

When did your journey start?

1. Who first raised concerns about your child's development (for example, about their behaviour, language development, physical development, or unusual responses to sensory input, like touch or smell)

- I did
- Member of my family
- School
- Nursery staff
- GP
- Health Visitor
- Midwife
- Other, please specify

split the survey up into Assessment Journey, Need Journey, NHS and Private journeys so capture each journey from start to finish as each will be different.

This would be better as question 2.

Re-word - Who first identified your child may have an unaddressed need around their health or development?

umm, not keen on the 'raised concerns' implies negativity when we're busy trying to say disability isn't negative, just a 'different ability'.

? noticed differences or delays perhaps?

also any areas they were forward in to give a positive balance

Once in a service the access time and wait is usually judged better than when waiting to be admitted into a service.

Open ended question - Tell us about what your first worries were in relation to your child - who raised these?

maybe add concerns / queries as some families aren't concerned as such but notice differences

reconsider the wording used

that it was felt needed further investigation or support. A problem could be noticed very early on but may be several years before someone thinks it is something that needs acting on e.g behavioural problems

I think language to parents needs to be clear and straightforward - I think concerns is fine. Wording such as 'unaddressed need' is confusing for parents. It is not language they use

Parents might have concerns for a really long time before they decide to raise this/someone raises this with them - do we want to capture this too?

Not sure if this sounds a little harsh/negative. We could say something softer e.g. 'Who first noticed that your child may be having difficulties with some aspect/s of their development? (for example....)'

2. What was the age of your child when concern was noticed ?

During pregnancy

0-2 years

2-5 years

5-11 years

12-16 years

17 and over

If it was you who first raised concerns, go to question 3

If it was someone else who first raised concerns, go to question 7

**Simplify?
How old
was your
child....**

**Re-word - How old
was your child when
you first became
aware of concerns
around their
development or
support needs?**

It would be really interesting to unpick whether they were male or female as girls seem to be diagnosed much later also children of ethnic origin are often missed too

again ? differences or delays and also what did you notice would be an interesting question

Are we trying to separate out professionals noticing and families and friends noticing here? If so, say a 'health or education worker' or 'professional' instead of 'someone else'

This would be better as question 1

question 1 re separating out when a concern was noticed and when it was felt it was a concern that needed further investigation or support. Length of time a concern was lived with before realising further

First 3 age groups overlap

I'm interested in why these age brackets were chosen - would it be more useful to know if early years (e.g. 2-4) and then primary school age 5-11 presuming most children are in school by 5?

cross over with groups should it be 0-2 3-4 5-11 etc

There is the issue of even if noticed 'conerns' they were acted on so knowing something & then acting on this needs to be separated out

Maybe different questions about the social media/internet and the professionals as the kind of help support/they offer is different.

3. If it was you who first raised concern, please go first for help/seek more information. Please order the first three places. 1 be first place you went to, 2 the second place you went to, and 3 the third place you went to.

Website .

If a website which one: _____

Online forum eg. Facebook, Twitter

Social media

GP

Another parent

Teacher/School Staff) etc

Midwife

Health visitor

Other, please specify?

Add something about nursery staff not just school plus childminders?

Re-word - What sources of support or information did you initially access...

used so only relevant questions show to respondents, based on their answers to the previous questions. (i.e. Qualtrics). Many parents of children also have ND or associated needs, and time is precious, so

Add in family member as an option

Are there any listed here which are very low in first choice so can take out?

Add family or friend...

I feel help and seeking information give 2 very different types of answers and maybe best to separate

May be think about wording, I spoke to a few of these people but wasn't asking for help or information about neurodisability, more discussing some issues I had noticed.

4. What did they do to help? (Choose all that apply)
signposted me to resources,
if resources, please state which resources?
suggested to wait and see how things develop
referred my child for an assessment
referred me for parenting support
offered direct support to me / my child
they did not offer any help
Other, please specify?

If no help was offered, what did you do next, please describe.

helped with
access to
finance advice
re. disability
living
allowance

Re-word - What
support, resources
or information did
you receive from
these sources?

Maybe not do as a
selection from a list,
but just have a free
text box. Might be
richer?

Some of these
options will not
apply to social
media or websites -
different options
needed for these

**When saying 'referred
for assessment' do
you mean for ASD
assessment
specifically? Just
thinking that quite a
few children are
referred to speech
and language therapy
first**

**Needs to be
clear what the
referral was!**

Clarify what
type of
assessment?
SALT? ASD?

'Referred my child
to a service' -
specify
which/multiple
choice, eg SALT,
Community
Paediatrics, 0-5
service.

maybe if they
were a
professional,
what did they
do to help

5. How satisfied were you with the help first offered?

Very satisfied

Slightly satisfied

Neither satisfied or unsatisfied

Not very satisfied

Very unsatisfied.

Explain your answer?

Needs to be clarified with "once seen" or will get comments on the waiting list not the service/care...

Maybe reword to "How satisfied were you with the help that you received?"

Re-word - How satisfied were you with the support, resources or information received at that time?

help first offered doesn't sound like the right wording in relation to looking at a website.

It may be useful to ask about impact this first offer of help had. What it meant to them and thier child. Other than just satisfaction level.

Do we need to link Q5 to which specific support service was accessed?

I am just wondering how this will be evaluated, if people indicate in question 3 they access social media/website/friends

6. What else would have been helpful?

Please state here

Re-word - what additional support resources or information would you have liked at this stage, if any?

maybe "What else would have been useful for 'X purpose'?"

Yes, like suggestion about what mattered - fits with 'what matters to me'

'what would have mattered most to you' can be a helpful question that often gets to the crux of what people need

What or who Helpful or could have been more helpful

Include suggestions on what could have been helpful as they won't know what is available, need to have ideas on what is possible

helpful as people can be helpful even if they're not the person who you ultimately work with on the diagnosis journey e.g. talking through your feelings with someone perhaps a TA, might be really helpful but they're not the person who you

What services are you aware of and what other things would make it better/more personal, what other services/support have made it better, how could they have been made more accessible

did you feel there was a plan in place?

7. If it was someone else who first raised concerns, what happened next? Tick all that apply

- signposted me to resources, If so, please state which resources?
- suggested to wait and see how things develop
- referred my child for an assessment
- they referred me to parenting support
- offered direct support to me and/or my child
- they did not offer any help
- I accessed the internet for help, if a website/forum which one:
- I looked for advice on social media
- I booked an appointment with my GP
- I asked another parent about it
- I talked it through with a Teacher/School Staff
- did not take any further action I decided to wait and see
- Other, please specify?

Re-word - What action did the individual who highlighted a possible unmet need take after sharing their concerns with you?

as 'possible unmet need' is not relevant to a lot of parents. There is a need to consider reading age when writing questions. There are online calculators you can put text into and it will tell what level of proficiency is needed to read and

In terms of forwarding a referral this would depend on who noticed the concern. Schools cannot refer to Ryegate currently.

Yes - maybe an option of told me how I could request a referral

Quite a complex sentence for parents with language or literacy difficulties - this will need breaking up/adapting

What happened next on your journey?

8. Which service did you access (or try to access) first?

- Multi Agency Support Team also known as MAST (via Sheffield City Council)
- Speech and Language Therapy (SLT) (via Sheffield Children's Hospital)
- Special Educational Needs and Disabilities Team (SEND within schools)
- Sheffield Occupational therapy / physiotherapy
- Childrens and Adolescent Mental Health service (CAMHS)
- Family Centre
- 0-5 SEND Service / Portage
- Parenting Hub (provides access to seminars and discussion groups)
- Local Children and Family Centres
- Other, please specify?

Ryegate/Neurodisability service

Re-word - Which service did you initially approach or access for support?

GP?

A lot of parents and staff talk about Ryegate referrals - they may not know which services fall under this umbrella

Did you feel there were any barriers put in the way such as having to access a parenting programme prior to even being referred

ASD Support Team for schools

Really useful question!

add health visiting

Some schools have own SALT therapist

Talked to family?

Add in here independent service, eg non-NHS SALT

9. How satisfied were you with this service on a scale of 1-10,
Very satisfied
Slightly satisfied
Neither satisfied or unsatisfied
Not very satisfied
Very unsatisfied.

Please explain your answer

**Switch
questions
9-10**

**Maybe 1-10 or
very satisfied
etc not both,
looks
confusing**

**Agree - worth
thinking how the
results will be
analysed to know
which is more useful
(maybe easier to
analyse with a 5 point
likert scale than a 10
point scale)**

**How
useful or
helpful?**

dissatisfied

10. How long did it take from when the first concern was raised about your child to accessing a service that gave you the help you needed

< 1 week

1 week to less than a month

1 month – 6 months

6 months – 12 months

1-2 years

More than 2 years, please specify

I haven't yet received the help I need

interpretation of what help is will be different, for some people it may just mean getting on a diagnosis pathway. Other people may have had lots of help but feel it has not met all their needs, the needs and help required will be

a variety of perceptions / needs may muddy this as even when services eg diagnostic assessments have been completed families have ongoing needs as these are life long issues

Wording 1 week to less than a month doesn't sound right. may be just less than a month.

Needs to clarify if time to 'support' as opposed to time to diagnostic assessment.

Rephrase? How long did it take for you to get support after you (or someone else) first raised concerns about your child's development?
Think the wording of this questions needs clarifying.

make it clear that this is about support, not necessarily a diagnosis.

They may have several services involved therefore varying answers

People might be confused by this -they might think it means raising concerns with a service.

Waiting for assessment

If not referred why, barriers to being referred? did they agree with reason for not being referred

11. Were you referred for an assessment?
Yes, If yes go to Question 12
No, If not please go to question 16?

referred for an assessment you may want to know what did happen next, how they felt about it, whether they felt they had enough of the right support going forwards. They should then be directed to the demographic questions and end the

I agree with this point above!

Needs to be more specific - what kind of assessment?

Maybe this questions needs clarifying to an assessment for ASD?

Clarify if you are meaning referred for an assessment or referred to a service as an initial appointment at a service is not the same as an autism assessment.

May be useful to know how easy or difficult it was to get a referral to a service e.g if it is a parent requesting the referral from a gp, were they listened to, were concerns taken seriously, did the gp say need to try other things before being referred.

Could ask about communication/booking the appointment

You could also ask people to rate how easy it was to get a referral for assessment or whether there were any issues with getting the referral.

Could ask people to rate the usefulness of the information about the assessment appointment that they were given beforehand.

- 12. If you were referred for an assessment, who was the assessment with?
- Speech and Language Therapy (via Sheffield Children's Hospital)
- Neurodevelopment Clinic eg. Autism (via Sheffield Children's Hospital)
- SLT
- Autism
- ADHD
- Community mental health services (via Sheffield Children's Hospital CAMHS)
- Community Paediatric Service (via Sheffield Children's Hospital)
- Other, please specify?

add
psychologist?

Add
GP...?

Might be useful to clarify NHS speech and language therapy as via Sheffield Children's might be confusing as children are often seen in home/nursery/school etc. rather than in a clinic

& ? add in here or somewhere - did you agree with where you referred to? we were referred to CAHMS rather than ryegate which I didn't want so we then had to wait another age to get into the ryegate system

Learning
Support /
Educational
Psychologists

Again need to clarify what you mean by assessment as initial appointment and assessment not the same thing. Someone may have an initial appointment with one service then be referred to another service for assessment.

clearer are autism and adhd meant to be autism clinic, adhd clinic? I'm under Ryegate, there are 3 options I could tick for this - neurodevelopment, autism, adhd. Are community paed and neurodisability part of

Need to explain what is meant by assessment as this could mean any appointment with any professional. Be clear

Learning
assessment in
school as an
option?

13. Once received, did you have to wait for the appointment?

Options

less than three months

3 – 6 months

6 months – 12 months

1-2 years

More than 2 years, please specify

Reasons for wait?
Was communication
about waiting lists
appropriate?

need to
specify which
service
waiting for to
show
blockages

appointment with
community
paediatrics or
Ryegate - very
different waiting
times

were you
notified about
wait times- if
so how and
when?

would love to talk to
someone about if
you want to go
private at this point
- there doesn't seem
to be a process for
this. Please ask me
- Rachel Welton!!

I asked about going
private - no-one I
spoke to could give
me clear
information about
this!

Ask about delays to
referral - i.e. were
you referred
elsewhere, did you
have any significant
barriers to referral
(i.e. School not
supportive).

Maybe add
"were you
given a reason
why the wait
time was
longer?"

Is this useful if we
dont know when
seen? Big difference
if child diagnosed 7
years ago vs 1 year
ago?

with
community
paediatrics or
Ryegate - very
different
waiting times

Please tell families
what will happen
next, where they are
within the process,
how long they will
have to wait and ask
for feedback on their
experience of
communication whilst
waiting - ask for ideas
on how to improve
this.

Time frames need
to be amended as
they overlap e.g 6
months is
mentioned twice

with the service or for
appointment for
actual autism
assessment - needs to
be clearer as there is a
big difference. e.g
waited 2 months for
initial appointment at
Ryegate but still on
waiting list for autism
assessment 12 months

14. While you were waiting for the assessment, what support did you access as a parent/carer (tick more than one box if relevant)

School support

Nursery support

MASTParenting

Family Centre

Seminars via Sheffield City Council

Sheffield Children's Hospital internet resources

Visit to local Children and ParentPeer support groups

Charities

I didn't access any support

Other, please specify

**Any
barriers to
accessing
these?**

**Did School support
the child with the
most appropriate
provision whilst
waiting for a
diagnosis**

**Do schools and
nursery offer specific
support to parents or
is their support more
for the child. Not sure
what the difference is
between these 2
options on questions
14 and 16**

**Informal
support
option i.e.
friends/family**

**childminders and
nursery need to be
added to list as well
as educational
psychologist.**

**what support
were you
offered? Did
you access
any support?**

**0-19 /
health
visiting**

15. Overall, how useful was the support that you accessed while you were waiting for an assessment using a scale of 1-10, 1 being not useful at all to 10 meaning very useful?

Very useful

Slightly useful

Neither useful or unuseful

Not very useful

Very unuseful.

Please explain your answer

needs to be on a scale of 1 to 10 for each support received so that we know how useful each of these was.

Confusing list an scale?

As before 1-10 OR very satisfied etc - confusing with both

Need to rate each of the services identified in qu 14

? helpful

Is it useful without knowing what they did access??

Scale should be Very useful, useful, neither useful or unuseful, unuseful, very unuseful

16. While waiting for the appointment, where/who did your child receive support from:

(tick more than one box if relevant)

Me / my family

school

Nursery

From a charity

Other, please specify

MAST?

**0-5
SEND**

The website materials developed recently - could indicate how many parents are accessing these

SSENDIAS

**health
visiting**

GP? Peer support groups? Internet resources?

CAMHS?

The phone calls that are supposed to be happening to families on the waiting list

make sure we give free text to put in other support.

Need to ensure that we ask how families "felt" at this time and what would have helped eg. a phone call from SCH to say still on waiting list, might be 2 years, what can we do to help.

The assessment and outcome

17. What was your experience of the assessment appointment,

Before appointment in the waiting area

Very satisfied

Slightly satisfied

Neither satisfied or unsatisfied

Not very satisfied

Very unsatisfied.

During the appointment

Very satisfied

Slightly satisfied

Neither satisfied or unsatisfied

Not very satisfied

Very unsatisfied.

After the appointment eg, follow up communication and contact.

Very satisfied

Slightly satisfied

Neither satisfied or unsatisfied

Not very satisfied

Very unsatisfied.

Scale is Very satisfied, satisfied, neither satisfied or unsatisfied, unsatisfied, very unsatisfied

I wonder if it would help to separate out the appointment into 'during the assessment' and 'during the feedback'? Just a thought as these can be two quite different experiences

Might need to separate out interactions with parents and those with the child

Assessment process could be a whole survey in itself - might need to break down the different sections

agreed

Need to make sure that during the appointment, the interactions are good with both the child and the parents/carers and that feedback is asked on each aspect - some clinicians good with children, but not with the parents!

Follow up communication and contact is a big area too - could refer to the report but could refer to next appointment etc

Suggest an open comment box after to highlight any significant highs or lows of each if families wish to share these

After the appointment, need to make sure that letters and reports are quickly shared with the family as soon as possible and that they include reference to resources, help, support.

18. Was your child given a diagnosis?
Yes Please go to question 19
No Please go to question 20

were you satisfied with the outcome?

question 18 doesn't flow - if yes, what was the diagnosis

and add health visiting / school nursing

19. If your child was diagnosed with a condition, what support did you access? Please go to Question 21

Please choose all that apply

Accessed support offered by Hospital , (e.g. Ryegate parent workshops, ASD nurse)

Accessed course(s) run by Sheffield City Council

Accessed MAST

Follow up appointment – please specify who with

Additional support provided by nursery / school, e.g. via a MyPlan

Applied for an Education Health and Care plan

Other

Add in SALT here

And what specifically this support was

Do you need to ask how satisfied people were with the support received after diagnosis?

And which service provided the best/most useful support?

Could ask - did you agree with the diagnosis? And then what happened after. We have a number of parents who do not agree with the diagnosis and we struggle with how to support them

20. If your child was not given a diagnosis, did it make a difference to accessing help and support to you or child ?

No.

Yes, a little difference

A lot of difference

Not applicable

Please provide further information

Would it be useful to know if education applied for the EHCP or parents or another agency?

Would it be useful to know further down the line, if an EHCP was provided?

was the diagnosis delivered sensitively? and did they mention neurodiversity and the brain just being wired differently?

Consider re-ordering some of these questions towards the end...

21. If your child was not given a diagnosis, what happened next?

Wait and see approach – put on a review list at Sheffield Children’s Hospital

Returned to GP for further information

Returned to the service you were most in contact with prior to the appointment for assessment.

Contacted Sheffield Parent Carer Forum

Returned to School for further information

No further action taken

Other, please specify

Communicate better across council and Sheff children's on neuro offer eg. MAST, Schools, Comm Paeds to all link up

Suggest need to pilot questionnaire with people who haven't been through the whole process, some in the middle of it and some who've been through it

22. If you were in charge of the services you accessed, what one thing would you change to improve your experience of neurodevelopment services in the city?

For your child

For yourself

23. Which neurodevelopmental need does your child have?

Attention Deficit Hyperactivity Disorder (ADHD)

Communication, speech and language disorders

Autism Spectrum Disorder (ASD)

Intellectual disorders (Learning Disabilities and Delayed Language Disorder)disorder)see above – is DLD an intellectual impairment?

No diagnosis yet

Other, please specify

Timely communications from health services so keep informed of what's happening, where on list, etc. proactively manage

Question 23, put straight after question 18

How frequently were you contacted by letter, phone or email and was that enough?

No diagnosis yet is different to no diagnosis - sometimes there might not be a medical diagnosis

Qu 23 - put after qu18. Need to separate out - do we need to know what the diagnosis is straight after 18

Qu 24 logically should come after 11

If a neurodevelopmental condition was not diagnosed should you ask outright if an alternative diagnosis or explanation has been provided?

When were you told about what will happen next?

24. If you were not referred, please describe what happened next.

Free text.

question 24 needs to come after question 11

DLD would not be considered an intellectual impairment

When did someone sit down and talk you about the pathway

Placeholder - possible question 25 regarding support offered in school or education setting (eg. nursery, primary, secondary school) - discussion

**What has worked well/helped in school and what has not helped?
(Schools often do some of the right stuff but maybe not as consistently as needed?)**

Letters need to be much clearer from SCH re the neuro appointment. One family received a letter and it was not clear what it was for. It was for triage, not assessment, so very confusing when arrived to be told it wasn't an assessment.

Could ask about support at transition points

pilot it first with small group before going wider

Schools are often struggling to gain support from external agencies/resources/capacity-budget

One family had assessment for ADHD and consultant referred onto for ASD assessment. Not yet on waiting list as consultant hasn't transferred notes over (presumably not done the referral). Chasing every week 1 year down line.

MAKE SURE WE LINK QUESTIONS TOGETHER

on a myplan before moving to an EHCP? In Sheffield schools get same funding for a child on a myplan as an EHCP but a lot more paperwork and meetings for an EHCP. This means only children whose parent who shout the loudest get the EHCPs. This

Health visitors have a disability guide which includes info on resources for virtual world - education, carers, etc. live links to web pages, it's for professionals to pass onto families. We need to put this on the neuro web pages at SCH etc.

Are there any services which would have been helpful to you and your child, which you did not access?

MAKE SURE WE REMEMBER PARENTS' NEEDS TOO PARTICULARLY IF THEY HAVE A NEURODEVELOPMENTAL CONDITION.

parents can be unrealistic about what support schools can offer e.g. 1:1 support or can not realise some of the provision that is in place to support. Could offer a checklist? Which of these does your school offer to support your child?

? how good was communication between services

Why can't ASD be assessed at the same time as ADHD if the consultant is the same. Why not combine the two in one appointment?

going private for assessment, can you re-join the pathway and how does this affect the ECHP process - will the private consultation information be taken into account how do you share info between NHS and