

**PACFOLD Focus Groups –
Highlights from Discussions**

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ADULTS WITH LEARNING DISABILITIES

PARTICIPANTS

In attendance: 7 participants

DIAGNOSES

I was diagnosed at university when I was 20 years old.

I was diagnosed in elementary school.

I was 39 years old when I was diagnosed.

I was diagnosed at university when I was 20 years old.

I was 27 years old when I was diagnosed.

I was 20 years old when I was diagnosed.

I was diagnosed in elementary school in the late 70s.

EXPERIENCES IN SCHOOL

I remember staying behind at recess and taking penmanship classes. I remember incidents where I would take the literal meaning of people's comments (raining cats and dogs). I recall being locked in lockers and bullied by classmates. I was very active with school activities and I remember teachers telling me it was ok if my work was not done because I was so involved with school activities, etc. So I learned at an early age to play that game. I still do it today.

Not being diagnosed early impacted on how I saw myself. I remember socially pulling back from individuals so that people wouldn't get to know the "real" me. I didn't want to expose myself. I didn't know what was wrong with me at the time. In grade school, I was the valedictorian; this created anxieties at trying to cover up the "real me." I did not want to be found out. "How could there be something wrong with me if I'm the valedictorian." Now, 20 years later and with a diagnosis, I am relieved and OK with myself and LD/ADHD.

I came from another province and no one in the education system knew about LD.

I went to a specialized class and was labelled stupid and "retarded." I was ostracized, had no friends and suffered high anxieties.

As a mom now, I had to make a decision about putting my son in segregated class and the impact this would have on him. Not being diagnosed early played a major role in my life. I remember report cards stating I could do better. I was always at principal's office or in the hallway at school. My mother overcompensated for me. I noticed this especially when I moved away from home. I was diagnosed as an adult and am very grateful I went through the experiences I did because I wouldn't be an effective advocate today without those experiences. I understand the challenges, frustrations and pain that individuals are going through.

My challenge comes with the social skills difficulties. I couldn't understand the concept of or read the time. These were big problem when I was growing up. Once I was diagnosed I received help to understand time, and I manage alright now.

I spent a lot of time writing exams and felt good about them when I was finished, only to find out I failed them because I missed a word in the question. Oral exams were much better for me. I remember comments from university professors when I disclosed. "You seem so intelligent!"

All my life I have had trouble getting into doors: education, employment, customer services, etc. because of my speech problems.

EXPERIENCES WITH WORK

Disclosure is difficult. It is hard to decide who to tell, when, where and why. It can also be used as an accommodation. The accommodations (requesting, finding out what kind you need, putting them into place) all fall on your shoulders. At the moment, no exterior accommodations are given by my employer. However, to keep up with the demand of report writing, I do a lot of work from home on my own time. This is difficult on my family life.

I do contract work and do not bill by the hour but by the job. With my time management difficulties, this is the only way it can work. I found it difficult to disclose in academia because I felt that once they knew of my LD, they treated me differently (the way they talked to me, their expectations of me, they "dummied" everything down for me).

My job allows me to set my own agenda and set the tone in my section. Deadlines are of my own choosing. I think longer term than my staff and I prepare ahead of time. I am able to think strategically and get things done on time.

In my undergraduate program, I took part in the first year of the Learning Task Force program and was able to learn a lot of strategies/technology. I have been fortunate in my work history because I have worked for agencies who are in the field of LD and are receptive to disclosure and accommodations.

I work in the education field and I always assumed they would be supportive and receptive to LD. I have found out differently. However, my sense of humour has helped in many situations. I am also very lucky that I is able to set my own agenda/timelines. The computer technology has also helped me and I am able to put everything on computer; this has helped enormously.

Only two people are advocating for people with LD in the military where I work. People still don't understand the need for accommodations at work. They develop the tests to match the job, design curricula to train, but do not create an accessible learning environment.

If you challenge professors/managers, then they challenge you. I never disclose at work; it was different at university. I have been fortunate that the jobs I've had have provided me with the control to set my own accommodations/timelines/agenda, etc. I have deliberately searched out opportunities that have provided this flexibility. I embrace technology. This helps me to be organized; however, the onus is on me to learn what's out there and how to use it in order for me to survive.

Whether it's at school or in the work place, using good teaching practices and good managerial skills will benefit everyone and will support the individual to reach his/her maximum potential.

Social workers and counselors need some training on understanding LD and what it is.

A tendency to procrastinate is affecting how I cope and deal with challenges/decisions. I have tried to change the internal dialogue from "should" to "could." I have forced myself to use the strategy of not making a decision right away; this has helped me. Negative self talk is

a huge problem for LD individuals because they already doubt their skills.

I was the first person in the family to make it to university. It was very important for me to get that piece of paper. I did get a lot of student loans out of it. The college avenue is more practical and hands on as opposed to core academics at university, where most of it is lectures and written assignments.

There is a longitudinal study from the Frosteg Centre in the U.S. that looks at what it takes to successful. The study has identified perseverance, self-awareness and goal setting.

I have never believed people who said I wouldn't make it. For me, the key was the family support I received. This also allowed me to make mistakes and to learn from them.

Family support is why I'm successful. I also attribute my success to self-awareness of my needs, of how I learn, the strategies I need to use, etc. This has taken me a long time to develop. Finding mentors I admire and learning how to accept both positive and negative feedback has also helped. I like to be around optimistic people.

Tenacity has helped to make me successful. I don't take no for an answer anymore. I think my success is due to perseverance, support from friends/family and knowing what works for me.

IMPACT ON FAMILY

My spouse sometimes gets it at a certain level. If I'm doing well in one area, she doesn't understand why I can't succeed in another area. She does not understand my weaknesses and how they impact on my day to day.

Time is a big problem. I understand that 60 seconds makes one minute, but I have difficulty in projecting the time I need to do things. This has caused major headaches in my life, especially as a mom managing a family schedule of activities/homework/appointments. I have no problem asking people to repeat themselves or to draw a diagram. I also find that I am not good with change (money). This causes a lot of anxiety.

My spouse went through a lot of turmoil during the first 10 years of our marriage. It was a living hell. I was almost at the point of being

kicked out of the military. Once I received my diagnosis, I understood how it impacted on me and what strategies I needed to put into place. It was a 380 degree turn and now I am a community leader. I could not have accomplished what I have without the support and encouragement of my spouse. When my family/siblings found out about the diagnosis, I received a lot of support from them.

Overall my family was very supportive. My mom noticed something was wrong and put me in an alternative school. I was the first in the family to be diagnosed with LD over fifteen years ago. Now, my two brothers have children with LD, and I act as a role model for them. My siblings are very supportive. My spouse could not understand about LD; she knew I did things differently, but did not get it. This had a major impact on the relationship and its break up. My daughter, who is now 11, has accepted the way I am. Overall, my family has been very supportive.

My sense of humour helps me through it. I feel that as a couple, we each balance each other out. I am a perfectionist with persistence and determination while my husband is a minimalist.

I have very supportive parents. My dad is a special education teacher and had difficulties in not being able to help me. My parents were always advocating on my behalf. The lack of understanding from teachers was overwhelming. I am now engaged to be married in November. My fiancée is aware of my LD and I am educating her about the impact LD has on my day-to-day activities.

Spouses don't understand the amount of effort needed to stay on track and the amount of energy needed to organize a family and a home.

Not having an early diagnosis met that I needed to have a plan A, B and C at all times; this caused many anxieties.