There is a notable degree of variation in the state and local design of IDEA Part C early intervention programs. In light of the increase of children under three years of age being identified and diagnosed with an autism spectrum disorder (ASD) and the vital importance of intervention support and services, the authors of this month’s KIT article set out to identify state’s Part C policies for providing early intervention services to children under three years of age with ASD.

The article “State Infant/Toddler Program Policies for Eligibility and Services Provision for Young Children with Autism,” by Aubyn Stahmer and David Mandell, was published as a National Institutes of Health (NIH) Public Access Author Manuscript (2007) and is available on line at:


The identification of children under three with an ASD is increasing. Subsequently, more Part C early intervention programs are providing supports and services to this very young population with ASD and their families. Yet, research supports that system wide resources are not consistently identified, available, or used, nor are standard practices for diagnosis and provision of services evenly regarded and implemented. This is in part due to variations in eligibility criteria and service provision decisions among and within states.

To discover the degree of variation in state policies around the identification and provision of services for children under three with or suspected of having an ASD, Stahmer and Mandell invited state Part C administrators to participate in semi-structured interviews to learn more about state policies and practices. Forty-six of the 50 states participated. Following is a synopsis of the variations the authors found across the states.

Variation in lead agency
- Dept. of Health & Human Services 31 (67%)
- Dept. of Education 11 (24%)
- Dept. of Developmental Disability/ Mental Retardation 4 (9%)

Primary Referral Sources
- External (physicians & parents) 31 (67%)
- Within system 15 (33%)

Who can provide the diagnosis?
- Physician or Psychologist 18 (39%)
- Appropriate Licensed Professional 10 (22%)
- Multidisciplinary Team 7 (15%)
- School Psychologist 1 (2%)
- No requirement 10 (22%)
- ASD experienced regardless of profession 10 (22%)

Diagnostic Instrument Used
- Specific requirement for all evaluations 3 (7%)
- Recommend specific diagnostic tool 6 (13%)
- Diagnostician choice for ASD-specific Diagnosis instruments 46 (100%)

 Automatically Qualifying DSM-IV Diagnostic Categories
- Autistic Disorder 45 (98%)
- PDD-NOS 39 (85%)
- Asperger’s Disorder 34 (74%)
- Rett Syndrome 33 (72%)
- Childhood Disintegrative Disorder 18 (39%)
- Any part of the spectrum excluded 13 (28%)

Early Intervention Services
- Children with ASD receive Part C
Mandated Services
- Specific ASD treatments provided

Intervention methods
- Specific intervention endorsed (e.g., National Research Council guidelines, TEACCH, Floor Time, Denver Model, Discrete Trial Training, Incidental Teaching, teaching within functional routines, Pivotal Response Training, Positive Behavior Support Prizant S.CRETS)

Practice Guidelines
- Have diagnostic guidelines
- Have treatment guidelines

Reviewing this table the reader can see that there is notable variation among the states. Because policies and practices have important implications for care, there is a critical need for policy research, development and implementation to facilitate evidence based practices.


The www resource this month is “Operation Autism Resource Guide for Military Families.”

http://www.operationautismonline.org/

This site is sponsored and maintained by the Organization for Autism Research (OAR), whose focus is “to use applied science to answer questions that parents, families, individuals with autism, teachers and caregivers confront daily.” The link specifically designed for military families includes a great deal of information organized by the following headings (illustrated as tabs at the website):

- Autism 101
- Raising a Child with Autism
- Autism and Military Healthcare

- Educating a Child with Autism
- Tips for PCS Moves and Other Transitions
- Search for Resources
- About Operation Autism

Under the tab “Autism & Military Healthcare” is a set of questions and answers about the TRICARE Autism Demonstration Project. The “Search for Resources” is not a typical search engine that references the entire internet. Rather it is uniquely filtered to draw upon resources of interest to military families. This feature alone makes this resource directory incredibly valuable for families, caregivers, and providers affiliated with the military. Be sure to check out the other tabs and associated resources as well.

**What Do the Data Say?**

What are known/estimated numbers of individuals with autism in other countries?

Not surprisingly, the prevalence of autism across countries vary considerably. Differing diagnostic criteria, data collection methods, as well as genetic factors and environmental influences likely contribute to these variations. Accordingly, the following information provided to answer this month’s question must be reviewed with great caution.

The following information is based upon single studies as reported the Doctor Evidence Database on Autistic Prevalence. The rates reported are per 1000 individuals and the source is noted in the parentheses. This information, and more including gender, autism type, and geographic type are all available at:


<table>
<thead>
<tr>
<th>Country</th>
<th>Rate/1000</th>
<th>Source(s)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Canada</td>
<td>8-22 : 1000</td>
<td>(Bryson, 1988; Fombonne, 2006)</td>
</tr>
<tr>
<td>Denmark</td>
<td>6-12 : 1000</td>
<td>(Madsen, 2002; Lauritsen, 2004)</td>
</tr>
<tr>
<td>England</td>
<td>17 : 1000</td>
<td>(Chakrabarti, 2001)</td>
</tr>
<tr>
<td>Finland</td>
<td>6-12 : 1000</td>
<td>(Makela, 2002; Keilinin, 2000 &amp; 2004)</td>
</tr>
<tr>
<td>Iceland</td>
<td>6 : 1000</td>
<td>(Magnusson, 2001)</td>
</tr>
</tbody>
</table>
Japan 14-38 : 1000 (Tanoue, 1989; Honda, 2005)
Norway 4-6:1000 (Sponheim, 1998; Herder, 1993)
Portugal 17:1000 (Oliveria, 2007)
Sweden 5-61 : 1000 (Steffenburg, 1986; Kadesjo, 1999)
UK 7-31 : 1000 (Webb, 1997; Baird, 2000 & 2006)

Consultation Corner

From September 2009 through January 2010 the consultation corner topic is:

ASD and the Role of Early Interventionists

Celine Saulnier, Ph.D., the Training Director for the Autism Program at the Yale Child Study Center and Karyn Bailey, the Social Work Director for the Yale Child Study Center’s Post-graduate Social Work Training Program are the KIT Consultation Corner experts sharing their knowledge and experience. This month we have the added benefit of hearing from Erin Loring, MS, Certified Genetic Counselor at the Yale Autism Program Child Study Center, as she responds to this month’s consultation corner question.

Families that have a child with ASD sometimes question if their younger child might also have ASD. Understanding that there may be a genetic link—what is a good way to discuss this with families?

After a couple’s older child has been diagnosed with ASD, it is not unusual for parents to have concerns about their younger child’s development. These concerns are not unfounded as ASD is known to have a strong genetic component. The empirical risk estimate for recurrence of ASD for a couple with one child affected is 2-8%. This risk is inclusive of all ASDs. The severity or type of ASD for a sibling is not predictable, even when the diagnosis of the older child is known—meaning a family may have one child with Asperger syndrome and another child with PDD-NOS. The risk of a sibling having some characteristics of ASD but not the condition itself (i.e. the “broader autism phenotype”) is ~30%.

Parents are certainly in the best position to observe how their young child is developing. They should trust their instincts. Rather than spending many days/ nights worrying, they should be encouraged to speak to their child’s practitioner if they have any concerns about their younger child’s development. While the concerns may end up being nothing at all, parents should not wait. Diagnosing delays early on, even if mild, will have the most success with appropriate early intervention services.

For more information regarding early signs of ASD refer to www.firstsigns.org or www.autismspeaks.org.

Continuing Education for KIT Readers

The Comprehensive System of Personnel Development (CSPD) is offering a continuing education opportunity for EDIS KIT readers.

In line with the focus on ASD and the Role of the Early Interventionist, readers are invited to receive continuing education contact hours for reading the monthly KIT publications (September 2009 through January 2010) and completing a multiple choice exam about the content covered in these KITs.

If you are interested, complete the exam online at www.edis.army.mil and upon successful completion, you will receive a certificate of non-discipline specific continuing education contact hours.

Please send your Consultation Corner questions and KIT ideas via email to ediscspd@amedd.army.mil.