

PHASE TWO SUMMARY REPORT

Persons with Developmental Disabilities

Safety Standards Consultation

SEPTEMBER 2016



MESSAGE FROM THE CHAIR

On behalf of the Consultation Team I want to thank all those who participated in Phase Two of the Persons with Developmental Disabilities Safety Standards Consultation. The passion, thoughtfulness and creativity you brought to the discussion on ideas about safety and inclusion was truly inspiring. Your spirited debate at the focus groups, detailed responses to the questionnaire and active participation in the webinars was invaluable in shaping our thinking about solutions. We are humbled that so many took the time again to share your views in Phase Two. The issues are complex and the needs are diverse. It is our hope that this Summary Report on Phase Two of the consultation is an honest and accurate reflection of feedback.

On behalf of the Consultation Team, I also want to thank provincial government technical and support staff who provided so much sage advice and logistical assistance to Phase Two. Without your dedication and commitment this phase of the consultation would not have been possible.

John te Linde, on behalf of the Consultation Team



BACKGROUND

PHASE ONE

Phase One of the public consultation to gather Albertans' input on what keeps individuals with developmental disabilities safe in their homes took place between February 18 and March 14, 2016. The focus was on listening to participants' opinions on safety and their experience with the Persons with Developmental Disabilities (PDD) Safety Standards Regulation, the role that various stakeholders play in supporting safety, as well as gathering ideas for how to address safety.

Based on the feedback received, the Consultation Team put forward the following three recommendations on April 1, 2016 which government accepted:

1. Repeal the PDD Safety Standards Regulation in its entirety.
2. Implement a coordinated approach across relevant ministries, including working with municipalities, to ensure clarity, consistency and alignment in and implementation of the repeal of the PDD Safety Standards Regulation.
3. Extend the Consultation Team's mandate to oversee Phase Two of the Safety Standards Consultation. Phase Two will explore potential solutions on safety in the broader context with relevant stakeholder groups, including individuals with developmental disabilities and those involved in supporting their safety and inclusion. Upon conclusion of Phase Two, the Consultation Team will submit a final report with recommendations to the Minister of Human Services.

The Phase One Summary Report and recommendations can be found on the PDD Consultation website: <http://www.humanservices.alberta.ca/pddconsultation>.

PHASE TWO

Phase Two of the safety standards consultation took place from June 12 to July 6, 2016 with a focus on exploring ideas for safety that would:

- Support the inclusion of individuals with developmental disabilities in their communities;
- Affirm the rights of individuals with developmental disabilities to live with dignity, opportunity and choice while recognizing and respecting their need for safe, healthy and supported lives;
- Respect the integrity of home;
- Foster safety in the community; and
- Recognize the Government of Alberta's role in providing supports and services to individuals with developmental disabilities.



“I really appreciated the opportunity to be able to share my thoughts and opinions.”

– FOCUS GROUP PARTICIPANT

The Consultation Team wanted to engage in smaller, more targeted conversations with a cross-section of stakeholders, including individuals with developmental disabilities, to gather input on proposed ideas for safety. To meet this goal, the Consultation Team hosted a series of focus groups and interactive webinars over the consultation period. This allowed participants an opportunity to share their opinions and discuss topics in more detail, both with Consultation Team members and each other.

ENGAGEMENT PROCESS

The public website <http://www.humanservices.alberta.ca/pddconsultation> developed in Phase One was used to support the second phase of engagement and provided a description of the engagement process and how people could get involved. Additional information included a Discussion Guide, Question and Answer documents, a Facilitation Guide for organizing and submitting group feedback, a fact sheet on Creating Excellence Together Accreditation Standards, and contact information for additional questions. The additional information was also provided in plain language format.

FOCUS GROUPS

A total of 142 participants attended 14 focus groups. Focus groups were held in both Edmonton and in Calgary with service providers, family members/guardians and front-line staff. The Consultation Team also hosted focus groups with individuals with developmental disabilities in Edmonton and Calgary including a session conducted in American Sign Language. Separate focus groups were also held with fire and building code officials and Government of Alberta PDD staff.

OTHER METHODS

Over 550 Albertans completed a questionnaire (also available in plain language) online or in paper format. The Consultation Team hosted two webinars with a total of 56 participants from across the province. In addition, feedback was collected through written submissions. Questionnaires, focus groups and webinars focused on the same topics, so participants had an equal opportunity to contribute – even if it was not in person.

The Consultation Team met with the family of Mr. David Holmes to hear their insights and suggestions about supporting the safety of individuals with developmental disabilities. The Holmes family has first-hand experience with safety as their son David passed away in 2011 from complications of thermal injuries due to a scalding incident in his home. At the time of his death, he was receiving services through an organization funded by the PDD program.

SUMMARY OF FEEDBACK

The focus groups allowed for in-depth conversations which provided the Consultation Team with rich information. Participants were passionate and open in sharing their thoughts and opinions. The questionnaires provided thoughtful and thorough information that helped to further inform the Consultation Team.

As in the Phase One Summary Report, the information that follows is a summary of the feedback expressed through all the methods of engagement. It is not meant to be a scientific analysis – the conversational format used does not lend itself to that type of analysis, but instead represents an overview of the feedback on five proposed ideas that were generated from Phase One.

Through all methods there were over 750 participants, with the majority being service providers/staff and family members/guardians. Phase Two engagement statistics are provided in Appendix 2.

PROPOSED IDEAS FOR SAFETY

The proposed ideas for safety developed by the Consultation Team were based on the feedback received in Phase One and fell into five broad areas: PDD Program; Staff Training and Education; Accreditation Standards for Agencies; *Safety Codes Act* Interpretation; and Other Ideas to support safety.

IDEA ONE: PDD PROGRAM

Feedback in Phase One emphasized that individuals are safest when they are connected to their community. This is thought to be best achieved through a PDD system that supports inclusion, works to align services to achieve the best possible outcomes for individuals, and has the trust and confidence of the people it serves.

The majority of participants agreed in principle with the idea of undertaking a review of the PDD program to enable safer lives in community for individuals with developmental disabilities. Although there was consensus that a PDD program review should take place, there was less agreement on what the review should actually entail. The main theme that emerged from respondents was the importance of defining the roles and responsibilities of stakeholders, including service providers, families/guardians, PDD staff and individuals themselves. Participants often noted the perceived duplication of work particularly around planning, determining outcomes and case management. This was seen as creating confusion about the roles of the service provider and families relative to the PDD staff.



“Reviews and their outcomes must be respectful towards people with disabilities and their senses of self, pride and privacy.”

– QUESTIONNAIRE RESPONDENT

A second theme noted was around the need for an individualized approach to service planning. Many felt that a standardized approach does little to recognize an individual’s unique needs, strengths and abilities. It was often relayed that PDD staff need more time to assess and get to know an individual before making decisions on the type and level of support needed. Participants also suggested that PDD staff should receive training on how to better support and work with people with developmental disabilities.

Participants also provided ideas on how a review should be conducted and by whom. Many felt it should be done independent of government and in close consultation with the community of families, individuals with developmental disabilities and those providing support. It was also clear that a review should start with the individual at the center and be based on values of compassion, mutual respect and transparency.

Participants were also asked how government could rebuild trust and support positive interactions with the disability community. The vast majority of questionnaire respondents supported the idea of a broader engagement model and developing a means of open communication between PDD and the community it serves. Although a specific model was not identified, participants did talk about the principles on which a model should be based including transparency, collaboration and mutual respect. The importance of ongoing and proactive consultation was frequently cited as being necessary for rebuilding trust among stakeholders and ensuring positive outcomes for individuals. The phrase “nothing about us without us” was used to describe expectations before program and policy changes are made that would affect individuals. Many pointed to the strained relationship that currently exists between PDD and the community it serves and noted that it will take time to rebuild no matter the approach put in place in the future.

“I believe that open communication would serve to build trust and positive interactions between PDD and the disability community.”

– QUESTIONNAIRE RESPONDENT

IDEA TWO: STAFF TRAINING AND EDUCATION

Results were mixed on the idea of requiring staff working with individuals with developmental disabilities to possess post-secondary education with just over half of questionnaire respondents agreeing with this idea, around a quarter disagreeing and a quarter holding a neutral view. Although participants generally agreed that a more skilled workforce is important for safety, the feasibility of moving this idea forward was noted as a challenge. The fact that only a handful of post-secondary institutions currently offer disability-related programs was stated as a barrier to requiring specific education to work in the field. Other concerns raised were the impacts to current employees who do not possess a post-secondary education and the costs associated with implementing a change of this magnitude. Additionally, some respondents felt this requirement would deter people from entering the field especially given current low wages.

There was broad agreement on the need to establish a minimum level of education and/or specific training for the field. Participants tended to categorize these into three areas: basic training (such as first aid and bathing protocols); ongoing/onsite training (such as supporting people to have as much autonomy as possible in their home and community lives); and specialized training related to the disability field or the individual receiving supports. Some participants said that qualifications should be dependent on position and level of support provided, suggesting that a specific skillset and/or specialized training may be needed when working with individuals that have complex medical and behavioural needs.

This was also echoed by the Holmes family. They have long advocated for better training and minimum qualification requirements for staff working with individuals with developmental disabilities. This is especially critical when supporting people with complex needs.

Most questionnaire respondents agreed with the idea that professional certification should be required for those working with individuals with developmental disabilities. Many considered certification an asset to professionalizing the field and a way to establish minimum competency requirements for staff in this area. Still, some questioned how competencies would be determined and who would be responsible for administering and overseeing the certification process.

The importance of soft skills such as compassion, patience and a genuine interest in working with people with developmental disabilities was repeatedly mentioned. Some expressed concerns that too much focus would be placed on education and training at the expense of other valuable qualities like caring and kindness.

“Compassion - The staff need this quality first and foremost.”

– QUESTIONNAIRE RESPONDENT



“Accreditation needs to be a partnership not just a book of rules.”

– FOCUS GROUP PARTICIPANT

The majority of questionnaire respondents agreed that staff salaries should be commensurate with position qualifications and experience. The predominant strategies highlighted as ways to retain staff were to increase wages and benefits and have them commensurate with the job position, education and needs of the person they are supporting. Many suggested health benefits and other benefits such as pension plans to help retain staff. Organizational culture was a major theme that emerged with respondents identifying staff empowerment, supervision and strong leadership, positive work culture and staff recognition as ways to keep staff. Opportunities for development and advancement were also mentioned as very important for staff. Flexible and stable work schedules, consideration for work classification (full-time/part-time) and providing holidays and sick days were also raised as possible solutions to attract and retain staff.

IDEA THREE: ACCREDITATION STANDARDS FOR AGENCIES

Strengthening accreditation standards for agencies providing services was an idea with almost half of questionnaire respondents in agreement, compared to around a quarter disagreeing and around a quarter neutral. The response at the focus groups was much more positive towards strengthening standards. The accreditation process was consistently stated as a way to monitor safety to ensure that agencies are doing a good job. There was considerable variation among respondents regarding the frequency of accreditation.

Some participants suggested that individuals and families/guardians and even PDD staff should play a more active role when agencies are being accredited. Respondents also mentioned the need for increased transparency about the accreditation process including who does it and how follow up is completed if an agency does not meet the standards. Several participants thought that the standards should be tailored to individuals instead of being one size fits all.

The most commonly cited examples of standards that should be added to accreditation included fire drills, site safety/maintenance checks, staff training and abuse prevention.



“STANDATA has turned safety into physical (but safety goes beyond physical).”

– FOCUS GROUP PARTICIPANT

IDEA FOUR: SAFETY CODES ACT INTERPRETATION

Respondents continued to state their frustration with the STANDATA guidelines and the notion that it turns homes into institutions. Majority of participants agreed that the homes of individuals with developmental disabilities should be seen as homes first, and not labelled as a facility by governments. Many participants were in favor of removing the STANDATA and felt there would be no consequences if it was not replaced with something else. Participants suggested things like checklists, basic standards, staff training and education, accreditation and individualized planning could be used instead of a STANDATA.

A small number of participants expressed concerns with removing the STANDATA and not replacing it with something else. These concerns included the potential for stricter and varying interpretations of the safety code which could result in safety requirements that resembled those under the now repealed PDD Safety Standards Regulation.

When asked if certain life circumstances may require additional safety measures, participants most commonly stated accessibility/mobility particularly around egress and cognitive ability as potential areas to warrant this. However, it was important that additional safety measures be individualized rather than having a standardized approach.

“Safety in home is not just PDD homes it is everyone’s home.”

– ONLINE SUBMISSION

OTHER IDEAS

There were three ideas under this category. The first was to encourage municipalities to develop a tool similar to the voluntary Vulnerable Person Self-Registry in Calgary. Slightly over half of questionnaire participants agreed with this idea, while a significant number wanted more detailed information. Many thought it was a good idea and an easy way to increase safety in the community, sometimes adding that it should be available to anyone and not just individuals with developmental disabilities. Others though raised concerns that a registry could stigmatize individuals and had concerns about personal information being misused and mismanaged. Confidentiality of the information and the voluntary aspect were stressed as important considerations if this idea was to be recommended. It should be noted that many respondents did not support the use of the term 'vulnerable' and strongly suggested it be omitted if new registries were to be created.

“Yes I believe that this is vital information that could be important to emergency responders, however it needs to be voluntary and the information gathered kept confidential.”

– QUESTIONNAIRE RESPONDENT

The second idea was the provision of additional supports to self and family advocacy efforts or the creation of an independent Disability Advocate or Ombudsmen. Two thirds of questionnaire participants agreed with this idea.

Several people highlighted the value of advocacy as a means for individuals to be heard and an important part of keeping government accountable. Others thought advocacy could help individuals and families navigate the PDD system and to investigate systemic issues. However, others were hesitant about the usefulness and effectiveness of establishing another advocacy body. Many felt this would only add administrative costs to an already cash-strapped system. Of key importance was the need for such advocacy bodies to be independent and neutral from Government and service providers.

“It’s a place to go when you need an unbiased, safe place to talk about your concerns.”

– FOCUS GROUP PARTICIPANT

The last idea was related to the role of health and safety officials as educators. In particular, the majority of respondents agreed that there is merit in having safety experts provide information and materials to individuals with developmental disabilities, their families and service providers on how to live safely in their homes and communities. Some participants noted that this information should be no different than what is offered to every other Albertan. Other respondents noted this to be a good idea for the community but the information should be tailored to the person’s needs. Specific examples of areas where education should be offered include safety from abuse, internet safety, financial safety, community safety, kitchen safety and physical home safety (e.g. fire extinguishers, fire alarms and fire drills).

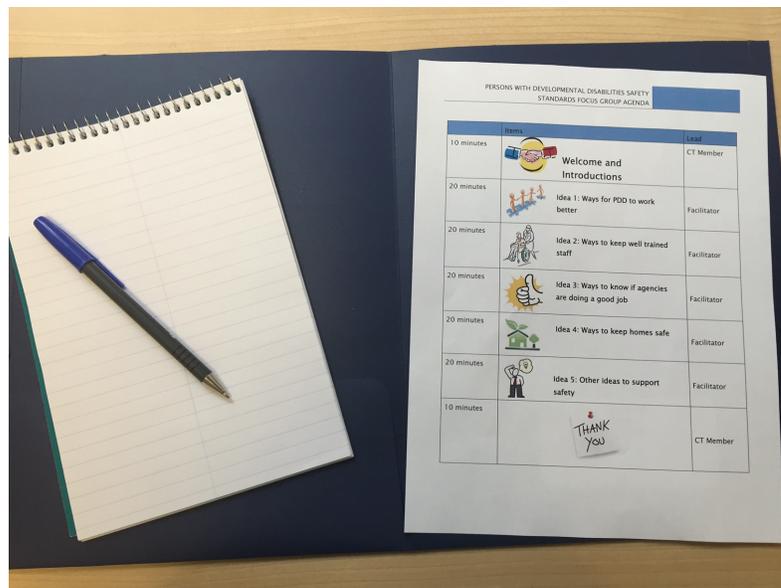


“Everyone with a disability is different. One thing that is common is the sense of belonging. That sense of belonging to a home and a community that includes people they like and love is the biggest and best safety tool one can have.”

– QUESTIONNAIRE RESPONDENT

CONCLUSION

The Consultation Team would like to thank everyone who participated in Phase Two by sharing a broad range of opinions on the ideas presented. Your feedback helped shape the final recommendations to government. We want to recognize the resilience of the Disability Community and the strength of your values and ideas. Thank you for sharing this process with us.



APPENDIX ONE

CONSULTATION TEAM MEMBERS:

John te Linde (Chair), Retired Manager of Social Policy and Planning for the City of Calgary, Psychologist

Michael Cooper, Community Member and Advocate

Ann Nicol, Chief Executive Officer, Alberta Council of Disability Services (ACDS)

Tammy Poirier, Member of the Disability Action Hall

Marie Renaud, Member of the Legislative Assembly (MLA) for St. Albert

Jennifer Stewart, Member of the Disability Action Hall

Cam Tait, Journalist, Member of the Premier's Council on the Status of Persons with Disabilities

Bruce Uditsky, Chief Executive Officer, Inclusion Alberta (formerly Alberta Association for Community Living)

APPENDIX TWO



PHASE TWO ENGAGEMENT STATISTICS

FOCUS GROUPS
142+ Participants

QUESTIONNAIRES AND ONLINE SUBMISSIONS
550+ Participants

TOTAL PARTICIPANTS INVOLVED

