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Families for Change

Stand by Me

Working in an advocacy agency that takes up the issues facing people with developmental disability can, sometimes, leave one feeling sceptical, cynical, jaded and convinced that the world really is a dreadful place, and we should all just get up and go somewhere else! Fortunately, cynicism is short lived, as there are places where children with disability are happily welcomed into ordinary, local schools, where businesses really mean it when they say they are “equal opportunity” employers, where everyone has the chance to live in their own home with people of their own choosing, and where people with disability have people in their life who value them, see them for all that makes them human beings, the strengths as well as the weaknesses, and that being in relationship with that person is no big deal, it’s just how it is.

This edition of Families for Change looks at a number of these relationships and seeks to showcase that friendships do happen between children with and without disability in school; employers do see the benefits of employing a person with disability and that having a sister or brother with disability isn’t a burden or a tragedy. The relationships written about here are all linked by a thread that connects the writers. They are all in relationships of one type or another, with a person with disability, and they haven’t seen the disability as a barrier to friendship, a collegial role or a loving, sisterly one. The children speak of their school friends Kaleb, Rhys and Joshua in ways that demonstrate the friendships aren’t all one way; they do things for their friends and their friends with disability have plenty to offer in return. Graham’s colleague enjoys his work role with Graham and would not hesitate to employ a person with disability again, and Sherryn Targett speaks fondly of her sister and reflects on how “ordinary” their bond really is and the important life-lessons she has learnt.

Relationships function on many levels starting with the brief nod to the person you pass on the street during your early morning walk, to deep, loving and intimate

partnerships. Some are short in duration and only last as long as the shared activity e.g. with a fellow student at TAFE during a 3 month course, to a friendship that spans a lifetime. Many of us would take the people we have in our lives for granted and spend little time reflecting on the importance of them, but it’s not hard to imagine how impoverished, narrow and lonely life would be without them.

Sadly, many people with developmental disability live lives that are devoid of relationships beyond that of immediate family and paid professionals. Many people accept this as the ‘norm’ and doubt that it is possible to bring others into the life of someone who perhaps doesn’t speak or who needs significant assistance in all areas of their life. This journal seeks to celebrate the exceptions to this accepted ‘norm’ and demonstrate that relationships are possible between people with and without disability. Not only are they possible, they should be seen as an essential element to a happy, fulfilled, rich, stimulating life full of the usual ups and downs, risk and benefits, joys and disappointments that being in relationship with others brings. In her article “Personal relationships between people with and without disabilities”, Zana Lutfiyya describes some of the ways families and workers can facilitate friendships between people with and without disabilities.

Relationships often won’t just happen, and effort is needed to ensure people with disability are in environments in which links can be made and connections can grow and flourish. This may take very deliberate intention, as mentioned in Sherryn’s article, where a circle of support is being created around her sister. This family has recognised how important others are in her life and that sometimes facilitation is required. This does not in any way lessen the importance or validity of these relationships, but is simply recognition that this is an area of struggle and challenge for people with developmental disability.

Promoting and defending the rights and interests of people with a developmental disability.

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ADVOCACY

“Relationships between people with and without disability should be seen as an essential element to a happy, fulfilled rich, stimulating life”

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Sisters being Sisters

By Sherryn Targett

Sherryn Targett lives in Queensland, where she works for Mamre as Finance and Administration Manager. Mamre has supported families who have a member with disability in the Brisbane area for over 20 years. In September 2005, Sherryn facilitated the "Life as a Brother or Sister" workshop at the Inspirit Conference. She has a special interest and passion about the role of siblings and she is studying a Master's degree in Community Management.

In my family there are five of us siblings - three brothers and two sisters. I am one of the sisters. As in most families I know, I have a particularly normal sibling relationship with my brothers and sisters and like to think vice versa; mind you, I am sure my brothers might think differently at times when big sister is maybe too protective! My sister and I stick together and the brothers do the same. We are fiercely protective of one another and always looking out for one another. Our own family advocacy!

My sister and I have what I consider a typical relationship. We regularly do coffee where we check out the... latest fashions! There are regular shopping trips with the girls (mum included) as football, and any sport for that matter, descends upon the household and escape of the retail kind beckons. We share clothes, and frequently go out for dinner even though we both love to cook. The art of cooking together is not the usual way, but it is our way of connecting as sisters, like our brothers do with going to the football together. There is lots of laughter and fun and it doesn't really matter what we are doing and how we are doing it - we are just sisters doing it for ourselves!

I remember a time when I moved back home and my sister and I were first up. We were both preparing our breakfast and mum came into the kitchen with a gasp as my sister was pouring the milk over her cereal. My sister had got a fright with mum's gasp and the milk went, well... everywhere except into the bowl! My

sister's coordination is not great, particularly in the morning! I later discovered that mum was still preparing her breakfast. This was a big learning for each of us, with mum realising that she was perhaps doing more than necessary.

I often reflect on this part of my relationship with my sister. Others may see this as not a typical sibling relationship whereas I beg to differ. I see this as simply being one of those times when you cherish the learning

"The art of listening and allowing each other space for expression facilitates great conversation and sharing"

you receive from your family or others. There are many times when my sister has taught me not to hurry. Now I see it as an opportunity to stop and acknowledge that life does not have to go full speed ahead right now and to just be. As a teenager, I usually saw these as frustrations and lots of other emotive emotions, particularly when she would just refuse to go where I wanted to go, always in the middle of a big shopping centre. It does not matter that it has taken until she is 24 that we can share clothes or that the way we have a "deep and

meaningful" after a girl's night in is not the usual way. We are sisters being sisters in our own way.

There are other examples. Our family is currently looking at creating a circle of support around my sister where she will gather together friends regularly to share with them her dreams and her goals. I do not see this as being different from my own group of friends. I often call on them for advice and a listening ear. We do things together regularly and are there for one another and they know what my goals and dreams are.

We have spent many times together and as with any relationship there are times when things aren't so great. Even though we do share the same size in clothes we don't have exactly the same tastes! Communication can be frustrating at times, but then I look at how easily this can happen with other relationships in our lives. Look at how many times we may have had disagreements or made judgements on the wrong information we have received or perceived. The art of listening and allowing each other space for expression facilitates great conversation and sharing.

I have many more reflections on my relationship with my sister, who has a disability. But what is at the forefront in these is that she is firstly my sister. This is really important for me, especially when others emphasise the latter and it is the sharing of such ordinary experiences that helps our relationship be sisters being sisters and nothing more. Right now that's the way we like it!

Resources from the Inclusion Collection

Below is just a small selection of books about the topic of this issue, relationships. You can order articles, books, videos and kits from the Inclusion Collection online on www.family-advocacy.com or by phone on 02 9869 0866 or 1800 620 588 (for non metropolitan callers).

Like a sweet cup of tea: shared lives, neighbourhoods and communities

Community Resource Unit - Parent Project File: 3289

With the intention of encouraging a stronger movement in favour of authentic community living, and underpinned by a theme of reconciliation, this book provides stories of people with disability living ordinary lives, in valued roles, and in love relationships, and explores the ethics and practices that make this possible.

Australia, 2004

Relationships and everyday lives: people with a disability and vital communities

Edited compilation of articles File: 3276

This book is a collection of articles dealing with the importance of strong relationships for people with disability. People with disability and their family, friends and assistants tell their personal stories of the struggles and triumphs involved in establishing and maintaining independence and friendship. Personal anecdotes are intertwined with informative pieces on supported living services and suggestions on helping people with significant disability overcome the barriers they face in forming relationships.

Australia, 2003

Creating Circles of Friends. A peer support and inclusion workbook

Newton, C. & Wilson, D. File: 3299

This book shows how building a child's circle of friends can increase their sense of belonging whilst reducing the incidence of disruption. The approach contributes to improved classroom performance and helps to strengthen friendships, personal relationships and growth. The book explains what exactly a circle of friends is, what it is for, how it is set up and how it helps. It includes outcomes and stories of real circles of friends both in primary and secondary school, and even photocopiable handouts for use in school and other settings

UK, 2003

Laying community foundations for your child with a disability: How to establish relationships that will support your child after you're gone

Stengle, Linda J. File: 3231

Every parent who has a child with disability wonders what their son or daughter's future will look like: this book shows families how to take action to ensure that their son or daughter's life will be more satisfying. Stengle emphasises the importance of building a support network of social relationships over time and gives strategies for seeking and cultivating relationships, illustrating this with examples. Stengle sends a clear message that it's never too early to start preparing for 'after you're gone'.

USA, 1998

Delicate Threads

Staub, D. File: 3272

"Delicate Threads" explores friendship between children with and without developmental disability. For three years, the author observed seven pairs of friends (each including a child with developmental disability) at an inclusive primary school in the U.S. Staub includes conversations and interviews in the book, as well as offering teachers and families useful suggestions on ways of supporting children's relationships.

USA, 1998

My Child's Future

Mauder, Mike File: 3213

'My Child's Future' addresses the fact that, for many people with disability, relationships outside paid workers and family don't happen naturally. This means that families need to purposefully work towards building up relationships in their family member's life. It is a manual designed to help families focus on their son or daughter's real needs, gathering others around them to help them achieve what it takes. (This could be, for example, planning for their son or daughter's future home.) 'My Child's Future' is a great tool for families, and contains worksheets to help parents put a plan in place for the time when they are no longer a part of their child's life. It's not surprising to find that there is a heavy emphasis on relationship-building.

Canada, 1997

Friendships and Community Connections between People with and without Developmental Disabilities

Novak Amado, Angela File: 3101

True community inclusion is much more than placing an individual with disability in a community setting, it also means belonging and being in close friendships with other community members without disability. This book gleans principles from successful experiences to help others build relationships of their own through natural social connections and explores how friendships can enhance the lives of every individual in the community. Each author considers a different facet of friendship, such as: work and leisure relationships, gender related expectations, community associations and groups, and the roles of love, affection and intimacy. It is an inspiring book that provides a deeper understanding of how to help build lasting friendships.

USA, 1993

Friends: A manual for connecting persons with disabilities and community members

Novak Amado, Angela et al File: 3076

This manual is for anyone who is interested in supporting a person with disability to widen his or her circle of relationships and develop deeper friendships. It describes the processes used in the 'Friends Project', strategies and methods that proved to be effective or non effective, observations based on experiences, and real life examples. This manual provides concrete suggestions about relationship building. The 'Friends Project' was a one year project whose purpose was to learn about and develop methods for the staff of residential service agencies to support people with disability in establishing friendships with others in their communities.

USA, 1990

Growing Up With My Friends... It's "cool" when friends are there for you!

*This article talks about friendships. Friendships seen through the eyes of three children of different ages, all of them playing the same role: "friend". Family Advocacy would like to thank **Janelle Cosier, Susanne Walden and Helen Meredith** for their contribution to make this article possible.*

“When children with disabilities have more opportunities to develop friendships with typical peers, their social interactions increase and their social skills improve” (Odom & Brown, 1993). These are the words of the experts, of those who spend time researching and analysing the outcomes of different models and practices in education. It is good, and of course absolutely necessary, to have studies that evidence that the inclusion of children with disabilities in mainstream settings is positive. But nothing is greater than seeing this reflected in the experiences of our own children.

Any parent loves seeing their kids making friends, and we are happy to share here some of the experiences that children - children who live in our community- have with their friends. These kids have no disability. Their friends do. But this has not been a barrier for them to become friends. Their views about inclusion are clear. For them, there is simply no question about inclusion, as they see it as a natural thing: as it is... or as it should be!

Lizzie is in Year 6. She has known Kaleb, who has a disability, from pre-school and they are classmates. They are good friends. “I think he is fun because he always likes to play and he is never mean. He always likes to play with me”, Lizzy says. Of course Lizzie is aware that Kaleb is “different”, but many adults could learn a lesson from her way of putting it: “Everyone else is always arguing and Kaleb never argues and if someone is being mean he always tells them to stop being mean, and to stop arguing”. She has clearly spotted the difference, yes: and she is talking about her friend and what she likes about him, not about a person with a disability and the things that he can't do.

As with any other friend, Lizzie tells us

that Kaleb and she help each other: “Well, sometimes when his hat blows away, I go and get it, and he helps me on the computer if I don't know what to do... And he looked after Rodney -my guinea pig- for two weeks while I was on holidays!”

Last year, when Kaleb and she were not in the same class, it was “pretty boring” for Lizzie because “it's fun when he is there”. However, there are other times when there is no fun at all in the classroom, and it is then when Lizzie gets angry: “I don't like it when he's got that talking thing on the computer [speech recognition] and he tells everyone to be quiet, and then people laugh when the microphone isn't working properly. Yesterday, he kept saying something over and over again because it wasn't working properly and all the year 5 students started laughing”. So, what would a friend do in a situation like this? “I tell them to be quiet, because he is my friend and they wouldn't like it if it was them”.

Next year, Lizzie and Kaleb will go to high school, but not to the same one. Her reaction is crystal clear: “It sucks! Why can't he come to my high school?” However, Lizzie is convinced that they will keep their friendship: “We always play fun games, and I like to race him on the Nintendo... And I like to play with him and Twinkles (his cat) in all those things he built for her, and when he comes to my place I like to play with him and Rodney, and play Midtown Madness with him”.

Amorah is 7 and among her friends is Rhys, who has a disability. They have been friends for three years. They attend the same local school and are in the same class. “I like him because he is a lot of fun. Sometimes he is silly and he is very funny too”, she says. Amorah and Rhys attend the same school, they enjoy spending time together, but they also have their own personal interests: “His

favourite things are tractors – he knows a lot more about tractors and trucks than I do!”

Also, Rhys and Amorah help each other, as good friends do: “Sometimes I help him put his shoes on and sometimes I help him with his school work. Rhys loves to give presents and helps other kids in general”. She enjoys encouraging Rhys and does so when he is shy: “At the Christmas concert Rhys was shy going on the stage. I talked to him and he went on the stage. He was really good!”

Amorah and Lizzie have been lucky to experience inclusion from a very early age. This has made them able to look beyond the differences, beyond the disability, to see children, just like themselves, with whom they have become friends. However, the prejudices and misconceptions about people with disability and their inclusion in society are still present. According to a study about children's attitudes towards kids with disability developed by L. Voeltz in 1980, “Children without disabilities positively changed their attitudes towards children with disabilities when given the opportunity to interact with them”. Sarah is 16 and has known Joshua for a while. Joshua –who has a developmental disability- is four years younger than her and their families are close. The age gap, obviously, makes them have different interests, but she is grateful to have met Joshua because she has learnt a good lesson for life: “I think Josh has taught me how to deal with people who have a disability, how to interact with them”.

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Making More Than Just a Living

By Chris Williams

Chris Williams works for Titan Ford in Brookvale. Over the last two years he has worked with Graham Reed. In this article, Chris describes his experience working with Graham, the benefits he sees for the company and the way he now looks at the inclusion of people with disability at work.

Graham was already in the company prior to my starting. Straight away I saw that he was a respected, hardworking and loyal employee. Last month was his fifth year here.

Working with Graham presented me with my first opportunity to work with a person who had a disability. I may have been a little apprehensive at first, but in no time at all Graham had proved his worth.

Graham works on a part time basis for four hours a day, three days a week, assisting us with our general car yard duties. He has a set routine that he completes each day. I believe that Graham's work ethics and dedication are a result of his appreciation for the job, for the opportunity. It would be great to see attitudes like this more often among employees.

The other thing that is quickly realised with Graham is his ability to get along with and communicate with his co-workers. Although Graham likes to keep to himself and concentrate on doing his own thing, once a conversation is started he is always more than happy to have a chat with the rest of us, tell us about his weekend or anything that he may have planned or coming up. Just like anyone else.

Graham has to plan for his days at work and commute like the rest of us, Graham often talks about going to the movies on his days off or

about his weekend activities. I am sure he has extra confidence due to his interaction with the people he is working with, and having to commute with each day.

Graham is considered as “one more” of the staff, not someone who is different in any way from the rest of us. He is treated as any other employee, he is required to

“I now see that anyone with a disability is just after a fair go and the opportunity to fit in and lead a normal life, like all of us”

clock on at the beginning and end of each shift, and as it happens with any other member of the staff, a high standard and quality of work is expected from Graham.

Graham contributes to the organisation in a number of ways. Firstly we have one of the cleanest dealerships around thanks to his work ethics and commitment to completing any given tasks correctly. I also think both myself and all of the staff have benefited from having Graham amongst us. Being able to picture the difficulties

that Graham and people with disability in general have to live with and endure on a daily basis, and still get up and try to lead a normal life, is truly inspirational for all of us.

Before meeting Graham, if anyone had asked me my thoughts about working alongside a person with a disability, I would have had mixed feelings and thoughts. As most people, I would believe that everyone deserves the opportunity to have a job, to be able to fit into society like the rest of us, but I would have been cautious and worried as to whether they would be able to cope in the workplace, to comprehend and complete all duties or interact with the other staff members and the general public. Graham has defiantly put any fears or doubts that I may have had to rest. I would not have any hesitation to work with people with disability in the future or help dismiss any doubts that any potential employers may have.

I have been very lucky and fortunate to work alongside Graham, it has opened my eyes and helped me understand what many people have to live and deal with on a daily basis. Most importantly, I now see that Graham and anyone else with a disability are just after a fair go and the opportunity to fit in and lead a normal life, like all of us, and Graham's experience shows that it can happen!

Personal Relationships Between People With and Without Disabilities

By Zana Marie Lutfiyya

After earning her Bachelor's degree in Psychology, Zana Marie Lutfiyya worked supporting individuals with intellectual disability to live and work in the community. Later, she earned her Master's and Doctoral degrees at Syracuse University while working at the Center on Human Policy, where she held a post doctoral position examining the factors that facilitate the social involvement of individuals with intellectual or developmental disabilities. Since 1992 she works at the Faculty of Education at the University of Manitoba, where she has continued her work on social inclusion. Dr. Lutfiyya has participated in several research projects about social participation of people with disability and other vulnerable groups.

Why are friendships between people with and without disabilities important?

Everyone needs friends. Friends are people who support us emotionally, who see things from our point of view, who give us feedback (sometimes critical) and cause us to grow. We think of our friends as people who choose us for ourselves, not because they have to, and who will be there for us when we are facing a crisis. With friends, we have opportunities to become involved in community and school activities, to be exposed to new experiences, and to enjoy life more fully. Friendships between people with and without disabilities enrich the lives of both, in many ways.

When should we begin to think about friendships between people with and without disabilities?

If we want the people we love to be connected to others and a part of their society as adults, we must think about their relationships when they are children. Their classmates and neighbours will grow into their co-workers and friends later in life.

Integrated classrooms and recreational activities are important first steps: in these settings children with and without disabilities get to meet each other. But many parents have found that even though their child is integrated in school, she or he has few nondisabled friends.

What makes the development of relationships difficult?

Many individuals with disabilities live largely in a world made up of their family, the people who take care of or provide services to them, and others in

the programs they participate in. These relationships can clearly be significant and should be encouraged. But outside of family members, people may have no freely given and chosen relationships.

Generally, many people with disabilities face certain disadvantages in getting to know others and forming connections:

Opportunity. Too many people with disabilities have limited opportunities to take part in activities where they can meet their typical peers. This can be due to physical segregation or to having a role as "client" or "special education student." Services may restrict people's chances to get together, through program or funder rules, curfews, transportation restrictions, and other restrictions. Whatever the reason, people with disabilities frequently become cut off and isolated from others.

Support. Relationships between people with and without disabilities are not formed by throwing unsupported people together. Some individuals need assistance with fitting into certain settings and activities. Others may need someone to facilitate their involvement or to interpret them to others in positive ways. Without subtle supports, people with and without disabilities might never get a chance to really get to know each other.

Continuity. While we enjoy meeting new people, we are sustained by those we have known over time. The continuity of our relationships over the years is an important source of security, comfort, and self-worth. Many people with disabilities do not have continuous relationships: they may leave their families, be moved from one program to another, and have to adjust to staff people who come and go.

What are some of the ways to facilitate personal relationships between people with and without disabilities?

It takes effort to help people establish connections. Described below are some of the ways that this has been tried:

"Bridge-Building": Facilitators who initiate, support, and maintain new relationships are called bridge-builders, as they "...build bridges and guide people into new relationships, new places, and new opportunities in life." Bridge-builders involve people with disabilities in existing groups or with specific individuals.

Circles of Friends or Circles of Support: Groups of people who "meet on a regular basis to help a person with a disability to accomplish certain personal visions or goals." Circle members try to open doors to new opportunities, including establishing new relationships.

Citizen Advocacy: Recruited and supported by an independent citizen advocacy office, a citizen (advocate) voluntarily represents the interests of a person with a disability as if they were the advocate's own. Citizen advocates may take on one or several roles (e.g., friend, ally, mentor, protector), and some of these may last for life.

There are different ways that personal relationships between people with and without disabilities may be encouraged. Perhaps more important than the specific method is the supporting, connecting role of one or more people - family members, staff members, friends, etc. - who can spend time and energy for this purpose.

What are some important dimensions of friendship?

Genuine friendships between people with and without disabilities do exist. While each friendship is unique, there are some shared ideas and expectations about what friendship means. According to a recent study of pairs of friends (Lutfiyya, 1990), these meanings include:

Mutuality. The people defined their relationship as a friendship and themselves as friends. Although they acknowledge differences between themselves, they clearly found a sense of mutuality in the friendship. Mutuality was expressed in the giving and receiving of practical assistance and emotional support, and enjoyment of each other's company.

Rights, Responsibilities, and Obligations. Once a friendship is established, it is assumed that friends can make certain demands on each other and be assured of a response. Nondisabled friends talk about the obligations that they had taken on vis a vis their friend with a disability, such as teacher, mentor, carer, or protector. The friends with disabilities perform certain responsibilities in maintaining the relationship: keeping in touch, suggesting possible activities, and so on.

Feelings, from Companionship to Intimacy. All of the friends held feelings of affection for each other, expressed through their actions and how they spoke with each other.

Freely Chosen and Given. Friends choose each other. It is this voluntary aspect of friendship that is regarded as the amazing and wonderful part of the relationship.

Private and Exclusive Nature. Within the boundaries of each friendship is a private relationship that is now accessible to others. The friends have a history and an understanding of their connection to each other that separates this from all of their other relationships.

People can establish friendships with each other, but it is not possible to create friendships between others. However, it is possible to create opportunities for people with and without disabilities to meet and spend time with each other in ways that encourage friendships to take root and flourish. Families and service providers can do different things to make such opportunities available.

Families can:

Work for the total inclusion of their son or daughter into the regular school system. In addition to being physically present, students with disabilities need adequate supports for the fullest participation possible. Parents can also insure that their child with a disability takes part in a variety of integrated recreation and leisure activities after school hours. A consistent physical presence in each others' lives is a necessary foundation for friendship to occur.

Insure valued social participation. How people with disabilities are supported within integrated settings is important. Students need to be enabled to participate as much as possible, and to do so in ways that other people value and appreciate. People without disabilities need the opportunity to meet their counterparts with disabilities as peers, not as tutors or volunteers.

Involve and trust others. All parents feel protective toward their children.

While there may be differences in how independent people can become, parents can come to believe that there are people in the community who would, if given the opportunity, enjoy and welcome a friendship with their son or daughter.

Service providers can:

Reduce barriers to friendship. The way in which support services are provided to people with disabilities and their families can enhance or reduce the opportunities for friendships to develop. By offering segregated programs, the service system dramatically lessens the chances for contact between people with and without disabilities. There are also problems within integrated settings. For example, transportation from school often means that students with disabilities cannot take part in extracurricular activities (e.g., choir, clubs, sports). When efforts are made to bring people with and without disabilities together, the people without disabilities are often treated as volunteers responsible to the teacher or program coordinator rather than as peers.

Many other human service practices present barriers to development of friendships, such as curfews, lack of communication with friends about a person's plans for a day, lack of privacy, and so on. Service providers can begin by recognizing and reducing the practices which curtail opportunities for people to meet and form friendships with each other. They can also encourage people who seem to like each other to pursue the possibilities.

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