

**VIRGINIA INTERAGENCY COORDINATING COUNCIL
MEETING MINUTES
Virginia Association of Community Services Boards
Glen Allen, Virginia
February 13, 2008**

The Chair of the Virginia Interagency Coordinating Council (VICC), Rick Beaman, called the February 13, 2008 meeting to order. Karen Durst called the roll. Thirteen (13) VICC members were present. (Please see the attendance sheet following the minutes).

Dr. Colleen Kraft provided a power point presentation on autism. The basics of autism were provided including the following:

- The onset of autism occurs during the first three years of life;
- Autism is a chronic, lifelong disorder;
- The male to female ratio is 4:1;
- There is a spectrum of severity with autism;
- Autism is a neurodevelopmental disorder with a biological basis; and
- There are genetic factors in etiology.

Based on the Diagnostic and Statistical Manual of Mental Disorders-IV (DSM-IV) Core Characteristics, the criteria for autistic disorders are:

- Deficits in reciprocal social interaction;
- Impairments in verbal and nonverbal communication; and
- Restricted, repetitive or stereotypical behaviors and interests.

There are five (5) specific spectrum diagnoses used by the DSM-IV. They include:

- Autistic disorder;
- Asperger disorder;
- Rett disorder;
- Childhood disintegrative disorder; and
- Pervasive developmental disorder-Not Otherwise Specified (PDD-NOS).

Dr. Kraft shared that there has been an increase in the prevalence of autism spectrum disorders. Rates are 3-4 times higher than in the 1970s and 1.5 times higher than in the 1980s and 1990s. The proposed explanations include better identification, sensitive diagnostic tools, a broader classification system and environmental factors.

The diagnosis of autism is often not made until 2-3 years after symptoms are recognized. Identifying children with autism and initiating intensive early intervention during the preschool years results in improved outcomes for most young children. Dr. Kraft shared that developmental surveillance and screening should be performed on all children. She also stated that a study that combined parental concern with a standardized parental report was found to be effective for early behavioral and development screening in the primary care setting.

Autism can be identified in very young children. Because parents are the experts regarding their children, eliciting and valuing parental concerns is imperative.

The following recommendations were shared by Dr. Kraft:

- Developmental surveillance should be performed at all well-child visits;
- Recommended developmental screening tools include the Ages and Stages Questionnaire, the BRIGANCE Screens, the Child Developmental Inventories, and the Parents Evaluations of Developmental Status;
- Because of the lack of sensitivity and specificity, the Denver-II and the Revised Denver Prescreening Developmental Questionnaire are not recommended for developmental surveillance;
- Further developmental evaluation is required if a child fails to meet any of the following milestones:
 - Babbling by 12 months;
 - Gesturing (e.g., pointing waving bye-bye) by 12 months;
 - Single words by 16 months;
 - Two word spontaneous (not echolalia) phrases by 24 months; and loss of any language or social skills at any age;
- Siblings of children with autism should be carefully monitored for the acquisition of social communication and play skills and the occurrence of maladaptive behaviors; and
- Screening specifically for autism should be performed on all children failing routine developmental surveillance procedures using one of the validated instruments such as the Checklist for Autism in Toddlers (CHAT) or the Autism Screening Questionnaire.

Dr. Kraft concluded her presentation with the following Autism Guidelines:

- Screening with surveillance should occur with best-practice indicating that all children be screened for autism spectrum disorders at 18 and 24 months of age;
- Parental concerns should be elicited and are valuable;
- Specific medical testing may be needed;
- Referral of children with possible autism spectrum disorders should be made for further diagnosis; and
 - Children should be referred to a developmental pediatrician and
 - Referrals should be made to Part C and to the school system.
- Coordinated care and a medical home should be established.

The complete power point presentation by Dr. Kraft is available on the Infant & Toddler Connection of Virginia website at www.infantva.org.

Discussion that followed Dr. Kraft's presentation included:

- Are enough developmental pediatricians available;
- Younger siblings of children with ASD should be monitored more closely;
- Intervention for children with ASD should be individualized and provide opportunities for engagement;
- The Virginia Association of Pediatrics does not support a specific frequency of intervention for children with autism;

- There has been no conclusive evidence that vaccinations cause autism;
- Professions that are recommended for diagnosing autism include, developmental pediatricians, neurologists, psychiatrists and some psychologists;
- Through continuing education efforts, more physicians are aware of the need to screen for ASD and are completing screenings; and
- Some individuals have seen improvement in autism through a casein and gluten-free diet.

On behalf of Delegate Valentine, Cindy Summers then shared information about the co-sponsorship by Delegate Valentine of HJR 105. The Joint Resolution directs the Joint Legislative Audit and Review Commission to study autism services in the Commonwealth. The purpose of this two-year study is for findings and recommendations to be made related to improving the delivery of autism services in the Commonwealth, including training and education of law-enforcement and judicial personnel. The Joint Resolution has passed the House and is now in the Senate.

Information was also shared by Mary Ann Discenza regarding a committee on autism that will be brought together by the Virginia Association of Community Services Boards (VACSB). This committee will be co-chaired by Mary Ann Discenza and Alison Standing and will focus on serving individuals with autism through the lifespan.

Discussion was held regarding existing committees that are addressing issues related to autism and the need to be connected with others. The issue of whether the VICC Autism Committee should join with the VACSB Autism Committee was discussed. Sheri Osbourne made a motion that the Autism Committee of the VICC merge with the VACSB Autism Committee. Phyllis Mondak seconded the motion. The motion was approved. VICC members volunteering to serve on the committee include Joanne Boise, Debra Holloway, Sheila Nelson, and a representative from the Department of Education, either Phyllis Mondak or Marie Ireland.

Discussion followed related to the provision of early intervention services for individuals with autism. The discussion included the following:

- Autism is a very complex and challenging issue and consideration must be given to what is best for a child;
- The intent of early intervention is developmental and services must be individualized; and
- Individual service planning must occur and should be evidence-based; and
- Some physicians have been prescriptive related to the frequency and intensity of services which often leads to frustration by the families.

Delly Greenberg then reported on the upcoming VICC Retreat which will focus on personnel shortages. She stated the following:

- The purpose of the Retreat is to identify the problems related to personnel shortages and for recommendations to be made;
- A complete understanding of the issues involved related to the personnel shortages must exist prior to the Retreat;
- Retention of employees/providers should be included;
- A questionnaire has been developed by the Retreat Committee for the 40 local systems to complete that includes questions about shortages, hiring efforts, etc.;

- A section of the questionnaire includes information to be provided by the State Part C Office; and
- University systems will be included in the discussions related to personnel shortages.

Mary Ann Discenza shared that the Governor's Early Childhood Initiative's Home Visiting Consortium has been meeting and has received support from the Governor's Working Group. She stated that James Madison University has been collaborating with the Home Visiting Consortium about collecting information about training and professional development of the various home visiting agencies and the data that is collected will assist in developing a gap analysis of training and help to formulate an interagency training plan to include the development of core competencies for individuals providing home visiting services. It was suggested that this existing informational process may be helpful in looking at the personnel shortages and would eliminate the need to duplicate such a program.

The following discussion occurred:

- Anticipated changes in the aging work force should be considered in looking at personnel shortages;
- Challenges exist related to the training of providers including payment for the time spent in training, coaching of providers and supervision for sustainability;
- Training and retention is a related focus of the personnel shortages;
- Data from the work of Solutions indicates that employees/providers in the early intervention system are staying for longer periods of time;
- The location of the Early Intervention Conference may be an issue for some providers attending and therefore, they may be missing that training opportunity;
 - The VICC Chair asked if it would be possible to obtain information on the number of providers who attended the 2006 and 2007 Early Intervention Conference and what their provider disciplines were. Mary Ann Discenza will check into obtaining this information.
- Could training be provided electronically;
- Part C Monitors have been gathering data on strategies used for addressing provider shortages; and
- Data from Solutions may be helpful in looking at personnel shortage issues.

Next steps in preparing for the Retreat include:

- Sending out the Personnel Survey which will be done through CoCoA;
 - Karen Durst will first add questions to the survey that were identified during the discussion related to training and the future of the work force and then forward the survey to Carol Granger as the CoCoA Chairperson.
 - CoCoA will send the survey to all local system managers and will request that it be returned to CoCoA within two weeks.
 - CoCoA will follow-up with those systems that do not respond.
 - CoCoA will send the finalized surveys to the Part C Office.
 - Final information will be sent to the VICC Retreat Committee.
- Mary Ann Discenza will contact Camille Catlett about facilitating the Retreat.

Public comment was received.

Susan Shaw, the System Manager for the Infant & Toddler Connection of the Blue Ridge spoke. The following italicized information is verbatim from the written report provided:

I would like to state that I agree with the CoCoA comments and recommendations. I do feel that we in the field need more guidance in working with children with autism and there needs to be more consistency among children and across early intervention systems (given that we individualize services for each child).

I have appreciated the support I have received from my Part C Technical Assistant when trying to work through requests for intensive services. But, generally, I don't think we feel we have "permission" to provide intensive services for children with autism. I also worry about the cost in that I quickly calculated on the way here that if I provided intensive services for the number of children that we currently serve it would be an additional \$100,000 that is not in our budget. Perhaps I need to start to estimate the cost and budget for it and or request funds. I am concerned that if we use the figure of an average of 30 hours per year of services, that this would not be an accurate reflection to base future costs to the system if we "opened the doors" to intensive services. Thank you.

Following lunch, Debra Holloway, Manager of the Family Involvement Project, presented the Family Report. The following italicized information is verbatim from the written report submitted.

The Family Involvement Project staff continues to be active participants on the VICC Steering Committee, VICC Advocacy Committee, Management Team, ITC Conference Committee, Infant and Child Mental Health Committee, The PTP of Northern VA workgroup, The Family Involvement Project Workgroup, the System of Payments Workgroups, the Hearing Workgroup, Monitoring and Supervision Stakeholder Committee, Child and Family Services Advisory Group and local and regional council meetings.

The Family Involvement Project continues to host our workgroup meeting consisting of our staff and parents working as liaisons on the local level. We have begun discussion and work on a "Transition Notebook" for families and continue to share ways to help families become more involved.

The Family Involvement Project is pleased to announce the Family Support Fund! We are offering to help cover the cost for families to attend the Sixth Annual Creating Connections Conference, please spread the word!

The Family Involvement Project is pleased to announce the Natalie Fleet is our new Tidewater Region Parent Representative, please welcome her!

A question was presented regarding how the assistance was being provided to families for attendance at the Early Intervention Conference. Debra Holloway reported that the Family Involvement Project was looking at how many requests were received from families for

assistance in order to determine what amount would be provided for each family. Assistance would be directed toward hotel expenses.

An update was then requested from the By-laws Committee. It was asked that this agenda item be moved to the March meeting. The By-laws Committee update will be added to the March VICC meeting agenda.

Representatives from CoCoA were invited to the VICC meeting in order to provide further information and to engage in discussion related to CoCoA's public comment on autism at the December 12, 2007 VICC meeting. Alison Standring and Carol Granger participated on behalf of CoCoA.

The CoCoA representatives provided the following information:

- Contact has been made with 12 states to gather information related to guidance provided on early interventions services for children with autism;
- Local System Managers provided a list of desired outcomes for autism;
 - It was noted that this information was gathered in a short time in order to report at this meeting.
 - Local system managers are looking for guidance on the process for serving children with autism. Information is requested on what needs to occur initially and how to make better decisions for serving children with autism; and
 - Consistency is needed across the state.

Discussion included the following:

- Individualization of services is required;
- Training and funding are areas of concern;
- Some areas do not have developmental pediatricians readily available in their communities and getting a diagnosis is often difficult;
- Research indicates that there is a need for more opportunities for engagement for children with autism;
- Does the engagement need to come just from early intervention or does it include all of the other individuals involved with a child;
- Applied Behavior Analysis (ABA) only measures what is being done and not other outcomes;
- There is a need for social and functional skills and generalization;
- The Supports and Services document addresses services for all children and not just those with autism; and
- Is there a possibility of changing the requirements for personnel standards so that with additional training early intervention assistants could assist with providing services for children with autism?

Next steps were then identified. They include:

- Determining if the supports and services guidance need to be updated;
- Exploring the use of paraprofessionals in providing opportunities for engagement for individuals with autism;
- Looking at credentialing for daycare providers, etc;
- Exploring if the draft federal regulations address serving children with autism;
- Exploring if the provision of services to children with autism by paraprofessionals would be billable under the new Medicaid Initiative;
- Giving the list of desires from local system managers related to autism to the VACSB Autism Committee to address;
- Exploring certification;
 - A list of core competencies for serving individuals with autism was developed by the Autism Council and addresses the lifespan.

Additional discussion related to autism included the following:

- There is a need for collaboration for treatment between physicians and Part C;
 - Physicians can be engaged in service planning; and
 - The education of physicians about Part C is needed for an understanding of what early intervention is about and that it is not necessary for Part C to provide all services.
- The problem needs to be defined;
 - Are there not enough services for children with autism and if that is the problem, what type of process is needed to get the services;
- There is a need for strengthening collaboration and building relationships with all of the other agencies that are serving children;
- The issues to be addressed through the VACSB Committee will be foundation work; and
- How will the Communities of Practice and the Mental Health Initiative interface with the VACSB Committee?

The following is a list of follow-up activities to be completed:

- Karen Durst will electronically send information on HJR 105 to the VICC members;
- Karen Durst will electronically send the power point by Dr. Kraft to VICC members and CoCoA;
- Karen Durst will add the suggested questions to the Personnel Survey and forward it to Carol Granger for distribution to local system managers by CoCoA;
- CoCoA will disseminate the survey to local system managers with a deadline for returning the within two weeks;
- CoCoA will follow up with those systems that do not return the survey;

- CoCoA will send the results to the Part C Office;
- The Part C Office will provide the information to the VICC Retreat Committee;
- Mary Ann Discenza will explore the draft federal regulations related to serving children with autism and will contact Mike Beerman from the Special Education Advisory Committee.
- Alison Standring will provide Karen Durst with information from the American Academy of Pediatrics (AAP) regarding recommending a frequency for engagement opportunities in serving children with autism. This information will be forwarded to VICC members;
- Karen Durst will provide Alison Standring with contact information for VICC members serving on the VACSB Autism Committee;
- Alison Standring will provide those members with information on the meeting date and location of the VACSB Autism Committee; and
- Mary Ann Discenza will obtain information for the VICC regarding providers attending the 2006 and 2007 Early Intervention Conferences.

Agenda items for the March 12, 2008 were identified:

- Sue Mackey Andrews will be attending and will provide an update on the work of the Stakeholder Groups;
- An update from the Autism Committee will be provided;
- Information for VICC decisions will be provided in advance and addressed at the meeting;
- An update will be given by the By-laws Committee; and
- A report on the work related to the Annual Performance Report/State Performance Plan (APR/SPP) will be sent electronically or mailed.

The Part C Monitoring Consultants will provide information at the April 09, 2008 VICC meeting as well as information from the Part C Office on the Federal Part C Application..

The meeting was adjourned.

VICC Member Attendance

VICC Members

Frederick Beaman
 Joanne Boise
 Delly Greenberg
 Virginia Heuple
 Dr. Colleen Kraft
 Rev. Brenda Laws
 Silvia Miseirvitch for Lyndell Lewis
 Phyllis Mondak
 Sheila Nelson
 Sharon Osbourne

Glen Slonneger
Cindy Summers for Delegate Shannon Valentine
Tammy Whitlock

ICC Members Not in Attendance

Corinne Garland
Mary Lou Hutton
Dina Kirby
Martha Kurgans
Laura Miller
Jacqueline Fagan Myal
Jeannie Odachowski
Leslie Hutcheson Prince
Yolanda Tennyson
Dr. Eva Thorp
Sandra Binns Whitaker