



## **Building a Network – A Call for Statewide Communication**

**September 28, 2006**

### **FINAL REPORT**

---

The Building a Network Statewide Conference was acclaimed a tremendous success by all who participated. From the facilities of the new Friday Institute at NCSU on the campus of the Centennial Middle School to the food to the presenters to the interaction of the participants – all aspects of the conference received outstanding marks on the evaluations.

The Conference offered an opportunity for networking and interaction both among the participants and between the presenters and participants. The presentations included information on resources as well as strategies for improving one’s communication abilities and how to communicate one’s issues to others. The presentation on TelAbility was unique in that a demonstration of the system was provided connecting the conference participants to the Tammy Lynn Center, a WATCH site for TelAbility, and the Wilmington CDSA in a scenario of a parent requesting augmentative communication supports for their child.

Assigned seating of the sixteen (16) tables of eight (8) – nine (9) participants assured a mix of perspectives from different areas of the state, different professional perspectives, parent perspectives and different agency perspectives. This planned arrangement received very positive feedback on the evaluation forms as it prompted lively exchanges of ideas and experiences.

## THE BASIC NUMBERS

1. 146 participants and we did have a waiting list which numbered four (4) on the morning of the conference even after increasing the original capacity number from 130 to 142. Despite anticipation of no-shows which we did have only five (5) and we had seven (7) people come that were not registered.
2. The following participant profiles and numbers were represented:
  - Parents (13)
  - Administrators (13)
  - Behavior Specialist (1)
  - Case Managers (11)
  - Community CBRS Providers (25)
  - Executive Directors/Directors (11)
  - Educational Diagnostician (1)
  - Family Liaison Specialist (3)
  - Nurses (3)
  - Occupational Therapist (4)
  - Physical Therapists (8)
  - Speech and Language Pathologists (4)
  - Service Coordinators (25)
  - Special Services Coordinator (5)
  - Pre-K Coordinator (1)
  - Program Manager/Supervisors (7)
  - Social Worker (1)
  - Teachers (4)
  - Office Manager/Secretary (2)
  - Students (4)
3. We had the following agencies/organizations were represented with the following being the primary affiliation:
  - DPH-EI Branch Office (1)
  - DPH-Children and Youth Branch (1)
  - DHHS-MHDDSAS (1)
  - NCPC (1)
  - NC ICC (2)
  - Regional Interagency Coordinating Council (1)
  - ECAC (1)
  - FSN –NC (2)
  - FSN- Other (7)
  - Partnership for Inclusion (1)
  - SNAP (1)
  - TelAbility (2)
  - Child Care Services Association (1)
  - Governor Morehead (1)
  - East Coast Migrant Head Start (1)
  - Developmental Day Centers/NCADD (34)
  - Children Developmental Service Agencies (20)
  - Local Education Agencies/Public Schools (5)
  - Public Health Departments (6)

- County Human Service Agencies (6)
  - Hospital/ Tender Health Care (2)
  - Local Smart Start Agency (3)
  - CBRS Provider Agency (11)
  - Therapy Agency (13)
  - Catholic Charities (4)
  - Home Day Care (1)
  - Meredith College (4)
  - Other (4)
4. We had folks from all over the state including the following cities other than the Triangle and Triad areas:
- Camden
  - Davidson
  - Eden
  - Elizabeth City
  - Forest City
  - Gastonia
  - Greenville
  - Hamlet
  - Hickory
  - Lawndale
  - Lenoir
  - Mooresville
  - New Bern
  - Newport
  - Polkton
5. The sponsoring agencies had the following participants present:
- NC Association of Developmental Day Directors (NCADD) (12)
  - Wake Local Interagency Council ( LICC) (24)
  - Pediatric Therapy Associates (4)

## CONFERENCE EVALUATIONS

The evaluations were overwhelmingly positive from the presentations and format of the conference seating to the facility, the lunch and snacks served, and even the flowers on the tables (made by the children at Learning Together). There were of course a few comments about temperature, breaks, etc. that are typical as it is hard to meet all the needs of a large group of individuals. A sampling of the comments on the conference includes the following:

- The speakers were fabulous and it was wonderful to meet such a savvy group of intellectual individuals who are so passionate about what they do
- To find out that the gap in communication across the state is being addressed with actual solutions and sharing activities that are important in order to make this move and bridge the gap.
- It was an honor to attend this conference. (these exact words were offered more than once)
- Loved getting together at the tables and talking about issues

- Collaborating with other professionals and families from around the state
- Interactive communication of and with the audience and networking opportunities were wonderful
- This was by far one of the best conferences I have ever attended
- Everybody needs to be at a meeting like this
- I am new to the state and amazed at the differences state to state and (within NC) county to county. Everyone everywhere seems to have to fight for funding. Very sad! Very educational. This was good networking!
- The interaction of parents and professionals was what I liked best.
- Well organized and seemed to run smoothly. It was obviously well planned
- There was a consistent correlation between objectives, presentations and presenters. Congratulations!
- This conference was energizing (These exact words were offered by more than one person)
- Critical conversations! Table and group discussions were facilitated by the mix/assignment of folks by discipline, agency, perspective, and geography.
- Thanks for the conference. It makes me inspired to be more a part of the effort!

## **BARRIERS TO COMMUNICATION**

---

The following are barriers that were identified by the participants at the Building a Network – A Call for Statewide Communication Conference. The responses were compiled and organized by those encountered by Families and Providers and then those deemed to be faced by the “System.

### **BARRIERS FOR FAMILIES**

- Being in a box and not stepping out, being overwhelmed by the situation, transportation, lack of phone, language, limited abilities, cultural differences.
- Recruitment - providers won't go to rural areas
- Lack of recognition of parents abilities (i.e. therapy)
- Case load volume leads to lack of time to truly communicate with families or coordinate services/transition
- Problems for families with multiple children having multiple needs; lack of family's comfort zone with multiple providers; or multiple agencies for one child
- Human services agencies not making referrals or educating parents

### **BARRIERS FOR PROVIDERS**

- Overwhelmed by all the regulations, changes in the regulations/system, shuffling among agencies, turnover, thinking outside the box
- Limited time, size of caseloads, travel time
- Providers: Overloaded/understaffed with 40 plus cases requiring direct treatment/monthly communication/coordination
- Limits on providers: Unable to provide coordination/communication even in discipline specific needs (example equipment) due to fiscal limitations on providers
- Too much information or not enough information

### **SYSTEM BARRIERS**

- Eligibility criteria has changed
- Each service agency has it's own interpretation of the eligibility criteria/definitions
- Family and professional/agencies have limited knowledge of system or other solutions/possibilities. (or family/agencies don't go seeking additional knowledge)
- Services vary from county to county
- There is often a diagnostic/professional difference of opinion regarding the services the child needs
- Lack of shared vision and support between EI (Part C) and Preschool (Part B) services
- Political will---those with power don't know about or care enough about this issue to put money/services behind them. Fend for themselves kind of attitude
- CDSA's are too protective of their resources - lack of flexibility to do things different by not thinking outside the box
- Lack of coordination of appointments among all people/agencies

- Prioritizing competing issues (family overwhelmed with priorities—each service agency probably believes their issue is most important)
- Hard to find common ground to have a discussion with so many issues
- Competing boundaries and limitations within each agency
- Changes in eligibility criteria
- Each service agency has it's own interpretation of the eligibility criteria/definitions
- Family and professional/agencies have limited knowledge of system or other solutions/possibilities. (or family/agencies don't go seeking additional knowledge)
- Services vary from county to county
- There is often a diagnostic/professional difference of opinion regarding the services the child needs
- Limited/tight budgets of EI system
- Physicians not informed as to resources
- Lack of fiscal resources for education/coordination
- Too many “cooks in the kitchen” primary care physicians/coordinators/providers/others
- Primary Pediatrician/family physician not adequately included in the process
- Coordinators overloaded/understaffed with 40 plus cases on caseload requiring communication/coordination
- Lack of cross utilization of skills of job duties of the team: coordination versus treatment and this lack of opportunity to practice both components of patient care (coordination versus provision of care) creates a barrier to effective communication for the team due to less empathy for different goals/ objectives paperwork versus treatment goals
- Families/Providers may not understand EI system/Redesign changed priorities and funding/more resources for paperwork/communication by service coordination/limited (no) resources for communication (indirect time) by providers. Indirect time was initially planned then cut during redesign
- Funding issues: POMCS- requirements/procedures, travel reimbursement limited collaboration/attendance at meetings, distance/time

## **STRATEGIES FOR IMPROVEMENT**

---

The following are the strategies identified by the participants and offered for consideration by the various state agencies, local communities, providers and families to improve the services available to children birth to five years of age at risk for or with a developmental disability and their families. The strategies are organized by various approaches and techniques.

### **INVOLVING THE COMMUNITY**

- Help the existing community to be in the loop: pediatricians, churches, other programs
- Provide more public awareness information
- Have community meetings
- Use LICC as a forum to streamline the process in each community.
- All providers attend meetings - everyone contribute - networking
- Reduce duplication of services – consider any meetings that may be combined

### **TOOLS TO FACILITATE COMMUNICATION**

- System for sharing information, such as an interagency database with information (could CECAS be used??)
- Video and phone conferences to encourage participation when can't physically be there
- Consistent training schedule and topics to the EISC staff and service providers so they are getting the same information and have opportunities to ask questions
- Establish advocacy groups if feeling "voiceless"
- Make communication for families/providers and service coordinators more efficient through paperwork reduction
- Revise handbook for EI to reflect up-to-date information

### **COORDINATION OF SERVICES ACROSS PROVIDERS**

- Look outside agencies for a coordinator of services. Someone who is invested in the family (another family member, faith community, volunteer service agency—as identified by family)
- Having one agency coordinator understand the need for integrated communication and decides to take lead to coordinate services
- Create coordination agencies for just this purpose
- Have families sign interagency release so can readily share information
- Use communication/coordination resources as per family need. Survey families. Ask about their need for communication with their service coordinator, with and among their providers.

### **INFORMATION ISSUES – EMPOWERING THE FAMILY**

- Change the approach by better explaining the EI system to families. Take time to answer questions.
- Empower parents to be advocates for their child to improve communication barriers including resource needs

### **TRANSITION ISSUES**

- Consistent implementation of procedures around transition
- Transition information (brochure) needs to be updated by the EI branch

- Bullet points to talk with families about info from CDSA and public schools (for providers). Create a transition checklist for families so they know what to expect and how to prepare
- Coordinate meetings between EISC and Preschool Services
- Communicate with the new state ICC subcommittee on transition
- CDSA's provide public school staff with a running list of kids in ITP turning three so can be prepared/work more collaboratively with the CDSA staff

## **AVAILABILITY OF SERVICES/FUNDING ISSUES**

- Need more time to spend with the families: Increase time allocated to providers to allow more time per visit.
- Use communication/coordination resources as needed: Some children/families will need 90% of resources for coordination/communication with their service provider and 10% of resources for their provider. Other families can provide their own communication/coordination (due to family education, family physician) and need 10 % for coordination communication and 90% for provider communication.
- New funding for EI added by legislature: Allocate percentage for community care/communication and percentage for coordination communication as per family needs survey
- Petition legislature to allow participation in meetings to be billable for all
- Education to LICC's so they can advocate with the legislature
- Other funding sources i.e. insurance
- Provide parenting skills for families in need.
- Use the System of Care Model
- Use of natural supports – determine family strengths and needs - find out who has expertise/resources to help and connect with them
- Framework for identifying all kinds of resources
- Utilize LICC/FSN
- Work with nearby CDSA to bring providers over to another region
- CDSA share their resources i.e. speech therapist
- State employ regional specialist for consultation to providers
- Empower the family to take responsibility and advocate for what they and their child needs. Encourage the family to research other resources
- The whole is greater than the sum of its parts. More efforts need to be put into coordinating services, increasing resources to encourage and facilitate person to person/agency to agency coordination.

## A CALL TO ACTION - *“Where do we go from here?”*

---

### COMMUNICATION IS CRITICAL

The Statewide Conference on September 28, 2006 clearly indicated the need for communication as expressed in the following statements:

- Opportunities need to be provided on a routine basis both statewide and locally.
  1. Annual conferences to address “where do we go from here”
  2. Definitely offer in all the areas of the state at least two times a year!
  3. Empower LICCs or RICCs to facilitate these conferences.
  4. Continue emphasis on communication and collaboration and political engagement and advocacy.
- Conference participants stressed the need for more interactive conferences like this to inspire continued networking and action.
  - The emotion /feeling of all the participants was moving.
  - It definitely should move everyone to exercise their right to vote!
- Family focused conferences are needed – bring parents and professionals together. Empower parents to answer all the questions asked.
- Communication from the state to community agencies and communication among agencies is critical. (i.e., an example cited at the conference was that there are EISCs, Day Care Providers, etc. who recognize a tremendous need for better communication among and between service providers for children and families.
- Distribute concrete “advocacy” opportunities for specific dates and times...perhaps a listserv operated by TelAbility and funded by the EI Branch.
- Discussions regarding the relationship/communication between LICCs/RICCs/NCICC and how they relate not only to each other but also to the EI System (state) proper needs to occur.

### SUGGESTED EI BRANCH ROLES TO PROMOTE BETTER COMMUNICATION.

- Form a task force of family representatives and providers work with the EI Branch on **reestablishing** a system of communication for providers across the state rather depending on the website for communication. Smaller agencies do not have the staff or staff with time to look for changes nor needed information.
  1. Information affecting services should be sent to all who are providing such or involved in the system.
  2. There are still lots of questions that need to be answered in order to provide funding and appropriate care for children. The EI Branch needs to reinstate a regular newsletter/update vehicle that offers Q & A opportunities to families and providers.
- Outline how the EI Branch communicates /collaborates with other groups/agencies that can be of support in meeting EI’s mission (i.e., businesses, community colleges, universities, professional associations, etc.)
- Ensure that “safety net” medical providers receive information about EI services as well as regular pediatricians, family practices. (Safety net providers include federally funded community health centers and free clinics for more information).
- Offer opportunities for providers to learn about all agencies that are available to their clients (a Child Care Subsidy Worker reported no knowledge of many EI services)
- Develop ways to increase providers in rural areas.
- Increase strategies to reach non-English speaking families.

**A Thanks goes to all who helped to make the  
“Building a Network – A Statewide Call for Communication”  
Conference from the conference sponsor organizations!**

**NC Association of Developmental Day Directors (NCADD)**



**Wake County Local Interagency Council (LICC)**



**Pediatric Therapy Associates (PTA)**

