The Healthcare and Support for Children with Intellectual Disability

Edited by

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And

**Chinese Parents Association—
Children with Disabilities Inc**

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This book is not for sale.

Content

From the Professionals:

From the Members of CPA:

Acknowledgement

I would like to express my gratitude to Dr Gabriel So, chairman of Fairfield Division Of General Practice (FDGP), and the Community Liaison Advisory Group (FDGP) for their advice and sponsorship in publishing this booklet.

I owe my thanks to Mr. Chris Pittaway, CEO of FDGP and Ms Allison Tran, Administration Manager of FDGP for their administrative support.

Thanks are also extended to the Executive Committee of the Chinese Parents Association-Children With Disabilities Inc, and Ms Pinkie Leung (CPA coordinator) for their assistance in organizing the publication of the booklet.

The contribution of articles from Winnie Chui, Sara Lam, Candy Leung and Angela Yee are most appreciated. They have offered us their professional information which is educational and beneficial to our members as well as to the public.

In addition, I would like to send my gratitude to CPA members, parents and volunteers for their article contribution. Through their articles, we are able to look at ‘children with intellectual disability’ from various perspectives. They have expressed their feelings, expectations, suggestions and information in the caring and provision of quality services to people with intellectual disability and their families.

I would also like to thank Dr KT Lai for proof-reading the booklet.

Dr Peter Leung

* * *

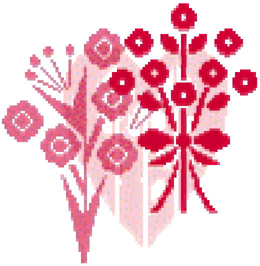
FOREWORD

This booklet is the combined effort of Dr Peter Leung (from FDGP) and the parents, members and volunteers of the Chinese Parent Association-Children With Disabilities Inc (CPA). We would like to send our gratitude to Fairfield Division Of General Practice (FDGP) for the financial support and to Dr Gabriel So, chairman of FDGP and the Community Liaison Advisory Group (FDGP), and the group members for their initiative and valuable advice.

My appreciation and thankfulness are also directed to the volunteers of CPA, Ms Candy Leung, Ms Angela Yee, Ms Zara Lam and Ms Winnie Chui for their article contribution and support.

Chinese Parents Association-Children with Disabilities Inc. is a non-profit organization set up solely by the parents of children with disabilities. With limited monetary support (largely through fund-raising activities), we endeavor to provide services, not only to people with disabilities, but to their parents, families and carers as well. The majority of our members are Asians, speaking mainly Cantonese and Mandarin. Some of them, because of cultural and language barriers, are having difficulties in communication and access to the available services. They are desperately in need of social, emotional supports, and appropriate information on the health and care of their children with disabilities. To meet their needs, we publish this booklet with help from the professionals. We sincerely wish the booklet will help to clarify some myths and present a clear concept about intellectual disability to the public as a whole.

Sylvia Tinyow
President of Chinese Parents Association
-Children with Disabilities Inc May 2006



PREFACE

The latest study by White, Chant, Edwards, Townsend & Waghom (2005) shows, in Australia, the prevalence of intellectual disability in the sampled population was 1.25%. Accordingly, about 1 in 100 people is having intellectual disability.

Throughout history, most societies have devalued people with intellectual disability. Incidentally, over the last decade, the field of ‘people with disability’ has undergone enormous changes. In Australia, in addition to the Commonwealth/State Disability Agreement (CSDA), the NSW Disability Services Act 1993 (DSA) has been implemented to protect the rights of people with disability in the provision of services. The DSA says that ‘persons with disabilities have the same basic rights as other members of the Australian society. They have the same rights needed to ensure that their specific needs are met.’ As a member of the society, I firmly believe that people with intellectual disability should be able to enjoy a quality and meaningful life as far as possible irrespective of colour, race or belief.

In Australia, it is obliged to use the term ‘people with disability’. The expressions such as ‘mentally handicapped’ or ‘mentally retarded’ are likely misleading and stigmatizing; they may give public a negative impression which will further disadvantage people with intellectual disability in the community.

People with intellectual disability and coming from non-English speaking background are often doubly disadvantaged in their communicative and social skills. They have both cultural and language barriers, and these often lead to their lack of confidence, social isolation and difficulties in seeking further community assistance and services. This booklet is written in Chinese and English, with the assistance of Chinese Parents Association-Children with Disabilities Inc, professionals from allied health services and the financial supports of Fairfield Division of General Practice Ltd, aiming to:

- provide updated information to the public on the understanding of people with intellectual disability, with special emphasis on children
- provide basic knowledge on the health and daily care for people (mainly children) with intellectual disability and their families/carers
- inform the public, people with intellectual disability and their families on the availability of the developmental assessments, recommendations and services from the Allied Health Services, so as to promote their learning and development of functional skills or abilities, as well as the assistance in accessing other services and activities in the community.

Peter Leung
General Practitioner
May 2006, Sydney

Intellectual Disability

I. The definition

In Australia, **Intellectual Disability** is a term used to mean someone who, after having been formally assessed by professionals (e.g. psychologists), is expected to be a slow learner for life.

Intellectual disability is a developmental disorder. It is not an illness, it is not infectious and it cannot be 'treated' or 'cured'. People with intellectual disability experience difficulties in their day-to-day activities, in understanding concepts and solving problems.

For a young child who is under the **age of five** and is developing more slowly than other children of the same age in one or more areas of development, professionals would prefer to use the term **Developmental Delay.** Sometimes, a child's learning will be slow for a short period due to illness or changes in the environment; the child may later catch up on learning and continue to develop as other children of the same age (Child and Youth Health 2006).

According to the definition put forward by DSM-IV (2002), **Intellectual Disability** refers to:

- someone whose intellectual functioning level (IQ) is below 70 on an individually administered IQ test
- someone who is having difficulties in functioning skills (in at least two of the following areas) viz.: communication, self-care, home living, social/interpersonal skills, use of community resources, self-direction, functional academic skills, work, leisure, health and safety
- someone whose limitations in intelligence and living skills are obvious before age 18 years

The American Association on Mental Retardation (AAMR) is a leading association in defining and classifying mental retardation. In their 2002 Manual, Mental Retardation is defined as a disability characterized by significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social and practical adaptive skills. This disability begins before age 18. The manual retains the term ‘mental retardation’ because, after considerable deliberation by the association, there is no agreement on any other acceptable term that bears the same meaning (p. xii).

II. Classification

The effects of Intellectual Disability vary in severity in individuals. People with intellectual disability exhibit a great range of abilities and personalities. Traditionally, they are identified as different groups in terms of their intellectual abilities and adaptive behaviour. Their intellectual functioning, or IQ, is usually measured by IQ Test. The averaged score is 100.

The DSM-IV-TR (2000), based on the degree of severity which reflects the level of intellectual impairment, has identified four levels of intellectual disability:

- Mild Intellectual Disability: IQ scores 50-55 to 70
- Moderate Intellectual Disability: IQ scores 35-40 to 50-55
- Severe Intellectual Disability: IQ scores 20-25 to 35-40
- Profound Intellectual Disability: IQ scores below 20 or 25

In 1992, the American Association on Mental Retardation proposed a new classification system on intellectual disability based on the **intensities of needed supports,** and this supports-based classification continues to be retained in the 2002 AAMR Manual (p.152).

To determine the individual support needs of people with intellectual disability, AAMR is using the **Supports Intensity Scale (SIS).** This Supports Intensity Scale is an assessment tool that evaluates practical support requirements of a person with an intellectual disability, serving the assessment functions as the **IQ Test**. Instead of measuring the **skills that a person lacks**, **SIS focuses on what supports a person needs.**

Four main types of support:

1. **Intermittent Support**:	Support on an "as needed" basis or short term nature
2. **Limited Support**:	Consistent support is needed over time, but is time-limited.
3. **Extensive Support**:	Long term support needed by regular involvement in at least some environments e.g. school, work or home
4. **Pervasive Support**:	Constant and high intensity support are needed, potentially in life sustaining nature.

This method of classification strongly emphasizes the role of 'needed supports' when identifying a person's strengths and weaknesses. It is not enough merely naming a person's limitation, a profile focusing on special areas and assistance the individual needs will be recommended, and these can be translated into individual training goals in order to improve functioning.

III. What Causes Intellectual Disability?

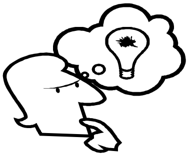
Medical researches have revealed many causes of Intellectual Disability. Researchers employ multifactorial approach to determine the causes (AAMR Manual 2002).

The multifactorial approach examines causal factors in two directions:

1. **Type of factors**: Biomedical, Social, Behavioural, Educational
2. **Timing of factors**: Prenatal, Perinatal, Postnatal

Known causes are:

- Abnormalities of chromosomes and genes
- Syndromes such as Down's syndrome, Fragile X Syndrome
- Maternal malnutrition
- Drug use, excess alcohol and parental smoking before and during pregnancy
- Infection during pregnancy – e.g. Rubella
- Prematurity
- Brain injury before, during or after birth
- Poor diet and health care
- Child abuse and parental abandonment of child
- Familial poverty
- Inadequate parenting
- Delayed diagnosis
- Lack of early intervention
- Lack of special educational services



In many cases, however, there are still **unknown causes.**

Sometimes, knowing the causes does not provide much information in helping people with intellectual disability to learn and develop to their potential.

Risk Factors for Intellectual Disability

Types Timing	Biomedical	Social	Behavioural	Educational
Prenatal	-Abnormal chromosomes and genes -Syndromes e.g. Down's Syndrome, Fragile X Syndrome -Parental age -Infection e.g. Rubella	-Poverty -Maternal malnutrition	-Parental drug use -Parental alcohol use -Smoking	-Cognitive disability in parents -Lack of preparation for parenthood
Perinatal	-Prematurity -Brain injury	-Lack of access to birth care	-Parental rejection -Parental abandonment of the child	-Lack of medical intervention at discharge
Postnatal	-Brain injury -Malnutrition -Seizure -Degenerative disorder	-Lack of childcare -Lack of adequate stimulation -Poverty -Poor health care -Institutionalisation	-Child abuse -Domestic violence -Social deprivation	-Impaired parenting -Delayed diagnosis -Lack of early intervention -Lack of special educational services

(Adapted from AAMR 2002 Manual: p.126)

IV. Healthcare for Children with Disability

In Australia, despite the fact that people with intellectual disability who are citizens are eligible for basic health care needs and have access to most of the health services under Medicare, they still have higher levels of health needs than the general population.

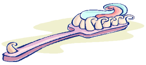
The illnesses they more often experience are:

- epilepsy
- gastrointestinal problems
- visual impairment
- hearing impairment
- osteoporosis
- schizophrenia
- dementia
- dental disease
- musculoskeletal problems
- accidents
- nutritional problems
- obesity

(Editorial, BMJ 2004)

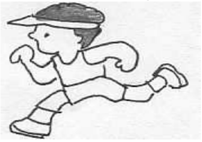
Their Healthcare Requirements:

- Try to reduce language and communication barriers between them and the medical professionals.
- Try to follow thoroughly the instructions given by their doctors, specialists and other professionals after consultation e.g. take medications on time.
- Attend Allied Health Services e.g. dental care; physiotherapy, occupational therapy for physical functioning etc.



- Check eyesight and hearing regularly.
- Maintain personal hygiene e.g. brush teeth regularly after meals to remove food residue staying in the gums.

- Keep the house/floor/carpets clean to eliminate the house dust mites.
- When having food, eat slowly and not too much at one time, so to avoid choking and indigestion.
- Obesity is one of the main problems with people with intellectual disability – control the child’s diet –introduce a daily routine with set rules and meal times.



- Avoid eating too much junk food – they have a propensity for sweetness

- Exercise regularly
- Adhere to home safety rules to avoid accidents
- If problem arises, consult family doctor or seek medical assistance immediately

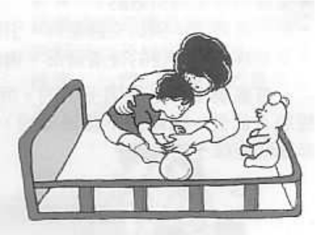
V. Support and Care for Children with Intellectual Disability

Intellectual Disability varies in degree and effect from person to person. Some individuals, with appropriate support, care and training can live independently and function well in our complex society. For others, Intellectual Disability may occur alongside other problems (e.g. with sensory deficits, physical impairment or have dual diagnoses of Intellectual Disability and mental illness). In general, there is expectation that they will participate in community life, attend schools, hold jobs and have an opportunity for meaningful social relationships. People with Intellectual Disability can learn and develop providing that they are supported and trained with early intervention, structured programs and appropriate services. Support, care and understanding from families and communities are vital in achieving these goals.

Early Diagnosis

When children are young, their limitation or disability may not be obvious. However, there are many signs indicating delayed development:

- If by six months, the child does not have appropriate responses towards objects, movements or sounds
- If between six months to 1 year, the child is unable to sit up



- If by 3 years, the child is still unable to walk
- If the child is having difficulty in remembering things.
- If by 3 years old the child is unable to speak in simple, short sentences
- If the child is too quiet or showing no interest in what is happening around her/him.

- If the child is too active or having trouble understanding the social rules

Where to get help?

If you are worried about the development of your child, you could seek advice from:

- your family doctor,
- the local Child Health Centre,
- the local Community Health Centre or
- the school.

Visiting family doctor

If necessary, they can refer your child to medical specialists (e.g. pediatrician) or the **Early Childhood Team (**IDSC 2006).

The Early Childhood Team consists of:

- **Social worker:** Provides information, coordination and support, counseling, and assistance with accessing a range of services.
- **Psychologist:** Provides advice and strategies relating to children's behaviour and development.
- **Occupational therapist**: Provides advice to encourage children's play, thinking, social and self-help skills e.g. dressing, toileting.
- **Speech Pathologist**: Provides advice to support children's communication, speech and language development.
- **Physiotherapist**: Provides advice to develop children's motor skills, e.g. sitting, walking.

Home visit by social worker

Physiotherapy

Looking after people with Intellectual Disability at home

1. Provide an interesting environment at home

- Parents have time to play with the child.
- Use different kinds of toys for stimulation, to get the child's responses.
- When playing with the child, follow the child's lead.
- Do not pressure the child to do something that he/she does not want to do at the time.
- Maintain a relaxing and happy environment at home.
- A child needs structure and predictable routine to feel safe.

2. Training of basic living skills/personal care at home

Children with Intellectual Disability learn slowly. When the child learns a new task, break down the task into small steps. Demonstrate how to do the task step by step. Help the child when assistance is needed. It is important to praise him/her each step he/she has learned. Do not wait until he/she has accomplished the whole task before praising him/her.

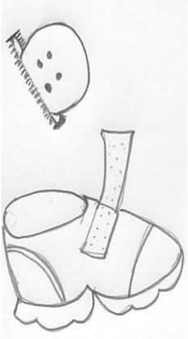
Eating:

- Teach the child, step by step, how to use eating utensils: from simple one to complicated one
  e.g. spoon → fork→ chopsticks.
- Maintain a relaxing atmosphere,
  have an enjoyable mealtime,
  no abusing or blaming.

Toileting:

- Start training when the child is ready.
- Watch for signs that the child is about to do a wee or poo.
- Teach the child the words or signs to signal if she/he want to go to the toilet, e.g. poo, wet.
- Praise/thank the child for telling you.
- Choose a potty or a special toilet seat for the child.
- Let the child wear the clothing that is easy to get on and off.
- Encourage the child to use toilet at a regular time.
- Teach them always to wash their hands after using the toilet.
- Praise them for going to the toilet themselves without help.

Dressing:



- Step by step, teach them to put on clothes.
- Make dressing or undressing easier by using special equipment, e.g. Velcro, big buttons etc.

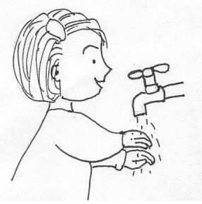
Other Social Skills at home:

- Give the child chores: assign the child the jobs that she/he is able to accomplish at home e.g. supervising her/him to wash her/his own cups/dishes, to set the table.
- Remember making the task as simple as possible, teaching them step by step and giving them praise.

3. Hygiene at home

- Always encourage the child to wash hands before and after meals, after using the toilet, etc.
- Teach, demonstrate and encourage the child to brush teeth daily.
- Comb/wash the hair regularly.
- Have a bath daily.
- Teach the child to put rubbish into the bin.
- Teach and assist the child to tidy up the place after play or work.
- Change the clothing if it is dirty or wet.



4. Communicating with them at home

- If the child does not speak clearly enough to be understood by others, listen to him/her patiently. Use language that matches the child's level of understanding.
- Try to teach the child to use sign language/ key word sign (Makaton) to express herself/himself.
- Make use of pictures or real objects to communicate to the child.
- Give the child clear and precise instruction, one at a time, repeat using the same word.
- Do not make fun of the child's unclear speech.
- Consult a speech pathologist.


5. Socialisation at home


say Hello

- Teach the child the proper manners at meal times.
- Show the child how to greet others.
- Encourage the child to play with other children.
- Teach them how to get along in a group.
- Provide them with opportunities to learn from real life experiences: e.g. taking them to shopping, to the market, to the parks and to the libraries.
- Teach the child the rules of conversation.


Playing with friends

6. Home Safety – for children with Intellectual Disability

- Never leave the child alone in the house. There should be a carer looking after the child at all time.
- Keep all poisons out of reach, including detergent and dish washing powder.
- Do not store poisons in food containers. Keep them in the original container which has warnings and safety precautions on it.
- Do not let the child play with electrical appliances at home. Cover all unused power points with a child safety cover.
- Keep away all matches, cigarette lighters and candles.
- Put hot water, hot drinks and hot pots out of the child’s reach.
- Keep sharp things out of reach of the child e.g. scissors, knives, pins or needles.
- Be sure that there are no small objects around to prevent from swallowing or choking.
- Do not leave the child to play alone in the bath or the bathroom. Beware of drowning or slippery floor.

- Make sure that the cords of curtains or blinds are short so that the child cannot get caught in the cord and choke.
- In a multi-story unit/apartment, ensure that windows are fixed so that the child cannot get out of the window.

7. **For the Parents:**

- Do not feel guilty.
- Get advice from professionals to get support as early as possible.
- Share the duty of caring the child.
- Get to know and make use of the available resources.
- Make contact with other parents at centres, schools or community groups. Attend regular meetings and discussion to get mutual support and help.
- Obtain acceptance and social help from relatives and neighbours.
- Take care of your own health and be optimistic.
- Leave yourself some private time by making use of the respite care.

VI. Conclusion

People with Intellectual Disability need information, services and support from the community. With training and education, there are chances yet that they will be living independently. They also experience emotions such as joy, anger, sadness, pride and jealousy, and it is essential to guide them to express their emotions in an appropriate way. Encourage them to participate in social activities such as sports, singing/dancing, to help them build up their self esteem and confidence. Hence it is also the responsibility of the public to offer people with Intellectual Disability our understanding, acceptance and affection. ☺☺

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Illustrations (插圖):

Some of the illustrations were adapted from the booklet: *Looking after Mentally Handicapped Children (1991)*, Hong Kong Education Department, Hong Kong
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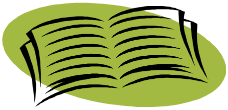
Microsoft Clip Gallery



From the Professionals:

Occupational Therapy for Children

by **Angela Yee**
Occupational Therapist

Occupational therapy promotes normal development and stimulates learning in children with specific learning difficulties, physical disabilities, delayed development or those recovering from illness or injury. Working with children, their families and their teachers, occupational therapists aim to improve the child's quality of life by helping them to participate in play, preschool, school and home activities.

An occupational therapist may work with children in any of the following areas:

- **Prerequisite activities** - the child's physical abilities, such as motor control, hand-to-eye coordination, body awareness and sensation.
- **Functional skills** - the child's day-to-day living skills, such as eating, writing, going to the toilet, interacting with other children and playground skills.
- **The environment** - such as classroom furniture, classroom and schoolyard access and equipment for woodwork, art and physical education.

What services do Occupational Therapists provide?

Occupational therapy services can be broken up into three categories:

1. **Assessment**
   This involves an evaluation of developmental and performance skills and how these relate to home, school and play environments reviewing progress.

2. **Treatment**
   Providing therapy and home programs to maximize the child’s skills.

3. **Consultation**
   This may Involve the provision of written information (reports, programs), or collaborating with schools and other health professionals.

Specific occupational therapy assistance may include physical rehabilitation, activity programs, use of adapted techniques, provision of aids and assistive devices, developing learning strategies and counseling.

<u>How can Occupational Therapy help your child?</u>

An occupational therapist can help a child, their care givers/parents and other people in the child's life to:

- Gain a better understanding of the child's illness, disability or difficulties;
- Learn ways to maximize the child's performance in everyday living;
- Promote and nurture the child’s strengths and self-esteem;
- Occupational therapy services are provided in a variety of settings including hospitals, community centres, private facilities and some educational facilities (e.g. schools and special units.

<u>Where can you find an occupational therapist?</u>

You may be referred to an occupational therapist by your doctor or specialist, or other health professional, friend, relative or by making direct contact yourself.

For more information about where you can find an occupational therapist and verify an Accredited OT contact the **OT AUSTRALIA National Office**.

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✧✧ Speech Pathology for Children ✧✧

By Candy Leung
Speech Pathologist

What is a speech pathologist?

Speech Pathologists have been trained to assess and treat people who have a communication disability, or swallowing difficulty. Speech Pathologists work with children and their families to promote communication and eating or drinking skills.

Why do we need speech pathologists?

Communication is the process of being able to understand and to be understood something most of us take for granted. Communication disabilities are the result of problems with speech, using and understanding language, voice, fluency, hearing, or reading and writing.

Speech pathologists might work with people who:

- are hard to understand
- cannot understand what their parents or teachers say
- have not started talking when they are supposed to
- interact minimally with other people
- have feeding difficulty, such as chewing & drooling
- have hearing impairments
- are learning to read and write
- stutter
- constantly lose their voice

How do speech pathologists work?

Speech Pathologists work in a variety of settings including, hospitals, community health centres, schools, preschools, government organisations (e.g. DADHC), non-government organisations (e.g. Learning Links), and private clinics. Speech therapists also work in a variety of ways. These include one on one therapy, group therapy, classroom-based therapy or home-based programs. Other roles of a speech pathologist are to, provide information and progress reports, provide therapy tools, conducting education seminars, and advice clients, carers and other professionals (e.g. paediatricians, teachers, respite workers) in helping the child.

What should I do to access a speech pathologist?

Anyone (e.g. parents, teachers) can refer to a speech pathologist. A GP referral is NOT required. Contact Department of Ageing Disability and Home Care (DADHC), your local non-government organisations, and Speech Pathology Australia for private speech pathologists.

(Speech Pathology Australia Fact Sheet 1.1)

* * *

What is music therapy?

Winnie Chui
Music therapist

What is Music Therapy?

Music therapy is a professional discipline that uses music to achieve therapeutic aims. Music therapy with young children is the functional use of musical interactions to enhance and develop socialization, communication, self-expression, and sensory-motor skills.

Who is registered music therapist (RMT)?

Registered Music Therapists (RMTs) are skilled and qualified musicians and therapists who assess, design and implement programs to meet the need of young children. RMTs work with young children in hospitals, early intervention facilities and private practice.

Why music therapy?

Music is a universal language that crosses boundaries of age and culture; it is a motivating and calming medium that stimulates all of the senses and facilitates age appropriate cognitive functioning, language skills and other developmental skills.

When applied therapeutically by a RMT, music becomes a pleasurable therapeutic medium that facilitates advancement toward articulated and often multi-purpose goals and objectives. Music therapy can address several needs simultaneously and is highly transferable to the home environment. Furthermore, as young children with delay in development are not necessarily delayed in their music skills, music therapy allows them to experience a sense of success and fun while pursuing other non-musical goals.

The Music Therapy Process

Specific music therapy goals are determined by the RMT through initial music therapy assessment and ongoing review of the child. During the assessment, the RMT will interact with the child through activities such as singing familiar songs, improvising, creating new songs and listening to music in order to develop a trusting rapport with the child and observe the child’s responses to music, before formulating specific goals and objectives.

Music Therapy Goals

As all music therapy programs are specifically designed for the individual child, the exact goals cannot be determined until after the assessment. Some examples of music therapy goals for young children are:

- To increase opportunities for cognitive, physical and sensory stimulation
- To develop motor skills (strengthening of muscles, increasing range of motion, training of movement coordination, etc.)
- To develop orientation and mobility (i.e. spatial awareness, confidence to move, gait, direction, and gross & fine motor skills)
- To promote social skills
- To increase vocal skills
- To develop speech and language skills, including complexity and completeness of sentences
- To promote emotional expression and self-confidence

Music Therapy Techniques

After assessment, the RMT selects and applies a range of techniques in order to achieve the program goals. Some examples of techniques adopted by music therapists in addressing the child’s needs include:

- Movement to music
- Singing and chanting
- Educational/instructional songs

- Involvement in a group
- Improvisation
- Instrumental playing
- Music listening

Results

A range of empirical literature supports the effectiveness of music therapy in increasing the skills and abilities of young children in the area of (1) social and emotional behaviour, (2) motor skills, (3) communication skills, (4) language and vocal production, and (5) pre-academic and academic skills. The efficacy of these outcomes is enhanced by the power of music to arouse engaged clients toward achievement of their therapeutic goals.

Access to music therapy programs

A free notice can be placed on the AMTA NSW Job Register for families seeking a music therapist. Jobs Register Coordinator Angie Swards: nswjobregister@yahoo.com.au

Information taken from Australian Music Therapy Association: www.austmta.org.au

From the Members of CPA:

GROWING UP WITH A BROTHER WITH SPECIAL NEEDS

LEANNE TINYOW
May 2006

My name is Leanne and my brother Leonard has autism. Growing up with a brother who has both a behavioural and intellectual disability, may be viewed by outsiders as a difficult journey. However, to me and many other people with siblings with disabilities, it is just a way of life.

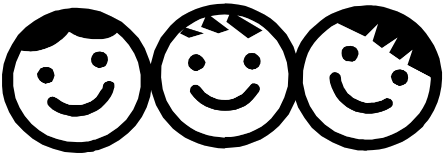
From an early age it was clear to me that my brother was different and had special needs. I was developing faster and simple games I would play with him would not be challenging enough. As a result of his learning difficulties, Leonard received extra attention and I resented that as child. I now look back and realise that all children cry for as much attention as possible and I was no different.

Despite the challenges of accepting Leonard's disabilities, I have had many fond memories with him as a child. We would go on outings with his fellow class mates and as the only "normal" child, it opened my mind to the acceptance of other people with disabilities while having fun.

As we grew older and with the arrival of our younger sister Linda, Leonard's behavioural problems became more prevalent. With most normal teenager, there are physical changes, rebelling against parents and emotional sensitivity, and Leonard was no exception. His inability to communicate his wants and needs led to a lot of misunderstandings and hurt. These were some of the most difficult years for me, not only was I going through my teenage years as well, I was also competing for attention with Linda.

Despite our differences during those years, Leonard and I remained close. Growing up together and being privileged to similar things, he has always accepted my changes. In recent years I learnt to drive and for Leonard this was hard to comprehend. Our parents have always driven and to see me drive him was quite frightening. However in time, he has learnt to trust me as more than just a little sister, but also a person with a responsibility to care for him.

I often reflect on my memories with Leonard and although there were some tough times, there were many more that we shared that were full of laughter and smiles. And for now I look forward to the future with Leonard and making more wonderful memories to cherish.



Peter Pan

an unformed mind
inner turmoil
anger hatred
hurt
grinding the hearts of
those who dare to love
bone to dust
tears to drought
Trapped in Neverland.

A world uncaring
No one understands
Miscommunication
Break down
Breaking-
down
Does anyone hear my cry?

I am not a robot
My feelings compel
Confuse
I lash out
Crumbling foundations

Everyone moves forward
Leaving me behind
A forgotten toy.
Time stands still
Only for me

A background….

Living with my brother is by no means an easy task. My parents are truly the strongest people I know. Yet I count my brother as a blessing. He has taught me a great deal about the world…about society, patience and myself...for that I am grateful.

I have always grown-up with the fact that my elder brother was unlike other people's elder brothers. He will never be able to do many of the things we do. And I often wonder what goes on inside his head. How much of his behaviour is due to his disability? And how much of it is him? How does the world look through his eyes?

I wrote this poem during one of his tantrums. I guess it is my way of making sense of my brother and his world.

Karen Yuen

Joanne

by Aileen Pang

Joanne is the only child in our family. She is now 9 years old. Joanne was born full term and had jaundice at birth requiring phototherapy at the hospital. Around the age of 10-12 months, even though Joanne could crawl she went from standing up to walking while holding onto supports without going through a period of crawling. Joanne also suffered from severe eczema to her face and body soon after she returned from hospital. This remains to be a problem until today, albeit nowhere as severe as previously been at her younger days. At the age of about 4 years old Joanne had an episode of anaphylactic reaction due to eating some grounded cashew nuts, which required emergency hospital treatment. Due to these experiences we had Joanne undergone skin prick tests at Westmead Children's Hospital for allergic reactions to various foods and known environmental particles. The results showed that Joanne's allergic reactions range from mild to highly severe to various foods. Foods, which are highly allergic, are nuts, and egg products. Other foods she showed reactions to include dairy products, seafood, strawberries, and tomatoes.

Joanne was assessed at the age of 3 ½ years old by Bankstown DoCS to be autistic ranging from moderate to severe. Joanne had difficulties with verbally expressing herself and interacting with her peers. She was unable to verbalise a single word until about 4 years old. It was only through persistence and coercion that she was able to utter her first word "milk" as indication of a request for milk, which she loves. At the suggestion of DoCS, Joanne attended firstly the Wattle Play Group at Revesby, then the Villawood Preschool. She also underwent the Autism Association's home Building Blocks Program in her preschool days.

Joanne was enrolled in Caroline Chisholm Special School full time for 3 years following preschool. Her language skills had improved by then to the stage that she could say and use certain words and phrases to indicate her needs. Her social skills however had hardly had any progress. She was however able to interact a bit more with the adult teachers. During her 3rd year Joanne attended the Revesby Public School for one morning each week as an integration program. At the end of the year she was offered a place in the school's IM/IO support class.

Inspite of all her shortcomings Joanne has shown great strengths in certain areas, which we were able to exploit to improve her language and understanding abilities. Foremost Joanne's innate sense of musical rhythm and her abilities and great passions for singing and music of all types have been a great platform for us to introduce Joanne to words and the English language. From this Joanne has been able to improve her word recognition skills, leading towards a much better understanding of the language. Joanne has now been attending private piano tuition once a week for over a year. She is able to read from musical notes and play a repertoire of nursery rhymes and songs.

Due to Joanne's lack of social interaction skills she had been reluctant to go to many public and even friends' home. Joanne used to display stress symptoms such as scratching herself, covering her ears, and protesting loudly if she was taken to too many places. There were only certain places such as playgrounds, shopping centres, and libraries that she would go to. We were therefore constantly on the lookout for places of group gatherings where Joanne could familiarise herself with the people and surroundings as a stepping stone towards desensitizing some of her aversions.

We learned about the Chinese Parents Association through Elena. Elena's son, Jonathan, is older than Joanne and is attending the same school at Revesby Public School. Elena explained some of the activities and programs of the Association. We felt that it was almost exactly what we were looking for and decided to attend one of its Saturday gatherings to see for ourselves.

The Chinese Parents Associations have a wide variety of activities that are interesting, stimulating, and fun specially selected to cater for children of diverse disabilities. These activities include: music therapy classes conducted by recognised music teachers; art and drawing classes; a wide range of other group activities such as Scouts groups, group singing by the children at concerts, fund raising functions, bus trips outings to gardens and clubs, to mention just a few. There are also monthly birthday celebrations and functions to celebrate the various events of the year such as Chinese New Year, August moon festival and various Australian events such as Easter and Christmas.

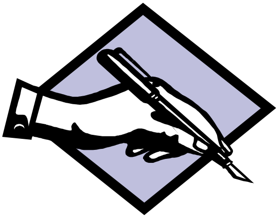
We are glad to say that the Association has played an important role in facilitating Joanne's improvements in her social skills and language skills in self-expressions through group and peer exposure. Prior to attending the gatherings, Joanne would often cover her ears or shout when confronted with loud noises or large noisy gatherings. She now accepts all these stimuli without the drama. She is now able to sit comfortably in a noisy restaurant and also loves to go to movies in cinemas where the noise can be deafening. These are two examples of the many places she would absolutely refuse to go to and would put up quite a fight so as not to go.

We would like to acknowledge and thank all the people, especially the committee members who are dedicated and untiringly sacrifice their time and efforts in organising and maintaining the activities of the Association. Due to the benefits Joanne has gained from the Association we are constantly recommending others to attend the functions and hopefully to be a member.

The Chinese Parents Association's very existence wholly depends on the efforts and of volunteers and public for financial support and assistance. The volunteers consist mainly of the committee members and also others who are supportive of the Association's constitutions. Financial support has been critical to fund the activities and programs of the Association. Financial support has come from various sources such as from individuals, Lions Club, individual shop owners and restaurants. In appreciation of the financial burdens of maintaining children with disabilities, membership fees have been kept to a minimal amount, which therefore is not a great pool of funds. In view of this we try our utmost to be of as much assistance as we are able to in our own ways. We therefore urge all those who are in sympathy with the Association to contribute in whatever ways possible – either financially or in kind. ☺☺

Educational Access Scheme (EAS) – Special Admission Application for Educational Disadvantaged People

By Daniel Chan



I would like to share my experience of how the Educational Access Scheme (EAS) assisted my son's enrolment to his studies in a university so that you can use or pass it on to someone who might benefit by using this service.

When my second son Michael was born, the pediatrician said that this child would not act like any other normal child and should not expect too much from him. I am a Christian and children are assets from God, I accepted this as a great challenge to my family. I remembered at one of Michael's early intervention program the therapist said that he showed a lot of determination although he was seen as abnormal. He started walking when he was exactly two years old. His balancing skill was poor he fell after 3 or 4 steps.

When Michael studied in primary school, he had learning difficulties and, was slow in reading and writing. I went to see his teachers and requested assistance from them on how to help him. He received programs for special need children.

When Michael studied in secondary school, he received general ability tests to determine what support could be provided to him to assist his studies. He received from NSW Board of Studies provisions of reader, writer and extra time for his school tests and examinations.

Michael's skill in reading and mathematics were marginal. He chose more technical subjects for his High School Certificate examination subjects in order to create his study interest. Although he was slow he tried very hard and studied till midnight almost every night.

During Michael's year 12 year I went together with him to attend the open day of the universities in Sydney. He could visit, receive information and asked questions of the faculties of the subjects that he was interested in. He could also appreciate the university environment and facilities. I also visited the student special need unit to ask what available support can be provided to students with special needs. They indicated that once enrolment was completed the students would be assessed and support services would be given to those who required assistance.

I took Michael to enroll in a few of the subjects that he would like to study at colleges of the NSW Department of Technical and Further Education (TAFE) and he was later admitted to study pending his HSC examination results. He also sent his university enrolment requirements to NSW Universities Admissions Centre (UAC) by end of September.

HSC results were announced shortly before Christmas and just a few days before the students had to finalise their university subject preference. Most of the universities in Sydney had an information day similar to the open day in early January to provide students the last minute inquiry or a second look at the courses that they were interested in. After assessing Michael's HSC results I took him to information day of the Macquarie University and University of Technology Sydney.

At UTS I went to the student special need unit again to ask what available support could be provided for students with special needs. Immediately she asked me whether I had applied through EAS. My reply was we hadn't and my next question was what EAS was. She replied that it was too late now because EAS closed on 30th September last year. She then added, "download the EAS application form from UTS website and submit all the relevant information within two days and let the university assess your situation." However, they could not guarantee that our late application would be accepted by them.

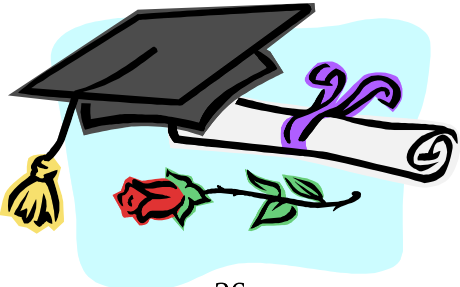
That night I downloaded the EAS application form. I also needed the other supporting documents such as:

- HSC examination special provision from NSW Board of Studies
- Medical reports from doctor or other health professionals.
- School reports from teachers in the high school

Next day I contacted the pediatrician who has been examining Michael since he was born to get a supporting medical report; luckily he hadn't gone on holidays and he was fully booked and could only see me after his last appointment. I found all Michael's therapist reports from all different disabilities health services. I also found all the past medical reports from all the specialists who examined him in order to identify what his abnormalities were. I could not get the high school teacher report since the school has been on holidays and all the teachers were not there.

The following day I went to UTS and met the deputy Director of the Equity & Diversity Unit. I explained to her our ignorance of EAS and submitted the EAS application form with all the supporting documents for her assessment. Finally she accepted our application.

Different university offers different concession to cutoff University Admission Index (UAI) to different courses. Now with the assistance from EAS Michael can enroll in the course that he is interested in. To some parents, they don't care whether their children can enroll in a university. To some other parents children's enrolment in a university can be seen as normal and it is nothing special. To my family this is definitely a blessing from God. To other people this is a miracle. It is not the end of the story though. It is only the beginning. ☺☺



A mother's feeling

As the mother of a disabled child, I feel my life has ended. Everything is hopeless because I see my child cannot do things like other children. My greatest fear is what will happen to my child after I have left this world. I have lived to bring up my child. My whole life revolves around her.

In everything I do, my child is always my first consideration. I am trying everything to educate my child and to develop her skills, so that she will be able to look after herself as much as she can and be part of the community, interacting and socialising in the society we live in.

I feel that I have little support from friends because some of them see my child as different to their children and they keep away from me.

Meanwhile I am very grateful and thankful to the Chinese Parents Association, children with disabilities for their help and support. They have given me an opportunity to meet other parents with children who also need support and friendship. I have gained respect from these parents. I am proud to be part of the group.

By Gracie Lee

Having a child with disabilities

By **Cindy Liu**

My daughter was born with a very rare syndrome that affects her abilities in many areas. Coming from a non-English speaking background, we have problem in communication, and this makes it even harder in caring a child with disabilities. At first, we tried very hard to get information in order to help my child. Sometimes we did not even know where to get the information, and we felt hopeless. Recently, the therapists who used to visit my daughter at home stopped coming because of shortage of staff. I felt lost as a parent worrying about my daughter's development.

My daughter needs to have injection and oral medication everyday. I am unable to work because my daughter has to visit different doctors regularly and often ends up in hospital. I need to pay for my child to attend a special preschool and extra expense on special milk formula and medication. The nutrient supplement itself has already cost me about fifty dollars per month. Though the government subsidizes some of them, I still need to pay a large amount for medical needs.

My husband wishes to earn more income, he works most weekends. We miss out our family day activities. He always worries about our daughter's problem and the family, he has headache all the time. I feel inadequate in taking care of my husband and my child with disabilities. As my child grows older and older, physically I find it more and more difficult to pick her up, and this often leaves me with backache. I feel that I could not breathe under the pressure of life.

When we walk on the street, it is so difficult to escape the strange looks from people's faces. Occasionally, we are treated unfairly.
I wish people in the community could come together to help child with disabilities so that they can develop in a healthy way. ☺☺

Resources

Department of Ageing, Disability and Home Care (DADHC)

The NSW Department of Ageing, Disability and Home Care funds programs and services that provide people with a disability opportunities to participate in community life

Tel: 02-82702000
www.dadhc.nsw.gov.au

Home Care Services:

Mandarin :	1800 666 431
Cantonese:	1800 018 828

Disability & Carers phone line:

132717
www.centrelink.gov.au/internet/internet.nsf

Family Advocacy

Tel: (02) 9869 0866
www.family-advocacy.com

Carers Respite Centre

Tel: 1800 059 059
www.health.gov.au/acc/carers/respcent.htm

Family Resource & Network Support Inc (FRANS)

Tel: (02) 9799 4333
www.frans.com.au

Intellectual Disability Rights Service-Legal, Help, Information, Education:

Tel: (02) 9318 0144
Freecall: 1800 66 66 11
www.lawlink.nsw.gov.au/lrc.nsf

Anti-Discrimination Board of NSW:

Tel: (02) 9268 5544
Freecall: 1800 670 812
www.lawlink.nsw.gov.au/lrc.nsf

Multicultural Disability Advocacy Association of NSW (MDAA)

Tel: (02) 9891 6400
www.mdaa.org.au

Council for Intellectual Disability

Tel: (02) 9211 1611
www.nswcid.org.au

Speech Pathology Australia

NSW Branch Office
Tel: (02) 97430013
(Mon,Wed, and Thurs
Between 9.30am and 2.30pm)
www.speechpathologyaustralia.org.au

Australian Association of Occupational Therapists – NSW

Unit 20, 8 Avenue of Americas
Newington NSW 2127
Tel: (02) 9648 3225
Fax: (02) 9737 0023
www.otnsw.com.au

ASPECT –Autism Spectrum Australia

Autism Spectrum Australia (Aspect) builds partnerships with people with Autism Spectrum Disorders, their families and the community to provide information, services, learning and research.

Email: contact@apect.org.au
Web: www.aspect.org.au

Centrelink

Tel: 13 10 21
www.centrelink.gov.au

Technical Aid to the Disabled

Tel: (02) 9808 2022
www.technicalaid.nsw.org.au

Learning Links

Learning Links is an Australian Charity and non-profit organization assisting children who have difficulty learning. Learning Links works with families to provide a complete service for children in need. Their service brings together teachers, psychologist, speech pathologists, occupational therapists and family counsellors to work towards each individual child's goals. Learning Links helps children to be the best they can be.

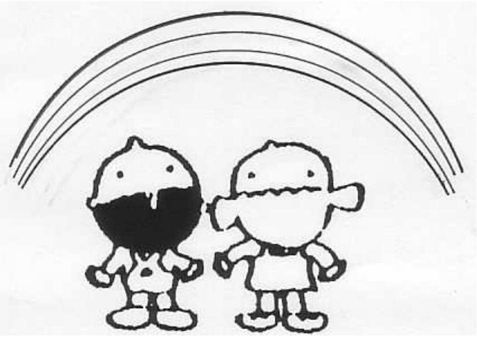
Head Office

12-14 Pinadari Road
Peakhurst NSW 2210

Telephone: (02) 95341710
Preschool: (02) 9533 3283
Fascimile: (02) 9584 2054
E-mail: mail@learninglinks.org.au
Web: www.learninglinks.org.au

Mission Australia

Reconnect Program
Tel: (02) 9740 6333
www.missiom.com.au



目錄

專題文章

感情的表白—澳洲弱能兒童協康會會員

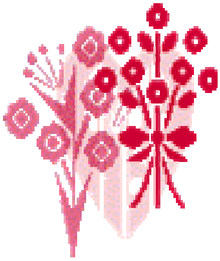
鳴謝

前言

「協康集」是由梁顯華醫生和澳洲弱能兒童協康會合編的小冊子。在此，感謝蘇精祥醫生和他主持的諮詢聯絡組提供整個計劃的構思；尤其更感謝 Fairfield Division of General Practice 的資助，讓我們能順利完成此小冊子，給智障人士(主要對象是智障孩子)，他們的家人及照顧人員提供寶貴的知識和資訊，使他們能適當地去照顧及支援智障孩子。同時亦可以給大眾人士傳送正確的訊息，使他們對智障孩子有進一步的了解和體諒。

澳洲弱能兒童協康會是一個非牟利的團體組織。由一羣有智障孩子的家長組成。在資源短缺的情況下，仍然盡心盡力為會員，家長，照顧人員及有需要幫助的人士，去提供優質服務。我們的會員，大多是來自亞裔家庭，包括新移民家庭。他們在言語溝通上，很多時會遇上困難，不知道如何去查閱資訊及申請有關的資助。本會的工作，就是作為他們與有關機構的橋樑，幫助他們去聯絡，查詢及申請他們所需要的服務。同時，會員間彼此也保持緊密的聯絡，互相支持，互助互勉。

祈望這本小冊子可以更正一些對智障人士/孩子的誤解，傳送給大眾對「智能障礙」和「智障人士/孩子的行為」一個正確的概念，使他們能給智障人士/孩子更多的諒解，關注及支援。



陳劉秀蓉
澳洲弱能兒童協康會會長
二零零六年五月

序

根據一項二零零五年調查統計，在澳洲，智能障礙人士佔全澳洲人口之比率是百分之一點二五，意指平均每一百人中，有一位是有智能障礙的。

自古以來，大多數的社會對智障人士都存有輕視和忽略。幸好，澳洲在過去十多年來，對於智障人士的關注，作了重大的變改。聯邦政府和省政府都議訂和執行了一些條例：如聯邦政府/省政府弱能協議 (Commonwealth/State Disability Agreement CSDA), 和新南威爾斯省弱能服務條例 (NSW Disability Services Act 1993 DSA) 來保障智障人士能享有應得的服務的權利。條例亦指示弱能人士與一般澳洲居民享有同樣的權利。他們有權去確保他們的特別需求能獲得照應。作為社會的一份子，我亦確信智障人士，不論是何種膚色，種族或信仰，都應獲得平等對待和享有豐富及多彩多姿的生活。

在澳洲，對於一般身體能力有障礙的人士，英語統稱 ‘people with disability’。而智力有障礙的是稱呼為 ‘people with intellectual disability’。在香港，一般是沿用「智力障礙人士」或「智障人士 」。

至於來自非英語家庭的智障人士，他們很多時在語言溝通，與別人交往和社交技巧方面都可能會出現困難。甚致因此會導至他們失卻自信、離羣、缺乏知識和途徑去參與社交活動，或向有關服務機構請求支援等。因此，我們特別編纂這本「協康集」，給智障人士，家屬，照顧他們的人員以及各公眾人士:

1. 提供日常一般保健護理常識；
2. 提供資訊: 有關智能評估服務，醫療護理服務等，使智障人士得到適當的支援，從而培訓發展他們的技能，得以參與各種社區動；
3. 提供資料，使他們對智障人士有正確的認識和了解，接受他們。

智障人士的身心成長，是比普通人士的身心成長，需要更多的關注，教育和開導。我們誠懇的盼望，透過人類互助互愛的精神，同心合力地協助他們去康服技能，享受一個彩色的人生。

梁顯華醫生
二零零六年五月

智力障礙

一．　甚麼是『智力障礙』？

『**智力障礙**』或『**智障**』是指在成長過程中，心智發展緩慢，智力低於一般水平，以致在學習和生活適應方面有顯著困難。

『**智力障礙**』不是一種疾病，不會傳染給別人。但它是不能給『治療』 或『治癒』的 。

孩子在五歲前出現了智力發展比同年紀的兒童緩慢，一般稱作『發展遲緩』。經專家測驗評估後，「智商」(IQ)是低於一般水平，才是『智力障礙』。

根據美國精神科學會的『診斷及統計手冊第四修訂版』表示，去評估智力障礙，是要附合以下三個原則：

1. 經過『智力測驗』(IQ Test)後獲得的評估，「智商」(IQ)是低於 70 分；
2. 在各種日常生活技能上(最少有兩樣)出現困難，如：言語溝通，個人護理，家居生活，人際關係/社交技巧，善用社區資源，自我監導，應用學術技能，工作，娛樂，健康和安全等。
3. 在 18 歲之前出現了心智發展緩慢。

二. 『智力障礙』的類別

每個人都有不同程度的智慧。如果用智力測驗 (IQ Test) 來評核智力時，一般人應有的標準評分,「智商」(IQ) 是 100 分。

美國精神科學會的『診斷及統計手冊第四修訂版』，根據智商，列出不同程度的智障:

輕度智障	智商是 50-55 分 至 70 分
中度智障	智商是 35-40 分 至 50-55 分的
嚴重智障	智商是 20-25 分 至 35-40 分
極嚴重智障	智商低於 20-25 分

用『智商』把智障分成不同組別，主要目的不是去標籤智障人士，而是希望根據智商的指引去給他們提供適合他們程度的照顧、教育、培訓和支援。

美國弱智學會 (American Association on Mental Retardation) 是研究分析『智力障礙』的權威。在一九九二年 倡議用『個人需求支援量』(Intensity of needed supports)的方法來分組。他們用『支援量度表』(Supports Intensity Scale (SIS)) 作為測量工具，為智障人士評估出所需要的支助，進而編寫出日後照顧，教育，培訓和支援智障人士的目標和計劃。自此，一直至今，美國弱智學會都沿用這個方法，其中包括有四種支援：

- **間歇性支援**：短暫或『需要時』才給以的幫助
- **有限地支援**: 連續地給以支援，但有時間限制的, 如一個月
- **廣泛性支援**: 在某些環境中需要長時期的幫助支援，如在學校上，工作上，或在家居中。
- **深遠地支援**: 常常需要大量的照顧，屬於終生的支援。

這種測量評估，不是要指出智障人士所得的『智商分數』，而是強調他們需要甚麼樣的『支援幫助』，使他們得到為他們貼身訂做的培訓教育計劃。美國弱智學會這個評估方法，正期待可以進一步被廣泛接受和採用。

三. 什麼原因導至『智力障礙』？

醫學研究報告指出智障的成因很多。

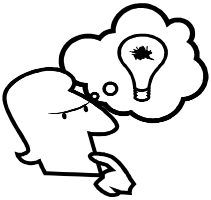
通常都是綜合了以下兩組因素，若在其中**類別因素上**或在**時間因素上**出現了問題，便有可能導至智力障礙：

第一組: **類別因素**： 例如 生命醫學科技方面，社會方面，行為方面， 和教育方面；
第二組: **時間因素**： 例如 出生前，出生時，及出生後

(見下頁附表)

醫學研究結果，已知的成因有：

- 染色體/遺傳因子 異常
- 綜合病徵： 如唐氏綜合症 , Fragile X 綜合症
- 先天不足
- 懷孕期間母親營養失調，
- 懷孕期間濫用藥物，如煙酒過量
- 懷孕期間染病，如德國疹
- 出生前，出生時，出生後大腦受損
- 出生後，嬰孩/兒童 飲食差，保健護理不足
- 兒童受虐待/給父母摒棄
- 家境貧困
- 父母缺乏照顧孩子的知識
- 延遲診斷
- 缺乏早期干預教育
- 缺乏特別教育服務



但是亦有很多的個案中，始終是**成因不明**

導至『智力障礙』的風險表

如在『類別因素』或『時間因素』上出現了問題，便可能產生表格內的徵狀，而導至智障。

類別因素 時間因素	**生命醫學科技方面**	**社會方面**	**行為方面**	**教育方面**
出生前	-染色體異常 -遺傳因子異常 -綜合症狀徵如唐氏綜合症 -父母的年紀 -感染傳染病，如德國痳疹	-貧困 -懷孕期間營養失調/不足	-濫用藥物 -酗酒 -吸煙	-父母的認知能力 有障礙 -親子知識方面準備不足
出生時	-不足月 -腦部受損	-缺乏生產時的護理	-父母有抗拒孩子的傾向 -孩子遭父母遺棄	-出院時缺乏醫療幫助
出生後	-腦部受損 -營養不良/缺乏營養 -癲癇症 -有萎縮/衰退的疾病	-缺乏兒童護理 -孩子缺乏鼓勵 -貧困 -健康護理不足 -曾入住醫院兒童院等	-虐待兒童 -家庭暴力 -受社會遺棄	-不健全的親子行動 -延誤疹斷 -缺乏早期干預教育 -缺乏 特別教育服務

(摘錄自 AAMR 2002 Manual, 126 頁)

四. 關懷智障兒童的健康

在澳洲，所有的澳洲居民都能享用澳洲政府推行的醫療服務(Medicare)。但很多時，智障人士對醫療服務的需求是比一般人士高很多的。

他們常患的疾病有：

- 癲癇症
- 呼吸系統/腸胃系統出現問題
- 視覺障礙
- 聽覺障礙
- 骨質疏鬆症
- 思覺失調
- 記憶力衰退
- 口腔炎/牙齒炎
- 肌肉/骨骼出現毛病
- 飲食失調
- 肥胖
- 容易發生意外

健康的護理：

- 減少言語溝通上的障礙，使他們正確明白醫生及其他醫護人員的講解
- 與醫生及醫護人員合作, 依照已訂的康服計劃去實行，如：依時服藥
- 定期接受其他醫療服務和輔導，如：物理治療
- 定期進行視力和聽覺檢查
- 進食時，慢咀嚼，避免食物阻塞喉嚨，引起打噎，或影響呼吸
- 每餐不宜進食太多，以防消化不良，或引致肥胖症
- 鼓勵他們勤做運動
- 保持個人衛生：常刷牙，維持口腔清潔
- 保持室內/地坂/地氈清潔，清掃塵蟎
- 謹守「家居安全守則」，避免意外發生
- 如有問題或發生困難，立即向醫生/醫療機構求助

五. 照顧及支援智障兒童

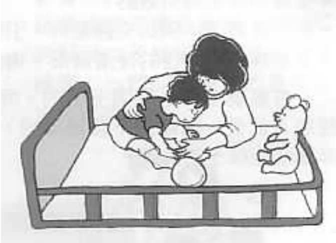
每一位智障人士需要不同的「特別照顧及支援」。有些智障人士，祇需要一些適量的訓練、教育和援助，便可以過獨立自主的生活。有些智障人士，同時患有其他障礙，如有視聽覺障礙，或行動不便，他們就要更多的援助了。其實，如果他們能及早獲得和接受「早期干預教育，結構性教學課程及適當的社區服務」，他們都像普通人一樣，可以去學習、去發展他們的所長。

要及早接受診斷

當孩子還小時，他們的障礙大多都不明顯。但若發現在成長過程中出現了一些顯著的緩慢時，家人應向有關的專業人士咨詢。以下各項表示兒童有「發展遲緩」的傾向：

- 到了六個月大，兒童對外界的事物、動作或聲音，未會作出適當的反應。

- 兒童到一歲時，還未能夠坐穩



- 到三歲時，還未能步行
- 到三歲時，還未能說出簡單的短句
- 兒童的記憶力弱
- 性格好動，過份活躍，對於明白遵守社交規則出現困難
- 過份沉靜，對四週事物缺乏興趣

到何處去求助？

如果家長對孩子的發展有所担心，可以到下列部門咨詢：

- **你的家庭醫生**
- **居住地區的兒童健康中心**
- **居住地區的健康中心**
- **學校**

如有需要，他們會將孩子個案轉介到**專科醫生**或**早期幼兒組**去跟進。

早期幼兒組工作人員包括：

- **社會工作人員：**提供資訊，支援，輔導和協調安排有關的服務
- **職業治療師：** 給家人提供意見，如何去鼓勵孩子發展遊戲技能，思想 技能，社區和自助技能，如穿衣服，如厠等
- **心理學家：** 對孩子的發展和行為方面提供意見和輔導策畧
- **言語治療師：** 給家人提供意見，教導孩子如何去與人溝通，運用言語 和説話
- **物理治療師：** 給家人提供意見，教導孩子動作技能，如走路，坐立等

社會工作人員家庭訪問

物理治療

在家裏照顧智障人士

照顧教育孩子，是一件繁重的任務。照顧智障孩子，更加費心。教育輔導他們，可從家裏開始：

1. 給他們提供一個啓發性和趣味性的家居環境:

- 安排時間與他們遊戲
- 用不同的玩具去吸引他們，引起他們的興趣，去獲取他們的反應
- 與他們遊戲，跟隨他們的指引，讓他們做主導，不要強迫他們玩他們不想玩的遊戲
- 維持一個輕鬆自如的環境。同時，亦儘量付予他們一個安定和有規律的生活程序

2. 訓練基本的日常生活技能和個人護理：

智障人士在學習能力方面是遲緩的。當學習一件新工作時，要採用「**小步驟**」的方法。分折學習內容，盡量作「**小步驟**」學習，先示範給他們看，然後讓他們自已一小步，一小步地去做。他們需要輔助時才去幫手。每當他們學習成功，要即時稱讚他們的表規，以強化他們的學習。

下列各項活動，可應用「**小步驟**」的方法去幫助訓練他們：

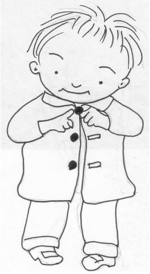
進食:

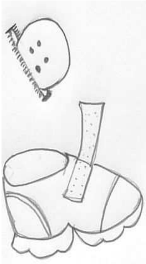
- 一小步，一小步地教智障孩子使用進食餐具，從簡單到複雜的，如:匙羹 → 义 → 筷子
- 儘量在輕鬆愉快的氣氛下進食，不要邊罵邊吃。

如厠

- 父母不要心急，當覺得是適當時才開始訓練孩子如厠
- 如果他要如厠時，教他如厠的言語或手語：例如 poo 或尿尿
- 為他選擇適合的坐厠/便器
- 給他穿上容易穿和脫的褲子
- 養成每日定時如厠的習慣
- 如厠後，要洗手
- 當能完成一小步驟，立刻稱讚獎勵他

穿衣:





- 採用「小步驟」方法，穿衣分多步驟進行
- 為方便訓練他們，初時，衣服最好沒有鈕扣
- 可用大些的鈕扣
- 可用尼龍貼的鞋子
- 每成功完成一步驟，切記加以獎勵他們

其他家居技

- 分派他們可以勝任的工作，以增強他們的自信，如洗杯子，擺放碗筷

- 記緊把工作分成小部分進行，並加以鼓勵稱讚

3. 注意家居衛生

盡量保持家居清潔，同時也要養成良好的衛生習慣：

- 如厠後，進食前後，都要洗手
- 每天都要刷牙 (尤其是臨睡前)，清潔口腔
- 勤於梳頭，洗頭，以防頭蝨
- 勤於洗澡
- 訓練他們把廢物垃圾放進廢物箱
- 訓練他們在遊戲或工作完畢後，清理場地
  如果衣服弄濕了或弄髒了，要換上清潔的衣裳

4. 語言溝通

智障人士在語言能力方面，表達能力弱，詞彙有限，句式簡單，甚或有發音 不準。父母家人在與他們溝通時，要耐心聆聽，作適當的回應。

- 與他溝通時，用他明白的語言
- 可以試教他用手勢表達，
  然後用言語輔助，逐漸再鼓勵
  他用簡單語句代替手勢
- 可用實物或圖畫教他說話
- 與他說話時，用簡單的語句
- 每次說話內容，祇限一個主題，
  若重複時，用回同一的語句
- 指示要簡單，清楚，直接
- 切勿譏笑他們或模仿他的
  不正確發音或言句
- 請教言語治療師

耐心聆聽

用實物來教導

5．社交技能

智障孩子的社交技能比一般孩子弱，對他一些不恰當的行為，應耐心去矯正。他有時會對別人表現出過份熱情，這祇是他表達感情和友善的一種方式，他亦希望別人對他關注。

- 教導他向別人打招呼
- 教導他正確的社交禮儀: 如ˉ謝謝ˉ
- 鼓勵他參與別的孩子的集體遊戲，從中學習與人交往
- 教導他正確的遊戲規則
- 提供機會，讓他能從實際生活中學習：如 逛超級市場，到公園去


打招呼


參加集體活動

6．家居安全

在智障孩子常患的疾病系列中，「意外」是其中一項。很多時，「家居」被認為是安全可靠的地方，可是，「意外」往往就在家裏發生。對於智障孩子在家的照顧，家人也需要多加專注，份外留神。

- 不要讓孩子獨自留在家中，要有家人陪伴
- 在露台，窗户加上適當的欄干或窗架，以防孩子爬出或從高處墮下
- 把家中用的藥物，化學物品 (如：洗潔精，漂白水等) 鎖好，或放在他不能觸及的地方
- 不要讓孩子把玩電器用品，電掣插上安全掣
- 把火柴，打火機，蠟燭收藏好，以免他把玩
- 小心滾燙的水，水壺，以免灼傷
- 把尖鋭的利器收藏好，如剪刀，針等
- 不要把細小的物品隨處擺放，以免孩子把它吞下
- 慎防孩子被厚棉被，膠袋，窗簾，繩索和頸鍊等弄至窒息
- 不要讓孩子獨自留在浴室洗澡，以防遇溺


慎防觸電

7. 給家長的支援

家裏有智障孩子，父母都要加倍用心照顧，歇盡所能，勞心勞力，做到無微不至。但同時，父母亦要對自已本身的身體及心理健康，詳加關注，經常保持客觀愉快的心情。


參加座談會

- 接受孩子，不用感到內疚，積極地去幫助孩子
- 盡早咨詢專業人士，尋求他們的意見和輔導，安排孩子的教育支援計劃，逐步實行
- 父母分担照顧，教育孩子的工作和責任
- 積極地去查詢及尋求可運用的政府/社會資源
- 盡量參加其他服務機構舉辦的家長活動，吸取輔導孩子的知識
- 通過服務機構舉辦的活動，多與其他智障孩子的父母交流，互通心聲，互助互勉
- 爭取親友，隣居的支持和幫助
- 保持心境開朗
- 尋求申請「暫居照顧」服務，給父母本身一些私人空間/時間


家長互相聯絡

六. 結 語

在照顧智障孩子的過程中，父母，親友和輔導人員等都要付出無比的愛心、忍耐和勞力。經過適當的教導和訓練，大部分智障人士都能過獨立生活。他們如常人般，也經歷喜、怒、哀、樂、愛、惡、慾等…在處理情緒方面，他們也需要輔導，使能正確地表達情感。常常鼓勵他們多參加羣體活動，結交多些朋友，擴潤社交圈子，使能加強自尊和自信。同時，社會人士亦要客觀及正確地認識，接受智障人士；給他們送上關懷、了解和支援。

※※※※※※※※※

專題文章

未能致人中龍鳳　卻能欣慰無窮:
了解智障人士及其家長的心理需要

作者: 澳洲中文廣播電台節目<心理藍途>主持藍兆雅 (心理家)

回想初次參加「澳洲弱能兒童協康會」的聚會時， 尚未有臨床經驗的我對智障人士的認識是非常淺薄的。 記得當時踏入會場的剎那間， 聽到從遠處響起了一把清脆的聲音。

‘…天造之才　皆有其用 振翅高飛　無須在夢中…’
(天才白痴夢 - 許冠傑)

回頭一看， 見到遠處坐著一位男孩， 一邊把弄積木，一邊唱著許冠傑的名曲。 很難想像這位有智力障礙的男孩竟能輕而易舉地把歌一字不漏， 倒背如流的唱出; 音色之準確， 節奏之強烈，你我都可能自嘆不如。好奇詢問一下其他家長，竟發現他的語言和接收能力都比較同人士低，平日沉默寡言的他， 連簡單去跟別人講句「你好嗎」都困難重重。這使我感到萬分驚訝。 而我的驚訝也代表了一般人對智障人士的誤解。

從誤解到了解

很多人以為智障人士就像長不大的孩子， 沒有能力去學習， 去進步。其實這是個錯誤的觀念。 智障人士和其他人一樣， 若能給予充裕的發展空間， 加上家長及導師的耐心教育， 他們的心智成長， 行為表現， 以及溝通技巧均能得到正面的提升。 秘訣在於因材施教， 將傳統的教學方法作出調整， 以配合智障人士的特殊需要。 要是你能夠耐心去發掘個別智障人士的獨特之處， 便會發現寶藏: 平日不發一言的他可能會為你「大開金口」!

以上提及的只是眾多謬誤中的冰山一角 (如想進一步了解關於智障人士的謬誤與論 http://www.nswcid.org.au/publications/fs/index.html， 然後按‘Myths and Facts’)。 很多人對智障人士的認識只來自某電視劇

<阿旺新傳>的阿旺身上。 除了「老婆仔」和「老婆湯丸」以外， 好像就一無所知。 有些人更採取不聞不問的態度， 抱著事不關己的僥倖心理，心想: 「世界上邊有咁多個阿旺? 無咁好彩俾我遇到嘅， 就算遇到都唔關我事啦! 」最近的一個問卷調查顯示， 受訪者平均認為普遍人口中智障人士所佔的比例是 0.5%[1]。 相比起新南威爾斯省智障人士委員會的官方數字 (2.3% 至 3%)[2] 大大低估了 46 倍以上。 在新南威爾斯省， 估計有 138，000 至 180，000 名智障人士。 像阿旺一樣傳奇的人氣角色， 我們只能在螢幕上一睹風采， 但在現實生活中我們和智障人士接觸的機會卻多的是。

的確，作為社會的一份子， 我們都能出一分力幫助身邊的智障人士融入社區。 根據新南威爾斯省 Department of Aging， Disability & Home Care 於 2002 年落實的一份名為 'Living in the community: Putting children First'[3] 的政策，智障人士及其家屬跟其他人一樣有相等的權利參與社區活動， 與非智障人士接觸及建立友誼。因此政府鼓勵普羅大眾多些了解智障人士及其家屬的各種需要， 其中包括心理需要。

了解智障人士的心理需要

在澳洲大概有 40% 的智障兒童以及青少年現正受心理疾病的纏擾，而一般兒童及青少年患上心理病的比率只是 10%[4]。從這個數字顯示， 智障人士比一般人容易患上心理疾病。 智障人士一般的溝通技巧比同齡人士差， 未必能夠有效地用言語表達他們的感受， 所以有些人以為智障人士沒有情感， 不會感到傷痛。 事實卻不然， 只是他們的情緒問題較難被察覺，較易被忽略。

不是所有智障人士都會有心理困擾， 究竟那些智障人士比較容易患上心理病? 研究指出以下的因素與智障人士患上心理病有正面的直接

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[1] Tachibana, T. (2006). Attitudes of Japanese adults toward persons with intellectual disability: Effect of Perceptions concerning Intellectual Disability. *Education and Training in Developmental Disabilities*, 41, 58-69.

[2] www.nswcid.org.au

[3] http://www.dadhc.nsw.gov.au

[4] Einfield, S., & Tonge, B.J. (1996b). Population prevalence of psychopathology in children and adolescents with intellectual disability.I. Epidemiological findings. *Journal of Intellectual Disability Research*, 40, 99-109.

聯系， 包括: 有身體殘疾， 成長於低收入家庭， 受照料於單親家庭， 成長環境經常「家嘈屋閉」，受刑罰性管制， 以及智障人士的看護人患有心理病[5]。男性的輕微智障人士， 特別是一些缺乏交際的， 較常有反社會行為和毀壞性的表現。而較嚴重的智障人士，較常有焦慮的反應和溝通障礙[6]。心理學家指出[7]，智障人士因為先天的障礙，比一般人感受更多負面的生活經歷， 有更少的機會建立社交網絡， 更難從工作中得到成就感， 也必未能體驗人生的幾個必經階段(例如結婚，生兒育女) 。這負面的生活經歷經過長年累月的積聚， 令智障人士認為自己永遠無法擁有美好的人生， 因而對未來感到無望， 抱放棄態度。 有些覺得自己有智障，再加上一些失敗的經歷， 便對自己去失信心， 害怕嘗試， 對新事物感到恐懼。

要協助智障人士重拾自信， 積極面對人生， 可以先從改變他們的經歷著手。而你和我都可以出一分力! 第一， 要現實地按智障人士的年齡、能力及經驗去要求他們的表現。 不要過份嚴格或過份保護！ 當他們達成任務的目標後， 作出合理的嘉獎。 其次是鼓勵智障人士參與不同的活動， 與不同類型的人接觸。智障人士很需要我們的接納。有時候他們會以擁抱及輕拍來表達善意， 令人誤解以為這是不禮貌的行為， 其實這是熱情的表現。有些智障人士的語言能力和溝通技巧較差， 在澳洲這個集結不同語言背景的多元文化國家， 與智障人士溝通更成為一個挑戰。以下是一些與智障人士溝通的方法:

- 運用簡單語句，避免抽象詞語及冗長句子
- 利用身體語言 (例如手勢、動作)
- 如有需要，耐心地重複解釋
- 按步就班， 避免跳話題
- 澄清問題及答案，確定彼此明白對方的意思

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[5] Wallander, J.L., Dekker, M.C., & Koot, H.M. (2005). Risk Factors for psychopathology in children with intellectual disability; a prospective longitudinal population-based study. *Journal of Intellectual Disability Research*, 50, 259-268.

[6] Emerson, E., Robertson, J., & Wood, J. (2005). Emotional and behavioural needs of children and adolescents with intellectual disabilities in an urban conurbation. *Journal of Intellectual Disability Research*, 49, 16-24.

[7] Dagan, D., & Waring, M. (2004). Linking stigma to psychological distress: Testing a social-cognitive model of the experience of people with intellectual disabilities. *Clinical Psychology and Psychotherapy*, 11, 247-254.

不少的家長曾經問我， 心理治療適用於智障人士嗎? 對於一些有行為問題的智障人士(例如經常無故吵鬧)， 行為治療能夠有效塑造以及矯正不良的行為。而情緒方面， 心理學上最常用的認知行為治療是針對改變不適當的行為和思考習慣。雖然現階段對於這方面的研究仍未發展完全， 最近的一些報告顯示， 若將傳統的認知行為治療改良， 對幫助輕度智障人士的精神分裂症治療[8]、焦慮感處理[9]、憤怒情緒管理、犯罪行為控制[10]、都能夠起正面的作用。

了解照顧智障人士的家長的心理需要

照顧智障人士對其父母以及各家庭成員來說，像是一個永無止境的重大任務。以下會著重討論家長的心理需要。

這個一生一世的重大任務由懷胎十月開始。 當家長初次聽到自己的孩子有智力障礙時，心裏都會感到很疑惑，震驚、甚至否認、拒絕接受事實。尤其一些有輕度智障的兒童平時表現和外觀可能和一般兒童無異，因此更會加深家長的拒絕相信與懷疑。有些家長則會感到憤怒，埋怨上天為何要待他們如此不公平。很多時候家長會設法了解情況， 但結果可能會帶來不同程度的自責和內疚， 覺得孩子的智力障礙與自己有關。有些家長會覺得悲傷、羞慚， 認為生下智障的兒童是家門不幸， 於是不敢和其他親人朋友接觸， 覺得「家醜不宜外傳」。 此外， 家長會對照顧智障孩子和不可預知的將來感到焦慮、困惑、甚至絕望無助。 每對家長的情緒反應都會不同，反應的程度也因人而異。 情緒是人感情的自然流露，沒有所謂對錯。一般來說，家長處於每個階段都會嘗試去適應，並作出不同的情緒調整。

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[8] Haddock, G., Lobban, F., Hatton, C., & Carson, R. (2004). Cognitive-behaviour Therapy for people with psychosis and mild intellectual disabilities: A case series. *Clinical Psychology and Psychotherapy*, 11, 282-298.

[9] Dagan, D., & Jahoba, A. (2006). Cognitive-Behavioural Intervention for People with Intellectual Disability and Anxiety Disorder。*Journal of Applied Research in Intellectual Disabilities*, 19, 25-33.

[10] Sturmey, P. (2004). Cognitive Therapy with people with Intellectual Disabilities: A selective review and Critique. *Clinical Psychology and Psychotherapy*, 11, 222-232.

智障人士的家長最需要的不是憐憫， 而是慰問與接納。有些家長可能需要較長的時間去接受孩子有智力障礙。他們的心理通常是矛盾的。他們的內心充滿悲哀和憂傷， 渴望向人傾訴，可是又怕被別人知道。一方面極力掩飾自己，另一方面又努力地在別人面前偽裝自己，「對人歡笑背人愁」。這時候， 家長的親友應該耐心地等待家長決定如何面對這個問題， 隨時準備仔細聆聽他們說出自己的感受，而非催他們談論孩子的智力障礙，也不用故意轉換話題。此外，親友也應給予家長關心及支持。多鼓勵及安慰家長，不要表現出過度擔心或過分批評家長對孩子的態度和處理方法。大多數家長要為照顧智障孩子而改變原有的生活模式， 重新安排及計劃未來。此時， 生活上的實際需要顯得特別重要。親友可以幫助照顧家長及孩子的實際生活需要例如家務，託兒管理。研究指出[11]，伴侶、朋友和家人(尤其祖父母) 對照顧智障人士的家長的支持，對他們的心理適應有明顯幫助。

家長在經過自我的調整之後，有的不但能接受孩子有智力障礙，更積極面對和克服照顧智障孩子的壓力， 向外尋求適當的協助。 有的可能因為想了解自己的孩子而精心探求智障的資訊， 甚至勇於走入人群， 與其他有相同情況的家庭分享心得。 可是， 有部份的家長會遇到心理失調， 其中以抑鬱和焦慮最為普遍[12]。「養兒一百歲， 長憂九十九」。很多家長擔心智障孩子沒有自立能力， 怕自己死後孩子缺乏照顧。曾經認識一對有極度嚴重智障孩子的父母，他們終日提心吊膽， 不敢離開女兒半步， 害怕她會一不小心弄破玻璃或是觸碰電源， 釀成家居意外。 親眼見證到父母為智障孩子不辭勞苦不計收穫的奉獻，才切切實實感覺到「愛是無條件的付出與忍耐」這句說話的真正意義。

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[11] Salovita, T., Itälinna, M., & Leinonen, E. (2003). Explaining the parental stress of fathers and mothers caring for a child with intellectual disability: a double ABCX model. *Journal of Intellectual Disability Research* 47, 300–312.

[12] Dumas, J. E., Wolf, L. C., Fisman, S. N., & Culligan, A. (1991). Parenting stress, child behavior problems, and dysphoria in parents of children with autism, Down syndrome, behavior disorders, and normal development。 *Exceptionality*, 2, 97–110.

令人心痛的是，一項關於照顧智障人士的家長的心理研究顯示[13]，當中有70%從亞洲移民的家長經歷達到病態水平的心理失調，相比於一般居民的47%明顯為高。比較一般居民，海外移民的智障家庭遇到更嚴重的溝通障礙[14]，而障礙不止於言語不通，文化交流同樣是困難之一。照顧智障人士的家長可能是新移民，朋友不多社交圈子狹窄，對於區內的援助服務感到陌生，而家人可能又在外地未能給予支持，種種問題都令照顧智障人士的家長感到求助無門，雪上加霜。除了依靠主流社會提供資源和培訓，他們很需要社區內的一些有心人士及互助組織(例如「澳洲弱能兒童協康會」)作出指引和支援[15]。

當家長慢慢掌握和適應如何照顧智障孩子後，他們的情緒仍然需要伴侶、朋友和家人的支持。家長有時要在孩子面前表現勇敢和平靜，但私底下卻感到無助，他們很需要找別人「吐苦水」。除了定時安排專業的心理輔導外，朋友和家人可以細心聆聽家長的心聲，給予支持和諒解。家長全心全意地照顧智障孩子的需要，有時會忽略了自己本身的需要。家長同樣需要正常的社交生活、娛樂活動，應該安排時間讓自己鬆弛一下壓力。擁有健康的身心，才可有效的照顧智障人士。

父母為著孩子們有更好的將來，能開心活潑健康的成長，都盡力給予他們最好的生活環境。一般的父母都望子成龍，光宗耀祖(雖然一個正常的孩子都未必做到)。對於智障人士的父母來説，他們對子女的期望不是成為人中龍鳳，而是平平安安。只要孩子開開心心，家長就已經欣慰無窮。如此簡單的夢想，為何難以達到?

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[13] Emerson, E., Robertson, J., Wood, J. (2004). Levels of Psychological Distress Experienced by Family Carers of Children and Adolescents with Intellectual Disabilities in an Urban Conurbation. *Journal of Applied Research in Intellectual Disabilities,* 17, 77-82.

[14] Franciso, I., Carlson, G., (2002), Occupational therapy and people with intellectual disability from culturally diverse backgrounds. *Australian Occupational Therapy Journal*, 49, 200-211.

[15] White, N., & Hastings, R.P. (2004). Social and Professional Support for Parents of Adolescents with Severe Intellectual Disabilities. Journal of Applied Research in Intellectual Disabilities, 17, 181-190.

智障人士及其家屬需要你的支持和鼓勵。當你用尊重的心去了解他們， 你會看到他們的深處隱藏了一顆快樂的種子。這顆脆弱的種子， 放在你手裡， 若不小心保管，任它風吹雨打， 受苦痛的煎熬，它會變得乾枯而失去生氣。倘若你用耐心去灌溉它， 用關懷去照耀它， 這顆種子不但會萌芽開花， 還會長出翅膀， 振翅高飛。尋獲快樂， 不再只是一個夢! ☺☺

安排與家人 參加社交生活，娛樂活動

言語治療

Candy Leung
言語治療師

甚麼是言語治療師？

言語治療師是受過專業訓練的人士，專門負責評估及協助有溝通或吞嚥困難的人士。言語治療師會協助家長及兒童發展溝通及進食的能力。

為甚麼要言語治療師？

溝通是一個理解説話及被人理解的過程 -- 是大多數人與生俱來的。溝通障礙是由不同的問題組成：發音困難、理解及表達能力困難、嗓音困難、口吃及流暢問題、聽覺問題、或讀寫障礙。

言語治療師會接見以下的兒童：

- 難以表達自己
- 不明白父母或老師的説話
- 還未開始説話
- 有社交能力障礙 (例如：自閉症)
- 吞嚥困難 (例如：咀嚼困難、流口水)
- 聽覺問題
- 讀寫障礙

- 口吃
- 經常失聲

言語治療師提供的服務：

在悉尼提供言語治療服務的機構包括醫院、社區健康中心、學校、托兒所、政府機構(例如：DADHC)、非牟利機構(例如：Learning Links)、及私人執業的言語治療師。言語治療師提供不同類型的服務：例如個人治療、小組治療、協助老師在課室提供治療、提供指引及資訊給患者，其家人及其他專業人士 (例如：兒科醫生、教師)。

尋求言語治療師的服務：

任何人均可以轉介至言語治療師 (例如：患者本人、家長、教師)。

毋須 醫生轉介。你可直接向 DADHC、所住區域的非牟利機構或澳洲言語治療師協會查詢。

職業治療與兒童

Angela Yee
職業治療師

職業治療的宗旨主要是在提升特殊兒童的正常發展及刺激他們的學習。特殊兒童包括那些被評估有學習障礙、身體機能障礙、發展遲緩，和因疾病或意外康服中的兒童。職業治療師透過與兒童，家人及教師的合作，去協助兒童參與日常活動：包括遊戲、入學前的學習、學校活動及家居活動。

職業治療師提供以下的協助：

- 首要必備的活動----兒童的體格能力，例如運動控制、手眼協調、身體意識及感官力。
- 功能性技能-----兒童的日常活動：例如進食、寫字、如厠、與其他兒童進行室內和室外的遊戲。
- 環境----例如課室內傢私；使用課室、操場及學校各範圍；運用木工、美術、和體育活動的輔助儀器。

職業治療師提供甚麼服務？

職業治療師服務可分為以下三個範圍：

1. 評估
   這包括發展性及工作表現能力的評估；以及這些能力對兒童在家裏，學校及遊戲環境的影響

2. 治療
   提供治療及家庭治療程序去提升兒童的技能

3. 諮詢
   這包括提供文字資訊 (例如：報告，治療程序)或提供意見給學校及其他專業人士。專門性的職業治療包括體能復康，活動課程，使用經改良的適應技巧，提供適應和改良儀器，提供學習技巧及輔導。

職業治療師能如何協助你的孩子？

職業治療師可以協助兒童，他們的照顧者/家長，及其他對兒童重要的人士：

* 增加對兒童的病況，殘障和困難的認識。
* 學習不同的技巧去充分利用及提升兒童在日常生活的表現。
* 提升及培養兒童的長處及自尊。
* 職業治療服務由不同的機構提供，包括醫院，社區中心，
  私家診所，和一些教育機構 (例如學校及特殊學校)。

在那裏可找到職業治療師？

你可以由你的醫生或專科醫生，其他醫護專業人士，朋友或親屬轉介至職業治療師；你亦可直接向職業治療師查詢。

如需更多關於職業治療師的資科或需要評估職業治療師的執業資格，請向澳洲職業治療師協會查詢。

感情的表白：

澳洲弱能兒童協康會會員

分享

轉瞬間，我的兒子今年已屆26歲。在過去廿多年間，經過不斷的學習，參考報章、雜誌及專家提供的專業知識，加上與其他弱智兒童家長交流的心得，我有以下體驗，可與大家分享。

（一）接受事實

孩子年幼時，學習遲緩，大概三歲才懂說話。醫生比喻他是一個氣球，多吹谷，會爆裂。所以，一直以來，我也不敢奢望他成龍，但求他學曉求生技能，快快樂樂地成長。

（二）正面教育 (Be Positive)

從前，我不懂怎樣是正面教育，孩子做錯事，我會着他「不要」這樣做，「不要」那樣做。後來，學懂了正面教育，把「不要」指示，換作「該做什麼」。這樣，孩子會接收到直接了當訊息，不用揣測父母的意思，並按着指示去做。

（三）讚賞

多年來，我學會讚賞對孩子的重要。其實，弱智孩子跟正常孩子一樣，喜歡被稱讚。不同的是弱智孩子的「成就」不多。所以，要在日常生活中，多加觀察，即使是微不足道的事，也可以大加讚賞，讓孩子明白那些行為是正確的，從而增加自信。

（四）專業輔導

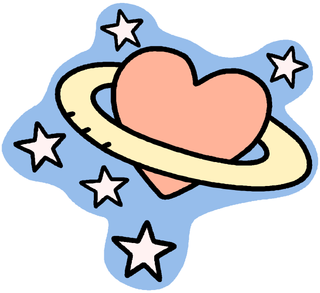
因為每個孩子的智能和行為有別，市面上沒有一本全面的教育子女手冊，告訴我如何處理及矯正孩子層出不窮的問題行為。在這方面，心理輔導員給我提供不少寶貴意見，為我分析那些是可接受行為，及引致問題行為的原因，從而改善行為。

這些年來，我習慣了容忍，包涵。在徬徨不知所措時會祈禱，求主賜我兒平安無恙。孩子犯錯，或說話冒犯，我不會記在心裡。孩子腦部受損是不變的事實。作為父母，希望可以儘量發掘他的潛能，加以引導，並讓他接觸新事物，增廣見聞，幫助他融入社羣，在社會上做個有貢獻的人。俗語有謂：「一分耕耘，一分收穫」。如果每天能夠多花點時間來教育孩子，陪他玩遊戲或閱讀，孩子的進步是指日可待的。

凡塵　2006 年悉尼

* * *

義工的心聲



兩年多前，我從香港移民來澳洲，不久就加入澳洲弱能兒童協康會義工。在長達兩年多，切身體會親眼現証協康會由小漸大，由艱難起步到今天初見碩果。其變化之大，進步之快，成績之顯著，均出乎人們想像，也是我當初萬萬預想不到的。我認識幾位智障兒童，曾經很自閉，沉默寡言，經常以一付冰冷面孔拒人於千里之外。但是參加協康會活動後，有了明顯地改觀，逐漸打開心扉，願意和外界交流，而且常有笑容，願意和外界親近。原來冷若冰霜的面孔消失了。亦有幾位語言木訥，不善言辭，當人們與之交談時，往往只是瞪大雙眼，望着對方，很吃力才説出一兩個單字。通過協康會長期活動，他們不單願意和人們交談，還可以唱出完整的一支歌曲。亦有不少孩子，不會用筷子，不會執鉛筆，在協康會繪畫班學習繪畫，不少兒童已經可以用微微顫抖的手，握住畫筆，畫出心中美麗的畫面…。所有這些變化，對於智商正常的兒童或許不足為奇，但出現在不同程度的智障兒童身上，這進步是十分難得，令人感慨萬分的。每一點一滴進步都與父母親傾注的悉心關懷分不開。他們不但沒有因為家中有這類困境而放

棄，相反是積極配合協康會，長期不懈地努力，終於現到曙光，看見希望。

我尤其敬佩協康會幾位領導成員。他們在繁忙的正職工作之餘，擠出寶貴的業餘時間，以高度熱情和愛心，以及最難能可貴的敬業精神，為協康會安排豐富多彩的活動內容，使每個周末僅僅三個多小時的康服活動，既有吸引力，又有啓發性，使到參加的兒童和家長均充滿欣喜和歡樂而離開，又熱切盼望下一次愉快的相聚。

回想兩年多巨大變化，我深有感慨。個人的力量畢竟是很有限的。因此，我由衷地期望，政府有關部門給這個協康會以支持，令協康會在現有良好基礎上，更進一步發展，有條件聘請多一些專業教師，使協康會的工職能進一步完善，並且能擴大社會影響，使更多智障兒童家庭認識協康會，帶孩子到協康會來參加活動，使至今仍留守家中的不少智障兒童得到進一步改善，令澳洲多元文化的大家庭更加和諧完美。

譚秀蓮
澳洲弱能兒童協康會義工
二零零六年四月一日

吾兒必誠

梁惠蘭

天下父母心無不希望自己的子女都能聰明伶利，健康活潑的成長。　但有時人不如願，當面對子女有些缺憾時，應如何面對？多少個悲傷和遺憾的故事徘　在每一個角落，以下謹將誠兒的故事，與大家分享！

誠兒今年六歲了，性情溫馴善良，但脾氣固執，有點偏激和偏食，無不良的暴力行為，外貌長得頗俊秀，我與誠兒外出時，常聽人稱讚道：妳兒子長得很好看！

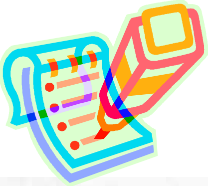
遺憾的是誠兒今年六歲了，仍未能與人互相溝通。每次暇時帶兒到公園遊玩，看到別的小朋友在一起玩得興高采烈的，誠兒亦想加入一起玩，無奈語言障礙，與小朋友們不能溝通，無形的便被排斥一旁，只好獨個兒玩，日久便形成了自閉症，故我想自閉症和語言障礙是相影成彰的·誠兒幼時二歲才敢獨自步行，三歲時便已發現語言方便表達能力差和注意力未能集中，經各醫療部門診斷後，證實誠兒患有自閉症和語言障礙·隨即便按步就班的聽從專科醫生和語言治療師的指導，隔週到語言治療師裡學習，四歲

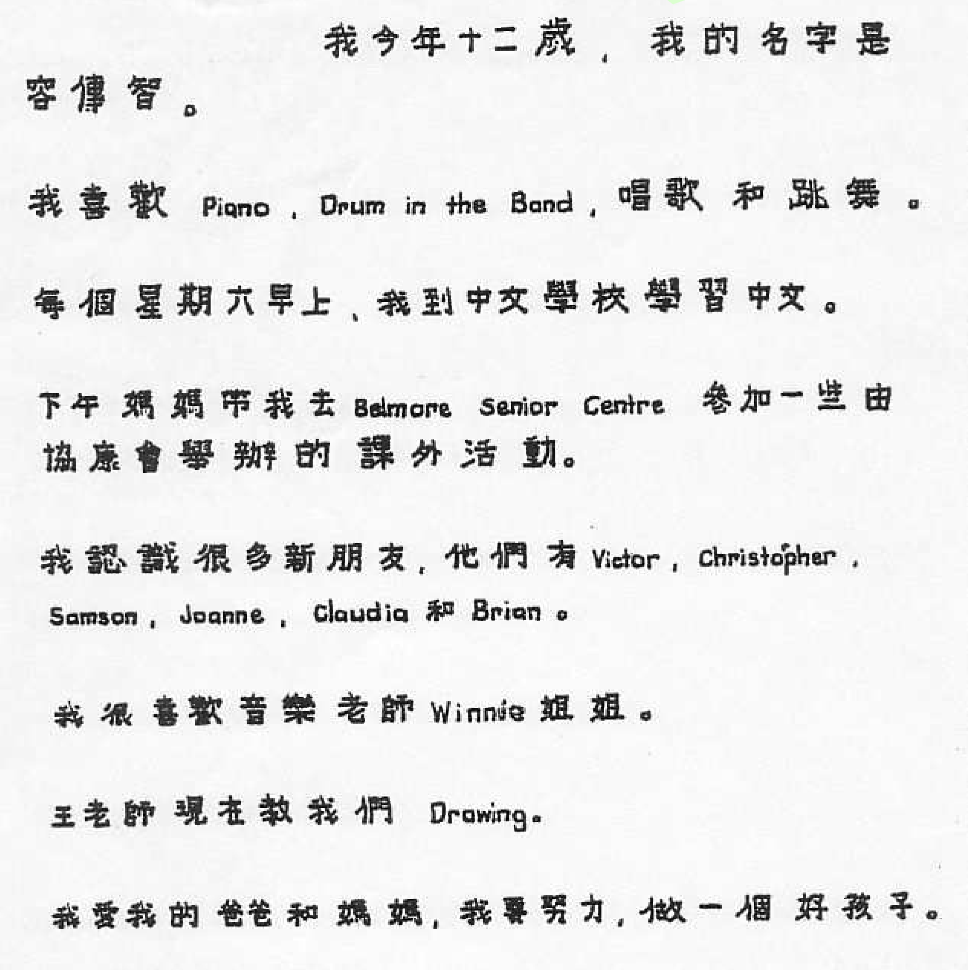
時申請上幼稚園特別班，五歲就讀普通學校特別班，因普通學校特別班未能設有語言治療師的課程，對誠兒語言方便未能有所幫助，故今年轉入特殊學校就讀，因特殊學校有機會跟語言治療師學習，課程方面是因各人所需而設，但讀寫方面就比較緩慢了·

誠兒就讀特別學校轉眼已快十週了，單字認識了不少，亦開始會利用圖案連成句子來索取食物，或有需要幫助時叫 Help! Help! 或時而自言自語，不知是否望兒心切，每感束手無策，百般無奈，心力交瘁時，亦不知措，幸得去年認識了澳洲弱能兒童協康會，並加入成為會員，協康會每週舉辦各項有益身心的活動，家長們在會中彼此交流心得和意見，互相扶持，像個大家庭般，一股暖流重現心霏，使枯燥的生活上重拾曙光，現每週帶著誠兒到會中參予不同的活動，讓誠兒有機會認識更多的小朋友，願以我們的愛心，耐心和恆心，陪伴著孩子步上漫漫人生路，不論路途踦嶇，排除萬難，勇敢面對·

* * *

我的日誌





我今年十二歲，我的名字是容傳智。

我喜歡 Piano，Drum in the Band，唱歌和跳舞。

每個星期六早上，我到中文學校學習中文。

下午媽媽帶我去 Belmore Senior Centre 參加一些由協康會舉辦的課外活動。

我認識很多新朋友，他們有 Victor，Christopher，Samson，Joanne，Claudia 和 Brian。

我很喜歡音樂老師 Winnie 姐姐。

王老師現在教我們 Drawing。

我愛我的爸爸和媽媽，我要努力，做一個好孩子。

一些感受，一點建議

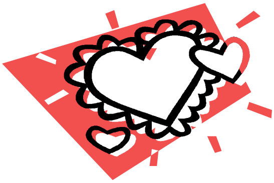
Cindy Liu

我女兒出生後，我被告知她患有一種罕有的綜合症。這種症狀引起她身體多方面功能的障礙。照顧一個有殘障的小孩，語言溝通對於我們來自非英語背景的家庭來說，也是一個問題。開始時，很多時候，我們想得到更多的信息去幫助我們的孩子，但是又不知道從那裡可以得到，真的感到很無助。而 DADHC 部門因人手不足，本來有語言、物理、職業治療師上門家訪，卻暫停服務，令我們家長感到很徬徨，為孩子的成長感到很担心。

我女兒需要每天吃藥，打針，經常看醫生，住院。由于孩子需要特別照顧，使我無法出外工作。孩子的特殊學校的費用，需全數支付。她所需要的特別奶粉，藥物花費比正常孩子要多得多。每月的營養素就要約五十元。雖然一些藥物有政府優惠，但是其他的藥還是要花一筆額外的費用。

我先生為了增加收入，不得不盡量加班，以至週末不能回家陪孩子玩耍，缺失了家庭樂。而他常為孩子的病和家庭負担感到担心，經常頭痛。我要照顧丈夫，家和弱能孩子，感到力不從心。孩子越來越大，我的體力就越不支，我現在幾乎抱不動她，腰經常痛。生活的重担壓得我們幾乎喘不過氣來，真是身心疲累。

有時走在街上，我們也難逃人們異樣的眼光。有時也受到不公平的待遇。我們建議：希望能結合社會的力量，伸出支援的手，幫助弱能孩子更好地成長。



共創前景

茫茫前路 人間悲劇

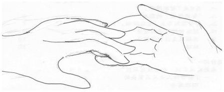
二零零四年八月中，澳洲新聞登出一段人間悲劇：一位母親生有先天殘缺，自閉症的兒子。長期承受沉重壓力，生活在痛苦與無望中，心力交瘁，精神崩潰，得不到有關方面的輔導和幫助，已經到了忍耐的極限，最後親手將兒子弄死。在法庭上法官判案時，內心也禁不住流下同情之淚，沒有嚴厲斥責被告，只表示這是一宗悲劇，最後被告也獲輕判。

希望在此 凝聚光輝

由於政府未能全面照顧弱能兒童父母的精神和壓力，本會就可在這方面給予適當的輔導，幫助父母在身心和希望上，去承擔這項辛苦的「弱能兒童的教育，工作和訓練」。希望有弱能兒童的父母能參加本會各項活動，把你自已和兒女帶出來，讓他們接受輔助和訓練，父母得到生活上和精神上的支持，協助彼此融入社會。

點滴能量 亮您路途

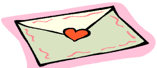
本會是由一羣育有弱能子女的父母組成，也可以這樣說：我們是很了解身為弱兒父母心理上和精神上的壓力。父母需要什麼？弱兒需要什麼？只有我們才真正體會到，因我們全部會員都身受如何面對養育和教導弱兒；曾經受過極深的壓力，痛苦和掙扎。每一心得，每一個故事，都充滿血淚。助人助己，發揮互助互愛的精神。父母們站起來吧！本會全力協助弱兒和父母在這崎嶇路途上，走出谷底，重見光明。



麥慶雲

澳洲弱能兒童協康會常務委員

鳴謝



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Fairfield Division General Practice (FDGP)

項目提議

蘇精祥醫生 Fairfield Division of General Practice 會長
Community Liaison Advisory Group, FDGP

事務安排

Chris Pittaway, CEO (FDGP)
Allison Tran –Administration Manager (FDGP)

文字校對

黎家津醫生

封面題字

趙大鈍老師

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Karen Yuen
Leanne Tinyow
Cindy Liu

(排名不分先後)

封面圖畫

澳洲弱能兒童協康會兒童會員

協康集

趙大鈍題

給智障兒童健康護理及支援

主編

梁顯華醫生

聯合編纂

澳洲弱能兒童協康會

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