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Why Do Families Relinquish Care of Children with Intellectual Disability and Severe Challenging Behaviors? Professional's Perspectives

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Abstract

Relinquishing care of a child with developmental disabilities can be a traumatic experience for parents. The aim of this study was to explore the perception of professionals regarding the relationships within families and service systems that contribute towards the relinquishment of children with Intellectual Disability (ID) and challenging behavior. Fifteen disability professionals were interviewed from a variety of disciplines, each having been involved in supporting a family while they relinquished care. A constructionist grounded theory approach was used for analysis, with data interpreted through a systemic lens. An accumulation of factors led to relinquishment, including the cumulative isolation of mothers within the family and within informal and professional networks of relationships. These findings must be understood in the context of societal discourses that both pathologise and overburden mothers with caregiving roles for children with disabilities. Interventions need to focus assertively on whole family involvement and repair, and on community development, if relinquishment is to be prevented.

Keywords

Relinquishment, Challenging Behaviour, Family Therapy, Discourse

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Relinquishing care of a child with developmental disabilities can be a traumatic experience for parents. The aim of this study was to explore the perception of professionals regarding the relationships within families and service systems that contribute towards the relinquishment of children with Intellectual Disability (ID) and challenging behavior. Fifteen disability professionals were interviewed from a variety of disciplines, each having been involved in supporting a family while they relinquished care. A constructionist grounded theory approach was used for analysis, with data interpreted through a systemic lens. An accumulation of factors led to relinquishment, including the cumulative isolation of mothers within the family and within informal and professional networks of relationships. These findings must be understood in the context of societal discourses that both pathologise and overburden mothers with caregiving roles for children with disabilities. Interventions need to focus assertively on whole family involvement and repair, and on community development, if relinquishment is to be prevented. Keywords: Relinquishment, Challenging Behaviour, Family Therapy, Discourse

Introduction

Intellectual Disability (ID) is typically a lifelong disorder, with deficits in both intellectual and adaptive functioning, including an intelligence quotient below 70 points and limitations in communication, social, vocational or self-care skills (American Psychological Association, 2013). Depending on the severity of the disability, it is consequently a disorder in which parents of children with ID often experience persistent care-giving demands (Cramm & Nieboer, 2011). In some circumstances this role, when coupled with multiple and severe stressful life circumstances, can lead to a breaking point where the parents feel that they are no longer able to care for their child. Parents can reach the brink of their capacity to cope, surrendering care for their child to the State without a long-term accommodation plan – this is known as relinquishment (Nankervis, Rosewarne, & Vassos, 2011a, 2011b; Victorian Equal Opportunity and Human Rights Commission [VEOHRC], 2012; Ellem, Wilson, & Chenoweth, 2015). In Australia this phenomenon is a by-product of the deinstitutionalization of the 1980's and the resulting pressure placed on parents to provide long-term care through the adult years (Australian Institute of Health and Welfare, 2008). The same phenomenon has been noted in the United States, exacerbated further by privatization of mental health care (Goodman, 2003; Lyon, 2012). While little research has been conducted in terms of intellectual disability specifically, Inglish (2010) notes that the failure of the private health insurers to provide mental health benefits means parents of children with complex needs are overtly advised by mental health professionals to relinquish custody to receive adequate care.

The term relinquishment does not sufficiently encapsulate the complexity and traumatic process that families endure. Relinquishment often occurs as the last possible solution within the context of acute familial crisis. Although parents are relieved from the burden of care, they report extreme feelings of guilt, anxiety and grief (Ellem, Wilson, & Chenoweth, 2015).

Parents may choose to surrender their care in a number of settings, but most commonly, children are left at a facility-based respite service (Nankervis, Rosewarne, & Vassos, 2011a, 2011b; VEOHRC, 2012). It is important to note that relinquishment into respite care results in a blocked bed – this risks a snowball effect where limited access for other families can potentially lead to a perpetual cycle of unmet respite needs (Nankervis, Rosewarne, & Vassos, 2011a, 2011b).

Due to the hidden and sensitive nature of relinquishment, there is no Australia-wide demographic data to guide service planning or the funding of specialist services (VEOHRC, 2012; Ellem, Wilson, & Chenoweth, 2015). Prevalence data is limited to the State of Victoria, with an estimate of fifty families relinquishing a child with developmental disabilities in 2012 (VEORHC, 2012).

A study by Nankervis, Rosewarne, and Vassos (2011a, 2011b), also conducted in Victoria, explored the factors that lead to relinquishment of children, adolescent and adults with disability into out-of-home respite care in Australia. They used case files and interviewed staff members who had worked with families in this predicament. Data, analysed using thematic analysis, identified three main groups of contributing factors. Individual client characteristics included high support and complex medical needs, limited communication skills, and adolescent or young adulthood age. Family characteristics included marital breakdown and single parenting. Wider support system issues included limited access to respite care, limited appropriate professional support, and acceptance of relinquishment as a strategy to secure an out-of-home placement.

A second study found similar themes based on case studies and interviews with families in Victoria (VEOHRC, 2012). Potential risk factors for relinquishment matched the Nankervis et al. (2011a) study in terms of isolating variables across individual, family and the support system contexts. Their primary conclusion, however, was that relinquishment is driven primarily by the unmet service system needs, rather than any distinct commonalities in client or family characteristics.

The aim of our study was to explore the factors that lead to the relinquishment of children with ID in New South Wales. The aim for this study was to interview disability professionals who have experience working with families who have relinquished care, looking specifically at the interpersonal, familial and service-system factors that might be at play (Pinsof, 1989). Our hope is that this research will provide a further source of reflection for clinicians, as they attempt to prevent relinquishment in complex systems. Professionals were seen to be an important starting point for this inquiry, given their direct relationships with families and long-term experience with many families. Their perceptions, however, cannot reflect the lived experience of families or the unique ways in which they make meaning in relation to relinquishment.

Our particular interest in this inquiry comes from our own role in the disability sector. Paul Rhodes is an academic who consults to government and non-government disability services, aiming to develop their clinical responses to familial distress. Jessica Ng is a Psychology research student who is beginning her career in the disability sector. This serves as the first of a series of studies on relinquishment, including further studies exploring the direct experiences of family members.

Research Design and Method

In this study we employed a qualitative means of analysis, informed by constructionist grounded theory (Charmaz, 2006), an approach that aims to represent themes and the relationships between themes and participant attributes rather than simply listing static concepts (Burck, 2005). Qualitative inquiry was chosen for this study over quantitative because

it allows rich description of lived experience. The constructionist approach recognizes the fact that the interpretation data is informed by the viewpoints of researchers and that findings are not discovered, but co-constructed between researchers and participants (Charmaz, 2006). This constructed nature of research is particularly relevant to recognize in a study which details researchers understanding of professionals reporting on the experience of families. This study cannot claim to directly represent the lived experience of families or people with disabilities.

Theoretical Perspective

Interpretation of data was informed by systemic theory, given the status of one researcher as a practicing family therapist and family therapy researcher. Systemic thinking shifts the focus from the concerned individual, to one that includes careful considerations of the interactions occurring between the individual and interrelated systems (Baum & Lynggaard, 2006; Breunlin & Schwartz, 1986). In terms of relinquishment this implies that our aim is not to settle on participant descriptions that might hold one specific person or interaction as primarily responsible for relinquishment, but rather seek to understand interactions between the network of stakeholders as a whole and the values, beliefs and discourses that govern those interactions (Anderson, Goolishian, & Winderman, 1986).

Ethics Approval

The approval for the current study was granted by the University of Sydney Human Ethics and Research Ethics Committee in May 2015.

Participants

The sample of participants consisted of 15 disability professionals working in New South Wales (14 females, 1 male), 13 of whom worked in the Government disability sector and 2 of whom worked in a non-Government organisation. Participants were qualified to participate in the study if they had experience in working with at least one family who had relinquished a child with ID. The age of participants ranged from 30-53 years ($M = 41.27$, $SD = 7.91$), and were from various practicing disciplines: 1 Special Education, 3 Psychology, 1 Speech Pathology, 5 Behaviour Support, 1 Occupational Therapy, and the remaining were case managers. Collectively they recalled 196 families they had supported during relinquishment over their careers, each serving a part of a multi-disciplinary team working with the families from their own specific discipline. The average number of families dealt with in terms of relinquishment was reported to be 12 ($SD = 11.69$). Families were not interviewed as part of this study.

Recruitment. Participants were recruited through passive snowballing. An invitation regarding the study was sent out to the team leaders of case management and clinical team in Government and non-Government developmental disability organizations, to send on to team members and other teams. Invitees who met the criteria of having worked with at least one family who relinquished care of a child with ID were given the option of contacting the researcher to express interest of participation. A recruitment email was provided to all participants who were interested in inviting other disability professionals to take part in the study. It is important to recognize, however, that in each case the professionals that agreed to participate had been attendees in at least one workshop presented by one of the authors in this paper and so were familiar with the concepts and practices of family therapy. This implies that they were well prepared to think in interactional terms about the questions that were asked.

Given our reliance on snowballing we were not able to follow the process of theoretical sampling typically used in grounded theory.

Interviews. Face-to-face, semi-structured interviews were conducted; participants were asked to recall information about the most recent family they had worked with where a decision had been made to relinquish care. All participants selected families they had worked with in the past 24 months. Each participant selected a family that they had worked with for a period of greater than three months, including community-based person-to-person support related to their discipline. Participants were asked to draw a sociogram for this family, which then served as an aid for interviewing. A sociogram is a detailed pictorial representation of the family genogram and the relationships between family members and a wider system (Rhodes et al., 2011). Professionals were asked about their perceptions in regards to possible interactions and relationships that may have led to relinquishment.

Data Analysis

Data analysis was informed by constructionist grounded theory, in that the aim was to develop complex relationships between concepts rather than a static list of themes. The following steps were used for data analysis (Burck, 2005). 1. Line-by-line coding of all manuscripts conducted by the first author. 2. Line-by-line coding conducted by the second author on three randomly selected transcripts, to support the reliability of analysis. 3. Themes and sub-themes developed from codes in joint meeting between both authors. 4. Between-subject contrast and comparison coding made by first author. 5. Both authors discuss these themes, elucidating links between them further using systemic theory. 6. Final summary of analysis sent to two participants for their comments, with only minor modifications suggested. This member checking was conducted to support the trustworthiness of findings.

Results

The relinquished clients described by professionals in this study were characteristically male, in their adolescent years, and diagnosed with ID and Autism Spectrum Disorder (ASD). Of the 15 families described by professionals, 1 involved a set of twins who were both relinquished, making a total of 16 individuals relinquished into State care. Of the 16 individuals described, 10 were male. Most of the relinquished individuals had an additional diagnosis of ASD, of which 9 individuals were described to be on the moderate-severe scale for both ASD and ID. A large majority were relinquished at adolescence, between the ages 10 to 19 ($M = 13.25$). All names of people with disabilities and their families are pseudonyms.

Almost all the relinquished individuals described by professionals had severe challenging behaviours. These behaviours included emotional dysregulation, self-injurious behaviours, and most notably physical aggression.

Physical aggression towards the mother and siblings was reported as being the most significant contributing factor for relinquishment. As the large majority of the relinquished individuals were approaching puberty, participants reported that it became physically harder to manage the child and their behaviours independently. It was reported that physical aggression was often severe enough to cause injuries, which caused mothers to fear for their safety or well-being and made the implementation of formal behavior intervention strategies difficult. Over time, much of the parental energy was spent protecting other family members, until the functioning of the family came to revolve around the child with disability.

So essentially the young man had control of the house – was kind of how it was explained – because of his behaviour, everyone had to retreat to try and stay safe. (P10, F10)

The Impact on Siblings

Participants expressed that the physical and mental well-being of siblings was often compromised. Depending on the age of the siblings and financial capabilities of the families, the impact and consequences for siblings unfolded in numerous ways. Older siblings, whilst capable of care giving, were said to move out of home in the hope of starting their own lives.

[The brother] later got into a relationship with someone and wanted to branch off from the family, live on his own, have his own family and things like that. So he had his own plans, which mum and the younger son was not included. (P9, F9)

In other cases, participants recalled that families actively chose to move their siblings away from home to boarding schools, in order to protect them from the physical violence of the child with disability. For nearly all of the remaining families where the siblings were still living at home, the concerns for the wellbeing of the siblings were described to be an influential reason to relinquish. In addition to the physical attacks towards the siblings and concerns for their physical wellbeing, it was reported that the mothers would feel a sense of guilt or sadness for not attending to the needs of the siblings equally. The disability professionals described that families felt apprehensive that they would be losing the non-disabled sibling too. This was also a factor contributing towards the decision to relinquish.

I think [the mother] started to feel like she was losing [the sibling] too, and she didn't want that, and she felt it was best to have possibly Tim out of the house so she could focus on John. (P8, F8)

Maternal Isolation

All of mothers in this study were described as the primary caregivers for the child with disability. Half were either in single parent household, where the father was no longer in contact or described to have provided limited support, or in de facto relationships where the partner provided very little physical or emotional support to the mother or child with disability.

[The father's role] was none. Not emotionally, not physically there very often. (P3, F3)

Service providers described little success in engaging distant partners.

Marital Strain

Half of the families in this study included both biological parents of the child with disability. In each case, participants described that marriages were under significant relational stress. For some, participants speculated that this was caused by differing and conflicting approaches to parenting. For others, participants felt there was little time to focus on anything but the needs of their child with a disability.

> The parents were on the verge of their marriage collapsing…I think that the parents were so focused on the child that other issues that were possibly there were not attended to, and then it all came out. (P15, F15)

Isolation from Extended Family and Friends

Familial stress, in nearly every case, was exacerbated by isolation from extended families. Participants recalled that extended families either resided in another country or state, or they had experienced tense or breached relationships. In a small number of other cases, it was expressed by the disability professionals that there was a sense of shame around having a disabled child, and as a result, they were reluctant or abstained from reaching out for support.

Only a third of families were described as having some friends for consolation, which were mostly parents from school or church. However, it was noted by many participants that although these friends provided emotional support, the practical support was often limited. It was mentioned that difficulties in managing the child's behaviour would restrain parents from socialising, which was difficult for developing an informal network of support.

> The other thing the mother mentioned was that they were very isolated from other people – because if Rebecca was with them all the time, and if Rebecca is displacing these behaviours, people would stop coming over eventually. (P13, F13)

Deteriorating Mental Health and Financial Stress

Mental and physical health issues were common amongst approximately half of the families discussed. There were two cases where both of the parents were diagnosed with severe levels of depression, which led to reports suicidal ideation and homicidal ideation regarding the child with disability.

> [The dad] had sadly a very clear plan for a suicide homicide. He had a plan that involved putting boys in his car and driving to a remote place, which he was able to describe, and using exhaust fume of the car to end all of their lives. Because it was more than his daughter and his wife could bear. (P1, F1)

A couple of mothers were reported to have experienced prior domestic violence. In one case, the participant recalled that that impact of growing up and witnessing the domestic violence affected and exacerbated his challenging behaviours.

> So Tim had basically seen and brought up in the family to witness domestic violence towards mother. He also started to grab mother inappropriately… but because of mum's mental health issues, it bought back memories. So she was obviously in panic and fear than to stand up and say to him no, you don't do that. (P8. F8)

Difficulties in financially sustaining the family, which brought about greater levels of parental stress and added to marital strains, were also reported by the participants. Half of the families were either of low socio-economic status, or had difficulties in sustaining employment and/or business. The necessity to provide high levels of care for their child with disability was often the justification for difficulties in maintaining employment.

> [The mother] had difficulties with holding down a job because she felt that when she got involved in a job, somehow she would blame and say [the child] was the reason why she couldn't work there anymore… because of his continuous ringing or his neediness… so that lead to financial issues as well. (P6, F6)

The Important Role of Schools

It was common for the families to have an engaging and positive relationship with their child's school. It was often said that school provided a good understanding of the circumstances, and consistently liaised with parents and service providers. In one particular case, the school played a vital role in advocating the mother to relinquish care having seen the impact the disabled child had on the mother.

> Oh school was very good, very good, very understanding and we kept in close communication between the school, the parents, myself and the service providers. (P5, F5)

Poor Relationships Between Professionals and Mothers in Distress

On the other hand, the families and the mothers in particular, were described to be ambivalent towards professional service providers. As the fathers were typically left out of the picture, the mothers were always the first point of contact for the service providers.

It was recalled that the large majority of families received case management and respite care as the minimum. A number also received numerous allied health services, such as behavioural support, occupational therapy, and counseling. In addition, a small number of families received specialised services, such as pediatricians or genetic counsellors, on limited occasions. Despite this service provision, however, participants recalled that mothers never connected well with the professionals. Participants reported that the service providers were seen to judge mothers' and see them as contributing to the child's problems, and at least half of the families were seeking more support than the services could actually provide.

> When I talked to the mental support, they said that [mother] was very difficult… things had not changed [since David was 12] and she was still a very difficult person, and she was part of the problem. (P6, F6)

It was commonly mentioned that the mothers felt unheard and were never well understood. There were two cases where the mothers were illiterate, which impacted how they accessed services, as well as how they were perceived by services. It was said that their disengagement with services was perceived as a reluctance to employ the strategies, when in fact they didn't have an adequate understanding of the information provided to them.

> The relationship with these people [services] had with mum was extremely distant because they didn't actually add any support or value to her. They'd write a complicated report and then ask her have you read it – she can't read. (P2, F2)

Several participants highlighted the fact that early preventative measures with families in distress may have prevented relinquishment of care.

> In terms of meeting the family's needs, if there were equally as many services…the picture may have looked different. (P14, F14)

Maternal Breaking Point

In the end, participants described how it was the mothers that were left to make relinquishment decisions. After the breakdown of relationships, the distancing of siblings, parental conflict, the absence of extended family and friends and poor relationships with service providers they were left as the last person standing and began to break down from exhaustion.

> The mother was the lynch pin of the entire family, and she wasn't coping herself. (P14, F14)

In desperation, the large majority of participants highlighted that these mothers relinquished the care of their child, in attempt of salvaging the well-being of their remaining family.

> At the end of the day, there was recognition that this was the only way their family was going to survive. (P1, F1)

Discussion

Findings from this study demonstrate an accumulation of factors that eventually led to the relinquishment of care of children with ID and challenging behavior. Mothers of children, primarily males with ID and ASD exhibiting challenging behavior in the form of physical aggression, found themselves more and more isolated within family, informal and professional networks of relationships. In terms of family and social support, fathers were often absent, disengaged or parents were polarized in their parenting approaches and under marital strain. Siblings were living out of home or under threat, or mothers experienced a lack of support from extended family and friends. Professional support was provided, but these relationships were also tenuous. The relationally-oriented approach of schools was seen to be an exception in this network of interactions, but relinquishment became an inevitable conclusion for all those families discussed in the current study. No single person, interaction or linear relationship (Sexton, 1997) between stakeholders were identified as causal in terms of relinquishment. Relinquishment can be understood as a systemic problem, namely, the gradual isolation of the family, and commonly the mother-child dyad over time, a systemic problem that is driven by challenging behavior and amplified by this lack of community responsiveness.

It is important again to recognize, however, that neither mothers, nor fathers were interviewed in this study and findings remain tentative because they only reflect the second-hand experiences of professionals. These findings suggest, however, that if relinquishment is to be prevented we need to understand more about the processes by which families, and particularly mothers, come to be so isolated in the community, in particular to elucidate the societal discourses that might maintain this type of systemic failure. Further work is required to answer a wide variety of questions raised including; How did it come to pass that the many mothers bore the brunt of caring for their very challenging children? Why is it that in a majority of cases fathers, older siblings and professional support services failed to take more responsibility? To what extent did mothers themselves come to feel that they had to care on their own? Are there any parallels between the experiences of these woman and the isolation and despair felt by those experiencing domestic violence? What are the stories of fathers in

these situations? What is missing in terms of our understanding of their experience, when they leave the family home or when they stay?

The role of longstanding societal narratives also need to be explored in reference to the phenomenon of relinquishment ones that mirror constructions of women's identities more generally in society (Welldon, 2000). Mothers of children with disabilities have a long history of demonization, despite their role as primary caregivers. Douglas (2013), for example, traces the history of the idea of the "refrigerator mother," in the scientific and popular press since the 1940's, mothers blamed directly for their child's autism. Mothers were described as having "just happened to defrost enough to produce a child" (*Time Magazine*, 1960, p. 78). Some psychoanalysts, like Bettelheim (1967) went even further, drawing parallels between mothers of children with autism and the prison guards of Aushwitz, who perpetrated the traumatic withdrawal and destruction of the Jews. These characterisations can perpetuate the idea that women must continue to bear the brunt of caregiving for challenging children. If they caused the disorder in the first place, they remain inherently responsible for the consequences. In more contemporary times, however, an alternative discourse has also emerged, that of the idealization of mothers of children with disabilities, as a self-sacrificing miracle-worker, fiery advocates, a warrior-hero (Sousa, 2011). This type of mother employs all her emotional and financial resources to garner the best medical and educational therapies, in hopes of providing her child with newer and better interventions that may eventually lead to a cure. Here again the result is isolation and the abdication of paternal and community responsibilities. Clearly there is a need for discourse analytic studies to further our understanding on relinquishment of care.

There are also questions to be asked about our engagement and understanding of fathers of challenging children with developmental disabilities at risk of relinquishment. It is evident in the general population of fathers of children with disabilities that there are many stories of fathers debunking these myths of motherhood and tasking responsibility for the fears, strains and opportunities for transformation that are involved (Dietz & Gallob, 2014). Direct interviews with fathers are required to understand their own journey as caregivers towards relinquishment decisions.

In clinical terms this research and the wider questions it raises serve as an important source of reflection for clinicians working with clients with developmental disabilities and severe challenging behavior. It raises questions about the need for community-based responses, rather than looking to, or settling with, the mother as the primary mediator of behavioral change. There is a need for research and interventions to investigate family involvement and repair on community development, and its impact on preventing relinquishment. Efforts have been made, in this regard, in the past decade, to integrate the principles of applied behavior analysis with those of systemic family therapy (Fennessey et al., 2015, Rhodes et al., 2014). The aim has been to educate case managers and clinicians with family therapy skills, so that they can better engage familial and community-wide support for behavioural intervention. Fathers are actively pursued and mobilized and the attachment needs of siblings are more fully considered. A strong focus is also placed on developing and maintaining therapeutic relationships, (Sheridan, Peterson, & Rosen, 2010; Stanbridge, Burbach, Lucas, & Carter, 2013) and making systemic formulations in complex scenarios.

Equally promising is the movement towards community-based "network therapy," also known as "open dialogue," although this has been primarily focused on the prevention of psychosis and not yet rigorously applied in developmental disabilities (Seikkula & Olson, 2003). This model brings a wide stakeholder group together at every stage of assessment and intervention, including family, friends and neighbors and professional staff, actively focusing on the development of a community of care. Such group meetings could be beneficial to identify where the fractured interactions are across the spectrum, and when the mother, or any other primary caregiver is isolated in the network of stakeholders. There are few professional

meetings behind closed doors and the coordinating role rests in the hands of the network rather than any single individual. There have been some rudimentary applications in developmental disabilities (Rhodes et al., 2014) but no comprehensive trials or studies.

The aim of this paper was to explore familial and service system processes that contribute towards the relinquishment of children with Intellectual Disability and challenging behavior. A number of failings were found in community responses to these situations, particularly failings towards mothers in many cases, who found themselves isolated in the face of insurmountable odds. This study, however, can only serve as a pilot in this line of inquiry, raising questions for further research. It is critical that participatory research be conducted with parents themselves, to explore their experience and their ideas about professional involvement. This research must also not privilege home-based care as an outcome over relinquishment, but rather look to parents themselves to explore solutions to this complex problem. Secondly, discursive research is required, which looks in greater depth at the assumptions held by professionals themselves that contribute towards the dislocation of women and families and that explore gender-based discourses with the parents themselves. A very particular group of professionals were involved in this study, namely those with some systemic training. Comparing their perspectives with a wider cohort is important, including direct care staff and managers in respite services who may have a more intimate knowledge of the experiences of families. It is also important to recognize that this study only investigated the experience of professionals working in New South Wales Australia, and cannot be generalized to other Australian States and countries where service provision and cultures may lead to different circumstances. Some of our findings resonate with those from Victorian studies (Nankervis, Rosewarne, & Vassos, 2011a, 2011b; VEOHRC, 2012), including the interplay between young people with complex needs, familial stress and inadequate service systems. This remains, however, a critically under-researched field of study.

References

American Psychological Association. (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). Arlington, VA: American Psychiatric Publishing.

Anderson, H., Goolishian, H., & Winderman, L. (1986). Problem determined systems: Towards transformation in family therapy. *Journal of Strategic and Systemic Therapies, 5*(4), 1-13.

Australian Institute of Health and Welfare. (2008). *Disability in Australia: Trends in prevalence, education, employment and community living. Bulletin No. 61*. Canberra, Australia: AIHW.

Baum, S., & Lynggaard, H. (2006). *Intellectual disabilities – A systemic approach*. London, UK: Karnac Books.

Bettelheim, B. (1967). *The empty fortress: Infantile autism and the birth of the self*. New York, NY: The Free Press.

Breunlin, D., & Schwartz, R. (1986). Sequences: Toward a common denominator of family therapy. *Family Process*, *25*(1), 67-87.

Burck, C. (2005). Comparing qualitative research methodologies for systemic research: The use of grounded theory, discourse analysis and narrative analysis. *Journal of Family Therapy, 27*, 237-262.

Charmaz, K. (2006). *Constructing grounded theory: A practical guide through qualitative analysis.* London, UK: Sage.

Cramm J. M., & Nieboer, A. P. (2011). Longitudinal study of parents' impact on quality of life of children and young adults with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities, 15*(2), 101-13. doi:10.1177/1744629511410922

Dietz, D., & Gallob, B. (2014). *Dads of disability: Stories for, by, and about fathers of children who experience disability (and the women who love them!).* Brookline, NH: Gary M. Dietz.

Douglas, P. N. (2013). As if you have a choice: Autism mothers and the remaking of the human. *Health, Culture and Society, 5*(1), 167-181.

Ellem, K., Wilson, J., & Chenoweth, L. (2015). When families relinquish care of a child with a disability: Perceptions from birthmothers. *Australian Social Work*, 1-13.

Fennessy, K., Rhodes, P., Wilson, V., Uddin, S., Dickens, K., Wilson, A., . . . Ogilvy, L. (2015). Systemic consultation in intellectual disability case management. *Australian and New Zealand Journal of Family Therapy, 36*, 256-272.

Goodman, G. (2003). Accessing mental health care for children: Relinquishing custody to save the child. *Albany Law Review, 67*(1).

Inglish, J. (2010). Preventing custody relinquishment for youth with mental health needs; Implications for the state of Utah. *Journal of Law and Family Studies, 2*, 237-245.

Lyon, J. (2012). Desperate parents surrender autistic children to state custody. *The Salt Lake Tribune*. Retrieved from http://archive.sltrib.com/story.php?ref=/sltrib/news/54836136-78/autism-garrett-utah-lines.html.csp

Nankervis, K. L., Rosewarne, A. C., & Vassos, M. V. (2011a). Why do families relinquish care? An investigation of the factors that lead to relinquishment into out-of-home respite care. *Journal of Intellectual Disability Research*, *55*(4), 422-433.

Nankervis, K. L., Rosewarne, A. C., & Vassos, M. V. (2011b). Respite and parental relinquishment of care: A comprehensive review of the available literature. *Journal of Policy and Practice in Intellectual Disabilities, 8*(3), 150-162

Pinsof, W. (1989). A conceptual framework and methodological criteria for family therapy process research. *Journal of Consulting and Clinical Psychology*, *57*(1), 53-59.

Rhodes, P., Fennessey, K., Dickens, K., Whatson, L., Wilson, A., & Donnelly, M. (2014). Transforming practice in developmental disability services through systemic and dialogical practice. *Journal of Systemic Therapies, 33*(3), 1-17.

Rhodes, P., Whatson, L., Mora, L., Hansson, A., Brearley, K., & Dikian, J. (2011). Systemic hypothesizing for challenging behaviour in intellectual disabilities: A reflecting team approach. *The Australian and New Zealand Journal of Family Therapy, 32*(11), 70-82.

Seikkula, J., & Olson, M. E. (2003). The open dialogue approach to acute psychosis: Its poetics and micropolitics. *Family Process, 42*(3), 403-418.

Sexton, T. (1997). Systemic thinking in a linear world: Issues in the application of interactional counseling. *Journal of Counseling and Development, 72*, 249–259.

Sheridan, M., Peterson, B., & Rosen, K. H. 2010). The experiences of parents of adolescents in family therapy: A qualitative investigation. *Journal of Marital and Family Therapy, 36*(2), 144–157.

Sousa, A. C. (2011). From refrigerator mothers to warrior-heroes: The cultural identity transformation of mothers raising children with intellectual disabilities. *Symbolic Interaction, 34*(2), 220-243.

Stanbridge, R. I, Burbach, F. R., Lucas, A. S., & Carter, K. (2003). A study of families' satisfaction with a family interventions in psychosis service in Somerset. *Journal of Family Therapy, 25*, 181-204.

Time Magazine. (1960, July 25). Medicine: The child is the father. *Time Magazine.* Retrieved from http://content.time.com/time/magazine/article/0,9171,826528,00.html

Victorian Equal Opportunity & Human Rights Commission. (2012). *Desperate measures – The relinquishment of children with disability into state care in Victoria*. Victoria, Australia: VEOHRC.

Welldon, E. (2000). *Mother, Madonna, whore: The idealization and denigration of motherhood.* New York, NY: Other Press.

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