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Neurodisability and Neurodiversity: A rights-based approach

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What is neurodisability?

- *‘Neurodisability describes a group of congenital or acquired long-term conditions that are attributed to impairment of the brain and/or neuromuscular system and create functional limitations. A specific diagnosis may not be identified. Conditions may vary over time, occur alone or in combination, and include a broad range of severity and complexity. The impact may include difficulties with movement, cognition, hearing and vision, communication, emotion, and behaviour’.*

Condition	Prevalence in incarcerated children (U18)	Prevalence in children in the general population
Attention-deficit hyperactivity disorder (ADHD)	30.1%	7.2%
Autism Spectrum Disorder (ASD)	3 -18%	0.3 – 1.9%
Communication impairments	60 - 64%	1-9%
Foetal alcohol spectrum disorder (FASD)	10.9 - 21%	0.7%
Learning disability	10 - 32%	1%
Acquired brain injury	50 - 87.1%	20.2%
Epilepsy	5.9%	0.3 - 0.6%
Developmental co-ordination disorder	30.3%	1.8 - 5%
Dyslexia	50%	7.1%
Tourette's syndrome	*6%	0.3 - 0.9%

David's Story



What is...?

- **Neurodiversity** – Refers to the whole population. We are ‘neurotypical’ and ‘neurodivergent’ so together we are neurodiverse. The term refers to the natural variation in cognitive function and thinking styles across the population.

Under the neurodiversity paradigm, diversity is a strength; just as diversity is a strength in a biological ecosystem.

- **Neurodivergence** – Refers then to anyone whose brain functions differently than what is considered typical
- **Neurodisability** – A term often used interchangeably with neurodivergence, but with stronger implications for the barriers that someone might face in day-to-day life, stronger associations with the social model of disability, and stronger implications for protections under international law.

The United Nations Committee on the Rights of the Child

General Comment no. 24 (2019)



‘Children with developmental delays or neurodevelopmental disorders or disabilities (for example, autism spectrum disorders, foetal alcohol spectrum disorders, or acquired brain injuries) should not be in the child justice system at all, even if they have reached the minimum age of criminal responsibility’.

The United Nations Convention on the Rights of Persons with Disability

Article 13: Access to Justice



- States Parties shall ensure effective access to justice for persons with disabilities on an equal basis with others, including through the provision of procedural and age-appropriate accommodations, in order to facilitate their effective role as direct and indirect participants, including as witnesses, in all legal proceedings, including at investigative and other preliminary stages.
- In order to help to ensure effective access to justice for persons with disabilities, States Parties shall promote appropriate training for those working in the field of administration of justice, including police and prison staff.

Outcomes in the Criminal Justice System

- In a Canadian study by Matheson and colleagues, one third of adults with Acquired Brain Injury had a serious disciplinary charge inside prison (30% higher than those without).
- In our research in the UK, we found that neurodisability is associated with suicidality and self-harm in prisoners
- We also found that care-experienced prisoners are more likely to have neurodisability, and more likely to be homeless

Matheson FI, McIsaac KE, Fung K, Stewart LA, Wilton G, Keown LA, et al. Association between traumatic brain injury and prison charges: a population-based cohort study. *Brain Injury*. 2020;34(6):757-65.

Kent, H., Magner-Parsons, B., Leckie, G., Dulgar, T., Lusiandari, A., Hogarth, L., ... & Kirby, A. (2024). Profiles of vulnerability for suicide and self-harm in UK prisoners: Neurodisability, mood disturbance, substance use, and bullying. *PLoS one*, 19(1), e0296078.

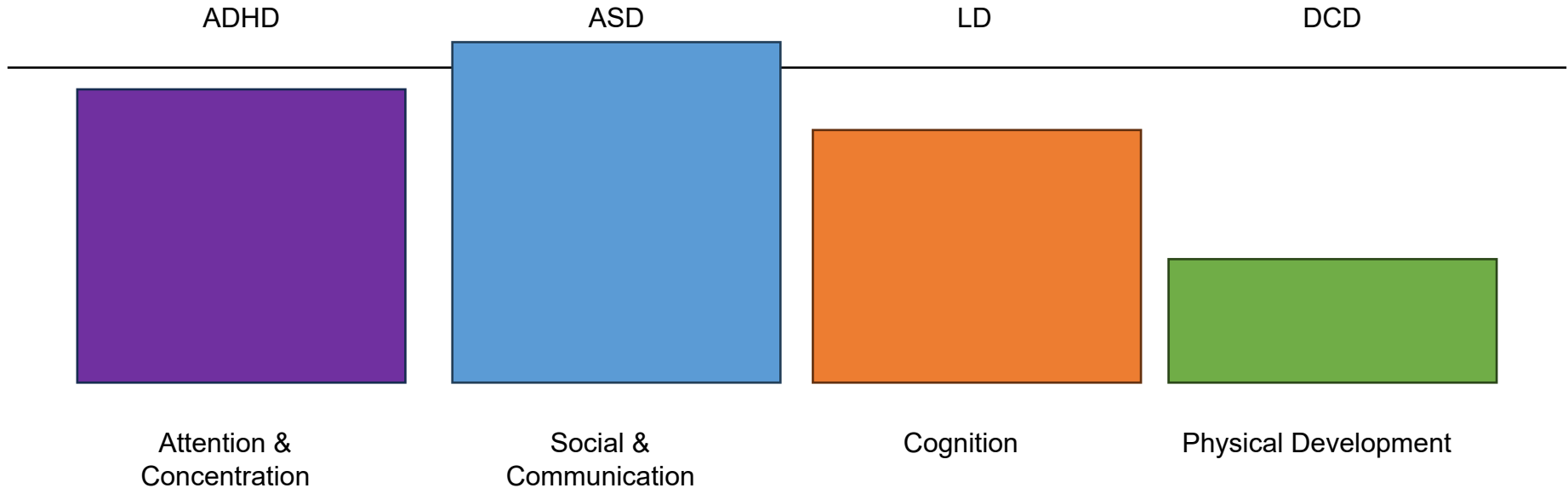
Kent, H., Kirby, A., Leckie, G., Cornish, R., Hogarth, L., & Williams, W. H. (2023). Looked after children in prison as adults: life adversity and neurodisability. *International Journal of Prisoner Health*, 19(4), 512-523.

The challenges of assessment

- Frontline staff aren't – and cannot be – experts in 10+ neurodevelopmental conditions.
- Screening for all these conditions is not feasible.
- There are also disparities in access to diagnosis – so many will end up in prison having never been assessed, so it's not enough to rely on existing information.
- Diagnosis doesn't tell us enough; two people with autism, or brain injury, will present very differently.



The problem with diagnostic thresholds



Transdiagnostic Approaches

ADHD

ASD

LD

DCD



Attention &
Concentration



Social &
Communication



Cognition



Physical Development



- A computerised, modular screening tool
- Used in education settings in prisons across England and Wales
- Assesses domains including attention and concentration; cognition; social communication; language and literacy; physical co-ordination
- Each question can be translated into different languages and read aloud
- It produces a 'profile' of strengths and weaknesses
- It also creates suggested techniques, tips, and tricks to support the individual

Accessibility

- Procedures in the criminal justice system are often complex, rigid, and punitive
- For example; in the court room, complex language may prevent someone with neurodisability from active participation in their trial, or having a thorough understanding of proceedings
- Life on probation requires appointments, paperwork, and curfews. But for someone struggling with executive function, this kind of planning can be difficult.
- Simple adjustments – easy read documents, or appointment reminders, can make a big difference
- It's about **dismantling barriers**



Good Practice Example – Brain Injury Linkworkers

- Support to engage with rehabilitative services
- Emotion management training
- Advocacy – e.g. joint sessions with prison and probation officers, increasing staff awareness
- Pre-release planning workbooks
- Appointment reminders, planners and diaries for the week
- Health and wellbeing interventions e.g. sleep hygiene and medication management
- Psychoeducation about brain injury
- Signposting to support services

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Understanding my brain injury has helped with my mental health, each session was the highlight of my week.

93%

fewer adjudications and incidents compared to the three months before receiving support, evidencing the impact of the support provided.

"SHE'S CHANGED MY LIFE IN HERE. THIS SENTENCE HAS BEEN A LOT EASIER CAUSE OF [THE LINKWORKER] ...I WAS SEEING HER... ONCE A WEEK AND IT WAS LIKE MY LIFELINE. SOMETIMES I COULDN'T WAIT TO SEE HER ...YOU'VE JUST A WAY OF TALKING TO SOMEONE THAT BELIEVES YOU FOR STARTERS AND SOMEONE THAT WANTS TO LISTEN TO YOU CAUSE YOU DON'T GET THAT IN PRISON YOU TALK TO AN OFFICER WHO THINK YOU'RE JUST A NUMBER, BUT SHE WAS MY LIFELINE ...BY THE TIME IT GOT TO ME SEEING HER I WAS A WRECK BUT THEN AN HOUR WITH HER AND SHE'D SORT OF BRINGS ME BACK DOWN ...EVERYTIME I SEE HER NOW, I'M JUST ALWAYS SO PLEASED." (Wendy¹⁴)

"SHE HELPED ME TO CREATE A WEEKLY CHART TO REMEMBER MY APPOINTMENTS AND WHEN TO CALL HOME TO SPEAK TO MY MUM..." (Olivia¹⁵)

Conclusion

- Creating an environment that is accessible for **all** will disadvantage none
- Fostering environments where compassion is the norm, and where staff look below the surface of behaviour to understand the needs of the whole person is essential
- There is no need to be an expert in every neurodevelopmental condition; an assessment of needs could give you all the information you require to support the people you are working with
- We have an obligation under the UN CRC and UN CRPD to assess for neurodisability, and to ensure that we create a more accessible justice system

Thank you

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