PACFOLD Focus Groups – Highlights from Discussions

Winnipeg, Manitoba

November 7, 2005

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YOUNG ADULTS WITH LEARNING DISABILITIES

PARTICIPANTS

In attendance: 7 participants

DIAGNOSES

I didn’t know that I had a learning disability until I was older; I just assumed that I was stupid and didn’t get things quickly.

I didn’t know I had a learning disability until I was 21. I couldn’t figure out why everyone else could get higher marks than I could.

I was diagnosed in school, but the teachers didn’t believe it. They thought I was just lazy. I felt stupid and began to think that the teachers were right. It was my mother who pushed to have me tested.

I was diagnosed when I was really young. I was ready to quit school when I was in grade three. I was diagnosed and then I got into a school for people with learning disabilities. That’s what turned things around for me. That school helped to give me the skills I need to manage things better and deal with the challenges that I have.

I was fortunate to be diagnosed when I was 10 years old and I received special tutorial help from that point on. I was fortunate that my parents could pay for the tutors. By the end of grade 12, I thought because I was no longer a child, I no longer had a learning disability. I didn’t get any additional help until one of my college professors picked up on my learning disability. Then I had to adjust myself to having to ask for help; I hadn’t had to ask for help before then because my parents were my advocates. Now, in a work situation, I have to learn how to trust my employers.

I was first tested when I was four or five. They didn’t really know then what learning disabilities were, let alone ADD. I went through lots of tests (some of them were really weird). The school didn’t know what was going on; I was put in a class with the bad kids. I ended up quitting school in grade eight. I only recently was truly diagnosed.

I had no idea what I was being tested for most of the time when I was a kid. Even if they had explained it to me, I probably wouldn’t have known what was happening.

Before I quit school, I was never there. I skipped constantly. I went to university as a mature student. That was impossible. I just muddled my way through. Once I had the test done as an adult, it opened up a whole new world for me. I knew what was going on. My wife mentioned to me that I might have ADD (she’s a teacher). I finally got diagnosed by a doctor.

When I got tested at school, I didn’t know what was going on either. They showed me pictures and asked me to make up stories. It got hard after I was diagnosed and the teachers didn’t believe it. I went from being the charming kid to being the lazy kid. I was also put in the class with the bad kids. I lucked out because I got pregnant and there was a new rule that as long as you came to school they passed you. So I did graduate from high school. Then when I had my second son and everyone was talking about ADD, I got him tested. He didn’t have it, but I did. After my diagnosis I went on to get a Bachelor’s of Social Work. The testing opened up doors as an adult, but it closed them as a child.

I don’t like surprises. When they pulled me out of a class at age six or seven for testing, I thought I had done something wrong. If you scare me enough, I’m going to turn into an idiot. That shows up on scores. My parents were told I was mentally retarded. My parents got me retested on a better day and my test scores were better. If my parents knew ahead of time that I was going to be tested, they told me, so I was prepared. I was told never to go with a stranger, and here were strangers trying to take me away. I threw a hissy fit. If I’m panicked, my test scores are going to be worse. Children should be told what is happening to them. I’d never surprise a child that way. When I finally got a diagnosis, they told me that I’m special and explained why sometimes I don’t understand things. They said that they were going to help me. Then I was able to gain some self-esteem and things started to go better for me. I wasn’t diagnosed with ADD until about three years ago. I didn’t want that; I had heard so many terrible things about ADD. I didn’t want to be crazy. Now I’m more accepting.

I found the process really long. By the afternoon, I was really tired. Every time I read the report, I don’t necessarily agree with it and it frustrates me. I know what I can accomplish, and I find the report is worded very negatively. I felt like everything was moving so fast that day; like I was in a race. I found myself exhausted.

EXPERIENCES IN SCHOOL

After I got diagnosed and knew that that is how I learn, I felt much better. There are some things that I'm better at than other people. I try to hold on to those things.

I used to put a lot of pressure on myself; the wrong kind of pressure. Now I've learnt how to study better. I had to learn how to do things without the anger, without berating myself over things.

I spent most of my time in school talking at the back of the class. I didn't have any trouble with reading.

I didn't have a problem with friends in school. I was always the class clown. That's how I dealt with stuff.

I moved around a lot and I'm a shy person. My lack of confidence in myself and my abilities didn't make it easy to make the transition between schools. I eventually learned how to deal with things better. I learned how to be less shy and nervous around people.
Sometimes if teachers don't know much about learning disabilities, they treat you like an idiot when they find out you have one.

When I went back to school, I didn't go directly to my teachers to tell them about my learning disability. I don't want to be treated differently. I also don't want the other people in my class to know because they might think that I'm being treated differently.

I almost wore my learning disability diagnosis as a badge as an adult when I went back to school. Some of my classmates even went and got tested because of me.

It is easier for my teachers to relate to me if they understand why I act the way I do.

The public school system could learn a lot about how to deal with kids with learning disabilities.

EXPERIENCES WITH WORK

I had a job in the summer, there was too much going on and it was stressing me out. I couldn't go to my boss to tell him I had ADD. To some people, it could sound like a cop out.

I have to tell people at work about my disability and about what accommodations I need. I tell them that if I get what I need, I will be their best employee.

It all depends on where you work and what you want to do. If you want to work in retail, they're not going to make accommodations for you because there are 400 people waiting to take your job. They don't have to make the accommodations because they can find someone else very easily.

Part of my job is taking phone messages; it's very hard for me. I sometimes have to listen to a phone message over and over again. I was caught up in not wanting anyone to know about this; then I found out that everyone can have this problem. I also sometimes have trouble with numbers. The people I work with know that now about me.

I gave up a whole career in child care because I wasn't going to be accommodated. I'm fortunate that I have people who understand me now and I have accommodations in my current job. I have help with my paperwork, but I always have to ask for it.

It was devastating to me to have to walk away from my dream job because of my learning disability. Everything that I did well wasn't recognized; the things that I had difficulty with were always being emphasized. It still upsets me because I think I could have made a big impact on children's lives.

I have learned what my strengths are so I know what careers are definitely not for me.

It takes me a while to adjust to things. My boss wasn't interested in trying to help me adjust. She was only interested in making money, not helping me.

IMPACT ON FAMILY

My wife really helps me to remember things and keeps me focused.

My parents never let me get away with things because I have a learning disability. But my parents also always praised everything that I did well.

I'm sure that my parents had to make sacrifices so that I could get the help that I need. If I showed the least bit of interest in something, they would enroll me in classes. They would do anything to help raise my self-esteem.

A lot more of the attention went to me, but my brother never seemed to resent that.

ADDITIONAL COMMENTS

As an adult with ADD, the hardest thing is deciding who I let know I have ADD. I try to surround myself with people who understand.

There’s so much going on in my head all the time; it never stops. ADD is a curse in that way, but it’s also why people with ADD can be so creative.

The more I disclose, the more people ask me if I think they might have a learning disability.

Every elementary school teacher should have to take a course about learning disabilities so they will be able to help recognize the disabilities earlier. Nothing is done without a diagnosis.

PARENTS OF CHILDREN WITH LEARNING DISABILITIES

PARTICIPANTS

In attendance: 8 participants; parents of 5 boys and 2 girls with learning disabilities who range in age from 9 to 20

DIAGNOSES

I had to go to private testing because of the 18 month wait through the school system. I didn’t want to wait.

In the life of a child, 18 months is too long.

I kept saying, from kindergarten on, that there was a problem. No one believed me.

He used to have problems and had to go to the office for behavioural issues. I went to his school to ask about his grades (which were poor) and they suggested that he be tested. I had him tested privately, mostly to disprove what the teachers were saying because I didn’t believe them. It’s been a learning experience.

Even when you tell people that there is a problem, you get ignored.

I got in touch with educational support services and I talked to the right person.

We were only in the province for a few weeks before we were called into the school and told that our son should be tested. He saw a psychologist within a month of us arriving in Manitoba. Our experience is different from the norm. He’s had a lot of early interventions. He’s been tested by many different people on many different occasions. He was finally diagnosed by the health science centre.

EXPERIENCES IN SCHOOL

Our son said again today that he was quitting school. He has developed an extreme phobia where he freezes when the work gets too hard.

What happened to him in earlier grades was devastating to him. His performance is very low but his intelligence is very high.

I've had some awful experiences with the school system. The system is truly paralyzed.

My son considers himself to be stupid because he can't read.

I can't believe the attitudes that teachers still have towards kids with learning disabilities. The child psychologist had to write a letter of complaint to the school system. He also offered to run a training session for the teachers to explain learning disabilities to them. The principal refused, saying that learning disabilities weren't a priority for them. We ended up changing school board divisions. This is his second year in the new school; it's like day and night. He used to cry every day before he went to school. Now I have a child who gets up every morning and sings; he comes home after school and wants to do his homework.

He told me that he's doing much better in school than he ever did before. When I asked him why, he said that maybe his teacher gets it this year. She knows that he learns differently than other kids do and she's teaching him the way that he needs to be taught. He said that other kids aren't nice to him; that because he can't read and spell, they think that he's stupid. He said they have to know that you can't judge a book by its cover.
He doesn't want to go to resource; he doesn't want to be different. He doesn't like the label of "learning disabled."

Each school seems to be different with how they treat children who have learning disabilities. The major problem seems to be funding for the extra resource help.

There is too much emphasis on putting children on drugs to calm them down in the classroom.

There is so much available in the school system, but my kids can't have it.

Her first year in grade one was a bad experience. Her second year in grade one was better, although we had to get her over her attitude that she didn't want to go to school.

I can't help her at home because there are no tools to work with; she hasn't had a text book yet.

My son failed all of his classes last year. I didn't have problems with him until last year.

He held himself back in grade three, even though the school wanted to pass him into grade four. His grade four teacher was an angel. He was fine until grade 10. Now we're back emotionally to where we were between grades two and four.

Throughout school, you're trying to hold your kids together. The focus in school is on the 20% that isn't working well, not on the 80% that is. That's why there's the frustration. I kept trying to see how he would be as an adult out of the school system. I tried to focus on that.

School doesn't hold up a mirror that lets them see themselves. They see only the stuff that doesn't fit. Their heart breaks. I just had to tell him all the time that he's special and that he's worth it.

Getting these kids through school is the hardest thing.

We found out that our school division doesn't want to hear the word "dyslexic" because it impacts on finances. If they hear the word, they have to spend the money to provide the services.

The LD kids are the forgotten children when it comes to inclusion. They get pushed through the cracks.

When my son would get overwhelmed at school, we would have a family mental health day. I'd buy him some Lego so he could focus on something that he was good at.

A lot of time is spent having to educate the teachers. You get a new teacher every year, and you have to start over from scratch.

You have to wonder how some of these people have become teachers. How can they not help these children who are in need?

Schools are set up for "normal" kids. When kids are special, it's difficult for them to be dealt with within the system.

My son came up with the name "bread and butter teachers." These are the teachers who are there for the pay, not ones who are there because of their heart.

You can see when they're learning from how they sound and how they act.

Our kids are like the canaries that they used to send into the mines. They are sensitive, so they can tell us about the real state of the education system.

A child's experiences are so dependant on the people in their particular school.

FINANCIAL IMPACT

I paid a tutor to do extra work with her, but I had to stop because I couldn't afford it.

If it wasn't for my employer, who has a wonderful benefit program, I never would have been able to get a private assessment. But it doesn't pay for everything. The assessments are a lot of money. And pharmacare doesn't pay for the medication he needs.

If you have financial resources, you have more access to speedier services.

Respite is a big issue for me because I'm a single parent.

You have to make the situation sound so bad that the system can't refuse you the money.

I paid for therapy, assessments, respite, and computer programs and other accommodations. I was really frustrated with the school.

If I had a child with cancer or diabetes, medication would be covered and they would get all of the necessary resources. If you don't have the resources, your child has to do without.

If we had had the resources, we would have home schooled our son.

You have to make sure your child is involved with things that build their self-esteem. Those things cost money.

I moved from one school division to another because I had to get my son out of a particular school. That's a huge expense.

IMPACT ON FAMILY

You need a community to support you because you can become the big bad adult if you're the only person working with your child.

There is also a big commitment in terms of your time commitment as a parent. You have to make sacrifices in terms of time. My son saves all of his school work for me to help him with. I'm his best teacher. But you get to a point where your child wants some autonomy from you.

My son's needs were more magnified than his siblings were.

I feel my daughter suffers because I'm a single parent and she is stuck in day care for a lot of the day.

My mental health can't withstand meetings about my son all the time. The emotional impact is draining for parents. There's a cost there as well.

Because my son was so stressed out, the other kids had to be quiet until he fell asleep. They couldn't watch television. They had to be extra sensitive to his needs.

My child's learning disability has made me a better parent. It's had a huge impact on my marriage and on my extended family.

My other child keeps saying that we don't do anything for her; everything is for her brother.

The learning disability has put tremendous stress on my marriage. We broke up for a little while because of the cumulative stress.

ADDITIONAL COMMENTS

I'm worried about my child, how it's going to be for her as an adult.

It's terrible to hear your child say that she wants to kill herself.

I'm most worried about my son's mental health and self-esteem.

I see in my son a young man who the world likes and who has a lot to offer.

Anyone going into this field to help kids like this are angels.

I don’t feel so isolated now because of the commonalities of our stories.

You get exhausted. You’re at war with the world. Helping my son reach his potential has been the biggest fight of my life.

I wouldn’t want any other son than the one God gave me. I’m incredibly blessed.