04. Script for ‘Autism Statistics and Prevalence’:

Slide 2: Common statistics related to autism

Autism is a relatively common condition that appears in all countries and across cultural, ethnic and economic contexts. However this does not mean that it is always recognised. Autism affects slightly more than 1% of the population although we will learn that there are differences between studies regarding these prevalence estimates. Autism affects males more frequently than females, although as of yet we do not know why this is the case. Autism is commonly associated with intellectual disability and with other mental and physical health conditions. These are all factors that can make autism more difficult to diagnosis accurately.

Slide 3: Autism occurs in all cultures, ethnicities and contexts

Epidemiological research studies estimate the rates of autism in the general population. To date, autism has been widely studied in western developed countries and Australia. These studies quote similar prevalence rates of around 1% or more, although we will see that over time these estimates have changed. Now, studies in other countries within Asia and Africa also show similar estimates of autism prevalence.

Although autism occurs in all of these contexts, there may be times when it is under-recognised. We know that particular factors leading to under-recognition include:

1. low awareness and training of health and education professionals;
2. underdevelopment of paediatric developmental services;
3. stigma;
4. barriers to accessing healthcare.

For example – Studies by the Autism and Developmental Disabilities Monitoring Group in the US showed lower autism diagnosis rates in Latinx populations who had limited healthcare access (ADDM, 2007). More recently they reported that the gaps in autism diagnosis rates between black, Hispanic and white children are closing, which is attributed to better awareness and improved access to autism diagnosis.

Slide 4: Autism affects around 1% of the population

Coming back to the question of autism prevalence, you might have a question about increasing prevalence. Maybe you have read about increased rates of autism more recently and wondered why this is occurring. This is a good question and sometimes in the past, this phenomenon was incorrectly interpreted as evidence that autism was related to vaccines like the MMR.

First, it is clear that the prevalence of autism increased significantly over the decades (I have a table on the next slide to illustrate this phenomenon).
Before we look at it, I would like to point out that autism epidemiology researchers have studied the prevalence of autism in numerous different studies, conducting a meta-analysis of previous epidemiology studies. A meta-analysis is a statistical method to analyse data from separate studies that are asking the same question to assess the overall conclusion. Fombonne et al. conducted a meta-analysis of previous prevalence studies and concluded that the prevalence rate is around 1.43% (Fombonne et al., 2009).

Another statistic you may hear is that 1/65 (1.5%) children in the Irish school system have an autism diagnosis (NCSE, 2016).

These two studies have similar prevalence rates even though they used different methods. It could be argued that counting the numbers with a diagnosis could give an elevated estimate of the number of children with autism. There could be a reason why children get a diagnosis – for example to get access to a service or educational resources. What I find reassuring about the NCSE figure is that it is similar to the estimate in Fombonne’s study.

Slide 5: Identified Prevalence of Autism Spectrum Disorder ADDM Network 2000-2016 - Combining Data from All Sites.

This slide illustrates the rates of autism that were reported in studies by the ADDM from 2000-2016. The ADDM is a group of programs that are funded to estimate prevalence of autism and other developmental disabilities in children in different areas of the United States using the same methods. What you can see from the table is that the prevalence rate from their studies in 2000 was 1/150. By 2016 this increased to an estimated rate of 1/54. The latter rate is almost 1.9% so it is quite a bit more than the rate reported in the meta-analysis by Fombonne et al.

Slide 6: What is causing rising autism prevalence?

Researchers think that a number of factors are driving these changes in the reported prevalence.

First, more awareness of the symptoms of autism and more access to autism diagnosis in general means that more individuals will be diagnosed.

This means that there has been better detection in previously under-served groups. As I mentioned earlier, in US the gap between diagnosis in black and Hispanic children with white children is reducing. It is also the case that autism diagnosis is increasing in those with normal IQ or severe to profound intellectual disability and in girls and adults.

With the exception of the ADDM studies, successive autism prevalence studies are not always directly comparable. They may have differed in relation to autism definitions, inclusion criteria and methods of diagnosis. More recent studies probably included ‘milder’ cases compared with older studies.
Finally some researchers argue that autism diagnosis is used incorrectly, for example to increase access to therapeutic or educational programs. There are varying opinions whether this is true, even in studies such as the ones cited here that both have studied diagnoses in California and reached different conclusions.

**Slide 7: Gender ratios and autism**

Autism is characterised by sex differences. Like many other early onset neurodevelopmental disorders, males are more frequently affected, on average four or five times more frequently. However considering only those with normal cognitive ability, the rate of males to females increases significantly to around 10 male cases to one female case. In contrast, in the presence of lower IQ the ratio falls to around two to one.

The reason for these sex differences are not fully understood. It is possible that biased diagnostic approaches may detect males more frequently than females. However, studies suggest that accounting for bias, a true ratio of around 2-3:1 exists, indicating that the sex difference is real (Zwaigenbaum et al, 2012).

There are theories as to what may cause sex differences in autism. These include:

1. **The female protective effect.** Researchers propose that females are biologically shielded from autism. Supporting evidence for this comes from family studies and genetics studies. Girls with autism tend to have more relatives with language impairments, perhaps suggesting that they need to inherit more autism related risks than boys. Younger siblings of girls with autism are more likely to have autism than siblings of boys with autism. Also genetic mutations causing autism in boys are less likely to cause autism in girls, suggesting that they may need to inherit more genetic risk factors.

2. **Autism is defined on the basis of the symptoms as they occur in males.** The tools that we use to diagnose autism have been developed and tested based on more male data. Therefore they may not be as effective in detecting autism in girls.

3. **Related to this, females may be better at masking autism symptoms.** There is some evidence that milder symptoms in females, such as more social awareness and better imitation means that females may ‘camouflage’ symptoms. They hide their symptoms by copying what they observe as socially acceptable behaviour. This still requires more research.

Taken together, we know that girls may be affected more frequently than is commonly reported but are detected later in adolescence or adulthood. This may be associated with difficulties with diagnosis. Many females report that they are diagnosed with a number of other psychiatric diagnoses before autism.

**Slide 8: Autism and intellectual disability**

Intellectual disability is strongly associated with autism. Data from population studies show the following rates of co-occurring intellectual disability in autism:

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- 31% intellectual disability (intelligence quotient [IQ] <70),
- 25% borderline range (IQ 71–85),
- 44% IQ scores in the average to above average range (i.e., IQ >85) (ADDM, 2018)

Conversely 18% of children with ID are reported to have autism (Tonnsen et al, 2016)

Data from US studies may not translate directly to other contexts. Some researchers think that autism and intellectual disability may be diagnosed separately in the US because of differences in accessing services. However these rates are likely to be similar if not the same in Ireland.

Slide 9: Co-existing conditions are common in autism.

An important feature of autism is that it very frequently occurs in association with other co-occurring mental health or physical disorders. This is very important to be aware of, as this may impact on the way that autism presents.

Mental health disorders frequently associated with autism include ADHD, anxiety and mood disorders, oppositional defiant behaviour, tics, OCD and aggression and self-injurious behaviour. I think it is of utmost important to screen for these conditions as part of an autism assessment. These conditions may need to be accounted for in the individualised care plan and in relation to the types of interventions that are required.

Medical conditions include epilepsy and seizures, genetic conditions such as chromosomal disorders or genetic syndromes like Fragile X, tuberous sclerosis etc. In addition (although not shown in this table), autistic people tend to have higher rates of obesity which places them at considerable risk for poor health outcomes in the longer term. It is really important to think about all of these issues.

Finally, functional disorders such as feeding and sleep issues, toileting, altered bowel habit and occasionally sensory impairments may also be part of the presentation.

Slide 10: In conclusion.

Therefore, to conclude, we know that autism is an increasingly recognised condition. The increased prevalence rates that are reported seem to be due to better awareness, detection and diagnosis. Sex differences occur in autism, but we need to be aware of our bias to only look for autism in males. Females may go undiagnosed or misdiagnosed. Intellectual disability, co-occuring mental health and physical disorders are common and may influence the presentation. They also need to be included as part of the overall needs within a care plan. Therefore we require accurate diagnostic approaches that account for these factors to ensure timely recognition and enable therapies and supports to be established.