LIVING AND LEARNING IN THE COMPANY OF COMPLEX HEALTH NEEDS:

EXPLORING PERSPECTIVES OF STUDENTS, PARENTS
AND EXCEPTIONAL PROFESSIONALS

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Abstract

School children who live with complex health needs that include respiratory technology dependence face more challenges than their well peers and require multisystem involvement. A recent mixed methods study of children and parents living with these needs in Midwestern Canada is described. Findings based upon qualitative interviews with participating children, their parents, and two educators identified by the parents as exceptional, are presented. Their perspectives on “what works” point to important strategies and unique insights consistent with best practices in inclusive education and characterized by the core elements of caring, competence, communication and collaboration. These new understandings can help to foster and validate the development of efficacious counselling and support approaches.

Introduction

Children living with chronic health needs and disabilities make up 15-20% of the proportion of children living in North America (Berk, 2007). Those who live with complex health needs are entering the community in increasing numbers. This is attributable in part to advances in medicine and technology, which have helped many more children to survive previously fatal conditions and move on to pursue a full life in the community. While being a cause for celebration, a new lease on life is not without its costs, as the child’s health needs continue to mediate their day-to-day circumstances, demanding more of their families, as well as impacting their long term potential. School children who live with complex health needs face stressors and challenges beyond those of their healthy peers. For example, they experience disrupted school attendance, school avoidance, and academic difficulties more often than their well peers. They also experience more physical difficulties, for example, fatigue, poor concentration, changed
body image; as well as, more psychological issues such as, frustration, social isolation, anxiety, depression and poor self-esteem (Nevile & Roberts, 1999). To support these children in pursuing a successful school career it is incumbent upon counsellors and educators to be aware of what life is like for them and to understand “what works” for them and their families as they strive to succeed in living and learning.

These areas of enquiry were investigated as part of a recent mixed methods study I conducted with children and parents who live with complex health needs that include respiratory technology dependence. I was also able, in an adjunct effort, to obtain the perspectives of two educators identified by parents as exceptional, using phenomenological, semi-structured interviews. This paper presents a description of the study, its theoretical organization, method (including the challenges I encountered in recruitment and data analysis) and qualitative results specific to the school-based context. School related themes that arose from the data with respect to the children, their parents and the exceptional professionals, a teacher and an administrator, will be presented. Through discussion I will link these findings to the theoretical framework, specifically, Bronfenbrenner’s bioecological systems theory of development (Bronfenbrenner & Evans, 2000) within a resilience-based orientation. Additional theories, including relational dialectics (Baxter, 2004), coping (Folkman et al, 1986), self-efficacy (Bandura, 1997) and resilience (Rolland & Walsh, 2006), will be used to consider the patterns of coping and relationship described by participating school-aged children and their parents. The participants’ perspectives on “what works” in this regard, will be seen to provide important evidence and unique insights that align with best practices in inclusive education, school communities, and home-school collaboration.

Area of the Writer
I have worked as a child life specialist, serving the psychosocial needs of children and families in pediatric hospital settings for 25 years. During this time I have witnessed a dramatic increase in the proportion of children and families who are affected by chronic, complex health needs. These children and their families experience frequent and prolonged hospital stays and significant alterations in their lifestyle.

Over the past decade I have primarily served children and families who must learn to live with complex health needs that include respiratory technology dependence. I have been present as a support person in their hospital lives, as they grapple with the grief of unrealized full health, learn to adjust their lifestyle to the hospital’s routines, pursue new goals and realign their priorities. I have helped them cope when confronted by crises and setbacks, and celebrated their victories as they strive towards fuller health and development. Within this context I have witnessed some family members who are able to rise to the multiple tasks set before them with courage and hope, the power engine of resilience. I have also witnessed those who are affected by the destructive nature of avoidance, aggression, depression, and addiction. I have asked myself what is it that works best to help children and their families navigate these adverse waters?

Not all of the children make it to the community, but for those who do – usually with the assistance of multi-system supports - the community presents its own challenges and rewards. Now that I am a graduate education student, pursuing training as in counselling, I seek to understand the patterns of coping and relationship that these children and parents experience as “working for them” as they pursue life in the world, beyond the hospital’s doors.

Context
I undertook the study in a major urban pediatric healthcare centre, situated in Midwestern Canada, and serving a large region including rural and remote Northern communities. Data collection occurred over an 18-month period ending in 2010.

The social-historical context in which the study is situated is noteworthy due to recent developments in both education and healthcare:

- The development and subsequent advocative efforts by the disability rights movement in Canadian society has led to its structural integration, with the introduction of the Canadian Charter of Rights and Freedoms in 1982, which enshrined the rights of all citizens, regardless of ability, to equal treatment under the law (Dworet & Bennett, 2002). This new direction is now being formally integrated into the structure of public education systems, with the passing of provincial legislation and the implementation of practices and procedures that promote the use of inclusive education practices (Hutchinson, 2002). A greater emphasis on early intervention and differentiated teaching has also contributed to greater opportunities for children of all abilities to realize their potential.

- New developments in medical technology and care have resulted in more children surviving fatal or life-shortening conditions. New complex care technology has led to the development of less cumbersome, more durable and consumer-friendly equipment suitable for use in the community. Concurrently, advanced training for parents and homecare support systems, have allowed children with respiratory technology dependence to successfully transition to the community, while continuing to receive care for their day-to-day medical needs (Rollins, Bolig & Mahan, 2005).

These two parallel developments have enabled many children with complex health needs to thrive in their communities and move on with their lives to the best of their ability.
The Child and Family Living in the Community with Complex Health Needs: Lived Experiences and Patterns of Coping and Relationship

This study was conducted to acquire an understanding of what life is like for children and parents who live in the community with complex health needs that include respiratory technology dependence. Specifically, the study focused on children who depend upon a tracheostomy and/or a ventilator (via mask if no tracheostomy) on either a full or part-time basis; participants recruited were also medically stable and had been living at home for at least six months. Furthermore, I sought to understand the patterns of coping and relationship that these children and parents’ viewed to be “working for them” within the contexts of their healthcare, community respite and school-based experiences.

Theoretical Organization

A contextual model was needed to address the multi-system involvement that is an integral part of these children and their family’s lives. Given the chronic nature of the children’s complex health needs, the dimension of time, was also a very important factor. Therefore, the model I chose to use as the study’s organizational framework was Bronfenbrenner’s (2000) Bioecological Systems Theory of Development, characterized by its multiple-level, concentrically organized and progressively encompassing systems: the microsphere, mesosphere, exosphere, macrosphere and finally, the chronosphere (time dimension). To explore the relational and coping aspects, this framework was combined with:

- **Relational Dialectics**: to address interpersonal and intersystem relational dynamics, specifically, their spiral and interdependent nature (Baxter, 2004), including those described more generally by Bronfenbrenner as “proximal processes” (Bronfenbrenner & Evans, 2000).
• **Coping Theory:** to describe the intrapersonal process of stress appraisal regarding perceived threats, and the selection and deployment of problem-focused and/or emotion-focused coping strategies (Folkman et al., 1986).

• **Self-Efficacy:** to describe the intrapersonal processes related to adaptation, specifically, in terms of the extent to which one perceives oneself to have the capacity to attain personal goals in the environment through self-initiated efforts (Bandura, 1997).

• **Resilience:** to describe the means by which people are able to navigate, rather than become overwhelmed by, the turbulent waters of adversity, and successfully arrive at their destination having acquired valuable skills and resources along the way. (Rolland & Walsh, 2006).

**Method**

**Sample and Procedure**

A mixed methods approach was used to collect the study’s data. Upon obtaining ethics board approval from the University of Manitoba, approval was also sought from the health care facility’s pediatric research activities committee and the facility’s pediatric respirology department head. Once all approvals had been secured, recruitment occurred over an eight-month period through the pediatric respirology department’s outpatient clinic. Children and parents fitting the study’s criteria were approached, offered information about the study and invited to participate. Informed consent was obtained from participating parents and adolescents, and assent was obtained from the children. All participants were voluntary and were offered the opportunity to withdraw at any time, without consequence, during the study; all participants in the qualitative portion of the study completed their interviews; four of 35 parents in the quantitative portion of the study did not return their survey packages.
Qualitative data was collected from parents and their children that were living with respiratory technology dependence, using semi-structured phenomenological interviews. The professionals identified by parents as exceptional were only contacted once those parents had given their consent for the contact, due to the disclosure of the parent and child’s identity. The identified professional was provided with information about the study and their informed consent was obtained prior to their participation. Their perspective was also obtained using a semi-structured phenomenological interview.

Parent and child interviews took place by their choice, in the family home, at a convenient time. To ensure sensitivity, I used interview schedules that had been previewed by a parent and adolescent living with respiratory technology dependence acting in a consultative capacity only on the study’s instrumentation. Parent interviews were conducted individually, children’s interviews varied according to the child and parent’s preference, with adolescents choosing private interviews and younger children electing either private or joint interviews (parent present). Professional adjunct interviews took place at the professional’s choice, in their school at a convenient time. Interviews were digitally recorded and ranged in length, depending upon the participants’ preference, from twenty minutes to two hours for children and adolescents, and up to two hours for parents. Professional adjunct interviews ranged from forty minutes to two hours.

The qualitative results related to the school experience will be provided and discussed in this paper. The quantitative results are not reported here, as they do not relate directly to the school context, however, details regarding the quantitative data collection instruments are provided below for informational purposes:
Quantitative data was collected from parents only (n = 31, representing parents of 36% of children who fit the study criteria and were served at the clinic) using a Family Information Checklist, designed for the study, and three self-report scales:

- CHIP: Coping Health Inventory for Parents (McCubbin et al, 1985), to explore family and intersystem-related coping.
- MPOC-20: Measure of Processes of Care (King et al, 2004), to explore parents’ perceptions of their relationships with their child’s health care providers.
- SCS: Self-Compassion Scale (Neff, 2003), to explore parents’ intrapersonal coping style.

The results of this aspect of the study are not directly related to the school experience and therefore are not reported in this paper.

**Qualitative Sample and Participant Selection**

I interviewed seven children and eight parents, purposefully selected for distribution across the developmental spectrum of childhood (from early years through late adolescence) and when possible, reflecting the range of respiratory technology dependence (mask-ventilation, tracheostomy, and tracheostomy-ventilator dependent). Participant details:

- One three year old boy (tracheostomy and ventilator dependent) and his mother (a custodial family member)
- Four elementary years children and four of their parents:
  - Two girls, six and seven year of age, both with tracheostomy.
  - Two boys, one at eleven years of age recently having started nocturnal mask-ventilation assistance and one at 12 years of age, with tracheostomy and nighttime ventilator assistance.
  - Two foster mothers, one foster father, and one biological father.
Two adolescents and three of their parents:

- One boy, 17 years old, and one girl, 18 years old, both formerly tracheostomy and ventilator dependent, now using night-time mask-ventilator dependent.
- One biological mother, one stepmother and one biological father.

The families in the sample were very heterogeneous in nature; however, their family structure variations were noteworthy due to the following characteristics:

- Three of the six families were single parent headed.
- Two of the six families were foster families.
- Divorce or loss of a parent during the child’s lifetime was a consistent feature in each of the four biological families, while being absent in the foster families.

I also interviewed two professionals who were each identified by a parent when they gave their interview. The two professionals consist of: a teacher situated in a private religious school setting, and an administrator in a public school setting.

**Challenges**

Recruitment took time, as the clinic I was recruiting from was held only one day a month. I learned by trial and error that it was necessary to make the transmission of study recruitment information as effortless as possible for the parents. Specifically, providing a written explanation (a pre-approved letter) was not useful unless accompanied by the opportunity to receive a timely in-person explanation between appointments on their child’s clinic day. Once I realized this, my success rate improved significantly.

The volume of data generated from this study has been huge. Data analysis has been a time-consuming but rewarding process: “the forest has a lot of trees.” A patient, methodical process and access to people with whom to discuss findings is important. Since returning to work I have
found data analysis much more challenging, as it requires sustained time, attention and focus. I have found it necessary to allocate blocks of time to the effort to attain meaningful progress. On the other hand, I have also found that this research effort has enriched and deepened my work experience and service focus with children and families in the field.

Results (School-based Context)

Data Analysis

Qualitative Data analysis took place on an ongoing basis in the field, using verbatim transcripts of interviews and field notes. Transcript content was analyzed for themes and patterns within individual interviews and categorically across interviews; thematic coding procedures and the “Find” function in Microsoft Word™, in addition to summary notes were used to identify key words and phrases that indicated emerging themes and meanings. Themes and patterns were interpreted in light of the multiple perspectives gathered. To protect the identity of the participants, given the unique characteristics of their situations, certain details were changed or modified. Individuals acting in the role of parent were referred to as such, with additional detail specific to their context (for example, foster parent, step-mother or custodial family member) included only where pertinent. The school-associated content used in this report is drawn from the perspectives of six of the study’s seven participating children and their parents, in addition to two professionals that were identified by a parent during their interview as exceptional.

Child and Youth Perspectives About School: Emerging Themes

The themes arising from participants’ perspectives ran the gamut from negative to positive. School provides a pivotal shift in perspective. Compared to the health care setting, where the child and parent occupy more dependent roles, and attention is focused on the child’s disordered health, school focuses on the child as an active learner, individually and in community.
Furthermore, school provides one of the biggest sources of community life for children and families whose lives are necessarily hemmed in by the need to keep expert hands close to the child, in a monitoring and caregiving capacity. The assistive presence of school-based nurses provide the child with the freedom to engage as an actor on their own behalf, in the social world of school, where the focus is on learning, individually and as a community, as reflected in the themes below.

**Making friends, playing and learning together.** Forming friendships was the most dominant theme in the children and youth’s school-based perspectives. Although expressed by all, it was most articulately conveyed by the older children, for example, 12-year-old Mike describes his best friend: “I have my best friend, I like him…Tim…When he was in grade three we met…he’s a very good friend and he doesn’t treat me – no bullying.”

**Getting friends’ support – helped with coping.** Obtaining social support from peers was important to children and youth in helping them to cope, in tough times and in day-to-day living, as 18-year-old Marie explains: “I didn’t really used to do that till I started high school…before it used to be just talking to the nurses…where s now it’s just my friends and just venting off each other.”

**Experiencing mastery and valued roles.** The opportunity school provided to be an active learner, to experience trying out different roles was very meaningful to children and youth, as 17-year-old Jim, who had enjoyed a work experience placement in a welding program explains: “I had a jumpsuit…had my name on it, too!...It’s in my closet right now…It’s hanging on there as a trophy …”

**Favorite teachers: those who made meaningful connections.** The child’s relationship with their teacher was frequently referred to as important, however some teachers stood out more than
others. Younger children depended upon their teacher as a source of situational support and assistance, while adolescents were attracted to teachers who used an actively engaging, respectful and personal approach. For example Jim, who reported having a very rocky school past and has taken numerous risks in his life, describes a recent, much more positive connection:

    They…talk to me like a person like, not as a student, but as a person with an ordinary life. Like, after class, they’ll…talk to me and after school, while I’m walking home they’ll stop and say ‘Hi’ if they see me…I haven’t actually had that with another teacher before…

**Being bullied and feeling marginalized.** Most of the children described experiencing some form of unkindness at the hands of others, including their schoolmates. The children described their difference in appearance, for example, a tracheostomy, as being a contributing factor. For example, Mike found it hard to make friends at times because of his tracheostomy: “They say…were you born with that?” Jim, whose narrative was characterized by an absence of actively engaged, protective adults in his life, experienced bullying as a chronic aspect of his early school life (his mother reported the school to have permitted and contributed to the bullying), followed by acting out behaviour once his tracheostomy had been removed:

    …when someone looks at someone, they tend to judge them…and since I had a trach they judged me by that…saw to be handicapped or retarded…when people think that, you kind of have limits as to who you can be friends with...
    And then one day when I got the thing taken out, they (his teachers) were happy for me and then they saw my plain attitude started changing, I started hanging with different people, started doing nothing in class…

Marie, who attended a school that practiced inclusion, did not encounter bullying directly, but experienced the less obvious form of social isolation, for example: “I guess people’s birthday parties would be really big. There was one birthday party where we actually combined birthdays…And then it turned out to be a sleepover party… I was like ‘oh’ and then I went home.” Passivity, as exemplified by Marie, was a common response to this kind of treatment.
Being stared at, feeling different. Closely related to the bullying theme was the children’s awareness that they were being viewed as different by their peers, for example, six-year-old Megan: “they stare at your trach.” While this bothered Megan, she relied upon her own advocacy: “I say that everybody is staring at my trach.” And a responsive teacher: “I tell the teacher…Sometimes (she will) send them to timeout.” Seven-year-old Anne also encountered stares and questions from her classmates, but wasn’t as bothered, stating: “It’s okay” when asked, and confirming that she provided a basic explanation so that everyone could then get on with playing.

Reflecting on Child and Youth Perspectives: Observed patterns

Reviewing the perspectives of participating children and youth, I noted four patterns in relation to their school experiences:

Child’s school goals: mastery experiences and social relationships. Each child described their school experience in terms of their main areas of focus, which were very typical for their development, as already reflected in the themes above, including:

- Making social connections in the school community.
- Experiencing competence and mastery.

Experience of difference in appearance. This was a factor that most children grappled with at both a personal level (body image) and at an interpersonal level (classmates, general public). Specifically, children and youth with tracheostomies (a visible difference), with the exception of Anne, described their own unhappiness with the difference their tracheostomy made to their appearance, in addition to their peers’ reactions. For example, both Mike and Megan stated that they did not like having a “trach”, in addition to not appreciating their peers’ responses. Anne, by way of contrast, accepted her trach and other equipment stating simply: “I have to have it”.
**Presence of bullying in school.** This seemed to depend upon several factors, including:

- the school culture,
- educator competence,
- parental engagement,
- extent of child’s social isolation (which may be related to social competence).

The child’s experience of a school setting in which inclusive and community-building practices were present (including anti-bullying), combined with parental engagement and social support, appeared to be preventative factors. For example, younger children who benefited from recently implemented inclusive practices in their schools, and reported less bullying than those who had been in school earlier.

The adolescents, Marie and Jim, had started school prior to the broad implementation of inclusion-oriented practices but had very different outcomes. Marie’s parents (engaged) had handpicked a school that already employed school inclusive community principles and had initiated regular home-school collaboration. Whereas Jim’s parents had registered him at his local school, which did not practice inclusion and by both his and his mother’s report, ignored the bullying. His parents expected the school to deal with Jim’s difficulties, which included developmental delay, without their collaboration. Jim’s mother described an adversarial relationship with the school’s administrator and deterioration in her son’s behaviour in response to the behavioural program that the teaching staff implemented. At the time of the study, Marie was attending university, while Jim had moved to a new school in a different community, due to being in danger, related to ongoing risk-taking and conflictual relationships. Now, he described finally experiencing an anti-bullying school culture, and was struggling to finish high school.
Issues relevant for counselling intervention. Some of these children and youth grappled with issues that would have benefited from more specific counselling help, including: coping with parental divorce and adjusting to life with disability, including visible differences.

For example, Marie and Jim had each struggled with their parents’ divorce. Marie described having had access to good social supports (peers and school nurses), which she leaned on heavily. Whereas Jim had been far more isolated, having lost his school nurse in grade two, when his tracheostomy was removed, which was close to the time that his parents’ marriage came to a conflict-ridden end (age six years). Jim had been overwhelmed and described an extremely negative and harmful spiral into depression:

…as every little kid does, go through a separation or divorce from their parents, they have some, well, problems just getting through it…so, mine was, I didn't talk for about six months. After that I had to start building up my emotions again…started coming out…I was six and I didn't really start having like, my character come back to me until I was about nine or 10…Oh yeah, when you lose your character it's kind of hard to build it up again so…

He described finally receiving medical and therapeutic intervention when he was about nine years old, and his older sister had discovered and reported the extent of his self-harm efforts to his mother. While this description suggests that other factors were also at work, a psychosocial service sensitized to these issues could have made a significant contribution to Jim’s quality of life.

Parents’ Perspectives About School: Emerging Themes

Parents occupied the role of navigator and negotiator on their child’s behalf. Their viewpoints related to two different aspects of the home-school relationship: their efforts on behalf of their child towards the school, and the extent and nature of the school’s efforts towards them in relation to their child.

Parent-to-School
Putting the child first: advocacy. When discussing their involvement with their child in relation to school personnel, parents consistently described their efforts to represent their child’s best interests through advocacy with the school. Some parents described this to be new personal ground, for example: “I’m usually a quiet person … when I first started it was like - … I don’t want to get anybody mad at me, but it was the only way to get things done, so it’s easier.” (Beth, foster mother).

Intentionally choosing the school and entry time. The majority of parents described hand picking their child’s school, for example: “the biggest thing is finding out about what other parents had said and hearing from other teachers because we had friends who were teachers they were saying ‘well yes that’s a very good school’.” (Don).

Most parents also described intentionally holding their child back for one to two years to allow time for their developmental lag: “I held him back two years ‘cause I wanted him to be at the same level as the children he went to school with. And he was always a smaller kid so it was easy to fit him in that way.” (John).

Normalizing the child’s disability: everybody has differences. All parents talked about striving for as normal a life as possible, including normalizing their child’s disability. Beth captured this most articulately in describing her approach with Anne:

she doesn’t see herself any different than any other person really and that’s what we kind of tried to instill… – so you’re a little different that’s still normal… I don’t want her to try and not do things because of her disability I want her to try, if you can’t you can’t.

School-to-Parent:

Home-school relationship. This was a necessary and interdependent effort on the part of the parent and the school, characterized by the key elements of: communication, collaboration and role delineation. Don’s description captures a very effective, collaborative approach,
emphasizing mutual responsibility for communication and particularly addressing role
delineation in the context of his child attending school with a nurse:

…we do this with all the kids…with Marie though, it was making or understanding… her
disability and…when we had the nurses, the roles of the nurses so everybody knew sort of what
was understood in the information, the history and then…“okay well you are the school you are
going to teach our child this is what we are expecting from you” and then how to interact in this
certain situation with having the nurse.

_Was it important to you that the school was open to you on being the experts and preparing them
for receiving Marie?_

Yes and I don’t think they ever when it came to that and her care and her lifestyle, they never ever
questioned us about that. When it came to education they were the experts but we knew that.

A similar approach was reiterated by other parents who, when met by collaboration on the
school’s part, also reported very positive home-school relationship.

One parent reported encountering an administrator and school team in which this was not the
case. Despite her advocacy efforts and eventually, her unilateral work to address her child’s
needs using outside help, the home-school relationship could not progress, and in fact became a
barrier to her son’s positive school progress. Only after a change in the school’s administrator,
and a subsequent shift in inclusive and special education practices, did her son’s attitude towards
school become positive once again. Here she states what she would like in the home-school
relationship: “I would like to be asked as a parent what could be done at school level to make
Mike’s life better.” (Laura, foster mother). This reflects the interdependent nature of the home-
school relationship and the necessity of mutual, competent and respectful two-way collaboration.

**School focus on caring made significant difference.** Parents were very sensitive to the
school’s attitude towards their child; they repeatedly raised the theme of caring as an essential
element that made a significant difference to their confidence level in the school and their
relationships. For example, in relation to working with the staff to make the child’s experience a
positive one, Beth shared her experience with Anne’s school principal, in which he had offered
to cover the cost of some special sanitizing supplies at school if the foster agency wouldn’t:
“…he is just showing that they are caring, which I like.”

Caring was also a factor in parents’ observations of how staff approached their child’s difficulties: “she wants to listen to what’s going on with him and…okay, ‘well let’s see if we can change this’…She listens to me and…the message that you get as a parent is she cares about him.” (Laura). Due to the frequency of illness-related absences, the school’s attentiveness and caring also became quite important to the child’s academic continuity, as Don describes:

when the child was sick, providing homework or communication and when they were feeling better…the added time with the child to be able to recover what was missed or what was maybe lost…. the school was very supportive because…they wanted the child to get better, to come back and they were concerned that way.

Finally, caring was also observed by parents to arise in relation to the school community’s culture, for example, in discouraging bullying and altering the way differences were managed: “I think it was the whole school in general … it was that idea of an openness, … that no bullying thing, everybody is part of the school.” (Don)

**School as a key social resource for child.** Parents were acutely aware of the school’s importance to their child’s social world, particularly given the constraints that their medical needs placed upon them in terms of opportunities to develop and pursue friendships. Parents strove to maximize the opportunities that school provided, as Laura describes her efforts on Mike’s behalf: “I (am) trying to…find kids that he does connect with in his school and invite them to my house because he can’t really go on a play date he can’t go ever on sleepovers.”

**Parents Identify Exceptional Professionals**

During their interview, two parents identified educators, who had made an exceptional contribution to their child’s school career. Don identified a teacher that his daughter Marie had been fortunate to have twice during her school career in the local private religion-affiliated
school system, once in elementary school and again, in junior high school. When asked what made this teacher exceptional he gave the following description:

Asking questions or listening, just general welcoming for the children. She was just a very kind person. Not to say that others didn’t try, she tried very hard to make sure that it was a good environment.

*By that what do you mean?*

Well, the environment was warm and in the best way there was the control of the class, presentation of the information so that they could get the most out of the …schooling as possible…

The other parent described an administrator who had taken over at her foster son’s public elementary school during a year when she had been stymied in her efforts to get his needs addressed. She described her experience as follows:

The principal at Mike’s school is outstanding and she is a star! She talks to Mike about himself and gets him to do activities based on what he enjoys. She has taken Mike on personally and is very focused on the child’s experience. I appreciated that this principal took initiative to look into Mike’s situation. She’s got Mike best interests at heart and she knows what she is doing. I see this principal is being very proactive with Mike and planful in the transition planning. (Laura)

Upon obtaining these parents’ consent, each of the identified educators agreed to an interview with me.

**Perspectives of Exceptional Professionals: Core Elements and Key Strategies**

What was most apparent about these educators was the extent to which they held goals in common with the parents and children, and employed their professional skills and personal caring to attain them. The core elements in their approach could by identified as: *caring, communication, collaboration and competence*. Each of these is demonstrated to some extent in their key strategies, - which can easily be viewed from the perspective of best practice in inclusive education:

**Recognizing teaching as grounded in relationship.** The interviews with each exceptional professional revealed educators who are competent in their respective work and able to see
beyond the curriculum’s content to the people with whom they are connecting to build good relationships. For example, Marie’s teacher stated:

“once you let go of the program and you think of yourself as a facilitator in a classroom …I think its better…the curriculum can’t be the focal point, it really can’t…someone is much more important than the curriculum.” These educators put the learner first: “in my philosophy as an educator, the most important part is the kids love to come to school, that they know that there are people here that love them and just want them to be successful,” (Mike’s new school administrator).

Relationship building and communication were also key areas of the educators’ focus with the parents and the team, in addition to the child. For example:

“I have the professional distance I think from my parents, I call them…Mr. and Mrs. Whatever they are and I like to keep them informed… Any time there are any kinds of issues I am on the phone,” (Marie’s teacher)

“Well when I’m working with the parents the biggest thing has always been relationships, that’s what it’s all about.” (Mike’s new school administrator)

Regarding interdisciplinary and inter-system teamwork, these educators shared a focus in common with the parents:

“You need the 24 hour plan and you need everybody on the same page, you need everyone to understand where we are going so there is common language… When you get all together sometimes you have different perspectives, …so it becomes important that everybody recognizes where people are coming from…keeping the focus …about this child, that’s where it needs to stay” (Mike’s new school administrator)

**Empowering the learner.** Both educators recognized their role as secondary and assistive to the active learner, and provided learning activities that fostered this, supporting the child’s goal as a learner and fostering their self-efficacy:
I ran the class in such a way that I felt I was giving the children most of the decision making in terms of how much they did and what they did, there were always the minimum things that were outlined and then some of them just chose to do that and others of course explored more. (Marie’s teacher talks about centre-based learning in grade two)

**Active engagement with the child and for the child – making learning personally meaningful.** These exceptional educators also recognized the need for active engagement on their part to successfully connect with and engage the student in a personally meaningful way.

For example, the new principal at Mike’s school describes how she was able to basically “unlock” Mike’s enthusiasm for learning:

He needed everything that I could give and that’s one of the things is the excitement of learning and he was really keen about Transformers and we had a little interview; what do you like to do? And I brought in all these books of Transformers and all of a sudden his whole being came alive and all of a sudden I could see through, not the medical piece, there is just this kid, there’s a kid in there and he has so many interests and so much energy and just a love of learning.

**Recognizing the child’s inherent worth as a member of the school community.** The child’s social needs were considered as a part of their school experience, a goal these educators shared in common with parents and students:

you want these children in the schools, you want them with other kids and you want people to see past the disabilities and see the kid and the sense of humor and how much they can be … my goal in this school is that your child develops friends that… they are part of a group. (Mike’s new school administrator)

**Open acceptance of the child’s disability and attending to others’ need to understand.**

Being comfortable with the child’s disability and demonstrating open acceptance was an important way that these educators validated the child’s inclusion in the school community and reassured their parents as well as other children and adults.

“in every school I’ve been there have been a few that have had complex needs and I just find I just have a comfort there….what I find is …that I am creating a village around that child. And that’s what adults do. If we do not do that, the children do not automatically come up, they don’t. And the other piece that I find is there is some adults still that are afraid of people with disabilities and when they see…my comfort, they all of a sudden see past the wheelchair, they see past the disability and they see the child inside.” (Mike’s new school administrator).
Recognizing that others have a need for information and meeting this need in a way that fosters the child’s self-efficacy when possible, demonstrates the insight of an exceptional educator. For example, Marie’s teacher recalled, “We did give information …when she came… at that age they want to know what’s wrong with you... by the time she got to grade seven…she herself did a presentation… she is an expert…and she did a great job.” In this way Marie was able to act as an ambassador for her disability, by acknowledging it in an open and matter-of-fact way, Marie made it okay to talk about, demystifying it, and creating an open space in which she and her peers could move forward together in their relationships.

**Practicing inclusion: Leading by example.** Both educators were very mindful of the leadership they could provide by their own actions. For example, Marie’s teacher was very mindful that the students’ eyes were upon her every action, as she strove for inclusion: “Very inclusive yes…We did everything together…I think just leading by example more than anything else…”

Mike’s administrator describes using a similar approach to influence teachers and energize the whole school community in the direction of positive encouragement and celebration:

> because of my ability … to see the kid and the sense of humor and teasing them and pointing out positive things about them and “oh this is going to be so exciting!” so you are kind of the cheerleader, then it’s contagious. Then all of a sudden you’ve got everybody saying, “Oh there he is, look at what he has done!” And they become a village instead of an individual, everyone gets excited.

This energy is then taken up by the child in the form of self-efficacy, as she illustrates:

> when Mike was doing the Harry Potter project and he had just finished it and his teacher was down the hallway and I had said to him ‘wouldn’t it be great to read that to your class?’ and he said ‘I can hardly wait’ and he saw his teacher and he goes running, running down the hallway ‘I’ve got something’ and she beamed and he’s beaming…

**Normalizing expectations and opportunities.** Both educators described the importance of maintaining normal expectations with the children, for example, in terms of their academic work,
as the teacher describes, regarding Marie: “I expected from her everything that I expected from the others…I did give her homework…and just like everyone else, if there were things that she didn’t do she had to stay in at recess until it was done…”

Mike’s school administrator also talked about creating more normalized opportunities with the staff:

the biggest thing that I give teachers is the ability to see past the disability, you know they are not china dolls, and they can do everything other kids can do in just a little bit different way, and if we look at it from that perspective, that they have huge potential and they are going to benefit from that.

And also with the parents: “what I try to do is help parents see a future… A great life is taking risks, it’s having fun and it’s that old piece that if you don’t take risks you don’t feel the highs of how great it can be.”

Planning for mastery, building self-efficacy. These educators spurred the child from their passive stance to a more active and engaged one, for example, by changing the inherent relational contract from one of dependency to one of expectation: “I find…a lot of these children… are used to having it done to them, so they sit back, and then all of a sudden you have a person saying no,…you have lots to offer… and their mind changes,” (Mike’s administrator).

An exceptional educator also anticipated and took preventive steps to minimize the child’s difficulties, in order to promote their self-efficacy and ensure mastery experiences. For example, social inclusion in junior high: “if anybody was going to be left behind it would have been her. If you give them choices …so I wasn’t giving choices because you don’t want to beat the kid down every time…she did make some good friends” (Marie’s teacher describes her intervention).

Discussion

Reflecting upon the perspectives of the children, their parents and the two exceptional
educators, what became clear was that good school experiences depended upon connection and relationship for all, that was characterized by the core elements of: *caring, competence, communication and collaboration*. These elements were also often present in mutually shared goals.

**Linking the Findings with Theory**

*Bioecological Systems.* Relationship was the interdependent ground from which both successes and difficulties arose, and where solutions could be found. The interdependent nature of the interactions among the various contexts of the microsphere, mesosphere, exosphere, and macrosphere, for example, were clear in relation to the child’s school experience.

For example, the data shows that parents (microsphere) who were actively engaged in their child’s school experience (mesosphere), and open to collaboration with a mutually engaged school team employing inclusive practices that had recently been approved by the government (macrosphere), and regulated by the school system (exosphere), were more likely to have a positive home-school relationship, and their child was more likely to experience success at school. Here, there was mutual connection, shared goals, leading to caring, communication, collaboration and by association, mutually shared and acquired competence (each stakeholder brought their own expertise to the relationship).

By way of contrast, parents who were not engaged in their child’s school experience, declined to collaborate with the school on addressing their child’s difficulties, and had experienced disregard from the school team for both their concerns and their child’s wellbeing, were less likely to have a positive home-school relationship, and their child was more likely to experience difficulties. Here, disconnection is the common theme, and the absence of mutual caring, communication, collaboration and competence is notable for all.
Relational Dialectics. The interdependent nature of relationship, the dialogue or spiral, as described in relational dialectics, is evident in many aspects of the data and is well illustrated in the above example, particularly where the parent and the school team are concerned. Each player contributes their personal response to the relational dance, depending upon the response of the other to determine the tension of the interaction, as well as their next move.

For example, where the parent does not perceive caring for their child from the school, they may, if they possess sufficient self-efficacy and relationship skills, cope by advocating more persistently and broadly to obtain the services they expect, possibly leading the relationship in a positive, upward direction, if the school team responds in an accommodating manner. Whereas a parent who has little self-efficacy and/or lacks relationship skills may become less engaged and more alienated, leading to conflict or withdrawal; either of which can result in a spiraling deterioration and eventual stall in the relationship with the other (the school).

The same could be said for the school team; particularly where there is a lack of awareness or competence regarding inclusive practices, and/or a lack of acceptance or understanding regarding disability. When these characteristics change, for example in the case of Mike, when the new principal arrived, the relational dance can begin to move again, as a new more compatible step is extended for the parent to respond to.

Coping. Going to school and helping your child to have a successful experience required parents to possess specific coping strategies. Avoidance, withdrawal, distancing and blame (primarily negative emotion-focused strategies) were shown to be ineffective in relation to school relationships and experiences, as they stalled the relational dance and perpetuated, perhaps even intensified, the difficulties they wrought. Assertive communication, accessing social support and other problem-focused strategies, such as seeking resources were more
helpful, in combination with emotion-focused strategies that provided comfort while maintaining personal responsibility and presence in the face of adversity (for example, acceptance and normalization of difference).

**Self-Efficacy.** This characteristic was a vital ingredient in the child’s learning experiences and social interactions. It was also a necessary aspect for parents who sought to navigate the their child’s school experience, and advocate on their child’s behalf. Significantly, self-efficacy’s cultivation and nurturance in students was key strategies of the educators parents identified as exceptional.

**Resilience.** Overcoming adversity and becoming more resourceful was a characteristic that revealed itself repeatedly in the narratives of children and their parents. This most often arose in association with a child or parent’s positive, resourceful and flexible orientation. The school community played a role in building up the child’s resilience when it provided opportunities for the child to perform from a position of support and acceptance (for example, Mike presenting his Harry Potter project to the class, Marie educating her classmates on her neurological condition, and Mike getting the opportunity to explore the welding trade).

**Conclusion**

The themes explored in this paper suggest that school is all about relationship; within and between systems, for example: nurturing positive home-school relationships, fostering acceptance and inclusion in the school community, confronting and addressing bullying and aggression. And, at a more personal level, providing and engaging the child in abundant opportunities to experience mastery, form friendships, and discover, develop and exercise their own personal agency and self-efficacy in community with others.

Schools are also well positioned, as reasonably resourced learning communities within our
society, to assist students in obtaining help for dealing with the not uncommon, but certainly more challenging parts of their lives, including: adjusting to living with disability, addressing bully-victim relationships and coping with parental divorce. Through these various opportunities, resilience and optimism for the future can be cultivated, and socially isolated students and their families have the opportunity to be drawn in and engaged.

Significantly, there is a strong convergence of valued goals (“what matters”) and helpful approaches (“what works”) between the child and parents’ perspectives and the exceptional educators’ description of their “approach”, including their commitment and caring to the child’s wellbeing, providing abundant opportunities for their experience of mastery in academic and social life, and ensuring their inclusion in the school community. Underlying all of this is the fundamental invitation into active, inclusive and continually evolving relationship for child, parent and educator alike, characterized by caring, competence, communication and collaboration. These new understandings, revealed through the voices of the participants presented here, can be used to foster and validate efficacious counselling and support services for children and families living and learning in the company of chronic and complex health needs.

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