“A UNITED VOICE”

Alberta Disabilities Forum

Caregiver Community Consultation

A Report on the Findings

20 November 2008

Introduction

Between 21 July and 21 October 2008, Alberta Disabilities Forum (ADF) and Alberta Seniors and Community Services, in partnership, held 23 community consultations with caregivers and the users of caregivers' services (individuals, families) in fifteen centres around the province. The purpose was to identify the need for respite and other supports or information. "Family Caregiver" was defined as an individual who provides unpaid help to a family member with disabilities and seniors.

The sessions were held in the following locations: Calgary (2), Camrose (1), Drumheller (2), Edmonton (2), Fort McMurray (2), Grande Prairie (2), Lethbridge (2), Medicine Hat (1), Red Deer (2), St. Paul (2), Vulcan (1), Whitecourt (1), Blood (1), Tsuu T'ina (1) and Peigan (1) Reserves.

Workshop Format

The same agenda and process were used in all sessions. Representatives of ADF and Alberta Seniors and Community Supports opened the session by welcoming participants and presenting an overview of their organizations, the purpose of the session and how the information would be used. The ADF representative also described the Respite Care Demonstration Project.

Following a warm-up exercise, participants worked in small groups to identify the challenges and potential solutions, all of which were recorded on sheets of paper posted on the walls. The small groups were given an opportunity to report back to the large group. Each workshop was approximately two and a half to three hours' long. Community Services Consulting Ltd. led by Peter Faid of Edmonton, facilitated the workshops.

For the Aboriginal consultations, a representative from the ADF met with families on the reserves and introduced the respite project and asked family members for their input and solutions concerning respite services.

Overview of Findings

Generally, participants identified the same key challenges and solutions regardless of location. The three most important challenges were: finding and retaining well-qualified, professional caregivers; finding suitable respite services; and coping financially. A few groups in the smaller centres identified additional issues associated with life outside a large city, such as the lack of public transportation, the shortage of services and programs, including publicly funded housing, and the disparity in choice between urban, rural and Aboriginal. The other key themes are presented here, illustrated by examples of participants' ideas quoted verbatim. Given the inter-related nature of the themes, the same ideas occur more than once.

Challenges and Solutions by Theme

I. Finding and retaining well qualified professional caregivers

Challenges

- There is a shortage of qualified caregivers, so families have difficulty finding paid staff to help and relieve them.
- The shortage is contributing to burnout among professional caregivers as well as families. Agencies are unable to compete with larger organizations for staff because others can pay more.
- Staff turnover is high, which affects the continuity of care and makes it difficult to build trust.

> *We have taken over the care of our 40 year old brain-injured son because the agency's care was not adequate due to insufficiently trained staff and inconsistent care. We are trying to find our own program and treatment, but are really having to search for resources.*

- People sometimes have to relocate to find care.
- Caregivers are not always suitably trained. They need to know how to address clients' physical needs as well as their emotional well-being. Training is needed in areas like first aid and conditions arising from being bedridden and foot care.
- Paid caregivers often lack understanding of the care needed by people with specific disabilities and are not always compassionate or empathetic for various reasons.
- There is no standardized education program for caregivers, so knowledge and standards are inconsistent.
- Families need caregivers who are trained, suitable, flexible and available at *all* times.
- Steps need to be taken to attract more people to the field.
- More male caregivers are needed.
- On a Reserve, safety is not considered an issue by the Personal Care Attendants (PCA) because they do not obey any protocol.
- PCA's are not held up to any employment standards. Even if they commit a wrongdoing, these individuals are not reprimanded for their actions.

Solutions

- Pay siblings, parents or other family members who provide care.
- Speed up the immigration process that allows caregivers from outside Canada to come here and provide services as paid caregivers.
- Advocate for and promote jobs in the sector.

- Form partnerships with schools and post-secondary institutes to eliminate stereotyping and attract more people into the profession. Introduce in high school.

- Validate the profession through accreditation and make it more attractive by increasing wages, benefits and the opportunities for ongoing training and education.

- Fund community colleges to provide adult training courses and subsidize individuals who take caregiver training modules.

- Extend existing resources and encourage people to make better use of them. (Foundations Training offered by the Alberta Council of Disability Services; the STRIVE program offered by CES; and on-line distance education offered by McEwan College are examples.)

- Provide a multi-media training package using DVD and reading materials on disability-specific issues and needs.

- Offer workshops and training materials to caregivers on topics such as worst-case planning and recognizing escalating situations. Some people who will be giving care for years.

- Provide families with training resources on how to recruit staff.

- Create accountability standards for Personal Care Attendants employed by the Reserve.

- Training in hospitals concerning aboriginal culture and needs.

The rehab course at Red Deer College was discontinued because graduates couldn't make enough to support a family

II. Finding suitable respite services

Challenges

- Some daily respite is available through home care and day programs, but it is not enough.

- Respite is designed for the schedule of others, not the caregiver. There is no weekend in-home respite because of staff shortages.

- The waitlists for respite are long.

- Respite has to be available when needed, not just once a month. It needs to be more flexible and responsive – available on short notice and in an emergency.

> *I have difficulty finding respite for my wife who has MS. What would happen if I had an accident?*

- There is a need for timely, culturally appropriate emergency, occasional, part-time and seasonal respite (for example during seeding and harvest).

- The lack of out-of-home respite care means that family caregivers have no chance to get away on holiday.

- There are no free respite beds in long term care.

- There are not enough respite workers because the pay is low and is not competitive and the job does not offer benefits.

- Staff are not well enough trained, so do not understand the needs.

- Staff turnover is constant.

- Transportation in rural areas is expensive for staff.

- On a Reserve, there is a 6 month waiting period on average to access Respite Care Service, and if you do not use it when it becomes available, you are put back on the bottom of the list.

- Personal Care Attendants only work from 8 a.m to 4 p.m and do not work on weekends.

- Each family can only receive up to ten hours of care per week from Reserve Home Care Services.

Solutions

- Fund respite activities in existing facilities, like the William Watson Lodge, where people can meet in support groups and do things together.

- Set up respite care homes with free beds, day programs and recreational activities, age-appropriate groupings, and quality care.

- Stay away from institutional respite.

- Expand existing programs such as Crossroads in Camrose.

I would like to stay in my own house for respite, but that's not possible.

- Set up services such as a 24/7 help line with information on where respite is available, an online peer support group, and a Provincial Caregivers Network.
- Increase the number of day respite options in the community; offer evening and early morning respite.
- Offer respite services at various locations.
- Make sure that respite is appropriate, so it's not a case of taking whatever is offered. It has to be flexible and meet specific needs, such as during the day.
- As much as possible, match the age, gender, and services of the person needing respite to acquired services.
- Provide in-home respite for those who cannot leave their homes for reasons such as food allergies, lack of familiarity, accessibility, and mental and physical comfort.
- Create a registry of care providers; set up cooperative and peer respite options.
- Identify the needs; then develop age appropriate, affordable respite.
- Make caregiving a more professional job with higher pay so that more people will be attracted to it.

I want to put my husband into respite for a week or two, but Duty Place is private and we can't afford the $865 a week fee.

- Introduce a case coordinator to ensure respite needs are met on a case-by-case basis.
- Make regular respite available through Home Care and ensure that the training and resources are sufficient to do so.
- Set up a new program under Alberta Health and Wellness that is strictly for respite.
- Introduce a provincial respite care program with grants to individuals or the community to support caregivers and relieve their stress levels.
- Explore new, creative models of paid and unpaid approaches to respite.
- Train more respite caregivers and compensate them appropriately.
- Accommodate the caregiver's needs for courses, programs and recreation on a regular basis.
- Allocate more hours of home care to each family on the Reserve.
- Create flexible hours and flexible respite care services, services that represent healthy and natural time apart.
- Creation of day and youth programs.
- Increase the number of staff for the organizations outside of the reserve.
- Establishment of a Disability Guidance Office that will assist Aboriginal people with a disability.

III. Coping financially

Challenges

- There has been no increase in financial support for a number of years and many expenses are not covered.
- The costs of medication, therapy, private care and nursing homes are too high.

[With regard to respite]
One size does not fit all!

- Because of the discrepancy in classifying people with disabilities as dependent versus independent, parents aren’t eligible for benefits.
- The administrative efforts required by family-managed programs are not recognized, and there are no funds for the extras that families must provide.
- Transportation or travel is not funded, even when a loved one has had to move to a facility elsewhere.
- Services are cut back when an annual income reaches $34,000.
- People have to travel to programs, and that is costly.
- The demands on caregivers’ time results in costs – loss of pay, expenses for travel or additional support.
- If there is available funding for respite service, it hard to obtain because of lack of information sharing on the reserve.
- How do you plan for the future when funding is not ongoing and continuous? This leads many people on the reserve to rely on AISH rather than reserve funding.

Solutions

- Compensate spouses, other family members and friends who provide care.
- Recognize that caregivers who quit a job to provide care lose CPP and other employment related benefits.

If someone were to give up their employment to care for a family member, is money available to help them?

- Educate families on how to allocate respite care funding in order to retain staff, and receive appropriate services.
- Compensate families for their administrative efforts.
- Remove the income-based eligibility requirement for funding and health benefits for caregivers.
- Allow direct billing of prescriptions and equipment that family caregivers need to purchase for their loved ones.
- Increase funding for companion services and Home Care.

- Fund travel expenses for the family in cases where the family member with a disability has to receive respite services outside of their community.

- Increase the funding threshold to reflect the reality of costs today.

- Conduct regular cost-benefit analyses to justify the funding.

- Make tax credits more accessible and extend eligibility to caregivers of all types of disabilities.

- Base funding on functional assessments, not IQ, and ensure it reflects individual differences. Clearly define the term “disability.”

- Organize a task force, reporting to the premier, to examine future care funding for people with disabilities.

- Plan and manage funds based on individual needs and an annual functional assessment.

- Set up a Registered Disabilities Savings Plan.

- Use input from caregivers to make government funding criteria more reasonable and fairer.

- Expand resources such as The Lending Cupboard in Red Deer.

- On the Reserve, distribute funding from the Disability Fund to families.

- Coverage of travel expenses for medical appointments outside of the reserve.

- Allocate funding for house maintenance, and increase funding for creating accessible homes.

- Allow living allowance for family caregivers unable to access employment.

- Increase funding for self-managed care because Personal Care Attendants ask for higher wages.

IV. Avoiding and dealing with burnout

Challenges

- Caregiving creates emotional and physical stress.
- Family caregivers are tired out and worn out, but have no breaks and nowhere to get away to.

> *We need to look after our caregivers better and address issues such as burnout and pay and benefits.*

- Caregivers and the person they're caring for often experience isolation, depression and fear of the future and have to deal with stigma.
- The caregiver feels worry, concern or guilt if he or she gets time away.
- Caregiving is a 24/7 job, so people need coping skills.
- If the health of the caregiver becomes poor, he or she has trouble providing care.
- The caregiving role has a profound effect on the caregiver's quality of life – financial, emotional, spiritual and physical.
- People need to know the signs of burnout (mental health awareness).
- How can caregivers cope with burnout? They need counselling.
- It's hard to balance caregiving of a family member and paid employment.
- Family caregivers are overburdened with work and under financial stress, but there are few programs for them. They need help with self-care, time management, and the emotional challenges.
- Emergency respite is not available, and the criteria for other respite services are inflexible. It's hard to screen and hire reliable staff.
- Caregivers of people with mental health issues have no system for respire or any supports.
- Caregivers sometimes experience abuse.
- Family caregivers need help with household tasks – cleaning, shopping, meals, yard work, etc.

Solutions

- Provide counselling support for caregivers, someone they can talk to. Revise the mandate of the Help Line to include counselling.
- Establish mentors, buddies and peer support groups for caregivers.
- Support day programs with meaningful activities for families' loved ones.

- Increase the number of respite beds and the options; give people the freedom to choose the appropriate usage of respite.

> *I need someone to talk to. I'm feeling overwhelmed. What support is there for family caregivers?*

- Set up communal respite services in care facilities or hotels on a permanent basis.
- Make respite more flexible to support families attending caregiver college or to help with medical appointments.
- Set up a website for caregivers, featuring a chat room, a web-medic, ideas to reduce stress and information on how to find funding, etc. Survey caregivers beforehand to determine what they would like to see on the site.
- Increase funding for Home Care.
- Publish a caregiver handbook.
- Introduce mechanisms to link caregivers to service providers.
- Ensure assessments are conducted quickly and that supports are in place immediately.
- Provide someone who can advocate on behalf of individual caregivers.
- Recognize family caregiving as a legitimate occupation and pay family members to provide care.
- Reduce the bureaucratic processes that caregivers have to follow to make life easier for family caregivers.
- Introduce steps to improve coordination between services and make navigation easier.
- Promote alternative health options such as meditation and yoga.
- Educate families – as a unit – about disabilities and how to cope. Make them aware of the need to reduce stress, for example, by having a regular night out.
- Develop a holiday retreat centre like William Watson Lodge for the North.
- Provide regular, reliable opportunities for respite.
- Make services easier to access. Reduce red tape and wait lists.

V. Knowing where to get information and how to navigate the system

Challenges

- Caregivers do not know where to go for information about services and the dollars available.

> *My hope was to get some answers*
> *about navigating through PDD.*
> *It's a nightmare, or a bad dream!*

- There is a need to improve the flow of information across agencies and between agencies and the community.

- The maze of services involves too many different ministries, sets up bureaucratic roadblocks and makes the system too difficult to navigate.

- There is no one-stop shopping, no single point of access.

- Funding for caregiving involves so many complications – paperwork, HR issues, changes in staff, freedom of information regulations.

- People have difficulty navigating the various systems: health, rehab, AISH, PDD, schools, etc.

Solutions

- Set up a single point of entry phone number to the system for all individuals (children and adults) and all services, including respite. Ensure it is operated by a real person and independent of government – a place where callers can be referred to the agency or service they need.

- Hire social workers who know the services and systems.

- Make more funding available for training, networking by service providers and the work of the Service Providers Council.

- Develop a regional 411 line and a website so people can get the information they need. Remember: people prefer to talk to others, and not everyone has a computer.

- Publish a guide to government ministries.

- Offer communication options that reflect the various ethnic origins, such as interpreters to match resources and clients.

- Set up a centralized organization, similar to ADF, with information and coordinator who can refer caregivers to relevant resources.

- Assign one person (case manager) to follow through with each family (caregiver and patient) across the systems. This person can provide information to the family and make referrals to services, specialists, etc.

- Assign case managers to specific disability groups or organizations.

- Create a non-profit, central information agency that can deal with issues of a private nature.
- Provide information in simple, easy to read formats.
- Make brochures and other information available to everyone – doctors’ offices, disability organizations, grocery stores, etc.
- Publish a monthly article in the Edmonton Examiner and newsletters.
- Use a team approach to help individuals. Make it user friendly and responsive and offer bite size pieces of information such as a list of respite providers.
- Ensure that families and caregivers have information on where to go for help. Even mental health workers lack this knowledge.
- Need for a neutral advocate for Aboriginal people with disabilities.

VI. Obtaining other supports and services, including peer support

Challenges

- Families are often required to find and manage caregiver staff but don't know how to.
- Information and support from the medical community is often lacking.

> *My son has cerebral palsy, and I was his primary caregiver until I lost my leg. I moved here one month ago and am still trying to find help with accommodation and other services.*

- Families need help to address safety and behavioural concerns and prepare other family members for the impact of looking after a loved one with a disability.
- There is no support or referral as a person leaves hospital and no crisis planning or management to support a caregiver.
- Care recipients need more age-appropriate services.
- Care receivers could often benefit from low impact exercise equipment and the opportunity to attend sports and other activities.

> *I need help planning for my child's adulthood.*

- Families are often not prepared for the challenges associated with providing care to a loved one.
- Caregivers need training on transitions at different ages and for all disabilities.
- Transitions are difficult and involve grieving and a change in relationships.
  People need information on what to expect and what to do. Parents worry about how to keep in touch with children and know that they are safe when they move out on their own.
- There is no assistance to help make the transition from Children's Services to Adult Services (PDD or FSCD).
- Caregivers would benefit from recreational opportunities, which help to reduce stress; but they often have no money, can't drive and have no one to go with.
- Both caregivers and recipients of care need support from peers and others, but they don't have opportunities to meet each other or to seek that support.
- Extend the scope of the Calgary Handibus service to enter the Reserve.

Solutions

- Provide or subsidize homemaking services delivered by Home Care.
- Provide information to paid caregivers on how to deal with behavioural challenges as part of the caregiving process.

Trying to find equipment is a source of stress. I need a wheelchair on loan.

- Publicize the availability of resources such as the Brain Injury Survival Guide, which is available through 1-800-disability link.
- Teach families to develop a behavioural and safety plan for care workers that will also be valuable if workers change (turnover).
- Provide families with training or other help related to case management, individual service plan development and transitional and succession planning.
- Offer incentives to agencies that provide services such as bookkeeping for families using care workers. Families do not want to be employers.
- Set up a service that families can contact for advice and training on HR issues associated with hiring caregivers, such as conflict resolution, legal implications and the like.
- Develop a list of agencies that caregivers can contact for advice and to get feedback from other users.
- Create opportunities for caregivers to set caregiving aside and participate in social and spiritual activities.
- Set up transparent, accessible caregiver support groups. Arrange meetings by neighbourhood or area.
- Host caregiver gatherings where care for dependent family members is available.
- Offer recreational therapy to care recipients, such as music therapy.
- Establish an Adult Day Care Drop-in Centre, like the START program, with programs that appeal to a wide range of interests.
- Introduce mechanisms of peer support such as support groups; retreats; conferences and teleconferencing; online programs, chatrooms and information; and a peer matching service for facility and service placement (like the CPA Peer Odyssey Program).
- Establish dementia and palliative groups to help people cope with emotional and practical issues.
- Extend peer supports to all rural communities and make them available in native languages.
- Ensure families have access to legal support for issues such as mental competency and guardianship.
- Take steps to address the gaps in services, particularly those affecting the transition from youth to adult.

VII. Coping with the bureaucracy (inflexibility and duplication of efforts)

Challenges

- There is too much bureaucracy: forms to fill out, unanswered questions, confusing eligibility requirements, repetition and not enough coordination. People get bogged down.

- People must jump through many hoops and are scared to push back for fear of losing services. There is no appeal process for someone denied services.

Will someone listen so the system can be changed to work more effectively?

- Several different government departments are often involved in a person's life.

- Ministries and organizations do not work together and organizations are not connected, so there is no pooling of information or resources.

- Government mandates are neither flexible nor aligned.

- There is no standardization across agencies. They all have different processes and support is inconsistent. They do not communicate and are not coordinated.

- Regional and provincial coordination of respite programs and resources is missing.

- It takes too long to see professionals and be diagnosed for early intervention.

- The transition from child to adult often involves moving between agencies, services or health care facilities.

- Services are inflexible. They must meet the needs of the caregiver, not the program, which is what happens now.

- There are no cohesive and consistent criteria for funding and support.

- The system is crisis driven.

- When the Chief of Council Members do not agree on issues, people with disabilities stop receiving any funding.

- An application process for installing a ramp takes more than a year.

Solutions

- Streamline the process, eliminate duplication and ensure that departments share information; for example, use the same application form for multiple departments, programs, and services.

- Work with PDD and home care to make better use of resources. Remove the boundaries, increase flexibility, and widen the mandate of both.

- Encourage more cross-ministry work to reduce duplication and referrals.

- Consider the needs of individuals, and stop assuming that people are trying to take advantage of government. Introduce checks and balances to catch people that scam the system.

- Conduct multi-purpose assessments and allow the results to be shared between departments to avoid duplication. The information requested is always the same.

- Cut down the repetitive paperwork; use computer technology to store and share information.

- Create ways for agencies to be cross-funded by government without the bureaucracy.

- Introduce a multi-purpose assessment that is conducted by a team, including a doctor.

- Reduce government administration and bureaucracy.

- Limit the consent requirement to one informed consent for all programs and services received. FOIP is a deterrent to collaboration.

- Set up an ombudsman-like office where families have access to community social workers and legal council who will act on their behalf.

- Clarify the definitions of family member and caregiver as a way to make funding more flexible.

- Improve the transition from children's to adult services by using the same doctor for example.

- Use a Youth in Transition Planning Protocol.

- Prepare a list of resources to be provided to families at the time of diagnosis. Include information on funding and supports; the names of associations, support groups, and lobby groups; and details on income tax rebates and deductions.

- Encourage groups to work together and share resources.

- Develop a system of navigators to convey information to families from all areas – health regions, municipalities, PDD community boards, Children's Services, service providers, etc.

- Improve communication between organizations to reduce duplication and close the gaps.

I'm glad to see two groups working together!

VIII. Dealing with a lack of understanding of disabilities and the caregiver role

Challenges

- There is a lack of understanding – by doctors, other health care professionals and the community – of the needs, challenges and stresses experienced by caregivers and family members.
- Employers will not hire people who need time off to provide care to a family member.
- People with disabilities are still treated like second-class citizens, when they are all contributing members of society. We need to remove the stigma.
- Family caregivers are often not respected. Their views are questioned or minimized.

There is no single disability organization in Fort McMurray.

- Caregivers are not recognized as caregivers, especially when they are females caring for a spouse or children.
- The aboriginal community does not understand what disability is. Old people and individuals with disabilities are not considered “worth the funds” and so are left on their own.

Solutions

- Make disability awareness courses mandatory for health care professionals.
- Work with hospitals to provide workers with disability-specific knowledge.
- Develop educational programs for youth and the general public.
- Start educating people early. Add a component to the CALM curriculum explaining what caregivers are, what they need, how to support someone needing care and the basic survival skills.
- Ensure services such as EPS and EMS are trained to deal with a crisis involving someone with a disability. Model the training on the elder abuse program.
- Conduct a public awareness campaign to raise awareness of the challenges of caregiving.
- Sponsor awareness training workshops on specific disabilities.
- Take steps to recognize the importance of what caregivers do.
- Ensure that physicians are sufficiently informed when they conduct their initial diagnosis.
- Promote the availability of services to increase awareness. Put up posters in the community and use other marketing strategies as part of a campaign.
- Offer workshops similar to the Living with Cancer workshop, and disseminate information about these sessions.

IX. Finding suitable housing, especially for young people

Challenges

- We need housing that is affordable, accessible and disability and age-appropriate – hostels, as well as lodges.
- There is a waiting list for housing.
- People can get caught between two systems, such as AISH and housing.
- People on AISH are living in hotels and not getting the supports and services they need.
- There is nothing available for low income families trying to access appropriate housing.

The only help for young people with disabilities is through the long-term care facility.

- There is a need for disability- and age-appropriate housing. Young people with mental health issues often have no housing or support. People with dual diagnoses fall through the cracks.
- Youth in need of respite have to go into continuing care.

Solutions

- Introduce rent ceilings.
- Set up a co-op housing project where services and supports are on site.
- Give tax incentives to developers to build affordable housing.
- Set up group homes for young people.

Some people in Vulcan are paying all their income on rent.

- Lobby government for more spaces for adult care and long-term care for young people.
- Remember: affordable housing is not the same as low-income housing.
- Work with organizations such as the Shriners who are funding a 24-hour accessible co-op residence.
- Develop a housing program that matches roommates by considering each person's strengths and needs.

Conclusion

The issues raised by caregivers in the province are shared by nearly all participants despite differences in location, income, and cultural context. Notwithstanding these differences, these consultations displayed strong province wide support for addressing respite as an outcome, and to provide respite care services that are flexible, reliable and needs based.