



**Coming of Age:  
Securing Positive Futures for  
Seniors with Intellectual  
Disabilities**

**Outcomes of the  
*Coming of Age* Dialogue  
Winnipeg, Manitoba  
April 29 – May 1, 2004**

**— Final Report —  
L'Institut Roehrer Institute**

**Written by  
Cameron Crawford  
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***“To plan for our future when we can’t plan for our today is a VERY difficult task!!!” – A self-advocate who participated in the dialogue***

## **Executive Summary**

This report documents the outcomes of the international *Coming of Age* dialogue that was held in Winnipeg, Manitoba, from April 29 to May 1, 2004. The purpose of the dialogue was to create opportunities for stakeholders in the aging of people with intellectual disabilities to meet with one another, share experiences and ideas and lay the basis for action plans to address present and future needs in this area. The event was attended by 240 participants from every province and territory in Canada and by distinguished speakers from Canada and the US. Participants included self-advocates with intellectual disabilities, family members, service providers and government officials.

*Coming of Age* was a working session at which participants explored and articulated:

- Their vision for the futures of aging people with intellectual disabilities;
- The social context of aging and intellectual disability, with a focus on positive developments that can be built upon in efforts to achieve the vision, and key challenges and barriers that need to be addressed;
- Principles to guide movement forward;
- Specific actions to be taken and measures that need to be put in place;
- Potential allies to engage in collaborative efforts;
- What stakeholders need from one another – self advocates, families and service providers – in order to move forward effectively together.

In terms of broad vision, participants want a future in which aging people with intellectual disabilities have personal control over their own lives, make everyday choices and are in good physical and mental health. It would be a future in which people are embedded in unpaid, reciprocal and respectful relationships with friends, family members, intimate others and community members more broadly. Aging people with intellectual disabilities would be safe and secure while taking ordinary risks that most people take for granted. It is a future in which people with intellectual disabilities would have decent, affordable homes and supports to meet their lifestyle and disability-specific needs. It is a future in which people have meaningful leisure and creative activities in their senior years, opportunities to continue learning, the supports needed to participate in welcoming communities, the finances needed for basic security and for some the “extras” that make life pleasant and enjoyable. It is also a future in which people meet the end of life well supported by knowledgeable, trusted others.

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The families, friends and trusted others of people with intellectual disabilities are integral to this vision, as are welcoming and supportive communities. In fact, these are so central that measures needed to foster them require major attention. Also needing attention are measures to foster positive societal values, as well as sound public policy and adequate, responsive social services.

Participants identified many positive developments that can be built upon, as well as new measures, for achieving the vision at the level of individuals with intellectual disabilities, family and friendships, the community and society more broadly. Participants also identified many things that they could do for and with one another to bring about positive futures for aging people with intellectual disabilities. Key among these is to make issues of aging and intellectual disability more accessible through better, straightforward information about the aging process. More and better professional training, and accessible information about the services and training that are available are needed as well.

Also needed is a new kind of working relationship between families, self-advocates and service providers. The new approach would be based on openness, collaboration, ongoing dialogue and common vision tempered by common sense. The new approach would take stock of what self-advocates want, the fears, experiences, knowledge and hopes of families and the constraints of services. It would be based in a common vision, common language and friendlier ways of working together to do things *with* people with intellectual disabilities as they get older, instead of doing things *for* them, as has often happened in the past.

Participants expressed keen interest in coming together within two years to continue the national dialogue and collaboration.

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## I. Introduction

### A. The *Coming of Age* Dialogue

This is a report of the proceedings of the *Coming of Age* dialogue, an international session on the aging of people with intellectual disabilities. The dialogue took place April 29 to May 1, 2004 in Winnipeg, Manitoba.

The purpose of the dialogue was to create opportunities for stakeholders in issues of aging and intellectual disability to meet with one another, share experiences and ideas and lay the basis for action plans to address present and future needs in this area.

The dialogue was sponsored by Winnserv, Inc. Winnserv is a non-profit organization providing services to people with intellectual disabilities in Winnipeg. It has been in operation for 26 years and is one of the largest agencies of this type in the Manitoba.

Planning partners were:

- Association for Community Living – Interlake
- Association for Community Living – Winnipeg
- Continuity Care
- Creative Retirement Manitoba
- Department of Family Services – Manitoba
- Disability and Community Support Program, Red River College
- People First Canada
- The Roeher Institute
- Shalom Residences
- St. Amant Centre
- W.A.S.O.

Funding partners were:

- Human Resources Development Canada
- Department of Family Services – Manitoba
- Winnipeg Regional Health Authority
- Association for Community Living – Manitoba
- Jewish Foundation of Manitoba
- Winnserv Foundation

The dialogue involved 240 participants from every province and territory in Canada. Participants included self-advocates<sup>1</sup>, family members of people with

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<sup>1</sup> I.e., people with intellectual disabilities.

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intellectual disabilities, service providers and government officials. Most participants were from Manitoba and Ontario. As well, distinguished speakers from Canada and the US participated.

The first and second days of the dialogue opened with the plenary presentations, “Getting the Context Clear” and “Imagining and Defining Better”, respectively.

On the first day, speakers presented information and analysis on a range of issues in concurrent sessions, during which participants had time to discuss key concerns. Presentations and discussions centred on the following topics in these streams:

- Making Choices as We Age (self-advocates stream, all day)
- Tools for Securing the Future (families stream, all day)
- Services Perspectives (services stream, morning)
- Making Agencies Dementia Capable (services stream, morning)
- Love Lost, Love Found (services stream, morning)
- A Change of Pace: Creative Options for a Satisfying Life (services stream, afternoon)
- Preparing Agencies to be “Aging Health Ready” (services stream, afternoon)
- Alzheimer’s – A Panel Perspective (services stream, afternoon)

On the second day, issues that were flagged on the first were explored in further detail in “hot topic” discussion groups that were flexibly structured according to the following topics and streams:

- Our Issues and Best Thinking (self advocates)
- Actions, Supports and Planning to Secure the Future (families)
- Preparing Staff for What Comes Next (Services)
- Critically Evaluating the Use of “Generic Services for Seniors” (services)
- Death and Dying, Life and Living (services)
- Square Peg – Round Hole (services)

In the “hot topic” discussions, participants brought to the foreground elements of their vision for the positive futures of people with intellectual disabilities as they get older. Participants identified promising developments that can be built upon and key challenges and barriers that need to be addressed in advancing the vision. Participants also suggested principles for guiding movement forward.

In the late afternoon of the second day, participants were invited to attend an optional design session, to map out key themes and issues that had been identified so far and that would be further explored on the final day of the dialogue. About forty people attended the design session.

On the final day of the dialogue, participants focused on actions and measures that are needed to advance the vision and considered potential allies

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to engage in collaborative efforts. They also shared in a plenary, interactive discussion what each needed from one another – self advocates, families and service providers – in order to move forward effectively together.

The present report provides a summary of the discussions that took place across all three days of the dialogue.

Cameron Crawford, President of The Roeher Institute, wrote the present report, assisted in shaping the design of the dialogue and was lead facilitator on the final day. Janet Forbes, Pat Golding, John Leggat, Judith McGill, Bill Forman and Debbie Taillefer played important roles in summarizing the discussions in each of the dialogue sessions so that the information could be incorporated within the present report. Marsha Dozar played a major role in organizing the dialogue and helped summarize the plenary discussions on the final day.

Thanks are also extended to Leslie Udell, Nancy Hughes, Peter Park, Shelley Raittai, Debbie O'Donnell, Cheryl Martens, Dale Kendall, Moira Graeham, Kim McIntyre Leighton, Nancy Rother, Jack Styan and Shelagh Balfour.

## **B. The Present Report**

The structure of the present report follows the general flow of the discussions:

- Vision for the futures of aging people with intellectual disabilities;
- Social context of aging and intellectual disability, with a focus on positive developments that can be built upon in efforts to achieve the vision and key challenges and barriers that need to be addressed;
- Principles to guide movement forward;
- Specific actions to be taken and measures that need to be put in place;
- Potential allies to engage in collaborative efforts;
- What stakeholders need from one another – self advocates, families and service providers – in order to move forward effectively together.

Participants' discussions moved across several levels of analysis and concern. These were:

- Individuals with intellectual disabilities;
- Families, friends and trusted others;
- Communities; and
- Society at large and social systems.

At each level several sub-themes emerged.

*Sub-themes for individuals were:*

- Personal goals, self-determination, choices and control

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- Physical health and well-being
  - Mental/emotional well-being
  - Relationships
  - Safety and security
  - Home
  - Leisure activities, creative outlets
  - Ongoing learning
  - Participation in the community
  - End-of-life issues
  - Finances
  - Supports for inclusion, participation and well-being

*Sub-themes for families, friends and trusted others were:*

- Their ongoing involvement
- Issues of status and respect

The *discussions on community* tended to revolve around community capacity development and engagement.

*Sub-themes for society and systems were:*

- Attitudes and values
- Policy commitments
- Programs and resources

The present report organizes key points according to the major levels of analysis and sub-themes.

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## II. Vision for the Future

On the second day of the dialogue, having listened to presentations and discussed key issues on the first, participants were asked to take a step back and talk about their vision for the futures of aging people with intellectual disabilities. The following is a summary of key points that emerged from the discussions.

### A. Individuals

#### 1. Personal goals, self-determination, choices and control

- People have the right to determine the course of their own lives, with supports (funding, personal and other) to exercise that right (supported autonomy). People and structures around people with intellectual disabilities listen and respond to this vision.
- People have imagined their dream house and the people they'd like to live with... or whether they'd prefer to live alone.
- People are making choices about...
  - What to eat.
  - What to wear.
  - What TV show to watch.
  - How to spend their money.
  - What time to go to bed.
  - What to do in their free time.
  - Who to call on the phone.
  - What type of exercise to do and when to do it.
  - What to do on their day off.

#### 2. Physical health and well-being

- People are in good health.

#### 3. Mental/emotional well-being

- People feel productive (e.g., through paid employment) so that, at the end of the day, they feel that they have contributed something to others.

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- Specialized programs are in place as needed in the community; institutions are not resorted to for people living with dementia or other complex needs.
  - The care needs of people with dementia are geared to their particular stage of dementia.

#### **4. Relationships**

- A range of unpaid, reciprocal relationships are in place that involve neighbours, friends, family members, intimate others and citizens more broadly.
- People are in relationships with friends and workers who they can count on, feel safe with and can trust. These people continue to be involved over the long term (continuity of relationships).
- People with intellectual disabilities have others to speak on their behalf if they can't speak for themselves.
- People are heard and have chances to identify with others who have similar stories.
- People have friends...
  - To talk with about things.
  - To go places with.
  - To do things for one another.

#### **5. Safety and security**

- Aging people with intellectual disabilities feel safe and secure in the context of having a personal vision and being able to exercise self-determination, choice and control in their own lives (reasonable risk-taking).

#### **6. Home**

- People have options to live in a variety of places, with the supports they need.
- People live in their own home that is pleasant, where there is stability, which is suited to their needs and interests, where

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housemates (if any) know them and like them, and where they have autonomy.

- People have access to affordable supportive housing.

## **7. Leisure activities, creative outlets**

- People are involved in meaningful activities, i.e., something to keep them going and to give purpose in life; interesting challenges and passions, and the support needed to pursue them.
- People have a clear leisure identity that includes others who share similar interests.

## **8. Ongoing learning**

- People are involved in lifelong learning, e.g., “stuff that is practical”; creative retirement learning.

## **9. Participation in the community**

- People are involved in their communities as vibrant, contributing and valued members.
- People have chances to give back through volunteering and other activities.

## **10. End-of-life issues**

- People stand for the dignity of dying.
- There is recognition that “human life is sacred and that every death is the loss of a universe.”
- People are supported at home for as long as it is good for them to be living there.
- Trusted others are present and involved as long as the individual wants and needs this.

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- People with intellectual disabilities' grieving is welcomed, respected and supported.

## **11. Finances**

- People have the financial security for basic needs – a decent place to live, nutritious food, clothing, transportation, telephone, utilities, furniture, discretionary income, etc.
- People have the financial security to do little extras, e.g., go out for a nice dinner once and a while, pay for the extras that families are presently paying for.

## **12. Supports for inclusion, participation and well-being**

- Relevant supports are available and accessible (e.g., community supports, disability-specific supports, home modifications/renovations).
- There is good support for future planning, both for short-term emergencies and for longer-term needs.
- People with responsibilities for planning and support are continually exploring diverse avenues of support.
- There is recognition of each person's uniqueness and supports are tailored to enable/support the life and lifestyle uniquely suited to them.

## **B. Families, Friends and Trusted Others**

### **1. Ongoing involvement**

- Families (parents and extended family) and friends maintain their involvement in the lives of people with intellectual disabilities, and have the support (e.g., peer support from other families, cash, tax breaks, respite/relief, support for grieving and loss) that they need.

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## **2. Status and respect**

- Families and/or unpaid caring persons have significant say in decision-making and support arrangements concerning people who cannot speak for themselves.
- Families and unpaid carers are not dominated or controlled by service providers or governments.

## **C. Community**

### **1. Community capacity development and engagement**

- Community members value and see a meaningful and rewarding role for themselves in the lives of people with intellectual disabilities.
- Communities are welcoming and supportive of the involvement and participation of seniors with intellectual disabilities.
- Relationship building between people with intellectual disabilities and members of the community at large is a regular part of service providers' work.

## **D. Society and Systems**

### **1. Attitudes and values**

- Negative stereotypes about aging people with intellectual disabilities have been dispelled.

### **2. Policy commitments**

- Socially valued roles and opportunities have been created and are maintained for seniors with intellectual disabilities.
- Social policy takes stock of issues of aging for people with intellectual disabilities, their need for relationships and connectedness to their communities, the need for financial security,

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affordable housing, leisure activities, safety and security and good health.

### **3. Programs and resources**

- Suitable support services, clinical resources, training and awareness-raising initiatives are in place.

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### **III. The Social Context of Aging and Intellectual Disability**

On the first day of the dialogue and on the second in “hot topic” discussions, participants identified a range of promising developments that can be built upon in efforts to ensure positive futures for people with intellectual disabilities as they get older. Participants also pointed to a range of challenges that need to be addressed.

#### **A. Individuals**

##### **1. Personal goals, self-determination, choices and control**

In the discussions the point was made that there is a better understanding, now, of factors that help constitute a “good life”. Elements of a good life are provided in Section II on Vision. Challenges that need to be addressed as people get older are being identified relatively early in life. Families and professionals are getting better at assisting people with intellectual disabilities to plan for their futures and at helping to ensure that the needed support arrangements are in place. As a result, the independence of people with intellectual disabilities is being sustained as they age.

However, self-advocates expressed concern about loss of personal control in decision-making as they get older.

As well, it was recognized that individuals’ lifestyle choices can butt up against controls set by staff and against the other limits of group living.

Age-related grief can result in a sense of futility, despair and helplessness. In part this is because grief has much to do with losing power – the sense that, “I didn’t have the power to change it.”

People are struggling with how to help individuals to do long term planning – e.g., advanced directives and funeral planning – while they are still able to do this planning. How to help individuals and their families in this area presents real challenges.

##### **2. Physical health and well-being**

There is an increase in the number of people with intellectual (and other) disabilities reaching the senior years. People over 80 are generally much healthier, now.

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People need and want to be part of their community. With improvements in community connectedness and involvement there are general improvements in the personal health and well-being of people with intellectual disabilities.

*“When we retire, we get to decide and become who we were meant to be.”*

Yet, people with intellectual disabilities are concerned about declining health in old age:

*“As you get older, you gain weight or may eat bad foods; you need to watch the food you eat and may have to eat less.”*

*“You may get heart trouble. You may get diabetes, high cholesterol or arthritis, osteoporosis, or you may fall and break a bone.”*

*“Your hair gets grey or you may lose it!”*

*“You need to exercise to keep fit (walking, aerobics, etc.).”*

*“You may have to take more vitamins as you get older.”*

*“Stress causes many issues...”*

Medical issues come to the foreground in the middle stages of dementia and there is a loss of mobility in the latter stages. The progression of dementia is unique for each person, which makes it difficult to predict with any real degree of accuracy what might be needed next.

When grieving, people often go into illness in order to go into breakdown so they can have a breakthrough. It is challenging to support people during this process.

### **3. Mental/emotional well-being**

Aging people with disabilities who are living in regular households in the community report that, generally speaking, they’re pretty happy with how things are going in their lives. Practical strategies are emerging for supporting people with dementia.

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*“Witnessing how short term memory is the first to go reminded me of what is important in life – those long term memories are significant – what you remember to the end.”*

However, people in institutional settings are considerably less likely than people in regular households to indicate that they’re happy with things these days. People fare less well when multiple disadvantages come together (e.g., low income, lack of positive social support).

There is a higher incidence of Alzheimer’s Disease among people with Down Syndrome. The cause is not known. With Alzheimer’s, it is easy to miss three vital pieces:

- How early the onset can be;
- How fast the progression can be; and
- The possibility of the individual developing seizures.

It is difficult to pinpoint the onset of Alzheimer’s. This is more complicated when there is already an intellectual disability and if person didn’t speak much before the onset. Definitive diagnosis of Alzheimer’s cannot be concluded until autopsy.

As well, there is a need for constant support for people with dementia (e.g., to help talk individuals through all the stages) and there are safety issues that have to be addressed in the early stages.

People are concerned about the trauma of loss; grief related to loss has to be addressed. Grief can result from the loss of home, job, capacity, identity or people; grief is not just about losing someone who is loved.

People with intellectual disabilities can be excluded from the grieving process; many people in organizations are told not to grieve. Grief is accentuated when people are not allowed to express it in their community.

Sometimes services group people with Alzheimer’s Disease together. This creates difficulties for people who find themselves surrounded by others who are becoming incapacitated and dying. This can cause “bereavement overload” for people served by agencies and for staff as well.

*“Social exclusion on top of grief leads to agony, terror, demeaning and diminishment.”*

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## 4. Relationships

Families and friends are being encouraged to stay involved in the lives of people with intellectual disabilities, providing life-long love and encouragement.

*“They know me – over time as people get to know one another they feel welcomed.”*

Yet participants reported that unpaid, reciprocal community relationships for people with intellectual disabilities are largely absent. Far-flung families and ‘unengaged’ family members shrink the pool of available people for relationships. Other people’s “limiting assumptions” can detract from the perceived ability of people with intellectual disabilities to take part in relationships. Communication issues (e.g., limited verbal communication) can compound relationship difficulties.

Relationships take time to develop and nurture. As families and service providers often get preoccupied with day-to-day priorities, the relationship dimension tends to get put on the “back burner”.

People who have been over-protected may experience difficulties entering into new relationships.

There can be a lack of respect for the relationships that people develop with staff. Sometimes these are not seen as “real” relationships, even though the people involved in the relationships may think otherwise.

There is a lack of support for people to explore their passions and the possibility of intimate relationships. Their passions are trivialized, but should be taken seriously.

Sometimes service providers over-generalize and assume that relationships should be *this* way, with little room for individuals’ say in the matter.

Self-advocates expressed concern about the following issues as they get older:

- Isolation;
- Loneliness;
- No one being there to listen;
- No one with authority to speak on their behalf;
- Lack of relationships, generally.

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*“You have a right to visit and spend time with family, and a responsibility to respect their rules and help them when needed.”*

*“You have a right to ask questions and get answers from staff, family and others, but [you also have] a responsibility to listen to them.”*

## **5. Safety and Security**

Canada is a comparatively safe country. However, some communities are less safe than others and people with disabilities are at higher risk than others of a range of harms. People with intellectual disabilities are particularly vulnerable.

*“We feel safe when:*

- with other people*
- at home or at work*
- the door is locked*
- we know what to do in a fire.”*

*“We feel unsafe when:*

- waiting at a bus stop in the dark*
- alone*
- walking”*

## **6. Home**

Many older people are still living with family members, which is positive when this is a freely made choice of individuals and their families. Families are also using – or are willing to use – their own resources to assist with the housing of family members with disabilities.

However, self-advocates expressed concern about having a home when they are older. Affordability and the availability of needed supports are key issues.

Many homes are not physically accessible. Dialogue participants told about their difficulties affording retrofits for family and group homes.

People who stay with their families until they are very old in some cases don't have a network of friends and are therefore isolated and highly dependent on their parents. The availability of affordable housing options has a bearing on the timing of when a person can leave the family home.

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Conversely, requiring that people with disabilities move to other facilities (e.g., Long Term Care) as their condition worsens makes little sense because that kind of change speeds up age-related deterioration. There is reportedly considerable pressure from government ministries to reinstitutionalize people in Long Term Care facilities.

## **7. Leisure activities, creative outlets**

Efforts are being made to maintain as many activities as possible in which people were involved before going into personal care homes.

*"It is powerful watching people enjoy simple pleasures right to the end..."*

However, dialogue participants pointed out the need for people to have meaningful activities in group homes and to create "spaces", there, for people with intellectual disabilities to be solitary when they feel the need.

*"Retirement isn't all a vacation."*

## **8. Ongoing learning**

Some people with intellectual disabilities are obtaining opportunities to learn from other seniors (e.g., new skills). However, seniors programs are not necessarily open to and welcoming of people with intellectual disabilities.

## **9. Participation in the community**

The point was made that there are insufficient resources to support people to participate in community programs. Self-advocates expressed concern about not having chances to contribute to the community as they get older.

*"While you should have the right to do things in the community, you have ... to be safe."*

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## 10. End-of-life issues

Participants commented on the general increase in openness to dealing with end-of-life issues in relationship with others.

*“When you walked into the room today, you brought with you all the stories of loss... You don’t stand alone. Others stand with you.”*

*“The whole experience [of end-of-life support to a person with an intellectual disability] enriched the lives of those involved. It helped us all deal with grief and loss – even of our own parents and siblings. We learned how to care for one another – staff to staff, staff to Board members, among Board members... It gave us pause to think about quality of life issues...”*

*“Watching that each person’s situation can be quite unique and the progression quite different made us realize that you can’t predict the end of life and that medical people can’t tell you when it will be or how it will go.”*

At the same time, practical issues require attention. Care needs are progressive for people with dementia and the end stage typically requires nursing care.

Sometimes drugs help and sometimes they make things worse by speeding up the progression of dementia. Some medical professionals prescribe Dilantin, which can cause rapid deterioration within hours.

Support workers/staff sometimes resist calling in palliative care support teams because they do not want to admit that the person they are supporting is dying. For their part, palliative care teams may be willing to deal with only the very end of life and to provide support for a short period of time, e.g., two months.

Some agencies that are committed to the individuals they are serving go into debt providing increased staffing for end-of-life support because they find it difficult to get funding increases from government.

## 11. Finances

While many families are helping to defray various expenses of people with intellectual disabilities, the families’ resources that are intended for this purpose are not always protected. Self-advocates expressed concern about poverty and about finding ways of affording the little things for which their parents are presently paying.

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## **12. Supports for inclusion, participation and well-being**

Dialogue participants expressed concern about poor quality of care, arbitrary placement, vulnerability and abuse. For those who have been involved in designing supports it is evident that people with intellectual disabilities need more people to “be there” for them and to provide the support as they get older.

Not everyone’s support needs are the same, however. For instance, aging couples have different needs that have to be addressed, e.g., one person may require more intensive support such as that provided in a personal care home where as the other may be able to live more independently with the appropriate supports.

### **B. Families, Friends and Trusted Others**

#### **1. Ongoing involvement**

Committed and savvy families are increasingly involved in the lives of people with intellectual disabilities as they get older.

However, many parents who are required to be primary, life-long care providers are themselves quite advanced in age. It is not uncommon for family members to feel betrayed after years of care giving and no or little additional assistance / resourcing. In effect governments have indicated that they’d be there for families later in life, but this isn’t happening.

At the same time, parents are not always receptive to outreach support; many mistrust the “system”. In part this is because families are often fatigued about telling agencies their issues and concerns. They want to see action.

As well, many families still do not know other families, in part because the opportunities are diminishing to connect with one another. The decreasing vitality of Associations for Community Living was flagged as a contributing factor.

Further, ways need to be found to help people through the grieving process. It can be hard for caregivers to know what is next as they journey with people during end-of-life issues and other losses. It can also be difficult and confusing for roommates of individuals who are unsettled and angry because they are going through traumatic changes.

Caregivers are themselves impacted by dementia (e.g., depression), which needs to be addressed.

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## **2. Status and respect**

Family members and trusted others are increasingly being given recognition and respect for the support they are providing to people with intellectual disabilities as they get older. Such recognition and respect is not universal, however.

## **C. Community**

### **1. Community capacity development and engagement**

Dialogue participants pointed to the importance of communities being interested in and capable of becoming involved in the lives of people with intellectual disabilities as they get older. Some groups have emerged that are taking on the challenge of addressing issues of aging and intellectual disability (e.g., PLAN, Continuity Care; support circles). In some cases, staff who are committed to individuals remaining in their own homes have advocated for this with their agencies' Boards of Directors.

Generally speaking, however, community members are not very involved in the lives of people with intellectual disabilities.

## **D. Society and Systems**

### **1. Attitudes and values**

There is growing awareness in society that people with disabilities have much to contribute to the life of the community. Yet it was observed that social devaluation is prevalent on the basis of age and disability, and intolerance to towards one another is not uncommon even in seniors' programs.

*"The day you retire, you're old and don't work."*

### **2. Policy commitments, programs and resources**

Professional groups such as the American Association on Mental Retardation (AAMR) have developed guidelines for the care of people with intellectual disabilities and dementia. Training is increasingly available to ensure

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that staff understand some of the key age-related changes and how to support people, e.g., irritability may be the result of too little sleep.

Some organizations have learned what it takes to “stretch” to provide a level of care has never been provided before. Some have understood the need to shift gears from fostering new skills and independence to maintaining people’s present skills and level of autonomy for as long as possible.

However, it was also observed that we are presently living through a policy and program context of cost-containment when overall demand for publicly-funded support for intellectual and other disabilities has been increasing. There is a lack of resources for training, family support and for clinical/medical specialists. Aging, dementia and intellectual disability are not generally seen as critical issues at this time; people either ignore the issues or say they can wait. We are also on shifting ground in the area of government policy for discretionary trusts.

For people with intellectual disabilities and their families, the challenge of aging and intellectual disability is a relatively new one owing to recent improvements in life expectancy. Old structures and approaches (of families, governments and services) are not as relevant as in the past, yet new approaches and structures have not fully emerged. Government funding and policy, and service structures, are often not flexible enough to allow for sufficient creativity and for unique solutions to aging people’s needs and challenges.

Educational print material on health issues for people with intellectual disabilities is almost non-existent.

Health staff are generally not trained to work with people with dual diagnosis. Yet turnover of staff requires *ongoing* training.

Similarly, social service agency staff who have not been trained to provide physical care assistance are not accustomed to playing a personal care support role. Yet they are increasingly required to play this role.

As neither governments nor service providers have a good grasp of the numbers of people with intellectual disabilities who are moving into their senior years, it is difficult for them to respond effectively. They’re caught in “crisis reaction” mode rather than “thoughtful, proactive planning” mode. Yet it is clear that many more people will require complex care in the future.

Compounding the problem is that government services lack coordination, that mental health services are typically poor for people with intellectual disabilities and that people with disabilities have less access than others to basic health resources. Sometimes ministries will not pay for the awake night staff who are needed in various care arrangements.

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Moreover, while there are many attractive Long Term Care facilities for people with Alzheimer's, people with intellectual disabilities are often told they are not able to move there – that they are not welcome. Some day programs for people with Alzheimer's will not welcome people with intellectual disabilities, and other generic programs are not very welcoming, either.

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## IV. Principles for Moving Forward

There are, then, positive developments that can be built upon and challenges that need to be addressed. Dialogue participants developed the following principles for moving forward:

- All people have potential to grow and contribute.
- People have control over their own destinies and destinations. (e.g., they have choices about the time that is appropriate to move from the family home into their own place, with or without others (i.e., people should not just be placed on a waiting list to live with people they may not know or care to live with).
- Supports are individualized.
- Supports are flexible and responsive to people's needs.
- Individualized funding is available.
- People use creativity and innovation in thinking through and putting together the living situations and support options that people with intellectual disabilities are seeking.
- There is significant use of non-conventional, non-formalized, non-professional support options and greater reliance on informal, "natural" relationships and supports. Measures are taken, however, to ensure that people aren't simply "dumped" into communities that lack the interest, will and capacity to be involved and supportive.
- Progress is being achieved in the short term in raising community members' awareness about how they can be involved in a mutually rewarding way in the lives of people with intellectual disabilities.
- Caregivers are supported to deal with a range of issues related to aging, including dementia.
- People are supported to live in their homes in the community for as long as they think this is the best option for themselves.
- As aging starts early in life and secondary conditions can be impacted, proactive approaches to planning and support are in place.
- Services are routinely planning to respond to the local and regional demographics of aging and intellectual disability.

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## V. Actions and Measures Needed

Dialogue participants identified 81 specific actions to be taken and measures that need to be put in place. An over-riding consideration was the need for a new kind of working relationship between families, self-advocates and service providers. The new approach would be based on openness, collaboration and common vision combined with common sense.

The new approach would take stock of what self-advocates want, the fears, experiences, knowledge and hopes of families and the constraints of services. It would be based in a common vision, common language and friendlier ways of working together. It would be an approach of doing things *with* people with intellectual disabilities, instead of doing things *for* them, as has often happened in the past.

A common advocacy agenda would also be developed. While self-advocates, families and service providers each have their own needs and perspectives, they also have interests, concerns and aspirations that they share in common. Recommended actions as follows:

### A. Individuals

#### 1. Personal goals, self-determination, choices and control

Participants' vision included that people with intellectual disabilities would have the right to determine the course of their own lives and to make choices, with the supports needed. People with intellectual disabilities will be imagining where they would like to live and the people with whom to live. The people and structures around people with intellectual disabilities would listen and respond to this vision. To that end, participants indicated that the following are needed:

1. Put in place planning support – including circles of support – so that individuals and their families can develop a vision for their futures, can find out about their options and can access information.
2. Work to develop documents and information on issues of aging that will be accessible to people with intellectual disabilities.
3. Ensure people have proper information about dual diagnosis and the training and services that are available.
4. Provide “senior awareness” presentations to individuals and families.

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*"I'm worried that people will make decisions for me... and will place me in an institution!"*

*"I'm afraid of not knowing what is going to happen to me."*

*"I'm afraid of losing my freedom."*

*CONCERN: "Substitute decision-making... !"*

*"We need better legislation to make sure that our wishes are followed."*

*"Identify things you like to do. Have dreams for the future. Talk to family and people close to you. Identify who will be the keeper of your dream."*

*"We need to understand documents that will help answer questions about wills, power of attorney, etc."*

*"I'm going to make a creative plan when I get home...."*

## **2. Physical health and well-being**

The general vision of dialogue participants was that people with intellectual disabilities would be in good health as they get older. To that end stakeholders need to:

5. Challenge the health professions to use clear language to assist people to make informed decisions about their health and their bodies.
6. Provide presentations to medical groups (provincial, national, university-based) and find out what these groups are doing in the area of aging and intellectual disability.
7. Seek out Early Screening and Diagnostics – at age 40 for people with Down Syndrome; at age 50 for all others with intellectual disabilities.
8. Advocate for the clinical support needed by physicians, social workers and nurses (e.g., care management plans).
9. Implement programs to deal with low activity levels and poor diets of people with intellectual disabilities who have problems in these areas.
10. Ensure that community resources such as illness prevention programs are inclusive of people with intellectual disabilities.

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11. Seek funding from Health Canada to undertake project work in the area of aging and intellectual disability.

*“It’s important to have exercise.”*

*“As health deteriorates, people begin to see us differently because they think we can’t look after ourselves.”*

*“I’m afraid of losing my eyesight.”*

*“What is happening (e.g., illnesses) as we age? It is not explained to us in a language we understand.”*

*“The less value placed on people with disabilities might mean that you get less than adequate health care.”*

### **3. Mental/emotional well-being**

Dialogue participants wanted people with intellectual disabilities to feel productive and that they are contributing something to others as they get older. Specialized programs would be in place as needed in the community, institutions would not be resorted to for people living with dementia or other complex needs, and supports would be geared to people’s particular stage of dementia. To these ends participants focused on needed actions to foster relationships and welcoming, supportive communities (discussed below). As well, the following is needed:

12. Put in place program adaptations to address age-related behavioural changes.

### **4. Relationships**

Ideally, as they get older, people with intellectual disabilities would be involved in a range of unpaid, reciprocal relationships that include neighbours, friends, family members, intimate others and citizens more broadly. People’s friends and workers would be responsible and trustworthy and there would be continuity of relationships. People would have chances to identify and share life with people who have similar stories, and people without a voice would have others to speak on their behalf. Actions to be taken are as follows:

13. Identify ways to help people with intellectual disabilities to meet and to keep in touch with friends.

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14. Get support from community care/home care programs that are willing to provide the trusted staff in the morning and at night.
  15. Maintain people's relationships so as to slow down the dementia process.
  16. When a person is placed in a Long Term Care facility, ensure that there is someone to provide daily visitation to ensure good treatment in the facility and to help the person stay connected with others.

*"I have a circle of friends who will speak for me when I can't speak for myself."*

*"As we get older, we want people, there, with us. Who? Friends who we trust. Family. Someone to call on the phone. Staff who we trust."*

*"As we get older we lose our friends and family. This is scary. We get old alone. We have less choices. It is difficult to cope on my own."*

*As we get older, less people call us. We have fewer friends."*

## **5. Safety and security**

Aging people with intellectual disabilities should feel safe and secure yet should also have a personal vision and be able to exercise self-determination, choice and control in their own lives. Participants identified the need for measures to:

17. Help people to develop relationships and to take ordinary precautions to maintain personal safety and security.
18. Further public safety initiatives in the community and ensure these are aware of and inclusive of people with intellectual disabilities.

## **6. Home**

People with intellectual disabilities should have choices about where to live, with whom to live, and should have access to the supports they need. Their homes should be pleasant, affordable, stable and suited to their needs and interests. If living with other people, those people should know and like them. Accordingly:

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19. People with intellectual disabilities should be encouraged to be clear on what they want, e.g., their “dream house”, the kinds of supports would need to be put in place, the people they would like to live with ... or whether maybe they’d rather live alone.

20. Various options to consider:

- Parents to purchase a home for their son/daughter and two others. Seek staffing through the local ACL. (Issues, to be addressed here: staff rotation in and out; orientation of staff; safeguards against traditional service approaches; shared staffing with family carrying some of the responsibilities).
- After identifying the important characteristics of the home for the son/daughter, parents purchase the home in his/her name. Build supports through partnership with the social services ministry and a friend.
- Joint tenancy. A percentage of the home is owned by the individual and the rest by a trusted other. This safeguards against people forcing the vulnerable adult to sell off their house because the sale must involve the trusted other.
- Individuals could live in a “nanny flat” within or adjacent to the family home.
- Self Managed Care in Manitoba has asked for a “global budget” that is not allocated for certain items, so the dollars can be used flexibly as needed.
- Use direct funding to provide home support. In Newfoundland, the individual is the employer (directs her staff). Revenue Canada has asked the parents to be co-employers.
- Alternative Family Care in Newfoundland funds families to take individuals in.
- Co-op housing within an apartment building has been designed as an intentional community that welcomes people with disabilities into the life of the co-op. The emphasis is on neighbourliness.
- Agencies can devise small social housing developments and housing co-operatives.
- In some co-op housing, families make a commitment to share their lives. They build public and private spaces, which requires capital investments.
- In Quebec, two families are exploring the purchase of a house together and are trying to negotiate supports through the ministry responsible for social services.
- In Alberta, a model has been implemented where the parents own the house and an agency staffs it; parents have a say in the staffing complement.

21. Seek more adequate public funding to modify environments so as to support people’s aging in place.

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## 7. Leisure activities, creative outlets

If people are to be involved in meaningful activities and to have a clear leisure identity that includes others who share similar interests, actions are needed to:

22. Provide opportunities that will get people “up and going” in the morning.
23. Provide a wide range of activities to keep them interested and active.

*“It’s important to have hobbies.”*

## 8. Ongoing learning

If people with intellectual disabilities are to be involved in lifelong learning, the following are needed:

24. Continue to support people to learn and to work towards reaching their individual potential.
25. Develop practical strategies to help people maintain their present knowledge and skills.
26. Create opportunities for people with intellectual disabilities to learn about their potential new roles as they age.

## 9. Participation in the community

Dialogue participants wanted to ensure that aging people with intellectual disabilities will be involved in their communities as vibrant, contributing and valued members with chances to give back to their communities. To that end, the following are needed:

27. Maintain people’s independence by building on individual strengths and community involvement.
28. Examine and apply current research findings that underscore the importance of relationships and community involvement to people’s health and wellness.

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*“It’s important to have community activities.”*

*“I’m really worried I won’t be able to go out any more.”*

## **10. End-of-life issues**

Dialogue participants explored the sacredness of every human life and the dignity of dying. Their vision was that people with intellectual disabilities would be supported at home for as long as it is good for them to be living there, that trusted others would be present and involved as long as the individual wants and needs this, and that the grieving of people with intellectual disabilities would be welcomed, respected and supported. Actions identified as needed include the following:

29. Talk about aging, death and grief with people with intellectual disabilities and their families.
30. Assist people to make provision for the end of life (e.g., wills, estate planning, funeral arrangements, etc.)
31. Ensure the availability of supportive, specialized care and hospice for end-of-life care.
32. Help people explore choices in the area of health care directives.
33. Ask local funeral homes to broaden their services.
34. Create life storybooks so that people can review their lives and so others can be grateful for the gift they have been to the community.
35. Help people experience their grief, e.g., conduct memorial services at home.
36. Publish an accessible book about grief.

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*“Will-planning makes wishes known. What will happen to my stuff?”*

*“...Who will get my things? How will they get it? I need more information.”*

*“Where will we end up (wills, remains, burials, etc.)? We want to learn more about this.”*

*“I want to get help from someone I can trust to make a will.”*

*“CAN I [i.e., am I allowed or permitted to] make a will?”*

*“We need to look at how we ritualize death. [For some], there are no longer the authorities telling us how to do it. There used to be rituals laid on. Now, we have to look at what rituals we can offer to each other. We can create those rituals.”*

*“We need to be careful about defining the responses of people with disabilities [to loss and death] as inappropriate grieving.”*

## **11. Finances**

Dialogue participants wanted people with intellectual disabilities to have the financial security for basic needs as they get older, as well as the personal finances to do and pay for the extras that families are in many cases paying for at present. Suggested actions in this area are to:

37. Foster relationships for people with intellectual disabilities, as these are important for helping people to secure their finances, as they get older.
38. Institute social policy reforms to make it possible for self-advocates to save for their future.
39. Work to achieve similarity in the rules for Discretionary Trusts across provinces/territories. Presently there is little consistency across jurisdictions.
40. Clearly define disability-related costs for the purposes of Trusts and secure the flexibility needed for hiring staff, supporting the development and maintenance of networks, etc. Advocate to have the limits taken off Trusts.
41. Seek policy changes that would allow for larger sized Trusts so they can be used for things above and beyond maintaining the basics. Governments should be persuaded to eliminate asset limiting and conditions on disbursements so families can offer firm security.
42. Work to create new financing and cost recovery options such as:
  - Registered Special Needs Plan

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- Registered Disability Savings Plan
  - More robust tax credits
  - Tax deductions
  - Provisions that would allow siblings to participate in RRSPs.

43. Shelter the dollars so that family contributions that are theoretically enabled/encouraged by the federal government are not clawed back by the provinces and territories.

## 12. Supports for inclusion, participation and well-being

Ideally, relevant supports would be available and accessible to aging people with intellectual disabilities (e.g., community supports, disability-specific supports, home modifications/ renovations). There would be good support for future planning, both for short-term emergencies and for longer-term needs. People with responsibilities for planning and support would be exploring diverse avenues of support, and supports would be tailored to people's unique needs and lifestyles. A key action identified in this area was the following:

44. Work to achieve accessibility, adequacy, affordability and portability of disability supports across communities and provinces. People should *be able* to move from community to community, but should not *have* to move in order to get the supports they require.

*"[Presently,] people need to leave their communities to get services."*

*"Often the supports are not adequate to support people in the community."*

## B. Families, Friends and Trusted Others

### 1. Ongoing involvement

Dialogue participants' vision included that families (parents and extended family) and friends would maintain their involvement in the lives of people with intellectual disabilities, as they get older, and would have the supports that they need to maintain this involvement. The following were identified as needed measures:

45. Revive the 'grassroots' to unite / re-unite families. For instance:
- Support families that are actively formulating new groups and opportunities to connect.

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- Try to revive associations like the ACL federation.
  - Build a context for siblings to re-connect (e.g., Baby Boomer Café).<sup>2</sup>
  - Start small, e.g., grassroots families educating/mentoring other families.
  - Foster kitchen table conversations, where people are invited to discuss what they need and why.
  - Explore the potential of the Internet to help people connect with one another.

46. Provide pastoral care for roommates to help them adjust when their roommate has to go into a Long Term Care facility.

## **2. Status and respect**

Dialogue participants underscored the importance of families and other unpaid caring persons having significant say in decision-making and support arrangements concerning people who cannot speak for themselves. As well, families and unpaid carers should not be dominated or controlled by service providers or governments. Accordingly, the following are needed:

47. Recognize and value the support that family members have been, and continue to be, to people with intellectual disabilities as they age.

48. Welcome and value other community members who are interested in journeying with people with intellectual disabilities into their senior years.

49. Strategize around how to foster value-based dialogue at the local, provincial and national levels. Do not limit conversations to staff but open up the dialogue to include people who are (or should/could be) indirectly involved in the lives of aging people with intellectual disabilities.

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<sup>2</sup> This was an evening social event conducted at the dialogue that brought together siblings of people with intellectual disabilities for food, music, discussion and fun.

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## C. Community

### 1. Community capacity development and engagement

Dialogue participants' vision included that community members would value and would see a meaningful and rewarding role for themselves in the lives of people with intellectual disabilities. Communities would be welcoming and supportive of the involvement and participation of seniors with intellectual disabilities, and relationship building between people with intellectual disabilities and members of the community at large would be a regular part of services' work. Accordingly:

50. Find and nurture new – and especially unpaid – forms and sources of support.
51. Develop mediating structures and mechanisms within communities that will help bring people together and that will foster relationships and neighbourliness. There is a need for intentional efforts, here.
52. Find ways to engage the community to fulfill its obligations, e.g., educate the community about welcoming people with intellectual disabilities in residential neighbourhoods.
53. Services should make a priority of people's need for relationships. They should be doing more community development and outreach, and should "open the doors" and welcome community members to be part of people's lives.
54. Ask governments to help families and organizations to build links between people with intellectual disabilities and the community, attaching few rules/conditions to the funding.
55. Use individualized funding as a tool to promote the development of relationships.
56. Services should be forming coalitions and partnerships with local, provincial and national groups. They could be developing an interactive Website, message boards, chat rooms, etc. The Council on Accreditation has a Website that perhaps could be used.
57. Foster dialogue between seniors and people with intellectual disabilities, individually, politically and non-politically at the local, provincial and national levels.

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58. Pull together what is being done well and share strengths. For instance, the ACL federation is good at providing community supports; seniors' services are not as good at this.

## **D. Society and Systems**

### **1. Attitudes and values**

If in the future there are to be no more negative stereotypes about aging people with intellectual disabilities:

59. Foster positive public images, attitudes and values towards people with intellectual disabilities who are getting older.

60. Develop a media strategy on aging and intellectual disability.

61. Do an OP Ed piece for the Globe and Mail. Contribute articles to seniors' journals.

*"People still see disability as a disease."*

### **2. Policy commitments**

The ideal future for seniors with intellectual disabilities is one where socially valued roles and opportunities have been created and are maintained for them. Social policy would take stock of issues of aging for people with intellectual disabilities, their need for relationships and connectedness to their communities, the need for financial security, leisure activities, affordable housing, safety and security and good health. It is important, therefore, to:

62. Find ways of engaging governments to fulfill their obligations.

63. Help to develop national principles and a national policy framework on aging and intellectual disability.

64. Help to develop provincial / territorial guidelines for supporting people with intellectual disabilities in hospitals and hospices.

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### 3. Programs and resources

Ideally, suitable support services, clinical resources, training and awareness-raising initiatives would be in place to address issues of aging and intellectual disability. Dialogue participants saw the need for the following practical measures:

65. Be aware that there are differences between urban and rural communities in terms of needs and services. Families need to remind governments (i.e., advocate) about the need for services, especially in rural communities.

66. Educate the health care and social services fields (focusing on attitudes and values) concerning dementia and end-of-life issues for people with intellectual disabilities. Staff training on the stages of Alzheimer's is critical.

67. Ensure that in-service training is available. Overall life-development and aging must be discussed. Identify the information and skills that support staff need. Develop agency-specific training. Create a training manual for agencies.

68. Educate the health system more generally on the needs of people with intellectual disabilities and dispel myths.

69. Develop standards of care for people with disabilities.

70. Develop national standards for training in language that is understandable.

71. Develop the skills needed to approach life planning in collaboration with families to achieve comfort and ease as people age.

72. Agencies need to be clear in terms of policy and practices about whether they will stand by individuals to the end of life and will accommodate these transitions.

73. Support caregivers who are dealing with end-of-life issues.

74. Government officials and service managers need to realize that an organization may be dealing with lot of grief associated with death and that it is struggling to figure out how to support individuals and the organization at the staff and board level.

75. Address the fact that people's needs change over time. Ensure lots of discussion among various players about how the support model needs to be adjusted and the kinds of resources that will be needed, e.g., planning, therapy, palliative care, medical support.

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76. Tell job applicants during interviews that the hiring organization supports adults to the end of life and provides personal care. If the applicant is not interested, he/she needs to seek out another job. Staff need to know in advance the organization's commitment.

77. Have outside people lend an eye to where the service's/organization's limits are. (Sometimes a service or organization can't hear what other "residents" and staff are saying about a person's situation and can't directly see what is happening in the life of the individual.)

78. Conduct board retreats to clarify the organization's values about the people served and what the organization is prepared to offer in the senior years.

79. Advocate for more money from funding bodies to support people through end-of-life issues.

80. Work to ensure that nursing support is available in all people's homes.

81. Plan for upcoming demographic changes to ensure that needed services are developed in advance.

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## VI. What Stakeholders Need from One Another

Self-advocates, family members and service providers were asked what they need from one another in order to move effectively forward together to achieve the vision, by putting in place the needed actions and measures, consistent with the guiding principles. Key points are as follows.

### A. Self-Advocates

Self-advocates spoke about what they need from families and from service providers. Generally they are looking for social support, accessible information and respect for self-determination.

#### 1. What Self-Advocates Need from Families

*"Networks in place....People still aren't listening to me...I'm unhappy, now, and no one is hearing.....Please listen to us!"*

*"To connect with a support network and talk about, 'What's going to happen to me in 20 years?' "*

*"Where will we be? Will we have a choice about where we will live?"*

*"Health things aren't in language that we understand...and that poses a threat."*

*"[There are] things about our bodies we don't understand."*

*"People assume we can't understand....We need people to try to put things in ways we can understand."*

#### 2. What Self-Advocates Need from Service Providers

*"We're unclear about aging....Please respect me....Help educate me on this issue."*

*"You have to listen to us....allow us to do what we want to do."*

*"Let us have choices!"*

*"Practice the language of CAN DO."*

*"It's OUR lives...we have a right to understand what's going on inside our bodies. Everyone deserves that right."*

*"Respect is a two way street....we need to respect the other person too."*

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*"Don't plan for me... I just want a life with support when and where I need it!"*

*"Don't make a program out of people." [Much applause followed this comment.]*

## **B. Families**

### **1. What Families Need from Service Providers**

Most of family members' comments centred on what they need from service providers. Families' needs include that providers would ensure basic understanding of issues of aging and intellectual disability, would work more effectively together, would respect people with intellectual disabilities, would place a focus on relationship development, and would accord respect for the role and competencies of families while addressing their need for support.

*"Recognize that there is an aging population of people with disabilities."*

*"Ongoing education needs to happen within services."*

*"Discussion/collaboration is needed among people from different groups."*

*"We appreciate the constraints of services. But services need to do better at respecting each other. Families shouldn't have to referee between services."*

*"Acknowledge that people [with intellectual disabilities] are real people and full citizens and deserve the same support as others. Understand the double jeopardy that people are in."*

*"Do more to promote and value relationships."*

*"Respect family members as people."*

*"Acknowledge that family members have knowledge/expertise."*

*"Acknowledge that families are capable...of designing supports and support plans."*

*"If families could get more funding and support... with a network or microboard... we could plan good lives for our children with support."*

*"We can take care of hiring workers...keeping control in the family... acknowledging the person at the core... taking care of safety... honouring the relationships that are in place. Services need to acknowledge that we can do this! Families can learn from services but if they want, they can do things for themselves."*

*"Acknowledge that we provide support to families."*

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*"We need more money to implement plans and to plan for the future."*

*"Please provide support to people and families to know where to go for help."*

*"Remove the barriers...so families can make sound plans."*

*"Acknowledge that people with disabilities' families have a right to support...this is not a favour."*

*"Don't make us feel guilty when we need support...Acknowledge that we are not a burden."*

*"Support the national disability support program."*

## **2. What Families Need from Self-Advocates**

While most of families' comments centred on service providers, a very clear message was sent to self-advocates as well:

*"We will stand by you... We will listen and hear... Keep telling us what you want."*

## **C. Service Providers**

### **1. What Service Providers Need from Self-Advocates**

Service providers at the dialogue encouraged self-advocates to talk about their needs, committed to being supportive and asked for patience along the way.

*"Don't be afraid to tell what you want as you grow older."*

*"Give us advice how to talk about these issues."*

*"Tell us what support would be helpful."*

*"We promise to listen... to keep your voice heard... to make your vision real."*

*"We encourage you to speak for your friends and others [who don't have a voice]."*

*"We would like to create life books with you and we'll go first."*

*"We want to support your choices."*

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*"Be patient with us."*

## **2. What Service Providers Need from Families**

Service providers had several messages for families. These included acknowledgement of the role and importance of families, service providers' need for family input, a commitment to being supportive and the request that families would themselves be less restrictive and more trusting of their sons and daughters, and that families would include service providers in their sons/daughters' end-of-life issues. Service providers also asked families to appreciate some of the limits under which they operate and to continue dialoguing and working collaboratively with service providers – governmental and non-governmental.

*"We believe that families are the safeguards for people and agencies."*

*"We need you."*

*"We want your advice."*

*"We want to say the door is always open."*

*"We support you."*

*"We care."*

*"You have had bad experiences... We need to spend time with you to understand and assure families. Common sense will be our guiding principle."*

*"We need to hear families' hopes and fears. This may not happen in an annual report."*

*"We promise that we will act respectfully."*

*"We value your sons and daughters... You have great influence over your family members... Sometimes you place great restrictions... Please be more trusting and open to your sons and daughters."*

*"We hope that families appreciate our constraints – like policy and funding – things that limit our creativity."*

*"If we approach you [to plan for the future] it's not to cause hurt... It's necessary... Please don't be afraid of this planning."*

*"We are responding to needs but it's hard sometimes."*

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*“Services have different issues to balance. Families want one thing and other people want other things.”*

*“Some things take time. Good ideas need time to develop.”*

*“Understand that we’ve been a part of your family member’s life all along... Please include us in end-of-life issues...”*

*“We also feel the loss when someone dies... Include us.”*

*“People have different investments in this... It’s important that people commit to work together... to step out of our boxes and get together...”*

*“Government is always on the other team. I’m on the wrong team! We need to clarify this. There are lots of government workers, here. We want to be on the same team. Government is us. That’s what they taught us in school. Government people have relationships. We care. Let’s work together!”*

*“This has to be a day to day effort...not once a year...”*

*“We must take time to speak – like this – with one another.”*

*“We want to meet again.”*

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## VII. Concluding Notes: Change in the Air

The last hour or so of the dialogue turned into a bit of a free for all in which participants got to voice their concerns and views on a range of issues. An overall impression was that participants recognized the need to do things differently.

For example, when asked for a show of hands of people connected with services that are presently using an “aging lens” to ensure that policies and practices are respectful and accommodating of people who are getting older, very few participants raised their hands.

When asked about the main factor that inhibits self-advocates, families and service providers from working collaboratively together towards furthering their vision for people with intellectual disabilities as they get older, the lack of respect and trust were identified as key issues. Said one, “The lack of trust is all over. We’ve been abused by the system and by other things. How the hell do we learn how to trust? And abuse is the right word for us.” Another spoke about constantly feeling “scrambled” and “tired”, which makes it difficult to be trusting. On a more optimistic note that opened the door for constructive change, another participant said, “I understand that families have been abused. However I have also heard gratefulness from families. It’s hard to trust, but services have seen relief from families who see a positive outcome.”

Said one family member reflecting on the need for change, “Forty years ago parents joined hands and produced the ACL’s. Now we need to change the way things are done. Parents need to come together again to bring about change.”

Several service providers echoed the need for change as well. Said one, “We’re running services that aren’t always responding to people’s needs. People who are looking for supports today are looking for different, more flexible models. Services are evolving, but the bureaucracy of organizations still contains people. The services of the future hopefully will be different.” Said another, “I’m running an older model of service that people aren’t opting into anymore. Newer models will take wings.”

Another commented, “How difficult it must be for individuals to have staff coming into their home. What can we do about this model...this system issue? I hate bureaucracy yet we’re in it as service providers. We have to go home and listen... really listen....even to those who don’t speak well. I’m looking forward to coming back in two years.” Another said, “Services need to be talked about a lot cause they’re complicated. The most clarifying comments are focused on people and how to support them in natural ways.... preserving real life.... making sure services don’t ‘commodify’ real life. Let’s not get distracted from supporting really good lives.”

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Service providers spoke about some of the dilemmas inherent in present models of service provision. Asked one service provider, “How do we balance ‘professionalism’ and ‘workplace’ issues on the one hand and natural experiences on the other. There are two models of service. The traditional model is impersonal. The non-traditional is more natural, humane and satisfying. We need to move towards the latter while still being professional.” Another observed, “The present service approach focuses on ‘what is measurable’. The important, more humane, issues are irrelevant or lost. Be aware that those models are out there. Are we buying into it? Is our organization getting caught up in that and is it having an adverse impact?”

Just before the dialogue closed, a self-advocate said, “We’re talking about healing because we’re caring about people. We’re problem solving...how do we help with health...helping people nurture their wounds? We probably can’t turn systems around. But we can look at the hearts of people... and can start talking with people about those wounds... Coming of Age is about the coming of healing.”

The dialogue ended on a very positive note. Said one participant, “This event was moving and soul searching.... We’re energized... I’m finally hearing self-advocates.”

Participants indicated the desire to come together within two years to rekindle the discussion. On balance it was agreed that, next time, perhaps rather than breaking the dialogue into separate streams for self-advocates, families and service providers for the duration, consideration could be given to ensuring that people would have opportunities to move in and out of such streams.

Participants had good reason to feel upbeat. For the first time in Canada, they had come together as self-advocates, family members and service providers, both governmental and non-governmental, to discuss the important issues that lay at the centre of the dialogue. The discussion was thoughtful, respectful and frank. Participants had worked solidly for three days and had put many ideas on the table for consideration. They had articulated their vision for the future, had identified positive developments that can be built upon, challenges that need to be addressed, and developed numerous ideas for practical action at the individual, family, community and systems levels. They laid a good foundation for further planning and action. Said one participant, “We all have the responsibility to go back and seek out people and talk to them...to use our power as individuals to influence.”

No doubt, if they had more time, participants would have developed further details on short-term and long-term actions and strategic partnerships for moving their vision forward. No doubt, too, participants are already giving thought to such issues and will have much to discuss the next time they come together

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## **VII. Post-Script: Note from the Organizers**

As indicated at the end of the report, a shortage of time resulted in an inability to set short-term/doable action steps. The result is a report that may leave people feeling unsure of what to do next in moving this issue forward.

We believe a productive way of bringing the Dialogue and report to life might be to continue the discussions in our home communities. Building on the 81 recommendations for action, perhaps each of us could consolidate and prioritize based on our experienced and needs.

Our goal for Manitoba is to invite individuals who participated into a follow-up process to do just that. We know that there is work to do. All that is left is to do it.

We offer the 'Coming of Age' Website as a sharing-ground for further discussion. Minimally we could come together through cyber methods and regroup in 6 months to share how we are individually and collectively going to move forward.

We, at Winnserv, once again thank you for your hard work and look forward to our national, provincial and local ongoing discussions around issues of coming of age