

EXCEPTIONAL SUPPORT WAIVER SERVICES TASK FORCE

Minutes of the 4th Meeting of the 2020 Interim

October 26, 2020

Call to Order and Roll Call

The 4th meeting of the Exceptional Support Waiver Services Task Force was held on Monday, October 26, 2020, at 1:00 PM, in Room 171 of the Capitol Annex. Representative Steve Riley, Chair, called the meeting to order, and the secretary called the roll.

Present were:

Members: Senator Julie Raque Adams, Co-Chair; Representative Steve Riley, Co-Chair; Senator Dennis Parrett, Representative Tina Bojanowski; David Allgood, LeeAnn Creech, Thomas Laurino, Wendy Morris, Bob Napolilli, Brad Schneider, Steve Shannon, Amy Staed, , and Bonnie Thorson Young.

Guests: Leslie Hoffmann, Policy Advisor, Department for Medicaid Services, Claudia Johnson, Division Director, Department for Behavioral Health, Developmental and Intellectual Disabilities, Alisha Clark, Assistant Director, Division of Community Alternatives, Department for Medicaid Services, Cabinet for Health and Family Services; James Cheely, Past President the Arc of Kentucky, Federal RAISE Family Caregiver and Advisory Council Member; Karen Napolilli, Jini Payne, and Becky Taylor.

LRC Staff: Chris Joffrion, and Hillary Abbott

Approval of Minutes

A motion to approve the September 28, 2020 meeting minutes was made by Steve Shannon and seconded by Senator Parrett and approved by a voice vote.

Input from Families Receiving Waiver Support Services

Steve Shannon, President of Kentucky Association of Regional Providers, read a letter submitted by Melanie Tyner-Wilson, a mother of a waiver participant and a nurse at the University of Kentucky Developmental Pediatric Clinic. Ms. Tyner-Wilson stated that her journey as a disability advocate began with her son Jay's diagnosis with autism, apraxia, and intellectual disabilities in 1993. Ms. Tyner-Wilson stated that her experiences as a mother of a waiver participant and a nurse in a clinic serving many waiver participants give her unique insight into the barriers to effective treatment these participants and their families face. Ms. Tyner-Wilson stated that navigating the system is one of the chief issues facing many caregivers and family providers, as well as the omnipresent question: "who

will care for my child when I am gone?” Ms. Tyner-Wilson stated that partnership between the state waiver services and caregivers would help alleviate barriers and help the state develop solutions to the many issues that plague the waiver program.

Karen Napolilli, mother of Robby Napolilli, a waiver participant, stated that her son, who has physical, intellectual, and developmental disabilities, has received support services since he was born. Mrs. Napolilli stated that as her son aged, the community supports that could meet his needs dwindled, and the support from the state decreased as his needs increased. Mrs. Napolilli stated that Robby lived temporarily in the community on the waiver but the state could not continue to support his independent living, forcing him back into an intermediate care facility (ICF). Mrs. Napolilli stated that Robby thrived in the community, socially and mentally, and the progress he made in the community regressed when he was forced back into an ICF. Mrs. Napolilli stated that she believes that there should be state-provided waiver resources in the community, so people like Robby with a complex set of needs, can live and thrive in the community.

Jini Payne, a mother of 3 adult foster children with intellectual and developmental disabilities, stated that despite having guardianship of her foster daughters she could not gain access to their records to enroll them in waiver services. Mrs. Payne stated that the gap in the application process for cases like hers does a disservice to the parents who have guardianship over children like hers and places unnecessary burdens on the families trying to help. Mrs. Payne stated that she had been frustrated by the process of receiving emergency services as it requires her to anticipate an emergency and will not cover emergency services after they have happened. Mrs. Payne stated that she and other participant families do not feel their concerns are being heard by the cabinet and suggested enhanced communication with the families of service participants.

Becky Taylor, a mother of an adult child receiving waiver support services stated that she feels her child is receiving great care under the waiver but would like to see a more stream-lined application approach. Mrs. Taylor stated that she feels the having to reapply for services every six months is unnecessary and that a more person-centered approach to the application process could be beneficial.

In response to questions and comments from Thomas Laurino, Jini Payne stated that being unable to get her daughter’s intelligence tests from the state has prevented the state from assessing her for appropriate waiver services.

The Need for Wavier Improvements

James Cheely, Past President, the Arc of Kentucky, Federal RAISE Family Caregiver, stated that his son Brian, who has intellectual and developmental disabilities, has had support from many community members throughout his life who have ensured that he is treated as an active member of the community. Mr. Cheely stated that Rep. Steve Riley, when he was the high school basketball coach in Barren County, invited Brian to be

a trainer on the team, which gave Brian a sense of inclusion and purpose. Mr. Cheely stated that he understands how lucky Brian is to have support and community inclusion and how many waiver participants do not have the opportunity to be a part of their community.

Mr. Cheely stated that improvements to the waiver program should include more choices for even the most disabled participants to be a part of their community. Mr. Cheely stated he echoes what families have already stated; his biggest fear is what will happen to his son when he is gone. Mr. Cheely stated that he does not want Brian to be sent to an ICF simply because it is convenient for the state to do so. Mr. Cheely stated that more investment needs to be made into the waiver programs and community resources to provide these participants with the ability to live and thrive in their community. Mr. Cheely stated that many caregiver families have expressed concern with the application process for waiver services and noted gaps in community resources for their loved ones. Mr. Cheely thanked Representative Riley for all he has done for his son Brian and the Barren County waiver community.

In response to questions and comments from Representative Riley, Mr. Cheely stated that he thinks caregivers should have a seat at the table when the cabinet decides to improve the waiver. Mr. Cheely stated that he fears the issues and problems facing caregivers and participants do not make it to the drawing board.

In response to questions from David Allgood, Director of Advocacy Center for Accessible Living, Amy Staed, Kentucky Association of Private Providers, stated that currently, waiver extended-stay hospital payments are authorized under the CARES act.

In response to questions and comments from Bob Napolilli, CEO, the Council on Developmental Disabilities, Alisha Clark, Assistant Director, Division of Community Alternatives, Department for Medicaid Services, Cabinet for Health and Family Services, stated that the claims review process often prevents double billing. Ms. Clark stated that even if a provider double bills, the claims process would resolve the claim, so the participant's waiver services quota is not billed twice.

Adjournment

There being no further business, the meeting was adjourned at 3:45 pm.