



Board Meeting Packet

July 18-19, 2018
The Jefferson Street Inn
201 Jefferson St
Wausau, WI 54403



Board Meeting

The Jefferson Street Inn • Wausau, Wisconsin • July 18th-19th, 2018

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July 1, 2018

BPDD Board Members,

Welcome Summer! Summer is a time that we retreat from our day to day work and spend some time refueling ourselves. I am anxious to spend time with all of you away from my daily work. I'm excited to reconnect with all of you for the purpose of improving the independence, productivity, and integration of people with developmental disabilities.

I encourage every one of you to come to the Board Retreat open to learn, eager to explore and ready to renew your purpose for serving on the board.

Thank you for all you are doing in your community and around the state. It is truly a pleasure to be part of true "Working" Board.









Sincerely,

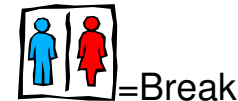
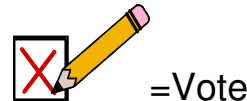
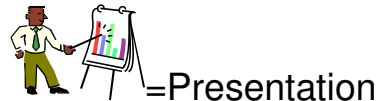
Pam Malin

Chair, Wisconsin Board for People with Developmental Disabilities









BOARD RETREAT JULY 18-19TH, 2018

WEDNESDAY, JULY 18TH, 2018

Time	Symbol	Topic	Facilitator/Presenter
11:00-11:45 PM		Welcome Overview of Retreat, Outcomes, Motivation & Engagement	La Toya Sykes
11:45-12:30 PM		Lunch Room:	All
12:30-1:30 PM		Housekeeping Warm-up Exercise	La Toya Sykes
1:30- 2:45 PM		Exercise 1 Appreciations/Accomplishments Value Exploration/Self Care	La Toya Sykes
2:45-3:00 PM		Break	All
3:00-4:30 PM		Exercise 2 Communication Strategies	La Toya Sykes
4:30-5:00 PM		Review of plans for Thursday	La Toya Sykes
6:00-8:00 PM		Community Conversation/Dinner	All



THURSDAY, JULY 19TH, 2018

Time	Symbol	Topic	Facilitator/Presenter
7:45-8:30 AM		Breakfast	All
8:30-9:00 AM		Welcome -Information Recall	La Toya Sykes
9:00-10:15 AM		Team Building Exercise -How to fall in love with your work again	La Toya Sykes
10:15-10:30 AM		Break – FILL OUT, SIGN, AND RETURN TRAVEL VOUCHERS to BPDD STAFF	All
10:30-12:00 PM		Next Step Exercise	La Toya Sykes
12:00-1:00 PM		Lunch	All
1:00-2:00 PM		BPDD Budget Platform Discussion	Tami J/Beth S
2:00-3:00 PM		Retreat Review & Close	La Toya Sykes



= Meal



=Meeting



=Presentation



=Vote



=Walking Activity



=Break

BOARD MEETING MINUTES

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

Present:	Chair: Pam Malin Vice Chair: Elsa Diaz-Bautista; Barbara Beckert, Aliza Claire Bible, Lynn Carus, Kevin Coughlin, Meredith Dressel, Ramsey Lee, Nathaniel Lentz, David Pinno, Delores Sallis, Lynn Stansberry-Brusnahan, Carole Stuebe, Liz Hecht, Patrick Young, Patrick Friedrich, Rita Fuller, Daniel Parker, Leila Solati, Kedibonye Carpenter
Absent:	Michael Hineberg, Wendy Ackley, Gail Bovy, Camille Nicklaus,
Staff Present:	Brenda Bauer, Fil Clissa, Natasha Fahey-Flynn, Jeremy Gundlach, Tami Jackson, Beth Swedeen,

Chair Pam Malin called the meeting to order at 12:40 PM.

1. Chair Report:

- Pam introduced BPDD's two new board staff. Molly Cooney is now staff for employment projects, state plan and diversity. Jeremy Gundlach is the communications specialist for BPDD and he also is the main contact for board member support.
- The board gave introductions as we have new board members/staff.
- We also talked about moving the dates of our September board meeting to September 25-26. All members present agreed on new dates.

2. Executive Director Report:

- Beth gave an update on staff Jenny's recovery status for her medical leave.
- Employment First conference is on Tuesday May 22nd and the focus has changed to educate service providers about employment and how to get people with disabilities in the community.
- Beth gave updates on our Partners in Policymaking application: It is now open and on our website.
- A group of board members went to the Disability Policy Seminar in DC during April.
- Beth gave an update on the board's funding on a federal level which is changing how long DD councils have to spend their money.

3. Executive Committee Report:

- Chair Pam Malin gave an update on the July board retreat. La Toya Sykes will be facilitating our retreat. One of the themes for the board retreat is to reflect and re-energize.
- There are several board members that will be heading to DC for the NACDD trip in July: Gail Bovy and Elsa Diaz-Bautista.

4. Government Affairs Committee Report:

- All board members were present for this meeting.

5. Nominating & Membership Committee Report:

- Greg talked about our current membership and how we have two open parent positions. After July we will also have a self advocate position open.
- Greg talked about creating position descriptions for each committee's chair, vice chair and members.

6. Diversity Committee Report:

- Partners in Policymaking 2019-2020 will have its first three meetings in Milwaukee.
- The September board meeting will be at Alianza and Independence First.
- New board member Kedi talked about some taglines and ideas to promote the diversity committee's goals. Specifically, Ubuntu which means "I am because We are"
- Elsa has volunteered to do the welcome for our conversation with the people from the Hmong community during our retreat.
- Elsa is also going to help gather information about Hmong culture that we'll share in the board packet so that we can all learn ahead of time.
- Barbara gave an update on DRW's diversity project. Delores hosted the group at Parent University in April.

7. Action Items:

Motion to accept the March, 21, 2018 minutes was made and seconded. The motion passed unanimously.

8. Agency Updates:

DRW- See Attached

DHS- See Attached

Waisman- See Attached

DVR- See Attached

DPI- See Attached

9. Other Agenda Items:

-

Motion to adjourn Patrick Young at 2:27 PM; seconded by Nathaniel Lentz.

Unanimously passed.

Board Meeting Dates & Locations:

January 17 & 18, 2018	Sheraton Madison Hotel 706 John Nolen Dr Madison, WI 53713		
March 21, 2018	Concourse Hotel 1 W Dayton St Madison, WI 53703		
May 16 & 17, 2018	Sheraton Madison Hotel 706 John Nolen Dr Madison, WI 53713		
July 17, 18 & 19, 2018	Jefferson Street Inn 201 Jefferson St, Wausau, WI 54403 http://www.jeffersonstreetinn.com/#gref		
September 25 & 26, 2018	Alianza- Sept 25 1615 S 22 nd St Milwaukee WI, 53204	Independence First-Sept 26 540 S 1 st Street Milwaukee WI, 53204	Lodging- TBD
November 14 & 15, 2018	Premier Park Hotel 22 S Carroll St Madison WI, 53703		

Executive Committee Meeting Dates

February 8 th , 2018	3:00-4:00 PM
April 12 th , 2018	3:00-4:00 PM
June 14 th , 2018	3:00-4:00 PM
August 9 th , 2018	3:00-4:00 PM
October 11 th , 2018	3:00-4:00 PM

Other BPDD Dates:

March 20, 2018	Disability Advocacy Day
May 22, 2018	Employment First Conference
October 29-31, 2018	Self-Determination Conference

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

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 BPDD Board Meeting
 BPDD Executive Committee Meeting
 Holiday

 Self-Determination Conference / Disability Advocacy Day / Employment Conference
 Partners in Policymaking



WISCONSIN BOARD FOR PEOPLE
WITH DEVELOPMENTAL DISABILITIES

BPDD Committee Assignments 2017 – 2018

<p><u>Executive Committee</u></p> <ul style="list-style-type: none"> • Pam Malin: Chair • Elsa Diaz-Bautista: Vice Chair • Patrick Young: Past Chair • Greg Meyer: Nom Co-Chair • Claire Bible: Nom Co-Chair • Gail Bovy: GA Chair • Lynn Carus: Diversity Chair • Carole Stuebe <p>Staff liaison: Beth Swedeen</p>	<p><u>Diversity Committee</u></p> <ul style="list-style-type: none"> • Lynn Carus: Chair • Barbara Beckert: Vice Chair • Elsa Diaz-Bautista • Nathaniel Lentz • Delores Sallis • Rita Fuller • Meredith Dressel • Kedibonye carpenter <p>Staff liaison: Molly Cooney*</p>
<p><u>Governmental Affairs Committee</u></p> <ul style="list-style-type: none"> • Gail Bovy: Chair • David Pinno: Vice Chair <p>Starting January 2017, the Governmental Affairs Committee will be a committee of the whole. All board members will now sit on this committee.</p> <p>Staff liaison: Tami Jackson</p>	<p><u>Nominating and Membership Committee</u></p> <ul style="list-style-type: none"> • Claire Bible: Co-Chair • Greg Meyer: Co-Chair • Ramsey Lee • Greg Meyer • Lynn Stansberry-Brusnahan • Carole Stuebe • Patrick Young • Nathaniel Lentz • Patrick Friedrich • Leila Solati <p>Staff liaison: Jenny Neugart</p>

** Still open for others to sit on this committee

* Interim until position is filled

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	Eau Claire Area-TBD
September 18 & 19, 2019	TBD-Milwaukee Area
November 13 & 14, 2019	TBD

Executive Committee Meeting Dates

February 7 th , 2019	3:00-4:00 PM
April 4 th , 2019	3:00-4:00 PM
June 6 th , 2019	3:00-4:00 PM
August 8 th , 2019	3:00-4:00 PM
October 3 rd , 2019	3:00-4:00 PM
December 5 th , 2019	3:00-4:00 PM

Other BPDD Dates:

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

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

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 BPDD Board Meeting
 BPDD Executive Committee Meeting
 Holiday

 Self-Determination Conference / Disability Advocacy Day / Employment Conference
 Partners in Policymaking

EXECUTIVE COMMITTEE MEETING MINUTES

BPDD Office and Teleconference

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

Staff Liaison: Beth Swedeen

Absent: Claire Bible, Gail Bovy, Lynn Carus,

Staff Present: Beth Swedeen, Jeremy Gundlach

Meeting called to order at 3:07 pm.

1. Board Retreat:

Noon-1:00 PM	Consumer Caucus
1:15-2:00 PM	Nominating and Membership Committee
2:15-3:30 PM	Governmental Affairs Committee
3:45-4:45 PM	Long-term Care Committee
5:00-6:00 PM	Presentation:

8:30-9:00 AM	Breakfast
9:00 -10:45 AM	
10:30-10:45 AM	Break
10:45-11:15	
11:15-12:00	
12:00-12:45 PM	Lunch
12:45-2:00 PM	

2. Discussion of BPDD Tagline/Marketing:

- Beth gave an update on the staff discussion about how we have a tagline "Real Lives, Real Change". Do we still want to update our tagline?
- Pam talked about having this as a discussion at a future board meeting especially since we need to focus on other topics during the retreat.
- The November Board meeting will be a good time to discuss what BPDD's branding should look like and discuss our tagline.
- Elsa discussed having this as a question at our community conversations in July and September.
- Beth talked about getting an estimate from a marketing consultant on rebranding costs.

3. Review of State Plan-Amendment Timeline:

- Beth talked about how if we want to amend the state plan it needs to be done now in order to get it approved on the timeline.

- Our state plan is written so that our goals are broad enough to encompass all of our projects, so we don't have to go through this process.

4. Retreat logistics:

- Exec discussed our possible community conversation and Bridge clinic tour. We still need to clarify our intent for the tour/conversation.
- Beth and La Toya Sykes have a final planning call next week to discuss the retreat agenda.
- Jeremy will be sending out the RSVP for the retreat without the agenda but will make it clear that once we have final agenda items it will be sent out to board members and staff.

5. September Board Meeting Logistics:

- Beth gave an update on Independence First having space for our community conversation on Wednesday the 26th. Alianza will be hosting us on Tuesday the 25th.
- We will be able to tour Independence First after the meeting on the 26th.
- Jeremy and Beth will put together a rough draft flyer for the September event.

6. Other Agenda Items:

- Beth, Elsa and Gail are attending the NACDD conference in DC shortly before the board retreat.

Motion to adjourn at 3:34 PM. Unanimously passed.

NOMINATING COMMITTEE MEETING MINUTES

Committee Present:	Co-Chairs: Greg Meyer Vice Chair: Open; Patrick Young, Nathaniel Lentz, Patrick Friedrich
Committee Absent:	Jenny Neugart, Claire Bible, Ramsey Lee, Lynn Stansberry-Brusnahan, Carole Stuebe
Staff Present:	Jeremy Gundlach
Guests:	Patrick Friedrich, Leila Solati, Robert Kuhr

Meeting called to order at 3:37 pm.

1. Update on vacant board positions/recruitment ideas:

- With the appointment of Kedibonye there are still 2 vacant parent positions on the board.
- Patrick Young suggested Nominating committee partner with Diversity Committee to find potential board members. Nominating co-chair Greg Meyer will attend the Diversity Committee meeting to discuss plans.
- Discussed the possibility of having board members attend Special Olympics WI events with staff to recruit new members.
- Working with the board to do outreach through social capital of current board members. Families, friends etc.
- Creating a flyer about how to become a board member and what your role is to hand out at events. Possibly have it be a tri-fold similar to our general BPDD flyer.
- Putting information on how to become a board member on the back of our business cards.

2. Member Role Descriptions:

- Nominating wants to make sure that the role descriptions are written in People First Language.
- The committee wants to have the descriptions done by the board retreat in July.
- All board members on Nominating and Membership will help to write descriptions.
- iTACC might have some sample descriptions on their website to investigate.

Motion to adjourn made by Nathaniel Lentz at 4:37 PM Seconded by Patrick Young. Unanimously passed.

BPDD Financial Summary				
Through 5/31/18				
		FFY2016	FFY2017	FFY2018
Revenue				
Federal Allotment				
Actual		1,311,944.00	1,344,077.00	620,686.00
Estimate				
Expenditures				
Personnel Expenses				
Original Budget		571,196.00	676,867.29	258,112.50
Adjusted Budget				
Personnel Expenses		545,464.50	546,011.00	0.00
Encumbrance		0.00		0.00
Total Expenses /Encumbrance		545,464.50	546,011.00	0.00
Remaining balance from Budget		25,731.50	130,856.29	258,112.50
Operating Expenses				
Original Budget		295,928.00	445,217.55	258,112.50
Adjusted Budget				
Operating Expenses		533,698.03	189,972.76	378.97
Encumbrance		0.00	32,579.68	0.00
Total Expenses /Encumbrance		533,698.03	222,552.44	378.97
Remaining balance from Budget		(237,770.03)	222,665.11	257,733.53
Grants & Projects Expenses				
Original Budget		444,820.00	221,992.16	104,461.00
Adjusted Budget				
Expenses		226,523.03	293,530.98	0.00
Encumbrance		0.00	126,572.55	0.00
Total Expenses /Encumbrance		226,523.03	420,103.53	
Remaining balance from Budget		218,296.97	(198,111.37)	104,461.00
Total Expenditures/Encumbrances				
		1,305,685.56	1,188,666.97	378.97
Balance/Deficit				
		6,258.44	155,410.03	620,307.03

Here are a few pearls to keep in mind. As you know these are generalizations & there are always exceptions to the rule.

1. Bring water. Hospitality is a key part of our culture. We show love & caring by feeding people. You don't have to bring any fancy. Bottles of water is fine. If you bring snacks, fruit is usually a safe choice. And people may not feel comfortable getting the water themselves. It's nice to actually bring it to them and say "please have some water. "

2. Learn a few Hmong phrases. Just like any culture, it's nice to show you tried to get to know them before you arrived. Examples:

NYOB ZOO means HELLO

Pronounced "nyaw zong"

UA TSAUG means THANK YOU

Pronounced "ua chow"

SIB NTSIB DUA means SEE YOU LATER

Pronounced "she jee dua"

3. Acceptance of persons with disabilities is not widespread -- very similar to most cultures unfortunately. From what I have observed, the family of the disabled actually does a great job of taking care of their loved one. They are very well groomed and loved. I find that it is the rest of the community that struggles with acceptance. Some very traditional Hmong may even believe that having a child with a disability is punishment from bad behavior in another life.

4. When we address people, we refer to them as Uncle, Aunt, Grandma, Grandpa out of respect. Their title with respect to their relationship to us matters. So if you meet a woman who appears older than you, referring to them as Auntie or Grandma is appropriate. Since you won't know the Hmong words for these titles, don't worry about using the Hmong terms. When you refer to someone in the room and you don't know their name, instead of saying "just like this woman was saying..." say "just like this auntie was saying."

YouTube Videos

[Speak Hmong 101 Lesson 1](#)

<https://www.youtube.com/watch?v=7PGvUYGjsAc>

[Speak Hmong 101 Lesson 2](#)

<https://www.youtube.com/watch?v=EaxXoq4Aj-U>

Supporting caregivers working to keep people in their homes

- In Wisconsin, the workforce shortage is in crisis now, and the need for direct care workers is projected to increase by an additional 20,000 workers by 2026.¹
- When there is no direct care worker, Wisconsin individuals with disabilities describe these common impacts on their daily lives: missing employment or having to leave employment altogether (38%), missed medical appointments (24%), missed meals (26%), missed medications or treatments (26%), being confined to bed all day (17%), and potential changes to housing (22%).²
- 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.³
- In Wisconsin, the annual worker turnover rate is more than 50% and can be as high as 67%.⁴
- Currently, 70% of personal care agencies are unable to staff all hours needed, and 93% of agencies find it difficult to fill job openings.⁵
- In Wisconsin, 51% of Home Care workers and 38% of Nursing Home workers rely on some form of means-tested public benefits.⁶
- 29% of the Home Care workforce are on Medicaid; 35% of Nursing home workers on Medicaid⁷
- 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.⁸

Recommendation:

- **Direct 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 may encourage workers to contribute more hours to Wisconsin's caregiving needs.

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

¹¹ Wisconsin Personal Services Association.

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

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

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

⁵ Wisconsin Personal Services Association.

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

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

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

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.
- More than 1.2 million Wisconsinites use Medicaid for essential health and long-term care services, including many people with disabilities. People with disabilities are in all of Wisconsin’s Medicaid programs.
- 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% of people with disabilities in Wisconsin rely on Medicaid. 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. 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)⁹.

Recommendations

- Create a Medicaid waiver for “pre-Medicaid” individuals. Wisconsin could use its waiver authority to grant access to a limited package of HCBS services for low income older adults, family caregivers, and people with disabilities who are financially eligible for Medicaid and need supports to remain independently in their homes, but do not yet meet the functional criteria (nursing home level of care) required by Family Care/IRIS.
- 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.
- Close the state’s remaining facilities regulated as institutions (ICF-IDs), and with adequate funding to facilitate successful transition of residents into Family Care/IRIS and expand access to the Adaptive Aids program and diagnostic capacity housed within Central Wisconsin Center to all state residents.

⁹ 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 Benefits

- People with disabilities may rely on multiple public programs to live in their own homes. Changes or threats to these programs can result in people with disabilities losing access to care or support they need and can result in individuals being forced into an expensive Medicaid-funded institutional setting.
 - 46% of Wisconsin families receiving SNAP have at least one member who is elderly, blind, or has disabilities.¹⁰
 - People with disabilities account for 15% of total Medicaid enrollment. Medicaid covers more than 30% of working age adults with disabilities¹¹
 - 38% of all households in a public housing program include a member who has a disability. 41% of working-age public housing tenants have a disability.¹²
 - 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.¹³
- 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.¹⁴
 - In 2016, a person with a disability in Wisconsin received SSI benefits of \$817 per month.
 - On average, a person with a disability would have to pay 68% of their monthly SSI income to rent an efficiency unit or 79% of their monthly income for a one-bedroom unit.
 - 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.¹⁵

Recommendations

- 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 services¹⁶
- Align the eligibility criteria—income levels, asset limits, income exclusions across critical health care (Medicaid/Medicare), nutrition (FoodShare), Housing (voucher and public housing programs) and Income (SSI, SSDI) public benefit programs—for people with disabilities and create a tiered path so that people with disabilities can make improvements in their lives—like gaining employment, increasing income, etc.) without jeopardizing access to all of the public supports they need to live independently and stay out of institutions.

¹⁰ Wisconsin Department of Health Services, FoodShare at a Glance, March 2017.

¹¹ 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.

¹² U.S. Department of Housing and Urban Development (HUD), Resident Characteristics Report as of December 31, 2017 (https://hudapps.hud.gov/public/picj2ee/Mtcsrccr?category=rcr_ttp&download=false&count=0).

¹³ All data from <https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html>

¹⁴ <http://www.tacinc.org/knowledge-resources/priced-out-v2/>

¹⁵ <http://www.tacinc.org/knowledge-resources/priced-out-v2/>

¹⁶ CMS encourages the use of Medicaid funds for these purposes. California, New York, and Tennessee -- are addressing the housing needs of dually eligible beneficiaries who use LTC. <https://www.medicaid.gov/federal-policy-guidance/downloads/CIB-06-26-2015.pdf>

Guardianship and Decision-Making

- Decision-making is a learned skill. Everyone, no matter their limitations, needs opportunity, experience, and support to learn how to make well-informed decisions.
- People with disabilities can acquire new skills and decision-making capacity throughout their lives.
- Unfortunately, guardianship—which removes an individual’s civil rights to make some or all of their own decisions and transfers those rights to a guardian—is used first and almost exclusively for people with intellectual and developmental disabilities (I/DD) when it should be used last and rarely.
- Parents routinely tell us that guardianship is presented as the only option and is portrayed as administrative process rather than a decision that has permanent legal ramifications for both the individual and families.
- Many families of children with disabilities are instructed to petition for guardianship by teachers, doctors, and other non-legal professionals without having any knowledge of the role/responsibilities or long-term implications and consequences.
- 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 before assessing competency.
- All guardians need training and continuing education to ensure that they understand their role and responsibilities and are employing best practices so that the ward is placed under the least possible restriction and has greatest possible integration of the individual into his or her community as required under current law.

Recommendations

- Create a Time-Limited guardianship option within the guardianship statutes for youth placed under guardianship between the ages 18 to 26 that requires judicial review of all guardianships granted—with limited exemptions—before the ward attains the age of 26. This would give young people the time needed for their brains to fully mature, gain life experience, and practice with decision-making, and would provide the court with an opportunity to review a more robust picture of the adult’s capacity and rescind or make adjustments to the guardianship order to ensure that it preserves the individual’s civil rights to the greatest extent possible, as required under current law.
- Require training for all guardians on: the role of the guardian; rights retained by the ward; best practices for guardians to solicit and understand the wishes and preferences of the ward, involve the ward in decision-making, and take the ward’s wishes/preferences into account in decisions made by the guardian; process to restore rights of the ward and remove the guardianship; futures planning and appointment of a successor guardian, administrative duties and requirements of guardians. Establish continuing legal education requirements for all guardians.

Transportation

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

Recommendations

- Direct DHS to require inclusion of transportation as a component of employment outcomes for LTC participants and establish three to six commuter pilot programs for long term care 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 HCBS settings rule within the timeframe of the pilot project.
- 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.
- Create a state-funded continuing appropriation lines for coordinating, operating, improving, and developing public transportation options, available to counties and transit commissions that are pooling funding for the purpose of regional transportation across and throughout their service area.

Increasing Competitive Integrated Employment

- Nationwide, the employment rate for people with disabilities is only 17.9%, compared with 65.3% for the general population.
- Nationally, studies consistently show that managers positively view their employees with disabilities, regarding them as easy to supervise and producing as much or more work than co-workers without disabilities.
- In Wisconsin, the competitive integrated employment rate for working-age people with disabilities in Medicaid-funded long-term care programs is 16.3%¹⁷
- More than 40% of people with developmental disabilities participating in sub-minimum wage pre-vocational placements say they want to or would consider community employment. Nearly the same percentage said they did not know about or currently were not connected to Vocational Rehabilitation (DVR) services.
- DHS's 2014 report on sustainability of Medicaid funded long term care programs stated that 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 programs¹⁸.

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 and require the Department to report measurable outcome criteria on grantees' progress.
- 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, which matches youth earnings to finance work-related expenses.
- 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.

¹⁷ Department of Health Services data pulled April 2017 from Long Term Care functional screen and Program Participation System (PPS) employment data.

¹⁸ <https://www.dhs.wisconsin.gov/publications/p0/p00590.pdf>

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 survey¹⁹ of almost 600 parents of students with disabilities:
 - 58% indicated concern for their child's future due to lack of special education funding.
 - 47% reported their child was more socially isolated in school, and 15% said their child was being placed in a more restrictive setting.
 - 38% reported a reduction in special education supports and resources, and 35% say their child is not making the same progress in the last 1-2 years.

Recommendations

- Increase state special education categorical aid funding to keep pace with local costs. Fund to at least 50% of costs up from 26%, addressing a decade-long funding freeze.
- 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.
- Increase the incentive payment funds for competitive integrated employment (CIE) outcomes DPI manages from \$1,000 per youth to \$1,500/youth and ensure that payments are targeted specifically toward youth directly engaged in competitive integrated employment or post-secondary education.
- Create a \$100,000 DPI incentive grant program fund for schools to engage in Community Conversations²⁰ related to employment for youth in their communities. Direct DPI to award funding in \$1000 grants and require demonstration that a defined number of youth with disabilities achieve competitive integrated employment in the following year that demonstrates an increase in CIE outcomes from the prior period.

¹⁹ http://www.survivalcoalitionwi.org/wp-content/uploads/2018/05/SurvivalCoalitionReportBooklet0518_Final.pdf

²⁰ [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.

Goal 1 Budget: \$186,000	
	<p>More people with Intellectual and Developmental Disabilities (I/DD) will be included in their communities.</p> <p>By September 2021, more people with I/DD including those with diverse identities will participate in integrated community activities of their choosing as evidenced by:</p>
	<p>Objective 1.1 2016 Number: 3,601 people</p>
	<p>More people with I/DD will be working in the community.</p> <p>By September 30, 2021, 50% more people with I/DD will be working in integrated employment of their choice at a competitive wage.</p>
Objective 1.2 2016 Number: **	
	<p>More people with I/DD have the support they need to make choices in their lives.</p> <p>By September 30, 2021, 25% more people with I/DD will make choices about their everyday lives.</p>
Objective 1.3 2016 Number: **	
	<p>More people with I/DD will have a way to get to where they need to go. (Transportation)</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>
Objective 1.4 2016 Number: **	
	<p>More people with I/DD will have people in their lives that they can count on to help them when needed.</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>
Objective 1.5 2016 Number: **	
	<p>More African American Families will be connected to their community and resources</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: 161



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

By September 30, 2021, 50% more **self-advocates with I/DD** 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.

Save the Date!

Community Conversation

Wednesday, September 26, 2018, 10:30 am - 1:00 pm
Independence First, 540 South 1st Street, Milwaukee, WI 53204



How can we better reach out to Milwaukee's diverse communities and be inclusive of all people with developmental disabilities and their families?

Lunch will be served

There will be an optional tour of Independence First after the Community Conversation. Please RSVP to this free event to Jeremy.Gundlach@wisconsin.gov or call (608) 266-7826.

*** Location is in an accessible building. If you need language translation or an accommodation, please contact us.**



**Wisconsin Board for People
with Developmental Disabilities**