

PHASE ONE SUMMARY REPORT

Persons with Developmental Disabilities
Safety Standards Consultation

MARCH 2016



MESSAGE FROM THE CHAIR

The Consultation Team wishes to thank all those who participated in phase one of the Consultation on Safety Standards for People with Developmental Disabilities. It was important for us to hear your opinions and ideas about what makes homes safe. Your stories and experiences left a lasting impression on the Consultation Team. We feel honoured that so many people took the time to sit and talk with us. Your stories at the conversation forums and responses to the questionnaire informed this report. It is our hope that this summary report on what we heard and the recommendations we have provided to the Government are an accurate reflection of your feedback. We look forward to continuing our work on effective provisions for home safety in phase two of the consultation.

We also want to remind you that this is not the end. The feedback you shared will help inform the next phase of the consultation that will take place in May 2016. We are committed to working together to identify solutions that will support safety in the homes of Albertans with developmental disabilities.

Finally, the Consultation Team wishes to thank the many provincial government staff who provided technical and logistical support to phase one of the consultation. Without their expertise this report would simply not have been possible.

John te Linde, on behalf of the Consultation Team





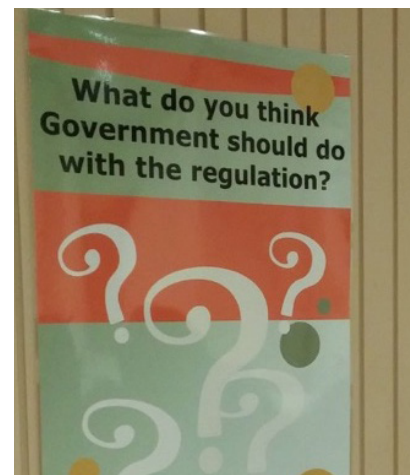
“I was overwhelmed by the public’s commitment to this process. It was evident right from the start how passionate and dedicated people are. I was also struck by their willingness to share and the appreciation of being heard.”

– CONSULTATION TEAM MEMBER

BACKGROUND

On September 18, 2015, Minister of Human Services Irfan Sabir announced that an extensive engagement would be undertaken to examine the standards of safety for individuals receiving supports through the provincial Persons with Developmental Disability (PDD) program. This was in response to concerns raised by Albertans about the *Persons with Developmental Disabilities Safety Standard Regulation*, which came into force in 2012.

An eight member Consultation Team (Appendix 1) composed of disability community representatives as well as representatives of the broader community was appointed in early December 2015 to consult with Albertans about PDD Safety Standards. The team was supported by a group of technical experts on safety code legislation such as building and fire codes, health and policy development. The scope of the consultation focused on safety in the homes of people receiving services through the PDD program.



ENGAGEMENT PROCESS

The Consultation Team wanted to create a positive and welcoming process. It was important to provide people a platform to share their experiences and thoughts in a variety of ways. The Consultation Team developed a two-phased engagement process. The first phase took place from February 18 to March 14, 2016, and focused on broadly engaging people with developmental disabilities and those involved in supporting their safety and inclusion to:

- Share their opinions on and experiences with safety in their homes and community; and
- Contribute to finding solutions that affirm the rights of persons with developmental disabilities to live with dignity and opportunity in the community while recognizing and respecting their right for safe, healthy and supported lives.

A public website humanservices.alberta.ca/pddconsultation was developed to support the engagement and provide background about the purpose of the consultation, a description of the engagement process and how people could get involved. Additional information included fact sheets about the PDD program, *the PDD Safety Standards Regulation*, Information Guides, Questions and Answers documents, a Facilitation Guide for organizing and submitting group feedback, and contact information for those with further questions.

“I am glad we are talking. It is important that the government consult the people the laws influence”

– CALGARY PARTICIPANT

COMMUNITY CONVERSATION FORUMS

Community Conversation Forums were held in eight communities across the province. Over 750 people attended forums in Westlock, Grande Prairie, Edmonton, Calgary, Red Deer, Lethbridge, Medicine Hat and Fort McMurray. The open-house format promoted inclusion and allowed participants to share their ideas, experiences and reflections in a variety of ways. Topics included: what makes a home safe; the role stakeholders play in supporting safety in homes; what is and is not working well; and possible solutions. Hearing directly from people with developmental disabilities, family members, service providers and others was an extremely compelling experience, one that is difficult to adequately capture in a brief written document. The Consultation Team gained valuable insight into the confusion and frustration the *PDD Safety Standards Regulation* created in the community.



“I really liked being able to share my story with people at the forum. They were open to listening to all my ideas and suggestions.”

– CALGARY PARTICIPANT

QUESTIONNAIRE

Over 1,300 Albertans completed a questionnaire online or in paper format. Both questionnaires and forums focused on the same topics, so participants had an equal opportunity to contribute – even if it was not in person.

OTHER METHODS

A number of people provided feedback through written submissions in the format of their choosing. This included email, mail and video. In addition, several organizations also hosted meetings to collectively capture and submit feedback as a group.

Eighteen people also attended as an American Sign Language facilitated community discussion in Calgary.

Phase one engagement statistics are provided in Appendix 2.



“I felt these people (Consultation Team) were really listening, this is a step in the right direction”

– RED DEER PARTICIPANT

SUMMARY OF FEEDBACK

The consultation brought together a wide range of participants with diverse backgrounds and experiences. The conversations were informative, spirited and, at times, challenging. Many people from across the province shared their experiences and struggles with the hope of bringing about positive change. This was not lost on the Consultation Team. While this report provides a summary of the feedback, it does not capture the true level of emotion that people expressed when sharing their stories. The information that follows is a summary of the ideas expressed through the Community Conversation Forums, questionnaires and online submissions. It is not meant to be a scientific analysis with statistics and graphs, the conversational format used does not lend itself to that type of response, but instead it represents an overview of the themes that emerged in phase one.

CONFUSION ABOUT THE PDD SAFETY STANDARDS REGULATION

It is clear that the *PDD Safety Standards Regulation* was very confusing to stakeholders and often interpreted differently by various parties. This led to widespread frustration and concern regarding the health and safety requirements for individuals with developmental disabilities, families and service providers. People also spoke of receiving conflicting information about the application of the safety standards, timelines for compliance and consequences for not complying. This added to a sense of vulnerability, insecurity and fear in the community.

Participants described the lack of consultation when developing the *PDD Safety Standards Regulation* as problematic. This led to a further breakdown in communication which increased anxiety and hardship for many people.

“Since the introduction of the Regulation, there has been mass confusion. Adding to this is the stress and anxiety of individuals who are afraid they may lose their home due to the Regulation. The time spent reassuring, researching, and investigating what to do, and or how to do it has added strain to already taxed agencies.”

– EMAIL SUBMISSION



“A home is safe when it has locks on the doors, fire extinguishers, my medications stored in a locked cupboard, warm in the winter, cool in the summer.”

– GRANDE PRAIRIE PARTICIPANT

HOLISTIC VIEW OF SAFETY

People in all areas of the province agreed that safety is much broader than that captured in the *PDD Safety Standards Regulation*. There is strong acknowledgement that physical things like fire extinguishers, smoke detectors, grab bars, structural elements of a building, and routine maintenance all contribute to physical safety. However, it is clear that other aspects are equally or more important. Participants spoke about the importance of social connectedness and inclusion in communities for people with developmental disabilities. Having a sense of belonging and feeling comfortable in your own home were consistently identified as important aspects to safety.

Participants also spoke about safety in relation to well-trained staff and access to services. Many people stressed the importance of having competent, caring support staff that know and understand those they are supporting. Staff were often cited as a reliable resource for teaching individuals how to be safe in their homes. Practicing fire drills and creating evacuation plans were also things many people referenced as contributing to safety.

“Having good neighbours and supports that really care about me. Having friends and family who visit and make sure all is good and I’m healthy and have everything I need.”

– EMAIL SUBMISSION

Being able to choose one’s own level of risk was frequently mentioned as important to supporting safety in homes and communities. Participants strongly expressed the value of being able to determine their own level of risk rather than being told what is and isn’t safe in their own homes. This was often linked to being able to exercise control over their own lives and treated the same as everyone else.

“Having the freedom to dictate how you want your home set up; Control over your own safety elements in your home (like any other citizen). When control and freedom is taken away from the occupant, the home becomes less safe.”

– EDMONTON PARTICIPANT



“Individuals with disabilities and their families play the central role when it comes to PDD supports. Service providers provide information and assistance, however, it is the individual that directs their life.”

– QUESTIONNAIRE RESPONDENT

ALL STAKEHOLDERS HAVE A ROLE TO PLAY

People were clear that safety is a shared responsibility. Many participants talked about the central role individuals with developmental disabilities play in securing their own safety. They spoke of supporting individuals to advocate for themselves by voicing safety concerns and defining what makes them feel safe. Participants also pointed out that family members and guardians play an important role by advocating for the safety and security of individuals as well as teaching safe practices. It was often stated that family members should be able to identify safety concerns in homes and feel empowered to raise their concerns.

Education and training were the two main themes highlighted as roles service providers play in supporting safety. Examples included providing training and education to staff, working with individuals to identify and implement safety solutions, as well as monitoring and ensuring protocols are met. Another commonly raised issue was the need for training of health and safety professionals. Many participants spoke of the lack of understanding and experience health and safety professionals had in working with individuals with developmental disabilities. This resulted in negative experiences and further frustration.

People expressed differing views on the role government plays in supporting safety in the homes of individuals with developmental disabilities. While many people viewed government’s only role as providing funding, some recognized government as having a responsibility to uphold reasonable safety guidelines and standards. This was not necessarily in support of the existing *PDD Safety Standards Regulation*; rather it was most often referenced in the context of more reasonable safety measures. Participants did at the same time acknowledge that health and safety professionals play an important role in helping to identify, educate about and address safety risks.

Municipalities and landlords were also viewed as having a role to play in maintaining dwellings, supporting inclusion and ensuring safety codes are followed. However, many emphasized that the role of inspectors and municipalities in upholding health and safety codes should be no different than any other Albertan.

“Municipalities need to provide accessible facilities and programs. Provincial government is required to protect the rights of individuals with disabilities.”

– EDMONTON PARTICIPANT



“The requirement of agencies to practice fire evacuation on a regular basis and to monitor safety plans is key. Retraining, reviewing and renewing training for staff and individuals we support is so important.”

– QUESTIONNAIRE RESPONDENT

WHAT’S WORKING WELL?

A majority of participants around the province consistently identified a number of things that are working well to support safety in the homes of individuals with developmental disabilities. Primary among them was ongoing education for staff and individuals on fire safety, evacuation procedures and other safety measures. Also noted was regular training on safety procedures such as fire drills and the use and maintenance of safety equipment (e.g. fire extinguishers). People also spoke about the value in routine checks by staff to identify and address safety risks in and around homes. Existing service provider policies and procedures and accreditation standards were seen as effective tools to promote safety while allowing for flexibility and personal choice.

A smaller number of participants expressed support for health and building standards and the role they play in safety. These participants viewed standards and inspections as a useful tool in helping to identify risks and as a way to keep ‘things in check’. This was seen as an important issue by those who have an obligation to uphold health and building standards and understand that it is their role to address situations they see as unsafe (e.g. Health licensing inspectors, public health inspectors and safety codes officers).

“Yearly inspections work great. Although they can be intrusive having a stranger enter your house and tell you all the things that could be changed and fixed. It does keep things in check to ensure they are doing everything they can to ensure the home is a safe and comfortable place to live.”

– QUESTIONNAIRE RESPONDENT



“I am fearful that the regulations will further restrict the supply of houses available for my son. We worked very hard to find him a home that he loves and is comfortable in. I don’t know what we will do if he can no longer stay there.”

– EDMONTON PARTICIPANT

KEY CONCERNS

A number of serious concerns about the *PDD Safety Standards Regulation* were identified. Costs associated with retrofitting homes with safety equipment, such as sprinklers, were frequently cited as a major issue. People talked about the fear of being evicted from their homes because they could not afford costly renovations. Many wanted to know who would help pay for sprinklers to be installed, if they were required, with confusion as to under what circumstances this might be the case. Many people were afraid that landlords would no longer want to rent to individuals with developmental disabilities because of the additional safety requirements, leaving some with little or no alternative housing options. Individuals often talked about their homes as being a place of security and comfort, and if forced to leave, would have serious negative consequences on their well-being.

People often used words like “invaded” and “scrutinized” to express the feeling when inspectors, often with little knowledge of people with developmental disabilities, entered homes to conduct inspections. Participants talked about the stress of having multiple inspectors coming into their home and checking the same things only to provide conflicting information on how issues should be addressed. This created confusion and left many feeling powerless on how to fix the situation. Individuals with developmental disabilities shared that often these inspections addressed trivial issues, such as how often the grass was mowed and filling barely visible cracks in linoleum.

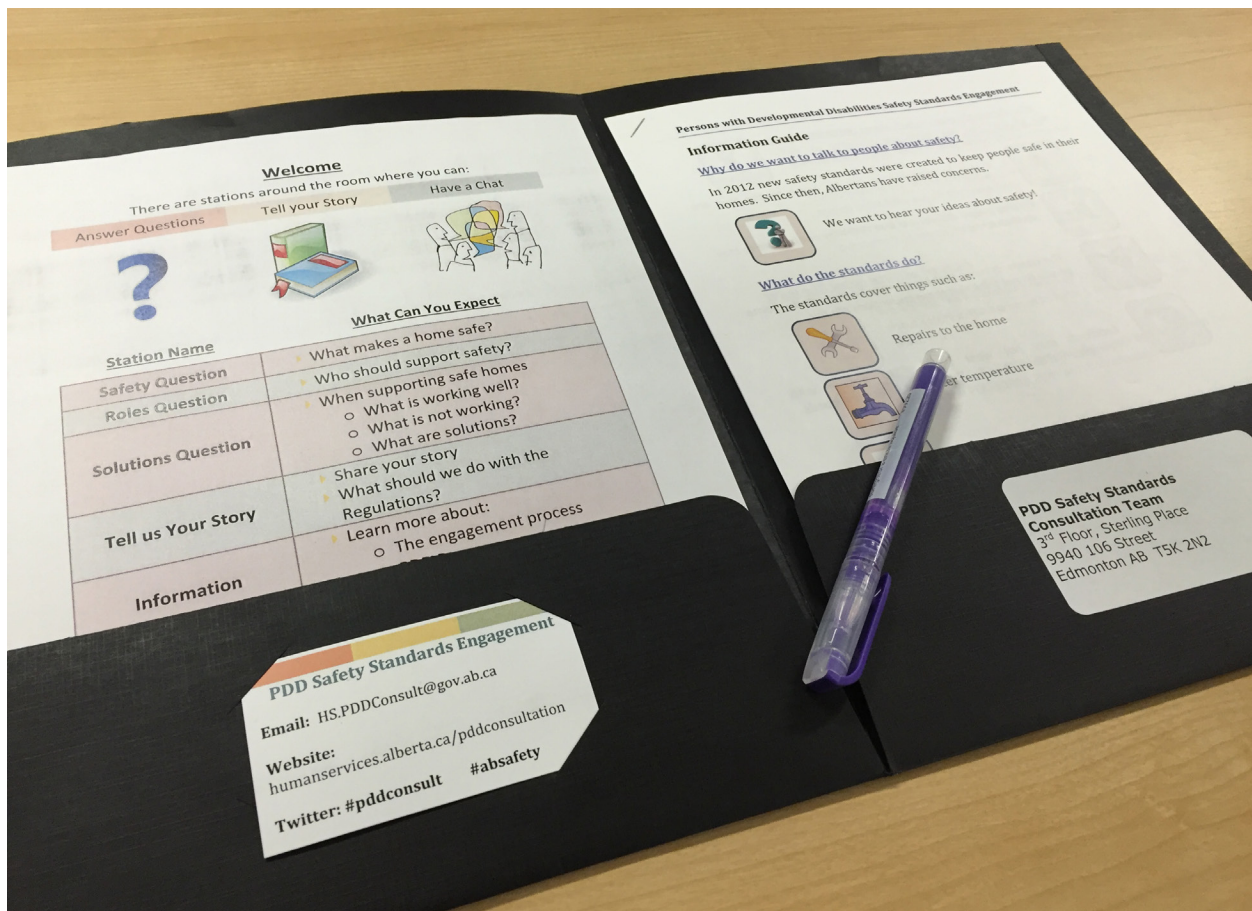
Many participants were very concerned that the safety standards would effectively turn homes into institutions or facilities thus requiring the property to be rezoned with a resulting NIMBY (Not In My BackYard) response from neighbours. Some worried that the installation of safety equipment (sprinklers) would also draw negative attention from neighbours, further isolating individuals from their community. Others expressed that current safety standards are discriminatory because they apply only to people with developmental disabilities.

“Arbitrary safety regulations that impose an unfair burden on individuals with developmental disabilities. The effect of these regulations is to push people into institutional settings or turn homes into institutions this is what we should be moving away from.”

– ONLINE SUBMISSION

Finally, many people expressed concerns about the PDD program itself. Although the program was not part of the scope of this consultation, many participants felt the standards were indicative of larger systemic issues at play. In sum, people felt the program was moving away from its primary objective of supporting Albertans with developmental disabilities to be part of their communities and live as independently as they can to one of primarily cost containment and adherence to standard processes.

To a much lesser extent, concerns were also raised about the quality and level of supports by some service providers. This was viewed as having a negative impact on safety in the homes of individuals with developmental disabilities.



PROPOSED SOLUTIONS

Participants also contributed ideas to address safety in the homes of Albertans receiving supports through the PDD program. These high-level solutions describe broad changes that are intended to help address the major issues and barriers identified.

Communication

Many people talked about the importance of clear and consistent communication between all stakeholder groups. This was often referenced beyond the safety standards themselves to include communication about the program and other services.

Training and Education

Increased training and education was repeatedly identified as being crucial to supporting safety in homes. Although this solution was most often about support staff, participants did acknowledge that individuals should also be provided with appropriate training and education so they can play an active role in their own safety.

Existing mechanisms or systems

Many suggested that existing mechanisms or systems, outside of the *PDD Safety Standards Regulation*, could be enhanced or revised to include a greater focus on safety. Accreditation standards, contract management and service provider policies and procedures were those most often referenced.

Meaningful Consultation

A reoccurring topic brought to light during this process was the desire for consultation on issues like safety, prior to development or implementation of future government policy. Given the often unique needs of individuals with developmental disabilities, participants continue to feel that it is imperative to have their concerns heard on matters that affect them or those they support.

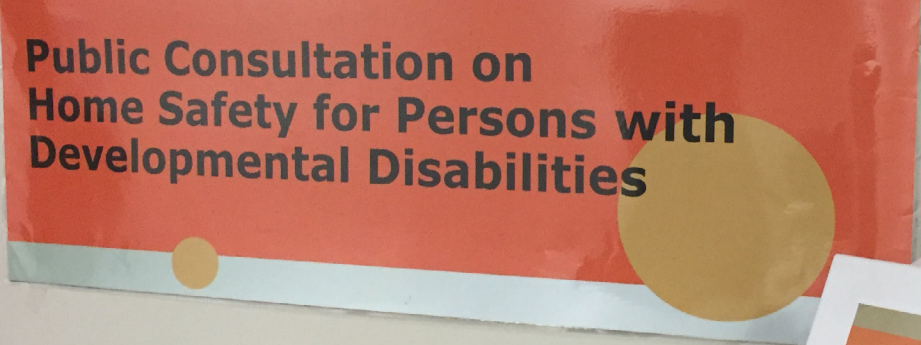
Of those participants that chose to provide feedback on the open house style format of the Community Conversation Forum, many cited positive responses emphasizing that 'they felt heard'. This presents an opportunity in phase two for the government to maintain and develop positive working relationships within the disability community.

RECOMMENDATIONS


It is clear from the feedback received during phase one that there is more work that needs to be done to develop solutions that will respect the rights of persons with developmental disabilities to live safely and with dignity and opportunity in the community. It is also clear however, that the current *PDD Safety Standards Regulation* is not the best solution. Confusion over its continued application may limit the actions and means necessary to finding and implementing acceptable alternatives.

Based on the feedback received in phase one of the consultation, the Consultation Team is proposing the following interim recommendations to support the next phase of this process.

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 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 and recommendations to the Minister of Human Services.



Public Consultation on
Home Safety for Persons with
Developmental Disabilities



Thank you for
Your Feedback

APPENDIX ONE

CONSULTATION TEAM MEMBERS:

- **John te Linde** (Chair), Registered Psychologist
- **Michael Cooper**, Community Member and Advocate
- **Ann Nicol**, Chief Executive Officer, Alberta Council of Disability Services
- **Tammy Poirier**, Member of the Disability Action Hall
- **Marie Renaud**, Member of the Legislative Assembly for St. Albert
- **Jennifer Stewart**, Member of the Disability Action Hall
- **Cam Tait**, Journalist and member of the Premier's Council on the Status of Persons with Disabilities
- **Bruce Uditsky**, Chief Executive Officer, Inclusion Alberta

APPENDIX TWO

Phase One Engagement Statistics



COMMUNITY CONVERSATION FORUMS 750+ Participants

Westlock 20 PARTICIPANTS	Grande Prairie 86 PARTICIPANTS	Edmonton 167 PARTICIPANTS	Calgary 233 PARTICIPANTS
Lethbridge 116 PARTICIPANTS	Red Deer 83 PARTICIPANTS	Medicine Hat 25 PARTICIPANTS	Fort McMurray 22 PARTICIPANTS

1,300+ Questionnaires Completed

PARTICIPANTS INVOLVED

