Travelling a Mirrored Pathway:
Care of Children and Adults With Special Needs in Aboriginal[1] Communities

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Introduction

"... it was a terrible thing for us... any family who has a child who's disabled, it can destroy a family or it can make them closer... they make you work so much harder."
(Parent of a deceased child with a disability)

"I feel I'm absorbing more ... special qualities of others. I could say that I'm so busy, but [my brother] gives me a touch of reality... [he] gets me to think more and maybe that's what others do too. If they can just stop and think sometimes of what others can offer..."
(Parent of an adult child with a disability, and caregiver of a sibling with a disability)

The words of the above participants reflect that a close relationship with a vulnerable person brings both a deepened appreciation of life as well as extreme stress. In this exploratory study, interviews with six Aboriginal caregivers and social service professionals reveal that traditional stories and legends uphold an "inclusive" approach to treatment of the vulnerable; individuals with developmental disabilities are "right pulled in" to the life of their communities. Their approach contrasts with the Western concept of developmental disability rooted in the Enlightenment era when capacity for "rational decision making" defined the freedom of individuals (Goodey, 2001). As a foundation for Western institutional structures, this view has led to devaluation and "exclusions" of individuals with developmental disabilities (Simpson, 2001), and poor services (Bogdan & Taylor, 1982).

[1] The term Aboriginal as defined by the Royal Commission on Aboriginal Peoples is used to refer to indigenous peoples in North America. In this paper the term is used to describe both First Nation and Metis peoples. First Nation peoples typically have membership in a Nation and have some rights guaranteed in treaty rights with the Federal Government. Metis peoples are Aboriginal peoples with shared European and First Nation heritage; Metis peoples did not enter treaty agreements with the Canadian government and therefore have the same rights and privileges as other Canadians.

The participants' sensitivity to the cultural values within their own communities, while struggling with societal institutions upon which they relied for assistance, placed them at what Vaughan (1992) refers to as a "critical nexus" within which complex and conflicting cultural values representing different world views intersect and impact upon children and families.

While working as a social worker in Winnipeg agencies, I had observed both inclusive values and extreme stresses in Aboriginal families with disabled members; over 60 % of First Nation and over 40% of Metis children live in poverty (Social Planning Council of Winnipeg (SPCW), 2003). Social disadvantage increases risks of individuals being developmentally disabled (Sinason, 1992; Patton, Payne & Bierne-Smith, 1990; Simpson, 2001). The rates of Aboriginal children with disabilities in Manitoba are double those of non-Aboriginals. Culturally appropriate services are not available (RCAP, 1996; SPCW, 1996).

Methodology

Personal Connection to the Topic and Research Design

This study explores the experience in Aboriginal communities of care of individuals with developmental disabilities from an "insider's" perspective, through the stories of participants. My experience transcribing spiritual stories in First Nation communities led me to wonder whether specific stories and legends might inform culturally appropriate care of community members with developmental disabilities. The questions asked of the participants in this study were: *How does your family or community care for children with special needs or community members with disabilities? What oral stories or community teachings might give insight into the values which shape care of the vulnerable? What is current practice? What are the challenges?*

The research design is based on the grounded theory approach developed by Glaser and Strauss (1967), intended to enable participants to share their experience in response to open ended questions. I think it is important to acknowledge my own connection to this topic. Vaughan (1992) asserts that bias is a theoretical tool, and so I choose to clarify my bias. My Metis childhood, my role as a designated decision maker for my sister who has a developmental disability, and my experience of parenting a disabled child who died in infancy, inform my approach to this topic. I shared my personal experience with participants as appropriate.

The Participants

All participants were Aboriginal; each was interviewed for 1 to 1½ hours. Two participants were parents of individuals with special needs; one parent was also a designated caregiver of a sibling with a disability. The third participant was employed at an Aboriginal resource centre; her child with a disability died in infancy. The fourth participant was a social worker who had been a designated caregiver of a deceased relative; the fifth was a child welfare worker and the sixth was a cultural enrichment instructor. Five participants lived in Southern Ontario while one lived in Manitoba.

Findings

The Use of "Story" in Research

Culture has been transmitted through oral literary traditions for centuries in Aboriginal societies. Historically, stories "connected" community members to each other and to the natural world which they relied on for sustenance. Aboriginal writer Storm (1972) describes stories as "a mirrored pathway" along which others may walk and recognize parts of their own stories. The metaphor: "the mirrored pathway" enables us to see both the roots of community based values around care of the vulnerable, as well as the impact of public policy on their lives.

Travelling the Mirrored Pathway

> *"...the lowly muskrat saved the world by being able to dive down in the waters and bring back some sediments that saved the world and restored Mother Earth. We're all meant to be who we are and it's no accident.... the extended family is the community and we're all within the circle and it's inclusive..."*
>
> > Father of an adult child with a disability and
> > designated caregiver of a sibling with a disability

The above participant likened the social structure of his community to a "spider's web". While each *part* of the "web" is fragile, the web itself is "powerful"; it brings life to the spider. In communities where "everyone belongs", the strength is in the interconnections. Persons who were vulnerable were described as bringing a "special" quality to communities; they were "closer to the Creator", "gifts" to their families. That individuals with disabilities help others *learn* spiritual insights was a recurring theme. A number of participants recalled "being exposed" to a person with special

needs as a way of "teaching" acceptance. Persons named as designated caregivers of individuals with disabilities considered their responsibilities "an honour", and were supported by the communities in their roles.

The Aboriginal inclusive model contrasts with the historic exclusions embedded in Western models (Goodey, 2001; Simpson, 2001) which persist; Hanvey (2002) noted that while inclusion is the current goal of social policy, Canadian society continues to view children with disabilities as "deficits". Sinclair (1994) has argued that the world views of Aboriginals and non-Aboriginals are so fundamentally different as to be inherently in conflict. Not surprisingly, social institutions based upon those understandings created tensions for participants.

The Critical Nexus:
Points of Tension for Caregivers and Professionals

Diagnosis, Testing and Labelling

An emphasis on collective values, noted by participants, means that while individuals with disabilities are to be "included", they are not to be "put forward" at the expense of others. The reluctance to "set apart" is contrary to a social service system predominantly based on "diagnosis" in mainstream culture; in mainstream medical and educational structures to receive support one must be regarded as "dis-eased". Participants objected to "medical diagnoses"; they preferred community based support to hospitalization.

School personnel were criticized for a tendency to "test" children; labels were seen to contribute to low self-esteem. Resource providers to child welfare systems tended to "see" children as "behavioural" problems rather than recognizing the cross-cultural challenges faced by the children. A child welfare worker reported repeated instances of children receiving such "mis-labelling". This resulted in a significantly increased workload, as she felt the need to provide "education" to resource personnel. At times, resource personnel resisted culturally appropriate treatment simply because this involved more work.

Moroney (1986) asserts that training of professionals in medical and psychiatric models is incompatible with "supporting families", a view which requires practical support, a listening ear – the kinds of support that

participants in the study described as a role of extended family. Intervention models emphasizing professional knowledge and encouraging dependence undermine families.

Child Welfare Systems

When tensions are so severe that families "breakdown", and children are apprehended, differences between cultures are exacerbated. In the view of an Aboriginal child welfare worker, every communication, decision and plan is more difficult on a daily basis for her as an Aboriginal person. When dealing with a medically fragile child, her first choice would have been to place the child within the community and extended family. While this option was in the child's best interest it was unavailable because of the structure of funding. Understanding the need of the child for visits with extended family and community, as well as the need of the community to remain involved, the worker found she faced resistance from many levels, including the supervisor of the unit with responsibility for care of the child, as well as from the family of the non-Native father of the child. While the participant summarized the problem as "no meeting of ... cultural needs", the situation also reflects what Moroney (1986) articulates: "[a]s structured, most agencies are equipped to provide a distinct set of services, and needs are translated into those services a particular agency has to offer" (p. 156). Moroney (1986) suggests the current system is "set up" to substitute for family – rather than to provide needed supports so that families can fulfill their essential function.

Critiques and Solutions Suggested by Participants: Connecting to Aboriginal Cultural Traditions

> *"When you come to the circle... you're all equal... you're not seen as more or less or better than anyone else... the mentally challenged... [are] included in the circle... never... are these people turned away from the circle... Everyone's created equal, and everyone's gifted... [a] way of working is within our ceremonies..."*
>   (Mother of a teenaged child with a disability, and
>   community social worker)

All participants felt that recovery of culture was important. Rituals, such as "naming" ceremonies for children with disabilities "...to help them know their special place in the universe" were described. Another example was

participation of troubled teenagers in "drumming" ceremonies. In the words of one participant, loss of culture resulted in being "lost ... like the tumbleweed". The roots come loose, and the bush, however large, drifts until it is "grounded" again in cultural traditions.

Recovery of culture for participants included use of holistic models of care of persons, as well as attention to spiritual, emotional, physical and mental needs. Services developed within communities included teams of professionals such as nurses and child welfare workers, but in addition often relied on informal community supports. These informal support persons were, in the words of one participant, "the biggest helpers", perhaps because they were aligned with traditions and were perceived by families as the most knowledgeable and the ones best able to understand.

Developing a Range of Services

Decisions made by non-Aboriginal agencies as well as those made by self-governing Aboriginal communities were described as often lacking in sensitivity to families. One participant suggested providing a "toolbox", with families "empowering ourselves". He did not feel government (including self-government within his community) should take away decision making from the family; instead, he suggested governments facilitate a range of services such as temporary support or alternate housing, to help when the support was needed, rather than attempting to "fit" the needs of families into existing programs. While this participant promoted the move to "self-government", one of the impediments to appropriate service was that local governments did not have sufficient management experience, and at times encouraged "dependence" rather than "independence". Moroney (1986) has suggested a similar model, development of a continuum of support, including financial support to enable families to care for their own members.

Discussion

While this exploratory research was limited by a small sample size, the results suggest there is a need for more research on this topic. The participants' view that children with disabilities should remain in the community, while acknowledging that they are often removed from families for care is confirmed by the statistic that Aboriginal children are disproportionately represented in child welfare systems (RCAP, 1996; Mandell, Clouston Carlson, Fine & Blackstock, 2003). The link between individuals with developmental disabilities and increased risk of abuse and neglect in mainstream society (Brown, 2002; Fudge Schormans & Brown,

2003; Fudge Schormans, 2003; Sullivan & Knutson, 2000; Randall, Parrila & Sobsey, 2000; Hingsburger, 1999) may be explained by policy analyst Moroney's (1986) observation that families with members with developmental disabilities (of all cultural groups) are among the most stressed and least served in North America. When they enter the child welfare system, Aboriginal children are in "triple jeopardy" with losses of family, community and culture (Johnston, 1983). Since socialization involves communication of deep values which assist a child in making sense of the world (McKay & Clouston Carlson, 2003), the difficulty of making sense of an "alien" world is exacerbated when these trends are combined for children with developmental disabilities.

McLaughlin (1993) suggests that as researchers we need to "[h]ear the power that sedimented, forgotten stories hold" (p. 239). The values of the participants of this study reveal that the stories have not been "forgotten"; they guide care, as well as professional values. Monture (1989) suggests peeling back "the layers of misunderstanding of both the dominant culture and First Nations culture which currently shape our cross-cultural communication". Examining meanings underlying "dominant social structures" as well as recognizing how those meanings "conflict with or contradict" those of First Nation families is, in her view, a way of finding "common ground" (p. 7).

The importance of finding "common ground" is critical. Using the metaphor, *"the mirrored pathway",* a beginning was made in *discovering* the meaning held in stories of Aboriginal tradition. Finding ways to *explore* how such meanings conflict with the meanings *embedded* in Western institutional structures, which we often accept without critique, will be an important next step. While Western values have the upper hand in being "embedded" in institutional structures, the powerful imagery of Aboriginal stories do connect with emotion, and are clearly "lived" in the lives of participants. When I worked with Elders on their spiritual stories, they often stated that their understandings didn't "fit" into English words (Clouston Carlson & Dumont, 2003; Carlson & Dumont, 1997; Carlson, 1994). Educator Kieran Egan (1992) offers insight into their experience, suggesting ancient cultures were able to survive because of the power of images held in oral stories, while Western thought and education systems "disconnect" us from emotions. On reviewing the initial results of the study, one participant noted that a painful thread throughout the stories was a sense of "disconnection" expressed by participants. Some participants also affirmed that within their own communities they attempted to resolve an "anger"about the injustices of the past, while encouraging use of mainstream resources.

Maori educator Smith (1999) asserts that "knowledge is deeply embedded in...multiple layers of imperial and colonial practices" (p.2) in complex ways. Knowledge is also expressed within our lives and families in complex ways, and public policy in care of the disabled has been unhelpful. The lives of vulnerable children and fragile families hang in a precarious balance. Stressed families in communities where social structures are "torn", "strained" or "conflicted", face overwhelming odds. Statistics do not begin to tell the inner pain experienced by abused and neglected children; they also do not reveal how the failure to care for children is experienced as "shame" by many Aboriginal peoples (RCAP, 1996).

The world view expressed by the participants of this study is shared by many non-Aboriginal people. An example is Catholic theologian and founder of the L'Arche community, Jean Vanier (1998) who challenges devaluation of the lives of individuals with disabilities, suggesting that living with persons with intellectual disabilities teaches us "about what it means to be human" (p.6). This study demonstrates that while the emphasis of participants is on recovery of culture, such recovery might be better supported by social policy which recognizes the often "unstated" positive valuing by Aboriginal people of a web of community support and involvement by family and community members in the lives of individuals with disabilities; recognition of these values could guide more inclusive and humane policy within newly emerging Aboriginal agencies as well as in Western institutional structures. The valuing of a perspective that sees a healthy community as needing to include all of its members, and the individual as healthy only when he or she is an integral part of the community provides some counterpoint to exclusions embedded within Canadian social policy that currently do not assist and support families as they care for members with disabilities.

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