

Natural Supports Listening Session

February 22, 2022

Agenda

- Introduction and purpose of listening session
- Experience of natural supports being utilized in service planning today
- Solutions that Medicaid could consider for improvement
- Next Steps

Natural Supports Utilization

- Right now system only sees mother as natural supports – it would be better if it would focus on what 24/7 services are needed
 - Would rather have mom be a mom and live her life
- Additional supports such as CNAs or nurses in school
- Limits individuals from getting outside resources and supports
- There is nothing natural about aging parents or family members being primary caregivers – need more formal supports
- Natural supports are not being leveraged for quality of life / interpersonal needs – it is instead, like said above, leveraged from primary caregiving
- Case managers are not encouraging/facilitating development of natural supports like friendships or community activities
- Can be a parent and a paid provider – quality of services received from a family member can be higher because they know what is needed
 - Families have made life choices so that they can be caregivers but perception is that they should feel guilty for also being paid but have to have income
 - Assumption that families are doing it for the money is disrespectful
- Important to consider the dignity of all parties involved (member being served, family members)
- System is frustrating and confusing rather than supportive
- Natural supports are often brought up to reduce paid services
- Having other supports available provides some level of security and confidence that bases are covered
- Can create strain with friends and family
- Pressure to rely on families and friends sometimes is not a good match
- Need to have a process within planning to do future planning rather than just focus on the now – what daily supports do they need, what natural supports do they have/need, what is missing

- Not all natural supports feel comfortable doing some of the skilled care
- Best practice in future planning – should include more than financials
- Perception that term natural supports has been corrupted
- Families need access to safety net when they are the only caregiver but they have an emergency or planned event that takes them out of the caregiver role temporarily
 - Example of Louisiana flexibilities to allow additional paid hours in emergency situations – notify CM and it would be authorized
- When parent becomes a paid support – respite is no longer an option but there are families that would benefit
- For individuals being cared for by their parent, would like to see them have time to get away and have freedom to live life more
- Alternative is institutional placement which is much more costly
- Example – child is 24 and receives authorization for 14 hours
 - Documents all services
 - Occasionally she does not sleep through the night
 - Recently IAC changed to not allow families to bill for overnight services
 - Didn't change the amount of care provided but changed the documentation requirements
 - If she was at a group home she would receive 24/7 and agency would be able to bill for sleeping hours
- Perception that fraud is suspected across the board or that people are intentionally breaking the law
- If there are needs that conflict with Iowa Administrative Code, the member and their team can request an ETP
 - Currently IAC doesn't recognize supervision needs with supports like a ventilator (short circuit, alarms, etc.)
- Lack of provider agencies puts a lot of pressure on families – fear of discharge, no-show, or staff reassigned during hospitalization
- Some agencies also do not want to accept clients with certain needs due to liability concerns

- During the pandemic, some family units tightened up their bubble and did not have staff in the home – makes the ability to get those staff back challenging because they have to move on to where they will get paid
- Skilled vs. unskilled CDAC
 - Perception that there are nursing agency requirements for supervision for things that don't seem very skilled (like stretching)
 - What do you do when you do not have a home health agency option with an opening
- Is it a requirements (federal or state) to list natural supports on the care plan and “hours” – putting it in the case plan in this way might be why it is perceived that natural supports are a replacement
- Mother with son who broke his neck 13 years ago – needs 24/7 support
 - Always feels that system is saying that family has to do more
 - Receives home health from county
 - Mother is CDAC
 - Unpaid hours = 16 hours
 - Home health used to be able to go to son's work but now not allowed – told that he has to ask coworkers to do services needed at work or to have family members come in
- Should be escalated if natural supports are providing unexpected and repeated supports

Opportunities for Improvement