CHESHIRE AND MERSEYSIDE, CHILDREN, AND YOUNG PEOPLE NEURODIVERSITY PATHWAY ENGAGEMENT

OCTOBER 2024

Cheshire West Voluntary Action
Championing the community sector

VS6

Cheshire & Merseyside
VCFSE Health & Care Leaders Group

Cheshire & Warrington
Infrastructure Partnership
Owned by and supporting the voluntary, community and social enterprise sector

Voluntary Sector North West

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INTRODUCTION

The ambition across Cheshire and Merseyside Health and Care Partnership is to view neurodiversity as a difference, from a strengths-based perspective rather than a disability, whilst recognising the challenges associated with lifelong neurodevelopmental conditions.

To consult and gather the views of those with lived experience, Cheshire West Voluntary Action (CWVA) led on the coordination of a children and young people's neurodiversity pathway engagement programme across the Cheshire and Merseyside footprint. This was delivered through the well established Voluntary, Community, Faith and Social Enterprise (VCFSE) networks across the region.

The VCFSE sector has always provided a wide range of support to health, care and wellbeing services, including meaningful engagement, with access to community voices and those with lived experience. The regions network consists of over 19,500 VCFSE organisations, ensuring a stronger collective voice across diverse communities.

The aim of the engagement was to hear and use the voice of neurodivergent children, young people and their families to influence the redesign of the current clinical-led offer across Cheshire & Merseyside to a needs-led approach.

Many of the views and experiences expressed throughout this engagement, resonate with the recent report (October 15th 2024) from the Children's Commissioner, Dame Rachel de Souza.

"The findings are a stark reminder of the daily fight children and their families face seeking support for neurodevelopmental conditions like autism and ADHD, and how the system has failed to keep pace with rising demand.

"These children face an invisible crisis, in a system that is working against itself by forcing families to jump through multiple hoops in a complex and lengthy process of assessment, diagnosis and intervention.

"Existing commitments from the government to fix the broken healthcare and SEND systems are warmly welcomed – but now we need urgent action. I'm calling for better support in mainstream schools, improved awareness and training for frontline professionals in education, health and care so that children are supported based on their needs, not a label. We need a system that moves away from a reliance on diagnosis – because failing to provide timely support is robbing children of their childhood and their potential."

"People (professionals) feel they know a lot more than the individual who has autism. We have our own personal traits on top of our diagnosis which makes us all different"

(female aged 17 with diagnosis of ADHD and anxiety)

METHODOLOGY

With £70K investment from Cheshire and Merseyside ICB, Cheshire West Voluntary Action led on the children and young people neurodiversity pathway engagement. The investment enabled the delivery of meaningful and effective engagement across the VCFSE over a 12 week period between August and October 2024.

This partnership approach, working with CWIP , VS6 and CWVA CYPF Alliance quickly mobilised the sector to engage with a broad range of ages and neurodivergent types, targeting those that have an understanding of the needs of both the neurodiverse Children and Young People (CYP) population, and those with undiagnosed neurodivergent needs. This approach provided extensive views and opinions from those with lived experience across Place, communities and neighbourhoods.

In total, 27 VCFSE organisations supported the engagement. Due to the 12 week timeframe, a targeted approach was implemented. CWVA utilised current networks to connect with and brief VCFSE organisations. This included the creation of the questionnaire and associated documents, reaching out across the CYP and VCFSE network and meeting with organisations on an individual basis.

Organisations were approached to either deliver engagement directly with their CYP members or through the CVS's to coordinate engagement at Place, utilising their knowledge of the most appropriate groups to work with.

All participating organisations completed a low-level expression of interest form, ensuring CWVA engaged with a wide range of cohorts. Due diligence was undertaken, seeking governance and safeguarding polices from participating organisations.

Engagement was delivered by sector organisations with the skills, expertise and passion to deliver meaningful and inclusive engagement to affect a culture change. All engagement was 'neuro-affirmative', ensuring that the language used resonated with CYP and their families with no 'deficit' focus.

The findings will inform the Cheshire & Merseyside Neurodivergent CYP Pathway Oversight Group and associated workstreams: Empowerment and Early Help and Ongoing Support, Clinical Professional Working Group, ADHD Shared Care Working Group.

"All she seemed to talk about was making me go on a stupid parenting courses and never really got to know me or my daughter as people"

(Cheshire parent of a 7 year old)

Throughout, VCFSE organisations have been creative in their delivery, organising pizza nights, encouraging doodling and drawing, utilising film and visual stimulants. Also organising social activities, trips etc. as well as engagement on a one-to-one basis with CYP and their families or carers.

Some of the most productive co-produced engagement was highlighted through the organisations that encouraged activities to be led by young people through advocacy, ambassador and buddy programs, with young people taking the lead on engaging with their peers and working through the questions in the most appropriate way. In many cases this took a number of sessions, focusing on a few themes at a time.

Many delivered workshops that offered a multi approach to responses, meaning young people could choose a way that was preferable to their communication style. This included emotions flashcards, post-it notes, verbal feedback and body language. Organisations adapted their focus groups and workshops to encourage more opportunity for discussion and response.

"School wise teachers shouting at me for absolutely no reason and being misunderstood, upsets me. Makes life difficult. Doctors have been really nice actually. That's about it. It upsets me that I choose the wrong people to be friends with"

(Female aged 11, ADHD support group)

Engagement delivery was an inclusive, coproduced model, relating to different age cohorts, to include young adults with additional needs up to age 25, neurodiversity type, geography, specific communities and those with protected characteristics. This in-depth qualitative approach through workshops, focus groups and semi-structured interviews, provided comprehensive insight and voices of those with lived experience to inform and shape future decision making. Activities included evening and weekend engagement, to ensure as wide a reach as possible.

> "He's been diagnosed with ADHD, He's on medication, I think he's got a lot more but no one has singled it out or seems to listen.
>
> (Halton parent of a 9 year old)

QUESTIONNAIRE

The questionnaire ensured consistency, and was used in a way appropriate to the child, young person or family member. CWVA encouraged VCFSE organisations to deliver creative and inclusive activities to ensure the best experience possible for CYP and their families to have their say. The aim was to understand what CYP and their families identified as being important to them and what they considered 'good would look like'.

Organisations carrying out the engagement were responsible for determining the most appropriate method of engagement, which questions to ask from the open-ended questions provided and the most appropriate language to use when speaking to children, young people, parents/guardians.

Not all the questions were mandatory, some were only appropriate for specific cohorts of children and young people. Additional questions were also included to provide views on transition to adulthood and were relevant identifying if there was support from CYP with ADHD and their families to have their medication supported and prescribed by their GP rather than secondary care.

The questionnaire and a glossary of terms made up part of an induction pack for participating VCFSE organisations, this included background context and purpose, funding allocation up to £5,000 and engagement criteria, the Lundy Model coproduction framework, a co-production checklist and the CWVA Local Voices principles of co-production.

DEMOGRAPHICS

CWVA utilised existing CYP networks and CVS's, connecting with 27 VCFSE organisations to provide wide reaching engagement across Cheshire and Merseyside. This approach ensured delivery was an inclusive, coproduced model and engaged age cohorts from primary school upward, to include young adults with additional needs up to age 25, all neurodiversity type's outlined below, and specific communities which included LGBTQ+, Young Carers and Care Leavers.

The coproduced wide-reaching engagement, allowing for flexibility in the use of the questionnaire does not highlight any comparisons in services across C&M or evidence any specific trends to particular cohorts. This data collation was merely to ensure CWVA engaged as widely as possible and could target as appropriate to meet any gaps in cohort type. The priority was to engage with as many CYP and families in activity led small groups, utilising methods of communication that would encourage meaningful and in many cases, powerful and emotional conversations.

The overall demographic data highlights the wide-reaching engagement delivered by the VCFSE within a 6 week period.

458 in-depth conversations.
267 engagements directly with children and young people,
191 responses from families and carers.

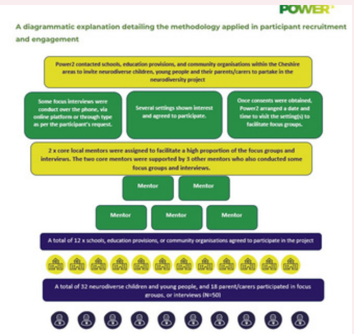
The responses provided by CYP have predominantly been from age 13 upwards

Sex:

41% Female
47% Male
11% unknown/other/preferred not say

Education:

Primary 34%
Secondary/College 39%
Specialist School/College 11%
Other/Employment 6%
None 4%
Unknown 6%



A diagrammatic explanation detailing the methodology applied in participant recruitment and engagement

Power2 contacted schools, education provisions, and community organisations within the Cheshire areas to invite neurodiverse children, young people and their parents/carers to partake in the neurodiversity project

Some focus interviews were conduct over the phone, via online platform or through type as per the participant's request.

Several settings shown interest and agreed to participate.

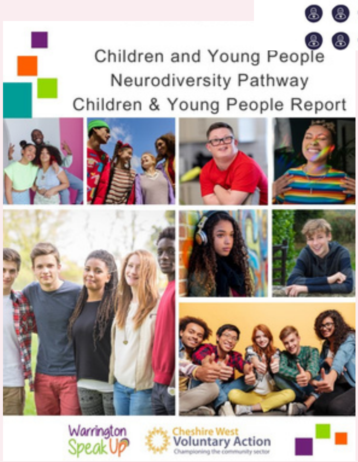
Once consents were obtained, Power2 arranged a date and time to visit the setting(s) to facilitate focus groups.

2 x core local mentors were assigned to facilitate a high proportion of the focus groups and interviews. The two core mentors were supported by 3 other mentors who also conducted some focus groups and interviews.

Mentor
Mentor
Mentor
Mentor
Mentor

A total of 12 x schools, education provisions, or community organisations agreed to participate in the project

A total of 32 neurodiverse children and young people, and 18 parent/carers participated in focus groups, or interviews (N=50)


Children and Young People
Neurodiversity Pathway
Children & Young People Report

DIAGNOSIS

The data highlights that the sector engaged with all the neurodivergent types below at varying levels:

- Autism or Autism Spectrum Disorder / Condition (ASD / ASC)
- Dyslexia
- Dyscalculia
- Epilepsy
- Hyperlexia
- Developmental co-ordination disorder (DCD), also known as dyspraxia
- ADHD - attention deficit hyperactivity disorder (ADHD)
- Obsessive-compulsive disorder (OCD)
- Tourette syndrome (TS)
- Learning Difficulty

Assessed with diagnosis 59 %
On the assessment pathway 27%
Not assessed 9%
Unknown 5%

The most common neurodiverse condition (singular or combined) at 60% was ADHD, followed by ASC being the second most prevalent singular neurodiversity.

As with the descriptions above, the term neurodiversity encompasses a broad range of conditions, 45% have more than one neurodivergent type. Not all types are diagnosed, which has been a reoccurring theme for CYP with multi-neurodiverse conditions.

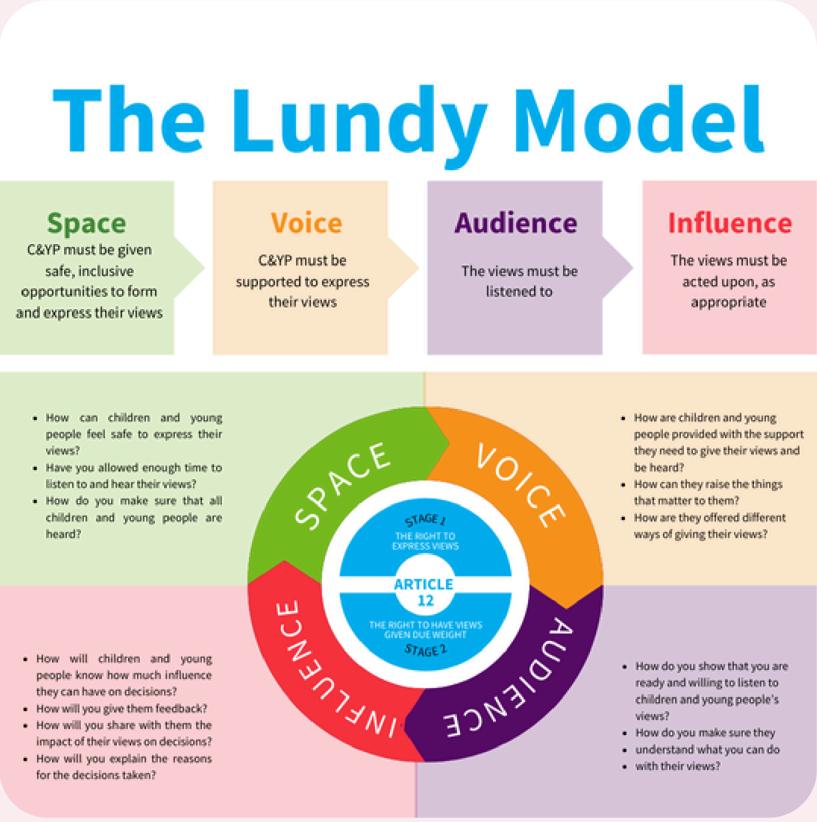
> "We are struggling to get any help. She's more stressed than anything. She ends up self-harming and angry because, no one understands or will help, we've been waiting too long"
>
> (Parent of a 12 year old)

CO-PRODUCTION

CWVA incorporated the 'Lundy Model' from the Beyond framework, making use of the models checklist and feedback forms to ensure a structured approach across all VCFSE engagement. The Lundy Model, looks at 'Space, Voice, Audience and Influence' throughout each stage of engagement activity.

These tools helped sector organisations to effectively plan, conduct, and evaluate their CYP participation and ensure that CYP were able to express their feelings and wishes in a safe environment, on their terms, giving them a voice and the power to shape and influence decisions that affect their lives.

It is important to acknowledge that for effective and meaningful participation for CYP with specific cognitive challenges and/or learning disabilities, time is needed to build relationships in order to understand individual needs particularly around communication and the tools required to fully and meaningfully engage. Some VCFSE organisations highlighted barriers in unpicking and clarifying individual stories, and expressed the need for more time to fully allow CYP to express their views.



The Lundy Model

Space
C&YP must be given safe, inclusive opportunities to form and express their views

Voice
C&YP must be supported to express their views

Audience
The views must be listened to

Influence
The views must be acted upon, as appropriate

- How can children and young people feel safe to express their views?
- Have you allowed enough time to listen to and hear their views?
- How do you make sure that all children and young people are heard?

- How are children and young people provided with the support they need to give their views and be heard?
- How can they raise the things that matter to them?
- How are they offered different ways of giving their views?

- How will children and young people know how much influence they can have on decisions?
- How will you give them feedback?
- How will you share with them the impact of their views on decisions?
- How will you explain the reasons for the decisions taken?

- How do you show that you are ready and willing to listen to children and young people's views?
- How do you make sure they
- understand what you can do
- with their views?

Throughout the engagement it was essential for VCFSE organisations to quickly establish a safe and trusting space in recognition of some young people's life experience and their need to share their whole life story in order to meet the engagement aims in relation to the questionnaire.

Organisation's noted on people's experiences of being a 'looked after child or young person' which often resulted in an initial mistrust of an adult asking questions. One VCFSE organisation worked with young people who identified as LGBTQ+ and had been invited to their 'safe space', some of whom were in the early stages of their transition, or were still questioning their sexual identity.

In all discussions it was essential that conversations were led by the young people involved and importantly language used to describe their identity and sexuality was respected and reflected in how they framed their questions. This enabled them to quickly establish a rapport, gain confidence and respect, and focus on what was important to the young person at that time, prior to the specific discussion around neurodiversity.

CYP and families have asked what will happen next, what changes will be made, will their experience make a difference?

Each VCFSE organisation involved in the engagement has their own observations, findings, questionnaire results and reports from their respective activity. They acknowledge the importance, to follow up and feed back to participants how the information has been used to help shape future decision making to encourage a needs led approach to neurodiversity.

THEMES

The findings reveal a range of systemic issues. Key themes detailed below, include delays in accessing services, fragmented communication and a lack of ongoing support. The current pathway is being described as fragmented, with no clear integration between healthcare, education, and other support systems. With parents particularly frustrated by the lack of coordinated care and young people feeling misunderstood or ignored. The identified themes were prevalent across Cheshire and Merseyside, in some cases specific services or professionals have been cited, both negatively and positively, however this report focuses on the overall findings from the voices of those with lived experience.

Lengthy Waiting Times:

The process to obtain a diagnosis can be complex, lengthy and lacking in appropriate and relevant information. A consistent concern was the excessive wait times for assessments and diagnoses. This was attributed to various factors, including backlogs in systems and limited resources. Participants identified an average wait of 18-24 months for diagnosis. CYP and families feel ‘left and frustrated’ whilst waiting for a diagnosis, with no support or access to any needs led early interventions. This has resulted in missed educational and social opportunities. Families and young people spoke about lengthy waiting times forcing them to seek out private diagnosis and support, alongside accessing support in the community where available. Many families spoke about delayed diagnosis having an emotional toll on CYP and families, affecting mental health, having financial implications and contributing to the breakdown of family relationships.

It’s like there’s no support and it’s a long process. You’ve got to wait and wait”

I’m waiting, I want to do things I like, but there's nothing in our area only the park.

"Right now as I’m talking to you I can hear keys jangling, a child on a bike, a bird and people talking inside. It’s all just too exhausting”

Diagnosis:

There was significant disappointment with what followed the diagnosis, with a variation in people's views on the relevance of a diagnosis and the impact on their day-to-day life. This ranged from relief, comfort and understanding to a diagnosis making no difference and being the start of another journey with limited advice, guidance and support. Others spoke of the threshold, and how the current model for diagnosis leaves many who just fall short of the threshold with little or no support, despite the impact on the day to day functioning and wellbeing of CYP.

"I have to access services through my daughters school ASD team, we are currently waiting for YPAS counselling but it's a drop-in in town and only open 9.30- 8pm this is difficult to get to after work, making tea and looking after siblings"

Language & Communications

With reference to the language that surrounds neurodiversity, CYP describe the impact, both negative and positive. CYP have experienced discrimination, fear and intolerance. Language used positively supports people to express who they are, their difference, and enable them to get access to the support they need. Used negatively CYP stated that it can isolate, create barriers, discriminate and undermine a young person's confidence and sense of self-worth.

Responses have highlighted how neurodivergent CYP have been 'labelled', which has affected their everyday life in education, health and social settings. In addition, some of the data highlights difficulties in language from parent respondents, generational conceptions of ADHD and terminology used. Interestingly, some parents noted finding the glossary provided with the information pack helpful in terms of understanding other neurodiverse types.

Language and terminology used by professionals was also cited as a barrier, with young people and parents highlighting consultations (especially online), documentation such as medical information, support guidance etc. was sometimes hard to understand or navigate. It was evident throughout the conversations with both CYP and parents of their broad range of understanding of neurodiversity, highlighting disparities across communities, from those further up the system and accessing support and those at the start of their journey. The data hasn't allowed this to be attributed to specific demographics.

"Neurodiversity, not a word I would use – I'm just me. I wouldn't use that word to describe my difficulties"

"I don't feel there should be a label. People like to label or generalise my condition"

"No communication, no support or help in understanding the process of how to manage and no direction of where to go or what I can do"

Families expressed frustration with the poor communication from service providers. They cited lost referrals, lack of follow-up, and difficulty in obtaining clear information about the assessment process and available support options. This lack of transparency leaves families feeling isolated and unsure of how to navigate the system. Young people spoke about the lack of communication and realistic expectations so they know how long the process will take. Some spoke about not getting a follow up after referral which reduced their trust in the health service. CYP and families spoke about being passed around the system, having to repeat themselves to different professionals, all of which has exasperated their frustration and significantly affected their health and wellbeing.

Across all groups of young people, they described a lack of awareness of where to go and how to find appropriate and relevant information about the pathways to a diagnosis and the support available. This included a lack of information written for young people and available in spaces that young people meet.

There were differing experiences of being offered and accessing medication and its impact on daily life. With positive short-term benefits but also the 'crash effect' that can follow. CYP and families felt they didn't have information on the effects of medication in an accessible format.

" My foster parents didn't understand all my needs. They thought I was a naughty girl and disrespectful. Had me down as an attention seeker - they didn't see the way I was as a symptom of my ADHD and autism. They didn't acknowledge my diagnosis at all "

Lack of Understanding or Adaptation for Neurodivergent Needs

There was an identified lack of understanding of neurodiversity, what it is and what can be done in the home, the school and the community to make things easier for CYP and families. Engagement consistently reports on encounters with professionals who demonstrate a limited understanding of neurodiversity and fail to adapt their approach to accommodate specific needs. Examples include insensitive questioning, insistence on online consultations despite children's discomfort, and disregarding established routines that provide comfort and stability. This lack of empathy and flexibility creates additional stress and barriers to effective support.

The findings also identified a distinct disparity in how neurodivergent conditions present and are understood across genders, a significant number of girls identified a lack of understanding from family members, GPs, teachers and other professionals.

Young people described their frustration around the assumption that people who identify as neurodiverse struggle to maintain friendships and relationships and therefore prefer to be on their own. Many cited issues of labelling all neurodivergent conditions together. They identified the need for education and greater awareness and understanding of the impact of neurodiversity within social environments.

> "I only have two friends. That's because I react to minor things and people don't understand me"

> "What would be great is if there were more places I could go to see friends. I just need a calmer and quiet space."

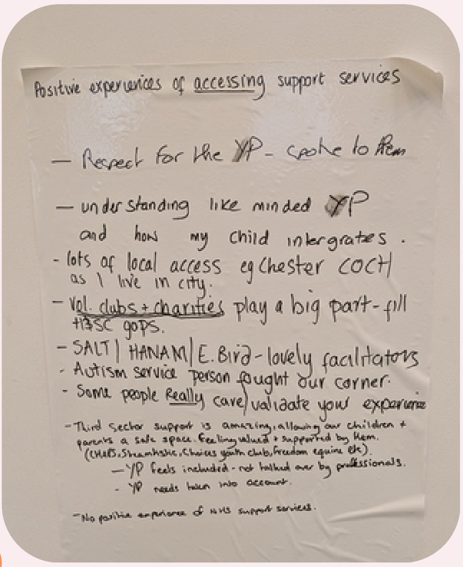
Inconsistent support across the system:

As expected, CYP and families had a lot to say about their experience of education and health services. There is recognition of the contribution teachers and health practitioners can make both in recognising symptoms, encouraging support for diagnosis and in providing practical and emotional support. From education to health services, to CAMHS and therapy services there is no one 'holding them'.

It is evident that education has often a negative experience for young people and can have a long-standing affect. CYP and families highlighted the importance of building trust and rapport with professionals, especially for children who thrive on routine and familiarity. Frequent changes in staffing disrupt this process, leading to negative experiences and setbacks in progress. What seems to be lacking is consistency and a positive whole system approach to neurodiversity.

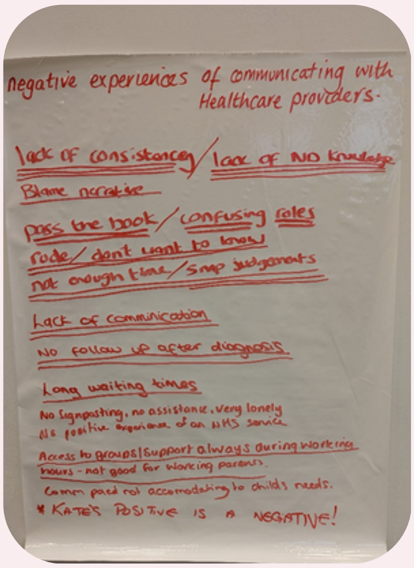
A disconnect was highlighted between healthcare and educational support, whereby school opinions sometimes overruled medical diagnosis, impacting on EHCP support.

On a positive note, many CYP and families praised specific teachers, GP's health professionals, support services and VCFSE organisations with understanding and empathy, identifying facilitated positive outcomes.



Positive experiences of accessing support services

- Respect for the YP - spoke to them
- understanding like minded YP
  and how my child intergrates.
- lots of local access eg Chester COCH as I live in city.
- Vol. clubs + charities play a big part - fill H&SC gaps.
- SALT | HANAM | E.Bird - lovely facilitators
- Autism service person fought our corner.
- Some people Really care / validate your experience
- Third sector support is amazing, allowing our children + parents a safe space. Feeling valued + supported by them. ([illegible], [illegible], Choices youth club, Freedom equine etc).
  - YP feels included - not talked over by professionals.
  - YP needs taken into account.
- No positive experience of NHS support services.



negative experiences of communicating with Healthcare providers.

lack of consistency / lack of ND knowledge

Blame narrative

pass the book / confusing roles

rude / don't want to know

not enough time / snap judgements

Lack of communication

No follow up after diagnosis

Long waiting times

No signposting, no assistance, very lonely

No positive experience of an NHS service

Access to groups | support always during working hours - not good for working parents.

Comm paed not accomodating to child's needs.

* KATE'S POSITIVE IS A NEGATIVE!

Lived experience voice and feeling ignored:

Parents highlighted that they are the experts in how neurodiversity affects their child on a day-to-day basis. Parents suggested that their views were often overlooked and treated as a secondary consideration. Young people also felt frustrated that their voice was not being heard and feel like they are being told they don't know their own mind.

"Neurodiversity pathways are taking years and it feels like every step from start of pathway to education placement is a battle"

"I was bullied badly at school. I feel more support and understanding was needed. I received more support at college but it was more from an emotional perspective than understanding my needs from an educational standpoint"

"At college I'm now getting good marks. My counsellor just got it."

I would have loved some help post diagnosis. You are given your child's diagnosis and I felt this is when the help will become available. Unfortunately it feels the opposite. It feels like here is your diagnosis letter please move on and try to find help yourself. I wish the pathway helped us to understand how we can help our children as much as possible

Additional Insights :

Those who responded to the question for children and young people with ADHD 'would families be supportive to have their medication supported/prescribed by their GP rather than secondary care'. The predominant response was yes, although some parents caveated this to state 'only if it comes with support'.

I don't know how I go about getting any sort of medication, even though it is evident that it is needed. No information has been given, we struggle to manage daily with the impact it has on us all as a family.

I feel this option would be more suited due to the high demand and wait with secondary care. I feel it would be a barrier if GP's could not prescribe and review medication as required

Yes as a familiar face helps, but there needs to be an extensive knowledge of ADHD medication and side effects which I'm not sure a GP can offer at present.

Less than 10% of parents acknowledged being neurodivergent themselves. Predominantly, this was undiagnosed, of which most talked about ADHD being classed as a 'naughty child' when they were younger, and only through increased awareness have they self-identified, with one or more. Interestingly, the glossary of neurodivergent types used throughout the engagement, provided information that highlighted unassessed multi-neurodiverse conditions for CYP already on the pathway, as well as for their siblings. There were no trends across Cheshire and Merseyside in terms of neurodivergent parents. However, one specialist children's CIC, had a 50% response of their parents being neurodiverse.

I don't think so I haven't been 'checked or tested'

"I am going to be assessed myself in the near future. I've realised through parenting a divergent child that I am and always have been a highly masking autism girl"

There were very mixed reviews from parents worried about their child's transition to adulthood, those that felt confident were more likely to already have had an early intervention with support and an EHCP in place. Those still on the pathway for an assessment were concerned about bullying, coping mechanisms, mental health, self-harm and general wellbeing.

"If they had interacted with me as well as him, so I could help him understand what was going on, what was happening it would have helped" .

(Parent of a 15 year old)

NEEDS LED APPROACH

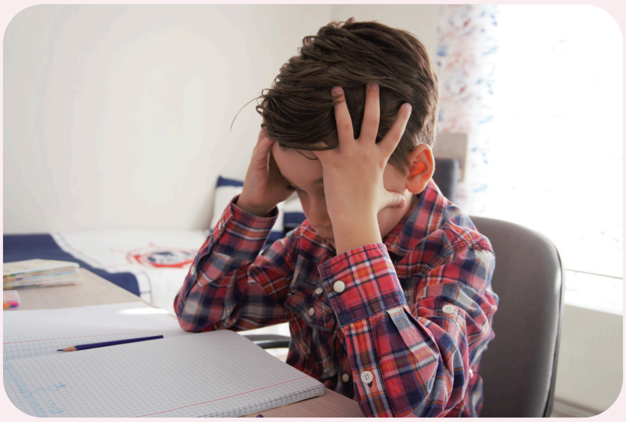
WHAT GOOD LOOKS LIKE

The comments and feedback from CYP and families are personal and powerful, highlighting their frustration and in many cases desperation. However, they were not absent of hope for the future. The feedback suggests that changing the environment and the way in which neurodiversity is approached can support children and young people to reach their full potential and take an active and fulfilling part in society.

When asked what would make things better and what good looks like the responses corresponded to the themes outlined in this report. Parents, advocated the need for earlier identification and intervention for neurodiversity, for clear and accessible information throughout the whole assessment and diagnostic process. Also, the need for a less complex pathway and a much timelier diagnosis. Young people had creative and positive ideas to give neurodivergent people a voice and raise awareness, although some struggled to explore this in any detail given the engagement timeframe and children expressed a need to improve their environment for example school or waiting rooms.

The engagement highlighted a consistent underlying message for a universal, system wide standard of support implemented across schools, health and support services.

CYP and their parents consistently identified the need for a key person, with many positive experiences highlighting empathy, understanding and continuity of support from individual teachers and health professionals. Many noted the difference positive early interventions, empathy and a ‘go to person’ had on a child or young person and their transition to adulthood



Feedback highlighted a need for a one stop shop as a single point of access, for children, young people and families to get information, advice and support. This was expressed as either a place or a digital offer. Many commented on the numerous places and people they need to see, suggesting this would be eased if people were together at the same time and place. This involved having a more person-centred and holistic approach to supporting neurodivergent CYP and their families, with improved service coordination, alongside an expansion of neurodiverse specific support. Feedback included providing individualised assessments and treatment plans, considering the needs of the entire family, and offering access to a wider range of support services, such as the VCFSE, counselling and peer support groups.

> It would be good to have an app to plan for what to expect, I like to know what is going to happen, when it will happen and who I will meet. Having a plan is less stressful"

Knowsley - Autism, Dyslexia, Dyscalculia age 14

CYP suggested educational and attractive displays about neurodivergence so that everyone accessing spaces in schools, youth clubs, GP waiting rooms etc. whether neurodiverse or not, may learn about neurodiversity. This in turn, will also help to reduce stigma and misinformation and help to normalise talking about differences and seeking support without people feeling judged or embarrassed.

CYP advised that good support consists of having a clear plan. This should include an outline of what to expect, maps of where services are within a building such as school or college, and a routine to follow. Many commented on and appreciated additional time given in schools for support, once diagnosed. Young people expressed the need to work alongside professionals to co-produce a plan that meets their needs or to be consulted in the design of any support spaces to ensure they are young person friendly and welcoming.

CYP stated good support should have easy to read and attractive information about a variety of support needs so that young people can look at displays and learn about different needs. One group advised that being able to use a sunflower lanyard has helped to provide non-verbal cues to other people that he may need additional time to process information and may need extra support.

Feedback emphasised the importance of clear communication and accessible information. CYP articulated the need to provide a range of information that is clear, accessible, relevant and presented in a format that they can relate to. Various groups of young people suggested opportunities to be involved in the co-production of information, including making videos, podcasts, and leaflets to promote awareness, education and understanding.

A crucial aspect of improving the support system is addressing the stigma associated with neurodiversity. Feedback suggested raising general awareness in a neuro-affirmative way so as not to label or differentiate. This also included educational initiatives, and promoting inclusive practices within healthcare and educational settings.

Awareness and advocacy is crucial in the role of empowering the different and unique needs and aspirations of CYP. Some suggested role models or neurodivergent ambassadors to be given a higher profile to raise awareness, they were keen to see people 'like them' normalised. Other ideas suggested creative resources about how to live well with neurodiversity, coproduced with those with lived experience.

Parents were also keen to have access to advice, guidance and tools, through apps, websites, easy to read leaflets etc. that will help them understand and respond to their child's neurodivergent needs, helping them to put the most appropriate coping strategies in place.

CYP suggested the need to adapt environments and practice changes, enabling them to feel welcome, more comfortable and less anxious and better able to cope in various situations. Many children and young people spoke about cluttered classrooms e.g. bags and coats on the floor, dark and disorganised GP waiting rooms e.g. not understanding the system of being called in to see a Doctor. This also included busy and noisy youth clubs and other spaces intended for those with neurodiversity but not really appropriate due to environment or capacity to support.

Many suggested more opportunities for small group activities, with small peer groups being frequently mentioned. A key message from young people was not to label all neurodiverse young people as the same, some described their frustration around the assumption that people who identify as neurodiverse prefer to be on their own. In many cases it is the environment that needs to be considered.

Feedback predominantly highlighted the need for education, this included increased awareness and training for professionals working with young children, such as nursery and primary school teachers. Education and an understanding of the complexities of neurodiversity was also cited as a need across all health professionals, support services and wider society.

The engagement has identified that far reaching education and awareness raising will enable a more inclusive, non-judgemental, tolerant and informed place to live for neurodivergent children and young people.

NEXT STEPS

- Production of short film to share with CYP and parents involved in the engagement. This accessible film will highlight emerging themes and how CYP voices will influence the Cheshire and Merseyside neurodivergent pathway.
- Continued VCFSE involvement with the Cheshire and Merseyside CYP Neurodivergent Pathway Oversight Group and associated workstreams, Empowerment and Early Help and Ongoing Support, Clinical Professional Working Group and ADHD Shared Care Working Group.
- Continued coproduction with CYP, by ensuring CYP identified through VCFSE engagement are involved in future neurodivergent pathway resources and communications, looking at language used and 'sense checking' accessibility. This should include listening to and learning from young people with lived experience and the challenges they face, in particular those who have been let down by the system.
- Identify opportunities for CYP neurodivergent ambassadors roles.
- Ensure VCFSE are involved in wider neurodivergent training and awareness raising opportunities to support a more inclusive and informed VCFSE offer.
- Identify opportunities for VCFSE investment to expand services and activities that are accessible to diagnosed and undiagnosed neurodivergent CYP.

"I just need information in a way I can understand, different people explain things in different ways, its complicated, but I just try to get on with it"

Female age 17 living in supported accommodation, ADHD undiagnosed

Documents related to the engagement, the questionnaire, background information, beyond programme Lundy Model, VCFSE reports etc. can be accessed via CWVA

VCFSE organisations involved in engagement across Cheshire & Merseyside

- Steamtistic
- Cheshire & Warrington Carers Trust
- Merseyside Youth Federation
- Cheshire Youth Federation
- Homestart Cheshire & Warrington
- Power 2
- ND Directed CIC
- Chester Schools Christian Work
- Speak Up
- TAGS LGBTQ+
- Warrington Youth Zone
- Halton & St Helens CVA
- One Knowsley
- Halton Citizens Advice
- Mind Mastery CIC
- East Liverpool Riding School
- Apollo Active Knowsley
- Splice Hart Hill Youth Club
- Sefton CVS
- Crewe Autism Inclusive
- CLASP (Crewe single parent support charity)
- Broken Cross Family Hub
- Audley Climbing Centre
- Good Time Charlies SEND
- Meols Cop Community
- Presfield
- BuddyUp+

Cheshire West Voluntary Action
Championing the community sector

CONTACT INFORMATION

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