

2017 TOGETHER WE CAN CONFERENCE



LEGISLATIVE FORUM DISCUSSION SUMMARIZED NOTES

Federal issues identified at the 2017 Together We Can Conference:

- Families are concerned about the possible replace or repeal of the Affordable Care Act (ACA), also known as “Obama” Care which became law in 2010 because they fear it may make health insurance too expensive or not available at all for their families given they have a child with a disability.
- Families are concerned about cuts to Medicaid at the Federal level that will impact state systems for Medicaid. Families indicated that any cuts to Medicaid should come with clear steps to address the needs of families who have a child with a disability before any changes are made that will impact their ability to work and receive the needed services for their kids. Families do not want a block grant in place unless it addresses the needs to families of kids with disabilities to work, have insurance and have needed supports in place for their children.
- Families do not appreciate in the inconsistencies from state to state regarding Medicaid. Some states have one waiver. Some have many. Some have wait lists. All have different exemptions. Families of children with disabilities have to move for work just like other families do. The inconsistency across the country in the delivery of services for children with disabilities is a significant barrier to families remaining in the workforce and helping their children become as successful at contributing to society as possible.
- Families know the Individuals with Disabilities Education Act (IDEA), the law that governs special education, is drastically under-funded. They pointed out how their children can become contributing citizens and tax payers when given the proper supports early on.

State issues identified at the 2017 Together We Can Conference:

- Families indicated that no statewide, adaptive P.E. curriculum exists to ensure children with disabilities receive the same access across Iowa. Without it, kids are less likely to learn social and physical coping and compensation skills that will help them become contributing citizens.
- Families are concerned about the lack of vocational programming for youth with disabilities aged 16-22. Without it, youth lack the abilities and information needed to tap into the workforce and seek appropriate education and vocational training.
- Families are concerned about Medicaid Managed Care and Iowa Medicaid in general for multiple reasons:
 - There are too many waivers with access to different kinds of services and there are no longer exceptions to policy to meet the unique needs of individuals. Creating one waiver with a “menu” of options to choose from would address the fact that no one size fits all and that most families and individuals have different needs.

- The wait lists for waivers are unreasonable. Especially for young children given research shows that early intervention is the best approach to successful outcomes.
- The funding for medications/formularies creates changes to mental health medications that are significantly detrimental. Not all medications are the same, and they should not be regulated as if they are – especially in cases of mental health diagnoses.
- There is no standardization of services in school such as nurse services, autism services and therapy services. There are also significant attendance consequences at school for kids who need to attend therapy sessions during the school day.
- Schools in rural areas with few nurses available are now dis-incentivized to work with families who need in home care to hire the same nurse for both services; thereby creating full time work for the nurse and care solutions for both the school and the family.

Ways families wish to be involved:

- Use social media to:
 - share with each other
 - capture stories
 - communicate data/solutions/resources to each other and policy makers
 - create online Town Hall Meetings for policy makers
- Use training, events and advisory boards to:
 - put youth and families on training panels and invite legislators to attend/listen
 - provide families and youth opportunities to serve on advisory boards
 - families and youth must seek out opportunities to serve on advisory boards
 - communicate about and attend local political events
 - share stories, data/information, and solutions at local political events

Ways families would like to be supported:

- Be provided with a directory of attendees from the 2017 Together We Can Conference
- Be informed of what events are occurring where and what information is needed to understand how to be a part of the solution
- Be part of creating easy to understand messages and key points to share out collectively
- Be provided facts, figures and costs of providing services to better understand possible solutions from all angles
- Be given opportunities to share individual and collective stories
- For organizations with a role to play in this to come together to assist families in the work they need to do
- For an action plan toward getting this work accomplished to exist

What has been done to date:

- Summarized notes from the Legislative Forum (this document) were compiled and shared
- A [directory of attendees](#) from the 2017 Together We Can Conference was created and shared
- [Questions for elected officials](#) that attendees submitted were compiled and sent to elected officials; any answers received will be shared with attendees
- 2017 Conference Partners and other organizations have begun conversations on how to assist families in getting this work accomplished; if you would like to get involved, please [click here](#).