

# 2009 Self-Advocacy Summit Report to the Funder



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*This is about more than mountains,  
water and trees. The mountains are like  
challenges for people with disabilities.  
You can climb a high mountain; you just  
have to try. People with disabilities can do  
anything if they just try. You have to look  
over the disability, not at the disability.*

*- Tammy Poirier Crosby*

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*November 27, 2009*

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## *Table of Contents*

|   |    |
|---|----|
| Plain Language Summary . . . . .                                  | 2  |
| Brief History . . . . .   | 3  |
| Theme and Goals . . . . .   | 4  |
| Plan to Achieve Goals . . . . .                                   | 4  |
| Outcomes . . . . .  | 6  |
| What Is Needed to Achieve Goals Identified at the Summit. . . . . | 10 |
| Appendices . . . . .  | 15 |
| Summit Program . . . . .  | 15 |
| Participant Feedback Details. . . . .                             | 31 |

## Plain Language Summary



The 2009 Self-Advocacy Summit was a big success. We did what we said we would do. Self-advocates learned things from each other to use back home. We were all loud and proud. Everyone was excited to meet other self-advocates from all around Alberta and catch up with old friends. We talked about what was important. We talked about how we could make life better for everyone. We made a video of what we did. The video will help tell stories of what self-advocates in Alberta have done. We talked about how we can give self-advocates a stronger voice.

We want to use what everyone said to form an Alberta self-advocacy group. The Alberta self-advocacy group will have self-advocates from all regions. We will ask for money and help so the group can meet and do its work. This group will ask self-advocates all over Alberta what they think. We will let the government know about this. This group will also tell self-advocates and groups in every town things to help them take action. The group will make an action plan out of what people said at the Summit.

Here is what self-advocates said is important and what will make things better:

- 1. We want to be accepted as equals.** To do this, each of us needs to do two things. First we need to take responsibility for what we do. Second, we must get involved in our communities. When we show others what we can do, they will be on our side. We can tell our stories at schools and group meetings. Self-advocacy groups can tell others that we need things in plain words. That way, we can understand and have our say. We can help folks make their words plain.
- 2. We want to have strong relationships.** To do this, we need workshops and information about how to make friends. We need to join groups and clubs and go to meetings and dances. It is there we can make friends. We need to phone and e-mail our friends and meet them for dates. We need money and support to get out to places to find and keep friends.
- 3. We want enough money to live on.** We need more money from AISH. And we need to keep more money from jobs. We need rent, utilities and transportation to cost less. To get these things, we need to talk to MLAs. We can tell them what it means to have so little money when things cost so much. We need to tell them what would help.
- 4. We want services that meet our needs.** To do this, we need government to ask us what we need. Government should listen to us when they want to make changes. We need information to be easy to understand. Then we can work together to give government good ideas. We also need AISH and other program rules and forms to be simple. That will help us not make mistakes.
- 5. We want nice, safe places to live.** To do this, we need to tell government about our needs. First, we need more places we can afford. Second, those places need to be in good neighbourhoods. Third, we need agencies and PDD to listen to us. If we need to live alone or have a pet to make us feel good, then hear that. Do not make us live with others to get the services we need if we do not want to. We need to be able to pick who we live with and the rules for our home.
- 6. We want to be strong self-advocates.** To do this, we need workshops on how to be leaders. We need information about issues to be in plain language, Plain words help us understand. We need



people and money to support self-advocacy. We need self-advocacy groups to help us. That way we can plan things that give us a say in our communities and what governments decide. We need a provincial self-advocacy group and more Summits so we can feel united and share what we have done.

## Brief History

This is the third Self-Advocacy Summit in Alberta. The first Summit was in 2004. It took 5 years to organize because while there were many self-advocates and self-advocacy groups around Alberta, there was no single provincial group to which they all belonged. It took awhile for the planners to figure out how they would work together without one person or group being the “boss,” or without individuals or groups having to belong to a particular organization, accept a particular philosophy, or adopt a particular campaign to be part of the provincial gathering. The vision was that the Summit would be about Alberta self-advocates connecting with each other, teaching and learning from each other, and being proud of themselves and each other as people with disabilities. At the time, most regional self-advocate conferences had speakers without disabilities, so it took time for self-advocate planners to envision themselves as the speakers and teachers. The months leading up to the first Summit were documented as part of a video funded by PDD’s Community Research Program called *Self-Advocacy in Alberta: A Growing Movement*.

The first Summit was eye-opening for participants. They were excited to meet self-advocates from all over Alberta and hear about what other groups were doing in their communities. They found out that the issues that people with developmental disabilities faced in their own community were pretty much the same all over.

A second Summit, held in 2006, focused more on group discussions of common issues identified at the first Summit (housing, AISH, transportation, services and plain language) and what could be done to resolve them. A general action plan was developed and some efforts were made for groups to work together to follow up on issues related to housing. Action was limited because although regional funding supported self-advocacy activities in the communities, it was not designed to routinely support the more expensive transportation, meeting and support costs for province-wide ventures. The Summit was documented in a video called *A Voice of Our Own*.

Planning for the third Summit began in early 2008 (conference call April 11, 2008). All six regions were involved in planning at some level, with self-advocates from five regions participating in face-to-face meetings. Although some self-advocates were included in conference calls, most found it difficult to participate in the conversation without the visual cues provided by face-to-face interaction. This is an important factor to consider in funding of self-advocacy ventures.

Key partners on the 2009 Self-Advocacy Summit planning committee were the Central Alberta Advocacy Network (CAAN), Disability Action Hall (Calgary), Northeast Region Community Councils and PDD, Northwest PDD, the Self-Advocacy Federation and SKILLS Society (both in Edmonton) and the South Region Self-Advocacy Network (SRSAN).

Donations of time and/or money were provided by the Alberta Ministry of Seniors and Community Supports through its Persons with Developmental Disabilities (PDD) Program, all six regional PDD Community Boards,



the Northeast region service providers, Save-On-Foods, Red Arrow Motorcoach, Southern Alberta Individualized Planning Association (printing), SKILLS Society (accounting), and K. K. Biersdorff Consulting (website and final report preparation). Numerous self-advocates and supporters obtained or donated door prizes.

### *Theme and Goals*

The theme for the Summit was *Self-Advocacy in Action*. Self-advocates on the planning committee identified what they wanted as Summit activities. These activities could be categorized into program areas captured by the acronym ACTION, namely

- **A**rts and Disability Culture
- **C**onnections and Fun
- **T**eaching and Learning
- **I**ssues
- **O**rganizing
- **N**etworking

Five goals for the Summit were also identified in the funding proposal to the Seniors and Community Supports Ministry's PDD Program:

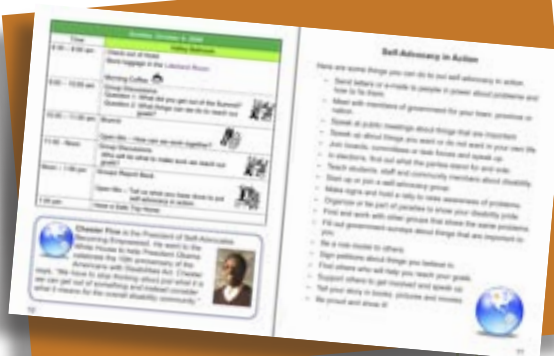
1. Self-advocates will gain knowledge and skills.
2. Self-advocates will teach and present.
3. Position statements will be affirmed or updated on a range of social issues (e.g., employment, community supports, income supports, transportation, education, human rights, affordable housing, health, education, networking and connections).
4. A small collective of regional representatives with a formal name will be formed to serve as a resource or reference group for PDD.
5. A presentation will be developed that chronicles or details work of the self-advocacy movement in Alberta in the last ten years.

### *Plan to Achieve Goals*

The agenda for the Summit was planned so as to emphasize the theme wherever possible and to cover all of the ACTION theme elements. For example, all of the self-advocate hosts for the Friday evening program introduced themselves, their region and how they personally put self-advocacy in action. The printed program for the weekend included

- examples of how self-advocates from around the world (e.g., United States, England, Malaysia) put self-advocacy in action
- a bullet list of ways to put self-advocacy in action
- references to the theme in the welcome messages from the Minister of Seniors and Community Supports and the planning committee

Our experience is that a number of self-advocates will review and share documents of this sort with others at later meetings.



The program also included a number of activities which fit within each element of the theme:

- **Arts and Disability Culture** – through a display of art by people with disabilities (from the Nina Haggerty Centre for the Arts in Edmonton) in the main ballroom and foyer throughout the weekend, a talent show hosted by Central region self-advocates, weekend emcee David Roche whose theme was disability pride, a rally and march from City Hall, and a Saturday session hosted by the Self-Advocacy Federation in which participants painted t-shirts with pride messages
- **Connections and Fun** – through a “Mix & Mingle” game hosted at regional tables on Friday evening, a “Topic Talk” lunch on Saturday in which people selected their table based on the issue they wanted to discuss, a talent show and dance on Saturday evening, and distribution of pre-printed individualized mailing labels which made it easier for participants to keep in touch with new connections
- **Teaching and Learning** – through 19 scheduled presentations on Saturday (i.e., breakout sessions and the lunchtime speaker) by people with disabilities and self-advocacy groups on a range of topics
- **Issues** – through note-taking of answers to questions at regional tables on Friday evening (e.g., what is most important to you, what change do you want to see in the world), discussions of themes generated from the Friday evening notes at lunch on Saturday, and further discussion on Sunday
- **Organizing** – through MLA Kent Hehr’s Saturday lunch talk on getting the ear of the government, and the development of action plans with respect to key issues from Friday evening
- **Networking** – through meeting of self-advocates from other communities and hearing what self-advocacy groups elsewhere have done in Saturday sessions, interaction with the Minister responsible for PDD and AISH programs and other government guests, distribution of the binder and video from Leadership Today’s “Stronger Voice” project (supported through PDD’s Community Research Program) to self-advocacy groups, and exchanging contact information

Plans were also made to meet goals and assess outcomes identified in the funding proposal:

1. **Knowledge and skill development** – Saturday sessions in the morning and afternoon were designed to build knowledge and skills in a variety of areas including self-advocacy, abuse recognition and action, guardianship, getting married, person-centred planning facilitation, plain language translation, and safety. On Sunday morning, participants were asked to identify what they had got out of the Summit to that point.
2. **Self-advocate teachers/presenters** – All 18 breakout sessions on Saturday morning and afternoon were presented solely by self-advocates or included self-advocates on the presentation team. All regional emcees who introduced speakers on Friday evening were Alberta self-advocates. The representatives of the Premiere’s Council who spoke on Friday evening included the chairperson and a self-advocate with developmental disabilities.



The Leadership Today project video included segments by many Alberta self-advocates and was introduced in part by the organization's self-advocate board chair. General emcee and presenter David Roche and MLA Kent Hehr who spoke after lunch on Saturday have visible disabilities. Open mic time was built into the program for Friday and Sunday to ensure that all self-advocate participants had the opportunity to speak to the group.

**3. Position statements on a range of social issues** – On Friday evening, participants were asked to identify the issues that were most important to them, what they were speaking up about currently, and what they wanted to see changed in the world. Further information was gathered as part of Saturday lunchtime “Topic Talks” at individual tables and “how to reach our goals” discussions on Sunday morning.

**4. Development of a named self-advocacy resource group with regional representatives** – Several Sunday group discussions were focused on the development of a province-wide group and how it would function in relation to the wide variety of regional and community self-advocacy groups and individual self-advocates. In addition, questions were asked Friday evening at several regional tables designed to provide information relevant to the formation and functioning of self-advocacy groups. Interest in continued involvement with a provincial self-advocacy organization was assessed by asking participants to return their name tag by putting it into either a “contact” or “do not contact” box, both of which would be eligible for door prizes.

**5. History of Alberta self-advocacy** – A videographer was contracted to document the Summit and is currently editing the extensive footage from the various sessions. Several breakout sessions focused on the history of particular self-advocacy groups (e.g., People First, SRSAN, and the VRRI's Client Advisory Committee) in Alberta. In addition, the “It's My History, Too!” project team has been documenting Alberta self-advocacy and gave a talk on Saturday morning. As part of this talk and throughout the Summit, this team conducted interviews with self-advocates and took pictures and video footage.

## Outcomes

**Attendance/Participation.** A total of 199 self-advocates and supporters pre-registered for the Summit, of whom 153 actually registered on-site. (Some no-shows were due to illness or missed transportation connections.) In addition to the 153 registrants, there were 12 volunteers, 2 video camera operators, and some non-registered support workers assisting registered participants. Also attending and speaking on the Friday evening were the Minister of Seniors and Community Supports, the Hon. Mary Anne Jablonski, and an aide, the Chair of the Premier's Council on the Status of Persons with Disabilities, Marlin Styner, the CEO of the PDD Edmonton Region Community Board, Hart Chapelle, and the Executive Director of Leadership Today, Sandra Mak. On Saturday, MLA Kent Hehr attended as a guest speaker and Minister Jablonski returned to conduct a wedding ceremony of two Alberta self-advocates.

Summit participants came from across the province from Fort McMurray and Peace River in the north to the Crowsnest Pass in the south. Regional distribution of those pre-registered is as follows:

- South Region – 26
- Central Region – 55
- Northeast Region – 19
- Calgary Region – 43
- Edmonton Region – 45
- Northwest Region – 11





Several self-advocates from Saskatchewan heard about the Summit through the summit website and asked if they could attend as there is no similar event in their province and the Alberta meeting would serve as a model for them. They are included in the Edmonton region numbers. A supporter from a B.C. group staffed a table on Friday night representing her group. She is included in the Calgary region numbers. David Roche is also from B.C. These represent the only individuals from outside Alberta who participated in the Summit.

**Evaluation Data.** On Sunday morning, participants were asked “What did you get out of the Summit?” This wording was chosen rather than asking about the “best and worst things” at the Summit to focus responses on the most influential experiences and learning that they would take back to their communities. Although there were still some comments about the food and hotel facilities (both good and bad), there were 192 positive comments related to learning sessions and other planned Summit activities. These were categorized as follows:

- **Connections/Networking and Fun (78)**  
– Activities that people commented positively on included the talent show and dance. The largest number of comments (54) related to the opportunity to meet new people or re-connect with old friends from across the province. Self-advocates typically have limited opportunities to travel and to meet others who are engaged in self-advocacy outside their own groups due to travel costs and/or support needs.
- **Inspiration and Pride (54)** – David Roche’s heartfelt stories of how he had dealt with rejection and negative comments and developed pride in himself and his disability resonated with four participants, as did his sense of humour. Some participants (14) were moved by the wedding ceremony, which was the first time that some had ever attended a wedding of their own friends rather than family or family friends’ weddings. Five individuals reported that the pride parade and rally were highlights for them. Several individuals mentioned with pride that they had spoken about their own activities at the open mic sessions. Participants (16) reported being energized to feel pride in their accomplishments and abilities.
- **Knowledge and Skills (52)** – Although only time will tell whether participants demonstrate increased knowledge and skills through their post-conference activities, evaluation comments indicate many felt that increased knowledge and skills were an important part of what they took away from the Summit. In addition to 20 general comments about having learned a lot from the Saturday sessions, participants also identified a number of specific topics that they learned about: abuse (5), plain language communication

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*“Great way to meet people and share what each of us is doing and help one another.”*  
*“Feeling connected with people from all over Alberta – felt united.”*  
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*“[I] Learned to appreciate being different and what talents I have.”*  
*“[I] Got to feel the pulse of the disabled community.”*  
*“Everybody working as a team, that we are all the same, that we don’t have to be ashamed. Speak up, speak out. We are proud and we are loud.”*  
•••••

•••••  
*“I learned a lot about speakers and other self-advocates; to stand up for what is yours and to know what other people go through with everyday life...”*  
*“Bringing down the hard words for talking with PDD.”*  
•••••

(7), building relationships (9), and political advocacy (2). Learning about other self-advocacy groups and their activities was cited by 14 individuals, and several said that they would be taking this learning back to their own self-advocacy group.

- **Issues (8)** – A few people commented about specific issues, such as money and services, although it is difficult to know how much this was influenced by the listing of the six goals generated on Friday evening, which was the second topic to be discussed during the same hour. Here are a few issue-related examples of what participants said they got out of the Summit:

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*“I got that the government needs to support people with disabilities better.”*

*“A little more understanding of some issues.”*  
•••••

**Key Issues and Positions Data.** Rather than ask self-advocates to state their positions on issues identified as important in previous Summits and government consultations, the planning committee chose to ask participants several broader, open-ended questions to identify what was most important to them now. In order to “earn” items commonly given away as part of the registration packages, participants were asked to answer a question at regional tables. The relevant questions to this section were 1) What is most important to you right now? 2) What is the most important thing you are talking about now? and 3) How would you like to change the world? Their answers were printed on post-it notes and analyzed for further expansion at the Saturday lunch “Topic Talk.” On Sunday, participants were asked to contribute to plans for how to reach goals related to the key issues identified on Friday. As part of those final discussions, participants often expanded further on the issues.

In response to the question of what is most important to participants right now, responses fell into five categories: strong relationships with friends and family, work, home, personal well-being and self-advocacy. In response to the question of what is most important thing participants are talking about now, responses fell into three categories: rights and self-advocacy, relationships and well-being. In response to the question of what participants would like to see change in the world, responses fell into eight categories: being accepted as equals, enough money to live on, being strong self-advocates, services that meet our needs, nice and safe places to live, relationships, the environment and world peace. Based on these data, we identified six goals/positions as currently of greatest importance to Alberta self-advocates:

- **Self-advocates want to be accepted as equals in society.** Self-advocates felt that they were not treated with the same respect or given the same opportunities as others to be heard and show what they can do.

Self-advocates’ sentiments were echoed by Hon. Mary Anne Jablonski who, when asked what change she would like to see in the world, said, *“I would like to see everyone live their best life in a world where they are respected and accepted.”*

•••••  
*“Everyone treated the same with the same rights and responsibilities.”*

*“Less people picking on people with disabilities.”*

*“Everyone should be seen for who they are. Look past disability.”*  
•••••

- **Self-advocates want to have strong positive relationships with friends and family.** Close, personal connections that are supportive are a key element of quality of life. Individuals deeply value their families, spouses, children, pets, boyfriends, girlfriends and friends. During Saturday learning sessions, some individuals said they did not have the privacy needed to pursue intimate relationships or lacked opportunities to form meaningful friendships. Others said they did not know how to “start the conversation” to make friends.
- **Self-advocates want to have enough money to live on.** Comments focused on both limited income and rising costs of housing, transportation, clothing, food and other costs associated with living in Alberta communities. In addition to money, jobs sometimes provide a place where self-advocates are accepted for their contributions and personality. Individuals felt that AISH should go up with the cost of living and that they should be able to keep more of their employment income. As transportation costs rise, self-advocates are less able to afford to participate in their communities.
- **Self-advocacy group support is important for people with developmental disabilities to speak up and make a difference in their communities.** It is not surprising that participants in a self-advocacy conference would talk about the importance of self-advocacy. Being part of self-advocacy groups helps individuals become more aware of the world around them and provides peer support to speak up about what is important to them. Groups provide a safe place to talk about their experiences of oppression and celebrate their personal achievements. They are places to learn and teach. They reduce shyness and increase self-confidence. They give people a sense of purpose and encouragement. They carry out or partner with other community groups on projects that improve the lives of themselves and others in the community. To the right are examples of self-advocate answers to the Friday evening question of how self-advocacy has changed their life.
- **Self-advocates want to have services that meet their needs.** Participants expressed concern about a wide range of services, including health, mental health, education and PDD services. More specifically, services need to be supportive and not leave the individual a prisoner through inadequate staffing or restrictive rules. In many cases information about services and supports (e.g., AISH, mental health) is not available in language that they understand. As a result, sometimes self-advocates unintentionally violate rules and risk losing access, do not understand their rights and how to make a complaint, or are restricted without having given informed consent. Self-advocates noted that changes are made to services without government or agencies consulting them.

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*“[I want] To shop in regular stores, not just second-hand stores.”*

•••••  
*“[We need] More subsidies for rent and utilities and bus passes.”*  
 •••••

•••••  
*“Being part of the big picture.”*

*“I am on fire.”*

*“[It is] Giving me my freedom.”*

•••••  
*“[I have] Been able to speak up more for myself and AISH has gone up.”*  
 •••••

•••••  
*“Government needs to look at my whole life including personal needs for connection to others.”*

*“Better health care. More doctors and nurses in hospitals so we don’t have to wait.”*

*“Make learning activities and information more accessible – easier explanations.”*  
 •••••

“Close all institutions.”

“Save Alberta Hospital.”

“[We need] More affordable housing for people.”

“[I want to] Be in control and set my own rules.”

“I want my own apartment with only the support I need.”

Although a few individuals said they would like to see institutions closed, others disagreed.

- **Self-advocates want nice, safe places to live.** Individuals in low-cost housing often do not feel safe in their homes and neighbourhoods. They may lack privacy or space and have inadequate supports for physical disabilities. There are not enough low-cost options in communities across Alberta. In order to live in nicer surroundings, they must sometimes live with others who are not of their own choosing. Their choice to have a pet may be restricted by rules or roommates.

**Development of a Provincial Self-Advocacy Group with Regional Representation.** The Summits have found a way for a broad and varied group of self-advocates from across the province to gather, learn from each other and to stay connected between Summits. In other words, the process of organizing these events has created a *de facto* provincial organization that can include everyone under its umbrella. We are now facing the need to formalize this group into a stand-alone organization that can continue to accept the diversity of self-advocates and groups across the whole province. There was support from the conference delegates for the development of a province-wide self-advocacy group that communicates with self-advocates across Alberta. Only 12 of the 153 self-advocates attending the Summit put their name tag in the “Do not Contact” container at the end.

The provincial self-advocacy group was envisioned as having a mission, budget, staff support and resources. The regional groups would feed information and goals into and out of the provincial group. It could coordinate its provincial advocacy with local efforts and build community. It would have a plan to work on and active communication with self-advocates across Alberta about activities by means of meetings, newsletters and pamphlets.

Although websites are an efficient means to broadcast information generally, only 49 of the 199 pre-registrants listed an e-mail address in their contact information and only 29 of the 104 self-advocates who requested address labels to share with new contacts included an e-mail address as a preferred means of contact. Many self-advocates still lack easy, direct access to the Internet. Although public libraries provide free Internet, access to these sites is limited by availability of transportation and sometimes by knowledgeable staff who can assist with searching. There is also generally a cost for printing information that is downloaded. Therefore, a website will most likely be a useful means of communication for self-advocacy groups with good staff/ally support and resources.

**History of Self-Advocacy Presentation.** Videographers contracted by the Summit attended and took footage at all sessions of the conference. They are currently editing footage. Videographers and photographers connected with the It’s My History, Too project were also active throughout the Summit and serve as a back-up source of images for the planning committee.

### *What Is Needed to Achieve Goals Identified at the Summit*

In general, strategies for reaching identified goals fell into four overlapping categories: raising public awareness, political advocacy, personal action/growth and working together. Public awareness is a critical step

in being accepted as equals in society, as well as generating support for other goals like having enough money to live on and good services. Actions include things like greater individual community involvement, presentations to schools and other groups, visibility in the media and rallies. Political advocacy includes meeting with public officials, writing letters, sending petitions, and partnering with government to solve problems. Personal action and growth includes learning new skills through workshops and Leadership Today courses, developing greater confidence and speaking out. Working together is accomplished through active involvement in self-advocacy groups at all levels, making language plain so everyone can participate and organizing to have a stronger voice.

More specifically, self-advocates discussed strategies for achieving goals in the six areas identified in the position statements. These could form the basis of an action plan for the provincial self-advocacy group, in addition to being adopted at regional and local levels. Some strategies that are effective in reaching one goal may also have an impact in other goal areas.

**Being accepted as equals.** From Friday evening through Sunday, self-advocates spoke passionately about their need to be included and accepted in society. In some instances they are denied opportunities because they are assumed to be incapable and in need of protection. Many of the identified strategies are individual in nature and involve learning to take on responsibilities instead of leaving them to others. This could include taking courses or workshops on managing money, learning and practising socially acceptable behaviour, making and living by rules in one's own home, directing their own supports and choosing what religious traditions to follow. A key strategy is demonstrating skills and pursuing interests through such activities as volunteering and joining groups.

Delegates felt that as community members, such as co-workers, got to know them socially, they would become allies in the struggle for fair treatment.

In addition to individual strategies, there were functions that could be taken on through self-advocacy groups, such as speaking about pride and the disability experience to schools and community groups. They thought it was important to have a real voice in government planning at all levels and were willing to stand up to government if it did not listen or communicate in plain language. Communications that are not in plain language have the effect of excluding groups and individuals with developmental disabilities from participation as full citizens. Self-advocates are prepared to partner with governments and other groups to create language that supports their inclusion.

**Strong relationships.** The focus of identified strategies was on developing friendships and intimate relationships. Areas of action were divided into developing or accessing resources to start or maintain relationships, and developing or accessing places where potential friends might be found. Resources include workshops and information on socializing and sex. Suggested places to form relationships included various social groups and clubs, community meetings, dating services and dances. Strategies for maintaining relationships included e-mailing and phoning people, going for coffee, to movies or out camping. Money was seen as a challenge to being able to pursue relationships as clubs may have membership fees and shared activities often have associated costs. Therefore, strategies to address this challenge are related to the next goal area.

.....  
*“Get out and involved so people know us.”*  
.....



**Enough money to live on.** Political advocacy was the main strategy for addressing problems related to income and cost of living. Self-advocates felt that government members do not truly understand the impact of poverty on quality of life because they are not required to manage expenses on an AISH allowance. Petitions and sharing the impact in meetings with MLAs were identified activities aimed at raising AISH and allowing earners to keep more of their employment income. Other areas of advocacy were rent control, subsidies for rent/utilities/bus passes and annual transit passes. Individuals who rely on staff for transportation because of limited public transportation are concerned with new policies that require them to pay staff directly for this community access support. Self-advocacy groups could work with local governments to identify changes that would reduce housing and transportation costs. A provincial self-advocacy group could gather information regarding living costs and options to support local self-advocacy group actions and to support their own advocacy regarding AISH amounts and rules.

**Services that meet our needs.** Main concerns were that government made decisions affecting services or eligibility without their involvement, and that information concerning supports (e.g., AISH rules) is hard to understand. When individuals do not understand AISH documents, they sometimes make mistakes that jeopardize their access and labeled as AISH abusers. Self-advocates could work together with government programs to streamline and simplify information to reduce errors and to help self-advocates understand the issues and be included in decisions affecting services.

It was clear that government decision-makers rather than the service providers were being held responsible for ensuring that services meet their needs. Political advocacy strategies focused on calling and meeting with MLAs and the Minister, as well as with city and town councils, depending on the level of government responsible for the service area.

Self-advocates felt that they needed to act as a united group and find allies to advocate effectively for good health and disability services. Strategies identified to find allies include making presentations to agencies and holding or speaking at provincial and regional conferences. Self-advocates also suggested using rallies to make issues more visible and generate community support.

**Nice, safe places to live.** Political advocacy is one strategy identified to address the issue of insufficient low-cost housing designed for people with disabilities and the fact that such housing is often in unsafe areas. People in low-cost housing are more likely to become victims of crime related to poverty and drug use. A system of rent subsidies could allow people with disabilities to have a broader choice of neighbourhoods and types of housing to live in. Self-advocates also felt that they could play a role in designing housing that met the needs of people with disability for space and privacy.

Other issues related to control over the home environment. Individuals often must live with others for support and/or cost reasons. They may have little say over who they live with or rules they must live by (e.g., visitors, no pets or overnight guests). Personal or group advocacy may be required with supportive roommates/neighbours, the agencies that set the conditions of service, or the system that may require group living in order to fund the support level required.



**Strong self-advocates.** Participants suggested that as individual self-advocates, they needed to be better informed about the issues (e.g., guardianship, housing, government) and leadership skills, such as how to speak out effectively. Strategies include sharing of information through videos, meetings, conferences like the Summit, workshops and training such as that provided by Leadership Today. Information needs to be in plain language.

The self-advocacy movement needs to be strengthened and numbers increased by having self-advocates and their groups speak about the importance of self-advocacy at rallies and to staff, families, friends, neighbours, other community members and the media. One suggestion was that PDD should hire self-advocates to speak out and provide self-advocacy training.

Whether locally, regionally or provincially, participants felt that it was important to have money and people to support self-advocacy. The outcome of such support to date has been increased community involvement and action that changes Alberta communities for the better, as seen in the self-advocacy group presentations at the Summit on plain language, abuse, pedestrian safety, working with PDD and other group projects.

There was strong support for the formation of a provincial self-advocacy group that would be composed of representatives of regional groups. This group could act as a unified voice for Alberta self-advocates with PDD and the government. It would take direction from self-advocates and self-advocacy groups regarding issues and positions, and would share information about issues and local, regional and provincial self-advocacy activities in plain language and a variety of media. This provincial group must be representative of the diversity of interests, advocacy styles and situations. The planning committee has included self-advocates who live in institutions as well as People First members, those who have participated in rallies and MLA meetings as well as those whose change efforts use theatre and the arts, those who have taken Leadership Today training and those who had not heard of Leadership Today, and those who are experienced as well as just beginning to speak out in their own lives. The Summit program reflected this range of interests and experience and was successful in making everyone feel welcome and proud to be a self-advocate.

Although e-mail and conference calls have allowed some groups to work together effectively for little or no money, our Summit planning experience demonstrates that self-advocates require face-to-face meetings to fully participate in discussions and decisions. Therefore, money for travel (including staff support, hotels and mileage) and meetings must be part of the budget. In areas where self-advocacy groups are inactive, funding and staff support are needed to create a means by which self-advocate input to the provincial group can be obtained. Although a provincial self-advocacy website could be an effective tool for communicating with well-supported groups and self-advocates who are active web users, some support must be made available to communicate with those individual self-advocates who are not part of such a group and/or do not access the Internet. There is also value in the synergy and energy that can only be created by events such as the Summit that allow self-advocates from across the province to ask questions about information shared during and between formal sessions, as well as see themselves and their self-advocacy activities as part of a bigger picture.

