WISCONSIN BOARD FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES

June 28, 2019

Department of Health Services, Division of Medicaid Services
Bureau of Adult Programs and Policy
Curtis Cunningham
Attn: Family Care 1915(b) and (c) waiver renewal
PO Box 309
Madison WI, 53701-0309

Dear Mr. Cunningham:

Thank you for the opportunity to provide public comments on the proposed Family Care waiver. The Wisconsin Board for People with Developmental Disabilities (BPDD) agrees with Survival Coalition's comments on the proposed waiver changes, and all their recommendations for additional waiver revisions that will stabilize the caregiver crisis, increase capacity to deliver community based supports and services, and improve community based outcomes (including community integrated employment, community supported living, integrated day services etc.).

We look forward to working with the Department on future Family Care waiver renewals to continue to improve the program.

In addition to Survival Coalition's recommendations, BPDD has included the following ideas which offer significant potential for systems change to improve the independence, self-determination, productivity, integration, and inclusion of people with Intellectual and Developmental Disabilities (I/DD).

Independence

- As the Department considers strategies to address Wisconsin's workforce crisis, BPDD recommends any increases to wages, extension of benefits, or other flexibilities given to agencies to increase worker retention be applicable to the entire Home and Community Based workforce. Many people with I/DD rely on many types of workers—including job coaches, respite care workers, certified nursing assistants, dementia specialists, behavioral support specialists, integrated day service staff, companions, mentors and other individuals someone might hire while self-directing etc.—to achieve care plan goals and outcomes.

- Modify the existing transportation services definition to allow creative billing solutions (paying families/community members giving rides, reimbursing mileage and fuel costs of volunteer drivers, allowing reimbursement for shared rides etc.) in instances and areas where transportation options are insufficient to meet plan goals.

- Require all care plans include the transportation services necessary to meet plan goals, including community integrated employment, integrated day services, and other community connections. Where families are contributing transportation services, these natural supports should be reflected and documented in the care plan.

- Require all care plans include an assessment of transportation needed to meet plan goals, transportation resource mapping, and an analysis of transportation options based on the following key factors: a) Reliability, ride comes on-time b) Availability, can be used routinely c) Flexibility, can go places after business hours and on weekends d) Affordability, fares or charges are within care plan or self-directed services budget e) On-demand scheduling, don't need to schedule days in advance f) Geographic range, can go farther distances/major destinations, next town or county g) Accessibility, vehicle can meet participant's mobility and other disability related needs.

- In addition to Survival Coalition's recommendation to add a robust service definition of Remote Support Technologies and Remote Monitoring Services, include training for families on services and supports included in these categories and benefits these services offer to participants' independence, self-determination, and safety.

- Ensure waiver service definitions are flexible enough to be inclusive of current and future cutting-edge technologies that can maximize independence, privacy, and improve overall quality of life for Medicaid-funded long-term care participants. Technology can help reduce costs and address the shortage of direct care workers.

- Within the individual's care plan, require that:

  - Participants are presented with options for use of supportive technologies in their individual support plans **before** assuming paid staff are necessary to enable independence in people's homes, workplaces, and communities. Eva

  - Supportive technology is evaluated as a viable resource to maintain a safe and quality lifestyle, particularly for people experiencing severe direct care staffing shortages.

  - Supportive technology is encouraged and used in conjunction with traditional staffing is used to create a cost-effective method to ensure support needs are met.

Self-Determination

- Require all service providers to confirm the identity of participant's guardian and scope of the guardian's decision-making authority by retaining a copy of the letter of guardianship on file.

- Add service definition for provider trainings on duties and required responsibilities of guardians under the law and limits of guardian's decision-making authority[1]; rights retained by the ward;

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[1] These requirements are outlined in Wis. Stats. 54.25: "When exercising powers as guardian of the person the guardian shall: 1) place the least possible restriction on the ward's personal liberty and exercise of constitutional and statutory rights, and promote the greatest possible

best practices for guardians to solicit and understand the wishes and preferences of the ward, involving the ward in decision-making, and taking ward's wishes/preferences into account in decisions made by the guardian; setting boundaries with family members and guardians; and strategies to prevent provider staff from asking guardians for input or permission on decisions they do not have authority to make; and strategies for providers and provider staff on how to handle guardians who are attempting to exceed their authority.

- Add a service definition for provider, participant, and family training on alternatives to guardianship including Supported Decision-Making agreements, as well as the use of Supported Decision-Making concepts within the person-centered planning process.

- Require Supporters identified in Supported Decision-Making agreements—as directed within the supported decision-making agreement—to be included within the person-centered planning process, participant directed services process, and any other meetings or processes where the participant is being asked to make a decision that falls within the parameter of the participant's supported decision-making agreement.

- Add service definition self-advocacy skills training for participants. Training would include strategies to communicate wants and needs; make informed choices, voice those choices, and develop trusted supports with whom participants can share concerns.

- Add a mechanism within the care plan for providers to document a participant's capacity for greater community integration, and for the participant to indicate their wishes for greater community integration in areas where a guardian's decision-making authority may result in a more restrictive residential placement or employment setting than desired by the participant.

- In addition to Survival Coalition's recommendations on adding service definitions of future planning, BPDD recommends requiring care teams to work with families to develop a clear succession plan to ensure their children can live in community supported living or other non-provider operated settings and avoid potentially decades of high cost, restrictive residential placement.

Productivity

- Tennessee's Employment and Community First CHOICES waiver supported employment service definitions provide a pathway to employment for participants in long-term care. BPDD recommends the following service definitions from the Employment and Community First CHOICES waiver are added to Wisconsin's Family Care waiver: Supported Employment – Individual Employment Support (includes Exploration, Benefits Counseling, Discovery, Situational Observation and Assessment, Job Development Plan or Self-Employment Plan, Job Development or Self-Employment Start Up, Job Development, Self-Employment Start Up, Job

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integration of the ward into his or her community. 2) make diligent efforts to identify and honor the ward's preferences with respect to choice of place of living, personal liberty and mobility, choice of associates, communication with others, personal privacy, and choices related to sexual expression and procreation. 3) take into account the ward's understanding of the nature and consequences of the decision, the level of risk involved, the value of the opportunity of the ward to develop decision-making skills, and the need of the ward for wider experience"

Coaching, Job Coaching for Individualized, Integrated Employment, Job Coaching for Individualized, Integrated Self-Employment, Co-Worker Supports, Career Advancement) and Supported Employment – Small Group Supports

- Similar to the Ohio's waiver, add a service category for employment navigator services to assist with the planning, authorization, and monitoring of community integrated employment supports to job-seekers with I/DD. Dedicated employment navigator service staff should be required to perform the following essential functions:

  - Development of person-centered support plans that assist job-seekers and their supporters to have a fuller understanding of how having a career, and a life, in the community fit together, and how effective, person-centered supports can help to make this happen.

  - Coordination of employment services by linking and referring individuals to needed services and supports offered by partner agencies and providers, routinely communicating with all parties involved (including individuals, their families, providers, and other team members), and assisting the support team to focus on outcomes.

  - Monitoring of waiver and other employment supports, to ensure outcomes, and in accordance with a well-structured person-centered plan.

  - Evaluation of the individual's current job satisfaction and identification of any possible risks to continued employment, as well as ensuring business satisfaction with the process.

- Continue to include paid coworker supports Supported Employment service definition

- Add the same language used in the IRIS waiver that requires plan review after two years of receiving prevocational services.

- Remove the master's degree requirement from Vocational Futures Planning Support service definition, but require certification using the advance training from the VSPS training program (www.vfpstraining.com).

Integration and Inclusion

- Add a Building Full Lives service category to support participant's ability to explore and connect to the community and develop or maintain specific life skills that lead to greater independence, meaningful connections and relationships, and community based integrated employment[2]. Services should include small group, community-based individualized, meaningful, using discovery and person-centered planning techniques to expose/explore the community and participant's interests, support focused on building life skills holistically (recognizing that many

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[2] services meet the new requirements of the Home and Community-Based Services (HCBS) Settings Rule and Workforce Innovation and Opportunity Act (WIOA)

independent living skills overlap employability skills) and independence, reporting on skill acquisition every 3-6 months, fading support as much as possible, and all other best practices from this service model.

- Add training and technical assistance for direct service providers to implement the Building Full Lives service model based on TransCen[3] community-based approach

- Add a service category to provide evidence-based Building Full Lives training to families and participants with disabilities on: a) Futures planning, establishing high expectations, and plan development focused on outcomes using tools from Center for Future Planning[4] and Your Child Can Work training for families[5]; b) Building social capital, increasing natural supports, and locating existing community opportunities using resource mapping c) Self-determination and self-advocacy skills using content developed by Green Mountain Self-Advocates[6] to foster individuals with disabilities making more informed choices, voice those choices, and develop trusted supporters with whom they can share concerns;

- Add a "Family Networking[7]" service definition for dedicated staffing, technical assistance, training and coaching, necessary to develop Family Networks, and collection of Family network data and outcomes.[8] Family Networks can help address fears and concerns that families have about community based services and community integrated employment. Many providers participating in BPDD's Building Full Lives grants consistently identify families as sometimes the biggest barrier about shifting from facility based to community-based services.

- Add peer and family mentoring services for improving self-advocacy and education on using community-based services.

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[3] TransCen offers Building Meaningful Lives, a comprehensive person-centered community-based approach to employment, community participation and full-life model of integration. https://www.transcen.org/training-consultation. (accessed June 2018)

[4] The Center for Future Planning offers online resources and training and has collaborated on coalition-building and training on future planning in six states over the past two years. https://futureplanning.thearc.org/ (accessed July 2018)

[5] Wisconsin Your Child Can Work training that doubled parent's expectations that their child could work in the community. www.witig.org (accessed July 2018)

[6] Green Mountain Self-Advocates is a well-known self-advocacy organization run by people with developmental disabilities. Training is provided by people with developmental disabilities and includes over 30 different types of training materials including: guardianship, employment, good relationships and sexuality, voting, and government advocacy work. http://www.gmsavt.org/trainings-and-resources/trainings (accessed June 2018)

[7] Family networking is one of three national standards for support to families. Family Networks seek out cost effective community-based solutions and resources, personal resources, and unpaid supports, in lieu of more costly Medicaid funded services. Family Networks have been demonstrated to result in increased community employment, independent living, and transportation, and can fill in service gaps especially in areas with limited access to qualified service providers.
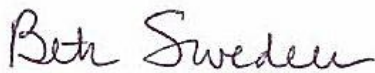
[8] Family network data and outcomes reporting should include: number of families receiving one on one conversation specifically about participating in a Family Network; Number of families expressing interest being connected to Family Networks; Number of families referred to dedicated Family Network staff; Number of family networks and number of families within each network; Types of Activities Family Networks are engaged in (e.g. connecting to other families, connecting to community activities, securing community employment, securing community independent living, supported decision making and self-direction, futures planning, transportation solutions etc.); Engagement of participants whose families are in Family Networks in community employment (hours, wages, employment supports used), community supported living, community engagement, quality of life measures, supported decision-making and self-direction as compared to participants whose families are not participating in Family Networks; The level of family engagement in networks and types of activities families are engaged in; issues identified by families including participation; quantify the participant's existing support system and how many/amount of services are being paid by family, other caregivers, other entities, services available from public or private funding sources.

- Add a "continuous outcome improvement initiatives" service definition to reimburse evidence-based pilot projects or approaches that seek to increase community integrated employment, transportation options, and community living outcomes for people with disabilities.

- Modify the integrated community day program service definition to clarify services meet outcomes including independent living skills experience and training, opportunities to build relationships and natural supports; opportunities to explore and engage in activities/interests of the person like in adult education, volunteering, community activities, and recreation/leisure opportunities. Include data elements to measure performance and outcomes of integrated day services.[9]

BPDD is charged under the federal Developmental Disabilities Assistance and Bill of Rights Act with advocacy, capacity building, and systems change to improve self-determination, independence, productivity, and integration and inclusion in all facets of community life for people with developmental disabilities.

Our role is to seek continuous improvement across all systems—education, transportation, health care, employment, etc.—that touch the lives of people with disabilities. Our work requires us to have a long-term vision of public policy that not only sees current systems as they are, but how these systems could be made better for current and future generations of people with disabilities.

Thank you for your consideration,

Beth Swedeen, Executive Director

Wisconsin Board for People with Developmental Disabilities

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[9] Data elements BPDD recommends include: How many and what types of community organizations or other partners does the pilot program have a relationship with; Hours of service delivered in each type of community organization or partner; Number and types of activities offered per month; Number of people participating in each type of activity; Number of people with I/DD in any small group; Number of people with I/DD doing individual activities; Ratio of staff to people with I/DD; Number of hours people with I/DD were engaged in activity without paid support there; How and who chose the activities and developed ideas for activities; Number of relationships individuals engaged in the community; Number of hours spent in the community and doing activities; Proportion of hours spend in activities designed for people without disabilities