

Thinking about...

Periodical of Personalised Lifestyle Assistance

Issue 1 ~ July 2009

Individualised funding



PLA believes that all people should have the opportunity to pursue a unique lifestyle that is personally meaningful, relevant and typically intertwined in the community.

Editorial ~ Individualisation of resources for people who have a disability

by Deb Rouget

Welcome to our first edition of “Thinking about...”!! PLA started from small beginnings in 2003. It emerged from individuals with a disability and families who sought a good community life that was unique, personally meaningful, and relevant and in which they had say so over their own life. Today we remain committed to these “ordinary” ethics and visions. We have few resources but have gained much richness from others. The periodical “Thinking about...” is one way we can share the wisdom of those who have inspired us to think deeply about human life. We hope you enjoy our first humble attempt to bring the voice of people with a disability, families and their allies to you.

This first edition aims to provoke some thinking around the current trend towards Individualised Funding i.e. funding being allocated to the person rather than a service. It doesn't aim to cover every issue involved and further information can be found in the links at the end of this Editorial.

Although there have been many benefits of Individualised Funding, as with all innovations or efforts there are limitations. Community Resource Unit's CRU e-News Nos 1-3 provides an excellent overview of self directed funding including information, papers and links. Two papers of interest are Blackman (2007) and Bigby (2008). Quite clearly Individualised Funding has the ability to empower people by giving them choice of services (Blackman, 2007). In examples of self directed resources, Bigby (2008) indicates that self directed funding redefines purchaser/provider/user relationships together with increasing satisfaction, emotional, social and psychological well-being, community presence and participation in employment and education. More use is made of family and friends to provide support and cost savings of up to 30-40%. Bigby also points out some areas of concern e.g. issues of power sharing within families, fear of the unknown etc.

Blackman (2007) also stated in his paper on Individualised Funding, according to a report done for the Canadian Labour Congress (2000), “studies have tended to be case studies utilizing anecdotal evidence

and may be biased to reporting favourable accounts.” Very limited systematic research was located which studied the overall quality, benefits, and deficits associated with self-managed funding and services.

This issue of “Thinking about...” is not to argue the pros and cons of Individualised Funding but provoke our thinking and suggest that there are very few unilateral solutions if a person is on the quest for a good life. There may be many things to consider.

Bruce Uditsky, Executive Director, Alberta Association of Community Living points out that “over time...individualized funding [in Canada] became more complex to administer and many families did not have the knowledge or means to apply this type of funding in the personalized and innovative ways that were possible. There were very few resources to assist families in thinking creatively or in managing the complexity of individualized funding. As a consequence, the vast majority of families simply purchased the very same agency services funded directly by government and in turn, rather than administer their individualized funding, had their funding payments go directly to an agency”.

As we head further into the realm of Direct Payments and Individualisation of Funding, we need to be cautious. As Michael Kendrick suggests “Like all mantras and incantations, words can be imbued with a magical quality depending upon what meanings we project onto them. For some people, agencies and governments, it would appear that simply by brandishing subliminally attractive words such as “individualized”, “empowered”, “person focused”, “socially inclusive” or whatever, is enough to make people believe that the words are actually being lived as we might imagine them to be if they were to be done well”. Thus words, good intentions, rhetoric and simply changing from “block” funded services to Individualised Funding will not necessarily, of their own accord, bring people good lives. As Pat Fratangelo suggests, like a pilot without a map or vision, if you do not know where you are heading you cannot get back on course and will never get to your intended destination.

Therefore the question may be “what is it that we

would like Individualised Funding to achieve”? Is it simply self direction or is it more? Could it also be about citizenship, a good community life, living in one’s own home, security, freely given relationships/ friendships, valued roles, contribution etc. As Maureen McLeish states “Without a commitment to inclusion, individualised funding or Direct Payments would only be “dollars and cents” or “The Money” and as we all know, money doesn’t do the thinking for us.” And as Dean highlights “Yet, with all of the pros and cons of individualised funding or Direct Payments, I know money itself (on its own) will not bring me a good life. It certainly helps but without engaging friends, family, community, helpful professionals...to assist me to live in my own home and continue to work, my life would not be as rich”. In this regard if there are not creative supports to help people achieve a good life then “choice” of service may be ineffective, especially for people with complex needs and without families.

Money on its own or the mere individualisation of funding may bring much too many people. However it may not bring all that is hoped for unless we build capacity in people and families, know where we are going, think creatively, act with humility and honesty about what is actually being achieved and have the ability to enact and foster the lives that are hoped for. For example, last year I met a family whose son had individualised resources that equated to one to one support but he was locked in a room all day! In this man’s life, Individualisation of Funding was not all that was needed. Interestingly surrounding him and his family with people who think differently and maintain positive assumptions and visions, this gentleman is beginning to live the life that most of us take for granted. He is pursuing his passions in the community.

We would like to thank our first contributors to our first edition. We hope you enjoy reading our first issue.

Deb Rouget and the PLA Team

Useful links

Community Resource Unit’s CRU e-news 1, 2 & 3 ~ www.cru.org.au

Family Advocacy NSW ~ www.family-advocacy.com

Department of Human Services Victoria ~ www.dhs.vic.gov.au

Duncan Blackman (2007) paper on Individualised Funding ~

www.craconferences.com/resources/3/Individualized_Funding_Backgrounder_Dec07.doc

Professor Christine Bigby (2008) paper on How does the research inform the debate about individualised funding? www.scopevic.org.au/Bigby121107.pdf

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Keep your eye on the compass and Never, Never, Never give up

by Pat Fratangelo

As a pilot, I see flying a plane and developing services for a person in close comparison. If I want to fly to a specific destination I need a compass heading. I may have winds blowing me off course, I may hit turbulence, I may be redirected based on weather or other air traffic, I may also have a mechanical problem and need to land, but if I do not know my compass heading and cannot get back on course, I will never get to my intended destination.

This is so true when developing a support for a person or managing an agency that does personalised (individualised) services which authentically include people in the community. If you know the person and know what they need, then you know the destination that you need to arrive at. It may also happen that you hit some turbulence during the journey; you may have some starts and stops, but in the end, if you do not know where you need to land with this person, you will never get there. Remember this and you will always get to the right destination, because just any location is not the right place to be.

This is a stormy story of one agency, committed to personalised inclusive supports who understood its compass heading and the struggle that it went through to maintain it and ultimately survive. It may help others to realise what they can do when they are threatened. Our threat was to the potential end of personalised supports.

Systems are typically set up to serve the masses, and funding is then set up which is typically determined by program models. As a system learns about a program type, and more and more of the programs are developed, the government then begins to standardize the funding mechanism. If the model is a group home for 4 people, then the system begins to structure the amount of money and staff support that will be provided to that program model. Most organisations that serve people look to the government for fundable program models that they can develop and maintain. Once the model is determined, then people are found to fill the program type. Program models then begin to flourish, but the real question is, do the lives of those

within the program model prosper and are they at the right destination?

Onondaga Community Living (OCL) is private not for profit organisation in Syracuse, New York, USA that chose to walk down a different path that separated the people and the agency from predetermined outcomes and models, and instead developed services and supports that were personally driven by the individual who was in need of it and pursue options that were “typically” available to all citizens i.e to live in one’s own place with a range of supports rather than a group home. Over the last 20 years OCL has been successful in helping people with disabilities (including people with complex needs) to live lives of distinction based upon their personal needs and within a funding mechanism that allowed flexibility and individual costs reimbursements. Through the years, OCL has proven that that personalised services are maintainable, fundable and have helped to reduce behavioral problems and medications to those served. As people served began to live lives of greater value to him or her, each person became more at peace with him or herself and happier with their own life. OCL has also proven, that when all individual budgets are examined that the service is no more costly, when viewed collectively, than the cost of those living in a group home.

Most people have chosen to live typical and ordinary lives along side of typical community members, which has reduced the reliance on paid supports and has ultimately driven down the costs associated with each person. Regardless of need level, it has been found that a personalised approach is not only cost effective to the system, but it is also of huge social benefit to the person involved. As each person lives in more valued social roles as a true community citizen, a neighbor, a coworker and a friend they learn to value themselves more and all that they have. It is a win/win situation for both the system and the people served through the system.

Unfortunately, although the positive effects of personalised services are proven, the idea of this service type is not on the radar screen of most

organisations. The easier method of support typically is what has been traditionally established for the population to be served e.g. segregated programs and congregate care. The standardisation of funding and models typically prevails. When funding changes, it typically changes to meet the needs of the largest constituency. Those outside of the purview are typically ignored or extinguished. This is the dilemma that OCL met with is government.

OCL set up each person to have their specific service and budget, their own unique destination. Each was tailored to the specific need of the person who came for support. No two budgets were the same. No standardised staffing pattern emerged for a personalised support; each support system was designed specifically for the person involved. Early on the funders did not know what to do when budgets for one person services came in and they all had different staff supports and were all submitted for different dollar amounts. The early question by the government was “what are the staffing needs and the budget needs for a personalised support”? Hence, what is the standardisation for this program model or the agreed upon destination that all personalised supports would end at? Since each person’s story and their support needs were different, there could be no standardisation or common destination! Given that each person’s budget was not exorbitant, the government saw no reason not to approve each one. As the years went on personalised services and budgets continued for each and every person served at OCL.

But as the government began to feel the pressures of cost containment and of increased regulatory compliance, the cost base of how services were to be funded would change. Although the governmental words spoke of the preservation and expansion of innovative personalised supports, their funding mechanisms were targeted to move to regional averages for program types and all personalised budgets were to be extinguished. It was going to be a long hard battle for one small agency to maintain what had been established.

Early discussions between OCL and the government met dead ends. Financial analysis was prepared

to show how regional averages would impact personalised supports. Governmental staff came to OCL to have deeper discussions and to meet some of the people supported, each going to a separate household. One worker came back early from her visit. She had spent some time in the home of a person who had been institutionalised for the majority of her life, who now lives peacefully with an unpaid community member who lives there as her housemate. They live together in a comfortable home that they have mutually set up. When the governmental worker came back from her visit, her

comment was that the person she visited was very lucky. But later as each worker came back and we met together again to review the visits and the financial analysis, although each spoke of their amazement with what

they experienced and saw, their collective decision was that average regional rates would still work.

A national review of what happens to personalised services when personalised funding is jeopardised is that the services and the organisation are either extinguished, are consumed by other larger organisations or they begin grouping people together for cost containment. There was no example found of a personalised service nationally that survived the impact of regional standardised rates. An analysis of our own budgets showed that we would only be financially able to sustain ourselves for approximately two years and then would be out of business.

We continued discussions. More and more governmental people talked with us and visited. It was at this time also that the government came up with a new mission statement. The new mission talked about personalised services, innovative approaches, generic supports, welcoming family and friends. We proudly displayed the mission on our office wall as it spoke to the services that we were doing and believed in. As higher level governmental staff visited, their mission was recognized and as their words or actions opposed the words of their mission, attention was brought back to their duty to have their actions follow their publically written words.

Families also became concerned that their family member’s services would be jeopardised. They

‘It takes time, effort, consistency, strong advocacy, developing and nurturing relationships, developing allies and knowing your final destination that can get you through the tougher times.’

began to write letters and voice their concerns. Board members invited governmental staff to their meetings. The government then began discussing other various funding mechanisms but at closer look we found that each would impact negatively on our ability to provide services constantly to what a person had set up. The government was trying to help. The government was now in agreement that they not only wanted to preserve what they had seen, but they wanted to see more of services like this happen state wide. They began to see that by including community people in people's lives that costs could be contained or lessened. They began to realise the high costs of operating services for groups of people. Discussions now included what the government could do to make personalized services a more enticing option for agencies to partake in.

After months of discussions, a funding package was agreed upon that allowed personalised services to maintain personalised budgets and funding would now be based on a person's need, not the program model. A unique funding package was now being developed following the focus of self determination but setting it up in a way that was manageable from an organisational level. This was a huge step for the government to set up a funding mechanism that supported agencies in providing personalised supports. Currently we are on a one year pilot study to look closely at the impact on the services of each person, the work load of the agency and the financial

and regulatory implications for the government. The jury is still out on where it will all end.

Personalised services are just that, personalised, and based on the needs of each person. Everyone lives a dynamic life and lives often change, just as every flight I take does not always go in a straight smooth line. Personalised funding (and my flight plan) therefore needs to be flexible to meet the changing needs of the person's life without a lot of governmental involvement slowing down the natural processes of life. People with differing abilities are not so unlike the rest of the people in their community, they also crave to live normal and ordinary lives without a lot of bureaucratic involvement. It is strange that something so ordinary in our society is really extraordinary when you have a disability. Systems do not typically look at individual people or normal lifestyles, they look at the masses and system centered services.

It takes time, effort, consistency, strong advocacy, developing and nurturing relationships, developing allies and knowing your final destination that can get you through the tougher times. Some fights (and flights) are for survival. Not all will partake in these but if you do the rewards can be great. Miracles can and do happen when you keep your eye on the compass and never, never, never give up.

Pat Fratangelo has been the Executive Director of a not for profit agency called Onondaga Community Living (OCL) in Syracuse, New York, USA for the past 14 years. OCL originally provided traditional group home and congregate supports to people who have a disability. Pat has led OCL through a thoughtful and creative transition so that the agency provides uniquely tailored and personalised services and living arrangements to each person. She has seen remarkable changes in the lives of those supported as each person has been considered one person at a time. OCL has been recognised both state wide and nationally for their work in personalised directed services. Pat has been appointed by the New York State Government to sit on key committees in her state. Much of her work has been published both nationally and internationally. She is a co-author of a book called "One Person at a Time".

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Avoiding “disappointing people one at a time”: What can happen when one is inadequately person-centered

by Michael Kendrick

Like all mantras and incantations, words can be imbued with a magical quality depending upon what meanings we project onto them. For some people, agencies and governments, it would appear that simply by brandishing subliminally attractive words such as “individualised”, “empowered”, “person focused”, “socially inclusive” or whatever, is enough to make people believe that the words are actually being lived as we might imagine them to be if they were to be done well. Idealism of this kind can actually be inspiring because of the hopes it excites for what could someday be true in people’s lives. Nonetheless, there are good reasons to be careful about what we put our trust in or we may risk being much more than just heartbroken.

It begins with the frequent confusion that we can all have at times between a (lofty) goal and the deeds, qualities and commitments that are necessary if we are to come closer to that goal becoming a reality. Many may sincerely believe that they are achieving a goal, such as individualisation simply because they have good intentions in regards to it. In this respect, they confuse their favor of a desirable goal with their embodiment of it. This might be seen in the instance of people operating an unmistakably segregated program, but being convinced that somehow they are not doing so simply because they are enthusiastic about social inclusion or have technically “individualised” each person’s resources or funding. Invariably, they are unable to distinguish between valid and even admirable goals and how their daily conduct is actually a striking contradiction to their espoused values and goals.

It would be tempting to evaluate this kind of common self deceptive thinking as essentially being an individual character weakness, but this would miss the fact that it has significant ideological and cultural dimensions, given that human services are often unconsciously driven by both. To be more specific, we are now awash in claims of all kinds from agencies and governments, as well as individual

practitioners, that services are somehow already “person centered” or will become so through simply individualising resources. In reality, the truth will likely be considerably more modest in actual practice, at least as is measured by the specifics of what is actually happening or not in the lives of people with disabilities.

It is only when we intentionally resist the ever present temptation to see what we want to see in the world that we will discover we have the freedom to see the world as it actually may be. If we are to apply this to the current greatly exaggerated claims that today’s services are, in effect, entirely “person centered”, that we might better see that they probably fall short of such an ideal in countless ways that may even lead to the neglect of the person and their important needs. This is not the same as saying that they might, at the same time, still be an improvement on what had preceded them, as both things can be true.

What is important are both the misleading expectations that are created by our use of overblown and uncritical rhetoric or systems and the fact that undue belief in such magical thinking too often makes adherents unable to see how impoverished people lives actually remain despite our best efforts and intentions. We can be inadequately person centered even at times when we are doing better with the issue than we did in the past because it is inherently difficult to assure that human beings will be fulfilled in even small parts of their lives, quite apart from the seemingly comprehensive way that is suggested by naïve claims of holistic triumphs of “person centeredness”. Not surprisingly, when the walk and talk are at odds with each other, the person themselves will likely experience disappointment given that much is promised and less is delivered.

If one wants to escape from the fantasy utopian world of slogans and absurdly improbable claims, then the more desired direction would be to do the exact opposite. That is, that person centered

proponents should continue strongly favour personalised options, but understate wherever possible, the extent to which success has been achieved or, as many others have said, “under promise and over deliver”. In effect, to make your case with deeds not words and lead with results, not promises. The value in this is that the words and the deeds tend to line up better, thereby giving the proponent the credibility that comes with results that meet expectations, since the expectations have been more realistically portrayed from the outset. It also means that the person is not misled and the real accomplishments are properly noted, but are contextualized better in terms of those aspects of their lives that still remain a difficulty.

This approach allows there to be ample areas of people’s lives where it is forthrightly recognised that much remains to be done other than say the

individualisation of resources. Though this sounds like drawing attention to shortcomings, it may actually have the effect freeing the people involved people to see people’s lives, not as we might prefer them to be, but as they are. This outlook empowers people to then act to change these for the better rather than being blinded by ideology and wishfulness and thereby misunderstanding the person. Of course, from misunderstanding of this kind will come inadequate solutions. On the other hand, when we make deep efforts to understand our responses to people’s needs better, our actual successes is more likely??. Our words and deeds will have integrity and we will have the pleasure of being useful without the pretense of having to be as perfect as the rhetoric. Lastly, the good that is done is real which will mean that the benefits will speak for themselves.

Michael Kendrick is currently an independent consultant in human services and community work with a focus on both national and international work in the United States, Canada, Australia, New Zealand and the United Kingdom as well as other countries. He has a passionate interest in the provision of quality services to people with disabilities and other marginalised people. Michael, who is Canadian but now lives in the USA, has been a regular visitor to Australia over the past 16 years. With over 25 years of experience, he has made a very significant contribution to the field as an educator, consultant, and advocate.



His interests have included leadership, service quality, the creation of safeguards for vulnerable persons, social integration and community living, change, innovation, values, advocacy, the role of individual persons and small groups in creating advances, evaluation, alternatives to bureaucracy, personalised approaches to supporting people, and reform in the human service field amongst others. He is particularly interested in individualised service responses for people considered ‘difficult to serve’.

He has most consistently worked in the disability, mental health and aged care fields for nearly 30 years but has also worked in areas such as drug abuse, aboriginal affairs, child protection and community education. In this work he has occupied a variety of roles including being the Assistant Commissioner for Program Development with the Massachusetts government, the Director for the Institute for Leadership and Community Development and the Director of the Safeguards Project. He is very active as public speaker and trainer as well as evaluator, consultant, and advisor to advocates, governments, agencies and community groups. His masters and doctoral work were in social work and sociology respectively. He regularly teaches at various universities both here and abroad as time allows. He is a citizen of both Canada and the US who currently resides in Massachusetts. A listing of his various publications and the more usual training he offers is available at www.kendrickconsulting.org.

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A family's reflection on direct funding

by Maureen McLeish

Maureen McLeish has three children and two grand children. She and her husband, Murdoch live in Melbourne and have a small printing business. Lauren is 25 years old. Lauren has a mild physical and intellectual disability due to a stroke at birth. With the right supports, she is able to pursue her passion around film, movies and television in the community. Lauren is a volunteer usher at a theatre and television organisation in the City of Melbourne. She also helps out in their marketing department. She has a job at a local farmers market selling produce, is an avid Kangaroos Football Club supporter/member and member of a local gym. She pursues all of her aspirations and needs as other people do — in the community!



Lauren McLeish

Leaving school

When Lauren left school we were astonished at how few options there were that would assist her to get a good life in the community. We wanted her to have the same options as her older brother and sister, i.e. to learn, work, recreate, have friends and pursue her own aspirations in the community. The only options that seemed to be available, given that she had support needs due to her disability, either segregated her from community life into a “special” program or meant she would have to spend all of her time with other people with a disability. This was not what we wanted as a family - nor did Lauren.

Thinking about a good life in the community

Our family has been encouraged to think about real community inclusion through being involved with a range of people and families who share similar values. This has been possible through Personalised Lifestyle Assistance (PLA), by being a part of a small family governed group called One By One in the past, Community Resource Unit in Queensland and many others. The principles of these groups are formulated around inclusive lives for people with disabilities and it has been those principles that have given our family the confidence to know we are on the right track in trying to find a typical life for our daughter.

Without a commitment to inclusion, individualised funding or Direct Payments would only be “dollars and cents” or “The Money” and as we all know, money doesn't do the thinking for us. My family's

commitment to inclusion has led us to head our daughter's plan for her life with the words. — “Getting a good life in the community”—this is the main focus for our daughter.

Direct payments

The move onto Direct Payments has been the next step for our family as we encourage her to become more independent and to assist her to manage her own life. The Victorian Department of Human Services (DHS) offers Direct Payments as an option in which a person with a disability (or nominated person) can choose to have their funding for disability supports paid directly to them. They are then able to choose, arrange and purchase the supports required to meet the goals they have identified in their individual plan. This approach aims to give people with a disability greater independence, choice, control and flexibility over their supports and how and when they are delivered.

In the past, many funding arrangements have happened without proper consultation with the person receiving the funds. In some cases once the funding had been approved the funds were either held by the DHS or sent to a service provider, such as a day service and people did not know how much funding they were entitled to or how much their support costed. With Individual Support Package Funding people now know how much funding they are getting.

How direct payments work for our family

In consultation with DHS we opened a new bank account and the department put our daughter's funds into that account on a monthly basis. We have two cards to access and pay the bills and our daughter can pay for things as she needs to. An example of this would be her community hydrotherapy class or gym program. She attends the class, pays the account with her card and just puts the receipt in a file. This has been a very empowering shift for her as she, with some support, is not only becoming aware of her funding but controlling it. Given her intellectual disability, this was something we thought would never be possible. It also reduces the accounts we need to pay. From our perspective it has not been a time consuming or difficult process and although we have increased direct accountability and responsibility by acquitting funds we can see exactly to the cent how much money is being spent supporting our daughter. She can spend every cent of her funds on achieving her lifestyle goals in the community that we set out in her plan.

With Direct Payments people hold the funds and this makes a big difference when talking to service providers about the kinds of services you want. You can approach service providers more specifically, ensuring that the service they offer is exactly what you need for good support.

With other families we are currently working with DHS on "The Direct Employment Project". This

will enable a trial of Direct Payments users either employing staff directly or establishing a legal entity such as a company, cooperative or association to employ staff. It is another way of people having more say and control over supports.

Some cautions

After going to Canada on a family leadership program recently, I remember almost gasping! As I heard that many people had used Direct Payments to purchase congregate care or segregated programs. Families who had once had control, who chose such services, were then convinced by service providers that it would be far easier if the money came directly to them rather than the person or family!

Conclusion

If our vision is to create good community lives for our sons and daughters then we must realise that people and families, after years of professionals and others telling them that they need "special" programs, work or friends, may need assistance to strengthen their thinking about community. Being in touch with likeminded people and investment in our capacity to "think" about community has helped us on our journey. I'm forever mindful that money alone does not always buy a good life, although it can be an excellent tool to assist in getting a good life if one needs support.

*"Our thoughts are a magic part of us and
they carry us to the places
that have no boundaries and no limitations"*



Wayne Dyer

My experience with Direct Payments

by Dean Richards

Dean Richards lives in Melbourne. He has a job and is an active contributor to his local footy club. He has been involved in the disability movement for about seven years. Dean's introduction to disability services came following an accident in 1987 which resulted in quadriplegia. He was to learn that services were not always flexible enough to meet his needs and his family was becoming increasingly worried about the day when they would no longer be around to support him. This led to Dean working with a small group of people in the Southern region of Melbourne to plan and create a flexible night time service that would assist people with disabilities.



Nightlife started in 2007 and has provided assistance to people mainly with physical disabilities so that they can remain living in their own homes. The service maintains strong life giving ethics and is consumer governed. It has helped to provide a sense of security to people with a disability and to their families as well as assisting individuals to live a more inclusive lifestyle. It has also decreased the dependence on aging parents, partners and siblings from the need to assist loved ones. In 2005 Dean, through further frustration, explored Direct Payments with the Victorian Department of Human Services (DHS) as a new mechanism to individualised funded supports. He started using Direct Payments in 2006 which has completely changed the way his support is administrated.

I did not receive compensation from my accident. As a result the only way I could return home (where I still reside) after being discharged from hospital was with the assistance of my parents. The alternatives were grim – either a group home or nursing home.

My parents provided all my care on my return for about 4 years. In 1992, I received 24 hours of support per week through an individualised support package called Home First. The DHS would forward the money for my care to a service provider.

In the early stages the service provider would advertise in local papers with me as the contact. I would then screen callers, arrange interviews and choose the applicant(s). I would then forward their details onto the service provider. I would also coordinate in-house training (shadow shifts) and rosters. The service provider would also arrange some internal training in their offices.

This worked well for several years and gave me control of when and how support was provided. It also reduced the dependency on

my parents, who are aging, to provide all of my care. However, my funding didn't cover all my needs but covered most personal care. Around 2002 the service provider I used had a change in policy. My coordinator was now controlling employment. I found they didn't understand my needs and would send people that were not suitable. I felt they no longer knew me as an individual or my needs.

I have always kept records of hours used and banked. I also started having issues getting statements on hours used/banked and when I did they were wrong. Reconciling accounts was difficult and time consuming. I found the work to manage my assistance and corresponding with my service provider was taking up more and more time. I also felt that all the work I was doing was for no reward. I was also paying the full unit cost to the service provider and they were not delivering on what they were funded for.

In 2006, I started using Direct Payments. Through Direct Payments I have taken control of how my support is performed and administrated.

I now use a different service provider and they, through agreement, take responsibility for payroll, OH&S and Workcover. I have an agreed service fee for their assistance. This has meant I'm now solely responsible for advertising and recruiting of staff. I'm also responsible for the quality of my own support, rostering and filling vacant shifts and completing and delivering of timesheets for staff.

Direct Payments has given me more control and flexibility. For example, it has meant that I can now stretch my funding to cover more hours. I can also use the funding for other services such as house cleaning. This has provided me with a feeling of contributing to the house and gives my parents a break.

I'm required to submit a funding plan outlining goals on initiation and annually. This plan is based on my needs and outlines what I use my funding for. I have created spreadsheets to keep track of expenses and it takes approximately an hour to an hour and half per week to keep track of incoming and outgoing expenses.

Direct Payments has enabled me to have more control on how the funding is used so that it is relevant to my life. I can also now choose different options e.g. support, recreation and pursuing a good community life. It also ensures that services are accountable to me.

However, with such advantages comes some extra work. It took a lot of effort to initially set up Direct Payments (to set-up bank accounts and alike). I have to keep detailed records of all money spent. Unlike Home First I'm required to submit a funding plan each year. This does take time and effort. I now have the responsibility of the buck stopping with me (if shifts aren't filled it's my problem). I also have to think about what sort of life I want.

Yet, with all of the pros and cons of individualised funding or Direct Payments, I know money itself (on its own) will not bring me a good life. It certainly helps but without engaging friends, family, community, helpful professionals and flexible additional services such as Nightlife to assist me to live in my own home and continue to work, my life would not be as rich.

It also seems that I need to remain vigilant as many people and professionals assume congregate care is the only way to meet the needs of people with quadriplegia, especially for those who don't have families. This is an option that I work tirelessly to avoid and hence my involvement in community and efforts that empower people with a disability to equality of choice and options that are available to all other citizens.

*“ We are not what we think,
or what we say,
or how we feel.
We are what we DO.”*



Gordon Livingstone

Individualised funding: Renewal or continued decline

by Bruce Uditsky

Bruce Uditsky, M.Ed., is the Chief Executive Officer of the Alberta Association for Community Living (AACL) and an Adjunct Professor, Community Rehabilitation and Disability Studies, Faculty of Medicine, University of Calgary. He has been invited to speak and consult on a wide variety of disability practice and research issues in Canada, United States, Mexico, Australia, New Zealand and Europe.

Bruce is also the author and co-author of numerous writings on community inclusion and social justice. He has been recognised for his public advocacy on behalf of people with disabilities and their families as the recipient of a number of awards. He is the father of two sons, one of whom has intellectual disabilities.

Alberta Association of Community Living website: www.aacl.org



Some years ago I wrote about individualised funding as a means of empowering families to develop creative supports for adults with developmental disabilities and how this funding is being eroded.

Individualised funds or direct funding are funds given directly to families to enable them to purchase the supports they require for their adult son or daughter. It began in Alberta about 20 years ago when families who had adult sons and daughters with developmental disabilities could not get the quality supports they required. Having direct funding from government enabled these families to be creative and individualised.

Until recently Alberta had the most extensive individualised funding program in the world. Thousands of families were able to use their funding to either contract for needed services from agencies and/or hire their own staff. Individualised funding provided Alberta families with choices that were the envy of families across Canada and most of the globe.

Initially individualised funding enabled many families to create individualised and personalised support for their sons and daughters. Over time, however, individualised funding became more complex to administer and many families did not

have the knowledge or means to apply this type of funding in the personalised and innovative ways that were possible. There were very few resources to assist families in thinking creatively or in managing the complexity of individualised funding. As a consequence, the vast majority of families simply purchased the very same agency services funded directly by government and in turn, rather than administer their individualised funding, had their funding payments go directly to an agency.

Only a minority of families hired their own staff or continued to administer their funds as a means of attempting to ensure quality and accountability. Today there are many families who do not even know if they have individualised funding and therefore don't know how to use this funding to their advantage.

In response to these developments and given the interest of AACL, government, and service providers in wanting families to have choices within a coherent funding framework, a new funding model that would enhance individualised funding and family choices was developed collaboratively and approved by Persons with Developmental Disabilities (PDD), but never fully implemented. Today Alberta stands on the cusp in either ensuring individualised funding remains a viable funding choice for many thousands of families, or one only available to a few.

Some positive steps include the support from PDD in partnering with AACL to pilot the development of new resources to assist families in better using individualised funding. Resources to help with the practical matters of recruiting and training staff, to helping families with strategies for increasing community inclusion. Community inclusion, natural supports and generic community resources are becoming increasingly important given the workforce challenges in Alberta.

If you have individualised funding today it is possible in the near future you will be asked if you would like to continue with that choice. If you currently do not have individualised funding, you

might want to learn if this funding option would work best for your son or daughter. If you are a parent of a child with developmental disabilities you need to become involved or there is a risk this funding option will no longer be readily available when your son or daughter becomes an adult.

If you would like more information on the potential benefits of individualised funding as well as the challenges or the new resources being developed to empower and support families, please contact AACL. It is time for families to become informed and knowledgeable about their funding options or we risk seeing the further decline of individualised funding.

*“You are unique, and if that is not fulfilled,
then something has been lost”*



Martha Graham

Community Vision Building for Families and Individuals

Weekend Retreat at Rutherglen

4–6 September 2009

This Retreat and introductory day will assist families to:

- Explore the importance of fundamental needs and personal fulfilment
- Build community relationships and valued roles
- Establish their natural authority enabling empowerment
- Build safeguards into their lifestyle
- Discuss, plan and pursue 'typical' pathways

This is an exciting opportunity for families who are interested in assisting their family member with a disability to plan for and pursue personalised lifestyle options that include natural pathways, valued roles and contribution to the community.

It also aims to provide a place where individuals and families who share a strong interest in community inclusion and individually tailored and meaningful lives can come together in mutual support and exchange.

This weekend has been developed in response to families who have not found congregate, group, segregated or 'specialised' services suitable to the needs and aspirations of their family member with a disability.

Speakers include: Jeremy Ward, Deb Rouget, Sally Richards

Venue: Tuileries Winery, 13-35 Drummond St, Rutherglen, Victoria ~ www.tuileriesrutherglen.com

Cost: \$130 (incl GST) per person

Presented by: Personalised Lifestyle Assistance (PLA) and Family Leadership and You (FLY).

PLA is a small Melbourne advisory service built around key values of inclusion, personalised arrangements and empowerment of individuals with disabilities and their families.

FLY is a Canberra based support group supporting families with disability.

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