



IOWA DD**Council**

Preparation, Participation, Power

LEGISLATIVE AGENDA

2022

Fully fund healthcare services and community-based supports to address the workforce crisis in both rural and urban areas.



CALL TO ACTION

Value and invest in direct support professionals.

1. Increase the direct care support wage by at least 6% to allow providers to recruit, train and retain quality employees.
2. Financially support evidence-based training for direct support professionals.
3. Allow guardians and family members to be paid to provide support through Iowa's self-direction options for both children and adults.
4. Support creative solutions that:
 - Provide state tax cuts for direct support professionals.
 - Providing loan forgiveness and low-interest loan consolidation programs for direct support professionals.
 - Invest in recruiting incentives that encourage health care providers to work in Iowa.

"I have the right to live in the community of my choosing. There is no place like home."

Tucker

Tucker goes to bed each night wondering if he will have a caregiver the next day. Unfortunately, this is all too common.

For a recent virtual advocacy meeting, Tucker was unable to turn on his camera because he was still in bed. The day began with several phone calls from his caregiving agency as they scrambled to cover care. Fortunately, the agency was able to provide essential care on that day but placed Tucker back in bed because they were unsure when the next caregiver could arrive.

Between nursing and personal care, Tucker is to be scheduled for four shifts per day. For weeks he has relied on no more than two shifts per day. On this same day, his most consistent nurse notified him that she is moving soon. Tucker laughed it off, saying, *"I guess Merry Christmas to me."*



The care support system is failing Tucker.

To have a fulfilling life in his own home in the community of his choice, Tucker must have personal care staff. He has since moved to Waterloo to find reliable care and to be closer to family, insuring backup care.

Tucker is a graduate of the University of Iowa and has a long history of advocating for people with disabilities.

Support an inclusive community for all Iowans.

CALL TO ACTION

1. Invest in addressing barriers to community living such as family restrooms and accessible sidewalks in all public spaces.
2. Improve access to reliable transportation that allows people with disabilities to live, work, and play in their communities.



"My disability exists not because I use a wheelchair, but because the broader environment is not accessible."

Rob

Rob wants to attend his children's events. Whether a basketball game, a play or a child's school conference, he wants to be there.

Schools, like many public places, are not fully accessible, as an example, they are not required to have a family restroom.

Rob needs his wife's assistance to use the restroom while at events. He must ask everyone to exit the restroom and wait while he and his wife go in. In some cases, Rob finds himself, his wife, and another individual in the restroom all together.

Of course, inaccessibility is not limited to restrooms. Sidewalks, transportation, businesses, and parks are other examples of public places and services that are not accessible. Rob knows that Iowa must continue to invest in making our state accessible for all people.

Rob is an entrepreneur and motivational speaker, living in northwest Iowa with his family.



Reduce or eliminate Home and Community-Based Supports (HCBS) waiting lists.

More than 17,000 Iowans are on waiting lists for home and community-based services. Iowans need early access to support so they can continue to grow and thrive in their communities.

"The wait is too long. I need services now."

CALL TO ACTION

More than 17,000 Iowans are on waiting lists for home and community-based services. Iowans need early access to support so they can continue to grow and thrive in their communities.

1. Invest in community-based services and eliminate Iowa's institutional bias revealed in the recent US Department of Justice report.
2. Simplify the current waiver system to increase the ability to serve the varied needs of Iowans.
3. Hold managed care organizations accountable to provide creative and specialized services that encourage community integration.

Rylee

Rylee has been on the HCBS waiting list for almost two years and has been told that the wait for services is over four years.

After spending more than 18 years on Iowa's intellectual disability waiver, Rylee and her family moved to Minnesota where there are no waiting lists for services. After two years, Rylee and her family decided Iowa was home and moved back. Unfortunately, Iowa currently cannot provide the services Rylee and her family need.



Rylee requires medical assistance that her mom is currently providing. Because of this, respite services would be highly beneficial to her and her family. Supported community living services are essential for Rylee to live a more independent life.

Rylee's mom, a special education instructor and consultant has said, "I can't imagine not knowing how to navigate the system but three years or more without service is just too much."

Rylee is 22 years old, lives in Clear Lake and works at Subway.



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MISSION

Create change with and for persons with developmental disabilities so they can live, work, learn, and play in the community of their choosing.

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