NHS
East Riding of Yorkshire
Clinical Commissioning Group

NHS
Hull
Clinical Commissioning Group

Children's Neurodiversity Services Report

Let's Talk …
Children's Neuro Stuff

A collaborative review of services for children and young people with Neurodiverse, Neurodisability and Neurodevelopmental conditions in Hull and East Riding of Yorkshire

Report following Stakeholder Engagement Event,
Let's Talk … Children's Neuro Stuff, held on 28 March 2019.

Document Management

Document	Children's Neurodiversity Services Report	
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Contents

1. Purpose

This report summarises the outputs of a system-wide stakeholder engagement event, Let's Talk … Children's Neuro Stuff, held in Hull on 28 March 2019. In doing so, it highlights the opportunities put forward by a wide range of interested parties and the benefits that can be achieved by progressing a collaborative place-based approach to the planning, design and delivery of services for children and young people with neurodiverse (neurodisability / neurodevelopment) conditions in Hull and East Riding of Yorkshire.

2. Introduction

2.1 From September 2018, the proposal to progress a system-wide review of services for children with neurodiverse (neurodisability/neurodevelopment) conditions has taken shape across Hull and East Riding. Facilitated by NHS England and reporting into the Hull and East Riding Children's Integrated Care Partnership (CICP), progress culminated in a place-based engagement event – Let's Talk …Children's Neuro Stuff.

2.2 This event, held in the centre of Hull on 28 March 2019, was designed to help clarify the scope of a collaborative review of children's neurodiverse (neurodisability and neurodevelopment) services across Hull and East Riding.

3. Scope and Definitions

3.1 The scope of this project includes neurodisability and neurodevelopment conditions, also known as neurodiversity. There are various iterations of the definition of these conditions that reflect the potential scope of the project and related conditions (Appendix A). For simplicity and inclusion of all conditions the project group named the workshop 'Children's Neuro Stuff'.

3.2 The NHS National Institute for Health Research (2014, page 11) reports:

> '*Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion and behaviour'.*

3.3 NHS England (2013) neurodisability service specification notes:

> *'Neurodisability is an umbrella term for conditions associated with impairment involving the nervous system and includes conditions such as cerebral palsy, autism and epilepsy; it is not uncommon for such conditions to co-occur. Children with a neurodisability have a range of impairments but many have complex and continuing need and as a result are frequent users of the health service at all levels, community, primary care inpatient and outpatient settings.*

3.4 Neurodevelopment disorders are a group of disorders in which the development of the central nervous system is disturbed. This can include development brain dysfunction, which can manifest as neuropsychiatric problems or impaired motor function, learning, language or non-verbal communication. This group of conditions (which includes autism, intellectual and development conditions) is of particular importance because the children and young people affected frequently have other conditions and complex medical and support needs (NHSE 2013).

3.5 Children and young children with neurodevelopment disorders are sometimes referred to as neurodisabilities. The term neurodevelopment disorders are used to describe similar conditions to those of neurodisability in children. NHS NIHR (2014) found a definition of neurodevelopment disorders as 'disorders where motor, cognitive, behavioural, and/or language functioning are affected by central nervous system impairments, resulting in a variety of challenges associated with ambulation, information processing, self-regulation and communication'. According to this research, no definition is widely agreed on.

3.6 Neurodiversity refers to the different ways the brain can work and interpret information. It highlights that people naturally think about things differently. We have different interests and motivations, and are naturally better at some things and poorer at others. Most people are neurotypical, meaning that the brain functions and processes information in the way society expects (Acas 2018).

3.7 A wide range of impairments and conditions is associated with child disability, with neurodevelopment conditions forming the largest group. Unlike the USA, the UK does not have a single survey or administrative source that can provide data on the number of children and young children with specific neurodevelopment impairments/conditions across the 0–18 age range. The estimated prevalence of neurodevelopment disorders in England is around 3–4% of children. ADHD, impairments affecting speech, language and communication, and specific and moderate learning difficulties are the most commonly reported primary disorders or diagnoses (NHS NIHR 2014).

3.8 The stakeholder pre-workshop survey identified a range of conditions within scope and recorded 38 such conditions, some of which are specific such as Downs Syndrome and others that relate to a broader spectrum such as autism, learning disabilities and difficulties, headaches (Appendix A).

3.9 Although neurodisability and neurodevelopment issues are clinically different, in the first instance children and families living with neurodisability and neurodevelopment issues will be treated the same i.e. they will access the service through one front door with one initial assessment, until their issues are identified. In addition, it has been identified that the new service needs to be needs-led and not diagnosis-led. For these reasons and ease of reading, this document will refer to neurodiversity as a collective term.

4. Background

4.1 Hull and East Riding Clinical Commissioning Group's (CCG's) were notified by the providers of community paediatric medical service (City Health Care Partnership (CHCP)) and acute paediatric medical services (Hull University Teaching Hospitals

NHS Trust (HUTHT)) of challenges within both services related to demand, capacity and workforce related issues. In response to this, an initial workshop was held in September 2018 that included both providers and commissioning leads from Hull and East Riding CCG's. This workshop identified a range of service related actions including a review of clinical pathways and potential for integrated working across the consultant teams.

4.2 In addition, the workshop identified the need to undertake a wider review that included related services, within a system-wide approach. This review would include service users, their parents/carers and the wider group of stakeholders who provide services to children and young people with neurodiverse conditions.

4.3 The imperative to undertake a collaborative place-based approach to the review, acknowledging that many of the challenges of delivering better services for children and their parents/carers could not be done by any one part of the system in isolation was informed by several issues including:-

- increased demand for children's services related to Autism, ADHD, Speech and Language Therapy and CAMHS
- NHS Hull CCG plans to pilot a Specialist Sensory Processing Assessment and Support Service; and
- plans for the transfer of Community Paediatric Medical Service from CHCP to HUTHT by April 2019

4.4 The shadow Hull and East Riding Children's Integrated Care Partnership (CICP) was formed in October 2018 and approved this review as a key priority within its system-wide programme. The Partnership has a formal Transformation Board from April 2019 which will oversee the review.

4.5 The stakeholder project team was supported by NHSE Virtual Academy of Large Scale Change in the planning and delivery of the review and engagement event.

4.6 Since the summer of 2018, around 55 children's services (not including schools or adult services) have been identified as key stakeholders within this review, many of whom have either been contacted directly or received communications about the proposed review.

4.7 Meetings have taken place to talk about the review with parents, clinical and non-clinical staff from a wide range of partner organisations and over 20 stakeholders have been engaged in face-to-face discussions to help shape the proposed review and the content of a wider engagement event.

4.8 The project group developed an on-line survey for completion by young people, parents/carers and those people and professionals working to support children and young people with neurodiverse conditions. This was widely distributed across the partnership and by the Hull and East Riding Parent Carer Forum's.

4.9 There were 104 responses to the survey by the time of the engagement event, with approximately half of the responses from parents/carers and half from professionals. The findings of this survey were used in the event providing additional evidence of the current issues and indicating what would make the most difference within a system-wide review to help shape the future of children's services (Appendix B)

5. Let’s Talk... Children’s Neuro Stuff Event

5.1 Over 100 people were invited to the engagement event, Let’s Talk … Children’s Neuro Stuff. Of the 75 registrants, 63 people attended on the day and contributed to group discussions to agree a shared vision and key themes.

5.2 Stakeholders attended from across Hull and East Riding and from a variety of organisations and backgrounds; Acute and Community Trusts, Hull City Council and schools, Third Sector, Clinical Commissioning Groups, GP’s and included both clinical and non-clinical staff. More than 15 parents/carers attended the event.

5.3 The event was designed to deliver a mix of keynote presentations and group work and system leader opinion and to ensure that the voice of children, young people and their parents/carers was central throughout.

5.4 A range of young people, parents and professionals from a range of services and organisations also contributed to the event, telling their story and aspirations for a future service through video blogs.

5.5 To provide a sense of ‘what else is out there’ examples of great practice was shared by a short video from the Great Ormond Street Development Communication Team and a keynote presentation from St Helens Neurodevelopment Pathway. This helped people to see the sorts of things that are possible.

5.6 Through the video’s, young people and parents video told personal stories about their experiences within a range of healthcare environments – revealing how they felt, the impact upon themselves and their families, what went well and what could have been better, and many more parents contributed to group discussions throughout the day, making true co-production a reality. The involvement of parents was extremely well received in the event evaluation.

6. Context for Engagement

6.1 A series of presentations by keynote speakers set the scene and provided context for the group discussions that followed, highlighting some of the challenges within the system in terms of equity of access, service coverage, performance, workforce, the roles of different providers across the ‘patient pathway’ (child and family’s journey), financial sustainability and the value of coproduction.

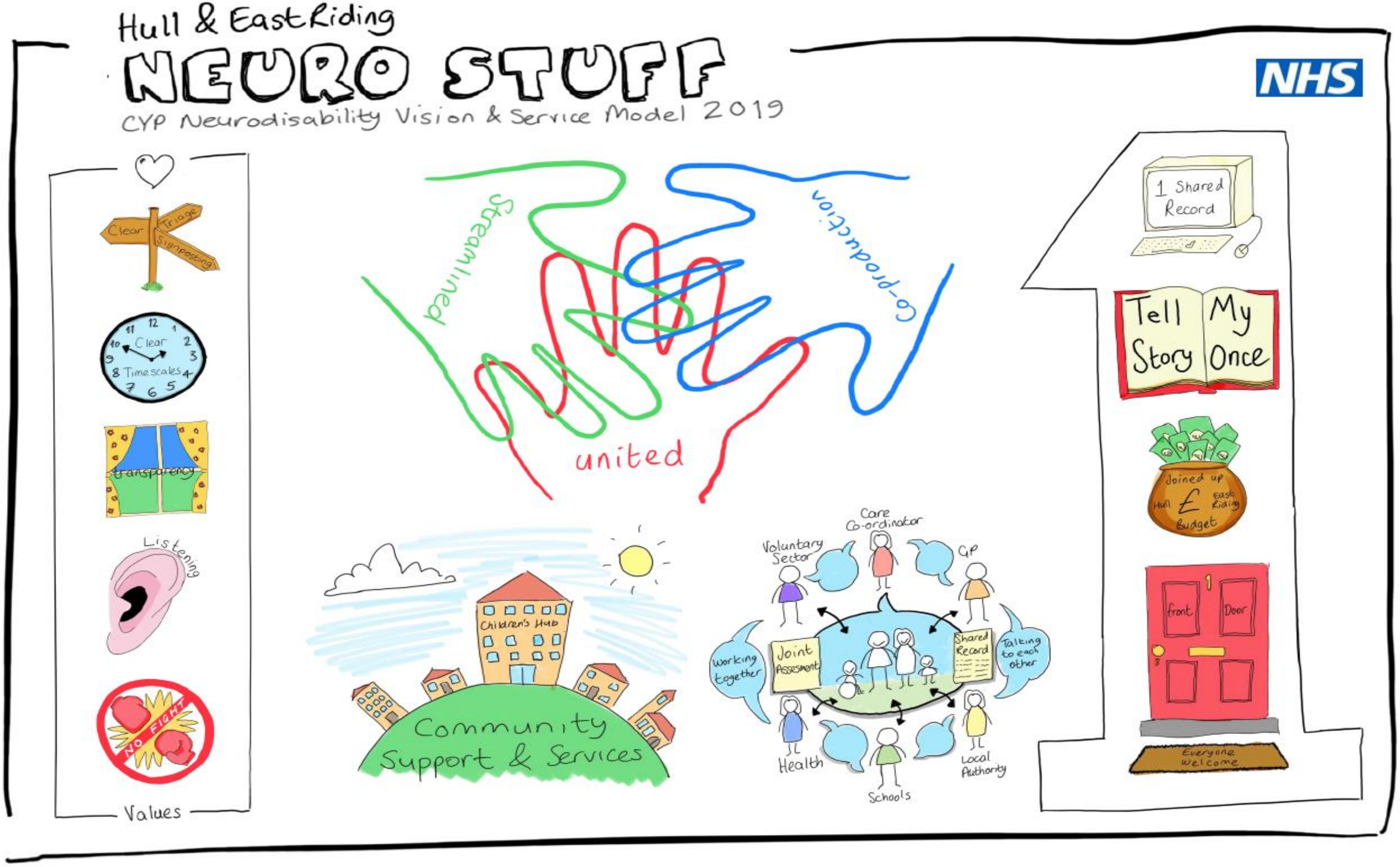
6.2 Early in the event, a range of system leaders took the opportunity to inspire and encourage a different way of thinking and collaboration prior to the commencement of group work.

7. Developing a Shared Vision

7.1 The first facilitated group task provided an opportunity for delegates to draw out their long term vision for the provision of services for children and young people with neurodiverse conditions across Hull and East Riding region and from these discussions, several common themes emerged (Appendix C).

7.2 Eight groups were asked to work independently to discuss, share and document their aspirations for a fundamentally better future. The posters they created have been collated into One Future Vision – see figure 1 below.

Figure 1. Our Future Vision and Service Model



7.3 The eight sets of ideas, drawing together all the key themes that emerged formed the narrative of a shared vision for the future (April 2021); as follows:-

Our Shared Vision. By April 2021

- ***There will be a coproduced, integrated children and young people's neurodiversity service across Hull and East Riding in place.***
- ***Parents/carers and professionals will access this service through a single 'front door' where they will receive, regardless of diagnosis, the right needs-led services and support, at the right time, in the right place and delivered by a competent, highly skilled knowledgeable workforce.***
- ***Parents/carers and young people will tell their story once, providing additional information through their journey as necessary.***
- ***Children, young people and their parents will feel listened to, heard and supported by the people and staff working to provide this service.***
- ***The child/ young person's journey including joint assessment, joint care-planning, delivery of services and support will be co-produced with the child and his/her parents/carers.***
- ***When intervention is required, children and young people will have easy and quick access to the most efficient and effective pathways, delivering the best outcome and service user and staff experience possible.***

8. Collaborative Working

8.1 The event identified collaborative working as the foundation and key principles in realising the shared vision. Members described the current system as 'hard to navigate' for those in the system never mind those needing to use it, fragmented, full of silos and barriers, lacking in clear and timely communication between those in the system, duplicative with long waiting times for some services.

8.2 Previous and current attempts to work in an integrated manner have not achieved the desired outcomes and it was acknowledged that the current system appears to work against such efforts. Workshop members agreed that true collaboration meant something fundamentally different to their experience to date.

8.3 Event members talked of the wider systems collective knowledge, skills and resources coming together with children, young people and their families, both in design and delivery to truly do what is best for everyone across Hull and East Riding. Whilst people recognised different skills being required at different parts of the system for different purposes, they envisaged all of that functioning as part of one team, in harmony and in partnership with the child/young person and family.

8.4 Being part of one team, across all disciplines and sectors, meant that every person and each role was important if the whole team was to succeed. People did talk of structure, but not in an organisational or geographical sense – instead they talked about a co-ordinated service operating without boundaries, where information and resource could be shared and flexed freely to meet changing demands.

8.5 There was much required to enable such a collaborative system to function well. If one could really foster the desire to truly collaborate, then much of the difficulty and complication of that could be much more easily overcome; barriers were only insurmountable if you considered, or desired, them to be such. Functions such as information and IT, workforce and training, communication and engagement, financial flows, standardised ways of working. This would require a big shift in thinking, and all of that is possible if we had the collective will to truly collaborate.

9. Key Themes

9.1 The common themes that emerged from the shared vision were reviewed and collated and used as the basis for the second facilitated group task which saw the gathered audience invited to go to the theme that most energised them and develop their ideas in relation to each.

9.2 The top 7 themes were as follows:

- Partnerships and relationships
- Single point of access, triage and care coordination
- Pathways and MDT
- People and skills
- Early intervention and transition
- Support
- Communication and information sharing

9.3 The detail from these group discussions has been reviewed and summarised in Appendix D. What was particularly interesting in the plenary that followed was the presence of a common thread across all 6 groups, giving rise to a set of big ideas or core principles that all participants and system leaders were keen to hold central to this review (Appendices E, F, G)

10. Big Ideas from a Mandate to Think Differently

10.1 Having been given ‘permission to think differently’ by system leaders early in the event, it was perhaps unsurprising that subsequent discussions gave rise to some big ideas or core principles to challenge existing thinking and arrangements within the system going forward.

10.2 Specifically, there was a wide consensus of the need to:

- Drive collaboration across the system
- Recognise children, young people and their parents and carers as partners in design and delivery
- Pursue efficiency and excellence across pathways
- Develop a system wide workforce
- Develop an integrated service delivery model.

11. Event Evaluation and Feedback

11.1 The feedback from attendees of the event was very positive with many applauding the integral involvement of parents and carers throughout the day – both in telling their stories and in contributing to group discussions to shape the review. The full event evaluation is summarised in Appendices G and H.

11.2 The majority of delegates who completed an evaluation expressed confidence that they had opportunities to give their views and experiences, that they felt listened to and that these will be used to make changes for the better following the event.

11.3 The next steps to maintain momentum are pivotal to future engagement and to delivering the shared vision and commitments of system leaders towards collaborative change expressed at the beginning and end of the event.

11.4 Rather encouragingly, following the event, many delegates including parents and carers offered their continuing support in shaping and contributing to the design and development of system wide improvements in children's neurodiversity services going forward.

12. Summary – Realising the Vision

12.1 Much has been achieved in a short space of time to raise the profile of children's neurodiversity services as a system-wide issue and to capture system-wide commitment to developing a fundamentally better future.

12.2 The NHS long term plan (2019) highlights transformation programmes aimed specifically for maternity and children's mental health as a priority for action nationally. The Plan focusses on:

- The value of prevention and self-management;
- The importance of primary and community services in early diagnosis and managing patients at home rather than in hospital where appropriate;
- The role of digital technology in reducing delays and improving the quality of referrals and face to face patient consultations;
- The benefits to be realised from better communications and information flows, reducing duplication and waste.

It also promotes the need for closer integration and place-based planning and delivery of services, removing the unhelpful barriers to commissioning whole pathways and reducing the competitive nature of service provision.

12.3 Given this focus, the evolving Hull and East Riding Children's Integrated Care Partnership (CICP), is perfectly placed to drive and support the transformational change required to deliver the shared future that has been developed conceptually by system partners.

12.4 Having successfully engaged and energised a vast array of people – parents and carers, clinical and non-clinical staff, local and third sector partners – in establishing a shared vision and key themes for development, it is now vital to keep up the momentum and gain rapid agreement on next steps to clarify local priorities and resources to take this work forward over the next 2 years.

12.5 The shared vision is clear: the commitment and energy from those who can make it happen is clear: system leaders have spoken as one and all are supportive of a fundamentally better future – we now need to make it a reality.

13 Actions and Recommendations

13.1 The Children's Neurodiversity Delivery Group have reviewed the work to date and through a model of true coproduction, agreed the following actions that will form the basis for a robust project plan:

a) Review and agree the scope of neurodiverse conditions that will be included in the development of a system-wide service delivery model. Conditions may be prioritised and included within the service through a phased approach. This will be supported by the development of a data repository that will inform decision-making and track performance and outcomes.

b) Develop and deliver a virtual needs-led service model and specification that includes a single point of access with support for children and their families from the point of access through a named lead worker and care co-ordination. This model will identify and work with interdependent services.

c) As part of b), develop:

    - a series of clinical care pathways related to the identified conditions from early identification through to diagnosis and post diagnosis services and support

    - an integrated multi-disciplinary team responsible for robust clinical triage and care co-ordination from the point of referral throughout the child and family's journey

    - systems, tools and documentation including a universal consent form, referral form and single care record that will be shared appropriately with the child/parents and those working to deliver care and support

    - a range of child and family support services that will be accessed through the single point of access that provide training, education and information for children, young people and their families that will support timely and appropriate access for clinical triage and onward services and support.

d) Develop a range of up-to-date resources and tools for children and their parents and the workforce alike. These will be accessible in a range of formats and delivered through a range of methods including digital and web-based platforms.

e) Develop and support a sustainable, innovative and responsive integrated workforce

13.1 In order to take these actions forward and plan how the shared vision for a fundamentally better future can be delivered, the following recommendations have been made:

a) To be successful the Children's Neurodiversity Delivery Group is given a remit by the CICP to move forward at pace, clarifying a programme of work that encompasses a focus on system-wide service transformation and excellent pathways in the spirit of true collaboration. Not a Delivery Group that is hampered by what exists in the present or by restrictive governance arrangements but a Group that is focussed on the future, fluid and free to work innovatively to deliver the best outcomes for children, young people and staff across the system: free to design solutions that work for all, using all available resources to deliver the better future that is described within the shared vision and narrative, linking with established networks and system workstreams to enable and drive change at pace and with the full agreement of those who will be affected most.

b) Secure a resourced Children's Neurodiversity Delivery Group with a system-wide remit to advance the programme of work, mapped against identified workstreams to enable innovation and change at pace. This will include a programme and project approach to lead the delivery of the project plan within agreed timescales.

c) Agree the terms of reference for the Children's Neurodiversity Delivery Group that will support a very different place-based approach to planning, design and delivery with children and their families at the heart of the process with a set of clear outcomes, and setting aside current commissioning and provider loyalties.

d) System wide agreement and sign up to all of the above by July 2019.

14 Next Steps

14.1 In synthesising the vision and key themes with the 'big ideas' (or core principles of design) generated by stakeholders before and during the Let's Talk… Children's Neuro Stuff event in March, recommendations for taking forward the review has been developed for consideration.

14.2 The next step is to deliver these recommendations to the Hull and East Riding Children's Integrated Care Partnership (CICP) for approval and for the Children's Neurodiversity Delivery Group to lead and deliver the shared vision for the benefit of children, young people with neurodisabilities and/or neurodevelopment conditions, their parents/carers and families and those who work to support them.

14.3 The timeframe for this approval is July 2019.

Appendix A

Scope of Neurodiverse (including Neurodisability and Neurodevelopment) Conditions *

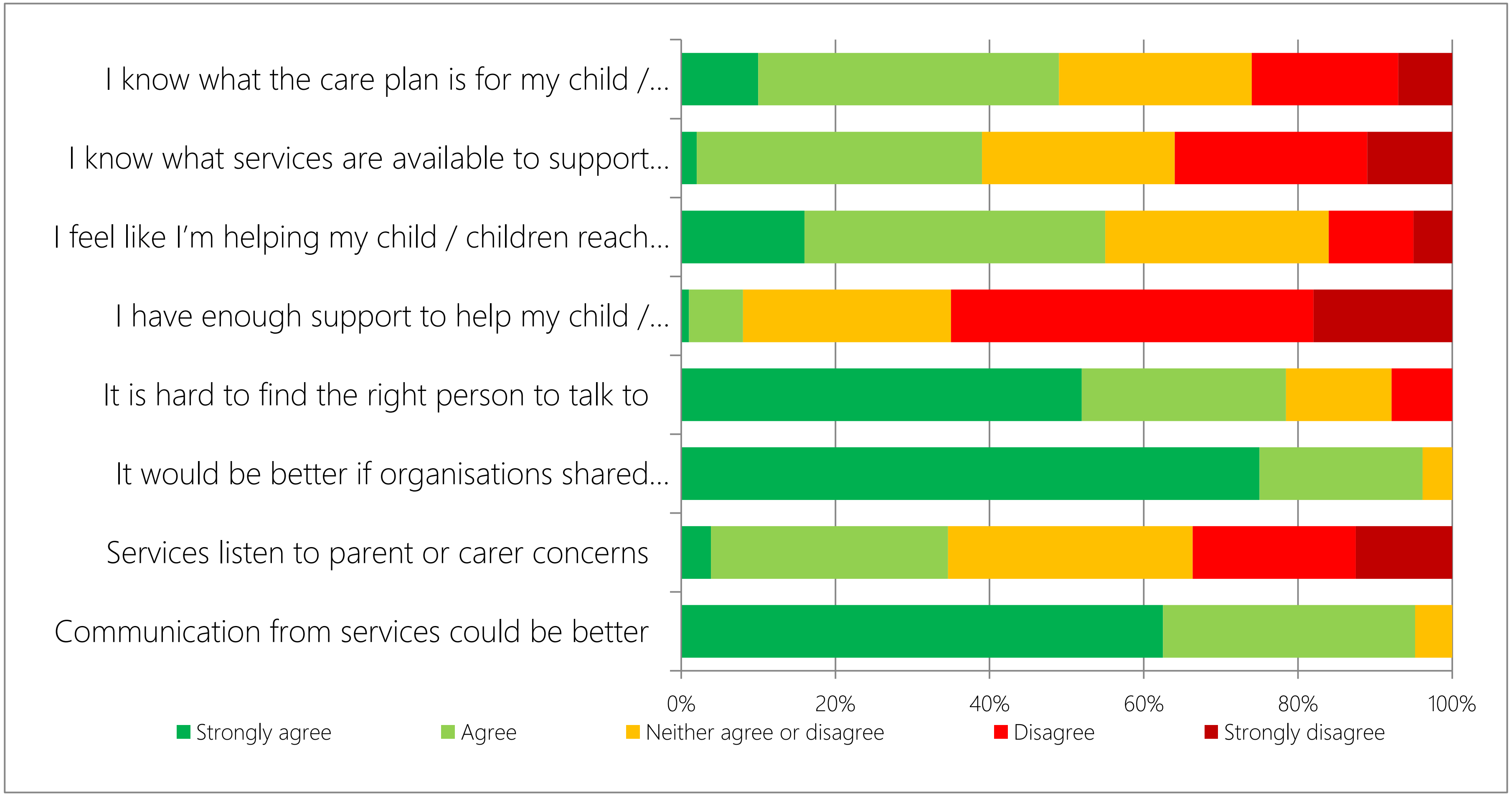
ADHD
Angel Man Syndrome
Anxiety
Acquired Brain Injury
ASD
Asperger’s
Autism
Birth Related Injury
Cerebral Palsy
Complex Disability
Congenital abnormalities
Depression
Development Disorders
Down's Syndrome
Dyslexia
Dyspraxia

Epilepsy
Executive Functional Issues
Foetal Alcohol Syndrome
Genetic Conditions
Genetic diseases
Global development delay
Headache
Learning Difficulties
Learning Disabilities
Muscular Dystrophy
Muscular Sclerosis
OCD

Pathological Demand Avoidance
Prader–Willi Syndrome
Sensory Processing
Sleep Conditions
Sleep problems
SMA
Spina Bifida
Spinal Atrophy
Sterg Webber Syndrome
Tourette’s and Ticks

* Not an exhaustive list

Survey Overview: What is it like now?



Appendix C

What is our future vision? Key Themes (AM Session)

Co-production	Collaboration, Joined up services, Partnership
Visionary	Streamlined, Trust, Shared vision and commitment, Better understood, listened and respected, Child and family focussed that supports the vision, Transparency, Confidence
Stakeholders	CYP, Parents and Carers, Health, Education, Social Care, Voluntary, Short Breaks,
Hull and East Riding	Service's money, Pathways, Equality, Joint commissioning, Health, LA and Education, Integrated commissioning
Service modelling	Family focus, 0-25, Child and family at the centre, 18 weeks referral to treatment, Personalisation, Needs led, Include CAMHS, Support without diagnosis, Integrated service, Links with specialist services e.g. Sheffield/ Leeds
Single point of access	One Referral Form, All under one roof, Hub and spoke model, Criteria – needs led, rather than by diagnosis, One door (with a listening ear), Support at the front door, Open consensus, One place, Single referral (e-form)
Triage	Clinical expertise present, Admin triage, Co-ordination, Multi-disciplinary triage, MDT Panel
Support	Support for parents, Support and help for families, Advocate, Support at the front door, Charity sector liaison, Accessibility via the telephone, Community resource services, Comprehensive early intervention offer, Closer links with schools
Care Co-ordination	Lead worker/ key worker, Navigator, Lead professional, Parental support, Advocacy, Care co-ordinator
Pathways & Assessment	Clinical Pathways, 18 weeks RTT timescales, Joint assessment, Shared Assessment, Holistic Assessment, Holistic support and approach
Transition	Co-ordinated transition,0-25 service provision
Single Record	Plain English, Shared information, Personal passport

Workforce	Supply and demand, Knowledge of services, Competent and confident, Innovative recruitment and retention, Excellence, No blame culture, Going for gold, Training for all staff
Information/ resources	Parents involved in developing letters and documents, Websites, leaflets and vlogs, Open access to information, Apps
IMT	One electronic system, Recording, Open consent, Telling the story once, NHS Number as identifier, Use of apps for accessing information, Shared care record
Hub	Friendly, accessible, calm environment, Evidence of people thinking about the place it would be delivered e.g. community hub, Referrals can be made by anyone, Signposting, Triage
Local offer	Available services listed, Understanding of interdependent services, Signposting, Self-help resources
How?	Project Delivery Group, Key members, Governance, Workstreams, Timescales, Communication plan, Parent, child and young people,Co-production, Review of the paperwork, Funding, Oversight Group

Appendix D

How do we achieve the vision? Key Themes (PM Session)

Table 1 **Partnerships and Relationships**		**Table 2 & 3** **Single Point of Access, Triage and Care co-ordination**		**Table 4** **Pathways and MDT**	
Co-production – parents and young people	“I feel listened to” “I know where to go” “I feel heard” “I feel supported” “I don’t have to fit into a particular pathway for a diagnosis” “I don’t have to tell multiple people the same thing”	**Single Point of Contact**	Integrated single point of access Simple, accessible, fluid One waiting list Single telephone number Self-referral Integrated front door Electronic referral form	**Pathway**	One pathway Longitudinal pathway Hub to simplify pathway Triage and MDT need to work hand -in -hand to make the pathway work Needs a hub to deliver Process: Assess MDT Plan Care Care planning included Child and family focussed 18 week timescale from front door to services Group of professionals working together
Information / Resources	One website for all services Improve the local offer One local offer for Hull and ER Sharing information – data sharing agreements, simple IT solutions One computer system or a reasonable solution Shared training/ resources Use of social media One page profile – with a picture for personalisation Communication and feedback	**Triage**	Key stakeholders identified Clinical lead Clinical admin Hub manager Booked call/ face to face with parent for triage Filter out the straight forward cases Point of referral to triage – timeless (to be measured) Flexibility and consistency Assessment in one place with specific teams and specialists followed by a quick report	**Triage**	Care co-ordinator Joint assessment wherever possible MDT Triage

Table 1 Partnerships and Relationships		Table 2 & 3 Single Point of Access, Triage and Care co-ordination		Table 4 Pathways and MDT	
Culture Shift	One telephone number for all services Can do – and will do flexibly Changing attitudes “They understand my child, they understand me, I feel listened to” Reflective practice – acting on feedback Money will be saved	**Care Coordination**	Funded key worker Clinical care co-ordinator Informative People need to understand who this is aimed at Know where to go	**Information**	IT systems integrated
Partnerships	Joint commissioning Funding and pooled budgets Joint governance and oversight to be trusted CCG’s, LA’s and NHS England	**Services**	Needs led, not diagnosis led Walk-in available Low level including emotional wellbeing Integrated systems and bottoms up approach Services equitable and uniform (Hull and ER) Under one roof Early intervention 0-25 provision Neurodevelopment and mental health Flexibility and consistent Uniform integrated pathway		
Hub	Safe place to talk Easy to access	**Information/ consent**	Shared information consent Shared consent Implied consent/ consistent consent form Same electronic system for record sharing Skype available New systems Shared consent Same electronic system for record sharing Implied consent/ consistent consent form		

Table 5 **People and skills**		**Table 6** **Early intervention and transition**		**Table 7** **Support**	
Workforce	Specialist services and staff Skill mix Strong leadership Sustainability Funding to develop Knowledgeable Networks Knowledge of conditions Awareness of the vision and services	**Capabilities required for a new service**	Educated workforce Community feel MDT approach Cultural development of the workforce Communication via secure e-mail/ letter optional Early intervention Changing the how/ now to what is required for the future Clear communication Everyone to listen and sign up Ownership of roles Electronic system with notes/ information available that is easily accessible and follows the patient journey	**Types of support available**	Community support Young carers Siblings Parents forum and support groups Enablement and empowerment Support from day one without a diagnosis Short breaks Someone to talk to Family counselling Peer supporters Social Groups and Support Post diagnosis support Professionals support Early help and intervention
Information/ support	Signposting Local offer: • No Jargon • Plain English • Accessible information Parent Groups Training and support for parents and children Coffee mornings Website Career Support	**Transition**	Well managed transition No onward referral Services liaise Training/ support for parents: • What to expect? • What support is available? Handover between professionals with parents involved Listening to parents – being mindful of discussions in front of the child Transparency Confidence in the system and processes	**Involved sectors**	Nurseries, child minder's and early years Voluntary community sector Charity links

Table 5 People and skills		Table 6 Early intervention and transition		Table 7 Support	
Service features	Needs led Gold standard Easily accessible/ friendly Streamlined – flow of pathway Child/ family centred Timely Supportive Co-ordinated Equipment No service border (regionally) Co-produced - Integrated pathways Sharing and collaboration Shared vision with agreed joint working principles and protocols			**Features of support**	No postcode lottery Chain of care Well communicated Listening to the child and parent Joined up working – hub and spoke model Facilitation and coproduction
Recruitment	Funding to develop staff Succession planning Joint recruitment with parent participation				
Aims	Gold standard Skilled workforce Parent co-production Joint Commissioned All sectors				

Table 8 **Communication and information sharing**			
Information sharing/ content	Health and education sharing information Consent to share – universal/ explicit Person centred and accessible by different people Non-medical jargon Patient held record – electronic/ paper Family – whether read by patients or clinicians; understood by all Prevent duplication and information recording Core information included e.g. early years information Family at the centre	**Communication**	The local offer threads and connects all Tiered stakeholders of those supporting the family: • Universal • Targeted • Specialist
Required changes	Children's campus Each service to map where they are now and where they need to be Equality of service provision – Hull and East Riding Key stakeholders need to agree who can make the change		

Appendix E

Reporting Back

3 Opportunities That Will Lead Us To A Better Future

1) Single point of access
   Single assessment (MDT)
   Clear and concise communication
2) Integrated working
   Earlier intervention
   Better journey for me and my child
3) Single point of access
   Shared vision
   Integrated working
4) Skilled workforce
   Single MDT assessment
   Co-produced
5) Transparency between partners
   Integrated working
   Joint commissioning
6) MDT from the beginning
   0-25 for everything
   Training and support for families
7) Admission without a diagnosis
   MDT Triage
   Hub/ build
8) Children LD Liaison Service
   Integrated Care
   Shared decision making

1 Key Issue to Solve

Information sharing

Shored Vision

Pooled budgets

General communication

Pro-Families

Waiting times from referral

Lack of communication between teams

1 Major Contribution

Signposting and support from day one

To persist with commitment to see it through

Signposting

Keep listening (to parents, carers and young people)

Realistic

Sign up stakeholders

Time

Motivation

1 Key Ask

Make it happen

Commitment to no postcode lottery

Move forward

When- timescale?

Keep going

Agree

Co-production

Work together

Appendix F

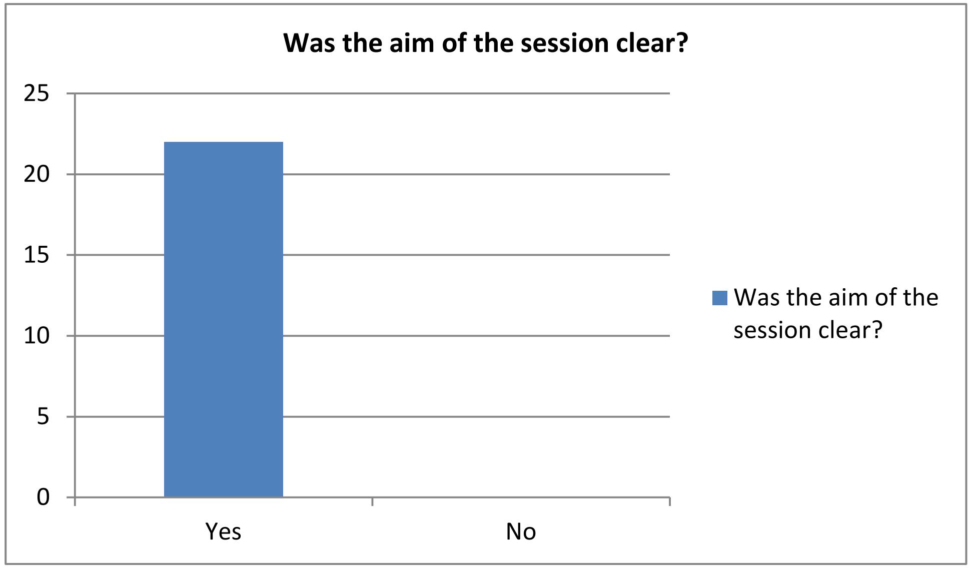
Organisational Commitments

Senior Lead & Organisation	Commitment
Erica Daley, Director of Integrated Commissioning NHS Hull CCG	I will commit to ensuring that this work is a strategic priority across the Hull and East Riding system and I will make sure that the senior leaders with responsibility for the organisations delivering the required services are fully briefed and informed. I will ensure that the plans created at this event and the aspirations of the parents , carers, children and staff are reflected in the transformation programme and I will check back to assess that we continue to work toward them. I will commit to the timescales that we agree and support their delivery so that when we do look back we can demonstrate progress, better outcomes and an improved experience for children and families.
Neil Griffiths Assistant Director – Services for Vulnerable People NHS East Riding of Yorkshire CCG	I will commit to supporting East Riding of Yorkshire CCG and its system partners to work proactively with parents, carers, colleagues and other providers across Hull and East Riding to make changes to our services which are person-centred, avoid duplication, are responsive and contribute to young people achieving their full potential. This means that individuals, families, teams and health, care and education services are supported in positive risk taking which supports quality improvement, and better experience and outcomes for children, young people, their families and carers.
Dr Sandhya Jose, Consultant Paediatrician Hull University Teaching Hospital NHS Trust (HUTH)	HUTH is actively committed to developing integrated care pathway for children with Neurodevelopment needs. HUTH has recently inherited the Community paediatric service portfolio. The key challenges within that service include nearly 2000 care review breaches and a 70% substantive Consultant gaps. Our priority is to restructure the service and engage with wider organisations to develop comprehensive integrated care pathways that support all the key elements of the service which include: • development disorders and disabilities, • complex health needs (including end of life care) • behavioural presentations of neurodevelopment disorders (e.g. Autism, ADHD) • Looked after Children and children with a plan of adoption The key objectives would be to facilitate: • early diagnosis and intervention • effective multidisciplinary and interagency interventions • proactive management of known disabilities to prevent unnecessary exacerbation of symptoms and deterioration of condition This would include establishing ensuring clear referral pathway through a single point of access.

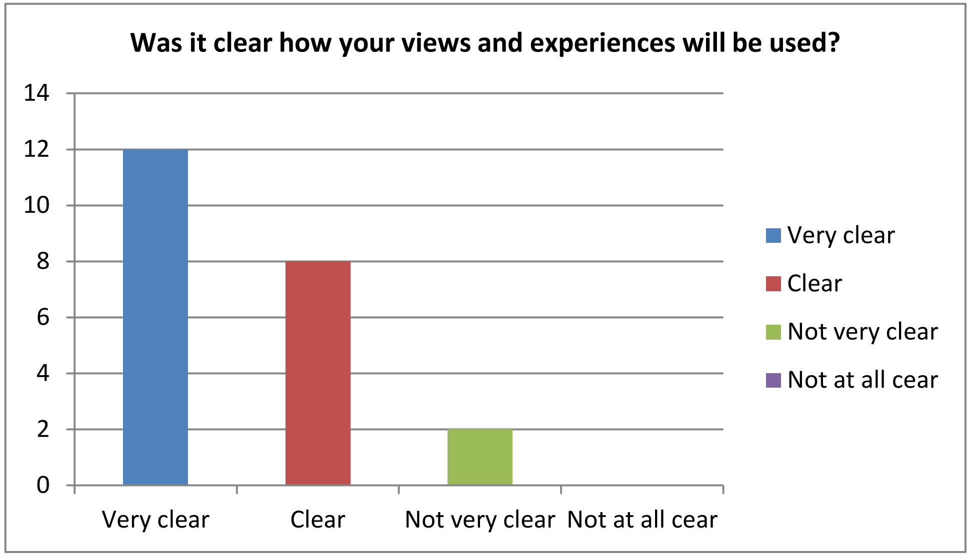
Sarah Herd General Manager – Health and Wellbeing Services City Health Care Partnership (CHCP)	CHCP CIC will continue to support the shared vision of an ICP approach, we are committed to continuing our contribution to the development of a children's neurodevelopment/disability hub to improve the lives of children/young people and their families. We will work with our partner providers, commissioners, children and their families to support this future vision and work collaboratively to deliver services. We will continue to support children and young people with complex health needs, who have neurological conditions requiring assessment and monitoring to prevent hospital admission and provide support and care in the community. Our community nursing team with continue to teach/train and advise carers to enable them to manage the care of children and young people at their place of residence to build confidence and skills and prevent hospital admissions.
Julia Harrison- Mizon Care Group Director Humber Teaching Foundation Trust	I will commit to supporting the Humber children's services teams to work proactively with parents, carers, colleagues and other providers across Hull and East Riding to make changes to our services which are person-centred, avoid duplication, are responsive and contribute to young people achieving their full potential. This means that individual, teams and services are supported in positive risk taking which supports quality improvement, and better experience and outcomes for children, young people, their families and carers

Appendix G

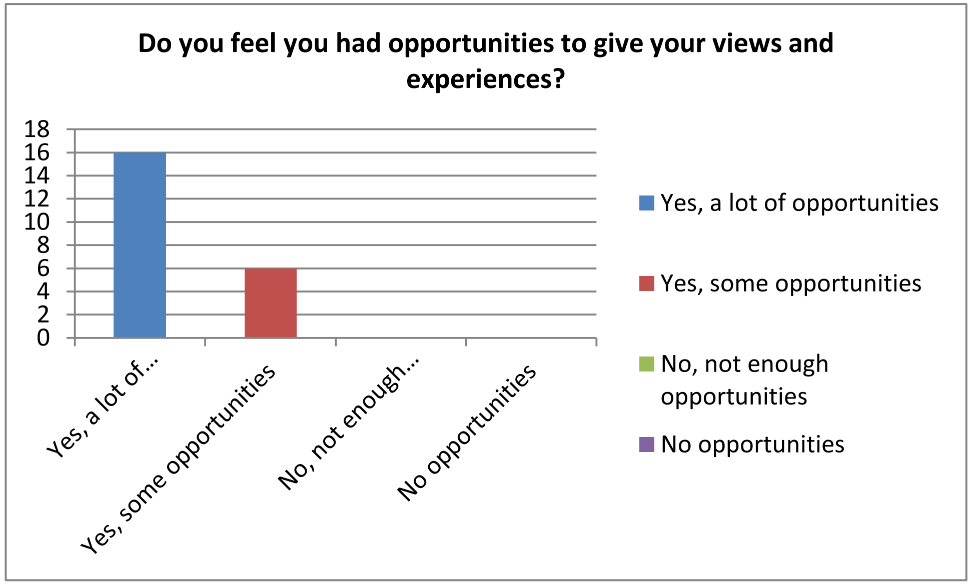
Workshop Evaluation



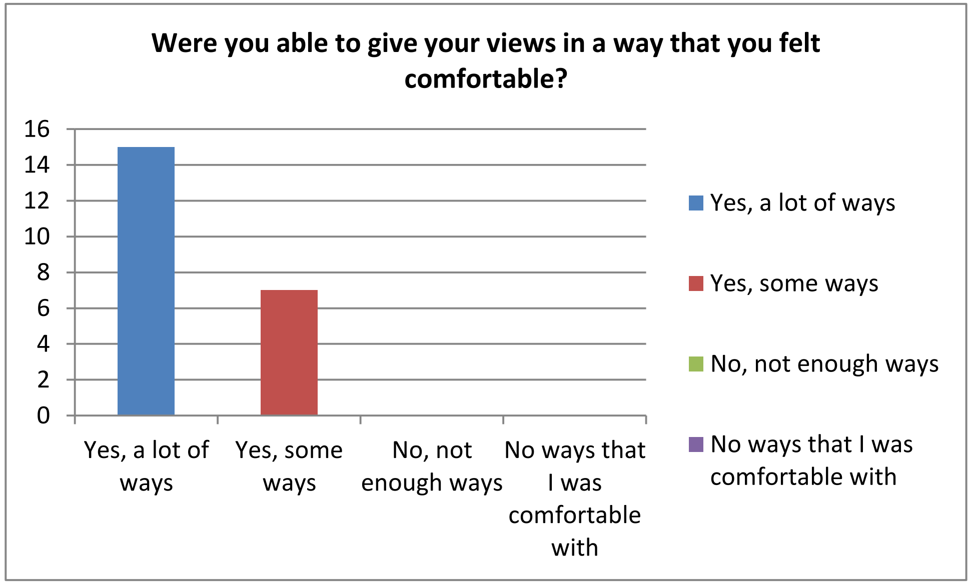
Was the aim of the session clear?



Was it clear how your views and experiences will be used?

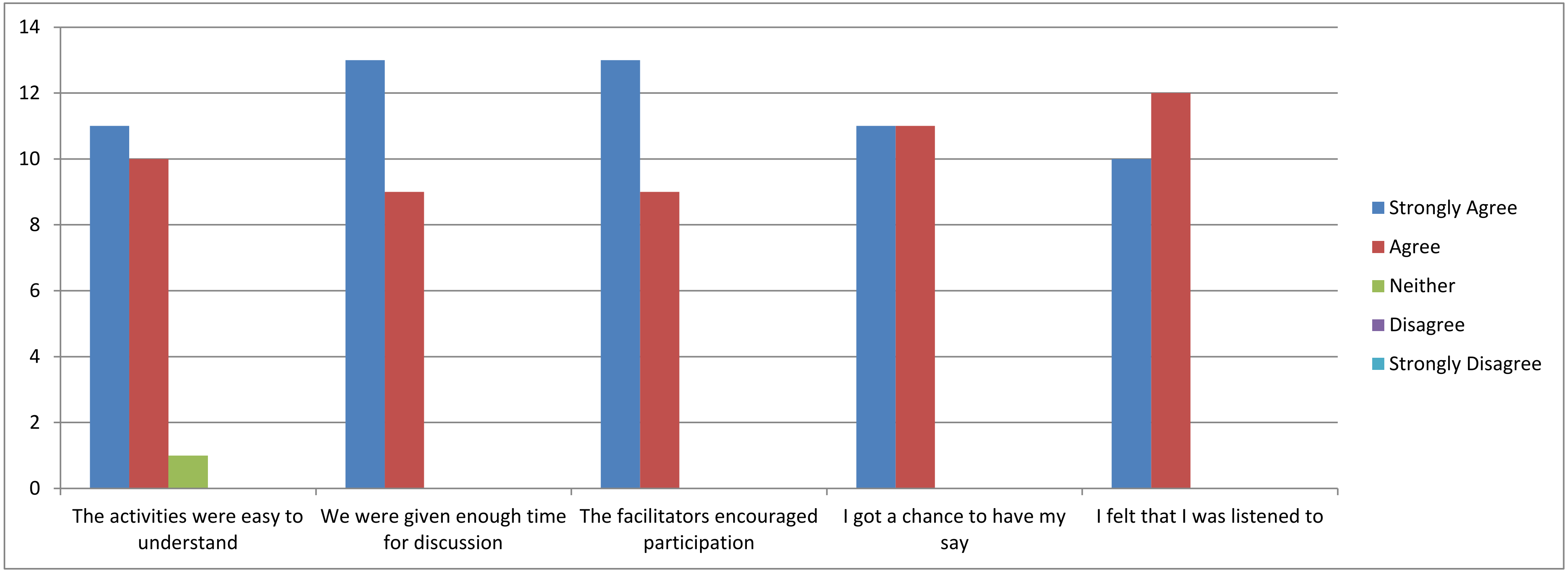


Do you feel you had opportunities to give your views and experiences?



Were you able to give your views in a way that you felt comfortable?

Overall Evaluation



Appendix H

Event Comments and Feedback

- Loved it! It feels amazing being heard, also to have a view for the future.

- We need to do this now in collaboration/ co-production but we need time to be involved and the resources to make it all work effectively and efficiently.

- Who will use the information collected for and what’s the plan?

- Very good session. Exciting times ahead.

- Would like to see more involvement from East Riding parents in video.

- If there are more to come – yes please. This could be a city legacy, we have to get this right.

- The facilitator was excellent… again. The mixture of PowerPoints, videos and experiences was a very powerful tool for change.

- There was no feedback from the afternoon session which would have been useful for those attending.

- I thought the session was really relaxed by informative. I enjoyed the whole day. Thank you to all the organizers. As a parent, I felt we were listened to.

- It was good to give a parent’s view of the difficulties we have experiences and I did feel listened to. The session was positive and I left feeling optimistic that we can create a better service for these young people in the future.

- The session was very informative, very positive and I felt there was so much inclusion for everyone, no matter whether you were a parent of professional. Thank you for the opportunity.

- Looking forward for more workshops for parents and also try to bridge the gap between East Riding and Hull.

- Brilliant session where co-production in action was evident.

- Loved everything about the day.

- I really enjoyed it and learnt a lot. The way it was structured lent itself to sharing information effectively and learning from others. I really appreciated the input from parents.

Appendix I

Event Delegates

Surname	Forename	Organisation
Abbott	Nia	Humber Teaching Foundation Trust
Ali	Bushra	Hull Clinical Commissioning Group
Allison	Joanne	City Health Care Partnership
Beilby	Dave	Hull Parent Carer Forum / KIDS
Bradbury	Melanie	Hull Clinical Commissioning Group
Brown	Vanessa	Hull University Teaching Hospital Trust
Burton	Catherine	KIDS
Chamberlain	Helen	Humber Teaching Foundation Trust
Colton	Becky	Hull City Council
Dawson	Bernie	Hull Clinical Commissioning Group
Dixon	Laura	KIDS
Flanagan	Peter	Humber Teaching Foundation Trust
Foers	Mike	Hull Clinical Commissioning Group
Fraser	Allison	Humber Teaching Foundation Trust
Gotts	Katie	Hull City Council
Griffiths	Karen	Humber Teaching Foundation Trust
Griffiths	Neil	East Riding Clinical Commissioning Group
Hanson	Helen	Humber Teaching Foundation Trust
Hamlyn	Jenny	Tweendykes School
Harrison-Mizon	Julia	Humber Teaching Foundation Trust
Hatley	Tony	Parent/ Carer Representative
Heenan	Nicola	Hull University Teaching Hospital Trust
Herd	Sarah	City Health Care Partnership
Hoodless	Leanne	Parent/ Carer Representative
Hurst	Colin	Hull Clinical Commissioning Group
Ibbotson	T J	Parent/ Carer Representative
Jones	Laura	Parent/ Carer Representative
Jose	Sandhya	Hull University Teaching Hospital Trust
Joyce	Garry	St. Helen’s Clinical Commissioning Group
Kemp	Michelle	Hull University Teaching Hospital Trust
Kenningham-James	Mika	Parent/ Carer Representative
King	Claire	Humber Teaching Foundation Trust
Lammiman	Kerrie	Hull City Council
Lead	Fiona	Hull University Teaching Hospital Trust
Leedham	Scarlett	Connect Therapy Services
Macleod	Jane	Humber Teaching Foundation Trust
Massey	Nina	Hull Clinical Commissioning Group
Mehrotra	Ankur	Parent/ Carer Representative
Mehrotra	Swati	Parent/ Carer Representative
Morley	Sally	Humber Teaching Foundation Trust
Nash	Lisa	Parent/ Carer Representative
Needle	Laura	Hull City Council
Ogle	Rachel	Parent/ Carer Representative
Pannhausen	Joanne	Humber Teaching Foundation Trust
Pickering	Laura	City Health Care Partnership

Powell	Andrea	Tweendykes School
Railton	Ian	
Richards	Jenny	Parent/ Carer Representative
Sanderson	Lorraine	Parent/ Carer Representative
Shepherd	Maria	Hull Clinical Commissioning Group
Smith	Cheryl	National Autistic Society
Smith	Simmone	Parent/ Carer Representative
Stericker	Tracey	Hull City Council
Titchener	Nikki	Humber Teaching Foundation Trust
Trotter	Kath	Matthews Hub
Upton	Carol	East Riding Clinical Commissioning Group
Walker	Gina	Parent/ Carer Representative
Walker	Helen	East Riding of Yorkshire Council
Ward	Angela	Hull Clinical Commissioning Group
Warwick	Karen	Humber Teaching Foundation Trust
Wilson	Louise	East Riding of Yorkshire Council
Withers	Sheena	Parent/ Carer Representative
Young	Patience	Hull Clinical Commissioning Group