Intellectual and Developmental Disabilities

A Research Agenda to Support Families of People with IDD with Intersectional Identities
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Abstract:	Family members provide significant practical and emotional support to people with intellectual and developmental disabilities (IDD) across the lifespan. In September 2022, a group of researchers, people with IDD, and family members met to review the current research about families and family support to develop research goals related to supporting families of people with IDD. There was a particular focus on families with intersectional social identities and minoritized communities. Recommended areas of future research include exploratory research to better understand the experiences of families with intersectional identities, perspectives of families with intersectional identities about the formal support system, funding options for family support and services, and research strategies that are inclusive of families with intersectional identities.

A Research Agenda to Support Families of People with IDD with Intersectional Identities

Abstract

Family members provide significant practical and emotional support to people with intellectual and developmental disabilities (IDD) across the lifespan. In September 2022, the *State of the Science Conference on Community Living: Engaging persons with intellectual and developmental disabilities from underserved racial, ethnic, linguistic, and cultural groups in research* was held. This paper summarizes the efforts of the workgroup that developed research goals related to supporting families of people with IDD. The focus was on families with intersectional identities and minoritized communities. Recommended areas of future research include exploratory research to better understand the experiences of these families, perspectives of families with intersectional identities about the formal support system, funding for family support and services, and inclusive research strategies.

Keywords: family support, intellectual and developmental disabilities, intersectionality, minoritized communities

As defined by its members, the family serves an essential function in our lives. All families need support at different times and for different reasons across the family cycle. Families are unique and complex, as are the supports they need – what works for one family might not work for another. Therefore, person-centered, family-centered, and culturally relevant approaches are needed to best support families across the lifespan. This is particularly true for families of people with intellectual and developmental disabilities (IDD). Family members often play various roles in the lives of people with IDD, including medical, emotional, financial, and day-to-day support. According to the seminal report, Building a National Agenda for Supporting Families with a Member with Intellectual and Developmental Disabilities, "the overall goal of supporting families, with all of their complexity and diversity, is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members" (Hecht et al., 2011, p. 12).

It is important to recognize that families from Black, Indigenous, and people of color (BIPOC), immigrant, and LGBTQ+ communities face additional barriers to accessing needed support due to persistent structural racism and systems of oppression. Even if services are accessed, they may be a poor fit. Including a dedicated focus on the unique needs and perspectives of diverse minoritized populations has been a thread throughout several initiatives focused on supporting families in recent years (e.g., Grossman et al., 2018). While this issue continues to be addressed, more must be done to understand these families' experiences and adequately address their needs in ways that build on their strengths and consider the cultural context of the family and community.

Importance of Family Support

Service systems have necessarily evolved to meet the changing expectations to support the right of people with IDD to live integrated lives as members of their community. Government institutions have moved away from segregated settings and toward more inclusive structures that support opportunities for people with disabilities to participate fully in all community life. Family members' support is a critical part of the overall system of long-term care for those with disabilities. The shift from institutions to community-based care has necessarily increased reliance on families to navigate, coordinate, and provide vital support. Most individuals with disabilities live in the community, in the family home, or independently, whether or not they receive formal services. For example, of people with IDD receiving long-term services and supports from a state IDD agency, in 2019, 62% lived in a family member's home (Larson et al., 2022). Adults with IDD from BIPOC communities are likelier to live at home than white families (Anderson et al., 2018).

Present approaches to support people with disabilities and their families vary significantly across and within states. Several concerns persist regarding the current approach to supporting families, including (1) a need to understand and address families' support needs during all phases of life and how the service and support needs of the family as an entity may differ from those of individual family members; (2) a growing demand for supporting individuals and families within a context of stressed state budgets; (3) a strong and growing reliance on federal Medicaid funding for supporting individuals and families; (4) a growing interest to establish systems of support across populations; and (5) concern over the direct support professional (DSP) workforce (Kardell et al., 2017).

While there continues to be a need to expand formal services, it is equally important to recognize and leverage existing resources to provide supports in ways that effectively reach more people and positively impact families and communities. These community resources are essential for families from minoritized communities who may experience additional barriers to accessing formal state or locally-funded service systems.

Definitions

We are using the following definitions to understand families and family support.

Family: The RAISE Report (2022) identifies family caregivers as someone with a significant connection or personal relationship with the person receiving support. This might include not only biological families but also chosen families, as well as friends and neighbors. A chosen family is a non-biological related group of people who provide ongoing social support to each other. Some people with IDD receive adult foster services and spend a reasonable amount of time with the family who supports them (Hall, 2009). Families of choice are especially important to LGBTQ people with IDD (Moreno et al., 2017). They form a community that promotes love and provides practical and social support. Biological and chosen families may need to negotiate how they support people with IDD. However, chosen families should not be seen as less important or valid in planning, decision-making, and providing support (Moreno et al., 2017).

Family Support: From a review of family support literature, Dunst (1995) identified six principles for family support: (1) enhancing a sense of community, (2) mobilizing resources and supports, (3) sharing responsibility and collaboration, (4) protecting family integrity, (5) strengthening family functioning, and (6) adopting proactive program practices. In 2011, the participants in the Wingspread Conference defined family support as "strategies designed to

ensure that families have access to person-centered and family-centered resources, supports, services, and other assistance. These strategies are directed to the family unit but ultimately benefit the individual" (Hecht & Reynolds, 2012).

Lifecourse: Giele and Elder (1998) describe the lifecourse as "socially defined events and roles that the individual enacts over time" (p.22). The lifecourse is a trajectory influenced by past events and experiences, both personal and those from the wider familial and social environment.

Overview of Supporting Families Research

The importance of the role of families has been recognized in research, and a body of research has focused on the experiences and outcomes of family caregivers that parallels the growth in community supports for individuals with IDD. Much of the research has focused on outcomes related to caregiver experiences. Difficulties defining families, family supports, and the lack of national data related to family supports increase the challenges related to research in this area. Finally, the failure to include families from diverse backgrounds and those not in the service system limits the full understanding of family caregiver experiences and what supports may be most beneficial to all families.

Families experience caregiving at many levels throughout their lifespan. Parents, siblings, or other family members may be the single caregiver for the person with IDD for many years. Many family members become compound caregivers at some point in their lives. Compound caregiving occurs when someone providing long-term support to a family member takes on an additional long-term caretaking role, such as a parent of a person with IDD starting to support another family member. Sibling caregivers enter the club sandwich generation while caring for their children, aging parents, and brother or sister with IDD (Lee et al., 2020).

Contexts of Support

Understanding the context of families' support includes understanding where individuals with IDD live. An estimated 7.3 million people in the United States live with an IDD (Larson et al., 2022). Of those, about 1.4 million individuals receive some long-term support or services (LTSS) under the auspices of their state developmental disability agency, with about 62% receiving LTSS while living in the home of a family member (Larson et al., 2022). LTSS recipients with IDD living with a family member comprise 62% or more of all recipients with IDD. Those receiving LTSS in a family member's home have grown by 159% since 1998 (from 325,650 to 849,104). Even though most LTSS recipients live with their families, they account for only 19% of Medicaid-funded LTSS expenditures ($8.7 billion of $45.0 billion), highlighting the importance of the support provided by family members of individuals with IDD.

Need to Support Families

Given that most individuals with IDD are likely living with or at least receiving some support from a family member, family support's impact on outcomes for family members has been an important area of research. Participants in a survey for family members who provide supports reported providing levels of supports that were greater in intensity, frequency, and duration that were significantly greater than caregivers responding to other surveys (e.g., Caregiving in the US; Anderson et al., 2017). Sixty percent reported providing more than 40 hours of support per week. They provided an average of 12 different supports in areas such as activities of daily living, health supports, and social and emotional supports. As many as a third of family caregivers of individuals with IDD become compound caregivers, adding an average of 12 additional hours of support per week (Perkins & Whaley, 2010). Of 86 siblings caring for their brother or sister with IDD, 77% also cared for their own children, 11% for parents, and 12% for their children and parents (Lee et al., 2020). Cultural differences also exist to the extent to

which family caregivers expect their family with IDD will continue to live with them and to which siblings will step in as caregivers in the future.

A literature review showed that family supports were significantly related to family outcomes (Kyzar et al., 2010). The authors noted that several types and sources of family support were included in these studies. However, the studies generally did not include family members' perspectives other than mothers' or families' experiences from different race, ethnic, cultural, or economic backgrounds (Kyzar et al., 2010). Cultural differences such as familism may be a protective factor for family caregivers' quality of life as measured in a survey of Latine and non-Latine mothers, along with emotional support (Cohen et al., 2014). Familism emphasizes family relationships over the self (Campos et al., 2014). In the 2016 National Survey of Children's Health (NSCH), respondents, regardless of race or ethnicity, reporting formal or informal emotional support, fewer adverse neighborhood conditions, and more family resilience factors also reported having better mental and physical health, regardless of race or ethnicity, demonstrating the importance of contextual factors (Anderson & Hawley, 2017). Another study using the 2016 NSCH found significant differences in the effects of family resilience on parents' stress (Kim et al, 2020). African American parents with higher levels of family resilience were more likely to report lower levels of stress than White and Hispanic parents. The association between lower resilience and higher stress was also stronger in African American parents (Kim et al, 2020).

Caregiver Health Outcomes

Research on family caregiver outcomes has included studies that examine mental and physical health, social outcomes, family quality of life, and economic impacts of providing care. Some studies identify differences across races and ethnicities. However, most are primarily

White caregivers or compare two groups (such as White and Latine caregivers). The preponderance of the literature describes outcomes for parents, usually mothers, across the lifespan and has often focused on the mental and physical effects of supporting a family member with IDD, often focusing on the negative impacts. For example, in a meta-analysis of caregiver studies, the authors found a positive relationship between parenting a child with disabilities and depression and anxiety (Scherer et al., 2019). However, these authors also noted quality issues in the extant literature. These included a reliance on self-reports or on depression and anxiety measures which were not intended to identify a clinical disorder. This may lead to overestimating the presence of these conditions in caregiving populations. In a review of the literature, Williamson and Perkins (2014) found a similar body of work that described the negative impact of caregiving on the physical and mental health of caregivers across the lifespan.

A study that used the National Health Interview Survey was the first to examine physical health outcomes for caregivers of adults with IDD and found that Latine and Black American older caregivers were more likely to have chronic conditions such as arthritis, diabetes, and heart problems than their non-caregiving counterparts (Magaña & Smith, 2006.) Building on these findings, a study of primarily White caregivers found that they also reported higher chronic conditions such as arthritis, activity limitations, and high blood pressure (Yamiki et al., 2009).

Hastings (2016) notes that there is a "negative narrative" about outcomes for family members of individuals with IDD that is not an accurate reflection of family experiences. Turnbull (2007) noted that most studies focus on mothers' experiences as a proxy for the family. A study of Cuban American mothers of adults with IDD found that family functioning was a key element of maternal well-being. In other words, if the family was doing better, the mother was doing better in psychological health (Magaña et al., 2006). Similarly, family functioning was

found to have a stronger relationship with depressive symptoms for Puerto Rican mothers of adults with IDD than for White mothers (Magaña et al., 2004). More research is needed on family systems, including the interactions family members have with each other, including the family member with IDD.

Studies examining differences across race and ethnicity noted some differences in reported outcomes across races and ethnicities. For example, studies show Latine mothers were more likely to report psychological and physical symptoms, while Black/African-American mothers reported physical symptoms (Magaña & Smith, 2006; Magaña et al., 2009). However, in a study comparing White mothers with Latine mothers of adolescents with autism, White mothers were likelier to report more distress (Magaña & Smith, 2006b). For both groups, family cohesion seemed to be a protective factor.

Stigma and shame related to disability in some communities may also play a role in the psychological and physical outcomes for family caregivers. Stigma may be a factor for poor health outcomes (Hatzenbuehler et al, 2013). For example, a qualitative of study on the barriers to autism and screening referrals for black children, found that some family caregivers noted that there was stigma and shame in their communities related to a child having ASD that ultimately led to the parents delaying follow-up for referrals (Dababnah et al, 2018). Immigrant Asian Indian families also described beliefs, particularly religious beliefs related to disability, in their communities and families which led to the family's social exclusion (Zechella & Ravel, 2016). Systematic of studies related to experiences of stigma in family caregivers found a positive association between experiences of stigma and poor mental health outcomes (Ali et al, 2012; Mitter et al, 2019). Both of these studies were cross-cultural, including studies conducted

internationally, however, more research needs to be done about the experiences of stigma and disability of families from diverse backgrounds in the US.

Arnold and Heller (2018) reviewed studies of siblings of an individual with IDD and found mixed results. Some studies reported good health and positive sibling relations. Others showed greater pessimism in siblings, more family distress, and more negative feelings about siblings. The experiences of siblings across cultural groups are limited. This is an important area to study since culture shapes family and individual understandings of disability, which can influence family expectations about caregiver roles (Williamson & Perkins, 2014). Understanding caregiving expectations and experiences across race, ethnicity, and culture are also crucial because family caregivers from minoritized communities experience additional stressors that may have an accumulative effect along with the stressors that may arise from the caregiving role (Magaña & Smith, 2006a).

Caregiver Financial Outcomes

Grant and colleagues (2017) reported that families that include a person with a disability have incomes averaging 30% lower than families without someone who has a disability. In a survey of more than 3,000 caregivers across the United States, more than half reported conflicts between their caregiving responsibilities and work (Anderson et al., 2018). The effects of caregiving on financial security are lifelong. Seltzer and colleagues (2011) reported that older co-residing caregivers experienced lower socioeconomic status. In a review of sibling outcome literature, negative economic impacts were also identified for sibling caregivers of individuals with IDD, including lower reported incomes and increased material hardship (Williamson & Perkins, 2014). The authors also noted that few studies looked at sibling outcomes across

minoritized groups. These effects are likely compounded among lower-income populations and less access to retirement savings programs.

Given the identified gaps in identified in the research, developing a research agenda to address areas where more research is needed is important to ensure that the needs of all families are understood in order to develop inclusive policies and practices. To that end, a working conference was held to identify a research agenda aimed at supporting all families living with IDD.

Methods to Identify Issues and Research Goals

The 2022 State of the Science Conference on Community Living was focused on engaging people with IDD from underserved racial, ethnic, linguistic, and cultural groups in research. Researchers, people with IDD, and family members participated in topically-oriented strands of the conference. The conference's Families and Family Support strand met to identify the issues, future directions, and research recommendations on supporting families of people with IDD. Each discussion included focused questions on the experiences and needs of families with intersectional social and cultural identities (See Appendix A for guiding questions). These questions aimed to identify ways the research may become more inclusive and relevant for families with diverse social and cultural identities. The strand met virtually over two days to engage in semi-structured discussions. The research recommendations presented below are the results of those discussions.

Issues and Future Directions in Family Support Research

Family support research needs to include the perspective of all family members, including people with IDD. More quantitative and qualitative research is needed to better

understand family support and generalize the findings. There is also a need to better understand families' experiences from different cultures and their perspectives on family support.

Including Self-Advocate and Family Perspectives

Many researchers have noted that failing to include the voices of people with IDD in research is an ongoing issue (e.g., Burke et al., 2015; Heller & Arnold, 2010; Heller et al., 2007). Further, it has been noted that there are differing views regarding the sometimes differing opinions of self-advocates and family members regarding the extent to which family perspectives should be considered (Hewitt et al., 2013). Researchers should explore family member dyads and multiple relationships in the family unit beyond dyads of siblings or other family members (Rossetti et al., 2020). It is also essential to ensure that self-advocates and family members who participate in research reflect the range of personal characteristics and experiences that individuals with IDD may have. Researchers should avoid partial representation, where claims are made for an entire group (e.g., all people with autism) when only a subset of that group is adequately engaged in the research (e.g., people with autism who use words to communicate; McCoy et al., 2020). This may include considering the roles of families for individuals with high support needs. It should also reflect the range of family structures and decision-making models that may differ across cultures.

Families, particularly parents, continue to provide an essential role in supporting individuals with IDD into adulthood. In a study in which adults with IDD identified their family networks, 91% listed parents as part of their significant family relationships as defined by the person (Giesbers et al., 2020). However, nearly a third (30%) also reported that they were significant support to someone in their families (Giesbers et al., 2020). According to Kerr and Brown (1998), families are complex social systems whose members influence each other's

behavior. This highlights the importance of approaching research from a family systems perspective, including understanding reciprocal roles in families, rather than focusing on individual family members to ensure that all family voices are heard, including individuals with IDD.

Siblings typically have the longest life relationship. Siblings of people with IDD provide a continuum of supports. They are the next generation of caregivers and advocates for their brothers and sisters with IDD (Heller & Kramer, 2009). Though many anticipate having a vital role in the lives of their brothers and sisters with IDD, they need more information and support (Heller & Kramer, 2009). Due to the inadequacy of the disability service system, siblings are needed to provide a higher level of caregiving (Burke et al., 2012).

Lack of Data

Most IDD-related national datasets (e.g., National Core Indicators) provide information on people receiving formal supports, making it difficult for policymakers to understand the full context of the caregiver experience. The National Core Indicators program includes a survey for families of adults with IDD that includes family outcomes such as choice and control, family outcomes, satisfaction, family involvement, community connections, access and support delivery, and information and planning; however, only 12 states participated in the 2020-2021 Adult Caregiver Survey (NCI, 2022). The National Caregiving Alliance and the AARP (2020) surveyed caregivers in the United States. While this study includes participants who support individuals with IDD, they represent only 9% of the sample. The University of Minnesota fielded the Family and Individual Needs for Disability Supports in conjunction with The Arc in 2017 and early 2023 (Anderson et al., 2018) and focused on family caregivers of individuals with IDD. One of the primary limitations of the 2017 survey was the lack of diversity in the sample

(Anderson et al., 2018). Results from the 2023 survey were not available when this article was written. Further, the Alzheimer's Association (2022) notes that the lack of diversity of participants in caregiver data and caregiver studies limits the ability to generalize or confirm findings or to look for deeper insights from the data.

Additional qualitative research is also needed to better understand the experiences and perspectives of families. Dyadic interviews may be used to get the perspective of the person with IDD and their family member, create a shared narrative, and analyze the interactions between participants (Morris, 2001). Though this has been done with sibling dyads (Rossetti et al., 2020), future research should examine multiple family relationships to better understand their roles, responsibilities, interactions, and support needs. Qualitative research is also needed to examine families of people with IDD with intersectional cultural and social identities.

Understanding Family Support From a Cross-Cultural Perspective

As previously noted, beliefs about disability and expectations regarding family roles and caregiving differ across cultures and from family to family. Understanding how families define these beliefs and expectations within their cultural context is necessary to effectively support families. Currently, most supports to families and individuals with IDD are provided from the frame of reference of the dominant culture of the United States, which values individualism over familism. One example is the self-determination principle that underpins much of the current supports and services system. However, Shogren (2011) noted that while there were some universal aspects to self-determination, how it was applied depended on cultural (and intersectional) contexts.

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Research Recommendations

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Improving Data

Caldwell and colleagues (2016) identified several recommendations to improve data about family caregivers. They recommended adding family caregiver questions to national surveys such as the American Community Survey (ACS) and the National Health Interview Survey (NHIS). Both of which would then gather caregiving information from national samples. The ACS would provide caregiver and household characteristics at a national, state, and local level. The NHIS would provide an understanding of the health status of caregivers on a national level. The Behavioral Risk Factor Surveillance System (BRFSS) included a caregiver question in 2009. Researchers were able to compare the well-being of caregivers across states. However, this question has not been asked since 2009 and should be reinstated (Caldwell et al., 2009). One of the benefits of these national survey programs is that, due to the sampling frame, they are generally representative of the overall population. This would enable researchers to compare caregiver outcomes across racially, culturally, and linguistically diverse groups as well as by age and household composition, enabling researchers to better understand LGBT families. Data improvements especially relevant to individuals with IDD include encouraging states to improve their reporting of family support services in Medicaid and family support services (e.g., respite or caregiver training). Finally, caregiver well-being questions could be added to the National Core Indicators (NCI) family surveys. However, not many states participate in the family surveys (between 10 and 15 states in any given year). NCI family survey participants only include caregivers of family members who receive long-term supports and services. Using national data sets allows for understanding the experiences of family caregivers of individuals with IDD who are not receiving disability-specific supports.

Areas of Future Research

The participants in the family strand of the State of the Science Conference identified four areas for future research: exploration and discovery, services and interventions, policy, and research.

Exploration and Discovery

Research is needed to better understand the experiences of minoritized families, particularly from a family systems perspective. Areas of interest include family strengths and resilience concerning family support, how families support individuals with IDD (particularly in families not using the formal DD service system), and the intersectional experiences of families with disability from minoritized communities.

Family research needs to include more longitudinal designs and systems analyses. It should be done with a family systems perspective that includes all family members, including the perspective of individuals with IDD (Hastings, 2016). Longitudinal research is needed to examine family transitions across the lifespan (Rossetti et al., 2020). Supporting families should be researched and understood using a lifecourse perspective, particularly since many individuals continue to live with a family member well into adulthood. Supports must change as families move through different life stages (Hecht & Reynolds, 2016).

Services and Interventions

There need to be efforts to identify how underserved families view the formal supports system and the barriers to access they face to better understand disparities. Access would need to be understood broadly and include physical and cognitive access, affordability, availability, accommodation, and, likely, the most critical area to understand regarding the needs of different cultural groups, acceptability. Understanding how families perceive and use services is key to developing interventions.

Policy

The primary policy research area proposed by the workgroup was the ability to understand the funding streams that are being used (or could potentially be used) to fund family supports and services, interventions, and other programs by state. This should include Medicaid-funded long-term supports and services. However, family support programs must be included outside of the Medicaid-funded long-term supports and services programs.

Research

The final recommendation for research activities was to identify effective research strategies to be more inclusive of families from minoritized groups. This would include recruitment strategies and community-based research methodologies, and novel data analysis techniques aimed at reducing disparities that may include statistical techniques such as Bayesian analyses (allowing for more robust analyses of small samples). Ideally, research would be designed and implemented using a data equity framework.

Conclusion

While increasing research has focused on families from some minoritized groups, particularly across certain races and ethnicities (e.g., Latine families), most of the studies are small. They are often comparing two groups within the caregiver population. Few studies look at outcomes for individuals who are and are not caregivers to understand the additive effects of intersectionality. Research that uses family systems frameworks is needed to understand family resilience, how family members influence and support each other, and the impact of family beliefs, roles, and expectations.

While there has been an increase in sibling research, other family members, including grandparent caregivers, spouses, and fathers, need to be included in supporting family research.

Finally, further research is needed about families rarely included in supporting family research, such as LGBTQ families.

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