# 2022-2026 Draft State Plan Wisconsin Board for People with Developmental Disabilities

Every five years, the Wisconsin Board for People with Developmental Disabilities (BPDD) submits a plan to the federal government for systems change focused on improving the quality of life for people with developmental disabilities through full inclusion and participation in all aspects of community life.

The Developmental Disabilities Assistance and Bill of Rights Act requires that each state establish a Developmental Disabilities (DD) Council. The Wisconsin Board for People with Developmental Disabilities is the state of Wisconsin's DD Council. The act also required each state to establish a Protection and Advocacy Agency and University Center on Excellence in Developmental Disabilities. In Wisconsin, Disability Rights Wisconsin is the Protection and Advocacy Agency, and the Waisman Center at the University of Wisconsin-Madison is the University Center on Excellence in Developmental Disabilities. Together the three entities are referred to as the Developmental Disabilities Network Partners.

To develop its next state plan, BPDD spent a year collecting public input on the most pressing issues and needs of people with developmental disabilities and their families. Nearly 500 people with disabilities, family members, professionals, and advocates provided input. Key issues raised include the need for social networks and relationships, inclusive communities, family support, caregiving, transportation, mental health, decision making (or having control over one's life), and employment. Board members reviewed the input to determine the best investment of available resources based on priorities identified statewide.

The state plan meets all the requirements of the <u>Developmental Disabilities Assistance and Bill of Rights Act of 2000 (DD Act)</u>. The federal government expects Developmental Disabilities Councils to identify goals that can be met in five years using available resources. In addition, the federal government requires that Council activities focus on efforts to change entire systems, not on direct service. The Council cannot be involved in legal action, such as lawsuits.

This plan will be in effect for the 2022-2026 federal fiscal years. The 5-year federal fiscal calendar begins October 1, 2021, and ends September 30, 2026. The plan will be submitted to the federal oversight agency, the Office of Intellectual and Developmental Disabilities, by August 15, 2021.

There are three required goals or objectives that must be included in every Council's state plan:

1. Self-advocacy: The Developmental Disabilities Assistance and Bill of Rights Act requires that Councils have a self-advocacy goal every year of the state plan that includes: 1) support to a statewide self-advocacy organization, 2) facilitating people with developmental disabilities providing leadership training to their peers, and 3)

- activities to promote the participation of people with disabilities in cross-disability and culturally diverse leadership coalitions.
- 2. Targeted disparity: Councils are required to identify a disparity faced by a group of people identified by the Council as unserved or underserved (this group may be based on race, ethnicity, sexual orientation, geography, gender, etc.). Councils must include a state plan goal or objective that seeks to address this disparity.
- 3. Collaboration The Developmental Disabilities Assistance and Bill of Rights Act calls for collaboration among the Developmental Disabilities Network partners, and Councils are asked to identify specific strategic activities to further this collaboration.

To reach the goals outlined in the state plan, the Council uses a number of strategies, including training and consulting, building coalitions, educating policy makers and the general public, organizing grassroots advocacy, and funding demonstration projects.

This draft includes the goals and objectives BPDD chose for the 2022-2026 State Plan. The draft also includes examples of activities that could be used to reach the identified goals and objectives.

<u>Public Comment:</u> The draft is now open for public comment. If you have comments or suggestions, please write to: BPDD-State Plan, 101 E. Wilson Street, Room 219, Madison, WI 53703 or email <u>beth.swedeen@wisconsin.gov</u> by May 17, 2021. You may also provide comment by completing our survey (<u>click here</u>). There are two public hearings being scheduled.

At its May Board meeting, the Board will review all public comments and decide how to address them. If the BPDD Board determines that significant changes to the plan are needed based on the public comments, the board will send out a revised plan for an additional 45 days to gather additional feedback. Once approved, the State Plan will be completed and submitted to the federal government.

<u>Accessibility info:</u> The State Plan draft is available in Spanish, Hmong, and in plain language English, Spanish and Hmong versions. If you need the draft in another language or format, please email <u>beth.swedeen@wisconsin.gov</u> or call (608) 266-7826.

<u>2022-2026 Draft State Plan:</u> The Board is dedicated to uniting all of Wisconsin in supporting our citizens with developmental disabilities to lead their most independent lives. BPDD is charged with bringing people together to solve problems, remove barriers and create statewide change for the developmental disability community. BPDD is dedicated to improving the **independence**, **productivity**, **and integration** of people with intellectual and developmental disabilities.

**Independence** means having choices available, being able to choose, and exercising control over one's own life.

**Productivity** means contributing to one's own household, neighborhood and community. It means working in the community and earning a living.

**Integration** means being present in the community, participating in the life of the community and being valued as a person, friend, family member and neighbor.

In addition, people with developmental disabilities have the same rights as anyone -- the right to life, liberty and the pursuit of happiness, the right to be treated with respect and dignity, and the right to control one's own life and destiny.

The state plan will advance the opportunity for people with intellectual and developmental disabilities to lead fulfilling lives. With the support of families and allies who believe in these values, people will pursue their own goals and be fully included in the community.

Goal 1: Amount for Grants: \$80,000

By September 2026, people with Intellectual and Developmental Disabilities and their families are aware of and able to access, use, and improve programs to maximize inclusion, self-determination, productivity, integration, and independence in community life as evidenced by:

**Objective 1.1:** By September 30, 2026, as a result of BPDD action, 1,000 people with intellectual and developmental disabilities and families will say they **know about** and **can access** the supports they need **to live the lives they want**.

**Objective 1.2:** By September 30, 2026, as a result of BPDD action, **100 families of young children of color** will use the **public services**, **public programs and community supports** they **need**.

**Objective 1.3:** By September 30, 2026, the Board will **act as a policy adviser** to the legislature, Governor, and other policymakers on policies that impact all aspects of community life, decision-making, and full inclusion, resulting **in 25 improved policies and practices** that increase community participation, decision making and full inclusion.

## Rationale:

People with intellectual and developmental disabilities and their families must be:

- a) aware of the services and supports available to them throughout the life span,
- b) able to understand what the services offer,
- c) able to apply for the services,
- d) able to use the services to build a meaningful life, and
- e) able to provide feedback and voice concern on the quality of services and ways to improve.

Despite efforts by service systems to inform eligible people of the available programs, many --especially people of color--remain either unaware of these opportunities or do not find that the services help them live full lives in their communities. The service systems are often fragmented and difficult to navigate. Program and service materials and websites are often

difficult to find, read and understand. Opportunities for input to improve services or voice concerns are either nonexistent or often do not result in positive change.

Participation in children's long-term care in Milwaukee County continues to lag compared to participation rates in other counties. Participation in Milwaukee County is 1,191 children, while Dane County with a population about half of Milwaukee county has 1,363 children on the waiver (March 2021). This continued disparity in the county with the highest cultural and linguistic diversity in the state, and among the highest poverty rates, continues to be a concern.

Tribal children and Latino children also are significantly under-represented in Children's programs related to Caucasian children.

Demographic data on applicants/participants is unavailable in some service systems. To address disparities, it is important that all systems collect demographic data and be able to readily share it when asked.

## **Definitions:**

**Plain Language:** communication your audience can understand the first time they read or hear it. Plain language is easy to read, understand, and use. It avoids using too many words and jargon.

**Self-advocates:** a person with a disability who speaks up for the rights, needs and wants of him/herself and of other people with disabilities

Stakeholder: a person or group of people who have an interest or concern about something

#### Suggested activities:

- Promote the use of plain language by agencies, service providers and other organizations so that people with disabilities, families and other users understand the information and are able to use it effectively
- Coordinate useability studies or stakeholder reviews of publications and websites
- Work with self-advocates and family members to educate others about the value of plain language materials
- Pilot innovative strategies to alleviate information gaps
- Pilot innovative strategies to empower people with disabilities and families, including people/families of color, to navigate service systems and support others to do so
- Inform policymakers on polices that impact all aspects of community life, decisionmaking and full inclusion
- Provide information and e-mail alerts on key policy and legislative initiatives affecting people with disabilities.

Goal 2: Amount for Grants: \$300,000

People with intellectual and developmental disabilities experience equity, access, and opportunity to foster authentic relationships and be seen as valued contributors to their communities as evidenced by:

**Objective 2.1:** By September 30, 2026, as a result of BPDD action, 650 people with intellectual and developmental disabilities will say they have **increased social connection and reduced isolation**.

**Objective 2.2:** By September 30, 2026, as a result of BPDD action and through collaboration with the Developmental Disabilities Network, 775 people with intellectual and developmental disabilities will **make choices** about their everyday lives.

**Objective 2.3:** September 30<sup>th</sup>, 2026, as a result of BPDD action, 900 self-advocates will engage in effective **advocacy**.

**Objective 2.4:** By September 30<sup>th</sup>, 2026, as a result of BPDD action, 250 self-advocates will **participate in leadership training** and **practice their leadership skills** across all aspects of community life.

### Rationale:

People with intellectual and developmental disabilities want authentic, meaningful relationships with people beyond family members, caregivers, and paid staff. These relationships are often made when participating in everyday life of a community: exercising at the gym, going to religious services, being a member of a club, volunteering, and working. People also want to make choices and decisions about their own lives, and they want to have a voice about the decisions that get made about their community, state and country. However, there are many barriers to this level of full, inclusive participation in community life.

Barriers stem from biases that perpetuate low expectations, attitudes, and systemic inequities that do not value and recognize the contributions possible by people with intellectual and developmental disabilities. These barriers result in limited opportunities. They also result in limited decision and choice-making, putting people with disabilities at greater risk for abuse and neglect.

Despite Wisconsin's focus on self-direction in managed care and an increase in the number of people who report self-directing some of their supports (NCI data), over 71% of people with intellectual and developmental disabilities who use the self-directed long term care program are under legal guardianship. Guardians sign their service plans and are often making multiple decisions every day (what clothes the ward can wear, what food they can eat) that go well beyond the intended role of a guardian, which is to ensure the health and safety of a ward. More training is needed on the range of decision-making supports available. Prospective and current guardians are also in need of education to better understand their role and its limitations.

Wisconsin, like most other states, has a fragmented reporting system for abuse and neglect, making it unclear when it happens, how often, and how to report. The Adult Protective Services system in Wisconsin is run by the 72 individual counties, and our state statute requires mandatory investigation ONLY for complaints of people over 60 (elder abuse). Complaints of adults 18-59 is at the discretion of the county. Likewise, people report being unsure whether to report to Adult Protective Services, Division of Quality Assurance, Wisconsin's Protection and Advocacy organization, or the police. People with disabilities need access to trainings on their rights and how to stay safe.

Expectations held by people with disabilities, their families, and the federal government about services are shifting away from a focus on caretaking and towards building skills and connections in the community. When services are used to connect people with disabilities to others and to opportunities, they gain skills, independence, and authentic relationships. This in turn positively impacts the attitudes and expectations of community members and employers.

## **Definitions:**

**Discretion:** having the freedom to make a decision about something

**Developmental Disabilities Network:** three agencies that each state is required to have: a Protection and Advocacy organization, University Center on Excellence in Developmental Disabilities, and Developmental Disabilities Council. In Wisconsin these include Disability Rights Wisconsin, Waisman Center, and Wisconsin Board for People with Developmental Disabilities.

**Prospective:** expecting to be something in the future

Self-direction: guiding or managing your own life or work or supports

**Systemic inequities:** the ways that our systems are not fair

## Suggested activities:

- Provide grants to develop and pilot innovative strategies to support people with disabilities to build connections in their communities
- Provide education and training to people with disabilities on their rights and ways to stay safe and connected
- Provide education to service providers and businesses about natural supports or mentoring in the workplace
- Provide education and training on the range of decision-making options available
- Promote collaboration among agencies and strengthen coalitions
- Support People First Wisconsin, a statewide self-advocacy organization, to strengthen their chapters and to provide members opportunities to engage in advocacy activities
- Provide grants to develop and pilot innovative strategies to support people, especially children and young adults, to make choices and decisions about their lives

- Support voting activities
- Support opportunities for people with disabilities to connect with legislators to educate and advocate on issues important to them
- Provide advocacy and leadership training and mentoring to self-advocates, including youth and families
- Engage in systems change activities that promote the inclusion of people with I/DD in all facets of community life
- Host statewide network/training events, such as the Self-Determination Conference
- Promote collaboration among the Developmental Disabilities Network partners— Disability Rights Wisconsin and Waisman Center