



**Transforming Neurodevelopment
Services for children and young people
and their families in Sheffield
First Priority for Integrated Care in
Communities**

**BREAK OUT INFORMATION
Presentations and What
people said**



WORK STREAM 1

Right Identification at the Earliest Time





Right identification at the earliest time

- Identifying at the earliest time, a vulnerability or very early signs of a neurodevelopmental need.
- Ensuring that all staff are able to support children and young people and their families who come to them, how to support, how to signpost.
- Supporting Staff recognise that there may be a vulnerability or a really early need, and what to do next.
- This covers pre-birth to young people –
- Vulnerabilities
- To date, the Parent Carer Forum with Council and CCG have developed training for staff working in early years (project started before this programme) and Katie will describe this now.





Health Education England



CONNECT INFORM EMPOWER



Sheffield

Clinical Commissioning Group

Neurodiversity: Parent-led training for early years professionals to help identify, support and signpost families of young children with neurodisabilities in Sheffield



Background

- Joint project developed by Sheffield Parent Carer Forum in partnership with Sheffield City Council and Sheffield Clinical Commissioning Group
- Parent-led
- Commissioned by Health Education England
- Aim – to develop and deliver training for early years professionals to improve knowledge and understanding around neurodisability
- Content been co produced by parent carers and professionals from early years sectors.



How the content was informed and developed

- Two focus groups held with parents who had lived experience of accessing early years services
- Looked at what was working well, what wasn't working well and solutions to overcome the issues
- Co production session held to gain wider views of the parent feedback
- Three priorities for change were identified:
 - Lack of joined up working between services and professionals
 - Lack of information for parents and professionals
 - Poor communication
- Training developed and draft shared in second co production session.
- Final review and first training session held 2nd March 2021.



Training session

The training is split into 3 sections and delivered by parents, Local Authority trainers and Health Trainers:

- The first section – Help us help you – developing understanding and confidence in supporting families (delivered by parents with lived experience)
- The second section – Working together to support families: Local Authority support and services
- The third section – Referrals and The Ryegate Children’s Centre: best practice to support a diagnosis pathway

There will also be a resources pack available to all attendees which is currently being developed.



Initial feedback

- 3 sessions taken place in March
- Rating of 4.5 out of 5 for attendees that would recommend the training
- Average 45% increase in knowledge from attending the session
- Overall ratings of between 7.8 and 8.8 (out of 10) for how useful the content of each section is.

“I would recommend this training to all new EY staff and trainees because it really gave a whole picture, perspectives from the parents, local authorities and health services. As a result of this training I have learnt how to approach and build a relationship of trust with parents, what services are on offer for parents, and how to gather information for the health services and the different types of routes to making a referral.”



Next steps

- Internal evaluation to amend content from initial feedback
- Continue running sessions up to end June
- Full external evaluation of the project
- Develop resource pack
- Ensure sustainability ie online module



Wider issues raised to feed into the wider Neurodevelopment work

- Lack of clear referral pathway info (map / timeline) for professionals and parents
- No shared system to record information about children / families
- Need a universal document to record early intervention (before referral) – similar / appendix to red book?
- Suggestion of regular sharing sessions between services to share good practice and up-to-date info on current offer
- Need for prevention workers specifically for SEND
- Lack of info about families for professionals
- All communication needs to be jargon free and easy to understand



Questions for discussion

- Whether you are a parent or a professional, how supported do/did you feel when a need or vulnerability was first identified in a child or young person?
- What would help you feel more confident or supported in managing those needs or challenges?



Discussion Notes

Whether you are a parent or a professional, how supported do/did you feel when a need or vulnerability was first identified in a child or young person?

Other workstreams

paperwork goes missing between ADHD/ASD

lost information -

Does feel that diagnosis is the door to access

Ryegate was the key

It did give me access

couldn't access parenting classes as during work time

Got help from Cerebra. Had early years information and access to information and support.

Early identification

don't know where to go to for help and support

what to do even before referral.

Who to go through first -

If professional could have come forward and help you about how to start the process

need to understand what's going on, to prepare. getting whatsapp groups with other parents, need hand holding.

Need to support parents right at the beginning. As there may be some signs. look at prevention.

GP referral and general referral

GP - signposting, not much time to do more

Push to get GP referral. Doing PPP course now. Support

It wouldn't have mattered what GP says

slow start to get diagnosis as moves around. When started to ask - hoops had to be jumped, needed GP and school backing. Go through MAST worker.

Not all GPs are familiar with the female signs of autism. GP didn't refer daughter as he said she had eye contact.

There's not enough information to help staff have honest conversations with families and then supporting them to that diagnosis.

siblings already diagnosed

Referred by speech therapist, parent knew as older brother, so younger son was picked up early enough

When early signs showed in younger brother had experience to push referral

Education and Transition

nursery didn't want to do the referral - we identified it early, did the my plan, private nursery said too early to look at referral

complex needs - at primary school but need to start identification in nursery.

didn't really think to look out for signs as early as nursery, but saw needs in primary school.

diagnosis came in secondary care after early identification in primary school at 5.

primary school is a nurturing environment but needs gets worse in transition to secondary as it is a different environment

Can schools share the referral

Behaviours and Expectations

health visitors and early years are keen to make sure we have 2 year check, but needs to be a better process. Can say anything in the health check.

there's an expectation that parents can manage it and actually they might not.

need honest and open conversations between schools and parents.

Frontline staff in other settings

SLT in the social care team - so can do some identification

youth justice - can do screening then refer to CAMHS officer. It feels like the referral gives the parents a gold bar when get that offer

What should be in place for children in the care system - what's the role of social workers,



Workstream 2 – Right Support, Right Time.

Transforming Neurodevelopment Services
First Priority for Integrated Care in Communities.



Workstream 2 Right Support, Right Time.

- Ensure parents have access to support advice with or without a diagnosis.
- Ensure all support and advice is consistent and accessible to parents.
- Improve communication between Rygate and SCC/Schools
- Develop information sharing protocols and practice between Rygate and SCC/Schools



Activity to date

Process in place between SCC and SCFT for all new additions to the ASD waiting list to ensure they have access to resources.

SCC staff contacted families on the Ryegate autism waiting list to offer help and support whilst they wait for assessment

SCC produced information on all resources and services available to families across the City.

Ongoing work to ensure SCC and Local NHS websites are consistent and up to date with ASD information for parents.

Using the feedback from Parent experiences and key themes to explore the gaps in information and advice offer and develop new activity to address the gaps.

Development of new information sharing protocols.

Improve the information flows and communication between SCC/schools and Ryegate



Key Themes

- Sleep
- Behaviour management
- Violence/vocal outbursts towards parent or sibling
- Emotional regulation, anxiety
- Some eating/food related issues.
- Sensory Issues – including food and toileting issues.



Our Offer



Discussion

- **In your experience are the key themes the issues you would expect to hear ?**
- **How do we ensure we support harder to reach groups with the above issues ?**
- **In your opinion what gaps exist in support information and advice to parents of children with ASD?**



Discussion Notes

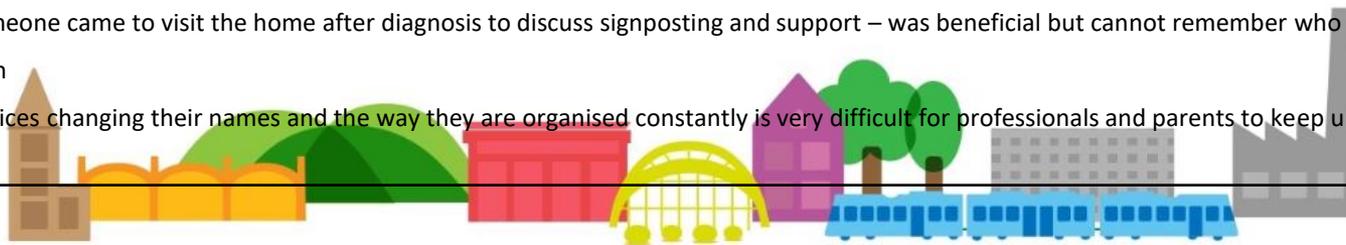
In your experience, are the key themes the issues you would expect to hear?

- The impact on parental mental health and ability to cope with life
- Impact on wider family including siblings.
- Self-awareness from the individual perspective not just emotional regulation. What it means from a young age
- During my PhD research I've met many parents with MH issues who are expected to arrange for their own paid carer alongside carers for their Autistic children. Tanya's `self-awareness concept is spot on.
- As there is no sticker to tell us that there are ongoing parental mental health concerns and understanding the sensitivity around this as well as the human nature of putting up a brave face we need information sharing and also how to help parents get appropriate help. Transference of anxiety, family stress etc are also key
- As a professional, some of the parents I meet feel frustrated about the speed of access to information or contact
- Sometimes I feel that schools work well with SALT to get a referral to Ryegate for ASD - and then there isn't a continued dialogue between Ryegate, SALT and schools - we don't get the opportunities to speak / communicate with anyone from Ryegate, so it's hard to be on the same page and to show a joined up approach for parents
- joining together pathway in the community care teams



How do we ensure we support harder to reach groups with the above issues?

- is there support in other languages? – Yes, it is, delivery can be in other languages/Online can be interpreted. Empowering parents empowering communities
- Locality B worker. A level of trust. Develop EPEC within communities
- Support in accessing clinics, a familiar person, could facilitate people within schools such as TA's. A drop in approach possibly?
- regarding hard to engage families I think there needs to be more recognition of supporting parents to engage with what is out there such as the workshops such EPEC workshops, as often people need a lot of support to attend appointments and improve their confidence in engaging with school\nursery and gain further knowledge about how to practically make use of support is out there.
- if school referrals did not take place due to Covid and the young person has left schools should the referral still take place at college? POST 16
- Are there opportunities for families not as confident in their English to take part in discussions such as this i.e. with interpreter support?
- I also think parents might need more information about what to expect from workshops, appointments etc - given that there are lot of parents who are autistic/neurodivergent themselves.
- The info from Ryegate is currently not translatable. No budget for getting things translated.
- EPEC groups led by community
- There are so many resources on the internet but so many people do not have any access to them because they don't have internet access due to costs
- Seldom heard (rather than hard to reach)
- Community champion: do they have to be social care or health professionals? Core community should take lead e.g. church/library/village groups.
- Needs to be looked at holistically.
- Social work England work with students in an attempt for normalising impairment and social modelling.
- Someone came to visit the home after diagnosis to discuss signposting and support – was beneficial but cannot remember who this may have been
- Services changing their names and the way they are organised constantly is very difficult for professionals and parents to keep up with



In your opinion what gaps exist in support information and advice to parents of children with ASD?

- Missing social interaction experiences. Friendships are becoming more important and are becoming increasingly difficult.
- Feel listened to when issues arise but then a misunderstood social situation leads to problematic behaviour. Those social issues and nuances which led to the event are easily dismissed by people like lunch supervisors.
- The problem with accessing these is sometimes for working parents they cannot attend during the day... is this something that will be engaged?
- Access to proper multiagency working - lack of ability currently for health to be actively involved in providing input to schools - even to attend multiagency meeting/real lack of understanding within schools still about neurodiversity
- Information provision should emphasise puberty and Social support in situations
- People need to use the same language, professionals/parents
- There is a gap between EY and parenting program relating to teens but nothing for pre-teen. Can be difficult if children don't fit in to those age brackets.
- Social overload – looking at why the behaviour is occurring and looking at root causes and what support can be given to school and parents to de-escalate
- I feel there is a gap after receiving the diagnosis and there is a huge impact on siblings and there is not enough support for the child and wider family.
- Need something which is simple to access but not time consuming when trying to juggle general family life plus autism/ADHD
- Need more information as to the basic information/advice/support forum/helpline
- Yes agree with the issues, would also add around anxiety - anxiety specifically about transitioning (year on year or school to school)
- People expect you to ask for services but we don't know what we are entitled to/signposting



WORK STREAM 3

Integrated Care in Communities



Break out questions for discussion:

- What are your thoughts about providing more services in school?
- What do you think about services sharing information about your child?

All the discussion notes can be found on:

https://jamboard.google.com/d/1ZinNawhL2qRW8likBTpoqXW4Z1sOI12CZsVSj_9LWYk/viewer?f=2



Summary of comments from workshop 23 March Workstream 3

Delivery of services into schools

Would help with anxiety as familiar surroundings and setting

Need to take into account different rules for Academy schools

Use of sensory rooms in schools for appointments would be brilliant

Give parents the option of Ryegate or community appointments.

Inequity of facilities in schools - must be consistent offer.

Co-location with schools with different services would work really well.

Prefer being seen in a GP surgery than a school.

No to delivery of appointments in secondary schools, due to stigma attached and sensitivity of teenagers to being different and being pulled out of class. Risk of disengagement.

Information sharing

Needs to be across all professions.

Need to be aware of sharing information when English is not the first language of the family as they might not understand the reasons etc.

Sharing info prevents children from being labelled as mad or bad.

Caution needs to be given to sharing information about a child that includes reference to parent's health, conditions. Some were keen to only share the child's health issues.

Information good for school ready purposes - sharing with schools what issues a child might have during the transition into school.

Could have a "passport"/personal profile

Have an opt out consent process for sharing information when a child starts school and that stays with them throughout their time at the school.

WORK STREAM 4

Improving Assessment Pathways for ASD



Recent Changes

- **Resources** on our website to better support children and families, before and after assessment
- Changes to **letters** to parents to link to resources and introduce contact from Council Key Workers
- Clear route to assesses and record **escalations** raised by parents, GP's and key workers
- Changes to information collected in **referrals** to improve ensuring children get the right assessment as soon as possible



Ideas we're interested in developing

- Sending a **letter to schools/nursery** at referral acceptance to outline helpful interventions that can be acted upon straight away
- Opening up the ability to refer for **SENCO's** who have engaged with training
- **Improving the environment** in which Assessments are undertaken – Artwork? Positive messages? Where?



What do you think?

- Sending a **letter to schools/nursery** at referral acceptance to outline helpful interventions that can be acted upon straight away

- Opening up the ability to refer for **SENCO's** who have engaged with training

- **Improving the environment** in which Assessments are undertaken – Artwork? Positive messages? Where?

Please click on the attached for all the raw information.



Key Messages from Discussion

Sending letters to Schools at referral acceptance

- Generally very positively received – more support at schools and earlier welcomed – helpful for parents who end up being ‘go-between’ – small thing that would make a big difference
- Need to **work out what letters should recommend** – will SENCos have knowledge to know what to do with recommendations if general? Would it be specific enough?
- If SENCo is involved in referral this would help cohesion of intervention
- What happens if a family don’t want this?
- **Parents must also have copy** of this information
- Also **provide schools with where else they can go for support** and perhaps a helpline – some schools know this and others appear not to have connections e.g. MAST, School Autism Team etc.
- This should also include access to training and encouraging for all staff to understand how to support not just SENCo
- Manage expectations – this is not diagnosis but supporting need, helpful regardless of future outcome

Opening up referrals for SENCos

- Generally **very positive** – they know child well/rounded referrals – leading to better support
- Concern over **SENCos capacity and varying capability** meaning inequity in system
- Would there be any information required from **GPs** – history/birth/weight?
- Mustn’t disadvantage **children masking in school** but struggling at home – unconscious bias
- But only in conversation with and at **request of parents**
- **Training essential** – breadth of content important
- How do we ensure other Neurodevelopmental needs are not missed?

How can we improve the assessment environment?

- Idea of mobile assessors – **closer to home/school/children centres**– driver is children and parents feeling safer/less uncomfortable/stressed etc and kids behave differently in strange environments –
- Concern over how to resource this model?
- Hospital infers sickness
- Or observations in school/home and then assessment at ‘Service’
- **Virtual assessments** for some – or part of the assessment like parent history
- **Better preparation for appointments** e.g. video of the environment, visuals of who they will meet, the rooms, what happens etc
- **Ryegate environment feedback** - too small, not accessible and although toys available feels clinical. Harsh lighting, sound proofing removed and sensory overload with SLT with child and Dr with parents
- How do we build in **patient choice** – some people like hospital sites and others find it challenging
- Also consider out of ‘main’ hours assessments – after school/wkd helpful for parents too
- Impact of PPE significant – concerns of inaccurate assessment

