Understanding parent advocacy during the transition to school of children with developmental disabilities: three Canadian cases

Nancy Hutchinson, Angela Pyle, Michelle Villeneuve, Jennifer Dods, C.j. Dalton and Patricia Minnes

Version
Post-print/accepted manuscript

Citation

Publisher's Statement
This is an Accepted Manuscript of an article published by Taylor & Francis in Early Years: An International Research Journal on December 1st 2014., available online: http://www.tandfonline.com/10.1080/09575146.2014.967662.

How to cite TSpace items

Always cite the published version, so the author(s) will receive recognition through services that track citation counts, e.g. Scopus. If you need to cite the page number of the author manuscript from TSpace because you cannot access the published version, then cite the TSpace version in addition to the published version using the permanent URI (handle) found on the record page.

This article was made openly accessible by U of T Faculty. Please tell us how this access benefits you. Your story matters.
Abstract

Research has shown the benefits of parent involvement for student participation in education. Parent advocacy is a critical form of involvement by parents for children who are young, have disabilities, and are making transitions. Studies have classified forms of parent advocacy but have not illuminated the components necessary for effective parent advocacy. In this study of three families of children with developmental disabilities making the transition to Kindergarten, we examined the applicability of Test’s conceptual framework of self-advocacy (CFSA) for guiding research and interventions for parent advocacy. The four components of CFSA were all reported in the parents’ experiences of advocacy. These cases highlight how parent advocacy is similar to, and more complex than, self-advocacy and suggest that parent advocacy is also influenced by the parent’s perceptions of the child’s needs and is context specific. In these cases, advocacy during transition reflects the parent’s priorities for the child’s inclusion.

Keywords: parent advocacy, transition, developmental disabilities, kindergarten, inclusion, self-advocacy
Understanding Parent Advocacy during the Transition to School of Children with Developmental Disabilities: Three Canadian Cases

Introduction

Transition into school has been a focus of research in recent years, with many researchers reporting specifically on the challenges for children with disabilities that arise from changing services, environments, and roles (e.g., Dockett et al. 2011; Villeneuve et al. 2012). This transition period usually involves the participation of parents, healthcare professionals, and educators. Although there is recognition of the need for links between early child development services and the school system, and of the need for collaborative teams to enhance school readiness (Williams et al. 2006; McCain & Mustard 1999; Hunt et al. 2004), such teams often face coordination challenges arising from changing roles and responsibilities of staff, and from confusion about overlapping roles (Lieber et al. 1997). Often parents must serve as the link between educational and health professionals (Glisson & James 2002; Pescosolido et al. 1998). Parental involvement in the transition process can also help to ensure that their child receives necessary supports and services (Janus, Kopechanski, Cameron, & Hughes 2008). Thus, parent advocacy is critical for students with disabilities, especially for those who cannot articulate their own needs (Stainton 2005). Canadian researchers reported that ‘advocacy was of utmost significance in the lives of parents and children with CP [cerebral palsy]’ (Reid et al. 2011, 179). Parents in the UK reported that they ‘spent an inordinate amount of time supporting and providing knowledge to others’ rather than focusing on the special needs of their children (Novak et al. 2012, 833). An American study found that advocating for their children with disabilities remained challenging for parents even after they had participated in a program to enhance their communication skills (Cunningham, Kreider, and Ocón 2012).
Researchers have proposed approaches to understanding the advocacy of parents of children with disabilities. Balcazar and his colleagues (1996) developed a taxonomy of advocacy, including actions such as joining an advocacy organization. Alper and her associates (1995) conceptualized four classes of advocacy including advocacy by parents, while Trainor (2010) described four kinds of parent advocates—intuitive advocate, disability expert, strategist, and agent for systemic change. Although these studies classified forms of advocacy, they failed to shed light on the components of effective parent advocacy or to suggest means of enhancing parents’ advocacy on behalf of their children with disabilities during transitions. Recently, researchers have recommended identifying these components and then developing ‘potential indicators that can be used to document the longer-term impact’ of programs to enhance parent advocacy (Carter et al. 2012, 21).

Research suggests two issues contribute to the lack of conceptual and practical progress on understanding parent advocacy: the lack of a robust model (McCormick and Ozuna 2012) and the way existing approaches have largely ignored the experience and perspective of parents (Reid et al. 2011). A recent model of self-advocacy (Test et al. 2005) has gained the attention of researchers and practitioners and may offer direction (Clemens, Shipp, and Kimbel 2011). However, this model has not been scrutinized for authenticity in the context of parent advocacy and ‘holding untested assumptions about children and families is a harmful place to begin when attempting to work out issues related to teaching, learning, and parent involvement’ (McKenna and Millen 2013, 10). Thus we sought to clarify the meanings parents and guardians held of their involvement as advocates for their children with developmental disabilities during the transition to the first year of formal schooling, referred to as kindergarten in Canada. We examined the ways in which their perspectives on advocating for their children are consistent with, diverge
from, and go beyond the key components of advocacy in Test et al.’s (2005) conceptual framework of self-advocacy (CFSA) for students with disabilities. We recognize that self-advocacy and parent advocacy are conceptually different because the parent does not personally experience the disability of their child; however, especially for children who are unable to advocate for themselves, parent advocacy replaces self-advocacy for young children with DD as they transition into school. Thus, Test’s model may be helpful in understanding parent advocacy.

**Review of Literature**

CFSA (Test et al. 2005) emerged from a critical appraisal of educational research that addressed the ability of students with disabilities to self-advocate in school. Existing research addressing parent advocacy includes data on factors similar to the four components of CFSA: *knowledge of self, knowledge of rights, communication, and leadership.* Thus, we argue that this framework provides a useful starting place for studying parent advocacy, but we recognize that we must also consider parents’ meanings for advocacy and acknowledge that there will be differences because the parent does not have first-person lived experience of being disabled.

**Knowledge of Self and Knowledge of Rights**

In CFSA, knowledge of self and knowledge of rights are viewed as the twin foundations of self-advocacy for students with disabilities. Knowledge of self includes knowing one’s own strengths, preferences, goals, disability attributes, and requirements (e.g., educational accommodations) (Test et al. 2005). Understanding and communicating the strengths and needs of their individual child also appears in the research on parent advocacy. Trainor (2010) described parents who used an intuitive approach to advocacy to help teachers know the child as an individual and parents who developed expertise specific to their child’s disability so they could advocate for services to enhance inclusion. This information—learned from experiences
with their child and from personal research about their child’s disability—is then shared with educators (Janus et al. 2007). If Test’s model is to be helpful, the first component must be re-thought as knowledge of one’s child.

Knowledge of rights includes one’s rights as a human being, a citizen, and a person with a disability. For parents advocating for their child at school, this knowledge is specific to the child’s rights within the policies that enable access to supports (Leiter and Krauss 2004), rather than specific to the parent’s rights. Duquette and her colleagues (2011) showed the impact of parents’ knowledge about their child’s rights to services included in Individual Education Plans (IEPs); parents who had the relevant information could ensure that IEPs included the necessary supports to which their children were entitled and were implemented by their children’s educators.

**Communication**

In CFSA (Test et al. 2005), becoming a self-advocate also involves utilizing knowledge about self and about rights to communicate effectively and to acquire information and supports to meet personal goals. If CFSA is to apply to parent advocacy, this component must focus on parents as the communicators. Researchers exploring parent advocacy describe the crucial role of parents’ communication in facilitating information sharing between the school and other service agencies (Janus et al. 2007), and report that parents act to ensure positive communication with educators ‘because they believed the teachers’ cooperation was essential to their children’s academic progress’ (Duquette et al. 2011, 131).

**Leadership**

The final component of CFSA, leadership, involves combining knowledge of self (or of one’s child), knowledge of rights, and communication to advocate at the system level for oneself
(or for one’s child) and for others. This requires understanding the needs of a group and enlisting other members to act on behalf of the group. Test and his colleagues argued that, while leadership is important, one can be a successful self-advocate before developing leadership qualities. Studies on parent advocacy have reported that most parents initially advocated for their own children and that many, who went on to advocate for systemic change, reported feeling a responsibility to advocate for other families unable to advocate for themselves (Trainor 2010).

Summary

CFSA (Test et al. 2005) has inspired research and practice in self-advocacy but has not been applied to parents’ advocating for their children. By applying the four components of the CFSA to the experiences of parents as advocates for their children with disabilities, we may develop a more nuanced understanding of the components essential to parent advocacy during the period of transition into school. By listening to the perspectives of parents of children with DD, we focus attention on the meaning they make of advocacy for their children during this transition.

Method

With help from agencies in our community, we recruited parents of children with DD who would begin Kindergarten, in integrated classrooms in mainstream public schools taught by qualified classroom teachers, in the subsequent school year. We conducted three multiple-perspective case studies (Stake 2000) on the transitions into school of children with distinct developmental disabilities. This enabled us to examine the similarities and the unique features of the cases and to develop a robust understanding of parent advocacy during this transition (Stake 2006).

Data Collection and Analysis
Data collection took place over 14 months, beginning in the spring prior to the children’s entrance to Kindergarten. We invited all parents of the three children to participate, but the two fathers chose not to take part in the study and the female guardian was a single parent. This is consistent with prior research where there has been greater research participation by mothers of young children with disabilities (e.g., Gershwin Mueller and Buckley 2014; Murphy, Christian, Caplin, and Young 2006). We conducted 6 to 8 interviews with each female parent/guardian. We did not introduce the word advocacy in these interviews. They raised issues about advocacy when asked questions like, ‘What is your role on the team that plans for your child’s participation at school?’ We conducted interviews with the children’s health care professionals (e.g., occupational therapists, speech and language pathologists) and educators (e.g., early childhood educators, Kindergarten teachers) who were involved in transition, and we observed each child at least 10 times in their homes, educational, and therapy settings. Observations were conducted at a range of times of day in each setting, but always at times convenient to those in the setting. Three research assistants (RAs), all doctoral students, collected the data with one RA responsible for each case. Two co-investigators guided data collection and analysis to ensure consistency. All interviews were transcribed verbatim except interviews with the mother of one child (Tristan) who requested that notes be made rather than audio-recordings. These notes were transcribed, including quotations from Tristan’s mother, immediately following each interview. Field notes of observations were also transcribed to be analyzed with the interview data.

After data collection was complete, five members of the research group used standard methods of qualitative research (Patton 2002) beginning by reading and re-reading the full data set. Three major issues were identified in these preliminary analyses, all of which were important to understanding the experiences reported by the parent participants: the nature of parent-
professional collaboration (Villeneuve et al. 2012), transition that promotes inclusion
(Villeneuve et al. 2013), and parents’ advocating for their children. Each of these issues has
formed the basis of a separate paper. The current paper is based on analyses conducted on the
data we found relevant to understanding parent advocacy. After reviewing survey research on
parent advocacy (e.g., Nachshen, Anderson and Jamieson 2001) and descriptive research on
parent advocacy (e.g., Itzhaky and Schwartz 2000; Trainor 2010), we began to consider whether
the model developed by Test and his colleagues (2005) on self-advocacy answered researchers’
calls for a model that could be applied to parent advocacy (e.g., McCormick and Ozuna 2012).

Many qualitative researchers have argued that ‘good research incorporates an integration
of both etic and emic perspectives’ (e.g., LaSala 2008; Lett 1990; Pike 1967; Sands and
McClelland 1994). Members of our research group worked together to reach agreement on etic
codes consistent with CFSA and emic codes that emerged from the observational and interview
data. We began by open coding each verbatim transcript and set of observational fieldnotes
(initially using structural coding and then moving to more detailed text coding; MacQueen,
McLellan, Kay, and Milstein 1998). The full group reviewed the codes to achieve clarity and
guidance for applying the codes. One experienced researcher led the group while relevant codes
were clustered to form categories, consistent with the advice of qualitative methodologists (e.g.,
MacQueen et al. 1998). Subsequently, employing the method of constant comparison (Patton
2002), we generated themes in each case, and then conducted cross-case analyses. In this paper,
we focus on parent perspectives on advocacy expressed in the parent/guardian interview data,
and include limited data from observations and from interviews with professionals.

Participants
In this section we report brief descriptions, of the children and their mothers/guardian at the centre of each of the three cases. These descriptions provide context for the parent interview data on experiences and meanings of advocating for children with disabilities (Patton 2002).

Abby and her mother, Colette

Abby was five and had Down syndrome (DS). She lived with her two parents and five older brothers. Colette had an undergraduate degree in nursing and a master’s degree in education. She surrounded Abby with educational toys, had researched Down syndrome since before Abby’s birth, and had attended conferences on the topic. When observed at home, Abby talked to her mother and the interviewer and completed tasks such as colouring independently. When observed at daycare, Abby watched the other children participate in circle time and engaged in solitary play during free time. To prepare for Kindergarten, Colette taught Abby the bus routine and how to pack and unpack her school-bag, took her to play in the school yard, and taught her the alphabet. She also requested that the daycare teach Abby counting and pre-printing skills.

When observed in Kindergarten, Abby participated in structured activities with her classmates including identifying letters and colours, dancing, and making crafts. However, the Kindergarten teacher described Abby as reluctant to play with others during free play. Abby played beside, but rarely interacted with, other children. When observed at school Abby occasionally used the signs her family had taught her, while at home she spoke to express herself. Colette described the family’s desire that Abby acquire the academic, language, and social skills necessary to become ‘a full member of society.’ After the school requested that Abby ride an access bus to school, her brothers convinced their parents to telephone the school
saying they would ensure Abby’s safety on the regular school bus. Colette said: ‘As long as she can manage the regular bus, she should take it.’ The school agreed.

Tristan and his mother, Jessica

Tristan was a five-year-old with fragile health and global developmental delays who lived with his two parents and an older brother in a rural farming community. Tristan spent his preschool years in hospital or at home with Jessica surrounded by games and books; when his health permitted he participated in play dates. In his fourth year, his health stabilized and he made large gains in language, mobility, and independence enabling him to participate in a 10-week, 25-hour school readiness program for children who had not attended preschool. The program taught routines and social skills (e.g., participating in circle time). Before he began school, Tristan visited the school and Jessica arranged for his physiotherapy to take place at the school playground. On his first day, Jessica and Tristan’s health team were present to support school personnel. An educational assistant was assigned to Tristan for the first month of school after which he received support only for personal care and medical procedures including feeding with a G-tube. Tristan’s classmates chose him as a playmate and he participated in classroom activities, but struggled with academic learning.

Jessica shouldered the responsibility for Tristan’s health and developmental needs. Health care professionals praised her ‘tireless efforts and commitment’ to both her sons’ well-being. She worked daily on the ‘homework’ given by therapists and negotiated with agencies to ensure Tristan’s health needs were met. These professionals described Jessica as maintaining a balance—meeting Tristan’s unique needs while ensuring that he was seen foremost as a child, and not simply as his disabilities. During Tristan’s year in Kindergarten, Jessica began studies as a full-time student in a community college program in social services.
Brady and his guardian, Allison

Brady was a five year old with severe bilateral sensorineural hearing loss, congenital cytomegalovirus (CMV), autism, global developmental delay, and a seizure disorder. Before Brady’s second birthday he and his two brothers began living with his aunt Allison, a single parent with two sons. Allison did not work outside of the home. One of Brady’s cousins also had autism and the three other boys had various learning difficulties. Healthcare professionals described Allison as ‘determined’ and ‘organized’ in caring for Brady’s physical, educational, and social development. Brady attended an inclusive daycare program where Allison said ‘he interacts with other kids.’ Although Brady still did not talk at five, Allison described him as ‘a lot more verbal than he used to be, he’s actually babbling.’ To communicate he used two hearing aids and a few basic signs. At daycare and at school, Brady used an FM listening system and Picture Exchange Communication. Allison said ‘at two he was in his own world…withdrawn’ but at five, he was ‘paying attention to the world around him’ and playing with toys; she attributed much of this progress to the ‘awesome’ daycare program. When observed at daycare, Brady played with toys and watched and imitated peers.

Before Brady started Kindergarten, Allison expressed her main concern: ‘Brady is so extreme in the differences [when compared to other children]; it’s hard to even picture what he is going to do.’ When observed in Kindergarten, most of Brady’s interactions were with his educational assistant.

Findings

The CFSA includes four linked constructs hypothesized to contribute to self-advocacy which provide a starting point for understanding parent advocacy during transition to school. Findings are reported separately for the cases of Abby, Tristan, and Brady; the etic themes
consistent with the four components of CFSA are reported first, followed by emic themes that emerged from the analyses. The themes consistent with CFSA are titled and described to highlight each parent’s/guardian’s personal experience and meaning.

**Abby and her Mother, Colette**

*Knowledge of Abby: I take every opportunity to learn about Down syndrome.*

Colette advocated for Abby by staying well informed and highly involved. She began reading about Down syndrome prior to Abby’s birth. She constantly sought opportunities to learn more about how to support Abby; for example, she described attending conferences as often as possible: ‘There’s yearly conferences; there’s the Ontario one and we try to go to it every year…we went to the world [Down syndrome conference] a few years ago.’ Colette worked with Abby at home and helped all of her family to do the same. She reported, and others confirmed, that she shared what she knew about Abby with healthcare and educational professionals.

*Knowledge of rights: I don’t know what actually goes on the IEP*

Colette was well informed about the expectations for Kindergarten students because Abby was her sixth child. However, because Abby was her only child with special needs, Colette found herself in an unfamiliar position. She did not know what Abby was entitled to have specified in her IEP, stating ‘We’ll see what this [IEP] is all about.’ She asked the interviewer, an experienced teacher, ‘I don’t know what else you’d put on it…Is it just behavior and communication? Do academics go on that sometimes? … Because it’s the first time through, now at this point I’m just waiting.’ Uncharacteristically, Colette lacked information about her daughter’s rights during the development of an IEP, resulting in her ‘just waiting.’

*Communication: I want reciprocal information sharing*
The health care and education professionals recognized Colette’s knowledge and communication skills reporting, ‘Colette is on top of everything. She has a medical background so we’ve relied very heavily on her for conveying concerns and for addressing those’ (occupational therapist [OT]). Similarly, the director of Abby’s daycare reported, ‘[Abby’s] Mom was…bringing [us] different books or information that she had.’ When the Kindergarten teacher reported that Abby sometimes refused to participate, Colette responded that ‘the stubbornness is Abby’s personality not the Down syndrome.’ Colette expected others to share information with her. The week before Abby began school, the school had not informed her about the supports they would provide for Abby, so Colette went to the school to ask, ‘Do they have the assistant and everything lined up?…I was looking for confirmation that somebody would let me know that everything’s going to be okay.’

Leadership: We formed a Moms’ group

Colette valued opportunities to learn from other parents and recounted advice she had received, ‘Be an advocate for your child, support them, be there for them, find answers, and see what you can do for your child.’ This parent had advised, ‘If the answer’s not there’ find ‘some type of support.’ When Colette sought opportunities to connect with others who had children with disabilities, she found that ‘there’s nothing specific in this city for Down syndrome.’ Her response to this lack of support was to work with other parents to organize a group for mothers of children with special needs. ‘We formed a moms’ group…it’s moms coming together with [their] children with special needs.’

Why advocate? I advocate for inclusion

Colette’s goal was that Abby participate fully in the academic and social life of the classroom. Colette described her observations, ‘If the other kids are doing it, Abby’s
participating in it as well, which is what we were hoping for.’ Colette advocated that ‘…if she’s in the classroom… she’s learning even just from the children… I mean just their day-to-day things, just the things that they’re interested in; then she’s interested in them [too].’ When the OT recommended that Abby have ‘a special chair’ and adapted scissors, Colette responded, ‘I don’t think it’s necessary.’ Colette advocated for inclusion for Abby.

*What is inclusion? To work on the skills the other children are working on*

Collette and other family members worked regularly with Abby on academic skills. During every observation in the home, Abby was completing learning games for colour identification and letter recognition, or colouring and drawing as pre-writing skills. Colette feared Abby was ‘flying under the radar’ and felt that ‘someone should be there to make sure that she’s following through with the program that’s being taught.’ She continued, ‘Otherwise Abby will just sit there quietly and doodle or colour where she’s not on task and I want her to be on task…because I know she can learn all of this, especially at this young level.’ Colette’s goals for Abby were ‘…just to get comfortable and familiar with her surroundings, with the other children in the classroom, and to be safe, and to work on the skills that the other children are working on.’

*Tristan and his Mother, Jessica*

*Knowledge of Tristan: I know him well, we’ve been through a lot*

Because of Tristan’s fragile health, Jessica had become attuned to his needs and developed excellent organizational skills to manage all the services he received. The healthcare professionals described Jessica as a skilled advocate who ‘can read him so well’ and they said they relied on her to ‘read his behavioural cues’ and to advise them about how much to expect of Tristan. Jessica identified her driven personality and her determination to do everything she
could for her children as central to her advocacy for Tristan. She believed she had learned about advocacy by ‘trial and error’ but had become ‘pretty good at it.’ Jessica reported that her longstanding relationships and weekly contact with Tristan’s therapists contributed to her knowledge about Tristan.

Knowledge of rights: Advocating is hard work!

Although Jessica described advocacy as ‘hard work,’ a therapist on the healthcare team explained that Jessica would ‘speak up for Tristan; she will ask questions…and if she’s not sure she’ll call and say this is happening, what do you think should be done?’ Transferring the advocacy skills used in the health care setting to the school setting was challenging for Jessica. She reported having little direct contact with Tristan’s teachers and little information about Tristan’s activities in the classroom. This left her anxious about his health and wellbeing, and also feeling unsure what she should do to support his social and academic inclusion as well as his overall development. She described receiving an invitation to attend a school meeting about Tristan that had been scheduled to accommodate the health and education professionals without consulting Jessica about her availability. Jessica reported that she struggled to advocate proactively for Tristan, as she had done in the past, because she was not sure what rights Tristan had in the school setting.

Communication: Talking is better than exchanging written notes

Jessica saw herself as a member of the healthcare team and offered input. She also sought answers from professionals and kept a detailed record of Tristan’s daily life to communicate with his team (e.g., intake and output of food and liquid). Jessica reported that the OT had informed her ‘about why I did this [detailed recording]’ and the OT said, ‘[Jessica] goes home and works [with Tristan].’ Jessica expressed frustration with receiving little detail about Tristan’s school
day; not knowing his intake and output made it difficult for her to calculate his G-tube feeds. Because of Tristan’s limited communication, Jessica requested a picture communication book, but that did not prove helpful. The teacher preferred written notes; however, Jessica felt disadvantaged because ‘I don’t express myself well in writing,’ and she worried about being seen as a difficult parent. After receiving a note about reduced educational assistant support for Tristan, Jessica telephoned the school for information, again reacting to a decision reached with minimal consultation.

*Sharing advocacy: I am being asked to give up control*

As the school year progressed, Jessica felt the school was making her ‘give up control’ of Tristan’s health and development, an emotional experience for her. Home and school shared the goal of social inclusion for Tristan. However, Tristan required daily medical procedures that the school viewed as needing sterile conditions; Jessica wanted less emphasis on sterility with the medical support provided in the classroom to minimize withdrawal time. The teacher acknowledged the disadvantages of, and tried to minimize, Tristan’s withdrawal from the classroom, but said being withdrawn ‘goes along with needing extra supports’ and expressed frustration with accommodating parents’ requests. The differences between advocating in a school and in health care settings led Jessica to observe that, ‘It would be so helpful to have some kind of training in advocacy on how to be an advocate for your child [in school].’

*Parent and educator as co-advocates: Sharing the role with Tristan’s teacher*

Although Jessica felt her role as advocate had been diminishing, she recognized that Tristan’s teacher had begun ‘to share this role.’ They both described the teacher telling Jessica, ‘It is important to take a step back and a deep breath, and realize…that we [all] want the best for Tristan.’ The teacher continued, ‘I just feel that my job is really being his advocate at school
because mom does a great job advocating but she’s not there during the day’ and ‘I’m with Tristan most of the time... so I’ve sort of decided that [school] things need to run through me.’ The teacher spoke of sharing the responsibility for advocacy with Jessica because ‘the teacher can only do so much.’ However, when pressed, neither the teacher nor Jessica could provide a clear description of Jessica’s changing role. The teacher viewed the school system as ‘hard to navigate,’ even for educators, and more challenging for parents whom she described as ‘outsiders’ to the school system.

**Brady and his Aunt, Allison**

*Knowledge of Brady: It’s hard sometimes to keep it all straight*

Allison reported relying on her sister, her friends, and a few trusted professionals for support and information about ‘websites…and resources.’ A preschool specialist in autism (Pam) and a specialist in hearing loss (Danielle) had worked with Brady almost since his birth. Allison felt ‘good’ about their support at Brady’s transition planning meeting, when they answered the school’s questions, because she thought they both knew Brady well. Allison said she was accustomed to meeting with ‘all these experts’ at an annual meeting of the team of healthcare and preschool professionals. ‘We all sit down at the table, “Brady is doing this, and we’re doing this”…I usually sit there and go “uh huh, uh huh.”’ Allison acknowledged sometimes feeling overwhelmed by the large team ‘because Brady has just got so much going on that it’s hard sometimes to try and keep it all straight.’ However, Allison knew Brady’s abilities; for example, she videotaped him to show his kindergarten educators that he communicated with many more signs at home than at school.

*Knowledge of rights: I can ask the professionals*
Healthcare and educational professionals spoke about encouraging Allison to advocate for Brady’s rights. The hearing specialist encouraged Allison to advocate for Brady’s communication needs at his first daycare. When ‘the needed changes never took place,’ she suggested Brady attend a daycare that focused on meeting the social inclusion needs of children with disabilities. Allison thought, ‘They sounded really good…and I was like ‘well okay.’”

When discussing Brady’s transition meeting, Allison listed nine individuals she thought would attend, identifying many by their professional titles, rather than by their names, and said she did not know much about the meeting. One autism professional who provided intervention for Brady reported that Allison called her during the first week of school, very upset: ‘I encouraged her to call the principal. I told her “it is ok for the parent to call the principal.”’

Communication: It would be nice to get a bit more information from the school

The two professionals Allison trusted most (Pam and Danielle) sat on either side of her at the transition planning meeting. When Allison appeared unsure about responding or gave brief answers, Pam and Danielle provided additional information. To prepare Allison and Pam had helped her create a book for school personnel containing pictures and information about Brady. Allison contacted Pam for help when she learned that Brady would not be starting school as planned or receiving the support that Allison believed had been promised at the transition meeting. Allison, who is soft-spoken and calm, expressed reluctance about communicating with the school, and one professional described Allison as ‘not terribly vocal or assertive.’ Another reported: ‘Allison is great, she does everything you tell her to support Brady. She will always protect Brady and do her best, but I wouldn’t consider her a strong advocate.’ Allison expressed her perspective on communication with the school, ‘It would be nice to get a little bit more information about what’s happening with him.’
Why advocate? Brady can’t speak up for himself

Although she was not comfortable advocating, Allison did it because she recognized the importance of ‘making sure Brady gets what he needs’ because ‘he can’t speak up for himself and say, “I need this.”’ When she learned, that Brady’s school had changed his scheduling and support, Allison was upset: ‘It was like they just took all of that information [from the transition meeting] and threw it out the window! I left the school in tears because I was so frustrated.’ Then, ‘I brought all of the information for Brady and started from scratch again with the educational assistant and the special needs teacher, about all of Brady’s needs because they had no idea.’ Allison reported feeling anxious about Brady in school because, unlike the trusted professionals she had worked with previously, these newcomers had not yet convinced her that they knew Brady and were working for his best interests. ‘Brady is Brady and it’s hard not to worry about him.’

Discussion

There was considerable evidence in the parents/guardian interview data to suggest that the four components of CFSA (Test et al. 2005) were applicable when described as knowledge of child, knowledge of child’s rights, communication, and, to a lesser extent, leadership. All three parents (two mothers and a female guardian) had extensive knowledge of their child and the child’s disability but each brought a distinct meaning that informed their perceptions of their child’s needs. Larson (1998) described the complex and unique meanings for disability embraced by parents of children with disabilities. Colette, mother of Abby, emphasized obtaining current information about Down syndrome, from conferences and other sources and sharing this information. Jessica reported she knew Tristan well, mainly from experience, and relayed this information to professionals working with him. In contrast, Brady’s guardian, his aunt,
sometimes felt ‘overwhelmed’ by Brady’s complex conditions, although she was aware of and communicated vital information about Brady (e.g., videotape of Brady using signs). These three cases demonstrate how knowledge of their child was critical to these parents’ advocating for their children with disabilities.

The second foundational component, knowledge of rights, was important but proved challenging for all three female parents who expressed frustration and suggested that insufficient knowledge about what their children were entitled to at school limited their effectiveness as advocates. Law and her colleagues (2003) reported on factors affecting parents’ views of the information and services they and their children with DD received, including issues like having to wait and the complexity of the child’s developmental disability. Colette recognized she needed to know more about IEPs and found herself ‘waiting’ for information while Jessica described advocating at school as ‘hard work.’ Allison was straightforward about her need to rely on professionals to inform her about Brady’s rights given the complexity of his disabilities. All three parents had older children in school, but this did not provide them with adequate knowledge about the rights of their children with DD at school.

All three parents expressed concerns about communication with the school, but each emphasized a different concern. In a study by Stoner and her associates (2005) parents described how critical communication was to their relationships with education professionals. While Colette focused on her desire for a reciprocal exchange of information about Abby, Jessica was concerned about the means of communication. She preferred to talk with educators about Tristan rather than communicate in writing because she believed she expressed herself better orally. Brady’s guardian, Allison, gradually recognized that she needed to work at expressing herself more independently and assertively with the school.
The fourth component of the Test model, leadership, was only apparent in the data provided by one of the three parents. Scorgie and Sobsey (2000) described how some parents of children with disabilities report transformational outcomes associated with activities such as assuming leadership roles and speaking to gatherings of parents. When Colette recognized that the community needed a support group for parents of children with Down syndrome, this educated and well informed woman joined forces with other mothers to take a leadership role and start such a group. Leadership did not emerge as a theme within Jessica’s or Allison’s experiences. Test and his colleagues (2005) acknowledged that one could be ‘an effective self-advocate without being a leader of others,’ (51) but their review of relevant literature pointed to the importance of leadership to sustained advocacy for those with disabilities.

Our data suggest that the three of the four components in CFSA were central to advocacy as described by the parent/guardian participants in these cases, and thus that these components may be applicable to effective parent advocacy in general. Colette and Jessica embodied these components more than Allison, and the professionals who worked with these two parents spoke often of how much and how well Colette and Jessica advocated for their children with disabilities. While the professionals admired Allison and saw her as knowledgeable and caring about Brady, they did not describe her as an effective advocate. This may have been because Allison—and the professionals who knew her—acknowledged her reluctance to act independently and assertively to represent Brady’s interests.

While the model, originally developed for self-advocacy, has proven helpful when extended for understanding parent advocacy, it appears necessary to add elements specific to parents’ meanings and experiences of advocating for their children with disabilities. One would expect that a model developed to understand self-advocacy would need alteration and elaboration
when applied to parent advocacy. Three additional elements are suggested by our data, all of which appear in the general literature on transition into school of children with disabilities. First, these female parents and guardian focused on their reasons for advocating, which was not in the CFSA model. For example, Colette emphasized that she was advocating for inclusion and described what inclusion meant to her (Villeneuve et al. 2012). This is consistent with Trainor’s (2010) review of the literature in which she highlights parents’ efforts through advocacy to secure inclusion and accommodations for their children with disabilities. Second, these parents recognized that their children with DD needed them to advocate. Allison expressed this most clearly when she emphasized that Brady could not advocate for himself (Brett 2002). This added component emphasizes another difference between self-advocacy and parent advocacy. Third, at different stages in the life of a child with disabilities, parent advocacy may take different forms and require different knowledge. For example, Jessica spoke of how advocating in school was different from her experiences advocating with healthcare providers—at school she had to reluctantly give up control and accept that the teacher was a co-advocate. Colette described needing to know more about the process and substance of IEPs now that her daughter was in school. Although not apparent in these case studies of young children, other researchers have suggested that some parents may also need to learn to gradually release responsibility for advocacy to their children (e.g., Trainor 2010). Again, this component highlights the limitations of CFSA for understanding parent advocacy.

These three cases demonstrate that the conceptual framework for self-advocacy (Test et al. 2005) has potential for informing conceptual and practical work on parent advocacy for children with DD. Knowing the child, knowing the child’s rights, and communication all appear to contribute to successful parent advocacy in these three cases, where all the parent data were
supplied by female parents and guardian. And future research can show whether they are vital components in advocacy interventions for parents, as well as what role leadership plays in parent advocacy. As anticipated, parent advocacy appears to be more complex and conceptually different than self-advocacy leading us to recommend additional components when researching interventions for parents who wish to increase their effectiveness as advocates. Specifically, parent advocacy appears to be informed by the parent’s perceptions of their child’s needs which, in turn, inform their understanding of and priorities for their child’s inclusion. This implies that future research on parent advocacy should consider how the lived experience of parenting a person with a disability differs, conceptually and practically, from the lived experience of being a person with a disability (Brett 2002). Further, consideration should also be given to the diverse meanings that parents assign to inclusion as we build a field of research on special education advocacy (Burke 2013).

Given that the findings of this study are based on analyses of only three cases, all of which were collected in one region of Canada with female parent/guardian participants, further research must include a validation study to ascertain the extent to which the findings for a population of cases (Stake 2006) are consistent with the CFSA. We have a population of ten cases from three other Canadian communities that were conducted by other researchers using methods consistent with the methods used in these three cases. Analyzing these ten cases systematically may enable us to discern the ways in which they are consistent with the findings of this study and can inform the revision and refinement of the CFSA, perhaps enabling us to advance a Conceptual Framework for Parent Advocacy (CFPA).
References


Dockett, Sue, Bob Perry, Emma Kearney, Anne Hampshire, Jan Mason, and Virginia Schmied. 2011. *Facilitating Children’s Transition to School from Families with Complex Support*
Needs. Albury, AU: Research Institute for Professional Practice, Learning, and Education. Charles Sturt University.


doi.10.1177/0741932508324401


Williams, Robin C., Anne Biscaro, and Jakcie Van Lankveld. 2006. “Improving Early Childhood