When Believers Encounter Early Intervention

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Abstract

This paper explores a point of contact between religion, spirituality, and the care of very young children with disabilities: the assessment interview and team meeting. One case study is presented, and interpreted in a contrast between biomedical and interactional models of disability (Smart & Smart, 2006). Issues are addressed in the larger context of the relationship between religious values and early intervention, and implications for training of interventionists.

Keywords: early intervention, religion, spirituality, team

Introduction

The clinic manager stuck her head around the corner into my office, where I waited for the next child and family on that day's list. Visitors to the Early Intervention and Evaluation Clinic varied, but all were worried about their child's development. Most had been identified with disabilities, at least by their parents. "This mom's ready for you now," said the manager, "and watch out -- she's really religious." What did the manager mean? What images were called forth in response to her words? Why was this family directed to me, the only psychologist in the

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clinic known to be a religious believer? What was going to happen when this religious family encountered early intervention?

Despite a more recent emphasis on the cultural diversity of families of children with disabilities, the discussion of religious values in early intervention remains on the theoretical periphery of work with very young children, rather than a part of daily conversations about individual differences, coping strategies, or family centered care. Health care for the "whole person" remains elusive, despite its popularity as a recommended practice (Kaslow, Bollini, Druss, Glueckauf, Goldfrank, Kelleher, Greca, Varela, and Wang, 2007).

Gallup pollsters (2012), who track American religious beliefs annually, found recently that 78% of Americans surveyed said they believe in God; most said that religious beliefs influence their daily decision making, and 58% said that they believed God could solve most if not all of their problems (Gallup, 2012). Religious belief is a part of the cultures and institutions that affect families, practitioners, and their relationships.

When interventionists do discuss spirituality with their clients, they may not have received any training in how to do this well. In one survey of 208 social work students, over 30% of respondents indicated that they had used religion or spirituality based interventions with their clients, while 66% reported receiving little or no graduate training in this area (Sheridan & Hemert, 1999). This paper explores a point of contact between religion and the care of very young children with disabilities in early intervention by exploring one case study and the interpretation of religious viewpoints by an assessment team. The issues raised are addressed from a Judeo-Christian perspective, but in the larger context of the relationship between values and intervention.   We will end with the implications of the issues for work with families.

<div align="center">Why my child? Religious responses</div>

Prest and Keller (1993) have noted that families often come to therapy because people are asking questions which have a spiritual dimension. These arise at predictable developmental points, such as during marital transitions, or as a child reaches adolescence. The birth of any child, but especially a child with a disability, provokes just such a point of existential crisis. Parents ask why this disability has happened to their child. Like the apostles who questioned Jesus about a man blind from birth (New Testament: John 9: 2-3), parents and interventionists may look for causal attributions. Is it the parents who have "sinned," perhaps through their high-risk behavior, deficit parenting, or failure to heed genetic counseling and a doctor's advice? Is the father to "blame" because of his genetic stock? Was it fate? Or, is it the child who is at fault, born with a "bad seed" of disability?

In response to the parents' concerns, those who work with very young children may give the platitudes of uncertainty. Practitioners say: It's a genetic mutation; they are random, and no one knows why it happened to your child. It's a result of anoxia, but no one knows when it occurred,

and the doctors are not to blame. With current methods (such as MRI and micro assay analysis) we can identify the cause of most severe disabilities; in the case of mild delays, etiology is more difficult to determine (Batshaw, Roizen & Lotrecchiano, 2012). Even when a disability can be named, and its origin detected, the question of "why my child?" remains. No answers. I believe that the biomedical model of care (Smart & Smart, 1996) fails families first because it did not predict this birth, and then because it offers no acceptable answers to their anguished questions.

Those who believe in a caring, personal God may find meaning in their child's birth and life in ways that seem antithetical to the paradigms of prediction and prevention common to intervention science. Belief in a God who orders the universe, and whose work is made manifest in all circumstances, allows them to "construct meaning out of the seeming chaos and randomness of life" (Prest & Keller, 1993, p. 138), and to provide religious explanations of events.

In the moral model of disability (Olkin, 1999), some parents of the Judeo-Christian perspective specifically believe that God sent them a "special child" for a reason (because they were loving and patient, for example). Others believe that the disability itself is evil, but that God will bring good consequences out of it in their lives (through growth in character, or through the life their child will lead). In fact, religious parents are more likely to say that their child was an opportunity, rather than a burden, and to describe the "purpose" of their children in their lives in powerful, meaningful ways (Weisner, Beizer & Stolz, 1991). However, religious communities and cultures have inconsistent, widely varying responses to disability, and generalizations are suspect (Selway & Ashman, 1995).

The common thread among these explanations may be that they serve to decatastrophize the disability, and the birth of the child, by making it an understandable and therefore controllable situation. If families may choose to interpret their child's disability as a blessing, rather than a curse, they gain interpretive control over this otherwise uncontrollable event (Rothbaum, Weisz & Snyder, 1982). In religious families, the child is then brought into a coherent, preexisting worldview in which God is preeminent.

This response is antithetical to what is expected of the family by the therapeutic community. These families may not show elements of anger or depression; the birth of a child with a disability may not even challenge parents' devout religious beliefs. Belief may be strengthened as family members work out their responses to the existential questions of "Why me? Why my child?" in a community of fellow believers, rather than with mental health or medical practitioners, who may feel left out. Conversely, a religious community can be rejecting, and parents may find acceptance and support through early intervention practitioners. The response of faith is often viewed by early interventionists as (at best) naive; at worst, it is termed repression or denial.

Following is one case story from my experience as the psychologist member of a multidisciplinary assessment team for very young children and their families. It illustrates the competing worldviews of a religious mother and the biomedical model of care (Smart & Smart, 2006), which focuses on disability as solely a matter of individual experience, leading to an aggressive treatment and cure. This model is less effective in dealing with people whose disabilities are chronic, or will lead to death. Clinical neutrality, in which an approach (such as team-based early intervention) is seen as "one size fits all," does not adjust for matters of faith or culture. In contrast, functional and environmental models of disability describe children with disabilities in relation to their environments, and the function of disability in those environments (Smart & Smart, 2006).

The assessment visit. The "really religious" mother Sara and her 6-month-old son Jonah (names changed) were brought into my office for a developmental evaluation. Sara said little as we settled into our seats. She was small and dark, clad in long sleeved navy blue cotton despite the summer heat. A black lace mantilla covered her head, secured by a silver pin. After a brief psychosocial interview, I asked her what she and her family wanted to get from today's clinic visit. "Nothing really," she said. "We know that Jonah is not doing well, but we believe God will heal him."

I held Jonah, a 6-month-old boy who had the black hair and startlingly blue eyes of his mother. Jonah was tiny, stiff, and unresponsive, an irritable baby who fussed intermittently throughout the visit. Jonah's medical tests showed continuous seizure activity and porencephalic cysts. He had been diagnosed as "failure to thrive," and a gastrostomy tube was being considered for feeding purposes. My exam showed that he had no responses to environmental stimuli, except a brief and repeated startling to a ringing bell that was as strong on the 5th presentation as on the first. I handed Jonah back to Sara. I explained the results of my examination to her, first complimenting her on all the work her family was doing with Jonah at home, and then using the simplest of language to describe the "openings" in Jonah's brain, and the lack of clear messages being transmitted there. I also mentioned that the early intervention team had tried for several weeks to schedule a home visit, but were "having trouble getting through." She interrupted me. "I've seen the CT scans," she said; "I've examined the EEGs, and he has continuous diffuse brain activity. Not much is getting in or out of his brain, is it?"

I must have looked shocked at her command of medical terms, because she smiled. "Look, I'm not denying Jonah is sick. I'm not ignoring anything. I know everything about him, just like I do for my other two. At first, I cried all the time. I got angry with God -- really yelled at Him. But He showed me how to love my baby. He showed me that He loved me and would stay with me. I take good care of Jonah. If he needs this G tube thing, we'll do that. But can you heal him? Can you really do anything for him? No? We think that God can, and we're in constant prayer for Jonah. We have laid his X-rays on the altar at our church. Over 200 people are praying for him every day. And we really don't have time for your home therapy visitor."

Despite my familiarity with religious practices, I drew back. Dear God, I thought -- what's going to happen to her faith when he dies? I couched my response in jargon, but said that children who are like Jonah often continue to get worse. Sara breathed deeply. "That's OK too," she said calmly. "God may heal him by bringing him home (to heaven). Satan may mean this for evil, but God will bring good out of it." We sat in silence for a moment. I couldn't think of anything to say. And then, with a pounding heart, I said -- would you like to pray for Jonah with me before you go?

The team's response. An hour later, in a staffing where we discussed recommendations for Jonah (Sara was not present), early intervention team members expressed a lack of confidence in Sara and her ability to care for Jonah. Sara had refused the Individualized Family Support Plan process and services from a home visitor, although she stated that she would bring Jonah to physical therapy once each week. Her faith assertions about his future healing were interpreted as a denial of his condition, despite her "excellent performance as an historian" of his case. Discussion focused on the belief system of Sara's religious group, rather than on evaluation results and recommendations for Jonah.

When it was my turn to contribute to the staffing, I focused on the instrumental value of religion for Sara and her family. I explained that Sara had achieved interpretive control over her son's disability by believing that God was in charge of their lives, and would heal Jonah. The baby was well cared for, physically. Her beliefs had also opened up an active, problem-centered coping response, as she had organized massive prayer teams for him at her church. These responses did not represent denial; rather, they had the effect of placing Sara, Jonah and their family solidly in the midst of an impressive system of informal, community-based social support and (incidentally) respite care. I did not tell the team that I had prayed with Jonah's mother, a practice that would've been considered appropriate by 60% of the interventionists in Sheridan & Hemert's (1999) interview study.

The team remained unconvinced of Sara's capacity to care for Jonah. A paradigm of scientific neutrality on matters of values and religion had left us without the shared vocabulary to discuss this family adequately. I left the meeting wondering at our collective denial of the reality of God in our client's lives. Sara's faith may not heal Jonah, but it had made her well.

Case story analysis. Would Sara have responded more fully to early intervention services if she thought that the team understood her worldview? Certainly, evidence indicates that distressed persons appear to desire help that is consistent with their spiritual beliefs (Bergin & Jensen 1990). While families can often choose their mental health provider or physician, they seldom choose their early intervention provider, and so are not afforded the opportunity for help congruent with their beliefs.

In this case, Sara refused more formal interventions, but the shared ritual of prayer opened up a channel for discussion of other value-based decisions, such as the importance of maintaining a healthy marriage covenant and the need for respite care in the face of the family's exhaustion. Sara may have needed additional psychosocial intervention, and our brief encounter was not enough to determine her emotional needs. However, the value of the encounter was not in my therapeutic interventions for Jonah, but in our communion. I could not fix Jonah, but I could be with Sara. I believe that this is the core of our resistance to the discussion of religious values in the care of very young children. Our scientific paradigms are based on prediction, prevention and cure, while spirituality deals with precisely what cannot be predicted or fixed.

As a part of culture, religious beliefs affect many aspects of early intervention practice. For example, Rogers-Dulan and Blacher (1995) reviewed the role of religion and disability in African- American families, and concluded that religious beliefs affected the families' interpretation of the meaning of an event, coping resources, and adjustment to a child's disability. African-American families in their study were more likely than Anglo families to be characterized by a sense of collective, not individual, responsibility for a child with a disability; to have a stronger sense of kinship obligation; to have strong parent-child and sibling ties; and to frequently participate in informal fostering of children in the community (p.233).

Religious belief is also a factor in the coping behavior of interventionists. The practice of religion, especially a belief that life has meaning and purpose, has been associated with a lower burnout rate among workers in residential treatment facilities for people with disabilities (Shaddock, Hill and van Limbeek, 1998). In fact, the increased use of paraprofessionals to support early intervention, particularly in home visitation programs such as Healthy Families America (Carnahan, Nelson & Gordon, 1999), may lead to an increased need to consider the role of religion in therapeutic relationships. Paraprofessionals have been shown to constitute a demographic group separate from teachers and therapists; they are more likely to belong to an established religion and to be members of minority groups for whom religion is known to be of increased importance (Haring, Saren, Lovett & Shelton, 1992).

Religious beliefs can profoundly affect therapeutic relationships, as well. In one study of families who were members of an ultra-orthodox Jewish community and who had children with disabilities, Leyser (1995) reported that 35% used prayers and faith in God as methods of coping with stress, while only 4% had contact with a mental health or intervention professional about their child. The study "underscored once more the need for professionals to become more sensitive to diverse family characteristics…and to match intervention programs that are consistent with these characteristics" (Leyser, 1995). For example, Leyser notes the strongly traditional sex role conventions in the ultraorthodox community and the assumption of nearly all childcare burdens by mothers and grandmothers, regardless of the difficulties in caring for a child. These practices are outside the more egalitarian ideal pursued by many in a less traditional therapeutic community. Leyser also notes the absolute necessity of involving the Rabbi, as

spiritual leader, in major decisions about a child (such as out of home or special school placement) (Leyser, 1995).

In practice, we are far from this ideal collaboration. Harry (2008), in a review of research about collaboration with culturally and linguistically diverse families, found that assumptions of deficit families, stereotypical beliefs about diverse populations, and poor cross cultural communication continue to mar the relationships between interventionists and families (Harry, 2008). Children in early intervention may be part of multiple minorities, of religion, disability, ethnicity, socioeconomic status, and gender (Olkin, 1999), compounding the problem.

When Sara and her son Jonah were assigned to my caseload, it was in part because a discussion of religious belief remains controversial in the intervention workplace, and I was a known "believer," the only one on my team.   A growing body of literature supports the view that religion affects a family's beliefs about disability (Weisner et. al., 1991), interpretation of the meaning of events, coping resources, and adjustment (Rogers-Dulan & Blacker 1995; Leyser, 1995), the coping behaviors and work patterns of interventionists (Shaddock et al., 1998), and cross cultural interpretations of the meaning of disability (Harry, 2008). The whole team would benefit from a systematic examination of the role of religious beliefs and values in all aspects of the early intervention process: screening and referral, diagnosis, access to community resources, family involvement, assessment, and intervention relationships. For example, cultural proscriptions against reporting about family members to outsiders may prevent members of ultra-Orthodox communities from using Child Find type referral services.   How can the early intervention community establish alternative means?

M. Farber has described a clinical center for child maltreatment in Jerusalem which is entirely staffed by members of the Orthodox faith (Farber, 1999). While a complete separation of services should not be necessary, we must respect the needs of families, and guard against the very real possibility of misunderstandings and manipulation.   For example, in giving advice to therapists, Prest and Kessler (1993) suggested ways in which the non-believing professional can use the language, ritual and metaphors of their client's religions as "resources for support and change" (p. 142).   They describe parents who were "challenged to reconsider their outmoded Biblical maps for living" (p. 143) by learning to substitute Biblical passages based on mutual self-sacrificial love for passages based on submission to husbandly authority in the home.   If a non-believing professional supplies the Biblical exegesis, these suggestions border on deception. The use of the beliefs of one culture by an outsider to change the behavior of another is manipulative in any context.

Next, we should continue to systematically describe the beliefs of religious groups concerning issues of the origin of disability, family privacy, hierarchies of decision-making, parental responsibility, and theories of change. While studies exist on these issues in the literature of cross-cultural psychotherapy, little conversation has taken place concerning the care of very

young children with disabilities. We should include members of the religious community as full partners in this research, and in community based planning for intervention services.

Finally, religious aspects of culture must be included in training in care for very young children with disabilities and their families. Both pre and in-service training are necessary as globalization brings increased diversity everywhere. While broad based training in cultural sensitivity is useful, there is no substitute for learning about the specific beliefs of the people we serve, especially as culturally diverse groups are under-represented among degreed professionals at this time.

Using both lecture based and case study methodology, trainers need to confront both their clients' possible views on religion -- and their own. For example, aspects of Christianity associated with U.S. churches such as a belief in a just world (where bad things only happen to bad people), meliorism (the perfectibility of humans through their own efforts), and beliefs about the inferior quality of households headed by single or divorced mothers, may affect judgments about client families.   While there are many examples of families who have been respected and supported in their views, a recent review indicates that such cross cultural communication gaps are common (Harry, 2008).

To be a religious believer in many health workplaces today is to be like Ariel in The Tempest: confined in a cloven pine, filled with a spirit, but without a voice. All around us, families struggle with the existential crises precipitated by the birth of a child with a disability, and the process of including that child in the family. We discuss every other topic with these families and each other, but cultural and scientific restrictions prevent us from a free discussion of the spiritual and moral aspects of our discipline, among each other and with families.

Previously, prohibitions against religious discussions in the workplace and a paradigm of scientific neutrality and detachment forbid the discussion of morality and religious issues between clients and professionals.   Prest and Keller (1993) attribute this to a quest for scientific respectability in our comparatively young field; "in order to become scientific, we must separate ourselves from the nonscientific constructs, metaphors and rituals" (p. 139).   Smart & Smart (2006) describe this as the persistence of a biomedical model of disability. On the contrary, we must bring the tools of science to our understanding of the profound influence of religion as we care for young children and their families.

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