

## A SELECTION OF TEN READINGS ON TOPICS RELATED TO IMPROVING HEALTHCARE FOR PERSONS WITH DISABILITIES

some available as free full-text and some requiring payment

Selection of readings made by A/Prof Goh Lee Gan

### READING 1 – CHALLENGING BEHAVIOURS IN AUSTISM SPECTRUM DISORDERS

**Poon KK.** Challenging behaviors among children with autism spectrum disorders and multiple disabilities attending special schools in Singapore. *Res Dev Disabil.* 2012 Mar-Apr;33(2):578-82. doi: 10.1016/j.ridd.2011.10.025. Epub 2011 Nov 26. PubMed PMID: 22119707.

URL: <http://www.sciencedirect.com/science/article/pii/S0891422211004124> – payment required.

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#### ABSTRACT

This study sought to understand the profile of and the factors which impact upon challenging behaviors among children with autism spectrum disorders (ASD) and multiple disabilities (MD). Teachers of 322 and 132 children with ASD and MD, respectively, attending special schools in Singapore, completed the Developmental Behavior Checklist, Teacher Version (DBC-T; Einfeld & Tonge, 1995). The findings suggest that children with ASD exhibit elevated levels of challenging behavior in all areas, relative to children with MD. Multiple regression analyses also indicate that diagnostic category was associated with all aspects of challenging behavior measured by the DBC-T. In addition, age was associated with only disruptive/antisocial behaviors in this study. Theoretical and practical implications were discussed.

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PMID: 22119707 [PubMed - indexed for MEDLINE]

### READING 2 – PROFILE OF CHILDREN DIAGNOSED WITH AUSTISM SPECTRUM DISORDER

**Lian WB, Ho SK.** Profile of children diagnosed with autistic spectrum disorder managed at a tertiary child development unit. *Singapore Med J.* 2012 Dec;53(12):794-800. PubMed PMID: 23268152

URL: <http://www.sma.org.sg/UploadedImg/files/SMJ/5312/5312a2.pdf> -- free full text

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#### ABSTRACT

**INTRODUCTION:** There has been a rising trend in childhood developmental and behavioural disorders (CDABD). This study reports the profile of children with autistic spectrum disorders (ASD) initially referred for evaluation of CDABD. **METHODS:** The CDABD database prospectively collected data of all consenting children referred in 2003 to the then Child Development Unit at KK Women's and Children's Hospital. All received medical consultation, followed by further assessments and intervention. Patients were tracked for one year. **RESULTS:** Among 542 referred children, 32% (n = 170) received a diagnosis of ASD one year after the first consultation. Most were male, with a male to female ratio of 4.5:1. The median age at the first consultation was 41 (19,109) months. The main presenting concern was a delay in the development of speech and language skills in 78% of the children. A significant number had behavioural (63%) and social interaction (34%) issues. Criteria for the diagnosis of ASD according to the Diagnostic Statistical Manual IV-Revised were fulfilled in almost 90%. With the remaining refusing or deferring evaluation, only 74% received a psychological assessment. ASD was

assessed to be severe or moderate in 86% of the children. Three-quarters remained on follow-up one year after the first consultation. The majority were referred for either centre- or school-based intervention programmes, with 70% assessed to have improved at the one-year mark. **CONCLUSION:** This is the first presentation of local data that aids programme planning and resource allocation. Children with ASD have varied outcomes. It is important to identify and intervene early in order to optimise development and functionality. PMID: 23268152 [PubMed - indexed for MEDLINE]

### READING 3 – NEONATES AT BORDERLINE VIABILITY

**Poon WB, Ho SK, Yeo CL. Short- and long-term outcomes at 2, 5 and 8 years old for neonates at borderline viability –an 11-year experience. Ann Acad Med Singapore. 2013 Jan;42(1):7-17. PubMed PMID: 23417586.**

URL: <http://www.annals.edu.sg.libproxy1.nus.edu.sg/pdf/42VolNo1Jan2013/V42N1p7.pdf> - free full text.

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#### ABSTRACT

**INTRODUCTION:** Neurodevelopmental outcome of borderline viability neonates have lagged behind improvement in survival figures. Accurate figures based on local outcome allow us to better counsel parents and to prognosticate with greater accuracy on both short- and longterm outcomes.

**MATERIALS AND METHODS:** A retrospective cohort study of 101 consecutively born neonates, born from 21 to 26 weeks gestation over an 11-year period from 1 January 1994 to 31 December 2005 was conducted. Long-term outcomes were assessed at 2, 5 and 8 years of age in terms of mental developmental index (MDI) or intelligence quotient (IQ) scores, hearing and visual impairments, handicaps and impairments, school placement and interventions required.

**RESULTS:** Survival rates were 20.0%, 60.9%, 70.4% and 73.2% for neonates born at 21 to 23, 24, 25 and 26 weeks gestation respectively. Factors that predicted increased mortality included higher alveolar-arterial oxygen difference (AaDO<sub>2</sub>) with odds ratio (OR) 1.005 and lower birth weight OR 0.993. Rates of severe retinopathy of prematurity (ROP) (stage 3 or worse) were 100%, 57.1%, 42.1% and 26.7% for 21 to 23, 24, 25 and 26 weeks gestation respectively. Rates of bronchopulmonary dysplasia (BPD) were 100.0%, 57.1%, 63.2% and 60.0% respectively. Rates of severe intraventricular haemorrhage (IVH) were 0%, 7.1%, 5.3% and 10.0% respectively. Moderate to severe disability rates at 2 years old were 100%, 44.4%, 33.3% and 30.4% respectively. At 5 years old, moderate to severe disability rates were 16.7%, 22.2% and 14.3% respectively for those born at 24, 25 and 26 weeks gestation. Interpretation at 8 years was limited by small numbers. **CONCLUSION:** Our results indicated that local figures for mortality and morbidity remained high at the limits of viability, although they were comparable to outcomes for large scale studies in advanced countries. PMID: 23417586 [PubMed - indexed for MEDLINE]

### READING 4 – CHILDREN WITH DEVELOPMENT AND BEHAVIOUR CONCERNS

**Lian WB, Ho SK, Choo SHT, Shah VA, Chan DK, Yeo CL, Ho LY. Children with developmental and behavioural concerns in Singapore. Singapore Med J. 2012 Jul;53(7):439-45. PubMed PMID: 22815011.**

URL: <http://www.sma.org.sg/UploadedImg/files/SMJ/5307/5307a1.pdf> - free full text

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#### ABSTRACT

**INTRODUCTION:** Childhood developmental and behavioural disorders (CDABD) have been increasingly recognised in recent years. This study evaluated the profiles and outcomes of children referred for developmental and behavioural concerns to a tertiary child developmental centre in Singapore. This is the first such regional database.

**METHODS:** Baseline information, obtained through a questionnaire, together with history at first consultation, provided information for referral, demographic and presentation profiles. Clinical formulations were then made. Definitive developmental and medical diagnoses, as well as outcomes based on clinical assessment and standardised testing, were recorded at one year post first consultation.

**RESULTS:** Out of 1,304 referrals between January 1, 2003 and December 1, 2004, 45% were 2-4 years old and 74% were boys. The waiting time from referral to first consultation exceeded four months in 52% of children. Following clinical evaluation, 7% were found to be developmentally appropriate. The single most common presenting concern was speech and language (S&L) delay (29%). The most common clinical developmental diagnosis was autism spectrum disorder (ASD) (30%), followed by isolated S&L disorder, global developmental delay (GDD) and cognitive impairment (CI). Recommendations included S&L therapy (57%), occupational therapy (50%) and psychological/behavioural services (40%). At one year, ASD remained the most common definitive developmental diagnosis (31%), followed by S&L disorder, CI and GDD. Most were children with high-prevalence, low-moderate severity disorders who could potentially achieve fair-good prognosis with early intervention.

**CONCLUSION:** Better appreciation of the profile and outcome of children with CDABD in Singapore could enable better resource planning for diagnosis and intervention.

PMID: 22815011 [PubMed - indexed for MEDLINE]

## READING 5 – DOWN SYNDROME CONGENITAL ANOMALIES AND ACQUIRED DISEASES

**Tan AP. Down syndrome: multimodality imaging of associated congenital anomalies and acquired diseases. Med J Malaysia. 2013 Dec;68(6):482-9. PubMed PMID: 24632922**

URL: <http://www.e-mjm.org/2013/v68n6/down-syndrome.pdf> - free full text

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### ABSTRACT

Down syndrome (Trisomy 21) is the most common chromosomal abnormality among liveborn infants. It is the most frequent form of intellectual disability caused by a microscopically demonstrable chromosomal aberration. Management requires a multidisciplinary approach to the ongoing evaluation and monitoring for associated congenital anomalies and acquired disorders. Trisomy 21 is characterized by a variety of dysmorphic features, congenital anomalies and associated medical conditions. Knowledge of these associated conditions are important for clinicians involved in the management of these patients. Appropriate radiologic imaging with prompt, accurate interpretation plays an important role in the diagnosis and management of these diseases. The primary goal of this pictorial review is to unravel the radiological findings of these associated conditions.

PMID: 24632922 [PubMed - in process]

**READING 6 – CONGENITAL HEART DEFECTS IN DOWN SYNDROME**

**Tan M, Xu C, Sim SK, Seow AL, Tan TH, Quek SC. Types and distribution of congenital heart defects associated with trisomy 21 in Singapore. J Paediatr Child Health. 2013 Mar;49(3):223-7. doi: 10.1111/jpc.12129. Epub 2013 Feb 26. PubMed PMID: 23437783.**

URL: <http://onlinelibrary.wiley.com/doi/10.1111/jpc.12129/pdf> -- payment required

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**ABSTRACT**

**AIM:** Atrioventricular septal defect (AVSD) is widely accepted as the most common type of congenital heart defect in trisomy 21. Most of these studies, however, were conducted in Caucasian communities. The few Asian studies that had been conducted on this subject yielded different results. In the largest study of its kind in Asia, we described the distribution of types of congenital heart defects associated with trisomy 21 in Singapore.

**METHODS:** Five hundred and eighty-eight patients with trisomy 21 born in 1996-2010, and confirmed by karyotyping, were included in the study. The diagnosis of congenital heart defects were made on echocardiography. Variables extracted for analysis were demographics (race and gender) and the types of congenital heart defects. Except for complex cyanotic heart defects, haemodynamically significant lesions were accounted for separately in cases where more than one type of congenital heart defect coexisted in a patient.

**RESULTS:** Ventricular septal defect (VSD) (39.2%) was the most common congenital heart defect associated with trisomy 21 in our study, followed by patent ductus arteriosus (34.3%), secundum atrial septal defect (23.4%) and AVSD (15.6%). This study validates previous smaller Asian studies identifying VSD as the most common cardiac lesion associated with trisomy 21. A high proportion (25.0%) of trisomy 21 patients with tetralogy of Fallot also had AVSDs. Coarctation of the aorta was uncommon.

**CONCLUSION:** VSD was the most common congenital heart defect seen in trisomy 21 in our study. A high proportion (25.0%) of trisomy 21 patients with tetralogy of Fallot also had AVSDs.

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PMID: 23437783 [PubMed - indexed for MEDLINE]

**READING 7 – HEARING LOSS IN DOWN SYNDROME**

**Raut P, Sriram B, Yeoh A, Hee KY, Lim SB, Daniel ML. High prevalence of hearing loss in Down syndrome at first year of life. Ann Acad Med Singapore. 2011 Nov;40(11):493-8. PubMed PMID: 22206065.**

URL: <http://www.annals.edu.sg.libproxy1.nus.edu.sg/pdf/40VolNo11Nov2011/V40N11p493.pdf> - free full text

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**ABSTRACT**

**INTRODUCTION:** Infants with Down syndrome (DS) are at higher risk of hearing loss (HL). Normal hearing at one year of age plays an important part in language development. An audit was conducted to determine the impact of the newborn hearing screening program on the incidence, type and timing of diagnosis of HL during first year of life.

**MATERIALS AND METHODS:** Infants with DS were scheduled for Universal Newborn Hearing Screening (UNHS) within 4 weeks of life. If they passed, they had a high-risk screen at 3 to 6 months. They were referred to the otolaryngology department if they did not pass the UNHS or the high-risk screen. Information was obtained from the computerised data tracking system and case notes. Infants born from April 2002 to January 2005 and referred to the DS clinic of our hospital were analysed.

**RESULTS:** Thirty-seven (82.2%) of 45 infants underwent UNHS, of which 12 (32.4%) infants did not pass. Of remaining 33 infants, 27 had high-risk screen done of which 14 (51.8%) did not pass. Twenty-eight infants were referred to the ear, nose, throat (ENT) clinic: 12 from UNHS, 14 from high-risk screens and 2 from the DS clinic. Eleven (39.2%) defaulted

follow-up. Fourteen (82.3%) of 17 infants who attended the ENT Clinic had HL. Twelve (85.7%) were conductive, and 2 (14.2%) mixed. Nine (64.2%) had mild-moderate HL and 3 (21%) had severe HL. The mean age of diagnosis was  $6.6 \pm 3.3$  months. All were treated medically, plus surgically if indicated. By 12 months of age, the hearing had normalised in 4 (28.6%) infants and remained the same in 3 (21.4%). Five (35.7%) defaulted follow-up. Thirty-five out of 45 (77.8%) underwent complete hearing screen in the first year of life (UNHS & High-risk screen). Six out of 45 (13.3%) had incomplete screening. Fourteen out of 41 (34.1%) had HL of varying degrees. Four out of 45 (8.8%) did not have any audiological assessment in first year of life.

**CONCLUSION:** The incidence of HL in the first year of life was high (34.1%). Eighty-five percent were conductive with 64.2% in mild-moderate range. One third of infants hearing normalized after treatment, one third remained unaltered and one third of infants did not attend follow-up. An aggressive approach involving early screening after birth and continued surveillance and early referral to appropriate agencies are essential for establishing timely diagnosis and treatment. Measures to reduce the high default rate during long-term follow-up are needed. Parent education and integrated multidisciplinary follow-up clinic may be useful.

PMID: 22206065 [PubMed - indexed for MEDLINE]

## READING 8 – BRIDGING THE HEALTH-SOCIAL DIVIDE

**Wei KC, Lee C, Mahendran R, Lim CG. Improving mental health care for people with an intellectual disability in Singapore: bridging the health-social care divide. Singapore Med J. 2012 Jul;53(7):428-32. PubMed PMID: 22815008.**

URL: <http://www.sma.org.sg/UploadedImg/files/SMJ/5307/5307co1.pdf> - free full text

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### ABSTRACT

Intellectual disability is known to be associated with a high incidence of psychiatric co-morbidity and problem behaviours. However, there are many challenges in trying to meet the mental health needs of people with an intellectual disability, and these are often not adequately addressed in Singapore's current healthcare system. This article outlines the present service provisions for this area in the country and details the importance of, as well as difficulties in the integration of health and social care measures in service development and delivery.

PMID: 22815008 [PubMed - indexed for MEDLINE]

## READING 9 – CHALLENGES FACED BY OLDER ADULTS WITH INTELLECTUAL DISABILITY

**Wee LE, Koh GCh, Auyong LS, Cheong AL, Myo TT, Lin J, Lim EM, Tan SX, Sundaramurthy S, Koh CW, Ramakrishnan P, Aariyapillai-Rajagopal R, Vaidynathan-Selvamuthu H, Khin MM. The medical, functional and social challenges faced by older adults with intellectual disability. Ann Acad Med Singapore. 2013 Jul;42(7):338-49. PubMed PMID: 23949263.**

URL: <http://www.annals.edu.sg.libproxy1.nus.edu.sg/pdf/42VolNo7Jul2013/V42N7p338.pdf> - Free full text

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### ABSTRACT

**INTRODUCTION:** Little is known about the sociodemographic and clinical profile of older adults with intellectual disabilities (ID) in Singapore. We studied the sociodemographic and clinical profile of older adults with ID and investigated factors associated with caregiver availability and identity in this population.

**MATERIALS AND METHODS:** The study population involved all adults with ID aged  $\geq 40$  years receiving services from the Movement for the Intellectually Disabled of Singapore (MINDS), the largest such provider in Singapore. Information on sociodemographic and clinical profiles, functional status, and availability of caregivers were collected via

interviewer-administered questionnaires from guardians of older adults with ID. Descriptive characteristics were computed and chi-square and logistic regression identified predictors of caregiver availability and identity.

**RESULTS:** Participation was 95% (227/239). There were differences in client age, gender, and caregiver availability between recipients of residential and non-residential services (all  $P < 0.05$ ). Common comorbidities included hyperlipidaemia (17.6%), hypertension (15.9%), psychiatric diagnoses (16.3%) and epilepsy (10.6%). The majority were fully independent in basic activities of daily living, but only 21.1% were fully communicative. Only a small minority (9.4%) were exercising regularly. The majority (73.5%) of clients had a primary caregiver; almost equal proportions relied on either parents or siblings. Older client age was associated independently with the lack of a primary caregiver, independent of greater functional dependence and presence of medical comorbidities in the client.

**CONCLUSION:** Older adults with ID have multiple medical, functional, and social issues. More can be done to support the care of this unique group of adults with special needs.

PMID: 23949263 [PubMed - indexed for MEDLINE]

## READING 10 – PSYCHOLOGICAL THERAPIES FOR PEOPLE WITH INTELLECTUAL DISABILITIES

**Vereenoghe L, Langdon PE. Psychological therapies for people with intellectual disabilities: a systematic review and meta-analysis. Res Dev Disabil. 2013 Nov;34(11):4085-102. doi: 10.1016/j.ridd.2013.08.030. Epub 2013 Sep 18. PubMed PMID: 24051363.**

URL: <http://www.sciencedirect.com/science/article/pii/S0891422213003727> – payment required

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### ABSTRACT

The aim of this study was to evaluate the efficacy of psychological therapies for people with intellectual disabilities (IDs) through a systematic review and meta-analysis of the current literature. A comprehensive literature search identified 143 intervention studies. Twenty-two trials were eligible for review, and 14 of these were subsequently included in the meta-analysis. Many studies did not include adequate information about their participants, especially the nature of their IDs; information about masked assessment, and therapy fidelity was also lacking. The meta-analysis yielded an overall moderate between-group effect size,  $g = .682$ , while group-based interventions had a moderate but smaller treatment effect than individual-based interventions. Cognitive-behaviour therapy (CBT) was efficacious for both anger and depression, while interventions aimed at improving interpersonal functioning were not effectual. When CBT was excluded, there was insufficient evidence regarding the efficacy of other psychological therapies, or psychological therapies intended to treat mental health problems in children and young people with IDs. Adults with IDs and concurrent mental health problems appear to benefit from psychological therapies. However, clinical trials need to make use of improved reporting standards and larger samples.

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PMID: 24051363 [PubMed - in process]