

Being a Parent and not a Teacher: the Case of Specific Learning Disabilities

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Living with a child with Specific Learning Disabilities (SLD) can be highly demanding or frustrating at times. In this paper we focus on the everyday reality and demands on the parents, their relationship with their children, and their reflection on these experiences. Through semi-structured focus-group interviews, we collected data from 15 parents (13 mothers and two fathers) in groups of 4-6 individuals. The two major questions around which the interviews were structured were 1) How did the child's Specific Learning Disabilities impact on the everyday life of the family and especially of the parents? 2) What would they need and what would they do differently, if they could go back in time, to support their child? Based on the analyses of the interviews, three major issues were revealed: the high time-demands and therefore, lack of leisure-personal time, the lack of knowledge regarding SLD, and the retrospective regret and guilt of the parents. All parents appeared to struggle to balance between two, conflicting roles: the parent and the teacher roles. Looking back, they strongly regretted the pressure they had asserted on their children, often leading to verbal and even physical abuse.

Keywords: Parenting practices, specific learning disabilities, guilt, academic support

Living with a child with Specific Learning Disabilities (SLD) can be highly demanding and frustrating at times. Even simple, everyday activities, such as picking the right socks to wear or running household chores may require the parents' intervention in order to be successfully completed (Donawa, 1995; Margalit, 1982). When it comes to school, homework and the required academic support, parents report significant demands on their part. They often spend many hours helping their children with their homework or tutoring their children on a daily basis (Donawa, 1995). Therefore, parents of students with SLD are often required to change their everyday personal programme, and find extra time to deal with issues involving school learning, non-academic behavioural issues and self-esteem building (Dyson, 1996; Waggover & Wilgosh, 1990). When children reach adolescence these issues become even more demanding, and the family needs to continuously readjust to new needs (Cordoni, 1990; Dyson, 1996).

Especially in regard to academic problems and the required support for the children, parents of children with learning disabilities provide support throughout the school years, with the demands growing as the child grows and the parents feeling more stressed and less capable in assisting their children (Petterson & Mattson, 2007).

There is often frustration, tension, conflicts and regrets on part of the parents (Mearig, 1992). Parents of children with SLD, feel more strained in their interactions with their children, and they sometimes report feeling guilty for their negative communication with their children (Lardieri, Blacher & Swanson, 2000). On the other hand, parents also report that their lives have been enriched through the experience of raising a child with SLD, and they have become more thoughtful, resilient and compassionate (Waggover & Wilgosh, 1990).

Most of the available literature refers to how parents of children with SLD cope with the idea of learning disabilities or with the school demands. Few studies have focused on family-level factors, although the role of parental personal resources is widely accepted (Belsky & Barends, 2002). Furthermore, in most cases, parental resources are conceptualized mostly as parents' psychological resources or psychopathology (Goodman & Gotlib, 2002), without considering the mediating role of existing support resources available to parents. In this paper, we look at parents' experience from a different view. We attempt to shed light on the existing high demands on the parents and on the significance of the existing support provided either within the family or in the school context. We focus on the everyday reality and demands on the parents, their relationship with their children, and their reflection on these experiences.

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Methods

The major research questions we sought to investigate in the study were: 1) How did the child's learning disabilities impact on everyday life of the family and especially the parents? 2) What would they need and what would they do differently if they could go back in time, to support their child?

In order to collect our data and respond to the research questions, we chose the qualitative approach, to reveal various unique issues that parents experience and the meaning they apply on these experiences (Denzin & Lincoln, 1994). Through semi-structured focus-group interviews (Krueger & Casey, 2000), we collected data from 15 parents (13 mothers and two fathers) in groups of four to six individuals. All parents had children attending late secondary education grades.

Results

1) How did the child's learning disabilities impact on everyday life of the family and especially the parents?

Children's learning disabilities had a significant impact not only on the parents' everyday life but the activities of all the members of the family as well. It appears that parents of children with learning disabilities take on most of the homework completion, and they spend long hours tutoring them, leading to almost non-existing free-time for both themselves and their children.

Yes, sure. Additional work, I used to follow all these strategies, which I implemented and learned. Yes, I was able to do so, because I was a teacher. I wanted to and I had the time. I remember, I started tape-recording the theoretical parts of the lessons for him to listen to, since he was in 3rd grade of Primary school. When he became an adolescent, he wasn't fond of listening to my voice anymore, so someone else's voice should have been recorded, because you know, my voice seemed to irritate him. (Mother 7)

He was patient, too. Peter used to come home, have supper and start his homework. Some days, it was only three thirty pm, when the home-tutor would arrive. He wouldn't even finish his supper... Nowadays, we are more conscious of the situation, and we are trying to give him time on-his-own. I specifically recall Peter, as a 2nd grader of Primary School, returning from school at 3 pm and then, at half past three, home-tutors starting marching in and not leaving until 9 pm. (Mother 12)

Forced to use all their free time assisting their children with homework and taking care of them as well, parents performed a double role: the role of the caretaker and the role of the parent. Although their personal time was very limited, they still had a great need and pursued some personal leisure time.

I always find (free time for myself). I try to do so. I mean, okay. But I'm not totally helpless. I mean I've hired a woman to give me a hand once a week, anyway, I also have flexible hours at work and my husband is helpful too, so there is personal life. There is also the Parents' Association. (Mother 11)

We've got free time. We try to find some. Personally, I have, because I spend my day at home, since I'm not working, but whatever she needs I'm there for her, aside the fact that she doesn't really ask for my help anymore. (Mother 6)

No, I was fully dedicated to him, at the time, no. Countless hours. (Mother 7)

Mothers who projected their need for personal time and succeeded in guaranteeing it, were the ones who either had extra help with the everyday household activities, or shared responsibility with their husband. Furthermore, these mothers either did not work or had a part-time, flexible job. This is similar to other cultural conditions, wherein parents of students with dyslexia who work have far fewer opportunities for leisure time (Karande & Kulkarni, 2009).

What I need to say is that we were lucky, like others, I guess, as a family, I mean we had a bond. And it is really easy for families to fall apart... (Mother 12)

My husband is dyslexic. So, we had to work it out, to keep the balance in our family. A dyslexic adult, who experiences... Do you know how many divorced couples we have (in the Parents' Association where she belongs to)? It's because they can't stand it... They just escape. Especially, the fathers, who have the tendency to run away. This is a divorce cause. All this has to do with a chain of things, and invisible things. The thing is that it is not visible, but in fact, it exists underneath and you never know where it's going to lead. (Mother 9)

Look. The conflicts between me and my son are really intense. The Oedipus complex exists between us and doesn't let

us balance, but Alexander (her husband) also used to help me in general, both with the house chores and the kids' homework, on everything, so our relationship wasn't so much affected. However, the conflict between me and the kids is huge, since I mostly helped them with their homework. (Mother 11)

Ehh...sure there was pressure. I put pressure without knowing, and I used to compare the older with the younger (kid). Comparison...There was a tension at home and a terrible family situation, and since I was a teacher, my husband put the blame on me. Because our relationship was already broken... I couldn't be both a teacher and a parent at the same time, the parent-child relationship was damaged, and so she couldn't accept me [...] I was psychologically exhausted. On one hand I didn't know how to help and on the other there was pressure, conflicts and tension. (Mother 9)

The bond between us is strong but my husband cannot realize yet that she's different. I mean, he treats her differently. He's not as friendly as I can be, and he doesn't accept her capabilities [...] Maybe he doesn't know how to handle this. Yes, yes, yes. (Mother 10)

When one member of the family faces significant difficulties it is not only this member that is affected, since any family functions are a system of interactions (Bubolz & Whiren, 1984; Grigorenko & Sternberg, 2001). The husband-wife relationship, the parents' attitude towards learning disabilities and their children, their relationship with their children (Karande & Kuril, 2011) and the relationship between siblings (Lardieri, Blacher, & Swanson, 2000), they are all influenced and interact with each other.

2) What would the parents need and what would they do differently if they could go back in time, to support their child?

Most of the parents participating in our study had children who were adolescents, attending high school. Therefore, these parents were past worrying about diagnosis, or helping them with homework and friendships. They appeared to hold different concerns that refer mostly to their future. Having left the intense problem of childhood and everyday life conflicts behind, they reflected on their past behaviour focusing on what they could do differently if they could turn back the time.

Some of the parents felt that, looking back, they would try to be more informed and knowledgeable about the nature and the

treatment of learning disabilities. They felt that if they had known more they would have been able to avoid any wrong or harmful behaviours they had towards their children.

The guilt has been built at this point, that you have no knowledge of what is going on and you act in a way that...the environment also affects you by calling your concerns "overreacting"...(Mother 4)

I would like to bring all those years back until we understood that it's all about dyslexia. Before that time I was strict and suppressive to him, in other words his first seven years...[...] I would like to have known better, to suspect, to be sensitive and tolerant with him...something, because this is where all my guilt lies, in those first years, when I accused him and scolded him. (Mother 7)

Knowing what is wrong and how to deal efficiently with any problem, would allow them to enjoy their children's childhood. Further, they would be more thoughtful and assertive in defending their children's rights in school, they would be less demanding and critical and more positive towards them.

Surely, I would spend the first school years in a more creative way, I would enjoy that period of time, which I neglected and this had an impact on my whole family and my two children. So...we all lost...we all lost...I would change a lot. I would be more informed and I would be more demanding from the school environment. It's possible that I'd change my child's environment, too. I would let my child know from his very first years, what exactly is difficult to him and what he's good in. Nevertheless, because there's no magic and no time machines, all this pain we went through, did happen, it was useful that I started realizing things differently. Even when I'm teaching my class, I see things differently, I foresee... and I notice behaviours...it's that...I'm a better listener and try to find the cause of behaviours. I've become a better human, I guess, I've searched it more extensively, and I believe I've become a better parent. (Mother 9)

I have lots of remorse, in that I was the mother - teacher for Peter. I would praise him more and I wouldn't have so many demands from him. I've always been a person who asked for more. I didn't use to praise him a lot. I always used to look for something wrong. Today, I'd spend much more time having fun with Peter. I

mean, I would not always drag him by the ear, and we would play much more. (Mother 12)

Mothers of children with SLD, may exhibit more dominance and less positive emotions and cooperation when they tutor their children than the mothers of typical children (Lyytinen, Rasku-Puttonen, Poikkens, Laakso&Ahonen, 1994). Furthermore, focusing almost exclusively on academic support, they may neglect their parental role and contributing thus to lack of positive communication (Karande & Kuril, 2011).

The fights we had in the first grades of primary school were huge. Huge fights, really, to make him start studying. [...] If I knew the problem since he was going to kindergarten? I would deal with it very differently, of course, I'd deal with it in the first grades as I do now, and I'd know how to handle his first steps in a much better way. (Mother 10)

I would definitely not yell at him so much. Because I put pressure on him consistently, I yelled at him, and I used bad language. And all this because I thought he was bored and he wasn't a good child, who is, let's say a very bad opinion to have for your own child. Very bad. I mean, you destroy his confidence. This is what I would fix more. And I would rather give him more initiative, even if he committed mistakes. This is what I'd do. This is what I'd change. Something that I hadn't done from the beginning. I'm trying now, but nevermind. (Father 2)

I would use less violence. I would avoid hitting her, which I did not. (Mother 6)

Unfortunately, it is not rare for parents of students with SLD to be less encouraging to their children (Lyytinen et al. 1995) or use less positive parenting practices, leading to negative relationships which in turn may lead to difficulties in future academic and social success for the children (Sin, 2008; Winter & Yaffe, 2000).

In the two next extracts, another issue that leads to guilt and regrets came up: the significance of early diagnosis and correct intervention choices made by the parents and the interaction between these choices and their behaviour.

My criteria would have been stricter in choosing therapies and of course I wouldn't have used verbal violence. I mean, I wouldn't compare him to sick students so as to hurt his feelings, nor call him stupid and that he doesn't know anything. So

useless... and it is (harder)...than to beat him once and after the pain is gone he forgets everything about it. But the pain accumulates. I should trust him a little bit more. (Mother 5)

What I would change. I would search for people who could help my child in a different way. Because I didn't know back then, I was going blindly and the child got stuffed, and now denies, he doesn't want to see anyone. Because going from one specialist to another (has started annoying him)....(Mother 2)

Besides changing him so he is not dyslexic anymore? () I think we dealt with it fine, we were lucky that he was treated with the right way at the hospital; I wasn't mistreated concerning the diagnosis. My instinct helped me making positive choices , I mean I found a way to get informed early, I neither scolded him nor beat him because he didn't understand something at school, he can't remember tragic situations, like other children do, who were diagnosed late. (Mother 1)

Discussion

Based on the analysis of the interviews, three major issues were revealed: the high time-demands and lack of leisure-personal time, the lack of knowledge regarding SLD, and the retrospective regrets and guilt of the parents. All parents referred to high time demands especially during school years. They reported that they had to tutor their children constantly, underlying that they were often forced into playing two, conflicting roles: the role of the parent and that of a teacher. They appeared to struggle to balance between these two roles, and often tilted towards the teacher one, focusing more on the academic support than the emotional support for their children. Forced to realize a role foreign to them, it is possible that they were not efficient, using for example, fewer high-level strategies and less encouragement, as documented elsewhere (Lyytinen et al., 1994). This finding is disturbing, though, since skillful and supportive practices can assist students with learning disabilities in compensating for their academic deficiencies.

Having left behind most of the school years, the parents appeared to shift their current interest away from school success and towards the need for self-determination, social adaptation and autonomy for their children. Looking back, they strongly regretted the pressure they had asserted on their children, often leading to verbal and even physical abuse. Fortunately, parents seem to realize that they should not place any

more strain on the adolescent-parent relationship during an already developmentally challenging period for both their children and their family as a system (Karande & Kuril, 2011).

Nevertheless, all the reported experiences of emotional strain, stress and pain on both the part of children and parents, is not inevitable and can be minimized. As suggested by the parents themselves in our study, what is needed is for the SLD to be diagnosed early, for the parents to be well informed about the condition and their children's needs and for appropriate educational

support to be provided within the school system. Parents of children with SLD need to be allowed to be the supportive, emotional parents they wish to be and be supported in building positive relationships with their children throughout life. It is with this support that they will be capable to fulfill their parenting role in providing a positive family environment for their children to grow in. In this way, parents can be parents and most importantly, children aren't denied their childhood.

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