

Building Ordinary Lives

By Sharon Ford

How can we, as families, support each person with Down syndrome to be the best they can be?

Raising the bar on expectations

The abilities and potential of people with Down syndrome have traditionally been under-estimated. Until recently, it had been assumed that, apart from a few exceptional cases, people with Down syndrome were not able to learn very much and would be destined for a life of dependency.

Happily, things have changed. For young people born with Down syndrome today, rather than speak about expected limitations we tend, more pro-actively, to refer to their 'potential' and how to support them to achieve it. Pinning down what this 'potential' is, however, is tricky.

A diagnosis of Down syndrome does not, in itself, determine development or potential. People with Down syndrome are naturally as varied in their abilities and capacities as people without Down syndrome. And we cannot project the future outlook of today's young people born with Down syndrome, based on any previous generation, because that generation have not necessarily been offered the same educational and social opportunities, or perhaps the chance to really show what they are capable of achieving.

What can we aim for?

Most parents are usually happy to just let their children's potential reveal itself, but we seem to be less able to do this with a child with a disability. Most parents experience acute anxiety after discovering that their baby has Down syndrome, as they wonder what they

will be capable of. "Will he or she be able to...?" is commonly one of the first questions asked – whether publicly or privately between parents and family. And the same question pursues families in a long succession of developmental milestones and life stages.

There is no blueprint for how potential is achieved, no standard indicators of its fulfilment, no obvious indication of its limitation. So parents constantly walk a tightrope between expectations and hopes for their child and wanting to be realistic in the face of an intellectual disability. How can we support our family member with Down syndrome to be the best they can be, without setting up and imposing unrealistic expectations?

There is no easy answer, but a couple of things are useful to keep in mind:

1. See the person before the disability

Striving to allow the person with Down syndrome to show us who they are and what they are capable of – always giving the opportunity to go further. This can be difficult when many of the professionals you come into contact with have a preconceived idea of the destiny of your child. But it is crucial that we do not create limitations by capping our expectations or working from a stereotype.

2. Keep an eye on the goal of an 'ordinary life'.

Some people with Down syndrome already lead what we might call an ordinary life, others are not so close. Almost everyone with Down syndrome is *able* to lead a more ordinary life, in some or many ways, than they do at present.

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Aiming for an ordinary life – in all its diversity

What is an ordinary life? There is no easy definition, but there are some key opportunities, which we all expect in our ordinary lives. These include the opportunity to:

- learn to read and write
- attend school
- attend post-school training
- find a partner
- participate in the community
- make choices about adult life options
- be independent

The majority of people with Down syndrome growing up today should have all these opportunities to some degree, and be able to take advantage of them if given an appropriate level of support. Of course, the level of support needed will continue to vary significantly from individual to individual, and a minority will require a much higher level of support to achieve a more ordinary life.

An ordinary life does not need to be full of bold achievements. An ordinary life for most of us is just that: it offers some sort of base line in options and opportunities. Each of us will add our own particular flavour, depending on our personal capacities and constraints, interests and opportunities. If we aim to enable people with Down syndrome to lead ordinary lives, we will be going a long way to supporting each one individually to achieve what they are capable of. And it does not matter that progress might come in small steps. Each step towards a more ordinary life is an achievement in itself, and deserves true celebration.

Below is a quote from *Living With Down Syndrome* by Sue Buckley, who has been researching and working with people with Down syndrome for 35 years. She is one of the world's foremost authorities in this field – and parent of Roberta, who has Down syndrome.

Sue describes how Roberta did not walk independently until the age of 4 years,

or speak until she was 5 years old. She left school with minimal academic skills, unable to read or count. Yet Roberta, now in her mid 30s, today lives a quite ordinary life, in contradiction to the picture of gloom and doom that Sue was given when her daughter was young. Sue says of Roberta:

“The older Roberta becomes, the more I see the likenesses between her and her brother and sister in important life skills and needs, and the less I see the differences. I wish that I had had a vision of the competent adult that she could become when she was a baby, rather than the vision of eternal childhood and dependency that I was given. I would then have been able to be a better parent for Roberta.”

This observation highlights the fact that the skills and capacities we need in order to lead ‘an ordinary life’ do not rely on academic skills learned in school. A longer extract from *Living With Down Syndrome* is reproduced on page 11 of this issue, or you can visit www.down-syndrome.org to read the entire text.

How to enable ordinary lives for people with Down syndrome

What do we need to make available to people with Down syndrome, to support them in moving towards more ordinary lives? There are many things, but we will look at five key points here:

1. The opportunity to learn and keep learning

People with Down syndrome learn, and continue to learn all through their lives, just as we all do. And today we know a good deal about the learning strengths and weaknesses commonly associated with Down syndrome: what strategies will support the learner with Down syndrome and strategies less likely to lead to success. What is needed now is more widespread practice of using this knowledge creatively to enable learning and ability in each individual. Not only in school, but throughout life. There is still a great deal of work to be done.

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An ordinary life does not need to be full of bold achievements

To have an ordinary life you need to be among other people leading ordinary lives. To be a part of the community.

2. A support network and support system which enables and empowers, and does not foster dependency

This will start with families. Giving families permission to better imagine the future for the person with Down syndrome is a crucial step in enabling and empowering people with Down syndrome. It is not easy as a parent to maintain that positive vision. It is a delicate balance to keep expectations high enough to challenge, but also realistic. And probably every parent of a child with Down syndrome has at some time lowered their expectations in order to avoid disappointment – both your disappointment and your child's. But families are the greatest asset of all for a person with a disability, their strongest advocates and traditionally, the driving force in all change. It is important that we support our family member with Down syndrome to show us their potential, and limitations, and always expect progress towards independence. If we don't do this, nobody else will.

When we reach the stage when support and intervention services clearly see the person ahead of the disability, and these services are guided by an overarching aim of optimising personal independence, we will be getting close to that elusive 'ordinary life' for everyone with Down syndrome.

3. Value

In order to enable and empower people we need to value them. All people with Down syndrome have the potential to contribute in significant and valuable ways to our society given the chance to do so. We sometimes fail to recognise this because as a society we attribute value to a limited range of talents and characteristics, with academic intelligence (IQ) ranking high on the list. In order for people with an intellectual disability to be accepted as really valued members of society, we will need to acknowledge the importance of a much greater diversity of talents and characteristics, and what each brings to other people and to society in general. Although it is difficult to influence

society to embrace this concept, we can demonstrate it through our actions.

4. Choices

We all need to have input into the content of our daily life. We all consider it a fundamental right to decide how and where to spend our time, who to share our lives with, and so on. This right is not always so obvious in the case of people with an intellectual disability, sometimes because we fail to acknowledge it, sometimes because of limited options. We need to address both of these. This does not mean unlimited choice, it means the option to make decisions and not have all your decisions made for you. It means having the right to make mistakes and learn from them.

5. Other people living ordinary lives

To have an ordinary life you need to be among other people leading ordinary lives. To be a part of the community. Happily, people with Down syndrome are today found in many walks of life and engaged in a whole range of regular life activities that any one of us would expect to be available to us. Each year more young adults are leading more independent lives, and succeeding in areas that were previously not considered open to them in a variety of employment opportunities, community endeavours and leisure options.

Unfortunately, in the broad scheme of things, these numbers are still small, and are still considered pioneers. The majority of people still do not habitually rub shoulders with a person with Down syndrome, or indeed any other disability. It will be up to the next generation to pick up the baton and ensure that social inclusion becomes widespread and commonplace.

With every child who grows up alongside a child with Down syndrome, or learns in the same class, or goes to the park with a child with Down syndrome, with every adult with Down syndrome out and interacting in the local community, wholesale inclusion becomes more of a reality. And with

inclusion comes that life more ordinary. It is worth reiterating that the smallest steps can make a life more ordinary. They are significant and they make a difference. What will make the life of your family member with Down syndrome more 'ordinary'? I am sure that everyone can think of something, and that is a good place to start.

References

- Living With Down Syndrome *Sue Buckley (www.down-syndrome.org)*
- Empowering Parents and Families – is this the way to meet family needs? *Sue Buckley (www.down-syndrome.org)*
- Why The Community Needs People With Disabilities: an explanation of some of the assumptions *Lorraine Zeni CRUcial Times 22, Nov 2001 pp6-8*
- The Challenge Of Creating 'Right Relationships' Between People Who Provide And Receive Services *Michael Kendrick (CRU Conference, Brisbane, 2001)*
- Relationships And Everyday Lives *Jane Sherwin and Anne Cross (CRU Conference, Brisbane, 2001)*

Bar None

by Kirsten Deane

A café employing young people with Down syndrome and Jamie Halliday - one of the first Australians with Down syndrome to achieve his black belt in Zen Do Kai Freestyle, were recently recognised for their efforts in Victoria's *Bar None* campaign.

A new initiative of the Office for Disability, the *Bar None* campaign aimed to recognise those individuals, businesses and organisations working to break down barriers and improve opportunities for people with disabilities to participate in community life. The philosophy of the campaign was summed up in its slogan – "We believe in a world where everyone can take part – bar none".

The campaign attracted more than 300 nominations from across the state and culminated in a celebration at Melbourne Town Hall where nominees and their guests were entertained by the *Choir of Hard Knocks* and congratulated by the Minister for Community Services, Lisa Neville.

"The aim of *Bar None* is to end the prejudice, exclusion and barriers which hold people back from fully participating in life," Minister Neville said. "This campaign has helped to build more inclusive communities, highlight the diverse skills and achievements of people with disabilities and discover new leaders... When we create more inclusive communities, everyone benefits."

Nominees included organisations providing employment for people with a disability as well as sporting, cultural and arts groups and individuals who have worked to make a difference in their local community.

Leader Newspapers partnered with the Office for Disability in the campaign and ran more than 70 stories featuring nominees and their achievements in local papers across the state.

In collaboration with the campaign's communication experts, the newspaper group also developed editorial guidelines for the reporting of disability issues, with particular attention paid to the importance of appropriate language. Trainers at a series of workshops held for journalists stressed the importance of always putting the person first and avoiding such terms as 'wheelchair bound' and 'suffering from Down syndrome'.

Improving the ways in which people with a disability are represented in the media may well be one of the most long lasting achievements of the campaign.

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