



# Board Meeting Packet

January 16-17, 2019  
Best Western Premier Park Hotel  
22 S Carroll St  
Madison, WI 53703





# Board Meeting

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Premier Park Hotel · Madison, Wisconsin · January 16<sup>th</sup>-17<sup>th</sup>, 2019

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January 1, 2019

Happy New Year;

I hope everyone has had the opportunity to enjoy the company of family and friends over the past month. Each year as we turn the calendar to a new number, I pause to reflect on all that has occurred the prior year. We have a lot to be proud of. BPDD is considered a leader in Wisconsin.

We are entering a time of transition. By the time we meet in January, we will already have a new governor in Wisconsin. Beth and the BPDD staff are working hard to ensure the lives of people with developmental disabilities are being considered, as the Governor makes plans for the future of Wisconsin. I am eager to be updated at our January board meeting.

As I look forward to 2019, I am grateful for each and every one of you who work for or are a board member of the Wisconsin Board for People with Developmental Disabilities. Together we will continue to advocate for better, more meaningful lives for people with disabilities in Wisconsin.




Thank you for all that you do.

Sincerely,





Pam Malin  
Chair, Wisconsin Board for People with Developmental Disabilities

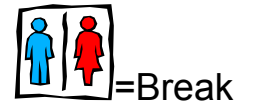
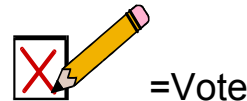
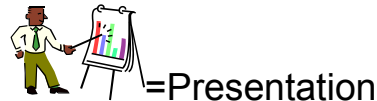
## BOARD AGENDA JANUARY 16-17<sup>TH</sup>, 2019






### WEDNESDAY, JANUARY 16<sup>TH</sup>, 2019

Time	Symbol	Topic	Facilitator/Presenter
3:30-4:30 PM		Diversity Committee	Staff: Molly Cooney
4:45-5:30 PM		Consumer Caucus	Staff: Fil Clissa
5:30-6:30 PM		Dinner	All
6:30-7:30 PM		Nominating & Membership Committee	Staff: Jenny Neugart

### THURSDAY, JANUARY 17<sup>TH</sup>, 2019

Time	Symbol	Topic	Facilitator/Presenter
7:45-8:30 AM		Breakfast	All
8:30-10:00 AM		Governmental Affairs Committee	Tami Jackson
10:00-10:15 AM		Break – <b>FILL OUT, SIGN, AND RETURN TRAVEL VOUCHERS to BPDD STAFF</b>	All
10:15-11:45 AM		State-Plan Updates -Staff will update on projects	



11:45-12:30 PM		Lunch	All
12:30 – 1:15 PM		2019 Legislative schedule discussion -DAD planning/discussion	
1:15 - 1:30 PM		Public Comments	
1:30 - 2:45 PM		<b>Business Meeting</b> <ul style="list-style-type: none"> <li>• Chair Report</li> <li>• Executive Director Report</li> <li>• Executive Committee</li> <li>• Diversity Committee</li> <li>• Nominating &amp; Membership Committee</li> <li>• Agency Updates</li> </ul>	All <ul style="list-style-type: none"> <li>• Pam Malin</li> <li>• Beth Swedeen</li> <li>• Pam Malin/Beth S</li> <li>• Lynn Carus</li> <li>• Claire Bible/Greg M</li> <li>• Agency Reps</li> </ul>
		<b>Business Meeting Action Items</b> Motion to accept November 2018 Board Minutes	All

The January Board Meeting will be held at the Best Western Premier Park Hotel located at 22 S Carroll St, Madison, WI 53703. Any Board members staying overnight will be staying at the Park Hotel. If you have any questions about the January Board meeting please contact Jeremy Gundlach at [Jeremy.Gundlach@wisconsin.gov](mailto:Jeremy.Gundlach@wisconsin.gov) or 608-266-7826.

 = Meal   
 = Meeting   
 = Presentation   
 = Vote   
 = Walking Activity   
 = Break

# BOARD MEETING MINUTES

Best Western Premier Park Hotel  
22 S Carroll St  
Madison, WI

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<b>Present:</b>	<b>Chair:</b> Pam Malin <b>Vice Chair:</b> Elsa Diaz-Bautista, Barbara Beckert, Aliza Claire Bible, Gail Bovy, Lynn Carus, Kevin Coughlin, Ramsey Lee, Nathaniel Lentz, David Pinno, Carole Stuebe, Sarah Lincoln, Leila Solati, Liz Hecht, Daniel Parker, Rita Fuller, Gail Bovy, Kediboyne Carpenter, Greg Meyer,
<b>Absent:</b>	Delores Sallis, Lynn Stansberry-Brusnahan, Patrick Friedrich,
<b>Staff Present:</b>	Fil Clissa, Jeremy Gundlach, Tami Jackson, Beth Swedeen, Jenny Neugart, Molly Cooney

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Chair Pam Malin called the meeting to order at 2:11 PM.

**1. Chair Report:**

- Pam Malin gave an update on how the SD conference went. She also gave the diehard award to Barbara Beckert.

**2. Executive Director Report:**

- Beth gave an update on BPDD’s budget and new federal ruling on how money is spent by DD councils. BPDD applied for a waiver so we didn’t lose \$46,000 and it was recently approved. Beth also gave an update on BPDD’s new Living Well grant over the next 5 years. BPDD will be hiring a .6 time and a full-time position for the grant.

**3. Executive Committee Report:**

- There will also be a review of the Executive Director coming out for board members to fill out soon. The next Executive Com mtg is December 5<sup>th</sup> from 3-4pm.

**4. Nominating & Membership Committee Report:**

- Greg Meyer gave an update on Nominating Committee’s plan for membership. The plan is to wait until the new governor is in office and then to reach out about getting appointments to fill vacancies. There will be a focus on the Northwestern part of the state.

**5. Diversity Committee Report:**

- Diversity Committee is planning a Zoom meeting for the near future. The diversity meeting was cancelled last night.

**6. Action Items:**

Motion to accept the September, 26<sup>th</sup>, 2018 board minutes made by Pam Malin. The motion passed unanimously.

## **7. Agency Updates:**

### **DRW-**

- Barbara updated that DRW received over 30 applications hoping to choose their new Executive Director by mid-December.
- Next DRW listening session is in December in La Crosse.
- DRW is looking for new members of PAMI, mental health council. New social security grant reviewing representative payees.

**DPI-** WSPEI has a new family phone support position that families can call to get questions answered and learn about resources.

- Daniel said Tony Evers will resign after inauguration and then appoint a new Superintendent.
- April 12<sup>th</sup> presentation on Family engagement and educating families on IEPs. Flyers will be available in the next month.

### **DHS- [See Attached](#)**

### **Waisman-**

- Project descriptions for all Waisman staff were shared at last meeting and is on the website.
- Wellness Inclusion Nursing (WIN) online video conferencing is doing 4 part series. 2 have already happened.
- Series of training/on-line on parenting a child w/autism.
- Day with the Expert series- the next are on Down syndrome and cochlear implants, this spring.
- Waisman received a grant to include people with I/DD to be co-researchers. Stakeholder group will be formed.

### **DVR-**

- Delora Newton the administrator will resign as of Jan. 4<sup>th</sup>. WIOA is required to spend 15% of funds on students. Their goal for FFY18 was \$9.6 M as of last week they spent over \$11 M. All VR agencies have been advised that WIOA could be re-opened. We have seen great progress, so VR agencies are not in favor of re-opening. The national group will submit comments.
- Competitive Integrated Employment work group has met. DVR is lead for all agencies to get a plan. The group has met 4 times. Each agency has at least 3 separate strategies and 2 shared strategies. A public hearing will be held between January and March. A report will be on the DVR website. BPDD has been identified as a stakeholder and will be alerted of opportunity to provide public comments.
- WIOA interviews are in their 3<sup>rd</sup> year, with UW Whitewater conducting the interviews. The number being interviewed is going down, partly because they aren't paying for sub-minimum wage and youth have to go to DVR before



pursuing sub-minimum wage. VR has developed a referral form for those in interviews who are interested in DVR.

**8. Other Agenda Items:**

- None

Motion to adjourn Pam Malin at 2:55 PM; Unanimously passed.

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- BPDD Board Meeting
- BPDD Executive Committee Meeting
- Holiday
- Self-Determination Conference / Disability Advocacy Day / Employment Conference
- Partners in Policymaking

Updated: 8/27/2018 NF

Exec meeting dates should be scheduled 6 weeks before board mtg dates

## Board Meeting Dates & Locations:

January 16 & 17, 2019	Premier Park Hotel 22 S Carroll St Madison WI, 53703
March 21, 2019	Premier Park Hotel 22 S Carroll St Madison WI, 53703
May 15 & 16, 2019	Premier Park Hotel 22 S Carroll St Madison WI, 53703
July 17 & 18, 2019	TBD
September 18 & 19, 2019	TBD-Milwaukee Area
November 13 & 14, 2019	TBD

## Executive Committee Meeting Dates

February 5 <sup>th</sup> , 2019	2:00-3:00 PM
April 2 <sup>nd</sup> , 2019	2:00-3:00 PM
June 4 <sup>th</sup> , 2019	2:00-3:00 PM
August 6 <sup>th</sup> , 2019	2:00-3:00 PM
October 1 <sup>st</sup> , 2019	2:00-3:00 PM
December 3 <sup>rd</sup> , 2019	2:00-3:00 PM

## Other BPDD Dates:

March 20, 2019	Disability Advocacy Day
May 15, 2019	Employment First Conference
October 14-16, 2019	Self-Determination Conference

\*Dates are not final and still need approval from the Board.

**EXECUTIVE COMMITTEE MEETING  
MINUTES - DRAFT**

**BPDD Office and Teleconference**

**Present:** **Chair:** Pam Malin **Vice Chair:** Elsa Diaz-Bautista, Greg Meyer, Gail Bovy, Carole Stuebe

**Staff Liaison:** Beth Swedeen

**Absent:** Lynn Carus, Claire Bible

**Staff Present:** Beth Swedeen, Jeremy Gundlach

Meeting called to order at 3:07 pm.

**1. Bylaws Discussion:**

- Beth Swedeen talked about Exec Committee’s charge of reviewing the bylaws every year. Should BPDD put a vote to approve the bylaws at an upcoming board meeting.
- BPDD chair and vice chair both agree that Exec Com will review the bylaws one more time before they are voted on.
- Possibly hold a special exec meeting so the bylaws are ready for a vote at our January meeting. Monday January 7<sup>th</sup> at 3:30 pm will be the special Exec committee meeting.

**2. Set January Meeting Agenda:**

3:30 – 4:30 PM	Diversity Committee
4:30 – 5:30 PM	Consumer Caucus
5:30 - 6:30 PM	Dinner
6:30 - 7:30 PM	Nominating & Membership Committee

7:45-8:30 AM	Breakfast
8:30 -10:00 AM	Governmental Affairs -state updates -federal updates
10:00-10:15 AM	Break
10:15-11:45 AM	2019 Legislative schedule discussion -DAD planning/discussion
11:45-12:30 PM	Lunch
12:00-1:00 PM	5-year plan update
1:00-2:30 PM	Business Meeting
2:30 – 2:45 PM	Vote on Bylaws

**3. May Board Meeting Conflict with EF Conference:**

- Beth Swedeen gave an update on the EF conference date which falls on May 16<sup>th</sup>. This is the same day as our board meeting.

- Jeremy will look into moving the board meeting to the Kalahari on Wednesday the 15<sup>th</sup> so we can have board members participate in EF and still have our board meeting. We would plan to meet from noon to 8pm.
- If the Kalahari/Park Inn can't accommodate the changes we will keep the plan as is.

#### **4. Policy Seminar:**

- Pam Malin talked about the DC Policy Seminar from April 10-12, 2019. BPDD is currently looking for board members to attend the trip. Leila Solati and Robert Kuhr are currently interested in attending. Beth S will be attending and Jeremy G is interested in attending for staff.
- Pam also talked about the NACDD conference coming up in July 2019 as an option for board members to attend. Carole S and Pam M are interested in attending NACDD.

#### **5. 2019 Executive Committee Schedule:**

- Pam talked about how they based the exec committee meetings around Patrick Y's schedule. Carole suggested that we meet from 2:00 – 3:00 pm
- February 5<sup>th</sup> from 2-3pm
- April 2<sup>nd</sup>
- June 4<sup>th</sup>
- August 6<sup>th</sup>
- October 1<sup>st</sup>
- December 3rd





#### **6. Other Agenda Items:**

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Motion to adjourn at 4:03 PM. Unanimously passed.

# Nominating Committee Agenda

**Members:** **Co-Chairs:** Claire Bible & Greg Meyer **Vice Chair: Open;** Ramsey Lee, Lynn Stansberry-Brusnahan, Carole Stuebe, Nathaniel Lentz, Patrick Friedrich  
**Staff Liaison:** Jenny Neugart

Symbol	Topic:	Presenter:	Time:
	1. Chair Update <ul style="list-style-type: none"><li>•</li></ul>		
	2. Board Member Recruitment <ul style="list-style-type: none"><li>• Discuss new application process under Ever's administration</li></ul>		
	3. Ideas for Members in specific areas of the state		
	4. Adjourn		

## Other Information:



=Meeting



=Presentation



=Vote

# NOMINATING COMMITTEE MEETING

## MINUTES

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**Committee Present:** **Co-Chairs:** Greg Meyer **Vice Chair: Open;** Ramsey Lee, Nathaniel Lentz, Lynn Carus

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**Committee Absent:** Claire Bible, Lynn Stansberry-Brusnahan, Carole Stuebe, Patrick Friedrich

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**Staff Present:** Jenny Neugart

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Meeting called to order at 6:22 pm.

### 1. Chair Update:

- Beth gave an update on the applications at the Governor's office and recommended not seeking more candidates for the Board until the Administration changes and BPDD can meet with the new appointments director

### 2. Board Member Recruitment- Discussion:

- Greg recommended that he join the meeting with the new Appointments director, whether by phone or in person
- The committee discussed the current board orientation. Everyone agreed that the change from a formal Powerpoint with lots of slides to a more informal discussion was a big improvement. No one had changes to the actual orientation.
- Leila suggested and others agreed that mentors for new board members would be helpful

### 3. Ideas for Members in specific areas of the state:

- Greg recommended focusing on trying to get more applications from candidates who are from under-represented and minority populations.

### 4. Adjournment:

Motion to adjourn at 6:40 PM made by Greg Meyer and seconded by Nathaniel Lentz. Unanimously passed.

January 16, 2019

3:30-4:30 pm





Best Western Premier  
Park Hotel

# Diversity Ad Hoc Committee Agenda

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**Members** **Chair:** Lynn Carus, **Vice Chair:** Barbara Beckert; Elsa Diaz-Bautista, Meredith Dressel, Delores Sallis, Nathaniel Lentz, Rita Fuller, Daniel Parker  
**Staff Liaison:** Molly Cooney

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Symbol	Topic	Presenter	Time
	1. Call Meeting to order	Lynn C	
	2. Review Diversity Action Plan/Activities	All	
	3. Identify Next Steps	All	
	4. Updates form Board Members	All	



=Meeting




=Presentation



=Vote



<b>Goal 1   Budget: \$186,000</b>	
	<p><b>More people with Intellectual and Developmental Disabilities (I/DD) will be included in their communities.</b></p> <p>By September 2021, more people with I/DD including those with <b>diverse identities</b> will participate in integrated community activities of their choosing as evidenced by:</p>
<b>Objective 1.1   2016 Number: 3,813 people</b>	
	<p><b>More people with I/DD will be working in the community.</b></p> <p>By September 30, 2021, 50% more people with I/DD will be working in <b>integrated employment</b> of their choice at a competitive wage.</p>
<b>Objective 1.2   2016 Number: **</b>	
	<p><b>More people with I/DD have the support they need to make choices in their lives.</b></p> <p>By September 30, 2021, 25% more people with I/DD will <b>make choices</b> about their everyday lives.</p>
<b>Objective 1.3   2016 Number: 20,337 people</b>	
	<p><b>More people with I/DD will have a way to get to where they need to go. (Transportation)</b></p> <p>By September 30, 2021, 25% more people with I/DD will reliably be able to get where they need to go each day.</p>
<b>Objective 1.4   2016 Number: 20,337 people</b>	
	<p><b>More people with I/DD will have people in their lives that they can count on to help them when needed.</b></p> <p>By September 30, 2021, 25% more people with I/DD say they have a network of community members they can rely on.</p>
<b>Objective 1.5   2016 Number: **</b>	
	<p><b>More African American Families will be connected to their community and resources</b></p> <p>By September 30, 2021, African American Families in the central city Milwaukee will be connected to community supports and have access to the resources they need.</p>

**Rationale:** The number of individuals who use self-directed supports is steadily growing. More than 13,000 are currently self-directing their long-term care services and supports in Wisconsin. Nearly half (48%) are individuals with intellectual and developmental disabilities. Anyone eligible for long-term care should have the opportunity to self-direct any or all services and supports. Individuals may use **Supported Decision-Making** tools to ensure independence and choice in making decisions about their lives. Individuals with I/DD and families need support and resources to create a full life. This means having access to transportation, paid jobs, volunteer work, community activities and clubs, etc. Having a full life means that people with disabilities have all the opportunities, supports, and resources that are available to individuals in their community without a disability. Employment is integral to most people's lives, yet people with I/DD continue to experience many barriers. Research has shown that individuals in long-term care who are employed in integrated jobs are less likely to be reliant on public supports and have better life outcomes. The lack of adequate wrap-around day supports and transportation reduces independence.

**Definition:**

**Intellectual Disability** is a disability characterized by significant limitations both in intellectual functioning (reasoning, learning, problem solving) and in adaptive behavior, which covers a range of everyday social and practical skills. This disability originates before the age of 18.

**Developmental Disabilities** is an umbrella term that includes intellectual disability but also includes other disabilities that are apparent during childhood.

**Diverse identities** refers to people of various races, cultural and ethnic heritages, genders, gender identities, gender expressions, sexual orientations, ages, and religions from diverse socio-economic and geographic backgrounds.

**Integrated employment** is a job in typical workplace settings where the majority of persons employed are not persons with disabilities, at least minimum wage or higher, where the person is paid directly by the employer and is given opportunities for advancement that are similar to those for other employees who are not individuals with disabilities and who have similar positions. Integrated employment includes self-employment and ownership of micro-businesses.

**Making Choices** refers to a person being able to make decisions about their own life: where to work, live, to have a roommate etc.

**Supported Decision-Making** means people with disabilities can get the help they need from friends, family members, and professionals to understand the situations and choices they face, so they may make their own decisions as an alternative to guardianship.

**Suggested activities:**

- Provide training and support to individuals and families,
- Work on reaching people with disabilities and their families from diverse (all) backgrounds,
- Training events, Employment First Conference and Self-Determination Conference,
- Partner with Disability Rights Wisconsin and Waisman Center,
- Provide grants to work on employment practices, self-determination, self-directed supports, supported decision-making, transportation, and peer mentoring,
- Work to increase self-directed supports in Wisconsin.

**Goal 2 | Budget: \$324,000**



More people with I/DD trained in advocacy and self-advocacy, resulting in an increase in the number of policies/laws that support people with disabilities to be more included in community life.

By September 2021, more people with I/DD including those with **diverse identities** and their families will increase their advocacy efforts, resulting in increased numbers of policies supporting inclusion of people with disabilities in community life.

**Objective 2.1 | 2016 Number: 200**



Support People First Wisconsin to increase the number of self-advocates with I/DD involved in local groups.

By September 30, 2021, 25% more self-advocates with I/DD will participate in a **state self-advocacy organization** led by individuals with intellectual disabilities.

**Objective 2.2 | 2016 Number: 243**



Increase the number of self-advocates with I/DD and their families trained in leadership skills and become leaders in their community.

By September 30, 2021, 50% more **self-advocates with I/DD and their families** will participate in leadership training and practice their leadership skills.

**Objective 2.3 | 2016 Number: New Project**



Work with Disability Rights Wisconsin and Waisman Center to identify and support people with diverse backgrounds to participate in different leadership groups.

By September 30, 2021, 50% more people with I/DD and their families will participate in cross-disability and culturally diverse leadership coalitions through collaboration with the **AIDD Partnership**.

**Objective 2.4 | 2016 Number:**



Support more people with I/DD and families from different backgrounds will increase their advocacy.

By September 30, 2021, 25% more people with I/DD with **diverse identities** and their families will increase involvement in advocacy activities.



## Work with legislators and policy makers to improve the lives of people with disabilities in Wisconsin.

By September 30, 2021, BPDD will act as a policy advisor to the Legislature, Governor and other policy makers on policies that affect all aspects of community life, decision-making, and full inclusion. This will result in 25 improved policies and practices that increase community participation, decision making and full inclusion.

**\*\* Data will be available 9/30/16.**

**Rationale:** Nothing about me without me. Individuals with disabilities and their family members must be included in the decision-making process on policies and practices that affect their lives and impact their ability to obtain the services and supports they need to live in the community. People with I/DD need support in exercising their rights and responsibilities as citizens. Speaking at a public event, writing a letter to an elected official, and voting are just a few examples. Self-advocacy and advocacy groups need training, education, and opportunities to practice their skills. Self-advocates and families provide vital and unique insight to their local communities on how public policies impact their lives.

### Definitions:

**Diverse identities** refers to people of various races, cultural and ethnic heritages, genders, gender identities, gender expressions, sexual orientations, ages, and religions from diverse socio-economic and geographic backgrounds.

**AIDD Partnership:** The Administration on Intellectual and Developmental Disabilities defines the partnership as being between The Board for People with Developmental Disabilities, Disability Rights Wisconsin, and Waisman Center.

**State self-advocacy organization:** People First Wisconsin is the self-advocacy organization in Wisconsin. They have a state office run by people with intellectual and developmental disabilities.

**Self-advocacy:** refers to an individual with a disability's ability to effectively communicate, convey, negotiate or assert his or her own interests, desires, needs, and rights.

### Suggested activities:

- Promote collaboration among agencies and strengthen coalitions,
- Provide information and e-mail alerts on policy and legislative initiatives affecting people with I/DD,
- Assist People First-WI with outreach and training activities,
- Provide grants and technical assistance to support local self-advocacy coalitions,
- Support joint policy positions with AIDD partners (Disability Rights Wisconsin and Waisman Center),
- Provide advocacy and leadership training and mentoring to self-advocates, including youth and families,
- Support voting activities,
- Engage in systems change activities that promote the inclusion of people with I/DD in all facets of community life,
- Educate policy makers, legal system on disability issues.

**Goal #1**

By September 2021, more people with Intellectual and Developmental Disabilities including those with **diverse identities** will participate in integrated community activities of their choosing as evidenced by:

Objective	Projects
<p>1.1. By September 30<sup>th</sup>, 2021, 50% more people with I/DD working in <b>integrated employment</b> of their choosing at competitive wage.</p>	<ul style="list-style-type: none"><li>• <a href="#"><u>Employment First Conference</u></a>: Annual conference championing competitive integrated employment by supporting stakeholders as services increasingly shift to more community-based employment and day services. Next conference May 15, 2019, at the Kalahari.</li><li>• <a href="#"><u>EF Partner grassroots grants</u></a>: Small grants to organizations throughout the state to work on grassroots efforts (e.g., connecting with businesses, chambers, holding legislative breakfasts) to expand competitive integrated employment. 9 sites @ about \$2,000 each for 2018-2019. Sites include: Waterloo School District, Westlake Enterprises (Ladysmith), SPARK (Middleton), Waukesha Independence Network, Camp Createability (Monona), Laconia High School (Rosendale), Opportunity Development Centers (WI Rapids), Green Valley Enterprises (Beaver Dam), Franklin School District.</li><li>• <a href="#"><u>Building Full Lives initiatives</u></a>: Funds technical assistance for organizations interested in shifting to a more individualized service model that better supports individuals with disabilities to live full lives in the community. 11 organizations receive technical assistance, including: Goodwill Industries of SE WI, Opportunity Development Centers (WI Rapids &amp; Marshfield), Headwaters Inc. (Rhineland), Bethesda Lutheran Communities (Watertown), Easterseals (Waukesha), VIP Services (Elkhorn), Threshold (West Bend), Green Valley Enterprise (Beaver Dam), Opportunity Center (Prairie du Chien), Ventures Unlimited (Shell Lake &amp; Hayward), RCS (Sheboygan).</li><li>• <a href="#"><u>Partners with Business</u></a>: Funds pilot sites and technical assistance to implement the employment support model with businesses. The cost-effective model uses co-workers, rather than job coaches, to provide support to co-workers with disabilities. 7 pilot sites currently; 5 more to add in spring 2019. Funds from legislature. Sites</li></ul>

	<p>include: School District of Altoona, Green Bay Area Public Schools, Green Valley Enterprises (Beaver Dam), VIP Services (Elkhorn), Opportunity Development Centers (WI Rapids), Easterseals of Southeast Wisconsin, Inclusa.</p> <ul style="list-style-type: none"> <li>• <u>Take Your Legislator to Work</u>: People with disabilities who have integrated jobs are encouraged to participate in the campaign to raise awareness about the importance of integrated employment by inviting their legislator to visit them at work.</li> </ul>
<p>1.2. By September 30<sup>th</sup>, 2021, 25% more people with I/DD will make choices about their everyday lives.</p>	<ul style="list-style-type: none"> <li>• <u>Sparks Grants</u>: Mini-grants that allow local groups to use innovative methods to spark a change that will improve the lives of people with developmental disabilities in their community. Grantees include: Opportunity Development Centers (WI Rapids), Celebrating Ability (Stoughton), Padres e Hijos en Accion (Madison), People First Fond du Lac, C.R.E.W. (Hales Corners), Transit Task Force Committee (Wausau).</li> <li>• <u>Supported Decision-Making</u>: resources and training to inform stakeholders about this recognized alternative to guardianship</li> <li>• <u>Mind and Memory Matters</u>: Federal grant designed to increase early identification of Alzheimer’s and dementia through outreach to paid and non-paid caregivers for people with ID/DD. Significant focus on Down Syndrome and Alzheimer’s because of their genetic link. Grant ended September 2018.</li> <li>• <u>Self Determination Conference</u>: Annual conference empowers people with disabilities to have more control over their lives by learning more about self-determination and self-directed supports, so they can more live independently, actively participate in their communities, and use public funds efficiently.</li> <li>• <u>National Core Indicators data</u>: Survey used across the country to assess the outcomes of services provided to individuals and families. Indicators address key areas of concern including employment, rights, service planning, community</li> </ul>

	inclusion, choice, and health and safety. DHS has embedded the survey (collection and analysis) into their structure/operations and no longer request funds.
1.3. By September 30 <sup>th</sup> , 2021, 25% more people with I/DD are able to reliably get where they need to go each day.	<ul style="list-style-type: none"> <li>• <a href="#">Sparks Grants</a> – see above</li> </ul>
1.4. By September 30 <sup>th</sup> , 2021, 25% more people with I/DD say they have a network of community members they can rely on.	<ul style="list-style-type: none"> <li>• <a href="#">Building Full Lives</a> – see above</li> <li>• <a href="#">Family Led Groups</a> – Five groups, three of the groups are in Milwaukee, one in Mukwonago and the newest one in Mineral Point. Milwaukee and Mukwonago are in the third year of their grant, Mineral Point in their first year.</li> </ul>

<b>Goal #2</b>	
<b>By September 2021, more people with Intellectual and Developmental Disabilities including those with <a href="#">diverse identities</a> and their families will increase their advocacy efforts, resulting in increased numbers of policies supporting inclusion of people with disabilities in community life as evidenced by:</b>	
Objectives	
2.1. By September 30 <sup>th</sup> , 2021, 25 % more self-advocates will participate in a <a href="#">state self-advocacy organization</a> led by individuals with intellectual disabilities.	<ul style="list-style-type: none"> <li>• <a href="#">People First Wisconsin</a>: Grant to People First Wisconsin and technical assistance supports statewide Self-Advocacy.</li> </ul>
2.2. By September 30 <sup>th</sup> , 2021, 50 % more <a href="#">self-advocates</a> will participate in leadership training	<ul style="list-style-type: none"> <li>• <a href="#">Voting Project</a>: An effort to increase voter turnout and education in the electoral process among members of Wisconsin’s disability community.</li> </ul>

<p>and practice their leadership skills.</p>	<ul style="list-style-type: none"> <li>• <a href="#">Partners in Policy Making</a>: Advocacy and systems change training program to develop a group of seasoned leaders who are able to work on policies and initiatives. About 30 participants each year.</li> <li>• <a href="#">Youth Leadership Forum</a>: Week-long leadership training and career awareness program for high school sophomores, juniors, and seniors with disabilities. About 25 students each summer.</li> </ul>
<p>2.3. By September 30<sup>th</sup>, 2021, 50 % more people with I/DD and their families will participate in cross-disability and culturally diverse leadership coalitions through collaboration with the <b>AIDD Partnership</b></p>	<p>Embedded into all projects</p>
<p>2.4 By September 30<sup>th</sup>, 2021, 25% more people with I/DD with diverse identifies and their families will increase involvement in advocacy activities.</p>	<p>Embedded in all Projects</p> <ul style="list-style-type: none"> <li>• <a href="#">Family Led Groups</a>: See above.</li> <li>• <a href="#">Promise Community Leadership Projects</a>: Supports family members and youth to complete a leadership project of their choice in their community. Approximately 80 projects underway. Grant ends September 2019.</li> </ul>
<p>2.5 By September 30<sup>th</sup>, 2021, 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 increases community participation, decision making and full inclusion.</p>	<ul style="list-style-type: none"> <li>• <a href="#">Take Your Legislator to Work</a>: See above.</li> </ul>





WISCONSIN BOARD FOR PEOPLE  
WITH DEVELOPMENTAL DISABILITIES

# **WISCONSIN BOARD FOR PEOPLE WITH DEVELOPMENTAL DISABILITIES**

## **BYLAWS**

**Draft- January 2018**

## **ARTICLE I PURPOSE AND RESPONSIBILITIES**

### **Section 1. Purpose**

To assure that people with developmental disabilities and their families participate in the design of, and have access to, needed community services, individualized supports, and other forms of assistance that promote self-determination, independence, productivity, integration and inclusion in all facets of community life.

### **Section 2. Responsibilities**

A. Engage in advocacy, capacity building, and systemic change activities that enable people with developmental disabilities to exercise self-determination and be independent, productive, integrated and included in all facets of community life.

B. Submit and carry out a 5-year strategic plan that meets the following requirements:

1. A comprehensive review and analysis of the availability of services for people with DD and the extent of unmet needs;
2. Goals that will achieve the purpose of the program and reflect the unmet needs described above.
  - 2a. At least one goal will establish a program to provide funding for a statewide DD self-advocacy organization, support leadership training for people with DD, and enable people with DD to participate in cross-disability and culturally diverse coalitions.
3. Assurances regarding use of funds, civil rights compliance, quality assurance, et al.

## **ARTICLE II DESIGNATED STATE AGENCY**

The Board is its own Designated State Agency, the agency which receives and controls federal funding. The Board exercises its statutory powers, duties, and functions, including operational planning, independently of any state Department.

### **Section 1. Board Staff**

- A. The Executive Director shall be directly responsible to the Board through the Co-chairpersons. The additional staff members are responsible to the Executive Director.
- B. The staff and other personnel of the Board shall be responsible solely for assisting the Board in carrying out its duties.

## ARTICLE III MEMBERSHIP

### Section 1. Eligibility

The Governor shall appoint Board members for staggered four-year terms as follows:

- A. At least sixty (60) percent of the membership shall consist of people with developmental disabilities or their guardians or immediate relatives, as follows:
  1. They may not be employees of any state agency that provides services under this subtitle.
  2. They may not be managing employees of any entity that receives funds or provides services under this subtitle under federal developmental disabilities funds.
  3. Of this sixty percent, at least one-third shall be people with developmental disabilities, and at least one-third shall be immediate relatives or guardians of people with developmental disabilities. The remaining one-third shall include a combination of the two groups.
  4. One member must be a person who lives in or previously lived in an institution, or an immediate relative or guardian of such a person.
- B. Local agencies, non-governmental agencies, and private nonprofit groups concerned with services for individuals with developmental disabilities
- C. Representatives of relevant State agencies are appointed to the Board by the Secretary or Director of the agency. These agencies include
  1. State agencies that administer funds provided under Federal laws related to individuals with disabilities, including
    - a. the Rehabilitation Act (DVR),
    - b. the Individuals with Disabilities Education Act (DPI),
    - c. the Older Americans Act, Maternal & Child Health, and Medical Assistance (DHS).
  2. The University Center for Excellence in Developmental Disabilities (UW Waisman Center)
  3. The State protection and advocacy system (Disability Rights Wisconsin) State Agency representatives shall-
    - (i) have sufficient authority to engage in policy planning and implementation on behalf of the agency or program they represent; and
    - (ii) recuse themselves from any discussion of or votes on grants or contracts, if their agencies or programs are grantees, contractors, or applicants

- (iii) State Agency representatives may appoint designees to attend meetings and vote when the representative cannot attend.

### **Section 2. Term Limits**

Members may be appointed to no more than two consecutive four-year terms, except that members whose terms expire may continue to serve until a successor is appointed.

An individual shall be eligible for reappointment two years after completion of his or her second consecutive term.

### **Section 3. Election of Officers**

- A. Board members shall elect a vice chair and chair every two years. The chair will appoint 3 at-large members to serve on the Executive Committee for a two-year term.
- B. Members eligible for executive committee include consumers (people with developmental disabilities/parents/immediate family members), providers or non-governmental (advocacy) agency members who have at least one year's experience on the Board.
- C. Elections shall take place at the annual meeting of the Board. Newly elected officers shall assume their respective offices upon completion of the annual meeting.

## **ARTICLE IV BOARD MEETINGS**

### **Section 1. Meetings**

- A. The annual meeting of the Board shall be held in July. Regular meetings shall be held at least four times yearly, unless determined otherwise by a majority vote of the Board.
- B. At the option of the co-chairpersons, emergency meetings may be called to consider issues that require action between regular meetings.
- C. Special meetings shall be called by the co-chairpersons upon the written request of three members of the Board.

### **Section 3. Public Participation**

Meetings are open to the public. The agenda for each meeting includes time for public comment.

### **Section 4. Conduct of Meetings**

- A. Meetings shall be conducted in accordance with Robert's Rules of Order, Newly Revised, unless otherwise provided herein.

- B. A quorum shall consist of a simple majority of total membership.
- C. Voting by proxy is not permitted, except that State Agency representatives may appoint designees to vote in their absence.

### **Section 5. Agendas**

- A. Prior to every Board meeting, an agenda shall be distributed to each member and staff. In accordance with Executive Order #235 the agenda and other meeting information will be posted to the Wisconsin Public Notice website. Public notice including the agenda will be posted to the official Public Notice newspaper (which is subject to change) and will be posted in at least two other public areas, to be in line with Open Meeting law.
- B. Requests for items to be included on the board meeting agenda shall be submitted to the Board Chair at least two weeks prior to the Executive Committee meeting.

### **Section 6. Attendance Requirements**

- A. A Board member absent from three consecutive meetings shall receive a formal communication from the co-chairs concerning the member's desire/ability to remain on the Board.
- B. The Board co-chairs may excuse a member's absence for good cause.
- C. Board members, with the exception of state agency representatives, shall not designate persons other than themselves to attend meetings and have voting responsibility.

## **ARTICLE V COMMITTEES**

### **Section 1. Standing Committees**

- A. There shall be three standing committees: Executive, Diversity, and Nominating and Membership.

### **Section 2. Election of Executive Committee**

- A. The Executive Committee has five members: 1 Chair, 1 Vice Chair and 3 at-large members appointed by the Chair at the July meeting.
- B. A quorum of the Executive Committee shall consist of three members.
- C. Members of the Executive Committee must have at least 1 years' experience on the Board at the time of taking office. Membership shall be representative of each category of Board membership whenever possible.

### **Section 3. Appointments to other Standing Committees**

- A. Committee chairpersons and vice-chairpersons shall be appointed annually by the Board chairperson.
- B. Committee members shall be appointed by the Board chairperson after consultation with individual Board members and committee chairs.
- C. All standing committees shall consist of no fewer than six members, all of which shall be Board members.
- D. Each Board member shall participate regularly on at least one standing committee.

### **Section 4. Time of Meetings**

- A. Standing and ad hoc committees may determine their own meeting schedules.
- B. Meeting notices and agendas shall be distributed to the public.

### **Section 5. Attendance Requirements**

- A. A committee member absent from three consecutive committee meetings shall receive formal communication from the Board chairperson concerning the member's desire/ability to remain on the committee.

### **Section 6. Conduct of Meetings**

- A. Meetings shall be conducted in accordance with Robert's Rules of Order, Newly Revised, unless otherwise provided herein.
- B. Voting by proxy is not permitted.
- C. A standing committee quorum exists when the chairperson or vice- chairperson of the committee and at least one other committee member or (in the case of a state agency member) his/her alternate is present
- D. An ad hoc committee quorum exists when the majority of the committee members present are Board members or alternates.

### **Section 7. Staffing of Committees**

- A. Each Board committee shall be assigned at least one staff member.
- B. The committee chair, in consultation with the Executive Director, shall determine the responsibilities of committee staff, which may include:
  - 1. Consult with the committee chairperson and make meeting arrangements.

2. Prepare meeting announcements and agendas, notify committee members, and attend and take minutes
3. Prepare committee reports, issue papers, minutes of meetings, and other documents as needed by the committee

### **Section 8 Committee Reports**

- A. Standing committees shall report to the Board at each meeting. The committee chairperson, vice-chairperson or her/his designee shall make the report.
- B. When committee reports require Board action, the issue requiring action shall have been voted on with one half of the membership present.
- C. Standing committees may report to the Board as a Committee of the Whole if quorum was prohibitive

### **Section 9. Standing Committees and Functions**

- A. Executive Committee
  1. Provide policy direction to, and annually evaluate the performance of, the Executive Director.
  2. Review the overall function of the Board and make recommendations for improvement.
  3. Annually review and recommend approval of the budget and use of any reallocated federal funds to the full Board.
  4. Annually review and recommend changes in the bylaws.
  5. Set meeting agendas.
  6. Determine participation in national meetings and trainings.
- B. Nominating and Membership Committee
  1. Present, in writing, a slate of nominees for officers and members of the Executive Committee 30 days before the annual meeting.
  2. Organize outreach/recruitment efforts to find people to recommend for appointment to the Board.
  3. Participate in planning and attending orientation for new members
  4. Recommend further training for members to ensure an effective Board.
- C. Diversity Committee
  1. Develop and monitor progress of overall diversity and outreach workplan.

2. Brainstorm and share ideas for outreach opportunities.
3. Review materials, products and trainings for cultural competency.

### **Section 10. Ad Hoc Committees**

- A. Ad hoc committees shall be created at the discretion of the Board to oversee activities related to the State Plan or other areas of interest and/or concern to the Board. Ad Hoc Committees shall have a specific charge and duration, which may be extended at the discretion of the Board.
- B. The Board chairperson shall appoint a Board member to chair an ad hoc Committee
- C. Membership on the ad hoc committees may include non-Board member consumers, family members and others with specific expertise and life experiences when appropriate and needed co-chair.

### **ARTICLE VI CONFLICT OF INTEREST**

- A. A Board or committee member shall not use her/his position to obtain anything of value (money, property, favor, service, payment, loan or promise of future employment.) for:
  1. The member.
  2. His/her immediate family.
  3. An organization in which the member, or someone in his/her immediate family:
    - a. is a director, officer, trustee, employee or paid consultant
    - b. owns or controls an equity interest, voting rights, or outstanding indebtedness.

### **Section 2. Disclosure**

If any of the conditions in Article VI, Section A, exist, a Board member shall disclose her/his interest and refrain from voting, or participating in any deliberation, on the proposal.

### **ARTICLE VII AMENDMENTS**

- A. The bylaws may be amended, or new bylaws adopted, after thirty days written notice, by a two-thirds vote of the Board members present at a regularly scheduled meeting.



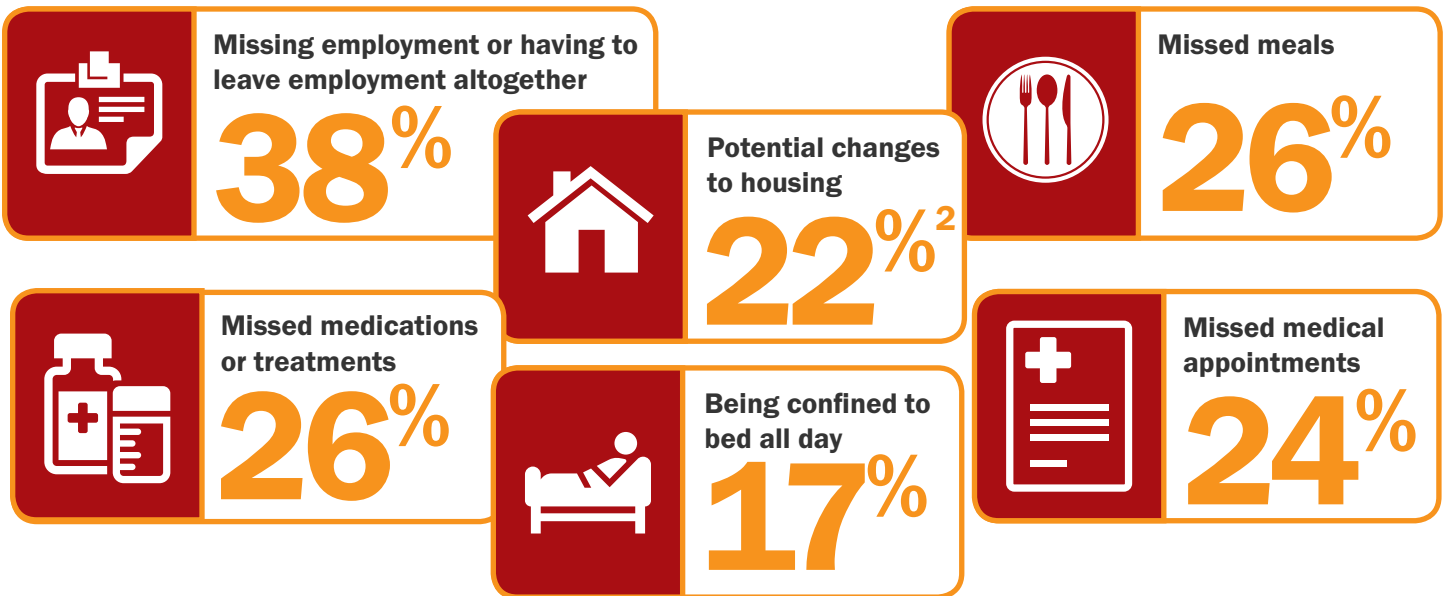
- B. To the extent that any provision of the bylaws is determined to conflict with federal or state law, the provision shall be deemed null and void and the Board will amend the provision to comply with law.

For consideration: January 2019

# Support the Professional Direct Care Workforce: Keep People in Their Homes

■ In Wisconsin a shortage of professional direct care workers has created a crisis for people with disabilities, older adults, and their families. **The need for direct care workers is projected to increase by an additional 20,000 workers by 2026<sup>1</sup>.**

When there is no direct care worker, Wisconsin residents with disabilities describe these common impacts on their daily lives:



■ In 2016, a statewide survey of more than 500 people who rely on direct care services and their families found **95% had trouble finding workers, 85% did not have enough workers to cover all their shifts, 43% couldn't find a worker 7 or more times per month, and 60% said they get sick more often when they do not have enough staff<sup>3</sup>.**

■ In Wisconsin, the annual worker turnover rate is **more than 50% and can be as high as 67%<sup>4</sup>.**

■ Currently, **70% of personal care agencies are unable to staff all hours needed, and 93% of agencies find it difficult to fill job openings<sup>5</sup>.**

■ In Wisconsin, **51% of Home Care workers and 38% of Nursing Home workers rely on some form of means-tested public benefits<sup>6</sup>.**

■ **29% of the Home Care workforce are on Medicaid; 35% of Nursing home workers on Medicaid<sup>7</sup>.**



**71% of Home Care and 70% of Nursing home workers are below 300% of the Federal Poverty Line; 22% and 18% are below 100% FPL respectively<sup>8</sup>.**

# Recommendations



Direct Department of Health Services (DHS) to create a Medicaid Buy-In waiver for direct care workers and unpaid caregivers. Many direct care workers are also Medicaid BadgerCare recipients. A Medicaid Buy-In model would allow workers to earn and save more in exchange for paying a premium, may encourage worker retention, and encourages workers to contribute more hours to Wisconsin's caregiving needs.



Direct DHS to include a mechanism within their rate setting formula to adjust direct care worker pay rates upward in counties adjacent to borders of other states (Iowa, Minnesota, Illinois, Michigan) so Wisconsin direct care worker rates are competitive with the rates in adjacent states. In some areas, Wisconsin workers are commuting and working across the border because the wages are higher; this exacerbates the existing worker crisis for Wisconsin residents living in border areas.



BPDD supports legislative efforts to address other factors that contribute to direct service worker turnover and vacancy rates including low wages, few or no benefits (including health insurance, paid time off, and retirement savings plans), transportation costs associated with commuting to client's homes, and lack of training/career advancement opportunities.



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<sup>1</sup> State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

<sup>11</sup> Wisconsin Personal Services Association.

<sup>2</sup> Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

<sup>3</sup> Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

<sup>4</sup> State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

<sup>5</sup> Wisconsin Personal Services Association.

<sup>6</sup> <https://phinational.org/policy-research/workforce-data-center>

<sup>7</sup> <https://phinational.org/policy-research/workforce-data-center>

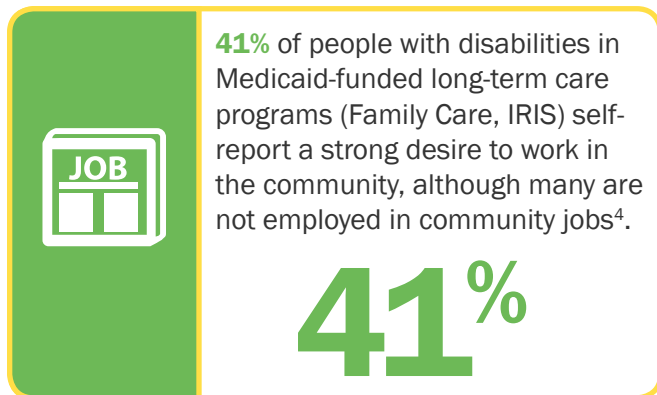
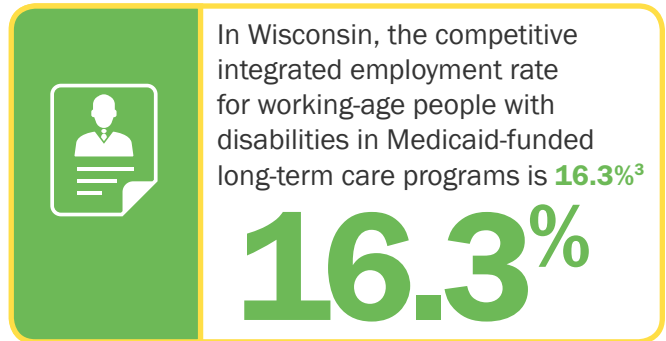
<sup>8</sup> <https://phinational.org/policy-research/workforce-data-center>

# Increasing Competitive Integrated Employment

**Nationwide, the employment rate for people with disabilities is only 17.9%, compared with 65.3% for the general population.**

■ Wisconsin's bi-partisan Employment First legislation, signed into law in 2018 by Governor Walker, recognizes community integrated employment as a priority for people with disabilities.

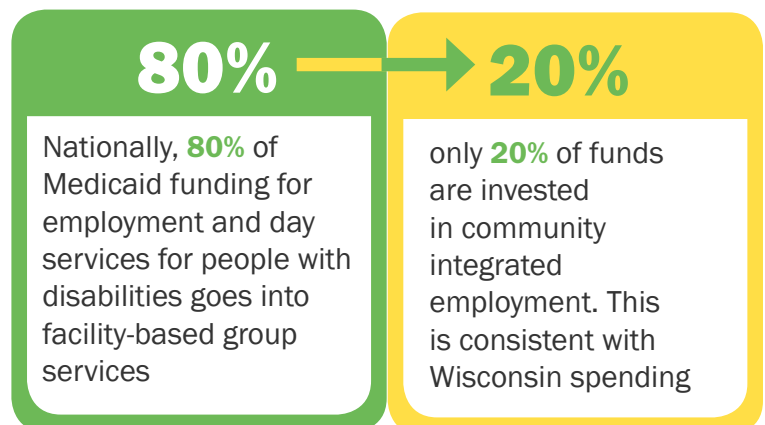
■ Wisconsin's Department of Health Services (DHS), in conjunction with a diverse group of disability stakeholders has developed community integrated employment principles<sup>1</sup> and is committed to increasing the number of people in Wisconsin's long-term care programs (Family Care, IRIS) that are working in the community<sup>2</sup>.



■ Wisconsin families want more employment choices. BPDD hears from many families and people with disabilities that they do not have the employment choices and options they want; many want to choose community integrated employment but are frustrated by provider's lack of capacity to offer those choices.

■ **More than 40%** of people with developmental disabilities participating in Medicaid-funded sub-minimum wage pre-vocational facilities say they want to or would consider community employment<sup>5</sup>.

**Some WI facility-based providers already are shifting their business models towards community integrated employment supports to respond to families and people with disabilities who want work in the community with positive results.**



# Recommendations



Create a one-time appropriation within the 2019-21 budget establishing an Employment Service Provider Transformation Fund for the purpose of transitioning the business models of long term care employment service providers to move people who have shown interest in working in community integrated employment into competitive-wage community jobs. Direct DHS to administer the appropriation as a competitive grant process that provides funding for technical assistance and uses a pay for performance model to award additional dollars to grantees based on the number of individuals that transition into sustained competitive-wage community jobs. Require the Department to develop and report on measurable outcome criteria that demonstrates sustainable policy and practice changes that will continue focus on and result in increasing community integrated employment for each grantee.”

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Direct the Department of Children and Families to create an Individual Development Account (IDA) program, modeled after success in the PROMISE Youth Supplemental Security Income pilot project<sup>6</sup>, which matches youth earnings to finance work-related expenses.

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Provide adequate Medicaid funds to provide employment supports to people with developmental disabilities who are eligible for Family Care but do not meet the nursing home level of care.



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<sup>1</sup> <https://www.dhs.wisconsin.gov/publications/p01786.pdf>

<sup>2</sup> Wisconsin's Medicaid-funded long-term care programs recognize community integrated employment is more cost-effective than facility-based employment, and that a shift to this type of employment is necessary for fiscal sustainability in state programs. Wisconsin Dept. of Health Services' 2014 report on sustainability <https://www.dhs.wisconsin.gov/publications/p0/p00590.pdf>

<sup>3</sup> Department of Health Services data pulled April 2017 from Long Term Care functional screen and Program Participation System (PPS) employment data.

<sup>4</sup> Wisconsin's National Core Indicators 2015-2016 survey.

<sup>5</sup> Department of Workforce Development Wisconsin WIOA Career Interview Project 2016-2017 Annual Report - a survey of sheltered workshop participants required under Section 511 of the Workforce Innovation Opportunity Act. It is estimated that a great majority of the 6,509 subminimum wage employees who were interviewed are also long-term care program (Family Care, IRIS) participants, many receiving facility-based pre-vocational services. <http://www.uww.edu/Documents/csd/WIOWA/Annual%20Interview%20Report%20FY2017.pdf>

<sup>6</sup> Wisconsin's PROMISE grant—funded by the Social Security Administration—has demonstrated tangible ways to double the number of youth with disabilities that have community-based paid work experiences that translate into a lifetime of employment and can help lift entire families out of poverty.

# Education



Wisconsin public schools educate about **118,000 students with disabilities**. Students with disabilities represent **14%** of the total student population.

- Research clearly shows that more than **99% of students** – including those with the most significant intellectual disabilities – **can learn grade-level content in the general education curriculum and achieve proficiency on grade level standards with the appropriate supports**.
- **Poor educational preparation of students with disabilities translates into a lifetime of high unemployment, lower wages,** and greater reliance on public benefit programs.

**In a 2018 Survival Coalition survey<sup>1</sup> of almost 600 parents of students with disabilities:**

**58%**

58% indicated concern for their child's future due to lack of special education funding.

**47%**

47% reported their child was more socially isolated in school

**38%**

38% reported a reduction in special education supports and resources



**35%**

35% say their child is not making the same progress in the last 1-2 years.

**15%**

15% said their child was placed in a more restrictive setting.

# Recommendations



Support the Department of Public Instruction's (DPI) budget proposal to increase special education categorical aid funding to 60% of costs, up from 26% addressing a decade long funding freeze.

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Enhance the current school accountability system to ensure that schools of all kinds – public, voucher, charter, County Children with Disability Education Boards (CCDEBs) report similar data regarding academic achievement and educational experiences of students with disabilities that allows families to make informed choices and compare between options.

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Raise the total amount of Transition Readiness grants from the current \$1.5 million up to \$5 million annually to better prepare students with disabilities for employment and life after high school.



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<sup>1</sup> [http://www.survivalcoalitionwi.org/wp-content/uploads/2018/05/SurvivalCoalitionReportBooklet0518\\_Final.pdf](http://www.survivalcoalitionwi.org/wp-content/uploads/2018/05/SurvivalCoalitionReportBooklet0518_Final.pdf)

<sup>2</sup> Community conversations have proven to be an extremely successful strategy for raising community and employer expectations for youth with disabilities, cultivating local commitment and getting youth jobs. These conversations would require participation from area employers, community leaders and other stakeholders.

# Ensure More People With I/DD Retain Their Rights and Have Support They Need to Make Choices in Their Lives

- People with disabilities can acquire new skills and decision-making capacity throughout their lives.
- Everyone, no matter their limitations, needs opportunity, experience, and support in order to learn how to make well-informed decisions. This include the opportunity to make and learn from mistakes.
- Too often, families of people with disabilities are advised—often when a child is just 17—to obtain guardianships, which once imposed are rarely changed or reversed.
- In many cases, restrictive guardianships can limit opportunities to make decisions, learn from mistakes, and impact individual’s “dignity of risk.”

**Under Wisconsin law, all adults are considered to have the capacity for decision-making.**



**34,000**

There are almost **34,000** people under guardianship in Wisconsin<sup>1</sup>

**\$690,000,000**

More than **\$690,000,000** in assets under the supervision of a guardian<sup>2</sup>

**6,000**

Almost **6000** guardianship petitions were filed in 2016 alone; the median age at disposition was 40.

- When guardianship is imposed at a young age, the court is limited in its ability to project the maturation and capacity-building that will occur over the course of a person’s lifetime.
- There is a need for an additional option in Wisconsin guardianship law that gives young people the time needed for their brains to fully mature, gain life experience, and practice with decision-making, and offers an opportunity to re-assess competency<sup>3</sup>.
- In addition, many families that pursue and obtain guardianships do not fully understand the what role and responsibilities of a guardian are under Wisconsin law.
- There is no consistent approach or capacity across the state to offer routine training to guardians—on roles, responsibilities, and duties required of guardians under the law<sup>4</sup>.
- There is a need for standardized, required training for guardians with a formal infrastructure to support and monitor training.



# Recommendations



Create a time-limited guardianship option within the statutes when the petition for guardianship is sought between the ages of 17 and 9 months and 25. Require an automatic review of the guardianship—with limited exemptions—so the court has the opportunity to review additional decision-making, life experiences, and other evidence of the individual’s growth and decision-making capacity. Wisconsin law requires the preservation of an individual’s civil rights to the greatest extent possible, the review process would enable the court to determine whether the terms of the guardianship can be modified, kept the same, or removed completely.



Create requirements within the statutes that specify core topics in which all guardians of the person and estate must be trained, a timeline by which core training must be completed, establish continuing education requirements for all guardians, and establish an advisory committee and oversight agency to administer the training program.



<sup>1</sup> 2015 Wisconsin Consolidated Court Automation Programs (CCAP) analysis conducted in August 2015 for Wisconsin’s Working Interdisciplinary Network of Guardianship Stakeholders (WINGS) group, formed to improve the court system’s ability to work with the elderly and other vulnerable groups in reducing abuse and improving guardianship practice.)

<sup>2</sup> This does not include money in small estates under \$50,000 where many counties do not require accountings to be filed; actual assets under supervision of a guardian would be greater than \$700,000,000.

<sup>3</sup> Several states have incorporated into their statutes an automatic court review process to evaluate whether to modify, continue, or terminate an existing guardianship. Kentucky, North Dakota, Missouri, Connecticut, Michigan, New Mexico, and the District of Columbia all have guardianship review or expiration processes within their statutes. [https://www.americanbar.org/content/dam/aba/administrative/law\\_aging/restoration%20report.authcheckdam.pdf](https://www.americanbar.org/content/dam/aba/administrative/law_aging/restoration%20report.authcheckdam.pdf)

<sup>4</sup> Currently, Wisconsin does not have any training requirements for family or volunteer guardians. Wisconsin requires limited training for Corporate guardians under Admin Code DHS 85.01. Some County Registrars of Probate are trying to offer voluntary trainings for guardians in their jurisdiction, despite having no budget to do so. Counties investing in training events assert these trainings save county-funded monitoring and enforcement work. Twenty-one states have training requirements for all guardians. Wis. Stats. 54.18(1).

# Medicaid and Medicaid-funded Long-term Care

Medicaid funds health and long-term care services provided under the Forward Health Card and 20 Wisconsin Medicaid programs—including BadgerCare, MAPP, Family Care, IRIS, Children’s Long-Term Support program, etc.

■ Medicaid provides services and supports that people with disabilities rely on—such as **personal care, school therapies, prescription drugs, transportation, job coaching and employment services, and mental health and substance use disorder services**—that are not available or are not available at the level needed on the private insurance market.

**50%**

50% of people with disabilities in Wisconsin rely on Medicaid.

**70%**

The vast majority of Medicaid funding—70%—is spent on people with disabilities and older adults.



■ Wisconsin Medicaid waiver programs (Family Care/IRIS) keep people with disabilities and older adults in the community, and out of costly facilities like nursing homes.

**26%**

Overall, care in the community is 26% less expensive than nursing home care

■ Family Care/IRIS have successfully supported people with complex needs in their own homes and community, including people who have previously lived in state institutions (ICF/IDs)<sup>1</sup>.

# Recommendations



Create a Medicaid waiver for “pre-Medicaid” individuals. Wisconsin could use its waiver authority to grant access to a limited package of Home and Community Based setting (HCBS) services for low income older adults, family caregivers, and people with disabilities who are financially eligible for Medicaid and need supports to remain independent in their homes, but do not yet meet the nursing home level of care required by Family Care/IRIS.

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Create a DHS appropriation line for continuous outcome improvement initiatives for the improvement of employment, transportation, and community living outcomes for people with disabilities, and analysis of innovation project outcomes within Family Care/ IRIS.

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Facilitate successful transition of the remaining residents of state facilities regulated as institutions (ICF-IDs) into Family Care/IRIS, maintain funding and expand access to the Adaptive Aids program and diagnostic capacity housed within Central Wisconsin Center to all state residents.

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Direct DHS to provide a central point of contact for families of children with disabilities for information, assistance, and eligibility determination for the Children’s Long-Term Support (CLTS) waiver and Medicaid card services, and navigators to help families access resources already available in their health, community, and school system.

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Provide adequate funding to ensure that all counties have the capacity to enroll all children eligible for the Children’s Long Term Support (CLTS) waiver program.



<sup>1</sup> Wisconsin spends an average of almost \$180,000 per year for each person living in a state-run institution compared to \$33,000 per year for each person receiving Home and Community Based waiver services (Family Care or IRIS). <https://risp.umn.edu/sites/risp.umn.edu/files/2018-03/Wisconsin-RISP-2016.pdf>

# Public Benefit Reform



People with disabilities may rely on multiple public benefit programs—including Medicaid, FoodShare, public housing, and Social Security Income or Disability Insurance—to access the health care, food, housing, and funding they need to live independently and stay out of institutions.

## 46%

46% of Wisconsin families receiving FoodShare have at least one member who is elderly, blind, or has disabilities<sup>1</sup>.

## 38%

38% of all households in a public housing program include a member who has a disability.

## 41%

41% of working-age public housing tenants have a disability<sup>3</sup>

## 15%

Nationally people with disabilities account for 15% of total Medicaid enrollment.

## 30%

Medicaid covers more than 30% of working age adults with disabilities<sup>2</sup>.

- Many people with disabilities want to make improvements in their lives—like becoming employed, increasing income, covering more transportation costs—but cannot take opportunities without losing benefits. **This so-called “benefits cliff” keeps many people with disabilities in poverty and reliant on public benefits.**
- **Unfortunately, strict income and asset limits—which may vary by program—mean working too much or for too high a wage or saving enough to cover larger bills (like a car repair, or first/last month rent and deposit money) is impossible** and can jeopardize eligibility for some or all the public supports the person needs to remain independent.
- There is no tiered path across public assistance programs for people with disabilities to gradually increase their income and assets while maintaining access to some or all supports across public benefit programs.
- **14% (or 1,820,000 people)** of SSI and SSDI beneficiaries have an intellectual/developmental disability (I/DD). More than **20%** of SSI recipients and **8%** of SSDI recipients have a primary impairment of I/DD<sup>5</sup>.
- Adults with disabilities who rely on Supplemental Security Income (SSI) are among the groups most severely affected by the extreme shortage of affordable rental housing. **There is no housing market in Wisconsin where a person would pay less than 68% of their SSI income towards renting a one-bedroom unit<sup>4</sup>.**

# Recommendations



To the extent allowable under federal law, align public benefit eligibility criteria for people with disabilities—including income levels, asset limits, and income exclusions—across Medicaid, FoodShare, Housing, and other public benefit programs Wisconsin administers.

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Direct DHS to use administrative Medicaid funds for housing-related activities like assisting with housing applications, developing a housing support plan, and providing tenant support services.

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Require disability advocate and stakeholder involvement before proposing changes to eligibility or other administrative requirements within public benefit programs and continue stakeholder engagement throughout any change or transition process.



<sup>1</sup> Wisconsin Department of Health Services, FoodShare at a Glance, March 2017.

<sup>2</sup> Figure includes people with physical disabilities, such as cerebral palsy, multiple sclerosis, and traumatic brain or spinal cord injuries as well as intellectual or developmental disabilities such as Down syndrome and autism; and mental illness.

<sup>3</sup> U.S. Department of Housing and Urban Development (HUD), Resident Characteristics Report as of December 31, 2017 ([https://hudapps.hud.gov/public/picj2ee/Mtcsrcc?category=rcc\\_ftp&download=false&count=0](https://hudapps.hud.gov/public/picj2ee/Mtcsrcc?category=rcc_ftp&download=false&count=0)).

<sup>4</sup> <http://www.tacinc.org/knowledge-resources/priced-out-v2/>

<sup>5</sup> All data from <https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html>

# Transportation

- People with disabilities are not able to get where they need to go on their schedule.
- Lack of transportation can mean people with disabilities are **unable to commute to work, get to medical and other necessary appointments, conduct civic business** (court house, post office, polling places), **go grocery shopping, or visit family and friends.**
- Barriers to transportation for people with disabilities include; **limited transportation on weekends and evenings, transportation options or routes not going where people need to go, rides being canceled or not arriving on time, and lack of accessible transportation.**
- Other barriers to transportation include **high fares or unaffordable rates, one-ride one purpose programs** that do not allow people to use the same ride to accomplish multiple tasks, **fragmented transportation systems** that fail to connect to each other (between towns, across county lines etc.).
- **If rides don't come or are late, it can cause other disruptions in an individual's life.** Increased costs can result when more transportation must be scheduled, appointments are missed, or jobs are lost because unreliable transportation makes commuting impossible.

**Access to transportation is consistently the top concern for people with disabilities in Wisconsin.**



# Recommendations



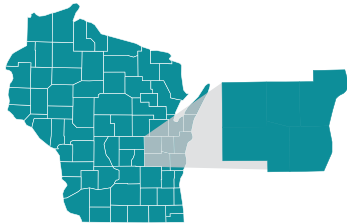
Direct DHS to require inclusion of transportation as a component of employment outcomes for long-term care (Family care or IRIS) participants and establish three to six commuter pilot programs for long participants who are working in community integrated employment or receiving community integrated employment services that are anticipated to result in a community integrated job compliant with the home and community based settings (HCBS) settings rule within the timeframe of the pilot project.

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Reform the Non-Emergency Medical Transportation (NEMT) brokerage to ensure pay for performance billing for all NEMT rides, establish additional criteria for the NEMT broker, and establish independent oversight and quality assurance of NEMT services.

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Incentivize a regional approach to transportation by creating statutory language allowing counties and municipalities to pool and coordinate existing sources of public and other transportation funding, and creating appropriation lines specifically for regional entities pooling funding to create, expand, and maintain public transportation capacity within the region.



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