

## *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 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 (<http://www.aacl.org>).*