

Small Group Discussion Notes

Topic: Reducing Health Disparities Across the Lifespan:
Adulthood

Existing Resources	New Resources Needed from TA Centers
<ul style="list-style-type: none"> • LEND/UCEDD/MCH emphasis on adulthood • Disabled parenting project – Boston • Arkansas LEND/UCEDD (Julie Petit) • NY – NIH Grant – health advocacy (recent clinical trial) • Health literacy • Peers Program • UAB Trip Lab Simulator (driving resource) • Wegman’s employment for people with disabilities • NY progressive in providing services to CYSHCN. Big nonprofit run by families for Autism. And do a lot of advocacy. Continuing care center in region (integrated services – ADOS). College programs for high functioning individuals; programs for teaching transition; work programs (3-4 years). Competitive work placement with local businesses. • Self-advocacy movement • Drexel University – Data available next year • AIR-P • Disabled Parenting Project – Cambridge, MA 	<ul style="list-style-type: none"> • Gap for individuals who can do multiple things. • Resources for people diagnosed as adults: Training programs for adults/adults with kids with disabilities; Are there any training programs for adults regarding raising children, etc.? • Self-advocacy resources • Sensory friendly recognition • Services for diagnosing Adults – many individuals that have never accessed services because they have never received services • Training for Autistic adults to transition from childhood to adulthood • Finding ways to access adults in order to determine priorities • How to reach providers that are serving adults? Providing resources ,etc. • Community- Based training and outreach (ex. Pharmacy)
Obstacles or Challenges Experienced	Lessons Learned
<ul style="list-style-type: none"> • Alabama is a very poor state; limited resources. Adult resources very limited. At the private level very few organizations and of those that exist, mostly focused on young adult or transition-aged. Most options are waiver programs. Most “high functioning” individuals do not qualify for waivers. Project Search (transition) • What terminology to use in research proposals so that it will be understood by those reviewing it as well as not to offend those referred to • Transportation – access is very limited • Independent living -daily living skills, limited comfort 	<ul style="list-style-type: none"> • Labels/ terms are important (high functioning vs. self-advocate vs. no label at all) when you are considering and creating services. Sometimes a different vocabulary is needed for different groups of people.

<ul style="list-style-type: none"> • **People with “high functioning autism” have the greatest difficulty accessing resources/services** • The term “high functioning” may be offensive to people with disabilities. 	
Opportunities for Grantee Collaboration	Outside Collaborators
<ul style="list-style-type: none"> • Health advocacy training manual clinical trial – University of Rochester (anticipated release Winter 2017/Spring 2018) • UAB TRIP Lab - Driving Program (Alabama) • What are other sites doing for Adults? Do LEND directors know? (MCHB LEND might have information) 	

Recommendations for future action by each grantee group

Research

1. What are the adults’ priorities?
2. Collecting data on who has ASD so you have the data and can reach them once they leave school

State Systems Change

Training

1. In-service/ Pre-service
2. Community based outreach