

VISIBLE
INVISIBLE



VISIBLE - INVISIBLE

- exploring disability within the family -

Children and young people play a large part within the family unit, if the child or young person has a disability life may be more challenging for the family as a whole. Chinese families from NSW Australia, are very proud of their children, they have shown this pride by allowing their families to be photographed and published within this booklet.

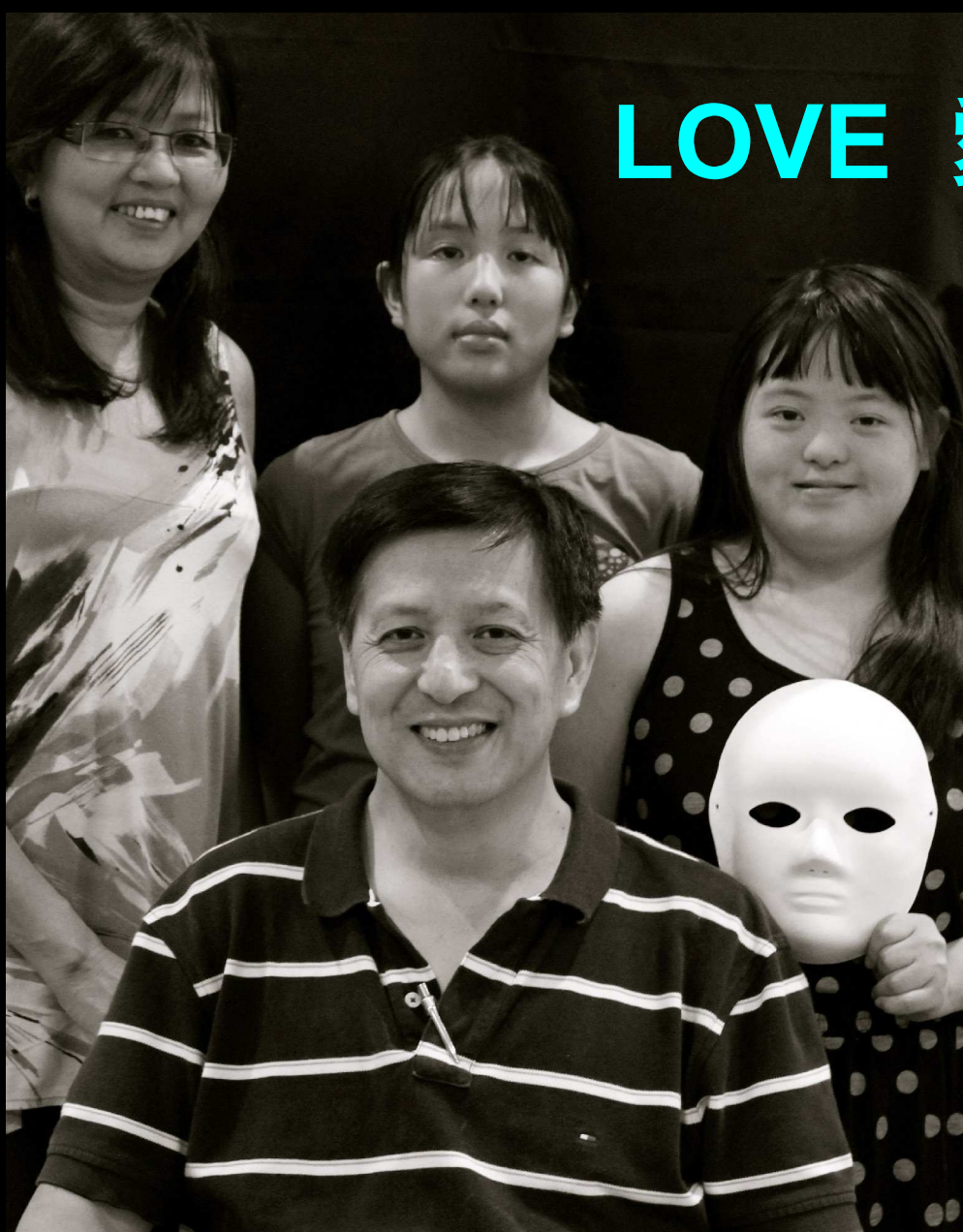
They have also taken the time to answer some very difficult questions regarding life at home with a child that has a disability, you will find a series of questions and answers at the back of this booklet and woven within these personal family portraits.

Within this booklet we also explore the hidden face of disability, which is represented by white masks. A disability may not be easily recognisable (hidden from view), or a person with a disability might find themselves isolated and alone (hidden from view).

Our **VISIBLE - INVISIBLE** booklet gives colour to these people/masks, bringing them out into the light. No longer plain white and invisible but now full of life and creative colour -VISIBLE for all to see, admire and love.

Nick Baldas

LOVE 愛



COMMUNICATE

溝通



兒童和青少年在每個家庭中都是非常重要的成員，
如果他/她們患有殘疾，
整個家庭將要面臨更多的挑戰。
這本小冊子，
表達了澳洲新南威爾士州的這些華裔家庭，
為自己的孩子而感到自豪，
他們願意被拍照，並樂於把家庭照刊登在這本小冊子上，
表示他們以此為傲。
他們還花時間回答了一些有關養育殘疾孩子的問題，
和在生活上遇到的困難 - 這些問題和答案，
您可以在小冊子的最後一頁找到；有些精簡的答案，
還被編在家庭照的內頁。
在這本小冊子中，
我們用白色的面具去代表和探索殘疾人士隱閉的一面。
有些殘疾可能不容易被察覺（表面看不見），
或殘疾人士可能會發覺自己被孤立和孤單（隱閉）。

Nick Baldas

“**VISIBLE/INVISIBLE**” is a collaborative project that connects families that have children with a disability. Young people of all ages are represented with their families in a series of black and white personal portraits. These young people were also given the opportunity to express their creativity by transforming plain white masks into colourful expressions of self.

These colourful masks are a step towards raising awareness of the creative abilities of people with disabilities to the general public, this booklet also goes one step further, it also explores the personal perspective of the parents through a series of questions in both English and Chinese.

Through **VISIBLE/INVISIBLE**, we hope to inspire other children with disabilities and their parents. Let's continue the journey together, so we can better facilitate and develop the potential locked in our children, and ultimately, improve and enhance our children's quality of life.

I would like to send my sincere thanks to Nick Baldas, who coordinated the project and played a key role in coaching our young people with disabilities, also to all the parents and volunteers for their efforts & time in assisting in the workshops.

Miranda Vuong

「可見的或隱閉的」

這本小冊子是一群弱能兒童家庭的合作交流項目。

這群不同年齡的弱能青少年及其家庭,利用一系列的
黑白肖像來表達自己。

這些年輕人也藉著這個機會,
來表達自我,把純白色的面具改變為七彩繽紛,
以突顯他們的創意。

這些多姿多彩的面具,
可以幫助社會大眾對弱能人士的創作力,有進一步的認識。
而這本小冊子也透過一系列中英對照的問題,
更深入地探討家長的個人觀點。

藉著「可見的或隱閉的」這本小冊子,
我們希望能激勵其他弱能兒童和他們的父母。
讓我們繼續同心向前邁進,
從而啟發我們孩子的潛能,
最終可以改善和提高孩子生活的質素。

在此,我要感謝這個項目的統籌Nick Baldas,
在指導我們的弱能青少年中發揮了關鍵的作用,
也感謝所有參與的家長和義工,
在工作坊中獻上他們寶貴的時間和精力,加以協助。

Miranda Vuong





UNDERSTANDING

瞭解



STRENGTH 力量





PATIENCE

忍耐





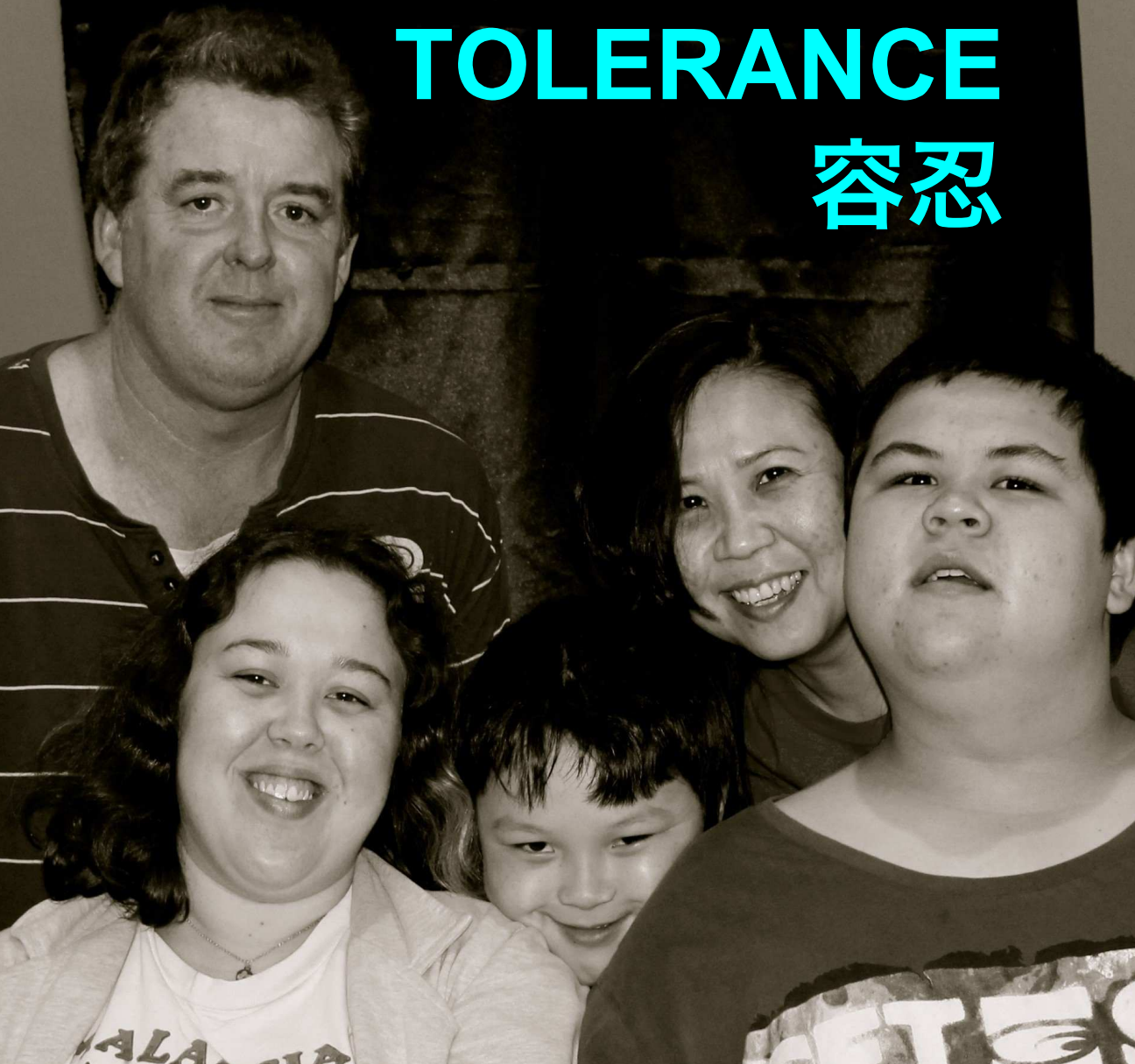
SUPPORT

支持



TOLERANCE

容忍





CHOICE

選擇









S
I
N
C
E
R
E

真誠



SAFETY

安全



ENGLISH QUESTIONS & ANSWERS

What support would you like as a parent with a child that has an intellectual disability?

1. Techniques to prevent harmful repetitive behaviour.
2. As a parent, we need more respite.
3. More Funding.
4. Support from the Government, community and disability organiser to provide the funding for my son to attend more activities.
5. Respite.
6. More healing sessions.
7. Healing sessions and respite.
8. Respite and healing sessions.
9. Support from family members, friends, professional when needed, and advice to correct his problem behavior.
10. From family, friends and community support program

How do you feel as a parent with a child that has an intellectual disability?

1. Trapped and helpless
2. Trapped 24 - 7.
3. Alone
4. As a parent, I accept that my son has an intellectual disability and that he is enjoying activities like singing, dancing, art & craft, and sport activities like ice skating, bowling and swimming.
5. Can be stressful
6. Everyday, I feel tired both physically and mentally, but I won't give up. Because of my son, I learnt how to bravely confront problems.
7. Feeling helpless.
8. Heart breaking.
9. I worry about my son's safety since he doesn't know how to protect/look after himself.
10. It was heart breaking at the beginning, he makes me change for stronger and tough, and he needs me there to guide him.

What are the difficulties you have faced with language while taking care of your child with an intellectual disability?

1. He is non-verbal and has simple limited communication.
2. Hard to communicate with kid who has no verbal skill and feel embarrassed in meetings with kid along.
3. Trying to think how they work in their mind and work with it! And get a new idea about how to work with them.
4. Yes, but we try to communicate well with our son. We try to listen to him slowly.
5. No difficulties.
6. Yes, as my son can't express himself clearly, he attracts my attention by creating behavior problem.
7. Difficult.
8. Yes.
9. Not much
10. No problem with me.

What worries do you have for your child as you age?

1. No idea what will become of him when we are gone.
2. Well being of the kid.
3. When they grow up no one will look after them.
4. Behavior problems, health, safety and security.
5. Someone to look after them as we age.
6. I dare not think of tomorrow. I can only live day by day or live in the moment.
7. I hope there will be a Centre for him to stay.
8. I worry he has no where to go.
9. Who will look after him and where will he live?
10. His everyday living, protection and care that he needs. I am trying to stay healthy and live as long as him.

How do you cope with the stress of being a parent with a child that has an intellectual disability?

1. No choice but to go on.
2. Have a duty to look after the kid no matter what happens.
3. Try not to think about it and keep going.
4. Love, patience & tolerance. Relax and take it easy.
5. Find time out for myself.
6. I go out with a few mums in the afternoon to have tea and chat.
7. I chat with other mums.
8. Go shopping and chat.
9. Keep busy doing other things and don't think about my worry that much.
10. Try to understand what cause it and seek for solution to avoid the stress, learn to deal with it. Chat with friends and socialise.

CHINESE QUESTIONS & ANSWERS

作為一個智障孩子的父母, 您希望得到哪些支援?

1. 學習如何防止重複危險行為的技巧。
2. 作為家長, 我們需要更多的暫息服務。
3. 獲得更多的資助。
4. 政府、社區和殘障服務機構提供支援及資助, 讓我的兒子可以參與更多的活動。
5. 暫息服務。
6. 更多有治癒功能的活動。
7. 有治癒功用的活動和暫息服務。
8. 暫息服務和有治癒功用的活動。
9. 在有需要的時候, 得到家人、朋友和專業人士的支持和改善問題行為的指引。
10. 得到家人、朋友和社區的支援服務。

作為一個智障孩子的父母,您有什麼感受？

1. 如身陷囹圄及無助。

2. 7天24小時被困。

3. 孤單。

4. 作為一個弱能兒童的家長, 我已接受他的弱智。

我很高興我的兒子很喜歡唱歌、跳舞、藝術和手工, 還有溜冰、打保齡球和游泳等體育活動。

5. 有壓力。

6. 我覺得每天都身心疲累, 但我不會放棄。為著我的兒子, 我學會了如何勇敢地去面對問題。

7. 感覺無助。8. 心碎。

9. 我擔心兒子的安全, 因為他不懂得如何保護及照顧自己。

10.最初是心碎, 但他讓我變得更堅強和有耐力, 他需要我從旁指導。

當您照顧有智障的孩子時,在語言溝通上,可有遇上什麼困難？

1. 他不會說話和祇有簡單及有限的溝通能力。

2. 很難與沒有語言能力的孩子溝通, 和他一起參加聚會, 我感到尷尬。

3. 嘗試了解他們腦部如何運作,從而找出協調的新方法。

4. 有,我們試圖跟我們的孩子進行良好的溝通,並耐心地聆聽。

5. 沒有任何困難。

6. 有,因我的兒子不能清楚地表達自己, 為引起我的注意而作出問題行為。

7. 有困難。8. 有。9. 問題不大。10.沒有問題。

當您年紀漸老，您對智障孩子的將來會有什麼擔憂呢？

1. 當我們死後，不知道他將會怎樣。
 2. 孩子的福祉。
 3. 他們長大後，無人會看顧他們。
 4. 問題行為、健康、安全和自衛。
 5. 當我們年老後，是否有人看顧他們。
 6. 我不敢去想及明天的事，我要活在當下，繼續生活下去。
 7. 希望有宿舍他可入住。
 8. 我擔憂他無容身之所。
 9. 誰會照顧他和日後住在那裡。
 10. 他日常生活所需、保護和照顧。
- 我會盡量保持健康和他一起生活。

您如何舒緩來自照顧智障孩子的壓力？

1. 沒有選擇，只能繼續生活下去。
 2. 不管以後發生什麼事情，我有責任照顧孩子。
 3. 盡量不去想它，並堅持下去。
 4. 愛心、忍耐和寬容。放鬆心情，別緊張。
 5. 為自己留點私人時間。
 6. 我會與其他母親一起喝下午茶及閒談。
 7. 我會與其他母親閒談。
 8. 去購物及閒談。
 9. 做其它工作使自己忙碌和不作無謂的擔憂。
 10. 嘗試了解智障的成因和尋找減壓的方法，與及如何面對壓力。
- 並與朋友見面及閒談。

HOPE

希望





The Chinese Parents Association - Children With Disability Inc.
Suite 4, Level 2, 59 Evaline Street, Campsie NSW 2194
PO Box 345, Campsie NSW 2194
t: 02 9784 8120 | f: 02 9718 0236 | m: 0406 233 222
www.chineseparents.org.au (<http://www.chineseparents.org.au/>)

Nick Baldas and the Chinese Parents Association - Children With Disability Inc
retain sole copyright of this book, which include all text and images.
Written permission must be granted for reproduction of any of the material found
within this booklet. Copyright February 2015

"Supported by Kogarah City Council Community Grants Program"





VISIBLE - INVISIBLE Exploring Disability Within The Family