

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 abuse<sup>1</sup>.

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

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<sup>1</sup>The 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 safety<sup>2</sup>.

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 sex<sup>3</sup>. 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 predictors<sup>4</sup> 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 victimization<sup>5</sup>, nor does it address the many systemic issues and cultural prejudices that contribute to the underreporting and inadequate response to abuse. Wisconsin data<sup>6</sup> 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 live<sup>7</sup>. 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

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<sup>2</sup> 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>

<sup>3</sup> 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](https://www.hhs.gov/sites/default/files/report_joint_report_hcbs.pdf)

<sup>4</sup> National Core Indicators

<sup>5</sup> 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.

<sup>6</sup> 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>

<sup>7</sup> 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.

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