

March 8, 2015

Care of Caregivers Survey

Colorado Senator Irene Aguilar and Representative Lois Landgraf requested that PAD-CO (Parents of Adults with Disabilities in Colorado) complete a state-wide survey to which they provided the questions. The survey was advertised to a number of listservs and other lists and families, and 317 responses were received between January 8, 2015 and January 15, 2015. Multiple responses to each question were allowed.

Several PAD-CO participants volunteered to categorize and classify the responses into broad categories, and choose representative quotes from parents.

The questions asked were:

What are the barriers to respite care. I.e. no providers? no money? both?

What types of respite care are needed? Overnight? Several Hours?

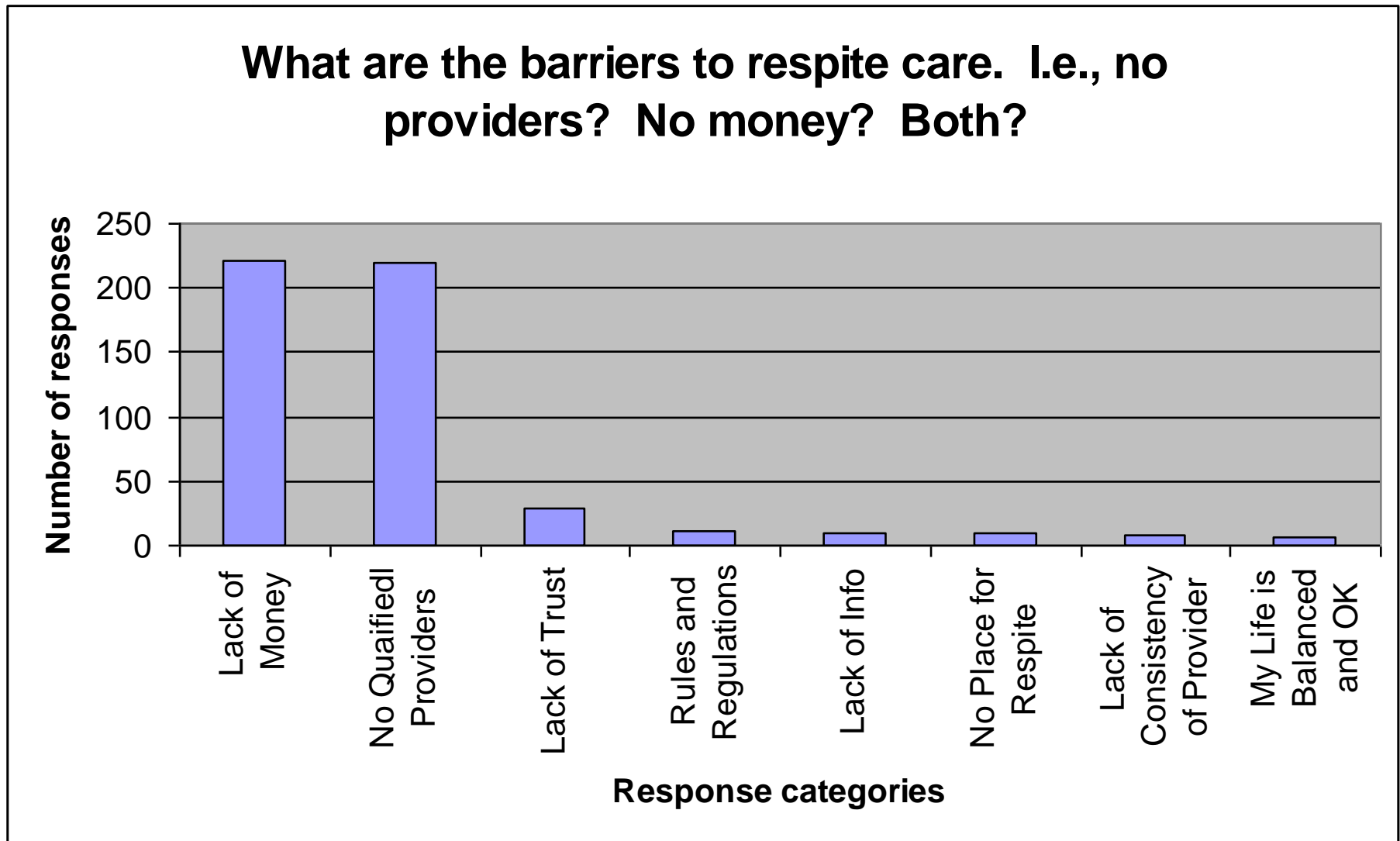
What resources currently exist that you use?

Any other comments regarding support of caregivers?

Please describe your caregiving situation.

The results are presented herein, along with some significant and representative quotes.

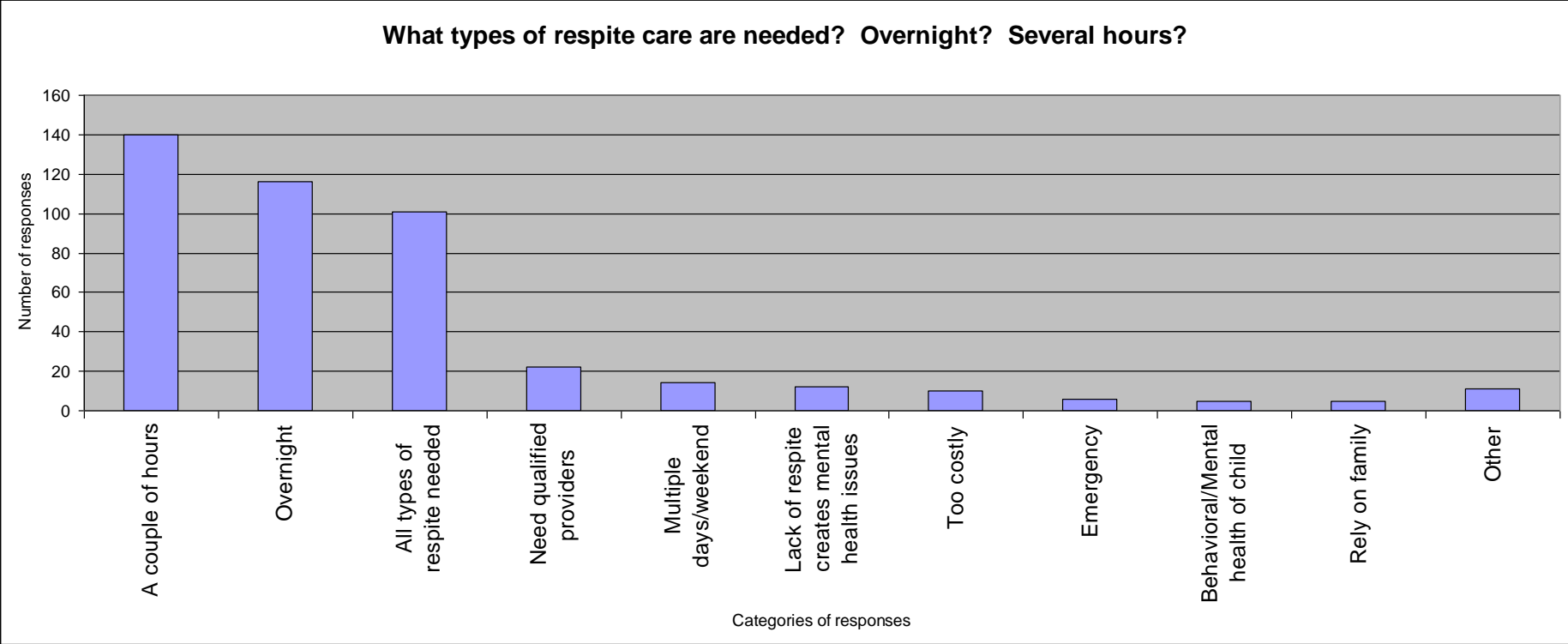
Question 1 - What are the barriers to respite care. I.e. no providers? no money? both?



Significant quotes

<p>Biggest barrier is that I have no information and don't know where to look for respite care. When my child with disabilities was a baby, I checked with our CCB because that was my contact to services. I got a list with some providers, none close to me, and all were extremely expensive or didn't offer services in my area. I've heard the ARC has respite services referral for other counties than mine. I haven't had time to ask someone there. When I call looking for help, there is a lot of run around from agency to agency and person to person. "Oh, you need to speak to so and so." So I call that person. "Oh you need to go to this organization." And so on.</p>	<p><i>finding quality providers is very difficult and took our family years. People who will do a decent job do not apply for respite care agencies because the pay rate is too low. Money is also an issue for most families, but for mine, the state of Colorado has done an amazing job of supporting us. My son is on the CES waiver because of his significant disability, and we feel well supported. Finding a respite provider we trusted was the hard part.</i></p>	<p>Lack of respite care for our family is part of a bigger issue that happens to all the services my son receives. That issue is by the time the agency skims off about half of the funding, the rate that actual respite care providers are paid is not high enough to (1) hire qualified respite care workers, (2) retain qualified respite care workers. Most respite care workers hired by agencies are college students who are willing to work for \$10 an hour or so. The problem is that they have very little experience with people with special needs,</p>
<p>Nurse Practices Act causing the hiring of only RN for a wide range of tasks that families are already doing, but cannot delegate themselves</p>	<p><i>My adult son is trached and on a ventilator, so he would require an LPN or RN for respite. Private duty nursing is too expensive for us to afford.</i></p>	<p>My son has very complex medical and behavioral needs. Providers have to work with him for a long time for me to feel safe leaving him with them for very long. Using waiver-funded respite, the pay isn't high enough to keep clever and motivated people long-term.</p>

Question 2 - What types of respite care are needed? Overnight? Several Hours?



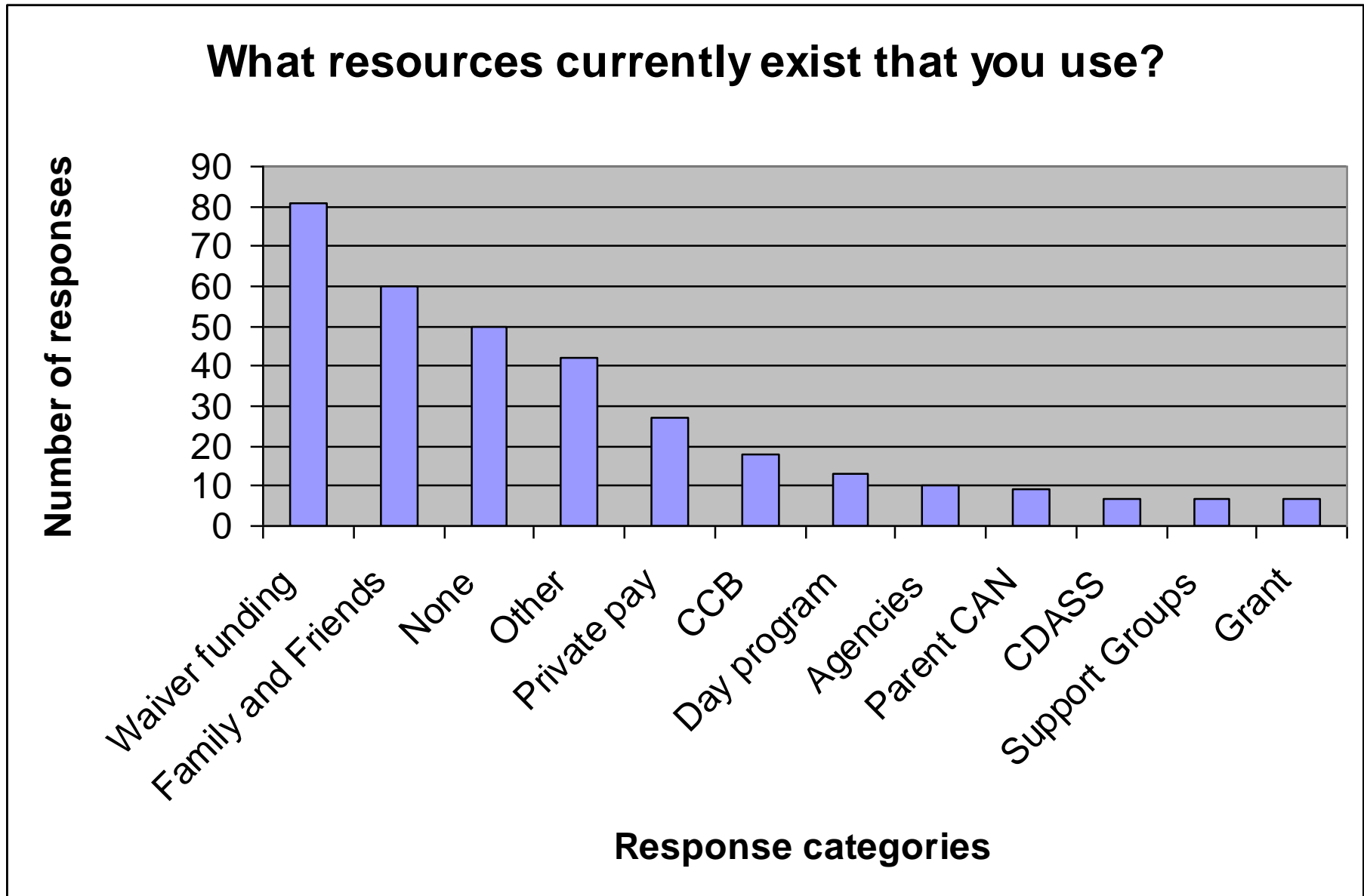
Significant quotes:

<p>you cant even be sick</p>	<p><i>Even an hour can help a parent get back their sanity.</i></p>	<p>All forms of respite are needed, ranging anywhere from a few hours daily to an extended period of time e.g. 2-3 days. Respite provisions should not be considered accomplished by a PASA when they provide only a single or short term option. All providers need support ongoing and at various times, not simply for a single night a month and constructed under the conveniences of staff, that is not supportive of clients' needs.</p>
<p>My husband and I have not left our daughter alone for more than 3 hours in 4 and a half years. We have zero time alone together and we do everything together. Which is fine but it would be nice to go to a movie every now and then. So I would say all of the above. Our daughter Is fragile and even going to the DMV is tough. I struggle daily with taking her out in public. Especially during flu season. He works and I could use help at least twice a week for at least a few hours. And that is to just get household errands done.</p>	<p><i>Any kind of respite care is needed, but especially overnight. In most cases caregivers with adult children have never had a family member even offer to provide respite for a weekend. Transportation is a place where I really struggle. Access A Ride isn't always available or appropriate. Often times I need to choose between transporting my special needs young adult to participate in an activity, or sacrificing for another family member. It's also very healthy for my son to have independence from me.</i></p>	<p>Anything would be appreciated. I am often told I should be seeing a therapist to help me cope with the stress I'm under 24/7 but I have no one to step in so I'm kinda stuck No therapists do house calls</p>

Several folks answered as to "why" respite is needed, and a summary of those responses is:

WHY – ability to recharge, no alone time, need to run errands or do chores, spend time with spouse or other children, caregiver sick days or for surgery, caregiver needs to work outside the home, to attend State or CCB sponsored meetings/trainings, caregiver medical appointments, pay bills, to get into Metro Denver for things and get back to the rural area

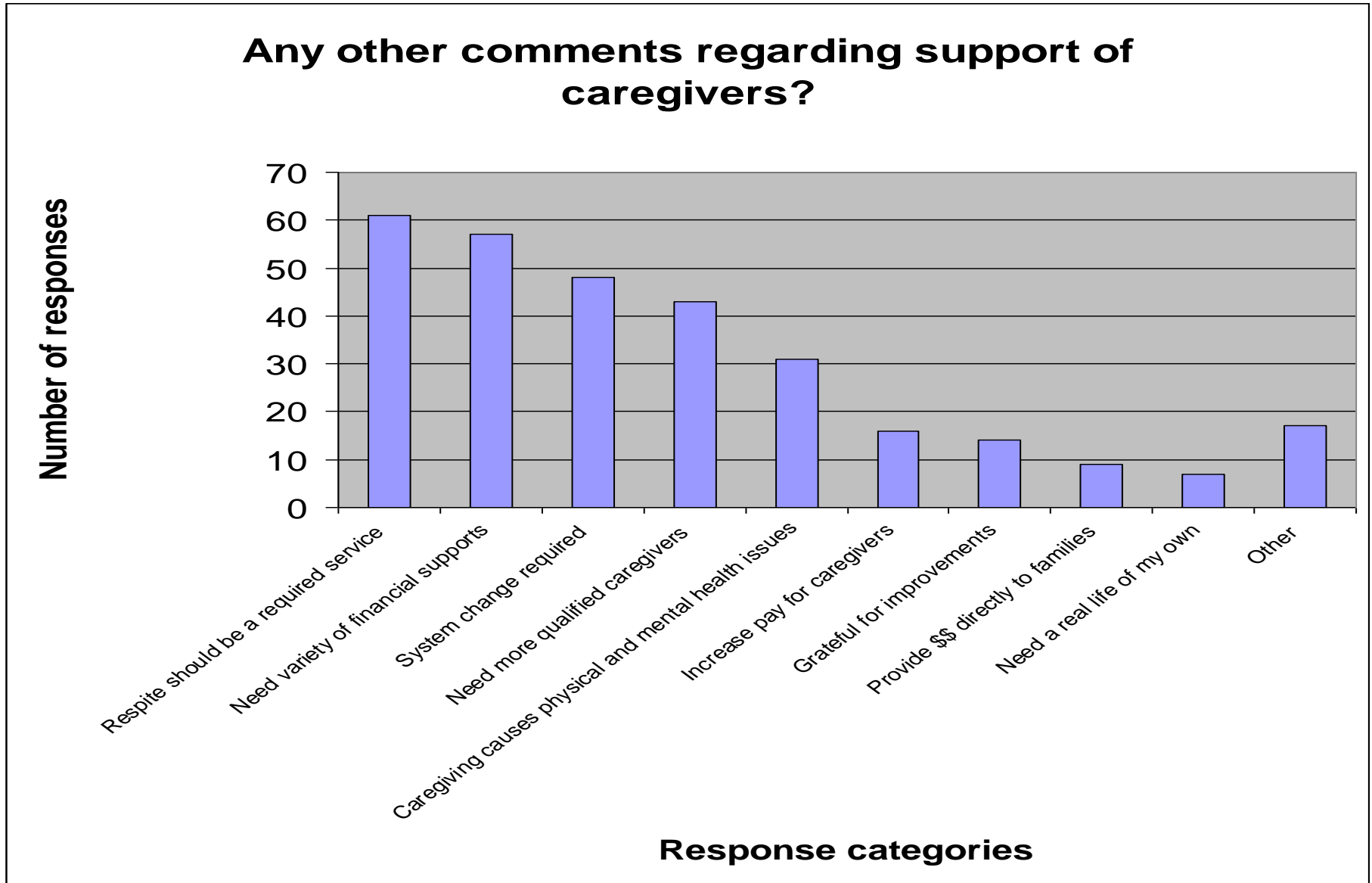
Question 3 - What resources currently exist that you use?



Some typical responses:

<p>CES waiver offers respite, but it does not pay enough for nursing level of care. The only way we can get out for a few hours now is to use our private duty nurses once our child has gone to bed</p>	<p><i>Current Resources: Family Support, CWA, CES and SLS waiver funded respite providers. Minimal and irregular "most in need" or "grant/scholarship" funding programs for wait-listed children/families from CCBs, Drop off weekend activities, Out of pocket caregivers and Specialized Sitters. Service needs mentioned above. Funding needs: no cap on respite, personal care, or behavioral services for all waivers. Access to appropriate waiver and resulting funding</i></p>	<p>Currently use respite care provided by the SLS waiver. However, good respite care is expensive and the waiver doesn't pay caregivers enough for them to continue long term as caregivers. We need experienced, committed caregivers so that we don't spend all of our time training new people.</p>
<p>Family recruited paid for by SLS medicaid waiver. More respite providers and of better quality. There's a reason respite is needed, we have a challenging person, we need providers that are committed to doing a good job.</p>	<p><i>I am on the Consumer Directed Attendant Support Services program (CDASS). This is overall cheaper in expenditures monthly compared to home care agencies or nursing homes. It increases consumer satisfaction and overall attendants providing care are happier than working through home care agencies or nursing homes.</i></p>	<p>I currently self pay for all respite care as there is not enough funding to cover any respite and mostly use family members for care. Resource coordinators have not been helpful.</p>

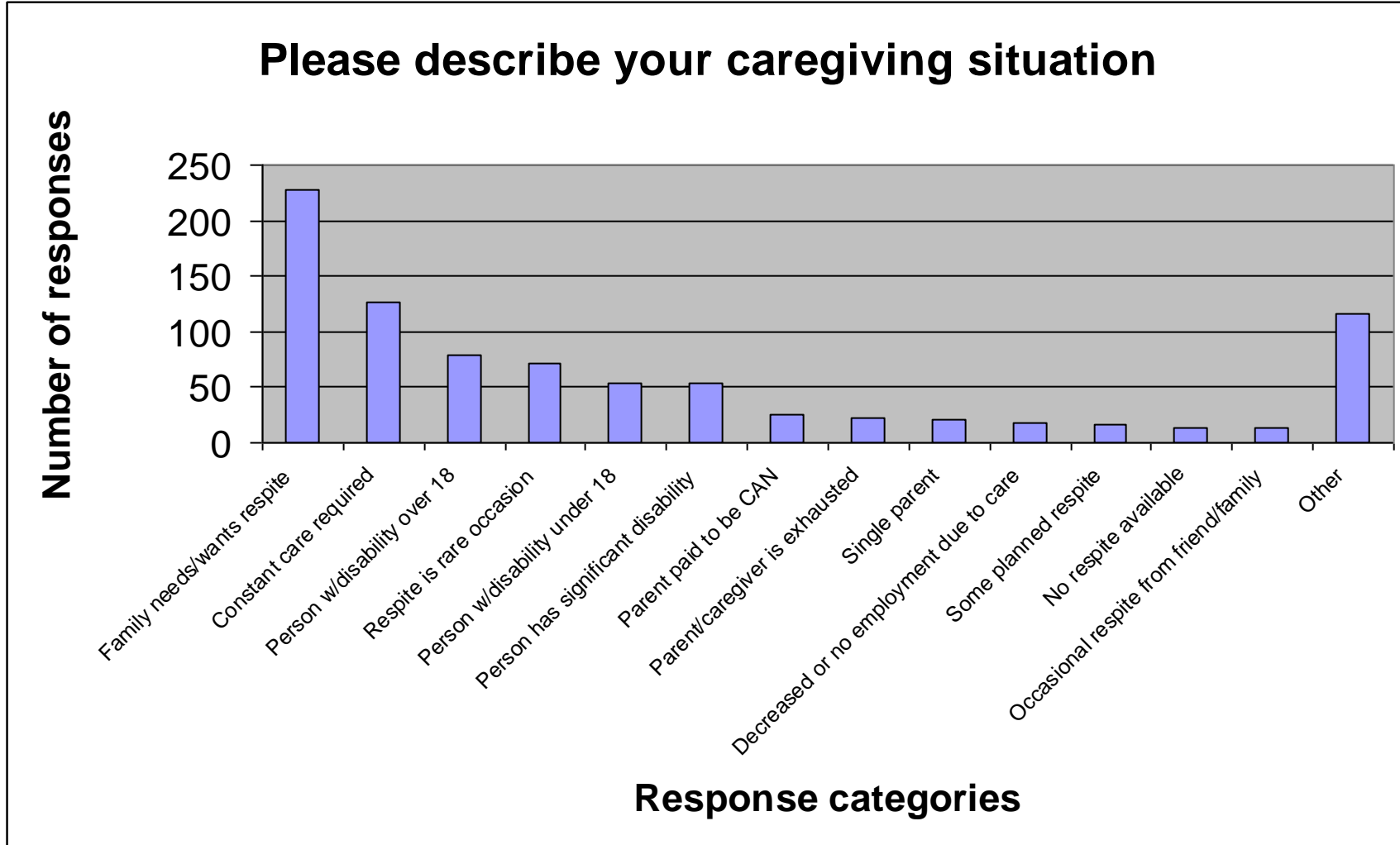
Question 4 - Any other comments regarding support of caregivers?



Some typical comments:

<p>A problem that will never be solved. Not enough qualified caregivers. Low pay. High turnover</p>	<p><i>Respite is a required service for all families so they can recharge themselves and carry on with all the extra duties required to support a loved one with disabilities</i></p>	<p>When there's no light at the end of the tunnel, when you have to take care of someone else even when you are sick and personally debilitated, this situation has a negative effect on mental health and health outcomes in general.</p> <p>When people are properly supported to have productive lives, both parents and children, health outcomes are better for everyone, and thus, a therapeutic level of respite saves lives and money for our nation.</p>
<p>As a caregiver of a person who has severe behavioral issues... after you live for so long under such high levels of stress that do not relent, you begin to question your own mental health. I'm certain it is reducing my life span</p>	<p><i>A caregiver job is one where you are on-call 24/7/365. Working 7 days a week quickly drains your physical energy (multiple transfers, etc.) and is emotionally exhausting. Unless you are doing the work, no one really understands all that goes into caring for a disabled person</i></p>	<p>Caregiving really gets in the way of making a living and being able to save for my child's future, as well as my own retirement. Our income isn't low enough to qualify for SSI, but isn't high enough to adequately prepare for the future. Thank you for doing this</p>

Question 5 - Please describe your caregiving situation



Selected quotes

<p>"We've lived in 4 other states that have less state funding than CO and somehow they don't have a problem with supporting families with persons with disabilities. I'm not sure why CO has the redundancy of their programs and lack of efficiency or organization in getting help to families with persons with disabilities."</p>	<p><i>" the rate is high to care for someone with physical needs and we can't justify spending so much on ourselves</i></p>	<p>"No one is willing to step in for respite for a person who requires full care and is medically fragile, such as my son, especially not for \$10 / hour!"</p>
<p>"we check on him throughout the night. Of course we're tired but he's our little angel so on we go. We both (his daddy and I) have sustained caregiver injuries and see no end in sight."</p>	<p><i>"My husband and I cannot even sleep in the same room because of overnight medical needs and seizures interrupting sleep, yet there is no funding for help caring for our son"</i></p> <p><i>"We are exhausted but can't leave him with anyone but an RN legally, unless it's a family member, and we have no family here, and no respite funds pay for an RN :(</i></p>	<p>" I (the father) am 72 years old and my wife is 69. We don't know how much longer we can manage 24 hour care"</p>

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