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Healthcare Practitioner Survey

HCP- Health care access experience of Autistic children in the UK

Start of Block: Block 1

Q1.1 Welcome! This study is being conducted by Tonia Babalola from City, University of London, as part of a PhD. The project supervisors are Professor Nicola Botting and Dr Lucy Dipper. Purpose of the research: To gain insight into the experiences of health care professionals in relation to Autistic children accessing healthcare in the United Kingdom.

Why have I been invited to take part? You have reached this page by clicking the link in our open social media invitation. You should only complete this survey if you are a health care professional who may have treated children with Autism, Asperger syndrome or Autism Spectrum conditions. Your role in this research: If you decide to participate, you will complete a questionnaire based on your experience. Time required: The survey will take approximately 20-25 minutes to complete. Data protection: Information collected will be used only for the purpose(s) set out in this statement, and your consent is conditional on the University complying with its duties and obligations under the General Data Protection Regulation (GDPR). All research with human participants by staff and students has to be scrutinised and approved by one of the City's Research Ethics Committees. This study has been approved by City, University of London, Language and Communication Science Proportionate Review Research Ethics Committee (Ethics no: -----).

The information from this questionnaire will be held by City, University of London as data controller and processed for the purposes of research. City, University of London considers the lawful basis for processing this data to fall under Article 6(1)(e) of GDPR (public task) as the processing of research participant data is necessary for learning and teaching purposes. Confidentiality: The questionnaire is anonymous and your answers cannot be traced back to you. Your geographical region will only be used by the research team and will not be identifiable in the final report of the project, or future publications, except in general summarised data. That is when research results are reported, responses will be aggregated (added together) and described in summary. Your anonymous responses for the questionnaire as a whole will only be seen by staff and students at City, University of London, and will never be shared with other organisations or any other third party.

Participation and withdrawal: By clicking the buttons below, you acknowledge that your participation is completely voluntary and that you are aware that you may choose to stop taking part

at any time by exiting the survey. Your responses will be saved at the point at which you exit the survey. You can exit the survey without giving a reason and without disadvantage to yourself.

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You could also write to the Secretary at: Secretary to Senate Research Ethics Committee Research Office, E214, City University London Northampton Square London EC1V 0HB. City holds insurance policies which apply to this study.

Q1.2 I understand that:

- ☐ The study involves me completing the questionnaire (1)
- ☐ The data will be held by City, University of London as data controller as a public task (teaching and learning) (GDPR 6(1) (e) (2)
- ☐ All information is anonymous and confidential (3)
- ☐ My participation is voluntary (4)
- ☐ City, University of London will process this information which will only be used for the purposes above (5)
- ☐ I agree to take part in this study (6)

End of Block: Block 1

Start of Block: Block 2

Q2.1 Where in the United Kingdom do you work?

- ☐ East of England (1)
- ☐ Midlands (2)
- ☐ Northwest (3)
- ☐ Northeast (4)
- ☐ Southeast (5)
- ☐ Southwest (6)
- ☐ Wales (7)
- ☐ Scotland (8)
- ☐ Northern Ireland (9)
- ☐ Ireland (10)
- ☐ Other country (11)

Q2.2 Are you?

- ☐ Female (1)
- ☐ Male (2)
- ☐ Identifies in a different way (3)
- ☐ Prefer not to say (4)

Q2.3 Please tell us your age?

Q2.4 What is the highest level of school you have completed or the highest degree you have received?

- ☐ No formal qualifications (11)
- ☐ GCSE, GCE, O levels, level 2 NVQ (2)
- ☐ A levels / level 3 NVQ (10)
- ☐ Vocational qualification (diploma, certificate, BTEC) (8)
- ☐ Undergraduate degree (4)
- ☐ Postgraduate degree or higher (7)

Q2.5 What is your ethnic group?

- ☐ White - English / Welsh / Scottish / Northern Irish / British (1)
- ☐ White - Irish (2)
- ☐ White - Gypsy or Irish Traveller (3)
- ☐ Any other White background (4)
- ☐ White and Black Caribbean (5)
- ☐ White and Black African (6)
- ☐ White and Asian (7)
- ☐ Any other Mixed / Multiple ethnic background (8)
- ☐ Indian (9)
- ☐ Pakistani (10)
- ☐ Bangladeshi (11)
- ☐ Chinese (12)
- ☐ Any other Asian background (13)
- ☐ African (14)
- ☐ Caribbean (15)

- ☐ Any other Black / African / Caribbean background (16)
- ☐ Arab (17)
- ☐ Any other ethnic group (18)

Q2.6 Which of the following best describes you?

- ☐ GP (1)
- ☐ Paediatrician (2)
- ☐ Other specialist doctor (3)
- ☐ Registered nurse (13)
- ☐ Nurse practitioner (4)
- ☐ Careworker (11)
- ☐ Optician (10)
- ☐ Dentist (9)
- ☐ Speech and language therapist (12)
- ☐ Occupational therapist (14)
- ☐ Physiotherapist (15)
- ☐ Psychologist or other therapeutic profession (16)
- ☐ Audiologist (8)
- ☐ Pharmacist (18)
- ☐ Other (17)

Q2.7 To your knowledge, have you ever treated children with Autism, Asperger syndrome or Autism Spectrum conditions?

- ☐ Yes (1)

- ☐ No (2)

End of Block: Block 2

Start of Block: Health care services

Q3.1 Health care services

Q3.2 Which of the following best describes where you work

- ☐ GP practice (1)
- ☐ Outpatients (12)
- ☐ Hospital emergency department (A&E) (6)
- ☐ Psychology / psychiatry department (14)
- ☐ All other hospital departments (2)
- ☐ Optician's (8)
- ☐ Dental practice (10)
- ☐ Health centre / community centre / children's centre (3)
- ☐ Psychological / therapeutic practice (outside of hospital) (13)
- ☐ Audiology clinic (15)
- ☐ School (Nurse's Office) (4)
- ☐ Pharmacy (16)
- ☐ Other (5)

Q3.3 Which of the following services have you ever provided for an Autistic child?

Yes (1) No (2)

General healthcare advice (11)	☐	☐
Accident & emergency services (1)	☐	☐
Mental health care or counselling (4)	☐	☐
Other specialist hospital care (3)	☐	☐
Eyeglasses or vision care (5)	☐	☐
Dental care (2)	☐	☐
Hearing aids and care (6)	☐	☐
Speech and language therapy (8)	☐	☐
Occupational therapy (7)	☐	☐
Physiotherapy (13)	☐	☐
Prescription medication (9)	☐	☐
Injections or vaccinations (12)	☐	☐

Q3.4 How long do patients wait in the waiting area before they are called in for an appointment in your setting?

- ☐ Less than 30 minutes (7)
- ☐ Between 30 minutes and an hour (1)
- ☐ More than an hour (2)
- ☐ I don't know (6)

Q3.5 How long do patients have to wait for non-emergency appointment in your setting?

- ☐ Less than a week (9)
- ☐ More than 1 week (2)
- ☐ More than a month (7)
- ☐ More than 6 months (8)
- ☐ I don't know (6)

Page Break

End of Block: Health care services

Start of Block: Healthcare practitioners' experience, knowledge and training

Q4.1 Healthcare practitioners' experience, knowledge and training

Q4.2 How well do you feel you understand Autism?

0 10 20 30 40 50 60 70 80 90 100

0-100% ()

Q4.3 Can you tell us a bit more about why you chose that rating?

- ☐ Yes - family (4)
- ☐ Yes - friend (7)
- ☐ No (5)
- ☐ Prefer not to say (6)

- ☐ Yes (4)
- ☐ No (5)

	Strongly disagree (1)	Disagree (2)	Somewhat disagree (3)	Neither agree nor disagree (4)	Agree (5)	Strongly agree (6)
I am knowledgeable in Autism-specific demand avoidance, Autism burnout and trauma (23)	0	0	0	0	0	0
I allow additional time for the assessment and treatment of Autistic children (14)	0	0	0	0	0	0
I understand Autistic children's communication needs (3)	0	0	0	0	0	0
I understand Autistic children's sensory needs (27)	0	0	0	0	0	0

I am knowledgeable about the available services for Autistic children (15)	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
I am aware of the referral process for Autistic children (16)	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐
I do not make assumptions about Autistic children's needs (22)	☐	☐	☐	☐	☐	☐
	☐	☐	☐	☐	☐	☐

Q4.7 In my setting, Autism training is provided for receptionists and other non-healthcare staff

- ☐ Yes (4)
- ☐ No (5)
- ☐ I don't know (7)

Page Break

End of Block: Healthcare practitioners' experience, knowledge and training

Start of Block: Access to care: Use of services and unmet healthcare needs

Q5.1 Access to care: Use of services and unmet healthcare needs

Q5.2 Which of the following do you feel would make parents delay or avoid seeking help for their child's healthcare needs?

Yes (1) No (2)

No appointment soon enough (24)	☐	☐	
Flexibility of appointment times (25)	☐	☐	
Limited appointment time to cover the needs (16)	☐	☐	
Not being able to see the preferred doctor (26)	☐	☐	
Limited reception staff knowledge about the child's symptoms (29)	☐	☐	
Limited healthcare practitioners' knowledge about the child's symptoms (43)	☐	☐	
Healthcare environment (e.g., parking/ parking charges/ building layout) (3)	☐	☐	
Communication with reception or healthcare practitioner (17)	☐	☐	
Waiting room environment (30)	☐	☐	
Child's sensory difficulties (32)	☐	☐	
Child's challenging behaviour (31)	☐	☐	
Stigma (40)	☐	☐	
Problem with referral (42)	☐	☐	
School Issues (41)	☐	☐	
Transportation (19)	☐	☐	
Travel time to see the healthcare practitioner (22)	☐	☐	
The type of care needed is not available in the area. (23)	☐	☐	
Other caring responsibility (20)	☐	☐	
Something else (11)	☐	☐	

Skip To: Q5.3 If Which of the following do you feel would make parents delay or avoid seeking help for their child... = Something else [Yes]

Q5.3 You chose 'something else'. Can you tell us a bit more about what you feel would make parents delay or avoid seeking help for their child's healthcare needs?

Q5.4 Has any reasonable adjustment been made to reduce difficulties experienced by families in accessing your service?

- ☐ Yes (6)
- ☐ No (3)
- ☐ I dont know (14)

Skip To: Q5.6 If Has any reasonable adjustment been made to reduce difficulties experienced by families in accessi... = No

Q5.5 Can you tell us a bit more about the reasonable adjustment that was made to reduce the difficulties?

Q5.6 Please tell us why you think no reasonable adjustment was made to reduce the difficulties.

Q5.7 Does the parent of an Autistic child receive a call before an appointment?

- ☐ Yes, always (6)
- ☐ Yes, sometimes (14)
- ☐ Rarely (15)

- ☐ No (3)
- ☐ I don't know (19)

Q5.8 Rate how easy you find treating Autistic children where 0 is easy, and 10 is difficult

Completely easy Somewhat easy Not easy

0 1 2 3 4 5 6 7 8 9 10

Ease of treating Autistic children ()

Q5.9 Can you tell us a bit more about why you chose that rating?

Page Break

Q5.10 Which of the following makes consultation with Autistic children difficult

Yes (1) No (2)

- | | | |
|-----------------------|-----------------------|-----------------------|
| Communication (11) | ☐ | ☐ |
| Time pressure (2) | ☐ | ☐ |
| Limited resources (3) | ☐ | ☐ |

- Work overload (4) ☐ ☐
- Sensory difficulties (e.g., noise, vision, smell, touch, taste) (5) ☐ ☐
- Challenging behaviour (6) ☐ ☐
- Lack of knowledge (1) ☐ ☐
- Lack of training (9) ☐ ☐
- Something else (10) ☐ ☐

Skip To: Q5.11 If Which of the following makes consultation with Autistic children difficult =
Something else [Yes]

Q5.11 You chose 'something else'. Can you tell us a bit more about what makes consultation with
Autistic children difficult?

End of Block: Access to care: Use of services and unmet healthcare needs

Start of Block: General Healthcare services: Referrals

Page Break

Q6.1 General health care services: Referrals

Q6.2 Has an Autistic child receiving care from you ever needed a referral to other health care
services?

- ☐ Yes (1)

☐ No (2)

Skip To: QID764 If Has an Autistic child receiving care from you ever needed a referral to other health care services? = No

Q6.3 Rate how difficult it was to make the referrals in your setting, where 0 means easy and 10 means very difficult

0 1 2 3 4 5 6 7 8 9 10

Difficulty of referral ()

Q6.4 Can you tell us a bit more about why you chose that rating?

Q6.5 Rate how easy it is to get the necessary referral information, where 0 means easy and 10 means very difficult

0 1 2 3 4 5 6 7 8 9 10

Ease of information for referral ()

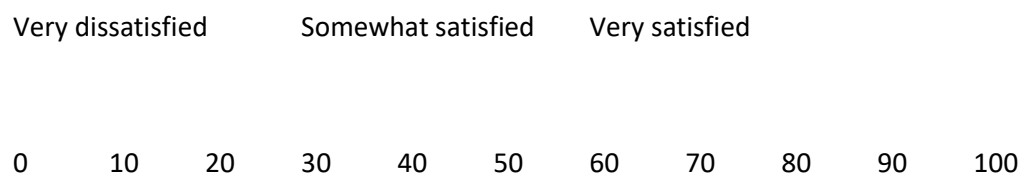
Page Break

End of Block: General Healthcare services: Referrals

Start of Block: Health care services: Communication

Q7.1 Health care services: Communication

Q7.2 Rate how satisfied you are with the communication between you and other healthcare practitioners about Autistic children in your care that need healthcare coordination



Level of satisfaction ()

Q7.3 Can you tell us a bit more about why you chose that rating?

Q7.4 Is communication a problem during a consultation with an Autistic child?

- ☐ Always (1)
- ☐ Frequently (2)

- ☐ Sometimes (3)
- ☐ Rarely (4)
- ☐ Not at all (5)

Q7.5 Which of the following would make communicating with an Autistic child difficult?

Yes (1) No (2)

- Sensory issues (15) ☐ ☐
- Child's inability to understand (5) ☐ ☐
- Child need extra time to process what is being said (14) ☐ ☐
- Child's difficulties in paying attention (4) ☐ ☐
- Child's inability to describe pain or symptoms accurately (13) ☐ ☐
- Parent's inability to understand terminologies (16) ☐ ☐
- It is difficult to communicate in a way that the child or parent can understands (9) ☐ ☐
- Something else (10) ☐ ☐

Q7.6 To what extent do you agree with the following statements:

Strongly disagree (1) Disagree (2) Somewhat disagree (3) Neither agree nor disagree (4) Somewhat agree (5) Agree (6) Strongly agree (7)

During consultations, I explain the things the parents need to do to take care of their child's health (4) ☐ ☐ ☐ ☐ ☐ ☐

During consultations, I involve the parents in decisions about their child's healthcare (3) ☐ ☐ ☐ ☐ ☐ ☐

During consultations, I acknowledge, consider and understand the parents' concerns (5) o

o o o o o o

During consultations, I encourage parents to talk to me about any health-related questions they have about their child. (6)

o o o o o o

During consultations, I give the parents time to express their emotions and feelings about their child's health. (7)

o o o o o o

During consultations, I am sensitive to the Autistic child's family's customs (10) o o

o o o o o o

Q7.7 Do you adapt your communication style when talking to an Autistic child or the parent?

- ☐ Yes, always (1)
- ☐ Yes, sometimes (3)
- ☐ Rarely (4)
- ☐ Not at all (2)
- ☐ I don't know (5)

Skip To: End of Block If Do you adapt your communication style when talking to an Autistic child or the parent? = Not at all

Q7.8 What kind of different communication style do you use?

Page Break

End of Block: Health care services: Communication

Start of Block: Healthcare services: Sensory specific challenges

Q8.1 The following questions are about Autistic children's sensory specific challenges

Q8.2 Which of the following do you feel are the most difficult sensory challenges for Autistic children during an appointment?

Yes (1) No (2)

Crowded waiting area / sitting next to strangers (6)	☐	☐
Uncomfortable furniture (3)	☐	☐
Bright or fluorescent lights (14)	☐	☐
Music playing in the waiting room (15)	☐	☐
Smells in the waiting room from other patients (16)	☐	☐
Noise in the waiting room from other patients (19)	☐	☐
Smells/taste in the doctor's office (20)	☐	☐
Noise from the reception desk (21)	☐	☐
Touch during an examination (22)	☐	☐
Autistic children don't have sensory challenges (11)	☐	☐

Q8.3 In your setting, is there any adjustment made specifically for Autistic children's sensory difficulties?

- ☐ Yes (6)
- ☐ No (3)
- ☐ I don't know (14)

Skip To: Q8.5 If In your setting, is there any adjustment made specifically for Autistic children's sensory diffic... = Yes

Q8.4 Can you tell us a bit more about why there is no reasonable adjustment?

Q8.5 Please tell us the reasonable adjustments available to reduce the difficulties.

Q8.6 Overall, do you think the right reasonable adjustments were made for the Autistic children and their families?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)

Page Break

End of Block: Healthcare services: Sensory specific challenges

Start of Block: Healthcare services: Perceived stigma

Q9.1 The following questions are about perceived stigma

Q9.2 To what extent do you agree with the following statements: Parents are anxious when going to the doctor because:

Yes (1) No (2)

They are worried their child might have a melt down (4) ☐

They are worried they will be judged (5) ☐ ☐

Parents are not anxious about doctor's visits (10) ☐ ☐

Something else (11) ☐ ☐

Q9.3 Does an Autistic child's stimming affect your appointments with them? (Stimming is repetitive or unusual body movement or noises)

☐ Yes (6)

☐ No (3)

☐ I don't understand what stimming is (14)

Q9.4 Does stimming or any unusual behaviour induce negative reactions from:

Never (8) Sometimes (9) About half the time (10) Most of the time (11) Always (12)

Other patients (1)	☐	☐	☐	☐	☐
Reception staff and medical staff (2)	☐	☐	☐	☐	☐
	☐				

Page Break

End of Block: Healthcare services: Perceived stigma

Start of Block: Experience of using the service: what's not working & what's not

Q10.1 Experience of using the service: what's working and what is not

Q10.2 In addition to what we have already asked about, what else do you think is not working well for Autistic children when accessing healthcare services, from your experience as a healthcare practitioner? Tick all that apply

Yes (1) No (2)

Hospital passport is not accepted at some hospitals (1)	☐	☐
The GP record did not say Autistic (11)	☐	☐
Limited support for mental health crisis at A&E; Focus on physical (16)	☐	☐
Lack of information about waiting times (14)	☐	☐
No alternative waiting arrangements such as pager, text or call when it is your turn (15)	☐	☐
No quiet room available (7)	☐	☐
Temperature of the room (8)	☐	☐
No reasonable adjustment (12)	☐	☐

Behaviour of others including staff (9)	☐	☐	
Something about the building/layout/location (13)	☐	☐	☐
Something else (17)	☐	☐	

Skip To: Q10.3 If In addition to what we have already asked about, what else do you think is not working well for A... = Something else [Yes]

Q10.3 What else do you think is not working well from your experience as a healthcare practitioner?

Q10.4 Experience of using the service: what's working

Q10.5 What do you think is working well with treating Autistic children?

Q10.6 What would make it easier for Autistic children to access the needed service? Check all that applies

Yes (1) No (2)

Telephone consultation (7)	☐	☐	
Timely/ Easy to book an appointment (5)	☐	☐	☐

Flexibility of time for the appointment (Last or first/ specific day and time) (9)	☐	☐
pre-arrival admission: staff notified about patient needs pre-arrival (16)	☐	☐
A calm and patient receptionist (3)	☐	☐
Reduced/No waiting time (2)	☐	☐
Dimmed lights (1)	☐	☐
A quieter waiting room or an available quiet room (18)	☐	☐
Sensory box or other sensory material in waiting room (35)	☐	☐
Ear defenders available while waiting (36)	☐	☐
Specific needs of the patients recorded (6)	☐	☐
Use of hospital passports (21)	☐	☐
Relationship with the same HCP (4)	☐	☐
Better healthcare practitioners' knowledge, training and understanding of Autism (10)	☐	☐
Additional time for assessment and treatment (23)	☐	☐
Adequate information sharing/ communication (15)	☐	☐
Different ways to diagnose physical health conditions, illnesses or pain levels. (27)	☐	☐
Autism specialist staff in A&E (25)	☐	☐
Direct referral to another department (19)	☐	☐
Self, online or text referrals (28)	☐	☐
Direct access to a mental health service (24)	☐	☐
Crisis unit/telephone service for Autistic young adults (26)	☐	☐
Transport provision (14)	☐	☐
Easier parking availability (13)	☐	☐
Easier physical access (12)	☐	☐
Something else (34)	☐	☐

Skip To: Q10.7 If What would make it easier for Autistic children to access the needed service? Check all that applies = Something else [Yes]

Q10.7 What else would make it easier for Autistic children to access the needed service?

Q10.8 Are the resources available to make these changes?

- ☐ Yes (4)
- ☐ No (5)
- ☐ For some but not others (7)
- ☐ I don't know (6)

Q10.9 Is there anything else you'd like to tell us, that we've missed in this survey?

Q10.10 The next stage of this project will involve interviewing healthcare professionals. Would you like to be involved in the interview stage?

- ☐ Yes (2)
- ☐ No (3)

Q10.11 If you will like to take part in the interview stage, please put your email here. This survey is anonymous until you input your email here

End of Block: Experience of using the service: what's not working & what's not

Parent Survey

Health care access experience of Autistic children in the UK

Start of Block: Block 1

Q1.1 Welcome! This study is being conducted by Tonia Babalola from City, University of London, as part of a PhD. The project supervisor is Professor Nicola Botting and Dr Lucy Dipper. Purpose of the research: To gain insight into the experiences of parents and their Autistic children when accessing healthcare in the United Kingdom.

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End of Block: Block 1

Start of Block: Block 2

Q2.1 Are you the child's...?

- ☐ Mother (1)
 - ☐ Father (2)
 - ☐ Other caregiver (3)
-

Q2.2 What is your child's age?

Q2.3 Is your child?

- ☐ Female (1)
 - ☐ Male (2)
 - ☐ Identifies in a different way (3)
 - ☐ Prefer not to say (4)
-

Q2.4 What is your child's education setting?

- ☐ Pre-school/Day care (1)
 - ☐ Nursery school (2)
 - ☐ Mainstream primary (3)
 - ☐ Mainstream secondary (4)
 - ☐ Further education college (5)
 - ☐ Specialist provision (6)
 - ☐ Home schooled (7)
-

Q2.5 How many siblings does your child have?

- ☐ 0 (6)
 - ☐ 1 (1)
 - ☐ 2 (2)
 - ☐ 3 (3)
 - ☐ 4 (4)
 - ☐ 5+ (5)
-

Q2.6 Where in the United Kingdom do you live?

- ☐ East of England (1)
- ☐ Midlands (2)
- ☐ Northwest (3)
- ☐ Northeast (4)
- ☐ Southeast (5)
- ☐ Southwest (6)
- ☐ Wales (7)
- ☐ Scotland (8)
- ☐ Northern Ireland (9)
- ☐ Ireland (10)
- ☐ Other country (11)

Skip To: End of Survey If Where in the United Kingdom do you live? = Other country

Q2.7 What is your highest educational qualification?

- ☐ No formal qualifications (7)
 - ☐ GCSE, GCE, O levels, level 2 NVQ (1)
 - ☐ A levels / level 3 NVQ (2)
 - ☐ Vocational qualification (diploma, certificate, BTEC) (3)
 - ☐ Undergraduate degree (4)
 - ☐ Postgraduate degree or higher (5)
-

Q2.8 What is your ethnic group?

- ☐ White - English / Welsh / Scottish / Northern Irish / British (1)
 - ☐ White - Irish (2)
 - ☐ White - Gypsy or Irish Traveller (3)
 - ☐ Any other White background (4)
 - ☐ White and Black Caribbean (5)
 - ☐ White and Black African (6)
 - ☐ White and Asian (7)
 - ☐ Any other Mixed / Multiple ethnic background (8)
 - ☐ Indian (9)
 - ☐ Pakistani (10)
 - ☐ Bangladeshi (11)
 - ☐ Chinese (12)
 - ☐ Any other Asian background (13)
 - ☐ African (14)
 - ☐ Caribbean (15)
 - ☐ Any other Black / African / Caribbean background (16)
 - ☐ Arab (17)
 - ☐ Any other ethnic group (18)
-

Q2.9 Is your child Autistic? (This includes Autism, Asperger syndrome, Autism Spectrum condition, formally diagnosed or on an Autism pathway).

☐ Yes (1)

☐ No (2)

Skip To: End of Survey If Is your child Autistic? (This includes Autism, Asperger syndrome, Autism Spectrum condition, form... = No

Q2.10 Rate how severe you feel your child's Autism is where 0 is the mildest and 10 is the most severe

0 1 2 3 4 5 6 7 8 9 10

Severity of child's condition ()



End of Block: Block 2

Start of Block: Access to care: Use of services and unmet healthcare needs

Q3.1 Access to care: Use of services and unmet healthcare needs. The following questions are about your experiences when accessing healthcare

Q3.2 Which of the following services does your child find challenging?

	Yes (1)	No (2)	Not visited (4)
GP practice (1)	☐	☐	☐
Outpatients (2)	☐	☐	☐
Hospital emergency department (A&E) (8)	☐	☐	☐
Psychology/ psychiatry department or clinic (14)	☐	☐	☐
All other hospital departments (9)	☐	☐	☐
Optician's (6)	☐	☐	☐
Dental practice (10)	☐	☐	☐
Health centre / community centre / children's centre (3)	☐	☐	☐
Audiology clinic (13)	☐	☐	☐
School (Nurse's Office) (4)	☐	☐	☐
Other (5)	☐	☐	☐

Q3.3 How often have you been frustrated in your efforts to get healthcare services for your child? (think about GP appointments, dental care including dental check-ups, mental healthcare, vision/eye appointments, hearing appointments, prescription medications)

- ☐ Always (1)
 - ☐ Frequently (2)
 - ☐ Sometimes (3)
 - ☐ Rarely (4)
 - ☐ Never (5)
-

Q3.4 Rate how often you felt your child needed healthcare but did not receive it: (think about GP appointments, dental care including dental check-ups, mental healthcare, vision/eye appointments, hearing appointments, prescription medications)

- ☐ Always (11)
 - ☐ Frequently (12)
 - ☐ Sometimes (13)
 - ☐ Rarely (14)
 - ☐ Never (15)
-

Q3.5 Rate how often you have delayed or avoided getting needed healthcare for your child.

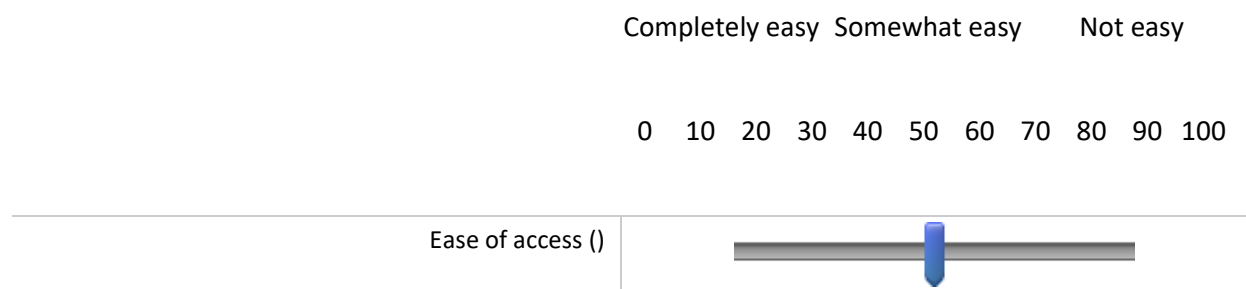
- ☐ Always (6)
 - ☐ Frequently (7)
 - ☐ Sometimes (8)
 - ☐ Rarely (9)
 - ☐ Never (10)
-

Q3.6 Which of the following might make you avoid or delay taking your child to see a healthcare professional when you need to? Please tick all that apply.

	Yes (1)	No (2)
Not being able to decide if the symptoms are severe enough to see a doctor (1)	☐	☐
No approval from your doctor or healthcare plan (8)	☐	☐
No appointment soon enough (17)	☐	☐
Limited appointment time to cover the needs (20)	☐	☐
Flexibility of appointment times (26)	☐	☐
Not being able to see the preferred doctor (12)	☐	☐
The healthcare provider did not have the skills the child needs (10)	☐	☐
The type of care needed is not available in the area (16)	☐	☐
Healthcare environment (e.g., parking/ parking charges/ building layout) (37)	☐	☐
Communication with reception or healthcare practitioner (9)	☐	☐
Limited staff knowledge about your child's symptoms (19)	☐	☐
Waiting room environment (11)	☐	☐
Child's challenging behaviour (34)	☐	☐
Child's sensory difficulties (35)	☐	☐
Stigma (36)	☐	☐
Limited treatment options (22)	☐	☐

The inability for GP to refer (23)	☐	☐
Referred to a service that was unable to help (24)	☐	☐
No information sharing (21)	☐	☐
School issues (38)	☐	☐
Transportation was a problem (15)	☐	☐
Travel time to see the healthcare practitioner (14)	☐	☐
Arranging for care for other family members (27)	☐	☐
Something else (33)	☐	☐

Q3.7 Please say overall how easy it has been to access healthcare for your Autistic child.



Q3.8 Which of the following are difficult for you or your child during an appointment?

	Yes (1)	No (2)
Communication (6)	☐	☐
Challenging behaviour (17)	☐	☐
Environment (e.g., parking/building layout) (3)	☐	☐
Sensory difficulties (e.g., noise, vision, smell, touch, taste) (14)	☐	☐
Stigma (16)	☐	☐
Something else (11)	☐	☐

Q3.9 Can you tell us a bit more about it?

Q3.10 Thinking now about communication: which of these are a barrier?

	Yes (1)	No (2)
Sensory Issues (21)	☐	☐
My child's inability to understand (20)	☐	☐
My child needs extra time to process what is being said (16)	☐	☐
My child's difficulties in paying attention (19)	☐	☐
My child's inability to describe pain or symptoms accurately (15)	☐	☐
I don't understand the terminologies (14)	☐	☐
The healthcare professional does not communicate in a way that my child and I can understand (6)	☐	☐
Something else (11)	☐	☐

Q3.11 Does your healthcare practitioner adapt their communication styles when talking to you or your child?

- ☐ Yes, always (1)
- ☐ Yes, sometimes (2)
- ☐ Rarely (3)
- ☐ Not at all (4)
- ☐ I don't know (5)

Q3.12 Do you agree with the following statements:

	Yes (1)	No (2)
During consultations, the healthcare practitioner does not explain the things I need to do to take care of my child's health (14)	☐	☐
During consultations, the healthcare practitioner does not involve me in my child's healthcare decisions. (3)	☐	☐
During consultations, the healthcare practitioner does not acknowledge, consider or understand my concerns. (5)	☐	☐
During consultations, the healthcare practitioner does not encourage me to talk about any health-related questions I have about my child. (13)	☐	☐
During consultations, the healthcare practitioner does not give me time to express my emotions and feelings about my child's health. (15)	☐	☐
During consultations, the healthcare practitioner is not sensitive to my family's customs (16)	☐	☐

Q3.13 Rate how easy you find dealing with the receptionists where 0 is easy, and 10 is very difficult

0 1 2 3 4 5 6 7 8 9 10

Ease of dealing with receptionists ()	
--	--

Q3.14 Can you tell us a bit more about why you chose that rating?

Page Break

Q3.15 Have you ever been called before an appointment so that the healthcare worker can better understand your child's needs?

- ☐ Yes, always (6)
- ☐ Yes, sometimes (14)
- ☐ Rarely (15)
- ☐ No (3)
- ☐ I don't know (19)

End of Block: Access to care: Use of services and unmet healthcare needs

Start of Block: Experience with child's GP

Q4.1 We will be focusing on three common healthcare areas which are: GP, Dentist and A&E.

The following questions are about your experience with your child's GP

Q4.2 How long do you have to wait for non-emergency appointment to see your GP?

- ☐ Less than a week (1)
 - ☐ More than 1 week (2)
 - ☐ More than a month (7)
 - ☐ More than 6 months (8)
 - ☐ I don't know (6)
-

Q4.3 How long does it take you to travel to see your GP?

- ☐ Less than 30 minutes (1)
 - ☐ Between 30 minutes and an hour (7)
 - ☐ More than an hour (2)
 - ☐ I don't know (6)
-

Q4.4 How long do you usually wait in the waiting area before you are called in for an appointment at the GP?

- ☐ Less than 30 minutes (7)
 - ☐ Between 30 minutes and an hour (1)
 - ☐ More than an hour (2)
 - ☐ I don't know (6)
-

Q4.5 Which of the following are the most difficult sensory challenges during an appointment at the GP?

	Yes (1)	No (2)
Crowded waiting area / sitting next to strangers (6)	☐	☐
Uncomfortable furniture (3)	☐	☐
Bright or fluorescent lights (14)	☐	☐
Music playing in the waiting room (15)	☐	☐
Smells in the waiting room from other patients (16)	☐	☐
Noise in the waiting room from other patients (19)	☐	☐
Smells / tastes in the doctor's room (20)	☐	☐
Noise from the reception desk (21)	☐	☐
Touch during an examination (22)	☐	☐
Something else (11)	☐	☐

Skip To: Q4.6 If Which of the following are the most difficult sensory challenges during an appointment at the GP? = Something else [Yes]

Q4.6 What other sensory challenges does your child experience during an appointment at the GP?

Q4.7 Was any adjustment made for your child's difficulties?

- ☐ Yes (6)
- ☐ No (3)
- ☐ I don't know (14)

Skip To: Q4.9 If Was any adjustment made for your child's difficulties? = No

Q4.8 Was the right reasonable adjustment made for you and your child?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)

Page Break

Q4.9 The following questions are about your GP's Autism knowledge and training.

	Strongly disagree (1)	Disagree (2)	Somewhat disagree (3)	Neither agree nor disagree (13)	Somewhat agree (4)	Agree (14)	Strongly agree (15)
My GP allows additional time for the assessment and treatment of my child (14)	☐	☐	☐	☐	☐	☐	☐
My GP understands my child's communication and sensory needs (3)	☐	☐	☐	☐	☐	☐	☐
My GP is knowledgeable about the available services for my child (15)	☐	☐	☐	☐	☐	☐	☐
My GP is aware of the referral process for my child (16)	☐	☐	☐	☐	☐	☐	☐
My GP does not make assumptions about my child (22)	☐	☐	☐	☐	☐	☐	☐

End of Block: Experience with child's GP

Start of Block: Experience with child's dentist

Q5.1 The following questions are about your experience with your child's dentist

Q5.2 How long do you have to wait for a non-emergency appointment to see your dentist?

- ☐ Less than a week (1)
 - ☐ More than 1 week (2)
 - ☐ More than a month (7)
 - ☐ More than 6 months (8)
 - ☐ I don't know (6)
-

Q5.3 How long does it take you to travel to see your dentist?

- ☐ Less than 30 minutes (1)
 - ☐ Between 30 minutes and an hour (7)
 - ☐ More than an hour (2)
 - ☐ I don't know (6)
-

Q5.4 How long do you usually wait in the waiting area before you are called in for an appointment at the dentist?

- ☐ Less than 30 minutes (7)
 - ☐ Between 30 minutes and an hour (1)
 - ☐ More than an hour (2)
 - ☐ I don't know (6)
-

Q5.5 Which of the following are the most difficult sensory challenges during an appointment at the dentist?

	Yes (1)	No (2)
Crowded waiting area / sitting next to strangers (6)	☐	☐
Uncomfortable furniture (3)	☐	☐
Bright or fluorescent lights (14)	☐	☐
Music playing in the waiting room (15)	☐	☐
Smells in the waiting room from other patients (16)	☐	☐
Noise in the waiting room from other patients (19)	☐	☐
Smells / tastes in the dentist's room (20)	☐	☐
Noise from the reception desk (21)	☐	☐
Touch during an examination (22)	☐	☐
Something else (11)	☐	☐

Q5.6 What other sensory challenges does your child experience during an appointment at the dentist?

Q5.7 Was any adjustment made for your child's difficulties?

- ☐ Yes (6)
- ☐ No (3)
- ☐ I don't know (14)

Skip To: Q5.9 If Was any adjustment made for your child's difficulties? = No

Q5.8 Was the right reasonable adjustment made for you and your child?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)

Page Break

Q5.9 The following questions are about your dentist's Autism knowledge and training.

	Strongly disagree (1)	Disagree (2)	Somewhat disagree (3)	Neither agree nor disagree (13)	Somewhat agree (4)	Agree (14)	Strongly agree (15)
My dentist allows additional time for the assessment and treatment of my child (14)	☐	☐	☐	☐	☐	☐	☐
My dentist understands my child's communication and sensory needs (3)	☐	☐	☐	☐	☐	☐	☐
My dentist is knowledgeable about the available services for my child (15)	☐	☐	☐	☐	☐	☐	☐
My dentist is aware of the referral process for my child (16)	☐	☐	☐	☐	☐	☐	☐
My dentist does not make assumptions about my child (22)	☐	☐	☐	☐	☐	☐	☐

End of Block: Experience with child's dentist

Start of Block: Experience at the A & E

Q6.1 The following questions are about your experience at the A&E

Q6.2 Has your child ever needed to use emergency services?

☐ Yes (1)

☐ No (7)

Skip To: End of Block If Has your child ever needed to use emergency services? = No

Q6.3 How long does it take you to travel to the nearest A&E department?

☐ Less than 30 minutes (1)

☐ Between 30 minutes and an hour (7)

☐ More than an hour (2)

☐ I don't know (6)

Q6.4 How long do you usually wait in the waiting area before you are seen by the doctor?

☐ Less than 30 minutes (7)

☐ Between 30 minutes and an hour (1)

☐ More than an hour (2)

☐ I don't know (6)

Q6.5 The A&E staff and doctors understand my child's communication and sensory needs

- ☐ Yes (5)
- ☐ No (1)
- ☐ I don't know (22)
-

Q6.6 Which of the following are the most difficult sensory challenges for your child at the A&E?

	Yes (1)	No (2)
Crowded waiting area / sitting next to strangers (6)	☐	☐
Uncomfortable furniture (3)	☐	☐
Bright or fluorescent lights (14)	☐	☐
Music playing in the waiting room (15)	☐	☐
Smells in the waiting room from other patients (16)	☐	☐
Noise in the waiting room from other patients (19)	☐	☐
Smells / taste in the A&E (20)	☐	☐
Noise from the reception desk (21)	☐	☐
Touch during an examination (22)	☐	☐
Something else (11)	☐	☐

Skip To: Q6.7 If Which of the following are the most difficult sensory challenges for your child at the A&E? = Something else [Yes]

Q6.7 What other sensory challenges does your child experience during an appointment at the A&E?

Q6.8 Was any adjustment made for your child's difficulties?

- ☐ Yes (6)
- ☐ No (3)
- ☐ I don't know (14)

Skip To: End of Block If Was any adjustment made for your child's difficulties? = No

Q6.9 Was the right reasonable adjustment made for you and your child?

- ☐ Yes (1)
- ☐ No (2)
- ☐ I don't know (3)

Page Break

Start of Block: The following questions are about perceived stigma

Q7.2 To what extent do you agree with the following statements: I feel anxious when going to healthcare settings because:

[illegible]

Q7.3 Does your child stimming affect your appointment at healthcare settings? (Stimming is repetitive or unusual body movement or noises)

- ☐ Yes (6)
- ☐ No (3)
- ☐ I don't know (14)

Q7.4 Does stimming or any unusual behaviour induce negative reactions from:

	Never (8)	Sometimes (9)	About half the time (10)	Most of the time (11)	Always (12)
Other patients (1)	☐	☐	☐	☐	☐
Reception staff and medical staff (2)	☐	☐	☐	☐	☐

End of Block: The following questions are about perceived stigma

Start of Block: Experience of using the service: what's not working & what's not

Q8.1 Experience of using healthcare services: what's working and what is not

Q8.2 In addition to what we have already asked about, what else do you think is not working well from your experience of using healthcare services in general? Tick all that apply

	Yes (1)	No (2)
Hospital passport is not accepted at some hospitals (1)	☐	☐
The GP record did not say the child is Autistic (11)	☐	☐
Limited support for mental health crisis at A&E; Focus on physical health (16)	☐	☐
Lack of information about waiting times (14)	☐	☐
No alternative waiting arrangements such as pager, text or call when it is your turn (24)	☐	☐
No quiet room available (7)	☐	☐
Temperature of the room (8)	☐	☐
No reasonable adjustment (25)	☐	☐
Behaviour of others including staff (26)	☐	☐
Something about the building/layout/location (9)	☐	☐
Something else (17)	☐	☐

Skip To: Q8.3 If In addition to what we have already asked about, what else do you think is not working well from... = Something else [Yes]

Q8.3 What else do you think is not working well from your experience of using healthcare services in general?

Q8.4 Experience of using the service: what's working

Q8.5 What do you think is working well when accessing healthcare for your Autistic child?

Q8.6 What would make it easier to access healthcare in general? Check all that applies

	Yes (1)	No (2)
Telephone consultation (7)	☐	☐
Timely / Easy to book an appointment (5)	☐	☐
Flexibility of time for the appointment (Last or first appointment/ specific day and time) (9)	☐	☐
Pre-arrival admission: staff notified about patient needs pre-arrival (16)	☐	☐
A calm and patient receptionist (3)	☐	☐
Reduced/No waiting time (2)	☐	☐
Dimmed lights (1)	☐	☐
A quieter waiting room or available quiet room (22)	☐	☐
Sensory box or other sensory material in waiting room (18)	☐	☐
Ear defenders available while waiting (34)	☐	☐
Specific needs of the patients recorded (6)	☐	☐
Use of hospital passports (21)	☐	☐
Relationship with the same HCP (4)	☐	☐
Better healthcare practitioners' knowledge, training and understanding of Autism (10)	☐	☐
Additional time for assessment and treatment (23)	☐	☐
Adequate information sharing/ communication (15)	☐	☐

Different ways to diagnose physical health conditions, illnesses or pain levels. (27)	☐	☐
Autism specialist staff in A&E (25)	☐	☐
Direct referral to another department (19)	☐	☐
Self, online or text referrals (28)	☐	☐
Direct access to a mental health service (24)	☐	☐
Crisis unit/telephone service for Autistic young adults (26)	☐	☐
Transport provision (14)	☐	☐
Easier parking availability (13)	☐	☐
Easier physical access (12)	☐	☐
Something else (30)	☐	☐

Skip To: Q8.7 If What would make it easier to access healthcare in general? Check all that applies = Something else [Yes]

Q8.7 What else would make it easier to access healthcare in general?

Q8.8 Is there anything else you'd like to tell us, that we've missed in this survey?

Q8.9 The next stage of this project will involve interviewing parents of Autistic children. Would you like to be involved in the interview stage?

☐ Yes (2)

☐ No (3)

Q8.10 If you will like to take part in the interview stage, please put your email here. This survey is anonymous until you input your email here

End of Block: Experience of using the service: what's not working & what's not
