

The Doubting Dance: Contributions to a History of Parent/Professional Interactions in Early 20th Century America

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The relationship of professionals with families of children and adults with intellectual disabilities is a key component in the planning and delivery of effective and enduring support services. Yet, the history of such relationships is not well understood. After briefly describing the context for these relationships in the early 20th century, a thematic analysis is presented of correspondence between parents and professionals at one institution for people with intellectual disabilities during the early 1900s. The study concludes with a brief discussion of what we can learn from this troubled history to improve family/professional relationships.

DESCRIPTORS: history, families, institutions, professional/family relationships

Parents of children and young adults with disabilities have always had a complicated relationship with the professionals in medicine, education, and other fields who claim special expertise to help, or even cure, their offspring. On the one hand, the families are often grateful for whatever help and support they can find. On the other hand, they equally often end up expressing a desire for more or different types of help than they find available. Throughout the history of disability and the formal service systems that emerged to respond to that segment of the population (e.g., special education, health care, rehabilitation), there has been a choreography of care as parents and professionals danced around the issue of who would take the lead in providing support for dependent children. This is no where clearer than in the evolution of formal services for children with intellectual disabilities (Farber, 1986).

This study explores one corner of the history of family-professional relationships in the area of intellectual disabilities by looking at a particular period of rapid expansion of services in the United States, roughly 1900 to 1930. In this era, professionals with new specializations (e.g., clinical psychology, special education, social work) pushed for new or expanded services that

would allow them to demonstrate their expertise. The call for new services, however, was often put forth as a response to the needs and demands of families who could not care for their children with disabilities. At the same time, these same professionals would also portray families as sources of resistance to their services, making it necessary to either avoid or overcome their opposition to "giving up" their children to the control of the experts (Deschenes, Cuban, & Tyack, 2001; Ferguson & Ferguson, 2006; Lazerson, 1983).

From the earliest specialized asylum for feeble-minded children in the middle of the 19th century up through the 1960s, the official public policy in most states was that the best situation for children with intellectual disabilities—especially those with more significant cognitive impairments and/or challenging behaviors—was to be placed in an institution specifically designed for their care and custody. Certainly, this was the opinion of most medical and health care professionals involved in the treatment of such children. Throughout this period, many parents seemingly agreed with this recommendation. Some of the earliest parent advocacy groups for families with children with intellectual disabilities were actually organized to provide political and financial support to the institutions where their children resided. The Children's Benevolent League of Washington began in 1939 with just such a mission (Schwartzberg, 2005). In a presentation by one of the founders of this group to an audience of institutional professionals (Sampson, 1947), the support of families for institutions was seen as both hard won and valuable.

[F]rom my experience, the League does eliminate, by training, by explanation, and by regulation much of the time that would otherwise be wasted by our superintendents, their assistants and attendants in useless conversation and argument with disgruntled individuals. Our members know better than to find fault with minor annoyances (p. 189).

For other parents, the recommendation to institutionalize their children became the only choice that could salvage the welfare of both the child with the disability and the rest of the family. As an anonymous parent framed

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the matter in 1951, the decision to place a child in an institution was, indeed, tragic. However,

[t]he greatest tragedy occurs in the many cases when parents cannot bring themselves to part with their child. Time and again this results eventually in even greater unhappiness, particularly in families where there are other children. Almost any social welfare worker can recite cases where hopelessly retarded children, kept within the family, have warped the lives of other children and, frequently have been the means of untold hardship and ultimate separation of the parents (Anonymous, 1951/1969, p. 87).

Each of these statements nicely captures both sides of the parental response to professional recommendations. In the midst of endorsing the policy of institutionalization, the parent-authors also acknowledge that many other parents rejected the experts' call to "part with their child" or refused to be silent about the "minor annoyances" they found in the care of their children after they were institutionalized. The statistics back up this acknowledgment. Never more than 10% of the population viewed as intellectually disabled was housed in the large state institutions that proliferated after the first one started in Massachusetts in 1848 (Ferguson, 1994, pp. 9–11). Still, the demand for institutional placement was real. Waiting lists for admission existed even before some institutions opened their doors. For many years, county poorhouses, reform schools, and other facilities took on many children viewed as feeble-minded. However, equally true as a factor in this gap between policy and practice was the steady countertheme of resistance that a significant portion of parents put forth to having their children institutionalized in the first place or leaving them there for long after an initial admission. This account explores one setting where examples of that family resistance arose to the recommendations of the helping professionals who were the main source of expertise and information about the appropriate care of their children.

A Typology of Family Narratives

Until the last few decades, the portrayal of families of children with disabilities of any kind, but especially those with intellectual disabilities, suffered from the same constrictions as the history of people with disability in general. The research literature was dominated by the voices of professionals, creating an official discourse of parental response to disability as, at best, one of moving gradually through stages of grief similar to those supposedly followed by news of a terminal disease (Ferguson, 2001). Although almost always available to some extent in the popular press, published accounts of their experiences written by parents themselves were

not to be taken as serious data for use in developing a research-based understanding of how parents reacted to having a child with a disability and what they needed to overcome that "tragedy." The need to preserve and to explore the parental voice directly is now seldom challenged. Indeed, most educators and disability specialists acknowledge those parental voices as essential parts of our knowledge base about the meanings of disability across cultures and class, categories, and contexts. Family-professional linkages are increasingly viewed, at least in theory, as mutual exchanges of information, planning, and support on behalf of the child involved (e.g., Ferguson & Galindo, 2008; Kalyanpur & Harry, 1999). However, much work remains to be done by scholars to fill out the historical record of how parents of earlier eras described their experiences (Abel, 2000; Brockley, 2004; Burack-Weiss, 2006; Richards, 2004).

Robert Berkhofer (as cited in Rury, 1993, p. 247) has argued that one of the main requirements for historians is to "fill in the gaps." The purpose of this report is to make a contribution to that effort with regard to the untold history of parent/professional interactions. This study narrows its focus to the relationship of families and professionals in first few decades of the 20th century and to one specific setting. It is part of a larger project that seeks to bring a disability studies orientation to the understanding and interpretation of families who have a child with a disability (Ferguson & Ferguson, 2006, 2008). The foundation of that effort is based in the collection and analysis of family narratives about that experience. The hope is eventually to create a digitized, searchable archive of family narratives covering the full range of disabilities and contexts within which parents and children build their lives.

The project has developed a three-part typology of family narratives, framed from the perspective of how they come to us: (1) received, (2) generated, and (3) found. Received narratives are those published accounts written by parents or other family members. Whether book length accounts, chapters in books, or articles in journal and magazines, these are intentional accounts written by individuals who have both the inclination and the opportunity to organize their thoughts into a narrative meant to be shared with others. Generated narratives, by contrast, are those created artifacts of (usually) qualitative research. These are in-depth oral histories and semistructured interviews, conducted by researchers to allow a purposeful sample of families to tell their stories in their own words. These are families who may or may not have otherwise preserved these experiences without a specific invitation. Finally, there are the found narratives. Found narratives are simply those primary sources familiar to historians, consisting of diaries, letters, scrapbooks, and other unpublished accounts created by families with no intention of sharing them with a larger public. It is these "found narratives" that serve as the primary source for this

