Key elements of successful housing for individuals with developmental disabilities and exceptional behavioural needs: Useful space designs and supportive residential models

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Successful Housing Elements and Developmental Disabilities (SHEDD)

Table of Contents

Section 1 – EXECUTIVE SUMMARY

The overall objective of the project was to describe successful physical space and design arrangements in housing for Ontarians with intellectual and developmental disabilities (IDD) who exhibit exceptional behaviours that challenge (BTC) (See appendix 1 for list of acronyms and glossary of terms). The multidisciplinary project team (architect, psychologists, nurse, occupational and physical therapists) used different methods to collect and analyze data on housing accommodations, and created a practical tool that can be used by stakeholders to guide future decisions related to physical space adaptations. To determine the key elements required for successful housing placements we adopted a mixed-methods approach consisting of different study designs, described in this report as 'outputs' which included:

1) A comprehensive literature review of 15 original, quantitative, peer-reviewed articles that included study participants with IDD who exhibit BTC, and described residential physical environments.
2) A qualitative study that consisted of semi-structured interviews of 18 individuals who had knowledge or experience regarding residences for persons with IDD who exhibit exceptional BTC. These key informants included a resident, residence staff and administrators, and clinicians.
3) Case-studies where we collected and analyzed administrative and other data from supported residences where people with IDD who exhibit exceptional BTC live. The data included resident and staff outcomes (e.g. PRN medication use, staff injuries), costs, drawings of building layouts, and physical descriptions and pictures of modifications implemented to meet resident needs.
4) A tool developed and informed by outputs 1-3. Called the Environmental Modifications Tool (EM Tool; see appendix 2), this instrument describes options for different physical environment adaptations to meet the unique and complex behavioural needs of this population.

Output 1: Literature Review

To our knowledge, this literature review is the first to summarize existing research on designs and modifications to the physical environment in supported housing for individuals with IDD who exhibit BTC. Fifteen (15) articles that described the characteristics of successful housing from an architectural lens at the building scale and/or community scale were included in this review. The review concluded that appropriate modifications to buildings were a necessity; without appropriate adaptations there was an increased risk for placement breakdown due to a mismatch between the needs of the resident and what the physical space of the home could provide. The included studies suggested that residences could promote successful placements by: providing safer environments and using more durable materials; constructing and providing more appropriate room layouts; managing levels of stimulation in the environment, tailoring the sensory experience to the individual; and by making design choices that are more homelike. Other areas of special consideration were the location or size of the building.

Output 2: Semi-Structured Interviews

Residence staff, administrators, a resident with IDD and health professionals were asked during interviews to describe key elements that lead to successful placements and that were specifically related to physical space and design arrangements used to address BTC. Analysis of interview transcripts (n=18) identified 5 major themes. The two most commonly reported themes were physical space adaptations and descriptions of the physical environment. Quotes from participants highlighted a number of adaptations addressing BTC, adaptations for improving safety, adaptations for increasing home-likeness, and options for residence location.

Output 3: Case Studies

We visited a number of high support residences (i.e. case studies) administered by 4 agencies located in Southern Ontario and documented their spatial layouts and examples of space modifications. The 5 case study descriptions in this report include text and drawings at the community, building and dwelling scale. At the community level a range of urban, suburban and rural buildings are shown. Within the buildings, most residents had access to a private bedroom, living area and bathroom, as well as

communal living and outdoor areas. Staff found a variety of ways to integrate storage room and office space for administrative tasks. Kitchens were often semi-restricted, depending on the behaviour of residents. Common modifications included hardened walls (to prevent damage), seamless installation of wall and floor finishes, padded walls (to prevent injuries), use of heavy durable materials and selective use of locks and surveillance.

For the case studies we also collected data on costs (capital and operating), frequency of behaviours, frequency of prescribed as needed medication (PRN) use and staff injuries. The average per year per resident operating cost was $356,000 and the average per year per resident capital cost was $10,839. The most common challenging behaviour were physical aggression (42% of behaviours among all behaviours reported in incident reports). There was an average 10.4 PRN psychotropic medications/person/month administered. Over a one-year period, our partner agencies reported 22 staff injuries.

Output 4: Environmental Modifications Tool Describing Design Strategies

Using findings from the other outputs, the project created a tool that provides strategies to modify the physical environment of residences to better meet the sometimes unique and complex behavioural needs of persons with IDD. The EM Tool (appendix 2) aims to summarize design solutions and promote discussion between stakeholders in an effort to put effective modifications in place. Modifications to the physical environment are summarized first as a list of broad design principles and considerations when making quick fixes, renovations or new purpose-built buildings. This is followed by a comprehensive and more specific list, described with text and pictures and organized by room and living area. The EM Tool is intended to be a stand-alone document that can be used by individuals who support and care for this population as well as those involved in the design or maintenance of the residence where they live (e.g. builders, designers, architects).

Section 2 – ACCOMPLISHMENTS

Research Questions and Objectives:

In our research proposal we asked: What are the characteristics (including physical space/design arrangements) of successful support models/living arrangements/residential models for individuals with intellectual and developmental disabilities (IDD) and exceptional behavioural needs? To address this question we developed 5 objectives:

a) To provide a review of the peer evaluated and grey literature on characteristics of support models/living arrangements/residential models for individuals with IDD and exceptional behavioural needs
b) To describe existing support models/living arrangements/residential models in Ontario that provide high support housing for persons with IDD and exceptional behavioural needs.
    - Include a description of physical space/design arrangements put in place to address the exceptional behavioural needs.
c) To identify key elements required for successful housing placement
    - Determine what is considered success and what contributes to achieving success
    - Determine the characteristics of failed housing placements
d) To determine resident and staff outcomes (e.g. frequency of staff/resident injury, serious incidents, PRN medication use etc.) within high support housing models located in Ontario
e) To create a tool that can be used to assess the presence and quality of key elements required for successful placements

Approach

Adults with IDD who exhibit exceptional behaviours that challenge (BTC; includes physical aggression towards the environment, others or one's self; see appendix 1 for other acronyms and glossary of terms) often have difficulty finding and/or maintaining housing or living arrangements that meet their high support needs. These extreme behaviours significantly impact those who exhibit them and those who care for them. Although there is no single underlying cause for the exceptional behaviour exhibited, several factors appear to contribute including psychological, biological, social and environmental (Tilley et al., 2015). Exceptional behaviours can be a response to an environment where there is poor quality support, as it is reported to be more prevalent in environments that are institutional, barren and unstimulating (Allen, 2009). Those who do obtain a placement may end up in a home that is not physically equipped to meet all of their needs because there are no other options. Subsequently, these homes are faced with the challenges of adapting the physical environment in order to best support the resident(s) needs.

A mixed-methods research project was planned in order to explore the characteristics (including physical space/design arrangements) of support models/living arrangements/residential models for individuals with IDD who exhibit exceptional BTC. We conducted a literature review, semi-structured interviews and completed case studies. Collecting and analyzing data from multiple sources (existing literature, residence documentation, building plans, photographs, personal reports and experiences) allowed the research team to identify a number of strategies and summarize them in a tool that can be used by organizations that provide residential support; the Environmental Modifications Tool (EM Tool; see appendix 2) is intended to help guide these organizations as they modify existing or build new spaces for people with IDD and exceptional behavioural needs.

To address objective a) we searched 3 electronic databases using a list of relevant terms (e.g. challenging behaviours, housing, design, modifications, accommodations, intellectual and developmental disabilities). After screening articles for relevant titles

and searching publication reference lists, 15 original, quantitative research articles were selected for further review and analysis. To address objectives b) and c), the research team conducted semi-structured interviews using a predetermined list of questions.

Eighteen participants were interviewed (1 group home resident, 2 clinical staff, 1 property manager, 5 residence administrative staff and 9 residence direct support staff). Participant recruitment was made possible through the support of grant partner agencies as participants consisted mostly of agency staff members and service users. The Project Advisory Committee members which included representatives from MCCSS and agencies that support people with IDD, also identified potential people to interview and facilitated participant recruitment. The research grant partnering agencies (Bethesda Community Services, Community Living Toronto, Reena, Vita Community Living Services) were from southern Ontario and included organizations from rural, suburban and urban areas. To address objective b), c) and d), 5 case studies were completed using data from the 4 partner agencies. The case studies consisted of data extracted and summarized from charts from high support residences, architectural drawings of home layouts, photos from residences to document different adaptations, and cost information. To address objective e), this study combined findings generated by the other project objectives to develop the EM Tool.

Major activities and specific objectives

1) Research ethics approval and consent procedures

The project coordinator for this project prepared two research ethics applications for the principal investigator's home institution. Specifically, a 'secondary use of data' research ethics application was submitted for the case-studies, and the ethics application for the key-informant interviews underwent a full board review. All partnering agencies were provided with the approved research ethics board applications to share with their own governing boards. We also completed the requirements from our agency partners in order to have permission to conduct research at their facilities and recruit staff and service users.

2) Completed literature review

To conduct the literature review, we first completed an electronic database search of existing publications. The search used demographic and health terms (i.e. individual with intellectual and/or developmental disabilities, behaviours that challenge) combined with terms consistent with physical environment modifications, renovations etc. Relevant publications were first screened for inclusion based on their titles, then abstracts. After this screening step, potentially relevant papers were fully read.

In order to be included in the review a study was required to be original, quantitative and peer-reviewed research. Inclusion criteria also required that: study participants had an IDD, or were the direct family member or care provider for individuals with IDD, or were directly engaged in the design and upkeep of housing for individuals with IDD. To be included a study must have also referred to behaviours that challenge and explicitly described the residential physical environment. Fifteen (15) publications met these criteria and were included in the literature review.

Subsequently, a content analysis of the selected sources was performed. This involved collecting all references to the physical environment and categorizing the modifications that were implemented to meet individual behavioural needs. This literature review is

currently in its final stages and will be submitted for potential publication to a relevant journal. The results are summarized later in this report.

3) Recruitment and completion of key informant semi-structured interviews

The research team prepared interview guides for each type of key informant participant (individual with IDD living in group home, staff at supported residences, and any other type of key informant interview). The interview guides were semi-structured allowing the researchers to engage in a guided conversation with informants and explore their responses. We contacted agencies who were aware of the project and they were sent a brief summary of the study and assisted in contacting interested participants. These individuals were invited to refer other participants. The goal was to recruit 15-20 participants.

Research team members travelled to locations where key informants worked in southern Ontario (e.g. high support residences, hospitals, community agency offices) and conducted interviews with 18 individuals. Each interview lasted 45 minutes to 1 hour and were audio-recorded.

4) Coding and analyzing of semi-structured interview results

Using the recordings, all interviews were transcribed verbatim by a research assistant. Consistent with thematic analysis methods, two research team members analyzed the interview data using open coding to identify features and themes. To enhance qualitative rigor, the thematic analysis was performed independently and the two research team members met afterwards to ensure coding was consistent. If any discrepancies were found, the two researchers discussed them in further detail and came to agreement.

5) Collection of data from agencies

Project team members visited and toured agency residences (n=5) that support people with IDD that exhibit exceptional BTC. During the tours, the team members discussed the various physical adaptations of the dwellings with staff members, obtained building

drawings, and took pictures of specific design features. The agencies also provided anonymized data on PRN medication use, incidents, staff injuries and costs.

6) Revisited all sources of data to prepare the Environmental Modifications Tool

One of the main objectives of this study was to develop a tool that agencies and other stakeholders could use to prepare the physical environment when an individual is moving to a new residence or when an individual needs changes to be made to an existing space. To address this objective, findings from the other project activities (literature review, interviews, case studies) were collected and synthesized into the EM Tool (see appendix 2).

Key outputs and related significant results, outcomes, major findings, and other achievements

The key outputs for this project were:

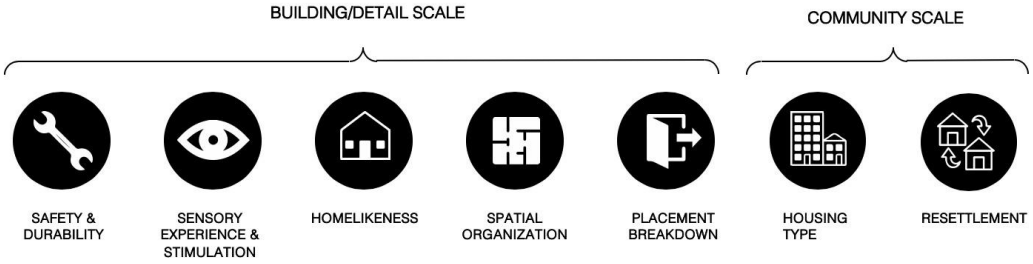
1) A literature review that aimed to identify and summarize existing research on designs and modifications to the physical environment of supported community housing for individuals with IDD who exhibit BTC.
2) Results from key informant interviews that generated qualitative data on elements related to physical space and design arrangements that have been used to address BTC.
3) Descriptions of high support housing case studies. The case studies describe characteristics and outcomes of high support housing environments provided by four Ontario agencies for persons with IDD that exhibit BTC. The case studies include architectural drawings and data on costs, frequency of PRNs, incidents, staff injuries and types of behaviours.
4) A tool that presents strategies to architecturally modify residences to meet the unique and complex behavioural needs of adults with IDD who exhibit exceptional BTC. The EM Tool was developed by collecting, summarizing and synthesizing the data and results from all the previously described research activities and outputs.

The significant results, key findings and other achievements of each output listed above are described in detail.

Output 1: Literature Review Results

Our literature review is currently in the final stages of preparation for submission for publication in the Journal of Intellectual and Developmental Disability (JIDD). Fifteen (15) articles met the inclusion criteria. Results from the review found that the existing literature can be categorized into 7 categories that describe options for modifications to the physical environment (Figure 1). Five of the categories fall within the 'Building/detail scale' and two others can be grouped as 'Community scale' strategies.

Figure 1: Categories of Literature Review



Safety and Durability refers to a robust environment, including safe and controlled access to risky areas, environments designed for ease of maintenance and with a tolerance for unintended uses (Lowe et. al, 2014). For example, securely fixing down moveable objects and installing temperature controls on hot water. Three (3) studies identified durability and safety to be a central concern in outfitting a supported home (Lowe et. al. 2014, Finlayson et al. 2015, Nagib & Williams, 2017).

Sensory Experience and Stimulation refers to adjusting qualities of the physical environment to better suit individual perception and preferences of what you can see, hear, feel and smell. Four (4) studies considered sensory experiences and/or stimulation as an option for modification. These studies documented modifications such as using questionnaires to determine individual sensory profiles, installing noise and echo proofing, changing wall colour and texture and paying special attention to ventilation in terms of both noise and odor (Mostafa, 2008; Lowe et al., 2014, Nagib & Williams, 2017; Thompson, 2000).

Homelikeness refers to the perception of the style and function of the built environment. One study investigated the connection between service outcomes and the perception of service buildings as either institutional or homelike (Thompson et al., 1996). Variables related to homelikeness included room size, doorways and other openings, finishing materials, exposed mechanical equipment, furniture (size, type arrangement), and disability specific adaptations (grab-bars, handrails). More specifically, finished hardwood floors and wall papered walls were found to be homelike while tile and vinyl floors and bare walls were found to be institutional. In homelike residences people were more likely to be involved in independent household chores and to experience more positive staff-to-resident interactions, and they were negatively correlated with stereotypic behaviour and aggression. However, no single set of physical features stood out as uniquely contributing to outcomes, instead a combination of space/features appeared to distinguish the perception of homelike versus institutional (Thompson et al., 1996).

Spatial Organization refers to the layout and spatial functioning of a house, this includes configurations of hallways and rooms, as well as how users enter and circulate throughout a residence. Three (3) studies were found with modifications about spatial organization. One such modification was one-way circulation to help activities flow as seamlessly as possible from one space to the next or organizing space into zones with different gradations of privacy. Another finding was that entrances were the most frequently modified area of the house, with living and circulation spaces being the second most modified. With regard to the overall space needs, 40% of respondents in one study added extra space specifically for a person with autism or added another room for siblings (Mostafa, 2008, Lowe et al. 2014, Nagib & Williams, 2017).

Placement Breakdown can result from a mismatch between characteristics of supported housing and individual behavioural needs (Allen, 1999). In addition, lack of information and communication with support staff and service providers about individual requirements in relation to physical space, can result in inappropriate placement and

eventual placement breakdown (Phillips & Rose, 2010). Two (2) studies in this review identified an association between placement breakdown and low scores on a housing evaluation tool called the Service System Assessment (SSA). Adequate personal space, light and ventilation, as measured by the SSA, were all qualities of the physical environment found in relation to placement breakdown (Phillips & Rose, 2010).

Housing Type refers to the overall scale and configuration of buildings included in high support housing. Three (3) studies compared the qualities of a variety of housing types: clustered housing (also referred to as residential campuses), dispersed housing, village communities, private family homes and hospitals. One study found clustered housing schemes were associated with a poorer quality of care and quality of life than dispersed housing schemes. Further, individuals supported in clustered housing were more likely to live in larger settings, be supported by fewer staff, be exposed to greater changes and inconsistencies in living arrangements, among other outcomes (Emerson, 2004).

As far as facility size, 1 study found smaller facilities with more sophisticated services were associated with higher costs, and higher levels of IDD and BTC (Hallam, 2002). In comparing buildings that support individuals with similar levels of BTC, those living in a family home had slightly higher adaptive behaviour scores than residents in community housing, and both groups had higher scores than those in hospitals (Lowe et al.,1998).

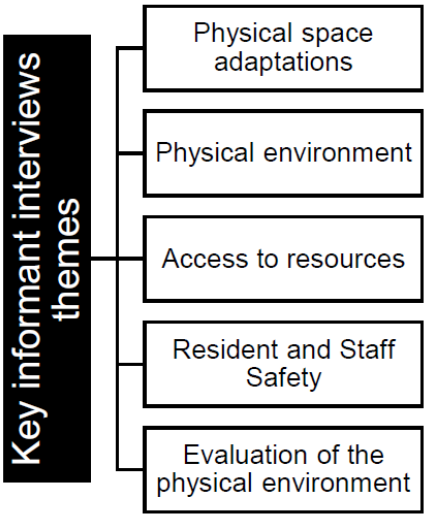
Resettlement, or moving from one supported housing program to another, may occur because of factors external to the individual, such as funding or policy changes. Two (2) studies documented resettlement into purpose-built accommodation. In one study, moving from a residential home to new, purpose-built flats decreased the amount of BTC, improved tenant mood, positive opinion from family and staff, and increased interactions between staff and tenants (Marlow, 2015, Perry et al., 2011). Another study demonstrated that emergency resettlement in the absence of appropriate high support housing can lead to individuals with IDD being inappropriately housed in psychiatric hospital settings (Lunsky, 2010). While the move to community living

marks a success in housing design, reports show that lack of suitable buildings have left adults with IDD who exhibit BTC with precarious housing options, sometimes leading to 'transinstitutionalization' in hospitals, long-term care facilities or even jails (Friedman, 2019; Dubé, 2016).

Output 2: Results From Key Informant Interviews

We interviewed 18 participants including hospital based clinicians, residence direct support staff and managers, agency administrators, a resident with IDD from a group home, and a building maintenance manager. Five (5) major themes were found (Figure 2).

Figure 2: Major themes of key-informant interviews



The 5 major themes each had 2-4 relevant subthemes. The major themes are presented in Table 1 with the sub-themes and quote examples.

Table 1: Semi-structured interview themes

Major Theme 1: PHYSICAL SPACE ADAPTATIONS	
Subthemes	• **Adaptations for behaviours that challenge** • **Adaptations for improving safety** • **Adaptations to increase home likeness** • **Flexibility of adaptations**
Quotes	"One individual…would urinate and defecate in the register vents…we ended up building columns and the register vents are about three feet off the wall now…so they are safe and clean and no further damage to the H.V.A.C" "We had an OT…who made essentially everything, the walls, all seamless…X used to pick at the walls..until something [came] off and then [would] ingest it" "The painting…it's like a very easy thing to make a house feel like fresh… Pictures!... You can go to like Michael's [art supplies store] and get like a plastic frame...And you can like screw them into the wall" "I think that monitoring piece is very important in evaluation…so that you can start fading out things, test it out but do it systematically…just because they needed that at one point doesn't mean it needs to be there [later]."
Major Theme 2: PHYSICAL ENVIRONMENT	
Subthemes	• **Location of the home** • **Desired elements of living environment** • **Undesired elements of living environment**
Quotes	"I definitely prefer a more rural area just because the home is usually larger, there's more space. In such an urban area it's a town house, there's three floors…a lot of the spaces are narrow and small which can put staff in danger" "Less furniture is always a good thing…the minute you go into a home where there's so much furniture it just becomes a hazard." "Individuals rooms are…restructured so that they would have like a bedroom but also a living space like attached to their bedroom" "We constantly….have challenges with stairs whether that's people having issues going up and down the stairs or managing crisis with stairs"
Major Theme 3:	

ACCESS TO RESOURCES	
Subthemes	• **Availability of funding** • **Staff resources/tools** • **Continuity of care**
Quotes	"We were able to get money to do that and it's incredible when you see, like when you actually invest, right? Into things like that…so like simple things, like having a cupboard that is like organized that has like a keypad on the outside that all of the locks are the same code" "Each floor had, they had to, they had the walkie-talkies to be able to call for help from different floors. Uh so you need to have a method if that's, if the space is too big." "One of the challenges that we have is uh securing the services of psychiatry and psychiatry is one of the big um key parts of um supporting our individuals because medication is not something that we are experts in"
Major Theme 4: RESIDENT AND STAFF SAFETY	
Subthemes	• **Precautionary measures** • **Staff training/education**
Quotes	"We have no glass, no ceramic. Everything is plastic. Staff eat off plastic, everybody eats off plastic. Um because it's just too dangerous. Ours are mag-locked. Our, all of sharps are locked up. We have two kitchens, so we have our general kitchen and a teaching kitchen that has nothing anything in it" "I find with the complexity of the individuals it is so important to have those familiar staff, well trained staff, staff who understand the individuals' background, information, history, typical characteristics, diagnosis all those things. "Okay so medication training definitely important so um we're able to give P.R.N.s."
Major Theme 5: EVALUATION OF PHYSICAL ENVIRONMENT	
Subthemes	• **Value of evaluating pre-placement** • **Elements of physical evaluation**
Quotes	"Highlighting sort of the smaller things whether it's like a railing or it's like specific toilet or like a bathtub, things like that. So through our environmental assessment we're now heavily focusing on that for a number of reasons…we have found it to be incredibly expensive um to figure those things out once they comes in." "So we have a checklist and it addresses more the environmental needs, technology, medical staffing requirements…So whether I need infrared cameras for evening monitoring or whether I need maglocks or whether I need a locked kitchen, open kitchen

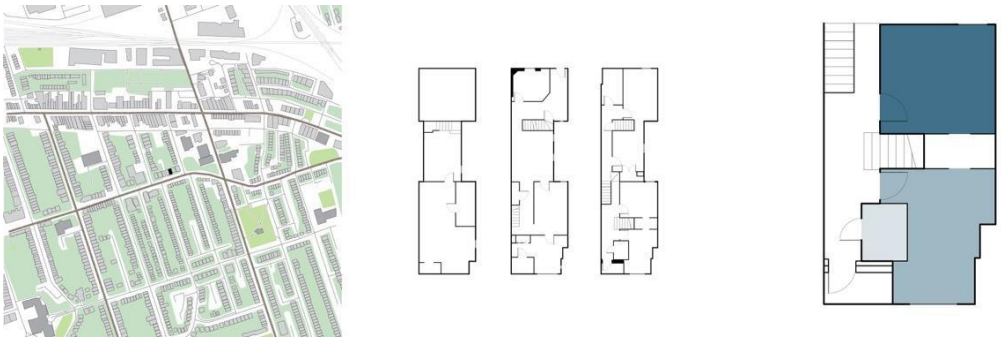
Output 3: Case Studies

From site visits of 4 agencies that provide high support housing for Ontario adults with IDD who exhibit exceptional BTC, we collected information on current modifications to the built environment. We include here descriptions of the residences we visited with a brief text accompanied with diagrams at the community, building and dwelling scale (Figures 4-8) and diagram legend (see figure 3 below).

Figure 3: Diagram Legend

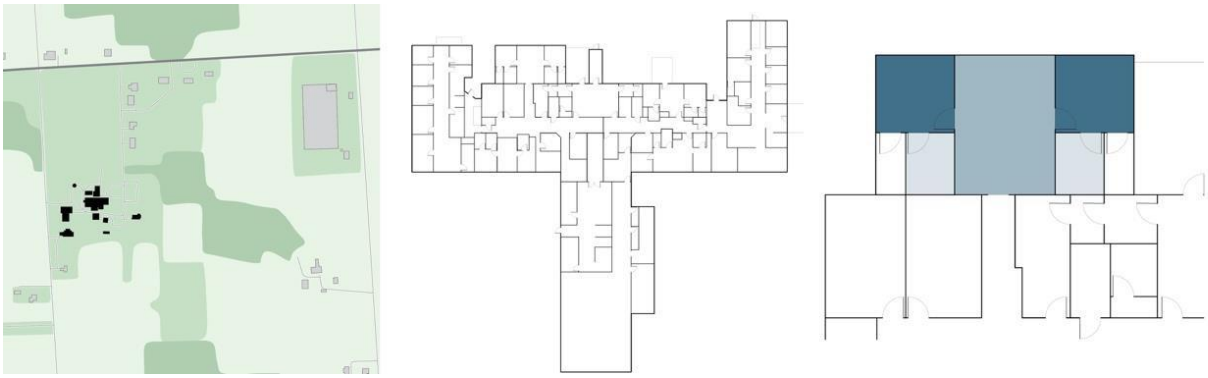
Case Study 1: This supported home is a renovated urban townhouse close to a busy commercial street. Each of the residents is supported on a different level of the narrow house and each has a dedicated bedroom, bathroom and living area. The front area of the house and the top floor are used as areas for the staff to meet, store programming equipment and perform administrative tasks. As a result of the surveillance provided by placing the staff area near the front door of the house the use of magnetic locks on the entrance was avoided. In the process of renovating this house to meet the needs of high support housing, changes were made that included extending the fence around the backyard for safety and a larger bathroom was added to the ground floor to avoid flooding.

Figure 4: Case Study 1 Diagrams



Case Study 2: This facility is located on a 90 acre rural site and includes a campus of buildings surrounded by generous green space. Residential and day programs are offered in a number of buildings. The space between the buildings is used for parking, outdoor furniture and swings; a river runs through the property that otherwise consists of cut grass with large trees. Part of the grounds are rented such as a building to a program for individuals who have experienced a brain injury. Individuals that exhibit exceptional BTC are supported in the larger central building and a former nurses' residence, both of which have areas converted into apartments. The larger building includes administrative, sports and recreation areas, and some of the building is organized as individual apartments or 'pods' with a personal bedroom and bathroom, and common kitchen, living room and patio areas.

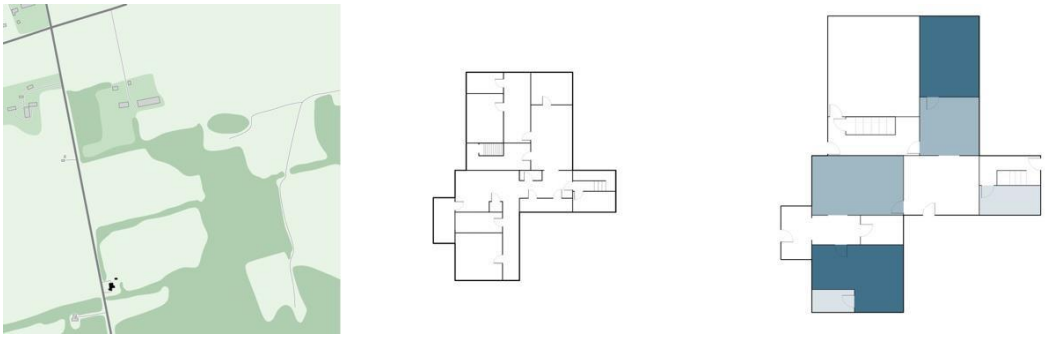
Figure 5: Case Study 2 Diagrams



Case Study 3: This rural single-family home is located beside a two-lane highway. The fenced property has parking space for staff and two vans, which are used daily to transport residents to and from day programs. Inside the house 6 bedrooms are divided 2 per floor on the basement, ground-level and upstairs level. Each floor is organized based on level of care and behaviour, those with the most extreme behaviour are housed in the basement, those on the first floor demonstrate less extreme behaviour and those on the top floor are residents with a mid-level behaviour relative to others in

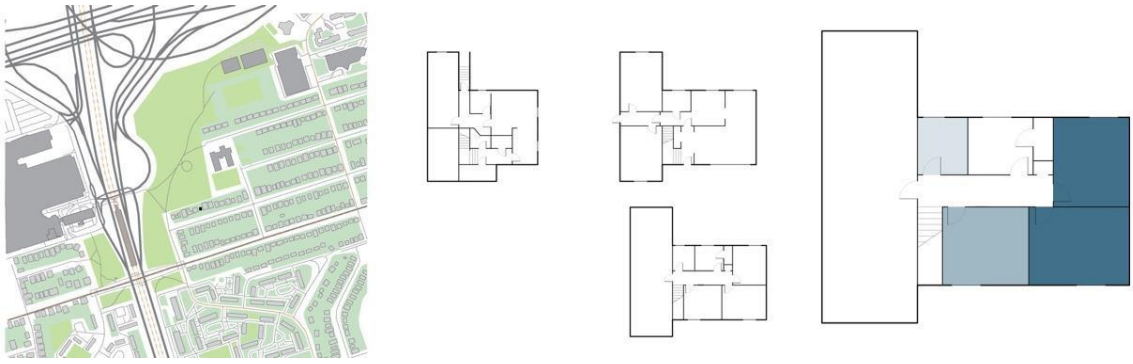
the house. Staff members use a variety of modes of communication including iPads and use dedicated areas of the house to store documents and conduct administrative activities.

Figure 6: Case Study 3 Diagrams



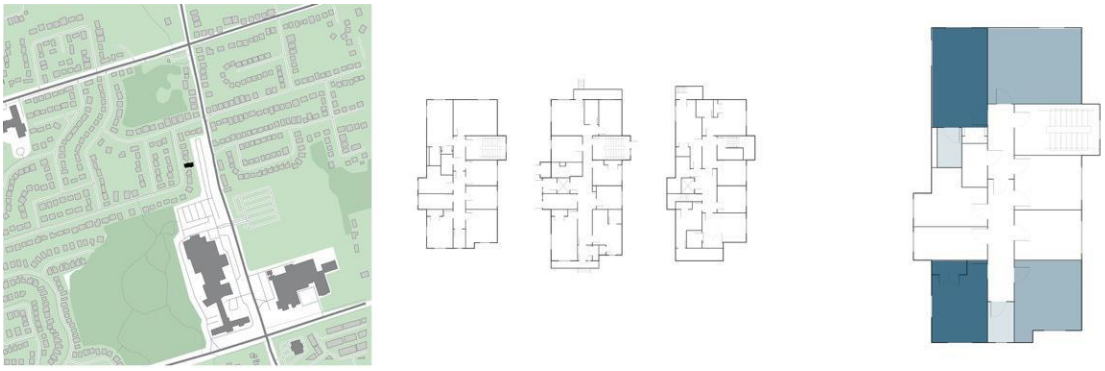
Case study 4: This single-family house is located in a neighbourhood of detached houses close to major public transport hub and a variety of public buildings. Staff and residents of this high support house use public transit and vans from day programs to access the surrounding community. Hospitals and recreation facilities (swimming pools, trampoline park) are nearby. The building has undergone several modifications, for example, the garage of the house has been repurposed as a staff office and walls have been carpeted to reduce impact of self-injurious behaviour.

Figure 7: Case Study 4 Diagrams



Case Study 5: This purpose-built house is located in a residential neighbourhood of single-family homes. While larger than the majority of the surrounding houses the gabled roof, porches and materials generally match the style of the neighbourhood. The ground floor of the building was built for a high level of accessibility and an elevator was installed to allow the possibility of aging-in-place. The building was constructed with a more robust structure, impact resistance drywall and durable flooring. The ventilation for the house is located along the ceiling of each room to avoid residents tampering with vents and a heating and cooling system with a large capacity relative to the size of the house was installed. Each resident has a bedroom, living space and bathroom. These units are of varying sizes and configurations, each include large locking storage closets.

Figure 8: Case Study 5 Diagrams



Case Study Results: Costs, Behaviours, PRN, Incidents, Staff Injuries

We obtained data from the agencies on costs, behavioural problems (by type), frequency of 'as needed' psychotropic medication use, and staff injuries.

Costs

Partner agencies provided data on operating (e.g. salaries, repairs and maintenance, food) and capital costs (e.g. addition of video surveillance, installation of resilient drywall (Acrovyn)). For 19 individuals, the

average per year per resident operating cost was $356,000 and the average per year per resident capital cost was $10,839.

It was reported to us that a purpose built home for six individuals was built for $2.6 million.

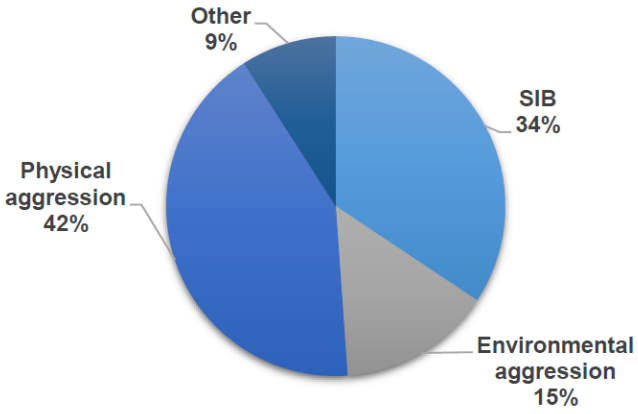
Behaviours

Our partner agencies provided us with data on the behaviours exhibited by residents. These behaviours were described in incident reports as potential crises, non-crises, and crises. A small number were considered serious occurrences (i.e. reportable events). Table 2 and figure 9 report the average number of behaviours and the proportion of behaviours by type described in the incident reports.

Table 2. Average number of behaviours by type and time period from incident reports

	Number of people	Self-injurious behaviour (SIB) average (min-max)	Environmental aggression average (min-max)	Physical aggression average (min-max)	Other (contrary, elopement, inappropriate touching) average (min-max)
1-month period	10	2.7 (0-15)	1.0 (0-6)	3.8 (0-22)	1.1 (0-4)
6-month period	9	12.9 (0-65)	5.2 (0-40)	14.1 (1-77)	3.4 (0-22)
1-year period	8	21.3 (0-96)	9.0 (0-64)	26.0 (0-120)	5.6 (0-27)

Figure 9: Proportion of behaviours by type in 1-year period



Frequency of PRNs

We collected data from the agencies on PRN (prescribed as needed) use of psychotropics medication. Psychotropic drugs include antipsychotics, antidepressants, anxiolytics, hypnotics, and mood stabilizers. Psychotropic medications like antipsychotics are meant to be used to treat symptoms of psychosis, but are also sometimes prescribed for adults with BTC. The frequency of PRN use of psychotropics can be indicative of the seriousness and frequency of psychiatric symptoms and/or behaviours.

Among a group of 13 residents who had at least 1 PRN in a given month over a 2.5- year period (Jan 2016-June 2018), an average of 10.4 PRN psychotropic drugs/person/month were used (Standard Deviation=12.6). The large standard deviation is indicative of the large variation in monthly frequencies for PRN use in individuals (min=1, max>15 in a given month).

Agencies monitor PRN medication use over time with the goal of decreasing their use. For example it is used as an outcome to assess the influence of changes in environment and interventions. Some individuals showed a seasonal pattern to their PRN use, with a decrease occurring in the summer months and an increase occurring in the fall and winter months, indicative of the influence of the environment on symptoms and behaviours. Any changes in PRN medication dosage or type is also monitored to verify if it is having the desired effect on

symptoms and behaviours.

Staff injuries

Our partner agencies also provided us with chart data that listed staff injuries as a result of resident behaviours. In one year, across 4 agencies, 22 staff injuries were reported. Of these, a small proportion (n<5) were reported to require medical attention and modified work duties. However, injuries were reported differently across agencies and for the majority (n>15), it is unclear if medical attention or modified duties were required. The most commonly reported injuries were scratches and bites as a result of trying to deescalate residents or while holding a resident in containment. Other reported injuries were a result of being kicked or punched while holding a resident in containment for a significant period of time. Hair pulling was very commonly described in incident reports but was not considered an injury unless the pulling resulted in a neck injury. We did not ask for agency reports regarding staff psychological abuse or harassment although future research should consider collecting this type of information as a type of mental health injury.

Output 4: Environmental Modifications Tool Describing Design Strategies

During the collection of data for output 3 (case studies), we also documented and photographed specific modifications during our visits. The photographs and other data and results from the project were used to create the EM Tool, a major deliverable from this project, which is included in appendix 2.

Section 3 – IMPACT

A disproportionate number of Ontario adults with IDD continue to experience hospitalizations that are longer than necessary. These Alternate Level of Care (ALC) stays are avoidable, costly for the government, and are a detriment to the quality of life of those that experience them. Agencies that support persons with IDD are helping to address the problem of ALC hospitalizations by providing high support housing for individuals that exhibit exceptional BTC. These residences are also providing relief to families that are no longer able to care for these same individuals in the family home.

There is no single underlying cause of BTC with several factors appearing to contribute including psychological, biological, social and environmental issues (Tilley et al., 2015). It therefore takes a comprehensive approach to address BTC. Caregivers, trained direct support staff and community mental health clinicians who are aware of the unique needs of individuals with IDD who exhibit exceptional BTC play key roles supporting these individuals in community based housing. The physical environment adaptations and strategies described in this report are a component of a multi-faceted approach.

In order to accommodate exceptional BTC, the project's partner agencies have had to make short and long-term changes to the physical environment of high support residences. This research project addressed a gap in our knowledge regarding the nature of these adaptations. The overall objective of the project was to describe successful physical space and design arrangements for housing Ontarians with IDD who exhibit exceptional BTC. The project team aimed to use a number of different methods to collect data on housing accommodations and use the data to create a practical tool that could be used by future stakeholders to guide decisions related to physical space adaptations. Ultimately, the goal is to simplify the process for putting in place resilient and homelike adaptations in an attempt to meet the housing needs of this population while reducing BTC and creating opportunities to engage in activities that improve quality of life.

How has the project contributed to current knowledge/understanding in the DS sector?

The following table summarizes some of the major products and findings of this project and describes the impact on base knowledge and research in the DS sector.

Description of project products and major findings	Impact on base knowledge, research in DS sector
Product: Literature review Summary of findings: 15 studies met inclusion criteria which identified cases of inadequate housing, as well as characteristics related to successful housing for individuals with IDD who exhibit BTC. Review conceptualized housing adaptations at the community, building and dwelling scales. Some studies only address issues of physical environment adaptations in tangential way.	- This review contributes to this field by summarizing existing literature focused on the architectural design of housing for individuals with IDD who engage in BTC (First study to do so) -The relatively low number of included studies and lack of focus on the topic suggest this is an area of research that needs more attention -Like Ontario, considerable challenges exist in other jurisdictions for finding adapted housing for people with IDD that meet their behavioural needs -Existing observational studies identify environmental characteristics that influence behaviour -Gap in research: Need intervention research that focuses on the effect of physical environment modifications specifically on BTC -Need to develop and use measures that not only measure negative aspects (PRN, injuries, behaviour) but also the positive outcomes (opportunities to achieve life goals, quality of life)
Product: Key informant interviews Summary of findings: Identified 5 major themes: Physical space adaptations, physical environment, access to resources, resident and staff safety, evaluation of the physical environment. Participants identify a large number of physical adaptation options for various behaviours.	-This is the first qualitative research study on this topic -Involvement of multidisciplinary participants means that a broad perspective was obtained -The participants in the interviews are developing expertise and valuable knowledge on physical adaptations -Working groups that involve these experts are recommended for larger building projects -Quotes from participants bring to life the significant and sometimes severe behaviours that are exhibited -Consistency of themes with literature review gives direction to content for EM Tool (see appendix 2)

	- Agencies found a way to strike a balance between the necessity of keeping residents and staff safe, while providing a homelike environment -Opportunities to focus on quality of life goals (rather than only BTC) were indicative of successful housing -Gap in research: Need to hear and know more about the experiences of families who endeavour to support persons with IDD who exhibit BTC in the family home

What is the impact or potential impact on the development of policy?

The project has developed resources that are intended to be useful to policy makers and other decision makers. The following describes and summarizes 1) the Case Studies and 2) the EM Tool, and describes the potential impacts and considerations related to the resource.

1) Case Studies

Summary of content

The case study diagrams and text shown earlier in this report describe different housing models where people with IDD and exceptional BTC live. Content is at the community, building and dwelling scale. Summary statistics of costs, challenging behaviours by type, PRN psychotropic medication use, staff injuries are provided.

Impact on decision making and policy, and other considerations

The case studies are useful to agencies who are planning new builds or making renovations to existing residences. The case studies show the multiple options available to agencies for providing housing for persons with IDD and exceptional BTC. Each option at each scale should be considered when making decisions regarding housing location and residence configurations:

-At the community scale there are urban, suburban and rural environments with different amenities

-At the building and dwelling scale a number of configurations are shown for consideration

Our agency partners stressed the importance of choosing optimal room configurations. Ideally, independent sleeping and living environments should be available in conjunction with communal living areas that make it possible for an individual to interact with staff and others residents when they wish. Some of the case studies have organized the living arrangements in the residences into 'pods' (see Case study 2, page 19) which successfully combines private and communal living opportunities. This arrangement allows for greater choice for the residents but also makes areas available where exceptional BTC can be addressed without disturbing or triggering behaviours in others in the residence.

Not surprisingly the operation costs for the residences were high relative to capital costs. This is due to the high staffing needs to support persons with IDD who exhibit exceptional BTC. However, the upfront capital costs for a new build are high (e.g. $2.6 million for one building for 6 individuals). The current funding mechanism from the provincial government is seen as a barrier to agencies pursuing innovative and long term solutions (e.g. purpose built housing). Some agencies would possibly consider a new build instead of renovating an existing residence, but the costs can be too prohibitive to pursue without government support. The Ministry should consider funding for purpose built housing as well as renovations/retrofits depending on the situation. This would allow more flexibility for agencies to create longer term solutions to address BTC through changes to the physical environment.

Many of the individuals living in these settings were receiving PRN psychotropic medications as one way to prevent or respond to challenging behaviour. Sometimes these medications were antianxiety (e.g. lorazepam) and sometimes they were antipsychotics (e.g. chlorpromazine). Use of PRN psychotropic medication was present in all the residential agencies and is something important to study and monitor, given that we know polypharmacy is a particular concern in supported residential settings in Ontario, even when there is no psychiatric or behavioural issue.

There were a relatively low number of staff injuries relative to the number of exceptional BTC. This may be a testament to the skilled staff and the training they have received in how to deescalate residents. Study participants, partner agency and advisory members stressed the importance of continuing education and refresher courses on containment procedures and behaviour therapy techniques etc. These direct support staff face stressful behaviours and situations frequently and their mental health wellbeing should likely be monitored closely. This may be an area that should be studied and addressed through preventive and other measures. The space arrangements may have also contributed to fewer injuries for example by giving staff opportunities to exit a room when a resident's behaviour escalates.

The agencies used a consistent definition to identify serious occurrences that are reportable to the government (e.g. instances of elopement and behaviours that involve the public). Behaviours that did not reach that threshold were, however, described less consistently across agencies. For example, severe behaviours were sometimes described as 'potential crisis' or 'no crisis' but it was unclear if this was based on consistent definitions. The Ministry or the agencies should consider agreeing on definitions for describing behaviours that are serious enough to require an intervention (e.g. containment) but not reportable to the government.

2) The Environmental Modifications Tool: A Guide to Housing Design for Adults with Intellectual and Developmental Disabilities (see appendix 2)

Summary of content

Using data and results from the other parts of the project, the EM Tool presents strategies to architecturally modify residences to better meet the unique and complex behavioural needs of this population. The EM Tool aims to summarize existing solutions and promote further communication and development of effective modifications. The modifications to the physical environment are summarized first as a list of broad design principles and considerations when making quick fixes, renovations or purpose-built new buildings. This is followed by a comprehensive

and more specific list organized by room and living area. This list uses pictures to give immediate understanding of some of the adaptations.

Impact on decision making and policy, and other considerations

Our agency partners have described the EM Tool as being immediately useful to their planning and decision making as some of them are currently embarking on projects to retrofit existing buildings and/or undertaking new builds. The EM Tool makes a number of recommendations and suggestions that should be considered at different stages of building or retrofitting. The EM Tool is seen as useful to guide decisions to address the specific needs of residents during the planning, designing and building stages of a project. The EM Tool is intended to be used as a stand-alone document and will be made available on the principal investigator's website at OntarioTech University (also known as University of Ontario Institute of Technology). We consider the EM Tool a 'living' document that will be changed and expanded over time so that it can continue to benefit people with IDD and be useful to those planning housing for them.

As described in its introduction the EM Tool is intended for both those caring for adults with IDD who exhibit BTC and those designing and caring for the buildings in which they live including: frontline support workers, administrators, therapist, family members, facility managers, building maintenance staff, contractors and architects.

This research project and specifically the creation of the EM Tool addresses the statement from the Ontario Ombudsman report (Nowhere to Turn) that highlights a need to "engage in research and consultation across the developmental service and health sectors with a view to developing residential resources that meet the exceptional needs of individuals whose extreme behavioural challenges….present placement challenges". (Dube, 2016)

Section 4 – KNOWLEDGE MOBILIZATION ACTIVITIES

The Advisory Group for the project played an important role in its knowledge mobilization activities. The Advisory included representatives from 3 agencies that support Ontarians with IDD who exhibit exceptional BTC and 1 from the Ministry of Children, Community and Social Services. All meetings with this group were conducted using web-conferencing with the first meeting held early on in order to familiarize members with project activities. Meetings with the cross-disciplinary advisory members helped to set priorities for the different stages of the research process.

The project team was also in regular contact with partner agencies (Reena, Bethesda, Vita, and Community Living Toronto). These agencies were very receptive to the project's goals, and were very helpful providing data and when organizing site visits. Importantly representatives from the agencies also provided insights on the implications and applications of the project's findings and deliverables such as the EM Tool.

Our agency partners and advisory group members told us that a working group with a multi-disciplinary makeup (e.g. home designers, architects, builders, staff and scientists) has been successfully used in the past and could be helpful to convene in the future when large renovations or new builds are planned. Such a working group could be used to help guide decisions related to content described in this project's EM Tool (e.g. room layouts and furnishing options, types of building materials, and specific room adaptations). This is in order to take advantage of the existing know how that has now been developed by these agencies.

The research team also presented the findings of the project at a number of provincial and international conferences such as the Ontario Association on Developmental Disabilities Research Special Interest Group Conference (Niagara Falls, April 2019) and the World Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (Glasgow, Scotland, August, 2019)

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