

June 29, 2018

We have lived in WI for five years. During that time we have depended on AT every day. We have enjoyed reading the Wisconsin's state plan for AT. First, we will provide our feedback. Then, we will describe the experiences we drew on to arrive at the rationale for our suggestions. We are grateful for the opportunity to provide this feedback to support the State Plan for Assistive Technology, and to strengthen AT access in WI.

Feedback on the State AT Plan Background, pages 1-3: We appreciate the information shared in the State Plan Background describing the scale of AT needs of older adults, and are excited about the goals of Awareness, Sustainability, Knowledge, and Universal Accessibility. We suggest the State AT Plan Background might also include more information to introduce readers to the AT needs of children with disabilities; as this is a demographic that may be increasing and diversifying in its needs. While availability of AT equipment for students outside of the classroom as mentioned in the plan is indeed an unmet need, it may be helpful for the State AT Plan to consider the possibility that there are additional unmet AT needs for children with disabilities in WI.

Feedback on the State AT Plan Goal 1, page 4: We are excited about the goal of increasing awareness! We would be interested in seeing expansion of strategies for this goal. We depend heavily on AT but until a few weeks ago, we did not know WisTech exists. Also, community providers that have been attempting to assist us with AT for years in WI had not known that WisTech exists. Therefore, fragmentation and lack of coordination between different components of AT service delivery systems in WI seem to be barriers to achieving this goal of Awareness.

Our suggestion would be to consider the idea of identifying the different major demographics of AT users presently in WI. This will help with targeted strategies to reach out to each of those demographics effectively, and will help to address the educational training needs and messaging opportunities that are unique to each demographic. This would allow levels of awareness in each of those groups to be properly measured in the future. This type of approach would be congruent with the spirit of the Assistive Technology (AT) Act's endorsement of efforts to increase coordination among State Agencies, and between State agencies, local agencies, and private entities that have activities related to AT. WisTech's mission seems compatible with a role as a centralized repository for identification of functionally distinct AT demographics in the state.

With regards to the current measure for this goal; we are concerned that an increase in referrals to WisTech could result not from increased awareness, but from decreases in the capacity of other WI community resources and agencies to meet AT needs.

Feedback on the State AT Plan Goals 2-3, page 5-6: We are excited about the goals of ensuring sustainability and knowledge! We really like the measures and deliverables to increase the number of certified ATP providers in WI, and expand professional training and skill

development opportunities! We would like to suggest expanding this avenue further. The American Speech-Language Hearing Association (ASHA) has an AAC Clinical Specialty Certification Program under consideration at the first of two stages of approval: (<https://www.asha.org/Certification/specialty/Approved-Petitioning-Groups-for-New-Specialty-Areas/>). We anticipate that the professional AAC Clinical Specialty Certification for SLPs will dramatically increase the capacity of providers to meet AT-AAC needs. We would like the Wisconsin's State Plan for AT to consider preparations to incorporate SLPs with the clinical AAC certification into AT workforce development arrangements, so that when this clinical specialty achieves approval for implementation, WI will be strategically positioned to expedite expansion of this much-needed workforce.

Experiences informing this feedback: At birth, our son was diagnosed with a genetic disorder that disrupts speech development. Because of this, he has always depended on AT for AAC (Alternative & Augmentative Communication); (AT-AAC). We also depend on AT for assistance in other aspects of daily life. Not all of our experiences with AT have occurred in WI, but many of them did occur in WI.

Experiences with AT access and implementation at ages 0-3:

1. Due to lack of progress in verbal development and lack of response to therapy, our son was discharged from private speech language pathology services during the birth-3 years period, without successful transition to services from an AAC specialist. Our son's public Birth-3 early childhood intervention team provided information about the existence of an AT-lending organization, and suggested the family should use the AT lending service to trial and select an AT-AAC solution. Through this route, our family selected and purchased an electronic AT-AAC system.
2. When our son turned two, our family attempted to enroll him in mainstream daycares and child development centers. Daycare administrators told us they had no obligations to accommodate the AT-AAC needs of our son. There were no means to provide daycare administrators or staff with training on how or why to accommodate the needs of children who require AT for communication. The AT that our family provided to the daycare was routinely taken away from our son by staff, and staff shared that they did not have time to make accommodations. It was explained to us that in order to ensure our son had access to his communication board during the day, we would need to withdraw our child from mainstream daycare, and enroll him in a special daycare for children with disabilities.

Experiences with AT access and implementation at ages 3-6:

1. When our son was 4 we were referred by a clinician in an interdisciplinary clinical team for a professional assessment for AT-AAC. We were advised that the waiting list for this assessment could be up to two years long.
2. After our son was provided with a professional assessment and recommendation for a specific AT-AAC device, our private health insurance denied coverage of the device. After the AT-AAC was finally provided through Medicaid, the device ultimately proved to be chronically defective. It had recurring manufacturer defects, and we experienced frequent loss of access to communication due to these malfunctions. Efforts on the part of the family and multiple providers to resolve the issues with the device manufacturer have been unsuccessful. The device is currently unused and gathering dust. Therefore our family has had to independently purchase a new device in order to ensure our son's access to functional AT is preserved.

Experiences with AT access and implementation for our school-aged child:

1. Our son attended a public school during the time that a private provider completed a formal assessment and provision of an AT-AAC device. Although the recommended AT-AAC was successfully implemented at home and community settings, our son's public school encountered multiple challenges in implementing the AT-AAC during the school day. Our son was the only student in the school that used AT-AAC, and staff and administrators seemed unfamiliar with principles of access and implementation of AT-AAC. Efforts to overcome these barriers were unsuccessful. Therefore we withdrew our son from public school and enrolled him in a private school for children with disabilities that had staff with special AT-AAC expertise. The private school was able to ensure proficient implementation of the AT-AAC during the school day. However, the private school imposed barriers that obstructed our son's access to a licensed teacher, and obstructed access to academic instruction aligned with the Common Core State Standards.
2. Because our son was enrolled in this private school during a time that the family was attempting to advocate for proficient AT support in the public school, the public school identified the child as a truant, and advised the family that the truancy could be grounds for involvement of Child Protective Services. This ultimately necessitated input from the state disability rights Protection and Advocacy Agency. In this way, caregivers' efforts to implement AT-AAC in community settings that were not equipped to support inclusion of people who use AT-AAC actually increased hardships for the person who depended on AT-AAC, by eliciting responses from the community that threatened care stability, reduced access to services, and degraded the mechanisms for critical coordination of care.

Lifelong barriers to AT access and implementation: Maintaining AT-AAC in working order, implementing AT-AAC in a way that is respectful of the user's self-determination, and maintaining team training for AT-AAC implementation according to best practices are all tasks that require special knowledge, devoted time throughout every day, and money. These are also tasks that are mandatory to ensure our son's care is congruent with the Communication Bill of Rights established by the National Joint Committee (NJC) for the Communication Needs of Persons with Severe Disabilities. It has been our experience that there is an absence of community awareness or resources available for these needs:

1. Personal care workers who work with our son currently depend on our family's personal resources and expertise for any training and professional development pertaining to implementation of AT-AAC. It is our experience that if our family does not design and administer training for best practices in AT-AAC support, our son will not be able to communicate with the workers who help to care for him. Because of staff turnover and the specialized skills required for proficient AT-AAC support, the burden imposed by this need is significant. Effective educational training for AT-AAC support for children and in the context of medical and developmental co-morbidities requires specialized expertise that is very different from educational training for other AT needs.
2. For AT-AAC users who require personal care assistance, the time and effort on the part of both the client and the caregiver required for communication is much greater than that required for verbal communication. Our son is eligible to receive personal care through the Medical Assistance Personal Care Program, as informed by the DHS Personal Care Screening Tool (PCST). It is our current understanding that there are no provisions in the PCST for the additional care needs that are associated with the use of AT-AAC for communication. It has been our experience that this mechanism of community support is, by itself, not sufficient to ensure successful AT-AAC implementation in daily life.
3. We have prepared a Special Needs Trust to help to provide for our son after we die. We've been advised that it is not possible to direct funds in the Special Needs Trust toward AT-AAC professional development or training for trustees or delegates. Because of the fragmentation of mechanisms for AT access and implementation in WI, it currently appears that our son will lose access to the means to communicate if he outlives us. Once he loses access to AT-AAC, he will have no means to advocate for himself or exert self-determination or influence on his care or environment.

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