**SHEDD** SUCCESSFUL HOUSING ELEMENTS
& DEVELOPMENTAL DISABILITIES

**SHEDD Webinar #4 Summary**
**Title:** What Makes a Home? Bricks, Mortar, & Beyond
**Date:** April 29, 2022 12:00pm – 1:30 pm
**Contact SHEDD Team:** toolSHEDD@utoronto.ca
**For information on SHEDD and to access the tool:** www.toolSHEDD.ca

**About SHEDD**
Successful Housing Elements and Developmental Disabilities (SHEDD) began as a research project to identify key elements of housing design and construction (e.g., materials, space) that can help to support people labeled with developmental disabilities and exceptional behaviours that challenge.* The SHEDD tool was developed to promote built environments that can improve the wellbeing and community participation of adults with developmental disabilities. Further information about SHEDD can be found at www.toolSHEDD.ca

The current project is funded by a Social Sciences and Humanities Research Council (SSHRC) Connection Grant (2021-2022) and aims to:
1. Share information about the SHEDD research and tool;
2. Make connections and share ideas about housing design with self-advocates, families, housing design and planning professionals, developmental service professionals and researchers; and,
3. Identify future research collaborations and ways to improve the SHEDD tool.

*Our team uses the term 'behaviours that challenge' to emphasize that behaviours such as self-harm, aggression, and property damage are forms of communication that may challenge people such as caregivers who provide support for people labeled with a disability.*

**What was the *What Makes a Home? Bricks, Mortar, & Beyond* webinar about?**
- This was the fourth and last webinar of a four-part series that aims to make connections and share ideas about improving built environments, such as the physical characteristics of homes and universal housing design. This webinar explored housing design for people with developmental disabilities from the perspective of universal design, law and healthcare. Panelists shared their perspectives on rights, well-being and autonomy as central to creating a home. This webinar included:
  - Presentations from housing design, legal, and health field perspectives; and,
  - A panel discussion where the presenters answered audience questions.

**Who were the presenters?**

*Moderator:*

- Yani Hamdani, PhD; Assistant Professor, Department of Occupational Science and Occupational Therapy, University of Toronto; Clinician-Scientist, CAMH

*Panelists:*

- The Kurdi; President, DesignABLE
- Tess Sheldone; Assistant Professor, University of Windsor
- Yona Lunsky; Director, Azrieli Adult Neurodevelopmental Centre, CAMH

**What was presented?**

The first presenter (Thea) focused on **universal design**. DesignABLE Environments, Inc. is an accessibility and universal design consulting specialty firm. The following information was presented:

- Most accessibility or disability initiatives focus on wheelchair users, however there are many other disabilities, and some that are "invisible." It is important to think of inclusive design that works for everyone, as disability is a normal part of the human experience. Accessibility is integral to success.
- Some key design elements that promote accessibility:
  - Consider sensory experiences and stimulation during the building process (e.g., purpose-built design elements to reduce sound stimuli).
  - There should be an emphasis on resident and staff safety.
  - Built environments should be individualized for different treatment options to meet individuals' needs.
  - Evaluate access to different parts of the home (e.g., in-house/unit laundry, private bedroom connected to living spaces to avoid isolation, grab bars for toilets and showers, sloped walkways to create zero-step entry, railing for ramps).
  - Other details to consider: homely aesthetics and finishes, slip resistant seamless flooring, U-shaped door handles that can be used with a closed fist; accessible recreation spaces, managing acoustics with sloped ceilings, using materials and finishes that have no volatile organic compounds (to avoid a strong smell for people with multiple chemical sensitivities).

The second presenter (Tess) discussed **disability, housing, and law** and made the following important points:

- Housing is a fundamental and universal human right; it is an essential part of one's sense of dignity, safety, inclusion, ability to contribute. Housing is a necessary condition for personal development, well-being, and a full community life.
- Canada has not realized its commitment to international legal instruments such as the United Nations Convention on the Rights of Persons with Disabilities, which states that

persons with disabilities must have the opportunity to choose their place of residence, and where they live with whom they live. There is an evident lack of adequate and accessible housing for people labelled with developmental disabilities, which creates further isolation. It is important to pay attention to the structural conditions that are built to exclude persons with disabilities.

- The presenter adopts a human rights-based approach to responding to housing injustice and disability injustice. This means that people with disabilities are not characterized as recipients of charity and care, but rather as subjects of rights and rights holders. Housing is a right, not a benefit.
- There are negative rights (i.e., the right to be left alone, a right to non-interference), as well as positive rights (rights that require action). For persons labeled with disabilities, there needs to be explicit recognition of a positive right to accessible, appropriate, and effective housing.

The third presenter (Yona) discussed the **impact of the environment in promoting health**.

- Health is crucial to the concept of a home. They should not be thought about in silos, as they are interrelated.
  - A [report](#) done in Ontario in 2019 looked at the health of the adult population with developmental disabilities versus those without. For adults with developmental disabilities, there is a higher likelihood of: returning to an emergency department or being hospitalized more than once within 30 days, remaining in a hospital beyond recovery because of a lack of alternative care or support at home, living in a long-term facility, and dying before the age of 75.
- If health is not supported appropriately, people have to leave their homes more often. For this reason, health needs to be supported in the home.
- The HELP Framework can be used to understand health issues of people labelled with developmental disabilities.
  - **H**ealth - For example, if someone is in pain, they might exhibit behaviours that challenge in the home. We need to think about what might be going on with their health.
  - **E**nvironment & Supports - What is going on in the space where they live? Are there distractions, sensory stimuli that frustrates or triggers behaviours that challenge? What supports are present in the home?
  - **L**ived Experience - Recognizing the experiences people have had previously (i.e., hospitalizations, previous housing environment, transition out of family home, etc.).
  - **P**sychiatric Disorders - What is their typical mood and behaviour? Perhaps there are other psychiatric disorders impacting the individual. What individualized supports are needed? How can we be adaptable to changing needs?
- It is important to always think about how health is supported in the home, and how the home impacts health.

**How can the SHEDD tool help with housing planning and design?**
The SHEDD tool provides information about:

- Design considerations: Let's look at the building (inside and out): How bright is it? How big are the rooms? How is the outdoor space used? Is the environment contributing to self-injury, aggression towards others or destruction of physical property?
- Design principles: Where are the rooms located? How do people use the space? Is the space accessible and comfortable? What colour are the walls?
- Design modifications: What are some specific suggestions for living areas, kitchens, bedroom, and bathrooms? Are locks in high-risk areas needed?

**Who can use this tool?**

- People labelled with a disability, people who care for them, and people who design and care for the buildings in which they live. This includes self-advocates, families, housing planners, builders, architects and building managers.
- The tool can be incorporated into universal home design elements for everyone.

**Where can you find this tool?**
You can access the tool for free on [www.toolshedd.ca](http://www.toolshedd.ca)

**SHEDD** SUCCESSFUL HOUSING ELEMENTS & DEVELOPMENTAL DISABILITIES

**Panel Discussion and Audience Q&A**

Question: **What is currently working well with respect to housing for people labeled with developmental disabilities or alternatively what's not working, and what might be the next steps to change things?**
Answer:

- o Some barriers include the lack of training for professionals to engage with and support people labelled with developmental disabilities, which leads to a lack of early planning to support this population. Some changes are quite simple, but the information is often siloed. We need to have more holistic conversations like this and share knowledge and resources. Supporting people labelled with intellectual disabilities requires support from people with different lived experiences and perspectives. We must be accountable to survivors in a way that confronts anti-Blackness, settler colonialism, and racism.
- o It is also important to acknowledge some of the gains made by advocates and accessibility, such as the Accessible Canada Act. However, there is a wide gap between law on paper and law in action. For example, with the Accessibility for Ontarians with Disabilities Act (AODA) there is provincial legislation in place related to accessibility to enter public spaces, washroom design, and more, however, most of this is related to physical disabilities. There is no legislation that applies to other types of support, such as sensory needs or those in the home.

Question: **There are always challenges related to the cost of housing. How does this impact planning?**
Answer:

- • It is important to plan early and incorporate accessibility into the budget and feasibility study. It might cost up to 1% more to include the type of flexibility and adaptability into a budget from the start, but it costs 22 times more to fix it later after you've built it. And in some cases, it cannot even be fixed or there is no space for accommodation. Therefore, early planning impacts sustainability and affordability. It is also important to consider health supports in housing planning. When health promotion is not considered during planning, there are larger costs associated with that, as hospitals, jails, or other placements that have societal expenses. Skills and independence also decline after hospitalization, so supports that once were useful in a household may no longer be sufficient after hospitalization, driving up expenses once again. It is also important to talk to individuals with lived experiences of maneuvering the housing and funding options (families, developmental service organizations) as they have a wealth of knowledge in this area. This is talked about more in webinar 3.

Question: **Regarding the comparison of health outcomes for people with developmental disabilities vs those who don't, are these statistics for Ontario or are they national?**

Answer: The statistics are Ontario specific. The report can be found [here](here) and additional information about the Burrito Test can be found [here](here).

Question: **How we might reconcile the idea of purpose-built design with the idea that folks might go through changes in where and who they might want to live with? I often talk with families about the idea that the first home you move into after leaving your family home probably isn't your forever home but if it's a purpose-built design, it might limit opportunities for change of location, neighborhood, housemates or other life changes.**

Answer: It is important to have a contingency plan and incorporate that into budgeting. A contingency fund could help to include things that may need to be added later.

Question: **What is a home versus an institution?**
Answer:
- One way to think about it is making sure that there is **choice and flexibility** that helps to make something a home versus an institution. It has been found that increasing choice and voice dramatically decreases behaviours that challenge in the home. It is also important to think about the space (the decisions you make in that space, how it feels in the space, etc.). In regard to **space**, we can think about it in different ways. There is the physical aspect of the space: Is it accessible? Can you do things you want to do in that space? From a design perspective, we have to think of ways to ensure that there is flexibility to allow for different forms of expression, but also consider how the person is impacted by that (e.g., seeing holes in the wall that remind them of a time when they were upset may result in different types of walls/materials to avoid this). Flexibility should also be considered with how people age and how needs change over time.
- Additionally, with regards to the built environment, it is important to think about the colour, amount of natural light, the ability to control (e.g., can people lock the door, open and close the blinds, access to views and able to get outside and feel safe). Yes, it is nice to be able to go out of the home and leave the space, however if that means you can run out into the street and into traffic then that is not a safe space. This means there might be conditions that provide less flexibility but help to ensure safety, and that is a delicate balance between a home and institution.

Question: **What do we need to do next in research for housing and design?**
Answer:
- Integrate the clients in the process from the start, not just consultation as needed. Consulting with disabled people largely has not been very effective, but new research is looking at co-design. Here's a [resource](resource) about **co-design**. If we work with people with lived experience, they will highlight what is important to them and what issues to focus on. Co-design can help bring together people with different backgrounds and experiences. There is also co-design in terms of how the research is carried out, with co-planning and engaging people labelled disabled in research. With these approaches, we should also remember how we can give people the skills to have their voices heard. Leaders with disabilities will be able to create more targeted interventions to address structural oppression.

- There also needs to be more research about this across disciplines (e.g., autism and architecture). Accessibility and disability planning is integral to the United Nations Sustainable Design Goals (SDGs) that everybody in the design industry talks about but have not been taught. Research involving different disciplines can help realize these goals. Research can also help fill the gaps between legislation and lived experience and can highlight the community needs. The collection of disability-based data would go so far to support mandates and disrupt longstanding barriers that affect disability communities.

**Additional Resources**

- A more inclusive ableism definition by Talila Lewis
- Built Environment Resources
  - CSA B652: Accessible Homes Standard
  - Canada Mortgage and Housing Corporation (CMHC) Universal Design for New Housing Units
  - Livable Housing Design Guidelines 4th Edition (from Australia)
  - Free illustrated guide to the Accessibility for Ontarians with Disabilities Act (AODA) Design of Public Spaces
- Legal Resources
  - ARCH Disability Law Centre:
    - https://archdisabilitylaw.ca/
    - 1-866-482-2724
  - Human Rights Legal Support Centre (HRLSC)
    - https://www.hrlsc.on.ca/en/contact-hrlsc
    - 1-866-625-5179
  - Advocacy Centre for Tenants Ontario (ACTO)
    - https://www.acto.ca/
    - 1- 866-245-4182
  - Centre for Equality Rights in Accommodation (CERA)
    - https://www.equalityrights.org/human-rights-and-housing
    - 1-800-263-1139
  - Joint Task Force on Deinstitutionalization
  - Video about accessibility problems at new Toronto area public transit stations
  - Article about parliament formally recognizing that housing is a fundamental human right (Bill C-97)
  - Press release about court ruling in Nova Scotia saying there are fundamental systemic barriers that deny equal opportunity for housing for persons with disabilities
  - Royal Commission investigation from Australia with recommendations to improve the lives of people living with developmental disabilities in group homes during COVID 19
- Health Resources

- HELP with Emotional and Behavioural Concerns in Adults with Intellectual and Developmental Disabilities
- Primary care of adults with intellectual and developmental disabilities 2018 Canadian consensus guidelines
- "This Is about My Health": Partnering with Patients and Families to Share Knowledge and Tools about Healthcare Communication for Adults with Intellectual and Developmental Disabilities
- Azrieli Adult Neurodevelopmental Centre Health Care Access Research and Developmental Disabilities (HCARDD)