

# DAKOTA AND RAMSEY COUNTY AUTISM GRANT

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**2016-2018 REPORT**  
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# NAVIGATING THE REPORT

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### Key Terms

**Autism spectrum disorder (ASD):** A complex neuro-developmental disorder that affects 1 in 59 children.<sup>1</sup> Though varying greatly from person to person, the core symptoms of autism include difficulty with social interactions and relationships, challenges with verbal or non-verbal communication, and narrow interests in activities or play.

**Respite:** Support for a child or adult that provides family caregivers a short break.

**Community Inclusion:** Process by which all people, regardless of disability, can fully participate in community life.

**Informal Supports:** Support received through friends, neighbors or community associations; not dependent on formal services for people with disabilities.

**Self-Direction:** Approach to planning where the person and his or her family decide which services and supports are best for him or her.

**Olmstead Plan:** Based on the overall goal that Minnesota will be a place where people with disabilities are living, learning, working, and enjoying life in the most integrated setting.

*For more information about the Dakota and Ramsey County Autism Grant, including free toolkits and additional success stories, visit*

<https://www.co.dakota.mn.us/HealthFamily/MentalHealth/Autism>

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<sup>1</sup> Baio, J., Wiggins, L., Christensen, D.L., et al. (2018). Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2014. *MMWR. Surveillance Summaries*. 67(6), pp. 1–23. <https://doi.org/10.15585/mmwr.ss6706a1>.

# IMPORTANCE OF THE ASD GRANT

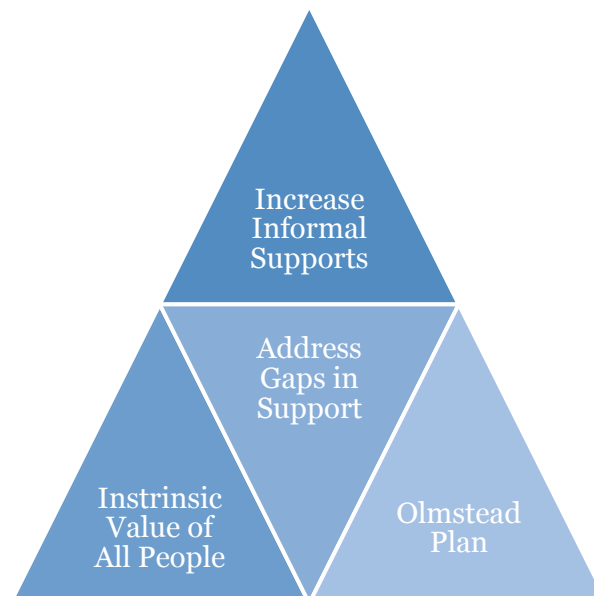
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The goal of the Dakota and Ramsey County Autism Grant was to increase community support for people with autism or related conditions and their families. To accomplish this, the grant team engaged a variety of stakeholders to understand what was already working well, leverage existing community expertise, and lend support to community-led efforts to increase capacity and sustainability. The ability to unite and succeed together as a community shaped the ASD grant from design and implementation to sustained programs. The efforts by so many have shown the strength in community-based programs, inclusion, and asset-based planning.

The Center for Disease Control and Prevention (CDC) estimates that 1 in 59 children in the United States have autism (2018).<sup>2</sup> The same study estimates the local (Minneapolis and St. Paul) prevalence of autism as 1 in 42, a rate higher than the national average. Given increased prevalence, as well as feedback from families about a lack of available support, the Minnesota Legislature appropriated funds in 2015 to address gaps in services for people with autism and similar support needs. As part of this initiative, the Minnesota Department of Human Services (DHS) awarded Dakota and Ramsey County a two-year grant in 2016 to accomplish the following objectives:

- Increase respite and community inclusion for people with autism and their families
- Train service providers on autism and methods of support
- Strengthen informal networks (friends, neighbors, etc.) for people with autism
- Develop a sustainability plan to ensure lasting impact of grant activities

Dakota and Ramsey County developed a work plan grounded in the belief that respite can be provided to caregivers by increasing community inclusion of people with autism. This concept reflects the intrinsic value of all people and provides a practical path for Minnesota's Olmstead vision of inclusion for all. By focusing on inclusion, the project also sought to address gaps in current supports and reduce stress on formal systems through more informal supports.




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<sup>2</sup> Baio, J. et al.

# PROJECT DESIGN

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The ASD Grant team spent the first several months of the project conducting listening sessions with various stakeholders to identify existing strengths and opportunities to better support people with autism and their families. Themes developed from these listening sessions served as the foundation for the work plan that guided the remainder of the project.



Based on listening sessions with 237 stakeholders - including people with autism, family members and professionals - **three primary opportunities** were identified to expand support for people with autism and caregivers.

**1**

**TRAINING**

Training opportunities for caregivers, community members, and organizations to expand knowledge and increase capacity to support people with autism and similar support needs. A total of 64 trainings were hosted reaching more than 2,000 individuals.

**2**

**FAMILY GRANTS**

Small grants for families to address system gaps, increase access for those not receiving support, and encourage self-direction to accomplish community inclusion and respite. The grant team approved 120 Family Grants.

**3**

**SERVICE DEVELOPMENT**

Service development partnerships to promote community inclusion and respite. In total, 10 organizations were awarded funding for new programs that served more than 220 individuals and families.

# PROJECT FINDINGS AND DATA

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Throughout the ASD Grant, the grant team gathered data and feedback from participants and partners to support the evaluation of the project. This included surveys of grant participants and training attendees, regular reports from partner organizations on successes and lessons learned, and follow-up listening sessions with stakeholders to add context to the data gathered. Below is a summary of what the grant team learned through that process related to the three core grant activities.

## Provider and Family Trainings

Trainings were conducted at a variety of locations and were often the result of engagement with community organizations seeking to expand their knowledge of autism and related topics. Trainings were provided by key partner organizations and were adapted to meet the needs of each specific audience, ranging from members of local faith communities to staff at the YMCA.

*“Wonderful/practical content that can be applied easily. [The presenter] was well spoken and easy to understand. Loved the way he answered questions with such practical advice.”*

- Training attendee

Training attendees were asked to complete evaluations following each session to provide feedback on the relevance of the information. Each training topic had a tailored survey, aimed at evaluating the key points of the sessions and key findings are summarized on page 6. In addition, attendees provided information on their role in supporting people with autism or related conditions and their families so that the grant team could track the reach of trainings.

- Over the two-year grant, 2,212 individuals attended 64 trainings
  - 1,174 providers of informal supports – family, friends, neighbors, community members at-large, etc.
  - 562 staff at traditional service providers – licensed support services, educators, etc.
  - 476 county employees

### How will you use the information shared today?

*“To affirm and support students and family at preschool level.”*

*“Definitely it will help me to treat people with ASD with respect or to feel welcome in the library.”*

*“It inspired me to be more vocal to clarify misconceptions among my various circles.”*



## Overview and Reach of Trainings



The Autism Society of Minnesota (AuSM) provided training to more than 390 individuals on autism and positive support strategies. In surveys, 95% of respondents ( $n = 285$ ) said the content was relevant to their role.

The Minnesota Organization on Fetal Alcohol Syndrome (MOFAS) provided training to more than 1,000 individuals, families, and professionals on Fetal Alcohol Spectrum Disorder (FASD) and strategies for supporting people with FASD. In surveys, 95% of respondents ( $n = 402$ ) said their skills were improved as a result of the training.



The Down Syndrome Association of Minnesota developed a 4-part, web-based training series for caregivers and professionals on supporting people with a dual Down Syndrome and autism diagnosis. More than 450 people participated in these trainings. Based on evaluations, 90% of respondents ( $n = 41$ ) reported the content was relevant for their life and work.



The Arc Minnesota facilitated workshops for over 100 individuals, families, and professionals on strategies for developing informal supports. On a feedback form, 94% of respondents ( $n = 63$ ) stated that they were more confident in their ability “to make community connections as a result of the training.

Isuroon, a nonprofit serving the Somali community, hosted trainings on Somali culture and how community service providers can best serve Somali families. More than 240 people attended these trainings and, based on evaluations, 83% of respondents ( $n = 132$ ) agreed that the content would improve their work with the community.



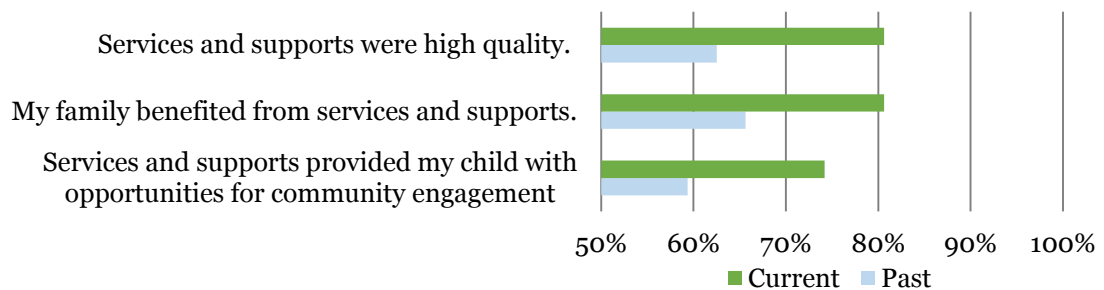
## Family Grants

A primary focus of the ASD Grant was to assist families who are not receiving formal county or state services, or are in need of services not reimbursable through traditional programs. Modeled after self-directed programs, the grant team created a simple grant application form that asked individuals and families to define what supports would work best for them. The family grant application was open to residents of both Dakota and Ramsey County and available online, in-person, and via email. Applications were reviewed by a team of Dakota and Ramsey County staff to ensure alignment with grant goals and approved on that basis. In total, more than 120 families were awarded grants, ranging in size from \$500 to \$3,000. Below are some examples of ways grant funds were utilized to support community inclusion and respite:

- To hire friends, family, or neighbors as support staff to provide in-home or community-based support
- To pay fees for adaptive recreation or community education activities, such as swimming, karate lessons, etc.
- To pay for camps or overnight activities that include people with disabilities and provide caregivers a break
- To purchase communication devices or applications that support greater community inclusion and respite

Grant recipients were asked to complete a survey to report on how their experience with the grant compared to previous supports utilized. As Figure 1 demonstrates, people consistently reported higher satisfaction with support received through the grant than previous supports.

Figure 1:  
Percent of Respondents Who Strongly Agree or Agree ( $n = 33$ )



### Family Grant Recipient Feedback:

*“Our daughter has become more verbal and expressive with other peers her own age.”*

*“This was our first time using it and what a difference this relief has made in our lives.... I don't know how we will cope without this help.”*

*“This was tremendous relief for our family...the driving back and forth for these activities was killing our family balance.... We were struggling and [the grant] helped with our quality of life tremendously and also helped [the person with ASD] significantly.”*

## Service Development Partnerships

The ASD Grant allowed Dakota and Ramsey Counties to partner with several community organizations to develop and expand programs that support people with autism and their families. In February of 2017, the grant team accepted proposals from community organizations interested in partnering on new programs that support respite by providing community inclusion opportunities. In total, 10 organizations were selected for contracts, ranging from \$1,000 to \$75,000. The resulting partnerships served more than 220 unique families and demonstrated several new and innovative approaches to respite and community inclusion.

Service recipients stated **100%** of the time they **agreed or strongly agreed** that the services provided **benefitted their family**, were **high quality**, provided **opportunities for community engagement**, and that the recipient **enjoyed and made friends** as a result of these opportunities.

### New community opportunities

Service recipients stated more than **90%** of the time they **agreed or strongly agreed** that the service helped build a **network of informal supports** and **allowed the recipient to participate in the community.**

Several service development partnerships focused on programs that encouraged people with autism and similar support needs to participate in their community alongside their neurotypical peers. The value of these opportunities centered on an event or environment built with inclusion at the core while having a secondary benefit of allowing primary caregivers a short break.

“Great respite time for our family. Our son got social, communication, and self-care assistance.”  
-Family Caregiver

“The caregivers truly care about the well-being of our son, creating opportunities for him to be a valuable part of this community.”  
-Family Caregiver

### Building informal networks

Other service development partnerships focused on providing assistance to individuals with ASD and their families to build informal support networks. This was accomplished through person-centered planning, a process of mapping out resources and opportunities within a person’s network and community, and identifying opportunities based on their own unique strengths and interests.



## Overview and Reach of Partnerships



Trinity Church hosted monthly “Parents Night Out” on Friday evenings. Events include sensory-friendly activities, and 49 children with autism attended an event.



AuSM partnered with Dakota County Library and the Minnesota Zoo to host learning experiences inclusive of people with autism, reaching 21 individuals.



The TAP is an inclusive social gathering space for people with and without disabilities. An estimated 60 youth and young adults with disabilities attended an event or social club.



St. David's supports young people to explore their community through fun and engaging activities, such as trips to museums and sporting events, while providing a short break for caregivers. 9 young people with autism participated in events.



Autism Works facilitated person-centered planning and community mapping for 3 people and families, expanding their informal network of support.



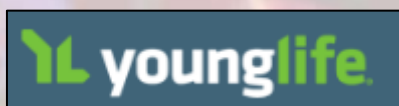
MOFAS provided individual and group mentoring opportunities for 15 youth with FASD interested in STEM careers.



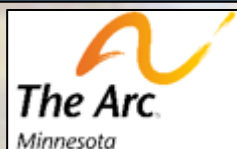
Isuroon facilitated a support group for Somali parents of kids and adults with autism, helping 27 parents find resources and develop a network of support.



Twin Cities Dream Team served 9 families through person-centered planning and helping build circles of support.



Young Life Capernaum paired individuals with ASD and neurotypical peers for social events and a summer camp, reaching 39 individuals with ASD.



The Arc facilitated person-centered planning and helped 3 families develop a circle of support.

# SUCCESS STORIES

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## *Increasing Informal Support...*

### **Bethlehem's story**

Bethlehem is an intelligent, imaginative young woman who lives with her mother in Eagan. Betty, as she's known to her family, loves to paint and especially enjoys painting animals and nature scenes. She is also on the autism spectrum, which can make social situations and friendship more difficult. Until recently, Betty didn't speak much and was often misunderstood as not having much to contribute to people around her.

Betty and her mother moved to Minnesota from Ethiopia in 2016 and immediately began looking for support. They learned of Dakota County's ASD Family Grant program through a family friend, and Betty's mother applied. Betty was awarded funding to pay for a number of community activities, including karate lessons, swimming at the YMCA, and a math tutoring group.

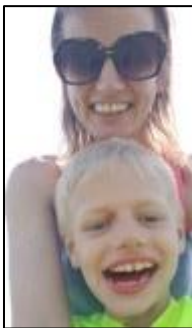


*Original artwork by Bethlehem entitled "Tropical Sunset"*

These activities helped Betty feel more confident and gave others opportunities to see her strengths, rather than her diagnosis. They also provided Betty's mother with a short break from the demands of caregiving, allowing her time to go to the gym or take a nap while knowing her daughter was enjoying herself in a safe and supportive environment.

Betty's mother also participated in a grant-sponsored workshop for families on how to expand their circles of support. Led by The Arc and Dr. Angela Amado from the University of Minnesota, the workshop encouraged Betty's mother to embrace this concept and has since established a number of new connections, including pairing Betty with a student mentor and finding classmates who invite Betty to join them at lunch.

Betty is developing friendships through these connections, leading to more social opportunities outside of school and planned activities. As her confidence has grown, so have her communication skills and relationships. Betty and her mother are excited about the future and finding more ways she can contribute to others.



### **Sterling's Story**

Sterling is a 7-year-old boy who loves running, swinging, and watching NASCAR. He is on the autism spectrum and moved with his family from Wisconsin to Apple Valley in 2017. After the move, Sterling's mother began looking for community opportunities where Sterling would be welcomed and she could get a short break from caregiving. An online search turned up Trinity Church's *Parents' Night Out* program in Lakeville, and they decided to give it a try.

*Pictured: Sterling with his mother, Kristen*

*Parents' Night Out* is a monthly program where parents can drop their kids off and spend a Friday evening doing whatever they choose. Kids of all abilities participate in a variety of sensory learning experiences, including games, stories and videos. Prior to partnering with the ASD Grant, Trinity had limited capacity to support children with autism during Friday events. Through the grant, Trinity received funding to purchase sensory equipment and training for program volunteers on supporting people with autism.

Sterling and his mother were immediately impressed. Trinity volunteers were kind and accepting of Sterling; they took time to ask questions about his interests and support needs to ensure his time with them would be safe and enjoyable. Sterling loved the sensory-friendly environment at Trinity, including kinetic sand, a sensory swing, and open space where he could run off some of his energy. This helped his mother feel confident Sterling was in good hands for a few hours so she could run errands and take care of other life demands.

Sterling is now a regular attendee of *Parents' Night Out*. He talks about the people he sees there and looks forward to each event. Sterling has made friends with other kids who attend and gotten together for playdates outside of the monthly program. His mother has been amazed to see Sterling develop relationships and be accepted by others, while enjoying a short break herself. “[Trinity] really understands where Sterling is coming from. They don’t treat him like a burden, but just like a cool kid.”

## ***Practicing ‘Olmstead’...***

### **Partnership with Dakota County Library**

In July 2017, Dakota County Library and the ASD Grant conducted an online survey and series of focus groups to gather community input on how Library programs could best include people with autism. A total of 156 people responded to the survey, and 17 participated in a focus group, including parents, self-advocates, educators, and other professionals that support people with autism. Overall, participants saw Dakota County Library as a trusted, safe, and welcoming space for people with autism and their families. They also suggested ways the Library could be more inclusive, such as providing training for staff on autism, offering more sensory-friendly programs and rethinking Library spaces to better accommodate the needs of people with autism or similar support needs.



Since the survey and focus groups, Dakota County Library has taken several steps to actively include people with autism and their families. The Library has partnered with the Autism Society of Minnesota to facilitate a monthly Book Club for adults with autism and other interested individuals, began offering Sensory-Friendly Saturday programs for children of all abilities, and hosted educational opportunities for the public to learn more about autism. With support from the ASD Grant, Dakota County Library has also partnered with the Autism Society to provide a series of “ASD 101” workshops for Library staff. During these trainings, staff members received an overview of autism spectrum disorder, learned communication strategies for people with ASD, and gathered ideas about



making programs and customer service more welcoming to people with ASD. As a result, 72 Dakota County Library staff members increased their awareness of ASD and are better equipped to support inclusion.



Partnering with the ASD Grant better equipped Dakota County Library to act on its values of providing positive and welcoming experiences and acting inclusively, valuing and respecting differences. While the ASD Grant is ending, Dakota County Library plans to continue this work through an “Innovations Grant” recently awarded by the Minnesota Department of Human Services. The Innovations Grant will fund development of programs and training that support inclusion, as well furnishing calming rooms for people with autism and others who benefit from quiet spaces in three locations. This partnership demonstrates what is possible when a community organization dedicated to inclusion receives additional resources to boost their efforts.

*Pictured: Library staff participate in “ASD 101” training led by the Autism Society of MN*

## ***Addressing Gaps in Support...***

### **Partnership with Isuroon**

Isuroon is a nonprofit organization focused on addressing the unmet health needs of Somali women. Through this work, the organization has often come into contact with Somali families of children with autism struggling to find support. In May 2017, Isuroon began partnering with the ASD Grant to lend more support to these families. They formed a support group to offer regular educational opportunities for Somali families, as well as connect them with others who shared a common experience. The ASD Grant provided Isuroon funding to plan and facilitate support group meetings and arranged in-depth training for Isuroon staff on autism and support strategies.



Parents – many of whom reported feeling isolated and disconnected – started attending monthly meetings to learn about autism and available resources and developed friendships with others in the group. One mother is the single parent of seven children, three who are diagnosed with autism. Her children require a lot of support, and this makes maintaining employment and housing even more challenging. She had never considered the possibility of getting a break from caregiving and said, “The only way I could rest is if I were arrested and put in jail.” Yet she

kept coming back to meetings and was eventually supported by Isuroon staff to apply for county services for her children. She was able to hire a family friend as a support staff and

now regularly visits Isuroon to greet team members and socialize. She says these visits are respite and allow her to maintain good mental health.

Looking forward, this mother wants to find permanent housing for herself and her children and get her driver's license so she is more mobile. Isuroon is helping to connect her with resources to pursue these goals. The organization plans to continue supporting these families after the ASD Grant ends. They have secured grant funds from other sources and are exploring providing similar support services through established disability services programs. Isuroon represents a great example of an organization that serves the broader community acting deliberately to include people with autism and their families. The ASD Grant provided essential resources to support them in that effort.

### **Larissa's Story**

Larissa is a funny and outgoing young woman who lives with her family in Rosemount. She is a natural entertainer who carries herself with a positivity that lifts other people. But she hasn't always been that way. Larissa is on the autism spectrum and until recently struggled in social situations and feeling comfortable around others.

In the summer of 2017, one of Larissa's teachers recommended she begin working with a Community Connector, a new support offered through the ASD Grant to help young people explore their interests and build relationships. Larissa agreed and was soon visiting community places where others shared her eclectic interests in skateboarding, gaming, and building things. She and her Community Connector started going to a skate park near Larissa's home, and she soon became a regular there, learning to skateboard and meeting friends. They toured a local technical college to learn more about trades that involve building and Larissa was fascinated by welding. After trying it herself, Larissa is considering enrolling in a welding program and pursuing it as a career.

These experiences motivated Larissa to strive for greater independence. In the fall of 2017, she was awarded ASD Grant funding to pay for driving lessons and get her driver's license. Larissa will be completing lessons soon and plans to take her driver's test in the coming months. Her mom speaks of the changes she's seen in Larissa, "She's more confident and positive. She's really started coming out of her shell and has become more independent, which gives me a break from having to do everything."



*Pictured: Larissa in her "M" jacket, for Michael Jackson*

Others have started taking notice too. Some of Larissa's teachers have started encouraging her to consider a different professional – personal care assistant. Larissa says, "I would love to work with teens or adults – maybe helping people on the autism spectrum." With her contagious smile and dry wit, Larissa will make a positive impact on others no matter what she decides to do.



# GRANT LESSONS AND RECOMMENDATIONS

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## Flexibility Is Critical

Flexible funding helps people build supports that work for them and have lasting impact. In many cases, providing a small amount of financial support upfront prevents the need for more expensive crisis services in the future. It is recommended that county and state agencies consider ways to create more flexibility in how program funds intended to support people with disabilities are distributed. This may include relaxing eligibility requirements and streamlining approval processes to ensure funds are available more quickly and flexibly.

## Support Community Efforts

The grant team found abundant interest and energy among community members in doing more to support people with disabilities and their families. Resources are needed to transform this energy into increased community capacity. It is recommended that county and state agencies dedicate more funds to building capacity within organizations that serve the general public to better include people with disabilities in their programs and services. This community-centered approach is necessary to realize Minnesota's Olmstead vision.

## Need for Sustained Attention

System change takes time and cannot be accomplished in a 2-year funding cycle. For example, developing partnerships and trust with communities of color and underrepresented groups is needed over the long-term to create lasting change. It is recommended that county and state agencies re-evaluate procurement practices and provider requirements to emphasize equity and community-based supports for people with disabilities.

## Help Navigating the System

The system of formal supports for people with disabilities is very complex and many people struggle to navigate it. The grant coordinators acted as designated contacts for people with autism and families seeking county or state services, providing information and referral to various support programs where needed. This extra help was essential for many families, including those less familiar with disability services or experiencing additional barriers to access (language, poverty, etc.). It is recommended that county and state agencies invest in on-going staff positions that provide this type of navigation assistance to people with disabilities and their families.

## Sustaining the Work

The grant team is sharing lessons learned and recommendations with policymakers and stakeholders to inform future efforts.

Service Development Partners plan to continue offering new programs, though in many cases, sustainable funding is still needed.

The grant team, along with training partners, developed free learning modules and toolkits to support continued capacity building.

An "Innovations Group" made up of various stakeholders passionate about inclusion will continue meeting after the grant ends to keep advancing this work.