THE SOCIAL INCLUSION OF ONTARIANS WITH DEVELOPMENTAL DISABILITIES

PICTURE THIS:

BENJAMIN (not his real name) is in his early 20s and has a developmental disability and epilepsy with regular seizures. Recently he has moved from his mother's home to live more independently. Most of his support comes from family members and his church community.

Benjamin said: "I want to get together with all the residents here sometime. I want to meet everybody and then socialize. I enjoy trying new things as well and I am pretty good at sports. Every time I look in the mirror I compliment myself for all the wonderful things I've been able to do. When making decisions, people encourage me to weigh up the pros and cons rather than just deciding on the spot. But, I find it hard when I agree to one thing and then something else comes up that I like too. That really throws me off course."

Benjamin's mother added: "I need to keep abreast of what he's doing just to make sure that he is managing by himself. The church is a very good group for him, people are a bit older, but that are supportive. He has got fantastic memory and would know a decimal system right down to the n^{th} degree, but there is no job using that skill. But, when he's upset and is trying to tell you about it, his reporting can get very confused. You can put something in three different ways with Benjamin and you'll get three different answers. In relationships he gets very frustrated with some friends who have a speech problem, especially girls that speak softly. He really wants a relationship with a girl and that just doesn't seem to happen. He's polite and kind but girls at his level don't seem to interest him. He is attracted to the people that are running the special sports programs, not those participating. Of course, they are not interested in him."

Benjamin's brother: "I think Ben is happy. Unfortunately, he is limited in his choices. He really wants to find a companion, a girlfriend. I think that he has unrealistic expectations about finding someone. He wants to be with people who are not disabled. Finding someone is not easy for anyone, so, it must be that much more difficult for him."

A friend said: "Sometimes, Benjamin would say, *'I like to be with regular people. I know I've got a developmental disability and I'm epileptic, but I'm a regular person too.'* He needs more stimulating conversation sometimes. He is always trying to find ways to meet new people. If you look at the list, he has bowling, swimming, skiing, epileptic meetings, church and so on, which is why he is where he is today. He is certainly very good at sports and comes back with medals after competitions. You know what, I actually need him just as much as he needs us. He makes me realize that I'm a worthy person too. He brings out the good in people, because he's pretty open and upfront. By him being himself, he gets respect and the rest of us don't need to hide behind some façade."

PICTURE THIS:

BRENDA and MARK (not their real names) are both working fulltime. They have three sons. **EWAN** (not his real name), the middle son, is in his early 20s and has a developmental disability. Most of his social activities were set up by his parents whom he lives with. Brenda and Mark want Ewan to reach his potential and be as independent as possible.

Brenda said: “I knew what I was getting into as I had an uncle who was ‘mentally challenged’. My great-grandfather was embarrassed of him and I watched them being stuck with him. So, when I had Ewan we knew that we had to make sure that we wouldn’t be in the same position. You are a bit of everything, a parent, a care provider, a social worker, a social events coordinator, an advocate and so on. Once he finished school, there was nothing suitable for him to join. There are programs, but many school leavers with a developmental disability are either too high or too low functioning and the programs just don’t fit them.

Ewan can’t be left alone as he has no sense of safety. He could walk out or burn the house down. But, he doesn’t need a lot of physical care and now he is pretty easy going. He used to be ‘quite psychotic’, sitting in a corner in his own little world. No one could go near him. It was worse after we moved house. Finally, I gave up and just let him be. He ended up moving his furniture and arranging his room exactly like it was in the old house. Then he started to settle. Because he is non-verbal, he couldn’t tell you. I learned from that and we all realized that it is OK to sometimes get mad. You do that with normal people and if your son or daughter is intellectually disabled, they push all your buttons. So it’s OK to get mad or to cry. It took us a long time to accept that. You can lose it and then you feel guilty for days in a way you wouldn’t necessarily with anyone else. We didn’t talk about that for a long time and it was hard on everyone, his siblings too.

With anyone who has a developmental disability, if they don’t use skills they lose them pretty quickly. They may gain certain abilities with maths, writing, social skills, even independent living skills, but they are going to lose these quickly. So, as a parent it is expensive to get them to a certain level. You have to go through hell but once Ewan gets it, he gets it. We won’t live for ever and he needs some level of independence, whatever that might be. When he was little I thought it was really important that he was toilet trained and that he could dress himself. Now we are working on cooking. He is really good at cooking and because he has an Obsessive Compulsive Disorder, he is paying attention to every little detail.

We are getting older and he is getting older. So, I am trying to push him more. I know he is not getting a place in a group home for a long time because he is not an emergency. At the end of the day, Ewan has to live like everybody else in society, whatever that might be. At the same time, we also have to survive as a family.”

PICTURE THIS:

NEIL and JACKIE (not their real names) are parents of two adult dependents with intellectual and developmental disabilities, **LUKE and ANGELA** (not their real names). They have finished school and there are no suitable jobs or opportunities for further studies. For their parents it is getting more and more difficult to have a social life, their energy levels are low and they feel discouraged. As they are getting older, they need more help.

Neil and Jackie said: "We have to say the High School students were great with our son Luke. They were very understanding and accommodating. The culture has changed for the better over the years. Some of the others even took on sign language. But in the end they get their own rhythm even if they don't talk. Some don't need to speak to each other, they put their arms around each other or hold hands and that's their method of communication.

Some parents seem too embarrassed to take their disabled son or daughter to the beach with everybody else, but we think that's OK. We also organize outdoor activities and always had a few disabled adults in the group. Sometimes they participate, sometimes they don't. When doing sports, even though it is all inclusive and they might use a soft ball for safety reasons. We found that some adults with developmental disabilities were too high functioning with others being left out. So, we created lower functioning and higher functioning teams to keep everyone happy.

We know many parents whose children have an intellectual or developmental disability. There is Matt for example and nobody knows that he has Autism until he opens his mouth. He's very good looking and when he walks into a room, everyone just loves him. In comparison, others are just a little slower than everyone else or they have to wear a helmet or they walk funny. So, you know straightaway that they are 'different' and then people are more accepting of any weird behaviour. But, if Matt acts strange they wonder what he is doing. It is hard to find 'normal' people who will spend time with those who are disabled and help them have a better life. Having said that, the building where our daughter Angela, goes for day care also hosts a small IT company. So, they get to know the other visitors and when they have a party, they are including them.

Despite some progress, there are still people who make bad comments. We have to educate them as they don't know any better. People with developmental disabilities can be noisy, some walk or talk funny. People get offended or they stare. Society is still like that and we only like to think that it is changing. Parents have to be realistic too. Sometimes we hear them say their child has a right to take part in an activity, even though they are not able to do it and wreck it for everybody else. That's not fair either."

PICTURE THIS

OLIVER (not his real name) is nearly 30 years old. He lives with his parents and brother. Since graduating from High School he has tried a range of low-skilled jobs at large retail units. However, to date no employer has hired him. His parents want him to be as independent as possible.

Oliver's mother explained: "He participated in an ODSP program where employers allow access to their businesses for unpaid work experience. His first placement was with a newly opened retailer. Everyone was new and didn't have time to support Oliver. He was asked to stock shelves which he hated. It didn't work out and he lasted only 3 weeks. Eventually he got a 2nd chance. They put him in a large chain store, but again, he wasn't thriving. In an environment with lots of customers he gets busy talking and not focusing on his job. As a result he was declared 'unemployable'. They closed his file and that was it. I confronted them, *'Just because he might be unemployable in a store, doesn't mean he is unemployable. It just means that's the wrong environment for him.'* In response they put him in yet another store. He also tried to work at the company which employs his dad, helping to compress paper for recycling. He was constantly asking his dad for help and was too easily distracted. One of his best jobs was in a small store, where we lived before. It made a difference that the manager took Oliver under her wings, kept an eye on him and made sure that he stayed on task. When he applies for work, he gets ignored. He put in his resume for a job at a large retailer. He waited and went back regularly to check on progress. Finally, they said, *'Oh, we don't handle paper resumes. You have to apply online*.' He came home and we did it again online. He waited and waited, nothing happened, then they said: *'Oh, we're not hiring right now.'* In the meantime, you could see new employees on the floor. He waited for 2 years and now they have conveniently lost his file. It seems like discrimination by neglect. We are just treading water, getting nowhere at all. Things aren't any different today than they were 4 years ago. He doesn't know where to turn to and we're not getting any younger."

Oliver described his search for work: "My first job was on work experience. I did cleaning, sweep the floor, vacuum, help unload the truck, take out garbage and flatten boxes. It's just a lot of stuff. I keep forgetting my timeframe and lose track of what I'm doing. I got complaints, people ask where things are. I couldn't understand what I was supposed to do. I couldn't find anyone to help me. I did a paper route for about 9 or 10 years. Dad drove our van and I delivered the papers. At Christmas I got treats from the families. One gave me a little envelope with a card and a little money saying, *'thank you for all the hard work.'* That was good. Then we moved."

"Well, there is this store. It's an easy walk over from the house instead of waiting for my parents to drive me. I see that they are so lousy with their shopping carts. Customers come and there are no carts around. It's better to reload them every time. That's what I want to do. But, they lost my resume. I don't like doing it twice. I couldn't get through on their internet site and my mom had to help me. I still haven't had a reply. It's hard finding something that would work. Hopefully, by trying, I will get a job. Hopefully they reply and ask me to work for them. Why is it like this? Next Friday I'm going to be 29 and I'm still waiting to find work."

PICTURE THIS:

VERONICA (not her real name) is in her mid-thirties and has a developmental disability. This affects her judgement in social situations and her ability to complete complex tasks. Her scope for choices and community engagement is relatively broad. She manages to live independently. She holds low skilled, paid and voluntary jobs. Veronica enjoys socializing with friends, eating out, and shopping.

Veronica: "I used to be a skier, but now I just do bowling and baseball. Sometimes I sit and watch TV. I love having a job and family. The workers help me with choosing the right healthy relationships with guys. Well, they just basically say, 'ok, Veronica, this is not the way to go' and they sort of direct me away from the guy. I've had guys take advantage of my money and so they steer me in the right direction and then I see it for myself.

My work is just doing dishes. You go in, you see if there's dishes to be put away, you go out and clean up the lobby and then do more dishes, or sweep. The other job, I just clean. It's a routine. I clean the windows and then vacuuming and then cleaning the toilets and then I do the garbage and then I dust and sanitize the light switches. So, there's really no choice to be made. You clean and then you go. Then I got into a job and I quit that because one assistant manager was making fun of me, he was teasing me.

My plan is to go on a vacation and own my own pet. I've had a couple of hamsters and they've died on me. I also like to go to the movies with my friends, go shopping or go on a little trip with them, say the Zoo or the Fair, that's my favourite.

Budgeting with the money, that's a really big thing. Mom helps me budget my money and she says, 'ok, well, you can't take out extra money this week because you don't have it'. If I have only a little bit of money, if my friends want to go out for a coffee, then I don't. I don't ask to borrow money. If I don't have it, then I don't have it. That's what mom's theory is. If you spend all your money in one day then you don't have it you know. So, you have to wait till Monday. I try to save money, like the long weekend is coming up, so I'll probably have a little bit of money but not a lot."

Veronica's mother: "I think she'll be fine. She's always had good jobs but what she brings to a job makes it good as well. She brings her happy personality and that makes the work environment a lot easier for everybody. She can be a very good worker if she knows exactly what the job is that you want done. Veronica has given us a lot. We had her involved in Sport at a young age and with that she took us to exciting places. That broadened our world.

She's a very caring person. I help with her banking. She asked me to go on as a co-signer on her bank because she's had people that ask her for money. She's very easy going and kind and if somebody asks her for money she'll go to the bank with them. So, she got into a situation and realized that she wasn't very good at saying 'no'. I will also encourage her in different ways to try to get her to eat healthy. We go shopping for groceries and she picks what she wants. She's got very good people skills. She enjoys being with people and that is one of her big strengths. She's kind to a point that sometimes she is too kind."

PICTURE THIS:

DENIS (not his real name) is in his 40s. He shares a home with caregivers and two other adults who also have intellectual disabilities. This living arrangement was set up by his older sister last year. Denis has been working in a local Café for several years now. He is being paid the minimum wage. Being able to work and interact with other people makes him feel useful and happy.

His sister reported: “I really care about him getting up and having self-worth. Having a place to go every day makes him feel good about himself. So, that is mainly the reason I want him to work. They gave him the minimum wage right from the beginning. They notice that he is doing a good job and the manager likes his positive personality”.

“When he was preparing to leave High School, he was offered some help. So, we organized a career planning session with him. We gathered his friends, workers, tutors and family. Together with Denis we then came up with ideas for what a career tree might look like in terms of his interests, matching his strengths with possible options in the community. At the time, he was really keen on doing something with children. Then someone suggested a food prep course to him. He did that and really enjoyed it. They did have work placements to choose from and he went for an interview, just like going for any proper job interview”.

“Now he is working in the Café. From an early age he has always been very helpful with clearing the table and wanting to set the table. He has always been in awe of food. So, we found a local place for him to work and that started out with a few hours a week. Now they’ve agreed to have him in every morning, from Monday to Friday, from nine to eleven. We have a community coordinator who meets with the Café manager to review his work, looking at his strengths, opportunities and generally how things are going. They are very happy with Denis' work. Customers also get to know him and appreciate him.”

Denis added: “I go to work. I meet people, new people. And then, they come for a cup of coffee or nice cake. We have nice stuff like that. I get paid. Everyone is great.”

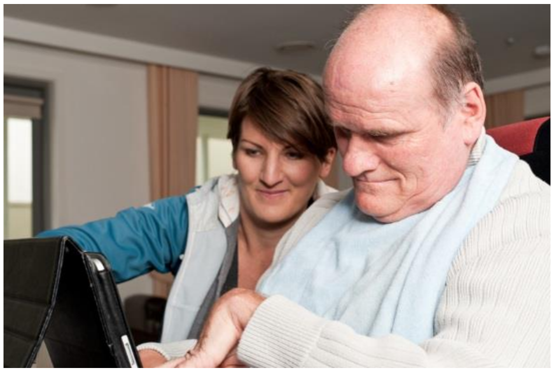
PICTURE THIS:

NATHAN (not his real name) is in his 40s and lives at home with his parents. He got tired of spending his days at home playing computer games and watching TV. A month ago he started a voluntary job at a not-for-profit community center which offers assistance to people who are differently abled. He works two hours per day, twice a week. It is a small and friendly place. Going to work makes Nathan feel positive about himself. At the same time, when he doesn't understand the process, he struggles.

Nathan reported "Nothing to do every day, I'm bored and I want to go out. So, my friend knows my boss, they are related. And then he told him that I am looking for a job. He's so nice. He found work for me. He talked for me and then I went for interview and I got a job. Where I work, they are all on disability, like me. Sometimes we vacuum, clean the windows if it needs cleaning or floors, we sweep the floor. I see people come in the store and buy clothes. They're nice people. Sometimes I see them at the bus station. Everybody goes, *'good morning Nathan, how are you doing today?'*"

His mom described some of the challenges: "Nathan has had some interesting experiences trying to fit in at this job. One day he took an hour long lunch break like everybody else. He got into all kinds of trouble over it. He didn't realize that he just gets a coffee break. Another time, he couldn't find the broom to sweep the parking lot. He got really irritated. So, he went into a store, selected a broom and went to the cash and paid for it. He got his money back from his boss who was a bit amazed. I wasn't surprised, but Nathan does stuff like that. He needs a clear structure and well-defined procedures. He likes this job, he runs into many people. They say *'hi'* to him. There are some cool female workers too and he likes that".

"Before that, he had tried a fully funded program to learn how to be a cook, an institutional type of cook. Unfortunately, Nathan is very slow and methodical in the kitchen and for that kind of work you have to be kind of fast. Once, he also didn't show up for work. His boss didn't call us because they wanted him to be responsible. So, in the end that didn't work out and he ended up being failed in the program. He then tried an unpaid job in a shop. That was longer hours and he did a good job. But, it was a lot of lifting and we just felt they were somewhat taking advantage of him. They wouldn't even offer giving him the money to cover his bus fare. I just thought that was a bit insensitive. I was even thinking of giving him an envelope with some money in it myself and just write *'job well done, thank you Nathan'* on it. So, that place didn't have a good attitude. Where he is now, he doesn't get a salary either, but they pay his expenses and treat him with respect. That makes all the difference."



PICTURE THIS:

PATRICIA and WILLIAM (not their real names) are retired. They live in a rural part of Ontario. Their son **ANTHONY** (not his real name) who is in his early 50s has a developmental disability. Anthony has an older brother and younger sister who live far away. His parents have always taken responsibility for his care. Following fifteen years in group homes, he moved to a long term care facility where he is benefiting from the social activities offered.

Patricia and William shared: "Anthony is non-verbal and very dependent. He needs a power chair, he doesn't walk and he doesn't talk. He uses a bliss board and a talker for communication. But he needs people who will listen to him. He is pointing to visuals and trying to say something. He can't sequence and things get mixed up. Unless you really know him or take time, everything falls apart. It's very difficult. The first time Anthony moved out of our home was when we were both working. We thought it would be best for him to settle into a place, make friends and stay there. When he was growing up, he went to a special children's centre, then to a school for *'retarded children'* and then to another school for *'handicapped people'*. He graduated at twenty-one. Until he was thirty-three years old, he attended a workshop which ended when he moved to another residence. Transportation was a problem as he has to be driven everywhere. So, now he hasn't been in a workshop for fifteen years.

He has a life but it is a lot of hard work for us. The last place he lived at wasn't right. It led to a big crisis and we had to take him out. But we really can't cope with him at home any more. We can't lift him and there are stairs. In the end, out of desperation, we put him in this long term care home. The place came up and the rest is history. Quite honestly, I thought this was a drastic measure to put someone his age into a long term care facility, but he has really adjusted well. They are all moms, dads, grandmas and grandpas to him and I am so happy for him. One fellow was a paraplegic who had been a schoolteacher and was only in his 60s. He befriended Anthony and was really keen on learning how his language worked. Unfortunately, then he died. That's a downside of living in a care home when you are young. Anthony took that really hard.

They do look after him. He is always clean and with the help of a dietician he lost the weight he doesn't need. It is quite a big place and they are kept pretty busy with social activities. For instance, once a month they celebrate all the birthdays; a lady and her dog visit; they do baking, making cookies; they have Bingo and music and on weekends there is church. A physiotherapist gets them up and moving which is very necessary. The downside is that people with Alzheimer's are also living with all the others. Sometimes, they tend to wander into rooms and take things, creating chaos. Anthony's roommate is in his 80s and they got to know each other quite well. He ties Anthony's bib and in turn Anthony gets chips from a vending machine. So, they help each other. He has some choices and Anthony likes to sleep in and not eat breakfast. He gets annoyed though that they come and shut his TV off at ten in the evening. Unfortunately, he lost the ability to dress and undress himself because there isn't enough space on the floor for him to do that."

PICTURE THIS:

LIAM (not his real name) is in his 50s. He has a developmental disability and limited verbal communication skills. He lives with two roommates and paid support staff in a home. This was set up and is managed by his parents. Liam has an unpaid job and is receiving funding for residential support and person-directed planning.

Liam's mother explained the situation: "Liam doesn't have a lot to say, but one thing that impressed everyone at a recent meeting was that we asked him to introduce the people. He had to say the name of each person and he knew all the names. We all got a good chuckle when he called Bill *'Billy'*.
As his parents, we are very involved in managing his care. We are so lucky that we live in a city big enough with a lot of options for him. Even though we are retired, until recently we still had a dependant living at home and we still have financial responsibilities for him. We didn't complain, but we didn't have a choice either. He is our son and we love him. Now that he isn't living with us anymore, it's weird. We are still really involved in his day to day life – maybe even more than when he was living with us.

Liam is very good at some things. For example, he would always run ahead of me because he's a much faster runner than I am. It used to scare me because I was afraid he would run out onto the street. We talked to him a lot about safety, and what could happen if he wasn't careful – you can't goof around near a busy street. Now, whenever he gets to the corner of an intersection, he stops running and waits for me to catch up. Then we cross together, and then he starts running to the next intersection. So, that's a choice he makes now for his own safety.

We really support the fact that he likes physical activity and that he is also good at it. We bought the new bicycle last year. We've also got this basketball net and hoop in our yard and got a basketball pump. So, they're all good things he is able to do and really loves doing.

For the last couple of years I have been thinking about how Liam has this great circle of support. We, as his parents, now need to do a little bit of a formal thing to get all of this support focused on him to help him live as independently as possible. To begin with, I was kind of dubious about spending time teaching Liam about computers and yet quite a few other people were adamant about the computer angle. I am glad that they persevered, so much so that they now have me going out to buy an iPad for Liam. So, I think the collaboration of having everyone's input into what they see as a necessary part of his world is really important."

One of Liam's support workers added: "His parents are advocates but don't force him. They also never leave him in a situation he is experiencing as uncomfortable. Liam is very intuitive although he doesn't say much. He does not like a lot of busy noise and he is a very orderly guy. You have to listen carefully as he speaks very quietly. It takes some adjustment to allow him to come out with what he wants to say. Don't underestimate him though, as he understands more than you think he does. To know what Liam is communicating, you have to know him."

PICTURE THIS:

HANNAH (not her real name) is in her mid-fifties. Measles at age seven left her with a developmental disability and limited verbal language skills. Recently she moved from an institution to a home in the community where she lives with roommates and receives 24 hour support. Hannah's sister visits regularly, she is a few years older and has been involved in looking after her for most of her life. Because of her lack of language communication skills, efforts to determine what Hannah likes or dislikes are based on trial and error. Everyone is trying their best.

Members of Hannah's family and care team: "Hannah moved here from her old institution which had closed. We had to get to know her step by step. Slowly we figured out what she is able to do. When she moved here, the first three years were hard about everything, like medication, food, toileting, and sleeping. All these habits had to be figured out.

At times it is hard because Hannah is in her fifties but in her mind she is not. Her set up now is more intimate and we can give her enough attention. The biggest thing is the interaction - getting her out into the community and letting her experience different things to figure out what she likes.

She is non-verbal and communicates in different ways. It's a guessing game and we try new things to see what is possible. Planning is hard unless you have really gotten to know her. It is good to welcome new people on the team who know of different things to do. Somebody said, 'you know Hannah likes to walk and touch things', let's go to a butterfly park'. It is about taking other people's input to enhance her daily activities. Especially for someone like Hannah who doesn't have a day program. It is important to give her day some meaning and provide opportunities for her to get out in the community.

We get cues. We try things a few times and find out what she likes or doesn't like. You really need to observe her. We tried horseback riding because apparently, that used to be very important to her as a child but not so much now. We know that she loves her showers. So, we let her lounge in there a bit longer. She likes swimming so much, that it can take twenty minutes to get her out of the water. So, we have taken her to water building creation, which is a huge whirlpool and she loves it. We find out about these things. We also know what foods she likes and we try to give her all those. From knowing her and knowing what she enjoys we make plans to give her happiness and joy.

At other times we are trying to get her in the van to go somewhere and she is resisting. If she doesn't want to go, her feet are planted firmly on the ground. That is her way of telling you that she doesn't want to go. So, as long as it is not essential, why force her? When she wants to go for a walk, she shakes the door. But she needs staff to go with her, which is not always feasible. So, as a group we have to make some choices for her which is based on safety or her physical health."