

## Tennessee Rare Disease Advisory Committee (RDAC)

*Our mission is to improve the quality of life of individuals affected by rare diseases in Tennessee through collaboration, education, support and advocacy.*

Agenda May 25, 2022

RDAC Members In Attendance: Terry Jo Bichell, Chip Chambers, Clay Callison, Megan Crow, Reginald French, Lora Underwood,

Others In attendance; Terron Collier, Carol Westlake, Ashley McMinn

		<i>Action Items</i>
<b>Call to order and Welcome</b>	<b>Gillian Hooker, Secretary Treasurer</b>	
<b>The TN Disability Coalition</b>	<p><b>Carol Westlake, Executive Director, TN Disability Coalition</b></p> <p>Discussed TN Disability Coalition and how the Katie Becket Waiver was passed in TN and to look at challenges and opportunities to make this program do what it was supposed to do.</p> <p>We are all in this together - Coalition is an alliance of 40 different disability groups. They formed 30+ years ago to build a community that would support people at any age, any diagnosis - shared experience of health care needs and disabilities</p> <p>Nearly 1/3 Tennesseans has a disability and that grows as population ages - we have a higher rate than across the country in general</p> <p>Have been working on Katie Becket since 2013</p> <p>Who is Katie Becket - she was a little girl in Iowa - when she was 5 months old, she developed a brain infection and ended up in a hospital on a ventilator - her dad worked at U of I, in 1981, the family hit their \$1 million dollar max on life insurance, and she qualified for medicaid. Her family wanted to bring her home, but if they brought her home, she would lose her medicaid.</p> <p>Her family started to work to change that institutional bias Eventually, the Becketts got the attention of the Reagan administration - making sure that middle class families have access to the supports and services they need- things that are often not available through typical insurance - not designed for those purposes</p> <p>Lots of families who were counseled to divorce to help kids get</p>	

on medicaid, people stay in poverty to keep insurance. People who purposefully work less than 30 hours a week to keep insurance.

2018-19- work with general assembly to get a program in TN - TN was the last state to implement a Katie Beckett Program

Lawmakers approved a state budget of 27.3 million to get this approved, -with government match - that made 72M dollars. Enrollment began in November 2020.

TN program is a little different - we developed a program with 3 parts - A) traditional Katie Beckett - must meet institutional level of care- wrap around services, things from DIDD- All kids assigned to TennCare Select -current enrollment is 150 children- tiers of eligibility in part A - held off enrolling a lot of kids in the early days - income above 150% of federal poverty level that they need to pay for their TennCare B) Medicaid diversion program- - enrollment is at 1441 - families have to apply and be turned down - can get help paying insurance premium, contract with PayFlex- reimbursement product - can use for support services C) hasn't been operationalized yet - because there's still space in part A program - kicks in if there's not a part A slot - helps kids rolling off of medicaid because family income has increased

Challenges and opportunities

There's a lot of bureaucratic complexity - b/c there was such an effort to make sure it's budgetarily stable

Families have found that it is not so simple to get needs met - Families who have kids with rare disorders who travel to other states for care - and if those states don't have a provider number, that doesn't get paid - they have been working to support families in organizing and making sure those things work as best they can.

Technical advisory group within TennCare - includes some families and providers

Network issues and workforce issues have been a challenge -

Opportunities for family engagement & community building - peer to peer networks

Making sure that the healthcare community

Families were clear as they were developing eligibility criteria - diagnosis is not an appropriate way to determine eligibility. Based on acuity and need - that's a strength of the program. She will share the eligibility criteria

Under part A - covers diagnosis work, Part B- families need to decide- using it for primarily therapeutic - extra OT and ST -

Are there still funds available? Yes, it is not filled- they slow walked enrollment in part A - Why not? Are there not enough

	<p>kids who would qualify? One, it's hard to get kids through the application process and families find the application process daunting - lots of information required by TennCare to apply</p> <p>Megan Crow - a portion of the hemophilia community does apply, but many wonder if they qualify. Degree of disability may not be there.</p> <p>Acuity and demonstration of impact on activities of daily living is key to eligibility.</p> <p>Legislators are very invested in this policy and want to see this succeed.</p> <p>TN Disability Coalition they have a staff person who works with Katie Beckett applicants every day. We can send folks their way.</p>	
<p><b>RDAC Members Finishing Terms / Succession Planning</b></p>	<p><b>Terry Jo Bichell, RDAC Vice chair</b></p> <p>We have in our charter specific membership requirements - for a nurse, for patient advocates- these are the upcoming vacancies.</p> <p>Still waiting on final appointment for the next new member.</p>	<p><b>Please nominate people who meet the requirements of the advisory council for new members - send recommendations to Terry Jo Bichell and Gilian Hooker</b></p>
<p><b>TN Expanded Genomic Diagnostics Program update / TN Rare and Undiagnosed Disease Network Update</b></p>	<p><b>Rizwan Hamid, RDAC Member</b>  <b>Scott Strome, RDAC Chair</b>  <b>Chip Chambers, RDAC Member</b>  <b>Terry Jo Bichell, RDAC Vice-chair</b></p> <p>Ashley McMinn provided an update - made progress on the document. Add or change in that document based on next conversations.</p> <p>Committee meets later today, exploring action items - legal or risk management - talking with other insurance companies - may help to guide the project in one direction or the other.</p> <p>Federal law working its way through congress. -</p> <p>Have someone come speak on the federal diagnostics bill on our next meeting</p>	<p><b>Identify a speaker to discuss the federal bills related to diagnosis.</b></p>
<p><b>Newborn Screening Opportunities Update from recent NBS Meeting</b></p>	<p><b>Kim Stephens, RDAC Member</b>  <b>Rizwan Hamid, RDAC Member</b>  <b>Abby Trotter, LifeScienceTN</b></p> <p>Will ask to submit a written update and circulate with the minutes.</p>	
<p><b>RDAC Step Therapy Working Group Update</b></p>	<p><b>Reginald French, RDAC Member</b>  <b>Megan Crow, RDAC Member</b>  <b>Kim Stephens, RDAC Member</b></p>	

	<p>The bill did pass and the governor signed HB 677 into law - this bill is very important for folks with rare disease in the state. Many people working to try to get this approved.</p> <p>Unanimously approved - goes into effect in 2023 - will offer patients opportunity to opt out of a step therapy protocol in some cases. This bill does not include TennCare - adding TennCare added a huge fiscal note to it, so it was removed. It's a Step Therapy regulation bill - it puts an exception process in place and a time limit for it to get approved. The exception process includes if you've taken medication previously and it's worked, and/or if you've had a reaction.</p>	
<p><b>Brief Updates</b></p> <p><b>Pharmacy Advisory Committee Update</b></p> <p><b>DUR Update</b></p> <p><b>Department of Intellectual and Developmental Disabilities</b></p>	<p><b>Reginald French, RDAC Member</b> <b>Lora Underwood, RDAC Member</b></p> <p>Notes will be circulated with the minutes from the meeting. Highly attended meeting - &gt;60 people on the call. There was only one medication for rare disease - Welireg - medication for rare pancreatic tumors - ACS says ~ 4300/yr in US get this type of cancer. Medications are mostly passing. Lora added that cancer drugs are not usually managed with a lot of criteria - there's a lot of trial and failure when it comes to cancer medications.</p> <p>The next PAC meeting is in August - we will have a new clinical pharmacy director in place. Considering moving to in person meetings.</p> <p><b>Megan Crow, RDAC Member</b></p> <p>DUR meets next July 12th - Megan will need an alternate for this meeting - Since that will be after Laura transitions to leading that group, she can provide an update on the July call.</p> <p><b>Terry Jo Bichell, RDAC Vice Chair</b></p> <p>Quick report from DIDD - Andy Kidd, deputy commissioner of DIDD - budget was expanded by 100M for DIDD - will go into expanding early intervention services program for kids with developmental disabilities.</p> <p>Transportation program expansion - for transition aged youth with disabilities to help them navigate transportation systems to promote independence.</p> <p>Increasing wages for direct service providers - until last year, hourly wage was \$10.50/ hour - crisis in the state where direct service providers were quitting and there's been a shortage - now it will go up to \$13.75 - still not as high as McDonalds - small portion that's going to inclusive higher ed programs</p> <p>Legislator in attendance</p>	
<p><b>Review of Action Items and</b></p>	<p><b>Scott Strome, RDAC Chair</b></p>	

<b>Agenda Items for December Meeting</b>		
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