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A Brief History of Services for Individuals with Intellectual Disability in Singapore

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President S R Nathan: Centre

Many Dawns encapsulates the continuing journey of individuals and organisations in Singapore towards improving the quality of life of persons with intellectual disability.

It tells a moving tale of the struggle of the intellectually disabled persons to find a place in society, and the plight and joy of volunteers, service providers and caregivers in bringing their dreams and hopes to reality. The snippets of information on intelligence and intellectual disability are most educational.

The book is a tribute to the indomitable spirit and courage of individuals who have strived to make a difference in the lives of the intellectually disabled persons.

I congratulate MINDS and many other organisations for their dedication towards bringing a fuller and productive life to intellectually disabled persons, and wish that the future spells greater fulfillment for all.

Mr S R Nathan
President, Republic of Singapore

Mr Gerard Ee: Seated second from right

We all live within our own spheres for our existence, interacting mainly with those who affect our lives. In the absence of personal interest or effort, none of us would be mindful of the existence of others outside of our spheres.

Many Dawns puts us into contact with the people who are coping with, dealing with or helping those with intellectual disabilities. Reading it makes us appreciative of our many blessings. Our own struggles are put into proper perspective as we read of the courage, commitment and hope of the afflicted, loved ones, and caregivers.

I salute all these angels on earth. I commend the people behind the publication for sharing the experiences of the journey with the rest of us. I hope that it will result in more people venturing out of their spheres to reach out to others in the footsteps of these angels in our midst.

Mr Gerard Ee
President
National Council of Social Service

Message

Message

Foreword

Many Dawns tells a story about parents, professionals and volunteers coming together to develop services for persons with intellectual disability in Singapore. Conveyed through the telling of the story is something of the spirit of the movement for persons with intellectual disability.

The movement began in the late 1950s. In 1962, the first local organisation for persons with intellectual disability, Singapore Association for Retarded Children (SARC), was registered. Soon, other agencies mushroomed in response to the continuing need to serve children and adults with intellectual disabilities.

An important part of growing and maturing as agencies was the establishing of separate corporate identities. With over 30 agencies providing services for intellectually disabled persons today, each will probably continue to carve niches and highlight unique strengths. However, many of these organisations are now mature and stable. We have become increasingly willing and able to transcend minor differences and enter multi-agency collaborations. Our annual reports clearly attest to this growing phenomenon.

In this context, *Many Dawns* is an outcome of one organisation's desire to break down walls and, instead, build bridges. When MINDS (the former SARC) celebrated its 25th Anniversary, it published a book on its own history. That was appropriate and necessary at the time. Now, in 21st Century Singapore, MINDS sees value in telling the story of a movement that is far larger than any one organisation. Over a hundred individuals from numerous agencies responded with their heartwarming memories, photographs and newspaper cuttings. We thank all of you for this powerful demonstration that it possible to celebrate together the milestones of each. May such a spirit of inclusiveness spread throughout our society so that every individual child and adult — regardless of ability — may be cherished and celebrated by all.

Professor Tan Ser Kiat
President
Movement for the Intellectually Disabled of Singapore

A Reason to Wake Up Every Morning

The alarm clock rang. Siew Ling got up. She wished she could sleep a little longer but she had to get ready for school. She did not want to miss the school bus. Her class would be going for an excursion to the zoo that day. There was nothing Siew Ling loved more than these class excursions. Yesterday, her best friend, Suraini, had told her that she would bring her camera along. Perhaps Suraini would allow Siew Ling to use the camera, too. Siew Ling had never used a camera before. In fact, she had never been to the zoo without her parents. By the time Siew Ling stepped out of her flat, she was very excited indeed.

Siew Ling's mother was also excited but she could not help worrying. Her 12-year-old daughter could finally dress and feed herself. She could do much more than just a year ago. But going on an excursion was different. What if Siew Ling wandered off from the group at the zoo? What if she somehow fell into a moat? Siew Ling's mother told herself to stop worrying but it was hard not to. After all, it was only last week that Siew Ling had strayed from her side at a crowded shopping centre. The security guard had to help her find Siew Ling.

A Reason to Wake

The neighbours pitied her because in their eyes, her daughter was 'not normal' or to be more specific, 'retarded'. But now, as she watched Siew Ling get into the school bus, Siew Ling's mother knew that her daughter was just like any other child in ever so many ways. She saw Siew Ling give her best friend a *high five*[1]. She heard the hellos, louder than ever today because of the zoo trip. Her daughter had friends to laugh and play with. Her daughter had things to do and places to go. Her daughter had a life.

Fifty Years Ago

Siew Ling's mother also knew that if Siew Ling had been born 50 years ago, her life would have been completely different. She knew because Siew Ling had a 50-year-old aunt who was very much like Siew Ling. But Siew Ling's aunt had never been to school. She had no friends and was too afraid to go anywhere without her parents. She stayed at home, watching television all day. The family worried about who would look after Siew Ling's aunt after her parents passed on. It was not that Siew Ling's mother did not worry about Siew Ling's future. Of course, there would be difficulties. Siew Ling was approaching puberty. That in itself, gave her mother all sorts of new worries. Yet, adult life for

Up Every Morning

Siew Ling could be different from that of her aunt's. When Siew Ling grew up, she would still have somewhere to go and something to do. There could still be meaning in her life.

Unprecendented Changes

In the last 50 years, there were unprecedented changes in what Singapore offered individuals with intellectual disabilities[2]. The contrast between Siew Ling's life and that of her aunt's illuminates the difference these changes have made. Now, there are opportunities for education, employment, leisure and recreation beyond the individual's home.

A long time ago, before we had large industries and highly specialised services, there was something for everyone to do. Whatever provided the livelihood — be it farming, fishing, craft or trade — all members of the family had to chip in, in one way or another, regardless of age and competence levels. Whole *kampungs*[3] took care of children and more dependent adults. With urbanisation, we lost some of that *kampung* spirit. Families also became smaller and less connected. By the middle of the 20th Century, families found it more and more difficult to meet the needs of children with disabilities. Our understanding of these children's needs also changed. We began to see that children with disabilities deserved an education and an improved quality of life as much as every other child. There was an impetus for change.

A Sense of Urgency

We needed special education schools, activity centres and sheltered workshops. And we needed them urgently. The 1960s, 70s and 80s saw a proliferation of special education schools. The 1980s was also the decade when vocational rehabilitation and other services for intellectually disabled adults grew and multiplied. Next, the focus broadened to services at the two ends of the life span. First, early intervention and then more recently, services for older persons with intellectual disabilities.

Parents, professionals, volunteers and others worked hard and long to bring us to our present landscape of services in Singapore. A few groups surged ahead of others. Some proceeded parallel to each other. Most connected somewhat superficially at, for instance, seminars, official opening ceremonies and gala dinners. More and more, however, agencies desired to work together in more meaningful ways. In time, they began to. And continue to do so. Meanwhile, half a century has gone by. It is time to stop for a moment to reminisce, to take stock of, and to celebrate all that has happened for and with people with intellectual disabilities here in Singapore. To this end, *Many Dawns*.

Endnotes

[1] A *high five* is a casual form of greeting where two persons raise their right hands to clap together.

[2] In this book, terms that were used during a particular period are retained in the sections about that period. The term 'intellectual disability' superseded 'mental retardation' in the mid-1980s. Thus, 'mental retardation' is used in the first half of the text and the term 'intellectual disability' is used in the later sections which refer to the mid-80s and after.

[3] *Kampung* in Malay means 'village'.

History of Intelligence and IQ

by **Thana Thaver**

The idea of intelligence testing was first mooted in the 1860s by Charles Darwin's younger cousin, Sir Francis Galton. Inspired by *The Origin of Species*, he studied prominent individuals, hoping to prove that intelligence was inherited. In the process, he developed a series of tests. This was followed by the work of French psychologist, Alfred Binet who constructed the first intelligence test and in 1905 introduced the concept of mental age.

According to Binet, in children of average ability, their mental age would match their chronological (physical) age. Mental age would exceed chronological age in bright children, and would be below in those of lesser ability. Binet's test was introduced in a modified form by Lewis Terman to the United States in 1916. The birth of an overall test score known as intelligence quotient (IQ) occurred with the development of a new scoring system for the modified test by German psychologist, William Stern. The score was arrived at by dividing mental age with chronological age and multiplying it by 100.

Although some concepts in intelligence tests, such as mental age and IQ, are questioned by many today, the tests are still widely used to assess mental abilities and often, to determine placement in special education classes. Traditionally, IQ scores of 90-109 are considered average, scores below 70 indicate mental retardation, and scores of 130 place a child into the 'gifted' category.

For more information

www.cpsimoes.net
www.xrefer.com/entry/217597

The Darkest Hour of the Night

Darkest Hour

There is an ancient Chinese saying that the hour before dawn is the darkest. In terms of services for people like Siew Ling's aunt, the 1950s was perhaps that last hour. In Singapore, we were recovering from World War II and, at the same time, transitioning into independence. The focus was on survival — meeting basic needs for food, clean water, shelter and sanitation. And so, Siew Ling's childhood was different from her aunt's partly because the world itself was different from what it is today.

Also, in the past, it was common for families to have many children. An advantage was that the older children would look after the younger ones. A disadvantage was that when money ran short, parents made decisions about who would get what. If you could afford it, you would send your sons to school. If you had the resources and could manage at home without your daughters' help, they might be educated as well. If the child was clearly not going to learn to read and write well, it was considered better for her to stay home and help with chores. Siew Ling's aunt fell into that last category. She looked like other children. But her parents did not send her to school because, as her father summed it up: 'wasted because no brains'. Siew Ling's mother was sent to school. It was considered worthwhile in her case. She studied hard and became a teacher.

The Problem of the

An exterior shot of the Singapore Association for Retarded Children Training Centre in Ah Hood Road. (Inset): A retarded child has his reactions tested.

THE PROBLEM OF THE RETARDED CHILD

WHAT is the age-old cry that issues from a mother's lips the moment her ordeal of delivery is over? What does she ask as. spent and breathless from her trial, her brain and body relax their tension? I think even before the eager question, "Is it a boy? Is it a girl?" will come the anxious query, "Is the child all right?"

IS THE CHILD ALL RIGHT? This unspoken anxiety through nine months of waiting is voiced at last in those first few seconds of the child's existence and the mother waits with suspended breath for the doctor's reassuring words, "It's all right mother, and it's a fine boy" (or girl), as the case may be. The mother smiles and is at peace.

But suppose the child is *not* all right? Suppose there is some defect of limb or eyesight? Then the mother has to face with sorrow, but a brave heart, the possibility that her child will have a restricted life unless, by surgery or special care and training, the little one can be helped to overcome its disability.

In the cases of blind, crippled and deaf children great success has been achieved by special training and devoted care but suppose a child is born bodily perfect, without a blemish, so that the mother (and even the doctor) expresses delight in the safe delivery of another healthy baby, and then after the lapse of a few months it becomes apparent that the child is not developing quite as it should?

As time goes on, the doctor sees the tell-tale signs. The lack of progress in the baby's reactions and he knows that this child has a mental retardation which neither surgery nor the greatest care in the world can ever cure. He knows that this child will never be able to read or write. That it can never have a normal school education.

He breaks it gently to the weeping mother. She weeps, how she weeps!

But, "Can a woman's tender care cease towards the child she bare?" The mother *knows* that she will never cease to care but she also knows that for the rest of its life this child will need more care and affection than any of the other children she may have. In fact, with the arrival of other children, this child's needs may become impossible to fulfil.

WHAT CAN WE DO TO HELP?

It is said that all children are God's flowers but this child is a special type of flower for, like the sleeping hibiscus, its petals will remain tightly closed and so we must accept it and love it for what it is. *Not* because it will someday expand and become a showy full-blown blossom. This can never be.

IN Singapore alone we have an estimated 8,000 such retarded children. Children whose mothers try against tremendous odds to care for them and, at the same time, bring up a houseful of other boisterous youngsters and small babies who also demand their full attention.

Often, without intention the retarded little one gets neglected. Left to sit in a corner or fastened, for safety, to a bed or chair. Too irresponsible to join in the other children's play and too dependent on the mother to be allowed to wander off alone.

Small wonder that the child will gradually lose even the restricted intellect it has until its only needs are to be fed at intervals and go to sleep in some neglected corner. This can easily happen when parents are impoverished through lack of wage-earners and an over-large family.

In the case of well-to-do parents the retarded child will have all the care, attention and love which they can bestow on it. It will be well-dressed, well-nourished, kept amused and taken for car or bus rides.

But such children are in a very small minority. They are the hot-house flowers in comparison with the thousands of retarded children who languish neglected and forgotten in a limbo of poverty and squalor.

It is for the sake of mentally retarded children that the newly-founded Singapore Association for Retarded Children has been set up.

It plans to secure an improvement in the general welfare of these children by encouraging a better public understanding of their needs and, with the support of its recently formed Parents Group and the help of public-spirited individuals, aims to provide treatment and specialised training at its new Training Centre in Ah Hood Road, Singapore which has been donated by the Social Welfare Department to assist the Association in its project.

Patience and *guidance* are the motive words in dealing with retarded children and if, by such means, they may be taught to feed, wash, and try to dress themselves, then a tremendous load will already have been taken from their parents' shoulders. The children themselves will have been made to feel that they, too, are part of "us" and we, to our deep and lasting satisfaction, can say with Wordsworth:

"Farewell, the heart that lives alone,
Housed in a dream, at distance from the kind."

If you are moved, as indeed you must be, by the plight of children labouring under a mental handicap, why not contact the Hon. Secretary, Singapore Association for Retarded Children and offer your voluntary services or become a member and help to raise funds for this most worthwhile cause?

By Dorothy Stevens

Her World, July 1962

In Siew Ling's aunt's case, there was another reason for keeping her at home. Her parents did not want their family image to be tarnished. If people knew they had such a daughter, there may not be good suitors for their other daughter. People might look down on the whole family. So Siew Ling's aunt was not only kept at home but was also hidden from visitors.

Dealing with Disability

Siew Ling's mother remembers being told that their family was compassionate: there were others who tried to get rid of such babies. One family they knew had sold their child to a passing street vendor. He hoped more people would buy his goods out of sympathy when they saw the child. A baby in another family suddenly disappeared. There were strong rumours about what the family had done to the baby. In contrast, Siew Ling's aunt was cared for by her family. In the 1950s and early 60s, poor families considered themselves fortunate to have that much.

Many families and individuals struggled to make ends meet in those days. Clan associations, temples, mosques, churches and philanthropic organisations gave whatever assistance they could. There were children's homes — mainly orphanages — that had

> *It is time to stop for a moment to reminisce, to take stock of, and to celebrate all that has happened for and with people with intellectual disabilities here in Singapore. To this end, Many Dawns.*

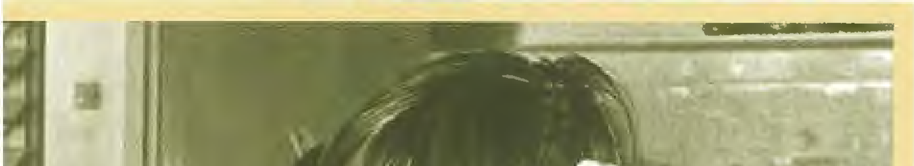
some children with disabilities. In 1952, the Red Cross started a home for physically disabled children. Some of these children also had mental retardation. Similarly, from 1957, the Spastic Children's Association served children with cerebral palsy. And some of them also had mental retardation. However, there were no services set up specifically for children with mental retardation. Perhaps their needs were not visible to the public because many families kept their mentally retarded children home.

In other parts of the world, similar scenarios were being played out. Some parents and professionals knew life could be better for children with disabilities. They advocated on behalf of such children. Their organised efforts led to the founding of Inclusion International in 1960. Meanwhile, doctors conducted research that would help the world understand how these disabilities occurred and what could be done to prevent and treat them. They shared their findings at international meetings. To enhance such networking, the International Association for the Scientific Study of Intellectual Disabilities (IASSID) was formed in 1964. Although the international organisations used terms such as 'inclusion' and 'intellectual disability', another

20 years would pass before these terms became commonplace in societies across the world. For most, efforts focused on more basic goals such as providing medical treatment and some training in activities of daily living for the children. It was in this larger context that the first services for children with mental retardation were organised in Singapore.

In the 1950s and 60s, children with disabilities were seen most frequently at the Singapore General Hospital (SGH) for treatment. Some of the doctors and other staff were deeply moved by the plight of these children. Fortunately, they were visionaries. They connected with other like-minded, concerned people to do something for these children.

The Darkest Hour of the Night



Intellectual

What is

Intellectual Disability?

by **Jenny Alexander**

Intellectual disability, intellectual impairment, developmental disability, learning disability and mentally challenged are terms that have evolved from the more discriminating labels such as idiot, imbecile, moron, defective and deficient.

The American Association on Mental Retardation (AAMR) defines mental retardation as 'substantial limitations in present functioning ... characterised by significantly subaverage intellectual functioning, existing concurrently with related limitations in two or more of the following applicable adaptive skill areas: communication, self care, home living, social skills, community use, self-direction, health and safety, functional academics, leisure and work'. Mental retardation manifests before age 18.

With the invention of IQ testing, persons with intellectual disability would typically have IQs of about 70 or lower.

Terminology has become important particularly when it comes to criminal justice. Australia and UK adopted the term 'learning disabled' to describe persons suffering from some form of intellectual dysfunction. Canada and US use 'developmental disability' to include mental retardation, cerebral palsy, autism, epilepsy and other neurological impairments.

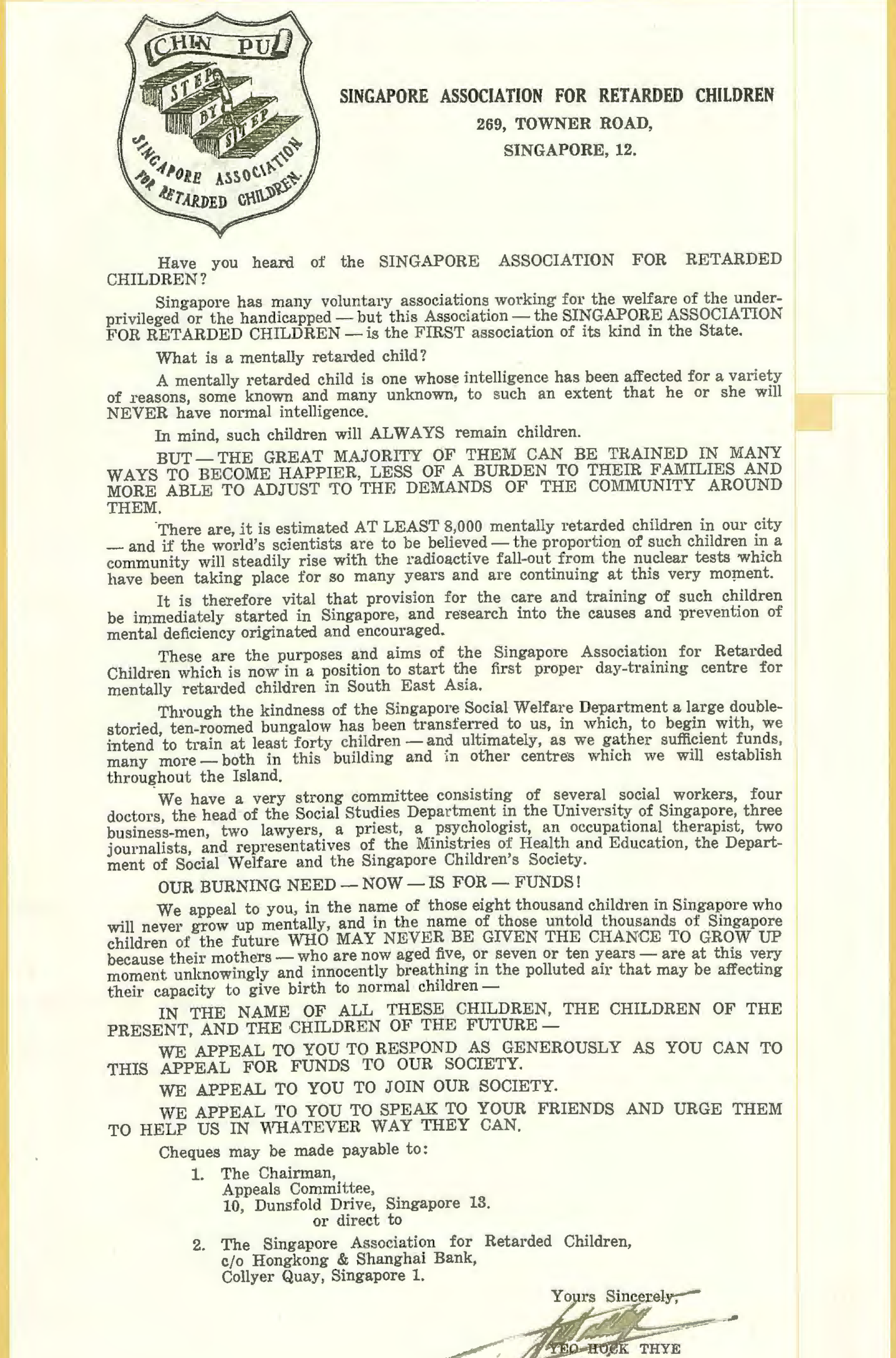
For more information

www.aamr.org

Child Maltreatment & Disability (Issues paper no: 7, Summer 1996) — National Child Protection Clearinghouse, Melbourne.

NSW Law Reform Commission discussion Paper – 35, People with an intellectual disability and the criminal justice system: Courts and sentencing issues, Oct 1994.

September 1962



CHIN PU

STEP BY STEP

SINGAPORE ASSOCIATION FOR RETARDED CHILDREN
269, TOWNER ROAD,
SINGAPORE, 12.

Have you heard of the SINGAPORE ASSOCIATION FOR RETARDED CHILDREN?

Singapore has many voluntary associations working for the welfare of the underprivileged or the handicapped — but this Association — the SINGAPORE ASSOCIATION FOR RETARDED CHILDREN — is the FIRST association of its kind in the State.

What is a mentally retarded child?

A mentally retarded child is one whose intelligence has been affected for a variety of reasons, some known and many unknown, to such an extent that he or she will NEVER have normal intelligence.

In mind, such children will ALWAYS remain children.

BUT — THE GREAT MAJORITY OF THEM CAN BE TRAINED IN MANY WAYS TO BECOME HAPPIER, LESS OF A BURDEN TO THEIR FAMILIES AND MORE ABLE TO ADJUST TO THE DEMANDS OF THE COMMUNITY AROUND THEM.

There are, it is estimated AT LEAST 8,000 mentally retarded children in our city — and if the world's scientists are to be believed — the proportion of such children in a community will steadily rise with the radioactive fall-out from the nuclear tests which have been taking place for so many years and are continuing at this very moment.

It is therefore vital that provision for the care and training of such children be immediately started in Singapore, and research into the causes and prevention of mental deficiency originated and encouraged.

These are the purposes and aims of the Singapore Association for Retarded Children which is now in a position to start the first proper day-training centre for mentally retarded children in South East Asia.

Through the kindness of the Singapore Social Welfare Department a large double-storied, ten-roomed bungalow has been transferred to us, in which, to begin with, we intend to train at least forty children — and ultimately, as we gather sufficient funds, many more — both in this building and in other centres which we will establish throughout the Island.

We have a very strong committee consisting of several social workers, four doctors, the head of the Social Studies Department in the University of Singapore, three business-men, two lawyers, a priest, a psychologist, an occupational therapist, two journalists, and representatives of the Ministries of Health and Education, the Department of Social Welfare and the Singapore Children's Society.

OUR BURNING NEED — NOW — IS FOR — FUNDS!

We appeal to you, in the name of those eight thousand children in Singapore who will never grow up mentally, and in the name of those untold thousands of Singapore children of the future WHO MAY NEVER BE GIVEN THE CHANCE TO GROW UP because their mothers — who are now aged five, or seven or ten years — are at this very moment unknowingly and innocently breathing in the polluted air that may be affecting their capacity to give birth to normal children —

IN THE NAME OF ALL THESE CHILDREN, THE CHILDREN OF THE PRESENT, AND THE CHILDREN OF THE FUTURE —

WE APPEAL TO YOU TO RESPOND AS GENEROUSLY AS YOU CAN TO THIS APPEAL FOR FUNDS TO OUR SOCIETY.

WE APPEAL TO YOU TO JOIN OUR SOCIETY.

WE APPEAL TO YOU TO SPEAK TO YOUR FRIENDS AND URGE THEM TO HELP US IN WHATEVER WAY THEY CAN.

Cheques may be made payable to:

1. The Chairman,
   Appeals Committee,
   10, Dunsfold Drive, Singapore 13.
   or direct to
2. The Singapore Association for Retarded Children,
   c/o Hongkong & Shanghai Bank,
   Collyer Quay, Singapore 1.

Yours Sincerely,

YEO HOCK THYE
Chairman,
Appeals Committee,
Singapore Association for Retarded Children.

Caring Professionals

At the SGH Paediatrics Unit, Dr Freda Paul conducted clinics twice a week for mentally retarded children. The Paediatrics Unit then referred the children to Daisy Vaithilingam, the chief medical social worker at SGH, for follow up. She worked directly with other agencies, referring children and their families for services. She championed their cause on as many fronts as she could. In some cases, when the parents discovered their babies had disabilities, they abandoned the babies at the hospital. In which case, it was often impossible to track down the parents.

Dr Elaine Field, Head of Paediatrics at SGH, felt training programmes should be started for these children[1]. This was not the first time that Elaine Field helped to blaze a trail. A few years earlier, she was one of a small band of medical professionals who started the Spastic Children's Association. In fact, their headquarters, Field House, was named after her. Elaine Field asked her colleague, Freda Paul, to visit centres for mentally retarded children in England before returning from her post-graduate studies there[2]. Inspired by what she saw, Freda Paul resolved to start a training programme in Singapore when she returned in 1959.

> ***At its deepest level, practicing inclusiveness requires that we are open to discovering and constructing solutions grounded in our unique local socio-cultural context. Being inclusive means recognising that there may be value in offering a variety of programmes so that there are choices at the individual level.***

That same year, Singapore's first psychologist, Wong Man Kee, also came back to Singapore after his post-graduate studies in England. At Woodbridge Hospital, he had come across many mentally retarded children. He, too, was determined to do something about it.

A small group came together in this way, united in their common desire to help children with mental retardation[3]. Some of these professionals were already active in the Singapore Children's Society. They convinced the society to pilot a programme in 1961[4]. Thus, it was under the auspices of Singapore Children's Society that the first training programme for 26 mentally retarded children was started in a shophouse at Towner Road. Rotary Club West donated a whopping $10,000[5]. The programme was managed by social worker E R Vaithinathan, assisted by Clare Goh. The government provided a large bungalow at Ah Hood Road, off Balestier Road, for just $1/- a month[6]. The Singapore Rotary Club donated another $18,000. The training programme was moved to the Ah Hood Road house and named the Chin Pu Centre. In Mandarin, *chin pu* means to move forward, step by step. True to its name, that is exactly what the Chin Pu Centre did.

The First Chin Pu Centre

The committee members spread the word through their professional grapevines and soon assembled a larger team at the centre. Warren Fox, at the University of Singapore's Social Work Department, convinced one of the fresh social work graduates, Damayanthi Muthuswamy, to volunteer[7]. Damayanthi Muthuswamy soon became the full-time supervisor and social worker of the centre and stayed until she retired. A circular was sent to mainstream schools, inviting teachers to join the centre. Some responded. The Ministry of Education (MOE) selected and seconded four of the teachers to this first Chin Pu Centre. In addition to the local staff, expatriate teachers formed a strong volunteer core. The centre flourished and this led to the founding of the Singapore Association for Retarded Children (SARC)[8] in 1962.

Darkest Hour of the Night

These dedicated early professionals set about making the Chin Pu Centre a second home for the children. With chickens and a couple of pigs in the yard, it was easy to feel at home here. The children probably did not notice that the building itself was somewhat dilapidated. Or that Ah Hood Road was a long, muddy, unlit track that became very dark at night when committee members arrived for meetings. The rooms were dimly lit and stark. However, like the children, that first committee did not mind. The committee was too engrossed in their big plans for the Chin Pu Centre.

Parents came forward to make enquiries about the centre. Every now and then, a parent would ask whether the Chin Pu Centre could also find a children's home for their child. Social worker Damayanthi Muthuswamy would nod her head and reply that she could. She would then write down that family's own address on a slip of paper and hand it to the parent. 'It always made them laugh. That's what I wanted — to make them laugh for a moment and then to show them that the child belongs in that family and should stay with the family.'

Lee Kong Chian Centre

Encouraged by the success of the programme, the committee approached the government for help. Government responded with a plot of land at Margaret Drive. Lee Siok Tin led the fundraising. Her father, philanthropist Datuk Lee Kong Chian, gave a substantial donation and construction began. By this time, there were three Chin Pu Centres. The original Chin Pu Centre moved from Ah Hood Road to a bungalow facing the sea at Pasir Panjang. The second centre used the Outram Road premises of the Young Women's Christian Association. The third was at the Margaret Drive plot itself. These were temporary accommodations. The centres' nomadic days ended in 1968, when all three merged and moved into the new Lee Kong Chian Centre. Woo Ti Soo, one of the first four MOE seconded teachers, became the principal and served in that capacity for two decades.

Finding Resources

Resources were scarce and hard to come by. Every day, for the children's snack, one of the school's vans would pick up buns and milk from the Social Welfare Department. Voluntary welfare organisations (VWOs) also supplied food and milk rations.

Both staff and committee members were always on the lookout for donations. One day, the staff learnt that a manager at Sony Corporation had a mentally retarded child. The staff wrote a letter requesting three radios. Sony responded immediately by delivering the radios to the centre. The children were overjoyed. Now they had music at the centre. For the playground, the Public Works Department was coaxed into donating a speedboat and a truck that were beyond repair. The children spent many happy hours pretending to ride in them.

Central Registries

In 1963, SARC started a central registry of mentally retarded children after alerting all doctors at infant welfare clinics, school clinics, outdoor clinics and general practitioners. This central registry served as a starting point for Freda Paul's research on the causes of mental subnormality in Singapore[9]. The registry had two lists. One list, the Mental Deficiency Register, had the names of

all known mentally retarded individuals. The second list, the Social Work Register, had only those considered 'trainable' and suitable for admission to schools, homes or workshops.

The lists were a stark reminder of the challenge that lay before service providers. By 1971, there were at least 2,000 listed but who were not being admitted to any programme

Williams Syndrome

by **Goh Siok Khoon**

- **Clinical findings** — A genetic disorder in chromosome #7. The current estimate of birth incidence is 1:20,000 (both sexes, all races). A wide variance ranging from mild to severe range of intellectual disability.
- **Physical characteristics** — Many of them have typical features: small upturned nose, full lips, small chin, puffiness around the eyes, small widely-spaced teeth and especially bright eyes. Stature at adulthood slightly smaller than average.
- **Major characteristics** — In the young child, feeding difficulties are common due to low muscle tone, severe gag reflex, poor suck/swallow. Some of them have high blood calcium levels (hypercalcemia), which cause extreme irritability or colic-like symptoms. Most of them suffer from an increased risk of narrowing of blood vessels or high blood pressure. They are also sensitive to hearing (hyperacusis); certain frequencies or noise levels can be painful or startling to them. They may also need to urinate more frequently. The learning difficulties of persons with Williams syndrome are often associated with visuo-perceptual-spatial deficits. They may exhibit anxious personalities, impulsive tendencies and poor concentration. Nevertheless, they are very outgoing and usually display great enthusiasm when making contacts.

- **Education** — In general, allow flexibility in requirement for time spent on task, minimise distractions, minimise paper-and-pencil demands and capitalize on their strengths in auditory memory skills and use of visual aids. They have an affinity for music; incorporate this into teaching numbers and language skills.

For more information

Williams Syndrome Association — www.williams-syndrome.org
Canadian Association For Williams Syndrome — www.bmts.com/~williams

Fragile-X Syndrome

by **Jenny Alexander**

Fragile-X syndrome is the most common cause of genetic inherited intellectual disability affecting 1 in 1,200 males and 1 in 2,500 females. Fragile-X syndrome was first discovered in the late 1970s. But it was the discovery of the fragile X mental retardation 1 gene later in 1991 that elucidated the cause of Fragile-X syndrome.

Carriers have a small defect in the FMR1 gene called a premutation. Carrier men pass the premutation to all their daughters only. Each child of a carrier woman has a 50% chance of inheriting the gene. The fragile X premutation can be passed silently down through generations in a family before the syndrome affects a child.

Males with Fragile-X are affected more severely than females. Approximately 6 to 14% of affected males have moderate to severe intellectual disabilities, about 7% of females have mild to moderate intellectual disabilities and approximately 10% of boys have diagnosis of autism. Some with Fragile-X have average intelligence with or without learning disability. Emotional and behavioural problems such as attention deficit and hyperactivity, anxiety and unstable mood and autistic-like behaviours are common in both sexes. Physical abnormalities include elongated face, broad forehead, large prominent ears, hyper-extensible fingers, flat feet and hypotonia.

Although there is no cure for Fragile-X syndrome, individualised education, behaviour management, therapy and medication help maximise the potential of each person. The possible biomedical approaches for Fragile-X treatment include Gene Therapy, Protein Replacement Therapy and Psychopharmacology.

For more information

American College of Medical Genetics, 1994 — www.acmg.net
Council for Exceptional Children — www.cec.sped.org
Fragile X Research Foundation of Canada — www.nsnet.org/fragileX
The National Fragile X Foundation — www.fragilex.org/home.htm

because of the shortage of staff and facilities[10]. By 1982, the registry had more than 5,000 names on it[11]. Although there were more centres and associations catering to the needs of the mentally retarded by the early 80s, waiting lists were still long. The Ministry of Social Affairs also had a Central Registry of Disabled People (CRDP) which was used to compile statistics for planning. By the early 1980s, the CRDP had 20,000 names[12].

The Charity Dollar

On one level, research and programme development were moving full steam ahead. On another level, fundraising efforts chugged along. It was a mammoth task. Flag Days were major fundraising events. Large numbers of volunteers braved sun and rain to approach the public. The public dropped their coins through slots into tins. At the end of the day, the organisers — committee members and senior staff — convened to count the money. The tins of money could be opened only with can openers. There were times when the organisers hands' bled because they had opened so many tins in this way.

However, even in those days, there were those who believed that such fundraising should not be necessary because disabled children should be allowed to attend public schools along with all other children, in mainstream settings. Others were more wary. They feared that if mentally retarded children were to be placed in mainstream schools without any supports in place, it would not be in the best interest of the children. However, both groups agreed that even if the children were to remain in special schools, the education of mentally retarded children should not have to depend on the charity dollar. But they accepted the reality that this was easier said than done. These pioneers of special education were gracious in their appreciation of whatever action the government took to support their efforts. Seconding teachers and making available school buildings topped the list.

> ***It takes a certain calibre of people to be able to tolerate these conditions and choose to remain. They are able to accommodate what is, without forgetting what could and should be. And many of them continue to advocate for better conditions even while acknowledging that things could have been even worse.***

The Darkest Hour of the Night

The Darkest

Hour of the Night

Residential Programmes

In 1969, SARC entered somewhat unfamiliar territory. SARC decided to start a home for adults with mental retardation. In those days, many adults with mental retardation were admitted to the wards for 'mental defectives' at Woodbridge Hospital. Although Woodbridge Hospital was for mentally ill patients, the mentally retarded adults lived there for years, often for the rest of their lives. SARC's decision to start a home for mentally retarded adults was in response to the long waiting list for admission to Woodbridge.

The Home occupied two temporary wooden buildings at Tampines Road. And remained there for seven years. Whenever it rained heavily, the Home flooded. Whenever it flooded, the British army carried the residents to higher ground. After the British troops withdrew from Singapore, the Singapore Armed Forces continued this tradition. Finally, in 1976, with donations from the public, Tampines Home was able to move into a new facility at Yio Chu Kang. A little over a decade later, it moved once again — this time to give way to the expansion of Woodbridge Hospital. Tampines Home now occupies the renovated premises of a vacated primary school at Thomson Road.

Weathering Difficulties

Tampines Home's experience with floods, being relocated and managing with makeshift arrangements is not atypical. In fact, most of the older voluntary welfare associations have similar tales to tell. They have weathered difficulties

with amazing resilience and, as a result, there is today a sense of camaraderie amongst the agencies that serve individuals with disabilities. Perhaps it is a bond that grows out of shared frustrations as well as achievements.

Perhaps common experiences of dealing with leaking ceilings, termite-infested beams and standing ankle-deep in murky floodwaters as a water snake slides by all have the capacity to help people stay focused on the common good. But for sure, it takes a certain caliber of people to be able to tolerate these conditions and choose to remain. They are able to accommodate what is, without forgetting what could and should be. And many of them continue to advocate for better conditions even while acknowledging that things could have been even worse.

Thus, although the 1950s to early 60s was like the darkest hour of the night, those who looked up at the sky would have noticed a scattering of lone stars shining steadfastly. Who were these stars? The first committee members and staff, parents who were willing to bring their mentally retarded children out of their homes and to school, volunteers (local and expatriate) who rolled up their sleeves and helped in a hundred tangible ways, philanthropists and corporate donors who trusted that their funds would be well spent, and government officers who worked quietly to support VWO efforts. When they connected, they formed small constellations that helped those who came later to chart the way.

Endnotes

[1] Ng, Evelyn (1982, September 15). *Doctor wins award for research on mentally retarded children*. The Straits Times. Singapore.

[2] Tan Cheng Lim (1974). *Forward of a survey of mental subnormality in Singapore children*. The Sixth Haridas Memorial Lecture. Singapore: Singapore Paediatric Society and the Society of Private Practice.

[3] Besides those mentioned above, the group included Ena Aeria, Ms Robertson and Warren Fox.

[4] Singapore Children's Society (2002). *50 years of growing up: The history of the Singapore Children's Society*. Singapore.

[5] MINDS (1987). *The story of MINDS. 25th Anniversary Publication*. Singapore

[6] For years, the temporary occupation licence fee was $12/- per annum for occupation of State land (see State Lands Act Chapter 314, State Lands Rules, 1968).

[7] At that time, Mrs McKee was the supervisor and E R Vaithinathan was the full-time social worker. They resigned soon after.

[8] Originally named the Singapore Central Association for Retarded Children, the 'Central' was dropped upon official registration.

[9] Chua Chong Jin (1997). A tortoise on his back. *The Alumnus*, Jan 1997, 50-51.

[10] Ling, Peter (1971, August 1). The unfortunate children. *Weekend*, pp 12-13. Singapore: Straits Times Press (M) Bhd.

[11] (Ng, 1982). Same as Note 1 above.

[12] Wee, Lawrence (2002). Personal communication. Singapore

Down Syndrome

by **Ong Liang Cheak**

- **Clinical findings** — The occurrence of Down syndrome is a result of a genetic abnormality where excess chromosomal material, known as the trisomy 21, is found in each cell of the human body.

- **Characteristics** — Common facial features of children with Down syndrome include upward slanting eyes that have abnormal skin folds, low set ears, a flat nose, and often a mouth held slightly open with the tip of the tongue protruding. Fingers and toes are usually broad and short. The palms of the hands usually have a single crease known as the 'simian crease'. Many of these children are short and stocky. They frequently also have low muscle tone, hypermobile joints and problems in sucking.

- **Related health problems** — Cardiovascular abnormalities, obesity, increased respiratory and other infections caused by immune system deficiency, thyroid deficiencies, gastrointestinal problems, poor visual acuity, and the potential risk for dislocation to occur between the first and second cervical vertebrae.

- **Life expectancy** — This has improved tremendously over the years. Those without cardiac problems can expect to live into late adulthood. It is common however for these individuals to develop a syndrome similar to Alzheimer's disease as they age.

- **Developmental aspects** — Cognitive, language, and motor planning skills develop slowly although the degree varies among individual cases. However, with a caring and enriching home environment, early intervention, and improved special education can greatly assist these children to achieve their optimal function. There are some who have made it through regular schools in regular education classes with differing levels of support, and some who have even completed post secondary education programs including colleges and vocational programs.

For more information

Rogers et al. (2002). Common diagnosis in pediatric occupational therapy practice. In J. Case-Smith (Ed.), *Occupational therapy for children* (4th ed.) (pp. 136-189). Toronto: Mosby.

Gunn, P. (1993). Characteristics of Down Syndrome. In Y. Burns, & P. Gunn (Eds.), *Down Syndrome: Moving through life*. (pp. 1-18). Madras: Chapman & Hall.

Roizen, N.J. (1997). Down Syndrome. In M.L. Batshaw (Ed.). *Children with disabilities* (4th ed.) (pp. 361-376). Baltimore: Brookes.

Rett Syndrome

by **Jenny Alexander**

Rett syndrome (RS) is a neurodevelopmental disorder seen almost exclusively in females. First described by Dr Andreas Rett in 1964, RS later received worldwide recognition following a well-published article by Dr Bengt Hagberg and colleagues in 1983. The prevalence rate is from 1:10,000 to 1:23,000 in female live births found in various races and ethnic groups globally.

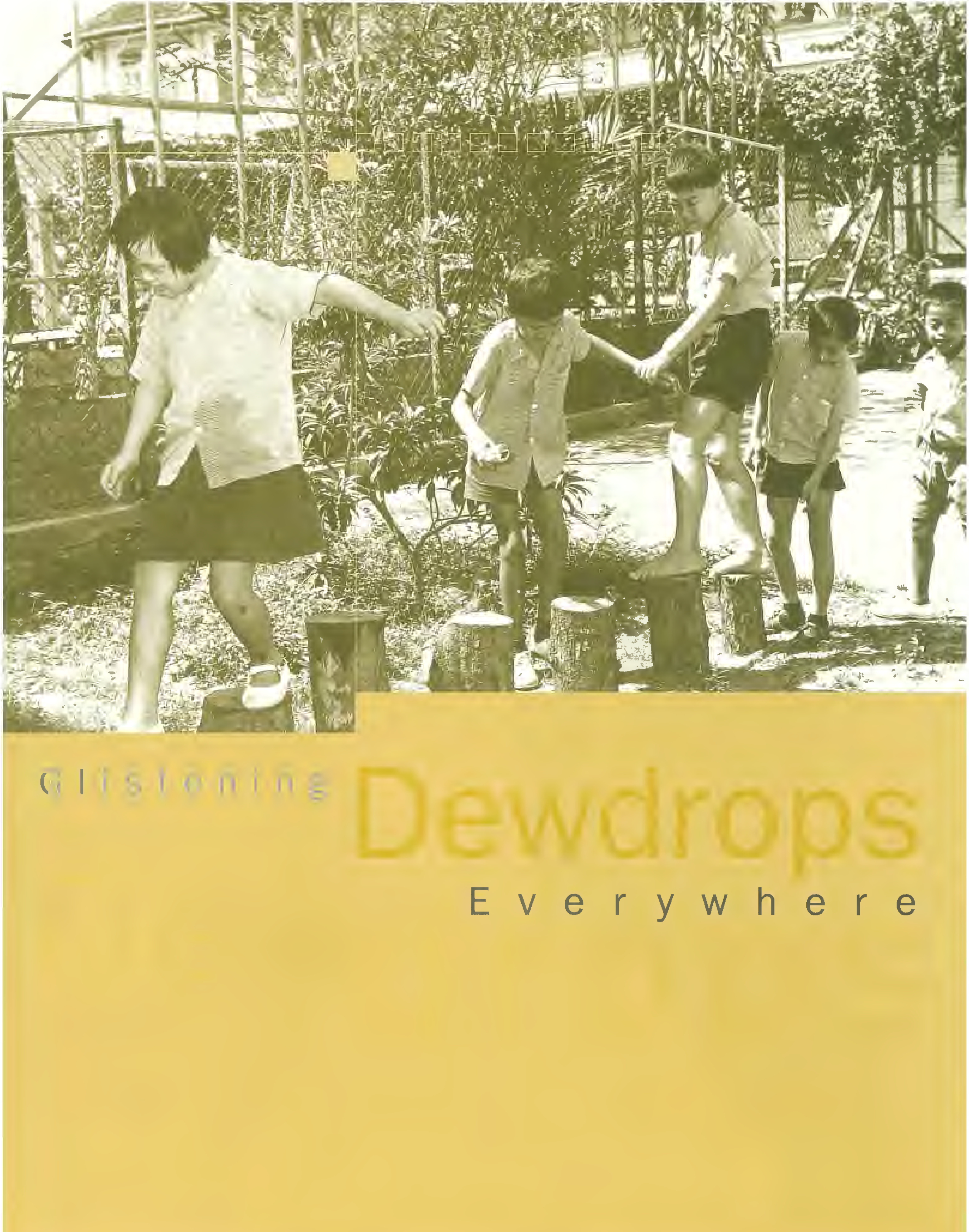
RS is a genetic disorder caused by a mutated gene on the X-chromosome called MeCP2, discovered by Dr Huda Zoghbi et al of Baylor University in 1999. Most researchers now agree that RS is a developmental disorder rather than a progressive, degenerative disorder, thought of previously. The course of RS follows four stages.

- **Early Onset Stage** — There is normal or near-normal development until age 6 to 18 months when the infant may show signs of having less eye contact and reduced interest in toys. RS is sometimes misdiagnosed as autism.
- **Rapid Destructive Stage** — Between 1 and 4 years, the child's purposeful use of the hands, spoken language and social interactions are lost either rapidly or incrementally. Stereotyped hand movements, like hand wringing, hand washing, clapping, and hand mouthing emerge. Gait disturbance also appears as seen in wide-based toe-walking, stiff-legged and jerky gait while initiating motor movements can be difficult. Other problems are breathing irregularities, seizures, chewing and swallowing difficulties and constipation.
- **Plateau Stage** — From age 2 to 10 years, following the rapid destructive stage, apraxia, motor problems and seizures are more prominent. Many RS girls remain at this stage for most of their lifetime.
- **Late Motor Deterioration Stage** — After 10 years with reduced mobility, some RS girls stop walking and Scoliosis is a prominent feature.

The course of RS with severity varying from child to child may be improved by therapies aimed at slowing down motor disability, promoting the use of hands and augmentative communication techniques.

For more information

International Rett Syndrome Association — www.rettsyndrome.org
Diagnostic and Statistical Manual of Mental Disorders (4th ed.) DSM-IV 1997 — www.psychologynet.org/dsm.htm



Glistening Dewdrops Everywhere

In humid Singapore, dewdrops start to form soon after the night air cools. By the darkest hour, every blade of grass may have a dewdrop but we are not able to see them yet. When they first become visible, you can be sure that dawn is near. It means there must be just enough light coming from somewhere to make the dewdrops glisten. In many ways, all that happened in the late 1960s and the 70s resembled glistening dewdrops in that early landscape of services for individuals with intellectual disabilities. Perhaps some of the early light came from the 1971 United Nations Declaration on the Rights of Mentally Retarded Persons.

In Singapore, more Chin Pu Centres were set up. Once again, the centres were housed wherever space was available. The quality of the programmes improved. Sports, swimming, home economics and travelling lessons were introduced into the curriculum. In the mid-1970s, Dover Court Preparatory School was started and became the first private school to offer special education.

Disabled children and adults had more opportunities for participating in competitive sports at their agencies. SARC president Lim Ewe Huat, Joe David from MOE and others paved the way for the next step — national participation. In 1973, they set up the Singapore Sports Council for the Disabled. Soon, the council had representation from 11 voluntary welfare organisations, four ministries and one hospital[1].

Some international organisations servicing persons with disabilities

by **Tiang Voon Cheng**

- Autism Association (various individual countries'/ states' websites)
- Disabled People's International — www.dpa.org.sg
- Down Syndrome Association (various individual countries'/states' websites)
- International Association for the Scientific Study of Intellectual Disabilities (IASSID) — www.iassid.org
- International Rett Syndrome Association — www.rettsyndrome.org
- Planned Parenthood Global Partners — www.plannedparenthood.org
- Special Olympics — www.specialolympics.org
- United Nations Human Rights — www.hri.ca
- Very Special Arts — www.vsarts.org
- World Association of Persons with Disabilities — www.wapd.org
- World Psychiatric Association — www.wpanet.org

Glistening Dewdrops

Dew

Special Events

Aside from regular centre activities at special schools and centres, there were special events as well. Concerts were highlights of the school year. The children practised for weeks. Staff and volunteers saw concerts as opportunities to show audiences what mentally retarded children could do.

As the performance days drew near, tension mounted. Teachers knew from experience that there would be one or two parents who could not be relied on to bring their children on time. Or worse, they may not be brought at all. The solution? Priscilla Theseira had a pragmatic one: 'I asked those parents to let their children sleep over at my home the night before. That way, I could be sure they would make it to the concert and perform. Sometimes, there would be seven or eight children staying with my family. We had fun.'

Fortunately, there are always a handful of such dedicated individuals among the staff and volunteers of the all the agencies serving people with intellectual disabilities. They worked tirelessly on several fronts to improve the quality of life for intellectually disabled individuals. And like true professionals, they kept up with what was happening in rehabilitation and special education around the world.

Regional Developments

The earliest professionals were trained abroad. They brought home insights about service planning and development. In addition, they studied more mature systems of rehabilitation and special education elsewhere. This healthy infusion of ideas from all over the world continues to this day. And even in those days, Singaporeans contributed where they could as well. In 1971, Wong Man Kee was invited to present one of the keynote speeches at the first Pacific Forum on Mental Retardation in Honolulu, Hawaii[2]. At that meeting, he met many Asian delegates who expressed a desire for an Asian platform.

Then in 1972, SARC celebrated its 10th Anniversary. One of the highlights was a special education and mental retardation regional conference. Here again, delegates identified the need for an Asian organization. A Catholic priest, Father Arthur Malin, strategized with Wong Man Kee.

Thus, the Asian Federation for the Mentally Retarded (AFMR) was born the next year. With UNESCO[3] funding, AFMR had its inaugural conference in Manila. Today, AFMR is well established, continuing to serve as an Asian platform for advocacy and planning.

Children with Multiple Disabilities

In the early 1970s, British forces were pulling out of the region. The VWOs lost a reliable pool of volunteers as many of the expatriate women were actively involved in the VWOs. Shakuntala Bhatia, wife of the Indian High Commissioner in Singapore, rallied other women to take the place of the expatriates who left. The group formed the Asian Women's Welfare Association (AWWA) in 1970. Initially, AWWA distributed food rations and conducted free tuition classes and, later, started a home for the elderly. In 1979, they were eager to reach children. Leaena Tambyah, a young social worker volunteering with AWWA, recalls, 'Because it was the International Year of the Child, everyone wanted to

Prader-Willi Syndrome

by **Goh Siok Khoon**

- **Clinical findings** — A disorder in chromosome 15 (which governs normal ability to feel full) The current estimate of birth incidence is 1:12,000-15,000 (both sexes, all races). IQ range from 40-105, with an average of 70.
- **Physical characteristics** — Many of them have typical features: small hands and feet, narrow face/bifrontal diameter, almond-shaped eyes, small-appearing mouth with thin upper lips and down-turned corners of mouth and short stature (as adults).

- **Major characteristics** — At infancy stage, they present feeding difficulties due to poor muscle control (hypotonia). However as the child grows older, caregivers will find that there is excessive weight gain. They manifest an obsession with food that can lead to life-threatening obesity if not controlled (hyperphagia). Their sexual organs are also underdeveloped (hypogonadism). Global developmental delay in sitting, walking and talking is also evident in the young child. Cognitively impaired and with their language development delayed, they have greater difficulties in expressive than receptive skills. They may demonstrate difficult behaviours such as temper tantrums, violent outburst, obsessive/compulsive behaviours, perseveration, picking at skin irritations, etc.
- **Education** — Intervention to manage their behaviour works best with daily routines and structure, firm rules and provision of visual cues and aids. Academically, they are poor in numbers, handwriting, abstract thinking etc. Tasks given must be practical and often repeated before there is understanding. However, they are receptive to learning and generally have good reading and fine motor skills.

For more information

Prader-Willi Syndrome Association(USA) — www.pwsausa.org
Prader-Willi Syndrome Association (UK) — www.pwsa.co.uk

Cri du Chat Syndrome

by **Teo Ginnyueh**

- **Clinical findings** — Cri du Chat syndrome (Cry of the cat in French) is a condition caused by the loss or misplacement of genetic material of the fifth chromosome. It was first identified in 1963 by Professor Lejeune and named after the sound that many young children make when crying. They make a high pitched cry that sounds like a cat due to laryngeal anomaly. Some alternative names of this syndrome are 5p minus syndrome and Le Jeune's syndrome. Cri du Chat syndrome is found in about 1: 50,000 babies. Approximately 80% of the incidents are caused by a spontaneous deletion of materials from the child's fifth chromosome, 10-13% by an error in chromosome number five in either parent and the remaining 7-10% result from rare genetic anomalies. If there is an error in a parent's chromosomes, subsequent children may be affected. Therefore it is important that parents of children with this syndrome receive genetic counselling.
- **Physical characteristics** — Persons with this syndrome may exhibit the following characteristics: high pitch cry, slow growth, small head, wide set eyes and downward slant, low set ears which may be malformed, mental retardation, incomplete development of motor skills, low muscle tone, speech and language delay.
- **Intervention** — Early intervention programmes and special education using a variety of therapies and educational strategies that enhance physical, intellectual, sensory and social development can help children with Cri du Chat syndrome reach their potential.

For more information

Cri du Chat Support Group of Australia — www.criduchat.asn.au
Medlineplus Health Information — www.nlm.nih.gov/medlineplus/ency/article/001593.htm

do something for children. We felt we should do more than just throw parties. We should do something meaningful and lasting.'

By now, SARC had several Chin Pu Centres but only children who had no other disability qualified for entry. Children with multiple disabilities had nowhere to go. Many of these children had intellectually disabilities. And so, AWWA started the Handicapped Children's Playgroup for such children during the International Year of the Child. Once again, medical social workers at SGH shared their lists of children. AWWA volunteers visited the families to persuade them to send their children to the Playgroup. A few were ready and willing. Like SARC, finding permanent premises was a challenge for AWWA. The Playgroup first started in the hall of St Ignatius Church, with seven children on two mats. But there was no storage space. Between sessions, all materials were stored in the boots of the volunteers' cars. Subsequently, Maris Stella Kindergarten at Holland Road offered the only space they could spare, the verandah. AWWA gladly accepted. Then they moved to the St James Church hall, where there was at least more storage possible. The search for premises continued. Despite these less-than-ideal arrangements, the programme benefited from strong volunteer support: some with teaching or rehabilitation expertise, others with fundraising zeal and yet others who offered whatever they could (including the use of a swimming pool for hydrotherapy).

Children with Mild Mental Retardation

By and large, parents appreciated the Chin Pu Centres. There was one concern though. Parents of children with only mild mental retardation felt their children could be better served if they were grouped together instead of being with the others at SARC. These children could not cope with the curriculum in mainstream schools but were too advanced for the SARC curriculum. Their parents met and initiated the forming of separate classes at SARC for 'higher functioning' children. The parents paid higher school fees for these special classes at SARC. As the numbers

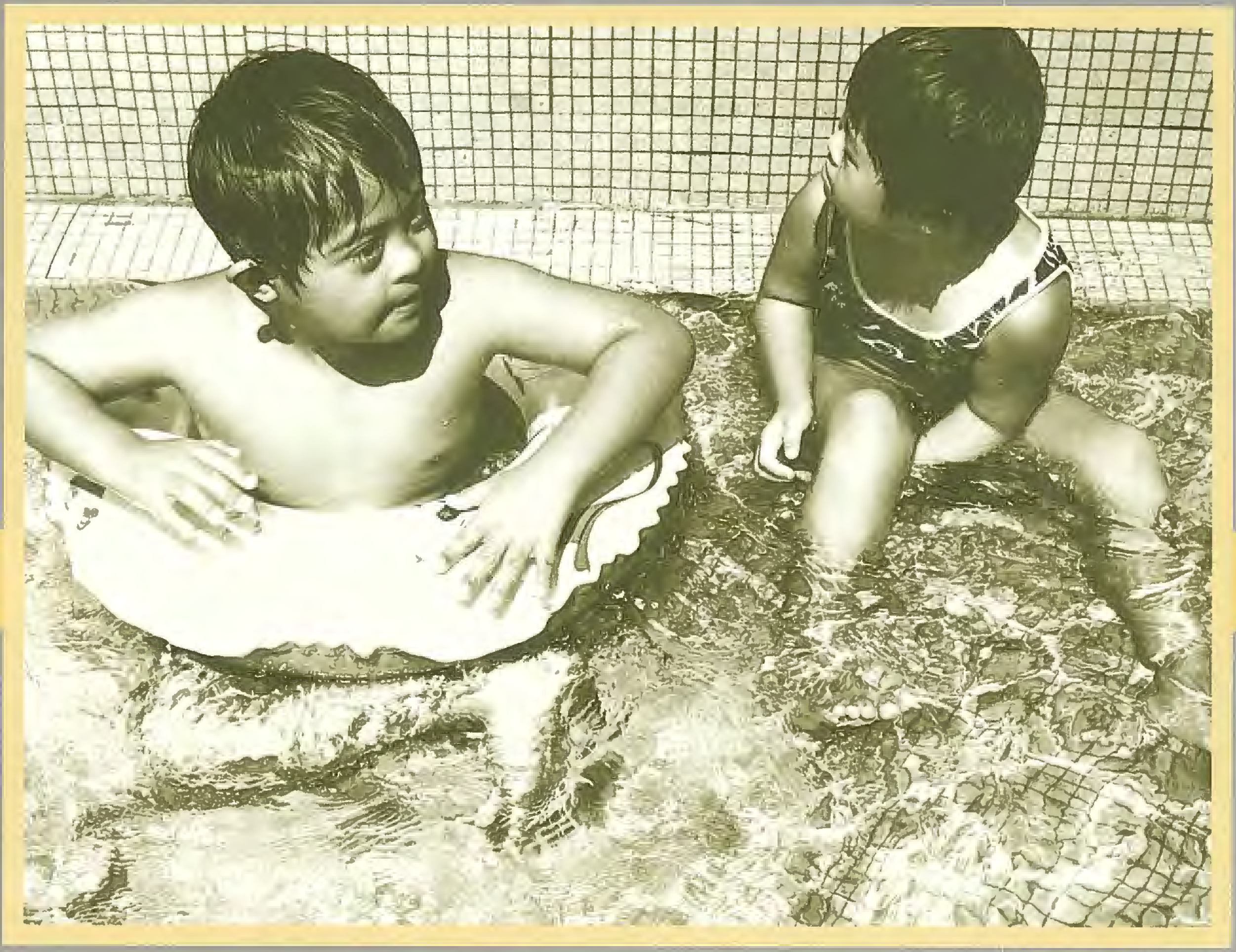
grew, three churches offered their premises. A few expatriate trained teachers were recruited. By 1974, the three little schools had a total of 90 children. Two years later, in 1976, the parents started their own association — the Association for the Educationally Subnormal[4] (AESN). MOE seconded an experienced teacher and supported AESN's application for a vacated school building. Thereafter, AESN grew rapidly from strength to strength, serving children and adults with mild intellectual disability.

Thus, by the late 1970s, children with mild mental retardation were channeled to either SARC or AESN, depending on their intelligence test scores. Some of the children entered mainstream primary schools but were referred to special schools when their mental retardation was diagnosed.

Sheltered Workshops

As the children of the special schools grew older, the need for adult programmes became evident. SARC started a sheltered workshop at its Pasir Panjang Centre. Teenagers and young adults were taught work skills and behaviour in the hope that they would be able to work in open employment at factories. More workshops sprouted over the years. Many parents liked sheltered workshops because their adult children would still be in a protected, caring environment. The sheltered workshops were happy to accept any work orders or contracts that came their way as long as the workshop team could do the tasks. Most of the contracts — more often, sub-contracts — were secured through goodwill connections.

Engeline Lee, a parent volunteer, chaired the SARC Sheltered Workshop Committee. Engeline Lee and her husband, Dr Lee Kum Tatt, were very eager to help individuals like their daughter. Lee Kum Tatt was chairman of RISIS[5]. He proposed that RISIS train intellectually disabled individuals and subsequently employ them. RISIS might stand to gain: the SARC trainees may turn out to be a stable, loyal workforce. SARC welcomed this mutually beneficial idea. In 1976, RISIS set up a special training room at SARC's Margaret Drive Sheltered Workshop and conducted the training there.



Dewdrops Everywhere

The next year, 18 of the trainees were employed as full time staff of RISIS, with the same remuneration as the other employees, a rare practice in those days.

RISIS did indeed enjoy loyalty in return. Most of the original 18 are still there after 25 years. Some served till retirement. As for SARC and other VWOs, placement officers had one more good example that could be cited to convince other employers to recruit individuals with intellectual disabilities.

Recruiting Volunteers

Parents, doctors and other professionals continued to volunteer their services and to serve on committees. Some came on board even before they graduated. Take Dr Victor Seah for example. He started volunteering on the executive committee while he was still a medical student. Then there were the social work students. Undergraduate social work students had practicum placements — and, in addition, were encouraged to volunteer — at the special schools. They went a step further and organised parties at the university

drops Everywhere

for intellectually disabled children. Young S. Vasoo was one of these social work students, inspired by his lecturer Daisy Vaithilingam's enthusiasm[6].

In the 1970s, S. Vasoo became deputy director of the Singapore Council of Social Service. From that vantage point, he persuaded many community groups and polytechnic students to get actively involved. The Polytechnic students responded enthusiastically, befriending and helping their peers at SARC. Activities included, for instance, teaching the SARC youth how to use public buses. Work preparation — or pre-vocational training — programmes developed from these early efforts. One of these students was Tay Tiong Beng. For years, Tay Tiong Beng rallied youth volunteers and spearheaded many special programmes and events at SARC.

The student days of Victor Seah, S. Vasoo and Tay Tiong Beng have long since passed. S. Vasoo became a Member of Parliament and head of the Department of Social Work and Psychology at the National University of Singapore. Tay Tiong Beng is a colonel in the Singapore Navy. Victor Seah has a thriving private medical practice. Despite their heavy commitments at work, they continue to help agencies that serve intellectually disabled individuals and their families. The cycle repeats itself. A decade later, in 1983, a young Dr Kenneth Lyen returned from his training abroad. Freda Paul[7] asked him to take over her clinic for disabled children when she retired. Victor Seah invited him into the SARC committee. Like the others, Kenneth Lyen served on various committees of several agencies for years. Perhaps when the lamp within is lit in one's youth, the flame burns for a very long time.

In contrast to those who served for decades, Desmond Loo became a student volunteer only three years ago. Desmond Loo reflects, 'The MINDS youth have become part of my life. Every Saturday, I come down and see them. We go out with them. We have fun, we learn, we grow together. Then after the programme, we volunteers meet for dinner to discuss our plans. So our lives revolve around these kids on Saturdays.' Already, the flame within burns strong.

Thus, the 1970s reverberated with the vitality of volunteerism. Existing programmes grew and multiplied even as new initiatives made their entry throughout that decade. Soon after AESN and AWWA were formed, two more dynamic organisations made their entry: the Thye Hua Kwan Moral Society in 1978 and the Christian Outreach to the Handicapped in 1979. There was no doubt now about whether services should be provided for persons with mental retardation. There were only questions about how best to go about it. Strong shafts of sunshine were beginning to penetrate that first dawn.

Endnotes

[1] See www.sscd.org

[2] The US President Nixon's Committee on Mental Retardation organised the forum.

[3] United Nations Educational, Scientific and Cultural Organization.

[4] In the 1980s, 'mild mental retardation' and 'educationally sub-normal' were common terms. Today, persons with IQ scores of 50 to 70 are referred to as persons with moderate learning difficulties.

[5] RISIS is known for its delicate process of gold-plating real orchids to produce jewelry.

[6] Daisy Vaithilingam, whose involvement started when she was the Chief Medical Social Worker at SGH, was lecturing at the university by now.

[7] Freda Paul was by then a professor with the medical faculty.

Turner Syndrome

by **Teo Ginnyueh**

- **Clinical findings** — Turner syndrome (TS) is a chromosomal condition that occurs when one of the two X chromosomes normally found in females is missing or contains some structural defects. Hence it is a diagnosis found only in females. Turner syndrome is named after Dr. Henry Turner who was among the first to describe its features in the 1930s. This condition is found in approximately 1: 2,000-5,000 live born girls. Diagnosis of this syndrome is made through a test called Karyotype, that is usually performed on cells in the amniotic fluid (before birth) or cells in the blood (after birth).

- **Common characteristics** — Persons with TS have primary characteristics like short stature and ovarian failure. Girls who undergo treatment for growth may probably reach the lower range of normal height for an adult female. Estrogen therapy will also help them develop secondary sexual characteristics and ensure proper bone development.

  Other common physical characteristics persons with TS may have are narrow and high arch palate, receding lower jaw, low-set ears, low hairline, webbed neck, eyes with slight droop, arms that turn out slightly at the elbows, flat feet, small and narrow fingernails and toenails that turn up, short fourth metacarpals, edema of hands and feet (especially at birth).

- **Education** — Although individuals with TS may have normal intelligence with the same variance as the general population, they often have difficulty with spatial orientation and moderate degrees of learning disorder.

For more information

www.turner-syndrome-us.org

www.icondata.com/health/pedbase/files/TURNERSY.HTM

Rubinstein-Taybi Syndrome

by **Teo Ginnyueh**

- **Clinical findings** — Rubinstein-Taybi syndrome (RTS), first described by Rubinstein and Taybi in 1963, is also known as Broad Thumb-Hallux syndrome (BTHS). It is a rare condition that affects both males and females equally and approximately 1: 125,000 people. This genetic multisystem disorder that affects many organ systems of the body, is caused by mutations in or loss of a gene on chromosome sixteen. Most cases of RTS are not inherited but sporadic.
- **Characteristics** — This disorder is characterised by mental retardation, broad thumbs and toes, short stature and characteristic facial features. Some of which are widely spaced eyes, broad nasal bridge, and 'beak-shaped' nose, low set ears, excess hair on body and narrow, small or recessed mouth with over crowding teeth. Persons with this condition may also have malformation of the heart, kidney, urogenital and/or skeletal system.
- **Intervention** — Specific therapies for the treatment of RTS are symptomatic and supportive. Medical intervention will be dependent on the physiological problems faced by the individual. Some may be more prone to malignancies than the general population hence need close monitoring by physician to ensure early detection and appropriate treatment. Language and speech therapy may be needed by some with expressive language delays. Generally, early intervention and special education can help children with RTS to reach their potential and hence better future outlook for them.

For more information

Yahoo Health — health.yahoo.com/health/dc/001249/0.html
National Organization for Rare Disorders, Inc. — www.healthwise.org/kbase/nord/nord461.htm

The First Shafts of Sunlight

If there ever was a culmination of events — of advocacy, of policy making, of spectacular declarations — in the international disability movement, it was during the 1980s. In 1976, the United Nations (UN) General Assembly declared 1981 the International Year of Disabled Persons (IYDP). Preparations for IYDP reached fever pitch and the year was filled with extravaganza. And it did not stop there. UN proclaimed 1983 to 1992 the Decade of Disabled Persons.

A great deal happened in that decade. People with disabilities were coming out and participating in different arenas for all to see. Horse riding courses were started by Riding for the Disabled Association of Singapore in 1982. Intellectually disabled youth from various organisations benefited. In 1983, a Singapore delegation competed for the first time at Special Olympics, an international event held every four years for intellectually disabled individuals. Thereafter, Singapore regularly sent participants.

The Disability Movement

Disabled people wanted to speak for themselves more than ever before. And they did. Till then, Rehabilitation International was the one international organisation that represented organisations of people with disabilities. But disabled people felt that Rehabilitation International was a stronghold of rehabilitation professionals rather than of people with disabilities.

The First Shafts of Sunlight

light

Singaporean Ron Chandran-Dudley and a few other vocal people with disabilities were active in Rehabilitation International. But they wanted more. They lobbied for the empowerment of disabled peoples, their own eloquence making it clear that they could represent themselves. This was more evident than ever during the International Year of Disabled Persons, when the first Congress of Disabled Peoples' International was held in Singapore. Thus, in 1981, Disabled Peoples' International (DPI) was born. With Ron Chandran-Dudley as its founder chairperson, DPI was not only for but *of* disabled people.

Back in Singapore, he also founded the local affiliate of DPI: Disabled People's Association (DPA), a cross-disability, grassroots national assembly. At that time, there was already another local association of disabled people: the Handicaps Welfare Association (HWA). Like the newly formed DPA, HWA took pride in the fact that it was truly for, of and by disabled people. Today, both continue to be self-advocacy groups. Whenever there are opportunities for doing so, each contributes to the planning and development of services for disabled people in Singapore.

How does all this play out in the ordinary, day-to-day lives of intellectually disabled individuals and their families? Intellectually disabled adults or their parents can become members of DPA. Does joining help? Yes, if being a member gives that person a sense of belonging just as club membership would for many of us. Yes, if being a member is seen as contributing to an important movement, even if one does not fully understand the complexities of that movement. Yes, if the individual has access to — and feels inclined to — participate in the events and programmes of these associations. Beyond that, in terms of true empowerment, there is no clear answer. Parents and professionals know that, in contrast to adults with other kinds of disabilities, intellectually disabled adults face unique challenges when attempting to speak for themselves. Even as adults, they are vulnerable to being exploited by others. True empowerment does not come easily to intellectually disabled people. It is possible but it takes more than being a member of an association.

Strong Ripple Effects

This is not to say that the disability movement boiled down to nothing but rhetoric for the intellectually disabled. There was a strong ripple effect. The flavour of professional conversations changed subtly but surely. Quality of life issues also came to the fore. Derogatory phrases gave way to the language of personal rights, dignities and freedoms. The use of politically correct terms became important: *persons with disabilities* instead of *disabled persons* (and then again, *disabled persons* but only if one wished to draw attention to the fact that these persons were indeed disabled by society); *intellectual disability* and not *mental retardation*. Names become labels and for marginalised groups, labels tend to define the individual and the group in stereotypical ways. We have come a long way since the days when individuals with intellectual disability were classified as *idiots*, *imbeciles* and *morons*. But even today, labels stick. And the connotations that go with certain words are not flattering.

> *Jaspreet Kaur Sekhon explains,*
> *'... People call me a Down syndrome.*
> *I am offended when they*
> *call me a Down syndrome.*
> *Actually I have Down syndrome*
> *but I am a normal adult.'*

Twenty-one-year-old Jaspreet Kaur Sekhon explains, 'It is quite hard. People call me *a Down syndrome*. I am offended when they call me *a Down syndrome*. Actually I have Down syndrome but I am a normal adult.' She is a warm, friendly teaching assistant at a mainstream kindergarten. She loves music, watching television and going out with her parents. She urges us to support the Down Sydrome Association and confidently adds, 'Don't look down on us. Make eye contact!' Jaspreet Kaur Sekhon is far more than a syndrome. It is in the same spirit that advocacy groups try to help society see that an individual who has intellectually disability is far more than a test score and an accompanying label.

Reconceptualising Intelligence

The early 1980s also saw timely attempts to reconceptualise intelligence. By default, how intelligence is defined impacts all who have been categorised as having intellectual disabilities. The IQ score was still the most common measurement. Psychologists relied on IQ tests to slot persons with intellectual disabilities neatly into categories based on IQ test scores. Howard Gardner, in his book *Frames of Mind*[1], proposed that we should move beyond such a narrow understanding of intelligence. He suggested that there were multiple intelligences. Gardner's Theory of Multiple Intelligences grew in popularity to become a viable alternative to relying exclusively on the IQ score.

The International Year of Disabled Persons 1981 (IYDP)

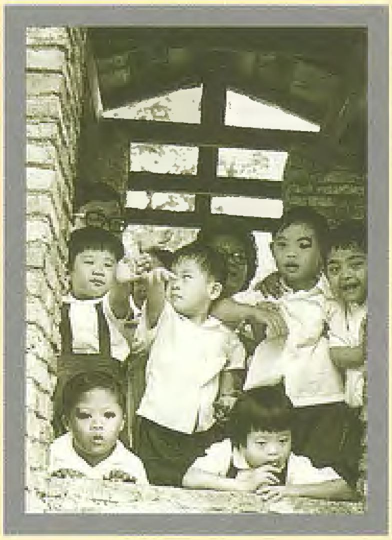
by **Teo Ginnyueh**

In December 1976, a United Nations resolution was passed proclaiming 1981 as the International Year of Disabled Persons (IYDP).

The theme of IYDP was 'full participation and equality' and called for action at the international, regional and national level to equalize opportunities, provide rehabilitation and prevent disabilities.

The Year hoped to promote the rights of persons with disabilities to:

- participate fully in their societies
- enjoy living standards similar to those of other citizens and
- have equal share in the improved living conditions resulting from socio-economic growth.



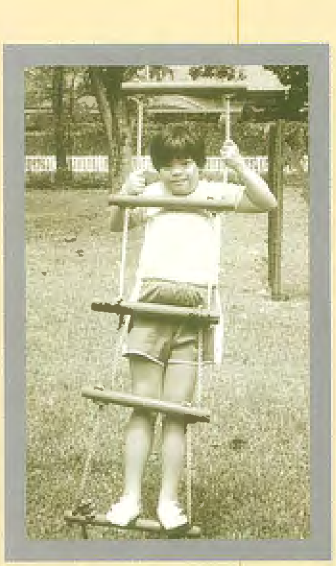
There were also aims to increase public awareness, promote understanding and acceptance of persons with disabilities and to encourage them to form organisations to advocate their needs.

Member States observed IYDP through various means like holding symposiums and conferences or establishing a National Committee to stimulate, publicise and co-ordinate efforts to increase national awareness of needs and aspirations of disabled persons.

For more information
www.un.org/esa/socdev/enable/disiydp.htm

Theory of Multiple Intelligences

by **Thana Thaver**



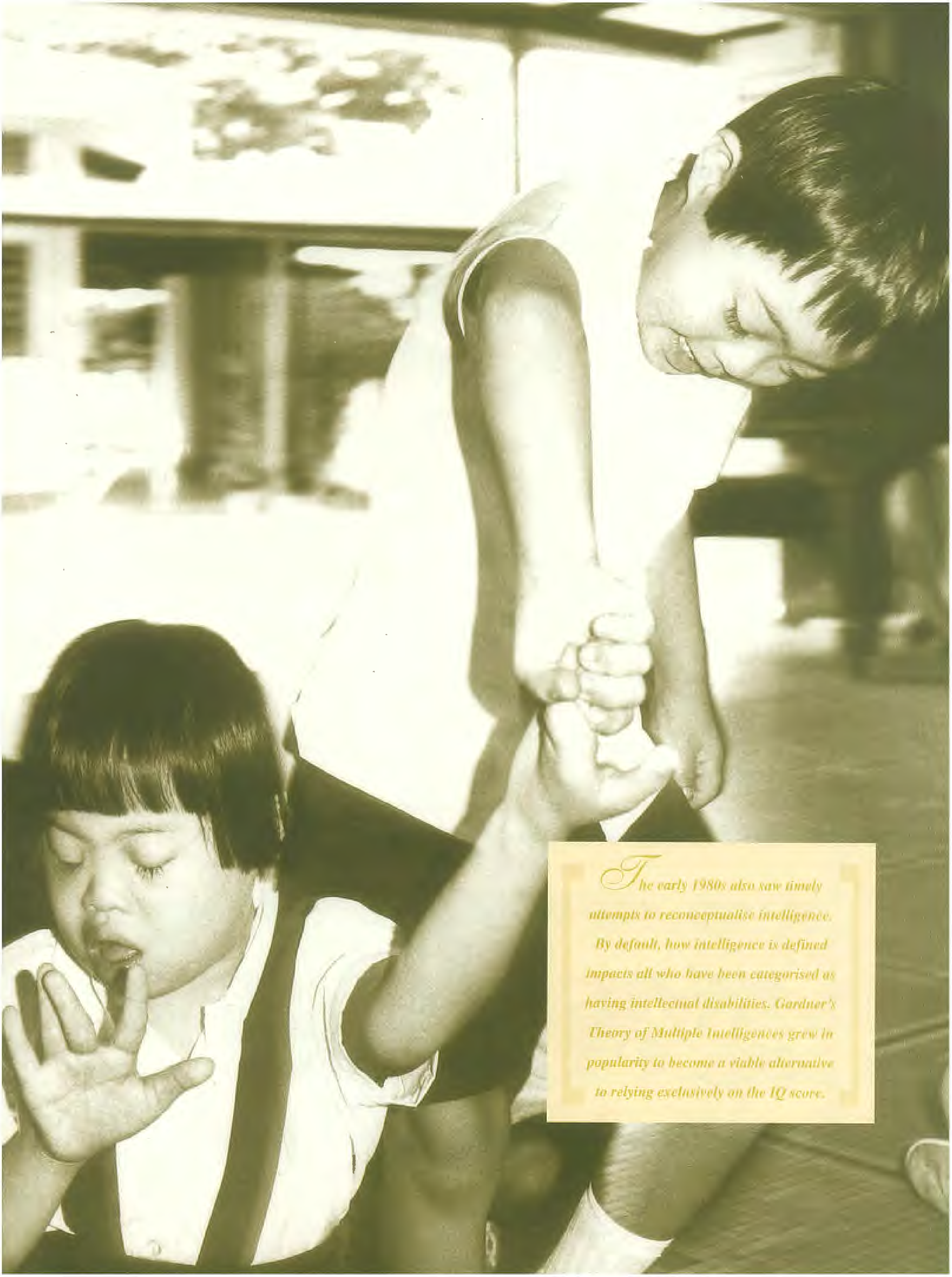
This theory of human intelligences, developed by Howard Gardner, suggests that there are at least seven intelligences. This view of intelligence differs from traditional conceptions which recognize only the verbal and logical-mathematical intelligences. Gardner identifies the seven intelligences as follows:

- Logical-mathematical — the ability to detect patterns, reason deductively and think logically.
- Linguistic — the ability to effectively manipulate language to express oneself and as a means to remember information.
- Spatial — the ability to manipulate and create mental images in order to solve problems.
- Musical — the ability to recognise and compose musical pitches, tones and rhythms.
- Bodily-Kinesthetic — the ability to use one's mental abilities to coordinate one's bodily movements.
- Interpersonal — the capacity for person-to-person communication and relationships.
- Intrapersonal — the ability to understand one's own feelings and motivations.

Although these intelligences are anatomically separated from one other, Gardner claims that these intelligences rarely operate independently. Every person possesses all the intelligences, albeit in varying degrees of strength, and they are used concurrently and complement one another.

For more information

www.funderstanding.com/multiple_intelligence.cfm
www.ed.gov/databases/ERIC_Digests/ed410226.html



The early 1980s also saw timely attempts to reconceptualise intelligence. By default, how intelligence is defined impacts all who have been categorised as having intellectual disabilities. Gardner's Theory of Multiple Intelligences grew in popularity to become a viable alternative to relying exclusively on the IQ score.

The First Shafts of Sunlight

Research on Mental Retardation

Freda Paul continued to conduct rigorous, world-class research on mental retardation. In Singapore, her contribution was recognised by her colleagues when she was presented the prestigious Haridas Gold medal in 1973 by the Singapore Paediatrics Society and the Society of Private Pratice[2]. Freda Paul's work also received international acclaim in the form of fellowships from the World Health Organization, Carnegie Foundation and Heinz[3]. For the first time, in 1982, the International Association for the Scientific Study of Mental Retardation gave four Distinguished Achievement Awards for 'research that has contributed significantly to combating mental deficiency throughout the world'[4]. Freda Paul was one of the four recipients.

Looking back years later, she said, 'Of course it's nice to do well in one's career. But to me, being in the field of medicine is about helping people. That's something I've tried to do even as I do my research. I will be most happy if my work means we are moving a little closer to realising that the intellectually disabled deserve a place in society like the rest of us'.

Adult Services

Both abroad and at home, service planning and development continued at a rapid pace. As the first graduates of our special schools reached adulthood, vocational rehabilitation and other adult services were given more importance.

In 1981, a Pre-Employment Vocational Training class was started at the AESN school site for 16-year-olds who had moved through the school programme. Similar developments at SARC reflected a change in the perception of adult programmes. Lee Chak Meng, an SARC parent volunteer, found that 'many parents were treating our centres like free babysitting services for their adult children. So we changed our ways of working at the training development centres. The clients are still cared for but it's a continuum of training that started in the special schools.' It was no longer acceptable to perceive adult services for intellectually disabled adults as purely custodial in the way that the Mental Defectives Ward at Woodbridge Hospital had been in the early days.

Vocational Rehabilitation

In keeping with these developments, in 1983, SCSS launched yet another pilot project — Singapore's first centralised Vocational Assessment and Placement Centre (VAPC) for disabled people. Funded from the start by HWA, the centre was divested to HWA a couple of years later. Clients were referred from over 15 agencies and a number of the clients were intellectually disabled. VAPC faced difficulties recruiting its multidisciplinary team. Once again, volunteers with the required expertise came forward. In fact, for months, the Singapore Association of Occupational Therapists provided a volunteer team of 12 to 14 occupational therapists.

The VAPC worked closely with referring agencies and brought together the job placement officers from these agencies. The placement officers met monthly at VAPC. They shared job leads. They articulated ideas about vocational rehabilitation in the Singapore context. They tried to professionalise job placement for their clientele, drawing on the standards of commercial placement and headhunting practices. A self-help Job Search Club and a social skills training programme provided work adjustment services that bridged the gap between assessment and placement. However, HWA found it difficult to

sustain the centre. VAPC was closed after a few years. But SCSS did not give up. Using the original VAPC testing equipment to start with, the services re-emerged as Bizlink. Bizlink survived.

More Special Schools

In 1983, SARC combined three Chin Pu Centres — the Geylang, Toa Payoh and Tampines centres — to form Towner Gardens School. Wong Soong Meng was its first principal. A parent volunteer for over a decade, Wong Soong Meng was a mainstream teacher. This was his opportunity to use his expertise for the good of intellectually disabled children.

Wong Soong Meng suggested calling the school *Gardens* because 'I wanted the children to love coming to this school, I wanted the teachers to enjoy teaching here and I wanted the parents to be happy sending their children to us'. Subsequently, all the SARC schools were named *gardens* as well.

As with the other special schools, Towner Gardens School was to occupy a former primary school building and premises. The place had been unused for months. Wong Soong Meng recalls, 'First we had to cut the *lallang*. Our families, our friends – they all helped us. We borrowed mowers and started cutting. It took us a week. We had 20 bags of cut grass. So we loaded them into two cars, drove to Tuas and deposited them at a large dumpster there.'

Next, they painted the building. They could only afford to paint walls up to a height of five feet. Windows were repaired and locks installed on doors. Volunteers helped with plumbing. A story that was all too familiar — doing whatever it took to make old buildings and premises safe and clean before disabled children arrived at their new schools. After a year, Chia Poh Hong took over as principal and is still at the helm.

The Integrated Education Programme

As for preschool children, most mainstream childcare centres and kindergartens hesitated to admit children with observable disabilities. One exception was the Chip Bee Child Care Centre at Holland Village. Started in 1977, Chip Bee was the Presbytarian Community Services' first child care centre. In 1988, the centre accepted a handful of children with special needs. They were mainly children with mild mental retardation. This practice continued. By the year 2000, the Presbyterian Community Services had ten child care centres and all accepted children with special needs as part of the organisation's Integrated Education Programme.

Centralised Fundraising

The year 1983 witnessed a major breakthrough in fundraising. The Singapore Council of Social Service launched its Community Chest. SCSS hoped that our non-profit sector would benefit immensely from a centralised fundraising mechanism. Member VWOs could concentrate on service provision and leave fundraising to the Community Chest. No more energy-sapping flag days, fun fairs and donation draws. Less flag days meant less donor fatigue. Flag days had become so frequent that stepping out of home on a Saturday morning meant facing an onslaught of volunteers at every turn.

While some agencies in other sectors declined the invitation to come on board, the VWOs serving children and adults with disabilities welcomed the reprieve. AESN, AWWA and SARC were amongst the earliest members. Freed from fund raising, these agencies could concentrate on expanding and professionalising services.

Evolving Identities

Meanwhile, the AWWA Playgroup for Multiply Handicapped Children had been in operation for nearly six years but still had no permanent premises. Then, in 1985, when Ramakrishna Mission put its building at Norris Road up for sale, AWWA bought it. The Playgroup finally had a home. It was renamed the Centre for Multiply Handicapped Children. Until that point, volunteers had run the programme. These volunteers included specialised professionals. Gradually, a staff team was recruited — a special education head teacher and a home visitor. In 1986, the programme was awarded the United Nations Community Excellence Award for an original project which benefited the whole community. The Centre grew into the current AWWA Special School.

As in AWWA's case, organisations reach points in their evolution when they decide they need organisational name changes. As far back as the 1970s, there were suggestions to change SARC's name because SARC sounded like *sa* which means 'stupid' in Hokkien dialect. Members did not want the word 'retarded' either, and the association had outgrown the reference to 'children' because it now served adults as well. Many suggestions were made. Finally, Robin Chua suggested Movement for the Intellectually Disabled (MINDS) and it was adopted in 1985. Robin Chua hoped that intellectually disabled people would soon be empowered to the extent that MINDS would have to alter its name to 'Movement *of* the Intellectually Disabled of Singapore'. With renewed enthusiasm, MINDS began recruiting its multidisciplinary team of specialised professionals. Within two years, physiotherapist Carola Pasari, occupational therapist Shanthi Ayinarappan and speech therapist Praemalatha Viswam came on board to be the first of their respective professions at MINDS.

A name change for AESN also took years of deliberation. Many were unhappy with the tag 'subnormal'. After studying numerous alternatives, AESN changed its name to APSN (the Association for Persons with Special Needs) in the year 2000. Such name changes reflect a desire to be sensitive to how an agency's name affects its members and clientele's image.

Seconded Mainstream Teachers

By the mid-1980s, there had been a small but steady stream of teachers who requested to move from mainstream schools to special education. What motivated them to do so? For Doreen Tan,

being invited to an AESN school's sports day did it. The event was her first encounter with the intellectually disabled. She was so moved by what she saw that she wanted to help them. It took a whole year to make the decision: she asked to be seconded. She was posted to AESN's Katong Special School and in no time, became its principal. Today, Doreen Tan is MOE's head of special education. And it all began with an invitation to a sports meet.

For some it was a more gradual process. In the 1970s, Fock Siew Lan was a music teacher at MOE's Extra Curricular Activities Centre. She worked with mainstream primary, secondary and junior college students. She helped to coordinate music and dance festivals, instrumental ensemble competitions and other exciting events. She was first awarded a Commonwealth Fellowship and later, a Colombo Plan Scholarship. Instead of resting on her laurels, she asked to work with special schools as well. MOE agreed. She started making weekly visits to special schools.

Fock Siew Lan's interest in special education grew. In 1982, she asked to be seconded to a MINDS school. 'It was not without a price that I made the decision to move over. I had to make big adjustments and change my paradigm to be able to work with intellectually disabled children and to be able to love, understand and communicate with them.' But Fock Siew Lan rose to the challenge and went on to set up and be the first principal of the Yio Chu Kang Gardens School four years later.

New Inexperienced Professionals

Unlike the seconded mainstream teachers, the majority of the staff at both the schools and centers came on board with limited teaching experience. Most had no prior experience of individuals with intellectual disability either. For some, it was their first job and they came fresh from school. Take Samsiah Menasrah, for example. During her student days in secondary school, her principal would talk about children with disabilities at every opportunity. In fact, he talked so much about them that after she completed pre-university, she applied for a job at SARC and was successful.

Samsiah Menasrah started teaching at the Jurong Centre, above a coffee shop in a block of flats. 'But my first day at work, I was terrified because I didn't know anything about teaching. I was fresh from pre-university.' Unlike mainstream teachers who received training before they started teaching, the special education teachers were sponsored for formal teacher training only after they started teaching at special schools. Fortunately, Samsiah Menasrah had a caring mentor in colleague Shafiyah Ahmad Sarwan. She soon began to

enjoy her work and even looked for new challenges. For instance, years later, she entered MINDS' 40th Anniversary Logo Designing Competition. Samsiah Menasrah's design won and in 2002, was launched as the new MINDS logo.

Learning on the Job

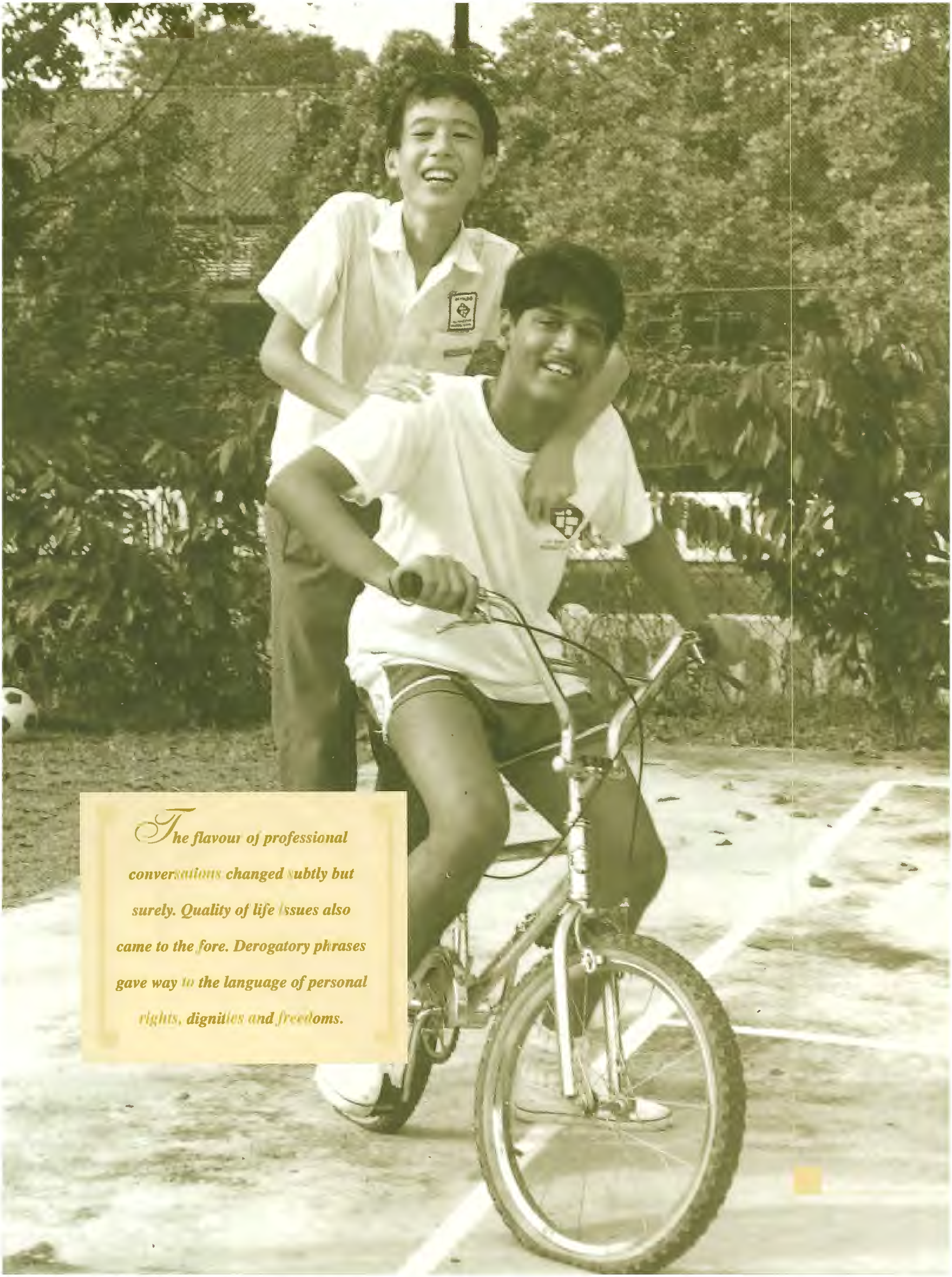
Like Samsiah Menasrah, every year there are others who step into special schools and workshops although they know they have neither the skills nor knowledge yet. For many, it is a calling. For some, it all boils down to a monthly paycheck. Whatever their reasons for joining, that first month or two can indeed be traumatic. Their more experienced colleagues, having been there themselves, are often willing to give whatever guidance and emotional support they can. And when they, in turn, reminisce about their early years in this sector, they fondly recall colleagues who inspired and encouraged them at every turn. The list of mentors runs long. Thanks to them, many of the novice professionals survived their early experiences at work.

In-service Training

Meanwhile, the need for local training for special education professionals grew. In 1982, the VWOs that served people with disabilities met with Dr Tay Eng Soon, the Senior Minister of State for Education, to discuss training for the teachers. Tay Eng Soon supported the request. As a result, the Certificate in Special Education (CISE) was launched by the Institute of Education[5]. Dr Lau Wai Har, the IE principal, also shared her expertise directly with AESN special schools by helping with curriculum development. The Diploma in Special Education (DISE) programme followed after some years. Dr Quah May Ling, head[6] of special education, worked with her team of teacher educators to develop and improve the CISE and DISE programmes over the next two decades. Says Quah May Ling, 'The future of special education depends on the teachers. You can have curricular reforms, impressive purpose-built buildings and wonderful resources but none of these matter as much as the teacher does. Good teacher preparation is a must.' Still at NIE, a facility primarily for mainstream teacher education, Quah May Ling continues to champion the cause of the special educator.

Strengthening Programmes

The government continued to support programmes for disabled people, either directly co-funding them or indirectly by strengthening infrastructure. In the early 1980s, the Ministry of Social Affairs[7] (MSA) held a well-attended seminar to construct a national definition of disability. MSA also conducted national surveys[8] for data that could facilitate planning. In 1988, the Advisory Council on the Disabled was set up. The Advisory Council made recommendations that would bring about better coordination amongst services and agencies. Often working in partnership with both the government and the VWOs, SCSS also directly supported programmes for



The flavour of professional conversations changed subtly but surely. Quality of life issues also came to the fore. Derogatory phrases gave way to the language of personal rights, dignities and freedoms.

disabled people through funding, service planning and development support. For instance, in 1988, SCSS drew up a five-year rehabilitation plan for the people with disabilities. In addition more than any other organisation, SCSS played a lead role in launching pilot projects in this sector.

Also in 1988, the existing Board of Special Education was replaced by the Coordinating Committee for Special Education (CCSE), established under MOE. From that year, the government gave a capitation grant for special education. The grant was calculated based on the cost of schooling a child for a year in a mainstream primary school. The capitation grant allowed for twice that amount per child per year in special education. This was a major development for special education in Singapore. In 1990, the capitation grant was increased to four times the cost of schooling a primary school child.

Early Intervention

Some parents and professionals knew that services for children with intellectual disabilities should start early. Dr Balbir Singh, a parent volunteer on the SARC executive committee, was one of them. His daughter was already in a home-based training programme being piloted by SCSS. Balbir Singh visited early intervention programmes in Australia before developing a proposal for early intervention by SARC. The proposal found strong advocates in Wong Soong Meng, Victor Seah and others. However, there was also resistance from some committee members. They questioned the wisdom of training infants. After much lobbying, SARC launched the Early Intervention Programme for Infants and Young Children (EIPIC). Entering the relatively unfamiliar territory of early intervention was not easy. Undaunted, the committee — chaired, in turn, by Balbir Singh, David Oon and Kenneth Lyen — worked with professional staff and developed an early intervention curriculum.

Other parents were concerned about children being on waiting lists for long periods before gaining admission to special schools. They too, knew that the earlier the intervention, the more likely that these children would benefit. Alice Shae was one such parent. She formed a church-based committee and in 1983, the Christian Outreach to the Handicapped[9] set up its Emmanuel Special Children's Centre. This centre helped to bridge the gap for children on special schools' waiting lists.

Soon after, SCSS conducted a needs assessment study that found more than 150 children with multiple disabilities not receiving any services. SCSS piloted the Programme for Children with Multiple Handicaps (PCMH) for these children. Margaret Drive Special School was set up in 1987 to deliver the PCMH. In addition, the school took over EIPIC from MINDS. Victor Seah and Kenneth Lyen continued to volunteer their expertise there. In 1989, June Tham came on board as the school's principal. June Tham brought to the table a wealth of experience as an education professional in management. She had been the executive director of AESN and, prior to that, had over ten years of mainstream teaching experience.

Differentiating between Austism and Intellectual Disabilitiy

Soon after, Margaret Drive Special School identified another group of unserved children — children with autism. In the 1960s and 70s, children with autism were invariably mixed with children with intellectual disabilities. Experts estimated that about 50 to 60% of children with autism were intellectually disabled as well[10]. Even for these children, their needs were not adequately met in special classes for intellectually disabled children taught by teachers with no training in working with autistic children. Worse than that, for autistic children who had no intellectual disability. Some of these autistic children were very intelligent children. For these children, placement in special classes for intellectually disabled children was not appropriate at all. Therefore, Margaret Drive Special School tapped on the expertise of Dr Vera Bernard-Opitz at the National University of Singapore and with her guidance, started a structured teaching programme for children with autism.

Children's Homes

In the late 1980s, the government started divesting its six Homes for Children and Young Persons to VWOs to manage[11]. This was in line with its intention to channel ministry resources to planning and policy making at the macro level. Thye Hua Kwan Moral Society was one of the agencies that was willing to start a children's home. The Moral Society's chairman, Lee Kim Siang, was told that there were over 20 intellectually disabled children. The Society agreed to set up a home for these children.

The Thye Hua Kwan Moral Society's decision was welcomed by social workers and others who had been concerned about intellectually disabled youth living in the same homes as juvenile delinquents. In the past, there were attempts to help these intellectually disabled youth. For instance, Linda Auyong, a MINDS social worker, initiated Programme Alpha, where volunteers helped to conduct a social skills training programme for the intellectually disabled teens at one of the Boys' Homes. The programme included learning to use public transport. Linda Auyong recalls, 'The training was so successful that the boys ran away from the Home and then we had to deal with that!' Thus, many were optimistic that a separate residential programme like the Moral Home would enable their needs to be met better.

The Moral Home for the Disabled was opened with about 30 intellectually disabled children as its first residents in 1989. The Moral Society had renovated and moved into one of the former government homes. Running a residential programme for this group posed unique challenges. Staff members had to make sure that children on

medication for epilepsy and other conditions were given their medicines on schedule. When children woke up at night, staff members tried to be there for them. The children had to be ready and waiting in line when the school buses arrived. And then the staff made sure the children got onto the buses safely. Lee Kim Siang explained, 'Running a children's home is like running a huge extended family. It's a 24-hour service. It's just like an ordinary household except that it's on a much larger scale.'

The Moral Home tried to teach responsibility and compassion. The children were encouraged to consider themselves brothers and sisters. There was a buddy system where older children were expected to care for the younger ones. All are credited with the responsibility of reminding each other to behave in acceptable ways. They were also taught to extend kindness to animals. There were rabbits which the children loved to cuddle. Stray animals sometimes wandered in and were made to feel so welcome that they stayed: dogs, cats and, once, even a beautiful cockerel. The only complaint that the Home received from its neighbours was when that cockerel started crowing loudly the next morning.

Life As It Should Be

Thus, the 1980s witnessed the coming out of children and adults with intellectual disabilities. Parents now wished to play a greater role in planning and decision-making. And to support each other in more formalised ways. Perhaps reflecting the optimism of the 1980s, the first parent group called itself HOPE (Helping Our Parents Emerge).

Ubi Hostel, a hostel for adults with disabilities, was piloted by NCSS in 1988. A community-based residential facility, intellectually disabled adults at the hostel soon became a part of the neighbourhood as they frequented the hawker stalls and other shops there. The hostel was transferred to Touch Community Services a few years later. Today, Touch Ubi Hostel is one of two centres that form TOUCH S.Com. The other is the Touch Centre for Independent Living, at a neighbouring public housing block at Ubi.

Not all members of the larger society were comfortable sharing public spaces with groups of intellectually disabled children on class excursions, with families taking their intellectually disabled members to restaurants and theatres or with intellectually disabled youth and adults hanging out together. A common excuse was that they were at times loud and boisterous. Such sentiments are prevalent even today. The truth, however, may be that some people would rather not be reminded that intellectually disabled persons are legitimate members of our society. How very like that neighbour complaining about the cockerel crowing at the Moral Home for the Disabled. How unreasonable when, after all, a cockerel crowing to greet the morning sun is part of life as it should be.

Endnotes

[1] Gardner, Howard (1993). *Frames of mind: The theory of multiple intelligences: Tenth anniversary edition*. New York: Basic Books. (Original work published 1983.)

[2] Paul, Freda (1974). *A survey of mental subnormality in Singapore children*. The Sixth Haridas Memorial Lecture. Singapore: Singapore Paediatric Society and the Society of Private Practice.

[3] Chua Chong Jin (1997, January). A tortoise on his back. *The Alumnus*, Jan 1997, 50-51.

[4] Ng, Evelyn (1982, September 15). *Doctor wins award for research on mentally retarded children*. The Straits Times. Singapore.

[5] The Teachers Training College (TTC) became the Institute of Education (IE) in 1970. In 1991, IE became the National Institute of Education (NIE) of the Nanyang Technological University.

[6] The department of Special Education at IE was combined with the Early Childhood Education Department to form the division of Specialised Education at NIE. After recent restructuring, the division is now the Specialised Education Academic Group.

[7] The Ministry of Social Affairs transferred its functions to the Ministry of Community Development (MCD) in 1985. MCD was renamed Ministry of Community Development and Sports in 2000.

[8] For example, a national survey on the employability of adults with disability.

[9] Christian Outreach to the Handicapped became an independent society and charitable organisation in 1987. See www.coh.org.sg/about_coh.htm

[10] Lam Chee Meng (2002). Personal communication. Singapore.

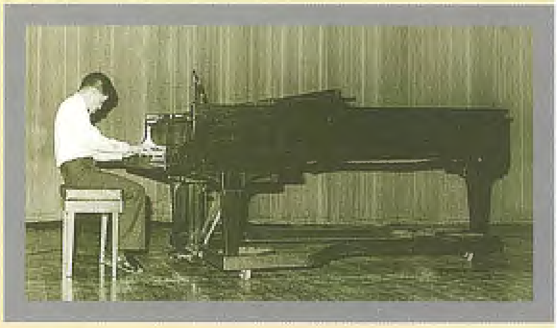
[11] Thye Hua Kwan Moral Society (2001). *The many helping hands*. Singapore.

Autistic Spectrum Disorder

by **Ong Liang Cheak**

Autism is often referred to as a 'spectrum disorder' meaning that the symptoms and characteristics of autism can present themselves in a variety of combinations, ranging from extremely mild to quite severe. ASD is intended to include the entire spectrum of autistic disorders.

ASD onset occurs typically before the age of three, and is four times more prevalent in boys than girls. Much research indicates the cause of ASD to be due to a complex combination of familial genetic factors and a disorder of neurological development.



ASD is characterised by the following impairments in the following areas: social interaction, communication, behaviour and sensory perceptual processing. Associated impairments include seizures and discontinuities in developmental rates.

Deficits in social interaction affect the ASD child's ability to form meaningful relationships. There is often poor eye contact, difficulty with the give and take of social relatedness, and an apparent aversion to physical contact. Common communication deficits include speech being repetitive or echolalic in nature. Other types of speech and language problems include difficulties with syntax and a lack of expression and emotion during communication. Impairments in behaviour are seen in the intolerance of slight deviations from routine, resistance to any type of change, and patterns of behaviour that are stereotyped (e.g. wiggling and flicking of fingers), repetitive, and lacking in pretend play. Disturbances of sensory processing and perception include abnormal and inconsistent responses to various visual, vestibular, and auditory stimuli; thus inhibiting the cognitive development of the child.

Treatment approaches: It is estimated that there are more than 400 treatment options for autism. To name some, they are: Occupational Therapy, Behaviour Modification, Medications, Augmentive/Alternative Communication, Play Therapy, Speech and Language Therapy.

For more information

Rogers et al. (2002). Common diagnosis in pediatric occupational therapy practice. In J. Case-Smith, (Ed.). *Occupational therapy for children*. (4th ed.) (pp 136-189). Toronto: Mosby.

Trevarthen et al. (1996). *Children with Autism: Diagnosis and interventions to meet their needs*. Pennysylvania: Jessica Kingsley Publishers.

www.geocities.com/Heartland/Fields/6979/autigen2.html

Listening and Learning from Insider Persectives

by **Levan Lim**

Listening to the personal stories and perspectives of persons with disabilities can open up new avenues for understanding and relating to disability. Take the example of Temple Grandin, a university professor based in the United States who has autism. She had the classic autistic features when she was a young child, but later developed fluent speech. Growing up, she was fixated on sliding doors and cattle squeeze chutes. Temple Grandin's recollection of how one of her schoolteachers dealt with her special interests (Grandin, 1990) is a powerful lesson and reminder that a creative response to work with the abilities and interests of persons with disabilities is necessary. Her teacher, Mr Carlock, capitalized on her fixation with cattle squeeze chutes to motivate her to study science, which eventually became the basis for a lifelong career in livestock science. Today, Temple Grandin travels all over the world designing stockyards and chutes for major meat-packing firms. She is a leader in her field, having written over a hundred articles on livestock handling. On the contrary, the psychologists and counselors she saw sought to get rid of her weird interests. Temple states that if they had succeeded, '... maybe I would be vegetating somewhere watching soap operas'.

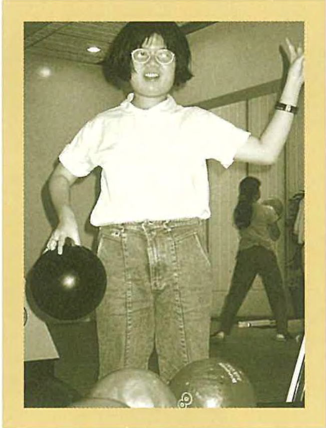
My work with persons with intellectual disabilities has also taught me the importance of listening not just to words but also to the underlying message conveyed by behaviours of persons with disabilities, especially for persons who are not able to verbalise their thoughts and feelings. I remember, in particular, a man with Down syndrome who had spent many years in an institution. After coming out to the community, he was sent to a work environment that offered him limited work options as well as limited opportunities to interact with people in the community. Being quite a sociable person, he became increasingly dissatisfied with his work arrangements, which was evident in his worsening behaviours. Fortunately, the staff at his work centre listened carefully to the underlying message (which was 'I am not happy here'), reflected on his abilities and interests, and planned and crafted a desirable work experience that honoured who he was and what he liked. His 'problem behaviours' subsequently became much less of an issue.

For more information

Grandin, T. (1990). Needs of high functioning teenagers and adults with autism (tips from a recovered addict). *Focus on Autistic Behavior*, 5, 1-15.

Then the Morning Sun Arose

Morning Sun



The 1980s benefited from being the International Decade of Disabled Persons. The first shafts of light pierced through during that decade. Then the morning sun finally arose, heralding in the last decade of the 20th Century. In 1992, the United Nations declared an International Day of Disabled Persons — on the 3rd of December every year. In 1994, the World Conference on Special Needs, organised by the Government of Spain and UNESCO, resulted in the Salamanca Agreement and the Framework for Action on Special Needs Education[1]. All over the world, advocates for inclusion rejoiced.

Here in Singapore, the Salamanca Agreement did not cause much of a stir. Special schools and centres continued to be set up by voluntary welfare organisations (VWOs) with support from government and the public.

Singapore celebrated her 25th Anniversary of Independence in 1990. A 25th Anniversary Fund was launched. For the voluntary welfare organisations, this meant there was one more source of funding. The Community Chest of the National Council of Social Service[2] (NCSS) continued to raise a substantial amount of money each year and programmes for disabled people received the largest slice of that pie. By now, the government subsidised 90% of VWO's capital expenditure, 90% of VWO's cyclical maintenance and facility repair costs and continued to pay 50% of VWO's recurrent expenditure.[3]

By the mid-1990s, a new player entered the non-profit arena — community development councils (CDCs). For the first time, Singaporeans had mayors and a semblance of local government. VWOs were pleasantly surprised to find that they could turn to CDCs for support in a variety of ways. CDCs were helpful in channeling resources and proved to be dependable partners in programme planning and development.

Then the Morning Sun Arose

The International Day of Disabled Persons

by **Tiang Voon Cheng**

'3 December every year' is the date declared by the United Nations General Assembly in 1992 as the **International Day of Disabled Persons.**

The objective is three-fold:

- to commemorate the anniversary of the General Assembly's adoption of the World Programme of Action regarding Persons with Disabilities
- to promote the understanding of disability issues; and
- to increase the awareness of benefits that stem from the integration of disabled persons in every aspect of political, social-economic, and cultural life, which should also comprise the monitoring of various implementation of proposals.

The International Day of Disabled Persons offers a platform for a tripartite relationship between governments, agencies of persons with disabilities, and everyone in society.

Prior pertinent proclamations that led to this designated day were the International Year of Disabled Persons (1981), and the International Decade of Disabled Persons (1983-1992).

For more information
The Division for Social Policy and Development, United Nations
2 United Nations Plaza
New York, NY 10017, USA
Fax: 1 (212) 963-3062
www.un.org

The Salamanca Statement

by **Levan Lim**

In June 1994, more than 300 participants representing 92 governments and 25 international organisations attended a World Conference on Special Needs organised by the Government of Spain and UNESCO, held in Salamanca, Spain. The delegates agreed upon a dynamic new Statement calling for the inclusive education of all children with disabilities within regular school communities to be the norm in the international community. This statement begins with the delegates reaffirming a commitment to providing education for children, youth and adults with special educational needs within the regular education system. The delegates of the conference declared that:

- Every child has the fundamental right to education, and must be given the opportunity to achieve and maintain an acceptable level of learning,
- Every child has unique characteristics, interests, abilities and learning needs,
- Education systems should be designed and educational programmes implemented to take into account the wide diversity of these characteristics and needs,
- Those with special educational needs must have access to regular schools which should accommodate them within a child-centered pedagogy capable of meeting these needs,
- Regular schools with this inclusive orientation are the most effective means of combating discriminatory attitudes, creating welcoming communities, building an inclusive society and achieving education for all; moreover, they provide an effective education to the majority of children and improve the efficiency and ultimately the cost-effectiveness of the entire education system.

In addition, the conference adopted a 'Framework for Action on Special Needs Education' to inform policy and guide actions by governments, international organisations, national aid agencies, non-governmental organisations and other bodies implementing the Salamanca Statement.

The Salamanca Statement and Framework for Action on Special Needs Education can be obtained from UNESCO, Special Education Programme, 7 Place de Fontenoy 75352, PARIS 07-SP.

For more infomation

www.unesco.org/education/educprog/sne/salamanc/index.htm

Then the Morning Sun Arose

Staffing Multidisciplinary Teams

The 1990s saw heightened awareness of the need for specialised professionals as service providers. The larger agencies had full-time positions for multidisciplinary teams of teachers, psychologists, social workers, occupational and physiotherapists, music therapists and speech and language specialists. Organisations such as the Singapore Psychological Society developed more discerning membership requirements. The Singapore Association of Social Workers sought to educate the public about the differences between professional social workers and volunteers. Occupational therapists and physiotherapists tried to clarify how each was a unique profession. The professional associations urged the VWOs to employ only qualified professionals to fill the positions meant for them. But with such an acute shortage of all these professionals, the VWOs frequently had to compete with hospitals and each other for them. It was a challenge to recruit and retain qualified professionals.

For one, opportunities to train locally were still limited and going abroad was not a feasible route for many. For those who wished to become social workers or psychologists, there was the Department of Social Work and Psychology at the National University of Singapore. Special education teachers continued to be sent for the CISE and DISE programmes at the National Institute of Education. In 1992, Nanyang Polytechnic started diploma programmes in occupational therapy and physiotherapy. To become a speech and language therapist, music therapist and so on, individuals still had to go abroad.

Then the Morning

One solution to the shortage of professionals was to offer scholarships. NCSS led the way once again, with scholarships for the specialised professionals who would then serve their bonds at member organisations. Programmes for disabled children and adults benefited from this arrangement even if the scholars left when their bonds were over. A few, like Sivaraj Mahaindra, stayed on. Sivaraj Mahaindra was an NCSS scholar in occupational therapy: 'I was posted here. After a while, I enjoyed it and liked the challenge. I am encouraged by the management to explore new and progressive ideas.' He became manager of the MINDS Employment Development and Training Service and worked hard at keeping his team of professionals and clients as motivated as he was.

New Organisations

Meanwhile, Margaret Drive Special School flourished as a pilot project of NCSS and was soon ready to stand on its own feet. In 1992, the Rainbow Centre was formed as its parent organisation. The school functioned at full capacity but waiting lists remained. And so, in 1995, Rainbow Centre launched its second school, the Balestier Special School.

Rainbow Centre had a parent training programme and two parent support groups — one for parents of children with Autism and the other for parents of children with Down syndrome. These grew to eventually become the Autistic Association of Singapore and the Down Syndrome Association respectively. Balbir Singh, founder chairman

of the Down Syndrome Association, pointed out, 'We make assumptions about what people with Down syndrome can do but, most of the time, we really don't know. There have been adults with Down syndrome in America who have entered universities.' Thus, the Down Syndrome Association resolved to move forward with unfettered thinking.

Purpose-built Buildings

The year 1995 was also a landmark year for school buildings. That year, the Ministry of Education approved, for the first time, plans for two purpose-built schools, the MINDS Towner Gardens School and Rainbow Centre's Margaret Drive Special School. Both organisations were elated. Towner Gardens moved into its new building in 1997 and Margaret Drive in 1998.

Why was a purpose-built building a dream come true? Standing on the outside, it may seem as though the main attraction would be the attractive architecture with state-of-the-art facilities (in contrast to some of the dilapidated, flood-prone buildings that special schools had moved into in the past). But special schools' resistance to a hermit crab lifestyle had less to do with the condition of the shell and more to do with the fact that some special schools could not squeeze into the run-of-the-mill mainstream school building. Only a hermit crab can fit into a shell that has been vacated by another hermit crab. Other varieties of crabs have to grow their own shells. And in the case of special schools that serve very diverse clientele groups, a carefully planned facility gives the programmes the best spaces possible for miracles to take place.

Special Features of Purpose-built Buildings

These purpose-built special schools have some certain features that make a difference in the quality of life within the schools: ramps for wheelchair users; rooms with attached toilets and bathrooms that permit teachers to supervise all children more effectively and enable more efficient toilet training; a hydrotherapy pool. There may also be extraordinary features such as Rainbow Centre's Snozelen. Snozelen is a multisensory room — lights, sounds and surfaces to feel — that helps teachers reach out to and connect with children. Rainbow Centre decided to have a Snozelen because there was compelling evidence emerging from schools in England that Snozelen could be very effective for children with severe intellectual disability, children with severe autism, and with multiple disabilities. Since then, the staff of Rainbow Centre have rich stories to tell about breakthroughs with children, some of whom have not responded to any other approach.

> *Lee Kim Siang comments,*
> *'In the old days, we didn't talk about things like this. It was all bread-and-butter issues ...*
> *Now we can talk about purpose-built facilities. I am glad we have come so far.'*

Residential Programmes

As it became less feasible for extended families to care for intellectually disabled adults, their ageing parents knocked on many doors for help. In 1997, the Thye Hua Kwan Moral Society opened two Homes — the Moral Home for Disabled Adults and Moral Welfare Home. The Home for Disabled Adults has a purpose-built building conducive to therapy programmes, and art, music and dance classes. Lee Kim Siang comments, 'In the old days, we didn't talk about things like this. It was all bread-and-butter issues. All over Singapore, it was a matter of survival — strengthening the economy, building public housing estates, making sure there were enough mainstream schools. Now we can talk about purpose-built facilities. I am glad we have come so far.'

There was a rush of applications — over 400 hundred — for the Moral Home for Disabled Adults but only 102 could be accepted. As for the Moral Welfare Home, it was meant to be one of four replacement homes. These *replacement homes*

Then the Morning

were so named because they were to replace the government's Woodlands Home for the Aged. Woodlands Home, which housed about 700 destitutes, had to be closed to make way for urban redevelopment[4]. As a *replacement home* with limited capacity, the Moral Welfare Home could accommodate 150 of the former Woodlands Home residents[5]. Government identified Thye Hua Kwan Moral Society as the agency to provide a home for those residents with disabilities while the rest went to the other three replacement homes. Amongst these disabled persons were many with intellectually disability. The Moral Welfare Home and the Moral Home for Disabled Adults developed a wide variety of activities for the residents. And a strong core of volunteers, many of whom were from the neighbourhood communities of these Homes.

The demand for adult residential facilities led to other organisations setting up homes over the next few years: the Bishan Home for the Intellectually Disabled in 1998; the Metta Home for the Intellectually Disabled in 2000 and the Blue Cross Thong Kheng Home for the Intellectually Disabled in 2002.

Day Activity Centres

While the need for residential facilities remained, day activity centers (DAC) became the new ideal for adults with intellectual disabilities. In 1990, SUNDAC Center for the Disabled became the first DAC to be located in a void deck. Others followed at its heel: including two MINDS DACs in 1992 and 1994, Metta DAC in 1995 and Blue Cross Thong Kheng DAC in 2002. Not only did DACs enable intellectually disabled adults to live with their own families, they also brought these adults out into public view.

Participation in Sports

Over the years, Singapore continued to send teams to Special Olympics. At first, an AESN-SARC committee was in charge. In 1991, Special Olympics Singapore was established as an independent association with Robin Chua at the helm.

In 1995, there were 7,000 athletes from 143 nations competing in New Haven, Connecticut, USA. That year, Singapore bagged seven gold medals, four silvers and nine bronzes with 12-year-old Siti Salfarina Salleh winning both a gold and a bronze[6]. When they returned, the celebrations continued: President Ong Teng Cheong invited the 16-member team and their families to the Istana for a tea party.

Chia Poh Hong is currently the honorary secretary of Special Olympics Singapore. She has no doubts about the value of participation: 'All these years that I have been involved, I have found that every individual we have taken for overseas participation has benefited greatly. They communicate with more confidence. Their self esteem improves. I really believe that every one of them is better off.'

Arose

For over 20 years now, the Singapore Sports Council for the Disabled had played a key role in sustaining involvement in competitive sports. Then, in 1998, the Sports Council entered a new league. For the first time, a person with a disability — athlete Frankie Thanapal Sinniah — became its president. Another giant leap forward for the empowerment of persons with disabilities.

Volunteer Management

The early volunteers were parents and professionals who came into contact with intellectually disabled people in the course of their work. By the 1990s, volunteer recruitment was done far more strategically. The NCSS Volunteer Action and Development Centre (VADC) encouraged better volunteer management. The VADC organised island-wide recruitment drives. Jeffrey Tan responded in 1990 by calling a VADC hotline. He indicated that he would like to work with youth but he did not expect to be placed with intellectually disabled youth. 'I was shocked. Five of us

turned up for the briefing about MINDS and we were asked to turn up the following Sunday for activities with MINDS youth. The next week, the other four were nowhere to be seen. So I felt I had to stay on.'

Jeffrey Tan not only stayed on, he took on greater responsibilities each year and is currently MINDS' honorary treasurer and supervisor of the school management committee. Incidentally, Tay Tiong Beng, who has been involved with the MINDS Youth Group since 1973, is now the MINDS honorary secretary.

Very Special Arts

While Doreen Tan was principal of AESN's Katong School, NCSS sent her to an arts festival in Taiwan to explore arts for the disabled in Singapore. The trip resulted in Very Special Arts (VSA) Singapore being launched in 1993. Its resourceful project director, Lim Lin Da, worked with a dynamic committee to organise a stream of arts-related learning and development programmes and events for disabled individuals.

VSA introduced *Saori* weaving to the special schools and it soon became a staple in the arts programme here. *Saori* weaving was developed in the 1960s by Misao Jo, a Japanese homemaker. Her son, Kenzo Jo, founded Very Special Arts (VSA) Japan in 1988 and since then, Misao Jo has taught the *Saori* technique to special education teachers and disabled people from VSA branches around the world. The art form was popular because it helped build confidence and independence, important goals in special education.

Public Education

The 1990s also saw large-scale public education programmes. NCSS and VWOs launched campaigns and special events. VWOs also produced publications to educate readers about children with disabilities. For instance, AWWA published *Three Special Friends*[7] and *Hey Listen: We Have Something to Say*[8], a collection of stories by the TEACH ME children. Rainbow Centre published *Rainbow Dreams*[9], and MINDS published *Intellectual Disabilities: Issues and Challenges*[10].

Interestingly enough, some of the public education was aimed at helping doctors communicate better with intellectually disabled patients. This reflected concerns that doctors in some specialisations had little contact with intellectually disabled individuals and may then be inexperienced in treating illnesses when they occur in these patients, unlike the paediatricians and rehabilitation doctors who helped start services for intellectually disabled children and adults and advocated on their behalf for decades. In the worst case scenario, the disabled person may have a chronic illness that goes undiagnosed or inadequately treated. Thus, at the 1996 Asia-Pacific Down Syndrome Conference, a plenary session focused on the need for doctors to learn more about disability medicine.

At the same time, experienced doctors continued to volunteer tirelessly to advocate for and represent the interests of intellectually disabled persons here and abroad. The profession had a stellar role model in Professor Lee Eng Hin, Dean of the NUS Faculty of Medicine. Over the years, Lee Eng Hin served on numerous government, NCSS and VWO committees that piloted services for children with disabilities. In the international arena, he contributed to the work of Rehabilitation International (RI) as a resource person and the Singapore representative on RI's Medical Commission[11].

Professionalisation of the Sector

To reach excellence in programming, agencies now conducted strategic planning sessions involving staff and volunteers. Reviews, refinement and standardisation of curriculum and assessments were becoming routine.

At the sector level, VWOs felt they should become more professional. Committee members and staff in management worked together to improve board leadership and agency governance. VWOs strove to

develop corporate images that would enhance their direct service as well as advocacy efforts. All this was in synchrony with what was happening in Singapore as a whole. As a country, she had emerged from the turbulent, survival-focused years of the 1950s and 60s, steadied herself during the 70s and 80s and now, could afford to reach for the higher-order ideals of nationhood. 'Excellence' was the buzzword of the 90s. Bathed by the morning sun, excellence did not seem impossible that decade.

The Significance of the Morning Sun

Why do we differentiate the *morning sun* from the *evening sun* when we know that it is one and the same? To many of us in Singapore, the perceived difference is real and significant. The air feels cleaner, cooler, crisper at sunrise. By midday, the sun can be relentless, sapping energy from all that was so alive just a few hours ago. By late afternoon on a hot day, the air is heavy with heat and dust of urban activity. Nothing quite compares with the morning sun. The 1990s was the decade of the morning sun. All that happened in the 1990s left us assured that the future augurs well for children and adults with special needs.

Endnotes

[1] See window on 'Salamanca Agreement' for details.

[2] SCSS changed its name to NCSS in 1992.

[3] Ministry of Information and Arts (1996). *Sharing success. Government programmes: 1990-1995*. Singapore.

[4] Wee, Lawrence (2002). Personal communication. Singapore.

[5] Thye Hua Kwan Moral Society (2001). *The many helping hands*. Singapore.

[6] The Straits Times (1995, 19 July). *Doing Singapore proud*. Singapore.

[7] Written by Leaena Tambyah & Kathleen Chia, illustrated by Hiroko Miyamoto. Published in 2000 by AWWA.

[8] Edited by Leaena Tambyah, published in 2001 by AWWA.

[9] Edited by June Tham & Kenneth Lyen, 1st published by Rainbow Centre in 1997, reprinted in 1999, 2nd edition launched in 2002.

[10] Edited by Rosaleen Ow, published in 1990 by MINDS.

[11] Lee Eng Hin was a resource person for the Asia Pacific Region in 1992 and from 1995 onwards, has been the Singapore Representative to RI's International Medical Commission.


Special Olympics
SINGAPORE

L’arche Communities

by **Levan Lim**

Founded by Jean Vanier, L’arche is an international confederation of communities around the world that intentionally seek to include and welcome people with disabilities. Long before the word ‘relationships’ became a significant term in the field of disability, L’arche’s philosophy emphasised the importance of relationships as the primary foundation of its community belief and practice in welcoming people with disabilities.

Jean Vanier began L’arche in 1964 when he welcomed two men with intellectual disabilities to live with him. For the past 38 years, L’arche has grown to over 120 communities around the world. In these communities, people with and without disabilities live together in friendship and mutual relationships. L’arche’s basic belief is that, through relationships, people with and without disabilities can become more whole and peaceful, grow humanly together and know the love of God. Many people without disabilities who go to live in L’arche communities (they are known as assistants in the communities) become transformed in their hearts and minds to become men and women of peace. These assistants learn to value the ‘hidden’ gifts of people with disabilities in teaching them about themselves, relationships, community and spiritual values.

Jean Vanier’s hope and vision for L’arche communities is to be witnesses of peace in a world that is rife with violence, unrest and war. Recently, Jean Vanier wrote that the objective of L’arche communities is to be ‘schools of relationships’ where love, peace, life and wisdom can blossom and grow:

> “Many schools exist which help people develop their intellectual capacities, ... But there are not many ‘schools of the heart’ ‘schools of compassion’, ‘schools of relationship’ which help people open up to those who are different and to understand them”. (Vanier, 2002).

By: Vanier, J. (2002). *Letter written to L’arche communities after the General Assembly Meeting in Swanick.*

For more information

www.larchecanada.org
www.larchecapebreton.com/larche.php
www.larchewashingtondc.org/contactus.htm
www.larcheusa.org

And Many More Dawns Thereafter

And Many More

Dawns

Thereafter

Once you have seen the morning sun, night takes on a different meaning. There will still be hitches and, at times, crises to be reckoned with. But the memory of that first sunrise assures you that dawn will always follow the darkest hour of the night. And that there will be many more dawns thereafter. Thus, we entered the 21st Century.

Partnerships and Collaborations

Corporate volunteerism became more common. There are now numerous partnerships between voluntary welfare organisations and commercial companies. For example, a significant breakthrough for MINDS came when Singapore Airlines (SIA) a successful local enterprise, decided to contribute significantly during its 50th Anniversary in 1997. One substantial contribution was the co-funding of the purpose-built SIA-MINDS Employment Development Centre officially opened in 2000. SIA became much more than a corporate donor of funds as staff and retirees become actively involved in various ways. The SIA-MINDS Community Project Committee worked hard to sustain this partnership.

And Many More

And Many More

Dawns

Thereafter

Dawns Thereafter

Some collaborations involve several partners. Merrill Lynch donated a substantial amount for MINDS to start up a business project that would employ individuals with intellectual disabilities. Bp Singapore offered space at their Pasir Panjang Petrol Station. A car wash business was born in 2001 with ten intellectually disabled adults working with two non-intellectually disabled workers.

Partners range from large multinational companies to small businesses such as Cristofori Music School. Cristofori Music School contributes in the form of weekly music lessons provided by its teachers at a MINDS school, free of charge. The Cristofori teachers find that once they have made the initial adjustment, the sessions at MINDs are a refreshing change from the rest of their work week.

Collaborations with professional organisations continue: 2001 saw the establishment of Rainbow Dental Clinic, a partnership between Rainbow Centre and The Singapore Dental Health Association. And corporate partnerships now include mutually beneficial joint ventures within the sector itself. From 2001, a BIZLINK-MINDS venture offers training in a purpose-built simulated training room, followed by employment in a professional cleaning service.

The likelihood of such innovative ideas surfacing is enhanced considerably by two networks formed by NCSS: the Special Education Network and the Training and Employment Network.

Lee Eng Hin, president of Rainbow Centre, observed[1], 'These NCSS Networks and their workgroups are good platforms to review existing services and identify gaps for improvement of service standards for the disability sector. These initiatives provide opportunities for all stakeholders and VWOs to actively participate in the process.'

Parent Support Groups

By now, parents were coming forward and talking openly about their children. Parents connected with other parents. Soon, there were caregiver support groups. Clara Ng, a parent, said, 'We didn't even know what a caregiver support group was but we just filled up the form and joined.'

Another parent, Carolina Chan, shared similar sentiments, 'As a parent, sometimes you are like a drowning man, clutching at straws. And you just hope some of the straws will save you. Honestly, I don't have the faintest idea how to handle an ID child. That's what I'm looking for. Help me to help my child. Help me to help myself. In the caregiver support group, I found hope.' At sessions, caregiver issues are aired. Sharing of personal experiences help new parents in particular. Parent Mike Sim reflects, 'At first, we were coming together to get information. It was mainly knowledge gathering. And that was helpful. But now, we are beginning to gel as a group.'

Siblings Get Support

Planning for the intellectually disabled adult drew in siblings as well. A MINDS Sibling Support Group was launched. Social Worker, Jamilah Binte Mustaffa is excited about co-facilitating the sibling support group with her colleague, Selvakumar Arumugam. She said, 'For me, it is a new

journey and I have learnt a lot from this group.' The group started with ten members ranging in age from 15 years to 45. Age differences do not seem to matter. What does matter is that all members have a brother or sister with intellectual disability.

Selena Chew, for instance, has a 42-year-old intellectually disabled brother and is now concerned about their 70-year-old mother being able to care for him. In a support group, she finds she is able to share her concerns and her thoughts about admitting him to a residential facility. The support group provides for a psychologically safe space to share her thoughts with others who are more likely to understand her good intentions for her brother and mother.

Use of Technology

Rainbow Centre's Snozelen is an example of how technology has enhanced the work of sensitive, skilled professionals. At the Moral Welfare Home, the use of technology has also changed ways of working. From the year 2000, once a week, the staff nurse has a video-conference with the doctor at Alexandra Hospital. The staff nurse can get advice on the medical conditions of the residents without having to send them to the hospital. The medical records of the residents can be entered online into

Care

Caregivers

Support Groups

by **Jeannie Ho**

> **'We must conclude that the psychology of groups is the oldest human psychology.'**
>
> ***Sigmund Freud***

Since the earliest civilization, people gathered in groups to ensure survival, mutual support and development. In more recent years, structured support groups evolved patterning after the Alcoholic Anonymous in the 1930s. Support groups have been found to be effective vehicles to draw people in similar predicament together.

Group meetings invariably involve caring, trust, the process of feedback, the sharing of perceptions, information, knowledge, skills and emotional struggles. The support gleaned from these group meetings help caregivers realise that they are not alone. Instead of feelings of isolation and being victims of circumstances, caregivers experience the empowerment as victors as they find strength, hope and courage from within themselves to face the unknown.

They are Overcomers. In the process of their own journey, they in turn empower and help others to overcome.

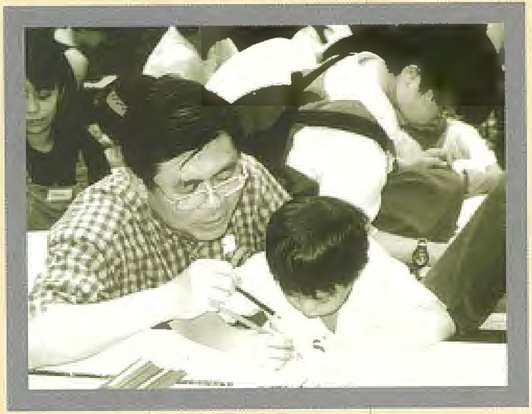
For more information

Posthuma, B.W. (1999). *Small groups in counseling & therapy: Process and leadership.* (3rd ed.). Needham Heights, MA: Allyn & Bacon.

Where are the Caregivers Support Groups?

by **Jeannie Ho**

Caregivers support groups have mushroomed within organisations servicing persons with intellectual disability. The following are some of them. Those interested to be part of a support group or wish to know more can contact:



Autism Association
Tel: 6774 6649, email: autism@singnet.com.sg

Autism Resource Centre
Tel: 6323 3258, email: arc@autism.org.sg

AWWA Special School
Tel: 6285 2515, email: awwass@singnet.com.sg

AWWA TEACH ME Services
Tel: 6454 8919, email: teachme@starhub.net.sg

Christian Outreach to the Handicapped
Tel: 6440 9740, email: admin@coh.org.sg

Down Syndrome Association of Singapore
Tel: 6278 3907, email: nc0156@starhub.net.sg

Movement for the Intellectually Disabled of Singapore (MINDS)
Tel: 6479 5655, email: MINDS@minds.org.sg

Rainbow Centre
el: 6475 2072, email: rspsn@hotmail.com

Touch Learning Support Services
Tel: 6281 1926, email: tcs@touch.org.sg

Alexandra Hospital's patient database. A webscan allows the attending doctor to examine patient's bruises, for instance, and advice what to do[2]. This arrangement stands in stark contrast to the earlier one where foreign workers at the home would accompany residents to the hospitals, posing problems in staff scheduling, transportation and communication with doctors.

For intellectually disabled individuals, technology can be a double-edged sword. Devices such as electronic augmentative communication systems are making a world of difference to those who use them. On the other hand, technological developments take place so fast that it is a challenge to keep up with the changes. Something as simple as taking a public bus has moved from paying the bus conductor, to dropping your coins into a slot as you enter, to debit cards and now *ez-link*[3] cards. Fortunately, with the help of volunteer groups such as the MINDS Youth Group, intellectually disabled individuals are helped to keep up with these rapid changes.

Youth Working with Youth

The MINDS Youth Group (MYG) has grown and diversified over the years. It provides training programmes and organises recreational activities. And is completely run by young volunteers. It currently has five projects, each in a different part of Singapore and each with its own focus. Lee Tian Lee, the chairman of the MYG, says, 'Being with the MYG has helped me. I feel more fulfilled in life. My own sense of self-worth has improved. And when other areas of my life are not going so well, my volunteering sustains me.'

Another volunteer disclosed, 'I didn't like kids, crying at the wrong time, making a din to get what they want.' A friend gently coerced her to volunteer at an MYG camp. She watched as the more seasoned volunteers played with the children. She noticed their patience and the excitement both volunteers and children shared as the camp culminated in a final night performance. At that point, the idea of becoming a regular Saturday volunteer seemed overwhelming. Nevertheless, she signed up.

Two years later, she recounts, 'I will always remember the first time my kid started to hold my hand, instead of me having to drag him along, how he uttered the words I taught him the previous week, and how he passed me some food from his plate at tea. Now I wonder what my Saturdays would be without the MINDS Youth Group.

This sentiment is a recurring theme when long-time volunteers are asked about what keeps them coming. Crystal Tan, project director of the NUS Student Union's Volunteer Action Committee puts it in a nutshell: 'I think the children give us more than we give them. The children give us unconditional love. They accept us just as we are. We don't accept them as they are. We are always trying to change them.'

Parents of the intellectually disabled youth appreciate the fact that the MYG volunteers do indeed try to change some of their children's behaviours. Molly Lee is a mother of a 40-year-old son, Lee Sze Min. After leaving school, her son had become increasingly fearful of stepping out of their home. He would keep his eyes closed if he did need to step out. Lee Sze Min attended an MYG camp. His parents spent sleepless nights worrying about him. 'But the spell was broken at that camp,' said Molly Lee. 'No more hiding himself in himself. Now we even take him on holidays abroad. We took him to Perth, Malacca, Kuala Lumpur and China.'

No wonder then that the MINDS Youth Group was awarded the National Youth Services Team Award in 1984, the Special Friends Award by the National Youth Council in 1999 and the first President's Social Service Award for the Group Category in 2001.

Reasons for Volunteering

Many who served on boards of management have received their Public Service Medals (Pingat Bakti Masyarakat) and Public Service Stars (Bintang Bakti Masyarakat). But when there is deep and sustained commitment, the motivation is seldom public recognition. An outstanding example is Lim Ewe Huat. Lim Ewe Huat has been conferred the PBM, BBM and BBM(L)[4]. Evelyn Lim, his wife, says, 'His heart has been in social service since his Boy Scout days and his evenings were always at meetings. We've had to postpone trips because of all his functions. I didn't mind because he was so satisfied and happy with what he was doing. He loves children and he loved to help others.'[5]

Lee Chak Meng started being actively involved in MINDS when his son joined a special school. He has become more and more involved over the years. Like many long-term volunteers, he gives time despite his own work schedule as a managing director of his firm. Why does he do this? 'My father came from China and he was illiterate. He came from a farm. He learnt by himself, was very hardworking and became a general manager of a company. I am like him. And now I feel I must give something to society. I have been lucky in life and so, I must pay back.'

And Many More Dawns

This is an explanation that is often heard when experienced and successful professionals are asked why they continue to volunteer in this sector.

The Current President of MINDS Professor Tan Ser Kiat said, 'I come from a humble background. I know what it is like to feel poor. I am grateful to society for the chances I have had to move up. If I'm in a position to help, I must give back to society. It's part of Chinese culture — part of Confucianism — to be always grateful to an organisation, or an individual who has helped you and then to try to put back something good into that society.'

Reciprocity and Interdependence

The desire to reciprocate is shared by intellectually disabled people themselves. Damayanthi Muthuswamy, supervisor and social worker at the Ah Hood Road Chin Pu Centre, is now in her 80s. She was out shopping with her son recently when a former trainee ran up to her. 'Teacher, teacher, I'll carry your things.' And he did. Damayanthi Muthuswamy introduced her son to him. 'Has he got a job?' She responded that he did not. 'I can go and talk to my boss to give him a job. I can help find a job for your son. You taught me. Now I help you.'

Doreen Tan, now head of MOE's special education branch, had a similar experience. She was at a supermarket about to check out groceries when she recognised a former student of AESN Katong Special School[6]. He was packing groceries at the check out counter. Doreen Tan deliberately stood in that queue, hoping to chat with him. When it was her turn, he greeted her, 'Good morning, madam.' She was disappointed. He seemed to have forgotten her. But she was pleased to see that he was packing well. He asked, 'Madam, may I bring your groceries to your car?' He did. She reached into my bag to tip him. He exclaimed, 'Mrs Tan, I can't take your tip! You helped me when I was in your school. You guided me. Now it's my duty to help you.' Doreen Tan was moved. He had remembered her after all. 'He greeted me *madam* because he was treating me as a customer. He became personal only when he had finished serving me as a customer. That's professionalism for you.'

When Doreen Tan comes across former students who are working in open employment and coping well, she is reminded of the value of specialised settings for preparing intellectually disabled children for

the real world. 'If not for the fact that the child was given individually tailored education according to the child's disability and needs, the child would not be as prepared for adulthood. In that specialised setting, the child's self esteem can be nurtured and the child's confidence can grow.' She adds that the family needs to help by including the child in the social life of the family, giving the child opportunities to have friends in the neighbourhood and taking the child out into the larger community for leisure and recreation. This might, in turn, make our society more inclusive. Such perspectives are invaluable at a time when parents and professionals abroad are having second thoughts about the unquestioning acceptance of the 'full inclusion'[7] movement. It is becoming increasingly clear that we need a continuum of services, offering individuals and families opportunities to make informed choices.

Assistive

Assistive Technology

by **Marissa Wettasinghe**

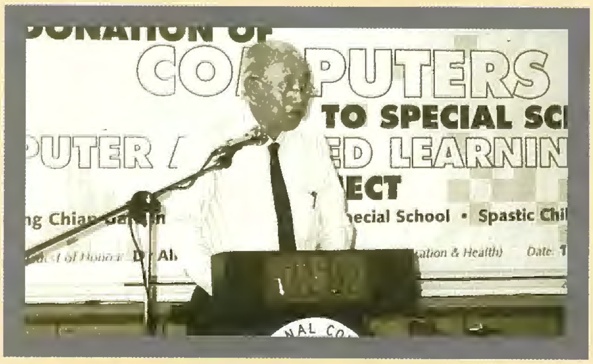
'Assistive technology means technology designed to be utilized in an assistive technology device or assistive technology service.'

Assistive Technology Act of 1998

Assistive Technology enables people with disabilities to accomplish daily living tasks such as assist them in communication, education, work or recreation activities.

Assistive Technology devices improve physical or mental functioning, overcome a disorder or impairment, help prevent the worsening of a condition or strengthen a physical or mental weakness. These include:

- *Communication Aids* such as tactile devices, note taking devices, modified typewriters
- *Computer Access Aids* like screen reading software and screen magnification/enlargement software
- *Environmental Aids* require work/school/home design modification for accessibility
- *Education and Learning Aids* can cover areas like cognitive software focusing on categorisation, matching, association, reasoning, decision making, problem solving and memory skills



Assistive Technology Services support people with disabilities or their caregivers to help them select, acquire, or use adaptive devices. These services may include functional evaluations of assistive technology devices, hands-on training, and equipment purchasing or renting.

For more information
www.rehabtool.com

To find out more about assistive technologies globally

by **Marissa Wettasinghe**

- Center for Applied Special Technology — www.cast.org
- Ability Hub – Assistive Technology Solutions — www.abilityhub.com
- Rehabtool — www.rehabtool.com
- Assistive Technology Online Community — groups.msn.com/adaptiveandassistivetechnology
- People with Special Needs (Apple) — www.apple.com/disability
- The Adaptive Technology Resource Centre — www.utoronto.ca/atrc/index.html
- Microsoft accessibility technology for everyone — www.microsoft.com/enable/at/types.htm
- SNOW (Special Needs Opportunity Windows) — snow.utoronto.ca/technology/products
- Independent Living Aids, Inc. — www.independentliving.com/frame_cando.htm
- IAT Services — iatservices.missouri.edu/adaptive/products.html

Becoming More Inclusive

In March 1996, a wave of celebration swept through the special education schools when Dr Aline Wong, Senior Minister of State for Education, announced in parliament that the Edusave Scheme would be extended to disabled children in government-supported special schools and the schools would receive Edusave[8] grants identical to mainstream primary schools. Prior to this, children in special schools had been excluded from the Edusave Scheme. The decision to include them was in response to many appeals by members of parliament, parents, VWOs and NCSS. It was seen by many as a step in the right direction in terms of practicing inclusion.

Meanwhile, several child care centres expressed willingness to accept some disabled children. Their staff needed training. Thus, in 2001, Rainbow Centre decided to provide training to these mainstream preschool teachers and child care staff to help them include children with Autism with special needs at their centres. The Rainbow Centre team, rolled up its sleeves and set to work. The team developed and taught the Pre-school Integration Enhancement Programme (PRIEP).

To many in this sector, it is important that we, as a people, become more inclusive in every way. At its deepest level, practicing inclusiveness requires that we are open to discovering and constructing solutions grounded in our unique local socio-cultural context. Being inclusive means recognising that there may be value in offering a variety of programmes so that there are choices at the individual level. An apt example would be Presbyterian Community Services (PCS). In 2002, after over 30 years of conducting its Integrated Education Programme at its mainstream child care centres, PCS started a special school — Grace Orchard Special School — in partnership with two churches. The result is greater choice: ten mainstream child care centres that practice inclusion and one special school exclusively for children with special needs. Likewise, Touch Learning Support Services operates a centre for children with special needs, two mainstream child care centers that include children with special needs, and at the same time, trains supervisors and teachers from other mainstream child care agencies to help them include children with special needs at their child care centres.

Appreciation of Special Programmes

The demand for special schools continued into the 21st century. Just before Grace Orchard Special School began, the Metta Special School started in 2001. It is important to realise that many families wish for a more inclusive society but are also pleased with the special school experiences of their children. One such parent, Sellaiah Muthiah spoke at his daughter's graduation from MINDS. He said, 'It came as a shock for us when we first learned of Chara's disability at birth. My wife and I were devastated and lost. We put her in a mainstream school but it was beyond her. The principal suggested a special school but we were afraid that society would alienate her and she would withdraw completely from society if she went there. We wanted her under our wings, secure and protected. However, the special school principal gave such a positive picture that we put her there. He was right. We saw her become happier and livelier. We

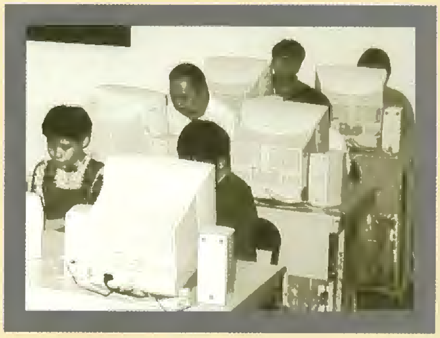
The Use of IT in Special Education

by **Marissa Wettasinghe**

IT for Special Education refers to the use of information technology to provide for the special educational needs of children with difficulties with learning.

- IT is especially valuable in enabling pupils to take charge of their own learning and to work at their own pace. In particular, pupils with learning difficulties find stimulation through enjoyable repetition, coupled with the gradual increase in level of challenge.
- IT has a significant impact on the quality of presentation of pupil's' work. It enables pupils, including those with difficulties of physical co-ordination, to produce neat and accurate work, and to concentrate on the quality of content.
- Increasingly, specially adapted IT systems offer an unprecedented degree of individual access to the curriculum for pupils with severe visual or physical impairment.

The value of IT in special education to enhance students' strengths, minimise their deficiencies, and enable their success within the existing classroom curriculum relies heavily on the importance placed on the training of teachers to reap such benefits for their students. Teachers need to be trained in technological such as the use of special types of hardware and software required for special education.



IT in special education can be utilised by teachers in the following ways:

- Using notebook computers, personal digital assistants (PDAs), or portable word processing keyboards to help students.
- Translating print-based notes to voice by using optical character recognition (OCR) software with a voice synthesizer.
- Word processing may be the most important application of information technology for students with mild disabilities.
- Motivation is often increased through the desktop publishing and multimedia capabilities of computers. A variety of fonts and styles allow students to customise their writing and highlight important features. Graphic images, drawings, video, and audio can provide interest or highlight ideas.

The potential of IT in special schools remains untapped due to a variety of reasons such a key management and training issues. At present, effectives use of IT in a school seems to be highly dependent on the creativity and initiatives of separate groups of special needs educators. There needs to be more collaboration and training for the majority to see a greater shift towards tapping on the strengths of IT in special schools.

Legal issues affecting persons with intellectual disability

by **Jeannie Ho** and **Sivaraj Mahaindra**

Persons with intellectual disability are:

- **Vulnerable to committing offences** — Many are unable to defend themselves from criminal abuse, nor understand when their behaviours are not socially acceptable hence landing them in trouble (eg. when they are too affectionate with strangers in public). In Singapore, the Mental Disorders and Treatment Act (MDTA), Cap 178 which defines mentally disordered persons as 'any person found by due course of law to be of unsound mind and incapable of managing himself or his affairs', may not adequately protect them because persons with intellectual disability do not fall under the definition of 'mental disorder'.

- **Unable to negotiate the terms of employment contracts that adequately meet their needs for fair employment** — This often results in vulnerability to unfair employment obligations. The Employment Development Services (EDS) arm of MINDS is pursuing the inclusion of the Contracts (Rights Of Third Parties) Act into Employment Contracts to give primary caregivers a recourse to negotiate for fair employment terms.

  MINDS EDS (the adult service sector) has form a legal network of volunteer lawyers to negotiate with the relevant authorities on the need for special legislation to protect the interest and well being of persons with intellectual disabilities.

- **Limited capacity to manage estate and financial resources** — Currently, they can only withdraw monies from their CPF, operate banks accounts or manage say, inherited property with the assistance of primary caregivers (parents, siblings) or appointed trustees upon the caregivers' demise. Not all caregivers can afford to engage private trustees. Thankfully, since February 1998, the Public Trustee has agreed to act on behalf of parents who take up the Disabled Dependent Insurance Scheme (DDIS). For more information on this, please contact the Disability Service Department at the National Council of Social Service, Tel no: 6210 2500.

saw vast improvements in her attitudes and behaviour. She learnt to count money, to tell time, do household chores, shop, travel by bus and, best of all, use a computer all by herself. We saw her grow up more confident, more determined, more independent. She became a prefect. She won awards in sports competitions. Now she even has a job. It is a dream come true for us.'

Still Vulnerable

In stark contrast to Chara's family, there are other families who remain in distress and at times, completely overwhelmed. Every few years, a grim reminder makes the news with a headline such as: *'Man Throws Down Syndrome Niece, then Jumps to His Death'*[9]. Apparently, the man was depressed about his sister's plight (having a child with Down syndrome). He walked into their home, carried off the 13-year-old girl while her mother was in the kitchen, went up to the 15th floor, threw her off the ledge and then jumped.

According to a witness, the trusting child had no idea what was about to happen. She was smiling happily. New buildings, exciting programmes and stellar professionals have made a world of difference but, in the final analysis, the intellectually disabled child is still very vulnerable and the child's family continues to be challenged in many ways.

Parents and professionals continue to worry about difficult situations — legal, sexual, financial — that persons with intellectual disabilities could inadvertently get into. Siew Ling's aunt and others like her have fallen through the cracks. Even today, every now and then, we hear of an older adult with intellectual disability, found sitting at the bedside of an even older parent but not realising that the parent has passed on. A stark reminder that we must work quickly to ensure formal as well as informal support systems for all.

Such supports would be possible if society evolved to the point of being far more inclusive than it is today. In the words of Tan Ser Kiat, 'Just as we are able to co-exist with people of different races and religions, we should learn to live together, regardless of intellectual abilities. Growing up in a family, you just accept all your siblings, regardless of what each is like. In the same way, as a society we must accept all members as equal members worthy of respect and dignity. Society should be like one big family'.

Endnotes

[1] In his speech at the Rainbow Centre's 10th Anniversary Dinner on 7 Sep 2002.

[2] The Straits Times (2001, April 3). *Doctor makes home calls via video*. Singapore.

[3] A debit card used for public transportation in Singapore.

[4] BBM(L) — Bintang Bakti Masyarakat (Lintang) — Public Service Star (Long Service).

[5] The Straits Times (1998, October 31). *His helping hand has come full circle*. Singapore.

[6] APSN Katong Special School since May 2000.

[7] See Kauffman, J.M. & Hallahan, D.P. (Eds.) (1995). *The illusion of full inclusion. A comprehensive critique of a current special education bandwagon*. Austin, TX: Pro-ed.

[8] The Edusave Scheme: Each child is given a yearly endowment fund of $130/- which may be used for school fees, school activities, personal development programmes, academic and therapeutic programmes, and sports. Each school is given an Edusave grant (of $50/- per child) for enrichment programmes, to procure additional equipment and materials.

[9] The Straits Times (1995, December 12). *Man throws Down syndrome niece, then jumps to his death*. Singapore.

The Straits Times, Friday 6 Sept 2002

Special-needs teachers deserve awards too

I REFER to the article, "Top teachers applauded for being class acts" (ST, Sept 1).

There are a number of awards for teachers from mainstream schools, such as the President's Award for teachers and the Caring Teacher Award.

All of them recognise and encourage our teachers in their important role of moulding our future leaders.

But what about teachers in special schools?

They make an enormous impact by maximising the contribution of special children.

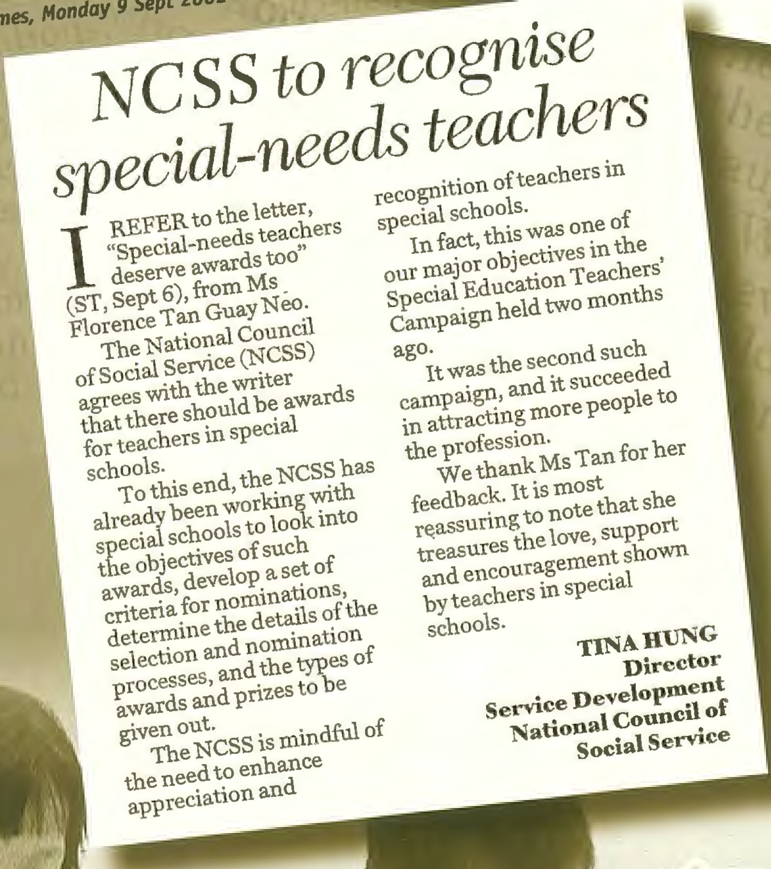
My daughter has been attending the Rainbow Centre at Margaret Drive Special School since she was five months old.

I am encouraged by the hard work, devotion, patience, perseverance and, most of all, love that these teachers have showered on my daughter.

Their love, support and encouragement have meant a lot to me and my husband, helping us come to terms with the fact that we have a daughter with special needs.

We therefore strongly believe that more recognition should be given to dedicated teachers in special schools.

FLORENCE TAN GUAY NEO



The Straits Times, Monday 9 Sept 2002

NCSS to recognise special-needs teachers

I REFER to the letter, "Special-needs teachers deserve awards too" (ST, Sept 6), from Ms Florence Tan Guay Neo.

The National Council of Social Service (NCSS) agrees with the writer that there should be awards for teachers in special schools.

To this end, the NCSS has already been working with special schools to look into the objectives of such awards, develop a set of criteria for nominations, determine the details of the selection and nomination processes, and the types of awards and prizes to be given out.

The NCSS is mindful of the need to enhance appreciation and recognition of teachers in special schools.

In fact, this was one of our major objectives in the Special Education Teachers' Campaign held two months ago.

It was the second such campaign, and it succeeded in attracting more people to the profession.

We thank Ms Tan for her feedback. It is most reassuring to note that she treasures the love, support and encouragement shown by teachers in special schools.

TINA HUNG
Director
Service Development
National Council of Social Service

1952 -1969

1952
Red Cross started a home for the physically disabled, some had intellectual disability

1957
Spastic Children's Association served children with cerebral palsy, some had concurrent intellectual disability

1960
Inclusion International founded

1964
International Association For the Scientific Study of Intellectual Disabilities (IASSID) founded

1962
Singapore Association for Retarded Children (SARC) established

1968
SARC Jurong Centre and Civic Centre started

1968
SARC Lee Kong Chian Centre started

1969
SARC Tampines Home started

1970 -1979

1970
AWWA established

1971
United Nations General Assembly proclaimed the Declaration on the Rights of Mentally Retarded Persons

1976
United Nations General Assembly proclaimed 1981 as International Year of Disabled Persons

1976
AESN inaugurated

1978
Thye Hua Kwan Moral Society registered

1979
AWWA Special School established as playgroup

1979
Christian Outreach to the Handicapped formed

1981 -1985

1981
Disabled Peoples' International founded

1981
International Year of Disabled Persons

1982
United Nations General Assembly proclaimed 1983-1992 the United Nations Decade of Disabled Persons

1982
Riding for the Disabled Association of Singapore was registered

1983
SARC Towner Gardens School set up with Amalgation of three centres — Tampines Centre, Toa Payoh Centre, Geylang Centre

1983
Christian Outreach to the Handicapped (COH) — Emmanuel Activity Centre (EAC) started

1983
SARC started the EIPIC program

1985
SARC renamed as MINDS

1985
MINDS Yio Chu Kang Gardens School started

1986 -1989

1986
SCSS started project to establish employment programmes for people with disabilities

1987
MINDS Yio Chu Kang EDC started

1987
Christian Outreach to the Handicapped registered as a society

1987
Margaret Drive Special School (MDSS) started — EIPIC program transferred from MINDS to MDSS

1988
Touch Ubi Hostel started

1988
MINDS Commonwealth EDC started

1988
SCSS project developed into Bizlink Centre

1989
MINDS Tampines Home moved to Thomson Road

1989
Moral Home for the Disabled started

1990 -1994

1990
SUNDAC Centre for the Disabled started

1990
AWWA Special School Registered

1991
MINDS Idea EDC started

1992
United Nations General Assembly declared 3 Dec of each year as International Day of Disabled Persons

1992
Rainbow Centre established

1992
TOUCH Community Services registered

1992
MINDS Guillemard Gardens School commenced

1992
MINDS Ang Mo Kio DAC started

1992
Metta Welfare Association founded

1994
Metta Welfare Association registered

1994
MINDS Clementi DAC started

1994
An extension of the Tampines Home, (Tampines Home-West Coast) started

1995 -2002

1995
Bizlink Centre registered as a co. ltd. by guarantee

1995
Balestier Special School started

1995
Metta DAC for the ID (MIDAC) commenced

1996
Down Syndrome Association registered

1997
MINDS — Towner Gardens School moved to Lengkong Lima

1997
APSN Centre for Adults formed

1997
Moral Home for Disabled Adults commenced

1998
Bishan Home for the Intellectually Disabled started

2000
MINDS Lee Kong Chian Centre rebuilt

2000
MINDS Commonwealth EDC renamed SIA-MINDS EDC

2000
Metta Home for the Intellectually Disabled operational

2000
AESN renamed APSN in May 2000

2001
Metta School started

2002
Blue Cross Thong Kheng DAC started

2002
Blue Cross Thong Kheng Home for the ID started

2002
Grace Orchard Special School started

N E

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“*Many Dawns tells a story of social service for intellectually disabled persons in Singapore in the last 50 years. I salute the people in the story — MINDS and the many volunteers, staff and supporters for bringing about the many dawns, the intellectually disabled persons for their courage and determination as well as, the family members for their love and compassion. These are fine examples of goodness in human character and strength in the human spirit. Many Dawns is a story of a marathon without a finishing line, of many dark nights followed by many dawns. It is moving, heartwarming and inspiring.*”

Mr Chan Soo Sen
Minister of State, Prime Minister's Office and
Ministry of Community Development & Sports

“*The story of Siew Ling, an intellectually disabled child, is an inspiring one. I share her ambition to lead a normal life. Although we have made progress, there is still much more we can do for our citizens with mental and physical disabilities. I commend this book to every one.*”

Prof Tommy Koh
Ambassador-At-Large
Ministry of Foreign Affairs

“*Many Singaporeans remain unaware of the challenges that those with intellectual disability face in our community. Many Dawns is a moving narrative of the extraordinary work performed over 40 years, bringing new hope and opportunity to the intellectually disabled, and helping build a stronger and more caring community.*”

Dr Cheong Choong Kong
Deputy Chairman and CEO, Singapore Airlines

“*The involvement of different individuals and communities has been captured in the milestones, from ramshackle facilities to modern impressive buildings. On reading the contents, one can simply sum up that the human software we have built and enhanced does contribute to make the difference today. Many helping hands can drive our organisations for intellectually disabled persons further ahead.*”

Dr S Vasoo
Advisor, Central Singapore Community Development Council
Professorial Fellow, Department of Social Work & Psychology, NUS

“*This book is educational, written with a spirit that upholds a basic respect for people. I am grateful to the professionals, caregivers and volunteers for having worked so hard in such a focused way to develop better services for the intellectually disabled.*”

Ms Claire Chiang
Executive Director, Banyan Tree Gallery

minds
Movement for the Intellectually Disabled of Singapore

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