

Draft NFCC Equality of Access to Services and Employment for Neurodiversity

Executive Summary

This document outlines what <u>neurodiversity</u> is, how you can recognise it, how you deal with it and, using KPIs and collected data, how you learn from it to develop strategies to improve employability and staff engagement with it in the workplace, in the wider community, and with working partners.

Introduction

As a public service focused on providing excellent service to our customers, we need to ensure equal access to our services for every person and those in temporary residence or in transit through the county.

We know through our incident data that certain groups are more likely to have a fire, and they include people who are living with dementia, mobility issues, and mental health issues. There are, however, other groups who aren't necessarily showing as being at higher risk of a fire or injury, but they may not be accessing our services such as 'Safe and Well' visits or engaging with the service because of barriers, which may include language, perceived prejudice and other societal factors. Equal access means actively seeking to engage these groups, who may be unaware or choosing not to access services from us and other public sector providers.

We need to work to reduce fire and other life risks, and that needs different approaches. Within our equal access approach, we also need to consider how we:

- Identify all the communities and customers resident in our area.
- May develop and improve the provision of goods, facilities, services, and access to all those communities across a range of variables including ethnicity, disability, gender, sexual orientation, religion or belief and age, health inequalities, etc.
- Learn from and enhance good practice identified through equality monitoring.
- Use the results of equality monitoring to mitigate any adverse impact of our goods, facilities, services, and access on diverse communities, and on groups within communities.
- Eliminate any unlawful discrimination identified through equality monitoring.
- Promote good community relations.
- Apply the rules of social marketing to make customers safer through changing unsafe behaviours.
- Best engage with partners and collaborate on sustainable solutions that make the best use of public funding and resources available.

Contextual Background

Historically, many conditions which come under the neurodiversity banner have previously been described as disabilities rather than different thinking styles and this has-created a stigmatised view of anyone who thinks or behaves differently. Children in classrooms without a diagnosis used to be considered either slow or disruptive. The social and occupational exclusion for neurodivergent people is clear:

Since the advent of disability legislation in 1995 with the Disability Discrimination Act, the current Equality Act (2010), and the <u>Autism</u> Act 2009 we have seen organisations try to comply with the law for all hidden disabilities or conditions.

Neurodiversity has its origins in the Autistic Rights Movement, which emerged in the 1990s. It is reported that the term 'neurodiversity' was coined in 1998 by an Australian sociologist named Judy Singer and was quickly picked up and expanded as a broader term for the infinite variation of neurocognitive functioning seen in people. The 1990s was also a time when Asperger syndrome became better understood and was thus diagnosed more frequently. People with autistic behaviours, without the associated learning difficulties and with average or higher than average IQs identified differently to their autistic counterparts who struggled with learning, and often other disabilities. Neurodiversity encompasses all specific learning differences (SpLD), many of which co-occur or overlap (Source British Dyslexia Association).

Neurodivergence and intersectionality

A person whose neurocognitive functioning diverges from dominant societal norms in multiple ways, for instance, a person who is autistic, dyslexic, and epileptic, can be described as multiply neurodivergent.

<u>Intersectionality</u> is the interconnected nature of social categorizations such as race, class, and sex as they apply to a given individual or group, regarded as creating overlapping and interdependent systems of discrimination or disadvantage. This can provide an added complication and additional layer to neurodiversity and how one deals with or risk assesses it.

Data

According to a report compiled by Julie Logan (Professor of Entrepreneurship) and accepted by the National Autistic Society:

- Only 16% of people in the UK with autism have a job.
- Only 1% of corporate managers have dyslexia compared to a population norm of 10%.
- 25% of the UK prison population have Attention Deficit Hyperactivity Disorder (ADHD).

Despite reports that 10% of the UK population is neurodivergent, Dyslexia specifically is the third most frequent condition reported to 'Access to Work', the DWP-funded service supporting the recommendation of reasonable adjustments. CIPD research found that only 1 in 10 organisations say neurodiversity is included in their people management practices – this is also in the context that the number of employees on the spectrum is likely to be far higher than that, as many mask their condition, or may have no formal diagnosis, or choose not to declare.

It is important to recognise that it is common for neurodivergent conditions to overlap – many autistic people show indicators of more than one. (Information sourced from ADHD aware).

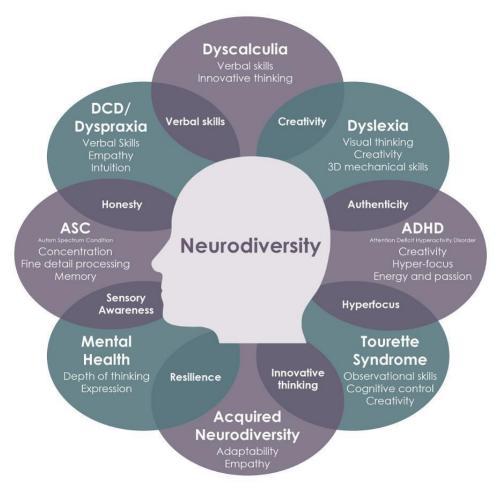
- Approx. 1 in 2 people with ADHD have dyslexia
- Approx. 1 in 2 people with ADHD have <u>dyspraxia</u>
- 9 in 10 people with Tourettes have ADHD

It is also common for neurodevelopmental conditions to concur with mental health conditions, e.g. ADHD and Bipolar. They are often misdiagnosed as mental illness due to a lack of awareness and understanding within healthcare settings.

In addition to the data from other sources, valuable additional insights have been gained from people's impact assessments and insights from working with charities and other organisations such as the Business Disability Forum, the National Autistic Society, British Dyslexia Association, RoSPA, and groups focused on neurodiversity.

This document outlines the case for additional work needed to support individuals who are neurodivergent, understanding at the outset that the term encompasses a wide spectrum of people and conditions. The concept of neurodiversity comes from a viewpoint that brain differences are normal, rather than deficits, and this can help reduce stigma around learning and thinking differences. It is, however, key that we treat people as individuals, despite being under a descriptive broad banner of conditions.

The term 'neurodiversity' applies to the range of differences in individual brain function and behavioural traits, regarded as part of the normal variation in the human population. Neurodiversity is most associated with dyslexia, Developmental Co-ordination Disorder (DCD), Attention Deficit Hyperactivity Disorder (ADHD) and Autism Spectrum Condition, but includes any condition that affects some, but not all, thinking skills.



Created by Dr Nancy Doyle based on the work of Mary Colley

Why should we be concerned about equal access for those with Neurodiversity in an FRS context?

This is not just an issue to be considered in relation to the services we provide, but also in relation to our own staff and the partners and agencies we work alongside.

In the workplace this is not just about inequality, it is also about nurturing talent and ensuring excellence through people.

In our Prevention activity it is about ensuring we design-in equal access for people who may not be able to access services such as 'Safe and Well' visits; who may have experienced poor responses and understanding in relation to hoarding; and other issues that may emerge during attendance to operational incidents.

The evidence base is broad, with significant literature sources and research reports, but limited in application to our sector.

Documented cases associated with inequality in relation to neurodiversity are increasing – both in relation to employment and in terms of access to services, with a prevalence related to restricted access to services associated with education and health. We are concerned that in our provision of prevention services and how we provide outstanding operational response we need to be inclusive of neurodiversity and the resulting differential needs of individuals.

Recommendations have been made by All Party Parliamentary Group on Autism (APPGA) which worked with the National Autistic Society (with further information in useful links at the end of this document):

- Despite equality legislation, evidence suggests people with thinking variations still face discrimination when accessing some public services.
- Neuronormative assumptions and both the experience and fear of discrimination prevent some with ND from accessing mainstream services.
- Evidence suggests public services do not routinely monitor neurodiversity within/amongst their staff and/or service users, nor are those with conditions routinely involved in consultative processes. This poses a significant barrier to the engagement of people in the design of services for the future.
- Some limited research suggests that staff and service users are reluctant to declare ND conditions, which does make identification and monitoring more challenging. It is important that Services make it very clear that they can adapt communication and provision of support if they are aware of needs.
- Many adults and children have never been diagnosed as having a ND behaviour and may not even be aware of it; and how it impacts theirs' and others' daily lives.
- Some evidence suggests those with an ND condition may be disproportionately negatively affected
 by spending cuts on Voluntary and Community Services (VCS). Some local networks and support
 groups are very small, and struggled with funding even prior to the current COVID situation.
 Partnership work with local authorities is important to understand if public services supporting
 those with ND are impacted during budgetary reviews.
- A key evidence gap is how best to amend service prevention work and information to support those with ND conditions. The issue of education of young people with ND is particularly important given that many may be in specialist education settings, or indeed be home educated. The British Dyslexia Association suggests that 80% of children on the spectrum will remain unidentified during their education, with many, therefore, unable to access adapted learning to improve their life chances and safety; and the LGA has stated that the demand for SEN services has risen faster than the funding available and is at 'tipping point'.
- Evidence provided by previous research reviews on the barriers those with ND conditions face (ACAS research paper: Neurodiversity at work ref 09/16, which was supported by the National

- Institute of Economic and Social Research) suggests that lack of awareness is a key barrier in relation to neurodivergence.
- The second finding was that those with ND conditions often have low esteem as they may have had historic negative experiences in both educational and employment settings. This could also be applied to domestic settings.
- The third finding was that organisations can be poor at clear and precise communications, which
 are very important for neurodivergent individuals. The research paper cites some useful case
 studies.
- Evidence suggests that those with Neurodiverse conditions are at risk of increased injury. This
 could be self-inflicted, or at the hands of an abuser or trusted adult.

How do we segment our focus for people with Neurodiversity?

Firstly, it is important to understand that there are different perspectives. The concept of the ND paradigm has been controversial among some autism advocates, with opponents stating that the concept of a spectrum and broader focus does not adequately reflect the realities and needs of those who have very high support needs.

There has been debate about the width of the spectrum, for example, should those with conditions such as cerebral palsy or those with brain injuries, both having divergent form of neurology, be encompassed? Others arguing that this medicalises the notion of neurodiversity.

The neurodiversity movement opposition to 'curing' autism has produced misunderstanding, with some saying that it attributes all challenges to social injustice and rejects interventions to mitigate symptoms. However, this could stem from historic treatments such as shock therapies and extreme medication. It is clear that useful support therapies are welcome, including but not exclusive to, building language skills flexibility and broader educational awareness.

As with the introduction of equality monitoring for other groups, early data outputs should be viewed with caution since it is likely that the ND population will be under-counted/reported.

Six identified segments in ND Communities requiring focus from an FRS perspective:

1. Children and young people

Neurodiversity is associated with increased risk of injury, particularly in younger people

A study conducted by Dr Li Guohua, director of the Centre for Injury Epidemiology and Prevention at Columbia University, researched specifically the link between autism and injury. It concluded that children and young teens are 40 times more likely to die from injury than the general population. With drowning being the most common fatal injury in the US among autistic children. It found that autistic children have later development in relation to understanding dangerous situations, may prefer to be alone, may tend to wander, and have 'hide' responses to loud noises or fear.

The Journal of Safety Research (Bonander, Beckham, Janson and Jernbro July 2016: Sweden) concluded similar findings focused on a study considering ADHD, suggesting a 65% increased risk of injury.

The National Autistic Society has also reported a high incidence of self-injurious behaviour associated with those on the spectrum, going on to identify the common causes are that individuals don't feel heard or supported, don't respond well to criticism or being told off, have suffered bullying or abuse, and are also a manifestation of frustration in trying to communicate their needs or feelings.

Atypical abilities in social interaction, social communication and social meaning often result in difficulty with understanding what others think, resistance to change and sensory sensitivity. 50% of individuals with autism are nonverbal throughout their lifespan, another 20% may present as nonverbal when stressed because of a shutdown or meltdown – common autistic responses to feeling overwhelmed, but widely misunderstood. This is significant when considering access to services.

Many autistic individuals have significant sensory issues and may display unusual responses to cold, heat, or pain. This is related to interoception, which is one of the 8 senses. Sensory sensitivity is one of the fundamental indicators required for an autism diagnosis. In fact, they may fail to acknowledge pain despite significant pathology being present, or show an unusual pain response such as laughter. Given autism is not identifiable by appearance, assurance of a greater understanding of associated behaviour is necessary to provide appropriate service provision.

Specific Issues

A high proportion of children on the spectrum will not be identified during their educational years.

Children with SEN statements may be in mainstream schools, but also many are in specialist education or home educated

Neurodiversity in children has been associated with increased risk of injury in the home

Suggested Actions

Target social media groups and work with charities to get service offer to this group.

Liaise with local education authority to gain access to SEN settings and those that are home educating.

Ask NHS if they are willing to share our offer to individuals known to them.

Review of how and when we deliver prevention and safety education programs is key, and liaising with other agencies.

Work with the burns specialists to track if there are more burns/scalds in children who are in the ND population.

Create a working group with representatives from local charities and organisations who support ND individuals to discuss strategies?

2. Those who have had to overcome previous access issues to service and are reluctant or fearful of large organisations.

As previously mentioned, many people with ND conditions may have had previous 'bad experiences' and may also be reluctant, or not know how, to access services.

Specific Issues

Some who have experienced past hostility or difficulty in accessing public services will need focused encouragement to receive services; and, to apply to work for us in corporate or operational teams.

Some adults may be undiagnosed entering the workplace as an employee and may not know they are ND. They might be considered difficult or disruptive or display ND characteristics without understanding or empathy from managers and co-workers.

Suggested Actions

Working with national charities such as National Autistic Society or British Dyslexia Association as well as identifying other local support networks and charities will improve access to those on ND spectrum.

Positive action and campaigns, such as advertising on social media that services are seeking to work with the aforenamed charities may encourage people to come forward.

Staff members may be experiencing repeated and unidentifiable behaviour issues in the workplace.

Managers should be trained to identify this and write a supportive adjustments risk assessment, including assistive technology, with a copy kept on their HR file so it can be managed more sympathetically by the incumbent manager and subsequent ones. A handover must be performed upon promotion or manager change so the person is not left exposed to detrimental welfare related issues as a result.

Our workforce - how do we encourage a diverse workforce and encourage existing staff to declare disabilities/ND conditions, and ensure we provide reasonable adjustment and prevent bullying/ostracising?

Our sector frequently declares the desire to be 'representative of the communities we serve' and, therefore, that should include encouraging a neurodiverse workforce.

It is also well documented that our workforce is reluctant to declare disabilities – some of this may be to do with a dominant culture, or fear of stigmatisation, or perception about the reaction of their peers or employers.

Neurodiversity and the law

The Equality Act 2010 (section 6) defines disability as a physical or mental impairment that has a 'substantial' and 'long term' negative effect on the ability to do normal daily activities.

Dyslexia, Autism Spectrum Condition and <u>Asperger</u> syndrome may be considered under this definition, and there have been cases that have succeeded, but as the condition does affect people to different degrees the final test will be if the impact is substantial or long term. Generally, employers do proceed on the basis that employees do have a disability and make reasonable adjustments.

Mental impairments do include some neurodivergent conditions. It is important to note that someone does not have to have a clinical diagnosis to be considered disabled.

Neurodiversity and workplace guidance

Organisations which have deliberate inclusion strategies do so for the benefits diversity and different thinking styles bring – well known examples include GCHQ, who targeted dyslexic analysts to 'think outside the box', and Microsoft, who have been seeking autistic coders.

Neurodiversity adjustments tend to fall into four main categories: assistive technology, workplace tools, coaching for literacy, and coaching for 'executive functions' such as concentration and memory, but there are many adjustments an organisation can make. Flexibility in the workplace, environment, coaching and feedback/tasking are amongst some of the most common adjustments.

Bullying campaigns also need to recognise that some ND behaviours may attract negative behaviour from others and/or lead to isolation, as people do not quite know what to do or say.

Specific Issues	Suggested Actions
Encouraging applications from people with	Make it clear in adverts and on your service website
a ND condition	that your organisations support people with different
	thinking styles. Services should monitor and assess their
	processes for negative impact on declared disability, to

Staff may be unaware of their own spectrum condition or be unwilling to declare it.

It can be that others detect certain behaviours which are perceived as 'different', and that either prevents discussion on how to offer reasonable adjustment or, based on evidence across all sectors, it can lead to bullying.

Inclusivity and access to reasonable adjustments and facilitating digital solutions.

Anxiety about inconsistency of treatment.

assess if their reasonable adjustments are fit for purpose.

It is important as employers that we understand the extent of those requiring support, but also as part of our workplace planning consider what training our people need to both understand ND and maximize their contributions and potential.

Awareness training for all staff is vital, as is management training to ensure managers do not ignore indicators of neurodiversity and that they combat any issues of bullying.

Access to IT or software such as 'read and write gold' or other text help should be available to all staff to reduce barriers.

It can assist if staff with an ND condition have a documented EQIA or 'Equalities passport' which documents what solutions or adjustments will assist them, particularly when accessing training or change of department or line manager.

3. Older people on the spectrum.

If older people are perhaps already vulnerable, having an ND condition can reduce their social interaction.

intordetion:	
Specific Issues	Suggested Actions
Older people on the spectrum may be	Alternative access pathways should be available to
reluctant to access Home Safety or	booking a Home Safety Visit.
Wellbeing visits and may have difficulty with	
some communication methods or be put off	Ask NHS if they are willing to share our offer to
by forms to fill in or long documents or lots	individuals known to them.
of leaflets.	
	Assess opportunities for Volunteering with FRS.
Autism is a relatively 'new' condition – the	
first people formally diagnosed in the 1960s	Collaborate with local charities and organisations
are only just reaching old age now and	supporting these individuals to discuss how to reach out
there are many undiagnosed/misdiagnosed	to them.
individuals who are very vulnerable due to	
lifelong social communication difficulties	
and the lack of support they have received.	
We do not yet fully know what the main	
issues affecting older autistic individuals	
are.	
Lagrding	

Hoarding

Hoarding Disorder often coexists with other conditions*. There is correlation between Attention Deficit Hyperactivity Disorder (ADHD) and Attention Deficit Disorder (ADD) as risk factors for hoarding disorder, although it is important to be clear that these neurodiverse conditions do not cause hoarding. *ADHD is the most common condition diagnosed alongside Autism Spectrum Disorder.

There are three primary pathways to hoarding:

- 1) Inheriting the vulnerability to hoard, either genetically or environmentally. It is estimated that between 50% and 80% of those who hoard have a first-degree family relative who hoards. Genetic similarities have been found in chromosomal markers. The chromosomes are 4, 5, 17, and John Hopkins University conducted an OCD Collaborative Genetics Study identifying chromosome 14 as linked by an autosomal recessive pattern to OCD.
- 2) Having a high-risk comorbid factor; this speaks directly to the characteristics and challenges of those living with ADHD/ADD daily.
- 3) Being (even mildly) chronically disorganised and then becoming vulnerable. Birchall Consulting conducted a random snapshot of cases over the past 10 years and found that only 2.8% of those who sought help for hoarding had been diagnosed with ADHD or ADD. This is concerning, because it could mean there are many more individuals with ADHD/ADD who are hoarding but are not getting help.

It is important to note that even though the optics of a hoarded environment may appear similar, those who hoard are not homogenous. Hoarding is found in all cultures, income, education levels, and for different reasons. Hoarding situations can continue to deteriorate until the health and safety of the individual and community are put at risk. In a situation that meets the standard for Hoarding Disorder, the only difference between an excessive accumulation of perceived valuable things and non-valuable things is the price tag on the items. The key factor is the excessive accumulation and the failure to resolve that excessive accumulation because of the risk it creates.

Specific issues	Suggested Actions	
Emerging evidence suggests that a high	Removal of hoarded materials will create extreme	
proportion of hoarders are found within the	anxiety in autistic people. They will typically have a	
ND population.	rationale for why they hoard and we need to work with carers and charities/agencies who have specialist skills	
	to try and access, and then support people who are	
	hoarding and increasing fire risk.	
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4. Recognising the need for support during operational incidents.		
Specific Issues	Suggested Actions	
Operational response.	Awareness training of operational staff is vital, as is	
Particularly in situations of heightened	consideration of mechanisms used to reassure	
emotion, staff may encounter atypical	individuals and reduce anxiety.	
responses from some people with ND		
conditions.		

Key areas of focus to improve sector evaluation and engagement with neurodivergent people

- 1. Monitoring equality outcomes for both our staff and service users.
- 2. Seeking qualitative evidence to support how we design future services.
- 3. Pledging work to seek personal commitment to the safe and well advice.
- 4. Seeking representation from the ND community for consultation on design of services and IRMP.
- 5. Asking charities and other public sector providers to help survey for needs and outcome measures.
- 6. Have a clear strategy for clear and inclusive communication.
- 7. Consider training and awareness for staff to improve their understanding of ND.
- 8. Further research with experts on how we support people with neurodiverse conditions.

Glossary of terms and Definitions

1. Attention Deficit Hyperactivity Disorder (ADHD)

NHS definition – is a behavioural disorder that includes symptoms such as inattentiveness, hyperactivity, and impulsiveness

2. Asperger Syndrome

National Autistic Society – the term was derived by an Austrian paediatrician Hans Asperger. It is considered a form of Autism and people with the syndrome are of average or above average intelligence and often do not have the learning disabilities that many autistic people have. They have fewer problems with speech, but may still have difficulties with understanding and processing language

3. Autism – also Autism Spectrum Disorder (ASD) and Autism Spectrum Condition (ASC)

National Autistic Society - Is a lifelong developmental disability that affects how people communicate and relate to people and the world around them. It is not an illness, but rather a different way of thinking. There are many terms used to describe autism, Opinion varies on the language used and it may vary according to the symptoms experienced. It is a spectrum disorder which means that the symptoms can vary significantly for individuals.

4. Dyspraxia – also known as Developmental Co-ordination Disorder (DCD)

NHS definition – Is a condition affecting physical co-ordination. It is a brain-based motor disorder and is not related to intelligence, but can affect cognitive skills

5. Dyscalculia

The Dyslexia Association – Is a condition associated with specific learning difficulties relating to arithmetical skills and numbers

6. Dyslexia

NHS definition – Is a common learning difficulty that can cause problems with reading, writing, and spelling.

7. Interoception

Sometimes referred to as the 8th sense – it describes sensitivity to stimuli originating inside the body. It is the perception of sensations from inside the body and includes the perception of physical sensations related to internal organ function such as heartbeat, respiration, satiety, as well as the autonomic nervous system activity related to emotions.

8. Neurodiversity

A relatively new term used to describe a range of differences in individual brain function. It is an 'umbrella' term and a concept that neurological differences should be recognised and respected like any other human variation.

9. Neurotypical (NT)

An abbreviation of neurologically typical, widely used in the autistic community to describe people who are not on the autism spectrum or have 'normal' brain function.

10. Tourettes Syndrome

NHS definition – is a condition that causes a person to make involuntary sounds and movements, which are commonly called tics.

11. Intersectionality

Intersectionality is a theoretical framework for understanding how aspects of a person's social and political identities combine to create unique modes of discrimination and privilege. Intersectionality identifies advantages and disadvantages felt by people due to a combination of factors.

Useful websites, publications, and published research

ACAS research paper: Neurodiversity at work ref 09/16

Supported by the National Institute of Economic and Social Research

https://archive.acas.org.uk/media/4655/Neurodiversity-at-work/pdf/Neurodiversity_at_work_0916(2).pdf

All Party Parliamentary Group on Autism

https://www.autism.org.uk/get-involved/campaign/appga.aspx

Attention Deficit Disorder Association https://add.org/adhd-and-hoarding-disorder-101/

Business Disability Forum https://businessdisabilityforum.org.uk/about-us/

In addition, several services seek to work with charities or forums that understand the conditions associated with ND and can provide support and guidance. Some, such as BDF (Business Disability Forum) are membership organisations who also provide advice but will screen policies and offer helplines for managers and provide network opportunities.

British Dyslexia Association https://www.bdadyslexia.org.uk/dyslexia/neurodiversity-and-co-occurring-differences/what-is-neurodiversity

CIPD with Uptimize: Neurodiversity at work guide. February 2018 https://www.cipd.co.uk/Images/neurodiversity-at-work_2018_tcm18-37852.pdf

Genius Within: supporting people with neurodiverse conditions to fulfil their potential at work and in their career https://www.geniuswithin.co.uk/

National Autistic Society: https://www.autism.org.uk/

https://www.autism.org.uk/about/family-life/everyday-life/road-safety.aspx

Information from other countries

Fire safety for Children on Autism Spectrum https://www.autismkey.com/fire-safety-for-children-on-the-autism-spectrum/

Fire evacuation procedures for Children on autism spectrum https://pathfindersforautism.org/articles/education/the-fire-drill-freak-out/

Research paper (2017): Characteristics of unintentional drowning deaths in children with autism spectrum disorder https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5721095/

Research paper (BM Journal): Autism spectrum disorder and unintentional fatal drowning of children and adolescents in Australia: an epidemiological analysis https://adc.bmj.com/content/early/2020/03/13/archdischild-2019-318658