

November 13, 2012

To: Representative Dan Knodl, Chair
Representative Penny Bernard Schaber, Vice-Chair
Members of the Legislative Council Special Committee on Legal Interventions for
Persons with Alzheimer's Disease and Related Dementias

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We write as advocates for people with disabilities throughout the state of Wisconsin to ask for your consideration of our perspective related to the work of the Special Committee on Legal Interventions for Persons with Alzheimer's Disease and Related Dementias. This letter shares our concern regarding the direction of the committee as reflected in the most recent drafts of proposals you are considering. While our comments do not relate to all the proposed changes, they do reflect our general concern that drafts currently under consideration require more thought, analysis and further opportunity for input and comment from a more inclusive range of voices and stakeholders.

The Wisconsin Supreme Court's ruling in *Helen E.F.* has served as a catalyst to call attention to some of the problems inherent in Wisconsin's current statutory approach to treatment of people with Alzheimer's disease and related dementias and clarify some areas of confusion that may have been created by the Court's decision. However, this important opportunity to address these issues cannot be realized by simply amending Chapter 55 to allow for inpatient psychiatric admissions and create an easier path to administer involuntary psychotropic medications to people with dementia who present a risk to themselves or others due to a condition or behavior linked to the dementia. We urge the committee to take this occasion to reach out to a larger group of experts, advocates and people with lived experience to identify opportunities to improve the way the legal system intervenes in these situations, rather than adapting Chapter 55 to return to procedures in place before *Helen E.F.* was decided.

Below are some of the areas of concern that we believe would greatly benefit from a broader discussion with the aging and disability communities to arrive at the best solutions possible and the achievement of better outcomes for people with Alzheimer's and related dementias.

WLC: 0017/4 Use of Psychiatric Inpatient Facilities

The decision in *Helen E.F.* pointed to certain shortcomings of the Chapter 51 process in dealing with the admission of people with dementia to psychiatric treatment facilities. Admission to a psychiatric inpatient setting under Chapter 55 instead of Chapter 51 does nothing to lessen the problems underlying the use of these facilities for people with dementia, including the potential

for transfer trauma, mental health stigma and the frequent difficulty placing these individuals once they have been treated for their challenging behaviors. Furthermore, while psychiatric inpatient facilities were often used as the place of last resort for such individuals before *Helen E.F.*, this begs the question of whether such facilities are actually appropriate and equipped with the staff who have the skills required to work with someone with Alzheimer's and certain behaviors.

It is an unfortunate fact that these challenging behaviors are often the result of a treatable medical condition, environmental or social problem at the current residential placement which has the capability of being addressed without inpatient psychiatric admissions. However, if it becomes necessary to admit someone to an inpatient emergency protective placement setting designated under Chapter 55, these units must be equipped and prepared to provide comprehensive treatment, specifically tailored to the needs of people with Alzheimer's and related dementias. It is not enough to use words such as "qualified and equipped" or "competent." Real standards and training protocols need to be promulgated so that any facility holding themselves out to be experts in Alzheimer's Disease and dementia must meet these criteria to hold such designation. We urge this Committee to extend their time frame to engage a broader group of stakeholders in a discussion of the standards and criteria necessary to assure these designated facilities can adequately meet this challenge.

Use of Psychotropic Medication WLC:15/2

We also have deep concerns about the expansion and relaxation of standards surrounding the involuntary administration of psychotropic medications. This is of particular concern because there are no psychotropic medications approved by the FDA for the treatment of Alzheimer's, and, in fact, most of these medications carry a "black box" warning against use for elderly patients with dementia. The current draft of this provision expands the use of involuntary psychotropic medication to individuals who, "based on observation and currently available information" appear to have dementia. However, no guidance is provided as to who is authorized to reach this conclusion or the exact nature of this observation and information.

Furthermore, the involuntary administration of medication as an emergency service can occur only after certain detailed and complex facts, many of which are based solely on opinion, are deemed to be "true." In the same vein as our comment above, the current draft does not indicate who is authorized to make this original determination, or how the truth of these conclusions is decided. Additionally, it is not stated how these facts are to be determined by the court upon later review. In the current emergency protective service statutes, the court only needs to find probable cause that certain facts exist, but it is explicitly aided by the statutes' specific requirements of statements and reports that need to be of record.

Finally, §55.13(2), Wis. Stats. only allows petition by "the county department or agency with which the county department contracts under s. 55.02 (2) that is providing emergency protective services to an individual." The draft of §55.133(3), Wis. Stats. appears also to allow petition only by the county, and seems to assume that the only provider of involuntary administration of psychotropic medication will be the county or agency with which the county department contracts. However, many people who may be considered potential candidates for these medications have no connection with the county, for example people in their own homes or receiving private pay services. The current proposal does not address this foreseeably large part of the population that does not come to the attention of the county.

Power of Attorney for Health Care WLC: 0018/3

We heartily support the concept of self-determination for individuals with all types of disabilities; therefore, it is troubling that the current iteration of this proposed draft creates an option that allows for people with one specific type of disability to be denied the rights and due process protections afforded to all other people who have been determined to lack capacity to make health care decisions. As is the case with most other disabilities and medical conditions, there is rarely one straight and invariable trajectory of illness; however, this draft does not accommodate the idea that capacity or incapacity for medical decision making is not always a static condition. Therefore, individuals with dementia who are actively objecting, not just non-consenting, to a certain treatment or placement can be put into a position where they are denied the right to be heard, unlike any other individual with an activated power of attorney for health care. There already exists a procedure to handle these issues, which is the guardianship law. Utilizing the existing procedure also provides safeguards and oversight by the Counties, Guardians ad Litem, and the Courts. Furthermore, because we do not consider inpatient mental health facilities to be appropriate placements for people with the *sole* diagnosis of Alzheimer's or related dementias, it follows that the health care agent should not be allowed to authorize this type of admission without any conditions or oversight.

Next Steps

We appreciate the challenging task before this committee in considering the needs of all those concerned with this subject, including counties, law enforcement and various service providers. However, the most important consideration must be assuring that these proposed changes will make this process better for people with Alzheimer's and their families.

The *Alzheimer's Challenging Behaviors Task Force* recently concluded two years of work with medical professionals, service providers, attorneys, adult protective services workers, aging resource center employees, family members, and many other interested and knowledgeable parties. This effort included the active involvement of an interdisciplinary group focused on Legal Interventions. The *Alzheimer's Challenging Behaviors Task Force* held a summit earlier this month, and will be releasing a report in mid-December which will include findings and recommendations that are directly relevant to the work of your Committee. We urge you to extend your deliberations so that you may consider the recommendations in this report, as well as drawing on the Legal Interventions work group as a resource.

Slowing down this process for a more complete and open dialogue would help to assure that there are not unintended consequences for people with other disabilities who are also served by the Chapter 55 system. To this end we feel that it is vital that this committee pause and expand their time line in order to give more careful consideration to the voices and perspectives of a wider group of stakeholders, including people with lived experience, their families and advocates, so that the end result is something that truly accomplishes the goals of such a worthwhile charge.

Thank you for your consideration and we stand ready to work with you in addressing these important policy concerns. We believe that slowing down the process, including more perspectives, and engaging in further discussions and deliberation will ensure the goal we all share of better outcomes for people with Alzheimer's Disease and their families.