...] when I’ve asked for an assessment or ECHP or anything to be done by any referral, they’ve done it straight away”.

Consistent and Dependable Provision (6 mothers)

Mothers reported valuing consistency in service provision, be that in the form of a key-worker or seeing the same professional multiple times, for example a health visitor:

“Because of the ‘Carers Trust Coventry’ they help out hand all the way through the different appointments when we went to the hospital, they made sure we had a keyworker to help at the hospital and they were amazing”.

“I mean the health visitor, we’ve only really, we’ve been lucky that, I mean when they were babies it was different, but since they’ve been older and we’ve accessed them, well actually since, we’ve had our own that we’ve been able to see”.

Provision: Practical Work with Child (7 mothers)

Although mothers named other provision they valued from services, including observations, financial support for resources, days out, and courses, the only provision which exceeded the threshold of four mothers were any references to service provision centred on working with the child:

“Yeah the play therapy that portage did, so the portage did, it was very good because it was just trying to teach her like social skills like in an easy fun way [...] she could express herself through play”.

This also included various activities conducted with children, as well as mothers being given strategies and resources from this practical work in order to aid their own development:

“And you would get a report from them every month and they would give me an action plan to do at home”.

“She teach me how to use the picture, giving me resources, working with him”.

Highly Informative for Parents (8 mothers)

Services were also valued by mothers for being informative. In part this related to the nature of the service, i.e. as an information outlet:

“Contact... I thought ‘Contact’ are brilliant. Their literature online is amazing”.

“SENDIAS. So SENDIAS and IPSY are brilliant for information”.

However, information also related to how services explained and signposted other services or how they provided information through reports or their own strategies:

“And you know they were able to [pre-school] recommend ‘have you tried this, have you tried that’, you know they really were a wealth of information”.

“They [Solihull Inclusion Service] were very good at signposting as well, that was the point that we claimed disability living allowance, just their knowledge and experience because at that point I was, felt quite lost with everything and they really put me in the right direction of what to do”.

4. Information received by parents

Mothers were asked during the interview to reflect on information they had been provided with over their children’s early years. This included information given in written form (for example, leaflets and booklets) or online resources (such as websites to visit).

4.1 Who provided or signposted information?

Parents reported information to have been provided by various service types. These are summarised in the Table 4.1 below. Services are referred to as mentioned by parents within their interviews, and only specific services named are included for reference.

Table 4.1. Provider of information or information signposted

Signposter/Provider	Service	Number of Mothers	Total
Charitable	Special Educational Needs and Disabilities Information Advice and Support Service	1	2
	Kent Autistic Trust	1	
Health	Neurological Development Service	2	10
	Paediatrician	2	
	Child Psychologist	2	
	Doctor	1	
	Hospital	1	
	NHS	1	
	Consultant	1	
Education	SENCO	1	4
	School	1	
	Solihull Inclusion Service	1	
	Nursery	1	
Therapy Providers	Occupational Therapist	1	3
	Speech therapist	1	
	Physiotherapist	1	
Early Intervention Course	Cygnets Course	2	3
	Early Bird course	1	
			22

It is important to note however, that 7 mothers reported they had received no printed information (39% of interviewees), and similarly 9 mothers reported they had received no online information (50%). However, only 2 mothers had received neither form of information source (11%)

It is also important to highlight the high proportion of mothers (N=12; 66%) who said that they had to, or wanted to, go and seek their own information, be that for their own interest or to receive enough information.

4.2 What content did the information cover?

Parents were asked what types of content was covered in the information they were provided with. The following themes surrounding content were identified. Only specific references were content were collated into themes, no inferences were drawn from sources e.g. website titles.

- **What is Autism (6 mothers):** this related to information specifically to do with what autism is
CS: *“You’d seen the paediatrician before you were referred to the coordinator and they printed you off a mass of leaflets and printed things to take away with you”*
I: *“Yeah”*
CS: *“What kinds of topics did they cover, those materials?”*
I: *“I... from memory I guess it was the kind of resources you’d find sort of on the main autism charity websites and any kind of NHS’y kind of ‘what is autism’ and what does it consist of and what can you do and this that and the other”.*
- **Child Development (3 mothers):** this relates to information focused on typical milestone progression or information regarding weening and feeding: *“we got kind of milestones in development stuff so you know I think you get something about this is what you know typical milestones stuff” .*
- **Products (1 mother):** information regarding products for purchase: *“the OT ones were more about products that would be beneficial and where they could be bought”.*
- **Services (9 mothers):** information about services that could be accessed to support their child: *“there were also leaflets about charities, parent groups”.*
- **Strategies/Exercises (1 mother):** information from therapists about exercises to do with their child: *“yeah they were mainly try these exercises”.*
- **Training Courses (2 mothers):** information provided about training courses, or handouts from said courses (without stating the information provided): *“I remember being given something*

[...] six week signet course [...] I did that one and at the end they give you this piece of paper that has some other courses that the neurological development team also run for parents with a newly diagnosed child"

4.3 Was this information considered 'useful'?

Although some mothers reported that the information provided had been useful, this reflected only just over 25% of the interview group (N=5; 28%). Therefore, information of this type was typically perceived not to be useful by mothers. Mothers reported various reasons for the information not being considered useful including: information not being specific information to their local area, the resource being too long, the information being difficult to apply to their child or not precise enough to their situation, information relating to services that could not be accessed e.g. due to child care situations, and information being purely advertising. The following quotes highlight how mothers felt the information may not be useful to themselves:

"It gives you the really bland 'what is autism' but I think to really understand it for yourself you have to learn about the autism that is your child"

"But you know the ones you get when they're born a lot of that is just blatant advertising. And you get a couple of little vouchers in it as well I think but yeah it's mostly advertising it's a gross waste of printed paper"

"It's hard to apply to your own situation, your own child, because they're all so different"

"They gave me a list of charities which I went through but none of those charities helped me"

4.4 What was useful?

Practical or personalised Information (6 mothers)

Mothers highlighted that practical or applied information was helpful. This included for example information about all the services accessible to a child: ***"when she started [first school] she was given a little blue book which basically had all the services available to her and all the charities that could help, all the organisations and groups that could help and it was a really good idea"***

Similarly, mothers highlighted that information about accessing practical resources or funds such as disability living allowance was considered useful when provided: ***"but I think what helps "you can apply for DLA and have you thought about these people and those kinds of people"***

4.5 What information might have been better or more helpful across the early years?

Mothers provided insight as to what information may have been more helpful, or useful in addition, to that which they had been given. Suggestions were organised into themes containing information from **5 or more mothers** (over 25% of the interview sample) are reported below. It is important to note that although some themes are not directly related to information being provided, they were developed out of responses to this question.

Actual Service Contact and Support (6 mothers)

Mothers reported wanting more contact with actual services providers:

“Talking to other parents, years ago, I know that there have been people that have been given this booklet when their child was diagnosed but they got no support whatsoever. They got given a booklet and told to literally go away. So in a way having a booklet but not having any support is just as bad. Is that making sense?”

It is important to consider that some of these comments appeared to highlight that increased actual service contact might be a way to get access to more information, but that information alone cannot occur in isolation from service contact: ***“I think to be able to get a diagnosis earlier than what they are doing nowadays, I think it just helps generally and to be able to get access to that information quicker than if you just not knowing what is going on. Even with that information that you’re getting you still need trained people to come and explain to parents”***

Similarly, other mothers highlighted that actual service contact was something they wanted in addition to existing information sources (***“information wise I think it is good but they need to be out there more”***) whilst others would have wanted actual service contact rather than information sources (***“just someone to see my son properly or like a speech therapist coming home, [...] that would of been very useful, more than any of those like leaflets and charities. Because the way of communication is open, and that is when life is getting easier”***).

Service Signposting (7 mothers)

Mothers reported it would have been useful to have information given about what services they were able to access, be that privately or through the NHS:

Mothers made comments in general about being made aware of services existing: ***“oh yeah, well being told about services even existing, certainly would have helped. I just didn’t even know that there was anything to do you know what I mean, I just had no idea what was even out there because there’s just not information readily available”.***

Another mother made a comment in relation to how support services could be signposted: ***“almost like a sort of how to guide, it’s almost like a support booklet that sort of, oh you’ve found out your child’s got this diagnosis, right this is the support you can access”.*** Similarly, it was noted that this role of signposting services has previously been undertaken by unofficial channels, and as such might be a useful thing for services to provide directly: ***“even accessing the DLA it was a friend that told me to access that I didn’t have any professionals tell me to access that. The short break fund was a colleague telling me as well to access that. So unless you know someone that knows about it it’s very hard to find out on your own”.***

5. Overall Conclusions and Recommendations

5.1 Conclusion

In summary, this research highlights that although parents may have quantitatively different experiences with service access (as demonstrated through accessing a wide variety and different numbers of services), parents across England identify similar factors acting as facilitators and barriers to accessing services for their young children with autism. Their own characteristics, such as financial resources, resilience, and determination are consistently perceived as clear facilitators of service access. However, parents experienced multiple barriers to service entry, including long waiting times, a lack of recognition of need from services, and limited or no service provision.

However, it is crucial to highlight the broad range of good service characteristics identified. Despite the many barriers reported, all mothers interviewed identified at least one or more professionals or services who they considered to exemplify elements of excellence. Examples of good practice provided by mothers, could be adopted by several professionals or services currently working with young people with autism.

5.2 Recommendations

1. Universal health services have very high levels of access during children's early years (0-5, e.g. GP, dentist, and paediatrician). Similarly high levels of access can be seen for some specialist services, notably speech and language therapy. Access to speech and language therapy may be strength in service provision given the centrality of communication problems in autism. More specialist services such as occupational therapy, and support for behaviour or sleep problems, were accessed by fewer parents but a large number of parents would have liked to have accessed such services. These findings suggest an unmet need in these areas of provision. Given the high prevalence of behaviour problems and sleep difficulties in children with autism, early intervention needs to include support for behaviour problems and sleep difficulties.
2. Mental health services, social care, and local authority services were perceived by parents to be the least easy to access and the least helpful services. While reasons behind these perceptions were not included in this research, frequently identified barriers were lack of services, long waiting times, and unhelpful communication with service providers or

professionals. Addressing all or some of these barriers is likely to increase access, and improve parents' perceptions of the helpfulness of mental health and social care services.

3. The proportion of respondents who reported accessing any intervention during the previous 12 months was only about one third of participants. While education about autism and support for communication were the main two areas where intervention was provided, comprehensive early intervention seem to be accessed by a very low number of parents (22% of those who accessed any intervention). Researchers and service providers need to work together to determine factors needed for take up and sustained implementation of comprehensive early intervention models across the country.
4. Good practice and good access start with timely identification of need. Timely identification of need might involve better education of both expectant parents and professionals who monitor development (i.e. health visitors). Parents and health visitors could be equipped to identify deviations from typical child development more successfully, be empowered to voice any concerns they may have, and to be empathetic in communication with each other (e.g. 'really listening' to parental concerns).
5. Empathetic communication is a key attribute of good practice. Empathetic communication can be developed as part of professional practice across a wide range of service providers who come into contact with parents.
6. Professionals who are knowledgeable, empathetic, and keen to build rapport with the child are those who parents value most.
7. Problems with structural characteristics of service provision (e.g. where no services are available, services with too restrictive inclusion criteria, long waiting times, not enough specialist staff, and poor communication systems) need to be addressed urgently. Resources may not be the only solution to addressing structural barriers. Service development requires an inclusive ethos: services need to be made available to address *need* in the population (as opposed to gatekeeping using age or diagnostic labels as barriers); to work collaboratively with parents and empower them to navigate the system of service provision. At the heart of a well-resourced service with an inclusive ethos is empathetic communication between professionals and parents, where the child's development and family's well-being is placed at the heart of conversations.