Arkansas Legislative Task Force on Autism
Report on UAMS Department of Pediatrics CoBALT Project

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1. What is CoBALT? <u>Community-Based Autism Liaison and Treatment</u> (CoBALT) Project

The CoBALT Project is designed to add to the state's second tier developmental evaluation capacity, in order to improve efficiency of referrals to Early Intervention services; and to boost diagnostic capacity for early-presenting developmental problems such as autism.

This UAMS program is currently funded by DHS / DDS Recovery Act funds. These funds will facilitate training of nine mini-teams by the end of 2011. Expansion and maintenance of the project will require renewal of funding.

2. Who is in charge of the CoBALT Project?

The project manager (principal investigator) is Dr. Eldon Schulz, the endowed Rockefeller Chair for Developmental Pediatrics at UAMS. Several faculty and non-faculty members of the UAMS Department of Pediatrics diagnostic teams at DDC have development and training roles within the project. The Project also utilizes the expertise of administrators from DDS CMS, El/First Connections, and Department of Ed Early Childhood programs for relevant areas of training. In addition, Information about research is provided by speakers from ACHRI, and about family support resources by speakers from AAROC.

3. Reasons for the CoBALT Project

Many eligible children in Arkansas are not referred for Early Intervention services. This is due in large part to inefficient triage of children into appropriate developmental, medical, behavioral and/or mental health services; and misunderstanding by parents and providers of referral requirements to El services (e.g., belief that a formal diagnosis is needed prior to referral, when such a diagnosis is necessary for El evaluation for services).

There is now a Federal mandate to perform "First Tier" Developmental Screenings by primary care physicians of all children at 9 months, 18 m, and 24 to 30 m, and "Autism-Specific" screenings at 18 m and 24-30 m. We expect increased numbers of first tier screenings will mean significantly more referrals for second tier evaluations. The increasing number of referrals is already taxing the diagnostic capacity of the primary diagnostic center in the state (UAMS JL Dennis Developmental Center). The result is increased waiting times for evaluation, and (because of misunderstanding of referral requirements) significant delays in initiation of El services, which could adversely affect outcome for many children and families.

Additionally, there are "Diagnosis-Specific" resources (such as Wavier programs) that are driving need for program-specific diagnosis. This further contributes to bottleneck of access to the UAMS diagnostic center (DDC).

Slow referrals, long waiting times, and lack of information contribute to family frustration. Families need local providers who are knowledgeable about the child's diagnosis, and knowledgeable about local resources. CoBALT trained Teams are given the knowledge base and information about resources, and are introduced to program personnel for EI, EC, DDS CMS, etc., to facilitate direct network building among those entities, which should result in much more effective communication.

We expect to see enhanced family support and education, better community awareness of and support for local children who need early intervention, and less stress for families who won't have to make as many trips to central Arkansas before they can get help for their children.

4. Who is on a mini-team?

Teams so far have consisted of a pediatrician and a speech/language pathologist. Other team members may arrange to attend the training (as one of our June teams brought a nurse with them), but the third member will not be financially supported in the training.

5. Who decides who / where / how to recruit teams for training?

Dr Schulz is recruiting the first nine teams for training. He has been able to recruit pediatricians who already have interests in serving children with developmental disabilities.

6. How are we insuring involvement of all parts of the state, especially the Delta region?

Dr. Schulz is recruiting from all across the state. For those parts of the state that have limited physician coverage, such as parts of the Delta region, UAMS outreach teams will continue to support local community providers as long as necessary until CoBALT teams can be recruited or expanded into those areas. (Families from those areas still have access to diagnostic teams at DDC.)

The first training session took place in early June, and included a team from El Dorado (Dr Robin Ray) and two teams from Jonesboro (Dr. Jane Sneed and Dr. David Matthews).

The next session is planned for mid-October, and will include pediatricians from Helena-West Helena (Dr. Jill Pillow); Texarkana (Dr. Belinda Hutcheson), and Ft. Smith (Dr. Jon Hendrickson).

The third session date has not yet been set. Teams are still being recruited.

7. How will we incorporate the AHECs?

The AHECS are a referral source for the Cobalt sites. So far all our teams have come from areas with an AHEC. We anticipate that there could be increased collaboration between the local CoBALT team and the AHEC physicians, as activity in the CoBALT clinic increases. The only AHEC site with an associated pediatric clinic is the Southwest site in Texarkana (UAMS Southwest "All for Kids" Pediatrics Clinic). One of the pediatricians at that site will be in our next training class. This will provide a stronger link between the two UAMS entities (CoBALT and AHEC) that should prove valuable to the community.

As we develop the telemedicine piece of this project (see below), we will look to the AHEC sites as logical partners in implementation of the tele-health component, since they already have infrastructure in place.

8. Is the training open just to pediatricians, or to any MD? Is it open to any other clinicians, such as nurses?

We expect to include physicians as part of all teams. Other team members can be from other disciplines, and we encourage SLPs particularly to be part of the trained team. We have not so far recruited non-physician practitioners, such as APNs, separately from physicians. Because of the way Part C is written with respect to "Medical Services," that is, "only for diagnostic or evaluation purposes provided by a licensed physician to determine a child's developmental status and need for

early intervention services," reimbursement to these teams as they establish these clinics may require that a licensed physician be part of the team.

We expect that pediatricians will be the first participants, as they are by training more familiar with the spectrum of developmental delays. There is no firm requirement that physicians be limited to pediatricians, only that the physician has experience in assessing young children with developmental delays, and an interest in expanding diagnostic skills and being a knowledgeable provider of El referrals and family support.

9. Goals of the CoBALT Project

The primary goal is to train and support community-based mini-teams to perform Tier II evaluations for more rapid enrollment into EI/EC services. Teams are trained in autism diagnostic assessments, and as their new skills mature, they can confirm diagnosis of some children on site. At least as important is that increased diagnostic awareness will make the teams more sensitive and specific to the need for which children should have more comprehensive diagnostic assessments, in addition to early intervention services. With more knowledge about the diagnostic process and the comorbidities that accompany ASDs, these teams will be stronger community resources for families, schools, and care providers.

10. Will we incorporate telemedicine?

Another important goal for the CoBALT Project is to develop Tele-Health support to the mini-teams. Tele-Health technology is planned for use in training and updates, continuing education, clinical consultations, evaluation and quality controls of the Cobalt sites, and as an additional source of billable activity. We expect to join the ongoing efforts at UAMS Center for Distance Health.

11. How will the teams get referrals for evaluations?

We expect referrals to be both internal, from the physicians' own practices; and external, from the surrounding community, and also from UAMS DDC, feeding back eligible children to the CoBALT Teams that may have been referred to DDC by a clinic unaware of the CoBALT Team available in their area.

12. Expectations/Performance Indicators

We expect to have trained nine teams by the end of 2011. Each team is expected to see 6-8 children per month for evaluation (after ASAP ramp-up period).

Teams will make referrals to DDS (EI) (or the Early Childhood Program, depending on age at referral) with enrollment in collaboration with parents' wishes. Team performance will be monitored to ensure implementation and schedule control; to track numbers of children/families served; and to track physician/team hours worked.

The CoBALT project manager will report quarterly to DDS. We will look at changes in Early Intervention access, including numbers of referrals from the CoBALT teams, time frames from identification of need to receipt of services, and some measure of cost effectiveness. The Project manage will obtain onsite evaluations of each CoBALT team with Continuous Quality Improvements (CQI) monitoring completed that includes a chart review of a representative sample of the children served at each site. Details of this monitoring methodology are being refined by Dr. Schulz and his staff. The first CoBALT teams will have the first monitoring visits within the next 4-8 weeks. (see Appendix A)

At this time the El Dorado Team has secured a clinic site for the evaluations and will be scheduling patients within the next month.

13. What are the future plans of the CoBALT Project?

Future plans that will require ongoing support include a) implementation of the Tele-Health component; b) support and maintenance of existing teams; c) refining the training component as indicated by analysis of outcome measures and success of the teams in practice; d) training additional teams as needs and interest manifest.

We envision A CoBALT Hub, with trained regional providers linked to UAMS Developmental Pediatrics for training, support, continuing education, and clinical consultation. This hub model has already proved successful in other UAMS Programs such as The Center for Rural Health/AHEC Programs; The Antenatal and Neonatal Guidelines, Education and Learning System (ANGELS) Program; The Arkansas Stroke Assistance through Virtual Emergency Support (Arkansas SAVES) Program; and the Pediatrics in Schools Program.

14. What are the cost projections for phase two of the CoBALT Project?

Being still in the pilot phase of the project, we do not yet have these numbers. We will be determining projected expenditures for phase two as we accumulate and analyze more concrete data from the pilot.

Appendix A

Proposed Quality Questions to be used for CoBALT Project monitoring:

- QQ1: Have you been contacted since completing CoBALT training?
- QQ2: Do you have the tools to provide diagnostic evaluations and appropriate referrals of patients suspected of developmental delays, including Autism?
- QQ3: Do you have a team in place to utilize a multi-disciplinary approach toward diagnostics and treatment?
- QQ4: Do you have more than two team members?
- QQ5: Do you think a non-physician practitioner, such as an APN, could help you in your practice serving children with disabilities?
- QQ6: Do you feel you can provide diagnostic evaluations for developmental delays, including Autism, to the region of the state you serve and make appropriate referrals?
- QQ7: Do you have an intake system in place for scheduling appointments for your diagnostic and treatment services?
- QQ8: Have you seen any children yet?
- QQ9: Have you made any referrals to Early Intervention yet?
- QQ10: Are you ready to accept referrals from UAMS to perform diagnostic evaluations?
- QQ11: Are you ready to accept referrals from the AHECS to provide diagnostic evaluations and treatment services for patients suspected of developmental delays, including Autism?
- QQ12: Have you ever used any type of telemedicine technology in your practice up to now?
- QQ13: Are you interested in participating in Tele-Health technology for ongoing support of your team, which could include training and updates, continuing education, clinical consultations?
- QQ14: Do you intend to continue as a certified CoBALT team, providing diagnostics and treatment services and making appropriate referrals for children suspected of Developmental Disabilities and/or Autism?