JUSTin Hope Foundation Respite Care

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The JUSTin Hope Foundation is a local 501(c)3 nonprofit that provides families who have a child/children with a neurodevelopmental disorder with:

**Resources**
- First Responder Training
- Monthly Family Support Groups / Workshops
- Sib-shops
- Respite
- Giving Awards Program

**THE PURPOSE OF THIS STUDY IS TO..**

*Look into the factors that inhibit families from receiving respite care from the JUSTin Hope Foundation.
*Gain a deeper understanding as to why participants were not applying for the Respite Scholarship offered by the foundation

**WHAT IS RESPITE CARE?**
Respite is temporary care for a person who may be elderly, ill, or a person with a disability, providing relief for the usual caregiver (10).

Due to the severity of the child’s condition, a parent who becomes a caregiver for a disabled child may often have to quit their job, social life, and normal daily routines in order to take on their new role as caregiver.

**WHAT ARE PREVIOUSLY STUDIED FACTORS THAT INHIBIT RESPITE?**
- Families’ belief system
- Parental guilt
- Leaving child with strangers
- Fear of judgment from family / friends
- Arranging transportation to and from respite services
- Consideration that respite care is a stepping stone to life-long institutionalization for the child

**OUR METHOD**
A voluntary survey was sent out to people who have either used JUSTin Hope’s respite care or who have shown interest in the service.

**WHAT IS HINDERING FAMILIES IN NEED FROM USING RESPITE CARE?**

* Those with children with more severe conditions were rated at a lower stress level, overall.
* Most said that their child’s condition was rated around moderate with high stress levels

**Social support group**

<table>
<thead>
<tr>
<th>Do you have astrong social support group?</th>
<th>Count</th>
<th>Percent</th>
<th>Cumulative</th>
</tr>
</thead>
<tbody>
<tr>
<td>10</td>
<td>6</td>
<td>71.14%</td>
<td>100%</td>
</tr>
<tr>
<td>0</td>
<td>4</td>
<td>42.11%</td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>10</td>
<td>100%</td>
<td></td>
</tr>
</tbody>
</table>

* The majority of participants in our study did not consider themselves to have a strong support group.

**Factors that inhibit families from using respite services**

For most families, the fear of inadequate care was the biggest factor preventing families from seeking respite care.

One participant stated in a follow up email that cost was the number one reason for not using respite services, but also stated that

**RECOMMENDATIONS**

*Adjust HUD income requirements online regularly for Respite Scholarship
*Create a larger awareness about the Respite Scholarship
*Focus on highly trained respite caregivers
*Offer two days of regular respite, with adequate provider to child ratio
*Hire more providers so that in-home respite is available more often

** WHY AREN’T FAMILIES APPLYING FOR RESPITE SCHOLARSHIP ?**

Two of the seven participants knew about the scholarship, but didn’t meet the financial guidelines.
Three of the seven participants stated they did not know that the respite scholarship was an available

**ACKNOWLEDGEMENTS**

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