Small Group Discussion Notes

**Topic:** Overcoming Barriers to Access for Underserved Communities – Racial, Ethnic and Cultural Minority Groups

### Existing Resources

- UCLA Center for Autism Research: currently conducting project on school transition
- NJ LEND program: currently conducting research on underserved minorities particularly with Latino/Latina populations
- WS LEND program: State’s first autism family advocate through a grant from HRSA (project specifically for underserved populations)
- WA Autism Alliance: WA is a very diverse but stratified state; many families in the area who are migrant workers
- University of Delaware: involved with LGBT rights and trained in African American history
- CO LEND Program: CO is not a very diverse state; constantly working to expand and attain trainees and staff from diverse backgrounds; a lot of health disparities between different regions of CO (metro, rural, frontier, etc.); many areas in the far east and in the far west and in the south, that are very poorly served
- Boston LEND Program: Boston very diverse with large immigrant and non-English speaking populations; a lot of community-based organizations (CBOs) in the area
- AR Regional LEND: trying to recruit minority students into the health profession (major initiative); Autism Satellite Program based in AR along the Mississippi River/Delta there are some of the most impoverished parts of the state and where there is also a large African American community
- UNC: involved with minority health issues
- Resources from local groups (i.e. churches, etc.) and professional groups (i.e. the National Society of Black Engineers)
- Grants to assess barriers in parent and community engagement/participation

### New Resources Needed from TA Centers

- Need for more incentives or sources for incentives for partnerships and participation
- Need for more bilingual and multi-racial multicultural centers to address diverse communities especially regarding medical issues
- Need to know how to more effectively form agencies
- Need to be able to move beyond assessments and evaluations into implementation/better bridge between assessments and evaluations of programs and implementations for improvements
- Need for better training to avoid tokenism
- Need to build system to be able to sustain momentum with families
- Need to constantly improve network for people to stay connected

(see other sections below for more potential needs for resources that TA Centers may be able to provide)
- Luncheons (i.e. with CBO directors, PCP program support, informational meetings etc.): to assess and evaluate the year’s efforts within various programs
- Project ECHO: for care providers (primary physicians, etc.) who particularly live far away (i.e. in New Mexico: support center-like program where individuals from all over the state would call in to speak with specialists)
- Resource centers for Spanish speaking families
- Video of diverse members of communities describing about the diagnosis process, the process of attaining resources, and areas for improvement
- State grantees in WA: Collaboration between the WA Autism Alliance (entrance navigation), Open Doors for Multicultural Families (only multicultural multilingual special health needs agency), NW Autism Center (delivers ADA): create trainings

<table>
<thead>
<tr>
<th>Obstacles or Challenges Experienced</th>
<th>Lessons Learned</th>
</tr>
</thead>
<tbody>
<tr>
<td>• In parent and community engagement: there has been difficulty in helping communities understand the incentive for participating in various programs.</td>
<td>• In parent and community engagement: Important to make sure that people’s time is valued; there is a need to provide some level of incentive for community participation, perhaps even asking communities what level of incentive would be necessary for participation) It sometimes does not occur to families that they need to be part of systems change, and thus there is a need to make the process as easy for families as possible.</td>
</tr>
<tr>
<td>• In communication and collaboration: Building relationships – takes a while (minimum: 1 semester, sometimes one year); Fellows and new CBOs have limited knowledge about LEND programs</td>
<td>• In parent and community engagement and in outreach: Importance of going into local groups within communities (i.e. in a church, etc.: for instance in AR working with Ministerial Alliance was helpful in getting connected with individuals who were looking for services such as diagnosis and interventions, etc.), and professional organizations within communities that are currently serving under-represented populations (i.e. the National Society for Black Engineers); importance with working with who/what the</td>
</tr>
<tr>
<td>• Participation: various projects (i.e. Project echo) Not attaining enough participation</td>
<td></td>
</tr>
<tr>
<td>• Attaining outreach to rural populations (not enough specialists in such areas)</td>
<td></td>
</tr>
<tr>
<td>• In parent and community engagement and outreach: Communities reluctant about participation (programs only here for a year – temporally – why should we participate?); issues with following up with families after initial contact/meeting</td>
<td></td>
</tr>
</tbody>
</table>

Overcoming Barriers to Access for Underserved Communities –
Racial, Ethnic and Cultural Minority Groups

#AutismCARES
• In working with families: Family pressures – how do we not add on to the existing pressures and burdens of families when seeking their participation in such programs?
• Within organization/organizational management: service delivery systems and agencies not well equipped in being a welcoming environment

community look to for information and trust; Importance of cultural brokering (i.e. in rural communities: often one or two leaders that initiative will have success if he or she supports initiative/program): importance in connecting/reaching out to community leaders with autism themselves or family members with autism
• In parent and community engagement and outreach: Allow communities to come in as the ones who are the providers of the information; Acknowledge that on the one hand there are universal institutional barriers in communities especially diverse multi-cultural communities, but on the other hand, everyone’s experience will be different
• In communication: Helpful to make sure that organizations that LEND Directors work with are also in communication with each other
• Luncheon: effective in meeting others working on the project; effective platform for collaboration and brainstorming; important to have similar practices where food is provided at events and/or lunch is provided at meetings and where meetings are located in multiple parts of an area/region/state especially areas where are far out from resources
• In outreach: importance of minimizing travel for participants (i.e. project echo: effective for minimizing referrals and time/expenses for travel); Importance of having staff members position in various areas across the state
• Within organizations: need to convince upper level management to integrate diversity and inclusion as a key priority
• With outlining goals: Need to equip communities to be self-sufficient
• In parent and community engagement/outreach: Importance of having ethnic diversity in leadership as a means of building relationships in the communities (i.e. community in AR with strong racial divide: having an African American
community leader and a White community leader working together was helpful in minimizing racial tensions; in Spanish speaking centers to have staff that are not only ethnically diverse but who also either have IDDs themselves or family members with IDDs
• Information dissemination: Constantly have to be in the know to be able to assist families as best possible
• Training: Not assume that students are better prepared than they are
• Assessment of communities: Very important: Need to evaluate strengths and assets of a community and not just weaknesses (high importance of strengths based model): build off the strengths in the community to improve the weaknesses

<table>
<thead>
<tr>
<th>Opportunities for Grantee Collaboration</th>
<th>Outside Collaborators</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Creating trainings and each agency is going to work on their areas of expertise (first time funding will play a huge role)</td>
<td>• National Center for Cultural Competence: leadership Training (very effective); monthly calls and TA meetings website: wealth of resources</td>
</tr>
<tr>
<td>• Importance of utilizing network of UCEDDs</td>
<td>• ACL funded community of practice: UCEDDs and DD Councils</td>
</tr>
<tr>
<td>• Community asset mapping: go out to different communities and map out what different communities and organizations are doing creating a foundation of an understanding of what resources are there to tap into (strengths based model)</td>
<td>• System change throughout the state to increase diversity in the field of DD: CA and WA having a kick off at the end of the month</td>
</tr>
</tbody>
</table>
Recommendations for future action by each grantee group

Research

1. Moving beyond identifying barriers:
   - Better connections between assessment and evaluations and implementations of suggestions
   - Evaluating different ways to overcome institutional barriers
   - Trying different types of interventions
2. Strengths based model
   - How to utilize strengths of a community to improve its weaknesses?
   - How do successful families do it? What works?
3. Parent and community engagement: participatory research: always being conscious of how others are interpreting your actions

State Systems Change

4. Supporting individuals with DD or allies (individuals with close family with DDs) who are currently in power or to be in positions of power
   - i.e. DE: governor is an ally because his niece has DD (why does it have to hit one personally for one to understand?)
5. Have constituents constantly coming forth and making their needs known
   - Support avenues for constituents to do so
6. Build rapport with legislators
7. Policy: identify pain points
   - Work towards convincing people that various programs know what to do with pain points
8. States are able to utilize 3 legs: board, person with disability, and UCEDD to come together
9. Community practice requires community partners
10. Breaking people out of their mindsets of what needs to happen
    - creating awareness that breaks down their preconceived ideas of what needs to happen
    - educating people
11. Need to integrate across systems so that when families access a system, they are linked to all the different systems that they may need; make it as easy as possible for families to link to all the possible systems they may need (i.e. when a family/individual acquires about a particular service or support system, they also are linked to information about all other services and support systems they may need)
12. States system change doesn’t have to be legislative: it can be grass roots, etc.
13. Make legislative simplified and working across agencies for implementation
    - Reduce bureaucratic barriers for families and individuals

Training

1. Understand that while there are universal institutional methods for training, each area in taking into consideration the racial, ethnic, cultural, linguistically differences, differences and histories will result in modifications to training
2. Finding ways to bridge gaps and misunderstandings between the culture of hospitals and culture of communities
3. Partnerships with other universities
4. Project Doc: families with individuals with disabilities give lectures to medical residents
5. Disability dialogues (monthly):
   - lunch is offered
   - a medical provider, a parent, and a child with disability: Medical Provider talks about giving the diagnosis, parent will talk about receiving diagnosis and what could have gone better, and child shares experience, and guidance counselor talks about working with families
6. Big need to educate health care professionals within the community in addressing the psycho social needs of families
7. In community training: at least one of the trainers represent that group (people with disabilities and other cultural groups represented)
8. Trainees need exposure to all levels of SES
9. Real case studies that takes a trainee from prior to diagnosis to diagnosis process to post diagnosis to providing resources
10. Trainees accompany families on day-to-day activities (i.e. at home, in restaurants, etc.)
11. Families come and class interviews the families
12. NCCC came and did trainings and seem so straightforward on paper, but how to go to the next level?
13. Trainees required to conduct a project in a community based organization (CBO) within a community that is not their own and does not have a similar culture to their own communities: exposing trainees to diverse settings