



WISCONSIN LEGISLATURE

P. O. Box 7882 Madison, WI 53707-7882

October 16, 2019

To: The Assembly Committee on Health
Fr: Rep. Rob Hutton and Senator Dale Kooyenga
Re: Support for Assembly Bill 462

Mr. Chairman and members of the committee, thank you for giving Assembly Bill 462 a public hearing. The bill you have before you today is because of the tireless advocacy of our constituents, Sam and Joanna Hughes, who will be testifying later. They first approached us almost two years ago with concerns about the rights their daughter would have when receiving treatment at one of the three DHS-run centers in Wisconsin. My office has spent two years speaking with DHS, disability rights advocates, parents, and other stakeholders to develop a piece of legislation that would ensure certain protections for residents while also accommodating the concerns of disability advocates.

We want to be clear, the bill before you today is about one thing: the right of parents and guardians to be able to choose what they feel is best for their children. Under this bill, a patient in an intensive treatment program has, if the patient or the patient's parent or guardian requests, a right to a staffing arrangement under which at least one person of the sex requested by the patient or the patient's parent or guardian be present for assistance with bathing, toileting, or any activity that requires removal of clothing other than outerwear, footwear, or accessories; movement within the center or other transfer that involves transport through an isolated area such as a stairwell or elevator or in a vehicle; or any interaction in a private room, bathroom, changing room, exam room, or any other isolated area.

In hospital and prison settings as well as privately run facilities across the state, these protections are already provided. In a hospital one can request and receive care from a nurse of their choice. Across the state, school districts and care facilities have accommodated the request of parents and guardians when they requested caretakers of a specific sex during specific settings, and we think the state should also provide these important protections.

In 2003 at Central Wisconsin Center a woman was sexually assaulted and became pregnant. Just this year in Arizona, a woman who was in a vegetative state was raped by her caregiver. This egregious crime was only discovered when she gave birth to a child. According to reports, the care facility where this incident occurred instituted a policy similar to the legislation in this bill. In their facility, male staff are not allowed to enter a female patients' room unless accompanied by a female employee. Wisconsin should be a leader in instituting this policy in our state facilities. The most vulnerable in our state don't deserve to be a part of the next tragic headline.

Thank you again for hearing the bill today. We are happy to answer any questions that you may have.



State of Wisconsin
Department of Health Services

Tony Evers, Governor
Andrea Palm, Secretary

TO: Members of the Assembly Committee on Health

FROM: Lisa Olson, Legislative Director

DATE: October 16, 2019

RE: 2019 Assembly Bill 462, relating to: a right to specific staffing arrangements for certain clients in an intensive treatment program

Good afternoon, Chairman Sanfelippo and members of the Assembly Committee on Health. My name is Lisa Olson. I am the Legislative Director at the Wisconsin Department of Health Services. With me today is Catherine Murray, Director of the Central Wisconsin Center – one of the Department's three centers that serve people with intellectual and developmental disabilities – and Rose Kleman, Division of Care and Treatment Services Administrator at DHS. Kevin Bailey, an attorney for the Department is also here and can help answer questions that may arise. We appreciate the opportunity to provide testimony for information only on Assembly Bill 462, to provide background about our three state Centers and the excellent care they provide for individuals with intellectual and developmental disabilities, and share how the bill would impact the Department's operation of our centers.

[Catherine Murray]

Central, Northern and Southern Wisconsin Centers are state-operated facilities serving individuals with intellectual disabilities who may also have significant medical conditions, sensory impairments and/or significant behavioral challenges. The Centers are under the direction of the Division of Care and Treatment Services within the Department of Health Services. The Centers provide services that are otherwise unavailable in the community. After receiving services from one of the Centers, individuals return to the community when their needs can be met at the local level. Individuals qualify for services by having a disability characterized by significant limitations in both intellectual functioning and in adaptive behavior, which covers many everyday social and practical skills, that originates before the age of 22.

All three centers have Intensive Treatment Programs which provide behavioral and psychiatric evaluation and treatment.

Admission to the Centers for services is voluntary. It is not mandated or court ordered. Centers are generally contacted by the county, managed care organizations, care providers, other social service advocates or a family member inquiring about our services. Referrals need to meet eligibility criteria and must be authorized by the county of responsibility. Each center, including Central, has an admissions team which completes an assessment to determine if the individual referred is clinically appropriate and the program has resource capacity to meet the individual needs. If the individual referred meets admission criteria, they are added to a list of prospective clients who are appropriate for services and admitted when feasible to do so. This list is not first come first served; admissions are scheduled when the program can best accommodate an individual's needs in terms of environmental and clinical supports available.

Services available at Central Center include medical, psychiatric, psychological, nursing, and direct care supports, physical therapy, occupational therapy, speech and language services, respiratory therapy, dental services, dietetic services, therapeutic recreation, vocational services, special education, music therapy, and specialized equipment fabrication.

Services provided are individualized to the greatest extent possible for all clients and residents and special requests are accommodated when feasible. Living and common areas are personalized and home-like, preferred activities are identified and offered, personal items are made available as appropriate, meal preferences are considered, and visits with family and friends are supported. Individual choice and active participation in daily care and programs is supported by all disciplines to maximize skill development and independence.

While we understand why specific staffing arrangements might be requested, there are significant practical limitations to the resource demands that would be created through this bill. As is the case in all health care settings, direct care staff are in high demand. As a result, we need to manage our resources carefully and make staffing assignments accordingly.

Client safety is our number one concern at Central Center, as well as for my colleagues at the other Centers across the State. We all have highly trained staff who provide excellent care – they assess each client's individual needs and develop a treatment plan that is unique to them. We provide quality service to each person that comes through our Center doors, and ensure they leave our facility with a plan to succeed when they return to the community.

Central Wisconsin Center has a Privacy and Safety Plan which aims to prevent abuse, and identify and mitigate areas of risk for abuse. Some of these strategies include staff background checks – caregiver background checks, sex offender registry checks, criminal background checks, and ongoing checks throughout employment. All new employees receive training on prevention of caregiver misconduct and prevention of abuse, among other topics, and are required to maintain & demonstrate competency based on refresher trainings. Our staff use privacy screens which have been shortened for visual oversight while maintaining client dignity. Clients (and families) are also taught how to advocate for themselves, and as appropriate, clients are taught protective behaviors and communication strategies. Our staff are supervised, and cares are monitored with client safety and privacy as our primary goals.

As it relates to AB 462 specifically, Central Wisconsin Center has received a request from one family seeking services at our facility for a gender-specific staffing arrangement. We have looked into this request, and ultimately found that we cannot guarantee that an individual seeking services at our facility will have their preferred staffing arrangement at all times. At times, a unit may have all male or all female staff scheduled for a shift. Our staff are trained to provide cares as professionals, regardless of client gender. Reassigning less familiar or additional staff to accommodate observation of care, transport or program sessions could introduce risk, result in delayed care or program access or reduce therapeutic interaction opportunities.

[Dr. Rose Kleman]

The nationwide shortage of caregivers continues to be one of the biggest industry-wide problems for health care agencies. Efforts are being made in Wisconsin to increase training opportunities but supply

is not keeping up with demand. Each of the Centers is working to re-think staffing assignments to best meet the needs of the residents within our facilities; however they would be challenged if additional restrictions were added to recruitment and retention efforts currently underway. To meet the requirements of this bill – ensuring sufficient staff members of a specific gender are available to assist on a 24 hour basis – the Department would need an additional 85.5 FTE resident care technician – advanced (RCT) positions. These additional RCTs would accompany residents throughout the facility, when requested and in the circumstances stipulated in the bill. To accommodate the requests, DHS assumed a staffing pattern that would provide one staff member for every two residents during the morning and afternoon shifts, and one staff member for four residents during the overnight shifts throughout the year. Assuming DHS was able to recruit and start an RCT training class by January 2020, the cost of providing six months of these services in FY 20 is expected to be 85.5 FTE and \$2,881,400, with costs increasing to \$5,335,200 PR in FY 21.

We understand that it is a difficult decision to have a family member cared for in a facility, and we work to support all families to be involved to the extent they prefer in the care and treatment of our clients and residents. We place high priority on providing quality services, ensuring the health and safety of those in our care. While we understand the intent behind Assembly Bill 462, we do not believe it would be feasible to implement and would not ultimately improve client care and safety.

We are happy to take your questions.

Sam Hughes Testimony

Re: AB462 & SB416

Assembly Men & Assembly Women, I want to say thank you for your time and your investment into serving our state.

As a Father of three wonderful daughters, one whom is present today, I am sure I share with other Father's in the room the unique love a Father has for his daughters. I express my love and care for my daughters by providing for their physical needs and their emotional needs. This requires me to play doll house with my youngest (which I consider a great sacrifice), to installing a therapy swing by crawling in the thick, scratchy insulation in our attic all for my middle daughter, Eden, so she can enjoy the sensory of a swing, and then also setting up a volleyball net in our driveway for my oldest daughter.

Our oldest and youngest daughter can verbally express their love rather easily, but Eden returns her love by soft, sweet kisses and snuggling. She often will come and sit on my lap and require that I tickle her on her neck with my scratchy beard. When Eden feels afraid (by escalators, unsteady ground and odd noises) she will grab me tight and even climb up on me when she feels unsafe or just afraid.

Even though Eden has a severe cognitive disability with an inability to talk, she still feels afraid, and she still feels sadness, just like my other daughters. Yes, as a married man and a father of 3 daughters, there have been many days where each family member has cried on my shoulder and I have the honor to comfort and console them.

Eden can't use words to express her love or express her pain, but as a Father, I see the comfort in her eyes when she knows that Dad is there to protect her.

Just a few weeks ago, her therapists spent over 45 minutes trying to get Eden to calm down and relax, but only a short time with Dad, holding her tight, telling her that I was there and that I wanted to know what she was feeling and what she needed, she was able to calm down and share what she wanted through her communication device and her few hand gestures.

Eden couldn't express to these professionals what she was feeling, she just felt upset, probably from something that happened to her earlier that day or the previous day. Once she felt safe, then she could tell me and them what she wanted through her basic forms of communication.

It would be extremely difficult for us to know if Eden was experiencing some internal physical disorder or pain and diagnosing emotional pain would be nearly impossible or just impossible. One traumatic event can set a fragile girl emotionally behind for months, years, maybe even decades. An environment must be established that allows these children and young adults to feel safe with dignity in these most vulnerable areas of their life

The program at Central Wisconsin Center states that it "provides short-term and residential services to assist individuals living with intellectual disabilities in acquiring the personal skills needed to reach their highest potential."

When my wife and I met with the Director of Central Wisconsin Center, I was shocked and horrified that they would disregard the basic right of Eden to choose the gender of the caretaker in her most vulnerable settings. I have always been able to choose male doctors and male nurses in my vulnerable hospital care, so why isn't my daughter allowed to choose an appropriate caretaker when she is under state care?

Central Wisconsin Center and other similar state run facilities should not gamble any longer with the dignity and basic protection of these children and risk another tragic outcome. The simple and common-sense steps to reducing the risk of sexual abuse to non-verbal and cognitively disabled clients in their facility should have started

Sam Hughes Testimony

Re: AB462 & SB416

when the "first guy was actually caught with his rape only by the discover of a pregnancy". Would I be bold to assume this wasn't a solo incident at CWC and legitimately wonder how many other cases went undetected or unreported? This saddens me to know by simply enacting this simple standard, the risk of sexual abuse can be significantly reduced.

Eden lives with intellectual disabilities and she wants to acquire the personal skills needed to reach her highest potential. You can now equalize the rights between verbal and non-verbal individuals by saying yes to this bill

Today, it is time to correct the wrongs and require these state-run facilities to give these most-vulnerable children the dignity and rights they deserve.

Dear Lawmakers,

I urge you to support patient rights for the most vulnerable, **Assembly Bill 462/Senate Bill 418**.

My 12-year-old niece, Eden, was born with severe special needs to my brother Sam and his wife, Joanna.

Shortly before her birth, my own son, Jack, was born.

Our two families imagined our children growing up as close cousins and friends. Unfortunately, that never happened as I have seen Sam and Joanna struggle for twelve years in a constant, exhausting battle to provide care, protection and support for Eden.

For Sam and Joanna, it's an uninterrupted hum of anxiety and stress as they care for a little girl who often resists care.

Much of what they endure on an hourly basis is out of their control. Frankly, it's out of any human's control.

Protecting her and other defenseless girls from male sexual predators is, however, something we have significant control over.

To a great extent, it's within your control.

This is not a partisan issue. This is a compassion for the weakest in our midst issue.

As far as I can tell, every lawmaker in Madison will say they seek to protect the weak and powerless in our community.

Voting in favor of this bill is your chance to walk the talk.

Thank you

Jeff Hughes
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To whom it may concern re: AB462/SB418,

Caring for and providing education to people with developmental disabilities is something that my family is passionate about. My mother, an RN, worked with developmentally delayed teenagers for nearly 20 years. As her daughter, I got to spend some time getting to know many of her students. I saw my mom teaching them how to care for themselves and teaching them sex education and how to keep themselves safe. My sister is an educator and is currently concluding her Master's in Special Education where she advocates daily for her students to receive the education and care they need in the school setting. I am a parent of a 9 year old son with Autism, and have been advocating on his behalf to receive needed services since he was three.

I was shocked to learn that, while schools already implement practices to ensure that students with disabilities are protected from abuse and harm, state-funded facilities do not have any laws in practice!

I believe it is vital that vulnerable individuals should be able to request the gender of caretaker, especially in private settings. Statistics show that individuals with cognitive delays are most often sexually abused by someone in their caregiving routine, such as a driver, personal care giver, or therapist.

As parents or guardians we are charged with the responsibility to keep our loved ones safe, advocating on their behalf. This absolutely includes being able to request care givers who interact, frequently one-on-one, with our family members.

Please allow families more choices and say in the care of loved ones! Support AB462!

Respectfully,



Jennifer Kroemer

213 N. Fowler St. #314

Oconomowoc, WI 53066

Date: October 16, 2019

Re: AB 462 Relating to right to specific staffing arrangements for certain patients in an intensive treatment program - *Informational*

To: Chairman Sanfelipo and Vice Chair Kurtz and Members of the Assembly Committee on Health

From: Barbara Beckert, Disability Rights Wisconsin, Director Milwaukee Officer

Thank you for the opportunity to share this testimony to inform your consideration of AB 462 relating to right to specific staffing arrangements for certain patients in an intensive. Disability Rights Wisconsin (DRW) is the designated Protection and Advocacy system for Wisconsinites with disabilities. DRW is charged with protecting and enforcing the legal rights of individuals with disabilities, investigating systemic abuse and neglect, and ensuring access to supports and services.

As Wisconsin's Protection and Advocacy system, a primary focus of our work is to provide advocacy assistance to people with disabilities who have experienced abuse and neglect, as well as advancing systemic and policy change to decrease the risk of abuse and neglect of people with disabilities in institutions, schools, and the community.

We respect the intent of the bill's authors to address the risk of abuse for individuals in an intensive treatment program in one of the state of Wisconsin centers for people with developmental disabilities; however, we have serious reservations about the feasibility and benefit of the solution proposed. Earlier this year, we were contacted by Representative Hutton's staff with the opportunity to share feedback regarding the proposal. We thank Representative Hutton for that opportunity. The suggestions we shared at that time still hold true and we wanted to share them with you today:

- Offenders come in all shapes and identities. Parents/guardians may sometimes think that by having a caregiver of the same sex present, that they can prevent abuse. This can lead to a false sense of safety. The sex/gender of a caregiver is not the sole or primary determinant of likelihood to engage in assault or other forms of abuse.
- The vast majority of people with disabilities live in the community rather than institutions. Policy proposals that address staffing concerns for individuals with additional vulnerability would want to consider the needs of those who live in the community as well as the small number of people in our state centers. The risk for abuse and neglect is a concern in all settings: institutions, community based residential facilities, as well as family homes. The bill's failure to offer similar staffing choices to similarly situated people in the community creates serious equal protection concerns.

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- The proposal would potentially require 2 on 1 staffing any time the resident is not in the common areas of the facility. This will be very difficult and impractical to implement – for example, if a person needs assistance with an immediate need such as toileting, it may not be practical or healthful to quickly find a person of the proper sex to assist in the resident care. The additional staffing costs could potentially be quite significant. At best it's unclear if this staffing practice would result in the desired outcome of greater resident safety. There is currently no evidence to support the proposition that it will. Given the absence of any new funding to support this proposal, resources to implement it would simply be shifted away from other resident needs. To divert already scarce resources without firm evidence of either an actual problem or evidence that this would solve it, would be irresponsible.

We thank the Assembly Committee on Health for your interest in decreasing the risk of abuse and neglect of people with intellectual disabilities and ask for your consideration of alternative opportunities for addressing these concerns:

1. The Wisconsin Board for People with Developmental Disabilities (BPDD) received a 5-year federal grant from the Administration on Community Living to develop and test approaches for improving home and community-based services (HCBS) for people with developmental disabilities. DRW is one of the partners in this initiative, *Wisconsin's Living Well Project*, which aims to increase health, safety, independence and well-being of people with intellectual and developmental disabilities living in the community. This will include developing policy recommendations to decrease the risk of abuse, neglect, and exploitation.

The *Living Well* recommendations will be available to you as a resource for a broader discussion of how to more effectively address the risk of abuse and neglect, and will offer evidence based solutions.

2. Representative Emerson is introducing a bill that would require the Department of Health Services to establish a council on effective abuse prevention and response for people with disabilities. Part of the charge for the Council would be to examine predictive factors of abuse and neglect of people with disabilities, systemic factors, and examine existing policies and procedures that have a role in preventing, reporting or responding to abuse and advance recommendations. We look forward to learning more about the proposal.

Thank you for your interest in decreasing the risk of abuse and neglect and your consideration of these informational comments.



My name is Cindy Bentley. I am the Executive Director for People First Wisconsin. Our statewide organization is made up of people with disabilities and is run by people with disabilities. We oppose AB 462. It doesn't make people safer. It doesn't stop abusers.

I lived in Southern Center for 18 years in the 1970s and 1980s. I saw what happened in the Center, and it happened to me too. I was assaulted, in my case by a male staff. I knew male and female residents that suffered abuse and injuries. Sometimes it was female staff that hurt residents. Sometimes it was male.

Many of our people are now living in the community instead of institutions. That's a good thing. We can work, we can see people and have friends, and contribute to the state. I'm a taxpayer. I want the same things you want. We all want to live our lives and do the best we can. But just because most of us aren't living in institutions doesn't mean that the abuse has stopped.

People First hears from members across the state. We hear what is happening or not happening in group homes. People feel unsafe and are being abused in group homes. There are injuries. There are punishments or restrictions that are meant to control or intimidate people or prevent them from reporting what's going on to others.

It's not the setting. Institutions have abusers. Community setting have abusers.

It's not the sex of the caregiver. Male caregivers can be abusers. Female caregivers can be abusers.

Family members and guardians can abuse.

Abusers know they can hurt people with disabilities wherever they are without anything happening to them. That's a real problem, and this bill does nothing about that.

People First believes the voices of people with disabilities should be heard. Nothing about us without us.

This bill gives parents or guardians the right to be present all the time and choose the people who are interacting with us. What about our choices? What about our rights?

What if we don't want our parents or guardians to be around when we are going to the bathroom, taking a bath, or in our own room? What if we want a different caregiver than the person someone else thinks is good? I've had male caregivers that are good, and female caregivers that aren't. I know what I want, why does someone else decide for me?

This bill lets other people's voices decide for us. Not being able to say no is why a lot of abuse happens.

Respectfully,


Cynthia Bentley



Martha Siravo
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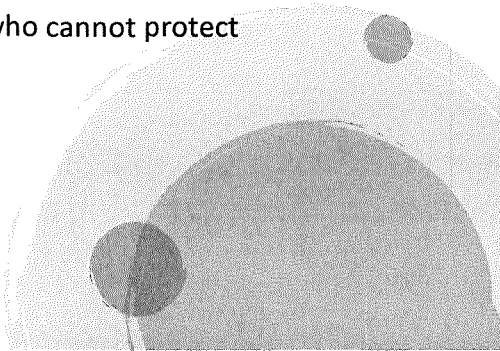
My name is Martha Siravo. I'm here today to support for AB462 which will give equitable rights for patients who are most vulnerable. Our voices are powerful, impactful, and is considered an identifying piece of who we are. If we choose to be LOUD, if we choose to speak *quietly*, if we use sign language, or even if we " ", we are still communicating in some way. Notably, the last version, where I did not say anything at all, left my intention open to interpretation to everyone in this room.

My daughter, Jasmine, is 7 years old and has cerebral palsy from hydrocephalus when she was 2 days old and was also diagnosed with epilepsy 2 years ago. She openly talks her way through every thought she has, often recites playtime from verbatim memorization of things she's heard, or sometimes misses/ignores direct conversation. Her constant shift of communication style can be confusing to people she is around every day, and it's even more difficult to follow when encountering someone new. I want her to be as independent as possible, but I also realize that I need to be identifying situations where she cannot give accurate direction or properly advocate for herself.

I had not realized until I met Joanna through BPDD Partners classes that in the state of Wisconsin, disabled individuals and families do not have the right to direct the composition of their care teams in DHS facilities. When I take my daughter to the clinic, the Hospital, or even to school, I have the right to give specific instruction - including gender specific instruction – about who is part of her care and within different context/activities. A care team in ANY facility should be applying this common-sense right as appropriate for every individual in their care.

Joanna, in one of the emails you said your voice was lonely. I know exactly what that feels like as I'm sure many people here today do as well. I hope that after today, with the help of this committee, and everyone who has come to show support of this bill, you feel empowered. Know that **your** voice, which brought us here today and on behalf of your daughter, Eden, is where true advocacy shines for all of our children.

I implore this committee to support AB462. It protects basic patient rights for an individual with a developmental disability, and protects our children who cannot protect themselves.





P.O. Box 7222, Madison, Wisconsin 53707

October 16, 2019

Representative Sanfelippo
Chair, Assembly Committee on Health
Wisconsin State Capitol, Rm 314N
Madison, WI 53708

Dear Rep. Sanfelippo and members of the Committee:

Survival Coalition is comprised of more than 30 statewide disability organizations, and has members with expertise in disability law, research and best practices, and providing direct services for people with disabilities. Survival Coalition members are concerned about the safety of people with disabilities and support policies that lead to prevention and effective response to abuse. However, our analysis finds that AB 462 will not increase safety and we have concluded this bill will result in negative unintended consequences.

Survival Coalition has substantive concerns about how such a policy intersects with employment and non-discrimination laws, the rights of the patient versus the right given to a parent or guardian when parties are not in agreement, the challenges of implementing such a policy especially in the context of the caregiver crisis, and fiscal concerns as this policy change may lead to increased staffing requirements without increasing quality of service or the amount of services provided to Medicaid recipients. Our testimony is focused primarily on whether this policy is an effective strategy to improve safety.

No evidence that choosing the sex of the caregiver is correlated with increased safety.

Survival Coalition members consulted with national disability organizations and partners for examples of similar policies that consider staff sex. Only one example was identified. A Georgia provider agency discontinued its policy after a court settlement; not only was there no legal precedent to support its policy, but there is no concrete evidence from research that supports selecting caregivers by sex has reduced abuse¹.

Survival members also reached out to experts on policies to prevent and respond to abuse within state institutions for the developmentally disabled. We are unable to find a state that has a policy that uses caregiver sex as the basis for determining what duties a caregiver can perform or whom they may serve, or a state that has established a right for a patient or other person to choose or reject a caregiver based on the caregiver's sex. In cases where institutional conditions have prompted U.S. Department of Justice

¹The Georgia provider was sued by a male worker who was seeking a promotion and would not have been allowed to apply for an available management position which required him to be available to perform all duties and fill in for shifts or be available as back-up at a facility. The provider has since changed the policy, and 1) cautioned against any policy that is inherently discriminatory and limits staff due to race, sex, orientation, creed, age, etc. 2) indicates their increased hiring of transgendered individuals would make such a policy even more problematic.

action, consent decrees have not directed states to implement policies based on caregiver sex as a best practice or strategy to improve safety².

Similarly, best practices suggested to improve safety in community settings, such as group homes, do not recommend policies related to caregiver sex or choice of caregiver sex³. Experts identified the best strategies for prevention of abuse and neglect are effective and timely investigations, reporting, and remediation. Training, supervision, and personnel actions for direct care staff is critical, but the sex of the workers is not identified as a factor that is related to safety.

The sex of a caregiver is not predictive or a risk factor for abuse.

Sex of a caregiver is not among the identified factors that contribute to the higher risk of victimization faced by people with disabilities. The eight predictors⁴ of abuse and neglect for people with disabilities include: social isolation (lack of relationships beyond paid staff); social stigma; lack of privacy; staff stress and lack of training; lack of control/decision making; significant dependence on others; lack of community participation; and ignorance of individual rights.

Allowing a patient, parent, or guardian to choose the sex of a caregiver does not address any of the underlying factors that contribute to higher rates of victimization⁵, nor does it address the many systemic issues and cultural prejudices that contribute to the underreporting and inadequate response to abuse. Wisconsin data⁶ underscores that the sex of the caregiver is not correlated with lower reports of abuse.

Abuse happens in many settings

Most people with disabilities live in the community. The presence of abuse is correlated to where people with disabilities live⁷. Survival Coalition questions why this institutional setting that is already heavily regulated is selected is the sole focus of this bill; prevention and effective response to abuse is needed

Whose rights come first?

The bill grants a patient, parent, or guardian the right to be present during certain interactions and choose the sex of a caregiver. The bill gives the same rights to multiple individuals. It is unclear how

² Many of these agreements do have requirements systemwide regarding quality management, risk management, and mortality reviews. <https://www.justice.gov/crt/special-litigation-section-cases-and-matters0#disability>

³ The Center for Medicaid Services (CMS), Administration for Community Living (ACL), and Office for Civil Rights (OCR) in conjunction with the U.S. Department of Justice (DOJ) recently released a report focused on improving safety in group homes which includes model practices for states. The full report is here: https://www.hhs.gov/sites/default/files/report_joint_report_hcbs.pdf

⁴ National Core Indicators

⁵ In some circumstances, this policy could be applied in a way that reinforces some of the factors that contribute to increased likelihood of victimization, especially lack of privacy and lack of control/decision making.

⁶ According to 2018 data, the sex of alleged abusers was 49% female, male 41%, unknown 10%. The sex of victims is evenly distributed, 51% female, 49% male. 59% of abusers are identified as parents or other family members; 9% are identified as service providers. 47% of abusers are identified as caregivers, which includes family caregivers and paid staff. Wisconsin's Annual Report on Abuse, Neglect, and Financial Exploitation of Adults at Risk: 2018. <https://www.dhs.wisconsin.gov/aps/publications.htm>

⁷ 58% of victims live in their own home, 20% relative's or friend's home, 13% in a community based residential setting (includes Adult Family Homes, Community Based Residential Facilities, and Residential Care Apartment Complexes), 6.5% in other places, 2.3% in nursing homes, 0.3% in institutions. Wisconsin's Annual Report on Abuse, Neglect, and Financial Exploitation of Adults at Risk: 2018.

<https://www.dhs.wisconsin.gov/aps/publications.htm>

conflicts are resolved if the patient wishes to exercise their right in manner that differs from how the parent(s) or guardian wishes to exercise the same rights afforded to them. Similarly, it is unclear how these rights would be exercised if the parent and guardian do not agree.

The term “guardian” appears to be inclusive of guardians appointed by the courts under Ch 48 (Children’s Code) or Ch 54 (Guardianships and Conservatorships for persons over age 18). The court may appoint any person it deems fit to fulfill the role and responsibilities of a guardian; corporate guardians, volunteer guardians, persons the individual knows, or relatives can all be guardians of a person. A guardian is not necessarily a parent or even related to the ward. It defines a legal relationship where authority to make some or most decisions has been transferred from the person to the guardian.

Wisconsin has a limited guardianship system. The Court may choose to grant a guardian authority to choose providers of medical, social, and supported living services under Ch 54.25(2)(d)2.i., however that is not necessarily the case. The bill appears to grant a guardian the right to choose the sex of a caregiver and be present when services are being delivered independently of whether they have been granted that authority by the courts.

In situations where a guardian has been appointed under Ch. 48 or Ch. 54 who is not the ward’s parent, it appears this bill elevates the “parent” to a co-equivalent role with the appointed guardian who is overseen by the court. Sometimes the court has purposefully chosen to not appoint a parent as a guardian; Survival Coalition is concerned that this bill grants rights to individuals that the courts have determined should not have that authority over the ward.

While the bill does not include a statutory cross reference to further define the term “parent,” Survival Coalition finds this term could potentially describe multiple individuals—such as a biological parent, foster parent, adoptive parent, legal custodian, or person acting in place of parent—all of which appear to be granted the same rights to be present and choose the sex of a caregiver under this bill.

Many people with disabilities have close, positive relationships with a parent or parents. But this is not universally the case. And parents may not have positive relationships with each other. In cases where the person with a disability is estranged from one or both parents or their familiarity with the person’s wishes, preferences, and daily living experiences is incomplete, Survival Coalition is concerned that the parent’s rights may be equal to or usurp the patients. Survival Coalition also notes that this bill does not exclude any parent from exercising these rights, which could mean parents whose rights have been terminated or who have been identified in reports of abuse and neglect etc. could be enabled to access the patient.

A patient can still be capable of expressing wishes and preferences regardless of whether guardian has been appointed or a parent wishes to exercise their rights under the bill. The bill does not indicate that the wishes and preferences of the patient are privileged or prioritized.

Survival Co-Chairs:

Beth Swedeen, beth.swedeen@wisconsin.gov; (608) 266-1166;
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Anna Hauser
626 E Johnson St #202
Madison, WI 53703
6087389143

Good afternoon, my name is Anna Hauser. I am asked EVERY medical visit I go to if I have a preference for gender of my practitioner. When that provider is male, I am ALWAYS asked if I would like a female present. Why should that be any different for a person with a disability?

When my 14 year old son Xavier stayed in a state care facility, his rights and ours were entirely invalidated to the point where the trauma caused me to exhibit symptoms of PTSD. It may have for Xavier too, but he has Cerebral Palsy and is not able to speak. What I know is he didn't laugh or smile for the months we were there. What I don't know, is if he was if someone took advantage of him. He was drugged up and recovering from a painful surgery, so his crying could have been related to that or something more sinister. I really don't have any way of knowing. What I do know is there is an overreach of staff behavior that extends past what is legal, even by those that probably mean no harm. During our stay, they put up signs forbidding us from closing our door, even after other patients would wander into his room without permission. That's not legal. Staff may enter for cares, but privacy is a basic right. I know this and I said as much, but not everyone is aware and able to speak up.

If this was happening at a facility you were staying at, you could stand up for yourself. You could say no. Xavier cannot say no. Xavier requires a team of trusted individuals to provide his care. Xavier and other vulnerable people should have the right to be protected. My vulnerable child had his human rights to privacy and safety violated by a care facility. This issue isn't an isolated one. It isn't one bound by gender or race. For a person with disabilities, things you take for granted—like consent are often overrun by well-meaning people. And then, there's the ones who aren't so well meaning. We are asking you to support this bill and make it the law to protect people with disabilities from sexual abuse.

Oct. 16, 2019

Re: Support for AB462

Thank you for your time this afternoon in addressing this crucial bill for the equitable rights of the most vulnerable of our population: those who are both non-verbal and cognitively or physically disabled.

My name is Karen Sharkey and I am the disabled mother of a cognitively and verbally advanced four-year-old son. I have been disabled with a number of invisible disabilities for the past twelve years, during which time I have learned what it is like to be, what I call, a "professional patient". Through the immense help of others over the years, I have had the privilege of learning firsthand how to advocate for myself, what questions to ask potential caregivers, the importance of a second opinion, as well as to become familiar with what my patient rights are. I know, for instance, that I can refuse treatment I do not want, or caregivers I am not comfortable with, and that when I utter the powerful words "I do not consent", I will be heard because I have the advantage of something we so often take for granted: speaking.

I have taught my son to do the same - to advocate for himself. To speak up when something makes him uncomfortable and to ask for help when needed. I constantly find myself repeating the phrase "use your words" in all kinds of scenarios. In teaching our son about body safety, I have taught him the correct anatomical words for his body parts, and have given him tools for keeping his body safe. And because of his highly advanced cognitive and verbal skills, at four years old he has often openly recalled and repeated these tools back to me and has felt free to ask me questions and bring up concerns. I can be assured that he not only knows what "safe touch" is, but he also knows what to do if, God forbid, he ever finds himself in a sexually vulnerable situation. I often take for granted how advanced my son is. I cannot imagine what life would be like if my son was in the opposite place of where he is now - if he were cognitively and verbally disabled. That would be challenging enough on a day-to-day basis at home. But then, to desperately need the help of facilities and caregivers while not being assured that those same facilities and caregivers were taking every precaution to honor his needs and keep him safe with common sense, built-in practices for his sexual safety is unfathomable. Honestly, as a mother, the thought alone is terrifying.

Being able to request same-gender caregivers in vulnerable situations, such as requesting to have a female nurse present while a male doctor is doing an examination, is something that is respected as a common sense patient right for all those who have a voice. And yet, we find ourselves here discussing something that should be and is even more common sense - the need for the protection of those same patient rights for those among us who are the most vulnerable - those who are disabled and do not have a voice. Those who are unable to advocate for themselves.

Myriad statistics show that those who are disabled, verbal and nonverbal alike, are most vulnerable to sexual abuse. However, statistics also clearly testify to the fact that those who are nonverbal are at an entirely different level of risk altogether. Not only are many of these beloved ones unable to sense danger in the first place, they are alone with caregivers around the clock, in extremely vulnerable situations (toileting, bathing, transportation) multiple times per day, and

their caregivers have little to no accountability to anyone else because of their inability to testify regarding events of the day. Furthermore, for many of them, the same non-verbal cues that would try and communicate something amiss could easily be written off as behavioural issues because of their diagnoses or disabilities.

What we are asking for is something that is respected and practiced in countless public and private entities (public schools, respite centers, ABA therapy groups, etc.). These places are already giving this demographic this common sense equitable right. We are saddened and horrified that this equitable right must be forced into existence through legislation so that it is practiced across the board, regardless of what center or facility is responsible for care. The Central Wisconsin Center, a center that is desperately needed by many Wisconsin families, has refused to honor this equitable right both in words and in practice, despite its egregious history of sexual abuse and impregnation within its own walls. We urge you to require all facilities, including the Central Wisconsin Center, to honor the personal requests of patients or guardians asking for ~~same~~-gender caregivers to be present during times of personal care and transitions.

✓ preferred

Thank you for your time and consideration of this crucial issue.

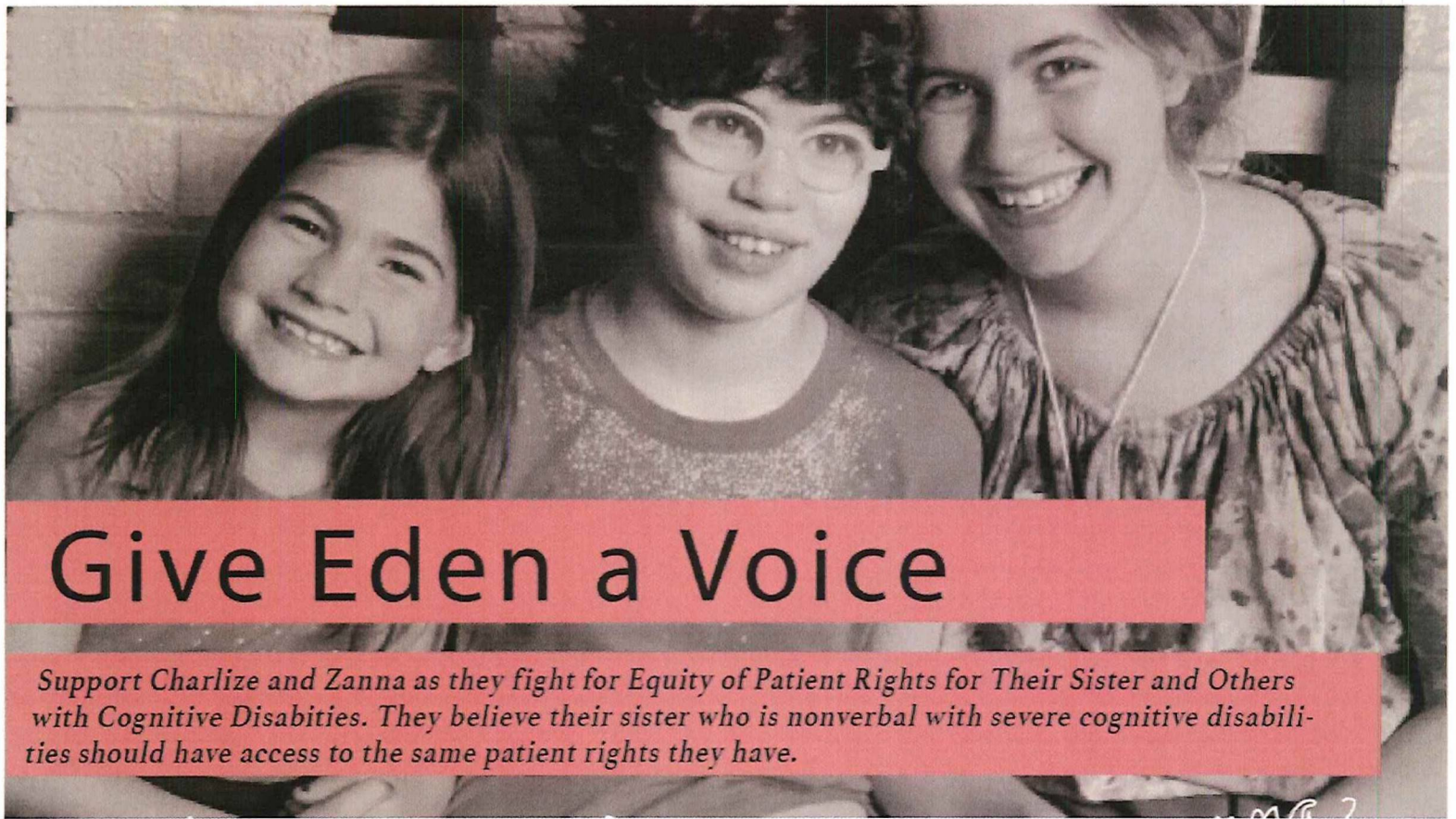
Karen E. Sharkey

Karen E. Sharkey

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Give Eden a Voice

Support Charlize and Zanna as they fight for Equity of Patient Rights for Their Sister and Others with Cognitive Disabilities. They believe their sister who is nonverbal with severe cognitive disabilities should have access to the same patient rights they have.

Re: AB462
Joanna Hughes
14050 Saint George Court, Elm Grove
414.559.5904

Dear Assembly:

My middle daughter, Eden, is 12. She was born with level 3 autism and a rare genetic disease that has left her nonverbal with significant developmental disabilities. She is funny and playful and curious. She also loves hugs and kisses and tickles from mommy, daddy, and her two sisters. Yet she also behaves in ways that overwhelm and exhaust. While she communicates with a few signs and crudely with a communication device, she communicates more often with extensive tantrums, aggression, and self-harm to express her feelings. Because of the challenging behaviors she was recommended to the state funded, Central Wisconsin Center's short term treatment program. We were ecstatic to access such important resources. Because of past abuse and knowing my daughter's comfort, we were eager to allow her to enter CWC with a care plan that allowed her to have a same-sex caretaker helping her with her most vulnerable cares, yet we were flat-out told -- NO! Our daughter who has severe autism and is nonverbal was not welcome to the same patient rights that people without disabilities access every day in their care networks. Our shock only increased when we learned of the horrors a previous patient at this same center faced. We are being asked to put our daughter in vulnerable situations that my other two daughters would never be expected to endure. Why does CWC not allow this most basic patient-right?

In 2005, a Central Wisconsin Center resident became pregnant after being sexually assaulted by a caregiver working in the facility. Just a few months ago, a woman in a vegetative state gave birth to a baby at Hacienda Health Care center in Arizona. These heartbreaking stories are far from the only cases of individuals like this suffering abuse, and this is especially concerning for those who are unable to communicate or communicate nonverbally. They are unable to speak for themselves, unable to report abuse, and are incredibly vulnerable in care facilities.

How many times have I been told, "I am my child's only advocate?"

How can I shut my eyes when I read in reputable sources and crime journals that:

"More than 90% of people with developmental disabilities will experience sexual abuse at some point in their lives. 49% will experience 10 or more abusive incidents." (Valenti-Hein & Schwartz, 1995)

Or

"44% of all offenders against people with disabilities made initial contact with their victim through the web of special services provided to people with disabilities." (Petersilia, 673)

Or

"When the person has a disability spends time in a developmental center, the person risks being sexually abused by those employed by the center. Again, one would hope that the developmental center would be a safe place, but, again, hope is not a method." (Baladerian, 15)

Or

Studies found that, "Disabilities resulting in the need for toileting assistance maybe associated with increased risk of abuse." (Petersilia, 670)

Uncovering the high risk of sex-abuse that my daughter faces, research revealed that:

"The vast majority of sex offenders are male. "In 1994, less than 1% of all incarcerated rape and sexual assault offenders were female." (Greenfield, 1997)

Nora Baladerian, an expert on DD and Sex abuse wrote that high-risk can be delineated when there is a plan in place for the person with intellectual disability.

"The person may not be selected for abuse, if reducing risk of abuse is planned for. Perpetrators always have a plan... victims do not. In this case, by having a plan, the tables are turned... Not only does the perpetrator have a plan. Your loved one does as well. (Baladerian, 7)

Having access to patients' rights to manage their care in the most vulnerable moments is necessary in forming this plan Baladerian suggests.

I have had sisters, aunts and friends experience the most heinous of sex abuse. I cannot shut my eyes to where it lurks and how it devastates.

But in reality this isn't ultimately about sex-abuse, this is about claiming the basic rights to direct the composition of my daughter's care while I am bound as her advocate, caretaker, and guardian. A right that had been already been acknowledged by Eden's school, therapy clinics, respite centers, and transportation services.

It is about acknowledging that because the majority of costs at the state center are borne by Medicaid, using state and federal dollars, that to allow this discrimination against those who are nonverbal, is not just a violation against my daughter's basic, it is also a violation of the Americans with Disabilities Act, but also Section 504 of the 1973 Rehabilitation Act.

This is about establishing that my daughter's equitable right to direct her care regardless of her disability or inability to speak. It is about having the same rights other have to limit risks and discomfort in their web of care. Just as those with voices are given the basic right to direct their own care every day—It is about having patient rights over their own bodies.

Let's put an end to this discrimination at CWC today! Please support AB 462. By taking action, you can say you have helped the most vulnerable children in Wisconsin take a step towards breaking free from discrimination and gain back the dignity and rights they deserve. Help be their voice with me.

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Individualized Risk Reduction Plan (IRRP)

Personalized Risk Reduction for individuals with cognitive disabilities against the high-risk factors of sexual abuse

Preface

Sex abuse is sadly prevalent in our culture, and we take great care to educate our children and students about it to reduce their risk of abuse and use their voice as their power if ever abuse does occur. Although sadly, the most vulnerable of all persons are those with cognitive disabilities, who received little to no education nor protection from this form of abuse, yet they are statistically at the highest levels of risk for sex abuse, and the least prepared reporters of abuse. An Individualized Risk Reduction Plan put into place for a person with a cognitive disability could significantly decrease that person's level of risk of sex abuse. Exercising the basic rights of managing ones own care plan is critical to risk-reduction of sexual abuse for those with developmental disabilities especially those who are nonverbal.

Markers to Consider for IIRP:

(See attached quotes of statistics, studies, and professional reports (regarding reality of risk involved), which are, in part, a guide for these markers).

- With no individualized risk-reduction plan, those with cognitive delays are left uniquely vulnerable *(Edelson, 12, 14), (Valenti-Hein & Schwartz, 1995)*
- The vast majority of sex offenders are biologically male. In 1991, less than 1% of all incarcerated rape and sexual assault offenders were female. *(Greenfield, 1997)*
- Those with cognitive delays are most often sexually abused by someone in their caregiving routine, whether a transport driver, personal care attendant, or private therapist. *(Baladerian, 40), (Petersilia, 669-670, 680)*
- Sex abuse to those with cognitive delays happens primarily in three main places: *(Petersilia, 670)*
 - Bedrooms
 - Bathrooms
 - Transportation
- Poor inclusion between guardians of person with Cognitive disabilities and their web of care increases likelihood of sexual abuse. *(Petersilia, 679)*
- Nonverbal children with extensive cognitive delay are inhibited from reporting abuse or notifying of an abusive situation, therefore repeated abuse may be forced upon that child. *(Baladerian, 28), (Valenti-Hein & Schwartz, 1995)*
- For children with autism there is an increased risk of reactive behavior to sex abuse being ignored and written off as behaviors of autism, rather than reactions to sex abuse (i.e. head-banging, aggressiveness). *(Edelson 2010), (Baladerian, 4, 40)*
- Those with cognitive disabilities who have been sexually abused can become unknowing perpetrators themselves, often lacking both inhibition or reasoning, they may, with no cruel intention, act out the very abuse done to them. *(Petersilia, 678, 680)*

Conclusions for Framing Plan:

Gaining education on sex abuse through traditional means, notifying of suspicious persons, and ability to report a crime which has occurred, are all deeply complex or even impossible for children with developmental disabilities, especially concerning those who are nonverbal with poor receptive or expressive language. Increased risk reduction occurs through eliminating joint cofactors of high risk settings with high risk perpetrators. Depending on the severity of cognitive disabilities, higher levels of avoidance of those scenarios may vary according to that person's level of dependency on involved protective measures. These particular measures placed in an individualized risk reduction plan and honored across environments may significantly reduce risks of sexual abuse for the cognitively delayed.

Sample of Individualized Risk Reduction Plan (IRRP)

Recipient of Plan: Eden Hughes

High Risk Characteristics of Recipient:

Eden Hughes's disability has such factors that contribute to high-risk of sex abuse. These factors include cognitive delay, autism, mutism, symbolic language disorder, and need for one-on-one support in nearly all daily living skills which include toileting, bathing, changing, and waking, and bedtime routines.

With very poor receptive and expressive language, traditional approaches to diminish sex abuse are not available to Eden. A voice to aid her in reporting perpetrated abuse is also oblique.

Conclusion:

The accumulated cofactors of risk escalate Eden's level of risk of sexual abuse to high, therefore her risk reduction best practices require high level risk reduction and will be reflected in her IRRP practices and exercised in her web of care.

Individualized Risk Reduction Practices:

1. Eden will not be left to the one-on-one care of males in bathrooms, bedrooms, and transportation. *(Baladerian, 40), (Petersilia, 670, 673) (Greenfield, 1997)*
2. Eden will not be left alone in one-to-one care of males in any secluded private locations (i.e. closets, private offices, rooms without windows, vehicles) *(Petersilia 673,680) (Greenfield 1997)*
3. To increase in Eden a sense of personal propriety, not undressing with males will be modelled for her by having her only undress (to change, bathe, toilet, swim) with female caregiver(s). *(Petersilia, 672)*
4. To maintain open communication to Eden's parents when substitutes are made to Eden's typical one-to-one personal aid, so they are informed whose charge their child is in. *(Petersilia, 672,673, 678,679)*
5. Eden will not be left unattended in a one-to-one setting with male peers with cognitive delays. *(Baladerian, 7), (Petersilia, 678, 680) (Greenfield, 1997)*

Relevant Research:

A. A crisis exists of sexual abuse *against persons with cognitive disabilities*

“More than 90% of people with developmental disabilities will experience sexual abuse at some point in their lives. 49% will experience 10 or more abusive incidents.” (Valenti-Hein & Schwartz, 1995)

“Not so long ago, child abuse was still a taboo subject, and the public was just barely getting used to acknowledging that children were beaten and physically injured by their parents or other caregivers. Despite the increasing public knowledge of [typical] child abuse, awareness that these things happen to people with intellectual developmental disabilities has been slow in coming. It is still a shock to many.” (Baladarian, 1)

“Know that children and adults with developmental disabilities are abused at rate far exceeding those without disability. To ignore this reality increases the risk that your loved one can be abused. To ignore this reality increases the risk signs of abuse be recognized as such, and abuse may continue for much longer period of time due to failure to understand the changes being observed indicate that abuse occurred.” (Baladarian, 4)

“Two main arguments are made with regard to children with autism and risk for sexual abuse. First, some children with autism maybe targeted for abuse by sexual offenders who may view them as vulnerable children. Second, when children with autism are sexually abused, they may show this in ways that get ignored or misattributed to autism rather than to possible sexual abuse.” (Edelson, 1)

“People with disabilities may be particularly vulnerable to crimes involving interpersonal violence, such as physical or sexual assault, because of the population—regardless of age or gender—they’re often the least able to recognize danger, the least able to protect themselves, and at least able to obtain assistance with the criminal justice system. People with disabilities may also misinterpret social cues and believe everyone is there friend. A desire for acceptance often leads people with cognitive disabilities to acquiesce to behaviors they do not like or do not want for fear of using social contact.” (Petersilia, 672)

Abusers typically abuse as many as 70 people before ever getting caught. Without reporting, there can be no persecution of the offenders or treatment victims. Underreporting of sexual abusive incidents involving people with disabilities has in the past, and continues to be, a major obstacle in preventing sexual abuse. Only 3% of sexual abuse cases involving people with developmental disabilities will ever be reported. Few people ever disclosed sexual abuse for variety of understandable reasons. However, Touch nondisclosure promote environment rights to continued victimization. (Valenti-Hein & Schwartz, 1995)

“Most people with disabilities have little access to resources, and most do not receive sex education (it is surprising that special education students do not receive the required sex education courses that students without disabilities receive). And the victim with cognitive disabilities may lack vocabulary to report abuse. Even if it is reported, the victim is not believed or it is thought to be fantasizing or to have merely misinterpreted what occurred. This leads the person with a disability continue to leave honorable to victimization, because perpetrators come to learn they may victimize them without fear of consequences. (Petersilia, 672)

“Offenders select targets that offer the greatest net reward. When one group is selected as a target more frequently than another, it usually needs three conditions: (a) Group members are exposed more frequently to motivated offenders (proximity), (b) Group members are more attractive as targets and that they afford a better yield to the offender (easy sex), and (c) Group members are more accessible or less defended against victimization (lack of guardianship or access to justice). Persons with developmental disabilities clearly meet all three of these conditions. For example, institutional care may function to increase the exposure of people with disabilities to potential offenders and may isolate their sources of protection, such as the police. An offender may choose an individual with a disability as a victim of the belief that apprehension is less likely and that punishment will be less severe if apprehension occurs”. (Petersilia, 673)

B. Perpetrator Profiles of those who commit sexual abuse crimes against persons with Cognitive Disabilities

"Offenders are overwhelmingly male, ranging from adolescent to the elderly." (National Center for Victims of Crime)

"Some perpetrators are female. It is estimated that women are abusers in about 6% of the cases among girls." (National Center for Victims of Crime)

"It is estimated that 98% of cases of sexual abuse the perpetrator it is well-known to, trusted by, and in a care providing position to the victim. (Supporting Victims and Witnesses with Intellectual Developmental Disabilities", The Arc of New Jersey's Developmental Disabled Offenders Program 985 Livingston Avenue, North Brunswick, NJ 08902 732.246.2525 www.arcnj.org . May 2010)" (Baladerian, 40)

"Perpetrators seek access to people with disabilities, as they believe that they will be less likely to be caught or convicted. Why? They believe that the person will not tell or not be able to tell. If they do tell, perpetrators know that the victim is not likely to be believed either by their parents or law-enforcement. They count on this. (Baladerian, 40)

"Only 3% of child molesters are prosecuted. This should be kept in mind when speaking about the importance of background checks. Conducting the background checks of any employee volunteer is of course an essential step in the employment interviewing process, but should not be depended upon to identify danger or convicted sex offenders." (Baladerian, 40)

"The vast majority of sex offenders are male." In 1994, less than 1% of all incarcerated rape and sexual assault offenders were female." (Greenfield, 1997)

"44% of all offenders against people with disabilities made initial contact with their victim through the web of special services provided to people with disabilities." (Petersilia, 673)

"Exposure to large numbers of caregivers increases the risk that at least one will be abusive." (Petersilia, 679)

Persons with cognitive disabilities who have been abused by caregivers may go on to abuse peers. "Some disabilities results and damage to areas of brain that control impulsive behavior, which can be directly due to lack of inhibition and greater probability of defending." (Petersilia, 678)

"Some authors suggest that at least some offenders against people with developmental disabilities fits specific profiles. Sobsey (1994) outlines two basic profiles for caregiver offenders: predatory care givers and corrupted caregivers. These profiles apply mainly to paid and volunteer caregivers.... "Predatory care givers seek or maintain employment as caregivers to have access to victims.... Corrupted caregivers typically do not plan to offend. Under some conditions, they may even be acceptable or exceptional caregivers. Lack of adequate training, supervision, or clear policy results in development of abusive patterns of interaction by these individuals. At some point in their caregiving activities, most caregivers experience inappropriate feelings-- anger or even sexual attraction towards client. Most recognize an acting on those feelings is wrong, but some will cross the boundaries into offensive behavior. Often these offenders are corrupted gradually, in stages, but sometimes the deterioration is sudden." (Petersilia, 677-678)

"Sometimes crimes against people with disabilities are committed by others with disabilities... two mechanisms may increase offensive behavior on the part of some people with disabilities. First residents who have been abused by staff make a lunch with use other residents. Second some disabilities result in damaged areas of the brain that control impulsive behavior, which can lead directly to lack of inhibition and a greater probability of offending" (Petersilia, 678)

60% of children are abused by someone in their social circle. Hence, the phrase "stranger danger" can be misleading. (National Center for Victims of Crime)

C. High risk places for persons with cognitive disabilities of sexual abuse

“One study found, for example, the majority of daycare abuse occurs around toileting, suggesting that disabilities resulting in the need for toileting assistance maybe associated with increased risk of abuse. Residential placement may also provide opportunity for abuse by caretakers. For example, a study of deaf youth found that sexual abuse tended to occur in bathrooms and bedrooms at residential educational facilities or in specialized transportation.” (Petersilia, 670)

“44% of all offenders against people with disabilities made initial contact with their victim through the web of special services provided to people with disabilities.” (Petersilia, 673)

“A study analyzing patterns of sexual abuse of children with disabilities and sexual assault of adults with disabilities found that 5% of the offenses committed by specialized transportation providers and 10% of the offenses took place in vehicles. In addition, people are often committed institutional care because they are unable to look after themselves or are dangerous to others. As a result, possible victims and prospective offenders are placed in close proximity with inadequate safeguards.” (Petersilia, 680)

“When the person has a disability spends time in a developmental center, the person risks being abused by those employed by the center. Again, one would hope that the developmental center would be a safe place, but, again, hope is not a method.” (Baladerian, 15)

D. Change must come to Reduce Risk of Sexual Abuse for Persons with Cognitive Disabilities

“As to minor children with disabilities, the bar has been set high for children to disclose what has happened. The “system” seems to prefer children who are verbal, open, and able to tell others what has happened to them. However, this leaves behind the traumatized child, the child who does not have words to put his experience of abuse, children who cannot overcome the fear of the threats that exist if they tell... and then many children’s cases are deemed “unfounded” or “unsubstantiated,” as they rest on verbal report of the child.” (Baladerian, 28)

“It is not possible to eradicate abuse from the face of the earth. There are many that proclaim this as their goal. [A realistic] approach is to significantly reduce the risk for abuse happening in the lives of individuals someone has responsibility and forget to contact.” (Baladarian, 2)

“Obviously, this is a violation not only of the Americans with Disabilities Act but also Section 504 of the 1973 Rehabilitation Act.” (Baldarian, 29)

“Implementing the laws already in place is a major problem. This is clearly delineated in “The First Report: Victims and Their Families Speak Out,” 2012 National Survey on abuse people with disabilities; disability and abuse project of Spector Institute, 2013 (disabilityandabuse.org/survey)” (Baladerian, 29)

“Because of this risk it is incumbent upon researchers to identify strategies to prevent sexual abuse, to develop protocols to assess accurately abuses occurred, to educate people with ASD’s about sexual health and abuse.” (Edelson, 12)

“Without the knowledge that sexual abuse is a real risk for children with autism, there cannot be adequate measures taken to ensure the safety of these children, help those who have been sexually abused heal from the abuse, and to prevent possible future victimization other children.” (Edelson, 13)

“It is imperative that we as a community of researchers, educators, parents, in south advocates find a way to increase the awareness of the risk of sexual abuse for those with autism and AST, to allow for a diversity of communication styles invoices to “hear” what abuses happened, and most importantly, to prevent abuse from occurring in the first place.” (Edelson, 14)

“Victims with cognitive disabilities are truly invisible, often being unable to advocate on their own behalf for services and equal justice. With better information, the issue should be become more visible to the public, policy makers, those who can fund training and education programs.” (Petersilia, 690)

E. Change can come in form of a plan *to reduce risk of sex abuse for those with cognitive disabilities*

High-risk can be delineated when there is a plan in place for the person with intellectual disability. "The person may not be selected for abuse, if abuse risk reduction is planned. Perpetrators always have a plan... victims do not. In this case, having a plan, the tables are turned... Not only does the perpetrator have a plan. Your loved one does as well. (Baladarian, 7)

"It is also true that in addition to regular staff, substitutes are caught in with regular staff can present. Make sure you put in the IEP and make it known the director of facilities that you want to be informed when substitute is present." (Baladarian, 7)

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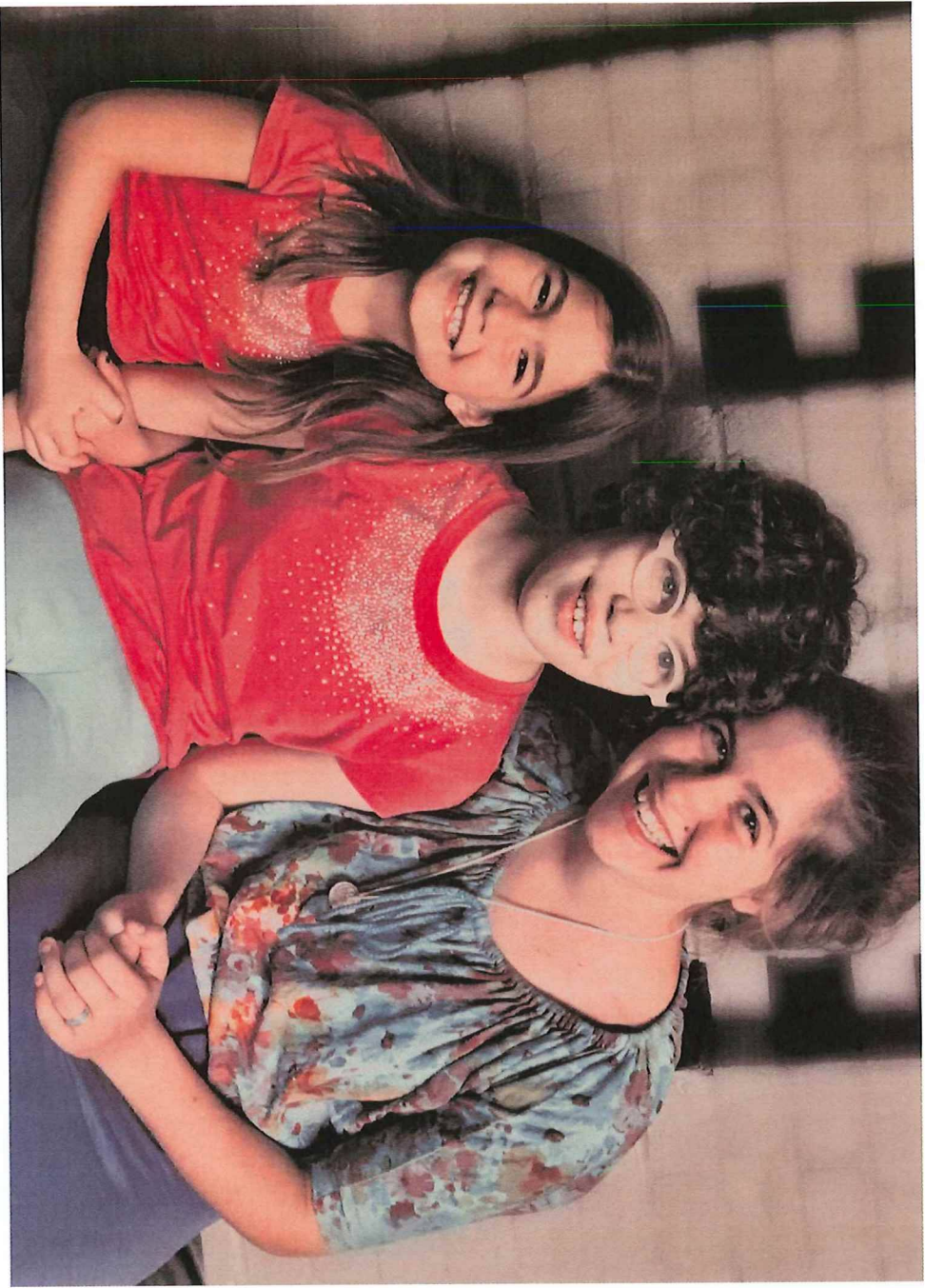
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October 11, 2019

To Whom It May Concern re: AB 462/SB 418

Unfortunately, not all environments designed to sustain and benefit non-verbal, vulnerable individuals can be protected by law. My 16-year-old adopted son could not be protected by law when his physical and cognitive abilities were diminished by alcohol consumption before he even left the womb, and when he began a lifetime of battling to understand everything basic – from navigating a lunch line to enjoying a positive social interaction.

However, support of Assembly Bill 462/Senate Bill 418 CAN work to protect many other non-verbal, vulnerable ones in the physical environments designed to sustain and benefit them – specifically, those state-funded facilities which provide short-term care for those with developmental disabilities.

Schools and private care facilities already give an individual (or their guardian) the basic right to choose the gender of the person who will assist with toileting, dressing, and other highly personal, daily routines. Please support AB 462/SB 418 so that the dignity, safety, and equitable rights of those with disabilities can be upheld in these state-funded facilities, as well.

Some life-long griefs and unjust consequences cannot be impeded by the passage of law, as in the case of my son. But – wonderfully! – the potentially devastating consequences of predators taking advantage can be deterred and denounced by law in the passage of this bill.

Thank you so much,

A handwritten signature in cursive script that reads "Kim Marino".

Kim Marino
N66W14444 Ash Drive
Menomonee Falls, WI 53051

Dear Assembly Committee:

My 12-year-old son, Liam, loves school. When his school bus pulls up in the morning to take him there, he often flaps his arms in excitement and laughs out loud. At school, Liam is comfortable, active, and challenged. He has friends who know him and staff who support him well. School is a place that he is cared for and safe. Because he is cared for and safe, he can learn and grow there.

Before I send my other children into the world, I teach them about body safety and respecting boundaries. I teach them to get away from uncomfortable situations and to speak up about them. I try to teach them how to protect themselves. I can't teach Liam these things because he cannot talk or walk. Liam can't speak out if someone makes him uncomfortable, and he can't get away from inappropriate touches. Liam depends on other people to feed him, dress him, and take him to the bathroom. This physical dependence on others makes it more complicated to keep him safe. When my other children go to the restroom, their bodies are kept private behind a closed door. For Liam, there is very little privacy since he depends on others to do his personal cares for him.

Statistics show that Liam (because he is non-verbal and disabled) is more likely at some point in his lifetime to be a victim of sexual abuse than he is to live a life free from sexual abuse. We want Liam to live a life free of sexual abuse. (Doesn't everyone want this for their child?)

Liam's IEP specifies that Liam must always be toileted by 2 staff members and one of those staff must be female. This protects Liam by keeping him from being in a closed space alone with a potential perpetrator. The presence of a female staff member also decreases the likelihood of abuse greatly since men are 80% more likely to perpetrate sexual abuse- even on a male victim. Liam's staff need to do intimate care needs for him, so he needs checks and balances in place to keep him safe while his personal cares are done.

I protect my other children by teaching them to protect their own bodies. Since Liam cannot protect himself, I am so thankful that we are able to protect him by setting guidelines about which staff provide his intimate care needs. This safety should be afforded to every person in every situation. Please support AB 462/SB 418 so that this safety can be afforded to everyone, including individuals who are in state-funded care settings.

Wendy Heyn
Parent of Liam Heyn
W212N4944 Weyer Rd.
Menomonee Falls, WI 53051
262-227-9296
wgouvion@hotmail.com

Dear Assembly Committee on Health,

I am a concerned local mother of a child who is 17 and a half years old and female. My daughter is non-verbal and requires a one on one caregiver at all times.

I am well aware that individuals with disabilities are seven times more likely to be sexually assaulted. My daughter is particularly vulnerable due to her not being able to share anything verbally. She also is not able to use a tablet or any other device for communication purposes. She has very few ways of communicating. She will grab a cup if she is thirsty and hand it to me. She will sit at the table if she is hungry. She will stand by the door if she wants to leave the house. She has no way of asking for anything specific. She has no way of telling me that she would prefer an apple to an orange. She has no way to tell me she wants to go to the park, not the grocery store. If she is sexually assaulted, she HAS NO WAY OF TELLING ME. This means that this type of abuse could go on for years before we would even know.

As she is almost 18 years old, I've been looking into resources for her when she becomes an adult. I was shocked when I spoke with the manager of an adult family home who stated that she would TRY to honor our request that our daughter always have a female caregiver. She specifically told us that she does not HAVE to honor our request though, and it could be a male who is taking care of our daughter, bathing her, dressing her, toileting her. This is not right. It is horrifying. How can I let her go into the community and have a social life when I can't even ensure that she has a female provider? Especially as she is not ABLE TO TELL ME IF SOMETHING INAPPROPRIATE OCCURS?

This bill is in complete alignment with my very own concerns for my own child. I empathize greatly with the families who need the services at Central Wisconsin Center, but have no right over who is with their child in the most vulnerable settings. And because of this I ask you to please support AB 462. It will help protect our children and give parents the right to decide which gender is taking care of our child in the most vulnerable setting of medical care at CWC. It is common sense and humane.

Thank you.

Sara MacDonald
1001 E Main Street
Little Chute, WI 54140

Dear Lawmakers,

Please support AB 462 / SB 418 and put into law today. We are in a time as a nation where we have momentum towards truly changing the trajectory in how individuals who have been marginalized in the past can be viewed and treated in the future.

This bill will help to protect those with intellectual and developmental disabilities - particularly those individuals who are nonverbal and therefore can at times be at the most risk for abuse.

Having been long time friends of a family with a nonverbal child has given my family awareness of this issue. We did not have prior knowledge to the potential risks and unfortunate factual cases of abuse to particularly non-verbal children in treatment centers. This is a cause that many people would rather turn the other way than to address. It is hard to look at the truth but with challenging truths, we have the options to look away or to look for solutions. Please consider supporting this law that simply allows families to have options to care - in many ways, just as otherwise healthy individuals have options for care - who they choose for their children's pediatricians or who as adults choose for their own care and medical needs.

When implemented this law will not only allow state-run facilities to align with what private care and schools already have in place, but it also should be felt as a true protection for the state as well as create a reputation that Wisconsin cares about all of its citizens. We want to be a state known for putting action into place to adjust laws as needed in order to protect those who need it most.

Our parents and grandparents and past generations have all stood behind "Do unto others as you would have them do to you" - and it is critical that we not lose sight of this simple truth and pass laws that we would want to have in place if ever put into a position where a disabled loved one needs care and protection.

Please protect our most vulnerable children when receiving care at state funded care centers and make each of us proud to be Wisconsinites.

Sincerely ~

Dawn Bowan

770 Rosewood Ct.
Brookfield, WI 53005

October 13, 2019

To whom it may concern:

RE: AB 462/SB 418

Our daughter, who has both cognitive and motor disability, will never be able to manage her own basic care needs, and will always require assistance. My husband and I will someday be unable to be her primary caregivers, and we need legislators to make the most ethical and responsible decision to fostering additional protections for children and adults with disabilities.

An alarming FACT: individuals with intellectual disabilities are seven times more likely to be sexually assaulted. SEVEN TIMES. Many of these individuals are nonverbal or have limited ability to communicate and report incidents of abuse. If they have a motor disability, they are often accustomed to others being in close proximity to help them with basic activities of daily living, like toileting, dressing and bathing, making it confusing for them when someone steps over the line in exploiting them when providing care. The fact is that they very help they need offers a type of PRIVATE ACCESS to these individuals that increases risk of abuse.

I can request a female Obstetrician to do pelvic examinations, help me through a pregnancy, and perform breast examinations for annual wellness visits. A male can request a male physician, who does prostate examinations. If you are pat down at TSA at the airport, it will be done by a same gender screener.

However, in the State of Wisconsin, disabled individuals and their families do not have the right to direct who will provide basic physical care in facilities and care settings. The lack of protections in place for these individuals has played out not only in Wisconsin, but all over the country, with generally females (with no capacity to consent) being violated. Some of the consequences have been females being impregnated by a caregiver, being given a sexually transmitted disease that no physician suspects assuming they are not sexually active, causing discomfort and further pain, and other physical and emotional harm.

It is absolute common sense to increase protections for the most vulnerable individuals in our community. Anyone who would consider voting against such legislation should consider their action as strengthening perpetration of abuse of these individuals, and should feel culpable when hearing about future cases of these situations occurring.

Thank you for considering the FACTS and this plea for your vote in favor of greater protections.

Sincerely,

Gina Rehkemper (414-573-4000)
Jan Mueller (414-899-6088)
PO Box 202
Elm Grove, WI 53122

To the Assembly Committee on Health:

I am a mother of 3, two boys and a girl. My oldest son, and my youngest child (a daughter) both have developmental delays (specifically Down syndrome). Hearing the horror stories, and learning the statistics, about individuals with developmental delays being sexually abused is absolutely horrifying! My heart breaks, not only the individuals who have had to endure this unimaginable treatment, but also the families. Ask any parent and they likely will say that their number one concern for their children is safety, especially in the type of world we live in today. As parents our worst fear is not being able to keep our children safe. Having a child (or children) with special needs, dramatically heightens this fear because there are so many cruel people in this world who can (and do) take advantage of their situation.

Having to make the decision to have your child placed into a treatment program away from you, and the rest of the family, has to be hard enough; but then to find out that there is not a Bill currently in place to implement the basic rights of the patients wherein that patient/their family and/or guardian has the right to request certain staffing arrangements is absurd and heartbreaking.

Please pass this Bill on behalf of my children, and all the others out there who have been overlooked for far too long.

Terri Hust
11924 W. Ohio Ave.
West Allis, WI 53227
414-702-0799

I am writing to let you know how critical it is to bring equality of patient rights to some of the most vulnerable individuals in our state as proposed in Assembly Bill #AB462.

I am the mother of two 13-year-old girls who have the right and the ability to say what they want in their personal care. I also run a gym for people with special needs and spend my days assisting them and their caregivers in any way I can. Many of the individuals I interact with on a daily basis are non-verbal. This doesn't mean they don't have thoughts and ideas and needs. They just aren't able to express them. I am reminded of one boy in particular. He is non-verbal and I have known him for two years. This summer, we had an occupational therapist in the gym who worked with him. After a few days, I began to understand what he wanted, even though he couldn't say it with his voice. He had the ideas and needs all along. We simply lacked the tools to communicate with each other.

Children and adults who are non-verbal still have needs and desires. Individuals who are unable to speak for themselves still have the rights of every other American. Or at least they should. We as a society are removing those rights when we don't allow their parents and/or guardians the right to choose who assists them with personal care, like bathing, using the bathroom, etc. We are placing the most defenseless among us in a completely vulnerable position.

An individual I know came to my work with a caregiver and had a significant injury. I can't even imagine how that injury could have happened accidentally. No one was held accountable because he doesn't have many words and couldn't verbalize what happened. Once the damage has been done, it's too late. We are able to protect these precious people and prevent abuse. Please help protect them by giving them, through their parents or guardians, the legal right to choose the gender of their caregivers.

Thank you for taking the time to listen.
Stephanie Bartelt
Delafield, WI

To whom it may concern re: AB 462/SB 418

As a mother of a non verbal child with an intellectual disability it is always a fear of mine that something may happen to him and he cannot tell me. I can imagine the fear deepening when he will need to depend more and more on people in the community caring for him as we, his parents, grow older.

It is difficult to talk about the statistics that individuals with intellectual disabilities are seven times more likely to be sexually assaulted. We believe that having a right to choose the gender of our child's caregiver who will be caring for him in the most intimate of situations like bathing and toileting will help reduce the risk. I am able to choose the gender of my physician, TSA agent doing a pat down and even massage therapist. Shouldn't disabled individuals and their families also have a say in who helps care for them in their most vulnerable of situations?

Please support AB 462. It protects children. It empowers the most vulnerable among us. It's common sense.

Reagan Jauch

8141 Warren Ave.

Wauwatosa, WI 53213

Dear Assembly Committee Members,

I urge you to vote YES and support **AB 462 / SB 418** to protect the rights of disabled people here in WI that have intellectual disabilities. This is a topic this is a tragic topic, but please, read and understand my deep concern as a caring constituent. We need to advocate and be the voice for those who are unable to communicate and advocate for themselves, such as children and animals.

This bill should be put into law - it's common sense. I am shocked to learn that this type of protection is not already in place. For years my mom worked with disabled children and I had the unique opportunity to volunteer and serve these special kids.

Parents and guardians know what is best for their children, I myself have an adult child with learning disabilities. While she is fortunate to communicate and function / exist on her own, she still needs help from her parents to complete certain tasks so as not to cause undo anxiety or to ensure she is not taken advantage of. I can only imagine the stress that parents of children who are unable to communicate endure every day.

Lastly, children should NOT be discriminated against and should be allowed to choose the gender of their caretaker in the most vulnerable and high-risk areas of their care. In this day and age with discrimination at the forefront of our society - someone has to be the voice of our children.

Please, do NOT let this bill go unnoticed and vote YES to protect those that do NOT have a voice of their own. ***Please support AB 462. It protects children. It empowers the most vulnerable among us.*** It is your responsibility as our leaders to provide that protection for them.

Thank you for your time!
Sarah Greco
414.588.1214
N112W17135 Vista Ct. Apt B
Germantown, WI 53022

October 13, 2019

To whom it may concern:

According to data from the Department of Justice, people with intellectual disabilities are seven times more likely to be sexually assaulted than those without disabilities. Furthermore, those who are unable to communicate or communicate nonverbally are at the highest risk for sexual abuse. This abuse is most likely to occur in extremely vulnerable situations such as toileting, changing, and during transportation.

In 2003, a Central Wisconsin Center resident became pregnant after being sexually assaulted by a caregiver working in the facility. Just a few months ago, a woman in a vegetative state gave birth to a baby at Hacienda Health Care center in Arizona. Her guardians had been promised that the gender preference for their child's caretaker would be honored, but this promise was not fulfilled. These heartbreaking stories are far from the only cases of individuals like this suffering abuse, and this is especially concerning for those who are unable to communicate or communicate nonverbally. They are unable to speak for themselves and are incredibly vulnerable in care facilities.

This legislation, AB 462/SB 418, comes at our request as parents who are concerned of the wellbeing of our daughter who has a verbal and developmental disability. This legislation implements commonsense practices to ensure that individuals who are unable to communicate or communicate nonverbally due to a cognitive or developmental disability are protected from abuse and harm. All individuals with disabilities and their families deserve to know that they have these rights at care facilities, and this legislation is vital in ensuring that.

Let's put an end to this discrimination today! Please support **AB 462/SB 418 today**. By taking action, you can say you are helping the most vulnerable children in Wisconsin break free from discrimination and gain the dignity and rights they deserve.

Sincerely,

Greg and Michele Smith

A handwritten signature in cursive script, appearing to read "Greg and Michele Smith". The signature is written in dark ink and is positioned to the right of the typed name "Greg and Michele Smith".

2025 Carrington Drive, Brookfield, WI

This topic is heartbreaking, Please hear my words as a concerned, local parent:

*As a mother of a very social, loving, non-verbal, cognitively delayed 12 yo daughter, I was DISGUSTED to learn that individuals with intellectual disabilities are seven times more likely to be sexually assaulted. **SEVEN TIMES.** Many of them are limited in their ability to report incidents of abuse - like my non-verbal daughter. Research and documentation shows that the vast majority of perpetrators of sexual abuse against this fragile population are male.*

I can request a female obstetrician to guide me through pregnancy. A teenage son can seek a male pediatrician. If you get a pat-down at TSA, it will be done by a same-gender screener.

However, in the State of Wisconsin, disabled individuals and their families have no right to direct the composition of their care teams in DHS facilities. Your disabled child, with or without your guidance, has no right to select the sex of the individual who bathes, toilets, or dresses them. He or she has no assurance against isolation in secluded areas with a lone chaperone of any given sex. This is degrading practice and needs to stop.

The consequences of these policies and lack of oversight are obvious and have played out in horrifying ways. The consequences are too horrifying for me to write down without weeping. The thought of my vulnerable daughter being a victim makes me sick. Especially when common sense laws could be put in place to protect her.

Please support AB-462, It protects children. It's common sense."

Robin Lane

2636 N 94th Street

Wauwatosa, WI 53226

October 15, 2019

Dear Honorable Members of our State Legislature,

Re: Support for Senate Bill 418/ Assembly Bill 462

Please consider my words as a concerned mother of a daughter with intellectual disabilities.

It may surprise you to learn that individuals with intellectual disabilities are seven times more likely to be sexually assaulted. SEVEN TIMES. Many of them are limited in their ability to report incidents of abuse. It probably doesn't surprise you to hear that most perpetrators of sexual abuse are male.

My daughter with disabilities can voice her own opinion. She can request a female primary care doctor, gynecologist, support worker or counselor. My mother who has had breast cancer three times and is 84 years old can request a same-gender screener do her pat down when she proceeds through TSA. They have a voice. We have a voice. We can choose.

However, in the State of Wisconsin, disabled individuals and their families have no right to direct the composition of their care teams in DHS facilities. Your disabled child, with or without your guidance, has no right to select the sex of the individual who bathes, toilets, or dresses them. They have no voice.

Isn't this a violation of person's basic rights as a citizen? Don't parents have the right and responsibility to protect their children when placing them in a school, daycare or in the hands of another caregiver?

The consequences of these policies are obvious and have played out in horrifying ways. There is a lot of discussion about disability rights in this state. Why aren't we giving individuals with disabilities and their families the same rights we enjoy?

We need this bill. It protects children. It empowers the most vulnerable among us. It's common sense. It's the right thing to do.

Sincerely,

Cheryl Smith
905 York Imperial Drive
Oconomowoc, WI 53066

October 16, 2019

**Support for equitable patient rights for the most vulnerable, Assembly Bill 462/Senate Bill 418
Assembly Public Hearing with Committee on Health**

To All This Should Concern:

It may surprise you to learn that individuals with intellectual disabilities are seven times more likely to be sexually assaulted. SEVEN TIMES. Many of them are limited in their ability to report incidents of abuse. My daughter is non-verbal would have great challenge in relaying to me any such incidents. It also may not surprise you to hear that the vast majority of perpetrators of sexual abuse are male.

I can request a female obstetrician to guide me through pregnancy. Your teenage son can seek a male pediatrician. If you get a pat-down at TSA, it will be done by a same-gender screener. However, in the State of Wisconsin, disabled individuals and their families have no right to direct the composition of their care teams in DHS facilities. Your disabled child, with or without your guidance, has no right to select the sex of the individual who bathes, toilets, or dresses them. He or she has no assurance against isolation in secluded areas with a lone chaperone of any given sex. The consequences of these policies are obvious and have played out in horrifying ways. It is a disservice to our disability community to not consider the repercussions of not demanding commonsense safeguards.

Please co-sponsor AB 462. It protects children. It empowers the most vulnerable among us. I have faith we have elected those that will stand up for all residents of the great state of Wisconsin.

Sincerely,



Kathleen Kelly Bathie

Mother of an 11 year-old female living with rett syndrome

New Berlin, WI Resident

October 12, 2019

Wisconsin Leaders,

Regardless of the sordid history of rape and impregnation of a patient with severe disabilities by her caregiver at a state funded facility, backs are turned. Even now disabled patients in that same facility are refused patient rights that people in the general public get every day.

A simple change to the law will allow the guardian or the children who have no voice and are most vulnerable to have some self-direction in their care allowing them to choose the gender of the person who helps them bathe, change, or assist in vulnerable settings.

You probably already agree that this is common sense. Afterall, we have the right to select a female obstetrician during pregnancy so why wouldn't we allow the same self-direction for those with disabilities? Almost fourteen years ago when an older male forcibly impregnated a female patient at this facility, this most obvious change was never made at this tax-payer funded facility. We need to protect these children.

Let's put an end to this discrimination today! Please support AB462 and help to protect the most vulnerable children by giving them the rights they deserve.

Sincerely,

Chelsea Crosby
1259 River Drive, River Falls, WI 54022