Siblinghood through disability studies perspectives: Diversifying discourse and knowledge about siblings with and without disabilities

Research about siblings where one has a disability has historically focused on the psychological outcomes of siblings of people with disabilities and has very rarely asked people with disabilities about their sibling relationships. This research focus represents the common individualizing approach and under-representation of people with disabilities that disability studies has argued against. Tracing the history of research about siblings and disability through de/institutionalization and towards current broader theories in disability studies, this article suggests that a range of disability studies perspectives can usefully de-individualize and expand research about siblings where one has a disability. Through examples of how materialist, feminist and inclusive perspectives can be applied to open up research about siblings and disability, the article argues that viewing siblinghood through the range of disability studies perspectives has the potential to expand this research field and represent new facets of siblings' identities and lives together.

Points of interest:

- There has been a lot of research about brothers and sisters where one has a disability.

- Most of the research has been about the impact of disability on what brothers or sisters of people with disabilities think and feel.

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- Most of the research does not ask people with disabilities about what they think of their brothers and sisters.

- Disability studies would give new and useful ways to do research about brothers and sisters where one has a disability. This is because disability studies includes lots of different ways to think about disability.

- This article uses different ideas in disability studies to suggest new focuses for research about brothers, sisters and disability.

Keywords: siblings; brothers and sisters; disability; disability studies; de-individualizing.

Introduction

Sibling-disability research is the study of siblings where one has a disability. This is an important field, as the sibling relationship is often the longest relationship in a person's lifetime, meaning that siblings have a significant capacity to influence each other's lives. Yet in the case of disability, studies of siblings have historically focused on the impact of disability on the psychology of siblings of people with disabilities, rather than exploring a range of ideas of what disability or siblinghood may mean in the lives of siblings both with and without disabilities. In response to this existing focus, this article explores how the multiplicity of perspectives within disability studies can open sibling-disability research to new perspectives on disability and can extend knowledge about experiences of siblinghood and disability.

The first part of the article outlines how sibling-disability research has tended towards a focus on the psychology and adjustment of siblings of people with disabilities. It explains the reasons for this as based within histories of institutionalization and deinstitutionalization, and outlines the outcomes for sibling-

disability research, where, historically, siblings without disabilities have been individualized and siblings with disabilities have been marginalized from the field altogether.

The second part of the article then introduces siblinghood to the multiplicity of perspectives used in disability studies, arguing that these perspectives can open new avenues for understanding siblings' experiences. Building on the few newer sibling-disability works that have applied similar approaches, the article applies some of the perspectives that have been used in disability studies to siblinghood to show how these offer possibilities for expanding sibling-disability research. Ultimately, the article suggests some future possibilities for how continuing to extend disability studies perspectives about siblings can strengthen sibling-disability research by showing how siblinghood intersects with a range of experiences of disability.

Institutionalized, individualized histories and the development of sibling-disability research

Sibling-disability research has developed differently to studies of siblings where neither sibling has a disability. In this broader research that does not involve disability, traditional approaches have explored siblings' shared experiences with a range of developmental (Dunn, 1985), life course (Goetting, 1986; Cicirelli, 1995) and cross-cultural (Cicirelli, 1995) focuses. Some studies where neither sibling has a disability have highlighted that siblings share experiences and transitions across the life course (Goetting, 1986; Cicirelli, 1995). Other studies highlight that siblings are commonly involved in companionship, emotional support, caretaking and assistance to each other (Goetting, 1986) and that, depending on culture, older siblings also sometimes contribute to younger siblings' education (Cicirelli, 1995).

Research where neither sibling has a disability has also commonly examined the sibling relationship, for example, with one influential approach exploring how siblings have relationships characterized by varying degrees of warmth/closeness, relative status/power, conflict and rivalry (Furman and Buhrmester, 1985). Frequently, explorations of siblings' experiences are stratified by birth order, age gaps, family size and gender (Toman, 1994 [1961]). In this research where neither sibling has a disability, studies have thus painted a broad picture of siblings' shared experiences, transitions and relationships.

Yet where one sibling has a disability, the focus of research has been narrower. Historically, studies of siblings and disability have predominantly focused on the problems that disability may cause for siblings without disabilities and its psychological impact on them. As detailed in the following sections, this main body of psychological work is situated within the historical context of institutionalization and deinstitutionalization and has led to an individualized view of siblings without disabilities and to the marginalization of siblings with disabilities.

Institutionalization, deinstitutionalization and siblings

The psychological focus of sibling-disability research can be understood as rooted in histories of institutionalization and deinstitutionalization. From the 1920s, professionals began to identify and focus on the damage that the presence of a child with a disability at home would cause to their families (Ferguson, 2001). By the mid-20th century, the accepted view was that there would be strain on parents' time and energy and that this presented a risk of trauma, stress, lack of attention, stigma, shame and isolation for siblings without disabilities (Castles, 2004; Jones, 2004; Brockley, 2004). As a result, particularly in the 1940s and 50s, there was a fear among parents and professionals that siblings would develop psychological problems (Castles, 2004). On this basis, as well

as for their own wellbeing, part of the reason that parents were encouraged to send their children with disabilities to institutions was to 'protect' the wellbeing of siblings (Castles, 2004).

However, around the same time in the mid-20th century, a confluence of factors also began to lead to questions about the value of institutions. This included advocacy by people with disabilities and by parents, exposure of abuse, neglect and poor living conditions in institutions and shifts in state policies and attitudes towards what constituted appropriate care and education for people with disabilities (Braddock and Parish, 2001; Castles, 2004; Jones, 2004). Some researchers also eventually argued that the living arrangements of children with disabilities in institutions or at home made little difference to the psychological adjustment of either siblings or mothers (Caldwell and Guze, 1960). Following these developments, from the 1960s and developing pace in the following decades, processes of deinstitutionalization began to take place and more children with disabilities were kept at home.

With deinstitutionalization, sibling-disability research emerged as a field, as the earliest sibling-disability studies date as coinciding with the late 1950s and 1960s when it began to occur (Farber, 1959, 1960; Farber and Jenne, 1963). With the prospect of residence of children with disabilities at home, the concerns about psychological problems and trauma for siblings were heightened (Castles, 2004). A review of research from the era highlights that studies began to ask questions about the impact of children with disabilities on the family and on siblings' relationships with parents (Farber, 1959, Farber and Jenne, 1963) and about siblings' experiences of stress, adjustment and burden (Breslau and Prabucki, 1987, McHale and Gamble, 1987). It can be argued that this research perceived a competition in family life between children with disabilities and their siblings. Who would receive parents' attention now that children with

disabilities again lived at home? Would children with disabilities dominate family life? What impact would care within the community have on siblings? Review of the focuses of research since this time suggests that these concerns came to dominate the discourse about siblings and the majority of sibling-disability research began to, and in many cases continued to, reflect this perspective. This history ultimately had two main impacts on narrowing the scope of traditional approaches in sibling-disability research: individualization of siblings without disabilities and marginalization of siblings with disabilities.

Individualization of siblings without disabilities

Since deinstitutionalization, a large body of sibling-disability research has consistently sought to determine the impact of a child with a disability on his or her siblings through measuring risks from disability to the psychological outcomes of siblings without disabilities. Early research focused on frustration, tension and anxiety among siblings without disabilities (Farber, 1959, 1960). Over time, a focus on adjustment crystallized (Breslau et al., 1981; McHale and Gamble, 1987; Bischoff and Tingstrom, 1991), for example, measuring siblings' emotional morbidity (Begun, 1989), self-esteem (Burton, 1988) and stress (Breslau and Prabucki, 1987). A particular focus was on links between psychology and caregiving (Stoneman et al., 1988; McHale and Gamble, 1989), as the 'burden' of care was seen to be a key issue now that children with disabilities were again living with their families. More recent research has also seen risk and protective factors layered in, for example, with explorations of how family factors, socio-economic status and community supports affect psychological outcomes (Giallo and Gavidia-Payne, 2006; Bellin et al., 2009).

These studies of psychological outcomes have dominated much of sibling-disability research and, as such, siblings without disabilities have been consistently

framed in an individualized way; that is, the focus has consistently been on the disruptions and impact of disability on siblings' development and psychology, reflecting a focus on their individual outcomes and condition. It can be argued that this individualized focus has narrowed the scope of the field and meant that other focuses, for example, exploring common experiences between siblings or the social and political forces shaping their experiences, were not historically emphasized. This individualized focus is linked to a second impact on the field: the marginalization of siblings *with* disabilities.

Marginalization of siblings with disabilities

While the focus on siblings without disabilities has been individualized, siblings *with* disabilities have historically been marginalized from sibling-disability research altogether. Early research very rarely sought the perspectives of siblings with disabilities about their brothers and sisters – given the focus on psychological problems and trauma for siblings without disabilities, the perspectives of siblings with disabilities were perhaps not seen as relevant. Yet examination of the few places where siblings with disabilities have been included reveals how their marginalization has been limiting, because where they have been included, siblings with disabilities influence different focuses and findings beyond psychology and trauma.

Only one early study examined the perspectives of people with disabilities about their siblings. Zetlin (1986) included siblings with disabilities in participant observation, including some brief quotes from them. In including siblings with disabilities, Zetlin's approach shifted out of a focus on psychology and trauma, and instead focused on a range of close, warm, distant and resentful relationships between siblings, as well as highlighting companionship and reciprocity between some siblings with and without disabilities. Alongside the now-acknowledged importance of including people with

disabilities in research (Walmsley, 2004), Zetlin's findings highlight the importance of including siblings with disabilities in discussion of their experiences with their brothers and sisters: when they are included, the scope of the field widens beyond psychology and trauma to reflect more about the experiences that both siblings share.

The marginalization of siblings with disabilities from sibling-disability research was sustained for a long time. It was only from the mid-2000s that research began to call for speaking "directly to the person with a… disability" (Seltzer et al., 2005:358; Heller et al., 2008; Dew et al., 2008). Following such calls, a small number of recent empirical studies have included siblings with disabilities (Kramer, 2009; Dew, 2010; Serdity and Burgman, 2010; Tozer et al., 2013; Petalas et al., 2013; Burbidge and Minnes, 2014). Like Zetlin (1986), such studies emphasize reciprocity (Dew, 2010; Kramer et al., 2013) and siblings' shared experiences and conflicts (Serdity and Burgman, 2010; Petalas et al., 2013). This new body of work then again highlights the importance of including both siblings for shifting out of the focus on psychology and trauma. Further, in non-research publications, such as life stories and autobiographies, people with disabilities have written about their experiences of growing up with their siblings (e.g. Finger, 2006) and of their family having different expectations of their life outcomes and possibilities, for example, in independence and intimate relationships, compared to their siblings, which they may not appreciate (e.g. Gilhooley in Murray and Penman, 2000). Whilst not research, these are again focuses contributed by siblings with disabilities that go beyond psychology and trauma, highlighting the perspectives they could bring to research if they were included more often.

Yet because the body of research that includes people with disabilities' views about their siblings is so new and small and because these other focuses remain untapped, still relatively little is known in the sibling-disability field about siblings with

disabilities' perspectives or about both siblings' shared experiences and conflicts. This is evidenced in the outcomes from sibling-disability research overall.

Outcomes from sibling-disability research

The outcome from the historical influences on sibling-disability research has been that a particular scope of knowledge has characterized the main bodies of work in the field, summarized in Table 1.

Table 1. Main bodies of sibling-disability research

Difficult experiences	Through the focus on adjustment and psychological outcomes, research has highlighted that in childhood, siblings without disabilities may feel confused, sad, afraid, anxious, ashamed, guilty, stressed, withdrawn or depressed because of their brother or sister's disability (Azeez, 2002; Siegel and Silverstein, 1994). In adolescence, some siblings may over-identify with or feel embarrassed by their brother or sister (Azeez, 2002). Meta-analysis has revealed that while having a brother or sister with a disability does cause psychological difficulty for some siblings, there is less negative impact than was first assumed (Rossiter and Sharpe, 2001).
Beneficial experiences	Alongside difficult experiences, many siblings without disabilities say they feel they have increased empathy, maturity, patience, acceptance of difference and appreciation of their own health as a result of their

experience with their brother or sister (Eisenberg et al., 1998). These findings highlight that while researchers originally assumed that disability would cause damage, siblings without disabilities also feel there are benefits to their experiences of their brother or sister's disability.

Contributing factors

Studies have also identified factors that contribute to siblings without disabilities' experiences, for example, studying the impact of children's understandings of disability on their experiences with their sibling (Glasberg, 2000) or looking at the impact of parenting factors on siblings' experiences (Giallo and Gavidia-Payne, 2006; Rivers and Stoneman, 2008).

Supports and interventions

Following from the range of siblings without disabilities' experiences, there has also been important study of supports and interventions to use in supporting siblings (Phillips, 1999; Lobato and Kao, 2002; D'Arcy et al., 2005; Giallo and Gavida-Payne, 2008).

Caregiving

Siblings without disabilities have also been shown to contribute to care across the life course (Arnold et al., 2012; Kramer and Coyle, 2013). Particularly in adulthood, adult siblings without disabilities are often expected to step into the care roles previously held by parents (Griffiths and

Unger, 1994; Dew et al., 2004; Coyle et al., 2014).
Particularly where their brother or sister has an intellectual
disability, adult siblings without disabilities may become
increasingly concerned with financial, advocacy,
guardianship and caregiving issues (Azeez, 2002) and with
what happens to their brother or sister when their parents
age and pass away (Greenberg et al., 1999; Heller and
Kramer, 2009). Such issues can be complex, as these are
often difficult topics for families to discuss and plan for.

These main bodies of work in sibling-disability research represent key concerns and important ways of supporting siblings across the life course, yet they also may not represent the full range of lived experiences of siblings both with and without disabilities. As highlighted earlier, new research that includes both siblings suggests that there is more to know about, for example, siblings' reciprocity (Dew, 2010; Kramer et al., 2013) and their shared experiences and conflicts (Serdity and Burgman, 2010; Petalas et al., 2013). Reviews of sibling-disability research have also questioned the explanatory power of disability as the primary factor influencing sibling relationships (Stoneman, 2005) and questioned whether there might be other factors useful in describing the shared experiences of siblings with and without disabilities. Such work also highlights the need for more theory and more consistent methodological approaches (Stoneman, 2005).

Taking up these findings that including the perspectives of both siblings is important for opening up new research avenues and that there is a need for more theory and consistent methodologies, this article suggests that as a theoretically-informed,

diverse and inclusive field of research, disability studies has important offerings for further developing sibling-disability research. As such, this article now turns to introducing disability studies' offerings for theorizing siblinghood, highlighting how these offerings give a basis for further opening sibling-disability research to new approaches and possibilities.

Introducing siblinghood to disability studies

Disability studies is a broad field of theory, research and activism that puts disability at the centre of interest. Resisting approaches that try to classify, treat or cure disability or incapacity, the range of approaches that together make up disability studies instead focus on unpacking a multiplicity of other, broader experiences of disability. This might be exploring disability's social, material and structural underpinnings (UPIAS, 1976; Thomas, 1999; Finkelstein, 1996; Longmore, 2003), the economic, political, cultural and historical conditions in which experiences of disability occur (Shakespeare, 2006; Erevelles, 2011) or the ways in which disability intersects with gender, sexuality, class, culture, nationality and ethnicity (Erevelles and Minear, 2010; Goodley, 2014). Reflecting diversity and inter-disciplinarity (Linton, 1998a; Meekosha, 2004; Goodley, 2011) and using a range of methodologies to foreground people with disabilities' voices (Zarb, 1992; Walmsley, 2004; Dowse, 2009), overall disability studies aims to bring new perspectives to bear on how disability is understood. The field also specifically works to shift views of disability from an individualized phenomenon towards a more complex understanding.

In this respect, disability studies has many diverse offerings for widening the theoretical perspectives, methodologies and approaches in sibling-disability research. Rather than the individualized view of siblings, disability studies can open new lenses

for how to view, understand and study siblings with and without disabilities. The following sections outline some of the many possibilities offered by disability studies, also highlighting and building on some of the most recent sibling-disability research that has begun to look towards these areas. The first section starts by showing how theory from disability studies can be used to de-individualize the view of disability in siblinghood. The remaining sections offer examples of how alternative materialist, feminist and inclusive perspectives can offer new insights.

De-individualizing disability in siblinghood

The individualization of disability – such as has characterized the discourse about siblings without disabilities in sibling-disability research – is one of the main issues that much early work in disability studies reacted against; indeed, Goodley calls individualization one of the "usual problem/s of disability" (2014:3). Many disability studies authors have done important work to de-individualize disability, that is, to shift the focus on disability away from individual psychology, bodily experiences or outcomes towards an approach that unpacks the assumptions behind such individualized approaches and instead offers explanations of how experiences of disability are made within society. Two works that have de-individualized disability are applied here to highlight how to go beyond the individual-level focus of much sibling-disability research and instead ask socially-informed questions about siblings.

Firstly, Rioux's (1997) work can be used to identify individual-level formulations of disability within sibling-disability research. Such identification is important for recognizing areas that may benefit from new approaches:

Table 2. Applying Rioux's work to sibling-disability research

Individual-level formulation	Individual-level formulation in sibling-disability

of disability (Rioux, 1997:103)	research
1. A positivist paradigm is used.	Siblings can be 'fixed' when their needs are 'addressed'.
2. Disability is characterized as a comparative incapacity in relation to people without disabilities.	Siblings with disabilities are seen as having asymmetrical, less engaged roles in the sibling relationship compared to their brothers and sisters without disabilities.
3. Disability is viewed as an anomaly and social burden, including costs.	Research has consistently looked for evidence of sibling burden through psychological studies and for the 'cost' of disability to siblings without disabilities' psychological wellbeing.
4. The point of intervention is the individual condition.	An individual sibling must seek individual-level support (e.g. counselling), rather than the common point of intervention also historically being what policies/services affect siblings.

*Table adapted from Kramer (2009:14).

Secondly, a selection of Linton's (1998a, 1998b) fault lines can identify similar individual-level formulations in sibling-disability research, but can also be used to identify alternative views of disability's social and environmental dimensions, both for siblings and for sibling-disability research:

Table 3. Applying Linton's work to sibling-disability research

Fault line (Linton, 1998a)	Individual-level formulation in sibling-disability research	Alternative based on disability's social and environmental dimensions

#1-The current presentation of disability, predominantly in rehabilitation and special education, individualizes disability (1998a:134).	Sibling-disability research locates the problem of disability as residing in the individual and family through its focus on psychological outcomes.	Disability is a lack of access in society and a cultural influence on the lived experiences of siblings with and without disabilities.
#3-The absence of the subjectivity and agency of people with disabilities is evident in a review of psychology, history, anthropology, literature (1998a:134).	People with disabilities are absent from the majority of sibling-disability research.	Researchers need to engage in research that is accessible to and represents the interests of siblings both with and without disabilities.
#7-An emphasis on intervention at the individual level (1998a:135).	Dominance of individual-level psychological studies about siblings without disabilities.	Research about and advocacy for siblings on a group level can lead to societal change.

#8-The preponderance of information on disability in applied fields sequesters the study of disability to an applied focus (1998a:135).	Sibling-disability research has artificially removed itself from family and other sibling research; sibling-disability research is treated as an 'extreme case'.	As in all sibling relationships, siblings with and without disabilities differ in the extent to which they feel close to each other and share interests. This may or may not relate to disability, even where one sibling has a disability.

*Table adapted from Kramer (2009:13).

Rioux (1997) and Linton's (1998a, 1998b) work is useful for moving sibling-disability research outside its individualized focus and for looking towards new insights. Some of the newest sibling-disability research has followed this de-individualising of disability, for example, putting individual-level support within the context of system improvement, funding and employment conditions in the disability sector (Arnold et al., 2012); describing how inadequate service provision is linked to negative experiences for siblings both with and without disabilities (Taylor and Hodapp, 2012); studying siblings' interactions with service providers (Bigby et al., 2014) and with new models of personalized disability support (Atkin and Tozer, 2014); or looking at how siblings' experiences of disability also reflect experiences related to their cultural or religious background (Jegatheesan, 2013) or to the cultural constructs of gender in different societies (McGraw and Walker, 2007; Kuo, 2014).

These studies represent important new developments in the contemporary expansion of sibling-disability research. These new developments recognize disability's social, cultural and environmental dimensions for siblings and they should be extended

in future studies. Once the focus on siblings is de-individualized, there are many possibilities for how to continue this expansion. While only three among the many possible options, perspectives drawn from materialism, feminism and inclusive research offer promising possibilities, as explained below. These three areas have been chosen as examples here for their diversity of coverage of different theoretical and methodological perspectives.

Materialism and siblinghood

A materialist perspective has commonly been used in disability studies to understand how experiences of disability are made in socio-economic contexts and in the structuring of economic, welfare and workforce systems (Oliver, 1993; Longmore, 2003). This materialist precedent could open new pathways for sibling-disability research, especially in an era where many states are shrinking welfare services and placing increased emphasis on economic participation. By stepping back from individualized approaches, it is possible to examine the economic policy considerations that shape the lives of siblings.

For example, popular media has begun to identify how workforce-leave policies may affect siblings. Until some recent clarifications highlighting that siblings may be eligible where they act *in loco parentis* ('in the place of a parent') (US Department of Labour, 2015a, 2015b), in the United States, the Family and Medical Leave Act (FMLA) has not included care for a sibling as a basis on which to take authorized family leave (Johnson, 2014). Popular media has identified that this policy has particularly affected those in low-paid or unstable work conditions, who often have less flexibility in their work hours than higher-paid counterparts (Swarns, 2015). The anecdotal accounts in popular media suggest that the inability to take leave for a brother or sister has restricted some siblings in low socio-economic conditions from spending

time together and restricted some siblings without disabilities participating in care responsibilities (Swarns, 2015; Johnson, 2014). Given mainly by women, the anecdotal accounts also suggest that the FMLA may have particularly affected *sisters* without disabilities, who other research has shown are more likely to provide care than brothers (Heller and Kramer, 2009) and so may more commonly need to balance work and care through the FMLA (Chen, 2014). While offering potential for more sustained gendered-materialist research into the impact of workforce-leave policies upon the economic participation of siblings (particularly in light of the recent clarifications which may change siblings' experiences), such an analysis has not yet been done. Its possibility however holds potential for identifying changes at a macro-policy level, in areas other than direct disability policy, that may benefit siblings.

Relatedly, sibling-disability research could focus on changes in economic policies for people with disabilities. In recent years, there has been an increased expectation in many welfare states that people with disabilities will be employed, increased policy investment in this goal and increased options for people with disabilities' employment (Dempsey and Ford, 2009; Novak, 2015; Migliore et al, 2007). Within this context, new research has also highlighted the role of siblings. Unwilling to take over all of their parents' responsibilities in later life and set in the context of an increased expectation that people with disabilities will work, siblings without disabilities often deploy their own social capital and connections to seek ways for their sibling with a disability to enter or manage in employment (Kramer et al., 2013). This change may be welcomed by some siblings with disabilities as a chance for new opportunities (Kramer and Coyle, 2013). The economic goals of both siblings may thus, to some degree, align with the current economic climate in many welfare states. Understanding more about this through future research may enable an understanding of

how siblings navigate changing employment expectations at a time when economic policy is shifting, social services are shrinking and the imperative for economic participation is growing.

These avenues highlight that, overall, a materialist perspective holds potential for opening sibling-disability research to the implications of macro-level economic policies. This materialist focus would open new research avenues with the potential to directly impact the policies structuring both siblings' lives.

Feminism and siblinghood

Disability studies' common use of feminist theory also holds potential for opening sibling-disability research to new possibilities. Feminist work on gendered care roles has been used in some of the most culturally-engaged sibling-disability research (e.g. McGraw and Walker, 2007), yet beyond care, feminist thought also has application to many other areas of siblinghood. In particular, feminist theorising of identity and personal experience provides important possibilities for appreciating how siblings both with and without disabilities may develop knowledge, understanding and identity around disability within their family context.

Thomas' (1999) and Stalker and Connors' (2004) work provides a good example of how feminist thought can be applied to siblings. Thomas' (1999) feminist social relational model of disability has been influential in differentiating, but also linking, structural and personal experiences of disability. Thomas highlights the interconnections between impairment effects (bodily functionality), societally-imposed restrictions of activity on people who experience impairment and psycho-emotional disablism, related to negative societal attitudes about impairment and disability.

Stalker and Connors (2004) applied Thomas' model to how siblings without disabilities understand their brother or sister's disability in childhood. They found that while siblings without disabilities often described their brother or sister's disability in medical and individualized terms, they also often felt distressed and angry at psycho-emotional disablism such as bullying or discrimination and often presented disability within a scope of other differences between themselves and their brothers or sisters, such as differences in personality. Stalker and Connors concluded that:

> These [siblings] inhabit the world of 'normals' outside the family and they spend time at home with their disabled brother or sister: thus they are well placed to mediate difference both ways. They have access to society's view of difference, which tends to be equated with 'abnormality', but also face the challenge of moving the boundaries of normalcy in order to include their sibling, if they choose to do so (2004:227).

In applying Thomas' (1999) model to siblings, Stalker and Connors (2004) have thus used a feminist theory to describe the understandings of disability that develop within a sibling and family context. They then shifted into description of what these understandings mean for siblings' navigation of the broader social experience of disability within both their home and society. This is a useful step that connects the dominant approach in sibling-disability research of examining siblings' individual, personal experiences to a wider, societal view of disability. In this way, feminist inclusion of personal experience allows a useful bridge from the existing individual-level focus on siblings to bring this towards new socially-informed insights.

A similar approach using other feminist theories could open other possibilities for sibling-disability research. For example, feminist work on disability and futurity (Kafer, 2013) could unpack how siblings with and without disabilities imagine their respective futures, both together and apart, within a context that may include the possibility of future care by siblings, but also the changing nature of attitudes and policies towards disability. Other feminist work on the body, intersectionality, politics

and agency (Hall, 2011) offers possibilities for examining what identities either or both siblings develop around disability and what these identities mean for their lives together. Such use of feminist theory offers rich pickings for sibling-disability research, which could develop many more personally-political and identity-based avenues in this field.

Inclusivity and siblinghood

Methodologically, disability studies is often associated with concepts of inclusivity. A number of inclusive (Walmsley, 2004), collaborative (Knox et al., 2000; Dowse, 2009), participatory and emancipatory (Zarb, 1992; Barnes, 2003) research approaches have been used in disability studies to include people with disabilities in research participation, but also in the design, conduct and dissemination of research. Intended to redress the historical marginalization of people with disabilities' voices from the research about them, these methodological approaches focus on foregrounding people with disabilities' perspectives and on ensuring that the research is meaningful to them and their lived experiences (Chappell, 2000; French and Swain, 1997).

These inclusive approaches have great pertinence for sibling-disability research, because application of inclusive methodologies could give a strategy for extending the relatively new body of work that does include siblings with disabilities. Tozer et al. (2013) broached questions about inclusivity and siblinghood in their consideration of how to include siblings with high autism-related support needs in their study of both siblings. They found that strategies of assent, photo-elicitation, 'meeting' for an activity and using communication supports such as plain language, photos and symbols were all beneficial in including both siblings together.

More broadly for sibling-disability research, the lens of inclusivity can open questions about what it means and what it takes to include both siblings in research together. This could be both siblings together taking part as research participants or could be both siblings working together to conduct research about and address issues that affect both of them. The egalitarianism and reciprocity that have recently been shown between at least some siblings with and without disabilities (Kramer, 2009; Dew, 2010; Kramer et al., 2013) also suggests that some siblings may sometimes wish to participate in research together – and that, as such, inclusivity may be a particularly appropriate lens to apply to research with both siblings. Indeed, Tozer et al.'s (2013) study also showed that siblings without disabilities were enthusiastic about including their siblings with autism in the research and worked with researchers to make it happen, while some self-advocacy groups have also engaged with siblings without disabilities and represented them in their publications (RIOT, 2012). Such existing expressions of inclusivity by both siblings suggest the pertinence of the concept as a focus within siblinghood.

Such examples of egalitarianism, reciprocity and enthusiasm would need to be balanced with considerations of power and shared voice, choice and control between siblings with and without disabilities in the research process. There would be a need to acknowledge that differential voice is an issue within inclusivity and that, as such, it is important to ensure that the inclusive principle of specifically hearing and foregrounding people with disabilities' perspectives is not lost in including them with their siblings without disabilities, who may find it easier to voice their opinions. Yet with a balanced approach to hearing both siblings, disability studies' lens of inclusivity can perhaps provide a pathway that facilitates sibling-disability research in finding out more about *both* siblings' experiences of siblinghood and disability.

Conclusion

This article has charted the history and scope of research on siblings where one has a disability and has suggested ways that it may expand. Ultimately, expansion of disability studies approaches in sibling-disability research is important for ensuring that the research goes beyond an individualized frame to also include other ways of understanding siblings' experiences. The options offered in this article may not be the only ways forward, yet they highlight that by de-individualizing the understanding of disability in siblinghood, there are new possibilities for expanding knowledge about the economic options available to siblings; new avenues for understanding what shapes siblings' identities and societal experiences; and new ways of including both siblings in building knowledge of their experiences. Ultimately, these possibilities and many others yet to be developed can lead to ways of using research to benefit siblings both with and without disabilities. Ultimately, this keeps the research useful and diverse for the siblings that it studies.

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