From Waiting to Relating: Parents’ Experiences in the Waiting Room of an Occupational Therapy Clinic

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Key Words: sensory integration • social environment • support system

Objective. The purpose of this study was to gain an understanding of parents’ perceptions of outcomes of occupational therapy intervention using a sensory integration approach.

Method. Interviews with parents regarding their children’s participation in occupational therapy were analyzed using grounded theory.

Results. The parents’ experiences of sitting in the waiting room while their children received occupational therapy emerged as a powerful outcome theme. Through their interactions with other parents, this particular group of parents gave and received naturally occurring support for parenting children with sensory integrative dysfunction. Additionally, by virtue of repeated experiences of waiting, parents moved to positions of liminality, shared weekly rituals, engaged in downward social comparison, and reframed their views of their children.

Conclusion. Implications are proposed for expanding the definition of family-centered intervention; attending to the meaning of the cultural world of practice; and directing future research related to how a physical setting, such as a waiting room, might shape naturally occurring support and social interaction.

Karen is the mother of a 7-year-old girl who received occupational therapy using sensory integration approaches at a private practice in a suburban community. Responding to a question about her experience of taking her daughter to the occupational therapy clinic, Karen said:

We’d sit in the waiting room and we’d always be reading. Gradually over the weeks, we just started talking. I really enjoyed talking with her [another parent], and it was like a little support group. She would share with me some of the things she was concerned with, and I would share my concerns. So, it was nice to have someone, to have a little support group, while we were there without having to go another night of the week. She had similar concerns.

The analysis of waiting room phenomena came about during a study designed to understand parents’ perspectives of outcomes of occupational therapy using sensory integration approaches for their school-aged children and their families. As I interviewed Karen and other parents to understand their perspectives, I started to hear a recurring pattern about the waiting room. Many of the parents repeatedly spoke about perceived benefits of sitting in the waiting room and chatting with other parents. Some parents in the study even suggested that I contact other people, now their friends, who they had met in the occupational therapy waiting room. Peggy, a mother of a 6-
year-old boy, said:

The waiting room was very helpful. It was a very helpful, quasi-spontaneous support group, and even though my son was probably the mildest of the group, it was a support group without having to make it happen. It was just very nice moms all there for the same reason, talking about various issues: advocacy issues, insurance issues, life-in-general issues. When you go week after week, you see the same people. It was really helpful.

During the interviews, parents reflected on their experiences and repeatedly spoke of the “unanticipated consequences” of bringing their children to therapy; that is, the parents anticipated that the therapy itself would be the main change agent for their children. They did not anticipate benefits for themselves as parents, and the benefits of the waiting room experience were an unexpected finding in this research. Merton (1936), a sociologist, explained that consequences (expected or unexpected) result from interplay between an action and the context of the action. The analysis here examines the context of the action: the waiting room and parents’ accounts of their transformative experiences of waiting while their children received occupational therapy. Implications for occupational therapy practice and research are discussed.

By striving to understand parents’ perspectives, I recognize the importance of family-centered care in providing services to children with special health care needs and acknowledge the influence of families in children’s development. Family-centered care involves meeting family concerns, building on family strengths, respecting family diversity and cultural backgrounds, sharing information, promoting partnerships and collaboration, and encouraging social support (King, King, Rosenbaum, & Goffin, 1999; Lawlor & Mattingly, 1998; Shelton, Jeppson, & Johnson, 1987; Shelton & Stepanek, 1994). Moreover, providing family-centered services requires practitioners to understand what the behaviors, events, persons, and institutions mean to those who participate in them (Cohn & Cermak, 1998; Llewellyn, 1994). Therefore, the study was designed to understand what children’s participation in occupational therapy using sensory integration approaches meant to parents.

Method
Participants

I interviewed 16 parents (14 families consisting of 12 mothers and 2 husband-and-wife couples) of children who received occupational therapy using a sensory integration frame of reference at a private clinic in the northeastern United States. Participants were parents of children who had documented conditions of some type of sensory integrative dysfunction as measured by the Sensory Integration and Praxis Tests (Ayres, 1989). The children (4–10 years of age) had participated in at least 32 1-hr therapy sessions and had stopped therapy 1 month to 2 years before the interview. All participating parents were white and in the moderate to affluent socioeconomic status range. A majority of the participants had master’s degrees, and except for one participant, all were college educated.

For the children whose parents participated in the interviews, therapy had typically involved a 1-hr session one time per week. Therapy consisted of the “use of enhanced, controlled sensory stimulation in the context of a meaningful, self-directed activity in order to elicit an adaptive response” (Fisher & Bundy, 1991, p. 23). Selected activities incorporated the use of suspended overhead equipment that provided tactile, vestibular, and proprioceptive input to which the child made adaptive responses. Therapists often invited parents into the therapy sessions to observe their children. A minimum of 32 1-hr therapy sessions (approximately 8 months) was the criterion selected to anticipate some type of change. This criterion is based on a review of nine sensory integration efficacy studies with children with learning disabilities (Ayres, 1972, 1978; Carte, Morrison, Sublett, Uemura, & Serrtakian, 1984; Densmore, Nutall, Bushnell, & Horn, 1989; Humphries, Wright, McDougall, & Vertes, 1990; Humphries, Wright, Snider, & McDougall, 1992; Law, Polatajko, Schaffer, Miller, & Macnab, 1991; White, 1979; Wilson & Kaplan, 1994). Twenty-four hours of intervention was the modal number of therapy sessions in the reviewed studies. Therefore, it is proposed that the children in the study reported here received enough therapy to anticipate some type of change.

A sample size of 16 was deemed adequate on the basis of two criteria. First, exploratory studies are recommended to use at least eight participants to obtain an adequate amount and range of information (McCacken, 1988). Second, the sample size is consistent with or even slightly larger than that of other qualitative studies recently conducted in the occupational therapy field (Anderson, 1993; Case-Smith, 1997; Case-Smith & Nastro, 1993; Hinojosa, 1990; Hinojosa & Anderson, 1991; Rudman, Cook, & Polatajko, 1997). Recruitment was stopped after the 16th participant because I reached a point at which findings from newly collected and analyzed data became redundant (Strauss & Corbin, 1998).

Parents of children given a primary diagnosis of autism, pervasive developmental disorder, or Fragile X syndrome were not included in the study. Parents of children with these particular conditions may have different concerns about the social–emotional and behavioral manifestations of their children’s conditions than parents of children without these conditions. The sample criteria are based on the assumption that they represent a relatively homogeneous subgroup of children who receive occupational therapy in private practice settings using a sensory integration framework.

Procedure

On the basis of chart review, 42 children met the inclusion
criteria. Names of parents of 22 children to be invited as potential participants were randomly selected from the total group of those eligible. A letter explaining the study purpose and procedure and offering parents the opportunity to remove their names from the potential participant list was sent to the selected families. Three families requested to have their names removed from the potential participant list, and eight families reported being “too busy” to participate in an interview. Potential participants (those who did not request to be removed from the list) were called to clarify the purpose and procedure of the study and to determine interest in participating in the study. All participants signed Internal Review Board-approved informed consent forms before the interviews began.

I conducted 1-hr to 2-hr semistructured interviews in each family’s home. Questions were adapted to respond to the discussion in the context of each interview. I asked participants to describe a typical day with their child, what about their child led them to seek occupational therapy, and what they had hoped to gain from therapy. I asked whether they saw changes in their child and, if so, to describe an incident that illustrated the change; whether changes they had hoped for had not occurred; and how they came to a decision to stop therapy. After each interview, I wrote reflective memos to record my immediate reactions to the interview. Each interview was audiotaped, transcribed, and checked by thorough review and comparison between the transcript and the original audiotape. In addition, I reviewed each child’s clinical chart to document reasons for referral and therapy goals. Throughout the research process, I wrote periodic analytical memos (Miles & Huberman, 1994) to record my evolving thoughts related to the research question and process. After the waiting room phenomenon became apparent, I spent time observing the waiting room.

Data Analysis

Hasselkus (1997) reminded us that as researchers, we are “positioned in relation to that which we are researching” (p. 81) and our particular position becomes the lens through which we make interpretations. Examining this lens is a starting point for all research and enables us to use our reflections productively for insight and analysis. In the spirit of reflexivity, I acknowledge the influences of my own background as both a parent of school-aged children and an occupational therapist who has provided occupational therapy using a sensory integration approach. As a parent, I know firsthand the experiences of striving to nurture a child’s growth and sense of competence. I share Llewellyn’s (1994) view that parenting is an intensely personal yet commonly shared experience. Sharing my parenting experiences, both joys and dilemmas, with other parents provides a powerful source of support and personal validation for the challenges inherent in the occupation of parenting. As an occupational therapist, I try to provide therapy that ultimately makes a meaningful difference for children in the contexts in which they live, learn, and play. I carry an underlying assumption that occupational therapy is effective and can contribute to changes in children and the entire family system. However, I also believe and have documented elsewhere (Cohn & Cermak, 1998) that we have not empirically examined which outcomes of occupational therapy are important to parents who bring their children for intervention.

Using grounded theory procedures recommended by Strauss and Corbin (1998), I reviewed the transcripts to name and categorize the participants’ perceptions of valued outcomes. The category of the waiting room immediately emerged after the first interview. As other parents talked about their waiting room experiences, all instances of waiting room talk were compared and contrasted to detect similarities and differences across all the transcripts. The QSR NUD*IST 4.0 (1997) qualitative data analysis software was used to manage and explore the data. To strengthen credibility and ensure that participants’ perspectives were accurately represented, I prepared written summaries of each interview and sent the summaries to participants for review. I then contacted each participant by phone to discuss the interview summaries and, on the basis of their feedback, made modifications to the summaries as needed. Finally, I analyzed the summaries along with the interview data. To honor confidentiality, pseudonyms are used throughout this article.

The Waiting Room Experience

For this particular group of parents, the waiting room was an important component of their experiences of bringing their children to occupational therapy. Webster’s Third International Dictionary (1976) defines waiting as staying in place in expectation of, deferring, holding back in expectation, delaying hope, or delaying hope of a favorable change. Waiting is at the crossroads of the present and the future and certainty and uncertainty (Gasparini, 1995). These definitions of waiting capture the essence of what the participants were doing while their children received occupational therapy. The participants brought their children to occupational therapy because they hoped for some change, and they held those hopes in abeyance while they sat with other parents. They waited in suspense, week after week, hoping for some change to unfold. The end result was unknown, the future uncertain. Deb, the mother of a first-grade boy, described how she would sit in the waiting room each week and talk with other parents about her hopes: “I sat in the waiting room hoping that there would be hope for him. That he could learn to live with his condition....We wanted him to be normal. We wanted him not to hurt himself or others.” Another mother, Lynn, said: “I felt like he [her son] was getting older, and I wanted him to...
be out in the world doing things that other kids do. There were a lot of us sitting there saying that."

**Liminality**

The participants’ children all have invisible conditions, that is, their sensory integrative dysfunction is not readily visible to the untrained eye. Yet, each participant’s presence in the waiting room made his or her child’s condition and need for intervention obvious to the other parents. In addition to being an assertion of hope, visits to the occupational therapy clinic each week activated feelings of liminality described by Murphy (1987) and Murphy, Scheer, Murphy, and Mack (1988) as a state of waiting. A distinguished anthropologist who developed quadriplegia from the effects of a spinal tumor, Murphy views disability as a form of liminality. In Murphy’s view, liminality is closely related to sociologist Victor Turner’s (1969) idea of rites of passage in which the purpose of the rituals of passage is to involve the community in the transformation of an individual from one position in society to another. This transformation typically occurs in three phases: isolation or separation, ritual emergence or transition, and reincorporation into society. During the transition from isolation to emergence, the person is thought to be in a liminal state, a state of waiting. A state of waiting helps parents to transform their experiences of parenting their children with sensory integrative dysfunction. The parents shifted from a position of isolation in which they shared their experiences. This weekly waiting room ritual helps parents to transform their experiences of parenting their children with sensory integrative dysfunction. The parents shifted from a position of isolation in which they shared their experiences. This weekly waiting room ritual helps parents to transform their experiences of parenting their children with sensory integrative dysfunction.

A Weekly Ritual

Bell (1992) claimed that ritual activities are set aside from the flow of other daily activities and that the distinction between rituals and day-to-day routines is based, in part, on the beliefs of the social group. I argue here, on the basis of what the participants told me, that the waiting experience in and of itself provided parents with a weekly ritual in which they shared their experiences. This weekly waiting room ritual helps parents to transform their experiences of parenting their children with sensory integrative dysfunction. The parents shifted from a position of isolation (parenting children with invisible, yet challenging conditions) to a position of shared experience in which others understood their concerns. Two major characteristics of ritual are predictability and sharing of experience. In fact, Durkheim (1915/1965) proposed that rituals provide a means for a group to affirm itself through shared experience. Unlike waiting rooms where there are different persons waiting at each visit, the waiting room experience described here had predictability. The participants repeatedly saw the same parents each week, which provided the opportunity to develop relationships and share common concerns and feelings.

Murphy (1987) observed that persons in a liminal state often put their differences aside and view others in the same position in an egalitarian manner. This nonhierarchical social position offers the potential for linking with other parents and sharing revelations frankly. For the participants in this study, the waiting room was found to have become a contained setting that facilitated interaction, and their experiences were transformed into something other than just “waiting.” In the context of the waiting room, participants found affiliation and a refuge from the world of others who could not understand their parenting experience. One mother, Nancy, talked about a parent she met in the waiting room:

She had similar concerns. It was very nice to have someone to talk to. I think any parent dealing with SI [sensory integration] therapy must experience doubts [about their parenting]. The mothers that I talked to in the waiting room certainly did.

**Naturally Occurring Support**

Karen, the mother whose interview opens this article, told me that over several weeks, parents gradually shifted from reading to talking to each other. Typical waiting room behavior usually involves reading or staring straight ahead. The chairs may be arranged in rows that minimize eye contact and the potential for interaction (Holmes-Garrett, 1990; Rodgers, 1990). The waiting room I observed was more like a family room than a waiting area. Comfortable couches facing a set of movable chairs sat in a sunny, welcoming room, with toys placed in an area behind the couches for the children. Perhaps the furniture and its arrangement coupled with the repetition of this particular waiting room experience invited parents to let go of the predictability and sharing of experience. The mothers that I talked to in the waiting room certainly did.

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I heard about a tutor through someone in the waiting room....The waiting room was really fun....Because you are in a vacuum, you are worried about things. I had a doctor who I had a really bad experience with....I found out another mother was going to him. He was the pits. So you weren’t alone, and everybody else has concerns. Everybody there had questions.

Marie and the other participants described important interpersonal, socially interactive, and supportive features of the waiting room experience. The perceived benefits derived from these spontaneous social supports are consistent with the benefits of social support described by other
researchers. Caplan (1974) examined naturally occurring social supports and concluded that a mutual and reciprocal quality exists in the interactions with people who help each other. The mutuality is emphasized by the fact that the support is voluntary and spontaneous. Both the giver and receiver of support are equally, though differently, benefited by the contact. Often, people prefer to receive help from others who have personally experienced the same or similar predicaments because the help appears more authentic.

In a comprehensive examination of parent support groups, Hauser-Cram, Warfield, and Krauss (1997) identified two functions of such groups. One function is to act as a form of intervention for parents who have unusual parenting challenges; another is to help parents be advocates for their children. Both functions assist parents in their parenting occupation. The link between social support and well-being is well documented for parents of children with disabilities. Support, both informal and formal, has been found to enhance well-being and family functioning by acting as a buffer to stress (Dunst & Trivette, 1990; King et al., 1999; Wallander et al., 1989). In related research, Quittner, Glueckauf, and Jackson (1990) suggested that social support mediates the relationship between parenting stress and outcomes. In both the “buffer” model of social support and the “mediator” model, social support is viewed as having a positive impact on family functioning. Furthermore, parent-to-parent programs (Llewellyn, Griffin, & Sacco, 1992; Santelli, Turnbull, Lerner, & Marquis, 1993) provide parents with the valuable opportunity to give as well as receive assistance, which has been found to enhance self-efficacy and self-esteem (Kagan & Shelley, 1987; Zigler & Weiss, 1985). On the basis of their research, many of these authors recommended that centers of care provide practical assistance for information and networking opportunities through such mechanisms as parent newsletters or parent support groups.

Downward Social Comparison

In listening to the words of the participants in this study, another waiting room phenomenon became apparent. In addition to the outward interactions resulting in social support, a quiet, internalized experience simultaneously occurred that resulted from comparing one child with another. Renowned social psychologist Leon Festinger (1954) identified the process of social comparison in which people use others both for determining how well they have done and for learning what they should do. In Festinger’s view, peoples’ attitudes and beliefs are based on particular reference points. Thus, one way in which we attempt to understand human experience or form beliefs is through social comparison. Other people serve as a reference to help us determine how we are supposed to behave and how good we are at a particular type of behavior. By design, the participants’ children all had more subtle forms of sensory integrative dysfunction than many of the other children receiving occupational therapy at this particular clinic. The social comparison process offered the participants a unique perspective that influenced their understanding of their children. Deb described her observation this way:

It was a really good thing for me to see the children that were treated at the clinic. It made me appreciate, help me remember how lucky we were not to have a really stressful [son]. Some of these children, my heart goes out to their parents....It was very therapeutic for me to see the other kids. Not all of them, but most of them at our time were in much worse shape than my son.

Many of the participants shared similar observations. Being better off than others in a similar situation, as described previously, has been identified by social psychologists as a downward social comparison. For example, studies have shown that stress from health problems induces a desire to compare one’s health with that of others (Mollerman, Pruyn, & van Knippenberg, 1986; Taylor, Buunk, & Aspinwall, 1990) and that downward social comparisons contribute to well-being and positive feelings (Hakmiller, 1966; VanderZee & Buunk, 1995; Will, 1981). Numerous participants echoed these findings as they spoke about observing parents with children who had more significant problems than theirs. This observation and downward social comparison process helped the participants reframe their perceptions of their children and helped them accept their situation. For example, the mother of a 5-year-old boy said:

I always felt like he was borderline whether he needed to be there because I would talk to other people there or see other children come in and they clearly needed some kind of help. They had bigger issues. So I thought, ‘Well, my situation isn’t so bad. There’s nothing really wrong with my son. He just needs help getting himself more cohesive.’

Another mother, Johanna, framed her waiting room experience in terms of sympathy. She explained:

I think I got a lot of sympathy for people whose kids who were in much worse condition than my son. Just spending time in the waiting room was an amazing, eye-opening, and heart-wrenching experience....I began to see my situation as a piece of cake compared to other people.

Reframing

The social comparisons that occurred in the waiting room led many of the parents to reframe their assessment of their children or situation. While reflecting on changes that may have occurred from bringing her son to occupational therapy, Johanna described how she reframed her expectations for him: “You know, I think I am less hard on my son. I gave up on the homework [being perfect]. Who cares? It doesn’t matter as long as an effort was made. It doesn’t have to be perfect.” Niehues, Bundy, Mattingly, and Lawlor (1991) and Case-Smith (1997) identified “reframing” as a process of coming to see a person or situation in a new way because one has changed the framework, or lens, through which he or she views the situation. These researchers claimed that reframing is a valuable service provided by
occupational therapists working in schools. Case-Smith noted that by educating teachers about the potential relationship between sensory processing and behavior, occupational therapists enabled teachers to view student behaviors in a more positive way and gave them a basis for developing effective teaching strategies. In the present study, therapists’ efforts to educate parents about sensory processing may have helped the participants reframe their expectations of their children. Perhaps unknown to the therapists, the comparisons participants made in the waiting room also had a powerful influence on their construction of their own children’s behavior. Comparing their children’s behavior to others less fortunate enabled the participants to see their children’s strengths. They reported a downward social comparison and a positive reframing of their children’s behavior. What about the parents whose children have more significant conditions? How do these parents perceive their waiting room experience?

Summary

The participants in this study took their children to therapy with the expectation that somehow occupational therapy would help their children’s future. It was surprising to find that the experience of simply sitting in the waiting room may have contributed to the process of expected change. Crossing the threshold into the waiting room moved these parents from the isolation of parenting children with invisible conditions to the liminal state of waiting or readiness for change. Through their weekly interactions with one another, sharing stories, experiences, parenting challenges, and resources, these parents gave and received naturally occurring support for parenting children with sensory integrative dysfunction. Although family-centered care encourages social support, this study shows us that support not only may come from professionals, but also can occur naturally in a waiting room environment. In addition to the natural support parents provided one another while in the waiting room, the parents were reassured by comparing their children with children who were more severely involved. This comparison seemed to play an important role in participants reframing their expectations for their children and for themselves as parents.

Implications for Practice and Research

At the theoretical level, this research echoes the importance of expanding the definition of occupational therapy beyond direct intervention with children to include parents as well. The findings raise our awareness that ritual interactions are complex and may have deeper meaning and consequences than we fully appreciate. Lawlor and Mattingly (1998) suggested that a redefinition of practice includes recognition of how encounters with family members are influenced by the cultural world of practice. As therapists and researchers, we need to pay attention to the entire context surrounding the intervention process, not just the explicit therapeutic encounter.

Findings from this research raise questions about what constitutes family-centered care. An outpatient clinic, by its very nature and no matter how family friendly the staff may be, is not inherently family-centered. Thus, we might ask, “How can we provide family-centered care in an outpatient setting?” Some practitioners might argue that family-centered care involves parents as active participants in the therapy, collaborating with the therapist and child in the therapy rooms rather than sitting in the waiting room. Although collaboration between professionals and parents is important, we have seen in this sample that the social support available in the waiting room might be another powerful aspect of family-centered care. If the experience of these parents has implications for others, then attending to the broader practice environment can be seen as part of a family-centered approach. We need to understand how parents are making sense of the entire therapy experience, not just interventions focused on children in isolation of their caregivers.

In this study, the waiting room experience emerged as a meaningful and symbolic feature of the entire therapy. Although occupational therapists have viewed occupation and adaptation as an interactive process between persons and environments (Barris, 1986; Barris, Kielhofner, Levine, & Neville, 1985; Frank, 1996; Spencer, 1998), we have not explored how a physical setting, such as a waiting room, might shape naturally occurring activity and social interaction with the symbolic meanings attached to places. Representing the field of humanistic geography, Rowles (1991) invited occupational therapists to consider the existential meaning of environments to their clients.

Hoffman and Futterman (1971) noted that most professionals aim to eliminate waiting room time, especially for busy parents. The insights from this research suggest that occupational therapists should aim to create in their waiting rooms a milieu to foster sharing so that parents can talk to one another. Practitioners in other fields have recommended that waiting rooms provide comfortable seating conducive to interaction; private space that is not shared with other professional practices; parenting information and education resources; a lending library; and beverages, such as water, tea, or coffee (Harman, 1997; Koepeke, 1993). Providing an inviting environment in which parents can share with each other may be an important component of family-centered care.

Koroloff and Friesen (1991) noted that members of self-help groups are likely to be white, middle income, and well educated, as were the participants in the present study, and Hauser-Cram, Pierson, Walker, and Tivnan (1991) reported that parent support groups were not universally appealing to all families. These findings remind us that the participants in this study represent a very small homoge-
neous group of parents of children who are likely to seek occupational therapy services. Although the naturally occurring “support groups” were perceived as a positive benefit of their children’s therapy, we must be careful to avoid assuming such a support group will be appealing to all our consumers or appropriate to all settings. Is it possible that the similarity of the families receiving occupational therapy at this particular clinic made sharing in the waiting room easier? Further investigation with a more diverse group of parents may help determine whether these findings have implications for other parents. The label “support group” was not formally applied to groups of parents in the waiting room. Rather, the group support occurred naturally, not institutionally. Does the naturally occurring phenomena make a difference? Might it be useful to schedule like children at the same time to enhance the possibility of parents developing naturally occurring support networks, or is the downward social comparison resulting from observing a variety of children a crucial change agent? Moreover, further investigation is necessary to test whether the perception of support exchanged in the waiting room and reframing are at all related to outcomes of perceived well-being and sustainability of family life.

Another possible implication of the research reported here is that the process of change resulting from occupational therapy using a sensory integration approach occurs, to some degree, not only with the children, but also with the parents. By reframing their children’s behavior and receiving support, parents reconstruct their image of their children and themselves in their parenting occupation and change their beliefs about their children. Some researchers have suggested that parental beliefs may directly affect children (Goodnow, 1988, Murphey, 1992). Research efforts need to further explicate whether parental beliefs are indeed connected to behaviors and child and family outcomes. If a connection can be established, then optimal mechanisms for facilitating “reframing” should be explored.

Finally, this research illustrates the importance of family-centered care. As we strive to provide meaningful intervention with children and their families, we must attend to the broader context of the therapy experience and carefully listen to how families are interpreting their experiences with intervention.

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