Summary Report for Partnership Services for Community-Based Organizations





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(also known as Families Supporting Families grants)

Background

The Wisconsin Department of Public Instruction (DPI) and the Wisconsin Board for People with Developmental Disabilities (BPDD) partnered with five community-based organizations (CBOs) that primarily serve families of color and their children with intellectual and developmental disabilities. All the CBOs are run by people of color and support families to navigate the complex service systems within schools and the broader community.

The funding from DPI and BPDD supports the CBOs to carry on their ongoing work and to expand their efforts. These established organizations are trusted leaders in their communities. They support children and youth with disabilities and their families to connect with each other and with available resources, to be empowered to advocate for one's needs, and to practice self-care. They know their families well and they know what types of events and support will be meaningful and useful to families. They also carefully listen to families and directly ask for feedback on what families need and what they would like to learn about.

Grantees (location; target population; number served)



<u>ALAS</u> - Elsa Diaz-Bautista, Executive Director
(Milwaukee and beyond; Spanish-speaking community; 607 people served)



 <u>Ho-Chunk Nation</u> and their non-profit partner <u>LOV, Inc.</u> - Cheryl Funmaker, Educational Disabilities Director and Stefanie Primm, Executive Director (Statewide; Ho-Chunk tribal members; 53 people served)



Mommy Beautiful Sunrise - Shanice Baquet, Founder (Milwaukee; Black community; 335 people served)



<u>Padres E Hijos en Accion</u> - Hector Portillo, Executive Director (Madison and beyond; Spanish-speaking community, 120 people served)



Parent University - Delores Sallis, Director (Milwaukee; Black community; 320 people served)

Grantees' project activities include:

- Supporting and educating their families on topics related to self-care, special education, disability services, housing, transportation, safety, and leadership. Grantees seem especially skilled at seeking feedback from families, listening, and then implementing programming to meet the needs and requests of families.
- Connecting families to each other, to community opportunities, to professionals, and to services and supports.
- Eliminating barriers by equipping people to know their rights and by empowering them to advocate for what they need and for change and improvements.
- Increasing citizen participation by supporting families to advocate for change through participation in councils, committees, and other community meetings.

Results and Impact

Evaluation activities include quarterly calls with each grantee to gather qualitative and quantitative information about activities, number of families and people with disabilities participating, barriers families face, strategies to overcome barriers, and success stories. Evaluation also includes surveys and conversations, carried out by grantees, with a subset of families to learn more about families' experiences and the impact of project activities.

Output numbers indicate that these grantees are effective at connecting with and supporting families. All the CBO's are growing as more families hear about the organizations and the excellent support and guidance they provide. At the beginning of the grant, as we planned for the year with a set of activities in

mind, we anticipated that about 20 families (or about 40-60 people) would be engaged during 2021-2022. However, rather than dictate a specific set of activities, we realized the need to honor the grantees' expertise

Over 1,435 people participated in at least one grantee coordinated activity

and knowledge about what would work best for their families. As a result, the grantees coordinated over 40 events designed specifically for their communities. These events ranged from "Tea and Talk" book club meetings to Zoom "Parent Hours" to in-person workshops. Over 1,435 people participated in at least one activity.

Results and Impact for Individual Organizations

Outcomes indicate that the support and guidance families receive helps empower them to connect with other families, to apply for services and programs they previously hadn't enrolled in or didn't know about, and to advocate for their child's needs with schools and other systems. When families come together with other families for learning, emotional support, and enjoyment, they connect, learn from each other, and feel empowered. Each grantee identified different goals for their families. They gathered outcome information from a subset of families and found the following:

Family and Youth Advocacy outcomes:

90% (163/182) of family members are participating in their child's IEP meetings.
 (Parent University, Ho-Chunk Nation)



- In less than one year, **10** additional families feel they have the skills to advocate for their child's education. (Padres e Hijos en Accion)
- 95% (349/368) of family members and youth with disabilities reported feeling empowered to advocate for their own needs and the needs of their children. (Mommy Beautiful Sunrise; ALAS)
- 10 family members reported that their children are more independent. (Mommy Beautiful Sunrise)
- 100% (170/170) of family members and youth with disabilities reported knowing it's okay to do self-care. (Mommy Beautiful Sunrise, Parent University)

Community connections outcomes:

- 100% (160/160) of family members are participating in programs they are eligible for. The programs and supports families connected to include Children's Long-Term Supports, Adult Long-Term Supports IRIS, Disability Rights Wisconsin, Independence First, Autism Society, Life Navigators, housing supports. (Parent University)
- 2 families used the CPR skills they learned at a grantee's training to save their children experiencing a medical emergency. (Mommy Beautiful Sunrise)
- 80% (346/431) of families are more connected and feel supported. (Parent University, ALAS)

 Over 20 families attended the annual Self-Determination Conference and the Circles of Life Conference. Families want to attend future conferences and they want to present! This desire to present is a huge change for families. (Padres e Hijos en Accion)

Results and Impacts from all Grantees

All grantees were asked to report on specific questions related to satisfaction and advocacy with their subset of families.

- 100% (779/779) of participants report being satisfied with the activities
- 93% (238/256) of youth with disabilities and 90% (471/523) of family members reported being better able to say what they want and need.
- 93% (237/256) of youth with disabilities and 85% (444/523) of family members reported increasing their advocacy.
- In less than one year, 6 youth with disabilities and 71 family members reported serving in a leadership or advocacy position (such as being on a board, committee, or council).

Barriers and Strategies

During our quarterly calls with grantees, they share barriers families face. Below is a list of these barriers and, when available, possible strategies used to address these barriers.

BARRIER: Some families fear retribution, or that things will get worse, if they advocate for their child or family. When families do advocate, their comments are often not well received. As a result, many families choose not to speak up.

STRATEGY: One grantee hopes bringing families together will create collective power. Perhaps through this collective power, it will feel safer and be safer to advocate for one's needs.



Another grantee encourages her families to use the pronoun "we" during IEP meetings so that no one feels a finger is pointed at them. Parents have noticed that backlash has decreased.

BARRIER: There are not a lot of inclusive opportunities for youth and families to be active during the summer.

STRATEGY: One grantee coordinated outdoor, active activities for the whole family. The grantee also supported families to put their ideas into action: one family started to coordinate meetups at different parks around town so that families would get more familiar and comfortable with the resources available in their area.

BARRIER: Discrimination from some county agencies' staff towards tribal families. This can limit whether people are found eligible for services or what and how much they receive for services.

STRATEGY: One grantee hired a family navigator, a person who is respected in the community, can build trust with families, and understands the service system. The navigator accompanies families to appointments and helps the family advocate for their needs and rights. The navigator can also try to work with professionals so that families experience a warm welcome/handoff.

BARRIER: Health insurance is very difficult to work through. It's hard to know to tap into other resources, like Well Badger.

STRATEGY: Working with a family navigator may help families walk through challenging systems and tap into other services they didn't know about yet.

BARRIER: Discrimination experienced at community meetings attended by family members. For example, one person attended a meeting for community health workers during which racist comments were made about the Black community not taking action to help others.

STRATEGY: The grantee suggested that the person thank the coordinator for running the group and then share their concerns and experiences.

BARRIER: Foster parents do not know about their foster child's educational needs, whether they have an IEP or what an IEP is. Often, no parental figure is attending IEP meetings.

STRATEGY: The grantee supports foster parents to get permission to attend the IEP meeting from the biological parent.

Other barriers shared: transportation difficulties; the school district doesn't seem to have the funds to provide services to their students with disabilities; society looks down on African American fathers and doesn't think they are present and engaged; a county tried to formalize a process to register families who receive Children's Long-Term Services in a statewide conference (rather than let the CBO coordinate the registration process). The new process was very difficult for families to navigate. One grantee reported 50% fewer families attending the conference compared to last year.

Leverage and Connections

The grantees are very connected to their communities and often get materials, meals, and opportunities for their families donated from outside organizations.

- One grantee leveraged this grant as she wrote for and was awarded an additional grant.
- One grantee shared that this grant allowed her organization to stay open during the pandemic.

Total leveraged from November 2021-September 2022: \$87,588

This means that DPI's and BPDD's investments in these organizations led to over \$87,500 in additional funding and resources going to these communities.

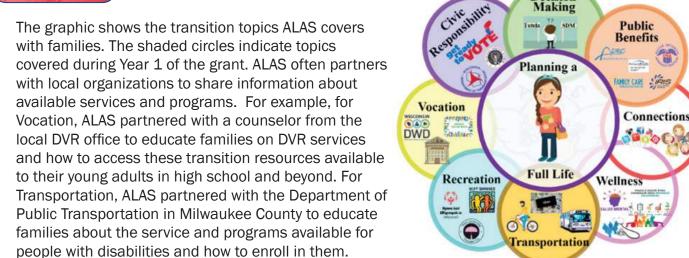


Testimonials and Stories



ALAS Elsa Diaz-Bautista, Executive Director (Milwaukee and beyond; Spanish-speaking community; 607 people served)

Decision



- For Decision Making, ALAS hosted 2 workshops: one
 on the definitions of guardianship and supported decision-making and the second on what supported
 decision-making is, how to use it, etc.
- 56 families with youth turning 18 have chosen supported decision-making!
- For Civic Responsibility, ALAS offered families a voter registration and voting rights workshop to inform
 and encourage them to have their loved ones with disabilities exercise their right to vote on local, state
 and national elections. One family who attended this workshop has a son who was turning 18. The
 parent used what she learned to support her son to register to vote on the day of the election and then
 he voted!
- ALAS also organizes events to celebrate families and culture. Over 50 families attended a Family Summer Camp Day event for a day of respite, relaxation, fun and networking. Over 1,000 community members participated in ALAS's Mexican Independence Day Culture Celebration. This was ALAS's largest community-wide, cultural event ever.
- ALAS assists many parents with the IEP process and ALAS staff will sometimes attend IEP meetings with families to support them. At one meeting, the student and school staff were together in a room while the parent and ALAS joined virtually (during COVID). The student was an active participant. The IEP team quoted something he said which showed they were listening and hearing him. The mom was elated. She texted ALAS after the meeting to say: "Thank you so much for all of your support that you have offered. I am so thankful because without you guys I don't think the IEP and eval would have been taken place. Blessing to you. I'm so thankful, I can't find words to explain how I feel."
- For another family with two young children with autism, ALAS had been helping the family for three
 years. ALAS often supported the mom at the IEP meetings, but ALAS challenged the mom to go
 independently. She did and it went well!



Ho-Chunk Nation and their non-profit partner LOV, Inc.

Cheryl Funmaker, Educational Disabilities Director and Stefanie Primm, Executive Director

(Statewide; Ho-Chunk tribal members, 53 people served)







- Ho-Chunk Nation and LOV, Inc. have partnered for several years. In a previous effort they brought together a group of 12 families for 3 family retreats. Through these events, families made strong connections with each other and with Cheryl and Stefanie. Although the group only met for three overnight retreats, the impact was significant and lasting. The group stopped meeting during the pandemic, but Cheryl has observed that over the last two years these families have adopted a more pro-active approach with IEPs: many will articulate that they know they can call an IEP when they need to, or they know how to connect with their child's case manager when they have a question. She's also seen families reach out to other families for support. This shows the strength and benefit of family events to empower Tribal parents. When parents are empowered effectively, they want to be an active, respected part of their child's education. With the funding from DPI and BPDD and as COVID recedes, they are resuming these impactful family retreats.
- New families are recruited as the older families develop their advocacy confidence and skills.
- Ho-Chunk Nation and LOV, Inc. have worked very hard to find a family navigator to provide 1:1
 support to families. Ideally, this person is an elder tribal member who is known and respected in
 the community. After a long search, they found a Ho-Chunk member who is a clan mother and elite
 member. She has a lot of status in her community which helped her connect with families.
- The Ho-Chunk family navigator helped a family get vaccinated. The family consists of a single parent
 with multiple children. They don't have a vehicle and live outside of town which makes it hard to get
 into town if needed. Besides transportation, the family faced several barriers to getting vaccinated.
 The family navigator gained rapport with the family over time and was able to help them make vaccine
 appointments and to arrange a ride from a relative.
- A lot of families receive a version of Children's Long-Term Services (CLTS) that is not following best
 practices. The family navigator helps families navigate how to word requests and concerns. One child
 needed a sensory tool. The family's experience with CLTS was not good, so they simply didn't ask if
 it would be possible to get the sensory tool. With support from the family navigator, they were able to
 provide a well thought out rationale for needing the device and they received it.
- 2 young adults who participated in grantee activities have started 2 separate college programs this fall.
- 4 tribal families are partnering with WISPACT to identify a mechanism that will allow tribal funds to
 be placed in a trust that will not count towards income and jeopardize people's benefits. If an effective
 mechanism is established, this could positively impact tribal members with disabilities across the state
 and nation.



Mommy Beautiful Sunrise Shanice Baquet, Founder

(Milwaukee: Black community: 335 people served)



- "As a teen I can say we all are looking to the Future of what we can be. Having an open mind that we are normal and can work whatever jobs we want to." Youth
- "Supported a mom with special need with an IEP talk to her about her rights like Shanice help me. I
 understand how it feels to have a disability but Shanice helps to understand that I can support others
 as well. I'm hoping to try it soon." Parent
- "I'm just going to say you can't find an organization like yours. We as parents feel comfortable to come to a parent session without judgment and was made in mind of color families. We get resources and learn more about programs for all of our children. We get one on ones, learn different skills training and meeting and the same with our children. To me Parent Night is just not for parents my mother-in-law was able to join. The family fun day is like our Parent Night but made for the whole family. M.B.S asks us what we need or want to do and they do it. They take everything everyone says and make it an event. My children really look forward to Family fun days My teen is even going to community events with me and talking. My 2 youngest children love to paint. Now we use it to help with stress and anger. My son is now looking forward to helping homeless people. and I really like community meetings. It helps me to connect and have a say on what is going on in my neighborhood. none of this can't happen without you. Thank you" Parent
- Parents have made their own texting groups pertaining to different subjects (IEP support, medical support, etc). Through this families are supporting each other in different ways: bringing food to the hospital for a family, sitting with a child in the hospital while the parent goes to get a meal, gathering to do yoga, etc.
- Families have started to seek out resources and help other families. They are becoming advocates and leaders. This is an exciting development Mommy Beautiful Sunrise has noticed in the last 3 months.
- Mommy Beautiful Sunrise has observed youth growing in their leadership as well. One teen was voted to be president of his high school. He has a sibling w/ Down Syndrome. He advocated for a student with a disability to be on student government as well.





Padres E Hijos en Accion

Hector Portillo, Executive Director

(Madison and beyond; Spanish-speaking community, 120 people served)

- Padres E Hijos en Accion hosts a radio program on La Movida each month. The program focuses on topics of interest to families of children with disabilities. Analytic information is gathered each month to track the number of people who listen to the program. In January, March, and April over 2,000 people listened each month. For the entire contract year, nearly 13,000 people listened.
- "They offer us a connection with other parents with kids with disabilities and most the kids that attended had the opportunity to participate in the conferences."
 - Parent who attended a conference



- "I attend to the workshops that Padres e Hijos offer and this organization has supported me a lot... Mainly they helped to be heard in the school...There was something happening with my son, so we called the school but no they didn't treat us as they should. Until this organization intervene." Parent
- "I thank Padres e Hijos En Accion, but mainly to Hector Portillo and his wife....For all the workshops they offer, such as the IEP workshop, the one where we organized folders, the guardianship workshops have helped me enormously." Parent
- "...We were parents that we didn't have no information of where to go and our daughter needed so much help. And like every parent we want to give our kids a better future but after the diagnostic the battle is tough." Parent
- "I'm grateful to Padres e Hijos for all the support and the workshops that help me get knowledge and with that I can take better care of my son." Parent
- Hear more <u>video testimonials</u> about the families' experiences with Padres E Hijos En Accion activities and their experiences attending a statewide conference.



Parent University

Delores Sallis, Founder and Director

(Milwaukee; Black community; 320 people served)



- At the end of February, Parent University organized a resource fair with an IEP clinic and vaccine clinic in the same day. Since many of Delores's new families have 6- or 7-year-old children, they are not very familiar with IEPs and special education. They thought the IEP was something like CPS. Parent University brought in a retired attorney to facilitate the IEP clinic and to answer people's questions.
- Families like to socialize with each other and to talk about different things with each other. Parent University has observed that the "Tea and Talk" book club, using resources from DPI, has been very successful and popular. Thanks to the book club, people's "voices are bigger than their shame and fear...These books are turning people's lives around in terms of kids with disabilities, especially the foster families". The group is on their fifth book. They've finished Opening Doors to Adult Services and are now reading about serving on groups.
- One family shared that their child bangs his head against the wall at school and gets sent home. This
 is a behavior the family had not seen before. Delores encouraged the mom to observe her son in class.
 She did so and realized that he was afraid of two students. As a result, he'd bang his head until he was
 sent home. Delores worked with the mom and the teacher to set up a sticker chart for him; if he stayed
 at school all week, he'd get \$2. This has greatly improved the situation.
- People don't know that there are resources available to them. One mom did not know about Children's Long-Term Support (CLTS) until Delores told her about it. She has since applied, and her child now receives helpful services.
- Parent University takes a personal approach to everybody. Two parents with disabilities didn't come
 to the first few meetings because they had never had anyone to talk to. They shared, "We are human
 beings but we're not accepted as human beings." They have started coming to the meetings and are
 opening up. Parent University hopes to support them to share their stories with others in the future.

Can you tell them thank you because we needed something like this. Taking a small organization that's wrapped around Black families...everything we have been doing have been helping my family.





WISCONSIN BOARD FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES