

LIVING WELL

Healthy, Safe and Connected

Living Well is a five-year federal grant from the Administration on Community (ACL) to improve home and community-based services for people with intellectual and developmental disabilities. ACL grant announcement: <https://acl.gov/news-and-events/announcements/new-living-well-grants-awarded>. Wisconsin is one of eight states to receive this demonstration grant under the leadership of the Wisconsin Board for People with Developmental Disabilities, and began work in 2019. The eight grantees were tasked to develop and test approaches for enhancing and ensuring the independence, integration, safety, health and well-being of individuals with ID/D living in the community. The core components of the grant focus on community monitoring of health and safety, and community capacity building to improve home and community-based supports.

THE KEY FEATURES OF THE GRANT INCLUDE:

<p>Partnerships with state agencies, provider networks and other key stakeholders in the design, implementation and replication of the model</p> 	<p>Reducing the incidence of abuse and neglect</p> 
<p>Engagement with self-advocates and families</p> 	<p>Developing/implementing data tools and evidence-based practices to monitor and address health and safety, especially for people at high risk</p> 
<p>Designing, identifying and implementing a range of evidence-based practices and/or innovative strategies</p> 	<p>Evaluation to assess progress and determine outcomes of the project</p> 
<p>Building the competencies of direct support professionals and capacity of HCBS providers</p> 	<p>Embedding promising practices to ensure sustainability</p> 

The Wisconsin Living Well grant has focused on implementing the grant through a model that would engage numerous stakeholders around the state. These include Waisman Center-UCEDD, Disability Rights Wisconsin, The Arc Wisconsin, Wisconsin Department of Health Services, Managed Care Organizations, IRIS Consultant Agencies, service providers, People First Wisconsin, self-advocates, and families. In addition to state partners, Wisconsin also contracted with the Council on Quality and Leadership (CQL). Each of these partners brings an area of expertise to help create and test promising and best practices across the long-term care system.

This project was supported, in part by grant number 90DNIQ0004-01-00, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.



The project design focuses on the four focus areas below

Stakeholder and Community Engagement



Peer Education and Network



Family Education and Network



Quality Home and Community Based Services (HCBS)



Each of these focus areas has a desired objective with interventions with the overall goal of healthy, safe and connected. To implement the interventions in these core focus areas, the project design includes a statewide consortium of stakeholders, a policy team, coaching and mentoring, an evaluation team, pilot sites, and self-advocate leaders.

The grant recruited 10 long-term care service providers across Wisconsin to implement the intervention package to test promising and best practices to improve quality home and community-based waiver services. Currently, the grant has 8 providers who continue implement the interventions. These services providers serve range in size and location serving over 8,000 people in over 20 counties in Wisconsin. Due to the ongoing caregiver crisis in Wisconsin and the challenges providers face to provide community services to people with disabilities, two providers in the grant had to end their participation. These remaining providers recruited up to 20 people with disabilities that they serve to participate in the evaluation portion of the grant.

Why focus on Abuse/Neglect and the Individual Rights of People with ID/D in Wisconsin?

People with intellectual and developmental disabilities nationwide are 7 times more likely to be the victim of abuse and neglect.¹ The National Core indicators lists the main predictors of abuse and neglect as:²

- **Social isolation (lack of friendships and relationships beyond paid staff)**
- **Social stigma related to a lack of respect for people with disabilities**
- **Lack of privacy within the residence**
- **Ignorance of individual rights**
- **Staff stress and lack of training**
- **Significant dependence on others**
- **Lack of control/decision-making**
- **Lack of community participation**



¹Crimes Against Persons with Disabilities, 2009-2015-Statistical Tables- <https://bjs.ojp.gov/content/pub/pdf/capd0915st.pdf>

²National Core Indicators Data Brief: Case Example, Predictors of Abuse and Neglect- https://wi-bpdd.org/wp-content/uploads/2023/01/Abuse_Neglect_Case_Example_formatted_Final.pdf

In addition, the Council on Quality and Leadership (CQL) works to define, measure, and improve quality of life and quality of services for adults with intellectual and developmental disabilities. Their research shows that people with disabilities are 3 times more likely to be free from abuse and neglect when they are able to exercise their rights.³

And finally, between 2016- 2018, the U.S. Department of Health and Human Services Office of Inspector General (HHS-OIG), Center for Medicaid (CMS), and U.S. Government Accountability Office (GAO) reviewed and released reports that found the following:⁴

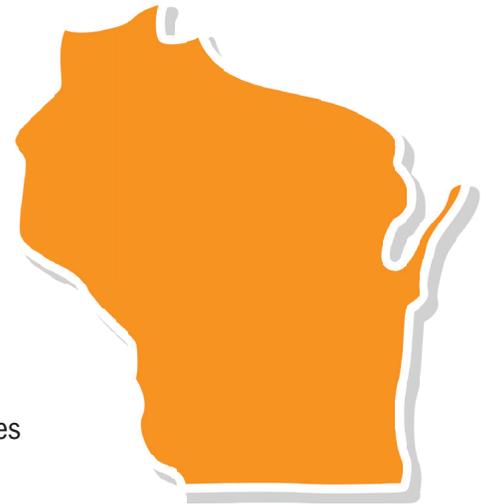
- The HHS-OIG found that several states did not comply with federal waiver and state requirements for reporting and monitoring critical incidents involving HCBS waiver individuals.
- CMS found that states have not been meeting their 1915(c) waiver assurances regarding health and welfare.
- A GAO study found large inconsistencies between states in their definition of a critical incident and their system's ability to report, track, and collect information on critical incidents that have occurred.

Data Collection on Abuse, Neglect and Rights

The Living Well grant has been gathering data from multiple sources to determine the landscape of what is happening at a systemic and participant level in Wisconsin. The systemic review included gathering information on:

- **Wisconsin abuse and neglect reporting systems**
- **Requirements in long-term care for reporting abuse and neglect**
- **Statutes that control reporting and investigative authority**
- **Annual reporting data from the Adult Protective Service**

At the participant level, the pilot providers recruited up to 20 people with disabilities they serve to complete several evaluation interviews and questionnaires. These evaluation tools provide insights into the current knowledge and experiences of persons receiving long-term care services. The Living Well grant reviewed this information to guide the focus of needed improvements in the areas of abuse, neglect and individual rights.



Personal Outcome Measure Interviews with Living Well Participants

The Living Well grant interviewed people with disabilities who are being served by the pilot site service providers, and their supports, around the state to obtain information on a variety of topics. The Council on Quality and Leadership's (CQL) Personal Outcome Measures (POM) interview tool has 21 indicators covering a variety of topics, including choice, health, safety, social capital, relationships, rights, and employment. This tool has been used across the U.S for over 25 years and is internationally recognized as a valid and reliable measurement of individual quality of life. To learn more about the POM, visit <https://www.c-q-l.org/tools/personal-outcome-measures/>.

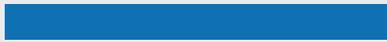
The grant uses this tool as an essential piece of the intervention for the pilot site participants and a data collection tool for the project evaluation. Since 2019, the Living Well grant has completed 155 interviews with participants and their supports. Agencies have reported that this tool has been useful in showcasing gaps in their practices and insights into areas of focus for the individual participant. This tool assists the sites to learn ways to improve agency practices based on how the people they serve are experiencing their services, and to follow up on areas where outcomes are not met for the individual participants per interviews.

³The Council on Quality and Leadership Presentation, "Quality 102: In Wisconsin", February 2022 Living Well Consortium, https://wi-bpdd.org/wp-content/uploads/2022/02/Quality-102-Wisconsin_Final_red.pdf

⁴<https://www.medicaid.gov/sites/default/files/2019-12/incident-management-101.pdf>

The grant team has focused on the predictors for abuse and neglect and whether these are present in people's lives. Outcome areas of free from abuse and neglect, exercise rights, connected to natural supports, participate in the community and have friends are present in less than half of the people interviewed.

All Indicators: Individual Outcomes Present Personal Outcome Measures interviews as part of the WI Living Well Project, Nov 2019 to Oct 2021 (n=155)

Live in Integrated Environments	73%	
Best Possible Health	70%	
Continuity and Security	66%	
Safe	64%	
Treated Fairly	64%	
Respected	59%	
Realize Personal Goals	59%	
Use their Environments	55%	
Choose Personal Goals	50%	
Choose Services	49%	
Choose Where & With Whom They Live	47%	
Choose Where They Work	45%	
Decide When to Share Personal Info	43%	
Interact w/ Community Members	42%	
Exercise Rights*	41%	
Free from Abuse & Neglect*	37%	
Participate in the Community*	37%	
Have Intimate Relationships	35%	
Perform Different Social Roles	34%	
Connected to Natural Support Networks*	33%	
Have Friends	32%	

An outcome present means the person was able to demonstrate to the interviewer they had knowledge or experience in the listed domains.

*Predictors of being safe from abuse and neglect

Living Well Abuse, Neglect and Rights Survey Results

The POM interviews were one source of data about the individual lives of the participants, but the grant team wanted to gather additional data on abuse, neglect and rights from a larger stakeholder group statewide. The project launched a survey in December 2021 to gather information from stakeholders on these areas. Over 400 people responded, and more than half were people with disabilities and their families. The survey goals were to learn if people with disabilities are:

Educated on their rights.

Able to assert their rights and file a complaint on rights violations.

Able to identify abuse and neglect and report that abuse and neglect.

The survey participants represented a wide stakeholder group and included people with disabilities, family members, supporters, guardians, direct service professionals, care managers, IRIS consultants, state agency staff, educators, health care professionals, and advocates. Respondents were asked a series of questions about their own experience as a person with a disability or as a supporter to a person or group of people with disabilities.

The first half of the survey focused on individual rights of people with disabilities. People who completed the survey indicated if people with disabilities were able to assert their rights in the following areas:

- Spend my own money how I want
- Say what I want
- Choose my church or faith
- Vote in elections
- Have privacy
- Choose my friends
- Be free from abuse and neglect
- Attend school
- Get a job I want
- Go to the doctor
- Live where I want
- Live with who I want
- Decide on my services and supports
- Plan my own schedule or day
- Make decisions about my life

Top Five Areas to Assert Rights

Spend my own money how I want	Say what I want when I want	Choose my friends	Go to the doctor when I need to	Chose my church or faith
				

Lowest Five Areas to Assert Rights

Get a job that I want	Attend School	Live with who I want	Live where I want	Vote in elections
				

In addition to gaining an understanding of their ability to assert rights, we learned if they received some level of education on rights and who were the people who provided that education. Over two thirds of the respondents received education with advocacy organizations and their long-term care teams being the main educators on rights. The survey also gathered information if the person was denied a right in the past and whether they know how to file a complaint. One third of the people did not know how to file a complaint.

Understand how to be free from Abuse and Neglect	56%	
Live where I want	53%	
Live with who I want	49%	
Get a job that I want	47%	
Have not received training or education on rights	32%	
Do not know how to file a complaint when rights are denied	32%	

In the second section of the survey, participants answered a series of questions related to abuse and neglect. This section included questions on:

- Different types of abuse
- Where did they learn about abuse and neglect
- Did they know where to report abuse and neglect
- Had they experienced abuse and neglect
- Did they report the abuse or neglect
- Where did they report the abuse or neglect
- Were they satisfied with the outcome of the report

People reported a good understanding about most types of abuse, with the greatest understanding of physical abuse and the least understanding of financial abuse. All categories of abuse were understood by at least 80% of the people surveyed. The majority of respondents learned about abuse and neglect from an advocacy organization training, their family, or in school and 80% of the people knew where to report abuse and neglect.



Why is Education and Self-Empowerment Important for People with Disabilities?

People with disabilities often have access to fewer or limited rights. This may be due to discrimination, low expectations, and even laws, both current and outdated, which may limit the rights of people with disabilities. When people understand and use their rights, they have better and safer lives. By educating people with disabilities and their family members on rights, the person is empowered to act on behalf of their preferences and goals to reach their full potential and stop others from using their authority in ways that puts unnecessary limitations on the person.

In addition, The Centers for Medicare & Medicaid Services (CMS) released a new rule for Home and Community Based Services settings, and people receiving supports through Home and Community Based Services waivers. The rule sets requirements for how Medicaid Home and Community Based Services must be provided to ensure people have full access to the community which must be implemented by March 2023. The rule focuses on issues such as choice, autonomy, and individual rights.

The Living Well grant has been focusing on rights education for people with disabilities, families and guardians, and service provider staff. The grant created 3 individual guides to provide education in 16 different rights areas and are piloting these guides with our provider sites. The grant policy team has also been working on embedding rights education and rights preservation in Long-Term Care contracts for home and community based wavier agencies.

The Living Well grant has also adapted a curriculum from Green Mountain Self Advocates to empower people with disabilities. This series called "Safe and Free" focuses on several areas for self-advocacy including understanding abuse, neglect and financial exploitation. These group conversations are led by our pilot site providers and a self-advocate leader. The grant has trained 150 people with disabilities using this series of conversations. During these conversations, people often disclose not being educated on rights, abuse and neglect and their own personal experiences being subjected to abuse.

The final education tool the Living Well grant has produced is the Healthy, Safe and Connected Toolkit. This toolkit provides information and resources to help keep people healthy, safe and connected. Each section provides some general information, tips and worksheets to help build a plan in each area.



The healthy section includes:

- Eating healthy
- Moving your body
- Taking care of your mental health
- How to prepare to see your doctor
- Health apps on your phone
- A fillable health history



The safe section includes:

- Information on rights
- How to recognize abuse and neglect
- Where to report abuse and neglect
- A plan of action to report abuse
- A call log to keep track of calls you make
- A plan to be sure you are safe in your home



The connected section includes:

- How to stay connected
- Mapping your relationships
- Ways to find new opportunities
- Activity suggestions
- How to connect with technology
- Your activity plan

These tools have been piloted as part of the Living Well grant and are a first step in evaluating promising and best practices for implementation across our long-term care system.

Policy and Budget Recommendations:

1. Expand and permanently fund the Department of Justice Elder Abuse Hotline to include people with disabilities age 18-59 with biennial funding of \$500,000.

Currently, DOJ funds a hotline at the Greater Wisconsin Agency on Aging Resources.

This grant only support adults over 60 and is set to expire this year. The hotline receives more than 300 calls annually. The National Adult Protective Services Association reports that 44 states have a hotline that takes reports of abuse and neglect; Wisconsin is not included on the list.⁵



2. Increase county Adult Protective Service funding to \$15 million annually. Since 2006, State General Purpose Revenue (GPR) funding to counties to investigate reports of abuse and neglect for people with disabilities and older adults has remained stagnant at \$5 million. Meanwhile, from 2013-2020, reports of abuse and neglect for people with disabilities and older adults has increased by 60%. An increase in funding would allow for staff/funding levels that align with both the increased number of people needing assistance, the complexity of cases, and increases in inflationary costs.



3. Increase funding for the Department of Health Services-Adult Protective Services to \$750,000 annually to provide technical assistance, training, case consultation, prevention and awareness and federally required data collection and analytics for the Wisconsin Adult Protective service system. In the last 2 years, the state has invested ARPA funding to make necessary and needed changes to support our county adult protective service system which protects the most vulnerable in our state. The projects included the development of a new reporting system, which will better enable consistent and more timely tracking and trending of incidents around the state. The additional funding will support ongoing agency case management, system improvements, training, tribal nation partnerships and increased capacity at the state level.⁶

4. Increase funding for the Division of Quality Assurance (DQA) by 20% to adequately regulate the current residential settings and to include 1-2 bed Adult Family Homes under DQA authority.

Currently, DQA- Bureau of Assisted Living regulates 4,175 facilities which are home to 64,000 Wisconsin residents. They are responsible for licensing and surveying these facilities on a rotation. They also investigate complaints from residents in these facilities. There are 1,500 1-2 bed adult family homes that are not included under the authority of DQA. Federal Medicaid regulations require Department of Health Services (DHS) to ensure all provider-owned or controlled residential settings occupied by Family Care or IRIS members comply with HCBS Settings Rules. 42 C.F.R. § 441.301(c)(4). DHS will have difficulty making that guarantee through the current process. Currently, the settings are “certified” by Family Care and IRIS. These entities currently charged with certifying 2 bed AFHs are not regulators.



5. Increase funding for additional staff in the Division of Quality Assurance Office of Caregiver Quality to allow for a 25% investigation rate.

The Office of Caregiver Quality received approximately 8,500 reports in the last year. Of these calls, 500 full investigations take place annually. This is approximately a 5% investigation rate. The Office currently has department staff of 6 with 2 additional contract investigators. In 1999, the Division had 20 department investigators. Currently, the office only investigates claims in regulated settings even though they have the legal authority to investigate all claims in unregulated settings and by any caregiver for people with disabilities using Medicaid. Additional staff is needed to complete the current investigations and to meet their responsibility under their authority to investigate all caregiver misconduct in all settings.



6. Expand the Department of Justice Medicaid Fraud Department to implement new oversight given by the federal government in 2020.

This oversight allows DOJ to investigate claims of abuse and neglect for people using Medicaid in unregulated settings, including 1-2 bed adult family homes, day services and other long-term care settings. Currently, Wisconsin has unregulated settings that do not fit into our current system of investigation, and DOJ has the authority, but not the staffing needed to provide oversight.



7. Expand training and education for people with disabilities, family members, guardians, long-term care providers, and long-term care managers and IRIS consultants on abuse, neglect and rights.

Education and training in these areas can assist people to recognize when rights are being limited inappropriately, which can lead to power and control over the person with a disability. In addition, explicit training and education around recognizing and reporting abuse and neglect, and rapid response to the victim would improve our system and would provide greater protection for people with disabilities.



8. Implement an Incident Management System through the Division of Medicaid Services with input from key stakeholders including people with disabilities, families, service providers, State agencies, and advocacy organizations that will do the following:



- With appropriate data sharing agreements in place, allow communication and collaboration between all DHS Divisions and County agencies responsible for oversight of abuse and neglect reporting and investigation.
- Identify adverse trends and patterns, proactive interventions, performance metrics and training needs.
- Implement common definitions across reporting entities.
- Provide detailed unidentifiable information that can be used to create a public facing annual report on the number and type of reportable incidents impacting health and safety by MCOs and ICAs.

⁵<https://www.napsa-now.org/get-help/help-in-your-area/>

⁶<https://www.dhs.wisconsin.gov/publications/p02449.xlsx>