

FINDING REST AT JILL'S HOUSE

THE IMPACT OF RESPITE ON FAMILIES
WHO EXPERIENCE DISABILITY



12.2024



Baylor University®

BAYLOR CENTER FOR DEVELOPMENTAL DISABILITIES

Table of Contents

| | | |
|----|---|-----------|
| 01 | Section 1 Introduction | 2 |
| 02 | Section 2 Our Approach | 4 |
| 03 | Section 3 A Portrait of Participating Families | 6 |
| 04 | Section 4 Need for Respite | 15 |
| 05 | Section 5 Barriers to Accessing Respite | 18 |
| 06 | Section 6 Impact of Overnight Respite on Parents | 27 |
| 07 | Section 7 Impact of Overnight Respite on Children, Youth, and Young Adults | 40 |
| 08 | Section 8 Impact of Overnight Respite on Siblings | 47 |
| 09 | Section 9 Impact of Other Jill's House Programming | 49 |
| 10 | Section 10 Our Recommendations | 52 |

Section 1 | Introduction

When asked about her experience receiving respite care through Jill's House, Tammy,¹ whose son has intellectual and developmental disabilities (IDD), passionately expressed, "We call it our little heaven on Earth. It's the one perfect thing of...any program that we've tried." Her words capture the strong sense of peace and gratitude that Jill's House brings to so many families—what parents repeatedly described as "life-giving" and "life-changing."

The origins of this enduring impact date back to 1992, when Pastor Lon and Brenda Solomon welcomed their daughter Jill, who was born with Dravet syndrome, a rare seizure condition. At the time, the Solomons could not have foreseen that within just two decades, their personal journey would impact the lives of hundreds of families across multiple states. The demands of caring for Jill's complex medical needs revealed to the Solomons the significant necessity for rest. Their experience of informal respite care, provided by members of their church, beautifully exemplified the biblical ideal of community. In Genesis 2:3, God powerfully models and commands rest: "So God blessed the seventh day and made it holy, because on it God rested from all the work he had done in creation." The respite the Solomons received followed this divine rhythm, providing their family with the opportunity to experience God's rest.



Founded in 2010, the vision for Jill's House came to life with the opening of a state-of-the-art facility offering families a rhythm of respite through quarterly overnight stays, weeknight stays, and other family programming. They welcomed six children as their first overnight guests. As of May 2024, they serve more than 250 families in the Virginia area, with programs in five additional locations.

The word respite holds profound meaning. Its origins are rooted in the Latin word *respicere*, signifying to "look back at" or "to regard." Respite care offers parents and families a chance to rest and recharge, knowing their loved ones are receiving nurturing support. For parents of children and young adults with disabilities, their daily responsibilities require ongoing attentiveness and an unwavering capacity to meet their family's unique needs in a world that often overlooks and undervalues people with disabilities. Respite provides critical assistance that helps families maintain the emotional and physical resilience needed to continue to offer the best care. Thus, respite opens a sacred space to acknowledge the need for the renewal of mind and body, while cultivating one's connection with both self and God. Paul's testimony underscores the crucial role of mutual support in finding respite, as he states, "For they gave me respite from labor and rested me" (1 Corinthians 16:18). The help he received from his companions in Corinth went beyond practical aid; it was a ministry that rejuvenated his spirit, offering him much-needed encouragement and refreshment.

¹ All names in this report are pseudonyms.

Our independent evaluation examined the vital place of respite in the lives of families served through Jill's House and its impact on their well-being. This report draws on survey responses from more than 200 parents and in-depth interviews with 26 families. It offers key insights into the far-reaching and multifaceted benefits of respite care. Likewise, it highlights the barriers families can experience when trying to access this much-needed form of support and care.

The overarching questions guiding this mixed-method evaluation were:

- What is it like for families to pursue respite care in their communities?
- How do parents describe the impact of respite care and family support?
- What recommendations do parents have for strengthening support for families through Jill's House?

We describe our evaluation approach in the next section, followed by various sections detailing our findings. We hope this report offers valuable insights to Jill's House. At the same time, our findings have implications for all communities and congregations striving to support the thriving of families in their midst. In particular, the results reveal a rich tapestry of compelling stories that represent the extraordinary impact of respite on family well-being. The accounts revealed in this report serve as an urgent call to churches, challenging the body of Christ to expand its care and support for families in need of respite.



***“We didn’t seek out Jill’s House—It found us.
It was the first place we could imagine leaving
our son in someone else’s care outside of family.”***

Section 2 | Our Approach



We adopted a mixed-method approach for this evaluation. We combined quantitative data obtained through surveys with qualitative data obtained through individual interviews. We briefly describe each approach below.

PARENT SURVEYS

We developed and distributed an online survey to all parents whose children were served through Jill's House between November 2023 and May 2024. We crafted the survey after meeting with Jill's House leadership, reading through program materials, and reviewing the peer-reviewed literature on respite care and families. The survey explored how respite care impacted parents and their children, the reasons parents initially sought respite, the challenges they encountered in doing so, their ongoing need for respite, and their perspectives on other Jill's House programming. In addition, we asked for demographic information about the parents, their children with disabilities, and their family. We incorporated a combination of forced-choice and open-ended questions. We anticipated the survey would take about 15-20 minutes to complete.

We invited each parent to complete the survey shortly after the first time their child or young adult participated in Jill's House during the six-month study window. In most cases, this was not the first time their family had received respite from Jill's House. Our email invitation explained that the study focused on Jill's House and its impact on families. We explained that participation was voluntary, and their individual responses would remain confidential. We also noted they would receive a \$10 gift card to their choice of stores (i.e., Amazon, Target, Walmart). We included up to three reminders to complete the survey. We did not ask parents to complete the survey again after any subsequent involvement with Jill's House during the study window.

A total of 208 parents completed the survey. We used descriptive statistics to summarize all close-ended responses. For some questions, we also used inferential statistics to explore variations in their responses. We analyzed open-ended responses using general thematic analyses.

² Jill's House serves children, youth, and young adults with disabilities (ranging in age from 6 to 22). We use the word children more generally when referring to the daughters and sons of participating parents.

PARENT INTERVIEWS

We invited a subset of parents who completed the survey to take part in an in-depth interview. We were interested in hearing more about their experiences with and recommendations for Jill's House. We purposely selected parents based on their survey responses, striving to obtain a diverse sample with regard to gender, race and ethnicity, marital status, household size, and community type. We also were interested in hearing from some couples within the sample. We continued recruitment until we experienced saturation (i.e., new themes were rarely emerging) and our sample was representative of families served by Jill's House. This phase of the evaluation involved 31 parents representing 26 families.

Our semi-structured interview protocol addressed the following areas:

- The challenges they encountered pursuing respite;
- How they learned about Jill's House and the hopes they had for their involvement;
- The impact of overnight respite for themselves and for their children with disabilities;
- Their experiences with and feedback on other family support programs at Jill's House;
- Their view of Jill's House as a Christian ministry; and
- Their recommendations for strengthening the programming of Jill's House.

We reminded parents that the information they shared would remain confidential and that they could skip any questions they preferred not to answer.

Most ($n = 28$) interviews took place through Zoom; three were held over the phone. The interviews averaged 43 minutes (range, 19-67 minutes) and were audio recorded. Three team members conducted the interviews; however, parents met with only one interviewer. All three interviewers had or were pursuing graduate degrees and had experience related to disability; one was the parent of a child with disabilities. Each received training on the interview protocol and procedures. Parents received a \$50 gift card as a token of gratitude for their involvement.

We had the audio recordings professionally transcribed, checked each for accuracy, and carefully de-identified them. We adopted a team-based approach to coding that involved five people: two graduate students studying special education or school psychology and three faculty members with expertise in the field of disability. Throughout the coding process, we strived to temper our own views and foreground the voices of families. Our iterative process focused on capturing the breadth of barriers and impacts parents experience in their pursuit and receipt of respite care.



208 PARENT
SURVEYS

MIXED-METHOD EVALUATION



26 FAMILY
INTERVIEWS

Section 3 | A Portrait of Participating Families

A total of 208 parents completed our survey and 31 participated in an interview. Participants included parents and other caregivers whose children with disabilities participated at Jill's House during the time frame of the study. Every parent whose daughter or son received care was provided the opportunity to complete the survey. This reflected 67% of all children, youth, and young adults served during this six-month time frame.

These children, youth, and young adults were served in the following programs.

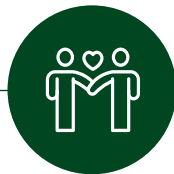
- Tysons/DC (Vienna, VA), Weekend Program: 55%
- Tysons/DC (Vienna, VA), Weekend Program: 55%
- Tysons/DC (Vienna, VA), Weeknight Program: 26%
- Blue Ridge (Middleburg, VA), Weekend Adventure Program: 12%
- Garden State (Hewitt, NJ), Weekend Adventure Program: 10%
- Windy City (Chicago, IL), Weekend Adventure Program: 9%
- Rocky Top (Nashville, TN), Weekend Adventure Program: 6%
- Puget Sound (Seattle, WA), Weekend Adventure Program: 4%

These percentages add up to more than 100% because some children participated in both weekend and weeknight programs. The average number of times children were reported to have participated in Jill's House was 26 (range, 1 to 300).



DEMOGRAPHICS OF CHILDREN, YOUTH, AND YOUNG ADULTS

Although most (94%) of the parents surveyed had just one child who participated in Jill's House, others had multiple children who were involved. Specifically, 5% had two children and 1% had three or more children. These 208 parents had a total of 187 children who were served by Jill's House; some children had more than one parent respond to the survey. In this section, we present the demographics of these children.

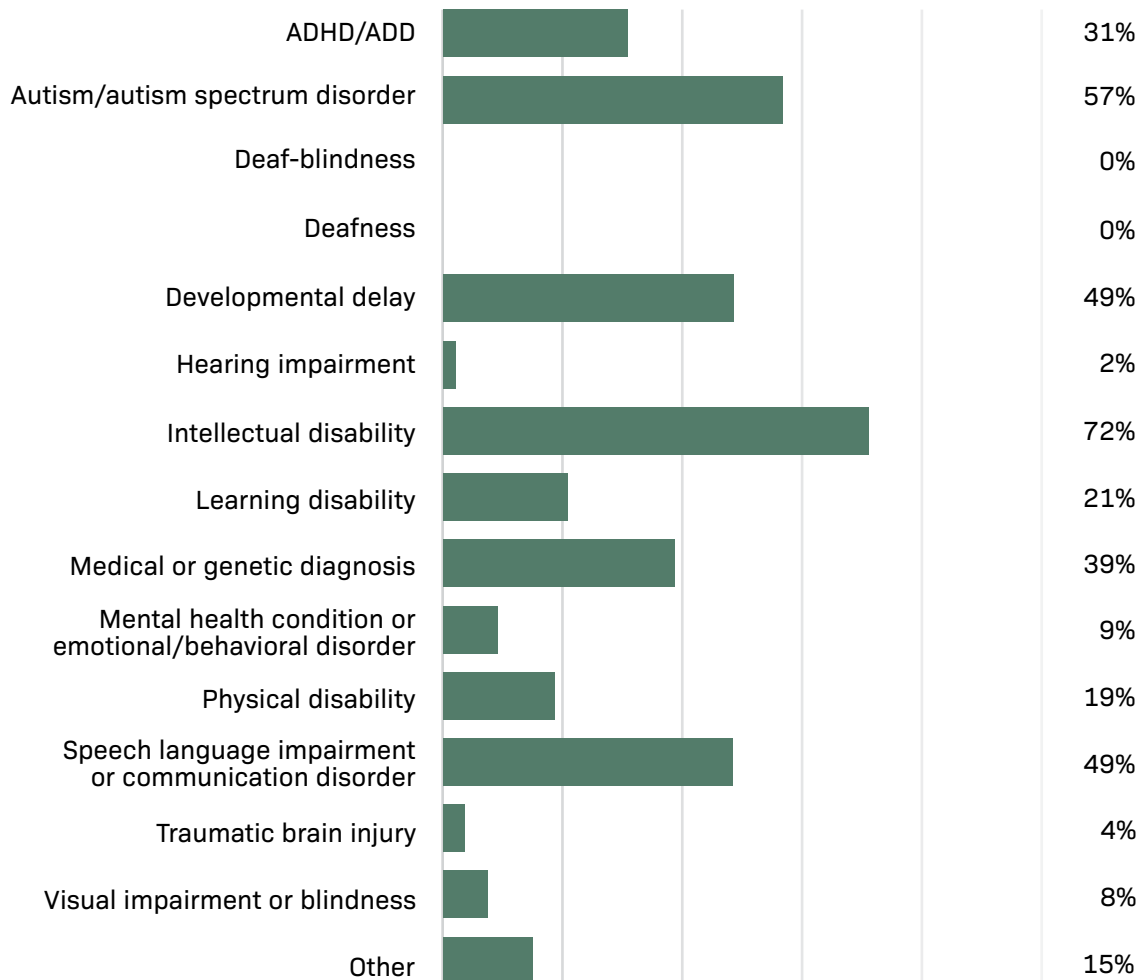


"This was the first weekend my husband and I got to spend together in 11 years."

DISABILITIES

We asked parents to indicate which disabilities their daughters and sons experienced from a list of 14 categories. Parents could select more than one disability; therefore, the total percentages can exceed 100%. The most common disabilities were (a) intellectual disability (72%), (b) autism (57%), (c) developmental delay (49%), and (d) speech language impairment or communication disorder (49%). The average number of disabilities selected was 3.9 (range, 1 to 12). Although every young person served through Jill's House has an intellectual disability, parents may not have always selected this option as other diagnoses can also include a cognitive impairment.

IMPACT OF RESPITE CARE ON CHILDREN WITH DISABILITIES



Twenty-eight parents also wrote in other disabilities, which often referenced specific genetic conditions or medical challenges (e.g., Angelman syndrome, Down syndrome, epilepsy, Prader-Willi syndrome).

SEX

Most of their children were male (63%); the remainder were female (37%).

AGE

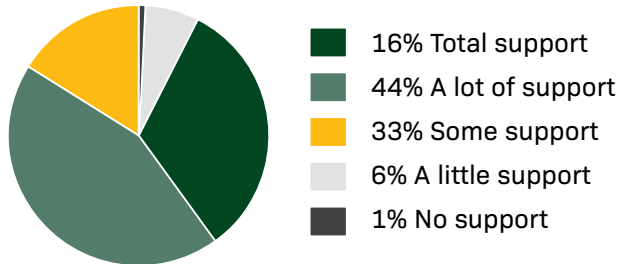
The average age of their children who had been involved in Jill's House was 15.2 years (range, 7 to 29). Specifically, 9% were between 6-10, 46% were between 11-15, and 39% were between 16-21. There were 8% who were older than 22 years at the time of their parents' survey completion (i.e., they had since aged out of eligibility for programming).

SUPPORT NEEDS

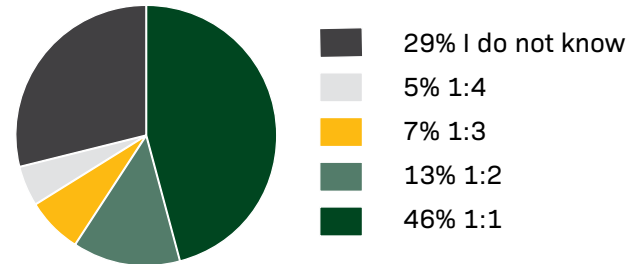
We asked parents how much support their child needs to complete most daily activities. They could respond with one of five choices: no support, a little support, some support, a lot of support, or total support.

We also asked parents about the ratio of support their child received at Jill's House. Every child is assigned a care ratio of support staff to child. For example, a 1:2 ratio would signify that one direct support professional can provide support for two children.

LEVEL OF SUPPORT



RATIO OF SUPPORT RECEIVED AT JILL'S HOUSE



BEHAVIORAL CHALLENGES

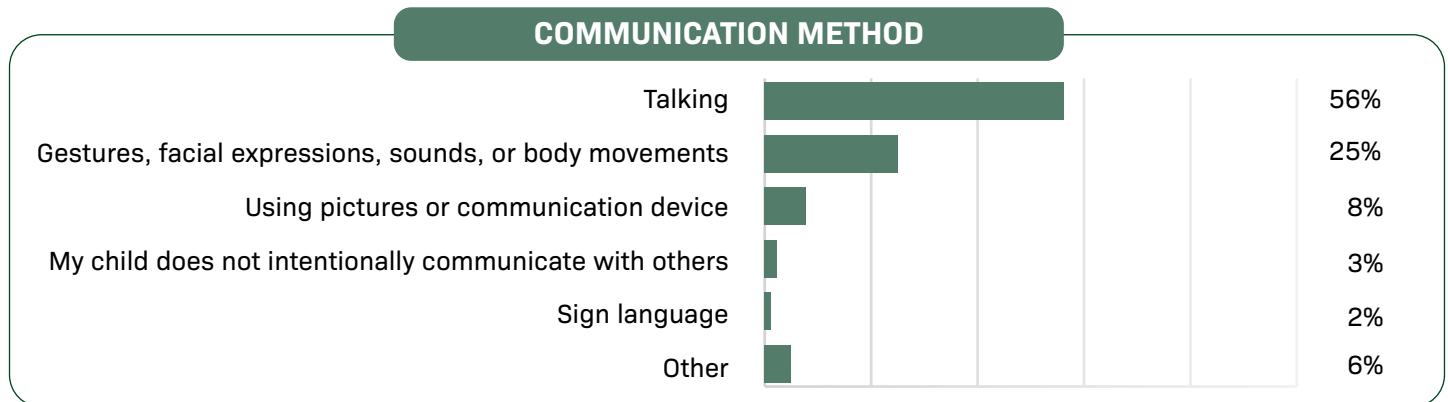
We asked parents how often their child exhibits challenging behavior, such as aggression, self-injury, or destroying property. They could respond with one of six choices: never, yearly, monthly, weekly, daily, or multiple times daily.

FREQUENCY OF BEHAVIORAL CHALLENGES



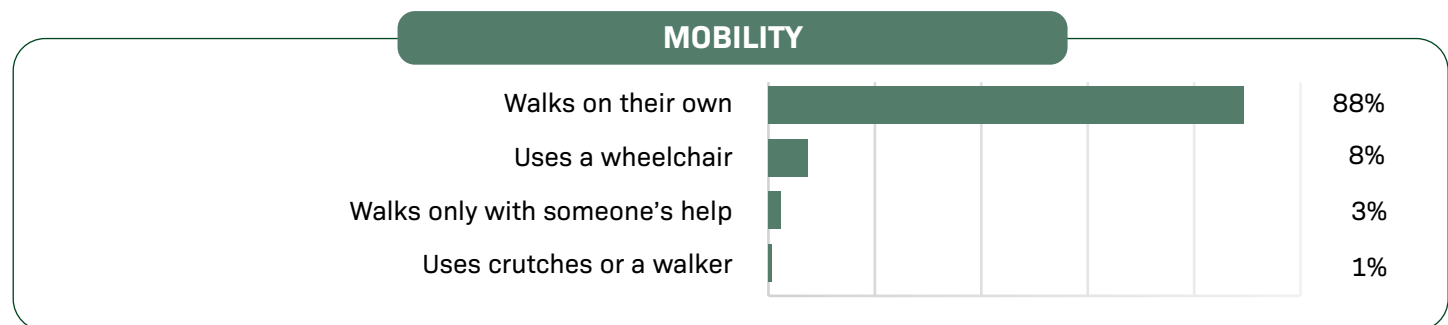
COMMUNICATION

We asked parents about how their child communicates with them. They could respond with one of six choices: talking, using pictures or communication device, sign language, gestures, facial expressions, sounds, or body movements, my child does not intentionally communicate with others, or other. Parents could also write in other communication methods (e.g., combination of methods).



MOBILITY

We asked parents about how their child typically gets around places. Parents had four response options: walks on their own, walks only with someone's help, uses crutches or a walker, or uses a wheelchair. Overall, most parents indicated their child walks on their own.



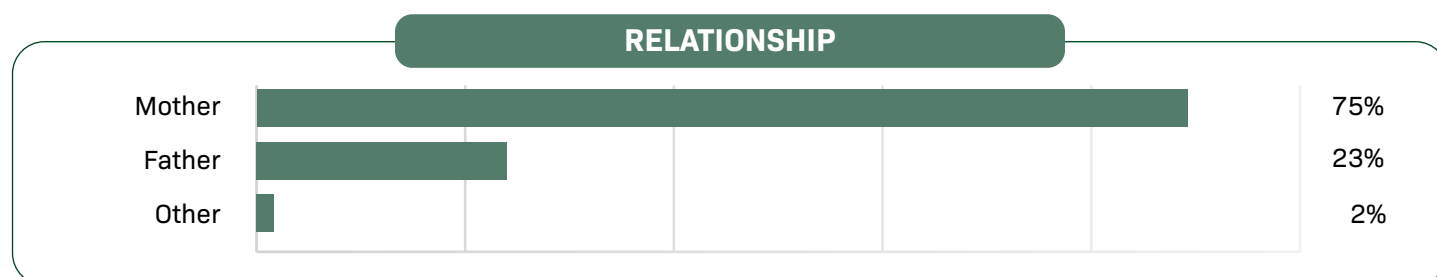
"I do feel like it's really encouraged Lacey's self-confidence, because they are so positive and they really get to know these kids for who they are. And they're so encouraging for them to be who they are and bring out their strengths."

DEMOGRAPHICS OF CHILDREN, YOUTH, AND YOUNG ADULTS

We asked parents to provide information about themselves, their family, and their community. The summary that follows reflects only the demographics of those parents who participated in this evaluation.

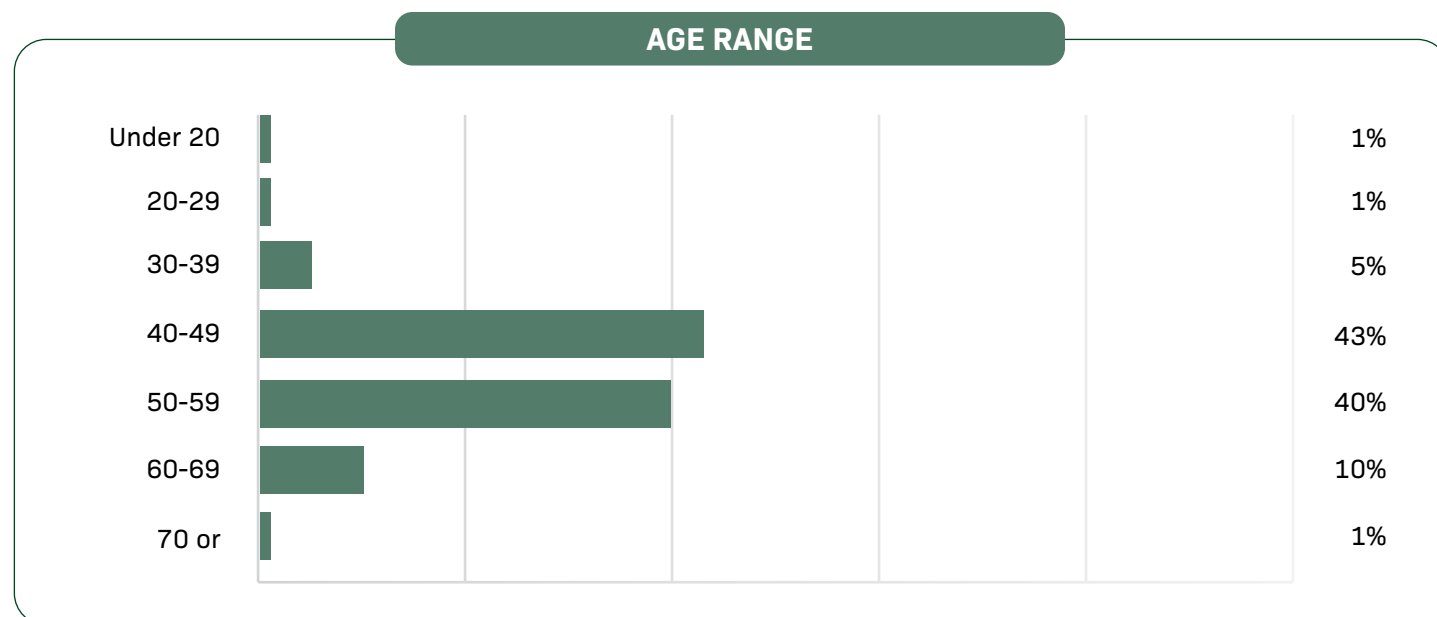
RELATIONSHIP TO THE CHILD, YOUTH, AND YOUNG ADULT

We asked parents how they were related to the child who participates at Jill's House. Most participants were mothers. Other responses included foster mother, stepmother, and guardian. (Three parents opted not to respond.)



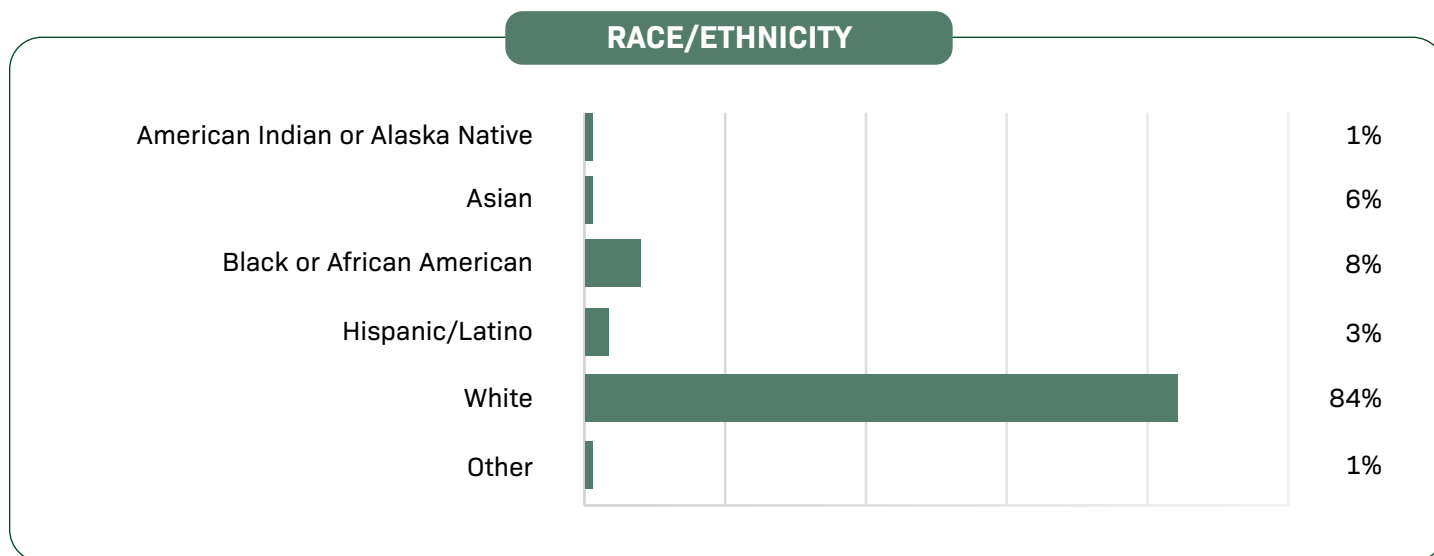
AGE

We asked parents to report their age by decade. The most common age groups were 40-49 years and 50-59. (Three parents opted not to respond.)



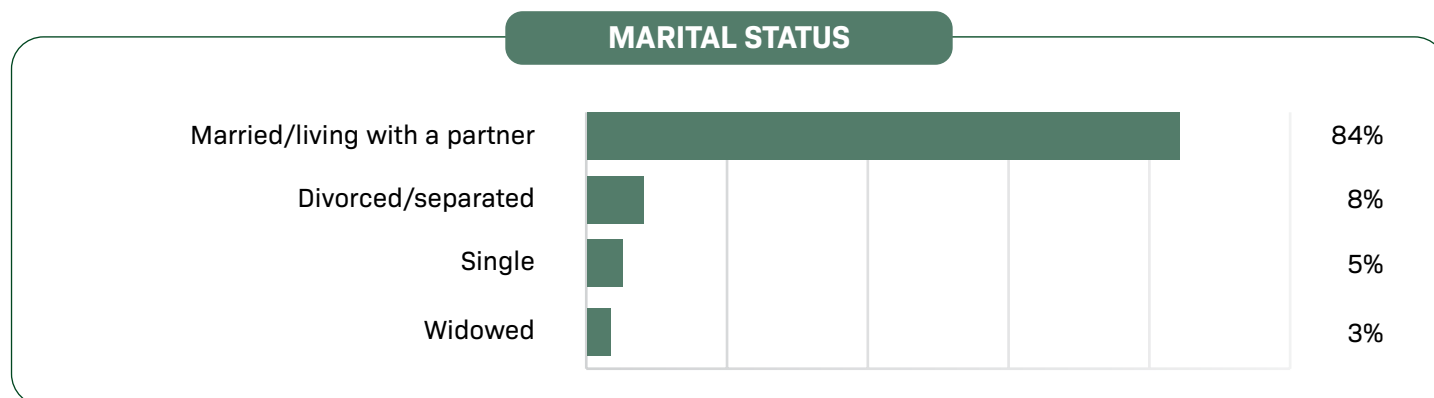
RACE/ETHNICITY

We asked families to describe their race/ethnicity when completing the survey. Parents could select more than one option and write in other descriptions. The most common responses were White, Black or African American, and Asian. (Five parents opted not to respond.)



AGE

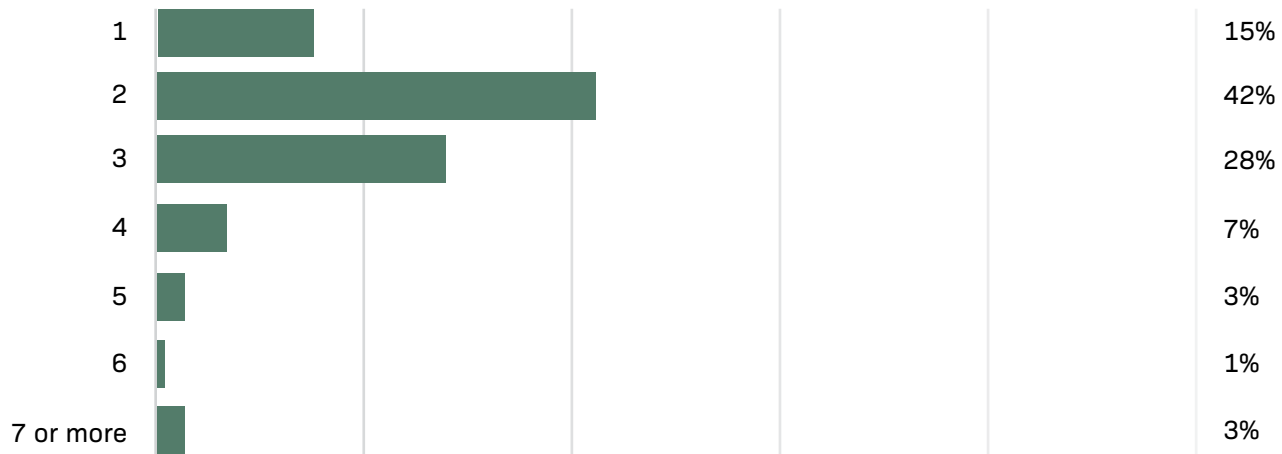
We asked parents about their current marital status. Most participants were married or living with a partner.



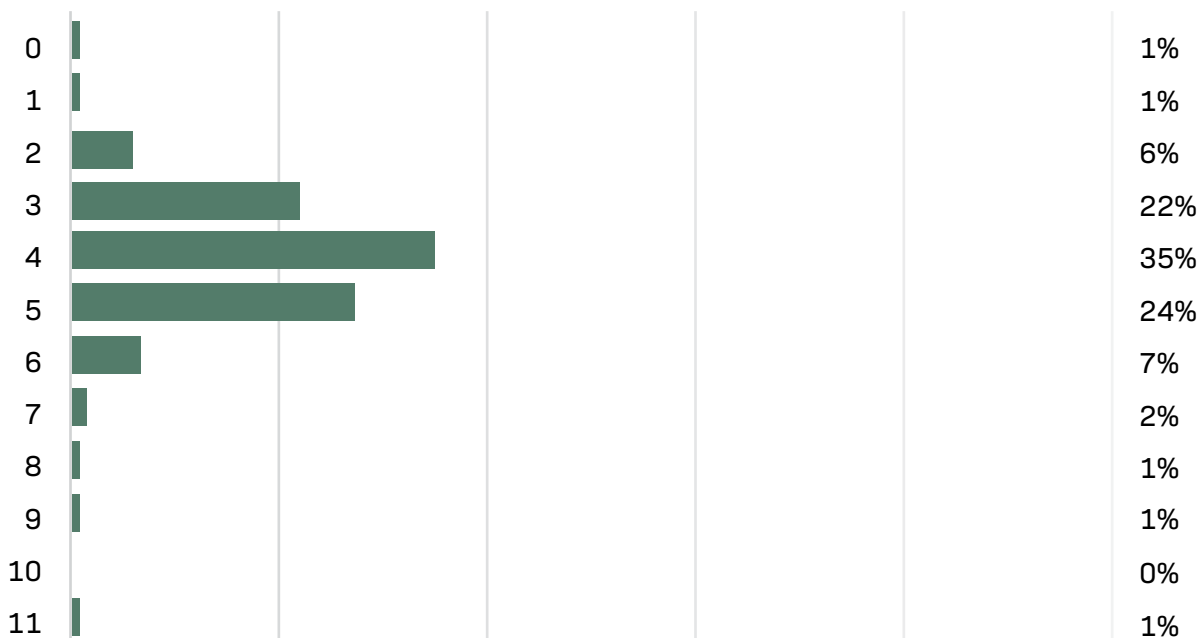
"I never really get a chance to just relax and to just take care of me and just say: What do I want to do? What do I want to eat for dinner? What do I want to do right now? Do I want to take a nap? Oh my God, do I want to read an entire book for five hours? Wow!"

NUMBER OF CHILDREN

We asked parents the total number of children in their family. Most had more than one child.

TOTAL NUMBER OF CHILDREN**NUMBER OF PEOPLE IN THEIR HOUSEHOLD**

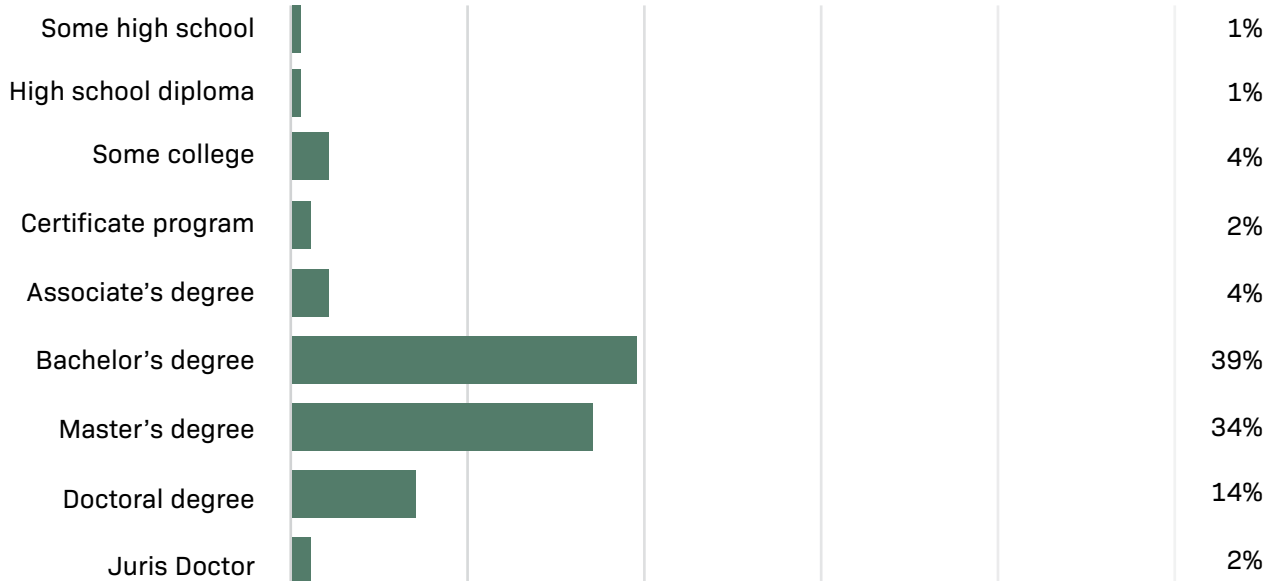
We asked parents how many people they lived with. More than half of all families had a least four members. (Seven parents opted not to respond.)

NUMBER OF PEOPLE IN THEIR HOUSEHOLD

EDUCATION

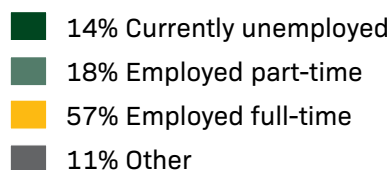
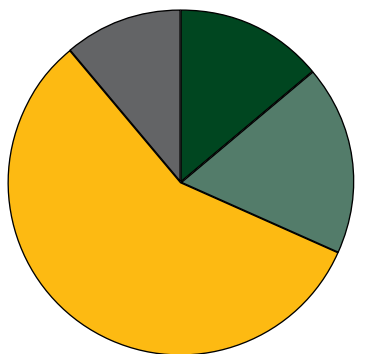
We asked parents about their highest level of education. Almost three-quarters had a bachelor's degree or higher. (Four parents opted not to respond.)

HIGHEST LEVEL OF EDUCATION



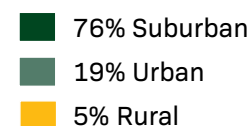
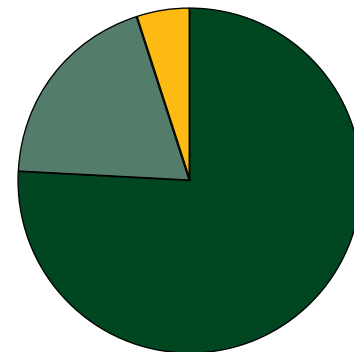
JOB STATUS

We asked parents about their current job status. More than half were employed full-time. Those selecting other indicated they were retired, searching for work, self-employed, or stay-at-home parents. (Six parents opted not to respond.)



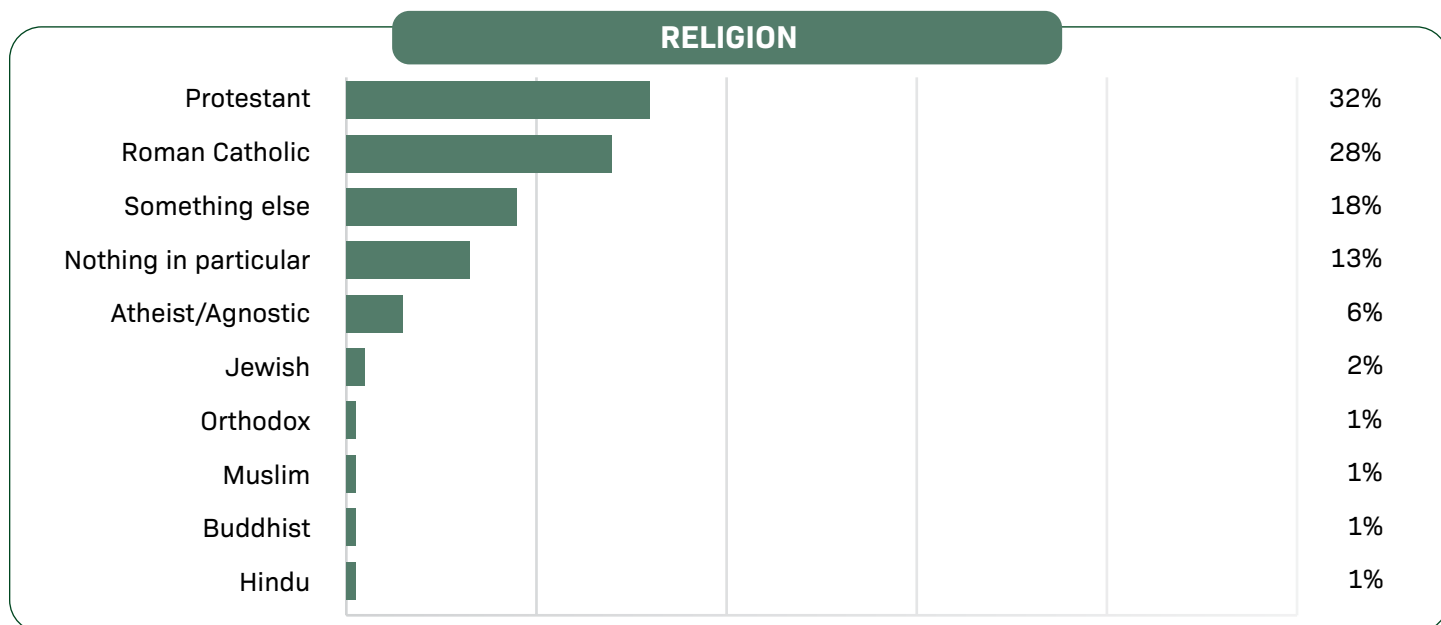
COMMUNITY

We asked parents to describe the community in which they lived. More than three-quarters lived in suburban communities. (Four parents opted not to respond.)



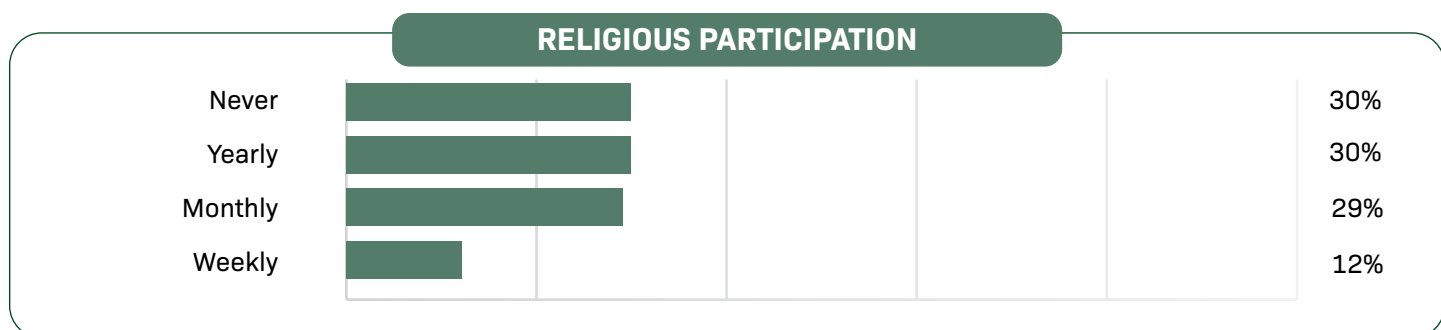
RELIGION

We asked parents about their present religion. Jill's House serves families regardless of their religious background. The most common religions were Protestant or Roman Catholic. Among those reporting something else, most said Christian or listed specific denominations. (Eight parents opted not to respond.)



FAITH COMMUNITY INVOLVEMENT

We asked parents how involved they were in a faith community in their area. Most reported some level of involvement. (Six parents opted not to respond.)

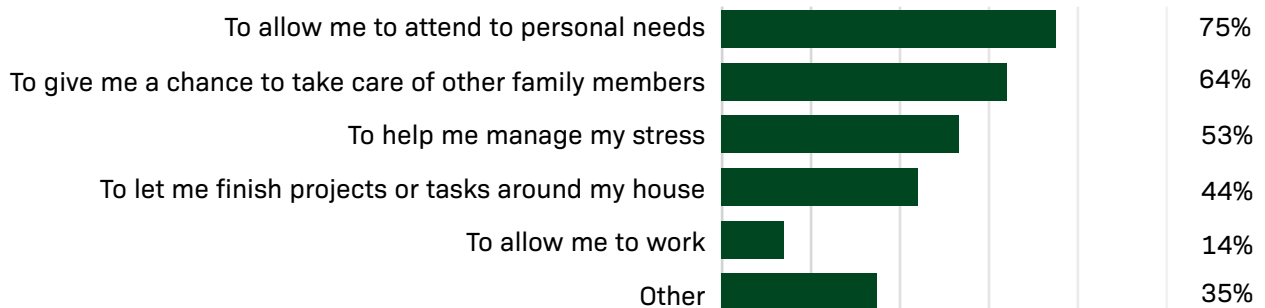


Section 4 | Need for Respite

We wanted to learn more about parents' experiences accessing respite care, the avenues through which they had received respite, and the degree to which they felt they needed respite. Parents had the opportunity to answer both closed- and open-ended questions.

WHAT WERE THE REASONS PARENTS SOUGHT OUT RESPITE CARE THROUGH JILL'S HOUSE?

REASONS FOR SEEKING RESPITE CARE



Parents could list other reasons in an open-ended section. Parents identified 13 additional motivations for pursuing respite at Jill's House. The most common reasons included giving their child a new experience ($n = 26$), helping their child increase their independence ($n = 11$), giving themselves a break ($n = 9$), providing their child more social opportunities ($n = 9$), and allowing their child to experience respite ($n = 8$). For example, one father said, "We didn't seek out Jill's House—it found us. It was the first place we could imagine leaving our son in someone else's care outside of family." Another mother said she pursued respite at Jill's House because she needed "to get a break as the only caregiver. There is no one else that I can turn to to care for him. That is a heavy burden, and I don't want to feel like my child is a burden. He also needs other people in his life...outside of me." Other reasons for pursuing respite at Jill's House were mentioned by just one to a few parents, including:

- To focus on their spouse or marriage
- To spend time with family
- To involve their child in an enjoyable activity
- To spend time with their other children
- To build community
- To participate in other activities
- To receive help
- To sleep



"My son loves it."



"I needed to find a community that I felt welcomed in and understood and that would accept her as she is."



AVAILABILITY OF RESPITE CARE OUTSIDE OF JILL'S HOUSE

We asked parents whether they currently receive respite care outside of Jill's House. More than half (59%) indicated they had no other options.

RECEIPT OF RESPITE CARE FROM OTHER SOURCES

We asked parents if they had received respite care from providers other than Jill's House in the past year, and almost half (45%) indicated they did not. Of those who did, most received respite care from family members (62%), followed by other community agencies (25%), someone else (e.g., camps, sitters, in-home aides, friends; 33%), their church or faith community (13%), or neighbors (3%). One mother shared, "Some months, the church has a respite night for 2-3 hours. Outside of Jill's house, that is all I get." Another mother said, "We have had a wonderful caretaker for the past several years, but she is no longer available."

COST OF OTHER RESPITE CARE

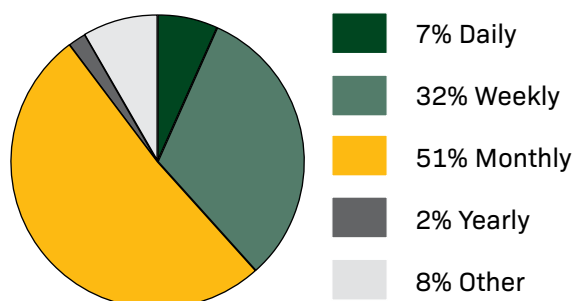
We asked families who had participated in respite services outside of Jill's House if they paid for these services. More than half said there was no cost (56%), one-third said there was a cost (38%), and the remainder did not recall (7%).

NEED FOR RESPITE CARE

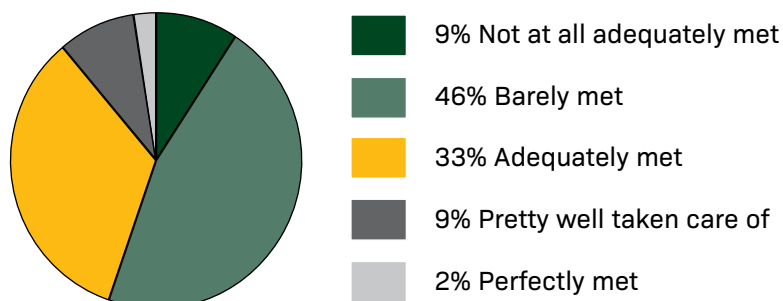
We asked parents about how frequently they need respite care. Nearly all parents indicated they needed respite at least monthly, weekly, or daily. Other responses endorsed needing respite less frequently (e.g., quarterly, bi-weekly, twice a year).

We also asked families about the extent to which their respite care needs were being met. We provided five response options. More than half of parents indicated their respite needs were either barely met or not met at all.

HOW OFTEN DO YOU NEED RESPITE?



EXTENT TO WHICH RESPITE NEEDS ARE BEING MET



When asked what would help them better meet their respite needs, parents offered a range of responses, including offering programs for adult children, increasing the frequency of respite, and extending the duration of respite. One father discussed the need for respite options for adult children, “There is an inverse relationship with the services and respite available versus the need. Children with intellectual disabilities have the most services available when they are young and school age and there are MANY less services when they become adults. Having respite for adult-age children with disabilities is desperately needed.” Even when their respite needs are not perfectly met, most parents still praised Jill’s House. One father said, “Jill’s House is doing excellent work, and if I had billions of dollars, I would give it all to Jill’s House.” Below is a list of other things that one to a few parents said would help better meet their respite needs. Although some suggestions were specific to Jill’s House, most reflected broader recommendations relevant to respite offered anywhere.

- Provide programming for adult children
- Provide additional respite options and programming
- Provide financial assistance and support
- Provide respite monthly
- Provide respite weekly
- Provide additional caregivers at home
- Provide day camps or programs for people with disabilities
- Provide transportation to and from respite
- Provide after-school programs
- Provide respite during school breaks
- Provide overnight respite
- Provide respite that supports their children’s behavioral needs
- Provide Christian-based respite
- Provide medical respite
- Provide respite before school
- Provide activities at respite drop-off points
- Provide emergency respite
- Provide daily respite
- Provide a group home living option
- Provide more information for parents
- Provide quarterly respite
- Provide full-time nursing care at respite programs
- Provide help finding respite
- Provide nursing care at programs
- Provide staff at respite who know and love the child
- Provide respite on weeknights
- Provide respite multiple times a week
- Offer trainings by Jill’s House for other organizations
- Provide social skills education
- Provide respite for children with severe needs
- Prove governmental incentives for respite organizations
- Provide respite during work hours
- Increase the number of respite weekend opportunities for families
- Increase respite weekends
- Increase opportunities for respite outside of Jill’s House
- Increase the frequency of respite
- Increase the duration of respite
- Provide training for caregivers
- Increase the availability of respite opportunities
- Increase staff trustworthiness
- Increase respite availability according to family schedules
- Increase support from extended family
- Increase scheduling ease and flexibility
- Increase family inclusion and participation in respite programs
- Increase Medicaid assistance
- Increase federal government support
- Increase staff in respite programs
- Increase attention to individual needs at respite
- Increase the professionalism of respite providers
- Increase compassion and understanding from organizations
- Increase the program’s reputation
- Increase reinforcement for meeting behavioral expectations
- Increase program safety
- Increase staff consistency to build relationships with family
- Increase parental awareness of their respite needs
- Decrease distance between families’ homes and respite programs
- Loosen eligibility requirements

Section 5 | Barriers to Accessing Respite

“Finding a place you’d actually want to leave your child is challenging to say the least.”

Although respite matters immensely in the lives of families, it can be elusive. In this section, we describe the array of barriers parents reported encountering in their initial search to find and access respite care. Our questions—and their responses—focused on barriers to accessing formal or informal respite, no matter where they sought care. Their challenges, while often pervasive, do not necessarily reflect their specific experiences with Jill’s House. Indeed, families were often reflecting back on their pursuit of respite prior to ever finding Jill’s House. Yet, it is clear that the challenges families experience can be pronounced and discouraging. We include this section with the hopes that parents’ reflections about difficulties they have encountered to accessing respite care for their children will be helpful to providers, congregations, or other community stakeholders working to support families.



SURVEY FINDINGS

We asked parents about their experiences navigating barriers to respite. We listed nine common barriers and asked parents to indicate which (if any) barriers applied to them.

BARRIERS TO RESPITE



We gave parents the option of listing other barriers in an open-ended section. The most common responses focused on respite providers not having the skills parents felt were needed ($n = 20$), their child or young adult being ineligible for programs because of their age ($n = 10$), and respite offerings being too infrequent or short ($n = 7$). One mother summarized some of the barriers she faced pursuing respite for her child, “It is extremely difficult to find reliable, trustworthy attendants to provide respite care for more than a few hours at a time.” Other barriers identified by one to a few parents included:

- Respite is difficult to schedule.
- Their child or young adult does not meet general eligibility requirements.
- Medicare/Medicaid/Insurance limits access to respite.
- Respite locations are too far away.
- Parents did not feel comfortable asking for help.
- Respite organizations do not have caring staff.
- Respite organizations have unreliable services.
- Respite organizations have a waitlist.
- There is a requirement that parents stay nearby during respite programming.
- Respite options are too strict.
- Respite duration is too long for their child.
- Respite care from nurses is inconsistent.
- The risk of COVID-19 is a concern.
- A language barrier exists.
- Programs lack one-on-one support.
- Parents experience transportation difficulties.
- Their child has complex behavior needs.
- Pursuing respite takes time for parents.
- Parents experience difficulties having in-home respite providers.
- The paperwork is challenging.
- Respite programs lack activities.
- Parents lack the energy needed to look for respite programs.

INTERVIEW FINDINGS

We interviewed 31 parents about their experiences pursuing respite care for their family. Although parents referenced barriers to respite throughout their interviews, the following questions directly addressed this topic: *How hard or easy has it been for your family to find respite when you need it? Describe some of the barriers to accessing respite care.*

Overall, parents identified 15 salient barriers to accessing respite care for their family. Table 9-1 lists and defines each barrier. In this section, we discuss the nature and impact of each barrier. As with the rest of this report, all names are pseudonyms. As noted earlier, their responses focused on barriers to accessing formal or informal respite anywhere and may not always have been specific to Jill’s House.

TABLE 9-1. PARENT-IDENTIFIED BARRIERS TO ACCESSING RESPITE CARE

| BARRIER | EXPLANATION |
|--------------------------------------|--|
| Trust | Parents have limited confidence in respite providers to care for their child or young adult. |
| Parent hesitancy | Parents are generally apprehensive or fearful about their child's or young adult's involvement in a respite program. |
| Parent's perception of child's needs | Parents are unclear about whether their child's or young adult's need can be supported within respite programs. |
| Lack of family support | Parents cannot turn to extended family for informal respite. |
| Reluctancy to seek help | Parents have reservations about asking others for help in the area. |
| Lack of availability | Respite options do not exist in their community. |
| Lack of awareness | Parents are not aware of what respite options are available. |
| Eligibility criteria | Age, diagnosis, income, or other criteria prevent participation in a formal respite program. |
| Waitlists | The time between applying for and receiving respite is too lengthy. |
| Complexity of the process | The process to learn about and sign up for respite is overwhelming. |
| Program configurations | The timing, frequency, duration, and regularity of respite offerings are a mismatch for families, |
| Financial barriers | The high costs and limited assistance make respite services cost prohibitive. |
| Program quality | The implementation, staff, or other resources of the program are considered to be inadequate or insufficient for their child or young adult. |
| Getting there | The distance to the program or availability of transportation is prohibitive for a family. |
| Lack of representation | People who use respite all share similar characteristics that make others feel like it is not for them. |



“The Jill’s House weekend stay program is unique in this area and I greatly miss being able to participate in it. When you have a child with significant disabilities, you can’t just have anyone take care of them while you get away. The respite services I currently use are adequate for running errands or completing tasks, but they don’t truly give you a chance to re-charge or do something special.”

“I feel guilty leaving her...but I get worn out.”

TRUST

Trust influenced the decision of twelve parents to pursue or use respite. Their limited confidence in the capacity of others to adequately care for their child or young adult was often framed broadly. As Nicole shared, “I trust no one. I’ve trusted no one for many years.” Frederick echoed this concern of many parents stating, “It’s difficult for us to trust.” Tammy, the mother of six children, articulated this same reluctance when asked about barriers, “I can’t trust just turning him over to somebody I don’t know. So, that’s what my initial thought was.”

Some parents referenced their child’s limited communication abilities as amplifying the importance of cultivating deep trust. Kathryn, whose daughter has complex communication needs, remarked, “We’ve been extremely careful about who we’ve allowed to take care of her. Because we don’t want anything bad to happen to her. And we don’t know if she can tell us if something bad happens to her.” This uneasiness was affirmed by two other mothers. Leslie shared, “It’s so tough! It’s a hard thing to trust somebody to take care of your kid, especially a nonverbal child. You don’t really know what’s happening.” Likewise, Emily voiced her fear of what might happen to her son in her absence: “That’s scary with a kid that can’t express like, ‘This person hurt me’ or ‘This happened.’ They can’t say any of that.”

Past incidents provided context for some parents’ constrained trust of respite providers, including haunting previous experiences and prior medical traumas. Frederick shared how his family “had some pretty terrible experiences” that made it “really hard for us—for me—to trust.” Andrew recalled a medical emergency from way back when his now 17-year-old daughter was an infant that still fueled his hesitation to trust her care to anyone else. “There [has been] a huge mental barrier to being comfortable leaving her with someone else. We’d ask all the questions—like CPR and all that stuff—all the basic things, I guess. But we were very nervous too!”

PARENT HESITANCY

Nine parents expressed apprehensions about sending their children off to respite care programs. Concerns about their child’s or young adult’s safety and/or a program’s credibility shaped their decisions about participating in respite services. This fear sometimes stems from past experiences of neglect or abuse in other contexts. Verónica described how fear “lives in the back of my mind. I’m also paranoid because I’m like, ‘Okay, I don’t know enough about this program.’” Even when they knew their program was reputable, worry still lingered for some parents. Other parents were concerned about whether staff had the competence to care for their child or young adult safely. As David explained, releasing his son to anyone was “a little bit of a scary proposition.” Shelley was quite candid about what made her hesitant to access respite from just anyone, “There’s no way anyone can take care of my child the way I can.”

PARENT'S PERCEPTION OF CHILD'S NEEDS

Sixteen parents held views about their children that impacted their pursuit of respite services. Parents' perception of their child's behavior was a primary reason for not considering respite care. Rhonda shared about her initial reluctance, "I was apprehensive at first because I didn't think that he would behave well and that he would miss us. Yeah, I was just concerned about sending him away from home." Erika described feeling similarly, "I mean, it wasn't like I couldn't leave Lacey with somebody else. But it's just that she was so difficult at that time. She would still elope, she would run off, and if we just tried to go to the park or something, she would run away." Amy shared that in the earlier years of her child's life, she considered respite. But when her daughter began displaying significant behavioral challenges, "We thought that there's just no way."

Other parents, like Jackie, wondered whether their children were really ready to participate in respite. She explained, "Early on in the process, I was like, well, I'm not really sure if he's ready to do an overnight camp just yet." Leslie went even further in questioning whether her daughter would be okay in the care of anyone else: "I would never send my baby anywhere. Nobody else could ever take care of her. Are you aware she's non-verbal? Who would ever be able to take care of her? No way. No way!" Knowing their particular needs and circumstances, many parents were unsure whether their children would do well unless strong support was available. Emily was convinced it takes a "special person to care for somebody with special needs." Likewise, Crystal explained, "Your children are different. They have more complexities. And you have to have somebody that really wants to do it. Finding those people is not easy."

LACK OF FAMILY SUPPORT

Four parents recognized they had few family members to turn to for informal respite care. For example, Leslie, a single mother whose teenage daughter has extensive support needs, said, "I don't have any family in the area. I don't have any family even externally that I can lean on. It is just me." After her divorce, Leslie's circle of extended family support narrowed dramatically. Gregory, the father of four children, found that his respite options diminished when his mother-in-law died. Now, he said, he and his wife "don't have much support really." Even when relatives were available, some parents felt care would not be possible because their family members "don't understand what [my child] needs" (Verónica).

RELUCTANCE TO SEEK HELP

Four parents expressed some reservations about seeking respite from family, friends, or formal programs. In some cases, they worried about imposing on or inconveniencing others. For example, Yuuko explained how she has a "self-imposed limit" on what she asks of her mother because she "[does not] want to burden her too much." For other parents, this reluctance emerged from a sense of guilt that they might be taking limited opportunities from others whose needs might be greater. Diana wondered aloud, "Were we taking this away from someone else who was more deserving or needed it more?" Verónica felt similarly when first reading about local respite offerings, "I never signed her up. I always thought respite care was for kids that were very high needs or severely disabled or needed constant care...I shouldn't be asking for anything...I felt guilty."

"I don't have anybody."

LACK OF AVAILABILITY

Six parents described the absence or paucity of respite offerings in their local area. Paula said it simply, “There just are not enough!” Similarly, Tammy noted, “There just aren’t very many programs.” Even well-informed families struggled to locate opportunities. Brittany, an experienced special education teacher, illustrated this challenge, “I’m good at knowing what resources are and how to help access them to help my children...Even with that advantage, I’m just telling you, there’s not a lot [of respite] out there.” Likewise, well-resourced families also found few options. Gina shared, “We’re lucky we have a nanny, but that’s during the days to get her from point A to point B. I don’t feel like that’s as much respite. It’s like I’m working while we have a nanny.”

LACK OF AWARENESS

Eleven parents described how hard it is to find those respite offerings that are offered in their area. Speaking about an overnight respite program she regularly accesses, Nicole explained, “Not everybody knows about the program...I tell everyone I meet with a disabled child. I do! Because these services are not known to everybody.” Frederick agreed, “There’s not a lot of programs [and] they’re tough to connect with.” Andrew suggested the challenge of awareness might go even deeper, “Most families don’t even know what the word respite means.” As a result, they may not know what to look for in their search for help. Respite care providers should “advertise more” and “[get] the word out more” so parents do not, as Verónica put it, rely on finding these critical resources “by luck.”

ELIGIBILITY CRITERIA

Ten parents described how stringent program qualifications further constrained their respite options. Having a child who was too old or too young, who lacked the right diagnosis or medical documentation, or whose support needs were too high or low—kept them from accessing existing offerings. Age restrictions were regularly mentioned, particularly among parents of youth and young adults. Shelley, the mother of two children, grieved “the lost weekend stays” when her disabled son “aged out” of existing respite programs after turning 23. Andrew, a pediatrician, described it as “a cliff at age 22...I’ve looked pretty deeply and there’s just not a lot out there.” Leslie also emphasized the aging-out problem, “It would be absolutely awesome to have a place where [my adult daughter] could go and have similar social, fun, joyous experiences. And I get the break that I need. Man, do I need it! Really.” Other eligibility requirements also impacted options, including those related to disability and income. Felicia shared about her son, “There’s really not a lot of places that can care for Mason...because he just needs more supervision than their [staff-to-client] ratio probably allows.” Diana added, “A lot [of programs] require a Medicaid waiver to pay for respite services, others require specific diagnoses and going to a doctor to get that diagnosis to qualify is another form of barriers.” Many parents were left wondering: Where does my child fit in? They wished there was someone to help them locate respite services for which their family was eligible.



“My child needs 1-on-1 care and Jill’s House has been the only program that provides the necessary care that my son needs.”

WAITLISTS

Eight parents cited long waits as a roadblock to accessing needed respite. Christopher, the single father of two children, described his experience as “sitting around for a few years and, when you finally get called, then it’s ‘Alright, get all this information in!’” This prolonged wait for an opening made it difficult for parents to manage their day-to-day responsibilities and plan for their child’s future needs. Shelley observed how the need for timely respite is most pronounced among “the younger families who are really, really struggling to keep above water,” highlighting the urgency to “get them integrated faster.” Most of these parents also mentioned other barriers (i.e., eligibility requirements, complex processes, lack of awareness) that kept or delayed them from even getting on a waitlist. Frederick attributed the ubiquity of waitlists to the scarcity of respite options, noting, “There’s not a lot of programs.” The unpredictability of “never-ending waitlists” exacerbated stress levels and fatigue, keeping families from receiving the restorative rest they desperately needed.

COMPLEXITY OF THE PROCESS

Sixteen parents lamented the complexities of applying to formal respite programs. The “long drawn-out [intake] process” and “giant piles of paperwork” required to access respite care were among the myriad hurdles they described. Brittany, who had considerable expertise as a special education teacher, remarked, “Doing the application [for respite] can be a daunting consideration for someone who’s already feeling overwhelmed.” Yuuko, a single parent of three children, described it as “a lot of desk work—many hours over many days and weeks.” The laborious process led some parents to forego enrollment altogether. Tammy offered context for this challenge, “I’m working and taking care of my other children. You just don’t have the time and energy and the resources when you’re dealing with all this other. And [yet] it’s what you need the most.” Gina felt similarly, “There’s a lot of red tape. There’s always a lot of forms with our kids.” Melanie, whose daughter required 24-hour care, conveyed how hard it was to actually apply for respite, “At the time, their website was such that you couldn’t save [your application] and I couldn’t find the key to save it. And so, I would spend an hour filling everything out and getting it all done and then it would all be lost. And I did it three times!” Brittany, the mother of three children, asserted, “If anybody was going to be deterred from doing [respite], the deterrent might be how involved the process to getting your child there is.” Felicia shared related frustrations, saying, “It [takes] follow up for some places just to get back to me ... some would just go to a voicemail, and I just don’t know what happened.”

PROGRAM CONFIGURATIONS

Twelve parents referenced the ways in which the timing, frequency, duration, or regularity of respite offerings could hinder some families from participating. In some cases, the timing of available respite was inconvenient or incompatible with a family’s schedules or needs. Some parents felt they had to jump through hoops to take advantage of respite because it was offered at times that just did not work well. Wearily, Nicole noted how “the timing is never good” for her. She was not alone. Yuuko remarked how the scheduling of respite often discouraged her from participating. Instead, she said she relied on “some combination of my mom and the nanny” for respite care. The frequency and regularity with which respite was typically offered also felt insufficient considering some family’s pronounced needs. Leslie, whose daughter received respite a few times each year, longed for much more: “I really wanted it to be once a month. And I knew that wasn’t going to be possible. There’s just so many people who need it.” Similarly, Rhonda attributed her irregular access to “the demand for the respite.” Finally, some parents addressed how the duration of most available respite impacted their involvement. For Gregory, the long drive “back and forth and back and forth” from home to the nearest respite location meant short experiences of just an hour or two were just not worth the effort.

FINANCIAL BARRIERS

Nearly half of parents identified finances as a barrier to respite care. The high costs associated with some respite programs presented a considerable challenge for many families. Kathryn expressed her shock when researching summer program costs for her 17-year-old child, “This camp is \$17,000! Who could pay that?” Other parents, like Verónica, gave up pursuing respite care due to financial constraints, “[It is] cost prohibitive. If I’m going to pay an hour and I’m going to pay that much, I might as well keep her at home.” Searching for financial support was itself a challenge. Andrew noted how “there’s no money for it. When are you going to find time to do paperwork to get on [financial] waitlists too?” A few parents referenced the impact of insurance coverage on their family’s respite access. Caps on the number of respite hours per year directly impacted those families. Amy, whose daughter had extensive support needs, explained, “They don’t understand a family like ours—where that weekend respite that’s now been taken away—how profoundly that affects us...Her respite hours from the state wouldn’t have covered 12 visits a year.” Finally, some parents felt they were at the mercy of how agencies allocate respite funding to families. Christopher expressed this bluntly, “It’s like you have a gun to your head.” Similarly, Nicole was frustrated by rules that led to her loss of funding, “I lost that 480 hours [of funding from waivers] because I didn’t receive my respite for nine months...that was a loss on my behalf.”

PROGRAM QUALITY

Eight parents described concerns regarding the standards of most available respite offerings. Some expressed their significant reservations about accessing formal respite programs without high confidence in its quality. Describing the already meager respite opportunities in her community, Tammy observed, “In general, there just are not enough and [they] could be improved upon. I will say—just not the highest quality, many of them.” For Kathryn, having only low-quality options was the same as having no options: “There are a lot of bad programs out there for kids with special needs that just aren’t very structured. I’m not willing to put her in a bad program just so I can have free time. I’d rather have her with me if it’s not going to be a quality program.” Programs whose staff were insufficiently trained or experienced were simply not considered viable options for families. William, the father of two daughters with extensive support needs, emphasized this challenge:

“It’s just the ability of having people that you trust and that have the level of training. And also the level of willingness to be able to come in and take on that level of responsibility for a long time to be able to do that. Again, I think there’s a certain level of training that’s necessary and a certain level of compassion that again, is not that easy to be able to come by.”

Other parents described the persistent challenge of finding sitters who could adequately care for their child with disabilities at home. Nguyen, whose son has significant challenging behaviors and limited communication, illustrated this obstacle: “I try to hire sitters to watch him, but most sitters don’t know what to do with him...So, I don’t feel comfortable leaving my kid alone with the sitters.” Amy emphasized this as a widespread challenge:

“There’s always, always barriers! I used to have a support group on Facebook of 2,000 moms who have a child with autism...And that was always a difficult situation in finding respite. Because you could hire somebody from care.com or put an ad somewhere, but the chances that they had experience with someone who had special needs was very low.”

GETTING THERE

Fourteen participants addressed the very real logistical challenges of actually getting their child to respite offerings, including the sheer distance, extended travel times, and work schedule constraints. Susan likened their “hours of traveling” to respite programming to “spending our whole life in the car,” which eventually led them to abandon this pursuit. For Shelley, the time required to get her son to respite squeezed other activities out of her life. She explained, “I make it a priority to get him to his programs, but I don’t do anything else outside of that because of the distance.” Even if the distance was not substantial, traffic patterns in some communities made the travel time untenable. Speaking of one opportunity in a nearby town, Yuuko explained, “The distance would impact my decision of whether to do that [respite program] because during those hours traffic from where I live to there. It would be significant.” Gina highlighted this challenge when accessing weekend respite, “It’s really hard on a Friday night to get people anywhere because traffic and everything is so bad. So, it takes several hours.”

The time required to get their children to respite also impacted parents’ ability to use the available time to relax. Emily explained, “I guess that makes me not sign up for it, because I’m like, oh geez, that’s a lot of back and forth and back and forth.” Susan explained how accessing overnight respite required a combined “four hours of traveling” on the day of drop-off and pick-up. “There was no respite involved. We had no relaxing. We barely could go out for supper before we have to go home, go to bed, because we have to get up early the next morning to go and pick him up and take him to school.” Melanie explained her own calculations, “It is an hour and a half in traffic, it could be two hours each way...It does dent some of the respite.”

LACK OF REPRESENTATION

One parent raised concerns about the degree to which respite programs were serving the diversity of families in her community. Nicole described respite access as profoundly unequal and “given to those [with] privileges.” She described the responses she received as she shared with others in her circles about the respite programs her son accessed: “I’ve heard people make the comment when I told them about [the program]: ‘Oh, they don’t allow our people.’” She felt strongly that respite programs should do more intentional outreach, “It shouldn’t just be one basic large setting of certain families. It should be a diversity—all kinds: Indians, Chinese, Spanish, Black, Africans. Let everybody in because we all bleed the same!”

“

***“With a 20 year old who is not toilet trained,
it has been impossible to find respite
outside of Jill’s House.”***

”

Section 6 | Impact of Overnight Respite on Parents

“This was the first weekend my husband and I got to spend together in 11 years.”

In this section, we describe how parents were impacted by having access to respite care through Jill’s House. Respite care represented much more than a mere break—it was a lifeline that brought hope and restoration to their lives. Amidst constant caregiving, respite provided parents a cherished time to reconnect with themselves, their families, their friends, and others in their community. Our findings capture just how deeply this relief resonated among participating parents.



SURVEY FINDINGS

We asked parents about the ways they felt they personally benefitted from accessing overnight respite care. We presented 25 areas of potential impact. All were preceded by the phrase, “Getting respite care through Jill’s House...” Parents had the option to select strongly disagree, disagree, somewhat disagree, somewhat agree, agree, or strongly agree. We order these areas from highest to lowest based on the percentage of parents who either agreed or strongly agreed it was an impact. Note that some items were omitted and not rated when it was not relevant to a parent’s situation (e.g., they were not married or they did not have other children).

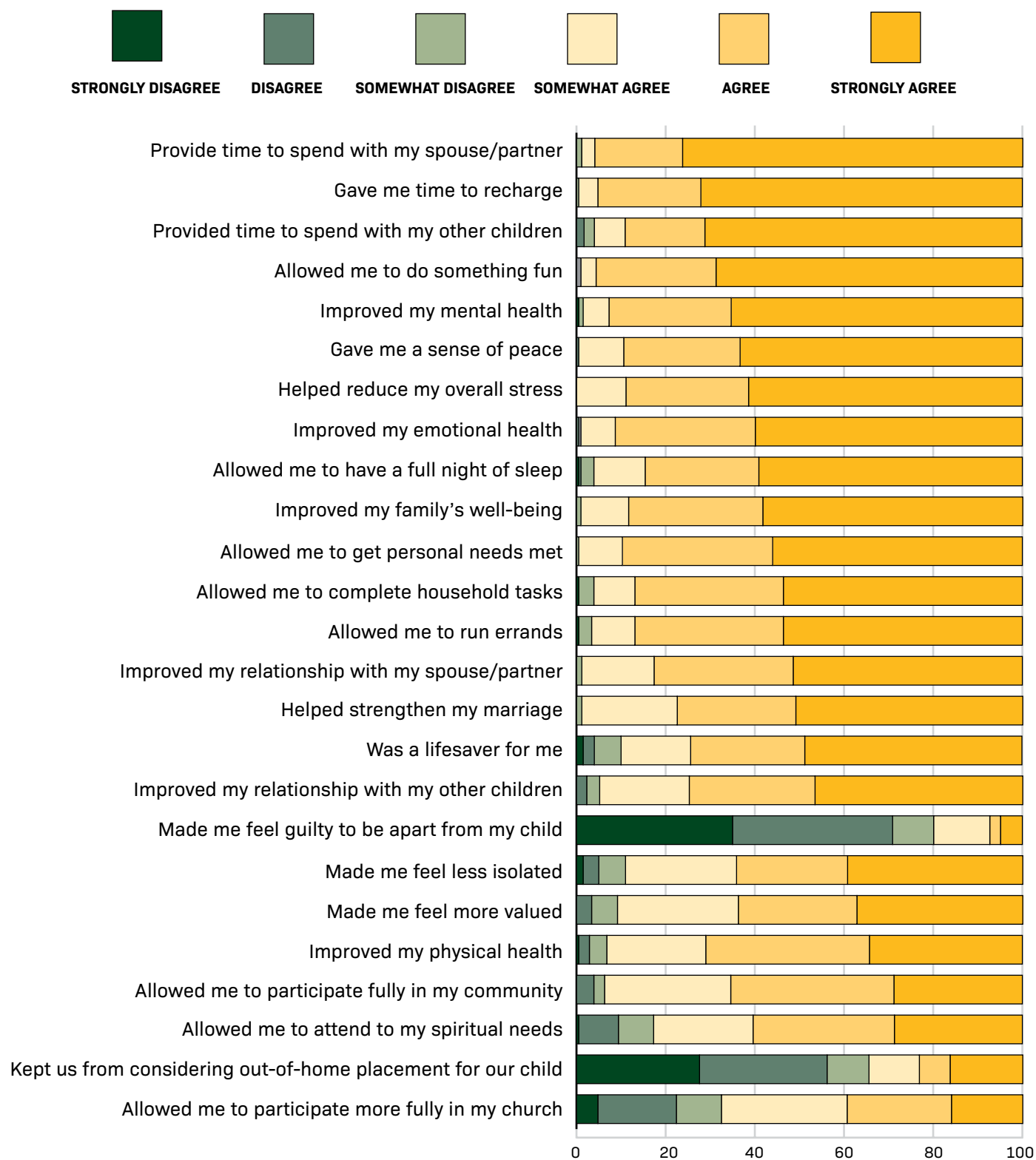
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“I was able to always feel like I was ‘me’ for a weekend or a weeknight... As a single parent navigating this life story you lose who you are as a person and it becomes all about your kids. I was able to focus and am still able to focus on finding out who I am after all of these years.”

“These respite times allowed my spouse and me to spend time together—whether it was for fun or more likely for errands and chores—but doing something together with them without caregiving felt wonderful.”

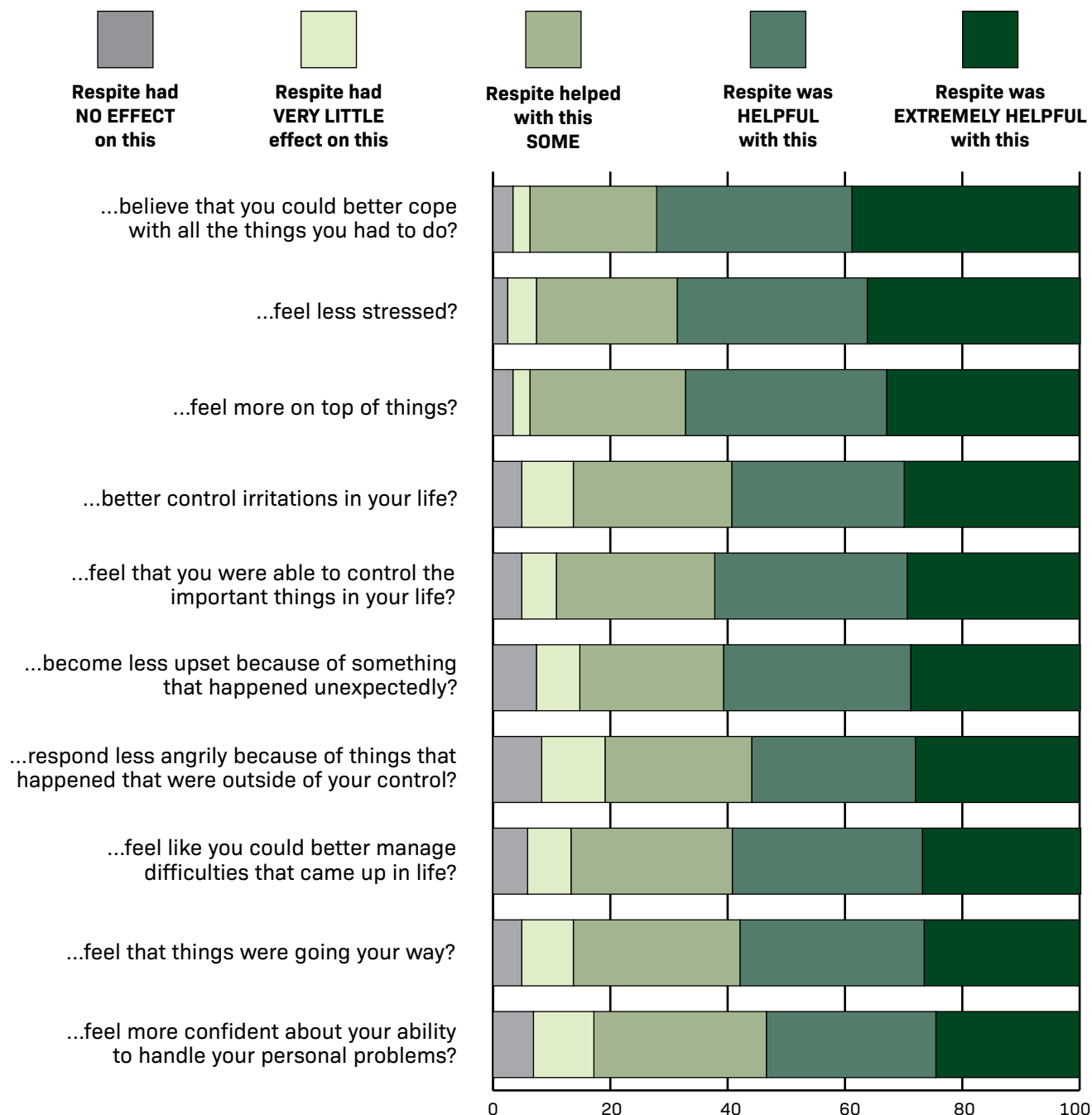
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IMPACT AREAS



We also asked parents to report how much respite impacted their stress levels and ability to cope. We presented ten areas of potential impact. All were preceded by the phrase, “How much did receiving respite through Jill’s House help you...” Parents had the option to select respite had no effect on this, respite had very little effect on this, respite helped with this some, respite was helpful with this, or respite was extremely helpful with this. Very few parents indicated that respite had no effect in any of these areas. On the contrary, the majority of families indicated respite was helpful or extremely helpful in all of the areas.

HOW MUCH DID RECEIVING RESPITE THROUGH JILL’S HOUSE HELP?



We also invited parents to list any other areas of personal impact not mentioned in the closed-ended questions. One mother said she “found a rare place where we feel we belong.” Another mother praised Jill’s House saying, “Respite at Jill’s House is heavenly sent. I know my son is safe and very well cared for. I feel free mentally and I am able to relax and enjoy my respite time knowing that he is safe...The staff members that have assisted my son—I can tell they are doing God’s work, true angels from above.” Other areas of impact mentioned by one or a few parents included:

- I could focus on myself.
- I could participate in activities I normally cannot do.
- I got to know other parents of disabled children.
- It enabled me to have a weekend away.
- It let me feel belonging.
- It helped me experience “normalcy.”
- It gave me confidence my child was having fun at Jill’s House.
- It deepened my appreciation of my child.
- It increased my faith in humanity.
- I felt supported and loved.
- I was able to seek employment to escape domestic violence.
- It enabled me to make long-term plans.
- It offered my child a camp experience.
- I viewed Jill’s House as family.
- I knew my child was valued by Jill’s House.
- It created a community where I felt understood.
- It allowed me to try new activities.
- I increased my knowledge through staff.
- I was inspired to become a better person after watching staff interact with children.
- It assured me my child was safe.
- It allowed me some privacy.
- It brought hope during tough times.
- It renewed me through seeing my child’s joy.

A few of the impacts shared by parents were not as positive.

- One parent said that self-transportation left little time for actual respite.
- One parent felt that fathers were valued and engaged less than mothers.
- One parent found that late Friday drop-offs and early Sunday pick-ups limited the break they needed.

“

“We have never taken a vacation as a couple since she’s been born because no one can care for her. Jill’s House gives us a quarterly ‘staycation.’”

“It made us see that our daughter can not only handle being away from us, but thrived and loved the experience. This confidence will open many doors for us!”

”

We invited parents to write in an open-ended section about what they did while their child with disabilities was at Jill's House. One mother said they were able to "realize that our disabled son is truly a gift from God. He is valued and loved by many, and his life is not a mistake. Also, since we have no family to provide care for our son, Jill's House has been our lifeline and has helped our family stay intact." Another mother talked about how they were able to "get together with friends, spend time with others in the family, have some calmness." Below are the other activities parents participated in while their child was at Jill's House overnight respite:

- Vacationed
- Participated in activities they normally cannot do
- Went out for dinner
- Attended sporting events
- Went to a movie
- Enjoyed quiet time
- Focused on themselves
- Went to a concert
- Went hiking
- Attended birthday celebrations
- Participated in hobbies
- Moved houses
- Read a book
- Attended a graduation
- Went shopping
- Explored natural and historical sites
- Felt the love of God's people
- Had time to cry
- Went swimming
- Attended a friend's party
- Went to a wedding
- Enjoyed an amusement park
- Saw a basketball game
- Went out to breakfast as a family
- Completed a medical procedure
- Experienced moments of calmness
- Helped another family move
- Went kayaking
- Organized their life
- Had a personal getaway
- Planned activities without having to consider their child's needs
- Played golf
- Read the paper with a cup of tea uninterrupted
- Realized their disabled child is a gift from God
- Ran a race
- Went sailing
- Took a walk
- Watched a TV show



"Parenting a child with severe special needs is very isolating. Having Jill's House gives me space and the opportunity for me to take care of myself is life-changing and vital."

INTERVIEW FINDINGS

We asked parents about how the respite experience impacted them personally. Example interview questions included: *How did this time of respite actually impact you and your spouse/partner? What did it enable you to do? How did you spend your time? How did it impact you? How critical were all of these impacts to you at that particular time? How long would you say the impact of respite lasts? Is it more of a short- or long-term impact?* Parents addressed 17 areas in which accessing respite care impacted them personally and often profoundly. In the following sections, we define and illustrate each impact area. We order the impact areas into six primary categories: family relationships, social connections, overall health, activity options, perspectives, and negative impacts.

TABLE 5-1. POSITIVE IMPACT OF OVERNIGHT RESPITE ON PARENTS OF CHILDREN WITH DISABILITIES

| IMPACT | EXPLANATION |
|---|--|
| FAMILY RELATIONSHIPS | |
| Strengthens connections among couples | Improves their relationships with their spouse or partner |
| Strengthens connections with other children | Improves their relationships with their other children without disabilities and deepens family bonds |
| SOCIAL CONNECTIONS | |
| Supports friendships | Allows them to spend time and build community with friends |
| Creates connections with fellow parents | Helps them meet and develop community with other parents of children with disabilities |
| OVERALL HEALTH | |
| Improves mental health | Enhances their emotional and psychological well-being |
| Reduces stress | Decreases the impact of daily stressors |
| Provides rest | Offers a time of refreshment and relaxation that is rejuvenating |
| Improves physical well-being | Provides space and time to address their physical needs |
| Addresses spiritual needs | Provides space and time to attend to spiritual aspects of their life |
| Is a lifesaver | Rescues them in the midst of a difficult situation or season |

| ACTIVITY OPTIONS | |
|-------------------------------|---|
| Provides a break | Offers time away from the daily responsibilities of parenting a child with a disability |
| Addresses practical needs | Provides rare space to run errands and attend to everyday responsibilities |
| Reintroduces choices | Provides some autonomy in selecting how to spend their time |
| Enables community involvement | Increases their opportunities to participate in community activities |
| PERSPECTIVES | |
| Improves child outlook | Gives them a sense of confidence in how their child is treated or cared for |
| Feeling known | Reminds them they matter in the eyes of others |
| Activates hope | Contributes to a sense of optimism regarding the future and others |
| Provides peace | Introduces a sense of calm and assurance in knowing their child is well cared for |

FAMILY RELATIONSHIPS

Respite care offered “priceless time” for couples to strengthen their relationships and spend meaningful time with their other children without disabilities.

STRENGTHENS CONNECTIONS AMONG COUPLES

Seventeen parents addressed the ways in which “these little breaks just lighten the load” (Brittany) in their marriage. From “having coffee” and “grownup conversation” to going on “long walks” and being “able to garden and go for a bike ride,” spouses (like Melanie) spoke of this time as “valuable for the peace of [their] home.” Several parents referenced the high divorce rate among parents of disabled children. Frederick, the father of a teenage daughter who requires 24-hour support, remarked, “[Respite] helps us stay together” and allows us to “focus on us.” For caregivers like Erika and her husband, who check on their 16-year-old daughter “five times a night” due to her severe sleep apnea, it means just “sleeping through the night” together. She reflected, “It is definitely challenging to have a child with special needs...My husband and I kind of give each other high-fives. ‘We’re doing it. We’re making it!’”

Crystal commented on how critical respite is for her relationship with her spouse, William, allowing time to “refuel and keep going,” partake in previously “inaccessible” activities together, or have “dinner without worrying about somebody that’s going to spill over the water glass or grab food from our plates.” Susan, the mother of a 20-year-old disabled son, reflected on the ways she was able to deepen her bond with her husband Barry during respite, saying, “There was no work, no phones, no emails answered...it was just 100% the two of us.” Echoing many of these parents, Melanie emphatically conveyed, “We’ll do almost anything to get it because it is so valuable for our marriage.”

STRENGTHENS CONNECTIONS WITH OTHER CHILDREN

Sixteen parents described the ways respite care “just strengthens the family bond,” providing more balanced and intentional interactions with all of their children. For many, it provided rare opportunities to spend quality time with their other children while their child with a disability enjoys activities elsewhere. Verónica felt these precious times together reinforced the siblings’ sense of value within the family: “My other kids—and my husband too—they get their time and then they’re happier and so everyone’s happier.” This gift of uninterrupted “one-on-one time” with their other children was enjoyed in myriad ways, including “a game night,” “going to the movies,” “going to dinner,” or simply “helping [their son] with algebra.” Christopher, a single father, relayed how important it was to connect with his other son who is a high school junior. “I’m going to be losing him soon to probably college...So, it’s a chance to just enjoy that time with him.” Similarly, Shelley said it enabled her to attend events that any other parent would normally go to like being “the parent who was in the stands who was getting to watch [her son’s] games.”

SOCIAL CONNECTIONS

Respite care helped strengthen relationships with friends and fellow families in ways that contributed to a deeper sense of belonging and connections.

SUPPORTS FRIENDSHIPS

Six parents illustrated how respite care granted the space and time needed to nurture friendships. Shelley, the mother of two children, cherished these times with her girlfriends, “I can go out and I can connect with a friend.” She emphasized, “It was a gift to get to have those opportunities.” Similarly, Heather delighted that “I get to go with my friends.” Tammy, the mother of six children, described how respite “allowed me to have some time where I could...meet a friend.” Gregory expressed how wonderful it was to finally be able to attend social gatherings with his wife: “Sometimes we’re invited to something, we just say no. Or one of us goes without the other.” But having respite care enabled “times when we got to do things with other people, which was a benefit.”

CREATES CONNECTIONS WITH FELLOW PARENTS

Three parents shared how the common experience of receiving respite from the same organization facilitated connections with other parents of children with disabilities. Gina adored the new relationships she developed, “Connecting with other parents who are kind of in your space is amazing.” Meeting these fellow parents enabled everything from the “sharing of resources” to “commiserating with each other” about the common challenges of parenting a child with disabilities. For Diana, “It gives you the opportunity to be connected, to be part of a greater community than just feeling so isolated and alone in what you’re experiencing.”



“My other kids—and my husband too—they get their time and then they’re happier and so everyone’s happier.”

OVERALL HEALTH

Respite care impacted multiple dimensions of the health and well-being of parents of children with disabilities.

IMPROVES MENTAL HEALTH

Nine parents described the ways in which respite care enhanced their mental well-being and reduced burnout. Words like “invaluable” and “uplifting” peppered their reflections on its impact. Some parents, like Andrew, described the reprieve offered through one night of respite as a “real emotional break” in which he and his wife “felt like we had taken a week off.” It provided parents the space and liberty to attend to their own emotional and psychological needs. Leslie, a single mother whose daughter required significant support, described respite as an intermingling of release and refreshment, “I would usually spend the first 24 hours basically sobbing and sleeping. It was the only time I could actually take care of me and let go.” This rare time away from caregiving responsibilities offered a much-needed window to re-center and focus on self-care. As Shelley described it, this invaluable time helped her “be the best parent” and “take care of [herself].” Likewise, Emily expressed how respite “really gives us a recharge in our soul and we just feel physically and mentally just better.” She continued, “It’s like, ‘Okay, we got this. We can do this.’ There’s light at the end of the tunnel for the [next respite weekend].”

REDUCES STRESS

Eight families detailed the ways in which their stress was diminished when their “load was lightened” through respite. For some families, it was the temporary reduction of responsibilities and competing demands that reduced their stress. Nicole shared a similar sentiment, “I didn’t have to worry. I didn’t have to stress. I didn’t have to meal plan.” Susan, whose son has high support needs, explained how their overnight respite often came right when she and her spouse were at their “highest limit of stress.” She characterized the respite she received as a “whole other world” and as “life changing.” In some cases, this particular impact was noticeable to others. For example, Verónica remarked how her two other daughters commented that she was “not as stressed out” as usual. Such respite—even if for just one night—felt like “going on vacation for a month” (Kathryn).

PROVIDES REST

Twenty parents spoke of the real rest that finally came when their child was away at respite. They described it variously as a time to “recharge our souls,” “decompress,” “reset,” “restock,” and experience “pure relaxation.” Shelly captured well this widely held sentiment when saying it felt like she “had a little wind underneath my wings.” She continued, “Getting that rest to catch your breath is something money can’t buy for a parent.” Brittany offered a parenting analogy to describe the way respite can reset life for a moment, “It’s like that rubber band—instead of stretching, stretching, stretching—it gets to come back and you get to kind of take a breath. And then we go again.” The time away from parenting created space to sleep (and sleep well), to change one’s pace, and to find some space. Melanie found that respite allowed her to “reset myself and then come back better for [my child], which makes the whole house better.”

IMPROVES PHYSICAL WELL-BEING

Fourteen parents connected this rest and emotional reprieve to better physical health and reduced fatigue. Most described finally being able to catch up on their sleep or engage in self-care activities. Emily described the tangible difference respite made in her overall health, “We just feel physically and mentally just better.” Andrew shared “how much more clearly we could focus when we actually slept for a couple hours.” Parents felt physically renewed when they had a chance, as Frederick shared, “To ease on into the day. Relax. Sleep.”

ADDRESSES SPIRITUAL NEEDS

For three parents, respite enabled them to attend to their spiritual needs. This was particularly true for weekend offerings, which allowed parents to attend church without worrying about their child. Yuuko addressed the joy of being able to attend worship services with her mother while her daughter participated in respite. For Rhonda, not having to be concerned about her son freed her to “engage in Mass more prayerfully [and] spend more time in prayer.” But the impact extended beyond church attendance. For Leslie, a single mother whose daughter required a lot of support, “Being more rested helps me feel more spiritual.” Rhonda also captured this broader impact of spiritual renewal, “I was able to have time where I felt like I was built up spiritually. That would be a more lasting effect.”

IS A LIFESAVER

Taken together, the collective impact of overnight respite care led six parents to characterize it as a lifesaver for them. This profoundly felt difference was captured in words and phrases like “life changing,” “life-giving,” “lifeline,” and “godsend.” Reflecting back on when her autistic son was younger, Shelley described weekend respite as “just life-giving for me for survival almost.” Similarly, Kathryn recalled how first encountering respite enabled she and her husband to see “the light at the end of the tunnel about what life could be like.” Close to tears, she described having a new assurance that her family would be okay.

ACTIVITY OPTIONS

Parents received the time and freedom to participate in other activities beyond their day-to-day parenting responsibilities.

PROVIDES A BREAK

Twenty parents focused on the impact of receiving a break from the everyday demands of parenting a child with disabilities. Capturing the views of so many other parents, Frederick explained, “It was just nice to take a break. We don’t get a lot of breaks!” As Susan shared, respite introduced a time to just be free, “After supper, I do not have to do anything. It’s like I’m free. So that’s awesome!” Verónica described the intensity of parenting her 11-year-old daughter, “She’s very attached to me. So it’s sometimes getting me a break from her just because—it’s not that she’s bad—it’s just sometimes, it’s too much with her.” A temporary release from responsibilities allowed parents to relax, spend time with family, enjoy other pursuits, and just “live regular lives.” For Emily, the break was also mental. “You get a true mental break for 48 hours where you know that your child is well taken care of and well-loved, with people that get it and understand it. So, you’re not having to worry. Your mind can shut off.” Such rare reprieves often elicited considerable gratitude. For example, Brittany shared, “We feel very blessed. But there’s just this extra gratitude we have because we just get this little break and we’re very, very grateful for it.”

ADDRESSES PRACTICAL NEEDS

Ten parents shared how respite enables them to complete household tasks, plan for the future, and focus on their work. Diana and Andrew described their to-do list as “always a million pages long.” For this couple, respite allows them to finally get “stuff done.” William also loved that respite enabled him to do things he “wouldn’t normally be able to get done because you don’t have the time” when parenting a child with disabilities. Felicia agreed, “It’s like you actually can bank on having that time to complete something that then won’t be more stressful later on.” Even having time to clean her house made Melanie feel “mentally more peaceful and squared away.” For a few parents, respite introduced the space needed to plan for their child’s future. For William, it allowed conversations with his wife to “focus on what we are going to do next.” Similarly, Melanie used these times to talk with her husband about future plans for her 11-year-old daughter with Down syndrome: “We figured out what we’re going to do.” Other parents, like Paula, used the time to focus on work responsibilities, “I can work a little bit longer hours or I can come in later.” For Kathryn, a busy teacher, respite allowed her to get work done on the weekends, “When she’s at that respite program, all I’m doing is lesson planning and grading...I’ve got to get some work done.”

PROVIDES A CHANCE TO CHOOSE

Respite care helped 16 parents recover a sense of autonomy. When so many daily decisions are driven by the needs of their child, respite reintroduced parents to options. Nguyen explained how it offered “one day you can be free by yourself and do anything you want.” Erika, the mother of four children, characterized respite as a “mini vacation” that offered her an array of choices, including “plan things like a date night.” Kathryn referred to it as “Christmas. It was amazing!” Leslie, the single mother of 17-year-old daughter with extensive support needs, explained how rare it was to truly direct her day outside of respite:

“I never really get a chance to just relax and to just take care of me and just say: What do I want to do? What do I want to eat for dinner? What do I want to do right now? Do I want to take a nap? Oh my God, do I want to read an entire book for five hours? Wow!”

ENABLES COMMUNITY INVOLVEMENT

Seven parents described the ways respite provided them the flexibility to re-engage in their communities through ordinary activities like a “Lenten fish fry,” an “annual auction,” or a “20-mile hike for the Boy Scouts.” Involvement in an array of community activities alleviated their feelings of isolation, enhanced their emotional well-being, and deepened their sense of belonging. Diana likened it to the safety announcement made on planes, saying:

“Put your mask on first before you put it on your child. I feel like your whole life is making sure that that mask is on your child, and you don’t realize [that], meanwhile, you’re suffocating and you’re about to stop breathing. And so, I think [respite] gives parents the space to recharge for the marathon that is their life.”



“God has helped us get ‘unstuck’ using Jill’s House. We are functioning better on every front. We are better parents for her because we have had time away from her for peace and reconnection with God and in our marriage.”

PERSPECTIVES

Respite helped shift parents' views regarding their child, themselves, and the future.

IMPROVED CHILD/YOUNG ADULT OUTLOOK

Six parents described how respite began to change their outlook regarding their child's potential for greater independence. Hearing positive reports about how well their child managed while being away from family for an evening or weekend helped them recognize their individual capabilities. Leslie explained her reaction to seeing Instagram posts from a weekend retreat, "It's rare that I can see her doing something and having a good time that I'm not actively involved in. It's just nice to get a picture when I'm not in it. It's just her. This is her experience, not mine." For Kathryn, learning how well her daughter did—and how much confidence and fun she had—in her absence was impactful:

"It gave me faith in Amy that she is going to find her way and totally be okay and thrive. She wasn't just okay, she was absolutely thriving at those retreats! You don't get to see that very often when you're a mom of a special needs kid. You get to see it in little glimpses here and there. But to see that that was true for her for—sorry, I'm getting emotional—to see that that was true for her for two and a half days, that meant a lot."

Emily emphasized why catching these glimpses of independence was so very important, "We're not going to be here forever. So, we need to know that Kingsley can function in a setting like that where he has other adults to take care of him."

HELPS PARENTS FEEL KNOWN

Four parents addressed how receiving regular respite care helped them feel known. The provision of respite—and the care with which it was delivered—assured them they mattered in the eyes of others. Shelley described the impact of respite as a gift to parents like her:

"It helps you feel seen. It helps you feel heard. It makes you feel like people get it, because so many people don't get it. So many people, I think, see my son and just see how lovely he is. Even though he's on the autism spectrum, they have no idea what it takes for me to navigate his life and what I still have yet to figure out for him before I leave this earth."

Other parents appreciated that someone actually understood their needs. As Erika explained, "I do feel like it's really important for families to feel like they're understood and then they actually just get a break and can live a bit of a regular life like most people, even for just a couple of days. It's a huge blessing!" Moreover, this understanding was affirming in counter-cultural ways, as illustrated by Leslie:

"They really see the value in everybody. And that includes me. They see my value and they get it, but they do it without pitying me. I'm sure we've all had this experience where you feel like you've made a new friend and you start explaining about what your life is like and you get the, "I could never do what you do. Oh, you poor thing." No, no. These are my challenges. We all have different challenges. Yes, mine may be a little bit more than somebody else's, but it doesn't mean that my life is crap. Instead, it is: "We know you work really hard and you love your kids. And we love your kids. And how do we help you?" Very different. It's empowering and bolstering, as opposed to sympathizing and pitying, which is not helpful."

ACTIVATES HOPE

Eight parents spoke of how the anticipation of forthcoming respite can fuel a certain hope. The rhythms of regular respite—whether monthly or quarterly—contributed to a sense of optimism about the future. Indeed, the word “hope” was often used to describe their feelings as parents talked about looking forward to the next respite offering (e.g., “the hope of knowing that it’s coming,” “[it] gives you hope for that week”). Amidst any present challenges or exhaustion, parents could look ahead with confidence to a future reprieve. Susan described this expectancy, “All month long, the respite is coming! And Spencer is driving you crazy and—whatever the case is—it’s okay. Because we know that on that date, we’re going to have respite.” Shelley, the mother of two children felt similarly, “It helps sustain you on the journey because when you actually know that you have this date coming up. It kind of almost gives you a lift to get to that weekend.” Even as one respite experience ends, as Emily shared, “There’s light at the end of the tunnel for the next one.”

PROVIDES PEACE

Nine parents shared how respite provided a sense of peace, feelings of calm, and reassurance in knowing their child was in capable hands. For example, Melanie described herself as feeling “mentally more peaceful and squared away” after respite. Likewise, Verónica shared the impact of having “somewhere that we know [my child is] going to be safe...that’s peace of mind for us.” Grateful for the newfound break and tranquility, parents highlighted this treasured time as “peace and quiet and no responsibilities.”

NEGATIVE IMPACT

Rarely was the impact of respite described in negative terms. However, five parents spoke about the worries they harbored as their child spent the night somewhere else. Initially, this concern overshadowed the restorative benefits of respite, but it always diminished over time. For example, Jackie said, “The first night was a little hard, but the second night I was able to relax.” A second concern related to medical emergencies, which were stressful for parents and children alike. For example, Christopher described picking up his 15-year-old daughter from respite after she had a seizure, “The joy of Jill’s House was dampened by my focus on my daughter and getting her the care she needed.”



“Having a community that understands me without having to say anything is a gift from God.”



“Jill’s House definitely helped my mental health and physical well-being.”



“Jill’s House gives our whole family a sense of belonging with a community that otherwise seems hidden.”

Section 7 | Impact of Overnight Respite on Children, Youth, and Young Adults

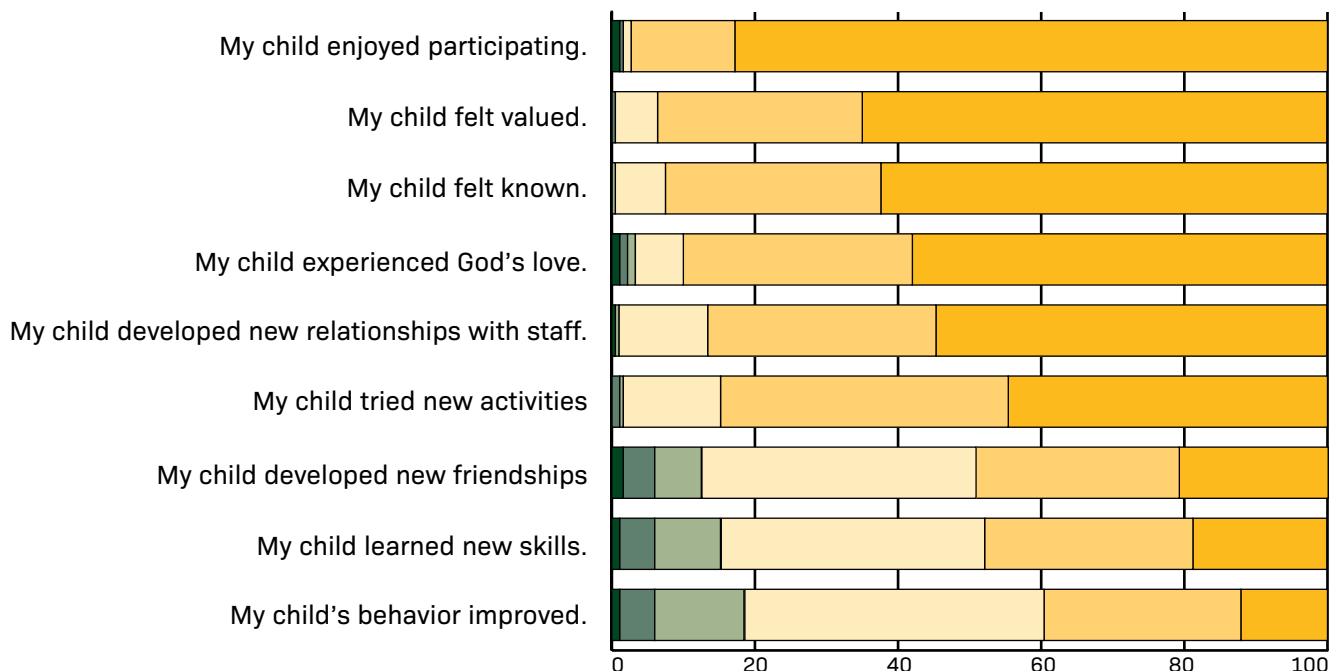
“She’s been loved and cared for, and been given the freedom to wholly be herself.”

In this section, we describe the multiple ways in which children, youth, and young adults were positively impacted by their involvement in Jill’s House. Although conversations about respite care often focus on the relief it provides caregivers, it also offers a fun and enriching break for children, youth, and young adults with disabilities. Moreover, time away from family fosters experiences of joy, independence, and a sense of belonging. Our findings point to just how transformative this care can be for young people with disabilities and the contributions it can make to their flourishing.

SURVEY FINDINGS

We asked parents about the extent to which they agreed that their child benefited from involvement in nine specific ways. Parents had the option to select strongly disagree, disagree, somewhat disagree, somewhat agree, agree, or strongly agree.

PERCENTAGE OF RESPONDENTS



We also invited parents to list any other areas of impact on their child not mentioned in the closed-ended questions. One major theme focused on how their child increased their independence ($n = 40$ parents). For example, one stepmother said, “Going to camp provides Evan with a sense of independence not found elsewhere. He’s able to participate in his own way and feel accepted while doing so. He absolutely loves camp. It’s his most favorite thing to do!” Other areas of impact mentioned by one to a few parents included:

- My child felt excited to go.
- My child experienced adventure.
- My child had new experiences.
- My child experienced a break from family.
- My child increased in confidence.
- My child felt free to be themselves.
- My child felt safe.
- My child felt love for the Jill’s House community.
- My child felt empowered.
- My child felt included.
- My child felt joyful.
- My child increased in self-esteem.
- My child increased their self-advocacy skills.
- My child read about and learned about the gospel.
- My child felt “normal.”
- My child was reluctant to leave Jill’s House.
- My child experienced growth.
- My child participated in social groups.
- My child treasured Jill’s House.
- My child gained leadership opportunities.



“

“The best hours of any month occur in the opening moments that follow a Jill’s House drop off for our daughter as we release ALL the sensations of covering and caring for her needs for physical, emotional and social support.

It truly is a release of all the pressure you get so used to that you don’t notice it ... until it isn’t necessary. A full exhale that you just want to sit in and savor for a bit ... just so you don’t miss it.”

”

INTERVIEW FINDINGS

We asked parents about how the respite experience impacted their child. Examples of interview questions included: *What did it enable your child to do? What did your child express to you when you first told them that they would be going to Jill's House? What did they share after their time at Jill's House? What (if anything) does your child love about Jill's House? What did people from Jill's House tell you about your child's time there?* Parents identified nine primary areas of impact for their child. In the following sections, we define and illustrate each impact area.

OFFERS A BREAK

In addition to parents receiving respite, seven parents also noted that participating at Jill's House is a form of respite for their child too. Children, youth, and young adults experience a break from family rules, family members, and life stressors. Erika, a mother to four children, described her teenage daughter's experience with respite care: "Sometimes life is stressful. [She] definitely gets stressed in life with chores or things... or if her siblings are being mean...Life is stressful. Jill's House is really just this sanctuary for her where it's pretty much all positive." Overall, parents view Jill's House as providing their child a break and a "relaxing weekend" away from family.

BROADENS EXPERIENCES

Parents shared that their children experienced new opportunities through participation at Jill's House. Children, youth, and young adults had the chance to visit novel places, practice life skills in a safe environment, and try new activities—such as archery and music classes. Nicole, a single mother to three, highlighted how her son had "the chance to learn to do other things. He got to experience things he never experienced before. Try new activities he never tried before." This "change of scenery" created opportunities to engage in new activities. Eric, a father to three children, praised Jill's House saying it furnishes "a diverse set of activities" that supports his son's "social engagement" and "autonomy." Alongside new activities, participating in Jill's House provided learning opportunities for children, youth, and young adults. Parents described how their children are "learning to operate without their primary caregivers, and they're learning to trust others in an environment that is different from their home." These learning opportunities expand their abilities and encourage personal growth. Emily, a mother to a child with high support needs, emphasized this, saying her child could "generalize [skills] in another environment with other individuals."



***"You don't realize until your child is away
(and you know they are in a safe, loving place)
how much you are on alert,
monitoring everything that is happening all the time.
Then you are alone, and you notice that weight off your shoulders.
It is indescribable."***

DEVELOPING RELATIONSHIPS

Most respondents reported that their child experienced social growth after participating at Jill's House through the development of new relationships with peers and staff, who parents say, "become like family." Fifteen parents referenced the supportive environment and "all the fun activities" and chances "to connect with other people" that are "super, super valuable to [their child's] continued development" (Shelley). Nicole, single mother of three children, confirmed, "I see my son sometimes when he leaves. He cries. He doesn't want to go. He has really gotten connected to so many of these nice young ladies, the staff members. And I'm like ... 'You know why you like them so much?' He said, 'Because they sang to me. They play games with me. We do activities.' ... They all made him very happy." Similarly, Gina said of her daughter, "She is learning independence, she's making friends when I'm not there. And she has a great time."

Parents mentioned how the staff become trusted figures in their children's lives, fostering a feeling of safety and being understood that promotes social interactions. Additionally, these relationships provide children, youth, and young adults with a broader support network and contribute to their sense of community as Crystal explained: "A program like Jill's House that provides overnight care is also a developmental opportunity for these children with special needs because they're also learning to operate without their primary caregivers, and they're learning to trust others in an environment that is different from their home. ... I'm not going to be here forever, so I need my girls to be able to trust and be able to work with other people, and I think this is a great steppingstone as they're aging." Several parents commented on how this growth has led their child to take a more active role in assisting their peers, increasing "their own awareness that they are special with their needs and to see others in that same light" (William). Erika offered, "As Lacey's gotten older, [the staff] really, I think let her and encouraged her to be helpful to the other kids there. ... If there's a child in a wheelchair, she likes to help push them or talk to them and help get them involved with the basketball or whatever they're playing with." Through these enriched social experiences, they build meaningful bonds with others that support their emotional and social development and, as Diana suggested, enjoy their own form of respite. "Being able to not be with your parents might be respite in a different way."

Parents also acknowledge the "wonderful notes" that they receive from the staff about their child's stay, saying, "It's heartwarming to read about all the interactions that she would have" (Leslie). Kathryn agreed, "They told us that she was grinning from ear to ear the whole time, that she loves to laugh. ... It's nice to hear when she connects with other people, and it's nice to hear that she's having a good time." Kate, a sixteen-year-old with IDD, who enjoys "art, making cards, and making invitations for staff and volunteers and friends to come to my concert," concluded, "It's good for me."



"I don't have help with Claire's care. I get so drained physically and emotionally, having this opportunity for Claire to be loved and cared for for a day or so is healing to my soul, my body and mind."

I lost a lot of friends when I adopted Claire. Jill's House allows me to get out and do something social and try to make new friendships."



PROVIDES FUN AND ENJOYMENT

Twenty-five parents said that an impact that respite has on their child is their child's enjoyment of it. This enjoyment included having fun, enthusiastic engagement in the various games and activities offered, and looking forward to their next respite experience. Many parents expressed how important it was to them that their child enjoyed respite. They felt more comfortable using respite when their child enjoyed participating, had fun, and actively looked forward to their next time at respite. Nicole, a single mother of three children explained, "this is the only place that I know he's safe. I don't have to worry. And not only that, he's having a great time." Parents also commented how the knowledge of their child's enjoyment enabled them to "relax."

Nguyen, a married mother of three, said, "And I'll ask him, 'Do you want to go to Jill's House again?' And he will say, 'Yes.' So, that means he likes it. It's very rare that he likes something." Melanie, a mother to a child who requires full-time support said, "Anytime she can go, she will go because it's her favorite thing, absolute favorite thing."

Parents also reported their children enjoying, "Swimming, basketball, bouncy house," and "the climbing wall." (Yuuko). Nguyen said that her child enjoys the "bouncy castle," while Paula, shared that her 11-year-old son's favorite activities were "zip-line and talent show." Verónica's 11-year-old daughter exclaimed, "My favorite is campfire. Because we roast lots of marshmallows."

Other parents emphasized that their children look forward to their next respite experience. Brittany, mother of three, said her daughter "gets very excited... She sleeps with her bathing suit. She brings it into bed with her and she starts to get her stuff ready. A couple of weeks ago when we went, she had pulled out all of her clothes out of all of her drawers... because she's excited to go." Tammy said her son "marks the days off" on a calendar giving him "hope and joy and love" that his time at Jill's House is coming soon.

EXPERIENCED LOVE AND INCLUSION

Ten parents discussed the inclusive environment at Jill's House and how their children experienced love, belonging, and confidence. Describing her son's experience walking into Jill's House, Nicole said: "The kids feel welcome, feel celebrated, feel loved and cared for...Can you imagine every time you went somewhere someone said, 'Hey, girl, how are you doing?' Smiling at you; hugging you. [That must] make you feel so good...That's how Jill's House is for Andy...It's the best feeling ever. The environment provided by Jill's House is welcoming and inclusive and centers around being "empowering and bolstering as opposed to... pitying" which fills parents' hearts knowing the staff values their children. Melanie communicated how intentional staff are with her daughter, "They just have so much love, and she feels just seen, loved, comfortable, and accepted." Other parents corroborated Melanie's observation; Erika, a mother to four children, discussed how Jill's House encouraged her daughter's "self-confidence," and that staff encourage participants by "[bringing] out their strengths." At Jill's House, children experience feeling known and valued. They have the chance to be themselves in a welcoming environment that values their strengths.

PROMOTES PERSONAL GROWTH AND AUTONOMY

Seventeen parents expressed that their child or young adult experienced personal growth and increased autonomy after participating in Jill's House respite care. They shared that their children learned new skills, experienced being away from their parents, got respite from their families, and developed increased confidence.

Respite provided children, youth, and young adults with an experience that was just for them. Leslie, a divorced mother, stated, "It's just her. This is her experience, not mine." Verónica, a married mother with three children said her child came home after having "...the best weekend she ever could have had... she came home telling us about how this is hers. This is her experience. Her siblings don't get to do it. Only she gets to do it because it's for her. So that was amazing." Melanie's daughter shared, "[What] I like about Jill's House is having fun with my own friends and hanging out, and... going out for a special lunch and dinner and breakfast."

Parents also commented on how their children developed new skills at respite. Jackie, a married mother with a child who has a lot of support needs said, "He brushed his own teeth. And at home, he never brushes his own teeth. We always have to brush his teeth. He has zero interest in even holding the toothbrush or anything." It gave him an "opportunity to be independent and kind of take some ownership for himself." Rhonda, a mother with seven children, highlighted how respite, "is nice for giving him an opportunity to practice his skills speaking and other skills in a different environment with different people." Kathryn's daughter shared, "My favorite activity is [the] big swing because it shows I am brave."

Respite also provided children, youth, and young adults with an opportunity to spend time away from and lessen their dependence upon their parents. Crystal, a married mother of two children, said, "they're also learning to operate without their primary caregivers, and they're learning to trust others in an environment that is different from their home. Ultimately, as they grow and age, I think that's going to be important." Speaking of her daughter, Gina said respite "gives her confidence in just being away from mom and dad and the family. I think that's invaluable for her. I mean, if she didn't have those opportunities, she would never be away from us. And that would be really weird for a 15-year-old." Melanie, a married mother with one child with a lot of support needs, said it has created a "spirit of independence in her" and it leaves her "feeling like she has her own life." Eric, a married father with three children, communicated "the sense of building autonomy is important for him."

Other parents shared that respite was for their child, too, in that it provided them a break from family. Diana and Andrew, a married couple with one daughter, said, "It's probably respite for her too because she was just always with us. And so being able to not be with your parents might be respite in a different way. Because we're always like, 'Don't do that.' or 'Pick this up.' or 'Don't wear that.' And when she's there, I'm sure she doesn't hear all those things." Shelley shared, "At this stage of life, he's 24 and respite means independence. It means mom is dropping me off and I have my thing."

Increased confidence was also an impact of respite for the child. Melanie shared that respite makes her daughter, "feel like she's a cool girl. She's got this cool life." Erika, a married mother of four, shared, "I do feel like it's really encouraged her self-confidence, because they are so positive and they really get to know these kids for who they are. And they're so encouraging for them to be who they are and bring out their strengths."

FOSTERS SPIRITUAL WELL-BEING

While Jill's House makes known that participation in religious activities is entirely optional and that they do not discriminate based on a person's faith or choice to not participate, several parents expressed their appreciation for having religious activities available, noting that it positively influenced their child's spiritual well-being. They attribute this to the nurturing atmosphere and the option for their child to attend "chapel time." This holistic approach to respite allows children, youth, and young adults to explore their own spiritual dimensions as Crystal remarked: "There is a spiritual component that is taken into consideration and used ... for the benefit of the girls and their well-being. I love seeing that they do chapel time and those kinds of things. ... giving them opportunities that we don't normally have for them." Nicole added, "And that's another wonderful thing about Jill's House because they got the church right inside and [my son] comes home singing the church hymns that he learned." Parents appreciated this chance for their child to "learn more about God and Christ" and participate in worship, which they say increases their child's sense of joy and fulfillment. Erika observed, "She loves the chapel time they have on Sundays and [the staff] say, 'She said such a nice prayer' ... So, I'm very thankful that they are encouraging that." Other comments highlighted how the program honors the child's individuality and family's personal beliefs. Shelley remarked, "The beauty of it is that's an outreach to the community for Jill's House to expose people to faith. ... I always loved that they had that option for them to go to [chapel]. I think it's done nothing but reinforce again, our core values, belief systems that I brought my boys up in. And so, I think that has made it very, very comfortable for him."

NEGATIVE IMPACT

One parent expressed that time at respite had negative impacts on their child. These negative impacts included difficulties when their child returned and difficulties sleeping by herself. Yuuko, a widowed mother, expressed that her daughter had a hard time sleeping alone and was, "...super difficult when we got her back both times." She also shared that her daughter has "only been to Jill's house twice, but the second we got her back both times, she just was at her worst." However, Yuuko shared positively that when Jill's House provided her daughter with a roommate, her daughter was able to enjoy the experience more.



"I have felt a sense of belonging that I haven't experienced since our son was born. We are recharged in so many ways by Jill's House. But knowing we're part of a bigger community who loves us and sees our son as a gift from God has been the biggest blessing to me."

Section 8 | Impact of Overnight Respite on Siblings



“We’ve made connections with families like ours and had the chance to focus on our other children.”

The experiences of siblings can be both wonderful and challenging. Having a brother or sister with intellectual disability can sometimes leave siblings feeling overlooked or disconnected. Respite can also bring benefits to these young people. In this section, we describe how parents reported how other family members were impacted by their child’s involvement in Jill’s House. This topic was not addressed directly on the surveys. However, during the interviews, we asked parents about how the respite experience impacted other members of the family. Example interview questions included: *What difference did it make for your family overall?* For example, how did it impact your other children. Overall, parents identified three primary areas of impact on the siblings of their child with disabilities. They recognized broad benefits for the entire family and rare moments for one-on-one attention and connection that are often difficult to find amidst their daily routines. In the following sections, we define and illustrate each impact area.

TABLE 7-1. IMPACT OF OVERNIGHT RESPITE ON SIBLINGS

| SIBLING IMPACT | EXPLANATION |
|--|--|
| Time with parents | Provided undistracted attention from parents and time to spend together |
| Opportunity to relax | Offered time away from daily responsibilities and stress related to having a sibling with a disability |
| Opportunities for different activities | Enabled autonomy in selecting how to spend their time |



“When John comes home from Jill’s House he has a ‘love glow’ about him – peace, happiness and joy. The pouring into him is literally so evident that strangers have noticed.”



“Jill’s House is a blessing for our son and family. We greatly appreciate Jill’s House and the team for creating a great camp experience. Our son enjoys going on each visit and we are able to have a respite of our own also.”



“He’s so full of joy like he’s exploding inside to non-verbally tell us he had the best time ever.”



“It’s literally a godsend.”

TIME WITH PARENTS

Eight parents highlighted how their other children had more time with them while their sibling participated in Jill’s House. As Verónica shared, “Their parents’ attention is not being torn in all these different ways.” As illustrated by Nguyen, respite provided a “special day for daddy and mommy to take [their daughter]. So she’s happy.” Increased time and attention with siblings were said to be “priceless” for siblings, granting them undivided attention from their parents. Felicia remarked, “It was good my other children got a little more attention than they would have if Mason was there.”

OPPORTUNITY TO RELAX

Two parents discussed how their other children also experienced a break when their sibling with disabilities attended Jill’s House. As they spent time with their parents, the other children had a chance to unwind and take it easy. Felicia described what this looked like, “The house is just quieter, so I just think it gives everybody in the household a little bit of a chance to relax.” Emily emphasized how important—and rare—it was for her other children to have uninterrupted time with her, “It’s been really great to have that break that Jill’s House has provided for us to focus on just the girls...It’s just been nice to have that reprieve.”

OPPORTUNITIES FOR DIFFERENT ACTIVITIES

Respite was said to give the other children the freedom to engage in a choice of activities without having to always consider the needs of their sibling with disabilities. Parents and siblings could do “different things” (Emily). As Christopher explained, “It was a chance to enjoy each other, which we don’t always get that chance.” Parents deeply valued this time with their other children. Felicia explained, “It’s like sometimes Mason needs so much attention that I feel like the other children don’t get the attention. So, it’s an opportunity, in that case. We spent time doing something that the other kids would like more.” They are offered a chance to engage in preferred activities with their parents while their sibling with disabilities participates in activities elsewhere.

Section 9 | Impact of Other Jill's House Programming



"It is really neat how Jill's House brings all of that together. The actual respite, the physical respite, and the emotional support—but also the spiritual piece of it. They just bring it all together."

The work of Jill's House extends beyond respite care, as does its impact. Families who participated in other program offerings shared about the myriad ways their lives were enriched by accessing these supports. In this section, we discuss how parents were involved in other family support programs at Jill's House and the impact they reported.

SURVEY FINDINGS

We asked parents whether they had participated in any of the following family support programs offered through Jill's House. Half of parents had participated in one or more of these various programs.

FAMILY SUPPORT PROGRAM PARTICIPATION



"It's our 'little heaven on earth.'"

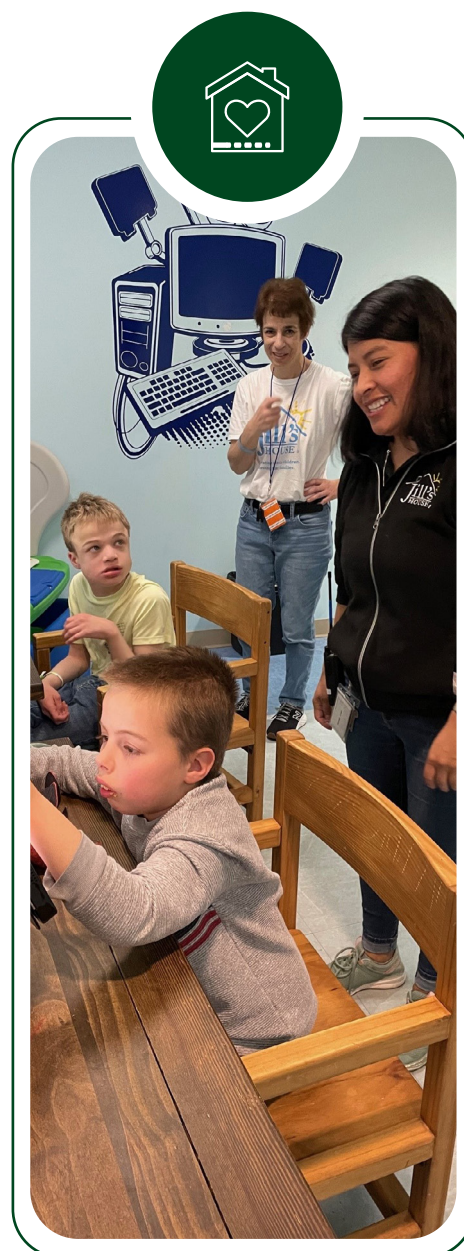
We asked parents to share how they were impacted—positively or otherwise—by their involvement in Jill's House family support programs through an open-ended question. The ability to meet and connect with other Jill's House parents was the most often mentioned benefit ($n = 39$ parents). For example, one mother shared, "The family support has been life-changing. It is so isolating being a caregiver for a special needs child. I have been alone literally and figuratively. Jill's House family support groups have changed that. I have friends that get it and are there for me and my children have friends that understand. I'm not alone and feel supported." Below are other impacts parents identified. The camaraderie and connection with other families who were navigating a similar journey was highlighted as a difference-maker.

Other areas of impact mentioned by one to a few parents were:

- They enjoyed the activities.
- It gave them a chance to relax.
- They felt less alone.
- They built community together.
- They connected with Jill's House staff.
- They received valuable resources and knowledge.
- They considered the support to be "lifesaving."
- Parents felt supported by other families.
- Their child(ren) experienced enjoyment.
- They experienced love.
- Their spiritual needs were met.
- They had time with their spouse.
- They had time with their family.
- They took joy in seeing other families also benefit from Jill's House.
- They experienced a vacation.
- They felt like they fit in.
- They gained confidence in their parenting skills.
- They knew their child with a disability was loved.
- They experienced peace of mind.
- They received time to focus on their other child(ren).
- They had time for friends.
- Their emotional needs were met.
- Their child(ren) connected with others.
- Their family life was enriched.

A few of the impacts shared by parents were not as positive.

- Some parents compared themselves to others.
- Some parents viewed some activities as too religious.
- One parent felt they had less time with family.



INTERVIEW FINDINGS

During the interviews, we asked parents to discuss how they have been impacted by participating in family support programs at Jill's House. The following questions addressed this topic: *Did you access any other family supports (e.g., retreats, moms'/dads' socials, parent support groups, Bible study, special events)? If so, tell us about the impact they had.* Parents addressed three primary areas in which family support impacted them personally.

TABLE 8-1. IMPACT OF FAMILY SUPPORT PROGRAMS ON PARENTS OF CHILDREN WITH DISABILITIES

| IMPACT | EXPLANATION |
|----------------------|--|
| Supportive Community | The opportunity to meet and build relationships with other parents of children with disabilities |
| Enjoyment | The joy of experiencing fun activities |
| Challenges | The challenges of balancing family responsibilities while participating in programs |

SUPPORTIVE COMMUNITY

Five parents detailed how participating in family support programs helped them build community with other parents of children with disabilities. Crystal explained how she benefitted in this way, "It is great connecting with the other families. It also gives you...a perspective on what other families are also going through...lets you know that you're not alone. And then...[it] also gives you a great opportunity to meet, mingle, engage, and network with families that maybe have done things before you are going to get there. It's a great way to learn as parents." Building community with other parents helped families feel understood and supported. Leslie emphasized this point, "It's just so helpful to know that I'm not alone...That is life-changing for me... It's really nice to get out and just kind of be able to talk real things with people who get it, and just kind of feel taken care of." The connections parents made pushed well beyond surface-level relationships. William communicated the depth of the relationships he formed, "[Being] around a group of people that [goes] beyond just somebody that you met. But people have become friends and get to do things with them, talk to them about challenges that they have and some of the opportunities that they've found that may apply for us or to others."

ENJOYMENT

Two parents expressed how much fun they had while participating in various family support programs. Leslie said her family would do "anything that we can" with Jill's House. She continued, "I do the family support group once a month, and I do the moms' nights out when they have them once a quarter. Those are great." Similarly, Erika described the family support as "so wonderful" for herself and her family. She said these shared experiences brought her family closer together.

CHALLENGES

For one parent, participating in family support programs sometimes felt like it competed with his family obligations. Gregory shared how his wife has to parent their child with disabilities alone when he attends certain family support events. In addition, he mentioned how he "didn't feel like [he] connected with the guys."

Section 10 | Our Recommendations

In this final section, we offer recommendations based on the insights we gathered from our surveys of and interviews with parents. Drawing upon these findings, we offer practical suggestions for how Jill's House may further enhance and sustain the positive impact of respite care, as well as ensure their services align with the needs and aspirations highlighted in this study.

OVERCOMING BARRIERS

DETERMINE WHY FAMILIES WHO ARE NOT CONNECTING TO JILL'S HOUSE STRUGGLE TO DO SO.

All of the parents described challenges they encountered when seeking respite care in their community (e.g., financial constraints, being unaware of programs, trusting providers). Families from diverse racial, cultural, and economic backgrounds may experience unique barriers to accessing respite care. They also may hold the perception that respite programs do not serve families similar to theirs. Barriers to accessing respite also may be location-specific. These factors warrant further exploration. Identify barriers families may encounter when attempting to access respite care at Jill's House and explore ways to alleviate these. Holding focus groups, assessing financial accessibility, and evaluating provider training and representation are potential mechanisms for gathering the information needed to reduce barriers.

STREAMLINE THE APPLICATION PROCESS AND OFFER HANDS-ON HELP TO ALLEVIATE STRESS.

Many parents mentioned the arduous and time-consuming application process of applying and enrolling in Jill's House. Consider holding on-site, guided workshops to help families complete the application with opportunities to ask questions specific to their circumstances and children. Additionally, help families identify and navigate other resources and support services in the community by providing information or partnering for educational workshops.

PROVIDE SCHOLARSHIPS OR OTHER FINANCIAL RESOURCES TO MINIMIZE COSTS.

Financial constraints pose a significant barrier for many families seeking respite care. Moreover, locating financial assistance was described as a challenging and time-consuming process. Consider assisting families to navigate government insurance programs to receive their full benefits. Develop and share other possible sources for financial assistance.

EXPLORE TRANSPORTATION OPTIONS FOR FAMILIES TO HELP REDUCE TRAVEL-RELATED BARRIERS.

Although the quality of care was highly praised, the logistics of reaching Jill's House was a notable challenge for some families. Many parents expressed that their travel time to Jill's House was strenuous and time-consuming, which impacted their overall experience of respite. Consider implementing a transportation assistance program that could include shuttle services, ride-sharing partnerships, or transportation stipends to enhance the accessibility and convenience of respite services and broaden the reach within the community.

CONNECTING WITH FAMILIES

PROMOTE JILL'S HOUSE AS A MINISTRY FOR THE WHOLE FAMILY AND FOR ALL FAMILIES.

Parents described the benefits and positive impact of Jill's House for their children with disabilities, for themselves, for their other children, and for the family's overall well-being. Be intentional in positioning Jill's House as a ministry that serves and uplifts the entire family. Highlight in promotional and outreach materials the many ways Jill's House provides emotional, physical, and spiritual rest and renewal for parents, caregivers, and siblings. Ensure that materials feature families from a variety of racial, ethnic, and cultural backgrounds to convey an atmosphere of acceptance and belonging for all families raising children with disabilities.

SHARE FAMILY SUCCESS STORIES TO ALLAY POTENTIAL HESITANCY PARENTS MAY FEEL ABOUT RESPITE.

Several parents acknowledged being initially fearful about their child's safety or comfort during a respite stay; others acknowledged feeling some guilt at first about using respite care. However, families were overwhelmingly positive when describing their actual experiences with Jill's House. Find ways to highlight and share these success stories with other families who may benefit from Jill's House. Examples include video testimonials featured on the website with families sharing theme-based stories (e.g., "First-Time Experiences," "Unexpected Joys of Respite"), weekly social media spotlights of families sharing short accounts of their experiences, family spotlights on printed materials given out during tours, and initial consultations may prove relatable and reassuring.

PROMOTE THE HEALTH BENEFITS OF RESPITE.

Overwhelmingly, parents connected respite through Jill's House with improvements in their own physical, emotional, and mental health. Several articulated how this positively affected their parenting and their family's overall well-being. Highlight the physical and mental health benefits by sharing information about how respite care can reduce stress and prevent burnout. Track and share health impact data to show families data-based positive changes they might experience such as improved sleep, reduced stress, and better coping. Incorporate regular segments in newsletters or website features that highlight the health benefits of respite, sharing tips, family stories, and expert advice.

PAIR PARENTS AS MENTORS WITH THOSE NEW TO JILL'S HOUSE TO HELP ALLAY FEARS AND PROVIDE OPPORTUNITIES FOR PARENTS TO SERVE.

Many parents highlighted the sense of community they found through Jill's House. Engaging current families in immediate efforts to connect new families with this community can benefit both. When families first seek information about Jill's House, ask parents with similar circumstances to connect with prospective families. Consider including current families in tours. Establish a parent mentor program, inviting established Jill's House families to participate as mentors to help guide new families in matters ranging from practical logistics to emotional reassurance.

EXPANDING PROGRAMMING

EXPLORE WAYS OF BROADENING THE AGE ELIGIBILITY FOR JILL'S HOUSE SERVICES.

Parents lamented the loss of respite when their child reached age 22. Continuing respite into adulthood is a matter of great urgency to many families who, as a result of their child's age, no longer have the availability of respite care. Explore ways to maximize and expand resources for adults with disabilities such as increasing the number of staff, evaluating current facility usage, and investigating funding possibilities (e.g. through grants or partnerships).

OPTIMIZE RESPITE SCHEDULING TO MAXIMIZE IMPACT AND THE NUMBER OF FAMILIES SERVED.

Families expressed varied needs regarding the frequency of respite care, with many desiring less wait time between visits. At the same time, some parents also wished that more families would have access to respite care. Evaluate factors such as staffing and facilities that might enable Jill's House to accommodate as many families as possible. Analyze usage patterns and seek feedback directly from families about how frequently they need respite. Consider piloting different scheduling models based on this feedback, monitoring and adjusting as needed based on the number of families served and their ongoing satisfaction feedback.

EXPLORING PARTNERSHIPS

RAISE AWARENESS THROUGHOUT NEARBY COMMUNITIES ABOUT THE URGENT NEED FOR RESPITE.

Most parents shared that their respite needs are still not fully met. The urgent need for respite care should be communicated throughout various communities in order to raise awareness across potential stakeholders who may have resources or knowledge that can help fill gaps in respite care services.

EXPLORE WAYS OF EQUIPPING CHURCHES TO OFFER RESPITE OPPORTUNITIES FOR FAMILIES.

Several parents shared that respite provided through church programs was also helpful in meeting their needs. There is a biblical imperative for churches to support the body of Christ in this way. However, most churches lack the resources or knowledge of how to provide these services. Explore ways of equipping churches to offer respite through training, guidance, mentorship programs, and other resources.

PARTNER WITH CHURCHES WHO HAVE A DIVERSE MEMBERSHIP TO EXPAND OUTREACH.

Parents may feel more comfortable using respite when they perceive that other people using it share similar backgrounds and demographic characteristics. Intentionally partnering with churches who have a diverse membership can provide opportunities to expand outreach. Consider designing advertising materials with diversity in mind, as well as intentionally partnering with diverse churches and directly communicating a message of acceptance and openness to families from all backgrounds.

PARTNER CREATIVELY WITH OTHER AREA RESPITE PROVIDERS TO IDENTIFY ALTERNATIVE OPTIONS FOR FAMILIES. Parents expressed a critical need for more and alternative respite options. Creating partnerships with other respite providers in the community is one way to identify alternative options for families. Through collaboration with other area respite providers, leverage shared expertise, resources, and facilities to create additional respite opportunities for families.

CAPTURING IMPACT

AFFIRM THE VITAL IMPACT OF STAFF AND VOLUNTEERS.

Participants were overwhelmingly positive about the impact of respite care, highlighting the dedication of the staff and volunteers and the crucial role Jill's House plays in strengthening family bonds and mirroring the love of Christ. Find ways of continuing to share how the Jill's House team's work is transforming lives. Hold celebratory gatherings to spotlight staff and volunteers and to share feedback from children and parents. Connect the feedback to the mission and core values.

STRENGTHEN THE ONGOING PROCESS OF CAPTURING THE IMPACT OF JILL'S HOUSE ON FAMILIES THROUGH STORIES, SURVEYS, AND MORE.

Parents were eager to share how their lives—and the lives of their children—were enriched by the support and ministry of Jill's House. As future families are served through Jill's House, it will be important to continue to capture their experiences using a combination of approaches. Survey all families at least annually, while also continuing to encourage them to share their stories and insights throughout the year. Consider how the questions addressed in this study might be incorporated into the ongoing evaluation work of Jill's House.

EXPLORE THE IMPACT OF THIS MINISTRY ON THE JILL'S HOUSE TEAM AND HOW THEIR TRANSFORMATIVE EXPERIENCES AFFECT THEIR CARE.

Many parents shared how the care and character of Jill's House staff, volunteers, interns, and fellows impacted them deeply. But the reciprocity of this ongoing relationship should also be captured. Staff and volunteers also benefit immensely from serving and coming to know children with disabilities and their families. Identify ways of soliciting their stories and insights to understand how their perspectives, faith, care, and lives are shaped by their experiences.

EXAMINE THE IMPACT OF JILL'S HOUSE ON CHILDREN AND YOUNG ADULTS WITH DISABILITIES.

Parents described the myriad ways their daughters and sons benefitted from their time at Jill's House. However, children and youth would also have much to share about why Jill's House matters so much to them. Explore ways of inviting their perspectives through supported interviews, art, PhotoVoice, observations, and other creative avenues. A follow-up study focused specifically on the experiences and recommendations of children and youth would provide a strong supplement to the current evaluation.

CAPTURE THE IMPACT OF JILL'S HOUSE ON THE BROADER COMMUNITY.

As families, staff, and volunteers bring their experiences at Jill's House into their churches and communities, there may be a ripple effect of impact. This impact may also be recognized by, or have an effect on, donors and policymakers, further amplifying the reach of Jill's House within the community. The witness and work of Jill's House may spur others to think about and support people with disabilities in new ways. Consider how this broader reach and impact might be captured.

STRENGTHENING QUALITY

INCLUDE BOTH POSITIVES AND CHALLENGES ON “MY STAY” FORM.

Most parents conveyed how much they appreciate and look forward to reading their child’s “My Stay” form. Some, however, expressed an interest in receiving feedback that captures the positive experiences their child had in addition to any challenging aspects that were observed. Such feedback would provide a more balanced view, highlighting areas of success as well as ways parents can reinforce positive practices. To address this concern, consider incorporating into the “My Stay” form sections for both successes and challenges. This will provide a comprehensive view of the child’s stay, thereby contributing to enhanced care and service quality.

INCREASE ENGAGEMENT WITH FATHERS AND CONSIDER THEIR UNIQUE NEEDS.

Feedback indicated a need to increase engagement with fathers and address their unique needs. Recognizing the distinct experiences and challenges of fathers is crucial for providing equitable support and fostering an inclusive environment. Consider developing targeted outreach efforts designed to engage fathers through personalized communication, dedicated events, and resources designed for fathers, emphasizing the value and importance of their role and to enhance their sense of community and belonging. This may also include highlighting that caregiving can be shared among various family members to ensure all caregivers feel recognized and supported.

CREATE A WORKING GROUP WITH PARENTS TO EXPLORE HOW JILL’S HOUSE CAN STRENGTHEN AND EXPAND ITS SERVICES.

Many parents expressed a desire to support the mission of Jill’s House and help expand their services throughout the community to reach additional families in need of respite. Consider establishing a working group with parents who represent a range of community and professional roles and disciplines such as healthcare, education, social work, advocacy groups, and churches. By bringing together this varied expertise, the group could aim to explore community partnerships, ways to broaden services at Jill’s House, and requirements and potential funding sources.

REFLECT ON HOW THE AREAS OF IMPACT IDENTIFIED IN THIS STUDY ALIGN WITH THE STATED GOALS OF JILL’S HOUSE.

This study identified several key ways that Jill’s House has had a profound impact, including strengthening the family, allowing for spouses to spend quality time with each other and all their children, and enabling much-needed self-care. Additionally, Jill’s House provided a nurturing environment, which fostered social connections and a sense of belonging among parents and children. Consider revisiting the stated goals and the strategic plan based on the findings to ensure the objectives are directly linked to the impact. Other steps might include ongoing parent satisfaction surveys and feedback sessions to ensure alignment and identify possible enhancements to services. Make a strong connection to this alignment in various internal and external communications and team meetings.



*“The staff and volunteers at Jill’s House are the absolute loveliest people. They surround my child with love and caring. **He leaves Jill’s House feeling amazing.**”*





For more information about Jill's House, visit jillshouse.org.
To access digital files of the full report or the report's Executive
Summary, please visit jillshouse.org/baylor.



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