

# Research

Natural Supports: The Impact on People with Intellectual and Developmental Disabilities' Quality of Life and Service Expenditures



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NATURAL SUPPORTS

**Natural Supports: The Impact on People with Intellectual and Developmental Disabilities'  
Quality of Life and Service Expenditures**

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**Acknowledgements:**

Thank you to the state developmental disabilities department for collaborating. Thank you to Mary Kay Rizzolo for reviewing this manuscript and providing feedback.

**Declaration of interest statement:**

No potential conflict of interest is reported by the author

**Citation:**

Friedman, C. (2021) Natural supports: the impact on people with intellectual and developmental disabilities' quality of life and service expenditures. *Journal of Family Social Work*.

<http://doi.org/10.1080/10522158.2020.1861158>

**The Version of Record of this manuscript has been published and is available in *Journal of Family Social Work* (January 11, 2021)**

<http://www.tandfonline.com/10.1080/10522158.2020.1861158>

### Abstract

Natural supports are informal (unpaid) relationships that support people with intellectual and developmental disabilities (IDD) in their natural environments and communities. A wide range of people can serve as natural supports for people with IDD, such as family (both biological and chosen), friends, neighbors, community members, etc. Natural supports can positively impact people's relationships, and community integration. The aim of this study was to examine the connection between natural supports for people with IDD, quality of life, and service expenditures. To do so, we analyzed secondary Personal Outcome Measures<sup>®</sup> quality of life data and service expenditure data ( $n = 251$ ) using linear regression models. Our findings suggest people with IDD with natural supports have better quality of life than people without natural supports. In addition, LTSS service expenditures were \$20,000 lower on average for people with IDD with natural supports compared to people without natural supports, regardless of their demographics. As such, we believe natural supports have the potential to improve people with IDD's lives, build their relationships, and help them integrate into their communities. However, there is danger in utilizing natural supports *in lieu of* formal services solely for cost-cutting, particularly in a service system that is already underfunded.

**Keywords:** People with intellectual and developmental disabilities; natural supports; relationships; quality of life; service expenditures

**Natural Supports: The Impact on People with Intellectual and Developmental Disabilities’  
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Natural supports are informal (unpaid) relationships that support people with intellectual and developmental disabilities (IDD) in their natural environments and communities (Chow, 2018; Duggan & Linehan, 2013; Kelley & Westling, 2013; Tsai et al., 2012). The concept of utilizing natural supports to promote community integration of people with IDD first emerged during the 1970s, when there was an effort to expand community supports for people with IDD, and also fiscal limitations and the need for cost-effective service delivery (Duggan & Linehan, 2013).

A wide range of people can serve as natural supports, such as family (both biological and chosen), friends, neighbors, community members, etc. However, natural supports should be developed based on the person with IDD’s “environment, interests, passions, ambitions... and desires. When the [person] has the opportunities to pursue their interests, passions, desires or needs [they are] able to develop these natural supports in a casual setting” (Chow, 2018, p. 9).

Natural supports can play a wide variety of roles in people’s lives. For example, they may provide emotional support, such as facilitating self-esteem, coping, and self-efficacy (Chow, 2018; Ingram & Drew-Branch, 2017). Natural supports can help with logistics, including accessing information and resources (Chow, 2018; Ingram & Drew-Branch, 2017). They can promote skill building and support people to achieve their goals (Chow, 2018; Duggan & Linehan, 2013; Ingram & Drew-Branch, 2017). Natural supports can also help promote social and community integration (Claes et al., 2012; Duggan & Linehan, 2013; Tsai et al., 2012), which is especially pertinent for people with IDD as they often experience social exclusion and isolation, even when physically living in the community (Duggan & Linehan, 2013; Friedman,

2019, 2020). In fact, Duggan and Linehan (2013) suggest a lack of natural supports is one reason people with disabilities cannot participate in their communities in the way they want to.

Having natural supports benefits people, including people with IDD, in a multitude of ways (Kelley & Westling, 2013). For example, natural supports can increase people's social connectedness and community integration, including by serving as a source of emotional support (Ingram & Drew-Branch, 2017). Not only can they help alleviate stress, they also promote security (Ingram & Drew-Branch, 2017; Peer & Hillman, 2014; The Council on Quality and Leadership, 2017b). People who have natural supports are less likely to participate in high-risk behavior; the presence of natural supports also reduces and prevents self-harm (Ingram & Drew-Branch, 2017).

Natural supports can connect people with meaningful opportunities. For example, research has found that natural supports promote successful supported employment for people with severe psychiatric disabilities, and improves job tenure (Corbière et al., 2014; Villotti et al., 2017). During transition from high school, natural supports can help ensure people have meaningful opportunities, including those related to education, work, housing, and community life (Chow, 2018). In addition to preventing people from falling through the cracks, natural supports often lead to people having more control over, and involvement in, their lives (Chow, 2018; Ingram & Drew-Branch, 2017).

Beyond the benefits for those people with IDD who have natural supports, natural supporters benefit from these relationships as well. Being a natural supporter often leads to meaningful relationships, leadership opportunities, engagement, and skill building (Kelley & Westling, 2013). Natural supporters working with people with IDD have more positive views of people with IDD and more knowledge about people with IDD's life experiences (Kelley &

Westling, 2013). These benefits for natural supporters themselves can make them better supporters – natural supporters will be more familiar with the lived experiences of people with IDD, and have more skills to provide support – which in turn will also serve to benefit people with IDD.

### ***Purpose***

It is also suggested that natural supports could result in more cost-effective service delivery because of the utilization of non-disability specific services, and community and family supports; it can also improve different areas of people with IDD's lives (Chow, 2018; Claes et al., 2012; Duggan & Linehan, 2013). Yet, there is less research examining the impact natural supports can specifically have on service expenditures, or how they can improve people with IDD's quality of life more broadly. For these reasons, the aim of this study was to examine the connection between natural supports for people with IDD, quality of life, and service expenditures. We had two research questions: (1.) what is the relationship between natural supports and the quality of life of people with IDD? and; (2.) what is the relationship between natural supports and service expenditures of people with IDD? To explore these research questions, we analyzed secondary Personal Outcome Measures<sup>®</sup> data and service expenditure data from a random sample of 251 people with IDD.

## **Methods**

### ***Data and Participants***

This study was a secondary data analysis, as such our institutional review board (IRB) determined it was exempt from review. The data were originally collected from adults with IDD who received services from one state's developmental disabilities department. This southern state has a moderately large population size and gross domestic product, both within the top third

of states. As part of its quality monitoring, the state developmental disabilities department interviewed a random selection of service recipients utilizing the Personal Outcome Measures<sup>®</sup> in 2018. The department then pulled the applicable long-term services and supports (LTSS) service expenditure data (2018) about the sample. After the data were coded with identifiers and all personal identifiers were removed, the data were transferred to the research team.

A total of 251 people with IDD were in our sample (Table 1). Slightly more participants were men (52.19%) than women (47.81%). Of the participants, 71.43% were White, 25.71% were Black, and 2.86% were from other races (this breakdown is similar to the demographics of the state). Age was relatively evenly distributed amongst participants. The majority of participants primarily communicated through verbal/spoken language (80.1%). All participants lived in the community; in terms of specific settings, participants lived in provider-owned or -operated homes (38.3%), their own homes or apartments (31.1%), family homes (22.7%), and other settings (8.0%). The participants had the following intellectual disability clinical (DSM) diagnoses: mild (40.0%); moderate (33.1%); severe (13.9%); and, profound (13.1%). Of the participants, 10.7% had complex medical support needs (required skilled nursing care 12+ hours per day) and 16.8% of people had comprehensive behavior support needs (required 24-hour supervision due to risk of harm or dangerous behavior).

### ***Measure***

We utilized the Personal Outcome Measures<sup>®</sup> (The Council on Quality and Leadership, 2017b) in this study. The Personal Outcome Measures<sup>®</sup> is designed to determine people with disabilities' quality of life, including self-determination, choice, self-advocacy, and supports, in a person-centered manner. Developed over 25 years ago based on focus groups with people with disabilities, family members, and key stakeholders about what really mattered in people with

disabilities' lives, the measure has been continuously refined over the years through pilot testing, 26 years of administration, commission of research and content experts, a Delphi survey, feedback from advisory groups, and validation testing (The Council on Quality and Leadership, 2017b). The Personal Outcome Measures<sup>®</sup> has construct validity, and reliability, as interviewers need to pass reliability tests with at least 85% agreement before being certified (Friedman, 2018; The Council on Quality and Leadership, 2017a).

The Personal Outcome Measures<sup>®</sup> includes 21 indicators divided into five factors: my human security; my community; my relationships; my choices; and, my goals (Table 2). Personal Outcome Measures<sup>®</sup> administration occurs in three stages. During the first stage, the interviewer has an in-depth conversation/s with the participant with IDD. The interviewer follows specific open-ended prompts regarding all 21 indicators. During the second stage, the interviewer speaks with someone who knows the person with IDD best and knows about organizational supports (e.g., support coordinator, direct support professional, etc.) and asks them questions about individualized supports and outcomes to fill in any gaps. During the final stage, if necessary, the interviewer observes the participant in various settings and/or conducts record reviews, and then completes decision-trees about personal outcomes and individualized supports are present (1) or not (0) based on all information gathered.

### ***Variables***

*Quality of life.* Our first dependent variable (DV) was quality of life outcomes. Quality of life outcomes were derived from the Personal Outcome Measures<sup>®</sup>. The Personal Outcome Measures<sup>®</sup> includes a total of 21 quality of life outcomes; these outcomes, with the exception of natural supports since it was the independent variable (IV; so out of 20), were aggregated to serve as people with IDD's total quality of life outcome score.



*Service expenditures.* Our other DV was LTSS service expenditures. In contrast to episodic acute care services, LTSS go beyond health and wellness, and typically cover more wrap-around services related to quality of life more broadly. For example, Home and Community Based Services (HCBS) LTSS often include medical and psychological services, but also personal care, residential supports, employment supports, transportation, respite, family supports, and many more (Friedman, 2017). The package of services a person receives may range based on their needs and wants, and therefore so can their expenditures.

The state provided us with the total aggregate expenditures for all LTSS for each person in the sample. The data included all of 2018 (calendar year).

*Natural supports.* The IV for this study was natural support. The presence of natural supports came from the Personal Outcome Measures<sup>®</sup> discovery tool, specifically the ‘people are connected to natural support networks’ outcome. Suggested questions for Personal Outcome Measures<sup>®</sup> interviewers regarding this indicator include:

- “Who are the people in your life that you can count on?”
- Who do you want to talk to or be with when you go through tough times?
- Who do you want to share your successes with? How do you maintain contact with these people?
- Have you lost contact with family members or others?
- Is the contact you have enough for you? If not, what is the reason?
- What type or frequency of contact would you prefer?
- What do you think could be done to change the situation?
- Where do you get emotional strength?

- Do you know who is part of the person’s natural support network? (for supporter interview)
- Do you know if the person is satisfied with his or her contact with these people? (for supporter interview)
- What assistance is provided to maintain the person’s contact with his or her family and others who provide emotional support? (for supporter interview)” (The Council on Quality and Leadership, 2017b, p. 53)

For the natural support outcome to be considered present (yes (1); no (0)), answers to both of the following questions must be yes: “Does the person have a natural support network? If the answer is yes, does the person have enough contact with the people in their natural support network?” (The Council on Quality and Leadership, 2017b, p. 54). (If the person does not have a natural support network due to informed personal choice, the outcome is also considered present.)

### *Analysis*

Our first research question was: what is the relationship between natural supports and the quality of life of people with IDD? To explore this research question, we ran a linear regression model examining the relationship between natural supports (IV) and total quality of life outcomes (DV), controlling for participant demographics (i.e., age; complex medical support needs; comprehensive behavior support needs; gender; guardianship status; intellectual disability diagnosis; primary communication method; race, and residence type).

Our second research question was: what is the relationship between natural supports and service expenditures of people with IDD? To explore this research question, we ran a linear regression model examining the relationship between natural supports (IV) and total service expenditures (DV), controlling for participant demographics (i.e., age; complex medical support

needs; comprehensive behavior support needs; gender; guardianship status; intellectual disability diagnosis; primary communication method; race, and residence type).

### **Results**

Of the 251 people with IDD in the study, 32.3% ( $n = 81$ ) were connected to natural support networks, while 67.7% ( $n = 170$ ) were not connected to natural support networks. On average, the people with IDD in the study had 8.5 quality of life outcomes present out of 20 ( $SD = 3.5$ ); quality of life outcomes present ranged from 1 to 18. On average, the people with IDD in the study had \$92,154 of expenditures in 2018 ( $SD = \$75,045$ ). Service expenditures ranged from \$128 to \$345,465 for the year.

#### ***Natural Supports and Quality of Life***

We ran a linear regression model to examine the relationship between natural supports (IV) and quality of life outcomes (DV), controlling for participant demographics. The model was significant,  $F(18, 232) = 2.44, p < 0.001, R^2 = 0.17$ . According to the model, controlling for all other variables, when people with IDD were connected to natural support networks, they had higher quality of life (Table 3); people that were connected to natural support networks had 11.1 out of 20 quality of life outcomes present (55.3%), whereas people without natural support networks had 9.3 out of 20 quality of life outcomes present (46.4%; see Figure 1).

One control variable was also significant: guardianship status. According to the model, controlling for all other variables, people with independent decision-making had more quality of life outcomes present (9.3 out of 20; 46.4%) than people with assisted decision-making (8.1 out of 20; 40.7%), people with full/plenary guardianship (7.4 out of 20; 36.8%), and people with 'other' forms of guardianship (6.1 out of 20; 30.5%).

#### ***Natural Supports and Service Expenditures***

We also ran a linear regression model to examine the relationship between natural supports (IV) and expenditures (DV), controlling for participant demographics. The model was significant,  $F(18, 220) = 12.67, p < 0.001, R^2 = 0.53$ . According to the model, controlling for all other variables, when people with IDD were connected to natural supports, there were significantly lower service expenditures (Table 4). People that were connected to natural supports had \$100,185 of service expenditures per person on average, whereas people without natural support networks had \$120,531 of service expenditures per person on average (see Figure 2).

The following control variables were also significant: complex medical support needs; comprehensive behavior support needs; intellectual disability diagnosis level; and, residence type. According to the model, controlling for all other variables, people with complex medical support needs had higher service expenditures (\$148,119) than those without these support needs (\$120,531). Controlling for all other variables, people with comprehensive behavior support needs had higher service expenditures (\$181,567) than those without these support needs (\$120,531). Controlling for all other variables, people with an intellectual disability diagnosis of profound had higher service expenditures (\$153,867) than people with a diagnosis of mild (\$120,531). Controlling for all other variables, people who lived in provider homes had higher service expenditures (\$120,531) than those people who lived in family homes (\$21,154) and people in 'other' residential settings (\$39,262).

### **Discussion**

Natural supports can help promote social and community integration, meaningful opportunities, social capital and relationships, and emotional well-being; it is theorized that they may also be able to help reduce service expenditures (Chow, 2018; Claes et al., 2012; Corbière et

al., 2014; Duggan & Linehan, 2013; Ingram & Drew-Branch, 2017; Kelley & Westling, 2013; Tsai et al., 2012; Villotti et al., 2017). For these reasons, this study explored the relationships between natural supports for people with IDD, and quality of life and service expenditures. Our findings suggested people with IDD in our study with natural supports had better quality of life than people without natural supports – controlling for all other variables, people with natural supports’ overall quality of life outcomes were 9% higher. In addition to being associated with increased quality of life, our findings also suggest an association between natural supports and lower expenditures. LTSS service expenditures were \$20,000 lower on average for people with IDD with natural supports compared to people without natural supports, regardless of their demographics. As such, our findings suggest natural supports have the potential to reduce costs, and also improve people with IDD’s lives and help them integrate into their communities.

The use of natural supports to promote community integration may be particularly useful for people with IDD who often experience social isolation even when they live physically in the community (Friedman, 2019, 2020). In fact, people supported by provider agencies often have smaller social networks (Duggan & Linehan, 2013; Fulford & Cobigo, 2018). Duggan and Linehan (2013) note, many people with IDD “experience a ‘Catch 22’, whereby they find it difficult to live independently and engage in community activities because they have few friends who could support them, but they have difficulty making friendships because they are excluded from their communities” (p. 205).

Moreover, unlike natural supports, professional staff often play a more ‘caring’ role as a form of risk aversion, rather than a supportive role, one hindering people’s opportunities (Duggan & Linehan, 2013). This may be in part due to the fact that many staff who provide the most support have the fewest qualifications, and many states do not require standards for direct

support staff beyond a high school diploma (or equivalent), passing a criminal background check, and a driver's license (Hewitt, 2014; Wachino, 2016). States also provide little guidance to provider agencies about training, resulting in a lack of consistency and gaps in skills (National Direct Service Workforce Resource Center, 2013). This lack of training directly impacts people with IDD as a fear that staff are not prepared to mitigate risks is one of the leading reasons people with disabilities are kept at home (Britton Laws et al., 2014). Rather than merely fulfilling a 'caring' role, staff should be trained to support people with IDD to develop and/or maintain relationships and connections based on people's choices and preferences, which could blossom into natural supports (The Council on Quality and Leadership, 2017b).

When utilized properly, natural supports can substitute for some formal services because of their association with non-disability specific services and community and family supports, and thus produce cost savings (Duggan & Linehan, 2013; Tsai et al., 2012). However, there is danger in utilizing natural supports *in lieu of* providing formal services solely for cost-cutting – we do *not* believe our findings should be interpreted to mean natural supports should replace all formal services and supports. In fact, it is important to recognize that the IDD LTSS system is already underfunded. For example, 589,940 people with IDD were waiting for Medicaid HCBS as of 2018 and the number continues to grow (The Henry J. Kaiser Family Foundation, n.d.). In addition, families of people with IDD already face an increased burden – the United States LTSS system is built largely upon unpaid informal labor (Gallanis & Gittler, 2012; Rizzolo et al., 2009). In fact, only 13% of people with IDD received formal out-of-home LTSS (fiscal year 2013; Braddock et al., 2015, based on Fujaira, 2012). Not only is unpaid caregiving associated with physical and emotional caregiver stress, it is also associated with poor caregiver health (Gallanis & Gittler, 2012; Maes et al., 2003; National Alliance for Caregiving & AARP, 2015).

In addition, unpaid caregiving puts a financial burden on families, resulting in increased out-of-pocket expenses as well as negatively impacting caregivers' formal employment (Gallanis & Gittler, 2012; National Alliance for Caregiving & AARP, 2015). This extra burden placed on families can impact the quality of their caregiving for the person with IDD, and also result in families no longer being able to care for the person with IDD, and the person having to move to other residential settings (Friedman, 2020).

Instead, we argue natural supports should embrace interdependence. Interdependence is “a powerful concept built from mutual respect, which ‘implies an interconnection, or an interrelationship between two entities’ ... all people are different, but through a framework of interdependence, differences are valued and all parties are empowered” (Bacon et al., 2017, p. 2). Interdependence challenges deficit-based understandings of disability (Bacon et al., 2017), and puts the person with disabilities in the driver's seat of their own lives because by its very nature it focuses on strengths and relationships, and is person-centered (Condeluci, 2014). For example, instead of focusing on independence, which might not be important or even possible for some people, interdependence allows people with disabilities to “use that energy for more satisfying activities” (Bacon et al., 2017, p. 2). In addition, interdependence is rooted in empowerment and self-determination (Ashby et al., 2015; Condeluci, 2014; Scott & Doughty, 2012). Interdependence as a framework for support also means services are not driven by professionals, but by people with IDD themselves (Condeluci, 2014; Ingram & Drew-Branch, 2017).

Embracing natural supports, and by extension interdependence, also reflects the values of self-advocacy and disability culture, which have long incorporated interdependence into their tenets. The IDD self-advocacy movement draws on the importance of interdependence,

especially when it comes to empowerment and self-determination (Goodley, 1997; Nonnemacher & Bambara, 2011). For example, interdependence is often evident during self-advocacy meetings where self-advocates assist each other where needed (Spassiani & Friedman, 2014). Gill (1995) even considers interdependence to be a core value of wider (non-IDD specific) disability culture.

Although in the United States there is a focus on individualism, *all* people are interdependent (Ashby et al., 2015; Ingram & Drew-Branch, 2017). As such, Rosenbaum (2007) suggests, “ideally, every housing unit, including those officially designated for supported living, would rely on natural supports to accomplish day-to-day tasks and supply all the other comforts of a home” (p. 173). Others, such as Keogh (2011), suggest that natural supports be used as “the first line of supports, followed by informal and community supports, to formalised (sic) individual supports” (p. 15).

### ***Other Factors Impacting Quality of Life and Service Expenditures***

Although not the main aim of our study, there were a number of control variables that had significant relationships with our dependent variables (quality of life and service expenditures). For example, people with IDD in our study with guardianship faced disparities in quality of life outcomes, regardless of the presence of natural supports. While there may be an interaction between guardianship and impairment severity that should be explored by future studies, it is important to note that in the United States courts tend to give guardians broad sweeping powers beyond just what the individual needs assistance with (Doron et al., 2013; Salzman, 2011). In fact, Salzman (2011) argues the current guardianship system violates the Americans with Disabilities Act (ADA) and *Olmstead v. L.C.* because it not only limits people’s decision-making rights, but also does not do so in a least restrictive manner. As such, the relationship between guardianship and lower quality of life in our study may also be a result of



guardians limiting people with IDD's ability to participate in opportunities and make choices; future research should explore this relationship.

In addition, in our study, controlling for natural supports, people with IDD with complex medical support needs, comprehensive behavior support needs, and a diagnosis of profound intellectual disability had higher total service expenditures than people with IDD without these support needs. We theorize this may be because people with these needs may utilize more services to support them, thereby incurring more costs. It may also be that complex medical, psychological, psychiatric, and/or behavior services have more expensive reimbursement rates than other types of services. Although people with more significant needs had higher total service expenditures in our study, it is important to recognize that complex medical and behavior supports help prevent re-/institutionalization (Lulinski-Norris et al., 2012; Lulinski, 2014). If anything, a stronger community infrastructure is necessary to help people with more significant needs stay in the community.

Finally, controlling for all other variables, there was a relationship between residential settings and total service expenditures. As a function of their design, service systems, and physical infrastructures, some residence types cost more than others (Braddock et al., 2017). This finding may also in part be due to the difference between the two types of LTSS HCBS waivers: support waivers; and comprehensive waivers. (HCBS waivers are the main Medicaid funding mechanism for HCBS for people with IDD (Braddock et al., 2017); they allow states to create community-based service packages tailored to populations that would otherwise require institutional care.) While comprehensive waivers provides a wide range of services, including residential supports in licensed settings – they are comprehensive – support waivers tend to rely on unpaid supports and do not include residential habilitation (Friedman, 2017; Rizzolo et al.,

2013). Support waivers typically include a fraction of funding for people compared to comprehensive waivers – in fiscal year 2015 the cost of support waivers was 26% of the average cost per person for comprehensive waivers (Friedman, 2017). We also suggest that the relationships between residence type, natural supports, and impairment severity be explored further as there may be interactions at play. For example, Claes et al. (2012) found that people with higher support needs were less likely to have natural supports, but Claes et al. suggest it is likely due to the fact that they live in settings which serve as barriers to developing and/or maintaining natural supports.

### *Implications for Practice and Research*

People with IDD and their families face many challenges, in part because of the limitations of the service system. Natural supports, which can include family members, can be a resource even when a person with IDD cannot access formal funding mechanisms and/or formal service structures. This is particularly important as so many people with IDD are on waiting lists for HCBS. While natural supports alone cannot fill in all the gaps of service provision, they can promote people with IDD's quality of life, provide a sense of security, and serve as a safety net for people with IDD. As such, social workers and other family practitioners should help support people with IDD to form, maintain, and grow natural support networks. Practitioners can help build people's capacity for support networks, particularly in ways that align with people's preferences and choices. They can help assist people to make connections with natural supporters. Sometimes this may be as simple as ensuring people with IDD have transportation or know how to use transportation to get to places where they can make or maintain a natural support network. Other times it may be more complex, such as helping people with IDD who have lost contact with their families to re-establish connection and grow those family

relationships into natural support networks. Practitioners can also work with family members who wish to serve as natural supporters to develop and grow the skills they need to serve as effective supporters.

In addition, research should continue to explore natural supports for people with IDD, including the best ways for practitioners to help facilitate them. For example, what is the best way for clinicians to facilitate natural support networks? What makes the most effective natural supporter? How can natural supporters help compensate for the burden placed on unpaid family caregivers? How do natural supporters impact family dynamics? These are only a few of many possible avenues for future research to explore the relationship between natural support networks and people with IDD.

Finally, states should introduce mechanisms and funding to promote the availability and use of natural supports in LTSS for people with IDD. In doing so, research should also be conducted to determine the best ways to promote natural supports in LTSS, particularly in ways that do not put an increased burden on family members, as well as how state natural support efforts improve people with IDD's quality of life.

### ***Limitations***

When interpreting the findings from this study, a number of limitations should be noted. This was not a representative sample. All the participants in this study represented one state. All participants were also receiving services from the state's developmental disabilities department, whereas most people with IDD in the United States receive informal services from family members (Braddock et al., 2015). In addition, this study was a secondary data analysis – we did not have the ability to add additional variables or questions, or select participants. For example, we did not have data about different types of natural support connections. The data in this study

was also cross-sectional. Finally, natural supports was removed from the aggregate quality of life variable in order to explore the relationship between natural supports and quality of life.

### ***Conclusion***

While natural supports – relational connections with common interests, goals, and attitudes – exist in all communities, if, and how, they are engaged varies (Ingram & Drew-Branch, 2017). People with IDD, who are often isolated and want more opportunities to make friends and relationships (Friedman, 2019, 2020; Ligas Consent Decree Monitor, 2017), would benefit from more natural supports (Duggan & Linehan, 2013). For example, most people with IDD in our study did not have natural support networks in their lives. According to research, natural supports can help promote social and community integration of people with IDD (Claes et al., 2012; Duggan & Linehan, 2013; Tsai et al., 2012). According to our findings, natural supports also represent an opportunity to promote people with IDD's quality of life, and also for cost-effective service delivery. As such, we believe natural supports should be utilized more frequently with people with IDD, particularly in a way that embraces interdependence, empowerment, and self-determination.

### References

- Ashby, C., Jung, E., Woodfield, C., Vroman, K., & Orsati, F. (2015). 'Wishing to go it alone': the complicated interplay of independence, interdependence and agency. *Disability & Society*, 30(10), 1474-1489. <https://doi.org/10.1080/09687599.2015.1108901>
- Bacon, J. K., Orsati, F., Floyd, S., & Khater, H. (2017). "Friends give meaning to life:" Reframing friendship for individuals with autism that type to communicate. *Review of Disability Studies: An International Journal*, 13(3).
- Braddock, D., Hemp, R., Rizzolo, M. C., Tanis, E. S., Haffer, L., & Wu, J. (2015). *The state of the states in intellectual and developmental disabilities: Emerging from the great recession* (10th ed.). The American Association on Intellectual and Developmental Disabilities.
- Braddock, D., Hemp, R., Tanis, E. S., Wu, J., & Haffer, L. (2017). *The state of the states in intellectual and developmental disabilities: 2017* (11th ed.). The American Association on Intellectual and Developmental Disabilities.
- Britton Laws, C., Kolomer, S. R., & Gallagher, M. J. (2014). Age of persons supported and factors predicting intended staff turnover: A comparative study. *Inclusion*, 2(4), 316-328. <https://doi.org/10.1352/2326-6988-2.4.316>
- Chow, M. (2018). *Inclusion of natural supports during the transition to adulthood for youth with complex communication needs: A review of selected literature* (<https://www.calgaryandarearcsd.ca/assets/Uploads/eNewsletter/Literature-Review-CCN-YTA-MChow-2019-01-18.pdf>)
- Claes, C., Van Hove, G., Vandeveld, S., van Loon, J., & Schalock, R. (2012). The influence of supports strategies, environmental factors, and client characteristics on quality of life-

- related personal outcomes. *Research in Developmental Disabilities*, 33(1), 96-103.  
<https://doi.org/10.1016/j.ridd.2011.08.024>
- Condeluci, A. (2014). Interdependence, inclusion and self-determination. *Interaction: The Australian magazine on intellectual disability*, 27(3), 1-6.
- Corbière, M., Villotti, P., Lecomte, T., Bond, G. R., Lesage, A., & Goldner, E. M. (2014). Work accommodations and natural supports for maintaining employment. *Psychiatric rehabilitation journal*, 37(2), 90. <https://doi.org/10.1037/prj0000033>
- Doron, A., Kurs, R., Stolovy, T., Secker-Einbinder, A., & Raba, A. (2013). Voting rights for psychiatric patients: compromise of the integrity of elections, or empowerment and integration into the community? *The Israel journal of psychiatry and related sciences*, 51(3), 169-174.
- Duggan, C., & Linehan, C. (2013). The role of ‘natural supports’ in promoting independent living for people with disabilities; a review of existing literature. *British Journal of Learning Disabilities*, 41(3), 199-207. <https://doi.org/10.1111/bld.12040>
- Friedman, C. (2017). A national analysis of Medicaid Home and Community Based Services waivers for people with intellectual and developmental disabilities: FY 2015. *Intellectual and Developmental Disabilities*, 55(5), 281-302. <https://doi.org/10.1352/1934-9556-55.5.281>
- Friedman, C. (2018). The Personal Outcome Measures<sup>®</sup>. *Disability and health journal*, 11(3), 351–358. <https://doi.org/10.1016/j.dhjo.2017.12.003>
- Friedman, C. (2019). The influence of residence type on personal outcomes. *Intellectual and Developmental Disabilities*, 57(2), 112-126. <https://doi.org/10.1352/1934-9556-57.2.112>

- Friedman, C. (2020). *There's no place like home: A national study of how people with intellectual and/or developmental disabilities and their families choose where to live*. The Arc of the United States and CQL | The Council on Quality and Leadership.
- Fulford, C., & Cobigo, V. (2018). Friendships and intimate relationships among people with intellectual disabilities: A thematic synthesis. *Journal of Applied Research in Intellectual Disabilities*, 31(1), e18-e35. <https://doi.org/10.1111/jar.12312>
- Gallanis, T. P., & Gittler, J. (2012). Family caregiving and the law of succession: A proposal. *University of Michigan Journal of Law Reform*, 45(4), 13-12.
- Gill, C. J. (1995). A psychological view of disability culture. *Disability Studies Quarterly*, 15(4), 16-19.
- Goodley, D. (1997). Locating self-advocacy in models of disability: Understanding disability in the support of self-advocates with learning difficulties. *Disability & Society*, 12(3), 367-379. <https://doi.org/10.1080/09687599727227>
- Hewitt, A. (2014). Presidential address, 2014—Embracing complexity: Community inclusion, participation, and citizenship. *Intellectual and Developmental Disabilities*, 52(6), 475-495. <https://doi.org/10.1352/1934-9556-52.6.475>
- Ingram, L., & Drew-Branch, V. (2017). Taking what we have and making what we need: Utilizing natural helping support networks to decrease self directed violence among adolescents of color. *Journal of Family Strengths*, 17(1).
- Kelley, K. R., & Westling, D. L. (2013). A focus on natural supports in postsecondary education for students with intellectual disabilities at Western Carolina University. *Journal of Vocational Rehabilitation*, 38(1), 67-76. <https://doi.org/10.3233/JVR-120621>

Keogh, F. (2011). *Report of disability policy review*

([http://fedvol.ie/fileupload/Next%20Steps/ERG\\_Disability\\_Policy\\_Review\\_Final.pdf](http://fedvol.ie/fileupload/Next%20Steps/ERG_Disability_Policy_Review_Final.pdf))

Ligas Consent Decree Monitor. (2017). *Stanley Ligas, et al. v. Felicia Norwood, et al.: Fifth annual report of the Monitor*. Author

Lulinski-Norris, A., Rizzolo, M. C., & Heller, T. (2012). *An analysis of movement from state operated developmental centers in Illinois*. Institute on Disability and Human Development, University of Illinois at Chicago.

Lulinski, A. (2014). *Community capacity to provide mental/behavioral health services to people with developmental disabilities*].

Maes, B., Broekman, T., Došen, A., & Nauts, J. (2003). Caregiving burden of families looking after persons with intellectual disability and behavioural or psychiatric problems. *Journal of Intellectual Disability Research*, 47(6), 447-455. <https://doi.org/10.1046/j.1365-2788.2003.00513.x>

National Alliance for Caregiving, & AARP. (2015). *Caregiving in the U.S. 2015*. Authors.

National Direct Service Workforce Resource Center. (2013). *Understanding your HCBS direct service workforce's strengths and preparing the workforce to serve all populations with core competency training*. [Paper presentation]. National HCBS Conference, Arlington, VA.

Nonnemacher, S. L., & Bambara, L. M. (2011). "I'm supposed to be in charge": Self-advocates' perspectives on their self-determination support needs. *Intellectual and Developmental Disabilities*, 49(5), 327-340. <https://doi.org/10.1352/1934-9556-49.5.327>

Peer, J. W., & Hillman, S. B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations



for practitioners. *Journal of Policy and Practice in Intellectual Disabilities*, 11(2), 92-98.

<https://doi.org/10.1111/jppi.12072>

Rizzolo, M. C., Friedman, C., Lulinski-Norris, A., & Braddock, D. (2013). Home and Community Based Services (HCBS) Waivers: A nationwide study of the states.

*Intellectual and Developmental Disabilities*, 51(1), 1-21. <https://doi.org/10.1352/1934-9556-51.01.001>

Rizzolo, M. C., Hemp, R., Braddock, D., & Schindler, A. (2009). Family support services for persons with intellectual and developmental disabilities: Recent national trends.

*Intellectual and Developmental Disabilities*, 47(2), 152-155.

<https://doi.org/10.1352/1934-9556-47.2.152>

Rosenbaum, S. A. (2007). Representing David: When best practices aren't and natural supports really are. *UC Davis Journal of Juvenile Law & Policy*, 11(1), 161-180.

Salzman, L. (2011). Guardianship for persons with mental illness: A legal and appropriate alternative? *Saint Louis University Journal of Health Law & Policy*, 4, 279-330.

Scott, A., & Doughty, C. (2012). Care, empowerment and self-determination in the practice of peer support. *Disability & Society*, 27(7), 1011-1024.

<https://doi.org/10.1080/09687599.2012.695578>

Spassiani, N. A., & Friedman, C. (2014). Stigma: Barriers to culture and identity for people with intellectual disability. *Inclusion*, 2(4), 329-341. [https://doi.org/10.1352/2326-6988-](https://doi.org/10.1352/2326-6988-2.4.329)

[2.4.329](https://doi.org/10.1352/2326-6988-2.4.329)

The Council on Quality and Leadership. (2017a). *The Personal Outcome Measures® 2017: Measuring outcomes now and into the future*. Author.

- The Council on Quality and Leadership. (2017b). *Personal Outcome Measures<sup>®</sup>: Measuring personal quality of life* (3rd ed.). Author.
- The Henry J. Kaiser Family Foundation. (n.d.). *Waiting list enrollment for Medicaid Section 1915(c) Home and Community-Based Services Waivers* <https://www.kff.org/health-reform/state-indicator/waiting-lists-for-hcbs-waivers/?currentTimeframe=0&sortModel=%7B%22colId%22:%22Location%22,%22sort%22:%22asc%22%7D>
- Tsai, J., Desai, R. A., & Rosenheck, R. A. (2012). Social integration of people with severe mental illness: Relationships between symptom severity, professional assistance, and natural support. *The journal of behavioral health services & research*, 39(2), 144-157. <https://doi.org/10.1007/s11414-011-9266-7>
- Villotti, P., Corbière, M., Fossey, E., Fraccaroli, F., Lecomte, T., & Harvey, C. (2017). Work accommodations and natural supports for employees with severe mental illness in social businesses: An international comparison. *Community mental health journal*, 53(7), 864-870. <https://doi.org/10.1007/s10597-016-0068-5>
- Wachino, V. (2016). *CMCS informational bulletin: Suggested approaches for strengthening and stabilizing the Medicaid home care workforce*. Centers for Medicare and Medicaid Services

Table 1  
*Participant Demographics (n = 251)*

Variable	<i>n</i>	%
Complex medical support needs ( <i>n</i> = 244)		
No	218	89.34
Yes	26	10.66
Comprehensive behavioral support needs ( <i>n</i> = 244)		
No	203	83.20
Yes	41	16.80
Gender		
Man	131	52.19
Woman	120	47.81
Guardianship status		
Independent decision making	61	24.30
Assisted decision making	121	48.21
Full/plenary guardianship	62	24.70
Other	7	2.79
Intellectual disability diagnosis ( <i>n</i> = 245)		
Mild	98	40.00
Moderate	81	33.06
Severe	34	13.88
Profound	32	13.06
Primary method of communication		
Verbal/spoken language	201	80.08
Face/body expression	43	17.13
Other	7	2.80
Race ( <i>n</i> = 245)		
White	178	72.65
Black	63	25.71
Other	7	2.86
Residence type		
Provider-owned or -operated home	96	38.25
Own home/apartment	78	31.08
Family's house	57	22.71
Other	20	7.97

*Note.* Participants could have more than one race.

Table 2

*The Personal Outcome Measures® Factors and Indicators*

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**FACTOR 1: MY HUMAN SECURITY**

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People are safe  
People are free from abuse and neglect  
People have the best possible health  
People experience continuity and security  
People exercise rights  
People are treated fairly  
People are respected

---

**FACTOR 2: MY COMMUNITY**

---

People use their environments  
Live in integrated environments  
Interact with other members of the community  
Participate in the life of the community

---

**FACTOR 3: MY RELATIONSHIPS**

---

People are connected to natural supports  
People have friends  
People have intimate relationships  
People decide when to share personal information  
People perform different social roles

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**FACTOR 4: MY CHOICES**

---

People choose where and with whom to live  
People choose where to work  
People choose services

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**FACTOR 5: MY GOALS**

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People choose personal goals  
People realize personal goals

---

Table 3  
*Quality of Life: Regression Coefficients*

Variable	<i>B</i>	<i>SE</i> ( <i>B</i> )	$\beta$	<i>t</i>
(Constant)	9.29	1.05		8.83***
Natural support networks (outcome present)	1.76	0.52	0.23	3.38***
Age	0.01	0.02	0.03	0.44
Complex medical support needs	-1.04	0.77	-0.09	-1.35
Comprehensive behavioral support needs	-0.64	0.66	-0.07	-0.97
Gender: Woman (ref: man)	-0.20	0.46	-0.03	-0.44
Guardianship status (ref: independent decision making)				
Assisted decision making	-1.94	0.68	-0.24	-2.83**
Full/plenary guardianship	-1.15	0.58	-0.16	-1.98*
Other	-3.19	1.40	-0.15	-2.28*
Intellectual disability diagnosis level (ref: mild)				
Moderate	-0.26	0.53	-0.04	-0.49
Severe	-0.57	0.73	-0.06	-0.77
Profound	0.19	0.88	0.02	0.22
Primary method of communication (ref: verbal/spoken language)				
Face/body expression	-0.55	0.77	-0.06	-0.71
Other	1.60	1.35	0.08	1.18
Race (ref: White)				
Black	-0.36	0.53	-0.04	-0.68
Other	0.56	1.44	0.03	0.39
Residence type (ref: provider owned/operated home)				
Own home	-0.04	0.55	-0.01	-0.08
Family home	0.64	0.64	0.08	1.00
Other	-0.55	0.93	-0.04	-0.59

Note. \* $p < 0.05$ . \*\* $p < 0.01$ . \*\*\* $p < 0.001$ .

Table 4  
*Service Expenditures: Regression Coefficients*

Variable	<i>B</i>	<i>SE (B)</i>	$\beta$	<i>t</i>
(Constant)	\$120,530.98	17,511.82		6.88***
Natural support networks (outcome present)	-\$20,346.14	8,744.22	-0.12	-2.33*
Age	-\$533.24	284.40	-0.10	-1.87
Complex medical support needs	\$27,588.50	12,998.68	0.11	2.12*
Comprehensive behavioral support needs	\$61,035.53	10,800.66	0.31	5.65***
Gender: Woman (ref: man)	\$6,200.73	7,730.84	0.04	0.80
Guardianship status (ref: independent decision making)				
Assisted decision making	-\$11,506.86	11,348.37	-0.07	-1.01
Full/plenary guardianship	\$11,956.50	9,571.02	0.08	1.25
Other	\$7,351.49	27,075.61	0.01	0.27
Intellectual disability diagnosis level (ref: mild)				
Moderate	\$6,050.31	8,805.83	0.04	0.69
Severe	\$21,632.54	12,340.45	0.10	1.75
Profound	\$33,336.49	14,728.58	0.14	2.26*
Primary method of communication (ref: verbal/spoken language)				
Face/body expression	-\$12,403.04	12,902.42	-0.06	-0.96
Other	-\$9,059.71	22,158.56	-0.02	-0.41
Race (ref: White)				
Black	\$13,796.38	8,804.08	0.08	1.57
Other	\$3,237.01	23,393.17	0.01	0.14
Residence type (ref: provider owned/operated home)				
Own home	-\$6,473.05	9,014.78	-0.04	-0.72
Family home	-\$95,376.83	11,115.29	-0.49	-8.58***
Other	-\$81,269.22	15,567.27	-0.28	-5.22***

Note. \* $p < 0.05$ . \*\* $p < 0.01$ . \*\*\* $p < 0.001$ .

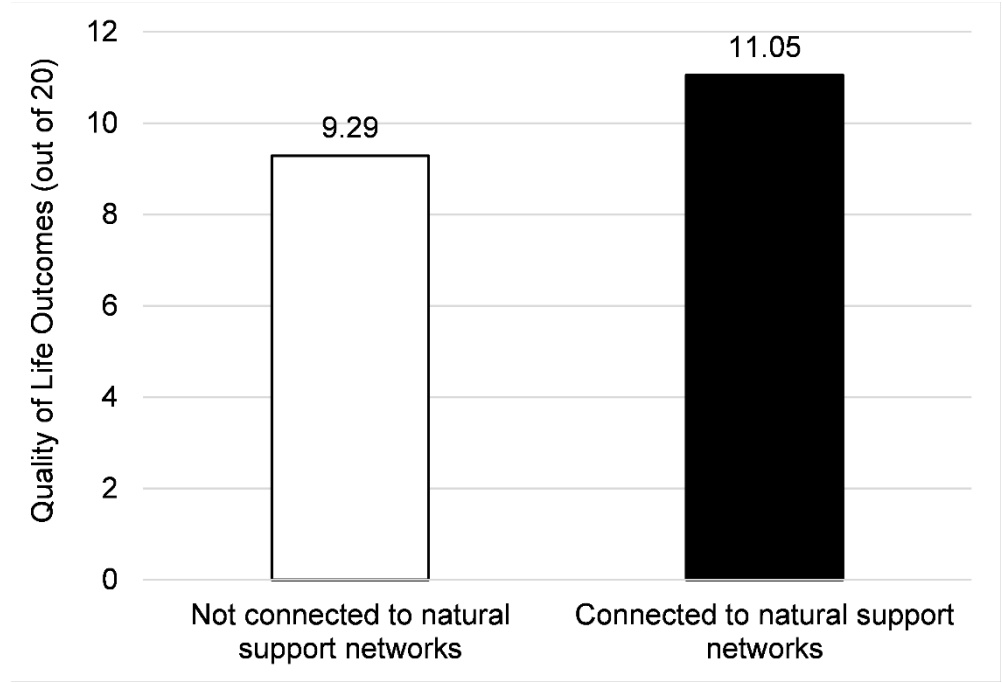


Figure 1. The relationship between natural supports and quality of life outcomes present.

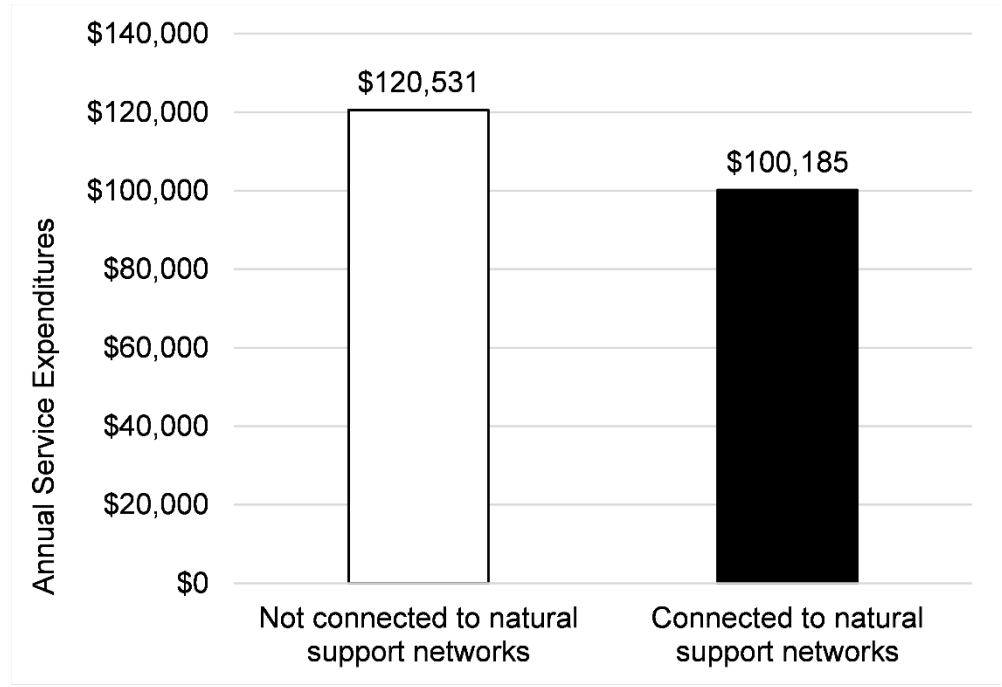


Figure 2. The relationship between natural supports and annual service expenditures.