# CRUCIAL TIMES

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Issue No. 15 July, 1999
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# EDITORIAL

While much has been said about the shocking legacy of financial neglect in Queensland, and the money question is far from solved, it is also apparent that financial resources are only part of the problem faced by people with disabilities and their families. In places all over the world it is possible to see people with disabilities doing badly, even when a lot of money is spent. So while the political struggle around funding continues, it is crucial that other important issues are not neglected.

This edition of **CRU**cial Times offers readers the opportunity to reflect on a number of the issues that face the disability field in Queensland at present. As the Queensland Government ponders the style and shape of the new Disability Agency, it is timely to consider what we expect from governments and their role in improving life for people with disabilities. We also need to continue to analyse the various schemes for delivering available resources and supports, as people with disabilities, families and agencies grapple with the complexity of disability 'reforms' that have been introduced and which are meant to be simpler, fairer, more responsive and more easily understood.

Much of what is wanted by many disability advocates only becomes possible if there is sufficient agreement at a values-level in our society: that people with disabilities deserve to exist, and deserve to be supported to enjoy similar benefits and opportunities to those of other people in the community. From outside the disability field, prominent writer and social commentator, Eva Cox, writes about the role of public policy in crafting what she calls a generous public ethos, and some very real risks and problems that arise when governments don't recognise that we are social beings rather than economic beings. Eva is a well-known critic of current government policies of self-reliance and selective benefits and, in contrast, poses the question of the role of government in supporting mutuality in our social interactions.

Several other writers deal with similar questions from quite different perspectives. Jenny Smith, of Rockhampton, points to many of the issues facing the new Disability Agency. Amongst them, Jenny laments the lack of information and co-ordination available to families and individuals. Dianne Hughes and Jenny Morrison write about similar issues that are informed by a Collaboration Project on the south side of Brisbane that has attempted to understand the experiences of families who need to patch together supports from several different agencies. This Project highlights many crucial issues that are pertinent to families receiving timely, responsive and pro-active support, and especially highlights the importance of quality relationships between families and service coordinators.

Queensland is about to embark on five pilot programs of Local Area Coordination, based on the Western Australia model, and this issue includes contributions from Chris Maher and Katrina Luckins from the Kimberley region of WA. Their contributions invite us to understand this unique approach to coordination, embracing elements of family empowerment, personalised supports, individualised funding, innovation, community development, utilisation of natural supports and avoidance of bureaucracy. It merits

## 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.

our attention as a systematic response to issues that have been raised over many years by people with disabilities and families.

As 'individualised packages' are a cornerstone of current State government policy, CRU invited Michael Kendrick to contribute an article on the potential and limitations of 'individualisation'. He reminds us that true person-centred responses come from people and not from formal systems, and that truly individualised responses are likely to be more complex and difficult to achieve than many other responses. He encourages us to consider the widely varying assumptions, goals, values and theories that underpin many individualisation schemes, as well as the critical importance of the qualities of people using such schemes and the wider social environment. Some of these elements are illustrated in an article by Bev Budden who exemplifies the importance of listening and flexibility in her story of individualisation from a community in Far North Queensland.

These rich contributions help me to reflect on the importance of being clear about what we are trying to do with the opportunities and challenges that exist in Queensland at this time.

*Anne Cross*

# A Just and Civil Society

*What is the role played by government in the creation of a just and civil society? In the second in our series on this topic CRU asked* **Eva Cox**, *well-known Australian writer and broadcaster, to contribute her ideas and insights. Eva is known for her work on the concept of Social Capital and in this article she links that concept to her ideas about Giving, which is such an important part of our social relationships.*

One of the many questions that arise for us at the end of the millennium is: what can we expect from those we vote into government? We have seen major changes over past decades that range from the growth of government services in the post-war Welfare State, to the rhetoric of safety-nets and self-reliance heard from economic fundamentalists. For those people who need support to help them to participate in society, such changes have been problematic. We seem to have moved from an earlier era where responsibility was left to families, to the present era where responsibilities are again being left to families, with only a brief period between the two that has been marked by an expansion of services.

The following section of this article forms part of some work I have been doing on the concept of Gift: specifically, why we offer our time with both love and concern as part of basic social relationships. This concept raises, I believe, the issue of how far governments can go in "using" our personal sense of social responsibility and our social bonds. We appear to be losing some aspects of what is called Social Capital, that is, an accumulated social wealth that makes us a good society; one that creates a sense of belonging and acceptance. Excluding groups such as people with disabilities from public life, increasing elements of inequality, and privileging a mythical mainstream of Australian society at the expense of the less powerful, all tend to make us less trusting of governments and of each other.

What makes a society? What makes us social beings rather than economic beings? I want to offer a way of looking at the public spheres of politics and economics that is not based on notions of competition, but on mutuality. Somehow, all the debates we have had in recent years about caring for others have not been part of our public conversations. Such conversations stay within our own homes and within our own circle of family and friends. In a world where there is an emphasis on economics, competition, and on taking care of oneself, I want to look at some ideas about giving and gifts.

Firstly, one of the major problems with Economics is that it is a body of theory and practice that is based on the concept of trading. Fundamentally, it is concerned with goods and services that are produced in order to be sold or exchanged. The construction of gift-relationships has always presented problems for economists who find all non-commodified relationships hard to define or categorise. For example, households (where much is exchanged for non-financial gain) are either left out of economic calculations or are costed as if households were business firms. Costing all the exchanges that occur in families would, however, create a very different social and economic environment.

We need to recognise that many of our interactions with those we love are based on the pleasure of giving - the desire to give pleasure as well as fulfilling obligations we may feel happy to meet. Such gifts are part of our social connections and, while not always altruistic, are part of what makes us feel good about ourselves. In these interactions there are gains for us over-and-above the expectation that we will receive something in return. As social beings we don't simply work on reciprocity.

Perhaps the idea of mutuality is a better way of understanding these social interactions, where there is a sense of all being part of each other, and that this sense is likely to be the source of wanting to give and to contribute. There is, of course, another side of this: when we feel we are always giving, or where the giving is unrecognised, or when we are over-loaded with obligations. We may then lose the pleasure in gift-relationships and may come to distrust people and systems that ignore our gifts or make us feel bad.

Gifts are one way of creating trust relationships when such gifts are freely given and are not based on expectations of return, or seen as some kind of exchange to be assessed in order to determine equal-value. I want to stress, however, that giving may not only be defined as that which is provided for free, because we often give, even when we are being paid to do so. We add value to our paid-work by giving more than required when we care about those we serve. We do not give when we are doing something reluctantly or when we feel obligated or have no alternative. Gifts come with good-will and have their rewards in the pleasure of giving.

The past few years have not been encouraging for many who feel that Australian public policies have become less generous and have come to represent a meaner and harder Australian ethos. We have become more judgmental about who we believe may be entitled to share from the public purse, and we hear a lot about taking care of ourselves and of our own, and less about sharing our resources. We seem to feel poorer, and some of us are poorer. We have seen cuts in many public programs and this means that more will be expected of us in unpaid work or donations.

However, these are not gifts, but enforced contributions from those who care enough to offer time or money to families or to others who can no longer be assisted from the public purse. Being conscripted into family care is not a gift. We need to be very careful that the reduction of public resources and the expectation that we will replace them by charity and voluntary effort is not assumed to be a gain either socially or economically.

Changes to public policies and their provisions may be some of the reasons that the Australian ethos has become less generous. Many public utterances relate to the feeling that some people are excluded while others benefit. With an increasingly targeted public sector, this spirit of meanness is a problem that we are likely to face more frequently. An international study in the late eighties suggested that the more selective benefits are, the more antagonistic people became towards the unemployed, who were seen as not contributing to the public purse.

When we abandon the needs of people to the vagaries of donations or time given by others, we reduce their citizenship and autonomy. Both those in need of care, and those who provide it, should have choices, and be able to negotiate to have their other needs met. Conscription is not acceptable and when this happens, it damages the social fabric. There is a clear role for governments to make sure that conscription is neither policy nor common practice, caused by lack of funds. We need government policies and resources which recognise that social capital is built on a sense of fairness, not surpluses. ■

# More Thoughts on the new Agency

*The new Disability Agency is currently being established by the Queensland government and **Jenny Smith** of Rockhampton suggests some important characteristics of the Agency.*

For many people, the biggest test surrounding the establishment of the new Disability Agency will be whether it really *is* able to support people to lead ordinary, everyday lives: lives that are no less valued or important just because disability features somewhere; lives that have meaning. What could the architects of the new Agency do to convince those who have come to settle for a "believe it when we see it" approach? Well, for a start, it would be pleasing to know that this Agency had enough authority within it and behind it to attract the resources required to meet people's needs. As a separate portfolio, the Agency should have its own separate allocations within the annual State Budget. But simply having a separate identity will not automatically attract the dollars. A clear priority, across the whole of government, of supporting the citizenship of people with disabilities, must be championed by the new Agency. It must be given an unambiguous mandate to do this, as well as taking a leadership role in disability issues across all government departments and it must be capable of influencing decisions within those other departments.

What else could make a difference to the lives of people with disabilities and their families? I believe that the new Agency needs to place a strong emphasis on good coordination. One of the things that never ceases to astound me is the number of people who have come through the service system without having gained any knowledge of their entitlements, either in terms of service provision or of income support. How is it that we still discover people who, as adults, are financially supported by their parents with no independent income of their own? How did this happen? Think of the unnecessary scrimping the family has been through. Why is it that families who have a child with a disability often just happen to ask the right question of the right person before being told of support services which they could have been accessing, and when they do have the information, why do they have to develop an unremitting tenacity in order to retain the assistance they need?

In taking on a strong coordination role, the new Agency should help to overcome the shopping-around that families and individuals have to go through when negotiating the service maze. Many people with disabilities and carers report how hard they have to work to get so little, and are then expected to be grateful. A coordinated approach would not be to hand over the mantle of Big Brother to the new Agency, but would ensure that all people are fully informed of their rights and entitlements and supported to have these put into place.

The Ministerial Reference Group recently released a consultation paper that discusses, in detail, the development of the new Agency. I recommend that it be read thoroughly; it contains much food for thought, and is a genuine attempt to shape the new Agency so that it will make a difference in the lives of people with disabilities and their families. In addition to the range of structures proposed by the Reference Group for the development and maintenance of a partnership with the community, I hope that there would be room for a council of people with disabilities (whether consumers of disability services or not). This council should have representation on the community board that has been suggested by the Reference Group as well as having regular, formal dialogue with the Chief Executive Officer and senior staff.

An Agency structure that truly reflects the vision developed by the Reference Group will sometimes be politically difficult but Queenslanders don't want the government to merely build an edifice of sincerity, or to simply do what is called changing the pieces on the chess-board. They want the new Agency to make positive change for people with disabilities and their families. Primarily, the Agency needs to be able to ensure that people's needs are met with quality services. It is equally important that the true value of informal community supports to people with disabilities is recognised.

In summary, people simply want their needs met. There is untold hope, time, and emotion invested in this outcome. The present government's concept of the Disability Agency, and the Ministerial Reference Group's vision presents the Queensland community with a covenant for reversing a legacy of neglect. I hope it lives up to this expectation. ■

# SHAPING FAMILY SUPPORT

***Dianne Hughes*** *from Sunnybank Family Support describes the development of a Collaboration Project, the purpose of which has been to identify the most beneficial ways of supporting families in the Brisbane South region who are assisted by two or more different services.*

The Collaboration Project is fundamentally about families and service providers working together. Its focus is on how families, who have a member with a disability, can use services to gain the type of support they need with the family itself defining those needs. The Collaboration Project came into being three years ago as a result of issues raised at Young People with Disabilities Network meetings. At that time it was more about co-ordination of services, with little mention of family input or processes of collaboration. Funding was sought for the Project and a number of different services supported the initiative. Joint funding was obtained from Home and Community Care, and Department of Families, Youth & Community Care, with Sunnybank Family Support Inc. taking on an auspice role.

By September 1997, although funds were in place, work had not begun on the Project and after discussions between a number of service providers, it was decided to hold a workshop in order to re-visit the issues and re-define the Project. The primary purpose of the Project was on collaboration, not coordination, and the main objectives of the Project were defined as: gaining an understanding of the experiences of families who receive support from more than one service; families remaining at the centre of the Project; families having input into the Project; documentation of research findings and implementation strategies for effective collaboration between services.

Following the workshop, a representative from Mamre, Family Respite Options, Cerebral Palsy League of Qld, Xavier Children's Support Network, and Sunnybank Family Support agreed to form a steering committee for the Project. They met regularly and put forward a new proposal to the funding bodies: the Project would gain an understanding of the experiences of families who used more than one service, and seek their suggestions for more effective ways of support being provided. The Project would also identify models of support on which agencies could base their work, and prepare a report outlining research findings, proposed options, and implementation strategies for effective collaboration.

It was agreed that a consultant should be employed to carry out the work. The steering committee advertised through their networks and also invited a parent onto the selection panel. Community Resource Unit was engaged to undertake the Project with Jennifer Morrison as principal consultant. At this stage of the Project it became clear that more involvement from family members was needed and two more parents joined the steering committee, along with the five service representatives.

Phase 1 of the Project was completed by Jennifer Morrison in November 1998 and it included a written report on the information and ideas collected from families, service providers, and funding bodies. Some months later the steering committee held another workshop for the purpose of determining the next phase of the Project. Four main issues arose: funding; "ownership" of families by service providers; families' fear of withdrawal of services; and guidelines relating to cash transfers to families. The steering committee decided to undertake work on the last item.

The practice of cash-transfers to families is already used by some organisations and has received positive feedback from families. Receiving cash in a direct way enables families to purchase the type of support that would most assist them. There are, however, a number of important issues relating to this practice, and the steering committee has taken a decision to look at these with a view to formulating some guidelines.

During the Project, some of the most valuable feedback from service providers and families has been that for collaboration to be effective, it is the *relationships* between family members and service providers, and between different service providers that are important. It has become clear that it is these relationships which need to be developed in order for families and services to work more effectively together. ■

# FAMILIES CONTRIBUTE THEIR IDEAS

***Jennifer Morrison**, who was engaged by CRU as principal consultant of the Collaboration Project, describes some important contributions made by families to the Project.*

The aim of the Collaboration Project was to gain an understanding of the experiences of families who received support from more than one service and to seek their suggestions for more effective ways of providing support to them.

Seven families participated in discussions during the Project. They identified many concerns that arose when they attempted to negotiate their way through what they found to be a confused service system. These issues had a major influence (for good or bad) in their lives. They told stories of how services had entered their lives; what their experience was; how they wish to be treated; what makes them feel uncomfortable; how they organised and arranged services; and what sort of relationships they want to have with service providers. They were open, honest, and generous with their comments, recognising the difficulties encountered by service providers in their work.

One of the most striking issues was that of the relationship between a family and co-ordinators of services. The families wanted such relationships to be characterised by confidence, trust and mutual respect and they considered that good co-ordinators made all the difference to situations. Such co-ordinators were seen as crucial for organising services and for monitoring their quality. The relationship was one of ebb-and-flow depending on family circumstances, but families suggested that co-ordinators had a pivotal role to play in particular sets of circumstances such as:

*Those times when their sons & daughters had changing needs as they got older*

*Emergencies*

*Providing updates on the progress of their sons & daughters*

*When the family was troubled*

*When there were changes in personal support staff*

*Anticipating and guiding the family through times of transition such as the start of schooling or the end of schooling.*

It was strikingly clear how important it is to families for a co-ordinator to take a pro-active stance towards the family's needs. Not only does this maintain and enhance the capabilities of families, but it also enables a family to anticipate possibilities and to have a vision of the future. Families valued this "guiding" approach.

Families wanted to be seen as "more than a job" by support workers and co-ordinators and suggested a set of principles that could be used by services in their efforts to collaborate with a family and with other service providers. These suggested principles were a reflection of a desire held by families to be in control of information about the family and a wish to have the privacy of the family respected. They wanted their involvement at meetings to be planned for, in a co-operative way, with a sense of common purpose.

Families also wanted to be seen as a whole family that includes parents, brothers, sisters and the young person with a disability. They were most concerned about ensuring that the privacy of brothers and sisters was respected when carers entered the family home.

Those people who work in services, or who use them, will be deeply informed by many of the issues raised by the families who contributed to this Project. ■

[The full report: *Collaboration Project for young People with Disabilities* is available from CRU for a small cost]

# Strengthening Families Through Local Area Coordination

***Chris Maher*** *writes from the Kimberley region about the role that Local Area Coordination plays in the lives of families in Western Australia. This article, and the following one, will be of particular interest as five LAC pilots will commence in Queensland this year.*

The Kimberley region of Western Australia covers a distance of 1050km between its northern-most town of Kununurra and its southern-most town of Broome. Since 1992 there have been many changes at the levels of government and agencies, but there has always been a consistency of approach in the delivery of services and supports to people with disabilities and their families in the region through the Local Area Coordination program.

Local Area Coordination (LAC) is a particular way of approaching the supports that people with disabilities and their families require, as opposed to a formal service model. It is built on a set of principles, values and beliefs, one of which is that people with disabilities and their families are best placed to identify their own needs and that, with access to relevant and timely information, they can make informed choices that will have a positive impact on their lives. The LAC program is very different from Case Management as the latter suggests that control exists outside of the family and that someone else is the expert and will make the decisions.

Local Area Coordination is founded on the belief that families should be central to all decision-making. While advocacy has a central role in the LAC approach, this is only done in ways that further strengthen the family, with the level of advocacy being determined by the family. Recently, LAC supported a number of Kimberley families to facilitate a forum on education issues for children with disabilities in the region. The forum was attended by parents, school principals and the Director for Schools, and has since led to numerous positive outcomes for families seeking inclusive education for their children.

Another major belief held by LAC is that everyone needs support from their networks of friends, family and associates and that LAC has a role in facilitating these informal networks for people with disabilities and their families. It links them with individuals and community groups that can contribute to the support they seek. The Kimberley region has a mix of families, some of whom have lived most of their lives here and are well connected to the community, while other families have moved to the region and have limited extended family and community connections.

Recently LAC worked with a small non-government agency to develop a proposal for funding from the state government Office of Senior's Interest which had called for expressions of interest from small agencies in developing projects that would provide positive roles for seniors in the community. The agency put forward a proposal that would focus on linking mature couples in the region with young families who have limited extended family networks. Should the project be funded, a number of young families who have children with disabilities will be linked to this valuable kind of local support.

A significant difference between Local Area Coordination and other human services is that LAC has few on-the-shelf products. This means that individuals and their families are not expected to simply fit in with a formulated service response but, rather, LAC works in a flexible manner to respond to the needs of individuals and their families. The challenge is to assist families to utilise community resources to access the level of support and assistance required. Local Area Coordination also assists individuals and their families to purchase supports or services that cannot be met within their existing networks or from community resources. This may be achieved by LAC approaching local funding bodies or groups such as Lions and Rotary, or by arranging direct consumer funding through the Disability Services Commission of Western Australia.

For LAC to contribute to the support of families in any way, the starting point is always in the development of a positive and trusting relationship with the family. I feel privileged in that, for the past seven years, I have been able to watch many people with disabilities and their families overcome major obstacles and achieve positive outcomes in their lives. ■

# The Story of One Family's Journey

***Katrina Luckins** also writes from the Kimberley region and tells of a remarkable journey that took her and her son around Australia, in a quest to find a welcoming community and a program that would link them to good support networks.*

Before coming to Western Australia, I lived in Sydney with my son, Nathan, who has cerebral palsy. Although a number of support services were in place, they were quite impersonal and a lot of travelling was involved. Nathan was in special school (which I didn't like) and generally, life was pretty tough. Eventually I felt we had had enough!

We set off around Australia to find the "perfect spot" which would meet my criteria: a good support network; family based respite; no special schools; some financial help; a warm climate; and services that demonstrate a positive outlook. We were in no hurry as I was providing home-schooling for Nathan, but we raced up the NSW coast to Queensland anyway.

The first place I tried to get respite care was in Noosa: "Sorry, we only help the old". Next was the Whitsundays but we were in the "high needs category" giving us 14 hours of respite per week. Next was Port Douglas but there was no respite service – it was only available in Cairns, 50km away. I would love to have stayed in Port Douglas as it had most of the things on my wish-list but the school principal did not want Nathan to attend his school and told me I should move to Cairns.

From Cairns we travelled across the top-end through Kurumba and Mt Isa, and down to Alice Springs. By this time I once more felt I needed a break and found an agency that was able to put me in touch with family-based respite, but arrangements could only be made for blocks of 3 to 7 days, so on we travelled, down through the centre of Australia, turned right at Port Augusta and arrived in Perth. Another city, another special school!

This is where I first came into contact with the Local Area Coordination program. For the first time in my travels someone else actually did the legwork for me and found a respite service with full costs met through the government Family Day Care subsidy and the Disability Services Commission. But Perth had special schools and was cold in winter so off we went again, finally finding the perfect place – Broome.

This is where most of my experience of Local Area Coordination has been gained. I guess that being in a small town has made it a far more personal service than it would have otherwise been, but LAC has helped with every aspect of having a child with a disability. Not only did LAC help me to find regular respite and help to finance it, but they also made themselves available to attend various interviews with schools, therapists, aides, doctors, counsellors and other service agencies. This has been of great value in helping to establish a support network for Nathan's schooling, therapy and medical needs. In addition, they facilitated forums for the Kimberley region on Special Education issues, involving all Kimberley school principals, therapists, parents, relatives and other interested people. This allowed all those involved to come together to air grievances, state preferences, needs and wants, and to be heard without prejudice.

Nathan now attends the local school and for the first time in his life, knows the name of his school and is proudly wearing his first school uniform. He is also playing football, cricket and other sports with his classmates for the first time. We are supported by a respite-family with whom Nathan stays one weekend each month. This has been a valuable experience for Nathan as he has no brothers or sisters.

The Local Area Coordination program has helped to instigate and coordinate all of these supports. Their approach of open-door policy, financial assistance, coffee-&-conversation, and introductions to Broome residents has been a priceless resource. Believe it or not, this is one government agency that I can truthfully say really does care. ■

# Formal Individualisation Systems:

## Their Potential & Limitations

*In this article,* ***Michael Kendrick*** *explores what is meant by "individualisation" and how the operation of the wider service system limits the application and potential of individualised service responses. Michael also argues that these systems and responses are profoundly dependent on the qualities of the people using them.*

The term "individualisation" is seemingly straightforward, but in fact its use may reveal many widely differing assumptions, goals, values, and theories. Furthermore, not every action taken in the name of Individualisation can be assumed to lead to individual benefits despite the appeal of doing so. Consequently, it is very important to be as clear and definitive as possible when we refer to what constitutes a desirable and beneficial form of individualisation, and what does not.

A good starting point would be to recognise that the various planning, funding, and service negotiation processes that are established in the name of individualisation may well lead to something quite unhelpful to the recipient. This is because the presence of a process, even a well-intentioned one, does not guarantee anything other than its existence. All of these processes are profoundly dependent on the qualities of the people using them, to say nothing of the wider social environment or resources.

This can be seen more clearly when one considers the extent to which personalised planning is dependent on the ability to actually implement the plans. Planning for things that are hoped for, but actually are not going to happen, has great inherent limitations. Nevertheless, all individualised planning systems will only be able to translate goals into results if the goals can be negotiated into existence with the many parties who might need to be relied upon. Virtuous intentions are commendable but do not guarantee quality results. This is particularly true when one considers that in most service bureaucracies, individualised planning is not usually well linked to resources or to implementive authority. It is also important to appreciate that the actual personal experience of individualisation may be one of harm, through the bureaucratic installation of individualisation measures such as standardised and compulsory individualised planning, service negotiation, service packages and so on.

When one considers that unique and specialised personal needs will require specific responses, and that most service systems have only a very limited set of offerings, then it will be seen that there is a crucial gap. This gap will only be realistically filled when there is a (prior) measure of investment in the personalised option. It has to be taken into account that the individualisation of support will be problematic if the services available are essentially irrelevant or unhelpful to the person's need. Equally, the assumption that an individualisation system and technologies will drive innovation and service reform is undermined by the fact that so many systems and technologies have become tools for streaming the service recipient into status quo options. Achieving a true personalisation of service is always subject to what is actually feasible or available at a given time. We cannot assume that creative options will spring into existence just because they are asked for or needed.

The capacity of individuals to imagine, pursue or negotiate positive arrangements is subject to any number of limitations and will vary widely. Service users and families who are astute about systems will benefit disproportionately from laissez-faire individualisation schemes, while those who are less astute about systems will benefit less. This observation also applies to those who support the prime user of the individualisation system. Those persons who have access to talented and committed assistance have an advantage that cannot be assumed to be universally available. For instance, a person who is fortunate enough to be in an environment that has positive values and attitudes, administrative flexibility and a visionary climate of innovation, will have a different experience of their individualisation system from that of a person using the same system in a less beneficial environment.

Achieving increased personalisation of support may also come at the cost of increased overall difficulty for all parties, simply because it will intensify the complexity of issues that need to be well managed by service recipient and service provider alike. Typically, an increased personalisation of support will require that the supporter simultaneously does many things well, whereas a standardised system is simpler and less demanding to implement, even if the outcomes are not very beneficial.

Individualisation will usually mean that the service user acquires more choices as well as more involvement in making them. While this may have positive aspects, it is also true that many individuals can flounder when an expanded array of choices is not accompanied by expanded supports that are appropriate to the new possibilities. Expanded choices and a new autonomy will often exacerbate inherent dilemmas such as: being able to discern the best balance of needs and wants; avoiding the destructive uses of choice; managing new responsibilities; or defining one's best interest.

In terms of cost, effective individualisation is not necessarily more costly, but can become so if the options that are taken up are not highly relevant to the person's needs. This is because a mis-fit between the person's needs and the person's support is a waste of scarce resources. At the outset, individualised funding schemes are often invested with panacea-like hopes but, in the end, they are just a financing method. The most critical variable is the human environment in which the funds flow, rather than the funds themselves.

It is always going to be the case that formal individualisation systems will fall short of expectations, because they can never escape the inherent limits accompanying all systems devised by humans. Consequently, a better way of viewing them is that they are either relatively better or relatively worse than other comparable systems. Furthermore, it is useful to recognise that it is possible to consciously build intentional safeguards that will enhance the strengths and lessen the limitations of such systems. For instance, in those individualisation systems that heavily rely on the service recipient taking the lead as a co-participant in the process, it strengthens such person's hand if the system routinely grants to the person some useful power or "official" role. Examples would include: being able to plan in whatever way that most suits the person, the power to use or refuse options that are offered, and to be recognised as being able to negotiate any matters of concern held by the person or their allies. The presence of such safeguards may enable service recipients to experience individualisation systems as being able to be modified through their own efforts. This does not mean that intentional safeguards are sufficient, but simply that they might render the system to be more responsive or, proportionately, more beneficial.

> ***"It is important not to lose sight of the fact that individualisation does not come, at its root, from formal systems but rather from people."***

When there is a spirit of deep respect for one's person then the possibilities of "person centeredness" grow dramatically. If such a spirit is present then it will suffuse all interactions with that person. It is people, one at a time, who either see and respond to our personhood or do not. Curiously, many formal systems of individualisation so overly-emphasise the people that it is almost to the point where each person is "atomised" or socially-disconnected. In the name of "focusing on the person", the people in that person's life who most and love and respect them are ignored in favour of concentrating on the formal services. If, on the other hand, one appreciates that it is the quality of the people in our life that is the foundation for authentic individualisation, then one can see formal individualisation arrangements as being only as good as the people that they bring into a person's life. ■

# A Story of Responsiveness

*The following story by* ***Bev Budden*** *of North Queensland is a good example of the importance of listening, and of the crucial part that is played by a direct worker and an agency in responding to need.*

As with any new job, it takes time to become familiar with the role and responsibilities that go with it. When I accepted the position of Indigenous Co-ordinator (Community Access) with Tableland Community Link, I had no idea of the diversity of needs I would encounter in my work over the following three years. Having never worked in the area of Disability before, let alone in the area of indigenous people with a disability, I thought to myself: "I'm aboriginal, I know what the needs of aboriginal people are, so how hard could it be in meeting their needs?" I was to find that it was a lot harder than I had ever imagined. It's one thing to try to meet the needs of a minority group in a community, but to try to meet the needs of a minority group within that same group becomes another issue on its own.

In many circumstances it is very common within the indigenous community to have needs met by natural supports such as family, extended family and friends. This unique support network is often independent of service providers unless there are special requirements. This stems from clients and their families having had a bad experience with a particular service or services. Many families simply say they "don't want to be a burden" or that they "don't want to put anyone out". Such a humble attitude is a common trait in elderly aboriginal people. This is the story of one such family.

Molly and Sam (not their real names) live in a small, remote town about 120kms from where my work place is based. It is a small, former tin-mining town with about a third of its population being aboriginal and is a close-knit community. Molly and Sam are in their early seventies and Molly became a client of our service after she suffered a stroke that left her with a physical disability. Because of this disability Molly has approval for an Attendant Care package which carries recurrent funding. The package provides her with 28 hours of support a week. She has two carers who provide the support she needs. Her carers are her daughters, which was Molly's choice. Molly and Sam live a simple life. They make-do with what they have, and for them life is comfortable. Even though Molly is paralysed down one side of her body, she is still able to get about with the aid of a walking-stick

Molly feels she is quite independent in some aspects of her life. Sam is still an active man and finds much to do while pottering around the home and yard, as well as being there for Molly. In all the time that I have been paying visits to them, I have never heard either of them complain. I am always welcomed into their home with a very warm and positive outlook on life.

One day I was informed that Molly had been allocated some one-off funding. I made a visit and asked Molly and Sam if there was anything that Molly needed which would help to make her feel a little more independent. Their initial reply was, "well, there is, but we don't want to be a nuisance to anyone". After convincing Molly and Sam that the funding was specifically for her benefit, a simple request was made: "Could we possibly have a system connected to our wood stove for hot water?" Until then, I had not realised that each day Sam made a fire out the back to heat water in an old copper, filling Molly's bath by carrying buckets of hot water up to the house. I found there were two main reasons behind their request, the first being, "I would feel a bit more independent when my carers are not here" and "the winter months can get a bit cold up here". The humbleness of their request will always be etched in my mind.

I immediately set about trying to have Molly's needs met. With approval from the Management Committee I organised for a plumber to go to the home of Molly and Sam, but after assessing the situation, the plumber recommended that the house be rewired for safety purposes before any hot water system could be connected. I had also been unaware that Molly and Sam ran power to the house from an outside source and it would have been too dangerous to try to run a hot water system through this source. I organised for an electrician to visit the house for the purposes of inspection and quoting. He recommended that the house be rewired as well as a hot water system being installed, and the work commenced.

Even though Molly still depends on her carers and Sam for most of her support she feels that she now has a lot more independence. Her quality of life has also improved. Having power connected to the home and a hot water system installed has made a difference to the life of Molly and Sam. ■

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**CRUCIAL TIMES**
ISSN 1323-2231

**Issue No. 15**

Print Post Approved
PP408233/00048

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