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GLOBAL E-HANDBOOK ON

INTELLECTUAL DEVELOPMENTAL DISORDERS

Kerim Munir, Ashok Roy, Afzal Javed
Editors

WPA WORKING GROUP AND SCIENTIFIC SECTION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

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PREFACE

In this open-access E-handbook we focus on aspects of Psychiatry of Intellectual Developmental Disorders (IDD) (also termed as Intellectual Disability), with invited authorship from both high and low-and-middle-income countries. We thank the WPA Secretariat for its support. The encouragement of President emeritus Afzal Javed from the outset of his presidential triennial in forming Working Groups on IDD as well as autism spectrum disorders, was a historic impetus that enlivened the activities of the WPA Scientific Section on Psychiatry of IDD, subsequently leading to several Presidential and State of the Art Symposia during ensuing World Congresses.

In this E-handbook we opt to provide a structured template for authors of each country chapter that emphasize country background, mental health burden and service availability for persons with IDD, challenges and opportunities in implementing person-centred care, priority setting for professional education and training in general psychiatry, child and adolescent psychiatry, and allied disciplines, and development of collaborations, advocacy, and community partnerships.

We included submissions, to date, from low-and-middle-income and high-income countries, with representation across all major world regions: East Asia and Pacific, Europe and Central Asia, Latin America and Caribbean, Middle East and North Africa, North America, South Asia and Sub-Saharan Africa. The E-handbook is intended to be a dynamic archive on global mental health and IDD, to be updated periodically, and accessible freely with a Creative Commons license on the WPA website.

In terms of limitations, we recognize the variance in individual authorship perspectives based on their unique experience and level of training. We understand this ought not always be interpreted as a cross-national difference. Nevertheless, the uniformity of information is likely to provide a reasonable cross-country comparator. Further, although our framework promotes an integrated, evidence-based approach on the mental health care of persons with IDD globally, the readers are also referred to a more comprehensive rendition on the science in the Textbook of Psychiatry for Intellectual Disability and Autism Spectrum Disorder (Bertelli, Deb, Munir, Hassiotis, Salvador-Carulla, 2022) also sponsored by the WPA Section on Psychiatry of IDD and published by Springer. A major effort, coinciding with the COVID-19 pandemic and led by Marco Bertelli.

A WPA Position Statement on the Rights of Persons with IDD and Co-occurring Mental Disorders is included as a penultimate chapter. An important justification for this effort also undertaken by the Working Group on IDD is that mainstream psychiatry as a profession has the means and motivation to appreciably improve the inclusive mental health care of persons with IDD. Our overarching goal is an outreach to improving conditions in low-resource settings, recognition of the need for multidisciplinary partnerships and community empowerment, and obligations to enhance medical education, psychiatric training, ethics, and human rights.

Kerim Munir, Ashok Roy, Afzal Javed
January 2024

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EAST ASIA & PACIFIC

AUSTRALIA & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

In Australia, "intellectual disability" (ID) is the most frequently used term in policy and legislative documents. However, as a legacy from the previous version of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), the term Intellectual Developmental Disorder (IDD) is increasingly used in a research context. The term ID/IDD is defined here as per DSM-5-TR (American Psychiatric Association, 2022) and is distinct from a broader term "developmental disorder" which is used in Australia to refer to developmental conditions which in addition to ID, include broader neurodevelopmental disorders (NDDs) such as autism spectrum disorder (ASD), attention-deficit hyperactivity disorder (ADHD), cerebral palsy and specific learning disorders (Finlay-Jones et al., 2019). The term ID has also sometimes been used as a broader term in government reports to include additional non-developmental conditions such as acquired brain injury, stroke, or dementia (e.g., AIHW, 2022b), underscoring the importance of review of definitions in such documents before interpreting their findings.

The focus of this chapter is IDD specifically, with some extension to broader NDDs where appropriate.

A.1 Demographics and Cultural Perceptions of IDD

Australia does not have a routine or systematic approach to the multiagency collection, linkage and reporting of data on the health and wellbeing of people with disability, by disability type. The proposed solution is the development of a new National Disability Data Asset (www.ndda.dss.gov.au). Scoping, design, and test case work has been completed which build a convincing picture of the value and feasibility of creation of this asset. Decision making about the next phase of its development is in train. In the meantime, the Australian Institute of Health and Welfare's (AIHW) 2022 report on people with disability in Australia (AIHW, 2022b) is the most recent and comprehensive resource on the demographics of people with IDD. Its data is mainly based on the Australian Bureau of Statistics' (ABS) 2018 Survey of Disability, Ageing and Carers (ABS, 2019), supplemented by other population-based surveys and administrative data. A major problem with ABS and AIHW data is the inclusion of dementia in their definition of IDD, resulting in inflated prevalence estimates and other possible inaccuracies.

Demographic Factors

IDD in Australia is most prevalent in young children and becomes less prevalent with increasing age, but AIHW prevalence estimates increase again in old age due to the conflation of definition in this report with dementia (AIHW, 2008; 2022b). Reduction in prevalence with age relates to both premature mortality and biased representation in administrative datasets, the latter favouring younger people who are accessing disability services and supports at higher rates than older persons. The prevalence of IDD also shows a gender bias, with a male-to-female ratio of approximately 3:2 (AIHW, 2022b; Reppermund et al., 2019). The 2018 Survey of Disability, Ageing and Carers observed a prevalence of ID of 3% in the whole population compared to a higher prevalence of 7.8% in Aboriginal and Torres Strait Islander Australians (ABS, 2019; 2021), though these figures conflate dementia with ID. Although IDD is generally considered to be more prevalent in Aboriginal and Torres Strait Islander Australians, the figure is likely also inflated by higher prevalence and earlier onset of dementia in this group (Radford et al., 2015). In support of a true increase in prevalence of ID in this population, historical data from the Disability Services Commission of Western Australia found an over-representation of Aboriginal Australians, who comprised 7.4% of service recipients with ID but only 3.5% of the Western Australian population (Glasson et al., 2005).

Living situations and locations

Available data suggest people living with IDD in Australia experience significant socioeconomic disadvantage, though the findings are confounded by the inclusion of dementia. The 2018 Survey of

Disability, Ageing and Carers reported that approximately 65.5% of people with IDD lived in major cities, a rate similar to people with other disabilities but lower than the overall Australian population estimates of 71.8% for the same year (ABS, 2022; AIHW, 2022b). The 2017 Household, Income and Labour Dynamics in Australia (HILDA) Survey reported that 46.2% of people aged 15-64 with IDD lived in areas considered "disadvantaged" on the Index of Economic Resources, compared to 32.5% of all people with disabilities (AIHW, 2022b).

Most people with ID live in private households (85.8%) rather than disability-specific accommodation or residential care, though they are less likely to live in households than people with other disabilities (AIHW, 2022b). Analysis of 2017 HILDA survey data showed that 40.3% of adults aged 18-39 with IDD have ever moved out of home, compared to 66.3% of adults with any disability (AIHW, 2022b). The same survey showed that 22.7% of people with IDD aged 15-44 have children, compared to 45.8% of all people with disabilities.

Education and employment

People with IDD are increasingly participating in mainstream education and attaining qualifications. Over 90% of school-aged children with IDD attend school (AIHW, 2022b), and of these, 59% attend regular classes at mainstream schools, 25% attend special classes at mainstream schools, and 17% attend special schools. School-based data indicate that 65% of male, and 54% of female, school students with disability have intellectual disability (AIHW, 2022). The proportion of working-age adults with IDD who have completed Year 12 (the final school year in Australia) or equivalent has increased from 19% in 2003 to 37% in 2018 (AIHW, 2008, 2022b). Seven percent of adults with IDD have completed a bachelor's degree or higher qualification (AIHW, 2022b), though these statistics likely reflect the looseness of definition in national datasets.

Existing data suggests adults with IDD experience significantly poor outcomes in employment and income. The 2018 Survey of Disability, Ageing and Carers found that labour force participation rate is lower in working-age adults (15-64 years) with IDD (38.1%) compared to all adults with disabilities (53.4%) and the general population (65.5%) (ABS, 2018), with men more likely to participate in the labour force than women (AIHW, 2022b). The unemployment rate of people with IDD is high at 18.2% compared to 5.4% in the general population (ABS, 2018; AIHW, 2022b). Among adults with IDD not in the labour force, 63.5% are considered permanently unable to work. People with IDD most commonly work as technicians and tradespeople (22.8%), followed by labourers (20.1%) (AIHW, 2022b). Among the 86.7% of working-age adults with IDD who have an income, nearly half (45.2%) are classified as low-income, earning $383 or less per week (AIHW, 2022b). Although 32% of working-age adult with IDD are employed, only 27.7% (of all with an income) can rely on wages or salary as their main source of income. Around 67.3% of working-age adults with IDD receive government benefits, most commonly the Disability Support Pension (71.3%).

Cultural perceptions

Sociocultural factors play a pivotal role in determining if and when Aboriginal and Torres Strait Islander Australians are identified as having IDD. A relative lack of culturally appropriate and sensitive tools, and lack of normative data, impact the ability to accurately assess both cognitive and functional status (Dingwall & Cairney, 2010). Given the reported high rates of IDD experienced by Aboriginal and Torres Strait Islander peoples, a greater focus on development of culturally appropriate approaches is a pressing priority for the Australian disability and health sectors. Australia is a multicultural society, but no population data exists to understand the influence of cultural and linguistic diversity on mental health outcomes for people with IDD.

A.2 Prevalence, Identification and Early Intervention

One in 6 Australians, or approximately 4.4 million people, are estimated to have a disability. Of Australians with disability, for 23% the main condition causing their disability is classified as mental or behavioural; which includes intellectual and developmental disorders such as intellectual disability and autism (6.5%), mood/affective disorders (3.8%), and dementia and Alzheimer's disease (2.6%) (AIHW, 2022b). Overall, the estimated prevalence of IDD is about 1-2% of the Australian population (Leonard et al., 2003; Reppermund et al., 2019).

The overall prevalence of any type of disability in children aged 0-14 years has remained somewhat stable at 7 to 8% with a slight decrease noted from 8.3% in 2003 to 7.4% in 2015 (AIHW, 2022b; Reppermund et al., 2019). Of these, the most common disability type in 2015 was intellectual, estimated to be 4.3% (i.e., 190,000 children) followed by sensory/speech disability impacting 3.2% (140,000 children). There were differences based on age and gender in that in children aged 5-14 years, 12% of boys had a disability compared to 7.1% of girls (AIHW, 2022b; Reppermund et al., 2019). Further, there were geographic and social gradients in that among children with severe disability aged 0-14 years in 2015, the rates were higher in inner regional areas (5.4%) compared to major cities (3.4%) and higher among low socioeconomic status (SES) households (5.2%) compared to high SES households (3.1%) (AIHW, 2022b).

The *National Disability Insurance Scheme* (NDIS) provides individual funding for people with disability and their carers to access support in Australia**.** The NDIS was established by the *National Disability Insurance Scheme Act* in 2013, which was the first major legislative reform to disability service provision in Australia since the *Disability Services Act* in 1986 (Kendrick et al., 2017). The NDIS offers people with disability in Australia entitlement to support, greater choice and control in the delivery of that support, and more personalised service delivery and portability of funding (Kendrick et al., 2017). NDIS data suggest that in 2022, there were around 519,000 active NDIS participants, and an additional 11,200 children were being supported by the *Early Childhood Approach* for early intervention (AIHW, 2022b). Among NDIS participants, the most common disability groups were autism (34%), intellectual disability (18%, including those with Down Syndrome) and psychosocial disability (11%) (AIHW, 2022b). The high representation of autism in the NDIS data is consistent with a 25.1% overall increase from 205,200 Australians in 2018 compared to 164,000 in 2015 (ABS, 2019). However, NDIS data captures a minority of all people with intellectual disability in Australia, and likely represents those with the highest support needs.

Identification

Most children with IDD are identified due to delays in reaching certain developmental milestones, though formal diagnosis may not be given until a child is 6 years old (Amor, 2018). Within the new definition and approach to IDD introduced by International Classification of Diseases 11th edition, cognitive skills should be assessed as comprehensively as possible, incorporating tests, semi-structured observations, and direct clinical examination, thereby moving away from the reliance only on IQ scores to identify and classify IDD. This would ideally include identifying the cognitive dysfunctions that have the greatest negative impact on an individual's life, and how these may be associated with behaviour, ability, adjustment, autonomy, and other factors recognised by person-centred heath (Bertelli et al., 2015; Salvador-Carulla et al., 2011).

There are state and federal initiatives for universal developmental surveillance checks for early identification of developmental concerns in preschool children. As outlined in the 2011 *National Framework for Universal Child and Family Health Services*, the program provides free of cost access to universal developmental checks through state child and family health services. However, there are significant jurisdictional differences in the resources available and the uptake of the voluntary developmental surveillance program especially in federally funded primary care settings (Woolfenden et al., 2016). Further, children from culturally and linguistically diverse and socioeconomically disadvantaged backgrounds are particularly overrepresented in those who are not participating in the program (Eapen et al., 2017). This is particularly important as a recent systematic review on the determinants of IDD (Leonard et al., 2022) found that there is often a clustering of risk factors in families from low socioeconomic status, teenage motherhood, minority ethnicity, alcohol abuse, and maternal mental illness which would necessitate targeted approaches to early identification in these population groups. When a health or developmental need is identified, there is provision of additional, targeted or specialist and intensive services. These include further assessment and investigations as indicated including metabolic screening and genetic testing. The advent of next-generation sequencing (NGS) technologies has driven the discovery of hundreds of new genes associated with IDD, though the diagnostic yield of whole-exome sequencing (WES) in children with IDD is likely to be highest in those with severe and syndromic disorders; available evidence suggest a diagnostic yield approaching 50% (Deciphering Developmental Disorders Study, 2017), with recent improvements due to technological advancement and increase in the number of known IDD-associated genes (Amor, 2018). In 2020, the Australian Government initiated funding to cover genetic sequencing to identify genetic causes of IDD.

Early Intervention

While some causes of IDD are diagnosed prenatally or in infancy (e.g., where genetic cause is identified such as Down Syndrome), most are diagnosed by assessing phenotypic or behavioural symptoms as they emerge later in childhood and with the opportunity to reach certain developmental milestones (Amor, 2018; Finlay-Jones et al., 2019). This introduces a major issue for best clinical management of these disorders, because the critical windows for early intervention may occur before sufficient behavioural symptoms emerge to diagnostic thresholds (Finlay-Jones et al., 2019). In response to this issue, research has begun to explore the potential for very early identification of risk and early interventions starting in the prenatal period (e.g., Inguaggiato et al., 2017), as well as adopting a transdiagnostic approach which identifies dimensional attributes of risk that may be shared by numerous developmental disorders, instead of conceptualising diagnoses as discrete. Finlay-Jones et al. (2019) reviewed a diverse body of research on understanding risk factors, prodromal characteristics, and mechanisms, and highlighted further avenues for transdiagnostic approaches which may improve rates of early identification and thus early intervention. In this regard, there are state and national programs comprising antenatal screening for known prenatal risk and protective factors, informing decisions for targeted early assessment and intervention. These include sustained nurse home visiting programs for disadvantaged mothers; though the effects of such programs have been shown to vary across outcomes and subgroups (Molloy et al., 2021).

Very early intervention provides the opportunity to engage families with service providers early on to consistently monitor outcomes. National guidelines have been developed to standardise diagnostic assessment and early intervention processes such as the *National Guideline for the Assessment and Diagnosis of Autism* (Whitehouse et al., 2017). Further, the NDIS *Early Childhood Approach* of providing funding for children under six identified to have early developmental concerns without needing a diagnosis was informed by the *Best Practice in Early Childhood Intervention* (Reimagine Australia, 2015). This national approach is for any child with a developmental delay or disability and allows children who have developmental concerns but do not fully meet the diagnostic criteria to be supported with early intervention.

A.3 Status of Social Inclusion

Australia has signed and ratified the *United Nations Convention on the Rights of Persons with Disabilities* and reports periodically under article 35. *The Disability Discrimination Act* of 1992 prohibits discrimination based on disability and ensures a broad framework of equal rights, opportunities, and access for people with disabilities. A national disability policy framework sets an ambitious agenda to lead developments in disability strategy (Australian Government, 2021), covering key outcome areas including employment and financial security; inclusive homes and communities; safety, rights and justice; personal and community support; education and learning; health and wellbeing; and community attitudes. Mental health is a specific policy priority with efforts to ensure that “mental health supports and services are appropriate, effective and accessible for people with disability" (Australian Government, 2021, p. 27). However, as this framework is relatively new, clarity around implementation and measurement of outcomes have yet to fully emerge.

At an administrative and practical level, various levels of government are responsible for ensuring that initiatives in education, housing, social services, health, and communities meet expectations of disability inclusion. While there are strong expectations and support for inclusion, there is also acknowledgement that health service provision is one key area in which mainstream capacity has yet to be built, and in which specialised service provision required to meet more complex needs is lacking in most settings. This has a direct impact on accessibility and appropriateness of mental health and whole of health services, particularly for people with ID (Disability Royal Commission, 2022).

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

B.1 Children and Adolescents

The mental health needs of people with IDD in Australia are substantial with 30-50% experiencing mental illness as children or adolescents (Einfeld et al., 2011; Reppermund et al., 2018). A recent systematic review by Buckley et al. (2020) found a prevalence of 38-49% for psychiatric symptoms in children and adolescents with IDD – much higher than the average of 14% in general population as identified in previous large-scale studies of the Australian population (Sawyer et al., 2001). Buckley et al. (2020) also examined prevalence of formal psychiatric diagnoses in children and adolescents with IDD, with the most common being ADHD (39%), anxiety disorders (7-34%), conduct and externalising disorders (3-21%) and depressive disorder (3-5%). Their analysis did not detect differences associated with IDD severity suggesting similar prevalence of psychiatric symptoms irrespective of the child's adaptive functioning levels and capacity for communication (Buckley et al., 2020). Researchers have noted that prevalence data is currently underreported for subgroups, including gender, age, and SES status, impeding more specific analyses (Buckley et al., 2020; Munir, 2016).

Mental health burden also extends to parents and carers of children with IDD with one study reporting that compared to mothers of children with no ASD/IDD, mothers of children with IDD of known cause (not including Down Syndrome) spent 25% more days in hospital for treatment of a psychiatric disorder; however, this varies significantly by subgroup, and may also reflect some pre-pregnancy differences in mental health diagnoses and demographics between these groups (Fairthorne et al., 2016). Contrastingly, a systematic review found that fathers are significantly less likely to exhibit poor mental health than mothers of children with IDD (Dunn et al., 2019). However, some reviewed studies including Giallo et al.'s (2015) Australia-based study found that fathers of children with IDD (aged 3-15 years) reported significantly higher levels of depression and stress, but not anxiety, when compared to normative Australian population data. Further, it is noteworthy that the recent COVID-19 pandemic has been a significant stressor for parents/caregivers of children with IDD with a recent Australian study (Masi et al. (2021) observing that around three quarters of parents of children with a developmental disability reported worsening mental health symptoms in both themselves and their children; the study also found that only 30% reported that telehealth worked well for their child/family.

D.2 Adults

Mental health prevalence and determinants in adulthood

Past ABS surveys suggest mental ill-health to be highly prevalent in adults with IDD, though data on specific mental health conditions were not always collected. Psychiatric disability was found to be the most common type of co-occurring disability in people aged under 65 years with ID, affecting 57.1% of this group (AIHW, 2008). The most common mental health condition was depression (8.1%) (AIHW, 2008), and 52% of people with IDD aged 18-64 scored in the "high" or "very high" range on the K10, a measure of psychological distress (AIHW, 2022b).

People with IDD are also overrepresented in the Australian criminal justice system (Baldry et al., 2013; Trofimovs et al., 2021), including youth (AHRC, 2019), and co-occurrence of mental health conditions within this population is high. In this regard, Vanny et al. (2009) , found that 46% of accused adults with IDD attending Magistrate Courts had a co-occurring mental health condition, while Dias et al. (2013) found that 52.5% of prisoners with IDD had a lifetime mental disorder, and 37.2% had a current mental disorder.

Vulnerability to poor mental health owes to the complex interrelationship between ID and other medical, social, and psychological factors. Besides genetic predisposition, people with ID may be more likely to develop mental illness due to experiences of stigma, discrimination, restricted social access, socioeconomic disadvantage, or the side effects of medication (Reppermund et al., 2018). For example, social isolation is experienced among 23% of those with IDD (AIHW, 2022b). Of people with IDD living in households, more than a quarter (27%) had experienced disability discrimination in the previous year. People with IDDs are more likely than other disability groups to have experienced violence (AIHW, 2022b), and children with IDD and mental and behavioural problems, are at greater risk of experiencing maltreatment than children without disability (AIHW, 2022b). People with IDD are also at risk of under-diagnosis and lack of treatment for mental health (Buckley et al., 2020), due to a range of documented barriers in accessing mental health services (Whittle et al., 2018).

Organisation and use of adult mental health services

Adult mental health services in Australia are provided across public, private and community sectors (AIHW, 2022a). Public services generally include inpatient units in public hospitals, emergency departments, residential mental health care, and outpatient community mental health services. Private and community services may include inpatient units in private hospitals, mental health practitioners in private practice, and non-government organisations providing crisis and ongoing support. Eligible patients may receive government subsidies to access certain private mental health services under Medicare. Private health insurers may also help finance inpatient and outpatient treatment costs.

A number of studies used NSW administrative data to examine mental health service use by people with ID. Srasuebkul et al. (2021) found people with IDD to be overrepresented in NSW public mental health services, accounting for 6.3% of service users and 12% of costs during 2014-15 and people with IDD having more non-admitted treatment days and admitted bed days than people without IDD. A study of hospital records found that IDD was associated with increased likelihood of emergency department presentation and readmission after an index psychiatric admission (Li et al., 2018). Lewis et al. (2020) examined service use patterns by people with IDD who received both disability and mental health services and found that receiving disability services was associated with increased odds of community but not inpatient mental health services.

C.3 Challenges in Implementing Person-Centred Care

Person-centred care

Person-centred care (PCC) as a model of care provision, individualisation, and supports, was developed earlier in the IDD sector than in other areas of health and social care (Bertelli et al., 2015). However in spite of aspirations towards person-centred care models, implementation faces barriers such as the slow pace of "change in the philosophy or culture of care, power and funding, structures, high levels of staff turnover and lack of training, inexperience among service management, inadequate staff supervision, and ambiguity among some stakeholders" (Bertelli et al., 2015, p. 246; Dowling et al., 2007). Children with IDD in particular encounter greater communication barriers when interacting with their parents, carers and teachers, as well as health professionals, and programs have been developed to address such barriers during patient encounters (Tomsic et al., 2016). Research has also identified the issue of "diagnostic overshadowing", whereby clinicians may attribute psychiatric symptoms as an expression of the existing IDD, rather than a separate mental health condition, and therefore fail to diagnosis and treat these issues (Buckley et al., 2020; Reppermund et al., 2018).

Person-centred diagnostic models

The Person-centred Integrative Diagnostic model (PID) covers both positive and ill health across three domains: health status (disease/disability vs. wellbeing); experience of health (aspirations, satisfaction, experiences of wellbeing and ill-being); and contributors to health (risk and protective factors) (Mezzich et al., 2010). The PID model emphasises the importance of assessing positive domains of wellbeing and functioning (strengths-based approach), as well as the negative (Bertelli et al., 2015). However, the application of the PID model to the assessment of wellbeing, experiences, satisfaction, and aspirations of people with IDD (often assessed as Quality of Life (QoL)) faces significant challenges, since self-report assessments of these concepts may be limited by cognitive and communicative impairments (Bertelli et al., 2015; Bertelli et al., 2014). The use of self-report measures to assess QoL has largely been documented in those with mild to moderate IDD. However, the assessment of QoL in people with severe IDD is more complex due to cognitive and communicative impairments which may make direct interview and self-report more difficult and tend to rely on proxy report. There is also a need for specific measures to identify issues relevant to individual disorders, such as the Quality of Life in Autism (QoLA) scale (Eapen et al., 2014) which can be completed by parent/carer or self-report.

Inclusion at the policy level

People with IDD are poorly recognised and represented within Australian mental health policy (Reppermund et al., 2018). A 2018 review of Australian mental health policy documents (Dew et al., 2018) found that of 37 relevant policy documents, less than half mentioned people with IDD and none had consulted people with IDD or their supporters as stakeholders in policy development. However, there are some recent examples of policy documents that directly address the mental health needs of people with IDD, including the 2014 NSW *Living Well Strategic Plan for Mental Health Services*, the 2009 Victorian *Because Mental Health Matters* reform strategy, and the 2017 *Fifth National Mental Health and Suicide Prevention Plan*. This positive shift has been achieved only due to concerted effort and pressure from health advocates, people with IDD, and health professionals working in this area, but these policies still lack coherence and detail as to how these needs can be met (Reppermund et al., 2018).

Reflective of their lack of inclusion in mental health policy in Australia, people with IDD also face substantial barriers to mental health service access. These barriers are magnified by disconnected disability and mental health service systems and are further influenced by funding via the NDIS. In a recent review, Whittle et al. (2018) outlined a range of barriers to mental health service access for people with IDD, including significant organisational barriers, lack of services and a lack of consensus around the most appropriate service models to rectify this, poor quality of available services, as gaps in clinical knowledge and diagnostic overshadowing contributed to poor recognition of need and subsequently to inadequate treatment.

Need for specialist mental health services

For the last three decades, dedifferentiation has characterised policies for people with disabilities in Australia, assigning them to the general group of "people with disabilities" rather than impairment-specific groups (Bigby, 2020). The debates about dedifferentiated policy revolve around the recognition of and response to difference, and the pros and cons of dedifferentiated policy for people with IDDs (e.g., Clegg & Bigby, 2017).

The Australasian Society for Intellectual Disability (ASID) recognises that differentiated policies may be beneficial in some circumstances:

> Policy, service systems and professionals should: Design different types of services for different types of people. Treat people with intellectual disability as members of the broad disability group wherever possible, and protect and develop differentiated opportunities, services and research whenever necessary (ASID, 2017).

Studies of people with IDD, carers, and health professionals have identified a common need for specialised IDD mental health services (Jess et al., 2008; Weise, Cvejic, et al., 2020; Whittle et al., 2018). People with IDD often receive inadequate care in mainstream mental health services due to a range of issues including insufficient clinician training, diagnostic overshadowing, clinician prejudice, overuse of antipsychotic medications, and poor communication between mental health and disability services (Hronis et al., 2018; Jess et al., 2008; Weise, Fisher, et al., 2020; Whittle et al., 2018). Jess et al. (2008) compared Australian psychiatrists with their UK counterparts and found that Australian specialists worked with a narrower range of mental health problems and were less confident in their ability to care for patients with IDD. Both groups believed it was necessary to have specialised inpatient facilities for patients with IDD. Weise, Cvejic, et al. (2020) surveyed support persons of people with ID about desired characteristics of a hypothetical tertiary IDD mental health service, and participants identified assessment of mental health and behaviours of concern, managing risk of harm to self and others, psychotherapy recommendations, and care planning as priority areas where general mental health services would benefit from specialist guidance.

D. SETTING PRIORITIES

D.1 Medical education in IDD psychiatry

Currently, health professionals in Australia lack confidence and skills in provision of mental health supports for people with IDD (Weise & Trollor, 2018). Although recommended (Department of Developmental Disability Neuropsychiatry, 2018b), mandated training in this area has not been instituted. Addressing this shortfall in capacity in mental health care requires a multilevel approach, which both equips future health professionals, and upskills current ones. However, national audits of IDD content in Australian Medical and Nursing Schools highlight that at present, the majority of future nurses and doctors will graduate with inadequate or no understanding of the specific health or mental health care needs of people with IDD (Trollor et al., 2018; Trollor et al., 2016). Twenty years after this issue was first identified (Lennox & Diggens, 1999; Trollor et al., 2020), as part of the implementation of the 2021 *National Roadmap for Improving the Health of People with Intellectual Disability*, the federal government has funded the development of a core capability framework for all medical, nursing, allied health and dentistry students. This framework will ensure some minimum content in relevant degree courses.

D.2 Clinical postgraduate training in IDD child/adolescent and general psychiatry, and interdisciplinary training opportunities

At present, there is no formalised training program on ID/IDDs in Australia as part of the psychiatry training by the Royal Australian and New Zealand College of Psychiatrists (RANZCP). A number of bespoke training experiences do exist in Australian public mental health services (Johnson et al., 2013), in both IDD mental health in children and young people as well as adults. Trainees have access to a diverse range of experiences and settings and seek funding for a 1-year training program, usually from competitive sources. Further specialised training for psychiatrists in the psychiatry of IDDs has also been recommended and its feasibility has been extensively scoped (Eagleson et al., 2019). Over time it is hoped that this area of practice will be recognised as a subspecialty area for psychiatrists, and that further capacity will result.

Historical calls for specialist training pathway development (Department of Developmental Disability Neuropsychiatry, 2018a) have been recently invigorated by a preliminary report by the *Royal Commission into Violence, Abuse, Neglect and Exploitation of People with Disability* (2020) that identified systemic neglect in health care of people with cognitive disability. The Commission has called for the establishment of both specialised training content in cognitive disability health as well as expanded pathways for sub-speciality training in cognitive disability health in postgraduate specialist medical education (Disability Royal Commission, 2022, p. 71).

D.3 Collaborations and partnerships

In the Australian context, significant advocacy partnerships have been developed with the aim of improving health services and outcomes for people with IDD. Partnerships between health advocates, people with IDD, clinicians and researchers have been pivotal to key actions including the recent establishment of the 2021 *National Roadmap for Improving the Health of People with Intellectual Disability*, and the development and maintenance of jurisdictionally specific mental health services, especially in eastern states of New South Wales, Victoria and Queensland. Substantial sector engagement and investment in research partnerships are emerging, led by key academic groups, and including international research partners. Critical elements of these research partnerships include co-design, a strong implementation science and translational research focus.

Case example:
Using hospitalisation data from the Sydney Children's Hospital, it has been found that children and young people with IDD are overrepresented in hospital admissions and they have higher associated complex medical conditions, but up to 30% are not identified and they are more likely to suffer adverse events (Mimmo et al., 2020). Hence, for supporting health professionals working with children with IDD and to improve their attitudes and skills, training programs have been developed and tested (Ong et al., 2016; Ong et al., 2017).
The '*Motivated for Change*' training program aimed to empower staff working with children and young people with intellectual and developmental disability (Ong et al., 2021) has identified the following components as critical:

- **Improving access:** Making all health care accessible to people with disabilities
- **Safety and quality of care:** Quality Improvement projects and Continuous Professional Development to improve patient outcomes.

- **Workforce and systems capacity building:** Increasing skills and behavioural change using integrated adult learning models and ‘flipped classroom’ with pre-session activities.
- **Positive organisational culture:** Meaningful objectives, values and purpose used as drivers.

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NEW ZEALAND & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions

Aotearoa New Zealand has a population of just under 5 million as of 30 June 2018 based on the 2018 consensus (www.stats.gov.nz) but is estimated to pass the 5 million marks in March 2020. The population is bi-cultural with 70% identified as being of European decent (which is a drop of nearly 5% since the 2013 census), and 16.5% Maori. The other ethnic groups include Asian (15.5%), Pacific Islanders (9%) and 1.6% identified as Middle Eastern, Latin American, and African. Aotearoa New Zealand has been influenced by the British colonization during the 18th Century which has influenced the current legal and healthcare systems of New Zealand. In addition, colonization has probably impacted on the health outcomes for the indigenous Maori people of New Zealand. From a historical perspective, the Treaty of Waitangi signed in 1840 was to give Maori people the same rights and privileges as European descended New Zealanders. However, whether the terms of the Treaty have been respected has been debated.

New Zealand provides a public funded health care system available to all as well as a private health care system through private health insurance schemes for those able to pay for it. Health Care was organized across New Zealand through 20 district health boards until 2022. Health care is provided by working in partnership with other agencies such as disability and children's services. However, a move to a federally administrative national health system known as Health New Zealand with the development of a Maori Health Authority came into effect in July 2022 which will work with the federal system to directly commission services to improve outcomes for Maori people. Also, in 2022 the government launched Aotearoa New Zealand's the new Whaikaha-Ministry of Disabled People.

Disability is a Western European concept and for Maori it may mean something different in terms of identity and values with a recognition that Maori values support the inclusion of those with disabilities (Bevan-Brown, 2013). There is no evidence to indicate that the mental health problems present differently in Maori to those of European descent but the lack of understanding of culture may lead to misdiagnosis of conditions such as psychosis for example when Maori people report the presence of ancestors.

A.2 Prevalence identification

There are few published studies on the prevalence of IDD in New Zealand (Bray, 2003). Bray reviewed number of studies prior to 2003 looking at prevalence of people with IDD. The review reported on two large studies though there had been smaller more local study such as one covering Auckland and the Northland (Densem,1972). This local study found a prevalence of IDD in children and adults defined as IQ below 85 with accompanying need to be 3.7 per 1000. The two larger studies reported by Bray included a study undertaken from May 1971 to August 1972 using the 1971 census data (Morrison, Beasley & Williamson, 1976). The definition used was intellectual handicap which was a term introduced in New Zealand in the late 1940s by a parent's organization. Intellectual handicap referred to those with at least a moderate degree of disability so in effect an IQ below 50. Five regions of New Zealand were screened based on the 1971 census by accessing various service data including data from educational services. These five regions were across both the North and South Islands and represented just under 28% of the total population aged 0-64 years. The overall prevalence using the unweighted mean was given as 3.5 per 1000 considering the low prevalence in the Wellington area. This figure was in effect an administrative prevalence. The proportion of Maori people in the sample was higher at 11.3% than would be expected based on the population at that time of 7.9% for Maori.

Bray also reported on a later study considered as the first national population-based study of Disability in New Zealand carried out in 1996–1997 by Statistics New Zealand (1998). This survey did include conditions such as ADHD, which was not typically classified as IDD, although it may co-occur with it. The overall prevalence was found to be 10 per 1000 of people. A further study of older people with IDD (Reid & Hand 1995) reported 40% with borderline intellectual functioning to mild IDD, wth 4% identified as Maori. IHC which is a national organization that advocates for the rights, inclusion, and welfare of all people with intellectual disabilities in New Zealand produced a report in 2017 titled 'Valuing All: Leave no one behind' (IHC, 2017). This was a progress report on the rights and wellbeing of people with intellectual disabilities and their families/ whanau across New Zealand. The IHC asked the question: "How is New Zealand doing for people with intellectual disabilities" by the participation of 700 people in an online survey or focus groups including 77 people with intellectual disabilities, more than 400 Maori families/whanau and a quarter of respondents worked in disability support services (IHC,2017a). The prevalence reported in this report was of 96,800 people with intellectual disabilities (2% of the population in New Zealand). Children with IDDs, those aged 0-14 years made up 5% of the children's population and adults with intellectual disabilities aged 15-44 years made up 3% and those over 45 made up 1% of the adult population (Statistics New Zealand, 2013). Maori and Pacific peoples had higher than average disabilities rates after adjusting for differences in ethnic population groups. There were more males living with IDD and this was the same for both children and adults.

A.3 Status of social inclusion

Many respondents to the survey by IHC (IHC, 2017a) despite the challenges to social inclusion found New Zealand was heading in the right direction for inclusion, being connected and participating in the community as reported for children by 43% of respondents and for adults by 38% of respondents. A global review of raising awareness and combatting stigma that included New Zealand described the overall view of IDD in Oceania as one of progression and inclusion (Scior et al, 2015). The main conclusion of this review was that IDD appeared to be subsumed within disability or is overlooked entirely.

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

B.1 Children and adolescents

New Zealand education legislative and policy framework provides for education at the local school and in special education setting for children with disabilities. Most disabled children attend the local regular school whilst a small number (3266) attend special schools, usually residential special schools (Ministry of Education, 2016). Families of children with intellectual disabilities in New Zealand articulate problems about accessing the curriculum, inadequate resources and specialist support and teachers lacking capacity in inclusive education. The Ministry of Education acknowledge gaps in identifying at a national level about the progress and achievements of students with additional learning needs with an acknowledgement that coordinated data gathering, reporting and monitoring is required (Ministry of Education 2106a).

B.2 Adults

Following on from the closure of institutions in New Zealand which started early in the 1990s and was completed in 2007, there was a splitting of health and social care. Overall, health care for people with IDD including mental health care is provided through mainstream services. Despite the high rates of mental health needs in people with intellectual disabilities, they experience difficulties in accessing mental health service which is compounded by the wider mental health services in New Zealand being under resourced (Elliott, 2017). This is especially the case for those with mild intellectual disabilities requiring mental health care. There are a few communities' IDD-based facilities with limited capacity which are in the larger cities so limiting availability to more rural areas. David/Jane can you add more about these teams.

Prior to 1992, people with IDD could be managed under mental health legislation in New Zealand. The Mental Health (Compulsory Assessment and Treatment) Act (MH (CAT) Act) 1992 intentionally excluded people who had an IDD and no coexisting mental health problems. This caused a problem for those with IDD presenting to the criminal justice system who could not be diverted to effective care and treatment. The Intellectual Disability (Compulsory Care and Rehabilitation) Act (IDCCR Act) 2003 was enacted in 2004 (Ministry of Health, 2003) to fulfil this gap with the provision of compulsory care and rehabilitation to individuals with an IDD who had been charged with or convicted of an offence leading to imprisonment. Regional Community Forensic IDD teams were set up to support this legislation with nursing, occupational therapy, psychology, psychiatry input and in many ways New Zealand has led on delivering specialist community-based forensic services for offenders with IDD (McCarthy & Duff, 2019).

B.3 Challenges in implementing person centered care

The policy document produced by the IHC 'Valuing All: Leave no one behind' (IHC,2017) also looked at inclusion across different aspects of the lives of people with intellectual disabilities. The report identified several key themes from the online survey and focus groups on the experience of social inclusion for people with intellectual disabilities in New Zealand:

- Across all areas of their lives people with intellectual disabilities tend not to be visible, counted or equally valued.
- People with intellectual disabilities continue to face unacceptable barriers and discrimination, undermining both their quality life and citizenship.
- The quality of people's lives depends on where they live, individual circumstances like wealth and connections and, too often, luck.
- Families/whanau feel worn down by the difficulties accessing support for their children and are worried if future access to support is even harder when their child is an adult.
- People with intellectual disabilities in their families often experience compounding disadvantage so that opportunities for a good life are limited in a multitude of ways.
- Government systems are not responsive enough to individual circumstances and do not deliver fairly. Although there are some promising signs, it is too early to assess whether all people with intellectual disabilities will benefit from the changes that are underway with the systems transformation.
- More and better impairment specific information is needed in order to inform planning and funding decisions and track progress in making rights real in the lives of people with intellectual disabilities and their families/ whanau.

The challenges to implementing person centered care in New Zealand as described in the themes above is a lack of responsiveness, the available capacity of the health and social care system, discrimination, and a lack of information for people with intellectual disabilities and their families/ whanau on their rights.

B.4 Opportunities for action

In 2011, the Ministry of Health published a summary on the health indicators for New Zealanders with IDD (Ministry of Health, 2011). The study population consisted of 31,847 people identified as having IDD and 4,261,600 not having an IDD. In effect 0.7% of the studied population were classified as having an IDD. Compared to the group without IDD, the group with IDD included a relatively high proportion of children, teenagers and people aged 85 and over. People with IDD were more likely to live in the most socially poor areas of New Zealand. The key findings of the report were that people with IDD living in New Zealand have poorer health and seem to be more at risk of illness, disease, death than those without IDD. This is consistent with international studies for this group.

The key findings were:

- Males with IDD have an average life expectancy of 59.7 years which is more than 18 years less than the life expectancy for all New Zealand males (78.4 years).

- Females with IDD have an average life expectancy of 59.5 years which is about 23 years less than the life expectancy for all New Zealand females (82.4 years).
- Compared to people without IDD, people with IDD were 1.5 times more likely to seek current treatment for one or more of six selected chronic health conditions. These included chronic respiratory disease, chronic heart disease, cancer.
- People with IDD are slightly more likely to be involved in a primary health care organization and nearly 1.5 times more likely to consult a general practitioner in a three-month period and are more likely to be dispensed almost twice as many different types of prescription drugs from the community pharmacist.
- People with intellectual disabilities will be twice as likely to receive elective or arranged public hospital treatment and over 4 times more likely to have public hospital admissions that could have been avoided.
- On average people with intellectual disabilities received 3001 NZD (New Zealand Dollars) worth of government funded primary and secondary care per person annually which is nearly three times higher than the same service received by people without IDD of 1028 NZD.

The report described that there were number of areas in progress to help support the health sector to better respond to needs of people of IDD and these included:

- A trial of health passports which contain personal health information to help health professionals working in hospital provide better care for the person and their families
- Improvements in pharmacy service for people with IDD living in the community with an emphasis on obtaining the clinical support they need with their medicines to achieve better health results
- Improving the health literacy of people with disabilities including people with IDD and their carers, family/whanau.

The report concluded that given the current financial restraints the focus was to ensure existing health and disability services adequately meet the needs of people with IDD.

C. SETTING PRIORITIES

C.1 Medical education in IDD psychiatry

There are two medical schools in New Zealand based at the University of Auckland and the University of Otago. There has been a key lecture covering IDD domain within the psychiatry module.

C.2 Clinical postgraduate training

The Royal Australian and New Zealand College of Psychiatrists has a New Zealand representation within the Section of Psychiatry of Intellectual and Developmental Disabilities of the College (David can you add more detail on the Section?). Analysis of work-force data for New Zealand showed that there are up to 18 psychiatrists working in intellectual developmental disability mental health (IDDMH) services on the North Island and seven psychiatrists on the South Island (Cvejic et al, 2018).

There are currently no formal arrangements for training in psychiatry of IDD across New Zealand. Unlike for example, in the UK in which there is a specialist training scheme in the psychiatry of IDD and once the training is completed the psychiatrist can enter onto a specialist register to be recognized as a psychiatrist in the field of IDD. In New Zealand there is no distinction between specialists on the vocational register which is equivalent to the specialist register in the UK. There are challenges in delivering specialist training as access to opportunities are limited as there are only a small number of services to gain experience on the mental health needs of children or adults with IDD.

However, the problem remains for many countries including New Zealand will be the lack of sufficient workforce who have the expertise in assessing and managing the mental health needs of young people and adults with intellectual disabilities.

C.3 Research and research training opportunities

There is no designated academic center in psychiatry of intellectual and developmental disabilities in New Zealand. However, there is the Donald Beasley Institute, which is national, independent, non-profit organization based in Dunedin, New Zealand and undertakes disability research and education with a particular expertise in IDD (www.donaldbeasley.org.nz). Further studies of the mortality and morbidity of people with IDD are needed and it may be their future projects that focus on the wider needs of people with disability will include people with IDD.

New Zealand is a world leader in population-based data sets for example a national birth cohort study utilizing linked administrative data covering a large whole population research database contains administrative and survey data, linked at individual level and is managed by Statistics New Zealand (Statistics New Zealand 2017). This world leading Integrated Data Infrastructure known as IDI may have the potential to inform research on the health needs of people with intellectual and developmental disabilities in New Zealand. For example one study using the IDI, in which data for 1197 people with autism and 147,879 without autism was acquired. The data showed that young people with autism have significantly lower rates of being proceeded against by the police, charged and convicted in the court compared to those without autism (Bowden et al, 2022). Those with autism who were charged with an offence was significantly more likely to be charged with serious and violent offences, offences against the person and against the property.

C.4 Collaboration and partnerships

The Donald Beasley Institute has strong links with Disabled People’s Organizations, people with disabilities and the wider community in developing a partnership to monitor and progress research on the needs of people with disabilities.

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EUROPE AND CENTRAL ASIA

World Psychiatric Association
Section on Psychiatry of Intellectual Developmental Disorders

AUSTRIA & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

The Republic of Austria is a federation of nine states with a population of 8.9 million (Statistik Austria, 2022). It is a wealthy country which offers high living standards and is ranked 18th in the Human Development Report (United Nations Development Programme, 2020) and 11th in the World Happiness Report (Helliwell et al., 2022). Furthermore, the capital city, Vienna, was recently named the most liveable city in the world due to its good infrastructure, high quality health care and rich cultural and entertainment offerings (Economist Intelligence Unit, 2022). The population of people with IDD is estimated at 1% of Austria's inhabitants, which corresponds to 89,000 people (Griebler et al., 2021). Today, almost 15 years after ratifying the UN Convention on the Rights of Persons with Disabilities (UN-CRPD), there is still little known about this population's health status and healthcare situation as there is hardly any official data available.

To understand the provision of disability support and the inclusion policies that exist in Austria today, it is worth taking both the political framework and historical context into consideration. Before and after World War II support for people with IDD was mainly organised in large, isolated institutional settings run by the state or the church, which left the residents with limited opportunities for self-determination. Many people with IDD lived in these environments from early childhood until old age. However, arising out of parents' initiatives after the war, community-based sheltered workshops were set up, followed by the establishment of group homes shortly after. Following a major reform of psychiatry from the 1980s onwards, people with IDD moved from psychiatric hospitals to community-based facilities. This process lasted until the 2000s. Today, however, the institutional model of care for people with IDD is largely rejected. This might be still due to the active involvement of institutions, psychiatrists, and psychiatric nurses in the systematic killing of people with IDD during the Nazi era's T4 programme.

In recent decades, national and regional policies for people with disabilities have followed a human rights-based approach. Since ratifying the UN-CRPD in 2008, the Austrian government passed the first National Action Plan (NAP) on Disabilities in 2011, with a second published earlier this year. As one of the first consequences of the new NAP, the lack of register-based data on people with disabilities and their quality of life is to be addressed by Statistik Austria, the federal statistics office. Overall, however, the implementation of the measures formulated in the NAP is challenging, due to the vagueness of indicators and a lack of allocated funding. Furthermore, health, education and social legislation fall under the responsibility of the federate states, which leads to a devolution of responsibility, varied competencies, and huge variations in the status quo on a federal level.

Terminology

In recent decades, the term 'intellectual disabilities' (German: *intellektuelle Behinderungen*) has become established in Austria, while the formerly-used term 'mental disabilities' (German: *geistige Behinderung*) has been abandoned, due to its inaccuracy and discriminatory connotations (Griebler et al., 2021; Zeilinger & Schossleitner, 2019). However, people with IDD prefer being referred to as having 'learning difficulties' (German: *Lernschwierigkeiten*), even though this term is technically not correct. Today, efforts are being made to promote the suggested German translation of the ICD-11 term 'intellectual development disorders' (German: *Störungen der Intelligenzentwicklung*).

A.1 Cultural Perception and Status of Social Inclusion

People with IDD are not yet part of public discourse in Austria, as there is a lack of social awareness of disabilities in wider society (BMSGPK, 2020; Mayrhofer et al., 2019). Furthermore, the perception of disabilities is focused on people with physical or sensory disabilities, with people with IDD left behind. Few efforts are made on awareness-rising campaigns. Instead, media presentations of people with disabilities are mainly deficit-oriented and dominated by charity (Monitoringausschuss, 2020), thus promoting the medical rather than the social model of disability. Furthermore, the eugenic indication for abortion is still applicable law and allows abortion exempt of punishment beyond the 12-week-threshold when 'the child is at risk of being seriously mentally or physically damaged' (§ 97 sentence 1 no 2, Austrian Criminal Code). This conflicts with the UN-CRPD and was found to be in breach of the Convention by the UN in 2013. This, as well as the lack to this day of an official statement by the medical association on its involvement in the Nazis' euthanasia programme, weakens the trust of relatives and disability service providers in the medical, and especially the psychiatric, system.

Despite these existing social and structural barriers, there have been efforts to promote a self-determined and human rights-based perspective on disability. Different areas of public life have begun to approach accessibility beyond merely physical barriers. Most recently, parliament correspondence has begun to be translated into easy-to-read language, and municipalities make their online appearances more easily accessible. Moreover, the cultural and recreational sectors have become more inclusive, offering participation opportunities like inclusive theatre, dance, and sports. Furthermore, the Essl Foundation, established in 2008 to support the implementation of the UN-CRPD, has its headquarters in Vienna. Through the Zero Project, the Essl Foundation is a global advocate for accessibility and awards prizes to innovative practices and policies worldwide (The Essl Foundation, 2022). On a national level, Lebenshilfe Österreich, Austria's leading non-governmental organisation in the field of IDD, honours inclusive projects and social innovations with the Austrian Inclusion Award (Lebenshilfe Österreich, 2022). Comparable state-led efforts to promote inclusive projects, however, are non-existent.

A.2 Identification and Early Intervention

Austria offers an optional, free-of-charge baby check as a preventive healthcare measure for young families. The baby check documents the results of examinations during pregnancy and during the first years of a child's life. However, there is no obligation to use standardised instruments to assess the child's general developmental milestones. The diagnostic process is often limited to intelligence diagnostics, with adaptive skills rarely being assessed. Specialised diagnostic centres can be consulted to get a comprehensive diagnosis. However, few such centres exist, and their services are not always covered by health insurance, thus bearing an additional financial burden.

If a developmental delay is suspected, early intervention can be requested from the social welfare system. However, identification and early intervention go hand in hand with long waiting times. In 2012, the Monitoringausschuss stated that families of children with an assumed disability often wait for several months before receiving an initial diagnosis. This long waiting period, which has since been exacerbated by the Covid-19 pandemic, was confirmed through personal communication with professionals working in a diagnostic centre specialised in developmental disorders and sensory impairment in Upper Austria. Early intervention programmes are the responsibility of the individual Austrian states, thus leading to variation in approaches and the extent of intervention available. As a result, early intervention programmes remain rather unspecific and without any nationwide standards. Despite some federate state-specific brochures and isolated regional coordination offices, there are clear gaps in the provision of information on early intervention.

A.3 Access to Education, Vocational Training and Work

Today, all children are considered to have the capacity for education. Children with IDD are fostered in inclusive educational settings from an early age, which complement and ultimately aim to replace existing special educational facilities. Since 2016, inclusive educational competence is an integral part of teacher training at university and therefore allows individually tailored and learning objective-differentiated teaching. After completing compulsory schooling, however, there are only a few vocational training opportunities available. As educational programmes beyond the nine years of compulsory education are not offered for people with IDD, many young adults with IDD transfer directly from school to sheltered workshops, which are officially defined as occupational therapy. Those working in sheltered workshops do not receive a salary, but so-called pocket money, and are normally considered unfit for work. In most cases, a transition from a sheltered workshop to the open labour market proves to be rather difficult. However, a recent study by Caritas, a major disability service provider in Austria, shows that 58% of people with IDD or multiple disabilities would like to work in the primary labour market, provided they receive sufficient assistance at work (Pateisky et al., 2022). Efforts are currently being made by government agencies to transform the pocket-money model into a salary model with the corresponding social security benefits (e.g., social insurance claim), with the goal of full participation in work life.

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

The illustration below, originally created for *The Lancet*, visualises the huge mental health burden of deaf people, symbolized by big backpacks, who have very limited access to appropriate healthcare. This also applies to individuals with IDD in Austria and in general.

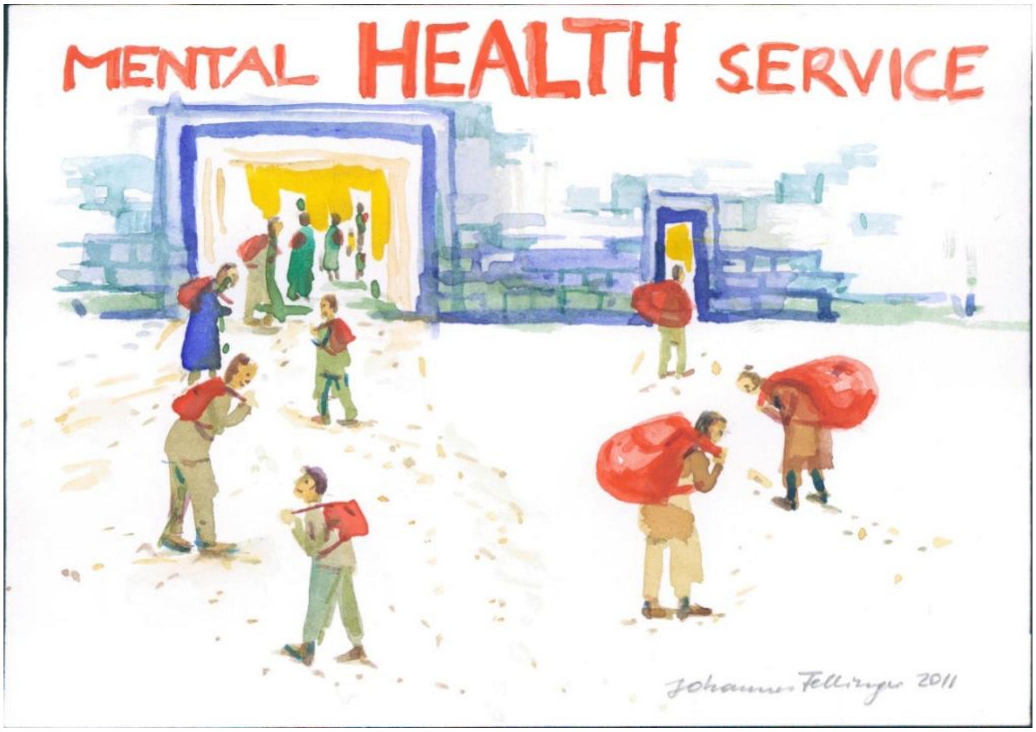

Figure 1. The mental health burden of people with disabilities. (Fellinger, J., Holzinger, D., & Pollard, R. (2012). Mental health of deaf people. *The Lancet*, 379, 1037-1044)

As noted earlier, there is little data available on the health status of people with IDD, as there are no established health indicators for this population in the national health programme (Griebler et al., 2021). This is particularly true when it comes to mental health. Zeilinger et al. (2011) reported a prevalence of 11.5% of mental disorders in individuals with IDD in a representative German-Austrian sample. To our knowledge, this is the most recent prevalence estimate for Austria, as there is little research interest in the (mental) health situation of this population.

In general, there is a lack of awareness of the mental health burden of people with IDD. Mental health professionals have little to no knowledge of mental health in IDD, as this population is not properly represented in their curricula. However, clinical psychologists and psychiatrists receive some training in developmental psychology and mental health in children with disabilities. The recently established Medical University in Linz offers a course on disability and human rights in their standard curriculum, while medical students in Vienna can take some electives on IDD. However, knowledge and practical training on the mental health of adults with IDD are scarce, as there are few specific training opportunities available. Indeed, the recent shadow report (Monitoringausschuss, 2020) assessed the knowledge of the UN-CRPD in healthcare professions as low.

Unlike the Netherlands or Germany, Austria does not offer a postgraduate diploma in inclusive medicine, and, consequently, there is a lack of knowledge and experience among primary care physicians and psychiatrists working with this population. This is also true for clinical and health psychologists as well as psychotherapists, as there are no postgraduate training opportunities specialising in people with IDD. To deal with this deficit, the umbrella organization of social services in Vienna (Dachverband Wiener Sozialeinrichtungen, 2017) has developed training modules for medical professionals on healthcare and support for people with disabilities. However, these remain largely unknown in the professional community and are not offered nationwide, resulting in little take-up. In addition, the Austrian Academy of Psychology occasionally offers seminars on clinical conversation and counselling focused on people with IDD. Although the general awareness of mental health in individuals with IDD is low, interdisciplinary networks are evolving, including a German-Austrian-Swiss association for inclusive medicine (DACH Inklusive Medizin), and a recently formed working group on IDD within the Austrian Association of Psychiatry, Psychotherapy, and Psychosomatics.

A recent survey among mental health professionals on mental health in IDD
In preparation for this chapter, we conducted an online survey among all mental health professionals in Austria (psychiatrists, clinical and health psychologists, psychotherapists) on mental health in people IDD and the specialised mental health services available. Initial analysis shows that the prevalence of mental disorders in individuals with IDD is estimated at about 50% and underlies a large scatter range. The same applies to the rate of undiagnosed mental disorders. Despite the very low response rate (N = 46), over 70% of the sample claimed to have experience in treating individuals with IDD. Aggression and social withdrawal were named as main indicators for mental health issues in individuals with IDD.

B.1 Children and adolescents

In general, healthcare for children and adolescents with IDD is covered by paediatrics. Within this speciality, social paediatrics and neuropaediatrics most commonly deal with the topic of IDD specifically. However, systematic training in the health needs of children and adolescents with IDD has yet to be established.

Due to the Covid-19 pandemic, mental health became more widely discussed, and state funding for psychotherapy for children and adolescents was promoted. However, young people with IDD were not represented in this discourse. Moreover, the prevalence rate of mental health issues in children and adolescents with IDD is not known, as national prevalence studies are not available. To make matters more complicated, the IDD diagnosis is often avoided and made late in the diagnostic process, as this diagnosis is still tabooed and causes fear. Children and adolescents with IDD and additional mental health issues currently have limited options available to them, as interventions focus on early intervention in younger years, and, in later years, on educational counselling, occupational therapy or youth welfare services, which remain rather unspecific. Austria thus lacks a structure specialised in the mental health needs of young people with IDD. While there are some mental health professionals specialised in this area, the amount is insufficient to meet the demand.

B.2 Adults

As in the case of children and adolescents, there is no nationwide framework specialised in the mental health needs of adults with IDD in Austria. In general, public hospitals are obligated to cover acute psychiatric conditions, which also includes the mental health needs of people with IDD. And yet most psychiatric wards do not offer appropriate services for people with IDD, as professionals are not properly trained for the needs of this population. There are, however, some exceptions, such as the specialised psychiatric ward based at Hietzing hospital in Vienna (Wiener Gesundheitsverbund, 2022). The ward follows an interdisciplinary approach and is run by a team consisting of psychiatrists, psychiatric nurses, clinical psychologists, and pedagogues. A wide range of therapy options (e.g., music therapy, occupational therapy, physiotherapy, hippotherapy, and garden therapy) are also offered in addition to classical psychiatric means (Harmankaya & Beharic, 2022). Yet, as the IDD focus of this psychiatric ward is unique, it has a huge catchment area. Due to the considerate selection process of patients and the limited bed capacity, emergency admission is not possible.

On the outpatient level, Vienna's department of social psychiatry for people with disabilities, which includes a centre for autism (SOMBA; Psychosoziale Dienste Wien, 2022), offers specialised medical and therapeutic services, including psychological testing, counselling, and qualified support from social workers. In special cases, temporary psychotherapy is also possible. In early 2022, SOMBA expanded to form SOMBA+, operating as a triage outpatient clinic, and liaises within the healthcare system.

Outside the capital, however, there are barely any specialised mental health services for adults with IDD. Existing facilities, such as the outpatient clinic for inclusive medicine in Linz with an additional neurological focus (AIM; Konventhospital der Barmherzigen Brüder Linz, Upper Austria, 2022), or the med-inclusion outpatient clinic in Melk (MIA; Landesklinikum Melk, Lower Austria, 2022), are characterised by the personal commitment of a few engaged people.

In the private practice sector, there are just a few dedicated experts, resulting in an unmet need for diagnostics, counselling, and treatment for people with IDD and additional mental health issues. In fact, while official search engines for mental health experts do filter for 'disability' or 'autism', they rarely offer the specific option 'intellectual disability'. Some disability service providers have started listing specialised psychotherapists. However, those lists are again mainly focused on the capital area. Furthermore, psychotherapy or psychological therapy is often not affordable for people with IDD (Buchner, 2012).

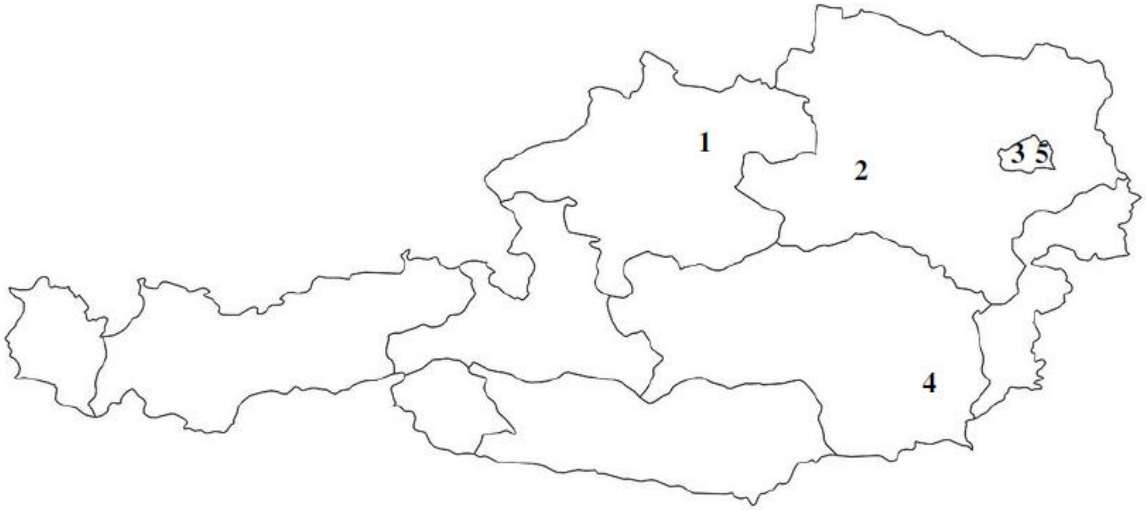

Figure 2. Map of Austria with the locations of specialised inpatient and outpatient services for adults with IDD.

1 = outpatient clinic for inclusive medicine in Linz (Upper Austria), 2 = med-inclusion outpatient clinic in Melk (Lower Austria), 3 = SOMBA and outpatient clinic for inclusive medicine in Vienna, 4 = institute for inclusive medicine in Kainbach (Styria), 5 = specialised psychiatric ward at Hietzing hospital (Vienna)

B. 3 Challenges in Implementing Person-Centred Care

In preparation for this chapter, we asked self-advocates from Lebenshilfe, Austria's leading non-governmental organisation in the field of IDD, about mental health, and the challenges in accessing professional mental health care.

> *"Many mental health professionals do not know at all how to deal with people with IDD because they are not informed."*

In the striking words of a self-advocate, a recurring theme in this group discussion were the difficulties in finding a suitable mental health professional. Furthermore, the self-advocates reported little awareness among mental health professionals regarding the needs of people with IDD. They criticised the usage of technical terminology and the lack of explanations in easy-to-understand language. Further challenges mentioned include long waiting periods, the high cost of psychotherapy, and overmedication. The self-advocates' points of criticism are also shared by the relatives of people with IDD (Lebenshilfe Österreich, 2019).

Barriers within the healthcare system make it difficult for people with IDD to access the specialised care they need. While several physical barriers have been removed in recent years, numerous services in the healthcare sector remain inaccessible to people with different kinds of disabilities, and structural, social and communicative barriers remain. On a structural level, only a small number of specialised services and dedicated experts for the (mental) health needs of people with IDD exist in Austria, leading to high demand and extensive waiting periods. The lack of financial resources and the influence of the medical, rather than social, approach (i.e., lack of time, fast processes) complicate person-centred care. Due to insufficient collaboration and coordination between the health and social sectors, the implementation of high-quality mental health care for people with IDD has proven rather difficult. This affects situations of transition, such as between adolescence and adulthood. Furthermore, mental health professionals are not trained properly to meet the mental health needs of people with IDD, as outlined above. The Austrian healthcare system has thus far not put sufficient effort into health promotion and health competence, particularly when it comes to mental health. Moreover, there is little research interest in the needs of people with disabilities, leading to a lack of data and knowledge. However, there are some research facilities which focus on the health needs of people with disabilities in Austria (e.g., Research Institute of Developmental Medicine at Johannes Kepler University in Linz; RID), and the Austrian Science Fund (FWF) recently allocated funding to a large-scale research project on mental health and IDD.

B.4 Opportunities for Action

From the above, it is evident that change is needed in terms of psychosocial service provision for people with IDD in Austria. Further education and training on the mental health needs of people with IDD are necessary to counteract the existing lack of specialised mental health offers.

Self-advocates from Lebenshilfe Österreich suggest the following:

> *"There should be mental health experts who are trained to work with people with IDD. A special training on IDD, that is what I wish for."*
>
> *"Maybe there should be peer counsellors too – people with IDD specialised in mental health. This allows for communication on eye-level. This might be a proposed solution for the future."*

However, the improvement of the mental health situation of people with IDD does not lie solely in the expansion and improvement of existing psychosocial services. As mental health is highly interrelated with social conditions, change is also needed on a societal level. Most importantly, awareness-raising and meeting opportunities for people with and without IDD are needed to reduce stigma and fear of contact. For over 20 years, the Hospital of St. John of God in Linz has been striving to implement this holistic approach of mental health through therapeutic living communities for people with deafness and IDD and other neurodegenerative or psychiatric disorders.

Inclusion and specialisation are not contradictory as the example of the therapeutic living communities shows. There is a need for specialised services for people with deafness and IDD. Guaranteeing accessible communication (e.g. sign language) within a larger social network is an essential human right, not only for deaf people but for everybody. In social communication, all communicative actions are addressed towards another person in order to share information, thoughts, and ideas with others (Mundy et al., 1986) and thus get in touch with each other.

The development and enhancement of social communication abilities is applicable to all, as it enables people to communicate on their highest possible level, thus leading to rich social engagement and participation which in turn improves mental health. Existing experiences and findings from the therapeutic living communities encourage multiplication and further research.

Case Example: A special focus on deaf people with IDD in Austria

Although hearing loss is a frequent condition in individuals with IDD with prevalence rates of around 40%, hearing impairment remains largely unrecognised without proper assessment (Fellinger et al., 2009; van Splunder et al., 2006). In recent decades, specific services for deaf people with IDD have been developed. The idea for specialised therapeutic communities for individuals with deafness and IDD or multiple disabilities originated in 1991 in an outpatient clinic for deaf individuals in Linz, where direct access to signing professionals for general, mental, and social health was provided. Deaf patients with IDD were mostly admitted after incidents characterised by challenging behaviour. Most of them came from a social environment which was unable to provide accessible visual communication. These observations led to the establishment of a specialised living environment that provides constant accessible communication, mainly in sign language. The first therapeutic living community was established at the heart of a village in Upper Austria in 1999. Since then, three centres (Lebenswelt Schenkenfelden, Lebenswelt Pinsdorf, and Lebenswelt Wallsee) follow the mission of providing a therapeutic environment for deaf individuals with histories of language deprivation to develop their human potential, especially by supporting their communicative skills and their ability to establish social relationships. One therapeutic community includes 12 to 24 residents with deafness and IDD and their respective staff, all of whom are sign language users, and of which 25% are deaf themselves.

Lessons learned from the therapeutic living communities:

- secured communication and unconditional acceptance are key to meaningful relationships and personal development
- person-oriented approach focuses on an individual’s needs and strengths, instead of their weaknesses, enabling personal growth
- inclusion in local communities and social-space orientation allows meeting on eye-level and social participation
- meaningful work provides recognition and social integration

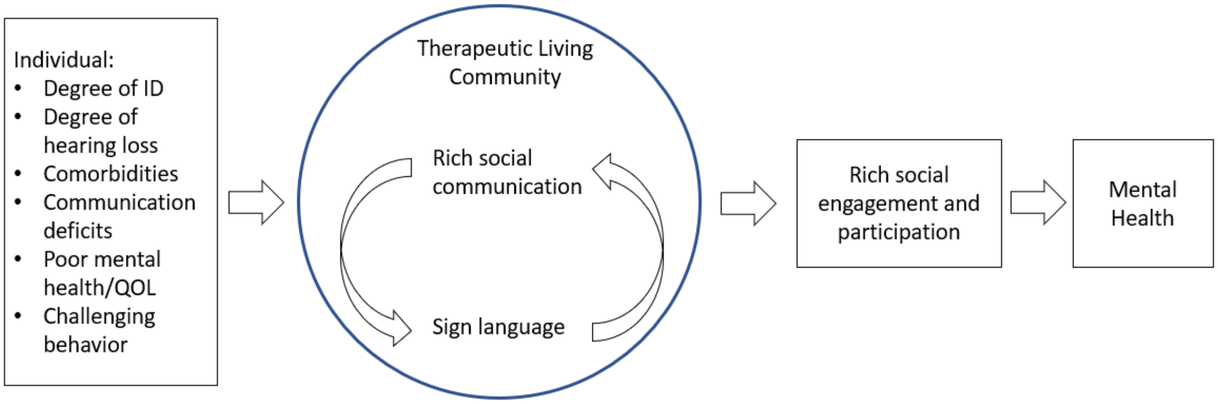

Figure 3. Model of social communication. (Fellinger J., Dall M., & Holzinger D. (2021). Therapeutic Living Communities for Adults who are Deaf and have Intellectual Disabilities: Development of a Conceptual Model Linking Social Communication and Mental Health. *International Journal of Developmental Disabilities*)

C. SETTING PRIORITIES

To deal with the lack of awareness of the mental health situation nd the existing shortage in ental health services for people with IDD in Austria, the following recommendations have veeb derived:
and summarised from the statements of self-advocates, relatives of people with IDD, disability service providers, and mental health professionals working in the field of IDD (Lebenshilfe Österreich, 2021; Weber, 2008, 2018; Zeilinger & Schossleitner, 2019).

C.1 Medical Education in IDD Psychiatry

- Universities, universities of applied sciences, and nursing schools should include inclusive health in their curricula.
- Inclusive medicine and inclusive psychology should be mandatory subjects in corresponding courses of study.

C.2 Clinical Postgraduate Training

- Formal postgraduate training in IDD should be promoted for psychiatrists, primary care physicians, clinical psychologists, and psychotherapists, as well as front-line staff.
- Professional associations should offer training opportunities on mental health in IDD.

C.3 Research and Research Training Opportunities

- An official database on the (mental) health situation of people with IDD in Austria is needed to guarantee effective planning and provision of coordinated and sustainable mental health care for people with IDD.
- More research on the health needs of people with IDD is necessary, especially concerning mental health.
- Inclusive health research should be promoted in Austria. People with IDD need to have the opportunity to contribute to research as co-researchers and experts by experience.

C.4 Collaborations and Partnerships

- The network between existing structures promoting mental health in people with IDD should be strengthened and expanded.
- Regular and coordinated collaboration among support organisations, service providers, national and local authorities, experts, and self-advocates is needed.

D. CONCLUSION

Although Austria is a relatively wealthy country with high living standards, progress on the path to inclusion has been slow. This applies also to the efforts in the field of mental health in IDD. As outlined above, mental health professionals are not properly trained in the mental health needs of people with IDD, and the few dedicated experts and specialised services in the country are not sufficient to meet the demand. The need for change is evident. In addition to incorporating IDD-specific knowledge into the education and training of mental health professionals, a systematic structure of stepwise (mental) health care for people with IDD is needed which includes both general and specialised services. Specialisation and inclusion are not mutually exclusive, but depend on one another to a certain extent, as the examples of the therapeutic living communities for deaf people with IDD and the outpatient clinics for people with IDD or multiple disabilities show. To achieve healthcare at the highest possible level, specialisation is necessary. Therefore, it seems reasonable to expand specialised outpatient clinics like the ones in Linz, Melk, Kainbach and Vienna throughout Austria.

However, the need for change does not only concern the (mental) health sector: Close collaboration between all those active in the field of disability is needed. The health, social and educational sectors need a common exchange platform to allow a cross-sectional perspective on disability support, thus reducing existing structural barriers and the devolution of responsibility. Additionally, people with IDD and their relatives should be more actively involved in decision-making and planning processes on both an individual and a structural level. In this context, one of the tasks of mental health professionals is to reduce the historically based fear of psychiatry and to re-build trust in the psychosocial system with a specific focus on the field of disability. A shoulder-to-shoulder approach between people with IDD, their relatives and professionals is needed to meet at eye-level. Mutual recognition of and respect for all parties involved are necessary to improve the situation of people with IDD in Austria in a sustainable way.

Social inclusion is usually considered to embrace an individual with disabilities into mainstream society. However, this approach still bears the potential risk of not being able to overcome isolation. The experience of the therapeutic living communities shows that the social inclusion of a group of people who are deaf and have IDD in the social environment of a village is possible and works to counteract isolation in society. Accessible communication in a larger social network is key to social inclusion and improves mental health in the long run. The enhancement of social communication should therefore be given increased attention in support structures and in developing the environment of people with disabilities. It is an obligation for all public stakeholders to support people with IDD in realising their human right to communication and to foster an attitude of active and intensive listening to the expressions of people with IDD.

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World Psychiatric Association
Section on Psychiatry of Intellectual Developmental Disorders

GERMANY & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographic data and cultural perceptions of IDD

Demographic data

Germany is a federal, liberal democratic state with a population of approximately 83 million people (2019) and ranks 6th in the world on the "Human Development Index" (prosperity indicator). Germany consists of 16 partially sovereign federal states. The federal states have their own legitimacy, rights and competences, which are based on the state constitution of the respective federal state. In this respect, the implementation of laws enacted by the federal government nationwide may vary to a certain extent from state to state (especially in terms of organization and the interpretation of certain legal details).

Of the approximately 83 million inhabitants in 2019, 7.9 million people officially had the status of a "severe disability." According to SGB IX (Sozialgesetzbuch; social law), the functional and social impact of a disability on participation in society is graded numerically (20 - 100) to determine the degree of disability. In the statistics of the Federal Employment Agency as well as in SGB IX, Part 2 (Severely Disabled Persons Act), a person is considered to have a "severe disability" if they have a degree of disability 50 or more. The type of disability is determined according to the most severe disability. In 2019, 311 027 individuals fell into the category of "intellectual developmental disorders" (IDD; e.g., learning disability, intellectual disability)" (Federal Statistical Office, Statistics on Severely Disabled Persons, Brief Report, 2019). Of these, 47 770 have one or more additional disabilities (15.4%), and 129 379 individuals (41.6%) are considered to have a "congenital" disability. However, only the most severe disability is counted in the official statistics on severe disabilities, and this does not necessarily have to be the cognitive-adaptive impairment in the case of people with IDD. It can also be epilepsy, cerebral palsy or another physical or mental disorder.

As the second or third most severe type of disability, the category "IDD (e.g. learning disability, intellectual disability)" applies to a further 17 306 persons. Thus, a total of 348 333 persons with IDD are recorded in the statistics.

Legal requirements

On March 26, 2009, the Convention on the Rights of Persons with Disabilities (UN CRPD), adopted by the UN General Assembly in New York in 2006, entered into force in Germany. Since then, numerous efforts have been made by legislators to provide a legal basis for the principles laid down in the UN CRPD with the Federal Participation Act ("Bundesteilhabegesetz", FPA) and to establish the idea of inclusion nationwide. This means a paradigm shift from the idea of providing for persons to a benefit legislation.

Cultural perception of people with disabilities in the media

The difficulties in implementing the idea of inclusion can be seen in the current controversial discussion on the draft law for the allocation of scarce medical resources (triage), e.g., in the case of serious Covid 19 infections and limited availability of ventilators. It was only after massive protests by people with disabilities, advocacy groups, disability care providers and various political parties that a public discussion was initiated. In the meantime, the Federal Constitutional Court has clearly pointed out that the protection of people with disabilities must be taken into account in the allocation of intensive care resources and a corresponding legal regulation (Ref.: 1 BvR 1541/20).

This must be of absolute priority in a country where the killing of persons with disabilities was systematically carried out with the Euthanasia Decree of 1939 and the subsequent Aktion T4 (von Cranach, 2018). In 2017, the German Bundestag commemorated the more than 200 000 victims of euthanasia for the first time in a ceremony on January 27, the Day of Remembrance of the Victims of National Socialism. Article 8 of the UN CRPD requires signatory states to raise awareness throughout society of the concerns of people with disabilities.

In film, radio and television, people with disabilities and the topic of inclusion are still underrepresented in Germany. Here, people with IDD are even less present than those with physical or mental disabilities (Frömmer, 2022). With few exceptions, they are primarily assigned the role of the vulnerable victim or the unpredictable evildoer in films.

Despite many efforts in various areas, such as in the form of exhibitions or documentaries, joint community events, neighborhood initiatives and many different regional inclusive projects, the public image of people with disabilities - and especially that of people with IDD - has changed little in recent years.

C.2 Prevalence, identification, and early interventions in the country

Prevalence

Assuming a prevalence of approximately 1% of people with IDD in scientific discourse worldwide, Germany, with its 83 200 000 inhabitants (2019), would therefore have approximately 832 000 people with IDD (Collaborators GBD, 2018). This number is significantly higher than the number of people with IDD in the statistics on severe disabilities (331 027), which would result in a prevalence of only 0.42% for this group of people.

The statistics on severe disabilities are also not very meaningful from the point of view of calculating prevalence, because people with severe IDD make up only a small proportion of people with IDD. Although there are no recent studies on this issue, the literature suggests that two-thirds of people with IDD have only mild cognitive impairments (WHO ICD-11 6A00; Patel et al, 2020). Since mild IDD without pronounced physical or social functional impairment are not legally included in the group of persons with severe disabilities, they appear insufficiently or do not appear at all in the official statistics. If all severe IDD were included, the prevalence would therefore be significantly higher than the statistically recorded 0.42%, but official data on this are lacking.

Despite these limiting factors, the internationally assumed prevalence of 1% may also be too high for highly industrialized countries such as Germany. Accordingly, the Institute for Health Metrics and Evaluation (IHME) also reports the range of prevalence as 0.55-1.4% (Collaborators GBD, 2018; also: Weih et al. 2022; Emerson and Llewellyn, 2021; McConkey, Craig & Kelly, 2019; Patel, Apple, Kanungo, et al., 2018).

Identification

Pediatricians first identify children with IDD. According to the German Medical Association, 14 703 of the total of over 385 000 physicians in Germany worked as specialists in pediatric and adolescent medicine in 2017. Of these, 7 357 worked as outpatient physicians in their own practices or as employees in third-party practices; 6 089 worked as inpatient physicians (clinics, social pediatric centers, etc.; retrieved on May 05, 2022, from https://www.praktischarzt.de/).

Immediately after the childbirth, parents in Germany receive an examination booklet listing the necessary examinations performed in the hospital (maternity clinic) or by pediatricians in private practice. These health checks are intended to contribute to the early detection of developmental disorders and diseases in children. They are financed by the health insurance funds until the child reaches the age of 18. Physical, mental and psychological functions of the children and adolescents are checked. The examinations to be performed are determined by a nationwide committee (Joint Federal Committee). Since 2008 and 2009, these examinations have been mandatory in Bavaria, Baden-Württemberg and Hessen until children reach the age of 6. In the other 13 federal states, there is no obligation to have these examinations performed (Federal Ministry of Health, February 21, 2022).

If a child shows developmental delays in these examinations, parents are instructed to organize further medical diagnostics and therapy for their children and to apply for social assistance from the relevant offices and authorities. The financial aid is a mix of various benefits from different agencies (e.g., youth welfare offices, social welfare agencies, health and long-term care insurance funds, child benefits from family insurance funds, tax relief). The institutions providing care advise parents on which agencies they should contact for their applications.

Early interventions

In addition to financial aid, early intervention is crucial. In early intervention, there is a distinction between general and special support. The former refers to children with IDD, the latter to children with special physical or sensory disabilities such as blindness or hearing impairments. As a rule, however, the assistance consists of a complex of interdisciplinary procedures such as the combination of remedial education, physiotherapy, occupational therapy or speech therapy. These complex services of educational and medical-therapeutic measures are provided in special early intervention centers (interdisciplinary teams with a focus on remedial education; support in the first years of the child's life) and social pediatric centers (SPC: focus is on medical diagnosis and treatment; from infancy to adolescence).

Social Pediatric Centers

The Social Pediatric Centers (SPZ; Z for “Zentrum”) are, according to §119 SGB V (in the 5th Social Security Code in Germany, the rules and regulations concerning the statutory health insurance funds are summarized), an institutional special form of interdisciplinary outpatient medical treatment and are financed accordingly by the health insurance funds. The treatment spectrum includes physical, mental and psychological disorders that can impair further child development. The SPZs differ according to their medical focus (orthopedics, neurology, psychiatry, endocrinology, human genetics, etc.).

However, they all have the following conceptual principles in common:

- Interdisciplinarity
- High proportion of psychotherapeutic / psychosocial and rehabilitation interventions
- Inclusion of the family in the therapy as a conceptual focus
- medical-technical interventions not in the foreground
- Childhood-long care into adolescence
- Combination of clinical pediatrics, pediatric rehabilitation and public health services
- Networking with non-medical services on a large scale, demanding high organizational effort

(Retrieved on September 01 2022 from https://www.dgspj.de/institution/sozialpaediatrische-zentren/)

C.3 Social inclusion status

School education

The right to an inclusive school system derived from Article 24 of the UN CRPD is discussed very controversially by school authorities as well as by teachers and parents in Germany. Critical comments are also being made from the scientific-pedagogical side,

- because the inclusion of people with IDD in mainstream schools was and is insufficiently accompanied by corresponding qualification of teachers or additional specialized staff,

- because the financing of the necessary additional personnel has not been finally clarified in terms of education policy. This is currently being discussed intensively, especially with regard to the group of people with autism spectrum disorders (with and without IDD).

It is feared that these deficits will inevitably lead to a loss of qualified individual support services for people with learning difficulties, such as those offered primarily in special schools. In the medium term, this will result in an underqualification of the group of people with IDD and thus lead to more exclusion instead of inclusion. In 2022, the president of the German Teachers' Association pointed out that there would be a shortage of up to 40,000 teachers in Germany (e.g., ZEIT online, retrieved on September 01 2022 from https://www.zeit.de/gesellschaft/schule/2022-08/lehrermangel-40-000-lehrer-fehlen-deutscher-lehrerverband?utm_referrer=https%3A%2F%2Fwww.bing.com%2F).

In Germany, children with IDD were educated in non-inclusive special education schools for many decades. However, with the ratification of the UN CRPD in 2009, Germany committed to an inclusive school system (Article 24 of the UN CRPD). The number of these special schools has decreased from 3,487 in 2002 to 2,806 in 2022 (retrieved on September 01 2022 from https://de.statista.com/statistik/daten/studie/235854/umfrage/foerderschulen-in-deutschland/).
In the 2018/19 school year, the percentage of students identified as needing additional support in primary and lower secondary education (International Standard Classification of Education, ISCED levels 1 & 2) (includes: Partial performance weaknesses such as dyslexia, dyscalculia and ADHD, language support needs in the case of an immigrant background, IDD), at 7.6% (support rate 2018/19). The proportion of students with special needs who attend a special needs school and are therefore not educated inclusively in primary level I (primarily children with IDD) was 4.4% (exclusion rate 2018/19). The proportion of students with special needs who attend a regular school in primary and lower secondary education was 3.2% (inclusion rate 2018/19).

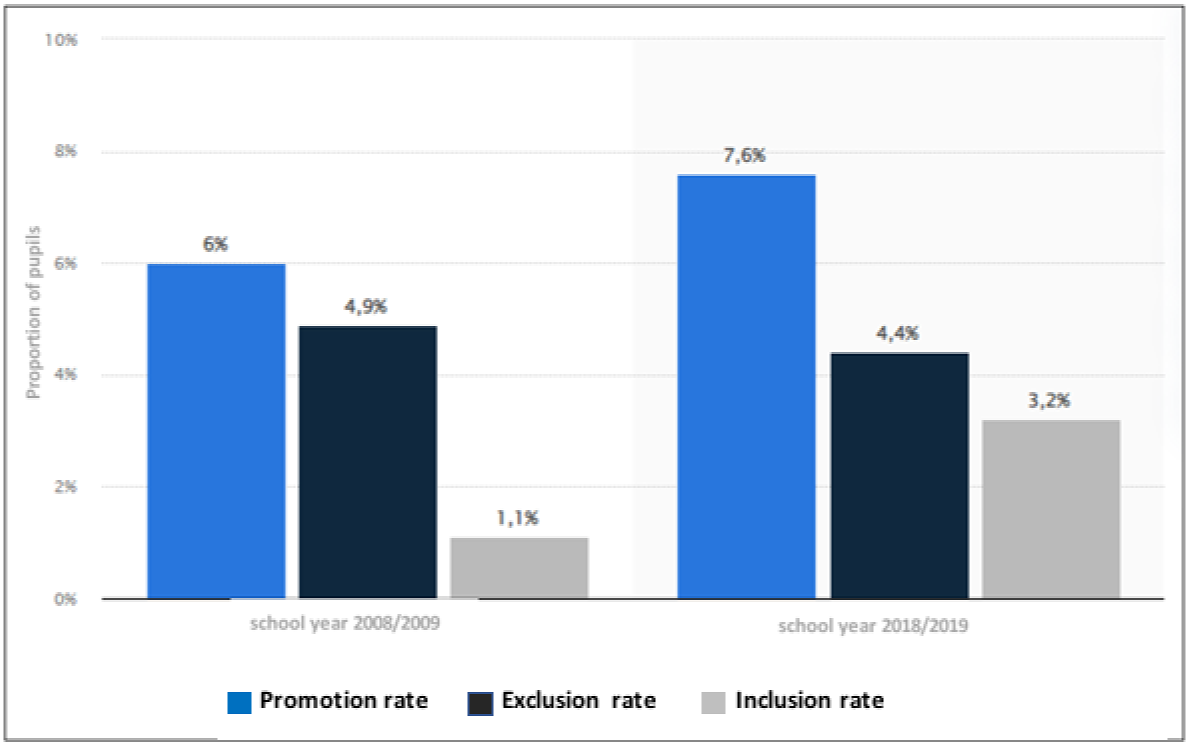

Figure 1. Inclusion at schools: Promotion rates, exclusion rates, and inclusion rates in Germany for the 2008/09 and 2018/19 school years (retrieved on September 01, 2022, from

https://de.statista.com/statistik/daten/studie/235854/umfrage/foerderschulen-in-deutschland/; see explanations in text.

Vocational training

After the 9 compulsory school years (inclusive in the primary grades or in the non-inclusive special education schools), school graduates with IDD in Germany - if they cannot complete regular vocational training - have access to vocational preparation measures. After completing these mostly one-year long state support measures (pre-employment training) the obligatory vocational school obligation is fulfilled, and the transition to a 2-year vocational training area starts. At the end of this period, representatives of the training center and the responsible employment office discuss with the respective person and their legal representatives (parents or legal guardians) if further special vocational training (specialist trainee or specialist craftsman training) or integration into a sheltered workshop should take place.

In response to the UN CRPD, which was ratified by the Federal Republic of Germany on March 26, 2009, vocational training to become a specialist trainee or specialist craftsman was created in various vocational sectors (e.g. services in the social sector, kitchen sector, housekeeping, office communication, industrial mechanics, painting or baking, electrical sector, woodworking). The content of the training is based on recognized training occupations but requires a smaller amount of theoretical knowledge. The training is intended to enable people with IDD to find subsequent employment on the primary labor market. It is legally based on Section 66 of the Vocational Training Act and in Section 42r of the Crafts Code.

In 2021, 6,969 such training contracts were made nationwide. This corresponds to 1.5% of the training contracts made with school graduates in Germany (Federal Institute for Vocational Education and Training: Vocational Training Report 2022).

Labor market

To be able to assess the development of inclusion conditions for people with disabilities (all forms of disability) on the labor market, a statistical value is calculated that indicates the degree of inclusion. In this so-called inclusion barometer, 10 equally weighted factors of labor market development are surveyed annually, and the five-year average is represented in index points. The index point average from 2006-2010 is used as a reference. Values above 100 represent favorable conditions for inclusion compared to the reference years. Values below 100 indicate a negative development.

In 2021, the overall value of the "Inclusion Barometer Labor" was 106.4 index points. This represents a long-term improvement in the situation for people with disabilities on the labor market (compared to the baseline value 2006-2010). However, the best value of 107.7 was achieved in the two previous years (Statista 2022).

Due to the Corona pandemic, the situation for people with disabilities on the labor market has worsened since 2020. The unemployment rate in 2021 is thus at the same level as in 2016 (Inclusion Barometer 2021).

Thus, the progress made since 2016 has been largely reversed by the Corona pandemic and the related labor market crisis. However, the proportion of unemployed people with disabilities, measured as a percentage of the total number of unemployed, rose less sharply than for the non-disabled workforce (Inclusion Barometer 2021).

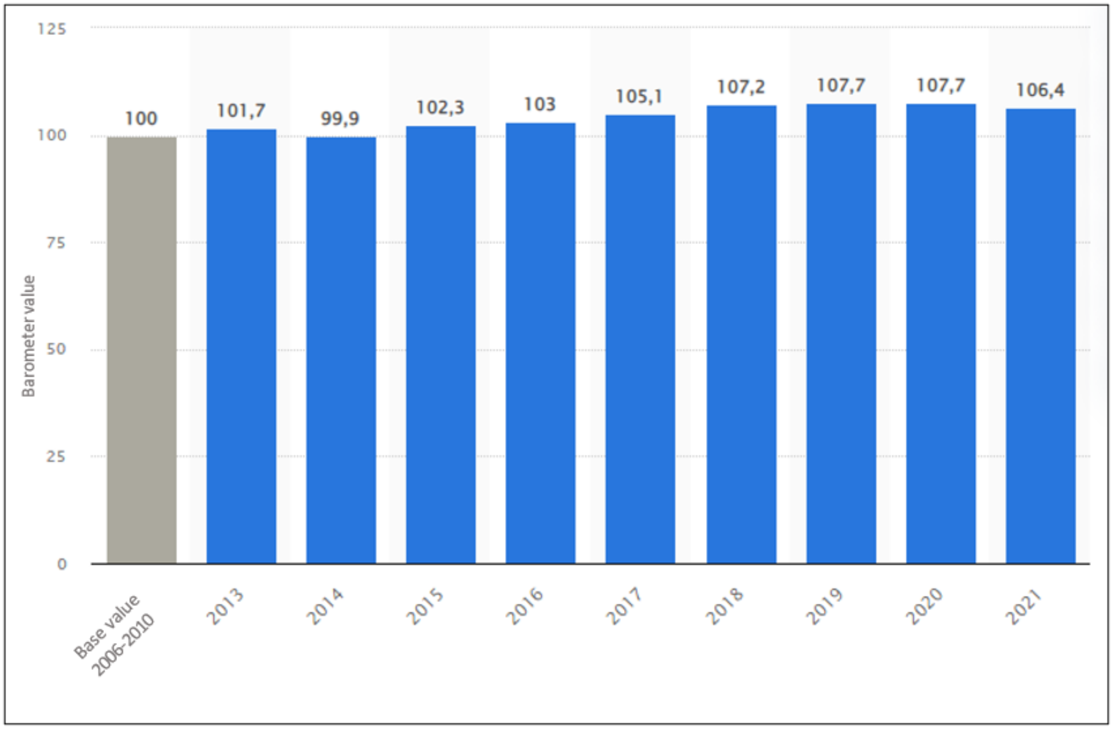

Figure 2. Inclusion barometer of people with disabilities on the labor market in Germany from 2013 to 2021(statista 2022; see explanations in the text).

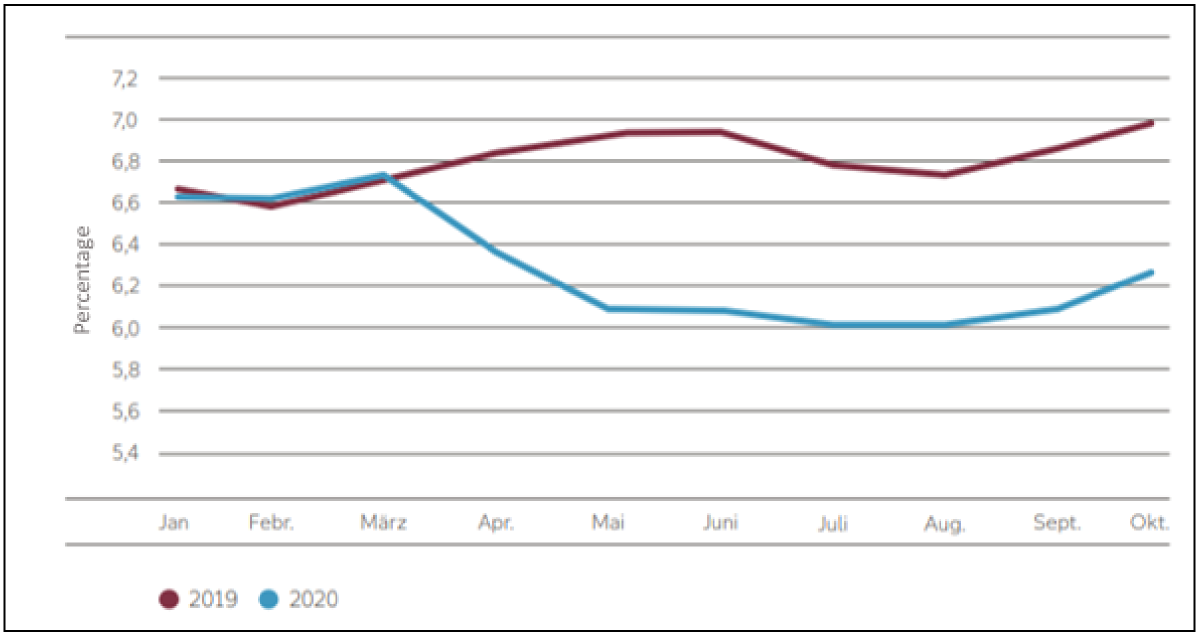

Figure 3. Percentage of unemployed severely disabled persons in all unemployed persons (Inclusion Barometer 2020)

Integration companies, enterprises, departments are part of the first labor market. They pursue the goal of profitability and at the same time employ a large proportion (30% to 50%) of employees with disabilities. Integration enterprises are independent, while integration companies and departments can be part of an organization, public institutions, or a larger company.

In 2020, there were over 1,000 integration companies, integration enterprises and integration departments in Germany. They receive state compensation for the special effort involved in employing a high proportion of people with disabilities. They are paid on a collectively agreed basis or, in the case of permanent employment contracts, at a rate that is customary in the locality (SGB IX (§§ 215 ff).
In addition to regular jobs, some inclusion companies also offer marginal employment opportunities as additional income.

The legal provisions are formulated in such a way that sheltered workshops are to be motivated to build up integration enterprises as a supplement and in this way to advance the integration of people with IDD on the first labor market. There are currently about 90 such integration companies or firms affiliated with the sheltered workshops (retrieved on September 01, 2022, from https://www.werkstaetten-im-netz.de/rubrik.html?&r=2342&rubrik=Integrationsfirmen).

In 2020, a total of just under 27,000 people with severe disability status were employed in inclusion companies. The proportion of people with IDD has fortunately increased continuously by around 16% since 2005. As already stated and commented in the Inclusion Barometer 2015 in a special survey among severely disabled employees, people with IDD have the lowest chances to get a job on the first labor market. Only 1% of respondents reported having an IDD. Thus, the success of inclusion in the German labor market is due to the integration of people with physical disabilities. Inclusion thus depends on the type of disability, and people with IDD are the least considered on the labor market (Inclusion Barometer 2015).

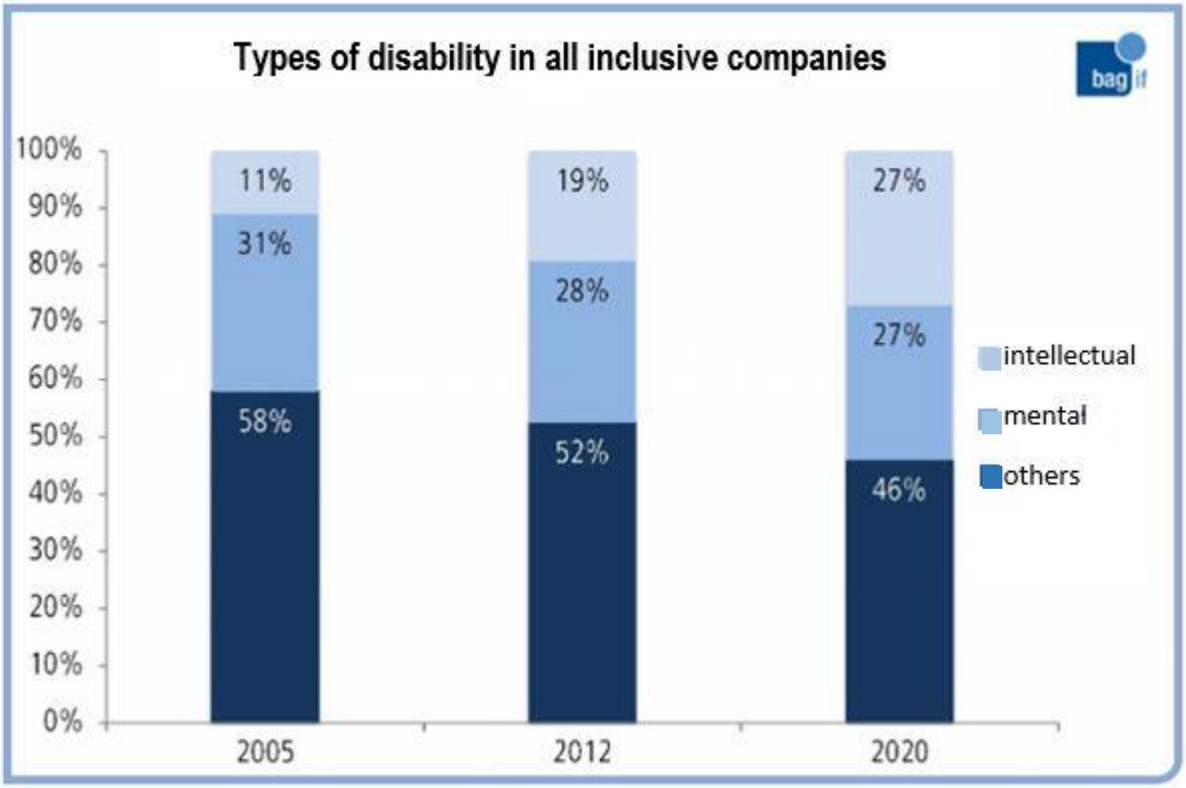

Figure 4. Types of disability in all-inclusive companies (Bundesarbeitsgemeinschaft Inklusionsfirmen 2020).

Sheltered workshops for disabled people

Majority of people with IDD in Germany work in sheltered facilities that have been built up by disability aid providers in recent decades, the so-called "workshops for disabled people" (734 in 2019). They are organized differently in the federal states and include so-called support areas for people with severe IDD or severe forms of multiple disabilities. In these special support areas, the workers are not covered by social insurance, i.e. they do not receive pension payments in old age. Their care is financed for life solely by social welfare. However, this does not put them at a disadvantage compared with workshop visitors who were covered by social insurance. Only employees who live independently in old age and are not cared for in or by institutions for the disabled receive their pensions.

In 2021, the Federal Working Group of workshops for people with disabilities determined that approximately 315,680 people with disabilities were employed at that time. The main group of disabled employees are people with IDD (75%) followed by the group of people with mental disorders (emotional disability) (21%) and people with physical disabilities with (4%).

Federal Working Group of workhops for people with disabilities (17.06.2021)

Type of work	Quantity
Entrance procedure and vocational training	29 315
Working	266 821
Support area without social security	19 544
Total number of employees with disabilities	315 680

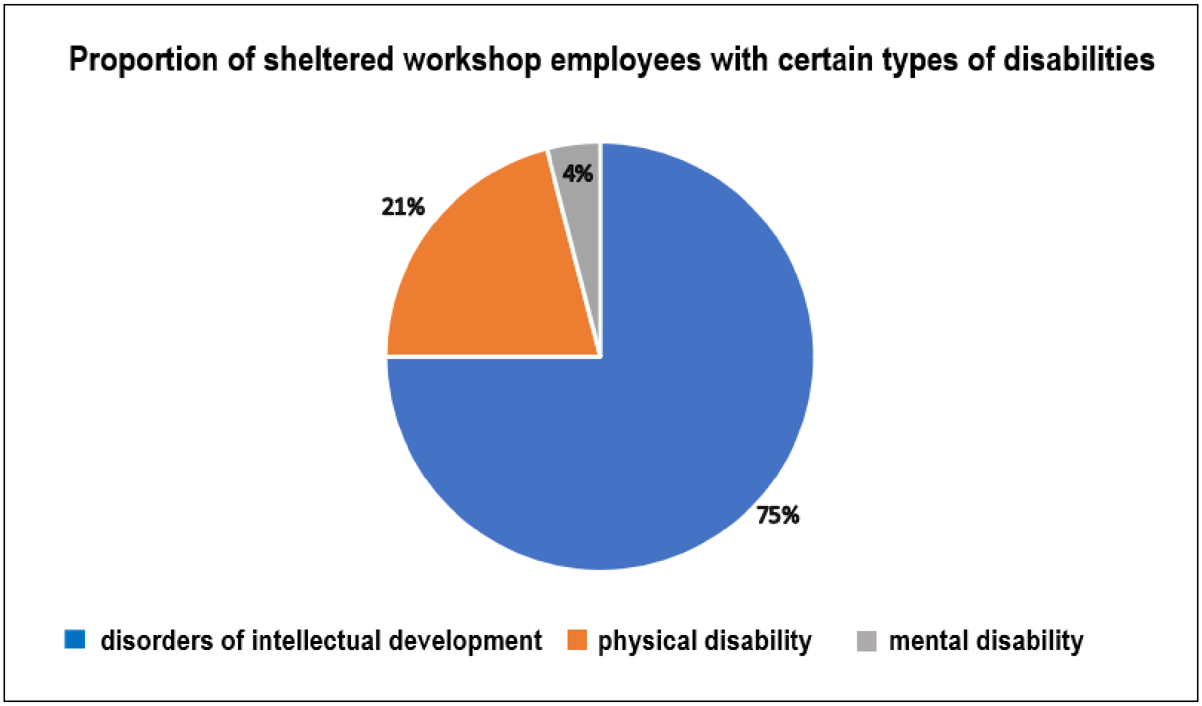

Figure 5. Proportion of sheltered workshop employees with certain types of disabilities as of June 17, 2021 (Bundesarbeitsgemeinschaft der Werkstätten für behinderte Menschen e.V. as of Aug. 31, 2021).

According to § 59 SGB IX, people with disabilities who work in sheltered workshops receive a state work promotion allowance of €52 in addition to their earnings if their earnings do not exceed €351. The average wage in Germany is €211 (including the state employment promotion allowance; see table of the Federal Ministry of Labor and Social Affairs - FMLSA, 2022).

Leisure

Inclusive leisure activities are organized regionally in very different quantity and quality by municipalities or welfare associations or are also offered by private tour operators. People with IDD are hardly considered. For them, small, private tour operators with special offers have developed regionally, but only a small part of them have an inclusive character and orient their offers solely towards the group of people with cognitive-adaptive developmental disorders.

Sport

The German Disabled Sports Association has set itself the goal of using and promoting disabled sports as a means of social integration and rehabilitation. Rehabilitation sport is at the center of these efforts. The offer is aimed especially at people who are at risk of disability, as well as people with health limitations. The target group is mainly people with physical disabilities; people with IDD have hardly been addressed so far.

The organization "Special Olympics Germany" organizes regional and national competitions for people with IDD. However, inclusive participation in sports clubs is still very underdeveloped in Germany. "Special-Olympics-Germany" has therefore launched the project "Wir gehören dazu - Menschen mit geistiger Behinderung im Sportverein" (We belong - people with intellectual disabilities in sports clubs) and is receiving financial support from the proceeds of the "Aktion Mensch" social lottery. The aim is to give around 6,000 people with IDD access to a sports club by 2024. In total, at least 100 sports clubs nationwide are to create inclusive structures through the support of the project coordinators. For 40 project locations, 300 exercise instructors are to be qualified. The project is being evaluated by the "Research Institute for Inclusion through Physical Activity and Sport" at the German Sport University in Cologne.

D. PSYCHOSOCIAL BURDENS AND CURRENT CARE PROVISION

In the MEMENTA (Mental Healthcare Provision for Adults with Intellectual Disability and a Mental Disorder) study published in 2014, 10.8% of people with IDD studied in two representative regions of Germany had a mental disorder and 45.3% showed behavioral problems. International studies estimate approximately 20% of people with IDD and mental disorders and 25% with severe behavioral problems (Sheehan, Hassiotis, Walters, et al, 2015; Platt, Keyes, McLaughlin, et al, 2019).

In the PINO study (Project Intensive Living Network Upper Bavaria) of the Ludwig Maximilian University of Munich, the group of people with IDD and aggressive behavior in Bavaria was examined in more detail. It was found that of the 325 people financed by the funding agency for an intensively supervised residential place (specialized residential offer with smaller group size and higher personnel key) due to their aggressive behavior, 51% had been diagnosed with a mental disorder and 23% showed aggressive behavior only in the context of challenging behavior. A high proportion of transfers to these intensive residential placements were from psychiatric units (Markowetz, Wolf, Lang, et al., 2021).

D.1 Children and adolescents

The professional association for child and adolescent psychiatry, psychosomatics and Psychotherapy in Germany currently states that of approximately 2,200 specialists in child and adolescent psychiatry and psychotherapy, more than half currently provide outpatient care. Children and adolescents with IDD and mental disorders are initially referred to this outpatient medical care system by the treating specialists in pediatrics. To date, there is no special medical qualification in Germany for the diagnosis and therapy of children and adolescents with IDD. Although developmental psychology plays a special role in training, only basic information is taught about IDD.

According to the Federal Working Group for Child and Adolescent Psychiatry and Psychotherapy, a total of approximately 155 clinics were available for inpatient treatment in Germany in 2021 (Federal Working Group for Child and Adolescent Psychiatry and Psychotherapy as of January 2021; retrieved on September 01 2022 from https://www.kinderpsychiater.org/startseite/).

In a survey of hospitals on the quality of psychiatric care for children and adolescents with IDD, 54% rated inpatient services in Germany as poor to insufficient, and 43% rated outpatient care similarly poor (Häßler, Paeckert, & Reis, 2020).

The average proportion of psychiatric inpatient children and adolescents with IDD was 6.6% of admissions, day hospital 7.9%, and outpatient 3%. Due to the lack of specialized diagnostic knowledge, limited experience in the field of therapy and care of young people with IDD in general psychiatric care, specialized services for this group of patients have been established in Germany in recent years. Eight psychiatric clinics for children and adolescents had either specialized outpatient or inpatient services in 2019, and three clinics had both (Häßler, Paeckert, & Reis, 2020).

D.2 Adults

A similar picture emerges for the psychiatric care of adults with IDD and mental disorders. Here, primary care is provided by practicing specialists in psychiatry and psychotherapy or by neurologists, who, however, were not specially qualified in their training and therefore have only limited knowledge regarding people with IDD. In addition, due to the standardized billing requirements of the health insurance companies, they cannot guarantee the increased time required for diagnostics and therapy that is necessary for this group.

The approximately 360 psychiatric clinics and departments at hospitals usually feel overwhelmed by inpatient care and not qualified enough. Thus, already in the 1980s, special areas were established in the hospitals. Currently, there are 27 specialized areas for people with IDD and mental disorders in Germany (own research 2022 based on empirically collected data from 2009). These specialized treatment areas are equipped with an average of 18 beds and admit a total of between 2,500 and 3,500 patients with IDD and mental disorders per year for diagnosis and therapy (own calculation 2022 based on data from 2009). Over the years, this specialization has contributed to an increase in knowledge about mental disorders in people with IDD. However, it has also led to a situation where general psychiatry, where there are specialized areas for this group of patients, hardly deals with this group of people in a specialized way. This indicates that the specialty areas have also not yet succeeded in integrating their knowledge into the medical training areas (medical studies and residency training). Improving the quality of care by considering the special medical and social aspects of disability contributes to improving or maintaining the mental health of people with IDD. In this respect, it has a socially inclusive orientation. But this special knowledge must become an integral part of medical education and training, because otherwise it would be feared that specialization could lead to exclusion from the general medical care system.

After many protests from people with disabilities, associations and from physicians who considered the general medical care for people with disabilities in Germany to be insufficient, the government formulated a mandate to improve medical care for the payers (health insurance companies) in its coalition agreement 2013 - 2017. After a long discussion, the recommendation was made to establish a network of outpatient medical centers for adults with disabilities (MCAD) in accordance with § 119c of the German Social Code, Book V (SGB V). In the meantime, there are more than 50 such centers in Germany, in which - with regionally different specialist focuses - multidisciplinary and multi-professional health advice and treatment is offered for people with etiologically different disabilities. Diagnostics and therapy there require referral by a specialist or family doctor and are financed by the health insurance funds. It can only be used if, due to the severity, type and complexity of the disability or illness, special and individually oriented outpatient treatment is required that cannot be provided within the framework of regular medical care. The groups of people cared for there also include people with IDD and clear mental disorders or other additional physical impairments such as cerebral palsies or epilepsies (Federal Working Group "Medical Centers for Adults with Disabilities” (FWG-MCAD), retrieved on September 01, 2022, from https://bagmzeb.de/). The problem is that in many cases payers only want to finance diagnostics and the provision of therapeutic services, and the actual treatment in the MCADs is not desired.

D.3 Challenges in the implementation of person-centered care

The different ways in which social legislation is implemented in the various federal states and financial compensation payments or financial relief are distributed among various institutions (youth welfare offices, municipal and supra-regional social welfare agencies, tax offices, etc.) make the application process for people with disabilities very difficult and confusing. This "over-bureaucratization" and the multitude and complexity of outpatient and inpatient care offers hinder effective, person-centered assistance. The legislature, in cooperation with associations, interest groups and providers of disability assistance, is attempting to contribute to a more effective design of support for people with disabilities through a gradual differentiation of the Federal Participation Act (FPA). In recent years, for example, inclusion guides have increasingly been established in various areas of life. Depending on the area, they are deployed by various ministries (job guides, for example, by the FMLSA), by municipalities or funding institutions such as “Aktion Mensch”. They are intended to help people with disabilities find their way through the bureaucratic thicket of applying for financial support and choosing the appropriate assistance measures. The FMLSA is implementing this positive development in law with the ordinance on the "continuation of supplementary independent participation counseling" from 2023. 65 million per year will be available for this from 2023 (§32 SGB IX).

E. SETTING PRIORITIES

E.1 Relevance of IDD in medical education

So far, the topic of disability - especially IDD - does not play a special role in medical education. In the coming years, efforts should be made not only to implement the topic of IDD in medical studies, but also to sensitize students to the special psychosocial aspects of the inclusion of people with disabilities as a whole.

Important, initial impulses for the implementation of this special knowledge in medical studies will come from the creation of the first chair "Medicine for people with disabilities, focus: mental health" at the medical faculty of Bielefeld University in 2023.

E.2 Clinical postgraduate training in child/adolescent psychiatry and general psychiatry as well as interdisciplinary training opportunities.

In 2007, the subject of IDD was included in the examination catalog for the specialist in psychiatry and psychotherapy. However, there is no specific additional specialist title with structured qualification for either the pediatric or the adult field.

Since 2008, there has been a curricular advanced training "Medicine for people with mental and multiple disabilities", which is recognized by the German Medical Association. Physicians who wish to work in a

Medical Center for Adults with Disabilities (German: Medizinisches Zentrum für Erwachsene mit Behinderungen; MZEB) are required to participate in this advanced training.

The advanced training includes 100 teaching hours and a 1-week observation in a medical facility for people with IDD (German Medical Association, Working Group of the German Medical Associations, 2020). Mental health plays an important role - in addition to medical factual knowledge. Curricular training specifically on psychiatric diagnosis and therapy for people with IDD does not exist for physicians in Germany.

E.3 Research and training opportunities in research

So far, there is no medical chair for psychiatric diagnostics and therapy for people with IDD and mental disorders. The subject of IDD has so far been represented at universities only in educational departments. The existing medical or psychiatric actors in the field are time-bound by practical care work and have few resources for care research. With the creation of the above-mentioned chair "Medicine for people with disabilities, focus: mental health" at Bielefeld University in 2023, scientific work will be stimulated.

Funding for research projects is possible through various foundations, the German Research Foundation (DRF) and in recent years also through funds from the European research project Horizon 2020. However, the German Federal Ministry of Education and Research has also provided third-party funding, for example, for the MEMENTA research project on the care of people with IDD and mental disorders in Germany. In recent years, the investment fund of the Joint Federal Committee (JFC) has invited tenders for health care research projects aimed at improving health care services for population groups that have been under-served to date.

E.4 Opportunities for action:

As a result of the discursive process of formulating and implementing the Federal Participation Act (FPA), initiatives have emerged throughout Germany and at regional and local level in recent years that are committed to implementing the principles of the UNCRPD. “Aktion Mensch e.V." plays a special role here, supporting inclusion projects nationwide, primarily through the proceeds of a social lottery. It was originally launched by "Zweites Deutsches Fernsehen" (ZDF) and has gained great popularity through its integration in entertainment programs broadcast nationwide. Today, in addition to ZDF, six welfare associations (Arbeiterwohlfahrt, Deutscher Caritasverband, Deutsches Rotes Kreuz, Diakonisches Werk der Evangelischen Kirche, Deutscher Paritätischer Wohlfahrtsverband and Zentralwohlfahrtsstelle der Juden in Deutschland) belong to this association. „Aktion Mensch e.V." not only acts as a financier of inclusive projects, but also initiates practical inclusion actions and research projects itself. It has become a kind of seal of approval that stands for inclusion and equality in society. It combines the smallest and nationwide inclusion projects into one big whole and today it is impossible to imagine social life in Germany without it.

Case study: Project Intensive Living Network Upper Bavaria (PINO)

After it became known that there was a massive shortage of suitable housing for people with SIE and challenging behavior in Upper Bavaria, the Intensive Living Network Upper Bavaria (PINO) project was launched in April 2020. In a joint effort, a research group of the Ludwig-Maximilian-University in Munich (Chair "Pedagogy in Behavioral Disorders and Autism, including Inclusive Pedagogy"), representatives of the institutions of disability assistance and the payers (district of Upper Bavaria) came together for this project. After a Bavaria-wide empirical study of the living situation of people with IDD, who are cared for in intensively supervised residential groups (smaller group size, higher staffing ratio) of the various providers of disability assistance because of their pronounced aggressive behavior, the standards for pedagogically adequate care for this group of people were developed in working groups and expert discussions. The structures of intensive living should represent a sustainable solution that can also be reliably financed by the funding agencies and consider the possibilities of inclusive employment and leisure activities. Care was taken to ensure that the special offers of this form of housing do not become a "care cul-de-sac" but are permeable and can be reacted uncomplicatedly to individual developmental progress with a change in the living environment. To ensure a productive trialogue between the university, the people with disabilities and the funding agency, a network was founded for the Bavarian sub-region of Upper Bavaria, in which providers of intensive living and representatives of pedagogical research can exchange ideas, continuously reflect on their concept and thus provide impulses for further development. The practical pedagogical guidelines derived from this for the 170 intensively supervised residential places in Upper Bavaria (that is 17% of the fully inpatient residential places for people with IDD in Upper Bavaria as a whole) have been accompanied by scientific studies in the past 3 years and will continue to be accompanied by scientific studies in the future in the case of special questions and advised on the basis of the results in an exchange with experts.

This example shows that there is a considerable care problem in the care of people with disorders of intelligence development and aggressive behavior in many regions of Germany and that concepts for action can be developed and implemented from research and care practice.

E.5 Cooperation and partnerships

German Society for Mental Health in People with Intellectual Disabilities (DGMGB). It has been advocating for many years for improvements in health care for people with IDD, especially in mental health.

German Society for Medicine for People with Intellectual or Multiple Disabilities (DGSGB). It is an association of physicians who focus on people with intellectual or multiple disabilities or who are interested in the topic. The DGMGB advocates for the health concerns of people with intellectual or multiple disabilities to improve medical care and to enable them to live in the greatest possible autonomy and dignity.

DACH e.V. (Germany, Austria, Switzerland). The focus of the association is the information, coordination and supplementary organization of German-language further education and training courses on medicine for people with severe developmental disabilities, intelligence impairment or multiple disabilities.

Working Group "Intellectual Disability" Federal Conference of Directors (BDK). Working group of staff of the special departments for people with intellectual disabilities and mental disorders.
https://bdk-deutschland.de/index.php/ak-geistige-behinderung

The Federal Working Group of MZEBs (BAG-MZEB). Aims to promote the development and work of MCADs and to support them in their work.

The Inclusive Health Working Group is a federation of independent professional societies whose purpose is to promote the health of persons with IDD. The overarching goal of IHWG is to improve the mental and physical health of this population through non-binding coordination and alignment of independent professional societies in the areas of health policy, science, and education.

In 2023: Chair "Medicine for people with disabilities, focus: mental health", Medical Faculty of Bielefeld University.

F. CONCLUSION

The introduction of the Federal Participation Act (FPA) has shown how, in the spirit of the UN CRPD, the legislative side can achieve productive cooperation in collaboration with persons with disabilities, their interest groups and the providers of disability assistance. In this respect, inclusion in the future will not only be shaped by the law itself, but hopefully also by this process of designing and implementing the FPA in Germany. In the sense of Article 8 of the UN CRPD, the productive force from this fought-for cooperation must be carried into society to contribute to a change in attitudes toward people with disabilities. The media have an important role to play here: not only must the quantitative presence of people with disabilities increase in film, radio and television, but in the portrayal of their social role and their cultural contribution, the outdated view of charitable care must be overcome; people with disabilities must be acknowledged and portrayed as self-confident actors. In this way, an important contribution is made to changing social attitudes towards people with disabilities.

The establishment of specialized psychiatric departments for people with disorders of intelligence development was an important step toward improving the quality of care. The establishment of the Medical Centers for Adults with Disabilities (MZEB) complements this gained expertise on an overall medical level. In the future, these areas must provide even greater impetus for professional policy, science and treatment practice, working towards the integration of specialized knowledge and practical experience into medical training and thus in turn into general medical treatment practice.

Until now, the still insufficiently networked treatment practice has lacked a complementary, scientific point of reference as orientation. The newly created chair in Bielefeld can become a crystallization point here and research relevant theoretical and practical topics. Finally, both evidence-based findings and practical experience and expert opinions from the specialty areas and the MZEBs should be integrated into medical training in the future.

A country like Germany, in whose history the guilt of the systematic extermination of people with disabilities is written, has a special responsibility for the social treatment of people with disabilities. It must create conditions that guarantee the participation of all people in the life of the community without exceptions. Today's social efforts in Germany must be measured against these goals.

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G. RESOURCES

G.1 Available National and Regional Resources

BAG MZEB e.V.
https://bagmzeb.de/
On this website you will find up-to-date information and the contact details of the responsible persons.

D-A-CH Inklusive Medizin (2022). *D-A-CH Inklusive Medizin*
https://www.d-a-ch-inklusivemedizin.org/
On this website you will find up-to-date information and the contact details of the responsible persons.

German Society for Mental Health in People with Intellectual Disabilities (DGMGB)
https://dgmgb.de/vorstand-und-beirat/
On this website you will find up-to-date information and the contact details of the responsible persons.

German Society for Medicine for People with Intellectual or Multiple Disabilities (DGSGB)
https://www.dgsgb.de
On this website you will find up-to-date information and the contact details of the responsible persons

Arbeitskreis “Geistige Behinderung” Bundesdirektorenkonferenz.
https://www.bdk-deutschland.de/arbeitskreise/ak-geistige-behinderung
On this website you will find a list of all specialist psychiatric outpatient clinics for people with IDD.

Deutsche Interdisziplinäre Gesellschaft zur Förderung für Menschen mit geistiger Behinderung e.V. (DIFGB)
Mail: info@difgb.de
http://dgmgb.de
On this website you will find up-to-date information and the contact details of the responsible persons.

Universität Bielefeld, Prof. Dr. med. Tanja Sappok, Professur „Medizin für Menschen mit Behinderung, Schwerpunkt, psychische Gesundheit"
https://www.mara.de/
From 01.01.2023 you will find further information on this website about the first professorship "Medicine for people with disabilities, focus, mental health" in Germany.

G.2 German textbooks that address the topic of IDD and mental disorders

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SPAIN & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions of IDD

Demographics of IDD in Spain

Spain is a country located in southwestern Europe, and it has been a member state of the European Union (EU) since 1986, following the signing of the Accession Treaty in Madrid. Its population density is 93,76 per km2 (240,86 per sq. mi.), being the fourth most populated country in EU-27 and the second-larger country (505,990 km2 - 195,360 sq. mi.) (Eurostat, 2022).

According to the census data on 1 January 2022, the Spanish population stood at 47.432.805 inhabitants, 24.195.806 (51,01%) females and 23.236.999 (48,99%) males, and the foreign residents accounted for 11,42% of the population (5.417.883 persons) (Instituto Nacional de Estadística, 2022a). Life expectancy at birth in 2020 was 82,4 years; 85,1 years for women and 79,6 for men (Instituto Nacional de Estadística, 2020a). Fertility rate in 2021 was 1,19, with a mean average age of 31,54 years for first-time mothers; and the annual population growth rate in relative terms was 0,07% (Instituto Nacional de Estadística, 2022d). Inhabitants under the age of 20 represent 19,22% (9.116.190 persons) of the total population, while citizens aged 65 and older are 20% (9.527.263 persons) (Instituto Nacional de Estadística, 2022e).

Spain ranks as the world's fifteenth-largest economy by nominal gross domestic product (GDP) and the sixteenth-largest by gross domestic product based on purchasing power parity (GDP-PPP) (International Monetary Fund, 2022). Among high income European countries, it is the fifth-largest economy by nominal GDP (International Monetary Fund, 2022).

Since the 1978 Constitution, parliamentary monarchy is the political form of the Spanish State. The country is divided into 17 autonomous communities and 52 provinces, which have their own political and administrative regulations. This implies that there are considerable differences between regions in terms of the health, social and educational services provided for people with IDD.

Cultural perceptions of IDD in Spain

During the first decade of the 20th century, and under the influence of international advances concerning the care and education of people with IDD, the Spanish Ministry of Public Instruction and Fine Arts created the "*National Council for the Deaf-Mute, Blind and Abnormals*". This council aimed to develop a system of education, social integration, law protection and medical care for people with sensorial and intellectual impairments, but the political instability at the time impeded most of its objectives (del Cura González, 2012). The Civil War in 1936 and the advent of Franco's dictatorship in 1939 led to a long period of rejection and margination towards people with IDD and their families. Most of them were confined to their houses or neglected in long-stay or charitable institutions, as IDD was seen as a punishment or trial sent by God (Del Cura & Martínez-Pérez, 2016).

In the second half of the twentieth century, the first Spanish associations of parents and families of people with IDD were formed to raise public awareness and defend their rights, along with the creation of the Spanish Federation of Societies for the Protection of the People with IDD (FEAPS, now called Plena Inclusión) in 1964. The work of these organisations, the loosening up of the regime in the dictatorship last years, and the growing knowledge about disabilities made possible the creation of care services, and educational and workshop plans for children and adults with physical and intellectual disabilities (Del Cura, 2016).

After the end of the dictatorship, the first inclusion policies in Spain started with the General Law for Persons with Disabilities in 1982 (*Ley 13/1982, de 7 de Abril, de Integración Social de Los Minusválidos.*, 1982), recognising the rights of people with disabilities and establishing the obligation to hire a minimum of 2% of workers with disabilities in companies with more than 50 workers.

Over the past 20 years, there has been a conceptual transition from a service-centred, institutional and paternalistic perspective of IDD towards a person-centred planning, focused on the best practices and supports that a person with disability may need to live in the community (Verdugo Alonso, 2018). However, in Spain there is still a long way to go to reach a full implementation of person-centred planning in practice.

The General Law of Rights of Persons with Disabilities and their Social Inclusion (*Texto Refundido de La Ley General de Derechos de Las Personas Con Discapacidad y de Su Inclusión Social. Boletín Oficial Del Estado*, 2013), which is currently in force, dates from 2013 and has recently been modified (March 2022) (*Ley 6/2022, de 31 de Marzo, de Modificación Del Texto Refundido de La Ley General de Derechos de Las Personas Con Discapacidad y de Su Inclusión Social, Aprobado Por El Real Decreto Legislativo 1/2013, de 29 de Noviembre, Para Establecer y Regular La Accesibilidad Cognitiva y Sus Condiciones de Exigencia y Aplicación.*, 2022) to establish and regulate cognitive accessibility for people with IDD and ensure their access to information. Also, the Spanish Strategy on Disability 2022-2030 (*Estrategia Española Sobre Discapacidad 2022 – 2030 Para el Acceso, Goce y Disfrute de los Derechos Humanos de las Personas con Discapacidad*, 2022) has recently been approved by the Spanish Council of Ministers (May 2022), in line with the current EU disability agenda, the International Convention on the Rights of Persons with Disabilities, and the United Nations (UN) 2030 Agenda for Sustainable Development. This strategy is a roadmap and a framework laying down the principles to make effective the human rights of persons with disabilities and their families through Spanish administrations and public powers.

A.2 Prevalence, identification, and early interventions in the country

According to the latest available Spanish Government official statistics, in 2020 the IDD rate was 16,16 per thousand inhabitants aged 6 or older, and 9,82 per thousand children aged between 2 and 5 years (Instituto Nacional de Estadística, 2022c). In percentage terms, approximately 1,30% percent of the Spanish Population had IDD. If the general population census enumerated 47.398.695 persons in 2020 (Instituto Nacional de Estadística, 2021), this means that around 615.709 people had IDD in Spain.

In terms of IDD gender distribution, 14,66 per thousand inhabitants aged 6 or older were men and 17,59 were women, whereas among children aged 2-6, 12,44 per thousand were boys and 7,05 were girls (Instituto Nacional de Estadística, 2022c). Taking into account all age groups, the gender distribution was 1,35% for males and 1,23% for females.

In Spain, early identification of IDD is carried out during pregnancy, right after birth and by public primary paediatricians during the infancy, which are also responsible for referral and coordination with early intervention centres, known as *"Centros de Desarrollo Infantil y Atención Temprana"* (CDIAT). These are multidisciplinary centres that provide early care for children aged 0 to 6 years with developmental disorders.

The Spanish Strategy on Disability 2022-2030 (*Estrategia Española Sobre Discapacidad 2022 – 2030*, 2022) recognizes early care as a subjective right and plans to guarantee equal access for all children, aiming to include these services in the common portfolio of public health and social services. Currently, there is no state legislation in Spain to guarantee equal access to early intervention, so access to CDIAT has long waiting lists and its provision depends on each autonomous community, as most of them are state-subsidised private centres. According to data from the Spanish Federation of Early Intervention

Professionals Associations (GAT) (Peña, 2021), Catalonia cares for 100% of children with early care needs, while other regions such as the Valencian Community, Madrid Community, Galicia, or the Basque Country do not reach 20% of children with those needs. In the Canary Islands, early attention was only formally organised in 2019, opening the first two early care centres in 2020. Furthermore, although early care is intended for children with developmental disorders until the age of 6, there is a general tendency to withdraw these services when Spanish children start primary schooling at ages 3-4 (Cabrerizo De Diago et al., 2011). Thus, there is a huge disparity between autonomous communities in public places available, access requirements, number of professionals involved and hierarchical organisation.

A.3 Status of social inclusion

Access and inclusion in public education and vocational training

At present, there are four types of schooling possibilities for children with IDD in Spain: Inclusion in an ordinary classroom at ordinary schools with educational supports, schooling in a special classroom at ordinary schools, combined schooling (alternating attendance to both ordinary school and special education centre), and schooling in a special education school in which all students have special educational needs.

According to the data of the Spanish Ministry of Education and Vocational Training (EDUCAbase & Ministerio de Educación y Formación Profesional, 2022), during the 2020-2021 school year, there were 227.979 Spanish students with special educational needs (30,10% women), of whom 62.467 (27,40%) had IDD (41,2% women), 60.198 (26,40%) pervasive developmental disorders (16,30% women), and 56.032 (24,60%) severe behavioural/personality disorders (23,10% women).

Most of the students with IDD (75,30%) attended ordinary schools (47.030 students, 41,40% women); just as those with pervasive developmental disorders (83,30%, 15,50% women) and those with severe behavioural/personality disorders (98,40%, 23% women). Percentages of students with special educational needs integrated in ordinary schools are presented in table 1.

Table 1. Percentages of students with special educational needs integrated in ordinary schools by autonomous community and type of disability during school year 2020-2021.

Region	IDD	Pervasive Developmental Disorders	Severe Behavioural/ Personality Disorders
TOTAL	75,3	83,3	98,4
Andalusia	75,2	77,2	99,1
Aragon	74,8	84,5	85,6
Asturias	86,2	90,3	98,4
Balearic Islands	83,5	83,4	95,7
Canary Islands	58,9	75,4	99,5
Cantabria	65,6	80,1	96,7

Castile and León	78,9	83,6	99,9
Castilla-La Mancha	83,4	85,7	96
Catalonia	76,9	86,1	93,9
Valencian Community	30,9	77,4	63,2
Extremadura	77,3	75,9	94,7
Galicia	82,4	90,7	99,2
Madrid	69,6	84,4	98,2
Murcia, Region of	88,8	88	90,6
Navarre	67,8	80,4	99,9
Basque Country	73,9	87,4	98,3
Rioja, La	92,4	82,9	82,1
Ceuta	94,5	84	73,6
Melilla	88,3	85,5	100

In relative terms, students with special educational needs represent 2,80% of the total number of students enrolled in the Spanish educational system during the scholar course 2020-2021. Regarding those integrated in ordinary schools, the rate is 2,40%. By educational level, students with special educational needs represent 2,90% of the total students enrolled in Primary education, 3% in Secondary education (E.S.O.) and 6,80% in Basic vocational training. The number of students with special educational needs in Baccalaureate or Advanced vocational education represent a small proportion of the total secondary school population (0,9% and 0,7%, respectively). The following table presents the number of students with special educational needs by Education level and type of disability.

Table 2. Students with special educational needs by Education level and type of disability during school year 2020/2021

Education level	**IDD**	**Pervasive Developmental Disorders**	**Severe Behavioural/ Personality Disorders**
Special Education	15437	10059	914
Pre-school Education	2251	9494	741
▪ First cycle	168	733	65
▪ Second cycle	2083	8761	676
Primary School	20967	23016	21903
▪ 1st year	2163	3743	1189

▪ 2nd year	2827	3774	2303
▪ 3rd year	3216	3884	3246
▪ 4th year	3592	3784	4361
▪ 5th year	3935	3824	5057
▪ 6th year	5234	4007	5747
Secondary School (E.S.O.)	15522	13533	22836
▪ 1st year	4805	3992	6267
▪ 2nd year	4934	3363	6582
▪ 3rd year	3369	3314	5377
▪ 4th year	2414	2864	4610
Baccalaureate	176	1517	2474
Basic Vocational Training	2120	364	2257
Middle Grade Vocational Training	1874	1243	3408
Advanced Vocational Education	293	514	1189
Other training programmes	389	30	108
Other Special Education training programmes	3438	428	202

Regarding ownership/financing, public centres and state-funded private centres showed a similar percentage of students with special educational needs in the course 2020-2021 (3% and 2,90%, respectively), while only 0,70% of students were enrolled in non-subsidised private education.

The recent Organic Law 3/2020, 29 December (*Ley Orgánica 3/2020, de 29 de Diciembre, por la que se modifica la Ley Orgánica 2/2006, de 3 de Mayo, de Educación.*, 2020), popularly known as LOMLOE, puts in place a reform of the Spanish Educational System. The law aims to ensure equal educational opportunities for all students, including those with special educational needs. More specifically, supplementary provision four of the LOMLOE allows a period of ten years for ordinary centres to put in place the necessary resources to be able to meet the needs of students with disabilities in the best conditions, in accordance with Article o 24.2.e) of the United Nations Convention on the Rights of Persons with Disabilities and the fourth objective of the 2030 Agenda for Sustainable Development. However, the Law has been criticised because of the lack of human and financial resources to plan and implement the envisaged measures (Esteban Bara & Gil Cantero, 2022; Plena Inclusión, 2022).

Access to employment

In Spain, there are different policies to promote the employment of people with disabilities (Ministerio de Derechos Sociales y Agenda 2030, 2022), aimed at facilitating their incorporation into both regular and sheltered employment. There are also other measures, such as occupational centres, more oriented to care, assessment, and occupational therapy.

Some of the targeted policies for regular employment are job reservation quotas for persons with disabilities, establishing that at least 2% of the workforce of private companies with more than 50 employees must be made up of persons with disabilities. For all Public Administrations, the reservation quota for workers with disabilities is 7%. Other hiring incentives focus on contract subsidies, bonuses and exemptions in Social Security contributions, tax deductions and subsidies for the adaptation of jobs. There are also other measures targeting promotion of self-employment through financing of business projects, associated work cooperatives or labour companies. The legislation also addresses individualised guidance and support provided by specialised job coaches, for workers with disabilities and special difficulties in finding a job on the ordinary employment market.

Besides the above-mentioned measures for accessing the ordinary labour market, there is a system of sheltered employment, organised through public and private Special Employment Centres, and designed for persons with disability who can carry out a work activity but not in the ordinary market.

According to Spanish National Statistical Institute data of 2020, 34,3% of Spanish people aged 16 to 64 with an officially recognized disability (includes mental, intellectual, sensory, or physical impairments) were active (labour force) (Instituto Nacional de Estadística, 2020b). Compared to that of the population without disabilities (76,1%), this activity rate was 41,8 points lower. The employment rate for people with an officially recognised disability was 26,7% (64,3% for people without disabilities). These rates for people with intellectual disabilities were 28,3% and 17,6%, respectively.

The latest available data on wages and salaries in Spain indicates that the average gross annual salary of employed workers with disabilities was 20.574,1 euros in 2019 (Instituto Nacional de Estadística, 2019). This figure was 16,1% lower than that of people without disabilities (24.512,2 euros). The same figure for people with IDD was 13.136,9 euros, a rate 36,1% lower than that of the workers with disabilities, and 46,4% lower than that of those without disabilities. Salaries were on average 19,2% lower for women with IDD than for men with IDD.

Regarding measures to promote employment for persons with disabilities, 25% of employed persons with disabilities received some kind of reduction or bonus in quotes to the Social Security System. More specifically, this rate was 39,2% for people with IDD. The National Statistical Institute reports that these measures to promote employment have primarily benefited men aged 16 to 44 years, with intellectual or sensory impairment, and people with a degree of disability greater than 75% (Instituto Nacional de Estadística, 2022b).

In 2020, 1.601.500 persons had an official disability certificate of a degree greater than or equal to 33% in Spain, of whom 54,5% were men and 45,5% were women (Instituto Nacional de Estadística, 2022b). Of them, 12,5% had IDD (200.000 persons), of whom 57,7% were men and 42,3% were women. The table below illustrates data for the year 2020 of people with IDD that had an official disability certificate:

Table 3. People with IDD and an official disability certificate of a degree greater than or equal to 33%, by sex and age group during 2020 in Spain.

People with IDD and official disability	**Total**	**Percentage over the total number of**	**Men**	**Women**

certificate		disability certificates		
Total	200.000,0	12,5%	57,7%	42,3%
Ages 16 to 24	41.000,0	2,6%	58,8%	41,5%
Ages 25 to 44	87.500,0	5,5%	58,2%	41,8%
Ages 45 to 64	71.400,0	4,5%	56,6%	43,6%

Access and inclusion in recreational and community life opportunities

Over the last two decades, the concepts of self-determination, participation and quality of life have acquired significant relevance for people with IDD in Spain. There has been a positive development towards social inclusion of people with IDD, thanks in large part to the efforts of the network of civil society associations drawing attention to their rights. Thus, while there has been significant progress in accessibility conditions, community resources, leisure services, and social attitudes towards people with IDD, participation in normalised leisure activities in the community continues to be a pending issue. The availability of leisure opportunities for people with IDD in Spain is generally segregated from that of the general population, taking place in specific environments for people with IDD such as occupational centres, schools, day-care services, etc. (Guirao & Vega, 2016; Madariaga Ortuzar, 2011).

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

In recent years, two epidemiological studies have been carried out in Spain to study the prevalence of mental disorders in adults with IDD. The first was a nationwide study (POMONA-ESP) with a representative, randomised, and stratified sample of 953 Spanish participants with different severity levels of IDD (Folch et al., 2019). The second study was carried out by *Plena Inclusión* and the Autonomous Community of Castilla and León (Morentin et al., 2021). Both studies concluded that the percentage of people with IDD suffering from mental health problems would be around 34%, so at least 209.341 people with IDD in Spain have mental health problems.

According to data from the POMONA-ESP study, 33,40% of people with IDD in Spain have a formal diagnosis of mental disorders, being the most frequent psychotic disorders, followed by affective disorders. A large proportion of the Pomona-ESP participants (70.8%) were taking two or more daily drugs, and the study concluded that there was a significant risk of over-medication in this population, with psychotropic medication being frequently prescribed as a measure of behavioural control without explicit clinical indication or monitoring (Folch et al., 2019). The study of (Morentin et al., 2021) reported also that almost 95% of their sample of people with IDD were taking psychotropic medication, and the most frequently prescribed medications were antipsychotics (71,12%), anxiolytics (48,75%) and antidepressants (35,82%).

In 2007, a previous study from *Plena Inclusión* (Salvador-Carulla et al., 2007) conservatively estimated that to care for people with IDD and specialised mental health care needs in Spain it would be needed, at least:

- 5 Comprehensive evaluation and treatment centres.
- 22 Medium-term residences
- 55 Specialised community mental health centres.
- Community residences for stable cases and family respite care.

- 67 psychiatrists and 67 psychologists specialised in IDD and mental health to cover basic outpatient and hospital services in Spain.

Nevertheless, the last Mental Health Plan 2022-2026 (Suárez Alonso, 2022) of the Spanish National Health System not only does not contemplate specific objectives or strategies oriented towards people with IDD, but the concept itself receives not a single mention throughout the entire document.

At present, there is no territorial equity in the access to public mental health services in Spain for people with IDD, as the management of health services is decentralised, and each autonomous region has their own regional health system. Thus, in some regions such Asturias, Basque Country, Castile and León, Region of Murcia, Valencian Community, and Ceuta and Melilla, there is no public specialised mental health care services for people with IDD, nor IDD is mentioned in their last regional mental health plans. In these regions, mental health care for people with IDD is provided by general mental health services. By contrast, specific measures towards the mental health attention for people with IDD appear integrated in the most recent general mental health plans of Andalusia, Aragón, Balearic Islands, Canary Islands, Galicia, and La Rioja. Other Spanish regions are in the process of developing specialised mental health services for people with IDD, such as Cantabria, Castilla-La Mancha, and Navarre; while in Madrid there is a specialised mental health service for people with IDD since 2008, and Extremadura launched a mental care unit for people with IDD and severe behavioural disorders in 2013. Catalonia was the first and only region to implement a comprehensive network of specialised mental health care, providing inpatient and outpatient IDD services since the early 2000s. This specialised mental health network for people with IDD includes 10 "Specialised community mental health centres: SESM-DI" distributed across the Catalan territory and 62 short-term acute inpatient places (UHE-DI).

These marked differences that may be observed between regions highlight the need to improve access to equal mental care for the citizens with IDD in Spain. Greater involvement is needed from the different Autonomous Communities and the Spanish Government Ministry of Health to implement and improve the socio-health care of people with IDD and mental health problems or behavioural disorders. It is also necessary to include IDD in all future regional or national Mental Health Plans.

B.1 Children and adolescents

In Spain, there are no specific mental health community services for children with IDD. Regions with specialised mental health services for IDD provide attention to children, adolescents, and adults. In those regions without specialised IDD services, children with IDD and mental health problems are attended in general mental health care services for children and adolescents. In some cases, children are treated in early intervention centres, but once they reach the age of 4-5 years, they are referred to the aforementioned services.

B.2 Challenges in implementing person-centred care

The current Spanish model of mental healthcare for IDD is highly uneven among regions and depends excessively on private institutional residential services. As the last report of the Catalan Federation of People with IDD (DINCAT) notes (Fitó i Frutos & Rovira i Martínez, 2022), people with IDD and mental health problems who live in community settings and use community resources have a better quality of life and a more active participation in public life. It is necessary to improve and strengthen the implementation of the person-centred planning for ensuring the protection and respect of the rights of citizens with IDD. This will require a reorganisation of the current social services portfolio towards a community person-centred model, along with the implementation and equalisation of public specialised mental health services for all Spanish regions. A strong level of coordination between professionals, services and regions will be also necessary, as well as the provision of the professional high-level training required for the implementation of these measures.

B.3 Opportunities for Action: Connecting families, developing programs, ensuring sustainability

The change towards a person-centred model provides increased opportunities for action for all the implied agents. Now, there is a favourable socio-economic context to address this challenge, since the COVID pandemic had long-term mental health implications, and Spanish regional and national administrations have committed themselves to make greater investments in mental health resources. This presents a major opportunity to compensate unequal access to IDD specialised mental health resources between regions, also taking into account that the experience of Catalonia could become a model which other Spanish regions can follow to develop their specialised mental care network.

A key contributor in tackling all facets of this problem will be *Plena Inclusión*, the Spanish confederation of associations for people with IDD and their relatives. They advocate for the rights and needs of people with IDD, as well as their inclusion in Spanish society. They also work against discrimination and overreliance on institutionalization, coordinating and promoting the implementation of measures and codes of good practices at national level, while working closely together with other European and international confederations.

C. SETTING PRIORITIES

C.1 Medical education in IDD psychiatry, Clinical postgraduate training in IDD child/adolescent and general psychiatry, and interdisciplinary training opportunities

As in the rest of Europe, in Spain the opportunities for IDD specialised training in health sciences are limited (Salvador-Carulla et al., 2015). Moreover, unlike other countries, such as the United Kingdom, in Spain there is no formal Psychiatry specialty certification in IDD. Some universities, however, offer Postgraduate and Master's non-clinical programs, for example, the Master's Degree in Comprehensive Care for People with Intellectual Disabilities (Universidad Católica de Valencia); Master's Degree in Special Educational Needs and Early Attention (Universidad Internacional de Valencia); Master's Degree in Autism Spectrum Disorder and Intellectual Disability (Universidad de Oviedo), Master's Degree in Integration of People With Disabilities (Universidad de Salamanca); Postgraduate Course in Mental Illness and Behavioural Alterations in People with Intellectual Disabilities (Universitat de Vic); and the Expert Course in Intellectual Disability and Special Education (Universitat de Barcelona).

More recently, on August 4, 2021, a new title of Specialised Physician in Child and Adolescent Psychiatry has been created, modifying some aspects of the psychiatry training. These new specialists will be competent for the promotion of mental health, diagnosis, prognosis, treatment, and rehabilitation of children's mental disorders, including IDD.

C.2 Research and research training opportunities

At present, there are various active research groups such as the Intellectual Disability and Developmental Disorders Research Unit (UNIVIDD - Fundació Villablanca) in Reus; the Germanes Hospitalàries Research Foundation (FIDMAG) in Barcelona; the Institut d'Assistència Sanitària (IAS) through the Biomedical Research Institute (IdIBGi), and the Research Support Unit (USR) in Girona; the Parc Sanitari Sant Joan de Déu in Barcelona; the LabDincat, a recently created intellectual disability research and knowledge laboratory in Catalonia; the University Institute of Integration in the Community (INICO - Universidad de Salamanca); or the Research Group to Improve the Quality of Life of People with Intellectual Disabilities

(GIPDI - Universidad Autónoma de Madrid). There is also the Spanish Centre for Documentation and Research on Disability (CEDID), a technical advisory centre of the Royal Board of Trustees on Disability; and Siglo Cero, a specialised scientific journal on IDD edited by Plena Inclusión that includes an Easy-to-Read version.

C.3 Collaborations and partnerships (include national, regional, and global networks as relevant)

The main national scientific research centres mentioned above have some well-established collaborations and partnerships at the national and international level. They participate in activities sponsored by international platforms and take part in various European research projects. For example, over the last years, they have maintained steady contact and co-ordination with international organisations such as the World Health Organization (WHO), or the World Psychiatric Association (WPA). It is also noteworthy the important work carried out by the Borderline Intellectual Functioning Consensus Group, an international group of experts created in Spain, that aims to promote worldwide awareness of borderline intellectual functioning as a health meta-condition. The group includes members of the World Psychiatric Association Scientific Section on ID/IDD, and members of the Fogarty/NIMH NCD-LIFESPAN Program.

There are also firmly established national networks and partnerships with civil organisations such as Plena inclusion, as well as with scientific institutions such as CIBERSAM. This Network Centre for Biomedical Research in Mental Health fosters leading-edge collaborative translational research in mental health, and currently comprises 24 research groups from public and private hospitals, universities, and public research bodies.

F. CONCLUSION

Having in mind that at least 209.341 people with IDD in Spain have mental health problems, it is urgent to move towards a more comprehensive mental healthcare model, ensuring equal access and availability of public services for all for people with IDD in all the Spanish Regions. It will be also necessary to broaden the opportunities for IDD specialised training in health sciences. To this end, the first step will be to promote transversal policies according to the principles of the Convention on the rights of people with disabilities.

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G. LINK TO AVAILABLE NATIONAL/REGIONAL RESOURCES

Plena Inclusión España. Confederation of Associations for People with Intellectual Disability: www.plenainclusion.org

Ministerio de Derechos Sociales y Agenda 2030. Información sobre Discapacidad. www.mdsocialesa2030.gob.es/derechos-sociales/discapacidad/informacion/index.htm

CERMI. Comité Español de Representantes de Personas con Discapacidad. www.cermi.es

Servicio de Información sobre discapacidad. www.sid-inico.es

Real Patronato sobre discapacidad: https://www.rpdiscapacidad.gob.es/

Oficina de Atención a la Discapacidad: https://oadis.mdsocialesa2030.gob.es/

Centro Español de Documentación e Investigación sobre Discapacidad (CEDID): https://www.cedid.es/

Confederación Salud Mental España: https://consaludmental.org/

World Psychiatric Association
Section on Psychiatry of Intellectual Developmental Disorders

UNITED KINGDOM & INTELLECTUAL DEVELOPMENENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions of IDD

Cultural perceptions of IDD have evolved over time in the United Kingdom (UK), reflecting changing attitudes towards people with IDD, de-stigmatization, and normalisation, recognising neurodiversity, development of service provisions for health and social care respecting individual needs and appropriate care planning. Legislative changes (Disability discrimination Act, 1995; Equality Act, 2010) in the UK have also tried to keep pace with ensuring reasonable adjustments are made for people with IDD. Regarding health care provisions the Mental Capacity Act, 2005 and Mental Health Act 1983 (as amended, 2007) have also helped in ensuring rights of people with IDD, regarding their assessment and treatment of health conditions are respected.

In the later part of the nineteenth century, most people with IDD (children and adults) were cared for in long stay institutions ranging from workhouses, asylums, and prisons.

Between 1880 and 1910, in each local authority area (county) barring a few, an asylum was built or repurposed from existing buildings with grounds, for people in society classed to have mental deficiency, mental handicap or learning disability, depending on the term in vogue at the time to describe IDD, which was often a broad definition and included people who broke societal norms (for example unwed mothers, a destitute person stealing a loaf of bread because they were very hungry and did not have the means to pay for it). Rehabilitation of people with IDD and training them to develop some skills would have been the aim and thought to be progressive and humane at the time. However, inadvertently this led to life-long segregation from society, thereby socially isolating people with IDD from the wider society in England. Asylums were re-designated as hospitals in 1948, when the National Health Service came into being due to the efforts of Aneurin Bevin and previously Lionel Penrose.

Legislation for compulsory detention to hospital for mental sub-normality was enshrined in the Mental Health Act, 1959. Until the 1970s hospital numbers increased considerably with people with IDD becoming institutionalized. The Department of Health and Social Security (DHSS) carried out major enquiries at Ely hospital in 1969 and Farleigh hospital in 1971, revealing institutionalised practices, abuse and dehumanising individuals (Morris, 1969), as also overcrowding and chronic under staffing.

These led to large scale closure of hospitals and deinstitutionalization with people with IDD moving to the community started in the 1980s. Influences from Scandinavia including normalization and social role valorisation influenced the ethos of care in the UK.
Access to mainstream services for both primary care and secondary care for people with IDD, gradually became the norm with reasonable adjustments from the 1990s and well into the 21st century.

A.2 Pevalence, identification, and early interventions in the country

Prevalence

The prevalence of intellectual developmental disorder (IDD) also known as learning disability or intellectual disability in the United Kingdom (UK) is about 2.16% (1.5 million people). Approximately 2.5% of children in the UK are believed to have learning disability.

Of the nearly 1.2 million adults with IDD living in the UK comprised of four nations, the prevalence of people with IDD living in England is 956,000, Wales 54,000, Scotland 145,000 and Northern Ireland 31,000. (Office for National Statistics, 2020; Public Health England, 2015).

Identification

Assessment for intellectual disability in each of the jurisdictions, would normally include assessment to identify whether a person has (i) significant impairment of intellectual functioning (Intelligence Quotient (IQ) < 70), (ii) significant impairment of adaptive behaviour and social functioning and evidence that both impairments started before adulthood (before the age of 18 years). In the UK, guidelines (Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood, 2015), recommend the *Wechsler Adult Intelligence Scale – fourth UK Edition (WAIS-IV UK),* for assessment of IQ, meeting these four criteria: (i) designed for individual (not group) administration; (ii) constructed on the basis of the normal distribution of general intelligence, and standardised using a representative sample of adults from across the UK; acceptable reliability and validity and (iv) based on a multidimensional, hierarchical model of intelligence, the breakdown showing both composite/relative index scores (Verbal Comprehension, Perceptual Reasoning, Working Memory and Processing Speed) and overall scores (Full scale IQ).

For assessment of adaptive functioning using the *Adaptive Behaviour System, Third edition ABAS-3* (Harrison & Oakland, 2015) or *Vineland Adaptive Behaviour Scales, Second Edition (Vineland-II),* (Sparrow, Cicchetti & Balla, 2005), are commonly used in the UK.

The UK is a multi-cultural society and hence "assessment of IDD in people whose first language is not English, or come from a different cultural background, pose challenges due to non-standardization of tests, possible cultural bias, issues with rapport building, relaying specific instructions for tests despite use of interpreters. These may increase the likelihood of a IDD diagnosis in someone without it in reality and hence important to identify and recognise cultural differences and assess in the best possible culturally sensitive environment with the right interpretation of tests used" (Guidance on the Assessment and Diagnosis of Intellectual Disabilities in Adulthood, 2015).

Early Interventions

Regarding early interventions "over the past decade, advancements in assessment tools and a range of evidence-based therapeutics techniques, with a clearer rationale have promoted evidence-based treatment in community and hospital settings for people with IDD and other neurodevelopmental conditions" (Biswas & Casey, 2022).

England and Wales

Local authorities in England and Wales are required to carry out assessments of needs for adults with IDD, under legislative duties (National Health Service & Community Care Act, 1990; Care Act, 2014). These two acts also define duties in other UK jurisdictions that apply to people with learning disabilities.

"Evidence based assessments and therapeutic interventions, have been incorporated into clinical toolkits and clinical care pathways, for example, clinical guidelines and quality standards, by the National Institute of Health and Care Excellence (NICE) and have included: (i) psychological treatments incorporating applied behaviour analysis, positive behaviour support, dialectical behaviour therapy, effective problem solving, mindfulness, environmental adjustment interventions, group cognitive-behavioural therapy and eye movement desensitisation and reprocessing; (ii) speech and language therapy and enhanced communication using Makaton, British sign language or picture exchange communication system (PECS) and using assistive technology; (iii) occupational therapy including sensory integration training; (iii) genetic screening panels easily accessible for determining aetiology of intellectual disability, autism and/or epilepsy; (iii) psychopharmacological interventions including rationalising treatment with psychotropic medication for mental illness, ADHD and for behaviours that challenge in individuals with IDD and/or autism, (iv) detailed risk formulation and the need for reducing restrictive practices and interventions, regularly reviewed; and (v) timely assessment, diagnosis and appropriate treatment for physical health conditions, aiming for early detection and treatment thereby reducing morbidity mortality" in this vulnerable population (Biswas & Casey, 2022).

Scotland

In Scotland two key strategy documents, published by the Scottish government (i) the Same as You? (2000) and followed up by (ii) the Keys to Life, (2013-2019), aim to improve the quality of life led by individuals with learning disabilities, respecting human rights, upholding dignity, equality and non-discrimination.
The Keys to Life (2013-2019) document defines, people with learning disabilities as "having a significant, life-long condition that started before adulthood, affecting their development meaning they need help to: (i) understand information; (ii) learn skills; and (iii) cope independently". The Mental Welfare Commission of Scotland has responsibility under statute, to ensure care, support and treatment for individuals with IDD, respecting rights and promoting their welfare.

The Mental Health (Care and Treatment) (Scotland) Act 2003 sets out powers and duties for the care of people with mental disorder. The Adults with Incapacity (Scotland) Act, 2000 provides the powers to protect and make decisions for people with incapacity regarding their welfare and financial matters. The Adult Support and Protection (Scotland) Act, 2007, provides the powers for the protection of vulnerable adults from harm, not restricted to physical, psychological and/or financial harm.

Northern Ireland

In Northern Ireland, the Mental Health (Northern Ireland) Order 1986, recognises three categories including mental handicap, severe mental handicap and severe mental impairment.

Severe mental impairment is defined as ‘a state of arrested or incomplete development of the mind which includes severe impairment of intelligence and social functioning and is associated with abnormally aggressive or seriously irresponsible conduct on the part of the person concerned.’ Apart from mental illness, severe mental impairment is the only other category that could be considered for detention in hospital for treatment, under the Mental Health (Northern Ireland) Order 1986. There is no separate mental capacity legislation in Northern Ireland and capacity test broadly uses the principles of the Mental Capacity Act, 2005.

A.3 Social inclusion

There have been several governmental strategies and other non-governmental initiatives over recent decades in the UK for people with IDD to have equitable access, inclusion in society, provisions for vocational training & employment, recreational and community facilities providing life opportunities and with reasonable adjustments to lead their best lives.

Valuing People (Department of health, 2001) put forward a new strategy for learning disability for the 21st century, at the heart of which were four key principles of Rights, Independence, Choice and Inclusion.

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

The DID faculty of the Royal College of Psychiatrists published a faculty report (FR/LD1, 2011) describing a four-tier model of care as listed in the below.

Tier 1 encompasses primary care and other mainstream services. It is the tier of service provision that serves the general health, social care, and educational needs of people with IDD and their families.

The community IDD team and the psychiatrist have limited direct clinical contact in this tier. Nevertheless, they are involved in activities which may influence patient’ care, and interacting with this tier is essential to the training of ID psychiatrist.

Tier 2 is general community IDD services. At this level the person with IDD starts to use specialist services. Most specialist services are provided jointly between health and social services or are moving towards such a model.

Tier 3 is a highly specialized element of community IDD service. This includes areas of specialized needs such as epilepsy, dementia, challenging behaviour, pervasive developmental disorders and community forensic services.

Tier 4 is specialist in-patient services. It includes all specialist in-patient services for people with IDD, ranging from local assessment and treatment services to secure forensic services.

England

Reducing health inequalities

People with IDD experience poorer health and die younger compared to the general population. The average age at death for adults with IDD is 22 years younger for men with IDD, and is 26 years younger for women with IDD, compared to the general population (Learning disability mortality review, 2021). It was noted that 41% of deaths in adults with IDD were from treatable medical causes and 24% were from preventable medical causes and 46% of adults with IDD had between 7 & 10 long term conditions when they died. In 2020, COVID-19 was the leading cause of death in people with an IDD in males over the age of 35 years and in females over the age of 20 years in England (Learning disability mortality review, 2020).

The common themes to reduce health inequalities in people with IDD include:

- Increasing health literacy – easy read format – information leaflets – communicating
- Helping people to access support and care, reasonable adjustments.
- Annual health checks – health education, healthy lifestyle, health promotion, early detection and prevention.
- Training of GPs, Physicians, General nurses in acute hospitals and other settings.
- Stopping the over-medication of people with intellectual disability, autism or both (STOMP).
- Reducing long-term hospitalisation – better community health and social care provisions.
- Care and support at the right time and in the right setting by the right people with appropriate skills.
- Commissioning resources, guidance, support and training for across health and social care staff, ensuring needs of people with learning disability are met – engage and capture lived patient and carer experience if planning services.

The Learning from lives and deaths – People with a learning disability and autistic people (LeDeR) programme, NHS digital, NICE guidelines and quality standards, NICE Impact: learning disability and STOMP, are some of the programmes providing principles & standards and good practice guidance to reduce health inequalities and improve outcomes for people with IDD in England and the UK.

Scotland

The same as you? 2000-2012: Consultation report, published by the Scottish Executive (2012), reviewed services available to people with IDD and people on the autism spectrum, evaluating the same as you? review that stated that people with IDD had the right to be included in, and contribute to society, to have a voice, and to have access, with their families, to support to live the life of their choosing (Same as you?, 2000).

Key priorities identified in the Consultation report (2012) are summarised below:

(i) *"Human rights and equality:* compliance with the Human Rights Act, 1998, Equality Act, 2010 and Public Sector Equality Duty to prevent inequality and discrimination faced by people with IDD; access to accurate, good-quality information with communication support; more changing places, toilets available throughout Scotland; ensure accessible transport is available working together with transport providers; recognition and reporting of hate crime and ensuring adult support and protection legislation is working effectively and appropriately.

(ii) *Criminal justice:* ensure people with IDD do not experience discrimination in the criminal justice system and easy read information and support is available.

(iii) *Children and young people:* joint working to ensure children and young people with IDD can expect to access the opportunities open to all children.

(iv) *Education:* review and continue work to develop the differentiated curriculum for excellence in achieving better education outcomes.

(v) *Work:* promote supported employment and access to work benefits to increase numbers in paid employment; adopting a joined up approach enabling employment across social care, health, education, employability and welfare and benefits strategies.

(vi) *Choice and control:* ensure people with IDD have greater choice and control over their lives, using self-directed support, choosing their own staff and continued progress towards independent living. No one's home is a hospital.

(vii) *Information and communication:* ensure accessible health information is available through the National Health Service and locally, and inclusive communication across agencies.

(viii) *Support for families and carers:* ensure timely support and information is available to families, respite care and short breaks are planned and provided.

(ix) *Reduce health inequalities:* focus on health improvement, robust primary and secondary care addressing specific needs of people with IDD, and implementation of the NHS quality strategy to ensure person-centred care. Ensure end-of-life access and care standards are met for people with IDD.

(x) *Public attitudes:* supporting people with IDD to participate in community life to improve awareness and public understanding through greater interaction".

Challenges in implementing person-centred care, capacity and safeguarding

Statutory legislation in the form of the Mental Capacity Act 2005 (England and Wales) and the Mental Incapacity Act (Scotland), were passed promoting the human rights of people with IDD. Ethical practice includes Beneficence, Non-maleficence, Autonomy and Justice. People with IDD if thought to lack capacity, are assessed with facilitation as is practicable (e.g. Speech and Language therapist involvement, using Beyond words books), for whether or not the individual with IDD have the capacity to make a specific decision for example whether or not they have the capacity to refuse an options from a range of treatments proposed for a physical health condition or mental illness (Mental Capacity Act, 2005). If the person with IDD lacks capacity a best interest decision could be taken by all involved in the persons care including professionals from health services, social services, the person's family members, advocate of the patient and other stakeholders (Mental Capacity Act, 2005).
This is illustrated in a case example of a person with a serious physical health condition (breast cancer) presented with complex treatment options, weighing them against risks and potential benefits whilst maintaining the person's wishes and respecting dignity (Biswas and Hiremath, 2008).

Another major development in the UK, is safeguarding procedures, practices, reporting and mandatory training for all professionals/care staff caring for children or adults with IDD.

The Care Act (2014), statutory guidance defines adult safeguarding as "protecting an adult's right to live in safety, free from abuse and neglect. It is about people and organisations working together to prevent and stop both the risks and experience of abuse or neglect, while at the same time making sure that the adult's wellbeing is promoted including, where appropriate, having regard to their views, wishes, feelings and beliefs in deciding on any action. This must recognise that adults sometimes have complex interpersonal relationships and may be ambivalent, unclear, or unrealistic about their personal circumstances". These include six principles of (i) empowerment, (ii) protection, (iii) prevention, (iv) proportionality, (v) partnership and (vi) transparency and accountability to be followed.

C. SETTING PRIORITIES

C.1 Medical education in psychiatry with relevance to IDD

The General Medical Council, the regulatory body for doctors in the UK in their publication 'Outcome for graduates, 2018' requires newly qualified medical graduates 'to be able to recognise and identify factors that suggest patient vulnerability and take action in response' implying the ability 'to assess the needs of, and support required, for people with a learning disability'.

C.2 Clinical postgraduate training in IDD general psychiatry and child/adolescent psychiatry, and interdisciplinary training opportunities

The Core curriculum of the Royal College of Psychiatrists (RCPsych, 2022) recommends training for six months for an experiential learning in developmental psychiatry, in Psychiatry of Learning Disability or Child & Adolescent Psychiatry.

The Higher curriculum of the Royal College of Psychiatrists (RCPsych, 2022), for Psychiatry of Learning Disability lays down higher learning outcomes to be gained over a period of three years, towards gaining a certificate of completed training in Psychiatry of Learning Disability for independent practice as a consultant psychiatrist in the UK. The RCPsych Silver Guide (2022) provides guidance for cross-specialty training for example higher trainees can include twelve months in another psychiatric specialty can include Psychiatry of Learning Disability or Child Psychiatry, higher trainees in Child and adolescent psychiatry, should be covering more specialist experiences for example in Child and adolescent – intellectual disability psychiatry.

C.3 Oliver McGowan training

The Oliver McGowan training in learning disability and autism (Health Education England, 2020), is now mandatory in England by statute, placing a legal requirement for training in ID and autism for all health and social care service providers regulated by the Care Quality Commission, and aligns with Tiers 1 and 2 of the Core capabilities frameworks in intellectual disability and autism. These core capabilities include (a) understanding intellectual disability and autism; (b) health and wellbeing; (c) personalised care and support; (d) risk, legislation and safeguarding and (e) leadership and management, education and research. Tier 3 capabilities provide guidance for staff providing care in complex situations, with a high level of autonomy.

C.4 Collaborations and partnerships

There are several key organisations working together with families, people with IDD and their carers and professionals in the UK aiming to work together to improve care, policy and practice. Although not claiming to be an exhaustive list these include: Mencap (www.mencap.org.uk), a learning disability charity working with people with learning disabilities and their families and carers; British Institute of Learning Disabilities (BILD), a charity that exists to improve the quality of life of all people with learning disability and includes the work of the Learning Disability Professional Senate (www.bild.org.uk); Scottish Learning Disabilities Observatory, set up to provide better information about the health and health care of people with learning disabilities and people with autism in Scotland (www.sldo.ac.uk); Down’s syndrome association, an UK organisation focusing solely on all aspects of living successfully with Down’s syndrome (www.downs-syndrome.org.uk); HFT-Family Carer Support Service, offering a variety of information and support to family carers (www.hft.org.uk); National Autistic Society, a charity championing the rights and interests of all people with autism (www.autism.org.uk) and the Challenging Behaviour Foundation (www.challengingbehaviour.org.uk).

C.5 Opportunities for Action

Strategies providing opportunities for action include individualised care and planning, which are at the foundation of government documents such as: NHS England: Building the Right Support (2015); NHS Long Term Plan (2019) and Transforming Care Programme in England (2012) recognising that a person with IDD has holistic needs encompassing several aspects and dimensions in their lives. These also address how best to meet the physical health, mental health, care, and social needs, by providers and organisations thereby improving the quality of lives of peoples with IDD.

The focus is on co-ordinated services for families of children with IDD, smooth transition into adulthood providing and appropriate follow through of mental and physical health needs, recognising and providing changing social care of the person with IDD. Other areas include: support for carers, directed particularly for those caring for people with complex needs; people with IDD being able to make their choices and have more control over their lives; facilitating support including communication support to make decisions as may be necessary for example with regard to choosing their housing/accommodation, day activities/day care provisions, welfare benefits & sheltered and paid employment, recognising needs of ethnic minorities and culturally appropriate provisions.

Ongoing strategies for monitoring care in the community and remaining inpatient units were strengthened with processes including the Care and treatment reviews (CTRs) and Care, education, and treatment reviews (CETRs) for those still in education, as well as regular reviews under the Care Programme Approach (CPA), aiming to monitor treatment based on need and minimising chances of abuse in care settings.

C.6 Research and research training opportunities

Research in IDD in the UK, would need to have an overview of key aspects such as: (i) strategy – developing the plan/s of action needed to achieve specific targets (e.g. health improvement in specific areas for example using Quality Improvement methodology); (ii) structure – evaluating and reviewing organisational support/framework needed for example provided by government departments, NHS Trusts; (iii) systems – evaluating technical resources needed and digital technological innovations (e.g. epilepsy or diabetes monitoring in people with IDD); (iv) operational –

increased funding, staffing and other resources for projects (e.g. funded by the National Institute for Health Research and the Health Technology Assessment programmes); (v) research training in IDD, supporting and funding higher degrees (MD/PhDs); (vi) recognising barriers to research and addressing them (e.g. capacity and consultation for a person with IDD to be involved in therapeutic interventions) and (vii) a plan for action listing and actioning steps, time-line and support needed for achieving targets.

D. CONCLUSION

The six areas of the WPA Action Plan (Roy *et al.*, 2021) include: "promotion of public mental health as a guiding principle; promotion of child, adolescent and youth mental healthcare as both a preventive and secondary treatment strategy to alleviate future burden; addressing physical and mental health related comorbidities especially in reference to the preponderance of noncommunicable diseases across the lifespan that often go unrecognised in persons with IDD; building capacity in terms of undergraduate medical, postdoctoral education and training including opportunities for research; partnering with other professional organisations and non-governmental organisations (NGOs); and continuing the work of the World Psychiatric Association and its scientific sections and components within a collaborative framework, including its prior work on prevention of stigma related to mental illness". In this chapter we have outlined and discussed advances made in the UK in each of these areas and hope we have achieved in our goal.

Box 1: Mental Capacity Act (two-stage test) description

Stage 1: Whether or not there is an impairment or disturbance of the mind or brain that can affect capacity to make a specific decision (e.g. IDD, Autism, Dementia)

Stage 2: If so, are they able to:

1. Understand (and use) the information relevant to the decision,
2. Retain the information necessary to make the decision,
3. Weigh up the information and decide for themselves
4. Communicate their decision

(If the person is unable to do one or more of the four actions in stage 2, they are deemed to lack capacity to make the specific decision in question.

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F. LINKS TO AVAILABLE NATIONAL AND REGIONAL RESOURCES

Social work with adults experiencing complex needs (NG216), *(26 May 2022)* Overview | Social work with adults experiencing complex needs | Guidance | NICE

Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social are and education (NG213), *(9 March 2022)* Overview | Disabled children and young people up to 25 with severe complex needs: integrated service delivery and organisation across health, social care and education | Guidance | NICE

Care and support of people growing older with learning disabilities (NG96), *(11 April 2018)* Overview | Care and support of people growing older with learning disabilities | Guidance | NICE

Learning disabilities and behaviour that challenges: service design and delivery (NG93), *(28 March 2018)* Overview | Learning disabilities and behaviour that challenges: service design and delivery | Guidance | NICE

Mental health problems in people with learning disabilities: prevention, assessment and management (NG54), *(14 September 2016)* Overview | Mental health problems in people with learning disabilities: prevention, assessment and management | Guidance | NICE

Transition between inpatient mental health settings and community or care home settings (NG53), *(30 August 2016)* Overview | Transition between inpatient mental health settings and community or care home settings | Guidance | NICE

Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges (NG11), *(29 May 2015)* Overview | Challenging behaviour and learning disabilities: prevention and interventions for people with learning disabilities whose behaviour challenges | Guidance | NICE

LATIN AMERICA & THE CARIBBEAN

MEXICO & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions of IDD

In 2019 Mexico had a population of around 126 million 600 thousand inhabitants, of whom 51% were women and 49% men, with a median age of 28 years. The largest proportion of Mexicans live in the center of the country, in the state of Mexico (located next to Mexico City), with 13.6% of the population, 7.1% in the capital Mexico City and 6.7% in the state of Veracruz which is located on the Gulf of Mexico, the third largest state in the country.

The national fertility rate was 2.08 children per woman in 2019, with higher numbers of children per woman in the poorer, southern part of the country (Chiapas state at 2.71%) and the lowest average number in the capital Mexico City at 1.47 children per woman. While 47% of births to adolescent mothers were unplanned in 2019, only 33% of those in older women were unplanned. Related to this, in 2019, 47% of adolescent women used contraception while 75.5% of all women did.

The infant mortality rate (of children under one-year-old) was 13.1 infant deaths per one thousand births in 2019; however, this rate ranged from 19.9 infant deaths in Chiapas in the south to 9.4 infant deaths in Mexico City. Infant mortality has decreased in Mexico since 1970, except for 1989-90 when a measles outbreak temporarily raised this rate.

While in 1990 life expectancy in Mexico was 70.9 years on average, by 2019 it had increased by 4.2 years and reached 75.1 years. However, the state with the highest life expectancy (Mexico City) has an expectancy 3.5 years higher than the state with the lowest (Guerrero, also a poor, somewhat southern state, like Chiapas). However, in Mexico life expectancy is increasing at a slower rate than it was during the first decade of the twenty-first century, due to the number of deaths caused by violence and diabetes mellitus (CONAPO 2019). Also, these statistics were registered before the COVID19 pandemic.

Mexico has had greater internal migration in recent years due to levels of violence that have forced people to move to different municipalities or states in order to find greater peace and security. Mexico is a country with a great deal of international migration; this includes Mexicans who migrate to other countries as well as international migrants from a large number of countries (Central and South Americans, Caribbean people, Africans and Asians) who immigrate to Mexico or travel through Mexico to reach other countries. Mexicans who have spent years or decades living in other countries also frequently return to Mexico to live for short periods or re-establish permanent residency in the country (CONAPO 2019).

An analysis done by the Mexican government found that people with disabilities in Mexico (grouped together) perceive as their principal problems lack of employment, discrimination and difficulty exercising their independence (SEDESOL 2016). People with IDD especially do not receive respect for their human, social or civil rights, as is indicated in their low participation in paid employment, deficient access to education, lack of access to or existence of accessible and necessary services and supports. The general public often holds erroneous perceptions about people with IDD's ability to be productive. There are high levels of discrimination towards people with IDD which leads to a lack of their empowerment (SEDESOL 2016). Although a small qualitative study found that young, primary school students in Mexico overwhelmingly express favorable opinions of inclusion of their peers with IDD and about them in general, little is known about children's attitudes towards other children with IDD in general (Nava 2017).

A.2 Prevalence, identification, and early interventions

Prevalence

In 2010, the Mexican Census estimated that 250,800 people of all ages in Mexico had cognitive difficulties, measured as difficulty learning simple things or paying attention and probably including people with intellectual development disorders (IDD) as well as some other neurodevelopmental disorders as well as people with age-related dementia. While 16% of these individuals had cognitive difficulties due to advanced age, 46% were born with the difficulty and in 22% the cognitive difficulty was caused by an illness (Instituto Nacional de Estadística y Geografía, México, 2013.).

Mexico's National Survey on Household Income and Expenses (ENIGH, acronym in Spanish) also measures disability including intellectual disability, albeit with a previous version of the Washington Group Instrument which appears to underestimate the number of people with disabilities, most especially people with intellectual disability (Cappa et al. 2018). Nevertheless, an analysis of the data provided by this survey indicates that of the total Mexican population (all ages) in 2016, 1% had an intellectual disability (José Urquieta, personal communication).

The National Survey of Boys, Girls and Women in Mexico carried out in 2015 (ENIM 2015, acronym in Spanish) was a UNICEF's Multiple Indicator Cluster Survey (MICS). This survey included the UNICEF-Washington Group Child Functioning Difficulties module to estimate functional difficulties in a nationally representative sample of 11,607 children and adolescents from 5 to 17 years-old (Instituto Nacional de Salud Pública y UNICEF México, 2016). This survey found that 3.3% of children 5 to 17 years old had some kind of severe cognitive functional difficulty (learning, memory or focusing), likely indicative of children and adolescents with IDD (Braverman et al. 2017).

Identification

People with IDD share inequities and disadvantages common to other disabilities but with limitations on exercising their rights and understanding their own needs. They also face high levels of stigma, similar (or greater) to that of leprosy, HIV/AIDS, and other mental illnesses and important social marginalization (Scior, 2016). These factors possibly contribute to IDD's low visibility and access to health services in many places and Mexico is, unfortunately, not the exception. The recognition of IDD as essentially a health condition (and not only a disability) is important for improving health policies in a range of countries. Specifically, including IDD as a health condition within the policy can influence whether an infant or child receives early identification of IDD, is properly diagnosed, and provided with early, evidence-based interventions, including receiving treatment for treatable conditions. One example is Inborn Errors of Metabolism since treatment for more than 60 of these conditions is already provided for children living in high-income countries. This implies that the prognosis and outcome for the infant or child, and therefore their entire family's experience, ultimately change, converting it into a reversible condition. However, this is still not available for children in lower- or even middle-income countries.

Identifying children with IDD and their families in the health scenario raises the need to know the structure and resources of the services providing detection or diagnosis for people with IDD. Assessment tools for detection or diagnosis need to be culturally pertinent, age-appropriate, and feasible. However, there is an acknowledgment of the variability in translation, adaptation, piloting, and standardization of assessment tools. These tools frequently disregard functioning and disability assessment preventing clinicians to capture an integrative child´s depiction (Smythe, 2021). As a coordinated mental health system is frequently lacking in countries like Mexico, little is known about the "real world" provision of services for IDD people in primary care centers, community mental health centers, pediatric hospitals, or specialized settings.

Diagnosis is based essentially on psychological tests that are not always available in low-resource settings or whose psychometric properties have not been assessed; factors influencing the administration and interpretation of IQ and adaptive behavior tests including examiner aspects are documented (Patel, 2020). Clinical guidelines are useful tools for detection and diagnosis; nonetheless, their value lies depending on their implementation according to the specific context. Adherence and applicability of a guideline increase with decision support tools such as algorithms. As Berdolini (2021) suggests guideline´s applicability did not markedly improve across time, advocating the need for better implementation instructions and tools (p. 23). Although Berdolini's paper relates to bipolar disorder guidelines and derived practice algorithms, in the case of neurodevelopmental disorders in children, including IDD, algorithms have shown also a high positive predictive value (82%-98%) using medical records as the reference (Straub, 2021). Nonetheless, the implementation of algorithms or any other base-evidence interventions in favor of people with IDD using adapted frameworks from implementation science in LMICs has rarely been assessed (Kemp, 2019).

Identification of IDD in children depends on the severity and underlying causes that exist in each specific individual. In terms of severity, since about 85% of people with IDD have mild disability, IDD is often not identified until the child is 5 to 10 years old (Patel 2020). Diagnosis of children with IDD requires three things, to have an accurate diagnosis: taking a clinical history, measuring intelligence quotient (IQ) and adaptive skills. It is essential to recognize that people with IDD have variability in cognitive levels and abilities, as well as different adaptive skills; these differences need to be determined through pertinent testing to provide a basis for each person's treatment plan (Marquez-Caraveo et al., 2021). However, most public institutions which provide care for children with IDD in Mexico have limited access to tests to determine IQ and adaptive skills and most pediatricians and general physicians who come into contact with children in public care receive no training or indications on when to refer a child for testing for IDD or other neurodevelopmental disorders. Experts propose that one solution to this lack of access to or existence of standardized, validated tests and adequately training professionals who can apply them, one solution could be the development of assessment instruments to evaluate behavioral indicators (Tassé et al 2019).

Clinical guidelines for the diagnosis of IDD in Mexico

In 2010, clinicians and researchers working in the most important specialized mental health facility for children and adolescents in Mexico City agreed to work on guidelines for the 10 most prevalent conditions. Derived from the above, an algorithm for screening and diagnosis of IDD was published in 2010 according to Agree-Guidelines https://www.gob.mx/cms/uploads/attachment/file/274355/Guia_Retraso_Mental.pdf.

This algorithm included a 1st and 2nd tier evaluation based on a previous proposal by Filipek et al. (1999) for ASD. Tier 1 relates to the identification of atypical development in primary health care settings with an emphasis on language delay and socio-emotional evaluation. Clinical surveys combine screening instruments properly adapted and validated. Tier 2 includes punctual measurement of intelligence coefficient and adaptive behavior, again with instruments properly adapted and validated. Mental health community centers, pediatric hospitals providing child psychiatric and psychological services, and psychiatric hospitals should offer this service. The implications of this algorithm and other intervention challenges in the context of healthcare services in Mexico are discussed by the authors in a later research paper (Marquez-Caraveo, 2011).

Algorithms for IDD diagnosis of genetic and/or metabolic etiology

Regarding the identification and diagnosis of DI of genetic origin, the intervention of the health professional begins with a careful medical history emphasizing family/genetic history (other relatives affected, consanguinity, sudden unexplained death, etc.). The physical examination consists of perfectly examining the individual and detecting data that deviate from the norm and that are not family traits. The medical history and physical examination are the most important diagnostic tools (Moeschler, 2019). This is true even in countries that have the support diagnosis based on costly studies such as those of the type cytogenetic with high-resolution techniques or procedures fluorescence in situ hybridization (FISH). These procedures are recommended in some clinical genetic guidelines, however, are rarely available in public health care institutions and if they are available, it is for research purposes (Marquez-Caraveo 2011). IDD is a mental disorder category under the ICD 11 and DSM5, for this reason, and because in psychiatry comorbidity is the rule more than the exception (van Loo, 2013) it is highly recommended to include a child psychiatric examination in the evaluation of people with IDD.

After the clinical evaluation, there are protocols such as the American Academy of Pediatrics, the American Academy of Neurology and the British Columbia-based Treatable Intellectual Disorders Endeavor (TIDE) proposing (as our 2010 and 2016 proposal) multitiered investigations of Global Developmental Delay (GDD) to guide physicians towards the etiology and that improve the therapeutic yield (Belanger, 2018). Other approaches recommend checklists, ending investigation when the clinician feels that it would not alter the outcome, even without a diagnosis (Jimenez-Gomez, 2014 as cited by Belanger, 2018).

Most algorithms suggest "behavioral evaluation" and "neurodevelopmental evaluation" in an inaccurate manner, we strongly suggest child psychiatric evaluation to establish a firm diagnosis and a geneticist and a metabolic specialist evaluation before metabolic screening, X-Fragil, MRI and genetic studies (microarrays, exome sequencing, etc.). We have provided evidence that metabolic testing *before* genetic or neuroimaging studies was capable of identifying two children out of seventy-four with NDD prospectively and firmly diagnosed, a case with isovaleric acidemia and a case with beta-ketothiolase deficiency (Marquez, 2021). Recent guidelines of the American College of Medical Genetics and Genomics recommend exome and genome sequencing for pediatric patients with IDD as either a first (or second-) line test emphasizing characteristics of the setting, the context and the service (Manickam, 2021).

Early Intervention

Basic neonatal screening is carried out on around 90% of newborns in Mexico, at least according to maternal report which is likely to be an over-estimate (De Castro et al. 2013). However, expanded neonatal screening appears to be less frequent, with reports of around 80% of newborns receiving this screening in better-funded healthcare institutions (Trigo-Madrid et al. 2014) while the percentage in most healthcare institutions appears to be much lower. This results in a lack of prevention of number of causes of IDD.

Mexico has implemented an early child development screening test (designed by Mexican scientists, called the Child Development Evaluation or EDI, acronym in Spanish) which can be applied by a pediatrician, general physician, nurse, or psychologist after a short training period and without specialized materials, and identifies children in need of further testing for developmental problems. Although this screening test is applied in public healthcare, coverage is uneven and the system for referring children for further diagnostic tests and treatment is weak and healthcare personnel face important barriers to providing either referral or treatment (Peralta González 2021). Thus, even when children are detected as having a possible neurodevelopmental problem, they are generally not referred for further diagnosis nor do they receive early interventions.

Also, when children receive a diagnosis of IDD or another neurodevelopmental disorder in Mexico, there is usually an important gap in care between detection and diagnosis, and their inclusion in early intervention services or education in general (either special education or inclusion in typical schools). Since psychiatric care in Mexico is still very much hospital-based (and not incorporated at the community level) early intervention programs for children with neurodevelopmental disorders and IDD specifically exist on a very small scale in psychiatric hospitals. Thus, access can be limited to children whose families live in large urban areas where there is a psychiatric hospital or other large medical center that provides early intervention; the families must also often find out by themselves about the existence of such early intervention programs, since referral systems are faulty if they exist at all. Finally, those early intervention programs that do exist provide care which in addition to not being provided in a standard manner, exists on a small scale, and cannot provide coverage for all the children who need such services.

There is a dearth of research in the Early Childhood Development (ECD) research field related to early intervention for children with developmental disabilities. Additionally, it is also noteworthy that variability in translation, adaptation, and standardization of measures of Functioning and Disability poses limitations in the comprehension of their needs (Smythie, 2021). This is the case in Mexico that a national initiative for assessment of children in economic disadvantage (cash transfer program) did not include assessment of functioning and disability. The follow-up of the screening with the Mexican Child Development Evaluation tool has faced several challenges and children are often not referred for diagnostic testing. Thus, no information is provided to parents of children who are evaluated with the Child Development Evaluation tool regarding the need for IDD diagnosis confirmation or how to obtain such an evaluation or test (Peralta 2021).

A.3 Measuring intellectual disability and neurodevelopmental disorders at the population level to estimate prevalence.

National prevalence of IDD can be measured in number of ways. In countries with good coverage of pediatric healthcare including well-child visits, a well-functioning system for referring children with developmental problems for diagnosis, and at least some availability of psychiatrists with training in neurodevelopmental disorders (NDD) and IDD diagnosis, prevalence can be estimated through registries of children who have been diagnosed. Some countries also have a registry of children and/or adults with disabilities, which specifies those who have NDD or IDD, that exist to provide people with governmental programs or benefits as well as to allow evaluating access and inclusion in different services which are more broadly available such as public education, those providing vocational training and other employment-related services. Most middle- and lower-income countries, including Mexico, do not have all (or any) of these systems and thus need to measure prevalence in other ways.

The lack of widespread early (or even delayed) diagnosis of NDD, and IDD specifically, which exists in many countries also complicates measuring prevalence through surveys since parents who are not aware of their child's diagnosis are less likely to report a developmental delay or difference, since they are unclear as to what their child's problem might be, may not have accepted that their child has certain difficulties or have clarity as to whether an issue exists. Given this reality, international efforts to measure disability at the population level in different countries is focused on problems people encounter in daily functioning and is based on the International Classification of Functioning, Disability and Health, or ICF (WHO 2001; WHO 2011; Charleton 1998).

The United Nations-sponsored Washington Group on Disability Statistics (or Washington Group) proposes six domains of functional difficulties and disability for adults: seeing, hearing, walking, cognition, self-care, and communication. The tools that the Washington Group and UNICEF have developed and made public operationalize the population level measurement of disability through the measurement of functioning difficulties in these six basic activities that, especially in an unaccommodating environment, could place a person at risk of limited social participation and therefore constitute a disability (Washington Group on Disability Statistics 2016).

The UNICEF-Washington Group created a module for measuring child functioning and disability for children aged 2 to 4 years and children and adolescents aged 5 to 17 years. For children aged 2 to 4 years this questionnaire includes questions about difficulties in 8 domains: seeing, hearing, walking, fine motor coordination, communication, learning, playing, and being able to control their own behavior. For children and adolescents 5 to 17 years of age, this questionnaire explores difficulties in 14 domains: seeing, hearing, walking, feeding, or dressing him/herself, being understood inside household, being understood outside household, learning, remembering, anxiety, depression, controlling their own behavior, focusing, or concentrating, accepting change, and making friends. The level of functioning difficulties or disability is estimated by asking the mother or primary caretaker about the presence and severity of basic functional difficulties related to those domains. Anxiety and depression are also estimated, by asking how often the difficulty occurs (daily, weekly, monthly, a few times a year or never); and the child's ability to control their own behavior is estimated by asking how much difficult is for them to control their own behavior compared to other children of the same age (none, the same or less, more, much more) (Loeb et al. 2018, Massey et al. 2018, Cappa et al. 2018).

Mexico first applied a pilot version of the UNICEF-Washington Group module for measuring child functional difficulties in 2015 in a national survey on women and children (ENIM2015, acronym in Spanish, Instituto Nacional de Salud Pública y UNICEF México, 2015). Since 2018 Mexico has included the final version of this module in its national health and nutrition surveys (except during the COVID19 pandemic, when the survey was applied in a much-shortened version). This allows measurement of functional difficulty which can be used as indicators of prevalence of intellectual development disorder, autism spectrum disorders and other neurodevelopmental disorders in children and adolescents. In 2018, this national survey also applied the Peabody and CDI-MacArthur instruments to measure vocabulary in young children, which allows estimating prevalence of non-verbal children or children who are delayed in the development of verbal skills (Shamah-Levy et al., 2020).

One may question why population level measurement of IDD (or disability in general) is useful, necessary, or important, and therefore why it matters if an instrument measures IDD specifically, and how accurate that measurement is. In a variety of cultural, socio-economic, and political contexts, well-established data about prevalence of these specific types of disability is useful to shape and improve national and regional policies on disability. That is, good data about the prevalence of IDD can allow stakeholders to advocate for better coverage and better quality of services, including expansion of existing programs and establishment of new programs. Such data permit evidence-based evaluation of new and existing services to guarantee the quality of care, that programs actually achieve the proposed outcomes and that they achieve good coverage of the population that requires those services. In addition, such data contribute to the development of broader social policies focusing on inclusion, equal opportunities, accessibility, respect for human rights as well as policy-formation in general and renovation of programs (Loeb et al. 2018).

Monitoring disability prevalence can also contribute to policy-formation related to prevention of some types of IDD. Data on disability prevalence in combination with data on other indicators allow monitoring the level of participation by people with disabilities in society (in terms of education, employment, residence, and other areas). Finally, data on people with disabilities is essential to guarantee financing of services and programs they need (Schneider 2016).

A.4 Challenges for identification of IDD in LMICs

Since the 2007 Atlas Report (WHO, 2007), the World Health Organization documented salient findings related to resources and services for people with IDD including the following:

1. Lack of information from a global perspective. This is particularly challenging because only 5% of scientific knowledge about childhood and adolescence is developed outside of North America, Europe, and Australasia (Tomlison, 2014).
2. Low reliability of epidemiological data due to lack of specific research on IDD. "What is not estimated, is not seen".
3. Low visibility due to the following:

a) Resources and services are embedded within other fields and scattered in diverse sectors and authorities; b) IDD is difficult to identify because it is not a conspicuous disability such as vision or locomotor impairment; c) It remains a largely theoretical condition without any specific national policy, protection law, government benefits, or public funding.

4. Access is a critical step in many countries because despite 75% of countries informing about services, there are not sufficient to meet needs. The socioeconomic and geographical barriers are the most important barriers to accessing services.
5. Provision of services is particularly low in residential facilities, literacy programs, and adult education, to mention the most outstanding.
6. Prevention: Efforts are required to include information about a wide spectrum of initiatives such as maternal care, childcare, and poverty alleviation. These factors are known to affect the incidence of IDD.
7. Human resources and training: In-service training dominates in most countries; graduate training is rare and it is even more unlikely for countries to train primary health care workers.

A.5 Status of social inclusion

Public education for children and adolescents with IDD in Mexico previously focused on the creation of schools for special education and then later integrating them into general education; both special education schools and inclusive schools exist. In 2011 a law mandating the inclusion of students with disabilities in education was implemented in Mexico. However, non-inclusive special education schools also exist for students, including the Multiple Care Centers (CAM, abbreviation in Spanish) for students who are unable to engage in the general education curriculum (SEP2006). A small number of private schools have inclusive policies focusing on children and adolescents with IDD and/or ASD and they provide extra support for these students. Inclusion may have promoted diversity in the classroom, but specialized teacher training is basically non-existent in the context of public schools and teachers often have large classes which impedes them from providing extra attention to students with IDD. Thus, lack of resources and especially teacher training mean providing inclusive education occurs without any funding or the necessary resources (Lavin, 2020).

National surveys show that in Mexico fewer children with functional difficulties indicative of neurodevelopmental disorders (including IDD and ASD) attend pre-school (for the 2–4-year age group) as compared to children without this type of disorder. Also, for the 5–17-year age group, more children and adolescents with functional difficulties indicative of neurodevelopmental disorders tend to be in primary school even when their age would merit them being enrolled at a higher level (i.e., they have a large educational lag) and fewer children with difficulties indicating these disorders attend secondary or higher education as compared with their peers (Franco Guevara 2022). Data on children who receive care and treatment for IDD in the public health system indicate many are not in special education programs (although they have a diagnosis), some not enrolled in school at all and their parents report feeling that their children with IDD are not paid attention to or supported by their teachers (Veronica Pérez Barrón, personal communication).

In Mexico, when children with IDD become adults, if they live in a public residential institution they must leave when they reach age 18 and after that point there is a lack of governmental services available to them to support them in finding employment, a place to live or even for basic needs such as food and clothing. Some may receive a small stipend from the government but only if they know this exists and are able to complete the paperwork necessary to receive it. In general, in Mexico, the public sector has almost no of public policies for people with IDD. Most glaring is the lack of an institutional model which supports people with IDD in terms of community inclusion, employment and acquiring the skills to live independently. Some not-for-profit organizations provide such services, but their coverage is very limited, due to lack of funding among other issues.

In Mexico, people with disabilities in general, and especially those with IDD, live in households which are poorer and have worse outcomes in terms of health, education, housing, income, and food securityy (Sedesol 2016; José Urquieta personal communication). Those people with IDD who still have contact with their families (i.e., have not been abandoned by them due to poverty or other reasons) are frequently dependent on their family members, which creates a situation rife for abuse and lack of respect for their human rights, including the possibility that they exercise autonomy and live as independently as possible (Sedesol 2016; Human Rights Watch 2020). For example, an evaluation of a pilot program that aimed to provide community-based rehabilitation for children and adolescents with disabilities who lived in poor, indigenous communities in the Mexican state of Oaxaca found that some adolescents with IDD were tied up and kept inside the home for hours due to the caregiver's poverty and lack of other options, while others were not allowed to attend school or to progress to a higher grade in school (this was impeded by their communities and not their caregivers) and/or did not have any interaction with children outside their household or with neighbors (adults or children). The pilot program was able to improve these situations (a girl with Down's syndrome was no longer tied up and kept inside another girl with borderline IDD was allowed to progress in school) but was unfortunately closed after a few years of existence (Allen-Leigh et al., 2010).

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

B.1 Mental Health Burden in children and adolescents with disabilities

The greater part of children with disabilities live in Low- and Middle-Income Countries (LMICs). For this reason and because the number of children and adolescents with disabilities is far higher than the 2004 estimate (Olunzaya, 2020) it is important to emphasize the impact of disability in this age group. The World Health Organisation (WHO) requested a group of experts to develop a more comprehensive indicator that would reflect not only the mortality but also the level of disability due to diseases. The former led to the concept of The Global Burden of Disease (Murray, 1997). GBD is assessed through an indicator called the DALY, for disability-adjusted life years. The DALYs measures the gap between the current health of the population and a normative standard life expectancy spent in full health (GBD, 2019). DALYs and GBD thus provide a comprehensive picture of the population (Baranne, 2018). According to the last GBD 2019 Study, findings reveal that idiopathic intellectual disability scores highest in the ranking of DALYs in all age groups than autism spectrum disorders and attention deficit disorder with hyperactivity (GBD, 2022).

B.2 Available services for children and adolescents with IDD

In Mexico, according to the mental health systems indicators in the WHO-AIMS Report (Berenzon, 2013) less than 30% of primary health settings have protocols for mental health conditions, access is available only in big cities, only 2% of health expenditure is directed at mental health issues and care and it is mostly funneled into psychiatric hospitals with low provision of mental health services in general hospitals, residential settings and limited services for children and adolescents.

A recent qualitative study on the perceptions of professionals in primary care centers reported that health personnel and patients mentioned: limited resources (which impact service quality), public mental health policies that are not always implemented in practice and a care model that does not make it possible to explore psychological or emotional problems (Berenson, 2018). Some current efforts reflect efforts towards transition from a fragmented model focused on tertiary (specialized) care towards the reinforcement of primary care (Cordero, 2021).

Mexico has fewer than 4 psychiatrists per 100,000 inhabitants and fewer than one pediatric psychiatrist per 100,000 children under the age of 15. There are very limited adequately trained professionals in the field of IDD in general and guidelines for prevention, early diagnosis and care are also lacking.

The lack of a well-organized mental health system articulated with maternal and child health care and early education systems makes it difficult to coordinate health interventions from birth to follow-up high-risk children. Provision of early interventions, with follow-up programs and confirmation of IDD at the earliest possible age, would also prevent educational lag in children with IDD.

Since early diagnosis of IDD is nearly nonexistent in Mexico, given the lack of training provided to pediatricians, referral to diagnosis sometimes happens once children with IDD lag in primary school and are unable to acquire basic skills relating to reading, writing and math, which leads parents to seek an evaluation. Children with more severe IDD are more frequently diagnosed at early ages and may be placed in public Multiple Care Centers (CAM). There are Multiple Care Centers labeled either basic and vocational; neither provide services or support once children reach age 18 and no other public services exist for these young people related to independent living, social and community inclusion or even vocational placement. Although some Multiple Care Centers are labeled as vocational, the training they provide is often extremely basic and focuses on a single type of employment for all students at that center, regardless of severity of their disability or individual abilities and tastes. There are also no services linking the Centers with the community, seeking to promote inclusion in non-protected employment or in the community.

During childhood and early adolescence, a reduced number of those with mild and moderate IDD receive support through Units for Support of Regular Education, which seek to provide children with disabilities support when they are included in general education. The guidelines for these Units indicate the need for evaluation and diagnosis of students who potentially have IDD as well as specialized teaching especially for reading and writing, but do not provide any guidance on who should do diagnosis, where to refer children or methods for specialized educational support. This leaves teachers with few tools and no guidelines for how to provide support to students with IDD.

B.3 Available services for Adults with IDD

In Mexico public expenditure on mental health has been only 2.1% of the total public health budget for years and most of this goes to care related to addictions; also, the amount budgeted for public mental health services decreased most years from 2013 to 2021. This funding (for any type of mental health care) is used to pay salaries and cover the costs of keeping psychiatric hospitals functioning and none is focused on vocational services or those related to social or community inclusion or recreation (Llanos Guerrero, Méndez Méndez, 2020).

In Mexico, services for adults with IDD has been basically non-existent in the public sphere, with a limited number of non-governmental organizations and private institutions providing care and services albeit with very limited coverage, given their lack of funding. Although Mexico has adhered to all UN initiatives related to respect for rights of people with disability, issues relating to people with disabilities is not part of the public agenda, is not recognized as an important public health and social issue and therefore health, social, vocational, and recreational services are nonexistent for adults. The result is that families (when the person with IDD has not been abandoned by their family, which may occur during childhood, or once the person becomes an older adolescent or adult) are forced to provide all care for the person. Evidently, these families have no training and are frequently lower income (this is true of all families with a member who has a disability, but especially so for those who have a member with IDD) this situation leads to abuse, lack of autonomy and extremely low quality of life in most cases. Given the lack of services, as they mature and age adolescents and adults with IDD in Mexico become increasingly confined to their homes, with no opportunities for social interaction or for any activities which can stimulate them and provide meaning to their lives. This results both in physical and psychological abuse towards them by their family members, and challenging behavior by the person with IDD, often towards their parents or caregivers, many of whom are women given gender norms. These caregivers have received no training about how to provide care, set limits, promote social inclusion and autonomy for their family members with IDD and it is unfair and damaging to society in general (and to the family and person with IDD specifically) that this work is required of them, given the lack of public services provided.

When health personnel are consulted, they have been found to be extremely paternalistic and give no priority to promoting or allowing people with IDD to exercise autonomy or even quality of life. People with severe or profound IDD in the past sometimes resided in psychiatric hospitals in Mexico, where their quality of life was generally low and there were no opportunities for community inclusion. A new policy of deinstitutionalization of people who are institutionalized in psychiatric hospitals for any reason is being implemented in Mexico which prescribes care be provided in general hospitals, which do not have the resources (including beds/placements, specialized personnel, etc.) to provide care for former patients of tertiary care. The probable result will be that most people who previously resided in psychiatric hospitals will have no options in terms of where to live or how to eat, much less any services or treatment they might need.

B.4 Opportunities for Action: Connecting families, developing programs, ensuring sustainability

As mentioned, there are very few programs for adolescents or adults with IDD in Mexico; one exception is Capacitación y Desarrollo Integral, A.C. "CADI" a non-profit private program for adolescent and adults with IDD. CADI offers a comprehensive program for people with moderate, mild and borderline IDD who are provided with training in skills for daily living and vocational skills. The skills acquired through this program allow people with IDD to live in the community and become employed. Once the program is completed, graduates can live independently in small groups of 6-8 people with IDD who rent housing together and use their pooled incomes (usually minimum wage) to support themselves, given that there is no available financial support from governmental institutions. As part of the program, there is a residential facility where they can develop their independent living skills before going out to live in the community with continued support and supervision from CADI staff.

The major challenge related to this care model is scaling it up. The adoption of the CADI model within governmental institutions would be the optimal way to scale this program up, implementing the teaching methods and especially the focus on providing skills for independent living and employment. This could be implemented in existing institutions such as the Multiple Care Centers or CAM, where children and adolescents with IDD live. Also needed would be the creation of centers for adults as well as options for adolescents who have IDD but live with their families instead of in a Multiple Care Center, but also need vocational training and education on skills for independent living.

Case example: CADI, Center for Integral Training and Development

The Center for Integral Training and Development (CADI per its abbreviation in Spanish), is a not-for-profit private organization that provides services for older adolescents and adults with IDD in Mexico. The program fosters autonomy, social inclusion, and high quality of life in people with IDD.

"The program encompasses four areas:

- a therapeutic academic area that teaches applied living skills
- development of social skills
- development of vocational skills, and
- skills for independent living

The program is divided into three levels:

- initiation to independent living, where clients develop basic abilities for autonomy,

- community integration and social independence, which provides clients with the skills necessary for social inclusion and economic independence, and
- practical and psychological support, which offers counseling for resolving psychological issues and enables subjects to maintain their autonomy.” (Katz et al. 2008)

C. SETTING PRIORITIES

C.1 Medical education in IDD psychiatry

Medical education in Mexico has practically no focus on IDD or neurodevelopmental disorders in general. Those specializing in pediatrics and even psychiatry also receive basically no training related to neurodevelopmental disorders. After a residency in general psychiatry that lasts 4 years, physicians who chose to specialize in child and adolescent psychiatry will have received no training in this type of disorders, although they will receive some training during their specialty training. There is a total absence of specialty training for care and treatment of adults with IDD in psychiatric specialty education.

C.2 Clinical postgraduate training in IDD child/adolescent and general psychiatry, and interdisciplinary training opportunities

There are basically no programs offering clinical postgraduate training in IDD in children, adolescents, or adults in Mexico. A few students within the doctoral and master’s programs at the INSP have, when interested in the topic, carried out thesis projects on IDD. For example, one student did his thesis for his master’s degree in public health on prevalence of functional difficulties indicative of neurodevelopmental disorders (including IDD and autism spectrum disorders) at the national level in Mexico and whether these children received educational and healthcare services to the same degree as children without such difficulties. Another student did a thesis for the master’s in sciences with a concentration in epidemiology which included an evaluation of the quality and the presence of social inclusion in guidelines for care and services for people with IDD in a series of countries. Students who are residents completing a psychiatry degree have also done their theses on topics related to children with IDD, most often at the Children’s Psychiatric Hospital “Juan N. Navarro” which is in Mexico City and is part of the public, free, Ministry of Health system. For example, in recent years residents at that hospital have worked on comparing language in children with a single neurodevelopmental disorder or more than one (in comorbidity), on describing non-verbal children with IDD, comparing the clinical diagnosis with diagnosis using psychometric instruments in children with IDD, mental health problems in children with IDD and evaluating adaptive behavior in children with IDD.

C.3 Research and research training opportunities

n Mexico, the purpose of the IDD Mexico Study (Lazcano-Ponce, 2016) was to fill this gap in research and intervention based on scientific evidence. The IDD Mexico Study is the first national study that evaluates everything from situational diagnosis, disease burden, and genomic and metabolomic aspects to intervention proposals for this disability. The identification and recruitment of the study population through the characterization of a clinical sample of children, adolescents, and their parents who attended a public institution for child psychiatric care included the steps needed to identify IDD of unknown etiology. Even though children were already attending a children's mental health specialized service, the research team agreed to propose a diagnostic algorithm to properly measure IDD with psychometrically sound instruments, not on the sole basis of a clinical diagnosis by a child psychiatrist. The analysis of the correspondence between the clinical diagnosis and the research diagnosis showed that it was at most 50% coincident (Castillo Mendoza), being the IDD in comorbidity with autism spectrum disorder the least established diagnosis with ASD becoming the "unique" diagnosis in the medical record.

Identifying children and adolescents with the suspicion of IDD of unknown etiology to carry out the genomic study of IDD, sampling and sequencing exome, corresponded to Stage 1 of the IDD-Mexico Study (Lazcano-2016), a research initiative previously described. The algorithm included: a) the study population identification; b) clinical diagnosis plus formal diagnostic assessments as a first selection filter; c) clinical evaluation by geneticist as a second filter; d) metabolic screening as a third filter; e) Fragile X screening as a fourth filter, and finally, f) the genomic analysis (Lazcano-2016, p. 701). We want to emphasize that this sequence of evaluations consisted of giving priority to the clinical evaluation by a child psychiatrist and geneticist, both supporting their evaluations through the locally available tools showing empirical evidence of validity and reliability in Mexican children (for example, WISC-IV, Vineland II) and preferably, free (for example the Mini-kid for ADHD diagnosis). It is also important to highlight that IEM screening preceded Fragile X screening and genomic evaluation. We recommend the IDD-Mx Study algorithm since: a) an algorithm is recommended intending to shorten the investigation of IDD, b) restraining tests that are time-consuming, and above all, c) promotes efficient use of limited health resources (Belanger, 2018).

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MIDDLE EAST & NORTH AFRICA

ISRAEL AND INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions of IDD

As of the time of writing, Israel is a country of about 9.5 million citizens (Central Bureau of Statistics, June 2022). Of these approximately 80 % are Jews and 20 % Arab (mostly Muslim, with a small Christian minority) by ethnicity.

People with disabilities in Israel, as seen elsewhere, are sometimes marginalized, and accessibility is not always prioritized. There is, however, a movement towards inclusion which is supported by changes in the law. This has been demonstrated in a number of different areas, varying from the current Minister for Energy, Minister Karine Elhararr, who uses a wheelchair, to the recent rise in popularity of the music band, Shalva (https://shalva.band/), which includes members with disabilities, including Intellectual Disabilities.

Intellectual Disability within the Ultra-Orthodox Jewish community, which constitutes approximately 10 % of the overall Jewish population (Central Bureau of Statistics, 2020) appears to be more prevalent than in the general population in Israel. This may be due to number of factors, including larger family size, and less pre-natal testing in this population (Nov-Klaiman et. al., 2022). The attitude towards people with intellectual disabilities amongst Ultra-Orthodox Jews is also often different from that of the general population, with a higher value placed on acceptance and inclusion. Thus, a study which examined coping strategies of parents of adolescents with developmental disabilities found that Ultra-Orthodox parents reported a higher sense of growth and a higher sense of coherence than the secular parents. (Manor-Binyamini, 2012).

In addition, the rate of IDD in the Arab population in Israel is almost double the rate in the Jewish population - 5.5 per 1000 people compared to 2.8 per 1000 people respectively. (Barlev, Pur, Bachar (2021))

A.2 Prevalence, identification, and early interventions in the country

Health services are provided by four not-for-profit health maintenance organisations (HMOs) which provide a government-mandated “basket” of health, including mental health, services. Israeli health services place a relatively strong emphasis on antenatal testing. Genetic testing is offered to women considering pregnancy, and includes screening for rare genetic disorders, which may be more prevalent in certain ethnic groups. (Hence the genetic tests offered vary according to the couple’s ethnicity.) Some Ultra-Orthodox Jews conduct genetic testing before matching prospective marital partners. Antenatal ultrasounds, including nuchal translucency, are offered to pregnant women in Israel. Amniocentesis is offered to pregnant women over the age of 35. At the time of birth, newborn babies are tested for hypothyroidism and phenylketonuria.

Child development is typically screened by community-based nurses and paediatricians; children under the age of six years raising developmental concerns are generally referred to one of a network of multidisciplinary child development centres (CDCs) [numbering 35 in total, as of 2015; up to date figures are not available (Ministry of Health, undated web page)] which are run by either of the Ministry of Health or one of the HMOs. These CDCs assess at-risk children, diagnose delays or disturbances in development, initiate and manage aetiological workups, and make treatment and educational placement recommendations. (Milder cases might only be identified later in school, often by educational psychologists.)

The true, or epidemiological, prevalence of intellectual disability in Israel is not known, however. The Ministry of Welfare and Social Affairs runs its own formal ascertainment process - this ascertainment being necessary for, amongst other things, accessing adult specialist services offered by this Ministry, such as out-of-home placement or placement in a daytime "vocational training centre" (VTC), and tends to thus become more relevant as the person reaches adulthood.

Recent records show that 33,999 people were registered as having an IDD with the Disabilities Administration in Israel. Of these, 67% received services (Barlev, Pur, Bachar (2021)). As application for the formal ascertainment is generally undertaken by the parents of PWID, its initiation (or non-initiation) is subject to such factors as lack of awareness of disability by parents, ignorance of the ascertainment process, lack of perception by parents of potential benefits of ascertainment, concern about potential negative effects of being registered, and broader cultural and developmental factors. Number of subgroups (children, Ultra-Orthodox Jews, people with mental illness or developmental deviance such as autism spectrum disorder) are especially likely to be under-represented in this ascertainment process. The administrative prevalence generated by this process, i.e. the number of people known to social services, is thus likely to be a gross underestimate of the true prevalence.

A.3 Status of social inclusion

Changes in policy concerning PWID have often been driven by non-governmental organisations (NGOs) such as Akim Israel. This body, founded in 1951, is the Israeli national organization for PWID and their families. According to its self- definition, it operates as a person-centered organisation (Akim, undated web page). It engages in both advocacy (political and public) and service provision, and deals with issues concerning both children and adults. According to an unpublished letter sent by Akim to the Minister of Education on 21-6-2021, "As of now, a large majority of the 10,000 children with intellectual disability are learning within the special education system and are not integrated into the general education system." However, in March 2022 the director-general of the Education Ministry declared that "the concept of integration sees everyone as part of the community… All pupils have the right to be part of the general educational system, and the educational system must suit itself to their various needs and strengths." (Ministry of Education Circular, 28/3/2022). This constitutes a clear policy statement, though it is unclear at present how this approach is panning out in practice.

At age 21, overall responsibility for (non-medical) service provision to PWID in Israel automatically moves from the Ministry of Education to the Ministry of Welfare and Social Services. Often, parents notice a dramatic difference in the general care package that is provided when their child becomes an adult, as PWID move from school to (daytime) VTCs, which offer fewer resources to support a person who often has changing needs at this time of transition.

As for community inclusion of adults, policy development concerning PWID in Israel has generally been like that in Western countries, though the trend towards deinstitutionalization and the developing of community services occurred later in Israel than in the West (Yurkevich and Rimmerman, 2022).

It is encouraging that a recent survey by Akim (Akim 2022) found that a large majority of the public thinks that PWID should be living in the community rather than in segregated residences. This is reflected in the stated principles of the Ministry of Welfare and Social Affairs, under whose responsibility services for people with intellectual disability in Israel mainly fall (Holler et al., 2020): According to information published by the Ministry, it "strives to integrate the individual with disability optimally in the community and his/her natural environment". Provision of social services, including out-of-home placement and vocational training centres, has moved over the second decade of the present century from diagnosis-based to needs-based and preference-based. (Ministry of Welfare and Social affairs, 2019). At the time of writing, however, there are still large institutions housing PWID. Management of these institutions is variable, with some set up as Kibbutz-style lodges, with a series of small houses and common central areas. Unfortunately, there are still occasional concerns of sub-optimal practice in some institutions.

An important aspect of social integration particular to Israel is that most healthy Israeli 18-year-olds are conscripted into the army (the main exceptions being some Ultra-Orthodox Jews and most Israeli Arabs). This is often seen as a rite of passage and an important part of Israeli life. PWID are generally excluded from serving in the army, although there are a few special programmes that allow a small number of young PWID to volunteer for adapted army service (Werner, Katz, Ayalon et al, 2018).
Another point to note, concerning legal "personhood" of adults with intellectual disability, is that the official attitude to guardianship is undergoing a change in Israel, with a 2016 amendment to the Legal Capacity and Guardianship Law restricting the use of guardianship to cases where it is necessary to protect individuals' interests, rights, and needs, after considering less restrictive options, and reducing to a minimum the appointment of plenary guardians. In practice, however. the Israeli legal capacity system is still dominated by guardianship practices (Holler and Werner, 2022)

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

Israel has a reasonably well-developed network of general mental health services. Every citizen or resident is by law obliged to be a member of one of the four HMOs and has a right to receive the services included in the government-mandated medical services basket, subject to medical discretion, at a reasonable level of quality, within a reasonable period and at a reasonable distance from his/her home. (Ministry of Health, Undated). The treatment is either provided by or funded by the HMO. This right is one that is difficult to put into practice, as there is no formal policy of provision of health service specifically for PWID, the expectation being that they can receive mental health treatment in generic mental health clinics which are run in various settings (pediatric / general / psychiatric hospitals or freestanding outpatient clinics, run by the government or by HMOs). Most psychiatrists, according to a survey (Werner et. al., 2013), think that this situation is inadequate since they often have not had the training necessary to deal with many of these problems.

In parallel, psychology input is variable as many psychologists and/or social workers feel inadequately trained, or feel they have inadequate supervision, to take on cases of PWID. (N.B. In Israel, social workers, as well as psychologists, can qualify to undertake psychological work). Moreover, some mental health clinics apparently refuse to accept PWID for treatment, essentially leaving them with nowhere to go. There are no dedicated psychiatric beds for PWID and therefore if admission is required, it will be on a general psychiatric ward.

As is true for medical services for the general population, for PWID living in the community, liaison between mental and general health professionals is often on an ad-hoc basis, and communication between different professionals (or lack of it) often depends on the specific professionals themselves. In the case of PWID living in institutions, both general medical and mental health care are often provided in-house, with professionals involved typically including nurses, family doctors, psychologists, social workers, and psychiatrists. However, psychiatric input may be limited to one or two visits to the institution per month.

The mental health burden borne by PWID Israel is not known. Specialized mental health services for adults with intellectual disabilities are scarce. A few ad hoc specialist services have, however, sprung up over the last decade or so; these will be outlined below. All but the first one provides services to either children or adults but not both; all are ambulatory services only.

B.1 Service Centers

Beit Issue Shapiro Dual Diagnosis Clinic, Raanana

This multidisciplinary team https://en.beitissie.org.il/education-therapy/professional-departments/dual-diagnosis/, functions as part of an NGO providing a variety of services to people with disabilities and offers mental health services to children and adults with intellectual disability. Professions represented include psychiatry, psychology, Occupational Therapy, social work, speech therapy, family therapy and behavioural analysis. The clinic is run jointly with Schneider Children's Medical Centre in Israel, which provides the psychiatric input.

Developmental Psychiatry Clinic, Schneider Children's Medical Center, Israel Petach Tikva

This clinic (https://www.schneider.org.il/?CategoryID=1049&ArticleID=3171) sits within the general psychiatric outpatient department of a general children's hospital. It accepts children aged 4 to 18 years with intellectual disability who show evidence of additional mental health problems. Specialties represented include child psychiatry, integrated arts therapy, parental guidance, and behavioural analysis.

Psychiatric Clinic for Developmental Disorders, Ma'ayanei Hayeshua Hospital, Bnei Brak

This is a specialized clinic (https://www.mymc.co.il/department/mental-health-marbe-daat-department/) within the adult psychiatric service of a general hospital in a predominantly Ultra-Orthodox Jewish city. It accepts adults with intellectual disability and/or autism spectrum disorder from any area of the country.

Lotus Clinic, Sheba Medical Center, Tel Hashomer

This specialised clinic for adults with intellectual disabilities and mental health problems is based in the psychiatric department of a large public hospital. Psychiatric, psychological, and family support is provided.
(https://shikum.sheba.co.il/%D7%9E%D7%A8%D7%A4%D7%90%D7%AA_%D7%9C%D7%95%D7%98%D7%95%D7%A1)

B.2 Challenges in implementing person-centered care

Access to suitable services is one of the major challenges regarding implementing person-centered care for PWID living in Israel. As mentioned previously, number of specialised services exist, but these have limited capacity and are all localised in the centre of the country, making it difficult for people who live further afield to access the services. Also, due to the limited capacity of specialised services, they are not often able to provide emergency treatment, which therefore falls to general mental health services. Another major challenge is that quite often there is a lack of understanding at the managerial / organisational level about the need to personalise care, including the need for longer clinic appointments, home visits and tailoring psychological therapies according to the patient's strengths. Inpatient psychiatric wards are also often not set up to manage the needs of a PWID. Behavioural analysis, a first line treatment for challenging behaviour, is not recognised by the Ministry of Health and is therefore very difficult to access for adults with behavioural problems.

B.3 Opportunities for Action: Connecting families, developing programs, ensuring sustainability (include international NGOs, sponsors/regional networks as relevant)

The challenges mentioned above have led families, patient groups and professionals in the field to push for improvements in access to suitable services for PWID. Beit Issie Shapiro has been leading in this area, as will be described in the case example below. The Ministry of Welfare and Social affairs has recently made a change from using the term "mental retardation" to "Intellectual Developmental Disability". They have also made changes in how care is provided, moving to a "needs based" approach rather than one based on diagnosis alone.

With the increasing use of telepsychiatry, it remains to be seen how this will be used efficiently and effectively with PWID. On the one hand, telepsychiatry may be able to provide access to psychiatry for people who would not be able to attend appointments physically, due to physical disability or practical limitations, such as travel time. On the other hand, it is likely to be more challenging to communicate with PWID over a computer screen.

Case example: Beit Issie Shapiro (https://en.beitissie.org.il/)

Beit Issie Shapiro is a charitable organisation that follows the vision of Issie Shapiro of building and developing a community that supports and assists those with special needs in Israel.
One of its initial projects was to provide a good quality day care for children with IDD. However, its mission has always been larger than this and its fundamental objectives are to promote social change through:

1. Development and provision of cutting edge services
2. Changing attitudes and advocating for better legislation
3. Sharing knowledge nationally and internationally

Beit Issie Shapiro continues to build on these principles, as mentioned elsewhere in this chapter.
Many services are provided by Beit Issie Shapiro, including schooling, hydrotherapy, dental treatment, and psychological therapies. The Dual Diagnosis clinic was set up 13 years ago. It works as a multidisciplinary clinic with initial assessments being conducted over a period, including an assessment in a home or school or day center environment and assessment in the clinic where all the team meet the patient and family. Over time, it has become recognised as a specialist mental health service for PWID by the Ministry of Health.

Recently, due to a national reform in the delivery of psychiatric services and liaison with the HMOs, the clinic has been recognised by the three largest HMOs in the country. On a practical level, this means that these HMOs pay for their patients to receive the clinic services (rather than the service being mostly paid for by the NGO).

This recognition by the Ministry of Health and the HMOs shows how collaboration, liaison and lobbying, alongside providing a good quality service, can make a practical difference to the lives of PWID.

Lessons learned:

- It is possible to provide high quality mental health services for PWID in Israel, though it is resource intensive.
- High quality care can be a driving force for making the case for the need for more support and resources.
- Alongside good clinical practice, it is important to build a network of collaborators who can liaise and lobby government and health providers to drive change.

C. SETTING PRIORITIES

C.1 Medical education in IDD psychiatry

There are six medical schools in Israel, although there are many medical students who choose to study overseas and many more doctors who train overseas and move to Israel after their undergraduate or postgraduate medical training. Hence, exposure to PWID in undergraduate training may be variable. Specific medical education in Intellectual Developmental Disability Psychiatry in Israel is lacking at both the undergraduate and postgraduate levels. There is no requirement for medical schools to teach about people with Intellectual Disabilities in the medical school curriculum.

C.2 Clinical postgraduate training in IDD child/adolescent and general psychiatry, and interdisciplinary training opportunities

There are two established subspecialties in psychiatry in Israel, namely general (i.ie. adult) and child/adolescent. There is a formal requirement for all psychiatry trainees to receive some training in Intellectual Disability Psychiatry, but in practice this rarely happens. (Additionally, psychiatrists do several months' rotation in neurology, which, in the case of child psychiatry trainees, provides some exposure to the ID population.) Typically, trainees may receive two 90-minute lectures on intellectual disability and on autism during their training, and probably treat a few PWID, usually supervised by a senior psychiatrist without specialist knowledge in the field.

The Dual Diagnosis clinic at Beit Issie Shapiro and the Developmental Psychiatry Clinic at Schneider Children's Medical Centre both have trainee Child and Adolescent Psychiatrists working in their teams. These trainees often go on to become ambassadors for Intellectual Disability Psychiatry amongst their colleagues. There has however been growing demand for training in ID psychiatry, and a number of courses aimed mainly at mental health and social care professionals have been run since 2013 within various frameworks, including Beit Issie Shapiro, Tel Aviv University and the Technion in Haifa.

C.3 Research and research training opportunities

There are several organisations in Israel that are involved in research in Intellectual Disabilities, including a research centre at Beit Issie Shapiro and another at the Paul Baerwald School of Social Work and Social Welfare at the Hebrew University in Jerusalem. However, much of this research is more related to social issues or general health issues rather than mental health issues. There are no formal research posts in Intellectual Disability Psychiatry, but Professor Doron Gothelf, a clinical Child and Adolescent Psychiatrist, based at the Tel Aviv University and Sheba Medical Centre, has conducted research in a variety of relevant areas, including on Williams and Velo-cardio-facial syndromes. Apart from this, there are plenty of opportunities for research for clinicians and researchers who are interested in the field. For example, a UK medical student was able to publish a piece of research after coming to Israel on her elective (Davies et al., 2017).

C.4 Collaborations and partnerships (include national, regional, and global networks as relevant)

There are several formal and informal collaborations and partnerships related to intellectual disability psychiatry in Israel.

- Beit Issie Shapiro hosts a coalition of interested parties with a view to lobbying for better access to healthcare (and mental health care) for PWID.
- Beit Issie Shapiro offers supervision for other mental health units that are interested in improving the service they offer to PWID and recently ran a series of lectures for mental health professionals working in Maccabi Health Services, one of the larger HMOs.
- Beit Issie Shapiro also hosts an international conference (which, pre-corona, was held every 2 years), bringing international speakers to Israel and providing a good base for networking and

expansion of ideas. This networking has continued, and recently, a delegation of people working in Mental Health Services in the UK came to visit Beit Issie Shapiro.

- Schneider Medical Centre and Beit Issie Shapiro have a long standing collaboration regarding their joint Dual Diagnosis Unit.
- Over the past ten years or so, an informal gathering of interested clinicians (mainly but not exclusively Psychiatrists) have been meeting on a regular basis for a lecture on a relevant topic related to Intellectual Disability Psychiatry and informal peer support. This group has grown and adapted in time and lately meets in a more formal setting, although less frequently.
- Israeli authors have contributed chapters to relevant national and international texts in German, English and Hebrew, have contributed to an international research paper (Howkins, Hassiotis, Bradley et al, 2022), and have recently contributed to a book in Hebrew (Al-Yagon and Margalit, 2022) on intellectual disabilities in Israel.

D. CONCLUSION

In general, the field of intellectual disability psychiatry in Israel is small but growing steadily. This is driven by patient need and by the increasing realization from health providers that they need to offer a suitable service. Although general psychiatrists continue to see the majority of PWID who have mental health needs, there are a few organisations that provide a specialized service to this population.

Over the past decade, developments have also been made in terms of research and training in the field of intellectual disability and mental health. Collaborations have also been formed and are working to support organisations to improve their services in intellectual disability psychiatry as well lobbying for political change.

We expect to see these developments grow in the future, as well as the strengthening of ties internationally, to continue to improve the lives of people with intellectual disabilities and their families.

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World Psychiatric Association
Section on Psychiatry of Intellectual Developmental Disorders

QATAR & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics, cultural perceptions, and social inclusion

Qatar is a relatively small country (11490 km^2) with a total population of 2.93 million, according to the Planning and Statistics Authority of the country (PSA, 2022). Due to the presence of natural gas and oil, the State of Qatar has had sustained economic growth since the 1990s. The country's infrastructure has changed because of population growth, accompanied by the introduction of various policies and reforms addressing the country's commitment to healthcare, research, and education. Within this process came several incentives, the most notable of which was the Qatar National Vision 2030, which advocated for education and healthcare under its Human and Social Development outcomes (Qatar National Vision 2030, 2016).

In 2020, the PSA conducted a detailed country census by collecting household data. The census report described the overall population in Qatar in terms of gender (71.5% males and 28.5% females), age range (<15 years: 13.7%, 15-24 years: 14.9%, 25-64 years: 70.6%, and >65 years: 0.8%), and nationality by employment (113,953 Qataris are in the workforce, and 1.94 million non-Qatari expats are in the workforce) (PSA, 2022). Qatar is a culturally diverse country. It is estimated that people from more than eighty-five nationalities work here and call it home, with people from India, Bangladesh, Nepal, Egypt, and the Philippines constituting most of them. Qatari nationals comprise about 10.5% of the total population. Regarding religious affiliation in Qatar, the overwhelming majority of the people are Muslims (67.7%), with similar sizes of Christians and Hindus (13.8% each), 3.1% of the population are Buddhist, and the remaining 1.6% of the people belong to other religious groups (Encyclopedia Britannica, 2022).

Through interviews and questionnaires as part of the census efforts, the PSA reported that 18,360 individuals were identified as having a disability. Notably, Qatar's reported proportion of disability (0.6% of the population) is much less than most of the world's estimates. The World Health Organization (WHO) reports that approximately 15% of the world's population has some form of disability (WHO, 2011).

Caring for individuals with intellectual and developmental disorders by their families is considered a religious and cultural duty in the Islamic world. Islamic law and spirituality emphasize a significant responsibility for parents and the community to provide care for family members with intellectual disabilities (IDs) in ways that honor the individual's dignity and rights (Morad et al., 2001). It is because of these values most intellectually disabled people in the Middle East reside with their families. Family members who care for these individuals consider religion their primary coping strategy (El Tahir, 2022). Whether religion creates a sense of morality and ethics for these families while encouraging them to take care of the disabled member, or the families resort to taking care of these individuals because of a lack of systems of care in the community and in turn, use religion as their coping strategy, is still debatable.

In the above context, it is worth noting that there is a significant stigma associated with IDs in both Muslim and non-Muslim societies. On one side individuals with disability internalize negative evaluations about themselves and their condition. On the other, even friends and family can experience "courtesy stigma," whereby they are bullied or shamed due to their association with and support for the individual (Hassiotis, 2012). Depictions frequently uphold these perceptions about ID individuals in the mainstream media. A study by Qatar Charity found that portrayals of disability in the entertainment media in the region tend to paint negative stereotypes and help to promote the idea that such individuals do not deserve empathy and support, tend to be a burden, and exhibit moral deviation (Bayoumy, 2012).

However, when the government and institutions normalize caring for those with special needs, this promotes better outcomes. A study of the psychological security in disabled children in Qatar found that students who were enrolled in public schools with special needs support exhibited better emotional security, social acceptance, personal security, and self-esteem than peers who were enrolled in private schools (Fakhrou et al., 2020). In recent times, Qatar has been enacting several measures to support the inclusion of individuals with disabilities to ensure their rights, improve their psychological well-being, and increase their interaction with the broader community (Al-Harahsheh et al., 2022). Qatar’s law (Law No. 2 of 2004 in respect of People with Special Needs) was established to ensure the care and legal protection of persons with disabilities. Then in 2019, Qatar enacted the Doha Declaration to make Qatar a more inclusive and welcoming country for individuals with disabilities.

A.2 Prevalence, identification, and early interventions

Out of those with a disability, a much smaller percentage are individuals with intellectual developmental disorders. A meta-analysis by McKenzie and colleagues (McKenzie et al., 2016) determined the prevalence of intellectual disabilities and found that the global prevalence of intellectual disabilities may be lower than 1 %. For the 2020 census in Qatar, disabilities were categorized into eight “types of difficulties,” including “communication, hearing, remembering, seeing, self-care, talking, walking & moving, and others.” The most frequently reported difficulty was with “walking & moving” (6,593 respondents), and the second most reported difficulty was with “remembering” (5,629 respondents) (PSA, 2022). Some problems, such as remembering, communication, and self-care, may correlate with intellectual disability, but this deduction is not a precise way to make a diagnosis. Al-Harahsheh and colleagues (2022) point out several challenges and barriers to making evidence-based conclusions regarding disabilities in Qatar because the data is inadequate. Some published studies focus on intellectual disabilities in Qatar, but they tend to focus on specific sub-samples or specific interventions. For example, there are studies about exploring the genetic etiology for a subset of patients (n=104) enrolled in the intellectual disability service at Hamad Medical Corporation (HMC) (Rustom et al., 2022; using assistive technology games to enhance cognitive skills with children (n=77) receiving services at Shafallah Center for Children with Special Needs in Doha (Dandashi et al., 2015); and a study to audit medical records of patients in the Mental Health Service at Hamad Medical Corporation who were diagnosed with intellectual disabilities and were prescribed antipsychotic medication (Elhusein et al., 2021).

In terms of identifying individuals with intellectual disabilities using the census data, 12,335 out of the 18,360 people with disabilities were registered at one of the officially recognized centers in Qatar, and 1,649 of those individuals were seeking services at those centers for intellectual disability (PSA, 2020). According to the census report, there are 36 such centers in Qatar, and most are specialized schools, suggesting that the data is somewhat skewed toward younger individuals. Most special needs schools and rehabilitation centers provide early interventions to children and families. Shafallah Center, one of the above centers, also offers vocational training and independent life skills to help young adults transition into possible employment for better community integration (Shafallah Center, 2022). The Best Buddies program, established in 2008, is a social integration initiative that pairs individuals with intellectual disabilities with same-age peers without a disability from schools around Qatar to develop social, cultural, and professional skills (Best Buddies, 2022).

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

In Qatar, mental and behavioral disorders count as the second highest cause of disability after cardiovascular disease (Alkaabi et al., 2015), with autism spectrum disorder having a relatively high prevalence rate of 1.14% (Alshaban et al., 2019). Key stakeholders in the country have demonstrated a positive understanding of the mental health burden and progressive reforms to the mental health system, including the country’s approach to persons with disabilities. Nevertheless, there remains a substantial gap in services provision for persons with special needs of all age groups concerning access to services, policy provisions, awareness and stigma, diagnosis and training, quality of care, and transition into adulthood.

B.1 Government strategies

Several strategic developments have been initiated since the 2000s. The first law regulating the rights of persons with disabilities was announced in 2004 (Qatar Legal Portal, 2004), but Qatar later endorsed the UN Convention on the Rights of Persons with Disabilities in 2008, adopting all stated rights by 2015 (Committee on the Rights of Persons with Disability, 2015). In 2006, the mental health section of the Gulf Corporation Council (GCC) health ministers' council released an official notice to develop a mental health law. The law delineated the rights of those with mental illness and was approved and issued in 2016 (Saeed et al., 2020).

Furthermore, the State announced numerous national strategies, including; the Qatar National Development Strategy 2011-2016, which outlined necessary measures regarding special educational needs to reach the goal of an educated population (Guldberg et al., 2017); the Qatar National Mental Health Strategy 2013-2018, which focused on reducing stigma and expanding psychiatric care to primary and community-based settings and was later further supported in the National Health Strategy 2018-2022; and finally the National Autism Plan 2017-2021, that was dedicated to increasing awareness, education, and training, in addition to ameliorating integrative service development processes, and addressing the needs and rights of autistic people and their families (Qoronfleh et al., 2019; Saeed et al., 2020; General secretariat of the supreme council of Health, 2018).

In 2007, the social security act was passed, securing benefits (financial and domestic help) for persons with disabilities (Committee on the Rights of Persons with Disability, 2015) who were Qatari nationals (Habayeb, 2021). In 2008, Qatar signed the Convention on the Rights of Persons with Disabilities (Persons with disabilities, 2022), passing the Additional Educational Support Needs (AESN) unit a year later and creating programs assisting children with autism to transition into mainstream education (Guldberg et al., 2017). In accordance with AESN, every government-funded school has an established department for students with special needs. As of the 2019-2020 statistics, 3,800 students with disability were integrated into public schools (Education annual statistics, 2020).

Also, in 2008, the Ministry of Education established the Evaluation Institute (or Roaa' Center), offering individual assessments for children with special needs attending mainstream schools (Alshaban, 2018). The ministry of information and communication technology also collaborated in the country's efforts. It opened the Qatar Assistive Technology Center (MADA) in 2010, providing assistive technology support for those with special needs. In 2012, Qatar joined the United Nations in announcing April 2nd as Autism Awareness Day, and autism was eventually documented as a separate disability category that year. Before that, it was classified under the broader umbrella of Intellectual Disability in Qatar's national statistics reporting.

B.2 Institutions and programs

Education

Over the past few decades, significant progress has been in accessing amenities through medical, therapeutic, and education centers (Alshaban, 2018; Guldberg et al., 2017). Services tailored to persons with special needs began in 1982 when Rumailah Hospital (Hamad Medical Corporation) opened the first unit dedicated to this cohort. In 1999, Shafallah Center for Children with Disabilities started its operation and has since helped raise public awareness and the rights of individuals with disabilities (Saeed et al., 2020). Today, Shafallah Center is the only center offering provisions from early intervention to employment and independent living training, catering to hundreds of individuals with intellectual and motor disabilities (Shafallah, n.d.; Alshaban, 2018).

With the rapid expansion of the Qatar Foundation (QF) came the Child Development Center in 2012 and Renad Academy in 2016, currently providing some of the highest quality care, education, service, and training. The Learning Center, also funded by QF, provides learning support for the special education department, serving all schools within the foundation except for Renad Academy, which operates independently (Guldberg et al., 2017). The only other specialized schools in Qatar are Awsaj Academy offering education from kindergarten to secondary school, Renad Academy (3 to 10 years old), and Al-Hidaya Primary Schools (Special Needs and Gifted Students, 2020).

The Ministry of Education also established education programs for adults who couldn't complete school, including special education services for adults with special needs. Prospective students can only enroll after a medical examination and assessment of needs by the Roaa' center for Evaluation and Consultation (Enroll students with special needs in school, 2022). However, no specialized higher-education programs have been curated as of yet for adults with mental disabilities. In fact, only Qatar University has developed the Inclusion, and Special Needs support center for postsecondary education, securing necessary accommodations for students with impairments, disabilities, or mental health illnesses (Guldberg, 2017; Alshaban, 2018).

Employment

Qatar's workforce has expanded rapidly over the years. Numerous private specialized centers dedicated to developmental/intellectual disability were introduced in the 1990s for counseling, behavioral and occupational therapeutic interventions, and social support. Although the Ministry of Education (MoE) provides curriculums and programs for vocational training (Ministry of Education, 2007), very few institutions offer vocational training, such as the Amal Center (Services, 2020), independent living skills, or integrated employment like Best Buddies Qatar (Alshaban, 2018).

In 2018, the Child Development Center, in collaboration with other QF programs, integrated the 'Career Readiness Program' into its curriculum, featuring project-based learning and cross-structural interventions for those with mild-to-moderate intellectual disability, as part of their integration into the workplace initiatives (The Peninsula, 2022). The Ministry of Interior does offer employment opportunities for persons with special needs after an assessment. However, there is limited information regarding this on online platforms (HUKOOMI, 2019).

This limited attention to the adult population with special needs is reflected in the census from Qatar's Planning and Statistics Authority. The statistics reveal that, in 2014, 1,570 out of 6,158 persons with disability were employed (~25.5%), mainly working in construction, trade, public administration, or compulsory social security. This figure remains the same in the 2021 census, with 3,274 individuals employed out of 13,044 (25%), albeit in more diverse settings (transportation, storage, education, etc.), shedding light on Qatar's exponential growth and increasing population demands (Qatar Planning and Statistics Authority, 2022).

Healthcare

Diagnostic services for intellectual disabilities are available at government or semi-government institutions, primarily at Rumailah Hospital, Hamad Medical Corporation (HMC), Shafallah Center, and Sidra Medicine. Generally, communication between (semi-)government institutions is well-established, fostering collaborative care. However, private establishments accept self-referrals and have limited interactions with other institutions to coordinate care.

Regarding medical services for adults with autism or intellectual disability, a Learning Disability department was recently established in HMC in January 2021, accepting internal and external (within HMC or from PHCC) referrals. The department consists of a multidisciplinary team managing patients in the outpatient and inpatient settings. Inpatient services for the child and adolescent population are non-existent in the country.

B.3 Challenges

Despite Qatar's steady commitment to those with intellectual/developmental disabilities, and the establishment of ground-breaking strategies and structures dedicated to improving their personal and social growth, there remain significant deficiencies and challenges in services and care for this population of all ages.

The World Innovation Summits for Education (WISE) Autism report 2017 (WISE, 2017) identified several themes of the challenges faced in Qatar from stakeholder data analysis:

1. Awareness, knowledge, and understanding
2. Policy provision and practice
3. Personal and professional development

As stated previously, there has been a significant shift in policy toward inclusive education in Qatar; however, applying these policies remains challenging (Guldberg et al., 2017). Although special needs classes and resources are available in public schools, the provision remains institution-based and segregated, with little capacity in education programs and limited interactions with other children. Moreover, transition programs for children are not yet available in many mainstream schools, and children/adolescents with disabilities have limited social and leisure activities. Education programs have little capacity, with differences in English and Arabic curricula, and school support staff and teachers are often untrained. Those unable to attend school are cared for at home by unskilled domestic workers and nannies who are already burdened with other household chores (Doha International Family Institute, 2018).

The WISE report of 2017 also emphasized ongoing concerns about stigma, lack of acceptance, and insufficient knowledge in public, particularly concerning developmental milestones and the need for specialized care and early intervention. Some institution websites are poorly maintained, there is no port of call for information assistance, and resources for families are limited. Deficient knowledge may extend to medical professions as well. The report highlighted inadequate information delivery by some professionals, for example, regarding prognosis. Poor training among other professionals, such as radiologists and dentists, also exists in handling children with autism with care (Doha International Family Institute, 2018).

The diagnostic process is often slow, taking on average months of navigating the healthcare system, from initial parental observations at home to eventually receiving a formal diagnosis. Because of this, some expatriates seek diagnoses from abroad. After diagnosis, stakeholders revealed shortcomings in the post-diagnostic provision of services and social support: therapy/treatment sessions are often of short duration, far apart, with little to no respite or afternoon care for youth with disability (Guldberg, 2017). In addition, government institutions have long waiting lists, causing delays in treatment which leads the families to see support from private institutions that are often understaffed and costly.

Another major challenge is the shortage of social support. Families of those with a disability feel stigmatized and report gaps in emotional, financial, and instrumental support. While centers provide some degree of support, families in Qatar primarily rely on friends and loved ones for moral and emotional support. Parents of children with autism have created informal support groups online, after recognizing insufficient advocacy and social support measures within the community. Families also endorsed a significant financial burden in caring for their children, higher costs in the private sector when public programs do not meet family needs, additional expenses for associated medical or psychiatric conditions, and leaving day jobs to care for children at home.

Instrumental support in the form of respite care, afternoon care, or daycare continues to be lacking for youths and adults with disability, especially in cases of intellectual disability who require sustained support into adulthood but have few services and limited opportunities available to them (Kheir et al., 2012; Guldberg et al., 2017). In their needs-assessment study, Habayeb et al. found that families of persons with Autism in Qatar have ongoing concerns regarding the deficiency in certified respite care, a service that provides appropriate supervision and support for individuals with disabilities while they are away from their families (Habayeb, S et al., 2021). Other needs identified in the same study were meaningful inclusion for young adults, citing ongoing stigma in the community, insufficient adaptive living training, limited funding for adult-focused programs with an inherent difficulty in navigating systems and ministries to create such programs, and challenges in accessing service systems.

The COVID-19 pandemic posed even more significant challenges in the past two years. With schools closed, students with disabilities were confined to their homes. The Ministry of Education and Higher Education took steps to ensure continued education delivery at home, implementing simple strategies to include learners' needs (e.g., sign language interpreters). Schools extended significant support to students and their families (COVID-19 efforts, 2020). But with diminished routines and a lack of access to therapists, parents reported higher levels of loneliness and anxiety in their children. Furthermore, one study reflected on deficiencies in teachers' training to respond to rapid demands and a lack of focus on continuing formal teachings for those with disabilities during school closures due to an underdevelopment of the online teacher-learner environment (Singal et al., 2021).

B.4 Opportunities for action

Despite the challenges above, there are opportunities for action, which are also noted by the WISE report of 2017. Regarding awareness and knowledge, enhancing the quality of information and delivery methods of awareness campaigns, involving vital religious leaders, and incorporating inclusive practices in all professional development programs is essential. Collaborative measures between the Ministry of Education and other ministries and stakeholders to advance strategies mandating post-diagnostic support, developing teachers' professional development frameworks, and supporting transitions out of schools are the next doable step. Developing sustainable and accredited personal and professional development programs for parents and practitioners, online resources for caregivers, advocacy services for the rights and needs of persons with autism and their families, and culturally appropriate training materials and diagnostic instruments with the help of qualified bilingual professionals are much-needed steps to improve understanding and access to care.

With the involvement and collaborative efforts of the World Innovation Summit for Health (WISH) and local stakeholders lies the opportunity for awareness, with regular outreach events, campaigns, conferences, and forums covering various topics. Several conferences and meetings took place in the mid-2010s, including recreation community programs in 2017 (swimming, horse-riding, and football training courses) (Qoronfleh et al., 2019). During the COVID pandemic, campaigning was primarily online. However, the MOPH's latest symposium on Autism was held in 2021, and the Qatar Society for Rehabilitation of Special Needs (QSRN) last training program on autism was conducted in 2020 (List of special needs centers in Qatar, 2016)). Because of the COVID disruptions, several institutions have not updated online directories, and the MOPH's E-learning platform is yet to go online ("MoPH organizes events on the development of Autism Spectrum Disorder Services", 2021). Some institutions, such as the CDC, HMC, Sidra, QBRI, and other private centers, have continued to host events to raise awareness about disabilities (Alshaban, 2018). The CDC, in particular, has targeted training for professionals and families. There are scarce announcements in 2022 regarding news and activities from several institutions.

Regarding professional development, Qatar Airways collaborated with Shafallah's post-secondary vocational track, hiring people with special needs in their production line (Guldberg et al., 2017). Furthermore, there has been a significant increase in the employment of persons with special needs in the government sector (Qatar Planning and Statistics Authority, 2022). Shafallah's adult training unit, the Roaa center, and the Inclusion Center at Qatar University have been supporting and improving the process of transition into adulthood (Alshaban, 2018).

Regarding training, the Roaa center and National Center for Educator Development at Qatar University are the only institutions advancing continuous training opportunities for teachers and specialists. Qatar University offers US-accredited diploma, bachelor, and master's programs in Special Education. The psychiatry residency program at HMC provides training for residents in Child and Adolescent mental health (CAMHS), including placements at Sidra Medicine, with exposure to youths with various forms of intellectual and developmental disabilities. Recently, Learning Disability (LD) for adults was introduced to the psychiatry residency and fellowship program, and HMC introduced its first Adult LD department. Still, in its infancy, the department is yet to establish a structured program with integrated diagnostic, outreach, training, and other services.

Regarding research, Qatar has had more publications about autism, including case reports, social robotics, caregiver quality of life, and a recent country-wide ASD prevalence study (Kher et al., 2012; Alhaddad et al., 2018; Khan et al., 2021). The country is home to several research institutions, such as Qatar Biomedical Research Institute (QBRI), which specializes in autism genetic research, collaborating with Shafallah's Medical Genetics Center, Sidra Medicine, and other international institutions (e.g., Cleveland Clinic) to further research opportunities. There remains a continued need for research on integration programs, access to programs and services, life opportunities after the pandemic, the insights of persons with disability (Singal et al., 2021), and economic costs.

With the involvement of international stakeholders and Qatar's already demonstrated commitment to persons with special needs, there is ample opportunity for improvement in advancing Qatar's vision 2030 and revitalizing inclusive systems. A comprehensive review of current systems and outcomes of previously approved programs and strategies is warranted to track Qatar's progress, improve ongoing systems, and identify remaining gaps.

Case example

S.M. is a young man diagnosed with autism, epilepsy, and severe intellectual disability. He spent most of his childhood attending the Shafallah center. After graduating, he stayed home with his family, displaying challenging and aggressive behaviors. His family couldn't afford private centers or other specialized care programs, so he started following up with mental health services. S.M. had unsuccessful trials of risperidone and haloperidol to manage his behaviors and eventually was admitted to the inpatient unit due to deterioration in his functioning.

At the time of discharge planning, it is noticed that the family's engagement with the treating team is deteriorating. They avoided phone calls from the health care team, missed scheduled meetings, and rarely visited their son. S.M. stayed in the hospital because his family refused to take him back for safety reasons. During this process, he had a seizure and fell, sustaining head trauma.

It was not until a year and a half after his hospitalization that the family finally met with the treating team. The team tried to arrange for a home visit, and financial support from charities and sought help from the

Amal Center for Special Needs to create a collaborative plan, but the family refused to take him back. Currently, S.M. is rarely visited by family or goes out on a pass. He's on 2:1 nursing observation, is nonverbal, and is dependent on his activities of daily life (ADLs). He suffered from valproic acid-induced thrombocytopenia with a weekly CBC. He does not engage in occupational or physical therapy. He is now 25 years old and has spent the past three years in the hospital unit with little hope of leaving.

S.M. is an example of a person with special needs who has the right to appropriate and timely care in a professional and well-equipped setting, with trained support staff for his needs and his family's support.

C. SETTING PRIORITIES

The health and well-being of people with special needs is one of the seven priorities of the Qatar National Strategy 2018-2022. In line with this, there is a need to train future doctors in Intellectual Disability. Within psychiatry general and subspecialty training programs, there is an embedded curriculum and clinical rotations that enhance the knowledge and expertise of future independent clinicians.

C.1 Medical education in IDD psychiatry

Worldwide gaps have been identified in ID education for medical students (Trollor JN, 2020). Similarly, medical schools in Qatar so far have not identified curricula specific to IDD. During their clinical rotations, medical students may have varied exposure and training related to ID.
Clinical postgraduate training in IDD child/adolescent and general psychiatry and interdisciplinary training opportunities

C.2 Clinical training

In 2020, Hamad Medical Corporation started a Learning Disability Service for adults (Marhaba Qatar, 2021). This service also offers a training program for general psychiatrists who choose to subspecialize in Intellectual and Learning Disabilities.

The Hamad Child Development Center (CDC) and Shafallah Center provide patient care and clinical rotations for General Psychiatry and Child and Adolescents Psychiatry residents and Developmental pediatric fellows.

The CDC offers training opportunities within their specialized child development services and programs for children from birth to 14 years old with Intellectual Disabilities. Pediatricians lead the clinics with specialist training in Developmental Disabilities. They include specialized multidisciplinary programs such as the Early Intervention Program, Autism Program, and Disability Support Program for students.

The Shafallah Center for persons with a disability provides educational services and rehabilitation, including vocational training to individuals under 21 years of age with ID or Autism.

In addition, clinical training for post-graduate trainees at Sidra Medicine includes a three-month rotation in private schools for children with special needs and a 1-month rotation in subspecialty Development Pediatrics Clinics with a multidisciplinary approach to treatment, including services like speech and language, occupational therapy, and psychology.

General and Child and Adolescent Psychiatry Training programs at Sidra Medicine and Hamad Medical Center include specific curricula on ID-related topics such as:

- Developmental Disorders
- Learning Disorders
- Communication Disorders
- Psychological and academic testing
- Psychopharmacology in ID

C.3 Research and research training opportunities

The Qatar National Research Fund (QNRF) actively funds research on disabilities as part of the seven National priorities. The National Priorities Research Program (NPRP) competitively selects research projects that address issues related to special needs populations. The QNRF also supports research efforts by graduate and post-graduate students through the yearly Graduate Sponsorship Research Awards and the Postdoctoral Research Award. Sidra Medicine has an active research division that partners with NPRP for funding. Qatar University is conducting research related to Autism, including the prevalence of the disorder amongst Qataris and innovations in treatment, including using technology to enhance the communication skills of children with Autism. The Qatar Biomedical Research Institute has several active research projects, including early screening, diagnosis, and phenotyping.

C.4 Collaborations and partnerships

Various Qatar organizations have partnered with NGOs to work on the development of policies and programs for people with special needs. Education Above All and the Ministry of Education currently partner with UNICEF to increase access to education and vocational skill training for children with disabilities. Ministry of Education and other local organizations have partnered with others to support the development of education for people with disabilities.

Case example

Project: Autism is a common comorbidity among children with Intellectual Disability, with approximately 10% of children with ID having a comorbid diagnosis of Autism (Oeseburg B et al., 2011). Parents of children with Autism and ID report higher unmet medical needs, healthcare disparities, including lack of shared decision-making and care coordination, and adverse impact on the entire family (Ní Shé É, 2021). The hospital environment can be very challenging for children with special sensory and communication needs.

The Autism Friendly Hospital Initiative at Sidra Medicine is a locally sponsored project which aims to: a) provide education to physicians about the unique needs of children with autism spectrum disorders and b) improve access to assistive devices for the unique sensory-communication and emotional needs of children with ASD. c) increase communication with caregivers to identify and meet the unique needs of these children by using a specific questionnaire.

The project committee includes post-graduate trainees in Developmental Pediatrics and Child and Adolescent Psychiatry. The performance indicators are the percentage of patients and families who access assistive toolkits and complete the parent questionnaire and the percentage of clinicians who complete training related to ASD.

The project is in the implementation phase, and lessons learned include:

- Families of children with autism and special needs are the experts on their children but often feel unheard in healthcare settings. Engaging them directly could improve our ability to meet the unique needs of these children.

- Healthcare staff are open to and appreciative of educational opportunities and skill-building specific to this patient population.

C.5 Future Directions

Qatar has made progress in developing clinical services for people with IDD. These services provide ample opportunity for IDD training to the new generation of physicians and psychiatrists. However, there is a lack of a specific IDD curriculum for broader training programs related to medical specialties, similar to the rest of the world.

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SOUTH ASIA

World Psychiatric Association
Section on Psychiatry of Intellectual Developmental Disorders

INDIA & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions of IDD

With a population above 1.3 billion, India is the 2nd most populous country in the world, next only to China. It is a country known for rich ethnic, linguistic, and cultural diversity, with wide regional variations, so much so that one could find marked diversity even within a few miles. It also remains predominantly rural – about two-thirds of the population live in villages. However, there has been a clear shift towards increasing urbanization with time, with the nuclearization of families. India also has a young population, about half under 25 years and one-third under 15. This has been changing steadily with time towards higher mean age and an increasing percentage of older people.

The country is divided into States and Union Territories with their own governments and a central government. Disability is both a central and state subject; there are central legislations and policies as well as state-level policies and programs.

Given this scenario, it is not surprising that there are wide regional variations in how IDD is perceived, people with IDD are treated, and the cost, availability, and accessibility of services. The life span of people with IDD is increasing, bringing with it new issues and challenges specific to adulthood (Lakhan & Kishore, 2016). In general, services are concentrated in metropolitan cities and urban areas; however, some of the central Government's recent initiatives have attempted to ensure uniform nationwide access to essential services such as early detection/intervention, inclusive education, and social security.

Cultural perceptions and beliefs about IDD vary widely across India, and one can see multiple and contradictory models of disability. They sometimes perpetuate negative attitudes towards disability. This may add to the burden on the caregivers (Edwardraj et al., 2010).

A.2 Prevalence, identification, and early interventions

Prevalence

An earlier systematic review of epidemiological studies found that the best-estimate prevalence in the general population is around 25 / 1000, with excess prevalence in males, rural areas, and low-income groups. This was especially applicable to milder forms of IDD. The review also noted that at least 25 % of the prevalence is preventable with appropriate public health measures (Srinath & Girimaji, 1999). A recent epidemiological study of childhood neurodevelopmental disorders (NDD's) reported that 1 in 8 children had at least one disability, and the prevalence of intellectual disability (ID) was 3.1 % for 2-6year-olds and 5.2 % for 6-9 year-olds (Arora et al., 2018). The study also reported significant modifiable perinatal and neonatal factors. A meta-analysis in 2022 of all the published epidemiological studies found the prevalence to be around 2 % (Russell et al., 2022). Thus, IDD continues to be a significant public health issue that requires attention in India.

Identification

India has two flagship programs for many years that have significantly contributed to health promotion, specific protection, and perinatal/postnatal care that have directly or indirectly have contributed to a reduction of childhood disabilities.

The first is Integrated Child Development Services (ICDS), which focuses on nutrition, immunization, and pre-school education for children under six years (see the link to resources below). The grassroots level workers in ICDS, called Anganwadi workers, serve as a critical link with the community for nutrition, immunization, and running pre-school education services called Anganwadi centres. These workers are also trained in early detection of childhood disabilities, basic counselling, and facilitating referral. However, this aspect of their functioning has not been adequately utilized for various reasons.

Another vast network of key grassroots-level workers is the Accredited Social Health Activists or ASHA's (ASHA means hope). These are local, trained women who work as an interface between the community and the public health system (see the link to resources below). As their primary focus of work concerns pregnancy, perinatal and neonatal period, they are expected to facilitate the provision of optimum per-peri and postnatal care, thereby addressing the risk factors for disabilities.

A more recent initiative is the introduction of Rashtriya Bal Swasthya Karyakram (RBSK), or the National child health program, in February 2013 under the National Rural Health Mission (see the link to resources below). This ambitious program has been formulated to cover the 4 D's of childhood – defects, deficiencies, diseases, and developmental delays, including disability. A mobile health team and district early intervention centre (DEIC) ensure early identification and interventions. The Mobile Health Team screens children in Anganwadi centres (at least twice a year) and schools (at least once a year). However, this program's coverage of developmental delays appears to be highly varied across different regions.

Despite these programs, early detection and intervention remain unrealized for many children with global delays and IDD's, especially in rural areas.

Neonatal screening

India does not have a national policy for neonatal screening programs. Genetic Centre at Government Medical College, Chandigarh, is the first public hospital to start a regular antenatal and new-born screening program (Chavan & Rozatkar, 2014). Three existing regional screening programs in Chandigarh, Goa, and Kerala can serve as models for other programs in India. The main barriers to the universal implementation of a neonatal screening program in India are lack of awareness, cost, lack of advocacy, public policy, and political will (Mookken, 2020).

A.2 Social inclusion and current services and support systems

This has been previously reviewed (see Girimaji & Kommu, 2016; Girimaji & Srinath, 2010). We provide a summary and update on recent developments here.

Education

The education for children with IDD has evolved from no education to special education, integrated education, to inclusive education (Chavan & Rozatkar, 2014). Special schools run by Non-Governmental Organizations (NGO's) / voluntary organizations in big cities starting in the 1960s and 70s marked the beginning of services for children with IDD. The idea caught up, and a review in 2016 (Girimaji & Kommu, 2016) documented a phenomenal growth in the number of special education and other training/ rehabilitation facilities. Most of these continue to be run by NGOs with or without Government support and are an essential source of educational and training opportunities for persons with IDD. They have continued to co-exist with the recent addition of inclusive education facilities.

A significant fillip to the concept of inclusive education was the formulation of Sarva Shiksha Abhiyaan (SSA) – education for all – in the year 2000-01. It aims to provide educational opportunities for all children between 6 and 14 years (till class VIII), including children with special needs (CWSN). This program has a zero-rejection policy, meaning every child will be provided education regardless of type and extent of disability, either in the regular schools on an inclusive basis or at home. SSA provided for Rs. 3,000/- per child per year for CWSN, of which at least Rs. 1,000/- per child is for engaging resource teachers.

Rashtriya Madhyamik Shiksha Abhiyan (RMSA)[for secondary education] provides all students with disabilities an opportunity to complete four years of secondary schooling (Class IX to XII) in an inclusive and enabling environment.

In 2018, Samagra Shiksha Abhiyan ('Samagra' means holistic) was launched, which subsumes Sarva Shiksha Abhiyan (SSA)[for elementary education], and Rashtriya Madhyamik Shiksha Abhiyan (RMSA)[for secondary education], to look at the education of all children, including CWSN, from pre-school to class XII. The new scheme advocates for CWSN toilets, transport, and escort facility for CWSN (see the link to resources below)

Each district is divided into several blocks with a block resource centre (BRC). Each block has several Cluster Resource Centres (CRCs) to conduct in-service teacher training, provide academic support to teachers and schools regularly, and help in community mobilization activities. Each CRC covers a small number of schools within easy reach. Samagra Shiksha Abhiyan provides around 4 resource persons per BRC for CWSN. The Rehabilitation Council of India (RCI) registered special educators should be mandatorily available for all CWSN, including children with high support needs. The educators may be posted at the block or cluster level or as per the requirement. They can operate in an itinerant mode, covering a group of schools where CWSN are enrolled so that each CWSN is adequately covered.

The National Council of Educational Research & Training (NCERT) has developed handbooks for primary and upper primary level teachers on curricular adaptations, inclusive teaching, and how to adopt flexibility in evaluating children with IDD in inclusive classrooms.

Over the years, inclusive education has been slowly and steadily growing in India and is more widely accepted by the educational community. However, significant challenges persist in the form of attitudinal and physical barriers, the adaptation of school pedagogy, lack of human resources, and quality of the educational process.

Vocational training and employment

This is one area that is woefully lacking, even in urban areas. There are few avenues for transition from education – inclusive or special schools - to job training opportunities or employment. Day-care centres run by psychiatric institutions and NGO's offer some training for adults in vocations and attempt job placement or self-employment. A small proportion of individuals with milder forms of disability get absorbed informally into the workforce but are often underpaid or exploited. An encouraging recent development has been the setting up of the Skill Council for Persons with Disability (SCPwD, see the link to resources below) with the explicit aim of addressing this area. A beginning has been made recently to address the issue of skills development in adults with IDD.

Self-advocacy

Persons with IDD are often considered incapable of making their own decisions, living independently, or getting a formal education. Proving this wrong, many persons with IDD came together to launch - the Self Advocates Forum of India (SAFI), which has held national conventions in different parts of the country. By forming such groups, persons with IDD gain self-awareness, collective action, and collaborative mutual support to transform from marginalized people to respected citizens. This initiative is slowly gaining momentum.

Community-based rehabilitation

The 1980s saw the emergence of community-based rehabilitation (CBR) programs funded by NGOs and governmental organizations. Initially, these programs focused on more 'visible' disabilities such as visual and locomotor impairment. Later, however, IDD was included in these programs(Girimaji & Srinath, 2010).

Community-based approaches initially started as outreach services, satellite clinics, and camps run by centres already providing some service. They felt the need to expand the services, driven by the "reaching the unreached" philosophy. As a part of this approach, some training of grassroots level workers was also carried out. The typical activities in CBR programs include a survey of individuals with IDD in a geographically defined area, improving community awareness and attitudes through street plays, rallies, and distribution of Information Education Communication (IEC) materials, to reduce social isolation and enhance participation of individuals with IDD and their families, helping individuals and their families to access services and social security benefits, transfer skills to families for a home-based training program, and school enrolment. Lakhan (2013) described a CBR approach for including rural children with IDD in regular schools and reported a reasonable success rate for children with milder forms of IDD (Lakhan, 2013).

Undoubtedly, the CBR approach holds promise, with a trained grassroots worker being the key professional. Realizing this, central and state governments have started funding more and more CBR programs all over India (Girimaji & Kommu, 2016).

Parent Associations

From its modest beginnings in 1980's, the idea that parents in a locality can get together and form Associations has caught on, and currently, there are around 300 such associations. They have formed an umbrella organization called Parivaar–NCPO ("Parivaar" means "extended family" in the Sanskrit language) with their own website (www.parivaarnfpa.org/). They play an increasing role in advocacy, awareness, organization of services, participation in legislative and policy-making, and the implementation of relevant policies and programs. Parivaar is a vibrant organization with recent innovative activities such as leadership development programs for parent associations, self-advocacy training, and supported decision-making for individuals with IDD (Girimaji & Kommu, 2016).

Family reintegration of homeless persons with IDD

Persons with IDD are overrepresented in homeless populations, with prevalence among homeless people with IDD ranging from 12 to 39% across countries. The rehabilitation needs of persons with IDD, who are homeless, are diverse; one of their most important emotional needs is the desire to be reunited with their families. Banu et al. (2020) discussed the opportunities and challenges in reintegrating persons with IDD admitted to a government-run shelter with their families. (Banu et al., 2020).

Legislations and policies

Table 1 summarizes the relevant, progressive legislations that have been enacted over the years. Legislations and policies concerning persons with intellectual disability:

Sl.No	Name of the Legislation/Policy	Key objectives
1	The Rehabilitation Council of India Act, 1992 (see the link to resources below)	Standardizing and monitoring training courses for rehabilitation professionals and maintaining a Central Rehabilitation Register of rehabilitation professionals
3	The National Trust Act for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999 (see the link to resources below)	This innovative Act provides for the establishment of a National Trust for the welfare of persons with ID and their families, focusing on the empowerment of individuals with ID and their families through several services such as caregiver training programs, health insurance, training centres, greater participation of parent associations and NGO's working in the area in the care process, provision to establish respite and

		residential care facilities funded by the Trust and run by parent associations, issue of guardianship for adults with ID, and for establishing service facilities to promote the development of self-help groups of persons with disability to pursue the realization of their rights
4	The Right of Children to Free and Compulsory Education Act, 2009 (see the link to resources below)	Mandates free and compulsory elementary education, access to school, and barrier-free access to a neighbourhood school to all children with disability, including IDD
5	The Rights of Persons with Disabilities Act, 2016 (see the link to resources below)	Recognizes ID as one of 21 disabilities. Adopts the rights perspective. Has provisions for inclusive education, reasonable accommodation, barrier-free access, universal design, high support needs, reservation in jobs, and education. It provides for 1% reservation in Government jobs for persons with benchmark disability due to ID, mental illness, specific learning disability, autism spectrum disorder, and multiple disabilities. It also provides a 5% reservation for persons with benchmark disabilities in government-run or aided educational institutions.
6	National Education Policy, 2020 (see the link to resources below)	The policy recognizes the importance of creating enabling mechanisms for providing Children with Special Needs (CWSN) the same opportunities of obtaining quality education as any other child. CWSN includes IDD.
7	The National Commission for Allied and Healthcare Professions Act, 2021 (see the link to resources below)	Recognizes the specialized skills and contributions of more than 56 types of allied and healthcare professionals, including behavioral health professionals, and mandates registration, regulation, training, and quality control of these professionals.

The National Trust offers a holistic model of providing community-based care to a person with IDD encompassing multiple dimensions. It addresses issues at all systemic levels of the socio-ecological model. The experiences gained in setting up the Trust and the benefits to society have important lessons for India as well as other low-and middle-income countries that are yet to develop such a platform (Menon et al., 2017)

Human resource development:

Apex institutions. A significant initiative in developing appropriate human resources at all levels in IDD has been setting up the National Institute for the empowerment of persons with intellectual disabilities (NIEPID, Secunderabad; www.niepid.nic.in). Established in 1984 as the National Institute for Mentally Handicapped (NIMH), this apex governmental institution has been active, besides human resource development, in promoting community awareness, developing models of care, and undertaking research, documentation, and service delivery.

The National Institute for Empowerment of Persons with Multiple Disabilities (NIEPMD, Chennai; https://niepmd.tn.nic.in) was established in 2005. It serves as a national resource centre for empowering persons with multiple disabilities, including developing human resources.

Social security measures. The Government of India provides several social security benefits for persons with ID and family members. Recently, the Government of India has started a unique disability identity card (UDID) initiative where families of persons with disabilities can apply online for a disability certificate at www.swavlambancard.gov.in

Table 2 lists some of these benefits.

Social security benefits for persons with intellectual disability:

- Disability pension
- Travel concessions [bus and train (for the person with IDD and escort)]
- Reservation in Government jobs
- Reservation in Government-run or aided educational institutions
- Scholarships for education
- Income tax exemption for the person with IDD and family caregiver
- Niramaya health insurance scheme
- Subsidized loans to start livelihood ventures for the family caregivers
- Pension transfer from parents/siblings to the person with IDD
- Free legal aid services
- Exemption from routine transfer in Government jobs for the family caregivers
- Exemption from customs duty for import of assistive devices

A recent multicentric study of disability certification across 11 centres reported that ID was the most common mental health condition to be certified in most centres (Sivakumar et al., 2022).

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES*

Like in other parts of the world, problem behaviors and comorbid psychiatric problems are common in children with IDD((Kishore et al., 2004, 2010). The facilities for evaluating and managing problem behaviors and comorbid psychiatric disorders in children and adults are limited and largely confined to urban areas.

It is a major source of family stress and often an important reason for seeking consultation. Traditionally, these children have been cared for in child guidance clinics run either by paediatricians or psychiatrists in general hospital psychiatry units. Not surprisingly, these facilities exist only in the urban areas, and children from rural areas are often brought to the urban areas.

Recently, the Indian Academy of Paediatrics (IAP) has started a childhood disability chapter to involve paediatricians in early detection and intervention. The IAP has recently come up with frequently asked questions (FAQ's) on the care of a child with ID (see the link to resources below). The IAP has also developed a guideline for diagnosing and managing global developmental delay(Juneja et al., 2022). The Indian Psychiatric Society has recently published clinical practice guidelines for ID (Kishore et al., 2019)

Adults: There has been very little focus on understanding mental health needs and providing adult services. Though India has a very elaborate and extensive primary health care system, the facilities and expertise available in the PHCs to manage mental health issues are grossly inadequate. Management of adults with problem behaviors typically happens in general hospital psychiatric units and mental hospitals with outpatients with or without inpatient facilities. However, there has been a recent improvement in the situation in the form of the active implementation of the District Mental Health Program (DMHP), which ensures that a person trained in mental health care or a psychiatrist is available in the district hospital. Recently, an online training program leading to a diploma in community mental health has been started to train doctors, psychologists, social workers, and nurses. A module focussing on ID has been included in this course. Several thousand such professionals have been trained so far (see the link to resources below).

B. 1 Challenges in implementing person-centred care

Lack of awareness about IDD breeds misconceptions and superstitions (Edwardraj et al., 2010). Planners give disability, especially IDD, low priority. Though many legislations, programs, and schemes exist, implementation is a significant problem. There is a highly uneven distribution of services concentrated in urban areas and major cities. It is not uncommon to see families feeling lost, unsupported, and stressed. Quality of life suffers, and the family often suffers in silence and isolation. There is a near-total lack of services for adults, whether training opportunities, job training, independent living, or respite / residential care services.

With the increasing longevity, more persons with IDD are outliving their parents. With the breakdown of the joint family system, parents are increasingly concerned about who will care for the person with IDD after their lifetime.

A recent major challenge has been the COVID-19 pandemic. Closure of schools and intervention centres, social isolation, and sometimes neglect and abuse at home has had a near-devastating effect on the lives of persons with disabilities in general and IDD in particular. It has also significantly increased caregiver strain among caregivers of CWSN (Dhiman et al., 2020).

B.2 Opportunities for Action: Connecting families, developing programs, ensuring sustainability

Strengthening families

India is a collectivistic society with a powerful family and kinship system across the breadth and length of the country. Most individuals with IDD live with their families, which has been a great source of support for persons with IDD, despite globalization, westernization, and urbanization. There has never been large-scale institutionalization of individuals with IDD. Families care for individuals with IDD with a sense of duty, compassion, and commitment. However, families (especially mothers) do suffer and experience high levels of stress and care burden (John & Zapata Roblyer, 2017). Recognition and acknowledgment of the roles played by families, taking steps to strengthen and empower them, and involving them in the planning and organization of services would make a major difference in the lives of people with IDD and their families. This has happened to some extent with the formation of the National Trust and Parent association movement, and there is great potential if there is a greater focus on this aspect. Home-based, parent-mediated early interventions have been shown to work and must be supported on a large scale. Improving awareness about available social security measures is also very much needed. Studies have reported poor awareness of government legislations and policies about disability benefits (Kashyap et al., 2012).

Recognizing and strengthening NGO’s contribution:

NGO’s have always played a major role in providing services, especially in inclusive/special education and rehabilitation. This is another sector with great potential to grow further in addressing the needs fulfilment of rights, especially of adults, such as vocational training, skill development, independent living skills, and respite and residential care services.

Utilization of corporate social responsibility funds

A critical source of funding has been the central Government's mandate for private companies to spend a certain percentage of their earnings on corporate social responsibility (CSR). It is encouraging to note that corporate houses are showing a growing interest in financing viable programs in the area of disability. Formulating much-needed, viable, and doable programs and implementing them as demonstration projects is likely to attract more funding.

Income-generating programs

One interesting aspect in India is that psychiatric rehabilitation centres also cater to people with IDD. To address this need, they facilitate skills training, supported employment, self-employment, and home-based work programs. They also run income generation programs in day-care settings such as manufacturing household consumables, paper products, textile products, handicraft products, food products, and jute products; animal husbandry and horticulture initiatives; running cafeterias and petty shops. The revenue generated from the income generation program helps centres sustain the vocational unit and offer monetary incentives to the clients involved (Roy et al., 2022). Such skill / job-training and income-generating opportunities need to be formulated as per the local needs and realities and replicated across the length and breadth of India.

Inclusion of IDD in public health insurance

Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PMJAY), launched in 2018, is a large health assurance scheme that aims at providing a health cover of Rs. 5 lakhs per family per year for secondary and tertiary care hospitalization to over 10.74 crores of poor and vulnerable families that form the bottom 40% of the Indian population (see the link below). There is a move to include IDD in PMJAY, which has enormous potential for the development of health services as well as health insurance coverage.

Case examples of promising and successful approaches and programs

Case 1: Quizabled

Quizabled is a unique quizzing program for children and youth with disabilities, organized by Seva-in-Action, an NGO in Bengaluru, and is corporate-funded. The event includes five different categories of disability, namely, Intellectual Disability (ID), Cerebral Palsy (CP), Autism Spectrum Disorder (ASD), Visual Impairment (VI), and Hearing Impairment (HI). It is the first of its kind in India, where children and youth with disabilities are allowed to showcase knowledge and capabilities. The primary purpose of this program is to provide a platform for persons with disabilities for knowledge development, to raise awareness by dispelling myths about the potential of children & youth with intellectual and developmental disabilities, and to promote and encourage the participation of persons with disabilities in quizzing events and competitive exams in the future. From its modest beginnings, this program has gained a lot of momentum and popularity with its activity sustained even during the pandemic by shifting to virtual mode and currently involving several States (see the link below).

- This is an example of how a creative and innovative approach can change attitudes, break myths, and increase social participation

Case 2: A successful school readiness program

A practical model of a school readiness program for children with mild intellectual disabilities has been described and evaluated recently(Chavan & Ahmad, 2021). It aims to provide sufficient training for meeting the prerequisite skills needed for inclusion in an inclusive classroom so that CWSN will have equal opportunities for curricular and co-curricular activities. It covers primary as well as pre-primary education. The curriculum is adapted and modified from existing curricula for inclusive schools. Besides academics, children with disability are provided adequate training on activities of daily living skills, social communication, and therapeutic interventions. Duration is for one year with some flexibility. An expert team supervises and implements the activities and also liaises with parents and schools to ensure adequate preparation of pupils, their inclusion into schools, and following them up after inclusion. The success rate of this program has been high, with a very low dropout rate (5 out of 63).

- This is a promising model of how a collaborative approach can address barriers and enhance the inclusion of children with IDD into the educational system

Case 3: A Group Housing Project run by the parent association

This ongoing, successful project is run by Karnataka Parents' Association for Mentally Retarded Citizens (KPAMRC). To answer the vital question of parents as to 'What after us?' KPAMRC decided to develop a group home rehabilitation complex to provide a home away from home for young adults. Support for this project has come from parents, organizations, and individuals in India and abroad and the National Trust. The Group Home Rehabilitation Complex can accommodate over 60 persons and has a day-care centre. Admission is for persons who are 21 years and above. Parents/guardians can take back their children at any time of their choice after three months of admission, giving 30 days' notice. Parents/guardians must provide required medicines, clothes, etc., for their wards, except those from poor backgrounds. The core group running the group home consists of two representatives from parents of persons residing at Vishwashanti Niketan and two from the Governing Council of KPAMRC. The monthly meetings are held to review and deal with any problems. Setting up this house has spurred many parent associations to start their own group homes.

- This initiative by the collective effort of a group of parents supported by the Government and other sources can be the way forward to ensure the welfare of adults with IDD with aging parents or when parents are no more.

Case 4: Community managed services in a rural area - a bottom-up grassroots strategy

In this unique approach in the rural areas of Unified Andhra Pradesh, a state in South India, women with disabilities who were willing to work as community resource persons were given hands-on training in identification, basic stimulation, and facilitating referral to concerned Government functionaries. In addition, neighbourhood centres were established to meet with families of persons with IDD collectively and to promote social participation, inclusion, recreation, and awareness-building. Sustainability was ensured by linking these activities to women's self-help groups and disability groups. Results were encouraging (Narayan et al., 2017).

- This approach built around ownership of the program by the community could be one answer to the issue of sustainability of the community-based approach.

C. SETTING PRIORITIES

Medical education in IDD psychiatry

Undergraduate medical education in India does not focus enough on psychiatry. Some learning happens in paediatrics to some extent, with modest coverage on developmental milestones and developmental disorders. The posting in psychiatry is too short and not taken seriously, with hardly any exposure to NDD's in general and IDD in particular. Postgraduate psychiatric education mandates child psychiatry postings for three months. But very few centres have a separate facility/department for Child & Adolescent Psychiatry. So, the residents are posted to big centres, which get crowded with trainees. Thus, the training suffers.

Research

Research focus on IDD has been steadily increasing in the last 2-3 decades by health, education, and disability sector professionals. Major areas have been psychological and behavioral characteristics, family stress and coping, parent-mediated home-based training, CBR programs, epidemiological studies, studies on special education, and habilitation processes. Another area is medical aspects such as genetics and etiological research (Girimaji & Srinath, 2010). Though one can find a number of studies covering different areas, the quality of research has been an issue.

Lakhan and Ekúndayò identified the following research priorities: large-scale epidemiological studies from a public health perspective with an understanding of the dynamics and determinants of the condition or time, unique needs of the aging IDD population, and developing models of care that includes physical and mental health needs, development of sustainable community-based intervention models, and understanding and addressing the learning needs of this population ((Lakhan & Ekúndayò, 2017). Undoubtedly, there is a need for research focussing on ground realities so that locally relevant policies can be formulated. Systematic reviews and strategic research studies are needed to build an evidence base. Description of successful programs and better networking of different professionals working in diverse sectors are required.

D. Conclusion

From the above account, it is clear that India is in transition in terms of services for people with IDD. Numerous encouraging initiatives in the governmental, NGO, and parent sectors cover health, education, and social justice. However, to a considerable measure, a rights-based approach for services for individuals with IDD is still a distant reality. Families continue to provide care with relatively insufficient degrees of support. Though many progressive legislations have been enacted, they must be fully implemented. One positive development has been the realization by the Governments of the need to formulate and implement various programs to support individuals and families throughout their life span. These are expected to significantly impact the quality of life of people with IDD in the years to come.

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F. LINKS TO AVAILABLE NATIONAL / REGIONAL RESOURCES

Integrated Child Development Services (ICDS). http://icds-wcd.nic.in/icds.aspx

Accredited Social Health Activists (ASHA). https://nhm.gov.in/index1.php?lang=1&level=1&sublinkid=150&lid=226

Rashtriya Bal Swasthya Karyakram (RBSK) https://nhm.gov.in/index1.php?lang=1&level=4&sublinkid=1190&lid=583

Samagra Shiksha Abhiyan https://samagra.education.gov.in/

Skill Council for Person with Disability(SCPwD) https://nsdcindia.org/nos-listing/38

The Rehabilitation Council of India Act, 1992 http://www.rehabcouncil.nic.in/writereaddata/rciact.pdf

The National Trust Act for Welfare of Persons with Autism, Cerebral Palsy, Mental Retardation, and Multiple Disabilities Act, 1999 https://thenationaltrust.gov.in/upload/uploadfiles/files/National%20Trust%20Act%20-%20Englsih.pdf

The Right of Children to Free and Compulsory Education Act, 2009 https://legislative.gov.in/sites/default/files/The%20Right%20of%20Children%20to%20Free%20and%20Compulsory%20Education%20Act,%202009.pdf

The Rights of Persons with Disabilities Act, 2016 https://legislative.gov.in/sites/default/files/A2016-49_1.pdf

National Education Policy, 2020 https://www.education.gov.in/sites/upload_files/mhrd/files/NEP_Final_English_0.pdf

The National Commission for Allied and Healthcare Professions Act, 2021 https://egazette.nic.in/WriteReadData/2021/226213.pdf

10 FAQ's on care of a child with intellectual disability.

https://iapindia.org/pdf/0409-Ch-021-IAP-Parental-Guideline-Intellectual-Disability.pdf

Course on diploma in community mental health. https://nimhansdigitalacademy.in/diploma-in-community-mental-health-for-doctors/

Ayushman Bharat Pradhan Mantri Jan Arogya Yojana (PMJAY) https://nha.gov.in/PM-JAY

Quizabled https://quizabled.com/home

World Psychiatric Association
Section on Psychiatry of Intellectual Developmental Disorders

PAKISTAN & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions of IDD

Demographics of Pakistan

Pakistan, a country in South Asia, is the world's fifth-most populous country, with a population of almost 242 million (Bureau of Statistics, Government of Pakistan,2021, at www.pbs.gov.pk). This figure includes Pakistan's four provinces, Islamabad Capital Territory, Azad Kashmir, and Gilgit-Baltistan. It is an ethnically and linguistically diverse country, with similarly diverse geography and wildlife. Pakistan has a relatively high, although declining, growth rate supported by high birth rates and low death rates. The country's urban population has more than tripled between 1981 and 2017 (from 23.8 million to 75.7 million), however despite this, the nation's urbanization rate remains one of the lowest in the world, and till 2017, 65% Pakistanis still lived in rural areas.

The healthcare delivery system of Pakistan (تحفّظ صحتِ عامّہ ، پاکستان) is complex because it includes healthcare subsystems by federal governments and provincial governments competing with formal and informal private sector healthcare systems. The country's health sector is also marked by urban-rural disparities in healthcare delivery and an imbalance in the health workforce, with insufficient health managers, nurses, paramedics, and skilled birth attendants in the peripheral areas.

Cultural perceptions

Pakistanis belong to a wide range of cultures and social groupings, from entrepreneurs to rural laborer's who still live by ancient tribal codes. The ways in which ordinary people, and educated people, think about Intellectual developmental disorders (IDD) in Pakistan have their own logic and cultural appropriateness. They are also in a continuous process of change through the experiences in social media, and through influences from the rest of the world. Families had previously always coped privately with their members having IDD, who in turn coped as best as they could with their limited, sometimes hostile, sometimes permissive, environment. Rural families would often take anyone with a `mental or spiritual' problem to saints' shrines where various rituals were conducted (Miles, 1992). Although it is worth noticing that Islam has a favorable stance on IDD, as a Quranic text exists that prescribes guardianship for the intellectually disabled. Muslim lawyers debated the civil rights of persons with IDD a thousand years before the current Western debate. Historically in various parts of Pakistan people with mild to moderate IDD are protected and considered Divine *(sai, saint, Allah wala)*, they are treated fairly and even considered to have special connection with God. The cases where severe or profound disability is present, families commonly link it to *dimaghi kamzoori, Doreey, nafsiyati kamzoori* which broadly translates to organic causes of the brain. Most parents hope that these children would 'grow out' of the disabilities. Traditionally most of them are sent to normal schools in the hope they would use rote memory to stay afloat the education system and a common perception is that marriage (especially in mild cases) would be an answer to the increasing behavioral issues which develop in adolescence. Persons with IDD have been a marginalized group of Pakistan's population who are not provided appropriate chances at being autonomous, however there is perception that the age of digital media is bringing about awareness and a change for the better.

C.2 Prevalence, identification, and early interventions in the country

Prevalence

IDD affects 1–3% of the world population; however, its prevalence in the developing world is almost twice that of the affluent world. Burden of mental disorders in terms of Disability-adjusted life years (per 100,000 population) for Pakistan is 2,430 and the percentage of DALY for intellectual disability is) 0.21% (WHO, 2015). The prevalence of IDD in Karachi, Pakistan, in children between the ages of 2 and 9 years old, based on screening with ten questions (TQ) was found to be 19.0 per 1000 children (Durkin, Hasan & Hasan, 1995), which is near the upper limit of reports of prevalence in developing countries. Poverty and severe malnutrition lead to approximately 28% of Pakistani children develop intellectual disability within a year of birth (Yaqoob, Bashir, Zaman, et al, 2004). Cultural practices such as consanguineous marriages may play a role in the etiology of learning or intellectual disabilities in Pakistan. In Pakistan, the exact number of intellectually disabled persons is not known due to lack of official census on regular basis as well as the inadequacy of census data due to lack of properly defined illnesses. According to the data obtained in the 1998 census the total number of persons with ID, both male and female were 249,823 in the entire population.

National Database and Registration Authority's report mentions generating 31,914 identity cards to individuals with intellectual disability proven by a medical board between the time period of February 2020-feburary 2021. (https://www.pbs.gov.pk/content/disability-statistics)
Pakistan Bureau of Statistics (PBS) being National Statistical Organization has taken initiative of including Disability module in Pakistan Social & Living Standard Measurement (PSLM) Survey.

As Disability is a relatively rare event, therefore for its true coverage and representation, the usual sample size of PSLM survey i.e., 80,000 households have been enhanced to 195,000 households which will enable PBS to develop disability estimates at the district level with desired reliability. The field work of PSLM District Level Survey 2019-20 has been completed and results will hopefully be available in near future. (https://www.pbs.gov.pk/content/disability-statistics).

Identification

Developmental monitoring of children is an important strategy for the early detection and management of IDD. Two promising methods being used in Pakistan are:

(1) Identification of delayed culturally appropriate age-specific milestones is the first sign noticed by care givers, and terms such as *kamzoor, seedha or sai* are commonly used to report these observations. Surveillance of the development of infants and pre-school children starts at home usually by the mother or other care givers as the joint family system prevails. It is also usually a first step to mobilizing formal and informal support networks.

(2) Use of the Ten Questions Screen (TQ) has been found to be effective in identifying children with any form of developmental disability, not specifically intellectual disability. It is a brief questionnaire administered to parents as a personal interview. Five of the questions are designed to detect cognitive disability, two relate to movement disability, and there is one question each on seizures, vision, and hearing. The target age group is 2–9 years. The TQ is intended as a rapid, low-cost method of case finding in communities such as those in low and middle income (LAMI) countries where many or most seriously disabled children have never received professional services. (Durkin et al. 1995).

Health care workers (traditional birth attendants, lady health workers) and general practitioners are available in even rural areas to guide the parents about referral pathways which ultimately lead them to seeking advice from Neurologists, Psychiatrists, Clinical Psychologists, Speech and language pathologists, Occupational therapists, Pediatricians or Physicians.

Standardized assessment instruments including Wechsler intelligence scale for children, Wechsler Adult intelligence scale, Vineland Adaptive behavior scales etc. are widely used for screening, diagnosing, and assessing the severity of developmental disorders and persons adaptive functioning. The choice and type of test is important because many psychometric tests are too difficult for some persons with ID. Genetic testing is available in Pakistan but sparsely ordered due to high costs and its unavailability in public hospitals.

Early intervention

A consistent evidence-based ante-natal care system is needed in the country to detect and prevent common errors during pregnancy, pre- or post-delivery. The following dimensions are the focus of intervention if a child with IDD is identified:

1. Determining the level of intellectual functioning (i.e., severity of IDD)
2. Etiology/syndrome
3. Associated medical problems
4. Associated psychiatric problems

All district and tertiary care hospitals offer specialist services for assessment and management of Intellectually disabled persons; however, these facilities are not available in the far-flung rural areas where basic health units are functional. The barriers in accessing early intervention in Pakistan include delay in detection and help seeking (average time 2-4 years after identification) either due to lack of knowledge or no social support or health care resources, financial constraints and stigma related to having a child with intellectual disability (Mirza, Tareen, Davidson, et al, 2009). Individualized educational plans along with early parent led initiatives (within first 5 years) based on the principles of applied behavioral analysis can benefit individuals with IDD.

Community based model

Due to barriers in service delivery, the focus of intervention should be shifted from city-based institutions to the community, involving persons with disabilities, family members and volunteers, supported by local health professionals as well as having a system of consultation/referral to more specialized services (a three-tier model). Apart from empowerment, this model is purported to provide local expertise in the community and minimize the cost of rehabilitation. Schools can be involved in this approach as students can pass on information to peers and family members.

Family network system

Practiced successfully in Pakistan, in this program families with developmental disorders were identified through a mobile phone–based interactive voice response system and organized into "Family Networks." "Champion" family volunteers were trained in evidence-based interventions. An Avatar-assisted Cascade Training and information system was developed to assist with training, implementation, monitoring, and supervision. 'Champion family volunteers,' worked under the guidance of mental health specialists and provide interventions to families with children having developmental disorders. It was suggested that this system can help minimize the treatment gap for childhood intellectual and developmental disorders in low- and middle-income populations (Hamdani, Atif, Tariq et al, 2014).

A.3 Status of social inclusion

Society has come a long way from looking at persons with IDD as a punishment for wrong doings of their parents, being possessed by evil spirits or capable of doing nothing (Ahmed, 2019). Over the years there has been a gradual change in the way people think about persons with IDD but still there is a proportion of public that finds it hard to differentiate between mental illness and IDD. This confusion can at times prevent them from appropriately approaching or interacting with the persons with IDD. Overall, the awareness has gradually improved in recent years and educated segments of society are becoming more accepting towards diversity.

This change also reflects in the official and academic language and nomenclature. The previously used terms like mentally handicapped and mentally challenged are being replaced with Intellectual disabilities and IDD. Government of Sindh province passed "Sindh Empowerment of Persons with Disabilities Act" in 2018 (Sindh, 2018). This act is aligned with the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). Other provinces are also making efforts in this direction. Special education department Punjab has also started a process to revise its official nomenclature and classification and align it with the international classification systems like DSM-V-TR (Diagnostic and Statistical manual of mental disorders 5 text revised) and ICF (International Classification of functioning, disability, and health).

In rural areas where literacy rate is not that high, people tend to have limited information about IDD. Interestingly, despite the lack of sufficient knowledge, the community is so closely knitted that social inclusion is far better there as compared to the urban areas. The simple life of a village is less demanding and easier to accommodate diverse needs of a person with IDD. In big cities people have comparatively easy access to well trained and qualified health professionals in public and private hospitals. Once the child is diagnosed by the health professionals, parents can contact any public or private school. In urban areas it is easier to approach a public or private run inclusive or special needs education school. It becomes challenging for children with IDD and neurodiversity living in rural areas to access any academic institute (Chauhdry, 2019).

Academic facilities for persons with IDD are provided by special education schools managed by government, private sector, and NGOs. After 18th constitutional amendment in 2010 many departments including education were devolved to provinces (UNICEF, 2017). In some provinces the special education department is independent entity for example in Punjab while in others it is working under social welfare department such as in Baluchistan.

Public schools of special needs education provide free books, academic facilities, and transport facilities. In Punjab alone, there are 303 govt. run schools for children with special needs, providing academic facilities to 38,000 children across province. Only 16% of the enrolled students are with IDD (SED, 2022). For a province with population of 208 million, this enrolment ration is alarming. Most children with IDD fail to get access to any public or private academic institute. Regular public schools in Punjab where more than 12 million students are enrolled, are managed by school education department of Punjab. Now serious efforts are being made to create a liaison between special education and school education departments so students with special needs can be enrolled in regular schools through inclusive education program.

Vocational training is essential for economic independence of persons with IDD. There are very few vocational training opportunities available for persons with IDD. The public technical training programs require high school certificate for enrolment. There is no alternate academic certification system presently available for students with IDD, therefore they fail to meet the admission criteria of public technical and vocational training institutes. Public schools for special needs education are mostly providing only pre-vocational or introductory training programs that does not equip the students with employable skills. There are only few non-profit organizations across the country providing quality vocational training facilities to the persons with IDD. Although a 3% employment quota has been fixed by the government for persons with disabilities but persons with IDD rarely or never get the employment opportunities. Mostly because the recruitment criteria require formal academic certifications. There are very few examples where, with the efforts of parents and training institutes persons with IDD were able to get and maintain a job. In such cases on job training and sensitization of co-workers and managers played a crucial role in successful transition from training institute to workplace.

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

Persons with Intellectual Developmental disorders (IDD) have higher frequency of mental health problems than the general population. It may be due to increased vulnerability because of higher incidence of Epilepsy, physical and sensory problems, poor communication, educational deprivation, poverty, and social and psychological hardships. High rates of comorbidity, if undiagnosed and untreated, is linked with poor prognosis and impaired quality of life for persons with IDD. There may be a tendency to attribute any behavioral disturbance to an individual's IDD rather than looking for comorbidities (diagnostic overshadowing), which may need additional support from the multidisciplinary team with regards to daily functioning.

B1. Mental Health problems in Persons with IDD in Pakistan

Although the evidence for association between IDD and Psychiatric disorders is compelling, there is paucity of published studies from Pakistan on this topic. There are not many epidemiological studies in the field of mental health overall and to our knowledge no national studies on the prevalence or incidence of mental health disorders in persons with IDD. Small scale, mostly single center studies focusing on younger population from Pakistan have reported variable, yet consistently higher rates (between 25%- 54%) of Psychiatric diagnosis in IDD. (Imran, Azeem, Sattar, et al, 2015; Sheikh, Ashraf, Imran, et al, 2018; Imran, Bodla, Shoukat et al, 2021). This variability may be due to different study population, settings in which studies were carried out, IQ levels and methodology for ascertaining psychopathology. The most common comorbidities observed included oppositional defiant disorder, conduct disorder, attention deficit hyperactivity disorder (ADHD), autism spectrum disorder and acute and transient psychotic disorders (Imran, Azeem, Sattar, et al, 2015; Sheikh, Ashraf, Imran, et al, 2018). Another study noted that children with IDD and comorbid ADHD are more likely to exhibit externalizing behaviors such as conduct compared to children with IDD without comorbid ADHD (Ali & Hakro, 2014). One fourth of Six hundred and thirty-four patients admitted in a dedicated child and adolescent psychiatry unit in Pakistan were found to have comorbid Intellectual disability (Imran, Bodla, Shoukat, et al, 2021). Furthermore, severely disturbed behavior often with underlying intellectual disability was identified as one of the most common reasons for admission of very young children in the facility (Imran, Bodla, Shoukat, et al, 2021). Presence of physical comorbid conditions like epilepsy, hearing, and vision disturbances among patients with IDD is also noted to be a strong predictor of psychiatric comorbidity among primary caregivers (Khalid, Arif & Hashmat, et al, 2021)

Caregivers have listed challenging behaviors like verbal aggression, physical aggression, self-injurious behaviors, sleep problems, inappropriate sexual behaviors, and integration in society as their major concerns in relation to Intellectual Developmental disorders in Pakistan. (Imran 2015, Sheikh MH 2021).

B.2. Challenges in implementing person-centered care.

There is growing interest in developing countries like Pakistan to focus on such factors that affect or compromise the provision of services to special needs population. Many challenges are noted in implementing person centered care. Most significant is that models of care are often unclear and data on service use or mental health outcomes are not systematically collected. This lack of epidemiological data in Pakistan represents a potential barrier in planning mental health and education services especially in reference to Persons with Intellectual Developmental disorders. Poor coordination among health, education and social sector is also a major challenge and so is the fact that policies do not uniformly address the needs of persons with IDD.

Only about 1% of Pakistan's annual budget is spent on health with no separate allocation for Mental health. Mental health services including inpatient units are mostly concentrated in large cities, and big University centers. Specialized Mental health services for IDD are limited by poor availability, accessibility, and adequacy. Some patients with IDD and comorbid mental health problems, who need admission end up being managed in general psychiatric units, far from the ideal scenario. Also, in Pakistani society and culture, it is commonplace to approach spiritual or traditional healers in cases of developmental delays or mental illnesses as people usually perceive these disorders to be the result of supernatural influences (Javed, Khan & Nasar et al, 2020). Although significant improvements have been noticed in the last few decades in provision of Pediatric intellectual disability services, unfortunately the areas of adults with IDD remain largely neglected. Services for adults with IDD are underdeveloped both in quantity, and quality of human and infra structure resources. Various other barriers like stigma, economic adversity, socio cultural factors are key barriers of utilization of limited services which are available. Most of regular schools and other higher learning institutions fail to cater for special needs of persons with IDD and as a result, they continue to struggle. The problem is further compounded by the fact that there are limited support services for care givers, who are responsible for looking after this vulnerable population. Families continues to struggle and gain social support. There is need to develop specialized programs geared towards person with IDD and comorbid mental illnesses and their families' needs, which are flexible, and strength based. The support services need to be responsive to the needs of the family in which they are living. Organized support groups for caregivers and families can play an enormous role in providing education and support for these families too. It will be imperative to look at building sheltered workshops, vocational services, appropriate living arrangements, and support for these individuals and families in order to empower them.

B.3 Opportunities for Action

Awareness is the most crucial aspect in a country like Pakistan. A regular show is telecasted from national television channel on every Eid with the title "Hum Sub Sath Hain" (we are all together). This show features the talents and achievements of persons with special needs. This program alone has played an important role in projecting a positive picture of persons with IDD and other special needs. Serious efforts are required for more awareness raising programs in national and local languages about the capabilities and rights of persons with IDD.

Children with IDD are usually diagnosed by psychiatrists or pediatricians, but it is the general medical practitioner who gets to see the child first. If the doctors are given a significant orientation and knowledge of special needs, including IDD, at their medical school, children can get detected and referred to relevant experts earlier.

Trained and professional human resource plays the most important role in providing quality educational, therapeutic, and vocational services to the persons with IDD. Few years back it was difficult to find allied health professionals (e.g., speech therapists, physical or occupational therapists) but now many universities have started graduate and post graduate programs. It was important that pre-service training of professionals met the requirements of the industry. Efforts are made by the HEC (Higher Education Commission) that curriculum review committee at federal and provincial level have representatives from the industry. Chartered universities in big cities are also developing collaborations with institutes providing services to children with IDD. When prospective teachers and professionals e.g., clinical psychologists, physical therapists, speech therapists and occupational therapists get the opportunity to do their clinical placements in institutes for special children, they are better equipped to extend quality services as professionals. These clinical attachments need to spread to professional training colleges and universities in other cities of the country (Memon. et. al. 2016).

Kids are more accommodating and accepting to physical and intellectual diversity. Inclusive education plays a vital role in making children accept diversity and support each other as they study and grow together. Access to regular schools' benefits both typically growing and children with IDD (Chauhdry, 2021). Historically, a major barrier in implementation of inclusive education has been the administrative structure of public education. In almost all provinces school education (regular education) and special education are managed by separate departments. Different initiatives have been taken in collaboration with school education and special education departments in past, but implementation of an elaborated inclusive education strategy is still a dream (UNICEF, 2021). In private sector we do see few small-scale successful projects for inclusion of children with IDD in rural and urban areas.

Few programs of sheltered or supervised employment are being run by few NGOs. Under these type of programs semi trained persons with IDD are adjusted on a specific workstation in an assembly line with proper modifications. For example, in a stitching unit, a person of IDD might be able to work on a finishing station to cut extra thread and pack the finished products. The working shifts are also reduced or split to accommodate two workers with IDD at the same station. For the work they do, they are given salary, and this contributes towards their economic empowerment under a supervised environment. In very few cases the organizations also succeed in helping workers with IDD transition to mainstream jobs with the help of job coaches.

Case Example: Special Chef Project

Vocational skills training is a long and painstaking process. Months and sometimes years are required for a person with IDD to get proficient in a skill. Persons with IDD can master the skill to a certain level based on their capabilities. It becomes very frustrating for persons with IDD and their families, when after years of efforts they fail to secure a job.

Rising Sun is a non-profit organization and was faced with the similar challenges. Their vocational training team in collaborations with the parents of persons with IDD produced a unique project named "Special Chef." Adults with IDD who had been trained in cooking combined with a trainer started preparing food items for the school canteen. They independently managed the procurement, preparation, packing and sale of food. Once they gain confidence, they started preparing frozen food items which were free from preservatives. Gradually this program spread from one campus to three campuses of Rising Sun.

Currently, twenty persons with IDD are associated with this project. They are managing three canteens and serving more than 500 people a day. Frozen food range of more than fourteen items and traditional sweets range is also being sold on market competitive quality. Most recently they have also started lunch delivery service for corporate offices. Now this project has become financially self-sufficient and special chef team independently manages the salary of all team members and cost of food production. In future Rising Sun aspires to develop this project into a social enterprise and open Special chef café so people can interact and get inspired by the talents of chefs with IDD.

Table 1. Lessons learned.

- It is very difficult to find jobs in recent times, need of the hour is to develop innovative programs to make persons with IDD financially independent.
- A vocational training program for persons with IDD should include hands own training of skills, professional communication, money management, record keeping and entrepreneurship skills.
- Entrepreneurship and self-employment programs for persons with IDD should be developed according to local market and social context.

The Pakistan Medical and Dental Council (PMDC) is the administrative regulatory organization for the medical profession in the country. Although there is acknowledgement of Psychiatry and behavioral sciences teaching in undergraduate curriculum by PMDC, the absence of psychiatry as an examinations subject has hindered progress for its teaching (Javed, Khan & Nasar et al, 2020). Currently, there are few lectures dedicated to Intellectual disability in Pediatric and Psychiatry syllabus and not much emphasis is observed on IDD and Psychiatric disorders comorbidity. As country has very high burden of mental illnesses and IDD, it is a pity that many of the future doctors are not completely equipped with the requisite learning of psychiatry and IDD.

C.2 Clinical postgraduate training in IDD child/adolescent and general psychiatry, and interdisciplinary training opportunities

The available capacity of adult psychiatrists in Pakistan is much lower than the number required meeting the needs of the population. The situation is even more serious for children and adolescents suffering from mental health disorders. In this background the College of Physicians and Surgeons Pakistan on the recommendation of its Faculty of Psychiatry has introduced a second Fellowship in the specialty of 'Child and Adolescent Psychiatry.' (Two years post first fellowship in adult Psychiatry)
Another university specific four-year degree program i.e., MD is also providing the opportunity to doctors to train in general adult and child and adolescent Psychiatry. Post graduate trainees have ample chances to learn and train under supervisors from various other related disciplines.

C.3 Research and research training opportunities

Pakistan is facing a multitude of medical, environmental, and psychosocial issues which are just waiting to be explored. However, research here like most developing countries is in its primitive stages. The country faces obstacles in medical research like flawed methodology due to lack of knowledge and expertise, Lack of funding and delay in receiving research grants, non-availability of a national data base, culturally specific validated tools of assessment & hi-tech research equipment in the universities. These factors act as major impediments to the development of scientific research in Pakistani universities. With a few exceptions, there is little quality research in Pakistan on IDD, however, there is an immense potential for further growth and development that needs to be appropriately and effectively nurtured and enhanced. Some efforts are being made to improve training in research both at undergraduate and post graduate level. e.g. Guidelines on assessment and management of Intellectual disability were published under the flagship of Pakistan Psychiatry Society in 2022. It is hoped that with the introduction of a second fellowship in Child and adolescent Psychiatry that impactful research will be conducted. Furthermore, Higher education commission of Pakistan should ensure that all medical Universities of the country include research methodology as part of the under and post graduate curriculum, organize frequent workshops on this topic and rigorously work on capacity building of faculty to generate innovative and relevant research.

C.4 Collaborations and Partnerships

A close liaison between health professionals and special / inclusive education institutes is catalyst in tailoring a good and realistic academic and training program for children with IDD. A child transits from health professionals to academic institutes, meanwhile all facilities available for persons with IDD by the government are managed by social welfare department. An important challenge arises when classification and terminology used in line departments is not similar or same terms have different interpretations. In Sindh and Baluchistan provinces legislations have been passed while in Punjab Empowerment of persons with disabilities act 2021 has been submitted to the provincial govt. and waiting for approval. This will pave the way for same official terminology across departments, which will improve the inter and intra departmental coordination. More structured coordination of line departments is required for an improved system of support for persons with IDD.
Parents are the first support system that a child with IDD has and there is a serious lack of parenting programs. Health professionals and academic instituted for children with IDD need to work collaboratively so awareness material on prevention of disability and developmental red flags can be developed and provided to every expecting and prospective mother in print or digitally through media. Currently only few hospitals and non-profits are running early intervention services for children below school age.

Considering the importance of early intervention services for future development of the child, early intervention facilities should be developed in all public hospitals. Pakistan developed its national policy of persons with disabilities in 2002 and plan of action for implementing the national policy came in 2006. In previous decade, many legislations have been passed by the provincial governments. The grey areas lie in implementing on the existing policies and laws. Parents of persons with IDD should be made aware of the rights of their children through parent support groups, this can be done through pro bono services by the lawyers, non-profit organizations, and human rights activists. Provision of market-oriented job skills to persons with IDD is imperative for their economic independence. It is the need of the hour that parents, advocacy groups and organizations working for persons with IDD establish links and collaborations with corporate sector. Corporate sector can not only provide support for innovative programs through their CSR (Corporate Social Responsibility) programs, once properly orientated, they can also create employment opportunities for persons with IDD.

D. CONCLUSION

To conclude, there is a high prevalence IDD in Pakistan. There are a number of factors and issues that increase their prevalence. There are also extensive co-morbidities which makes the prognosis of all the diseases involved worse, their complications more frequent and their treatment more complicated. Clinicians must be able to adapt to ensure they ascertain the relevant information that will allow them to make a diagnosis. Furthermore, individuals with a psychiatric disorder and ID may require additional multidisciplinary support. A need exists in Pakistan for a continuous review about existing strategies with a focus on setting sustainable priorities in the field of Intellectual Developmental disorders, especially in policymaking, capacity building, awareness among public, and the use of media and other relevant forums to minimize stigma.

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SUB-SAHARAN AFRICA

World Psychiatric Association
Section on Psychiatry of Intellectual Developmental Disorders

KENYA & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

Intellectual developmental disabilities (IDDs) are defined as neurodevelopmental disorders (NDD) that may begin in childhood and characterised by below average intellectual functioning and impairments in adaptive behaviours (American Psychiatric Association, 2022). IDD severity varies from mild to profound and is associated with other causal factors such as genetics and environmental determinants or an interaction of both. Children with IDDs are at a higher risk of presenting with comorbid physical and psychiatric disorders, which may include growth failure, epilepsy, autism spectrum disorder (ASD), attention deficit hyperactivity disorder (ADHD), psychiatric illness, sensory (vision and hearing) impairments, skeletal issues, and endocrine/metabolic dysfunctions (Chen et al., 2021; Uzun Cıcek et al., 2020).

Kenya has a paucity of data on intellectual developmental disabilities (IDDs). Evidence from large-scale epidemiological studies to determine IDD prevalence in Kenya is needed. The 2019 national census estimates persons with disabilities (PWDs) at 2.2% (0.9 million), although disabilities are not disaggregated. Causes of IDDs vary from biological factors such as prenatal and perinatal exposures, genetic syndromes, and environmental determinants. In the general public, there are also cultural explanations such as witchcraft. Early identification of IDDs is a challenge in Kenya like in many other low- and middle-income countries. Due to co-occurring conditions, a deliberate and often multi-disciplinary approach in management of individuals with IDDs is necessary to ensure they can maximise their developmental potential. IDD symptom presentation varies some people with IDDs require extensive care than typically developing persons, which could lead to care burden, fatigue, isolation, and financial difficulties for families of individuals with IDDs. Furthermore, they experience barriers to accessing healthcare, educational, social, and employment opportunities, and must deal with pervasive stigma and discrimination. Kenya has made progress in the establishment of legislative and policy guidance promoting and protecting rights for PWDs, and with recent addition of IDDs in diagnostic assessment guidelines; initiatives aimed towards reducing delays in identification and early interventions; interventions targeted at improving behaviour and communication challenges for children with IDDs, among others. Priority areas for Kenya include broadening inclusion of PWDs across different sectors, multi-sectoral engagement, increasing availability and access to care under the universal healthcare reforms, and expanding funding and institutionalising national disability inclusive budgeting across all government departments.

C1. Demographics, prevalence, and cultural perceptions of IDDs

Prevalence

A systematic review on the burden of neurodevelopmental disorders in low- and middle-income countries (LMICs) estimated the mean prevalence of neurodevelopmental delay as 3.28 per 100 persons (Bitta et al., 2017). A national survey conducted in 2018 on children with disabilities and special needs in education established that 2.5% (190/7609) of children aged 3-21 years had an IDD (Kenya Institute of Special Education, 2018). Majority of children with disabilities surveyed were males (56.3%) and lived in rural settings (43.7%). Nemirimana and colleagues (2018), conducted a cross-sectional study to explore risk-factors associated with severity of non-genetic IDD among 97 children aged 2-18 years presenting at the paediatric and mental health departments of a public tertiary referral hospital. The study found that complicated labour and delivery, admission to the neonatal intensive unit, and having cerebral palsy were associated with increased risk of severe/profound IDD (Nemerimana et al., 2018). However, there was insufficient evidence on the role of other known factors associated with IDDs identified in existing literature e.g., advanced maternal age, and environmental exposure such as smoking (Huang et al., 2016). In rural Western Kenya, a cross-sectional study in two special needs schools among 115 children between 6 and 28 years established 1 in 4 children had IDD and autism comorbidities, with the majority being males

(Khabala, 2018). This corroborates with existing evidence, whereby nearly one-third of IDD cases have comorbid NDD diagnosis, most notably ASD, ADHD, and other neurological disabilities such as epilepsy, cerebral palsy, and motor impairments (Bitta et al., 2021).

Cultural perceptions

There are various views on how IDDs are understood and their causes among the Kenyan community. In Coastal Kenya, Bunning, and colleagues (2017), identified explanatory models linked with the local understanding and attributions for childhood disability. In their typology, disabilities are perceived to be due to biological factors including inheritance, pregnancy, and birth complications; supernatural causes e.g., belief in God's will/plan; self and other people's acts such as extra-marital affairs during pregnancy, incest among same family members, witchcraft, or being possessed by demons or evil spirits (Bunning et al., 2017). These underlying reasoning and cultural beliefs have similarly been reported in other parts of the country, for instance, among the pastoralist in Kajiado county (Manyara, 2020), in (peri)-urban contexts (Chabeda-Barthe et al., 2019), and among communities in humanitarian context (Zuurmond et al., 2016). These studies highlight the need to address cultural issues when addressing the needs of persons with IDDs.

C2. Identification and early interventions

IDD is associated with challenges in communication, academic and social functions, and depending on the severity of the presentation, may have an individual with IDD dependent on their caregiver than the typically developing person (Ademosu et al., 2021). Children with developmental disorders, including IDDs are not adequately identified and are often diagnosed much later than children in well-resourced countries (Marlow et al., 2019). Factors associated with delayed identification include limited public knowledge and awareness of IDDs and their manifestation, late health seeking and engagement in care, and the limited capacity to diagnose and manage IDDs in healthcare settings. IDDs presentation cuts across the life course. For instance, prenatal assessments and family history checking can help identify babies that may be at risk of being born with congenital conditions. During routine postnatal check-ups, growth monitoring and developmental milestone charts are used to flag problems with delays and caregivers are guided on required interventions. However, there are limited specialised clinics such as occupational therapy, ear, nose, and throat (ENT), speech and physiotherapy including other service providers, and these are mostly accessible in higher-level facilities and private practice, which may not be readily accessible to the larger population. Furthermore, timely diagnosis of IDDs requires specialist practitioners like developmental paediatricians who are very few, with many stationed in private/tertiary referral hospitals such as the Aga Khan University Hospital, Kenyatta National Hospital and Gertrude's Children's hospital, all based in Nairobi, Kenya's capital city.

Within learning institutions, IDDs are identified through school performance, that is; students with learning difficulties may show deterioration in academic performance and a manifestation of challenging behaviour. This may prompt the need for specialised assessments involving medical and education assessment and resource centre (EARCs) personnel, who could further determine learning needs and prompt other interventions such as placement in special needs schools (Mwoma, 2017).

C3. Status of social inclusion

The Convention of Rights of Persons with Disabilities (CRPD) identifies participation and inclusion of persons with disability as an essential principle (United Nations, 2006). Kenya's national disability mainstreaming strategy (2018) articulates inclusion is achieved through the removal of multiple barriers to access in society as a key requirement for inclusion of PWD. Accessibility is thereby envisioned as physical accessibility, information and communication accessibility, institutional accessibility, and economic accessibility (Ministry of Labour and Social Protection, 2018).

The education sector has undergone several historical reforms towards ensuring the right to basic education for learners with special needs is attained. The national special needs education policy framework (Ministry of Education, 2009) outlines 22 categories of disabilities and special needs. This includes hearing, visual, and physical impairments, cerebral palsy, epilepsy, down syndrome, autism, emotional and behavioural disorders, learning disability, speech and language disorders, multiple disabilities, and albinism. In 2013, the Education Act was implemented, which included free basic education for all and the creation of EARCs (Mwoma, 2017), whose primary role is to conduct assessments to aid the screening, identification, diagnosis, and placement of children with special needs including IDDs to schools and related services.

The Kenya Institute for Special Education (KISE), a state agency, was established in February 1986 with the aim of training teachers and other affiliated personnel who offer services to learners with disabilities and special needs (Chabeda-Barthe et al., 2019). By 2018, there were 29,406 special needs education teachers and instructors that had graduated from KISE (Chabeda-Barthe et al., 2019). The Kenya Institute for Curriculum Development (2019), released a basic education competency-based curriculum framework, which makes provision for learners with special needs, who upon functional assessment and depending on the severity of disability, are offered placement in mainstream integrated schools, special schools, or special units. Further, the framework categorises learners with intellectual disabilities under the specialised curriculum organised in four levels (foundational, intermediate, pre-vocational, and vocational), whose goal is to enable learners to acquire daily living skills, basic academic, and work-related skills for independent living (KICD, 2019). Ongoing initiatives spearheaded by the Africa Special Needs Network (ASNEN), are aimed towards championing an inclusive education model and driven by the African philosophy of 'Ubuntu', which recognizes the importance of multi-sectoral engagement in educational reforms

Related to inclusion for PWDs in other service sectors, the Disability Act of 2003 was passed by an act of parliament, and later led to the establishment of the national council for persons with disabilities [NCPWD] (Kabare, 2018). After the amended Kenyan constitution was promulgated in 2010, there was a change to devolved governance system with the establishment of 47 semi-autonomous counties (Government of Kenya, 2010). The NCPWD works with health facilities in each county to offer disability assessment services, and upon confirmation of a diagnosis, the individual receives a disability card. This card accords the individual with disability benefits including fast tracked care at public facilities, tax exemptions, tuition fee waiver, cash transfers for individuals with severe disabilities among others, (Kabare, 2018), though dependent on meeting stipulated requirements (Ministry of Labour and Social Protection, 2020; Persons Living with Disability, KRA, n.d.). According to the annual NCPWD report (2021), 35,599 PWD (from a target of 100,000) were newly registered with the organisation, although it is unclear how many of these include persons with a diagnosis of IDD. Furthermore, there have been widespread concerns over the eligibility and registration procedures, thus locking out many families of PWDs from rightfully accessing these services. In January 2022, NCPWD rolled out an electronic registration system, following its official launch by Kenya's President during the international day of PWD in December 2021. Alongside this initiative was the introduction of new disability assessment and categorisation guidelines by the Ministry of Health to standardise the assessment process nationwide (Ministry of Health, 2022). The guide includes assessment for IDDs, and since its release health professionals in 40 out of 47 counties have been trained (Training of Disability Medical Assessment and Categorization Guidelines Developed by MOH. NCPWD, n.d.). It will be valuable to track how these initiatives count towards increasing participation and inclusion of PWD in the long run.

The right to employment for persons with disabilities is key in societal inclusion as underscored by the CRPD, which was ratified in Kenya in 2008 (Kabare, 2018). The Kenyan Constitution recommends the 'progressive implementation of the principle that at least 5% of members of the public in elective and appointive bodies are persons with disabilities' (Government of Kenya, 2010), while the persons with disabilities bill (2021), further stipulates provisions to be met by public and private sector employers, penalties for non-compliance and favourable work conditions to minimise stigma and discrimination

(Government of Kenya, 2010). Available evidence estimates employment for PWD, including those with IDDs, in the formal sector is very low (1%) and disproportionate to the general population (73%) (Ebuenyi 2020), while those who secure employment receives low wages (Rohwerder 2020). Barriers to employment related to persons with disabilities include low levels of education, skills, and confidence; lack of family and community support; and inaccessible public transport and technology (Rohwerder 2020). Other barriers related to employment include lack of compliance with legislation; negative attitudes, stigmatisation, and low expectations of persons with disabilities (Rohwerder 2020; Ebuenyi 2020). The Global Summit on Disability hosted in Kenya in 2018, sparked renewed hope in championing an increase in economic opportunities for PWD (Government of Kenya, 2021). To date, notable achievements in line with the summit's commitments include: i) the launch of an economic empowerment programme and disbursement of disability grants worth Kenya shillings 28.5 million targeting PWDs in self-help groups and facilitating entrepreneurship skills training; ii) initiating a Tools of Trade empowerment programme, where PWD received toolkits worth Kshs. 15.41 million to enable employment and wealth creation opportunities in sectors such as catering, automotive engineering, and agriculture; iii) expanding opportunities for youth with disabilities through access to technical and vocational training; and iv) launching of an online career portal with NCPWD to increase employability chances of PWD, through the Innovation to Inclusion (i2i) project initiative involving government and non-state partners (Government of Kenya 2021).

B. MENTAL HEALTH BURDEN AND AVAILABLE SERVICES

According to the World Health Organisation (WHO) latest mental health report (World Health Organization, 2022), over 970 million people have a mental disorder, of which 10.9% live in Africa, and these conditions are the leading cause for years lived with disabilities at 15.6%. In Kenya, 1 in 10 adults experience mental health problems, and a growing concern among children and adolescents (Taskforce on Mental Health, 2020). Mental health service provision in Kenya is limited due to few mental health specialists, in addition to limited mental health facilities in communities (Bitta et al, 2017). Allied health services for individuals with IDDs include audiology and speech therapy, ENT specialists, occupational therapy, physiotherapy among others. For many Kenyans, affordable healthcare is offered in government sponsored health facilities. Recent changes to the National Health Insurance Fund (NHIF) includes the provision of rehabilitation services such as physiotherapy and occupational therapy, however, coverage is quite low at 16% (Barasa et al., 2018). Private medical insurance covers are unbalanced in their coverage of mental healthcare and allied services such as occupational therapy, thus subjecting clients to out of pocket spending (Taskforce on Mental Health, 2020). The National budget allocation for mental health services in 2021-22 is estimated at 1.5 billion, with the bulk of these funds channelled to national mental health board and mental health tertiary facilities (Mental Health Investment Report, 2021). Within this period, mental health conditions cost to the national economy was estimated at 62 billion Kenya shillings, with 90% linked to lost productivity because of premature mortality, absenteeism, and presentism (Mental Health Investment Report).

Like many LMICs, Kenya has a limited number of mental health workers, particularly in rural and remote areas (Mulaki & Muchiri, 2019). Estimates from 2015 and 2016 put the specialist mental health workforce at 116 psychiatrists, and approximately 500 registered psychiatric nurses against a national population of approximately 47 million people (Mulaki & Muchiri, 2019). In 2022, available evidence indicates there are 1,382 mental health professionals countrywide, of which the majority are posted in tertiary facilities, and 354 employed by the National Government (Mental Health Investment Report). Further in this report, mental health professional figures are disaggregated by county (Mental Health Investment Report, pg 18-20). Figures from the Kenya Medical Practitioners and Dentists Council (KMPDC) website (https://kmpdc.go.ke), which keeps an updated registry for licenced and practising professionals in the medical field, indicates 115 psychiatrists are currently registered in their database. The Clinical

Psychologists Association of Kenya (https://clinicalpsych.co.ke) has 51 registered psychologists in its database, with more possibly not registered. In sum, Kenya experiences a critical shortage of mental health personnel within a backdrop of high health workforce brain drain (Brownie & Oywer, 2016), and these have been identified in the Kenya Mental Health Policy (2015), as major barriers to providing treatment and care, alongside the maldistribution of this workforce in the country.

In the absence of strengthened mental health systems in Kenya, additional management of individuals with IDD is carried out by educational services, non-governmental organizations, and community-based organizations. Informal support structures such as friends and religious groups has also been seen as helpful in providing respite care and has been associated with reduced mental health problems in caregivers of children with disabilities.

B.1 Children and adolescents

Children with disabilities, including those with IDD have lower formal education outcomes and require more health-related care (Trani et al., 2011). Many of the children also continue to receive training in special schools regardless of age, ability and time spent in a particular class. There are higher rates of emotional and behavioural disorders in children and adolescents with IDD compared with their typically developing counterparts (Kariuki et al., 2017), with higher likelihoods that these difficulties will persist into adulthood. The psychiatric comorbidities, in combination with the difficulties in social, academic, cognitive, and adaptive functioning, add on to the challenges, including limiting access to social support. Other co-occurring conditions range from primary neuromotor conditions such as cerebral palsy, neurological conditions such as epilepsy, and genetic disorders such as Fragile X syndrome and Down's syndrome, among others (Abuga et al., 2021). Care for the complex needs required by children and adolescents with IDD is often coordinated at health care facilities as well as education services in schools. Parental and peer support has also been shown to aid adolescents' (in typically developing children and children with IDD) school engagement, and outcomes, and enhance academic motivation, as well as alleviate mental health problems (Simons-Morton & Chen, 2009).

B.2 Adults

There are limited studies in ageing adults with IDD and their health outcomes in Kenya with the existing research evidence arising from high income countries. Co-occurring conditions associated with adults ageing with IDD include both mental and physical health conditions. Studies in these settings have shown that individuals with IDD may have poorer health outcomes as they age, compared to the typically ageing adult. Psychiatric conditions such as depression, sleep disorders, memory loss, and regression in language are commonly reported as well as decline in hearing and vision abilities, bone degeneration among other chronic health conditions (Lin et al., 2014; Stranges et al., 2012).

The risk of premature mortality has been found to be higher in individuals with severe or profound IDD. In a systematic review detailing premature mortality and causes of death for individuals with childhood onset neurological impairments, including IDD, Abuga and colleagues found that individuals with IDD and co-occurring genetic disorders such as Fragile X or Down's syndrome, neurological conditions such as cerebral palsy or epilepsy, had significantly increased mortality rates (Abuga et al., 2021). Many studies in this review reported mortality rates as higher than the typical ageing population (60 years and above). Causes of death of individuals with IDD, as noted in the review includes respiratory infections (34%), accidents (18%), and complications associated with epilepsy (10.7%). It is important to note that only one of the studies included in this review included an LMIC country (Kenya) signalling an opportunity for more research involving adults with IDD in research activities.

B.3 Challenges in implementing person-centred care

Persons with disabilities are not conferred the same rights as other individuals in society and attribute this to the historical use of the medical model and moral model of disability (Retief & Letšosa, 2018). The medical model contextualises disability as a disease necessitating medical treatment and finding solutions to cure the 'disease', while the moral model regards disability as a punishment by a higher being for wrongdoings done by the individual or the parents (Retief & Letšosa, 2018). The person-centred care model, however, is a holistic approach to care that involves healthcare providers delivering interventions and management plans that are respectful of and responsive to the individual's characteristics, needs, preferences, and values (Yun & Choi, 2019). Healthcare and services for people with IDD has come a long way, with clearer policies and guidelines in the health, advocacy, and education sector. However, the current healthcare system in Kenya does not seem adequately equipped to achieve person-cantered care in individuals with IDDs due to many factors, some of which are aforementioned e.g., limited number of specialists trained to offer care and limited health facilities in the communities. A person-centred approach, where the specific needs and goals of individuals with IDD and improvement of quality of life are prioritised, is key to integrated care (Tournier et al., 2021). Family members and caregivers of individuals with IDD, who will many times continue living with individuals with IDD well into adulthood, play a significant role in their care as well and should be considered in involvement of care, with collaborative relationships fostered between healthcare professionals and allied care providers (Tournier et al., 2021).

B.4. Opportunities for Action

The first Kenya Mental Health Programme of Action was implemented in 1996 and discussed the need for development of infrastructure and training of mental health workers, however, it employed a top-down approach and did not outline community involvement exhaustively, only mentioning its importance (Kiima, Njenga, Okonji, & Kigamwa, 2004). The strengthening of the mental healthcare system and its integration into primary care has been slow and there is opportunity for more to work on in connecting individuals with IDDs and their families with appropriate care. The mental health investment case report (2021 - 2041), provides a roadmap and actionable steps to be prioritised by government and stakeholders for the next two decades that is evidence informed (Ministry of Health, 2021). Key among the proposals include investing 209 billion in clinical interventions for common mental disorders such as anxiety and depression, and universal school-based socio-emotional learning interventions to prevent depression and suicide among children and adolescents, including those with IDDs, with an overall target of averting 4.3 million cases and 2000 deaths attributed to mental health conditions by 2041.

Similarly, a multidisciplinary approach including diagnosis and treatment planning from different care providers is proposed as the model best practice (Mental Health Investment Report, 2021). This would include the comprehensive discussion from different specialists – including psychiatrists, psychologists, occupational therapists, speech and language therapists, neurologists, geneticists, audiologists and more. As number of individuals with IDD will have a dual diagnosis of other neurodevelopmental, neurological, psychiatric, or other health conditions, it is important the management of these needs are accommodated. There is also evidence that interventions started in the early developmental period are relatively more effective. Establishing early interventions to improve developmental outcomes of children with IDD requires that clinicians and other health specialists can reliably identify and diagnose IDD early.

Non-governmental organisations, faith-based institutions, advocacy groups, social service sector, and the community play a critical role as (in)formal care providers and referral points for individuals with IDD. An example is the Association for Physically Disabled of Kenya who organise mobile clinics in various parts of the country and in addition to mobility devices, offer occupational therapy, speech therapy, and other services (Community Based Rehabilitation (CBR) – Association for the Physically Disabled of Kenya

– APDK, n.d.). The users and survivors of psychiatry in Kenya (USPK) is an advocacy group championing the rights for PWD, offering peer-support mental health services, and proactive engagement in legislation and policy participation (Users and Survivors of Psychiatry in Kenya (USP Kenya) | Mental Health Innovation Network, 2014).

Case Examples

Case 1: Capacity building initiative for frontline workers to manage psychiatric disorders.

Between 2005 and 2010, the Kenya Ministry of Health, in partnership with the WHO Collaborating Centre at the Institute of Psychiatry of London, the Kenya Medical Training College (KMTC), and the Kenya Psychiatric Association (KPA) rolled out a national programme to integrate mental health into primary care settings. The initial phase involved curriculum and training materials development, adapting the WHO primary care guidelines to the Kenyan context. Supervisors underwent a trainer of trainer model of learning, and thereafter trained junior staff at primary care settings (dispensaries and health centres). The curriculum was taught in five days using multi-method approaches i.e., theory, role plays and videos, all aimed at acquisition of practical skills and competencies for clinical assessment, diagnosis, and management. Modules covered were i) mental health and mental disorders and their impact on physical health, economic and social outcomes; ii) core skills in communication, diagnosis, management of common mental disorders; iii) common neurological disorders like epilepsy; iv) psychiatric disorders; and v) mental health linkage with other health domains and an orientation to general health system/functions.

Lessons learned and impact:

- Over 2000 primary care staff including community health volunteers, district psychiatric nurses, district public health nurses, and regional psychiatrists have been trained.
- Forty hours of continuous professional development were awarded upon completion of the course, and the course is now available in the nationwide KMTC short course training programme.
- Clients of trained health workers reported better health, social, and quality-of-life outcomes compared to clients of untrained health workers.

Sources: (Brownie & Oywer, 2016; Jenkins et al., 2010)

Case 2: Kenya Pilot of The WHO Caregivers Skills Training (CST) Programme.

The WHO CST programme is a psychosocial intervention targeting caregivers of children 2 to 9 years with developmental disabilities (DDs), including IDDs. It was developed in 2016 and field trials have been conducted in nearly 33 countries across the globe, including Kenya. CST programme aims to improve behaviour and communication challenges in children with neurodevelopmental conditions and improve the mental health and wellbeing of caregivers (CST programme applies a task-shifting approach by using trained non-specialists as programme facilitators and delivered in nine group sessions and three individualised home visits over 12 weeks. In 2018, CST was piloted in Korogocho, an urban informal settlement in Kenya's capital city, and in Kilifi, a rural county along the Kenyan coast, reaching over 100 families of children with DDs.

Lessons and impact

- The programme is acceptable and feasible to implement in diverse socio-cultural settings.
- There were improvements in child socio-behavioural outcomes and enhanced caregivers' mental health and quality of life.
- Caregivers reported improved knowledge, skills, and confidence in engaging their child in activities of daily living[1].

Sources: (Salomone et al., 2019; SPARK Project Policy Brief No.1)

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[1] CST pilot in 'SPARK Project Policy Brief No.1'
https://www.thesparkproject.net/_files/ugd/d31332_f8edd33b82ae45e0bbebc632402e7f26.pdf

C. SETTING PRIORITIES

C.1 Medical education in IDD psychiatry

Medical education is offered at different levels, however, the depth of focus on IDD varies. According to Kenya's healthcare workers training track, the lowest cadre are enrolled psychiatric nurses who undergo 12-month training, while registered mental health and psychiatric nurses undergo 36-month training (Ministry of Health, 2017). These foundational basic training are offered in over 50 accredited institutions, comprising 13 universities and all 72 medical training college campuses across Kenya's 47 semi-autonomous counties - see additional details in Box 3 (Ministry of Health, 2017). Clinical officers, who often serve as mid-level managers in level two and three facilities in Kenya, can opt to select mental health and psychiatry as a specialisation during their post-basic training program (Ministry of Health, 2017). However, the curriculum content on IDD and psychiatry for the above workforce is in most instances covered under one module during their entire training. Medical doctors pre-service training is university based and takes 5-6 years, with psychiatry offered as a specialisation course (Ministry of Health, 2019). In the education sector, KISE offers a teacher training programme with specialisation in inclusive education as a short course. KISE's syllabus on special needs education offered as a diploma course covers a variety of topics including autism, emotional and behaviour difficulties, intellectual disabilities, learning disabilities and functional assessments - see Box 3.

Table 1. Select medical and special needs education programmes in Kenya learning institutions.

Institution (location/campus)	**Minimum entry**	**Course and certification**	**Duration**
Kenya Institute for Special Education (Nairobi campus) [a]	P1 certificate	Diploma in special needs education	2 years
	Diploma in special needs education	Certificate in Functional Assessments	4 months
	P1 certificate or certificate in ECDE	Certificate in inclusive education	6 months
	KCSE grade D	Certificate in Kenya Sign Language	3 months
	KCSE grade D+	Certificate in Braille Proficiency	4 months
	Unspecified	Selected short course programmes · Disability Mainstreaming · Counseling Skills for PWDs · Community Mobilization for PWDs · Introduction to Persons with Disabilities	Unspecified
Undergraduate (Kenyatta, Pwani University)		Bachelor of Arts in Special Education	4 years
Undergraduates (USIU, Moi, Kenyatta University)		Bachelor of Arts Psychology (counselling)	3-4 years
Undergraduates (Moi, University of Nairobi, Kenyatta University)		Bachelor of Science in Nursing	4 years
Kenya Medical Training College (selected campuses) [b]	KCSE grade C	Diploma in Registered Nursing Mental Health and Psychiatry Diploma in Clinical Medicine Diploma in Clinical Medicine and Surgery	3 years

Kenya Medical Training College (Mathare campuses) [b]	i) Diploma in Nursing or in Community, Health Nursing ii. Diploma in Nursing and one-year Post Graduation experience	Higher diploma in Psychiatric Nursing	1 year
Kenya Medical Training College (selected campuses) [b]		i. Short courses in Child and Adolscent Mental Health and Psychiatry	6 weeks
Undergraduate medical education (11 approved universities: Nairobi, Moi, Kenyatta, Egerton, Kenya Methodist, Maseno, Jomo Kenyatta University of Agriculture and Technology, Mount Kenya, Uzima, Masinde Muliro University) [c]	i) KCSE grade A- and average B in Biology, Chemistry, Physics/Maths and English/Kiswahili ii) Diploma in medical science grade C+	Bachelor of Medicine (MBChB)	5-6 years
Postgraduate medical education (3 approved universities: Nairobi, Moi, Kenyatta) [d]	i) medical degree (MBChB) ii) +1-year medical internship iii) +1-year clinical experience in recognised hospital	Master of Medicine degree in medical psychiatry (M. Med Psych)	3 years
Postgraduate medical education (3 public universities: Nairobi, Moi, Kenyatta) [d]	i) Undergraduate degree major in psychology, counselling psychology, sociology, or social work	Master of Science Degree in clinical psychology (MSc Clinical Psych)	2 years
Postgraduate (USIU)	i) BA Psychology degree	Master of Arts in Clinical Psychology Doctorate in Clinical Psychology (DClin)	2 years 4 years

Notes:

*P1 is a professional educator or teacher certificate award on completion of 2-year training programme

**KCSE: Kenya Certificate of Secondary Education completed and attained grade

[a] https://www.kise.ac.ke/

[b] https://kmtc.ac.ke/

[c] https://kmpdc.go.ke/undergraduate-training/

[d] https://psychiatry.uonbi.ac.ke/index.php/programs-content-type/master-medicine-degree-psychiatry-mmed-psych/

C.2 Education of health professionals

For health professionals, opportunities should be explored to motivate and attract enrolment of nursing, clinical officers, and medical graduate students to take up psychiatry as a specialisation to help build up a pool of workforce that can offer general mental health services across all health system tiers. Related to training resources and the era of digitization, medical institutions should provide learners with accessible and cost-free virtual resources to keep abreast with the latest evidence in psychiatry, and especially in the treatment and management of IDDs in LMIC context. The World Psychiatry Association recent launch of its virtual educational portal is a step in this direction, where learners at all stages and professionals across the globe can access a variety of training resources to enhance their scholarship and build a community of practice (Retrieved June 24 2022, from https://www.wpanet.org/education). Initiatives such as the University of Nairobi's Partnership for Innovative Medical Education in Kenya (PRIME-K) programme demonstrate innovations in a medical training model, which includes collaboration with rural and urban health facilities across the country as decentralised training sites for medical placements and appointing medical staff from these sites as adjunct faculty, thereby promoting local capacity (Nyaga et al., 2017).

C3. Clinical postgraduate training in IDD child/adolescent and general psychiatry, and interdisciplinary training opportunities

Medical doctors and allied health professionals can enrol for clinical postgraduate specialisation in psychiatry. In Kenya, these are offered through a master's in medicine (psychiatry) or master's in arts (clinical psychology) programme in a few public and private universities - see Box 3. These courses entail didactic learning, clinical practicum within teaching hospitals or other accredited health facilities, and research dissertation, and are often pursued while the incumbent is still on active duty. Since the devolution of health functions to county governments, a notable challenge has been the lack of clear mechanisms to release doctors for specialisation training and their retention post-training (Ministry of Health, 2019). Similarly, challenges in securing educational loans and the length of years to become a specialist have acted as barriers (Ministry of Health, 2019). Long-term solutions to this permeating crisis would be working towards a sustainable task-shifting model and strengthening continuous professional development.

C4. Research and research training opportunities

There has been growing interest to advance the evidence on mental health and particularly for conditions that have been previously neglected or received little attention such as NDDs. In the taskforce report on mental health in Kenya (2020, p. 79), the proposed recommendations on research and mental health data include; 1) conducting national mental health surveys to establish the burden, determinants, and impact of mental ill health; ii) include mental health data collection from community and health facilities through integrated health information systems; and iii), increasing funding to support research at the institute of mental health and neuropsychiatry working in collaboration with other research organisations to promote and conduct research on mental health. In line with this call, Kenya has made progress in the adaptation, contextualisation and scale-up of the World Health Organisation (WHO) Mental Health Gap Action Programme (mhGAP) established in 2008 (Bitta et al., 2020). The mhGAP Intervention Guide (mhGAP-IG) is an evidence-based manual used for assessing and managing priority mental, neurological and substance use disorders for non-specialist healthcare workers through a task-shifting model (World Health Organization, 2008). Established evidence in Kenya has so far focussed on the adult module (Bitta et al., 2020; Mutiso et al., 2018). Ongoing and future planned research in the Kenyan context will focus on the adaptation and contextualization of the child and adolescent behavioural disorders modules, which cover clinical protocol for diagnosing and managing DDs such as IDDs (Kumar et al., 2021; Mkubwa, 2022)

C5. Collaborations and partnerships (include national, regional, and global networks as relevant)

Mental ill-health is garnering attention particularly given the devastating effects associated with the global COVID-19 pandemic and have seen country efforts in prioritising mental health in policies and programmes, and empirical evidence generation (Ministry of Health Kenya, 2020). Over the years, the World Health Organisation has spearheaded the development of multifaceted interventions to bridge the mental health treatment gap, expand service delivery platforms, and build human resource capacity, especially in low-resourced and non-specialised settings. Kenya has partnered with the WHO in several of these collaborative initiatives involving government, academia, research institutions, non-governmental, and international agencies. Examples include the earlier mentioned mhGAP intervention targeting different mental health conditions and population; participating in field trials to evaluate the training programme for caregivers of children with developmental disorders e.g., autism and other intellectual disabilities (see Box 2); and delivering psychological interventions through trained community health volunteers and psychologists through the Ensuring Quality in Psychological Support (EQUIP) initiative[2]. Equally important is the increase in advocacy efforts and interest groups/networks championing the rights and inclusion more broadly for persons with disabilities, as well as IDDs (USP Kenya) | Mental Health Innovation Network, 2014; Action Network for the Disabled, n.d.).

D. CONCLUSION

Kenya has made strides in laying down legislative and policy guidance promoting and protecting rights for PWDs, and with recent addition of IDDs in diagnostic assessment guidelines. There has been notable progress through the formulation of inclusive education sector policy and plans and expanding teaching professional capacity through training on inclusive education. As a country, there is still a need for actualising person-centred care, whereby PWD and their caregivers are part and parcel of the care process, and its integration in primary care settings. The evidence presented illustrates a critical shortage in psychiatric specialists, comparable to other low-resourced settings. However, there are opportunities to experiment and reorient the health workforce, through task-shifting approaches and capacity building as showcased in the case example (Box 1), PRIME-K and EQUIP collaborative initiatives. Participation and inclusion of PWD, including those with psychiatric problems in the Kenyan context is acknowledged in paper and gaining momentum. However, more is needed to ensure PWDs access essential support services and can fully exercise their rights. By implementing the Quality Rights Initiative, which takes a societal and rights-based approach, this presents opportunities to transform health services and social care by ensuring quality care is provided, whilst protecting the rights of persons with intellectual, psychosocial, and cognitive disabilities. This requires multi-sectoral engagement and collectively working towards ensuring disability mainstreaming cuts across all sectors. Finally, the vision of achieving universal healthcare for persons with IDDs can only become a reality if more funding is allocated and commitment towards institutionalising national disability inclusive budgeting across all government departments at all levels happens.

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[2] (Retrieved August 24, 2022, from https://www.who.int/teams/mental-health-and-substance-use/treatment-care/equip-ensuring-quality-in-psychological-support)

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NIGERIA & INTELLECTUAL DEVELOPMENTAL DISORDERS

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A. COUNTRY BACKGROUND

A.1 Demographics and cultural perceptions of IDD

Nigeria is the most populous country in Africa with an estimated population of over 200 million persons (National Bureau Statistics (NBS), 2021). Also known as the Federal Republic of Nigeria, is a country located in the West African sub-region bordered by the Republic of Benin in the West, Chad, and Cameroon in the East, and the Niger Republic in the North. The Nigerian coast in the South lies on the Gulf of Guinea on the Atlantic Ocean. Nigeria is a country with over 250 ethnic groups, but the three major traditional groups are the Hausa-Fulani, the Yoruba, and the Igbo. Geopolitically, the country consists of six regions or zones, 36 states, and a Federal Capital Territory located in Abuja.

Nigeria's population consists of mostly young people, with persons aged 0 – 14 years constituting the majority (NBS, 2021). The large population of children may be attributable to many factors including those affecting neonatal and under-5 mortality. Data from the demographic and health survey shows that under-5 mortality in Nigeria decreased to approximately 16% from 2008 to 2018 (National Population Commission, 2018). The improvement in neonatal services and efforts to eradicate causes of preventable deaths through immunization has implications for the number of children surviving with disability including intellectual developmental disorder (IDD). Our earlier paper has suggested that with improved under-five mortalities in Nigeria, the tendency for more children to be living with neurodevelopmental disorders is high (Bakare, Munir, Bello-Mojeed, 2014).

The terms used to describe 'Intellectual Disability,' a neurodevelopmental disorder, have undergone a series of changes in the last century. The past two decades observed a substantial replacement of 'pejorative' terms with more dignifying and acceptable alternatives. The DSM-5 and ICD-11 replaced the term 'Mental Retardation' with 'Intellectual Disability' and 'Disorder of Intellectual Development,' respectively. Intellectual developmental disorder (IDD) has been defined as a neurodevelopmental disorder that begins in childhood and is characterized by intellectual difficulties as well as difficulties in various domains of social, conceptual, and practical areas of living (DSM-5)

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Though a universal phenomenon, it is perceived differently across cultures. In Nigeria, persons with IDD are often thought to be inferior to others and are used for social and economic benefits such as street begging. In addition, the cause of the condition is commonly attributed to supernatural forces including curses from the ancestors and witchcraft (Etieyibo and Omiegbe, 2016). The implications of these beliefs are many. Apart from implying that these patients and their families are deserving of their predicaments, it also influences the pathway to and type of care. In other words, a belief in the supernatural causation of IDD may delay early intervention.

A.2 Prevalence, identification, and early interventions

It is known that the highest burden of IDD is seen in low and middle-income countries (LAMICS) (Maulik et al., 2011). Despite this finding, there is a big disparity in the volume of research on IDD between the global south and north. In Nigeria, a community-based prevalence study on IDD is lacking. A recent scoping review of the empirical literature on IDD in Nigeria found no population-based prevalence studies (Sango & Deveau, 2022). An international review of the state of IDD surveillance, indicators, and indices in Nigeria examined four primary statistical agencies involved in coordinating recurring data, namely: Federal Ministry of Education (FME), National Bureau of Statistics (NBS), National Population Commission (NPC), and Universal Basic Education Commission (UBEC). Their analysis showed that Nigeria has a growing body of disability data and collection systems, but none specifically extended to persons with IDD. In other words, of the 12 countries examined, Nigeria was said to be an outlier with virtually no systematic data or recurring data collected on IDD (Fujiura & Corbin, 2017). Despite the lack of epidemiological data in Nigeria, it has been reported that families usually recognize signs of developmental delay in their children early, but, usually do not seek help due to several factors including, stigma and lack of availability of services until the child starts elementary school at about six years of age or older (Adeniyi & Adeniyi, 2020; Bello-Mojeed et al, 2017). In school, teachers usually identify pupils with IDD, draw the attention of family members, and may suggest a referral to healthcare professionals. In cases, where comorbid mental health condition is present, visiting a specialist may lead to a diagnosis of IDD; unfortunately, in Nigeria, this does not necessarily translate to optimal treatment.

IDD is the term often used to describe situations in which intellectual disability and other neurodevelopmental disabilities are present. Examples of these neurodevelopmental disabilities include Autism Spectrum Disorder, Behavior Disorder, Brain injury, Cerebral Palsy, Down syndrome, and Spina bifida among others. Data about these neurodevelopmental disorders can be examined in the Nigerian context as follows:

Autism Spectrum Disorder (ASD) and Intellectual Disability in Nigeria

Previous studies in sub-Saharan Africa have suggested that more than fifty percent of children diagnosed with ASD in the region often have co-morbid intellectual disabilities of varying degrees of severity (Bello-Mojeed, Bakare, Munir, 2013). On the other hand, in a pocket of study among a group of Nigerian children with Intellectual disability, 11.4% met the criteria for diagnosis of ASD (Bakare, Ebigbo, Ubochi, 2012).

Behavior Disorders, Brain Injury, and Intellectual Disability in Nigeria

A range of behavioral disorders, such as attention deficit hyperactivity disorders (ADHD) are common among Nigerian children. The diagnosis of ADHD is often associated with number of prenatal, perinatal, and postnatal factors that result in injury to the developing brain (Bakare, 2012). Some of these factors include maternal infection, lack of adequate antenatal care during pregnancy, substance abuse in pregnancy, prolonged labour, assisted delivery, and various early childhood neurological infections such as meningitis, cerebral malaria, and kernicterus among others resulting in permanent neurological damage leading to mild to moderate intellectual disability.

Cerebral Palsy (CP) and Intellectual Disability in Nigeria

Intellectual disability often co-exists with cerebral palsy, and this is not different among the population of Nigerian children and adults with CP. The percentage of individuals experiencing intellectual disability in some form ranges from 25 to 75 percent among individuals with CP. Prevalence of Cerebral Palsy in Nigeria is estimated to be about 2.3 per 1000 children (Duke, Torty, Nwachukwu, et al, 2020).

Down syndrome and Intellectual disability in Nigeria

The earliest reported study on the incidence of Down syndrome in Nigeria was by Adeyokunnu, in Ibadan, Southwestern Nigeria, who reported an incidence of 1 in 865 live births (Adeyokunu, 1982). Most children with Down syndrome have some level of intellectual disability, usually in the mild to moderate range. This often allows some level of independent functioning.

A.3 Status of social inclusion (access and inclusion in public education, vocational training, employment, recreational and community life opportunities)

A vast number of Nigerian children face major challenges to meet even basic needs. The education system for the inclusion of individuals with IDD in the country is seriously constrained by a lack of infrastructural facilities, teaching aids, scarce resource materials, poor collaborative system, and personnel with little or no training in person-centered approach required for individualized or special education needs of the affected persons. As early as 1977, a section on special needs education was created in the document for the National Policy on Education (NPE, 1977). However, not much action was taken until after about three decades when the national policy on special needs education in Nigeria was developed (Federal Ministry of Education, 2015).

The Nigerian government's policy on specialized education is hinged on a tetrad of: creating the least restrictive environment, zero rejection, total inclusion, and diversification of services beyond the school setting to include the home and the hospitals (Federal Ministry of Education, 2015). Situation analysis as noted in the policy document shows that special needs education lags global practices in the areas of classroom activities (i.e., facilities and inadequate training of practitioners) and rehabilitation (i.e., lack of middle and high-level manpower and lack of self-reliant community-based rehabilitation facilities) (Federal Ministry of Education, 2015).

The poor governmental attention to education generally and special education specifically contributed greatly to the under-development of special needs education in Nigeria. In other words, special needs education was perceived as voluntary and humanitarian affairs, hence, most facilities are owned by faith-based and non-governmental organizations without clear supervision. Attempts have been made to make available laws and other policy documents that could promote social inclusion; however, these attempts have been stalled by number of political and cultural factors. For instance, despite the adoption of the Child Rights Act in 2003 that promised equal opportunities to every Nigerian child, full implementation has reached an impasse because not all the Nigerian States have adopted the Act, and among those that have done so, its implementation has been hindered by number of cultural and socio-political factors (Assim, 2020). Many children with Intellectual Developmental Disorder (IDD) are still being locked up or hidden away in their homes and have subsequently been prevented by burdened parents and relatives from accessing any form of intervention.

This seclusion of individuals with IDD could be attributed to common derogatory comments and stigma associated with having such children that parents often must face with little or no advocacy (Sango & Deveau, 2022). In addition, health insurance policy is not available for most parents, and when available it may still not cover chronic and long-term care for children with IDD. This exposes parents to out-of-pocket costs and huge costs of care for their children with IDD. Therefore, a mixture of stigma, psychological and financial burdens have combined to prevent many children and adolescents with IDD from having the opportunity for any form of intervention, either medical or special education services, despite the existence of the federal law that promises equal opportunities for every Nigerian child.

Adults with IDD are also denied access to basic rights because of stigma. Many faces exclusion in employment opportunities despite being qualified to take available positions due to stigma and discrimination. Although the Nigerian Disability Bill has been signed into law in 2019, its effect on equal opportunity for Adults with IDD is yet to be experienced in Nigeria.

B. Mental health burden and available services for Children, Adolescents, and Adults

Research has established that individuals with intellectual disabilities have a higher risk of psychiatric disorders than those with intelligence in the normal range (Lakhan, 2013). The common co-morbid psychiatric disorders in intellectual disability are problem behavior, affective disorder, autism spectrum disorder, psychotic disorder, and anxiety disorder (Cooper, Smiley, Morrison, et al, 2007). These co-morbidities are also common in children, adolescents, and adults with IDD in Nigeria.

Diagnosing mental health problems among individuals with IDD often poses some challenges and this often results in frequently missed diagnoses. One of the reasons why missed diagnosis is common is that individuals with intellectual disabilities can experience communication difficulties that vary from problems expressing psychological experiences to being unable to produce speech. This results in an under-reporting of psychiatric symptoms (Veerhoven, Tuinier, 1997).

Treatment and management of any disease condition are often influenced by the health behavior of the people, which in turn is a function of attributed etiological explanations. Majority of the Nigerian populace, especially in rural communities attributes the etiology of IDD to spiritual causes (Etieyibo and Omiegbe, 2016). Hence, the tendency for parents and relatives of children with IDD to seek succour from traditional and religious healers as the first point of contact before seeking help from orthodox practitioners (Anjorin and Hassan, 2022). Interventions for IDD in Nigeria are available at psychiatric and pediatric facilities of national and states teaching hospitals, specialized psychiatric hospitals, and general hospitals spread across the 36 states of Nigeria and the Federal Capital Territory in Abuja. Pockets of privately owned hospitals that are spread across the country also provide interventions. Treatments offered in these settings focus largely on alleviating associated problem behaviors and treating medical comorbidities like seizure disorders and attention deficit hyperactivity disorder symptoms, among other disruptive or injurious behaviors. Treatment centers available in Nigeria that the patients and their relatives present to can be categorized as follows:

Traditional healers. Based across the country, especially in rural communities, traditional healers provide a form of psychological support or comfort, which often compound the problem of early identification and intervention.

Religious healers. These include mostly religious clerics (Alfas) and Pentecostal Churches that often promise spiritual healing and exorcism. Such centers provide support and reassurance and false hope, resulting in delayed presentation in health settings in most cases.

Private homes/schools and nongovernmental organizations (NGOs). Most of these private homes and schools as well as NGOs found across the country often do not provide evidence-based services, nevertheless, they offer some form of support. Many provide stimulating play environments and some form of remedial education for the children. The practices of these private homes and schools and the NGOs are not properly regulated, and the local standard of care or interventions they offer may not meet ethical and scientific standards to be considered evidence based. However, they provide a ray of hope in an environment where there is little or no hope. The services are often expensive and mostly unaffordable for average parents.

Orthodox medical practices. these consist of settings like teaching hospitals, specialized psychiatric hospitals, general hospitals, and private hospitals that offer services to children with neurodevelopmental disorders. These practices also provide limited psychological support and address associated problem behaviors and medical comorbidities.

The core of treatment, which is special education that focuses on social stimulation, language development (speech therapy), occupational and physical therapies, and community social inclusion programs is largely lacking in most of these centers. This is an area where future social policies and legislations need to be targeted.

Most educational settings in Nigeria are mainstream schools designed for normally developing children. Most special schools available, which are quite few and exorbitant in costs are privately owned. Future direction needs to enact legislation to incorporate special education facilities into normal mainstream schools. This would promote social stimulation for Nigerian children with IDD and promote community inclusion and therefore reduce stigma. The sad reality in Nigeria is that adult services for individual with IDD are practically non-existent.

B.1 Challenges in implementing person-centred care

Individuals with intellectual disabilities have fundamental human rights to access mainstream systems and services. Important barriers to accessing health care services include a lack of adequate professional training in intellectual developmental disability (Jess G et al. 2008; WHO and World Bank Group, 2011). In medical and educational settings, lack of adequate capacity development has led to a lower ratio of personnel to clients, and this has deprived many individuals with IDD of having access to person centred care. However, advocacy is continuously ongoing to give voice to individuals with IDD and their families to get involved in their own care and management. In addition, some schools of thought believe that parental skills training would afford more opportunities for person-cantered care in Nigeria in view of the low number of health and educational personnel available.

B.2 Opportunities for action

With improved childhood survival and a dire need for developmental services across the lifespan, the research and policy landscape must change. With improvement in under-five mortality across Nigeria and other sub-Saharan African regions, there will be a steady rise in the number of children and adolescents, as well as adults, living with intellectual developmental disorders (IDD).
For cases of IDD in Nigeria, the need to involve parents and non-specialists in providing interventions to reduce the direct and indirect cost of care, as well as productivity losses, has been emphasized and should be given due consideration, even as the capacity of other multi-disciplinary health care professionals is being developed (Bello-Mojeed and Bakare, 2013).

At the present time, there is no established or nationally adopted research and social policy direction on IDD in Nigeria.

We, therefore, recommend several important steps to be taken to improve the status of care for IDD among Nigerian children, adolescents, adults, and their families:

- Define the magnitude of the problem of IDD and conduct needs assessment for affected individuals through a well-implemented nationwide epidemiological study, or a national network of studies.
- Carry out genetic and environmental studies of IDD in Nigeria, which are of importance in understanding the various risk factors.
- Build capacity for training of health care personnel, promoting human resource development in interventions for IDD.
- Establish special education facilities incorporated into normal mainstream schools with the aim of promoting inclusionary educational practices, social stimulation, and community inclusion to reduce stigma. This should be based on the fundamental principle that social inclusion is an important remedy for the reduction of stigma through the experience of coping with disabilities in the community.
- Implement existing legislation fully, including the commendable Child Rights Act and the Nigeria Disability Act. These would promote education and employment opportunities for people with various disabilities.
- Formulate social policy to address the financial side of health care and special education provision for individuals with IDD, since this is not presently covered under the Nigeria National Health Insurance Authority (NHIA) or any existing social policies.
- Finally, focus research and social policy on public health education campaigns to positively influence help-seeking behavior for children, adolescents, and adults with IDD, to reduce the social and economic burdens and promote the improvement of quality of life across the lifespan in the country.

Case example, local, regional, national

Example of regional activity in relation to IDD in Nigeria is found in the corporate social responsibility of Guaranty Trust Company (GTCO). Over the past decade, the Guaranty Trust Bank of Nigeria has been organizing an annual autism conference that afforded opportunities of advocacy and promotes prompt diagnosis of ASD and IDD during routine annual screening going on in Lagos State, Nigeria (GTCO, 2022). However, support for long-term follow-up is still lacking regarding this annual program (GTCO, 2022). Otherwise, there are limited outlets for advocacy, and follow-up on human right issues that has to do with IDD in Nigeria.

C. SETTING PRIORITIES

C.1 Medical education in IDD Psychiatry

In Nigeria, there is no study on the content and teaching methods for IDD in medical schools. The undergraduate medical training opportunity for IDD is covered during pediatric and psychiatric rotations in various medical schools in Nigeria. At the undergraduate level, medical students undergo postings in pediatrics and psychiatry, where they may be exposed to cases of neurodevelopmental disability associated with intellectual disability. However, oftentimes this exposure is not enough for capacity development to effectively manage cases of IDD. For example, in many medical schools in Nigeria, psychiatric rotation is less than 8 weeks. Early exposure of future doctors to IDD in medical education may enhance knowledge, competence, perception, positive attitude, and confidence to work with persons with IDD and other neurodevelopmental disabilities in the community.

C.2 Clinical postgraduate training in IDD

At the postgraduate level, sub-specialties of pediatrics and psychiatry also provide further opportunities for exposure to training in IDD. As the management of these cases are multidisciplinary, and may involve professionals like developmental psychologists, social workers, occupational therapists, speech therapists, pediatricians, psychiatrists, and teachers with skills in special education among others, there are training institutions and facilities for some of these professionals across the country. However, the training turnover among these professionals is still limited compared to the burden and challenges that IDD present in Nigeria.

C.3 Research and research training opportunities

Research on neurodevelopmental disability including IDD is essential for improved awareness of the burden and magnitude of the topic, informing policy and programs on disability, and efficient resource allocation. As indicated in our previous review (Bakare, Munir, Bello-Mojeed, 2014), the research and policy health focus for IDD is limited when compared to the focus on communicable diseases in Nigeria. There is a need to create more opportunities for research and training relating to IDD in Nigeria. This is one of the directions of the future action plan.

C.4 Collaborations and partnerships

Collaboration and Partnership in IDD should include educational personnel, allied health professionals, rehabilitative facilities, Parents, NGOs, and governments. The priority given to IDD in the Country is very low at present and there are not many areas of collaboration and partnership addressing issues of IDD in children and adults in Nigeria. Barriers to effective collaboration and partnership in IDD could negatively impact child outcomes. The area of collaboration and partnership represents another direction of the future action plans.

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ASOCIACIÓN MUNDIAL DE PSIQUIATRÍA

WPA WG POSITION STATEMENT ON THE RIGHTS OF PERSONS WITH IDD & MENTAL HEALTH

Beyond the initial task to develop an overarching Global Framework to stimulate and enhance the status of care of persons with IDD, and to identify opportunities and community linkages to improve the visibility and engagement of medical students, clinical trainees, psychiatrists, and allied professionals in the field, the WPA leadership also assigned the task to develop a position statement on human rights for persons with IDD facing co-occurring mental health related challenges.

The document appended in the following section represents a broader and more extensive preamble and framework for action on mental health rights and rights related issues involving persons with IDD and is appended to the Global E-Handbook.

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WORLD PSYCHIATRIC ASSOCIATION POSITION STATEMENT ON THE RIGHTS OF PERSONS WITH INTELLECTUAL DEVELOPMENTAL DISABILITIES AND MENTAL DISORDERS

Kerim M. Munir, Ashok Roy & Afzal Javed

Preamble

The Working Group (WG) on Intellectual Disabilities/Intellectual Developmental Disorders (IDD) under the auspices of the World Psychiatric Association (WPA) leadership was charged for developing a comprehensive statement on the Rights of Persons with IDD with co-occurring mental disorders. To date, no such prior document exists. The statement addresses the needs for inclusive services, training, and research for improved mental health outcomes for persons with IDD across the lifespan. An important justification for this effort is that mainstream psychiatry as a profession has the means and motivation to appreciably improve the mental health care of persons with IDD with special relevance for low resource settings.[1] A major change is required in emphasis that is inclusive of grassroots efforts in implementing person-centered care tailored to the abilities and aspirations of persons with IDD and their families and communities, blending the social and medical models of development and disability within a human rights framework.

Foremost, in considering the preparation of this statement we would like to address head on:

- Why we believe the United Nations (UN) Universal Declaration of Human Rights[2] serves as the foundational framework and why universalism and world citizenship on this topic is critical
- How such a statement on the rights of persons with IDD and co-occurring mental disorders interfaces with the UN Convention on the Rights of Persons with Disabilities (CRPD)[3]
- How such a statement on rights of persons with IDD and co-occurring mental disorders is relevant for optimal Public Mental Health globally as intended in the WPA Presidential Action Plan[4] – providing synergies between Public Mental Health, Disability, and Human Rights and points of reference in terms of development of "benchmarks" to be assessed and compared across persons with and without IDD and across world populations
- What can be learned in adapting these benchmarks in terms inclusive services, training, and scholarship in psychiatry and allied mental health sciences

Universal Declaration of Human Rights

A year following the introduction of UN Universal Declaration of Human Rights in 1948, the philosopher Hannah Arendt, in the aftermath of Second World War and Holocaust, was first to wonder about their universalism[5]. The Declaration had been adopted emphasizing the right to life, liberty, and security of all persons in society, but there was only secondary mention of disability. The idea of human rights belonging to all, simply by virtue of being human, is the basis of the Universal Declaration.

According to Mahatma Gandhi this moral entitlement was not seen as adequate unless it was combined with duty. In a letter written to Julian Huxley, then Director-General of UNESCO, Gandhi boldly asserted that "all rights come to be deserved and preserved from duty well done." For Gandhi, "the very right to live accrues to universalism to be achieved there would need to be an open world where human beings transcend borders and national jurisdictions. Universal Human Rights therefore applies beyond state borders, and to all persons who are citizens of the world, including those who are stateless and those who are state protected wards, among whom persons with IDD stand as a most vulnerable group.

The Universal Declaration Foundational Article 1, translated in 500 world languages, asserts that all human beings are "born free and equal in dignity and rights" entitled to full equality under the law, including free speech, freedom of assembly, social and economic rights, education, social security, right not to be tortured, not to be subject to arbitrary arrest, and with right to seek asylum from danger and persecution. The Declaration, as well as the treaties and conventions that have flowed from it, is not merely a secular numeration of these basic rights, but the essential point is that the character of such rights are inalienable and cannot be taken away or given up.

The rights imbued in the Declaration were therefore not created in 1948, but rediscovered, and part of an international magna carta of human rights worldwide. Indeed, when the UN human rights commission membership were convened at Eleanor Roosevelt's home in Manhattan in 1947, as the United States delegate, to draft the Universal Declaration (to which Mahatma Gandhi had been invited but could not attend due to other commitments), the voices of many traditions and peoples of the world were absent, including the voices under colonial rule from Africa, India, as well as China, and the Islamic world[8].

Ironically, the same year in 1947, in Staten Island, 20 miles southwest of Manhattan, the New York State Department of Public Health opened the Willowbrook State Residential School for children with IDD, among those housed there were many with autism spectrum disorders, cerebral palsy with and without intellectual impairments, as well as Down syndrome, and other congenital developmental conditions, referred to then as "the mentally retarded". Children were tied to chairs, slept naked on cold floors, and were denied medical care and food. Many were also used in the notorious hepatitis research studies and countless died. After a visit, the late Senator Robert Kennedy called the place "a snake pit."9 With the efforts of families, activists, and lawyers Willowbrook finally closed in 1987. A US Congressional bill, drafted by the Disability Rights International (DRI) would help support disability activists and families in many countries worldwide to make sure that children grow up within families and help shut down Willowbrook like institutional settings that still exist around the world10.us only when we do the duty of citizenship of the world," encouraging us to "begin with a charter of Duties of Man." The rights he promised the will follow "as spring follows winter."[6,7]

The ratification of human rights by states has been necessary, but not sufficient, and for the question then and now remains: Is human rights universal as they apply to the most vulnerable with IDD and co-occurring mental disorders? Are human rights immersed in cultural values, or are they universal because they are considered natural and inalienable? As the rise of fundamentalist and authoritarian regimes further challenge universalism in many world contexts, our world order now is vastly different than in the aftermath of the Second World War.

On the upcoming 75th anniversary of the Universal Declaration of Human Rights, irrespective of these challenges to universalism by politicization and by authoritarian revival, a central framework is a timely undertaking for the WPA, that human rights of persons with IDD with co-occurring mental disorders ought not be based on the good faith alone, but a professional ethos in promoting care linked with rights for all vulnerable persons with IDD and co-occurring mental disorders. Such a framework needs to be attentive to poor resource settings, attentive to women and children, people with limitless sexual orientations and gender identities, minorities, people of all races, religions, and ages. Indeed, such an idea of universalism is not a Western construct, its roots lie across time and space, beginning in 539 B.C., when Cyrus the Great, first king of ancient Persia, on conquering Babylon, declared that all people had the right to choose their own religion, establishing racial equality, and freeing the slaves with decrees recorded on a baked-clay cylinder in the Akkadian language in cuneiform script[11]. The

Cyrus Cylinder record is now recognized by the UN as the world's first charter of universal human rights.

United Nations Convention on the Rights of Persons with Disabilities (CRPD)

In 2001, initiated by Mexico, with subsequent crucial support of New Zealand, the UN General Assembly established the ad hoc committee for a Convention to be developed to uphold dignity and rights of persons with all disabilities. In December 2006, this work eventually led to the CRPD, and its accompanying Optional Protocol (OP) that eventually entered in effect in May 2008. The CRPD is currently ratified by 186 member states, with 164 signatories of OP emphasizing "one voice" and the notion of "nothing about us without us." The OP endorsement signifies intent of state legislatures to take binding steps for (1) reasonable accommodations; (2) no-gaps; (3) habilitation and rehabilitation (Article 26); (4) international cooperation (CRPD article 32); and (5) assistance in situations of risk and emergencies. The CRPD has come to represent a "paradigm shift": persons with disabilities are no longer to be considered as objects under the law but citizens with equal rights. An 18-member Committee on CRPD continues to annually monitor the application of the treaty with representation of persons with lived disability. Although disability is not specifically defined under CRPD, it includes long-term physical, mental (euphemistically referred as "psychosocial"), intellectual, or sensory impairments which in interaction with various barriers hinder effective participation in society on an equal basis with those without disability.

In 2015, the UN Department of Economic and Social Affairs (DESA) in collaboration with the Secretariat of the CRPD and Government of Japan, organized the Sendai Framework 2015-2030 for Disaster Risk Reduction[15] that adopted the Charter on Inclusion of Persons with Disabilities in Humanitarian Action with 5 commitments:

(1) non-discrimination.

(2) participation.

(3) inclusive policy.

(4) inclusive response and services, and

(5) cooperation and coordination.

The goal has been to enhance recovery needs of persons with IDD with provision of psychosocial support and mental health services. Further, in 2015 the UN also adopted the 2030 Agenda for Sustainable Development Goals (SDGs) emphasizing disability-inclusive development as an essential condition for a sustainable future16. In 2018, the UN launched a first-ever, flagship report on disability and the SDGs entitled, "Disability and Development Report on the Realization of the SDGs by, for, and with Persons with Disabilities" pledging to leave no one behind[17.] Finally, in 2018, the Sphere Handbook was published and has become an interactive movement allowing posting of links to newly published resources, share of case studies and success stories of persons with disabilities and their families in decisions affecting their lives[18].

In summary, the CRPD has been an extraordinary instrument supporting the lives of persons with disabilities, mental and physical, with unprecedented implications for social, economic, political, and legal systems with relevance for mental health providers globally. Significant changes have arisen in the aftermath of the CRPD, notwithstanding the remaining challenges. Most important among these has been the protection from non-discrimination and freedom from coercion based on legal capacity (CRPD Article 12) representing a shift from a substitute decision model to supportive decision making[12]. First, this has necessitated a shift in emphasis from an impairment-focused Biomedical to Social Model of Disability (as a product of an individual's interaction with his or her environment), applied to both mental and psychosocial disabilities. Second, there has been the Social Model of Disability needing to be assessed with relevance to context – equalizing differentially abled persons with the same rights and opportunities. Third, since the Social Model could not offer adequate guidance in changing the circumstances that marginalize persons with disabilities as equal citizens, further shift was needed for persons with disabilities (especially those with co-occurring mental disorders) to be valued as part of human diversity. Therefore, the Human Rights Model has emerged as the foundation stone of CRPD, with the social justice discourse in terms of disability laws and policies representing a revolution in thinking.

An important question remains with respect to the question of "legal capacity" related to circumstances of persons with impaired Decision-Making Capacity (DMC) and the exercise of their rights. The UN system has remained somewhat divided on this issue. The International Covenant on Civil and Political Rights (CCPR) has accepted the "necessary and proportionate" involuntary placement and non-consensual treatment of persons with mental health problems ("psychosocial disabilities") as a last resort[19]. On the other hand, CRPD calls for their elimination. Indeed, the UN Working Group on Arbitrary Detention (WGAD) states, "denial of legal capacity of persons with disabilities with detention in institutions against their will, without their consent or with the consent of a substituted decision-maker constitutes deprivation of liberty in violation of international law."[19] The contrast between substitute vs. supportive decision-making is highly salient in the care of the most vulnerable persons with IDD with adaptive and cognitive impairments and co-occurring mental disorders. The discussion is also relevant across the psychiatric care of persons with loss of DMC, e.g., dementias, schizophrenia, and bipolar illness, irrespective of a pre-existing diagnosis of IDD[13, 14].

Increased prevalence and ascendant recognition of the importance of mental disorders in the Global Burden of Disease (GBD) and the rise of neurodevelopmental disabilities with improved childhood survival in LMICs disproportionately effects the most marginalized communities (10-15% of the global population with range of disabilities, and 80% of persons with disabilities live in LMICs)[1, 14, 20]. The GBD burden therefore is increasingly highlighting a significant role for the Human Rights Model in addressing disparities in the care of vulnerable persons with IDD with co-occurring mental disorders.14 In such poor resource settings health systems continue to lack capacity to provide basic services, including access to basic primary healthcare[21.] The COVID-19 pandemic has further exacerbated inequities producing further obstacles in mental health care with disproportionate impact on persons with disabilities[22].

It is clearly not adequate for mental health services to prioritize certain rights, as in access to care and treatment, while not emphasizing importance of autonomy, choice, and community care. This underscores the inter-sectoral commitment of psychiatry, i.e., in humanizing our understanding of mental health, access to education, habilitation, rehabilitation, and alliance with work environments that are "open, inclusive, and accessible" (CRPD Article 27 of CRPD – Right to Work and Employment). Consistent with this view, the CRPD Article 7 emphasizes early intervention approaches combined with taking "all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children." Development of child and youth orientation with (1) robust tele-health access and legal platforms, financially supported intervention packages for economically distressed families; (2) appreciation of Adverse Childhood Experiences (ACEs) and social determinants disproportionately impacting persons with IDD[23]; and (3) reduction of pathologizing with emphasis on healthy parenting and caregiving.

World Report on Disability and WHO Rehabilitation 2030

In 2017, the World Health Organization (WHO) in tandem with CRPD published the World Report on Disability in 2011[24], has followed by the launch of an important initiative to promote universal access to rehabilitation entitled "Rehabilitation 2030: A Call for Action" with more than 200 rehabilitation experts from 46 countries in attendance[25]. The goal was to develop a "unified message" to become a "political priority worldwide." In July 2019, the WHO convened a "Second Global Rehabilitation 2030" meeting with stakeholders from member states, international and professional organizations, NGOs, rehabilitation service users and experts—including journal editors. This was followed In May-July 2021, by the convening of the WHO Development Groups on Rehabilitation 2030, including sections on IDD, autism spectrum disorders, schizophrenia, and dementia with (1) linkage to Chronic Non-Communicable Disease (NCD) framework, (2) creation of a Crosswalk between WHO International Classification of Disease (ICD) and International Classification of Functioning (ICF), (3) emphasis on preventive interventions and habilitation entails, (4) emphasis on habilitation as well as rehabilitation, and (5) application of evidence-based approaches and developing further research to study contexts.

Statement on Rights of Persons with IDD and Mental Health

The Human Rights Model therefore represents a "consilient" approach (linking-together)26 IDD and mental health long beset by a historic cleavage since 1980s with paucity of mainstream inclusive psychiatric services, training, and research[27,28]. This WG on the rights of persons with IDD and co-occurring mental disorders proposes several principles, envisioned as "benchmarks" to be implemented with implied responsibility in remedying the current situation that is especially urgent in the context of LMICs globally:

Persons with IDD with co-occurring mental disorders shall enjoy the same human rights and fundamental freedoms as all other citizens (Benchmark: Equitable Human Rights and Freedoms)

- Persons with IDD ought not to be subjected to stigma and discrimination on the grounds of co-occurring mental disorders. They ought to be protected from exploitation, abuse, and degradation, in accordance with the Declaration of Hawaii ethical standards approved by the General Assembly of the WPA in Vienna, Austria, in July 1983[22] (Benchmark: Protections from Harm).
- Persons with IDD and co-occurring mental disorder have the right to humane, dignified, and professional treatment. The aim of psychiatry, as affirmed in the Declaration of Hawaii[29], ought to be inclusive of the treatment of persons with IDD with co-occurring mental disorders and the promotion of their mental health consistent with accepted scientific knowledge and ethical principles. Persons with IDD and co-occurring mental disorders, as a principle, ought to be treated along the same lines as other patients, favored by the fact that great majority of patients may be treated informally and voluntarily in outpatient facilities without hospitalization (Benchmark: Equitable Care and Treatment).
- Whenever possible, psychiatric services for persons with IDD and co-occurring mental disorders ought to be integrated within the general health and social care system and all such persons ought to be cared for, as far as possible, in the community where they live, and not excluded in receiving the same standard of treatment as those without IDD. (Benchmark: Integration and Inclusion in Mainstream Health and Social Care).
- The mental health services for persons with IDD and co-occurring mental disorders ought to be of adequate standard with safeguards of both their right to effective treatment within the care system (Benchmark: Standard of Care).
- The mental health service provision to persons with IDD and co-occurring disorder ought to pay attention to the training of care personnel (Benchmark: Training of Care Personnel).

Action Points

As directed by this statement, the WG on IDD will:

- Take steps to enhance and further the public mental health with regards the human rights of persons with IDD with co-occurring mental disorders (Benchmark: Enhancing IDD and Public Mental Health Interface)
- Include perspectives of persons with IDD and co-occurring mental disorders from low-resource regions and LMICs, as well as perspectives of persons with lived experience of disability to reclaim their histories (Benchmark: Including LMIC and Lived Experience Perspectives)
- Plan to understand communities — past, present, and future — drawing upon efforts to consult and convene resource persons, enable consequential conversations, and help set agendas for action (Benchmark: Consulting, Convening, Collaboration)
- Embedding the work into the life of WPA with visibility and accountability. Ensuring that the efforts continue with assessments, improvements, and new ideas over time — not just over the

short term — this is critical, as the human rights perspectives in IDD and mental health and disabilities is at an important threshold (Benchmark: Visibility, Accountability, Continuity of Efforts)

- Attract individuals who will carry on this work, and who can contribute to the thinking on: How can we move ahead in improving the status of IDD and mental health within psychiatry? It is important to establish a sustainable framework to pursue efforts, to ensure cross-fertilization, and sharing across sections (Benchmark: Recruitment, Training and Cross-Fertilization)

Postscript

The WG on IDD and the President of the WPA are committed to the success of this effort, and an important aspect of the effort is to support the implementation of the recommendations. For the achievement of these benchmarks, the commitment needs to be long term, the effort does not operate as a grant-sponsored body, but nevertheless the WPA will stay committed to a long-term process in terms of building a foundation for learning, teaching, and research promoting human rights and care of persons with IDD and co-occurring mental disorders.

This statement recognizes that there is still a lot to learn, both about how to address and redress the human rights violations of persons with IDD and co-occurring mental disorders, and their legacies, in specifically creating and support educational opportunities for those who do not have real, effective access to knowledge and resources in the field. We approach this work with humility, and it needs to be a long-term commitment, that needs to be sustained well beyond the work of the WG on IDD is completed.

We are very grateful for the time and reflectiveness of those who helped assist in this process, and in beginning to address legacies of human rights violations of persons with IDD, thankful for the wisdom and experiences of the contributors to this process. The persons with IDD with lived experience of stigma, discrimination, and suffering, have taught us important lessons, and there is still much more for us to learn. For too long, people whose lives have been affected most directly by the legacy of discrimination and abuse have not had the sustained attention, not only the WPA, but across other institutions in society, in terms of health, education, and social care, that has often contributed to the supporting hierarchy, and injustice and suppression of the rights of persons with IDD and co-occurring mental disorders.

This is a time for listening and learning while dedicating ourselves to a different future. This statement emphasizes the need for repair of the legacies of locked institutionalization, eugenics, inhumane care ('out of sight and out of mind')[30] and invasive treatments of persons with IDD and co-occurring mental disorders. In the light of lived experiences of persons with IDD and co-occurring mental disorders, we need to be cognizant of our shared responsibilities especially with respect to establishment of these principles and benchmarks for LMICs[31,32.] We are inspired by the examples of persons globally who have committed themselves to thoughtful and intensive efforts to address human rights violations, past and present, of persons with IDD and co-occurring mental disorders. The WG on IDD is not the first to undertake work, and we must learn from those who are already doing it.

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