

# CRUCIAL TIMES

Community Resource Unit Inc.  
Level 2, 43 Peel Street,  
South Brisbane QLD 4101  
(P.O. Box 3722, South Brisbane, QLD)

JUNE 2012 ISSUE 43  
Ph: 07 3844 2211 Fax: 07 3844 3400

Email: [cru@cru.org.au](mailto:cru@cru.org.au) Website: [www.cru.org.au](http://www.cru.org.au)

## Editorial

In western societies, most people want to have the final say about what happens in their life. From young children who can't wait to grow up, confident that they know much more than their parents to employees who buy lotto tickets that promise you can 'say goodbye to your boss' or who dream of retirement as a time when they can do their own thing in their own time there is a common resistance to being corralled, controlled or dictated to by others. Whether we make our decisions in line with a well thought out plan or by a more intuitive process, the decisions and choices we make set the direction of our lives and ultimately shape who we are. Losing personal control and power, be it through illness, aging or unemployment, is something that we strongly resist and seek to insure ourselves against. As we anticipate or prepare for the times in our lives when we can't speak for ourselves we look to appoint people we know and trust to speak for us or represent our interests.

In this edition of Crucial Times, which explores the topic of self-direction for people with disability, it is important to keep in mind these very ordinary aspirations and impulses in the lives of all people.

When people with disability are supported by family and friends, from time to time there can be justifiable questions about who is setting the direction of the person's life. However, it is when formal support is provided by services that the issues of power and control become much more complex. Asking for assistance from a paid service shouldn't mean that people have to lose a significant amount of say over their own lives.

## Contents

- 1 Editorial**  
Margaret Rodgers
- 2 From the President**  
Matt Stone
- 3 Leading my life through my vision**  
Narissa Wilson
- 5 What are self-directed options and what should we expect from them?**  
Michael Kendrick
- 6 Re-shaping a life: changing the hole to fit the peg**  
Jan & David Goldsmith
- 7 A journey with people towards self-direction**  
Leanne Burke
- 8 What does it really take to live my life to the max?**  
Jaquie Mills
- 9 The erosion of individualised funding**  
Bruce Uditsky

### 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.

We have invited seven people, who have different experiences of what self-direction involves, to share their thoughts on this topic. From this small group of articles, common messages emerge about what is required for people with disabilities and the people who support them to maintain or regain a more respectful and egalitarian relationship with the formal services in their lives.

Throughout this edition of CRUcial Times you will read a number of different terms used to describe structures that support people with disability to direct their own support. For the purpose of this edition, we use the term *self-direction* when we are describing arrangements where the decision making and choices that determine the direction of the person's life rest with the person and their close supporters – this does not mean that the person needs to take on all the administration and human resource management tasks. When people who are self-directing do also take on the majority of the administration tasks they are said to be *self-managing*. In some instances this is referred to as *family-management*.

When Bruce Uditsky from Alberta in Canada uses the term *individualised funding*, he is also referring to funding that is provided directly to families and adults with disabilities to enable them to design and purchase the supports they require to live in community and participate in community life. This term has a different meaning in Queensland where it refers to funding allocated by government, to an individual but paid to their nominated service provider.

Jaquie Mills, who writes about her family's experience of microboards in Western Australia, looks forward to a time when her son's funding will come directly to their family and she refers to that as *direct funding*.

Our writers are clear about the benefits of self-direction and self-management but they are also clear that they should not be seen as a panacea. They cite many more things that need to be in

place for people who live with disability to have decent lives that are comparable to those of other people in the community and for this quality to be sustained throughout the person's lifetime. From their experience, the authors nominate other essential elements to be an investment in people and their families - that they are assisted to develop and articulate their vision; to plan; to expand their thinking and to

develop leadership and advocacy skills. There also needs to be a commitment to inclusion, an investment in human services and their staff; infrastructure funding, streamlined administrative arrangements and intentional and explicit safeguards. Investment in people and investment in human services needs to be matched with the inclusion of family and friends and the development and engagement of the general community. Only when all these elements are routinely provided will self-direction be achievable for the majority of people with disability, including those who have been disconnected from their family and who only have paid relationships in their lives. Our writers make it very clear that we need to have structures in place that do much more than simply distribute money directly to people with disabilities.

People taking charge and making the majority of choices around their paid service is not new. There are examples of people and their families doing this either individually or collectively for some decades. This has not been a general approach to how the majority of people could or should receive service but the option for a few who were either able or prepared to forge something different or in some cases just happened to be in the right place at the right time. At this point in our history there is a lot of interest in providing this opportunity to many more people and it is important we approach this change carefully and thoughtfully so that it provides the benefits we hope for.

**Margaret Rodgers**  
Director

*"It has been important to consider how self-direction arrangements can be safeguarded, as much as possible, into the future. These safeguards are important for the service as well as for individuals and families."*

**Leanne Burke**

## From the President

I think it was Confucius who said, “If you don’t change direction, you will end up where you’re going”.

Paying attention to direction is something that the staff and management of CRU take seriously when we work together each three years to develop and record our strategic plan. The CRU Committee of Management has the overall responsibility for ensuring CRU, as an organisation, works towards achieving the goals detailed in the Plan.

One of the goals in the current 2011-2014 Strategic Plan is to “promote, strengthen and defend person-centred and directed responses”. Having support systems that are person centred is a key component of self-direction. It makes sense to ensure that the person being served and those who know and love the person are at the centre of any planning and decision making processes that impact on their lives.

The promotion and strengthening of person-centred and person-directed responses is also likely to result in more people having greater autonomy over their own lives. We wish to promote and strengthen self-directed responses that honour the humanity of each person and lead to life-giving opportunities. It is also important to acknowledge the potential risks and vulnerabilities in misusing or under-utilising person-centred and directed responses.

This edition of CRUcial Times deals with self-direction for individuals and families, particularly in the area of formal support. It aims to share knowledge, wisdom and personal experiences of self-direction as another way in which CRU can help promote and defend the practice of working one person at a time.

Self-direction is not new in Queensland and therefore knowing the history will further assist in promoting and defending this practice. As the articles in this edition demonstrate, self-direction has great promise; a promise that must be balanced with an equal part of caution. With reference again to Confucius, we hope that pausing to reflect on self-direction now will help to ensure we don’t just end up where we are going.

I hope you enjoy this edition of CRUcial Times and its theme of self-direction. In my role as a service manager, I always enjoy CRUcial Times turning up in my in-box or letter-box. On behalf of the Committee, I would like to take this opportunity to thank the contributors and the staff of CRU who have worked to bring this edition to print.

**Matt Stone**

President of Community Resource Unit

CRU has a website, please go to

[www.cru.org.au](http://www.cru.org.au)

• For more information about CRU • Details on upcoming events • Bookshop • CRUcial Times including previous editions

# *Leading my Life through my Vision*

**Narissa Wilson** was born in Mount Isa and lived there with her older sister and parents. She was diagnosed with Spinal Muscular Atrophy at 18 months of age. Narissa has been living independently and calling the Sunshine Coast home since 2004. She now lives in her own home with her partner and house mates of her choice. She manages her own funding which she ensures is aligned with her vision of the life she wants and needs.

Life is not a painting on the wall, nor is it to be lived lonely. It is a substance you inhale and live happily. We strive for the best, unfold our wings and believe. Life is fundamentally unstable, though we all carry a false sense of stability, control and power. Our relationships, endeavours and our lives are all simply systems. Systems can absorb damage, change and growth, to a point, then, all of a sudden, everything switches to a whole new set of rules. My family learnt this twenty six years ago when the stable state of their healthy new born baby girl switched to a whole new set of rules.

When I was little, hiding in my cubby house, made of duck printed flannelette sheets, with my heart open, I had a vision for my future, just like the one I was creating for Barbie and Ken. Barbie had the best life! She had beautiful long blonde hair, silky plastic legs, great clothes, and a beautiful yellow Sesame Street house, with a blue roof. She was intelligent, had a white double bed, a handsome husband, Ken, and she was in control of her life. Barbie and Ken lived their life happily under the duck printed flannelette sheets until one day, Barbie's hair got cut off by my big sister. Ken's arm broke off and got sucked up by the vacuum cleaner. The yellow Sesame Street house got stored in Dad's shed and the white double bed Uncle Snow built was given away to another little girl along with Barbie's clothes. Thankfully, I got to keep her intelligence and the vision that life could be great. My legs are not silky and plastic, and I settled for black metal and round motorised wheels to make my way through life.

Within the world I created, Barbie had control and power over her life; this was what I wanted for my life and what I now feel I have. Having control and the power over the direction of my life allows me to live. For me, Self-Managed

Support means that I, the individual, direct the way my life lies, faces and moves in reference to my visions. Working with, and alongside, a service is much more satisfying than against. I was previously supported by a traditional service provider who endeavoured to be individualised but was unfortunately limited in its ability to colour outside the lines. Traditional services are not necessarily big bad wolves; they are simply bound by regimented ways of thinking that expect they can control those sudden changes in a stable state.

Self Managed Support works for me through a hosting agreement with a service. To me it is a business and I am the CEO of my life. The business is like any other and requires annual planning, weekly analysis of operations and staff, budget reviews, team meetings, team professional development (for myself and staff), policies and procedures and much more. My business operations consist of my service receiving and reporting funding to the Department of Communities. I have a direct relationship with my service, whom I have a Self Directed Hosting Agreement with. I am the person receiving and directing support (the business). I share the Governance with key people of my choice such as my partner, family and people I have identified to assist in the direction. To assist me in the management and HR, I have a paid Key Worker who communicates with the Staff, Governance group and myself under my direction. My support team (HR) consists of 5 Support Workers. To occasionally supplement my support team, I maintain a casual support team (contractors) who are people in my life that I have built relationships with. They are able to support me in the need of an emergency or over the holidays.

*Self Managed Support has allowed me the flexibility and freedom to live a life style that is bound by my choices, in my home and community. I now have the ability to build the relationships with the people I choose to be a part of my life.*

Self Managed Support has allowed me the flexibility and freedom to live a life style that is bound by my choices, in my home and community. I now have the ability to build the relationships with the people I choose to be a part of my life. For me, what I appreciate the most about Self Managed Support is that I can now create a workplace culture with my employees that enhances our productivity, knowledge, willingness and overall happiness. I can align my philosophies of good business practices with, most importantly, a positive culture for people with disabilities.

To be in control, doesn't come easy! It took an investment in myself as a leader for Self Managed Support. It was time consuming in the beginning to gain the knowledge and set up processes that would work for my life. I need to be willing to make mistakes and learn from them. Communication is a skill that opened doors for me to improve my business, the relationships I had with my staff and my life. Like any challenge it can be overwhelming and for Self Managed Support it is 100 times more because it is personal. Thus, I have had to learn (which I am still not good at) to separate myself from the "issue/incident" and analyse it critically. One of my biggest learning curves is that I cannot do it on my own. I require assistance with Governance, from a group of people who can offer me support. Every business has an advisor.

Barbie and Ken did not get to where they are by just sitting on a store shelf. It is about leadership in their market. This is no different for Self Managed Support. I am the leader for my life and my business. A leader needs to know who they are, what they want and how they are going to get it. To understand how and why I make decisions is what has helped with being a leader. My partner, family, governance group, key worker and support workers are all leaders too. They share my vision, my dreams, the good times and the bad times.

Barbie's hair never grew back and Ken's arm couldn't be re attached. However, I crawled out from the duck printed flannelette sheets, and I worked hard to move out of home with formal and informal support. I also worked hard to receive a degree in Information Technology (e-commerce & design), to be a general manager and project manager, and to run my own web and graphic design business. This was all possible because of my vision and those who shared it with me. I want to continue to be a successful business woman, to travel and to be the best sister. I want to be a daughter who my parents can be proud of and a girlfriend who loves and supports her man. I want to continually grow, expand my knowledge and to simply just live to love life. I can dream and plan for all these things because I know that I have the power and control I need over my own life.

---

## *What are self-directed options and what should we expect from them?*

**Dr Michael Kendrick** is well known internationally as an educator, advocate, consultant and author. He has worked in government and non-government agencies and consults on issues such as service quality, safeguards, and design of personalized services. He lives in the United States, but as a regular visitor to Queensland, he also understands the local and national issues that people with disability and their supporters face as they strive to live in their community. Michael's website [www.kendrickconsulting.org](http://www.kendrickconsulting.org) contains further information and resources.

The attempt to create services that are designed and directed by service users has been growing in prominence in many human service sectors and has spawned a wide variety of policies, systems and examples in many jurisdictions.

Part 1 of this article has a focus on how decision making of this kind can be operationalised by demonstrating how organisational authority can be transferred to and employed by service users and their allies both singly and in conjunction with others parties. It describes various levels of

empowerment relative to service decision making as well as the common organisational forms that user directed services have taken to date.

Part 2 warns against exaggerating the benefits of such arrangements and outlines common limitations and constraints within self-direction as well as listing some potential safeguards for remaining realistic in our expectations.

## PART 1

**Extract from “Empowerment and Self Direction Relative to the Design and Governance of Personalized Service Arrangements”. *Journal of Human Development, Disability, and Social Change*. ISSN 1499-5549 57. 2011, (19), 2, p. 57-68.**

Conventional services will, on occasion, speak the language of partnership and empowerment however their actual habits of service decision making are largely unilateral, top down and nonnegotiable. Since, the service is "theirs" to manage then the role of those who get the service is described with terms such as "service user", "service recipient", "consumer", "client", etc. These terms quite correctly portray the person as taking advantage of a service, but clearly not designing and overseeing that service, hence their passive role as "receiver" of a service designed and overseen by others. Curiously, a person who may have been hired the previous week, will normally have more authority in regards to what the service user may receive than will the service user, even though it is their life that will be impacted by such decisions.

In response to this kind of disempowered role for service users, it has become increasingly common for governmental systems to create policy in favour of ways of operating that are variably referred to as "self-directed", "self-determined", "consumer/ family governed" and the like. In most instances, some version of individualized funding is simultaneously put in place to enable the person to have an allocation of a set amount of resources over which they have a measure of conditional authority for spending purposes. These remain public funds usually, but with the provision that the person now has a say in how they should be spent. Typically, these notably more empowering options can be subdivided into service arrangements that the person directly oversees *and* administers or service arrangements which the person opts not to administer directly, but, in regards to decision making, still retains considerable key decision making authority. Often, they will leave many decisions with the service provider when they have confidence in that provider. The former option is quite attractive to people who feel they cannot or prefer to not manage the workload, demands and bureaucracy involved in the self-management of an individual service arrangement. Those who opt for personal

governance, but without an accompanying set of administrative duties, will usually be people who want to maintain unambiguous decision making authority, but are averse to what they see as the burdensome tasks that come with direct service management responsibilities. As such, the "personal governance" of an individual service arrangement can be achieved with either option.

Obviously, when all aspects of an individual service arrangement can be negotiated and decided by a partnership between the provider and the person with disability then the person is no longer passively involved but has decision making rights. These "rights" to negotiate would not be the same as "entitlement rights", since an entitlement bestowed by a government or system is essentially a guarantee of a particular outcome, such as a right to an education, a minimum age, access to housing or health care. In contrast, "participation rights" are rights to be part of *the service design and operation process*, but these do not extend to the assurance of a particular outcome or entitlement. In many systems, authorities are not authorized by law to make such "outcome entitlement" commitments but decide, rather, on a "resource-permitting" or priority driven basis. Flexibility of service may be gained through having "participation rights" but such gains are still inevitably constrained by the capacities of the service itself. In essence, the service user would normally seek the best available service arrangement, but would eventually have to settle since that is always the ultimate result of a negotiated solution. While the service user is notably empowered as a decision maker in negotiated flexible arrangements this does not mean that the service arrangement itself will be entirely satisfactory, whatever its comparative advantages with what might have preceded it.

### **Common Well Established Organizational Options That Are Empowering For Service Users**

There exists, in many locations, a variety of organizational options that routinely ensure that the service user exercises a high level of decision making authority. These examples have often been in operation for decades, though it is quite common that many people do not know that they exist and how they operate. This is likely to change as the principle that the service user is best served in comparatively empowering service models gains greater policy prominence. This gain in authority for the service user does not necessarily mean that the service arrangement itself will be of high quality, as these challenges are separate matters and are

driven by distinct additional factors. Even so, there would still be some people who would assume that if a service is self-directed it will also be of good quality given how much the empowerment dimension has been touted by advocates as being the "*sine qua non*" of desirable service practices. In reality, achieving comprehensive service quality at a high level is a complicated and multi-dimensional undertaking that is only partially helped by self-direction.

- **The Member Directed Mini Agency – (eg.Cooperatives and Collectives)**

Some service users who have wanted a more empowering service arrangement have joined common cause with others who shared this same ambition. Together they have formed small member governed agencies that have ensured that they had the ultimate authority to design and oversee their own service arrangement as a matter of organizational policy. Since they are not hostage to the policies of an existing agency controlled by others, all of the residual decision making authority regarding the design and ongoing oversight of their service arrangements is theirs. The mini agency's governance board is dominated by the service users who are the organization's members; the members essentially have collective governance authority over the agency itself. At the level of each member's personal service arrangement, it is normally the case that each member would direct their own service, though its actual administration might be assigned to the mini agency. The mini agency typically would have its own distinct philosophy with service user empowerment as one of its core aims. Its legal status is that of an incorporated body with a governance constitution that ensures that the members remain in control of their agency. This type of organization would have essentially the same administrative relationship with funders as would any agency. Much of this bureaucratic work would be carried by the organization and, it is quite common that the service user is spared having to carry it personally. In some instances, if the mini agency is allowed to grow in size to the point where the governance board represents only a small portion of the actual members, then a given member may retain considerable authority over their own personal service arrangement i.e. "personal governance", but have only weak influence on collective governance. This is why many of these organizations limit their size so that the individual members have significant influence and authority in regards to both forms of

governance. In many localities, these mini agencies may be referred to as "collectives" or "cooperatives" with the focus of their work being to support the members to have the capacity to be in charge of their own service arrangement and the service's philosophy.

- **Incorporated "One Off" Individual Service Arrangements ("Microboards")**

In various jurisdictions, most notably in western Canada, "microboards" have existed for some decades. These are incorporated "agencies" designed to support the administration of a single person's service arrangement. They often arise because individuals or families are dissatisfied with what is offered by mainstream agencies and want to design and oversee their own service arrangement. In most instances, this will mean that they also have to administer it as well, though some aspects of this task can be sub contracted. Since all incorporated bodies need to have a constitution and a governing board, the individual service user needs to share governance of their service arrangement with a sufficient number of other people. This can create an opportunity for the person's control and authority to drift into the hands of others, thereby potentially leaving the person somewhat vulnerable if they do not have the means to control who gets appointed. His or her personal empowerment needs to be enshrined as a core purpose in the constitution. Like all other incorporated agencies, these "microboards" will have to partner with funders and this brings with it all of the usual compliance requirements of governments as well as compliance requirements of not for profit associations. Combined with ongoing service administration responsibilities such as staff recruitment, supervision, scheduling, insurance, payroll and ensuring cash flow would have to be managed.. It is a testimony to the level of dissatisfaction with the disempowerment encountered in conventional agencies that people would take on such burdensome responsibilities and see them as still being better than being subordinate to conventional services.

- **Unincorporated "One Off" Individual Service Arrangements**

It may not always be a requirement that individuals be legally incorporated in order to receive government monies. In some localities, it is possible for individuals to obtain funding for individual service arrangements directly from governments. They can administer these monies through a special contractual agreement with the

funder. Typically, this requires budgetary transparency and all of the usual compliance obligations of agencies, but often with an intentional reduction in the bureaucratic burdens for the individuals whose service arrangement it is. In some instances, the funder will allow or even encourage the involvement of various support organizations to ease the workload and demands on the person. These could be payroll services, "fiscal intermediaries" or even subcontracts with existing agencies for various routine administrative or bureaucratic functions. While the individual may be more empowered relative to what might be the case in conventional service arrangements, it should not be assumed that the level of funding will be adequate, nor that the person will be proficient in creating a high quality service arrangement, quite apart from whether there will be worrisome vulnerabilities present for the person that are not properly offset by sufficient safeguards. These qualitative dimensions of the service arrangement and its overall effectiveness, apart from its empowerment dimensions, will vary from one situation to another and whether the individual is supported with these challenges will often depend upon whether these types of issues are recognized and taken seriously by both the service users and the authorities.

- **Agency Hosted Unincorporated Individual Support Arrangements**

In these kinds of arrangements, the service user will seek out an existing agency that they can partner with while still maintaining a high level of decision making authority. Typically, the agency will take care of most of the administrative and bureaucratic work as per the individual's specific preferences. The decision making regarding the design and oversight of the service arrangement then technically is supposed to be entirely shared between the person and the agency

though many agencies initially find this joint decision making to be contrary to how they usually operate. This is because the "hosting" or "auspice" role can mean that the service arrangement is seen by the host agency to be legally the agency's sole responsibility, even if that agency chooses to assure, by written agreement with the person, that the person will remain an empowered decision maker. This view would be incorrect as service users and agencies can both be seen as ultimately responsible but explicitly working in a partnership. Nonetheless, hosting arrangements do mean that the person does not need to be incorporated, as the agency takes up this function as well as most of the other bureaucratic, financial and administrative functions subject to whatever supervision arrangement the two parties negotiate. The "employer of record" would be the host agency, though typically the individual provides the oversight and supervision of the staff that they select and utilize for their supports. It is common practice that the hosting arrangement can be dissolved by either party, usually in an orderly way, should they no longer want it to continue. This requires the tacit or explicit consent of the funder that the individual's funding can be moved to another agency. In effect, the hosting arrangement could in theory be a "stand alone", internal, semi-autonomous, arms-length, self-governing individualized service arrangement that is able to function quite autonomously in most matters from how the given agency might operate its other services. The limits of this operational autonomy are normally specified in the hosting agreement and concluded by negotiation. Nonetheless, this will entirely depend upon whether the person and the agency have been able to generate a common understanding of what is intended and how it should work in practice.

The tendency for many may be to assume that what generates good lives is simply having the power and financial resources to make decisions. .... there are many other resources and human factors that will ultimately determine whatever good will derive from a given self-directed arrangement.



## **Agency Hosted Unincorporated Collectively Governed Individual Support Arrangements Project**

This option is based on the creation of a member governed (collectively governed) project to provide individual service arrangements. It largely resembles an incorporated member governed mini agency or cooperative, except for the fact that it is hosted by an existing agency rather than being incorporated itself. The project would seek a negotiated hosting agreement with the host agency and thereby come under its legal authority but retain a semiautonomous, internal, arms-length manner of operating. It is common that the governing board of these projects negotiates and settles their host agreement details with the board of the host agency rather than the senior staff of the agency, thereby cementing a board-to board relationship. This negotiation can often take several years to finalize. However, once finalized they can often be in place for years without any adjustment. These projects can provide their members with the kind values solidarity they seek concerning their shared needs for empowerment and personally tailored individualized services. The people that start them normally will have to be very proactive and provide considerable leadership to bring them into existence. However, people who join them once they are established will bypass these challenges and simply have to contend with the comparatively easier ongoing operational issues. Like all of the previous examples, these projects may also have quality of service issues and similar challenges notwithstanding whatever empowerment gains they may ensure.

## **PART 2**

### ***Self-Direction: Distinguishing between wishful and realistic expectations***

It is clear that a variety of self-direction arrangements are feasible in terms of ensuring that the person and their allies become principal decision-makers relative to oversight of their personal service arrangements. Further, when done properly and linked with a variety of key supports, such newfound power regarding service decision making can often become an important, but possibly not always a key ingredient, in a much more expansive process of helping the person generate many highly needed and desirable lifestyle developments. These potential benefits are not illusory, as can be witnessed in any number of instances where people's lives have meaningfully progressed within the context of some version of a self-directed arrangement.

However, it is important that we do not exaggerate the benefits we anticipate from such arrangements nor fail to perceive in advance the harm that may be present in what appears to be a desirable reform. Can these benefits be attributed solely to self-direction rather than to other variables at work alongside self-directive governance of service arrangements that may be even more crucial in improving life circumstances? Is what is often a success attributed solely to self-direction instead a combination of crucial contextual ingredients summing eventually into improved life circumstances? Some of this will become apparent if one considers the inherent limitations that may be present in any self-directed arrangement as well as noting the features of the many self-directed arrangements in which a given person did not particularly thrive.

### ***Common Limitations And Constraints Within Self-Directed Arrangements***

#### **• Personal And Network Capacities**

Not all people and their personal networks have the same capacities and this variability provides quite different starting points for generating lifestyle advantages for the person. For instance, people will vary greatly in their awareness of positive possibilities for their lives and their capacity to generate new ones. In a similar way, some people may lack the confidence to undertake change, the skill to negotiate with systems, the sophistication with which they can manage people, their familiarity with good practices elsewhere, their experience with generating and sustaining natural supports and so on.

#### **• Motivations And Resolve**

Individuals will normally vary in their motivations and agendas for their lives and these differences can be quite marked and consequential. For instance, some people may be quite uncertain about what to do with their lives while others may tackle many life challenges with impressive resolve and determination. Some may be unfocussed, frivolous and easily distracted whereas others may be organized, systematic and even driven. Even where promising personal agendas may be present, the capacity of people to persevere in the face of daunting challenges can be expected to vary.

- **Resources And Supports**

If one were to take a broad view of the variety of resources and supports available to a given person and their networks, it would become apparent that self-directed arrangements are not comparably endowed with equivalent resources of this kind. These resources extend beyond monies to factors like relationships, levels of experience, connections, leadership abilities, guidance, allies, advocates, available technical assistance, educational opportunities, coaching and mentoring, personal financial assets, social and political standing and so on. Since these ingredients and others like them are not trivial, the presence or absence of them will have real effects.

- **Perverse Constraints**

While there may be a great deal of theoretical potential in a given self-directed arrangement, it can easily be thwarted by factors at work that hold back a specific person from achieving their potentials. This can be due to unnecessarily low expectations held of the person by others, structural barriers as to what constitutes legitimate uses of funding, the person's own irresponsibility or inadequacies, exploitation and manipulation of the person by their own paid or natural supporters, pressures to please others, a general lack of vision or the adoption of vision that is damaging or limiting, the squandering of time, talent and priority on directions that do not address the person's most significant needs, the use of the person and their monies to benefit other corrupt conduct, the intimidation and domination of the person and so on. It should be recognized that human nature can be perverse and this will inevitably manifest in undesirable practices.

**Some Potential Safeguards That May Be Pertinent To Keeping Expectations Of Self-Direction Opportunities As Realistic As Possible**

- **See Each Situation In Its Overall Context**

If each self-directed situation is evaluated in its entirety the specific blend of strengths and weaknesses can be better appreciated. This is in contrast to presuming that all self-directed situations are equivalent. This in turn enables there to be a more acute sense of the advantages and disadvantages that may be present and their potential effect on the person's life.

- **Assume That Not All Self-Directed Situations Will Have Comparable Capacities, Resources And Supports**

Since the contextual starting points may be quite different for individuals, some will make progress that would not be possible for others who are not as fortuitous in terms of the advantages they can draw upon. Some people may have obstacles that they must address and contend with that are simply much more challenging.

- **Assume That Perverse And Undesirable Human Conduct Will Often Be Present And Generate Negative Consequences**

Though "people will be people", it should not be assumed that the shortcomings of human nature are equitable in terms of how they appear in a given person's life. Some people may simply be in situations that are much more perverse than others and this reality must be engaged.

- **Recognise That Some Individual Situations Are Comparatively Exemplary And May Be Hard To Replicate**

It is important to recognise that excellence does exist and therefore some situations may generate achievements that are not likely to be as easily accomplished by others. This does not detract from the achievements of others who are less well endowed, but it does mean that favourable and unfavourable circumstances alter what can be achieved. Consequently, the factor of self-direction may not be what is ultimately most significant in terms of a given person's well-being.

The quality of self-directed options is developmental in nature. Having enriching supports and other resources does matter. However, the tendency for many may be to assume that what generates good lives is simply having the power and financial resources to make decisions. This view is very simplistic as there are many other resources and human factors that will ultimately determine whatever good will derive from a given self-directed arrangement.

In our hunger for such good we may unconsciously elevate the promising practices of self-direction to a moral standing whereby they are perceived as having no worrisome shortcomings and can do no harm. We thereby turn potentially valid progressive developments into panaceas and replace realistic thinking with magical longings. Being alert to the possible limitations and constraints of self-directed arrangements and being alert to the need for safeguards in our thinking and practice can assist us to have a realistic expectation of what self-direction can offer.

## *Re-shaping a life: changing the hole to fit the peg*

**David Goldsmith** is a young man in his late 20s who lives in Boondall and is assisted by his parents, two sisters and support workers to have an interesting and challenging life. Bespoke Lifestyles supports David and his family to manage his funding and provides advice and education on family-managed arrangements for example employing support workers. David and his mother Jan write of their experience with self-direction.

I remember when David was at school, I didn't want that part of his life to finish. During those years, I knew exactly what was required and that he was in a safe and nurturing environment. Leaving those school years behind in 2001 felt terrifying and we felt unprepared for the future. With support and advice from his school, we secured some post school funding and over the next 8 or 9 years, David attended programs under three different service providers. As we moved along this journey, we learnt more of what David wanted and needed to be the person he felt he could be.

In 2005 David discovered Facilitated Communication (FC) which enabled him, for the first time, to articulate what he wanted to do with his life. Before this, he had been limited by his verbal communication to very basic needs and wants. This meant we were only really guessing what he wanted but with FC, he could convey his deepest feelings about self-worth and participating in society. There was a huge readjustment in everyone's expectations. It took a year or more to adjust to this new skill of David's and to become accustomed to his voicing his own opinions. There was no place in his new world for sitting on buses and going to the movies with a group of people not of his choosing to fill in the day.

*I found it frustrating when I was at the day centres. They would choose an activity that the majority would like and usually I wasn't interested in that, so I spent the time being quite frustrated and cranky inside.*

*FC was a great awakening; it let the light into my life. I could now participate in decisions about my life.*

Our family, including David attended conferences and workshops over the years which showed us a future for David we never thought possible. Hearing words like family governance and the possibility of David living in his own home was a revelation. We learnt that we could have a plan and a vision for David and the future became something we had control over and not something to dread. We applied for funding to support David in this new plan and have been successful in securing a small amount of ongoing funding for this purpose.

David is well supported by three terrific support workers who all contribute something unique to his life.

*I would like to add that I really feel well supported by my workers because they know me so well and we don't do things that don't interest me. FC has given me the opportunity to speak up and express my desires.*

David always wanted to be a mower man so he is now mowing on Mondays and Fridays. He goes to TAFE on Wednesdays and Thursdays. He also contributes by volunteering at a school and in a community garden and being a member of a writers' group. He finds time for golf; has tried sailing and is open to other adventures. Grocery shopping and cooking are also part of the week.

Hearing words like family governance and the possibility of David living in his own home was a revelation. We learnt that we could have a plan and a vision for David and the future became something we had control over and not something to dread.

As you can see, there is a rich mixture of education, work and pleasure in his life – something we all aspire to. There has also been the chance to gain confidence and make friends. He isn't doing anything just to fill in his days idly, in fact he craves being busy and useful. David has voted in the last few elections and is proud of his status of being, as he says a “fully-fledged member of society”.

It was challenging to work out where to start so that David could have a home of his own. His name was on the list for Public Housing for some years, but we realised that this wasn't going to be a reality for some time. How could we plan for him to be in his own home when we didn't know when and where that would be? There was also the issue of support. He needs someone with him and there will never be enough funding for that to be a paid worker. We thought about flat mates but knew that public housing had stipulations about who is eligible.

We made the big decision to purchase a property for him, close to our home. This was a huge commitment, but we felt it was best as the family is totally in control. Currently his sister Lisa is sharing with him. Their home is 800 metres from ours. David is spending about half the week there and lives the rest of the time with Mum, Dad and the cat. Having two homes has its funny moments. If I don't keep an eye on things all his pyjamas, jeans or socks are in the wrong house! However, plans are on track for David to be living full time in his own home with Lisa by the end of the year.

David still needs lots of support and reminders to get ready for each day. We are trying to get a mixture of paid support and natural, family

support. If and when Lisa wants to move to the next stage of her life, we plan to advertise for a flat mate to share his home and be there at night. He wouldn't be a support worker as such, just someone to be there and provide security. David would still have paid support to work and participate in the community the way he is now.

Until we did this  
ourselves, money was  
spent on things I wasn't  
interested in and that is a  
waste. I used to feel like a  
square peg in a round  
hole; now I'm making the  
hole just my shape.

While this all sounds wonderful, it is constant work to oversee it all and a large commitment from the family. If one of his workers has holidays or is sick, back up has to be arranged by us. However, we are learning from our mistakes and growing in confidence with our planning and coordinating. I'm relieved we started this process while we are nearby and young enough to work this out with our family. Our daughters have been involved from the beginning and are committed to David as well. They will take over from us when we are no longer able to do it.

*There are many things I want to try and learn about and I have more confidence now that it will eventually happen. I was on the edge of society but now I'm more mainstream and not so marginalised. I like to be part of what's going on and not stuck away doing something different from everyone else. There are days I don't feel very strong and my workers provide that extra power for me to contribute to the world in my small way. So, yes, I feel much more a real person and not just an autistic twit. I like my workers very much and look forward to each day which brings something different with it. Until we did this ourselves, money was spent on things I wasn't interested in and that is a waste. I used to feel like a square peg in a round hole; now I'm making the hole just my shape.*

# *A journey with people towards self-direction*

**Leanne Burke** works for Staffing Options in Queensland. She manages the establishment of systems to enable people who want to direct their own support or direct on behalf of their husband, wife, son, daughter, brother, sister or another person they are in a committed relationship with. Leanne, along with a small team of development workers, can provide assistance with planning, implementing and reviewing the supports required. She has previously worked for, and assisted to establish, several small family- and member-governed services. Leanne is also actively engaged in a family-directed support arrangement on behalf of her sister. This role is undertaken as part of a loving family who collectively have a life time of experience in creating informal and formal responses, some more successful than others.

Staffing Options has been actively engaged in establishing self-directed support since 2006 and hosts individual self- and family-directed arrangements as well as a collectively member-governed group of 10 people. Staffing Options works one person at a time with individuals who have no or very little family support through to individuals who have a large amount of informal support in their lives.

The article that follows has been adapted from a presentation at a series of workshops held by the Alliance for Self-direction, a group of people who have actively engaged in the foundation of a range of self-direction initiatives either within or outside of existing service structures. The Alliance has a vision that all Queenslanders with a disability will have the autonomy to envision, live and direct their own lifestyles.

---

It starts with getting clear about your business.

To cut a long story short Staffing Options began negotiating self-directed support arrangements because we were asked to. Staffing Options has been operating for 15 years in Queensland and is principally a staffing agency. As such, we struggle with the notion of being a service provider. However, we have always demonstrated a willingness to work with individual requests and to grow in response to these requests. Being asked to negotiate self-directed support arrangements was another opportunity to do this.

Staffing Options has responded to requests to hold funds on behalf of individuals since its early days so, in a sense, has developed a self-directed response over some time, though unintentionally and rather reluctantly at first. We had no issues with administering the funding but were rather reluctant about being in the role of 'service provider'. A further development was

in response to a member-governed collective which approached Staffing Options to be a 'Host Agency' for its project funds and the funds of the individual members. In agreeing to do this, Staffing Options gained experience in developing an agreement and negotiating roles and responsibilities as a means to delegate authority to a collectively member-governed group.

However, it was when Staffing Options was asked to hold funds on an ongoing basis on behalf of individuals that we had to intentionally set up a system that was going to meet the requirements of funding bodies while allowing people to be as free as possible to manage their own supports in the course of directing their own lives.

We used experience that we had gained internally. We also harnessed the experience gained from a number of family and service user- or member-governed organisations in Brisbane who over many years had laid the foundations of self or family-directed support in Queensland. We also read a lot and spoke to a lot of people who had experience of self-directed support.

This time of learning and exploration led to the development of a culture within Staffing Options based on the belief in people having authority over the supports they receive. Time was also spent on the development of the structures and practices to enable that to happen.

As this work developed we were advised of the importance of being very clear about what was and wasn't our business. The business of everyday life that we all cherish, our private lives, customs, relationships, security, preferences, is clearly not the business of service. Nor is decision-making which belongs with each individual, based on the authority they have over their own life or on the natural

authority for support in decision making that is sought from family and friends. The business of 'service', on the other hand, is clearly about the business of distributing public money and ensuring that processes are in place so that certain standards can be met and outcomes reached with that public money. Staffing Options believes that part of our business is also to work out how we can legitimately minimise bureaucracy in people's lives.

## HOW IT WORKS

A traditional approach to support could be described as the delegation of authority from the funding body to paid managers and co-ordinators to ensure outcomes. In a self-directed arrangement authority is delegated instead to 'non-paid' people to direct service provision - the person in receipt of funding or someone very close to them. It is important to note that, although funds are given directly to individuals or families in some jurisdictions, this is not the case currently in Queensland. In self-directed arrangements, funds need to be brokered through a recognised service provider.

## Structures

Staffing Options uses the term 'Host Agency' to describe the relationship between the service and the individual. This term was used by the collective that first asked us to consider this kind of arrangement. It was felt that the term 'hosting' reflected the relationship Staffing Options has with the people in receipt of funding.

The Host Agreement is the document that outlines the roles and responsibilities of each party to the agreement. It lists the conditions under which the relationship between the person directing support and Staffing Options can be sustained and also the requirements that Staffing Options must meet to administer the funding. The Agreement and the attached conditions form the core of the safeguarding process for all concerned and make clear the delegation of authority and responsibilities for both parties.

## Policy and Practice

We were helped in the process of developing policy and practice by our contact with the people who originally asked us to help them with self-directed support. They were all people who could reasonably articulate their vision, who had done the necessary planning and who were looking for an agency that would let them put

their plans into action. We had good mentors to learn from. As a result of these early experiences, Staffing Options has come to believe that self-directed support is for people, and their supporters, who have a genuine desire to make the majority of decisions about things that happen for themselves and to have primary control of their support arrangements.

In developing policy and practice decisions it became apparent that there were some matters that must remain non-negotiable in order for Staffing Options to be able to meet its obligations to the funding body and to ensure that we stick to 'our business'. Other matters remain open to negotiation.

## Core Elements

These non-negotiables have become the Core Elements that we consider necessary before Staffing Options will agree to 'host' a self-directed support arrangement:-

### 1. Leadership exists

The person with a disability and their family and/or supporters have a vision for a good life and can clearly identify how funded supports will assist or they are willing to work to develop this.

### 2. Authority for decisions is as close to the person as possible

The person wants to remain in control of their own life influencing decisions and choices. Staffing Options defers to the natural authority of family and committed friends to make decisions on behalf of the person requiring support where the person cannot do this for themselves or can do so only partially.

### 3. Administration of Funds

The individual or family has private resources or government funding that they wish to use to create a personalised service by directing their own supports and influencing service design and implementation.

According to the conditions of the Host Agreement the person directing support has the authority to select and direct the level and type of administration support from Staffing Options that they desire.

- Staffing Options can provide all the payroll services of a 'legal employer' for any staff required (eg. support workers, key workers,

co-ordinators), however each individual or family would take on the responsibility of recruiting, selecting and managing their own staff.

- Staffing Options can also set up each individual or family to manage their own funding through a transfer of funds so that they can then either employ their own workers or engage contractors and other supports directly. The individual or family has responsibility for recruiting, selecting and managing staff as well as the administrative roles involved in being an employer. Staffing Options brokers the funds and has responsibility for matters such as meeting all the accountability requirements of the funding body.

Some people choose to use a combination of both systems. Staffing Options ensures that the two systems remain viable options in the sense of being both legally viable and easy to use.

#### **Developing roles and responsibilities – access to ongoing support**

Whichever option or combination is chosen, Staffing Options is the administrator and it is important that its role remains purely administrative. According to the Host

Agreement, Staffing Options delegates responsibility for recruiting and directing workers to the individual or person delegated to direct support.

Examples of what the person directing support would be required to do include:-

- determining the amount and type of support required
- deciding who to employ to provide support
- providing adequate induction and training opportunities to people employed
- directing the support provided
- ensuring a safe work environment
- following any guidelines established designed to ensure sound employment practices
- ensuring supports provided are within budget and forwarding all documentation as required

The person directing support may choose to delegate some of these 'service business' roles to paid workers. This can be organised as part of the funding arrangement. In some cases a key worker is employed to manage these tasks. In other cases the tasks are shared between the staff team or are delegated to staff hired through a recruitment service.

The challenge for individuals and families in terms of the future for any self-directed arrangement is the sustainability of the arrangement – what safeguards can be put in place for the time when the person or persons currently directing support can no longer do so.

## WHAT WE HAVE LEARNED

Staffing Options has learned much during the past 5 years of this journey with people towards self-direction. It is clear, first of all, that each self-directed arrangement can be very different to the next. We know that tasks that are easy for some people are a major challenge to others. We recognise that many people need time to firmly establish one part of their arrangement before being ready to move on with other elements.

We have learned that the more intensive support we can provide in the set up phase the more likely the sustainability of the arrangement. In recognition of this we have recently begun to use funds from the administration fees to employ support development workers to assist people in the establishment phase. Support development workers can assist each person individually with what they identify to be the more challenging aspects of the arrangement e.g. assistance with developing interviewing skills or assistance with running a meeting. The aim of the work is to build capacity in people and to help establish more autonomous arrangements.

People who have been self-directing have indicated that they are experiencing increased choice over the people they engage and greater control over the type of supports they receive and how these are delivered by staff. One of the most commonly reported benefits is that people now feel that they have the opportunity to talk directly to the people they engage. This has led to support requirements being better met, improved relationships with staff, improved retention of staff and the ability to disengage people who are not suitable.

There is also a sense of improved value for money amongst people involved in self direction.

Administration costs are clearly defined by the percentage charged and people generally report being able to purchase increased support and/or have better outcomes for their dollar.

People have also commented on having improved emotional health and a sense of being able to get on with life now that they have the control and ability to make decisions about their own life.

These benefits may not be easily recognised when people are starting the process of self-direction. There is much to negotiate and many processes and procedures to establish.

However, in the main, people find that the choice to self-direct has been a positive move.

## SAFEGUARDS

### Strategies for organisational sustainability

It has been important to consider how self-direction arrangements can be safeguarded, as much as possible, into the future. These safeguards are important for the service as well as for individuals and families.

Staffing Options makes the assumption that the person and their family and committed friends are best placed to know their own needs and that they have the capacity to assume the responsibility to direct their own support. However, under the terms of its service agreement, Staffing Options is delegated authority from the funding body to ensure outcomes. In a self-directed arrangement this authority is then delegated to the individual or family who wish to become the directors of their own supports. This delegation of conditional authority is based on a mutually respectful relationship where ethical and honest behaviour is expected from both parties. Negotiations under this relationship include an assessment of risk and viability measures to manage potential risks to the person receiving support, the person directing support and to employees and contractors as well as methods of meeting administrative and legal requirements.

Staffing Options forms a "bureaucratic shield" or buffer from departmental requirements so people's lives are not consumed by paper work, administration, management or reporting requirements. However, conditional authority allows Staffing Options to step in to over-ride any action or decision which would place it in breach of its legal obligations. The general intention remains, however, that the support arrangements would operate as autonomously as possible.

The administration fee charged to individuals or families is another safeguard for Staffing Options. It provides a financial basis to administer the funds and to provide staff who are able to assist with the establishment and development of self-directed support arrangements and the development of assistance that may be required in the future to sustain the support arrangements.



## Strategies for sustaining individual arrangements

The challenge for individuals and families in terms of the future for any self-directed arrangement is the sustainability of the arrangement – what safeguards can be put in place for the time when the person or persons currently directing support can no longer do so.

Staffing Options believes that it has an obligation to invest in planning activities with each person and their family and committed friends when we establish self-directed support arrangements. We encourage individuals and families to engage in planning for the future and recommend that they seek assistance from programs specifically established for succession planning or to include planning in their budget allocation. Planning support can be purchased within Staffing Options or we can assist individuals and families to engage a person of their choice from outside the organisation who is skilled in person-centred planning.

We are also starting to make plans to invest in further strategies to address this important question of sustainability. These include:

- Succession planning activities
- Further implementation of supporting roles – similar to the establishment of the recruitment service and the service development worker
- Development of more collective approaches
- Skilling up or collaborating with other family members in self-direction roles
- A framework to direct support into the future

As we continue to learn more about how self-direction can best work for people and to develop strategies for sustainability for individual arrangements and for our service, we know that staying clear about what is our business will remain fundamental to this process.

## *What does it really take to live my life to the max?*

**Jaquie Mills** is Chair and founding member of Vela Microboards Australia (VMA). She is also Chair of the Positive Behaviours guiding committee, a university lecturer at Edith Cowan University and board member of the Foundation for Social Inclusion. Jaquie and her partner Darryl, believe their son Eli's success so far in creating a good life despite his complex disabilities, can be credited to the process supported by Vela Microboards Australia.

My son, Eli, celebrated his recent 21st birthday recently. More than 100 people of all ages gathered at a local pub to celebrate the joyful life this young man has had, as well as his magnificence in the face of sometimes gruelling challenges. Most of these people were Eli's friends - people who were there because they have a real relationship with him. It was one of the most joyful nights of my life and I could not help remembering what we were told by the doctor when Eli was diagnosed with Angelman syndrome 18 years ago - that he would never walk, talk or be able to do anything independently, and that a typical life was out of the question as he faced a life of 24/7 care.

The predictions that doctor made all those years ago have mainly come true - except for the typical life part. Eli may be 'uniquely verbal' (the term we prefer to 'nonverbal'), he may need

support with pretty much every aspect of his life and he may have behaviours which could be seen as very challenging most days, but he also has a close group of friends who love him and take him to the footy, to live gigs and to parties where he is known for his love of Jim Beam and coke and a crazy night dancing to ACDC.

He has just finished a semester studying drama at university where he has been successfully included not just in terms of his learning, but also socially, and he has his own business 'Merger of Minds' which hires out technology to other young people who need support to access technology. He is an experienced presenter and co-facilitates presentations at universities and to the general public using whatever his communication device of choice is at the time and his gregarious sense of humour.

Eli has been living independently for nearly three years with no formal funding for the support he needs at home which is provided by the four friends he lives with and by his microboard members most weekends.

It is this microboard that we believe has been fundamental to the making of Eli's 'typical life'. In fact, for our family, we believe that none of this would have come about without the community of learning and practice that is Vela Microboards Australia (VMA). We were founding members of this organisation along with a small group of families who have all worked together since 2007 to create the outcomes described by our vision statement 'My life to the max - choice, control, friends'.

Microboards are an innovative concept started in the mid-1980s by David and Faye Wetherow in Manitoba when they successfully designed a process around a young man leaving an institution. Microboards engage community members in supporting an individual by providing an enduring structure to maintain the support throughout a person's life.

Microboards have most notably been developed as a sustainable model in British Columbia, where they are still growing in strength after 25 years. There are over 700 microboards in BC currently, with examples emerging in many states in the US as well as in other countries.

A microboard is formed when a small group of friends and family gather around a single individual to form an incorporated association for the benefit of that individual. Depending on a person's particular needs, a microboard's role can include assisting with coordinating support services, finding and keeping employment, meeting a person's social needs and managing living arrangements and funding.

Whilst microboards in Western Australia don't yet have access to direct funding, the intent of government is that this is one of the capacities they will have in the future. In the meantime, government funding for microboards needs to be brokered through services. In most cases these services work with microboards on a shared management model to develop a simulated experience of direct funding which has worked well in terms of offering a greater degree of flexibility and control.

People often assume that the incorporation process is mainly to create a transparent and accountable vehicle for managing funds or sometimes for raising money. As a charitable organisation, some microboards establish their own small business activity to augment or create funding. Whilst having an incorporated body to deal with financial management is an appealing aspect of the model, it doesn't represent the full story. Many microboards in British Columbia, for example, receive no funding at all, but still manage to create good outcomes as a result of relationship based work.

The group of pioneer families who started Vela Microboards Australia five years ago all have sons and daughters with very complex needs. Most of our sons and daughters have started from a position of profound social isolation and a lack of quality educational opportunities, and as for most parents, we have all had wounds which needed acknowledgement and some support to heal.

One of the realisations we have had is that whilst at the outset we thought we were just going to create microboards, what we have actually been tackling additionally is a number of other distinct tasks which are pre-requisites to having a Microboard.

We like to remind people, for example, of the wise words of the Beatles song - 'money can't buy me love', and that it is too easy to forget that it is loving relationships which give us all real quality, security and meaning in our lives. We think there is something about microboard

*Whilst flexibility and control  
of our funding is an  
essential part of the  
process of forming a  
microboard, it certainly isn't  
the only part of the answer,  
and we have found that it  
can in fact make little  
difference if other  
understandings and  
processes aren't in place.*

members having made a legal commitment to supporting the person to experience a full life which creates a more robust level of sustainability - mature microboards tend to function independently of external support or facilitation for very long periods of time, depending on only occasional support from the parent organisation. It is our hope that we can create a similar resilience in Western Australia, and to date the most effective work of our microboards has had little to do with managing funds and much more to do with building relationships, having fun, dreaming big and creating a strong and expansive network of people committed to social change.

We'd like to finish this discussion by sharing two of the many building blocks we have identified as being essential for the foundation of a Microboard. Whilst flexibility and control of our funding is an essential part of this process, it certainly isn't the only part of the answer, and we have found that it can in fact make little difference if other understandings and processes aren't in place.

#### 1. Expanded possibility thinking

We've become aware of the importance of 'expanded possibility thinking', which really means that we as parents need to stretch the limits of our beliefs about what is possible. Our decision making is profoundly impacted by how we think, as we can easily shut down opportunities because of our disbelief, or fears of being hurt or rejected. Moving past years of chronic exhaustion, social isolation and perpetual grief to a state where we can believe that a person who can't walk or talk can have a paid job and a terrific group of mates, to taking the complex steps needed to make that happen, requires expansive thinking.

The shift in how we think about what's possible in our own, and our family member's life, has led us to explore our engagement with collective support, both freely given and paid, which can help meet our family member's needs, including their need to self-determine. As a community we do intentional work such as workshops, mentoring, coaching and retreats to explore the ways in which parents can be supported to dream beyond what they currently believe is possible.

#### 2. Building collective capacity

Another common question is what is it really like to invite people in to our lives - what are the

challenges? Well, it isn't easy, and the challenges are many - but the results make it worth the effort. We use the image of 'constellation' to describe the complex relationships we notice and build around our loved ones. We've discovered that really we are in the business of building individual communities who provide support and attend to the needs of all of their members - this is the essence of their sustainability.

On the other hand, recruiting and managing paid teams has its own challenges and Vela Microboards Australia have most recently engaged a business coach who has worked with us to build highly individualised and successful recruitment processes. We have been delighted with the results of that - the majority of people we now recruit have no disability sector experience, so that we can create an expectation of high level outcomes much faster, as well as not having to untrain people exposed to out of date thinking.

Our reflection on the question of building collective capacity is that the disability sector and families generally lack awareness of just how complex this task can be, and of the level of energy and investment of resources initially needed to establish what is really a small business structure.

We look forward to the introduction of direct funding! However, our learning is that this is just the beginning of the journey. Families need each other and need to be connecting with each other as we create new ways of doing and being. We need support to think big and to let go of the wounds of the past. We need help in learning how to welcome others from the community into the lives of our sons and daughters, and the community needs help to find its way in. We need support to learn business practice too because the responsibilities of being an employer are way more complex than many of us realise - and they can change daily as new legislation is introduced. We have a responsibility to future parents to make sure that we do this very well indeed, so that direct and individualised funding can be a choice well into the future.

*For a detailed explanation of the thinking and history behind microboards, see:*

<http://www.communityworks.info/articles/microboard.htm>.

# *The Erosion of Individualised Funding*

**Bruce Uditsky, M.Ed., CEO, Alberta Association for Community Living (AACL) and Adjunct Professor, Community Rehabilitation & Disability Studies, Community Health Sciences, Faculty of Medicine, University of Calgary.** Bruce currently serves in an advisory capacity to a number of government ministries on policies and legislation affecting individuals with intellectual disabilities. He has also played a leadership role in the development of a number of innovative community initiatives particularly in the fields of employment and post-secondary education. Bruce is frequently invited to speak and consult internationally on inclusion, social justice, family advocacy and community capacity. He is the parent of two adult children, one of whom is adopted and has intellectual disabilities.

---

The following article is an extract from "The Erosion of Individualised Funding", written by Bruce Uditsky in 1999 published in Connections, V. 6, Issue 1, Spring. Edmonton, AB.: Alberta Association for Community Living. This article was written at a time when the Province of Alberta was a world leader with thousands of families accessing individualized funding for adults with intellectual disabilities. However, as the following extract from the article shows, the future of individualised funding was under threat, even at that time.

To clarify, the term "individualised funding" can be used to describe different levels of personal control over the use of government funds. In this article, the term "individualised funding" describes one particular type of funding in Alberta whereby funds are paid directly to families and adults with disabilities enabling them to design and purchase supports to live in community and participate in community life.

Following the extract, Bruce lists some of the major problems encountered, outlines what is happening now in Alberta and talks briefly about plans to help re-establish individualised funding as a viable means of funding.

---

With individualised funding money is provided directly to families and adults with disabilities to enable them to design and purchase the supports they require to live in community and participate in community life. This funding is typically provided by governments or government authorities.

In Alberta, individualised funding is provided by the Persons with Developmental Disabilities Community Boards. The amount of funding is determined by a plan that is ideally developed by parents, adults themselves and friends, often with the assistance of service providers or professionals, and submitted to the authorities

for approval. The plan may attempt to address all of a person's needs (eg employment, support staff at home, recreation etc) or only some needs. Usually negotiations will take place in relation to how much funding will actually be provided and to the nature of the plan, which will be adjusted accordingly. There is an appeal process for disagreements over funding and/or the plan.

Alberta is now considered an international leader in individualised funding because there are virtually no waiting lists and everyone who is eligible is able to access assistance. Individualised funding has helped to broaden the array of service choices across the province and improve the capacity of many services to respond individually to families and adults with developmental disabilities. Families, often with assistance of professional allies, were able to develop unique and creative responses to accommodate the needs of their sons and daughters with developmental disabilities. Individuals with significant challenges were able to have a home of their own and highly personalised supports 24 hours a day if needed.

Individualised funding, as practiced in Alberta or elsewhere, is far from perfect. Yet in spite of its shortcomings, individualised funding remains one of the most powerful and enabling means of a greater degree of family empowerment. However, for this to be achieved, parents and people with disabilities need to understand the value of individualised funding, the history of human services, how the benefits of individualised funding can be applied, the limits of individualised funding and how to protect individualised funding.

It is important to note that individualised funding is one of two principle methods by which services are funded in Alberta. The other funding approach is called contract or block

funding. Contract funding means that a service-providing agency enters into a contract with government or an authority to provide a set of services to a number of individuals. The contract spells out how much money the agency will receive and this money is typically provided quarterly and in advance to the agency.

Overtime many families and adults found that individualised funding began to lose its creative edge, as it became a more entrenched part of the human service system. It had moved from a funding mechanism, which enabled families to challenge the existing service system, to a major means of regular agency funding.

A number of factors contributed to a reduction in the potential of individualised funding to empower adults with developmental disabilities and their families. As it grew, a bureaucracy grew up around it, increasing the complexity for accessing and administering individualised funding. As more and more funds were allocated through individualised funding, the government found it necessary to exercise more control, limiting, for example how the funding could be applied (e.g. requiring staff to be paid low wages). Low wages increased staff turnover and reduced the number of people interested in establishing a career in working with people with disabilities. This further led to a reduction in the quality of staff available to support adults with developmental disabilities as individualised funding could not be applied to staff development. As this funding became more complex, and as services became more responsive, more and more families purchased the standard services offered by agencies. As more and more people purchased the standard services, agencies could argue that individualised funding wasn't necessary (N.B. there are still providers across Alberta that are committed to empowering families and support individualised funding, but this number is diminishing).

As individualised funding came to be more a way of having money flow to agencies than a means of empowerment, individual planning decreased and group planning increased. With individualised funding as an established routine for having money flow to agencies, many families were left unaware of their role in individualised funding and its potential empowering application. So while the funding continued, it retreated, for example, to planning for three or four individuals to live together, or a larger number of individuals to be served in a day program. Individual needs became secondary.

One of the most significant factors leading to the erosion of individualised funding was the development of a requirement for most agencies and families to be reimbursed after the incurred expenses rather than before. Individualised funding had become far more complex than the process whereby agencies received quarterly block payments up front. There was less control and paperwork applied to an agency receiving millions of dollars in advance of expenses, than the paperwork and control applied to a family or agency receiving \$36,000 per year. Contract dollars could also be used more flexibly and for a greater range of expenses. Agencies on contract funding might only have had to adjust their funding annually while individualised funding was accounted for monthly – thereby increasing the need for monitoring and reporting.

Given all of this, more and more families, unaware of the potential or unaware of what might be lost in the future are agreeing to have their individual funding converted into contract funding. In many instances families are being told that the agencies will provide individualised service and choice into the future. What is being forgotten is the influence that individualised funding has had on creating choice and individualised service in the first instance and that where this doesn't exist in other parts of Canada and other parts of the world there is less choice and individuality in service provision.

*'Individualised funding' is not a panacea; nor is it a power unto itself, but it does have a valued place in enhancing the lives of families and adults with developmental disabilities. It provides a mechanism by which families and creative service providers in the future will be able to step outside today's traditional human services. Individualised funding can support the possibilities of tomorrow's vision*

Individualised funding is not sufficiently empowering or creative in and of itself, but is an integral component to empowerment. There are at least six other essential components that need to be present to maximise the potential benefit of individualised funding.

- Commitment to inclusion – this must be more than a stated commitment; it must be lived out in practice. The commitment to inclusion is so tenuous that the moment the system experiences funding pressure, community inclusion and the services that enable community inclusion are some of the first things to be sacrificed. Today, more energy, time and funds are now expended managing the human service system and managing adults with developmental disabilities than in facilitating community inclusion and the development of relationships, or learning the art of inclusion.
- Community development – community inclusion cannot be accomplished by funding human services alone. For community inclusion to move forward, efforts have to be directed at working, for example, with the business, faith or recreation communities. In fact, families and adults with developmental disabilities are in as good or better position than human services to contribute to the development of community inclusion possibilities. Individualised funding can be used to assist the generic community in accommodating individuals with developmental disabilities. For example it could be used by a business to create and sustain on the job employment supports.
- Family and self-advocate leadership development – for the ideals of community inclusion to be realised in practice, there needs to be investment in developing and supporting family and self-advocate leaders. Policies, legislation and concepts like community governance need to be influenced and shaped by the voice and activism of parents, people with developmental disabilities and advocates.
- Knowledgeable, consistent and values based human service providers and human service practitioners – facilitating community inclusion is an art form. As an art form, it requires practitioners who are committed to people with developmental disabilities and their families, committed to learning the values,

- understandings and talents that will make a qualitative difference to the lives of people. Human services staff play a vital and intimate role in supporting adults with developmental disabilities.
- Person/family centred focus – the design of supports and services, which promote community inclusion, must be based on the intimate and respectful knowledge of each adult with a developmental disability and their family. Many human service practices, rules and policies are designed to meet the needs of governments, authorities and service providers. Actions, which de-individualise and thus de-humanise adults with developmental disabilities create an ethic and culture of practice, which places the needs of the system above those of families and adults with disability.
- Infrastructure funding – staff development, staff recruitment, administration. There needs to be funding, other than individualised funding, which addresses the need for core agency functions. It is possible to create a model of funding whereby an agency would receive contact or block funding for core functions, while families and adults with developmental disabilities receive individualised funding, which they would use to purchase support from these same agencies. This model of funding would likely help to reduce the pressure from agencies to convert individualised funding to contract funding. It would also contribute to the ongoing development of qualified staff.

As individualised funding continues to be eroded and negated, Alberta is in danger of losing one of the essential building blocks which can empower families and adults with developmental disabilities while contributing to individualised services that promote community inclusion. Individualised funding is not a panacea; nor is it a power unto itself, but it does have a valued place in enhancing the lives of families and adults with developmental disabilities. It provides a mechanism by which families and creative service providers in the future will be able to step outside today's traditional human services. Individualised funding can support the possibilities of tomorrow's vision.

## 2012: What is happening now in Alberta?

This extract was from an original article written in 1999. It predicted the potential demise of individualised funding in the Province of Alberta. Today the picture in Alberta is very different with less than a 1000 families of adults with intellectual disabilities accessing individualized funding. The majority of these families use their individualized funding for respite services in contrast to applying individualized funding in creative and innovative ways to achieve a good and inclusive life in community. Today the number of service providers amenable to having families contract and pay for services and supports is down to less than a handful from hundreds.

As the article points out, one of the most critical variables in the demise of individualized funding was the lack of sufficient family/individually governed community resources to support and enable individualised funding.

Resources to

- enable planning and the implementation of plans with a commitment to an inclusive life;
- assist in the recruitment, retention, training and payment of staff hired through individualised funding;
- facilitate the management of administrative requirements; assist with initial negotiations and amendments to plans and funding when needed;

- offer mentorship from experienced families and individuals who successfully apply IF; to name a few.

There were other reasons for the loss of individualised funding in Alberta, as noted in the excerpt, from changes in government funding to the false assumption that individualised funding was a powerful enough mechanism to drive a market approach to quality service provision.

It is hoped that Alberta's lessons with respect to the demise and current resurrection of individualised funding will be instructive to other jurisdictions implementing direct payments, those interested in sustaining direct payments where they exist and advocates committed to seeing individualised funding become a reality and accessible choice for individuals and families.

In an effort to re-establish individualised funding as a viable and effective means of funding, the Alberta Association for Community Living (AACL), in partnership with the Alberta government and other allies, has recently launched a resource centre to precisely offer individuals and families the assistance they require to benefit from the advantages of individualized funding ([www.aacl.org](http://www.aacl.org)).

## CRU Committee Members 2011-2012

Matthew Stone  
Margaret Geldard  
Sherryn West  
Mike Duggan  
Richard Warner  
Sharon Daley

President  
Secretary  
Treasurer  
Member  
Member  
Member

## CRU Staff

Margaret Rodgers  
Lisa Bridle  
Bill Kyle  
Suellen Welch  
Kim Jensen  
Bobby Noone  
Kathleen Flemming

Director  
Senior Consultant  
Finance Officer  
Consultant  
Administration Officer  
Administration Officer  
Administration Support

