

MISSION POSSIBLE:

**Advancing Whole-Person Care by Employing
People with I/DD & Family Members
As Care Extenders**

- **Kelly Friedlander, MSW, MPA, Community Bridges**
- **Karen Luken, Disability and Health Consultant**





Mission Possible: Advancing Whole-Person Care By Employing People with I/DD And Family Members As Care Extenders

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Agenda

- Introductions
- Project Background
- Importance of Employing People with Lived Experiences
- Interview Summaries
- Recommendations
- Q & A

The full report and supplemental materials can be found at cb-cg.com/care-extenders

Nothing is Impossible

What this image shows us:

- The importance of Accommodations
 - harness, glasses
- The role of Technology
 - computer
- The need for Teamwork
 - communication, headset
- Evaluation
 - all those data points, what's essential?

**“Nothing is impossible
if you have the strongest will”**



Project Background

In April 2022, The North Carolina DHHS published a new waiver service definition: **Care Extenders**

Care Extenders will:

- Be a member of multi-care managers in de
- Perform activities services and appoin promotion

Care Extenders can be:

- Be a person with lived experience with an I/DD or a TBI
- A parent or guardian of an individual with an I/DD or a TBI or a behavioral health condition

Creates a pivotal opportunity to advance paid, professional **family navigation** and **peer support** in the I/DD service system



Vignettes

Individuals with I/DD Serving as Care Extenders

“Can I Get a Ride?”

An adult with I/DD living in rural Madison County is unable to access the medical care they need because of a lack of providers in their small rural county and limited access to transportation. As a Care Extender, I would educate them on how to access Medicaid transportation in their home county. Steps could include identifying potential community resources, helping them make the initial phone call, and setting up the practice ride with them. I would also discuss who else might be available to assist with their need for transportation. I would check back after the scheduled transportation appointment to see how it worked out. I would keep the care management team informed of the goal, resources used, and outcome. I would check back with the individual at an agreed-upon time to see if the transportation is still working for them and if they have been able to access the needed medical care.



Care Extender Role	Addressing health-related resource needs, resource identification, community outreach, tracking referrals to obtain community services
Required Training	Goal setting, motivational interviewing, person-centered principles, documentation
Outcome	Accessing needed health care in a timely manner and within the member’s community. Promoting independence in meeting ongoing health needs. Increased use of community resources

“I just feel really alone.”

A family member feels isolated and has many questions about her child’s diagnosis and what to expect as he enters school. I would provide examples of family support activities in our area and explain the potential benefits of talking with others who share similar experiences. I would help the family member identify their skills and life experiences that could be helpful to others. I would help them locate potential groups and training in their community. I would help them find available webinars and other resources. I would offer to introduce them to another family member. I would keep the care management team informed of the goal, resources, and outcome. I would check back with the individual at agreed times to see how things are going for their child and the family and what other needs they have identified.



Care Extender Role

Outreach and engagement, identifying family short-term and long-term needs, connecting with community resources, tracking referrals, connecting with other community members

Required Training

Goal setting, motivational interviewing. Documentation. Information sharing with the care manager.

Outcome

Use of community resources. Increased member/family independence. Decreased family stress.



Interview with Project Team Member:
Jade McWilliams
(they/them/theirs)



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The Importance Of Lived Experience In Achieving Whole Person Care for the Member

We believe that family navigation & peer support can have a role in **achieving value, whole-health outcomes** for people with I/DD receiving Care Management services.

The value of Peer Support for others behavioral health populations has been well researched and documented.

Peer support:

Improves quality of life measures

Improves engagement and satisfaction with services and supports

Improves whole health, including chronic conditions

Decreases hospitalizations and inpatient days

Reduces the overall cost of services



Emerging National Trend: Medicaid -Funded Peer Support Programs for Individuals with I/DD

- States are increasingly covering peer support providers as a distinct provider type.
- The Center for Medicaid and Medicare Services (CMS) recognizes that the experiences of peer support providers can be an important component in delivery of effective treatment.
- CMS has repeatedly reaffirmed its commitment to State flexibility, increased innovation, consumer choice, self-direction, recovery, and consumer protection through approval of these services.

I/DD Peer Support Programs are currently in:

- Michigan
- Philadelphia County, PA
- Tennessee
- Texas

I/DD Family Peer Support Programs currently in:

- Michigan
- Tennessee





Interview with Project Team Member: Sheron Mosby (she/her)



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The Process & Goals

The North Carolina Council on Developmental Disabilities (NCCDD) funded Community Bridges to research and write a Care Extender Research Paper. The focus was...

- **Strategic recommendations, focusing on scalability and sustainability.**
- **Identification of policies** that support and limit family navigation and peer support in the Care Extender definition.
- Identification of changes in practices that **promote statewide adoption of family and I/DD peers** as Care Extenders.
- Vignettes that illustrate the role that family navigation and peer support can have in **achieving valued outcomes** and how they **align with value-based care and reimbursement.**



Our Questions of Focus



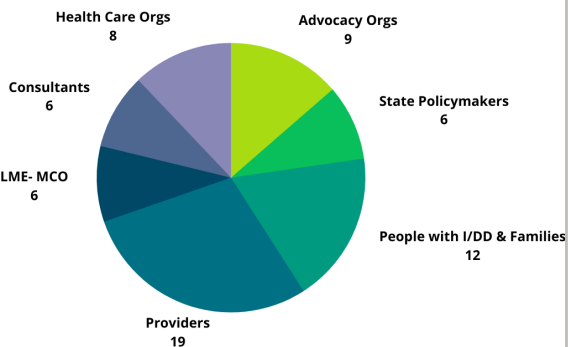
- **Policy:** What policies may hinder the success of Care Extenders with I/DD and family members? What should be done?
- **Practice:** What programs, procedures, and techniques will **advance whole-person care and result in the best outcomes for the member** and the state? What should be done?
- **People:** How can people advance policies and practices **that support whole-person care** by employing persons with I/DD and family members as Care Extenders?



The Steps

Our interviewees have over 1,250 years of experience in the behavioral health field

Types of Stakeholders Interviewed



- Hire project team members
 - Sheron Mosby (she/her)
 - Jade McWilliams (they/them)
- Recruited a diverse Advisory Group
- Environmental scan
- Conducted **66** information-gathering Interviews
 - The interview selection process was designed to gather information and perspectives from a diverse group of individuals with lived experience, professional roles, race and ethnicity, and geographic locations
 - North Carolina & national participants



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**Successful
Implementation of
Care Extenders with
Lived Experience will
require attention to...**



What We Heard:

Recruitment and Hiring

"I am worried people with I/DD won't be prioritized in hiring. Not due to ill will, just because people are trying to get things done." – Advocacy Organization

"Just having lived experience isn't enough to do the work. It allows connection and perspective, but a candidate will still need training and supervision, because it's hard." – I/DD Provider

"Treat me as a regular employee. Help me navigate the onboarding process." - Person with I/DD

"(I'd) rather see fewer people (be hired) and go through training who are qualified and motivated instead of mass adoption for the sake of adoption." – Provider

"This is a great chance to think creatively and include a real population that's rich in knowledge like this. This could be great for so many people." – Family Member





What We Learned: Recruitment and Hiring

Recruitment and hiring will require **creativity and commitment**. Employers need to go beyond the “usual suspects” and sources for qualified and interested candidates.

Job flexibility will be necessary.

Hiring will start slowly and evolve as Care Management and Tailored Plans launch.

An **inclusive, equitable workplace** that reflects the members and communities served will require an intentional recruitment and hiring plan with input from targeted constituents.

What We Heard: Employment Realities

*"I want to work and come off benefits, but I **don't want to lose my benefits all at once.**" – Person with I/DD*

*"People with I/DD know how hard it is to get a seat in the room; **it can feel really fragile.**" – Person with I/DD*

*"Make sure the Care Extender has **support to avoid burnout.**" – Care Management Agency*

*"The thing with the Care Extenders that worries me is that **you're probably going to have more parents (and maybe DSPs and other professional types)** before they get to us [meaning people with IDD] because, in my mind, **they're going to be easier hires,** because they come with less accommodation needs." – Person with I/DD*

*"It's hard to get and keep a **job that matches the needs of my child.** It takes time to find a trustworthy caregiver and have them and my son get adjusted." – Family Member*





Interview with Project Team Member:

Sheron Mosby

(she/her)



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Interview with Project Team Member: Jade McWilliams (they/them/theirs)



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What We Learned: Employment Realities



Competent, accessible **benefits counseling** will be critical for PWIDD and families to ensure Care Extenders are not at risk of losing essential benefits or having payback situations.

Training on the **Americans with Disabilities Act** job accommodations and real-time guidance on **reasonable job accommodations** for employees, the supervisor, and HR will be critical.

Alignment of a PWIDD's and Family Care Extender role with their **life situation** needs to be considered so they can balance life situation, self-care, and their services.

Lack of a **driver's license** or access to a car would pose a major barrier for people with I/DD to become potential Care Extender team members.

Managing self-care is a priority that must be addressed by employees, supervisors, and hiring organizations. Care Extenders provided with adequate support will be more effective in their positions.

What We Heard: Training

*"As the system evolves, **explore the development of a credential**, like BH peer support specialists and community health workers." – Person with I/DD*

*"Have a **clear job description**. Train to the job description." – Health Care Provider*

*"Training should be **vetted by folks who are in the field who have this lived experience**. I think that's the best chance of making sure it is accessible." – Family Member*

*"Training should be the same for all team members, **don't set up a separate system**." – I/DD Provider*

*"Consistency across the state is needed. Maybe core training and then supplemental by region to ensure it is **locally and culturally relevant**." – Multiple Interviewees*





What We Learned:

Training

Lived experience is essential for **relevant training** and setting the stage for the Care Extender as a valued team member.

Focus on **employee engagement, support, and success** through training and coaching.

Candidates will have different ways of learning or understanding new information. Training and supervision needs to accommodate diverse learning styles: **Visual, Auditory, Read/Write, and Kinaesthetic**.

Training needs to be relevant to the job role and tasks. There is a “fire hose” of information related to “the system”; not all of it is necessary for the Member or Care Extender. The training a Care Extender needs to do their job day-to-day differs from high-level training on Medicaid Transformation and Tailored Plans.

With so much system change underway, there will be a need for organizational proponents of Care Extenders with lived experience to **champion** their recruitment, onboarding and retention in Care Management Agencies.

What We Heard:

Team Role & Supervision

*"We need to give Care Extenders **space to prove their competence** in a realistic timeframe. Allow opportunities and time for Care Extenders to execute good work. Don't give up too quickly." – I/DD Provider*

*"The Care Extender has got to be an **equal voice** at the table and someone who really helps to drive a conversation." – Advocacy Organization*

*"How do we share **power**?" – Family Member*

*"Shape the Care Extender position using the **individual's lived experience and knowledge**." – CMA Supervisor*

*"Our goal is for this to be a successful role: meaningful, has richness, **connection**." – DHHS Official*

*"I've been in the system 31 years; I have lived experience. Don't treat me as a child, treat me as an equal." – **Person with I/DD***





Interview with Project Team Member:

Jade McWilliams

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What We Learned:

Team Role & Supervision

Success will require that Care Extenders are treated as a **valued team member** on the Care Management Team.

Open and effective communication within the Care Management team and organization is critical.

Allow for **creativity and diverse Care Extender roles** that meet member needs and maximize a Care Extender's lived experience and expertise.

Develop opportunities for **peer mentoring and support and collaborative learning**.

What We Heard: Implementation

*"It is harder to **start** than to improve." - LME MCO /Tailored Plan*

*"The ideal would be to have **a peer and family member on the same team** to get both perspectives." - Family Member*

*"Community providers will **need to be educated** about what Care Extenders can offer."
- Medical Provider*

*"How do we make this service change **not a disruption** to the person's life?" - Person with I/DD*

*"Don't want the state to be too restrictive in the beginning; we need to be able to create, experiment, etc., **allow people to pivot. Give us the ability to experiment.**" – I/DD Provider and CMA*

*"Care Management team caseloads are a concern. Need to **balance business models and human service models.**" – I/DD Provider and CMA*

*"Some of the things you might want to do **puts you at more risk** when the dollars just aren't there, even if it's the right thing to do." – I/DD Provider and CMA*

"What comes up in those spaces where people feel safe for the first time, does not (always) come up in the service definition." – I/DD Provider



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What we learned:

Implementation



The Care Management and Tailored Plan launch will be an **ongoing process** with confusion and tension among members, families, and providers. It is necessary to acknowledge that **progress will evolve and occur over time.**

Need for **continual pressure** on the system to focus on the Care Extender service and its outcomes, in the midst of overwhelming changes.

Care Management Agencies and Tailored Plans will need to recruit **diverse providers** that reflect the communities and members they serve. It will take **time to build the capacity** to meet the needs of all the members.



What we heard:

Evaluation

*"Tailored Plans are not going to pay for important things to be addressed unless we have **data to prove their importance.**" – I/DD Provider*

*"There are only so many things a practice can measure. **Limit to what matters the most.** Focus on a few things at a time." - Healthcare Provider*

*"If someone declines an intervention, Care Extender shouldn't be penalized. **Be careful about an over-emphasis on numbers** (numbers of contacts required). Allow members to say no." – State Policymaker*

*"The first goal should be centering the potential for self-determined goal setting. What does thriving look like to you? A successful life as defined by the individual." - **Person with I/DD***



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What we learned :

Evaluation

Clarity about intended and valued **outcome measures** relevant for the member and family that are feasible for Care Management Teams and Care Extenders

Care Management providers will need to **balance and align** person-centered practices with the requirements of multiple reporting and oversight systems.

Dedicating time, resources, and expertise to the evaluation of this new service in the midst of overwhelming changes.

A **sense of urgency** about **data collection, analysis, and reporting** to inform the state, providers, payors, members, and General Assembly how Care Extenders contribute to valued outcomes.



Interview with Project Team Member:

Sheron Mosby

(she/her)



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Recommendations for Next Steps...

1

Assemble a **stakeholder group** to focus on quality improvement efforts for the Care Extender role. Review data and set priorities for improvement.

2

Gather data to help inform the priorities for improvement. Once data is collected, performance measures that represent the primary goals for the Care Extender service can be identified. Modify Care Extender role and business systems as necessary.

3

Incorporate data collected, ideas for improvement, and evaluating the changes' effects. Continuously improve performance and maintain changes.

4

Review of **clinical and person-centered outcomes** and making adjustments for continued improvement.



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***“Be brave enough...
Take a chance on us”***

Your Personal Action Plan

In the next month I will ...

1. Identify potential champions in your organization you are affiliated with
2. Provide them with information on Care Extenders and why your organization would benefit from hiring some with Lived Experience
3. Establish goals!

By October 1st, my organization will

_____.

By the end of the year, my organization will

_____.

4. Schedule time to reconvene on internal efforts, reflect, add revise goals



Call To Action

Care Extenders Advocacy Action Plan



North Carolina has an unprecedented opportunity to ensure that individuals with I/DD and family members are employed and serving within Care Management Teams as Care Extenders to advance whole-person health.

DATE: _____

My Goal: Educate and advocate within my network to ensure the successful employment and deployment of this new Care Extender (CE) role to serve members in achieving their whole-person health goals.

Identify Champions	Organization I Engage With:	Leaders I Engage With:
	_____	_____
	_____	_____
	_____	_____

Get & Provide Information on Care Extenders	Goals
	<ul style="list-style-type: none">• Number of Care Extenders (CE) hired: ____• How many Care Extenders are people with I/DD: ____• Number of Care Extenders who are family members of people with I/DD: ____• Discuss the benefits of having PWIDD and Family Members as Care Extenders.• Send them the Care Extender Paper.• Request a meeting: ____/____/____ with _____

Establish Goals	Timeline
	By ____ months my organization will _____
	Within 12 months, my organization will _____

Schedule Time To Reconvene, & Revise Goals	Meeting Details
	We will meet on ____/____/____ at _____
	Who will attend: _____

More information can be found at cb-cg.com/care-extenders

Questions? Thoughts? Ideas?

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