Using outcome measures effectively with neurodivergent children and young people

as part of support for their emotional and mental health.





Contents

- Background and context
 Pages 2 7
- > The challenges
 Pages 8 12
- Developing better practice Pages 13 - 24
- Acknowledgements and references

 Page 25 27

Summary

At CORC we have heard discussion about a range of reported challenges associated with using measures as part of support for the emotional and mental health of neurodivergent children and young people.

These challenges mean that there is a risk that neurodivergent children and young people do not experience the full benefits associated with outcome measurement. It also means that their experiences of mental health support may not be captured in the evidence and research base.

CORC facilitated a working group of practitioners and researchers committed to improving support for neurodivergent children and young people, to create this guidance.

The views and insights from a group of neurodivergent young people who are Peer Researchers employed by Young Person's Advisory Service (YPAS) as experts by experience (10 young people aged 16-25) have also informed the content.

The guidance aims to highlight and address challenges that have been identified by professionals and young people, and to suggest ways of working with measures that can make outcome measurement more meaningful and beneficial. It focuses on emotional and mental health support for neurodivergent children and young people and does not intend to explore assessment and diagnosis of neurodivergent conditions

These recommendations are potential ways to improve practice. We recognise that no recommendation will work for every person in every situation.

This guidance focuses on emotional and mental health support for neurodivergent children and young people and does not intend to explore assessment and diagnosis of neurodivergent conditions.



What is this guidance and who is it for?

The working group and young people identified a range of challenges associated with using measures effectively with neurodivergent children and young people.

These challenges have been grouped under three themes:

- > challenges associated with commonly used measures
- challenges associated with the practice of using outcome measures
- challenges associated with the capability and confidence of professionals.



When using outcome and feedback measures with neurodivergent children and young people, the working group's advice to professionals is to:

- select and use measures better suited to neurodivergent children and young people
- capture the perspectives of parents and carers and professionals
- give it time to introduce and administer measures
- be prepared to introduce and explain measures, including response options
- make measures more accessible and be creative in how you use them
- ask for and respond to feedback
- provide options for how measures are completed
- > set and track goals collaboratively
- develop staff skills and confidence
- consider how support is designed and offered.

Neurodivergence: a spectrum of differences

Neurodiversity refers to variation in human brains and how they function. These differences are natural variations rather than disorders that need to be cured.

Neurodivergence refers to a range of differences in brain function. The term neurodivergent is used to describe an individual whose brain functions differently from what's considered 'typical or within the societal norm.

Neurodivergence is often described as a spectrum of differences in brain function and behaviours. Neurodivergent children and young people are a highly diverse group with different communication styles, cognitive profiles, and sensory needs. Not only are there differences between different types of neurodivergence, but there are also significant differences between individuals with the same types of neurodivergence, and it is not uncommon for people to have more than one type of neurodivergence.

This means that each child or young person referred for mental health support will have their individual ways of thinking and needs. As with neurotypical children or young people, neurodivergent children and young people experience their own intersection of culture, gender, disadvantage, adversity and marginalised identities that should be considered as part of their support.

A large part of the research, professional input and lived experience about neurodivergence that informs this guidance relates to young people with autism and Attention Deficit Hyperactive Disorder (ADHD). We would like to highlight that the guidance is skewed this way and to acknowledge that the use of the term neurodivergence in this work relates primarily to these conditions.

We are aware this piece of work will not fully reflect the experiences of all neurodivergent children and young people. We do not have all of the answers, but we are committed to ongoing learning and further collaboration to update guidance and resources.

Contact us at **corc@annafreud.org** if you would like to contribute to our ongoing work.

If you have any feedback on our use of language that would help us to refine our approach, please contact us at corc@annafreud.org.

See more about our commitment to equity, diversity and inclusion <u>here</u>.

Context to this guidance

It's estimated that 15-20% of children and young people in the UK are neurodivergent^[1].

Figures from academic journals report a rise in the identification of some neurodivergent conditions in children and young people since 2000 in the UK^[2]. As one illustration of this, a 2024 report found demand for autism assessments among children and young people had increased by 306% following the Covid-19 pandemic^[3]

There are long and growing waiting times for assessment of neurodivergent conditions in children and young people in the UK^[4]. Studies also show that there is an underdiagnosis or misdiagnosis of such conditions^[5]in particular in relation to autistic young women and girls^{[6][7]}. It is likely that not all neurodivergent children and young people who are accessing emotional and mental health support will have a diagnosis.

Neurodevelopmental conditions are not mental health problems. However research indicates that neurodivergent individuals experience high rates or co-occurring mental health difficulties^[8].

For example: there is evidence of higher rates of depression and anxiety co-occurring with autism, dyspraxia, and ADHD, when compared to the general population. Autistic people and those with ADHD have a high risk of developing an eating disorder and autism has also been associated with higher rates of mood disorders, personality disorders, schizophrenia, and substance misuse, contributing to considerable long-term negative effects on health and quality of life^[9].



Anxiety can be part of the everyday experience of neurodivergent children and young people due to challenges associated with sensory sensitivities, social anxiety, loss of control and difficulties with communication and understanding.

One study has found that negative school experiences generate twice the emotional burden in autistic and ADHD adolescents compared to their neurotypical classmates, and that this is significantly correlated with the incidence of depression and anxiety^[10].



Studies show that neurodivergent individuals frequently encounter high rates of trauma including bullying, exclusion and feeling misunderstood.

These experiences can be compounded by the stress of navigating a predominantly neurotypical society.

Disentangling mental health difficulties from neurodivergent traits can be difficult due to:

- poor clinician knowledge of neurodivergence
- diagnostic overshadowing^[11] (where only the primary neurodivergence is identified, and other co-occurring conditions are overlooked)
- a lack of suitable validated measures for these children and young people, resulting in challenges and delays to diagnosis of mental health difficulties and, subsequently, a lack of or ineffective mental health support^[12].

Key terms

Monotropism

<u>Monotropism</u> is a way of describing how neurodivergent people often experience and focus their attention. It's like their brain forms a deep tunnel of focus - they can give a lot of attention to one thing at a time, and that focus can become very intense and absorbing. Shifting onto a different task when they are not yet 'done' with the task they are focused on can feel distressing and physically painful.^[13] This means that neurodivergent children and young people often find it overwhelming to jump between questions on a questionnaire.

Cognitive and sensory overload

Cognitive overload refers to the state where the amount of information and tasks exceeds an individual's cognitive capacity, leading to difficulties in processing, retaining, and recalling information. This is particularly relevant for neurodivergent individuals and can significantly affect how they respond to multiple, often broad, questions on a mental health questionnaire.

Interoception

Neurodivergent children and young people can struggle to notice or interpret their internal body signals, feelings and emotions (called 'interoception'), so that they can respond or behave in the same ways as neurotypical people. Limited interoception affects emotional awareness and is often experienced in different ways by neurodivergent individuals, impacting their emotional wellbeing. This impacts how they respond to questions about feelings and emotions that feature on many outcome measures.

Masking

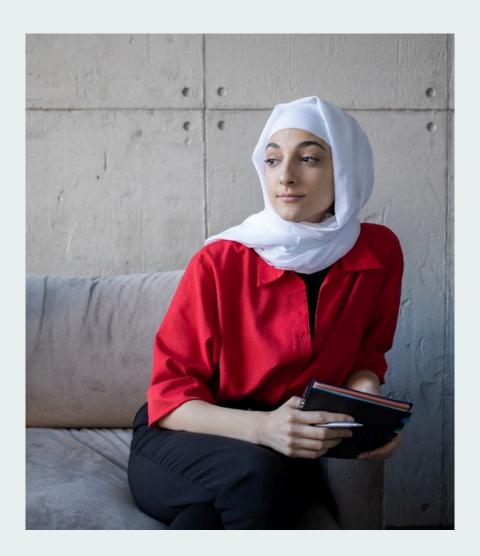
<u>Masking</u>, also called camouflaging, refers to consciously or unconsciously suppressing natural neurodivergent traits to appear more 'neurotypical'^[14]. Masking can be considered as part of neurodivergent children and young people's everyday experiences and indeed, their development. It can also affect the way that they respond to questions on outcome measures as they mask their real feelings and symptoms on a questionnaire.

The challenges related to using outcome measures with neurodivergent children and young people

The working group and young people identified some key challenges associated with outcome measurement and monitoring with neurodivergent children and young people.

Those challenges are presented here in three groups:

- challenges associated withcommonly used outcome measures
- challenges associated with the practice of using outcome measures
- challenges associated with professional confidence



Challenges associated with commonly used outcome measures

A number of features of commonly used outcome measurement questionnaires were identified as being challenging for neurodivergent children and young people.

Our working group and young people highlighted that questionnaires:

- can be long, resulting in disengagement (see cognitive and sensory overload and monotropism above)
- can feel formal or 'clinical' in the way they are presented, leading to disengagement
- may ask broad questions which are difficult to relate to or interpret
- can include language, terminology and concepts that are difficult to understand, especially for those whose verbal language is limited
- can include numbers and feelings scales that are abstract and inaccessible
- can offer response options that are difficult to interpret or relate to - for example calling for a differentiation between 'certainly true' and 'true'
- questions about frequencies and timeframes can be vague and difficult to respond to - for example would the answer options 'occasionally' or 'most of the time' mean every day? or once a week?
- can use reverse questions that are difficult to understand.*

Practitioners also noted that since anxiety is often an everyday experience for neurodivergent children and young people, they often score highly on common anxiety measures such as <u>GAD-7</u> and <u>PHQ-9</u>.

Measures have not been generally developed and tested with neurodivergent young people, and the normative reference values, or 'norms'** for outcome measure scores generally reflect the neurotypical population.



*Reverse phrasing questions involves asking a question in both a positive and negative way and is a technique used to ensure that respondents fully understand the question.

^{**}Normative data is used to determine thresholds for some measures and to provide mental health professionals with a guide to the level of severity of needs or difficulties based on the scores from measures.

Challenges associated with the practice of using outcome measures

Other identified challenges relate to how measures are used with neurodivergent children and young people.

For example, neurodivergent children and young people's responses to questionnaire may be more likely to be affected by:



*Rejection sensitive dysphoria (RSD) refers to the emotional pain and discomfort that individuals experience in response to perceived or actual rejection, criticism, or failure. This condition is particularly associated with attention deficit hyperactivity disorder (ADHD)

- feeling overwhelmed by a large number of (sometimes similar) emotive questions: the cognitive load of questions may be too much resulting in a panic or anxiety response
- feeling drained at the end of a support session and therefore if they are asked to complete a questionnaire at this point, feel overwhelmed and disengage
- ➤ tendencies to mask their distress (see Masking above), which may result in misleading scores on standardised tools perceiving measures as a test and feeling they need to give the 'correct' answers
- experiences of Rejection Sensitive Dysphoria*, which means neurodivergent children and young people can have an emotional reaction to feelings of failure or criticism. They may seek to receive positive responses and praise from their mental health professional. As a result, they provide inaccurate responses to questions
- different auditory or sensory processing that may impact on how they respond to questions.

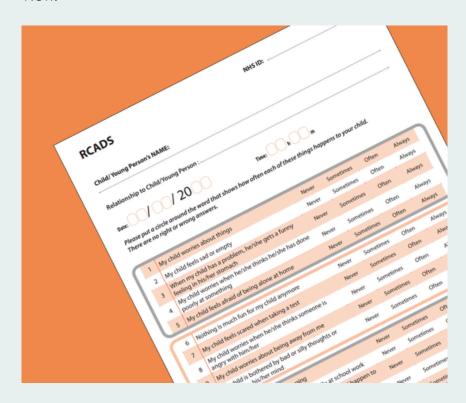
The working group reported that in some cases measures are being used in an unhelpful way that can feed into situations in which the mental health distress of neurodivergent children and young people is not recognised and addressed, and the distress is instead labelled as a behavioural issue.

Mental health services can have assumptions relating to outcome measurement including expectations that:

- honest about difficulties at assessment or in early sessions: it may can take more time for neurodivergent children and young people to be able to reflect and understand themselves so that they can give honest responses to questions. Also when they feel disengaged and bored by the questions they are unlikely to provide honest responses
- scores should demonstrate improvement: whereas it is common for scores on measures to worsen over early sessions, as the neurodivergent child or young person understands more about themselves and how they are feeling. This means that overall, the measure is less likely to demonstrate meaningful change.

Additional challenges were identified that relate to parentcompleted questionnaires. It was perceived that there can be a tendency for parents to exaggerate responses when they are asked to complete measures about their child to secure further support.

Furthermore, neurodivergent young people told the working group that they don't feel understood by their parents or carers, and therefore parent and carer responses to questionnaires may differ from the child or young person's view.



Challenges associated with the capability and confidence of professionals

Neurodivergence encompasses a range of needs and mental health professionals need the skills and confidence to consider and respond to these in the way they use outcome measures.

In particular we would highlight:

- staff awareness, understanding and confidence around the use of measures was identified as a challenge by the working group
- there is a lack of consistent training and on how to use, adapt, and interpret outcome measures with neurodivergent children and young people
- many clinicians report limited confidence and knowledge in assessing needs of, and supporting neurodivergent children and young people with cooccurring mental health difficulties.



Developing effective practice

Young people and the working group suggested a number of ways in which the practice of using outcome and feedback measures with neurodivergent children and young people could be improved.

Select and use measures better suited to neurodivergent children and young people

The working group recommend that services and professionals think carefully about which measures are most suited to the needs of neurodivergent children and young people.

Commonly used measures such as the Strength and Difficulties questionnaire (SDQ, 25 items) and the Revised Child Anxiety and Depression Scale (RCADS, 47 items) have a high number of questions and are symptom-based measures. Both measures provide thresholds, based upon normative data that is unlikely to reflect neurodivergent populations.



Young people and practitioners recommend:

- shorter measures and those that are easier to read and understand
- selecting measures with appropriate language, including tone, expression and word choice
- using measures that focus upon strengths as well as struggles. Wellbeing and resilience based measures can provide a useful mix of questions that achieve this.
- considering aspects of life that are important to young people beyond mental illness symptoms, including measures of life functioning and satisfaction, quality of life, coping and resilience
- choosing measures that reflect the individual's needs and preferences. For example whilst the measures listed in the table below have been validated for their respective age ranges, the individual ability of a child or young person to understand and respond to the questions should be considered

Some measures to consider

Brief self completed measures	Туре	No. of questions	Age range
Me and My Feelings	Emotional and behavioural difficulties	16	8+ years
Kidscreen-10	Health and wellbeing	10	8-18 years
CORE-10 or YP-CORE	Psychological distress	10	11-18 years
<u>SWEMWBS</u>	Mental wellbeing	7	10-18 years
Child and Youth Resilience Measure: Child Version (CYRM), short form	Resilience	12	5-9 years (child) 10-23 years (youth)
Outcomes Stars	Various	Various	Various
Brief Multidimensional Student's Life Satisfaction Scale (BMSLSS)	Life satisfaction	6	8-18 years

Measures have been developed to meet the needs of neurodivergent young people, for example the 'Anxiety Scale for Children - Autism Spectrum Disorder - Child version' (ASC-ASD) which has been developed based upon the anxiety subscale of the RCADS. The working group report that this measure is more sensitive to picking up anxiety-based difficulties in autistic children and young people than the standard RCADS.

There are versions of the <u>Short Warwick-Edinburgh Mental</u> <u>Wellbeing Scale and Kidscreen10</u> intended for young people with intellectual difficulties that might be more accessible for neurodivergent young people.

Image-based measures can be more accessible for neurodivergent children and young people. Often these are described as measures for children and young people with learning difficulties or disabilities. As research highlights the co-occurrence of intellectual and learning difficulties and autism, these measures can be more suitable for neurodivergent children and young people than standard measures.

Some examples to consider:

- Meet My Needs outcome measures for young people with Learning Disabilities
- **LD-CORE-14** co-designed with people with learning difficulties/disabilities to assess psychological distress

There are benefits in being able to provide flexibility or choice over which measures are used with individual service users and using a combination of shorter measures that focus on different aspects of emotional and mental health. Be aware that offering choice and using multiple measures has the potential to overwhelm neurodivergent children and young people.

When selecting a measure with parents and carers, also consider that parents and carers may be neurodivergent and therefore the choice of measures for them and the ways in which they are introduced should reflect this.

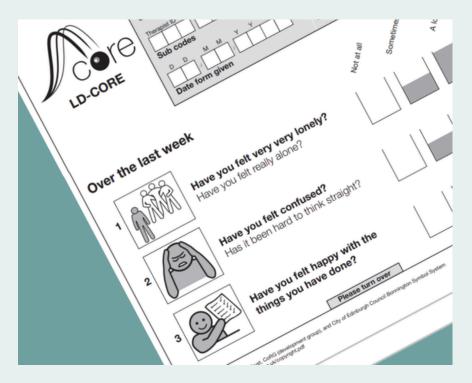


Image source: www.coresystemtrust.org.uk

Capture multiple perspectives

Using measures to capture the perspectives of parents, carers, teachers and mental health professional, alongside self-reported measures, can capture a wider understanding of the child's strengths and needs. They also provide a wider measure of any change that might be happening during support or treatment.

Be aware that young neurodivergent people can feel that their parents don't understand how they are feeling so the results of parent or carer completed measures should be interpreted accordingly and alongside child self-reported measures when possible.



Professional completed measures

Parent and carer completed measures



CGAS

HONosCA Learning Disabilities

HoNOSCA

HONosCA Intellectual Difficulties Kidscreen parent version

RCADS-P (parent version)

<u>Anxiety Scale for Children - Autism</u> <u>Spectrum Disorder (ASC-ASD) - parent version</u>

<u>CYRM person most knowledgeable</u> version

Give it time

To get the best engagement with measures and to improve the accuracy of responses, it is recommended that they are introduced once a sense of trust and rapport have been developed. Work with neurodivergent children and young people so that they feel comfortable with describing their feelings and experiences before administering questionnaires.

Be prepared that neurodivergent children and young people may need more time to complete measures, to respond honestly and to avoid overwhelm. While there is limited time available in sessions, the working group stressed that in the long-term taking more time can be beneficial for the therapeutic alliance and ultimately benefits the service user as they feel heard and safe.



Be prepared to introduce and explain measures, including response options

CORC guidance on the best practice use of outcomes measures suggests that professionals should familiarise themselves with a measure before asking service users to complete it and this is crucial in this context. It is important to consider the challenges that neurodivergent children and young people might have with completing measures (see above), including any wording or phrasing that might be difficult to understand or interpret, questions that might be unsettling and the reasons why individuals might struggle to provide honest responses (e.g. masking, Rejection Sensitive Dysphoria, perceiving measures as a test).

Consider these challenges when introducing and explaining measures to neurodivergent children and young people so that they feel more comfortable to complete measures honestly.

Neurodivergent young people reported that it would be helpful for them to watch a coproduced video that explains measures, what they are, how they are used and why they are helpful, in a neurodivergent young person friendly way, prior to their appointments. They also told us that it can be helpful for them to see the measures prior to having to complete them so that they have time to consider the questions and their responses.

In sessions with neurodivergent children and young people, it can be helpful to have a printed-out explanation of what the questionnaires are and why they are helpful, and to offer the child or young person the choice to either read this themselves and/or to listen to your explanation.

Young people told us that questions such as 'I have felt useful' or 'How are things in your family?' are unfamiliar to them and confusing. Consider how to give relevant context to each question on a measure and provide examples. It can be helpful to develop an aid to each question on a measure.

The young people also told us that answers to a question like 'I have been feeling optimistic' will depend on when and where it relates to (at home, at school, in the mornings or weekends). So be prepared to provide an explanation and examples of the response options to measures. This includes an explanation of response options such as 'sometimes' and 'often'.

Help the child or young person to understand the time frame assessed in the outcome measure, for instance, the last week, last month.



Be flexible and provide options

Neurodivergent children and young people told us that they can feel uncomfortable answering questions in front of their mental health professional, and they can feel under pressure to answer positively. To help them to feel at ease, explain that there is no expectation or pressure on their responses.

Provide a range of options for how measures are completed, either on paper, on electronic systems, completing measures together in conversation (service user and practitioner) or providing unpressurised space for the service user to complete them.

Neurodivergent young people told the working group that they have a preference for using electronic systems not only for completing measures, but also as a way for them to understand the results. Suggestions include:

- providing a progress bar to show how much of the questionnaire has been completed
- providing a 'drop-down' or 'hover-over' explanations of questions to provide more clarity over the question, its timeframe and response options
- > sliding scales can be offered so that a young person has to move a slider to represent their answer.

The young people also told us that they would like a visual representation of how their scores change such as a simple chart, to help them to reflect on what has changed and what contributed to the change.

Young people also told us that they would like to use electronic systems or apps that would allow them to complete measures in their own time and to reflect back on previous responses and scores. Consider the option of providing a link to a measure to be sent to service users electronically so that they can be completed in their own time before the next session.

Also consider how frequently measures are used as neurodivergent young people told us that being asked to complete measures during each session can be very tiring and sometimes distressing.



Be creative and make measures accessible

To increase engagement with measures, consider how they are presented. Whether using paper or electronic forms, consider:

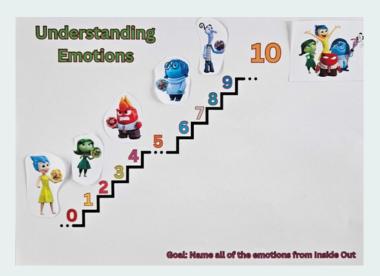
- making the forms more engaging and accessible including the choice of fonts, font sizes, colours and their layout or visual presentation.
- using coloured paper, and using a larger font size and good quality of print. It can be helpful to use dark backgrounds and lighter fonts. Ensure that questionnaires are uncluttered with key terms in bold.
- splitting questionnaires into their individual questions and focus on one question at a time. Give time for service users to consider their answer to each question before moving onto another question.
- wising measures creatively with neurodivergent service users to make them more accessible and engaging. It can be helpful to have a visual representation of responses using images and smiley faces or emoji's (ensure that there is a shared interpretation of these). Icons such as PECS (Picture Exchange Communication System) images next to the questions can help service users to conceptualise what the questions mean. (PECS is used to teach individuals with autism and special needs to initiate functional communication primarily through picture symbols). See also image-based measures listed above.

Consider how measures might be completed via an activity rather than a form; could accessories such as Lego or Play-Doh be used to make measures interactive?

Goals-based measures are a good example of how measures can be creatively adapted to meet the needs and interests of the individual child or young person. As there is no requirement to use a standardised form to track progress to goals, it means that the look and format of your goals tracker can be designed to make it accessible and attractive to the service user.

The <u>Accessible Goals Project</u> has developed some examples of how they have designed goals forms in this way.

Young people told us that they want to be involved in deciding how measures are used creatively as for example, whilst many neurodivergent young people find that visual representations are highly useful others can find them distracting.



Consider language when discussing scores

Neurodivergent children and young people tell us that they want to hear feedback on the measures that they have completed. It is important therefore to have a conversation about their responses and scores, both to check out responses and to ensure the best interpretation of the results.

Care should be given to how measures are explained and interpreted to avoid emotional distress. Often the language used around mental health outcome measures is medicalised, including references to disorders, deficits and difficulties. This can lead to service users having feelings of inadequacy or 'being broken' (see Rejection Sensitive Dysphoria above). Be mindful of the language used and avoid using unsupportive labels. It can be helpful to use strength-based language and to respond to results with a sense of curiosity.

Often there is need for mental health professionals to keep parents and carers informed about their neurodivergent child's support and progress. Language again can be a challenge, as it might lead to struggling parents feeling blamed for the situation. Just as with children and young people, be considerate of the language used when interpreting measures with parents and carers.

Ask for and respond to feedback about sessions

Neurodivergent young people told the working group that they want to give feedback on how sessions are going but they often find it uncomfortable and feel under pressure to provide positive feedback.

The use of feedback as part of treatment or support should be explained before the first appointment and further explained throughout. Consider how a neurodivergent child or young person might be able to provide feedback safely, for example: filling in the form in front of the professional and not having the professional read their feedback in front of them.

It is valuable to use measures to capture feedback from children and young people about their support or treatment, such as the <u>Session Rating Scale (SRS)</u>, the <u>Sessions Feedback Questionnaire (SFQ)</u> and the <u>CARE Patient Feedback Measure</u>. These measures should be used routinely throughout support.

Make use of electronic systems to capture feedback from the young service user whilst they are away from the session, as they may feel less pressured and have time to reflect on their experiences.

Young people asked for systems to allow them reflect on their responses after the session, including using notes, voice notes, and more creative methods.

Think about how you can use creative ways to solicit feedback such as providing an array of images (have a look at Blob Trees or Blob Classrooms) or smiley faces or emoji's for a service user to pick from. Once selected, develop a conversation around the young person's interpretation of that emoji or image to ensure that it is interpreted correctly. By doing so, a valuable conversation can be developed around how they found the session.



Set and track goals collaboratively

As with neurotypical children and young people, goals should be set and tracked collaboratively to offer agency to those accessing support. Neurodivergent children and young people told the working group that goals can provide structure to treatment, can provide motivation and can boost self-esteem. Some considerations that were highlighted in doing this with neurodivergent children and young people:

- they may have limited experience setting goals and may initially think about goals or expectations that others have for them - perhaps their parents, or the reason they have engaged with support (e.g. conduct or behaviour difficulties they may feel they are in trouble for)
- it may be difficult to consider 'what do I want?'; this might be a question they have never been asked before
- they may have had experiences (for example in their education setting) of targets and being set for them: the idea of another goal may feel unsupportive and or like an additional stressor
- they are likely to feel overwhelmed when asked for their goals for therapy, and under pressure to disentangle the array of challenges that they are experiencing. This can lead to panic and/or shutting down
- They may feel pressure to achieve a 10/10 on any goal set (perceiving measures as a test and wanting to avoid feelings of failure or inadequacy).

Consider how a neurodivergent child or young person might feel and react when asked to consider their treatment goals. Goals should be introduced with care. Consider using questions such as 'what are you hoping for from our sessions?' or 'how will you know if our sessions have helped you?'. These questions give the neurodivergent child or young person the opportunity to share what is on their mind and to talk about their lived experiences. This allows the practitioner to listen out for and to suggest potential short and long term goals. Care needs to be taken to ensure that these have been interpreted appropriately and to give the child or young person choice over which to focus on.

It can take more time to set goals with neurodivergent service users than with neurotypical children and young people. Be considerate of Masking (see above) and ensure that any goal relates to what the child or young person wants to change rather than the expectations of others: the goal should relate to who they are rather than them fitting in.

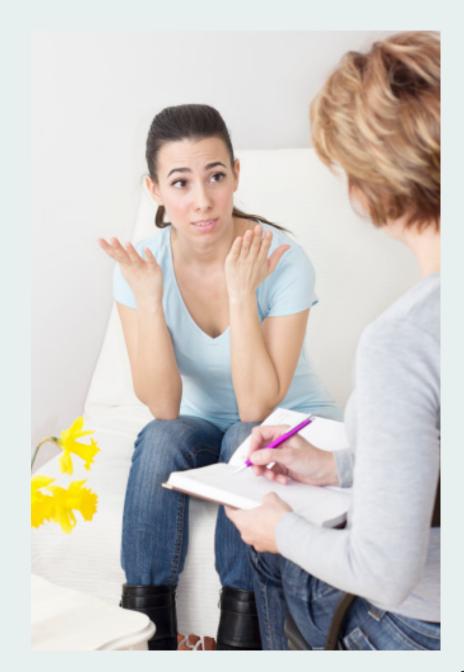
It is crucial to explain that goals are about progress, moving toward where they want to be in small steps. It can be helpful to break goals down into smaller, more achievable sub-goals or aims.

Neurodivergent children and young people may need help fulfilling goals they are more likely to forget their goals and often find it difficult to plan. It can be helpful therefore to involve parents and carers, to help their child with these things, and to provide support for their child in carrying out any agreed practice or actions.

When working collaboratively with neurodivergent children and young people to identify and set goals for their support it might be helpful to explore more practical goals, which can be more easily understood, where emotional goals may be harder to identify and work on.

As interoception can be limited, it can be beneficial to focus on goals related to noticing the signals of emotional distress and communicating feelings. For example, a young person experiencing overwhelm which affects their mood resulting in anger. This young person struggles to recognise and communicate their feelings which can be perceived as dysregulation or a lack of emotional regulation. In this example, goals can be collaboratively set around the young person's awareness of feeling overwhelmed and how they communicate this to parents.

Be aware that goals can change overtime so you may need to adapt accordingly. This means checking in on the relevance of a goal and giving time to make sure that it is still important to the child or young person.



Developing staff and the implementation of outcome measurement

Consider how the skills and confidence of mental health professionals can be developed so that they are better able to understand and respond to the individual needs and preferences of children and young people. This can be achieved through a combination of internal and external staff training and staff support networks (e.g. communities of practice) that support reflection and shared practice.

Flexible and creative solutions to the challenges presented above need time and space to develop and are best co-created with service users who are the experts by experience. As a service or team, plan how a range of creative resources can be co-developed for all staff to make use of. Think about how staff can be supported to use the resources confidently in their practice.

The working group recommends that, as part of tailoring mental health care to individual differences (given that support needs vary), flexibility in service provision be considered, including:

- Offering extended triage time that can be used to explore and identify measures that suit the needs and preferences of neurodivergent service users.
- Allowing appropriate time for measures to be completed meaningfully beyond the first session (often assessment or choice).
- > Supporting and developing staff to integrate the recommendations made in this guidance.

To understand more about how to improve mental health support for neurodivergent children and young people, read:



'Making Mental Health Services Better for Neurodivergent Children and Families: A Practical Guide for Professionals and Parents'. [15]



'Improving Mental Health Therapies for Autistic Children and Young People: Promoting Selfagency, Curiosity and Collaboration'. [16]

Working Group

Our thanks to the energy and input from everyone who was involved in the working group, including:

- Emma Cosslett
 Children's Psychological Therapist
- Georgina Johnson
 Highly Specialist Clinical Psychologist and Principal
 Psychologist Outcomes Lead
- Hyelin Kye
 Educational Mental Health Practitioner
- Kate Vingoe
 Pastoral Mentor (SEN Specialist) and
 Neurodiversity Practitioner
- Liz Long
 Children and Young Person's Therapist
- Marina Kruger
 Clinical Lead at Independent SEN schools
- Phoebe Cooper, Lisa Crawford and Nazia Chowdhury West Sussex CAMHS

- Rachel Cullen
 Assistant Headteacher and Speech and
 Language Therapist
- Ruth McElvanney
 Learning Disability and Autism Keyworker (CAMHS)
- Ross Lawton
 CBT Therapist and SEND Lead
- Young Person's Advisory Service (YPAS) as experts by experience (10 young people aged 16-25)
- The internal Anna Freud EDI
 Neurodiversity and Mental Health staff
 working group
- Lee Atkins
 CORC Regional Officer
- Chrissy Norwich
 CORC Communications and Marketing Officer
 and Children and Young Person's Therapist

The Child Outcomes Research Consortium (CORC) brings together organisations and individuals committed to using and improving evidence to improve children and young people's mental health and wellbeing. We are experts in measuring mental health outcomes.

Founded in 2002 by a group of mental health professionals determined to understand the impact of their work, today our network includes mental health providers, education settings, cultural and community services, local authorities, professional bodies and research institutions from across Europe and beyond.

We hold data relating to mental health and wellbeing outcomes of more than 400,000 children and young people in the UK. We support others to gather and understand their own data. We build expertise about using this information to improve support.

CORC is a project of Anna Freud.





Visit the CORC website for resources and information associated with outcome measurement, plus services to support you.



©CORC on Twitter





@corc-annafreud





CORC on LinkedIn
Child Outcomes
Research Consortium





Newsletter sign up





corc.uk.net



References

- ¹ https://explore-education-statistics.service.gov.uk/find-statistics/special-educational-needs-in-england/2024-25
- ² Russell, G. et al. (2022). Time trends in autism diagnosis over 20 years: a UK population-based cohort study. J. Child Psychol. Psychiatry, Vol 63, 674-682. Sayal, K. et al. (2018). ADHD in children and young people: prevalence, care pathways, and service provision. Lancet Psychiatry, Vol 5, 175-186. Elsevier
- ³ N8 Research Partnership (2024). A country that works for all children and young people. Centre for Young Lives.
- ⁴ Children's Commissioner for England Annual Report and Accounts, 2024-25
- ⁵ Support for neurodivergent children and young people, UK Parliament POST, 2024
- ⁶ National Autistic Society, 2021; Rudy, 2020
- ⁷ What is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis, Journal of the American Academy of Child & Adolescent Psychiatry (2017)
- ⁸ Psychiatric Disorders in Children With Autism Spectrum Disorders: Prevalence, Comorbidity, and Associated Factors in a Population-Derived Sample, Simonoff, Emily et al. Journal of the American Academy of Child & Adolescent Psychiatry, Volume 47, Issue 8, 921 929
- ⁹ Prevalence of co-occurring mental health diagnoses in the autism population: a systematic review and meta-analysi, Lai, Meng-Chuan et al. The Lancet Psychiatry, Volume 6, Issue 10, 819 829
- ¹⁰ Emotional burden in school as a source of mental health problems associated with ADHD and/or autism: Development and validation of a new coproduced self-report measure, Lukito et al, 2025
- ¹¹ Support for neurodivergent children and young people, UK Parliament POST, October 2024
- ¹² Approaches to improve mental health care for autistic children and young people: a systematic review and meta-analysis, Pemovska et al, 2023
- ¹³Murray D, Lesser M, Lawson W. Attention, monotropism and the diagnostic criteria for autism. 2005
- ¹⁴ Autistic Masking: Understanding Identity Management and the Role of Stigma, June 2023, Kieran Rose and Amy Pearson
- ¹⁵ Williams, N., Torr, H., Patel, D., Edinborough, A., & Torr, M. (2025, October 15). Making Mental Health Services Better for Neurodivergent Children and Families: A Practical Guide for Professionals and Parents. Retrieved from osf.jo/3vtdx
- ¹⁶ Pavlopoulou, G., Crane, L., Hurn, R., & Milton, D. (Eds.). (2024). Improving Mental Health Therapies for Autistic Children and Young People: Promoting Self-agency, Curiosity and Collaboration (1st ed.). Routledge