Deep In Dad's Mind

- Raising a child with a disability

協康集之三

爸爸的心事與期望

Chinese Parents Association - Children with Disabilities Inc.

澳洲弱能兒童協康會

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CPA History

The Chinese Parents Association - Children with Disabilities (CPA) Incorporated was established in 1988. CPA was endorsed as a deductible gift recipient by the Australian Taxation Office in July 2001.

It is a non-religious, non-political and non-profit making organization with the aims to provide a range of services specially needed by people with disabilities and their families.

The Management Committee comprises of a group of parents of children with disabilities. There is a team of volunteers offering their time and skills in the day-to-day office administration, running programs and activities for the members and the community.

Our Mission

To provide a range of services and support to people with disabilities, especially those with Chinese background; as well as to promote a caring community for the optimal growth of people with disabilities.

Our Belief

It is our belief that people with disabilities irrespective of color, race or creed should be treated equally and to enjoy a rich and meaningful life as far as possible.

Letter from the CPA President

Elly Li

It is my great pleasure to announce the launch of the third publication of CPA (Chinese Parents Association-Children with Disabilities Inc.)!

The theme of this publication is about sharing the views, experiences and emotions of fathers on raising children with disabilities. For most of our families in CPA, the father plays a very important role. Family harmony and happiness are closely related to the leadership and support from the father.

Caring for children with disabilities and special needs can be a lifelong journey. Every now and then, there are differences in opinions and type of stress which can inevitably result in dispute and discontent. It is imperative that both couples remain calm, be composed and seek solutions together.

Most men are reticent. They decline to and may have difficulty disclosing their inner thoughts to others. In CPA, we are deeply moved by the fathers who quietly take on the important responsibility of supporting their wives, caring for their child/ren with disabilities and other children.

In this publication, there are articles exploring the responsibilities and roles of fathers. It provides useful hints on how to achieve mutual understanding amongst couples and enhance harmony within families.

CPA is grateful for the tremendous support and help from our community. We would like to give back to the community by sharing this new publication with all families in the whole community. We hope that our experiences with raising children with disabilities may inspire other families.

On behalf of CPA, I would also like to thank the Editorial Committee, authors and volunteers for generously giving their time and effort in producing this resource book. A big thank you also needs to be given to our generous donors, in particular, Club Central Hurstville, Marigold Restaurant and Samuel Chu, the optometrist for their continuous support to provide this latest CPA publication.

From the Editor

Chun Wing Fan

I would like to begin by commending everyone who contributed to this new CPA publication. Their contributions have allowed us to compile this insightful profile of various fathers who have a child with a disability as well as explore different perspectives and anecdotes from the fathers themselves, their spouses, children and the wider community.

For many contributors - especially the fathers - talking about their children, families and marriage is not easy; many have kept their stories to themselves for many years - to open their view to the public domain is an enormous step. A few articles were based on in-depth interviews with these fathers, as well as siblings. A special thanks to Unis Goh and Eugenia Liang for their efforts.

These stories are powerful and inspiring – they tell us how a family can survive and bounce back from early stages of extreme despair filled with stress and anxiety. Many families can return back to normal, a few can create a better life. In many cases fathers help a torn family to remain stable, support their spouses in caring for their child, comforting family members through the grief and uncertainties and support other siblings.

However, it is clear that some fathers themselves can suffer even more in this process. The lifelong journey of fatherhood can be bittersweet. There are unending struggles associated with the growing path of raising a child with a disability. We celebrate and congratulate these families, who have grown from strength to strength.

However, we acknowledge that such may not always be the case - some families have struggled, some have fallen apart, and we realise they deserve greater attention and support.

Testimonials by spouses and children confirm that a strong and supportive father's role is integral in a resilient family. We were thrilled to receive 39 suggestions for the publication's title when we consulted CPA members for any suggestions. Many of these suggestions pointed to their positive recognition and appreciation of fathers' roles.

The production of this new publication has been made possible through the active involvement of many volunteers over a period of 5 months. We formed an editorial committee that met frequently to manage the production progress. There are others who took up the important tasks of writing articles, translating, proof-reading, and liaising with sponsors and printers. There was also a successful fathers' forum held in early December last year.

Through this publication, we hope to raise awareness about the needs and concerns of fathers in these families. To effectively support their families, the fathers need support and recognition as much as other family members such as the mothers and siblings. The resilience of these fathers and their roles in fostering their families, as well as their children with disabilities, are admirable and warrant greater recognition.

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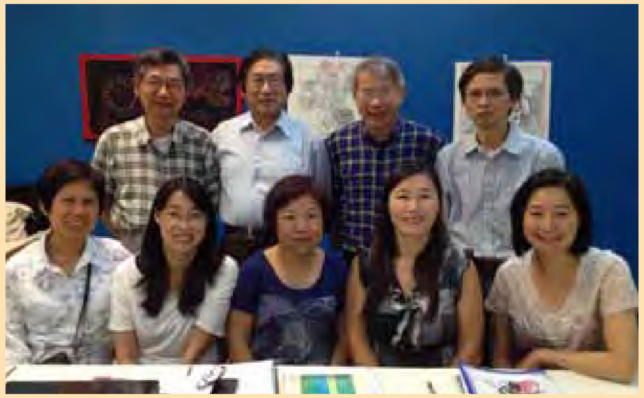


Editorial Board and MC members
編輯委員和協康會幹事合照

Bernie Holdsworth

President Club Central Hurstville
好市圍 *Club Central* 主席

As a father of four healthy and now grown up children, I can only attempt to understand the additional responsibility and deep compassion that springs from a father of a child with disabilities. What greater love has a father than to devote himself to empowering and growing his disabled son or daughter? As a community, we stand in awe of this, but we also must attempt to stand alongside that parent through his struggles by offering our friendship and assistance, financial and otherwise.

作為一個有四個健康成年子女的父親，我只可以嘗試去了解有弱能子女父親所需要承擔的額外責任，和他們不離不放棄的情懷。他們窮一生，為幫助自己的弱能子女成長，費盡心思，這樣的父愛，又有誰能及？ 作為社區，我們除了敬佩之餘，也要嘗試與他們站在同一陣線，用我們的友誼、幫助、資援和其他，與這些父親共渡艱難。

The Hon. Victor Dominello MP

Minister for Citizenship and communities
Minister for Aboriginal Affairs

紐省公民和社區部部長
澳洲土著事務部部長

CPA's members reminded me of the words of Javier Perez De Cuellar: "Let all bear in mind that a society is judged not so much by the standards attained by its more affluent and privileged members as by the quality of life which it is able to assure for its weakest members." As a MP, I have a responsibility to represent those in need, especially the disabled people. I have enormous respect for carers. I want to express my gratitude for the invaluable work they do for our community day after day.

協康會的成員令我想起祕魯政治家 Pérez de Cuéllar 的名句：『要緊記，一個社會的成就，決不以社會上有權貴者成就為標準，而是以這個社會怎樣為它最弱少社群的生活素質提供保證。』作為省議員，我有責任代表所有有需要的人，特別是弱能的人。我敬重所有照顧者。他們長年為社區作出寶貴貢獻，我僅此致謝。

Victor Tsang 曾令德

Dentist, Lieutenant Colonel of the Australia Army Reserve,
Chairman of the Australian Chinese Community Commemoration Organising Committee 2012

牙科醫生，澳洲後備軍中校，
2012年澳洲國慶日唐人街典禮委員會主席

The performance of the CPA Choir for the Chinatown Australia Day Celebration 2012 was impeccable and of high standard. For all the challenged fathers who support their children, I commend you for your patience and your hard working. You have helped to build the foundations of your child's confidence. Keep it up, it is worthwhile.

今年澳洲國慶日，弱能兒童協康會青少年音樂團在悉尼唐人街的表演是十分精彩和高水準。對所有在甘苦中仍不斷支持自己子女的爸爸們，我讚賞你們的堅毅和努力。你們為幫助子女建立自信，打下重要的基礎。繼續努力，這是值得的。

Councillor Steve McMahon

Mayor of Hurstville Council

好市圍市長

On behalf of Hurstville City Council, I congratulate CPA on meeting the social and cultural needs of our Chinese-Australian residents with disabilities, and their families. As a father of two young children, I understand both the joys and pressures in raising a family. This booklet is a positive initiative which actively supports fathers as well as shares their personal experiences on raising a child with a disability.

我謹代表好市圍市政府祝賀澳洲弱能兒童協康會滿足了我們澳洲華裔弱能人士及其家庭的社會和文化需求。作為兩個孩子的父親，我明白養育孩子的樂趣和壓力。這本小冊子能正面積極支持弱能兒童的父親，以及分享他們的個人經歷。

Dianne Giblin

Chief Executive Officer - Australian Council of State School Organisations

澳洲州立學校組織議會總幹事

Both my sons each has a child with a disability, one child was born at 25 weeks gestation and the other with chromosome duplication. I see first-hand how important a father's role is in the lives of these beautiful precious children. As first educators of their child, it is wonderful to see them together supporting their young one's opportunities. Congratulations to CPA for the work in supporting fathers (and mothers) to meet the challenges but most importantly enjoy the achievements of their children.

我兩個兒子他們的孩子都有弱能，一個是廿五周早產兒，另一個有一條染色體重覆。我親眼看到父親在這些漂亮寶貝的生命裡，所扮演的重要角色。看到他們作為自己子女的啟蒙者，幫助子女發展潛能，使我感到振奮。恭賀協康會支持父親(和母親)面對挑戰的努力，而最重要是他們都支持子女，為子女的成就而歡欣鼓舞。

Elena Lau 劉敏兒

Former president of CPA (2008-2010). She is the major force in behind CPA's successful weekend program since 2007. Currently she is CPA Youth Program co-ordinator.

協康會2008–2010年度前會長，自2007年她是協康會周末活動中心的支柱，青少年組統籌會

All father stories are unique on its own, the message is unequivocal: that there are three common cores– Love, Special Love, and Infinite Love of fathers. The input from all authors is invaluable, it will further encourage families who have children with disabilities to continue working together, and keep focusing on a positive outlook for our families.

書中每一個父親故事都有它獨特的內容，但同時亦表達出一個明顯共同的訊息：『父愛，特別的父愛，無盡的父愛。』各位作者的文章及支持是無價的；希望可以藉此鼓勵家長們，促進團結互助，推動我們的家庭正面的向前方邁進！

Hui Tan 譚慧

Professional welfare worker
She is currently a Senior Policy Officer of the NSW Department of Ageing, Disability and Home Care

專業福利工作者
目前在新州高齡，殘障和家務助理部門任職高級政策科主任

Due to stereotype of men as the strong silent type, the needs of fathers of children with disabilities for support have long been neglected. Research has shown that engagement of fathers in nurturing their children with disabilities leads to better development of these children and a healthy family relationship. So it is very important for our community to support the fathers as part of a holistic family unit.

傳統觀念中，男性都有剛強寡言的形象。這種觀念使得大多數弱能孩子的父親都得不到其應有的支援。研究表明，父親的支持能夠使弱能孩子得到更好的發展，同時也促進家庭良好關係的形成。所以我們社區支持父親作為家庭重要的一員是非常重要的。

Ruby Chan 陳鄭鳳儀

Registered member of the Psychotherapist and Counselor Federation of Australia.
She helped to chair the CPA forum for fathers

澳洲註冊心理輔導員
協康會父親研討會主持人

Research evidence continues to show that close relationship with fathers is beneficial for children in their physical, emotional, psychological, academic and social development. I believe that the role played by fathers of disabled children is of equal significance and should be acknowledged. In fact, supporting fathers in their carer's role is an effective and efficient way of supporting the whole family.

研究報告一再指出親密的父子或父女關係有助孩子的身體、情緒、心理、學業及社交發展。我相信父親的角色對智障孩子的成長同樣重要，也應當受重視。其實適當地支持這些父親也就是支援這些家庭的一個有效方法。

Challenges for Chinese fathers raising a child with a disability

Unis Goh

Member of the Disability Council NSW, PSM

Preamble

In writing this discussion paper, I have had in-depth discussions with a few fathers from the CPA (Chinese Parents Association- Children with Disabilities Inc.) who generously gave their time to talk with me. I am grateful for their sharing of experiences, hopes, aspirations and worries regarding raising children with disabilities. Their sharing has helped tremendously to give me inspiration, understanding and valuable insight while gathering my thoughts for this paper. I am humbled by the invitation and hope this discussion will interest more people in our community.

The main challenges for parents in raising a child with disability

Parents who have a child with a disability would have encountered a number of challenges. The first challenge is being parents for the first time. Then to face the challenge of being parents of a child with disability. This is the challenge of dealing with the unknown. The uncertainty of how to raise a child with disability and what their future might be.

The uncertainty impacts on the parents' current and future lives as well as the other siblings in the family. These impacts could have variable effects/stresses on your own physical and emotional coping mechanisms to survive on a daily basis.

Raising a child with a disability involves many additional costs. We often take for granted our general state of wellbeing without ever needing special medical and dental treatments, dietary requirements and interventions in speech and learning. These all lead families towards becoming financially stressed.

The physical care for a child with a disability takes a great deal of time. Being time poor can lead to frustrations for the parent's and others in the household as everything is done for the child. As a result this frustration could inadvertently affect the child with a disability. Social isolation can be another challenge as a result of lack of time and lack of energy to foster contacts to connect with friends, extended family and people in the community.

The challenges that create hardships throughout the families' journey in raising children with disabilities can be an enriching experience. It can be viewed upon as giving added meaning and purpose to their lives. While these challenges and experience of hardships vary in times, it can be said to strengthen parenting abilities. At the end of the day parents know that they are giving their children the best care and support. It is important for parents to maintain hopeful that their children can still achieve their potential and live a meaningful life.

The unique roles of father in caring for the child and supporting the family

In the past, the father often played an unspoken role as the pillar of strength and as the head of the family who made final decisions in the marital relationship and in the family.

Mothers often turned to fathers for immediate emotional and physical support in the caring of a young baby especially during the first 9-12 months. For some there is the need to adjust to the realities of having a child with a disability whether it is a fact known at birth or later in development.

In contemporary Australian society, with parental leave provisions in the workplace legislation, some couples manage to share caring responsibilities and decision making. The most important thing, however is to support each other and develop good communication. The load is much lighter when it is shared.

Fathers can assist with the physical care such as bathing, nappy changes, feeding and domestic duties like cooking, cleaning, shopping, paying bills; provide transportation, look for information and resources to aid understanding of their child's disability.

As the child gets older, increased involvement from father is required. The father needs to act as a role model to the child and work in partnership with the mother and other family members to ensure the child experiences love and affection as well as be monitored in all the developmental and learning milestones. The father also provides support to the mother in behaviour management and seeking advice from a professional team (speech therapist, OT, psychologist, nutritionist, doctor and other medical and education specialists etc).

Fathers often have a strong duty to ensure there is adequate household income and financial stability. It is important that couples work together to balance financial stability and care for their child. Sometimes fathers might take on the caring role to allow mothers to continue her work.

Fathers can have a shared responsibility to care for the other children without disabilities and possibly even support elderly grandparents.

Is it more difficult now to get disability services than previous?

The Government is aware that government funding has not been adequate enough for decades to meet the growing needs in disability services. In future, there will be more services available to develop the capacity of families and carers so that they can better support their children to achieve independence.

The current strong push by Federal and State Governments in the disability sector for a National Disability Insurance Scheme (NDIS) and the NSW government's implementation of a Person Centred Approach (PCA) is intended to make it less difficult for families to get services than previous years. The NDIS will give greater certainty for people with a disability, their families and carers in accessing services and support in the future.

The NSW Government has been implementing a program called Stronger Together 1 since 2006. This program has been successful in expanding the service system to enable more

people to receive support. The program is now moving into the second 5-year phase called Stronger Together 2 which will further expand the service system to enable people with disabilities, their families and carers to have more opportunity in taking control and making decisions about what services they need by adopting a Person Centred Approach.

It is important to enable children to develop independent living skills to the fullest in order to participate in an inclusive society in the future. This would be a positive way forward.

What are the major changes to disability services in coming year?

Federal Government is planning to implement a National Disability Insurance Scheme in 2013 to provide improved financial and service assistance to people born with disabilities, have acquired a disability, have a chronic illness and or mental health illnesses. You can show your support for this by join up the national campaign called Everyone Counts by website www.everyaustraliancounts.com.au

The National Disability Strategy is approved by the Federal Government as the working framework which provides a nationally co-ordinated approach to bring about improvements in mainstream systems and the disability services system in order to improve the lives of people with disabilities, their families and carers. To get a copy of the National Disability Strategy visit www.fachcsia.gov.au

NSW Government, through the Ageing, Disability and Home Care Service is continuing in the implementation of the Stronger Together 2 program and is developing an implementation plan for the rollout of the Person Centred Approach (PCA) in 2013. The PCA is about putting people with disabilities at the centre of decision making. This new approach will radically change the funding system to enable people with disabilities, families and carers to control the allocated funds and make decisions about which services to use. This will encourage greater flexibility and access to both mainstream and disability specialist services in the future.

In 2012, a wide community consultation program involving people with disabilities, their families and carers including people from Cultural and Linguistic Diverse (CALD) backgrounds & Aboriginal community is underway. Your feedback and suggestions to Government will be important input in developing an implementation plan to achieve the goals of the PCA. You can participate in the discussion about PCA by attending the consultation workshops or visit website www.adhc.nsw.gov.au/pca.

Australia signed up to the United Nation Convention on the Rights of Persons with Disabilities in 2008 and lodged the first national report to the United Nation Human Rights Council's universal periodical review in November 2010. The report stated that "Australia is in the process of developing a comprehensive policy framework that aims to bring about change in all mainstream services and programs so that persons with disabilities have the same opportunities as other Australians".

You can see these major changes in disability services are encouraging and should give us hope in the coming years. It will fundamentally shift public attitude towards people with disabilities from a Charity-based model to a Rights-based model. The social barriers will be removed and people with disabilities could achieve more independence in the future.

Will it be changed for better or for worse for Chinese parents?

Chinese parents are actively encouraged to have a say about the Person Centred Approach. Take part in ongoing discussions with Government and service providers in the planning for the changes first hand. www.adhc.nsw.gov.au/aboutus/strategies/

Chinese parents are not disadvantaged. They have the same rights to quality services and timely support as any parents in Australia. Chinese parents should get involved like other Australian parents to be part of influencing the change.

The fathers who were involved in my discussion successfully managed to share their caring responsibilities with their wives from the time of the birth of their children. The couples made sacrifices in their own professional careers in order to provide better care to their children with disabilities. The comments came from their hearts and clearly showed their unfailing commitment, endless love and timeless aspirations for their children with disabilities. Above all, their generosity in sharing their knowledge and advice is most encouraging.

In conclusion, I hope this paper resonates with your own experiences as Chinese fathers and also mothers in raising a child with a disability in Sydney. I wish to encourage you to act now by taking part in the ongoing discussion with Government regarding the Person Centred Approach throughout 2012. Your input can make a real difference.

Special fathers, incredible sharing

CPA Reporter

CPA Seminar

In the disability community, the topic of discussion would normally focus on the children with disabilities: for example, how to develop their ability and maximise their potential? How to facilitate their integration into the mainstream community? How to help children to be independent? Attention is relatively less on parents or carers and it is rarely talk about the roles of fathers. This negligence does not mean that the roles of father are not important in the process of raising a child with a disability.

To highlight the important roles of fathers in supporting families and assisting their children with disabilities, CPA organised a seminar in December last year. Seven parents attended this seminar. The seminar was chaired by Ms. Ruby Chan, a registered counsellor. This article is a record of the main discussion and issues raised.

Ruby : As a father of a child with a disability, would you please share your experience in caring for your child?

Sam's son is now 19. When he was 2 or 3 years old, it was a shock to Sam and his wife to find out that his son had a deviant chromosome that would affect his normal development. It was indeed hard for them to accept. They asked time and time again why this happened to them as there was no such precedent in both sides of the family. They were very worried as this would affect their normal life with a child who would demand a lot of care everyday.

As a Christian, Sam and his wife finally accepted this gift from heaven. They made a great effort to ensure that this gift was the same as any other similar gift. They took their child to find a possible cure – and tried the most expensive medicine. They found that tongue acupuncture was the most effective as their son showed significant improvement in speech after three treatments.

Their path has been lonely. Sam said it was even hard to find assistance from friends as all his friends did not have the experience of having a child with a disability. Even in his own Church, he felt very isolated.

Jeff is very humble to say that his experience of caring for his son with autism has not been successful. It is because both he and his wife had a long period of denial in the beginning. From kindergarten to Year 3, his son's teacher kept pointing out to them that his son could have autism, which was different from what they thought of their own son. As a minimum, he was talkative, his academic performance was moderate and his Year 3 Statewide assessment showed that his study result was above average.

After continuous requests by the teacher, they sent their son to undertake an autism assessment which showed negative. Jeff and his wife thought they were correct all along - their son was normal. However, this belief was subsequently derailed by their son's misbehaviours. At Year four, Jeff and his wife had to transfer him from a mainstream school to a school with a support class. This signified that they had finally accepted the harsh reality that their child had autism.

Based on his own experience, Jeff has summarised a few pointers in which he would like to share with parents who might face the same problem as his.

In young age, the gap between normal and autistic children is small and inconspicuous to the extent that most parents might overlook it. However, the gap increases when the child gets older. The earlier denial and attitudes held by parents would cause delay for the child to receive early intervention and assistance.

Children who have no concept about selfishness may have autism.

It is necessary for parents to adjust their expectations of the child. It is unnecessary to make the assumption that the additional time and effort you put toward your child in his/her study, would help them catch up with other normal kids.

It is important to raise the awareness of our society towards children with special needs. Organisations such as CPA take up this important social responsibility as educator.

Amongst all fathers, Andy gave the shortest speech and clearly he was the one who accepted destiny. Seventeen years ago, the happiness associated with the birth of his first son vanished quickly, as the doctor told them that their tiny and weak baby might not be able to walk when he grows up, and his other developments would be slower. The new parents simply accepted it and had passed through more than ten years in a state of no regret.

Andy thought that the relationship with his wife has even got better due to the care for his son. His son started to walk when he turned five. Raising this child has been a tough task, however, Andy takes it all in his stride.

He said, “Strangers sometimes asked me why on earth I need to carry my son who has grown up physically? I responded by telling them that he is sick.” His stoic calmness is extraordinary. In order to spend more time with his son, they waited until his son turned 11 before they gave birth to a lovely daughter.

Bruce’s daughter was diagnosed with Down syndrome immediately after she was born. It was a great shock to the couple as this was their first child. After she released from the hospital, the couple were engaged in a deep psychological conflict…

Do we really have the ability to raise this child?” “Is it more suitable to send the child away for adoption? “How do we proceed on this path?

At the end, they decided to take the child home. Some more drastic events had happened to Bruce and his family; and all these events led him to understand that suffering was part of life. Therefore the fact that having a daughter with Down syndrome is nothing compared to those events. They started to see life suffering as a form of endurance and a way for someone to grow stronger.

In order to look after their daughter, Bruce’s wife had to resign from her Bank job so she could help her daughter with a lot of early intervention programs. Bruce is grateful of the Australian Government’s system to give care for children with special needs. His daughter is currently studying in a special class within a mainstream school. Apart from speech, her other developments as well as academic results are satisfactory. She even has some good friends.

Ruby: What you have described has been very positive in your life, in terms of helping your child with special needs. You are not just focusing on what you have missed, you are aware that while you may be worse off than some, you are better off than many. Apart from this positive attitude, could you tell us something that can be of use for you in helping your roles as father?

Sam said this must be CPA, he was pleased to see his son playing joyously with other kids of his age. In addition, parents have the opportunity to discuss and share their experiences. He has witnessed the development of CPA from its earlier days and thinks it is important to continue supporting CPA.

Jeff thought that it is important for society to have greater awareness of children with special needs as this is crucial for their survival and their future development. Our children will benefit when the mainstream community is more accepting and inclusive of them.

Furthermore, it is natural for parents to give unconditional love to their children. Parents cope better by lowering their expectations of their children in terms of academic results and career development.

Jeff’s expectation of his son could be referenced to an instruction by a priest when his son was in high school. The priest said, “Your son will need to learn two things - one is English so he can communicate, the other one is religion so he can get comfort.”

Andy agreed that CPA has given a lot of support to families. He was recommended by friends to join this organisation. As such, he and his son have one more place to visit on the weekends. It is better than visiting shopping centres. The support for him and his wife has been most significant. In the meeting, fathers unanimously raised the concern about discrimination. Sam regretted that the Church he attended could not accept his son, and as a result, he left the church for up to 3 years.

Jeff approached the issue of discrimination from a rational perspective; he ultimately considered that society does not have enough understanding about autism and people who have developmental barriers. As such, society sees these people as strange. If everyone accepted that this world consists of people who have weaker physical and intellectual abilities, they would be more tolerant. Therefore he emphasised on the need to raise social awareness.

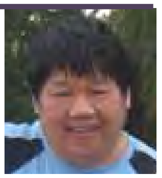
A mother at the seminar offered some feedbacks to the group of “special” fathers. There are many ‘good’ fathers in CPA who are willing to take up their responsibilities and she is delighted to know them. In fact, she also heard some sad stories about some fathers who gave up their wives and children and left, mainly due to having a child with a disability. The burden was passed to the poor mothers who have to care for the kids on their own and bear all the pressure and pain. She is grateful for her husband who has been very supportive in a quiet manner because her husband has also shared the pain for having a child with a disability.

Conclusion

All participants thought the seminar was a great success and positive. It provided a platform for parents to share their experiences and emotions. They hope CPA will continue to hold these seminars on a regular basis.

My daughter and I

Tim



I work night shift in a post office. My sleeping time has been thus reduced over the years due to these work commitments - this is not a healthy living style, yet I am grateful that I am able to look after my family during the day despite the reduction of my sleeping hours.

In no time at all, my daughter Aliza, who has Down's Syndrome, has turned 15 years old. I thank God for his blessing and guidance every day. Aliza is now studying in St. Edmund School which is a special school for people with visual impairments. Next year, she will be in Year 10.

There are ten students in her class and the class curriculum has been designed by the teachers based on individuals' learning capacities. Although there are teaching aides, it is not an easy task to implement the teaching programs. At present, apart from learning simple academic subjects, Aliza mainly learns independent living skills, such as catching the train, going out and how to use a walking stick for blind people. She has also been learning to play piano for over 2 years. For a young lady who has a moderate intellectual disability, her performance has been brilliant.

Aliza is an active and cheerful child, and understands the need to care for others including family, teachers and friends. All her fellow classmates and teachers like her. She has a good memory, but is a little bit stubborn, something common amongst children with Down's Syndrome. Nonetheless, I am so pleased and consoled to see that she has made progress in many aspects of life.

Initially I worked night shifts in a post office which is about six minutes drive from home; however since January last year, I had been transferred to another post office which is a twenty-five-minute drive from home. During the week, I work seven-and-half hours each day, and I only sleep two hours in the morning and two at night. Often I have to catch up with my sleep during weekends. Although this is not entirely an ideal arrangement, it offers me an advantage which allows me more time to help and support my family, so the gains and losses do break even.

There are great concerns for Aliza's and my health and weight. In recent years, her weight has been increasing, and the doctor reported that she also has high blood pressure and regulating her diet is crucial. Fortunately, my wife has adopted a tough approach and so Aliza's weight has become more stabilised. Personally, I have also experienced weight issue, possibly as a result of workload and lifestyle choices. I have tried to go to gym for exercise; I am not always able to maintain the regular routine. I do understand it is important to have constant health check-up, just as much as it is important to look after my daughter.

Both I and Aliza have sleep apnoea which means we need an apnoea monitor to aid our sleep. Last year, Aliza had undertaken a small operation and currently she does not require the monitor any more while sleeping.

The time we spend together with Aliza goes pass like a fleeting wave. Life moves on. We are grateful for God's guardianship and will continue to follow his lead.

We are one

Sunny Tan

We were greatly shocked, like other parents who have an autistic child, and we refused to accept the fact that Yee had been diagnosed with autism at the age of four. We hardly knew how to face and handle the situation. However as the evidence mounted, we had to acknowledge that our child was different from other ordinary children.

Now my daughter has just turned eight years old. During the past years, we had been looking for all sorts of resources that would be of benefit to her. She displayed tendency of retreating into her own lonely world; we regularly took her to various kinds of programs implemented by different community organisations, offering her opportunities to be socialising with other children. When she missed out on making friends, we were her closest companions.

My daughter was lack of communication skills which affected her learning; we had to spend more time and to be more patient in helping her out in her daily homework and study.

As her father, I always made an effort to take Yee to and pick her up from school so I could have more time with her. Every weekend, I sent her to the Chinese school; and once a week, I accompanied her to swimming class and basketball practice. It was encouraging to see the gradual improvement in her physical development and in body-coordination. We went to Sunday schools where she could play with her peers and I found out that Bible study help to enrich her life.

At bedtime, she used to have read me an English story first, followed by reading aloud together the Chinese story books in Mandarin. We then kissed each other good night. Whenever we met some friends or relatives who spoke Mandarin, she would greet them in Mandarin in return; Yee loved to show off her language skills by reciting a Chinese poem or singing a song in Mandarin.

Her swimming coach showed a great fondness for Yee. She had learned different swimming styles and even diving. At the school presentation ceremony last year, I was so pleased to see her receiving a Principal's award on stage; she was so excited that she laughed heartily and danced around.

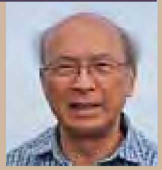
Her progress has been obvious – she has grown up and is nearly as tall as her mother. None-the-less, we know from the bottom of our heart that she is different from other children; occasionally she talks to herself – something that is beyond my comprehension.

In terms of communication, she is always behaving like a small child who does not know how things should work. Whenever we went out, I would always be nervous and would not allow her to stay out of my sight. When she is irritated, I feel frustrated as well. I do wish she would be more independent and less shy. She always feels uneasy with strangers and she is hesitant to try anything new. She is my daughter and I accept her disability. I sincerely wish that she would continue to make good progress and develop to her potential.

My lifeline

Daniel Chan

Author



We shared our challenges; we understood, learned, encouraged and comforted each other.

211-211 is a special number that I will always remember. It is the short form for 21-12-11. On this date, 21/12/2011, my son told me that he had completed his study requirements for graduation. I remembered when I was in my teens, there was a television series; in the opening scene, a boy was running home and shouting, “I have graduated”, and then the camera turned to his mother who is sporting a very delighted grin. At that time I did not appreciate how this mother felt, however, now I share that same feeling and I am so delighted as well.

Throughout the years, we have faced a lot of challenges - especially when my son was born. The paediatrician said that our son has special needs; will be slower in every aspect, will need to spend more time to complete any tasks and will expect his intelligence to be below average. We needed more patience to bring him up, spend more time to help him. How do we do it? I want to share my experiences with you all. We need to persevere and not give up.

Initially we denied the abnormalities of our son; we sent him to see almost all of the specialists in the hope that they would diagnose him as normal. We visited many specialists and the outcomes were not certain.

I am a Christian; my family believes in Jesus Christ and he is our lifeline. In the Bible, John chapter 9 verses 1 to 3 said: As Jesus went along; he saw a man blind from birth. His disciples asked him, “Teacher, whose sin caused him to be born blind? Was it his own or his parents’ sin?” Jesus answered, “His blindness has nothing to do with his sins or his parents’ sin. He is blind so that God’s power might be seen at work in him.” He helps us to meet all our life time challenges. I can move forward and be positive, meet our daily challenges head on. I am just like any other father; I have the following tasks to overcome:

- Look after this son,
- Provide support to my spouse,
- Provide support to my other child, and
- Face the outside world

Then we accepted his conditions and started to bring him up as a normal child. Although he is slower, he can do a lot of things. He can do things at his own pace. A lot of things can be achieved in its miraculous way. I also joined a couple of parent support groups for children with special needs. There I met other parents in similar situations. We shared our challenges; we understood, learned, encouraged and comforted each other. We also watched our children grow together. It was a kind of experience that drew us all closer.

Watching television, one of the programs has the title of ‘112’ which is the emergency help number in an European country. In Australia, we have 000, in the USA, they have 911; and in Hong Kong, they have 999. Different countries have a different set of numbers. Watching another television game program, when contestants have trouble continuing, they can ask for help. One of the methods is called a ‘lifeline’ where they can ring a friend on the phone to assist them to answer the question. My lifeline is Jesus Christ. Who is yours?

Author: Daniel Chan is one of the founders and former president of CPA.

Son, you have changed my path of life!

Eugenia Liang

When his wife was pregnant, William had a bright vision for the future of his child, something experienced by every father. William clearly remembered that when the chid was born, he embraced his son and experienced a joy that was hard to be described by words. Tears were rolling in his eyes.

Around the age of two, when other children have begun to babble and call out their first word, William and his wife discovered that their child was “different”. Search back into the memories, William recorded that his son did not speak at the age of two, did not play with other children, and barely looked other people in the eyes. His son was aggressive most of the time and difficult to control.

At the beginning, the couple thought that the child is young and has hot temper. However, when these developmental problems continued for another three years, they were worried and finally decided to look at the issue seriously. After repeat tests and observations, the child was diagnosed as autistic. When the news arrived, William could not believe his ears. Originally, his life was filled with goals and hopes, but at that moment, he was surrounded by pain and confusion, lost and struggled.

However, life has to go on. Since then, William and his family search everywhere for a cure, but the final conclusion is that autism can not be completely cured so far. It is a life-long progress of intervention and rehabilitation treatment. It is something they have to face and accept.

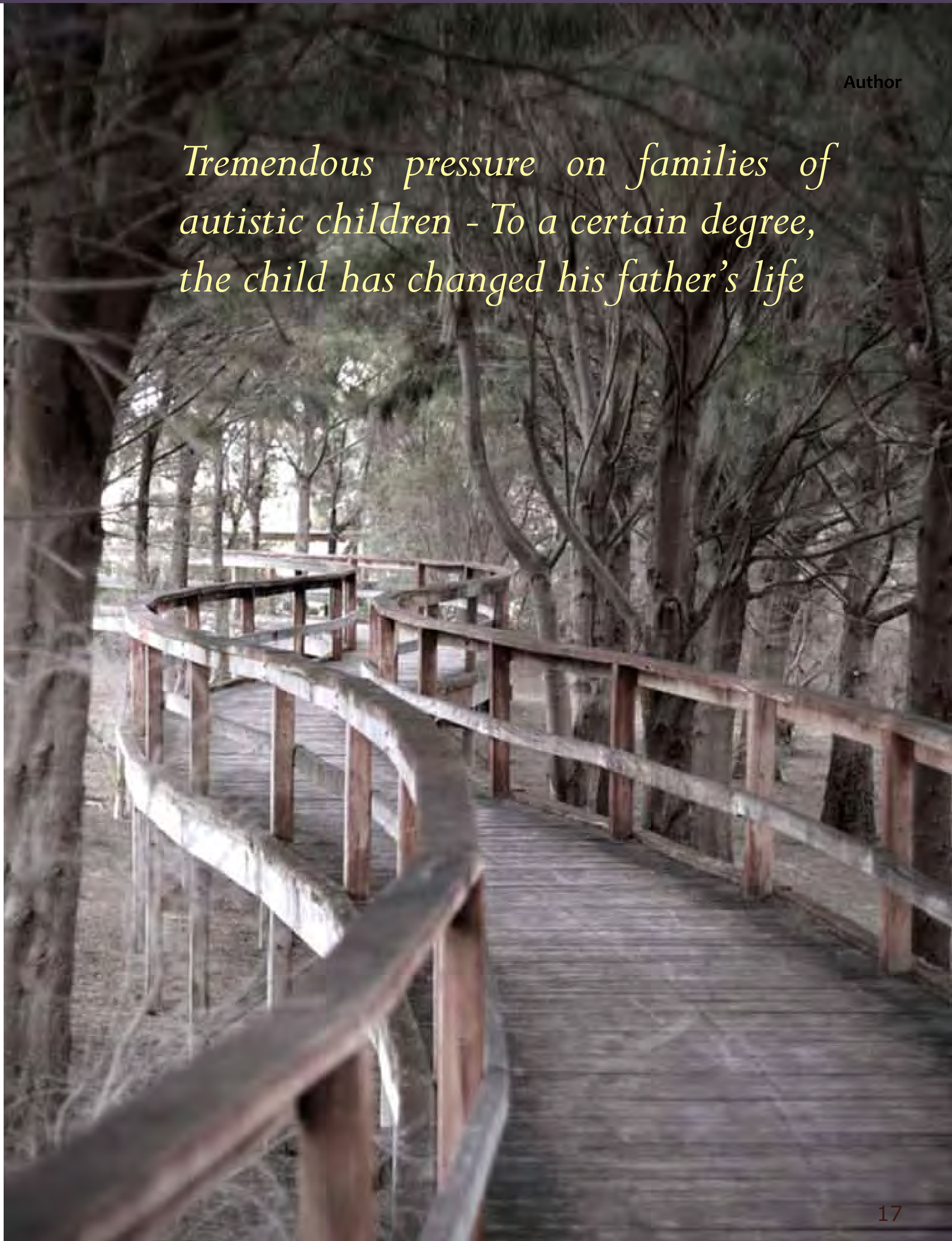
As a father and a husband, William gave up his challenging career and selected a stable financial job to support his family. In order to help his son, William read a lot of books, including children’s education, child development theories, training for children with autism. Through helps from the society, they also joined the CPA. Within this organization, his family received a lot of supports. It provides a platform for William and his family to link with the wide society, to gain more acceptances, to share information and to support each other emotionally.

After the sun is set and darkness arrives, William searches deep within him and feels the pressures and disappointments. He felt sorry, because no matter how hard he tries, he can not establish a normal father-son relationship with his son. There is no father-son time, no exchange of emotions and life knowledge. It takes him days, weeks or even months and numerous repetitions to train his son to perform a simple task. These long and exhausted processes become part of his life, and he becomes pessimistic. When compared with other children, his son will always be “different”.

Looking into the future, he can not construct any plans. Children with autism display extreme behavioral characteristics in the sense that they might either be overly aggressive or abnormally passive. They do not pay attention to other people around them and do not reciprocate to communication - verbal or non-verbal. A child who suffers from autism has difficulty in the development of play and usually uses only parts of toys or displays repetitive actions in playing.

With all these characteristics, it is easy to understand that children with autism are difficult to integrate into society. As a father, William is worry. But he also understands that the most important thing to help his son is to raise social awareness, to increase social understanding, concern and involvement in this area. The ultimate goal is to let the children integrate into our society, to live with others. In reality, such understanding is hard to achieve.

As a father, William plans the future step by step, according to the development and progress of his son. He does not know where the end of the road is.



Author

Tremendous pressure on families of autistic children - To a certain degree, the child has changed his father’s life

The father who enjoys his family

Eugenia Liang

"To the public, the term 'family man' has always been referred to a full-time house-bound father. The classic scene that frequently flashes through our minds is an image of a "male nanny" - the special troop agent, in the movie "The Pacifier", who took over the tough mission of frantically caring for a group of five very active children. In modern days, the role of coaxing the child, feeding, and changing nappies are no longer confined to the responsibility of mothers."

Andy and Eric

Traditionally, most Chinese families are patriarchal families in which men are the main bread winners. It was almost unheard of for men to abandon their careers to take up the domestic chores. However, in recent years, society has changed. Many men are willing to spend more time at home, helping out with the household duties and enjoying time with their family. One such man is Andy.

Andy is a Chinese from Vietnam. At the age of 13, due to social unrest and uncertainty in Vietnam, he and a few friends decided to leave their country of birth. They travelled by boat, passing through stormy waters around the Indonesian Islands. It took him a whole year to arrive finally in Australia. Life was gradually improving. In 1993, by a strange, twist of fate, he met his girl friend who became his wife. They happily had their first child; a son they named Eric.

When life seemed to be going well, fate played a trick on them. The couple was told by their doctor that their son was a child with disabilities. There were delays in his intellectual, physical and digestive system developments.

The child started to walk when he was five years old while other five-year-olds are actively engaging in various forms of activities. Whilst other teenagers are going through puberty; socialising with their peers, or searching for summer jobs, sixteen-year old son still depends heavily on his parents and family to care for him. Occasionally, the family met with misunderstanding and intolerance in public, followed with strange looks and comments.

As a parent of a child with a disability, Andy experienced constant pressure that was almost suffocating. However, an optimistic and cheerful altitude, as well as a feeling of gratefulness, are essential elements in learning to cope with stress and finding happiness. To Andy, family always comes first. He chooses a job with flexible working hours and proactively helps with the household chores.

Andy takes a sanguine disposition, being happy and grateful and he enjoys his family life. He feels excited with every step his son has made and satisfaction with every improvement in his son's development in life. He will never forget the first trembling steps his son took whilst he was learning to walk at the age of five. Andy was in tears and knew that his son had become more independent.

Living in harmony at home, and with Andy's guidance, the child has grown to be a gentle teenager who is not so easily agitated or anxious and is full of light heartedness and cheerful.

There was an addition of a new member to the family when his son was eleven years old – a sister was born and she has brought a lot of cheer and blissfulness to the family. The son has learned how to look after his sister. Andy has to share his love and care fairly and equally amongst his two dear children.

Andy always maintains an optimistic outlook and is full of laughter whenever he talks about his family and children. May his family be full of happiness and joy for many years to come!

The five lessons I learned as father of a disabled child

David Cameron

By staying strong and holding their families together, these parents are doing a great, unsung service to our society.

– David Cameron, Prime Minister of the United Kingdom

My son Ivan was born with a profound disability, and my experience of looking after him has changed the way I see a lot of things – not just as a father, but as a politician, too. Samantha and I went on a steep learning curve. From that I learned five big lessons that have had a direct impact on what my party wants to do in government for those with disabilities and their families.

The first lesson I learned was the importance of early intervention and help. The day you find out your child has a disability you’re not just deeply shocked, worried and upset – you’re also incredibly confused.

It feels like you’re on the beginning of a journey you never planned to take, without a map or a clue which direction to go in. That’s one of the reasons why the next Conservative government is going to increase radically the number of health visitors. I’m not suggesting it’s their job to diagnose disabilities, but for decades they’ve been in the home with parents, spotting warning signs early and offering sound advice. I know how crucial that early help is, which is why we need more of it.

The second lesson was that life for parents of disabled children is complicated enough without having to jump through hundreds of government hoops. After the initial shock of diagnosis you’re plunged into a world of bureaucratic pain. Having your child assessed and getting the help you’re entitled to means answering the same questions over and over again, being buried under snow drifts of forms, spending hours on hold in the phone queue.

I am determined to make life simpler for parents. One option we’re looking at is inspired by something they’re doing in Austria. There a crack team of medical experts – doctor, nurse, physio – act as a one-stop-shop to assess families and get them the help they need. That would have been such a help to us and families like us, so we’re looking closely at the evidence and considering how we could do something similar here.

The third lesson is that we’ve got to make it easier for parents to get the right education for children with disabilities. So many parents get stuck on a merry-go-round of assessments, appeals and tribunals to get a statement of special needs and the extra help their child needs. There’s a structural reason for that. The people that decide who gets specialist education – the local education authorities – are also the ones who pay for it. We’re seriously looking at how we can resolve that conflict of interest so that parents don’t have to enter into such a huge battle for special education.

Something else that many parents have to fight tooth and nail for is a place in special school. Following the gospel of inclusion, the Government has closed dozens of special schools down in the last decade. Inclusion is great for some, but it’s often the case that putting a disabled child in a mainstream classroom is a square peg-round-hole situation. So we’re going to stop the closure of special schools and give parents more information and greater choice.

The fourth lesson is that like all other carers, parents need a break. One of the biggest challenges when your child is severely disabled is finding time to do normal family stuff – playing in the park with your other children, doing the weekly shop, mum and dad going out for a meal.

Respite made a massive difference to my family. Knowing that Ivan was with people who knew him, who would love and look after him gave us a huge wave of relief. Backing respite means backing the voluntary sector, giving parents and carers greater choice over the respite that suits them and looking at all ways of making sure there’s a clear entitlement to respite.

The fifth and final lesson I’m going to share is this. The very painful thing about disability – whether your own or your loved one’s – is the feeling that the situation is out of your control. When the system that surrounds you is very top-down, very bureaucratic, very inhuman, that can only increase your feelings of helplessness.

So a really big difference we can make is to put more power and control right into the hands of parents, carers or those with disabilities – through personal budgets and direct payments. That means that instead of giving a little bit of money from health, from education, from children’s services, we say to people: “Here is the total budget for you or your child, you choose how it’s broken down.” And instead of insisting on separate, bureaucratic bank accounts for that money, it is right people should be paid directly if they choose. This is the support, trust and respect that parents of those with disabilities deserve.

Because we can never forget what an amazing job they do. Just consider what it would mean if the army of parents and carers in this country gave up, packed up, said they couldn’t cope any more. The financial cost of looking after those children would be immense – and the emotional cost doesn’t bear thinking about. We need to recognise that by staying strong and holding their families together, these parents are doing a great, unsung service to our society.

Source: The independent, 16 July 2009

David Cameron, Prime Minister of the United Kingdom, was a father whose son, Ivan, has cerebral palsy and severe epilepsy. His son passed away in 2009. This article was published in UK before Ivan died. It presents what parents feel about having a child with a disability and what parents should seek to achieve to lessen their burden and maximise their capacity in supporting their children – Editor

Stuart speaks out about his daughter

Paul Kent

Ricky Stuart, a famous Rugby League player and is currently the coach of the NSW State of Origin Team, speaks out for his daughter

For 14 years Ricky Stuart, often regarded as one of the more transparent of coaches, has kept a secret.

Not from those closest to him. Not from the media either, who kept the secret safe for the NSW coach until the time came when he believed it was right to reveal it.

Stuart and wife Kaylie's 14-year-old daughter Emma is autistic. She has never spoken a word except "Mum" and "Nan" in a low hum. She has never said "Dad". "We didn't feel we needed to make a big deal of it, our family knew, our friends knew and that was enough," Stuart said.

Stuart has long resisted urges to reveal his own situation, but relented after a recent incident in a McDonald's restaurant when Emma threw a milkshake on him. Fellow diners thought she was a spoilt brat and Stuart believed it was unfair to her for people not to know the truth.

Stuart also admitted that before her proper diagnosis he, too, struggled with her behaviour.

"It wasn't fair on her as a kid," he said.

It still took several months before he fully convinced himself to go public. As he mulled the idea over, he found only reasons to convince himself it was the right decision.

Emma was diagnosed with autism two years ago, after doctors initially diagnosed her with Global Developmental Delay, which gave her parents few places to go for treatment.

He and Kaylie simply got on with the job of raising their daughter as best they could, which would come as no surprise to anyone. But now that the path is clearer, following her autism diagnosis, Stuart has launched the Ricky Stuart Foundation for autism and aftercare*.

"The big picture is to have enough corporate and government backing so we can build the support and hopefully a respite centre," he said.

Stuart's greatest fear is the same one every parent of a disabled child has. "What happens when Kaylie and I are no longer around?" he said. "They have homes for aged care, but not for kids."

"I'd love this foundation to get enough support and backing so that we can build a 10 or 12-bedroom house for them."

** The website of the foundation: http://www.rickystuart.org/*

Source: Sunday Telegraph 29 Jan 2012

A thorn in my heart

A Father

This article may represent the voices of many fathers of Chinese background, however it is also a matter that is extremely difficult for me to verbally convey, let alone in writing.

Most Chinese still hold the concept that out of the three forms of unfilial conducts, the worst one is not to bear an heir to continue the family line. Perhaps you may think this is a stale and backward thought but it lies in the subconsciousness of most Chinese, especially the males. If you do not bear an heir, it will be shame when you face your ancestors and feel sorry for life. The ideal case is to have children and grandchildren all under one roof.

The one-child policy in China caused a lot of tragedies. As there is no such restriction in the Western world, it is common practice to have more than one child, especially a boy, in order to continue the family line. This is reliant on factors such as a couple's financial position to raise more children, a partner's fertility or infirmity including disability.

Sometimes fathers might accept this reality as God's will. Though there are others who are in denial and may choose to take deviate actions. This could result in having an affair, or they could head towards divorce so they can remarry, or bear a child through a surrogate mother, so on and so forth.

My mother passed away when I was very young, and my father also took up a mother's role to look after my sister and I. When my son was born, he was diagnosed as having autism and my family migrated to Australia later. Initially my wife and I planned to have another child after we settled. However, my wife was so worried about bearing another child with a disability, that we finally abandoned the plan.

In a CPA seminar, I learned that people with disabilities can be assessed to determine whether their genes can carry autism to their offspring. This inspired me like a ray of hope.

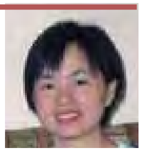
My son looks like a normal person. He is always positive and would never show any worries. He is efficient at work and is willing to help others. He likes watching TV and can memorise all TV programs. He can even fix the sound system when I am not around. It appears that he has learnt by observation though he is reluctant when finding solutions. I asked my wife to take him for a genetic assessment but it has never been put into action.

My son has now approached the age of marriage. I have a friend who married a man with autism. I told her about my son's situation and asked her to find my son a girlfriend, with the possibility for them to get married in future. Some days ago, she found a girl and wanted to introduce to my son, however my wife strongly objected, fearing that autism would be passed on to the offspring. My daughter was also concerned that my son is not able to look after himself, let alone look after a family. Hence the matter was drawn to a halt.

The thorn stays in my heart. I feel that it is unfair for my son. Why can't he live like a normal person, have girl friends, experience romance, get married and have children?

In the same boat

Katherine Wang



Life will become much easier if there is someone who can share with you your worries and offer you mutual support and compliment.

As my son Leon was getting older, the difference in his temperament development as compared with other children of similar age was becoming more apparent. Following serious consultation with my husband, in late 2008, we decided to sell off one of our businesses, to allow me to become a full-time mother to support Leon with his intervention therapy. My husband Tom backed my decision entirely.

In the following year, Leon started to undertake different types of training and therapies. The severity of his disability meant that these processes took up much more of my time and energy. Moreover, we also had to look after my two other young daughters; this further reduced the time for both Tom and I to compromise many of our own needs. Frequently, we had disputes on matters concerning our children's education, and these contentions often spilled over to other small aspects in our daily lives. Fortunately, Tom is in many ways a very supportive husband and he quietly took up an active role in helping with household duties; over time, we were able to live in harmony at home.

In the following year, Leon began to show evidence of improvement in his cognitive well being. I decided to look for another school for him. It had been a prolonged and painful process; it occasionally interrupted his on-going training and therapies. Now and then, I was under a lot of pressure and easily became distressed, probably due to my high expectation. However, Tom was very positive about and acknowledged my work in the caring of our three children.

In May last year, Leon finally was admitted into a local high school. Tom began to encourage Leon's physical development by exercising together with him, shopping or going for a walk. Leon enjoys getting out with his father immensely. It is such a great joy to witness his growing-up.

I have come to appreciate the importance of the support and encouragement from my husband and his willingness to share the workload and problem-solving during our difficult times. Conflicts can be avoided with tolerance and mutual understanding amongst family members. Our harmonious relationship resulted in part from our unanimous goals.

It is inevitable to encounter many hurdles and hassles on our path of life. We can neither avoid nor ignore them. Life will become much easier if there is someone who can share with you your worries and offer you mutual support and compliment.

My beloved husband

Anonymous

My husband is a family man. He is a very quiet person who does not talk much and finds it hard to express himself, but he is always there to give me support.

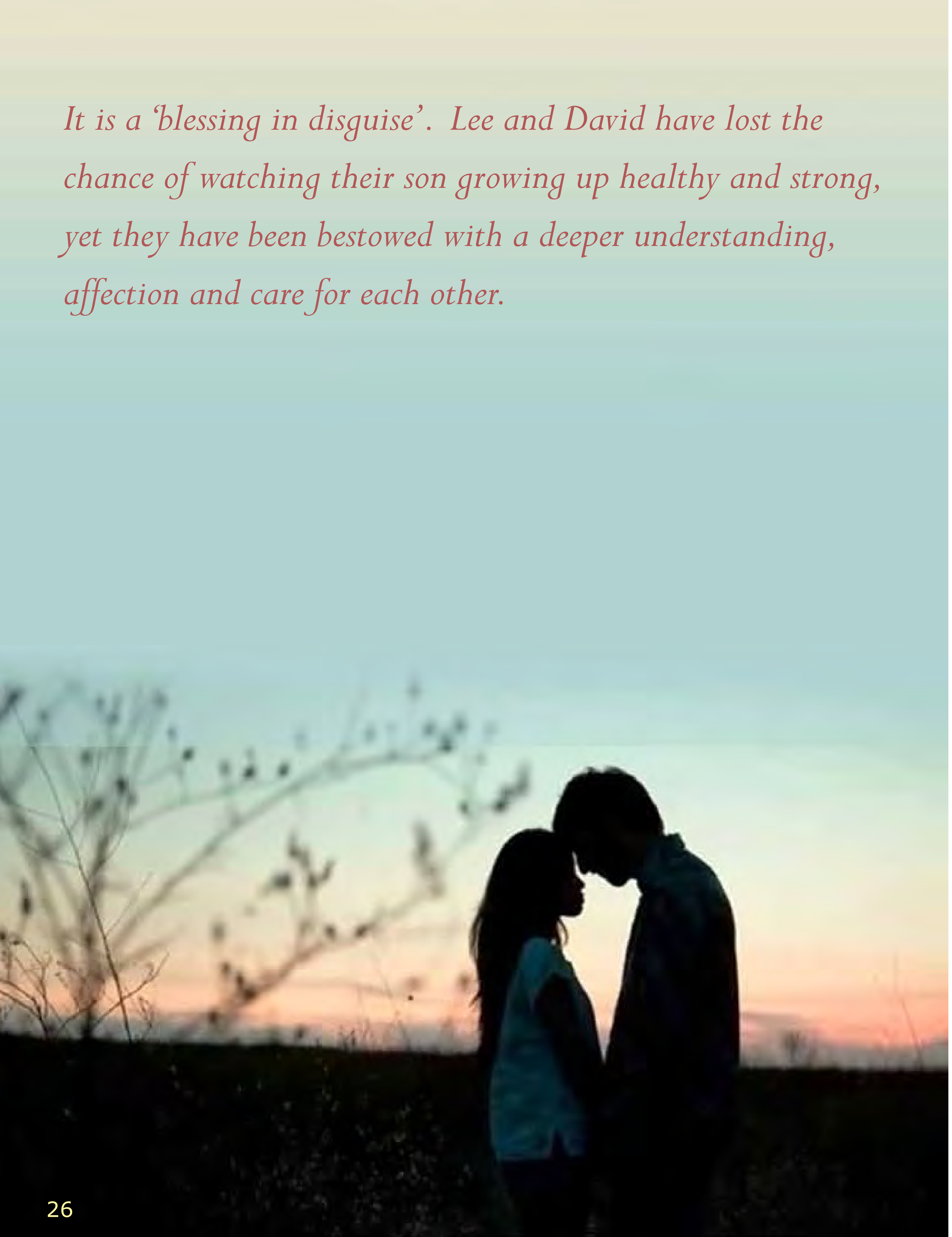
He retired a year ago. Now he spends most of his time at home and does a lot of housework including cooking, washing, grocery shopping, fixing things, pulling rubbish bins to the front yard and gardening - any chore in the house that you can name; he is also my chauffeur. As he has taken up most of the housework, I can concentrate on my full-time job as well as fulfilling my commitment in the Chinese Parents Association as a volunteer.

We found out that our son had a mild intellectual disability when he was three or four years old. My husband and I never discussed how distressed we were when we discovered our son had an intellectual disability. We accepted the fact that he was different from a normal child.

Time flies - our son is an adult now and he is now working in a sheltered workshop. All these years, my family, including my daughter, have gone through some difficult times. Our son's ignorance makes us worry. My husband is quite strict with him. Sometimes, we have different opinions about the way we bring him up. But I know he loves us all.

We are both getting old now and worry about our son's future. Will he be able to live by himself? Who will look after him when we both pass away? We try to train him to be more independent. It is a life-long task but hopefully one day, we will get there.

It is a ‘blessing in disguise’. Lee and David have lost the chance of watching their son growing up healthy and strong, yet they have been bestowed with a deeper understanding, affection and care for each other.



A wife’s message to her husband

Eugenia Liang

Expressing herself in a few simple words, Lee has disclosed her intimate feelings towards her husband David, their love story and affection for each other:

“ I am incredibly blessed to have you by my side. Knowing you, loving you and living together with you for many years, you have brought me an abundance of joy, delight and warmth. Deep in my mind, I will never forget the things that we have done together, and am still touched whenever I reminisce about these memories. Being happy together, having mutual support for each other and staying up all those nights dotted with never-ending conversations … I wish I will spend many more days with you in my life…”

It is always sweet to fall in love. Once the passion has subsided, and both lovers have returned to the reality of life, they are able to find out if love exists between them. During the interview with Lee, she slowly unlocked her memory box and re-visited her recollection of the past.

Lee and David came to Australia in 2003. They were happy that they had a very good start to live here. Very soon came the arrival of their first child. After the son was brought home, they were told that he was an autistic child who will be easily distracted, have a short attention span and have difficulty in socialisation. Lee and David were both shocked by the news, and continuously wondered why this happened to their son?! Lee felt very bad and sorry at the time. But now, looking retrospectively, she has learnt something else – it is her son that pulled her and David closer to each other, allowing them to build a better relationship.

It is a ‘blessing in disguise’. Lee and David have lost the chance of watching their son growing up healthy and strong, yet they have been bestowed with a deeper understanding, affection and care for each other. Lee has been grateful for having David as her spiritual support.

Being a father and husband, David has never complained to Lee; quite contrary, he understands and is tolerant with Lee’s occasional negative feelings. When Lee is feeling down, lonely and helpless, she longs for someone that gives her warmth, confidence and strength. David is her shelter.

David is the breadwinner, looking after the entire family. Lee feels that she is fortunate to have David as her husband who is considerate and never expresses his negative experiences at work when he is home. He also assists in doing the housework, manages and solves other household problems together with Lee.

Most importantly, David is a very compassionate man. He has never given up caring for his child with a disability. Even when his is busy, he is still the son’s great playmate. Hopefully, with his help and guidance, the child will learn to be more relaxed, more confident and more courageous in his life ahead. While Lee has been looking after the special needs of her child, David has already set up his son’s future plan.

Currently, each day, Lee and David lead their own busy lives. Lee works hard at home whilst David has been fully occupied at his workplace. Lee is looking forward to the days that they will have more time to spend together. She has a lot of thoughts and feelings which she would like to share with David, but at present she hardly has a chance! Well, never mind, there will be many, many days to come when they are able to connect more closely and enjoy each other’s company.

My Dad

Jessica Mu

If my sister could write, this is what she would say ...

My Dad, he's alright.
He goes to work so we always have food to eat and a roof over our heads.
He loves playing on the computer. Sometimes he lets me play too.
I love when he reads to me.
My dad, he's alright.

He drives me to places.
He fills in the missing words to my songs.
He lights up my world when he is around to keep me company.
My dad, he's alright and I love him very much.

I watch from a distance and I can see a twinkle in her eye when she knows that she has Dad's attention. Very clearly she'll say, "read 'My Dad'" (a book by Anthony Browne). I think it's her favourite book because it's her way to communicate with him. My sister doesn't use many words to communicate but when she does we know that she means business.

Over the past few years I have watched my family become more involved in CPA. As our involvement has grown, I have also witnessed a stronger bond amongst our four family members. Mum, the primary caregiver, has always been the main instigator for fostering and developing our relationships with my sister. Whilst Dad's main role was to work and financially provide for the family.

As we, the children, have gotten older, Dad has decreased his working hours and utilised some of his spare time to help in CPA. CPA has provided our family a common goal and interest. We discuss suggestions and help where we can. I believe we all want the best for CPA and hope that it continues for a long time to come because it is a place that my sister loves. Watching my Dad give his all to help also encourages me as well. Seeing my Dad talk to the other children in CPA makes me proud. Most of all, when he spends time interacting with my sister I know that she feels special.

** This article has been inspired by Anthony Browne's 'My Dad'*

Author: Jessica Mu is a founding member of CPA's Sibspace, a group that is formed for siblings of members who have a disability to promote mutual support and raise awareness.

What a father can do for his daughter

Eugenia Liang

There is no power on earth like a father's love. He always loves you in his own way. He may be quite, speechless, strict or bossy, but he is always there. The image of a father is always deep and tall. He gives you shelter, gentle protection, endless support and dedication. He may not be warm, talkative or sweet, but he is always there, especially when the world is cold and cruel.

The above descriptions of paternal love come from a sweet girl – Eleanore, who is devoted to the study and performance of music. Just entered the door of university, her future is full of light and hopes. But her growth process is not always sweet. Compare with children from the same age, Eleanore is careful, thoughtful and highly independent. One of the main reasons is because she always needs to take care of his younger brother, who was diagnosed with autism.

Eleanore's only brother is seventeen years old. Family members were thrilled to welcome a new member to the family, however, with the birth of her brother, also came with some unexpected pressures. At an early age, her brother was diagnosed with autism, thus his physical and mental developments are always slower than other children. His mood swings will be larger.

As a big sister, Eleanore is expected to take care of her younger brother, as well as performing numerous housework tasks. During these processes, she developed an independent personality. Nevertheless, there are times for all of us to experience doubts and confusions. Like all children, when we are lost, we will seek helps from our parents.

Compare to the gentle and warm impression of a mother, Eleanore's impression of her father is lack of time, lack of words to communication and lack of hugs. He has a tide work schedule and is always on the run. In his spare time, Dad loves to drive and travel. When spending times with the family, father is quite, not particularly fond of sharing feelings and thoughts. However, Eleanore can still sense the love from her father is truly there, and always will be there.

Search in the memories of the past, Eleanore is most impressed by the silent love of her father. Although they do not communicate all the time, but he is there when she needs a hand. The most memorable exchange of feelings and thoughts happened by chance. One evening, father was able to spare some time and took a walk with her. They discussed about a lot of things, including directions of life, how to face problems and make up tough decisions, how to make study selections or how to choose study targets or goals.

That was the first time she had a deep conversation with her father. It was unexpected and happened by chance, but she could truly feel the love from her father, like a guardian, like a light in the dark. The presence of her father and his supports give her the strength to go on with life, to make choices and to face problems. Because she knows that no matter what happens, her father will always be there to accompany her to go on to the next stage of life.

One simple conversation, carved the feeling of paternal love into the heart of Eleanore. She realizes that even though he is always occupied, but he did not forget or ignore her. On the contrary, her father is always there to provide, to support and to observe silently. Father's love for her is everywhere and always there. As life goes on, they will have more opportunities to communicate and share feelings. Their relationship will continue to consolidate over time. Given the chance, she would like to tell her father: "Daddy, I love you!"

Kimberly's view of father

Kimberly Zhou

My Dad is clean, not clumsy, organized, efficient, proficient, passionate, not rude, nice, professional, a great chef and has a great sense of humour!

A father's love

Karen Yuan, Eleonore Vuong, Kimberly Zhou

Fathers are important to families in supporting all children including siblings who do not have disability. We asked some siblings to describe their Dads. Here are their replies and their graphic depiction of their dads.

Always there for me even though he is risking his own life

Constant, reliable, warm and quietly shows his love

Cooks yummy food for the family

Can amazingly fix things when they are broken

Always puts everyone first

Courageously left everything he knew to build a better life for his children

Strong and reliable rescuer

On the train

Chun Wing Fan

On the train, the father and son sat close to each other. Concentrating on a piece of paper filled with some maths exercises, the father kept talking softly to help his son to find a solution. I knew both of them from the CPA circle; the son has autism and intellectual disability, and is a student. They were so focused that I did not want to interrupt them.

It appeared that the son must have been on his way to attend an exam or present an assignment; and the father, on his way to work, was determined to make use of the 30 minutes train time to help and support his son. Passengers came and went, but it did not disturb them.

I watched them from behind and felt strongly of the father-son bond, filled with an intangible common wish to overcome a barrier - a barrier not always straight forward or natural. For a parent to support his child with a disability, the barrier can always be like an uphill battle.

I recall seeing parents helping their child to learn how to walk; parents jumping and dancing in front of their children to motivate them in musical sessions. I recall a parent who instructed his child to follow him to say something to greet a friend. I was very touched by a youtube video showing athletic fathers who deliberately took their disabled sons in the races – marathon, cycling, rowing, swimming and others – to share their life experience and to show their love for their child (1).

These may look like normal parent-child interactions or teaching, but what aroused special attention is when the child is of older age and has a disability; and when the interactions involved would otherwise be unusual for a child of that age. Others may find it odd, but the parents are very persistent, focused and determined to make progress, disregard of what others would say or perceive.

Back on the train, the father explained time and again and used pencil to draw and demonstrate. It was very clear that he wanted his son to be able to do the exercises just as other children did. He was very patient and determined to achieve this aim. The gesture was clear – he wanted his son to do what other children can do, to achieve what other children can achieve, despite his disability that remains a hurdle for both to overcome.

Over the past years, I have noticed a significant change of profile of carers and volunteers in CPA. Many years ago, with very few exceptions, all parents and volunteers were mothers and I could hardly see a father who took an active role to take his son / daughter to attend CPA's functions. Even if they came, they only provided driving service and would disappear soon. Even if I invited them to come in, they would decline.

In recent years, the presence of fathers has started to become increasingly obvious, providing a supporting role to mothers/volunteers in the functions and talking to one another. There are a few fathers who are elected to the Executive Committee and they are more vocal in decision making. The Dad to Dad group has provided a platform for fathers to meet and share. A few fathers have taken a leading role in organising activities, especially outdoor sports.

This development has coincided with the change of needs of our CPA members. When they first joined CPA, most of their children were in childhood and their needs were generally basic. At an early stage, the concern was to motivate them to have an interest in early intervention activities. Mothers, as things stand, spent more time with them as primary carers and the fathers' role could remain secondary.

As many of our members have now reached adolescence and early adulthood, fathers have gradually become more involved in matters that affect longer term development of their children and family. CPA is where you can find examples of role models for fathers who support and assist their children with disability; they share the burden of their partner as supporters and occasionally as primary carers. They also provide support to other siblings. They are often the economic backbone of a family and are required to provide leadership at critical moments in the child's development as well as the family.

Having known these CPA fathers for some time, it can be noted that some fathers are more fragile than mothers in receiving the initial news about their children's disability. While grief is a common reaction to both parents when they found out that their child has a disability, in most cases, it is the father who would experience a longer period of grief. In research, it has been found that fathers would have a bigger chance of depression, in much longer episodes, as compared to their wives.

Generally speaking, it can be in the nature of a 'man' that most fathers are more reluctant to talk about their feelings and frustrations, even with family and friends, let alone taking an initiative to consult a professional. Fathers who are more closed up tend to experience a longer period of shock, anger, sadness, fear and resentment.

Having a child with disability means the child may need constant supervision and care during infancy, childhood and later parts of life; and this will correlate with the severity of the child's disability. The stress level, relating to this long term and intensive care without seeing the final end point, is always high for both parents, especially at times of isolation.

While a mother's stress is normally associated with the pressure in coping with additional amount of physical and emotional care of their child, father's stress is likely to relate to coping with the family's financial demand. Because of these stresses, emotional disturbance such as anxiety or depression are common for CPA families.

Some families can never resolve these conflicts or settle these stresses. We occasionally hear of sad news about family break-downs, starting with relationship strains between the couple, very often over stress associated with looking after the children and/or family finance; this could be followed by separation or divorce. In these cases, the children's well being is more likely to be affected.

In CPA, successful cases of a father role model is built on the father having a good relationship with the mother and who is more likely to be spending time with his children including a child with disability. As a result, the children are more psychologically and emotionally healthier.

Similarly, a mother who feels affirmed by her husband and has a better marriage relationship is more likely to be a better primary carer for the child with disability. Indeed, the quality of the relationship affects the parenting behaviour of both parents and has a direct positive impact on the well being of the child with disability. A strong family relationship includes good marriage relationship, which leads to stronger parent-child bonding and better outcomes for children.

In psychology, the term 'resilience' refers to the idea of an individual's tendency to cope with stress and adversity. This coping may result in the individual "bouncing back" to a previous state of normal functioning, or using the experience of exposure to adversity to produce a "steeling effect" and function better than expected. Using 'resilience' to reflect on CPA families is very relevant and a positive father's role is crucial in leading to this effect.

The father and the son on the train represented a testimony of the positive father-child bonding. The son who has the involvement of his father is likely to be more emotionally secure and more confident in his venture in this new world of study. Though the disability remains a hurdle, it is not something that cannot be overcome.

(1) http://www.youtube.com/watch?v=eG-GMXcNaqo

The author Chun Wing Fan has associated with CPA for more than 20 years. He is a trained social worker and is currently working for the NSW government.

What to do when your child is 'naughty'?

Some children with disabilities also exhibit symptom of hyperactivity. Dr Wong, a psychiatrist, states a child who is hyperactive may behave aggressively and out-of-control in public. This often would embarrass the parents who would feel losing face.

Dr Wong suggests, under safe circumstances, parents should let their children express their emotion and avoid having conflict with them; blaming them being naughty would only make the situation worse. When the child becomes too aggressive, the parents can make an attempt to hold the child's hand tightly, embrace and comfort him or her.

Often the hyperactive child is perceived by the parents as naughty and rebellious. Dr Wong advises parents should find out what hyperactivity is. The child's behaviour is out of their control largely due to concentration deficiency. Consulting medical practitioners and counselling could help to improve parent-child relationship.

Dr Wong implies that if the parents are suffering from emotional disturbance themselves, they may become impatient when taking care of their child. It is a vicious cycle. It will be vital that the parents should take care of their own health by seeking medical advice and receiving proper treatment, and then they are able to cope better with caring for their child with a disability.

子女「唔聽話」怎辦好？

有些弱能兒童都同時會有過度活躍的問題，甚至是一種症候。精神科專科醫生黃重光表示，患過度活躍的兒童可能在大庭廣眾下吵鬧，雖然令家長沒面子，但在安全環境下，他建議家長可任由子女發泄，避免正面衝突，這時亦不應長篇大論，「做乜咁曳」之類的批評更是大忌。當子女「郁手郁腳」，家長可選擇握緊子女拳頭、攬着對方作安撫。

過度活躍兒童往往被父母誤會成頑皮、反叛，黃重光表示，家長首先須了解何謂過度活躍，體諒子女「唔聽話」多因身不由己，專注力差造成，帶孩子接受治療、訓練，對親子關係會有幫助。

黃續稱，若家長本身有情緒困擾，耐性會變得更差，照顧子女更顯得力不從心，情況只會陷入惡性循環。他建議家長應先正視自己問題，無論是對於自己或子女的病，都切勿諱疾忌醫。

What are we concerned about?

Vincent Yu

With funding from local councils, some CPA parents had enthusiastically organized a number of meetings since 2009, targeting CPA fathers who have a child with disability. As we all worked in the day, these meetings were held in the evenings and this had not deterred our members to participate. Of course, we need to thank our wives for their supports. In some meetings, we would invite family members to join so all could be benefited from the discussion and inspirations from our guest speakers.

Since April 2009, the "Dad to Dad" project was initially a social function for fathers. Daniel Yung, the founding coordinator, led the 2009 meetings and he proposed that the function should not be confined to social gathering only but should also aim at exchanging experiences and ideas amongst fathers.

Since I took over Daniel's roles as coordinator after 2009, I had organized 15 functions between 2010 and 2011. A number of issues have been raised and discussed in our meetings including inputs by guest speakers and they are outlined as follows:

Social Enterprises

We were interested in a report by Mr. Chun Wing Fan on the development of social enterprises in Hong Kong. This could be an employment model that helps people with disabilities to be independent so they can take on a more active role in the community. It triggered our concern about the future employment opportunities for our children and difficulties to find a job. Can we setup a social enterprise to help our children with cultural and linguistic difficulties?

Employment opportunity for people with disabilities

Ms. Audrey Honsebey from Sydney Employment Development Services shared with us information on job prospects for people with disabilities. Members were interested to know the conditions required of our children who participated in the Transition to Work programs or sheltered workshops, especially the prospect for people with disabilities to obtain a stable work so they could support themselves independently in future. Members were pleased that Ms Honsebey offered to provide information and assistance to our members in future.

Sex Education

Ms. Liz Dore talked about how parents should need to deal positively with sex development of their children with disabilities, as part of the overall development, rather than suppressing it. It opened our eyes and mind to see what could be done and what need to be learnt in this area which is an important issue to many fathers.

Government funding policy

Professor Karen Fisher and her Co-worker came to explain to us the government's independent support living funding policy in which the government would provide funding that offers a choice for carers and the clients, so they can decide on the kinds and quality of services that would benefit them.

Legal matters – Will

While many members may not have much idea about legal matters in relation to supporting their children with disabilities, we had the pleasure of inviting a specialist lawyer, Mr. Stephen Booth, who helped us to understand how and why a will should be made. Ms. Hong Ong from the Department of Attorney General presented information on legal matters in relation to people with disabilities and had offered valuable advice for our members.

Health consciousness and good diet

Dr James Chin and Mr Don McNicol gave us good lectures on health nourishment in relation to body and mind. There were a few functions that focused on healthy life including a lecture by Vincent Yu on Qi Gong and simple exercises to improve body circulation system. Dad to Dad had organized a ball room dance, led by Mr. William Mo, in which many of our parents expressed an interest in having more sessions in future.

Conclusion

Dad to dad is a very important mutual support network in CPA as it provides a platform for fathers to get together in a relaxed environment. It promotes sharing of experiences and ideas, and ultimately, a mean to support CPA families in helping their children with disabilities.

Author: Vincent Yu, Dad to Dad Coordinator

What is Disability Council of NSW?

The Disability Council of NSW is the official advisory body to the NSW Government on disability matters; it also provides advice to the Commonwealth on the effect of national policy at State level.

The Council seeks to provide the best quality advice to Government and promote a positive vision of the future for all people with disability. There are 12 places for membership on the Disability Council which is a committed group of people with a balance of diverse life experiences and professional experiences in disability policies and practices. Mrs. Unis Goh was appointed by the Hon. Andrew Constance, Minister for Ageing and Disability Services in July 2011

For more details please visit the website www.disabilitycouncil.nsw.gov.au.

紐省弱能人士議會簡介

紐省弱能人士議會是紐修威省政府在殘疾服務和事務上的法定咨詢機構。它也在影響全國的政策議題上向聯邦政府提供意見。

議會為政府提供最佳的意見，並致力推廣殘疾人士在未來的正面形象。議會共有十二個席位，包括在殘疾政策和實務方面富有經驗和來自不同背景的人士。有華人背景和富有社會服務經驗的吳于艷華女士在2011年7月獲現任老年和殘疾服務部部長 Hon. Andrew Constance 委任為議員。請溜覽紐省弱能人士議會網站 www.disabilitycouncil.nsw.gov.au□

Community Resources

Peter Wong

Legal Help
法律支援

Find a list of local Legal Aid offices at:
http://www.legalaid.nsw.gov.au/asp/index.asp?pgid=20
1300 888 529

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

Level 4, 74-76 Burwood Road
Burwood NSW 2134
Tel: (02) 9745 6155
Website: http://www.legalaid.nsw.gov.au/what-we-do/civil-law/mental-health-advice

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

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

Tel: (02) 9310 7722 (voicemail)
Tuesday Wednesday and Friday 9:30am - 12.30pm
Website: http://www.ddlcnsw.org.au

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

Information and Referral Services
訊息及轉介服務

Statewide Behaviour Intervention Service
紐省行為干預服務

Ageing Disability and Home Care – ADHC Department of Family and Community Services

Building B Level 1, 242 Beecroft Road,
Epping NSW 2121
Tel: (02) 8876 4000
Website: http://www.adhc.nsw.gov.au/sp/delivering_disability_services/behaviour_support_services

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

ADHC Region Contact details

Metro South - covers Sydney, Strathfield, Bankstown
Phone: (02) 9334 3700
Information.Referral@facs.nsw.gov.au

Metro North - covers Parramatta, Blue Mountains, Ryde, etc
Phone: (02) 9841 9350
MetroNorth.Intake@facs.nsw.gov.au

Family Advocacy
家庭倡議

Tel: (02) 9869 0866
Freecall: 1800 620 588
Website: http://www.family-advocacy.com/

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

社區資源

王友國

Brain Injury Association
腦部受損協會

17 Macquarie Road, Auburn NSW 2144
Tel: (02) 9749 5366
Freecall 1800 802 840
Website: http://www.biansw.org.au/

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

Carers NSW
紐省照顧者協會

Level 17, 323 Castlereagh Street,
Sydney NSW 2000
Tel: (02) 9280 4744
Website: http://www.carernsw.asn.au/

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

Guardianship Tribunal
監護仲裁會

Level 3, 2a Rowntree Street,
Balmain NSW 2041
Tel: (02) 9555 8500
Freecall: 1800 463 928
Website: http://www.gt.nsw.gov.au/

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

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

Justice Precinct Offices
160 Marsden Street, Parramatta NSW 2150
Tel: (02) 8688 6070
Freecall: 1800 451 510
Website: www.lawlink.nsw.gov.au/opg

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

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

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

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

Compiler

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

資訊由王友國編寫.王先生是資深的移民社會工作者, 他退休後仍積極參與義務工作,他是協康會的社會服務顧問

協康會的歷史

澳洲弱能兒童協康會(前身為華裔弱智及傷殘子女家長會)是由一群有弱能子女的華裔家長組成,於一九八八年正式成立。澳洲弱能兒童協康會沒有宗教或政治立場,以非年利慈善團體註冊。其成立的目的是為弱能人士提供服務,活動及提倡一個關懷的社區,使弱能人士得到最理想的成長。通過互相帮助,為弱能人士及其家人提供生活和精神上的支持。

管理委員會是澳洲弱能兒童協康會的會務最高決策組織,策劃審核計劃,政策及服務方向。還有一組義務工作人員,獻出他們的時間,專業知識,技能和支持,幫助處理澳洲弱能兒童協康會的日常事務。

我們的信念

弱能人士,無論是何種膚色、種族或信仰皆應獲得平等對待及享有豐富及多姿多采的生活。

我們的使命

致力為弱能人士提供一系列服務,尤其是華裔人士,使他們能夠得到適當的照顧,及推廣一個對弱能人士關懷備至的社會。

鳴謝

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Chinese Beneficence Federation of Australia Incorporated 澳洲華人慈善總會

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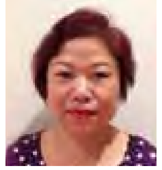
Congratulation to Miranda Vuong whose suggestion was selected through voting:
“Deep In Dad’s Mind - Raising a child with a disability” 『爸爸的心事與期望』

特別感謝協康會會員為今期協康集之三的書名建議命名。共收到39個建議。
恭賀王太，她的建議經投票及整理後，獲選為今期書名名稱。

會長前言

李羅艷娟



我十分高興向大家宣佈協康集之三已出版了。

今期主題是圍繞著有弱能子女父親的心聲，經驗和感受。對我們這些家庭來說，父親的角色是非常重要的，家庭和諧和快樂與父親的領導和支持，息息相關。但我們也很清楚，由於長時間照顧有特別需要的孩子，家庭內都不時會有不同的壓力和意見，導致爭吵和不歡，都需要夫妻兩人冷靜面對和處理。

大多數男士都比較沈默，不喜歡和不容易表達自己的內心世界。但是，在協康會成員家庭中，不少父親都是默默的支撐家庭，支持他們的配偶和其他子女，在幫助自己的子女成長上，扮演一個重要角色。

協康集之三深入探討父親的責任和角色，使家庭內增加互相了解和體諒，以促進家庭和諧。

藉出版協康集，我們也以此回饋社區對協康會的長期支持和關懷。希望我們的分享，對社區內其他家庭也有所啟示。我也代表執委會感謝協康集編委會各位成員，作者和義工。他們的辛勞和所付出的寶貴時間，令今期協康集內容更加豐富。也感謝所有資助我們的團體，特別是好市圍市的 Club Central，富麗宮酒樓，朱署南先生，今次是他們第二次支持我們出版協康集。

致讀者

范鎮榮

首先，我要感謝所有協康集之三的作者，他們的貢獻使我們對有弱能子女父親的概況，有更深入和廣泛的了解。文章包括父親自己的描繪，也有配偶和子女提供的軼事，和社區人士的觀察分析等。

很多作品，特別是父親的文章，要他們講述自己兒女，家庭，甚至婚姻關係，的確不是容易的事。許多時，他們都會把這些事埋在心裡。要他們願意執筆成文打開心扉，的確是向前跨了一大步。一些文章是通過向父親作深入的採訪而成，我要特別感謝梁玉華和吳于艷華兩位所作的努力。

他們的故事都有很強的感染力，故事訴說一些家庭如何在人生的谷底，在充滿失望，擔憂和焦慮的情況下掙扎求存和反彈。許多家庭都能回復正常，一些更能練就鋼鐵一般的力量。很多情況下，父親幫助撕裂開的家庭回復穩定，在面對迷惘的前路上，支持傷心欲絕的配偶，安慰家人和輔助子女。

但我們都知道，不少父親在過程中也經歷過很多痛苦。弱能子女的父母們在漫漫人生旅程是甘苦相伴。在子女成長的過程上，每每都有新的考驗。我們慶幸很多家庭能夠克服困難，穩步向前。同時，我們也知道有些家庭抵受不了壓力煎熬，有些更導致家庭破裂，這些家庭實在是需要我們更多的支援和同情。

配偶和子女的文章肯定了父親肩負重任和不離不棄，是使家庭能夠反彈的重要因素。在我們所收到有關協康集之三主題命名的39份建議裡，所有建議對父親的角色都是肯定和讚賞的。

協康集之三的制作時間長達五個月之久。我們組織了一個編委會，通過幾次業務會議管理制作過程，一些義工執筆為文，一些幫忙翻譯，校對和編輯，一些擔任聯絡和外務。我們在去年底亦舉辦了一次成功的父親論壇。這些都是多謝義工們不懈的努力。

今次出版協康集之三，我們希望能夠引起更多社會人士對弱能子女父親的關注。因為這些父親的努力能使自己家庭由谷底中再振奮起來。要有效地幫助這些家庭，我們需要支持這些父親。他們的故事給我們帶來一些啟示，他們是值得我們讚賞和認同的。

華裔殘疾兒童父親的挑戰

吳于艷華

PSM 紐省殘障人士議會會員

前言

寫這篇文章過程中，我曾與協康會數名父親有好幾次深入的傾談。我很感謝分享了他們照顧殘疾兒童的經驗，期望和憂慮等。這些分享不但啟發了我，更為文章的構想提供了很多寶貴的見解。我有幸被邀提供文章，盼望能藉此廣泛引起社會人士對殘疾問題的注意及興趣。

殘疾兒童的父母的主要挑戰

育有殘疾孩子的父母會遇到許多挑戰。第一個挑戰是初為人父和人母。第二個挑戰則是成為一個殘疾孩子的父母，而挑戰就正正在於不曉得及不肯定及如何去養育這個殘疾的孩子。

這些不明朗的因素直接影響了父母的生活及夢想，同時也影響了家庭中的兄弟姊妹。這對他們的身體，情緒及日常生活都做成很大的壓力。

養育殘疾兒童比一般家庭需要更多額外的費用，例如醫療、牙齒保健、飲食、語言治療及學習等，這都會導致家庭面臨財政上的緊張和壓力。

照顧殘疾兒童需要特多的時間。父母往往因為不夠時間去照顧其他家庭成員及自己而感到挫折。而由於缺乏時間和精力，未能與朋友、親戚或其他人仕接觸和聯繫，結果做成個另一個挑戰，就是自己與社會隔離。

這些挑戰雖然為您在照顧孩子的過程中帶來很多艱辛和困難，卻也可以成為豐富的生活經驗，為您的生活帶來意義和目的。每次經歷這些挑戰和困難的同時，都有助加強您育兒的能力，最終您都會知道，您已經給予孩子最好的照顧和支持。非常重要的是要抱有盼望，相信您的孩子仍然可以實現他們的潛能和能夠過有意義的生活。

父親在照顧孩子和支持家庭的獨特角色

過去，父親是家庭的領導及支柱，是婚姻關係和家庭的最終決策人，但在照顧初生兒上，母親仍是主要的照顧者。在最初 9-12月，母親經常會就餵食、輪流睡覺或做家務和如何適應及面對殘疾的孩子等問題上，而經常向父親尋求即時的情緒及體能上的支持。孩子的殘疾可能在出生時已察覺到，有些時要到幾年後才知道。

孩子小時候，父親可以為他們作一些輔佐性的照顧工作:例如洗澡，換尿布，餵食等。家務工作方面，父親可參與烹飪，清潔，購物，付賬單，交通接送，尋找信息和資源等，有助了解自己孩子的特別需要。

隨著孩子漸長，父親的角色和責任日益增多，他們需要更多為孩子作榜樣，並支持妻子和其他家庭成員，讓孩子體驗到愛心，親情，和監管孩子各方面的發展與學習里程碑。此外，亦要支持母親在孩子行為管理方面，與專業團隊（言語治療師，職業治療師，心理學家，營養師，醫生和其他醫療和教育專家等）的合作，聽從他們的建議。

父親有很大的責任去確保家庭有足夠和穩定的收入。更重要的是，夫妻要共同努力，在確保家庭經濟穩定和照顧孩子之間作出適當的平衡。有時父親可能需要負上照顧孩子的責任而讓母親去繼續她的工作。如有需要，父親可以分担照顧其他沒有殘疾的孩子，及家中的老人如祖父母等。

在現今澳大利亞社會中，工作場所已有明文立法規定夫婦育兒的假期，讓夫婦可以一同分担照顧孩子的責任。最重要的還是夫婦間需要互相支持和有良好的溝通。這樣担子就會輕鬆得多。

殘疾服務的未來轉變

政府是知道這幾十年來殘疾服務需求是與日俱增，卻仍沒有足夠資金去滿足所有的需求。在將來，政府會提供更多的服務，供殘疾人仕的家人和照顧者，支持他們能更好地幫助孩子實現獨立。以下讓我解釋一下這些發展的大概。

國家殘疾保障計劃 (NDIS)

目前，聯邦，各州政府和殘疾服務業界正大力推動國家殘疾保障計劃（NDIS），並計劃在2013年實施，這項計劃是幫助殘疾人士，他們的家人和照顧者，使他們有更多的保證，在將來獲得足夠和合適服務和支援。計劃對象是各類殘疾人仕包括先天和後天的殘疾人仕，有慢性疾病和心理健康疾病的人仕，為他們提供更多的金錢援助和更好的服務支援。

”Stronger Together 2” - 擴大殘疾服務系統

在2006年，新州政府已實施一個名為 ”Stronger Together 1” 的計劃，這計劃已成功地擴大殘疾服務系統，使更多人受惠。該計劃現正進入第二個5年階段名為 ”Stronger Together 2”，並將繼續擴充，好讓殘疾人士，其家人和照顧者，透過”以人為本”方法，有更多的機會參予控制和決定他們需要什麼的服務。

<以人為本>的服務模式(PCA)

新州政府殘疾服務將於2013年推行<以人為本>服務模式，正正是為了使您更容易獲得殘疾服務。

這服務模式方法是把殘疾人放在決策中心，嘗試將從根本上改變撥款制度，使殘疾人，其家庭和照顧者對服務的資金分配有控制和決策權。這樣會為主流和殘疾專科服務帶來更大的靈活性，更能達到資金運用的目的。目前州政府正推行廣泛社會諮詢，直至2012年底。您的寶貴意見和建議，將有助推行和達到<以人為本>的目標。歡迎您參與諮詢研討會，或溜覽 www.adhc.nsw.gov.au/pca。

“聯合國公約”有關殘疾人仕的權利

2008年澳大利亞簽署了“聯合國公約”有關殘疾人仕的權利條文，並於2010年11月在聯合國人權理事會提交了第一份國家報告。報告指出，“澳大利亞在制定一個全面的政策框架，旨在帶來主流服務和活動的變化，使殘疾人仕與其他澳大利亞人享有同等的機會”。

以上你可以看到殘疾服務的重大變化，的確是令人興奮的，它帶給我們將來的希望。從以往以慈善為基礎的模式，將從根本上轉變為以人權為基礎的模式。殘疾的障礙將被消除，以便在未來實現更多的自主獨立。

這些改變對華裔父母來說是更好或是更差?

如果我們關注和及時參與這些改變，我們華人將會得益。在澳大利亞任何一位父母都有同等的權利去獲得優質服務和及時的支持。如果華裔父母能好好利用這個機會，就好像任何其他澳大利亞的父母一樣，一切都會變得更好。

和我一起討論的數位父親指出他們由孩子一出生就已經與他們的妻子分担照顧的責任。夫婦為更好的照顧殘疾的孩子，不惜犧牲自己的職業生涯和改變生活方式。他們的意見都是由心而發，並已顯示出他們對殘疾孩子不變的承諾，無盡的愛和永恆的盼望。他們都希望有更好的殘疾服務，好支持他們繼續幫助其有殘疾子女，使他們將來能夠獨立生活。

我希望本文能引發華裔父親及母親在悉尼養育殘疾孩子的共鳴。我想鼓勵您關注殘疾服務的發展，並採取行動，在2012年參與政府的 <以人為本> 的持續討論。您的付出可以帶來真的改變。

特殊的爸爸，非凡的分享

勤勤

在育有特殊需要孩子的社群中，研討課題常常聚焦在孩子身上，例如：如何因材施教，如何使孩子們融入主流社區、盡可能學習獨立等等。而以家長或照顧者為對象的課題相對較少，尤其是父親的角色往往受到忽略。而被忽略並不代表父親在養育這些孩子的過程中，功過不存在，有鑑於此，協康會在2011年12月初舉辦了一次研討會討論父親的角色和責任，還特別邀請了心理輔導員陳鄭鳳儀作主持，當晚有七位家長出席討論。本文旨在以紀實的方式，記載當天研討的內容。

陳：請大家談談，身為爸爸，照顧有問題的孩子的經驗是怎麼樣的？

Sam的兒子今年十九歲，在他兩、三歲時被確診為天生染色體有異，引致整體發展遲緩。Sam兩夫婦當時彷如晴天霹靂，難以接受。他們反覆自問，兩個家族中都沒有這種先例，為什麼會發生這種事情呢？對未來的路，他們也感到十分徬徨，帶著一個這樣的孩子，整天要照看著他，什麼都做不了，該怎麼辦呢？身為基督徒的 Sam 夫婦最後還是接受了這份天賜的禮物，還盡了最大的所能，讓這份“禮物”與別的“禮物”沒有不同。坊間盛傳的各種正方偏方，他們都試遍了：帶孩子做頭皮針灸、喝幾萬元一劑的藥…讓他們感到效果較顯著的是舌針，他們聲稱孩子在做過三次療程後，講話的能力進步了很多。

這條路，走起來還是很孤獨的，Sam 說朋友很難幫到他們，因為朋友們沒有這種孩子，難以理解他們所面對的困境。即使在教會內，他們也感到被排擠的無奈。

Jeff自謙，養育自閉症的兒子的經驗並不成功，因為他們兩夫婦否認兒子有病這個事實的時間太長。兒子從上幼稚園到小學三年級期間，老師都不斷地向他們指出他可能有自閉症。但是他們眼中的兒子並不見得有問題，至少他能說會道，學業方面亦中規中矩，參加三年級的統一測試成績還高於平均線。但經不起老師一而再，再而三不斷的敦促，Jeff夫婦終於帶兒子去做測試。結果似乎並沒出乎他們所料，連心理學家都表示他們的兒子的智商正常，這就更加堅定了他們認為兒子沒有問題的信念。

但是，這個堅定的信念，漸漸還是遭兒子的異常行為所瓦解了。終於，在兒子上四年級時，Jeff夫婦將他從一間主流學校轉到一間設有支援班的學校。這標誌著他們真正接受兒子有自閉症這個殘酷的事實。

Jeff 以自身的經歷特別提出了幾點寶貴心得，希望對未來有可能面對同樣問題的家長有所幫助：

1. 年幼的自閉症孩子與正常孩子的差距可能不顯著，因而往往被家長忽視，但是隨著年紀的增長，這種差距會與日俱增。而家長所持的否認或忽視的態度往往會使孩子錯過了及早培育和幫助的時間；
2. 沒有自私概念的孩子可能有自閉症；
3. 要調整對孩子的期望。不要企圖認為只要付出多幾倍的時間或精力去幫助孩子的學業，就可以讓這個孩子趕上其他正常孩子的水平；
4. 提高社會人仕對特殊需要孩子的認識尤為重要；CPA 這類團體需肩負起這種社會責任。

Andy 是這些父親中說得最簡短但能看得出最安心立命的一位。17年前，兒子的降生所帶來的喜悅稍瞬即逝，當醫生告訴他們夫婦這個孩子骨質較弱，很可能長大了都不會走路，及其他各種發展都會較緩慢時，這兩位新爹媽聽罷也只是”哦”了一聲，無怨無悔地拉扯著孩子走過了十多個春秋。他覺得夫婦之間相互支持在哺育有病的孩子這一歷程中尤為重要，他甚至覺得因為這個兒子，讓他們兩夫婦的關係拉得更緊密。

這個孩子5歲才會走幾步，其間遭遇的困難可想而知。可是他像在談笑一件平常不過的事：「街上經常有人問：這麼大了還要抱？」我只有笑一笑說，他有病呀！就算了。他們泰然的態度令人動容。為了費多點時間在兒子身上，他們在兒子11歲時，才再添了一個可愛的女兒。

Bruce 女兒甫出生便被證實是唐氏綜合症患者，這對於首為人父母的Bruce 夫婦來說是莫大的打擊。在太太出院前幾天，他們夫婦兩人陷入了一個激烈的內心交戰中....

「我們是否真的有能力養育這個孩子嗎？」

「讓別人收養孩子會不會更適合呢？」

「這條路應該怎麼走呢？」

最後他們還是把孩子抱了回家。其後，Bruce 家中又接連發生了幾件令人震驚的事件，這些遭遇讓 Bruce 明白到磨難是人生的一部分，其曲折程度往往更甚於戲劇。因此，唐氏綜合症的女兒實不算是什麼，他們把生命的坎坷視作磨練，變得更堅強。

為了照顧這個有病的女兒，Bruce的太太辭去了銀行工作，陪著她做了大量的早期培育。Bruce感激澳洲政府和學校給予特殊需要孩子的照顧。這個女兒在主流學校的支援班就讀，除了說話較弱外，其它的表現還令人滿意，在學校的進度也可以，還交上朋友。

陳：從你們的分享，我發現你們都能非常正面地面對你們生命中的波折。你們非但沒有停頓在失落的情緒中，且能體會比上不足、比下有餘的道理。你們各人可否例舉一樣最能幫助你們、讓你們能堅持下去的東西？

Sam回答得乾脆利落；他說是協康會！看到兒子在這裡可以與年齡相若的孩子一起玩耍，他覺得很開心，家長之間亦可以互相傾訴分享。他眼見著協康會由無到有。所以，他對這個會是鼎力支持的。

Jeff就覺得外界社會對特殊需要孩子的認識和醒覺對他們的存在和未來發展都有幫助，如果主流社區能更多了解特殊需要人仕的生命模式，對接受他們融入主流社區甚為重要。另外，父母對孩子無盡的愛、為孩子謀求最大福祉是父母的的本能和動力。這種動力讓父母不斷自

我調整，而非企圖改變兒子。這些調整，包括對兒子的期望、選校、發展的方向等。正因為父母學會了調整，他們可以從養育特殊需要孩子的過程中，所產生的焦慮和壓力，得到了舒緩。

Jeff 夫婦對兒子的期望可以從他對引述兒子中學時神父的一番話中見到：「你的兒子只需要學習兩種東西：一是英語，用以溝通；二是宗教，得到安慰。」

Andy 也覺得協康會對他們家庭的幫助很大。他是在朋友推薦下加入協康會。就這樣，他們與兒子每周多了一個好去處，並不只是帶兒子去逛商場。此外，他還覺得與太太的互相支持也是重要的助力。

在交流會中，眾父親不約而同地提到弱能孩子受到歧視的問題。其中，Sam覺得最令他失望的是，他所參與的教會也未能接受他的兒子。因而使他們曾經一度脫離教會。

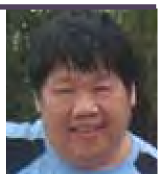
Jeff 以較理性的態度看待歧視現像，他始終覺得社會對自閉症和發展障礙的人仕認識不足，才會造成怪異的眼光。如果大家都知道在這個世界上，的確存在一些能力和智商都較弱的社群，大家就可能會以較接納的態度待之。接著，他重提必須提高社會醒覺的觀點。

在場的一位母親也發表了對這些「特殊父親」的意見。她說她很慶幸在協康會認識了不少願意承擔的好爸爸。而事實上，她聽聞過不少育了弱智孩子的父親最後狠心拋妻棄兒不顧而去的悲情故事，最後，那些可憐的母親們不但要獨力哺育孩子，還要完全地承受著弱能孩子所帶來的壓力和痛苦。她對自己丈夫在整件事上的默默支持表示感激，因為，丈夫不但與她一樣為育有這樣的孩子而痛心，還要承受著她常常失控的情緒。

與會的人仕最後一致認為，本次研討十分正面和成功，為家長提供了一個分享經驗、舒緩情緒的平台，並希望這類型的研討會能夠定期舉辦。

女兒與我

添



我在郵局返夜班工作，睡眠時間因為工作的調動而再減少……這樣的生活方式雖然不太健康，但卻因此得到在照顧家庭上的方便，算是得失各半。

眨眼間頌恩已經十五歲了。藉著神的祝福及帶領，我們一直都能夠為她找到合適的學校而感恩。頌恩現在於一所主要服務有視力殘障人士的特殊學校 St Edmund School 就讀，下一個新學年開始便已經是十年級了。

班中共有十位同學一起上課，老師要依據各人的學習能力去設計個別的課程。雖然有輔助老師協助，但也殊不簡單，她現在除了學習簡單學科外，主要學習照顧自己生活上的技能，如乘搭火車和出街，如何使用盲人用的滕竹等。此外，她學彈鋼琴已有兩年多，以一個中度弱智的小朋友來說，她的表現也算是中規中矩了。

頌恩是一個活潑開朗的孩子，她愛護別人，經常主動幫助老師，所以深得同學和老師們的愛護。她記性很好，不過性格有點倔強，可能這方面是唐氏綜合症小朋友的通病。無論如何，見到她在各方面都有進展，我們也深感安慰。

我原本在一間離家六分鐘車程的郵局返夜班工作，但去年一月我被調往離家二十五分鐘車程的郵件中心。每天仍然工作七個半小時，但開工時間則提早了差不多一個小時。基本上過往我每天上午及晚上各睡兩個小時，現時睡眠時間因為工作的調動而再減少了。現在全賴週末的兩個晚上爭取充足的睡眠，這樣的生活方式雖然不太健康，但卻因此而得到在照顧家庭上的方便，算是得失各半。

我跟頌恩一樣，也頗擔心彼此健康和體重的問題。最近幾年她體重持續上升，醫生說她的血壓有點高，所以要調節食量。幸好媽媽在這方面執行較為嚴格，平日頌恩的體重也較為穩定。我這幾年體重不斷上升，雖然也有去做健身，但已沒有開始時那麼積極，加上進食方面未能好好配合，所以未收到預期效果。一到假期我又忍不住帶頌恩四圍搜尋美食，看來自己真要認真的檢討檢討了。

我和頌恩一樣患有睡眠窒息症，睡眠時需要用吸氧機輔助。去年頌恩做了一個小手術，暫時無須使用呼吸器來幫助睡眠。但由於我的睡眠時間太短，情況沒有太大改善。最近見醫生，他認為我並無配合療程，治療也沒有顯著的改善，遂終止了這項治療。

與頌恩一起的日子，如似水流年，一切但求神繼續保守帶領。

我的求助熱線

陳紹光

> 我們分享我們的挑戰，大家明白對方的處境，彼此學習，鼓勵和互相安慰。

211-211是一個我會常常記得的很特別的號碼，這是211-211。在2011年12月21日，我的兒子告訴我，他已經完成學校的需求，可以畢業了。我還記得在我年青的時候，有一部電視片集，開始時有一個年青人正在跑回家，他喊著”我畢業了”，跟着鏡頭轉到他的母親，正在露出一個燦爛的笑容。那時候我不會理解這母親的感覺，可是現在我有同一個感覺，我是同樣的雀躍。

這些年來，我要面對很多的挑戰，尤其是當兒子出生的時候，兒科專家曾告訴內子和我，你們的兒子有特殊的需要，凡事都會比正常人慢，要花多些時間去完成他的工作，而且他的智慧會比別人低，你們需要費多些耐性去養育他，花多些時間去幫助他。接着我們怎樣做?我想和你們分享我的經驗 – 我們需要堅持到底，不要放棄。

開始的時候，我們否認兒子的不正常。把他帶到所有的專科醫生處去檢查，希望醫生診斷他是正常的。可是所有的檢查報告都是否定的。

我是一個基督徒，我全家都相信主耶穌基督；他是我們的求助熱線。在聖經約翰福音第九章第一到第三節:「耶穌路過的時候，看見一個人生來是瞎眼的。門徒問耶穌說，老師，這人生來是瞎眼的，是誰犯了罪，是這人呢?還是他的父母呢?耶穌回答說，不是這人犯了罪，也不是他的父母犯了罪，是神要在他身上顯出神的作為來。」祂幫助我面對人生的挑戰，使我可以向前漫進和積極地應付日常的挑戰。我像其他的父親一樣，有以下的事情要克服:

- 照顧這個兒子
- 支持我的配偶
- 支持我的大兒子
- 面對外面的世界

然後我們接納兒子的情況，把他視作正常的孩子一樣看待。雖然他做事比較慢，但是他可以做完很多事情，他用自己的速度去完成工作，很多的工作就奇跡地完成了。

我也有參加兩間為有特殊需要(弱智)兒童的家長而設的支緩小組，我遇見和我有相同處境的家長們。我們分享我們的挑戰，大家明白對方的處境，彼此學習，鼓勵和互相安慰。我們看著我們的孩子一起長大。這是另一種的經驗，把我們的距離拉近。

有一個電視節目名為「112」，是一個歐洲國家的緊急求助節目，也是這國家的緊急求助電話號碼。在澳大利亞是「000」，在美國是「911」，在香港是「999」。不同地方，有不同的緊急求助電話號碼。另外一個電視遊戲節目，當參賽者遇到困難，需要幫助的時候，其中一個辦法被稱為「求助熱線」，他們可以打電話給朋友求助，幫忙解答問題。我的求助熱線是主耶穌基督，你的是誰呢?

作者: 陳紹光是協康會創立者之一和前會長

孩子改變了父親的人生軌跡

梁玉華

看著妻子十月懷胎的幸福，對孩子未來的憧憬，每個父親都曾有過這樣的經歷，他也不例外。William 清晰地記得，當孩子呱呱落地時，懷抱白白胖胖的兒子，那一刻他的眼睛內滾動著幸福的淚花。

但在孩子兩歲左右，在別的孩子已經開始咿呀學語，并且能夠清楚地叫出第一聲“媽媽”、“爸爸”時，夫妻倆卻發現了自己孩子的“與眾不同”。William 回憶，兩歲多的兒子遲遲沒有開口說話的跡象，大人叫他，他也跟沒聽見似的；他不跟別的孩子玩，也很少用眼睛與人對視；很多時候，他會因一點小事突然的焦慮、大發脾氣和難以控制。

一開始只是覺得孩子可能是孩子脾氣，可能是發育慢一些而已。但當問題一直延續了三年多之後，他們終於決定要認真看待這個問題。經過了醫生反復的檢查，孩子確診為患有自閉症。William 說那個時候，他“就彷佛跌進了黑暗的谷底，完全不敢相信這會發生在自己孩子身上。”

此後，就像所有自閉症孩子的父母一樣，William 和妻子四處地尋醫問藥，但最終得到的結論是：自閉症目前沒有特效藥可以完全治愈，唯一的方法就是終生干預、康復治療。痛苦和迷惘將他緊緊包圍。原本充滿了人生目標，一個事業型的男人，內心從此變得迷失和掙扎。

當不得不面對自己的孩子患有自閉症這個殘酷的現實時，身為男性、作為父親，William 放棄去為事業打拼，找了一份穩定的財政工作，為的就是方便照顧家庭。為了讓兒子能夠進步得快一點，作為爸爸的他翻閱了很多兒童教育的資料，重點關注包括自己的兒子在內的自閉症，智障兒童的教育和訓練。通過各方面的幫助，他和兒子加入了澳洲弱能兒童協康會。在那裏，William 認識了很多面對相同問題的父母。而他的兒子也多了很多接觸朋友和社會的機會。某程度上做到了相互鼓勵和相互扶助，讓他在精神上放鬆了許多。

不過，熱鬧散去之後，回顧自己的內心，William 的心情還是沉甸甸的。他覺得遺憾，因為他無法和兒子建立正常的父子關係，享受正常的父子樂和感情交流。為糾正一個口形，教兒百上千遍；為訓練一個動作，練上一個星期，甚至更長時間，這都成了William 的生活常態。恰恰是這種漫長的訓練過程讓他變得悲觀。和其他的孩子相比，兒子總會落後於他人。

談到未來，William 說見一步走一步。自閉症兒童的一個突出表現是：他們特立獨行，讓外人覺得難以捉摸；他們身處人群，卻難以融入現實環境，正因此，也讓作為父親的他更加為之揪心。自閉症孩子的救助，需要社會更多人的理解、關注和參與。救助自閉症的孩子，最終的目標是讓孩子走向社會，融入普通人的生活，但現在社會上又有多少人了解自閉症孩子呢？然而，更為嚴峻的現實還在後面。隨著孩子年紀的增長，成年後的自閉症孩子如何自食其力？作為父親，他也不知道這條路的盡頭是什麼。

Author

自閉症患兒家庭的巨大壓力，
從某種意義上來說，
孩子改變了父親的人生軌跡

Ricky Stuart 的憧憬

Paul Kent

Ricky Stuart 是著名澳洲式足球球星，目前是新州 State of Origin 隊的總教練，他為女兒做了一件重要的事。

Ricky Stuart 常被認為是一個透明度頗高的教練，但十四年來他保持了一個秘密，他一直保持這個秘密，直至他相信應要把這秘密透露出來。

Ricky 的14歲女兒 Emma 是患有自閉症，她除了會低聲叫「媽」和「奶」之外，從不說一句話，也從不叫「爸爸」。他說:「我們不覺得這大不了，我全家，我的的朋友都知道，這已經足夠。」

一直以來，Ricky 都抗拒透露自己家人情況，尤其是有關 Emma。但最近報章報導在麥當奴餐廳，Emma 將奶昔擲向他身上，他開始改變了態度。報導稱，餐廳內其他人都認為 Emma 被寵壞了，但 Ricky 覺得這對她並不公平，因為他們都不知道事實真相。Ricky 亦承認在未有適當診斷前，他也曾為她的行為問題感覺煩惱。

他說:「這對孩子很不公平。」

還是經過了幾個月，他才完全說服自己把這個秘密公開。他唯一說服自己的理由是這是一個正確的決定。

Emma在兩年前被診斷患上自閉症，醫生初步用「全球發展障礙」(Global Developmental Delay) 方法診斷她，給她父母提供了幾個機構去尋求治療。

Ricky 和太太都很自然地竭盡所能，承擔起照顧及扶養的女兒的職責。隨著女兒自閉症的診斷更確定了，Ricky 對未來的路向也有了清晰的看法，他開始為自閉症和照顧工作成立一個基金會*。他說:「目前最主要的工作是取得大機構和政府的足夠支持，這樣我們就能夠建立支持網絡，並希望成立一個暫歇中心。」

Ricky 最大的恐懼與其他有殘礙孩子的父母都是一樣。他說:「當我和太太死後會怎麼樣呢?澳洲有長者照顧之家，但沒有為這些兒童而設的家」

「我想通過基金會取得足夠支持，這樣我們就能夠為自閉症兒童建立一個10-12床位的家了。」

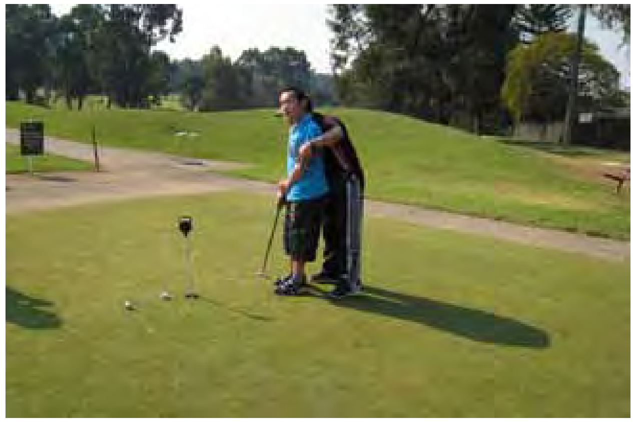
* *http://www.rickystuart.org/*

資料來源: *Sunday Telegraph 2012年1月29日*

爸爸 － 回歸家庭樂的另類感覺

梁玉華

一提到家庭型男人，相信大家首先想到的就是全職奶爸這個詞。很多人腦海中會閃現出的，是美國電影《超級奶爸》中那個做過特種兵的“超級奶爸”，手忙腳亂的看管幾個小家伙的場景。如今，哄孩子、喂奶、換尿布這些事情不再是母親的“專利”。



傳統的感觀裏，中國男性都具有一點大男子主義，所以說放棄打拼事業，多在家裏照顧家庭和孩子似乎是不太可能。但最近幾年觀點似乎開始改變，不少男性開始回歸家庭，享受另類的家庭樂。Andy 就是其中一個享受家庭樂的男人。

Andy 是越南華僑。由於社會的動蕩和不安，在十三歲時，Andy 毅然決定和朋友一塊離開自己出生的國家。帶著類似船民的身份，穿過印度尼西亞的島嶼，經歷一年的時間轉而抵達澳大利亞。當生活逐漸好轉的同時，在1993年，他巧遇了自己的太太。緣份的牽引使得兩人結合到了一起，并且有了自己的第一個孩子。

但命運之神似乎總愛作弄人。當生活看似越來越好的時候，醫生卻告知他們一個壞消息兒子是一個智障的孩子。從他出生開始，他的消化系統，身体發育和各方面的成長都會比正常的寶寶差。

其他的小孩子在五歲的時候已經非常活躍，但小兒子在五歲時才剛剛學會走路。其他的男孩子在青春期或許已經開始認識女朋友，或許已經開始找暑期工作，但十六歲的兒子還是黏在父母的身邊，極其需要家人的耐心照顧。帶孩子出去時，偶爾還會碰到不能體諒和包容人，伴隨而來的是奇異的眼光和討論。

無形的壓力凝聚到一塊會讓人喘不過氣，但是一份開朗的心態卻能讓人在壓力裏尋找到快樂。不像傳統男人那樣瘋狂的追求事業，Andy 選擇了以家庭為主。除了選擇一份時間較靈活的工作來配合家庭以外，他也拋開了傳統男性的觀念，主動幫助處理家務和減輕妻子的負擔。一顆樂觀，開朗和感恩的心，讓 Andy 享受著另類的家庭樂。

兒子人生的每一步，每一份成長，給了這個父親一份人生的滿足。在分享人生的苦與樂時，Andy說自己記憶猶新的是兒子第一次學會走路，那一年他五歲。兒子顫顫抖抖地踏出的這一步讓作為爸爸的感動流淚，覺得兒子長大了。

直到現在，每次回憶起來的時候，他還是會紅了眼眶聲音顫抖。受到爸爸和家裏和諧氣氛的熏染，兒子的脾氣也漸漸在改善。家庭的溫暖，讓兒子少了一些煩躁，少了一些不安，多了一份放鬆與快樂。

在兒子十一歲的時候，家裏多了一個新成員!而她就是兒子的妹妹。女兒的出生給家裏帶來了很多歡樂。哥哥學會了讓著妹妹，而作為父親的Andy則是學會了平均分配關心和愛。

現在每次談到這對子女，Andy 總是笑容滿面的。一顆感恩和樂觀的心讓他和家裏人真實的感受到了幸福。這個家庭，靠著父母的這一份樂觀和一份感恩，相信會越走越遠，越走越幸福!

作為殘疾兒的父親，我領略到的五線譜

David Cameron

這些父母堅強地維繫他們的家庭，
他們偉大地、默默地服務我們的社會。

－ 英國首相卡梅倫

我的兒子 Ivan 自出娘胎就患上嚴重的殘疾。從照顧他而得到的體驗，令我改變了對很多東西的看法－不只是從父親的角度，亦從政治家的角度看。我和妻子 Samantha 經歷了一段艱辛的學習過程。從中我領略了五個大的啓示。這些都直接影響了保守黨政府對殘疾人仕及其家屬的政策。

我學到的第一個啓示是早期干預和幫助的重要性。當你發現你的孩子有殘疾時，你不只深感震驚，擔心和不安，同時也使你感到極為困惑。這感覺就像你剛開始一個你從沒策劃的旅程，沒有地圖或提示來幫助你去尋找方向。這就是為什麼下一屆保守黨政府大幅增加社區健康護士的原因之一。他們的職責不是去診斷殘障，而是憑着他們多年家居護理的經驗，可及早發現警示標誌，從而提供中肯的意見。我知道早期的幫助是多麼重要，這就是我們增加這方面服務的原因。

第二個啓示是殘疾兒童的家長無需再在政府部門間往來奔走。因為他們的生活已十分繁忙，經歷確診後的震驚，繼而陷入一個痛苦的官僚主義世界。為要給孩子作評估和取得可享有的幫助，意味著他們要重覆地回答同樣的問題，埋首於像雪片般飛來的表格，和長時間在等候電話的回覆。

我決心要簡化殘疾兒童家長的生活。其中一種選擇，是啟發自奧地利的經驗。他們的醫療專業團體，包括醫生，護士，物理治療師，提供一站式服務，評估家庭，為他們取得需要的幫助。這模式定可幫助這些家庭，所以我們正密切研究如何在我們國家實行。

第三個啓示是我們要讓家長更容易為他們的殘疾兒童取得合適的教育。那麼多的家長為要給子女取得特殊需要的認可和他們額外需要的幫助，不斷周旋於評估，上訴和裁決間，這是一個架構上的原因。地方教育當局決定誰可獲得特殊教育，同時也是資助者。我們正認真考慮如何解決這利益衝突，讓家長不需為取得特殊教育而捲入這樣一場巨大的戰鬥中。

另外，很多殘疾兒童家長須出盡法寶去爭取特殊學校的學位。自從「把殘疾人士融入主流」的呼聲廣為接受之後，政府在過去十年間已關閉了數十所特殊學校。融合主流學校很適合部分殘疾兒童，但通常來說把殘疾兒童放在主流學校並不合適。因此，我們將停止關閉特殊學校，讓家長有更多的選擇。(編者按：這政策是否適用於澳洲？)

第四個啓示是殘疾兒童家長也像其他的照顧者一樣需要休息。對育有嚴重殘疾子女的家長最大挑戰之一，是需要騰出時間來過正常的家庭生活，例如和沒有殘疾的子女在公園裡玩耍，每週例行的購物，或父母二人一同出外吃一頓飯。暫息計劃(Respite)帶給我的家庭很大的分別。付託Ivan給一位認識他、愛護他及照顧他的人，令我們安心地放下重擔。支持暫息計劃，包括支持志願機構，給家長和照顧者有更多暫息服務的選擇，並盡量使所有人認識到他們享有暫息服務的權利。

第五個，也是最後一個和大家分享的啓示，是殘疾最痛苦之處是那份處身於一個您無法控制的情況時的感受，不管殘疾的是你自己或是你的親人。處身於一個從上而下，官僚，僵化的制度下，只會更加深你的無助感。

因此，一個真正的大改革是透過個人預算和直接援助，把更多的控制和權力交到家長、照顧者或殘疾人手上。我們不再區分這是醫療、教育，抑或是兒童服務的援助、而是說：「這是您的孩子的總預算，你可以自行決定如何分配。」將援助金直接交到受助者手中是正確的。殘疾人的父母和照顧者是值得這樣的支持，信任和尊重的。(編者按：紐省正研究改革殘疾服務提供的方式，使有需要的家庭，更有效和快捷地獲得所需服務。)

因為我們永遠不能忘記父母和照顧者了不起的服務。試想像一下如果他們放棄承擔照顧工作，照顧這些兒童的財務負擔是十分巨大的。我們更難想像情感成本有多大。我們必須認識到，這些父母堅強地維繫他們的家庭。他們偉大地、默默地服務我們的社會。

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英國首相卡梅倫的兒子Ivan患有腦癱和嚴重的癲癇。這篇文章是在Ivan2009年去世前在英國發表。它道出父母對育有殘疾子女的感受，及他們應尋求甚麼方法去舒緩自己的負擔，並盡量提高支持自己孩子的能力。 － 編者

妳是我…我是妳…

譚顯輝

誰家的孩子能讓你一輩子掛念?誰家的孩子常常讓你緊隨不捨?誰家的孩子能讓你愛他要特別多?誰家的孩子是把不易打開他心門的鎖?我家有這麼一個孩子,她是自閉症的孩子。

當狄菜霓四歲被確診為自閉症的孩子時,我們像任何有這麼一個孩子的父母一樣,難以置信,不能接受,要如何去面對呢?然而事實擺在面前,我們都得承認我們的孩子跟一般的孩子真的很不一樣了。

這樣一路走來,現在她剛滿八歲了。我們曾四處奔波,尋找各種能幫助她的資源;我們要經常帶她參與不同機構舉辦的各種活動,協助她開拓她那容易封閉的小天地;我們要用更多的時間陪伴她,當她朋友不多時,我們做家長的就是她最靠近的朋友;他學習上因為溝通上的天生障礙,我們惟有付出更多的耐性去教導她的功課。

我這個做父親的,早晚開車接送她上學放學,更多了親子時間;每個周末帶她去中文學校,那又是一個歡樂學習的時刻;每周一次陪她去游泳和打籃球班,親眼看到她的肢體發展和協調功能的進步,怎不令人欣喜!禮拜天帶她參加教會的主日學,她又多了一個接觸不同學習伙伴的机會,聖經真理培育她的心靈,滋潤她的生命。

過去的日子裏,每天的枕邊時間,她首先讀英文書給爸爸媽媽聽,然後是她跟著我讀國語中文書,要爸媽親過她的小臉臉才安然入睡。碰到說普通話的親戚朋友,她會秀幾句國語,主動打招呼,然後唸些童詩或唱些兒歌,表示自己會多說一種語言,好不得意。游泳教練最喜歡她,她可以在小池子裏自由式或仰式游個來回,至於潛水尋寶更是再拿手不過的了。去年學校的頒獎禮上,我這個父親可以遠遠望著她上台從校長手中接過獎狀,也看著她在台下,站在班級導師旁邊又唱又跳,欣慰之情不言可喻。

她的進展是明顯的;她日漸長高,她的頭已經高過媽媽的下巴了。但是我們心裡明白,她還是跟一般的小朋友有所不同;她自言自語跟自己說故事的世界裡,我仍有解不開的疑問;跟人溝通,仍然像不懂事的孩子;出外上街,我還是會不放心,不敢讓她離開我的眼目,怕她走失;她憋扭起來,仍然會令我皺起眉頭;我希望她能更獨立、不怯生,但她始終對陌生人有不安全感,常常纏著我,也不敢嘗試新的事物。然而,她就是我自閉症的孩子,活生生的事實,只希望能幫助她從成長中過得更好,將來能接受自己是這樣的一個孩子,跟自己比有突破,而不必跟其他人比較。

最近聽到一首歌,是幾年前中國流行的溫馨電視劇集<我愛我家>的片尾曲,我聽了很感動。我只想改動其中的一些稱呼,來表達我和我自閉症孩子狄菜霓間的一些真實,一些真情,一些感受,一些愛。

我是妳記憶中忘不了的溫存
妳是我一生都解不開的疑問
妳是我懷裡永遠不懂事的孩子
我是妳身邊永遠不變心的愛人
我是妳迷路時遠處的那盞燈
我是妳孤單時枕邊的一個吻
妳是我愛妳時改變不了的天真
妳是我怨妳時刻在心頭上的皺紋
妳是我情願為妳付出的人
我是妳不願讓妳纏住的根
我是妳遠離我時永遠的回程票
我是妳靠近我時開著的一扇門

心裏的一根刺

淡如水

吾寫此文,欲道出多數中國人父親的心聲,此乃是吾輩難以啓齒之事。

中國人均具有此觀念:「不孝有三,無後為大」。或者,汝等會認為此思想太汙腐,太落後。但此是不爭之事實,均存在很多中國人之心,尤其是身為男子,所負之責任頗重,如繼後無人,會感到對不起列代祖宗,並抱憾終身!故如環境許可,皆冀兒孫滿堂,五世其昌。

在中國,提倡一孩政策,引發很多悲劇。而身在國外,不受約束,皆會一生再生,均冀一索得男,得以光宗耀祖。但往往事與願違,由於家境清貧,不容生育衆多,或為父不育,或為母不願生育,基於體弱,患有殘疾等。如為人父者能體諒,便順從天意。但有些人思想根深蒂固,為達目的,因而做出越軌行為,在外有第三者,或離婚,另結新歡,更有些借腹產子,無所不出其極。

吾慈母早逝,吾父身兼母職,撫養吾與姊成人。吾首索得男,不幸有自閉症,及後吾等移民澳洲,為了生計,待生活安定後,再作生育打算。其後基於吾妻畏懼再生特殊兒童,此計劃祇好作罷。

後在協康會一場講座中,得悉特殊兒童可經檢驗,以証明是否存有自閉症遺傳因子,使吾仍存有一綫希望。吾兒外表正常,沒有憂慮,為人樂天,做事手快,並樂於助人,在家喜看電視,對電視節目時間表,瞭如指掌。常在旁觀吾做事,吾不在,他會膽粗粗自己來做,尤其對音響接縛調較,頗有心得,吾想他是有點悟性,但懶於用腦。吾曾要求妻子帶他去醫生處檢驗,但結果沒有下文。

吾兒現已屆結婚年齡。剛巧有一位女性朋友嫁給有自閉症丈夫。吾與她談過兒子的事,希望她能介紹女孩,給吾兒認識,如有可能,可以結婚生子,以除我心中之刺。日前她欲介紹一位女士,讓吾兒認識,但吾妻恐怕自閉症或會遺傳給下一代,所以一再反對,而吾女兒亦覺其兄未能獨立生活,如何能照顧家庭,結果事情不了了之。如今心中之刺仍未除去,吾覺對兒子不太公平,難道特殊成人不能如正常人一般,結交異性朋友,談戀愛,結婚生子嗎?

風雨同舟

Katherine Wang

倘若獨自承擔，會很累很疲憊；如果有人一起分擔，互相安慰鼓勵，會輕鬆很多。

2008年下半年，看著兒子Leon逐漸長大，和同齡正常的孩子差距越來越大，我和我先生商量，決定賣掉一個生意，全心投入到兒子的康復治療。我先生Tom很贊成，讓我無後顧之憂，得以全職在家照顧孩子們。

接下來的一年，正式開始各種各樣的訓練和治療，因為Leon 的症狀較嚴重，所以消耗了我的大部分精力，加上我還有兩個女兒很小也需要照顧，根本無暇顧及Tom 和自己的需要。我們開始在孩子的教育方面有些分歧，漸漸地其它一些生活細節也有了分歧。當時我根本沒有精力和耐心和丈夫去磨合這些分歧。好在Tom選擇了退讓和默默支持，還幫忙做家務，所以日子過得還算平靜。

第二年初，Leon 在強化訓練下進步很多，我想給他另找一所學校，這過程是漫長又折磨人，而訓練和治療又不能停下，這期間，我有時也會鬧情緒，因為要求太高而給了自己和老公很多壓力。但是Tom更理智，他看到了三個孩子的進步和成長，經常肯定我的工作，這給我很大的鼓勵。

去年5月，Leon終於上了本地的中學。Tom也開始帶著他做一些體育鍛煉，有時帶他去購物和散步，Leon也很喜歡和爸爸一起出去。看著他一天天成長，我們的喜悅也與日俱增。

通過這樣的一段經歷，我也體會到老公的支持，鼓勵和分擔，他也看到了我的努力。這使我們的家庭更和睦。生活當中，難免會產生磨擦。少一些抱怨，多一些寬容和理解，和睦相處就不是一件難事。

在人生旅途中，我們每個人都要背負重擔，無法逃避，倘若獨自承擔，會很累很疲憊；如果有人一起分擔，互相安慰鼓勵，會輕鬆很多，就更有勇氣去面對前面的路程。

我摯愛的丈夫

逸名

我的丈夫是一個很顧家的男人，他不善辭令，沉默寡言。但是他常在我身旁，默默地給我支持。他自去年退休後，大部份時間留在家裏，處理家務，包括下廚，清洗衣服，購物，維修家具電器，清理垃圾，剪草，打理花園等等，出外時亦兼任司機，好像是無所不能。有他幫忙家務，我可以無後顧之憂，尊心工作，並騰出時間，為協康會作長期義工。

當小兒三四歲時被診斷患有輕度弱智，我和丈夫從來沒有談論過大家心內的傷痛，祇是默默地接受現實，知道他和正常孩子不一樣。

時光飛逝，轉瞬間，我們的兒子已長大成人。他日間在一所庇護工場工作。多年來，我們一家(包括女兒在內)經歷過不少困難時刻。兒子的無知和愚昧，著著使我們為他擔憂。丈夫在家裏充當嚴父角色。偶爾，我們在育兒方法上有所分歧，他也會嚴詞厲色斥責，但是我知道他是很愛我們的。

我和丈夫日漸老邁，很擔心兒子將來是否能夠獨立生活？ 我們百年歸老後，是否有人可以照顧他呢?我們只有儘量訓練他獨立，但這是長遠計劃，希望終有一天，夢想可以成真。

有失必有得，或許上天讓他們失去看見兒子健康成長的機會，卻賜予夫妻倆可以更深入了解對方，體諒對方和呵護對方的機會。

妻子要對丈夫說的話

梁玉華

雖是最簡單的話語，但卻透露著Lee對她丈夫的感覺，透露出兩人間不間斷的愛情與親情：

「我深切地知道，此生擁有你，是我最大的幸福。與你相識、相戀、相濡以沫這麼多年，你帶給我多少的快樂、感動與溫馨；和你共有的點點滴滴，在我記憶深處，絲絲縷縷沁入心底，每每想起，都覺得好溫暖。太多太多的快樂、太多太多的共同扶持；沒完沒了的徹夜長談的時。… 和你一起的日子，過一輩子都不夠……」

戀愛的時候，倆人總是甜蜜的；但在熱情退卻之後，平淡生活裏的考驗或許才真正的體現出愛是否存在。和Lee聊天的時候，她的精神有點恍惚，彷彿回到了過去，打開記憶的盒子之後細細的翻看裏面每一頁。

Lee說，她是在2003年和丈夫一塊來到澳洲的。來澳之後覺得生活會有個美好的開始，而他們的確很快有了屬於他們的第一個兒子。遺憾的是，孩子出生不久，夫妻倆就被告知孩子有自閉症，精神不容易集中，在與人相處上會有困難存在。這個消息讓倆人震惊，他們都深深地問自己，不停的問自己為什麼這事情會發生在孩子身上。一開始的時候，Lee說她的心情非常難受。但現在回顧回去，她有了另一番的體會。或許就是由於孩子的事，才把兩個人拉得更近和維繫得更好。

有失必有得，或許上天讓他們失去看見兒子健康成長的機會，卻賜予夫妻倆可以更深入了解對方，體諒對方和呵護對方的機會。在妻子的眼裏，丈夫是家裏的精神支柱，她覺得很感恩。

作為父親和丈夫，David在知道兒子情況的時候就表現出了理解和諒解的情緒。他並沒有責怪妻子，並沒有咆哮，反而用一顆包容和溫柔的心開解妻子的負面情緒。像所有的女性一樣，當自己感覺害怕，孤獨或無助的時候，總希望有個人可以給自己溫暖，可以讓自己的信心更加的堅定。而丈夫就是她這個安全港灣。

在妻子的眼裏，丈夫是家裏的經濟支柱，辛勞的支撐起整個家庭。某些男人在負起養家責任的同時，也變得霸道和脾氣暴燥。在外面工作受到的壓力，理所當然的帶回了家中，發泄在妻子和家裏人身上。但Lee很慶幸自己的丈夫并非如此。David除了努力掙錢負擔起家裏的所有開支，他還會幫忙做家務。在時間許可的情況下，他會貼心的陪伴妻子共同商量和處理問題。

在妻子的眼裏，David還是一個好爸爸。他並沒有因為孩子的不完美而離棄他。工作和生活的瑣碎時間佔用了David大部分的時間。但爸爸還是孩子重要的游戲伙伴；他的體貼和善意總有一天會傳遞到孩子的心裏，讓孩子的情緒慢慢放鬆下來，讓他更有勇氣克服苦難。當媽媽還擔心著孩子每天的生活需要時，作為爸爸的你已經為孩子的未來安排而操心。

夫妻倆現在都很忙。作為妻子的Lee要努力照顧家庭，而David則是忙於工作。但是Lee說，希望有一天，等生活的各種事情整理得順暢一點了，夫妻倆可以多點時間相處，父子倆可以多點時間交流。她有太多太多的感覺想和丈夫分享，但在David每天忙碌的時間表裏，又如何說起呢?不過沒有關係，以後的日子還長，可以慢慢的訴說慢慢的領略這份愛。

我的爸

繆韻婷

如果我的妹妹能夠寫字， 她會寫以下的詩句 。。。

我爹，他很棒。
他努力工作，使我們生活無憂。
他嗜好電腦游戲，有時也讓我玩上一手。
我喜歡他為我閱讀。我爹，他很棒。

他為我管接管送，我唱漏歌詞，他會為我補上，
他是我小天地裡的伴侶，並為我帶來歡樂。
我爹，他很棒，我也很愛他。

每當爸爸與我們在一起，妹妹感到爸爸的關懷時，我留意到她一雙眼睛閃爍著喜悅的光芒。她會很清晰地說，「讀<我的爸爸>*這本書。」我想這是她所愛讀的書，因為這是她與爸爸溝通的方式。我妹妹不會用太多語言去溝通，但當她要表達的時候，她知道如何能夠達到最佳的效果。

過去幾年，我留意到我一家人愈來愈多參與協康會的事務，與此同時，我們一家四口的關係也更加鞏固。我媽是我家的第一號照顧者，她經常發揮最主要的推動力，鞏固和發展我們與妹妹之間的關係，我爸最主要的角色是為一家出外工作，在經濟上照顧全家。

我和妹妹都成長了，不需要太多的照料，而爸爸也縮短了工作時間，在工餘時為協康會服務。協康會為我們一家帶來了共同的目標和興趣。在可能的範圍內，我們都會給予意見和幫忙。我相信這會持續一段長的時間，因為這是我妹妹喜歡參與的團體。看見我爸爸的參與和服務他人，也給我帶來很大的鼓舞。在協康會看見爸爸與其他弱能兒童談話，更令我感到驕傲。最重要的是，當他花時間與妹妹在一起，參與她所喜歡的羣體活動時，我知道妹妹會感到十分自豪。

*本文靈感來自 Anthony Browne 的“My Dad”

作者： 繆韻婷是協康會 Sibspace 發起人之一。
Sibspace 是協康會弱能子女的兄弟姊妹互助小組。

在女兒眼裏，父親能為她撐起一片天

梁玉華

父愛如山，父愛似海。父愛，是默默無聲的，沉靜內斂的情感。父親或許剛硬嚴格，或許沉默少語，但在我們的心目中，父親的形象永遠是深沉高大的。父親可以為我們遮風擋雨，可以為我們付出全部，相對於母愛的溫柔細膩，父愛更多的是悄無聲息，默默付出，但無論如何，愛子之心卻是無處不在。

Eleanore和爸爸

這一段內心的獨白，來自一個活潑可愛，陶醉在音樂海洋那裡的女孩子 – Eleanore。剛剛邁入大學門口修讀音樂系的她，在世人的眼裏，她的未來充滿了光明和希望。可是她的成長過程並非如此的甜蜜。和同年齡的孩子相比，她多了一份細心，多了一份體貼和多了一份獨立。其中一個原因是因為她經常需要照顧有自閉症的弟弟。

弟弟現年17歲。弟弟出生的時候，除了給家裡添加了一份喜悅以外，也增加了額外的壓力。由於弟弟從小就有自閉症，除了發育和溝通都比別的小孩子慢，他的情緒波動也會偏大。作為姐姐，她從小就被要求學習照顧弟弟，在她力所能力的範圍裡幫助處理家務。特殊的成長過程，讓Eleanore養成了一個獨立的性格。然而，獨立的人就沒有疑惑嗎？像所有的孩子一樣，當我們疑惑的時候，當我們害怕的時候，都會向父母求助。

相對於母愛的溫柔細膩，爸爸給與Eleanore的感覺是是默默無聲的。在Eleanore的印象裏，她的爸爸總是很忙，工作安排得很緊。在業餘時間裏，爸爸還喜歡去替別人開車。Eleanore說，爸爸有點深沉，不是特別愛分享感覺，但是卻很喜歡開車，那是他的興趣。陪伴家裡人的時間不多，但是父愛的感覺卻是真實的存在的。

回顧過去，Eleanore印象最深刻的就是爸爸無聲的愛。雖然平時話語不多，但是當她需要幫忙的時候，需要開車接送的時候，爸爸總是在。最難忘的一次交流，是在自己讀高三，準備考大學的時候。那是她印象裏，第一次單獨跟爸爸深入的溝通。偶然的一次機會，讓父女倆可以單獨的在街上散步。邊走邊聊，倆人談了很多，包括了人生目標，學習上的選擇，未來的方向和處理問題時的人生態度。

爸爸就像是一個指南針，在女兒迷失的時候，跟她分析，指明人生的大方向。有爸爸的存在，讓女兒有了更多的信心，面對未來生活裡的挑戰。本來對大學生活和未來有著擔心的自己，在聊完天之後感覺充實了很多，信心提高了很多。因為無論有什麼困難，爸爸總會陪伴在旁。

那一次單獨交流的感動，把父愛深深的刻在她的心裡。父親並沒有因為工作忙而忘卻她，並沒有因為弟弟的自閉症而忽略她。相反，深沉的父親總是悄無聲息，默默的付出，愛子之心無處不在。Eleanore覺得，隨著自己慢慢的成熟，以後和父親交流的話題將會更多。兩人之間的感情將會隨著時間不斷地發展，不斷地鞏固。同時，她很想對爸爸說一句：「爸爸，我愛你！」

他是誰？

周金瑩

我的爸爸是一個愛整潔的人，他辦事靈活，很有條理和有效率，對人對物充滿熱情，和藹可親，處事專業。他是一個十分好的廚師，有相當的幽默感。

我們心中的爸爸

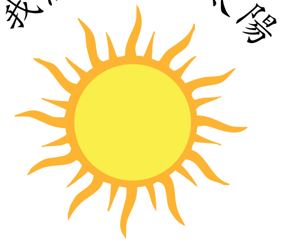
阮嘉恩，王韻妍，周金瑩

爸爸是家庭的支柱，照顧所有的子女，包括沒有弱能的子女在內。我們詢問過一些子女，有關他們對父親形象的了解，以下是他們所提供的...

海灘的救生員

永遠看顧著我，甚至不顧自身安危

我們心中的太陽



恆常，可靠，溫暖和沉默地表達他的愛

大廚

入得廚房，為一家煮得一手好菜

一切都會「搞得掂」

任何東西損壞，都會神奇地修復原狀

忘我

永遠以家人的需要為先

開拓者

勇敢地拋開他所熟悉的一切，義無反顧地，為子女的未來，開拓新的領域。

光芒燦爛的武士

我們堅強和可靠的拯救者

父親牽腸掛肚的問題

俞高昆

過去幾年協康會獲得地方政府資助，一群家長組織了好幾次弱能子女父親的聚會。雖然我們白晝忙於生計，但也風雨不改的參與晚上聚會。當然我們要感謝賢內助的支持。一些有專家出席發表專題討論的聚會，我們會廣邀家人，使大家都獲益。

「爸爸對對碰」計劃開始時是以父親社交活動為主。自2009年四月發起人 Daniel Yung 主持後，逐漸從社交聯誼性質轉變成父親交換經驗和意見的活動。

我繼承 Daniel 主持這項目計劃以來，在2010和2011兩年內我們一共舉辦了十五次節目，討論了多項社會性的議題，也邀請了專家出席提供寶貴意見，總括如下。

社會企業

我們對范鎮榮先生有關香港「社會企業」的進展報告都感到興趣。「社會企業」可以是一個幫助弱能人士就業的可行模型，使他們能自力更生地在社區內生活。這也啟發我們對弱能人士將來在就業機會和獲長期工作所遇到困難的思考。我們是否能夠可以組成一個幫助不同文化和語言弱能人士就業的社會企業呢?

弱能人士就業機會

我們邀請到雪梨職業發展服務社的 Audrey Honsebey 對弱能人士求職就業問題作解釋。她使我們明白到「過渡工項目」 (Transition to Work) 和「庇護工場」(Sheltered Workshop) 都是針對弱能者將來能夠自力更生。我們非常高興 Audrey 在將來會幫助我們的弱能孩子找工作。

性教育

Liz Dore 是一位弱智或殘障者性教育專家。她強調，父母需要正面看待弱智青年的性發展，這是他們個人全面發展的一部份。她幫助我們打開眼界，知道需要更多學習和了解這方面的問題。父親決不能卸職。

政府輔助金政策

Karen Fisher 教授和她的同事講解政府為弱能人士提供獨立生活資助的政策。這政策將使照顧者和弱能人士自己可以策劃那些服務和其質數，是更能符合他們的需要。

法律問題－「遺囑」

由於很多會員很少接觸照顧弱能兒童須知的有關法律知識，我們邀請到這方面的專家律師 Stephen Booth 先生，為我們解答很多遺囑的問題。例如為何及幾時需要訂立遺囑，以及怎樣才是週全。律政部門的 Hong Ong 小姐出席我們的聚會介紹自己和她的部門。她為我們會員在法律問題上提供很多資料。

健康知識和養生飲食

我們邀請營養專家 James Chin 教授和 Don McNicol先生為我們演講「營養對身體和大腦發展的關係」。今年也有其他幾個節目是針對生態保育的。例如 Vincent Yu 的氣功講解和幾個基本動作練習，幫助我們了解氣在體內運轉。同時我們舉行了一次交際舞會由 William Mo 先生教授。家長們都希望能有機會再次學習。

總結

「爸爸對對碰」計劃是協康會的互相支持和分享的網絡，為父親在一個輕輕鬆鬆的環境下彼此交流和聚首，推動大家互相認識和分享意見，最終能支持協康會成員家庭能更好地幫助我們有弱能的孩子。

作者； 俞高昆
協康會「爸爸對對碰計劃」義務統籌

火車上

范鎮榮

在火車上，一對父子並肩而坐，他們的目光都集中在一份數學習作上。父親盡量降低自己的聲量，教導兒子如何計算出答案。他們都是我在協康會認識的朋友，兒子是一位學生，患有自閉症和弱智。他們專心一致，令我不好意思打擾他們。

相信孩子正在準備考試或遞交功課，而父親利用上班途中30分鐘火車時間，盡力幫助和支持兒子。乘客在他們身旁上上落落，但他們毫不在意。我在後面觀察，深深體會到這對父子之間血濃於水的感情，他們正在集中意志力，一同解決數學上的難題。但是生命中的難題，有時並不容易解決。

> 父母幫助弱能子女成長，有時好比希臘神話裡西西弗斯（Sisyphus）的故事一樣，需要與命運做永恆的對抗，儘管你努力去做，所得的成效進展緩慢，或甚至原步不前，但仍然要週而復始地做下去。

例如，我曾看見一些父母耐心地幫助其弱能子女學習行走；父母為了要引發子女對音樂的興趣，他們甚至在子女面前手舞足蹈，作為輔導。在Youtube*有一個相當感人的特輯，是由本身是運動員的父親帶同弱能的子女一起參加運動比賽，除了讓子女分享自己的經驗外，也表達對子女的愛。

上述情況，驟眼看來似乎是一般父母與子女之間的正常互動，或父母教導其子女的行為。但引起注意的是這些子女都不是年幼，他們都是弱智或弱能人士。他們與父母之間的互動內涵，與他們的年齡並不相配。平常人看見，可能覺得怪異，但這些父母都心無旁騖，只是專心一致地做好幫助子女的工作，至於旁人在說什麼或想什麼，他們也毫不在乎。

在火車上，那父親重複地給兒子講解數學難題，也在紙上勾畫陳述；間中停歇一下，讓兒子發問。明顯地，他希望兒子能夠像其他同年人一樣，明白和掌握這些數學習作。他的身體語言顯示，他希望兒子能人所能，儘管他兒子的弱智需要努力去克服。

近年我注意到，協康會的照顧者和義工群體有一些顯注的改變，多年前，大多數家長和義工都是母親，很少見到有父親在協康會的活動裡擔當任何角色。即使父親帶孩子來協康會參加活動，他們都衹是充當司機，管接管送，來到後很快便不見蹤影，或者留在車內作息，我邀請他們出來傾談，他們也不大願意。

近年來，愈來愈多的父親在協康會的活動中出現，他們積極的支持母親/義工在各項工作上提供輔助，他們之間也多了交往。幾位父親也獲支持在會員大會上被選為理事，在協康會的決策上，也有父親的聲音。「爸爸對對碰」更為父親提供了一個討論平臺。個別的父親在協康會戶外體育活動上，扮演了重要的角色。

這些令人振奮的發展也與協康會會員對該會的服務需求改變而吻合。當他們最初加入協康會時，他們的弱能子女大多數是兒童，而當時最關注的，除了基本的服務外，是鼓勵他們參與「早期干預活動」。像其他家庭一樣，因為母親和子女相處的時間較長，所以母親是主要的照顧者，而父親的作用較為次要。這也是一般傳統父母角色有別，對母親的期望，和男主外女主內的觀念有關。

近年來，協康會的孩子日漸長大，他們都進入青少年或成年期，而父親也愈來愈關注孩子的成長。協康會裡你會不乏找到模範父親角色的樣板，他們不懈的照顧和支持有弱能的子女，分擔妻子的煩瑣家務，偶然擔任主要照顧者角色。他們也是非弱能子女的重要支持者，是家庭經濟的支柱，在子女和家庭成長關鍵時刻，他們會挺身而出，承擔領導責任。

與這些父親認識也有一段時間了，起初當他們知道自己的孩子患有弱能時，很多父親的承受力都不及他們的妻子。難過和傷心都會是很自然的反應，但在很多情況下，男人的難過和傷心會持續更長。據已知的研究資料，男性會有更大機會患上抑鬱症，煩躁症或焦慮症；如果父母都患有上述病症，男性患病的時間比女性更長。

一般而言，這可能是男人天性，他們都不會主動地向別人表露自己內心感受，特別是痛苦和挫折；對自己親友亦然，更遑論向專業人士求助。父親中愈是不能打開心扉的，他們會愈長時間感受心理症狀包括震悚，動輒生氣憤怒，不能自我，悲傷，莫名恐懼，怨恨等等。如果他們遇到更多困難，例如找不到合適的服務，他們會有更多的挫敗和失落感。

父母需要花更多時間和心力照顧弱能兒，不單是嬰兒期，兒童和青少年期，甚至是成年和中老年期，也是一樣。這長期的緊張和永無止境的感覺，會形成心理壓力，使身心都被這內心的壓力所壓垮，特別是當父母覺得他們是孤立無助的時候。母親的壓力一般與照顧弱能兒所付出的勞心勞力有關；而父親的壓力，會源自家庭財務的負擔。如果其他家人不諒解，這壓力和緊張將會更甚。上述種種原因，父母在不同的時間都會有不同程度的感受。

部份家庭最終都未能消除這些壓力和心理負荷。我們偶爾聽到一些令人悲傷的情況，都是由於照顧弱能兒的壓力，致身心疲乏，加上家庭經濟負擔，影響夫妻間和諧關係，而最終導致分居和離婚，而子女的成長也受到影響。

在協康會，成功的父親例子都是源於夫妻雙方都有深厚的感情基礎和有共同的信念，無論順境逆境，都以維繫家庭為目標。父親都會不吝嗇時間，多與子女，包括有弱能的子女相處，提攜指導。使子女在身心和情緒發展，都會更為健康。

同樣，母親得到丈夫的支持和有一個良好的婚姻關係，她們的照顧者角色會做得更好。事實上，夫妻關係質素會影響父母對子女的關係，對弱能兒的福祉，有長遠的影響。一段好的家庭關係，包括婚姻關係，會帶來更強的親子聯繫，也為子女帶來更好的發展。

心理學有一個概念叫回彈或恢復力(Resilience)，這是指一個人對逆境或厄運的承受力和傾向。這回應會表現在回彈到以前正常情況下的現象，或在逆境情況下，會鍛鍊成堅強的身心效果，而表現得比以往更勝一籌。用回彈或恢復力來應用在協康會的家庭是很合適的。父親的角色在使家庭回彈和恢復的過程上是非常重要和關鍵的。

火車上的父子，見證了父親角色的重要。兒子有父親的支持和輔助會倍感安全，同時培養到自信心，繼續學業。無疑，他的弱能對完整的成長仍會構成障礙，但這並不是永遠不能克服的。

*http://www.youtube.com/watch?v=eG-GMXcNaqo

作者註：這篇文章表達我對所有協康會家長的敬意，他們終生幫助弱能子女，義無反顧。我對協康會父親們在維繫家庭的完整和支持妻子子女的重大責任和貢獻，深感體會。

作者:范鎮榮認識協康會超過20年。他是一位社工，目前在政府工作。

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1. 「爸爸對對碰」活動 – 旅行 Picnic
2. 「爸爸對對碰」活動 – 交際舞 Ballroom Dancing
3. 新年大遊行 Chinese New Year Parade 2011
4. 「爸爸對對碰」活動 – 父親與大廚 The chefs
5. 「爸爸對對碰」活動 – 保齡球比賽 Bowling Competition
6. 新年大遊行 Chinese New Year Parade 2010
7. 「爸爸對對碰」活動 – 聚餐 “Dad to Dad” gathering
8. 遊行合照 Elena, Jonathan and Daniel Yung
9. 添分享一家照片 Tim and family
10. 做女兒的馬夫 James and Eleanore
11. 小時候 Katherine and family
12. 一家旅行合照 Daniel Chan and family
13. 一家盛裝赴會 Vincent Yu and family

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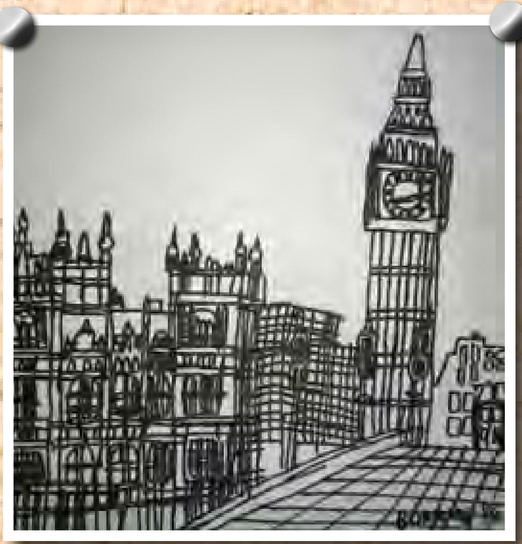

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1. The cock and his family - Mathew Ye
2. Panda – Bowman Yu
3. Deer – Barry Mak
4. My father is a lion – Barry Mak
5. Dragon – Victor Wu
6. The Big Ben - Bowman Yu
7. My family – Joanne Pang
8. The boat
9. Penguin – Jonathan Yung
10. London Bridge – Bowman Yu

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By Bowman Yu

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