I/DD STAKEHOLDER MEETING MINUTES

Date: April 6, 2021 **Time**: 3:00 pm – 5:00 pm **Location**: Web-Conference

MEETING CALLED BYKenneth Bausell, Chair and LaToya Chancey, Co-ChairTYPE OF MEETINGDHHS I/DD Stakeholder Workgroup Meeting

ATTENDEES

COMMITTEE MEMBERS			STATE STAFF ATTENDEES		
NAME	AFFILIATION	PRESENT	NAME	AFFILIATION	PRESENT
Alisha Tatum		PRESENT	Alice Ferrar	DVRS	PRESENT
Ashley Young	Lifespan Stakeholder	$\vdash \vdash \vdash$	Deb Goda	NC Medicaid	+ $+$
			Katie Visconti/Monica	DSOHF	
Ayelet Heckathorn	Charles Lea Center		Harrelson		
Byron Hall	Stakeholder		Kenneth Bausell	NC Medicaid	\square
Carol Conway	Stakeholder	\boxtimes	Lauren Howard	DPH	
Cindy Ehlers	Trillium	\boxtimes	LaToya Chancey	DMH/DD/SAS	
Danyale Sturdivant	Stakeholder		Mya Lewis	DMH/DD/SAS	
Dakota Lanay Wilson	Stakeholder	\square	Niki Ashmont	DSOHF	
Despina Karras	Stakeholder		Pam Scott	DHHS	
Dotty Foley	Stakeholder		Patricia Hill	CAP-DA	
Erin Nantz	Cardinal		Sherry	DPI	
			Thomas/Kellyann		
			Breest		
Holly Watt	Provider Agency		Talley Wells	NCCDD	\boxtimes
Janet Price-Ferrell	FIRST		Wrenia Bratts-Brown	NC Medicaid	
Jenny Gadd	Alberta Professional				
•	Services				
Jessica Aguilar	Stakeholder			GUESTS	
Joan Fischer	Stakeholder	\boxtimes	Allison Cecil		
Jody Miller	Partnership for Children/Family Support Network		Angelia Lightfoot		
			Ann Roth		
Kerri Erb	Autism Society of NC		Ashley Donadson		
Lisa Nesbitt	DRNC		Christina Dupuch		
Mark David Patrick	Provider Agency		Felcia Williams		
Melvin Anthony Neal	DECI		Jennifer Kelly		
Richard Edwards	Community Based Care		Kathy Reiter		
Rita H. Oglesbee	T.L.C. Home, Inc		Kelly Friedlander		
Robin Marx	Stakeholder		Laurie Radulescu		
S. Michael Chapman	UNC TEACCH Autism Program		Marianne Ferlazzo		
Saskia Barnard	Corporation of Guardianship		Michelle Merritt		
Shirley Moore	Partners		Mike Chapman		
Tara Fields	Benchmarks		Ray Hemachand		
	21121111111111111		Robin Devore		
			Stephanie Jones		
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1. Agenda topic: Welcome

Presenter: Kenneth Bausell, I/DD Manager, NC Medicaid

Discussion	•	 Kenneth Bausell called the meeting to order at 3:00 p.m. and welcomed the members to the DHHS I/DD Stakeholder Meeting. Kenneth took roll call and opened with an ice breaker. 		
Conclusions				
Action Items			Person(s) Responsible	Deadline

2. Agenda topic: Public Feedback outside meeting

Presenter: LaToya Chancey, I/DD Team Lead, DMH/DD/SAS

Discussion	No feedback provided		
Conclusions			
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Action Items		Person(s) Responsible	Deadline

3. Agenda topic: Establishing Shared Vision Draft Presenter: Kenneth Bausell and LaToya Chancey

3. Agenda topic: Esta	ablishing Shared Vision Draft	Presenter: Kenneth Bausell and LaToya Chancey		
Discussion	The following feedback was provided:			
	Substitute the word personal support to natural support.			
	Develop professional supports instead forcing natural supports to volunteer their time			
	The waiting list of unmet needs- increase access to supports and services			
	Pay direct support staff more income instead of requiring additional training – Need to earn more than \$15.00 per hour			
	 Is there a deadline or timeline to reach goals and visions? Milestone dates are important. Add something around safety net/crisis services and coordination with LME-MCOs/First responders/MH, etc. Mental Health and I/DD – how does the State respond to individuals with I/DD that is having a MH crisis 			
Conclusions				
Action Items	Person(s)	Deadline		
	Responsible			
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4. Agenda topic: Current I/DD Projects and Initiatives Presenter: Kenneth Bausell and LaToya Chancey

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Discussion	The following feedback was provided re: Supported Employment:
	Give examples on how individuals have utilized this evidence based models successfully
	 Discharge/ Fade-out planning means these individuals are going to go to 0 services and supports. Some I/DD individuals need support for the rest of their life.
	What if we didn't fade out altogether such as maybe always check in at least once a month or unless the individual does say they no longer need the staff support however can always reach out should things change.
	Don't restrict options for SE (i.e., Extraordinary adventures in Chapel Hill employed individuals with disabilities)
	 Employers don't take risk with individuals with I/DD (i.e., individual with disability worked at golf course but with new management felt like he was an insurance liability and ended employment)
	The assessment component in identifying the individual's strengths to find the right job match. Look at the person as an individual instead of looking at everyone as a group.
	 Training regarding internships and volunteers is needed — Don't be so descriptive as the service need to be more individualized

	Some places don't have public transportation, but transportation service is needed to work Don't miss connection between occupational course of study and post-secondary education Training opportunities are available with APSE		
Conclusions			
		Person(s) Responsible	Deadline

5. Agenda topic: Un	ified Waitlist Project	Presenter: Kennet	:h Bausell	
Discussion	 The following feedback was provided: Parents having trouble navigating thru the waiver when they don't speak English; Also, some parents put their children on the waiting list at age 3 because it will take 10 yrs. or more to obtain services. It is hard to find some services like home skills services - no providers or waiting list for over than 1 year or more. With tailored plans and care managers role working with individuals on waiting list, should individual's information be updated from time to time? 			
Conclusions	Primary language spoken added to list – Have conversations with LME-MCOs			
Action Items Person(s) Responsible		Deadline		
Add Primary language spoken to waitlist metrics		DHHS		
Discuss how language barriers are addressed with LME-MCOs				

6. Agenda topic: Public Comment

Presenter: Workgroup Discussion The following public feedback was provided: Ray Hemachand – Representing family members of people with lived experience on the workgroup seem bias towards adult families rather than including families with children. But to think the group is going well by educating, supporting, and including families with children with I /DD is terribly mistaken. Employment, housing, independence, education - special education for children and children's families is not in the world cloud at all. Many are concerned with how this workgroup was formed and selected by the Department and if potentially if corrections are not made then the representation of inclusion will be compromised. I appreciate representation from DPI and Children and Youth but representation from families is needed. Even the shared vision during the first meeting speaks to post-secondary education but no mention of s PreK-12 at all. Also in talking about community inclusion, the shared vision mentions community living, self-advocacy but not schools where there's often failing badly but the best opportunity to make the biggest difference in the lives of people with I/DD. Being a member of an autism support group, just this week parents advise families with a kid with autism not to move to NC. How is this workgroup or Department going to better represent families with IDD children? How will this workgroup actively seek out public comment from families? We need to know what families are experiencing when they are first encountering systems today and as they struggle through them during childhood. Where are the deficits and strengths? What needs to be improved immediately and long-term? We don't know if parents with IDD adult children know what those challenges are today. Families that has been doing this longer and had more interaction with the systems and DHHS need to be included. I appreciate that my public comment from the first meeting was shared in the beginning of this meeting, but how is broader feedback from I/DD lived experience going to be supported and solicited by the workgroup and incorporated fully into the work being done especially for families with young children and will a new member be brought on representing those families so that critical populations are represented. Marianne Ferlazzo – One of the vital services that's doing self-direction is community navigator but with Medicaid Transformation its going away. This service is critical. Will this group advocate for this service or look at what's the plan after it end?

	 Jane Lindsey – Is this group composed by age and by condition (mild, moderate, and profound). service needs and how their needs will be met; The waivers always go back to one size fits all. 		
Conclusions	The slides from the presentation will be disseminated amongst the workgroup for additional feedback. Complete a survey to determine if parents of children are represented on the workgroup.		
Action Items		Person(s) Responsible	Deadline
Survey workgroup members based on feedback received		DHHS	
Share slides from presentation		DHHS	

6. Agenda topic Conclusions	 Future agenda items: Increasing community living and sustainability Finding Services that is available Provide information around (b)(3) Service Options Prepare information for parents of children w/I/DD regarding school navigation. Confirm via survey if there are parents with I/DD children age 0-3 represented on the workgroup? 				
Action Items		Person(s) Responsible	Deadline		
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Meeting Adjourned 5:15 p.m.

Next Meeting: The next meeting is scheduled for Thursday, May 20, 2021 from 3:00 p.m. – 5:00 p.m. Via WebEx