
Parents of Children with Disabilities: Telling a Different Story

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ABSTRACT

This study explored a deconstructed view of disability with parents of children with disabilities. We analyzed stories collected in open-ended focus groups using criteria derived from constructivist principles of narrative therapy. A thematic analysis, grounded in a critical constructivist perspective, yielded four thematic categories: stories about other people's assumptions, stories about dealing with difference, stories about professionals, and stories about disability. These parents' narratives define and deconstruct the dominant discourse about being the parent of a child with disabilities and reveal insights about the impact of stereotypic views of disability. Implications for counselling parents in ways that honour their insights are discussed.

RÉSUMÉ

Cette étude a exploré auprès de parents d'enfants déficients les implications d'une vue déconstructiviste de la déficience. Les récits de groupes de réflexion informels ont été analysés à l'aide de critères dérivés de principes constructivistes de la thérapie narrative. Une analyse thématique qualitative, fondée sur une perspective constructiviste critique, a produit quatre catégories thématiques : récits relatant les suppositions des gens de l'entourage, récits concernant le traitement à l'égard des différences, récits au sujet des professionnels et récits concernant la déficience. Les récits narratifs des parents définissent et déconstruisent l'idée dominante d'être les parents d'un enfant déficient et révèlent leur habileté perceptive relative à l'impact de la vision stéréotypée de la déficience. Les auteurs discutent des implications de cette étude pour le counseling avec les parents de manière à respecter leur habileté perceptive.

This study uses a constructivist theoretical framework as implemented in the narrative therapy approach (Parry & Doan, 1994; Peavy, 1993; White & Epston, 1990; Zimmerman & Dickerson, 1996) to explore the notion of disability as experienced by parents of children with disabilities. Our purposes were to examine the constructed nature of disability, to explore how counsellors and other professionals help families of children with disabilities given that they have as-

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sumptions about disability, and to consider implications of the many possible stories about being different. We conducted a thematic analysis of narratives of parents of children with disabilities to explore the theoretical concept of deconstruction within narrative therapy (White, 1991) and to deconstruct notions about disability and about being the parent of a child labelled with disabilities. In particular, we considered whether participants have been stereotyped by others' reductive assumptions about the possibilities for adjusting to disability within a family.

Conceptual Framework

We distinguish *impairment* (the actual condition of functional difference) from *disability* and *handicap* (various social impositions of disadvantage on people with impairments). This social model of disability adopted by the World Health Organization is described in recent critical disability research (Finkelstein, 1993; Shakespeare, 1993; Smith, 1999). We see disability as an "interaction between societal conditions or expectations and the abilities of the individual" (United Nations, 1993, p. 6), rather than accepting a traditional medical or deficit model that defines disabilities, handicaps, and impairments as problems of individual adaptation. As stated by Lenny (1993), disability is a problem not of the individual but of the disabling society.

Constructivism represents an epistemological position based on the central concept that "reality is constructed by the observer and is not an external entity entirely separate from the observer" (Gallant, 1993, p. 119). Marshall (1996), Prawatt (1996), Lapadat (1997), and Dolittle (1999) distinguish several versions of constructivism in the fields of psychology and education including cognitive, sociocultural, and radical approaches. In this study, we follow Olssen's (1996) definition of constructivism as a social thesis with implications for discursive therapies. Olssen does not deny measurable conditions of physical or mental impairment, but emphasizes the constructed nature of how such conditions are perceived and accommodated within particular social and historical contexts. To restate his view, individual stories about disability are shaped by larger cultural narratives about the value of being functionally different.

In the field of counselling, narrative therapy represents a critical social constructivist position, derived from the philosophical work of Foucault (1954). As a therapeutic school, it is concerned with issues of social and historical context (Parry & Doan, 1994). Narrative therapists propose that "it is the meaning that [family] members attribute to events that determines their behavior" (White & Epston, 1990, p. 3). A theoretical notion underpinning narrative therapy is that meaning is shaped by larger and often subjugating cultural discourses (Zimmerman & Dickerson, 1996). *Subjugating cultural discourse* refers to a set of culturally derived values about reality and what is considered normal. White (1991) describes subjugating discourses as "problem saturated narratives."

Although parents' counselling needs vary (Berry, 1995; Blacher, 1984), several studies suggest that traditional counselling and support practices have contrib-

uted to the problem saturated narrative about parenting and disability (Affleck & Allen, 1985; Beresford, 1994; Glidden, 1993; Hanline, 1991). Much research and practice in narrative therapy aims to depathologize the experience of being the parent of a child with disabilities (Bennett, DeLuca, & Allen, 1996; Trute & Hauch, 1988; Turnbull, 1988). Such work challenges "tragic" theories of parental adaptation and coping such as chronic sorrow (Kratochival & Devereaux, 1988; Olshansky, 1962) and grief stage theories (Ziolko, 1991). Researchers who are also the parents of children with disabilities write from a new, more critical perspective that does not deny stress and sadness, but, rather, extends the scope of the study of raising a child with a disability to include more positive focuses (Ferguson & Ferguson, 1995; Sobsey, 1995; Turnbull, 1988).

Many researchers and advocates argue that counselling for parents needs to become consistent with this theoretical redefinition of disability and impairment (Kunc, 1992; Oliver, 1993; Turnbull, 1988). Counselling ought to empower parents using the dialogue that they articulate, rather than reflecting practitioners' assumptions about what they imagine it is like to have a child with disabilities, based on tragic conceptualizations of disability. Such counselling practices, intended as sympathetic, can play out as patronizing and stigmatizing. As Smith (1999) points out, "the stories told about disability have been spoken by professional voices" (p. 118), and "physical and social boundaries are used to otherize those outside normalized power discourses" (p. 120). We believe that constructivist counselling provides a theoretical framework that guides counselors in helping parents of children with disabilities to make sense of the ways disability is socially constructed and to recontextualize problems.

Therefore, we sought to describe the experiences of a group of parents by focusing on the meanings the parents gave to their experiences in raising a child with disabilities, rather than imposing an interpretive model based on affective and stage-related theories of coping and adaptation. We speculated that the stories of these parents about their own processes of adaptation, growth, and coping would deconstruct the dominant (traditional) discourse on disability and its effect. We wondered about what kinds of problems they would identify. For example, would they be concerned with their own grieving and sadness, or with making sense, reframing perceptions, and reauthoring their experience, or would there be other main focuses? We examined the parents' stories for descriptions of help-givers' assumptions that appeared to be based on dominant disability discourses and for parents' perceptions of the impact of these assumptions on the counselling and support they received. Finally, we asked how constructivist principles of narrative therapy were useful in counselling parents of children with disabilities.

METHOD

We used three focus groups (Morgan, 1988; Stewart & Shamdasani, 1990) of parents of children with disabilities to collect parents' narratives about their experiences raising a child with a label of disability. Study participants were a

convenience sample of fifteen parents of children with disabilities. Two groups ($n = 7$ and $n = 3$) were recruited in Lakeville¹ and one ($n = 5$) in Mill Town, British Columbia. Two were pre-existing parent support groups, whereas the smaller Lakeville group was formed through the local Child Development Centre for this study. We chose focus groups over individual interviews to provide a richer and more dynamic context of discussion. Parents' sharing of stories led to discussion of shared or divergent experiences with respect to particular issues, thus facilitating deconstructive or critical dialogue on issues facing these parents that might have been difficult to achieve using individual interviews.

Participants

The 15 participants represented 12 families (12 mothers and 3 fathers) and 15 children ranging from 18 months to 30 years of age. There was one foster mother of 4 children with various impairments, and 1 couple of adoptive parents of a child with disabilities. The rest of the parents (10 mothers and 2 fathers), were biological parents.

All but 2 of the participants described their ethnic origins as European or Canadian. More than half ($n = 7$) the families had combined incomes of more than \$50,000 per year. Two single mothers had incomes less than \$20,000. With respect to highest education level attained, 1 parent had a bachelor's degree, 4 had some university education, 8 others had some college or technical training, and the 2 others had completed high school. There were 2 parents between the ages of 25 and 34, 7 parents between the ages of 35 and 44, 4 parents between the ages of 45 and 60, and 2 parents who were more than 60 years of age.

Parents reported various sources of emotional and psychological support. The most common supports were those provided by family or friends ($n = 11$) or professionals (who were not counsellors) involved with their children ($n = 11$). Four of the parents reported receiving the services of a trained counsellor. Ten parents said they had sought emotional support from other parents of children with disabilities, whereas two said they had not sought any support.

Researchers' Roles

The three researchers each have many years of professional experience working with families and children with disabilities in teaching, counselling, and other clinical contexts. In addition, we each teach and conduct research on disability related topics as academics. The first author collected the data and took a primary role in the analysis, with the other two making secondary analytic contributions. We all contributed to the theoretical framework, design, interpretation, and writing. In addition, four assistants helped with the data collection, transcription, and dependability checks.

Procedure

Each parent group participated in one 90- to 120-minute focus group session, conducted in a college or university meeting room with the assistance of a co-moderator. The role of the moderator was to listen, reflect, and clarify statements

made by parents. The co-moderator took notes on broad themes and topic areas. Sessions were audiotaped and subsequently transcribed.

The moderator began each session by posing an open-ended question: "What has been your experience in raising a child labelled with disabilities?" The participants determined the content of subsequent discussions. The moderator formulated reflective statements guided by two principles of narrative therapy — externalization of problems (Silvester, 1997; White, 1991) and deconstructive questioning (Parry & Doan, 1994; Zimmerman & Dickerson, 1996). For example, when a parent described difficulties in looking for support, the moderator used externalization by phrasing the issue as *the* problem rather than *your* problem of looking for support. As the participants actively engaged in discussion in every group, there was little need to probe for elaboration. The few times it was used, deconstructive questioning focused on participants' perceptions of change, using these questions: How has [the problem] affected you in the past and how has your relationship to [the problem] changed? How do other people's ideas about how [the problem] affects parents of children with disabilities strengthen [the problem's] position? How has your involvement with [the problem] influenced how you look at other people?

The focus group interactions yielded broad, open-ended discussions about these parents' experiences in raising their children. To conclude the sessions, members of each group were asked to identify three of the most pressing or important problems or issues. This use of prioritization provided a check of trustworthiness as participants restated salient points, and also privileged the parents' views over ours as researchers in assigning importance to key themes.

Data Analysis

The first author began the data analysis by transcribing the audiotaped focus group sessions and compiling the demographic data, facilitator debriefing notes, and the groups' prioritization of issues. With help from the second author, he sorted statements exhaustively from the transcribed interviews through three rounds into ten final descriptive thematic categories, which, in combination, yielded four pattern categories (Miles & Huberman, 1994). Each of the themes was examined to identify deconstructive and nondeconstructive statements based on the constructivist idea of subjugating cultural discourses. Finally, two independent observers (a graduate student in counselling and a special education teacher), who were provided category labels and samples but no training per se, reviewed selected data for both thematic (60% agreement) and interpretive (85% agreement) consistency. (We acknowledge that we co-constructed the analysis, and debated among ourselves on epistemological grounds whether to include such a checking procedure. Nevertheless, the coding audit does suggest that certain themes in the narratives were salient to multiple observers.)

We used the following criteria for identifying statements as deconstructive: (a) the statement questioned points of view offered as legitimate knowledge or as a core cultural value; (b) the statement appealed to individual validity of interpreta-

tion rather than to “widely held beliefs;” (c) the statement pointed to a contradiction in taken-for-granted assumptions about the nature of the phenomena in question; or, (d) the statement contextualized or reframed the issue. The following remark by one of the participants is an example of a deconstructive statement:

Debbie: I used to have people say, “I don’t know how you cope,” (I couldn’t cope) and, you know, I really think that it’s not Roberta that is the problem. It’s the hoops that I have to jump through the rest of the time and that’s the problem. The child is not the problem. It is what I have to do to go through the steps to get the service I need for my child.

In the parents’ narratives, we also looked for views that did not challenge or deconstruct traditional perspectives. Such statements tended to appeal to the notion of “accepted wisdom.” For example, one of the parents in the study referred to guilt as “something every parent of a child with disabilities experiences.” Other parents talked about their “chronic grief” and the inherent stresses in caring for a child with disabilities.

We also identified statements that suggested the presence of a subjugating cultural discourse. Examples of stories or discourses that parents perceived as having had a negative effect on them emerged in their criticisms of professional discourses and their discussions of popular disability metaphors. This analytical framework is derived from Berry’s (1995) idea about revealing the realities of systems within people’s stories, as well as Woodill’s (1994) description of popular and professional metaphors of disability. The process was interpretive, subjective, and unapologetically grounded in a particular theoretical and philosophical position. In acting as a conduit for these parents’ stories, we worked from our own position on disability, which is that impairment need not be dysfunctional or tragic, but that it is socially and historically constructed as such, often to the detriment of individuals who have impairments.

RESULTS

Within the three focus group sessions, the parents² raised many issues related to their experiences in raising a child with disabilities. They provided richly detailed accounts about the struggles they have faced as well as the rewards they have gained. In telling their stories, these parents reflected on wider social issues, related provocative as well as positive statements about the professionals in their lives, and shared their frustrations, sorrows, and joys poignantly, honestly, and often humorously. We present examples of their stories in each of the four pattern categories: Stories about Assumptions, Stories about Dealing with Difference, Stories about Professionals, and Stories about Disability.

Stories About Assumptions

In this category, there were two themes: horrible pictures and stereotypes. Within both themes, parents’ stories demonstrated that tragic and dysfunctional discourses on disability, and on being the parent of a child with significant impairment, persist. Furthermore, these negative views often contrasted with the

parents' lived experiences. The following is an example of one parent's story of a horrible picture involving a doctor's advice.

Carla: I had a pediatrician say to me once oh! you know, — she painted the most terrible picture. I left; I cried; I was so depressed. She said, Oh, they just get so much harder to look after when they reach 12 and they are just so difficult. I mean, she just went on and on and I left there thinking "good God! Thanks for all the encouragement."

Stereotypes reported by parents included assumptions about their children as well as others' views of themselves. One parent related a story about being perceived as a stoic survivor. Another anecdote reflects a profound lack of understanding of living with severe disability on the part of one professional.

Debbie: Something a social worker told me many years ago, this was when I was still new at [service agency] and he was actually the best social worker I ever came across (I still have some educating to do with him). But he said to me, "Don't ever let Roberta's disability change your lifestyle." Now, . . . I left there crying, thinking, "Okay, I can't ever let this happen." I can just laugh myself right off the chair now to think that how you could have a child with that severe a disability and not have it affect your lifestyle. It's not even a realistic statement.

Other stereotypes parents reported included being seen as in denial, unrealistic in their expectations, and more prone to abuse their children.

Nancy: So sometimes you are afraid to say that you do need help too. We've heard some of the mothers say that too — if I say that I can't cope they will take my kid away. I'm not asking them to take my kid away. I'm asking for a service that I need or something like that. . . . The social services . . . is there to help you but . . . it's the apprehension thing. That never goes out of your mind because you also know well, gee, my kid cries when I give them physio — are the neighbours going to call them. . . . Or they fell and they got bruised because they don't walk as well.

Finally, one parent described the somewhat contradictory assumption of being seen as the sole champion of advocacy.

Karen: The general population tells you — you're the parent, you're the advocate. You're the only one that will advocate for your child so you've got the guilt on your forehead so my God! If I don't do it. You're the continuity, because the professionals change.

These parents' stories about assumptions suggested that they frequently encountered stereotypical or one-dimensional views. In attempting to be good parents, they encountered other people's preconceived appraisals of what being the parent of a child with disabilities entails. They were not claiming that parenting was easy, but they pointed out that it was often made more difficult by these kinds of narrowly defined stereotypes.

Stories About Dealing with Differences

This category encompassed three themes related to larger social discourses on being different: affective issues, assessments of "normal" parenting, and making comparisons. Parents talked about the emotional issues involved in coming to terms with their child's impairment, and commented on issues of grieving, stress, and humour. On the topic of grief, many of their stories were consistent with, rather than deconstructive of, assumptions about feelings of sadness and guilt in

the literature on counselling parents of children with disabilities (Olshansky, 1962). In reference to what she called chronic grief, Karen said:

Karen: I can remember thinking when Susan was first diagnosed, you could only look at the calendar two days at a time. You couldn't look at a week. You couldn't look at the future because you would just sit down and cry because you didn't know what the future was going to be because you knew the child had a lot of problems. And so I couldn't even picture her at the age of 15. Whereas you could picture a brand new baby at the age of 15 or going off to college, getting married and all those kinds of things that you couldn't do.

These stories demonstrated that features of cultural discourse often compounded feelings of guilt and sadness. The lack of accommodation for their children's differences that these parents describe can be seen as a consequence of the traditional discourse on disability. For example, Karen related her feelings of sadness to the experience of physical barriers. She said that the most acute reminder of her daughter's differences was when she could not get into a hand-capped parking space.

Another example of how affective issues relate to larger issues of social discourse involved an exchange between mothers discussing the subjugating gaze of others with respect to prenatal care. Legitimate concern for good prenatal care and maternal health became a guilt-producing issue for these mothers of children with impairments despite what they did to achieve a healthy pregnancy.

Mary: We have no other child so I would like to have another child to feel okay about me. When I have a child with a disability people look at me like "there's something wrong with her." — No, I didn't do drugs and no I didn't drink, "but didn't you take folic acid?"

Karen: Even when it's a genetic disorder, which is a total accident, you still want to prove something to yourself — that you could do it again.

A similar attitude of blaming the parent, this time in regard to expectations for managing a child's behaviour, is portrayed in the following example:

Jeanette: The only grief I ever had with the [local agency] was that everybody keeps pushing parenting courses at you. If your kid's acting this way, take a parenting course. I've taken them all — the kid figures the stuff out before I do. All they've succeeded in doing is making me feel like an awful parent.

The following discussion of guilt about appropriate toilet training provides another example:

Debbie: Regular kids in preschool have to be trained. In other cultures they're not. My son was three when he entered preschool and I said to her is it okay if I send him in a diaper; he's more or less potty trained but rather than have an accident. . . . She goes, "Well, I don't know, we've never had one." And I turned to my husband and said, "oh my god! We're the first parent who took a kid to preschool when he's still in a diaper." (Laughter) Karen: And then you have a kid with a disability and it's like, yeah, you just got kicked twice.

These examples provide a context for understanding parents' feelings of guilt. Rather than assuming that guilt is a justified response to the assumed difficulty of having a child with a disability, these stories suggest a need to reevaluate rigid social standards that portray parents as being "the problem." Blackford describes

these standards as “the patriotic ideal for women [that] has been translated into a moral responsibility to produce children who are healthy, bright, and motivated enough to compete with children from Japan and Germany” (1993, p. 290).

In contrast to such descriptions of being negatively positioned or “otherized” (Smith, 1999) by such subjugating gazes, participants also discussed processes of positively reframing or reconstructing the experience of having a child with a disability.

Peter: It ceases to be a nightmare. When you accept the fact that’s just the way they are. Everybody’s different and you have to . . . accept the fact that that’s the way they are. . . . Either you adapt your lifestyle or you put your kid in respite all the time. Those are the two options and for us, that’s not an option.

These kinds of statements suggest a process of deconstruction and reconstruction of problems that is congruent with the social model of disability, and that counters the conceptualization of disability as tragic.

Parents also saw optimism and humour as important antidotes for sadness and guilt. One parent talked about optimism in the following way:

Helen: You always have to keep saying you are doing your best and it’s going to get better, maybe not tomorrow, maybe not next year. So there’s that sense of optimism which is probably why I first spoke about positive things that we experienced rather than negative.

In recent years, a strong sense of humour has emerged in the disabled activist movement (Smith & Sapon-Shevin, 1999). The following exchange is an analogous example of how these parents used humour to make sense of their situations, in this case, in a parent support group.

Mary: I was looking for weeping and whining. (Laughter)

Nancy: So was I and there was none — not even five minutes. I thought we were supposed to have a glass of wine, all break down and get this out and — nothing. They made rude comments and smart remarks. (Laughter)

Mary: I thought, “Who are these people?”

Karen: But you kept coming. You persevered.

Humour, from a deconstructivist perspective, involves laughing at assumptions about what is supposed to be the correct response to a given situation, as seen in this dialogue. Instead of “weeping and whining,” the parents of younger children not only received useful information, but also had the chance to laugh. Perspectives like chronic sorrow are stereotyping in that they fail to recognize that having a child with a disability includes laughter along with the tears.

In summary, the category of Dealing with Difference included stories of how these parents made sense of having a child who was significantly different or atypical. While some of their stories expressed traditional views, parents told many stories that reflected a critical constructivist framework. They talked about sorrow and guilt but they also related how these issues could be situated in dominant social discourse, deconstructed, and ultimately reconstructed through an emphasis on acceptance, optimism, and humour.

Stories about Professionals

This category included themes of meeting children's needs and bureaucracy. We sought to locate these parents' perceptions about the variety of professionals and systems they encountered, such as early intervention, rehabilitation, schools, behaviour management specialists, medical professionals, and social services. Parents spoke of feeling out of control:

Nancy: Once you have a child with a disability, it's almost like it's not your child; it belongs to the system. Like, I already had a child and nobody came into my life. I had this child, and within 3 months, I had probably visits from 4 different professions — the health unit, child development centre, infant development on and on. . . . You had speech therapy, physiotherapy, occupational therapy. I never had so many people in my life at one time and you felt like this child did not belong to you.

Several stories addressed the invasiveness of intended help and lack of appreciation of the parents' personal context. One parent described being asked by a psychologist whether her daughter ever was rough with animals. She responded that she was, meaning that her daughter sometimes was rough in a playful way. The psychologist's written report stated that the child "displayed cruelty to animals," which could be read as a reference to clinical research associating psychopathic behaviour with childhood cruelty to animals. Although the parent laughed as she told this story, she also expressed her grave concern at the time about how her daughter would be perceived by others because of this report.

The parents' stories sometimes suggested that they lived in very different realms of experience than professionals in relation to their children with disabilities. For example, one parent described how her priorities had changed with time and how these priorities may have been at odds with those of rehabilitation professionals.

Debbie: We've sort of come to the understanding that speech, OT, PT — all that's on a consultative basis. If it was not an integrated classroom, she would probably be in a segregated school getting services to meet all those needs and probably would be developmentally further ahead but the trade-off is she goes to birthday parties; she has friends come to the house.

Some parents spoke of perceiving some medical professionals as objectifying their children:

June: And I mean, they just went like this (rubbing hands together) when they saw . . . because she was so rare. It's like, "We've only ever had three cases of this in Canada but now we have one in [city]." It was wonderful, right? . . . Also, the idea that you are an experiment, or they're experimenting on your child, bothered me a lot.

Perhaps the most persistently troubling system for these parents was that of the bureaucracy. In all three groups, parents expressed their frustrations about how they have received the bureaucratic "runaround," especially from the social welfare system:

Nancy: I had a social worker. . . . She just keeps going on and on 'til I'm so tired I go with my phone and I sit down at the table and I'm saying, "listen to me, this is a simple thing. Don't

make my life crazy. All I want is the cheque to come to my house, okay.” And she goes, “But no” and I’m going. . . . And eventually I’ve got my head down on the table, and I’m going, “Don’t make me crazy; listen to me. This is a simple thing. Do what I’m asking; call me back” and I hang up the phone. I can’t believe this. Honest to God, she phones me back after making me crazy for probably half an hour and says, “Oh Nancy, that’s quite all right; you can still have the cheque come to your house.”

In contrast to various other kinds of service systems, bureaucratic concerns were seldom discussed in a positive light. It was not particular professionals per se who represented a problem in their lives, but a bureaucratic discourse that set the context of supports. They described a system that compartmentalized, that regularized, and that fostered fear, confusion, and frustration. Within this overriding system, problems of coping with disability emerged.

From a constructivist perspective, the parents’ stories about interactions with professionals spoke to the need to make sense of bureaucratized systems and how they come to play a key role in their lives. Although these parents tended to normalize their experience of multiple involvements with professionals as part of being the parent of a child with disabilities, they also represented these systems as invasive, lacking contextual understanding, overly bureaucratic and impersonal, and often dominated by an unquestioned adherence to traditional medical models. Offsetting their negative stories of relationships with professionals, they also described positive experiences and relationships, particularly when they felt some equality with the professionals. Working from a critical agenda, however, we feel it is important to expose subjugating professional discourses that persist in influencing the lives of parents of children with disabilities. Clearly, these parents’ stories reveal that many of the “older stories” persist.

Stories About Disability

The final category included themes of larger discourses, diagnosis and labeling, and nonpathological views. Parents discussed their own historical and sociological analyses of what it meant to be different within the existing culture. They provided examples that situated their stories within a historical framework, revealed idealism about diversity, and suggested that problems of disability can be attributed to existing social structures. The following story from a parent of an adult child compares professionals today with the older institutional approach:

Howard: And I think that they are a lot more sensitive to recognizing the differences in people with developmental difficulties. . . . they are avoiding even labelling people now . . . everybody has possibilities and they should be encouraged to develop to the potential, whatever that potential is — you don’t measure people according to somebody else but according to their own individual potential. I think the philosophy has changed a lot.

The parents’ stories about the way their children were categorized and accommodated within society suggested a critical evaluation of the dominant discourse rather than acceptance of the “truth” of disability labels. One parent described how she educated her doctor about her understanding of the difference between the systemic need for a specific diagnosis and the social meanings ascribed to the label:

Sarah: And her doctor said to me, "You know Sarah, I really don't like having labels on kids." But I said, "We have to have the labels to get the funding; otherwise she's going to be left to fend on her own at school and that's not fair." . . . he said, "I don't like labels on kids." I said "It's not really a label on her — it's a label for the school system so she can get funding." He said, "Okay, as long as that's the only reason you're doing it." Well what else would I do it for? I already know that she has problems.

Ironically, despite this parent's conviction that the label was only for the purpose of funding, this same parent said she later needed to remove her child from a school because she felt the staff had prejudged her child based on the diagnosis.

These parents' stories about labels suggested that the issue was far from resolved. For example, some parents described certain diagnoses as "fitting exactly." There are measurable differences in human neurology and physiology that cannot be ignored, but the risk is that those differences come to stand for an individual's identity and the label becomes paramount.

Nancy: There isn't a day goes by that I don't look at her as a child with [name of syndrome] as opposed to my daughter. She still can make me laugh and we still have lots of good times and she is still my baby even though she is 5 and a half, and that's been good for me too. I mean most mothers love that part of it and think. . . . I don't know that I'll ever just see her as a child — not with the disability.

In contrast, the following parent of a young adult reflected on her own personal growth through her lifetime of work with her daughter:

Helen: People that I have met through having our child . . . have been wonderful people and there have been a few that have really helped a lot in the big picture. Generally, they have been wonderful people. We have gained a lot of knowledge ourselves. We had pretty positive experiences.

The narratives we collected suggest that these parents of children with disabilities exist at a crossroad of discourses — one, a traditional discourse of pathology and sorrow, and the other, a newer and more critical discourse of acceptance and empowerment of people with disabilities.

Summary

The four pattern categories and the themes within them that we derived inductively from the parents' narratives reflect key concepts of critical constructivist counselling theory. In telling stories about other people's assumptions, these parents revealed the persistence of reductionist, stereotypical views of physical and mental impairment and what it means to be a parent of a child with disabilities. Their stories about dealing with difference elaborated many affective issues discussed in the research. Their stories are rich in contextual detail, situating narratives within larger social discourses about the value of normality and judgments about what constitutes good parenting. Stories about professionals point to the subjugating effects of a clinical, invasive, bureaucratic, and decontextualized professional agenda. Finally, these parents' stories about disability showed that they were concerned with the bigger historical and sociological issues, and that a reconstructed view of their situation may evolve through their experiences.

DISCUSSION

We found that many stories of these parents of children with disabilities about their own processes of adaptation, growth, and coping reflected a deconstructed view of the dominant discourse on disability and its effect on parents. The narratives of parents in this study showed many consistencies with White's (1991) notion of deconstruction as procedures that subvert taken-for-granted realities and practises. These parents questioned assumptions about disability and about being the parent of a child with disabilities, as well as the complex set of social and professional relationships situating their experiences. Their remarks also point to ways in which constructivist counselling practices provide a good fit with their experiences and needs.

Much of what these parents said did not fit with the dominant social discourse on being the parent of a child with disabilities, which centres on a tragic or pathological view. These parents did not present themselves as suffering from chronic sorrow or inordinate amounts of stress. Although many of them acknowledged feelings of sadness and guilt, and that stress was a reality in their lives, their main emphases were on making sense of disability, advocating for their children, and sharing stories about both the rewards and difficulties of parenting.

These parents' statements often challenged aspects of the professional discourse on disability. For example, although they did not question expertise and they welcomed useful advice, they also talked about the need to question professional certainty. In particular, they questioned the idea that there was a single solution to every problem, and they felt professionals lacked breadth of understanding about their life contexts. Parents expressed the view that their children were not "broken." Going to birthday parties, having friends, and being independent and safe often were considered to be more pressing concerns than therapeutic agendas.

These parents' discussions indicated that having access to discourse about historical and sociological aspects of disability was important in helping them make sense of their situations. Their remarks revealed support for the move away from segregation and institutionalisation towards greater inclusion and tolerance, while also identifying cultural and systemic barriers to change. Many of their stories illustrated how others tend to hold stereotypic assumptions about disability and about parenting children with disabilities. For example, the social worker who advised a mother to not let her child's disability affect her lifestyle showed a profound lack of understanding of living with disability. Such stereotypes reflecting the dominant story are based on tragic views and assumed pathology. Parents reported that they risked being seen as trouble-makers or labelled as being "in denial." They also reported struggling with the expectation of being a "super-parent," with sole responsibility for advocacy. Similarly, the persistence of outdated stereotypes about disability, or horrible pictures, affected how their children were evaluated. One parent was urged to consider institutionalisation.

Another was asked if she wished she could give her child back. These parents said people assumed that their children caused them more stress and grief than was the reality. These parents' stories point to the need for more education about disability issues, consistent with inclusive service philosophies.

We conducted this study from a social constructivist theoretical perspective, collecting parents' stories as shared and discursively interpreted within focus groups. We believe this theoretical orientation, as reflected in narrative therapy, provides a good match with the counselling and support needs of parents of children with disabilities. For example, the ideas that problems are not within people, and that parents' voices make a key contribution to discourse on disability, are particularly relevant to working with parents of children with disabilities.

Whereas expert-led skills-oriented approaches seek to remediate inadequacies or deficits and thus reiterate dominant cultural stories, a narrative approach draws on the knowledge and skills present within the lived experiences of participants. Narrative therapists do not treat people for their problems; they listen to their stories. In using a narrative style to facilitate these focus groups, a space was opened for these parents "to story their own strengths and preferred ways of being" (Silvester, 1997, p. 233). Because our participants had lived experiences of being seen as different, "not normal," or "the other," they came to question the dominant discourse on disability and parenting. We used narrative therapy processes of externalizing problems and deconstructive questioning to validate their critical questioning and help them to unmask the implications of subjugating stories, opening the way for their own alternative stories.

We agree with Peavy (1993) that no single counselling approach is appropriate for all counselling situations. Nor do we wish to overgeneralize our results. We worked with just fifteen parents, who were, on the whole, vocal advocates for their children. They do not represent all parents of children with disabilities. Different stories would emerge in other contexts depending on the participants and their issues of concern. Also, although our main aim was to listen to the parents in the groups sharing their narratives, we acknowledge that we encouraged a critical, questioning atmosphere in the focus group sessions, and particularly attended to deconstructive elements in the thematic analysis process. Therefore, in keeping with a narrative therapy approach, our findings represent a coauthorship of meaning.

A central aim of narrative therapy is to help individuals reauthor their lives, based on their own stories, rather than on the subjugating stories of others (White & Epston, 1990). These results show how some parents have managed to do that, often in the face of imposed other realities. As Karen said, in one group, "You never think of your life as dysfunctional. Everyone around you does. It's just different." Our study illustrates how a narrative approach to group work allows, in Silvester's (1997) words, "space for the telling of alternative and preferred stories of group members" (p. 240), thereby challenging oppressive stereotypes and systems, or "old stories." Parents in this study are telling a different story.

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Notes

¹ Community and participant names throughout the study are pseudonyms.

² We have used the term 'parent' rather than 'mother' or 'father.' This is not meant to ignore the fact that many issues are particularly critical for mothers of children with disabilities. Although not the focus of the current study, a feminist analysis of gender-based experiences begs to be done (see Thacker, 1999).

References

- Affleck, G., & Allen, D. A. (1985). Are we stereotyping parents: A postscript to Blacher. *Mental Retardation*, 23 (4), 200-202.
- Bennett, T., DeLuca, D. A., & Allen R. W. (1996). Families of children with disabilities: Positive adaptation across the life cycle. *Social Work in Education*, 18 (1), 31-44.
- Beresford, B. A. (1994). Resources and strategies: How parents cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35, 171-209.
- Berry, J. O. (1995). Families and deinstitutionalisation: An application of Bronfenbrenner's social ecology model. *Journal of Counseling and Development*, 73, 379-383.
- Blacher, J. (1984). Sequential stages of parental adjustment to a child with a handicap: Fact or artifact? *Mental retardation*, 22 (2), 55-68.
- Blackford, K. A. (1993). Erasing mothers with disabilities through Canadian family-related policy. *Disability, Handicap and Society*, 8, 281-294.
- Doolittle, P. E. (1999, November). *Constructivism and online education* [Online]. Paper presented at the international online conference on Teaching Online in Higher Education, Indiana University Purdue University Fort Wayne, IN. Available: <http://www.chre.vt.edu/f-s/doolittle/tohe/tohe2.html>
- Ferguson, P. M., & Ferguson, D. L. (1995). The interpretivist view of special education and disability: The value of telling stories. In T. Skrtic (Ed.), *Disability and democracy: Reconstructing (special) education for postmodernity* (pp.104-121). New York: Teachers College Press.
- Finkelstein, V. (1993). The commonality of disability. In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers — Enabling environments* (pp. 9-16). London: Sage.
- Foucault, M. (1954). *Mental illness and psychology*. New York: Harper.
- Gallant, P. J. (1993). New ideas for the school social worker in the counselling of children and families. *Social Work in Education*, 15, 119-128.
- Glidden, L. (1993). What we do not know about families of children who have developmental disabilities: Questionnaires on resources and stress as a case study. *American Journal on Mental Retardation*, 97, 369-375.
- Hanline, M. F. (1991). Transitions and critical events in the family life cycle: Implications for providing support to families of children with disabilities. *Psychology in Schools*, 28, 53-59.
- Kratochival, M. S., & Devereaux, S. A. (1988). Counselling needs of parents of handicapped children. *Social Casework*, 69, 420-426.
- Kunc, N. (1992). The need to belong: Rediscovering Maslow's hierarchy of needs [Online]. Available: <http://www1.us.nizkor.org/~axis/maslow.html>

- Lapadat, J. C. (1997). Student's construction of scientific knowledge: Cultural context, mutual focus, and conversation. In S. McLarnon & D. Nord (Eds.) *Northern Parallels: 4th Circumpolar Universities Co-operation Conference Proceedings*. Prince George, BC: UNBC Press.
- Lenny, J. (1993). Do disabled people need counselling? In J. Swain, V. Finkelstein, S. French, & M. Oliver (Eds.), *Disabling barriers — Enabling environments* (pp. 233-240). London: Sage.
- Marshall, H. H. (1996). Implications of differentiating and understanding constructivist approaches. *Educational Psychologist*, 31, 235-240.
- Miles, M. B., & Huberman, M. A. (1994). *Qualitative data analysis: An expanded sourcebook* (2nd ed.). Thousand Oaks, CA: Sage.
- Morgan, D. L. (1988). *Focus groups as qualitative research*. Newbury Park CA: Sage.
- Oliver, M. (1993). Conductive education: If it wasn't so sad it would be funny. In M. Swain, V. Finkelstein, S. French & M. Oliver (Eds.), *Disabling barriers — Enabling environments* (pp.163-168). London: Sage.
- Olshansky, S. (1962). Chronic sorrow: A response to having a mentally defective child. *Social Casework*, 43, 190-193.
- Olssen, M. (1996). Radical constructivism and its failings: Anti-realism and individualism. *British Journal of Educational Studies*, 44, 275-295.
- Parry, A., & Doan, R. E. (1994). *Story re-vision: Narrative therapy in the postmodern world*. New York: Guilford Press.
- Peavy, R.V. (1993). Envisioning the future: Worklife and counselling. *Canadian Journal of Counselling*, 2 (2), 18-41.
- Prawatt, R. S. (1996) Constructivisms, modern and postmodern. *Educational Psychologist*, 31, 215-225.
- Shakespeare, T. (1993). Disabled people's self organization: A new social movement. *Disability, Handicap and Society*, 8, 249-264.
- Silvester, G. (1997). Appreciating indigenous knowledge in groups. In G. Monk, J. Winslade, K. Crocker, & D. Epston (Eds.), *Narrative therapy in practice: The archaeology of hope* (pp. 233-251). San Francisco, CA: Jossey-Bass.
- Smith, P. (1999). Drawing new maps: A radical cartography of developmental disabilities. *Review of Educational Research*, 69, 117-144.
- Smith, R., & Sapon-Shevin, M. (1999, April). *Stereotyping disability humor and the promotion of empowering imagery*. Paper presented at the annual meeting of the American Educational Research Association, Montreal, QC.
- Sobsey, D. (1995). Our kids news group archive [On-line]. Available: <http://wonder.mit.edu/Our-Kids.html>
- Stewart, D. W., & Shamdasani, P. N. (1990). *Focus groups: Theory and practice*. Newbury Park, CA: Sage.
- Thacker, J. (1999). *Mothers who live apart from their children*. Unpublished master's thesis. University of Northern British Columbia, Prince George, BC.
- Trute, B., & Hauch, C. (1988). Building on family strength: A study of families with positive adjustment to the birth of a developmentally disabled child. *Journal of Marriage and Family Therapy*, 14 (2), 185-193.
- Turnbull, A. P. (1988). The challenge of providing comprehensive support to families. *Education and Training in Mental Retardation*, 23, 261-272.
- United Nations (1993). *Standard rules for the equalization of opportunities for persons with disabilities*. G. A. res. 48/96, 48 UN GAOR Supp. (No.49) at 202, UN Doc. A/48/49.
- White, M. (1991). Deconstruction and therapy. *Dulwich Centre Newsletter*, 3, 1-21.
- White, M., & Epston, D. (1990). *Narrative means to therapeutic ends*. New York: Norton.
- Woodill, G. (1994). The social semiotics of disability. In M. H. Rioux & M. Bach (Eds.), *Disabilities is not measles: New research paradigms in disability* (pp. 201-226). North York: The Roehar Institute.

- Zimmerman, J. L., & Dickerson, V. C. (1996). *If problems talked: Narrative therapy in action*. New York: The Guilford Press.
- Ziolko, M. E. (1991). Counselling parents of children with disabilities: A review of the literature and implications for practice. *Journal of Rehabilitation*, 57, 29-34.

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