

RESPITE INITIATIVE FINAL REPORT

Respite is a time for caregivers of people with special needs to get a break from providing care. It takes trust by caregivers to leave the person in their care with a provider, and skills of the provider to give the necessary care. While respite options are available in the area, those opportunities are limited and often do not meet the needs of caregivers. Additionally, many caregivers are either unaware of the respite options or do not trust others to care for their loved ones. The Respite Initiative sought to increase the use of respite through expanding respite options, informing caregivers of respite options, enhancing trust in respite providers and strengthening our RFP process.

+ Intended Benefits

- Caregivers know of & have access to desired respite at the time it is first needed and trust providers enough to use the services.
- Providers offer enough of the desired type of respite to meet caregivers' needs
- Parents/caregivers trust respite providers

> Intended Outcomes

- Decrease in lag to receive services from RFP process
- Increase in respite options: emergency, day to day, events
- Develop positive (trust) image of respite

RESEARCH

The Community Outreach Department at Developmental Pathways conducted qualitative research through individuals in service, families, providers and Program Approved Service Agencies (PASAs). Data collection included surveys and focus groups. The research supported the strategy development of the initiative.

Surprises

- ★ There was no notable difference in overall comfort level of respite among different ethnicities
- ★ 60% of respite providers offer in-home care
- ★ Caregivers in the focus groups were not fully informed of all respite options available through the Medicaid Waivers

Key Findings

CAREGIVERS

- Top challenges given for not using/identifying respite are: cost and lack of skilled providers
- Caregivers of different ethnicities have different comfort levels for respite different options
- For Bilingual and non-English speakers, family members are the most trusted respite option
- Importance of providers to administer medication is great for adults in care
- Caregivers/parents often use longer and more frequent periods of respite when caring for older individuals

PROVIDERS

- Of current respite providers, 76% are looking to expand services
- Limited number of staff and building size are biggest barriers to expansion
- For those not currently providing respite, 50% indicated a need for additional funding and an increase in reimbursement rates to support expansion
- There are providers serving or interested in serving all parts of our catchment area



Activities

Respitality

"Respitality" is a combination of two components, respite and hospitality. At Developmental Pathways, our method of "respitality" provided parents/caregivers to an overnight hotel stay and a break from parent duty. Parents/caregivers were able to spend a peaceful Saturday night at a hotel, enjoy dinner, adult activities, and a good night's rest. Children hung out at a nearby hotel participating in fun games, activities, dinner, and sleepover!



Overnight Respite

Overnight respite was identified as a priority from families. Overnight and multiple night opportunities and providers are limited and therefore families often do not get the longer breaks they need for full recuperation. Opportunities for overnight respite were provided by Developmental Pathways through special camps at Easter Seals and through an ongoing monthly two-night respite pilot program.

Provider Grants

Provider grants were awarded to enhance and increase respite options for caregivers of individuals with intellectual and developmental disabilities and delays. The grants covered new respite centers, staff training, new programs and caregiver support.

GRANT RECIPIENTS

- Adam's Camp
- Angels of Colorado
- Autism Community Store
- Care and Community
- CentrePointe Support Living
- Friendship Circle
- GoldStar Learning Options (GLO)
- Hope Farms
- Megan's Place
- STAR Institute & TACT – FUSE program
- Tall Tales Ranch
- YMCA Littleton



Provider Outreach

To connect with the community and gather information on provider needs, we spent time reaching out to new contacts with opportunities to create or grow respite resources. Community Outreach staff reached out to current providers who indicated interest in increasing capacity and found that most are at capacity and struggle to hire or maintain enough staff to increase services. Community Outreach staff connected with school districts about the potential to connect paraprofessionals and teachers with respite opportunities during school breaks. An example of the outreach connection is our new partnership with Great Play to provide respite for families with young children with developmental disabilities and delays.

Newsletter

Our new quarterly Respite Newsletter purposes to break down negative stigmas against the use of respite, spotlight the many trustworthy providers in our area and share various ways that families make respite work for themselves.

Provider Guide

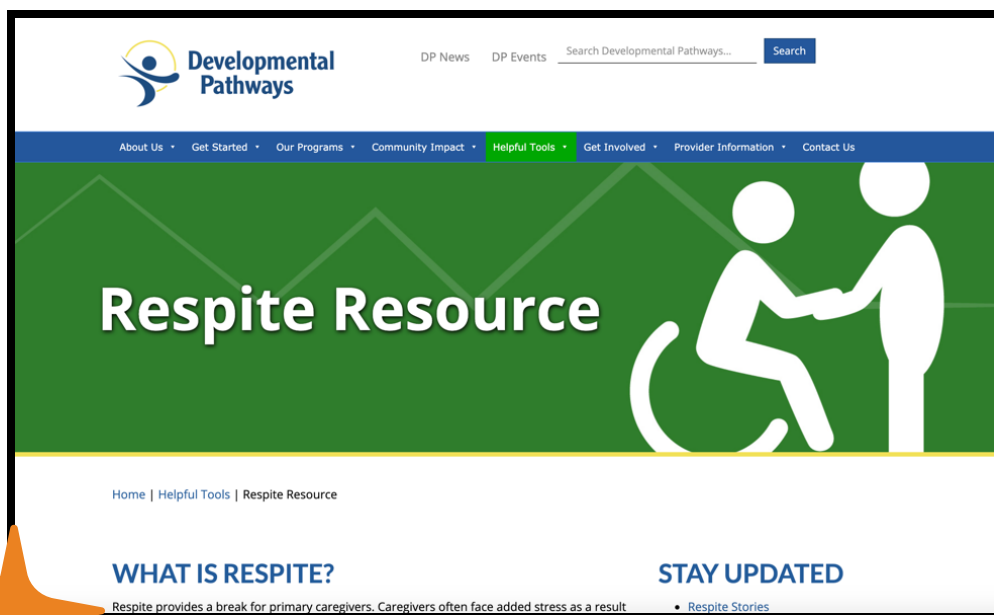
Prior to the initiative, the Community Outreach team at Developmental Pathways had begun collecting respite resources for families during the summer. Through the initiative, the project grew to be two annual Out of School Guides, one for summers and another for breaks during the school year. The guides, which are each updated annually, are shared electronically with families, providers and the community at large.

Respite Webpage

Our [Respite Resources page](#) on the Developmental Pathways website provides resources for parents/caregivers and providers. There are video resources and links to respite resources. The website makes the respite content easy to access for everyone.

Videos

A series of six respite videos was created to support parents/caregivers in their search for respite, inform the community on opportunities to become providers and share personal stories of the positive impact of respite.





State Respite Care Taskforce

Developmental Pathways actively participated on the Respite Care Task Force (established through HB 15-1233 and continued with HB16-1398) through CEO Melanie Worley and Program Manager Janis DeBaca. The Task Force studied respite care across the State and reported its findings to the General Assembly. Work of the Task Force continued into 2019 with additional projects and research, including a Tailored Caregiver Assessment and Referral (TCARE) protocol to address caregiver burnout.

Respite + Recreation Fair

A respite and recreation fair was held to provide opportunity for parents/caregivers to connect directly with respite providers. Over 20 providers attended the fair to share about their services. Because of low attendance, it was decided to include multiple types of services at the resource fairs.



Emergency Respite Funds

Developmental Pathways raised private funds, through the SUN Foundation, to provide respite for families. The SUN restricted donations are used for emergency respite requests necessary for unplanned situations.

Parent/Caregiver Support

Parent support provides resources to parents/caregivers such as training, funds for parent groups, information sharing, and respite during sponsored activities. Developmental Pathways considers this parent support necessary respite for parents and caregivers. This practice allowed the initiative to allocate resources to enhance supports for parents/caregivers. Throughout the initiative, Developmental Pathways offered 31 trainings and events to support parents/caregivers and began regular participation in the Special Education Advisory Committees (SEACs) in each school district.

RFP Process

Both providers and parents/caregivers identified concerns with the Request for Proposal (RFP) process to request waiver services, specifically respite. To facilitate change in the process, Developmental Pathways worked with a contract agency to evaluate the process and provide recommendations for change to the process. The contract agency provided six recommendations for Developmental Pathways:

Exceptional Family Member Program (EFMP)

The Air Force and Navy Exceptional Family Member Programs (EFMP) have EFM Respite Care to ensure that Air Force and Navy exceptional family members (EFMs) receive respite care services. The Air Force and Navy program contractor, Child Care Aware® of America, subcontracts with Developmental Pathways to recruit, train, match, and provide technical assistance to childcare programs and providers eligible to care for Air Force and Navy families with children enrolled with EFMP.



IMPACT

**\$191,649
IN GRANTS**



benefiting



12 provider agencies



2k people



66 new respite spots

OVERNIGHT RESPITE

Easter Seals Camps

Three overnight special camps were offered to families between November 2016 and February 2019. The camps each served between 15-25 campers for 44 hours each. Together, the camps provided over 2,600 hours of respite.

Respitality

An incredible 125 children, or 76 families, were served with the three “respitality” pilots. This adds up to 2,375 individual hours of respite.

NEWSLETTER

1,500+

people reached by our respite newsletter 4 times a year

\$31,000 IN EMERGENCY RESPITE FUNDS

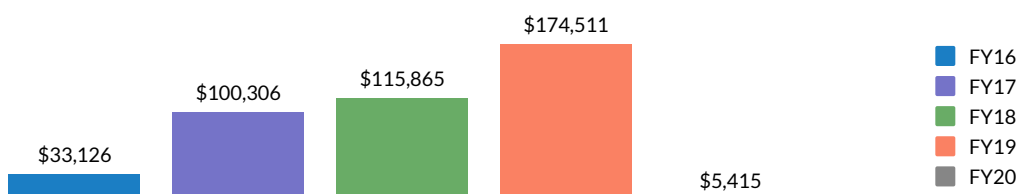
given to 29 families



Financials

Total Board Designated & Donation Funds: \$429,223

Expenses FY16 - FY20





Lessons Learned

Job Board

One project the Respite Team worked on was the development of an online respite job board. This was challenging work to find the correct organization to host the site without creating a great deal of ongoing work. While a willing host started the online site, there ended up not being enough people who would use the site.

Online Respite Training Program

The Respite Team wanted to develop a program to provide online respite training for providers as was suggested by parents in the parent/caregiver focus group to make training uniform across the state. Providers interviewed had concerns as many of them choose additional trainings and prefer in-person trainings for some things. The verdict was that the scope of trainings would be too broad to provide them all.

Provider Capacity

Increasing provider capacity is challenging in a job market replete with well-paying jobs. Providers are interested in serving more people, but struggle to maintain highly qualified staff with the current Medicaid reimbursement rates received through waivers. There is also difficulty in funding capital expansion projects.

Overnight Respite

Adam's Camp bills waivers for most of their specialized camps which is a great option for overnight respite and a model for other providers to follow. People who get waiver services can write this into the annual service plan so they can plan for a longer break. Angels of Colorado has also figured out a way to bill waivers for their version of "respite". Since this unique service is available through a provider, Developmental Pathways will not continue to provide the event.



Next Steps

Parent's Night Out

The Community Outreach Department will continue to provide more Parents Night Out events as an opportunity for respite to parents who do not have waiver resources. Respite is also a regular part of all Developmental Pathways parent/caregiver events, when feasible.

EFMP

The Community Outreach Department will work with the EFMP staff at Buckley Airforce Base to connect more families with EFM Respite.

Parent/Caregiver Support

Developmental Pathways will continue to invest in parent/caregiver supports through trainings, events and funding opportunities. The Community Outreach and Case Management Departments will continue to work with the school districts' Special Education Advisory Committees.

RFP Process

The Case Management Department will work to implement the recommendations from the RFP analysis.