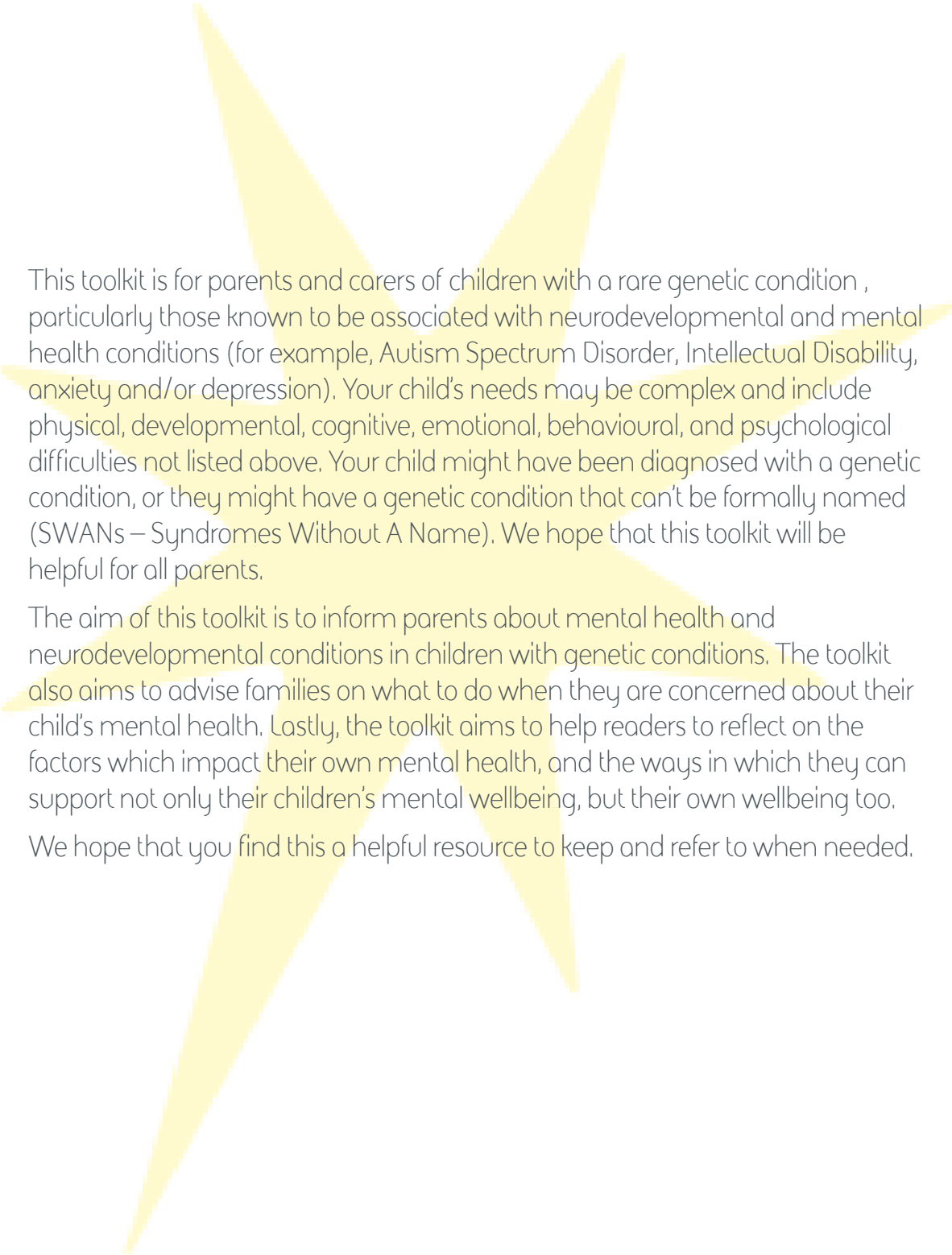


Mental Health in Children with Rare Genetic Conditions

A Guide for Parents and Carers



A large, faint yellow star graphic is centered on the page, with its points extending towards the corners. The text is overlaid on the star.

This toolkit is for parents and carers of children with a rare genetic condition , particularly those known to be associated with neurodevelopmental and mental health conditions (for example, Autism Spectrum Disorder, Intellectual Disability, anxiety and/or depression). Your child's needs may be complex and include physical, developmental, cognitive, emotional, behavioural, and psychological difficulties not listed above. Your child might have been diagnosed with a genetic condition, or they might have a genetic condition that can't be formally named (SWANs – Syndromes Without A Name). We hope that this toolkit will be helpful for all parents.

The aim of this toolkit is to inform parents about mental health and neurodevelopmental conditions in children with genetic conditions. The toolkit also aims to advise families on what to do when they are concerned about their child's mental health. Lastly, the toolkit aims to help readers to reflect on the factors which impact their own mental health, and the ways in which they can support not only their children's mental wellbeing, but their own wellbeing too. We hope that you find this a helpful resource to keep and refer to when needed.

Contents

Neurodevelopmental and mental health conditions in children with genetic conditions	5
Diagnosing mental health and neurodevelopmental conditions	14
Information about the increased risk for mental health and neurodevelopmental conditions in children with a genetic condition	25
Protecting parent/carer mental health	27
References	32
About the authors	35



Neurodevelopmental and mental health conditions in children with genetic conditions

Neurodevelopmental conditions and mental health conditions: What are they and what is the difference?

We often hear people talking about *neurodevelopmental conditions* and *mental health conditions*, but what are they actually talking about when they use these terms?

Neurodevelopmental conditions

Neurodevelopmental conditions are a group of conditions which include:

- Attention deficit hyperactivity disorder (ADHD)
- Autism spectrum disorder (ASD)
- Communication disorders
- Intellectual disability (ID)
- Motor disorders
- Specific learning disorders (involving reading, writing, and arithmetic)
- Tic disorders

They are often mistaken as mental health conditions; however, they are different. Neurodevelopmental conditions are **not** mental health conditions.

How are they caused?

Neurodevelopmental conditions occur when a person's cognitive or motor skills have not developed in the way we would expect them to. This is usually the result of biological factors and environmental factors (i.e., the things we experience in our life) working together.

Definitions

Cognitive skills - Cognitive skills are a set of brain skills. They help us to do things like learn and remember information (including languages), solve problems, pay attention, and make decisions. They help us to make sense of the world around us.

Motor skills - Motor skills are movements and actions. Motor skills include 'gross motor skills' and 'fine motor skills'. Gross motor skills require large muscle groups to perform an action (for example, walking or throwing a ball). Fine motor skills require the use of smaller muscle groups to perform more precise actions (for example, fastening buttons or writing carefully).

The following are examples of some biological and environmental factors that have been linked to increased chance of having a neurodevelopmental condition(s):

1. Birth complications such as premature birth and low birth weight¹
2. Being male - neurodevelopmental conditions are more commonly seen in males however this might just be due to an under diagnosis of neurodevelopmental conditions in females²

Note: We see this trend generally even out between males and females during adolescence so that the rate of neurodevelopmental conditions is more equal between girls and boys

3. Our genetic make-up³
4. Socio-economic position⁴ – this is a broad social measure which includes information about a person's occupation, financial income, and education. For example, people who have less access to education and a steady income will score lower on socio-economic factors. People who score lower are more likely to have one or more neurodevelopmental conditions compared to people who score higher, however not all people with lower scores will have a neurodevelopmental condition(s) and some people with higher scores will have one or more neurodevelopmental conditions.

Neurodevelopmental conditions typically appear in childhood. They can't be 'cured', so symptoms experienced by children don't tend to 'go away' completely when they are adults, but they do tend to lessen with age⁵.

The impacts of these conditions will be different for everyone, but children with neurodevelopmental conditions typically have more difficulties with social, cognitive and/or motor skills⁶ than children without a neurodevelopmental condition. These difficulties can cause challenges for children in social and educational activities^{7, 8, 9, 10}.

Mental health conditions

Mental health conditions are health conditions which are linked to atypical emotion regulation, thinking and/or behaviour. Conditions and examples include:

- Mood Disorders (e.g. depression, bi-polar disorder)
 - Anxiety Disorders (e.g. phobias, panic attacks)
 - Eating Disorders (e.g. Anorexia nervosa, Avoidant Restrictive Food Intake Disorder - ARFID)
 - Psychotic Disorders* (e.g. schizophrenia, schizoaffective disorder)
- * Schizophrenia is classed as a mental health condition, however there are an increasing number of professionals who now consider it to be a neurodevelopmental condition¹¹.*
- Personality Disorders (e.g. borderline personality disorder)
 - Addiction

Individuals with a mental health condition often experience distress which can manifest itself in various ways (for example, unusual and/or worrying behaviours like withdrawal, restlessness, and self-harm). Mental health conditions also tend to cause children difficulties engaging in day-to-day activities (for example, social, and educational activities). Like neurodevelopmental conditions, both biological factors and environmental factors, including our life experiences cause us to experience problems with our mental health¹².

However, anybody can experience a mental health condition, and they can appear for the first time at any age. They are also common (39% of adults accessed mental health treatment in England in 2014¹³). Mental health conditions are largely treatable and many people who receive treatment will make a full recovery, however it is important to note that not all people will fully recover and will need ongoing support to manage their condition. Some people may recover and

then later become unwell again. Again, with treatment, it is possible to make another full recovery. Others may have long-term conditions which are more resistant to treatment and so will often need support with daily living.

The chance of children with a genetic condition developing a neurodevelopmental or mental health condition

Children with certain rare genetic conditions have a higher chance of developing a mental health and/or neurodevelopmental condition compared to children who have not got the genetic condition¹⁴. They also have a higher chance of experiencing motor, cognitive, social difficulties and sleep impairments.

How rare is rare?

The genetic conditions we're talking about are called 'rare'. When we talk about rare conditions it is important to emphasise that whilst it is correct that individually each of these conditions are rare (i.e., not many people will have the same genetic condition), altogether these conditions are common. 1 in 17 people are said to be affected by a rare condition at some point in their lives¹⁵.

Also, genetic conditions are collectively found in approximately 15% of children with neurodevelopmental conditions/difficulties¹⁶. It is important for professionals to know this and to be alert for signs of neurodevelopmental difficulties in children with genetic conditions so that children's needs are more likely to be identified and supported at the earliest opportunity.

Definitions

Psychotic experiences - "psychotic experiences" include hallucinations and delusions, however the experiences are not severe enough that the person having them is considered unwell. This means the person experiencing them is not considered to have a mental health condition.

Hallucinations - Hallucinations are sensory experiences (sight, sound, touch, taste, smell) caused by a person's mind. They happen when someone sees, hears, smells, tastes, or feels things that aren't real. Their mind has created the sensory experience and they feel real, but there is no actual environmental reason for the experience. For example, hearing voices that aren't real or feeling things crawling on your skin that aren't there are hallucinations.

Delusions - Delusions are beliefs which are not real, however they are absolutely true to the person who believes them. Delusions are caused by abnormal thinking and do not include cultural or religious beliefs. The person will not be swayed from the belief, even when there is evidence that shows their belief is untrue. For example, a person might believe they are being followed when there is evidence that this is not true, or that they are a celebrity and everyone knows them when they are not.

Research Evidence

Genotype–phenotype associations in children with copy number variants associated with high neuropsychiatric risk in the UK (IMAGINE-ID): a case-control cohort study¹⁴

In one study, researchers found that 80% of children with certain genetic conditions met criteria for at least one mental health or neurodevelopmental condition. They were also more affected on cognitive and behavioural traits compared to their siblings who were not diagnosed with a genetic condition.

This research also suggests that children with different rare genetic conditions do not present all that differently from one another. That is, we see that the effects on mental health and neurodevelopment are more similar across a range of rare genetic conditions than they are different.

Different behaviour at different ages

The study found that older children were more likely to experience difficulty with memory, mood problems and psychotic experiences compared to the younger children. The younger children were more likely to have hyperactivity and attention problems.

Note: It's important to note that psychotic experiences are seen in the general population and that the people experiencing them aren't classed as having 'a problem'. Because psychotic experiences are not severe enough to be considered a symptom of being mentally unwell, the children in this study would not have received a formal diagnosis of psychosis.

Not all children with a genetic condition who experience psychotic experiences will develop a mental health condition, however, because they are at a higher genetic risk for problems with their mental health, professionals should monitor children who are having psychotic experiences in case they need help in the future.

Are there differences between boys and girls?

This study also found that there are differences between between boys and girls, but the differences were small. Boys seem to have more difficulties with hyperactivity, attention, and sleep. However, girls seem to have more problems with processing certain types of visual information.

Genetic and environmental risk factors for mental health conditions

We've spoken a lot about how having certain genetic conditions can increase a child's chance of developing neurodevelopmental and mental health conditions. However, it is important to stress that not all children with a genetic condition will develop them.

As mentioned previously, we can't 'cure' neurodevelopmental conditions, but we can do things to protect our mental health. Understanding what causes mental health conditions can help us to do this.

Whilst our genetics are important in making us who we are, so is our environment (i.e., the experiences we have in life). Our genes and our environment and experiences all play an important part in whether we experience problems with our mental health.

To illustrate how our genes and experiences interact to cause mental health conditions, we will present the 'Mental Health Jar' (see next page).

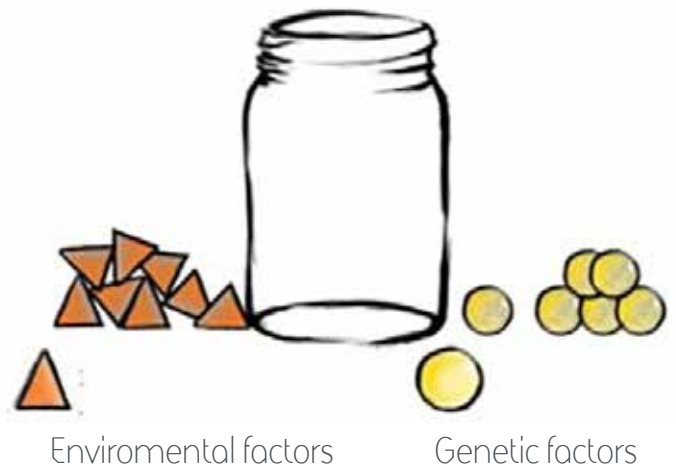
The Mental Health Jar¹⁷

Adapted from "How To Talk To Families About Genetics And Psychiatric Illness" by Holly Landrum Peay, Jehannine Claire Austin. Publisher WW Norton.

We all have a Mental Health Jar. Our jars represent how vulnerable we are to experiencing a mental health condition. We have different things inside our jar that increase and decrease our vulnerability.

Factors which affect our jar:

- a) **Genetic factors** (our genes) which **increase** our risk of developing a mental health condition.
- b) **Environmental factors** (our life experiences and stressors) which **increase** our risk of developing a mental health condition.
- c) **Protective factors** which **decrease** our risk of developing a mental health condition



The genetic, environmental, and protective factors which affect our jars are different for everybody, so our jars will not look the same as each other's.

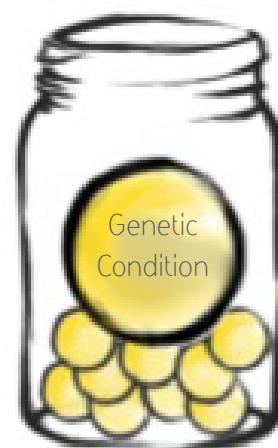
We all have some genetic factors which put us at risk for mental health conditions, but the number and type will be different depending on our genetics. Some of us will have a small amount, some will have a medium amount, and some will have a large amount. We are born with our genetic factors and so we cannot change the amount we have. Children with certain rare genetic conditions have a higher genetic risk of developing a mental health condition and so have a larger genetic factor in their jar that takes up a bit more room.

Child without a genetic condition



Some genetic factors in the jar

Child with a genetic condition

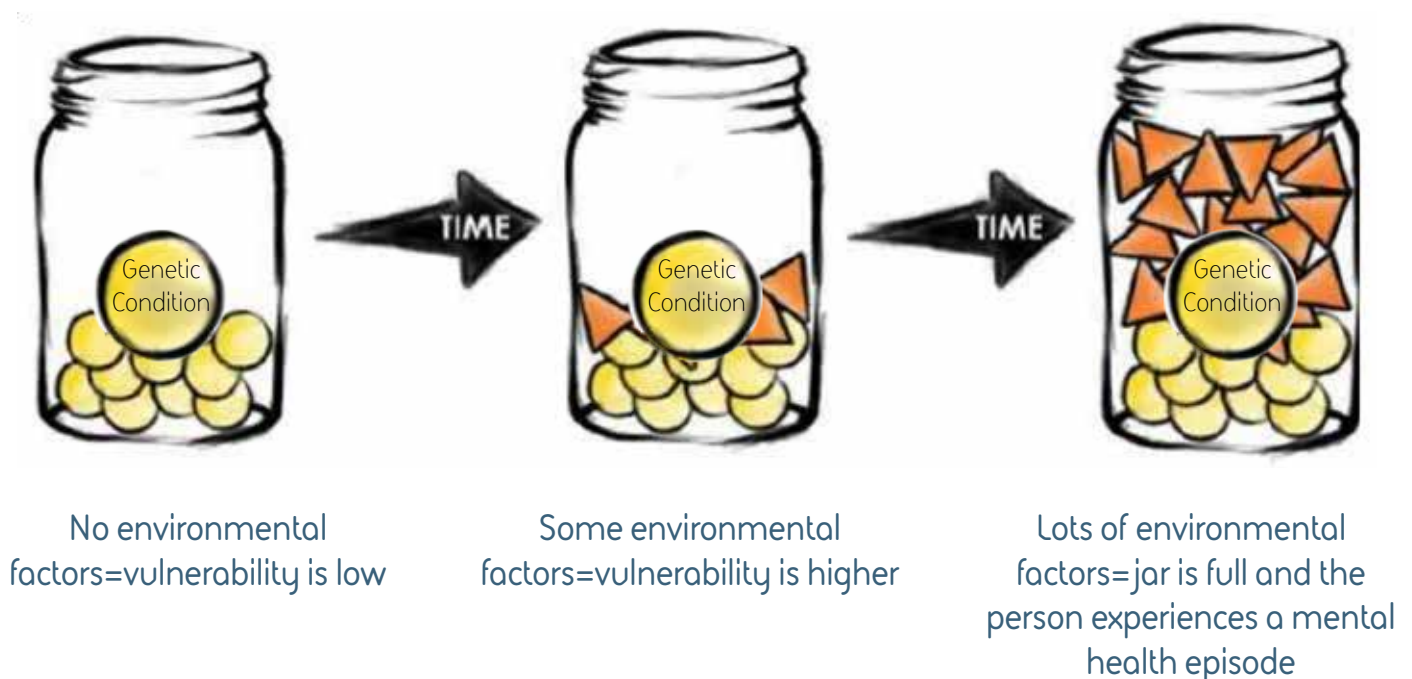


Some genetic factors in the jar, including one big genetic factor

Environmental factors also play a very important role in whether a person develops a mental health condition. For example, not everyone with a mental health condition will have lots of genetic factors in their jar. These people will have lots of environmental factors in their jar instead.

The number of environmental factors can change depending on what is going on in our lives. If the number of environmental factors in our jars are too many, and our jars become full, we will experience a mental health episode. Therefore, how full our jar is tells us how vulnerable we are to experiencing problems with our mental health. If our jar is nearly full, we are more vulnerable, and if it is less full, we are less vulnerable.

Environmental factors can increase overtime and make us more vulnerable to mental health conditions:



Your Child's Mental Health Jar

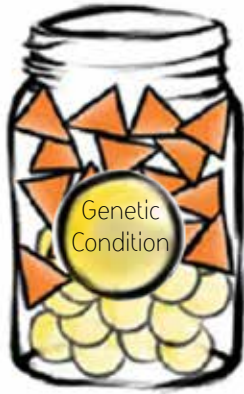
Your child's genetic condition takes up more space in their jar.

Think about your child's environmental factors and how much space they would take up in their jar (i.e., how much of an impact does each environmental factor have on them). This could be something you could do with them. This exercise can help you and your child to visualise their environmental factors which can help you both become more aware of them. Being more aware of them can help us to control them better. For example, if we know that being tired impacts our wellbeing negatively, we can make more of a conscious effort to go to bed earlier or establish a good bedtime routine.

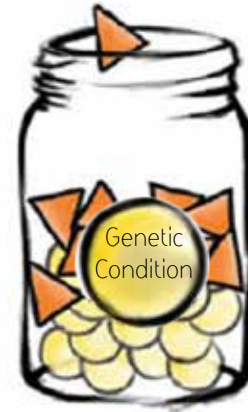
How can we minimise the effects of our environmental factors?

There may be some environmental factors that we can take away from our jars to help us decrease the number of them inside it. For example, children who experience a high sensitivity to noise might find being in public spaces distressing. Things like ear plugs or noise-cancelling headphones might help reduce distress and take the environmental factors, 'public spaces' and 'loud noises', out of their jar.

Taking away environmental factors protects our mental health:



Jar is full of environmental and genetic factors = person will experience a mental health episode

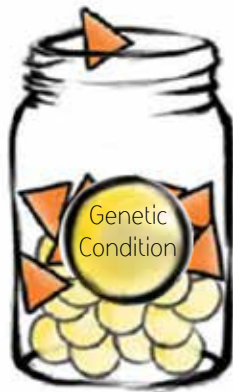


Taking away environmental factors makes jar less full = vulnerability is lower

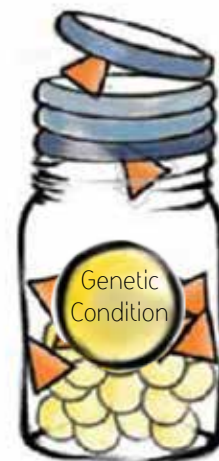
However, there are some environmental factors we can't control or take away completely. These include experiences in our lives which we cannot change, for example, the death of a loved one. In these cases, we can add protective factors to our jars.

Protective factors protect us from the negative impacts our environmental factors can have on our wellbeing. Protective factors are all the things in our life that make us feel happy and have a positive impact on our wellbeing (for example, eating and sleeping well, spending time with friends and family, our hobbies). Protective factors work by making our jars bigger and therefore harder to fill.

Protective factors make our jars bigger and harder to fill:



Jar without protective factors is *smaller* = vulnerability is *higher*



Jar with protective factors is *bigger* = vulnerability is *lower*

Think about what environmental factors you can take away from your child's jar and what protective factors can make their jars bigger. Again, this exercise could be done with your child to help you both recognise what things have a positive impact on their wellbeing.

Is it possible to predict who will develop a neurodevelopmental and/or mental health condition?

We know that children with genetic conditions have a higher genetic chance for developing a neurodevelopmental or mental health condition. However, we still cannot tell who will or won't develop one of these conditions.

There is great diversity in how much an environmental factor will impact us – the same environmental factor in one person's jar might be much bigger and take up more space than in someone else's jar and so will therefore have a stronger effect on their mental health. This is not a weakness, but just personal difference.

Ultimately, we have different experiences, and these experiences impact us in different ways. This makes it hard for health professionals to tell us who will and who will not develop a mental health condition. It is impossible for them to know which environmental factors we will encounter in our lives and how much these factors will impact us individually.

Comorbidity

If a child with a genetic condition does experience mental health and neurodevelopmental conditions, it is common for them to experience more than just one mental health and/or neurodevelopmental condition(s). We often see this pattern in the general population too¹⁸ (for example, people without a genetic condition who have ADHD often also experience depression¹⁹).

Neurodevelopmental comorbidity

Definition

Neurodevelopmental comorbidity – Neurodevelopmental comorbidity – when two or more neurodevelopmental conditions are present in the same person. For example, if a child is diagnosed with Intellectual Disability **and** Autism Spectrum Disorder.

As we have discussed, neurodevelopmental conditions are more often seen in children with genetic conditions compared to children without a genetic condition.

Neurodevelopmental comorbidity is common²⁰. That is, children with neurodevelopmental conditions are likely to have more than one neurodevelopmental condition. For example, Intellectual Disability, ADHD, ASD, and problems with coordination and/or language skills can be seen in the same person.

Children with neurodevelopmental conditions are also more likely to experience problems with their mental health compared to their peers²¹.

Why do we see such high rates of neurodevelopmental comorbidity?

1. Neurodevelopmental conditions and difficulties share some genetic risk⁵. This means that the genetic factors that increase the risk of one neurodevelopmental condition can also increase the risk of other neurodevelopmental condition(s). So, if a child has a higher chance of experiencing a certain neurodevelopmental condition, they could have a higher chance of experiencing other neurodevelopmental condition(s) or difficulties if the same genes are involved.

Conditions we know to have shared genetic risk:

- ◆ Reading and language skills
- ◆ Reading and mathematics skills
- ◆ Language and mathematics skills
- ◆ ASD and ADHD
- ◆ Inattentive traits of ADHD and reading disability and arithmetic disability
- ◆ ASD and language and learning impairments in relatives
- ◆ IQ and ADHD
- ◆ IQ and ASD traits
- ◆ ADHD, ASD, motor co-ordination problems and tics

2. Different neurodevelopmental conditions also share environmental risk too⁵. This means that certain environmental factors increase the chance of the person experiencing all the neurodevelopmental conditions associated with that environmental factor. For example, low birth weight is associated with both ASD and ADHD, so children born with a low birth weight have a higher chance of developing both of these conditions compared to children born in the 'normal' weight range.
3. Neurodevelopmental conditions may share underlying biological processes involved in brain development (for example, the way our brain creates and maintains our synapses)⁵. This means developmental processes in the brain which increase the chance of a child experiencing one neurodevelopmental condition might increase the chance they will experience others. These biological processes are themselves influenced by both genetic and environmental factors.

Definition

Synapse - Synapses help to carry information through the nervous system and they help carry information from one brain cell to the another.

Diagnosing mental health and neurodevelopmental conditions

Diagnostic Criteria

When professionals assess children for a diagnosis, they are looking to see if that child meets the diagnostic criteria of that condition.

Definition

Diagnostic criteria – Diagnostic criteria are like a set of instructions for clinicians to help them diagnose patients. They are a list of specific signs and symptoms and tell the clinician how these signs and symptoms should present for a diagnosis to be given. The diagnostic criteria for mental health and neurodevelopmental conditions are found in diagnostic manuals called *The Diagnostic and Statistical Manual of Mental Disorders (DSM)*²² and the *International Classification of Diseases (ICD)*²³. We use the ICD in the UK.

*The Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation (DC-LD)*²⁴ and the *Diagnostic Manual – Intellectual Disability*²⁵ have been specifically designed for the diagnosis of psychiatric conditions in people with ID.

For example, the diagnostic criteria for ASD will list several symptoms which are commonly seen in children with the condition. For a child to be diagnosed with ASD, the professional must see that the child has a certain number of those symptoms and that those symptoms present in a certain way. If they do not, the child has not met the diagnostic criteria and will not receive a diagnosis of ASD.

Why do we have diagnostic criteria?

Diagnostic criteria are helpful and important because:

1. They provide professionals with a guide to follow which helps them to diagnose people in the same way. This means that if a child were to see two different doctors separately, both doctors are likely to give the child the same diagnosis.
2. Diagnostic criteria also help professionals understand exactly what a diagnosis is. A group of professionals who are talking about a certain diagnosis will be on the same page about what that diagnosis is and understand how the patient is affected.

Ultimately, diagnostic criteria help clinicians to make diagnoses and makes those diagnoses easier for everyone to understand. This is very important to ensure peoples' health is managed quickly and correctly.



Disadvantages of diagnostic criteria

Diagnostic criteria can be an oversimplification of human behaviour. For example, children who are experiencing challenges do not always present in the way that diagnostic criteria say they should. It is also common for children to present with 'not enough' symptoms for a specific diagnosis. These

children can nevertheless experience considerable difficulties in their daily lives.

When emphasis is put on the diagnosis versus the individual child and the specific symptoms they present with, some of the child's needs can be missed.

Research evidence in children with genetic syndromes

A Genetics-First Approach to Dissecting the Heterogeneity of Autism: Phenotypic Comparison of Autism Risk Copy Number Variants²⁶

Mental health and neurodevelopmental conditions in children with genetic conditions cause emotional, behavioural, and social challenges which impact day-to-day activities. However, children don't always meet the full criteria to receive a formal diagnosis.

One research study conducted at Cardiff University investigated ASD in children with genetic conditions*. The researchers found that many children met diagnostic criteria to receive a diagnosis of ASD. However, in the group of children who didn't meet the criteria for an ASD diagnosis, many still experienced ASD symptoms which were considered clinically impairing.

This suggests that children who do not meet ASD criteria, but who experience daily difficulties with ASD symptoms could be overlooked by services and don't receive support.

**This study focused on children with 16p11.2 and 22q11.2 duplication and deletion syndrome.*

Professionals are aware that children do not always fit into neat diagnostic boxes and there are changes being made to account for this. Some services are trying to move away from ways of working that make diagnoses the 'golden ticket' to services by trying to support children who do not receive an overarching diagnosis too. However, there is recognition that there is still a way to go to ensure that all children are supported appropriately.

If diagnostic criteria are too heavily relied upon, children can receive a number of different diagnoses in response to a relatively small set of symptoms they show. This can happen when different diagnoses have similar symptoms as part of their diagnostic criteria. For example, some of the symptoms listed in the DSM-V manual for anxiety and ADHD are similar. For example:

ADHD Symptoms	Anxiety Symptoms
Difficulty in sustaining attention	Difficulty concentrating
Fidgets or squirms Difficulty remaining seated A persistent pattern of motor activity	Restlessness

Diagnostic overshadowing

Definition

Diagnostic overshadowing -diagnostic overshadowing is when a person's symptoms are wrongly attributed to a health condition they have already been diagnosed with, instead of an additional condition the person has.

Diagnostic overshadowing is a problem for children with genetic conditions²⁷. This is because symptoms children present with can be automatically attributed to the genetic condition rather than additional health needs they may have.

For example, professionals might think the social difficulties a child experiences are a symptom of the genetic condition instead of exploring if they have ASD. By doing this, they are overlooking that a child with a genetic condition may have ASD. Likewise, if a child with a genetic condition has been diagnosed with ASD, clinicians might attribute other underlying health needs to this ASD diagnosis and not explore other possibilities.

Diagnostic overshadowing is an important issue because when it happens, additional health conditions are not investigated and therefore remain undiagnosed. This reduces the opportunity for children to receive optimal care.

How can diagnostic overshadowing happen?

1. Mental health and neurodevelopmental conditions in children with genetic conditions cause emotional, behavioural, and social challenges which impact on day-to-day activities. However, children don't always meet the full criteria to receive a formal diagnosis.
2. Children with genetic conditions can present differently to what is considered a 'typical' presentation. For example, ADHD does not always present in children with 22q11.2 deletion syndrome in the same way it does in children without the 22q11.2 deletion syndrome²⁸. However clinical training generally does not prepare health professionals for working with people with genetic conditions. This limited knowledge about rare genetic conditions makes it harder for professionals to spot symptoms of other health conditions.
3. Parents and carers find it difficult to get their voices heard when trying to communicate their child's needs.
4. Failure to investigate explanations for symptoms presented by a child, other than the genetic condition.

How can we reduce the risk of diagnostic overshadowing?

Diagnostic overshadowing can have seriously negative consequences for families. Firstly, it prolongs the time it takes to reach the correct explanation for the child's difficulties and delays proper management of symptoms. We know that early identification of problems and subsequent access to the appropriate treatment/support has a positive effect on a person's health outcomes, meaning diagnostic overshadowing can create health inequalities between those who

are at risk of diagnostic overshadowing and those who are not.

Secondly, failure to investigate and explain the underlying cause of symptoms can result in parents being blamed for their child's symptoms. Parents' concerns can be dismissed and there are instances where parents have only been advised to take part in parenting courses. This is not helpful for either the parents or the child.

Professionals do not set out to purposefully do this, but it can happen.

Below are some ways in which the risk of diagnostic overshadowing could be reduced.

1. Evaluate the overall presentation of the child first, before taking into account their genetic condition - symptoms presented by children that are not known to be typical of the genetic condition should not just be attributed to a genetic cause. Alternative causes should be investigated in the first instance.
2. Understand that the presentation of health complications in children with a genetic condition may be different compared to children without a genetic condition.
3. Genetic conditions can affect the whole body and changes in the way a child presents can occur because a whole host of reasons. Physical, psychological and social (for example, bereavement) reasons should be explored when investigating the reasons behind a behavioural change.
4. Behavioural treatment for symptoms should not substitute medical investigation for the underlying cause of those symptoms. If professionals believe behavioural treatments will be helpful to manage a child's symptoms, the underlying cause should still be sought. Behavioural treatments can be administered at the same time as other explanations for a symptom are investigated.
5. Communicate with the child directly to get a better grasp of the symptoms they are experiencing. If a child cannot verbally communicate, other methods like pictures, photos, symbols, and signs can be used.
Note: The Books Beyond Words give a good example as to how pictures can be used to communicate with children who do not communicate verbally.
6. Value the information provided by parents and carers - To better understand the child, professionals can seek information from parents/carers and learn from them how to communicate effectively with their child.
7. Pay close attention to non-verbal communication (sounds, body positions, facial gestures, and other signs).
8. Professionals could familiarise themselves with appropriate assessment tools to measure things like distress and pain, etc.



Child and Adolescent Mental Health Services (CAMHS)

CAMHS is a specialist service provided by the NHS. They specialise in diagnosing mental health and neurodevelopmental conditions in children and supporting them. You may also hear CYPMHS mentioned which refers to Children and Young People's Mental Health Services. CAMHS and CYPMHS refer to the same service.

CAMHS teams can be made up of these professionals (however this does vary between teams):

- Psychiatrists
- Psychologists
- Social workers
- Nurses

- Support workers
- Psychological therapists (for example, child psychotherapists, family psychotherapists, play therapists, creative art therapists)
- Other professionals such as occupational therapists, dieticians, pharmacists, speech and language therapists, primary mental health workers and charity support workers may also be part of your local CAMHS team

Getting a CAMHS referral

Each CAMHS is a local service and so is run by the local team in your area. Referral processes and support offered can be slightly different and waiting times can vary between areas. This means getting mental health support can be influenced by where you live.

Below is some information which you might find useful if you are concerned about your child's mental health and are seeking support.

- Speaking to your GP is generally the first step to getting a CAMHS referral. GPs can make direct referrals to CAMHS and give you more information about them as a service. It might be worth asking if one of the doctors in your surgery specialises in mental health.
- Some other professionals can make referrals to CAMHS including your child's paediatrician, staff at your child's school, social workers, youth workers or key workers. These professionals can also write a letter to your local CAMHS to support a referral that has already been made by somebody else.
- If you have spoken to one of the above professionals regarding a referral for your child but feel your concerns have not been dealt with as you would have liked, you can try speaking to a different professional. For example, if you have spoken to a GP and not been referred, you can ask to speak to another GP within your surgery.
- Some CAMHS teams accept self-referrals which means that you can refer your child yourself.

As the above information suggests, the referral process to CAMHS can be different depending on where you live. Most CAMHS have their own website so that you can find out more information about how referrals are managed by your local team. Your team's contact details will likely be listed too, so you can get in touch and speak with a member of staff directly. To find your CAMHS team's website, Google 'CAMHS' followed by the area you live. If finding information online is difficult, speak with your GP surgery and they should be able to direct you.

What happens at a CAMHS assessment?

After your child has been referred, they will be put on a waiting list for an initial 'assessment' appointment. This may be a face-to-face appointment or may take place virtually or on the phone. Face-to-face appointments typically take

place at your local CAMHS clinic but could also be at your home and/or your child's school.

Generally, one or two members of the CAMHS team will meet you and your child. They will ask you and your child questions to understand what your child is struggling with and to get a better idea of what support they need. They may also observe your child in different settings, for example, at school.

At the end of your child's appointment, the team will explain the next steps, including what help they think your child might need. This is a chance for you to ask questions too. You should also receive a follow-up report with the outcome of your child's assessment.

If you are unhappy with the assessment outcome, you can ask your GP or paediatrician to arrange for a second opinion, however this may not always be given.



Neurodevelopmental Assessment Pathways

Some areas have a specialist 'Neurodevelopmental Assessment Pathway' service. These services deal with assessment and diagnosis of neurodevelopmental conditions specifically. They may sit within another service (for example, CAMHS or Paediatrics).

Getting a referral

Referral processes vary between areas so again, it is best to check for more information on your local team's website. It is generally a good idea for referrals to be made by the professionals who are involved in your child's care because they can communicate the clearest picture of what your child's strengths and difficulties are across different settings. These professionals might include your child's GP and/or their paediatrician, teachers at their school, educational psychologists, social workers or CAMHS (if they are already involved).

If your child is referred to a neurodevelopmental service, the referral will likely be considered by a panel of professionals who have different expertise. Based on the information they receive they will decide whether they think it appropriate that your child has a full assessment. There will be instances where a child is referred but the panel decide against a full assessment. In these cases, your child will not be assessed further. The team may consider alternative explanations for your child's needs and may provide suggestions/advice about what next steps might be helpful.

If your referral is accepted by the panel, your child will be put on a waiting list for an assessment appointment. The wait for an appointment can be lengthy so you might be recommended to try other services, websites or strategies while you wait.

The assessment

Assessments with a neurodevelopmental service usually involve meetings and discussions between the team and you, your child, your

child's school and other professionals involved in your child's care. The team will ask some general questions but also for some specific information. You may also be asked to complete some questionnaires. The team may also observe your child in different settings and complete some assessments with your child. They will consider all the information they've gathered about your child and evaluate your child's strengths, difficulties and support needs, which may or may not include a diagnosis.

The team's conclusion will be fed back to your family. They may decide your child needs further support from CAMHS or the neurodevelopmental team. This will not be the case for all children. If they conclude your child does not need further support from these teams, they may recommend other support services/groups or make recommendations to your child's school.

The whole process of referral, receiving an assessment and if necessary, receiving support from CAMHS and/or neurodevelopmental services can be very long. It can be difficult to get a referral and it can be a long wait for your child to have their assessment. You may also have to wait a while to hear the decision that has been made.

The experience can be tiring and frustrating. Professionals are also often frustrated that they cannot provide support to children any more quickly and work hard to keep waiting times to a minimum. Sadly, there is very high demand for CAMHS and neurodevelopmental services, and teams often do not have the resources they need.

Although it might seem daunting, try not to be put off by pursuing an assessment if your child needs support.

Going through this process can be stressful, and we encourage parents to speak with family and friends for support. Additionally, many charities have helpline services to offer a listening ear (for example [Unique](#) and [Contact](#)).

Private healthcare

If it is an affordable option, you might consider pursuing an assessment for your child from a private psychologist or child and adolescent psychiatrist. If you do take this route, be clear for what purpose you are seeking a private assessment. There are instances where public services do not accept the results of private assessments. For example, not all local authorities accept private diagnoses as evidence for Educational Health Care Plans (EHCPs). Assessments are costly, so make sure to check that a private assessment will help you obtain the support you're looking for before you embark on this process.

How to choose the right person and service?

1. The internet

The internet can be a good resource to find private practitioners in your area. The websites of accredited bodies (for example, the British Psychological Society) allow you to search for professionals who are registered with them. Being a registered practitioner demonstrates that the practitioner adheres to recognised professional and ethical standards.

● Psychologists

The British Psychological Society (BPS)

The BPS is the representative body for psychologists in the UK. On their website you can find the following search functions:

- ◆ [Directory of Chartered Psychologists | BPS](#) - The Directory can help to find chartered psychologists in your area.
- ◆ [List of Chartered Members | BPS](#) - The public can use this search function to identify whether a particular professional is a Chartered Member of the BPS. You can use this function if you already know the name of the practitioner.

● The Health and Care Professions Council (HCPC)

The HCPC are the regulator for practitioner psychologists in the UK and keep a register of professionals who meet their standards for training and professional skills. You can search whether a professional you have found is a registered with the HCPC here - [Check the Register and find a registered health and care professional | \(hcpc-uk.org\)](#)

● Psychiatrists

The General Medical Council (GMC)

The GMC is the official register for doctors in the UK. They confirm the identity and qualifications of doctors before they join the register and check doctors' ability to practice safely.

You can check whether a psychiatrist is GMC registered here - [The medical register - GMC \(gmc-uk.org\)](#)

2. Ask for advice

- Your child's GP may be able to advise you on the use of private practitioners.
- Other families who you know have been through the process of seeking support for their child may have information to share with you about 'going private'.
- If you are looking for an assessment for the purpose of securing a particular kind of support, it might be worth asking the professionals involved in the process of applying for that support. For example, if you are looking for an assessment to secure an EHCP for your child to be supported at school, you could ask your caseworker whether they accept assessments completed by private practitioners. If they do, they may be able to direct you to a known practitioner.

Alternative places to look for support

Community support services families might find a helpful alternative to CAMHS.

Below we give some ideas of services that may provide support alternative to CAMHS. The type of support these services offer will vary depending on where in the UK you live but it may be helpful to know what they offer either as an alternative to CAMHS or whilst your child waits to be seen by them.

Social Prescribing

Social Prescribing services aim to address people's needs in a holistic way. Professionals can refer patients with social, emotional or practical needs to a range of local, non-clinical services (for example, exercise classes, self-help groups, social or hobby clubs). Those under the service are assigned a link worker to help them access these services.

NHS England has a 'Frequently asked questions' page which provides some good information about social prescribing - [NHS England » Social prescribing – frequently asked questions](#).

Social Prescribing is a relatively new service, and so you might need to check whether it is available in your area. All nations within the UK have made formal commitments to extend Social Prescribing services, however it does remain quite difficult to find information about services within a particular Health Board/Health Trust. We recommend getting in touch with your GP or key worker and asking them if this service is available to their patients.

Your local council

Local councils deliver a host of services and activities which can help to indirectly improve wellbeing (for example, exercise classes, arts and crafts classes, volunteering opportunities or kids' clubs). It is worth having a look on these sites to give you some ideas of what groups/support is available in your area. Many of the activities available feed into the 'Five Ways to Wellbeing' - Connect, Be active, Take notice, Keep Learning & Give - and therefore could help improve wellbeing.

Hub of Hope

The Hub of Hope is the UK's leading mental health support database provided by Chasing the Stigma. It holds information about local and national peer groups, community groups, charities and private and NHS mental health support and services together in one place so that individuals can search what support is available in their area.

You can access and use their search tool here: [Mental Health Support Network provided by Chasing the Stigma | Hub of hope](#).

Same but Different

[Same but Different](#) are a charity which provides a host of services for individuals with a rare condition and their families. This includes the [Rare Navigator](#) service. The Rare Navigator service is only available to families living in North Wales and provides the family with a family-focused care coordinator and advocate and 'aims to ensure that each family is able to access the level of support they require to meet their needs'.

Team Around the Family

Many areas have a Team Around the Family service. Team Around the Family is an early intervention and prevention service that works with families to help them identify their support needs and then supports them to achieve their individual goals by offering advice, guidance and support. You can research whether there is a TAF service in your area by Googling 'Team Around the Family' and your location.

Helplines

Nation or region-specific mental health helplines are available to those seeking support.

England

NHS England provides an urgent mental health helpline. You can search for the correct number to ring for your area for support here: [Mental Health Helpline for Urgent Help - NHS \(www.nhs.uk\)](https://www.nhs.uk).

Wales

Wales advises calling NHS **111** for urgent advice and support.

C.A.L.L. (Community Advice & Listening Line) is a Welsh Government funded helpline hosted by Betsi Cadwaladr University Health Board. The helpline is available to anybody in Wales and offers emotional support and provides information about local statutory and voluntary agencies: [C.A.L.L. Mental Health Helpline - Community Advice and Listening Line \(callhelpline.org.uk\)](https://callhelpline.org.uk).

Scotland

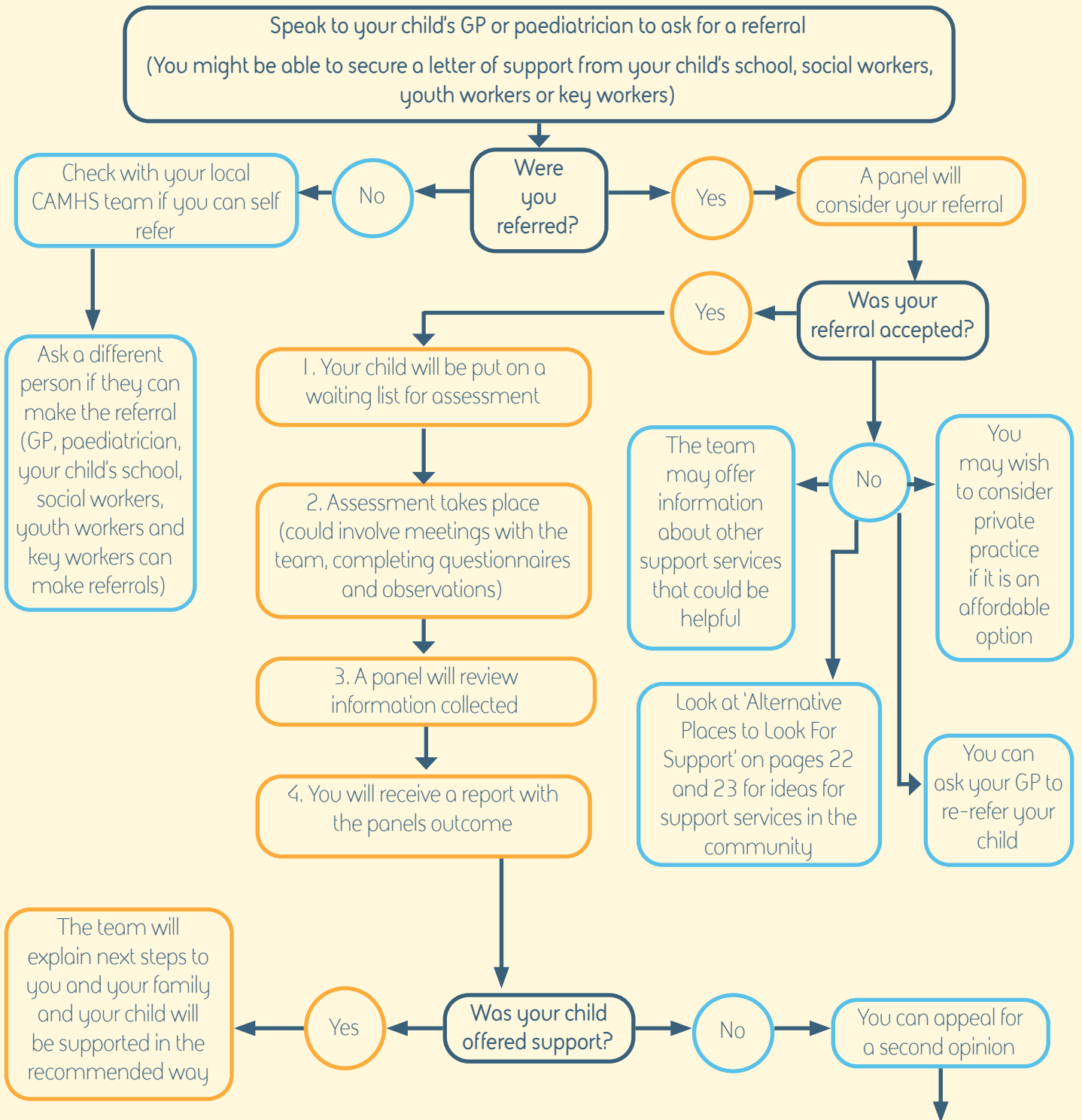
Scotland also advises calling NHS **111** for urgent advice and support.

Northern Ireland

Those in Northern Ireland are advised to call Lifeline when in crisis for urgent mental health support. They have a specific number for those who are deaf or hard of hearing: [Lifeline I nidirect](https://lifeline.nidirect.com).



Accessing CAMHS and Neurodevelopmental Services



- Some tips:
1. This flowchart gives a general indication of the process, however the process may be slightly different where you live.
 2. Look at your local CAMHS website for more information on how to refer your child to their service.
 3. Look to see if there is a specific neurodevelopmental team/pathway in your area.

You may have been recommended alternative support services or groups, and your child's school may have been given information or support (if you have not, it is worth asking the team if this information can be given)

Information about the increased risk for mental health and neurodevelopmental conditions in children with a genetic condition

How do parents find out about the risk of mental health and neurodevelopmental conditions?

Research suggests that parents of children with genetic conditions are concerned about the potential mental health and neurodevelopmental conditions their children might experience²⁹, however, they tend to receive information about the risk for such problems from non-medical sources.³⁰

Research Evidence

Disclosure of psychiatric manifestations of 22q11.2 deletion syndrome in medical genetics: A 12-year retrospective chart review³⁰

In this research study the researchers found that the mental health and neurodevelopmental symptoms of the genetic condition 22q11.2 Deletion Syndrome were discussed with only 26% of families whilst they were under the care of medical genetics services. Instead, parents found out about these symptoms on the internet.

Genetic counsellors and medical geneticists agreed with this finding and reported that they discussed mental health and neurodevelopmental symptoms with families less often than they did other symptoms.

Professionals reported that they tended to discuss mental health and neurodevelopmental symptoms with families when the children were older. The reasons for this were because:

1. They thought this information is more relevant for the family when the child is older
2. They did not want to overwhelm parents with inappropriate information at the first appointment

However, findings from the same study also suggested that mental health and neurodevelopmental symptoms are not actually discussed more with families as children get older.

Why not?

1. Follow up visits with medical genetics were suggested for less than half of children
2. Only a third of the children for whom a follow-up appointment was suggested attended their appointment

This research suggests that only a small number of parents are ever told about the mental health and neurodevelopmental risks associated with their child's genetic condition by health professionals.

What are the implications of this?

There are important implications of not being informed about the risk of developing certain health conditions.

Ultimately, failure to inform parents about risk creates a barrier to accessing early interventions for mental health and neurodevelopmental challenges. When families are unaware that their child is at higher risk for mental health and neurodevelopmental conditions, they may be less aware of symptoms which could indicate their child is struggling with one of these conditions. In these cases, they will be less able to seek and secure timely and appropriate support for their child.

We know that quicker intervention increases the chance of better outcomes for children, so we encourage professionals to inform parents of mental health/neurodevelopmental risk associated with their child's genetic diagnosis.

Communicating information about risk

We have considered why it is important to inform families about the risk of mental health and neurodevelopmental conditions. However, it is important to think about the difficulties professionals face doing this in a sensitive way that puts the needs of families first.

Professionals want to do right by their patients, but it is not always clear how. For example, it's hard to know the amount of information a family would like before the conversation starts and there is risk in telling the family too much or too little. It is right that informing families about mental health and neurodevelopmental risk at the time the family receives their child's genetic diagnosis will sometimes be insensitive and overwhelm parents during an already stressful time. However, no official guidelines and/or 'best practice' exists for professionals to help them navigate this conversation.

There is no 'right' way to have this conversation. Open discussions between professionals, families and patients could go some way in helping navigate this sensitive issue and could help those involved think about best practice guidelines.



Protecting parent/carer mental health

The different levels of prevention

It is unlikely that we will never experience problems with our mental health, but there are things we can do to reduce the chance of becoming unwell. These 'things' are called prevention techniques.

Prevention techniques aim to try and stop the onset of mental health conditions before they occur. They also help support people who have experienced problems with their mental health and have recovered, to stay well.

There are 3 different levels of prevention technique:

1. Primary prevention:

This level involves techniques which try to stop mental health conditions before they start. They are often targeted at everyone and are good for the overall community's mental health. Examples include things like raising awareness campaigns or anti-stigma campaigns which aim to get people talking about mental health.

2. Secondary prevention:

These prevention techniques aim to support people who have a higher risk of experiencing mental health conditions. Some people might be at higher risk because they have certain biological characteristics they are born with (for example, a genetic condition) or because they experience certain things in life. For example, community mental health teams (CMHTs) tend to keep individuals who have recently recovered from a mental health episode under their care for a while. This allows them to monitor the person's health and intervene if they show signs of becoming unwell again.

3. Tertiary prevention:

Tertiary prevention techniques help people who live with mental health conditions by managing the impact their symptoms have on day-to-day life. Essentially, these techniques help people maintain a good quality of life despite experiencing challenges. They do not include clinical treatment but are usually provided by the community and/or the person's family/friends. A community support group is an example of a tertiary prevention technique.

Self-care

Self-care is an important thing to do to help us look after our mental health.

Making time for ourselves can be hard. We know that this is particularly true for people with caring responsibilities. Parents often feel guilty about taking time to take care of themselves, and doing things for themselves tends to be on the bottom of the 'to do' list (if it's on there at all). However, looking after ourselves is an important way of protecting our mental health. Self-care helps to replenish our mental and energy reserves so that we're not running on empty.

The first step to effective self-care is to recognise what impacts our wellbeing negatively (stressors) and what impacts it positively (boosters). Then we need to find ways to keep our stressors under control so that we don't get overloaded with them. Equally, we need to realise how we include more boosters into our day-to-day lives.

Keeping our stressors under control

Step 1: Know your stressors and boosters

We all have stressors and boosters which are individual to us, however they do tend to be similar. For example, we know that things like loneliness³², feeling overwhelmed or not feeling in control of what is happening in our lives³³ have a negative impact on wellbeing. Similarly, things like our diet³⁴, sleeping well³⁵, social connectedness³⁶ and taking part in our hobbies boost wellbeing³⁷.

Identifying our stressors and boosters can be difficult. Here are a few tips which might help you do this.

Your mental health jar

Earlier in the toolkit, we introduced the Mental Health Jar. We thought about your child's jar previously, however, it could be worthwhile to complete your own jar to help you identify your own environmental (stressors) and protective factors (boosters) too.

Recognise your symptoms of stress

Sometimes the things that cause us stress are not obvious to see and so knowing the root cause of your stress can be hard. In these cases, it can be helpful to familiarise ourselves with the symptoms of stress and to become more aware of when we experience them. We are all different so the symptoms of stress we experience will be slightly different. Below are some of the classic psychological, physical, behavioural and emotional signs of stress.

Psychological signs: Difficulty concentrating and making decisions, excessively worrying about things, thinking negatively, feeling unmotivated, racing thoughts.

Physical symptoms: Body aches and pains, changes in appetite, weight loss or gain, stomach pain/problems, feeling sick, feeling tired.

Behavioural signs: Not wanting to spend time with others, being forgetful, not taking care of yourself (for example, eating poorly, not exercising), inability to relax, trouble sleeping, becoming snappy with others.

Emotional symptoms: Irritability, mood swings, loneliness, low self-esteem, sadness.

If you can identify with any of the above, they could be the symptoms you experience when you are stressed and so they should be the stress signals you should look out for. If you can identify the times that you show and feel these symptoms, you might find it easier to discover the root cause of your stress, i.e., the stressor.

Likewise, when our wellbeing is in a good place, we generally act and feel the opposite way to that above (for example, we sleep well, we feel more sociable, we are better able to relax). Identifying when you show and feel symptoms of wellbeing will help you to identify the root causes of your happiness, i.e., your boosters.

Keep a note of how you feel throughout the day

Keeping a very informal diary might also help you to identify your stressors and boosters. At the end of the day note if you felt any of your signs of stress and whether you can identify any reasons for why you felt them. Also note if you did anything or spent time with someone that helped you feel better. Keeping a diary in this way won't be for everyone, but doing so might help you to connect situations to feelings more easily and therefore help you to realise what has a negative and positive impact on the way you feel.

If you'd rather use an app, several exist to help people track and manage their stressors. For example:

- ✦ **Stress & Anxiety Companion** is recommended by the NHS. The app helps users identify their stressors and 'transform negative thoughts into positive ones'.
- ✦ **Daylio** is an award-winning app that helps users track their mood.
- ✦ **Moodtrack Social Diary** helps users simply track their mood.

Step 2: Managing the impact of our stressors

Unfortunately, stress is an inevitable part of life. It is impossible to never experience periods of stress, but it is possible to put methods in place to minimise the harmful effects of stress. We give some ideas below:

Avoid unnecessary stressors

There are many stressors that are unavoidable. An obvious example is the stress parents feel when they must manage and coordinate their child's care. However, there are stressors that are avoidable once you know what they are.

For example, whilst social media and online support groups can be a great source of support for parents, you might find at times that engaging with these groups can be stressful. If this is the case, there is nothing wrong with stepping away from these groups until you are ready to participate in them again.

Learning to say 'no'

Saying 'no' can be difficult, especially when we feel like we're letting people down. However, it is important to put ourselves first sometimes and doing so can help us avoid unnecessary stressors. Knowing what you can say no to can itself be difficult. To help with this, try to distinguish between the things you need to do, and things you should do. Things you *should* do can usually wait for another day.

Make time for your boosters

Plan and guard your time

Planning your 'boost time' in advance will help you to dedicate time to doing something that will have a positive effect on your wellbeing. Ideally, we would have the time to do this every day, however that might not be feasible on some days, and that is okay. The time we dedicate to selfcare can vary depending on what things we have going on – it could be as long as an hour, or

as short as 5 minutes. The important thing is to plan that time and guard it, so that other things which crop up don't stop you from taking it. The ability to make time for yourself is very much related to giving yourself permission to say 'no' sometimes.

Make it social

Your boost time doesn't have to be time you spend on your own. If you have an activity that you know you like doing, you could think about joining a local group to do that activity with other people (for example, if you like reading, maybe

you could join a book club). It is easier to protect time to attend a pre-scheduled activity or club compared to time you might set aside for yourself to read in the evening. Group activities also have the benefit of being social activities and socialising with others helps us to protect our mental health.

Your boost time might also involve doing things as a family (for example, baking, planting seeds, watching a film, etc). This has the benefit of everyone in the family feeling the positive effects of boost time.

Research Evidence

Socialising and mental health:

Park Run³⁸

Park Run is a free community run that takes place every week and is available to anyone. They are organised by volunteers and take place across the world.

Participants who took part in a study which explored the benefits of Park Run for people with mental health conditions reported taking part was good for their mental health. This was partly because doing so helped them connect with others.

Community Gardening Projects

Community gardening projects have been found to increase how socially included people feel and to improve wellbeing by allowing people to engage in a social activity.

Community Arts Projects³⁹

Significant improvement in mood was reported in people with mental health conditions after they took part in a community arts project.

Health services have realised the benefits community support initiatives can have on our mental health and many are now rolling out Social Prescribing Services (see page 22 for more information about Social Prescribing).

Be kinder to yourself

Notice how you speak to yourself

We can either speak to ourselves in a positive way or a negative way (for example, 'I can't do this' versus 'this is hard, but I've done it before, and I can do it again').

People who show self-compassion tend to be happier than people who do not show compassion towards themselves (for example, people who judge themselves harshly)⁴⁰.

Try and notice when you have negative thoughts or when you speak to yourself in a negative way, and flip the thought round (for example, 'I've messed up and ruined everything' to 'Everyone makes mistakes – is there something I can do to fix it?'). It might feel silly to do this at first, or that it won't make much difference, but the evidence shows that people who are kinder to themselves are generally happier. Old habits are hard to break, and new habits take time to build, so allow yourself time to form this way of thinking. Noticing the thoughts that come into your head and whether they are positive or negative is the first step.

Celebrate achievements

Being kind to ourselves also involves acknowledging and celebrating our achievements. These could include success we've had at work, getting a step closer to securing support for your family, that your child was praised at school, or simply that you've had a good day. Reflecting on the positives of the day and the things we feel grateful for not only makes

us feel better in the moment but helps protect our wellbeing too⁴¹. Some people like to write down 'things I am grateful for today' at the end of each day to help reflect on the positives.

Ask for help when you need it

Self-care is central to wellbeing; however, it is also important to ask for help when you need it. Ask for support from friends and family around you or arrange an appointment with your GP if you want to speak with a professional.

There are charities too who can offer support via their helpline, or other information resources. Mind and Samaritans run helplines if you'd like to speak to someone and ask for advice. They also have additional information resources.

Mind - Helpline: 0300 123 3393

The Samaritans – Helpline: 116 123

You can also download the following guide from Cerebra:

[Looking after your own wellbeing as a parent/ carer of a child with a brain condition](#)



References

1. Gibson, A. T. (2007). Outcome following preterm birth. *Best Practice & Research Clinical Obstetrics & Gynaecology*, 21(5), 869–882.
2. May, T., Adesina, I., McGillivray, J., & Rinehart, N. J. (2019). Sex differences in neurodevelopmental disorders. *Current opinion in neurology*, 32(4), 622–626.
3. Doherty, J., Cooper, M., & Thapar, A. (2018). Advances in our understanding of the genetics of childhood neurodevelopmental disorders. *Evidence-based mental health*, 21(4), 171–172.
4. McGinnity, Á., Meltzer, H., Ford, T., & Goodman, R. (2005). Mental health of children and young people in Great Britain, 2004 (p. 2005). H. Green (Ed.). Basingstoke: Palgrave Macmillan.
5. Thapar, A., & Rutter, M. (2015). Neurodevelopmental disorders. *Rutter's child and adolescent psychiatry*, 31–40.
6. Micai, M., Fulceri, F., Caruso, A., Guzzetta, A., Gila, L., & Scattoni, M. L. (2020). Early behavioral markers for neurodevelopmental disorders in the first 3 years of life: An overview of systematic reviews. *Neuroscience & Biobehavioral Reviews*.
7. Fox, C. L., & Boulton, M. J. (2005). The social skills problems of victims of bullying: Self, peer and teacher perceptions. *British Journal of Educational Psychology*, 75(2), 313–328.
8. Best, J. R., Miller, P. H., & Naglieri, J. A. (2011). Relations between executive function and academic achievement from ages 5 to 17 in a large, representative national sample. *Learning and individual differences*, 21(4), 327–336.
9. Cameron, C. E., Cottone, E. A., Murrah, W. M., & Grissmer, D. W. (2016). How are motor skills linked to children's school performance and academic achievement?. *Child Development Perspectives*, 10(2), 93–98.
10. Kanioglou, A., Tsorbatzoudis, H., & Barkoukis, V. (2005). Socialization and behavioral problems of elementary school pupils with developmental coordination disorder. *Perceptual and Motor Skills*, 101(1), 163–173.
11. Murray, R. M., & Lewis, S. W. (1987). Is schizophrenia a neurodevelopmental disorder?. *British medical journal (Clinical research ed.)*, 295(6600), 681.
12. Rutter, M. (2003). Categories, Dimensions, and the Mental Health of Children and Adolescents: Keynote Address. *Annals of the New York Academy of Sciences*, 1008(1), 11–21.
13. McManus, S., Bebbington, P. E., Jenkins, R., & Brugha, T. (2016). Mental health and wellbeing in England: The adult psychiatric morbidity survey 2014. NHS digital.
14. Chawner, S. J., Owen, M. J., Holmans, P., Raymond, F. L., Skuse, D., Hall, J., & van den Bree, M. B. (2019). Genotype–phenotype associations in children with copy number variants associated with high neuropsychiatric risk in the UK (IMAGINE-ID): a case-control cohort study. *The Lancet Psychiatry*, 6(6), 493–505.
15. Raredisease.org.uk. 2021. What is a rare disease? - Rare Disease UK. (online) Available at: <<https://www.raredisease.org.uk/what-is-a-rare-disease/>> (Accessed 8 December 2021).
16. Miller, D. T., Adam, M. P., Aradhya, S., Biesecker, L. G., Brothman, A. R., Carter, N. P., ... & Ledbetter, D. H. (2010). Consensus statement: chromosomal microarray is a first-tier clinical diagnostic test

- for individuals with developmental disabilities or congenital anomalies. *The American Journal of Human Genetics*, 86(5), 749-764.
17. Peay, H. L., & Austin, J. C. (2011). *How to talk with families about genetics and psychiatric illness*. WW Norton & Company.
 18. Kessler, R. C., Chiu, W. T., Demler, O., & Walters, E. E. (2005). Prevalence, severity, and comorbidity of 12-month DSM-IV disorders in the National Comorbidity Survey Replication. *Archives of general psychiatry*, 62(6), 617-627.
 19. Riglin, L., Leppert, B., Dardani, C., Thapar, A. K., Rice, F., O'Donovan, M. C., Smith, G. D., Stergiakouli, E., Tilling, K., & Thapar, A. (2021). ADHD and depression: investigating a causal explanation. *Psychological medicine*, 51(11), 1890-1897.
 20. Dewey, D. (2018). What is comorbidity and why does it matter in neurodevelopmental disorders?. *Current Developmental Disorders Reports*, 5(4), 235-242.
 21. Alexander, R. T., Langdon, P. E., O'Hara, J., Howell, A., Lane, T., Tharian, R., & Shankar, R. (2021). Psychiatry and neurodevelopmental disorders: experts by experience, clinical care and research. *The British Journal of Psychiatry*, 218(1), 1-3.
 22. Edition, F. (2013). *Diagnostic and statistical manual of mental disorders*. Am Psychiatric Assoc, 21.
 23. World Health Organization (WHO). (1993). *The ICD-10 classification of mental and behavioural disorders*. World Health Organization.
 24. Szymanski L. S. (2002) DC-LD (Diagnostic Criteria for Psychiatric Disorders for Use with Adults with Learning Disabilities/Mental Retardation). *Journal of Intellectual Disability Research* 46, 525-527.
 25. Bailey N. (2008) *Diagnostic Manual – Intellectual Disability: A Textbook of Diagnosis of Mental Disorders in Persons with Intellectual Disability (DM-ID)*. *Advances in Mental Health and Learning Disabilities* 2, 60-61.
 26. Chawner, S. J., Doherty, J. L., Anney, R. J., Antshel, K. M., Bearden, C. E., Bernier, R., ... & van den Bree, M. B. (2021). A genetics-first approach to dissecting the heterogeneity of autism: phenotypic comparison of autism risk copy number variants. *American Journal of Psychiatry*, 178(1), 77-86.
 27. Minnes, P., & Steiner, K. (2009). Parent views on enhancing the quality of health care for their children with fragile X syndrome, autism or Down syndrome. *Child: care, health and development*, 35(2), 250-256.
 28. Niarchou, M., Martin, J., Thapar, A., Owen, M. J., & van den Bree, M. B. (2015). The clinical presentation of attention deficit-hyperactivity disorder (ADHD) in children with 22q11.2 deletion syndrome. *American journal of medical genetics. Part B, Neuropsychiatric genetics : the official publication of the International Society of Psychiatric Genetics*, 168(8), 730-738. <https://doi.org/10.1002/ajmg.b.32378>
 29. Hercher, L., & Bruenner, G. (2008). Living with a child at risk for psychotic illness: the experience of parents coping with 22q11 deletion syndrome: an exploratory study. *American journal of medical genetics Part A*, 146(18), 2355-2360.
 30. van den Bree, M. B., Miller, G., Mansell, E., Thapar, A., Flinter, F., & Owen, M. J. (2013). The internet is parents' main source of information about psychiatric manifestations of 22q11.2 deletion syndrome (22q11.2DS). *European journal of medical genetics*, 56(8), 439-441.
 31. Baughman, S. T., Morris, E., Jensen, K., & Austin, J. (2015). Disclosure of psychiatric manifestations

- of 22q11.2 deletion syndrome in medical genetics: A 12-year retrospective chart review. *American Journal of Medical Genetics Part A*, 167(10), 2350-2356.
32. Andersson, L. (1998). Loneliness research and interventions: A review of the literature. *Aging & mental health*, 2(4), 264-274.
33. Kurtović, A., Vuković, I., & Gajić, M. (2018). The effect of locus of control on University Students' Mental Health: possible mediation through self-esteem and coping. *The Journal of psychology*, 152(6), 341-357.
34. Bremner, J. D., Moazzami, K., Wittbrodt, M. T., Nye, J. A., Lima, B. B., Gillespie, C. F., ... & Vaccarino, V. (2020). Diet, stress and mental health. *Nutrients*, 12(8), 2428.
35. Freeman, D., Sheaves, B., Goodwin, G. M., Yu, L. M., Nickless, A., Harrison, P. J., ... & Espie, C. A. (2017). The effects of improving sleep on mental health (OASIS): a randomised controlled trial with mediation analysis. *The Lancet Psychiatry*, 4(10), 749-758.
36. Saeri, A. K., Cruwys, T., Barlow, F. K., Stronge, S., & Sibley, C. G. (2018). Social connectedness improves public mental health: Investigating bidirectional relationships in the New Zealand attitudes and values survey. *Australian & New Zealand Journal of Psychiatry*, 52(4), 365-374.
37. Fancourt, D., Opher, S., & de Oliveira, C. (2020). Fixed-effects analyses of time-varying associations between hobbies and depression in a longitudinal cohort study: support for social prescribing?. *Psychotherapy and psychosomatics*, 89(2), 111-113.
38. Morris, P., & Scott, H. (2019). Not just a run in the park: a qualitative exploration of parkrun and mental health. *Advances in mental health*, 17(2), 110-123.
39. Whatley, E., Fortune, T., & Williams, A. E. (2015). Enabling occupational participation and social inclusion for people recovering from mental ill-health through community gardening. *Australian occupational therapy journal*, 62(6), 428-437.
40. Dolling, S., & Day, J. (2013). How working with a community arts project benefits service users. *Mental Health Practice*, 16(8).
41. Neff, K. D., & McGehee, P. (2010). Self-compassion and psychological resilience among adolescents and young adults. *Self and identity*, 9(3), 225-240.
42. Sztachańska, J., Krejtz, I., & Nezelek, J. B. (2019). Using a gratitude intervention to improve the lives of women with breast cancer: A daily diary study. *Frontiers in Psychology*, 10, 1365.

About the authors

Lowri O'Donovan

Whilst writing this toolkit, Lowri O'Donovan was completing a Knowledge Transfer Partnership (KTP) with Cerebra and Cardiff University's Division of Psychological Medicine and Clinical Neurosciences. The project was a collaborative one which aimed to help improve the access to information and support services for families with a child with a rare genetic condition. Lowri has a degree in Psychology and has worked in the field of mental health research for 7 years. She is currently completing her PhD, investigating the school experiences of children with a genetic condition and how these experiences impact them and their family.

Jane Godfrey

Jane Godfrey is a parent to Joel (13) who has a rare genetic condition called SCN2a. Joel is a full-time wheelchair user with complex needs and epilepsy and enjoys lots of varied activities, smiles lots and enjoys life. Jane supported the KTP as a parent volunteer. She was a member of the parent steering group for the project and a member of the working group who helped create this toolkit, drawing on her knowledge and lived experience of being a parent of a child with a rare genetic condition. She is currently doing a university degree in mental health and well-being for children and young people. Alongside this she works voluntarily in her local G.P. practice with the Social Prescribing service.

Craig Mitchell

Craig Mitchell is Chief Operating Officer of Unique, a charity providing support and information to those diagnosed with rare chromosome and gene conditions, their families and the professionals working with and caring for them. Craig's background is in HR, operations management and communications and he has a diploma in fundraising. In his current role, he oversees the charity's day-to-day operations, fundraising and infrastructure, ensuring Unique has the capacity to help all those who need it. Craig's daughter has a rare chromosome disorder so through this lived experience he understands all-too-well the physical and emotional challenges living with such a condition can bring to the whole family.

Lindsey Stedman

Lindsey Stedman had a career in training and development and has contributed to education research papers and policy. She is the Chair of Trustees for The Genie's Wish charity and a peer leader supporting coproduction in personalised care. She has been a trustee at two other charities, a co-opted governor at a SEN school for 8 years and is the parent of a young person with 22q11.2 Deletion Syndrome.

Laura Billing

Laura Billing is a parent/carer of two offspring severely affected by Neurofibromatosis Type 1. She has wide-ranging specialist skills to support children with genetic and neurological conditions. Laura's work and lived-experience encompass being a long-term multiple kinship carer, therapeutic gardener (Thrive and Holland House Carers' Retreats), organiser of the Nf Family Support Group (West Midlands) and socially engaged community artist (The Big Draw and B&SMH NHS Trust). She worked with Professor Dawn River (IASS, The University of Birmingham) for ten years on the Post-Grad 'Recovery Through Arts' programme as contributing artist and Visiting Lecturer. She currently has

a virtual exhibition with Outside In and a new arts project on mental health resilience (SANE Creative Awards).

Professor Marianne van den Bree

Professor Marianne van den Bree was the Lead Academic for the KTP project at Cardiff University. She has been doing research into the characteristics of young people with rare genetic conditions for about 15 years. She aims to better understand why these genetic conditions increase the risk of mental health issues and the reasons that there are differences in this risk between these young people.



Neuroscience & Mental
Health Research Institute

Sefydliad Ymchwil y
Niwrowyddorau ac Iechyd Meddwl



Innovate UK



Ariennir yn Rhannol gan
Lywodraeth Cymru
Part Funded by
Welsh Government

The findings of this report are those of the author, not necessarily those of Cerebra.

First edition: 2023

This edition: 2023

Review date: 2026



Working wonders for children with brain conditions

Postal Address

Cerebra
The MacGregor Office Suite
Jolly Tar Lane
Carmarthen
SA31 3LW

Tel: 01267 244200

Freephone: 0800 328 1159

www.cerebra.org.uk

Registered Charity no. 1089812 Company no. 4336208

