

Respite Needs Among Developmental Disabilities Administration No-Paid Caseload

Past Experiences, Barriers to Current Use, and Feasibility of Assistive Technology

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Report to the DSHS Aging and Long-Term Support Administration

THE COMPLEXITY AND TASK DEMANDS of caring for individuals with developmental disabilities are substantial and consistently associated with increased caregiver stress on all aspects of life, including health, relationships, family functioning, and financial stability¹. Thus, respite care, a break to provide brief, personal time away from daily caregiving, is a recommended intervention to support caregivers. Given some of the potential benefits of respite care (e.g., decreased caregiver burden, increased family cohesion, and care recipient social and behavioral adaptation), the Department of Social and Health Services (DSHS) Developmental Disabilities Administration (DDA) offers respite as part of their service array. However, in 2018, 30 percent (or 14,448 individuals) of DDA clients were categorized as 'no-paid' clients, or persons who have been determined eligible to be a DDA client, but are not receiving services through DDA.²

In order to better understand the needs among the no-paid client population and use of non-DDA sources of respite, the DSHS Aging and Long Term Services Administration (AL TSA) administered a short survey. The goal was to find out more about no-paid clients and their caregivers, their experiences with respite services, potential barriers to respite care, and interest in assistive technology.

Survey Background and Methods

AL TSA Lifespan Respite grant staff collaborated with the Developmental Disabilities Council to explore respite needs of specialized populations of caregivers in Washington State (e.g., caregivers who care for people with traumatic brain injuries, people with developmental disabilities, and American-Indians/Alaskan Natives) across the lifespan.

AL TSA administered the survey by providing a survey web link through the Informing Families No-Paid Services newsletter, enabling no-paid caregivers and clients to self-identify and complete the survey. Research and Data Analysis (RDA) collected survey responses via Survey Monkey from April 22 to May 28, 2019 allowing only one response per device. In total, 164 caregivers and clients responded and over one-third answered an open-ended question. Because survey respondents were a self-selected sample, they may not represent all no-paid DDA clients. Thus, readers should use caution when trying to generalize results to the larger no-paid DDA population.

1 Neece, C. & Chan, N. (2017). The stress of parenting children with developmental disabilities. In Deater-Deckard, K. & Panneton, R. (Ed.). *Parental Stress and Early Child Development* (107-124). New York, NY: Springer, Cham

2 DSHS Developmental Disabilities Administration. 2018 Caseload and Cost Report. Retrieved August 1, 2019 from <https://www.dshs.wa.gov/sites/default/files/DDA/dda/documents/2018%20DDA%20Caseload%20and%20Cost%20Report.pdf>.

No-Paid Clients and Their Caregivers

70% of no-paid DDA client caregivers surveyed were parents or guardians.

- Nineteen percent reported they were primary caregivers other than a parent or guardian, while the remaining 11 percent reported they were neither parents, nor guardians, nor primary caregivers.
- Most respondents (78 percent) were from high-density urban counties, while 22 percent were from urban/medium and low density, large towns, or rural counties.



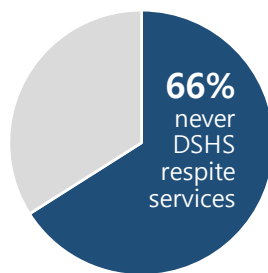
76% of clients were 18 years and younger.

- Sixty-one percent were children 0-12 years. Of these clients, almost half (46 percent) were on the no-paid caseload for 2 to 10 years.
- Fifteen percent were teens age 13 to 18 years. The majority of these clients (35 percent) were on the no-paid caseload for 6 months to 2 years.
- No-paid clients 19 years and older contributed twenty-four percent of responses. Most of these clients (56 percent) were on the no-paid caseload for more than 10 years.

Children and Youth **76%**

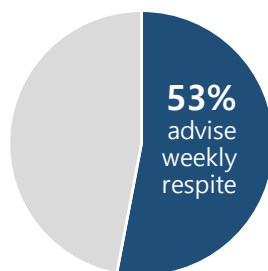


Past Experiences and Current Barriers to Respite Use



66% of caregivers reported never receiving respite from DSHS DDA, despite rating respite care as very important.

- Instead, most caregivers relied on informal support networks such as family members or friends for assistance (77 percent), or local/area program activities (17 percent). Very few caregivers (10 percent) reported using other local organizations (e.g., faith-based, recreation, or secondary learning programs).



53% of caregivers said a weekly respite break would be beneficial.

- Weekly respite was rated the most beneficial followed by 34 percent who said respite was needed at least once a month and 10 percent who wanted respite every 6 to 12 months.
- Very few caregivers (4 percent) said respite was not needed. However, given most of the no-paid clients were under 18 years of age, some caregivers mentioned the summer months as an ideal time for respite.

Caregivers in this sample reported on average four barriers to respite use. The most commonly cited barriers to formal respite service use were:

Percent of respondents who mentioned lack of . . .

"We need more flexibility in order to be able to use respite monies."



"As a college educated person with no language or other barriers, I find it terribly difficult to figure out how to even go about finding a respite care provider."



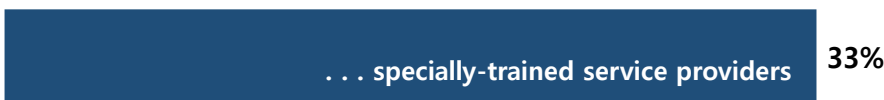
"She could use more social gatherings, but most parks and rec programs are for adults and older teens. I have a tween."



"If the pay per hour was more, as well as the training to be a respite provider easier. The barriers to becoming a care provider are cumbersome."



"Need [a] caregiver who knows ASL [American Sign Language]."



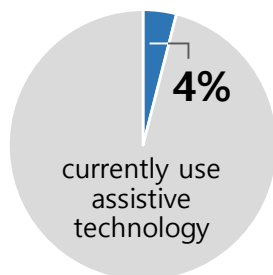
"Respite is not respite for me when I have a complete stranger in my home who is supposed to be overseeing the needs of my son."



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The least cited barriers to formal respite service were: timing of available services (26 percent), transportation (15 percent), and care recipient refusing to be 'taken care of' by anyone other than caregiver (6 percent).

Feasibility of Assistive Technology



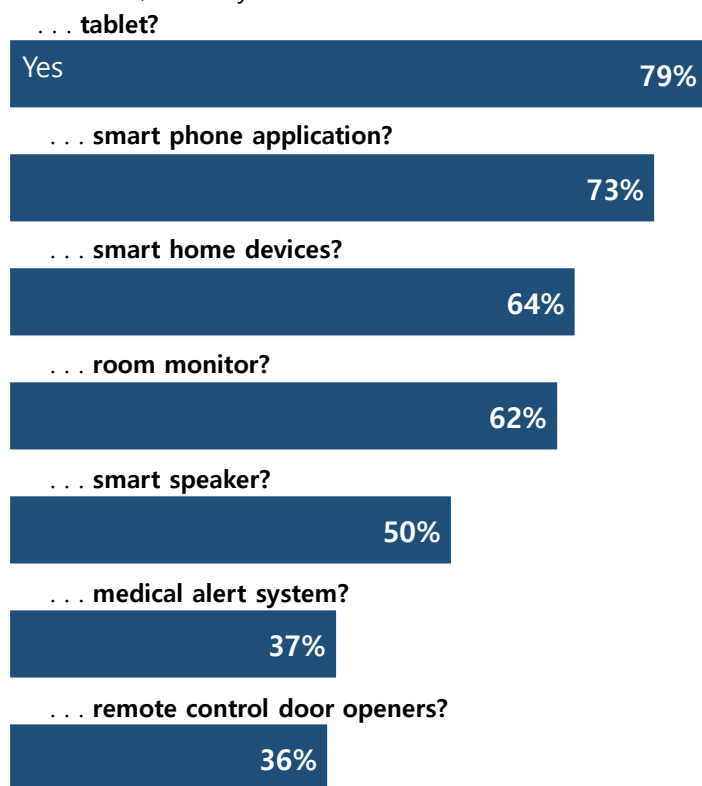
4% of caregivers said they were currently using assistive technology to take a break from caregiving.

Assistive technology (AT) includes devices used to maintain or improve the functional capabilities of developmentally disabled persons by providing them alternative means to actively engage in daily activities/routines. AT also provides a form of respite for the caregiver by increasing independence of the care recipient. According to responses, very few (4 percent) no-paid caregivers in this survey were currently using assistive technology to take a break from caregiving.

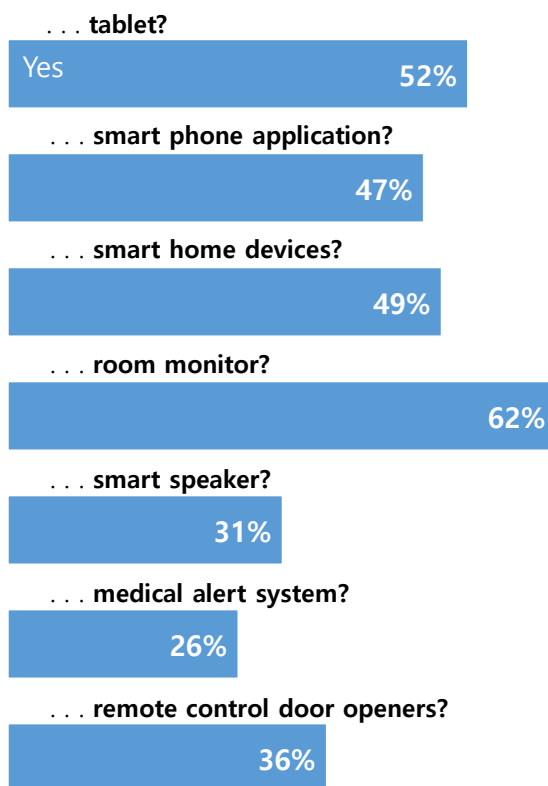
Respondents were asked which types of assistive technology they would use and to rate how helpful the devices would be in providing respite opportunities. Caregivers reported differences between AT use and helpfulness suggesting that caregiver/care recipient technical assistance (e.g., training, demonstration/loan) might be needed.

For example, while 79 percent would use tablets, only 52 percent would find tablets 'very helpful' for respite. This suggests confidence in using a tablet, but perhaps lack of familiarity in software apps developed for specific disabilities. On the other hand, most respondents (62 percent) stated that room monitors would be 'very helpful' for respite (more than any other AT), but fewer would use room monitors, pointing to potential barriers to AT adoption. In general, underutilization of assistive technology has been associated with cost/funding, caregivers' unwillingness to accept devices, and insufficient training.³

If available, would you **USE** a:



How **"VERY HELPFUL"** would it be to have a:



³ Kling, A., Campbell, P.H., Wilcox, J. (2010). Young children with physical disabilities caregiver perspectives about assistive technology. *Infants & Young Children*, 23(3), 169-183.

Discussion

Nearly all respondents to this survey are in need of respite and currently rely on an informal network of friends and family members for assistance. Despite the aforementioned limitations of the survey (such as a small self-selected sample and limited survey items), these results are consistent with more comprehensive studies. For example, other studies report extensive barriers to accessing respite services, which vary depending on the context and care recipient characteristics (e.g., care recipient level of functioning, existence of multiple conditions, or gender).⁴ Other research has found perceived respite benefits to care recipients and caregivers, such as preventing burnout as suggested by this caregiver response:

“I think the earlier respite begins the more likely burnout can be avoided later. Young kids are so impressionable and to have burned out parents can’t be good for them.”

— *Caregiver Response*

Using assistive technology (AT) to increase care recipient independence may be a new concept to these survey respondents. AT is likely available in schools, and since 76 percent of the ‘no-paid’ client survey sample were 18 years and younger, eligible students should have experience using AT.⁵ Therefore, increasing caregiver awareness of DDA and Washington State resources regarding AT home use could be beneficial to this population. Finally, introducing AT and respite at earlier ages has the potential to strengthen social and behavioral adaptation and decrease caregiver stress.

These results suggest additional research is warranted in a number of areas. First, designing and conducting a phone survey with a representative sample would provide more generalizable results about no-paid client needs. Second, describing the utilization of respite services for DDA Paid clients, specifically the type of respite used, client characteristics and related outcomes would provide better information about access, availability, and the health of populations served. Third, an evaluation of the acquisition process detailed in WAC 388-845-0415 regarding assistive technology currently available in the DDA Children’s Intensive In-Home Behavioral Support (CIIBS) and Individual and Family Services (IFS) waivers would help determine whether waiver resources have been implemented as intended and if there are long-term impacts of AT on client functioning.

TECHNICAL NOTES

URBAN RURAL COUNTY CLASSIFICATION

Respondents who reported their county of residence were recoded into one of four urban rural classification descriptions.

- **Rural Counties:** Adams, Asotin, Columbia, Ferry, Garfield, Jefferson, Klickitat, Lincoln, Okanogan, Pacific, Pend Oreille, San Juan, Skamania, Stevens, Wahkiakum
- **Large Town Counties:** Chelan, Clallam, Douglas, Grant, Grays Harbor, Island, Kittitas, Lewis, Mason, Whitman
- **Urban–Medium and Low Density Counties:** Benton, Cowlitz, Franklin, Skagit, Walla Walla, Whatcom, Yakima
- **High Density Urban Counties:** Clark, King, Kitsap, Pierce, Snohomish, Spokane, Thurston

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VISIT US AT: <https://www.dshs.wa.gov/rda>

⁴ Robertson, J., Hatton, C., Wells, E., Collins, M., Langer, S., Welch, V., and Emerson, E. (2011). The Impacts of short breaks on families with a disabled child: an international literature review. *Health and Social Care in the Community*, 19(4), 337-371.

⁵ Assistive Technology. *Tips and Resources for Funding and Technical Assistance*. (2013) Retrieved from https://informingfamilies.org/wp-content/uploads/2015/07/Bulletin_AT.pdf September 30, 2019.