

**PACFOLD Focus Groups –
Highlights from Discussions**

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Table of Contents

Adults with Learning Disabilities	1
Participants	1
Diagnoses	1
Experiences in School	3
Experiences with Work	4
Impact on Family	6
Additional Comments	6

ADULTS WITH LEARNING DISABILITIES

PARTICIPANTS

In attendance: 6 participants

DIAGNOSES

I had a rather tumultuous primary school experience and the school did not want me to go on to high school. My mother fought for me and I did go to a regular high school and ended up in a regular English class. One day I had to read Shakespeare and write about it. The next day my teacher asked me a bunch of questions about what I had read. He said that it was obvious that I'd read the book but that what I submitted in writing didn't make any sense. At the same time, my mother heard about a group at the Royal Ottawa that was starting to look into learning difficulties. Between the two of them, they hooked me up with people there and I went through psychometric testing. It was a great relief to find out that I wasn't stupid or lazy. It was great to have something to put around all of this noise in my life (why I wasn't doing as well as everyone else and why I had been getting into trouble). The diagnosis didn't make a big difference in high school because people there didn't know what to do with me. It made a bigger impact on my university career because people there were more aware of learning disabilities.

My diagnosis was a good experience for me. I had dropped out of high school at 15 and only went back to law school as a mature student. I knew then that I had some processing difficulties, but I had learned how to adapt. I bumped into a neuropsychologist through my contact with LDAC. She assessed me and identified my processing issues. She played a pivotal role in communicating with the law school and the Law Society in terms of the licensing exams that I had to take. I did law school in four years instead of three. I was the only student in my year without a university degree. It was really good to have that diagnosis because it allowed me to put the pieces together. Before my diagnosis I knew on some level that I had learning disabilities because it is in my family.

I was diagnosed at 45 as a result of having my son identified when he was in grade one. I had developed coping skills throughout my life. I did a Bachelor of Commerce without knowing that I had learning disabilities. The diagnosis just brought things together in my mind.

Now I can pass onto my son my own experiences and knowledge. I did what I did through sheer determination.

I was diagnosed as an adult when I moved from the U.S. to Canada to go to university. My schooling in the U.S. was in an alternative school, so even though I knew I couldn't spell it didn't keep me from passing because the school focused on other areas that I excelled at. When I went to university, I hit a brick wall. The amount of effort I was putting into studying wasn't paying off. The teacher would say that I understood when I verbalized but that I couldn't write it down. I made friends quickly with graduate students who would review my papers. One graduate student suggested that I might have dyslexia and put me in touch with a psychiatrist who happened to be doing a study on learning disabilities. I was able to have an initial quick assessment as part of this research project. The diagnosis kept me in university because I was able to access services. It was a great relief to be diagnosed because I always knew that there was something different about me.

My diagnosis happened in two tiers. I was identified as a young adult. I'm the poster boy for falling through the cracks in the public education system. I was treated as a problem child in the school system. My own self-advocacy helped me to get a diagnosis. In a grade seven math class I realized that my difficulties couldn't be because I wasn't trying or because I was stupid. I never graduated from high school. It's turned into a point of pride for me because I've done well without graduating. I spent the early part of my 20s trying to figure out what was wrong and how to get the help that I needed. The John Howard Society was running a youth employment centre, and someone there suggested that I might want to look into learning disabilities. At 24 I began screening and was identified. I did nothing with it then. I thought it was just another label and I didn't have the maturity to understand what the implications of my diagnosis were. So I continued unsuccessfully to pursue post-secondary education as a mature student. After three years of trying and only one successful course, I had a fit and said that something was wrong and I wasn't getting the help I needed. They gave me a proper assessment then that again indicated learning disabilities and ADHD. I had gone down the timeline far enough and felt enough suffering due to underachievement and chronic failure that that experience provided just the right mixture to allow for a fresh start.

I was diagnosed when I was very young. My father was a senior educator in the community I lived in and my mother was a retired

nurse. She became my advocate. I was diagnosed then, and interestingly the doctor who diagnosed me then was the same doctor who diagnosed me five years ago when I was starting an MBA program. The latter diagnosis was a mixed blessing because the doctor got a copy of my original report from 1976. None of the recommendations he had made then had been followed through on. He said that it was a shame that the system had failed me. Even though I had had an assessment, the system wasn't able to provide me with what I needed.

I had to find the money to pay for my first assessment. I managed to get the funds for my assessment through a network that I was involved with. When I was 22 or 23, I was on social assistance and I begged for some help and was rejected. I wonder if money wasn't one reason for that rejection.

It would have been better if the assessment hadn't been done at the local psychiatric hospital. That isn't the case today, but it made it difficult then.

I was scared about what would happen if the assessment said that I didn't have a learning disability but something else instead. I have that fear every time I'm assessed.

The issue is the implementation of the recommendations from the assessment. My last assessment (before I started my MBA) cost me \$4,000, and very few of the recommendations were implemented. The school picked and chose the things they wanted to do for me.

EXPERIENCES IN SCHOOL

I was identified as a problem when I was in school. That put the focus on correcting my behaviours rather than meeting my needs. That haunted me throughout my academic career in the public education system. If you're told frequently enough over a long enough period of time that you don't try, that you don't care, that you're lazy and a brat and bad, you believe it. By 12 or 13 I had completely bought into the notion that it was my fault, and I started to behave accordingly. So for me, that literally cost me a decade. No one ever sat down and asked me why I was having a hard time. A teacher's idea of help was to force me to stay in after school and over lunch to do school work, but with no help. It was always a punishment. This profoundly affected my relationship to learning. School became prison and teachers became prison guards. That feeling is still there to this day.

I had huge problems at law school. The prevailing thinking was that the faculty knew how to teach law. They weren't willing to look at what my needs were. Part of the problem was that there is a stereotype that legal knowledge supercedes all else. I'm also fairly articulate and I write quite well. The difficulty is in how I process information. The coping strategies that I had developed earlier in my life didn't work for me in law school.

I spent a lot of time in high school visiting the guidance counselors. They weren't much help. And when you fail with them, they put you in the class with all the kids they think will go to technical school. They sort of give up on you. I did go to high school and I did do fairly well. They intentionally failed me in one of my English classes. Did they think that that would motivate me? They had no concept of what to do to help me. There was still little understanding when I went to university, although there was some tolerance. When I did my Masters in the mid-80s, there were programs in place.

Public school was a bad fit for me. I was like the square peg in the round hole. My university experience was completely different. I had developed coping strategies that helped me, and there was a program there for people with learning disabilities. I had all my success after high school. Public school was a nightmare for me — socially as well as academically. If you're the dumb kid in the classroom, then you're the dumb kid on the playground.

Public school was very difficult because there was no understanding of what learning disabilities are. I spent time with resource teachers. I had to repeat grade three twice. I just managed to finish high school, and my grades were only just acceptable enough to get into university. It was in university that a life change occurred. I enjoyed what I was doing and the classes that I was taking. There were difficulties because I hadn't been diagnosed. I graduated with my class. University was the best time in my life. I enjoyed learning there because I was in an environment where I wasn't looked upon differently. What people brought to the class wasn't questioned; it was valued.

I was in regular schooling until third grade and I received resource help. I had to keep going to this room with different teachers and they worked on things like my hearing or my speech. My parents said that the problem was with the school, not with me, and they moved me to an alternative school. I blossomed there because there weren't the

same barriers. It was open-concept and you progressed at your own level. Teachers were facilitators rather than guards. I still had difficulties though. I had a lot of anxiety and fear of failure. My high school was also alternative. University was a big eye-opener. I was assessed at university. That assessment put the focus on my learning disability, not on me. But even though I had the assessment, there were no services available to me. I had the label, but I didn't know what to do with it. At the Masters' level the focus is on keeping you in school and helping you to graduate. It was there that I started to access the services that I needed.

Because people with learning disabilities are given a lot of support in the different school settings, their sense of what they can do in an academic environment is inflated. When they leave a school setting, those supports are gone. That can be devastating. There is also no transition training.

EXPERIENCES WITH WORK

I have difficulties in the work place. Open-concept offices are terrible for someone with ADHD. When I was first diagnosed, I was in a great group and I trusted my boss enough to tell him what was going on. The person who replaced him was not so understanding. I subsequently left that group. It took me a while to build up trust with my current boss to disclose my learning disability to her.

Often when I made a request for an accommodation, it was seen as an excuse. That wasn't the case for my colleagues with other types of more visible disabilities. There is still a lot of prejudice and discrimination.

People just don't understand what learning disabilities are.

The question of language rights in the public service is a serious one. I keep winning competitions but I can't get the job because I'm not bilingual. If employment equity is going to work, we have to deal with some of the sacred cows in the federal public service. We have to balance the competing rights between employment equity and bilingualism. There is no willingness to address that. I've raised this issue repeatedly. This raises barriers for people with learning disabilities as well as other designated groups like Aboriginal peoples.

The *Nancy Green* decision means that government groups have to assess and provide adaptive language training. That doesn't mean much.

The competitive process itself in the public service is another challenge. The people who administer the tests don't understand people's special needs.

I keep fighting and threatening to file a human rights complaint.

It's more difficult to get into the public service than it is to fight once you're in it.

You can have managers who understand and who want to accommodate you, but with the vast majority, it's just the opposite.

I've learned to deal with an open-concept office. If it gets too noisy, I take a break.

Staffing has been problematic for me. I've hidden my learning disability. I can't learn a second language. I've weaved my way through my career so that I haven't been threatened to have to expose myself as not being able to learn a second language. I've decided that I'm going to be an advocate in the last five years of my career. I applied for a position and got a letter that said I had to take a test. I called the staffing officer and told her I had a learning disability. She didn't know what to do. She told me I didn't have to take the test and then she sent me a form that asked me to describe how my learning disability affects me. The form was very difficult to fill out; it was a barrier in itself.

Having to learn a second language is another barrier to me. I can't get through the tests.

You can get an exemption from taking the language tests, but the exemption is only for the position. You have to apply for an exemption each time you apply for a new position. You have to wonder if a manager will be even bothered to go through the process.

In my work, I constantly have to manage my disabilities at work. It's exhausting. I don't disclose at work but I choose the type of job I do and type of working environment I'm in. I'm very selective.

An informal support network exists among people with learning disabilities. We help each other.

You have to manage your managers at work. You have to say to them, "This is what I can do for you, and this is what I can't do for you." Computers really help in the work place. I had to write an exam to become a manager in the public service. I self-declared to the adjudicator before the test. I had to push to re-write the test. I recently failed another exam and I took them through the appeals process because they didn't accommodate me. It took two years and a lot of energy. There was a feeling among people where I worked that I didn't really have a learning disability and that I was faking it.

Your success at work shouldn't be dependent on your boss and your boss's attitudes. There should be some standards.

IMPACT ON FAMILY

I'm divorced. My current wife is quite understanding of me. She knows when I haven't taken my medication. Our awareness of each other provides us with the capacity to live with each other.

I have an outstanding partner, but I think it must be exhausting for her. Her work day doesn't end when she comes home. She has to help me with my work when she comes home at night.

My partner is an academic and she has been wonderful in supporting me through law school.

I have a very different attitude towards learning than my wife does. I don't want my kids to use their learning disabilities as a crutch. You can manage quite well with a learning disability, and I want my kids to know that.

It's hard to manage my family life. I have to structure my daughter's life, which is difficult, because I have to structure mine first. My tendency is to be unstructured, but then that affects her.

My nieces and nephews have been identified with learning disabilities. I'm a bit of a role model for them. I've also helped my brother deal with his children better. It's good that I've been able to help other family members deal with learning disabilities.

The lack of identification of my learning disability made me a bit of a black sheep in my family. It had a profound impact on me. My extended family really judged me. I got involved with alcohol and drugs. Maybe if I had been diagnosed, these other secondary issues wouldn't have arisen.

My learning disability was devastating to every intimate relationship I had because I didn't know about my disability. People with ADHD can be very emotional. This can have a profound impact on your relationships. ADHD impacts every area of your life.

We all bring our frustrations home with us. It does spill over into our home lives.

ADDITIONAL COMMENTS

People don't understand what learning disabilities are. There is an advocacy requirement.

There is a hierarchy of disabilities. There are visible versus invisible disabilities. People also think that if you're smart you can't possibly have a learning disability.

People with learning disabilities aren't going away. We're going to university more. We're entering the work force more. We have to educate people in all areas about what it means to have a learning disability.