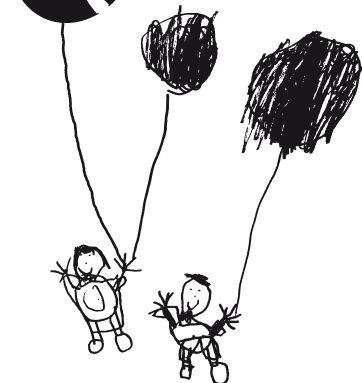


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Information Sheet 46

When family and quality services just are not enough

This article, by Dr Keith R McVilly, Lecturer & Clinical Psychologist, School of Health Science, Division of Disability Studies, RMIT University Melbourne, first appeared in the Down Syndrome Ireland Newsletter, Spring 2006 and the Down Syndrome NSW Newsletter Winter 2006. It is reprinted with the kind permission of both Dr McVilly and Down Syndrome NSW.

The concerns and efforts of families, service providers and governments have historically, for good reasons, focused on promoting quality of life for people with disability through initiatives in accommodation, education and employment, and more recently in the area of health care.

However, despite many good service initiatives, the lives of people with a disability are commonly characterised by a lack of friendships and limited opportunities to spend time with the friends they do have. Their social networks tend to consist predominantly of family members and paid carers. Furthermore, for many, there appear very limited opportunities to change this situation and consequently the experience of loneliness.

We know from research in the general population (and our own personal experience) that relationships, and in particular friendships, are integral to promoting health and well-being, and coping with life's challenges. Furthermore, the absence of significant interpersonal relationships is associated with increased vulnerability to illness, poor health outcomes and premature mortality.

For people with an intellectual disability, impediments to diverse and rewarding social networks could also be a contributing factor in the onset of mental health conditions such as anxiety and depression, and subsequently linked to behaviours of concern.

While considerable energy and resources are being expended on education and accommodation, health care and addressing 'behavioural problems', what do we know about the social life of people with a disability from their perspective; and their expectations and aspirations for friendship? Is it sufficient to have a loving family and dedicated support staff; or do people need more in their life; and how might this be achieved?

Over the past few years we at the University of Sydney's Centre for Developmental Disability Studies (CDDS) have been interviewing young adults with a disability about relationships and in particular their aspirations and experiences of friendship.

It has become increasingly apparent that while many of these young people with a disability have loving families as well as access to a range of appropriate services, the support they need to make and maintain friendships has been seriously lacking. The result has been that while young people with disabilities appear physically much healthier, better educated and have greater chances of getting a job than in the past, they continue to report being lonely, and in need of friends.

This lack of friendship could be very serious, affecting their mental health and in some instances contributing to their presentation of behaviours of concern.

Many of the young adults with a disability we have interviewed report the value of family; of mum 'who always understands', of dad 'who takes me everywhere', and of brothers and sisters 'who are heaps of fun'.

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We raise funds to help children from birth to 18 years by offering a range of services including the following.

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- Early childhood intervention and support for very young children.
- An inclusive preschool for children with and without special needs.
- An assessment and consultancy service for families who are concerned about their young child's development.

- Specialist early childhood teaching and therapy.

School Age Services for children from Kindergarten to Year 12 who have low support needs.

- Comprehensive assessments.
- Small group tuition and therapy.
- Occupational and speech therapy programs combining specialist education services and therapy.
- Outreach programs.
- The Ronald McDonald Learning Program for seriously ill children and the Reading for Life Program for children falling behind in their reading.

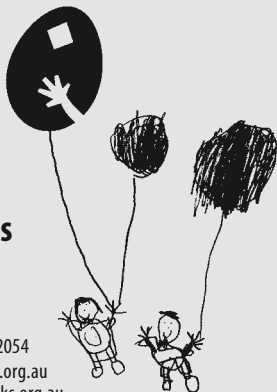
Family Services helping and supporting families and health professionals.

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However, many of these young people also identify the importance of friends; of peers outside their family with whom they want to spend time, *'cus they're my age'*; *'cus they're just like me'*; *'cus they got a disability too and know what it's like'*. Many of these young people have a good idea of the people with whom they would like to be friends, but report that they *'just can't make it happen'* or that they *'just don't know what to do'*.

Parents and siblings have an important role to play; not just in being there for their son/daughter or sibling (though this is so very important), but also in enabling and supporting their son/daughter or sibling to forge friendships outside the family; with peers, including peers with a disability.

Finding out who your son/daughter or sibling might like or who they might want to get to know and setting up opportunities for them to spend time together could be one of the most important things you do in terms of their long-term happiness and positive mental health. Importantly, where friendships arise, doing your best to maintain opportunities for contact if they change schools or jobs or move house is also very important.

Many of the young people we interviewed reported having had a *best friend* with whom they lost contact, because when they or their friend moved house no one wrote down the new address or telephone number. Similarly when they left school or changed jobs, they never saw their friends again and had no idea of how to get in contact with them.

It was clear that while many had been asked by family or service providers about what activities they might want to do in their spare time (e.g., at the weekend or as part of an activity program), no one had asked with whom they would like to do that activity.

For many of us, it's not just what we do in life that's important, but with whom we do it; and this appears to be no different for people with a disability.

Some of the young people we interviewed reported having made friends at work, but reported that they only ever saw their friends at work and never had a chance to see them at the weekend or to spend time with them in a more relaxed, social setting.

Commonly their weekends were spent with family or the people with whom they lived. While this was sometimes OK, often they had other people outside the family or group home, with whom they wanted to spend time their spare time.

They also commented that when they went on holiday (commonly with their family) or when their place of work closed at Christmas, they often did not see their friends for many weeks at a time. People commented on how they became worried if their friend from work was away sick, and how no one ever told them if their friend was OK or if they could visit them in hospital, or at least get some help to send them a 'get well card' or flowers.

The young people with a disability we interviewed have repeatedly talked about wanting to invite their friends to come over to their house, to *'watch a video'* or *'just spend time in the yard'*. Importantly, they have talked about valuing the opportunity for *'time together alone; without mum or dad listening in'*.

They have asked for help to use the telephone to speak to their friends and help to remember their friends' birthdays; so they could send a card or buy them a present. They have asked about how they might get help to buy their friend a present at Christmas or a chocolate egg at Easter. These are the sorts of things that the rest of us might take for granted when making and maintaining friendships for ourselves, but present as quite complex problems for people with a disability.

It has been clear from our interviews that friendship is experienced by many young adults with a disability as an opportunity for them to do something meaningful for someone else, who is important to them.

Friendship provides a unique opportunity for people with a disability to experience more than just being on the 'receiving side' of a relationship, which can commonly be the case where people are perpetually in the role of being 'cared for' or living life as a 'service recipient'. It provides an opportunity for people to experience what it means to be a contributor; an experience we all value and which is important to our self-esteem and personal identity.

Helping people to work through disagreements with their friends and the complex process of 'fixing broken friendships' also appears an important area where young people with a disability are looking for support from parents, siblings and support staff. While social skills classes often take place at school, when people leave school they still need support with this most complex area of life. Sometimes professional tuition is needed, but often the companionship and personal support that comes from membership of a peer group can be very helpful.

Participants in our study in Australia have reported that some of the best help they get with relationships comes through their involvement in 'self-advocacy groups', and other disability-specific organisations or clubs.

This is not to say that getting involved in the wider community is not important (and many of the people we interviewed spoke of the importance of 'doing things in the community' and friendships with people without a disability). However, many identified that being with other people who 'knew what it was like to have a disability' was also very important to them.

Life is full of challenges, and for these reasons family support and quality services can be of immense value.

However, as with most people in the wider community, for adults with a disability the support of friends can also be critical to achieving happiness, health and well-being. Our research at CDDS highlights that the need for supportive relationships outside family and a network of service providers, and in particular involving peer-based friendships, is a priority for adults with a disability. The research suggests that people with a disability not only need appropriate accommodation, education, employment, health-care and a chance to participate in their community, but that they also need and indeed want support from parents, siblings and service providers to make and maintain friendships.

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School Age Services

– contact your local branch

Family Services

– contact your local branch

All other enquiries

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