

Explore Dreams 2019 Report

A Community Seed Research Project for and with Adults with Developmental Disabilities



**A partnership between Oak Park Neighbourhood Centre and
The Community Oak Park**

Prepared by Heryka Miranda



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Introduction

The Explore Dreams pilot project ran from January to September 2019 and was funded by the Trillium Foundation and carried out by the Oak Park Neighbourhood Centre, (OPNC) www.opnc.ca in partnership with The Community Oak Park, (TCOP) - a parent-led support network to support families and their children with developmental disabilities. www.wearethecommunity.org

Explore Dreams was an Ontario Trillium Foundation Seed research project with and for adults with developmental disabilities in the Halton and Peel regions of Ontario. The focus of the project was to recruit and engage adults with developmental disabilities and their community to participate in accessible and inclusive interview experiences to explore and identify their strengths, barriers, interests and life aspirations.

Group interviews were experiential and interactive in nature, using visual arts and movement – based methods and approaches as tools of engagement. Support for participants in the interview experiences were provided by the research facilitator, a research assistant and two co-researchers in-training who identify as having a developmental disability. On three occasions, ASL interpreters provided communication support for participants who are Deaf.

A survey was developed that was available in hard copy, and online. Assistance was provided for completion where needed to maximize the participation of adults with developmental disabilities and their families.

Focus groups were held with three sectors of the community to discuss and identify barriers and resources needed to provide adults with developmental disabilities with a strong sense of belonging to their respective community. The three sectors of the community included parents with adult children with developmental disabilities, local community business members and volunteers, students and neighbours.

Explore Dreams provided three adults with developmental disabilities with a person-centred support circle. This process is highly beneficial for participants and their families, enabling them to spend time envisioning and preparing for the future, providing an opportunity to ask for help, and widening the circle of people who can enrich each other's lives.

What follows is an explanation of the background of the pilot study, along with an explanation of the participants in the project, outreach and recruitment strategies, methods used, including using an expressive arts therapeutic theoretical framework when engaging participants and gathering data, findings, and conclusion.

Origins of Explore Dreams

The origins for the pilot study came directly from parents who have an adult child(ren) with developmental disabilities who are members of TCOP. Too often their adult child(ren) with a developmental disability are left out of important decision-making opportunities that impact their lives. For example, the creation of new programming or decisions around how and what they want to spend their time doing. Seldom are they asked about their interests or the types of programs that they need or would like to participate in. The overarching concern of aging parents with an adult child(ren) with developmental disabilities is the overwhelming task of planning an independent living or alternative living transitional process for their loved one. For some parents, not knowing where or how to begin or knowing where to begin but lacking sufficient moral, emotional, and economic support to do so. Societal barriers continue to be a source of much anxiety and fear for parents trying to let go and attempt to give their adult child(ren) with a developmental disability cautious autonomy to achieve a sense of freedom and dignity.

According to The World Health Organization (WHO) barriers are factors in a person's environment that through their absence or presence, limit functioning and create disability. These include aspects such as: a physical environment that is not accessible, lack of relevant assistive technology (assistive, adaptive, and rehabilitative devices), negative attitudes of people towards disability, and services, systems and policies that are either nonexistent or that hinder the involvement of all people with a health condition in all areas of life (World Health Organization, 2001). Often there are multiple barriers that can make it extremely difficult or even impossible for people with developmental disabilities to function. According to the Centers for Disease Control and Prevention, the seven most common barriers for people with disabilities include — attitudinal, communication, physical, policy, programmatic, social and transportation (2019).

Research in the field of disabilities has typically been done **on** individuals with disabilities, rather than **with** them, disempowering this already vulnerable population and taking away their voice (Coons, K., and Watson, S., 2013). Despite the acknowledgement that individuals with developmental disabilities are the experts on their own experiences, these individuals, in particular individuals who are non-verbal or with intellectual disabilities have been largely omitted from the disability discourse (Kitchin, 2000). Explore Dreams was a community initiative to create intentional spaces for vulnerable voices to come forward. Explore Dreams was also a way to learn about how to even go about asking adults with a variety of unique forms of communicating to express what matters most to them. The Explore Dreams interview experience offered an opportunity to unpack a dream – a goal, a wish, the inner fire that needs attention and to be simply reminded that adults with developmental disabilities have the right to dream and be heard.

Participants

The project participants all had developmental and intellectual disabilities however the focus was not on their disability or medical diagnosis but on their abilities. The average age range of participants in the study was 20 to 35. The youngest participant was 18 and the eldest was 72 years old. 95% of respondents needed support to complete online or paper surveys.

Most participants identified as an adult with a developmental disability or as having a disability. A few participants neither identified as a person with a developmental disability nor as having a disability. These participants have a mild to moderate cognitive impairment and are limited in their verbal communication or have a moderate to severe cognitive impairment and appeared to have no understanding of the term. Confirmation of diagnosis of intellectual and/or developmental disability was confirmed by participant parent or legal guardian. A couple of participants with mild cognitive impairments understood disability to be someone who has a visible physical impairment.

Individuals from the Deaf community who have a mild to moderate developmental disability also participated in the interview experiences. Many members of the Deaf community do not identify their lack of hearing as a disability in itself. The Deaf community has a long cultural history that this report will not get into however important to clarify here.

The medical diagnoses that were disclosed during the parent and individual interviews, which by no means represents all participants and the complexities and intricacies that go along with having a developmental and/or intellectual disability included the following:

- Autism Spectrum
- Cornelia de Lange Syndrome
- Down Syndrome
- Williams Syndrome
- Cerebral Palsy
- Developmentally delayed (Global)
- Fetal Alcohol Syndrome

Definitions

For the purposes of this report, the following definitions are provided as a point of reference with the understanding that there are various interpretations about the concept of disabilities.

According to the National Institute of Health (NIH), developmental and intellectual disabilities can be defined as the following:

<https://report.nih.gov/NIHfactsheets/ViewFactsheet.aspx?csid=100>

Intellectual disability refers to a group of disorders characterized by a limited mental capacity and difficulty with adaptive behaviors such as managing money, schedules and

routines, or social interactions. Intellectual disability originates before the age of 18 and may result from physical causes, such as autism or cerebral palsy, or from nonphysical causes, such as lack of stimulation and adult responsiveness.

Developmental disability is a severe, long term disability that can affect cognitive ability, physical functioning, or both. These disabilities appear before age 22 and are likely to be life-long. The term “developmental disability” encompasses intellectual disability but also includes physical disabilities. Some developmental disabilities may be solely physical, such as blindness from birth. Others involve both physical and intellectual disabilities stemming from genetic or other causes, such as Down syndrome and fetal alcohol syndrome.

Disability - The UN *Convention on the Rights of Persons with Disabilities* describes persons with disabilities as those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an equal basis with others. For more information, please consult the following link:

<http://www.un.org/disabilities/convention/conventionfull.shtml>

Outreach and Recruitment

Outreach and recruitment of participants was carried out in a multitude of ways. TCOP parent representatives Karen Alexander and Vicki McCallum and Program lead Heryka Miranda spent considerable time reaching out to agencies, families, support workers, and community members in the Halton and Peel regions, including 25 local day programs that were contacted. Each participant and family received a formal invitation letter (**Appendix A**) that included details of the study and what to bring and expect at the interactive group interviews.

To promote engagement in the project we held two parent meetings and participated in Community Living Oakville's open house

Flyers were distributed in hard copy, by email and via facebook at OPNC (2011 followers), TCOP (350 subscribers), Community Living Mississauga, Oak Park Family Group, Adults in Motion, Developmental Services Ontario – DSO (1600 followers), Community Living Oakville and their programs Raise Your Voice, In the Loop Media, and STEPP; Bob Rumball Centre for the Deaf, Camelot Centre, Oakville Special Olympics, Parent Connections, Halton Parents, Special Friends Networks, Central West Specialized Developmental Services, Autism Ontario, Halton Region, Family Alliance Ontario, Yoga program in Mississauga

Word of mouth and sharing on social media by parents and community members.

Community Living Oakville's 'In the Loop Media' did two promotional videos that were circulated on Facebook and by email.

<https://www.youtube.com/watch?v=XnGDG34iMiw>

<https://www.youtube.com/watch?v=n3NZ53SsITY>

Research Methods

Qualitative and quantitative methods were used in collecting data using online survey via Survey Monkey, conversations over the phone with a parent, support worker and/or interviewee and small group interview experiences.

Survey (Appendix B) (62 completed). The survey consisted of 44 questions targeted at persons with developmental disabilities and their families. The first 36 questions asked about participant's interests, volunteer and work experience, housing/living arrangements and relationships. Questions 40 to 44 were designated for a family member to fill out. Family members' questions were open-ended, focused on identifying barriers that impact their loved one, while identifying supports needed from their communities to better support their loved one and what family member's hopes and dreams are for their loved one with a disability. A total of 62 individuals who identify as having a developmental disability completed the survey with support by a family member or someone from our research team. Forty-four individuals completed the survey online, while 18 filled out printed surveys. The printed surveys were completed at community events with volunteers assisting.

Interactive Interview Experiences (Appendix C) (158 Participants). The group interviews created accessible and inclusive 'interview experiences' with adults with developmental disabilities where they were recognized as the experts on expressing their strengths and life aspirations – awakening the artist within to explore and create the life that they want to live in through the expressive arts.

158 individuals with a developmental disability participated in this experience in 15 group opportunities. These took place at four different locations, including the Glitz and Glam, COVE conference at the Sheridan College Conference Centre.

We completed 63 pre-interview phone calls with participants/families and co-facilitators to prepare them for the interviews. In these conversations we answered questions about the project and asked about best practices for communicating with the participant, which for many turned into rich conversations about the trials and triumphs for the participant and their families.

Group Interview Facilitators in Training. The Explore Dreams project had two interview facilitators-in-training, Karina Scali and Nic Ulmer, who identify as individuals with a developmental disability. They had already participated in a group interview and had a positive experience. Both were interested in developing their capacity in facilitation and were curious about the interview process. Since they were already comfortable with public speaking and active members and advocates in their respective communities; we ended up designing co-facilitating roles and responsibilities to assist the interview experiences. These facilitating roles included developing the interview questions, greeting interviewees upon their arrival and escorting them to the interview room, making sure consent forms were signed, opening up the interview by formally welcoming participants and assisting in going over ground rules, animating the space and providing support and encouragement to interviewees.

Their presence and assistance made a significant impact in the interview process by providing the interviewees with an increased level of comfort and trust. Karina and Nic supported the process by participating and providing responses to questions from their personal life, which opened up the conversation. Through this process they gained confidence in their facilitation and leadership skills. One of the facilitators-in-training was part of a promotional video created by In the Loop Media.
<https://www.youtube.com/watch?v=n3NZ53SsITY>

Arts-Based Interview Approaches. The arts-based approaches that were used in the interview experiences are therapeutic in nature and come from the field of Expressive Arts Therapy, EXA¹. They were used as creative tools of engagement to ease tension and anxiety, inviting participants to play and co-create together and as a means to provide a variety of forms for participants to express themselves with no expectation of artistic skills or abilities or to create a tangible piece of art.

In the interviews, we used what is called “low-skill, high-sensitivity”² approach in EXA. This means that the participants do not have to be artists or have any particular artistic ability. Participants were encouraged to become sensitive or mindful to whatever they are experiencing, whether they are engaged in play, movement, vocal expression, sound-making, work with colours and shapes, dramatic action and other forms of expression (The Create Institute, 2005). The researcher and research assistant sensitized participants to the materials they used and helped them engage creatively in whatever medium they choose (The Create Institute, 2005).

The rationale for using principles and approaches found in EXA is its ability to be inclusive and accessible – inviting and encouraging when it comes to self-expression. It

1

Expressive Arts Therapies: According to the International Expressive Arts Therapy Association (IEATA), founded in 1994: The expressive arts combine the visual arts, movement, drama, music, writing and other creative processes to foster deep personal growth and community development. IEATA encourages an evolving multimodal approach within psychology, organizational development, community arts and education. By integrating the arts processes and allowing one to flow into another, we gain access to our inner resources for healing, clarity, illumination and creativity (IEATA website).

Knill, Barba, and Fuchs (2004) observe that while all expressive arts therapies (EXA) involve action, each also has inherent differences. For example, visual expression is conducive to more private, isolated work and may lend itself to enhancing the process of individuation; music often taps feeling and may lend itself to socialization when people collaborate in song or in simultaneously playing instruments; and dance/movement offer opportunities to interact and form relationships (Malchiodi, 2005). EXA involves a strong experiential element that provides holistic healing that the verbal therapies are less able to offer (Graham, 2013). Many or all of the senses are utilized in one way or another when a person engages in art making, music playing or listening, dancing or moving, enacting, or playing (Graham, 2013).

² In the field of EXA, Paolo Knill (Knill et al. 1994) coined the phrase “low skill, high sensitivity.” This phrase points to the importance of the capacity for aesthetic response over the development of technique and skill for client or participant’s own sake (Halprin, 2003).

places a high value on what the individual brings and wants to express in the moment. These moments in whatever expressive form it comes brings to the participant an increased sense of belonging, value and self-esteem.

Philosophy that guided the researcher and research assistant of the interview experiences included the following principles found in Movement-Based, Expressive Arts Therapies - MBEAT:

- There is a relationship and interplay between the physical body, emotions, and thinking.
- Body sensations, postures and gestures reflect our history and our current ways of being.
- When we bring sound in our movement, we are giving voice to our feelings and stories.
- When we work on our art (whether a dance, drawing, poem, or performance), we are also working on something in our lives.
- The symbols we create in our art contain valuable messages, which speak to the circumstances of our lives.
- The ways we work as artists teach us about the ways we relate to ourselves, others, and the world.
- When we enact positive visions through our art, we create images and models that can become guiding forces in our lives.
- As we learn how to work with the principles of creativity and the practice of the arts, we are able to apply what we learn to all aspects of ourselves, including the challenges in our lives (Halprin, 2003, p. 20-21).

The researchers borrowed the principles and guidelines from EXA and MBEAT and made sure to work in a highly intuitive and imaginative way while remaining grounded in certain objective frameworks, using methods that support the embodied experience and the aesthetic response (Halprin, 2003). They were also careful to refrain from imposing formulas and agendas and not to place emphasis on how something should look according to formal ideas regarding order, beauty, or unification (Halprin, 2003). Nor was there attention placed on set outcomes in terms of creating a tangible work of art.

Consent. Consent was asked through a discussion about what is meant by requesting consent. Many participants understood that it was providing permission. Another method that we used at times to gather consent was through a game called 'I'm in...boop!' – after discussing the concept of consent we all stood up in a circle, took our turn saying our name and saying 'I'm in' while putting a foot forward into the circle as a way to provide consent and then after the last participant took their turn, we all said 'boop' and tapped our foot into the circle signaling our embodied symbol of giving consent. A consent letter and form (**Appendix D**) was also sent via email and signed by parent/legal guardian or by participant themselves before partaking in the interview experience.

Participants in the interview experience benefited from:

- two hours of meaningful engagement with peers and research team
- creative time, sharing what is important to them individually and in a group
- value placed on a process-oriented approach using the expressive arts to express dreams/aspirations
- opportunity to practice autonomy (independence) in a group process with supporters that are non-relatives
- opportunity to engage with volunteers/research assistants who were interested/curious about their lives
- opportunity to create works of art together that represent participant achievements and their aspirations/hopes/dreams

What follows are the findings and insights from the experiential interview experiences and survey responses.

Explore Dreams Findings

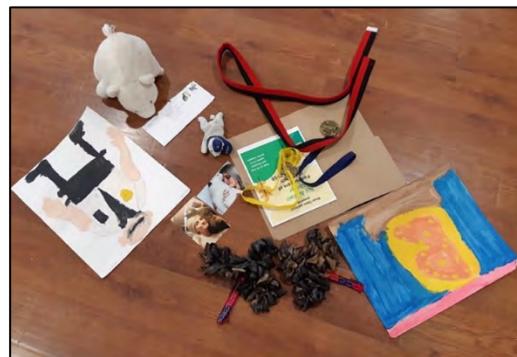
Interactive Interviews - Special Interests. The group interview experiences that supported 158 individuals were divided into three main sections. The first activity was to co-create an artistic installation with objects/artifacts brought from home that hold special meaning to participants.

This activity provided the following benefits for the participant:

- Accessible and interactive activity to invite storytelling
- Opportunity to take risks in sharing something meaningful in their life,
- Independent decision making to place object of significance and team building to choose a collective name for the artistic installation
- Create a visual representation of a story – recalling a memory that was meaningful and given value to it through an artistic visual representation

Objects that were brought (or developed onsite at the interview³) were:

- pictures of loved ones, especially of parents or a pet or someone who had passed away that was important to their lives
- pictures of places that they have traveled to
- pictures of famous singers or people that they admire, such as Terry Fox
- birthday cards and letters
- awards achieved at Special Olympics and/or certificates of recognition for volunteer participation in a community activity or High School diploma
- favourite stuffed animals and toys
- t-shirts or caps from favourite sports team
- favourite books or magazines with special interests
- electronic devices such as cell phones and iPads
- collective mural of favourite colours and images of symbols that represented their interests or a special memory



Artistic Group Installation Pic 1

³ If a participant(s) forgot to bring an object from home, they were given time to draw or share a story about one of their favourite memories. On two occasions at day programs, participants drew a collective mural.

Completed Artist Installations: Wonderful Wonders, Trip Down Memory Lane, Special Memories, Smiles, Happy Things.

Participants took turns around the circle to share their special object. They would then proceed to decide where to place their object in the middle of the circle. Taking turns brought a sense of feeling proud and being special because each person was given the group's full attention; they had the floor. It also increased their sense of self-importance. Participants showed positive responses to this activity with their body language and gestures – smiles, laughter, lifting their head, providing eye contact at times and taking their time in deciding where they would place their object. After everyone had a turn, the group offered a name to the artistic installation.



Artistic Installation Pic 2

One participant's object of special meaning was a letter that a family member wrote to her before they died. She read the letter in front of everyone, shedding some tears as she read. She shared that it was the first time that she read the entire letter and that she was grateful to have people hear these words that mean so much to her. Participants consoled her by telling her how sorry they were for the passing of her family member. Everyone clapped for her and one participant told her that she was brave.

Participants who were non-verbal were able to participate by holding and showing their object to everyone and placing it into the circle. This activity provided a safe way to take risks and express themselves emotionally. For example, one of the participants brought a toy truck and communicated his love for trucks by using gestures and facial expressions. His mother kindly wrote down what his gestures meant for us. He shared the story twice – once before the interview started where his mom interpreted while he communicated the story using gestures and then once on his own during the interview. The research assistant remembered the story and gestures and referenced the notes that his mom left to verbally share the story with others. He was filled with great excitement as it made him feel important and proud of himself.



Artistic Installation Pic 3

Key Insights - Special Interests: This exercise served to highlight and represent what was important to participants and how they see and define themselves. Their objects and the learning from the discussion around why they selected those particular objects disclosed personal stories of gratitude, triumph, loss, and great achievement. The following are themes that were important to them:

1. Connection and support from families and friends is essential
2. People need to feel loved, important, valued, accomplished and part of something with their families, peer group, team and community
3. Feeling safe is important with people who cheer(ed) them on and with things that bring them comfort and joy
4. Participants have a strong sense of curiosity and adventure to learn about new places and activities
5. They have hobbies and special interests and heroes that help define them
6. There is a need for intentional creative and inclusive spaces to build community that provide the care, attention and sensitivity to be seen, heard and celebrated

Interactive Interviews, Exercise Two - Strengths. The second activity was an opportunity for participants to explore and share their strengths, which included time to reflect on what are blessings in their lives, accomplishments that they feel proud of and what they considered are their talents and gifts. Second activity provided the respondents with the following benefits:

- Participate in a discussion/brainstorm of the concept of strengths
- Witness co-facilitators that identify as having a developmental disability
- Participate in a traditional one-on-one interview experience
- Forum to be heard and share their thoughts and ideas
- Space to think about their abilities, uniqueness and awesomeness to build confidence and self-esteem

The following were reoccurring themes that in participants view are considered blessings, accomplishments and talents and gifts:

Blessings

- Family (spending time with family and being close to a parent(s))
- Meaningful relationships with friends or a romantic partner
- Pets/Animals
- Faith/Spirituality
- Having a safe home to live in
- Opportunities to travel with family
- Feeling important, useful and valued by having a part-time job and being compensated

Accomplishments

- Finishing high school, completing or being in college, course certificate (Conestoga, Seneca, Mohawk, Humber, and Sheridan colleges, cooking, first aid course)
- Volunteering (ie: taking care of the environment - picking up trash in the park, spending time with pets, seniors, and children)

- Receiving awards (including medals for sports-basketball, swimming, gymnastics, dance, singing, martial arts; awards for advocacy and public speaking)
- Doing household chores (help prepare a meal came up consistently)
- Having efficacy - feeling masterful and skillful in playing a sport, instrument, martial art, proficient in a dance genre or visual art
- Traveling independently or with someone – knowing how to take a bus to a destination, knowing how to walk to the store or volunteer opportunity with someone
- Confronting fears (loud noises, fear of dogs or crowded places)
- Having a healthy romantic relationship
- Speaking up for oneself

Talents and Gifts

- Interpersonal and Intrapersonal intelligences and skills were by far the reoccurring theme – knowing oneself and being sensitive to energies of people and situations around them. Being empathic. Knowing how to be a good friend. Knowing how to comfort and care for others. Good listening skills. Knowing how to love others and not make fun of others. Having a great desire to help others. Knowing how to make people smile and laugh. Making people feel like they are special.
- Risk-takers and being willing to try new things, even if feelings of fear arise.
- Being honest
- Being good observers and witnesses of life. Learning by observing real-life in real time situations and circumstances. Most participants seem to be hands-on – visual and kinesthetic learners. Learning by doing and teaching others.
- Artist- A profound appreciation, interest and efficacy in a music, art, dance, theatre/drama, photography, and martial arts
- Knowledgeable in reporting and interviewing skills.
- Technology proficiency (computers, iPad, social media, Youtube, Instagram, Pinterest, games on cell phone)
- Disney experts (shows and characters)
- Sport athlete
- Baking and cooking

Key Insights – Strengths: This exercise yielded the following overall takeaways/insights about study respondents' strengths that include:

1. A deep appreciation and value for people and meaningful relationships and things that make them feel safe, secure and important.
2. A heightened sense of self-esteem and self-worth by being able to accomplish small to big goals, of being independent, of giving back, of growing and learning to speak up and be heard. Being recognized and celebrated as an important and valuable contributing member of society.

3. An ability to be a bright light, a teacher of empathy, patience, tolerance, and honesty.
4. The ability to be present and in the moment - embodying kindness, authenticity and genuine humbleness.

Interactive Interviews, Exercise Three - Community Impact. The third activity was a group discussion where respondents shared and brainstormed ways in which they can use their strengths to make a significant impact in issues that they feel passionate about in their community.

- Voice issues that are important to participants.
- Opportunity to think practically about where they could have or enhance a meaningful role in the community
- Wear a forward-thinking lens to carve out a future role for themselves built on gifts, talents and passions
- Path to explore potential volunteer/work opportunities in the community

This part of the interview was the most difficult as many didn't know what to say. There were a few respondents who admitted their anger and sadness with tears in their eyes, while sharing personal stories of being bullied or made to feel less than human – admitting not knowing where to access resources. It is evident that participants want to build on their passions and interests. It was clear that many respondents have a connection with pets/animals as they feel safe and unconditionally loved and accepted by being in their presence. There is an interest in raising consciousness about helping the environment, through recycling, composting, and the impact of pollution. However, participants have a narrow scope of where or how they can contribute because they don't know what opportunities are available to them in their communities. They don't have enough human resources/mentors/role models to show and teach them about roles/contributions that they can make.

Key Insights - Community Impact:

1. Participants don't sufficiently feel included.
2. Communities would benefit from education/sensitivity training around interacting with people with disabilities or people who are simply different.
3. Participants fear bullying if they step out to be involved in the community
4. Need for more facilitated support to develop and identify specific community opportunities and supports
5. Participants would welcome opportunities to work with pets/animals
6. Need for pamphlet on bullying resources and supports for people with disabilities
7. Participants are interested in being leaders in helping the environment. This is something to pursue in future programming.

Survey Responses. Desired Occupations

“If I could be anything in the world, I would be a _____.”

Teacher	Newscaster	WWE Wrestler	Chef
Flight Attendant	Mother	Gemologist	Librarian
Chocolate Maker	Librarian	Surfer	Gardener
Baseball player	Musician	Actor/voice actor	Dog Walker
Marine Biologist	Veterinarian	Zoologist	Design/sell shirts

Like most people, respondents want to do something that reflects their interests and provides a service that is helpful and meaningful to others. They have untapped potential and need more opportunities to share their talents. The responses highlight the desire to help others (teaching, working with people). It is possible that they have had limited exposure and knowledge of potential occupations and so using facilitated support to expand knowledge of and potential opportunities would be helpful.

Employment Details

Of the 62 respondents who completed the survey, just more than half (55%) spend time working and/or volunteering in some capacity in their communities.

However, the most common amount of time spent working/volunteering was only 1-3 half-day shifts per week. Only 2 of the respondents have a consistent work schedule, working close to full-time hours. They are over the age of 35, live on their own and they work at a grocery store, and as an office receptionist at an organization for people with developmental disabilities.

Volunteering

33% of respondents volunteer (at places like daycares, summer camps, food banks, community events, hospitals, and community centres) and enjoy...

- Meeting and being with people
- A sense of accomplishment, feeling important and a great sense of pride
- Feeling good about helping people
- Feeling capable and useful
- Learning new skills
- Love working with children and making a difference

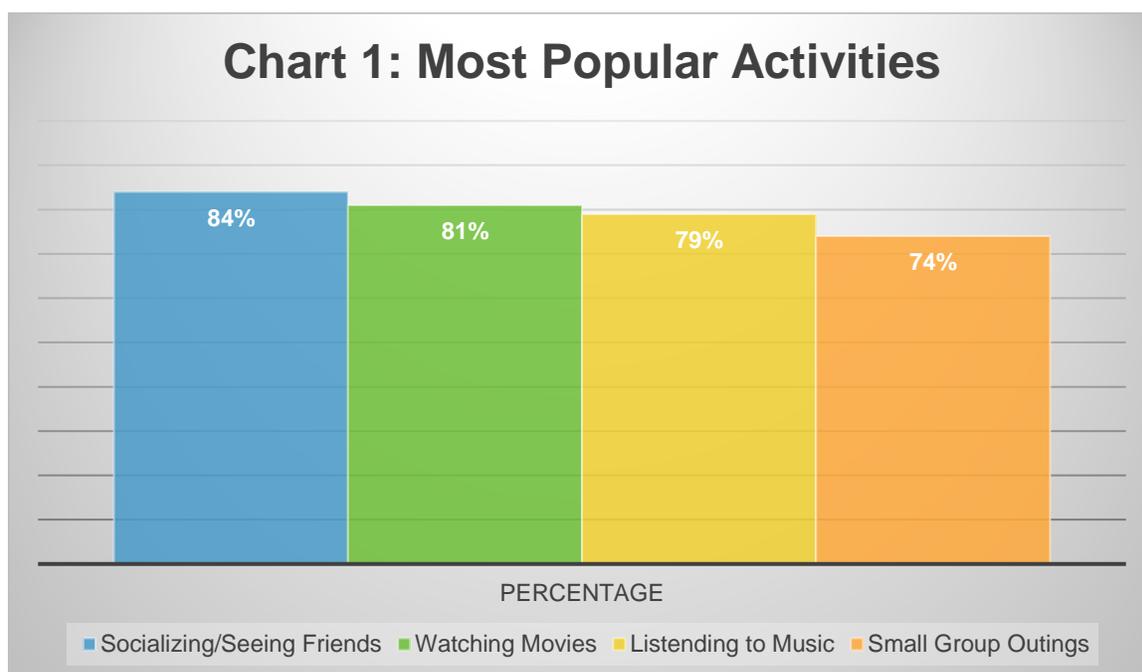
Key Insights - Employment & Volunteering:

1. It is key to develop business relationships and training opportunities for the role of teacher's helper, caregiver for animal shelters/stores, entrepreneurial dog walking/sitting and garden care worker, grocery store and restaurant greeter, cleaner, server, etc...

2. It is imperative to provide adults with developmental disabilities and their families with knowledge and exposure to opportunities not traditionally considered as well as support to develop work/volunteer plans.
3. Respondents continue to demonstrate the ability to provide empathy and a willingness to care for others. There is much opportunity here to invest and explore creative and innovative roles and training to bring a greater sense of harmony and inclusivity to various business and community-based spaces.

Exploring Leisure Time Activity

What activities or interests do you most like to do for fun?



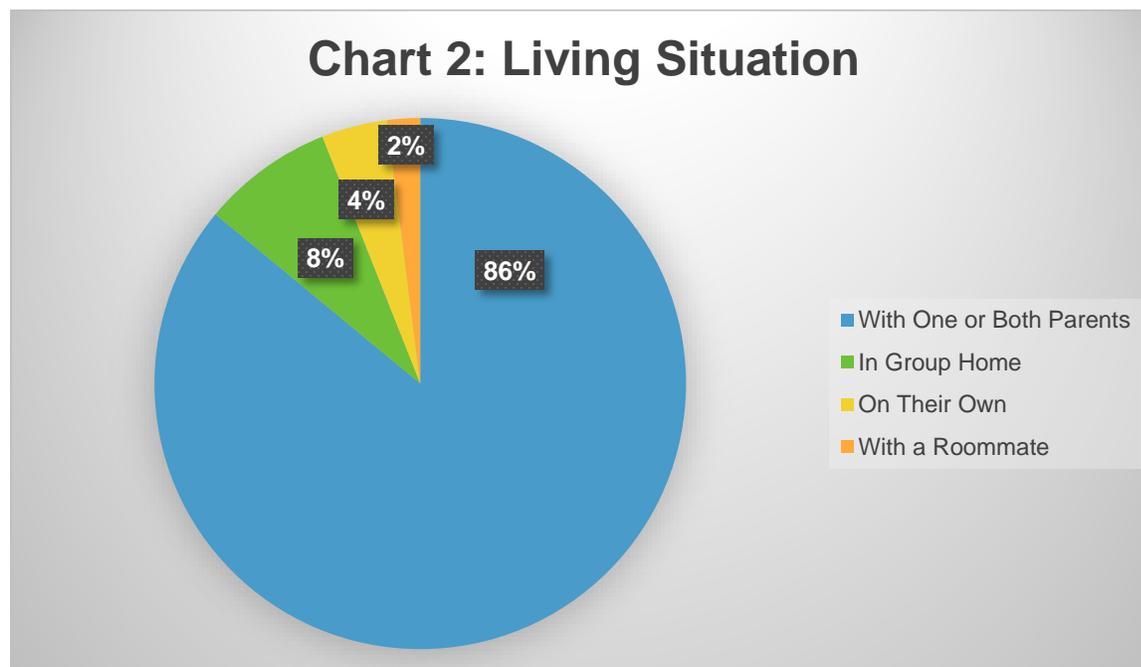
Over 50% of survey participants said that they need support to enjoy these activities. Participants are interested in exploring new activities that are around health and wellness, for example trying out a new sport and activities where they can socialize and meet people, make new friends. Over 60% responded that they need support to participate in new activities.

Key Insights - Leisure Time Activities

1. Having supports in place for transportation and participation in existing and any new activities is required by at least half of the participants
2. Participants have the greatest interest in socializing by watching movies, listening to music, or going on outings in small groups.
3. Participants are interested in trying out new activities and sports where they can socialize and meet new friends

4. Having connections with other people is key, socializing and exploring hobbies like movies and music brings people together. Respondents are open to new activities and experiences to learn and grow. Whether exploring current interests of or developing new ones, having the right support to facilitate success is needed and valued.

Living Arrangements



By far, the most common living situation is with parents!

68% of respondents would like to live outside of the family home in the next 5 years. Either with a roommate, alone, or in another housing alternative. It is interesting to note that there is a preference to live with someone with a disability rather than with someone who is not labeled. Of the 68% who want to move out of their family home only 59% think it is likely to happen.

70% of respondents feel their family needs support for them to transition out of the family home. Those wanting to move out and people currently living on their own provided the following list of support needs.

- Safety and transportation
- Managing money, bank account and budgeting
- Meal preparation, grocery and personal shopping
- Housework: laundry and chores
- Getting ready for work or volunteer opportunities
- Socialization and friends
- Conflict resolution with roommates for personal space, sharing belongings

Respondents who currently live on their own provided the kinds of supports that helped them in transitioning to independent living or alternative living options.

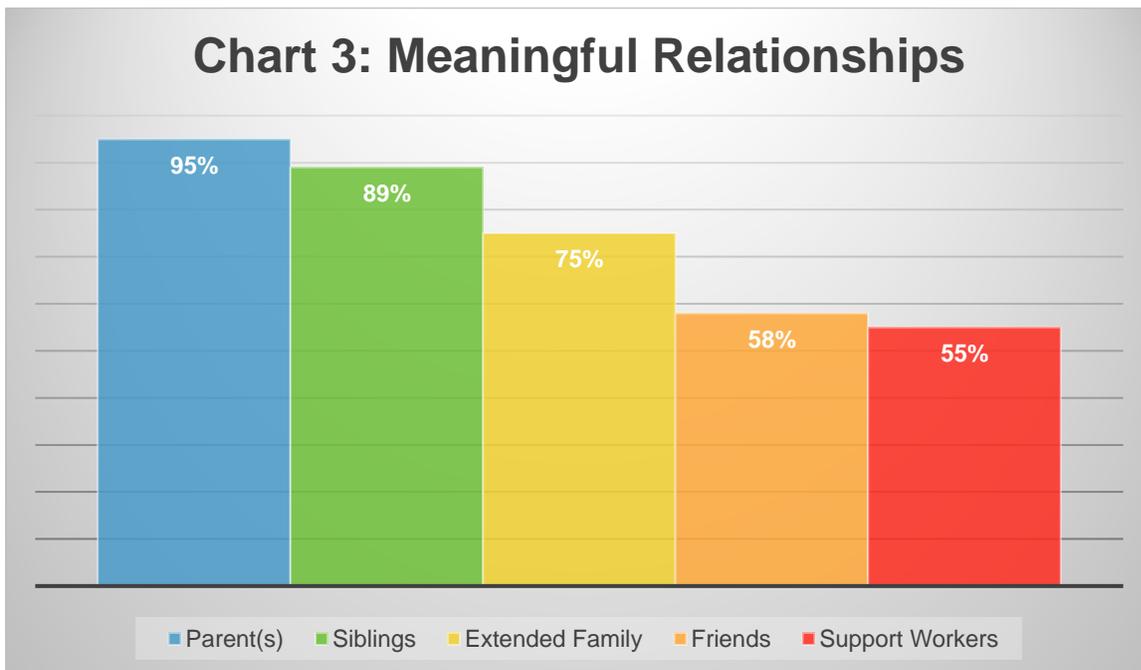
- Visited a community living home several times as a way to ease into transitioning to own home.

- Working one-on-one with a support worker for life skills training – cooking, cleaning, budgeting, laundry, etc...
- Practiced sleep overs at friends' house and prepared breakfast, made bed, got dressed with help from a support worker

Key Insights - Living Arrangements:

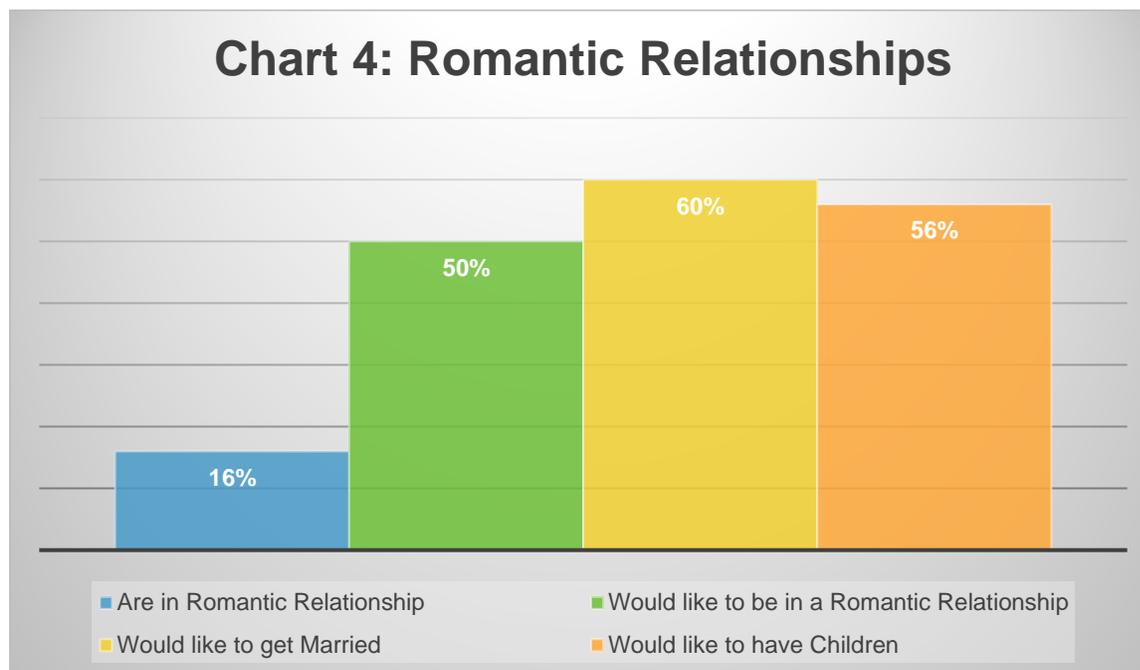
1. Skill building supports are needed in transportation, money management, shopping, cooking, housework, work/volunteer opportunities, socialization and conflict resolution to help the 68% of respondents who would like to live outside the family home.
2. Resources including facilitated support are crucial in order to develop intentional community and neighborhood support for safety and overall well-being.

Meaningful Relationships



It is evident that respondents rely on family for their most meaningful relationships, with friends and support workers also important.

Romantic Relationships



Key Insights – Relationships:

1. 50% or more of respondents would like to get married and have children
2. There is a need for the cultivation of meaningful relationships that are not just parent, sibling and extended family relationships
3. There is a great need for community training on disability culture and sensitivity
4. The list provided above with statements by adults with developmental disabilities about how they would like to be treated would be worthwhile to promote in social media, emails and if funding is available an investment to create educational opportunities as a way to spread their messages to public spaces in their communities.

Community Relationships. Participants want to be engaged, included, and acknowledged in their communities and they want their communities to better understand how to do this. Like everybody else, they want connections to avoid loneliness and isolation, and to be treated like adults with respect and patience. Respondents from the Deaf community expressed the need for people to learn American Sign Language (ASL).

They urge people in society to relax, be patient and not be afraid to use facial expressions and gestures as communication tools. The effort that a non-ASL language speaker puts into trying to communicate is appreciated. The language barrier is a big obstacle for the Deaf community that increases frustration. Relying on interpreters is

also a challenge as sometimes schedule conflicts occur that causes anxiety and reduces their ability to trust others.

What follows are responses from participants about how they would like to be treated:

- Be patient with me
- Allow time for me to express myself
- I can hear you even if I am non-verbal
- Learn how to sign
- Show an interest in my life
- Include me, visit me & invite me
- Treat me like an adult and not a child
- Speak to me directly and not the person I am with
- See me and acknowledge me
- Don't ignore me or act like I am not there
- Educate yourself on how to interact, engage and include me

Community & Family Input

The following section covers the responses and reflections of support staff, students, local business owners, and parents/caregivers that participated in focus groups, online surveys and individual interviews for the study.

Agency Support Staff & Students. Interest in working with people with developmental disabilities from respondents came from personal experiences engaging a person with unique needs. Program leaders that participated in the study are educated as developmental social workers, community workers and psychology as a field of study at colleges and universities. They admit that several colleagues have been afraid of working with people with disabilities and state that the fear stems from not being able to handle potential uncontrollable outbursts or violent behavioural issues. These fears and assumptions have created negative attitudes and beliefs that have served to discourage upcoming professionals and community workers from working with this population. Respondents also stated that they feel uncomfortable and get angry when they receive unwanted praise for choosing to work with people with disabilities. For example, respondents emphasized that several colleagues, friends and family members have stated that they are extraordinary human beings (angels) because they choose to spend their time with people with disabilities.

Respondents have had to challenge colleagues around demystifying negative assumptions, attitudes, stereotypes and beliefs about people with developmental disabilities.

Barriers that exclude people with developmental disabilities:

- **Stigma** - society assumes people with developmental disabilities' cognitive intelligence is younger than they really are, babylike, instead of valuing important talents and gifts.
- **Communication barriers** are a big social barrier where most people get stuck and don't know how to even go about trying to engage. It seems as if people who are not able to communicate verbally or in a way that fits the social norm are considered inferior.
- **Not having adequate resources and training** on communication (including ASL) and engaging strategies with people with developmental disabilities for lifeguards, bus drivers, taxi drivers, police officers and overall community at large

Respondents shared the following approaches and insights on how to engage people with developmental disabilities:

- Compassion and kindness
- Recognize abilities and if one doesn't know what they are, try to find out
- Active listening

- Providing and organizing options and welcoming spaces for engagement
- Setting healthy boundaries in terms of physical space/distance with people
- Keeping an open mind and not to talk down
- Try to find common interests
- Adapt communication styles - learn how to use user-friendly language and use body language or find ways to simplify language
- Come with an open heart – calm, patient and friendly demeanor and presence

Business Voices. Businesses sometimes don't have enough training, understanding and consistent human resources to provide the support needed for a person with developmental disabilities to be successful within the company's context. It is important to have all staff trained in inclusion and to challenge any assumptions about people with disabilities. Small businesses do not have the funds to pay for training that is needed for proper inclusion in the workplace.

Parents/Caregivers. Barriers to someone with a developmental disability living on their own and integrating into the community, according to parents and caregivers:

- Not having reliable people for loved one to access – 24-hour support
- Finding unpaid meaningful relationships to support loved one or to be a friend
- Not knowing how to take care of themselves – personal, day-to-day needs and managing an independent living situation
- Fear that loved one will not have any input in transitional living process or who they would like to care for them
- Discrimination of rental owners
- Overall safety
- Ability to communicate and be heard
- Lack of education, interest and awareness of neuro diverse community
- Lack of employment opportunities
- Lack of sensitivity or interest and dismissive/belittling attitudes and behaviours towards people who are non-verbal
- Ignorance and discrimination against people with developmental disabilities causing increased feelings of rejection and betrayal
- Lack of programs and 1:1 support for people who are non-verbal, limited in verbal expression, or who struggle with social skills

Family supports needed from the community

- Safe and inclusive communities to live in
- Support - 1:1 support, 24-hour support, respite workers
- Safety- neighbours who make sure adult children cross the street safely or who know their neighbours and help with not talking to strangers
- Building support networks of trusted people who can support life skills and socialization like housekeeping, job coaching, groceries, laundry, cooking, community socials and outings.

- More awareness of disabilities – patience, kindness, compassion and understanding from the community

Key Insights - Community & Family Voices:

1. Staff and students who support individuals with developmental disabilities need access to training/resources on communication and engagement strategies to be able to better support and understand the abilities and dreams of individuals.
2. Business owners need staff training, as well as resources to ensure successful workplace opportunities for people with disabilities.
3. Facilitators are needed to work with business owners, community organizations and people with disabilities to create, implement and support inclusive roles and spaces in the community.
4. Community events and activities that foster inclusion and provide volunteer opportunities for people with disabilities are needed to build awareness, friendships and a supportive and inclusive community.
5. Supportive networks are crucial in the development of intentional support systems and community capacity for individuals with developmental disabilities.
6. Community education and awareness is essential to increase inclusion and supports
7. Families require supports and funding to transition family members to housing opportunities in a safe, supportive manner.

Conclusion

The Explore Dreams community seed research initiative was able to gather a variety of voices that are often unheard from the developmental disabilities' community. People with developmental disabilities have long been considered marginalized because they are perceived as less than or not as valuable as other voices in society and experience subtle and explicit moments of discrimination, humiliation and dehumanization. This is evident in some of the responses, concerns and reflections gathered from respondents with a developmental disability, family members, business owners and community and support workers.

The interactive interview experiences created activities that were inclusive, accessible and meaningful to the participants. The process of recruiting and engaging participants was just as important as gathering the perspectives of the participants. The therapeutic guidelines and framework that come from the field of expressive arts therapy that assisted in designing the interactive interview experiences were positive facilitation, communication and engagement approaches that meets people where they are and places value on the process rather than on expected outcomes or pressuring participants to perform or get something right.

Being messy, confused, not understanding or not knowing how to respond to questions was acceptable and a valid response. Regardless of how loud, quiet or how engaged in the interview experience participants may or may not have been; what mattered was the manner in how each participant was invited to participate, valued and the manner in which questions were asked or brought forward, which took patience, time, sensitivity, vulnerability and creativity on the part of the research team. The survey was a tool to increase the reach for more participation from people with developmental disabilities and their families.

For the most part, parents and adult children with a developmental disability want the same thing: to be unconditionally loved, safe and secure in a home and community that is equipped for the social, physical, emotional, psychological and spiritual needs of the individual with developmental disabilities; to feel like they matter and belong to a thriving community, to have meaningful work opportunities and feel useful and are a contributing member to society; to mature and develop healthy life skills and meaningful relationships that are unpaid, to achieve personal goals and life aspirations surrounded by people who encourage, support and appreciate them and to have enough money, resources, human supports and services to thrive outside of their family.

People with developmental disabilities **continue** to extend an open invitation to teach others the power of vulnerability and how to genuinely accept being fully human. They do this through the growth and development of interdependent relationships with their family members and caretakers. Through these symbiotic relationships with others who are open and willing to listen, learn and possibly communicate and interact in a different way; a greater emotional intelligence is achieved and valued. A greater sense of empathy, patience and understanding is gained while being in relationship and of

service in achieving the personal needs and personal aspirations of a person with developmental disabilities. They continue to be an untapped source of invaluable resources for teaching others about the practice of unconditional love and the beauty that can come from the development of interdependent relationships.

What follows are some recommendations under meaningful relationships and education and an **Explore Dreams Call to Action!** for further consideration that come directly from the reoccurring themes and insights gathered in the findings.

Recommendations

Meaningful Relationships. There is no question that what people with developmental disabilities need and thirst for is **human contact and meaningful human connection**. As parents age and for some with declining health, they worry and are fearful of what will happen when they are no longer capable of supporting their adult child with unique needs or when they simply pass away.

What respondents and their families most need are caring, empathetic, understanding, kind, patient, open-hearted and open-minded people involved in their lives. In order for people with developmental disabilities to thrive in their local communities; they, along with their families need unpaid and paid caring relationships from the community.

The following highlights some recommendations to support the need for meaningful relationships:

- Training for community-at-large on how to be a good friend/ally/neighbour to individuals with developmental disabilities. An understanding and appreciation of neurodiversity, along with tools and training on what meaningful accompaniment looks like to ensure the safety and wellbeing of vulnerable persons.
- Intentional networks of support/life planning to be effectively facilitated. This is particularly important for individuals with developmental disabilities because they experience an increased level of isolation and loneliness – for many it can be a daily struggle and challenge. Many want to participate in events and try new activities, volunteer and work but need someone to accompany them. Support circles are crucial because they provide a myriad of support and resources for the individual and their family. Lots of brainstorming, planning and action steps with the vulnerable person is the essence of the support circle process.
- Training and workshops for individuals with developmental disabilities around how to be a good friend, how to make friends and how to have a romantic relationship that include simple guidelines around creating healthy boundaries, conflict resolution and consent are needed.

Education. There is a **desperate need for educational awareness campaigns** for communities and public-at-large that include:

- Inclusion and sensitivity training with a focus on developing cross cultural skills that help shift and challenge irrational fears and negative beliefs/ideas about individuals with developmental disabilities with respectful attitudes and positive engagement behaviours and approaches. In particular for members of society that for practical reasons come in more contact with people with disabilities.

Those who provide a public service (ie. bus and taxi(uber,lyft) drivers, potential employers, cashiers, librarians, life guards, potential landlords, community workers, food service workers, grocers, etc...

- A value and investment in learning and appreciating diverse nonverbal communicative forms that include ASL, gestures, facial expressions and body language.
- An understanding of the concept of embodiment as a resource towards understanding how one experiences the world around them. The tools a person possesses through their body to take in the world that include – senses, feelings and emotions, abilities in mobility and postures, gestures and shapes and the ways in which our biology and personality is expressed.
- A process of understanding and placing value on the existing multiple intelligences/multiple literacies of people with developmental disabilities is needed. There are many programs that focus on keeping people with developmental disabilities entertained instead of providing real learning and skill-building. There are a multitude of opportunities for creativity, innovation and ‘out of the box’ programming that directly serves the interests and learning styles of individual(s) with unique needs.

Explore Dreams – Call to Action!

Community Impact

1. Communities would benefit from education/sensitivity training around interacting with people with disabilities or people who are simply different.
2. Need for more circle of support opportunities to develop community opportunities, friendships and supports
3. Need for information and awareness on bullying resources and supports for people with disabilities
4. There is a need for welcoming, intentional creative, inclusive spaces and events to foster community.

Employment & Volunteering

5. Develop business relationships for teacher's helper, animal shelters/stores, entrepreneurial dog walking/sitting and garden care, grocery stores, restaurants,
6. Provide circles of support to develop work/volunteer plans
7. Participants are interested in being leaders in helping the environment. This is something to pursue in future programming.
8. Business owner and staff training, as well as agency support workers are needed to ensure successful workplace opportunities for people with disabilities.
9. Educating people with developmental disabilities on broader options that could be pursued.

Leisure Time Activities

10. Having supports in place for transportation and participation in existing and any new activities is required by at least half of the participants
11. Staff who support individuals with developmental disabilities need access to training/resources on communication and engagement strategies to be able to better support and understand the abilities and dreams of individuals
12. Participants have the greatest interest in socializing by going on outings in small groups, getting together to enjoy music and/or see movies.
13. Participants are interested in trying out new activities and sports where they can socialize and meet new friends
14. Having connections with other people is key, socializing and exploring hobbies like movies and music brings people together. This audience is also open to new activities to learn and grow. Whether exploring current interests or developing new ones, having the right support to facilitate success is needed and valued.

Living Arrangements

15. Skill building supports are needed in transportation, money management, shopping, cooking, housework, work/volunteer opportunities, socialization, safety and conflict resolution to help the 68% of people with a disability who would like to live outside the family home.
16. Planning resources and support would assist the person with a disability and their family to make the transition safely, successfully and with less stress and anxiety.

References

- Center for Disease Control and Prevention. (2019). *Common barriers to participation experienced by people with disabilities*. Retrieved April 5, 2019, from Centers for Disease Control and Prevention:
<https://www.cdc.gov/ncbddd/disabilityandhealth/disability-barriers.html>
- Coons, K. D., & Watson, S. L., (2013). Conducting research with individuals who have intellectual disabilities: Ethical and practical implications for qualitative research. *Journal on Developmental Disabilities*. 19(2), 14-22.
- Halprin, D. (2003). *The Expressive Body in Life, Art and Therapy*. London, UK: Jessica Kingsley Publishers
- International Expressive Arts Therapy Association. (2014). *Who we are*. Retrieved October 1, 2019, from International Expressive Arts Therapy Association:
www.ieata.org
- Kitchen, R. (2000). Using participatory action research approaches in geographical studies of disability: Some reflections. *Disability Studies Quarterly*. 21(4), 61-69.
- Knill, P., Barba, H., & Fuchs, M. (2004). *Minstrels of Soul. Intermodal expressive therapy*. Toronto. ON: EGS Press.
- The Create Institute: Centre for Expressive Arts Therapy Education. (2005). *Explore Expressive Arts Therapy*. Retrieved October 1, 2019, from The Create Institute:
www.thecreateinstitute.org
- World Health Organization. (2001). *International classification of functioning, disability and health*. World Health Organization: Geneva.

APPENDIX A

Explore Dreams, Letter of Invitation

Dear Participant

I would like to invite you to participate in a research study called **Explore Dreams** - a partnership between The Community Oak Park and Oak Park Neighbourhood Centre. A research study is a detailed study or investigation of a subject, especially in order to discover (new) information or reach a (new) understanding.

Explore Dreams is a research study that seeks to provide individuals who identify as a person with a disability to share their dreams! aspirations! and the many ways that they would like to contribute to their community. Every research study has a research question and the questions that we would like your participation in answering is:

What are some personal goals that you would like to achieve in your life?

How would you like to contribute to your community?

The Explore Dreams interview experience recognizes YOU as the expert on expressing your strengths and what it is that you want to aspire to, in collaboration with a friendly volunteer research assistant whose main role is to encourage and support you to participate in the activities to the best of your ability. The interview experience will have a total of five participants, yourself and four more people, along with research assistants, and myself – Heryka (pronounced Erika)!

The research experience will be interactive, meaning that it will be fun and use the visual arts to bring symbols, colours and shapes to your dreams. There is absolutely NO EXPECTATION that you must possess ARTISTIC ABILITIES. We will do a fun warm up that will include a circle dance (that you can do standing or sitting) to get started as we meet and greet everybody.

What to expect at your Interview Experience?

We ask that you bring with you to the interview an object that is special and meaningful to you. It could be a photograph, a book, a figurine, an item of clothing, etc. Any object that means something special to you and be ready to share why its special to you.

You will participate in a combination of one-on-one and two group activities that will include two visual art pieces: an abstract artwork that you do one-on-one with a research assistant and a group art installation with your object. This is for you, not your parents 😊. We kindly ask that your parent drop you off and pick you up afterwards, however parents can come inside a bit earlier and greet the research assistant, volunteers or myself.

Benefits that you may experience as a participant of the study:

- A flow of inspiration, creativity and pleasure
- A sense of belonging
- Spontaneous bursts of joy, laughter and tears
- Acceptance of self and others
- Opportunity to be seen and heard
- Opportunity to do something by yourself, without your parents 😊

Confidentiality

I will ask everyone participating in the interview process to respect everyone's privacy. Meaning that whatever we share and discuss in the interview experience is private. I will ensure that your privacy and confidentiality will be protected in my written research, and that you will remain confidential. Your real names will not be included in the written research and I will use a different name to identify you if needed.

I will keep information that you provide confidential. All research data, transcripts, audio recordings and photographs of artwork will be stored in a secure location on my Oak Park Neighbourhood Centre computer.

I want you to know that your participation is optional and that you are free to withdraw your participation at any time for any reason.

By signing the consent form document you agree that you understand your role in the research study and the contents of this document.

Documentation

In order to document the interview experience, with your permission, I may ask if we could audio-record your interview with a recording device (cell phone, computer, recorder). The research assistant or myself will also be documenting your verbal responses via written form using a notebook. Any recordings taken will be erased after I listen and transcribe your responses. With your permission, I would like to take pictures of your artwork and possibly your hands. Your faces will not be photographed in order to keep your identity confidential.

If you have any questions, please feel free to email me at heryka@opnc.ca or call me at: (905) 257 6029 ext. 1.

Thank you.

Heryka Miranda
Inclusive Community Engagement Coordinator
Oak Park Neighbourhood Centre
The Community Oak Park

APPENDIX B

Explore Dreams Survey

Who Are We?

Oak Park Neighbourhood Centre (OPNC) is a charitable organization created by the community for the community. www.opnc.ca

The Community Oak Park (TCOP) is a program of OPNC that is a parent-led support network to support their children with developmental disabilities to be engaged and valued in their communities. www.wearethecommunity.org

What Are We Doing? This survey is for you to have a say - a voice in shaping your future! There is also a section at the end for your family or caregiver to fill out if they helped you with completing this survey.

Thanks to the Ontario Trillium Foundation for funding this project!

What Will OPNC Do With The Information? The information gathered in this survey will be used to identify what matters most to you and your family and to advocate for the hopes and dreams that you say are important to you.

Protecting Your Privacy: None of your personal information will be shared. The results will be summarized in a report with non-identifying information to the Ontario Trillium Foundation.

Some of the questions on this survey are open-ended, which means that they are meant to make you think. You can skip questions and answer the ones that you want. It is not necessary to complete all sections to submit the survey.

Please contact Heryka Miranda at heryka@opnc.ca if you have any questions or prefer a paper copy of the questionnaire in print format.

Thanks for taking part in the Explore Dreams Survey!

Tell Us A Little About You

1. What are three things that I like best about myself:
 - a.
 - b.
 - c.
2. The most important people in my life are:
 - a.
 - b.
 - c.
3. I am happiest when _____
4. The thing that upsets me the most is: _____
5. The thing that calms me down is: _____
6. Others can help me calm down by: _____
7. The place I feel most peaceful and comfortable is: _____
8. The thing that makes me laugh out loud is: _____
9. My favourite animal is: _____
10. The animal I chose in Q9 is my favourite because...: _____
11. If I could be anything in the world, I'd be: _____

Your Interests

12. What do you most like to do for fun? Please list any activities/interests you enjoy doing and are currently involved in. Check all that apply.
 - Sports
 - Computer games/video games
 - Social media (Facebook/Twitter)
 - Listening to music
 - Playing an instrument
 - Attend live performances theatre/musicals/dance/concerts
 - Drama/Acting
 - Dance
 - Knitting

- Yoga
- Meditation
- Cooking
- Crafts
- Movies
- Outings small groups
- Outings big groups
- Socializing/Seeing friends
- Reading
- Gardening
- Spending time with seniors
- Outdoor activities, specify here
- Board games
- Puzzles
- Spending time with animals
- OTHER, please specify: _____

Support Used, If Any

13. Do you need any supports to enjoy activities that you mentioned above?

- Yes, please describe: _____
- No

14. Are there **NEW** activities that you'd really like to try?

- Yes, please specify here _____
- No

15. Do you need any supports to participate in this **NEW** activity?

- Yes
- No
- If yes, please specify the type of support needed: _____

Volunteering/Work Experience

16. Do you currently work or volunteer?

- Yes, I work
- Yes, I volunteer
- Yes, I work and volunteer
- No, I don't work
- No, I don't volunteer
- No, I don't work or volunteer

- Please specify where you work or volunteer here: _____

17. How many half days do you work or volunteer?

- I work or volunteer one half day per week
- I work or volunteer two half days per week
- I work or volunteer three half days per week
- I work or volunteer four half days per week
- I work or volunteer five half days per week
- Other (please specify): _____

18. How many full days do you work or volunteer?

- I work or volunteer one full day per week
- I work or volunteer two full days per week
- I work or volunteer three full days per week
- I work or volunteer four full days per week
- I work or volunteer five full days per week
- Other (please specify): _____

19. Do you need support to work or volunteer?

- Yes
- No

20. What do you like best about working or volunteering?

21. What do you like least about working or volunteering?

22. If you are currently working and it were up to you, would you prefer to work:

- More hours per week than you currently do
- Fewer hours per week than you currently do
- The hours I am working now are fine for me

23. If you are not currently working, how interested are you in having a job?

- Very interested
- Somewhat interested
- Not very interested
- Not at all interested

24. What would be your dream job? Where would it be? and how many hours per week would it be?

Housing/Living Arrangements

The next few questions are about your housing/living arrangements.

25. What is your current living arrangement?

- I live at home with my family
- I live with friend(s) or roommate(s)
- I live on my own
- I live in a group home
- Other: _____

26. Where would you like to live in the next 5 years?

- Live at home with my family
- Live with a friend/roommate(s) with a disability
- Live with a friend/roommate(s) without a disability
- Live on my own
- Other: _____

27. If you live at home with your family, how likely is it that you will transition to live independently or with roommate(s) in the future?

- Very likely
- Somewhat likely
- Not very likely
- Not at all likely

28. If you answered very or somewhat likely in Q. 27, how likely is it that you and your family will need support to transition to live independently or with roommate(s) in the future?

- Very likely
- Somewhat likely
- Not very likely
- Not at all likely

29. If you answered very or somewhat likely in Q. 28, what kinds of support(s) do you think you would need the **most**. Please specify your top three areas where you would most need support.

-
-
-

30. If you currently live on your own, what kinds of supports helped you to achieve living independently or with roommate(s)? Please describe:

31. If you currently live on your own or with a roommate(s), what types of supports do you still find that you need? Please describe:

For resources about transitioning to independent living, please go to TCOP website: www.wearethecomunity.org

Relationships

32. With whom would you say you currently have meaningful relationships in your life (that is, people you count on, who support you, whom you feel close to and are important to you)?

- Parents
- Brothers or Sisters
- Friends
- Romantic Partner
- Extended family (grandparents, aunt/uncle, cousin)
- Teachers
- Coaches
- Support Workers
- Faith leader(s)
- Neighbour(s)
- Other (please specify): _____

33. If you do not currently have a romantic partner, how interested are you in having one?

- Very interested
- Somewhat interested

- Not very interested
- Not at all interested

34. Are you interested in getting married or living with a romantic partner?

- Very interested
- Somewhat interested
- Not very interested
- Not at all interested

35. Are you interested in having children someday?

- Very interested
- Somewhat interested
- Not very interested
- Not at all interested

36. If you could change anything about how people interact with you or support you, what would you change?

-
-
-

Demographics

37. What is your age? _____

38. What is your postal code? _____

39. The last open-ended questions are for your parent(s)/caregiver(s) who helped you fill out the survey today. If nobody helped you with the survey please skip questions 40 to 44. Thank YOU! You have completed the survey! Please email or scan survey back to heryka@opnc.ca

Barriers to being involved in the community

40. What barriers do you see for your loved one in terms of living on their own?

41. What are the barriers to your loved one integrating into their community?

42. What supports do you require from your community to help your loved one?

43. What are your hopes and dreams for your loved one in the next 5 years?

44. Anything else that you would like to share?

Thank you very much for taking the time to complete this survey.

APPENDIX C

Draft Agenda for Exploring Dreams Interview Experience (1.5 to 2 hours)

I. **Getting to Know You** (name game and moving through space and greeting each other/creating community)

II. **Welcome and Ways of Being Together**, role of research assistant, consent (ground rules for interview process) (*Interviewing - Briefly role play what interviewing is. The process of interview will also be written up on chart paper.*)

III. **Why are we here?** Three pics with short description of people achieving their dreams.

IV. Interview Experiences

First interview activity: Brief breathing and reflecting visualization using object of significance as focus. Each participant will share their object and express why its meaningful to them with research assistant will do the same. Research assistant will record their reasoning via written form. (*If person with disability is nonverbal than research collaborator will engage with object with person with disability and explore its textures, colours and record person's facial expressions and body language. Research collaborator will be asked to not interpret but to personally reflect on their engagement with the object and the person that is non-verbal.*)

Second interview activity: *Group Thinking/Discussion about Strengths:*

- What are strengths?
- People who use their strengths are more likely to ...
- What are blessings, accomplishments, talents and gifts

Pairs will fill out a fun sheet together about what the individual has to say about above.

Third interview activity: Abstract art piece - Using pastels and paper, pairs will create an image with specific ideas on how interviewee would like contribute to their community while taking in consideration their strengths.

V. **Gratitude Circle** Closing circle ritual

APPENDIX D

Participation in Explore Dreams Consent Form

You are being asked to participate in a research study, called *Explore Dreams*. This is a research study project partnership between The Community Oak Park and Oak Park Neighbourhood Centre. The principal researcher Heryka Miranda; and principal researcher supervisor, Michelle Knoll, Director of Oak Park Neighbourhood Center can be reached at (905) 257 6029 ext. 1., and emails are: heryka@opnc.ca and michelle@opnc.ca to answer all of your questions.

Your participation is entirely voluntary. If you decide to participate, you are free to withdraw your participation at any time during the study without any adverse consequences from Oak Park Neighbourhood Centre or The Community Oak Park.

By signing, you give consent to participate in *Explore Dreams*:

- Consisting of a two-hour interview experience that will include traditional interview style methods and artmaking activities that can help express your daughter/son personal aspirations and ideas on how she/he/they would like to contribute to their community.
- All data collected will be through written observations by research assistants or principal researcher, audio recordings and photographs of any artwork and possibly your hands creating the artwork.
- There are no immediate risks for you to participate. Our intention is to make the interview experience as safe, friendly and accessible as possible.
- The letter of invitation provides you with more details of the project. Please read before signing consent form.

Consent Form Signature Page

Please sign below. There is also a space for your parent or legal guardian to sign who is aware of what is expected and is supporting you in reading the consent form and letter of invitation. There is also a space for me to sign, so we are all on the same page! If you need more space to sign, please use the back of this page 😊

Printed Name of Participant: _____

Age: _____

Participant Signature: _____

Date: _____

Signature: _____

Parent/Guardian

Printed Name: _____

Parent/Guardian

Date: _____

Signature: _____

Oak Park Neighbourhood Centre and The Community Oak Park Principal Researcher

Printed Name: _____

Oak Park Neighbourhood Centre and The Community Oak Park Principal Researcher

Date: _____