



COLLEGE OF FAMILY PHYSICIANS SINGAPORE

THE SINGAPORE FAMILY PHYSICIAN

PERMIT NO. MCI (P) : 167/12/2013

VOL 40(2) APRIL - JUNE 2014

IMPROVING HEALTHCARE FOR PERSONS WITH DISABILITIES





Inclusive Society. Enabled Lives.

**"Disability is
a matter of
perception.**

**If you can do just one thing
well, you're needed by
someone."**

Martina Navratilova
(winner of 18 Grand Slam Singles Tennis Titles)

Established in July 2013, SG Enable is a one-stop agency seeking to empower and enhance the lives of persons with disabilities. The agency adopts a life-course approach to look at the continuum of a person's life in a holistic manner.

Our Offerings and Services

Recognising the varying needs of persons with disabilities, SG Enable offers a suite of information and referral services, grants and support for children and adults with special needs. Ranging from early intervention programmes for children below the age of six, before- and after-school care services to adults looking to join day activity centres or residential homes, persons with disabilities can now turn to SG Enable for a one-stop solution.

Creating and Enabling Employment

The agency also seeks to enhance employability and employment options for persons with disabilities

by rallying stakeholders' support. SG Enable works closely with Voluntary Welfare Organisations (VWOs) to support persons with disabilities with vocational assessment, pre-employment training, job placement and support services, and continuous education and training.

For employers, SG Enable provides consultancy services in recruitment of persons with disabilities, from job and workplace re-design advice to guidance on HR matters. SG Enable also administers the Open Door Fund which supports employers in hiring persons with disabilities and implementing job re-design and workplace modifications.

Reach Out to Us

Striving to meet the needs of persons with disabilities is at the heart of what we do. We believe that everyone has a latent talent waiting to be discovered. SG Enable seeks to be the epicentre to fulfill the aspirations of every person with disabilities in Singapore to pursue independent and dignified lives.

C O N T E N T S

EDITORIAL

4

Improving Healthcare for Persons with Disabilities

A/Prof Goh Lee Gan

DISTANCE LEARNING COURSE ON “IMPROVING HEALTHCARE FOR PERSONS WITH DISABILITIES”

6

Overview of “Improving Healthcare for Persons with Disabilities” Family Practice Skills Course

A/Prof Goh Lee Gan

8

Unit 1: Epidemiology and Overview of Disability

A/Prof Goh Lee Gan

12

Unit 2: Information and Referral Touchpoints

Tay Mui Chin

15

Unit 3: How do General Practitioners Foster Mutual Support with Family Caregivers
in Optimising Healthcare for Persons with Disabilities?

Anita Ho Yin King

18

Unit 4: Recognising Children with Developmental Delays: A Strategy for Surveillance

Dr Sylvia Choo Henn Tean

34

Unit 5: Persons with Intellectual Disabilities and Autism Spectrum Disorders

Dr Diana Ruth Andrea Barron, Dr Wei Ker-Chiah

43

Unit 6: Adults and Elderly with Multiple Disabilities

Dr Ng Yee Sien

56

Assessment of 30 MCQs

READINGS

61

A Selection of Ten Current Readings on “Improving Healthcare for Persons with Disabilities”

USEFUL INFORMATION

69

Useful Resources for Medical Practitioners:

Ministry of Social and Family Development (MSF) Disability Resource List

73

Useful Resources for Medical Practitioners:

Application for Disability Schemes, Functional Assessment Report

Useful Resources for Medical Practitioners: Mobility Report

Compiled by Institute of Family Medicine (IFM) &
Ministry of Social and Family Development (MSF) Workgroup

PRISM SECTION

When Paired HbA_{1c} and Fasting Glucose Don't Match, Which is Telling the Truth?

Dr Kee Kok Wai

Guidelines and Information for Authors

Permit No. MCI (P) 167/12/2013

JOURNAL OF THE SINGAPORE FAMILY PHYSICIAN

Printed by Providence Company

The Singapore Family Physician is published quarterly by College of Family Physicians Singapore. All articles published, including editorials, letters and book reviews represent the opinion of the authors and do not reflect the official policy of College of Family Physicians Singapore or Institution with which the authors is affiliated unless this is clearly specified. The Publisher cannot accept responsibility for the correctness or accuracy of the advertisers' text and/or claim or any opinion expressed. The appearance of advertisements in this Journal does not necessarily constitute an approval or endorsement by College of Family Physicians Singapore of the product or service advertised. The contents of this publication are not to be quoted in the press without permission of the Editor.

COLLEGE OF FAMILY PHYSICIANS SINGAPORE 24TH COUNCIL (2013 - 2015)

PRESIDENT	A/Prof Lee Kheng Hock
VICE PRESIDENT	Dr Tham Tat Yean
CENSOR-IN-CHIEF	A/Prof Tan Boon Yeow
HONORARY SECRETARY	Dr Tan Tze Lee
HONORARY TREASURER	Dr Lim Fong Seng
ASSISTANT HONORARY SECRETARY	Dr Ng Chee Lian Lawrence
ASSISTANT HONORARY TREASURER	Dr Subramaniam Suraj Kumar
HONORARY EDITOR	Dr Tan Ngiam Chuan
COUNCIL MEMBERS	Dr Eng Soo Kiang
	Dr Farhad Fakhruddin Vasanwala
	Dr Leong Choon Kit
	Dr Low Sher Guan Luke
	Dr Ng Lee Beng
	Dr Pang Sze Kang Jonathan
	Dr Tan Hsien Yung David
	Dr Yee Jenn Jet Michael

COLLEGE SECRETARIAT

SENIOR MANAGER	Ms Jennifer Lau
ACCOUNTS & MEMBERSHIP EXECUTIVE	Ms Rachel Koh
CORPORATE COMMUNICATIONS EXECUTIVE	Ms Stella Teh
PROGRAMMES & IT EXECUTIVE	Ms Anica Goh
PROGRAMMES & TRAINING EXECUTIVE	Ms Tan Sixuan
PUBLICATIONS & PROGRAMMES EXECUTIVE	Ms Patricia Cheok
ADMINISTRATIVE ASSISTANT	Ms Briana Ko

Improving Health Care for People with Disabilities

A/Prof Goh Lee Gan

SFP2014; 40(2): 4

Improving access to healthcare and other services for persons with disabilities (PWDs) is one of the five cross-cutting issues in the Ministry of Social and Family Development's Enabling Masterplan 2012-2016. The other 4 cross-cutting issues are caregiver support and transition management, manpower and technology, transport and public education in the enablement of PWDs to participate fully in society. In this Family Practice Skills Course the focus is on touch points for access to care for PWDs. Thanks are due to the Ministry of Social and Family Development (MSF) for sponsoring this Family Practice Skills Course.

Unit 1 covers the epidemiology and overview of disability. In Singapore, 3% of the resident population is estimated to have some form of disability. The four pillars in the life course approach to enable PWDs to participate fully in society are: early intervention, education and healthy lifestyle, employment, and adult care. Family physicians are often the first touchpoint to services or schemes that PWDs need to improve their health.

Unit 2 covers the information and referral touchpoints for persons with disability. SG Enable is an agency dedicated to promoting an inclusive society through enabling persons with disabilities. SG Enable seeks to provide comprehensive disability support to persons with disabilities through provision of easy access to information, referral services, grants and schemes, as well as enhancing employability and employment options for persons with disabilities. Medical practitioners play an important role of medical assessment of people with disabilities and referral of eligible applicants for receipt of services and benefits from financial schemes and non-financial assistance schemes.

Unit 3 answers the question "How do General Practitioners foster mutual support with family caregivers in optimising healthcare for PWDs?" It is important for GPs to cultivate supportive relationship between members of the care triad in order to optimise the healthcare for the PWD. Caregiving can be a challenging task and have both positive and negative impacts on caregivers' physical, mental, psychological, social and financial wellbeing. Timely support to caregivers can help to reduce stress, burnout and depression, so that they can continue to provide quality care to PWD. GPs can help to enhance the healthcare experience of PWD and caregivers, with some external support.

GOH LEE GAN,
Senior Consultant Physician & Professorial Fellow,
Division of Family Medicine, University Medicine Cluster,
National University Health System;
Director, Institute of Family Medicine,
College of Family Physicians Singapore

Unit 4 covers the recognition of children with developmental delays. Developmental delays are common. Use the developmental checklists and red flags in the health booklet at every immunisation and well child visit. Early detection of developmental delays lead to referral for assessment and appropriate early intervention, which is important and can influence outcomes. Avoid 'waiting and watching'. Refer early if there are any concerns.

Unit 5 covers Persons with intellectual disabilities and autism spectrum disorders. People with intellectual disability and autism spectrum disorder are vulnerable to the same spectrum of mental and physical illness as the general population. Due to unique challenges, they remain at risk of health inequalities resulting in elevated mortality from preventable causes. Equipping the primary physician with greater familiarity and understanding of the varied needs for this sub-group of patients will support such patients to lead healthier lives.

Unit 6 covers adults and elderly with multiple disabilities. In Singapore and worldwide, large numbers of people live with disabling illness. Using definitions from the ICIDH and ICF models, the assessment of disability involves strictly the assessment of the severity of activity limitation including ADLs, and not the assessment of the severity of loss of body structure or function (or termed impairment in the older ICIDH model). Disability charting is important as a clinical tool to document functional recovery as well as to assess the effectiveness of medical and rehabilitation interventions. The identification of frail elderly people is key as it is not cost-effective or operationally feasible to deliver rehabilitation to large numbers of people. Clinically, the frailty syndrome can be defined as three or more variables of a phenotype consisting of unintentional weight loss, self-reported exhaustion, low energy expenditure, slow gait speed and weak grip strength. Rehabilitation now addresses recovery through a holistic multisystem perspective rather than through the traditional approaches of a specific disease.

In addition, there is a section on useful information for medical practitioners namely, the MSF Disability Resource List; Application for Disability Schemes Functional Assessment Report; and the MSF Mobility Report.

Finally, in the PRISM (Patients' Revelations as Insightful Studies of their Management) section we have a report that deals with the question: "When paired HbA_{1c} and fasting glucose don't match, which is telling the truth?"



“IMPROVING HEALTHCARE FOR PERSONS WITH DISABILITIES” FAMILY PRACTICE SKILLS COURSE

- Overview Of “Improving Healthcare For Persons With Disabilities” Family Practice Skills Course
- Unit 1 : Epidemiology and Overview of Disability
- Unit 2 : Information and Referral Touchpoints
- Unit 3 : How do General Practitioners Foster Mutual Support with Family Caregivers in Optimising Healthcare for Persons with Disabilities?
- Unit 4 : Recognising Children with Developmental Delays: A Strategy for Surveillance
- Unit 5 : Persons with Intellectual Disabilities and Autism Spectrum Disorders
- Unit 6 : Adults and Elderly with Multiple Disabilities

OVERVIEW OF “IMPROVING HEALTHCARE FOR PERSONS WITH DISABILITIES” FAMILY PRACTICE SKILLS COURSE

A/Prof Goh Lee Gan

SFP2014; 40(2): 6–7

INTRODUCTION

Improving access to healthcare and other services for persons with disabilities (PWDs) is one of the five cross-cutting issues in the Ministry of Social and Family Development's (MSF) Enabling Masterplan 2012-2016. The other 4 cross-cutting are caregiver support and transition management, manpower and technology, transport and public education in the enablement of PWDs to participate fully in society. In this Family Practice Skills Course, the focus is on touch points for access to care for PWDs. Family physicians are key touch points to the services and benefit schemes that PWDs require. Also, a greater understanding on the importance of life course and integrated approach of early intervention, education and healthy lifestyle, employment options, and adult care will enable family physicians to optimise doctor-patient and doctor-family caregiver encounters. Family physicians also need to be familiar with assessments and onward referral to receive care or benefits for PWDs. Thanks are due to the Ministry of Social and Family Development (MSF) for sponsoring this Family Practice Skills Course.

COURSE OUTLINE AND CME POINTS

This Family Practice Skills Course is made up of the following components. You can choose to participate in one or more parts of it. The CME points that will be awarded are also indicated below.

Components and CME Points

- Distance Learning Course – 6 units (6 Core FM CME points upon attaining a minimum pass grade of 60% in Distance Learning Online MCQ Assessment)
- 2 Seminars (2 Core FM CME points per seminar)
- 2 Workshops (1 Core FM CME point per workshop)
- 10 Readings – read 5 out of 10 recommended journals (maximum of 5 CME points for the whole CME year)

Distance Learning Course

Unit 1: Epidemiology and Overview of Disability

A/Prof Goh Lee Gan

GOH LEE GAN, Senior Consultant Physician & Professorial Fellow,
Division of Family Medicine, University Medicine Cluster,
National University Health System;
Director, Institute of Family Medicine,
College of Family Physicians Singapore

Unit 2: Information and Referral Touchpoints

Tay Mui Chin

Unit 3: How do General Practitioners Foster Mutual Support with Family Caregivers in Optimising Healthcare for Persons with Disabilities?

Anita Ho Yin King

Unit 4: Recognising Children with Developmental Delays: A Strategy for Surveillance

Dr Sylvia Choo Henn Tean

Unit 5: Persons with Intellectual Disabilities and Autism Spectrum Disorders

Dr Diana Ruth Andrea Barron, Dr Wei Ker-Chiah

Unit 6: Adults and Elderly with Multiple Disabilities

Dr Ng Yee Sien

COURSE TOPIC DETAILS

Unit 1: Epidemiology and Overview of Disability

- Introduction
- Epidemiology
- Better health for people with disabilities
- A life course and integrated care approach
- Role of family physicians
- Conclusions

Unit 2: Information and Referral Touchpoints

- Introduction
- Overview of SG Enable
- Schemes and services for Persons with Disabilities (PWDs)
- How can medical practitioners help

Unit 3: How do General Practitioners Foster Mutual Support with Family Caregivers in Optimising Healthcare for Persons with Disabilities?

- Introduction
- Identifying family caregivers
- Understanding caregivers' challenges and needs
- Factors affecting the caregivers' experience with GPs
- Fostering supportive relationship between members of the care triad
- Conclusions

Unit 4: Recognising Children with Developmental Delays: A Strategy for Surveillance

- Introduction

- Overview of concepts & terminology
- Methods of early identification
- What have others been doing?
- What have we been doing?
- Conclusions

Unit 5: Persons with Intellectual Disabilities and Autism Spectrum Disorders

- Introduction
- Overview of terms: Intellectual disability and autism spectrum disorders
- Physical and mental health problems commonly encountered in clinical practice
- The assessment of persons with intellectual disability
- An approach to a patient with developmental disabilities and behavioural concerns
- Conclusions

Unit 6: Adults and Elderly with Multiple Disabilities

- Introduction
- Overview and framework of disability assessment
- Current disability assessment tools
- Disability assessment: General principles of disability assessment
- Practical administration of disability assessment
- Experiences, strengths and weaknesses of disability assessment
- Frailty, Comorbidity, disability and geriatric rehabilitation
- Screening for frailty
- Treatment for frailty

FACE-TO-FACE SESSIONS

Seminar 1: 26 April 2014, 2.00pm – 4.00pm

Unit 1: Epidemiology and Overview of Disability

A/Prof Goh Lee Gan

Unit 2: Information and Referral Touchpoints

Tay Mui Chin

Unit 3: How do General Practitioners Foster Mutual Support with Family Caregivers in Optimising Healthcare for Persons with Disabilities?

Anita Ho Yin King

Workshop 1: 26 April 2014, 4.30pm – 5.30pm

Case Study Discussion

Dr Balbir Singh, Anita Ho Yin King, Manmohan Singh, Dr Bhavani Sriram

Seminar 2: 27 April 2014, 2.00pm – 4.00pm

Unit 4: Recognising Children with Developmental Delays: A Strategy for Surveillance

Dr Sylvia Choo Henn Tean

Unit 5: Persons with Intellectual Disabilities and Autism Spectrum Disorders

Dr Wei Ker-Chiah

Unit 6: Adults and Elderly with Multiple Disabilities

Dr Ng Yee Sien

Workshop 2: 27 April 2014, 4.30pm – 5.30pm

Assessment and Communication Skills

Dr Wei Ker-Chiah, Francis Lim Chin Pei, Tang Wei Kiat, Dr Lohsnah J

ABSTRACT

Persons with disabilities (PWDs) form an integral part of our community. The Ministry of Social and Family Development (MSF) in Singapore has developed the Enabling Masterplan (EMIC) 2012 – 2016 with the vision of an inclusive society where PWDs are enabled to participate fully. A life course and integrated approach is adopted in caring for such persons with the 4 pillars of early intervention; education and healthy lifestyle; employment; and adult care. Five cross cutting issues need to be addressed: caregiver support and transition management; manpower and technology; Transport; Public education; and accessibility. Family Physicians being the medical practitioners in the frontline of medical care are touchpoints in accessibility to healthcare services and benefit schemes for this group of people.

Keywords:

People with disabilities, enabling masterplan, early intervention, education, employment, Adult care, cross cutting issues.

SFP2014; 40(2): 8-11

INTRODUCTION

Persons with disabilities (PWDs) form an integral part of our community. The Ministry of Social and Family Development (MSF) in Singapore has developed the Enabling Masterplan (EMIC) 2012 – 2016 with the vision of an inclusive society where PWDs are enabled to participate fully. Figure 1 shows the areas of emphasis in this vision. A life course and integrated approach is adopted in caring for such persons with the 4 pillars of early intervention; education and healthy lifestyle; employment; and adult care. Five cross cutting issues need to be addressed: caregiver support and transition management; manpower and technology; Transport; Public education; and accessibility. Family Physicians being the medical practitioners in the frontline of medical care are touchpoints in accessibility to healthcare services and benefit schemes for this group of people.

EPIDEMIOLOGY**Singapore prevalence rates**

As is stated in Singapore's Enabling Masterplan of 2012-2016,¹ there is no official central registry of persons with disabilities. Existing data from government agencies such as MCYS, MOE are estimates based on incidence rates and service utilisation.

GOH LEE GAN, Senior Consultant Physician & Professorial Fellow, Division of Family Medicine, University Medicine Cluster, National University Health System;
Director, Institute of Family Medicine, College of Family Physicians Singapore

Approximately 3 percent of the resident population is estimated to have some form of disability. This figure is higher than incidence rates and takes into account acquired disabilities which are expected to be more prevalent in the ageing population. The 3% prevalence figure also provide a buffer for non-service users. Table 1 shows the incidence rates and the estimated number of PWDs based on 2010 Singapore population.

Nature of disabilities

The disabilities in children, youth, and adults are fairly broad ranged. The common denominators are such persons require the help of family members, caregivers, and voluntary helpers in the daily activities of daily living to greater or lesser extent:

- Children and youth – Developmental disability, intellectual disability and autism spectrum disorders, hearing loss, visual loss, physical disability
- Adult – Disability from childhood, stroke, spinal cord injury, traumatic brain injury, musculoskeletal injury, psychiatric illness, dementia.

BETTER HEALTH FOR PEOPLE WITH DISABILITIES

Better health for people with disabilities is also recognised by member countries of the World Health Organisation² in its resolution adopted in the 66th World Health Assembly in 2013. The resolution calls for Member States to:

- Make all mainstream health services inclusive of people with disabilities.
- Provide more support to informal caregivers.
- Ensure that people with disabilities have access to rehabilitation services that can enable them to achieve their full potential and have the same opportunities as others to participate fully in society.

A LIFE COURSE AND INTEGRATED CARE APPROACH**Life course approach**

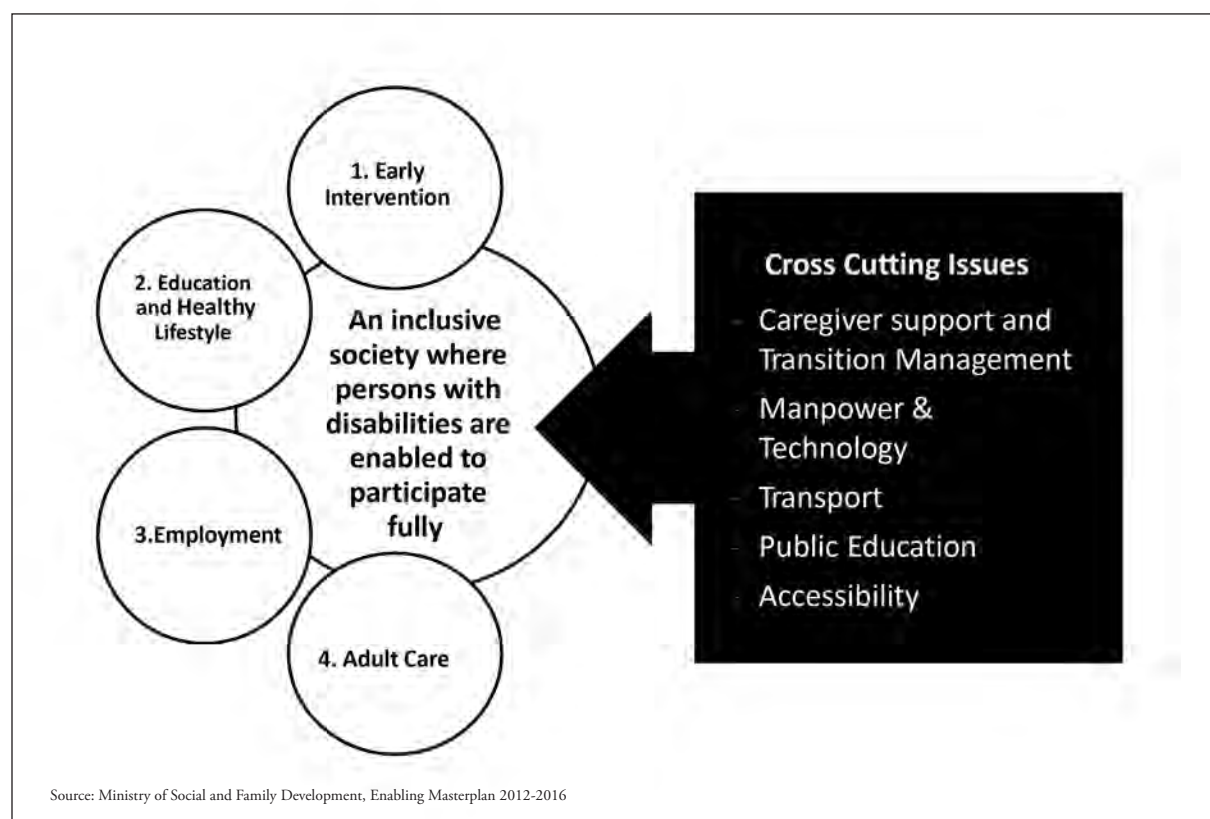
Using the life course approach in the framework of the Enabling Masterplan as shown in Figure 1, the following are keypoints to note.

Early intervention. The early formative years are critical in a child's development. For children with developmental delay, there is strong evidence to support early intervention and its effects in improving the long-term outcome of the child and the family. Effective intervention services share common critical success factors, namely involvement of family, early detection, inclusion, and qualified professionals.

TABLE 1. INCIDENCE AND ESTIMATED NUMBER OF PEOPLE WITH DISABILITIES		
	Incidence rate	Estimated number of PWDs (based on 2010 population)
Pre-school (0 – 6 years) ^a	3.2%	7,000
School (7 – 18 years) ^b	2.5%	13,000 (7,600 mainstream, 5 400 SPED)
Adulthood & Aged (More than 18 years) ^c	2.5%	77, 200

Source: Enabling Masterplan 2012 – 2016, Singapore – Ministry of Social and Family Development, 2013.
Footnotes: a = MOH's Child Development Unit statistics 2006 – 2011; b = MOE data on school-going cohort 2005 – 2010; and c = MOH's National Health Surveillance Survey

FIGURE 1. AREAS OF EMPHASIS: ENABLING MASTERPLAN 2012 – 2016



A study by Lian et al (2012)³ of the profiles and outcomes of 1,304 children referred for development and behavioural concerns to a tertiary child development centre in Singapore between Jan 1, 2003 and Dec 1, 2004 concluded that most were children with high prevalence, low-moderate severity disorders who could potentially achieve fair-good prognosis with early intervention. 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 diagnosis (31%), followed by S&L disorder, CI, and GDD.

Education and healthy lifestyle. Education is the cornerstone for individuals to be independent, self supporting and contributing members of society. For children with special needs in particular, having quality education in their formative years will be critical in maximising their potential in independence, gainful employment, lifelong learning, and community integration.

Employment. A value-chain framework to enable persons with disabilities to achieve self-reliance through employment is important. Vocational assessment, training, job placement, and support is important. Sustained employment is dependent on availability of employment opportunities, job readiness, and quality of job support services.

Adult care. This is an important growing area in the context of a rapidly ageing population in Singapore. Care arrangement is also a serious concern for many aging parents of disabled children. A spectrum of care options need to be in place to support the varying needs of PWDs and their family caregivers.

A recent local paper by Wei et al (2012)⁴ highlights the need to bridge the health-social divide for improving the mental health for people with intellectual disability. People with intellectual disability are known to be associated with a high incidence of psychiatric co-morbidity and problem behaviours.

Another recent local paper by Wee et al (2013)⁵ presented the results of a study on the sociodemographic and clinical profile of 239 older adults with intellectual disability aged 40 and older receiving services from the Movement of the Intellectually Disabled of Singapore (MINDS). The authors concluded that older adults with intellectual disability have multiple medical, functional and social issues and that more can be done to support this group of adults with special needs. The majority were fully independent in basic activities of daily living but only 21.1% were fully communicative. The majority (73.5%) had a primary caregiver; almost equal proportions relied on either parents or siblings. Older client age was associated independently with lack of a primary caregiver. The common co-morbidities included hyperlipidemia (17.6%), hypertension (15.9%), psychiatric diagnosis (16.3%), and epilepsy (10.6%).

Cross cutting issues requiring an integrated approach

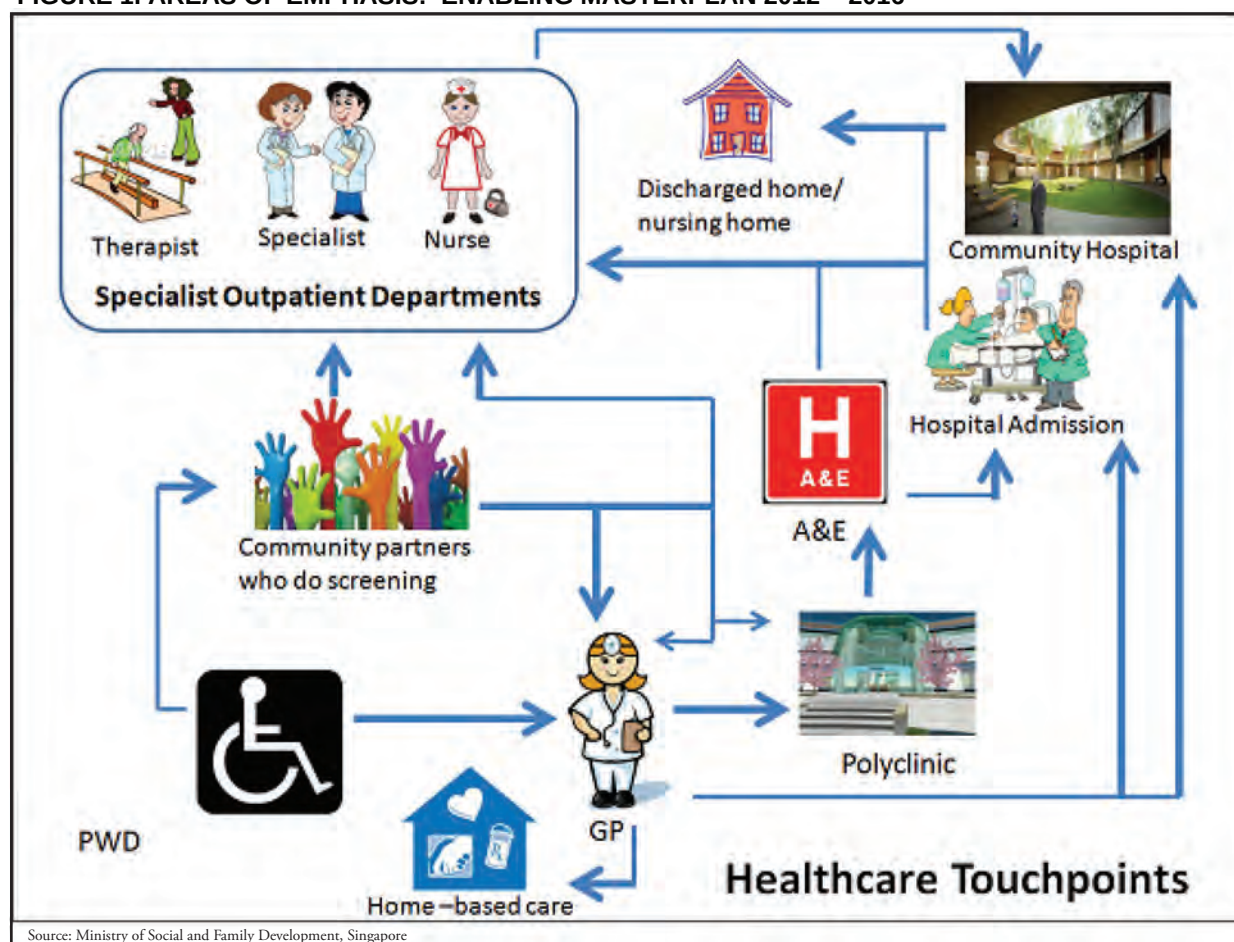
Five cross cutting issues affect persons with disabilities across their lifecourse. The keypoints are summarised below.

Caregiver Support & Transition Management. Two key areas are important in supporting caregivers. One, caregivers need the necessary skills and knowledge to be competent; two, respite care options can provide caregivers with short-term and temporary relief from their care giving duties. Proactive approach to support PWDs through their different transition point of their care is needed and this is undertaken by SG Enable.

Manpower & Technology. Skilled manpower is crucial in ensuring that services are accessible and effective. Scaling up training of care staff to meet the projected demand will be needed. Increasing the attractiveness of jobs in the social service sector will also be needed. The use of assistive technology (AT) and information and communications technology (ICT) enhance the quality of life of PWDs and their potential to lead productive lives.

Transport. Several transport assistance schemes have been created, namely the taxi subsidy scheme for PWDs who cannot take public transport to school or work, VWO transport subsidies for PWDs using VWO transport to school and care services, and Car Park Label Scheme for vehicles carrying persons with physical disabilities to park at designated parking

FIGURE 1. AREAS OF EMPHASIS: ENABLING MASTERPLAN 2012 – 2016



lots to allow them to get in and out of the vehicles with ease.

Public Education. Public education is important in changing mindsets and promoting an inclusive society. Effective public education must be sustained and co-ordinated.

Accessibility. Accessibility to services, information and communication is needed for PWDs to be included in society. Accessibility to healthcare services, information and schemes can be facilitated by Family Physicians functioning as touchpoints.

ROLE OF FAMILY PHYSICIANS

Based on what has been discussed, it is clear that Family Physicians can play a major role in the care of PWDs through the execution of the following.

- Being the first touch point to services. See Figure 2.
- Communication and explanation to PWDs and caregivers.
- Early intervention
- Ongoing care
- Preventive care
- Public education
- Being the patient centred medical home

Patient centred medical home

This is a team based health care delivery model led by a Family Physician, or other care provider that provides comprehensive, continuous medical care to patients with the goal of obtaining maximal health outcomes. The provision of patient centred medical homes may allow better access to health care, increase satisfaction with care, and improve health. There are 4 elements of importance:

- Patient centred care
- Quality care
- Health information technology
- Practice organisation

Within such a model of care, accessibility, care co-ordination, continuing care, and health promotion and disease prevention can be fostered. Looking at the health care needs of PWDs, there is much more satisfying care that such a care model can provide.

Prevention is always important. People with disabilities suffer

from acute and chronic medical problems just like those without disabilities but the consequences may be magnified because of the disabilities. It is noteworthy that some disabilities can be prevented from recurring, as for example the recurrence of complications of the cardiovascular complications of the metabolic syndrome; some disabilities can be prevented through appropriate screening measures e.g. antenatal screening of high risk mothers, and much future disabilities can be prevented by primary preventive measures targeted at the risk factors e.g. attention to prevention of falls resulting in traumatic brain injuries or severe musculoskeletal injuries, or the prevention of metabolic syndrome through attention to diet, exercise, and weight control.

CONCLUSION

Persons with disabilities (PWDs) form an integral part of our community. Family Physicians being the medical practitioners in the frontline of medical care are touchpoints in accessibility to healthcare services and benefit schemes for this group of people.

REFERENCES

1. Ministry of Social and Family Development. Enabling Masterplan 2012-2016 Full Report. Executive Summary. MSF: Singapore 2013 March 8.
2. WHO. WHO initiates process for developing action plan to ensure better health for people with disabilities. <http://www.who.int/disabilities/actionplan/en/> accessed 2014 Dec 4.
3. Lian WB, Ho SK, Choo SH, Shah VA, Chan DK, Yeo CL, Ho LY. Children with developmental and behavioural concerns in Singapore. *Singapore Med J* 2012; 53(7): 439-45.
4. 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; 53(7):428-32.
5. Wee LE, Koh GCH, Auyong LS, Chong AL, Myo TT, Lin J, Lim EM, Tan SX, Sundaramurthy S, Koh CW, Ramakrishnan P, Ariyapillai-Rajagopa R, Vaidynathan-Selvamuthu H, Khin MM. The medical, functional and social challenges faced by older adults with intellectual disability. *Ann Acad Med Singapore* 2013;42(7):338-49
6. AAFP. Patient centred medical home. http://www.aafp.org/dam/AAFP/documents/practice_management/pcmh/PCMHChecklist.pdf. Accessed 2014 Apr 24.

LEARNING POINTS

- In Singapore, 3% of the resident population is estimated to have some form of disability.
 - The four pillars in the life course approach to enable PWDs to participate fully in society are: early intervention, education and healthy lifestyle, employment, and adult care.
 - The five cutting issues that need to be addressed in implementing the enabling masterplan for PWDs are: caregiver support and transition management; manpower and technology; transport; public education; and accessibility.
 - Family physicians are often the first touchpoint to services or schemes that PWDs need to improve their health.
-

ABSTRACT

SG Enable is an agency dedicated to promoting an inclusive society through enabling persons with disabilities. It seeks to provide comprehensive disability support to persons with disabilities through provision of easy access to information, referral services, grants and schemes, as well as enhancing employability and employment options for persons with disabilities. Medical practitioners play an important role of medical assessment of people with disabilities and referral of eligible applicants for receipt of services and benefits from financial schemes and non-financial assistance to meet their needs ranging from accessibility, transport to assistive devices.

Keywords:

SG Enable, Schemes and services, Persons with disabilities, Children and youth, Adult, Medical practitioners, assessment, referral.

SFP2014; 40(2): 12-14

INTRODUCTION

The Ministry of Social and Family Development (MSF)'s Enabling Masterplan 2012 to 2016 seeks to build on the foundation laid by the earlier initiatives for Singapore to strive towards an inclusive society. The Enabling Masterplan sets out to address the needs of persons with disabilities as well as the needs of caregivers. The vision of the Enabling Masterplan *sees Singapore as an inclusive society where persons with disabilities are empowered and recognised, and given full opportunity to become integral and contributing members of society*¹. SG Enable is an agency set up by MSF dedicated to the disabled. It serves as a focal point for their needs.

OVERVIEW OF SG ENABLE

Formed in July 2013, SG Enable is an agency dedicated to promoting an inclusive society through enabling persons with disabilities. We seek to provide comprehensive disability support to persons with disabilities through provision of easy access to information, referral services, grants and schemes, as well as enhancing employability and employment options for persons with disabilities.

We believe that everyone has latent potential waiting to be discovered regardless of their abilities. Adopting a person-centric approach through a life-course perspective, we seek to equip persons with disabilities with essential resources at different life

stages so that they and their caregivers can explore various options best suited to their needs.

SCHEMES AND SERVICES FOR PERSONS WITH DISABILITIES

SG Enable provides information and referral on the following programmes and services, adopts a life course approach covering early intervention, employment, and adult care.

For Children and Youth

- **Early Intervention Programme for Infants & Children (EIPIC)**

EIPIC provides therapy and educational support services to children with special needs, enhances their developmental growth potential, and minimises the development of secondary disabilities.

- **Enhanced Pilot for Private Intervention Providers (PPIP)**

PPIP provides additional options in early intervention programmes for children. It is a subsidy scheme which helps parents defray the cost of enrolling their children in selected private intervention centres.

- **Integrated Child Care Programme (ICCP)**

ICCP enables children with mild special needs to learn, play and socialise with their peers in mainstream childcare centres so as to prepare them for future entry into mainstream education.

- **Development Support Programme (DSP)**

DSP is an early intervention programme which provides therapy and learning support services to children with mild developmental needs enrolled in pre-schools.

- **Special Student Care Centres (SSCC)**

SSCCs provide before- and after-school care services to children with special needs. SSCCs also provide educational support and impart social and life skills for independent living.

For Adults

For adults with disabilities, SG Enable focuses on enhancing the employability and employment options. The agency adopts a coordinated approach to serve as a common touch point for persons with disabilities and employers. The agency also leverages on the strengths of existing partners and schemes to facilitate training services, employment services and employment opportunities.

- **Employment Facilitation Services**

We work closely with various partners like Voluntary Welfare Organisations (VWOs) and training providers to support persons with disabilities with vocational assessment, pre-employment training, job placement and job support services, and continuous education and training. Our goal is to help persons with disabilities find and sustain meaningful employment.

TAY MUI CHIN,
Senior Manager, Enabling Services, SG Enable

We also provide consultancy services to employers to help them in hiring and retaining persons with disabilities. We work closely with employers to tap on incentives and grants to support companies' initiatives such as job redesign and workplace modification, mentoring and integration, apprenticeship, work experience and training programmes for persons with disabilities. Our goal is to grow the pool of employers hiring persons with disabilities as they recognise that this is a viable and sustainable option to augment their manpower needs.

We also provide information and referral to the following services:

- **Sheltered Workshops**

Sheltered Workshops provide work therapy for adults with mild to moderate disabilities who are not in employment.

- **Day Activity Centres (DAC)**

DACs provide care and skill training, as well as physiotherapy and occupational therapy sessions that promote the development of cognitive, social, communication, language and motor skills for adults with moderate to severe disabilities.

- **Residential Homes, Hostels and Community Group Homes**

Residential Homes, Hostels and Community Group Homes provide alternative housing arrangements for adults with disabilities whose families are unable to provide care for them.

Other Support

SG Enable administers various schemes to provide financial and non-financial assistance to persons with disabilities to meet their needs ranging from accessibility, transport to assistive devices.

- **Assistive Technology Fund (ATF)**

ATF provides financial assistance to persons with disabilities in mainstream and special education or open employment to purchase assistive technology devices.

- **Special Assistance Fund (SAF)**

SAF provides financial assistance to low-income families in purchasing assistive equipment, technical aids or home retrofits to aid persons with disabilities in their mobility, independence or rehabilitation.

- **Computer Access Trust Fund (CATF)**

CATF enables students in special education schools from low-income families to buy computers and computer-related assistive technology for educational purposes at home.

- **Traffic Accident Fund (TAF)**

TAF provides financial assistance to needy persons who have acquired permanent or temporary disabilities due to traffic accidents.

- **Concession Scheme for Persons with Disabilities**

The Concession Scheme allows persons with disabilities to enjoy 25% discount off the adult fares when they travel on public transport. They do not have to pay additional fares for distances beyond 7.2km. In addition, they may opt to buy a Monthly Concession Pass with unlimited bus and train rides at \$60 per month.

- **Taxi Subsidy Scheme (TSS)**

TSS caters to the transport needs of working adults and students from low-income families who have permanent disabilities and are certified as unable to take public transport and totally dependent on taxis for travelling to school or work.

- **VWO Transport Subsidies**

VWO Transport Subsidies provide support for persons with disabilities who need to take dedicated transport provided by Voluntary Welfare Organisations (VWOs) to access school and care services.

- **Car Park Label Scheme (CPLS)**

CPLS enables persons with physical disabilities who drive their own vehicles and use a bulky mobility aid, or who are ferried by their family members, to park at designated parking lots to allow them to get in and out of the vehicles with ease.

- **Special Needs Savings Scheme (SNSS)**

SNSS allows parents to set aside a portion of their Central Provident Fund (CPF) savings by disbursing a monthly sum upon their demise for the long term care of their children with special needs.

HOW CAN MEDICAL PRACTITIONERS HELP

Medical practitioners can help by conducting medical assessment of people with disabilities and making referral of eligible applicants for receipt of services and schemes. Please refer to the section on "Useful Resources for Medical Practitioners" in this issue.

Services for care for children and youth

- General eligibility criteria - Singaporean / Permanent resident (with at least 1 family member who is a Singaporean. Children and youth diagnosed with developmental, intellectual, hearing, visual, or physical disabilities.
- Application requirements – assessment for suitability by a doctor from the Children Development Unit (CDU) at KK Women's and Children's Hospital (KKH), National University Hospital (NUH) or Singapore General Hospital (SGH).
- Medical social worker or doctor to submit referral form to SG Enable.

Adult care services

- General eligibility criteria – Singaporean / Permanent resident (with at least 1 family member who is a Singaporean); aged 16-55; disability types – intellectual, physical, sensory, autism, or other developmental condition; free from infectious diseases; and having no serious psychotic disorder or challenging behaviour.
- Application requirements – referrals from restructured hospitals, community hospitals, SPED (Special Education) Schools, Polyclinics, and Family Service Centres.
- A professional (e.g., doctor, social worker, or therapist) to be consulted for assistance in submitting an application to SG Enable,

Financial schemes

- General eligibility criteria – assistive devices that help to enable the pursuit of education or open employment; assistive devices that help to improve mobility, enhance independence or rehabilitation; Singaporean / permanent resident (with at least 1 family member is a Singaporean); gross monthly per capita household income is less than 1500 Sing dollars.
- Application requirements – referrals from hospitals, VWOs, SPED Schools.

- Medical social worker from hospital or Social Worker from VWO or SPED School to submit application.

Transport schemes

- General eligibility criteria – Singaporeans or permanent resident; PWD with permanent disability.
- Application requirements – certified by doctor or specialist to have a permanent disability of any one of the following – physical, visual, hearing, intellectual and autism spectrum disorder; or a member of a relevant VWO, or undergo a

Functional Assessment Report by a doctor.

- For taxi subsidy, need to undergo medical assessment by specialists at designated medical institution to certify totally dependent on taxis for travelling.

REFERENCES

1. Ministry of Social and Family Development. Enabling Masterplan 2012-2016 Full Report. Executive Summary. MSF: Singapore 2013 March 8.

LEARNING POINTS

- **SG Enable is an agency dedicated to promoting an inclusive society through enabling persons with disabilities.**
 - **SG Enable seeks to provide comprehensive disability support to persons with disabilities through provision of easy access to information, referral services, grants and schemes, as well as enhancing employability and employment options for persons with disabilities.**
 - **Medical practitioners play an important role of conducting medical assessment of people with disabilities and making referral of eligible applicants for receipt of services and benefits from financial schemes and non-financial assistance schemes.**
-

UNIT NO. 3

HOW DO GENERAL PRACTITIONERS FOSTER MUTUAL SUPPORT WITH FAMILY CAREGIVERS IN OPTIMISING HEALTHCARE FOR PERSONS WITH DISABILITIES?

Anita Ho Yin King

ABSTRACT

The number of persons with disabilities (PWD) that GPs will attend to will increase due to the rapid ageing population and increasing life expectancy in Singapore. It is important for GPs to work in partnership with family caregivers in order to optimise the healthcare of all PWD, including those with congenital and acquired disabilities. This paper examines the challenges and needs of caregivers; and suggests ways for GPs, caregivers and government to enhance the healthcare experience of PWD.

Keywords:

Care Triad, Caregiver Stress, Caregiver Support.

SFP2014; 40(2): 15-17

INTRODUCTION

Based on service utilisation and recent national health survey, the estimated number of persons with disabilities (congenital and acquired) was 97,200 or 3% of the resident population in 2010¹. Currently, there is no official central registry of persons with disabilities (PWD). With the rapid ageing population and the increasing life expectancy in Singapore, the number of older persons with acquired disabilities will increase. PWD, just like the rest of the population, have their primary health care needs met by outpatient polyclinics and private medical practitioners' clinics. Though the population of PWD is small, it is believed that many general practitioners (GPs) would have treated a PWD before and that they will be seeing more patients with disabilities in future based on the increasing prevalence rate.

Very often, in the course of providing primary health care to PWD, GPs have to work with caregivers closely in order to optimise the medical care of PWD. It is imperative for GPs to support caregivers in their care for the PWD, so that they in turn can support GPs in their provision of healthcare to PWD in an effective manner. This kind of mutual support between members of care triad (GP, caregiver and PWD) will help to prevent relapse, delay revisits and achieve positive healthcare outcomes for PWD.

IDENTIFYING FAMILY CAREGIVERS

In order to cultivate strong mutual support with family caregivers, it is important for GPs to identify them as partners and understand their roles as caregivers. The term "caregivers" as used in this paper refers to unpaid family members, relatives or friends who primarily look into the physical, health, financial, social, emotional and spiritual needs² of PWD and related legal issues involved; while providing support to meet most or some of the needs, while seeking help from others to meet the rest of the needs. Some families have only one main caregiver; some may have more

than one caregiver; and some caregivers receive help from others for care and ad-hoc support. Sometimes, GPs have to also work with other care members of the PWD such as professional caregivers and domestic helpers.

UNDERSTANDING CAREGIVERS' CHALLENGES & NEEDS

Caregivers face challenges such as taking on many roles and performing many tasks, and most of them are unprepared to provide care, have limited or no knowledge to deliver proper care, receive little guidance from healthcare professionals and limited support from others³. Regardless of the type of disability their charge has and number of years in caregiving, caregivers may experience stress at any point of the journey. This could occur due to change in the medical or behavioural conditions of the PWD, family discord over care, imbalance between caregiver's work, family and caregiving, financial stress, or worries over the future of their charge especially after they have passed on. Caregivers often have to deal with negative feelings like frustration, anger, guilt and despair.

Challenges arise throughout the four stages of a caregiving journey. During the beginning stage, also called the "questioning" stage, caregivers struggle to accept the loss of ability of their loved one and understand the medical conditions, diagnosis and prognosis. Some of them may be in a state of denial or anger, questioning why things have turned out the way they have. Most caregivers in this stage feel lost and hopeless. When caregivers eventually move on to the "acceptance" stage, they will be challenged by the many care tasks to perform, with more social and health care agencies to coordinate with. They have to juggle between work, family, leisure and caregiving. Very often, they have to put on hold their own plans for their charge. When situation stabilises somewhat and caregivers become more familiar with their caregiving role and resources available, they would have reached the "established" stage. They may start to think about the future of their charge and try to anticipate all possible future plans, and hold family meetings to share the care and plan ahead. It is understandable that caregivers will never stop worrying about their charge's future. An especially worrisome aspect for the lone caregiver is contemplating the thought of their own passing before their charges. In the last stage of a caregiving journey, caregivers prepare to learn how to "let go and move on". This will be the stage where caregivers learn to let go of guilt and worry after having done whatever was possible for their loved one/ charge. This may also be the time for grief when their charge has passed on.

Studies^{4,5,6} have found caregivers are likely to be in distress if they:

- provide more than 21 hours of care per week;
- experience physical stress;
- juggle with work, family, leisure and caregiving;
- are economically disadvantaged;

ANITA HO YIN KING,
Assistant Director, AWWA Centre for Caregivers

- have poor coping skills;
- have low education level;
- have minimal support network;

and their charge has:

- moderate to severe cognitive impairment;
- aggressive behaviour;
- impairment in instrumental activities of daily living;
- symptoms of depression.

Caregiving may have both positive and negative impacts on caregivers. Positive aspects include nurturing stronger family ties, developing meaningful relationship with care triad members and care recipients, discovering new areas of personal growth, and feeling competent and empowered as a result of the caregiving experience. However, negative impacts are many as well, and need to be recognised and dealt with. Caregivers who under-prioritise self-care may expose themselves to the risks of burnout, depression and other stress-related illnesses which impact their overall health and undermine the quality of care they deliver to their charges. In Singapore, it was estimated that 30% of elder abuse cases occurring annually were due to caregivers' stress⁷. In extreme cases, caregivers have been driven to attempt suicide and homicide⁸.

Caregivers' needs are usually "invisible" to the families', health workers', agencies', society's and policy makers' attention. GPs are important touchpoints to identify caregivers' stress and help them cope before the caregiver is overwhelmed into desperate actions. For example, GPs can help improve the experience of caregivers of PWD. Studies show that GPs are well-placed persons to guide caregivers in need of information and support⁹. Very often, caregivers do not know when they need community resources, or how to access and utilize them. They require not only physical help but also training, psycho-education and emotional support³. Support for caregivers can help alleviate the burden of care, improve health and quality of care/ life, and reduce burnout and depression¹⁰.

FACTORS AFFECTING THE CAREGIVERS' EXPERIENCE WITH GPs

A study by Greenwood, Mackenzie, Habibi, Atkins and Jones¹¹ found that most GPs recognised the need to support PWD and caregivers but felt that they lack time, resources and training in doing so. Another study by Schoenmakers, Buntinx and Delepeire¹² found that caregivers felt GPs lacked appropriate communication skills, were unaware of their worries and feelings of grief and distress, and failed fully to take their perspective into account. Others studies have identified communication as a common barrier^{13,14,15}.

There are many other factors affecting caregivers' perceptions of weak support received from GPs. This includes the tendency to stereotype, negative attitude, lack of commitment and cultural sensitivity, GPs' limited knowledge of disabilities, limited time spent per visit, lack of expressed empathy, and management policies (e.g. protocol in handling patients with disabilities).

There are dilemmas GPs face in seeking to provide support to caregivers. First, there is limited support they can offer caregivers due to pressure of time, especially in busy clinics. They will not be able to identify caregivers' stress if caregivers do not bring it up with their GPs. Second, there are also issues of confidentiality and autonomy, when caregivers do not allow space for patient-physician communication, patients and caregivers do not have shared interest, or whether patients are able to make decisions. Some studies have found that patients with mild to moderate cognitive impairment are able to make valid statements of wishes, values and preferences^{16,17}. Third, whether GPs should bill caregivers when they tag along with patients and seek a medical opinion for their own ailments. These dilemmas may put GPs in difficult positions when they try to develop positive partnerships with caregivers.

FOSTERING SUPPORTIVE RELATIONSHIP BETWEEN MEMBERS OF THE CARE TRIAD

In order to foster supportive relationship with caregivers, GPs can do much to support caregivers and elicit support of caregivers to support them (GPs) as well, in the mutual interest of delivering effective and efficient healthcare to PWD.

Things GPs can do:

- Treat PWD as individuals with unique needs rather than as "disabled" persons. Speak directly to them when they are able to communicate before seeking additional information from caregivers.
- Engage caregivers as part of the healthcare team and make use of their care expertise.
- Prepare caregivers in advance by discussing patient's treatment plans over life course, and allow time to discuss diagnosis and care arrangements.
- Ensure a common and accurate understanding of medical instructions when communicating with caregivers¹⁴. Minimise medical jargon; provide written instructions and pamphlets on medical conditions for reference.
- Follow-up with calls to check compliance.
- Assess caregivers' wellbeing, pick up signs of burnout and promote caregiver self-care.
- Show understanding of caregivers' challenges and speak with empathy.
- Use supportive and non-judgemental communication; choose positive or neutral words when discussing care and avoid negative ones like burden or suffering.
- Sign-post caregivers to community services for PWD and for caregivers, and help them understand the role of such additional services in improving their quality of care/ life.
- Equip yourselves with knowledge about disabilities and community resources, build networks with care specialists and community service providers.
- Consider shorter wait time or separate waiting room where possible for PWD such as those with autism spectrum disorder or attention-deficit hyperactivity disorder.

Things GPs can advise caregivers to do:

- Prepare their charge for doctor/dental visit through role-play, books, and pictures.

- Note down the medical history and their questions in point form before visits if they need time to organise thoughts/information.
- Call before visits, prepare staff ahead of time, and remind them of the needs of their charge.
- Schedule either the first or last appointment (if applicable) for shorter wait time or a less crowded waiting room.
- Bring distractions to engage their charges at the waiting room and exam room.
- Act as one point of communication instead of sending different people to accompany their charge for medical appointments each time.
- Bring a support person if they have difficulty in understanding medical conditions and care instructions.
- Have separate consultation time for their charge and themselves.
- Give space for patient-doctor communication, assure that they will be given time to supplement information.
- Plan ahead, prepare for emergency and alternative care arrangement².
- Practice self-care, take a respite break if needed, seek help and support when they feel stress or find difficulty in coping with caregiving.

CONCLUSION

Beyond the willingness of GPs in supporting PWD and caregivers, additional community support to GPs is required to enable them cope well. Ministry of Health can provide simple referral guides and operation guidelines for GPs and clinic staff in working with PWD and their caregivers. Literature on caregiver burnout, self-care, and up-to-date community resource directory can be made available for distribution to caregivers. Simple assessment tools can be developed to aid assessment of caregivers' wellbeing by GPs. Health ministry can also provide platforms for closer liaison between GPs, agencies and other professionals. As some GPs impose additional charges for longer consultation time, subsidies to PWD for such purpose would also be helpful. It is recommended that research be done on the care triad comprising GPs, PWD and caregivers or on related topics to identify salient issues and best practices in Singapore.

REFERENCES

1. Enabling Masterplan 2012-2016. Ministry of Social and Family Development Singapore Web site. [http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling Masterplan 2012-2016 Report \(8 Mar\).pdf](http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling Masterplan 2012-2016 Report (8 Mar).pdf) Accessed March 19, 2014.
2. Caregiving... the journey starts with you! AWWA Centre for Caregivers Singapore Web site. 2010.

<http://caregiversconnect.sg/content/caregivers-handbook> Accessed March 19, 2014.

3. Reinhard SC, Given B, Petlick NH, Bemis A. Chapter 14: Supporting Family Caregivers in Providing Care. In: Hughes RG, ed. Patient safety and quality: an evidence-based handbook for nurses. Rockville, MD: Agency for Healthcare Research and Quality; 2000: 1-22. <http://www.ahrq.gov/professionals/clinicians-providers/resources/nursing/resources/nursesdbk/nursesdbk.pdf> Accessed March 19, 2014.
4. Supporting Informal Caregivers – The Heart of Home Care. Canadian Institute for Health Information Canada Web site. 2010. https://secure.cihi.ca/free_products/Caregiver_Distress_AIB_2010_EN.pdf Accessed March 19, 2014.
5. Poon CH. Most caregivers are elderly spouses. The Straits Times. August 3, 2012: B5.
6. Stephens MA, Townsend AL, Martire LM, Druley JA. Balancing parent care with other roles: Interrole conflict of adult daughter caregivers. J Gerontol B Psychol Sci Soc Sci. 2001; 56(1): 24-34.
7. Basu R. Care for the carers of the old. The Straits Times. November 3, 2009: A2.
8. Lee WL. Who cares for the caregivers? The Straits Times. January 31, 2011: 31.
9. Murphy B, Nankervis J, Schofield H, Herman H, Bloch S, Singh, B. The role of GPs and pharmacists in information exchange with family caregivers. Aust N Z J Public Health. 1997; 21(3): 317-22.
10. Seow, CCD, Yap, LKP. The role of GPs in helping caregivers of persons with dementia. The Singapore Family Physician. 2013; 39(2): 27-32.
11. Greenwood N, Mackenzie A, Habibi R, Atkins C, Jones R. General practitioners and carers: a questionnaire survey of attitudes, awareness of issues, barriers and enablers to provision of services. BMC Fam Prac. 2010; 11: 100. doi:10.1186/1471-2296-11-100
12. Schoenmakers B, Buntinx F, Delepeleire J. What is the role of the general practitioner towards the family caregiver of a community-dwelling demented relative? A systematic literature review. Scand J Prim Health Care. 2009; 27(1): 31-40. doi:10.1080/02813430802588907
13. Lennox NG, Diggins JN, Ugoni AM. The general practice care of people with intellectual disability: barriers and solutions. J Intellect Disabil Res. 1997; 41(5): 380-90. <http://www.ncbi.nlm.nih.gov/pubmed/9373818> Accessed March 19, 2014.
14. Mitnick S, Leffler C, Hood VL. Family caregivers, patients and physicians: ethical guidance to optimize relationships. J Gen Intern Med. 2010; 25(3): 255-260. doi:10.1007/s11606-009-1206-3
15. Rowe J. Enhancing carers' experiences of mental health services. Mental Health Practice. 2013; 17(2): 24-26. doi:10.7748/mhp2013.10.17.2.24.e846
16. Hirschman KB, Joyce CM, James BD, Xie SX, Karlawish JH. Do Alzheimer's disease patients want to participate in a treatment decision, and would their caregivers let them? The Gerontologist. 2005; 45(3): 381-388. doi:10.1093/geront/45.3.381
17. Whitlatch CJ, Feinberg LF, Tucke SS. Measuring the values and preferences for everyday care of persons with cognitive impairment and their family caregivers. The Gerontologist. 2005; 45(3): 370-80.

LEARNING POINTS

- It is important for GPs to cultivate supportive relationship between members of the care triad in order to optimise the healthcare for the PWD.
- Caregiving can be a challenging task and have both positive and negative impacts on caregivers' physical, mental, psychological, social and financial wellbeing.
- Timely support to caregivers can help to reduce stress, burnout and depression, so that they can continue to provide quality care to PWD
- GPs can help to enhance the healthcare experience of PWD and caregivers, with some external support.

RECOGNISING CHILDREN WITH DEVELOPMENTAL DELAYS: A STRATEGY FOR SURVEILLANCE

Dr Sylvia Choo Henn Tean

ABSTRACT

Developmental delays and disorders are not uncommon and affect 10 to 20% of children under the age of 5. Early identification of children with delays allows referral for assessment and appropriate intervention, which can influence the child's developmental trajectory, allowing optimisation of his potential.

The family physician has a very important role to play in monitoring the development of children under his care. He is well placed to do this in a longitudinal sense, as he already has an ongoing relationship with the family, and has many opportunities repeated contact with the child in the first few years of life.

Developmental surveillance using the checklists, limit milestones and red flags in the Child Health Booklet is described.

Keywords: Child development, developmental screening, developmental surveillance, developmental delay, family physician

SFP2014; 40(2): 18-33

INTRODUCTION

It has been estimated that developmental delay occurs in about 15% of children under 5 years of age¹. It is therefore not uncommon. One out of perhaps 6 children in your practice may have a developmental delay or disorder.

The monitoring of development in young children is an important component of family practice, as family physicians have the opportunity to

1. Know the whole family and its particular strengths and risk factors – there is an existing relationship of trust.
2. See the child and family for routine visits such as for immunisation as well as for acute illnesses – there is the possibility of regular, frequent contact.

If there are concerns about a child's development, an early referral for diagnostic assessment will expedite appropriate early intervention. This can make a significant difference to outcomes for both the child and the family. It has been well documented that healthy early child development is crucial, not only for long-term development for learning, but also for physical, emotional and mental health throughout one's

lifetime. The evidence for early intervention, though somewhat limited in a medical sense, shows that it confers long term benefits for these children.

Research has shown that identifying developmental delays may be erratic if physicians rely solely on clinical judgement and informal milestone reviews². We aim to discuss ways of increasing the likelihood of identifying children who need help, in the context of a busy family practice.

OVERVIEW OF CONCEPTS & TERMINOLOGY**Normal development**

Developmental progress is about gaining functional skills, which will over time, allow a child to become independent of its adult caregivers. Developmental skills are achieved sequentially following a remarkably consistent pattern, though there may be a wide variation in the time frame. This development reflects the interaction of the child's developing neurological system with the environment. Each developmental phase builds on previous ones and allows for further aspects of development to take place. Hence, difficulties within one domain can lead to delays in acquiring skills in another field. For example, a child who has a hearing impairment that is left untreated, will likely be delayed in acquiring language and speech. This may in turn limit play opportunities and affect the child's social development.

- Developmental milestones: Age at which a specific and important developmental skill is achieved
- Median age: Age at which 50% of children acquire a specific skill
- Limit age: Age at which a specific skill should have been achieved (reflects 2 S.D. from the mean)

Typical developmental trajectories

Development has been described to involve a progression of emphasis from neurologic → motor → sensorimotor → cognitive function. It has been proposed that development proceeds from a basic skill to a function, to an integrated functional unit. This last step blends skills and functions and may form the basis for later 'intelligence'. For example, reaching or grasping can be considered a skill. Reaching grasping and bringing an object to the mouth is a function. Overcoming a barrier to obtain an object that could then be brought to the mouth involves integration and coordination of various functions (problem solving, object permanence, motor planning); by blending skills and functions, this would become an integrated functional unit.

Motor development occurs in the following patterns:

1. From head to toe (cephalo-caudal) – a child will acquire head control, then truncal control and eventually be able to walk.
2. From inner to outer (proximal to distal) – the muscles of the face and trunk are the first to develop, followed by muscles controlling large limb movements and finally moving out distally

SYLVIA CHOO HENN TEAN,
Senior Consultant, Department of Child Development,
KK Women's and Children's Hospital

to the fingers controlling finger movements.

3. From simple to complex movements - a child must stand, before he walks, and subsequently, runs, skips, jumps, hops.
4. From general to specific – a child progresses from general stimulus-based reflexes to specific goal-oriented reactions that become increasingly precise – e.g. from a palmar grasp to a pincer grasp of a small object to pencil control to handwriting skills.

The separation of cognitive, language and social-emotional domains into separate categories is somewhat artificial, as these domains are inextricably linked. While most of us are quite aware of the chronological sequences for gross motor, fine motor and speech-language skills, knowledge of the less visible domains of cognitive and personal-social development is often limited, for both physicians and parents. There is a need for physicians to be familiar with the early signs of social and/or cognitive difficulties, as they might be the first indicators of conditions such as autism or intellectual disability, so they can refer such children for further assessment and intervention.

Abnormal Development

Development should be a process of progression. The following 'abnormal' or 'atypical' patterns may be seen.

- Developmental Delay: in which a child is not developing and/or achieving skills according to the expected time frame. A developmental delay may be specific (only 1 domain is affected) or 'global' (defined as 2 or more domains affected). There is the implication that development has occurred in the typical order or sequence, but not by the typical time, and that there may be

'catch-up' later.

- Developmental Disability/Disorder: refers to a childhood mental or physical impairment or combination of mental and physical impairments that result in substantial functional limitations in major life activities. The implication is that development does not follow the typical pattern or sequence and timing, and that the child may not achieve 'catch-up' with his same aged peers.
- Developmental Arrest/Stagnation: There is a standstill in developmental progress for a longer period than expected
- Developmental Regression: There is loss of previously attained skills. This is always a cause for significant concern, and should always be investigated.

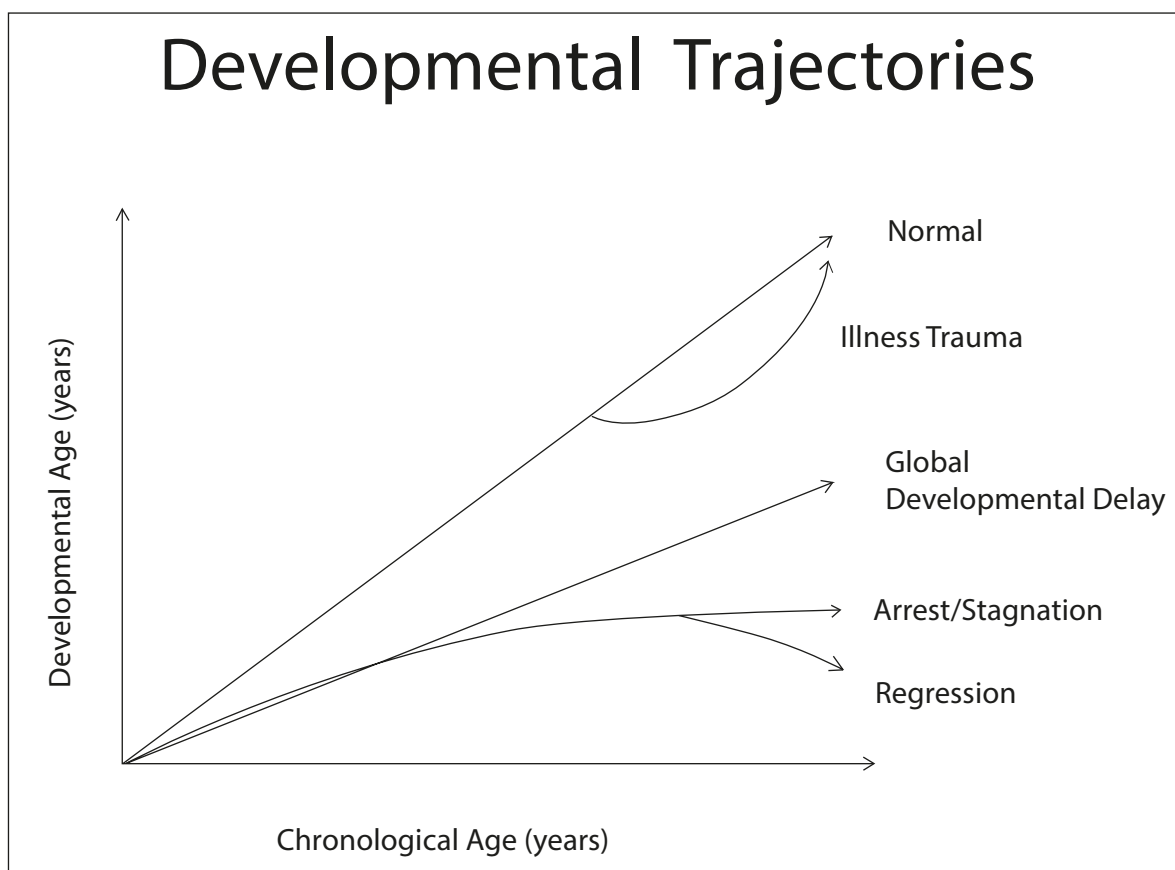
Factors Influencing a Child's Development and Learning

Genetic and environmental influences continuously interact with and alter each other in a dynamic manner. These can be classified into:

- Influences within the Child – these include the child's genetic inheritance, temperament, gender, physical health
- Influences within the Family – family relationships, parenting styles and values, the family's financial situation, parents' level of education/occupation, parents' physical and mental health, siblings
- Influences within the Community – children's services, support for parenting, housing
- Influences within the Culture – for example, when children are weaned off the milk bottle, when children are expected to feed themselves etc.

FIGURE 1. DEVELOPMENTAL TRAJECTORIES

(adapted from Tervo: Red Flags and Rules of Thumb 2009)³.



As the child and family's physician, you are aware of many of these environmental and family factors.

METHODS OF EARLY IDENTIFICATION

It has been estimated that only about half of the children with developmental problems are detected before they begin school. This means that developmental problems commonly escape detection in the first 5 years of life, despite frequent well child visits ⁴.

Disorders on the more severe end of the spectrum, such as cerebral palsy and profound intellectual disability, are clearly recognisable and have well-known consequences. These are identified early as the children present with significant delay, and the appropriate referrals for intervention and education are made.

Mild to moderate problems such as language impairment, mild intellectual and learning disabilities, and high functioning autism spectrum disorder are more subtle and difficult to identify in the early years. However, these conditions are associated with poorer health status, higher rates of school failure, and poorer adult long-term outcomes – academic achievement, criminal behaviour, long-term employment and income level ⁵.

Parents are usually the first to pick up signs of possible developmental delay – any concerns that parents have about their child's development should always be taken seriously; on the other hand, the absence of parental concerns does not necessarily mean that all is well. If parents suspect a delay, they may first seek reassurance from their family physician. Hence, the physician will need to have an understanding of normal

development, a strategy to detect the likelihood of problems, and a system to whom children can be referred when necessary and appropriate ⁶.

Physicians generally acknowledge that screening for developmental disabilities is important, but most rely on clinical judgement and milestone review. There is evidence to suggest that relying on clinical judgement and/or developmental milestone review does not allow timely identification of developmental delay ^{2,4}.

Developmental Surveillance, Developmental Screening, Developmental Assessment

Surveillance and screening are complementary but distinct processes. Table 1 attempts to distinguish these 2 concepts ⁷.

Developmental surveillance is a much broader concept than developmental screening. It is a longitudinal process that relies on repeated purposeful review of the child and family. It aims to not only detect delays early, but also identify risk factors for child development. It involves eliciting any parental concerns, making skilled observations of the children, and giving parents information and guidance on health and developmental issues relevant to the child's age and parents' needs ⁶.

Hence, surveillance does not only rely on monitoring developmental milestones, which should be anchored in the best available evidence, but it also needs to be grounded by a good understanding of the role of the gene-environment interaction that makes every child unique. Observing and documenting these findings at each health maintenance visit is critical to the delicate balance between continued monitoring or referral for

TABLE 1. DIFFERENTIATING DEVELOPMENTAL SURVEILLANCE AND DEVELOPMENTAL SCREENING

Developmental Surveillance	Developmental Screening
Monitoring of development over time	Monitoring of development at specific age
Longitudinal - flexible, continuous, cumulative process	Cross-sectional, administered at specified time points
Aim is to recognise children who may be at risk of developmental delays	Aim is to identify and refine that recognised risk, decide who needs further evaluation. It lets us know who in the population is at risk for a disorder, but it does not make the diagnosis.
Less time taken	More time intensive
Universally implemented, for all children	2 types of screening tests: 1. Children flagged by developmental surveillance to have risk of DD 2. All children (e.g. M-CHAT), but at specific time points
Opportunistic, should take place at all well child visits, such as immunisation visits. Also at other visits, if parents have a concern.	At specific ages or time points
Uses 'an informal collection of age-appropriate tasks'	Uses a validated standardised screening instrument with published sensitivity and specificity and targeted at specific ages.
Can be viewed as a 'video' which may have a lower resolution and is grainy – longer term, less specific	Can be viewed as a detailed high resolution 'snapshot', at a particular point in time.
Few clear cut directives	Clear screening guidelines by AAP

further evaluation.

Developmental surveillance alone lacks the sensitivity and specificity of validated screening tools, but both methods could complement one another when there is a robust developmental surveillance in place. In this regards, the 'red flag' approach (upper limit of attainment of the specific skill) increases the quality of surveillance and could enhance its validity. This approach needs the support of evidence-based milestone acquisition timelines⁸.

Developmental Assessment/Evaluation is, on the other hand, a complex process aimed at identifying specific developmental disorders that are affecting a child. Validated tools for developmental assessment are used, with standardised tools, such as Bayley Scales of Infant Development, Griffiths Mental Development Scales, and Gesell Developmental Schedules. These assessments are formally administered and are an in-depth evaluation of a child's abilities, giving a detailed understanding of a child's strengths, weaknesses and attainment levels. They will answer the question "at what level is this child functioning and why?" A developmental assessment is usually part of a process of establishing a developmental diagnosis. It will yield a score in the form of a developmental quotient, a percentile and/or age equivalents.

Rationale for Monitoring Development: Why repeated surveillance or screening is necessary

- Development is malleable.

Children's language, social and other developmental skills are influenced in positive directions by healthy environmental forces. This means that developmental progress can be changed, for better or for worse. To monitor changes in developmental status, repeated screening is necessary.

- Development manifests with age.

Developmental problems arise as children develop. Children whose skills appear typical at one age, may still demonstrate developmental problems later on. E.g. a child with good motor, communication and social skills at age 3, may nevertheless manifest a reading disability by age 6, but this condition cannot be readily observed or measured until later in life, the age which most children are beginning to read.

The concept of 'age-related developmental manifestations' means that every child has an increasing risk of disabilities. Only 1-2% of children between 0-24 months of age have developmental problems, while the prevalence increased to 8% when children up to age 6 are included².

WHAT HAVE OTHERS BEEN DOING?

Currently, recommendations vary for the use of developmental surveillance and/or developmental screening in different countries.

In Asia, Hong Kong has a very well developed and well utilised Integrated Child Health and Development Programme

(ICHDP) which is a population based, health promotion and disease prevention programme for children 0-5 and their families, delivered through their network of 31 Maternal and Child Health Centres. This programme covers about 90% of Hong Kong children. It utilises a systematic developmental surveillance system by trained MCH nurses and doctors⁹.

The Taiwan Birth Cohort Study (TCBS) included all babies born between October 2003 and January 2004. Child development was measured using an age-appropriate TBCS Development Instrument, a parental report instrument measuring the children's daily performance. This was evaluated and found to be a valid and reliable developmental screening instrument in the Taiwanese population and recommended to be used in continuous surveillance of children's development in community and clinical settings from 6 months to 5 year of age¹⁰.

In Japan, public health examinations for infants and young children conducted under the Maternal and Child Health Law (Boshi Hoken Ho) include 3 principal health check-ups at the following times: infancy, 1½ years old and 3 years old. Developmental examination is part of these check-ups¹¹.

Closer to home in Malaysia, a developmental screening checklist is administered at 3 months, 4-5 months, 12-15 months and at 4-5 years. Autism screening using the Modified Checklist for Autism in Toddlers (M-CHAT) is recommended to be carried out at 18 months¹².

Most European countries focus on child development surveillance and do not recommend routine developmental screening. This includes the United Kingdom where 8 month, 2 year, and 3-4 year developmental and health reviews are no longer recommended as a routine part of the core programme for all children, and there is a shift of emphasis from 'Child Health Surveillance' to 'Child Health Promotion', where primary health care teams will take a flexible approach and offer health reviews and health promotion advice for children and families most in need, or most 'at risk'.¹³

The Australian National Health and Medical Research Council (NHMRC) last published 'Child Health Surveillance and Screening: A Critical Review of the Evidence' in 2002. Current advice states the importance of developmental surveillance, and the broader concept that it now encompasses, including "eliciting parental concerns, performing skilled observations of the child, and providing guidance on health and development issues that are relevant to the child's age and the parent's needs"⁶.

Canadian guidelines have not yet been established, but the Canadian Paediatric Society has endorsed the Rourke Baby Record recommendations. These include developmental surveillance at all well baby or well child visits, with further assessment of development recommended if there is either a lack of attainment of any 'red flag' milestones or parental or caregiver concern about development¹⁴.

In direct contrast to the above, the American Academy of Pediatrics recommends developmental surveillance at all well child visits, and the routine use of formal developmental screening at the 9, 18 and 24 or 30 month well child visits and in addition, at all other well child visits should concerns arise during developmental surveillance at any visit¹⁵. The screens that have been recommended include the Ages and Stages Questionnaire, Parents Evaluation of Developmental Status (PEDS) and the Denver Developmental Screening Test –II (DDST-II). The response in the United States to these AAP recommendations, which were made in 2006, has been inconsistent, and physician acceptance as well as time-resource concerns, are believed to be partially responsible for this. Revisions have been recommended to optimise early detection, prevention, and monitoring¹⁶.

What have we been doing?

Locally, we have gone through a cycle of sorts. The Denver Developmental Screening Test (DDST), Singapore was developed in 1989 to fulfil the need for a locally suitable developmental screening test, for early detection of developmental problems in Singapore children. It was derived from both the original DDST and the Denver II and was standardised on 2194 Singapore children aged 4 weeks to 6 years 11 months. There are 115 test items for the 4 developmental sectors (gross motor, fine motor-adaptive, speech-language and personal-social domains). Maternal and Child Health (MCH) nurses were trained to administer the DDST, Singapore to the children who attended the MCH clinics for their well baby and child visits. In the early to mid-1990s, there were 17 MCH clinics providing developmental screening services for approximately 50% of each year's birth cohort of children. With the integration of MCH services into the main Polyclinic system, as well as changing demographics, the polyclinics were no longer the main providers of immunisations and developmental screening for children. At this point, the DDST, Singapore remains the only standardised developmental screen for Singapore children^{17,18}.

The ASQ and PEDS are both parent filled questionnaires. The ASQ has been used in a number of local research projects and as a triage tool in our clinic at KKH. Local parents have not found the language in the ASQ to be easily understandable, and assistance to fill the form is often required. Over- and under-reporting are also concerns¹⁹.

The Parents Evaluation of Developmental Status (PEDS) was also evaluated by Kiing et al, to explore its potential roles and utility in the Singapore context. 1806 parents, teachers and child care workers participated. Only parent results were analysed. The reporting of significant parental concern was considerably higher than US norms and Australian pilot figures when western cutoff scores were applied. Parents' interpretation of the concept of 'concern' varies across language and culture. Findings highlight the importance of evaluating a screening tools' use in the local context before its widespread implementation to yield clinically meaningful results²⁰.

What is being suggested?

Both developmental surveillance and screening are important in order for children with special needs to be identified early so that they can receive intervention promptly. The Enabling Masterplan 2011-2016 recommends strengthening the national developmental surveillance and screening system by establishing a network of early detection touch points in the community with the support of different stakeholders. This network will comprise primary health care professionals, child care centres, preschools and family service centres. Professionals at these critical touch points will be equipped with skills to detect children who are displaying signs of developmental problems, as well as at-risk children from disadvantaged social backgrounds²¹.

To address the current gap in developmental surveillance, the Enabling Masterplan 2011-2016 proposes that the Child Health Booklet be used as a main tool for routine developmental surveillance. That is a reasonable plan. Work with what we have. The Health Booklet does have parts of the DDST, Singapore embedded in it, and the current Health Booklet has recently been updated to reflect some of the 'Red Flags'. Best of all, every child in Singapore has a copy of the Health Booklet. If not, it is readily available from the nearest Polyclinic or at the Health Promotion Board, at a nominal cost.

This concept of surveillance via age-specific milestones is not new. Dosman et al describes the format for a valid, reliable and practical mechanism for monitoring child development. They have published a clinically relevant 'red flags' milestone chart, which uses the uppermost published age limits for items (as opposed to median age) so that a missed milestone will usually be clearly delayed and require further action. They propose that milestone ages used during surveillance be evidence-based, with evidence most robust for milestone acquisition for fine and gross motor development, less so for speech and language, and least robust for cognitive and social-emotional development^{8,14}.

5 components of developmental surveillance are described in the AAP Policy Statement on Developmental Surveillance and Screening 2006¹⁵. These are:

- Eliciting and attending to the Parents' Concerns
- Obtaining/maintaining a Developmental History
- Making Accurate and Informed Observations of the Child
- Identifying the Presence of Risk and Protective Factors
- Documenting the Process and Findings

Strategy!

Every child who is born in Singapore will have a Health Booklet, which will be with him from birth through school. Parents should be encouraged to bring the health booklet whenever the child visits the doctor, for any reason.

Infants have many opportunities for developmental surveillance. If they come for all the recommended immunisations, they would be expected to have at least 6 visits before the age of 2

years. That makes 6 opportunities for developmental surveillance!

Apart from the all-important immunisation record, which is needed for registration into primary school, the Health Booklet can hold a wealth of important information. The child's birth records and perinatal history, as well growth charts and developmental progress, any significant medical information, can be found in there. Please refer to Table 2.

There are 3 areas relating to red flags for child development to note in the developmental and health screening pages.

1. **Child Developmental Screening** (pages 5-6) Figure 3
This has some questions for parents at 3, 6, 15 months and 3 years – these are meant to directly elicit Red Flags. It also gives a framework for the visits. Please refer to Table 3.
2. The **Developmental and Health Screening pages appropriate to the child's age**
These are colour-coded according to age, for ease of reference: Pink 4-8 weeks, Blue 3-5 months, Yellow 6-12 months, Green 15-18 months, Orange 2-3 years, Purple 4-6 years

Red flags for ASD are boxed in the age-appropriate colour above the developmental checklist for ages 12-18 months, 2-3 years

TABLE 2. STRATEGY FOR SURVEILLANCE

Strategy

When:

1. At every well child or immunisation visit
2. When parents have concerns
3. When you have concerns

If seeing a child for the first time:

1. Birth Record (page 3-4) Figure 2.
 - a. Place of delivery
 - b. Duration of gestation
 - c. Mode of delivery
 - d. Apgar Score
 - e. Weight/length/Head Circumference at birth
 - f. Significant events during pregnancy and delivery
 - g. Jaundice/phototherapy/exchange transfusion
 - h. Newborn screening
 - i. G6PD deficiency
 - ii. TSH
 - iii. IEM screening
 - iv. Hearing screening
 - i. Investigations done (if any)
 - j. Information on discharge from hospital
2. Summary of Clinic/Hospital Medical Records (page 59-63)

Discharge summaries (patient version) are sometimes clipped to the back cover of the health booklet – this is especially pertinent if the child was a premature baby

3. Growth Charts are in the middle of the health booklet (page 26-49)

The above pages will assist with identifying some of the risk factors which predispose a child to developmental delay and disorders.

Next:

1. Weight/Height/Head Circumference
2. Plot in growth charts, fill in Growth on health screening page (if age applicable)
3. Ask parents about any concerns they may have
4. Check Red Flags (page 5-6)(Table 3)
5. Check Red Flags (age appropriate)(Table 4)
6. Go through developmental checklist (age appropriate) (summarised in Table 5) – Limit Age(s)
7. Physical examination
 - a. Tick boxes (age appropriate)
 - b. Check on findings in developmental checklist
8. Observe child's behaviour, parent and family interactions and responses
9. Fill in Outcome of Examination
10. Speak with Parents about the Outcome of Examination
 - a. Findings
 - b. Anticipatory Guidance
 - i. information on current and expected development
 - ii. how to promote health & development
 - iii. need for further review or referral

If red flags for ASD are present, please consider administering the M-CHAT-R

FIGURE 2. BIRTH RECORD

BIRTH RECORD AND PARTICULARS OF CHILD									
Name of child (in BLOCK LETTERS)									

Birth Certificate No:									
Date of Birth:									
Time of Birth:									hrs
Address:									

Place of Delivery:									

Sex:									
☐	Male	☐	Female	Ethnic Group:					

Duration of Gestation:									
		Weeks							
Mode of Delivery:									
☐	Normal	☐	LSCS	☐	Vacuum extraction	☐	Forceps	☐	Other
Apgar Score:									
	1 min		5 min						
Weight at Birth:									
				gm					
Length at Birth:									
				cm					
Head Circumference:									
				cm					
PARTICULARS OF PARENTS									
MOTHER									
Name:									

NRIC/Passport No.:									

Occupation:									

Tel (RES):									

Tel (OFF):									

Tel (HP):									

FATHER									
Name:									

NRIC/Passport No.:									

Occupation:									

Tel (RES):									

Tel (OFF):									

Tel (HP):									

SIGNIFICANT EVENTS DURING PREGNANCY / DELIVERY

Jaundice ☐ No ☐ Yes

Phototherapy ☐ Yes

Exchange Transfusion ☐ Yes

NEWBORN SCREENING

G6PD Deficiency ☐ No ☐ Yes

TSH: _____ mIU/L FT4: _____ pmol/L Date: _____

*IEM Screening Done ☐ No ☐ Yes Date: _____

Hearing Screening

☐ ** OAE Date: _____ ☐ *** ABAER Date: _____

Left Pass: ☐ No ☐ Yes

Left Pass: ☐ No ☐ Yes

Right Pass: ☐ No ☐ Yes

Right Pass: ☐ No ☐ Yes

Needs further evaluation: ☐ No ☐ Yes

Remarks (if any): _____

INVESTIGATION(S) DONE (if any)

Serum Bilirubin (highest level) : _____ μ mol/L Date: _____

Blood Group: _____ Date: _____

Other Tests: (please specify) _____ Date: _____

_____ Date: _____

INFORMATION ON DISCHARGE FROM HOSPITAL

Date: _____ Weight: gm Breast Feeding: ☐ Yes ☐ No

Serum Bilirubin (if done) before discharge : _____ μ mol/L

Instructions to doctors and nurses:

All weight, length and head circumference measurements are to be entered on the charts on pages 26-41

Please document additional medical findings in the summary of clinic/hospital medical record section on pages 59-63

*IEM = Inborn Errors of Metabolism, ** OAE = Oto-Acoustic Emission, and ***ABAER = Automated Brainstem Auditory Evoked Response.

FIGURE 3. CHILD DEVELOPMENTAL SCREENING

CHILD DEVELOPMENTAL SCREENING

AGE	TYPE OF SCREENING	IMMUNISATION
1 month	- Growth monitoring : weight, length, OFC* - Feeding history - Hearing screening if not done at birth - Physical examination and developmental check on page 7-8	BCG, Hep B-1 at birth Hep B-2 1 month after Hep B-1
3 months	- Growth monitoring : weight, length, OFC* - Feeding history - Hearing screening if not done at birth/4-8 weeks	DTaP-1, Polio-1, PCV-1
	1. Parents/Caregivers please answer the questions below***: - Can your child keep his/her head upright when held in a sitting position? Yes/No - Can your child respond to the parent's/caregiver's voice by quietening down if crying or smiling? Yes/No - Can your child visually follow the parent's/caregiver's movements, including turning his/her head from side to side? Yes/No	
	Physical examination and developmental check on page 9-11	
4 months	- Growth monitoring : weight, length, OFC* - Feeding history	DTaP-2, Polio-2
5 months	- Growth monitoring : weight, length, OFC* - Feeding history	DTaP-3, Polio-3, PCV-2
6 months	- Growth monitoring : weight, length, OFC* - Feeding history	Hep B-3**
	3. Parents/Caregivers please answer the questions below***: - Can your child roll over? Yes/No - Can your child turn towards a sound? Yes/No - Can your child reach out for things? Yes/No	
	- Hearing screening - Physical examination and developmental check on page 12-14	
9 months	- Growth monitoring : weight, length, OFC* - Feeding history - Hearing screening - Test for squint - Physical examination and developmental check on page 12-14 (if not done at 6 months)	

Legend: * OFC - Occipital - Frontal Circumference

All height, weight and OFC measurements must be charted into the appropriate growth charts

** The 3rd dose of Hepatitis B vaccination can be given with the 3rd dose of DTaP and Oral Sabin (DTaP-3, Polio-3) for the convenience of parents.

*** If the answer to any of these questions is 'No', please refer to your doctor.

CHILD DEVELOPMENTAL SCREENING

AGE	TYPE OF SCREENING	IMMUNISATION
12 months		PCV Booster MMR-1*
15 months	- Growth monitoring : weight, height, OFC Parents/Caregivers please answer the questions below***: - Can your child walk a few steps? Yes/No - Can your child wave bye-bye or clap hands? Yes/No - Can your child say Papa or Mama? Yes/No - Physical examination and developmental check on page 15-17	MMR-2**
18 months	- Growth monitoring : weight, height, OFC. - Physical examination and developmental check on page 15-17 (if not done at 15 months)	DTaP Booster, Polio Booster,
3 years	- Growth monitoring: weight, height, OFC, BMI - Test for squint Parents/Caregivers please answer the questions below***: - Can your child climb stairs without assistance? Yes/No - Can your child speak spontaneously in sentences with 4 syllables? Yes/No - Physical examination and developmental check on page 18-21.	
4 - 5 years	- Growth monitoring: weight, height, BMI - Visual acuity and test for squint - Stereopsis - Physical examination and developmental check on page 22-25	

Legend: * Babies who turn 12 months of age on or after 1st December 2011 should receive 2 doses of MMR vaccine as per new schedule on page 55.

** MMR-2 can be given at 18 months with DTaP Booster and Polio Booster for the convenience of parents.

*** **If your answer to any of these questions is 'No', please refer to your doctor.**

and 4-6 years. Please refer to Table 4.

3. The age-appropriate Developmental Checklists

Ideally parents would have filled these in and brought up their concerns, but in reality they rarely are.

Please do consider running through and 'counter-checking' the screening checklists which are appropriate for the child's age. The age (in months) which is in the right hand column next to the yes/no boxes indicate the age at which 90% of children in Singapore would have achieved that milestone. Hence attention should be paid to any child who is past that age and still not achieved that milestone. Checking with other skills that the child should have reached at a younger age would be helpful in this situation. Please refer to Table 5.

If there are Red Flags for ASD, the doctor may want to consider administering the Modified Checklist for Autism in Toddlers, Revised with Follow-Up (M-CHAT-R) which is a 2 stage parent-report screening tool to assess risk for Autism Spectrum Disorder (ASD). It is available as a free download for clinical, research and educational purposes from <https://www.m-chat.org/>. Figure 4.

The M-CHAT-R can be administered and scored as part of a well-child care visit. There are 20 questions. Scoring takes less than 2 minutes, and will indicate if a child is at low, medium or high risk of ASD. There is a high false positive rate, so as not miss any cases of ASD. Also, although a significant number of

TABLE 3. QUESTIONS TO ELICIT RED FLAGS

Age	Red Flag
3 months	Can your child keep his/her head upright when held in a sitting position? Can your child respond to the parents'/caregivers' voice by quietening down if crying or smiling? Can your child visually follow the parents'/caregivers' movements, including turning his head from side to side?
6 months	Can your child roll over? Can your child turn towards a sound? Can your child reach out for things?
15 months	Can your child walk a few steps? Can your child wave bye-bye or clap hands? Can your child say Papa or Mama?
3 years	Can your child climb stairs without assistance? Can your child speak spontaneously in sentences with 4 syllables?

TABLE 4. RED FLAGS FOR ASD

Age	Please inform your dr if your child:
By 12 - 18 months	Does not babble, point or use gestures by 12 months Does not speak a single word by 18 months Has lost any language skills Does not respond readily to affection
By 2 - 3 years	Does not use spontaneous (non-echoed/non-imitated) 2-word phrases by 24 months Has lost any language or social skill Does not point to show things he is interested in Does not follow when someone is pointing something out to him Does not respond readily to affection Prefers to play alone
By 4 - 6 years	Does not follow when someone is pointing something out to him Does not respond readily to affection Is not interested in playing with others Seems to be in his own world Is unable to sit through, follow instructions and take turns when playing Becomes very upset/anxious/clingy when separating from you, e.g. when dropping him off at school or when he is going to a new place Has great difficulty controlling his temper or gets very moody/physically aggressive when upset Finds it hard to make friends

TABLE 5. SUMMARY OF LIMIT AGES FOR MILESTONES (BASED ON DDST, SINGAPORE)

Please refer to Health Booklet for details

AGE	GROSS MOTOR	FINE MOTOR- ADAPTIVE	SPEECH- LANGUAGE	PERSONAL- SOCIAL
4-8 weeks	Equal movement [1 month] Lifts head [1 month]	Follows to midline [1.5 months] Follows past midline [2.5 months]	Responds to a bell [1 month] Vocalises [1.5 months]	Regards face [1 month] Smiles spontaneously [1 month]
3-5 months	Head up 45 degrees [3 months] Head up 90 degrees [5 months] Sits, head steady [5 months] Rolls over [5 months]	Hands together [3.5 months] Grasps rattle in hand [4 months] Follows 180 degrees [4.5 months] Regards a raisin [5.5 months]	Laughs [4.5 months]	Excites at a toy [5.5 months]
6-12 months	Bears weight on legs [6 months] Holds chest up, arm support [7 months] Sits, no external support [7.5 months] Stands holding on [9 months] Pulls to stand [10 months] Stands alone [14.5 months]	Reaches for an object [6 months] Looks for a fallen object [7 months] Passes a cube from hand to hand [7.5 months] Finger-thumb grasp [10 months] Bangs 2 cubes held in hands [10.5 months] Pincer grasp [13.5 months]	Responds to sounds [7.5 months] Says single syllables [10 months] Imitates speech sounds [10 months] Says Papa/Mama specifically [14.5 months]	Works for a toy out of reach [6.5 months] Reacts to stranger [10 months] Waves bye-bye [10.5 months] Claps hands [11 months] Indicates wants by gestures [13.5 months]
15-18 months	Stoops to recover [15.5 months] Walks well [16 months] Walks up steps [21.5 months]	Scribbles [16 months] Builds a tower of 2 cubes [17 months]	Points to own body – 2 parts [19 months] Says 3 words other than Papa/Mama [21 months]	Imitates household activities [16 months] Drinks from a cup [18.5 months] Uses spoon [22 months]
2-3 years	Walks down steps [24.5 months] Kicks ball forward [26 months] Jumps up [32.5 months] Balance on each foot – 1 second [37 months] Pedals tricycle [41.5 months]	Builds a tower of cubes [4 blocks – 23 months, 6 blocks – 29 months, 8 blocks – 35.5 months] Imitates a vertical line [38.5 months] Picks longer line [46.5 months]	Points to pictures [2 pictures – 25.5 months, 4 pictures – 28.5 months] Combines 2 words [27 months] Names pictures [2 pictures – 30 months, 4 pictures – 37 months] Knows age/sex/name [40 months]	Removes garment [24 months] Combs doll's hair [24.5 months] Puts on clothing [34 months] Names friend [45.5 months]
4-6 years	Hops [53.5 months] Balances on each foot, 5 seconds [57 months]	Copies a circle [47 months] Copies a cross [50 months] Copies a square [56 months] Draws person [3 parts – 57.5 months, 6 parts – 62.5 months]	Rote counts to 10 [52 months] Knows functions of objects – cup, pencil, chair [55.5 months] Names 3 colours [63.5 months] Place and count [64 months]	Brushes teeth [51cm] Dresses, with no help [54 months] Brushes teeth, no help [69 months]

The age-appropriate health screening pages follow the developmental checklists.

The child's weight, height and head circumference may be filled here, and charted in the appropriate Growth Charts (page 26-49). A quick physical examination will give the information needed for the health screening. Opportunistic observations of the child's behaviour and responses, as well as of the parent, can also be made.

children who screen positive on the M-CHAT-R will not be diagnosed with ASD, these children are at high risk for other developmental disorders or delays, and therefore, evaluation is warranted for any child who screens positive²².

For these children, a referral for further developmental evaluation would be necessary.

When to Refer

Please refer to Table 6. If red flags are present for ASD, or if there are any concerns regarding speech, language and communication or motor development, the child should theoretically be administered a developmental screen. In our

local context, we currently have the DDST, Singapore, which has been standardised locally, but perhaps not many of us are trained to use it, at this time. Currently, in our setting, a referral to the Child Development Programme at either KKH or NUH may be appropriate.

For children who present quite equivocally, you may want to consider reviewing the child soon, perhaps in the next 1-3 months, to monitor developmental progress. This may help to clarify their developmental status. A decision on whether to make the referral could be made after the review.

FIGURE 4. M-CHAT



www.m-chat.org

Child's name _____ Date _____
Age _____ Relationship to child _____

M-CHAT-R™ (Modified Checklist for Autism in Toddlers Revised)

Please answer these questions about your child. Keep in mind how your child usually behaves. If you have seen your child do the behavior a few times, but he or she does not usually do it, then please answer **no**. Please circle **yes** or **no** for every question. Thank you very much.

- | | | |
|---|-----|----|
| 1. If you point at something across the room, does your child look at it?
(FOR EXAMPLE, if you point at a toy or an animal, does your child look at the toy or animal?) | Yes | No |
| 2. Have you ever wondered if your child might be deaf? | Yes | No |
| 3. Does your child play pretend or make-believe? (FOR EXAMPLE, pretend to drink from an empty cup, pretend to talk on a phone, or pretend to feed a doll or stuffed animal?) | Yes | No |
| 4. Does your child like climbing on things? (FOR EXAMPLE, furniture, playground equipment, or stairs) | Yes | No |
| 5. Does your child make <u>unusual</u> finger movements near his or her eyes?
(FOR EXAMPLE, does your child wiggle his or her fingers close to his or her eyes?) | Yes | No |
| 6. Does your child point with one finger to ask for something or to get help?
(FOR EXAMPLE, pointing to a snack or toy that is out of reach) | Yes | No |
| 7. Does your child point with one finger to show you something interesting?
(FOR EXAMPLE, pointing to an airplane in the sky or a big truck in the road) | Yes | No |
| 8. Is your child interested in other children? (FOR EXAMPLE, does your child watch other children, smile at them, or go to them?) | Yes | No |
| 9. Does your child show you things by bringing them to you or holding them up for you to see – not to get help, but just to share? (FOR EXAMPLE, showing you a flower, a stuffed animal, or a toy truck) | Yes | No |
| 10. Does your child respond when you call his or her name? (FOR EXAMPLE, does he or she look up, talk or babble, or stop what he or she is doing when you call his or her name?) | Yes | No |
| 11. When you smile at your child, does he or she smile back at you? | Yes | No |
| 12. Does your child get upset by everyday noises? (FOR EXAMPLE, does your child scream or cry to noise such as a vacuum cleaner or loud music?) | Yes | No |
| 13. Does your child walk? | Yes | No |
| 14. Does your child look you in the eye when you are talking to him or her, playing with him or her, or dressing him or her? | Yes | No |
| 15. Does your child try to copy what you do? (FOR EXAMPLE, wave bye-bye, clap, or make a funny noise when you do) | Yes | No |
| 16. If you turn your head to look at something, does your child look around to see what you are looking at? | Yes | No |
| 17. Does your child try to get you to watch him or her? (FOR EXAMPLE, does your child look at you for praise, or say "look" or "watch me"?) | Yes | No |
| 18. Does your child understand when you tell him or her to do something?
(FOR EXAMPLE, if you don't point, can your child understand "put the book on the chair" or "bring me the blanket"?) | Yes | No |
| 19. If something new happens, does your child look at your face to see how you feel about it?
(FOR EXAMPLE, if he or she hears a strange or funny noise, or sees a new toy, will he or she look at your face?) | Yes | No |
| 20. Does your child like movement activities?
(FOR EXAMPLE, being swung or bounced on your knee) | Yes | No |

© 2009 Diana Robins, Deborah Fein, & Marianne Barton

In general, refer early if developmental problems are identified, or if the risk for developmental problems is considered to be high.

Difficulties with Monitoring Development and Behaviour

All children are different. So many factors can affect the course of development. Development in a young child can be very dynamic, and the changes may be very rapid. There is always the danger in doing too little versus doing too much. However, "He's a boy!", "He'll grow out of it!" are dangerous statements to make.

On the other hand, as children are so different – there may be individual variability in development, manifestation of particular temperament, environmental circumstances – for example if a child is unwell, hungry or tired - which may conspire to produce a certain behavioural response in the child, on that particular day.

Communicating with Parents

Well child visits always provide a good opportunity to speak with parents and understand their concerns (or lack of), as well as explain our concerns, if any. If there are no concerns, it is still a good opportunity for anticipatory guidance – that is, sharing information that helps families prepare for expected physical and behavioural changes during their child's current and approaching stage of development. Resources for these are shared below.

Sharing Concerns with Parents²³

1. Highlight some of the child's strengths, letting the parent know what the child does well.
2. Use materials such as the health booklet and fact sheets. This will help the parent know that you are basing your comments on facts and not just feelings.
3. Talk about specific findings and behaviours that you have observed.
4. Try to make it a discussion. Pause, give the parent time to think and to respond.
5. Expect that if the child is the oldest in the family, the parent might not have experience to know the milestones that the child should be reaching.
6. Listen and watch the parent to decide how to proceed. Pay attention to tone of voice and body language.
7. This might be the first time that the parent has become aware that the child might have a delay. Give the parent time to think about this and speak with the child's other caregivers, such as a grandmother or domestic helper.
8. The language should be couched around "helping the child optimise his developmental potential" – which is really the main aim for any referrals.

Research has shown that most mothers reported a preference for a nonalarmist style of communication when developmental delays are suspected. In contrast, some mothers preferred a more

TABLE 6. REFERRALS: WHO, WHEN, WHERE

Referrals	
Indications for Referral	
1. History a. Developmental regression or stagnation b. Seizures c. Risk factors, such as prematurity <28 weeks, BW <1500g, history of meningitis etc. 2. Physical examination a. Macrocephaly or microcephaly b. Focal neurologic lesions c. Facial, skin or other lesions suggestive of neurocutaneous or other syndromes 3. Any suspicion of sensory impairment (hearing, vision) 4. Red flags present 5. Developmental checklist limit milestones not met 6. Major and persistent parental concerns, even in the face of normal observation	
Where to Refer	
1. Child Development Programme a. KKH DCD Department of Child Development b. NUH CDU Child Development Unit 2. Paediatric Neurology 3. General Paediatrics 4. Child Psychiatry a. Child Guidance Clinic IMH b. Psychiatry/Psychological Medicine in KKH, NUH, KPTH	Children with developmental-behavioural concerns age below 7, not in mainstream primary or special education school Mainly motor concerns or if a neurologic condition is suspected If only growth is a concern (failure to thrive or short stature) Children with behavioural or mental health concerns who are above age 7 or already attending mainstream primary or special education school

direct style, including the use of labels to help them understand their child's development. The importance of preparation to accept information about developmental delays emerged as a theme in all groups. Elements contributing to preparedness included information about expected developmental skills, suggestions for promoting skills, and a specific time frame for follow-up evaluation. Mothers of children with disabilities perceived that early reassurance of normalcy by providers in response to their concerns led to self-doubt and increased difficulty accepting the diagnosis²⁴.

Local Referral Patterns & Services

Children with developmental and/or behavioural concerns who are below the age of 7, and not yet in mainstream primary school or special education school, can be referred to the Department of Child Development at KKH, or the Child Development Unit at NUH, which both run the Child Development Programme (CDP) in Singapore.

Locally, the vast majority of children are delivered in hospitals. Hence, many of the children who have diagnosed 'syndromes' and significant motor impairments, such as cerebral palsy, are often diagnosed early. They present to, are diagnosed and managed by their neonatologist, geneticist or neurologist. These conditions are not often seen as primary referrals by the developmental paediatricians in the CDP.

The pattern of referrals to the above 2 hospital services in the last 5 years shows a predominance of referrals for delays in speech, language and communication. These account for more than

50% of referrals – including children with speech and language delays and disorders (30-35%), as well as children with autism spectrum disorders (ASD)(20-25%). The 2 other groups of diagnoses seen at presentation are children with global developmental delay (10-15%) and children with behavioural problems (10-12%).

The 2 hospital services provide diagnostic and assessment services, as well as interim intervention services. Please refer to Table 7 for intervention and support services for young children with developmental delay.

CONCLUSION

Every encounter with a child is an opportunity to consider that child's developmental progress. Family Physicians are well placed to detect problems at an early stage, and promote optimal child development because of their ongoing relationship and frequent contact with the child and family.

A framework for developmental surveillance can be helpful, with limit age milestones set after the time of normal milestone acquisition, as set out in the Singapore Child Health Booklet. Thus absence of any one or more items is considered a high risk marker, and indicates consideration for further screening and possibly referral, as does parental or caregiver concern about development at any stage.

There is further work ahead to develop clear guidelines for developmental surveillance and screening in our local context.

TABLE 7. INTERVENTION AND SUPPORT OPTIONS FOR YOUNG CHILDREN WITH DEVELOPMENTAL DELAY *Please refer to <http://www.sgenable.sg/>*

Intervention and Support Options for Young Children with Developmental Delay
Early Intervention Programme for Infants and Children
- Age 0-6, children with moderate-severe developmental delays 17 EIPIC centres island-wide, 3 of which cater to children with ASD - Referral via SG Enable
Integrated Child Care Programme
- Age 2-6, children with mild-moderate developmental delays 17 ICCP centres island-wide - These are regular child care centres, but have specially trained teachers and are able take in a quota of children with mild to moderate needs - Referral via SG Enable
Development Support Programme
- Currently K1, K2 children with mild developmental needs, or at risk - In the midst of rollout to different preschool centres - Provides short-term (maximum 15 weeks), focused (only 1 type of intervention) within the preschool setting - Referral via preschool centre - Children who are in EIPIC or ICCP are not eligible for DSP
Hospital Rehabilitation Services
- The CDP provides assessment and interim intervention services for pre-schoolers with developmental-behavioural concerns - Public hospitals have their rehabilitation units, but not all are able to cater to children with developmental issues
VVO Rehabilitation Centres
- Children's Therapy Centre - Society for the Physically Disabled
Private Intervention and Therapy Centres

REFERENCES

1. Lian WB, Ho SKY, Yeo CL et al. General Practitioners' Knowledge on Childhood Developmental and Behavioural Disorders. *Singapore Med J* 2003; 44: 397.
2. Glascoe FP. Screening for Developmental and Behavioral Problems. *Ment Retard Dev Disabil Res Rev* 2005; 11: 173.
3. Tervo R. Red Flags and Rules of Thumb: Sorting Out Developmental Delay. *Gillette Children's Specialty Healthcare: A Pediatric Perspective* 2009; 18: 1.
4. Hamilton S. Screening for developmental delay: Reliable, easy-to-use tools. *J Fam Pract* 2006; 55: 415.
5. Barnett SW. Long-term effects of early childhood programs on cognitive and school outcomes. *Future Child* 1995; 5:25.
6. Oberklaid F, Drever K. Is my child normal? Milestones and red flags for referral. *Aust Fam Physician* 2011; 40: 666.
7. Sheldrick RC, Perrin EC. Surveillance of Children's Behavior and Development: Practical Solutions for Primary Care. *J Dev Behav Pediatr* 2009; 30: 151.
8. Dosman CF, Andrews D, Goulden K. Evidence-based milestones ages as a framework for developmental surveillance. *Paediatr Child Health* 2012; 17: 561.
9. Leung SSL. The Child Health Programme for Hong Kong. *HK J Paediatr (New Series)* 2008; 13: 275.
10. Lung FW, Chiang TL, Lin SJ et al. Child developmental screening instrument from 6 to 36 months in Taiwan Birth Cohort Study. *Early Hum Dev* 2010; 86:17.
11. Morooka K, Arimoto K, Takagi K et al. Neurodevelopmental Screening Public Health Services. Chapter 27. Screening for Developmental Disorders in Infants. *Neurology and Public Health in Japan: proceedings of the Congress on Neurology and Public Health in Japan, Tokyo, Japan, 26-28 September 1995 / editor-in-chief Kiyotaro Kondo; co-editors, Masao Kanamori* (accessed 7 April 2014). <http://apps.who.int/iris/handle/10665/63537?mode=full>
12. Amar-Singh HSS. International Perspective on Screening and Detection of Disability in Children 2006 (accessed 7 April 2014). <http://www.necimaleaysia.org/newsmaster.cfm?&menuid=6&action=view&retrieveid=6>
13. Blair M, Hall D. From health surveillance to health promotion: the changing focus in preventive children's services. *Arch Dis Child* 2006; 91: 730.
14. Rourke L, Leduc D. Improving the odds for effective developmental surveillance. *Paediatr Child Health* 2012; 17: 539.
15. Council on Children with Disabilities, Section on Developmental Behavioral Pediatrics, Bright Futures Steering Committee. Identifying Infants and Young Children with Developmental Disorders in the Medical Home: An Algorithm for Developmental Surveillance and Screening. *Pediatrics* 2006; 1: 405.
16. Marks K, Glascoe FP, Macias MM. Enhancing the Algorithm for Developmental-Behavioral Surveillance and Screening in Children 0 to 5 years. *Clin Pediatr (Phila)* 2011; 50: 853.
17. Lim HC, Chan T, Yoong T. Standardisation and Adaptation of the Denver Developmental Screening Test (DDST) and Denver II for Use in Singapore Children. *Singapore Med J* 1994; 35: 156.
18. Lim HC, Ho LY, Goh LY et al. The Field Testing of Denver Developmental Screening Test, Singapore: A Singapore Version of the Denver II Developmental Screening Test. *Ann Acad Med*

Singapore 1996; 25: 200.

19. Personal Communication. KKH DCD Physicians and Psychologists. April 2014.
20. Kiing J, Low PS, Chan YH et al. Interpreting Parents' Concerns about Their Children's Development With The Parents Evaluation of Developmental Status: Culture Matters. *J Dev Behav Pediatr* 2012; 33: 179.
21. Enabling Masterplan 2012-2016 (accessed 24 March 2014). [http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling%20Masterplan%202012-2016%20Report%20\(8%20Mar\).pdf](http://app.msf.gov.sg/Portals/0/Topic/Issues/EDGD/Enabling%20Masterplan%202012-2016%20Report%20(8%20Mar).pdf)
22. <https://www.m-chat.org> (accessed 8 April 2014).
23. www.cdc.gov/actearly (accessed 8 April 2014).
24. Sices L, Egbert L, Mercer MB. Sugar-coaters and Straight Talkers: Communicating about Developmental Delays in Primary Care. *Pediatrics* 2009; 124: e705.

RESOURCES

Provide Information and Anticipatory Guidance

HEALTH PROMOTION BOARD

Healthy Start For Your Baby

<http://www.hpb.gov.sg/HOPortal/health-article/12206>

Healthy Start For Your Growing Child

<http://www.hpb.gov.sg/HOPortal/health-article/12294>

EARLY CHILDHOOD DEVELOPMENT AGENCY

Growing with Your Child booklet

<http://www.ecda.gov.sg/growatbeantalk/Pages/articledetail.aspx?type=4&category=Growing+With+Your+Child+Booklet>

Care & Development: A Resource for Parents of Children with Developmental Needs

<http://www.ecda.gov.sg/growatbeantalk/Pages/ArticleDetail.aspx?type=4&articleid=145>

<http://www.childcarelink.gov.sg/ccls/uploads/MSF-ChildDevelopment-Booklet.pdf>

CENTERS FOR DISEASE CONTROL AND PREVENTION USA

Learn the Signs. Act Early

<http://www.cdc.gov/ncbddd/actearly/milestones/index.html>

MINISTRY OF HEALTH

AMS-MOH Clinical Practice Guideline on Autism Spectrum Disorders in Preschool Children 2010

http://www.moh.gov.sg/content/moh_web/healthprofessionalsportal/doctors/guidelines/cpg_medical/2010/cpgmed_autism_spectrum_disorders_preschool_children.html

Summary

[http://www.moh.gov.sg/content/dam/moh_web/HPP/Doctors/cpg_medical/current/2010/ASD%20CPG\(Card\).pdf](http://www.moh.gov.sg/content/dam/moh_web/HPP/Doctors/cpg_medical/current/2010/ASD%20CPG(Card).pdf)

Patient Version

http://www.moh.gov.sg/content/dam/moh_web/HPP/Doctors/cpg_medical/current/2010/Autism%20Spectrum%20D.pdf

LEARNING POINTS

- **Developmental delays are common.**
- **Use the developmental checklists and red flags in the health booklet at every immunisation and well child visit.**
- **Early detection of developmental delays lead to referral for assessment and appropriate early intervention, which is important and can influence outcomes.**
- **Avoid 'waiting and watching'. Refer early if there are any concerns.**

PERSONS WITH INTELLECTUAL DISABILITIES AND AUTISM SPECTRUM DISORDERS

Dr Diana Ruth Andrea Barron, Dr Wei Ker-Chiah

ABSTRACT

People with intellectual disability and autism spectrum disorder are vulnerable to the same spectrum of mental and physical illness as the general population. Due to unique challenges, they remain at risk of health inequalities resulting in elevated mortality from preventable causes. This article aims to equip the primary physician with greater familiarity and understanding of the varied needs for this sub-group of patients and hence supporting them to lead healthier lives.

Keywords: Autism spectrum disorder, Assessment, Intellectual disability, Mental health, Primary care, Physical health, Singapore

SFP2014; 40(2): 34-42

INTRODUCTION

At the time of writing the population of Singapore was 5.4 million¹. The worldwide prevalence of intellectual disability is estimated to be 10.37/1000². While there is no current data about Autism Spectrum Disorders (ASD) in Singapore, worldwide, we are experiencing an increase in the number of people affected by ASD; in the USA 1 in 88 children are affected by autism³.

Given that each General Practitioner (GP) in Singapore sees an average of around 1000 patients a month⁴, the number of people with developmental disabilities a GP sees is estimated to be definitely more than 10 per month.

International studies show that this group remains at risk of health inequalities, both in third world and first world health contexts, resulting in elevated mortality from preventable causes. There are 5 factors that lead to health inequalities for this group described by Emerson and Baines (2010)⁵:

1. Adults with Intellectual Disabilities are more likely to be exposed to the social determinants of poor health including poverty, poor housing, unemployment and social disconnectedness.
2. There is an increased risk of health problems that are associated with the specific genetic and/or biological causes of learning disabilities.
3. Impaired communication skills and reduced literacy limits the ability of people with intellectual disability to report

problems and symptoms to others, to seek help, to understand and access health education and health information

4. There are increased personal health risks and behaviours such as poor diet and lack of exercise, which can be due to intrinsic factors of the individual or the restricted opportunities available both within institutions and the community.

5. There is a worldwide deficiency relating to access to healthcare provision for individuals with intellectual disabilities.

Of these only points 2-4 are potentially modifiable by adapting our practice within the primary care context.

This paper aims to help practitioners to tackle these barriers by equipping the reader with the following:

- A familiarity with the terms Intellectual Disability and Autism Spectrum Disorders
- An understanding of the physical and mental health problems commonly encountered in clinical practice
- An overview of the medical and behavioural assessments of persons with intellectual disability

OVERVIEW OF TERMS: INTELLECTUAL DISABILITY AND AUTISM SPECTRUM DISORDERS

Definition

Intellectual disability is defined by the World Health Organization (WHO) as

“a significantly reduced ability to understand new or complex information and to learn and apply new skills (impaired intelligence). This results in a reduced ability to cope independently (impaired social functioning), and begins before adulthood, with a lasting effect on development. Disability depends not only on a child’s health conditions or impairments but also and crucially on the extent to which environmental factors support the child’s full participation and inclusion in society.”

The use of the term intellectual disability in the context of the WHO initiative “Better health, better lives” also included both those with autism who have intellectual impairments and those who due to placement in institutions or family rejection, acquire developmental delays and psychological problems.

(Source: WHO (2010) Better health, better lives: children and young people with intellectual disabilities and their families. 26 November 2010)

(1) Intellectual Disability

Intellectual Disability is a diverse condition that encompasses a very broad range of presentations. The condition is therefore

DIANA RUTH ANDREA BARRON,
Consultant, Institute of Mental Health

WEI KER-CHIAH,
Consultant and Head of Adult Neurodevelopmental Service,
Institute of Mental Health

TABLE 1. A CLINICAL PICTURE OF ADULTS WITH INTELLECTUAL DISABILITY

Mild IQ 50-69 (85-87%) 'Equivalent' to 9 - 12 years	<u>Communication</u>: Some delay in language acquisition, most individuals are able to use speech for everyday purposes, for example to hold conversations, and to engage in the clinical interview. <u>Independent living skills</u>: Most individuals will achieve full independence in self-care (eating, washing, dressing, bowel and bladder control) and in practical and domestic skills. Main difficulties are seen in academic schoolwork, and many have particular problems in reading and writing. Potential benefit from education designed to develop their skills and compensate for their handicaps. <u>Employment</u>: Most of those with milder intellectual impairment are potentially able to maintain employment including unskilled or semi-skilled manual labour. <u>Socio-emotional</u>: There can be noticeable emotional and social immaturity, which can lead to difficulties for example inability to cope with the demands of marriage, or child-rearing, or difficulty fitting in with cultural traditions and expectations, will be apparent. Aetiology of mental retardation is more commonly unknown/idiopathic for this group this group
Moderate IQ 35-49 (6-10%) 'Equivalent' to 6 - 9 years	<u>Communication</u>: There is marked delay in developing comprehension and use of limited language. There is wide variation in language within this group, with some individuals able to participate in simple conversation and others only being able to communicate their basic needs. <u>Independent living skills</u>: There is also a delay in achievement of self-care and motor skills often requiring supervision throughout life. Completely independent living in adult life is rarely achieved. Progress in academic work is limited, but a proportion of individuals learn the basic skills needed for reading, writing, and counting. Educational programs can provide opportunities for them to develop their potential and to acquire some basic skills <u>Employment</u>: It is possible to maintain work doing simple practical work, if the tasks are carefully structured and skilled supervision is provided. <u>Socioemotional</u>: Most individuals are fully mobile and physically active and the majority show enjoy social development by developing contact with others, to communicate with others, and, engaging in simple social activities Aetiology for intellectual disability and co-morbidities become more common with increasing severity of Intellectual Disability and decreasing IQ.
Severe IQ 20-34 (3.5%) 'Equivalent' to 3 - 6 years	This category is broadly similar to that of moderate mental retardation in terms of the clinical picture. However, in addition many individuals with severe intellectual disabilities suffer from a marked degree of motor impairment or other associated deficits, indicating the presence of possible damage to, or, abnormal development of neurological system. Such individuals are usually dependent on others for all basic skills such as self-care.
Profound IQ less than 20 (1%) 'Equivalent' to below 3 years	The IQ in this category is estimated to be less than fewer than 20, which means in practice that affected individuals are severely limited in their ability to understand or comply with requests or instructions. <u>Communication</u>: Comprehension and use of language is limited to, at best, understanding basic. Most language is limited to non-verbal understanding of basic commands or making simple requests. <u>Independent living skills</u>: Individuals may be able to undertake the most basic and simple visuo-spatial skills of sorting and matching may be acquired, and the affected person may be able with appropriate supervision and guidance to take a small part in domestic and practical tasks. Most individuals are immobile or severely restricted in mobility, incontinent, often there is little or no ability to care for their own basic needs, and require constant help and supervision.
(Adapted from ICD-10 Guide for Mental Retardation 1996)	

sub-classified into Mild, Moderate, Severe and Profound severity. Adaptive function rather than IQ alone increasingly determines the severity of Intellectual Disability and this is reflected by the changes in the DSM5 6 classification system. Adaptive function refers to an individual's ability to interact with their environment independently and comprises skills such as communication, reading, writing, arithmetic, reasoning, knowledge, memory, empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships. Further to this are impairments in self-management in areas such as personal care, job responsibilities, money management, recreation, to name but a few and organizing tasks⁷. Clearly each individual with ID will present with a unique constellation of abilities and impairments. Please see table 1 for clinical picture ID.

Individuals with intellectual disabilities often show specific impairments that appear disproportionate to their overall level of functioning, for example there may be a difference between verbal and nonverbal IQ as determined by psychometric

testing. This may lead to the consideration of specific learning disabilities such as dyslexia, social communication disorders or Autistic Spectrum Disorder.

(2) Autism Spectrum Disorders

Autism Spectrum Disorders (ASD) are classified within the DSM-5⁸. The alternative classification system, ICD-10⁹, codes these conditions under the umbrella term Pervasive Developmental Disorders and includes conditions such as Childhood Autism, Atypical Autism, and Asperger's Syndrome. At the time of publication, the systems of classification were being revised, with the forthcoming ICD-11 and the recent publication of the DSM-5. For this reason the following text will be based on DSM-5 classificatory system. The key features of ASD are: impairment of social communication and interaction, restricted, repetitive patterns of behavior, interests or activities present since early childhood and causing significant impairment in the social occupational or other important areas of functioning. Please see table 2 for the DSM-5 diagnostic criteria for ASD.

TABLE 2. DSM-5 DIAGNOSTIC CRITERIA FOR AUTISM SPECTRUM DISORDER

A Persistent deficits in communication and social interaction		B Restricted repetitive patterns of behavior, interests or activities	
Examples:		Examples:	
1. Deficits in social-emotional reciprocity, ranging, for example, from abnormal social approach and failure of normal back-and-forth conversation; to reduced sharing of interests, emotions, or affect; to failure to initiate or respond to social interactions		1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases)	
2. Deficits in nonverbal communicative behaviors used for social interaction, ranging, for example, from poorly integrated verbal and nonverbal communication; to abnormalities in eye contact and body language or deficits in understanding and use of gestures; to a total lack of facial expressions and nonverbal communication		2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns or verbal nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat food every day).	
3. Deficits in developing, maintaining, and understanding relationships, ranging, for example, from difficulties adjusting behavior to suit various social contexts; to difficulties in sharing imaginative play or in making friends; to absence of interest in peers		3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interest).	
4. Hyper- or hypo reactivity to sensory input or unusual interests in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).			
C Symptoms must first present in early childhood	D Symptoms cause clinically significant impairment in social, occupational and other areas of functioning	E Impairments are not better explained by intellectual disability or global developmental delay.	

Individuals with ASD can have normal intelligence though many also have Intellectual Disability. This can present difficulties when making a diagnosis of ASD in people with Moderate to Profound Intellectual Disability, who often share many of the impairments and behaviours described in ASD, but which are also proportionate to an individual's overall level of functioning. In this case the diagnosis is less likely to be ASD.

PHYSICAL AND MENTAL HEALTH PROBLEMS COMMONLY ENCOUNTERED IN CLINICAL PRACTICE

People with Intellectual Disabilities are at elevated risk of most physical and mental health diagnoses encountered in medicine.

Common physical health co morbidities for people with ID are epilepsy with a prevalence of between 20-50%, the prevalence increases with severity of Intellectual disability, coronary Heart disease 14-20% and respiratory disease 46-52%. Furthermore there is a marked increase in sensory impairment such as hearing

impairment affects 40% of adults with ID and visual impairment is 8 times more common than in the general population. A recent Singaporean study¹⁰ of adults with ID resident in Singapore showed that among adults with ID, 15.9 % had hypertension (compared to a national average of 16.7%), 7.5% had diabetes mellitus type 2 (12.1% national average) and 17.6% (18% national average) had a history of dyslipidemia. Mental health diagnoses are similarly over-represented in people with intellectual disabilities, in particular affective disorders, schizophrenia and dementia. (See Table 3 for further details).

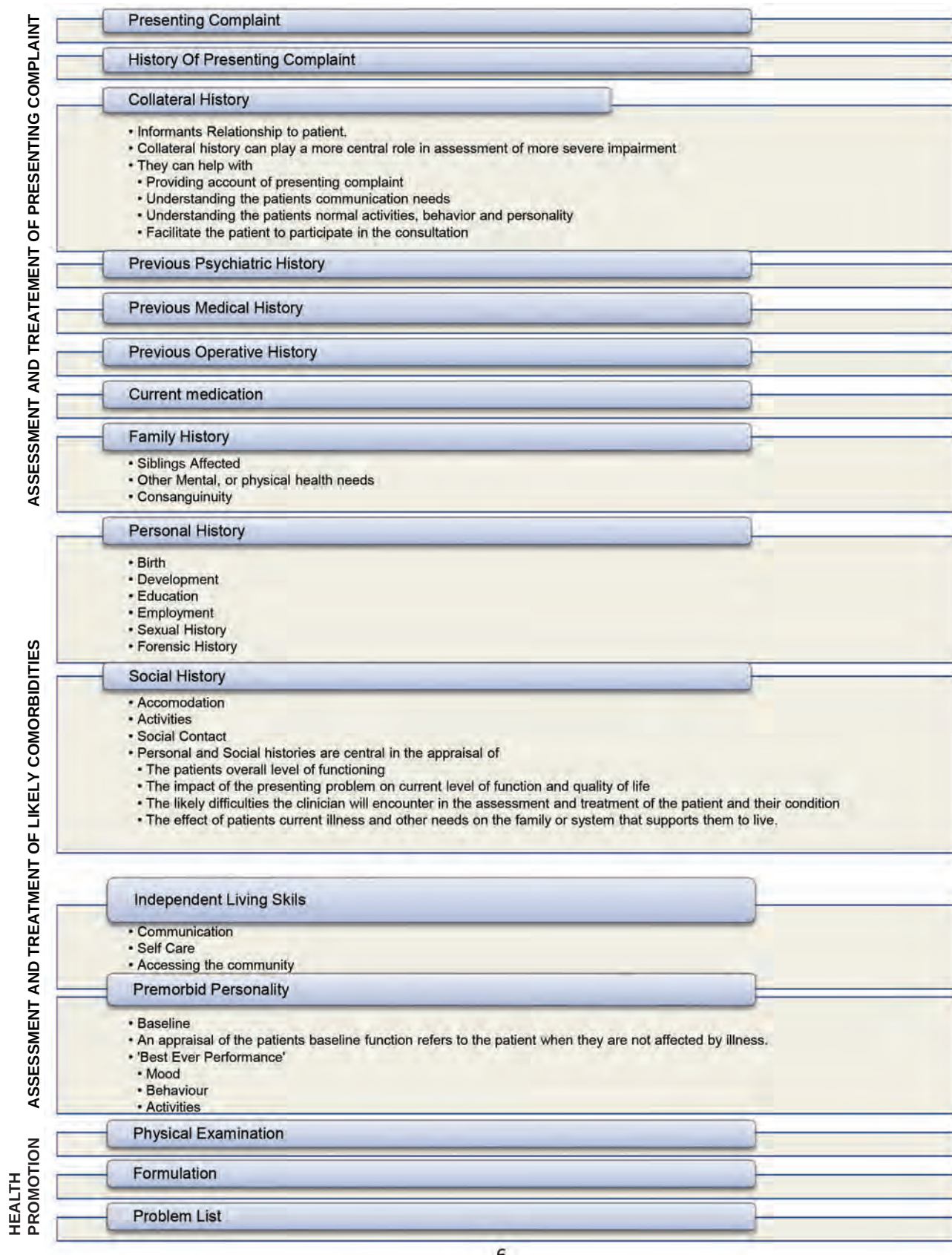
THE ASSESSMENT OF PERSONS WITH INTELLECTUAL DISABILITY (FIGURE 1)

The assessment of an individual with intellectual disability can be more complex than other assessments however the objectives of the consultation remain the same as for any other patient these are first, the assessment and treatment of the presenting complaint, second the assessment and treatment of any likely co morbidities, and thirdly health promotion¹⁵.

TABLE 3. PHYSICAL AND MENTAL HEALTH

Physical health	Wee et al 2013 (Singapore) ¹¹	Lin et al 2004 (Taiwan) ¹²	Emerson and Baines 2011 (UK) ¹³	Cooper et al 2007(UK) ¹⁴
Epilepsy		23.5		
Coronary Heart disease		7.5	14-20%,	
Respiratory disease		3.1	46-52%.	
Hearing impairment affects		8.5	40%	
Vision		16.5		
Hypertension	15.9%	0.5%		
Diabetes Mellitus type 2	7.5%			
Dyslipidemia	17.6%			
Mental health any type				40.5
Autism				7.5
Psychotic disorder		4.5		4.4
Affective disorder				6.6
Anxiety disorder				3.8
OCD				0.7
ADHD				1.5
Personality disorder				1.0
Sleep disorder				0.6

FIGURE 1. CLINICAL ASSESSMENT



The reasons for the added complexity are many and can arise from many sources, including those that are intrinsic to the individual, their physician and their environment. It is helpful to gain an understanding of these difficulties to better inform the assessment process and the consequent differential diagnosis.

The key barriers to the clinical assessment of people with Intellectual Disability were described previously by Sovner¹⁶ and elaborated upon by several other key authors. These barriers are usually described within the context of the psychiatric assessment of mental illness. Here we consider the impact of

these barriers in the family practitioner's assessment of people with Intellectual Disabilities within a primary care setting. For a more detailed description of these process see Psychiatry of Intellectual Disability: A Practical Manual ¹⁷.

(1) Communication impairment

Communication uses the combination of hearing, language, and speech in order to send, receive and understand messages. Communication in the average population occurs through five key modalities: listening, watching, speaking, reading, and writing. Among people with Intellectual disability the rate of development and final achievement levels of communication may be slower and more limited than that of the general population. Generally communication skills improve with increase in IQ. This means that individuals with mild intellectual disability may be able to understand and express themselves independently but might find difficulties understanding the written word for example. An individual with moderate Intellectual disability may have a more restricted understanding of vocabulary in both receptive and expressive language. There is also an increase in the frequency of visual and hearing impairments, as severity of intellectual disability increases, which further inhibit effective communication with people with intellectual disabilities.

Learning point: Many measures can be taken to enhance communication with people with Intellectual Disabilities. Provide written material in an accessible format using language and pictures that are appropriate to the developmental level of the individual. Frequently written information provided by drug companies for example is written in complex language format, such information is often not accessible for many adults in the population including those with intellectual disabilities.

(2) Intellectual distortion

Intellectual distortion occurs when the individual's cognitive development limits their ability to comprehend abstract concepts such as idioms. As such symptoms may be difficult to elicit because of these deficits for example when interviewing an individual about the autonomic features of anxiety idioms and phrases such as 'butterflies in the stomach', 'dry mouth' might not be understood and the patient may therefore respond inaccurately.

Learning point: Consider your patient's developmental level when assessing the patient. Is he able to comply with your instructions e.g. "point to where the pain is" An individual with severe or profound intellectual disability may not be able to localize pain, this does not mean that an individual is unable to perceive pain. Often behavioral change can be caused by physical discomfort such as toothache, earache, or constipation. As such a thorough physical examination is an indispensable part of any assessment of an individual with Intellectual Disability.

(3) Psychosocial masking

Psychosocial masking is the phenomena where by an individual's limited social experiences impact upon the content of the

symptoms that they express. This is seen frequently in psychiatric assessments, for example in mania. Mania is characterized by elevated mood and frequently associated with delusions of grandeur, within the general population a typical grandiose delusion may be that an individual believes they are a senior academic with multiple degrees. For individuals with mild intellectual disabilities delusions may appear to be subtler, for example, the belief that the individual has many friends, can drive a car or wishes to be an air-hostess. As an interviewer, it is easy to miss such symptoms of elated mood and assume that these are reasonable ambitions and beliefs.

Learning point: Difficulties differentiating between a grandiose delusion and a reasonable ambition or belief may be reduced, in part, by testing the individual's understanding of their statements and seeking a collateral history from the family to identify if these beliefs and preferences are long standing or if they are intermittent or new which would point towards the possibility of a change in mental state suggestive of mental illness.

(4) Cognitive disintegration

Cognitive disintegration refers to the impact of a decreased ability to tolerate stress, which can lead to anxiety-induced decompensation presenting as frank psychosis. This phenomenon relates to the Yerkes-Dobson observation that performance generally improves with stress until performance reaches a plateau. If stress continues to increase eventually productivity reduces precipitously and is associated with the experience of anxiety. For a more detailed description of these processes see Gentile and Gillig (2010) Psychiatry of Intellectual Disability: A Practical Manual ¹⁸.

Learning point: In people with ID it has been postulated that the threshold at which productivity declines may be lower and triggered by stressors such as a change in care giver, the death of a relative, pain, or another stressor. It is important therefore to take a thorough history that incorporates thorough consideration of socio environmental and psychological factors that could increase stress experience by an individual.

(5) Baseline exaggeration

Baseline exaggeration refers to changes in the severity or frequency of chronic maladaptive behavior associated with the onset of an illness. Many individuals with Intellectual Disabilities have behaviours that deviate from that expected of an individual without intellectual disability, for example sensory seeking behaviours such as rocking or self talking which do not indicate mental or physical illness per se. Often families will attend clinic and describe these behaviours as long standing and details about changes in these behaviours can be missed.

Learning point: A history of an increase in frequency, duration or severity of a baseline behavior can be an indication of change in mental or physical health and should be investigated.

(6) Diagnostic overshadowing

Diagnostic overshadowing is the tendency in the clinician to overlook symptoms of one disorder by attributing them to

another. This has been described in relation to the tendency to overlook symptoms of mental illness and attributing them to intellectual disability. It is possible for this phenomenon to occur in any condition and as clinicians doctors must be aware of the potential to make this kind of error and seek support from peers either through clinical supervision, support or reflective practice to minimize the risk of this type of diagnostic error.

Learning point: Consider the developmental level of the individual when examining a patient with intellectual disability.

(7) Misdiagnosis of developmentally appropriate phenomenon

Misdiagnosis of developmentally appropriate phenomenon, described by Hurley in 1996, occurs when a diagnosis is made based on behaviours that are inappropriate to an individual's chronological age but are proportionate to their cognitive ability. An example of this is the diagnosis of antisocial personality disorder in an individual with severe intellectual disability. In this scenario, diagnostic criteria for antisocial personality disorder include lack of feelings of guilt; a typically developing child acquires the cognitive ability to understand and express guilt at the age of 6 years, whereas an individual with severe intellectual disability is functioning at the age equivalent of a child between the ages of less than 6 years.

Learning point: In situations such as these, it is useful to request a detailed assessment of adaptive and intellectual function to better understand the validity of the proposed diagnoses.

(8) Suggestibility and Acquiescence

Suggestibility refers to the increased likelihood of believing another person's information and adapting behaviour

accordingly. For example, during police interrogation, an individual maybe offered a hypothetical scenario to help them explain their case better, however, the individual may then adopt the hypothetical scenario as their own thus increasing the risk of them providing an inaccurate history. Acquiescence is related to the above concepts of passing and suggestibility. It relates to the increased likelihood of providing an answer according to perceived social desirability, so called yea-saying, for example, when the doctor asks "Are you feeling better now?".

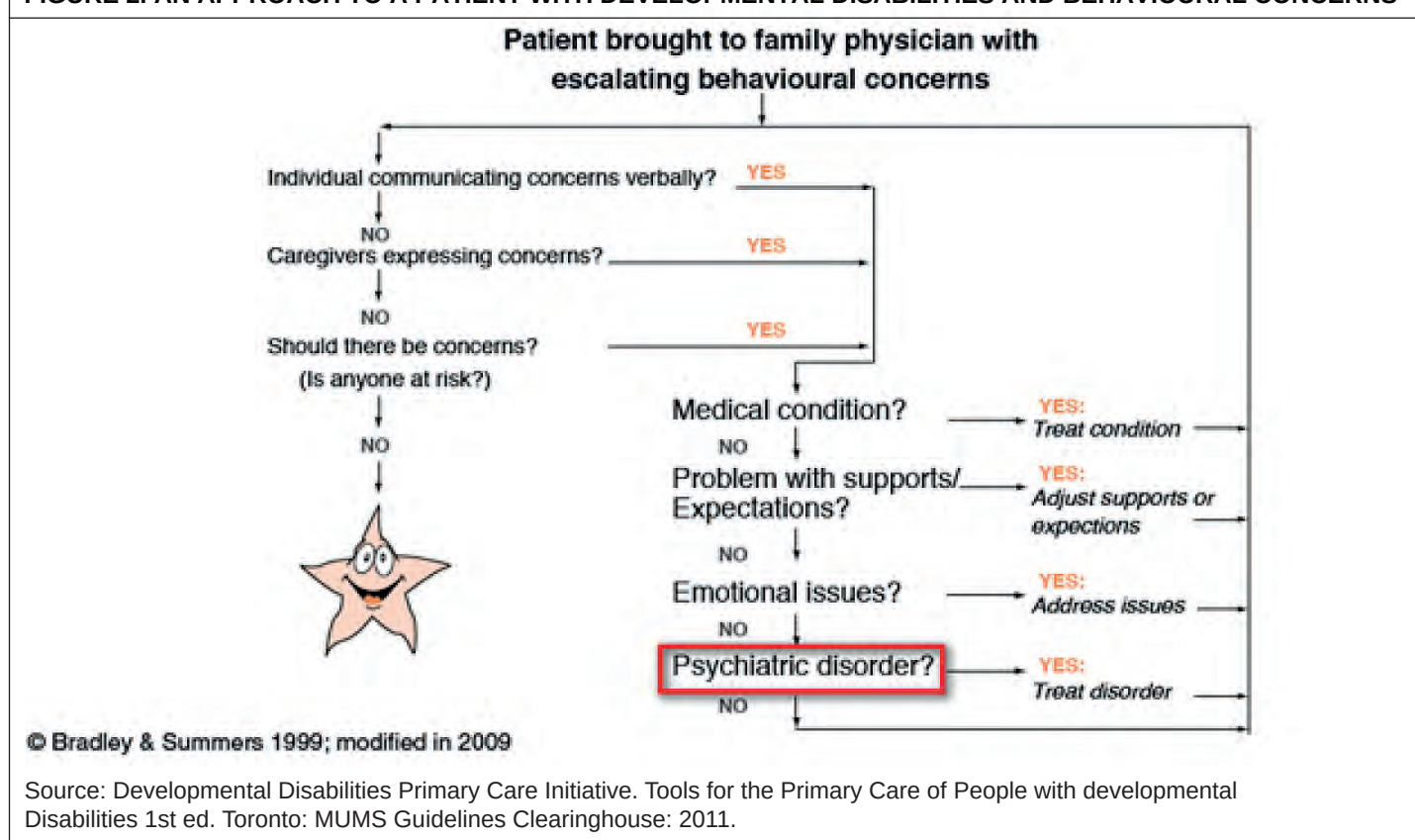
Learning point: It is difficult to assess suggestibility and acquiescence during a brief clinical interaction. 'Bedside tests' include eliciting the individual's responses to absurd statements, contradictory paired-statements and concurring paired-statements.

(9) Behavioural Correlates

Behavioural correlates are the behavioural manifestations of symptoms that the patient may or may not be able to report themselves. An example of this is dry mouth; the patient is unable to describe this symptom to the doctor, however the carer reports that the individual with ID drinks more water than previously. Another example of this is self-harm. Banging ear with fist suggests ear infection in an individual who is unable to verbalise pain.

Learning point: Be mindful that behaviours are often exhibited as a communication of an underlying physical symptom for example and individual banging his ear with his fists suggests ear infection in an individual who is unable to verbalise pain.

FIGURE 2. AN APPROACH TO A PATIENT WITH DEVELOPMENTAL DISABILITIES AND BEHAVIOURAL CONCERNS



AN APPROACH TO A PATIENT WITH DEVELOPMENTAL DISABILITIES AND BEHAVIOURAL CONCERNS (FIGURE 2)

A person with a Developmental Disability often presents to the General Practitioner with behavioural problems, such as aggressive or self-injurious behaviours. Figure 2 shows a simple approach one can take to formulate the reasons for the behavioural issues so that appropriate interventions can be carried out. Besides symptoms such as pain that may present as behavioural correlates as stated above, problem behaviours can also be brought about by a relative lack of support for the disability, such as a noisy or over-stimulating environment for someone with sensory modulation issues. In addition, people with a developmental disability are also as, or more, sensitive to the psychological impact of losses, transitional or traumatic events as people without disability, and problem behaviours can be the result of an emotional response or maladaptive coping strategies to these. For example, someone who has had a traumatic experience with being physically or sexually abused could hit out easily at people who remind him or her of the past perpetrators. Finally, problem behaviours could be a result of psychiatric comorbidities such as a psychotic disorder, anxiety or depression. Being aware of the above issues in clinical assessment could help in accurately diagnosing these, and for someone with a mild disability; it should be similar to diagnosing psychiatric conditions as in the general population. For someone with a more severe disability or if difficulties persist, it might be more helpful to seek the opinion of a psychiatrist when it comes to this stage of assessment.

CONCLUSION

This paper demonstrates that people with Intellectual disability are vulnerable to the same spectrum of physical and mental illness as the rest of the population at large. We have also seen that the way people with Intellectual Disabilities express their symptoms or manifest the signs of disease are diverse and can be atypical. This means that assessing clinicians are required to be vigilant, thorough and astute in their appraisal of patients with intellectual disabilities who present to their surgery. Working in this way practitioner will gain greater familiarity with the viewpoint of people with intellectual disabilities about their patients' own health and appraisal of quality of life. Equipped with this knowledge health care providers can maximise the individual's health and opportunities to demonstrate the many valuable contributions that this group can make to their families and our community in Singapore.

Acknowledgements

The authors also wish to thank Dr Jyoti Singh for proof-reading this article.

REFERENCES

1. Department of Statistics, Ministry of Trade & Industry, Republic of Singapore 2013 (Department of Population Trends 2013)
2. Maulik P. K., Mascarenhas M. N., Mathers C. D., Dua T. and Saxena S (2011) Prevalence of intellectual disability: a meta-analysis of population-based studies *Res Dev Disabil* 32(2): 419-36
3. Centers for Disease Control and Prevention, DC. Prevalence of Autism Spectrum disorders – Autism and Developmental Disabilities Monitoring Network, 14 sites, United states Morbidity and Mortality Weekly Report 2008 61(No SS-3): 1-19
4. Wong CY, Tan K, Foo G, Chua A, Lee Y V, Wong T H, Chong Y W. 2006 Survey of GP Clinic Practice Costs in Singapore.
5. Emerson E and Baines S (2010b) Health inequalities and people with learning disabilities in the UK: 2010. Improving Health and Lives: Learning Disabilities Observatory.
<http://www.improvinghealthandlives.org.uk/publications>
6. American Psychiatric Association. Diagnostic and statistical manual of mental disorders. 5th edition Washington DC: American Psychiatric Association 2013
7. DSM 5
8. DSM 5
9. International Statistical Classification of Diseases and Related Health Problems 10th Revision World Health Organization (2010) ICD-10 Version: 2010, International Statistical Classification of Diseases and Related Health Problems 10th Revision. WHO: Geneva
10. Liang En Wee, Gerald CH Koh, Linda S Auyong, Angela LK Cheong, Thant Myo, Jingyi Lin, Esther MK Lim, Serene XY Tan, Sridevi Sundaramurthy, Chu Wen Koh, Prabha Ramakrishnan, Reena Aariyapillai-Rajagopal, Hemamalini Vaidynathan-Selvamuthu, Ma MaKhin (2013) The Medical, Functional and Social Challenges Faced by Older Adults with Intellectual Disability *Annals Academy of Medicine* July 2013, 42 (7) 338-349
11. Liang En Wee, Gerald CH Koh, Linda S Auyong, Angela LK Cheong, Thant Myo, Jingyi Lin, Esther MK Lim, Serene XY Tan, Sridevi Sundaramurthy, Chu Wen Koh, Prabha Ramakrishnan, Reena Aariyapillai-Rajagopal, Hemamalini Vaidynathan-Selvamuthu, Ma MaKhin (2013) The Medical, Functional and Social Challenges Faced by Older Adults with Intellectual Disability *Annals Academy of Medicine* July 2013, 42 (7) 338-349
12. Jin-Ding Lin¹*, Pei-Na Lee², Chia-Feng Yen³, and Jia-Ling Wu³ 2003 The Health Status Profile of Persons with Intellectual Disability in Institutions in Taiwan *J Med Sci* 2003;23(5):285-290 Jin-Ding Lin, et al. <http://jms.ndmctsgh.edu.tw/2305285.pdf>
13. Health Inequalities & People with Learning Disabilities in the UK: 2011
Eric Emerson, Susannah Baines, Lindsay Allerton and Vicki Welch 2011 Department of health accessed on line at <http://www.improvinghealthandlives.org.uk/>
14. Cooper SA1, Smiley E, Morrison J, Williamson A, Allan L. 2007 Mental ill-health in adults with intellectual disabilities: prevalence and associated factors *Br J Psychiatry*. 2007 Jan; 190:27-35.
15. Blake and Kerr (2011). Assessment in Primary Care
<http://www.intellectualdisability.info>
16. Sovner R. Limiting factors in using DSM-III criteria with mentally ill/mentally retarded persons. *Psychopharmacol Bull*. 1986; 22:1055-1059.
17. Gentile and Gillig (2012) *Psychiatry of Intellectual Disability: A Practical Manual* Wiley-Blackwell
18. Gentile and Gillig (2012) *Psychiatry of Intellectual Disability: A Practical Manual* Wiley-Blackwell
19. Developmental Disabilities Primary Care Initiative. Tools for the Primary Care of People with developmental Disabilities 1st ed. Toronto: MUMS Guidelines Clearinghouse: 2011.

LEARNING POINTS

- Many measures can be taken to enhance communication with people with Intellectual Disabilities by ensuring written material is presented using language and pictures that are appropriate to the developmental level of the individual.
 - Consider your patient's developmental level when assessing the patient. Is he able to comply with your instructions e.g. "point to where the pain is" An individual with severe or profound intellectual disability may not be able to localize pain, this does not mean that an individual is unable to perceive pain. Often behavioral change can be caused by physical discomfort such as toothache, earache, or constipation. As such a thorough physical examination is an indispensable part of any assessment of an individual with Intellectual Disability.
 - Difficulties differentiating between a grandiose delusion and a reasonable ambition or belief may be reduced, in part, by testing the individual's understanding of their statements and seeking a collateral history from the family to identify if these beliefs and preferences are long standing or if they are intermittent or new which would point towards the possibility of a change in mental state suggestive of mental illness.
 - In people with ID it has been postulated that the threshold at which productivity declines may be lower and triggered by stressors such as a change in care giver, the death of a relative, pain, or another stressor. It is important therefore to take a thorough history that incorporates thorough consideration of socio environmental and psychological factors that could increase stress experience by an individual.
 - A history of an increase in frequency, duration or severity of a baseline behavior can be an indication of change in mental or physical health and should be investigated.
 - Consider the developmental level of the individual when examining a patient with intellectual disability.
 - In situations where it is not clear whether antisocial behaviour is due to antisocial personality or severe intellectual disorder, it is useful to request a detailed assessment of adaptive and intellectual function to better understand the validity of the proposed diagnoses.
 - It is difficult to assess suggestibility and acquiescence during a brief clinical interaction. 'Bedside tests' include eliciting the individual's responses to absurd statements, contradictory paired-statements and concurring paired-statements.
 - Be mindful that behaviours are often exhibited as a communication of an underlying physical symptom for example an individual banging his ear with his fists suggests ear infection in an individual who is unable to verbalise pain.
-

ABSTRACT

In Singapore and worldwide, large numbers of people live with disabling illness. In the first part of this paper, we address the assessment of activities of daily living (ADL). Disability charting is important as a clinical tool to document functional recovery as well as to assess the effectiveness of medical and rehabilitation interventions. Disability assessment is also important epidemiologically, in developing social policies, planning disability resources and in medical research and education. We review the concepts and general principles of disability assessment with reference to the WHO International Classification of Functioning, Disability and Health (ICF) as well as to local contexts. We also describe in further detail 6 basic ADLs of feeding, dressing, toileting, transfers and mobility used in disability-related national schemes.

In the second part of this article, we introduce how the concepts of frailty have changed the paradigm in which we approach geriatric rehabilitation, through interactive overlaps with the psychosocial, disability and comorbidity domains. We describe the consequences of functional deterioration in the frail elderly, and how to screen for frailty. We also outline therapeutic exercise as a form of prehabilitation to improve the resilience of these vulnerable people and possibly return them to robust health. Family physicians are best equipped in the management of frailty, as they have the holistic and comprehensive medical skill set to treat the associated comorbidity, disability and psychosocial domains in integrative geriatric rehabilitation.

Keywords: Functioning, disability and health, disability assessment, disability charting, basic activities of daily living, frailty

SFP2014; 40(2): 43-55

INTRODUCTION

The World Health Organization (WHO) recently published the World Report on Disability¹. This landmark paper reports that the burden of global disability is staggering, with an estimated one billion people or 15% of the world's population experiencing mental or physical disabilities^{1,2}. Further, 190 million people worldwide have severe disabling illness which impact considerably on survival, daily function, employment and quality of life².

The prevalence of disability in Singapore is rapidly increasing for two major reasons. Advances in acute medical care result in

a larger proportion of patients with chronic diseases surviving with residual impairments and disability. In addition, the ageing of the population also results in the exponential increase of the disability burden due to the direct association of increased chronic disease incidence with the more elderly³. However, it is a common misconception that disability only occurs in the elderly and preliminary local data indicate there are large numbers of disabled younger adults as well, particularly with stroke, spinal cord and traumatic brain and musculoskeletal injuries⁴.

Disability results not only in individual loss of self-esteem and quality of life, but also increases tremendously the social and financial burdens of their involved families, society and the country-at-large⁵. Families need to adjust their expectations and care for the disabled, resulting in changes of family routine and activities, as well as often a loss of income as a direct or indirect consequence of loss of time available for remunerative employment^{5,6}.

OVERVIEW AND FRAMEWORK OF DISABILITY ASSESSMENT

The need for accurate determination of disability arose in the early 1900s during the industrial revolution whereby a worker sustaining a work-related injury resulting in a medical impairment which affected his employability could seek redress from the courts⁷. This led to the development of workers' compensation systems in many countries and the Ministry of Labor in Singapore has recently released updated guidelines⁸. Accurate determination of disability became essential because of the direct correlation between the degree of disability and quantum of financial remuneration common in these guidelines.

The further need and development of disability assessment moved in tandem with the exponential increase in medical knowledge as well as a worldwide change in disease profile in developed countries from one of infectious disease and *death*, to chronic disease and *disablement*. Singapore shares a common trend with most developed countries whereby the principle causes of morbidity and mortality (accounting for more than 80%) are non-communicable diseases including cancer, coronary artery disease, stroke, diabetes, hypertension and injuries.⁹ This has led to spiraling health care costs for health-care systems and governments for managing both the disease itself, and the costly burden of managing the consequence of disability. The current urgent need for disability assessment could be summarised thus^{1,10}:

1. Epidemiologic data in population studies and to establish the extent of disability burden.
2. Clinical tool both to measure baseline disability, the natural recovery of chronic disabling illnesses, as well as to assess the effects of the wide array of medical and rehabilitation interventions available on disablement.

NG YEE SIEN,
Head & Senior Consultant,
Department of Rehabilitation Medicine,
Singapore General Hospital

3. Research tool for outcome measurement and factors that impact on disability.
4. Social policy instrument in planning for health care funding, insurance systems and formulation of health-care policies
5. Educational tool in medical school curriculum design as well as for advocacy and the raising of social awareness of the disabled.
6. In the local context, disability assessment is required for many insurance and funding schemes. Family Physicians may be involved in certifying disability in the ElderShield/ Interim Disability Assistance Programme for the Elderly (IDAPE), Disability Protection Scheme (DPS), Primary Care Partnership Scheme (PCPS), the Foreign Domestic Worker (FDW) Levy Concession, handicapped parking labels and claims for Handicapped-Related Tax Reliefs. In the near future, many other initiatives such as transport subsidies for the disabled administered through the Ministry of Social and Family Development also require disability assessment.

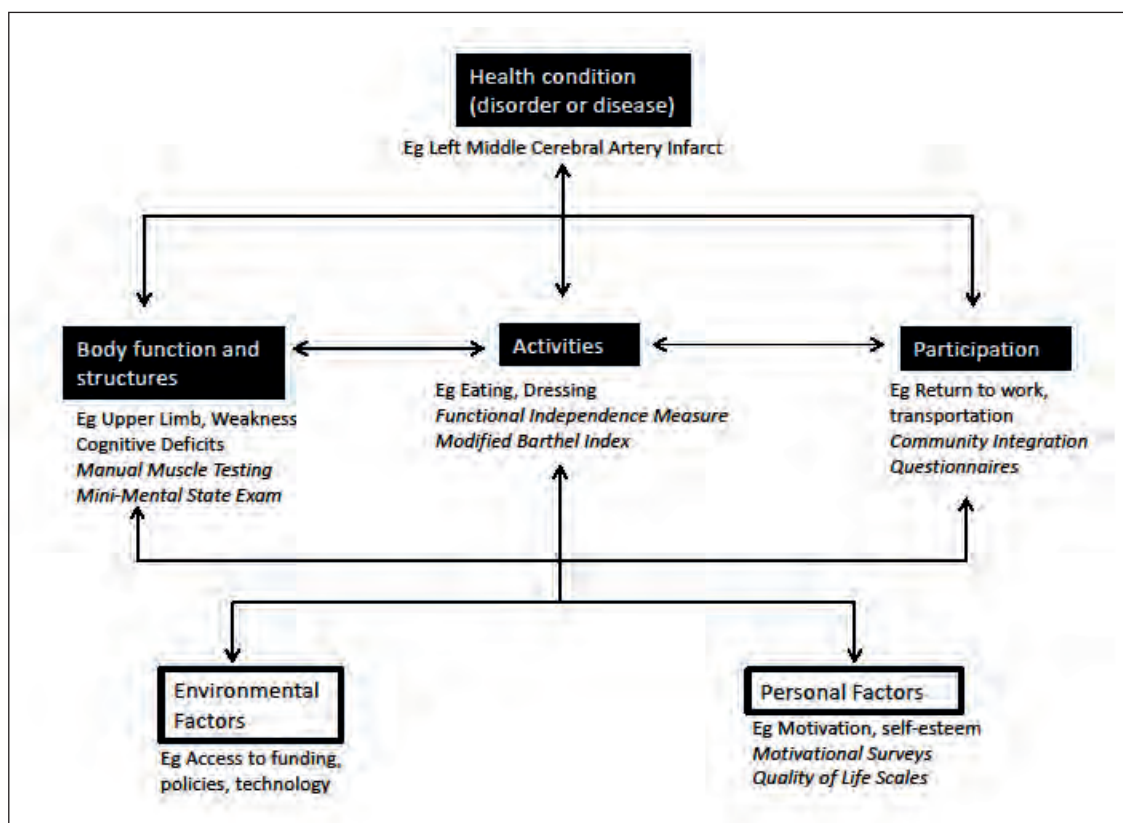
The World Health Organization (WHO) has recognised this need and continually develops conceptual disablement models for international acceptance and use and these frameworks are employed in the development of various disability measures. The International Classification of Impairments, Disabilities and Handicaps (ICIDH) developed by WHO in 1980 describes consequences of disease and disablements and is still used in the American Medical Association Guides to the Evaluation of Permanent Impairment (AMA guides)^{2,11}. The International Classification of Functioning, Disability and Health (ICF) developed in 2001 and detailed in the World Report on

Disability focuses on the components of health rather than the consequence of disease. It also further recognises the important role of the contextual environmental and personal factors which may include human and technological social support systems which impact on health (Figure 1)^{1,12}. In addition, a comprehensive hierarchical coding system which includes codes for body structures and functions, various ADLs and the severity of the disablement are described, and these codes can be expanded to great detail allowing for further development. The ICF has been adopted by more than 190 countries throughout the world and its key elements have been incorporated into various disability assessment scales for use by clinicians and administrators involved in health-care. Importantly the concept of disability has changed from simply an inability to perform ADLs, to a paradigm that includes impairment of body structure and function, activity limitation and participation restrictions^{1,12}.

CURRENT DISABILITY ASSESSMENT TOOLS

Using definitions from the ICIDH and ICF models, the assessment of disability involves *strictly* the assessment of the severity of activity limitation including ADLs, and *not* the assessment of the severity of loss of body structure or function (or termed impairment in the older ICIDH model)¹²⁻³. For example, in the common scenario of a patient who has a left middle cerebral artery stroke resulting in a right hemiparesis, it is not an assessment of degree of loss of strength of the right arm (loss of body structure/function), but an assessment of the

FIGURE 1. THE WORLD HEALTH ORGANIZATION (WHO) INTERNATIONAL CLASSIFICATION OF FUNCTIONING, DISABILITY AND HEALTH (ICF)



amount of assistance a subject requires to dress himself or groom himself *because* of the loss of strength in the right arm (activity limitation). This is important conceptually because the loss of body structure/function or impairment may *not* correlate to disability and activity limitation and it is the severity of disability that is far more important in the determination of caregiver and societal burden¹⁴.

Unfortunately, there is no consensus in the rehabilitation or geriatric literature as to what constitutes the core group of ADLs that need to be measured. However most authorities and texts agree that ADLs can be divided into the following¹⁵:

1. Basic ADLs (BADL). These can include some or all of these activities deemed critical to basic self-care:

- i. *Self-care*: Eating, Grooming, Bathing, Dressing, Toileting.
- ii. *Continence*: Bladder and Bowel Continence
- iii. *Mobility*: Transfers (for example bed to chair, chair to toilet seat), Walking or Wheelchair Use, Climbing Stairs
- iv. *Cognition*: Communication including Comprehension, Expression, Memory and Simple Problem Solving.

2. Instrumental ADLs (IADL) or Extended ADLs (EADL)

This list is long but generally involves more complex activities such as food preparation, medication use, telephone use, transportation use, housekeeping and laundry.

3. Community Reintegration and Participation Activities

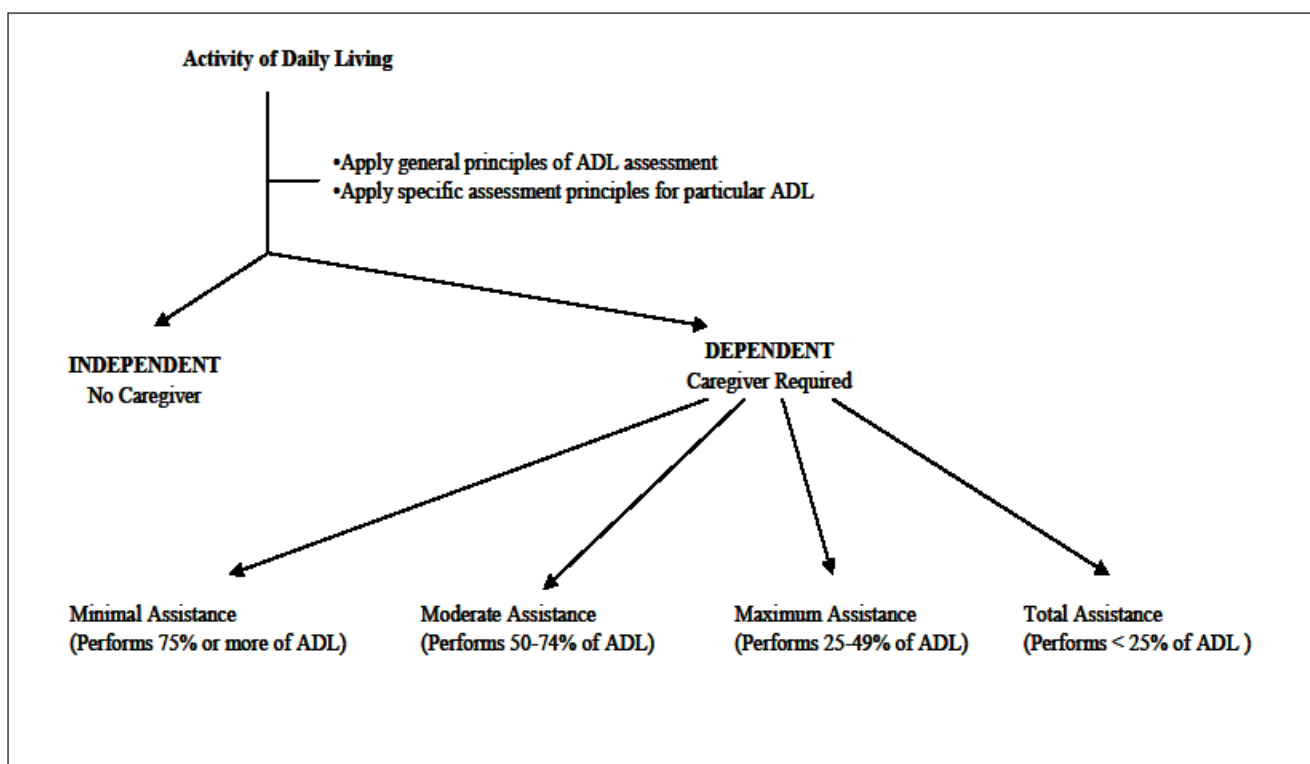
These form the highest tier of activities in daily living and include employment, leisure activities and various recreational activities.

Instruments exist that measure any or all of these three categories

of ADLs. For the purposes of this discussion, we focus only on tools that measure BADL as these have the most direct and significant impact on caregiver burden. BADL assessment is also directly relevant in the disability assessment for the disability-related national schemes (DRNS).

There are only two major general BADLs scales of disability used consistently throughout the world presently and these are the Barthel Index (BI) and the Functional Independence Measure (FIM), both of whom have undergone modifications and revisions over time¹⁶⁻⁹. Both these scales also have good test-retest and interrater reliability, content validity for the measurement of activity limitation and are sensitive to changes over time¹⁹. Importantly, there is a direct correlation between the severity of activity limitation and ADL performed and the amount of care required^{5, 14-20}. The BI has the following items: eating, grooming, bathing, dressing, toileting, maintenance of bowel and bladder continence, transfers and locomotion. The more recently developed FIM has similar items to the BI but further include items on cognitive BADLs such as communication skills, problem solving and memory. This reflects principles explored in the ICF that these cognitive BADLs are not only essential to everyday living and can impact on the better-known physical BADLs^{1,18}. The BI and the FIM have shortened versions which are also valid and reliable in measuring BADLs²¹. Similarly, the current DRNS including ElderShield/ IDAPE, DPS, PCPS and the FDW levy concession and claims for handicapped-related tax reliefs employ⁶ selected BADL items in *bathing, dressing, feeding, toileting, transferring* and *mobility* these items are essentially part of the BI and FIM.

FIGURE 2. GENERAL SCHEMA OF DISABILITY ASSESSMENT FOR EACH ADL FOR THIS ARTICLE TEXT



DISABILITY ASSESSMENT: GENERAL PRINCIPLES OF DISABILITY ASSESSMENT

(In the subsequent discussion that follows, ADL is synonymous with BADL)

We provide a general applicable framework for the subsequent discussion on disability assessment (Figure 2 and Table 1). Our aim is to illustrate the key concepts of disability assessment rather than follow any particular disability scale. Throughout, we advocate the use of the terms *dependence* and amount of *assistance* rather than terms indicating the amount of *ability* in each ADL (Table 1). This is because the aims of disability assessment used in the original (including the WHO-ICF, BI and FIM instruments) and usual contexts is to correlate to the burden of care required^{1, 14-20}.

Each ADL is first categorised into an independent versus dependent group (Figure 2). This dichotomisation is critical and this distinction is consistent in the disability assessment literature¹⁴⁻²⁰. **Independence** is the performance of an ADL *without* the need for a helper *regardless* of whether aids (such as modified eating utensils or walking frames) are used. **Dependency** is defined as the need for assistance from a helper and so indicates presence of caregiver burden.

Total assistance or disability is clearly distinct in disability assessment. The degree of disability and the categorisation of amount of assistance between the two extremes of independence and total dependence however is subjective. The continual refinement and advancements in disability assessment aim to improve the objectivity in assessing these shades of grey²².

In this paper, we group each ADL into 4 generally accepted dependent categories for ease of discussion.

In summary then, we have 1 independent and 4 dependent categories (Figure 2 and Table 1) for the discussion that follows¹⁴⁻²⁰. These are:

1. Independence: No helper or assistance required.
2. Dependent: Minimal Assistance: Subject does 75% or more of the ADL.
3. Dependent: Moderate Assistance: Subject does 50 to 74% of the ADL.
4. Dependent: Maximal Assistance: Subject does 25 to 49% of the ADL.
5. Dependent: Total Assistance: Subject does less than 25% of the ADL

General principles follow:

1. Assess and score what the subject actually does and *not* what the subject can do.

It is important to differentiate between *capacity* (what the subject can do) and *performance* (what the subject actually does). This is because performance and *not* capacity determines caregiver burden.

Examples are:

- i) *Both* cognitive/mental and physical impairments should be taken in consideration for each ADLs. In patients with dementia, they may be able to wear a shirt independently in

front of an assessor (capacity), but are fully unable to do so at home because of memory impairment, severe apraxia or significant depression (performance). The subject should be scored as maximal or total assistance (performance).

- ii) A spinal cord injured patient with complete paraplegia may be able to propel a wheelchair more than 50 meters in a gym or a straight well-paved corridor. However, he is unable and does not want to do so at home because of multiple steps, small doorways or cramped confines of a single-room flat. He should be scored as maximal or total assistance (performance) because of the large caregiver burden required for household ambulation as part of his ADL.

2. Score the lowest or maximal assistance for that particular ADL if the performance on that ADL fluctuates¹⁶⁻⁸.

This is to ensure a fair appraisal of the subject's performance and to reflect caregiver burden. Examples include:

- (i) In a patient has severely impaired vision due to advanced diabetic retinopathy or cataracts, he may be able to transfer from bed to chair with minimal assistance in the daytime but requires maximal assistance at night because of the high risk of falls. He should be scored as maximal assistance required for transfers.
- (ii) If a patient has advanced rheumatoid arthritis of the hands and requiring maximal assistance in the morning in eating because of early-morning stiffness or fatigue but subsequently performs better in the evening, he should be scored as requiring maximal assistance in eating.

3. If an ADL has more than one component, the lowest or maximum assistance required for a particular component is the score for the ADL. Examples include:

- (i) If a patient with a stroke requires only minimal assistance with dressing of the upper body such as wearing a shirt but requires moderate assistance in dressing of the lower body such as wearing of trousers, then the score should be moderate assistance in dressing.
- (ii) Likewise if a subject needs only minimal assistance to move from bed to chair, but moderate assistance from chair to bed, he should be scored as moderate assistance for transfers.

4. Supervision (no contact required) is considered minimal assistance. If two persons are required for a ADL, this automatically is scored total assistance.

5. If there is doubt in the scoring of a particular ADL, it is helpful to rephrase the question from 'how much can the subject perform' in that ADL to 'how much assistance from the caregiver' is required, as the major goal of the disability assessment is to determine caregiver burden.

PRACTICAL ADMINISTRATION OF DISABILITY ASSESSMENT: ASSESSMENT OF THE SIX ITEMS OF BASIC ACTIVITIES OF DAILY LIVING IN DETAIL

In this article, we focus on 6 core ADLs of *bathing, dressing, feeding, toileting, transferring* and *mobility* as they form the main

TABLE 1. SUMMARY AND COMPARISON CHART OF INDICES OF DISABILITY ASSESSMENT IN ADULTS

Terms and Definitions used in this Article Text		Detailed Definition based on Amount of Assistance*	Definition based on Ability*	Arranged from latest → earliest time of development**				
Percentage of ADL Performed	Definition based on Amount of Assistance*			FIM†	MBI‡	BI§	BI	Katz#
All	Independent	Independent	Able <i>Independent</i>	7	5	3	2	Independent
		Modified Independence		6				
All	Minimal Assistance	Supervision	Partially Able <i>Some help or Supervision is needed</i>	5	4	2	1	Dependent
75% or More		Minimal Assistance		4				
50 to 74%		Moderate Assistance		3	3			
25 to 49%	Maximal Assistance	Maximal Assistance	As Good As Not Able <i>Need someone to help most of the time</i>	2	2	1		
Less than 25%	Total Assistance	Total Assistance	Not Able <i>Not able to do at all</i>	1	1			

* In general, definitions based on the amount of assistance are preferable compared to definitions based on ability. This is because the amount of assistance better reflects the amount of caregiver burden required and had been the original aims of most of the disability scales. This does not follow the Eldershield categorization strictly as it is intended rather to provide a conceptual correlation to other scales. Words in italics in this column indicated suggested categories as in Eldershield.

** Various widely-used disability scales arranged from latest to earliest time of development. Note that the numbers in the columns do not refer to the points scored, but the grouping of disability categories.

† FIM: Functional Independence Measure. Note that the FIM categories correspond to the column 'detailed definition based on amount of assistance'. Each ADL is scored from 1 to 7.

‡ MBI: Modified Barthel Index. Each ADL is grouped in 5 disability groups, however the weightage is different for the ADLs. For example, eating and toileting points range from 0 to 10 points (0,2,5,8,10 points respectively) whereas transfers and ambulation range from 0 to 15 points (0,3,8,12,15 points).

§BI: Barthel Index. ADLs for eating, toileting, dressing, bladder, bowel and stair climbing are grouped into 3 groups (0,5,10 points).

||BI: Barthel Index ADLs for toileting, bathing, and locomotion are grouped into 2 groups (0,5 points)

Katz Index of Independence in ADLs. The Katz Index simply dichotomizes ADLs into independency or dependency and then groups all ADLs to give a summary group of A to G to determine the degree of disability.

items required in DRNS. We use Figure 2 and the first 2 columns in Table 1 as the basis of the discussion that follows. We also arrange the 6 ADLs in order of difficulty consistent with prior disability assessment scales^{14,20}.

In each ADL, decide firstly whether the subject performs the task independently or is dependent, and then determine the level of dependence.

FEEDING

Definition: Ability to feed oneself food after it has been prepared and made available. The assessment begins when someone places the food within the reach of the patient^{16,18}. It involves the following subcomponents: cutting up the into bite-size portions, bringing food to the mouth with the use of utensils, chewing and swallowing it safely. If a subject relies on other means of feeding, usually a nasogastric tube, then the

assessment is how the subject administers the feeding himself.

Practical Points: First decide whether a helper needs to be present at all during the actual eating process to decide between independence and dependence. Amongst the 6 ADLs discussed, the amount of assistance is probably the most subjective for feeding. The final score needs to take into account the subcomponent with the most assistance needed.

Independence is then the ability to cut food, bring food to mouth, chew and swallow without a helper needing to be present. This is regardless if adaptive cutlery (for example long handled or built up forks and spoons) is used. If a subject feeds via a nasogastric tube, he must be able to pour the enteral feed down the tube independently. This usually requires an additional funnel to guide the feed down to the tube and he

should hold the funnel independently together with the nasogastric tube.

Dependence means a helper needs to be present during the feeding process. The following are some useful guides. Minimum assistance implies that set-up in the eating process is required. This includes the helper opening containers, cutting meat, pouring liquids or helping the subject wear a cuff to hold utensils. The need for preparation of modified food consistencies such as a pureed or thickened diet would be considered minimum assistance. We would consider maximal assistance if the helper needs to scoop food onto a spoon repeatedly before the subject brings the spoon to his mouth. Examples of total assistance include the need to manually feed every mouthful or the need to check the mouth for residual food with each mouthful or the need to prompt safe swallowing with each swallow to prevent choking (for example the need to remind the patient to chin tuck and do a double swallow with each swallow).

Example: A patient has severe rheumatoid arthritis of hands. She needs assistance in cutting up food and opening containers due to restriction in hand dexterity. However she can bring the food to her mouth by herself, chew and swallow safely any consistency of food. This would be considered minimal assistance. If however she has temporo-mandibular joint involvement and has a lot of pain in chewing and requires checking at every mouthful for residual food to prevent choking, this would be total assistance.

Other Points: Some texts consider independence of eating regardless of food consistency so long as the subject does not require a helper present¹⁸. We disagree as this represents a limitation of the swallowing component of eating and caregiver burden is present.

DRESSING

Definition: Ability to put on, take off, secure and unfasten upper and lower body garments. Garments will include prostheses (artificial limbs), orthoses (braces such as a thoracolumbar corset), and specialised garments which are deemed necessary for the patient such as compression stockings for lower limb oedema. The patient should be assessed on clothing that he wears on a regular basis and of appropriate decency if he appears in public. We do not recommend that the wearing of undergarments and of footwear be considered as this complicates the assessment.

Practical Points: Divide the task first into upper and lower body dressing and score the amount of assistance required for each. Subsequently score the lower of the two scores as the ADL score for dressing. Lower body dressing is usually more difficult^{18,19}.

Independence is then the ability to dress the upper and lower body completely without the need for an assistant. The subject may use aids such as a long-handled reacher to pull up his trousers if he is unable to bend his trunk.

Dependence means that a helper is required and may range from minimal assistance whereby a helper instructs verbally the steps required to put on clothes or total assistance. If the degree of assistance becomes difficult to assess, we suggest dividing the

garments in parts:

T-shirt: 3 parts: (1) thread the right sleeve, (2) left sleeve and (3) pull it down the head and body.

Buttoned shirt: 4 parts: (1) thread the right sleeve, (2) left sleeve, (3) pull the shirt across the body and (4) fasten (or unfasten) the buttons.

Shorts: 3 parts: (1) thread through the right leg, (2) left leg and (3) pull the shorts up over the pelvis.

Buttoned or zipped trousers/pants: 4 parts: (1) thread through the right leg, (2) left leg, (3) pull the trousers/pants up over the pelvis and (4) fasten (or unfasten) the buttons or zips.

Example: The stroke patient with a left hemiparesis wears a T-shirt and a pair of zipped pajama pants at home and in public. He is able to thread the left sleeve of the T-shirt with his good arm, but not the right sleeve of his T-shirt. He is however to pull the T-shirt over the head and down the body once the helper threads the right sleeve of his T-shirt for him. So for upper body dressing he performs in 2 out of 3 parts = 66.6% of the ADL = *moderate* assistance.

He is however not able to reach and thread the shorts through his right leg and left leg, but is able to pull up the pants over his trunk once it is threaded. He also needs help to pull up his zipper. For upper body dressing he performs only 1 out of 4 parts = does only 25% of the ADL = *maximal* assistance.

His score for dressing would then be *maximal* assistance based on the lower score.

Other points: Garments, which are deemed necessary for the patient's condition, are best scored as an able or not able situation. For example, a patient has been prescribed a rigid thoraco-lumbar orthosis for severe osteoporosis of the spine with compression fractures for prevention of further deterioration and is instructed to wear it. If he is unable to put it on himself, then this should be scored as total assistance and the score for dressing will be total assistance *regardless* as to the score for wearing of the clothing.

Garments that are *not* absolutely necessary for the patient's condition, for example a sports-type knee brace that the patient wears for warmth and comfort for osteoarthritis of the knee should not then be taken into consideration in the assessment for dressing.

BATHING

Definition: Ability to wash or bathe in a bathtub, shower or sponge/bed bath. This has the 3 subcomponents of washing, rinsing and drying. For practical purposes, it is reasonable to assess bathing below the neck only.

Practical Points: *Independence* is then the ability to *wash, rinse and dry* the body without the need for a helper. This is regardless of whether the subject bathes himself in a tub, showers or does a bed-bath.

Dependence indicates the need for a helper. If the amount of assistance proves difficult to establish, we suggest dividing the

body into ten parts. The 10 parts are the left arm, the right arm, the chest, the abdomen, the front perineal area including the genitalia, the back perineal area including the buttocks, the left upper leg, the right upper leg, the left lower leg/foot and the right lower leg/foot. Note that portions of a body part will be considered as unable, so the ability to wash only half the chest is considered as the chest is not washed.

Example: A patient who has a dense left hemiparesis can only wash, rinse and dry his left arm and chest with his right arm. He is unable to wash his right arm, abdomen, perineal region and unable to reach both the lower limbs. He performs only 2 out of 10 required steps = 20% of the ADL performed = *total* assistance

Other Points: The back is excluded from bathing because healthy non-disabled people may be scored as disabled! Many people do not wash their back every day or use an assistive device like a long-handled sponge. A clearer picture of disability will result if the back is not included.

The face and neck is excluded because of two reasons. Firstly, in many of the ADL scales including the BI and FIM, washing the face and neck is a separate ADL assessment in *grooming*, and grooming may further include brushing the teeth, shaving and washing the hair. Secondly, washing the neck and the face has a fairly strong functional overlap with eating and the functional scores generally correlate. The aim of this particular ADL assessment is to assess the disability in bathing in isolation.

Note that the definition of bathing includes *wash, rinse and dry*. The amount of assistance is often under-estimated because a subject may be able to wash, but has difficulty manipulating a towel to dry. This should be scored as unable to bathe in accordance to the general principles described above.

TOILETING

Definition: Ability to use the lavatory and manage bowel and bladder hygiene. It consists of 4 steps: (1) maintenance of balance, (2) adjusting clothing before using a toilet, (3) maintaining perineal hygiene and flushing the toilet and subsequently (4) adjusting clothing after using the toilet. The definition remains the same if a bedpan or commode is used. If a bedpan or commode is used, then step (3) would be the need to clear the bedpan and commode as well.

By strict definition, do *not* take into account other aspects of toileting. This includes:

- Transferring from a bed or chair onto the toilet seat. This would be assessed under transfers.
- The actual bladder or bowel function including whether the subject is continent, leaks, soils the bed or uses a catheter. This is more correctly assessed under bladder and bowel continence.

By definition, it *includes* however:

- Maintaining the balance during clothing adjustment and the actual act of urination and defaecation.
- Perineal hygiene issues including using toilet paper to clean

the perineum and the ability to flush the toilet or clear the bedpan.

If a subject uses a diaper, then the assessment includes the entire process of removing the diapers, perineal hygiene, putting on a new diaper and discarding the old diapers.

If a subject is on a long-term indwelling catheter, do not assess the component of changing the catheter under toileting, as there is usually no caregiver burden involved. If a subject is on self intermittent catheterisation, then he should be assessed as per the definition of toileting given above.

Practical Points: To determine the level of assistance, required, it is often useful to divide the ADL into 4 steps listed above. For ease of assessment, a part of a component that is not performed should be scored as not performed.

Independence: No helper required to perform all 4 steps.

Dependence: Minimal, moderate, maximal and total assistance would then be the inability to do 1, 2, 3 or all 4 steps described in the practical points above.

Examples: A bedbound severe stroke patient who requires a helper to change his diapers is assessed as total assistance. Another stroke patient who uses a bedpan can remove and put on his clothing but requires a helper to lift his pelvis onto a bedpan (balance), and clean his perineum and carry the bedpan away after use. This implies that he can do 2 out of 4 steps and this would be considered moderate assistance. If the same latter subject can only thread one leg during the removal and putting on of his pants, he would be considered as unable to do these steps as well. This would imply that he can do none of the 4 steps and this would then fall under the total assistance category.

Other Points: Not all disability assessment scales require the ability to flush the toilet or clear a bedpan¹⁸. We believe that this should be included in the definition for hygiene reasons!

TRANSFERS

Definition: All aspects of transferring from bed to a chair or wheelchair and back to a bed. This tests several skills including doing first a sit-up from a lying position, a sit to standing position, a weight or pivot shift and a controlled descent to a sitting position in another location.

Practical Points: The heights of the bed and chair are often different and the assessment should score the direction of transfer that comprises the most difficulty. In a hospital, the bed is often higher than the chair and it is more difficult to get back to the bed from a chair. In homes where mattresses are often placed directly on the ground (futon-styled beds) the opposite occurs.

Independence: To transfer from bed to chair and vice versa without the need of a helper. If in a wheelchair, then approaches, locks brakes, removes foot and arm rests and does a

transfer often with a sliding board. Regardless, all these are done independently.

Dependence: Minimal assistance means requiring only coaxing, cuing or at most steadying assistance to guide the subject to transfer. If the body requires support during transfer, this indicates moderate assistance. If a lot of weight is required to support to body or the legs need to be supported as well, this would indicate maximal assistance. Total assistance means that one helper is insufficient to do the transfer or the subject is unable to transfer regardless of assistance.

Other Points: The act of transferring is basic and critical in ADL. Many of the other basic ADLs such as eating, bathing, toileting require an initial act of transfer to a sitting position prior to ADL performance. This importance is recognised in many scales including the BI and its modifications whereby a higher weightage is given to transfers compared to the ADLs¹⁶⁻⁷. In other instruments such as the FIM, there are three types of transfers including the transfer from bed to chair, transfer to a shower or a bathtub and transfer to a toilet and hence the ADL 'transfer' is triple the weightage of other ADLs¹⁸. Transfer from bed to chair or wheelchair is often the most important, common and difficult, and hence this particular transfer forms the definition for this article.

MOBILITY

Definition: The act of walking, once in a standing position. If a wheelchair is used for locomotion, assessment commences only from a seated position on a level surface. The distance that is considered significant is controversial (see *other points* below). For this article, we use a distance of 8 meters as significant. This would be approximately the end-to-end distance between 2 HBD apartment rooms, or twice the length of an average size GP clinic.

Practical Points: Record the score with the mode of locomotion that the subject uses most often, either walking or wheelchair. The distance that is considered significant is the same for walking or wheelchair mobility. The discussion that follows applies for both forms of locomotion.

Independence: The ability to walk independently 8 meters. This is regardless of walking aid used and the speed of walking. Common walking aids are a cane (single-point stick), quad (4-point) stick, forearm or elbow crutches, axillary crutches and a walking frame (with or without wheels, the latter termed a rollator frame).

Dependence: Minimal, moderate and maximal assistance all indicate that the subject is still able to walk 8 meters but a helper needs to assist. Minimal assistance indicates usually contact guarding and gentle guidance to prevent falls. Moderate and maximal assistance imply that the weight of the patient needs to be supported by the helper. The difference is that maximal assistance means supporting the body weight considerably and with difficulty. Total assistance indicate

either (1) The patient is unable to walk, (2) The patient cannot cover 8 meters regardless of the amount of assistance or (3) Two helpers are required. Points (1) to (3) indicate a very large burden of care.

Other Points: The assessment of walking does not usually include the subcomponent of standing up initially from a seated position. This is more accurately assessed under transfers.

The main issue of debate lies in the distance that needs to be covered to be considered significant. Most authorities divide threshold distances into household ambulation and community ambulation. Household ambulation is the distance required generally to move within the home environment and would plausibly cover the distance between a room and a toilet. This is taken as 50 feet (17 meters) in the FIM instrument¹⁸⁻⁹. However, the FIM was based on home sizes in the United States which are probably larger. The average 3-room HDB flat (2 bedrooms, 1 kitchen/dining room and a living room) measures about 64 square meters²³. A reasonable distance for significant household ambulation would then be 8 meters.

Community ambulation is the distance required to move for IADL purposes such as grocery shopping or to the nearest bus-stop. This is generally taken as one 'block' in Western societies and measures 50 meters in the modified BI and FIM¹⁶⁻⁹. Fifty meters also seems a reasonable distance in the local context: this is the minimum distance between a pedestrian crossing (for example, traffic lights, overhead bridge or zebra crossing) and a point where we can cross the road without using the pedestrian crossing! However we use a household ambulation of 8 meters as our threshold significant distance because we feel that a large majority of disabled patients are house-bound in Singapore and this more accurately reflects burden of care.

Some patients with significant paralysis of the all limbs including patients with high cervical spinal cord injury or multiple sclerosis use a powered or electric wheelchair for mobility. The threshold distances do not change because again, we are measuring the amount of assistance required and not the patient's ability to propel a wheelchair primarily.

EXPERIENCES, STRENGTHS AND WEAKNESSES OF DISABILITY ASSESSEMENT

We have published local data on more than 1500 patients with various diseases in which we have performed disability assessments on during their rehabilitation course⁴. Our experience is that clinicians often overestimate the capabilities of the patients and consequently underestimate the amount of assistance required, and this has been a common experience in many rehabilitation centers¹⁵. Some care in assessing disability using the guidelines above will overcome this issue. There are also concerns with regards to false self-reporting of disability among claimants, but because of the high prevalence of

disability locally particularly with evidence of a chronic disease such as stroke or diabetes, it is necessary to apply some common sense for patient beneficence^{3,24}.

All scales or instruments whereby disabilities are measured are subject to several weaknesses and the assessor in scoring and interpretation should take these into account during test administration. Major weaknesses include:

1. Disability scales are by nature quantitative and ordinal. Categories of disability severity are not equal. For example, on a scale of 1 (most severe) to 10 (least severe), 2 may not be twice as severe as 1, or 3 twice as severe as 2.
2. There is subjectivity in how each disability item should be measured. What constitutes a certain quantum of assistance cannot be perfectly objectively defined. As such there is continual refinement in the disability assessment literature itself and the focus currently is on refinement of existing scales rather than developing new ones¹⁵.
3. Content validity. There is no agreement which and how many items need to be included in any disability instrument provide the optimal representation of disability.
4. Inter-rater reliability. Clinicians who administer disability testing on a regular basis will have better inter-rater reliability versus those who perform testing only occasionally or rarely.

In conclusion, accurate disability assessment of the basic activities of daily living is important as a clinical, research, education and epidemiologic tool. It also functions as a social policy tool for health-care funding, directing rehabilitation resources, as well fulfills an important role in advocating for the disabled in Singapore. Disability assessment requires review over time to maintain relevancy and long-term goals could be the development and maintenance of a disability database in Singapore.

FRAILTY, COMORBIDITY, DISABILITY AND GERIATRIC REHABILITATION

Just prior to a decade ago, approaches to geriatric disability and rehabilitation were non-specific and empirical, largely consisting of the general management of deconditioning and ADL training.

With the advent of frailty concepts and its overlapping interactions with psychosocial issues, disability and co-morbidity (Figure 3); there has been rapid development of geriatric rehabilitation and the medical management of disability in the elderly²⁵⁻⁶. With rapidly aging populations in developed countries like Singapore with significantly lower health-adjusted life years and increasing burden of disability, geriatric rehabilitation will assume specific prominence in the future of local healthcare²⁷.

Frailty is a geriatric syndrome of increased vulnerability due to diminished physiologic reserves in multiple organ systems¹²². The frailty cascade describes a series of sentinel events in the elderly (Figure 4)²⁸. The frail state results from physiologic deterioration coupled with comorbidities, poor exercise, nutrition, psychosocial and mental stressors. Unless specifically

screened for, these elderly persons may otherwise appear clinically and functionally normal. With subsequent stressors such as acute infections, illness or falls, the frail elderly are highly susceptible to adverse health outcomes leading to significant disability, hospitalisation, consequent institutionalisation and death²⁵⁻⁶.

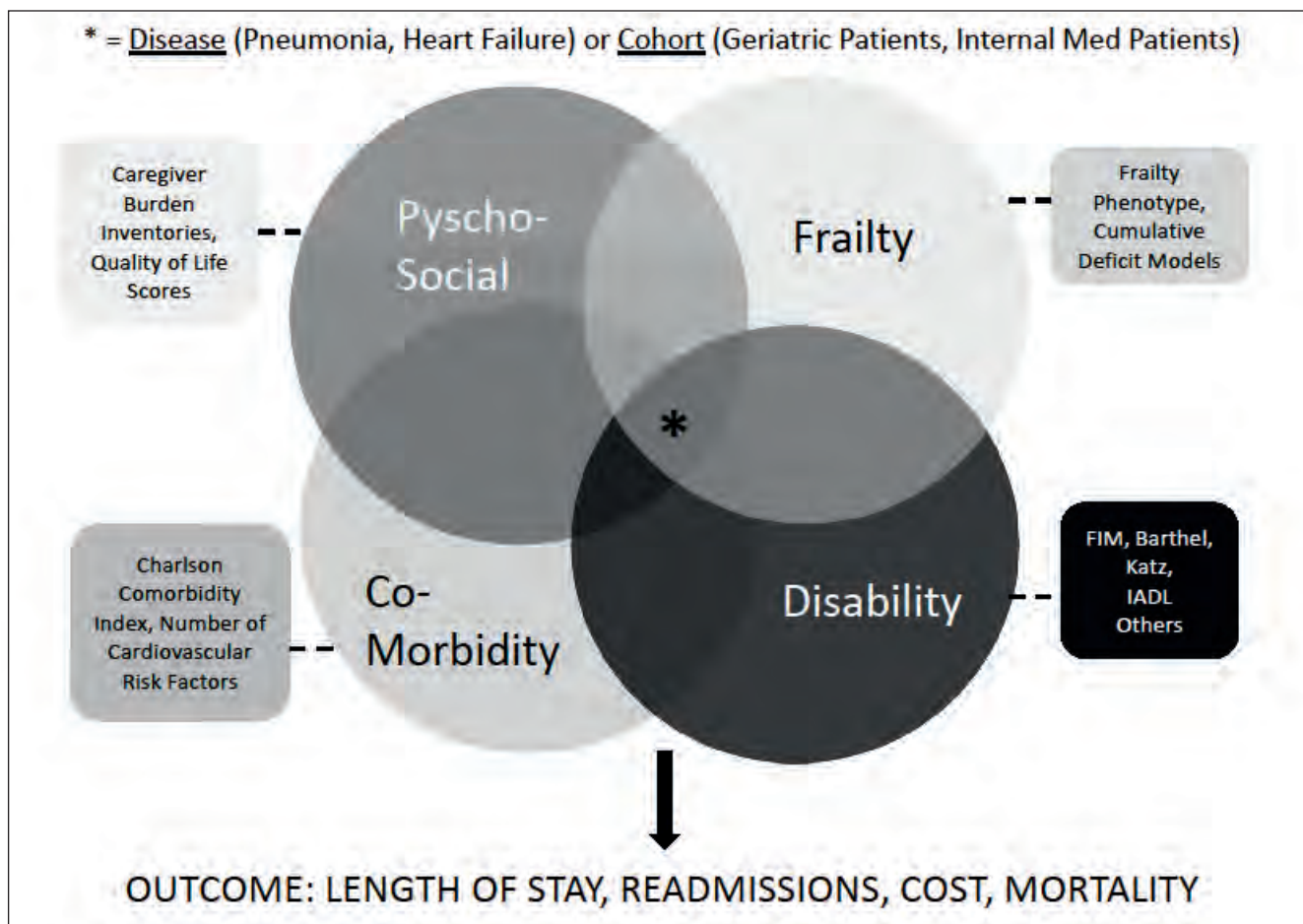
Frailty illustrates a paradigm shift in rehabilitation, which addresses recovery through a holistic multisystem perspective rather than through the traditional approaches of a specific disease²⁵. For example, rather than further developments of rehabilitation modalities in traditional areas of stroke, traumatic brain injury, spinal cord injury, hip fracture and amputee rehabilitation, rehabilitation principles of exercise and interdisciplinary care apply across the frailty syndrome without the need to identify a disease that causes it.

This approach is important due to several reasons. Firstly, frailty is interconnected, but can occur independently of a disease state, comorbidity or disability (Figure 2)^{29,30}. About a quarter of frail patients may have chronic disease but many are free of comorbidities. As such, valuable resources may be exhausted while searching for causes of falls or generalised weakness where no single cause actually exists, as frailty reflects multisystem failure.

Secondly, frailty is associated with an increased risk of readmission, nursing home admission, worse outcomes after surgery, postoperative complications, as well as higher risks of falls, dementia, general morbidity and mortality^{26,31-2}. Targeting frail patients with closer monitoring and psychosocial support can feasibly reduce the risk of complications and adverse outcomes. Thirdly, frailty is potentially reversible with specific interventions, rehabilitation and exercise³¹. This reversibility of the frailty cascade is very promising as it is extremely cost ineffective to treat and manage already disabled and hospitalised patients and interventions need to occur higher up prior to the development of disability. This is often termed prehabilitation. Finally, the presence of frailty is an important consideration in the decision-making process for medical conditions, including risk-benefit decisions in cancer therapeutics or even the triaging of patients for rehabilitation as frail patients have poorer outcomes³¹.

Sarcopenia is a key feature of frailty and is defined as the age-related loss of muscle mass, strength, power, quality and function³³. There is significant uncoupling of muscle-cross sectional area and fiber strength and loss of type II fast motor units (muscle quality), with fat accumulation in muscle (myosteatosis) resulting in a deterioration of muscle function²⁸. Genetic factors and age-related changes in the neurologic and endocrine systems, low-grade inflammation and loss of muscle homeostasis are thought to give rise to sarcopenia^{26,33}. Conceptually, sarcopenia is important as many screening tools for frailty indirectly measure for presence of sarcopenia, including lower limb strength, ability to rise from a chair and climb steps³³.

FIGURE 3. THE INTERACTION BETWEEN DISABILITY, PSYCHOSOCIAL, CO-MORBIDITY AND FRAILITY DOMAINS IN THE MANAGEMENT OF CHRONIC DISEASE OR A COHORT OF PATIENTS



SCREENING FOR FRAILITY

The identification of frail elderly people is key as it is not cost-effective or operationally feasible to deliver rehabilitation to large numbers of people. Clinically, the frailty syndrome can be defined as three or more variables of a phenotype consisting of unintentional weight loss, self-reported exhaustion, low energy expenditure, slow gait speed and weak grip strength³⁴. The lowest quintile values are used to define the presence of the frail state. Those with one or two factors are defined as having a pre-frail state. Frailty indices, which are cumulative deficit scores of multiple variables, including symptoms, signs, abnormal laboratory values, diseases and disabilities, are also used to define frailty^{29,35}.

Depending on criteria, about 10 percent of people older than 65 years and between a quarter to half of the elderly older than 85 years are estimated to be frail. The risk of frailty is dependent on the setting (frail elders in nursing home >50%), and more likely in females, lower income and less educated elders. Frailty is more common in patients with comorbidities and depressive disorders emphasising the overlap between these domains.

Previously, frailty was grimly associated with the desolation of irreversible ageing. Recent large surveys however indicate that a higher level of physical activity correlate strongly with the development of frailty. Also, groups of elders who engaged in

specific exercise activity of more than 1000kcal/week rather than merely being community ambulant and generally active were three-fold less likely to progress down the frailty cascade and develop severe disability³⁶.

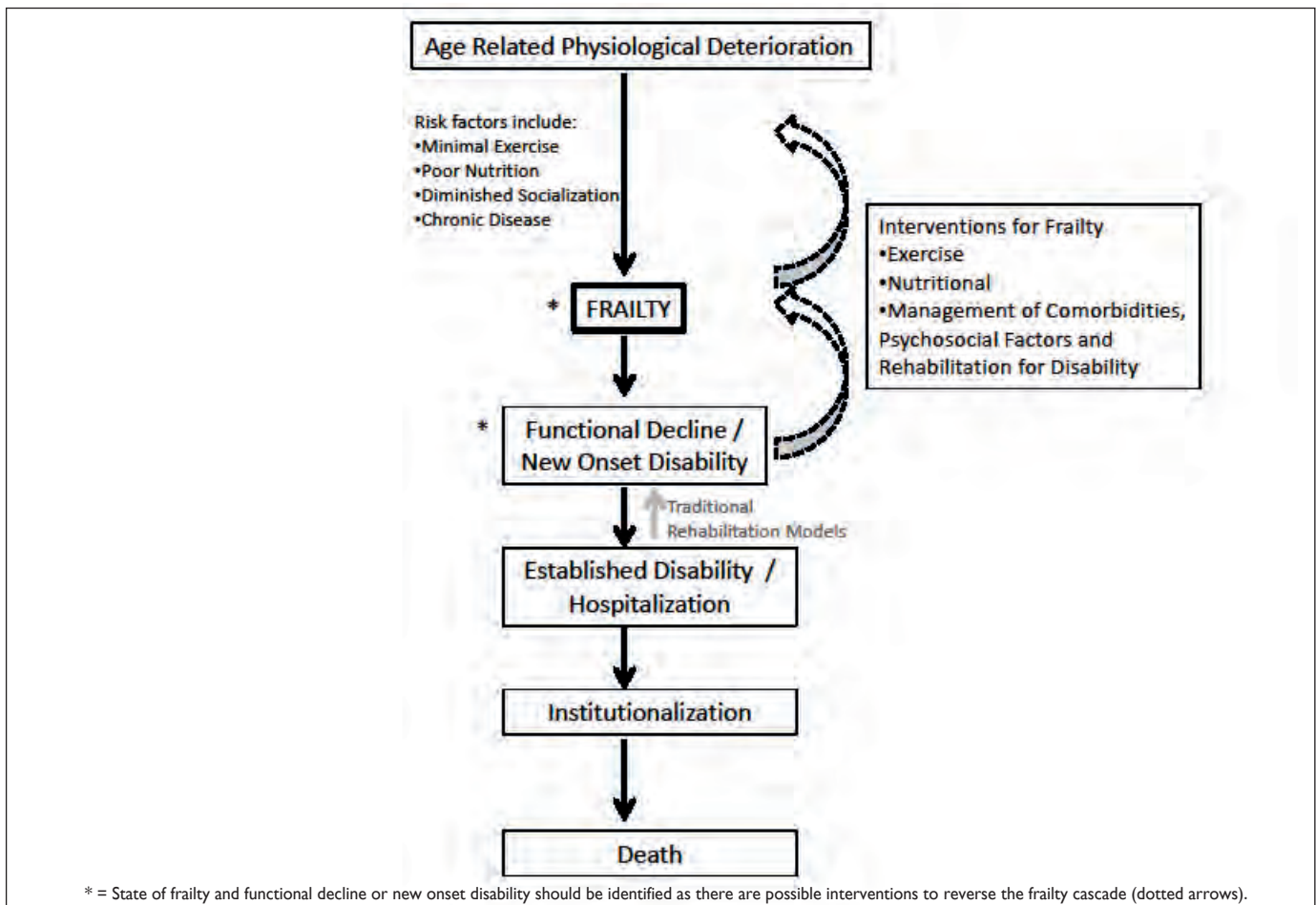
TREATMENT FOR FRAILITY

Exercise still remains the best proven modality to address frailty and a number of trials on exercise have been conducted³⁷. The optimal type of exercise has yet to be established, but general guides indicate multimodal programs comprising strength, endurance, balance and flexibility components are ideal. Most guides indicate that programs performed at least two to three times a week for about an hour for at least 3 months to provide significant benefit^{30,37}.

Strength or resistance training has been best studied, and is found to improve muscle strength with consequent better motor performance and gait speed. As such, all multimodal programs include strength training as an integral component^{30-1,36}. Strengthening exercises are also easier to commence in previously sedentary older adults and even small gains in strength translate into significant functional gains²⁵.

The addition of an endurance programme consisting of moderate aerobic exercise such as jogging or swimming about

FIGURE 4. THE FRAILTY CASCADE



two to three hours weekly improves maximal oxygen uptake and reduces fatigue^{31,36}. Balance and flexibility training, particularly incorporated into programs such as Tai-Chi are popular and effective as well³⁶. Exercise in general reduces chronic elevations in inflammatory mediators, lessens insulin resistance and stimulates muscle anabolic effects in the presence of amino acids^{26,31}.

Nutritional interventions, including systematic nutritional assessments and supplementation with proteins such as leucine, address weight loss in frailty and may prevent falls especially if combined with a well prescribed exercise program²⁵. Several pharmacologic agents for the treatment of frailty have been studied. These include the administration of testosterone or selective androgen receptor modulators to improve body composition and muscle strength in the hypogonadal elderly³¹. Myostatin inhibitors, ghrelin, angiotensin converting enzyme inhibitors and vitamin D supplementation may also have beneficial effects on enhancing musculoskeletal system functioning³¹.

Family physicians are well equipped with the medical skills necessary to incorporate the concepts of frailty and its corresponding management of comorbidities, disability and psychosocial domains into the care of their elderly patients. They have the skill set coupled with the mindset of comprehensive, holistic patient care to optimise the health of the aged in our society²⁹. By appreciating the complexity of each individual and screening for frailty albeit in a busy clinic, family physicians can make important clinical decisions,

recommendations of exercise, rehabilitation and treatment of frailty and its consequences if not addressed early in the aging process²⁹.

DISCLAIMER

In this article, we provide a general overview of disability assessment and a possible schema of assessment based on published literature and our experiences in this field. The text will not be applicable to all schemes and policies and the views and opinions expressed are of the authors only.

The ADL definitions and the method in which the severity of disability is categorised vary considerably between the disability-related national schemes and third-party insurers. Similarly the thresholds and disability category whereby the claimant is successful in obtaining claims also vary significantly between the disability-related national schemes and insurers. The author will not be held responsible for any disputes that arise in the claims process and the assessor is advised to check with the particular scheme and insurer for details and updates on the assessment process regularly. The author is currently not affiliated to any disability-related national scheme or third-party insurer.

REFERENCES

1. World Health Organization [WHO] and World Bank. World Report on Disability. Geneva: World Health Organization; 2011. Available from: http://www.who.int/disabilities/world_report/2011/en/index.html
2. Kostanjsek N, Good A, Madden RH, Ustün TB, Chatterji S, Mathers CD, Officer A. Counting disability: global and national estimation. *Disabil Rehabil* 2013;35(13):1065-9.
3. Ng TP, Niti M, Chiam PC, Kua EH. Prevalence and correlates of functional disability in multiethnic elderly Singaporeans. *J Am Geriatr Soc*. 2006;54:21-9.
4. Ng YS, Jung H, Tay SS, Bok CW, Chiong Y, Lim PA. Results from a prospective acute inpatient rehabilitation database: clinical characteristics and functional outcomes using the Functional Independence Measure. *Ann Acad Med Singapore*. 2007;36:3-10.
5. Adelman RD, Tmanova LL, Delgado D, Dion S, Lachs MS. Caregiver burden: a clinical review. *JAMA*. 2014;311(10):1052-60.
6. Berg-Weger M, Rubio DM, Tebb SS. Living with and caring for older family members: issues related to caregiver-well being. *J Gerontol Soc Work* 2000;33:47-62.
7. Ranavaya MI, Rondinelli RD. The major U.S. disability and compensation systems: origins and historical overview. In: Rondinelli RD, Katz RT, eds. *Impairment rating and disability evaluation*. Philadelphia: EB Saunders 2000, 3-16.
8. A Guide to the Assessment of Traumatic Injuries and Occupational Diseases for Workmen's Compensation (GATOID). Workmen's Compensation Medical Board, Ministry of Manpower, Singapore. Fifth Edition, December 2006. Available from <http://www.mom.gov.sg>
9. Principle Causes of Death and Top 10 Conditions of Hospitalization. Singapore Health Facts. Ministry of Health, Singapore. Available from <http://www.moh.gov.sg/mohcorp/statistics.aspx?id=240>
10. Ottenbacher KJ, Smith PM, Illig SB, Linn RT, Ostir GV, Granger CV. Trends in length of stay, living setting, functional outcome, and mortality following medical rehabilitation. *JAMA* 2004;292:1687-95.
11. American Medical Association. Guides to the evaluation of permanent impairment, 5th ed. Chicago: American Medical Association, 2001.
12. World Health Organization. International classification of functioning, disability and health: ICF. Geneva: WHO, 2001.
13. World Health Organization. International classification of impairments, disabilities and handicaps: ICDH Geneva: 1980.
14. Johnston M, Pollard B. Consequences of disease: testing the WHO International Classification of Impairments, Disabilities and Handicaps (ICIDH) model. *Soc Sci Med*. 2001;53:1261-73.
15. Christiansen CH. Functional Evaluation and Management of Self-Care and Other Activities of Daily Living. In DeLisa JA, Gans BM, Walsh NE, eds. *Physical Medicine and Rehabilitation: Principles and Practice*. Philadelphia: Lippincott Williams and Wilkins 2005:975-1004.
16. Mahoney FI, Barthel DW. Functional evaluation: the Barthel index. *Maryland State Med* 1965;14:61-5.
17. Shah S, Vanclay F, Cooper B. Improving the sensitivity of the Barthel Index for stroke rehabilitation. *Journal of Clinical Epidemiology*, 42, 703-9.
18. Hamilton BB, Granger CV, Sherwin FS. A uniform national data system for medical rehabilitation. In: Fuhrer MJ, ed. *Rehabilitation outcomes: analysis and measurement*. Baltimore: Paul H. Brooks 1987:137-47.
19. Granger CV, Hamilton BB, Keith RA, Zielezny M, Sherwin FS. Advances in functional assessment for medical rehabilitation. *Top Geriatr Rehabil* 1986;1:59-74.
20. Katz S, Ford AB, Moskowitz RW, Jackson BA, Jaffe MW. Studies of illness in the aged. The Index of the ADL: a standardized measure of biological and psychosocial function. *JAMA* 1963;185:914-9.
21. Hsueh IP, Lin JH, Jeng JS, Hsieh CL. Comparison of the psychometric characteristics of the functional independence measure, 5 item Barthel index, and 10 item Barthel index in patients with stroke. *J Neurol Neurosurg Psychiatry*. 2002;73:188-90.
22. McGinnis Ge, Seward M, DeJong G, Law M, Letts L. A critical review of scales of activities of daily living. *Am J Occup Ther*. 1989;43:522-8.
23. Typical 3-Room Floor Plans. Housing and Development Board, Singapore. Available from: <http://www.hdb.gov.sg/fi10/fi10321p.nsf/w/BuyingNewFlat3room>
24. Main CJ, Waddell G. Behavioral responses to examination. A reappraisal of the interpretation of "nonorganic signs". *Spine*. 1998;23:2367-71. 121.
25. Clegg A, Young J, Iliffe S, Rikkert MO, Rockwood K. Frailty in elderly people. *Lancet* 2013; 381:752-62.
26. Ruiz M, Cefalu C, Reske T. Frailty syndrome in geriatric medicine. *Am J Med Sci* 2012; 344:395-8.
27. Healthy life expectancy (HALE) and life expectancy (LE) at birth and age 60, by sex, WHO Member States, 2000. Available from <http://www.who.int/healthinfo/paper38.pdf>
28. Morley JE, Haren MT, Rolland Y, Kim MJ. Frailty. *Med Clin North Am*. 2006;90(5):837-47.
29. Lacas A, Rockwood K. Frailty in primary care: a review of its conceptualization and implications for practice. *BMC Med* 2012; 10:4.
30. Liu CK, Fielding RA. Exercise as an intervention for frailty. *Clin Geriatr Med* 2011; 27:101-10.
31. Rolland Y, Dupuy C, Abellan van Kan G, Gillette S, Vellas B. Treatment strategies for sarcopenia and frailty. *Med Clin North Am* 2011; 95:427-38.
32. McMillan GJ, Hubbard RE. Frailty in older inpatients: what physicians need to know. *QJM* 2012; 105:1059-65.
33. Cooper C, Dere W, Evans W, et al. Frailty and sarcopenia: definitions and outcome parameters. *Osteoporos Int* 2012; 23:1839-48.
34. Fried LP, Tangen CM, Walston J, et al; Cardiovascular Health Study Collaborative Research Group. Frailty in older adults: evidence for a phenotype. *J Gerontol A Biol Sci Med Sci* 2001; 56:M146-56.
35. Mitnitski AB, Mogilner AJ, Rockwood K. Accumulation of deficits as a proxy measure of aging. *ScientificWorldJournal* 2001; 1:323-36.
36. Peterson MJ, Giuliani C, Morey MC, et al; Health, Aging and Body Composition Study Research Group. Physical activity as a preventative factor for frailty: the health, aging, and body composition study. *J Gerontol A Biol Sci Med Sci* 2009; 64:61-8.
37. Theou O, Stathokostas L, Roland KP, Jakobi JM, Patterson C, Vandervoort AA, Jones GR. The effectiveness of exercise interventions for the management of frailty: a systematic review. *J Aging Res*. 2011;2011:569194.

LEARNING POINTS

- In Singapore and worldwide, large numbers of people live with disabling illness.
 - Using definitions from the ICIDH and ICF models, the assessment of disability involves strictly the assessment of the severity of activity limitation including ADLs, and not the assessment of the severity of loss of body structure or function (or termed impairment in the older ICIDH model)
 - Disability charting is important as a clinical tool to document functional recovery as well as to assess the effectiveness of medical and rehabilitation interventions.
 - The identification of frail elderly people is key as it is not cost-effective or operationally feasible to deliver rehabilitation to large numbers of people.
 - Clinically, the frailty syndrome can be defined as three or more variables of a phenotype consisting of unintentional weight loss, self-reported exhaustion, low energy expenditure, slow gait speed and weak grip strength.
 - Rehabilitation now addresses recovery through a holistic multisystem perspective rather than through the traditional approaches of a specific disease
-

ASSESSMENT OF 30 MCQs

FPSC No : 58

MCQS ON IMPROVING HEALTHCARE FOR PERSONS WITH DISABILITIES

Submission DEADLINE: 10 JUNE 2014, 12 NOON

INSTRUCTIONS

- To submit answers to the following multiple choice questions, you are required to log on to the College Online Portal (www.cfps2online.org)
- Attempt **ALL** the following multiple choice questions.
- There is only **ONE** correct answer for each question.
- The answers should be submitted to the College of Family Physicians Singapore via the College Online Portal before the submission deadline stated above.
- There will be **NO** further extension of the submission deadline.

- About the life course approach in the Ministry of Social and Family Development's Enabling Masterplan 2012-2016, which of the following is one of the 4 areas of emphasis?**
 - Weight control.
 - Adolescent health.
 - Early intervention.
 - Preventive care.
 - Vocational training.
- In the Ministry of Social and Family Development's Enabling Masterplan 2012-2016, which of the following is identified as a cross cutting issue?**
 - Accessibility.
 - Adult care.
 - Employment.
 - Health literacy.
 - Respite care.
- In Singapore it is estimated that a percentage of the resident population will have some form of disability. What is this percentage?**
 - 3%.
 - 4%.
 - 5%.
 - 6%.
 - 7%.
- About the patient-centred medical home as a health care delivery model, which of the following is NOT a characteristic feature?**
 - Use of health information technology.
 - Patient centred care
 - Residential care.
 - Quality care.
 - Practice organisation.
- In a local study by Wee et al (2013) on the sociodemographic and clinical profile of older adults with intellectual disability aged 40 and older receiving services from the Movement of Intellectually Disabled of Singapore (MINDS), the authors found that the majority of the persons with intellectual disability had a primary caregiver. Who was the primary care giver?**
 - Seventy percent from parents.
 - Fifty percent from parents.
 - Seventy percent from siblings.
 - Fifty percent from siblings.
 - Equal proportions from parents or siblings.
- About services for children and youth with special needs, which of the following statement is CORRECT?**
 - Early Intervention Programme for Infants & Children have services focused on treatment of secondary disabilities.
 - Integrated Child Programme (ICCP) provides training for children with moderately severe intellectual impairment.
 - Development support programme (DSP) teach social and life skills for independent living.
 - Special Student Care Centres (SSCCs) provide before- and after-school care services.
 - Early Intervention Programme for Infants & Children (EIPIC) provides skills training for independent living.
- For adults with disabilities, which of the following statement is CORRECT?**
 - Day Activity Centres provide care and skill training to adults with mild to moderate disabilities.
 - Community Group Homes provide respite care for families unable to cope.
 - Sheltered Workshops provide therapy for adult with mild to moderate disabilities who are not in employment.

- D. Sheltered Workshops provide alternative housing arrangements for adults with disabilities who can work.
- E. Day Activity Centres provide physiotherapy and occupational therapy for adults with mild to moderate disabilities.
8. For adults with disabilities and financial assistance funds, which of the following statement is **CORRECT**?
- Computer Access Trust Fund (CATF) provides financial assistance to middle-income families in purchasing assistive equipment to aid persons with disabilities in their mobility, independence or rehabilitation.
 - Special Assistance Fund (SAF) provides financial assistance to low-income families in purchasing assistive equipment, technical aids and retrofits to aid persons with disabilities in their mobility, independence or rehabilitation.
 - Assistive Technology Fund (ATF) provides financial assistance to persons with disabilities to purchase computers and IT devices.
 - Assistive Technology Fund (ATF) provides financial assistance to persons with disabilities purchase electronic educational equipment.
 - Special Assistance Fund (SAF) provides financial assistance to buy mobility aids for adults with disabilities from traffic accidents.
9. The concession scheme allows persons with disabilities to have a percentage discount off the adult fares when they travel on public transport for distances shorter than 7.2km. What is the percentage discount?
- 10.
 - 15.
 - 20.
 - 25.
 - 30.
10. For persons with disabilities, there is a **Monthly Concession Pass** with unlimited bus and train rides. How much does this cost per month?
- \$80.
 - \$70.
 - \$60.
 - \$50.
 - \$40.
11. With regards to the consequences of caregiver stress in looking after elderly family members with disabilities, in a percentage of elder abuse cases occurring annually, the underlying cause is caregiver stress. What is this percentage?
- 14.
 - 18.
 - 22.
 - 26.
 - 30.
12. About what the family physician can do in improving the experience of family caregivers of persons with disabilities, which of the following is **LEAST** likely to be overlooked by the family physician in attendance?
- Caregiver training.
 - Psycho-education.
 - Emotional support.
 - Caregiver stress.
 - Physical help.
13. Family caregivers often perceive that the support received by the attending family physician is weak. Which of the following is the **LEAST** likely factor resulting in such a perception?
- Management policies in handling patients with disabilities.
 - Tendency to stereotype.
 - Negative attitude.
 - Lack of commitment.
 - Limited knowledge of disabilities.
14. In order to foster the supportive relationship between family physicians with family caregivers, which of the following actions on the part of the family physician is **MOST** likely to be effective?
- Assess family caregivers' wellbeing.
 - Follow-up visits with calls to check compliance.
 - Tell family caregivers the right thing to do.
 - Engage family caregivers and make use of their care expertise.
 - Tell family caregivers the wrong thing to avoid doing.
15. About advice that family physicians can give to family caregivers, which of the following is **MOST** likely to be useful?
- Advise family caregivers to have a separate consultation time for their family member with disability and themselves.
 - Advise family caregivers to schedule either the first or last appointment for shorter waiting time or a less crowded room.
 - Advise family caregivers to feed their family member with disability well before the visit to prevent hunger causing disruptive behaviour.
 - Advise family caregivers on the need to discipline disruptive behaviour.
 - Advise family caregivers to bring distractions to engage their family member with disability at the waiting room and examination room.

- 16. Developmental delays and disorders are not uncommon. These are present in a percentage of children under age of 5. What is this percentage? n?**
- 5 to 10%.
 - 10 to 20%.
 - 20 to 30%.
 - 30 to 40%.
 - 40 to 50%.
- 17. Jim is a 1 year-old-boy. There is parental concern about a child's development, and there is evidence of delay in that he is able to shuffle around but unable to stand up and walk. Which is the next step you would take?**
- Tell the parents this is often seen so there are no worries he will walk.
 - See in a week's time to make up your mind.
 - See the child in 6 months' time and refer if he still cannot walk.
 - Make an early referral for diagnostic assessment.
 - See the child in a month's time to make up your mind.
- 18. About the definition of a developmental milestone, which of the following is the BEST description?**
- A developmental milestone is the age at which 50% of children acquire a specific skill.
 - A developmental milestone is the age at which a specific skill should be achieved for 95% of the children.
 - A developmental milestone is the age at which 75% of children acquire a specific skill.
 - A developmental milestone is the age at which 99.5% of children acquire a specific skill.
 - A developmental milestone is the age at which a specific and important development skill is achieved.
- 19. About the order of fine motor development, which of the following is the CORRECT order?**
- Palmar grasp – Pincer grip – Pencil control – Handwriting skill.
 - Palmar grasp – Pencil control – Pincer grip – Handwriting skill.
 - Palmar grasp – Pincer grip – Handwriting skill -- Pencil control.
 - Pincer grip – Palmar grasp – Pencil control – Handwriting skill.
 - Pincer grip – Pencil control – Palmar grasp – Handwriting skill.
- 20. About the sequence of gross motor development, which of the following is the usual order of development?**
- Roll over -- Head control – Sit – Stand -- Walk.
 - Head control – Roll over – Stand – Crawl -- Walk.
 - Roll over -- Sit – Head control -- Crawl -- Walk.
 - Head control – Sit – Crawl -- Stand -- Walk.
 - Head control – Roll over -- Crawl -- Sit – Walk.
- 21. About the worldwide prevalence of intellectual disability per thousand population, which of the following figure is CORRECT?**
- 8.37.
 - 9.37.
 - 10.37.
 - 11.37.
 12. 37.
- 22. About the risk factors that lead to health inequalities in adults with intellectual disabilities, which of the following is the LEAST IMPORTANT factor?**
- Impaired communication skills.
 - Reduced health literacy.
 - Social disconnectedness.
 - Poor housing.
 - Easy going personality.
- 23. About the clinical picture of adults with intellectual disability which of the following statement is CORRECT?**
- Most of adults with milder intellectual impairment are able to maintain skilled manual labour.
 - In a person with moderate disability, completely independent living in adult life is rarely achieved.
 - In adults with profound intellectual disability, the majority will still be continent.
 - In an adult with severe intellectual disability, the IQ is equivalent to one who is below 3 years.
 - In an adult with mild intellectual disability, the IQ is equivalent to one who is 8 years.
- 24. In persons with intellectual disability, the prevalence of epilepsy is of certain percentage that is sizeable. What is this prevalence?**
- 35-65%.
 - 30-60%.
 - 25-55%.
 - 20-50%.
 - 15-45%.
- 25. About the diagnostic DSM-5 criteria for Autism Spectrum Disorder, which of the following criteria is NOT CORRECT?**
- Persistent deficits in communication and social interaction.
 - Restricted repetitive patterns of behavior, interests or activities.
 - Symptoms must be present in early adolescence.
 - Symptoms cause clinically significant impairment in social, occupational and other areas of functioning.
 - Impairments are not better explained by intellectual disability or global developmental delay.

- 26. The number of people worldwide who have severe disabling illness which impact considerably on survival, daily function, employment, and quality of life is substantial. As of 2011, what is the number of people worldwide who have severe disabling illness?**
- 170 million.
 - 190 million.
 - 210 million.
 - 230 million.
 - 250 million.
- 27. In Singapore and worldwide, large numbers of people live with disabling illness. What is the proportion of the world's population have mental or physical disabilities?**
- 15%.
 - 17%.
 - 19%.
 - 21%.
 - 23%.
- 28. About feeding as an activity of daily living, which of the following statement is CORRECT?**
- Minimal assistance in feeding means the helper needs to scoop food on to a spoon repeatedly for the person who is feeding.
 - Preparation of modified food consistency is considered moderate assistance.
 - In a rheumatoid arthritis patient with temporo-mandibular joint involvement and has a lot of pain in chewing, assistance required is likely to be moderate.
 - Cutting meat for the patient to eat is considered as moderate assistance.
 - Independence in feeding is the ability to cut food, bring food to mouth, chew and swallow without a helper.
- 29. About dressing as an activity of daily living, which of the following statement is CORRECT?**
- If a person is able to do 2 of the 3 parts of upper body dressing, he is scored as maximal assistance required.
 - Independence in dressing is the ability to dress the upper and lower body completely without the need for a helper.
 - Wearing undergarments is counted in assessing the ability to dress.
 - Wearing socks is counted in assessing the ability to dress.
 - If a person is prescribed a rigid thoraco-lumbar orthosis and he is unable to do it but he can dress with clothing is scored as dressing independent.
- 30. About toileting as an activity of daily living, which of the following statement is CORRECT?**
- A patient who is unable to maintain continence is scored as maximal assistance required for toileting.
 - Perineal hygiene maintenance is not a step in toileting.
 - The person is scored as independent if he is able to perform all the 4 steps of toileting.
 - Transferring from bed or chair into the toilet seat is counted as a step of toileting.
 - Maintaining balance during toileting is not counted as a step in toileting.

FPSC No. 53 “Chronic Lung Disease” Answers to 30 MCQ Assessment		
1. A	11. A	21. D
2. D	12. A	22. A
3. B	13. E	23. E
4. B	14. B	24. C
5. E	15. C	25. D
6. D	16. C	26. B
7. D	17. E	27. A
8. C	18. A	28. B
9. C	19. B	29. D
10. E	20. E	30. C

FPSC No. 54 “Dementia” Answers to 30 MCQ Assessment		
1. D	11. A	21. E
2. B	12. A	22. B
3. C	13. E	23. A
4. D	14. B	24. C
5. C	15. C	25. C
6. D	16. C	26. B
7. D	17. E	27. A
8. C	18. A	28. B
9. C	19. B	29. D
10. E	20. E	30. C

FPSC No. 55 “Emergency Medicine” Answers to 30 MCQ Assessment		
1. D	11. A	21. D
2. B	12. A	22. A
3. B	13. B	23. C
4. D	14. E	24. E
5. A	15. C	25. D
6. E	16. C	26. B
7. D	17. E	27. B
8. C	18. A	28. A
9. E	19. B	29. C
10. C	20. E	30. D



READINGS

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

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.

National Institute of Education, Nanyang Technological University, 1 Nanyang Walk, Singapore 637616, Singapore. kenneth.poon@nie.edu.sg

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.

Copyright © 2011 Elsevier Ltd. All rights reserved.

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

Department of Neonatal and Developmental Medicine, Singapore General Hospital, Outram Road, Singapore. lian.wee.bin@sgh.com.sg

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.

Department of Neonatal and Developmental Medicine, Singapore General Hospital, Singapore.
woeibingpoon@yahoo.com

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 (AaDO₂) 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

Department of Neonatal and Developmental Medicine, Singapore General Hospital, Outram Road, Singapore 169608.
wblian@specialkidsclinic.com.sg

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

National University Hospital, Diagnostic Radiology, 5 Lower Kent Ridge Road, Singapore 119074, Singapore.
tan_ai_peng@hotmail.com.

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

Yong Loo Lin School of Medicine, Singapore.

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.

© 2013 The Authors. Journal of Paediatrics and Child Health © 2013 Paediatrics and Child Health Division (Royal Australasian College of Physicians).

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

Department of Neonatology, KK Women's & Children's Hospital, Singapore. pradeep.raut@kkh.com.sg

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 ± 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

Department of Community Psychiatry, Institute of Mental Health, 10 Buangkok View, Singapore 539747. Ker_Chiah_Wei@imh.com.sg

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

Yong Loo Lin School of Medicine, National University of Singapore, National University Health System, Singapore.

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 ≥ 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

Department of Psychological Sciences, Norwich Medical School, University of East Anglia, Norwich, United Kingdom.

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.

Copyright © 2013 Elsevier Ltd. All rights reserved.

PMID: 24051363 [PubMed - in process]



Useful Information

- Useful Resources for Medical Practitioners: Ministry of Social and Family Development (MSF) Disability Resource List
- Useful Resources for Medical Practitioners: Application for Disability Schemes Functional Assessment Report
- Useful Resources for Medical Practitioners: Mobility Report

USEFUL INFORMATION

All information is correct as of April 2014.

Compiled by Institute of Family Medicine (IFM) & Ministry of Social and Family Development (MSF) Workgroup

Useful Resources for Medical Practitioners: Ministry of Social and Family Development (MSF) Disability Resource List

Life Stage	Service	Short Description	Referral Point
Children and Youth	Early Intervention Programme for Infants and Children (EIPIC)	✓ For children with moderate to severe developmental delays in specialised centres	SG Enable http://www.sgenable.sg/ Infoline: 1800 8585 885 Fax: 6226 2366 Infoline Operating Hours Monday to Friday: 8.30am to 6.00pm Saturday: 8.30am to 12.30pm Closed on Sundays and Public Holidays
	Development Support Programme (DSP)	✓ For children with mild developmental delays in mainstream pre-schools	
	Integrated Child Care Programme (ICCP)	✓ For children with special needs for preparation to enter into mainstream education	
Education	Special Education (SPED) Schools	✓ Customised educational programmes with Individual Education Plans for all pupils ✓ Support from paramedical professionals such as psychologists, speech therapists, occupational therapists, physiotherapists and social workers	MOE Schools
Employment	Open Door Fund	✓ Funding of up to \$100,000 per company for job redesign or workplace modifications ✓ Apprenticeship training allowance for persons with disabilities	SG Enable http://www.sgenable.sg/ Mainline: 6505 9748 Fax: 6226 2366 Email: opendoor@sgenable.sg

	Workfare and Special Employment Credits for Persons with Disabilities	✓ Extended to persons with disabilities who have attended SPED schools	CPF Board For queries on WIS, Hotline: 1800-222-6622 (Mondays to Fridays: 8am-5:30pm) Email: member@cpf.gov.sg Website: http://mycpf.cpf.gov.sg/Members/Gen-Info/WIS For queries on SECs, Hotline: 1800 2222 888 (Mondays to Fridays: 8.00am to 5.30pm) Email: employer@cpf.gov.sg Website: http://www.sec.gov.sg/sec2012.html
	Vocational Assessment, Job Placement and Job Support Services	✓ Vocational Assessment: Evaluation of skills, interest and employability for employment suitability ✓ Job placement and Job Support: Employment opportunities for both employers and people with disabilities	SG Enable http://www.sgenable.sg/ Mainline: 6505 9748 Fax: 6226 2366 Email: opendoor@sgenable.sg
Adult Care	Adult Disabled Homes/Hostels for PWDs	✓ Residential services for persons with disabilities who are either destitute, neglected or whose caregivers are unable to take care of them	SG Enable http://www.sgenable.sg/for-adults/ Infoline: 1800 8585 885 Fax: 6226 2366 Infoline Operating Hours Monday to Friday: 8.30am to 6.00pm Saturday: 8.30am to 12.30pm Closed on Sundays and Public Holidays
	Day Activity Centres (DACs)	✓ Community-based service for care and skills training	
Financial and Legal Security	Special Needs Trust Company (SNTC)	✓ Non-profit trust services for persons with special needs ✓ Development of care plans	Appointment to be made with SNTC http://www.sntc.org.sg/ Main line: 6278 9598 Email: enquiries@sntc.org.sg

	Special Needs Savings Scheme (SNSS)	✓ Monthly disbursements of nominated CPF monies upon CPF member's demise	SG Enable http://www.sgenable.sg/schemes/financial-support/special-needs-savings-scheme/ Infoline: 1800 8585 885 Fax: 6226 2366 Infoline Operating Hours Monday to Friday: 8.30am to 6.00pm Saturday: 8.30am to 12.30pm Closed on Sundays and Public Holidays
	Mental Capacity Act	✓ Legal framework to enable and support persons who lack mental capacity ✓ Provision of safeguards (i.e. court-appointed deputies and donees)	Office of Public Guardian (OPG), MSF http://www.publicguardian.gov.sg/About-OPG/The-Office-of-the-Public-Guardian Main line: 1800 226 6222 Email: enquiry@publicguardian.gov.sg
Grants and Schemes	Foreign Domestic Worker (FDW) Grant	✓ Monthly \$120 grant ✓ Over and above \$95 levy concession	SG Enable http://www.sgenable.sg/ Infoline: 1800 8585 885 Fax: 6226 2366 Infoline Operating Hours Monday to Friday: 8.30am to 6.00pm Saturday: 8.30am to 12.30pm Closed on Sundays and Public Holidays
	Assistive Technology Fund (ATF)	✓ Financial assistance for purchase of assistive technology for education or work purposes	
	Car Park Label Schemes (CPLS)	✓ Eligibility to park vehicles at designated parking lots	
	Caregiver Training Grant	✓ Subsidies for caregivers to attend relevant training courses/programmes	
	Computer Access Trust Fund (CATF)	✓ Financial assistance for purchase of computers and computer-related assistive technology devices for educational or work purposes.	
	LTA Cares Fund	✓ Charity Fund catering to the transport needs of working adults and students in mainstream schools who are financially and physically disadvantaged	

	Special Assistance Fund	✓ Provides financial assistance to low-income families in purchasing assistive equipment to aid persons with disabilities in their mobility or rehabilitation	
	Traffic Accident Fund	✓ Provides financial assistance to persons who have acquired permanent or temporary disabilities due to traffic accidents	
	Public Transport Concession for Persons with Disabilities	✓ Concessionary travel on public transport for persons with disabilities	
	VWO Transport Subsidy	✓ Transport subsidies for persons with disabilities accessing community based services such as EIPIC, SPED schools, Day Activity Centres and Sheltered Workshops	
	Taxi Subsidy Scheme	✓ Taxi subsidies for persons with disabilities who are unable to take public transport and rely on taxis to commute to work and school	

Useful Resources for Medical Practitioners: Application for Disability Schemes Functional Assessment Report

Application for Disability Schemes Functional Assessment Report

APPLICANT

Type of scheme(s) you wish to apply (please tick):

☐ **Foreign Domestic Worker (FDW) Levy Concession (Persons with Disabilities)**

Aims to provide support to families of persons with disabilities to employ FDW to assist the persons with disabilities who are likely to require permanent assistance in performing at least 1 activity of daily living (ADL). Eligible employer will pay a lower monthly FDW levy of \$120 to the Ministry of Manpower.



☐ **Foreign Domestic Worker (FDW) Grant**

Aims to provide more support to families who care for persons who have at least moderate disability. They are likely to require permanent assistance in performing at least 3 ADLs. Eligible employer of FDW will receive a monthly grant of \$120 given by the Ministry of Health. The Grant applies to households with a per person household monthly income of up to \$2,600. The FDW must also attend caregiver training courses pre-approved by AIC.

Please send this report together with the completed application form and supporting documents **via mail** to:
Agency for Integrated Care
No. 7 Maxwell Road, #05-08,
Annexe B MND Complex,
Singapore 069111

☐ **Special Needs Savings Scheme (SNSS)**

Aims to encourage parents of child(ren) with special needs to use their CPF monies to save up for their child(ren)'s long-term care needs. The child with special needs has to require assistance in at least 1 ADL, or be attending a Special Education school.



☐ **Public Transport Concession for Persons with Disabilities**

Aims to assist persons with disabilities in their transportation needs by providing concessionary rates for travel on buses and trains. Eligible persons should be aged below 60 years of age, are Singapore Citizens or Permanent Residents, and have a permanent disability of in one or more of the following: physical disability, visual impairment, hearing impairment, autism spectrum disorder or intellectual disability. Persons with permanent physical disability who have yet to be assessed may use this form to support their application for the scheme. Persons with permanent disabilities other than physical disability should not use this form. Instead, they may provide their latest doctor's memo or verification form endorsed by VWOs providing disability services and programmes, to support their application for the transport concession.

Please send this report together with the completed application form **via fax or mail** to:
SG Enable Ltd
141 Redhill Road
Singapore 158828
Website: www.sgenable.sg
Fax: 6226 2366 | Infoline: 1800-8585 885

☐ **Enhancement for Active Seniors (EASE)**

Aims to enhance the safety and comfort of seniors living in HDB flats through the installation of improvement items at subsidised rates for Singapore Citizen households. Eligible persons include seniors aged between 65 years and 69 years who require assistance for at least 1 ADL. Seniors aged above 70 years and above need not undergo an ADL assessment.

Contact No: _____

Address: _____

Please send this report together with HDB EASE Application to the respective HDB Branches*.

Alternatively, please attach this report when submitting the EASE application via e-services on HDB InfoWEB or m-service in Mobile@HDB.

*Note: Please refer to HDB InfoWEB (www.hdb.gov.sg) for a list of HDB Branches or call HDB toll-free EASE enquiry line at 1800-9332990 on weekdays (excluding Public Holidays) from 8.00am to 5.00pm for assistance.

Please note that this assessment form is **not** valid for ElderShield or the Interim Disability Assistance Programme for the Elderly (IDAPE). If you are applying for ElderShield/IDAPE, please use the ElderShield/IDAPE claim form instead. More information is available from the websites of Aviva, Great Eastern and NTUC Income.

ASSESSOR**FUNCTIONAL ASSESSMENT***(if no patient's sticky label)***Name of Person Assessed** : _____**NRIC/BC** : _____Patient's Sticky Label
(where applicable)

Section 1: Functional Assessment*		Yes	No
a. Activities of Daily Living (ADLs)		Requires help/supervision most of the time	No help is required
i	Washing or Bathing	☐	☐
ii	Dressing	☐	☐
iii	Feeding	☐	☐
iv	Toileting	☐	☐
v	Transferring	☐	☐
vi	Mobility	☐	☐
Section 2: Comments by Assessor			
b. Are the disabilities permanent*?		Yes ☐	No ☐
d. Date of onset of impairment		(estimated dd/mm/yyyy)	
Additional comments (if any) _____ _____			
I confirm that the assessment done for the above applicant is true and correct to my best knowledge. I am aware that the assessment for this application will serve as reference only. The Scheme Administrator reserves the right to make the final decision on the application outcome and reject any application if the information is found to be inaccurate, or if any relevant information has been withheld by the applicant.			
Name and Signature of Assessor		Stamp of Clinic / Hospital	Tel / Fax Nos.

Important Note:

Assessor must sign against any amendment made and affix the official stamp of the clinic / hospital. If not, the report will be deemed to be incomplete.

*** Notes for Assessor**

- a. *Washing or Bathing* Ability to wash in the bath or shower (including getting into and out of the bath or shower) or wash by other means.
- b. *Dressing* Ability to put on, take off, secure and unfasten all garments (upper and lower) and any braces, artificial limbs or other surgical appliances.
- c. *Feeding* Ability to feed oneself after food has been prepared and made available.
- d. *Toileting* Ability to use the toilet or manage bowel and bladder functions through the use of protective undergarments or appropriate surgical appliances.
- e. *Transferring* Ability to move from (a lying position on the) bed to an upright chair or wheelchair, and vice versa.
- f. *Mobility* Ability to walk indoors from room to room on level surface, without the use of assistive devices such as walking frame, walking stick, brace, cane, crutch, prosthetic device, or assistance of another person. To also take into account the applicant's restriction to walk due to medical conditions such as lung, cardiac, arthritic, neurological, or orthopaedic condition and the use of oxygen.

ONLY FOR FDW GRANT APPLICATION**CAREGIVING TRAINER****CAREGIVER TRAINING RECEIVED BY FOREIGN DOMESTIC WORKER (if applicable)***(for use by authorised caregiver trainer only)***Name of Foreign Domestic Worker (FDW) :** _____**FIN / Work Permit of FDW :** _____**Section 3: FDW has been trained in the following components (please tick)**

- | | | |
|---|------------------------------------|--|
| ☐ Washing / Bathing / Personal Hygiene | ☐ Dressing | ☐ Transferring / Bed Care |
| ☐ Feeding / Medication Serving | ☐ Toileting | ☐ Mobility |
| ☐ Others (please state) _____ | | |

I confirm that the training done for the above applicant is true and correct. I am aware that the training for this application will serve as reference only. The Agency for Integrated Care (AIC) reserves the right to make the final decision on the application outcome and reject any application if the information is found to be inaccurate, or if any relevant information has been withheld by the applicant.

Name and Signature of Trainer_____
Stamp of Organisation_____
Date_____
Tel / Fax Nos.

Trainer must sign against any amendment made and affix the official stamp of the organisation. If not, the report will be deemed to be incomplete.



MOBILITY REPORT

ASSESSMENT (To be completed by Medical Doctor ONLY)

Assessing Doctor must sign against any amendments made on this form. If not, it will be deemed as "Incomplete"

Name of Applicant: _____ (Mr / Ms/ Mdm) Identification No: _____

Does the applicant need a mobility aid when travelling outdoors? ☐ YES ☐ NO

If "YES", please tick ✓ the applicant's **MAIN MODE** (please select one only) of mobility aid used :

☐ Wheelchair ☐ Prosthesis / Orthotic ☐ Crutches ☐ Walking Frame ☐ Quad Stick

☐ Others (Please specify) : _____

Does the applicant have any physical disability or medical condition which causes mobility constraint? ☐ YES ☐ NO

If "YES", please tick ✓ the type of physical disability:

☐ Cerebral Palsy

☐ Loss/Deformity of limbs

☐ Quadraplegic

☐ Paraplegia

☐ Spina Bifida

☐ Osteogenesis Imperfecta

☐ Muscular Dystrophy

☐ Tetraplegia

☐ Poliomyelitis

☐ Others : _____

Nature of disability/ condition: ☐ Permanent

☐ Temporary

(INDICATE estimated recovery period) _____

CONFIRMATION OF ASSESSMENT BY MEDICAL DOCTOR

I confirm that the assessment done for the above applicant is true and correct. The SG Enable reserves the right to make the final decision on the application outcome and reject any application if the information is found to be inaccurate, or if any relevant information has been withheld by the applicant.

Name and Signature of Assessing Doctor

MCR Number of Assessing Doctor

Stamp of Clinic or Hospital

Tel and Fax Nos.

Date of Assessment*

**Mobility Report is valid for a period of 6 months from the date of assessment.*



P R I S M S E C T I O N

(Patients' Revelations as Insightful Studies of their Management)

- When paired HbA_{1c} and fasting glucose don't match, which is telling the truth?

WHEN PAIRED HbA_{1c} AND FASTING GLUCOSE DON'T MATCH, WHICH IS TELLING THE TRUTH?

Dr Kee Kok Wai

ABSTRACT

This article explores the pitfalls in using glycated hemoglobin A (HbA_{1c}) as a glycaemic monitoring tool in a patient with alpha-thalassemia intermedia. It includes the methods used for HbA_{1c} measurement, such as charge-based or structure-based, presence of hemoglobin variants, ineffective erythropoiesis, concomitant iron deficiency and peripheral hemolysis. For such cases, the use of blood sugar profiles can be a useful alternative to monitor glycaemic control.

Keywords:HbA_{1c}, thalassemia, iron deficiency, anemia

SFP2014; 40(2): 78-80

PATIENT'S REVELATION: WHAT HAPPENED?

WMW is a 77 year old Chinese gentleman who was seen at the polyclinic regularly for diabetes mellitus after being discharged from the hospital in year 2006. He was diagnosed with alpha-thalassemia intermedia in year 2006 when he first presented with hemolytic anemia. Anemia work-up showed iron saturation of 48% and Vitamin B12 level of 191 pmol/L (reference range 133-675 pmol/L). Folate level was 7nmol/L (reference range 8-30 nmol/L) and he was started on regular folic acid supplement. There was no history of regular blood transfusion and his baseline hemoglobin level ranged from 8.7 to 10.6 g/dL in year 2012.

I saw him during a regular follow up, his baseline dose of oral hypoglycaemic agents was metformin 500mg BD and glipizide 5mg BD. His glycated hemoglobin A (HbA_{1c}) was 6.9 % but his paired fasting glucose was 20.2 mmol/L. After ensuring the validity of fasting glucose level by checking the fasting status, overnight heavy meal and hyperglycemia symptoms, I suggested home blood sugar monitoring to monitor glycaemic control. Patient was not competent in using glucometer and depended on his son to do it. However, home blood sugar monitoring was not done as the son worked long hours outside the home. Risk of hypoglycaemia with increased in oral hypoglycaemic agents was discussed with the patient and his son. Careful instructions and patient education on hypoglycemia symptoms were administered. The dose of glipizide and metformin was then increased gradually.

Patient subsequent HbA_{1c} decreased to 4.6% with paired fasting glucose level of 10.5 g/dL after increased of metformin

to 850mg TDS and glipizide to 10mg OM and 5mg ON. There was no hypoglycemia symptoms experienced. Glipizide dose was not decreased despite low HbA_{1c} level even though glipizide was halved (glipizide 2.5mg BD) in October 2012 when HbA_{1c} is found to be 5.7%

GAINING INSIGHT INTO THE CASE MANAGEMENT: WHAT ARE THE ISSUES?

WMW has a background history of hypochromic microcytic anemia due to alpha thalassemia intermedia with increased hemolysis. A big discrepancy existed between the paired HbA_{1c} and fasting glucose result. In majority of patients, HbA_{1c} is the more reliable marker for glycaemic control while glucose level can fluctuate according to the fasting or prandial state. In this case, reliability of HbA_{1c} results should be questioned in view of low hemoglobin, presence of hemoglobin variant and ongoing increased hemolysis.

The relationship of HbA_{1c} and glucose level was established in the ADAG (A_{1c}-derived average glucose) study group¹. Calculated average glucose levels on linear regression model is equal to [(28.7mg/dl x HbA_{1c}) - 46.7mg/dl] or [(1.6mmol/L x HbA_{1c}) - 2.6 mmol/L]. This formula can be a rough guide on the expected average glucose level with the reported HbA_{1c} level. The estimated average glucose level for a HbA_{1c} level of 6.9% is 8.4mmol/L. However, the fasting blood sugar for this case was 20.2 mmol/L.

TABLE 1. ESTIMATED AVERAGE GLUCOSE LEVEL BY LINEAR REGRESSION MODEL:

[(28.7mg/dl x HbA_{1c}) - 46.7mg/dl] or [(1.6mmol/L x HbA_{1c}) - 2.6 mmol/L]¹

HbA _{1c} (%)	Glucose in mg/dl	Glucose in mmol/L
4	68	3.8
5	97	5.4
6	126	7.0
7	154	8.6
8	183	10.2
9	212	11.8
10	240	13.4
11	269	14.9
12	298	16.5
13	326	18.2
14	355	19.8

The presence of anemia is another confounder leading to incorrect HbA_{1c} measurement for this patient. HbA_{1c} is formed by non-enzymatic addition of glucose to N-terminal valine of the hemoglobin beta-chain². Alpha thalassemia intermedia which is a hemoglobinopathy affecting the alpha globin chain, theoretically will not affect the glycation on N-terminal of beta-chain. However, in a study by Pravatmuang et al, HbA_{1c} levels in HbH disease were found

KEE KOK WAI

Family Medicine Resident,

National Healthcare Group Polyclinics – Toa Payoh

to be significantly lower by high performance liquid chromatography (HPLC) relative to immunoturbidimetry assays in HbA_{1c} measurement. The observation was postulated due to early elution of beta-4 tetramers and HbH in HPLC chromatogram³.

Besides that, alpha thalassemia intermedia is associated with ineffective erythropoiesis and peripheral hemolysis. Erythropoiesis is ineffective due to the imbalance in the production of alpha and beta-globin chains. Unstable globin chain tetramers precipitate and oxidise into methemoglobin and hemichromes with eventual separation of heme from globin. The free iron released from heme disintegration catalyzes the formation of reactive oxygen species. It causes oxidation of membrane proteins, structural membrane defects, and exposure of red-cell senescence antigens causing premature cell death within the bone marrow (ineffective erythropoiesis) or peripheral circulation (peripheral hemolysis)⁴. Hence the HbA_{1c} level can be falsely low in this case of HbH disease of alpha thalassemia intermedia.

Reduced life span of the red blood cells due to peripheral hemolysis will affect the HbA_{1c} level as it is a time-weighted measurement of the blood sugar levels. The average life span of red blood cells is 120 days. The HbA_{1c} level at any point in time is contributed by both the oldest and youngest red blood cells. Plasma sugar for the past 30 days contribute to 50% of HbA_{1c}; plasma sugar from 30 to 60 days earlier contribute to 25% of HbA_{1c} measurement; and the remaining 25% of HbA_{1c} measurement contributed from plasma sugar of 60 to 120 days earlier. Plasma sugar levels from 90 to 120 days earlier contribute only about 10% of HbA_{1c} measurement^{5,6}.

STUDY THE MANAGEMENT: HOW DO WE APPLY IN OUR PRACTICE?

HbA_{1c} measurement is currently a standard measurement for diabetic control. The Diabetes Control and Complications Trial (DCCT) in 1993 found the concentration of HbA_{1c} to be an excellent predictor of diabetes-related long term complications⁷. Any condition that shortens erythrocyte survival or decreases mean erythrocyte age, namely hemolysis and recent blood loss, will falsely lower HbA_{1c} test results regardless of the assay method used⁸.

Besides alpha thalassemia, other hemoglobinopathies have different influences on the HbA_{1c} measurement. There are 2 main methods of HbA_{1c} measurement, namely by charge-based or structure-based. Examples of structure-based analysis are immunoassay, which involves antibody recognition of the N-terminal of beta chain of HbA_{1c}, and boronate affinity methods. In other common thalassemias that we seen in Singapore, namely beta-thalassemia and Hemoglobin E (HbE) disease, immunoassays and boronate affinity methods may underestimate HbA_{1c} measurement due to the elevated fetal hemoglobin (HbF). Both immunoassay and boronate affinity methods show interference from HbF levels above 10-15%^{9,10}. National Healthcare Group Polyclinics use an ion-exchange

high performance liquid chromatography (HPLC) method, i.e. charge-based method, for both capillary and venous whole blood sample. Bio-Rad Variant II, one example of HPLC method, only shows interference from Hb F levels of above 25%⁹. However, other studies^{11,12} found significantly lower HbA_{1c} values measured by HPLC when compared to the immunoassay, in patients with heterozygous Hb E. The reason postulated is the fact that lysine for glutamic acid substitution at position 26 in HbE was far from the N-terminal of the beta-globin chain where HbA_{1c} glycation and antibody binding took place^{11,12}.

Other glucose control markers such as fructosamine can be an option in this case as it is not affected by hemoglobinopathies. However, it is not readily available in primary care, more expensive and fluctuates with serum albumin level¹³. Major trials on diabetes do not use fructosamine even though there is generally good correlation between serum fructosamine and HbA_{1c} levels¹⁴.

Another common cause of hypochromic microcytic anemia, other than thalassemia, is iron deficiency anemia. Malondialdehyde increases in patients with iron deficiency anemia and enhances the glycation of hemoglobin¹⁵. Patients with iron deficiency anemia thus present with higher HbA_{1c}. Iron replacement therapy lowers HbA_{1c} in both diabetic and non-diabetic individuals¹⁵⁻¹⁷. In United States, National Health and Nutrition Examination Survey 1999–2006 reported among women with iron deficiency (at least two abnormalities including free erythrocyte protoporphyrin more than 70 g/dl erythrocytes, transferrin saturation less than 16%, or serum ferritin of less than or equal to 15 g/l) was associated with increased odds of an HbA_{1c} more than or equal to 5.5% before and after adjustment for age and race, waist circumference, parity, and hysterectomy¹⁸. However, iron status did not significantly affect HbA_{1c} concentrations in a regression study model¹⁹.

In patients with microcytic and hypochromic anemia, pitfalls to HbA_{1c} measurement exist as described above. The common differential diagnoses for hypochromic microcytic anemia are iron deficiency anemia and thalassemias. From the various methods of HbA_{1c} measurements, the HbA_{1c} results can be falsely low in thalassemias and falsely high in iron deficiency anemia. It is reported locally that 4 % of Chinese and Malays possess the gene for alpha thalassaemia, 3% of Chinese, Malays and Indians possess the gene for beta thalassaemia whereas 5% of Malays are heterozygous carriers for HbE compared to < 1% in Chinese and Indians²⁰. Iron deficiency anemia however tends to overestimate the HbA_{1c} level. Therefore, a high clinical index of suspicion should exist especially for patients with anemia, when HbA_{1c} level does not correlate with the blood sugar profile despite no recent changes in diet or medication. It will be a good alternative practice to use blood sugar profile as an indicator of diabetes control in patient with thalassemia intermedia and severe iron deficiency anemia.

The use of estimated average glucose level $[(28.7\text{mg/dl} \times \text{HbA}_{1c}) - 46.7\text{mg/dl}]$ or $[(1.6\text{mmol/L} \times \text{HbA}_{1c}) - 2.6\text{mmol/L}]$

can be considered in routine diabetic care by family physician. It gives a better measurement relates to the numbers that patients get on the glucometer. This gives a better glycemia control reflection during patient education. A wide disparity of estimated average glucose and fasting glucose levels suggests underlying confounders affecting the readings. Besides small chance of picking up “silent” anemia, it does give a clue of a possibility of non-compliance. A much higher estimated average glucose level derived from HbA_{1c} compared to fasting glucose level may signify a bad ambient glucose control for the past 3 months and a very tight control or compliance for the past few days before the laboratory testing, besides attributing it to high post prandial glucose contribution.

CONCLUSION

This case illustrates an example of HbA_{1c} underestimation in alpha thalassemia intermedia. It reminds us to question the validity of HbA_{1c} results when a discrepancy exists in a paired HbA_{1c} and fasting glucose levels. Home blood sugar profile may provide a more accurate measurement of glycemic control of our diabetic patients with thalassemia intermedia. Estimated average glucose derived from HbA_{1c} can be a useful tool in diabetic care by family physician.

REFERENCES

1. Nathan DM, Kuenen J, Borg R, Zheng H, Schoenfeld D, Heine RJ. Translating the A1C Assay Into Estimated Average Glucose Values. *Diabetes Care*. 2008; 31(8): 1473-8.
2. Sacks D. Carbohydrates. In: Burtis CA AE, Bruns DE, Eds, editor. *Tietz Textbook of Clinical Chemistry and Molecular Diagnostics*. St. Louis: Elsevier Saunders; 2006. p. 837-902.
3. Pravatmuang P, Sae-Ngow B, Whanpuch T, Leowattana W. Effect of HbE and HbH on HbA1C level by ionic exchange HPLC comparing to immunoturbidimetry. *Clinica Chimica Acta*. 2001; 313(1-2): 171-8.
4. Musallam KM, Rivella S, Vichinsky E, Rachmilewitz EA. Non-transfusion-dependent thalassemias. *Haematologica*. 2013; 98(6): 833-44.
5. Rohlfing CL, Wiedmeyer H-M, Little RR, England JD, Tennill A, Goldstein DE. Defining the Relationship Between Plasma Glucose and HbA1c: Analysis of glucose profiles and HbA1c in the Diabetes Control and Complications Trial. *Diabetes Care*. 2002; 25(2): 275-8.
6. Dorchy H. What Level of HbA1c Can be Achieved in Young Diabetic Patients Beyond the Honeymoon Period? *Diabetes Care*. 1993; 16(9): 1311-3.
7. Diabetes Control and Complications Trial Research Group. The Effect of Intensive Treatment of Diabetes on the Development and Progression of Long-Term Complications in Insulin-Dependent Diabetes Mellitus. *New England Journal of Medicine*. 1993; 329(14): 977-86.
8. Goldstein DE, Little RR, Lorenz RA, Malone JJ, Nathan D, Peterson CM. Tests of Glycemia in Diabetes. *Diabetes Care*. 1995; 18(6): 896-909.
9. Little RR, Rohlfing CL, Hanson SE, Schmidt RL, Lin C-N, Madsen RW, et al. The Effect of Increased Fetal Hemoglobin on 7 Common Hb A1c Assay Methods. *Clinical Chemistry*. 2012; 58(5): 945-7.
10. Rohlfing CL, Connolly SM, England JD, Hanson SE, Moellering CM, Bachelder JR, et al. The Effect of Elevated Fetal Hemoglobin on Hemoglobin A1c Results: Five Common Hemoglobin A1c Methods Compared With the IFCC Reference Method. *American Journal of Clinical Pathology*. 2008; 129(5): 811-4.
11. Little RR, Rohlfing CL, Hanson S, Connolly S, Higgins T, Weykamp CW, et al. Effects of Hemoglobin (Hb) E and HbD Traits on Measurements of Glycated Hb (HbA1c) by 23 Methods. *Clinical Chemistry*. 2008; 54(8): 1277-82.
12. Nasir N, Thevarajah M, Yean C. Hemoglobin variants detected by hemoglobin A1c (HbA1c) analysis and the effects on HbA1c measurements. *International Journal of Diabetes in Developing Countries*. 2010; 30(2): 86-90.
13. Howey JE, Browning MC, Fraser CG. Assay of serum fructosamine that minimizes standardization and matrix problems: use to assess components of biological variation. *Clin Chem*. 1987; 33(2 Pt 1): 269-72.
14. Narbonne H, Renacco E, Pradel V, Portugal H, Vialettes B. Can fructosamine be a surrogate for HbA1c in evaluating the achievement of therapeutic goals in diabetes? *Diabetes Metab*. 2001; 27(5 Pt 1): 598-603.
15. Sundaram RC, Selvaraj N, Vijayan G, Bobby Z, Hamide A, Rattina Dasse N. Increased plasma malondialdehyde and fructosamine in iron deficiency anemia: Effect of treatment. *Biomedicine & Pharmacotherapy*. 2007; 61(10): 682-5.
16. Tarim Ö, Küçükerdoğan A, Günay Ü, Eralp Ö, Ercan . Effects of iron deficiency anemia on hemoglobin A1c in type I diabetes mellitus. *Pediatrics International*. 1999; 41(4): 357-62.
17. Coban E, Ozdogan M, Timuragaoglu A. Effect of Iron Deficiency Anemia on the Levels of Hemoglobin A1c in Nondiabetic Patients. *Acta Haematologica*. 2004; 112(3): 126-8.
18. Kim C, Bullard KM, Herman WH, Beckles GL. Association Between Iron Deficiency and A1C Levels Among Adults Without Diabetes in the National Health and Nutrition Examination Survey, 1999–2006. *Diabetes Care*. 2010; 33(4): 780-5.
19. Ford ES, Cowie CC, Li C, Handelsman Y, Bloomgarden ZT. Iron-deficiency anemia, non-iron-deficiency anemia and HbA1c among adults in the US*. *Journal of Diabetes*. 2011; 3(1): 67-73.
20. Wong HB. Thalassemia in Singapore: problems and solutions. *Ann Acad Med Singapore*. 1984; 13(3): 473-86.

GUIDELINES AND INFORMATION FOR AUTHORS

THE SINGAPORE FAMILY PHYSICIAN

Authors are invited to submit articles for publication in *The Singapore Family Physician* on the understanding that the work is original and that it has not been submitted or published elsewhere. Your original article will be considered for publication on the understanding that they have to be approved by the Editorial Board via a double-blinded peer-review process and subject to revision. Authors are encouraged to consult the recommendations in the *Uniform Requirements for Manuscripts Submitted to Biomedical Journals* (<http://www.icmje.org/index.html>) which the SFP is in accord with.

The following types of articles may be suitable for publication: case reports/ study, original research works, audits of patient care, protocols for patient or practice management and letters to the Editor. The CME and review articles will be published under the prerogative of the Institute of Family Medicine (IFM) in the College of Family Physicians Singapore. The article should be written in British English, and not be more than 3000 words in length. This must be submitted in an electronic form and of a format that is compatible with major word processor applications. Submissions in Microsoft Word in Word 1997-2003 format (.doc) is preferred, later versions (.docx) will not be accepted.

From 31 January 2010 all articles submitted for publication must be submitted electronically through the **SFP Editorial Manager**, our online submission and peer-review system which can be accessed at www.editorialmanager.com/sfp/default.asp.

All instructions for registration and submission can be found at the webpage. Authors and reviewers can follow clearly the progress of the manuscript submission and review process by logging into the **SFP Editorial Manager**. An online users' guide, authors' and reviewers' instructions are also located at the website in case of queries and difficulties. Any problems encountered logging in can be addressed to editorialoffice@cfps.org.sg.

RECOMMENDED FORMAT FOR THE MANUSCRIPT

The submission should comprise of the following:

1. Title Page
2. Summary/ Abstract
3. Key Words
4. Text/ Manuscript (anonymised version)
5. Tables
6. Illustrations
7. Authors Agreement/ Copyright Assignment Form
8. Patient's Consent Form, if necessary (including consent for photograph or illustration taken of human subject)

and each one of these sections should start on a fresh page.

Authors are advised to ensure the anonymity of study subjects and patients by removing any and all information that could compromise their privacy from the submission.

The text should be typed in Arial font, 12 point size with a 1.5 line space.

The Title Page

- The title should be concise and highlight the key elements of the article.
- Include on the title page first name, qualifications, present appointments, type and place of practice of each contributor.

- Include name, address, handphone number and email address of the first author to whom correspondence should be sent.
- Insert at the bottom: name and address of institution or practice from which the work originated.

The Summary/ Abstract

- The summary should describe why the article was written and present the main argument or findings.
- Limit words as follows: 250 words for major articles; 200 words for case reports.

Key Words

- Add, at the end of summary in alphabetical listing, keywords of up to 5 in number which will be used for article indexing and retrieval under Medical Subject Headings or MeSH. MeSH is the NLM controlled vocabulary thesaurus used for indexing articles for WPRIM and PubMed. Please refer to www.nlm.nih.gov/mesh/ for details.

The Text/ Manuscript (full complete)

The text should have the following sequence:

- **Introduction:** State clearly the purpose of the article.
- **Methods:** Describe the selection of the subjects clearly. Give References to established methods, including statistical methods; provide references and brief descriptions of methods that have been published but are not well known. Describe new or substantially modified methods, giving reasons for using them and evaluate their limitations. Include numbers of observations and the statistical significance of the findings where appropriate.

Drugs must be referred to generically; all the usual trade names may be included in parentheses.

Dosages should be quoted in metric units.

Laboratory values should be in SI units with traditional unit in parentheses.

Do not use patients' names, initials or hospital numbers to ensure anonymity.

- **Results:** Present results in logical sequence in the text, table and illustrations.
- **Statistics:** Describe statistical methods which can be easily understood and verified by the reader. Use technical terms in its proper place, and where possible quantify readings and indicate errors of uncertainty and confidence intervals.
- **References:** The author(s) is/ are responsible for the accuracy and completeness of the references, which should be identified in the text by superscript Arabic numerals in the order of first citation and noted in numerical order at the end of the text.

Digital Object Identifier (DOI) citation information must be included as a full DOI URL by prepending <http://dx.doi.org/> to any DOI reference. To identify a DOI reference, please visit CrossRef at <http://www.crossref.org/guestquery/> and enter in the reference information in the box provided to locate the DOI where available. Such DOI information will facilitate readers to trace referenced papers easily.

Where there are more than three authors, the first three should be named and then followed by et al.

Example:

Tan and Ho. Treat-to-target approach in managing modifiable risk factors of patients with coronary heart disease in primary care in Singapore: What are the issues? Asia Pacific Family Medicine, 2011;10:12. doi:10.1186/1447-056X-10-12.

Authors may wish to familiarise themselves with the AMA style for the citing of references for BioMedical publications at www.amamanualofstyle.com.

Tables

Tables should be submitted on a separate page. Label them in roman-numeric sequence [I,II,III etc] and ensure they are clear and with explanatory legends as required.

Illustrations

- Illustrations must be submitted in a separate page, and should be provided whenever appropriate. Illustrations should be cited in the text. When required, it is the author's responsibility to obtain permission to reproduce illustrations. Authors need to ensure that photographs, illustrations and figures do not contain any information that will reveal the identities of the patients and authors. From 1 January 2012, all photographs and illustrations taken from any human subject must be accompanied by the respective endorsed consent form. Clear captions to the figures should be provided.

Anonymised Text

As the original article will be subjected to a double-blinded peer review process, all identification of names and institutions have to be removed from this version to facilitate the peer review process.

Author Contributorship for Original Article Submission

Author details must be included in the relevant fields when submitting an article. Only those who have made substantial contributions to the study and/ or preparation of the article should be acknowledged as authors and named in full. The SFP follows the International Committee of Medical Journal Editors (ICMJE) criteria pertaining to authorship (refer to http://www.icmje.org/ethical_1author.html). The precise role(s) of each author should be included in the 'contributorship' declaration.

Declaration of Conflicts of Interest

The SFP requires the author(s) to provide full and detailed declarations of any conflicts of interest. Where there are none, please use the following declaration: "The author(s) declare(s) that he/she/they has/have no conflict of interest in relation to this article."

RECOMMENDED FORMAT FOR PRISM (Patients' Revelations as Insightful Studies of their Management) SECTION

Authors planning to submit their case studies to the PRISM section should structure their article according to these headings:

Title

- The title should be framed into a question to define the key focus of the case study.

Patient's revelation: What happened?

- The author(s) will provide a concise description of the setting on which the subject raised his/her medical or psychosocial issue pertaining to their health or disease management. It should cover the background, encounter and interaction of patient with the healthcare professional (doctor, nurse or allied healthcare professional). Author(s) should conceal the identity of the subject and/or related or accompanying personnel: abbreviation should be used instead, if necessary.

Gaining insight: What are the issues?

- The issue(s) raised by the patient should be framed into question(s). The question(s) will constitute a problem list and will serve as a focus for the management of this subject.

Study the management: How do we apply in our clinical practice?

- This section covers the approach to the management of the subject by the author(s). The author(s) should provide a literature review of current evidence, if any, of the basis of the subject's management, or to highlight the gaps of knowledge if such evidence is lacking. The author(s) will suggest ways to apply the new knowledge in clinical practice or to highlight the limitations of its applications, if any.

Conclusion

- The author(s) will provide a concise summary of the lessons learnt from this case study.

The article submitted to the PRISM section should be written by not more than three authors. Each article should not exceed 2000 words. Photographs or charts may be included but should conform to the specific instructions for any other articles submitted to The Singapore Family Physician.

Revised Manuscript Submission

Manuscripts may be returned to their respective authors for revision. This will be accompanied by an Editor's email for which comments and recommendations may be made. The authors are advised to read and to take note of these comments carefully and to revise their articles accordingly. The authors need to reply to the editor's email to outline their response before the resubmission of the revised manuscript. They should exclude the identity of the authors and their institutions, as the email may be redirected to the reviewers during the resubmission process. The resubmitted manuscripts should include the revised complete version, as well as the anonymised version as before.

Proofs

Prior to publication, the Editorial Team will copyedit the article to fit the format of the Journal. The author will be sent the copyedited proof of the article, and the author should read carefully the proof and give comments and/or confirmation within 48 hours of receiving the proof. This will greatly facilitate the SFP to proceed to printing without delay, or to have to go to print without the corresponding author's comments.

Reprints

1 complimentary copy of the article will be given to the authors. Additional copies can be ordered at authors' rates at time of printing.

Correspondence & Enquiries should be addressed to:

The Honorary Editor, The Singapore Family Physician
College of Family Physicians Singapore
College of Medicine Building
16 College Road #01-02
Singapore 169854
Tel: 6223 0606 Fax: 6222 0204
Email: editorialoffice@cfps.org.sg

Circulation

The Singapore Family Physician is published quarterly. It is circulated to all Fellows, Collegiate Members, Ordinary Members and Associate Members of the College of Family Physicians Singapore, and to private and institutional subscribers. It is also published online and can be found at www.cfps.org.sg

The journal is also circulated to all relevant government, professional, medical and academic organisations in Singapore, sister Colleges overseas and to the World Organisation of National Colleges and Academies of General Practitioners/ Family Physicians (WONCA).



Caring for your loved one with special needs when you are no longer around

Special Needs Planning is necessary to ensure the welfare and financial security of your loved one with disabilities. We understand that it is important to you that when you are unable or no longer around to take care of your loved one with special needs, he continues to receive the same financial and care support. So plan and set up a trust with the Special Needs Trust Co. (SNTC) to provide for your loved one's accommodation and daily living needs, his education and employment training, medical and any other professional support needs.

The SNTC is a not-for-profit trust company, with Charity and Institution of Public Character (IPC) status and supported by the Ministry of Social and Family Development (MSF), to provide affordable trust services to persons with special needs.

What is a Special Needs Trust?

A Special Needs Trust manages and administers the funds for the sole benefit of someone with special needs. Caregivers may set up a SNTC Trust and set out their wishes on the use of the funds to meet the care needs of their beneficiary. A Special Needs Trust will give the caregivers peace of mind that the trust funds intended for their beneficiary are in safe hands and will be used to meet their care-giving needs.

Who will administer and manage the trust funds?

SNTC as trustee, will manage and administer the trust funds for your loved one with special needs. The Public Trustee invests the trust funds in low-risk financial instruments to generate a modest return and the principal value of the trust funds is guaranteed by the government.

Why set up a SNTC Trust?

SNTC Trust service is provided by a dedicated team of Case Managers trained in social work and has good network with colleagues from various agencies in the social service sector who can provide support to beneficiaries of SNTC Trust. SNTC trust is very affordable, fees are 90-100% subsidised by MSF.

Make an appointment with a SNTC Case Manager to develop a Personal Care Plan and set out your wishes for your loved one today.

Call the SNTC hotline: **6278 9598**
www.sntc.org.sg



When interacting with persons with special needs...



- **Put the person before the disability,** e.g., say 'persons with physical/intellectual disabilities' instead of 'physically/intellectually disabled/handicapped persons'.
- **Ask if they need your help before extending it.**
- **Speak directly to them** instead of their caregivers or companions, e.g., when speaking to a deaf person, speak directly to him or her, not the sign language interpreter.
- **Ask for their opinions.** Do not make assumptions about what they can or cannot do.
- **Be mindful of physical contact.** Wheelchairs, white canes and guide dogs are considered part of their personal space.



The National Council of Social Service (NCSS) works closely with member voluntary welfare organisations to help persons with special needs attain quality of life and integrate into society. This includes raising awareness of the needs of persons with disabilities, developing and funding/administering critical social service programmes, such as Early Intervention Programme for Infants and Children, Special Education Schools, vocational training and job placement, and family support services. For more information on building an inclusive society for persons with special needs, please visit www.ncss.org.sg/UNCRPD.

Besides persons with special needs, NCSS also develops and funds/administers social services to help other vulnerable populations, such as isolated and vulnerable elderly, at-risk children and youth, families in need and persons with mental illnesses, as part of its mission to provide leadership and direction in social services, enhance capabilities of social service organisations and promote strategic partnerships for social services.