

# **REPORT ON THE FIRST INTERNATIONAL CONFERENCE ON SELF-DETERMINATION & INDIVIDUALIZED FUNDING**

**Seattle, July 29-31, 2000**

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## **Conference Vision**

***Self-determination*** and ***individualized funding*** have become focal points for the worldwide disability movement. Individualized funding is now recognized as a fundamental requirement for the meaningful exercise of personal choice (i.e. self-determination) because it enables people to purchase and therefore gain control over the supports needed to enjoy meaningful lives in the community. Throughout the world, most notably in the USA, Canada and the United Kingdom, numerous projects using individualized funding are underway in response to the lobbying efforts of people with disabilities (and their supporters) seeking full citizenship rights and opportunities.

With these developments in mind, conference organizers sought to provide a forum for people from different countries where they could 1) share the experiences and lessons they are learning from programs, demonstration projects and research initiatives now underway; 2) discuss critical political, policy and implementation issues; 3) participate in consensus building activities designed to develop a shared view of the fundamental principles and critical components of individualized funding and self-determination; and 4) build collaborative partnerships.

The conference attracted 1260 people from 22 countries and regions, with representation from a wide range of disability groups, different levels of governments, human service professions, academic institutions and service providers. There were 70 general sessions, 5 pre conference sessions and 146 speakers. Almost every session included a person with a disability, family member or other advocate.

## **Guiding principles**

Three principles shaped the program design and the style of presentations and discussions.

### ***i) accessible and inclusive***

Organizers not only wanted users of support services to actively participate in the sessions, they wanted them to often take the lead. At a minimum, speakers were asked to provide opportunities for people with disabilities to respond to presentations. Speakers were also requested to avoid difficult language and jargon. Where a topic's complexity made accessibility difficult, presenters were asked to produce plain language summaries of their remarks. It was hoped that this would assist people who were unfamiliar with a topic to still make a contribution. Handouts were available in a variety of accessible formats, and foreign language interpreters were available in some sessions.

### **ii) International**

Clearly, people in many countries have started to develop new ways of organizing personal support based on the mechanism of individualized funding. It is equally clear that people use

different words to describe these arrangements, and have differing views of what they are working to achieve. For some the key word is 'self-determination', for other it is 'citizenship' or 'rights'. To respect these different traditions, everyone was encouraged to look beyond mere differences in words, in search of the *real* similarities and differences between developments in different places, and the lessons that could be learned from each other.

### **iii) Searching for Consensus**

It is exciting that many individualized funding programs are now operating or being planned. However, there is a risk that the real aim – self-determination and citizenship for all - will be forgotten, and that programs claiming to use individualized funding will really be no improvement on the systems which now operate. In the hope of keeping these initiatives 'on track', a process was developed by Steve Dowson (Co-chair, Program Planning Committee) to draw up and announce a *Declaration* that would identify a set of principles to guide how stakeholders across programs, groups, states and nations might think about and implement individualized funding in the future.

Since it seemed unlikely that agreement could be reached at a large conference on the ideas for a Declaration without help, three small working groups were identified. The members of these groups were called *Prospectors* because, like people sieving a stream for grains of gold, they engaged in a search for the grains of truth that needed to go into the Declaration. They did this by making presentations and receiving feedback, attending sessions and listening, and seeking out conference participants to get their views.

While members of the Prospector Groups took on the task of writing the *Declaration*, organizers wanted the process to be democratic and to accurately reflect participants' ideas. For this reason, people were encouraged to: 1) record their views on special poster boards; 2) comment on the ideas of the Prospectors and fellow attendees that were also on display; 3) speak directly with a Prospector; 4) suggest to a session moderator that any important points by presenters or developed from discussion, be sent as a message from the session to the Prospectors; and 5) attend one of three formal feedback sessions where Prospector Groups offered their draft Declaration statements for discussion.

The outcome of all of the hard work of the Prospectors and those who attended the conference was presented at the closing plenary as the . . .

## **THE SEATTLE 2000 DECLARATION ON SELF-DETERMINATION & INDIVIDUALIZED FUNDING**

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### **PREMABLE**

This conference has been founded on the certainty that people with disabilities have the same rights as other citizens to freedom, equality, equal protection under the law, and control over their own lives. These rights must be honored if people who have disabilities are to be fully included as valued citizens in the relationships and opportunities of community life.

Many people require personal supports or other services to ensure their full citizenship and inclusion. These supports and services must be funded and provided at a level and in ways that uphold the rights of the individual.

This conference is no less certain that these rights have often been disregarded. Citizens who have disabilities experience oppression in many aspects of their lives. The causes of oppression include poverty, other people's attitudes, and the systems of publicly and privately funded support services, comprising –

- laws, policies and regulations;
- state and private sector funding bodies;
- agencies which provide services.

These systems operate in ways that deny control to those they are intended to serve. Without accountability to those who require their assistance, these systems decide how, where and with whom people shall live and spend their days. While this situation persists, people of many nations will not be able to exercise their rights or fully participate in their communities. For these reasons, this conference calls on policy makers in all countries, at all levels of government, and on agencies which provide support, to ensure that the assistance made available to all citizens is based on the following principles:

### **SELF-DETERMINATION: FOUNDING PRINCIPLES**

- 1 Self-determination for people with disabilities must be the founding principle of public policy.
- 2 Legislation to promote self-determination or individualized funding must be grounded in the principles of human rights and social justice.
- 3 Self-determination is a birthright which must be upheld by government. It is not a commodity to be delivered by services.
- 4 All people, including individuals with disabilities, have rights and responsibilities to live as full citizens. The barriers that stand in the way must be eliminated.
- 5 The development and implementation of policy must take account of the interdependence of the individual; others with disabilities; the community; and government.
- 6 Policy and practice must acknowledge and honor risk-taking as an essential element of self-determination and an important part of life.
- 7 Demands that individual self-determination should only be allowed when certain standards are met must be rejected.
- 8 The many contributions made by people with disabilities, which include innovation, problem-solving, improvements in accessibility, and other contributions to humanity, must be recognized.

### **ACTION REQUIRED TO SUPPORT SELF-DETERMINATION**

- 9 People with disabilities speak from personal experience, and so with authority and expertise. Their views should be valued, and not regarded as having less importance than those of professionals.

- 10 People with disabilities and their families must be present and central at all planning and decision-making tables in policy development.
- 11 Citizens with disabilities and their supporting networks and organizations must be in charge of developing and promoting public policy which is related to the provision of supports.
- 12 Policy must be designed and implemented to ensure the inclusion of people who are at the risk of exclusion or disadvantage on the basis of ethnicity, culture, gender, race, religion, sexual orientation or other grounds.
- 13 Negative, entrenched attitudes, both within and beyond services for citizens with disabilities, must be addressed.
- 14 An understanding of disability as a consequence of society's organisation and other people's attitudes (the 'social model') rather than the inevitable result of the individual's impairment (the 'medical model') must be promoted.
- 15 Other citizens must be encouraged and educated to recognize that people with disabilities are entitled to access, accommodation and supports; and that individualized funding is the best way to target supports that meet peoples' needs.
- 16 Governments must require that public funding is used to create systems which support self-determination. Such systems will be characterised by innovation, a focus on results, and employ people with disabilities and their families.

#### **INDIVIDUALIZED FUNDING: GUIDING PRINCIPLES**

- 17 Individualized funding arrangements must allow for flexible practice within consistent guiding principles.
- 18 Individualized funding and planning systems must be flexible and responsive to the culture, values and preferences of each person and their family.
- 19 People must not be required to give up their right to acquire income and personal assets in order to access public funding for disability supports.
- 20 There must be universal access to funding and support, within a range of individual need which must be defined through a collaborative process.
- 21 Individual funding systems must include arrangements to provide assistance, where required, in the management of funding and supports, and not limit eligibility on the basis of judgements of 'capacity'.
- 22 The design of individualized funding systems must reflect the reasonable assumption that recipients are trustworthy.
- 23 Individualized funding must be recognized as a means to honor people's vision for the future.
- 24 Individualized funding must be recognized for its value as an investment in people and communities.

## **INDIVIDUALIZED FUNDING: PRINCIPLES FOR IMPLEMENTATION**

- 25 The funding allocated to each person should be based on their individual need, not on pre-defined and arbitrary limits.
- 26 Individuals must be free to pay the providers of their choice, including family members.
- 27 Individuals must have full control over their supports, including the planning of supports, and choosing and directing their support providers.
- 28 People must have a choice of budgetary and administrative support services to assist them in using and tracking their individualized funding.
- 29 People must be given the opportunity and support to explore options and make their own choices of sources for forms of assistance such as brokerage, advocacy, and peer support.
- 30 Service providers and agencies must be encouraged to endorse and apply the principles of self-determination and individualized funding; and, in an expanded organizational role, to deliver supports that minimize dependency and strengthen partnerships with the larger community to address barriers to freedom and opportunity.
- 31 Individualized funding systems, support services, and technical assistance services must be designed and provided so as to ensure that their forms of communication, physical and environmental characteristics, and overall quality do not undermine their accessibility.
- 32 Individualized funding arrangements must be straightforward and easily understood by everyone.
- 33 Action must be taken to encourage the recruitment and employment of people with disabilities in the administration of individualized funding systems.

## **INDIVIDUALIZED FUNDING: EVALUATION**

- 34 When the success of Individualized Funding is assessed, the evaluation must take due account of the improvements in quality of life, and in particular the extent to which personal choice, control and sense of belonging are enhanced.
- 35 When proposed or implemented individualized funding systems are compared with block-funded services, it must be recognized that block-funded services have not been generally successful, either in terms of the efficient use of public funds, or in the quality of life provided to the people who received the services.

## Contributors to the Development of the Seattle 2000 Declaration

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If you want more information about the conference (e.g. the program, list of speakers, etc.) please visit the Seattle 2000 Declaration Website: <http://members.home.net/directfunding>