

INNOVATIVE INTERVENTIONS TO REDUCE THE STIGMA ATTACHED TO INTELLECTUAL DISABILITIES: A NARRATIVE REVIEW

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SUMMARY

The stigma attached to intellectual disabilities (ID) can have profoundly adverse effects on the lives of people who suffer from these conditions. Stigma is also a major barrier to accessing specialist services and consequently many people with ID continue to suffer in silence. A confidential inquiry into the premature deaths of people with ID in England and Wales revealed the median age at death of individuals with this condition was 13 years (for males) to 20 years (for females) younger than the median age at death of the general population. It has been posited that stigma is a factor that contributes to the mortality gap between those with ID and those who don't have this condition. The COVID-19 pandemic has created new challenges for people with ID and has further fortified the barriers to specialist services. To reduce stigma, improve the quality of healthcare that is provided to people with this condition and to break down the barriers to specialist services, we must pioneer innovative interventions that leverage the power of technology and 'virtual' contact with people who live with these conditions.

Key words: intellectual disability - stigma - 'diagnostic overshadowing' - innovation - contact - video interventions

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INTRODUCTION

The World Health Organization (WHO) defines intellectual disability (ID) as a 'significantly reduced ability to understand new or complex information and to learn and apply new skills' (WHO 2015). ID originates during the developmental period and is characterized by significantly below average intellectual functioning and adaptive behaviours based on standardized tests or clinical judgement (WHO 2021). According to the Diagnostic and Statistical Manual of Mental Disorders (DSM-V), individuals diagnosed with ID not only have deficits in intellectual functioning such as reasoning, abstract thinking, and problem solving, they also experience difficulties in conceptual, social and practical domains (APA 2013).

The prevalence of ID ranges from 1% to 2% globally (Zablotsky & McKenzie et al. 2016). This prevalence varies between countries and across socio-cultural contexts. A meta-analysis found higher rates of ID in low-income countries and among children and adolescents. The higher prevalence of ID in the low income countries was in part due to the use of psychological assessments, scales and instruments that were developed specifically to identify ID compared to standard diagnostic tools used in high-income countries

(Maulik et al. 2011). The high prevalence of ID was attributed to severe malnutrition, increased risk of exposure to diseases, lack of medical and perinatal care, and the limited availability of resources (Maulik et al. 2011).

DEFINING AND OPERATIONALIZING STIGMA

Stigma has been described as a 'wicked problem' (Henderson & Gronholm 2018) and it is one that people with ID often encounter. In this narrative review, we will provide a broad definition of stigma. We will then analyse and discuss the stigma that individuals with ID and their families and those who care for them regularly experience. We will conclude with innovative interventions to reduce the stigma attached to individuals with ID.

Evans-Lacko et al. conducted a systematic mapping of the literature pertaining to the state of the art in European research on reducing social exclusion and stigma related to mental health and revealed that Goffman's seminal definition of stigma was used often (Evans-Lacko et al. 2014). Erving Goffman defined stigma as a 'Deeply discrediting attribute that reduces the bearer from a whole and usual person to a tainted and discounted one. The individual is thus disqualified from full social acceptance' (Goffman 1963). According

to Link et al. in their paper entitled, 'Measuring mental illness stigma', stigmatization is a process that starts with labelling which is then followed by stereotyping, separation, emotional reactions, status loss and discrimination. This process usually happens in the context of a power dynamic between those who label and those being labelled (i.e., psychiatrists and psychiatric patients respectively).

Stigma is an umbrella term that can be deconstructed into three main components: Problems of knowledge (ignorance or misinformation), problems of attitudes (prejudice), and problems of behaviours (discrimination). This is helpful from a public health perspective when we want to operationalize stigma and evaluate anti-stigma campaigns as there are validated psychometric stigma scales in each of these domains (Henderson & Gronholm 2018).

THE STIGMA ATTACHED TO INTELLECTUAL DISABILITIES

The Convention on the Rights of People with Disabilities by the United Nations (UN-CRPD) was drafted in 2006 with the aim to "promote, protect and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities" (Members of The Epa Executive et al. 2018). Among all disabilities, individuals with ID are prone to be stigmatized and marginalized globally. They are subject to stigma from the public, courtesy, and self-perceived (Ali et al. 2015a), and have been perceived as aggressive (Slevin & Sines 1996) with lower potential for change (Jahoda & Markova 2004). A study conducted in Ireland on different groups of disabilities found that the general public were least comfortable with people with mental illness and people with ID, compared to those with physical disabilities (McConkey 2015).

Individuals with ID experience discrimination such as being labelled by school and welfare systems (Chen & Shu 2012), having inequality in access to services and treatment within hospitals (Jahoda & Markova 2004), facing disadvantage in the judicial process, and have poorer quality of life compared to people without disability (Ncube et al. 2018). Furthermore, people with ID are at higher risk for developing mental illness (White et al. 2005), and this "dual disability" increases the rate of criminality and victimization among people with ID and mental illness (Thomas et al. 2019). These egregious effects of stigma can have a profoundly negative impact on individuals with ID, such as resulting in low self-esteem and self-efficacy (Paterson et al. 2012). People with ID who have higher levels of self-perceived stigma were more likely to have psychological consequences such as anxiety and depression (Ali et al. 2015b).

Stigma is not only experienced by individuals with ID, but it also extends to people around them. Often, family members who are caregivers experience stigma

which leads to negative consequences on their psychological wellbeing (Cantwell et al. 2015). Furthermore, stigmatizing attitudes were also found among mainstream health professionals, which add on to the barriers for people with ID to access healthcare services (Pelleboer-Gunnink et al. 2017).

Various factors contribute to stigma attached to ID. A study which compared ID literacy level and stigma in UK, Austria and Germany found that people in the UK had higher awareness level and were less hostile towards people with ID, suggesting the importance of improving awareness of ID to reduce stigma (Zeilinger et al. 2020).

Besides literacy level, ethnicity has also been found to be a strong predictor of negative attitudes towards people with ID (Scior et al. 2010). Although stigma is evident across all ethnic groups, it was higher among ethnic minorities such as Black African or Caribbean background compared to white Westerners or Asians (Scior et al. 2013).

THE INFILTRATION OF STIGMA INTO CLINICAL PRACTICE: DIAGNOSTIC OVERSHADOWING AND THE SCANDAL OF PREMATURE DEATHS IN PEOPLE WITH INTELLECTUAL DISABILITIES

People with ID have a higher risk of developing both physical and mental health problems, and age-adjusted rates of mortality and morbidity compared to the healthy population (Emerson et al. 2014). Various reasons have been found to contribute to the disparity between this group and the general population. Among the factors that contribute to reduced life expectancy in people with ID are the higher risk of developing co-existing medical conditions such as epilepsy, cerebral palsy and Down's Syndrome, and a four-fold increase in risk of death when presented to the emergency department or following hospital admissions when compared those who do not have ID (Reppermund et al. 2020).

Another explanation which is increasingly gaining recognition in contributing to premature deaths in people with ID is 'diagnostic overshadowing', a form of discrimination from healthcare professionals. The term 'diagnostic overshadowing' was first coined by Reiss, Levitan, and Szyszko in 1982 in relation to people with ID (Reiss et al. 1982). In this context, 'diagnostic overshadowing' referred to the tendency for clinicians to attribute symptoms or behaviours of a person with learning disability to their underlying cognitive deficits and which led to co-morbid psychopathology being underdiagnosed (Jones et al. 2008).

Diagnostic overshadowing has more recently been defined as a process that contributes to the misattribution of physical illness signs and symptoms to a concurrent *mental disorder* that results in misdiagnosis and undertreatment of the physical condition (Jones et al.

2008). However, the results of a confidential inquiry into the premature deaths of people with ID in the UK would suggest that ‘the misattribution of physical illness signs and symptoms to a concurrent *intellectual disability* resulting in misdiagnosis and undertreatment of the physical condition’.

As part of the confidential inquiry, a population-based study was carried out which revealed the median age at death of male individuals with ID was 65 years, 13 years younger than the median age at death of male individuals in the general population of England and Wales (78 years). The median age at death of female individuals with ID was 63 years, 20 years younger than the median age at death for female individuals in the general population (83 years). The investigators report that avoidable deaths from causes “amenable to change by good quality health care” were more common in people with ID than in the general population of England and Wales (Heslop et al. 2013). We hypothesize that ‘diagnostic overshadowing’ contributes to the mortality gap between those who have ID and those who don’t. Diagnostic overshadowing is an example of how stigma towards those with ID has infiltrated clinical practice.

INNOVATIVE INTERVENTIONS TO REDUCE THE STIGMA ATTACHED TO INTELLECTUAL DISABILITIES

Various interventions have been suggested to reduce the stigma attached to ID. Psychoeducation initiatives targeting the public helps to improve literacy about ID and neurodevelopmental disorders and can be an effective way of reducing the stigma attached to these conditions (Zeilinger et al. 2020). Another method found to be effective in reducing stigma in ID is by empowering and dignifying people with ID by providing them with a platform to advocate for themselves (Anderson & Bigby 2016).

Intergroup face-to-face contact between someone living with ID and those not living with this condition is one of the most effective ways of reducing stigma. However, in current COVID-19 world, face-to-face contact is associated with risks of transmitting the infection. Indeed, throughout the pandemic, mental health events, including, those aimed at reducing stigma, have largely been held online and this is likely to continue for the foreseeable future.

There has been growing interest in harnessing the power of digital platforms and e-interventions to reduce the stigma attached to ID. Several studies have shown that ‘virtual contact’ with an individual living with ID is effective at reducing stigma. These studies will be briefly described below:

Walker and Scior carried out a small study to assess the impact of two brief indirect contact-based interventions on lay people's inclusion attitudes, social distance and positive behavioural intentions. Participants

were randomized to watch either a 10-minute film based on intergroup contact theory, or a film based on a protest message. In total, 403 participants completed the survey at one-month follow-up. Both interventions were effective at changing inclusion attitudes and social distance in the short term (Walker & Scior 2013).

Lindau et al. conducted a pilot study that compared the effects of brief digital interventions on attitudes towards those with intellectual disabilities. 401 adults from the general public were recruited to participate and were randomised to six brief digital interventions consisting of different combinations of education, indirect and imagined contact. Participants’ attitudes, intergroup anxiety and social distance were assessed post-intervention and at four to six-week follow-up. The results of the research revealed that an intervention combining film-based education about intellectual disability and indirect contact had small positive effects on all three outcomes. Social distance was further reduced with the addition of a positively toned imagined contact task. These effects were maintained at follow-up (Lindau et al. 2018).

Odukoya conducted a study on a complex e-intervention that focused on an integrative approach of education and indirect contact through film as a tool to combat stigma towards people with intellectual disabilities in Nigeria (Odukoya 2017). The e-intervention was faith and culture appropriate since it included interviews with a Christian faith leader and a psychiatrist who both spoke about the explanatory models that many Nigerians formulate for mental illness (i.e., the attribution of psychological, behavioural, and perceptual disturbances to supernatural causes) (Odukoya 2017).

The interventions described above have shown promise at reducing the stigma attached to intellectual disabilities, however, the digital age and social media have arguably reduced our attention span. For example, the maximum duration of a TikTok video is 180 seconds. The window of opportunity to engage with people to reduce the stigma attached to ID is thus very narrow. We must therefore pioneer innovative interventions to reduce the stigma attached to ID that reflects this reality.

Amsalam and colleagues conducted the first intervention study to reduce the stigma attached to First-Episode Psychosis. The anti-stigma intervention was a 90-second video the protagonist of which was an empowered African American woman describing her experiences living with schizophrenia. 1203 adults were recruited to participate in the study and were allocated to either (a) video intervention, (b) written description of the same content (“vignette”), or (c) non-intervention control arm. Web-based self-report questionnaires assessed stigma domains, including social distance, stereotyping, separateness, social restriction, and perceived recovery. Sophisticated statistical analyses were conducted on the results and the authors concluded that a very

brief social contact-based video intervention efficaciously reduced stigma toward individuals with FEP (Amsalam et al. 2021) We propose that research assessing the efficacy of brief video interventions (i.e. 180 seconds in duration) at reducing the stigma attached to ID should be conducted.

CONCLUSION

Stigma is a major barrier to specialist services for people with intellectual disabilities and consequently people with these conditions continue to suffer in silence. The COVID-19 pandemic has created new challenges for people with intellectual disabilities and has further fortified the barriers to specialist services. To breakdown these barriers, we must pioneer innovative interventions that leverage the power of technology and 'virtual' contact with people who have intellectual disabilities. Brief video interventions that have been developed to target the stigma attached to mental illness have shown promise. Similar interventions targeting the stigma attached to intellectual disabilities must also be developed and evaluated to help improve the lives of those who suffer from these conditions.

Acknowledgements: None.

Conflict of interest: None to declare.

Contribution of individual authors:

Poh Khuen Lim conducted the literature review and co-wrote the entire manuscript.

Ahmed Hankir conceived the idea for the paper, conducted the literature review and co-wrote the entire manuscript.

Rashid Zaman was the senior supervisor and carried out revisions.

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