

Fostering teacher understanding of parent issues when a child has a disability: A brief report

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The paper reports on parent survey comments to raise awareness of teachers of children with disabilities and facilitate the parent-teacher collaborative experience. The Life Management Survey (LMS) was designed (Scorgie, Wilgosh, & McDonald, 1997) to corroborate nine themes (Scorgie, Wilgosh, & McDonald, 1996) identified through in-depth interviews, on parent effective life management strategies, personal qualities, and transformational outcomes from parenting children with disabilities. For 196 parents of children with disabilities in two Canadian survey studies, written comments supplementary to parent responses on the LMS were examined to give teachers insight into perspectives parents bring to the parent-teacher collaborative process. The paper will focus on the primary roles parents have identified as parents of children with disabilities. These include roles as child's advocate, facilitating decision-making on educational and other life choices; as information gatherer and resource; and as creative problem-solver. Each of the parent-identified roles is richly supported by the parents' written comments.

The focus of the paper is on fostering parent-teacher collaboration by raising teacher awareness of perspectives of parents of children with disabilities. Previously unanalyzed parent survey comments shed some light on pertinent parent perspectives.

We have been conducting research for over 10 years on parent effective life management when a child has a disability. Over that time we have identified and extended our understanding of nine themes related to parent effective life management, originally identified through a qualitative/interview study (Scorgie et al., 1996), with themes covering parent effective life management strategies, personal qualities, and

transformational outcomes from parenting children with disabilities. These themes have been corroborated over four survey studies using the Life Management Survey (LMS) with parents of children over a range of ages and disabilities, in Canada (Scorgie et al., 1997; Wilgosh, Scorgie, & Fleming, 2000) and cross-nationally in Italy (Nota, Soresi, Ferrarai, Wilgosh, & Scorgie, 2003; Wilgosh, Nota, Scorgie, & Soresi, 2004). In addition, we have continued our qualitative research longitudinally and cross-culturally, developing a model of the parent transformational process (e.g., Scorgie, Wilgosh, & Sobsey, 2004), based on parents' reports of how they have been transformed as parents of a child with a disability.

Andrews and Lupart (2000) stated that parents and teachers can work well together in meeting children's educational needs when they have awareness of each other's respective roles and responsibilities. By actively involving parents in the schools, collaborative partnerships can be developed. Parents' comments about how they have been affected by parenting a child with a disability can also serve to provide teachers with insight into parent strengths and concerns.

Carter, Clark, Cushing, and Kennedy (2007) emphasize the strong link between parent involvement and student achievement, and the need for schools to encourage parent involvement, particularly as their involvement tends to fall off over the years of schooling.

Therefore, the purpose of this paper is to examine the comments the Canadian parents have written, related to and in addition to their responses on the LMS, which instrument requires responding to items on a five-point scale and allows for additional written parent comments for each item and the scale as a whole. These comments have not been examined previously, and the specific purpose of doing so now is to provide possible insights into parenting issues for teachers, to facilitate the parent-teacher collaborative process. It is hoped that, through increased awareness of parent comments on their roles and responsibilities as parents of children with disabilities, teachers may come to a greater understanding of parental issues, thereby promoting positive parent-teacher relationships in the education of children with disabilities.

Procedures

The first Canadian LMS study was conducted with parents who had been identified as managing life effectively, by support agency personnel, who distributed the survey by mail to the identified families. For the first study (Scorgie et al., 1997), LMS responses were returned by mail by 80 parents of children with a broad range of ages and disabilities. The second study (Wilgosh et al., 2000) used the same procedures, but broadened the focus to all parents of children with disabilities, not just parents who had been identified as managing life effectively. LMS responses were returned by 116 parents. This gives a total of 196 parent LMS completions, from which parent written comments have been reviewed, to select those best representing parents' perspectives on parenting children with disabilities as related to the parent-teacher collaborative process. These will be organized into topical areas for discussion.

Results and Discussion

Parent comments fell into five topics or categories, each of which will be outlined briefly and illustrated directly by parent quotations. In the final section of the paper, implications of each category for teacher-parent collaboration will be articulated.

Valuing the Child

Parents of children with disabilities offer insights for teachers and others into recognizing the inherent worth of individuals with disabilities to their families and broader communities. Parents accept and recognize their child with a disability as an individual with unique strengths and challenges. "It's important to accept who your child is really, not to accept others' views." "All children need to feel fully loved, warts and all, as they are, for themselves. You do not have to like the disability, but need to see the child first." "I do not accept bad behaviour. It is hard sometimes to figure out what needs to be changed (e.g., swearing, undressing in public), what can be changed, and what you must simply accept."

Parents value what their child has brought to the family. "One must value

each child and what they bring." "All children need to feel valued as a person of worth and have their talents and work recognized." "We are all individuals with very different qualities, talents and abilities. Each of us can contribute to our separate levels in our own ways." "We don't celebrate this enough sometimes." Parents report that their child with a disability has positively affected the lives of others. "Certainly has raised self-esteem for certain individuals who have assisted our son." "Made others thankful for their blessings and aware of the needs of the disabled."

Responsibility and Decision-making

The issue of responsibility for the child's well being and success has been seen as strongly within the control of the family. "I will not let others control me or my son. I am his mother and I know him better than anyone." "The child and family have control of what is considered success for them." "We do not accept or allow others to control our circumstances." "I do not believe my success or my son's success is in control of other people or circumstances. I view them as resources and I am responsible for accessing and coordinating what is best." "His or our success is under the control of other people and external circumstances only to the degree that we allow." "I do not believe that our family's success is under the control of others. I feel that our success is primarily a result of our choices." Parents strive to discover what their child views as important, so that the child has consideration and responsibility in the choices made. "When we have failed as a family, it was in not considering our child's views but accepting others' views instead." "All children need to be heard and their views respected and encouraged to aim for their goals." "Unless we and the existing community recognize our child's interests, it's not likely that his fullest potential will be reached. Schools also need to treat special needs persons as individuals, not as a category." "We have been able to establish this by giving lots of opportunities and choices."

Parents believe that they know as well as anyone else what is right for their child; they trust their instincts. Many parents indicated that they know their child best. "I feel the parent usually knows best but needs support to carry it out." "No one else has the right to decide what is best for my child." "I do know my son best and it is essential that professionals and

government recognize this." "It's very easy to be intimidated by others, even when you have a good educational background. Not trusting myself has led to negative experiences for our son." "We know her as a whole person not a disability or some thing to be fixed."

Parents want their child to learn to make decisions but recognize that they may always have to be involved in decision-making for their child. "I believe my child can learn to make decisions as long as he has support from family and friends." "I believe in empowering my daughter to make decisions for her life." "Give as much choice where possible to the child." "Expect the most from your child - they may surprise you, and prepare for the time when you aren't there to make decisions for them." Tied to this point, parents want their child to be a part of the decision-making process, making choices. "He knows what he likes and needs to be included." "When he feels control, he manages his behavior better." "This helps the child to develop control over his/her own life and as a result there are fewer problems with behavior." "Learning occurs if one is active and allowed to make mistakes. Living independently requires making decisions."

Advocacy/Parent as Expert

Parents have learned to feel self-confident as advocates for their children, and are not afraid to speak out. "The children often don't get what is needed unless you speak out." "If parents don't get involved, their children will fall through the cracks." "My child's success depends on my ability to advocate for him." "Very sad too many parents are too intimidated to speak out." "Just being stubborn and not giving up. Believing she has a right to lead as normal a life as possible." "I didn't have confidence to ask questions in a group forum or meeting; needing to advocate changed that!" "The parent who accepts the status quo has lesser chance of success."

Parents have had to become experts on their child's condition, collecting and categorizing information. "Because you are the advocate, you need to be a knowledgeable one." "Knowledge is strength and shows choices." "Knowledge of the condition has helped in understanding the child's behavior and learning problems and what services and programs to use." "To gain more information, I gained more skill in problem-solving and

motivation techniques."

Parent-Professional Collaboration

Parents recognize that they cannot do everything alone, they must be willing to accept help. "Our failures were when we did not reach out for help." "Rely on the professionals and their expertise, as long as these same people recognize no one knows my child like we do." "To co-operate/work with those who have skills and insights I don't have allows much greater progress and development. Nobody can do everything alone."

Parents caution that they must set limits on external expectations, balancing roles of parent, teacher, and child advocate, because they are first and foremost the child's parent. "The system has forced us into an unbalanced role." "Seems the advocacy role is growing and sucking up a lot of energy." "It's all a balancing act - you learn by trial and error." "I learned to be a mom first and not turn into a teacher only, but to work teaching into the normal home routines as possible." "Always an expectation for parents to do therapy or be the teacher."

Parents have developed skills in working with professionals, encouraging a team approach. "Get a lot further if we work together." "We need to work together and respect each other equally." "Often parents are still looked on as inferior team members." "I am learning that I have to be a role model to set a positive focus for the team. Anger plus frustration do not ultimately help my child." "Sometimes professionals need to listen." "Some of our greatest support has been from professionals in the education system." Creative problem-solving has been essential to the process. "Ask questions, question everything, is it working? There is always an answer or solution out there." "If something doesn't work, change it." "Problems arise that are very unique so solutions are usually very creative." "Encourage innovative and creative solutions to problems."

Parent Strengths

Parents have indicated that they have developed strong personal qualities and characteristics as a result of parenting a child with special needs. A

number of qualities frequently named by parents will be listed, along with parent written comments. (1) Creativity: "Because our daughter's condition is so rare, we have had to be creative. We have always had the attitude that she can and will progress." "If it doesn't work, try something else." "Ready to 'swim against the tide' to meet his need." (2) Determination: "Stick to your guns. Do not worry about rocking the boat." "If I was not determined I would have quit a long time ago." "Never give up, no matter how hard things seem." "If it wouldn't have been for my determination this child may not have survived." (3) Flexibility: "I believe it's important to listen and to negotiate." "We had to proceed by 'trial and error.' No maps to guide us." "Very important to be flexible to handle setbacks." (4) Self-esteem: "Believe in yourself and what you are doing." "I need good self-esteem in order for my child to succeed." "My self-esteem developed as I advocated on behalf of my son." (5) Patience: "Need lots, lots, lots of patience." "Things take a long time to happen." "What appears impossible many times has happened when patience and expectation are teamed up appropriately." (6) Positive Outlook: "Look at the 'tiny' steps of achievement." "Always look for positives, they will be there." "Try to find something good in everything he does, even the negative." (7) Resourcefulness: "If I can't find an answer, I'll find someone who might." "Always more than one way to do something." "If you do not know the information, find it. If your doctor doesn't have it, give it to him." "A parent needs to know resources to help us suit our child's needs." (8) Sense of Humor: "Laughing is better than crying." "A good laugh makes any situation lighter." "The special needs person already has enough 'negative pull' without emphasizing it." (9) Willingness to Grow and Learn: "If you don't learn, how can you teach your child." "We are amazed at how much we have learned through our having, caring for, and loving this delightful child." "Our son's development has depended on our knowledge of developments and progress in other places." (10) Strong Personal Convictions: "Without strong convictions you would give up." "You have to believe in what you are doing and that you are doing it for the right reasons." "Parents need to demonstrate their belief in their child's ability and worth." Weill (2007) captured this sense of parent strength with the statement, "You don't want to ever have to tell your kids that you DIDN'T TRY your best" (p. 154).

Summary and Conclusions

The common thread throughout the parents' comments is their certainty that they know their child best and want a major role in making decisions for their child with a disability. They value each child with his/her unique strengths and challenges, talents and abilities. They emphasize the positive effects of their child on the family and the community.

They believe they have the primary responsibility for their child's well-being and success, recognize their strong need to be involved in the decision-making with regard to their child, and want their child to have experiences in choice-making to develop his/her own decision-making skills, to the extent possible. (To illustrate strategies for teaching choice-making to students with severe disabilities, see Stafford [2007].)

Their strong conviction that they have primary responsibility for their child has reinforced their development of a strong knowledge base on disability and confidence in their advocacy skills. They recognize, however, that they cannot do it all alone, and rely on professional collaboration, with the proviso that their role as parent comes before expectations that they serve supplementary roles as teacher, facilitator, etc.

These parents are strong parents, with creative problem-solving skills, determination, resourcefulness, and definite personal convictions. Teachers must demonstrate clearly that they value each child. They must recognize the parents' roles and responsibilities in problem-solving and decision-making as well as parents' strong advocacy and other strengths, and their knowledge base related to their child's disability. Recognition of these parent qualities and strengths can only enrich the parent-professional collaborative relationship. Teachers should be prepared in pre-service and in-service programs to work directly with these parents, recognizing their strengths without being threatened, as true collaborative partners (Brownell & Walther-Thomas, 2007).

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