

Neurodiversity Needs Analysis, Limerick Youth Service, November 2023

For the purpose of this needs analysis:

Neurodiversity refers to the diversity of human brains and minds. It spans both the neurotypical and the neurodivergent.

Neurotypical refers to brains and minds that fall within what is considered standard or typical.

Neurodivergent refers to brains and minds that differ from the typical and can include Dyspraxia, Dyslexia, Attention-deficit hyperactivity disorder (ADHD), Dyscalculia, Autism Spectrum Disorder (ASD), Tourette Syndrome, and others¹.

Respondents:

- After consulting with their teams, 7 staff from Ability+, Youth Diversion Programme, UBU (2 x staff), Youth & Family Support, Be Well and the CTC completed a short survey, that asked about numbers of young people presenting with neurodivergent conditions, the types of conditions and the impact on their engagement with young people, and about staff support needs including training and capacity building.
- 11 survey responses were received by individual young people attending Lava Javas UBU, Be Well, and Ability + with the support of their key worker. The survey asked what being neurodivergent means to them, how it affects their engagement with LYS, and the supports that they require. 1 X focus group of ? young people was facilitated in Lava Javas UBU and 1 with 8 X CTC young people.

It is important to note that the quotes used in the findings below are taken from surveys, which have been filled out by staff on behalf of their teams and on behalf of young people. Staff took notes from focus group discussions, and from one to one interviews/survey completion, which were then submitted on the survey. Therefore, quotes in italics are not direct quotes from staff or young people but more a summary of their answers.

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¹ https://www.autismtoolbox.co.uk/understanding-autism/what-is-autism/



Findings

- 1. Numbers of young people presenting with neurodivergent conditions
- All staff indicated that there has been an increase in the numbers of young people presenting with neurodivergent conditions.
- A review of programme registration forms, 2023 identified the following additional support needs, which may be relevant in terms of neurodiversity:
- 5% of CTC learners are in receipt of Disability Allowance; 19% stated a mild learning disability and 1 learner stated that they are on the Autism Spectrum. 79% respondents did not answer.
- 39% of Ability+ young people stated Autism as a disability; 81% identified a Mental Health condition and 46% are in receipt of a Disability Allowance.
- 48% of young people referred to Be Well stated a diagnosis of ASD; 4% stated a diagnosis of ASD along with a mental health diagnosis and 4% stated diagnosis of ASD, a mental health diagnosis, a learning disability and a hidden disability.
- In 2022, 28% of young people registered with YDP Ballynanty stated a disability, 5% with Irishtown and 1 requested but not provided) and 5% with Kings Island.
- Across UBU, high percentages of young people registered across City Suburbs & East Limerick stated 'referred by school principal' with respect to additional support needs. Approx. 30% 40% of young people attending Lava Javas highlighted mental health; social skills/isolation & inclusion; anxiety, bullying and autism/spectrum/ASD with mental health referenced most. Approx. 14% of young people in Kings Island referenced mental health and social isolation and in Garryowen, approx. 20% of young people referenced Community Engagement, mental health and self-esteem.

With respect to registration data, a staff survey respondent noted that there can be difficulties in declaring a disability and often parents/guardians may not want that, and so neurodivergence isn't always captured on registration forms. Staff surveys also highlighted 'self-diagnosis' as an increasing challenge and highlighted the large number of young people waiting on a diagnosis.



2. Types of Neurodivergent Conditions

The most prominent conditions that staff highlighted young people as presenting with were Attention Deficit Hyperactivity Disorder ADHD (7), Dyslexia and Autism Spectrum Disorder (ASD) (6), Dyspraxia (DCD or Developmental Coordination Disorder), Dyscalculia & Tourettes Syndrome (1). 2 respondents indicated Other, and explained:

'anxiety, concentration issues, stress, paranoia, depression, ODD, trauma, social anxiety, PTSD, survival guilt'.

'development language difficulties'.

3. What does being neurodivergent mean to young people?

A focus group discussion and survey responses to this question highlighted that a few young people do not feel defined by neurodivergence:

'Being neurodivergent is a part of who I am, it doesn't define you as a whole but it makes up parts of you'.

One young person noted their acceptance of neurodivergence as being part of who they are, despite it challenges:

'It's part of who I am it doesn't define me but makes me, me. I know it causes me difficulties in certain areas like social groups, but it also forms part of who I am in those'.

However, most young people highlighted understandings based on its negative impact on their lives in terms of social isolation, difference, discomfort, misunderstood, nervousness and fearfulness:

'Feel isolated. Behind everyone else. People don't understand me and think I'm slow'.

'a struggle socially to feel normal'.

'not being comfortable in a world built for neurotypicals'.

'It means I can't enjoy socialising..... I'm really nervous about working in case I say the wrong thing to a customer or staff member'.



'I think it effects my social interaction, I have a small friends group but always struggled to make friends and would describe myself as socially awkward and nervous'.

Focus group discussions noted similar points in terms of not fitting in and feeling misunderstood:

'people who don't fit into the general neurotype of society'.

'Sometimes I might feel patronised.....I hate telling teachers, they always assume they understand and know best. But are often ill informed, ill prepared, and don't take it seriously enough'.

A smaller number of young people referred to their own knowledge of the condition itself, or lack thereof:

'Different things that go on in your head. Like ADHD you can control it yourself but not many people can'.

'My behaviour and brain functions different to other people'.

'Sometimes I don't really understand. When I was a child my mother always told me I have autism but I don't fully understand what that means'.

'I'm not sure what it means to me it was never explained properly. but I think it effects my social interaction'.

and the need for young people themselves to be informed:

'To me it's important to know about it. I think it's important to recognize it as soon as possible because then you can have accommodations made to support you and it'.

4. Impacts of neurodivergence

Impacts were explored with respect to young people's engagement with LYS. The CTC focus group highlighted challenges in the classroom in terms of maintaining focus, fear of talking and needing the freedom to move about:

'difficult to focus....social issues - reluctance to talk.....sitting on a chair with feet on the ground / the need to move / becoming entrapped / overwhelmed / needing to leave the group need to decompress'.



In terms of engagement with a youth group, a focus group highlighted that impacts were minimal and if any, they related to sensory overload and tiredness:

'I don't think it effects at all, Sensory overload might inhibit ability to participate. Often too tired, and by the time you realise you are too tired to cope it is too late'.

Findings from surveys emphasise the negative impacts, socially, and not only in their engagement with LYS but within other setting such as education institutions; particularly feelings of difference, exclusion, humiliation and not understanding social norms:

'People automatically don't like me. After talking to me they think I'm weird. People would laugh at me'.

'It affects me a lot as I find it a struggle to do social communication most of the time'.

'Made me very quiet. Social isolation. Not understanding how I sound. Lacking in certain emotional intelligence. Bullied. Feel like a freak'.

'Working harder to interact with others. Fit in'.

'I have a tendency to speak my mind unfiltered which doesn't always go down well with others and has led to difficulties in groups in the past. I have had to take a break'.

'Talk too much in class, out of turn. Group projects, I'd avoid. Socially in class, I wouldn't talk to my peers. They considered me weird. I have been bullied, social exclusion and didn't talk to me'.

'I don't really engage with other classmates socially, I just keep to myself unless someone speaks to me. This makes me sad sometimes because I would like to do more but I get extremely anxious and it's easier to keep to myself'.

Other impacts related to sensory challenges, tiking and the anxiety that this can cause, reduced self-belief, the need for access to one to one and more tailored learning supports, reduced concentration and focus, anxiety and worry:

'Sometimes I get uncomfortable with strong smells and have to leave places'.

'Its distracting and anxiety inducing too, worrying about what others might think. I sometimes "be ticking" in lectures and it can be distracting for me and everybody else'.



'Question my ideas compared to others. Too many instructions are difficult'.

'Sometimes I don't always understand stuff and I learn it better when somebody explains it to me on my own'.

'dropped out of school early because no accommodations were put in place for me...my ability youth mentor is the first person to actually understand my needs without me having to spell them in black and white'.

'Hard to sit still and hard to concentrate'

'I also get headaches from ticking and this can cause me to lose focus'.

'I try to avoid group situations because they make me anxious. I worry a lot about saying the wrong thing and often spend hours after class analysing everything I said and what others have said to me in case I misinterpreted the meaning or just said what I was thinking without considering the feelings of others'.

With respect to staff feedback, 57% of staff rated 'Difficulties in Managing Emotions' as their first choice in ranking how neurodivergence affects their engagement with young people, followed by difficulties in social interaction/social isolation at 29%. 57% of staff ranked Sensory Sensitivity, for e.g. noise, light, smells and colour as the least relevant followed by 43% of staff ranking difficulties in language and communication. Other impacts noted by 5 staff included young people being 'Subject to bullying', and demonstrating 'All or nothing – thinking, emotions'; 'substance misuse......learning difficulties, general health and wellbeing....' and 'school refusal'. The need for more relaxed one to one settings for young people who find it 'difficult to control their emotions, anxiety & reactionary responses when placed in a group setting, especially when there are higher numbers of youth participants within the group'.

5 Supports Prioritised by Young People

Young people were asked to list 3 supports that they would value most. One focus group highlighted support with identifying goals/action planning, and another highlighted more varied food options, support in study planning, and provision of appropriate spaces/tools to release tension

'Seating plan and class or syllabus plan in school is really important to me'.



'Variety of food options - issues with food colouring and/or textures, additional work recovery time (less anxiety trying to make up time), boxing bag to release energy and / or tension / autism friendly space'.

Survey responses prioritised mental health supports and counselling with particular reference to managing social anxiety and anger management: 'someone to listen', someone who understands'; 'Quiet, open, calm neurodivergent zones and spaces' and an 'Understanding of non-verbal moments' were mentioned a number of times, support with diagnosis, routine and planning were also highlighted, as was improved staff attitudes and understanding. Language and understanding were also highlighted by one focus group as lacking in terms of the survey devised for this analysis:

'this is not written by someone with Autism or clearly has not been informed or checked by someone on the spectrum'.

One focus group highlighted the importance of youth voice:

'having a say in how we learn'.

In terms of supporting young people, a couple of staff members highlighted counselling supports, support with goal setting and planning and access to physical activity:

'Mental Skills Development: (Goal Setting, Resilience, Positive Imagery, Gratitude, Self-Affirmations).....Physical Activity as a positive coping mechanism'.

5. Supports Prioritised by Staff

71% of staff identified 'Training and Capacity Development' as the most relevant support, followed by 'Neurodiverse Friendly Spaces' listed by 43% of staff as their 2nd choice. 'Organisational Policies and Procedures' were listed as least relevant followed by 'Technical & Digital Supports for e.g. Assistive Technology & Digital Methods'. Other supports listed by 5 staff highlighted additional resources & funding, an understanding of existing practice in LYS and tools in managing anger and emotional distress.



6. Training Prioritised by Staff

Staff prioritised a basic knowledge and understanding of neurodiversity with an emphasis on language, need areas and practical tools/methods, delivered using a workshop type format.

Conclusion

- High numbers of young people with neurodivergent conditions are accessing LYS services and supports.
- The most prominent condition is ADHD.
- Most young people feel that neurodivergence has a negative impact on their lives, particularly in terms of being socially isolated; feeling different and uncomfortable; being misunderstood and feeling nervous and fearful.
- In terms of their engagement with LYS, young people emphasise social anxiety and a fear of participating in group work, and challenges with focus and concentration.
- Support with setting goals and action planning was a key support noted by young people, as was one to one and counselling support and the provision of spaces conducive to rest and relaxation.
- Staff prioritised supports in terms of training and capacity development with an emphasis on basic knowledge and understanding along with practical tips and tools.