



MISSION POSSIBLE:

Advancing Whole Person Care by Employing People with I/DD & Family Members as Care Extenders

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Researched & Written by Community Bridges



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Introduction

Project Background

In April 2022, The North Carolina Department of Health and Human Services (DHHS) published a new waiver service definition: Care Extenders. The Care Extender position will be part of the multidisciplinary care team and support care managers in delivering Tailored Care Management by performing activities with members such as coordinating services and appointments, accessing care, and health promotion. This new service definition includes the incorporation of people with **lived experience** and their family members into a paid service and presents a unique opportunity to advance Family Navigation and Peer Support Services for people with I/DD in North Carolina. See the Appendices for the NC DHHS Guidance document.

While the proposed Care Extender service definition creates a **pivotal opportunity to advance paid, professional family navigation and peer support in the I/DD service system**, it has come at a challenging time. The I/DD, Behavioral Health, and Medicaid service delivery systems are undergoing a seismic shift as they transition from the current LME-MCO and fee-for-service physical health model to the NC Medicaid Managed Care Behavioral Health and Intellectual/ Developmental Disabilities Tailored Plan on April 1, 2023.

This report includes:

- **Strategic recommendations** for short-term and long-term implementation and growth of family navigation and peer support in the proposed Care Extender definition, **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 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.**

"Without lived experience, not only can we not understand what a person has been through, we simply cannot judge them by the same standards we judge ourselves...When we judge others by the same standards, we use to judge ourselves, we are, in essence, saying, "only my experience matters and not yours."

- Aditi Subramaniam, Ph.D.

Funder

The [North Carolina Council on Developmental Disabilities](#) (NCCDD) funded [Community Bridges](#) to develop a Care Extender White Paper that summarizes the perspectives of families, individuals with I/DD, LME MCOs, DD Providers, policymakers, and healthcare providers AND identifies strategic recommendations to address potential challenges that could impact success. The project time period was June through October 2022.

The Project Team

Kelly Friedlander

MSW, MPA, (she/her/hers) has worked in the intellectual and developmental disabilities field for over 15 years and consults primarily around stakeholder engagement, advocacy, and managed long-term supports and services. In North Carolina, she worked on stakeholder engagement and policy analysis projects for clients such as the National Association of State Directors of Developmental Disabilities Services, RHA Howell, the National Association of Councils on Developmental Disabilities, Vaya Health and UnitedHealthcare. Her specialty is convening and facilitating diverse work and advisory groups, with the goal of infusing individuals with IDD and their family members' voices into the public policymaking process.

Sheron Mosby

(she/her/hers) is the parent of two children with Autism. She became interested in learning more about systems of care when her oldest son was unable to obtain the services he needed. Sheron is committed to helping families in Northeastern NC access quality healthcare and reducing the barriers they face when trying to access specialty services and care in their rural communities.

Karen Luken

(she/her/hers) has more than 40 years of experience in disability and health consultation, recreational therapy practice, research, teaching, and grants management focused on integrated care, Medicaid managed care, access to healthcare and health promotion for persons with disability, accessible environments, and inclusive community services. Karen received her bachelor's degree in therapeutic recreation from the University of Illinois-Urbana, and her graduate degree in Recreation and Leisure Studies and certificate in public health from UNC-Chapel Hill.

Jade McWilliams

(they/them/theirs) is a multiple disabled activist, artist, and speaker in Western North Carolina. They focus on community organizing and education around the intersections of poverty, disability, queerness, and abuse. Jade began mentoring young neurodivergent people in 2013, and has continued working with them ever since. Jade serves as co-chair of IDDAC (IDD Action Coalition), which seeks to end the sexual exploitation of people with IDD. Jade has been honored with the following awards: The 2020 Essential Piece Award by Arms Around ASD; The 2021 Tzedek Impact Award; and The 2022 NC Tide Empowering Hope Award. Jade is currently working on becoming certified as a Mental Health Peer Support Specialist.

Words Matter

Person first language emphasizes the person before the disability, for example, "person who is blind" or "people with spinal cord injuries." Identity first language puts the disability first in the description, e.g., "disabled" or "autistic." Person first or identify first language is equally appropriate depending on personal preference. For this report, we have honored the preferred language of those who participated.

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Policies, Practices, People

To honor the lived experience of persons with I/DD and their families, meet the goals of Medicaid Transformation, and promote systems change, we have considered the following questions:

Policy

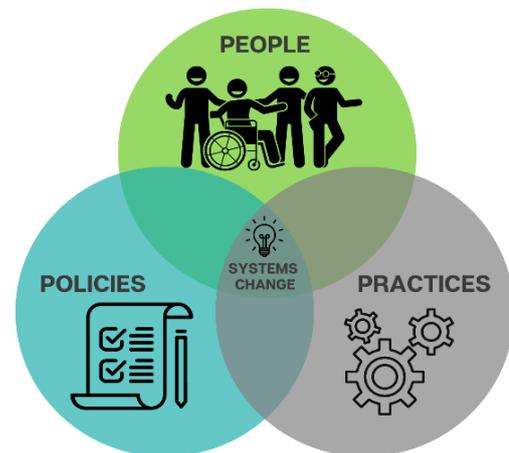
What policies may hinder the success of Care Extenders with I/DD and family members?
What should be done?

- Identify policies that hinder the role of Persons with I/DD and family members from being employed as Care Extenders.
- Identify policies that can be changed by Care Management Agencies and Tailored Plans.
- Identify policies that will require state-level action.
- Identify those supportive of identified policy changes.
- Identify those with authority to make requested changes.
- Offer example(s) of modified policy.

Practices

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?

- Identify practices that produce desired results for the member and the state.
- Develop a plan for how best practices can be shared and promoted across the state.
- Identify strategies that will incorporate these best practices into hiring, training, and evaluation.



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?

- Identify champions who promote the employment of people with I/DD and family as Care Extenders.
- Identify people and organizations that have reservations about the employment of people with I/DD and family as Care Extenders.
- Identify who has the authority to make needed policy changes on a state and organizational level.
- Develop a plan of action that ensures the voices of people with I/DD and their families are heard.
- Identify organizations that will assume leadership roles in training, evaluation, and information dissemination.

The Importance of Lived Experience

Using peers and individuals with lived experience is a key strategy for reducing personal and institutional stigma, and more state, federal, managed care and provider organizations are beginning to recognize the importance of having “experts by experience”¹. Research and experience show that the utilization of peer support has a transformative effect on both individuals and service systems. Peer support ²:



In addition, receiving peer support empowers people to make the best decisions for themselves and strive towards their community goals. Professionals with similar lived experience are especially suited to serve individuals who have behavioral health needs as well as complicated health issues as they:

- Offer hope through their own life example.
- Share strategies and skills to promote self-direction, community inclusion, and self-management of health conditions.
- Convey respect and empathy for the impact of the effects of intellectual and developmental disabilities on all aspects of life.
- Use their personal story consciously and deliberately in the service of helping another.

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

States are increasingly interested in covering peer support providers as a distinct provider type for the delivery of support services to Medicaid-eligible adults. The Center for Medicaid and Medicare Services (CMS) recognizes that the experiences of peer support providers- as consumers of behavioral health services- can be an important component in a state’s delivery of effective treatment. CMS has

¹ <https://www.sciencedirect.com/science/article/abs/pii/S0260691722000600>

² <https://www.mhanational.org/sites/default/files/Evidence%20for%20Peer%20Support%20May%202019.pdf>

repeatedly reaffirmed its commitment to State flexibility, increased innovation, consumer choice, self-direction, recovery, and consumer protection through approval of these services³. Below are some examples of CMS-approved and funded Peer support services that cover people with intellectual and developmental disabilities.

1. Examples of I/DD Peer Support Programs approved by The Center for Medicaid & Medicare Services (CMS):

Michigan	Philadelphia County, PA
<p>Peer Mentor candidates must complete the Michigan Developmental Disabilities Council’s training and a 90-hour internship in order to be certified. The Community Mental Health Service Provider (CMHSP)⁴ agency nominates individuals to attend the training and host graduates for a 90-hour internship in order to be certified. 62 certified peer mentors are employed at 11 Community Mental Health Service Providers (CMHSP).</p> <p>CMHSPs are the public provider of services for people with intellectual/developmental disabilities, serious mental illness, and/or substance use disorders in Michigan.</p>	<p>Community Autism Peer Specialists (CAPS) are adults with a diagnosis of autism and/or a co-occurring mental health diagnosis. Peer specialists take a 75-hour training course that includes a mixture of in-person classroom instruction, self-paced learning activities (homework), and field observations (potentially virtual) through job shadowing.</p> <p>Completion of this training allows graduates to qualify for future positions as Community Autism Peer Specialists (CAPS) with the Mental Health Partnerships in Philadelphia County. 35 individuals have graduated from the training program, and five have become employed as CAPS peer specialists.</p>
Tennessee	Texas
<p>The Employment and Community First CHOICES waiver provides a “Peer-to-Peer Support and Navigation for Person-Centered Planning, Self Direction, Integrated Employment/Self - Employment and Independent Living” services. In addition, Tennessee is looking to integrate peer mentoring formally into the MAPS program that will support Tennesseans with I/DD to create a vision for their lives and increase their independence at home, at work, and in the community. MAPs will provide services to:</p> <ul style="list-style-type: none"> Transition-age youth during their last three years of high school Individuals who have already left high school Individuals who are waiting for services from the CHOICES Waiver 	<p>The enhanced behavioral peer supports benefits within Texas’ STAR+PLUS Pilot program provides people with I/DD or similar functional limitations with access to peer support.</p> <p>The Association for Texas Advocates, a statewide advocacy group operated for and by adults with I/DD, is using Optum’s Peer Mentor Training Program curriculum to train their peer specialists.</p>

2. Examples of I/DD Family Peer Support Programs approved by Center for Medicaid & Medicare Services (CMS):

Michigan	Tennessee
<p>Michigan’s Parent Support Partner Project is a statewide initiative in partnership with the Michigan Department of Health and Human Services that provides Medicaid-reimbursable peer-to-peer parent support to eligible families.</p> <p>Through a Parent to Parent relationship, Certified Parent Support Partners (PSP) who have or have had a child with a serious emotional disturbance (SED) and/or I/DD will impart skills, ability, and knowledge while supporting the parent/ caregiver through their child’s treatment experience.</p> <p>The Association for Children’s Mental Health (ACMH) provides training, certification, and ongoing supervision and technical assistance for Michigan’s parent support partners. The curriculum consists of 5 days of classroom training with additional requirements of monthly coaching calls for 11 months and quarterly professional development activities⁵.</p>	<p>Family-to-Family Peer Support is covered within Tennessee Employment and Community First Choices Group 4 Essential Family Supports and Group 7 Intensive Behavioral Family-Centered Treatment, Stabilization and Supports. Services are designed to be flexible and responsive to individual or family needs.</p> <p>The program funds services and needs that are not covered by traditional resources. The program is funded by state dollars and designed to assist individuals with severe disabilities and their families to remain together in their homes and communities.</p>

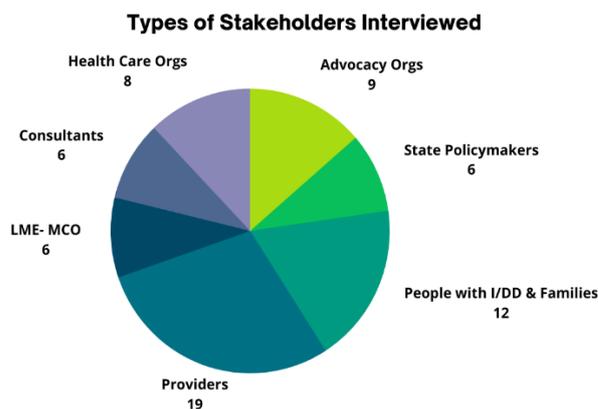
³ <https://www.medicaid.gov/federal-policy-guidance/downloads/SMD081507A.pdf>

⁴ <https://www.michigan.gov/mdhhs/keep-mi-healthy/mentalhealth/developmentaldisability/advocacy/Michigan-Peer-Mentor-Program>

⁵ <http://www.acmh-mi.org/get-information/acmh-projects/parent-support-partner-project>

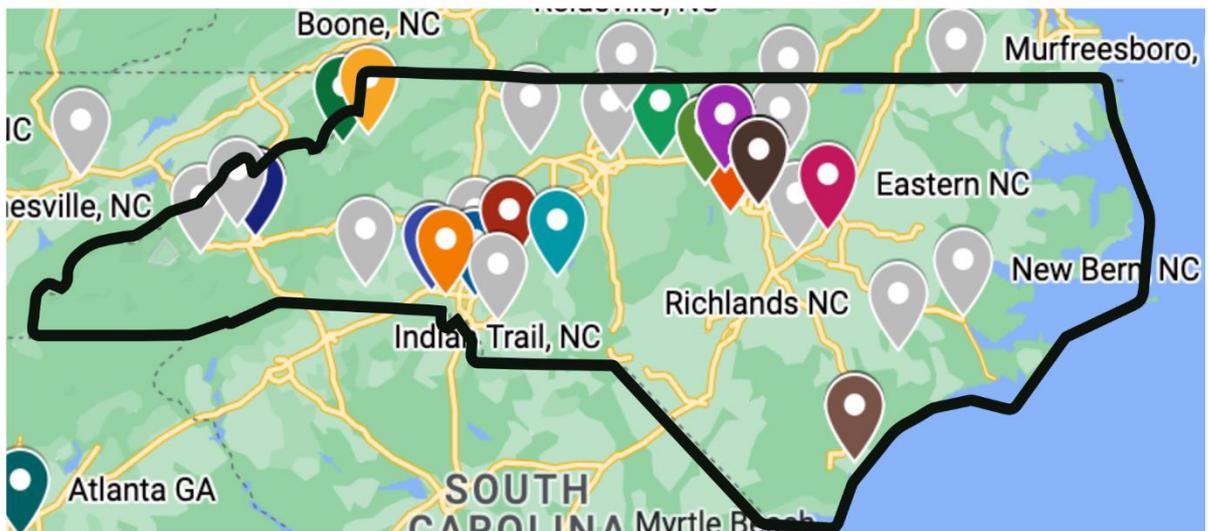
Key Project Activities

- Convened the Care Extender Advisory Group to provide feedback and guidance in the development of actionable strategies for the successful implementation of Care Extenders for the I/DD population. Three meetings were held in July and August, 2022. See the appendices for a list of Advisory Group members.
- Conducted information-gathering interviews with 66 individuals with I/DD, families, DD providers, healthcare providers, NC DHHS, healthcare providers, and national experts. 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 location. Interviewees were asked to identify others the project team should contact to expand the project's reach.
 - Many of the people involved in systems advocacy have intersectional roles. The interview count is based on the primary designation provided by the individual. There were twelve individuals who identified as another stakeholder type who are also family members.



Our interviewees have over 1,250 years of professional experience in the I/DD and behavioral health fields combined.

Location of Interviewees*



Interview Summary

After reviewing the 66 interviews and information gathered from other states, the following themes emerged.

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



Recruitment & Hiring

What people are telling us...

*"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 this means...

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.**

Employment Realities

What people are telling us...

*"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**

"HR is not a benefits counselor." – **Tailored Plan**

*"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***

What this means...

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 transportation 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.

Training

What people are telling us...

*"Training should be **vett**ed 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*

*"There should be no training that is **discriminatory** towards the populations who is best suited to do the work." – 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*

*"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

What this means...

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.

Team Role & Supervision

What people are telling us...

*"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

What this means...

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.**

Implementation of Care Extender Role

What people told us...

*"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***

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

*"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***

What this means...

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.

Evaluation

What People told us...

*“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***

What this means...

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.

Recommendations

Based on what was learned through stakeholder interviews and research, we have:

- Developed strategic recommendations for short-term and long-term implementation and growth of family navigation and I/DD peer support in the proposed Care Extender definition, focusing on scalability and sustainability.
- Identified policies that support and limit family navigation and I/DD peer support in the Care Extender definition.
- Identified changes in practices that would promote statewide adoption of family and I/DD peers as Care Extenders.

All systems change efforts require collaboration, diverse stakeholder input and involvement, and resources for successful implementation. Implementing these recommendations and producing meaningful, sustained systems change will require a collaborative approach and a variety of skills, ideas, and resources. Systems Change is not a linear process but does require a commitment to the following steps:

- 1 Getting started.** The first phase involves **assembling a stakeholder group** to focus on quality improvement efforts for the Care Extender role. The team should include senior leaders, clinical champions (clinicians who promote the redesign), people with lived experience, and administrative leaders.
- 2 Review data and set priorities for improvement.** The second phase involves gathering 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.
- 3 Modify Care Extender role and business systems as necessary.** The third phase involves **incorporating data** collected, ideas for improvement, and evaluating the changes' effects.
- 4 Continuously improve performance and maintain changes.** The fourth phase includes an **ongoing review of clinical outcomes** and making **adjustments for continued improvement.**

“Learners need endless feedback
more than they need endless teaching.”
- Grant Wiggins

Recruitment Recommendations

Short Term (Within first year of Care Extender Service implementation)	Long Term (Within 2 - 3 years of Service implementation)
Develop proactive recruitment plans with benchmarks, ensuring a focus on rural communities and marginalized groups.	Collect and analyze benchmark data in an annual report. Reset benchmarks based on annual implementation and progress.
Allow a flexible definition of “family” that includes non-traditionally defined roles (civil partnerships, multi-generational households, etc.)	Collect and analyze and report data annually.
Recruit for Care Extender roles utilizing various methods, including virtual, USPS mail, social media, and in-person outreach.	Identify best practices for recruitment. Interview and compile Care Extender experiences related to recruitment.
Conduct outreach to various sources, including post-secondary education programs, high school transition programs, DD advocacy, support and provider organizations, and current beneficiaries.	Identify and interview organizational champions within Care Management Agencies and Tailored Plans who have been proactive in hiring people with lived experience to compile best practices and policies.

Employment Realities Recommendations

Short Term (Within first year of Care Extender Service implementation)	Long Term (Within 2 - 3 years of Service implementation)
Identify - or develop - a centralized benefits counseling resource that provides potential Care Extenders with benefits counseling so they can make informed employment decisions.	Track requests for benefits counseling services and expand service as needed.
Review the hiring requirement for a driver's license and outline necessary steps for policy modification, including the identification of appropriate authorities	Modify the hiring requirement for a driver's license and communicate it with TPs, CMAs, AMH+, and stakeholders.
Understand that accommodations needed may include transportation, communication, and administrative task assistance and must be individualized. Plan resources accordingly.	Track job accommodations. Develop sample Care Extender scenarios for HR and training curriculum.
Identify community advocates and professionals knowledgeable about ADA and job accommodations. Incorporate their expertise and lived experience into hiring practices.	Track requests over time and share best practices.
Incorporate the topic of job accommodations into CMA training. Develop sample scenarios that illustrate a variety of job accommodations.	Interview Care Extender with lived experience to compile best practices and policies. Interview CM and TP staff involved in and responsible for hiring.
Offer Care Extender job flexibility through policies and procedures. CMAs and employing organizations should identify essential job functions, including work location and potential travel options.	Inventory policies and best practices and incorporate them into employment policies and procedures and CMA training.

Training Recommendations

Short Term (Within first year of Care Extender Service implementation)	Long Term (Within 2 - 3 years of Service implementation)
Contract with a statewide training organization to involve PWIDD and families in revised Care Mgt and Care Extender training development, delivery, and evaluation.	Evaluate updated training annually to identify necessary changes as the service evolves. Distribute to all TPs, CMA,s AMH +
Incorporate experiential learning activities across CMA training. Evaluate and incorporate into standardized training.	The Care Extender State Advisory group reviews sample learning activities to develop an inventory of best practices and resources for members and staff.
Provide alternative and accessible training resources, such as large print, multi-sensory learning activities, and visuals. Use plain language in training materials.	Track THE use of training materials, modify them as lessons are learned and disseminated
Accommodate diverse learning styles and offer individualized accommodations (note taker, audio recordings, etc.)	Inventory accommodations and sample materials and incorporate them into training.
Provide Care Extender with additional, ad hoc training to ensure that they are adequately prepared for their position. Suggested topics includes: Person-centered principles, Motivational interviewing, Confidentiality, Boundaries, Self-care, Crisis response, Trauma-informed care, Charting the Life Course, Health literacy & Health coaching	Monitor supplemental training needs and report to NC DHHS. Incorporate the most utilized supplemental training into the Care Extender training curriculum. Document regional training topics and variations that reflect diversity, equity, and inclusion.

Team Role & Supervision Recommendations

Short Term (Within first year of Care Extender Service implementation)	Long Term (Within 2 - 3 years of Service implementation)
Consider relevant factors when making member assignments by reviewing the Care Extender's lived experience, knowledge and skills (for example, living independently, getting a driver's license, using VR services, and managing a chronic health condition).	Develop "floating" or specialized Care Extender roles (e.g., Housing, employment, guardianship); life cycle expertise (early childhood, aging); lived experience (community residence, transition from DD Center or ICF to community).
Establish a Community of Practice and Project ECHO for Care Extenders with lived experience to meet and share best practices, learn from one another, and create new knowledge that advances the role and services.	Develop a Care Extender State advisory group with majority representation by Care Extender with Lived Experience
Develop personalized supervision plans based on employees' background and what they need during the formal company onboarding, 2) team orientation, and 3) ongoing individual specialized supervision.	Develop training tools/resources for CM supervisors that provide information on supervising and supporting Care Extenders with I/DD or family members.
Encourage Care Extenders to develop a self-care plan and incorporate it into their work and supervision plans and coaching.	Inventory sample plans and incorporate them into CMA and CE training.

Implementation Recommendations

Short Term (Within first year of Care Extender Service implementation)	Long Term (Within 2 - 3 years of Service implementation)
Set benchmarks for employment of Care Extender with lived experience.	Track employment numbers, and employment distribution. Revise benchmarks on an annual basis.
Identification of “champions” who advocate for and support the employment of PWIDD and family members.	Interview “champions” to inform policies and practices. Identify key elements that contribute to successful Care Extender services.
Clear, easy-to-navigate communication (Plain Language) that enables members and others to understand the evolving Medicaid and healthcare system and services.	Ongoing review of communication methods and materials.
Establish a state-level advisory group to track implementation, successes, barriers, best practices, and policy changes needed.	Review membership on an annual basis. Publish summary report.
Track diversity of Care Extender and representation from small CBOs, rural communities, and marginalized populations	Document the alignment of Care Extender with lived experience with DHHS’ values of diversity, equity, and inclusion.

Evaluation Recommendations

Short Term (Within first year of Care Extender Service implementation)	Long Term (Within 2 - 3 years of Service implementation)
Review Community Health Worker and Peer Support sample protocols, evaluation measures, and tools.	Compile and distribute best practice resources, update them on an annual basis, and incorporate them into trainings.
Survey PWIDD and families to determine outcomes they find most important. Review in State advisory group and report to DHHS leadership.	Incorporate feedback into Care Management Agency and Tailor Plan contracts.
Assess current data collected that could be utilized in the evaluation, such as CQL, POM, and/or HEDIS.	Convene experts to identify any unmet data needs and assess options and/or develop procedures to collect.
Determine key indicators of the effectiveness of the Care Extender role and establish relevant outcome measures for the Care Management/ Tailored Plan Team to monitor.	Conduct annual review and report of outcomes and revisions as systems and services evolve and distribute statewide.
Develop an evaluation plan with input from multiple stakeholders. Consider utilizing established models already used to evaluate peer support, like the RE-AIM. The RE-AIM framework offers a practical means of evaluating programs, practices, policies, and environmental changes.	Revise the evaluation plan on an annual basis. Review findings with multiple stakeholders and incorporate them into training, guidance, contracts, etc.

Conclusion

Towards the end of researching and writing this report, we asked Team Member Jade McWilliams if they had any advice for Care Management Agencies, Tailored Plans and Advanced Medical Homes as they move forward. After participating in countless hours of interviews and being immersed in the topic for months, they did:

“Be brave enough to take the chance and hire people with disabilities to do these jobs. I feel like we have so much untapped potential. So many of us really, really care about our communities and helping each other. I think you might **find a dedicated labor force** with far **less turnover** than you might expect from other populations. **Take a chance on us.** You may be surprised and rewarded in ways you can’t even think of right now.”

Achieving sustainable systems change requires stakeholders to **commit to centering the voices of people with lived experience** in identifying needs and issues and developing solutions. Together, systems must explore best practices, including utilizing individuals with lived experience to improve whole-person care, while also being mindful of opportunities to implement and scale new innovations and promising practices.

We hope that the recommendations in this report foster conversation and support the framing of the Care Extender position through the lens of **whole-person care**. With shared values focused on **equity, diversity, and inclusion**, as well as the knowledge of research and results-based practices, we believe **Care Extenders with lived experience can help improve the lives of those receiving behavioral health services in North Carolina.**

“Great changes can emerge from small actions. Change involves a belief in the possible, even the “impossible.”

Michael Quinn Patton

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 Want to Work .”

A young adult with I/DD has been offered a job, but they are unclear how this positive life change may impact their benefits. They do not know how to report their job earnings to the necessary government agencies. As the peer Care Extender, I would help them set up an appointment with a benefits counselor. I would help them prepare for the appointment by outlining the questions they want to ask and organizing information and needed documents about their job, current benefits, and services. I would encourage them to have an advocate (perhaps the Care Extender) with them when they go to the appointment—someone to take notes and help them outline the next steps. I would help them identify others who have been down this path and can share lessons learned. I would help them figure out if they could set up an ABL account to offset work expenses, like transportation or uniforms. I would keep the care management team informed of the goal, resources, and outcome. I would check back with the individual at an agreed-upon time to see if they have questions and have been able to follow through with the benefits counselor’s recommendations.



Care Extender Role	Coordinating services and appointments; sharing information about employment and benefits; connecting member to others with related experiences
Required Training	Goal setting, understanding of state and federal services and regulations, motivational interviewing, person-centered principles, documentation
Outcome	Accessing accurate employment and benefits information. Promoting independence in meeting community living needs. Preventing a payback situation or loss of benefits

Family Members Serving as Care Extenders

“How Much is that Service Dog?”

A family wants to acquire a service dog for their child. The Care Extender would help the family research costs, application process, and training requirements. They could assist the family with requesting the needed documentation for medical necessity. If necessary, they could help brainstorm and implement a fundraising plan. The Care Extender could put in touch with other people in the community who have or train service animals. They could help the family learn about laws regarding service animals in public spaces. I would keep the care management team informed of the family’s goal, planning steps, and outcome. I would check back with the individual at set intervals to see how the plan is progressing.



Care Extender Role	Addressing family resource needs, identifying community resources, community outreach, 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.

“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.

Care Extender Candidates: Ready! Willing! Able! But...

Applicant Name: Cheryl Powell
Resident of: New Hannover
Services Received: SSDI, Medicare
Education: Bachelor of Social Work (BSW)



System Expertise: (in a volunteer capacity)

- NCCDD Council member since 2015 (co-chair twice)
- Advisory Group for Care Extender White Paper Project
- Technology Advisory Group for Tailored Plan Care Management
- Member, DSP Workforce Group
- Member, DD Consortium
- Advisor, Meet The Need NC
- Member, Work Together NC

What hiring criteria would keep you from applying or disqualifying you?

- Having to have a driver's license
- Any weight-lifting requirements

"I want to see the state put their money where their mouth is, ya know? 'We support people with disabilities' and all of this... Are they going to be the ones to lead the way and actually do it? I guess what I mean is that it's not enough to say that we are going to include people with disabilities in the people we hire."

"I understand that it's not going to be a quick hire for some folks [with disabilities], but, if you really want to do what you said you're going to do, this is part of it."

Applicant Name: Jonathan Ellis
Resident of: Hetford County
Services Received: Innovations Waiver
Education: Bachelor of Arts in Communication w/Emphasis in Public Relations



System Expertise: (in a volunteer capacity)

- Advocate for 31 years
- ADA Coordinator Training Certification
- NCCDD member for 8 years
- Executive Board for 4 of those years

What hiring criteria would keep you from applying or disqualify you?

- No driver's license. My disabilities prevent me from ever being able to get one.

"Because of our technology use now, of Zoom, I don't see why someone like us [people with disabilities], or me, could not be utilized as a Care Extender. If we are able to use some sort of technology from our house."

"I'm tired of being looked over, ya know? They ask for our opinion but we don't get paid for it. As many opinions as we give out, you'd think we'd be rich by now!"

Applicant Name: Jessica Aguilar
Resident of: Union County
Services Received: mother of premature twins diagnosed with spectrum disorder
Education: Degree in economics, focus on community development (received outside US)



System Expertise:

- Member, NC Olmstead Plan Stakeholder Advisory
- Advisory Council Member, Thriving in Transition Project, Duke University of Medicine
- Member, DHHS IDD Stakeholder Workgroup
- Member, DHHS TAG
- QPR Instructor, Mental Health America
- Advisory Council Member, Partners Health Management
- Advisory Council Member, Stake Consumer, and Family Advisory Committee
- Spanish-speaking Parent Educator, Exceptional Children’s Assistance Center
- Advisory Council Member, Special Needs Advisory Council
- Advisory Council Member, NC Child
- Parent Advocate, Grupo Poder y Esperanza
- Parent Advocate, Local Interagency Coordinating Councils
- Hispanic/Latinx Community Response Team, North Carolina Community Engagement Alliance (CEAL)

What hiring criteria would keep you from applying or disqualify you?

- College degree earned outside of the US.
- Unable to obtain a Driver’s license.
- Children receive in-home therapy because of her transportation limitations. She must be present for therapy.
- Transportation cost for outside employment is prohibitive.

“I am a community organizer and a passionate advocate for families whose children have special needs or medical conditions. All the volunteer service I do is to increase my knowledge and share my personal history to help, motivate and give hope to the Hispanic community to navigate services - especially to families facing a diagnosis.”

“I am working so hard. I live for these kids and find a way. I don’t know how, nobody knows how.”

“People don’t understand the effort it takes to get here.”

Applicant Name: Gerald Parrish
Resident of: Wake County
Services Received: Vocational Rehabilitation
Education: Bachelor in Arts & Music



System Expertise:

- Co-Facilitator, Ability Leadership Program of North Carolina (ALP-NC)
- Community Inclusion Specialist/Travel Trainer, Alliance for Disability Advocates

What hiring criteria would keep you from applying or disqualify you?

Does not have Driver’s License

“There is a lack of representation of people of color in the I/DD field. It would be good to raise awareness of our intersectional needs and make sure we get the same quality of care that our white peers get.”

“Peers are aware of the barriers we face. They’ve faced them. They know how frustrating it is to not be able to access things that will improve their quality of life.”

“In my experience, people are like, ‘You don’t look like you need this service or that modification.’ So I tend to fall into the cracks, even though I do experience a disability. I think I could help others with less visible disabilities that require less support feel validated.”

Appendices

All appendices' materials can be found at: cb-cg.com/CareExtender. Materials include:

- List of all individuals interviewed
- NC Department of Health & Human Services: "Guidance on the Use of Care Manager Extenders in Tailored Care Management"
- DD Consortium Statement: "Family Navigation and Peer Support: Equity for People with I/DD"
- Medical Health Homes Initiative: "Family Support and Navigation: Where Compassion, Empowerment, and Community Connect"
- Supplemental Resources

Care Extender Project Advisory Group

- Jessica Agulars
 - Parent
 - Advocate
 - Resides in Union County
- Andrew Clendenin
 - Executive Director, Behavioral Health, UnitedHealthcare Community Plan- NC
 - Resides in Moore County
- Kayla Davis
 - Person with Intellectual and/or Developmental Disabilities
 - Advocate
 - Staff at FIRST Resource Center
 - Resides in Buncombe County
- Cindy Ehlers
 - Parent
 - Chief Operating Officer, Trillium Health Resources
 - Resides in Craven County
- Jonathan Ellis
 - Person with Intellectual and/or Developmental Disabilities
 - Advocate
 - Resident of Hertford County
- Cheryl Powel
 - Person with Intellectual and/or Developmental Disabilities
 - Advocate
 - Resident of New Hanover County
- Holly Richard
 - Director of Program Development, The Arc of NC Resident of Wake County

Acronym Glossary

I/DD	Intellectual and/or Developmental Disabilities
NCCDD	North Carolina Council on Developmental Disabilities
LME-MCO	Local Management Entities/Managed Care Organizations
DD Providers	Developmental Disabilities Providers
NC DHHS	North Carolina Department of Health & Human Services
ADA	Americans with Disabilities Act
PWIDD	Person with Intellectual and/or Developmental Disabilities
BH	Behavioral Health
CMA	Care Management Agency
TP	Tailored Plan
AMH+	Advanced Medical Home
HR	Human Resources
CM	Care Management
VR	Vocational Rehabilitation
ICF	Intermediate Care Facility
CE	Care Extender
CBO	Community-Based Organization
CQL	The Council on Quality & Leadership
POM	Personal Outcome Measures
HEDIS	Healthcare Effectiveness Data and Information Set