A SELECTION OF TEN READINGS ON TOPICS RELATED TO PERSONS WITH INTELLECTUAL DISABILITIES 3

FPSC121 – SATURDAY, 20 JULY 2024 AND SUNDAY, 21 JULY: 2.00pm – 5.30pm
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Selection of readings made by A/Prof Goh Lee Gan

READING 1 – HEALTHCARE – ACCESS TO GENERAL PRACTICE FOR PWIDS IN AUSTRALIA

Shea B,[1] Bailie R,[1] Bailie J,[2,3] Dykgraaf SH,[4] Fortune N,[5,6] Lennox N.[7] Access to general practice for people with intellectual disability in Australia: a systematic scoping review. BMC Prim Care. 2022 Nov 29;23(1):306. PMID: 36447186.

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ABSTRACT

BACKGROUND: People with intellectual disability experience inadequate access to general practice and poorer health outcomes than the general population. While some access barriers have been identified for this population, these studies have often used narrow definitions of access, which may not encompass the multiple dimensions that influence access to general practice. To address this gap, we conducted a scoping review to identify factors impacting access to general practice for people with intellectual disability in Australia, using a holistic framework of access conceptualised by Levesque and colleagues.

METHODS: This scoping review followed Joanna Briggs Institute methodology and was guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses Extension for Scoping Reviews. Medline (Ovid), Scopus, CINAHL, Informit, and PsycINFO databases were searched. Screening, full-text review, and data extraction were completed by two independent reviewers, with consensus reached at each stage of the study. Data were extracted, coded, and synthesised through deductive qualitative analysis, using the five corresponding conceptual dimensions within Levesque and colleagues' theoretical framework of access, which incorporate both supply-side features of health systems and services, and demand-side characteristics of consumers and populations.

RESULTS: The search identified 1,364 publications. After duplicate removal, title and abstract screening, and full-text review, 44 publications were included. Supply-side factors were more commonly reported than demand-side factors, with the following issues frequently identified as impacting access to general practice: limited general practitioner education about, and/or experience of, people with intellectual disability; communication difficulties; and inadequate continuity of care. Less frequently included were factors such as the health literacy levels, promotion of general practice services, and availability of complete medical records.

CONCLUSIONS: This is the first scoping review to assess access barriers for people with intellectual disability using a comprehensive conceptualisation of access. The findings highlight the need for increased efforts to address demand-side dimensions of access to general practice and offer a basis for a balanced portfolio of strategies that can support recent policy initiatives to enhance access to care for people with intellectual disability.

READING 2 – HEALTHCARE – TRANSITIONS FROM PAEDIATRIC TO ADULT CARE IN PATIENTS WITH DOWN SYNDROME

Iriowen R,[1] Varshney K,[1,2] Pillay P,[2] Morrell K,[3] Fossi A,[4] Stephens MM.[5,6] Disparities and outcomes of patients living with Down Syndrome undergoing healthcare transitions from paediatric to adult care: A scoping review. Am J Med Genet A. 2022 Aug;188(8):2293-2302. PMID:35686676.

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ABSTRACT
Down Syndrome (DS) is one of the most common chromosomal disorders worldwide, and people with DS experience more co-morbidities and have poorer health outcomes compared to the general population. An area that is not well understood is how patients with DS transition from paediatric to adult care, as well as the details, barriers, and difficulties of these transitions for patients. Hence, we aimed to provide a scoping review of the literature in PubMed, Scopus, and CINAHL on the topic of healthcare transitions (HCTs) for patients with DS. Findings suggest patients with DS who continued receiving care as an adult from a paediatric care provider tended to experience co-morbidities and other adverse health issues at higher rates than those who entirely switch to an adult-care team. Patients with DS were unable to undergo transition due to multiple barriers, such as low income, limited/public insurance, sex, and race.

We propose potential steps for transition, which focus on ensuring early planning, communicating better, coordinating services, assessing decision-making capacity, and providing ongoing social and financial support. Future research must further identify and address barriers to HCTs for people with DS.

READING 3 – HEALTHCARE – FAMILY-ORIENTED PRACTICE IN DISABILITY SERVICES IN HONG KONG

Xun K,[1,2] Cui J.[3] Family-oriented practice in disability Services in Hong Kong: A cross-sectoral social work perspectives in the fields of intellectual disability and mental illness. Health Soc Care Community. 2022 Nov;30(6):e5714-e5724. PMID:36069289.

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ABSTRACT
Supporting the families of people with disabilities has become a crucial aim of disability services. In disability services, where people with disabilities are usually positioned at the centre of service provision, family-oriented practice implies practice directions to work with clients' families in service delivery. The study aims at exploring how social workers in intellectual disability services and mental health services deliver a family-oriented practice in Hong Kong.

We performed a qualitative analysis, using in-depth interview data collected from two broader studies about social workers' experiences in the fields of intellectual disability and mental illness respectively. Thirteen participants in intellectual disability settings and another 13 participants in mental health settings shared their understanding of and concern with family-oriented practice. Four themes were identified in the participants' accounts regarding the importance of family connectedness, family members' constructions of clients' identity, the scope of activities, and the intervention space between individual and family. These findings reflect that family-oriented practice was jointly shaped by clients' family systems and disability service system, and shed light on the strategies for future service development at the broader systematic level.

READING 4 – SOCIAL PERSPECTIVES – REPEATED CLINICAL INCIDENTS IN CHILDREN WITH INTELLECTUAL DISABILITY

Walton M,[1] Ong N,[1,2] Barnett D,[2] Mimmo L,[3,4] Long J,[5] Weise J.[6] Reported clinical incidents of children with intellectual disability: A qualitative analysis. Dev Med Child Neurol. 2022 Nov;64(11):1359-1365. PMID:35578400.

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ABSTRACT
AIM: To qualitatively explore reported clinical incidents of children with intellectual disability aged 0 to 18 years.

METHOD: A secondary qualitative evaluation using latent content analysis was used on retrospective hospital incident management reporting data (1 Jan-31 Dec 2017) on 1,367 admissions for 1,018 randomly selected patients admitted to two tertiary children's hospitals in New South Wales, Australia. Sex and age at admission in children with and without intellectual disability: 83 (43.7%) versus 507 (43.1%) females and 107 (56.3%) versus 670 (56.9%) males, p=0.875; median age 3 years (0-18y) versus 4 years (0-18y), p=0.122. Of these, 44 patient safety incident reports for children with intellectual disability (sex, SD, and range) and 167 incident reports for children without intellectual disability (sex, SD, and range) were found and analysed.

RESULTS: Ten themes were synthesised from the data and represented the groups with and without intellectual disability. Children with intellectual disability had a significantly higher proportion of care issues identified by their parents. They also had higher rates of multiple reported clinical incidents per admission compared to children without intellectual disability.

INTERPRETATION: Mechanisms to advocate and raise patient safety issues for children with intellectual disability are needed. Partnerships with parents and training of staff in reporting clinical incidents for this population would enhance the embedding of reasonable adaptations into incident management systems for ongoing monitoring and improvement.

WHAT THIS PAPER ADDS: Children with intellectual disability experienced multiple patient safety incidents per admission compared to children without intellectual disability. Children with intellectual disability had significantly increased rates of parent-identified incidents. Issues with medication, communication, delays in diagnosis and treatment, and identification of deterioration were noted.

READING 5 – IMPROVING ORAL HEALTH OF ADULTS WITH INTELLECTUAL DISABILITY

Kangutkar T,[1] Calache H,[1] Watson J,[2] Taylor S,[2] Balandin S.[2] Education/Training Interventions to Improve Oral Health of Adults with Intellectual Disability. Healthcare (Basel). 2022 Oct 17;10(10):2061. PMID: 36292510.

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ABSTRACT
People with intellectual disability have poorer oral health outcomes and experience greater difficulties accessing dental services than the rest of the community. Interdisciplinary educational programmes for those involved in oral health decision-making for people with intellectual disability aim to improve their oral health. This scoping review explored education/training interventions related to the oral health of adults with intellectual disability. Interventions targeted dental health and non-dental health professionals, adults with intellectual disability, and their paid and unpaid supporters. Six electronic databases were searched using PRISMA guidelines and the Crowes critical appraisal tool. The search strategy, plus the application of the inclusion and exclusion criteria, presented in the body of the manuscript, led to the selection of 20 papers for inclusion into this review.

The quality of undergraduate tuition relating to disability was reported to be poor, but students and dental health professionals expressed interest in expanding their knowledge in this area. Disability-support workers and primary carers of people with intellectual disability reported improved knowledge and attitude, but the oral health status of the people they supported was not impacted. No research was found that explored the perspectives of non-dental health professionals. Oral health training/education contributes to systemic barriers in general health, wellbeing, and social inclusion of people with intellectual disability. Revision of disability-related programmes in general dentistry courses and longitudinal impact research is needed.

READING 6 – MANAGING DENTAL CARIES IN PEOPLE WITH DISABILITIES

Molina G,[1,2] Zar M,[2] Dougall A,[3] McGrath C.[4] Management of dental caries lesions in patients with disabilities: Update of a systematic review. Front Oral Health. 2022 Oct 28; 3:980048. PMID:36389277.

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ABSTRACT
The aim of this systematic review was to update an existing review on the management of dental caries lesions in patients with disabilities so as to provide an up-to-date summary of the evidence. Randomised clinical trials and cohort studies related to preventive and restorative programmes for dental caries among people requiring special care, published in English, Spanish, Portuguese, French, and German from 1 February 2011 to 1 April 2022, were retrieved from three databases ("updated review").

From the 1,105 titles identified using the search topic "Caries AND Disability", 17 papers informed in the analyses: 6 referring to caries preventive strategies and 11 related to restorative care strategies. Most of these studies targeted children and adults with intellectual/physical disability, although preventive and therapeutic strategies were also reported for frail older adults and onco-haematological patients. Fluorides in tablets, gels, or varnishes forms and the use of xylitol as a sugar substitute were reported as effective approach to prevent the onset of caries in high-risk groups. Minimally invasive intervention treatment options such as the Hall technique, the ART approach, and the use of SDF for arresting caries were deemed suitable and effective strategies for treating existing lesions in-office. In conclusion, in the past decade (2011-2022), an increased number of articles reported strategies to prevent and manage caries among people requiring special care. Although an array of preventive and therapeutic strategies for dental caries exists, more and better-quality clinical evidence is needed to offer guidance to inform policy and practice for special care dentistry.

READING 7 – INTERVENTIONS FOR SOCIAL AND COMMUNITY PARTIPATION FOR ADULTS WITH INTELLECTUAL DISABILITY

Randjelovic I,[1] Giummarra MJ,[1,2] O'Brien L.[1,3] Interventions for social and community participation for adults with intellectual disability, psychosocial disability or on the autism spectrum: An umbrella systematic review. Front Rehabil Sci. 2022 Aug 19;3:935473. PMID: 36189003.

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ABSTRACT
OBJECTIVE: This umbrella systematic review examined the effectiveness, facilitators, and barriers of interventions for social, community, and civic participation for adults on the autism spectrum, or with intellectual or psychosocial disability.

DATA SOURCES: Eight databases were searched to identify eligible reviews defined by the: Sample (≥50% adults on the autism spectrum or with intellectual or psychosocial disability), Phenomena of Interest (interventions in community settings that aimed to improve social, community, or civic participation, or capacity to participate), Design (any), Evaluation (any method that evaluated impacts on participation or capacity to participate), and Research type (reviews as journal articles, dissertations, or in grey literature, in English, published 2010-2020).

REVIEW METHODS: Rapid review methods were used. One researcher screened 27,890 records and 788 potentially eligible full texts. A second reviewer independently screened 20% of records, and ambiguous full text publications. Study quality was extracted, and review quality was assessed with the Assessing Methodological Quality of Systematic Reviews (AMSTAR) checklist. Data from 522 studies in 57 eligible systematic reviews were extracted for narrative synthesis. The Corrected Covered Area (CCA) was calculated to indicate overlap between reviews.

RESULTS: There was a pooled sample of 28,154 study participants, predominantly from studies in North America, the UK, and Europe. There was very low overlap between reviews (CCA=0.3%). Reviews were predominantly low quality: 77.2% of reviews met <50% of AMSTAR criteria. Most studies were low (45.4%) or moderate (38.3%) quality. Three broad intervention categories improved participation, inclusion, and belonging outcomes: (1) interventions to help people identify and connect with participation opportunities (e.g., person centred planning); (2) participation opportunities or activities (e.g., joining a community group, sports or outdoor activities, or arts-based activities); and (3) supports to build skills and capacity to participate socially and in the community.

CONCLUSIONS: The evidence highlighted that improved social and community participation requires purposeful strategies that identify meaningful participation preferences (e.g., where, when, how, and with whom) and provide support to build capacity or enable ongoing participation. Community capacity building, peer support, and advocacy may also be needed to make the community more accessible, and to enable people to exercise genuine choice.

READING 8 – NURSES' PERCEPTIONS OF GOOD EXPERIENCES OF CARE FOR CHILDREN AND YOUNG PEOPLE WITH INTELLECTUAL DISABILITY

Mimmo L,[1,2] Hodgins M,[2] Samir N,[2] Woolfenden S,[2] Travaglia J,[3] Harrison R.[4] "Smiles and laughter and all those really great things": Nurses' perceptions of good experiences of care for inpatient children and young people with intellectual disability. J Adv Nurs. 2022 Sep;78(9):2933-2948. PMID:35451515.

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ABSTRACT
AIM: To understand what constitutes a good experience of care for inpatient children and young people with intellectual disability as perceived by nursing staff.

DESIGN: Interpretive qualitative study.

METHODS: Focus groups with clinical nursing staff from speciality neurological/neurosurgical and adolescent medicine wards across two specialist tertiary children's hospitals in Australia were conducted between March and May 2021. Data analysis followed interpretative analysis methods to develop themes and codes that were mapped to a conceptual model of safe care.

RESULTS: Six focus groups with 29 nurses of varying experience levels were conducted over three months. Themes and codes were mapped to the six themes of the conceptual model: use rapport, know the child, negotiate roles, shared learning, build trust and relationships, and past experiences. The analysis revealed two new themes that extended the conceptual model to include: the unique role of a paediatric nurse, and joy and job satisfaction, with a third contextual theme: impacts of COVID-19 pandemic restrictions. With the perspectives of paediatric nurses incorporated into the model, we have enhanced our model of safe care specifically for inpatient paediatric nursing care of children and young people with intellectual disability.

CONCLUSION: Including perceptions of paediatric nurses confirmed the position of the child with intellectual disability being at the centre of safe care, where care is delivered as a partnership between nursing staff, child or young person and their parents/family, and the hospital systems and processes.

IMPACT: The enhanced model offers a specialised framework for clinical staff and health managers to optimise the delivery of safe care for children and young people with intellectual disability in hospital.

READING 9 – PHYSICAL ACTIVITY AND HEALTHY EATING INTERVENTION FOR ADULTS WITH INTELLECTUAL DISABILITY

Salomon C,[1] Reid R,[1] Bellamy J,[1,2] Hsu M,[1,4] Evans E,[3] Teasdale S,[5,6] Trollor J.[7] "Get Healthy!" physical activity and healthy eating intervention for adults with intellectual disability: results from the feasibility pilot. Pilot Feasibility Stud. 2023 Mar 22;9(1):48. PMID: 36949532.

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ABSTRACT
BACKGROUND: People with intellectual disabilities (ID) experience high rates of lifestyle-related morbidities, in part due to lack of access to tailored health promotion programmes. This study aimed to assess the feasibility and preliminary efficacy of a tailored healthy lifestyle intervention, Get Healthy!.

METHODS: Get Healthy! is a 12-week physical activity and healthy eating programme designed to address lifestyle-related risks for adults with mild-moderate ID. The feasibility pilot was designed to assess subjective participant experience and programme feasibility across: recruitment and screening, retention, session attendance and engagement, adverse events, and practicality and reliability of outcome procedures. Exploratory programme efficacy was assessed across the following measures: anthropometry (body mass index, weight, waist circumference), cardiovascular fitness, physical strength, dietary intake, healthy literacy, and quality of life.

RESULTS: Six participants with moderate ID and two carer participants completed the feasibility trial, representing a 100% retention rate. Qualitative data indicated the programme was well received. Participants with ID attended 75% of sessions offered and displayed a high level of engagement in sessions attended (91% mean engagement score). While most data collection procedures were feasible to implement, several measures were either not feasible for our participants, or required a higher level of support to implement than was provided in the existing trial protocol. Participants with ID displayed decreases in mean waist circumference between baseline and endpoint (95% CI: -3.20, -0.17 cm) and some improvements in measures of cardiovascular fitness and physical strength. No changes in weight, body mass index, or objectively measured knowledge of nutrition and exercise or quality of life were detected from baseline to programme endpoint. Dietary intake results were mixed.

DISCUSSION: The Get Healthy! programme was feasible to implement and well received by participants with moderate ID and their careers. Exploratory efficacy data indicates the programme has the potential to positively impact important cardiometabolic risk factors such as waist circumference, cardiovascular fitness, and physical strength. Several of the proposed data collection instruments will require modification or replacement prior to use in a sufficiently powered efficacy trial.

READING 10 – EXPLORING EFFECTS OF DIET, PHYSICAL ACTIVITY, HEALTH KNOWLEDGE, AND CARDIOMETABLIC PROFILE OF YOUNG ADULTS WITH INTELLECTUAL DISABILITY

McDonald R,[1] Lambert GW,[1] Lambert EA,[1] Zwack CC,[1,2] Tursunalieva A.[3] Exploration of diet, physical activity, health knowledge and the cardiometabolic profile of young adults with intellectual disability. J Intellect Disabil Res. 2022 Jun;66(6):517-532. PMID:35137997.

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ABSTRACT
BACKGROUND: Young adults with intellectual disability (ID) are experiencing early mortality, and it is suggested that they are living with undiagnosed cardiovascular and metabolic risk factors (hereafter referred to as cardiometabolic).

METHODS: We investigated the association between modifiable risk factors and cardiometabolic health profile in adults with ID aged 18-45 years through clinical evaluation of traditional cardiometabolic parameters, and assessment of physical activity levels, diet, and associated health knowledge.

RESULTS: We found that young adults with ID have an increased obesity (mean body mass index; ID group: 32.9±8.6 vs control group: 26.2±5.5, P=0.001), are engaging in less physical activity than the age-matched general population (total activity minutes per week; ID group: 172.2±148.9 vs control group: 416.4±277.1, P<0.001), and overall have unhealthier diets. Additionally, knowledge about nutrition and physical activity appears to be an important predictor of cardiometabolic risk in this population. If young people with ID are to improve their cardiometabolic health to reduce morbidity and early mortality, we need to further explore how to consistently apply health messaging to get lasting behavioural change in this population.