

FINDING REST AT JILL'S HOUSE

THE IMPACT OF RESPITE ON FAMILIES
WHO EXPERIENCE DISABILITY



Baylor University®

BAYLOR CENTER FOR DEVELOPMENTAL DISABILITIES

*"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.**"*

*Rebecca, mom of a
15-year-old son
with disabilities*



Overview

When asked about her experience of receiving respite care through Jill's House, Tammy, the mother of a son with 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."



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. We surveyed more than 200 parents and conducted in-depth interviews with 26 families. Our guiding questions 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 ARE THE IMPLICATIONS FOR JILL'S HOUSE AND COMMUNITIES?

Our findings offer powerful insights into the far-reaching and multifaceted benefits of respite care. Likewise, they highlight the numerous barriers families can experience when trying to access this much-needed form of support and care. 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 communities—and to churches in particular—to prioritize respite care for families who experience disability.

A full report can be found at <http://bcdd.soe.baylor.edu>

Our Approach

We distributed an extensive online survey to all parents whose children were served through Jill's House between November 2023 and May 2024. 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. More than 200 parents completed the survey. We then interviewed 31 parents (representing 26 families) about their experiences pursuing and receiving respite. Our mixed-method evaluation combined both qualitative and quantitative analyses using a rigorous, team-based approach.



208 PARENT SURVEYS

MIXED-METHOD EVALUATION



26 FAMILY INTERVIEWS



Jill's House is a Christian nonprofit organization that provides families raising children, youth, and young adults with intellectual disability (ages 6 through 22) with short-term overnight respite care in the DC metro area and, through their Weekend Adventures program, around the country. Families enjoy rest, renewal, and relationships, while their child with disabilities enjoys a time of adventure.

Why Do Parents Seek Respite?

Parents shared a range of reasons for seeking respite care.

THEIR TOP REASONS WERE:

- ✓ TO ATTEND TO PERSONAL NEEDS (E.G., SOCIAL, RECREATIONAL, MEDICAL)
- ✓ TO TAKE CARE OF OTHER FAMILY MEMBERS
- ✓ TO HELP MANAGE THEIR STRESS
- ✓ TO FINISH PROJECTS OR TASKS AROUND THEIR HOUSE
- ✓ TO WORK
- ✓ TO PROVIDE THEIR CHILD A NEW EXPERIENCE

“

“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.**”

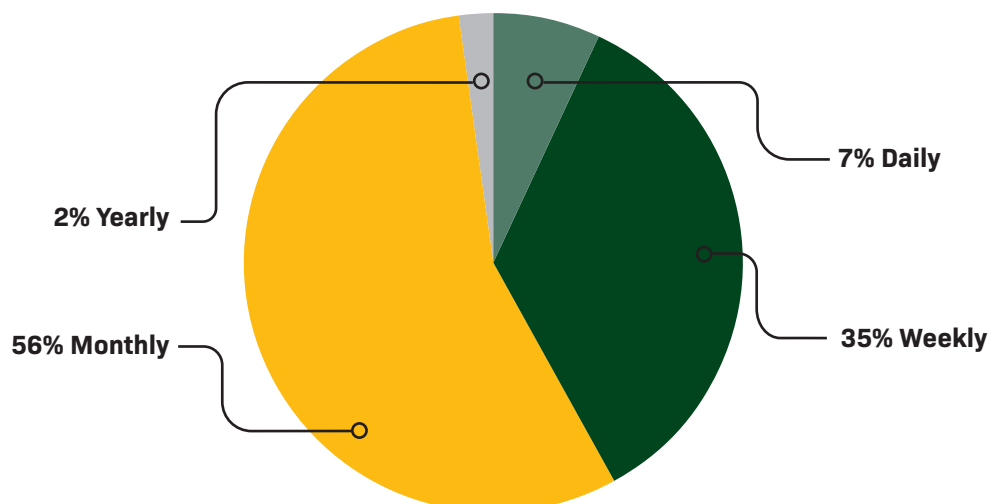
Michael, father of a 15-year-old son with disabilities

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More than half (59%) of families said they had no other respite options outside of Jill’s House. Yet, their need for respite was clear and pressing:

HOW OFTEN DO YOU NEED RESPITE CARE?



What Makes Finding Respite Hard for Families?

Although respite matters immensely in the lives of families, it can be hard to find and access. As parents reflected back on their pursuit of respite *prior* to finding Jill's House, their stories were often marked by frustration and exhaustion.

Our interviews highlighted 15 barriers that can keep families from accessing the respite care they need:

15 BARRIERS TO ACCESSING RESPITE CARE

1

PARENT
LACKS TRUST
IN RESPITE
PROVIDERS

2

PARENT
HESITATES
TO LEAVE
THEIR CHILD

3

CHILD'S
NEEDS EXCEED
PROGRAM
CAPABILITIES

4

EXTENDED
FAMILY
SUPPORT NOT
AVAILABLE

5

PARENT IS
RELUCTANT
TO SEEK
HELP

6

LIMITED
AVAILABILITY
OF PROGRAMS

7

CHILD DOES
NOT MEET
ELIGIBILITY
CRITERIA

8

LACKS
AWARENESS
OF RESPITE
OPTIONS

9

LONG
WAITLISTS

10

APPLICATION
PROCESSES
ARE
COMPLEX

11

PROGRAM
CONFIGURATIONS
MAY NOT ALIGN
WITH FAMILIES'
NEEDS

12

HIGH
COSTS
LIMIT
PARTICIPATION

13

UNEVEN
PROGRAM
QUALITY
LEADS TO
INCONSISTENT
EXPERIENCES

14

TRANSPORTATION
DIFFICULTIES

15

DIVERSE
FAMILIES
ARE NOT
REPRESENTED

How Does Respite Impact Parents?

Respite care meant much more than a mere break – it was a lifeline that brought hope and restoration to the lives of parents. Amidst constant caregiving, respite provided parents with cherished time to reconnect with themselves, their families, their friends, and others in their community.

OUR INTERVIEWS HIGHLIGHTED FIVE AREAS IN WHICH RESPITE HAD A POSITIVE IMPACT ON PARENTS:



STRENGTHENS FAMILY RELATIONSHIPS | Strengthens connections among couples | Strengthens connections with their other children



TRANSFORMS PERSPECTIVES | Gives confidence | Helps parents feel known | Activates hope | Provides peace



DEEPENS SOCIAL CONNECTIONS | Supports friendships | Creates connections with fellow parents



IMPROVES OVERALL HEALTH | Improves mental health | Reduces stress | Provides rest | Improves physical well-being | Addresses spiritual needs | Is a lifesaver



ENABLES ACTIVITIES | Provides a break | Addresses practical needs | Reintroduces choices | Enables community involvement

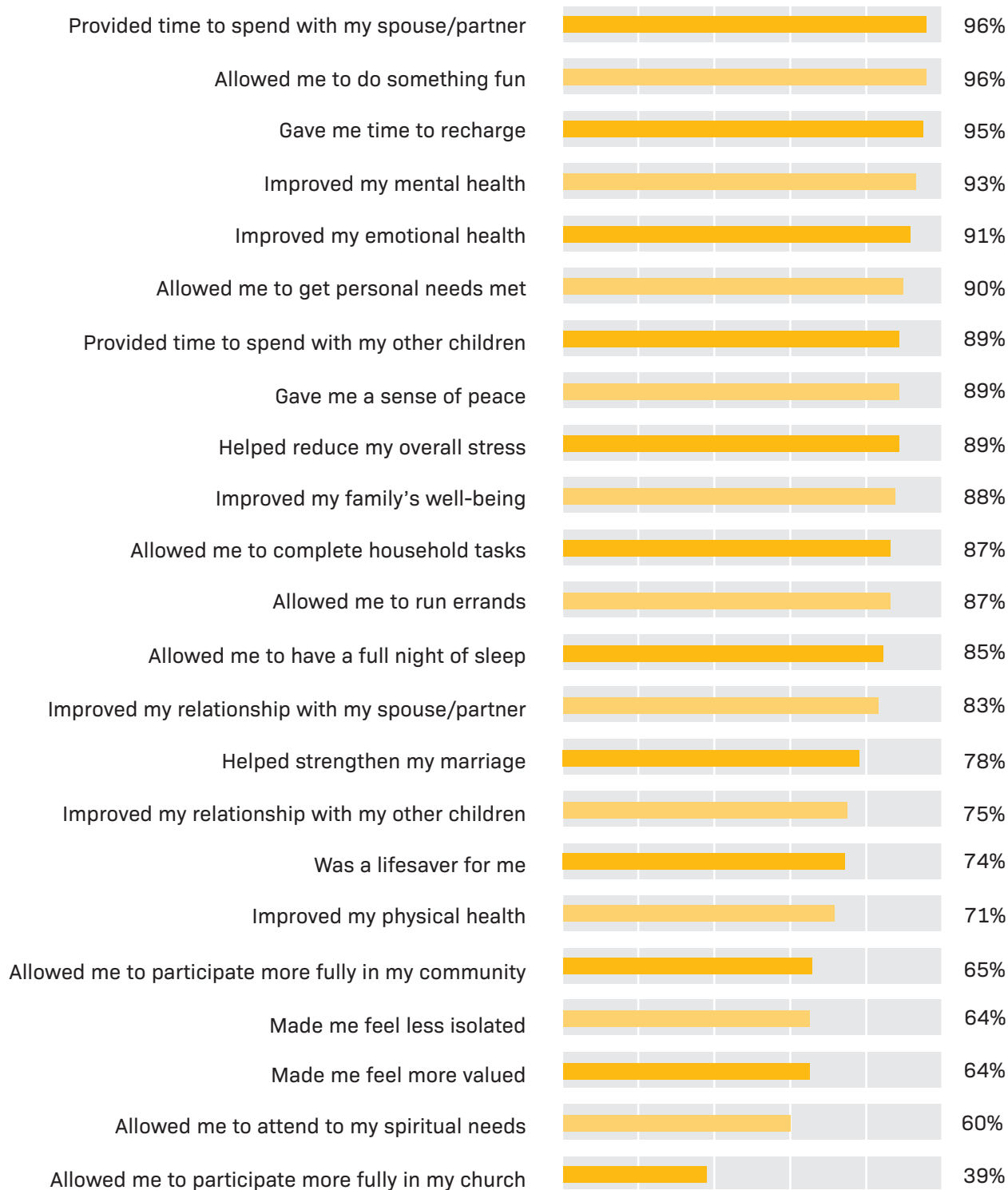


“This was the first weekend my husband and I got to spend together in 11 years.”
Jana, mother of a 11-year-old daughter with disabilities

“Being more rested helps me feel more spiritual.”
Leslie, mother of a 17-year-old daughter with disabilities

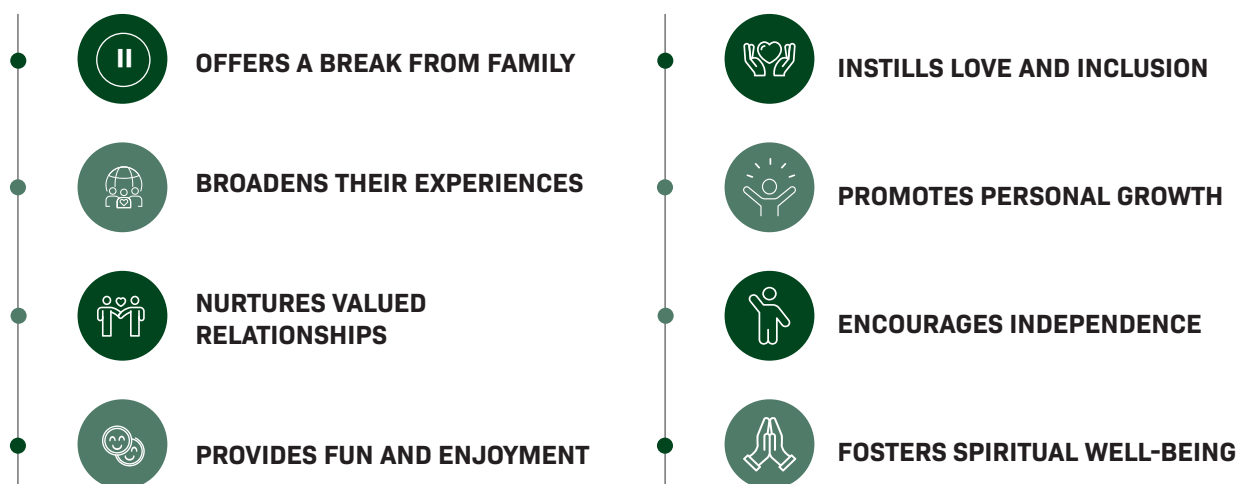
Our surveys addressed many areas in which respite from Jill’s House may have impacted parents. The percentage of parents who agreed or strongly agreed with each area is shown below:

RESPITE CARE IMPACT ON PARENTS



How Does Respite Impact Children, Youth, and Young Adults with Disabilities?

Respite doesn't just benefit parents; it also offers an enriching and much-needed 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.



Our surveys addressed 9 areas in which respite care was said to impact children, youth, and young adults with disabilities. The percentage of parents who agreed or strongly agreed with each area is shown below:

IMPACT OF RESPITE CARE ON CHILDREN WITH DISABILITIES



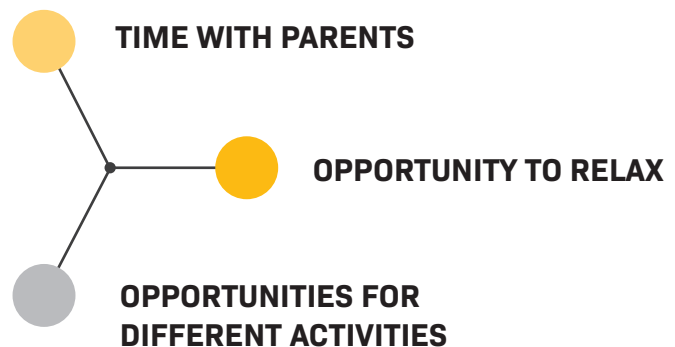
How Does Respite Impact Siblings?

The experiences of siblings can be both wonderful and challenging. Having a brother or sister with intellectual and developmental disabilities can sometimes leave siblings feeling overlooked or disconnected. Respite also offers significant benefits to these young people and merits further exploration.

Our interviews highlighted three areas in which respite had a positive impact on siblings:



Sibling Impact



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

*Verónica,
mother of an
11-year-old
daughter with
disabilities*



“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.”

*Emily,
mother of an
11-year-old son
with disabilities*



“The house is just quieter, so I just think it gives everybody in the household a little bit of a chance to relax.”

*Felicia,
mother of a
15-year-old son
with disabilities*

What is the Impact of Other Family Support from Jill's House?

The work of Jill's House extends beyond respite care, as does its impact. Families who participated in other program offerings shared about the many ways their lives were enriched by accessing these supports. Below are examples of the ways parents benefitted from other family support programming:

- 1 IT GAVE THEM A CHANCE TO RELAX.
- 2 THEY FELT LESS ALONE.
- 3 THEY BUILT COMMUNITY TOGETHER.
- 4 THEY RECEIVED VALUABLE RESOURCES AND KNOWLEDGE.
- 5 THEY EXPERIENCED LOVE.
- 6 THEIR SPIRITUAL NEEDS WERE MET.
- 7 THEY FELT LIKE THEY FIT IN.
- 8 THEY GAINED CONFIDENCE IN THEIR PARENTING SKILLS.
- 9 THEY EXPERIENCED PEACE OF MIND.
- 10 THEIR EMOTIONAL NEEDS WERE MET.
- 11 THEIR FAMILY LIFE WAS ENRICHED.

*"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.**"*

Erika, mother of a 16-year-old daughter with disabilities



"We've made connections with families like ours."

Mary, mother of two children with disabilities

Our Recommendations

Drawing upon our findings, we highlight a number of recommendations to further strengthen the impact and reach of respite and family support at Jill's House and beyond.

OVERCOMING BARRIERS

1. Determine why families who are not connecting to Jill's House may struggle to do so.
2. Streamline the application process and offer hands-on help to alleviate stress.
3. Provide scholarships or other financial resources to minimize costs.
4. Explore transportation options for families to help reduce travel-related barriers.

CONNECTING WITH FAMILIES

5. Promote Jill's House as a ministry for the whole family and for all families.
6. Share family success stories to allay any hesitancy parents may feel about respite.
7. Promote the health benefits of respite.
8. Pair parents as mentors with those new to Jill's House.

EXPANDING PROGRAMING

9. Explore ways of broadening the age eligibility for services.
10. Optimize respite scheduling to maximize impact and the number of families served.

EXPLORING PARTNERSHIPS

11. Raise awareness throughout nearby communities about the urgent need for respite.
12. Explore ways of equipping churches to offer respite opportunities for families.
13. Partner with churches who have a diverse membership to expand outreach.
14. Partner creatively with other area respite providers to identify alternative options for families.



Our Recommendations

CAPTURING IMPACT

15. Affirm the vital impact of staff and volunteers.
16. Strengthen the ongoing process of capturing the impact on families through stories, surveys, and more.
17. Examine the impact of Jill's House on children and young adults with disabilities.
18. Capture the impact of Jill's House on the broader community.

STRENGTHENING QUALITY

19. Create a working group with parents to explore how Jill's House can strengthen and expand its services.
20. Reflect on how the areas of impact identified in this study align with the stated goals of Jill's House.



"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."

Aretha, mother of a 21-year-old son with disabilities



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This evaluation was conducted by Erik W. Carter, Melody V. Escobar, Sarah S. Mire, Carlee Hollinger, and Shannon R. Eshman through the Baylor Center for Developmental Disabilities at Baylor University. To learn more about this evaluation and our findings, visit <http://bcdd.soe.baylor.edu>.