Family Theories and Siblings of People with Intellectual and Developmental Disabilities

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Abstract

Family theories have been used in intellectual and developmental disability (IDD) research as a legitimizing tool for focusing on non-disabled siblings. Although there is value in understanding siblings' outcomes, family theories have utility beyond this narrow scope. This chapter will draw on social learning theory, embedded family systems theories, the Double ABCX model, lifespan and developmental perspectives, and post-structuralist perspectives, to examine how these theories can be used to understand siblings' experiences, family relationships, and outcomes. For example, these theoretical ideas enable us to further our understanding of the wider and more interactive factors related to siblings' psychological, social, familial, community, and societal outcomes, as well as relationships. These theories highlight the need for analyses that include the whole family system and that move beyond simple main effects to include interacting factors, and beyond unidirectional effects to bidirectional effects. Clarifying a broad array of factors that may explain sibling outcomes may help us to consider what covariates to include in statistical models. This chapter will also consider how family theories can help us to consider methodological and epistemological challenges related to sibling IDD research. For example, although these family theories are often described as dynamic, the transient and heuristic nature of capturing any perspective – about a theory, model, or from a research participant – ultimately reinforces how vast and unknowable individual and family experiences are. These family theories also have utility as a self-reflexive tool to consider researcher positionality. Family systems perspectives emphasize the insider-outsider boundary in family systems. Researchers must navigate, respect, and ultimately accept this boundary when researching families and siblings that are not their own.

Keywords: Siblings, Family, Intellectual disabilities, Developmental disabilities, Autism, Family systems, Theory, Relationships, Support, Methodologies.

Introduction

Context and Definitions

An intellectual disability (ID) is defined as a disability that affects an individual’s adaptive behavior as well as their intellectual functioning that has an onset before the individual is 18 years of age (AAIDD, 2019). A meta-analysis of international prevalence studies indicated that the prevalence rate for ID is approximately 1% (10.37/1000 population, 95% CI 9.55, 11.18 per 1000 population) of the global population (Maulik et al., 2011). A study using USA-based population data indicated this figure could be higher, estimating that the ID prevalence rate was 3.2% (Platt et al., 2019). Developmental disabilities (DD) include disabilities such as autism, Down syndrome, Fragile X syndrome, Williams syndrome, Cerebral palsy, or (for young children) global developmental delay. For some DDs such as Down syndrome, ID is an integral part of the condition. For other DDs, such as autism or Cerebral palsy, ID may or may not be present. Given these prevalence data and the range of relevant conditions, it is clear that a substantial minority of the population will have a family member with an intellectual or developmental disability (IDD).

Currently, and at least for the past five decades, there has been a considerable volume of research about families of people with IDD. Empirical research suggests parents and siblings of people with IDD may be at risk of worse psychological outcomes than other parents and siblings (Singer & Floyd, 2006; Emerson et al., 2010; Hayden et al., 2019a; Marquis et al., 2019). Research often positions siblings as a solution to future caregiving needs for people with IDD (Leane, 2019), with siblings potentially caring for their brothers and sisters with IDD when their parents are no longer able to. People with IDD are living longer lives than ever before (Coppus, 2013). Improvements in health and life outcomes for disabled people (e.g., increased life expectancy amongst people with Down syndrome; Hodapp & Urbano, 2007), along with the reduction in state welfare available in various national contexts, has prompted questions surrounding the uncertainty of care and support for people with IDD (Power & Bartlett, 2019). Therefore, if we care about the outcomes and the quality of life of people with IDD, then we must also consider the outcomes of their brothers and sisters without disabilities. If we are interested in siblings’ caring potential, then we should also be interested in understanding and fostering sibling relationships, as this has been associated with a willingness to take on this caring or supporting role in the future (Burke et al., 2012).

A family is characterized, in essence, by relationships between a group of individuals that holds socio-cultural-legal significance. Although a thorough exploration of the family is beyond the scope of this chapter, we will attempt to provide a working definition of both the family and the sibling relationship. Raymond Williams (1976) summarized the significance of the concept of the family through social history and traced etymological usage of the term. Earlier conceptualizations of the family, such as the household (referring to a dwelling where relatives and servants resided together), familiar (referring to a range of relationships but in essence indicated a closeness or familiarity without a genetic relationship), or references to the family in religions (e.g., the father, the son, the holy mother, brothers and sisters), were essentially referring to large kin-groups.

Williams (1976) indicates that the more familiar conceptualization of the family as a small kin-group emerged as dominant in the Western context between the 17th to the 19th centuries before dominating in the 20th century. This highlights to us that the 'traditional' nuclear family, consisting of a mother, a father, and children, is a relatively modern social structure. Therefore, it is important to emphasize that the concept of the family is not universal or fixed, it is socio-culturally constructed and perpetually changing. For example, the latter half of the 20th century in Western societies saw medical advances such as the introduction of in-vitro fertilization as well as increases in divorce rates, leading to single-parent households and stepfamilies becoming more common. The early 21st century has seen the recognition of LGBTQ+ people's rights to marriage, adoption, and access to medical fertility options in several Western countries. There is not and there has never been a 'traditional' family and, therefore, we need to think openly and flexibly about how we define the family. Rosenblatt (1994) provided the following definition:

> '…the essential character of the family entity includes culturally defined family roles and role interactions that differ by age and gender. It includes culturally defined family identity

> markers as, for example, a name, a dwelling, genealogical relations, commitments made by members to each other, or legal rights and obligations to one another' (Rosenblatt, 1994: 35).

This definition is useful because it is relatively flexible and open. It emphasizes that the family is culturally and socially defined, it allows for the inclusion of extended family members as well as immediate family members to be included, and it does not prioritize only, for example, genetic relationships or those where people reside with one another. The simplest definition of siblings would be people who share one or two parents. Sanders (2004) highlights that this may exclude various sibling relationships, such as step, adopted, or foster siblings, as well as children that are raised together but share no genetic or socio-legal relationship. Reading Rosenblatt's definition as quoted above to understand sibling relationships would allow us to incorporate these non-genetic sibling ties, maintaining an open and inclusive definition of both the family and the sibling relationship.

Siblings of people with IDD

Empirical research about siblings of disabled people has tended to focus on psychological outcomes, particularly for child siblings. This focus stems from the way family systems theory intersects at times with a negative societal narrative, whereby siblings are assumed to be negatively affected in some way due to having a disabled brother or sister. Family systems, as we shall discuss later in this chapter, are not inherently negative. In fact, Hastings (2016) argues that family systems perspectives may be used in order to reject a negative narrative about the affect people with IDD may have on their families and siblings. The most consistent point made in existing sibling studies is that findings about siblings' outcomes are mixed and inconsistent. For example, some studies have found that siblings have worse outcomes (Hastings, 2003; Verté et al., 2003; Ross & Cuskelly, 2006; Orsmond & Seltzer, 2007; Goudie et al., 2013) and some studies have found no evidence of differences in outcomes (Cuskelly & Gunn, 2006; Hastings, 2007; Howlin et al., 2015) compared to individuals without disabled brothers and sisters. These mixed findings are likely due, at least in part, to methodological issues, such as an over-reliance on small, convenience-based samples that were biased. Population-level data about siblings of children with ID (Hayden et al., 2919a) have found that on straight comparisons, siblings of children with ID had worse behavioral and emotional symptoms.

Further analyses indicated, however, that these group differences were mainly accounted for by other within-family variables (e.g., single parent household, maternal mental distress) and wider structural variables (e.g., socio-economic position). Other population data about the outcomes of siblings of children with DD (Marquis et al., 2019) also found evidence that socio-economic status was an important explanatory variable. However, siblings of children with DD remained at greater odds of depression and other mental health problems even after these predictors were controlled for (Marquis et al., 2019). This discrepancy in findings may be due to differences in outcome measures used, different populations (i.e., UK vs Canada, ID vs DD more broadly), but it may also be due to the wider covariates available to control for in the dataset available to Hayden et al. (2019a) in comparison to the dataset available to Marquis et al. (2019).

Sibling relationships are important for both individuals in the relationship, with siblings having the potential to influence one another's lives (Meltzer & Kramer, 2016). The relationship is unique in that it has the potential to last across the entire life-span – from early childhood into old-age. Children learn social behaviors within their sibling relationships (Mandleco & Mason Webb, 2015) that may have an impact on their future relationships beyond the family system. Wider sibling research has found that sibling relationship quality is associated with both childhood and adulthood mental health outcomes (e.g., depression; Feinberg et al., 2012; Waldinger et al., 2007). For people with IDD, sibling relationships may be particularly important, with Richardson and Jordan (2017) stating that sibling relationships are 'imperative to the lives of people with disabilities' (2017: 1536). The value of sibling relationships goes far beyond siblings' ability or willingness to provide care. Siblings are able to offer friendship and support where elsewhere in society, many disabled people continue to face discrimination and exclusion.

Many empirical studies in the sibling IDD research field have hypothesized that sibling relationships where one sibling has an IDD may be more 'negative' than sibling dyads where neither sibling has an IDD. This premise, however, is not clearly supported by empirical evidence. For example, Doody et al., (2010) found that adult sibling pairs where one has an ID had similar levels of conflict to sibling pairs where neither had an ID. Other studies have found that in sibling dyads where one sibling has an ID, their relationships have less conflict compared to sibling dyads where neither had an IDD (Floyd et al., 2009; Kaminsky & Dewey, 2001). Although much IDD sibling research positions the sibling as the provider of support with the person with IDD as the recipient, the relationship should be seen as reciprocal and bidirectional, even if this reciprocity manifests itself in unfamiliar ways.

Research in the siblings and IDD field has often been critiqued as ‘atheoretical’ (McHale et al., 2016: 589; Saxena & Adamsons, 2013: 300). The most commonly cited theory is arguably ‘family systems perspectives’ which, perhaps due to the word count constraints in psychological journals, is often referred to briefly before the focus shifts towards more empirical matters. More recently, we have seen several papers in the sibling IDD field that have been more theoretically driven (e.g., Meltzer & Kramer, 2016; Meltzer & Muir, 2021; Richardson & Jordan, 2017), particularly those drawing on qualitative data. Theories are important in all research, however, as they help us to conceive studies and understand phenomena. Theories help us to not only understand and consider how things are, but also help us to imagine how things could be. In this way, theorizing is an important process in social change.

This chapter is formed of two main sections. The first section provides an overview of theories in relation to families, and specifically siblings, of people with IDD. We consider social learning theory, family systems perspectives, lifespan and developmental perspectives, the Double ABCX model, and post-structuralist theories. The second section concentrates on the applicability of these ideas in relation to families and siblings of people with IDD. Specifically, we consider two broad areas of applicability. First, we consider methodological implications, including epistemological, reflexivity, ethical, and then analytical implications. Second, we consider empirical implications, including clinical, practice, and political implications.

Conceptualizing Families and Siblings

Social Learning Theory

It has been suggested that social learning theory is the most commonly applied conceptual framework in the broader, non-disability, sibling research (Feinberg et al., 2012; Whiteman et al., 2011). Social learning theory has often been used in the broader sibling research to consider how siblings influence one another's behaviors, especially 'risky' behaviors (e.g., smoking, drinking alcohol, substance abuse, criminal and deviant behaviors etc.).

Social learning theory considers the way that we learn from our social environments. It can be seen as a general theory of behavior, with a focus on social factors rather than factors within the individual (Bandura, 1977; Maisto et al., 1999). This can be direct, through personal experiences, or indirect, through modeling by others, and can be used to help us understand how personal characteristics can be developed from our social contexts (Maisto et al., 1999). Although social learning can lead to similarities between siblings, 'children within the same family may develop dissimilar personality characteristics by drawing upon different parental and sibling attributes' (Bandura, 1977: 48). The behaviors developed though social interactions can of course be both 'positive' and 'negative'. Social learning theory suggests that the more similar a child sees themselves to their brother or sister (e.g., similar age, same gender), the more likely it is that they will be influenced by them (Whiteman et al., 2011).

Maisto et al., (1999) suggest that there are four main cornerstones of Bandura's account of social learning theory:

(1) Differential reinforcement – variations of consequences for behaviors in different environments. For example, a child with IDD and echolalia or tics, may be responded to very differently in the home environment than in the school environment. If their sibling attended the same school, they may behave in a more relaxed way at home in response to their brother or sister's behavior than in a school environment.

(2) Vicarious learning – how we learn behaviors through modeling (i.e., through observing others or through communication). For example, siblings may observe and imitate one another (Whiteman et al., 2011). Parents may also model conflict resolution skills for their children.

(3) Cognitive processes – how information about, for example, the likely consequences of our actions, regulate our behavior. For example, when parents are stressed, siblings of children with IDD may reduce their problem behaviors in response to an increase in their siblings' problem behaviors. Conversely, when parents are stressed and providing attention to their child with IDD exhibiting problem behaviors, a sibling may increase their problem behaviors to receive parental attention.

(4) Reciprocal determinism – the bidirectional effects between our behaviors and our environments. For siblings, this emphasizes the need to include data about both siblings in the relationship in research – as there are bidirectional and reciprocal associations between their behaviors.

Bandura considered the way that relational reinforcement not only affects behavior, but also discontentment or satisfaction as children can be highly sensitive to differential treatment between siblings. For siblings of people with IDD, differential treatment between siblings is intensified, and for good reason, as children and adults with IDD often require extra support and care throughout their lives. Helping non-disabled children to understand and appreciate that being treated unequally to a disabled sibling is not necessarily unfair, is a significant challenge for parents. This is concerning, according to Bandura as 'the displeasing aspects of unfair treatment continue to be reinforced in later years' (Bandura, 1977: 118). Unequal treatment for families of children with IDD can also be confusing for children because the differences often do not follow the same conventions as they do for other families. For example, usually older children have later bedtimes than younger siblings, but children with IDD may be allowed to stay up later even when they are younger, especially if they have sleep problems. Younger siblings may have more chores and responsibilities than an older sibling with an IDD. Fostering strong sibling relationships is important as, according to social learning theory, negative patterns of behavior from both siblings towards the sibling relationship can be transplanted to other social settings, possibly influencing children's relationships outside of the family home and into adulthood.

Lifespan and Developmental Perspectives

Siblings and Family Theory

To consider the importance of understanding change within the family system, it is useful to consider family life course perspectives and family developmental perspectives. Some writers have incorporated developmental frameworks with family systems perspectives to explore, for example, anticipatory loss related to disability (Rolland, 1990). These ideas help us to consider how families change over time through stages and events in the family life course. For White and Klein (2002), these perspectives are conjoined – or perhaps conflated – into a single framework, which we adopt in this chapter: 'The Family Life Course Developmental Framework'. These perspectives consider the ways in which families are embedded within a kinship structure, with changing family positions, roles, and norms.

For families with a family member with IDD, siblings may provide more support and care for their brothers and sisters with IDD than in other families, blurring some of the distinctions of these roles and family positions. This concept overlaps with the focus on boundaries in the family systems framework. Siblings are often expected to care and 'watch out' for one another, particularly older siblings for younger siblings (White & Klein, 2002). For siblings with a brother or sister with IDD, these norms may differ, as they may provide more support than would usually be expected, and younger siblings without a disability may provide care and support for their older brother or sister with IDD. Societal norms expect siblings to provide friendship and support for one another in adulthood but for sibling dyads where one has an IDD, these may appear to outsiders as less reciprocal or balanced than for other sibling dyads.

Developmental perspectives suggest that sibling relationships become less salient in early adulthood, and more important again in later life (White, 2001). Family life course and developmental perspectives also focus on family stage and transitions between these stages. For siblings where one has an IDD, their relationship may not follow this pattern. Some work has been done to explore transitions from childhood to adulthood for siblings of people with ID or autism (Todd, 2019) and consider how sibling relationships and experiences when one sibling has a disability change over time. Transition periods for families of a child with IDD may include 'typical' transitions, such as biological and social changes in adolescence. Transitions may also be different, such as the transition from childhood to adulthood leading to a disruption in support, as the disabled child moves from child to adult services. There may also be additional transitions for the families of a disabled person, such as during the diagnosis process, or during developmental milestones for the person with IDD (Cridland et al., 2014) which may be more spaced out, and potentially perceived as more significant by the family.

These perspectives highlight the importance of understanding siblings' relationships, outcomes and experiences throughout the life course, rather than focusing predominately on, for example, childhood or later adulthood (White, 2001). Reading developmental and lifespan perspectives in relation to family systems perspectives helps us further understand how families change over time.

Double ABCX model

The Double ABCX model (Hill, 1949; Hill, 1958; McCubbin & Patterson, 1983) considers how the family system adapts in response to a situation, or stressor. The ABCX model is conceptualized as: the *A factor,* the stressor event and hardships; the *B factor*, the family's resources to respond to the stressor, such as family integration and family adaptability; the *C factor,* which is the focus the family have on the stressor and their perceptions and outlook of the event; and the X factor, how factors A, B, and C interact within the family system to produce, or prevent, a crisis. The Double ABCX model was developed by McCubbin & Patterson (1983) to expand the ABCX model to consider the dynamic processes and cumulative stressors that families experience:

> **aA** considers the pile-up of stressors or demands, and these may stem from an individual, the family system, or the wider community or society in which the family is embedded. If we apply aA to families of a disabled person, the initial situation would be the birth or the revelation that their child has a disability (e.g., through the diagnosis process). Stressors may pile up, for example, one parent may decide not to work to provide extra support to their child, and this may lead to a reduction in financial resources and stresses related to loss of income. An inescapable problem with this model, and the aA construct in particular, is the

conceptualization of the disabled person as a ‘stressor’ on their family system. It is important to also highlight that a ‘stressor’ is not always a negative or unwanted event. The birth of a child is often simultaneously a ‘stressor’ as well as a celebrated event.

bB considers the resources families apply in response to the situation. These resources could be existing resources, such as being part of a religious community, financial resources, or having the social and cultural capital to effectively navigate support services for a disabled family member. It could also be resources that the family acquired to respond to the situation. These resources could include accessing community-based support groups for parents of disabled children, developing skills to more effectively navigate support services, or applying for extra support from local government for educational or home adaptations and adjustments.

cC describes the changes families make to their interpretation of the situation or stressor. Families may find the initial diagnosis upsetting, or they may find it affirming of the differences they have observed in their child, and a tool for getting their child the support they need. For families of disabled children their perceptions may oscillate. For example, a parent who has spent the afternoon observing and comparing their child to other children of a similar chronological age may interpret their situation less favorably than a parent who has just witnessed their child reach a developmental milestone or display prosocial behaviors towards them.

xX describes the way the family adapts to the stressor. For families of a disabled child, the xX factor considers whether there is a balance between demands and capabilities. For example, that the demands of the child are met by the capabilities of the family, and that the demands of the family system are met by the wider community, services, or societal context. It also considers how the coherence of the family, along with the balance between demands and capabilities, leads to the outcome. The outcome is understood as a continuum (i.e., a continuous variable), that is expected to constantly fluctuate due to the changes and processes occurring as described above (i.e., aA, bB, and cC).

Applying the Double ABCX model to statistical analyses, the effects between aA, bB, and cC can be conceptualized as direct effects to xX; bB, and cC could be conceptualized as mediating variables between aA and xX (Saloviita et al., 2003); and the interaction between bB and cC can be seen as moderating effects (i.e., BC; Meleady et al., 2020). In this way, the model can not only help us consider which variables we should include in our analyses as covariates, but also consider analyses that move beyond direct main effects, for example, by considering moderating effects. The Double ABCX model has been used to understand the experiences of families of autistic children (McStay et al., 2014; Bristol, 1987; Pakenham, 2005; Meleady et al., 2020), as well as parents of children with ID (Saloviita et al., 2003).

The model is useful because it helps us conceptualize why some families and siblings of disabled people may have better outcomes or are considered more ‘resilient’ than others. The extended ABCX model provokes consideration of multi-level and contextual factors in our analyses, as it incorporates individual-level, family-level, and societal-level factors. These levels can be seen to overlap with Bronfenbrenner’s macro, exo, meso, and microsystems (Bronfenbrenner, 1979) and the Siblings Embedded Systems Framework (Kovshoff et al., 2017). This model, therefore, indicates that stress is not uniform. We should expect to see siblings and families of disabled people responding differently from one another. McCubbin and Patterson (1983) also introduced the ‘Family Adjustment and Adaptation Response’ (FAAR; Patterson, 1988) model which brings in further consideration of changes over time and a phased approach to considering family adjustment and adaptation. These models can, therefore, help us further consider the non-static nature of the family system. FAAR is also seen as a turning point in the conceptualization of family stress as a move away from family weaknesses towards considerations of family strengths and resilience (White et al., 2015); helping us to move beyond an assumed negative narrative about sibling and family experiences. However, theories related to family and individual ‘resilience’ present issues related to individualization whereby families and individual disabled people are seen as responsible for their own outcomes (xX). This is a problem because it often coincides with a scaling back of what the state and society is expected to provide by way of support for families.

Post-structuralist theories

The next set of theories we shall consider fall under post-structuralism. We consider specific writings from Foucault to think about the relationship between individual families and the state. To help us consider the complexities of studying families and conducting social research, we will also draw on rhizomatic thinking from Deleuze and Guattari.

Foucault

Perhaps the most commonly drawn upon post-structuralist theorist in critical disability studies is Michele Foucault (*cf.* Tremain, 2005). Foucault examined the ways in which power structures use and produce knowledge about human subjects to exert control. Foucault examined how institutions of power-knowledge:

> '…permit an internal, articulated and detailed control – to render visible those who are inside it; in more general terms; an architecture that would operate to transform individuals: to act on those it shelters….to make it possible to know them, to alter them' (Foucault, 1975: 172).

In a practical way, we can see how state apparatuses such as hospitals, mental institutions, prisons, and schools are all collecting data on individuals that serve to normalize, pathologize, hierarchize, and individualize. For example, these data allow individuals to be labelled as disabled/not disabled, autistic/neuro-typical, intellectually disabled/typically developing, mentally ill/mentally healthy, chronically ill/ healthy. These categories are ultimately socially constructed and over-simplified. Another area where Foucault's ideas can be helpful, is when thinking about the language we use to talk about siblings, and to help us move away from binary definitions of disability. Referring to siblings as 'typically' developing and their brothers and sisters as having IDDs is often inappropriate and inaccurate. Neurodiversity is very common, particularly amongst siblings. Furthermore, some people identify as 'siblings', and then receive late diagnoses themselves for neurodevelopmental conditions such as autism – and are left having to grapple with where they fit within the binary code. Sibling IDD research has focused on the mental health outcomes of siblings, arguably pathologizing siblings. Foucault's ideas could, therefore, help us to resist the pathologization of siblings, but it also raises questions about how these binaries are internalized by family members. When one child is seen as disabled, and one is not, it raises questions about how these individuals see themselves and one another, as well as how they are seen by their parents, their wider families, their schools, and their communities more generally. This raises important questions about how this binary affects the relationships of siblings where one has an IDD.

For Foucault, this power-knowledge paradigm makes it possible to ‘transform…know…[and] to alter’ individuals (Foucault, 1975: 172). For example, people with mental health diagnoses can be institutionalized against their will, disabled children are carefully monitored at school and separated from their peers, with extra interventions, extra support from specialists, and modified classwork. Children and families who are deemed ‘at risk’ are carefully monitored by public services. This monitoring, or even just the possibility of being monitored (*cf.* The Panopticon), serve to change our behavior so that we respond ‘appropriately’. As social science researchers and practitioners in the social sphere, we are inherently a part of this mechanism that produces knowledge, and we must be self-reflexive about what this means for our work. Foucault’s ideas can also help us consider epistemological questions about the social sciences, data, statistics, and psychology specifically:

> ‘To Foucault, there can be no such impersonal ‘scientific’ truth. Ever mutating and ever dangerous, power and the so-called truth it uses to justify and extend itself are always in all of their forms to be met with skepticism and resistance’ (Mansfield, 2000: 53).

Post-structuralist ideas can help us to consider more interpretivist ways of understanding our research. Although Foucault’s ideas can be useful for criticizing governments and power structures (including academic disciplines, such as psychology) he urges us to resist understanding power purely in ‘negative terms’:

> ‘We must cease once and for all to describe the effects of power in negative terms: it ‘excludes’, it ‘represses’, it ‘censors’, it ‘abstracts’, it ‘masks’, it ‘conceals’. In fact, power produces; it produces reality; it produces domains of objects and rituals of truth.’ (Foucault 1975: 194).

Foucault therefore asks us to acknowledge the potential benefits of power-knowledge. For disabled people, these benefits could include extra support in schools, workplaces, in the community, appropriate adjustments in social and health care, and state welfare and benefits. As researchers, we produce knowledge and we produce or test interventions, both of which can be used to support the populations that we research about (or with).

Foucault's ideas hold value for understanding the experiences of families and siblings of people with IDD – particularly for carers. Mansfield stated that, according to Foucault's ideas, '…we fit into the needs of the larger political imperatives of the capitalist state. It requires us not only to behave in certain ways, but to be certain types of people' (Mansfield, 2000: 53). This concept influences what it means to be a 'good' parent or sibling of someone with an IDD. This influence can result in parents holding on to being a primary carer and feeling guilty for drawing on residential services or offers of support from adult siblings. This internalization of a family carer identity can make it difficult for adult siblings in particular to have conversations with their parents about taking over care roles for their brothers and sisters with IDD.

The opposite can also happen. Some parents may assume that siblings will take on care roles. Siblings may feel pressured to take on care giving roles, by family obligation, but also from societal and community expectations. These pressures are likely to be affected by gender and by culture. Therefore, for siblings, their choices around caring are often highly constrained – even assembled and constructed – in a way that reinforces the capitalist system. These socially constructed choices serve the state as it encourages families to take on individual responsibility for family members who need support and care, thereby reducing dependency on a capitalist state, allowing them to reduce the provision of high-quality welfare services. Foucault's ideas can therefore help us question how we can resist this in our work as researchers, and it also asks what role siblings can play in resisting this system. Foucault's ideas can also help us resist the over-pathologization of siblings and they can help us to criticize governments for the lack of support for people with IDD, and by implication, the lack of support for their families.

Deleuze and Guattari

Deleuze and Guattari’s rhizomatic thinking can be seen as a way of modelling society and thought (2013; first published in 1987). Deleuze and Guattari suggest that trees are the dominant metaphor in European thought. The metaphor of a tree is arborescent thought, that is, totalizing, binary, and characterized by dualism. We can see this metaphor of trees and root structures applied to families and genealogical structures. Families are structured in family trees. Colloquially, we might speak of knowing or ‘going back to’ our roots. Deleuze and Guattari introduce nomadic thought and the metaphor of rhizomes as an alternative, or possibly co-existing, metaphor for understanding the world. Rhizomes are subterranean root structures, such as bamboo or ginger, characterized by horizontal off shoots rather than a more hierarchical linear root structure. Mansfield highlights the utility of rhizomatic thinking to family studies:

> ‘Family relationships, however, could be more fully modelled as rhizomatic. Patterns of intermarriage and birth expand infinitely from any one point. Your birth connects you to two families via your parents; through them to four families via their parents and so on. The complexity of the picture is intensified by lines of flight conjoining you to siblings, cousins, their children, their partners, their partners’ families, and so on to infinity’ (Mansfield, 2000: 146).

The metaphor of Rhizomes highlights that relationships are non-hierarchical. Applied to family studies, this non-hierarchical approach would de-center the parent-child dyad and may help us to consider the importance, also, of sibling-sibling dyads. It would also avoid the prioritization of the nuclear family in Western society. This de-prioritization of the nuclear family would not only make space for definitions of family that reflect and respect people’s varied experiences and relationships, but it may also help us consider the importance of community, as well as family, in our lives. Acknowledging the ways in which the nuclear family are socially and culturally constructed would allow a shift in the assumption of care primarily falling upon the nuclear family, emphasizing a support structure that draws on community and societal supports.

Rhizomatic thought is a useful way of considering society and community as a collective, as well as our relationships with one another. Deleuze and Guattari highlight ‘principles of connection and heterogeneity: any point of a rhizome can be connected to anything other, and must be’ (Deleuze & Guattari, 2013: 5). This conceptualization of connection highlights the importance of relationships and community rather than individuals. We would argue that all social relationships are rhizomatic, but for families of people with IDD, we could argue that these relationships are even more rhizomatic. The boundaries described in the family systems section earlier may be more blurred or changeable to allow for more fluctuating needs in the families of disabled people. There may also be many more people involved in the family system, such as transient care services and support staff.

Rhizomatic thinking can be thought of, in part, as a theory about becoming – rather than ‘to be’: ‘A rhizome has no beginning or end; it is always in the middle, between things, interbeing, intermezzo’ (Deleuze & Guattari, 2013: 26). In this way, rhizomatic thinking accounts for the ever-changing nature of our reality, and can help us work with our data in more complex and nuanced ways. This concept has real practical implications to the field of family and disability studies. Some work by Dan Goodley has applied Deleuze and Guattari’s ideas to disability studies. Goodley’s research has included some work about families – specifically about parents of disabled babies (Goodley, 2007). Deleuze and Guattari’s theories about the perpetual process of becoming lend themselves well to studying parents of disabled children, according to Goodley, because these ‘parents consistently defy categorization’ (p. 146). There is a sense, therefore, that given the complexities and perpetual motion experienced by the families of people with IDD, that rhizomatic thinking can help us understand these experiences better.

Family Systems Perspectives

The final theory that we will discuss is family systems perspectives, arguably the most common theory used in the IDD specific sibling literature (Cridland et al., 2014). The application of systems thinking to family studies was initially advanced by Murray Bowen (1966) who argued that understanding individuals as part of a family, and the family as a system, may help us move beyond static conceptualizations of people and families (Bowen, 1966). The basic premise for Bowen, was that ‘a change in one part of the system is followed by compensatory change in other parts of the system’ (Bowen, 1966: 351). He described the way in which one family member ‘over functions to compensate for the dysfunction [sic] of the other’ (Bowen, 1966: 351) and that if the conditions are ongoing, this can lead to a lack of flexibility and reduced functioning within the family system. Family systems are, in essence, a way of understanding the way in which a person within a family system can have an effect on other people within the family system ‘wherein individual family members are necessarily interdependent, exerting a continuous and reciprocal influence on one another’ (Cox & Paley, 1997: 246). Something that is at times lost in the IDD sibling research, with its heavy focus on siblings’ outcomes, is the reciprocal influence siblings and family members can have on one another.

According to White and Klein (2002), family systems rests on the following four principles: first, that every element of the family system is interconnected. Second, only by considering the whole family system, can individuals within the family be understood (i.e., a ‘meaningful whole’; Smith-Acuña, 2011: 6). Third, there is ‘feedback’ within the system, or reciprocal effects (i.e., ‘necessarily interdependent…and reciprocal influence’; Cox & Paley, 1997: 246); and last, the theory should be understood merely as a ‘way of knowing’ (White & Klein, 2002: 123) rather than as a reality. In terms of the latter point, reification should be avoided and a family systems perspective should be used heuristically to help us understand families further.

This fuller definition of family systems emphasizes the potential of family systems perspectives to move beyond simple effects that are premised on the assumption that family members will be negatively affected by having a family member with an IDD. This feedback within the system is described by Meltzer and Muir (2021) as a ‘feedback loop [that] can have both intended and unintended consequences, positive and negative effects, and may either spark or block change’. This can, therefore, have important implications for considering how to influence and improve sibling relationships. Meltzer and Muir (2021) go on to describe the concept of a ‘lever’ that creates change within the family system – representing an intervention that breaks an existing feedback loop somewhere within the family system – the change reverberating through the whole family system.

Turnbull and Turnbull (2001) define three main assumptions related to family systems perspectives. First, they describe *inputs and outputs* related to the interactions between family members and the roles the family members perform. Second, they emphasize the *wholeness and subsystems* within the family system. Third, and most distinct from the description provided by White and Klein (2002) is the assumption of *boundaries*. Boundaries are formed by interactions between family members and outside interactions that define, or create norms, for behaviors, roles, and expectations between members of the family, including those outside of the household. Boundary ambiguity occurs when these boundaries are more permeable (Cridland et al., 2014).

This boundary concept may be particularly salient for families of people with IDD, where these boundaries may at times become blurred. More frequent changes in the system, such as in behaviors perceived as challenging or the involvement of external services, may result in some siblings taking on more household tasks or caring responsibilities than would usually be expected (Cridland et al., 2014). Ideally, boundaries within subsystems are flexible, and therefore more able to be influenced, although not determined, by other elements of the family system (Whiteman et al., 2011). This concept of boundaries also has implications for practitioners and researchers. Families vary in how open their boundaries are to outsiders (Turnbull & Turnbull, 2001). For researchers, the data we are able to collect from family members may be defined and restricted by this insider-outsider boundary.

The Sibling Subsystem

Family systems are understood to be structured and organized hierarchically (Smith-Acuña, 2011) with subsystems embedded within the overarching family system ‘that are really systems of their own’ (Cox & Paley, 1997: 245). Subsystems may include the couple/parental subsystem, the parent/child subsystem, and the sibling subsystem – along with subsystems involving extended family members and grandparents (Dallos & Draper, 2015). Only by understanding the subsystems can the wider family system be understood, and *vice versa* as ‘any individual family member is inextricably embedded in the larger family system and can never be fully understood independent of the context of that system’ (Cox & Paley, 1997: 246). Therefore, a focus on siblings and the sibling subsystem has value from a family systems perspective. A focus on the sibling subsystem also highlights the reciprocal nature of the effects. Much of the empirical research about siblings focuses on the outcomes of the non-disabled sibling (Cridland et al., 2014), which conceals the emphasis family systems theory puts on the reciprocal effects, for example, that the non-disabled sibling has on their brother or sister with IDD and their parents. The way in which these different sub-systems interact is complex (Cox & Paley, 1997). Subsystems and dyadic modelling of sibling relationships have been criticized for oversimplifying the complex and overlapping nature of sibling and family dynamics (Sanders, 2004). This complexity comes from the ways in which interfamilial relational pathways are more than simply the association between the different individuals within a family, but also the influence between the relationships and the individuals, as well as the influence of these relationships with other relationships.

To add to this complexity, these influences and dynamics are constantly changing. Therefore, Sanders (2004) calls for us to ‘adopt a position of humility in the face of the immense complexity of this social system called a “family”’ (Sanders, 2004: 33). The inter-related and reciprocal nature of these subsystems is important in understanding the overall family as well as each aspect of it (Cox & Paley, 1997; Cox, 2010). The hierarchical aspect of the way family systems are conceptually organized does emphasize the importance of the parent-child relationship, potentially neglecting other aspects of the system, such as the sibling subsystem (Cox, 2010). Rosenblatt (1994) highlights the root of ‘sub’ as less than or secondary to something else – i.e., the wider family system. If we consider the uniquely long-lasting nature of a sibling relationship, this ‘sub-ness’ may have the effect of minimizing the importance of sibling relationships.

Taken cumulatively, at the sibling dyad level, we must consider not only how each sibling affects the other, but also how the dyad as a whole functions to help us to understand the sibling dyad, and the sibling as an individual. It is worth re-emphasizing that subsystems, as with the overall family system, have ‘heuristic value but no “ontological” reality’ (White & Klein, 2002: 127). It is important, therefore, to draw on theories, or indeed parts of theories, in a pragmatic way, rather than becoming too attached to any one way of seeing the world.

Embedded Systems Thinking

A criticism of family systems perspective is that it can be seen to isolate a family from their wider context and the larger systems in which the family is embedded (Rosenblatt, 1994). However, family systems are open systems (Whiteman et al., 2011) and are, therefore, affected by external influences. General systems theory (i.e., applied beyond the family) acknowledge that systems are not closed, that systems are affected and embedded within other systems. Cridland et al. (2014) explored systems perspectives in relation to families of autistic people. Cridland et al. (2014) divided family systems perspectives into broadly two categories: *macroscopic* approaches and *microscopic* approaches to family systems. Macroscopic approaches consider the way that the family system interacts with other systems external to it, such as schools or community contexts. Microscopic approaches consider within-family factors, such as focusing on subsystem analyses. Both approaches are important in helping us understand the family system, but it is important to also consider the way these factors interrelate (Cridland et al., 2014).

Some work has been done to further incorporate elements from the macrosystem, exosystem, mesosystem as well as microsystem (*cf*. Bronfenbrenner’s ecological model; 1979; and Saxena & Adamsons, 2013 for a sibling-specific application) into a more comprehensive model about siblings of autistic children (*cf* ‘the Siblings Embedded Systems Framework’; Kovshoff et al, 2017). Kovshoff et al’s (2017) approach helps us to consider the multiple, interacting factors at play in understanding the experiences of siblings who have a disabled brother or sister. A full range of factors were incorporated into the framework such as: the influence of peers, school, social media, social class, culture, and ideology. These variables enable us to further our understanding of the wider and more interactive factors related to siblings’ psychological, social, familial, and educational outcomes as well as relationships. In a more practical way, this model helps us to consider what factors (e.g., covariates) we might include in our statistical models. It also highlights the need for analyses that move beyond simple main effects, and to consider how these different factors may interact and overlap with siblings' experiences. Although the 'Siblings Embedded Systems Framework' was about siblings of autistic people, it likely advances our understanding of siblings of people with other disabilities as well, such as ID and other DDs.

Challenges with Conceptualizing Change

Now that we have provided an orientation of each of the theories presented within this chapter, we now consider some critiques and challenges with how these family systems perspectives, indeed how all of these theories, conceptualize change. What is most interesting about family systems perspectives, as highlighted by the four aspects defined by White and Klein above (2002), is the conceptualization of movement and exchange between members of the family. This element of change within the family system highlights the need to move beyond psychological and individualized approaches, to not merely think about the individual elements of the family system, but to consider the ways in which these elements interact with one another (Rosenblatt, 1994). Therefore, family systems perspectives justify exploring sibling relationships as well as considering the outcomes of children with IDD and their siblings as individuals. For Rosenblatt (1994), family systems perspectives have the potential to help us understand families beyond the sum of each part of the system, or each individual family member, but this understanding can only come from also exploring the way each part of the system interacts, such as with sibling dyad-level analyses.

Family systems perspectives might appear to be rather static, and not dynamic enough for social, family research, where change is constant. Some models have been called 'structure and process models' to capture the way in which the family system is unstable (Buckley, 1967). Cox and Paley (1997: 245) apply general systems theory to further capture the dynamic potential of family systems. They describe family systems as having homeostatic features, compensating 'for changing conditions in the environment by making coordinated changes in the internal workings of the system' and having 'the ability of open, living systems to adapt to change in or challenge to the existing system' (Cox & Paley, 1997: 245).

This conceptualization is helpful for understanding families as the changeable and unpredictable entities that they are. Although family systems are described as dynamic, the nature of modelling such an ambivalent and unstable concept as the family may obscures this dynamic aspect. Rosenblatt argues that 'despite the notion of family systems as dynamic, the system metaphor obscures the fluidity of family composition' (Rosenblatt, 1994: 55). This issue may be due to the nature of physically drawing out a family system – the fluidity and dynamic-ness of the system is lost because committing anything to the page makes it somewhat static and permanent. Family relationships, particularly siblings' relationships are very changeable and dynamic. Any theory attempting to model 'the family' as a complex psychosocial construct will inevitably oversimplify the concept.

Inadvertently, therefore, any statistical analysis or modelling of questions related to sibling relationships or experiences will over-simplify them. This over-simplification is not just a matter related to quantitative research and family systems perspectives; it arguably permeates all social research. For Rosenblatt (1994), this is described as:

> '…fluidity arising from the multiple ways in which the reality of the moment can be perceived and characterized. Yes, the system is dynamic, but perhaps what seems like dynamics arise in part from our limited capacity to know or make sense of what is going on at any given moment' (Rosenblatt, 1994: 55).

Family systems perspectives, as understood here by Rosenblatt, can be seen as not just a tool to model and contextualize families' outcomes and experiences, but also as an epistemological framework to consider the limitations of conducting sibling and family research. This issue is not, however, a problem only for family systems perspectives. This limit in our 'capacity to know' (*Ibid.)* permeates all social research. Family systems perspectives are, therefore, useful for precisely the reason that they are limited. By defining, simplifying and essentializing a process, we can never adequately capture the phenomenon itself. In this way, these issues mirror the research process – whereby we collect specific data from our participants at specific points in time, cognizant that the moment we do, and certainly by the time we begin our analyses, their perceptions about their experiences and outcomes would have changed and, therefore, our interpretations of their perceptions are already outdated. These problems are not to say that our data and findings are not useful and valuable, but that any dissatisfaction with one theory, or one broad methodological approach (i.e., quantitative *vs.* qualitative research) can surely be levelled at the other. We need to adopt a flexible and pragmatic approach to the theories, methods, and approaches that we use.

A common question asked about a family systems approach is the extent to which it is a ‘theory’ or whether it is a ‘model’ (White & Klein, 2002). Systems thinking can be used as an overarching theory to consider siblings as the subject of research attention and potentially as recipients of supports and interventions, because we could use family systems to explain that siblings may experience different outcomes, such as being at risk of worse outcomes, because they have a brother or sister with IDD. These perspectives can help us explain, conceptualize and interpret our research in broad ways. However, no theory or model can fully capture the reality of socialized experiences – and so we will always question to what extent a social hypothesis is testable. Whenever any social idea is thought, spoken, modelled or written about, something is lost, the idea or model almost fossilizes. The idea entombs reality, and the reality ceases to exist. A more important question is: is the idea *useful*? Does it help us understand phenomena further? Does it resonate across families? Does it help us conceptualize and design our research better? Is it dynamic enough to account for differences and changes both within and between families? Does the concept help us to support and improve the lives of the people and the families we work with? A family systems perspective may not be a particularly beautiful concept, but it is useful. Another criticism of a family systems perspective is that it is so broad and general that it is meaningless (White & Klein, 2002). However, its generality provides its flexibility and therein lies its utility for researchers.

Rhizomatic thinking, family systems, and change

We have discussed to this point a dissatisfaction with the way that family systems thinking deals with change, and concerns about how the fixed nature of these models may lead us to over-simplify the complexities inherent in family studies. The metaphor of a family system suggests that the system is finished or complete. Deleuze and Guattari’s theory of becoming is so useful in the context of a model of a family system because it highlights that it is not just that the family is always changing – it is that it is never complete – it is never fixed, it is never done. We are called to not 'be one or multiple, be multiplicities!' (Deleuze & Guattari, 2013: 26). Rhizomatic thinking highlights that there are multiple realities and experiences happening simultaneously when we examine families. Despite a critique of family systems perspectives and the modelling of these approaches we can acknowledge that it is fundamentally a representation and not the reality – with pragmatic value to family studies.

From Social Learning to Family Systems

As mentioned, it is noteworthy that in the wider sibling literature, social learning theory is the most commonly applied theory (Feinberg et al., 2012; Whiteman et al., 2011), and it is valuable to question why this model is underutilized in the IDD sibling literature. One reason may be that sibling IDD researchers have, in the past, assumed a negative, one-sided, and non-reciprocal narrative about siblings of children with IDD. Reciprocity is the essential premise of social learning theory, whereas for family systems perspectives, it is one component of an overall concept. Social reciprocity considers the ways in which siblings learn and develop from one another, acquiring behaviors, attitudes, and beliefs (Whiteman et al., 2011). Evidently, a family systems perspective also allows for this sort of modelling through the assumption of reciprocity. It is important, therefore, that the examination of bidirectional and reciprocal effects inherent in family systems theories are not lost in IDD sibling research. An issue with the way in which a family systems perspective has often been applied in the IDD literature is that it has been arguably used to justify a more negative narrative about siblings' outcomes and experiences. This negative narrative is illustrated in the psychological outcomes literature about siblings, whereby the design and conceptualization of these studies rest on the assumption that the sibling is the target and receiver of research attention due to the effect we assume having a brother or sister with IDD may have on the sibling. We have seen a shift in recent years, especially amongst qualitative studies, to focus on more positive aspects of siblings' experiences. An increase in studies examining sibling relationships, rather than sibling outcomes, have also supported this shift towards a focus on positive factors. Hastings (2016) argues there is a case for rejecting the negative narrative often premised in IDD family research more widely. Hastings selected empirical data about families of children with IDD to highlight that families do not universally experience ‘negative’ outcomes, and some studies indicate ‘positive’ outcomes for families. Hastings (2016) suggests that further systems-based analyses and questions may provide an appropriate framework for disrupting the negative narrative about families of people with IDD, such as by exploring reciprocal effects, rather than focusing on the one-way effect that the person with IDD has on each family member. It is also important to emphasize, that despite these conceptual ‘negative narrative’ problems, the study of psychological outcomes and sibling supports is still important, given that population level data suggests that some siblings of people with IDD are at risk of slightly worse psychological outcomes compared to siblings of people without IDD (Hayden et al., 2019a; Marquis et al., 2019; Rai et al., 2018; Stark et al., 2022). Overall, a deeper overview of family systems perspectives is, therefore, necessary to understand how it can help us re-conceptualize families and sibling dyads.

Summary of Theoretical Approaches

In summary, social learning theory considers the way that siblings learn from their social environments, with siblings potentially developing behaviors and characteristics from one another. This reciprocal emphasis inherent in social learning theory is neglected somewhat by IDD sibling researchers, who tend to favor family systems perspectives. Family systems perspectives have commonly been used in IDD sibling research as a legitimizing tool for focusing on siblings, by suggesting that the person with IDD may be having some sort of ‘negative’ effect on the sibling. This focus on the psychological outcomes of siblings is still an important issue to understand, but sibling research must move beyond these types of assumptions as well. As explored in this section, family systems perspectives also enable us to conceptualize more interesting questions than these direct effects, such as reciprocal effects at the sibling dyad level. Embedded models and models that explore effects outside of the family system help us consider which variables to include in our analyses and reinforce how vast and unknowable individual and family experiences are. They help us consider that communities external to the family system (e.g., schools; Hayden et al., 2019b) may be associated with siblings' outcomes and relationships.

The Double ABCX model helps us understand family stress and resilience when a child in the family has an IDD, further mapping variables we could include in our models, such as the effect of socio-economic factors. It also encourages us to move beyond direct effects where possible by, for example, exploring moderating effects. The lifespan and developmental perspective briefly introduced, highlighted the importance of understanding change and transition, but also justifies exploring the outcomes of child and adult siblings as interconnected rather than as separate entities. Although the concept of time is often included in all of these models, this element of change within the family system also highlights an issue with these models and research generally, and that is the transient and heuristic nature of capturing any perspective, about a theory or model, or indeed data from a research participant. Foucault's ideas help us consider the relationship between the power and the state, which has important political implications. Rhizomatic thought helps us to consider sibling dyads and families as the complex social entities that they are. The second part of this chapter considers the empirical and research implications of the theories that we have discussed in the first part of this chapter.

Theoretical Implications

Methodological Implications

How we conceptualize our research topics can be reinforced, challenged, and driven by theoretical frameworks. At the earliest stages of research design, we can see how our research questions and earliest design decisions are saturated in theoretical conceptualizations, whether acknowledged or not. For example, the concept of reciprocity in the sibling relationship which is inherent in social learning theory and embedded in family systems perspectives may encourage us to include a stronger focus on sibling relationships in our research, as opposed to a more traditional focus on siblings' psychological outcomes or siblings' caregiving potential. Applying this assumption of reciprocity in the sibling relationship alongside a critical disability lens, we may be drawn to ensure that we include the perspectives of not only the sibling without an IDD, but also the perspective of their brother or sister with IDD. The methodological challenges associated with including people with ID in our research in meaningful ways (particularly people with moderate-severe-profound ID) require innovative yet pragmatic approaches, illustrating how theoretical approaches (or the absence of them) drive our methodological decisions throughout the research process. This section will, therefore, examine these methodological implications of the theories that we have discussed in more detail, particularly focusing on epistemological, reflexive, ethical, and analytical implications of the theories just discussed.

Epistemological Implications

There is a sense that rhizomatic thinking in this field of study can help us in two main ways. First empirically, for us to conceptualize the complex experiences such as family relationships and the experiences of disabled people and their siblings. Second, epistemologically, for us to consider the complexities of the social world and the challenges we face researching it. Rhizomatic thinking can also help us to consider theory and social research. Deleuze and Guattari question if it is possible to know the world, and even if it is, is this knowledge transmissible? They resist the concept of a fixed or absolute truth, a knowing subject or an overly simplistic representation (Mansfield, 2000).

Their ideas consider multiplicities, dynamic interconnectedness, pluralities, and resist fixed-ness. Rhizomatic thought is non-hierarchical, it resists categorization and binary thinking. Rhizomatic thinking can, therefore, help us to adopt more interpretivist ways of understanding in our research, that does not assume that our work is knowable. Interpretivism lends itself more naturally to qualitative methodologies. However, there is something to be learnt about interpretivist epistemologies from a quantitative perspective; that is, it encourages us to consider more complex models to match complex social questions, and to apply more tentative interpretations of quantitative analyses. For example, conducting structural equation modelling analyses involves an initial confirmatory factor analysis, whereby researchers test that the items on a social construct adequately measure the immeasurable construct (i.e., a latent construct/variable). Latent constructs, therefore, acknowledges that certain social constructs (e.g., relationship quality, mental wellbeing) are not objective and fixed truths. We could, and perhaps we ought to, take this thinking further, and argue that all variables in social research are socially constructed and subjective. This must have consequences for how we interpret quantitative research, and these consequences bring into sharp focus how limited and overly simplified the research in our field so often is. These criticisms are of course also relevant to qualitative research, but qualitative researchers tend to have a heightened awareness of these limitations.

Acknowledging the unknowable nature of our research is relevant to all research, but it is important to emphasize in sibling IDD research. Sibling IDD researchers are primarily positioned in the psychological sciences, particularly applied psychology studies. There is a tendency amongst this group of researchers to place epistemological and ontological matters to one side and concentrate more on empirical, practical, and pragmatic matters – that have real world impact in the lives of people with IDD and their families. This undoubtedly has value, but researchers must also consider epistemological matters in order to understand the complex nature of sibling and family research. We hope to have persuaded our readership throughout this chapter that sibling and family research are complex, dynamic, ever-changing entities. Only by considering epistemological questions can this be fully highlighted, and we believe that family theories can help support this reflection. For example, family systems perspectives highlight the insider-outsider boundary that make learning about siblings' experiences somewhat unknowable. There are things that siblings will say to one another, and then there are things that siblings will say to non-siblings. This boundary is relevant, because it raises important epistemological issues in our research. What is sayable and unsayable within these research exchanges? What will our participants share with us, and what are they not telling us? What are the implications of these gaps in our knowledge? What participants are willing to share is an issue in all social research, but within IDD family research the implications are particularly complex, compared to other social sciences research, because we are including people in our research by merit of their relationship with another person, of whom our participants are protective. The problematic nature of our work is exacerbated by our social context, so often emulated in our research, which excludes and marginalizes people with IDD.

Siblings and Family Theory

Family systems theories highlight the homeostatic nature of a family system, adapting to changes and challenges within other parts of the system. Although these family theories are often described as dynamic, the transient and heuristic nature of capturing any perspective – about a theory, model, or from a research participant – ultimately reinforces how vast and unknowable individual and family experiences are. How we conceptualize change and ‘dynamicness’ when theorizing siblings and families is difficult, and all the theories we have discussed attempt to deal with this process. From an epistemological perspective, this conceptualization of change highlights a problem in wider social research that it is impossible to understand such non-permeant and static concepts such as families, and that we have a ‘limited capacity to know’ (Rosenblatt, 1994: 55). The data or the narratives provided to us by research participants are always transitory and partial (at best) in nature: ‘We want to believe that the purpose of our dealing with things is to find their fixed essential nature, to turn it into knowledge so that we will be free to move on to the next analysis’ (Mansfield, 2000: 139-140). As highlighted by White and Klein (2002), family systems perspectives are a way of knowing rather than a reality.

Reflexivity and Positionality Implications

Family theories have utility as a self-reflexive tool to consider researcher positionality. Reflexivity describes a process whereby researchers reflect on how their assumptions, biases, approaches and presence will affect their research, calling for us to interrogate hierarchies and power imbalances within our research (Potter & Hepburn, 2012). Self-reflexivity is defined as a process whereby we as researchers ‘critically interrogate ourselves and one another regarding the ways in which research efforts are shaped and staged around the binaries, contradictions, and paradoxes that form our own lives’ (Lincoln & Guba, 2003: 283). Therefore, it is an important process for all researchers, although it is more often explicitly explored by people with personal experience of the subject matter, and qualitative researchers.

Researchers who are siblings themselves or who have a personal experience of the subject they are studying, can be seen as research ‘insiders’ (Hodkinson, 2006). Insider researcher status does afford certain benefits, such as being able to design and analyze research from perhaps a closer perspective, and it may help researchers to build trust and rapport with participants. This 'insider' position also carries risks related to allowing researchers' own experiences and 'un-elucidated prejudices [to] dominate' (Finlay, 2003: 108) the research process. Therefore, self-reflexivity is a fundamental part of social research, particularly for those that have some sort of 'insider' status. As emphasized by Griffiths (1998), we are only ever partial, relative insiders. Family systems perspectives emphasize the insider-outsider boundary in family systems. Researchers must, therefore navigate, respect, and ultimately accept this boundary when researching families and siblings that are not their own. Even when we have experience and knowledge of a given population, such as siblings of people with IDD, whether through personal relationships and shared identities or through years of academic study and research, we cannot pretend to fully understand and share other people's familial experiences.

It is important that as sibling researchers that we do several things. Researchers should adopt self-reflexive processes. Self-reflexivity is important whether or not the researcher has a personal connection to the subject matter. We live in a disablist society and so it is unimaginable that someone with no personal connection or relationship with someone with IDD has not absorbed some of these disablist assumptions. It is, therefore, fundamental that all sibling/IDD researchers engage with this process, irrespective of their personal relationship with the subject matter. Foucault highlights that, as social science researchers, we are producers of knowledge in a system of power which is fundamentally disablist – and we must reflect on what our role in this power system means. This responsibility also applies to anyone who gathers data, such as teachers, clinicians, charities or non-governmental organizations, and governments. Self-reflexive practices should be applied to quantitative research methodologies as well as qualitative research methodologies. Self-reflexive practices are seen as essential in qualitative research, yet it is less often included as a practice in quantitative social science research. This tendency is perhaps why we see a fewer explicit mentions of self-reflexivity practices by researchers in the sibling field (as it is predominately a psychological and quantitative field). There is always a risk in research that we find what we choose to find, and we interpret and write in such a way to say what we want to about the world. Engaging meaningfully with self-reflexive practices enables researchers to make the implicit explicit.

Overall, self-reflexivity and the consideration of positionality is an important practice for all researchers. We have presented a ‘Morton’s Fork’ in relation to this practice: Either a researcher has personal experience of the subject nature (e.g., the researcher is autistic, or a sibling, or a parent etc.) and therefore needs to interrogate how their own personal experiences and assumptions may impact the research process; or the researcher does not have a personal connection to IDD, and their earliest assumptions about disabled people have been socially constructed in a disablist society. Therefore, it is particularly important that all IDD researchers engage with self-reflexive and positionality practices in order to challenge this disablism. Before we move onto consider ethical implications, it is worth highlighting that there are ethical issues related to insider research. For example, there are issues related to researchers with familial experience of IDD being unable to anonymize themselves, and by extension, their families. There are also ethical issues related to using insider-status as an ‘authority move’ (Chapman Hoult, 2012) and to use shared identity with participants, and the trust that can build, to coax participants to share more than they otherwise would (Griffiths, 1998).

Ethical Implications

Along with the ethical issues highlighted in relation to being an insider, it is important to note that there are ethical issues related to the very nature of sibling research. That is, when researching siblings, there is almost always some element of reporting on someone that has not consented (or assented) to take part in the research (i.e., their brother or sister with IDD). Even when this data collection is done in a very light-touch way, such as by asking a sibling to confirm that their brother or sister has an IDD or to specify which IDD they have, this is significant, personal information. The focus on the sibling sub-system in family systems perspectives would encourage us to include both siblings in the research, and this is one way to attempt to tackle some of the ethical issues with only asking one sibling about their relationship and their experiences. Studies involving both siblings’ perspectives are still quite rare, however, and direct data (rather than observation data) have tended to only include siblings and their brothers and sisters with mild ID, or autism and no ID. Researchers need to develop innovative methodologies to include people with moderate-severe ID in research. Including the perspectives of people with ID with more moderate-severe ID produces considerable challenges and is a methodological and practical priority across IDD research. Observation studies, where a researcher observes how a sibling and their brother or sister with IDD interact, can provide useful information about the lives and experiences of people with IDD and their siblings. However, it does not allow the person with IDD to provide their own views and interpretation of the sibling relationship. This inequality is often exasperated by the way in which these studies tend to then go on and interview a parent or a non-disabled sibling – and these data can then overshadow the observation study, further marginalizing the experiences of the person with IDD. These studies again, have value for helping us to understand sibling experiences and the lives of people with IDD, but we must push the methodological boundary about how we support people with IDD to share their own life experiences and views on their relationships. There already exists a range of Augmented and Alternative Communication (AAC) strategies that various people with IDD use in their day-to-day lives. Researchers should attend relevant training in order to be able to administer these AAC techniques and incorporate them in their research methodologies. Researchers should also collaborate with speech and language therapists who are expert in AAC in order to further enhance these studies, pushing the boundaries regarding who we can interview about their experiences beyond people with milder forms of ID, and including people with moderate-severe ID.

This focus on relationships and dyads supported by family systems perspectives can help us to overcome some of the fundamental ethical difficulties with sibling IDD research. If we consider sibling studies from the perspective of the individual with IDD, it rests on a negative assumption (Hastings, 2016) that having a brother or sister with IDD may be a risk factor for worse outcomes for family members. There is also an argument to be made that it positions people with IDD as dependent on their siblings for support and care, and this fails to acknowledge the reciprocal potential of siblings' relationships. Sibling research has been considered as 'perhaps being in itself disablist in its orientation' (Sanders, 2004: 127) as it can be seen as marginalizing the disabled sibling whilst centering the non-disabled sibling. Sanders (2004) suggests that to understand the effect on a non-disabled sibling, you would not just need to compare dyads of sibling pairs where one has a disability, with sibling pairs where neither has a disability, but also compare sibling dyads where both are disabled. Therefore, analyses should be conducted on sibling dyads where both have an IDD as well as those where only one has an IDD.

Embedded systems perspectives emphasize the importance of factors such as socio-economic status, religion, culture and ideology. Sibling and family IDD research is predominately conducted with Global North samples, and these studies disproportionately sample white, middle class, women. There are significant ethical problems with using unrepresentative sibling data to inform interventions and supports for all siblings. Where possible, large-scale, nationally representative data should be drawn upon to understand siblings of people with IDD. Such data benefit from advanced sampling and stratifying techniques that ensure the datasets are representative of a population. Nationally representative datasets are limited, however, in that their existence is finite and that the measures are pre-defined for a broader purpose. Therefore, there is a need to still draw upon non-representative large-scale survey data to be able to examine more nuanced research questions relevant to families of people with IDD.

The question then becomes: how do we ensure that these samples are more representative? Sibling IDD research, and indeed social research more generally, consistently fails to recruit participants from marginalized communities. As researchers, we must find ways of effectively and meaningfully working with people that we have, inadvertently, excluded from our research. There have been only a handful of studies that have provided data specifically about Black and Asian siblings in the USA (Sonik et al., 2016, Richardson & Stoneman, 2019, Sage & Jegatheesan, 2010, Jegatheesan & Witz, 2013), and we have identified no comparable studies focusing on the experiences of siblings from ethnic minority groups in the UK. There have been cultural comparative studies, such as comparing the experiences and psychosocial adjustment of siblings of autistic children in the UK and Taiwan (Tsai et al., 2016; Tsai et al., 2018) and studies about siblings living in the global South (e.g., India; Dickinson, 2020). Studies such as these are important for understanding how sibling experiences and outcomes may differ based on socio-cultural factors. Future research should seek to both make general sibling samples more representative in terms of ethnicity and religion, but also specific studies should be conducted to understand the experiences of Black, Asian, and where geographically applicable, Indigenous siblings' experiences in Western contexts, as well as the experiences of siblings in non-Western countries.

The Double ABCX model also highlights the importance of understanding the experiences of groups that are under-represented in sibling studies. This focus is important, because experiencing socio-economic deprivation or experiencing being an ethnic minority in a racist society, could contribute to a pile up of stressors for siblings. For example, poverty is a highly stressful experience. Broader population-based data tell us that having lower socio-economic status and experiencing deprivation is a consistent and considerable risk factor for worse outcomes, such as being more likely to have mental health disorders (Skapinakis et al., 2006), health conditions such as type 2 diabetes (Connolly et al., 2000) as well as engaging with behavioral risk factors related to poorer health, such as smoking more and eating fewer fruits and vegetables (Lakshman et al., 2011). These structural factors related to the pile up of stressors could be better understood by a consideration of Crenshaw's (1989) theory of intersectionality. Intersectionality theorizes the way in which people's identities – such as race and gender, social class, sexuality, and disability – can intersect in a way that affords certain advantages or disadvantages, resulting in privilege and/or discrimination. Although the Double ABCX model tends to view the pile up of stressors as internal to the family, intersectionality emphasizes the psychosocial nature of the experiences of families.

Recruiting representative samples is a problem across social research and there are no evidence-based solutions for how we overcome these sampling issues yet. There may be some practical steps that researchers could take to recruit more representative samples, such as working with non-governmental disability organizations that represent specific ethnic, cultural, or religious groups, or that provide funds for families of disabled children experiencing poverty. Ideally, researchers should include third sector collaborator costs (i.e., honoraria) in funding bids to support this work. Small-scale qualitative studies should be co-designed and undertaken specifically with under-represented groups in sibling IDD research, with researchers reporting not only on empirical findings, but also on methodological matters related to sampling and participant engagement. For large-scale quantitative studies, researchers should consider whether sampling methodologies, such as weighting data to be representative of a given population, may be appropriate. There are more medium- and long- term considerations too, such as supporting and/or mentoring early career researchers and colleagues who are under-represented in academia (e.g., Black academics, working-class academics). This representativeness is important, as potential participants may be more likely to respond to a researcher who shares identity characteristics with them. Importantly, we must acknowledge that the onus and responsibility for recruiting representative samples in our research remains with us.

Analytical Implications

For statistical analyses, a theoretical approach is important for developing analytical models and selecting variables. For qualitative research, theoretical assumptions and approaches often drive our codes, categories, and theme generation (whether or not we are self-aware about it). For all empirical research, the theories we rely upon will help us to understand and interpret our findings. It is important to be cognizant of the ways in which the analytical process is not confined to the time between data-collection and study write-up. We make analytical decisions when we design a study and select our research questions, and we begin to see patterns and form judgments whilst we are collecting data.

For qualitative research in particular, where data collection and capture is more flexible, these analytical thought processes will affect what researchers focus on next in an observation study, or what researchers ask next in a semi-structured interview or focus group. Qualitative researchers are usually self-aware about their involvement in the analytical process, often drawing on self-reflexive techniques as already discussed. However, quantitative researchers are also active participants in the analytical process, making countless decisions that impact the outcomes of the research. These influences do not simply disappear when analyses are pre-registered; though this advance in transparency is welcomed. Quantitative researchers select which variables to include and decide how to construct their statistical models. They decide whether and how to transform data, what constitutes an outlier, and whether to remove or use computation methods to manipulate outliers. How we conceptualize our work has direct implications for how we build our analytical models, ultimately driving our findings.

There are significant challenges in analyzing complex psychosocial experiences such as the family. Analytical models will always over-simplify these complexities, whilst simultaneously helping us to understand and support families and siblings. The theories discussed in this chapter can help us develop and justify these analytical models. For example, focusing on bidirectional effects within the sibling sub-system is supported by family systems perspectives (Cebula et al., 2019) and social learning models. Family systems perspectives can also help to justify analyses that focus on interfamilial relational pathways (e.g., triadic analyses of parent, child with ID, and sibling; Williams et al., 2022). Analyses that focus on within family factors, or even at the dyad-level, have value for helping us to understand the experiences of siblings and families of people with IDD. We are also interested in understanding how the family system is affected by wider systems. Embedded systems perspectives help us to consider how siblings and families interact with the world in which they are embedded. From an analytical perspective, and a research-design perspective, this theory can help us to decide which covariates, mediators, and moderators to include in our models. The Siblings Embedded Systems Framework (Kovshoff et al., 2017) supports the inclusion of within-sibling factors, such as gender, as well as social factors in the macrosystem, such as wealth and social class. Systems perspectives help us to ask more interesting questions that consider how these factors interrelate and interact. Family systems perspectives also encourage us to move beyond analyses examining simple main effects, and to consider indirect effects. The Double ABCX model also supports exploring family resources (bB) and the pile up of stressors (aA) that may exist if families of people with IDD are also experiencing material deprivation, or a parent is experiencing mental distress. The Double ABCX model can help us conceptualize covariates, mediating variables, and moderating variables, supporting us to move beyond direct effects and consider more complex analytical models that better help us to conceptualize families.

It is important that sibling research includes adult sibling studies as well as child sibling studies. Aside from the obvious statement that all adults were once children, there are theoretical reasons for this. Developmental and lifespan perspectives consider the ways in which families change over time, including changing family positions, roles, and norms. We may expect to see over the life course, that the role non-disabled siblings have in the lives of their brothers and sisters with IDD will change over time. We may expect that many young adult siblings move out of the family home and have a more independent life whilst their parents are still able to care for their brothers and sisters with IDD.

Over time, and as parents age, siblings may increasingly take over aspects of care for their brothers and sisters with IDD. Lifespan and Developmental perspectives, therefore, support examining not only how the family system changes over time, which would require longitudinal data and analyses, but also key transitions in siblings' lives (e.g., moving out or going to university, key career decisions, marriage, having children). These key transitions and life moments could all be considered stressors. Reading stress models and lifespan and developmental perspectives together would provide further support for studying these key transitions in siblings' lives.

Although many child siblings provide informal care for their brothers and sisters with IDD (often referred to as 'young carers' in the literature and support field), adult siblings are more likely to take on a more formal care role than child siblings. Therefore, fluctuations in caring levels would also be an important focus of study from a developmental perspective. The focus on change over time highlighted by all of the theories described in this chapter, also support longitudinal data collection and analysis. Longitudinal analyses are important to understand how siblings' experiences change over time, but they are also required for methodological robustness, to confirm the direction of analytical pathways (or causality).

Post-structuralist ideas are more naturally applied to qualitative analyses, as the theories are interpretivist at a fundamental level. These ways of seeing can also be useful for quantitative analyses. As explained, rhizomatic ways of thinking enable a conceptualization of families that allows for change and are flexible, and non-hierarchical. This non-hierarchical approach can help us to consider whole-family analyses that do not conceptualize the sibling dyad as a subordinate dyad to the parent-child dyad. Fundamentally it can help us understand the limitations and critique our statistical analyses, aiding interpretation. It reminds us how over-simplified and artificial our analytical models are. The post-structuralist ideas we discussed also ask that we resist binary thinking. We have seen this binary notion resisted in the sibling carer literature, with Lee et al., (2018) for example calling for us to see caring as a continuum rather than a binary activity. Overall, there are multiple, interacting, reciprocal factors that could explain siblings' experiences. Applying theoretical models to the way we design studies, build analytical models, and then interpret our findings are important tools for us to ask better questions and apply more nuanced statistical techniques to examine the outcomes and experiences of siblings.

Empirical Implications

Clinical Implications

A great deal of the sibling IDD research has focused on psychological outcomes. This focus would be resisted by the post-structuralist theories discussed. For example, Foucault's ideas would encourage us to resist the over-pathologization of siblings and their families, including their disabled brothers and sisters. Rather than focusing on the sibling as an individual, potentially a family-systems based intervention would be appropriate, whereby the whole family are involved in an intervention. There is evidence that there is an association between the behavioral and emotional outcomes of siblings with their brothers and sisters with IDD (Cebula et al., 2019). This finding indicates that it is important to include the disabled sibling in an intervention and to consider fostering family relationships, and not merely focusing attention on individual family members' psychological outcomes. Family systems perspectives can, therefore, support a different way of positioning clinical interventions for people with IDD and their families, with a focus on bidirectional effects, in line with systems thinking.

Hastings (2016) argued that more systems-based questions and analyses would support a rejection of a negative narrative in family IDD research. Family systems perspectives can be used both to advance a negative narrative if used over-simplistically, as well as to disrupt it, particularly when focusing on the reciprocal effects siblings can have on one another. We need to avoid pathological assumptions about siblings' outcomes, because it is disablist at a fundamental level. However, there are robust population level data (Hayden et al., 2019a; Marquis et al., 2019; Rai et al., 2018; Stark et al., 2022) that indicate that there are a small group of siblings that may well be at risk of worse psychological outcomes. Therefore, we cannot ignore that some siblings experience poorer psychological outcomes and need support. If some siblings are experiencing poor outcomes, this appears to be because of indirect factors, and systems-based thinking can help us to model future analyses to ensure the complexities and intricacies of siblings' experiences are fully realized by our data in the questions that we ask.

Applying the stress models discussed to consider clinical implications for siblings might suggest that we focus on developing therapies or interventions that would help families rethink their roles and shift their perspective on their situation (i.e., cC – the changes families make to their interpretation of the situation or stressor). Existing therapies related to mindfulness and acceptance (e.g., mindfulness interventions, Flynn et al., 2020; Acceptance and Commitment Therapy, Lunsky et al., 2018) may therefore have utility for siblings and families of people with IDD. These stress models are also associated with theories of resilience, which could be an important dimension for both potential family systems-based interventions and interventions that focus on siblings' interpretations of their experiences and roles.

Overall, clinical and pathological approaches may not be appropriate interventions for supporting siblings generally, and focusing on 'fixing' siblings, when most siblings are doing well, is not appropriate. This pivot is needed because pathological approaches to sibling studies is highly individualistic and ignores some of the structural reasons why some siblings may need support, such as indirect factors related to socio-economic disadvantage, as informed by family systems and stress theories. Furthermore, advancing a negative narrative, a pathological narrative, or an overly deterministic narrative about the outcomes of siblings, and seeing them as individuals that need 'fixing' stigmatizes disability and mental health problems. Some siblings will experience psychological problems and receive clinical diagnoses for mental health problems, and these siblings are likely to receive psychological and/or psychiatric support through medication and/or talking therapies. Therefore, clinical support ought to be more needs-led (or targeted) for some siblings, as their needs for support may not be directly related to having a brother or sister with an IDD.

Practice Implications

There are various practice-based implications related to the theories discussed. Theoretical models, along with empirical findings, can drive the development of interventions and support models. These theoretical approaches might be used to guide and provide direction for supports by researchers, charities and non-profit organizations, grassroots community groups, and schools. We can conceptualize an intervention using the Double ABCX model, whereby an intervention becomes a resource that siblings can apply to the situation (bB), it could help siblings interpret their situation (cC) and could help siblings adapt to their situation (xX).

In IDD research and in practice, particularly in family and sibling research in practice, we have a tendency to focus on immediate issues and needs of individuals, without thinking about the wider societal problems that allow these issues to exist. As emphasized by embedded systems perspectives and ecological approaches to family systems perspectives, it is important not to see the experiences of the sibling and family as isolated experiences. This shift in focus has been heavily emphasized by current events at a global level at the macrosystem level. For example, globally, people with IDD and families generally are still being affected by austerity measures and a reduction in state welfare brought about by the 2008 global financial crisis. More recently, the effects of the COVID-19 pandemic have been devastating for people with IDD and their families; although again it is important to acknowledge that not all IDD family research findings are consistent with an overall negative pandemic effect (e.g., Bailey et al., 2021). At an intervention level, ecological approaches and embedded systems perspectives would encourage us to consider more how these structural and global problems are affecting siblings, and what we can do to support them. We can also see how, from a lifespan and developmental theoretical perspective, we would perhaps position the COVID-19 pandemic as a key transition or life phase, which is likely to hold an ongoing significance. It is also a time when many siblings and many people with IDD ‘skilled-up’ in terms of being able to use and engage (and be supported with) using video conferencing software. This increase in technological skills has, and will continue, to provide opportunities for practical support that can be delivered online to a wider range of people. However, some families living in poverty may not have regular, private access to the internet, and so these types of support may exclude the most vulnerable siblings.

Potentially, part of sibling support may involve campaigning at a political and structural level to reduce poverty and enhance state welfare for all people. It is justifiable for sibling support to include working to enhance the lives of disabled people, given that population-level data indicates families of people with ID experience more socioeconomic deprivation (Emerson, 2003; Emerson, 2004) and from a family systems perspective, the outcomes and experiences of disabled people affect their families, including siblings. Practice-based organizations supporting siblings may decide to dedicate some resources to collaborate with other disability-related organisations to campaign at a more structural and political level to enhance the lives of disabled people and their families as well as to continue supporting siblings in a practical and focused way. Therefore, we can see how on a practical level, these theoretical models would encourage us to support siblings beyond the individualized level and consider how we could enact change at a more structural level.

Realistically, however, limitations in funding and resources for siblings will result in siblings continuing to be supported in an *ad hoc* way. These supports should involve a multi-level and co-ordinated approach to sibling support rather than a scattergun approach. Deciding on what and who these interventions or supports should focus on, should be supported by robust research evidence, and also should make theoretical sense. For example, large-scale data suggest that poverty and experiencing socio-economic deprivation are associated with siblings' psychological outcomes (Hayden et al., 2019a; Hayden et al., 2022). Focusing on poverty and socio-economic deprivation is also emphasized and explained by some of the theoretical models discussed in this chapter. As explained, embedded systems would consider the macro effects of poverty and socio-economic status on the lives of siblings and families. The Double ABCX model would also help us to understand how experiencing socio-economic deprivation could contribute to the pile up of stressors experienced by siblings and families (aA), how families having more financial resources may be protective, and how interventions that provide siblings and families with more financial resources (bB) can add to their resources to improve their outcomes (xX). Benefits and state welfare provision should be sufficient so that individuals and families do not experience poverty. Services that can help siblings and families to navigate a convoluted and penurious systems (of supports in various forms) are valuable. The model can also help us to consider how these different variables or experiences interact, for example, it could help us to theorize how siblings' outcomes may be mediated or moderated by socio-economic status. Therefore, we can see here how empirical findings can be understood and explained in order to consider how the information may be used in a practical sense to support siblings.

Political Implications

There is a tendency to focus on more clinical and practical implications of sibling research. Given the structural and social factors driving the outcomes and experiences of siblings, families, and disabled people, it is important to consider the political implications of these theoretical approaches in sibling research. The Siblings Embedded Systems Framework explicitly considers political implications (both with a small 'p' and a big 'p'). On the macrosystem level the model includes political structures and legislation. The model also includes wealth and social class. Poverty is fundamentally a political decision. As already emphasized, poverty is an important factor to consider, given that socioeconomic factors are a consistent predictor of sibling outcomes (and the outcomes of all children and adults). The cultural and ideological factors influencing attitudes to disability and parenting at the macro level of the embedded system could also be seen as political if we consider politics with a small 'p' that may focus more on changing attitudes and behavior on a more individual level. At the ecosystem level of the Siblings Embedded Systems Framework, the model includes local political and social structures, as well as formal and informal social support for parents. It is often at the local government level that decisions are made about adult social care and child schooling support for disabled people. If we apply the Double ABCX model to the Siblings Embedded Systems Framework, we can see how this is an important place where resources can be added (bB) and stressors reduced (aA). The demographic factors at the within-sibling level of the framework can also have important political implications if we were to consider identity politics, whereby individuals' political approaches or agendas are informed by their demographic identities, such as race, religion, disability, gender, or socio-economic background.

Siblings and Family Theory

Some of the theories we have discussed, such as family systems theory and the Double ABCX model, can fall into an individualistic narrative. We are using the concept of individualism as an antithesis to anti-community or anti-society discourse and policies, not its literal conceptualization of a single person being self-sufficient or insular. Therefore, we see a focus on the immediate, nuclear family (as opposed to government and community support) as the main source of support for a disabled person as individualistic. For example, the C in the Double ABCX model is about how families interpret their reality. Families can be seen to 'fail' to be resilient. It places the responsibility on individual disabled people and their families, when arguably, the root problem is social if we consider the social model of disability, and the unequal, disablist, and capitalistic, nature of society that undervalues disabled people, and their carers. Future research should consider the potential of sociological theories to explore sibling IDD research in more critical ways and to resist negative narratives that may be inadvertently disablist, or by positioning siblings as only valuable as potential sources of free labour.

Foucault's power-knowledge paradigm provides a satisfying conceptualization of the relationship between the family and the state. Encouraging siblings and parents to take on care roles reduces state dependence, maintaining the capitalist state's resources. Therefore, we must seek to understand what role siblings have, or could have, in challenging and resisting the lack of appropriate supports for people with IDD and their carers. Siblings have the potential to be important allies and advocates for their brothers and sisters with IDD, challenging normalcy and disablism in their everyday relationships and associations, as well as at the level of campaigning at the local, national, and even international level. Applied psychology researchers must also work to resist and challenge these political issues. We must consider how our research can be used for positive social change and to influence policy, rather than primarily focusing on how we can support individuals with interventions at the psychological, rather than the societal, level. We acknowledge that there are important pragmatic reasons for a psychological focus. It may not be realistic to seek to drive change at a societal level, but we can begin by supporting people with IDD, their families, and their siblings specifically, by first and foremost caring for and supporting those in our immediate network, and those we get to work with in our wider communities, in our research, or in our clinical work. These pragmatic reasons are why the practice-based and clinical implications discussed above remain important areas of work, despite the constraints that exist in our work at the structural level.

Nonetheless, the overarching solution to supporting siblings is more political and structural. Poverty needs to be eradicated, the world needs to become more equal, and there needs to be comprehensive and extensive governmental support for disabled people and people with mental health support needs throughout the lifespan. People need to stop judging humans' worth based on their ability to contribute economically to society. This call may well be a naïve and grand position – to suggest the eradication of poverty and the achievement of equality as something remotely achievable – but in reality, every world problem could be improved by these structural shifts.

If we were to pivot away from focusing on siblings as future caregivers in our research, then we would probably see less focus on the outcomes of siblings. For siblings, a focus on psychological outcomes rests on siblings being 'healthy' and best able to provide care for their brothers and sisters with IDD, which emphasises the individualistic ideological context in which much sibling research is situated. By individualism, we mean the way in which families, rather than communities and societies, are expected to support disabled family members that verges on individualistic (rather than societal). In this way, an interest in siblings is justified by some contribution siblings may provide which saves societal economic resources (i.e., siblings' unpaid, informal labour). These arguments are both gendered and racialized, given that population data tell us that carers are more likely to be women and Black (Sonik et al., 2016). Therefore, there is scope for more sociological and psychosocial theories to be employed to critique and understand sibling and family experiences further. Future research should consider how class, feminist, disability, post-colonial, critical race, and post-structuralist theories may be applied to sibling and family research to further understand siblings' experiences and disturb the assumptions we make about the families of people with IDD. There have been some important sibling IDD studies that have drawn upon transformative and emancipatory perspectives (Richardson & Jordan, 2017) and criticisms of individualization (Meltzer & Kramer, 2016). There is scope for further ideological critique about how siblings and families are expected to provide care that would allow us to position our research, and the impact of our research, in the political sphere.

Summary of Theoretical Implications

This second section has sought to apply the theories discussed in the first half of the chapter to various methodological and empirical questions. This section included epistemological, reflexivity and positionality, ethical, and analytical implications in terms of methodology, and clinical, practice and political implications in terms of empiricism. Overall, theories should be useful and have practical implications. Although perhaps somewhat arbitrarily divided in this section, theory, research, and practice are interconnected. The best sibling IDD research reflects an ongoing conversation between researchers and siblings, families, people with IDD, charities and non-governmental organizations.

Conclusions

In this chapter, we have described various theoretical perspectives relevant to studying siblings of individuals with IDD. Although often seen as conceptual rather than practical, theories should be useful. They should help us to understand phenomena better. They should resonate with the siblings and families that we work with. They should be able to help us conceptualize and design better research. Most of all, theories should help us to support and improve the lives of the people and the families that we work with. Therefore, we have also considered how these theories can be applied to both methodological and empirical matters to enhance sibling research and practice. Applying more critical, sociological, and psychosocial theories to what remains, a relatively ‘atheoretical’ (McHale et al., 2016: 589; Saxena & Adamsons, 2013: 300) research area, is an important next step in understanding and overcoming some of the problems related to family IDD research. Future research should consider how class, feminist, disability, post-colonial, critical race, intersectionality, and post-structuralist theories may be applied to sibling and family research to further understand siblings' experiences and disturb the assumptions we make about the families of people with IDD.

In effect, we are arguing for a significant expansion in sibling IDD family research. The existing research effort has only begun to scratch the surface of this field of enquiry. There are many research and practical questions raised within this chapter. Family IDD research is an exciting, practically and theoretically relevant field for researchers. Our analysis also emphasizes that this area of research is not just for researchers. Much more research needs to be carried out in co-production with siblings, including individuals with IDD.

Although this chapter has focused on siblings and families of people with IDD specifically, this chapter does have applicability and relevance outside of the IDD research and practice field. The first section provided an overview of common theories related to sibling and family research that will provide an orientation of key theories relevant to a broad range of family researchers. This section also discussed some less-commonly explored ideas in the field, such as post-structuralist theories, conceptualisations of the nature of research and knowledge, as well as the conceptualisation of change in the family. Mainstream sibling and family researchers may also decide to explore these ideas further. The implications sections, although specific to IDD, are related to areas relevant to all social researchers, especially to sibling and family researchers. Furthermore, disability and IDD are common human experiences, and so family and sibling researchers in the mainstream research field will inevitably work with or research with disabled people and their families through the course of their work. Therefore, taking the time to learn about and reflect upon inclusive practices and considerations is important across sibling and family researchers. Mainstream family research may have a lot to learn from IDD family research.

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