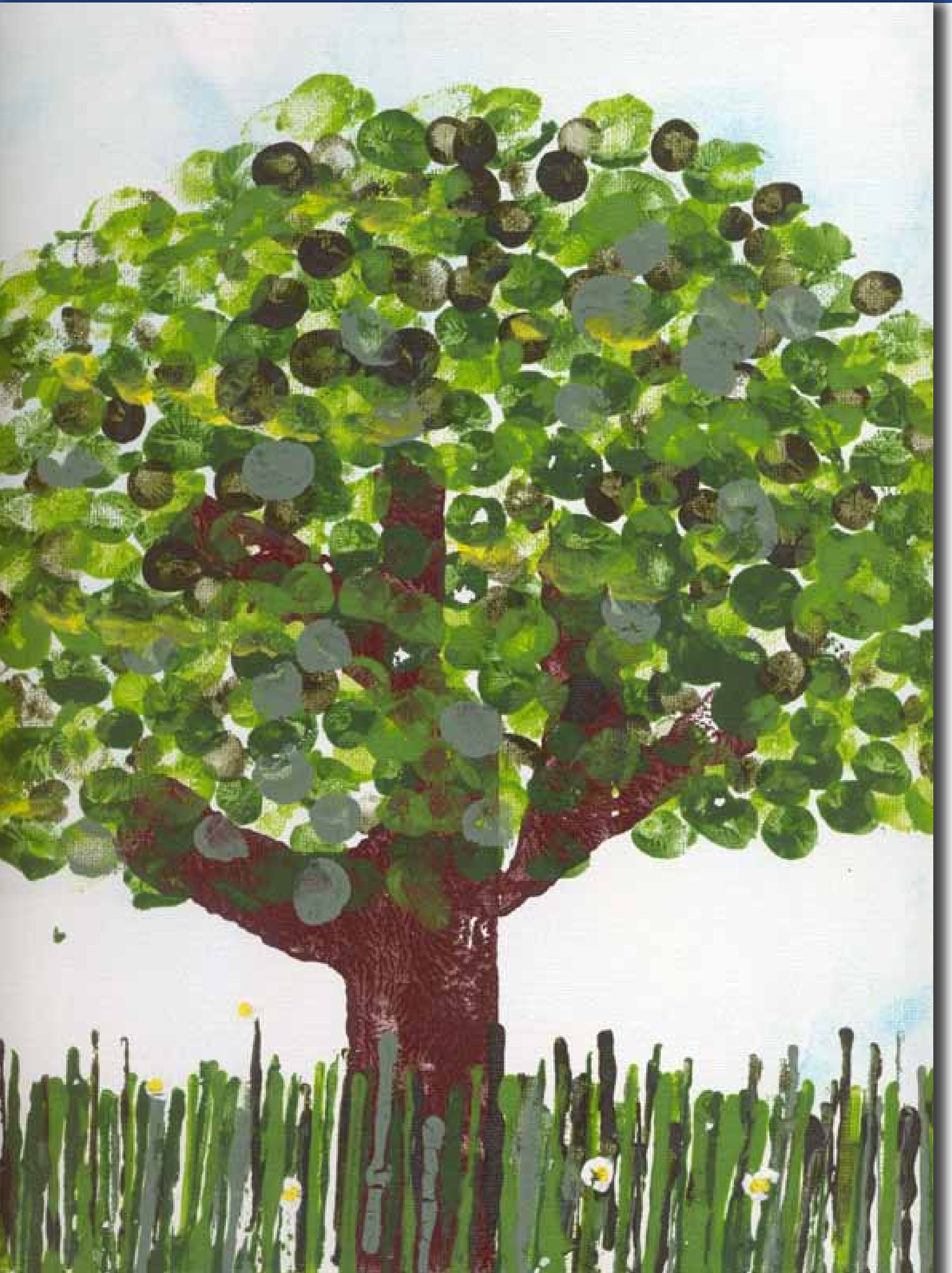
Growing Path -

Raising a child with disabilities

澳洲弱能兒童協康會
Chinese Parents Association - Children with Disabilities Inc.



協康集

之二

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Responses, comments and donations are welcome
歡迎讀者回應賜教或捐助

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- Maria Jones
- Dr Anthony Chan
- Amen Lee
- Ann Wong

For the calligraphy of Chinese cover title
封面「協康集」題字:趙大鈍老師

這繪圖象徵着您...
...對自己充滿信心, 發揮潛能
...勇於踏出溫室, 去嘗試新事物
...超越自己或他人為您所定下的極限
...無論身處逆境順境, 都會保持堅強,
安然以對!


滿懷信心地向前躍進 – 阮嘉恩繪
A Leap of Faith by Karen Yuen

This painting symbolises...
...trying to reach your potential by trusting in yourself and your abilities
...having the courage to leave your comfort zone in order to try new things
...breaking free from the limitations placed on you by others and by yourself
...and knowing that whatever happens, you are a strong individual and you will be okay!

Foreword

Ping Mu, President

The Chinese Parents Association (CPA) is proud to present their second book entitled "Growing Path-Raising a child with disabilities". This book could not have been published without the dedication and efforts of many people. To begin with, we are indebted to Dr. Peter Leung who is the originator of the CPA book and the editor of its first edition. His efforts have motivated us to continue this meaningful initiative and we thank him for this.

We also thank our two advisers, Chun Wing Fan and Peter Wong who formed an editorial board with other CPA parents. Their devotion and involvement has made this second book a reality.

In this book you will find valuable articles written by many professionals from a variety of fields. You will find their contributions provide readers with both insightful and easy to read information. The list of professionals includes Ruby Chan (Counsellor), Joyce Man and Noris Ma (Psychologists), Virginia Cheng (Speech Pathologist), Siu Ling Leung (Dance Therapist) and Dr Clive Sun and Dr Danforn Lin.

In addition, we have heartfelt articles written by our parents and siblings. These articles are extremely moving and share the personal thoughts and experiences of the CPA families. The Association would like to pass on a special thanks to the children of our members who have contributed to the book with their artworks. Finally, our gratitude is extended to April Cheung-Baker for her graphic design, which has bound all of our writings together.

To have a child with a disability is hard to come to terms with. To share thoughts with others is even harder. For some families, this involves many years of internal struggle. Over the years, CPA has built up a support network inviting parents and siblings to listen to the experiences of others and to provide them with an opportunity to voice their own thoughts. We are very fortunate to have the ever increasing support from the community, allowing CPA to continue these encouraging forums.

Finally we need to thank Illawarra Catholic Club Ltd - Hurstville CDSE for their financial support in the publication of this book. This support signifies their understanding of the positives our association provide in helping people. We hope that this is the beginning of an even greater partnership in years to come.

Editorial Notes

Fan Chun Wing

This book "Growing Path-Raising a child with disabilities" has included many articles by both parents and siblings from the association. The articles included are based on issues that the CPA families have and continue to encounter. In this book we have invited several professionals from various fields to share their knowledge and experiences, thus offering our members with guidance and additional knowledge.

Health and nutrition has a direct correlation to developmental benchmarks for children and can greatly affect the wellbeing of people with disabilities. Dr. Sun, Dr, Lin and Mr. Ma all provide advice to this. Similarly, Clinical Psychologist Miss Man has provided useful angles and reference to assist with behaviour management.

In addition, there are articles written by siblings which explore and share heartfelt stories. Such articles reflect the concept of brotherly and sisterly affection and the bonds that hold them together.

With more than ten children under the age of eleven regularly attending the Saturday programme, CPA offers two main therapies. Currently the children are offered Dance and Music therapy. To assist parents to understand the significance of these different therapies, we have included articles written by two of our volunteers who have had firsthand experience.

Whilst the advice and comments from the professionals and siblings are important, it is ultimately the parent that is the lifelong advocate and carer. Our members convey the roles they take on as a parent to make life decisions for their children. At times this has meant fighting for their children to have the right to good accommodation and job opportunities whilst dealing with discrimination.

The parents have also reflected on their everyday experiences and the difficulties they face when raising a child. The difficulties being the prejudices and misunderstandings society brings about. Ruby Chan acknowledges these experiences of hardship and encourages parents to rise above the lack of knowledge some people may have. She encourages readers to recognise that whilst these are troublesome experiences, it is important to take a positive approach to such issues. Doing this will enable them to look beyond the daily struggles.

Finally, this book is embedded with meaningful artworks. This demonstrates the ability of these young people to contribute to our community effort. Their involvement in our book is a clear example of the abilities that they hold.

We urge the community to continue their highly appreciated support in both maintaining and building upon this vital parent network and service. It is in supporting CPA that the hard working and dedicated parents of children with a disability recognise that they do have a support network. A network that offers education, friendship and a hopeful future for all.

Community Views

Everyone needs love, care and help; more so for people with intellectual disability because they are disadvantaged. In our humane society, they have equal rights to enjoy quality of life and happiness. Therefore, we have the responsibility to help them and support them to achieve their full potential.

Hon Helen Sham Ho - *Former member of the NSW Legislative Council. Honorable President of the Chinese Parents Association- Children with Disabilities Inc.*

每一個人都需要愛,被照顧和幫助,特別是智障人士,也是由於他們有一定的限制。在社會裡,他們都有平等的權利享受生活和過快樂的日子,因此,我們有責任幫助和支持他們能達到他們最高的能力。

何沈慧霞 - 前紐省上議會議員,協康會名譽會長

Intellectual disability or not, all humans have the same right to learn, love, be loved and be supported. We should all be given equal opportunities for our futures. It makes perfect economic sense for us as a society to ensure all are independent and resourceful.

Cecilia Tsai - *Social worker graduated from Sydney University. A devoted volunteer for many years .*

無論智障與否,任何人都有平等的權利去學習,去愛,被愛和接受幫助。對社會來說,使每一個人的將來都有相同的機會,人人都能夠過獨立生活和有充裕的資源自我發展,這才符合社會經濟之道。

蔡心穎 - 悉尼大學社工學系畢業,多年來曾積極參與義工服務

An Association like CPA is important to inform the community what extra demand there is to parents with a child with disability. It is a good revenue for its members to learn how to deal with the problem common to one another. CPA has been doing great work within the Chinese Community for many years and it will always have my full support in future.

Samuel Chu - *Optometrist, Region Chairman of Lions Club, Council member of Parkinson's NSW, Director of Lions Saved-Sight and Public Health Foundation.*

像協康會這樣的團體才能知會社區有關弱能子女家庭的特殊需要。會員可從協康會內互相學習和鼓勵,解決共同問題。協康會為華人社會做了非常重要的工作,我也會繼續支持這個團體。

朱署南 - 視光師,獅子會區會長,紐省柏金遜症協會理事,熱心公益的社區義工

社區感言

Hurstville City Council is pleased to support Growing Path: Raising a Child with Disability. People with disability are valued in Hurstville City and it is vitally important that they are given the support they need to lead healthy and fulfilling lives. This timely resource will help ensure that children with disability and their families can fully engage in community life.

Cr Philip Sansom - *Mayor of Hurstville City Council*

好市圍市議會十分樂意支持出版協康集之二。在好市圍市,所有弱能人士都享有平等的待遇和權利。特別重要的是他們都會有足夠的支援去過健康和充實的生活。協康集之二正好為他們提供有用的資料,使弱能子女及其家庭都能充份的參與社區生活。

Cr Philip Sansom - 好市圍市議會市長

As a mother who has a child with disability, I have been very fortunate to receive a lot of support from the community to help my son to be independent. These supports have given me warmth and confidence. Knowing that I have no need to hide myself because of my child, I was encouraged to play an active role to support other parents.

Sylvia Tinyow - *Founding member of CPA, former president for many years. In 2008, she was awarded NSW Premier Community Service Award for her voluntary work in the disability area*

作為一個智障兒的母親,我十分幸運社區給了我很多的支援,幫助我兒獨立.這些也帶給我不少溫暖和信心,我知道我不需要因我兒而愧于人前,這也鼓勵我積極地幫助其他的家長。

陳劉秀蓉 - CPA的創會成員,也出任多屆會長。2008年,她獲得紐省省長社區服務獎。

I believe everyone deserves an opportunity for growth and self-realization. This is also equally applicable to people with a disability. I support CPA because it provides people with a disability the opportunity for developing their potential and it has achieved what it intents.

Peter Wong - *A retired professional Chinese Community Social Worker, CPA Community Service Consultant and volunteer*

我深信每一個人都應有平等的成長和自我發展機會,這包括弱能人士.我支持協康會的工作,因為他們正提供機會給弱能和智障人士,幫助他們發展本身的潛能,而且有很好和平實的成績。

王友國 - 已退休的深資華人社會工作者,協康會義工和社區服務顧問。

People With Developmental Disability And Health Issues

Dr Clive Sun

What is considered normal in our society? How 'normal' or how 'smart' should one be to be accepted by the society these days?

What is considered normal in our society? How 'normal' or how 'smart' should one be to be accepted by the society these days?

As the society is now more open and more accepting of people who may be slightly different, maybe we don't have to be too perfect in order to be part of the community.

However, in order to lead a 'normal' life, people with developmental disability should have equal access to medical treatment and more importantly, access to specialist care.

The transition from childhood to young adulthood and from adulthood to old age has different challenges at different stages, and such transitions may not always be smooth or easy. This is true for everyone, including people with developmental disability.

With improved medical care and better understanding of different medical conditions, people with developmental disability is living much longer and in many cases to old age.

It is known that people with developmental disability have a higher incidence of medical illness and require more frequent medical reviews and a look out for specific complications. Conditions such as thyroid disorders, heart and stomach conditions are more common.

Issues on obesity

Obesity is often overlooked and may result in further medical complications. It is important in these cases to involve a nutritionist or dietician. I have a 16 year old patient with intellectual disability living with his parents. He consumes an enormous amount of unhealthy snacks and although tall (5' 9"), he is over 120kg. He can become violent with his parents when he is hungry. The mother in particular, stocks up the pantry with food that is high in sugar or fat.

I tried to convince the parents to see a dietician and replace the unhealthy food items with more fruits and vegetables, but the parents were too afraid of the son getting unhappy and violent. Choice of the right food stuff and more appropriate portioning is required to gradually change the eating habits to reduce the chance of developing more medical complications. The other issue in this case is to involve a psychologist to advise on behaviour management.

General health check is very important. There should be an annual blood test and regular eye, dental and hearing checks. This is particularly relevant to having good lifestyle including physical activities and regular exercises, which are often lacking and difficult to organise for people with disability.

Epileptic seizures are common medical conditions especially when there was history of neurological insult when young. I have one particular patient who has been referred from the paediatrician, as she is over 17. Her condition affects multiple locations and result in frequent seizures, which come in multiple episodes on the same day; however she can be seizure free for many months. Understandably the mother is always by her side and would not dare to leave her alone. The most important thing is to optimise the anti-convulsants medications by an experienced neurologist.

Mental Issues and Social Needs

People with intellectual disability have a higher incidence of psychiatric conditions. When they start to develop unusual behaviour or deviate from their usual self it may be necessary to involve a consultant psychiatrist to determine if there is 'dual diagnosis'.

In some, the most resistant habit to change is cigarette smoking. This can sometimes be limited in sort of quota arrangement. The push for more independence and financial self-management can interfere with efforts to reduce smoking.

Another area of concern is the social needs of people with intellectual disability. I currently have at least 2 patients in the late teens, who are very much under the close supervision from the mother and with no other social interaction. Their circle of friends is limited to the immediate family members, school staff and professional contacts such as the local doctor. I have spent quite some time counselling the parents as to the importance of them investing more effort in facilitating their child in meeting people of similar age and to create opportunities for their child to meet others.


By Bowman Yu

People with intellectual disability must be given the chance to express their emotions such as at times of grieving. It is easy to underestimate their ability to do so.

Parents need support

Parents must be made aware that the community is now more accepting and more supportive. The feeling of shame or guilt must be discarded early. There will always be some sacrifice as in most families but the family must try to live a near normal life as practical. Their children have every right of access and entitlement as any other member of the society.

Parents and family support group with regular meetings should be organised and can be very valuable in sharing difficulties, the highs, the lows, the heartaches as well as sharing management strategies.

For parents, they need to realise that when their age advances they would need to offload their children to the care of 'others' - mostly care workers or health workers. The establishment of various group homes to accommodate people with developmental disability and more standard training of care workers is becoming more and more professional.

In medical care, this may also mean moving from the care of their family doctor or paediatricians to the care of specialists who are more skilled in caring for adults.

It may be difficult in finding the 'adult' equivalent of their paediatricians and the approach might often be 'less involved' and less engaging but nonetheless just as important.

Many of the local doctors are now managing the general health checks well but there are specific units in Ryde, Westmead, Kogarah and Burwood for adults with developmental disability.

Rehabilitation Medicine is a unique speciality that manages all kinds of disability and impairment to minimise handicap. In the last 5 years there are a growing numbers of rehabilitation specialists working in the area of adults with developmental disability.

My special interests are looking at muscular problems, arm or leg deformities, the use of wheelchairs and equipments, exercise and treatment to improve mobility and function. I would like to take up the challenge of improving general health by improving diet and encouraging physical activities. I would also like to facilitate early efforts to widening the social circle.

Author: Dr Clive Sun is a specialist in rehabilitation medicine and pain medicine, is part of the NSW Developmental Health Clinic in Ryde and also a staff specialist at St Vincents Hospital Darlinghurst. He has specialist practices in Haymarket, Hurstville, Cabramatta, Parramatta, Fairfield, Bankstown and Darlinghurst.

Brief Discussion On Developmental Delay

Noris Ma

Developmental delay means some children fail to achieve certain developmental milestones within an expected time frame and what are these five main developmental targets?

What is developmental delay?

We all know that in the course of growth, children should be able to capture certain basic skills such as crawling, standing, talking, thinking and learning, through language development and social skills etc. Based on vast observations and statistics, modern science has now confirmed that a time schedule exists in the child's developmental process known as developmental milestones.

Developmental delay means some children fail to achieve these milestones within an expected time frame. For example, in normal circumstances, a child will learn how to walk within 9 – 15 months. If this child fails to start walking after 20 months, this could be refered to as developmental delay.

Five main developmental targets of children

1. Cognitive development

This refers to the ability of children to learn and solve a problem. For example a two months old should be able to explore his / her immediate surrounding with eyes and hands; a five year old child should learn simple mathematics. Children who have development delay will find difficulties to achieve these tasks.

2. Social and emotional development

This relates to the child's ability to communicate, self control and regulate. Examples of this target include: a six weeks old baby able to smile, a ten month old knowing how to wave goodbye, or a five year old boy knowing the rule to wait for his turn in games. (Not every one can do this and children with autism would may not have this ability)

3. Speech and language development

The ability of a child to comprehend and speak a language. For example, the first spoken language from a baby; ability to read during school age; ability to speak and write. Children with developmental delay will comparatively be less able to perform these tasks.

4. Fine motor development

The ability of a child to exercise small muscles, especially in applying his / her hands and fingers – pick up small items; turn over a page, etc.

5. Gross motor development

This refers to the ability of a child to apply his / her big muscles. For example a six month child to sit straight with some supports; one year old should be able to hold the edge of furniture and a five year old can jump.

Children who have developmental coordination disorder are unable to achieve the above tasks within an expected time schedule.

Developmental delay can be simple or multiple dimensional and various developmental aspects can be interrelated. Therefore delay in speech could affect the child's other developmental areas such as emotion, self-confidence and social ability.

The causes of developmental delay could be due to genetic or environmental factors. Genetic factors could include the variation of genes or chromosomes. Environmental factors could relate to toxic substances contracted before or after birth. The malnutrition of a mother could also increase the risk of giving birth of a child with developmental delay.

By Tim Yau

Areas that need to be aware of

The following are a few areas that might indicate a child's developmental delay:

- Unable to pay attention for a prolonged period on one single activity
- Easy to be distracted
- Unable to mix with others
- Minimal or no eye contacts with others
- Unusual distress
- Unable to achieve tasks that are attained by other children of the same age
- Aggressive behaviour
- Obstinate
- Clumsy behaviour, unusual in comparison with other children of the same age
- Difficult to comprehend
- Unable to speak and communicate

If you have concern about your child having a developmental delay, you should contact your family doctor who can refer you to other suitable assessment clinics and treatment.

There are a number of services or resources in the community that can support families to enhance the development of their children. These services are established to meet the needs of individual children. These include:

- Auxiliary technology
- Hearing service
- Counselling and family training
- Education
- Medical services
- Health and support
- Nutritional services
- Occupational therapy
- Physiotherapy
- Psychological counselling
- Respite
- Speech Pathology

Early intervention is most important and without which the child could lose the opportunity to get assistance to improve their ability. This will affect their self-dignity and confidence and could lead to truancy, avoidance to learn and other behaviour or emotional problems.

Author: Noris Ma is a Registered Psychologist of NSW, accredited supervisor and he holds a Master degree in education and psychological development

Nutritional needs for children with an intellectual disability

There are several nutritional needs that are required by children with an intellectual disability. Energy and nutrient requirements for them vary depending upon the level of severity, age, sex, and activity level.

Energy intake is influenced by the number of meals and snacks that are eaten during the day, the energy density of foods consumed, and portion size. Children generally can self-regulate energy intake. However, self-regulation may be overridden if eating behaviours are driven by factors other than hunger and fullness.

Parents should provide a range of nutritious foods for meals and snacks, but children should be allowed to decide how much, if possible, they eat. Parents must be cognizant that peers and others outside the family greatly influence food choices of intellectual disabled children and adolescents. Body image concerns and societal attitudes may affect the energy intake and nutritional status of older children.

A variety of nutrient-dense foods from the basic food groups should be offered each day. Foods and beverages should contain or be prepared with little added salt, sugar, or caloric sweeteners.

Energy is provided through three primary macronutrients: protein, fat, and carbohydrates.

Protein — Protein should comprise 5 to 20 percent of total energy intake for children one to three years of age and 10 to 30 percent of total energy intake for children 4 to 18 years of age.

Fat — Dietary fat is an important source of energy, supports the transport of fat-soluble vitamins, and provides the two essential fatty acids, alpha-linoleic acid (ALA) and linoleic acid (LA). Total fat intake should be between 30 and 35 percent of energy intake for children two to three years of age; total fat intake should be between 25 and 35 percent of energy intake for children 4 to 18 years of age. Essential fatty acid intake, primarily as linoleic acid, should be 3 percent of total daily energy intake.

Carbohydrate — Carbohydrates supply numerous vitamins, minerals, and trace elements. Adequate carbohydrate intake contributes to sufficient intake of dietary fiber, iron, thiamine, niacin, riboflavin, and folic acid. Carbohydrates should comprise 45 to 65 percent of total energy intake.

Micronutrients

Micronutrients include vitamins, minerals, and trace elements. Dietary Reference Intakes (DRI) for micronutrients are available through the NHMRC Nutrients Reference Value for Australia & New Zealand website : http://www.nrv.gov.au/nutrients/index.htm.

Fostering the development of healthy eating behaviours is an important goal of early childhood nutrition. Several national health organizations have issued dietary guidelines for children and adolescents.

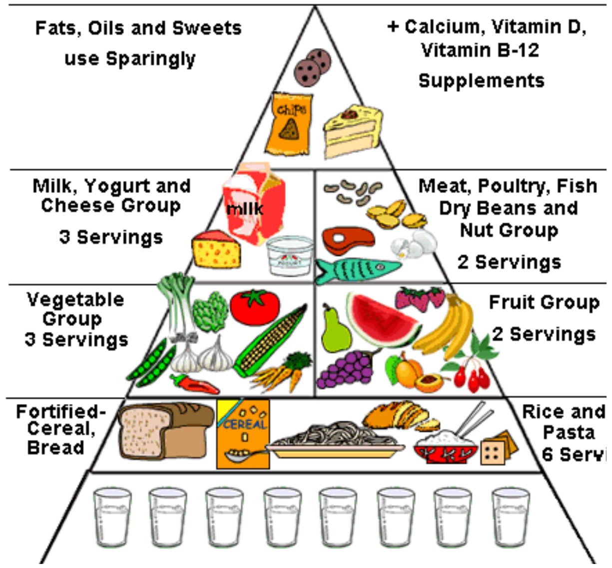
Dietary composition

Certain young children with mild intellectual disability may have the innate ability to adjust their energy intake to the energy density of their diet, but not to choose a well-balanced diet. They depend upon adults to offer them a variety of nutritious, developmentally appropriate foods to meet the recommended number of servings per day.

Fat and cholesterol

The recommended intake of fat and cholesterol varies depending on age. Fat and cholesterol intake is not restricted for children younger than two years. Total fat intake should be between 30 and 35 percent of energy intake for children two to three years of age; total fat intake should be between 25 and 35 percent of energy intake for children 4 to 18 years of age. Fat intake should not be restricted below 20 percent of total energy intake.

Most fats should come from polyunsaturated and monounsaturated fatty acids. For children older than two years, saturated fats should make up less than 10 percent of total energy intake, cholesterol intake should be less than 300 mg per day, and the intake of trans fats should be as low as possible.



Meat and protein

When choosing and preparing meat, poultry, and other high-protein foods, make choices that are lean, low fat, or fat free. An estimated 65 to 70 percent of protein intake should come from sources of high biologic value, typically animal products, which contain a full complement of essential amino acids. Animal products are not necessary to provide optimal protein, but most alternative sources from plants (eg, legumes, grains, nuts, seeds, and vegetables) do not contain a full complement of essential amino acids, and therefore greater dietary planning is required for diets without meat.

Two servings of fish per week is recommended, not including commercially prepared fried fish, since these products may be high in trans fats and relatively low in omega-3 fatty acids. To balance the cardiovascular benefits of fish consumption with the possibility of mercury contamination, it is recommended that children eat up to 12 ounces (two average meals) per week of fish with low levels of mercury (eg, shrimp, canned light tuna, salmon, pollack, and catfish), but that young children avoid consumption of shark, swordfish, king mackerel, and tile fish (sometimes called golden bass or golden snapper)

Many sources of protein are also common allergens (eg, milk, eggs, soy, fish, shellfish, peanuts, and tree nuts). Insuring adequate protein intake in children with food allergies should also be taken into consideration for certain children.

Fruits and vegetables

A colourful variety of fruits and vegetables should be offered each day. One-half of the recommended daily servings of fruit can be provided in the form of fruit juice. One 4-ounce glass of 100 percent fruit juice equals one fruit serving for children two to three years of age, and one 6-ounce glass of 100 percent fruit juice equals one fruit serving for children older than three years.

Children between one and six years of age should limit fruit juice consumption to 4 to 6 ounces per day. Children older than seven years should limit fruit juice consumption to 8 to 12 ounces. Fruit juice generally lacks the fiber of whole fruit and provides no nutritional advantage. Reliance on fruit juice to provide the recommended daily intake of fruits does not promote eating behaviours associated with consumption of whole fruits.

Grains

At least one-half of total grains consumed should be whole grains.

Fiber

The optimum intake of dietary fiber for children younger than two years of age is not known. Studies of weaning diets with the gradual introduction of solid foods, including increased fiber, suggest that an intake of 5 grams per day is beneficial provided the children ingest adequate calories, vitamins, and minerals.

For children older than two years, a safe range of fiber intake equals the age (in years) plus 5 to 10 g per day (maximum 30 g per day). This goal is best met by eating a variety of fiber-rich fruits, vegetables, cereals, and whole-grain products.

Cow's milk/calcium

Children between 12 and 24 months of age should drink whole cow's milk (rather than skim milk, 1 percent milk, or 2 percent milk). They should consume between 1 and 2 cups (each cup equals 8 ounces and contains approximately 300 mg of calcium) per day to meet their daily calcium requirement (500 mg/day). Excessive milk intake can displace the desire for foods that provide nutritional requirements (eg, iron). Children older than two years should consume fat-free (skim) or low-fat milk (1 percent milk, 2 percent milk) or equivalent products. Children between two and eight years should consume 2.5 to 3 cups per day to meet their daily calcium requirement (800 mg/day), and children and adolescents 9 to 18 years should consume 4 cups per day to meet their daily calcium requirement (1300 mg/day).

Snacks

Snacks are an essential component of the young child's diet. Healthy snacks should be planned so they contribute to the day's total nutrient intake. Healthy snacks include fresh fruit, cheese, whole-grain crackers, bread products, milk, raw vegetables, 100 percent fruit juices, sandwiches, peanut butter, and yogurt.

Sweetened beverages

The consumption of soft drinks and other sweetened beverages (eg, fruit drinks, flavored water) should be discouraged. These beverages are a major source of added sugar in the diet. Their consumption is associated with lower intake of key nutrients (particularly calcium) because they generally are consumed instead of milk. Plain, unflavored water is the preferred beverage for children, particularly when fluids are consumed outside of meals and snacks.

Frequency of feeding

Most young children should be fed four to six times per day. Snacks are an essential component of the young child's diet. Toddlers eat an average of seven times per day, with snacks accounting for approximately one-fourth of daily energy intake. Children before 6 years of age generally eat three meals and several small snacks per day. School-age children typically eat fewer meals and snacks per day than younger children, although they may continue to have a snack after school. Children who skip breakfast tend to consume less energy and fewer nutrients than those who eat breakfast.

Portion size

The appropriate portion size varies depending upon the child's age and the particular food. Serving children portions that are larger than recommended for their age may contribute to overeating.

Vitamin and mineral supplements

Routine supplementation of vitamins and minerals is not necessary for healthy children who are growing normally and consume a varied diet, regardless whether they have intellectual disability or not. In a survey of the dietary habits of infants and toddlers in the United States, more toddlers who received supplements had excessive nutrient intakes of vitamin A and zinc than those who did not (97 versus 15 percent and 68 versus 38 percent for vitamin A and zinc, respectively); 18 percent of toddlers who received supplements had excessive intake of folate.

If parents wish to give their children supplements, a standard paediatric multivitamin poses no risk. Mega-dose vitamins and doses of any nutrient in excess of the recommended daily allowance should be discouraged because of the potential toxic effects. Vitamin and mineral supplements, particularly those designed to appeal to children (eg, vitamin gum), should be kept out of reach of children.

Many severe intellectual disabled children are suffering from underweight due to vomiting that is self-induced and refusal of food. On the other hand, children suffering from mild intellectual disabilities are likely to be overweight, which expose them to great risk of contracting diet-associated chronic illnesses. The risk of type I diabetes appears to be increased in intellectual disabled children, particular those with Down syndrome.

Data from a Dutch study in children up to 14 years of age suggest the risk of type I diabetes is three times greater in Down syndrome than in the general population (50 versus 12.4 per 100,000 per year). In another study, the estimated prevalence of type I diabetes in Down syndrome children up to nine years of age was eight times greater than the age-matched control population (335 versus 40 per 100,000). Therefore it is important for care-givers to understand that while one hand we have to ensure the nutritional needs is met for the intellectual disabled children, but on the other hand we should prevent them from having chronic medical conditions.

NOTE: A completed version of this article as well as a copy of the Chinese translation can be found in the CPA website. www.chineseparents.org.au

Author: Dr Danforn Lim is a registered medical practitioner as well as a registered Chinese medicine practitioner in Victoria. He teaches in the Faculty of Medicine at the University of New South Wales. He has a broad research interests, especially in the areas of reproductive health, women and health, acupuncture and traditional Chinese medicine and vaccines preventable diseases.

Understanding And Managing Challenging Behaviour - People With Intellectual Disabilities

Joyce Man

Challenging behaviour involves behaviours of such intensity, frequency, severity or duration that it creates barriers to an individual's access to the community. It may also involve a risk of harm to oneself or to others. It is often more of a challenge for the people caring for the individual rather than a problem for the individual themselves.

Why are there challenging behaviours?

All behaviours have a purpose and a function. Behaviours should always be viewed within context with the environment in which it occurs. It is not unusual for challenging behaviours to be present in one setting only. Examples of challenging behaviours include hitting, pinching, kicking and biting others, self-injurious behaviours, resistance to get in a car and damaging property.

All people have basic needs as human beings including a need to be understood by others, a need for social interaction and acknowledgement from others, engagement and for accomplishment. Some common functions of challenging behaviours related to these needs include:

1. Communication:

When an individual has limited language and communication systems, this can create a lot of frustration for the individual trying to get message across. Without augmentative and alternate communication systems to express the needs, an individual may have no choice or capacity but to use their behaviours to get their message across despite it being perceived as socially inappropriate.

2. Expressing feelings:

Individuals with intellectual disabilities have more difficulty in regulating their emotions and finding more appropriate ways to manage difficult feelings. Feelings of anxiety, fear and anger may be exhibited through aggressive behaviours.

3. Escape and avoidance of undesirable situations:

For whatever reason, challenging behaviours may be used as a way to avoid having to deal with certain situations, and to avoid exposure to certain people or situations that we do not like or are downright boring! For example, an individual may have had a particularly negative experience at school or out in the community and may refuse to participate in the situation as a result. Individuals may also learn that by exhibiting certain challenging behaviours, they will not have to face a situation they do not enjoy.

By Bowman Yu

By Bowman Yu

4. Sensory:

Individuals such as those with Autism may show difficulties regulating their sensory needs. Some behaviours are done in attempt to regulate any sensory overloads or deficits. It is best to consult an Occupational Therapist with experience in providing support to people with an intellectual disability to determine if any sensory needs are involved.

5. Entertainment/stimulation

All people need to feel engaged and have opportunities to participate in activities they find interesting and meaningful. When there is a lack of engaging activities available for someone, they may be more likely to seek their own source of entertainment or activity through their behaviours. Many people with intellectual disability benefit from participating in regular and structured activities.

How do we figure out the functions of the behaviour?

It is important first to rule out any medical problems that could impact on the behaviour. For example, a person may be banging their head because of underlying medical causes such as a bad headache or toothache rather than as a result of any of the other potential functions.

To determine why a behaviour happens, it is a good idea to keep a record of the behaviour. Make note of how often it happens, where it happens, any changes to the environment or potential triggers for the behaviour, your response and the consequence of the behaviour. Also get information from the people involved when the behaviour happens, the individual's emotional response during and after the behaviour takes place. This information will help you identify any common patterns you may find. For instance, a child who demands for lollies and is then given a lollypop is more likely to engage in this behaviour next time! It is also common for behaviours to have more than one function.

How to deal with Challenging Behaviours once functions have been identified?

1. Communication

If the behaviour occurs as a result of the individual trying to communicate something to you, find out exactly what is the message he/she is trying to communicate. This may be 'I want to play'; 'I want your attention right now' 'I need the toilet' etc. Like anyone else, it is crucial for people with intellectual disability to have the means to communicate and be understood by others. Communication can be via verbal language, sign language, written language or body language depending on the individual's communication style and ability level. Consult a Speech Pathologist with experience in working with people with intellectual disabilities for assistance to find the most appropriate communicative system.

2. Expressing feelings

The lower an individual's intellectual functioning, the lower the person's ability to regulate one's emotions. It is natural for people to get angry and frustrated at some time or another. It is important to teach individuals with an intellectual disability to express negative feelings in a more appropriate way. For instance, to support someone to calm down, you may guide them to a less crowded place to sit down, reduce your talking and demands on the person, role model calm behaviour, reduce verbal instructions and provide distractions or calming activities such as calming music, slow breathing, stress balls etc. to support the person to calm.

It is important to be aware of your own safety and the safety of others. If the individual finds it too difficult to use the calming activities, it is best to avoid the potential triggers that lead to their anger and agitation in the first place.

3. Avoidance/ Escape

Think about the situation in which the challenging behaviour occurs. Are there too many demands placed on the individual and can they be avoided? Are expectations on him/her realistic?

When it comes to new situations, places and people, it is best to prepare the individual as much as possible beforehand. This may mean talking through or communicating via a social story or visual routines what the individual can expect to happen. This will ease feelings of anxiety the person may feel. This may need to be repeated many times to remind the individual. It is important to provide the individual with some choices around what they do, what they can bring along, what they can do after the activity etc, in order to give feeling of security. For instance, ask the individual to choose from two possible options what they may like to do during or after the planned activity. You may also need to motivate the individual by offering something they find enjoyable and rewarding during or after the planned activity.

4. Sensory regulation

Some individuals with Autism may find particular settings difficult to cope with. For example, shopping centres may be too noisy and crowded. Occupational Therapists can assess for any sensory regulation difficulties and provide recommendations to manage or replace any challenging behaviours that may be an individual's attempt to regulate their own sensory needs.

5. Entertainment/ stimulation

People with intellectual disabilities get bored like everyone else but have fewer problem solving skills to come up with ways to occupy and engage themselves. Be realistic about how long an individual is capable of waiting. Assist them to cope more easily in situations where they are likely to have to wait by providing engaging activities, toys and other distractions. Inform the individual where they are going, what is expected of their behaviour and what will happen afterwards. You may also consider motivating a person to wait with a reward of a more interesting activity afterwards. Be sure to keep your promise!

When to Seek Help

Sometimes it can all seem too hard! Behaviours that have been present for a long time can also be harder to change since they have reinforced over time. Sometimes when you have been dealing with a particular behaviour for too long, it may also be difficult to view things objectively and tease out the reasons why the behaviour occurs. Behaviour management strategies can also be difficult to implement without support from others. Strategies also need to be implemented in a persistent and consistent way before you see any benefits. Disagreements between family members and/or other support persons can also pose risks to the success of behaviour strategies. A referral to a psychologist specialising in intellectual disability or a behaviour intervention specialist may be required in these cases.

Last but not least, it is crucial that you recognise your own needs and look after yourself as a carer. It is natural to feel overwhelmed and unable to cope sometimes. Recognise when you may need some support from others, whether it be family members, friends, professional advice, respite, counselling. Don't be afraid to ask for help!

The author gratefully acknowledges Emma Moore, Kala Ram and Suzanne Davies for their clinical input and expertise.

Author: Joyce Man is a Clinical Psychologist working with DADHC. She had helped CPA to run workshops for parents and siblings as a volunteer

Facing The Future Together

Karen Yuen

Growing up with a brother with an intellectual disability, there were many times when I felt very much alone. No matter how empathetic my friends tried to be, I felt that they did not really understand the issues I had to deal with.

By Bowman Yu

I felt my parents were facing their own battles and did not need to be troubled by my worries. So instead I carried the burden of my worries on my own. I remember nights where I would lay there thinking about the future and silently crying myself to sleep.

Years have passed and I find myself turning twenty-five this year. The future is something I continue to worry about. The difference now is that I have grown up a little in that time. With some help, I now realise that how I pictured my future as a little girl (as a brick wall)…is not necessary my destined path. I am not alone and there are other options out there…ones that do not require me to 'give up my own life' in order to take care of my brother.

I believe support; ongoing dialogue and information have helped me reach this stage of realisation.

Up until the end of high school, I found it extremely difficult to talk about my brother to anyone outside my immediate family. However I found that the more I spoke to others, the easier it became and the less alone I felt. This was partially why I started-up SibSpace; CPA's sibling peer support group. I find that simply, hanging around other siblings and talking (or not) helps.

As I have grown older, I have discovered that there are countless disability-related services in NSW that are funded to assist people with a disability and their families/carers. Whether it is counselling, respite or recreational activities - many of these services are free-of-charge…so why not use them? There is no shame in accessing support.

I recently visited a counsellor who specialised in dealing with families with someone with a disability. The visit helped me realise that my worries and fears about the future stemmed from 'not knowing'. Where will my brother live in the future? Is an intellectual disability hereditary? Will my future husband and children accept my brother? I had heaps of questions that I did not have answers for. I now believe that in finding out these answers, I will start to overcome my worries and fears and not allow them to trap me.

I think it is important for parents to maintain an open dialogue with their children (and vice versa) especially about things relating to the future. Of course, each person is unique and some siblings (and parents) may not be ready or willing to talk – it is a difficult topic and will probably be a slow process. But I think just asking each other questions, listening in a non-judgmental way and finding answers together can be very helpful. After all, as Henry Ford once said "Coming together is a beginning. Keeping together is progress. Working together is success."

The future starts today.

Author: Karen has a brother who has an intellectual disability and she is the founder of a sibling group within CPA and this group aims to bring siblings together to get mutual supports.

The Thoughts Of A Sibling

Anonymous

If someone asked me "What is it like to have a brother or sister with autism?" I would answer…it's not easy and sometimes you just feel so pissed at your sister or brother that you feel like doing something bad to him/her.....not that I have done anything to my brother but......yeah it's not easy to understand your sibling. It took me years to figure out why my brother exists to be like that. It's not easy.

I enjoy going to CPA because I feel as if I belong. I feel at ease because I know that there are other people in Australia who know what it's like to have an autistic brother or sister and the fact that I'm not the only one with this situation......

The thing that I've had trouble before going to CPA is being uncomfortable going to public places with lots of people like Macquarie Centre or the cinemas. Now I am no longer embarrassed and I feel relaxed when going to public places now.

A Certain Kind Of Happy Ending

Jessica Mu

A tale of two sisters and different paths they are venturing. And lastly, how a happy ending is reached through sisterly bonds and a shared understanding of love.

Once upon a time there were two sisters. Their mum and dad loved them equally. And whilst they both loved their parents, the love they shared for each other was not equal. The younger sister, Stephanie, would have done anything to be in the company of the older sister, Jessica, who feigned indifference. From playing in the backyard together, ballet lessons in the community hall to bike rides in the park, the younger sister would follow. Then one day things began to change. A spell to lead a different life was cast on the younger sister.

As Stephanie began her new life, the change she experienced slowly rippled through the family. She had become a pebble that shattered the family's peaceful waters. The changes developed slowly over the many years and Jessica, being only two years older, never really understood what all the fuss was. Confused by the panic occurring around her she sat quietly while her parents ventured into the exploration of finding the "magic potion" that would heal their daughter and bring back the normality that they had once enjoyed.

From dawn to dusk, the exhausted parents and their dependent younger daughter would follow different paths on the treasure hunt in hopes to find the cure that would set their daughter free. Little did they know that such a cure did not exist.

Jessica watched as her sociable younger sister slowly lapsed deeper into this spell. The once vibrant and captive child had become too eccentric to fit into the norm of social circles. During the process of change Jessica often pondered about the trapped thoughts that filled her sister's head. Had she too felt the changes? Did she know who she was now? And whom she had once been? Would she ever understand the lengths at which their parents had gone to?

With no understanding herself, Jessica continued with her own life and watched curiously at the sibling relationships of her peers. She would frequently wish that she too could interact freely with her sister without the communication barrier. As much as this saddened her, life continued on.

Years passed and as they did, the hunt for the cure slowly faded. The parents came to a realisation that the ripples caused by the spell would stay with them for life and rather than searching for a "cure" they would accept them as part of their lives. Their thoughts evolved, as did their actions, all with the new goal to provide their eternally dependent daughter with happiness. Energy was no longer consumed on "saving" Stephanie.

The parents lived in peace knowing that they had, and would continue to provide their youngest daughter with a joyful and fulfilled life. Stephanie continued to love both her parents however became less of a shadow as their lifestyles lead them on more busy paths. And finally Jessica recognised the deeply embedded bond that she and her sister had always shared. And amidst their arduous beginning they finally arrived at their own version of a happy ending, a shared understanding of love through actions.

Advocating For Leonard – My Experience

Sylvia Tinyow

Parent advocacy is a concept that I have learned through experience and it requires us to make a move to understand the service that Leonard received and whether this service met my son's needs and if not, how to make the services changed to achieve the desired objectives for my son.

By Barry Mak

My son Leonard has an intellectual disability and needs intensive 24-hour care. By the time he reached adolescence, he was found to have emotional problems. He was lucky to get admission to a government Large Residence where a place was vacant. A few years later, government deregulated Large Residences and relocated all residents to group homes that accommodated up to six people with disabilities.

The relocation caused problems to many residents in making adjustment, especially those who needed special care. Leonard was the one who found adjustment very difficult and his behaviour deteriorated. In one incident, the neighbour called the police and Leonard was separated and placed in an isolated house with his own carer.

That was not an ideal living environment for people who have autism and could lead him to isolating himself. With official arrangement, we were lucky to have an experienced advocate working for Leonard to search for a more suitable accommodation option.

However, this process took up to a year with a lot of delays and the decision had not been made. When finally the decision was made to settle Leonard in a Group Home, we found that the treatment of staff of this group home towards residents was inappropriate. Leonard was unable to tolerate and he was admitted to hospital due to injury. We could not visit him for fear that he would demand coming home with us.

We were heart broken, uncomfortable, angry and helpless, as we did not know which accommodation option was suitable to Leonard and finally we had to approach the advocate again. We finally chose the group home, which Leonard has resided until present. It was designed to meet Leonard's needs and placed residents whose nature is close to one another.

As parents, we take along time to accept and face your own child with an intellectual disability. Very often we experienced sadness and frustration. We have tried our very best to help them to make progress. However, we also need to think rationally. As our children have limited abilities, without the parents taking up this advocacy role, no one will help them to fight for their rights.

Parent advocacy is a concept that I have learned through experience and it requires us to make the move to understand the service that Leonard received and whether this service met my son's needs and if not, how to make the services changed to achieve the desired objectives for my son.

In summary, we need to have courage and spend time to seek for suitable professional help, so our children can get the best way to help themselves.

Author: Sylvia Tinyow has a son who has intellectual disability. She constantly advocated for him and helped other parents to do the same. Sylvia is a CPA founding member and was its president for many years. In 2008, she was awarded the NSW Premier Community Service Award for her voluntary work in the disability area.

Post School Programs - My Son's Path

Paula Su

Brian is my twenty one years old son. He has intellectual disability with learning delays and has difficulty in speech and communication. It is my wish that he can integrate into the mainstream community, work according to his ability and earn his own living. I hope that he will be able to communicate with others with confidence and have his own social life. I wonder when my dream will come true.

When Brian was in Year 12, his school arranged for him to gain work experience in Woolworths, Kmart and Hungry Jacks. He also attended a special course for students with disability in TAFE in order to help him find a job after leaving school.

We visited several Disability Employment Agencies in order to find the most suitable one for him. These agencies provided specialist assistance to job seekers with disabilities who require on going support to find and maintain a job. They sent him to several fast food restaurants, Kmart and a food factory for interview, unfortunately without success. A reason was that his language skills in which he had difficulty to communicate effectively. This disadvantaged him as his real ability was not being assessed.

Since he was four years old Brian started to see a speech therapist and I practiced with him every day at home. Though his speech improved he was still not up to the standard. Although we were disappointed, I encouraged him not to give up but to keep trying hard.

In 2007, we went to the nearby Padstow TAFE to apply for a Hospitality course for students with disability. The course was cancelled so Brian had to go to Campbelltown TAFE, which was much farther away from home. It was a big challenge for both of us. I had to teach him the route to the Macarthur Station by train and walked over the bridge and went up the hill to get to the TAFE. He had to get up at 5:30 am and we had to rush to the Riverwood Station and catch a train. I thought he would give up soon and I could spare my constant worry and fear, yet Brian persisted and continued.

The chefs in the Campbelltown TAFE were excellent teachers and Brian learned a lot of basic cooking skills from them. Brian did two cooking demonstrations run by Chinese Parents Association—Children with Disabilities Inc. at Belmore Centre to help him develop his potential. This was one of his happiest years in his life!

CPA helped Brian to prepare a resume and developed a mother's recommendation letter. I accompanied Brian to a café in Normanhurst for an interview. Brian was confident that he had sufficient skills to do that job well. Unfortunately, someone got that job before him. I went with him to Centrelink to do a Job Capacity Assessment in 2008. After the assessment, he was referred back to the same Employment Agency. A lot of people lost their jobs due to the global financial crisis in that year. The Agency could not find him a job.

In 2009, Brian did a Hospitality Certificate III non-Trade course in Campbelltown TAFE. It was a mainstream course. There were six students with disability and fourteen other normal students in the class. The course required a total of 13 hours for practical, however, supporting teacher only worked for three hours and this was grossly inadequate to support students with disability. Brian was required to work in a much more competitive environment with a lot of exams and practices; he could no longer hide behind the comfort of a 'special' class. Brian found himself unable to cope and was very disappointed. At times, he also had to bear the unfriendly comments from other unsympathetic students.

Although the ultimate goal of 'Integrated Education' is to end all forms of discrimination and foster social cohesion, everyone will only benefit from it if there are extensive professional supports and all students are genuinely valued and respected. Brian plans to re-enrol in the same course next year. Hopefully he will do better this time.

I do believe that, given more support and recognition as well as training, Brian should have the ability to work in an open employment. Instead of focusing on his disabilities, I hope the community will instead recognise and put more emphasis on recognising Brian's abilities.

Individual Advocacy

MDDA

By Barry Mak

Multicultural Disability Advocacy Association of NSW - MDAA aims to promote, protect and secure the rights and interests of people from NESB with disability and their families and careers of NSW.

"To advocate" means to "stand beside" you and support you so you can make your own decisions and get what you need.

The Individual Advocates at MDAA will help you to make sure that your rights are recognised and respected. We support you to understand your rights, what services are available in the community and what choices are available to you.

When you contact MDAA, an Individual Advocate will ask you questions about your issues and support that you need. You and your Individual Advocate will make a plan together to work out ways we can solve your problem together. If you need an interpreter, the Individual Advocate will arrange one.

Where to find MDAA

Tel: (02) 9891 6400

www.mdaa.org.au

In summary, we need to have courage and spend time to seek for suitable professional help, so our children can get the best way to help themselves.

Joyce And Her Daughter

Leah

Most people in the community are aware of children with disability and their families, unfortunately, discrimination still exists.

The effects of disability vary in severity in autistic children: some involve delay in language development, while others bear more severe disability, affecting the functioning of many parts of the body. Joyce's daughter falls into the latter.

Her daughter is almost 9 years old at present. She has been receiving medical consultation since she was one year old, and until now there is not much significant improvement in both her physical and intellectual development. She has an IQ equivalent to a few months old and her physical ability is not much better than a child of 3 years old. Joyce has no choice but to accept her daughter's disability half-heartedly, feeling desperate and a sense of helplessness.

She also has encountered numerous unpleasant experiences in the course of raising her daughter. Most people in the community are aware of children with disability and their families, but unfortunately, discrimination still exists. She had an unforgettable experience whilst travelling on the plane. She inquired the airline for special services on board the aircraft to meet her daughter's needs, In return, Joyce was queried if her daughter's behaviour would disturb other passengers on the plane. She was upset and disappointed, like rubbing salt into her wound.

It is absolutely possible to minimise discrimination in the society. To enhance the confidence and resilience of Joyce, her daughter and other families with children with a disability, it is an imperative to provide them with social and emotional support, and to build for them a friendly, harmonious living environment with tolerance, understanding and empathy.

By Bowman Yu

Dance Therapy - People With Special Needs

Leung Siu Ling

Dance therapy (DT) has been developed for more than half a century. In fact, the American Dance Therapy Association had celebrated its 40th anniversary in 2006. Even so, DT is still unknown to many.

In April 2009, the Chinese Parent Association – Children with Disabilities (CPA) introduced Dance Therapy (DT) to their Junior and Youth groups. CPA has organized Dancing Group for the young members, teaching them a variety of dances. For the children group, the dance activity was designed in accordance to the keys elements of dance therapy .

Children Group - Dance/Exercise

The dance therapy program includes four main parts: welcome and warm-up; personal activity; group activity; relaxation and rest. It is based on the children's needs, with focus on their skills in communication, social, cognitive and physical.

The objectives are to improve their concentration, to encourage them to use visual contact, to teach them turn-taking, co-operation, visual-body coordination and body control and balancing.

Progress for children with disability

During the past six months, there has been evidence of improvement in the participants. It shows that some children have started getting involved in the group activity and coming out of the isolated world of their own. At the beginning of the program, some of them rarely had any eye contact with others, they joined in the 'pass the parcel' game, and gradually began to cast their eye-sights on their playmates. Through playing together in controlling the balls roll along on the parachute, they learned co-operation and turn-taking.

The dance therapy program provides children with disabilities with a stable and secure environment in which they are able to join in and play without any worry or feeling anxious. Children are able to foresee and get ready for the next step, and this helps to improve their ability to memorise as well. As soon as the "relaxation and rest" section began, children would take the initiative to help in getting the cushions and turning off the lights. They had learned and established the routine of the program.

Youth Group - Dance/Exercise

For the youth group, the program starts with welcome and warming up, followed by dancing, then finished off with relaxation and stretching exercises. The purpose for this youth group activity is to develop communication and social skill, to adjust their personal physical abilities through dancing and to enjoy dancing.

At the completion of the dance therapy program, significant improvements are reflected by increasing communications amongst young members, as well as an overall improvement in their concentration during group activities and more participation.

Conclusion

It has been a process of putting theory into practice in the planning and designing of dancing program for the youth and children. I have been able to learn more about DT, its theory and skills in practicing. Indeed, for me, it has been a valuable learning experience.

The success of the performance and achievements of the children and youth group reflects a positive impact on each of them. I do hope that DT would be recognized by the community in helping people with special needs. DT will be of tremendous benefit to the physical and emotional development of people with special needs and they can also enjoy dancing / exercise as much as anyone in the community.

Author: Leung Siu Ling is a music therapist,. She has helped to develop a music therapy program for CPA on an on-going basis every weekend throughout the year.
Translation: Terry Li

Speech Pathology And Children With Disabilities

Virginia Cheng

To show what speech pathologists can do to help children with disabilities, particularly those who have communication disabilities.

By Bowman Yu

Speech pathologists assess and provide intervention to those who have a communication disability and/or swallowing difficulties. Speech pathologists work in a range of settings including schools, nursing homes, hospitals, community health centres, etc. Speech pathologists can provide individual or group therapy, work in the classrooms, provide information to clients, families and professionals or work in a multidisciplinary team.

A communication disability is when one or more of the five areas of communication are affected. The five areas of communication are:

Speech – the ability to produce sounds

Language – the ability to understand and use words, to construct words together, to write and to read

Pragmatics – the ability to interact with others on a social level

Fluency – the ability to speak in a pattern or rhythm

Voice – the ability to produce sound by coordinating the vocal cords

A communication disability can be acquired at birth or later in life. It can also range from being mild, moderate or severe.

Children with complex communication needs have communication problems that are attributed to physical, sensory and environmental causes. These causes limit their ability to function independently in society.

Augmentative and Alternative Communication (AAC) is a specialised area that provides alternative forms of communication options and interventions for a person with complex communication needs. An AAC System is a system of components including symbols, aids, strategies and techniques that enhances communication for the individual with complex communication needs.

An AAC System includes aided or unaided strategies. Aided Strategies incorporates a physical object or device that is used by the person with complex communication needs to enhance their communication. This is divided into high technology systems (where computers or specialised software are used) and low technology systems (where communication boards, books and object boards are used). Unaided Strategies incorporates strategies that don't require any form of physical aids (i.e. gestures, sign and facial expression).

A speech pathologist can assess and provide the necessary intervention for a person with complex communication needs. This could include incorporating a suitable AAC device for the individual with complex communication needs.

Speech pathology services can be accessed in a variety of settings including community health centres, hospitals, rehabilitation services, schools, specialist disability centres, early intervention programs and private practice. For more information about speech pathology services visit:

http://www.speechpathologyaustralia.org.au/or
http://www.health.nsw.gov.au/

Author: Virginia Cheng is a practising Speech Pathologist. She has helped CPA for many years in the early intervention program as a volunteer

Four Short Stories

Leah

These four stories are about raising a child with disability – with laughters and tears, with difficult times as well as moments of happiness

Mummy Sammy

Five years old BoBo behaves like a normal child, without displaying any distinctive autistic characters. Thanks to her mother Sammy's work.

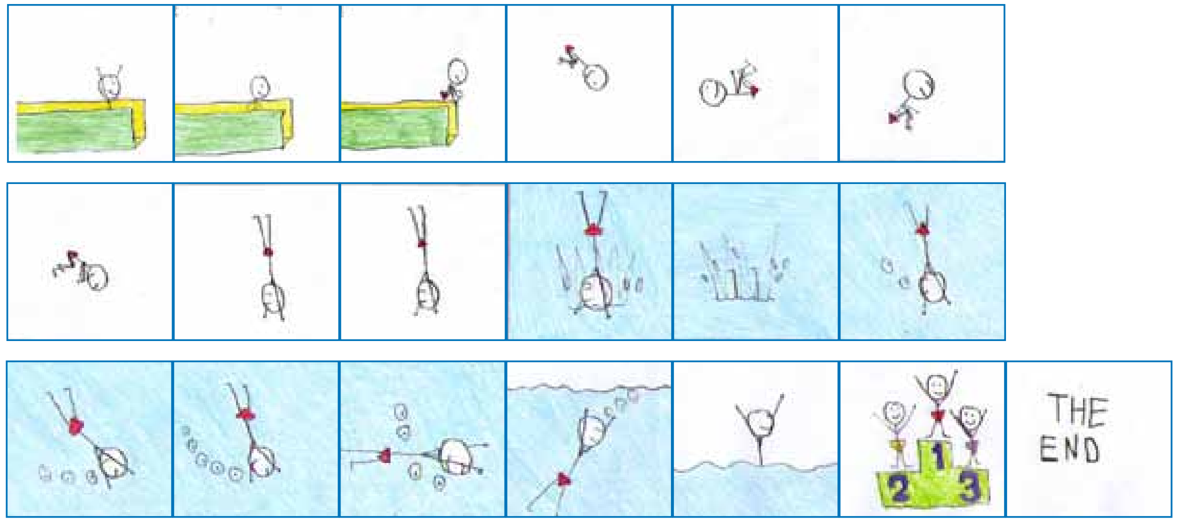
When BoBo was three, she was only able to manage about twenty short phrases. She never initiated a conversation and tended to express herself through hand gestures. Apart from the delayed development in speech, she seemed normal in all areas. Her parents attributed the cause of her delayed speech development to their multi-language background. They stopped her speech therapy after the fourth session, overlooking the possibility of autism spectrum disorder. In response to a friend's advice, Sammy sent BoBo for an assessment when she was four with the diagnosis of autism as the result returned.

Time is the best medicine. Three months after BoBo's diagnosis with autism, Sammy slowly recovered from her grieving and started seeking help for her daughter. She had approached various organizations for disability services but in vain. Due to limited available resources she often ended up waiting at the end of the long queue. It is antagonizing for parents who are earnestly looking for help, especially when they are lack of knowledge and access to informational and professional services. Those difficult days and hardship remain vividly in her memory.

In the course of caring for BoBo, Sammy found out that her daughter scarcely expresses her emotions. Whenever BoBo had emotional disturbance, Sammy would carefully guide her daughter to voice her feeling by probing: "Do you feel like this?" Gradually BoBo was capable of showing her feeling such as sadness and fear. Sammy also learned that children with autism are often very sensitive to touch and sound. BoBo was afraid of the sound of the toilet flushing. Sammy would gently hold her daughter's hand and press the flushing button together to reduce her fear. BoBo managed the flushing procedure independently after a number of trials. According to Sammy's experience, to eliminate a child's fear of certain sound, it is advisable to introduce the sound at its minimum volume to the child initially, and gradually increase the sound volume to the level that the child feels comfortable with. Of course, it requires the effort from both parties to achieve a satisfactory result.

As BoBo is her only child, Sammy is eager to provide for her daughter more opportunities for socialisation and communication. Through attending the music therapy sessions organised by CPA, BoBo has obtained more chance to interact and communicate with other children.

Sammy wishes that her daughter will lead a normal life like other children, and establish a good relationship with them. We, well and truly, trust that with the unceasingly tireless effort and support from all parties, BoBo will develop to her full potential.



By Barry Mak

The Story of Andrew

Andrew is the first teenage with autism I have ever met. He seems to be a quite, shy and kind young teen. His father, Mr Li, told me that sixteen years old Andrew is a good helper at home. He has acquired appropriate independent living skills which would be potentially helpful for him should he live on his own in future.

Mr Li came to learn of Andrew's autism only when he was at his teenage. In Andrew's early childhood, he did show some autistic symptoms which Mr Li thought to be caused by lack of care. After Andrew started his schooling, the differences between Andrew and his classmates in school performance became increasingly apparent. Mr Li had to accept that his child has a disability.

Andrew has no conception of ownership, and does not care about his own belongings or others' property. He shows a sense of apathy even when his toy was snatched by other kids. Mr Li attended a Motor car show with Andrew, while the visitors were fascinated by the flashy cars, Andrew displayed no interest at all, with eyes wandering elsewhere.

To provide Andrew a good study environment, Mr Li enrolled him in a special class of a religious school.

In addition, they started to attend social group activities in the community. Andrew now makes friends with other group members and enjoys the gathering.

"Children with Autism are quite straightforward, simple and no worries. They adopt their daily routine and expect other to follow," Mr Li expressed with some anxiety.

Mr Li lives with worries as Andrew behaves immaturely for a sixteen year old teenage, "although Andrew is capable to live on his own, he has no sense of precaution. In case of emergency or should an accident occur, the consequence will be very undesirable."

Despite uncertainty and worry prevail, Mr Li tries to lead a positive life. He hopes that his son could develop to his full potential, build a social friendship network and live an independent life in the time to come.

Out of The Bush

Victor, son of Mr Wu, is thirteen years old now. When he was about one year old, his body movement was sluggish; his speech developed much later than the cohort of his age. His parents were not aware of his developmental disability, thinking that Victor was still young and would catch up in time. After having started pre-school and observed the performance of other school children, Victor's delayed development in speech and cognition became more apparent. At four years of age, His parents arranged for him an assessment with the result indicating Victor scored below average both in IQ and EQ.

Knowing his son had developmental delay, Mr Wu was very upset. He recalled that when Victor was two years old, one day in pre-school, he started crying unceasingly. At home, he hugged closely to his mum at all time and did not want to sleep. This incident had lasted for three days. The parents could hardly rationalize the cause of such behaviour.

"We would not allow him to play with other children", Mr Wu explained. "He would suddenly throw his temper tantrum, overturn all the toys and frighten other kids." Children with autism are often lack of concentration with short attention span, hence, they do not gain much benefit even with one-to-one therapy sessions. When Victor was in primary school, Mr and Mrs Wu had sought help by consulting speech pathologists and pediatric psychologists, nevertheless, with not much improvement. Victor is 13 years old now, behaving as if he was a three-year old, simple and naïve. He would not have learned anything in which lacks interest. He has poor communication skill and is unable to express what he feels and thinks. Others find it hard to comprehend what he tries to convey.

Mr and Mrs Wu never give up helping Victor despite all the hardship. They constantly praise him for his achievement even though it is a minor one. Victor loves physical exercise such as ball games. Every week, Mr Wu would regularly accompany him to basketball and tennis practice, so to encourage the development of Victor's confidence.

Victor has been a CPA member for four years. He attends music therapy, singing and dancing with other children with autism. He socializes with his friends and has participated in various music performances. In the mean time, Mr Wu has had the opportunity of meeting up with other parents with children with autism. They share their experiences in raising their children and attend stress management workshops & seminars. Slowly, he has moved out of his son's shadow of autism, leading a more positive life.

Seeing The Light Ahead

Lee's son is 4 years old this year. When he was two, he was diagnosed as having mild autism.

Lee was prepared for the worst before the assessment of his child, she still could not help being disappointed at the disclosure of the result. She was extremely heart-broken.

She often experiences embarrassing moments with an autistic child. Whenever her son has challenging behavior in public, such as screaming and snatching toys from other children, Lee has to explain the cause of his behavior. Very often, she has to be very patient, and bears with those strange glances from others. She is under a lot of stress and wishing there will be more understanding and support from the community.

Lee is happy to receive the grant from the government providing early intervention program for children under six years old. It is important to provide early intervention help as children learn better at the early age.

Having received the systematic early intervention program provided by various government disability services, there is an apparent significant improvement in her son's speech and behaviour. Lee is grateful for such adequate resources and services provided by the government and wishes that other children with autism would also get support as well.

Author: Leah is a student journalist and she had helped CPA to prepare the above stories based on interviews with parents.

Parental Hope

Kuen

New Birth

One day in November, I was busy leading a team of programmers finalising the HSC and University Entrance Marking System when I received a telephone call from Jane. She had just received a telegram from Hong Kong saying that my father was very ill. With no hesitation, she rushed to book me a plane ticket to return to my father. My only concern was that she was about to go into labour with our second child anytime, but she assured me that her midwifery knowledge should be able to handle the situation well.

Three days later in Hong Kong, I heard that Jane was well and a boy was born in Australia. As soon as I told my father in hospital about this good news, he was so happy and asked to name the boy "Yeo Chung", and ordered me to buy some buns for celebration. However, on my return, he passed away in bed however in comfort and pleasure. The new baby must have been his last enjoyment before he died.

By Bowman Yu

Growing Up

Yeo Chung had his grandfather's facial features and was so full of life and happiness. When he was given a homemade vegetable meal, his little feet would dance on the bouncer bed. We had never heard him cry even when he received his immunization needles. He started walking when he was one but had never crawled. Whenever he heard his younger brother crying, he would be annoyed. In his mind there should not be any suffering in this world. Whenever he needed anything, he was lucky that his mother was always around.

When he turned three, his mother started to worry that he could not say "Mum" and was not responsive to talking and lacking coordination. He walked with pigeon toes. Therapists and even putting on "wrong footed shoes" could not improve much. Various specialists looked at his sight, hearing and all sorts of allergies. After three years of consultations, specialists finally diagnosed him with autism with symptoms including a lack of concentration, minimum eye contact as well as incontrollable hand movements and repetitive motions. The psychologist advised us to accept that he might never be normal in the future.

Schooling was the biggest problem. Since he was four, we wrote to the education ministers, health ministers, premiers and Federal departments almost every year. Their replies usually showed sympathy, but were not substantial.

Finally, we got a funding for a teaching aide to assist Yeo Chung in the classroom. We placed him in a special school, which promised to have speech therapy and other activities. My wife spent nearly six hours a day with him, helping him to learn through using reinforcement approaches like the use of reward and getting his attention by giving him food. She had manufactured hundreds of flash cards, which had a picture on one side and the English word on the other, and these efforts had helped Yeo Chung to learn spelling properly.

In three years, Yeo Chung was able to produce drawings and artwork. When we found out that the speech therapist in the school did not know our son well, we decided to move him to a small Christian school near us. His progress was a bit slow. We also exposed him to more external materials and activities such as piano and Scouts. Although he could not learn to perform all activities, we hoped everyone would treat him like normal person.

He was lucky to be admitted to a Catholic high school, which made a rule to penalise any student who might tease him. Yet in the classroom his noises and motions disturbed others. Out of necessity, my wife sought medical advice, which would improve his concentration in class. In the school, he found his taste for modern music. He was likeable and went to perform on stage a few times and he also learnt guitar. Twice he obtained the Reuben Scarf award for the most improved student, as well as a few other awards. His high school life was enjoyable and colourful.

Difficulties in Real World

Post high school period was the most difficult stage in his life. As he grew older, he felt that he had transformed from a protected environment into an adult world where he should make his own decisions. Because his IQ was at borderline level, he could not get job support from the government. For three years he did not get routine work/home activities, and his autistic symptoms reappeared with more severity. His only pastime was listening to pop music and watching movies on TV, and repeatedly play his favourite scenes until he could recite every sentence.

As referred by Centrelink, he was admitted to work in a sheltered work place near our house, and his life gradually returned to normal. However movies and Internet exposure had some bad influences on him. Firstly, he occasionally spoke bad language for which he was warned. Then he started chatting with young girls in the office and later asking them for hugs and kisses. Finally he was sacked in the fifth year for hugging a female colleague without her consent.

Though in movies, scenes of hugging and kissing occur frequently, yet these imply willingness and affection, which he did not understand. Should he be expose to sex without understanding "love", he might have turned himself to becoming a paedophile or rapist.

Because of his peculiar behaviour and communication problems, his opportunity to talk to other people was getting less frequent. He often felt that he was ignored. He became less confident and more autistic. Recall of unpleasant experiences and encounters had an impact on his normal life and he could not manage himself independently. Gradually he lost interest in drawing and music and of course, the pressure exerted on the family members were tremendous.

Stronger Parents

We cannot imagine what would happen if we were not around. Although his autism has not improved much, we still want him to join all sports and activities. We realised that these activities cannot be stopped even for a short period, for fear of worsening his autism. Moreover, we made an effort to meet service providers in order to get more experiences and increase our ability to handle our son. We have noted that some organisations are specialised in supporting carers' wellbeing. Their objectives are that stronger and capable carers are able to help their dependents better. These organisations gave us free services such as massages and respite service. During our trips, they would arrange for carer to temporarily look after our son and gave us a respite.

Parent's Wish

With the increase in children being diagnosed with autism all around the world, the cause may lie in genetic or food. Like allergies, we should identify the cause and get prevention as early as possible. In retrospect, if we knew that Yeo Chung was autistic in an earlier day, we could have resorted to medications/therapy to assist him much earlier.

One day, we hope that Yeo Chung would find a group of friends with whom they could discuss anything, and could share amongst themselves. Moreover, we would like him to know some friends more intimately so that they could live close and support each other. Financially, we would not expect them to live lavishly, but would satisfy all the basic needs to live happily in their lifetime. It could even be possible for him to meet a girl for marriage, but he would have to understand how to care for her and to love her first.

Author: Kuen (a pen name) is a father who has a child with autism. His son who has autism, is a talented painter and who has produced many art works, some of which were in public display. Some of his works are used as illustrations in this resource book.

Climb Over Mountains

Ruby Chan

The author reviews an article – Unforgettable Experience and notes that accepting reality is critical for some parents in facing unfavourable circumstances in life.

While reading this article, I was deeply touched by the unconditional love parents have for their children, particularly those parents who have children with developmental delays. Their love is selfless: they simply give without expecting a return. In fact, the author sets an excellent example for all other parents. Realizing that their children have an intellectual disability, parents often need an enormous amount of courage and patience. The process to acceptance is often long and painful!

By Bowman Yu

In my work, I have encountered a number of people who do not have the capacity to accept unfavorable circumstances in life. They have lost the will to live, and their lives are often filled with anguish, inner struggle and bitterness. They lead rather passive lives with self-imposed limitations. Much can be learnt from the Chinese character 'LOVE', which comprises two different characters literally meaning "acceptance" and "heart". This word teaches us that in order to love we have to accept reality whole-heartedly!

Accepting certain realities can be difficult and painful, especially when in face of adversity and we feel helpless. If we simply refuse to accept these realities, we could end up wasting all of our energy on endless struggles and internal conflicts. It is only when we are able to accept reality that we can begin to deal with these difficult situations.

In this article, the author depicts how he and his wife had been teaching their child Yeo Chung tirelessly since he was born. They had made great efforts to explore and develop Yeo Chung's interests and abilities, enabling him to ultimately lead a more fulfilled life – going to school, attending drawing and music lessons.

The article reveals the positive attitude this couple has towards life. They have accepted Yeo Chung's limitations, but they never gave up on the opportunity to teach him and help him developing to his full potential. If they had not adopted a mind set to accept the disability of Yeo Chung at start, their lives might have been filled with anger, disappointment or frustration. They might have simply kept Yeo Chung at home in order to avoid others' curious glares, and might not have considered taking him to all those extra-curriculum activities in which he was ultimately able to participate and enjoy.

The author states that Yeo Chung has reached adolescence and has experienced physical changes. He has expressed curiosity and interest in the opposite sex. Due to his lack of comprehension, and as a result of influences in popular culture, he has not been able to understand how to appropriately interact with the opposite sex and behaved inappropriately at times. As his parent, the author has been vexed by this.

Sexual need is a basic human need and one should not be ashamed of. This is a fact that all parents should accept as a starting point. It is on this basis that we can continue to discuss and develop ways to help our children learn about the concept and appropriate behaviors. If parents do not accept the idea that their children do have sexual needs, they will naturally avoid touching this topic, or simply turn a blind eye to their children's behavior.

As far as I know, there is no standardized teaching material on sex education for autistic adolescents. Parents need to be patient when explaining the concept to their children. However, it should be noted that there is no guarantee as to when their children would understand and behave appropriately, or whether they would understand at all. The reality is that there appears little else we can do in this area.

Although grim, let us not simply dismiss this feeling of helplessness. Let us be guided and facilitated by this feeling to live in the 'here and now'. Let us be reminded that what has happened in the past is a history from which we can learn a lesson and that the future is not in our control. Although we can make plans about the future, we should not invest all of our energy and time into it. The most important moment for us is the present moment! When we learn to focus on the 'here and now', we become alert because no energy is wasted. When we are alert we are able to deal with any issues that arise calmly and with flexibility.

We are told that Yeo Chung has exercised inappropriate behaviors towards a female. This was probably embarrassing for his parents. However if we cannot let go and dwell on past events, we continue to live in the past. No doubt as parents in this situation, we would be concerned about whether our children would repeat the inappropriate behavior again. However we must also understand that at this point in time, our concerns are merely fears, and those fears may or may not eventuate. Excessive worrying can drain our energy, and prevent parents from allowing their child to socialize with people of the opposite sex. Parents who behave in this way are preoccupied by fear and worry of the unknown future.

Focusing on the present moment means we allow ourselves to take one step at a time. We become willing to learn from experience. We enable our self-esteem to develop gradually. We become confident with ourselves. We know that we are capable of dealing with any situation with care and flexibility. Focusing on the present moment also allows us to be more relaxed so that our energy is not wasted.

We may not be able to choose our path in life, but we can always choose the type of attitude we hold while walking this path. Apart from learning the concepts of "acceptance" and "focusing on the present moment", there is one more thing that we can do to help ourselves lead more relaxing lives. I am referring to the power of mutual support and encouragement amongst parents. Do not underestimate this intangible power. I believe that together we can climb the mountains, helping each other be more open, relaxed and be prepared for any obstacles we encounter.

Author: Ruby Chan holds a master degree in counseling and is a registered member of the Psychotherapist and Counselor Federation of Australia. She specializes in the areas of bereavement, cancer counselling, carers' issues, problem gambling, stress, anxiety, depression, marital relationships and parenting issues.

Unforgettable Experience

A Mother

To raise a child with a disability is not easy. Sometimes, you may be frustrated due to their ignorance. However, if you focus on their achievements rather than failures, you will enjoy your time with them more.

By Bowman Yu

There are some experiences and memories about raising my son with a disability, in which I would like to share with you. Have you got similar experiences?

It happened on my daughter's 21st birthday. After the party held at a restaurant, I brought home the helium balloons which I believed would last for a few more days. However, as soon as I woke up the next morning, all the balloons were gone; the strings detached and the balloons flattened. I knew without a doubt that my son did it. Obviously, he did not realise that the balloons wouldn't be blown up again without helium gas. Everyone (except my son) in the family was upset.

We discovered that the birthday cake bought for a family member's birthday had mould on it when we were about to blow the candles. So, we decided to put it back into the box and returned it to the bakery the next day. However, the next day, when the shop-keeper at the bakery opened the box, I noticed that the cake was not intact; a slice of cake was taken out of it. I was certain that my son had eaten the piece. I was embarrassed although the shop-keeper returned the money to me without asking any questions about the missing piece.

One evening, my son rang me from a public phone at about 5 pm saying he was at Emu Plains, a place where our family had never visited. In those days, he loved to travel on the train after work with his $1 pensioner train ticket. However, after 9 pm, he wasn't home yet and didn't call home again. It was unusual that he came home after 7 pm. My husband and I started to panic. We called the police to see if they could find him. After a few hours of wait, two police officers arrived at our house. I showed the police my son's photo and his brief description hoping they would be able to locate him. As soon as we finished giving out his details, my son was standing at the door, panting...

Apart from the above, there were occasions when I was thrilled. For example, when I noticed my son was able to fill in the form by himself at his first visit at the dentist. He put "no" to all the questions about allergies. Sometimes, he updated me with the news which he got from the radio or television. In the last year of high school, he received an unexpected excellence medal from the school. All these moments brought me joy.

Community Resources 社區資源

Peter Wong 王友國

Legal Help
法律支援

Find a list of local Legal Aid offices at:

http://www.legalaid.nsw.gov.au/asp/index.asp?pgid=20

Mental Health Advocacy Service（MHAS）
精神健康倡議服務

Level 4, 74-76 Burwood Road
Burwood NSW 2134
Tel:(02)9745 4277

Website: http://www.legalaid.nsw.gov.au/asp/index.asp?pgid=205

If you have been taken to hospital against your wishes and will be brought before a magistrate, Legal Aid can represent you for free. Legal Aid lawyers or private lawyers arranged by Legal Aid attend each hospital in New South Wales that has involuntary or 'temporary' patients. We represent most people who will be seeing the Mental Health Review Tribunal in hospital. We also represent people appearing before the Guardianship Tribunal. We provide telephone advice about mental health law.

Disability Discrimination Legal Centre (NSW)
歧視殘障法律中心

Tel: (02) 9310 7722 (voicemail)
(Advice line Tuesday and Friday 10am-12.30pm)

Website: http://www.ddlcnsw.org.au

Provides free legal advice, representation and assistance for cases involving discrimination against people with disabilities and their associates. The Centre assists in cases of disability discrimination under the federal Disability Discrimination Act or the NSW Anti-Discrimination Act.

Information and Referral Services
訊息及轉介服務

Intervention Service – DADHC
紐省行為干預服務

Department of Ageing Disability and Home Care

Building B Level 1, 242 Beecroft
Rd Epping NSW 2121
Tel: (02) 8876 4000

Website: http://www.dadhc.nsw.gov.au/

A specialist service of the Department of Ageing Disability and Home Care (DADHC). The Behaviour Intervention Service works with agencies and DADHC services that provide care to people with intellectual disability who have challenging or offending behaviours.

Family Advocacy
家庭倡議

Tel: (02) 9869 0866
Freecall: 1800 620 588

Website: http://www.family-advocacy.com/index2.php

Family Advocacy's work is directed towards enabling and supporting families to speak up for opportunities for people with a disability to enjoy the same environment, lifestyle and living conditions that are available to the majority of Australians.

Brain Injury Association
腦部受損協會

17 Macquarie Rd Auburn NSW 2144
Tel: 02 9749 5366 Freecall 1800 802 840

Website: http://www.biansw.org.au/

Services include: Information and referral, library resources, resourcing of self help and support groups, self advocacy development and training, policy work, systemic lobbying and advocacy, quarterly newsletter, interagency meetings, service provider training, special projects (e.g. publications, research and events), as well as fact sheets in a variety of languages.

Carers NSW
紐省照顧者協會

Level 17, 323 Castlereagh Street,
Sydney NSW 2000
Tel: (02) 9280 4744

Website: http://www.carernsw.asn.au/

Carers NSW is an association for relatives and friends who are caring for people with a disability, mental illness, chronic condition or who are frail aged.

Guardianship Tribunal
監護仲裁會

Level 3, 2a Rowntree Street
Balmain NSW 2041
Tel: 02 9555 8500
Freecall: 1800 463 928

Website: http://www.gt.nsw.gov.au/

A legal tribunal that conducts hearings throughout New South Wales. The Guardianship Tribunal makes decisions in relation to the appointment of guardians and financial managers, or in relation to medical and dental consent, for people with disabilities who do not have the capacity to make their own decisions. The Tribunal may make a range of other orders as well.

Office of the Public Guardian (OPG)
公共監護人公署

Level 15, 133 Castlereagh Street Sydney 2000
Tel: 02 9265 1443
Freecall: 1800 451 510

Website: http://www.lawlink.nsw.gov.au/opg.nsf/pages/index

OPG promotes the rights and interests of people with disabilities through the practice of guardianship, advocacy and education. The Guardianship Tribunal (see above) appoints the NSW Public Guardian as guardian of last resort and the Office is part of the Attorney General's Department. The OPG can:

- make a particular lifestyle decision on behalf of a person under the guardianship of the Public Guardian when given the authority to do so;
- provide or withhold consent to medical and dental treatment on behalf of a person under guardianship of the Public Guardian when given the authority to do so;
- advocate on behalf of the person under guardianship for services the person may need;
- be the guardian for time specified in the guardianship order;
- provide information and support to private and enduring guardians; and
- provide information on the role and function of guardians to the general community

For a completed list, please contact CPA office on 97848120 or browse CPA website

請致電協康會 02 97848120 索取全份機構和其他服務名單, 或上協康會網站 *www.chineseparents.org.au*

Compiler: Peter Wong is an experienced social worker for migrants. He has retired recently and has contributed a lot of voluntary work for CPA as its service adviser

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