



Navigating School Interactions: Parents of Students with Intellectual Disabilities Speak Out

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Abstract

Purpose of Review Our attraction to the verbiage of partnership casts a misleading conjecture that schools and parents are a collaborative unit with a single purpose. For too many parents, especially for those whose children present “problems” for schools, the relationship can be fraught with disillusionment and frustration. The purpose of this work is to highlight and contextualize the complex experiences of parents of children with intellectual disabilities as they navigate their child’s schooling.

Recent Findings Through the presentation of research findings and project data, we explore the nature of the school parent relationships within the context of inclusive practice in schools.

Summary Presented using data collected from 33 parent interviews, this work presents a summary of the struggles and successes of parent engagement within a system that vacillates between innovation and stagnation, between hypocrisy and integrity and between one version of school and another.

Keywords Intellectual disabilities · Inclusion · Parents · Special education

Introduction

Schooling has a major impact on the development and success of all students. School experience is, in part, shaped by the relationship between parents and the school. For parents of students with intellectual disabilities (ID), this relationship can play a pivotal role [1–3, 4••]. Within school systems across the world, the dichotomy of inclusive versus segregationist settings for students with ID is played out on a daily basis. Despite a clear momentum towards inclusive practices [5–7] paired with mounting evidence of the positive effects of inclusion [8–10], embedded segregationist practices in some settings remain entrenched. For example, a current examination by the authors, of Ontario English-speaking public secular school boards’ special education policies, shows that 31 of the 34 school boards continue to offer segregated class settings, meaning that only 3 are fully inclusive.

While polarizing views on inclusive education attract attention and divert discourse, there exists a larger discussion, one that has, at its core, the quality of services and interactions that surround the experiences of parents within a system that is predicated on partnership. What we present are voices of parents with children in inclusive as well as segregated settings. We found issues of partnership from all parents. This work is therefore not about setting; rather, it is about partnership where both sides are working together for a common goal, in this case, the education of a child.

Our work focuses on the voices of parents of students with ID in Ontario, Canada, and the experiences of those parents as they navigate the school system. Parent voices play an essential role in informing practice and ensuring success in particular when working with students with ID [11, 12]. Literature has demonstrated that parents and professionals that work in schools can have differing views in terms of the role parents play in advocating for their children’s needs [12, 13]. While overall the value of advocacy is recognized, it can also be negatively perceived within schooling settings where parents do not receive positive responses to their advocacy; rather, they are faced with strife [14, 15•].

Being inclusive is arguably a place, but it is also much more than a place [16, 17••]. As we move towards inclusive practices and the recognition that all students have a right to

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the best that education has to offer, it can be helpful to stop the divisive discourse that can serve to diminish and distract. It can help to think of inclusion as a concept that permeates every aspect of a student's experience and serves as an essential building block to ensure a student's future success. The struggle to achieve successful inclusive practice is more than an argument over physical access; it is a complex discussion of admittance—who gets “in” and who does not [15•, 17••, 18]. For parents of students with ID, their participation in the current discussion reveals an ongoing struggle to achieve equal voice in the decision-making [2, 19]. The data presented in this work are not divided along the traditional lines of segregationist settings and inclusive settings. Rather, this work explores the quality of the relationships, between and within families and schools, from multiple points of focus. Utilizing interview data collected from 33 parents of students with ID (from both segregated and inclusive settings), this work strives to contextualize their experience within the larger framework of belonging. The work centres around three important foci: people, placement and practicalities.

People

Individual and system responses to working with students with ID can often be framed within a philosophical orientation as well as practical considerations. School boards, government organizations and even individual school settings can have “ways” of doing things. Often what seems like individual practice framed within independent decision-making can be steeped in the culture and messaging of a system or organization [17••, 20, 21]. The complexity of how people interact and why they make the decisions they do is impossible to dissect. Within this reality, we are left looking at pieces and trying to discern from them what picture emerges. The community of professionals that interact with parents is large and includes teachers, principals, educational assistants and allied health professionals (e.g., psychologists, occupational therapists, speech and language pathologists) [5, 22•, 23, 24]. What we can say with confidence is that individual decisions, attitudes and actions have a real impact on the experiences of students with ID, while in school and afterwards [9, 13, 25].

Within the context of our interview data, parent experiences of their child's success or failure at school were reported by participants as often being dependent on the school-based individuals (the people) who were in their child's life at any particular period of time. Even one significant advocate within the school (e.g., a principal, a teacher or an educational assistant) could impact the overall experience of the child. Sometimes, a transition from one school to another could make a positive or negative difference.

So the school must be very welcoming because he doesn't mind going to school, he's excited to go to school, the school counselor just called me right before you and she said he's doing fantastic. So I don't know what they're doing, I think they're including him in a lot of stuff, which I think is great because he's never had this before. We thought we were going to have to battle it out, September and October because I swear to God every September, we must have about five meetings with the teachers trying to get him adjusted. He's transitioned very well, very, very well and I'm so impressed with him, so happy for him because it's been a long horrible road.

At other times, responses and treatment would vary within a particular setting, “I mean nobody ever rejected him but then the quality of his school year and inclusion were different according to different teachers”, and individuals, “Yes, his teacher, he has one main teacher, is very good. I have seen other teachers, another teacher - very unwelcoming, so I've seen both”.

Parents were in a state of perpetual navigation, “Every year was different, it just depended on the principal, who the EA was, who the teacher was. It was never a consistent thing”. Within the same school system, the same school, the same grade interactions, student failures and successes were dependent on the vagaries of those with whom they came into contact, “One school is more welcoming than another. It all really depends on who the principal is”.

While larger policies and orientations may message down within a system, and influence one's decisions, the interpretation of these messages still becomes the property of the owner and their decision of how it is interpreted is what makes an impact [9, 11, 13, 17••]. Within the same systems, same schools and over the same time period, parents reported the mercurial nature of their child's school experiences. “[Child's name] has missed a lot of days his life because it's easier to keep him home.”

Inconsistent experiences highlight the concern of how fundamental one person can be whether holding favourable or unfavourable beliefs about inclusion [26, 27]. Research into the successes and failures of inclusive and segregated settings and the importance of philosophical orientations that are rights based versus charity based can become murky in the day to day reality of parents' experiences and satisfaction. As noted by one parent participant; “It's not rocket science; at the end of the day it's who we are and how to treat each other right”.

Placement

The implications of where a student is placed within a school and the effects on students with ID have long been discussed and debated within the research world [13, 17••, 28]. When systems and schools adopt an orientation (for example

segregated or inclusive) towards where a student is placed, the impact of that placement can have far reaching effects. Even though we know that individuals with ID desire and benefit long term from opportunities to access inclusive education [25, 29, 30], there still seems to be an imbalance in the decision-making process [3, 11]. Often, through standardized procedures or through regulation, the decision of where a student is placed is advertised as a shared decision-making process, “And during the IEP meeting, I got so much pressure from the principal to move my daughter to specialized class and I didn’t even know what happened, even though we said we didn’t agree”. In reality, decision-making meetings can be fraught with manipulative agendas, information can be withheld or over emphasized, and parents can be left feeling overwhelmed and powerless [11, 31–33].

The institution that is education has power within its structure to take decision-making away from parents [15, 34]. The cache of professional knowledge and established system practices form a wall of potential resistance that can be difficult to breach. For some, the conversation never even begins.

Originally they said ‘no she cannot come, we have nothing for her. We have nothing, we have no special needs, we have no one not earning any credits, we have nothing here for her, why would you do this to her? It would not be of any benefit for her to come to this school’.

Other parents who may have more resources and/or resiliency utilize additional resources and supports to “fight” for what they believe is best for their child.

We called for an IPRC [Identification Placement and Review Committee meeting]. They were still fighting me tooth and nail, demanding that I move him and then when I brought an advocate, who basically didn’t say anything, they were like ‘okay we’ll do it’.

While many others succumb, hoping for the best, “I knew it was best for her to stay in the community but that time we were kind of forced to go to, to move to that different, far away school”.

When there is a lack of authentic collaboration with parents, “I think they try and intimidate parents honestly”; a huge swath of vital information about the students overall well-being can be disregarded. [11, 13, 28, 35].

They put him in a very low functioning segregated class and by October of that year, he started to become very depressed, you could see it. He wasn’t himself, and by January he refused to go to school so I switched back to the previous school board. Last year he had a great year.

If we are to move forward in a positive direction for students within the school system, it is clear that parents play an essential

role in that journey. Not listening to parents puts school systems at a disadvantage. More importantly, it disenfranchises parents and students as they try to move forward [36].

The administration, it wasn’t like anyone was nasty to him, but it seemed like no matter what meetings we had, no matter what was said, they just did whatever they, you know, you had the odd teacher, and by odd I mean two out of the eight years, who actually listened and tried. It was just everything made the kid feel like he couldn’t, wasn’t part of something

If the goal is to deliver genuinely effective educational experiences for students in their schools, partnerships need to be authentic and balanced [25, 36]. Yet parents, who continue to advocate for their children to have access, continue to experience rejection and inconsistent access.

There’s a lot of tension because, I guess because we constantly advocate for our son, we are sort of in one sense seen as troublemakers or as extremely demanding parents when we really aren’t demanding anything extraordinary. We’re just asking that he gets the support that he’s entitled to, but we often run up against roadblocks.

Practicalities

It is not only the people involved on a daily basis, or the placement decisions, that impact the experiences of these parents and their children but also the practical implications of schools functioning effectively for all students [20]. Parents of students with ID are forced, through circumstance and bureaucratic structure, to engage in a problem solving and planning exercise that is often skewed to the advantage of the system over the individual [17, 31]. Their capacity to engage as equals is compromised by multiple factors that are in part wittingly and unwittingly engaged in by the players within the existing system.

I mean I’m paying for people to try and teach my kid to write and read because the school hasn’t figured out how, that costs me money. I feel like I have to go buy coloured photocopies and materials and adapt the material because they haven’t figured out how, so that’s a time and money issue.

What is clear is that this engagement comes at a cost [28]. Parents report that dealing with schooling practices and staff can cause a strain on their resiliency [31, 33, 37] and in essence make the situation more untenable.

Working with schools and individuals in schools can come at a time cost.

Oh sure [laughs] oh sure I mean they, they yeah. I guess more in terms of sometimes they would call and want you to take your kid home because they don't have support. Or well, they wouldn't come right out and say that, or they talk about how they don't want to order a wheelchair accessible bus, so can I drive.

While time is an important factor, many parents indicated that there is also an economic cost.

I haven't been able to work because I've always, when [child's name] was put on a three day week, he was home 68 days and I had to be available for him and then as I said, for eight years he was on a half day schedule or less

What is most distressing is the emotional cost that must be endured by parents when partnerships break down or worse are not allowed to be truly formed [31, 38].

You know the dukes are up all the time, all the time, So you carry on again until the next time, until the next time and that's kind of where you're at, you leave no stone unturned and all of a sudden there's another boulder in the way and you think gosh I thought we already got through this but no there's something else. And that's kind of been the experience all along through school. Partnerships break down or were never allowed to truly start.

Well whenever there was any issue, anything at all, he was sent home. He was always sent home instead of listening to, like there's only so much as parent you can say in this situation, don't do A, B and C and then they proceed to A, B and C and then it leads to coming home and it makes you wonder whether they do this on purpose just so they don't have to deal with it right?

What is clear is that schools and the individuals that work in them have the capacity to make the relationships and collaboration successful and fulfilling [3, 11, 28]. When it works, it really works. "I think we have a really good relationship, they really keep me in the loop".

It's been a positive experience so far. They're a very up-front school and I find they're always leaving voice messages just saying, you know, this is happening at class this week and I don't know, I think it's pretty good actually.

Conclusion

Within this paper, we have discussed the need for true parent partnership within the school system. Research literature indicates that parents must be key members of the school team [3,

28]. Our findings bring into focus critical concerns raised by parents that indicate they are not viewed as true partners in the education of their children.

Beyond the desire for their children with ID to have access to equitable education, it is clear that parents face challenges navigating the school system and advocating for their children [11, 13, 14]. Within the context of this work, the challenges are focused in three pivotal areas: people, placement and practicalities. On a regular basis, parents experience the impact of individual perceptions and interpretations of school personnel that may positively or negatively impact the experiences of their child. As these parents navigate the education system, they are faced with the practicalities of the system structures, funding models and supports that are in place. These practicalities create some real-life challenges for families often increasing stress levels [31, 38, 39].

Fraught with the stress of wanting what they believe is best for their children and the bureaucracy of the public education system, they often feel at conflict [17••, 38, 40]. Research tells us that individuals with ID need access to diverse opportunities and communities in order to support their development of professional goals [29], yet for these parents, and many more, the discussions can still be about whether a student can go on a field trip or participate in extracurricular activities. The discussion can be whether their child can take a certain course or earn a credit and whether they can attend a certain school or, worse, attend school at all.

To consider these types of issues, within such a large field of research, insignificant is to entirely miss the point of why systems of education continue to do what we do. The voices of parents tell us that relationships matter [4••]. The system has the power to make changes. Parents are our partners, and this partnership must be supported and nurtured [19, 39]. The overall goal for families of children with ID must be to make inclusive practice work every day, in every setting, especially at school. Students and parents need to belong within their community settings—all of them, not just some of them.

Including parents as partners requires strong leadership [23, 37, 41]. Leadership takes many forms, but at the school level, it is key that partnerships are truly formed between school leaders, staff and families. Policies and procedures are in place to support students with ID and their parents, but unless they are enacted by the local school, beginning with the administrator, they are hollow. To ignore the policies and procedures invites legitimate criticism. Educators can only claim that parents are our partners if indeed we act in ways that validate that message and provide for deeper and more honest conversations that work to achieve true partnership. Only then can the system best meet the needs of students with ID in an honest and equitable way.

Compliance with Ethical Standards

Conflict of Interest The authors declare that they have no conflicts of interest.

Human and Animal Rights and Informed Consent “The Inclusion of Students with Developmental Disabilities” has been approved by the Western University Research Ethics Board. The Western University NMREB operates in compliance with the Tri-Council Policy Statement Ethical Conduct for Research Involving Humans (TCPS2), the Ontario Personal Health Information Protection Act (PHIPA, 2004) and the applicable laws and regulations of Ontario. Members of the NMREB who are named as Investigators in research studies do not participate in discussions related to, nor vote on such studies when they are presented to the REB. The NMREB is registered with the U.S. Department of Health & Human Services under the IRB registration number IRB 00000941.

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