"A Home, A Job, A Friend
Persons with Disabilities Defining Community

A report to the Disabilities Services Program,
Nova Scotia Department of Community Services

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1.0   Executive Summary

The government of Nova Scotia has developed a ten-year plan to transform and modernize services for persons with disabilities and create a more personalized and responsive Disability Support Program (DSP). The Choice and Inclusion Implementation Plan provides a roadmap to transform the DSP based on the principles of choice, inclusion, and sustainability.

One of the focus areas of DSP transformation is to place less reliance on larger residential institutions, and to increase opportunities for persons with disabilities to live in, contribute to, and experience social and economic inclusion in their community. The term "community" is an over-arching theme in the transformation work. The term "community", however, can mean different things to different people. As part of a person-directed approach, the DSP believes it important to develop a definition of "community" that rings true for both the program and the people who use it. Developing a definition of community that reflects the goals and principles of transformation requires first voice input from the people who participate in the program.

In January 2016, the DSP held three facilitated sessions with DSP participants to discuss on what community means to them, and to develop recommendations for the themes and components that should be included in the DSP's new definition of community. Although focus group participants were from a variety of backgrounds, and had a range of living experiences and level of supports needed, common themes emerged that can assist the DSP in creating a definition of community.

2.0 Summary of Approach

To prepare the recommendations for what should be reflected in the DSP's definition of community, consultants were engaged to review the literature and facilitate key informant focus groups. Three focus groups were held between January 18-22 with a total of 18 DSP program participants from Quest Regional Rehabilitation Centre in Lower Sackville, NS; King's Regional Residential Centre in Waterville, NS, and; Breton Ability Centre in Sydney, Participants were reminded that their participation was voluntary. They were also told that the focus groups were a safe place to share their ideas and stories, and that their answers would not in any way affect the service they receive.

A total of ten facility and DSP staff also attended the focus groups as observers. During the Breton Ability Centre focus group, staff supported participants to take part in the discussion by providing personal prompts and reframing questions as necessary, and provided emotional support to a participant who became upset while sharing a story. Staff at the other focus groups did not actively engage in the discussion.

Each of the three focus group discussions lasted approximately 90 minutes. The facilitator guided the discussion using a semi-structured discussion guide. Questions were reframed or simplified depending on the participants' needs, as there was a wide range of experience, ability to articulate, and emotional comfort in each focus group. The goal of the focus groups was to solicit feedback from DSP participants regarding what community means to them, and aspects of belonging, inclusion, and influence. The discussion guide is included as Appendix A.

Feedback and presentations from the DSP Advisory Committee were also considered in developing this report and recommendations.

3.0   Literature Review

A literature review was conducted to explore definitions and concepts of community in academic and grey literature, as well as in the first-voice blogs and web-based articles of community development workers, sociologists, and psychologists. Specifically, the literature review attempted to identify:

- Definitions of community;
- Factors that contribute to a sense of belonging to a given community;
- What it means to be part of a community, and;
- Definitions of community in the context of persons with disability.

Searches emphasized Canada and the United States.

3.1   Findings

Inquiry into the meaning and nature of community began in the early 20th century, as the environments where people lived shifted from predominantly rural, closely-knit small communities to more geographically disparate and socially isolating urban environments. Definitions of community during this time period well into the 1960s focus on community as a geographic place, or community as an "elective group" of people with a common interest, such as religion, ethnicity, or profession.

In 1974, psychologist Seymour Sarason introduced the concept of "psychological sense of community," – the idea that community is not a brick-and-mortar entity, but a socially constructed one. By the late 1980s, McMillan & Chavis were using the abbreviated label "Sense of Community," and proposed that sense of community has four elements: membership, influence, meeting needs, and a shared emotional connection. They developed the following one-sentence definition of community, which is still widely held to be the most valid sociological definition of community:

"Sense of Community is a feeling that members have of belonging, a feeling that members matter to one another and to the group, and a shared faith that members' needs will be met through their commitment to be together."

Further research has found that a sense of community is one of the most important factors needed for social, psychological, and physical well-being. In fact, the Government of Canada recognizes the sense of belonging to community as a key indicator of well-being. However, despite community's importance to well-being, little research has been conducted on what community means to persons with disabilities. Much of what is found in the literature is about "community living" – e.g., inclusion of persons with disabilities in the broader community. Others approach a definition of community for persons with disabilities by describing what it has traditionally meant to be excluded. As policy for persons with disabilities is transformed from

institutionalization to community-based care, developing ways to better understand what can increase the sense of community for persons with disabilities may make a critical contribution to them becoming actively involved and included community members.

3.2   Key Themes Emerging from the Literature

3.2.1 Community does have a physical element…but a physical, bricks and mortar building does not create a community.

The fact that people live close to one another does not necessarily mean that they have much to do with each other. People often don't interact with or even know their neighbours. Living in a group of people or in a place where one feels like an outsider, or doesn't feel listened to or valued, can be just as isolating as living completely alone. It is the nature of the relationships between people and the social networks that they are a part of that one of the more significant aspects of 'community'.

The notion of living in an institution seems the antithesis of living in community, although some researchers point out that even institutional settings can foster a sense of community; it is institutional *thinking* and *behaviour* that isolates and takes control away from those who live there, no matter whether the building houses two or 200.

3.2.2 Community is made and defined by social bonds.

Community means a place where we like to be – a place where we find rest, family and friends. More than a residence or physical shelter, community is the focus for our relationships. It's the commonality of experience that creates community, even among people with diverse characteristics and backgrounds. People in a community tend to make social bonds with people:

• who they can trust;
• with whom they feel comfortable;
• who care about each other;
• with whom they interact, choose to be sociable, and connect with.

Canadian first-voice writer and mental health advocate, Pat Capponi, lived much of her life in psychiatric hospitals and substandard community-based housing in Ontario before going on to be a strong advocate for persons with disabilities and mental illness. She defines what community should be as "stability, love, a safe place to live, a purpose." In short, she says, community should be what we all deserve: "a home, a job, a friend."

3.2.3 Community is acceptance and belonging.

People need to feel that their presence matters. Inclusion in a group and a sense of belonging is a basic human need. Our identity is formed, in part, out of the experience of belonging to a group or a community. The sense of belonging involves the feeling, belief, and expectation that one fits in the group, is accepted, and has a place there. Belonging leads people to feel, "It is my community" and "I am part of the community."

The Tamarack Institute for Community Engagement conducted a survey on what community means, as part of its "Seeking Community – Finding Belonging in Chaotic Times" project (Tamarack Institute). When asked "What does community mean?" over a third of respondents used the words "belonging" or "Sense of connectedness". When asked to define what 'belonging to a community' means, common responses were "feeling wanted and comfortable with a group of people who you care for and who care for you", and; "being heard, accepted and supported".

3.2.4 Community allows both safety and risk.

Belonging to a community comes with a sense of boundaries; this means that there are people who belong, and people who do not. The boundaries provide members with the emotional safety necessary to risk exposing their needs and feelings, and for intimacy to develop. That safety also provides the support for a person to grow through taking a degree of risk that is acceptable within the community. People in a community trust that their needs and feelings are valued and understood.

Although not writing specifically about community in the context of persons with disabilities, educator Margaret Wheatley offers insights into a challenge facing many persons with disabilities, families, caregivers and policy makers: the challenge of balancing the need for safety and structure with the desire to live with independence and choice. Wheatley points out that while a sense of belonging to a community is a basic human need, it exists in conflict with the human desire to be independent. In order to develop a definition of community, we must honour both sides of the paradox – our individuality and desire for risk, and our need for relationships and desire for safety.

3.2.5 Community is a place where we play a role, to contribute, and find meaning in life.

Community is place where each member can (and is expected to) contribute, to whatever extent possible, and their role is valued (conversely, an institution is a place where people have things done to or for them). Having a role in a community allows personal growth, and supports community members to reach their full potential.

3.2.6 Community offers the ability to participate in decision-making and creates pathways for people to contribute to the collective good.

Members are more attached to a community in which they feel that they are influential and are listened to. Being in a community but not being allowed to shape it, contribute to it or make decisions about it can be just as isolating as living alone.

Decision-making can be formal, such as voting or taking part in meetings to set goals for the community. It can be informal, such as talking through a problem with a staff member or official, or making plans with a friend. Decisions may also be about the way an individual lives his/her own life within the community.

With decision-making comes power, which is an important consideration in community. Trust develops through a community's use of its power. Who has it? When do they have it? Structure is necessary in community, but power and decision-making roles must be clear and provide meaningful roles for everyone. Opportunities should be created for everyone to participate.

3.2.7 Community relies on each individual's responsibility and role as part of that community.

In a geo-political community, the responsibility might be a tax. In a small community, like co-housing, the 'tax' might be the little annoyances that every individual puts up with in order to enjoy all the other benefits of living in a high-functioning community. People within a community do not just take things or have things done for them; they feel a responsibility to give back, enhance and build their community.

3.2.8 Community offers members a reward.

In order for members to want to contribute and to feel they belong, there needs to be a reward. A reward might be something specific like an answer to a question or networking. Or it could be something a bit more intangible like a sense of belonging, a support network, thoughtful conversations, or meaningful employment.

4.0   The Focus Groups

The seven women and 11 men who participated in the focus groups range in age from late teens to seniors, and live with a diverse range of physical, intellectual and/or mental health challenges. Many have lived in a number of different settings, including family homes, Aboriginal communities, group homes, small options homes, and regional residential centres. Their experiences and ability to communicate ideas varied greatly, but the themes emerging from their discussions were quite similar.

4.1   Themes Emerging from the Focus Groups

4.1.1 Safety and Trust

Some participants described their lives prior to becoming DSP clients as feeling dangerous, frightening, lonely, and confusing. They shared stories of abuse and isolation – isolation that occurred both in large institutions, and at home with family. Being able to trust the people around them, in a place where they felt emotionally and physically safe, were key concerns.

"I'm sheltered in this place. The outside world, you can get in ruts out there, but everything is taken care of here."

"I just got out of the East Coast Forensic. This place shelters me a bit, it gives me a chance to get back into public, but slowly. It helps me adjust, and move ahead, with no stress."

"I like having people we know and trust and care."

"I have people to talk to. I have a hard time trusting a lot of people. I don't always want to talk to staff about things. You have to have someone you can trust that you can take your issues to."

"Staff make it so easy here. If you have a problem, they're here for you."

"Makes me feel safe. I like being safe. This is a great place to live."

"I'm thankful to be at Breton Ability because they all try to make me happy. It's all about making me happy. Life wasn't good before, but now I have what I need. I'm safe here."

4.1.2 Acceptance & Belonging

Almost all focus group participants said that being accepted by and connected to others are important aspects of community. Some described that connection as friendship with the people around them, or the ability to socialize. Others described identifying with and being accepted by the people they live with, including staff members who they've often known for a long time. Many shared experiences of feeling like they don't belong, either in the place they live now, or in the broader community.

"Where I used to live, they weren't nice to me. I was stuck and couldn't see my family much. Here I can."

"This is my second home. I'm friends with lots of different people."

"I used to go to bowling and dances and parties, and I felt like I was a part of things."

"I like volunteering. I used to volunteer and that made me feel important, like I belonged."

"I'm more in a community here. I was teased at school. Here, clients accepted me. I'm accepted for who I am."

"People in this community don't give up on you. When I was really sick, people took care of me. They were there for me. I didn't even know who was there, but they were there with me. That made me feel good."

It's acceptance. Comfort and acceptance."

"Having people to talk to who are like you. I don't have much in common with people here. I'm the youngest. I don't have anyone to talk to."

"Some of the staff I've known a long time, for years. They know me."

"Sometimes people out there aren't nice. They don't think we belong."

4.1.3   Feeling needed

While participants acknowledged that they get important things like safety, social networks, personal care and employment from their community, they wanted ways to give back and make a difference, too. In some cases, this was finding simple ways to be helpful to the people around them. Others said they would like more of a formal mentoring role.

"I can help people if there's a problem. If there's an emergency. I can help or call 911."

"I like to open doors for people, being nice to people and doing things for them."

"It feels great when someone looks at me as a role model. I try to teach my friends about what I know, what I care about. I make You Tube videos, tell people my ideas on Facebook."

"I cook breakfast for other people."

"There's a lot of stuff that goes on in my community. A lot of problems. I wanted to become a councillor to take on some of the problems. I feel more at peace, more happy, knowing my people are really trying their best."

"I like it here because I work in the cafeteria."

"You can change someone's life just by helping them out."

4.1.4   Freedom balanced with support

The literature revealed a common theme that community must balance safety with the comfort to take risk. This theme was also an important one in focus group discussions. Participants in all three groups discussed the importance of a community supporting them to grow, learn, develop confidence to try new things, and work towards achieving goals. Most participants shared stories of having felt held back or confined. The majority found this frustrating, although a small number of participants appreciated the restrictions as a short-term necessity.

"It's important that I can have free access. I can take the bus."

"I can come and go as I please. I go to the Evangeline Club, go shopping."

"Someday I want to move into another community, one with seniors."

"I want to be in the community more. I can't do things here. I'm stuck here all the time because I have to ask or need someone to help."

"Our OT has been going on the bus with me to get me used to it, so I can go out more and do what I want on my own."

"I want to do things on my own – cooking, doing my own stuff. I miss it. I don't get to do that here. Not at all."

"Small option is different because you don't have people telling what to do. You get lots of freedom. I can come and go as I please. Don't have to be told when to go to bed and when to get up."

"Sometimes they take us on tours of banks and other places so that we know how they work and how to get around."

"I want to move to Glace Bay and be closer to my boyfriend. I want to be free to come and go and do what I want."

"I wouldn't want someone doing everything for me. I like being independent, a place to teach you to do things on your own. People live with us who care for us if we need them but let us do what we want".

4.1.5 Being listened to & treated fairly

Few of the focus group participants felt they have a say in big decisions about their lives (e.g. where to live, who they want to live with). Many felt they don't have much say over the day-to-day decisions that impact their life, either (e.g. when to eat, when to go out, what to do when they go out). Some may need support to understand what their choices are and what the outcomes of their decisions will be. Others may need support to articulate their decisions and to make their voices understood by others. In most cases, though, participants want to have the opportunity to tell someone about their ideas and issues, and to share their experience and talents with others.

Concerns were raised at two of the focus groups about inequality participants have experienced in their communities. They expressed frustration at organizational hierarchy that made them feel powerless and silenced, and at social assistance policies which kept them feeling dependent and unable to move forward in their lives.

"People in a community should be treated the same. Paid the same."

"I want to be accepted when I say something. I want to hear compassion, instead of 'Oh, I've got lots of problems myself'. I want you to hear me."

"Everyone should have opportunities. They need to help people get jobs to get off community services, but they want to keep you down. They want to keep you in a place."

"I can't tell people how I feel. I am an important person, only with people who are staff members, I feel intimidated by them and don't know how to speak up."

"I want to be respected for my opinions. Be a leader for things that matter to you."

"Everyone should be treated the same. Staff aren't better than us. Everybody should be together. How can we be one society if everyone is treated different?"

"[When I have an issue] I can go to management. I don't always go to staff because sometimes they don't want to listen. So I go right to management. They make the decisions anyway."

"If I have something to say or problems, I go right to my social worker. Sometimes staff is too busy to talk to me, but I can always talk to [my social worker]."

"I would love to be on a committee. I'd love to be involved like that."

"We have a client council. We talk about stuff we want to do, like ideas for events and things. Then we do activities after. It's a place to talk about what we like."

5.0   Developing a Definition of 'Community'

When asked, "What does community mean to you?" many participants responded that community is a feeling and experience; something they are part of that is safe, familiar and friendly:

"It's the people."

"Friends, good people, family."

"The whole world is a community."

"A group of people. It's where you are at now."

"Even on the bus you take every day, that's a community."

"Whatever group you're in at that moment, that's community."

"We socialize together. Live like a family."

Other participants, who have lived for a number of years in more institutionalized settings, felt that where community is concerned, they are outside looking in. To them, 'community' is something "out there" that belongs to other people, and to which they have to gain admittance when others decide they are ready. The term 'community', in fact, becomes almost a synonym for everything the person feels distanced from - friends, family, employment, or even the freedom to take the bus to the mall when they wish. 'Community', to many of the participants, is everything they can't have, according to the people who make the rules.

"Community isn't in a group home, it's outside."

" I can't live out there. They told me I can't live out there."

"Sometimes I feel shut off from the world. It can be really depressing being away from family and everything out there."

'Community' means more than just the people you live near, yet the focus group participants made it clear that the people around them have a profound impact on their worldview and quality of life. Relationships with the people around you, then, are an important aspect of what community means. The discussions also made it clear that *where* a person lives greatly influences who they are – yet real estate and physical boundaries don't provide the full picture of 'community', either.

Neither of these constructs is right or wrong, or inherently good or bad. For some people, the physical aspect of community – e.g., safety, structure and services – will be need to be the most dominant defining aspect of community. For others, having the emotional safety to make connections and grow will be most important. The idea of

community in the context of persons with disability, then, isn't an absolute thing, but is a continuum with variability between the personal and physical aspects. The constant, though, is *quality*: the interplay between the *quality* of relationships and the *quality* of the physical aspects of communities that makes a community a desirable place to live.

5.1   Recommendations

Although many face similar challenges and obstacles to living 'in community', persons with disabilities are all very different people. There is no right answer or one picture of what community looks or feels like for persons with disabilities; there will ultimately be millions of individual pictures defined by persons with disabilities and their families – not by government and service providers. The focus groups did, however, reveal five aspects and concepts of community that are important to people who use the DSP, which should be reflected in any definition of community adopted by the DSP:

5.1.1 Community is where people are empowered and supported to make decisions about their life and what they want

5.1.2 Community provides practical supports and options to make those decisions a reality.

5.1.3 Community is a place where a person's voice is heard, acknowledged and respected by others.

5.1.4 Community provides meaningful and realistic opportunities to be included as full citizens

5.1.5 Community balances the desire for independence with the need for safety and support

Based on these concepts, a definition of community for the Disability Services Program might be:

Community is where a person feels safe, valued for their contribution and able to pursue the life they choose. It is not defined by geography, location, architecture, size or demographic.

6.0   Conclusion

The four and a half hours of discussion that took place in the focus groups uncovered a number of ideas about community that are important to people using the Disability Services Program, but those ideas really all boil down to this: 'community' should be about the quality of life a person can enjoy when properly supported, not about how much support they need.

Despite the promise of the United Nations Convention on the Rights of Persons with Disabilities, the vast majority of persons with disabilities are almost always denied the right to make decisions about where and with whom they want to live – a fundamental aspect of 'community' for most of us. Seeking input on what community means to the people who use the DSP is an important step in transforming services. Defining community can provide the program and the people who use it with a clear vision and mutual understanding of what is needed and what is wanted. Making that vision a reality will be one of the key things that define success for the work of transforming services for persons with disabilities in Nova Scotia.

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Appendix A: Facilitation Guide and Discussion Map

Facilitation Guide: "Defining Community"

1.**Welcome & Explanation of the Process**
- You've been asked to take part in this conversation because the Disability Services Program is creating a definition of community, and they want to make sure that it reflects what community means to *you.*
- There are staff are in the room, but they are here to listen. You're the experts, and you're the ones we want to hear from.
- Being part of this focus group is voluntary, and it won't affect your care or services.
- Our discussion will take about an hour. If there are any questions that you don't want to answer, you don't have to; however please try to answer and be as involved as possible.
- I'm taking notes that we'll use to write a report, but I won't use your name on any comments we use (unless you ask that they be quoted on things that are really important to you).

2. **Introductions**
- My role is to guide the conversation, make sure everyone has a chance to speak, and that we follow ground rules. Since we only have an hour, I might move you along in conversation I'll ask that questions or comments off the topic be answered after the focus group session.
- Roundtable introductions (Ask the group if anyone has participated in a focus group before).

3. **Ground rules**
- The most important ground rule is that only one person speaks at a time. You may be tempted jump in when someone is talking and you have an idea, but please wait until they've finished.
- There are no right or wrong answers.
- You don't have to agree with the views of other people in the group, but if you disagree, please be respectful.
- You don't have to speak in any particular order.
- This is a safe place to share your thoughts. When you leave here today, please don't talk about what other group members have said.
- Does everyone agree with these ground rules?
- Does anyone have any questions?

5. **Discussion of Focus Group Questions**
- See Table 1 below.

6. **Closing & Thanks**
- Brief summary to confirm (eg "So today, we've talked about …") Is there anything we missed?
- Your feedback will help DCS create a definition of community.
- We can send you the report if you are interested.
- Thank you for joining us and sharing your thoughts.