

2021 Legislative Issues and Priorities

Topical Summary

Advocacy and Lending Support

Caregiver Compensation

Summary

Currently, the Division of Services for People with Disabilities (DSPD) does not allow for reimbursement of services by family members or others who have a legal obligation to provide care. This rule prevents families from receiving payment for services they provide related to their family member's medical or disability needs. Previous legislation in Utah allowed a family member who was trained as a Personal Care Attendant to receive payment under waivers that allowed Self-Administered Services. That rule was removed, but proposed legislation for the last three years has sought to make it possible again. This was evidenced through the pandemic response bills that reimbursed families broadly. A bill in 2020 session passed with unanimous support through the Senate, but failed to reach the house floor after the Covid response began. That same legislation has been proposed again and would reimburse spouses through a new waiver program. This program could help build capacity in the system as well as financially aid those families who have extraordinary needs related to caring for their loved one with a disability. It allows families to direct their services and to reduce the effects of provider turnover with continuity of care.

Related Proposed Legislation

- Caregiver Compensation Amendments
 - Sen. Wayne Harper - Asks the Dept. of Health to write for a new waiver allowing for spouses to be reimbursed for extraordinary care - will have a fiscal note; 2020 note was ~\$500k.

Crisis Intervention

Summary

Numerous legislative proposals this year focus on crisis intervention. This change is due in part to protests and other long-standing feelings over the need for qualified personnel to respond to various situations that are outside of a police officers training or experience. Crisis intervention methods have been used for decades, but the last

few years have shown an increase in funding and other efforts to ensure that responses to crisis are done by trained personnel with an intent to deescalate the situation. Currently Division of Substance Abuse and Mental Health (DSAMH) administers 16 grants statewide for mobile crisis response teams. These grantees are working to build capacity through training and operations and have started to see improvements in their communities; one such grantee has chosen to integrate their mobile crisis team with their sheriff's dispatch, with the dispatcher sending the team that best meets the need of the family in crisis. Legislation around this area is numerous, including surrounding police reform but also toward improving access to mental health services for those in crisis or just before they reach that level.

Related Proposed Legislation

- Behavioral Emergency Services Amendments
 - Sen. Daniel Thatcher - Department of Emergency Medical Services (EMS) would add a Behavioral Emergency Service Tech as a certification program in addition to existing EMT and Paramedic licensure.
- Mandatory Autism Training Bill File
 - Rep. Steve Eliason - Working with the Autism Council to create a mandatory training for law enforcement
- Sen. Jake Anderegg - Police Reform
- Sen. Jani Iwamoto - Officer Intervention and Reporting Requirements-

Community Supports

Summary

In recent years, the Council has taken an approach to legislation that improving the social networks of individuals with disabilities will have the broadest impact on their ability to live in a setting of their choice, independently and with meaning. This perspective has allowed the Council and staff to support legislation around food and housing stability; mental health and crisis intervention; healthcare and delivery systems; improved employment opportunities; and access to services or supports for rural Utahns. While these types of policies tend to broadly to impact all Utahns, the disability community stands to benefit as much if not more than Utahns as a group.

Related Proposed Legislation

- Special Education Least Restrictive Environment Requirements
 - Sen. Jake Anderegg

- Task Force on Systemic Inequalities and Disparities
 - Sen. Luz Escamilla - Intended to take a systematic approach to police reform
- Task Force on Food Security
 - Sen. Luz Escamilla - Bill intends to take a systematic approach to statewide food security

Initiatives and Monitoring - Legislative Awareness

End the Wait

Summary

The UDDC has started the *End The Wait, Utah!* (ETW) initiative which intends to find innovative ways to provide supports to individuals currently waiting for services from the Division of Services for People with Disabilities (DSPD) with the goal of reducing the number of individuals waiting for services. The UDDC also intends to identify and share ways to maximize the existing spending for those currently in services or who are currently receiving limited support. This system overload is due, in part, to an emphasis on providing resources to urgent in-crisis cases, leaving the non-urgent cases to languish until a crisis emerges (often at a higher cost to the state and individual). The primary identified issue affecting individuals with disabilities' access to care is that they do not have sufficient access to support until their situation turns to crisis. The primary identified solution is to get individuals with disabilities services in the correct doses at the correct time.

Talking Points

- There has been a 25.6% increase in the number of people receiving services since 2010 yet,
- There has been a 109.2% increase in the number of people on the waiting list since 2010
- Primary issue: individuals do not have sufficient access to support until their situation turns to crisis
- Primary solution: get individuals with disabilities services in the correct doses at the correct time.

Strategy

- Increased understanding of program cost per client, and associated legislative support

- Increased throughput process via application and provider workflow
- Increased capacity in the service system via service delivery and product design
- Reducing throughput cliffs and information silos via enhanced evaluation process
- Increased synchronization via communication between providers and agencies

2021 Session Timeline

- Phase One: Platform Development and Plan Creation (April 1, 2020 to June 30, 2021)
- Phase Two: Build Capacity (June 30, 2021 to March 30, 2022)
- Phase Three: Implement Statewide (April 1, 2022 and Forward)

Limited Support Waiver

Summary

Providing Long-Term Services and Supports (LTSS) through a 1915(c) Home and Community Based Services (HCBS) waiver is a fundamental tool for people with disabilities of all ages to live, work, and participate in integrated settings of their choosing. These supports and services make personal care, employment, health and safety, transportation and other community living services possible for people with developmental disabilities. A LSW is a capped set of HCBS options to meet a person's needs. The LSW offers person-centered services that can be self-directed. Services options include personal assistance and technologies appropriate for each individual. Services should assist the person to access the community in the most inclusive and integrated setting.¹ SB44 in the 2020 General Session, which allowed families to access LSW services without losing their spot on the waitlist for broader services, was passed and signed. However, necessary pandemic responses called for cuts to the budget. The current funding appropriation for this bill remains intact, with \$400,000 appropriated to this service, including \$335,000 for direct services. The new waiver will be submitted to the CMS in the coming months, and any cuts or additions to funding will be made clear when the budget is released.

Autism and Disability Registries

Summary

¹ Olmstead v. L. C. 527 U.S. 581 (1999).

There are multiple kinds of registries used across the state for everything from voting to criminal acts to healthcare. An autism registry already exists within the Department of Health. According to the National Institute of Health, “a registry is a collection of information about individuals, usually focused around a specific diagnosis or condition; registries can provide health care professionals and researchers with first-hand information about people with certain conditions, both individually and as a group, and over time, to increase our understanding of that condition.” The ability to track and evaluate individuals can be beneficial to an extent. If informed and well-taught, police officers, social workers, and health care workers would be able to use this information to better handle emergencies. If made public, a disability registry would allow not only government and health care workers but community members in general to be more aware of those around them and ways in which they can help. A registry could also present lawmakers with a clear list of those within society who have a disability. This would make legislators more aware of the discrimination those with a disability often face.

However, at times, registries can be overbearing, even intrusive. Proposals have been made this year to create a disability registry that would be provided to law enforcement or other public personnel with the intent to offer customized services and supports to these families. However, questions about due process and personal rights, as well as discrimination and fear of retribution, remain on both sides. It also takes a deficit-based approach and encourages labeling by oneself as well as by others through which their response is metered. Moreover, costs for implementation, monitoring, and maintaining the database are extensive and any lack of funding could put the intent of the policy at risk.

Other Relevant and Important Legislation

- Competency-Based Hiring Amendments
 - Rep. Norman Thurston - Amends provisions related to hiring principles for certain state and local government employees.
- Students with Disabilities Amendments
 - Rep. Marsha Judkins - Related to add-on weighted pupil units for students with disabilities.
- Health Insurance and Early Intervention Services
 - Rep. Paul Ray
- Telehealth Mental Health Program
 - Rep. Ray Ward - Modifies provisions relating to a program for providing

telehealth mental health services

- Joint Resolution Recognizing Cost Savings by Accountable Care Organizations
 - Rep. Norman Thurston - Joint resolution recognizes the success of Utah Medicaid's accountable care program
- Digital Opportunity Access Amendments
 - Rep. Jen Dailey-Provost
- Utah Antidiscrimination Act Amendments
 - Sen. Derek Kitchen - Amendment on previous bill regarding discrimination complaint and grievance process in public organizations