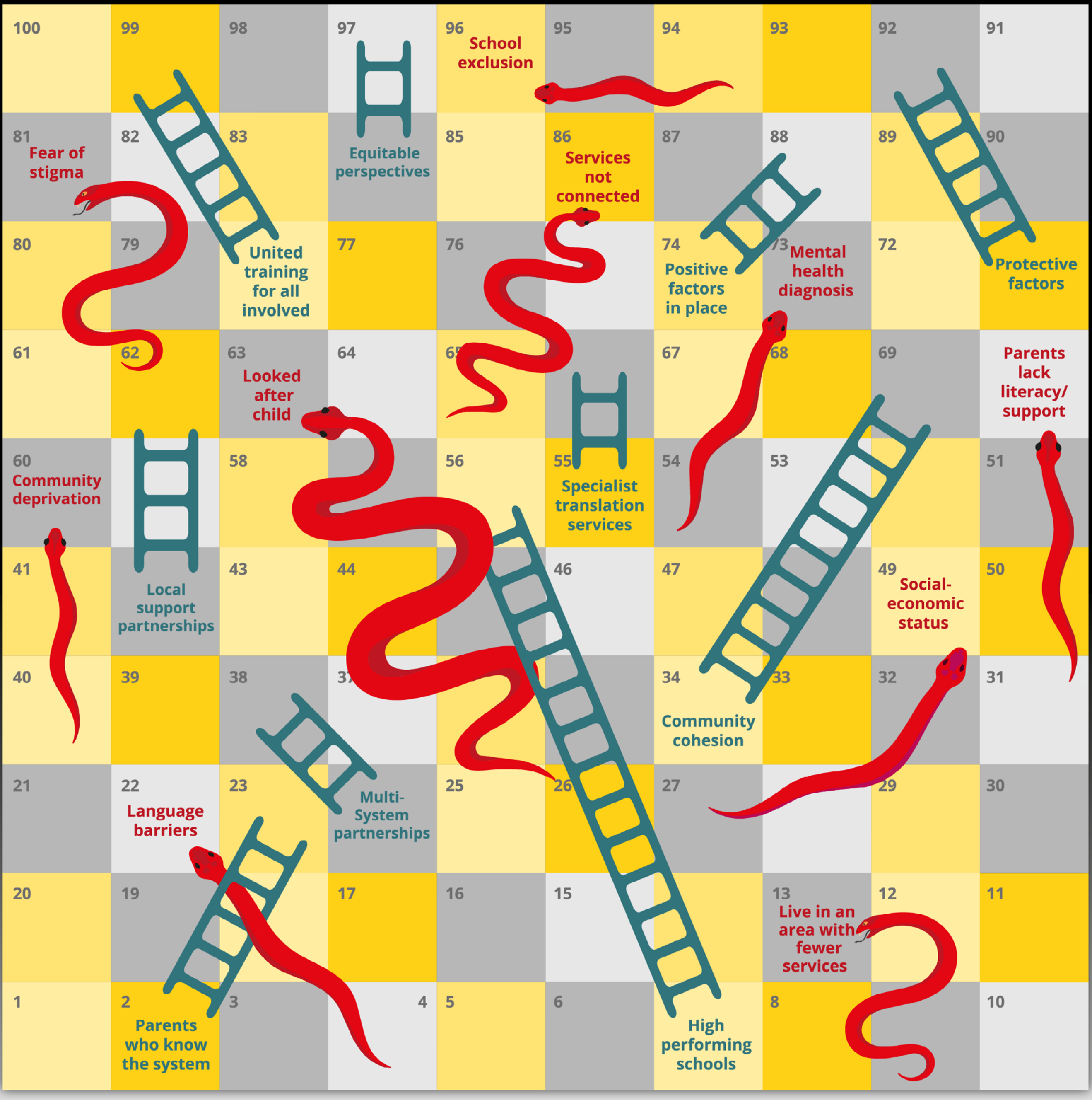
ETHNICALLY DIVERSE CHILDREN & NEURODIVERSITY:

PINBALL SYSTEMS, SNAKES AND LADDERS OR PERSON-CENTRED PROVISION

Prepared by Prof. Amanda Kirby - April 2024



ALLIANCE OF SPORT in Criminal Justice

Youth Justice Board
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Contents

Foreword

I'm proud to say that I am dyslexic and the more I get to understand me, the more I'm able to use the talents and skills that dyslexia brings, and not focus just on the reasonable adjustments that I might need in work or everyday life. Life wasn't always like that for me. Growing up I knew that I was different, but I couldn't put my finger on it. The slower reading, the poor spelling and handwriting, I put down to me having to work harder and develop more by going on different training courses. In the intervening period before I found out I was dyslexic, I obtained five good level passes, a degree, a successful career in policing and a senior police officer where I was a head for 13,000 people, etc. etc. Why do I say this? One – it's to understand that despite my struggles and having to work harder, I was still able to achieve. Two – I have come on leaps and bounds since getting to know myself better after diagnosis.

Although I'm in an amazing place, my experience of telling others in work wasn't wholly positive, and there was a focus on my challenges and making sure I got the right reasonable adjustments. Initially, I was pretty sure myself, that as a dyslexic, it took a little bit of time to come to terms with what that meant and feeling comfortable about telling others. I was aware of the possible stigma and possible ramifications of others finding out. But the more I read, the more I researched, the more I found countless examples of successful people who were dyslexic/Neurodivergent. That gave me the strength to be more open about my diagnosis, to be proud of who I am and to start to understand my strengths. A significant step forward in that journey was when I met Prof Amanda Kirby, she really opened the door to the strengths that I possessed, and this enabled me to leap into another chapter in my life. I am in and extremely positive place about being dyslexic and developing understanding of my strengths, and not just focusing on the apparent challenges.

I am now Chair of the Youth Justice Board for England and Wales, Chair of Local Partnerships (which operates across England, Wales and Scotland), a developing people coach, organisational coach and a supporter of many charities, I say this to encourage others. As the Chair of the Youth Justice Board, I'm struck by the fact that Neurodiverse children are over represented in the youth justice system and this is becoming increasingly apparent in the custodial estate. It is particularly stark as the United Nations Committee, on The Rights of the Child, stated that children with neurodevelopmental disorders, should not be in the youth justice system at all. This overrepresentation and other factors demonstrate the need for a system change to ensure that all aspects of the youth justice system and with a practice that is based on individualised strength-based, trauma informed, and child first approaches.

With the right for thought, we can support children earlier and identify those who might need extra support earlier. Together, it is possible to ensure that all children are supported to have hope and not have their dreams restricted by our thoughts about what they can achieve.

Publications like this are great because they help understanding, raise awareness, ask questions, and drive action.

Well done to all involved.

Keith Fraser

Chair of the Youth Justice Board

Foreword

As a young woman from a low socio-economic background, ethnic minority group and who was born and bred in Tower Hamlets, I have first-hand lived experience of how education and sport has served as a key positive influence during the formative years of my childhood. I mainly played football but also accessed local services offered by smaller sports organisations and my youth club that provided holiday sports activities. Without these opportunities to continue to be involved in sport or football outside of school (when many girls my age were not taking part in football or sports more generally), while developing my aptitude for academics, I know I would have struggled to live an active, fulfilling, and healthy lifestyle. Being involved in community-based sports throughout my lifetime has given me important life skills that have enriched my life to no end. I am a disciplined, diligent, and confident person which I believe has helped me to work hard in my studies, to this point I find myself in now – pursuing a neuroscience PhD at the University of Oxford. Community sport has helped me defy and break through the barriers a girl raised on a council estate in Tower Hamlets. Sport has given me the drive to chase my dreams and help those around me do the same.

My work with community-based sports organisations with Levelling the Playing Field while at the University of Birmingham, has also helped me to understand and cement the idea in my mind that communities are living mosaics – a big heterogenous pool of people that live in synergy to bring their neighbourhood to life. Neurodivergent individuals are at the centre of that melting pot – an essential cog in the wheel, not square pegs that should be shoved into round holes. Given that neurodivergence within communities, especially among young people, is still considered a burden through individuals' apparent non-compliance with what the wider society expects of them (most apparent in how they engage with education), it is necessary that how education is accessed via communities is rethought. Looking at neurodivergent individuals' supposed innovation, thinking outside of the box or reshaping of how education fits into their lives is a battle, we as a society of educators, have not been willing to fight, especially for neurodivergent young people.

As a neuroscientist, I am mindful of the duty we have to uphold individuals in a holistic way, acknowledging the person in the midst of the neural processes that underly all the wonderful human expressions of behaviour that we see present in our communities. It is our job to nurture these to create positive formative experiences for our diverse groups of young people – knowing that such experiences will significantly impact how they go on to navigate society for the rest of their lives.

From a scientist's perspective, I also understand the importance of data in these discussions, and it is reports like this one that make all the difference in a world where strings need to be pulled. More importantly, they make all the difference to the world that our vulnerable young people grow up in. This report addresses the current unmet need for practical and pragmatic guidelines that are not only accessible and intelligible for a range of groups, but that are also backed by rigorous and conscientious research. These are all essential components needed to create a holistic, person-centred and effective approach to supporting neurodivergence within our communities."

Ms. Morgan Mitchell

PhD Student in Clinical Neurosciences,
Wellcome Centre for Integrative Neuroimaging,
University of Oxford.

Foreword

As a Father to a Son who was diagnosed with Autism when 2 years old. Not only do I hold a parent's perspective on Neurodiversity, but I support many aspects of proactive neurodiversity promotion and engagement, daily. To be able to best support our son, as a family, we had to look outside of the UK for help. Researching and participating in a programme in America, for us, this has been a long and yet positive journey of discovery. From this programme, and deciding to remove our son from mainstream education, we have been able to implement a home-based programme tailored to his needs. This has been a continual journey for 21-years (and counting). Whilst I am fully aware this is not possible for all families in a similar situation, especially within my Asian community, I was and am still inspired to do something about it. Currently we are supporting an inclusive running programme organised by the Wrestling Club and Gurdwara to promote awareness, understanding, and community engagement for both mainstream activity participants and Gurdwara attendees. Educating within the Asian community to understand Autism and to help manage symptoms through delivering group workshops from the Gurdwara, with Parents and Volunteers + Working with community groups set up by Families affected by Autism + Inclusive activities we run include Boxing, Kabaddi and Wrestling + Autism Awareness is raised through our Social Media + Onsite promotion and provision of Sports Kits, all of which holds a global reach.

From reading this report it is clear, this must all be connected, properly funded, and driven by people the 'community' can identify and connect with. Due to our reach and having seen the development of my Son, more and more people feel less judged and feel comfortable to bring their Children out to activities, where previously within the Asian community especially, they were hidden away at home, disconnected from a powerful and supportive opportunity. From my personal situation this has been a great journey and has generated a positive understanding for and with others in need. Now, with organisations like Autistic Alliance, I am hoping to connect and create programmes that reach all who need it. From this report, and all I have met, I am sure we can all agree, that there isn't enough readily 'accessible' help and support for Parents of children with Autism, from the process of diagnosis or throughout their life.

Thankfully, I have been able to have been able to attend a programme, in another country and it helped immensely, however this is not accessible to the majority of those in need, in the UK. However, to help in my community, with the footfall from the Gurdwara and activities run sometimes amassing thousands of people a week, we have the reach to raise awareness needed, within a diverse and connected community, which has made this journey a lot easier than trying to do this alone. I hope this report opens the door for more family support and direct action in the UK, to build better, more localised research, services and connections."

Ranjit Singh

Head of Projects at Wolverhampton Wrestling Club, Head Coach for WWC, Head Trustee on the Board of Cannock Road Gurdwara, Sports Secretary for Cannock Road Gurdwara, British Wrestling Diversity & Inclusion Board, National Project Development Lead for British Kabaddi League, Head Coach & Partner of British Judo and GB Level 2 Coach

Foreword

Pinball / snakes and ladders sums my experience up perfectly. I am from a low-socioeconomic and complex background, a neurodiverse individual, father of an gifted neurodiverse 27 year old and criminal justice, health and lived experience practitioner, that has supported Neurodiverse people of all ages, for over 30 years. It is a complex and often exhausting process for the individual, their support network, practitioners, leaders within this process and sector. None of which stops when a neurodiverse child, becomes an adult, nor I have I found the key to making this an easy process within personal or professional settings.

Whilst professionals involved are doing their best, are caring, compassionate and skilled at what they do, for the individual and family/carers around them, all too often, the process of 'the systems' around them can generate further confusion, stress, trauma, rejection and doubt in the world and the people around them. I have experienced this firsthand as an individual, parent, and practitioner. However, I have also seen, felt and experienced 'the magic' of when systems work together, too.

Having now worked with and learnt from Prof. Amanda Kirby and from this report, I am eternally grateful for her passion which is clearly demonstrated in this comprehensive literature review, research and set of proportionately universal recommendations. This indicates how far we have come for some, but vigorously highlights how ethnicity and understanding of it remains under the radar in terms of research, practice, and investment here in the UK and Internationally and highlights how far we still must go.

This report highlights the need for more research and holds strong, pragmatic recommendations for us all to utilise. I strongly urge all practitioners, leaders, and supporters, to engage with and use this resource to build more shared understanding and evidence. Together, we can build a brighter future for our support systems to connect, effectively transition and holistically support Neurodiverse children and adults in the UK, and beyond.

Justin Coleman

COO at Alliance of Sport

Author profile

Professor Amanda Kirby is an emeritus professor at University of South Wales and honorary professor at Cardiff University. Amanda is also a qualified medical doctor and has a PhD in emerging adulthood in neurodiversity.

Amanda has written ten books in the field of neurodiversity including Neurodiversity at Work and Neurodiversity in Education as well as 100 research papers.

Amanda is the CEO and founder of Do-IT Solutions, a tech-for-good company that has developed neurodiversity screening tools used in education, justice, and employment settings. Amanda has extensively worked in the justice and youth setting for more than 15 years and can be contacted via amandak@doitprofiler.com.

Introduction

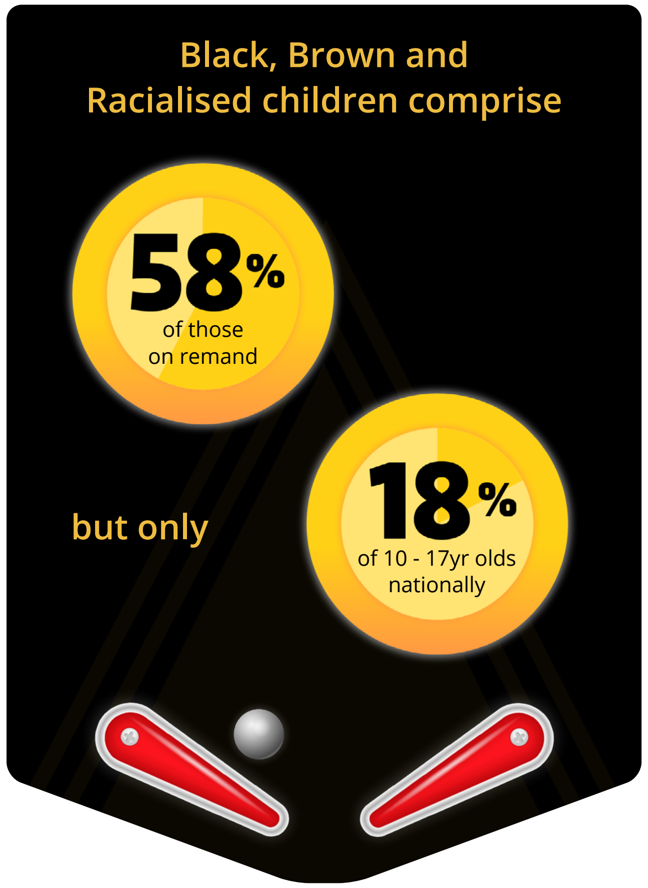
At least one in three people in the justice setting may be neurodivergent and they often also have several other challenges in their life both past and present. This may include homelessness, having experienced traumatic brain injury, coming from an ethnic minority group, having been in care and or having been excluded.

Combinations of vulnerability will be highly variable but what is consistent is the young person and their family are either having contact with multiple systems and telling their 'tale' again and again or being out of systems and ending up being under the radar. We can assume people will know what's available to them and how to seek help. However, for many people they may also not know there is a system where help is available or know who or how to make contact.

According to the Howard League for Penal Reform, Racial disparities in youth justice – 'from policing to custody blog, When Black, Brown and Racialised children comprise 58 per cent of those on remand, but only 18 per cent of 10 to 17 year olds nationally'.

Which indicates that the above one in three people who are neurodivergent and out of systems, are also more likely to be ethnically diverse and supporting services need to ensure they ensure cultural understanding sits alongside neurodivergent support.

Recognising the variability of each experience and that inequity is a common theme means we need to learn to create a formulation for each young person. This approach means moving away from labels to being more child-centred and towards inclusive and not exclusive approaches. This has secondary benefits as it can lead to having more appropriate referrals to over-stretched services, for example ADHD assessment.



What is key is that the child or young person needs to be at the centre of delivery and not bounced around or feel like they are in a pinball machine. Appropriately trained keyworkers who are consistent and stay with that person along their journey would make a real difference. These trusted keyworkers need to be an important link with local communities as well as be able to signpost to local services. By creating a 'tell it once' approach that has is gathered within the social setting and cultural context that is trusted and understood by that person, their family/carers and all connected supporting organisations around them can result in enhanced engagement and improved outcomes.

During Covid-19 young people who were neurodivergent and had childhood adversity are now increasingly being recognised as having become more disengaged in society and consequently to be very likely to have has less identification of their needs and less support. This means now more than ever mapping adversity AND neurodiversity combinations is going to be essential and not looking dichotomously from a trauma OR a Neurodiversity lens.

It is important that there is adequate and high-quality training relating to neurodivergent traits is undertaken by all who meet young people. This should not be done by using a narrow medical model by specific condition as this may preclude also an understanding of co-occurrence that may be, and often is, present. It will also miss the intertwined relationship with childhood adversities (which will vary and be unique to that young person) +/- trauma.

Staff need to have practical tools to support each child. They also need to have a system that allows them to review information and add to it and not expect the young person and the family to start all over again.

Taking sufficient time to use screening tools at the point of engagement is important. Taking time to tell it once should be the approach taken. How information is gathered needs also to be accessible as some communities will have low levels of literacy and digital skills, and/or English may not be their first language. We need to put the child at the centre of the system rather than having a label led or narrow siloed approach which may potentially lead young people to not have their needs fully met or to end up having limited contact time with some workers before being bounced into or out of other systems.

What is neurodiversity?

Neurodiversity means that everyone's brains are differently connected. The term basically means the way we think, move, act, see, hear, and process information varies for us all. Some of us do things differently from the 'average' person in society.

Neurodiversity is thought to have been coined by Australian sociologist Judy Singer in the late 1990s and was also used by journalist Harvey Blume in the US at a similar time.

The construct of neurodiversity moves away from seeing conditions such as dyslexia and autism spectrum conditions as disorders with a focus on deficits, cures and prevention (known as a medical model) to considering a more social model of disability.

The social model is at the heart of the United Nations Convention on the Rights of Persons with Disabilities, which identifies disabled people as having impairments that 'in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others'.

There have been several umbrella terms used now and, in the past, associated with cognitive differences, including:

- **specific learning difficulties (SpLD)** (used in education)
- **neurodevelopmental disorders (NDD)** (used by health professionals)
- **learning difficulties and learning disabilities (LDD)** (used in justice settings).

The varying terminology by different professionals is one of the reasons for confusion and often leads to different perceptions of challenges and siloes of service provision.

A move to more consistent terminology is leading to the term neurodiversity increasingly being used. In the context of youth justice, many people will have had associated childhood traumas (see the earlier Academic Insights paper 2020/05 by Kieran McCartan), and sometimes there can be a focus on this and a lack of consideration of the interaction with neurodivergent conditions.

Neurodiversity is about us all

The term neurodivergence is used when we diverge from the average way we do things in society. Divergence can be related to great skills in some areas or having weaker skills or challenges in others. For example, someone can be fantastic with numbers or a great sports person, but may have challenges with handwriting, reading, spelling, or being able to socialise easily in a new or unfamiliar setting. Each person's profile will be different. This is sometimes called a 'spiky profile'.

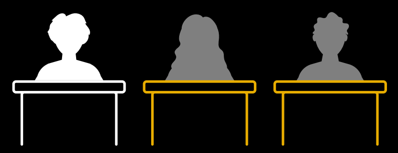
When we diverge this can be interpreted in different ways. Some children who are seen as having behavioural or emotional challenges end up being excluded from school. Other young people may have gained some support and a diagnosis of ADHD and receive an educational health care plan (EHCP). Different interpretations by different professionals can result in different endpoints.

Key facts and figures area as follows:

about **one in six** people in the mainstream population are thought to be neurodivergent

one in four in the unemployed population are thought to be neurodivergent.

at least **one in three** people moving through the justice system are thought to be neurodivergent; many will not have been diagnosed during school days.



Recognising neurodivergent traits and why tailor approaches

Conditions and diagnoses

Some examples of conditions that have been associated with neurodivergent traits includes:

- **Attention Deficit Hyperactivity Disorder (ADHD) –** the person may be more impulsive and have challenges concentrating on tasks of less interest to them. Strengths include being able to see connections where others cannot.
- **Autism Spectrum Condition (ASC)** also known as autism spectrum disorder (ASD) – can lead to challenges with social communication and interaction with others and the person may have specific sensory preferences and dislikes. Strengths include being able to focus intensely on specific interests.
- **Developmental Co-ordination Disorder (DCD) also known as dyspraxia –** relates to challenges with physical coordination, with tasks such as handwriting, learning to drive and with self- organisation. Strengths include higher levels of empathy.
- **Dyscalculia –** is associated with challenges with math's, time concepts and managing money.
- **Dyslexia –** is associated with challenges with reading, spelling, comprehension of the words and the content of writing. Strengths include creativity.
- **Developmental Language Disorder (DLD) –** this is associated with speaking, understanding, and communicating clearly and picking up the nuances of language.

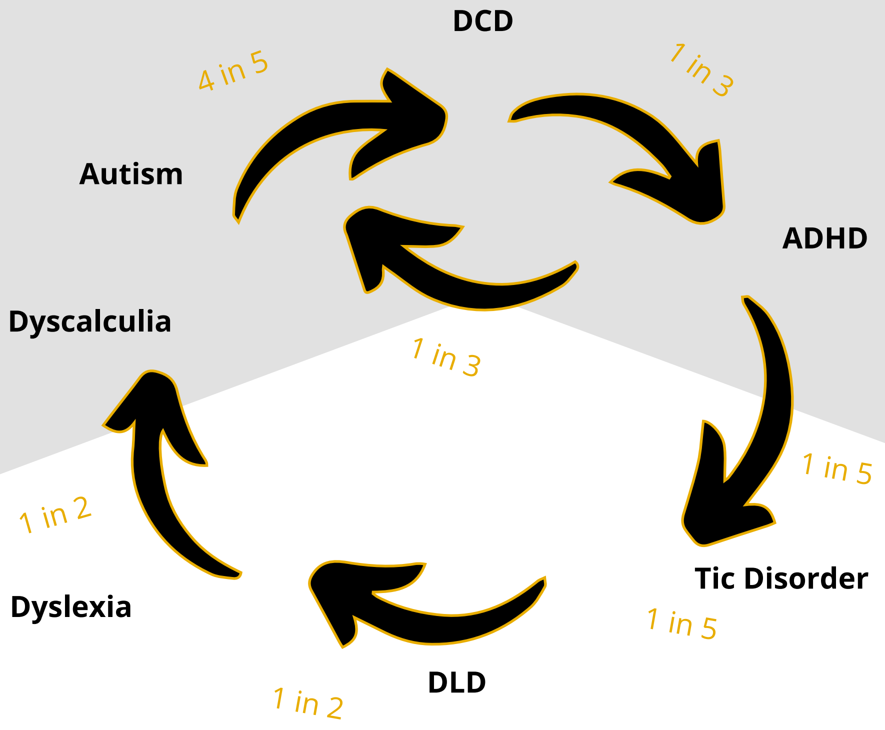
Other conditions include Tourette's syndrome /Tic Disorders and Auditory Processing Disorder (APD) (which affects the way that sounds are understood). Each person with a diagnosis may be different from the next person and they don't need to have challenges in all areas associated with the condition.

No neat boxes!

Historically conditions such as dyslexia, DCD, ADHD and ASCs were viewed as separate disorders or conditions. More recent research has shown these should not be considered as a binary diagnosis, in that you either 'have it or do not' but more like continuous traits such as height or blood pressure where everyone lies somewhere along a continuum. The impact and presentation of having one or more condition for the individual can vary substantially.

There is extensive research that shows there is often overlap with one condition or another (also known as co-occurrence). For example, people with ASC[1] often also have ADHD and dyspraxia. ASC often overlaps with DLD. Individuals with ADHD also often have DCD and so on..

Additionally, child or young person's pattern of strengths and challenges will be different (Cleaton and Kirby, 2018).



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[1] This is person first language, which puts the person before their diagnosis. Some people prefer identity first language which puts the diagnosis first, for example saying autistic people instead of people with ASC

Who gets missed, misunderstood, misdiagnosed or moves through multiple systems?

For young people to gain support and a diagnosis, they still often must meet a set of criteria and they also need to be recognised as potentially having one or more conditions. Services and knowledges are often in professional siloes. Speech and Language Therapist would diagnose Developmental Language Disorder, an Occupational Therapist may diagnose DCD, and a psychiatrist may diagnose ADHD for example.

For many young people, 'behaviour' has been seen as the diagnosis without considering the underlying reasons. There is evidence that children and young people from lower socio-economic groups are more likely to get a diagnosis of social, emotional and mental health (SEMH) needs, rather than autism or speech, language and communication challenges. This is called 'diagnostic overshadowing' where we look for one thing more than another.

SEMH needs have been defined as a type of special educational needs (SEN) in which children have severe challenges in managing their emotions and behaviour. They often show inappropriate responses and feelings to situations.

Some characteristics of children with SEMH may include:

- **disruptive, antisocial and uncooperative behaviour**
- **temper tantrums**
- **frustration, anger and verbal and physical threats/aggression**
- **withdrawn and depressed attitudes**
- **anxiety and self-harm**
- **stealing**
- **truancy**
- **substance misuse.**

There are many reasons why a young person's neurodivergent traits may have been missed. These may include:

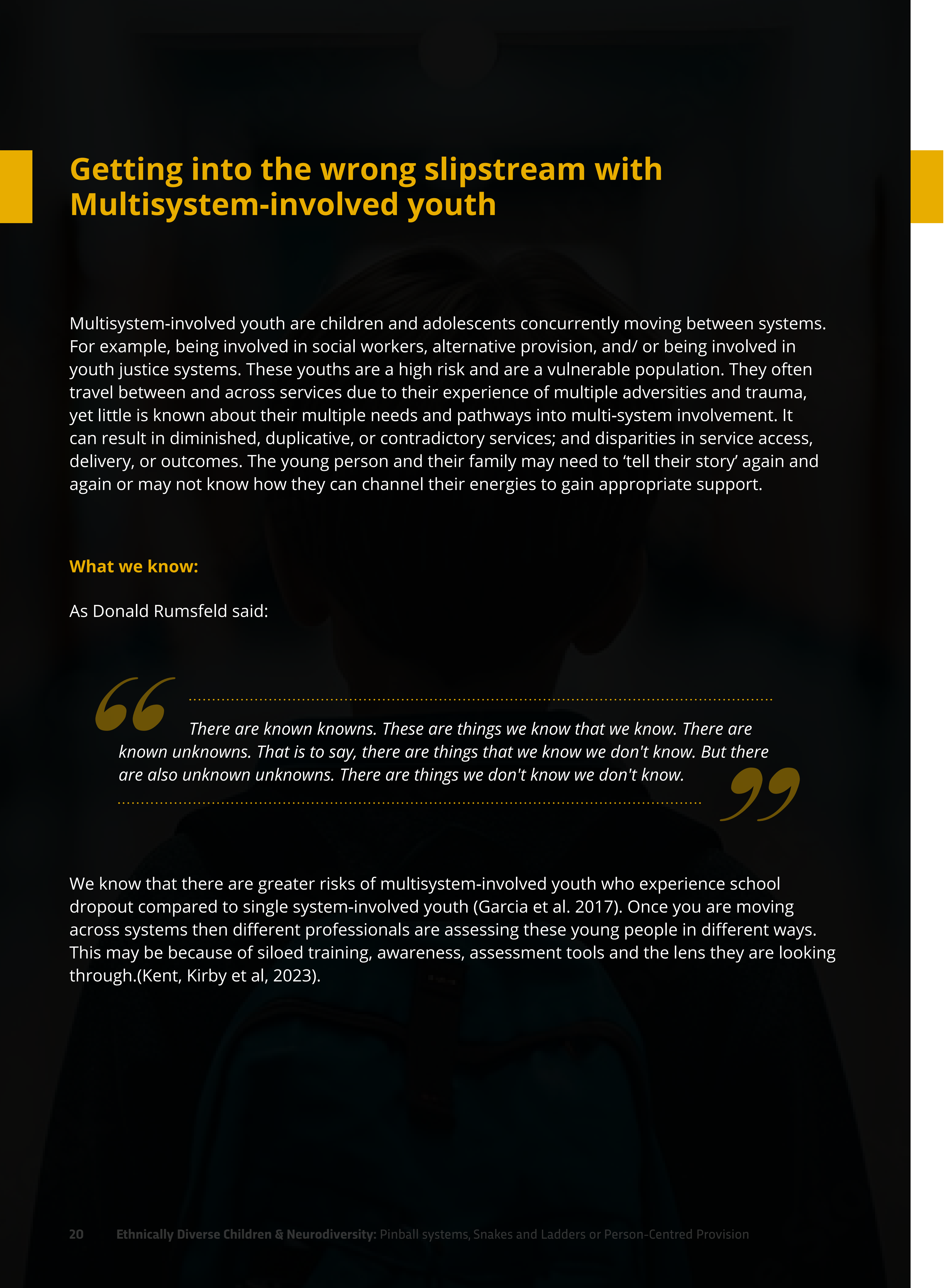
- **More limited parental engagement** with health and educational services (Astle and Bathelt, 2019).
- Some children may be or have been **excluded from school** several times.
- Some children and young people may have **moved around systems** e.g. because of being a Looked After Child/ Care experienced) (Oak Foundation, 2019).
- Child or young person may have had an **undetected traumatic brain injury** and may be seen as ADHD.
- They may be at greater **risk of homelessness** and because of this moved schools or missed schooling.

One or more of these factors may cumulatively impact and result in the young person being less likely to have gained or gain a diagnosis.

It may also mean because of a lack of considering the 'whole child' they are either being passed from service to service, or they are under the radar for detection of one or more neurodivergent conditions as they are 'out of the system' all together.

Gaining a diagnosis of one or more conditions may require screening using specific tools. These tools often have a 'cut off' which can result in an 'all or nothing' approach with scores below a given level not being registered having a diagnosis. This can lead to very different outcomes with some children gaining support and for others it can leave them sitting in a 'missing middle' and again not receiving help as they are not seen as quite 'bad enough'.

The reality for many people is that they can experience challenges across several areas which interact and overlap. For example, one person may have difficulties with reading, attention, and writing (challenges linked to three distinct conditions) but may not get a diagnosis of any one of these specific conditions. The reading challenges the young person has may not be 'bad enough' to gain a diagnosis of dyslexia but their challenges still may have a real daily impact for the young person when trying to engage in education.



Getting into the wrong slipstream with Multisystem-involved youth

Multisystem-involved youth are children and adolescents concurrently moving between systems. For example, being involved in social workers, alternative provision, and/ or being involved in youth justice systems. These youths are a high risk and are a vulnerable population. They often travel between and across services due to their experience of multiple adversities and trauma, yet little is known about their multiple needs and pathways into multi-system involvement. It can result in diminished, duplicative, or contradictory services; and disparities in service access, delivery, or outcomes. The young person and their family may need to ‘tell their story’ again and again or may not know how they can channel their energies to gain appropriate support.

What we know:

As Donald Rumsfeld said:

> *There are known knowns. These are things we know that we know. There are known unknowns. That is to say, there are things that we know we don't know. But there are also unknown unknowns. There are things we don't know we don't know.*

We know that there are greater risks of multisystem-involved youth who experience school dropout compared to single system-involved youth (Garcia et al. 2017). Once you are moving across systems then different professionals are assessing these young people in different ways. This may be because of siloed training, awareness, assessment tools and the lens they are looking through.(Kent, Kirby et al, 2023).

Why does identification rates of neurodivergent traits and conditions vary among different groups?

It starts at the beginning. In the world of child development there has been a recognition of gaps and inadequacy about the data we have and how we use this to plan and provide services. On the one hand, researchers and others will freely admit to the huge gaps and problems with developmental data. One example has been related to gender where we missed out on the different symptoms and signs of Autism and ADHD and assumed girls, we far less likely to have these conditions until recently.

We can downplay the unreliability of the data we have. But if all our research and clinical activity has been framed around a narrative that represents the 'majority' of people (but there is missing information for selected groups) it is hard for us not to challenge this status quo.

Where are the gaps in knowledge about our systems?

There are huge gaps in gender, racial and ethnic data. Misclassification can also lead to inaccurate measurements and reporting. This can result in underestimating the burden in minoritised populations while overestimating it some specific groups. Delay in accessing services and support can lead to a secondary impact and disengagement not only of young people but also their families too.

The lack of an accurate picture can lead to an underestimation of health disparities. This can result in the longer-term impact of not a section of society with high support needs not gaining appropriate support. It can also lead to misdiagnosis or being misunderstood, or needs missed altogether.

One thing we find even harder than anything is gathering data across systems. There is specifically a lack of an accepted and systematic approach for specifically considering and identifying multisystem-involved youth. As a result, prevalence estimates of multisystem-involved youth vary widely from one study to another and across systems.

There is a need for appropriate staffing of systems, that can connect through cultural understanding, and to aid system engagement and the knowledge gap. For example, this has been described within the Criminal and Youth Justice System, according to Criminal Justice Alliance report, 'Beyond a Numbers Game, Diversity and inclusion of Black, Asian and minoritised staff in the criminal justice workforce' June 2023.

There is also a disparity between ethnically diverse staff and ethnically diverse people who are journeying through the system. "A stronger focus on retention and progression is crucial to make a long-term difference to workforce diversity." This equally applies to all services that support Neurodiverse children. A key worker coming from the same settings that the young people live would be an appropriate bridge and link.

Where are the gaps in knowledge, for the potential ethnically diverse beneficiaries using it?

Neurodiversity and its wider public understanding is still growing. When working with and in ethnically diverse communities with children, in the 'systems' there is a reliance on family/career involvement for supporting the young person with attendance in the process, their 'system navigation' and an understood consensual representation of support for and with the child.

One clear example that exemplifies the gaps in knowledge is when the 1st language of the family isn't English or Welsh (when in Wales). This requires a translator, and more critical still, the translation service must be trained and understand the neurodiversity identification process, language, system, and context of support. How often do we consider neurodivergent traits when someone is not speaking the same language as the professional they are engaging with?

One example of good practice is, the Chinese in Wales Association who have formed 'The Autism Project'. Translators are additionally trained to support the families' understanding of Autism and the systems supporting this. As stated by the organisation, Autism "is still a relatively new concept within the Chinese community" and the direct translation of the word 'Autism' is interpreted as **自閉症** (lit. self, closed, disease), so requires further interpretation and explanation.

This challenge equally applies to all languages and interpretation of them. A focused approach to translation, whilst resource intensive initially, would enable more support in the home and/or from supporting professionals, beyond diagnosis and save resources in the long term.

Appropriate systems and people in place, can prevent ethnically diverse children from entering the wrong slipstream or withdrawing from support altogether. It can also generate vital knowledge within and from ethnically diverse communities that will otherwise remain below the knowledge radar, these learning points or translation techniques if shared across the system will further improve communication and support for all operating and utilising the systems.

To conclude, the words we use can have different meaning entirely for different communities. This needs to be remembered and explored sensitively to ensure everyone is of the same understanding. Where we are seeing proactive and developmental focus on words and their translation or interpretation internationally. Within Māori or te reo Māori ('the Māori language'), a new, more enriched language to support systems and people in them, has been developed. The creation of "Te Reo Hāpai - The Language of Enrichment", is where many new translations have been created in an enriching way. A cultural translation and interpretation focus within a complex medicalised system, would enhance experiences, save money, and further resources.

Where are the inaccuracies and gaps in data relating to neurodiversity?

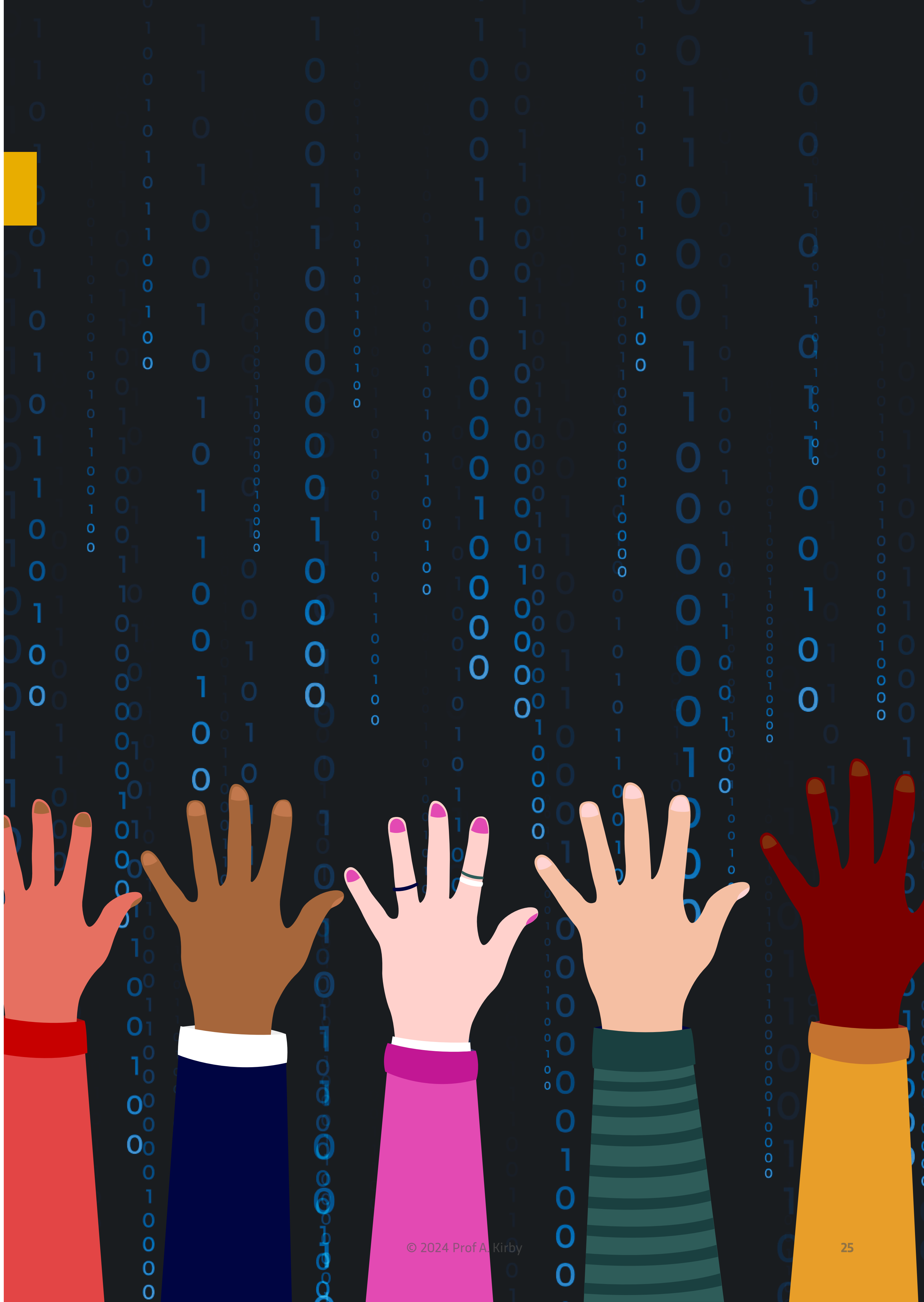
Accuracy and reliability of any research findings can be influenced by various factors, including the sample size, study design, assessment methods, and cultural considerations. Additionally, cultural, and linguistic diversity within and across racial and ethnic groups can pose challenges in accurately assessing and identifying neurodivergent conditions i.e. how we ask the questions, the words and terms we are using, when we ask the questions, and the way we ask the questions makes a difference to the responses we get back.

Just think about if you need to read and fill in a form. If you are under time pressure ; you don't read well or read English at all, or have difficulties understanding the terms and jargon being used then what is your response going to be? What does that mean for the data that has been captured? Fear of saying the wrong person to someone in power can also vary the response given.

Much of the research relating to ADHD and Autism Spectrum Conditions until recently has been undertaken predominantly relates more to 'white middle-class boys' .... so how do we know if the same approaches will work for girls, or boys from a different social, cultural or ethnic backgrounds?

If we are deciding on who gets help, what help and the pathway to gaining support and alternatively who does not then we know that timely and accurate identification is often necessary for children to receive services in health, community services, and in education. Delay in recognition can lead to a secondary impact. Bullying can lead to lower self-esteem, this can lead to disengagement in education, and can lead to further social isolation. This can lead to lower educational outcomes too.

We know that outcomes will vary depending on identification of needs for example, there is evidence that obtaining an ASD (Autism Spectrum Disorder/condition) diagnosis is positively related to significant strides in skill development (e.g., Estes et al., 2015;) and with having better long-term outcomes (e.g. Anderson et al., 2014; Zwaigenbaum et al., 2015).



Outcomes vary

Most studies indicate that 'minority youth' are more likely to be concurrently involved in multiple service systems than 'White youth'. These findings are consistent with research on disproportionate minority contact across different service systems. For example, 'Black youth' are more likely to enter the foster care system than 'White' or 'Hispanic youth' even after accounting for a range of youth and case characteristics. Black youth are also more likely to be recommended for formal processing, prosecuted for crime compared to White youth, even when prior records are considered.

There is increasing evidence to show differences in diagnostic rates for a range of neurodivergent conditions in children coming from ethnically diverse communities/immigrant families. However, some of the data is variable and depends on the country as well.

One recent study in the United States found that Somali children born outside of Minnesota received a comprehensive diagnostic evaluation at about 5.80 years, 2 years later than children from White backgrounds who received a comprehensive evaluation at about 3.80 years (Hall-Lande et al., 2018). However, one study from Austria found that children from immigrant backgrounds received an ASD diagnosis approximately 13 months before children from non-immigrant backgrounds (Primo et al., 2020).

These families may face additional challenges accessing healthcare and related services for their children. The reasons for this may be diverse, including a lack of awareness of healthcare policies, knowledge of the systems of care, availability of information across minority languages, and limited financial resources. (Rivardetal.,2019).

Parents have also reported that the way they present information to others and how this may also be misinterpreted. One study explored the immigrant parents' emotional experiences in child welfare services as well as parents' emotional management and their interpretations of the role of emotions in the child welfare system. The analysis revealed that strong negative emotions dominate parents' experiences and correspond to immigrant-related challenges and factors associated with child welfare involvement, the study suggested.

One study from Australia also showed the level of neurodisability in ethnically diverse population. This study, in a representative sample of young people in detention in Western Australia, has documented a high prevalence of FASD and severe neurodevelopmental impairment, the majority of which had not been previously identified. These findings highlight the vulnerability of young people, particularly Aboriginal youth, within the justice system and their significant need for improved diagnosis to identify their strengths and difficulties, and to guide and improve their rehabilitation.

When we consider certain children and young people it is important to understand the unique perspectives of families from diverse backgrounds. This includes clinicians making diagnoses, researchers, and policymakers, who are dedicated to understanding racial and ethnic perspectives and developing ecologically appropriate and family-based interventions for youth with ADHD. Understanding the unique perspectives of families from diverse backgrounds is essential for clinicians, researchers, and policymakers, who are dedicated to understanding racial and ethnic perspectives and developing ecologically appropriate and family-based interventions for youth with ADHD (Paidipati, et al ,2017).

Mohamed and colleagues (2022) undertook a review of research including one study from Hassan (2012) and showed among Somali communities living outside Somalia that Autism Spectrum Disorder, is three to five times more prevalent among children of Somali descent than their peers from other backgrounds. Importantly, Somali children were generally diagnosed much later than their peers and often presented with lower intellectual abilities than their peers. Furthermore, Somali immigrants were found to have low levels of knowledge about autism, faced stigma and discrimination and often resorted to religion and a small tight circle of friends and family for social support. They faced a huge challenge of seeking access to healthcare and schools for their autistic children and have a mistrust of social services for fear of the government taking away their children.

Shaw and colleagues looked at outcomes for people with ADHD and reviewed 244 studies. 74% of the studies reported poorer outcomes in people with ADHD without support compared to those without ADHD. For example, people with ADHD had 2x risk of death, 2x more likely to sustain an injury.

When Glasofer and colleagues reviewed in 41 studies in 2022 they identified significant disparities in ADHD diagnosis and medication treatment (again important to note that these were US studies) between African American and White children. While diagnostic disparities showed a trend toward reduction over time, the reality was that African American children were less likely to get diagnosed and far less likely to gain access to medication.

Review of services for black autistic children (also in the US) has been shown that they are still more likely to receive a diagnosis later than their white peers (e.g. Maenner, 2020) up to a 1.5 - 2 year difference (e.g.,Mandell et al. 2007) thereby delaying their access to early support.

It is important to note that most studies have been predominantly published in the US and there is a lack of research undertaken in the UK.

Cultural and ethnicity in education and exclusion rates

The Timpson report (DFE, 2019) has evidenced differences in exclusion rates across the UK. When we consider school engagement (or disengagement), we also see a disparity in different ethnic and cultural groups. that parents perceive that the way child welfare workers interpret their emotions affects the decisions the workers make and how the parents are perceived during the case. (Tembo,2022).

Rates of exclusion by differing characteristics as reported by Timpson (DfE 2019)

Below national rate	National rate (0.10%)	Above national rate
Any other Asian (0.02%)	Black African (0.09%)	Irish (0.14%)
Bangladeshi (0.03%)	White & Asian (0.09%)	Any other Black background (0.15%)
Girls (0.04%)	Looked after children (0.10%)	Statement or EHCP (0.16%) *(highest level of SEN)*
Pakistani (0.05%)	White British (0.10%)	White & Black Caribbean (0.24%)
Any other white background (0.06%)	White & Black African (0.11%)	Black Caribbean (0.28%)
	Any other mixed background (0.11%)	Free school meals (0.28%) *(ever in the last 6 years)*
		Boys (0.35%)
		SEN support (0.35%)
		Gipsy/Roma (0.38%)
		Traveller of Irish heritage (0.45%)

Exclusion rates for black Caribbean students in English schools are up to 6x higher than those of their white peers in some local authorities, reported in the Guardian. Roma children are 9x more likely to be suspended in some areas.

Exclusion rates for mixed-race white and black Caribbean students have been cited as more than 4x higher than their white peers in several local authorities in the UK. This is important to note. As it is harder to access mainstream opportunities if you are not participating in education. Opportunities to play team sports such as football are much harder for you even if you have good motor skills.

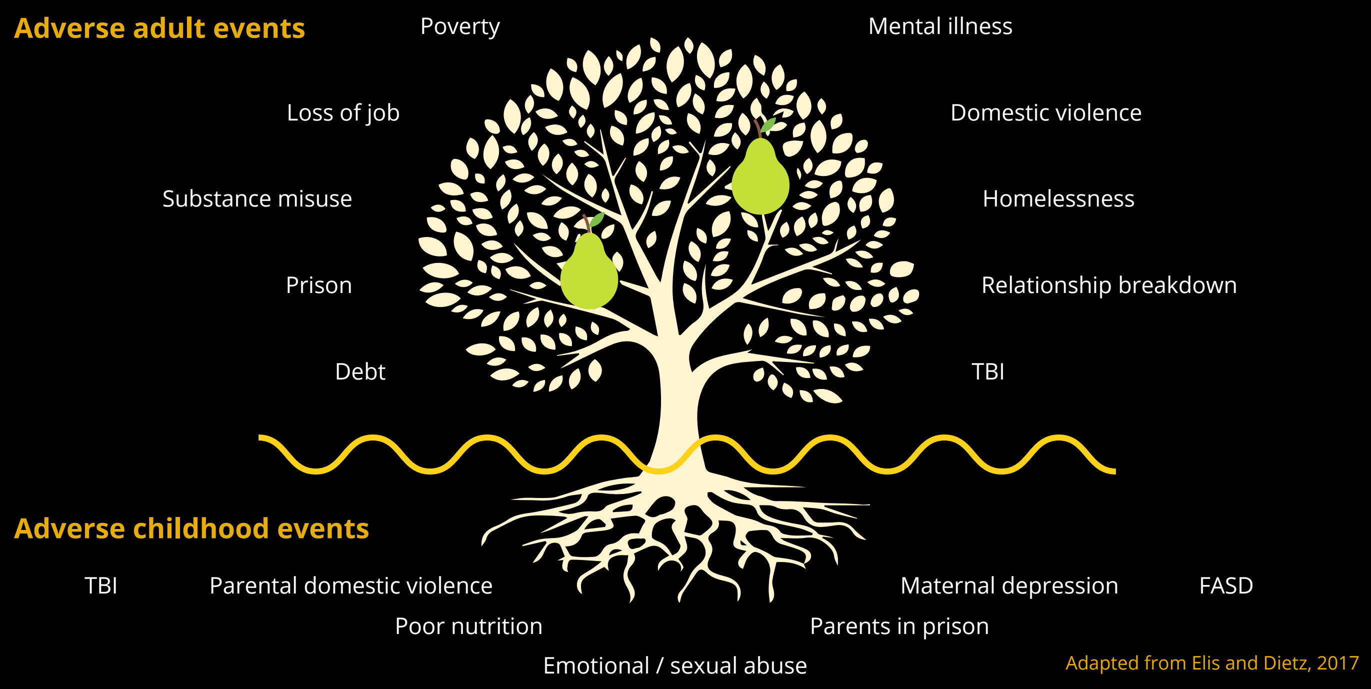
The double whammy effect - Neurodiversity and cumulative adversity.

Social inequality leads to lack of opportunity to shout for what you need. It may be practically and economically difficult for some parents to attend a series of appointments if they cannot take time off from their job or could potentially lose their job by doing so lost income may have a real impact on the whole family.

There is good evidence now that past childhood trauma **and** a genetic risk of neurodivergent traits increases the chances of that young person by 6 x of having three or more neurodivergent conditions (Dinkler et al., 2017). This is additive, i.e. the sum of the parts is more than one on its own.

There are also higher rates of neurodivergent traits among children excluded from school, **but** usually no routine screening for these traits. In one study of excluded children, the rate of ASD was 20 x the national average (Barnard et al., 2000). In a large-scale longitudinal study in Avon, of those excluded by the age of eight, 19% had ADHD and 23% had language development in the bottom 10% (Paget et al., 2018). In an older study, involving a sample of pupils who had been permanently excluded from 33 Sheffield secondary schools, it was found that about three in four (76%) were at least two years behind their peers in reading (Galloway et al., 1985).

Despite extensive evidence of co-occurrence between conditions and interlinking with adversity, we often still seek single diagnoses for children who have intersecting challenges (Cleaton and Kirby, 2018). Diagnoses may often be reliant on which professional the young person has been referred to and the training they have had. For example, if the child sees someone with expertise in ASC, the specialist may not be trained to screen for ADHD or dyslexia. Without appropriate training, a professional screening for ADHD may not consider other reasons for attention problems and not ask about the child having had traumatic brain injury (TBI), which can present in a similar manner.



Adapted from Elis and Dietz, 2017

There is good evidence of an association between higher SES-related factors linked to the receipt of an ADHD diagnosis and the opposite for those with lowest SES. The reason for this may be that social vulnerability, lack of cultural, and economic capital or immaturity can be a basis for difficulty concentrating and sitting still, e.g., in a school environment.

Intergenerational factors including lack of cultural capital, in the form of the parent's level of education, may also present poorer language competence.

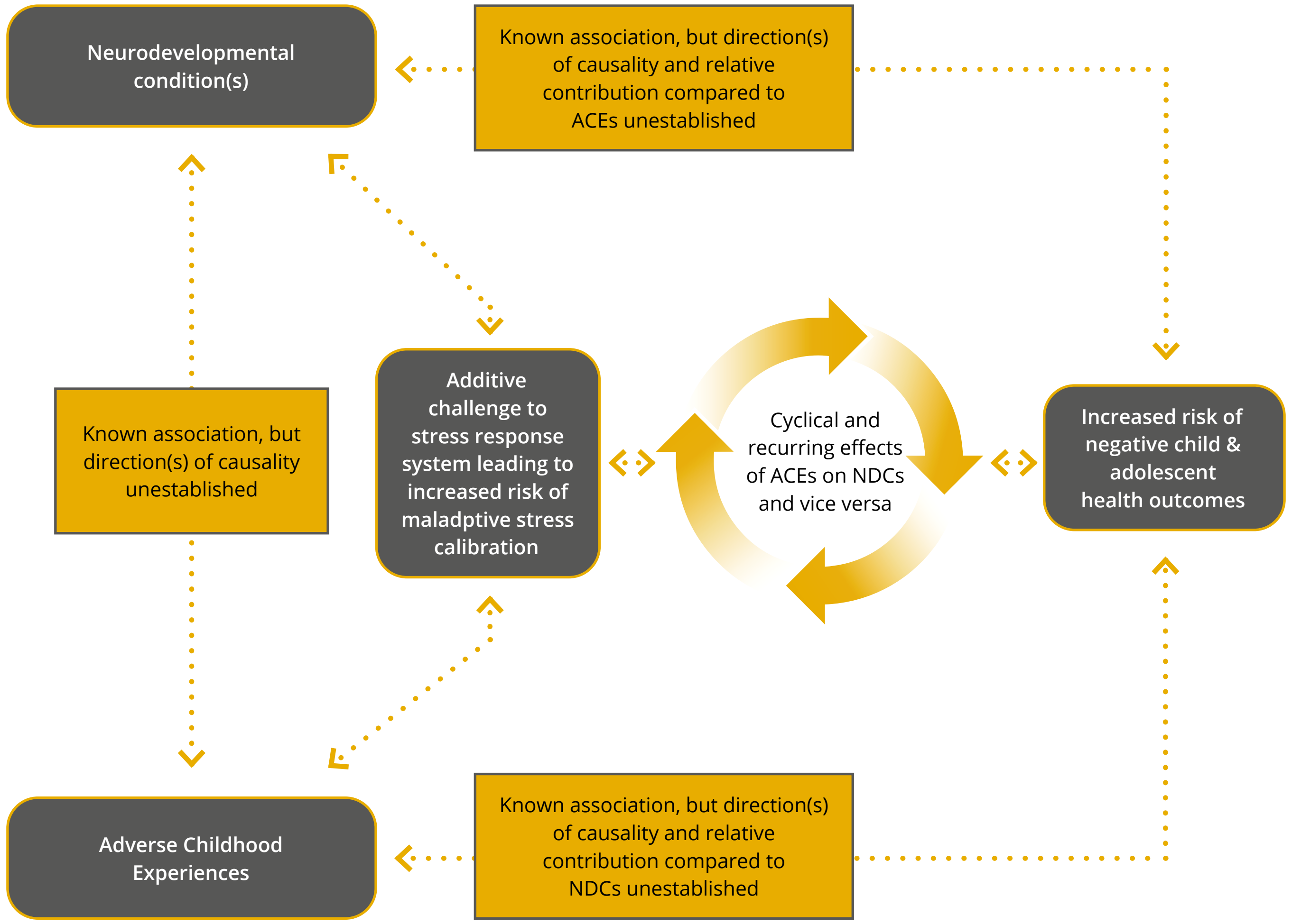
We know that parental socio-economic-status has also been shown to be related to language development. Lower levels of literacy in parents mean they are less likely to be reading to their children and their level of language and communication content will be lower and impact on the child's preparedness for school. If the child has dyslexic challenges or language delay this can have a greater impact.

In contrast a resourceful family may have greater opportunity to stimulate and educate their children and provide and pay for sporting opportunities. They may also have greater knowledge to find out what support is possible and advocate for their children. They may also have the resources to seek alternative support if there are waiting lists including paying for an assessment and interventions.

You don't know what you don't know

If you don't know what is out there or what you can access, you will not get the help your child or you require. In Papoudi and colleagues' study (2012) of caregivers of children with ASD from different racial and ethnic backgrounds different perceptions of support altered the way they asked for help. This may be independent of their child's specific needs.

Gajwani and Minnis (2023) have shown the impact of this and called it double jeopardy.



Ref: https://link.springer.com/article/10.1007/s00787-022-02081-9

This study shows that prolonged exposure to stress (if not diagnosed and supported) can result in those who are neurodivergent having a greater impact. They say that: "Individuals differ in their susceptibility to environmental stressors". They go onto describe an example that: "Children with ADHD are more likely than their peers to experience stress linked to forgetting homework, missing what the teacher has just said in class or impulsively saying/doing things that get them into trouble—and their impulsivity might also lead to temper tantrums which will, in turn, undoubtedly make their environment even more stressful. "This secondary impact is one we often don't map but is often the one we need to consider. If children don't understand what they need to do...get frustrated... get excluded for 'behaviour'... or opt out of going to school, then the result can be less schooling... leading to greater social isolation and missing skills others are gaining and so on.

Disparity gaps can widen over time. This has been shown in the study by Doherty and colleague's study. They showed that "autistic adults" were associated with barriers to accessing healthcare. Adverse outcomes included untreated physical and mental health conditions, not attending specialist referral, or screening programmes, requiring more extensive treatment or surgery due to late presentations and untreated potentially life-threatening conditions".

Professionals outside the field of education who work with children and families can help to ensure all children gain access to screening and early intervention services. This may be social workers, youth workers and GPs who may encounter families. This means designing services that are understandable and accessible across society.

Implications for youth justice and youth offending services and community services

Communication and comprehension issues can result in lack of understanding of charges, cautions, bail conditions or court orders. For example, not being able to understand the process might affect a young person's experience of the justice system such as misunderstanding questions during interview leading the child to make false admissions or 'overly honest' comments which may affect their defense (if not properly supported at interview, e.g. by an appropriate adult). If a young person is not able to read written communications, they might not be able to comply with them, e.g. receiving confirmation of a court date by post.

Not understanding the case and evidence against them may result in the young person pleading guilty (or not guilty), without being able to fully consider the effect that this may have on their case. Nodding or agreeing without understanding what has been said can have an impact on several points of the case: including police interview, first hearing and sentencing.

For several reasons, some children will not tell you that they are neurodivergent or mention their diagnosis(es) specifically. Many young people will not know or may be reluctant to disclose or share information because of past experiences of a negative response or bias against them or fear of misunderstanding.

Some young people differ in their sensitivity about disclosing their challenges and may not have the words to express how challenges make them feel; some may not view themselves as disabled or it may be that they are not comfortable disclosing personal information. Rather than focusing on diagnoses, it may be more helpful to look at behaviours and importantly, ask each individual if there are any aspects of communication that they find challenging or where they may need support, and adapt processes accordingly.

Children themselves have reported that they value being listened to and given a chance to 'tell their story', with practitioners taking the time to recognise them as individuals, understanding their specific needs and expectations. In some situations, negative impacts may be due to context (such as their lives both past and present) and structural settings (such as in a courtroom) rather than neurodivergence itself.

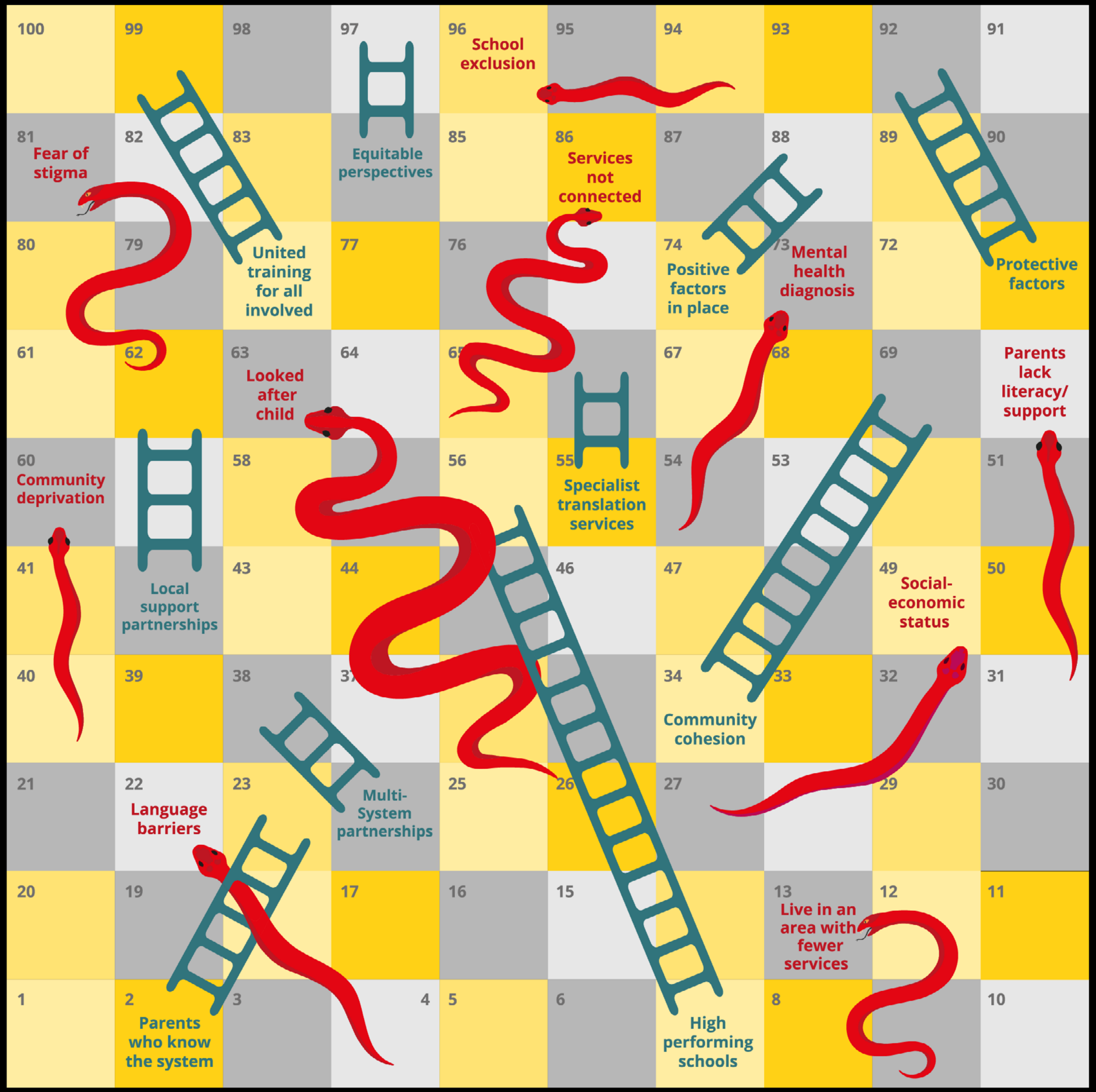
The Equal Treatment Bench Book was updated in spring 2020. It states: 'Effective communication underlies the entire legal process: ensuring that everyone involved understands and is understood.'

It goes on to say: 'Treating people fairly requires awareness and understanding of their different circumstances, so that there can be effective communication, and so that steps can be taken, where appropriate, to redress any inequality arising from difference or disadvantage.'

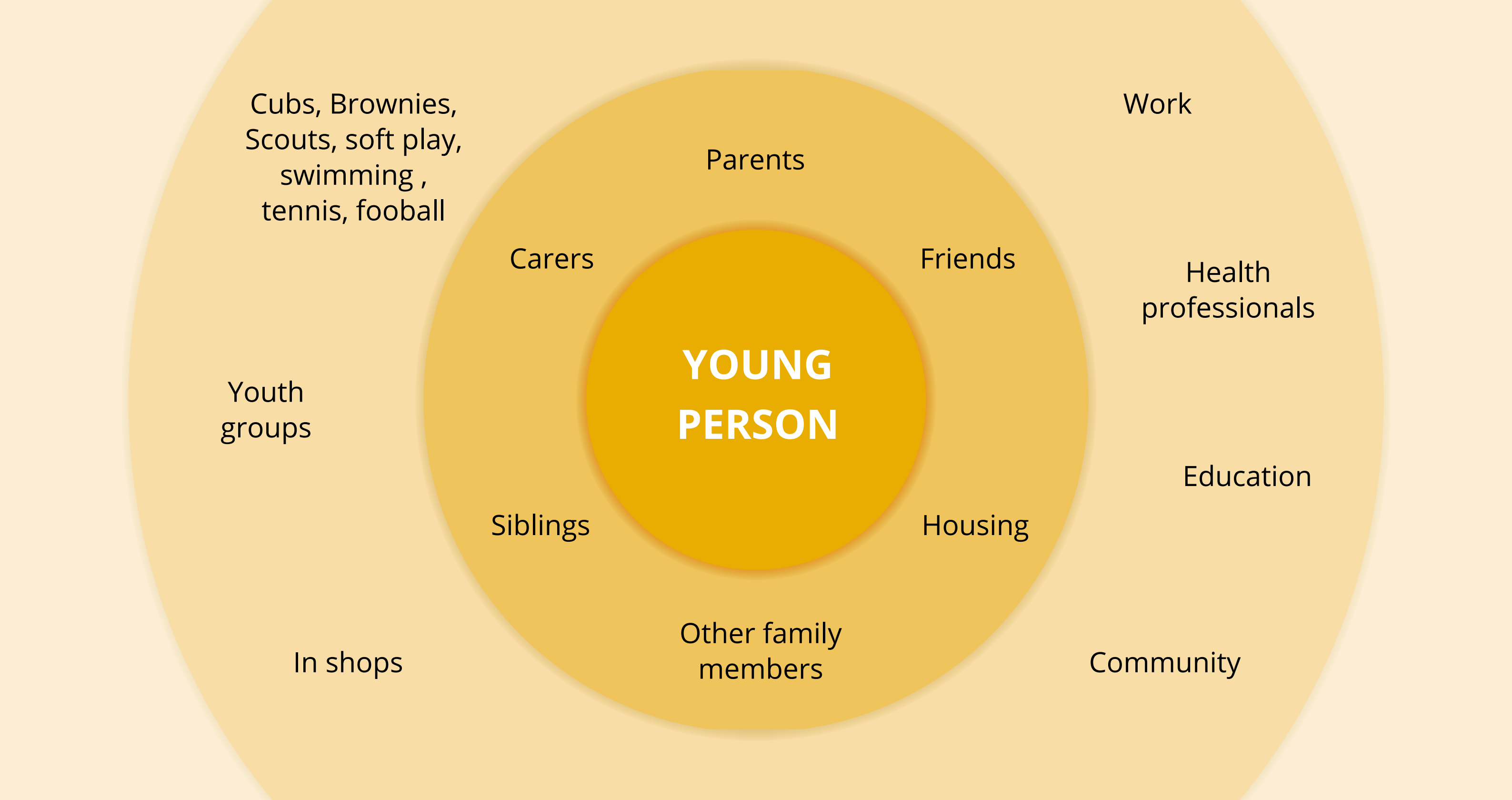
In order to support all young people in all places in society and within the community, it is essential that information is given in an accessible manner and also to check for understanding. Assuming that communication challenges are common and not rare would be very helpful for all.

There is clear alignment here with the relationship-based practice framework for youth justice which highlights the value of establishing relationships that are open and honest, and empathetic.

However, the status quo for ethnically diverse children is represented by this game of 'snakes and ladders':



A whole systems and whole person approach



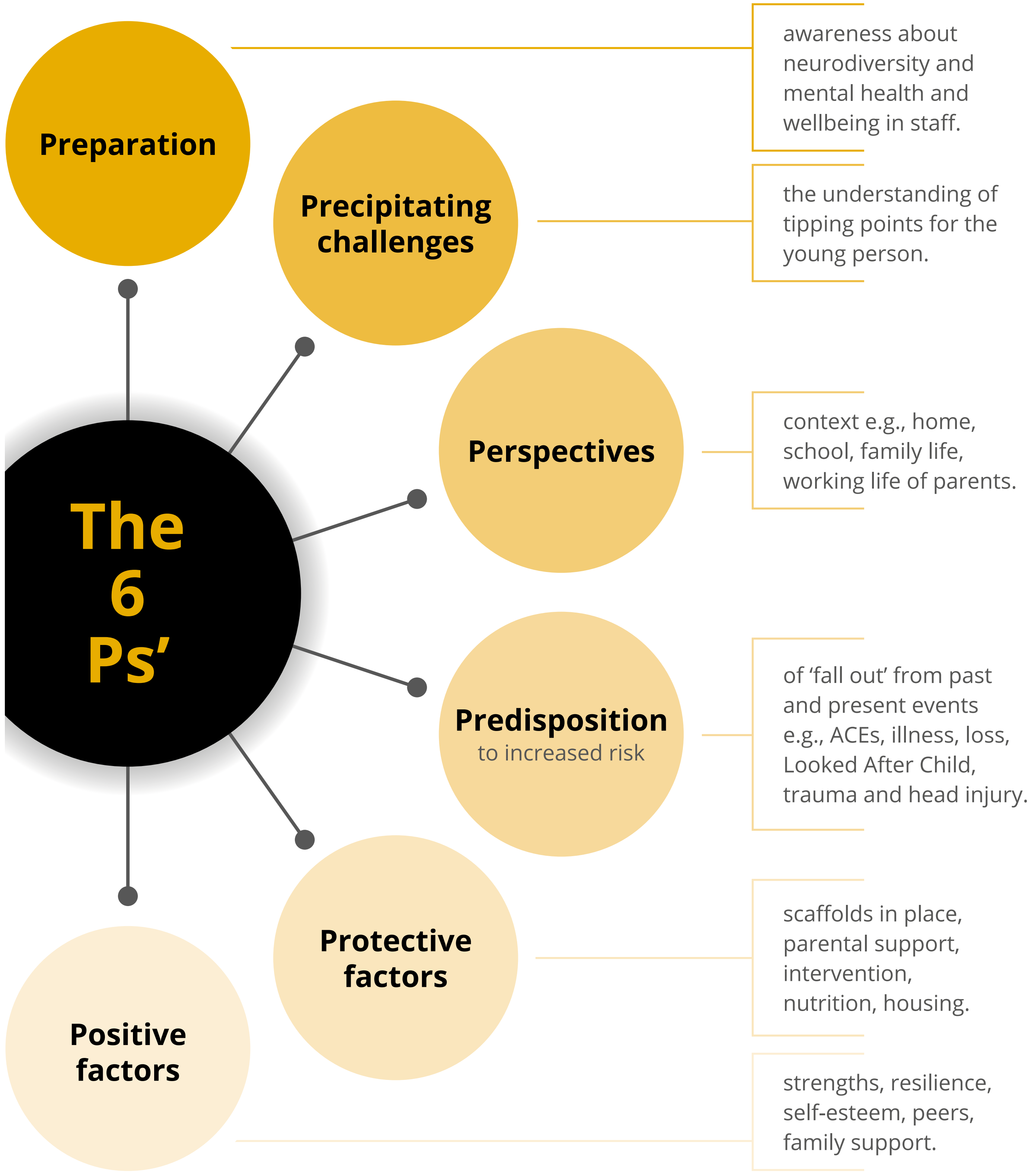
Bronfenbrenner (1978) described ecological systems theory and the importance of understanding the person in the context of their lives. To plan support, we can create a formulation from information gathered from multiple sources to appropriately support the young person functionally. This potentially allows each young person to have an equal opportunity to gain support earlier and reduce biases. If we continue to have a model that only intervenes within a narrowly framed diagnosis, we will inevitably see the same cycle of the person opting out of education, unemployed and eventually another intergenerational cycle.

In some youth offending groups, the rates of neurodisability are much higher, especially relating to ADHD traits and speech, language, communication challenges. Bronfenbrenner was one of the first people to discuss the need to understand the ecology of each young person, and a social-ecological framework for youth justice has more recently been promoted (Johns et al., 2017).

By taking an inclusive approach to service delivery and design we can engage more people in an accessible manner.

To fully understand a child and apply a whole-child approach, it can be helpful to pay attention to the 6 Ps' set out opposite.

The focus is on protective and positive factors aligning to desistance, strengths-based, trauma-informed and Child First models.



Martine Smith, Teacher in Maindee Primary School coaching boxing as part of the multi-agency Newport Levelling the Playing Field Partnership

Implications for future work

How can we change the trajectory?

Sport can be one very positive way of changing the way young people engage in society. Young people who are 'out of systems' are less exposed to opportunities for supportive engagement. Levelling the Playing Field (LtPF) has been a project run with the Youth Justice Board to support ethnically diverse children and support community centred ethnically diverse focused organisations, to get upstream and change the trajectory.

There are many community organisations, in a working partnership, in the community that are working ‘upstream’. Many are in formative education, alternative education, and community settings, operating during the day, evening, and weekends – connection, before correction is key not only for supporting children, but between organisations that are supporting children, especially Neurodiverse children. It is the consistent staff working across these settings that can form ‘key’ understanding and lasting proactive and prosocial relationships that offer a supportive connection to reconnect young people back into mainstream and statutory services. They do this through consistent community-based connection, building and rebuilding understanding of services around children and families, long-term and consistent trust building and increase communication between systems and the professionals working in them. These ‘Specialist Delivery Organisations’ hold a unique community perspective of the child and family/carers and offer a diverse view and understanding of the whole young person. In Newport, the Multi-Agency Team state they are a ‘commUNITY’ around the child, that is full of “safe faces, in safe places” – to change trajectory, we need more effective partnership working and communication across systems.

Visit www.newportlive.co.uk/en/news-events/levelling-playing-field-joins-unique-partnership-using-sport-support-children-newport/ for more information.

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Attainment gap and poverty

The Conversation: https://theconversation.com/poorer-pupils-do-worse-at-school-heres-how-to-reduce-the-attainment-gap-205535

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Useful links

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