

Supporting Safe and Inclusive Lives

Report of the Persons with Developmental
Disabilities Safety Standards Consultation 2016



Message from the Chair

As Chair of the Consultation Team, I am pleased to present our report – “Supporting Safe and Inclusive Lives” – to the Honourable Irfan Sabir, Minister of Human Services, for his consideration.

The Persons with Developmental Disabilities (PDD) Safety Standards Consultation was an excellent opportunity to collaborate with Albertans and the PDD community on safety standards for individuals with developmental disabilities. On behalf of the Consultation Team, I thank Minister Sabir for this opportunity.

I would like to sincerely thank those who participated in these remarkable and enlightening discussions. We heard from various stakeholders, including service providers, municipal officials, individuals with developmental disabilities, their families and their loved ones. It was a pleasure to passionately discuss and debate ideas related to safety and work together to support those with developmental disabilities. Your feedback shaped this report and our recommendations to the Minister of Human Services. We are proud of the collaborative process that was undertaken.

I would like to express my heartfelt appreciation for the work of Government of Alberta staff in facilitating these discussions and providing technical and logistical support. The Technical Team was invaluable in helping us understand the complexity and scope of the issues behind the discussions.

I would also like to thank each and every member of the Consultation Team. Your passion and dedication to safety for individuals with developmental disabilities is extraordinary. This process and report would not have been possible without the contributions of each team member.

Last, but by no means least, I would like to thank the Honourable Irfan Sabir, Minister of Human Services and the Government of Alberta for accepting the recommendations in our Phase One report. The prompt repeal of the Persons with Developmental Disabilities (PDD) Safety Standards Regulation on April 1, 2016 demonstrated genuine commitment and action in listening to the voices of the developmental disability community.

This report provides direction and effective policy options to foster safety in the PDD community. We wish to affirm the right of individuals with developmental disabilities to live with dignity, opportunity and choice, while recognizing and respecting their need for safe, healthy and supported lives.

Respectfully submitted,

John te Linde, Ph.D.

Chair, Persons with Developmental Disabilities Safety Standards Consultation Team

Executive Summary

The Consultation Team received feedback from well over 2,000 Albertans across the province. People spoke passionately about the importance of inclusion and belonging as contributing factors to safety in communities for individuals with developmental disabilities. Although meaningful actions towards safe and inclusive lives for individuals with developmental disabilities are recommended, the Consultation Team would like to stress that it is impossible to create a risk-free environment and individuals' dignity of risk and individual preferences must be respected.

The Consultation Team's recommendations fall under five broad areas: Persons with Developmental Disabilities (PDD) Program; Staff Training and Education; Accreditation Standards for Agencies; *Safety Codes Act* Interpretation; and Other Ideas to support safety.

PDD Program

1. Undertake a review of the PDD program to foster safer lives in the community for individuals with developmental disabilities.
2. Develop a means of open, meaningful communication between the PDD program and the disability community that will build trust and support positive interactions.

Staff Training & Education

3. Government of Alberta work with community partners to create and implement a human resources plan for Community Disability Services to better ensure safety and meaningful inclusion. This plan should incorporate the following requirements:
 - A. Require training and post-secondary educational standards to bring more qualified workers into the field and ensure consistency among staff qualifications.
 - B. Require staff working with persons with developmental disabilities to be professionally certified.

Accreditation Standards for Agencies

4. Strengthen accreditation standards for agencies that provide PDD-funded services in the areas of health and safety to reflect the critical individualized safety requirements in the homes of people with developmental disabilities.

Safety Codes Act Interpretation

5. Municipal Affairs withdraw the August 2015 STANDATA.
6. Government of Alberta provide guidance to municipalities on how to interpret and apply the safety codes using the following principles:
 - A. Residences occupied by individuals with developmental disabilities who rent, lease or own are not "PDD residences" or facilities.

- B. The starting point for safety code assessment of homes for individuals receiving support from PDD should be that they are residential dwellings, in the same manner as any other home.
 - C. The source of financial or service support being received by a person living in a home is not relevant to how the building codes are interpreted and applied to that home. That is, homes of people receiving support through PDD should be treated no differently from the homes of people not receiving publicly funded support, or receiving it from another source. Any change of use or alternative classification under the *Safety Codes Act* (including building and fire codes) should be assessed as it would be for any Albertan living in similar circumstances.
 - D. Measures required under the *Safety Codes Act* should be affordable, enforceable and meaningful so that compliance can be achieved within the circumstances where people live.
7. Government of Alberta request that Municipal Affairs staff and municipal inspectors be offered education from Inclusion Alberta, Alberta Council of Disability Services (ACDS) and individuals with developmental disabilities in understanding the homes and residences of individuals with developmental disabilities.

Other Ideas:

Emergency Voluntary Self-Registry

- 8. Government of Alberta encourage municipalities to investigate a voluntary database for First Responders¹ containing emergency contact information and the needs of individuals requiring particular attention in an emergency.

Advocacy

- 9. Provide additional supports to strengthen independent self-advocacy and family advocacy efforts and organizations.
- 10. Investigate the creation of an independent Disability Advocate Office.

Health and Safety Officials as Educators

- 11. Health and safety officials continue to provide information on a voluntary basis to individuals with developmental disabilities, their families and service providers on how to life safely in their homes and communities.

¹First Responders includes police, firefighters, Emergency Medical Services (EMS) and Search and Rescue Alberta.

Background

On September 18, 2015, the 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 Persons with Developmental Disabilities (PDD) program. This announcement was in response to concerns raised in the community over the (now repealed) Persons with Developmental Disabilities (PDD) Safety Standards Regulation.

An eight member Consultation Team comprised of disability and broader community representatives was appointed in December 2015 to lead the engagement and provide recommendations to government on how to support the safety of individuals with developmental disabilities. The Consultation Team was supported by Government of Alberta staff with technical expertise in relevant legislation and policy.

The Consultation Team developed a two-phased engagement approach with the objective of creating a transparent, inclusive and welcoming process that would develop practical and supported ideas. It was important to provide individuals, their families/guardians, service providers and other stakeholders with a safe space to share their thoughts and opinions.

Phase One

Phase One took place between February 18, 2016 and March 14, 2016. The focus of Phase One was to listen to participants' opinions on safety and their experience with the PDD Safety Standards Regulation, the role that various stakeholders play in supporting safety, as well as to gather ideas for how to address safety.

More than 750 people attended eight community forums and 1,300 questionnaires were completed online or by mail. Participants included Albertans with developmental disabilities, their families and guardians, service providers, health and safety professionals, landlords and other stakeholders.

The Consultation Team drafted a Summary Report highlighting the following feedback from Albertans:

- The PDD Safety Standards Regulation was very confusing to stakeholders and was often interpreted differently by various parties.
- Safety is much broader than that captured in the PDD Safety Standards Regulation.
- Safety is a shared responsibility.
- Appropriate education and on-going training for staff were identified as working well to support safety in the homes of individuals with developmental disabilities.
- A number of serious concerns about the then PDD Safety Standards Regulation were also identified, including cost and perceived discrimination.

Based on this, the Consultation Team proposed the following recommendations on April 1, 2016, which government has 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: Persons with Developmental Disabilities Safety Standards Consultation can be found on the PDD Consultation website: <http://www.humanservices.alberta.ca/documents/PDD-standards-consultation-summary-report.pdf>.

Phase Two

Phase Two of the safety standards consultation took place from June 12, 2016 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.

The objective in Phase Two was to engage in targeted conversations on ideas for safety generated from Phase One.

These ideas were organized into five broad areas: PDD Program; Staff Training and Education; Accreditation Standards for Agencies; *Safety Codes Act* Interpretation; and Other Ideas to support safety. A total of 142 participants attended 14 focus groups and over 550 questionnaires were completed online or by mail. Focus group participants included Albertans with developmental disabilities, their families and guardians, service providers and front-line staff. The Consultation Team also hosted separate focus groups with self-advocates, fire and building code officials and Government of Alberta PDD staff.

The Phase Two Summary Report: Persons with Developmental Disabilities Safety Standards Consultation can be found on the PDD Consultation website: <http://www.humanservices.alberta.ca/pddconsultation>.

Context

The PDD and broader disability communities have long advocated for community-based supports and inclusion. For the past 60 years in Canada, there has been a gradual movement of services away from charity based to government funded supports and from large institutions that were custodial in nature to smaller, community-based support services². In addition, the majority of individuals with developmental disabilities grew up with their families and it was largely the advocacy of families that led to the establishment and funding of the Human Services system that we know today. The developments corresponded with the recognition that individuals with developmental disabilities have the right to live in communities where their choices and individual preferences are respected.

More recently, creating inclusive lives in the community has become a priority for Albertans³. Making communities inclusive and welcoming where all people enjoy opportunities to fulfill their potential and benefit from strong social, economic and cultural life is of utmost importance to safety.

This sentiment was echoed throughout the consultation. Participants advocated for a holistic view of safety that looks beyond structural elements of a building to include community connectedness and social inclusion for individuals with developmental disabilities. Feeling comfortable and connected in your home and community is an important aspect of safety.

From this perspective, multiple stakeholders support the safety and well-being of individuals with developmental disabilities in overlapping ways, including service providers, families/guardians, PDD program staff and municipal officials. The roles and responsibilities of these various stakeholders can vary depending on individual and community needs. Despite their varying roles, stakeholders must work together to foster safety and meaningful inclusion.

² Lord and Hutchison, Individualised Support and Funding: Building Blocks for Capacity Building and Inclusion; 2003. Available from: http://www.johnlord.net/web_documents/individualized_support_and_funding....pdf

³ Alberta Association for Community Living and Persons with Developmental Disabilities (PDD) Alberta Human Services, Creating Inclusive Lives: Blue Sky Conference Report; 2013. Available from: <http://open.alberta.ca/dataset/68a356bf-82ad-4608-9d76-cd1e0624b5e2/resource/889bbe6b-1b10-4f3c-88d3-1cb7d75a508f/download/pdd-blue-sky-conference-report.pdf>

Recommendations

The following recommendations are meant to give broad direction to the Government of Alberta on how to support the safety and inclusion of individuals with developmental disabilities. In developing the recommendations, the Consultation Team used the following principles as a framework to guide their discussions:

- Safety is valued by everyone and our approach to safety needs to consider individual circumstances and needs;
- People are safest when they are included in and connected to their communities;
- Safety is about more than just physical structures and elements;
- Having a sense of belonging and feeling comfortable in your own home are vital components of safety;
- Safety is increased when people are informed and aware of how to be safe;
- Safety and well-being are best supported when people have the necessary knowledge and skills;
- Ideas require creativity and this is best accomplished through collaboration and partnership; and
- Ideas that put the individual first and provide a foundation of inclusion will be more successful.

Regardless of what is recommended, it is important to consider individuals' dignity of risk and the impossibility of ever creating a zero-risk environment. The rights of individuals with developmental disabilities to live with dignity, opportunity and choice remain paramount.

Government should be mindful of the complexity of the PDD program when considering the development and implementation of these recommendations. The Consultation Team also recognizes that many of these recommendations have financial implications that will have to be considered by Government in responding to our recommendations.

PDD Program

The mandate of the Consultation Team was to engage the community in conversations about the PDD Safety Standards Regulation and what keeps individuals with developmental disabilities safe in their home. The starting focus was the Regulation but, given the opportunity to have input, the community did not hesitate to identify numerous areas in which safety was compromised by policies, practices and changes in the PDD program, often introduced without consultation.

Feedback in Phase One confirmed that individuals are safest when they are connected to their community. This is 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. It was clear that the PDD program plays a vital and integral role in supporting individuals with developmental disabilities and their families.

The Consultation Team heard that the PDD program has shifted from a system of supporting individuals to one focused on administrative efficiencies and standardized approaches⁴. This has created a sense of mistrust and frustration in the PDD community. Many individuals and their families/guardians felt reluctant to voice these concerns for fear of retribution from the PDD program.

To add to this change, the PDD program has been the focus of numerous administrative and program reviews⁵, has moved frequently between multiple government departments and has been subjected to repeated reorganizations within those government departments. This made it difficult for individuals and families to navigate the new requirements and changes to the system and for the program to develop a consistent identity in the community. Over the course of this consultation the PDD program has undergone another reorganization with little or no involvement from the community it is supposed to serve. Under this current reorganization it is not clear how services and supports will be delivered or improved for individuals with developmental disabilities. Historically, the governance structure has undergone repeated changes from centralized to community governance to regionalization. Most recently, the governance structure has been centralized again with integration into broader Human Services programs.

Coherent, consistent and transparent policies and practices are key elements in providing quality supports for individuals. Receiving supports and funding in an environment of seemingly constant change and complexity has led to confusion and uncertainty. Demand for services continues to increase yet PDD program resources have not kept pace, resulting in limited options and delays in support. Individual safety is then compromised as people are less safe when they cannot get basic or timely access to the program and information.

Continued evaluation and innovation are needed to ensure the PDD program is supporting individuals and their families in the best way possible through personalized and individualized support. For example, the Achieving Better Outcomes Initiative (ABOI) funded innovative pilot projects, but these were not implemented province-wide, although some initiatives continue to be used as best practices for the PDD program. Consultation participants advocated for a review of the PDD program to enable more inclusive lives in the community and thus a safer life for individuals with developmental disabilities⁶.

Ideas are best developed and delivered through collaboration and partnership. Community Boards were disbanded in 2013 based on recommendations from the KPMG report⁷ but no other substantive ongoing engagement models or means of communication between the PDD program and the disability community were put in place. Moreover, advice from PDD Advisory Committees (i.e. PDD Provincial Advisory Committee and PDD Provincial Self-Advocates' Advisory Committee) has not always been seriously considered. For example, the PDD Safety Standards Regulation was created despite the PDD Provincial Advisory Committee being unsupportive.

⁴ Alberta Human Services, PDD Program Change Initiatives: Before and After; 2013.

⁵ For example: KPMG, Administrative Review of the Persons with Developmental Disabilities (PDD) Program; 2010, and Government of Alberta, Transforming the PDD Program within the Context of Disability Service; 2014.

⁶ Phase One Summary Report; 2016 and Phase Two Summary Report; 2016. Available from: <http://www.humanservices.alberta.ca/pddconsultation>

⁷ KPMG, Administrative Review of the Persons with Developmental Disabilities (PDD) Program; 2010.

A strained relationship exists between the PDD program and the developmental disability community. Consultation participants supported a broader engagement model that invites participation and advice to inform program policy direction proactively, and open and transparent communication as a way to address this relationship issue. Many participants vocalized their appreciation of the Consultation Team members' efforts to listen to the individuals that are most affected. Participants noted that they would like to continue being engaged in a similar manner, with the assumption that what is heard will be acted upon. Broad and open communication can allow the disability community to be actively involved in a program review, track its progress and provide input on how to proceed with findings.

Recommendations

1. Undertake a review of the PDD program to foster safer lives in the community for individuals with developmental disabilities.
2. Develop a means of open, meaningful communication between the PDD program and the disability community that will build trust and support positive interactions.

Considerations

Participants indicated that a PDD review should be conducted by a neutral body independent/ external from government. Many felt that a review should be conducted in close consultation with individuals, their families and those providing support. The individual should be at the center of the review based on values of respect and transparency.

The review should clearly define the roles and responsibilities of various stakeholders in a vast and complex system. This includes individuals receiving support, families/guardians, service providers, PDD program staff, municipalities and other government departments such as Municipal Affairs, Health, Justice and Advanced Education. Clarity in roles and responsibilities can increase safety for those receiving services by removing barriers to accessing supports and duplication of work and by streamlining communication between various stakeholders.

Consultation participants indicated that a review should respect and incorporate an individualized approach to planning. Safety is valued by everyone. Individual circumstances and needs must be paramount in the context of a meaningful and inclusive life.

Participants indicated that transparency, collaboration and respect need to be at the forefront of any engagement model developed. The importance of ongoing and proactive consultation was also emphasized. Engagement models should continue to build on the goodwill that was created through this consultation. Future engagements should be created using a similar model.

It is important that the review and any engagement model be clearly representative of the disability community and their perspective. This requires working in partnership with a broad, diverse range of perspectives that includes citizens, individuals with developmental disabilities and families, employers, community organizations and academic leaders, the full spectrum of service providers and representatives of the appropriate government agencies and departments.

Staff Training and Education

Quality support services are an important contributor to the health, safety and inclusion of individuals with developmental disabilities. Safety is increased when staff possess the necessary knowledge and skills to meet the needs of the individuals they support and facilitate their meaningful inclusion in home and community life. Staff should have specific knowledge, skills and experience working with individuals with developmental disabilities. Currently, there are no provincial minimum educational or certification requirements for staff working in the Community Disability Services sector.

Consultation participants raised concerns about a number of critical staffing issues⁸. The Community Disability Services sector experiences extremely high turnover rates⁹, low wages and low staffing levels. Reducing turnover is important for continuity of services, developing rapport and providing individualized supports to persons with developmental disabilities. Quality care is diminished when staff are not familiar with the individuals they are supporting. High turnover rates also result in additional recruiting and training costs for service providers. High turnover rates stem from a lack of valued identity for the sector and low wages¹⁰. Low compensation does not recognize the valuable work performed by this sector and fails to attract staff with higher qualifications. This is a long standing issue¹¹.

Concerns were also raised about the level of training and education among support staff. There has been a significant decline in the number of post-secondary programs for disability studies in Alberta, which once provided certificates and diplomas, undergraduate and graduate degrees¹². The decline in training opportunities and the lack of training and educational requirements undermines safety and inclusion for individuals with developmental disabilities. The loss of many post-secondary disability services diploma programs has eroded qualifications and opportunities for staff to view working in this field as a career. Higher credentials are needed to attract and retain those interested in a career in the field, to provide staff with the knowledge and skills required to facilitate greater degrees of inclusion for individuals receiving supports and to address the increasing numbers of complex cases. Currently, the highest level of education for most support staff is a high school diploma¹³. Agencies must draw from a limited pool of workers with post-secondary education and typically provide in-house training. In-house training is not equivalent to post-secondary education and is inconsistent across agencies.

⁸ Phase One Summary Report; 2016 and Phase Two Summary Report; 2016. Available from: <http://www.humanservices.alberta.ca/pddconsultation>

⁹ Alberta Council of Disability Services (ACDS), Current Post-Secondary Programs and Recent Closures; 2014. Available from: http://www.acds.ca/web/images/webpages/training-events/Training-Education_post_secondary_closures_FINAL.pdf

¹⁰ Eugene Zwozdesky for Alberta Health and Wellness, Building Better Bridges: Final Report on Programs and Services in Support of Persons with Developmental Disabilities; 2000. Available from: <https://archive.org/details/buildingbetterbr00zwoz>

¹¹ For example, ACDS Provincial Workforce Council has researched and pursued critical staffing issues for over ten years. More information available from: <http://www.acds.ca>; <http://www.acds.ca/web/index.php/divisions/workforce/human-resource-strategy>

¹² Between 2008 and 2013, eight diploma and certificate programs were closed or suspended in Alberta.

¹³ See above, ACDS; 2014.

Recommendations

3. Government of Alberta work with community partners to create and implement a human resources plan for Community Disability Services to better ensure safety and meaningful inclusion. This plan should incorporate the following requirements:
 - A. Require training and post-secondary educational standards to bring more qualified workers into the field and ensure consistency among staff qualifications.
 - B. Require staff working with developmental disabilities to be professionally certified.

Considerations

Child Care Certification in Alberta¹⁴, the Health Care Aid model and The Health Workforce Action Plan¹⁵ could be used as guides when developing a human resources plan for Community Disability Services. The Government of Alberta worked with stakeholders to modernize these sectors in response to similar issues such as a lack of consistent standards and absence of higher qualifications. Training and educational requirements were developed for differing levels of career advancement, a certification scheme was developed for Child Care staff, and partnerships were formed with educational institutions to create career pathways. These changes were based on research that quality outcomes and supports depend on qualified, well-trained staff.

Consultation participants stressed that competencies are important for staff that support individuals with developmental disabilities. Required competencies did exist within college diploma programs and still do for those programs which remain. Collaborating with stakeholders and incorporating current initiatives into training or educational standards should be considered. For instance, Alberta's Disability Worker's Association (ADWA) is beginning to pilot the use of core competencies as professional standards for Community Disability Services Workers (CDSWs)¹⁶. Also, Alberta Council of Disability Services (ACDS) Provincial Workforce Council is currently working on incorporating competencies as a Human Resources strategy. These could be incorporated and built upon within a human resources plan for Community Disability Services. To address concerns over staff communication skills, certification should include language proficiency requirements, similar to those accepted for Child Care Certification.

¹⁴ Government of Alberta, Child Care Staff Certification Guide; 2015. Available from: <http://www.humanservices.alberta.ca/documents/child-care-staff-certification-guide.pdf>. More information available from: <http://www.humanservices.alberta.ca/family-community/child-care-providers-staff-certification.html>

¹⁵ Government of Alberta, Health Workforce Action Plan: Addressing Alberta's Health Workforce Shortages; 2007. Available from: <http://www.health.alberta.ca/documents/Workforce-Action-Plan-2007.pdf>

¹⁶ Alberta Disability Workers Association (ADWA), Certification Standards for CSWs; 2016. Available from: http://www.adwa.ca/draft_certification_standards

Consultation participants also stressed the importance of having higher education and specialized training based on the particular positions held by staff. Consideration could be given to differing levels of certification based on position, similar to what exists in the Child Care field. For example, all staff working directly with children in licensed day care programs, out-of-school care programs and pre-school programs must be certified at one of three levels of certification: Child Development Supervisor (e.g. two-year Early Learning and Child Care diploma); Child Development Worker (e.g. one-year Early Learning and Child Care certificate); Child Developmental Assistant (e.g. completed the child care orientation course)¹⁷. Requiring specific training and education based on position creates a pathway for career advancement that may help to retain staff.

Post-secondary institutions and government departments should be brought to the table when designing training and educational standards to consider connections and equivalencies between certification requirements and available courses or programs. Incentives to enroll in approved post-secondary programs may be considered as a way to attract talent to the industry and widen the hiring pool of support staff. Post-secondary institutions and government should also be brought to the table to discuss how to reestablish discontinued certificate and diploma training programs.

Training and educational standards should be phased in to accommodate the current workforce. New educational and training standards should recognize existing staff and their qualifications. New standards should also be accessible online and on-site. They should be flexible enough to allow for equivalencies in experience and education.

Creating professional standards and formally recognizing qualifications can bring more value to the work of staff. Staff wages should be commensurate with the professionalization of the workforce and an indicator of the valued work performed by this sector. More specifically, staff wages should be increased to reflect higher educational and training requirements implemented through a human resources plan.

Accreditation Standards for Agencies

Accreditation standards for agencies that provide PDD-funded services are a means to monitor safety and safe practices. These accreditation standards measure quality of service, organization, governance and operational effectiveness, and how these factors impact quality of life for clients. Currently, contracted community service providers are required to obtain and maintain accreditation standards at least every three years.

Accreditation standards can be used to foster safety by reviewing processes, resources and training to ensure that staff and individuals are safe, and to develop deeper feelings of trust and security for everyone involved. This can include fire drills, the installation of approved safety equipment such as fire alarms, fire extinguishers, carbon monoxide detectors, emergency kits and other site safety/maintenance checks. Accreditation standards can also be used to increase personal safety and well-being by monitoring elements such as abuse prevention, staff training and inclusion.

¹⁷ Government of Alberta, Child Care Staff Certification Guide; 2015. Available from: <http://www.humanservices.alberta.ca/documents/child-care-staff-certification-guide.pdf>. More information available from: <http://www.humanservices.alberta.ca/family-community/child-care-providers-staff-certification.html>

Consultation participants often referenced accreditation standards as a means to support safety in homes. The process was viewed as less intrusive and more collaborative than inspections carried out by health and safety officials. Many also liked the idea of using existing structures and processes rather than creating something new.

Recommendation

4. Strengthen accreditation standards for agencies that provide PDD-funded services in the areas of health and safety to reflect the critical individualized safety requirements in the homes of people with developmental disabilities.

Considerations

It is important to reflect on individuals' dignity of risk and the impossibility of ever creating a 'zero-risk' environment, regardless of what is changed or added to accreditation standards for agencies. The rights of individuals with developmental disabilities to live with dignity, opportunity and choice remain paramount when strengthening accreditation standards.

Consultation participants advocated for a holistic view of safety. Strengthening of accreditation standards should consider personal safety, a safe home environment and community inclusion.

Changes to accreditation standards should be phased in to allow service providers time to implement processes and train front-line staff accordingly. This should also include training and education for individuals and their families/guardians.

Consultation participants discussed various considerations related to the process of accreditation. For example, participants noted that the frequency of monitoring for compliance with safety requirements could be increased, but should do so without jeopardizing the integrity and essence of home.

While many service providers actively engage individuals and their families/guardians in the accreditation process, many consultation participants expressed a desire to see these efforts increased. Individuals and families/guardians should be afforded a more active role in the accreditation process when possible. This will help increase their knowledge and capacity to support safety.

Engagement with accreditation bodies and other stakeholders, including individuals and families/guardians should take place prior to devising changes to existing standards. Standards and the corresponding indicators should be tangible, concrete and measurable.

Participants clearly stated that the accreditation process for agencies should continue to be independent of government as a way to maintain confidence in the standards and the process itself. However, contract managers within the PDD program should continue to be involved, although in a limited way, since they may have valuable insights into agencies' performance over time.

Finally, information on the accreditation process and standards should be made readily available to individuals funded under Family Managed Services (FMS) agreements. Individuals and their families should be able to access important information about home safety such as maintaining safety equipment and implementing fire exit plans.

Safety Codes Act Interpretation

The *Safety Codes Act* provides a system for the safe management and control of any thing, process or activity regulated under the Act. Safety codes regulated under the Act, such as the Alberta Building Code and Alberta Fire Code, set minimum mandatory safety standards for the protection of all Albertans.

For buildings in which we live, work and play, the use or purpose of a building combined with the capacity of persons to self-evacuate are key factors for determining the level of safety required under Alberta's building and fire codes. Building and fire codes regulate the design and construction of new houses and buildings, the requirements when a building undergoes a change of use, and the maintenance and operation of fire safety systems in existing buildings.

While these safety codes apply to buildings and homes where persons receiving services under the PDD program reside, as they do in anyone else's home, assessing these accommodations for appropriate safety has been challenging with costly and upsetting consequences for the residents. Under the former PDD Safety Standards Regulation, safety codes officers and health officers were required to inspect these accommodations, which were sometimes identified as PDD facilities, in accordance with the *Safety Codes Act* and the *Public Health Act*.

Given the above, in the opinion of the inspector, if the individual was incapable of self-evacuation without assistance either from a physical or cognitive disability, or if the individual was restrained from evacuating because of security measures, the more restrictive standards for care or detention, as opposed to residential, would be applied. The minimum safety standards required for care or detention are far more restrictive and costly than the standards used for a residence, including such measures as sprinkler and fire alarm systems. As safety code compliance would be extraordinarily difficult or impossible for families, rental owners and service providers, a guidance document known as a STANDATA Approved Guideline was provided by Municipal Affairs using measures less restrictive than for care or detention, but still more restrictive than residential. Under STANDATA the measures remained restrictive and costly for many homes and the issue of applying a care or institutional standard to a home was not resolved.

Throughout the consultation, participants expressed concerns about the varying interpretations and practices in the application of the safety codes across the province, even with the STANDATA in place¹⁸. Many felt the STANDATA was too restrictive and did not appropriately apply as it was designed for facilities and did not recognize homes of individuals with developmental disabilities as residential occupancies. After the repeal of the PDD Safety Standards Regulation, many participants questioned the need for the STANDATA and its application going forward given earlier concerns.

¹⁸ Phase One Summary Report; 2016 and Phase Two Summary Report; 2016. Available from: <http://www.humanservices.alberta.ca/pddconsultation>

Most fundamentally, individuals and families strongly opposed the presumption made under the PDD Safety Standards Regulation and STANDATA that receiving services through PDD changed their private homes to care facilities that require institutional health and safety measures. They felt that the sanctity of an individual's home and their rights within that home were not respected. Feelings of being treated with fewer rights and less respect than other citizens, coupled with the possibility of forfeiting their funded supports should they not comply with the requirements left them feeling angry, powerless and devalued.

Recommendations

5. Municipal Affairs withdraw the August 2015 STANDATA.
6. Government of Alberta provide guidance to municipalities on how to interpret and apply the safety codes using the following principles:
 - A. Residences occupied by individuals with developmental disabilities who rent, lease or own are not "PDD residences" or facilities.
 - B. The starting point for safety code assessment of homes for individuals receiving support from PDD should be that they are residential dwellings, in the same manner as any other home.
 - C. The source of financial or service support being received by a person living in a home is not relevant to how the building codes are interpreted and applied to that home. That is, homes of people receiving support through PDD should be treated no differently from the homes of people not receiving publicly funded support, or receiving it from another source. Any change of use or alternative classification under the *Safety Codes Act* (including building and fire codes) should be assessed as it would be for any Albertan living in similar circumstances.
 - D. Measures required under the *Safety Codes Act* should be affordable, enforceable and meaningful so that compliance can be achieved within the circumstances where people live.
7. Government of Alberta request that Municipal Affairs staff and municipal inspectors be offered education from Incusion Alberta, Alberta Council of Disability Services (ACDS) and individuals with developmental disabilities in understanding the homes and residences of individuals with developmental disabilities.

Considerations

People receiving support through PDD have a wide variety of living situations with different legislative and regulatory rules that apply to those different situations. For example, some individuals rent, some own their homes, some live with family or roommates, etc. Some live in residences that are licensed under the *Supportive Living Accommodation Licensing Act (SLALA)*, which has its own specific inspection and licensing requirements. The recommendations made here are not intended to apply to residences approved and licensed under SLALA.

Consultation participants were clear that safety standards should not be developed based solely on the funding an individual is receiving from a government program, such as PDD. However, some did recognize circumstances in which additional safety measures may be required in homes to meet the safety needs of individuals. The most frequently cited circumstances included individuals who are restrained or in a detention situation, or individuals who have no ability to self-evacuate where staff are not trained or in sufficient numbers to assist with exiting the home or building. These are the situations most frequently cited by safety officials as well.

Guidance for inspectors is necessary to address those situations so that individuals receiving PDD services have the same safety protection as other Albertans living in their homes. But it must start with the approach that the places where individuals receiving PDD services live are homes – intended to be lived in and used as homes. This will require timely work with municipalities to reduce inconsistent application and interpretation of safety codes. Many municipal development, building and fire officials currently take the approach that homes where PDD services are provided are care occupancies or group homes operating as businesses providing rental care accommodations for persons with disabilities. Changing this view will require government to provide significant communication, education and guidance to municipalities and their safety officials.

The risk that safety codes will continue to be interpreted and applied in a restrictive manner that is inconsistent with our recommendations is increased because addresses were provided to municipalities under the now repealed PDD Safety Standards Regulation. The practice of requiring business licenses or changes in zoning for residences previously and inappropriately identified as care facilities should be discouraged.

There may be safety measures beyond those that are required in a home that are advisable in individual circumstances, such as improved accessibility, posted fire safety plans and visual alarms. What is needed is a collaborative and educational approach by the PDD program, service providers, safety officials and individuals and families to tailor voluntary safety measures that are appropriate for the situation. Participants in the consultation strongly supported having the choice to obtain this type of assistance as would any other homeowner.

In the longer term, Municipal Affairs should also consider measures that would be of value to improving safety in the broad range of circumstances in which Albertans live consistent with the recommended principles. Any such measures should be implemented only after carefully consulting with all potentially impacted groups, for example seniors, persons with disabilities, others with limited mobility or receiving in-home staff support.

Other Ideas

Emergency Voluntary Self-Registry

Consultation results confirmed the importance of well-informed first responders in emergency situations. The majority of questionnaire participants agreed with the idea of encouraging municipalities to adopt a voluntary database similar to the Calgary Police Service's Vulnerable Person Self-Registry¹⁹. In fact, many people indicated that some individuals and their service providers already work with first responders to provide information on specific needs and circumstances. A self-registry can act as a more formal means to support the safety of all individuals who wish to register.

Calgary Police Service's Vulnerable Person Self-Registry is a database where individuals can register if they have a condition requiring particular attention in an emergency. Individuals can register by entering their name, date of birth, physical description, contact information, methods of approach/communication and a description of any life threatening medical conditions²⁰. The registry is open to individuals who spend the majority of their time in Calgary. Information must be updated 6 months, 1 year or 2 years from the initial entry or it will be removed.

Recommendation

8. Government of Alberta encourage municipalities to investigate a voluntary database for First Responders²¹ containing emergency contact information and the needs of individuals requiring particular attention in an emergency.

Considerations

Consultation participants stressed that registries must remain voluntary. Respecting the rights of individuals to live with opportunity and choice is of utmost importance.

Registries should not be used outside of an emergency situation and information should be stored securely and only accessible to first responders for the purposes of safety.

Registries should be available for any individual who wishes to provide information on their physical, developmental or medical needs and not restricted to those with developmental disabilities.

It should be noted that the term "vulnerable" is strongly discouraged when designing registries as it does not recognize the strength and independence of individuals with developmental disabilities.

¹⁹ Phase Two Summary Report; 2016. Available from: <http://www.humanservices.alberta.ca/pddconsultation>

²⁰ Calgary Police Service, Vulnerable Person Self-Registry; 2016. Available from: <http://www.calgary.ca/cps/Pages/Community-programs-and-resources/Diversity-resources/Vulnerable-Person-Self-Registry.aspx>

²¹ First Responders includes police, firefighters, Emergency Medical Services (EMS) and Search and Rescue Alberta.

Advocacy

Advocacy is critical within the PDD community to ensure that individuals with developmental disabilities are supported to achieve the best possible outcomes. Consultation participants valued advocacy as a way to be heard in a complex system of programs and services²².

Participants indicated that self-advocacy and family advocacy is paramount. Self-advocacy allows individuals to communicate their needs and exercise control over their lives, increasing their independence. Family advocacy provides opportunities for families/guardians to enable individuals to pursue an inclusive life and to ensure access to appropriate and needed resources. Both individual and family advocacy efforts provide a means for organizations to address issues and advocate for change at the individual and systemic level.

In addition to sustaining and advancing self and family advocacy, some consultation participants were supportive of investigating the creation of a Disability Advocate Office. Across Canada there are two Disability Advocate Offices: Advocate for Service Quality in British Columbia and Office of the Vulnerable Persons' Commissioner in Manitoba. The roles of these offices include helping individuals understand government systems, providing an avenue for their voices to be heard, and assisting with their decision-making rights.

Disability Advocate Offices tend to consider the systemic needs of the disability community as a whole, while self-advocacy and family advocacy efforts focus on both individual and systemic issues.

Recommendations

9. Provide additional supports to strengthen independent self-advocacy and family advocacy efforts and organizations.
10. Investigate the creation of an independent Disability Advocate Office.

Considerations

Existing self-advocacy and family advocacy efforts and organizations should be promoted when providing additional supports. It is important to raise awareness of the rights and services available to individuals and families.

Consultation participants stressed the importance of independence from government and service providers. A Disability Advocate Office, if forthcoming, must be independent and maintain clear reporting streams.

Concerns were raised over the administrative and overall costs of a Disability Advocacy Office. Caution should also be given to further segregating avenues of support for individuals with developmental disabilities. The investigation of a Disability Advocate Office should include how the Office would fit in with existing networks and forms of advocacy in this complex system.

²² Phase One Summary Report; 2016 and Phase Two Summary Report; 2016. Available from: <http://www.humanservices.alberta.ca/pddconsultation>

The review of child and youth advocacy in Alberta completed in 2009 can inform the creation and implementation of a Disability Advocate Office²³. This review indicated core functions of the Child and Youth Advocate²⁴. Consideration should therefore be given to clearly defining the core functions of a Disability Advocate if it were introduced, how it could be empowered to create systemic change, and the need for open transparent communication avenues between it, the Ministry, and the disability community. Clarity should also be given to whether the Disability Advocate would solely serve those with developmental disabilities or individuals with other disabilities as well.

Finally, the establishment of a Disability Advocate's Office should not be seen as a replacement for the increase in supports for self-advocacy and family advocacy efforts and organizations.

Health and Safety Officials as Educators

During the consultation, health and safety officials expressed their appreciation for opportunities to help educate individuals with developmental disabilities, their families and service providers on best practices for safety in homes and communities²⁵. Developing and maintaining these positive relationships between safety officials and the PDD community is important for meaningful inclusion and safety in homes.

Education can help build capacity in individuals and front-line staff to live safely. In addition, health and safety officials can increase their knowledge of individuals with developmental disabilities and how to best support their health and safety needs.

Recommendation

11. Health and safety officials continue to provide information on a voluntary basis to individuals with developmental disabilities, their families and service providers on how to live safely in their homes and communities.

Considerations

Safety education should be accessible but not mandatory. Individuals with developmental disabilities and their families felt "invaded" or "scrutinized" when health and safety officials entered their homes to conduct inspections. It is important for health and safety officials to respect the integrity of a home and avoid intrusiveness. Education should be differentiated from inspection.

²³ Government of Alberta, Review of Child and Youth Advocacy in Alberta; 2009. Available from: http://archive.org/details/reviewofchildyou00albe_0

²⁴ These core functions include individual advocacy, systemic advocacy, professional advocacy and natural/community advocacy.

²⁵ Phase One Summary Report; 2016 and Phase Two Summary Report; 2016. Available from: <http://www.humanservices.alberta.ca/pddconsultation>

Conclusion

The PDD Program and the disability community must work together to support safety and inclusion for individuals with developmental disabilities. Individuals, their families and guardians, service providers and government all have a role to play. The recommendations in this report provide a starting point for action and change. They are intended to form a foundation of inclusion that puts individuals first and provide a rationale for focusing on individual circumstances and needs to support safety in communities.

Appendix

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