

## A SELECTION OF TEN READINGS ON TOPICS RELATED TO "PERSONS WITH INTELLECTUAL DISABILITY"

Dates: Sat 16 July 2022: 2.00 pm – 5.30 pm and Sun 17 July 2022: 2.00 pm – 5.30 pm  
All available as free full text

Selection of readings made by A/Prof Goh Lee Gan

### READING 1 – VOCATIONAL INTERVENTIONS TO IMPROVE EMPLOYMENT PARTICIPATION

**Weld-Blundell I,<sup>1</sup> Shields M,<sup>1</sup> Devine A,<sup>1</sup> Kavanagh A,<sup>1</sup> Marck C,<sup>1</sup> Dickinson H.<sup>2</sup> Vocational Interventions to Improve Employment Participation of People with Psychosocial Disability, Autism and/or Intellectual Disability: A Systematic Review. *Int J Environ Res Public Health*. 2021 Nov 17;18(22):12083. doi: 10.3390/ijerph182212083. PMID: 34831840.**

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#### ABSTRACT

**Objective:** To systematically review interventions aimed at improving employment participation of people with psychosocial disability, autism, and intellectual disability.

**Methods:** We searched MEDLINE, Embase, PsycINFO, Web of Science, Scopus, CINAHL, ERIC, and ERC for studies published from 2010 to July 2020. Randomised controlled trials (RCTs) of interventions aimed at increasing participation in open/competitive or non-competitive employment were eligible for inclusion. We included studies with adults with psychosocial disability autism and/or intellectual disability. Risk of bias was assessed using the Cochrane Collaboration Risk of Bias II Tool. Data were qualitatively synthesised. Our review was registered with PROSPERO (CRD42020219192).

**Results:** We included 26 RCTs: 23 targeted people with psychosocial disabilities (n = 2465), 3 included people with autism (n = 214), and none included people with intellectual disability. Risk of bias was high in eight studies, moderate for 18, and low for none. There was evidence for a beneficial effect of Individual Placement and Support compared to control conditions in 10/11 studies. Among young adults with autism, there was some evidence for the benefit of Project SEARCH and ASD supports on open employment.

**Discussion:** Gaps in the availability of high-quality evidence remain, undermining comparability and investment decisions in vocational interventions. Future studies should focus on improving quality and consistent measurement, especially for interventions targeting people with autism and/or intellectual disability.

### READING 2 – ASSESSMENT AND INTERVENTION IN SUPPORT NEEDS FOR PEOPLE WITH INTELLECTUAL DISABILITY

**Esteban L,<sup>1</sup> Navas P,<sup>1</sup> Verdugo MÁ,<sup>1</sup> Arias VB.<sup>1</sup> Community Living, Intellectual Disability and Extensive Support Needs: A Rights-Based Approach to Assessment and Intervention. *Int J Environ Res Public Health*. 2021 Mar 19;18(6):3175. PMID: 33808617.**

**URL: doi: 10.3390/ijerph18063175. PMID: 33808617. (Free full text)**

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#### ABSTRACT

Persons with intellectual disability (ID) and extensive support needs experience poorer quality of life than their peers whose disability is not as severe. Many of them live in residential settings that limit community participation and prevent them from

exercising control over their lives. This work analyses the extent to which professional practices are aimed at promoting the right to community living for persons with ID and extensive support needs, as well as the rights that are particularly linked to it, such as the right to habilitation and rehabilitation and the right to privacy. A specific questionnaire was designed and administered to 729 adults with intellectual disability ( $M = 37.05$ ;  $DT = 12.79$ ) living in different settings (family home, residential facilities, and group homes). Measurement and structural models were estimated using exploratory structural equation modelling. Results obtained reveal that people with extensive support needs receive less support in terms of guaranteeing their right to independent living and privacy, especially when they live in disability-related services. This study highlights the need to implement and monitor, using valid and reliable indicators, mesosystem strategies that guarantee the right to live and participate in the community, especially for individuals with ID and extensive support needs.

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### **READING 3 – INTERVENTION MEASURES IN EMPLOYMENT AND AGEING FOR PEOPLE WITH INTELLECTUAL DISABILITY**

**Ortega-Camarero MT,<sup>1</sup> Cuesta-Gómez JL,<sup>2</sup> de la Fuente-Anuncibay R.<sup>2</sup> Intellectual Disability, Employment and Aging: Intervention Measures. *Int J Environ Res Public Health*. 2021 Mar 14;18(6):2984. doi: 10.3390/ijerph18062984. PMID: 33799429.**

**URL: doi: 10.3390/ijerph18062984. PMID: 33799429. (Free full text)**

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#### ABSTRACT

Workers living with intellectual disability suffer in a special way from the onset of premature ageing. Hence the need to generate alternatives and policies for the development of a new model for active ageing and the care of workers with intellectual disability. Our objective in this study is, therefore, to devise intervention measures that can minimise the effects of ageing on the lives and the activities of these workers. Employing the Delphi technique, we assembled and consulted a panel of eight experts with relevant expertise in the fields of intellectual disability, ageing, employment, and dependency. The panel included employers, families, and workers with disability. Each expert reached a prior consensus over every response and contribution after having consulted four other experts with similar backgrounds, a consultative process in which a total of 40 experts participated. A total of 68 measures were proposed, which correspond to three lines of action or key contexts: Firms and Organisations that employ People with Intellectual Disability; People with Intellectual Disability; and Family setting. In all, 10 recommendations with a focus on both firms and organisations were advanced to implement the proposed measures. The conclusion was that interventions are needed from the time at which the first symptoms of deterioration are detected, which should not necessarily lead to immediate loss of employment, as well as individualised and coordinated interventions among all relevant stakeholders, including the families.

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### **READING 4 – COMORBIDITIES ASSOCIATED WITH GENETIC ABNORMALITIES IN CHILDREN WITH INTELLECTUAL DISABILITY**

**Chen JS, I Yu WH,<sup>2</sup> Tsai MC,<sup>2</sup> Hung PL,<sup>3</sup> Tu YF.<sup>4,5</sup> Comorbidities associated with genetic abnormalities in children with intellectual disability. *Sci Rep*. 2021 Mar 22;11(1):6563. doi: 10.1038/s41598-021-86131-3. PMID:33753861.**

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#### ABSTRACT

Intellectual disability (ID) has emerged as the most common manifestation of underlying genomic abnormalities. Given that molecular genetic tests for diagnosis of ID usually require high costs and yield relatively low diagnostic rates, identification of additional phenotypes or comorbidities may increase the genetic diagnostic yield and are valuable clues for pediatricians in general practice. Here, we consecutively enrolled 61 children with unexplained moderate or severe ID and performed chromosomal microarray (CMA) and sequential whole-exome sequencing (WES) analysis on them. We identified 13 copy number variants in 12 probands and 24 variants in 25 probands, and the total diagnostic rate was 60.7 percent. The genetic abnormalities were commonly found in ID patients with movement disorder (100 percent) or with autistic spectrum disorder (ASD) (93.3 percent). Univariate analysis showed that ASD was the significant risk factor of genetic abnormality ( $P = 0.003$ ; OR 14, 95 percent CI 1.7-115.4). At least 14 ID-ASD associated genes were identified, and the majority of ID-ASD associated genes (85.7 percent) were found to be expressed in the cerebellum based on database analysis. In conclusion, genetic testing on ID children, particularly in those with ASD, is highly recommended. ID and ASD may share common cerebellar pathophysiology.

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#### READING 5 – TELEMEDICINE TREATMENT AND CARE FOR PATIENTS WITH INTELLECTUAL DISABILITY

**Krysta K,<sup>1</sup> Romańczyk M,<sup>1</sup> Krzystanek M,<sup>1</sup> Diefenbacher A.<sup>2</sup> Telemedicine Treatment and Care for Patients with Intellectual Disability. *Int J Environ Res Public Health*. 2021 Feb 11;18(4):1746. doi: 10.3390/ijerph18041746. PMID: 33670152.**

**URL: doi: 10.3390/ijerph18041746. PMID: 33670152. (Free full text)**

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#### ABSTRACT

In recent years, telemedicine has been developing very dynamically. The development of new technologies allows their use in the treatment of dermatological, cardiological, endocrine, and other diseases. However, there are few reports on the use of digital technologies in the mental healthcare of people with intellectual disabilities. Intellectual disability is a disease that affects a large number of people. Patients suffering from intellectual disability encounter barriers that make it difficult for them to fully use telemedicine; however, these barriers can be overcome with appropriate support and adaptation. A review of the literature on telemedicine solutions in the care of people with intellectual disabilities indicates that the applications support the communication of these people with the doctor, enable simple behavioural interventions, stimulate cooperation in treatment, provide simple medical education, and record medical data for the doctor. The authors present the potential risks related to the use of telemedicine solutions for people with intellectual disabilities as well as the project of creating a new, multi-module telemedicine system.

## READING 6 – ROLES OF FAMILY MEMBERS OF ADULTS WITH INTELLECTUAL DISABILITY

**Zambrino N,<sup>1</sup> Hedderich I.<sup>2</sup> Family Members of Adults with Intellectual Disability Living in Residential Settings: Roles and Collaboration with Professionals. A Review of the Literature. Inquiry. 2021 Jan-Dec;58:46958021991301. doi: 10.1177/0046958021991301. PMID: 33631985**

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### ABSTRACT

The aim of this article is to review the literature concerning the role of family members of adults with an intellectual disability living in diverse residential settings and their collaboration with residential staff. Whenever the scarce literature on the subject allowed, the focus was laid on family members of persons with additional challenging behaviour. Electronic databases, reference screening, and a hand search of selected journals were employed to collate literature using key terms such as family members, intellectual disability, and residential setting. By extracting relevant data of the 18 articles that fulfilled all inclusion criteria, the following three main themes with each subthemes were identified inductively: roles of family members after the transition, the effects of the transition on family members, and the collaboration between the family members and professional care staff. This review presents the different roles family members partake and highlights the importance of regular open two-sided communication for collaboration with professional staff to be successful. Practical implementations are discussed and the need for further research in the field is indicated.

## READING 7 – MAKING THE PUBLIC MORE COMFORTABLE WITH MEETING PEOPLE WITH INTELLECTUAL DISABILITY

**McConkey R,<sup>1</sup> Slater P,<sup>1</sup> Dubois L,<sup>2</sup> Shellard A,<sup>2</sup> Smith A.<sup>2</sup> An international study of public contact with people who have an intellectual disability. J Intellect Disabil Res. 2021 Mar;65(3):272-282. doi: 10.1111/jir.12809. PMID: 33404100.**

**URL: doi: 10.1111/jir.12809. PMID: 33404100. (Free full text)**

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**BACKGROUND:** People with intellectual disability (ID) are often socially isolated, and many experience stigma and discrimination. Increased contact with the general public is thought to overcome prejudices. This large-scale international study had three main aims: to determine the type and frequency of contact that the general public has with people with ID; to identify the personal characteristics of those who have greater contact; and to examine the public's level of comfort at the prospect of having contact with people with ID.

**METHOD:** Self-completed online questionnaires were administered to nationally representative panels of respondents in 17 countries, totalling 24,504 persons. Multivariate analyses were used to identify respondents more likely to have had frequent personal contact with persons with ID from those with infrequent or no contact and those respondents who were most comfortable with meeting a person with ID.

**RESULTS:** Internationally, around one in four of the general population reports having frequent personal contact with people who have an ID, although this varied from 7 percent in Japan to 46 percent in Panama. The principal forms of contact were through friendships, neighbours, or extended family members. For all countries, volunteering and engagement in the Special Olympics were the two main predictors of frequent personal contact followed by employment in the education, health, or social care field, being a parent of children under 18 years, playing sports, and being employed. People who reported frequent personal contact were also more comfortable with meeting a person with ID.

**CONCLUSIONS:** This international dataset provides a baseline against which public contact can be compared across countries and changes monitored over time. The findings suggest ways in which greater contact can be promoted and making the public more comfortable with meeting people with ID.

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## READING 8 – DIABETES AND COMPLICATIONS IN PEOPLE WITH AND WITHOUT INTELLECTUAL DISABILITY

**Cuyppers M,<sup>1</sup> Leijssen M,<sup>2</sup> Bakker-van Gijssel EJ,<sup>2</sup> Pouls KPM,<sup>2</sup> Mastebroek MM,<sup>2</sup> Naaldenberg J,<sup>2</sup> Leusink GL.<sup>2</sup> Patterns in the prevalence of diabetes and incidence of diabetic complications in people with and without an intellectual disability in Dutch primary care: Insights from a population-based data-linkage study. *Prim Care Diabetes*. 2021 Apr;**15**(2):372-377. doi: 10.1016/j.pcd.2020.11.012. PMID: 33323353.**

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### ABSTRACT

**AIMS:** To conduct an epidemiological analysis of patterns observed in diabetes care provided to individuals with and without intellectual disabilities (ID) in primary care settings.

**METHODS:** An ID-cohort (N = 21,203) was compared with a control group of similar age and sex from the general Dutch population (N = 267,628). Distinctive data for diabetes (both type 1 and type 2) and related complications were retrieved from national databases.

**RESULTS:** The prevalence of diabetes was higher in people with ID than in the general population (9.9 percent versus 6.6 percent). Largest differences were seen in younger age groups. Women with ID had diabetes more often than men with ID. Complications were less common in people with ID than in the general population (IR 58.6 versus 70.4). In particular, cardiometabolic complications were noted less, while surgical interventions and hospitalisation occurred more often.

**CONCLUSIONS:** Although diabetes was 1.5 times more prevalent in people with ID than in other people, related complications were less common, followed different patterns, and were more severe than in the general population. Future research is needed to understand the underlying causal mechanisms and to lower the risk of severe diabetic complications among people with ID.

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## READING 9 – SELF-DETERMINATION IN PEOPLE WITH INTELLECTUAL DISABILITY

**Vicente E,<sup>1</sup> Bravo-Álvarez MÁ,<sup>1</sup> Mumbardó-Adam C,<sup>2</sup> Guillén VM,<sup>3</sup> Coma-Roselló T,<sup>4</sup> Sánchez S.<sup>5</sup> Self-Determination in People with Intellectual Disability: The Mediating Role of Opportunities. *Int J Environ Res Public Health*. 2020 Aug 26;**17**(17):6201. doi: 10.3390/ijerph17176201. PMID: 32859080.**

**URL: doi: 10.3390/ijerph17176201. PMID: 32859080. (Free full text)**

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### ABSTRACT

The Convention on the Rights of Persons with Disabilities have proclaimed the basic right of people to make one's own choices, have an effective participation, and inclusion. Research in the field of disability have stressed self-determination as a key construct due to its impact on their quality of life and the achievement of desired educational and adulthood related outcomes. Self-determination development must be promoted through specific strategies and especially by providing tailored opportunities to practise those skills. Providing these opportunities across environments could be especially relevant as a facilitator of self-determination development. This manuscript aims to ascertain if opportunities at home and in the community to engage in self-determined actions are mediating the relationship between people intellectual disability level and their self-determination. Results have confirmed direct effects of intellectual disability level on self-determination scores. Indirect effects also predicted self-determination and almost all its related components (self-initiation, self-direction, self-regulation, self-realisation, and empowerment) through opportunities in the community and at home. Autonomy was predicted by the intellectual disability level through an indirect effect of opportunities at home, but not in the community. These results highlight the need for further research to better operationalise and promote contextually rooted opportunities for people with intellectual disability to become more self-determined.

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### **READING 10 – INTELLECTUAL DISABILITY AND NUTRITION-RELATED HEALTH**

**Kolset SO.<sup>1</sup> Intellectual disability and nutrition-related health. *EMBO Mol Med.* 2020 Oct 7;12(10):e12899. PMID: 32812690.**

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### ABSTRACT

Intellectual disability (ID) is a condition that affects approximately 1 percent of the population (Maulik et al, 2011). The numbers may differ across nations, owing to different systems and diagnosis entries or lack of such, but usually range between 0.6 and 3 percent (Stromme & Valvatne, 1998). Persons with ID are a heterogeneous group with different diagnoses and different levels of intellectual ability. These range from profound (IQ <20) and serious ID (IQ 20-34) to moderate (IQ 35-49) and light ID (IQ 50-69); this roughly translates into the intellectual capacity of children between 3-12 years of age. More than 75 percent of persons with ID have the mild form and their intellectual capacity and potential may be underestimated in some cases if IQ is the only diagnostic criteria. However, the range in itself is an important factor to take into account when addressing nutrition and health issues. It is further important to recognise that ID is also a feature of several rare disorders, and many disorders not yet identified, adding to the complexity of this group.