



## Respite Program Case Study *Respite in the Time of COVID-19*

### Assistance with Residential Care in the Home (ARCH) Respite Care

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The St. Louis Arc's ARCH (Assistance with Residential Care in the Home) Respite Care program is a consumer-directed respite service that helps a person with developmental disabilities live at home by providing intermittent, short-term relief to primary caregivers. It is one of the largest and longest running programs of this type in the United States.

The program is open to any age person in St. Louis County and to people 3 years of age and older in St. Louis City who with a diagnosis of an intellectual or developmental disability such as autism, cerebral palsy, epilepsy or brain injury that occurred before the age of 22. Specialized services are provided to children and adults with medical or high behavioral support needs in addition to their other developmental disability. Each year, more than 1,400 families in St. Louis County, and over 200 families in St. Louis City are served. Primary caregivers are reimbursed for respite services they receive in their own home or the home of a care provider. Registered families can use the ARCH care provider listing or find potential caregivers on their own.

The model is one of family-driven supports, implemented through a family reimbursement model paired with St. Louis Arc's comprehensive family supports, information and resources and planning tools. Families are engaged in planning that includes not just how to successfully access and use respite care, but also what are the goals they want to accomplish through respite.

#### *Planning and Guidance for Ongoing ARCH Voucher Services*

The St. Louis Arc's In-Home Support (ARCH) respite program continued to provide respite reimbursement for families during the COVID-19 pandemic. To ensure that services could continue to meet individual family needs, several changes were discussed and the following steps were taken:

- **Reached out to families** to determine changing needs during the pandemic. Discussions with families revealed that many were having difficulty finding providers during the pandemic or were uncomfortable having outside providers come into their home.
- **Conducted internal planning** through staff discussions around family needs and potential program flexibility.
- **Coordinated with two local program funders** – Productive Living Board for St. Louis County Citizens with Developmental Disabilities (PLB) and the St. Louis Office for Developmental Disabilities Resources (DD Resources) – and jointly agreed on respite program changes to provide more flexibility for the use of funds during the pandemic. Due to changing needs, additional funding was requested and received.
- **Initiated respite reimbursement program changes** by offering more flexibility that allowed families who were having difficulty finding providers to use family members currently residing in the home – these changes have continued:
  - Families with high school and college students now at home, who were over the age of 18, could now use those family members to provide respite care.
  - ARCH program staff provided monitoring through phone calls and emails to ensure caregivers were getting needed respite breaks.
  - With these changes, approximately 10 families used family members living in the household, with most using family members from outside of the home, and fewer using outside care providers.
  - Families were provided increased respite hours to address changing needs related to the pandemic. Many families' respite hours were doubled over the pre-pandemic numbers.
- **Participated in the St. Louis Family Support and Respite Coalition** which has representation from three counties and

discussed how members were addressing COVID issues for their family support and respite services.

- **Reached out to providers**, and although there are only 20 respite providers on the list, all except 1 indicated that they were available to provide respite during the pandemic. Providers are independent contractors.
- **Supported families to continue to find providers** using the provider list, family members, websites and friends.
- **Provided families with the [Tips for Finding a Respite Provider](#)<sup>1</sup>** resource to assist them in finding, screening, interviewing, and sharing pertinent information before respite is provided.
- **Updated policies and procedures** to reflect changes for how families could use their respite care funding. Previously families could not be reimbursed for work related care needs. However, during the pandemic, many families were working from home, or were essential workers and needed to work outside the home. The policies and procedures were changed so that families could use respite care for work and could provide virtual school supports if their child was no longer able to attend school. Families are able to utilize more daily care and use more than 14 days in a month.
- **Conducted outreach to families not using respite** to discuss their needs. This led to the agency as a whole developing and offering virtual educational programs to respite and adult day program participants through recreation programs such as bingo, book clubs, meet-ups, yoga and more to all those who were interested. Outreach was provided through newsletters, emails and phone calls, and networking with other community agencies.
- **Provided face masks for families** upon request. Also had families volunteer to make face masks and donate.
- **Changed intake procedure for new families** to a virtual format instead of doing a face-to-face interview which has continued. Also highlighted how to use the program during the pandemic, emphasized key changes, and directed them to online [COVID resources](#).<sup>2</sup>

### **COVID-19 Training and Resource Dissemination**

- **Provided online [COVID-19 pandemic resources](#)<sup>3</sup> and information for families** including St. Louis area resources for food, education, utilities, technology, and more.
- **Provided COVID-19 resources** such as links to the [United Way](#)<sup>4</sup> and the [St. Louis Regional Data Alliance](#).<sup>5</sup> Also included pandemic resources such as [What is COVID-19?](#)<sup>6</sup> and the [COVID-19 Symptom Guide](#).<sup>7</sup>

- **Provided virtual meeting support** since many Arc programs and services are offering virtual meetings using Zoom. Developed [Zoom Audio and Video Conferencing](#)<sup>8</sup> guidance so families could use this free resource.

### **Challenges and Opportunities**

- **Significant increase in number of respite hours** used from 240 hours per year to 400 hours per year. Since funders put a cap of 504 hours per year for respite, this has been a challenge for some families who are exceeding that cap due to health situations. For these families sometimes respite care needs have resulted in needing upwards of 1,000 hours of care or more.
- **Challenging family situations** such as older caregivers who have had a heart attack, mothers who need full bed rest due to complicated pregnancy, multiple family members with health conditions, and other health conditions or illnesses for the caregiver and/or care recipient.
- **Increase in need for other services beyond respite**, such as food, housing, health care, and families who have become homeless. Providing referrals to other services and in general offering more information and resources around these issues.
- **Due to the need for more providers reached out to colleges and universities** in St. Louis area (Washington University; Maryville) and recruited respite providers who might be available to work during the COVID-19 pandemic. Included various departments: Education, Occupational Therapy, Social Work, Nursing, Music Therapy, Psychology, and others. In addition, explored having students provide remote educational supports. Although this was not as successful as hoped, there is now a mechanism in place for families to recruit providers using this option.

### **ARCH Respite Reimbursement Program Continuation**

- **Continue to use an informal needs assessment process** to reach out to families to discuss their individual family situation, ages of family members, and other services they are receiving. This process has helped to determine how many respite care hours might be needed moving forward.
- **Continue to provide increased respite hours for families** as needed to address changing needs related to the pandemic.
- **Provide ongoing supports to families and providers** through phone calls and online resources.
- **Monitor ARCH program usage** and identify and address caregiver and provider issues and concerns as they occur.

- **Continue to use new quarterly reporting mechanism** for collecting key data related to COVID. This includes numbers of individuals served remotely each quarter and narrative of current issues families are dealing with. Service provision mechanisms used during COVID and how this differs from original funding application was also tracked. The quarterly report is then shared with funders.
- **Focus for the future will be transitioning families back to regular respite care** that allows them to thrive and be intentional about their respite breaks. Will involve a phased in approach and could build in flexibility to be individualized for certain family situations.

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### Respite Contact, Email and Phone Number

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<https://www.slarc.org>

<https://www.slarc.org/programs/family-support/in-home-support>

For ARCH Respite Care program related questions or for additional information email [arch@slarc.org](mailto:arch@slarc.org)

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### Website Link URLs

1. [https://drive.google.com/file/d/1RWl\\_1U8dgH6h-xvQoBk7HYCT5XoZoQt9/view?usp=sharing](https://drive.google.com/file/d/1RWl_1U8dgH6h-xvQoBk7HYCT5XoZoQt9/view?usp=sharing)
2. <https://www.slarc.org/resources-for-families-during-covid-19>
3. <https://www.slarc.org/resources-for-families-during-covid-19>
4. <http://www.211helps.org/covid-19-where-to-turn/>
5. <https://www.stlresponse.org/>
6. <https://3d1.bd5.myftpupload.com/wp-content/uploads/2020/04/Access-COVID-Guide.pdf>
7. <https://3d1.bd5.myftpupload.com/wp-content/uploads/2020/04/Access-COVID-Symptom-Guide-11x17-1.pdf>
8. <https://3d1.bd5.myftpupload.com/wp-content/uploads/2020/03/Using-Zoom-for-Families.pdf>