

“It Takes a Village”: Factors Related to Coping in Families Raising Children with Disabilities

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Abstract

In this paper, the author argues that caregiver coping in raising children with disabilities extends to include not only the parents but the rest of the family system as well. Adjustment, social and emotional support, resiliency and adaptability, and flexibility are examined by the author as specific factors contributing to successful coping of parents, siblings, and grandparents in raising children with disabilities. A critical literature review by the author discusses the current state of knowledge in this area and explores themes of research in each of the categories described. The author discusses conflicting interpretations of prominent caregiver coping research by Mattingly and Ingstad, and concludes with a discussion of global perspectives on this issue and recommendations of further research to contribute to understandings of coping in family systems raising children with disabilities. Implications of this research relate to improving clinical practice, service provision, and public policy development on this topic.

Keywords: coping, disabilities, parents, siblings, grandparents

Raising children is a formidable task by any household standard. However, when a child is diagnosed with a disability or placed upon a disability continuum, the challenges involved are known to escalate. In this situation, the adjustment and coping of caregivers involved become crucial to adaptability, and the roles of parents and surrounding family support networks begin to differ from the norms of families that are not raising children with disabilities. Historically, the topic of parental coping has been studied from a stress and wellbeing perspective, focusing on family structure, support systems as well as critical time-periods throughout the developmental process (i.e. time of diagnosis, milestones in the child’s life, changes

in care situations; Beresford, 1994). Recently, however, research in this area has been driven by investigating specific variables in coping mechanisms utilized by caregivers raising children with disabilities. This shift in focus was driven by a desire to widen the range of perspectives being examined of individuals involved in family systems raising children with disabilities, and to increase the efficacy of supports available to those families involved. This shift put family wellbeing research on a trajectory to partial out specific coping mechanisms and support systems that have high success rates in increasing family wellbeing overall. Thus, outcomes of studying this topic have led to changes in diagnosis communication by physicians, types of support groups

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accessible to parents, and evolutions in the services offered by programs in this area.

In this paper, the author argues that caregiver coping in raising children with disabilities extends to include not only the parents, but the rest of the household family system as well. For the purposes of this discussion, the author places a focus on adjustment, social and emotional support, resiliency and adaptability, and flexibility as factors contributing to successful coping of parents, siblings, and grandparents in raising children with disabilities. The author conducts a critical literature review to discuss the current state of knowledge in this area and explores themes of research in each of the categories described. The author also discusses conflicting interpretations on prominent caregiver coping research, and concludes with a discussion of global perspectives on this issue and recommendations for future research to contribute to further understandings of coping in family systems raising children with disabilities.

Critical Literature Review

The literature reviewed in this discussion falls into three main domains: factors related to coping in parents of children with disabilities, the siblings of children with disabilities, and grandparents of children with disabilities. Within each category, the author outlines factors related to effective coping in family systems.

Factors Related to Coping in Parents of Children with Disabilities

Parental units comprise the largest subgroup studied in research pertaining to coping styles within family systems raising children with disabilities. This category reviews literature illustrating how adjustment, social support, resiliency and adaptability, and flexibility are each specific factors that relate to coping in parents of children with disabilities.

Adjustment

In 2017, Avieli and Band-Winterstein conducted retrospective interviews with aging parents who shared their experiences of the collective process of raising a child with cerebral palsy (CP). The researchers utilized a holistic theoretical framework which examined child-rearing processes as interconnected and dynamic stages summing to overall experiences as whole events. Three common phases of adjustment periods following the receipt of a child's disability diagnosis were identified through interpretive phenomenological analysis (IPA): seeking extrinsic recognition of the pathology; perceiving the bad news as a turning point; and a lifetime of maneuvering between disabled and able-bodied society (Avieli & Band-

Winterstein, 2017). The authors of this study interpreted these phases as parents' initial searches for concrete diagnoses followed by their processes of acknowledging the diagnosis and then navigating new meanings of normality as they adjusted into their new parental roles. Implications of this research pertain to using life review as a therapeutic practice for parents in the initial phase of receiving their child's diagnosis. Life review refers to the in-depth process of examining a specific area of a person's life in its entirety to assess the various components and outcomes associated with those experiences (Avieli & Band-Winterstein, 2017). This process may help parents to understand that their experience of raising their children with disabilities as a whole will continuously evolve, and with it, so too will their parental identities (Avieli & Band-Winterstein, 2017). This notion of identity evolution was found to be helpful by many of the parents interviewed in this study (Avieli & Band-Winterstein, 2017). A critique of this study lies in the argument that the experiences of parents receiving and adjusting to a child diagnosis like CP differs from other diagnosis processes, as CP provides a concrete pathology for parents to follow. In many cases, such concrete pathologies are often not provided to parents and thus adjustment and closure are more difficult to obtain.

On the topic of parental adjustment following the receipt of child disability diagnosis, Hazel (2010) focused on how quality of daily life and activities differ for mothers raising children with spina bifida (SB) versus mothers who are raising children without the added challenges. Using thematic analysis, Hazel (2010) identified three common themes from semi-structured interview responses: the overall experience; the mother role; and adjustments for success. Hazel (2010) noted that participants described the overall experience to begin with the time of diagnosis, followed by the positive experiences, challenges and changes in relationships during the adjustment period afterwards. Hazel (2010) discussed this cycle as the concept of habituation, a similar notion to the adjustment phases where parents navigate a new normalcy to parenting children with disabilities as described in Avieli and Band-Winterstein's (2017) work. Hazel (2010) argued that mothers who are able to habituate in their changed roles exhibit successful adjustment and higher senses of wellbeing which predict higher qualities of daily life. While Hazel (2010) excluded paternal perspectives from analysis, this concept of habituation remains similar to Avieli and Band-Winterstein's (2017) participant experiences in that parents who viewed their overall experience as a continuum of adjustment also felt a greater sense of satisfaction and closure concerning how they handled the novel challenges of raising their child with CP.

Social Support

With data obtained through self-report questionnaires, Manor-Binyamini (2016) concluded that mothers of children with developmental disabilities (DD) report higher levels of adaptability to change and perceived personal growth in comparison to mothers raising children without DD. Following a positive psychology approach which focused on a family-systems methodology, Manor-Binyamini (2016) discussed the importance of family cohesion and emotional support as factors contributing to positive coping in mothers of children with DD. The parents interviewed in both Avieli and Band-Winterstein (2017) and Hazel (2010)'s studies emphasized social and emotional support as contributing factors to positive coping experiences as well. Similar to a critique of Hazel's (2010) study, this research focused only on coping from maternal perspectives. Furthermore, Manor-Binyamini (2016) conceded that qualitative explorations may yield more representative results for family experiences rather than questionnaire responses.

Resiliency and Adaptability

Tiba, Johnson and Vadineanu (2012) examined how cognitive vulnerability, a term that refers to persistent negative automatic thoughts and irrational beliefs (Tiba et al., 2012), mediate stress and positive emotions in parents raising children with Autism Spectrum Disorder (ASD). Results from their survey analysis indicated that higher levels of cognitive vulnerability in parents of children with ASD may prevent experiences of positive emotions, a pattern influenced by stress (Tiba et al., 2012). The authors suggested that this pattern then hinders positive parental coping mechanisms, and that more effective management of chronic stress during adjustment periods following the diagnosis may increase resiliency in parents of children with ASD. Avieli and Band-Winterstein (2017), Hazel (2010) and Manor-Binyamini (2016) collectively emphasized this focus on the critical period of adjustment following the initial diagnosis as well. However, it is argued in this discussion that limitations of Tiba et al.'s (2012) study lie in the small sample size, which presents difficulties in generalizing findings to a broader population of parents raising children with ASD. Moreover, the majority of the sample again contained maternal responses, demonstrating the neglect of experiences of fathers in this matter. Conducting research that explores paternal perspectives of child rearing experiences could contribute to more effective parental supports available to both mothers and fathers raising children with disabilities.

Flexibility

Rieger and McGrail (2013) used a family-systems theoretical perspective to investigate humorous outlook and

optimism, concluding that coping humour is associated with increased family cohesion and flexibility. This concept reflects adaptability to change and resiliency as discussed in the previously reviewed literature (Avieli & Band-Winterstein, 2017; Hazel, 2010; Manor-Binyamini, 2016; Tiba et al., 2012). Rieger and McGrail (2013) argue that family cohesion and flexibility of outlook is crucial to the adjustment in family functioning following the diagnosis of a child with a disability. A limitation of this study can be found in the sample containing a nonresponse bias. This participation bias makes it difficult to generalize results to wider populations of families who do not feel as comfortable discussing their rearing situations, which means entire subgroups of families raising children with disabilities could be excluded from research perspectives on this topic. Implications of this research are fundamental to honing family-systems interventions and support programs offered to families raising children with disabilities.

Overall, current research investigating parental coping in raising children with disabilities outlines the common experiences reported by members of this shared population. Studies done by the authors discussed in this section identify adjustment, social support, resiliency and adaptability, and flexibility as factors relating to positive coping in parents raising children with diverse disabilities. Additionally, the moment a diagnosis is received and the period of adjustment following the life-altering news are critical to constructing the experience of parenting a child with a disability. Gaps in existing literature surrounding family system coping show a neglect of paternal perspectives of fathers raising children with disabilities, as well as a trend for studies to examine parental coping in relation to children who have received concrete diagnoses to work with. Furthermore, it has been argued that qualitative research yields a more robust understanding of the experiences of parents involved in family systems raising children with disabilities. The implications of investigating these factors emphasizes resiliency, flexibility and social support as important elements in aiding in the adjustment process of families raising children with disabilities.

Factors Related to Coping in Siblings of Children with Disabilities

In research centred upon family systems raising children with disabilities, the focus is primarily on the specific child involved, or on their parents. Recently, however, further attention in current research is being allocated to the siblings who grow up alongside children with disabilities. This category covers the perceptions of siblings who have been raised with a brother or sister diagnosed with a disability and discusses the factors related to positive coping and strength within the larger family unit of a household.

Flexibility

In Mandleco and Webb (2015) identified five major themes which emerged from the information reporting the experiences of siblings living with a young child diagnosed with either Down Syndrome (DS) or ASD: knowledge of the condition; relationships with others; perceptions of the condition; emotional reactions; and behavioural/personality outcomes (Mandleco & Webb, 2015). Mandleco and Webb (2015) concluded that these five themes had life-changing impacts on the siblings of children diagnosed with DS or ASD, and that their adaptability following their sibling's diagnosis was especially affected. However, challenges were viewed predominantly with demonstrated understanding and resilience by the siblings of the child with DS or ASD, a notion related to the concept of family cohesion and flexibility discussed by Rieger and McGrail (2013). This research shows the importance of professionals including sibling perspectives into interventions, as well as for support programs to educate parents on the importance of consistency of parenting between their able-bodied children and their child with a disability.

Under the umbrella of flexibility, Schuntermann (2009) defined mentalizing as a gradual process of self-understanding as well as developing an understanding of others. Based on his findings, Schuntermann (2009) concluded that increased mentalizing in siblings of children with DD is associated with higher resilience, more connective social relationships, and greater ability to understand a person's role within their family dynamic. This concept of mentalizing as a coping mechanism is similar to role acceptance discussed by Mandleco and Webb (2015) and relates to flexibility of roles and responsibilities in families outlined by Rieger and McGrail (2013). Schuntermann (2009) argued that difficulties with mentalizing can result in poor mental coping and increased vulnerability, similar to the cognitive vulnerability discussed in Tiba et al.'s (2012) work. Thus, the implications of this research into family systems coping provides insight into clinical interventions working with the mental health of siblings growing up with a brother or sister with DD.

Adjustment

Gorjy, Fielding and Falkmer (2017) focused on how the strengths, abilities, assets, coping strategies, resourcefulness, resilience and goals of siblings of ASD individuals interact to construct their experiences of growing up alongside children with disabilities. This constructivist positive psychology framework is similar to that employed by Manor-Binyamini (2016). Using thematic analysis, Gorjy et al. (2017) identified six themes: "It's hard," "It's different," "It affects my life," "Adaptation," "It's worth it," and "But it's normal for us." Gorjy et al. (2017) concluded that these themes have lasting impacts on sibling lives, which is similar

to Mandleco and Webb's (2015) conclusions discussed earlier in this paper. Moreover, the themes of "Adaptation" and "But it's normal for us" are parallel to habituation as discussed by Hazel (2010) and adjustment as discussed by Avieli and Band-Winterstein (2017). However, where participants of previous research categorized their experiences as positive or negative (Mandleco & Webb, 2015; Rieger & McGrail, 2013; Tiba et al., 2012), Gorjy et al.'s (2017) participants tended to view their lives simply as "different." Their perspective reflects the mentalizing strategies discussed by Schuntermann (2009) and suggests positive adjustment to be an integral coping factor in siblings of children with ASD. This study is limited in its narrow focus on siblings growing up with a sibling diagnosed with ASD specifically, and in the fact that the sample consisted entirely of siblings whom were older than the child with ASD. This narrow sample presents challenges in generalizing the findings to experiences of a wider population of more diverse family systems and structures raising children with disabilities.

Overall, the category of research about coping in siblings of children with disabilities draws attention to a facet of family systems that has been neglected until recently, despite the prominent effects reported in the everyday experiences of individuals who grew up with a sibling with a disability in the house. It is well established in modern psychology that childhood experiences of feelings of caregiver responsibility or parental neglect can have significant effects on adult adjustment (Gorjy et al., 2017), thus it is argued here that research in this area of the experiences of siblings raised alongside children with disabilities be further developed to better understand any long-lasting effects on personality. Implications of research into sibling experiences are found in demonstrating the importance of developing a complete family-systems approach to understanding the experience of raising a child with disabilities. This development includes placing an emphasis on flexibility and adjustment as integral factors to foster within family systems raising children with disabilities. Subsequently, the most significant limitation of current research into sibling perspectives is the lack of existing literature to draw upon to inform such expansion of service provision. Should future research yield more concrete trajectories for coping mechanisms to be used by children growing up alongside siblings with disabilities, the counselling and educational resources provided by family wellbeing clinics and schools could evolve to create a more encompassing approach to supporting the development and wellbeing of children in these unique sibling situations.

Factors Related to Coping in Grandparents of Children with Disabilities

The final category of research discussed in this paper extends the family system beyond the traditional household to include the grandparents in families raising children with disabilities. Research in this category examines how relationships and emotional support are central factors relating to the coping experiences of grandparents of children with disabilities.

Relationships

Mirfin-Veitch, Bray and Watson (1997) identified two major themes through thematic analysis of interviews with grandparents supporting grandchildren with disabilities: "sort of family" and "relationships with the parents". Mirfin-Veitch et al. (1997) concluded that the most prominent factors of research relating to the grandparents coping mechanisms utilized while raising their grandchildren with disabilities were the type of family they perceived their system to be, and the quality of relationship with their adult children (i.e., the parents of the child with disabilities). Unconditional love and acceptance, family contact, and traditional role all emerged as factors that saw the grandparent role remain intact pre- and post-diagnosis. These results contradict earlier viewpoints of the diagnosis and adjustment period defining major role changes leading to re-evaluation of identity and responsibilities (Avieli & Winterstein, 2017; Hazel, 2010). These findings indicate that grandparents maintain integral rearing roles in family systems, thus interventions and support programs should expand to include grandparents in the realm of caregivers that receive information, resources and support in raising children with disabilities. However, paternal perspectives were again ignored.

Katz and Kessel (2002) explored the attitudes of grandparents towards their grandchild's disability, and how their perceptions mediated their involvement in care. Through qualitative interviews, Katz and Kessel (2002) identified that the level of involvement and role satisfaction described by these grandparents was determined by their attitudes towards children with disabilities in general, plus their own life experiences. Their relationships with their adult children reported similar trends as those in Mirfin-Veitch et al.'s (1997) study. These factors relate to impact on relationships and perceptions that was discussed by Mandlco and Webb's (2015) sibling participants as well, in that social interactions are mediated by a family member's attitudes towards their relative with a disability. A critique of Katz and Kessel's (2002) study, however, is that the sample consisted of grandparents with grandchildren of considerably young ages which excludes the generalizability

of findings to family systems with adult children with disabilities, or who have raised a child with disabilities over a longitudinal period.

Emotional Support

Using both surveys and interviews, Green (2001) employed a serial model of caregiving approach which focused on caregivers who seamlessly transition from caring for one facet of immediate family to another with no reprieve period in-between. Green's (2001) findings suggested that grandparents were more likely to offer weekly assistance to households raising children with disabilities compared to any other extended relative. This frequency was positively correlated with levels of outside social support for the household as well, suggesting that social support originates from parental request (Green, 2001). Moreover, parental wellbeing was positively associated with grandparent assistance (Green, 2001). Green (2001) concluded that from a parental perspective, involving grandparents as secondary caregivers enabled further knowledge of the child's condition and therefore enabled greater understanding and attitudes maintained towards their grandchild. These findings support the importance of knowledge in bettering communication and perceptions of a child's disability condition, as discussed by Mandlco and Webb (2015). Green (2001) argues that grandparents are vital for emotional support, a factor widely demonstrated to relate to positive and effective coping in caregivers of children with disabilities (Avieli & Band-Winterstein, 2017; Hazel, 2010; Katz & Kessel, 2002; Manor-Binyamini, 2016; Tiba et al., 2012).

Trute, Worthington and Hiebert-Murphy (2008) conducted a statistical analysis which demonstrated that maternal grandmother support in raising children with DD was anticipated regardless of the situation. However, if a paternal grandmother provided both present assistance and emotional support, stress felt by parents was significantly reduced (Trute et al., 2008). This concept of stress reduction is related to the idea of family cohesion and flexibility discussed by Rieger and McGrail (2013), in that higher perceived unity in family systems appears to lower feelings of stress and increases adaptability to change and adjustment to challenges.

Overall, research concerning grandparent perspectives in this area provides insight into the importance of relationships and emotional support involved in grandparent coping. Strengths of this category are outlined by the demonstration of the crucial nature of having family intervention practitioners extend attention to grandparents when considering coping strategies employed by parents as well. Conversely, a weakness of this category is the lack of literature pertaining to the support of grandparents extending to siblings in a family raising a child with

disabilities. Additionally, paternal perspectives are predominantly neglected in this category as well.

In conclusion to the critical literature review of this discussion, it has been demonstrated that there are three major facets of family systems raising children with disabilities: the parents, siblings, and grandparents of the child with disabilities. For the parental category, it has been illustrated how adjustment, social support, resiliency and adaptability, and flexibility all contribute to effective parental coping in raising a child with disabilities. In terms of siblings, flexibility and adjustment have been demonstrated as integral to positive coping with having a sibling with a disability. Lastly, grandparents have been demonstrated to be an essential facet of family systems raising children with disabilities, of which relationships and emotional support are major contributing factors.

While each of these categories of research has provided valuable insights into the experiences of raising children with disabilities, paternal perspectives have been largely neglected in this research. This negligence of such an integral parental role stunts overall understandings of how family systems as complete units cope with the challenges associated with raising children with disabilities. For example, existing literature on the topic of parental coping mechanisms of raising children with disabilities suffers a complete lack of research on single-father family units who face similar severities of challenges that single-mother households do. This lack of paternal perspective research suggests that single fathers raising children with disabilities do so without a focused research component to improve support services available to them. Similarly, same-sex parental unit research in rearing coping practices is lacking as well. Additionally, the majority of this research has focused on coping in relation to children with concrete diagnoses, which effectively ignores entire populations of families still in search for answers about the challenges their child may face. Moreover, while parent-sibling and grandparent-parent relationships have been explored in this area, grandparent-sibling relationships remain a recommendation for further investigation.

Another largely ignored dimension to caregiver coping of those raising children with disabilities includes paid caregivers who may or may not be live-in but still work very closely with families as additional help with caregiving duties. While paid aid appears to be rare in the literature as families tend to bear financial losses due to the additional costs associated with the challenges of raising children with disabilities (Beresford, 1994), the subpopulation of external caregivers who are paid and work closely with families deserves attention in future research concerning coping mechanisms utilized by such a unique caregiving sector. On a similar note, material and financial hardships are often discussed only briefly in relation to family coping mechanisms in the literature; however, the author of this

paper recommends that future research produce better understandings for community support service providers of how financial and material support directly relate to the emotional and social support perceived by caregivers of children with disabilities. Beresford (1994) established that socio-economic status is directly correlated with a family's ability to adapt to the news of a disability diagnosis for their child, and that parents often take hits to financial stability in order to provide physical aid (i.e. lifts, ramps, accessibility adaptations to the home) and psychosocial aid (i.e., daycare, playgroups, special education considerations) for their child with disabilities. Thus, more specific understandings of what kind of financial and material support service provision could offer would aid in decreasing stress on family units raising children with disabilities.

The next section of this discussion consists of an alternative dialogue between two core authors in research of family experiences with disabilities diagnoses, focusing specifically on the lived experiences and coping mechanisms of families raising children with disabilities. The author of this paper then proposes further recommendations for study to advance service providers' understandings of family systems raising children with disabilities.

Conflict of Interpretations

Due to its multidisciplinary approach, anthropology provides valuable qualitative research findings that aid in helping researchers and service providers create more robust understandings of the experiences and coping mechanisms of families raising children with disabilities. Anthropologist Cheryl Mattingly is renowned for her work studying multicultural experiences of families dealing with chronic illness in particular. Mattingly explores the experiences of family clinical interactions through focused case studies using a narrative approach, meaning her findings are based on the recurring messages individuals share through the telling of their stories and experiences (Mattingly, n.d.). Mattingly's body of work includes "Rival Moral Traditions and the Miracle Baby" (Mattingly, 2014). Focusing on an African American parental unit in urban California coping with the birth of their daughter with SB, Mattingly discusses how the moral traditions in a family's "authoritative cultural space (the church and its religious practices)" often conflicts with their "authoritative space (the clinic and its biomedical practices)" (Mattingly, 2014, p. 155). Essentially, Mattingly explores the challenges this family faced when coping with their daughter's SB diagnosis. Two key concepts central to Mattingly's methodological framework are narrative phenomenology and ontological arguments. She utilizes a narrative phenomenology through case study interviews to thoroughly engage in understanding the experiences of what individual families in these situations go through. Mattingly then focuses on the ontological arguments (the

philosophical discussions of the nature of being) that arise in the morality of coping decisions parents make when faced with encountering cases of disability in their children. This ontological approach enables a discussion of how different moral authorities and traditions create a fundamental divide between how disabilities and chronic illnesses are viewed, understood, and managed by different families. More specifically, Mattingly focuses on the ontological divides between biomedical models used by Western healthcare professionals, and religious moral models of families accessing care for their children with disabilities or chronic illnesses.

Mattingly's framework to investigate coping in family systems raising children with disabilities could contribute to the expansion of how professional practitioners provide support and care to the families involved. Understanding the narratives of such families would further illuminate the kind of unique position families raising children with disabilities occupy and what kind of services could be provided to increase the use of positive coping mechanisms by such families. Additionally, incorporating an acknowledgement of differing moral stances on raising children with disabilities would create a more inclusive support system for examples of families who may be in constant conflict with Western models of care while fighting for their right to care for their child as they see fit, and according to their values. Furthermore, exploring ontological differences in the perceptions of disability and chronic illness would create more robust understandings of how such perceptions differ among global communities of different cultural practices. As such, it can be seen how Mattingly's combined ontological and narrative frameworks both confirm current understandings in the categories discussed previously in this paper, and expand upon the recommendations provided by the author of this paper for further research. Narrative phenomenology is a widely used framework of choice by qualitative researchers looking to provide valuable insight into the experiences of those raising children with disabilities and for disseminating knowledge for other families that are perhaps in search of guidance and reassurance during the adjustment period following an initial diagnosis for their child. Ontological examinations of moral attitudes towards raising children with disabilities can illuminate the unique moral conflicts such families face and can challenge the ineffective universal approach utilized by many service providers and healthcare institutions managing disability cases.

Parallel to Mattingly's work, Benedicte Ingstad examines disability and human rights using anthropological narratives to examine the lived experiences of individuals with disabilities, including their family systems. In Ingstad's (2007) work, she looks at universalist versus relativist phenomenology approaches in particular. Ingstad (2007) insists that universalist approaches dictate that some

concepts have universal applicability for equal compatibility across any situation, whereas relativist phenomenology emphasises creating a distinction between individual scenarios to determine concepts of best application and compatibility. However, where Mattingly advocates a relativist approach to acknowledging differences in moral practices in raising children with disabilities, Ingstad provides a conflicting stance in that she argues for the importance of navigating between universalist and relativist approaches. Essentially, Ingstad's framework exposes the problematic nature of universal approaches to global disability rights movements, but also the pitfalls of wholly relativist attitudes. In her work "Seeing Disability and Human Rights in the Local Context," her key argument is for the importance of examining disability in a local, sociocultural context. To illustrate this argument, Ingstad discusses how perceptions of disability are influenced by the "possibilities, constraints, and beliefs imposed by the local physical, social, economic, and cultural setting" (Ingstad, 2007, p. 250). Universal disability rights movements are examined in terms of how they often miss the mark, not only for specific needs arising in different contexts but also how extreme relativism can hinder progress when needs are incorporated into a hierarchy often used for publicity and approval leverage in countries where disability rights are not prioritized (Ingstad, 2007).

In relation to the dimensions of coping within families raising children with disabilities discussed earlier in this paper, Ingstad's localizing framework complements both the demonstrated use of qualitative research to explore experiences at an individual level and lends support for the call for further patient- and client-centred care. Should a methodology such as Ingstad's be used for future research in this area, differing individual needs among family systems raising children with disabilities would be illuminated by taking the differing sociocultural influences outlined by Ingstad into account. Furthermore, research conducted through an individualistic lens could begin to address the lack of perspectives from fathers raising children with disabilities.

The final section of this paper will examine the dialogue between the key concepts discussed by Mattingly and Ingstad, and how they relate to the previously discussed literature on this topic to complete the author of this paper's overall examination of coping mechanisms used by families raising children with disabilities.

Conclusion

The purpose of this paper was to demonstrate the major factors involved in effective coping of family systems raising children with disabilities. The literature reviewed for the parent, sibling and grandparent categories impressed the importance of adjustment, social and emotional support,

resiliency and adaptability, and flexibility as specific factors contributing to coping with raising children with disabilities. A common argument in the research centers around the importance of extending service provision to encompass siblings and grandparents as part of the support model for raising children with disabilities. This argument also parallels the notions described by both Mattingly and Ingstad, in that narrative research provides more robust literature on the experiences of families raising children with disabilities, as does the acknowledgment of differing moral perspectives and the influences of local contexts on families involved.

Contributions to the literature of experiences and coping mechanisms of families raising children with disabilities relate to advocating for change to create more effective care provided by practitioners in the form of community support for families engaging with the challenges involved in raising children post-disability diagnosis. Relative to clinical practices, the author of this paper argues that mental health services should stress the importance of emotional and social support for parents raising children with disabilities, and acknowledge that any receipt of diagnoses and subsequent adjustment periods present different challenges to different families. The author of this paper also recommends that social services and support programs extend consideration to include sibling and grandparent perspectives into caregiver plans. In terms of public policy changes, ontological acknowledgements of conflicting moral traditions and local sociocultural considerations are argued by the author of this paper to be crucial in creating policies around disability rights that satisfy individual needs and expectations while providing higher quality support for families raising children with disabilities. As such, the author of this paper notes that federal policies are often too broad to be effective to handle clinical cases of disability management at an individual level, and that patient-centred policy approaches are demonstrated in this paper to better enable positive coping mechanisms in families raising children with disabilities.

Finally, the author of this paper recommends several areas for future research. First, the author recommends that paternal perspectives be examined not only to address the missing perspectives from the literature, but also to extend into different domains such as single fathers who may be lacking social and emotional support. Second, the author recommends conducting further research which utilizes anthropological approaches to understanding perspectives on raising children with disabilities across different cultural contexts. The adoption of critical qualitative approaches like those recommended by Mattingly and Ingstad would contribute more robust understandings of the unique challenges families face in raising children with disabilities across the varying contexts different families face such challenges. This research should include increased qualitative research to inform future

development of policy that is more effective in addressing individual families’ needs. Third, the author of this paper demonstrates that family-systems approaches to interventions in raising children with disabilities is crucial, and it is recommended that further research increase the use of this framework to contribute to effective clinical practice, support service provision, as well as public policy development to support the experiences of family systems in similar situations to those discussed here. The author of this paper suggests to further legitimize the value of perspectives of siblings growing up with a sibling with a disability in the household, as well as stress the value of including grandparents into the acknowledged support systems of families raising children with disabilities. Same-sex families should be included in future research on this topic, as should the consideration of paid caregivers and the effects of financial and material stress on the ability of families to positively cope with the challenges of raising children with disabilities.

In conclusion, this discussion has explored factors contributing to current understandings of specific coping mechanisms used by the parents, siblings and grandparents of children with disabilities, and has provided an outline of a variety of perspectives that recommend future research to evolve the infrastructure in place to support the unique challenges families face when raising children with disabilities.

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