IOWA DEVELOPMENTAL DISABILITIES COUNCIL
2023 LEGISLATIVE AGENDA

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 (DSPs).
1. Wages MATTER. Continue to support living wage increases for direct support professionals.
2. Financially support evidence-based training for direct support professionals.
3. Allow guardians and family members to be paid to provide support to both children and adults through Iowa’s self-direction options.
4. Support creative solutions that:
   ◦ Provide state tax cuts for direct support professionals.
   ◦ Provide loan forgiveness/low-interest loan consolidation for direct support professionals.
   ◦ Invest in recruiting incentives that encourage healthcare providers to work in Iowa.

Dr. Conaway

With multiple degrees, including two doctorates, Dr. M.J. Conaway, a.k.a. Matt, is an intellectual, polymath, and scholar. Also, he is a 54-year-old man with mixed spastic athetoid quadriplegic cerebral palsy, autistic characteristics, post-traumatic stress disorder, and more. Despite having dysarthric speech, he is bilingual in English and German. He types very fast with his mouthstick and drives a power chair with his head.

Even though he requires total assistance with activities of daily living, Matt has been on his own for 30 years. He lived all over the country, far away from so-called ‘natural supports’, before settling in Iowa. Currently, due to the home care shortage in Iowa City and elsewhere, he lives in a nursing facility in Indianola.

After losing home care in 2019, Matt’s initial institutionalization at the University of Iowa Hospitals and Clinics (UIHC) was isolating. Before UIHC, he appreciated his privacy, his autonomy, living in his own home, and the freedom to go out into the community.

UIHC denied Matt “day passes” to leave because if he was stable enough to leave, Medicare would not pay for his stay. The cost of his ten-month hospital stay of unskilled care was $750,000. In 2020, he was transferred to a nursing home in Indianola and later transitioned to a host home in Ankeny. Matt only stayed for six months as the requirements of that funding program were not flexible enough to meet his needs. He ultimately chose to return to the nursing home as they allowed him some freedom, autonomy, and independence.

Matt would like to have his own home again where he enjoys cooking and being out and about in the community. He can only do this if he can get supported community living set up. He is no longer willing to do come-and-go care from individual providers, as the risk of abandonment by underpaid caregivers is much too great.
Support an inclusive and accessible community for all Iowans.

Robert is an active member of the Adel community. He has been advocating for some time to make his post office accessible.

The door to the post office meets the Americans with Disabilities Act (ADA) legal requirements but yet Robert cannot open the door. The ADA, a historic civil rights law that is over 30 years old, was meant to be a baseline for accessibility and does not always meet the current needs of people with disabilities.

Robert uses a wheelchair due to cerebral palsy and cannot easily open the post office door on his own. Robert has asked his local postmaster for a push-button door mechanism. “I must wait in the parking lot every time to have someone open the door for me,” Fisher said. “That is demeaning, I’m sorry, but it is demeaning for people in wheelchairs.”

CALL TO ACTION

1. Invest in addressing barriers to community living such as family restrooms, adult changing tables, accessible sidewalks, parks, and public spaces.
2. Increase access to affordable, reliable, and convenient transportation that allows people with disabilities to live, work, and play in their community during day, evening, and weekend hours.
3. Invest in Iowa businesses that hire people with disabilities. Diversify Iowa’s workforce.

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Robert

In Mason City, they have discontinued transportation in the evening and weekends. This limits social and work options for Alecia. She must rely on family members, friends, and cabs. Limited transportation leaves people with little flexibility. Alecia can’t work late and pick up extra hours when asked by her boss. She cannot grab coffee with a co-worker after work. People without disabilities would never be this patient. Alecia is blessed with family supports, but adults do not want to be picked up by their mom.

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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 2021 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.

Reduce and eliminate ALL Home and Community-Based Services (HCBS) waiting lists.

“The wait is too long. My son needs services now.”

Charlie

Nancy and her family moved back to Iowa on June 8th of 2018. Days later, Nancy applied to have her son, Charlie, added to the health and disability waiver list. Charlie was on the waiting list for 3 years and 10 months. While they had physical therapy and occupational therapy, they were not able to access important services like respite or supported community living. “It is difficult because you know these services will make a difference in Charlie’s life”, said Nancy.

During this time Nancy did not work. With one income, long-term planning was not possible. Sometimes their 10-year-old daughter Sophia has to be the caregiver for Charlie when all she wants to be is his sister.

Peter

Peter, a young man with autism, has greatly benefited over the years from HCBS waiver services. He has become more independent and has a part-time job at Fidlar Technologies with this support.

“Addressing the critical need and investing funds so all Iowans can grow is a win for all.”

Waiver services are funded 1/3 by Iowa dollars and 2/3 by federal Medicaid dollars. Such an investment by the State of Iowa could leverage significant federal dollars to help individuals with disabilities, their families, and Iowa businesses that provide services to this population.

Artwork by Peter

Pete

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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This project was supported, in part by grant number 2101IASCDD, from the U.S. Administration for Community Living, Department of Health and Human Services, Washington, D.C. 20201. Grantees undertaking projects with government sponsorship are encouraged to express freely their findings and conclusions. Points of view or opinions do not, therefore, necessarily represent official ACL policy.