

OCALICON 2021

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Housing through an Autism Lens: A *pathway from crisis to solution*

Today's structure

Introduction to the project and team

Learning outcome 1: A life course approach to housing for autistic adults

Learning outcome 2: Opportunities to better understand the autistic housing experience through Sensemaking

Learning outcome 3: The importance of the whole housing eco-system participating in the research and the developing of solutions for sustainable housing

Discussion & questions

Introduction to the project

- A “Solutions Lab” is a space that enables diverse groups of people to come together to develop solutions to a problem that no one person or group could solve alone. These challenges are typically complex and systemic – and are not easy to deal with.
- The goal of this 18-month Solutions Lab project is to develop relevant and immediately useable pathways to secure housing options for Autistic adults that include supports, services, and resources.
- This project is funded by Canada Mortgage and Housing Corporation’s (CMHC) National Housing Strategy.



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Introducing The Presenters



Courtney Weaver



Maddy Dever



Pari Johnston

The project team

- We are a group representing the whole system around an Autistic adult and the issue of housing.
- This includes Autistic adults, family members, service providers, housing providers, researchers, professionals and subject matter experts.

The problem definition

- Many Autistic adults face a housing crisis and population-based trends increasingly describe them as at risk for food and shelter insecurity and homelessness.
- Many Autistic adults face unique housing-related risks:
 - Due to heightened social and stress vulnerabilities;
 - Significantly higher than average co-existing mental illness and chronic health problems;
 - Variability across the ASD spectrum and related support needs; and specific pain points along the life-span.
- Research shows most autistic adults:
 - Live at home well into adulthood, and often middle age, with their family functioning as their fundamental source of support;
 - Are much more likely to be on social assistance;
 - And have the poorest employment outcomes of people with disabilities

**Learning
outcome 1:**
A life course
approach to
autistic housing

The importance of considering the life course and all the changing needs that may take place in that time & introducing the “Double Cliff” model of housing transitions and vulnerability

HOUSING THROUGH AN AUTISM LENS: THE DOUBLE CLIFF

Research shows that most Autistic adults live at home well into adulthood, and often middle age, with their family functioning as their fundamental source of support. They are also much more likely to be on social assistance and have poor employment outcomes. As young people transition to adulthood — and as their parents/caregivers age — they face unique and urgent housing needs. Commonly, a shortage of solutions means the situation becomes a crisis for them, their parents and siblings. **THIS TYPICALLY HAPPENS DURING AT LEAST TWO PRESSURE POINTS ALONG THEIR LIFECOURSE.**

FIRST CLIFF: EARLY ADULthood

When an Autistic teenager enters adulthood, they may strive to live independently — with a level of support if needed. Sometimes it works and sometimes it does not. Typically both suitable housing options and the right level of support are scarce. If housing is found, the young adult may return home if the arrangement is not working out. Some will not leave home at all. This first cliff can be a very messy and stressful situation.

CHALLENGES FACING FAMILIES INCLUDE:

FEW SUPPORTS.

Young adults transition from school-based supports to an underfunded and uncoordinated adult service system.

LONG WAITS. In communities across Canada, the wait for affordable housing is long. On the Ottawa waitlist, for example, 13,000 people will wait up to 10 years.

MENTAL ILLNESS.

One in two young adults with ASD have at least one psychiatric diagnosis, compared to 1 in 5 in the non-ASD young adult population. This population is also at greater risk of addictions and substance use.

SKILLS GAP. In many cases, barriers and challenges mean these young adults need significant support navigating what it means to live independently and live well.

CONTINUING CONCERNS.

When housing is finally found, families often worry about:

- lack of quality support
- housing setting (i.e., congregated living), support qualifications
- social isolation
- their continued role as safety net for problem solving
- safety and abuse prevention
- affordability and financial security

THE HARD REALITY

Very often, serious problems coexist with or result from these housing crises, including:

POVERTY

POOR MENTAL HEALTH

ISOLATION

FOOD INSECURITY

POOR PHYSICAL HEALTH

LACK OF SUPPORT

SECOND CLIFF: TRANSITION INTO SENIORITY

As parent caregivers grow old, the need to find housing becomes urgent. Parents may no longer be able to provide care, or they may pass away. Too often, Autistic adults are forced to accept the first available living arrangement, even if it takes them out of their home community and networks of support.

CONTRIBUTING TO THE CRISIS IS:

LACK OF FUTURE PLANNING

HIGH COST OR LACK OF AVAILABLE SUPPORTS

INCREASING NEEDS AS THE AUTISTIC ADULT AGES


THE INVISIBILITY OF THE CRISIS, WHERE STOP-GAP SOLUTIONS ARE USED OVER THE SHORT-TERM

THE SEARCH FOR SOLUTIONS

Housing through an Autism Lens is an 18-month Solutions Lab project to identify and address the barriers Autistic adults face — especially in young adulthood and early seniorhood — in acquiring and maintaining affordable and stable housing that meets their needs over a lifetime. For more information contact:

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 @HousingAutismLens

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The First Cliff: Early Adulthood

Challenges Facing Autistics and Their Families:

- Few Supports
- Long Waits
- Mental Illness Onset
- Skills Gaps
- Complex Systems

The First Cliff: Early Adulthood

After Housing is Found

- Lack of Quality Supports
- Social Isolation
- Continuing Caregiver Role
- Affordability and Financial Security
- Maintaining Employment and Housing

The First Cliff: Early Adulthood

“

One place I lived, my sensory challenges were magnified by living with many different people in a small space with uncomfortable furniture. One roommate liked to collect dried flowers and hang them on the walls, the sight and smell of which repulsed me. Another roommate would often cook very strong-smelling food with a scent that filled the house and was inescapable. The house had mould and rodents and I did not know how to deal with it. I did not have the social capital to ask for help with anything. I did not have an autism advocate to direct me to community resources, if there were any. I felt I wanted to escape the house every day, so I spent a lot of time outside or in the library or café, but these places were not comfortable for other reasons.”

The Second Cliff: Transition to Seniorhood

Challenges Facing Autistics and Their Families:

- Lack of Future Planning
- High Cost or Clack of Available Supports
- Increasing Needs as we age
- Stop-gap Measures
- Autistics Lose Autonomy, Ability to Make Own Decisions
- Siblings and Children may become involved

The Second Cliff: Transition to Seniorhood

“ I am an Autistic parent of Autistic children both teens and adults. I became more physically disabled and spent time in the hospital. Coming out I am less able to support my adult Autistic children, and my house isn't conducive to supporting me either. there is no affordable or available housing in our rural community. We are barely surviving in our housing condition and have no options in our community. We have nowhere to go except continue in unsafe living.”

“I am an Autistic parent with significant physical disabilities and have several adult Autistic children, with my oldest being an Autistic adult. He is mostly independent at home, but not very independent out of the home. I have had several hospitalization in the past year, and my oldest daughter has come to live with me and can help my son with his out of house needs, but this causes strain in their relationship. I am worried about what local semi-independent housing would be available to him, if I were unable to be home any longer.”

When Housing System Fails Autistics

- Autistics become homeless
- Autistics become institutionalized
- Autistics experience significant physical and mental health challenges
- Family members feel sadness, guilt, grief, anger.

We NEED to find SOLUTIONS...

Learning
outcome 2:
Stories we
heard

The possibilities inside Sensemaking (story collection) research for Autistic population and the disability rights movement.

What is Sensemaking?

The SenseMaking approach to data collection and analysis involves collecting large numbers of short stories or 'micro-experiences'. When we put the stories together, we can create a clear and detailed picture of a given topic, in the same way that many individual pixels come together to produce a clear digital image.

The Sensemaking method is not looking for an individual's opinion on what needs to be done; instead it collects **experiences**. Then we can put these collective experiences together to create a clear picture of what needs to be done.

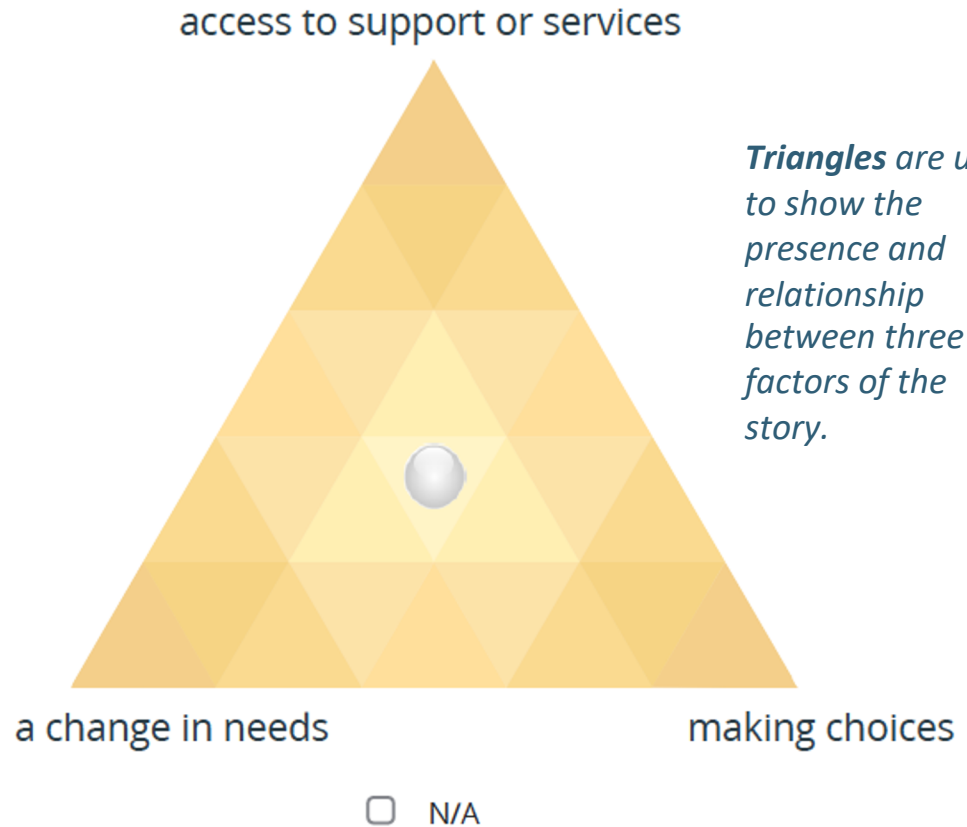
The SenseMaking Process

- Uses stories and their context to make sense of a situation.
- Collects experiences and their interpretations.
- Allows the storyteller to retain control of the interpretation of their story.
- Extracts data from the stories that are shared and the questions of the contributor.
- Image shown here (<https://www.hal-lab.ca/>)



An example question

T3 - This experience mainly had to do with...

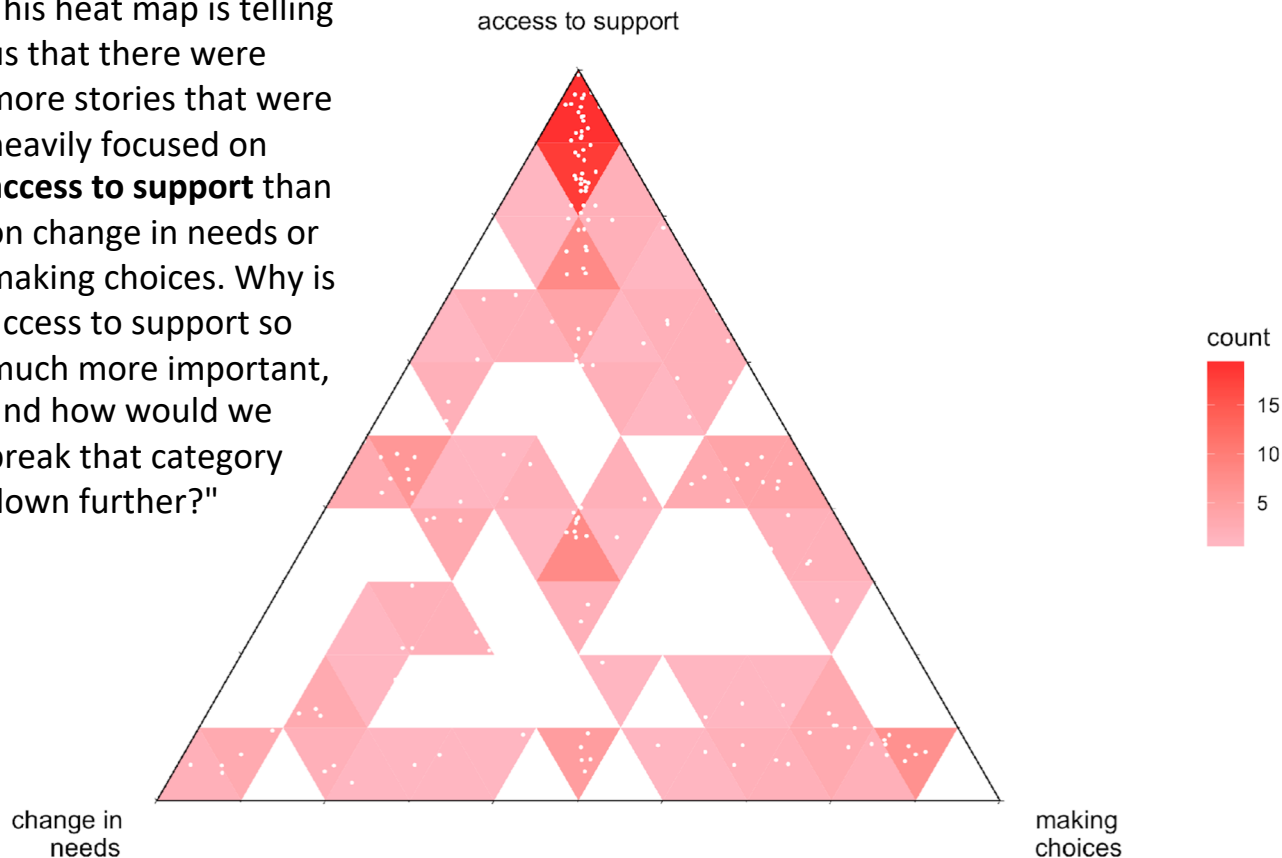


Triangles are used to show the presence and relationship between three factors of the story.

Example output

This heat map is telling us that there were more stories that were heavily focused on **access to support** than on change in needs or making choices. Why is access to support so much more important, and how would we break that category down further?"

T3 Needs & issues



Sensemaking themes

We held 4 interactive workshops with people within the system and determined and defined seven themes of the autistic housing experience.

Agency: the capacity of individuals to act independently and to make their own free choices.

Co-existing health factors: the simultaneous presence of two or more health conditions

Income: money received on a regular basis, for work, from benefits or investments

Safety: being protected from physical and psychological danger, risk, or injury.

Social Relationships: recurring connections and interactions that exist between people that are perceived by the participants to have personal meaning.

Suitability (including sensory): the housing quality of being right or appropriate for a particular person, purpose, or situation.

Support (Paid and Natural): Assistance given to support daily living. Natural support included the unpaid assistance given by family, friends, neighbours or others in a personal network. Paid support includes paid assistance given by government-funded or privately hired staff.

Why SenseMaking can work well for the Autistic Population

- Allows us to tell our own story in our own voice
- Allows for honesty and authenticity
- We can't guess what the researcher wants
- We can't tell the researcher what we think they want to hear
- We can personalize the data responses.

What opportunities for improvement exist for using SenseMaking in the Autistic population

- The platform (Spryng.io) needs more accessibility features (eg. ability to add visuals, change font sizes)
- Use of scribes or proxies for people who need support to tell their story
- Explicit clarity around confidentiality of stories
- Accessible on iPads

My experience of Sensemaking

- Tremendous learning experience

Learning outcome 3

The importance of the whole housing
eco-system participating in the
research and the developing of
solutions for sustainable housing

Questions and discussion

1. In terms of working together in co-creation, what were the biggest lessons learned so far by the project team?
2. What makes this project different from others you have been involved in and what difference do you hope it will make?
3. What are some of the challenges that we faced as Autistics in how Sensemaking worked both for the contributors and the Autistic advisors (marbles, specific terms)
4. What were our reactions to the stories we collected?
5. Were there any themes discerned from the stories that surprised us?

For More
Information

www.HAL-Lab.ca



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