

## Summary

### **Early Intervention Autism Initiative**

#### **Planning Session**

June 25, 2003

Henrico Mental Health Center, Richmond

**Present:** Pasquale Accardo, Deana Buck, Carol Burke, Jane Carlson, John Clary, Sherry Confer, Kim Cretich, Brenda Crockett, Mary Ann Discenza, Jill Donaldson, Karen Durst, Liz Fletcher, Dawn Hendricks, Linda Hutton, Sharon Jones, Janet Lachowsky, Tracey Miller, Phyliss Mondak, Donna Rimmel, Beth Sarrett, Bruce Schaffer, Sharon Sikes, Beth Tolley, Charlene Wentland, Noel Wodlard, and Judy Burtner, facilitator. Present by phone: Nancy Bailey, Rebecca Berlin, Carol Schall and Beverly Crouse.

#### **Objectives**

1. Determine the next steps in the planning process
2. Set priorities among the possibilities of next steps
3. Determine the issues to be addressed in each of the high priority areas
4. Organize around the work of the high priority areas.

Note: Participants decided not to address objective #4 at this session and only partially dealt with objective #3.

#### **Ground Rules**

Participants agreed to the use of the following ground rules:

- Take care of your own needs
- Participate but share airtime
- Focus – the next steps
- Work toward consensus
- Limit side conversations
- Cellphones on stun/mute
- Work to stay present, focused and conscious

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#### **Identification of Next Steps**

During introductions participants identified the following next steps in their planning process:

- Development of clinical practice guidelines
- Identify implications for invention
- Define “appropriate” for young folks
- Fit into the Part C philosophy of natural environments and parent involvement

- Who is going to pay? The issue of finances
- Training service providers when they go into homes on the spectrum of possibilities so there will be the appropriate approach/response
- System of service delivery and resources – Will autism have its own system or can it be plugged into an existing system?
- Gaining consensus on where this process will end
- Gathering information on other programs and sharing it
- Identifying specific ways to support children/families relative to early intervention – what can be done now within current resources?
- Negotiate how services can be provided under Part C
- This group needs both short-term and long-term outcomes
- There needs to be a level of understanding and competence among providers working with children with autism – where can they go for training on competences?
- Intensive parent training
- Local councils need a process and service guidelines focused on outcomes to serve children with autism – it is a capacity issue.
- All localities need providers trained in the concept of natural environments
- Eclectic training for providers that meets short-term and long-term goals and contains accurate information
- All options available to the child/family including sensory integration. Families made aware of all approaches
- Identify all resources throughout the state for families including both private and public as well as industry (insurance companies)
- Providers collaborate for the benefit of the parent streamlining the process
- Research needs to be evaluated and a decision made on how training can support families
- How to define the population – IFSP teams and parents need to play an active part
- How to help children/families/providers within the Part C program?
- Prepare 3-6 fact sheets within 6 months for parents and professionals. Topics might include: What is autism? How to screen for autism? Different interventions, etc.
- Develop a system (long-term) for ongoing training

Participants agreed on the following:

- Early diagnosis is important
- Early intervention services are needed

They also agreed they would select both long-term and short-term goals. Their definitions of long-term and short-term were as follows:

#### Long-term

- It doesn't now exist
- Longer than a one-year perspective

## Short-term

- It can be done within current resources/services
- It can be accomplished within a year

Participants were divided into small groups and asked to collectively decide on no more than 3 short-term objectives and 3 long-term objectives they would like to propose to the total group. They were encouraged to use the following criteria in their deliberations:

- It would make the biggest difference/have the greatest impact relative to providing services
- There is a sense of “urgency” – may be a first step/sequential
- It is within the group’s influence/reach/ability to develop plans and share in the implementation of them

## **Short-term goals**

### Group 1

1. Fact sheets (dozen)
2. Information gathering

### Group 2

1. Implement proposed Philosophy/Guidelines Document for all children (including children with autism)
2. Develop a training package for early intervention service providers using existing resources
3. Promote awareness of and disseminate existing information and resources for service providers and providers

### Group 3

1. Develop fact sheets for professionals and families – including diagnosis, resources, and interventions and ways to process and evaluate
2. Summarize clinical guidelines from other states
3. Identify all current funding sources for families and services

### Group 4

1. Fact sheets
2. Develop a list of existing resources based on education and experience
3. Training (resources for families and providers)

### Group 5

1. Find out what provider skill levels we have in place across 40 councils then increase capacity through mentoring, providers, consulting and serving multiple areas. Establish baseline level of skills.
2. Begin training providers and families
3. Fact sheets for families, providers, referral services

### Group 6

1. Training and technical assistance and ongoing support for service providers, including physicians and psychologists and families
2. Develop written materials, including listings of resources in Virginia via survey of existing resources for families and providers
3. Clarify and define responsibility of Part C system for kids with autism (relate to service delivery models, funding, interagency, natural environments philosophy)

In looking for some agreement among the reports, the following items were identified by more than one group:

- Develop fact sheets for professionals and families – including diagnosis, resources, and interventions and ways to process and evaluate – 6 groups
- Develop a list of existing resources based on education and experience – 6 groups
- Training and technical assistance and ongoing support for service providers, including physicians and psychologists and families – 4 groups
- Find out what provider skill levels we have in place across 40 councils then increase capacity through mentoring, providers consulting and serving multiple areas. Establish baseline level of skills – 2 groups

### **Long-term goals**

#### Group 1

1. Clinical practices guidelines
2. Seminars for families (with training aids) and professionals
3. State plan (\$) beyond Part C

#### Group 2

1. Financing
2. Outcome research for toddlers up to age 3
3. Ongoing training that incorporates new information as well as ongoing for providers and families

### Group 3

1. Define what the service delivery system should look like
2. Figure out how to pay for it
3. Develop clinical practice guidelines within Part C

### Group 4

1. Identify new long-term funding sources for families and services
2. Develop clinical guidelines for Virginia
3. Build statewide infrastructure to support training of qualified professionals and parents

### Group 5

1. Develop a comprehensive statewide developmental disabilities services system for clients/children, families

### Group 6

1. Develop clinical guidelines for infants and toddlers and families in Virginia (consider long-term view of children's needs in communities, families – information and support system of service delivery)
2. Funds
3. Systematic approach to training for providers and families

In looking for some agreement among the reports, the following items were identified by more than one group:

- Financing – 5 groups
- Clinical best practice guidelines – 4 groups
- Systematic approach to training for providers and families – 4 groups
- Develop a comprehensive statewide developmental disabilities services system for clients/children, families – 4 groups

### **Decisions made**

Participants made the decision to focus on short-term goals for the present. They chose the two areas that all six groups identified as potential goal areas:

- Development of fact sheets for families and professionals
- Develop a list of existing resources – professionals, programs, schools, therapists, other providers by skill-level, by districts/regions – information package

It was acknowledged that the long-term areas would be addressed as soon as plans are being implemented for the short-term items. The long-term items would have to be sequenced dealing with the issues of building a comprehensive system including the development of clinical best practices first followed by work on the training and funding items.

To begin the work of developing fact sheets everyone was asked to turn in suggested topics before leaving the meeting. A listing of the topics is at the end of this meeting summary.

**Next Meeting – Wednesday, July 23, 2003, 1:00-4:00 p.m., Location to be announced**

Agenda items (not necessarily in this order):

- Development of a value set to undergird the work
- Fact sheets – decision on how many, what topics for what target audience(s), who will develop, development of an oversight group, deadlines, etc.
- Formation of possibly two groups and the setting of deadlines, etc., for the resource area:
  - List of existing resources statewide – schools, clinics, programs, professionals – public and private
  - Skill level of resources within each coordinating council area

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Attachment: Potential fact sheet topics