



Board Meeting Packet

May 16-17, 2018
Premier Park Hotel
22 S Carroll St
Madison WI, 53703



Board Meeting

Premier Park Hotel • Madison, Wisconsin • May 16th-17th, 2018

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May 1, 2018

BPDD Board Members,

A lot has happened since we last met. I'm so proud to be a part of this Board. The staff and the appointed board members are truly working our Mission:

The Board is dedicated to improving the independence, productivity, and integration of people with developmental disabilities.

I would like to take a moment to highlight just some of the amazing work that is being done between board meetings.

- BPDD Board member David Pinno has worked with multiple legislators on Employment First legislation, telling his own story about how working at a competitive job in the community allows him to be a home owner, make car payments, and live a full life. Gov. Walker thanked him for his hard work during the bill signing for Employment First.
- Supported Decision-Making Bill was signed by Governor Walker with many Partners in Policy Making in attendance. This bill allows people with disabilities and aging adults to choose who they want to support them on important decisions as an option instead of guardianship.
- Partners with Business was also signed into law the same day. Funding to help WI businesses to hire and support employees with disabilities, reducing the need for formal publicly funded job supports.
- The harmful HR620 bill that would weaken the Americans with Disabilities Act (ADA) and that passed the U.S. House will NOT go on to the Senate. Sen. Duckworth (D-IL) announced that she and 42 of her colleagues wrote to Senate Majority Leader Mitch McConnell (R-KY) saying they would oppose HR620.

A few other great things that happened since our last meeting, two new additions to the BPDD Staff:

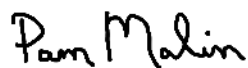
- Molly Cooney - Employment and Diversity Outreach
- Jeremy Gundlach - Communications Specialist

Both, Molly and Jeremy, are known to the Board and their work in their prior roles has been invaluable. Please join me in welcoming them both to BPDD in their new capacity.

Finally, I want to bring it to your attention that during our May meeting we will be voting to change the role of some of our current committees in the By-Laws. Please be present so your input and vote are heard.

Thank you for all you are doing it is truly a pleasure to be part of true "Working" Board.

Sincerely,







Pam Malin





Chair, Wisconsin Board for People with Developmental Disabilities

BOARD AGENDA MAY 16-17TH, 2018

WEDNESDAY, MAY 16TH, 2018








Time	Symbol	Topic	Facilitator/ Presenter
3:30-4:30 PM		Nominating & Membership Committee Room:	Staff: Jenny Neugart
4:30-5:00 PM		Consumer Caucus Room:	Staff: Fil Clissa
5:00-6:15 PM		Dinner Room:	All
6:15-7:00 PM		Diversity Committee Room:	Chair: Lynn Carus

THURSDAY, MAY 17TH, 2018

Time	Symbol	Topic	Facilitator/ Presenter
7:45-8:30 AM		Breakfast Room:	All
8:30-10:00 AM		Governmental Affairs Committee Room:	Vice Chair: David Pinno
10:00-10:15 AM		Break – FILL OUT, SIGN, AND RETURN TRAVEL VOUCHERS to BPDD STAFF	All
10:15-11:00 AM		Mind and Memory Matters: Project Update Room:	

THURSDAY, MAY 17, 2018 CONTINUED

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

11:00-11:45 PM		Transportation Project Updates Room:	
11:45-12:30 PM		Lunch Room:	All
12:30-12:45		Public Comments	Members of the Public
12:45-1:00 PM		Review of Bylaws	All
1:00-2:00 PM		Business Meeting Room: <ul style="list-style-type: none"> Chair Report Executive Director Report Executive Committee Governmental Affairs Committee Nominating & Membership Committee Diversity Committee 	All <ul style="list-style-type: none"> Pam Malin Beth Swedeen Pam Malin Gail Bovy Greg Meyer/ Claire Bible Lynn Carus
2:00-2:15 PM		Business Meeting Action Items Motion to accept March 2016 Board Minutes	All
2:15-3:30 PM		Memorial Tree Service for Jennifer Kuhr Location: Capital grounds	All

The May Board Meeting will be held at the Best Western Premier Park Hotel located at 22 S Carroll St. in Madison. Any Board members staying overnight will be staying at the Park Hotel. If you have any questions about the May Board meeting please contact Jeremy Gundlach at Jeremy.Gundlach@wisconsin.gov or 608-266-7826.



= Meal



=Meeting



=Presentation



=Vote



=Walking Activity



=Break

BOARD MEETING MINUTES**The Concourse Hotel
Madison, WI**

Present:	Chair: Pam Malin, Vice Chair: Elsa Diaz-Bautista, Kevin Coughlin, Ramsey Lee, Nathaniel Lentz, Camille Nicklaus, David Pinno, Delores Sallis, Michael Hineberg, Patrick Young, Claire Bible, Patrick Friedrich, Liz Hecht, Leila Solati, Robert Kuhr,
Absent:	Meredith Dressel, Lynn Stansberry-Brusnahan, Rita Fuller, Lynn Carus, Carole Stuebe, Sarah Lincoln, Gail Bovy, Amy Polsin
Staff Present:	Brenda Bauer, Fil Clissa, Natasha Fahey-Flynn, Jeremy Gundlach, Tami Jackson, Beth Swedeen,

Vice Chair David Pinno called the meeting to order at 9:15 AM.

1. Chair Report:

- Pam Malin gave thanks to the board members and staff for a great Disability Advocacy Day.

2. Executive Director Report:

- Beth gave an update on the upcoming Employment First Conference. The conference will be a little different this year due to the Employment First bill getting passed.
- The Disability Policy Seminar is in April and BPDD is sending multiple board members and staff.
- Beth also discussed Molly Cooney starting on BPDD staff as of April 1st this year. Molly will be splitting her time between the Promise grant and BPDD until the Promise grant ends in September.

3. Executive Committee Report:

- Pam discussed Board retreat 2019, possible locations and topics to cover.
- Executive Committee talked about having our other committees to write up position descriptions for chairs and vice chairs.
- Executive also discussed board members social media boundaries and privacy settings.

4. Government Affairs Committee Report:

- David Pinno gave an update about creating a way for people to give BPDD feedback more effectively.

5. Nominating & Membership Committee Report:

- No updates at this time.

6. Diversity Committee Report:

- Beth gave an update from Jenny N about what has been going on with Diversity Committee. See attached.

7. Action Items:

Motion to accept the January 18th, 2018 minutes made by Robert Kuhr and seconded by David Pinno. The motion passed unanimously.

8. Agency Updates:

DRW- See Attached

DHS- See Attached

Waisman- See Attached

DWD- See Attached

DPI- See Attached

9. Other Agenda Items:

- Pam Malin mentioned that David Pinno won the Badger Award, the board congratulated him
- Robert Kuhr mentioned that his plans to have a tree planted in Jennifer's name is moving along and he has selected a place and a tree.
- Greg Meyer discussed a training that he is planning for local firefighters and EMT's to learn about disabilities.
- WSPEI is having a webinar on supported decision making soon and is
- Mike Hineberg is having a presentation with Life Navigators in MKE

Motion to adjourn made by Greg Meyer at 1:59 PM; seconded by Patrick Friedrich 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 19 & 20, 2018	TBD- Milwaukee Area
November 14 & 15, 2018	TBD- Madison Area

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 <p>Staff liaison: Jenny Neugart*</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 • Open: Vice Chair • Ramsey Lee • Greg Meyer • Lynn Stansberry-Brusnahan • Carole Stuebe • Patrick Young • Nathaniel Lentz • Patrick Friedrich <p>Staff liaison: Jenny Neugart</p>

** Still open for others to sit on this committee

* Interim until position is filled

EXECUTIVE COMMITTEE MEETING

MINUTES

BPDD Office and Teleconference

Present by Teleconference: **Chair:** Pam Malin **Vice Chair:** Elsa Diaz-Bautista; Gail Bovy

Absent: Claire Bible, Greg Meyer, Lynn Carus, Carole Stuebe, Patrick Young

Staff Present: Beth Swedeen, Jeremy Gundlach

Meeting called to order at 3:07 pm.

1. May Board Meeting:

3:30-4:30 PM	Diversity Committee
4:30-5:00 PM	Consumer Caucus
5:00-6:15 PM	Dinner
6:15-7:00 PM	Nominating and Membership Committee

7:45-8:30 AM	Breakfast
8:30 -10:00 AM	Governmental Affairs Committee
10:00-10:15 AM	Break
10:15-11:00 AM	Mind and Memory Matters Project Update
11:00-11:45 AM	Transportation project updates
11:45-12:30 PM	Lunch
12:30-12:45 PM	Public Comment
12:45-1:00 PM	Review of By-laws
1:00- 2:15 PM	Business Meeting
2:15- 3:30 PM	Memorial Tree service: Jennifer Kuhr

2. July Board Retreat:

- The committee discussed many topics but chose to have LaToya Sykes be our facilitator and work with her to flush out the ideas below.
- Exec discussed celebrating our members who will be leaving the board this summer. Appreciations/Accomplishments.
- Exec discussed using the retreat to motivate, engage and reengage board members
 - Why are you invested?
 - What do you need?
 - Burnout/self-care
 - Energizer activities
- Exploring board members/staff values
- How to fall in love with your work again
- A-ha moments, support
- Feeling comfortable in your own comfort zone
- How do we prepare to work/communicate where we are not familiar with?

- Talking about new legislation ideas
- Appreciations from last year. Things the board/members have done.

3. NACDD Trip:

- Discussion on who should be going to the NACDD meeting. Possible people to attend: Robert Kuhr, Beth Swedeen, Leila Solati, Gail Bovy

4. Other Agenda Items:

- Job descriptions for BPDD committees. Each committee should be writing these.
- Possibly changing the by-laws to reflect changes in committees (GA and Diversity)

Motion to adjourn at 3:48 PM. Unanimously passed.

May 16, 2018

6:15-7:00 PM





Premier Park Hotel

22 S Carroll St

Madison, WI 53703

Nominating Committee Agenda

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

Symbol	Topic:	Presenter:	Time:
	1. Call to order/welcome	Claire Bible/Greg Meyer	
	2. Updates on vacant board seats <ul style="list-style-type: none">Ideas for recruitment	Claire Bible/Greg Meyer	
	3. Member role descriptions	Claire Bible/Greg Meyer	
	4. Adjourn	All	

Other Information:



=Meeting



=Presentation



=Vote





May 16, 2018

3:30-4:30 pm

Location

Diversity Committee Agenda

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

Symbol	Topic	Presenter	Time
	1. Updates from BPDD Staff	Molly Cooney	
	2. Updates from Board members	All	
	3. Review of the workplan	All	
	4. Discussion: Ways to have meaningful roles and ideas for taking action.	All	



=Meeting



=Presentation



=Vote




Government Affairs Committee Agenda

May 17, 2018

8:30-10:00 AM

Location

Members: **Chair:** Gail Bovy **Vice Chair:** David Pinno; All board members now sit on Governmental Affairs Committee
Staff Liaison: Tami Jackson

Symbol	Topic:	Presenter:	Time:
	1. State Updates	Tami J.	35 min
	2. Federal updates	Tami J.	35 min
	3. Review of By-laws	All	20 min

Other Information:



=Meeting



=Presentation



=Vote

Three New Laws Supporting People with Disabilities in Wisconsin

Supported Decision Making



As of April 16th, 2018 Wisconsin, is the fourth state in the nation to have a Supported Decision-Making Law; no other state's law is as comprehensive and stands to benefit so many of its citizens. People who can use Supported Decision-Making agreements include people with intellectual/developmental disabilities, people with physical disabilities, people with mental health conditions, and people of any age with degenerative diseases or conditions that

substantially interferes with activities of daily living or with the ability to provide self-care. The

- Link to statutory language for 2017 Wisconsin Act 345 here: <https://docs.legis.wisconsin.gov/2017/related/acts/345>
- Register for a free webinar on **May 21** to learn more: <https://thearc.webex.com/mw3200/mywebex/default.do?siteurl=thearc&service=7>
- BPDD's Alternatives to Guardianship booklet can be found here: http://wi-bpdd.org/wp-content/uploads/2018/04/Supported_decision_making_booklet.pdf

Employment First

On March 28th, 2018 Governor Walker signed the Employment First bill into law. The law requires state agencies (DVR, DHS, DPI) that provide services and supports for people with disabilities to make competitive paying jobs in the community the priority. It also requires these agencies to develop a plan as well as benchmarks and goals to increase the rate of competitive paying jobs in the community.

The Employment First legislation is now known as 2017 Wisconsin Act 178, direct link to statutory language here: <https://docs.legis.wisconsin.gov/2017/related/acts/178>.



Partners with Business

The Partners in Business Disability Employment Law provides direct support and technical assistance to businesses interested in hiring people with disabilities. The Partners in Business legislation is now known as 2017 Wisconsin Act 323, direct link to statutory language here: <https://docs.legis.wisconsin.gov/2017/related/acts/323>. This law expands a successful model that has resulted in a 75% community employment success rate during the project.

Who is eligible for Partners with Business Grants?

- Public schools
- Managed Care Organizations that administer Family Care or Family Care Partnership
- IRIS Consultant agencies
- Employment services providers
- Private businesses

Expect to see this technical assistance and grant announcements coming out from BPDD in 2018.

Here is one example of Partners with Business Success:

Traditional Agency or School Supports		Partners with Business <i>Plus</i>	
Number of job coaching hours per week (4x1 hour plus 30 minutes for transportation per visit)	6 hours	Co-worker paid supports needed per week	4 hours
Cost for job coach per hour	\$15 per hour plus benefits	Cost for employer to provide co-worker supports	\$15 per hour
Total weekly costs for job support	\$ 90 per week plus benefits	Total weekly reimbursement to employer for co-worker supports ¹	\$60 per week
Total annual support costs (37 weeks of employment) *	\$3,330 + benefits	Total annual support costs (37 weeks of employment) *	\$2,220

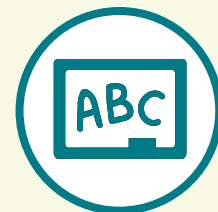
*July 31, 2017 to June 8, 2018

Savings to the Public System with Partners with Business *Plus* = *over \$1100 per year*

Improving Education for Wisconsin Students with Disabilities

Wisconsin public schools educate 867,800 students; approximately 14% of those children have disabilities and qualify for special education services through an Individualized Education Plan (IEP). These services may include education related therapies, classroom accommodations, modified curriculum, or one-on-one support. [Research shows us even students with the most significant disabilities can make progress in grade level content when provided with appropriate supports.](#)

Poor Academic Performance Unfortunately, academic performance for Wisconsin students with disabilities is poor. The 2017 4th grade reading scores recently released by the National Assessment of Educational Progress show Wisconsin students with disabilities scoring nearly 10 points below the national average (177 to 184). Approximately 76% of Wisconsin 4th graders with disabilities scored “below basic” in reading.

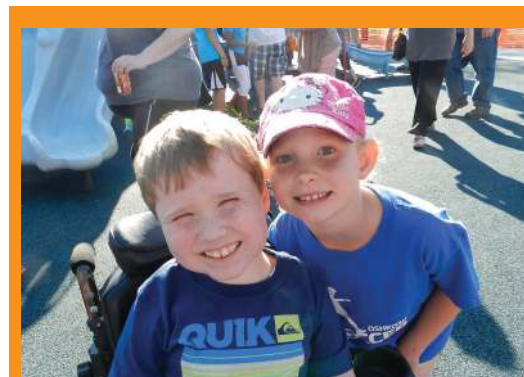


Lack of Funding Congress originally committed to covering 40 percent of the average cost to educate a student with a disability; however federal funding never met that mark and has not increased with inflation. Federal funding for students with disabilities currently hovers at 16 percent of special education service costs.

Parent Dissatisfaction Wisconsin parents of children with disabilities are reporting significant dissatisfaction with special education supports, sometimes reporting critical concerns. 574 parents of students with disabilities responded to a recent survey distributed by the Survival Coalition of Wisconsin Disability Organizations. Key findings:



- Nearly half of respondents indicate the school is not implementing the IEP in a way that allows their child to make meaningful progress.
- 21% report that their child is being bullied.
- 9% report that their child has been inappropriately suspended or expelled while 8 % report inappropriate or overuse of seclusion or restraint practices. Overall more than 25% saw an increase in disciplinary measures of their child at school, including 16% of parents who say they are now called to pick up their child during the school day.
- More than half report their child has experienced a loss of support staff over the last two years with nearly a third (31%) indicating their child has lost a special education aide in the classroom.
- While about one-fifth of survey respondents indicated they had considered other school options (e.g. virtual or home schooling, special needs voucher, open enrollment) to improve their child’s educational future, 133 parents said they felt like they had no options to improve the situation.
- 154 parents (27%) of survey respondents said the reduced quality of their child’s education makes them concerned for their child’s future.



Stories from Wisconsin Families

“My daughter always loved school but now she comes home in a terrible mood and sits in her room. She worries the whole weekend about going to school, says she hates school constantly and makes the morning routine very stressful for me and my son. The whole family is exhausted and frustrated.”

“My son has seen an increase in bullying. He feels that he doesn't have friends and most kids just want to hurt him. He is only 8 years old.”

“The most significant impact for my son is the increase in his anxiety. He has now become a target of bullying and fear by other students, due to the outbursts, which has also resulted in social ostracization. Although I actively advocate and fight for proper supports, I feel as if I am watching a train wreck in slow motion that I have no chance of stopping. It is the worst feeling in the world as a parent to be unable to make it all better for your child.”

“My child often has the brakes on his wheelchair set because there are not enough aides in the classroom. It saddens me when I enter the classroom and he is sitting alone and he's unable to interact with anyone.”

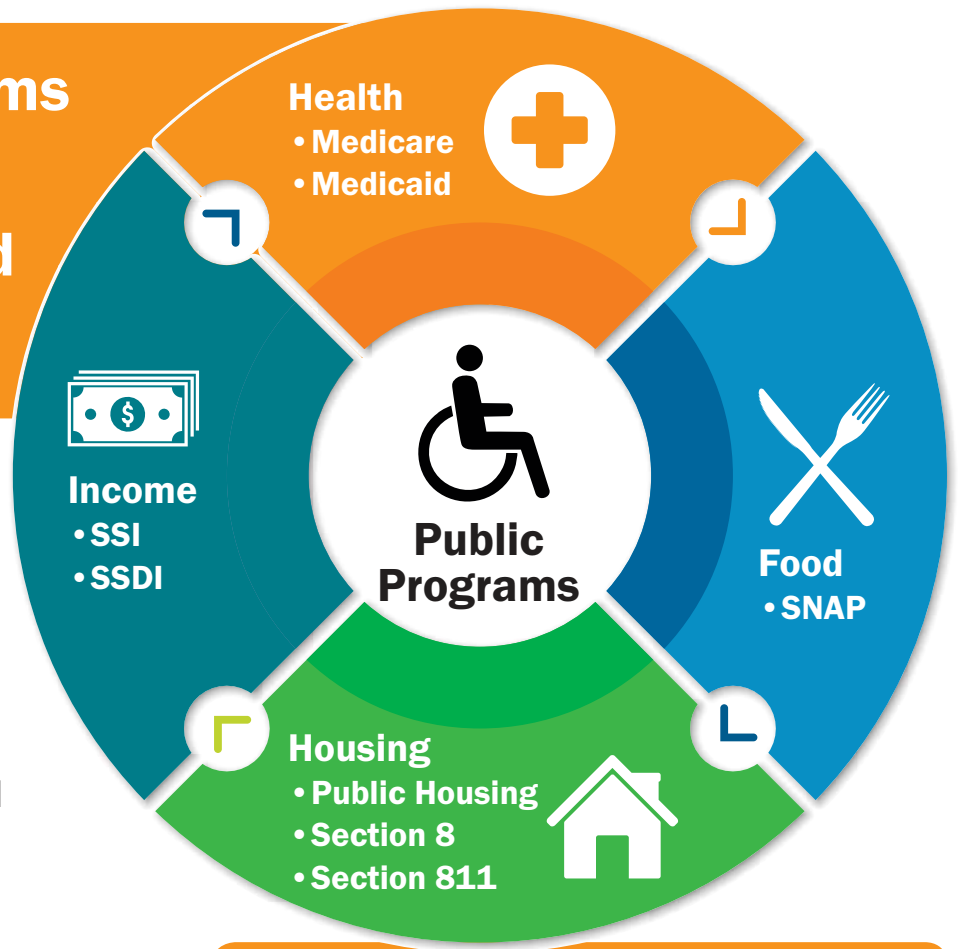
“Our child is being segregated and isolated at his high school. He has been kept in windowless rooms with no access to any programming. We have picked him up early every single day he's attended, once while he was having a seizure that was completely unnoticed by staff.”

RECOMMENDATIONS:

- Significantly increase federal Individuals with Disabilities Education Act (special education) funding.
- Invest in Positive Behavioral Intervention and Supports (PBIS) as an evidence-based strategy that gives teachers critical tools to increase academic performance of all students while managing a positive environment and contributing to school safety. School safety proposals must include funding for increased PBIS in Wisconsin schools.
- Support legislation to limit the use of restraint and seclusion in schools.
- Initiate a meaningful audit of special education quality and outcomes, including the preparation of students with disabilities for college and the workforce

Public benefit reforms will harm people with disabilities and their caregivers

People with disabilities may rely on multiple public programs to live in their own homes. Changes or threats to these programs can unravel supports and could result in an expensive Medicaid-funded institutional setting.



Supplemental Security Income (SSI) & Social Security Disability Insurance (SSDI)

- **14%** (or 1,820,000 people) of SSI and SSDI beneficiaries have an intellectual/developmental disability (I/DD).
- Children with I/DD make up **9%** of the children enrolled in SSI; **80%** of these kids will remain on SSI after age 18.
- More than **20%** of SSI recipients and **8%** of SSDI recipients have a primary impairment of I/DD.¹

Medicaid

- People with disabilities account for **15%** of total Medicaid enrollment.
- Medicaid covers more than **30%** of working age adults with disabilities.²
- **More than half** of Medicaid enrollees live below the federal poverty level.

Medicare

- **4.1 million** individuals under the age of 65 are dually eligible for both Medicare and Medicaid.
- **21% of Medicare beneficiaries and 15% of Medicaid enrollees are “dual-eligibles.”** About **7%** of dual-eligible are people with I/DD.
- More than **60%** of dual eligible beneficiaries are below the poverty level.³

Supplemental Nutrition Assistance Program (SNAP)

- **25%** of SNAP recipients (**11 million people**) are elderly, blind, or have a disability.⁴
- **46%** of Wisconsin families receiving SNAP have at least one member who is elderly, blind, or has disabilities.⁵
- Wisconsin’s direct care providers and family caregivers who support people with disabilities to live independently are some of the top occupations with low-wage workers using FoodShare. **28%** of personal care aides and **25%** nursing, psychiatric, and home health aides depend on SNAP benefits⁶

Public Housing

- **38%** of all households in a public housing program include a member who has a disability.⁷
- An estimated **41%** of working-age public housing tenants have a disability, and many participate in multiple public benefit programs.⁸
- People with disabilities make up **20%** of HUD Public Housing program recipients, **30%** of Section 8 Housing Voucher recipients, and **100% of Section 811 recipients** which focuses on affordable, accessible housing for low income people with significant disabilities.⁹



RECOMMENDATIONS:

- **Improvements Are Needed:** Many parts of the Social Security and SSI disability systems need to be strengthened to better meet the needs of people with disabilities. These include: increasing the substantial gainful activity (SGA) level for people with disabilities (currently \$1,180 per month) to the level for people who are blind (currently \$1,970 per month); increasing, and indexing for inflation, the asset limits and income exclusions for SSI; eliminating marriage penalties for people with disabilities; eliminating the two-year waiting period for Medicare; improving work incentives; and addressing policy issues which have a harsh impact on people eligible for OASDI benefits as disabled adult children.
- Congress should reject any cuts to Social Security or SSI, including any proposals to cut benefits or limit who can qualify.
- Congress should request a beneficiary impact statement on any proposal to change Social Security or SSI, to look beyond budgetary issues to the impact on people's daily lives.
- Congress should not consider adding work requirements in the Medicaid program.
- Congress should reject reductions or caps to the Medicaid program and reject any effort to block grant Medicaid.

¹ All data from <https://www.ssa.gov/policy/docs/ssb/v77n1/v77n1p17.html>

² 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.

³ All data from <https://www.thearc.org/what-we-do/public-policy/dual-eligibles>

⁴ <https://www.cbpp.org/research/food-assistance/snap-provides-needed-food-assistance-to-millions-of-people-with>

⁵ Wisconsin Department of Health Services, FoodShare at a Glance, March 2017.

⁶ <https://www.cbpp.org/snap-helps-workers-put-food-on-the-table#Wisconsin>

⁷ U.S. Department of Housing and Urban Development (HUD), Resident Characteristics Report as of December 31, 2017 (https://hudapps.hud.gov/public/picj2ee/MtcsrCr?category=rcr_ttp&download=false&count=0).

⁸ <https://www.urban.org/urban-wire/disabilities-and-public-housing-closer-look>

⁹ <https://www.thearc.org/what-we-do/public-policy/policy-issues/housing>

Wisconsin is Facing a Caregiver Crisis That Must be Addressed

■ In a 2016 Survival Coalition of Wisconsin Disability Organizations survey 85% of the more than 500 respondents said they cannot find enough direct care workers to meet their daily needs.

■ People with disabilities rely on unpaid (often family) caregivers to make up for gaps in paid support.

■ 40% of the people receiving caregiving from unpaid caregivers are people with disabilities.¹

■ In Wisconsin, an estimated 549,000 informal caregivers are providing 588,000 million hours of care, valued at nearly \$6 billion dollars.²



■ A 2016 AARP report found more than half of family caregivers reported a work-related strain, such as having to take unpaid time off, and the average caregiver spends nearly 20% of their income on out-of-pocket costs.³

■ Wisconsin disability organizations hear from families across the state that they have often had to rearrange schedules and even leave their jobs to fill in caregiving gaps.

■ When family caregivers work fewer hours or leave their jobs to do caregiving work, their reduced income may result in increasing reliance on public benefits (Medicaid, SNAP, Public Housing) to remain stable.



■ Changes or cuts to public benefit programs that reduce the hours of paid caregiving help or result in fewer workers providing services, put additional strain on family members providing care. Leaving the workforce or placing the person in an expensive Medicaid funded institution could result in unintended consequences.

■ Wisconsin parents of children with special health care needs are more than three times more likely to report having to quit a job or reduce their work hours because of child care issues than are parents of children with no special health care needs.⁴

Changes and cuts to public benefit programs harm caregivers and impact people with disabilities Paid caregivers' low wages mean they are on public benefits too

■ 50% of the nation's caregiver workforce⁵ rely on government-funded and means-tested benefits⁶ (like Medicaid, FoodShare, and Public Housing).

■ 25% of Wisconsin's caregiving workforce is living below the federal poverty level. More than half rely on some form of public assistance, including SNAP (35%) and Medicaid (29%).⁷

■ A 2017 national analysis⁸ found most workers have two or three jobs and have an average wage of \$10.72 per hour (below the federal poverty level for a family of four). In Wisconsin, the average worker's wage is \$10.47 per hour.

■ National turnover rates for these critical positions top 45% (range 18-76%). In Wisconsin, the annual turnover rate is more than 50% and can be as high as 67%.⁹



■ In Wisconsin, the workforce shortage is a crisis now, and the need for these workers is projected to increase by an additional 20,000 workers by 2026.¹⁰

■ Currently, 70% of personal care agencies are unable to staff all hours needed, and 93% of agencies find it difficult to fill job openings.¹¹

■ 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%).¹²



■ 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.¹³

RECOMMENDATIONS:

- Congress should direct the U.S. Department of Health and Human Services, Centers for Medicare & Medicaid Services to ensure that states include sufficient Direct Support Professional wages and compensation packages in their rate-setting methodologies for long-term services and supports to people with intellectual and developmental disabilities.
- The U.S. Department of Health and Human Services should work with states to expand utilization of self-direction in long-term services and supports so that family, friends, and neighbors can be hired as Direct Support Professionals.
- Members of Congress should act to remove the institutional bias of federal programs and eliminate waiting lists.
- Congress should protect the integrity of the Home and Community-Based Services (HCBS) Rule.



¹ National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

² National Center on Caregiving <https://www.caregiver.org/caregiving-across-states-50-state-profiles-2014>

³ The Cost of Family Caregiving: Out-of-Pocket Spending Surprisingly High. AARP. 2016 <https://www.aarp.org/caregiving/financial-legal/info-2017/out-of-pocket-cost-report.html>

⁴ Healthiest Wisconsin 2020 Report.

⁵ Professional home health, personal care, direct care, and other community-based care workers support people with disabilities and older adults in their homes and keep them out of expensive Medicaid-funded institutional settings.

⁶ Report to the President 2017 America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy. https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

⁷ State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

⁸ Report to the President 2017 America's Direct Support Workforce Crisis: Effects on People with Intellectual Disabilities, Families, Communities and the U.S. Economy. https://www.acl.gov/sites/default/files/programs/2018-02/2017%20PCPID%20Full%20Report_0.PDF

⁹ State of Care: Wisconsin's Home Care Landscape. PHO. 2017. <https://phinational.org/resource/state-of-care-wisconsins-home-care-landscape/>

¹⁰ 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.

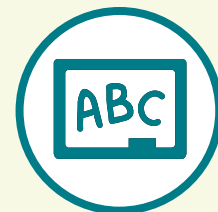
¹² Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

¹³ Survival Coalition Consumer Survey, November 2016. <http://www.survivalcoalitionwi.org/wp-content/uploads/2016/11/SurvivalSurveyFactSheet.pdf>

Improving Education for Wisconsin Students with Disabilities

Wisconsin public schools educate 867,800 students; approximately 14% of those children have disabilities and qualify for special education services through an Individualized Education Plan (IEP). These services may include education related therapies, classroom accommodations, modified curriculum, or one-on-one support. [Research shows us even students with the most significant disabilities can make progress in grade level content when provided with appropriate supports.](#)

Poor Academic Performance Unfortunately, academic performance for Wisconsin students with disabilities is poor. The 2017 4th grade reading scores recently released by the National Assessment of Educational Progress show Wisconsin students with disabilities scoring nearly 10 points below the national average (177 to 184). Approximately 76% of Wisconsin 4th graders with disabilities scored “below basic” in reading.



Lack of Funding Congress originally committed to covering 40 percent of the average cost to educate a student with a disability; however federal funding never met that mark and has not increased with inflation. Federal funding for students with disabilities currently hovers at 16 percent of special education service costs.

Parent Dissatisfaction Wisconsin parents of children with disabilities are reporting significant dissatisfaction with special education supports, sometimes reporting critical concerns. 574 parents of students with disabilities responded to a recent survey distributed by the Survival Coalition of Wisconsin Disability Organizations. Key findings:



- Nearly half of respondents indicate the school is not implementing the IEP in a way that allows their child to make meaningful progress.
- 21% report that their child is being bullied.
- 9% report that their child has been inappropriately suspended or expelled while 8 % report inappropriate or overuse of seclusion or restraint practices. Overall more than 25% saw an increase in disciplinary measures of their child at school, including 16% of parents who say they are now called to pick up their child during the school day.
- More than half report their child has experienced a loss of support staff over the last two years with nearly a third (31%) indicating their child has lost a special education aide in the classroom.
- While about one-fifth of survey respondents indicated they had considered other school options (e.g. virtual or home schooling, special needs voucher, open enrollment) to improve their child’s educational future, 133 parents said they felt like they had no options to improve the situation.
- 154 parents (27%) of survey respondents said the reduced quality of their child’s education makes them concerned for their child’s future.



Stories from Wisconsin Families

“ My daughter always loved school but now she comes home in a terrible mood and sits in her room. She worries the whole weekend about going to school, says she hates school constantly and makes the morning routine very stressful for me and my son. The whole family is exhausted and frustrated. ”

“ **My son has seen an increase in bullying. He feels that he doesn't have friends and most kids just want to hurt him. He is only 8 years old.** ”

“ The most significant impact for my son is the increase in his anxiety. He has now become a target of bullying and fear by other students, due to the outbursts, which has also resulted in social ostracization. Although I actively advocate and fight for proper supports, I feel as if I am watching a train wreck in slow motion that I have no chance of stopping. It is the worst feeling in the world as a parent to be unable to make it all better for your child. ”

“ My child often has the brakes on his wheelchair set because there are not enough aides in the classroom. It saddens me when I enter the classroom and he is sitting alone and he's unable to interact with anyone. ”

“ Our child is being segregated and isolated at his high school. He has been kept in windowless rooms with no access to any programming. We have picked him up early every single day he's attended, once while he was having a seizure that was completely unnoticed by staff. ”

RECOMMENDATIONS:

- Significantly increase federal Individuals with Disabilities Education Act (special education) funding.
- Invest in Positive Behavioral Intervention and Supports (PBIS) as an evidence-based strategy that gives teachers critical tools to increase academic performance of all students while managing a positive environment and contributing to school safety. School safety proposals must include funding for increased PBIS in Wisconsin schools.
- Support legislation to limit the use of restraint and seclusion in schools.
- Initiate a meaningful audit of special education quality and outcomes, including the preparation of students with disabilities for college and the workforce

Program Outcomes

Updated March 2018

FAMILY

Employment

306

Family members worked 320 jobs before enrollment.

608

Family members worked 791 jobs after enrollment.

Family members earning over \$25,000/year increased from 98 at enrollment to 165 as of March 2018.



Promise Improves Employment Outcomes

1,012 youth are participating in Promise.

YOUTH

Employment

17 (2%)

youth worked 18 jobs before enrollment.

523 (52%)

youth worked 918 jobs after enrollment.

Earnings

\$92

median weekly wage before enrollment.

\$145

median weekly wage after enrollment.

Hours worked

13 hrs

per week before enrollment.

19 hrs

per week after enrollment.

Substantial Gainful Activity*

0 SGA

before enrollment.

38 SGA

after enrollment.

*SGA = \$1,180/month.



Social Services and Employment Outcomes

Benefits Counseling

Since meeting with a benefits specialist:



Youth had twice as many jobs.

69

of 455 youth who met with a benefits specialist have worked since enrollment.

32%

of 557 youth who have not met with a benefits specialist have worked.

Youth earning SGA

69%

met with a benefits specialist.



31%

have not met with a benefits specialist.

Financial Coaching

Since meeting with a financial coach:



Youth had twice the total weekly earnings.

73%

of youth who met with a financial coach have worked since enrollment.



32%

of youth who have not met with a financial coach have worked since enrollment.

Youth earning SGA

69%

met with a financial coach.



31%

have not met with a financial coach.

Individual Development Accounts (IDAs)

Of the 130 youth with an IDA account:

85%

worked since enrollment as compared to:

44%

of the 882 youth who worked but do not have an IDA account.

Family Advocacy

66%

of the 276 youth whose families completed the Family Advocacy training have worked.

45%

of the 726 youth whose families did not complete any of the Family Advocacy trainings have worked.



Work Social Skills (Skills to Pay the Bills)



74% of the 341 youth who completed training have worked since enrollment.

36% of the 671 youth who have not completed training have worked since enrollment.

Self-Advocacy

69% of the 267 youth who completed training have worked since enrollment.



42% of the 745 youth who have not completed training have worked since enrollment.

Collaboration with Schools



57% of the 596 youth who have a school person on their Resource Team have worked since enrollment.

36% of the 416 youth who don't have a school person on their Resource Team have worked since enrollment.



Promise Enrollment

Since 2015, Wisconsin Promise has enrolled 2,024 youth ages 14-16 who receive Supplemental Security Income (SSI) and their families:

1,006 randomly assigned to receive services as usual.

1,018 randomly assigned to receive access to Wisconsin Promise Services.



Wisconsin Promise Services:

For both youth and their families.



Provided by the Wisconsin Division of Vocational Rehabilitation (DVR) in collaboration with schools, mental health programs, long term care programs, and child welfare programs working together to support youth and families.



Services include: career exploration and planning, job development and placement, on-the-job supports, Work Incentives Benefits Counseling (how to increase overall income through work) and self/family advocacy training.

Services are available for at least 2.5 years to both youth and their families.

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