

**I/DD STAKEHOLDER
MEETING MINUTES**

Date May 20, 2021 **Time:** 3:00 pm – 5:00 pm **Location:** Web-Conference

MEETING CALLED BY		Kenneth Bausell, Chair and LaToya Chancey, Co-Chair			
TYPE OF MEETING		DHHS I/DD Stakeholder Workgroup Meeting			
ATTENDEES					
COMMITTEE MEMBERS			STATE STAFF ATTENDEES		
NAME	AFFILIATION	PRESENT	NAME	AFFILIATION	PRESENT
Alisha Tatum	Lifespan	<input checked="" type="checkbox"/>	Alice Farrar	DVRS	<input checked="" type="checkbox"/>
Ashley Young	Stakeholder	<input type="checkbox"/>	Deb Goda	NC Medicaid	<input type="checkbox"/>
Ayelet Heckathorn	Charles Lea Center	<input checked="" type="checkbox"/>	Katie Visconti OR Monica Harrelson	DSOHF	<input checked="" type="checkbox"/>
Byron Hall	Stakeholder	<input type="checkbox"/>	Kenneth Bausell	NC Medicaid	<input checked="" type="checkbox"/>
Carol Conway	Stakeholder	<input checked="" type="checkbox"/>	Lauren Howard	DPH	<input type="checkbox"/>
Cindy Ehlers	Trillium	<input checked="" type="checkbox"/>	LaToya Chancey	DMH/DD/SAS	<input checked="" type="checkbox"/>
Danyale Sturdivant	Stakeholder	<input type="checkbox"/>	Mya Lewis	DMH/DD/SAS	<input checked="" type="checkbox"/>
Dakota Lanay Wilson	Stakeholder	<input checked="" type="checkbox"/>	Niki Ashmont	DSOHF	<input checked="" type="checkbox"/>
Despina Karras	Stakeholder	<input checked="" type="checkbox"/>	Pam Scott	DHHS	<input checked="" type="checkbox"/>
Dotty Foley	Stakeholder	<input type="checkbox"/>	Patricia Hill	CAP-DA	<input type="checkbox"/>
Erin Nantz	Cardinal	<input checked="" type="checkbox"/>	Sherry Thomas	DPI	<input checked="" type="checkbox"/>
Holly Watt	Provider Agency	<input type="checkbox"/>	Talley Wells	NCCDD	<input checked="" type="checkbox"/>
Janet Price-Ferrell	FIRST	<input checked="" type="checkbox"/>	Wrenia Bratts-Brown	NC Medicaid	<input type="checkbox"/>
Jenny Gadd	Alberta Professional Services	<input checked="" type="checkbox"/>			
Jessica Aguilar	Stakeholder	<input checked="" type="checkbox"/>	GUESTS		
Joan Fischer	Stakeholder	<input checked="" type="checkbox"/>	Allison Cecil	<i>Additional stakeholders called in via phone, which resulted in being unable to capture their name from the roster.</i>	
Jody Miller	Partnership for Children/Family Support Network	<input checked="" type="checkbox"/>	Angelia Lightfoot		
Kerri Erb	Autism Society of NC	<input checked="" type="checkbox"/>	Amie Brendle		
Lisa Nesbitt	DRNC	<input checked="" type="checkbox"/>	Bill Donohue		
			Brandi Baker		
Mark David Patrick	Provider Agency	<input checked="" type="checkbox"/>	David Ingram		
Melvin Anthony Neal	DECI	<input checked="" type="checkbox"/>	Guynette Hartman		
Richard Edwards	Community Based Care	<input checked="" type="checkbox"/>	Jennifer Kelly		
Rita H. Oglesbee	T.L.C. Home, Inc	<input checked="" type="checkbox"/>	Lynn McIntosh		
Robin Marx	Stakeholder	<input checked="" type="checkbox"/>	Melissa Mentz		
S. Michael Chapman	UNC TEACCH Autism Program	<input checked="" type="checkbox"/>	Michelle Harper		
Saskia Barnard	Corporation of Guardianship	<input type="checkbox"/>	Michelle Merritt		
Shirley Moore	Partners	<input checked="" type="checkbox"/>	Rachel Noell		
Tara Fields	Benchmarks	<input checked="" type="checkbox"/>	Sarah Potter		

1. Agenda topic: Welcome

Presenters: Kenneth Bausell, I/DD Manager, NC Medicaid and LaToya Chancey, I/DD Team Lead, DMH/DD/SAS

Discussion	<ul style="list-style-type: none"> Kenneth Bausell called the meeting to order at 3:00 p.m. and welcomed the members to the DHHS I/DD Stakeholder Meeting. May's meeting agenda was reviewed. LaToya shared updates to April's meeting minutes and solicited approval. The minutes will be posted to https://www.ncdhhs.gov/divisions/mhddsas/councils-commissions. CORRECTION: LaToya Chancey mispoke regarding new member and this will be discussed at the next meeting. 		
Conclusions			
Action Items	Person(s) Responsible	Deadline	

2. Agenda topic: Public Feedback Received Outside of Meeting

Presenter: Kenneth Bausell

Discussion	<p>The following feedback was provided:</p> <ul style="list-style-type: none"> It would be beneficial to obtain needs and characteristics information of individuals on Registry of Unmet Needs (RUN). Can LME-MCOs publish a number that will represent the years they are serving to advise individuals/parents on where they are on the waitlist? It is important that the process be simpler in the sense that it is difficult for families to fill out some forms that the MCOs have, additionally explain why it takes years, it is important that they enter the list of unmet needs. Regarding supporting aging caregivers, the role of case managers needs to be more interactive for the individual and parents. Review the different tasks, i.e., paperwork, LME-MCOs require from their care managers and providers. Is an effort being made to determine why the hours aren't being used, such as the staffing agencies fail repeatedly to staff without any consequence? If so, is the state planning to enact consequences for staffing agencies who continue to fail to keep their contracts by providing staff? The same for those who are EOR (employer or record). It has been an incredible challenge during COVID for everyone to hire and maintain staff. CAP/C may provide support for a child on a ventilator. 		
Conclusions			
Action Items	Person(s) Responsible	Deadline	
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3. Agenda topic: Workgroup Composition

Presenter: LaToya Chancey

Discussion	<p>The following feedback was provided:</p> <ul style="list-style-type: none"> Individuals need to be educated on the difference between an ID and DD. It is a waste of resources to require an individual with a physical disability to take intellectual exams. Medicaid and State Funded policies don't clearly articulate the needs for individuals that are ID vs DD. For example, some individuals with physical disabilities are required to take psychological evaluations. The SIS score can be used to obtain the needed information. Individuals with Autism Spectrum Disorders receive the same challenges. The focus is on intellectual evaluations when their needs are in other areas that are not identified in such evaluations. We need to look at those requirements from the state and individual payors across the state. A member reported having experienced this hurdle as well with their 18-year-old son with developmental disabilities and genetic disorders. CAP said he didn't qualify for their waiver and should instead be served by Innovations, and was told he didn't qualify for Innovations because his IQ is too high. Outside of CCP 8P, include access to (b)(3) and IPRS (state-funded services). 		
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	<ul style="list-style-type: none"> Knowing that the intelligence score is not valid to determine intellectual functioning, why bother using the IQ test? Utilization Management [at LME-MCOs] need education to recognize the distinction between ID and DD. 				
Conclusions					
Action Items	<table border="1"> <thead> <tr> <th>Person(s) Responsible</th> <th>Deadline</th> </tr> </thead> <tbody> <tr> <td>Kenneth Bausell</td> <td></td> </tr> </tbody> </table>	Person(s) Responsible	Deadline	Kenneth Bausell	
Person(s) Responsible	Deadline				
Kenneth Bausell					
<ul style="list-style-type: none"> Clinical Coverage Policy 8P will be reviewed for clarification of ID vs. DD. 					

4. Agenda topic: Review of Shared Vision Draft

Presenter: Kenneth Bausell

Discussion	No feedback provided				
Conclusions					
Action Items	<table border="1"> <thead> <tr> <th>Person(s) Responsible</th> <th>Deadline</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> </tr> </tbody> </table>	Person(s) Responsible	Deadline		
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5. Agenda topic: Accessing Services in NC

**Presenter: Jennifer Kelley
IDD Consultant
NC DMHDDSAS**

Discussion	<p>The following feedback was provided re: Accessing Services:</p> <ul style="list-style-type: none"> Where will this infographic be hosted? <ul style="list-style-type: none"> The information would be good in hospitals for social workers. Does the State have resources to get this document to healthcare workers? Public school system would benefit from this document because most individual's entry to the system is through school-based supports. The Council offered to post the document on their website. Define the meanings of some words; Simplify language. Most families don't know they can place their child on RUN because of no previous experience with Medicaid. Need State systems designed to find and ID children with FASD. <ul style="list-style-type: none"> Another member noted agreement about FASD – adding a need for the MCOs to be educated about how prevalent this is in NC and that it qualifies as a developmental disability. Are the CDSAs serving children beyond age 3? Has that changed? Do we need to make something similar tailored to younger age groups? Once this document is printed, it become obsolete due to changes. <ul style="list-style-type: none"> This document will be regularly updated by DMHDDSAS 				
Conclusions					
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6. Agenda topic: Medicaid Transformation Corner

Presenter: Kenneth Bausell

Discussion	<p>The following information was provided:</p> <ul style="list-style-type: none"> Look forward to more services in the State Plan. What is the timeline around this option? i-options can be the fastest way to reduce RUN. Concerns with staffing i-options with current staff pay rates. 				
Conclusions	Mobile Crisis services will not go away.				
Action Items	<table border="1"> <thead> <tr> <th>Person(s) Responsible</th> <th>Deadline</th> </tr> </thead> <tbody> <tr> <td></td> <td></td> </tr> </tbody> </table>	Person(s) Responsible	Deadline		
Person(s) Responsible	Deadline				
<ul style="list-style-type: none"> 					

7. Agenda topic: Supported Decision Making Infographic

Presenter: Jennifer Kelly

Discussion	<p>The following information/feedback was provided:</p> <ul style="list-style-type: none"> • This information would be beneficial to the community, i.e., school system. • Family members are encouraged to become the guardian of individuals with disabilities. Oftentimes education is needed. • Include a link to Psychiatric advance directives (PADs) in your supported decision making options under the Advance Directives section. • Psychiatric advance directives should be added under advance directives. https://www.nrc-pad.org/ and https://www.nami.org/Advocacy/Policy-Priorities/Responding-to-Crises/Psychiatric -Advance-Directives are two resources on PADs • Need to start thinking self-determination at an early age. • Discussion around dignity of risk and how this fits into supported decision making. • Many persons see guardianship as the forever parent and at that point they are not doing guardianship correctly. • The school system creates barriers for kids obtaining services. 		
Conclusions			
Action Items	Person(s) Responsible	Deadline	
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8. Agenda topic: Cross Divisional Collaboration

Presenter: LaToya Chancey

Discussion	<p>The following information/feedback was provided regarding competitive integrated employment:</p> <ul style="list-style-type: none"> • Education is needed because many people believe if they make money it will result in loss of Medicaid. Employers aren't hiring or training individuals with disabilities. • Start working earlier (i.e., in middle school) to help with independence. Starting in high school is too late. • Funding is needed to create a stable workforce to support individuals with I/DD. The national turnover rate for SE programs is 64%. Recognize after the training is completed with VR, State Funded and Medicaid funding is needed to provide ongoing support to maintain employment. • Exposure to work and internships at an earlier age thru the school system. • A member reported it would be very unlikely for her son to come out of his ICF group home and get CIE--he's mostly non-verbal and inattentive. Microenterprises and business developed with individuals with disabilities in mind may be an option. Not a lot of people are looking for a type of job providing one on one services a good number of persons will need. Low pay for the service is another barrier. • Long-term vocational support is critical. SE programs with greatest success don't operate in unit cost reimburse system but more on a case management service. • Create jobs with a bigger incentive for employers to hire individuals with I/DD. • Transition to employment thru Easter Seals with Trillium was discussed. Individuals working on food truck earning minimum wage is working. • IDEA requires Transition @ least by 16; Transition discussions are required in NC to begin at 14 in some cases an early plan will begin. • Vaya Health has a small but effective department that is deinstitutionalizing individuals and supporting some of them with starting microenterprises, which is one option that is often overlooked when discussing SE. One common concern is the lack of understanding of how much money someone can earn while still maintaining their benefits (SSI, Medicaid, SNAP, etc.). Benefits Counselors can provide education on this topic, so perhaps we need to fund them more • Preemployment structure would be helpful. • More funding is needed for Pre-ETS through VR. 		
Conclusions			

Action Items	Person(s) Responsible	Deadline
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9. Agenda topic: General Assembly Corner

Presenter: Kenneth Bausell

Discussion	<p>The following feedback was provided regarding S103, Reduce regulations to help children with Autism:</p> <ul style="list-style-type: none"> • A lot of providers have challenges with having enough staff to do 1:1 for the requested hours the families need. There are concerns with staff having the level of experience needed to work with Autism. Who has oversight over those professionals? • Hopefully, this bill will improve access for kids to ABA but right now there are long wait times for this service. • We need to think about what happens to kids who get ABA services but fall off the EPSDT cliff at 21. Offering Waiver services like CLS is unhelpful if ABA is what is needed. • Families need to travel for this service if they can get it as it doesn't exist in the western part of the state. • Access to ABA for adults is needed. • With the change, can the separate codes go away since that would help utilize this service? • Hopefully this bill will improve access for kids to ABA, but right now there is long wait times for this service. 	
Conclusions		
	Person(s) Responsible	Deadline

10. Agenda topic: Public Feedback

Presenter: Attendees

Discussion	<p>The following feedback was provided:</p> <ul style="list-style-type: none"> • Melissa Mentz - When thinking about the service array consider the needs of parents. The rates of removal of those children from the custody of their parents with I/DD is high. Consideration for Medicaid to cover Reproductive rights assisted reproduction technology, preconception consultations, Medicaid transportation being more family friendly i.e., I/DD meetings at school, adaptive equipment and durable medical equipment. 	
Conclusions		
	Person(s) Responsible	Deadline

11. Agenda topic: Future Agenda Items

Discussion	No feedback provided.	
Conclusions	Direct Support slides will be included in the presentation and discussed at the meeting. General Assembly information note reviewed during the meeting will be accessible via the slides sent/posted to the website.	
	Person(s) Responsible	Deadline

Meeting Adjourned 5:05 p.m.

Next Meeting: The next meeting is scheduled for Thursday, July 15, 2021 from 3:00 p.m. – 5:00 p.m. Via WebEx.