



Working with Families of Students with Disabilities in Primary Schools

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Abstract

Internationally, jurisdictions are enacting legislation and comprehensive procedures that recognise the right of all students, irrespective of their abilities, to receive an education at their local school. As well as recognising this right, schools are increasingly being held accountable for making appropriate adjustments and accommodations that facilitate learning for students with disabilities. Despite this, surveys of parental attitudes consistently find significant concerns with the implementation of inclusive practices in primary schools. The need for educators to work collaboratively with parents and families with children with disabilities has repeatedly been stressed in the early intervention and effective schools literature. Well documented advantages of closer school-family relationships include smoother transitions into school, higher levels of academic achievement, improved acquisition of reading, higher motivation for learning, and fewer school-based behavioural problems. Importantly, there is evidence that the effects of parental involvement in schools may also be stronger during

the primary, rather than the secondary school years. Long standing research has highlighted that teachers believe that building parental and family engagement with schools should be a priority and that professional development to support teachers to work collaboratively with families is required. In this chapter, international findings from quantitative surveys of parents' perceptions of inclusion will be reviewed and summarised. Although early research in the US found that parents with children with disabilities often reported less favourable attitudes towards inclusion than parents of typically developing children, more recent findings indicate strong support for inclusion across various parental groups in widespread jurisdictions. Parental support for inclusion has been found to be influenced by the prevailing social norms, and it is likely to be enhanced when key education professionals promote inclusion as a school norm. In addition, findings from qualitative research will be reviewed which suggests that even in jurisdictions which have been at the forefront of developing inclusive education practices, parents often report feeling disempowered. Too often parents continue to report that inadequate school supports, the use of gate-keeping, and other restrictive practices prevent students with disabilities from accessing the full range of curriculum options that are available to their peers. It is argued that the use of seven collaboration principles and

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best-practice individual plans (IPs) can be effective to ensure families are respected partners in the education of children with disabilities.

Keywords

Inclusive education · School-family collaboration · Parents' perceptions · Primary school

15.1 Introduction

15.1.1 Parental Involvement with Education

Parental involvement in students' education has been defined and measured in different ways; however, a consistent finding from the broader educational literature is that when parents keep in contact with teachers and are involved in school activities, particularly in the primary school years, better outcomes on a range of measures are found. Advantages of having parents involved in schools include smoother transitions into school, higher levels of academic achievement, improved acquisition of reading, higher motivation for learning, and fewer school-based behavioural problems (Jeynes 2012; Kohl et al. 2000; Perkins 2014; Shute et al. 2011; Wilder 2014). The effective schools literature also highlights that by strengthening positive family connections and by buffering potentially negative family influences, schools can obtain better learning outcomes for their students (Reynolds et al. 2016).

Parents of children with disabilities have played a critical role in advocating for better support, improved services, and increased opportunities for their children to attend mainstream schools. Parents typically decide which school their child attends and entrust the school to educate and socialise their child. The extensive knowledge that parents can bring to a school about their child's needs and how to manage their child's behaviour is invaluable for both

teachers and support staff (Ashman 2015; Leyser and Kirk 2004; Turnbull et al. 2015).

15.1.2 Parents' Perceptions of Inclusive Education

Three decades of intermittent Western research have confirmed that most parents of children both with and without disabilities hold positive perceptions towards inclusion. Pioneering studies even found that some parents preferred to have their typically developing child in a multi-ability classroom because best-practice inclusion was seen to improve learning, behaviour, and the socialisation of all students (Lowenbraun et al. 1990). Kelly (2001) surveyed parents in Nevada, US, and found consistently favourable ratings for inclusion. However, statistically significant higher ratings were found for parents of children with disabilities on two out of the six questionnaire items they used. These items related to the social benefits of inclusion and the need to place special education teachers in mainstream classrooms.

Peck et al. (2004) found that 64% of US parents surveyed after their typically developing child had been taught in an inclusive classroom held positive attitudes towards inclusion. A further 26% of their sample were neutral towards inclusion. If given the opportunity in the future, 73% of parents indicated they would enrol their child in a classroom that included children with disabilities. Parents of typically developing children frequently noted the social benefits that inclusion provides for all students.

As well as highlighting the benefits of inclusion, parents of typically developing children in Australia, the US, and Western Europe have at the same time consistently articulated concerns with integration. Earlier research findings (e.g., De Boer et al. 2010; Duhaney et al. 2000) concluded that parents were concerned that teachers in multi-ability classrooms would lower the expected achievement standards for all students, irrespective of the students' ability level. As a consequence, parents believed that less time

would be available to deliver quality instruction. Parents were also concerned that children with disabilities could use inappropriate behaviours or communication and that undesirable behaviours could be copied by their classroom peers.

In addition, De Boer et al. (2010, 2011) emphasised that parents' attitudes and behaviour will have an influence over the attitudes and behaviours of their children. Parents who did not support inclusive education were seen to have a negative influence over their child's attitudes and behaviour. In turn, this affected the way their child perceived and interacted with school peers. Finally, parents have consistently reported that there is a lack of training for teachers in how to effectively manage inclusive classrooms (De Boer et al. 2010; Duhaney et al. 2000; Elkins et al. 2003).

From their international review of the literature De Boer et al. (2010) found that a prominent concern of parents of children with disabilities was related to the amount of individualised instruction and teacher attention their children would receive in inclusive classrooms. Additionally, the extent to which parents of typically developing children accepted having children with disabilities in regular classrooms was an important consideration for parents of children with disabilities. Overall, early studies concluded that parents of children with disabilities were more likely to hold more negative attitudes towards inclusive education than parents of typically developing children.

Irrespective of where research has been undertaken, or whether survey respondents were parents of a child with a disability or not, significant concern about the preparation of regular teachers to support children with disabilities has been consistently noted (Elbaum et al. 2016; Leyser and Kirk, 2004; Love et al. 2017; Starr and Foy 2012; Westwood and Graham 2003; Whitaker 2007). Leyser and Kirk found that more than a quarter of parents surveyed felt that inclusive classroom teachers are unable to adapt classroom programs for students with a disability. Similar comments were made by Australian participants in a study conducted by Elkins et al. (2003). Parents felt that teachers and school staff

tried to meet students' additional needs, but lacked the knowledge and skills required to effectively teach their child.

More recently, Love et al. (2017) concluded that the situation had not changed and that specific school structures and institutionalised procedures regularly exclude parents from school decision making processes. Teachers continue to report that working with families is one of the most challenging aspects of their work and that they do not have the skills and knowledge to collaborate effectively with families (Elbaum et al. 2016). Adding to this concern, Rodriguez et al. (2014) found that just as many parents became involved with schools because of their child's unsatisfactory educational progress as those who became involved because of proactive family engagement attempts that were initiated by school personnel. The future of classroom preparedness for inclusive education is anticipated to improve as nations employ the United Nation's Sustainable Development Goals (SDGs). The promotion of and guidance towards equitable education for all will facilitate inclusive structures that parents and teachers can help create, manage, and implement.

Participants in Whitaker's (2007) research in the UK highlighted how a lack of understanding of disabilities was linked with a failure to deploy appropriate, inclusive teaching strategies. Concerns were raised by parents about the lack of resources and support materials available to teachers in mainstream schools. Runswick-Cole (2008, 2011) conducted in-depth interviews with parents of children with disabilities and concluded that schools in the UK continue to construct barriers that hamper inclusion. Parents often believed that schools lacked the experience and commitment that is necessary for successful inclusive education. Of significant concern, some parents believed their children were being taught almost entirely by teaching assistants and that individualised instruction from the classroom teacher was very limited. This was more likely to be the case when students had more substantial learning needs.

Leyser and Kirk (2004) found the severity of the child's disability, the child's age, and the

number of years the child had been in mainstream schooling were related to parents' perceptions of inclusion. The level of schooling a parent had completed, as well as their occupation, also influenced their perceptions. Parents with more favourable perceptions had children with milder levels of disability, had younger children, and their child had only been in a mainstream school for a year or two. Parents with higher education levels were more positive towards inclusive education, and this was explained by their better access to information and resources. It has also been recognised that a parent's culture is likely to influence their perceptions of inclusive education (Carter et al. 2012; Duhaney et al. 2000) and the different experiences of non-Western parents warrant further investigation. Nevertheless, results from a recent Hong Kong study are broadly consistent with the above findings. Major variables that predicted positive perceptions of inclusion in Hong Kong were parental knowledge and the promotion of inclusion as the social norm for schooling by key stakeholders (Lui et al. 2015).

15.1.3 Contemporary Parental Perspectives and the Reality Gap

In contrast with early findings, more recent Western studies have found even stronger support for inclusion. Sosu and Rydzewska (2017), for example, reported that 90% of parents in a nationally representative Scottish sample held a generally positive overall perception of inclusive education. When more specific perceptions were examined, such as the benefits of inclusive education for typically developing children or children with disabilities, perceptions were less favourable. Similarly, in our own research, Stevens and Wurf (2018) reported that the majority of parents that were surveyed strongly agreed that children with disabilities have the right to be educated in inclusive settings. Parents also agreed that inclusive education benefits their children.

Stevens and Wurf (2018) also reported that parents' satisfaction with inclusion was more varied than their strong belief in the right of children to be educated in inclusive settings. Parents we interviewed were 'undecided' about the progress their child was making in inclusive classes and expressed concern about the ability of teachers in primary schools to support inclusion. This included expressing negative or undecided perceptions about teachers' knowledge of and ability to deliver individualised instruction. Further, parents were concerned about the lack of specialised supports that could be accessed in mainstream primary school settings.

While quantitative investigations into parents' perceptions have continued to show strong, and even increasing support for inclusive education, qualitative analyses of parents' satisfaction with inclusion have highlighted significant concerns with the uptake of classroom practices that foster inclusion. From our work with parents, inclusive education was seen as having multiple, beneficial effects, and all parents agreed that it was a right of children with disabilities to be educated in mainstream schools. Parents felt that inclusion prepares all children for the real world and that it provides children with disabilities the opportunity to participate in a wider range of activities than are offered in specialised schools. Inclusion also provides opportunities for all students to learn about individual differences. In contrast to previous research which found parents of typically developing students had significantly more positive attitudes towards inclusive education, we found no statistical differences between parents except that parents of children with disabilities were more likely to strongly agree that it is their child's right to be educated in mainstream schools. This may reflect a growing awareness and acceptance of inclusive education within Australian schools.

When we discussed inclusive education with parents, a gap between the ideals of inclusive education and school practices was evident. Parents' generally positive perceptions of inclusive education were tempered by the reality of

everyday school practices, and they raised broader themes related to ongoing discrimination, everyday frustrations, restrictive practices, and the need for well-coordinated, consistently delivered instructional programs and services for students with disabilities (Stevens and Wurf 2018).

From our research parents of children with disabilities also highlighted school practices which restricted opportunities for the broader participation in the everyday routines of school. They strongly agreed that teachers lacked adequate training in managing students with disabilities and outlined their frustrations when excursions were planned and funding/additional supports were needed. A lack of coordination and consistency in the use of discipline/consequences and inconsistent school-home communication about educational performance were specific issues noted by parents.

Parents also discussed their frustration with a lack of appropriate resources, negative peer influences, and a lack of understanding by staff about the needs of students with disabilities. Many of these issues appear to be systemic, school-wide issues, rather than specific issues with individual class teachers. Poed et al. (2017) found similar concerns across a survey of Australian parents and advocates for children with disabilities. They noted that 70% of respondents reported that one or more instances of gate-keeping and other restrictive or exclusionary practices had been used by schools. Practices that were reported included students spending large amounts of time outside the classroom, being sent home or suspended for minor transgressions, limited instruction from the teacher, and inadequate support from teaching assistants. Worryingly, practices that may breach policy and law were also reported including the use of restrictive practices for behaviour management and refusal by some schools to enrol a child with a disability.

From our research it was not uncommon for parents of children with disabilities to feel that they were treated differently by both teachers and parents of typically developing children. Parents of children with disabilities acknowledged that they may pose a greater problem for classroom

teachers than parents of typically developing children. They felt that they are often perceived as ‘helicopter parents’, continually hovering around the school to check on their child. Frustration with the perceived inappropriate spending of government allocated funding was common. Parents felt that funds were unfairly allocated and they should be prioritised to support students with the highest needs. Better targeted funding that was directed towards training teachers in inclusive education and supporting a wide range of learning and behavioural disorders was preferred.

Despite the need for regular school-family communication being stressed in their early research on inclusion, and being acknowledged as an essential principle in best practice collaboration (e.g., Elbaum et al. 2016; Grove and Fisher 1999; Turnbull et al. 2015), parents still stated that open and honest communication was not consistently delivered. Nevertheless, good school-family communication was seen as essential for successful inclusion. Parents wanted schools to maintain an explicit focus on their child’s education, social, and behavioural development. They were keen to hear about their child’s progress. They did not want to be constantly relied upon as an extra school resource, but they wanted to be consulted and kept up to date.

An analysis of the parent data yielded four major themes. Firstly, parents perceived discrimination still occurred in inclusive settings. Inequalities in how students are disciplined, discrimination from parents of typically developing children, and discrimination from peers were raised as salient issues. As one parent noted:

I had parents coming up to me and going, you know, is this the best environment for your child? Shouldn’t he be at a special school?

A second theme identified was that parents were often frustrated and disappointed with educational services. In particular they were frustrated with a perceived lack of training and support for teachers, a lack of school-home communication, and a lack of empathy shown by

some school personnel and peers towards students with disabilities.

Some teachers ... don't seem to have empathy and understanding of what's going on. It could be as simple as the lights too bright ... or the fan ... making too much noise... some teachers seem to think [students] are using that as an excuse for their behaviour when they are not, it's a sensory thing ... it's a real issue.

Participants also outlined how parental knowledge can contribute to more effective educational outcomes and that when schools promote open and regular communication with parents, additional expertise can be accessed.

Listen to the parents, we know our children ... first and foremost I am an expert on my child.

All parents agreed that while some school staff were excellent, there was a lack of on-going school wide professional development related to inclusive education. Frustrations with funding were also raised, and there was a perception that teaching assistants worked with students with the greatest behavioural challenges, rather than students with established disability diagnoses and targeted funding.

I get frustrated because I think teachers blame the lack of funding too much. At the end of the day you've chosen to be a teacher, you should have the children's best interests at heart and you should do the training that needs to be done to cater for that child. If you're serious about education and you're serious about your students then you go out and you educate yourself.

A third theme related to restrictive practices and exclusion from participating in a full range of educational opportunities. This theme was especially apparent when excursions and other school events were planned. Often, planning failed to take account of the needs of students with disabilities because of poor planning access to activities was often restricted or denied.

I probably have a tiny issue with ... a couple of excursions that require walking and they don't have an aide. If I can't go to the school, [my child] is actually excluded. ... they'll ring me [and] give me the option of keeping him home for the day. ... I've said to them to ask [my child] what he wants to do, whether he wants to go to the library or he's happy to go on the iPad.

A final theme was the lack of well-coordinated, individualised, and consistently delivered services and strategies to support learning for students with disabilities. Parents felt that teachers were sometimes inconsistent with implementing discipline strategies and in utilising resources. All parents agreed on the need to maintain consistent and coordinated approaches. As one participant stated, an issue at her child's school is

Not following through with the strategies, getting comfortable with them and thinking they don't need them.

Another participant stated that while her child was consistently disciplined for inappropriate behaviour, other students were not disciplined for the same behaviour.

... some of the kids ... bait him and they'll stir him up and they'll push him to the point where they know he is going to snap ... he is the autistic child, so he is the one ... who's gonna get into trouble.

Although parents of children with disabilities and parents with typically developing children held similar, positive attitudes towards inclusive education, it was also evident that parents of children with disabilities struggle with additional school related issues. As Carter et al. (2012) argued, parents are not just support networks for schools or recipients of information. Our research suggests that parents need to be clear about what they want from an inclusive school setting and schools and teachers need to be consistent in providing agreed supports. Findings from as far back as 1997 (Bennett et al. 1997; Carter et al. 2012; Grove and Fisher 1999; Elkins et al. 2003; Leyser and Kirk 2004; Westwood and Graham 2003; Whitaker 2007) have highlighted that whereas parents and teachers are generally positive about inclusive education they are dissatisfied with the lack of specialist professional development for teachers and the transparent allocation of resources. These results again underscore that high levels of parent-teacher collaboration need to be maintained for inclusion to be successful. It is one thing to have positive perceptions of inclusive education, but these perceptions need to be put into effective

practice and to be supported by ongoing education and professional development. Similarly, if the targeting and training in the use of additional resources is ineffective, then the value of these resources will remain limited.

15.1.4 Teachers and Students' Perceptions of School-Family Collaboration

The educational literature acknowledges that it is not just parents who want closer communication and involvement with schools. Building parental engagement with schools has also been widely recognised as a long standing, key priority by many teachers. In a comprehensive Australian survey of 4574 teachers, for example, 82% of respondents identified that they required additional professional development in order to work more effectively with families (Doecke et al. 2008). Indeed, working with families was the most requested professional learning activity. Teachers have also been found to share similar perceptions as parents in relation to the need for more comprehensive preparation and ongoing training in inclusive education (Boyle et al. 2013; De Boer et al. 2011; Westwood and Graham 2003). Within the academic literature extensive concerns have been expressed about the quality of the preparation provided in initial teacher education courses as well as the need for additional programming time.

Students also recognise the overarching importance of family in their school learning and personal well-being. Results from a representative sample of years 4, 6 and 8 students who participated in the Australian Child Well-being Project showed students consistently ranked family above school, health, friends, neighbourhood and money/things as the most important factor in their well-being (Redmond et al. 2016). There is also strong evidence showing that when children are involved in setting educational goals and are consulted about solutions for challenging behaviours their learning and behaviour improves (e.g., Greene 2018).

15.1.5 Collaboration and Individual Planning

When considering high leverage practices for educating students with disabilities, McLeskey et al. (2017) identified collaboration as a key element in ensuring effective learning and teaching. Collaboration with families/caregivers and other professionals has been found to be essential in designing and implementing effective educational programs that meet the needs of students with disabilities. Turnbull et al. (2015) identified seven principles that are supported by research and best practice recommendations to define collaboration. These seven principles are as follows:

1. **Communication:** Teachers and families communicate openly and honestly in a way that is accessible for the family.
2. **Professional competence:** Teachers have the qualifications and competencies to work with diverse students, are committed to life long learning and hold high achievement expectations. High expectations are communicated to students and families.
3. **Respect:** Teachers treat families with dignity, honour cultural diversity, and affirm family strengths.
4. **Commitment:** Teachers are available, consistent, and go 'above and beyond' what is expected.
5. **Equality:** Teachers recognise the strengths of teams, avoid hierarchies and foster empowerment. They focus on working in partnerships with families.
6. **Advocacy:** Teachers focus on forming partnerships with families and getting the best solution for students.
7. **Trust:** Teachers are reliable and act in the best interest of the student, sharing their vision and actions with the family.

Although the benefit of collaboration with parents is well acknowledged, effective partnerships are not necessarily easy to achieve. Collaboration is influenced by a range of factors including the amount of time and ongoing effort

that is required to build trust and sustain open communication (Murray et al. 2013). Conflicts can also occur when teachers and parents' priorities differ. It may be necessary to overcome past negative and difficult interactions to build trust. Further, family experiences with the recurrent grief that can accompany parenting a child with complex disabilities and significant socio-economic disadvantage can complicate effective collaboration with schools. Adding to this, efforts to promote school-family collaboration are likely to be even more crucial and difficult to achieve when students lack family support for their learning.

In work where we analysed data obtained from a sample of regionally located students in socio-economically disadvantaged, inclusive schools (Hall and Wurf 2018) students identified issues with low family support for their school learning. Using the Student Engagement Instrument (SEI; Appleton 2012; Appleton et al. 2006) our data revealed that students rated teachers highly on subscales measuring supportive student-teacher relationships and the use of classroom behaviours that promote engagement with learning. In contrast, the lowest ratings on the six subscales that are derived from the SEI were obtained from students' ratings of family support for their learning. This finding underscores the challenges for schools in collaborating with parents who have limited resources and social capital to support their child's learning. A direct policy implication is the need for increased coordination of services offered by schools, health authorities and family support/welfare organisations to ensure socio-economically vulnerable families have sufficient resources to enable young students with disabilities to experience success at school.

Fundamental to the delivery of appropriately tailored educational interventions for students with disabilities has been the Individual Plan (IP). IPs are student-centred and articulate specific goals for learning as well as individual learning needs and supports. McLeskey et al. (2017) recognised IPs as a high leverage educational strategy for delivering services to students with disabilities, and it is not uncommon that

they are required to be reviewed regularly, at the least on an annual basis. Blackwell and Rossetti (2014) cite a range of evidence that links active involvement of students and their families in the IP process with improved learning outcomes.

Despite this, it is not uncommon for families to leave IP meetings feeling overwhelmed and to report that they did not understand the proceedings. Family members have also been noted to be more passive recipients of information at IP meetings, rather than equal and active partners (Hammond et al. 2008; MacLeod et al. 2017). Too often they feel like outsiders in the process. Without a strong foundation of collaboration, the effectiveness of the IP in improving learning outcomes is diminished. To improve this process it is recommended that families be given multiple opportunities for full participation in the IP process (McLeskey et al. 2017). This can include measures such as sending out information and maximising opportunities for participation in the planning and assessment process prior to the actual IP meeting. The value of all team participants input into the IP needs to be stressed and equal partnerships honoured. McLeskey et al. further highlight teachers' roles in encouraging families to learn how to self-advocate and to effectively support their child's learning.

As well as embedding best-practice school-family collaboration into the IP process, Elbaum et al. (2016) found that out of the multitude of specific strategies that have been identified to improve school-family collaboration two additional strategies were most predictive of positive school-family partnerships. Firstly, schools with teachers who were responsive to family input more generally i.e., beyond just input into the development of the IP, obtained higher ratings on measures capturing school-family collaboration. Responsive communication was timely, respectful, accepting and positive. The second strategy involved the rigorous monitoring of student progress and providing periodic feedback to parents. This feedback should include information about positive progress and alerting parents to any challenges and problems with progress. Elbaum et al. recommend direct invitations to parents to participate in a problem solving

process as a follow-up activity when problems are recognised. Both responsive communication and regular feedback about academic progress underpinned successful school-family collaboration with families of students with disabilities.

15.2 Conclusion

In this chapter, evidence has been reviewed that demonstrates strong and increasing support for inclusive education by parents of children with and without disabilities. Support for inclusion has been found to be strongest in the primary school years. Nevertheless, parents have also repeatedly articulated a range of concerns with the actual practice of inclusive education in primary schools. These concerns include: ongoing discrimination, frustration with the lack of adequate training for teachers and support staff, and the use of restrictive and exclusionary practices. Parents were also concerned about poorly coordinated and inconsistent use of effective instructional strategies and school-family communication.

It was argued that school-family collaboration using the seven principles outlined by Turnbull et al. is essential in designing and implementing effective inclusive education. The IP was seen as fundamental to the delivery of appropriately tailored instructional programmes, and IPs are enhanced when families are actively included in the pre-assessment of student's learning needs and goals, as well as the actual planning meeting. Nevertheless challenges with collaborating with families were acknowledged. Evidence was reviewed that suggests that students facing significant disadvantage may rate family support for their learning much lower than the support they receive from schools and teachers. The role of teachers in promoting self-advocacy by students and their families is highlighted, as well as teachers' roles in educating parents about how to best support their child's learning. The role of responsive teacher communication and regular feedback about academic progress was stressed in successful school-family collaboration with

families of students with disabilities. Furthermore, families can provide valuable inputs that can help schools develop inclusive education policies and ensure equal learning opportunities for all students.

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