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# Neurodiversity and Data: If it does not get measured it does not get done.

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## Abstract

Inadequate data, acts as a barrier, making it difficult for public bodies, to measure the impact of neuro inclusion policy.

The Neurodivergent (ND) community suffers from a problem of triple invisibility.

-ND people are frequently not visible to themselves - Most ND people are never diagnosed and therefore do not know they are neurodivergent.

-ND people are not visible to other people. You cannot tell if someone is ND by sight or casual observation.

-ND people are not visible in public policy. Without good data it is hard for public policy to measure differences between the experiences of ND people and other members of society.

While this issue of visibility is significant to the ND community, failure to recognise the significance of neurodivergence has a wider impact on the economy and society. For example, in the UK around 9m working-age people are not in employment. 2.6m are not working for health reasons. (Sky News , 2024) Many in this category are ND, not diagnosed at school and wanting to work. If they were able to work it would increase economic growth, reduce benefit bills and lift a pressure on the NHS. However partly because of lack of quality data Neurodivergence is rarely identified as a focus for employability policy.

This paper concludes with a call to action to researchers and advocates. The ND community should pragmatically build a data toolkit, which would embrace shared definitions, a shared approach to estimating the incidence of neurodiversity in the population, a shared approach to using survey data to estimate the incidence on neurodivergence in various settings and a shared convention on how to benchmark data.

**Keywords:** Neurodiversity, Data, Public Policy

## 1. Introduction

It is said if something does not get measured it does not get done. The lack of widely recognised data, relating to neurodivergence, acts as a barrier making it difficult for public bodies and businesses to measure the impact of neuro inclusion policy.

The Neurodivergent (ND) community suffers from a problem of triple invisibility.

- ND people are frequently not visible to themselves - Most ND people are never diagnosed and therefore do not know they are neurodivergent.
- ND people are not visible to other people. You cannot tell if someone is ND by sight or casual observation.
- ND people are not visible in public policy. Without good data it is hard for public policy or equality diversity and inclusion policy (EDI) to measure differences between the experiences of ND people and other members of society.

While this issue of visibility is significant to the ND community, failure to recognise the significance of neurodivergence has a wider impact on the economy and society. For example, in the UK around 9m working age people are not in employment. 2.6m are not working for health reasons. (Sky News , 2024) Many in this category are ND, not diagnosed at school and wanting to work. If they were able to work it would increase economic growth, reduce benefit bills and lift a pressure on the NHS. However partly because of lack of quality data Neurodivergence is rarely identified as a focus for employability policy.

Donald Rumsfeld former US Secretary of Defence said: (Wikipedia, 2002)

- There are known knowns. These are things we know that we know.
- There are known unknowns. 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. This category tends to be the difficult one.

I think this statement sums up the current state of play when considering, the data set relating to Neurodivergence.

## 2. Understanding Terminology

Before considering the dataset it is useful to note, the language relating to neurodiversity, neurodivergence and neurominorities is contested and evolving.

An article in Psychology Today, 5 things you should understand about Neurodiversity by Erin Bulluss and Abby Sesterka, together with a comment posted on LinkedIn by Tony Lloyd then CEO of the ADHD foundation (Sesterka, 2023) illustrate this is a live debate. Personally, I am comfortable to describe myself as neurodivergent but can understand why people like Tony are uncomfortable with the term.

- The term Neurodiversity as Bulluss and Sesterka point out embraces everyone. 100% of the population. The term as one of its originators Judy Singer explains deliberately draws on the concept of biodiversity making the parallel argument that everyone's different thinking style is valuable and contributes to the richness of society. (Lutz, 2023)
- Neurodivergence and Neurominorities - The way some peoples brains work, differs sufficiently from the norms for them to meet the criteria for diagnosis for a range of conditions. In most discussions about neurodivergence these conditions include Dyslexia, Dyspraxia (DCD), Dyscalculia, Dysgraphia, ADHD, Autism, and Tourette's. However, this list is not exhaustive, and debate exists about other conditions which should be included on

the list. Nancy Doyle when compiling the genius within diagram included Mental Health conditions, Learning Disabilities and Acquired Neurodivergence. (Genius Within, 2025) Her logic being that if neurodiversity includes all thinking styles, and neurodivergence refers to people with thinking styles which significantly differ from the norm, the category should not be restricted to the seven or eight conditions usually cited.

- However, many ND people are not comfortable in identifying themselves as having a disability, let alone a learning disability. Disability Wales explains this point well

"Not everyone who is neurodivergent will identify as disabled. Many like the way their brain works.

They will probably still struggle with aspects of daily living or work, or both, but on the whole they are managing their lives, so they do not identify as disabled. " (Wales, 2024).

On the other hand, much of the employment protection ND people enjoy is embedded in disability rights legislation. If ND people choose not to identify as having a disability they may not benefit from this protection. In reality like many people with disabilities, ND people are disabled in some contexts and unaffected in others. This is consistent with the social model of disability. (IOSH, 2024)

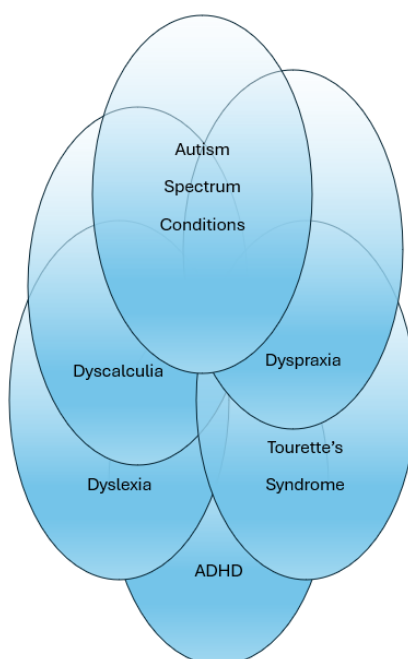
### 3. Known Knowns - What we think we know about the ND Data Set

The incidence of Neurodivergence in the population is frequently estimated to be 15-20%. This section explores the basis on which this figure has been estimated, and some of the reasons why this calculation may not reflect the actual situation.

#### 3.1 Calculating the incidence of neurodivergence in the population

Mary Colley in her classic diagram drew attention to the high level of overlap between conditions included in the Neurodivergent Family (Colley, 2009).

Overlapping Neurodivergent Conditions based on original diagram by Mary Colley



**Figure 1:** Overlapping Neurodivergent Conditions, based on a diagram by Colley (2009).

Professor Amanda Kirby notes Co-occurrence is very common and probably the norm with Neurodivergent Conditions. (Kirby, Neurodiversity 101 Co-occurrence, 2021) In an article she wrote with Mary Cleaton she includes a table including various estimates of neurodiversity in the population as well as estimates of co-occurrence.

**Table 1:** Estimated Co-occurrence of Neuro Developmental Conditions. (Cleaton, 2018)

Table adapted from Why Do We Find it so Hard to Calculate the Burden of Neurodevelopmental Disorders? (Cleaton, 2018)

			Proportion with Secondary Diagnosis %							
		Childhood Prevalence UK % from Kirby and Cleaton, National Charity estimates in brackets	ASC	ADHD	DCD	DLD	Dyscalculia	Dyslexia	ID	TIC
Primary Diagnosis	Autism Spectrum Condition ASC	0.6-3.5  (1-2 (NAS, 2023))		3-78	25-85	21	NE	14	15-51	8-60
	Attention Deficit Hyperactivity Disorder ADHD	0.5-2.2  (2 – 7 Ave 5 (ADHD UK, 2025) )	6		18-53	24	7-18	18-45	11-24	9-33
	DCD Dyspraxia Developmental Coordination Disorder	1.8%  (6% (FPLD, 2025)	6	19-53		>45	31-51	24-56	Na	<34
	DLD Developmental Language Disorder	>0.5-<2.2  (7.5 (DLD project, 2016)	4-8	18-61	30-71		62	48-87	<27	NE
	Dyscalculia	3.6  (6% (BDA, 2025)	NE	39	25-44	NE		26-48	NE	NE
	Dyslexia	2.3-6.2 (10 (BDA, 2025)	NE	18-50	16-53	NE	39-48		NE	8
	Intellectual	0.3-0.5 severe	10-28	18-55	NA	54-79	5	14-17		NE

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	Disability (Severe IQ <50 Mild <70)	2.2-2.5 Mild								
	Tourette's Syndrome	6	3- 22	26-82	13- 24	18	22-23	22-36	3	

NA Not Applicable, NE No estimate Available

The frequently quoted estimate that 15%-20% of the Population are neurodivergent (ICAEW, 2023), can be calculated by combining the incidence of the listed conditions in the population and discounting the degree of overlap between these conditions.

Table 2 sets out the calculation using Mary Colley's diagram as a starting point for a definition and national charity estimate of prevalence of individual conditions. The calculation looks something like this:

**Table 2:** Calculation of total ND population

Neuro difference	prevalence	Discount Co-occurrence	Non - overlap
Dyslexia	10%		10%
Dyscalculia	6%	Dyslexia	3.8-4.4%
Dyspraxia	6%	Dyslexia & Dyscalculia	2.9-3.4%
ADHD	5%	Dyslex & Dyscalc & Dysprax	1.4-3.4%
ASC	1%	Dyslex & Dyscalc & Dysprax & ADHD	0.1-0.5%
Total with co-occurrence discounted			18-22%

My calculation reaches a slightly higher estimate than the 15 to 20% regularly quoted figure, this is probably due to changes in the estimated level of co-occurrence changing through time. If TIC conditions were added to the calculation due to the level of overlaps the totals would not rise very significantly.

It is also interesting to note that in 2024 Birmingham University used a survey-based approach to estimate on a transdiagnostic basis the incidence of neurodivergence in the UK population . This survey estimated that 3.23% of the population had a formal diagnosis for at least one Neurodivergent condition and that 12.97% identified themselves to be neurodivergent (Apperly, 2024)

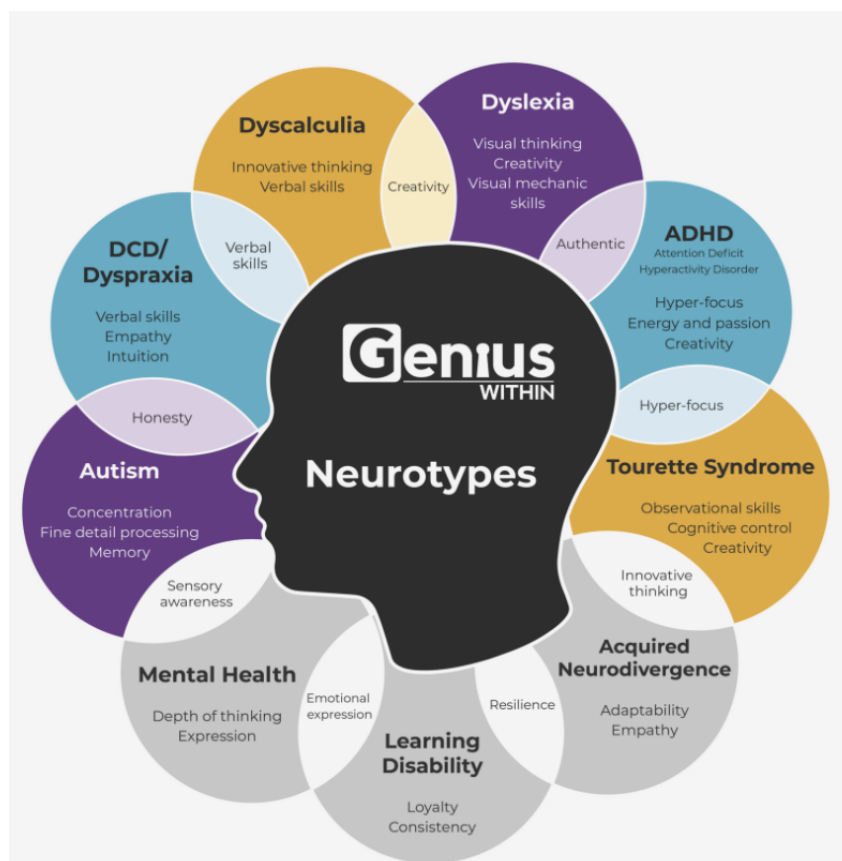
### 3.2 The reasons why the arithmetic calculation of neurodivergence in the population is problematic

This calculation of incidence in the population is however not straightforward. Professor Kirby points out several researchers who have identified different levels of co-occurrence between the listed conditions. (Kirby, Neurodiversity 101 Co-occurrence, 2021) Estimates of the incidence of individual conditions in the population also vary greatly depending on the organisation providing the data.

Furthermore, for some ND conditions the estimated level of incidence in the population is based on actual levels of diagnosis, while for other conditions it is based on a statistical projection. The National Autistic Society estimate 700,000 people 1% of the population are autistic. (National Autistic Society , 2025) This figure is based on numbers with a diagnosis. Some people believe the actual incidence including people who have not been diagnosed could be as high as 3% (Nion, 2023)

The Estimate of the incidence of Dyslexia (10%) and ADHD (5%) by contrast is based on a statistical projection of how many people meet the criteria for diagnosis. (British Dyslexia Association, 2022) However, the rate of actual diagnosis for dyslexia is far lower. Only 20% of Dyslexic pupils are diagnosed at school. (BBC, 2019). The figure for ADHD is similar with only 10%-20% of people with ADHD receiving treatment. (Doyle, 2022) The lower estimates quoted by Kirby and Cleaton tend to reflect actual diagnosis.

If the definition of Neurodiversity is widened in the way set out in Nancy Doyle's Genius Within Diagram the 15 to 20% estimate also needs to be extended. The NHS estimate more than 20% of the population have a mental health condition. (NHS England, 2025)



**Figure 2:** *What does neurodiversity mean?* From *What does neurodiversity mean?* by N. Doyle, 2025, *Genius Within*. Devised by Professor Nancy Doyle of Genius Within and derived from the work of Mary Colley. Reprinted with permission.

#### 4. Known Unknowns – Our understanding of neurodivergence is uncertain

Aside from the challenges of arithmetic discussed in section 3, the assertion that 15% to 20% of the population are Neurodivergent are unreliable for a range of reasons relating to language and logic. I will highlight; issues related to definitions, input data, and interpretation. My list is not exhaustive.

##### 4.1 Challenges with definitions

The terms Neurodiversity, Neurodivergence and Neurominorities do not have a medical definition. Language is constantly evolving, and no methodology has been agreed for quantifying their incidence. The following list outlines some of these issues.

#### 4.1.1 Lack of consensus regarding the conditions which count as being part of the neurodivergence family

The framing of neurodivergence as just including ASC, ADHD, Dyslexia, Dyspraxia and Dyscalculia as depicted in Figure 1 is uncomfortable. As Nancy Doyle argues, whether the term neurodiversity embraces natural differences across everyone in the population, and the term neurodivergence identifies people whose thinking styles differ significantly from the societal norm. It is logical for the term neurodivergence to not only include people with the conditions identified in Mary Colley's diagram but also cover people with other thinking styles which differ from the societal norm. (Genius Within, 2025)

Professor Amanda Kirby convincingly argues through her Balls in Bucket analogy (Kirby, Balls in Bucket, 2021) that many people with ND traits do not fit the diagnostic criteria for any of the individual ND conditions but will have similar traits, and experiences.

Professor Kirby also points out in a recent blog post "Neurodiversity 101 Newsletter, Navigating the landscape of neurodiversity, in awareness month", (Kirby, 2023), that many people have acquired neuro-differences or conditions which co-occur with ND conditions. These conditions often have similar impact to the normally recognised ND conditions; Professor Kirby therefore encourages the ND community to be more rather than less inclusive of people who may wish to be viewed as neurodivergent.

This advice resonates with me. One of my early diagnoses in the late 1960s referred to minimum cerebral palsy. All the educational psychologists focused on my dyslexia, but the minimum cerebral palsy label stuck in my mind. I wanted a more definite diagnosis as I was aware of my difference but was frequently being told by family, friends, the media, teachers, and health professionals that dyslexia did not exist.

A few years ago, Amanda Kirby explained to me, that minimum cerebral palsy would now be described as DCD or Dyspraxia (Kirby, Developmental Co-ordination Disorder (DCD), 2021) The notes in my diagnosis then started to make sense. In the same conversation I was made aware of the shared traits between DCD and Cerebral Palsy, as well as the way the definitions and diagnostic practice relating to the two conditions have evolved.

One of the strengths of the neurodivergent movement is how it unites people with similar experiences. These experiences of sometimes being perceived as being part of the mainstream and sometimes being perceived as having a disability are as important as meeting diagnostic criteria. However, this is delicate, from my experiences as a carer I noticed my mother with dementia undoubtedly had a thinking style which significantly differs from the neuro typical norm and was therefore neurodivergent. I am however unsure if people with dementia have the same shared experience particularly in education and the workplace which has unified much of the self-identified ND community over the past 25 years.

I am sure the concept of neurodivergence has further to evolve. My personal view is the group which identify with, and self-identify as being Neurodivergent. Is one of many neuro-tribes with a thinking style which differs from what is assumed to be the norm. The tile diagram of all these groups has not yet been fully mapped. (This continuing evolution is perhaps one of the key unknown unknowns of type referred to by Rumsfeld).

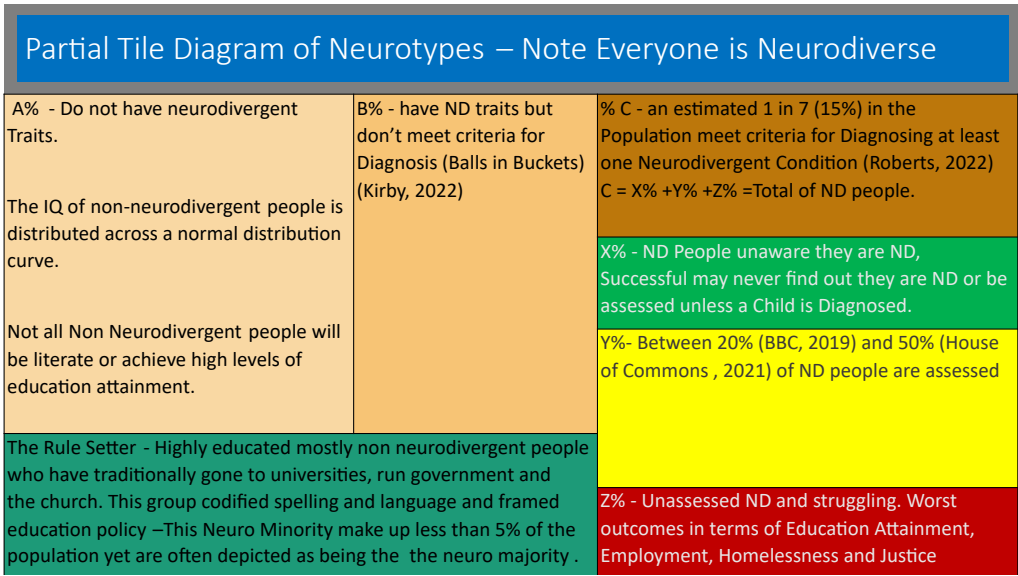


Figure 3: How can different neurotypes be mapped? (Freeman, 2024)

Neurodivergent people, on account of our different thinking styles, form a group on the margin of the labour force. On the one hand we do not have a profound disability which excludes us from work indeed most of us want to work. On the other hand, we experience disadvantage in the labour market and during our working lives are significantly more likely to experience periods out of work than most people in the population.

Those of us lucky enough to have a diagnosis, usually gained the diagnosis because in some way we (or one of our children) struggled. Usually, (but not always) the struggle leading us to diagnosis was with education or work. Post-diagnosis, most of us have also been able to achieve a level of success in education and at work when we have received appropriate support (reasonable adjustments).

Other people without a formal ND diagnosis or with other hidden disabilities or mental health conditions face very similar challenges in the labour market. They therefore share common experience with the ND community.

4.1.2 Different ND conditions are not consistently defined

Dr Martin Bloomfield in his Dyslexia Bytes Video Blog (Bloomfield, 2023) draws attention to the wide range of definitions used to define dyslexia worldwide. Definitions also change through time. ADHD was not recognised as a condition in the UK until 2000 (LancUK, 2016). The definition of Autism was expanded to include Aspergers Syndrome in the 1990s (National Autistic Society, 2024). More recently it has been recognised that labels such as low or high functioning can be damaging. (Katy, 2024)

This lack of consistency of definition makes it hard to compare data over time, or on an international basis or indeed between different studies in the same country. Good Quantitative data is therefore extremely scarce.

4.1.3 The Language used by official bodies is inconsistent

The UK Governments Disability Action Plan Consultation 2023-24 makes 13 mentions of neurodiversity (Gov.UK, 2023). Eight refer to the Department for Justice, which has a neurodiversity action plan. Other departments such as the Department for Health and Social Care, The Department for Work and Pensions and Department for Culture Media and Sport focus





exclusively on Autism. No Mention is made of Dyslexia or ADHD. The final Action Plan (GOV.UK, 2024) dropped the term neurodiversity altogether.

In its Outcomes for Disabled People Report the Office for National Statistics (ONS, 2021) publishes data relating to people with specific learning difficulties and autism but does not use the term neurodiversity.

The Higher Education Statistics Authority collects data relating to “students with a specific learning difficulty such as Dyslexia, Dyspraxia, or ADHD” and “students with a social or communication impairment such as Asperger’s syndrome or other autistic spectrum disorders”. (House of Commons, 2021) The Warnock Report in 1978 on the advice of the Department for Education avoided using the term dyslexia instead referring to specific learning difficulties (Dr Kirby, 2007). This term specific learning difficulty is still used by many education authorities.

This inconsistency in use of language across government departments and within official statistics makes it hard to compare published data and relate the available data to the term Neurodivergent.

## **4.2 Challenges with Input Data**

The base data relating to the diagnosis of each ND condition is based on arbitrary thresholds, Most ND people are never diagnosed so don’t know they are ND, and the methodology used in diagnosis has frequently been subject to class, gender, and racial bias.

### **4.2.1 Diagnostic thresholds for ND conditions are arbitrary**

The British Dyslexia Association (British Dyslexia Association, 2022) quotes an estimate that 10% of the population are Dyslexic. The European Dyslexia Association puts the figure at 9-12% with 2-4% experiencing a serious impact. (European Dyslexia Association, 2020) The Yale Centre for Dyslexia and Creativity (Yale Centre for Dyslexia and Creativity, 2022) uses a figure of 20%. The differences are explained by differences in definition and diagnostic threshold. The same differences are reflected in the range of estimates used in Table 1. Furthermore, as pointed out in Amanda Kirby’s balls in bucket analogy people 1% either side of a diagnostic threshold will have much the same traits (Kirby, Balls in Bucket, 2021). The point at which the threshold line is drawn for each individual condition is essentially arbitrary.

### **4.2.2 The estimates of ND conditions in the population, greatly exceed the number of people who have had a diagnosis or been able to access support**

A Birmingham University Study using a representative sample of 995 people aged between 17 and 77 found that only 3.23% of the sample had a formal diagnosis for any neurodivergent condition, however 12.97% of people in the sample self-identified as being neurodivergent. (Apperly, 2024) People with a diagnosis therefore make up less than 22% of the total estimated ND population.

On this basis, many ND people will not know they are ND and will therefore not identify as being ND in surveys or disclose to employers. The actual level of disclosure in employment surveys is likely to be further reduced due to the high level of stigma associated with neurodivergence and a fear that disclosure (even in a confidential survey) could lead to discrimination. (Achievability, 2017)

### **4.2.3 The diagnosis of individual ND conditions has historically been subject to significant biases**

A recent article in Scientific American highlighted the way in which cultural biases in the tests used to assess dyslexia frequently prevented black students from getting the support they required in order to fulfil their potential. (Carr, 2023) In recent years, the under diagnosis of

women and girls with ADHD and Autism has been highlighted. (Kirby, Where have all the girls gone, 2021) The Joseph Roundtree Foundation noted that the incidence of Dyslexia appeared lower in deprived areas than it is in more affluent areas. They speculate that this is down to under diagnosis. (Bart Shaw, 2016)

### 4.3 Challenges with Interpretation

Statistical Data relating to neurodivergence also needs to be interpreted with care. Low levels of actual diagnosis mean that comparisons with the estimated incidence in the population as opposed to actual number diagnosed may distort research findings. People with different ND traits may not respond to surveys in the same way, leading to differential response rates, and changes in diagnostic definitions and methodology together with lack of available data makes timeseries analysis challenging.

#### 4.3.1 Using the correct benchmark

Some reports use the estimated incidence of neurodivergence in the population (15 to 20%) as a benchmark against which to identify an over or under representation in a population. This approach is likely to lead to an unreliable interpretation of the data. The Birmingham study found that 3.23% of the population have a formal neurodiversity diagnosis and that 12.97% self-identify as neurodivergent. (Apperly, 2024) These figures might provide a more reliable benchmark.

The finding in the British Interactive Media Association BIMA equality survey show that over 20% of the interactive media workforce are neurodivergent. (BIMA, 2019) The report identifies a 50% over representation of ND people in the industry, compared to the benchmark of 15% in the population. In reality, it is likely that the over representation is significantly higher when compared to the number of people who have had a diagnosis.

Similarly, the finding that 7% of the games industry workforce are dyslexic. (UKIE, 2022) is likely to represent an over representation rather than an under representation. Despite the estimated incidence of dyslexia in the population being 10%. The number who identify as being dyslexic is considerably lower. Only 2% of the population have a formal dyslexia diagnosis at school. (BBC, 2019). While some others will gain a diagnosis after leaving school and more will self-identify, it is likely the community who are prepared to identify as being dyslexic in a population wide survey is far less than 7%. The 7% who did identify in the UKIE survey is therefore a high rather than low number.

#### 4.3.2 The response rate to surveys of ND people with different traits appears to differ

Responses to the Neurodiversity in Business, neurodiversity at work survey, prepared by Birkbeck University in 2023 (McDowall, 2023) attracted a disproportionately high number of responses from people with ADHD and Autism and a disproportionately low response from dyslexic people.

This can be explained in two ways:

- When actual numbers of people with a diagnosis are used as opposed to projected estimates of incidence in the population, the ratio between the different ND conditions flattens. The publicly quoted ratio is 1 Autistic Person (National Autistic Society, 2025) to 10 Dyslexic People (British Dyslexia Association, 2022). However, most of the 1% of the population with Autism have an actual diagnosis while only 20% of the Dyslexic population have a diagnosis. So the actual ratio of people with a diagnosis is 1 Autistic Person to 2 people with Dyslexia. (BBC, 2019)
- It has also been suggested that the differential response rate might be attributed to ADHDers and autistic people quite enjoying completing surveys, as opposed to dyslexic people who actively dislike filling in forms. This would also explain the relatively low

response by dyslexic people to many creative industry surveys (e.g. British Interactive Media Association Tech Inclusion and Diversity Survey (BIMA, 2019), Games Industry Survey (UKIE, 2022) UK Music Diversity Report (UK Music, 2022) and Inclusion and Diversity in VFX Animation and Post Production (Screen Alliance, 2019)). The Higher Education Statistics Authority HESA and many arts schools report large numbers of dyslexic graduate progressing into creative employment. (Rankin, 2015) These numbers are not showing up in industry surveys.

It may also be that dyslexic graduates find it easier to mask at work, than autistic graduates and are therefore less likely to disclose their neurodivergence. (The balance between the benefits of disclosure in terms of reasonable adjustment and the risks in terms of discrimination, will be different for each ND person).

#### **4.3.3 Comparisons through time are difficult**

The terms neurodiversity, neurominority and neurodivergence have only come into usage since the 1990s. The definitions of conditions which are generally regarded as being part of the ND family have also changed within the past 50 years. Professor Amanda Kirby suggests that frequently the diagnosis that an ND person receives depends on the lens through which they are viewed by a professional. (Kirby, Which Lens do you Look Through, 2022). Most ND diagnoses only pick up 1 or 2 diagnoses even though a person may experience overlapping traits. In my case my diagnosis in the 1970s was for dyslexia and dyspraxia. I almost certainly have dysgraphia but suspect I may have ADHD and possibly autistic traits, but due to definitions available at the time I was diagnosed, these traits were basketed within my dyslexia diagnosis.

### **5. Conclusions – Creating new knowns.**

#### **5.1 Absence of Evidence is not Evidence of Absence (Sagen, n.d.)**

The weakness of the data set relating to neurodivergence does not undermine the validity of ND lived experience either reported through anecdote or collectively in surveys.

The media frequently runs stories which cast doubt on the validity of ND experience. These often cause hurt and anxiety. The ND community should however be confident about the validity of their experience. The National Institute for Health and Care Excellence (NICE) and the National Health Service (NHS) recognise the validity of ND conditions including Dyslexia and ADHD. Growing quantities of anecdotal evidence point both to the successes and challenges faced by ND people.

ND experience is real. Collecting qualitative and quantitative data regarding the experience within the ND community is valuable it can also be a foundation for sound policy.

#### **5.2 Better Data would make neurodivergence more visible both within EDI work and public policy**

Professor Ludmila Praslova argues that ND people are the canaries in organisations and in society. We are the first to react to toxicity. (Praslova, 2022) Being able to track the way change impacts on ND people would therefore be valuable not only to the ND community but also to HR departments and policy makers.

While individual data sets for ND conditions e.g., autism, dyslexia and ADHD are useful. In my view we are also stronger together, not least as Amanda Kirby points out individual diagnoses rarely pick up the range of traits an ND person experiences. (Kirby, Neurodiversity 101 Co-occurrence, 2021)

In order, to strengthen the position of Neurodiversity as a dimension within both EDI policy and more generally within public policy a consensus on collecting and interpreting an ND data set is required.

### 5.3 Developing an ND data set is not impossible but will require pragmatism

Many organisations are already attempting to monitor neurodivergence within diversity surveys. The UK government until 2023 used the term within its disability strategy and action plan. However, the way surveys ask questions, accounts for differentials in response rates and interpreting responses is not consistent. This makes comparison between studies problematic.

Within the UK government, different departments use different language to describe neurodivergence.

For the neurodiversity movement to move forward, a more standardised approach to collecting and interpreting data is required. Such an approach would help employers, public bodies and the ND community.

The challenge requires pragmatism. A perfect definition of neurodivergence does not exist and we are still learning about the impact and incidence of neurodivergence and particularly undiagnosed neurodivergence.

The challenge is similar to that faced by the UK Creative Industry sector in the late 1990s. The then UK government decided it wanted to define a new industry sector, made up of many business groupings which had previously been viewed as separate - (Architecture, Advertising, Craft, Film & TV, Games, Publishing, Software Design, Visual and Performing Arts. These businesses were also fast evolving due to new technologies, much of the creative sector as exists now including digital marketing and immersive technology did not exist in the 90s . The sector faced similar shifting sands of definition to the neurodiversity movement.

The new sector was defined following the publication of a mapping document in 1998 (DCMS , 1998), and the development of the Department for Culture Media and Sport DCMS data evidence toolkit. (DCMS, 2004) Definitions and methodology have since evolved, but an authoritative data set has now emerged.

Now is the time for academics within the ND community to develop a data evidence toolkit for neurodivergence, which can be used as a template to authoritatively guide future research. This toolkit will not be written in stone and will need to evolve through time. Consistent data and a more standardised methodology would make it easier for the ND community to argue its case. The Birmingham University Transdiagnostic survey seems to pioneer this approach. (Apperly, 2024). Data will never be perfect, but through collective agreement it can be made good enough to be useful to the community and policy makers.

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