## Table S1

*Key Professionals: Access to, Unmet Need and Ease of Access Ratings*

|  |  |  |  |
| --- | --- | --- | --- |
| Support source | Access to support (*N* = 673) | Unmet needa | Ease of access ratingsb |
| *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, preschool, 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 a team responsible for assessing 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 |
| *Health care 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 medical practitionerc | 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 |
| Pediatrician | 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.* SEN = special educational needs.

a An unmet need was defined as support wanted but not accessed (i.e., if participants reported they had not accessed support from the professional *and* wanted support from the professional). 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 this as an unmet need. b Ease of access ratings were completed by participants who had accessed the respective professionals using a 5-point scale. Higher scores indicate the professional was rated easier access.c A general medical practitioner is a community-based medical doctor that treats common medical conditions in the UK.

## Table S2

*Access to Other Support Sources*

|  |  |
| --- | --- |
| Support source | Access to support (*N* = 673) |
| *Accessed* |
| *N* | *%* |
| *Health specialists*a |
| 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 center  | 154 | 22.9 |
| Carer’s center | 44 | 6.5 |

*Note.* SEND = special educational needs and disabilities. LA = local (government) authority.

a In addition to the health specialists listed in the survey, 9.8% of participants reported access to other health specialists in a free-text response box (e.g., otorhinolaryngology, orthopedics, optometry, orthoptics, rheumatology, dermatology, diabetology, nephrology, chiropractic, immunology).

## Table S3

*Packaged Interventions Reported by Participants*

|  |  |
| --- | --- |
| Packaged interventionsa | Participantsb  |
| N | % |
| Early Bird  | 26 | 3.9 |
| ABA | 17 | 2.5 |
| Hanen Programs® | 16 | 2.4 |
| Triple PTM / Stepping StonesTM | 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 counseling | 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 interventionsc (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 Program®, reading interventions, sleep therapy) | 43 | 6.4 |

*Note.* ABA = Applied Behavior Analysis. ADHD = attention deficit hyperactivity disorder. E-PAtS = Early Positive Approaches to Support. PACT = Pediatric/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®.

a Packaged interventions were identified by analyzing participants’ free-text responses on interventions accessed using our coding scheme (see Analysis). b 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%). c Specific interventions included in ‘other interventions’ were reported by <4 participants.

## Table S4

*Barriers of Access to Support in the Early Years*

|  |  |  |  |
| --- | --- | --- | --- |
| Barrier code | Total Na | 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 professionals’ engagement with parents (e.g., negative attitudes, not listening, being dismissive or obstructive, not providing information) and limited knowledge of DD 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 recognizing 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 DD, 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’ |

*Note.* DD = developmental disabilities.

a Total reflects the count of mentions of barrier codes across participants (not the frequency of participants who reported each barrier). This was used to capture when participants described multiple things that impacted their access related to one overarching barrier. For example, one participant reported *“Waiting lists”* and *“Long forms to fill in”* were barriers, which were both coded as service-level barriers (i.e., reflecting two mentions of this barrier).

## Table S5

*Facilitators of Access to Support in the Early Years*

|  |  |  |  |
| --- | --- | --- | --- |
| Facilitator code | Total Na | Description  | Example |
| Supportive and competent professionals | 151 | Supportive elements of professionals’ engagement with families (positive attitude, 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 behaviors, and knowledge of services and DD.  | ‘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 both 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 (e.g., criteria, location, contact), flexibility, provision of resources (e.g., benefits, childcare), financial set-up (free, low-cost), availability and capacity, and continuity of provision. | ‘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’ acknowledgmentof need | 79 | Professionals’ acknowledgment 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. | ‘GP advising to see the Pediatrician because of autistic traits’ ‘developmental assessment’ ‘carers assessment’ ‘Getting a diagnosis’ ‘Pediatrician 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’  |

*Note.* DD = developmental disabilities. MP = Member of Parliament in UK government. EHCP = Education Health and Care Plan (i.e., statutory statement of special educational needs in England). IPSEA = Independent Provider of Special Education Advice.

a Total reflects the count of mentions of facilitator codes across participants (not the frequency of participants who reported each facilitator). This was used to capture when participants described multiple things that impacted their access related to one overarching facilitator. For example, one participant reported *“Ability to fund private assessments”* and “*My determination to access support”* were facilitators, which were both coded as empowered parental caregivers (i.e., reflecting two mentions of this facilitator).