

## **Autism Spectrum Disorders Guidance Workgroup March 18, 2008**

Members in Attendance:

**Joanne Angel** – CMS, Tampa Bay Region  
**Kathleen Armstrong** – Provider Bay Area Early Steps  
**Steve Coleman** – Representative, Agency for Persons with Disabilities (APD)  
**Terri Daly** – UCF Center for Autism & Related Disorders (C.A.R.D)  
**Randee Gabriel** – Parent, Florida Interagency Coordinating Council for Infants and Toddlers (F.I.C.C.I.T)  
**Arnetta M. Givens** – Liaison, Early Steps State Office (ESSO)  
**Pat Grosz** – Bay Area Early Steps  
**Joy McAfee** – Western Panhandle Early Steps  
**Martha Murray** – Representative, Department of Education (DOE)  
**Kelly Purvis** – Parent Consultant, Early Steps State Office (ESSO)  
**Ellie Schrot** – Gold Coast Early Steps  
**Lori Shamroth-Carver** – Treasure Coast Early Steps  
**Glenda Thomas** – CMS, North West Florida Region

The workgroup established the following ground rules for the meeting:

- No idea is a bad idea!
- No cell phones – please place on vibrate!
- Keep focused – No sidebars!
- Don't lose sight of our consumer!
- Be mindful of Early Steps guidelines!
- Embrace all expertise in discussion!

Kelly Purvis, Parent Consultant with Early Steps State Office and the parent of a child diagnosed with autism, walked the workgroup through entry into the Early Steps system. She emphasized that referral to the program is varied, but eligibility is primarily based on the child having documentation of an established condition or results from a multidisciplinary evaluation that show a developmental delay. She continued that service delivery within Early Steps is determined by functional outcomes developed by a child's Individualized Family Support Plan team and are based on the child's needs as identified on the assessment, combined with the family's priorities and concerns. The group recognized the change in current policy that recognizes Autism Spectrum Disorders (ASD) as an established condition.

1. A request was made for there to be more clarification on Early Steps policy 3.1.3 (a) regarding who is appropriate to make the diagnosis of Autism Spectrum Disorders (ASD). Current policy indicates a healthcare practitioner acting within his or her scope of practice. The Early Steps system includes numerous licensed practitioners, i.e. would a speech therapist or occupational therapist be able to make the determination for the diagnosis?
2. A recommendation was made that Early Steps consider adopting or aligning their program eligibility criteria with those established by either the Department of Education or the Agency for Persons with Disabilities.
3. A recommendation was made that a framework and training be developed for IFSP teams to assist in determining appropriate service delivery for children with autism.
4. A recommendation was made that the ESSO have an expert on ASD.

While all local Early Steps are distinct, the four program areas represented at the meeting described their current practices in serving children with ASD.

- **Western Panhandle Early Steps (Pensacola area serves 4 counties)**

This Early Steps program is managed by Sacred Heart Hospital who has partnered with their local Children's Medical Services office to establish a clinic for diagnosing autism two times monthly (one by CMS and one by Early Steps). APD criterion for who can diagnose a child is used. Early Steps eligible children that exhibit red flags are referred to the local CARD facility to be screened. Families can choose to go to the clinic without going to CARD for screening if they prefer.

If a child is diagnosed with autism, the program is looking at offering approximately 25 hours of active engagement services to the family. These services will be a combination of professional/community resources and family interaction with child.

In addition, Sacred Heart Hospital has received a \$300,000 donation toward establishing a one stop facility for diagnosis, therapy, training and support for children with autism. A Behavioral Analyst is being sought to launch the center on the Sacred Heart campus and serve as the director. Anticipated training will include Applied Behavioral Analysis (ABA) and CERTS.

- **Bay Area Early Steps (Tampa area serves 2 counties)**

This Early Steps program has partnered with their local Children's Medical Services and CARD offices to form a clinic for children diagnosed with autism. The following screening, evaluation and treatment tools are utilized: Modified Checklist for Autism in Toddlers (M-CHAT), Autism Diagnostic Observation Schedule (ADOS), Temperament and Atypical Behavior Scale (TABS) and Positive Behavioral Supports (PBS) and Helping Our Toddlers, Developing Our Children's Skills (HOT DOCS).

- **Treasure Coast Early Steps (West Palm area serves 5 counties)**

Area has formed a specialty clinic for children that have communication disorders. All children 16 months and older are screened using the M-CHAT prior to being referred to the Specialty Clinic where the ADOS is administered by a psychologist and speech therapist.

- **Gold Coast Early Steps ( Ft. Lauderdale area serves 1 county)**

This program has implemented the use of the M-CHAT screening tool for all children 16 months and older that enter their system. The Psychoeducational Profile (PEP 3) is the assessment used. This program has experienced some challenges with families pertaining to the appropriate intensity of service provision for children. As far as diagnosis, the program has adopted the following strategy from the New Jersey Early Intervention System Services Guidelines: For children without a diagnosis, evaluators have a professional responsibility to inform the family that the developmental evaluation and screening questions have raised behavioral concerns that are consistent with possible autism spectrum disorder. Families should be encouraged to discuss the findings and concerns of the EI team with their primary health care provider.

### **Screening:**

Workgroup discussed the merits of whether universal screening for all children would be feasible for Early Steps. Concern was expressed about how much of a work load such a process would add to the Early Steps system. The group unanimously felt that the community pediatricians should cooperate in ensuring screening is available to children and families. Workgroup was reminded that recommendations should include actions that Early Steps has authority to affect. Group desired more information on what other states are doing with screening. Information will be submitted to the group by Arnetta Givens. Access to all other states' information on serving children with autism is not available; what is available can be found on the National Early Childhood Technical Assistance Center (NECTAC) website <http://www.nectac.org>. On this website choose Autism under Topics

Page. On this page there is a section for State Guidance, Initiatives and Projects where all available state information is listed.

Possible recommendation includes use of the Communication and Symbolic Behavior Scales Developmental Profile: Infant and Toddler Checklist (CSBS DP; Wetherby & Prizant 2002) for children identified as exhibiting concerning behavior to family or Service Coordinator. The use of this or any ASD tool would be to aid in identifying the appropriate assessment team.

#### **Evaluation:**

Florida has made the determination to include autism as an established condition; thereby making a child with this diagnosis eligible for the Early Steps program without having to complete an eligibility evaluation. Those children without an established condition must have an eligibility evaluation to determine eligibility for the program. In addition, while Early Steps does not need a diagnosis of autism to serve a child, the program is responsible for assisting a family to obtain a diagnosis, as desired. This responsibility includes facilitation of family's access to other community resources that are available in the area.

#### **Assessment:**

All eligible children in Early Steps must have an assessment for intervention planning that identifies the child's strengths and needs in terms of each of the developmental areas and the services appropriate to meet those needs. There was dialogue regarding the way progress is measured within Early Steps. It was relayed that the assessments listed in the Policy Handbook under 3.6.2 were the approved tools. Workgroup showed some interest in the Individual Growth and Developmental Indicators (IGDI) as a more family-friendly and consistent tool that could measure progress for children with ASD. Information regarding this tool will be made available to the workgroup members by Arnetta Givens. Information on the IGDI can be accessed at [www.igdi.ku.edu.documents](http://www.igdi.ku.edu.documents).

Possible recommendation would be that Policy 3.6.2 be amended to allow other appropriate assessment tools after the initial assessment. Current policy indicates that for some children more than one assessment tool would be administered each time an assessment is completed. Another possible recommendation is to have the IGDI identified as an approved assessment tool for children with ASD.

The following issues were identified as possible barriers to providing appropriate service delivery to children identified with ASD:

- Parents not having a clear understanding of the IFSP process and/or experiencing a perception that the IFSP process is not being followed. Service Coordinators, IFSP teams and families must have a clear understanding that an IFSP must be individualized to a child's specific needs. Training is needed in this area.
- IFSP teams not appropriately trained on the IFSP process and/or on the ASD diagnosis to assist the family to determine appropriate services for their child.
- ESSO has under utilized available community resources, i.e. CARD, CMS, APD, etc – Possibly develop interagency agreement or organize outreach to all other agencies that serve children with ASD.

Ideas to consider when discussing Services and Supports:

- Ensuring that Primary Service Provider is trained on how to use "active engagement" intensity charts as shared in the power point presentation handout entitled: National Academy of Sciences Committee on Educational Interventions for Children with Autism Birth to 8 Years and in the Early Steps Workgroup on Autism Spectrum Disorders Practice Recommendations and Guidelines.

Next meeting scheduled for Monday and Tuesday, May 12<sup>th</sup> & 13<sup>th</sup> in Tallahassee, more information is forthcoming.

### Questions

1. **Provide clarification on whether the decision to make autism an established condition is based on federal regulation or not.**  
Federal regulation does not list specific conditions for eligibility for Part C services. Each state is given the autonomy to determine which conditions would be included under established conditions category.
2. **What services are available with CARD?**  
There are 7 CARD centers statewide. Information for each can be found <http://card-usf.fmhi.usf.edu/centers.asp>.
3. **Who is allowed to diagnose?**  
On March 1, 2008, Early Steps implemented Interim policies. Policy 3.1.3 indicates that "If a child has an established condition that is likely to lead to developmental delay, a written confirmation from a licensed physician of the diagnosis is required to establish eligibility OR in the case of (a) severe attachment disorder or autism spectrum disorder, a healthcare practitioner acting within his/her scope of practice or (b) in case of hearing loss, a licensed audiologist. Written confirmation of the diagnosed condition must be in the child's Early Steps Record. Although nurses and therapists are licensed practitioners neither have been approved to diagnose a condition. Their scope of practice includes treatment of a diagnosed condition.
4. **What happened to the Autism Specialist Provider that was once in the Personnel Development and Training Guide?**  
Neither the current Personnel Development and Standards policy (Component 10 of the Interim policies) or the prior Personnel Development and Training Guide included this provider type. Although there may have been intent to develop such a provider, this has not occurred.