CRUCIAL TIMES

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Issue No. 14 March, 1999
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EDITORIAL

In this edition of **CRU**cial Times writers challenge us to consider how we might wisely use opportunities that currently exist in Queensland. Whether progress will be made in Queensland at this time will greatly depend on our capacity to discern what is important to do, and our will to actually do it.

Some writers challenge us to think critically about the role of government and the development of the Disability Services Agency shortly to be established by the Minister. Other writers remind us that community living only happens in families and local communities. Some contributors have written about services and professionals who have been helpful, but remind us that governments and human services don't and can't do everything. Both have valuable roles to play, but these roles need to be subordinate to the real tasks of strengthening families and local communities and enabling people with disabilities to fully participate in the life of the community.

I recently returned to Brisbane after two months of working and holidaying in Canada and the United States. While I was there I was fortunate enough to meet some families, people with disabilities, advocates, and others who work in the disability field. I sought out particular people and met many other people at various training events while in both countries. Even though I visited a limited number of places I met a very interesting cross-section of people. As well as what I saw and learnt, one of the greatest benefits of the trip was that it enabled me, with the clarity that often comes with distance, to have a good look at what we have in Queensland and to reflect on the current challenges and opportunities in this State.

On a number of occasions during my trip I met or heard about people with disabilities, including people with severe disabilities, who are living fulfilling lives in their community. I also met many people who are working to improve community living options for people with disabilities. Whilst much progress has been made in North America to support people to leave institutions, legal cases are still being brought by advocates in order to get people out of nursing homes and institutions. Other people were struggling against their own or someone else's risk of institutionalisation because inadequate resources have increased the person's vulnerability.

I met many workers from group homes and wondered, as I often have, about the seemingly endless capacity of humans to create standardised solutions on a mass scale for people with disabilities. I met people receiving individualised funding who were able to use their resources creatively and successfully, whilst others had no option but to use their individual service allocation for purchasing a place in an uninspiring group home or day program. I heard a great deal about standardised solutions being offered in the name of individualisation. It was clear to me that the main difference to be found in the more inspiring situations was the strength of families and grassroots support for people with disabilities. I also observed that the capacity of people with disabilities and their families to negotiate innovative solutions, the presence of positive ideas and values, and good support services were all

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CRU's MISSION STATEMENT

- To challenge ideas and practices which limit the lives of people with disabilities.
- To inspire and encourage individuals and organisations to pursue better lives for people with disabilities.

necessary parts of these more inspiring arrangements.

It was very evident that individualised funding by itself does not produce 'good lives' for people with disabilities. What was evident was that when families and communities are strengthened, then services can remain solely in a service role. This allows the person who is being supported to have a life outside of the service. On the other hand, in jurisdictions where investments have not been made in strengthening families and communities, governments and service systems deliver services that become the only 'life' that is available for the person with the disability. In these cases every aspect of their lives becomes service-controlled.

Inspiring arrangements for supporting people with disabilities cannot be divorced from the people who are involved in them. Uninspired people deliver uninspired results. Making wise use of the present opportunities in Queensland is a key leadership challenge. Even though individualised funding, standards, monitoring and priority panels might have a role to play, our task is to resist the appeal of simple, technocratic solutions. Governments do need to attend to the common good, but it will not be in our interests if this weakens and regulates the community where the real work of the community living movement actually happens. ■

Anne Cross

CONFERENCE IN BOSTON, USA

Creating Possibilities

The difference Social Role Valorisation Makes

June 1 – 4 1999

The second international conference on Social Role Valorisation will be a gathering for individuals committed to enabling devalued persons to become valued members of their communities. SRV is considered an important guide by many people working toward this purpose. This event offers an opportunity to fully explore SRV, including the viewpoints of serious dissenters. The conference aims to link theory and practice, training and implementation. One intended outcome is for the further development of the SRV movement. We invite you to take part in this historic occasion.

Speakers include people from Australia, New Zealand, United Kingdom and Europe as well as the U.S.A. and Canada.

For further information contact CRU.

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From the President

The word "community" is high on the list of overused terms today. For me, community is aligned with the notion of belonging. Belonging to, and being-there for others is a part of our human psyche but at this stage of our evolution we seem out of touch with ourselves and with one another. Instead of drawing people to ourselves, we seem intent on shunting them away. What is more disturbing is that the very people we are turning away are those we need the most – those from whom we can learn: people who are marginalised; people with disabilities. Instead of being marginalised, people with disability must be embraced and welcomed into the community because without access to community, they cannot participate in the fullness of life.

An understanding of love and friendship in the Celtic tradition includes the notion of "soul love" or "soul friend". This type of deep friendship incorporates ideas of welcome, recognition and belonging in a place where the superficial and the functional fade, and spaces are made for "the other" simply to be. Fundamentally, this idea encapsulates the notion of community and describes a social-exchange process.

If people with disability are to experience "soul love" or "soul friendship" they have to take part in the social exchange. When we are excluded, we virtually take on the role of outcasts and then find ourselves implicitly or explicitly acting out such a role. Too often people with disability are seen only as being on the receiving end of a social exchange. They are either not presented with opportunities for giving, or are expected not to be able to give at all. Society gives people with disability a particular role, and expects us to play it out scrupulously without any freedom to depart from the script.

I want to quote from the book, "The Careless Society – Community and Its Counterfeits" by John McKnight:

Community is about the common life that is lived in such a way that the unique creativity of each person is a contribution to the other. The crisis we have created in the lives of excluded people is that they are disassociated from their fellow citizens. We cannot undo that terrible exclusion by a thoughtless attempt to create illusory independence. Nor can we undo it by creating a friendship with a person who lives in exclusion. Our goal should be clear. We are seeking nothing less than a life surrounded by the richness of diversity of community. A collective life. A common life. An everyday life. A powerful life that gains its joy from the creativity and connectedness that comes when we join in association to create an inclusive world.

The crisis is that people with disability are not only being excluded from associating with their fellow citizens but their fundamental rights to citizenship are also being denied. Not until this is atoned will people with a disability be able to take up their rightful place in the community. ■

Mike Duggan

Editor's note: the book by John McKnight referred to in this article is held in the CRU library collection.

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A Promising New Agency

The Queensland government has promised a new Agency that will strategically focus on the needs of people with disabilities and their families in this state. While not prescribing the "ideal" new Disability Services Agency, ***Margaret Ward*** *identifies some important factors that the Queensland community would want the Minister and her government to consider and resolve.*

We live in exciting times. The Queensland government has made a commitment to rise to the challenge of rectifying legacies of neglect in the area of disability services in this state. In July 1998 Anna Bligh, Minister for Families, Youth & Community Care made a stirring speech at the CRU Conference promising funding, the establishment of a Disability Services Agency, a five-year strategic plan, and a personal commitment to change. You should have seen the dancing at the CRU dinner that evening!

Six months later we are into the nitty-gritty of making these things happen. Naturally, everyone wants to have a say. The Minister has the difficult task of sticking to her promises within deadlines set by Treasury while bringing a strongly opinioned disability community along with her. And the disability community has been asking: What is your government's vision for people with a disability? How are you going to change the culture of the Department? What developmental work needs to be done in the community? How can you make change and continue old service practice at the same time? Who is going to lead this process?

It didn't take long for the disability community to come up with these questions. They have been thinking about them for decades. The last ten years have not seen strong leadership from the State Government in the field of disability services – it has been the vigilance of the community sector and their demands for a better deal that has kept them to the task.

This does not mean that there haven't been some changes. The Government has embedded a set of principles for service provision across all departments, closed down some institutions, expanded housing services, and made transport, education and government buildings more accessible. The Moving Ahead Program has demonstrated that funds can be provided to support individuals in flexible ways at the same time that they meet accountability requirements. Of significance is the commitment of funds for community-based services and, for the first time in our history, a sincere attempt at an assessment of need.

It is in the community, however, where we participate in serious debates on moral leadership, vision building, planning around individuals, long-term investment in families, and creating safeguards against the inevitable entropy of service provision. These are some of the issues that the Government will need to tackle if they are not simply going to do more-of-the-same, and this will be the challenge for the Strategic Leader who will hold a short-term Government position to develop the new Disability Services Agency. The community supports the Minister in her objectives and is already participating in the planning process through a Reference Group. Here is a chance to plan for the ideal Agency.

But what is the ideal Disability Services Agency? I dare not outline a possible structure or resource allocations. I am chastened enough by my own time in the Public Service to respect the inevitable compromises the Minister will have to make. However, if the Minister is to maintain the support of the community there are some things on which she will have to stand fast. They could be described in the following three ways.

The Strategic Leader will need to engage in a process of *building*. The building-blocks of co-operation and collaboration from the community sector are already in place; the Minister has worked hard for that. The knowledge base, the leadership skills, and a vision for the future for people with disabilities presently come from the community. On a more pragmatic level, the best practices for supporting people and creating positive changes are presently being achieved by small but vulnerable community organisations that work closely with families. The Strategic Leader cannot ignore this fact and will need to co-opt key players to help in making systemic change.

The Minister's Strategic Leader will need to consciously *lead*. This means being clear about personal values, standing fast on principles, knowing when positive change is possible, and when to control the damage of poorly conceived influences. This does not mean being universally liked but, if this leadership is respected, the community will take the time to consider, debate, influence, and finally trust and follow.

The Minister's Strategic Leader will need to consciously *influence*. Good bureaucrats, as well as understanding the formal processes of influence, listen carefully, talk to everyone, never hold grudges, are relentlessly enthusiastic and positive, and have a wheelchair accessible office. Good bureaucrats are also tenacious, focussed and patient. When things get tough (and they will), the Strategic Leader will need to continue to influence, to lead, and to build.

We have a unique window of opportunity – we have a Minister who is willing to take risks and has a track record for doing so, and her most senior staff are committed to cultural change. We have a community that is ready to co-operate and an agreed plan for going forward. With the establishment of the new Agency, at best we will see significant, positive and sustainable changes in the lives of people with disabilities. At worst, the Government will no longer be able to ignore the plight of this group of its citizens as has happened in the past. ■

moving ahead

__Anne Hilton__ describes a collaborative effort by a group of people sharing a common vision for a young man at an important stage of his life.

As a family friend I felt very privileged when invited to join a group of people who would assist in planning a future for a young man called Chris. When Chris completed four years of high school education at the end of last year, a number of big questions arose: What will Chris do now? What can we put in place so that he can lead a life befitting an 18 year old? How can we make this happen? What does Chris want?

It was not as if Chris' family and friends had never thought about these questions before. But the energy needed to maintain everyday school life and recreational activities for a young man with significant disabilities leaves little room to plan for the future or the time and energy to overcome the many obstacles that confront people with disabilities and their families.

Realising the task that lay ahead of her, Pam (Chris's Mum) gathered a group of friends who were interested in the task and willing to lend a hand in whatever was needed on the journey towards Chris' future. None of us had any easy answers but we all shared a common vision for Chris and wanted to support Chris and his family on their uncharted journey. In the early group meetings we became familiar with the Moving Ahead Program and also became clear about the purpose of the group. We discussed issues about the implementation of the Moving Ahead Program and what that would mean for Chris, as well as giving a great deal of thought to how we could optimise the Program in order to achieve Chris' goals.

A very important part of these meetings was listening to Pam describe her vision for Chris. We created a vision of what "a week in the life of Chris" might look like. Because Chris cannot communicate verbally these initial meetings were also a time to get to know him better – his likes and dislikes, his interests and social activities. Early in this process we decided to involve other people in Chris' life so that they could help us map a picture of his future. This process was facilitated by one of the group members and the group invited input from a wider circle of people including school friends, service providers, and other family members and friends. Collectively, we had the chance to create a vision of where we could see Chris in twelve months time. We looked at that image and asked what steps needed to be taken in order for the vision to be realised. This process allowed us to allocate tasks and determine time-lines for our activities. Over time, we became more focussed as a group and gained the momentum and enthusiasm that was needed for moving forward with purpose.

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As a consequence of our planning, Chris has been accepted for work-experience in a nursery and as a participant in a horticulture course at TAFE. These plans resulted from the enjoyment and interest that Chris showed towards the subject of Horticulture while in Year 11. Although these are positive and fulfilling activities in Chris' week, we face the reality that the number of hours which are available for a support worker through the Moving Ahead Program still leave a large gap in achieving Chris' goals. We are now trying to solve the problem of how to juggle these hours of support in order to optimise experiences and opportunities for Chris. Another dilemma which we need to solve is the cost of transport in Chris' budget which is proving to be a very expensive item.

The group held discussions about how a service agency could be engaged to assist with the implementation of the Moving Ahead Program for Chris and we decided that it was vital to find a service that upheld our own values and beliefs. It was also deemed important that we maintain as much control as possible in the implementation of the Program because we were clear about not wanting a service to take over all the decision-making.

We chose a service agency and presented them with a proposal for working collaboratively while dividing responsibilities between their service and our group. Basically the service would take responsibility for the tasks of: administration of funds; legal requirements of employing personnel; and inducting and supporting workers within the organisational structure of their service. The group, made up of family and friends, would take responsibility for designing and managing the content of the Moving Ahead Program for Chris and supporting Pam in pursuit of the vision for Chris. The group was very clear about the importance of the service being willing for us to oversee the Program, to review it, and to remain the major decision-makers.

We are presently in the process of employing a support worker for Chris and the service has agreed to support us in this venture. Members of the group are involved in the interviewing process and will also be involved in the induction and training of workers that follows.

Writing this article has highlighted for me how much we have achieved in the last nine months. At times, however, it seems as if we have hit brick walls – we become frustrated with bureaucratic processes, red-tape and questions that never seem to be answered. Our goal to have Chris' Program up and running early this year has been delayed by circumstances beyond our control, but the stress and frustration of this is lightened when shared by the group.

There are times, in the group, when we sit in silence because we have no solutions to offer. Such times seem quite hopeless, but because we operate in a group there is always someone with a comment, a thought, or a magnificent insight that frees us to move beyond feelings of hopelessness and on to the next step. As a group we are on a journey of discovery and are committed to moving ahead on our journey with Chris and Pam. ■

A JUST AND CIVIL SOCIETY

__Donna McDonald__ writes the first in a series of articles by different contributors who consider the question: What is the part played by government in the creation of a just and civil society?

Government. Justice. Civility. Society. Four simple words. Each on its own conceals layer upon layer of meaning and conjecture. Combined, they pack the punch of a hand-grenade, exploding our certainties and assumptions of who does what, when and why.

In his latest book, *Eat the Rich*, P.J. O'Rourke writes: "I am in favour of keeping government to a minimum - not eliminating it or even making it tiny. Just keeping it to whatever minimum is compatible with the maximum amount of individual freedom that is compatible with public order; the maximum amount of individual responsibility that is compatible with compassion." He goes on to say "You can't give complete responsibility to people who are helpless. You can't give total freedom to people who are evil. You have to have both freedom and responsibility."

The thing that strikes me most about O'Rourke's position is the underlying mistrust he reveals towards the capacity of governments to care wholeheartedly and without reservation about the people for whom they are responsible. O'Rourke's view of government is that these elements must be finely calibrated - a little to the right perhaps, and then a little back to the left, and there! nicely centred, plumbed comfortably within the reach of expectations of the lowest common denominator - so that they don't engorge themselves on the diversity and complexity of the needs, hopes, and aspirations of their constituencies.

O'Rourke's mistrust of those in power is not, of course, unique. When I asked some friends for their views on the role of government in creating a just and civil society, their responses ranged from the derisory to the cautionary. They spoke variously of the need for individuals to look out for each other; for communities to be caring and inclusive; for governments to listen; and for governments to lead on the basis of what they learn from listening. They said that government should lead by both example and by reflection.

A just and civil society cannot be attained via a single, linear trajectory. The competing multiplicity of individual and community needs means that governments - and the people who put them there - must engage in an active and constant assessment of their priorities. The law of physics says that every action has an equal and opposite reaction. Does this mean that when one group's needs pull in a certain direction, someone else's needs are inevitably going to be overlooked?

John Ralston Saul takes up these issues in *Voltaire's Bastards*, in which he analyses the nature of power - especially government and corporate power, and the potential strength of individuals against such power. Saul acclaims Voltaire as "the single most famous individual of the eighteenth century", who was a "leading defender of human rights and the most ingenious advocate of practical reforms". And yet Voltaire was never in government himself; his power lay in his ability to act as a catalyst to reform through his writings, his zeal and his influence.

Justice and civility in our society - embracing fair play and respect for *all* of us - can perhaps be seen as an outcome of the very tension between a seemingly monolithic government and the milling, massing people struggling to have their individual voices heard above the rabble of competing priorities and rivalries.

Clearly, the odds of society developing a consistent, coherent world-view based on shared common values such as recognition of rights, harmony and mutuality, are not in our favour. Instead, you and I are left with the task of influencing our immediate and more domestic spheres of life: our families, our neighbourhoods, our communities of education, work and play, and our community of government. And so at the end of the day, perhaps the more useful question is: "What is my personal responsibility in the creation of a just and civil society?" ■

Looking for Quality Support

***Tanya Barton** highlights some of the issues that she has encountered since making a decision to live in a home of her own, leading a lifestyle of her choice. What Tanya has learnt will be of interest to others because, like so many things in life, there has been more to deal with than first imagined.*

When I was in my teens I began to think about the kind of life I wanted for myself in my late teens or early twenties. I wanted to do what I saw my sister doing – getting a job and moving out of home. I remember thinking about what kind of person I would want to assist me in my lifestyle. I believed that all that was needed was someone who would do what needed to be done, and had a sense of humour. I also remember friends and family saying that it did not matter who I got as long as the person could take orders.

I was on a waiting-list for government housing for five years. When a home unit was finally offered to me I wasn't sure that I was ready to move at that point and I encountered one of the many issues that are faced by people with disabilities. If I accepted the offer of the unit but was unable to create the lifestyle I hoped for, I might be seen as a failure. But I made the decision to take up the offer and organised everything for the move. There were two major challenges for me: getting used to the idea that I was finally going to be living away from my parents; and dealing with the need to employ support workers.

I have been living independently now for approximately four years, but I have only been receiving accommodation support service since the middle of 1998. Prior to that I survived with help from my supportive family, a few friends, eight hours of paid service from a respite agency, and by tapping into three other services who made me feel that I should be grateful for whatever I was given. These arrangements really tested the strength of many relationships as well as my own organisational skills. My family was at my home every day doing things just as they had when I was living with them. Each week my mother would cook a week's meals for me to freeze. My family was still my main source of care. The only difference was that they were having to constantly drive between my place and theirs.

I couldn't wait to receive a more appropriate number of support hours so that I could get on with life. When I finally heard that I would receive funding for the support I needed, I recall wearing the biggest grin the whole day. I held myself back from phoning my parents because I wanted to tell them face to face. All I could think about that day was the question of which services I could get rid of first, and how it would all work out now that I had sufficient funding.

It was fantastic. I could have the workers I wanted, when I wanted, for as much time as I wanted. But after about a month, as I settled into this new pattern, I began to wonder if I had been better off with the former arrangements. I sometimes feel restricted by the number of support hours I now have. For example, I have to be home by a certain time of day because a worker will be there. I also have to take the phone numbers of workers wherever I go. Occasionally I just don't want to face anyone coming to my home at all. It is also very hard for me to be spontaneous. If I'm talking to a friend on the phone who says, "I'll pick you up in half an hour", I'm not able to contact my worker because she is already on her way to my place.

One of the biggest roles in my life is the role of managing workers. I'm quite fortunate in that most of my workers have stayed with me for long periods. When I am interviewing prospective workers I rely on my skill of being able to "read" people well. For example, I might ask someone: "What is your interpretation of confidentiality?" The person might reply: "It means that whatever happens in your home I should not discuss anywhere else." From that answer I go to the next question and say, "If someone asked you who you worked with, would you give them my name?" Imagine that the person being interviewed says: "I don't know" and then goes on to say, "Would it be all right for me to say that I was going to work at Tanya's place or would you not even want me to say that? Would you prefer me to just say that I was going to work and not mention you by name? What would you like me to do?"

In this case I would probably read this person as being open and honest and as someone who would genuinely seek my preferences or ideas on things that concerned me.

Like most people when they first move out of home, I had to quickly learn how to run my household. Unlike others I had to learn how to choose, manage and train staff. I learnt that I needed people who had more qualities than those I had first imagined were important. ■

Looking after the wellbeing of the whole community

Felicity Taylor-Edwards *of Goondiwindi is the Executive Officer of range of services that involves the whole community. Felicity says that through the involvement of local citizens, service recipients and service workers know that they are sharing in the creation of a better community for all.*

Care Goondiwindi is a small community organisation serving the border township of Goondiwindi and districts. These areas encompass a population of approximately 10,000 people. The township, located on the Qld-NSW border, is five hours drive from Brisbane. The McIntyre River forms the border, and while we see it as a river, funding bodies see it as a wall. This split responsibility between state authorities is just one of the obstacles that we have to overcome on a regular basis, but the beauty and strength of our community is that we can overcome obstacles. If we can't overcome a problem in one way then we will find another way of doing it.

This ability to find solutions in our community is the power behind a small group of service providers working alongside the NSW border communities of Boggabilla and the Aboriginal township of Toomelah. We serve a cross-cultural, cross-state population that swells by 2000 during the seasons of harvest, cotton chipping and picking.

A team of 16 workers provides seven services that are co-ordinated through Care Goondiwindi: Respite care, Employment options for people with disabilities, Rural Family support, Youth work, Drug & Alcohol problems, Parenting & Families support, and Lifestyle support for people with disabilities. The organisation arose out of the local community identifying a need for locally based services that would address the needs of the Goondiwindi community, and has been providing a range services for the past ten years. Each service is driven by members of local families, teachers, friends and others with an intimate knowledge of the needs of people they know.

An example of the total involvement of the whole community can be seen in a recent strategic planning afternoon that was open to the whole community as a way of ensuring that we remain in touch with the community that we serve. During the meeting it became clear that despite the current political thinking and the availability of specific funds, our organisation needs to stay on track with what the local community needs and not be attracted to programs that may not be of relevance to it.

We believe we enhance the whole community through our work by listening, seeing, and often experiencing at first-hand what is needed. We do this by having a management committee comprised of business owners, public servants, parents, church members and others from our community. We employ staff members from our local population when qualifications and experience allow. The body of our organisation is comprised of community members who pay a membership fee and are encouraged to be involved in the organisation. Because of the size of our community, we mix socially with service users as well as through our work roles, on a daily basis.

One of the most important features of this strong sense of community is that clients of our service are aware of the valued contributions they themselves are making to their own community. The extent to which people with disabilities are integrated in our community is summed up in this quote from an external assessment of Care Goondiwindi conducted a few years ago: "The consumers in Goondiwindi appear to enjoy a degree of integration which would be the envy of their metropolitan peers." ▶

Clients of Care Goondiwindi are placed in valued roles throughout the community either in paid employment or voluntary work. Employers in the district are keen to employ local people who can do the job or can be trained to do so. Our employment service placements are well above the national average due to the personalised approach between service providers and service users, and because relationships within the community carry the potential for employment opportunities.

At a time when many small organisations are feeling more and more vulnerable, Care Goondiwindi has a strong sense of security, knowing that the degree of community ownership that comes from sharing and solving community needs will go a long way to ensuring its longevity. We are also looking at alternative self-funding measures and community sponsorship in order to give us the power to determine our own values and direction and the capacity to remain in the hands of a community that had the foresight to address its own issues in the first place. ■

When The Right Supports Are In Place

***Elsie** and **Bill Butler** of North Queensland describe some of the turning points in their son's life and say that it's amazing what can happen when the right supports are in place.*

As we reflect on the past twenty-six years of our son's life, many people come to mind. During those years we have been supported, encouraged and inspired by other parents, professionals and many others. Many of these people have made the difference to our experiences by sharing the celebration of good times and helping us to find a renewed sense of direction in times of trouble.

We live in a northern region of Queensland and when our son, the fifth child in our family, was born there were no support services in our area for families who had a child with a disability. Our extended family lived in the Brisbane area. We knew we would have to do the best we could for our son, as we had done for our other children, but at this stage we had no idea what lay ahead. This was an era when it was generally accepted that a child with a disability would live in a segregated setting and not within the family.

When our son was aged two an Early Childhood professional visited our home. She believed that attending the local kindergarten would be the best option for our son and she assisted us with his enrolment at our local crèche. Around this time, Noah's Ark Toy Library was founded in Cairns and we had the opportunity to meet a number of other parents who gave us encouragement and advice on how to seek ordinary and typical activities in the community for our son. During his two years at Kindy it was necessary for us to make time available for supporting teachers in their understanding of our son or to be present when extra supervision was necessary.

Our son's two years at Kindy were followed by his entry in the local pre-school, and about this time he was introduced to one of the two segregated schools in the area where he was to begin his Primary School education. Other activities over these years included his attendance at storytelling sessions in our local library and vacation-care at our local school. These activities provided avenues for him to be in ordinary settings, doing exciting things.

Our son's High School years brought change. The Education Department was setting up a Special Education Unit at one of the large high schools in our region and our son was in the first intake of students. We will never forget our son's pride in being able to wear the school uniform and say, "I go to Woree High School". His self-esteem soared and during the next few years whenever an advertisement for a segregated workshop appeared on TV he would say, "Not me!". It was very clear to us how he saw himself. These years were not plain-sailing, however, and we had to pursue some very important issues in relation to our son's schooling during this period.

High school opened the door to normal work experience programs for our son and our goal was to try to find out what skills our son had and what kind of work he would like. Over the years, he had some work experiences that he liked and others that he hated. His final work experience placement, at the local Library, was just perfect. Having found this "perfect match", we wondered: What now? We decided to approach the Library with the suggestion that the work-experience hours become a paid position. They agreed, and when our son finished high school he became employed at the Library one day each week.

During his final year of high school we had to work out how our son would occupy his time after leaving school. For him to have nothing to do was unthinkable. Because we ourselves had involvement with a local charitable organisation, it seemed that if it was normal for us to do voluntary work, then this could be an option for our son. Along with his teacher and the same charitable organisation, we set about making this a work-experience placement with the usual supports provided by the school. The intention was that at the end of his school life, it would become regular voluntary work. Six years on, our son continues to work at the Library and with the voluntary organisation. He enjoys the work and is a valued worker in both roles.

We needed to plan the next stage of our son's life – independence. Although our son had some work and recreational activities, his life and ours seemed to be tied together: what we did, our son did, and vice versa. This did not seem to be much of a life for any of us. We are mature-aged and our interests are very different from our son's. What was needed was individual support for our son to have a life of his own.

At this stage we joined with a small group of parents who have a vision for their sons and daughters to live in a place of their own in the community. These parents realised that if their dream was to come true, they would have to do something about it themselves. A submission was made for the development of a service which would be community-based and responsive to the individual needs of the people it served. Through some very serious lobbying, we made politicians aware of the fact that there were no existing services in our city that offered support for people with disabilities to lead ordinary or typical lifestyles. After a period of three years some funds were received and a service was set up. A small number of people, including our son, received individual support.

Having found this "perfect match" we wondered: What now?

So that our son could have a place of his own, we enlarged our home to include a small self-contained unit for him. This unit is his own home where he can make his own choices. He is supported by lifestyle assistants and we also share in his support as funding is inadequate. In his new lifestyle our son becomes more and more capable and his sense of independence grows.

We do not know what the future holds but we believe that if we do our best to build networks of support around our son these will be a safeguard for the day when we are no longer able to be involved in his life.

Even though we have had to juggle our lives in order to devote many hours to services for people with disabilities, we feel this level of involvement has been worthwhile. It has given us an opportunity to stay informed about political and social changes. It has also allowed us to be in a position to try to influence decision-making about the way disability needs are funded and the way people with disabilities are treated. It has affirmed our view that small parent-driven services have demonstrated to governments and the community that such organisations can provide a service which, in flexible and responsive ways, supports people to develop an independent, authentic lifestyle.

Our experience has found that it is amazing what can happen when the right supports are in place. ■