

COMING OF AGE 2013

THE PROCESS:

The Coming of Age – *the dialogue continues* was held in Winnipeg, Manitoba from April 18-20, 2013. Approximately 140 people took part in this dialogue, focusing on the various aspects of growing older for people with an intellectual disability. It was a follow up to the first national dialogue, held in Winnipeg in 2004. People First of Canada was a key partner in the event and they had representation from every province and territory. Additional participants consisted of self-advocates not affiliated with People First, family members of people with intellectual disabilities, seniors and senior serving organizations as well as professionals who support people with disabilities. The majority came from Manitoba, Saskatchewan and Ontario but people also came from as far away as Alberta, British Columbia and Newfoundland.

The first day began with a panel report card where participants brought their perspectives on what had been achieved since the first dialogue in 2004. The remainder of the day entailed panel discussions on: Abuse, Healthy Aging, Dementia, Financial Concerns, Staff Training, Grief, Loss and End of Life, Aging Caregivers, Redefining Retirement, Housing, Age-Friendly Communities and Planning for the Future. The panels consisted of self-advocates, family members, seniors and senior serving organizations and organizations that support people with an intellectual disability. Information was shared about best practices that are offered to seniors with and without disabilities and suggestions made about new avenues of exploration. The goal was to stimulate ideas to be discussed and shared within working groups, as the dialogue unfolded.

Day two of the dialogue began with Senator Sharon Carstairs, who shared her perspectives on what the future holds for all older adults and where changes are required to provide a good quality later life. Her points reinforced much of what was discussed throughout the dialogue. Highlights of her presentation were:

Highlights from her presentation:

By the year 2013, 25% of Canada's population will be seniors, with more people experiencing older age than people under the age of 18. Despite this ongoing change in demographics there are currently 3,000 pediatricians in Canada and 150 geriatricians with only two doctors currently training as geriatricians in this country. Compounding this concern is the fact that seniors are the most intensive users of health care. We need timely, quality, accessible health care that is patient-focused. Health care practitioners must come with a broad knowledge base, as opposed to specialization, as

many seniors have multiple chronic conditions and can't be dealing with multiple specialists. All physicians should be trained in palliative care. Most Canadians die without good palliative care.

Recommendations:

- 1. Active aging must be promoted and ageism eliminated*
- 2. There is a need for a national Pharmacare program. There is currently no national formulary for drugs or a national list of approved drugs. A national program would allow for massive bulk purchasing power and could save \$10 billion a year. Manitoba's Pharmacare program is income tested so it allows for the most benefit to be given to those most in need. Ontario, on the other hand, pays for all medications for everyone over the age of 65 regardless of income or access to other coverage so dollars are not being maximized for those most in need of financial assistance.*
- 3. There must be a well thought out caregiver strategy. All caregivers must be protected, especially aging caregivers.*
- 4. There must be pension reform as well as reforms for income security. C.P.P. must be carefully examined and people allowed to add to their C.P.P. This does not, however, help low income people as they would not have additional funds to access for additional contributions.*
- 5. People need to be able to age in their place of choice. Unfortunately, governments are no longer investing in low income housing and/or seniors' housing. A long term care bed costs approximately \$850/day while the Home Care maximum is about \$350/day.*
- 6. Funding per capita does not fit into the actual distribution*

Seniors are often being stripped of their rights as they encounter ageing-related challenges. Broad reaching powers of attorney are being given to family members and it would be much more useful if they could be amended to give partial as opposed to absolute powers. There has to be a balance between keeping people safe and facilitating continued choice and control.

There is an acute need for the integration of services. All governments must work together including municipal governments. Companies of all sizes need to be engaged. The federal government should be overseeing certain services so that there is equality across the country.

After Senator Carstairs' presentation, participants then broke out into the following discussion topic groups:

- ❖ Social Policy Reform
- ❖ Preparing Support Staff for Aging Issues
- ❖ Futures Planning
- ❖ Use of Generic Services
- ❖ Dementia Supports
- ❖ Later Life Pursuits

Each group had a facilitator and recorder and was asked to explore a set of questions:

- What is the vision for the future?
- What are the good things that are currently happening that can be built upon?
- What challenges/difficulties need to be addressed?
- Potential solutions?
- Potential allies/partners?

Notes from the group discussions were submitted to Dr. Nancy Hansen, Director of Interdisciplinary Masters Program in Disability Studies and Kristina Zawaly, a student from the University of Manitoba, who completed her Specialization in Aging. They reviewed the notes, pulled out key themes and concepts, and opened the final half-day of the dialogue by presenting the highlights. The following key themes were found to run throughout many or all of the groups:

- The need for good, safe, low income housing
- A living wage for all
- Breaking down silos to work together on common issues
- Collaboration and advocacy
- Cross-sectoral knowledge building
- Need for improvements in transportation options.

Disability is not personal, it is social, and society needs to treat each one of us equally

Most areas of concern were identified as common to all seniors, regardless of abilities, and the solutions also were found to apply across the board.

Important to note: A commitment had been made with a university professor to oversee the data collection process, organize the information from the second and third day, report to the group and prepare a final report. Unfortunately, circumstances led to the individual being unavailable so that Dr. Hansen and Ms. Zawaly were recruited at the last minute. This change in plans led to some confusion in the flow of information resulting in an incomplete synopsis of the rich discussions that occurred within the break out discussion groups. As will be noted, much of what was produced by the *Preparing Staff for Aging Issues* group was misplaced.

Common Vision for the Future

Social Policy Reform:

- People have a good quality of life in all areas of their life
- Quality of life should not be determined by an individual's finances

Futures Planning:

- A healthy retirement with support: continuing to do what I am doing now with a positive attitude
- Healthy living – active, good nutrition, care and medical supports
- More inclusive medical & health coverage

- Surrounded by loving people (rich relationships)
- To be part of the community – side by side
- Support networks (people respect each other, the connections and commitment are strong)
- Living where you choose and want to live – close to amenities – within walking distance
- Knowledgeable about what is available
- Inclusive services & supports
- Consistency of supports
- Safety & security
- Choice & control

Later Life Pursuits:

- Good transportation
- The ability to be your own person
- Independence
- Quality of life with community involvement
- Choice
- Awareness of all the options that are available and affordable, a reduced fear of retirement and the fear of isolation
- Retain meaning in life including the ability to be productive and contributing to society
- No magical number when you are “supposed” to retire. People retain the right to retire at whatever age they like
- Continuing to have dreams to enhance your life
- People have planned their retirement, set clear goals and are taking vacations to those places they have always wanted to visit

Aging is not a disease, it is a natural, lifelong process.

Generic Services:

- All seniors are vibrant, valued and actively engaged in the community. Seniors are valued and seen as a resource, contributing gifts and strengths. Seniors with disabilities are actively engaged in and participating in the community.
- Communities benefit, barriers are broken and doors opened through shared generic and specific services. People are truly included in generic services.
- Services are consistent nationally. Cross-sectoral navigation is easier: service information is readily available, services easy to access and people don't bounce between services.
- Monies are less of a factor when accessing resources and resources are not siloed. Governments look at person centered and family centered services and support plans are funded across sectors. Joint models and partnerships of services exist such as sharing staffing between sectors.
- The choice to stay in place, to live and die at home is supported
- The right people are at the table, collaborating and talking face to face. Governments are educated. Ministers are committed to the vision.

Dementia Supports:

- Valuing the person and the shift that comes with age and dementia ...seeking out the “new things” that give a sense of life & joy in the journey.
- Ageing in place is normal, whether someone has dementia or not. Required funding is in place and there is a cross-sector sharing of responsibilities and supports.
- Person and family centered planning is in place so that all people receive the supports and information they require.
- The cause of Alzheimer disease is known, prevention is possible and cures are available.

Current Positive Practices to Build Upon

Social Policy Reform:

- As institutions close there is a transfer of funding into the community
- Age Friendly Manitoba – it started small and was mostly P.R. but there are now 83 communities involved in the initiative
- Intergenerational housing
- In Quebec one central agency coordinates efforts and networks around abuse
- Seniors’ Centres in Manitoba have had a program that has now been in place for three years that assists people to guard against financial abuse
- Ontario has an arm of government responsible for implementing and monitoring the Accessibility for Ontarians with Disabilities Act.
- Manitoba is about to pass accessibility legislation
- Long Term Care legislation, such as they have in Ontario, helps to set some standards for care
- There was a pilot project in Dauphin, Manitoba that had good outcomes around the provision of guaranteed incomes

Futures Planning:

- Use of PATHs (Planning Alternative Tomorrows with Hope) as a tool to do person-centered planning
- Person centered – tools, processes, planning, review, personal futures planning should not just be utilized for people with disabilities but should be applied when planning with all older adults
- The development of support networks:
 - For individual & for caregivers
 - Circles – Inviting people in (choice & control)
 - Senior Circle & Junior Circle.
 - Circle for Individuals
 - Circle for Families

- Start process early in an individual's life
- Having a champion/advocate
- In the Company of Friends in Manitoba ex: Individual Funding models & New Story Models
- External (Independent) facilitation (outside of the service system)
- Conflict (i.e.: messiness, noise etc...) is good
- Meals on Wheels
- Promotion of supported decision making
- C.A.C.L. "Ready, Willing & Able" initiative. "Stories of Successful Employment" booklet
- Financial literacy & education (knowledge is power)
- Helping people find jobs:
 - West Nova Inclusive Employment – Nova Scotia
 - Pro-Active Strategies – Northwest Territories
- Transition Classes – College of the Rockies – Community Colleges & Universities
- Nova Scotia – Streams of learning – vocational development
- Inclusive post-secondary (Best Practices) education
- Continued education – adult learning is encouraged for older adults
- Inclusive education
- Retirement planning is occurring with people
- Opportunities for employment & education later in life
- R.D.S.P (Registered Disability Savings Plan)
- Income security that is tied to the individual, not where they live, who supports them
- In Alberta the A.I.S.H. funding model has earning exemptions so that funding is not clawed back, allowing people to own their homes and vehicles

Later Life Pursuits:

- People with an intellectual disability are accessing seniors' programs, at least to a limited degree
- There are inclusive and welcoming senior serving organizations such as Good Neighbors in Winnipeg
- There are some senior serving organizations that are wheelchair accessible so they can be utilized by all older adults with mobility concerns.
- There is some government funding in place for senior serving organizations but there could certainly be an improvement
- Barrier Free legislation in Ontario and Manitoba

Generic Services:

- Recognize and join forces with these existing strong advocacy groups:
 - Baby boomers as advocates, resources and supports
 - Natural supports (ex: family) in breaking down barriers and changing culture
 - Disability sector strengths ex: living at home vs institution
 - Advocates do exist that are strong and have expertise
- Building Blocks – existing good practices:
 - an understanding of aging ex: disability sector access, specialized health care
 - existing good relationships in home care ex: nurses doing checks in group homes, home care being offered to people in the community who have an intellectual disability
 - pilot projects such as the Ontario adult senior day care joint proposals

- partnerships ex: disability support workers as staff in long term care facilities
- generic programs such as Age and Opportunity's hoarding program, "seniors centres without walls", elder abuse resources
- coordinator positions to help cross-sectoral navigation: ex: health care facilitator role in Ontario for cross sector navigation
- palliative care programs (Manitoba). Supports for end-of-life care in the community
- senior day programs
- palliative care, grief and dying/compassionate care training/supports i.e. training program offered in end-of-life care for support staff working with people with an intellectual disability (Manitoba)
- current active planning and talking ex: Coming of Age conference

Dementia Supports:

- There is more information, awareness and understanding about dementia than there has been in the past
- More resources are available for people with dementia and their families
- Dementia is a research priority
- There are some medications that are helpful
- The Alzheimer Society offers Safely Home and First Link – better access to programs and services
- Groups are being challenged to provide dementia care in the person's location of choice/close to home
- There are tools available for assessment and diagnosis of Alzheimer disease in people with an intellectual disability and an opportunity to engage in early bench marking
- There are more opportunities for staff to obtain training/information in dementia supports
- People are being supported to do more forward planning around dementia
- There has been more education and discussion of a preferred future
- Potential users of dementia services are speaking up about their wants, needs
- Increased advocacy around people with an intellectual disability and Alzheimer Disease and related dementias (ADRD)

Preparing Support Staff for Aging Issues:

- Hospice Palliative Care Manitoba has a course they offer that is specifically aimed at staff who support people with an intellectual disability
- L'Arche has an online resource that is a Grief Support Group Kit for people with intellectual disabilities – www.aging-and-disability.org/grief_support_kit. It can be used by support staff who are assisting someone to deal with the issues of grief and loss
- As part of the Coming of Age project (2008/2009) run by Winnserv in Winnipeg, a Senior Services Resource book was developed and distributed to every organization in Manitoba that supported adults with an intellectual disability

Challenges That Must Be Addressed

Social Policy Reform:

- All Canadians need to have a “living wage”
- Part of our problem is our reliance on government. We can’t rely on political will
- Canadian quality of life is dropping
- Our social structure needs an overhaul (i.e. variances across Canada)
- A tendency to find new ideas, not necessarily GOOD ideas
- Silos – aging, disability sectors have created parallel systems when it makes much more sense to work together
- Getting people to admit that they are “seniors”
- Decreased participation
- Lack of value associated with seniors and individuals with a disability
- 4000 people in need of low income housing
- Aging in place is sometimes only an option for those who have the financial resources
- There are divisions even within the disability community
- Not enough discussion/dialogue

Futures Planning:

- Housing
 - Not compatible with roommates
 - People are placed, not choosing to move or leave
 - Restrictions
 - Rules imposed
 - Limited by your income
- Supports/Staffing
 - Not understanding needs
 - Lack of training
- Having to try and work within the System
- Crisis-driven responses to issues rather than pro-active planning
- Mobility
- Affordability
 - Fixed incomes/limited incomes
 - Options are minimal and limited
 - Funding attached to service provider/agency, not to individual
 - Community agencies can be as institutional as institutions themselves
- Transportation
 - Lack of bus system
 - Book in advance so no ability to do anything on short notice.
 - Limited service
 - Affordability – taxis expensive
 - Accessible but limited routes
 - No service after certain times

- Rural vs Urban (fewer options outside of cities/larger centres)
- Winter: snow/weather limits
- Transportation viewed as a luxury
- Attitudinal:
 - Disrespect
 - Employer’s view of abilities (or lack thereof)
 - Being told you don’t have the intellectual ability for schooling
 - Having to prove that you can do it
 - Protectiveness that leads to restrictions, removal of choice.
 - Assumptions about needs for support
- Relationships and support networks:
 - Asking and inviting people – how to invite, finding people to invite to be a part of a support network
 - Building & maintaining trust
 - Support staff can be a barrier as they are sometimes “glued to the hip” and don’t allow time and privacy
- Parents and/or siblings can be a barrier in their child’s relationships, but this is improving
- Unionized & Professionalization of staff: volunteers/role/job
- Information needs
 - Understand – plain language, information not offered in alternate formats
 - Lack of recognition of people’s right to have the info you need
 - Knowing what questions to ask
 - Knowing what is available in the community
 - Technology—can be a barrier (i.e. telephone system prompts)

Later Life Pursuits:

- Information needs
 - Support givers are not always getting information
 - Plain language is required
- Legal asset restrictions that impact financial stability
- Seniors and people with an intellectual disability seen as a “burden on society”
- Seniors reluctant to embrace the population of people with disabilities
- Staff changeover
- Low salaries and support for staff
- Inequities in funding for resources and support services, between rural and urban areas

Generic Services:

- Political, Policy and Standards Issues:
 - People making decisions have little experience in direct service and do not understand the impact.
 - Committees lack cross-sectoral representation and inclusion of vulnerable persons.
 - Disability support services are not mandated: People with disabilities are not valued.
 - Provincial/federal standards of care are lacking i.e.: Access to services (ex: home care) is inconsistent within the province and across provinces.

- Legislation often does not mean anything as there are no consequences or enforcement policies or practices.
- There is a disconnect between policy writers and implementers.
- Definition of vulnerable persons (especially by health authorities) is dated.
- Funding:
 - Funding is inadequate and lacks flexibility. Disability support wages are lower than other sectors.
 - Adult disability services are not as richly funded as children's services so people cannot access the same level of services as when they were a child.
- Systems Issues:
 - Services/systems are too complex and challenging to navigate and challenging to dismantle.
 - General public does not understand what it's really like in institutions.
 - We struggle with being creative and thinking outside the box.
- Lack of Knowledge and Awareness:
 - Lack of media focus on disability to build community awareness.
 - We often lack awareness outside our own sectors, have limited attendance at conferences, committees etc. outside our sector, and have limited inter-sectoral training.
 - Communities/neighbourhoods may not know how to connect people to services
 - We don't teach how to reach out to families
 - North American culture makes us reliant on the system (ex: by being self-centred, etc.)
 - We do not advocate enough to demand change.

Dementia Supports:

- Staff/resources in the health and long term care sector have little knowledge around intellectual disabilities (I.D.), the interaction between Down syndrome and Alzheimer disease, and how to support people with this dual diagnosis.
- There is minimal recognition and treatment for depression and delirium experienced by people with I.D. and dementia.
- Families and some agency staff have little information about dementia and how it impacts people with I.D., what resources may be available and how to support people.
- Communication pathways between everyone involved with someone with I.D. and dementia (health care, families, long term care, agencies) can be very disjointed.
- In some communities, agencies or families no longer have the resources to support someone with both I.D. and dementia but long term care facilities are refusing to provide services and supports.
- Agencies that support people with I.D. are sometimes ill-prepared for providing end-of-life care.
- Support staff from both generic services and services that support people with I.D. have minimal training around the behavioral skills that are needed to understand how the dementia process impacts a person's abilities, interactions and interpretation of their environment.

- The general population often does not value the worth of people with I.D., people with Alzheimer disease and related dementias and certainly not people with the dual diagnosis.
- Lack of recognition or support for the emotional impact of dementia on families, friends, housemates and support staff.
- Need for recognition that a long term care facility is not the most suitable place to be for all.

Preparing Support Staff for Aging Issues:

- There is a need for shared housing strategies and cost sharing between different government departments
- Some older adults benefit from being supported by staff in their age category, who may understand their needs better, as opposed to staff who are in their twenties
- No accreditation for staff who work with people with an intellectual disability
- Sometimes it is impossible to access Home Care services for people, with an intellectual disability, who live in community living homes even though support staff do not have the training to provide the required care

Possible Solutions

Social Policy Reform:

- Bring different departments of government together in forums such as Round Tables
- Hear from community
- More transparent information
- Pensions that actually give people a living wage
- Tax incentives/breaks – if active
- Equity...across provinces
- National Pharmacare [optical, hearing, dental, occupational therapy, physiotherapy]
- Forming partnerships
- Conferences that are cross-sectoral so people can gain a better perspective of the issues, concerns and goals of the various groups. Use webinars/technology to communicate with partners nationally. Governments at all levels must be approached, educated and involved in the issues of concern and in finding solutions (this includes

POTENTIAL ALLIES & PARTNERS

- C.N.I.B
- Deaf Blind Association
- Occupational Therapists
- 1-800-O-CANADA
- Physiotherapists
- Seniors secretariat & services
- Baby Boomer generation – piggyback –ride the tsunami wave
- Municipal government
- Accessibility advisory committees
- Provincial government
- Federal government
- An advocate/friend – your “go-to person”
- People First
- C.A.C.L. (Canadian Association for Community Living & locals
- Non-profits (generic, seniors, disabilities)
- Neighbours

municipal governments, Chambers of Commerce etc.). Cohesive advocacy efforts formulated by consumers/self-advocates, seniors advocacy groups coming together on issues

- Practices to look towards/expand upon:
 - Accessibility for Ontarians with Disability Act in Ontario
 - Long term care legislation (ONT)
 - Transfer money from closing institutions into community based supports and services
 - Age-Friendly initiatives across Canada, that are inclusive of disability
 - Intergenerational housing

Futures Planning:

- Informational needs could be better met if organizations/companies had telephone systems where a live person answers the phone and people are given enough time to process information and ask questions.
- Larger print/alternate formats should be used by any organization, government department etc. who is providing information to older adults
- Integration of services as a matter of course. Services offered to all people based on need rather than on a label
- Shift away from crises driven responses

Later Life Pursuits:

- Collaboration/Co-operation – break down the following silos:
 - Government with Government
 - Government with Non-Profit
 - Non-Profit with Non-Profit
- Formalize specific representation on issues – don't just rely on ad hoc representation (hope that someone will show up). Make sure the right people show up.
- Don't take no for answer
- Compare goals from the Coming of Age in 2004 to see what, if any changes have occurred.
- Changes start with one person
- Unified communication on key points
- Finding ways to make better use of the internet to share links, resources, information
- Communicate positive communications to society
- Increase awareness in various segments of society
- Partnering with Consumer Protection Bureau & Securities Commission
- Access seniors as volunteers
- Doing a lot more networking across systems as well as organizations
- Enroll and enlist University system to help move towards a change in terminology, change in attitude, enroll Service clubs, Chambers of Commerce, United Way, NGOs, churches and other place of worship.
- Message of inclusiveness and support
- Mythbusters: seniors are cool and are contributing to society

- Choice can only be fostered by awareness and opportunities, therefore, there must be opportunities and support to explore choice

Find one champion, identify allies: political businesses, non profit groups

Generic Services:

- Community Role:
 - Be known, contributing and vocal in our communities.
 - Spend time building relationships with other community groups
 - Show up at community events (ex: MP/MLA hot dog lunches)
 - Give back to other community groups so that we can partner when needed
- Cross-Sectoral Role:
 - Everyone join the aging and developmental disability community of practice
 - Partner with generic services (ex: via community coordinator or equivalent)
 - Link with seniors re: developing a national Alzheimer's strategy which in turn will guide funding, service development, etc.
 - Have Abilities MB (or equivalent provincial coalitions of service providers) sit on committees in other sectors
- Build Voice and Power:
 - Need to have a loud, unified voice (values based message)
 - Find where the power is and influence it (ex: key committees)
 - Facilitate 'practice meetings' to prepare for meetings with politicians
 - Refer people to local political official (ex: MPs, MLAs)
- Education and Media:
 - Allow time to give information, increase awareness cross sector
 - Educate that people with disabilities age (combat 'perpetual child' myth)
 - Build media attention
 - Partner with public broadcasting
- Engage Families:
 - Engaging families ex: act as a bridge, organize meetings, create opportunities for families to tell their stories
 - Engage families in planning and education as people age (ex: prepare them for the fact that goals may change as you age)
 - Link families/caregivers to support groups (specific and generic services)
 - Build health care facilitator role in cross sectoral linking i.e: Ontario has health care facilitators that build that bridge between disability services and generic health care services
- Pay support workers a wage that recognizes the important role they play

Dementia Supports:

- Formalized staff training opportunities for both long term care/health staff and staff working specifically with people with dementia and an intellectual disability (I.D.). The training needs to be offered to the direct line staff.
- Ongoing in-service opportunities followed up by tailored coaching and mentoring from supervisory staff.
- Training that focuses on providing information about the disease progression in both people with and without I.D. and the interaction between the disease and the individual.
- Staff working in health care and long term care need to receive information about what it means, in general, to be someone with I.D. and the skills, abilities and different learning modalities for people with I.D.
- See families as experts – view them with respect, include them in decisions and truly hear what they have to say.
- Launch an anti-discrimination campaign so that individuals with I.D. and dementia have the same access to the supports and services offered to the general population. This includes the right to be supported in a long term care facility if it is determined that is the best resource.
- Creating supportive physical environments, in the community, for all people with dementia
- Work towards inter-agency inter-dependence. Supports, training, resources developed cooperatively. Sharing best practices, resources etc.
- Advance planning with the individual and their support network, early on in the diagnosis of dementia, so the person can make choices and plan ahead for their needs

Preparing Support Staff for Aging Issues:

- Boards of agencies need to adopt aging in place mandates
- Specific training and education, aimed at aging related issues, for support staff
- Create a provincial guide for staff training
- Ongoing networking conferences to foster and build relationships between generic services and services that work specifically with people with an intellectual disability
- Partnerships with health services to share knowledge and to share costs when it comes to aging related health needs
- Need increased resources for grief and end-of-life/palliative care (especially for younger support staff)
- Including direct care staff in discussions about meeting the needs of older adults and providing applicable staff training
- Developing resource guides to all available resources for older adults, with an without a disability

Goals

Everyone should be in the community and the mistake of building separate places for older adults with intellectual disabilities needs to stop at once

Social Policy Reform:

- Make advocacy for living wage legislation a number one priority as it creates links between us for a common vision. Ensure an adequate income for all
 - Increase awareness, knowledge building. Seniors with and without disabilities need to connect and understand the commonalities amongst them. All levels of government also need to understand the issues and to be coordinated in their efforts
 - Strong advocacy for all. When common issues/concerns arise each advocacy group must band forces with each other for a united front rather than also working in their silos. Develop a framework for organizing and mobilizing collective voices.
- Geographically and provincially enlist key leaders from government and non-government to find solutions together
- Continue to enlist all levels in government in listening to consumers

Futures Planning:

Goal 1: To Be Financially Secure.

- Organize a national dialogue about income security reforms and consistency across provinces
 - Enlist other poverty reduction groups, other like-minded groups, grass roots organizations and people with political influence from all levels of government
 - Share progress through networking opportunities such as this dialogue, user friendly technology “create an app for that”, Dec. 1-3 – Policy Reform Ottawa: International Day of Persons with disabilities

Goal 2: To live where we want and with whom we want in a safe, accessible and affordable home in a welcoming community.

- Utilize Article #19 and #12 of the U.N. Convention to create awareness and move on implementation
- Keep working on closing institutions and preventing re-institutionalization
- Ensure people have the knowledge of the options that are available – creative new options
- Enlist the Right to Live in a Community task force (C.A.C.L./People First), unions, private and business sectors, communities and general citizens
- Share progress through the Institution Watch magazine, web sites and national and community dialogues

Goal 3: To be surrounded by people who love and care about me

- First Steps:
 - Start with one person—a “go-to” person or your champion—who is unpaid and is someone you choose
 - Grow your network from there
 - Getting out in the community – engage in community and they will engage with you
 - Share your interests, passions and gifts
- Enlist: Family, friends, knowledgeable support staff, community/grass roots

Later Life Pursuits: unable to locate goals that were identified.

Generic Services

Goal 1: Practice and invest in community development

- Collaborate/partner/be involved in cross-sectoral groups and events and in general integrated services
- Be respectful, open and non-judgmental regarding people’s language, perspectives, etc. when they have not been involved in the community inclusion movement.

Goal 2: Build a national voice

- Identify key messages (ex: 3) that can be carried forward cross-sectoral and cross disability, cross-senior, disability and community)
- Build on social determinants of health (ex: NB: safe, affordable, accessible housing)
- Lobby:
 - always lobby and start with person who is directly affected (ex: person with disability, family member, senior)
 - include municipal/provincial members

Goal 3:

- Within one month, everyone in the room connect with a person in generic services (i.e., senior centres, senior adult program, home care) to seek and share information

Dementia:

Goal 1: Strategic Planning

- Government departments and organizations that support people with dementia, with or without intellectual disabilities, need to have a clear, accurate picture of the current and future needs of families and individuals
- Once a picture is formed of the needs of families and individuals then there must be a thorough assessment of the current and future needs of agencies supporting people with dementia and the services that will need to be offered

Suggested steps:

- Provincial, geographical working groups to prepare a template for action
- Tools to be developed that will assist families in making decisions as they support their family members with dementia
- Explore and investigate community integrated models
- Much of this information is already a part of work done by the National Task Group on dementia and people with I.D., out of the U.S. Guidelines on structuring community care, assessment and screening etc. can be found at [//aadmd.org/NTG](http://aadmd.org/NTG))

Who will each of us find with whom we can hold hands and play to move forward?

Goal 2: Education – What is Alzheimer disease and related dementias? (ADRD)

- For support staff who work with people who have an intellectual disability and ADRD – what are the skills required to support people with the disease
- The medical system requires education and advocacy in order to be prompted to use diagnostic tools that have been developed specifically for people with ID/ADRD so that people receive accurate diagnosis
- The health care system and those who support people with ID must develop a common language to improve communication and avoid misunderstandings and this can only be done collaboratively. There must also be mutual understanding of the needs/perspectives of all parties and what it means to assist people to maintain their functioning for as long as possible
- Training developers must be identified with potential partnerships between the Alzheimer Society, health services and agencies that support people with I.D.