

**PACFOLD Focus Groups –
Highlights from Discussions**

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PARENTS OF CHILDREN WITH LEARNING DISABILITIES

PARTICIPANTS

In attendance: 6 parents of children with learning disabilities (their children range in age from 9 to 13)

DIAGNOSES

My son was diagnosed at three-and-a-half/four-years old. It was picked up at daycare. He was having problems interacting with other children and learning speech. We went through our family doctor who referred us to a psychologist. Having a diagnosis meant that other people (daycare) understood. It also helped with school because right upfront they were aware of and able to deal with his needs.

Two months into his grade two, I was doing homework with him, and I couldn't understand why he couldn't get "sun, fun, run". His teacher called and asked if it was okay with me if she called in a resource person. We were lucky to get that. We eventually did a developmental assessment and then my Employee Assistance Program at work referred us to a psychologist. We were very lucky because we were able to get the psychological assessment done quite quickly. I've heard horror stories of other people waiting a long time and it costing a lot of money.

I knew very early that there was something very different about my son. What was tough was that no one would believe me. I ended up going through two family doctors because I felt that nobody was listening to my concerns and finally, through a lot of research on the Internet, I wrote a report that I brought to my doctor requesting that certain tests be done. It was probably a year's worth of research that I did every night to try to figure out what to ask for. It was a long process. I own my own business, so I had to pay for the speech therapy out of my own pocket. At the time, there was a 15-month waiting list, and I felt that I just couldn't afford to wait that long. I was trying to get my son talking. At the same time, it took more than six to eight months to get all of the tests done. I almost went broke trying to get a diagnosis. And then we went through many wrong diagnoses.

We went through the Progress Centre for Early Intervention; that was the only thing that saved my sanity.

Both my husband and I have learning disabilities, so we have the difference of having grown up with it. I was always aware that it was something that would move down through another generation.

In grade primary, our son's teacher told us that she thought that he might have a learning disability. We were able to get an assessment and get resourced; we maxed out the school system. It was a really supportive school at that time. I'm eternally grateful for having a group at his school that was so on the ball.

We did our assessment through the school system as well. It was in grade one, when they started doing the reading programs, that they picked up that he wasn't as quick as the other children. In grade one, they put him on a list to get psychological testing. It was only in grade three, after me calling three times a week, that he got tested.

I found the "Links" program purely by accident on the Internet one day. Since then, I've found that he has done extremely well. I have found that he does better with assistance from outside of our family group than he does working with me (his mother), his father or his step-father. With us, he's more reluctant to put the effort into it.

FINANCIAL IMPACT

With the amount of money I've spent, I probably could have bought a house.

I often tell people that if I hadn't owned my own business, I would have been fired because I had to take so much time off work to bring him to all these different appointments. I would have never been able to hold down a job. It was very painful.

The tuition at his private school is \$9,500 per year. We did get a tuition agreement (partial support for two years) last year from the school board. But it's very hard to come up with that money.

I'm \$45,000 in debt because I've had to pay for additional services for 10 years. We have to pay the equivalent of a year of university education each year that our children are in school.

EXPERIENCES IN SCHOOL

My son was diagnosed prior to starting school. We met with the school before he started. He had resource help all the way through school. He has difficulty with peers. He doesn't have a whole lot of friends and he isn't super outgoing.

I have to point out the help we got from one teacher. She was our son's primary school teacher, and the next year she was his resource teacher. She really focused on him and said "I'm going to help this child through this." The next year she was resource and vice-principal. We had someone within the system who had the ability to walk us through it and help our child through.

The stigma is very painful. Before our son started primary, all of the parents had somehow found out that there was a "special needs" child starting at the school. So he was labeled before he even started at the school. The other kids knew that he was different. It didn't help that he was being yanked out of class once a week for speech therapy and every day for resource. They were good, but at the same time, he never got invited to go to birthday parties. Public school was not a good thing for my son. He found it very hard to keep up. The last year he was there (grade two), he was in a class with 30 kids, 7 of whom needed resource. That last year, the teacher didn't know what to do to help him. At the end of that year, when I told them he was going to Bridgeway Academy (private school for children with LD), they said that was the best decision for him because there was no way for them to help him. They didn't have the resources and they didn't know how to help him.

It was a hard decision to make to pull him out of his community school. In Bridgeway, there are only five kids in his class. They get a lot more one-on-one and each child has his/her own curriculum so they go at their own speed. There is no trying to keep up with other kids. That was a huge benefit for us. Because by the time my son was in grade two, the tantrums were starting. It was becoming way too much for him. There would be two to three hours of tantrums every night. I had to stop working full-time because I couldn't deal with the stress. That immediately stopped when he started at Bridgeway because he felt comfortable — he felt like he could be himself and that people understood him.

Psychologically, you get to a point when you finally accept that this is a part of your life and you're comfortable with it and things are going

great. You get to a point where you don't want any more assessments or diagnoses — you don't want someone to bring up all of the dirty baggage again. And the whole tuition agreement thing is great, but in order to get it you have to jump through so many hoops. You had to bring up old baggage and dig through old files. You have to write a letter to the school board explaining why your child deserves to get \$5,000. Well, he deserves to get \$5,000 because he's a Canadian citizen and he deserves an education like every other Canadian citizen.

Every year is a challenge. He's going to be 13 and he fights every step of the way to hide his learning disability.

His self-esteem is very low. This is the first time that he has a best friend that does not have a learning disability. He felt that he could only hang around with children with learning disabilities.

He gets so frustrated all day trying to hide his disability that it comes out when he gets home.

Every year I fight to get a one-on-one interview with his resource teacher and his classroom teachers.

The biggest problem that we faced in school was shared teaching (one teacher three days per week; another two day per week). The two teachers taught totally differently. It didn't help us get him through the process.

The resource in his school isn't one-on-one, but two or three at a time. This might be better because then it isn't just one kid who is being taken out of class. I did have problems with them taking him out of math class to do English; take him out of English to do English.

He says he doesn't take the initiative to do things in school because he doesn't think he can do them. His biggest problem going through school is the fear of failing in front of the other children.

I was at the point when I would come through the door at 3:45 and the bottle of wine would be open. I'd pour a glass of wine and I'd tell my son that I needed 15 minutes. I had to have a glass of wine before I could tackle the homework with him.

You're expected to be a teacher on top of your other profession.

I find that there is a certain amount of discrimination in the school system towards kids with LD. When they call it the “invisible disability”, it certainly is. I’ve always been a little resentful that the school system seems to provide services for children who have what they consider to be severe problems; but those problems are no more severe than what our children have. But the children who are in wheelchairs or who are blind or deaf — other disabilities that are more visible — there seems to be a real willingness to provide services. That’s discrimination in my opinion.

My son knows he has a learning disability, but he would never talk to anyone about it.

A big part of the curriculum at Bridgeway is to foster an understanding of what a learning disability is, how to stand up for yourself and some strategies that you can use.

Group sessions are a good way for kids to know that they’re not alone.

IMPACT ON FAMILY

I would never give my child up. I feel really blessed having him and I’m really glad that he was born to me because he’s an unbelievably special human being and he has made me such a better person. He has enriched my life in so many ways and I feeling very blessed by that. I have a greater understanding of people and I accept people — with all of their quirks and idiosyncrasies — much better than I think I would have.

Our family has been through a lot, but it’s also made us very close.

CHILDREN WITH LEARNING DISABILITIES

PARTICIPANTS

In attendance: four participants

DIAGNOSES

I was diagnosed at school. They said my brain just works a bit different.

I was happy that they said I had a disability and that I wasn’t just dumb.

It would have been easier if people had noticed before; I always knew because I felt stupid.

The assessment was boring and long.

EXPERIENCES IN SCHOOL

I don't know why they have to come and get me to go to resource; I could go on my own. I don't want to have to explain it to everyone.

This is my last year in resource. My teacher is giving me tips for studying because I'll be on my own next year when I change schools.

When I was struggling, school just felt like a big chore.

It's so much easier to read if you enjoy the book that you're reading and if it's interesting.

Before I was diagnosed, I couldn't understand why school was so hard for me.

The transition from elementary to junior high wasn't hard. The teachers made it sound like it was going to be very hard.

I usually get the notes from my friends instead of writing things off of the board. It's easier for me that way.

I can't just read something and now how to do it; I need someone to show me how to do it. I'd rather tell someone about something than to have to write it down.

IN THE FUTURE

I think I'll be able to grow out of my learning disability. This year is so much better than last year; it's almost gone now.

My learning disability is hardly a factor anymore.

ADULTS WITH LEARNING DISABILITIES

PARTICIPANTS

In attendance: 7 participants

DIAGNOSES

I couldn't find a job and, if I could, I couldn't keep it for some reason. Then I got tested.

I was diagnosed with a learning disability when I was in grade four or five.

They didn't piece together my different difficulties (eye/hand coordination, motor skills, social skills) while I was in school. It was only as a young adult that I was diagnosed with a non-verbal learning disability.

Through elementary school, junior high and high school, everyone knew that there was something wrong, but I was always pawned off as the dumb kid. I wasn't diagnosed until I was 26.

I always had problems. But they kept passing me through school saying that I would do better next year and that it was important to keep me with my friends.

I'm allergic to numbers and big letters.

I started lashing out when I was in grade two. My mother pressed for testing throughout my elementary school. In grade six, I was diagnosed with dyslexia. I didn't learn how to read until part way through grade seven.

I wasn't diagnosed until I was an adult. I got my son diagnosed early when I saw he was having the same problems I had in school.

When I found out I had a learning disability, I was proud. It was a new beginning.

When I was finally diagnosed, I had a sense of closure.

You have to be able to laugh at yourself, or you're never going to get through this. It's like a boxing match; you take some wicked blows.

EXPERIENCES IN SCHOOL

I had a tough time in high school. I always felt like my back was against the wall.

I was never happy or fulfilled in what I was doing in school because I just couldn't get it.

I failed every grade, but they kept pushing me through. I was in school in the late 1960s, and people just didn't know about learning disabilities. When I got to junior high, I had no idea what was going on, so I left. I maintained two or three jobs and taught myself how to read and write. I never backed down from a challenge.

My grade three teacher told me that I'd never graduate from high school. That motivated me to prove her wrong.

I didn't read a novel until grade 10 when my English teacher introduced me to some novels that he thought I'd like. I loved them.

In school, you're either one of the popular smart kids, or you're outside smoking on the sidewalk with all of the kids who are considered to be the losers.

The majority of my learning I had to do myself.

When you're weak in school, you compensate by being more sociable.

I decided to hold my son back in grade three. The school looked at me like I had five heads when I suggested it. I said I'll tell you my experience and what he'll go through. I thought it would be better for him to stop at that point and get him the help he needed rather than pushing him through.

I was pushed through my early grades because I was strong in certain areas of school, although I was lost in others. I got tested for the first time in junior high school. I wish I had the voice back then to tell them what I knew I was going to go through. When I did try to say something, I was dismissed. It was very frustrating.

The resource program in high school was integrated with the special needs program. It was hard because the doors were always open and people could see in. I was classed with the mentally challenged people and I was looked down on. I started to rebel.

Because of my disability I started to hate everyone. I felt that everyone was against me. I changed high schools and discovered that, at the new school, people accepted me. They didn't care that I couldn't read as well as the other kids.

In junior high school they put me in the adjusted program with everyone else they felt wouldn't make it through high school. Unlike all of them, I actually wanted to learn.

Luck got me through the school system; the school system didn't get me through the school system. I was in the right place at the right time for things to happen.

The teachers are doing what they can with what they have. They are in a system where if you get 85% through, everyone is happy. We make up the other 15%.

If you don't have the support system, you will just fall through the cracks and disappear.

I went through a university that had a centre for students with learning disabilities. I was very lucky.

When I went through school, the teachers didn't have the resources that they needed. They were as frustrated as I was.

It was my own persistence that got me through school.

I got good grades, but inside I knew that I had a problem with reading. At the time, they didn't understand what a learning disability was. Today, people are more able to recognize what a learning disability is.

My son's friends didn't want to see him fail at school, so they kept helping him.

There was emphasis on my weaknesses, not my strengths. The learning disability program emphasizes my strengths instead.

I don't know that I would choose university again if I were to do it again. There are other options out there.

Sometimes you get bounced around in the school system. It's easy to slip through the cracks.

I learned to be my own self-advocate while I was in university.

There has to be people in the school system who know how to recognize and teach people with learning disabilities.

You need education/services between school and work to smooth that transition period.

There needs to be more guidance in the school system to help students decide what careers are available for them.

EXPERIENCES WITH WORK

I have a tough time filling out applications and my resumé isn't up to par. I can understand why an employer would dismiss my application if there are misspelled words. They are looking for who they think will be the best person for the job.

There's not enough information about learning disabilities in the work force. Employers don't have the information they need. They often see people with learning disabilities as too much of a risk to their businesses.

Many employers have been very accommodating about my learning disability. They just want to know what I need. Others places treat you like dirt and you just lose your motivation to want to be there.

I was surrounded by good people at work who weren't afraid to teach me what I needed to know.

The employer needs to know that a person with a learning disability might need some extra information to do their job.

Some employers, if you tell them you have a learning disability, they're not going to hire you. They'll treat you like you're mentally challenged and think that you can only wash dishes.

I always question how my employers perceive me. Other people who I came into the organization with are further up the ladder than I am. They all have their weaknesses too. It sometimes makes me doubt myself.

IMPACT ON FAMILY

My mother putting me down through school actually motivated me to prove her wrong.

I make sure I read to my son. When he starts school, I can learn along with him.

My wife is very aware of who I am.

I've become a better person since I learned about my learning disability.

My parents didn't really help me when I was in school. It didn't really concern them.

My parents didn't have any learning themselves. They couldn't help me when I was in school. However, they have always been very supportive of me and my son. They're very proud of everything I've accomplished.

My mother fought for me everyday to get me diagnosed and to get me the help I need. We have a very strong relationship.

My girlfriend knows all about my learning disability and she wants to help me and be there for me. Because I have this weakness, she's found her way to help me.

There wasn't a door that my mother didn't kick in for me. It took a lot out of her. By the time I got into university, she was tired of the battle. It shouldn't have been a battle for her.

ADDITIONAL COMMENTS

I want to try to do something so that other people won't have to go through what I went through.

I'd love to live in a perfect world where you say your child has a learning disability and the pieces just fall into place.

I find it sad to hear parents of young children with learning disabilities say that their children will grow out of their disability. It doesn't go away. It isn't the common cold or the flu. Acceptance will make it a whole lot easier for the child.

I had no idea of the support that was out there for people with learning disabilities until I went out looking for help.

There also needs to be more general awareness about learning disabilities. People have to know that anyone can have a learning disability.

There is an opportunity for people like us — people with learning disabilities — to help others in the community and to show young people with disabilities that they deserve to be treated well.

I think that we're a lot stronger because of our learning disabilities. We're jumping over the hurdles that are put in front of us. We don't give up.

When people hear "disability", they want something they can qualify, quantify, touch and see — something they can believe. With a learning disability, you don't get any of that.

Not all cars are put together the same; not all people are put together the same. It doesn't mean that one model is better than another.

Education is key in schools and in the work place.