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NECTAS ASD Forum Update

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# Forum Update:

# Services For Young Children with Autism Spectrum Disorders (ASD) And Their Families

## Forum Overview and Background

To address the national challenge of providing high quality, effective and appropriate services for young children with autism spectrum disorders (ASD) and their families (birth through five), the National Early Childhood Technical Assistance System (NECTAS) has undertaken a series of related activities known as the NECTAS Forum on ASD. This report is intended to provide an update on Forum activities and plans for continued product development efforts, for the timeframe from initiation in October 1996 until completion projected for September 1999.

NECTAS is funded through a cooperative agreement with the US Department of Education, Office of Special Education Programs (OSEP) to provide technical assistance to support the early childhood initiatives of the IDEA (Individuals with Disabilities Education Act). Our clients include: the Infant and Toddler (Part C) Programs and the Early Childhood Special Education (Part B, Section 619) Programs in all states and jurisdictions and other early childhood projects, funded by OSEP. One of the technical assistance objectives outlined in this cooperative agreement was to conduct a Forum on issues of national significance, affecting the fields of early intervention and preschool special education.

Because of numerous requests for information and technical assistance (TA) from state agencies, service providers and parents, NECTAS, with the concurrence of OSEP, has focused a national Forum on policy and service issues related to meeting the needs of young children with ASD and their families. To oversee the efforts of the Forum, a NECTAS Core Forum Workgroup was assembled (see membership below). Over the past two years, we have conducted a series of problem solving and information gathering activities, which will be synthesized as descriptive papers and recommendations to the field. The ASD Forum activities to date have included three "think tanks", multiple information generating activities and two national conferences for state teams. The participants involved in these Forum activities have included a diverse group of stakeholders, including state agency personnel, service providers, families of young children with ASD, advocates, parent organizations, health care professionals, researchers, and model developers of nationally-known service approaches.

**Technical Assistance Conferences**

In 1997, NEC*TAS conducted two national TA conferences on developing state and local capacity to serve young children with ASD and their families. The first in Denver, included teams of people from 13 states and territories; the second meeting in Clearwater, FL included teams from 18 more states. A total of 204 participants attended the conferences. State teams included interagency groups of state planners, local service providers, parents and resource people who attended substantive sessions on effective practice and other service issues, and met together to develop plans for enhancing their state and local services. Both conferences had excellent faculty, representing a variety of service approaches and research interests. Most faculty members stayed throughout the meetings making themselves available to participants and state teams. These meetings offered the opportunity to conduct focus groups of parents, local service providers and administrators. Issues, barriers, expectations and recommendations from these groups were recorded and used to inform the ASD Forum activities. State team challenges, issues and plans were also documented. The information collected via these TA conferences was organized as additional data on national needs and the status of services. It has been used to focus, clarify and prioritize Forum work and products.

**Forum Activities and Products**

To date, the Forum activities have incorporated a variety of methods, including: "think tanks", focus groups, conference calls, web-based discussion Forums, literature reviews, policy analysis, survey research and other strategies. A large body of current information with relevance for the provision of effective developmental interventions and educational services for young children with ASD and their families has been generated, collected, organized and synthesized. Continued Forum work will translate these efforts into a number of products. During 1998 – 1999 the Core Forum Workgroup (see next page) will prepare Forum products (listed below), conduct broad reviews of them and disseminate these products nationally.

1. ***NECTAS Resource Collection on Autism Spectrum Disorders (May be ordered through NECTAS Publications)***

   A collection of articles and information materials which describes resources, organizations, research, special projects and other state and national initiatives related to young children with ASD. Special pieces created via Forum activities include:
   - *OSEP-Funded Early Childhood Projects and Project Resources on ASD* that focus on serving young children with ASD & their families, contains excerpts from a database of OSEP funded early childhood projects maintained by NECTAS on our website: ***http://www.nectas.unc.edu/;***
   - An *Annotated Bibliography* of published articles and books; and
   - *National Resources on ASD in Early Childhood.*

2. Journal and Newsletter Publications

Sperry, L.A., Whaley, K.T., Shaw, E. & Brame, K. (April 1999). Services for young children with autism spectrum disorders: Voices of parents and providers. *Infants and Young Children*, 11(4), 17-34.

The perspectives and experiences of parents and service providers were examined using a focus group methodology and analyzed for emerging themes regarding service delivery systems. Areas of convergence between the two groups included issues related to finance, training, family support, early identification, collaboration, advocacy, equity and inclusion.

Hurth, J. Shaw, E., Izeman, S., Whaley, K., & Roger, S. (in press). Areas of agreement about effective practices among programs serving young children with autism spectrum disorders. (Article requested for submission for a special issue on autism scheduled for 1999.)

For more information about the journal, Infants and Young Children, please contact:
Aspen Publishers, 7201 McKinney Circle, Frederick, MD 21704
800-638-8437, Web: http://www.aspenpublishers.com

Ziegler, M. (1999, Winter). One mother's reflections: Recent readings about autism. *Early Childhood Bulletin*, 1-6 [Available from the Federation for Children with Special Needs, 1135 Tremont Street, Boston, MA 02120, 617-236-7210]

This issue of the *Early Childhood Bulletin* is written by the parent component staff of NECTAS at the Federation for children with Special Needs. Personal perspectives are provided about interesting and useful books and booklets by the author who is the parent of an adult diagnosed with autism.

Ziegler, M. (1996, Winter). Report on autism conference sponsored by NECTAS. *Early Childhood Bulletin*, 1-4 [Available from the Federation for Children with Special Needs, 1135 Tremont Street, Boston, MA 02120, 617-236-7210]

This issue of the *Early Childhood Bulletin* written by the parent component of NECTAS is a summary of the content and activities of a national conference held in Hartford, Connecticut in February 1996.

3. ***Quality Practices / Service Approaches Monograph*** (working title)

This NECTAS monograph will describe quality practices, as implemented by various intervention approaches or model programs. Its summary will provide guidance to families and local service providers about program /resource development and decision-making regarding services. Chapters will address the following topics:

- Principles and values
- Characteristics of effective programs (instructional/developmental, not medical)

- Elements of effective programs (aspects of practice common among valid program models will be described. An exploration of how different programs or models theoretically and practically address or incorporate these elements will illustrate variations in implementation)
- Closing guidance and considerations for making choices and planning services

4. ***Policy Options and Considerations*** (working title)

   This NECTAS monograph will describe the following major national issues that could be impacted by policy at the federal, state or local levels:
   - Service Guidelines/Guidance;
   - Interagency Collaboration and Funding
   - Developing an Adequate Infrastructure for State and Local Service Systems
   - Early Identification
   - Training
   - Family Involvement
   - Inclusion

   For each of the above issue / policy areas, a set of policy options will be presented, and considerations and implications discussed. In addition, examples of different approaches and activities that states are using to address these issues will be described.

**Core Forum Workgroup**

NECTAS staff at the Coordinating Office, University of North Carolina, Chapel Hill, NC:
Joicey Hurth, Evelyn Shaw, Kathy Whaley, Kim Brame, & Lynne Kahn
NECTAS staff at collaborating programs: Roxane Kaufmann and Don Kates (Georgetown University, Washington, DC), Ruth-Ann Rasbold (Federation for Children w/ Special Needs of Boston), Cindy Oser (ZERO TO THREE, Washington, DC).
Core consultant: Sue Izeman, NY
Graduate student assistants: Laurie Sperry, Heather Whiteford and Lisa Napp, UNC, Chapel Hill

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# Quality Practices / Service Approaches
(Working title)

## Background

A section of the Quality Practices / Service Approaches monograph will describe elements of effective programs (aspects of practice common among validated, nationally known program models). An exploration of how different programs or models theoretically and practically address or incorporate these elements will illustrate variations in implementation.

The first step in developing this section of the monograph was to bring together (during the November 1997 Developing State and Local Services for Young Children with ASD and their Families technical assistance meeting) prominent researchers, program developers and parents. The task of this group was to identify those program components that are essential in high quality early intervention and preschool programs for young children with ASD. While the group of ASD experts and families approached intervention utilizing different approaches, they came to consensus on six key program areas: 1) earliest possible start to intervention, 2) individualization for children and families, 3) systematic, planful teaching, 4) specialized curriculum, 5) intensity of engagement, and 6) family involvement. In addition, this group identified three program components that are central to some but not all high quality programs. These three components are structured environment, developmentally appropriate practices, and intervention in settings with typical children or in natural environments.

The next step in developing a paper describing quality practices was to gather information from 19 programs from around the country that serve young children with autism and their families. The final monograph developed from this information will be disseminated to state and local agencies, early intervention and preschool providers, families, and others in the field of autism.

# Areas of Agreement

## Area #1: Earliest Possible Start to Intervention

Children who begin appropriate services earlier have better outcomes. During recent years, our concept of "early" has changed dramatically. As diagnostic procedures and tools improve, identification of children with ASD occurs earlier. Research has indicated that certain observable behaviors of the infant / toddler are predictive of being "at risk" for ASD or social / communicative delays. On the average, children are being diagnosed between the ages of 2-2 ½. While children under age two may be given a diagnosis within the spectrum, the reliability of such a diagnosis is unknown. Earliest intervention may also mean that children receive services appropriate to their needs before they have received a diagnostic label.

## Area #2: Individualization of Services for Children and Families

Individualization refers to adjustments in goals and intervention strategies for each child and family receiving services. Individualization means that the child's needs, strengths, and interests along with the family's concerns, priorities, and resources determine each child's program, as well as the overall theoretical and conceptual framework of the program. Individualization for children also means that families have a decision-making role, and that each family's individual needs for support and participation are honored. Usually, individualization for children and families occurs as part of the IFSP and IEP team process.

## Area #3: Systematic, Planful Teaching

In order to address the needs of children with ASD programs and services teach new skills in a manner that is both systematic and planful. Systematic means that the instruction or intervention is carefully thought out, logical, and consistent with a conceptual or theoretical basis. A program's underlying conceptualization is used to decide what to do, and to explain why intervention choices are made and/or modified. Systematic teaching involves planning, implementing, and assessing intervention steps. Planful teaching means that each step in an intervention is intentional, coordinated with an overall approach, and builds toward meaningful goals.

Systematic, planful teaching occurs within a wide variety of program models, and can look different within different programs. For example, programs may vary in terms of how child vs. adult-directed their intervention is. However, both child-centered and adult-directed programs can be very systematic and guided by underlying conceptualization, and both kinds of programs can be eclectic and spontaneous.

### Area #4: Specialized Curriculum

While children with ASD share many instructional needs with other children, there are developmental delays and difficulties that are specific to ASD. These areas of need include the development and use of language, the development of appropriate social interaction skills, restricted interests, and repetitive behaviors. Programs serving children with ASD address these specific areas of need with core curricula. Specific instructional goals and curriculum content typically address five skill domains outlined by Dawson and Osterling, 1997: attending to elements of the environment, imitating others, comprehension and use of language, playing appropriately with toys, and interacting socially with others.

### Area #5: Intensity of Engagement

Engagement refers to the amount of time that a child is attending to and actively participating in the social and nonsocial environment. In programs for children with ASD, intensity of engagement may be expressed as the percent of enrolled time that is spent in teaching interactions. In addition, the time that a child is engaged in learning opportunities may occur both during program time and during time that the child is at home or in community settings. Engagement may be facilitated by a variety of techniques including changes in materials and environment, activity-based or incidental teaching, and direct instruction. All programs who where represented at the NECTAS meeting described above reported that children are actively engaged at least 15 hours weekly and often 20 hours or more weekly. Programs varied in where, how and who instructed or supervised a child's participation in various instructional and social interactions.

### Area #6: Family Involvement

While there is widespread consensus that family support, training, and other forms of involvement play a key role in maximizing learning and skill gains of the child, there are at least five ways that families are involved in high quality programs for young children with ASD. These are: 1) **Family involvement in their own child's program; 2) Services that are provided to families primarily because their child has ASD; 3) Services that are provided to families that are not directly related to ASD; 4) Family support and networking; 5) Family involvement in the overall program.**

## Areas That Are Part Of Some, But Not All Programs

Three additional program components are key parts of several programs represented at the NECTAS meeting described above, but were not common to all participating programs. These three areas are a structured environment, developmentally appropriate practices, and intervention in settings with typical children or in natural environments.

### Structured Environment

Many programs arrange the environment, instructional materials, and teaching interactions to elicit, facilitate, or support specific skill attainment or development. This structure may include use of environmental arrangements or visual cues to organize or schedule activities, to facilitate choices, and to define work, play, or rest spaces.

### Developmentally-Appropriate Practices

Many programs use teaching practices that have been designed for all young children, with and without disabilities, as the core of a program for young children with ASD. Developmentally appropriate programs are guided by information about child development and learning, each individual child's strengths, needs, and preferences and knowledge of the social and cultural contexts in which children live. Programs using developmentally appropriate practices build knowledge and skills through child-directed activities, responsive teaching, and children's active learning.

### Intervention in Settings with Typical Children or in Natural Environments

Many programs that serve young children with ASD plan for some or all interventions to occur in settings that with typical children. This may include designing fully integrated toddler or preschool settings, supporting children with ASD in community childcare or preschool settings, and providing intervention in community recreation activities. For children under 3, intervention in natural environments means providing support to children and families in the home and community settings.

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# Policy Options and Considerations
(Working title)

***Background***

The first step in the development of this draft monograph was to ask each of the 31 state teams that attended a NECTAS technical assistance meeting on "Developing State and Local Services for Young Children with ASD and Their Families" in 1997 to identify three challenges in developing services for young children with ASD. These challenges were categorized into 6 policy areas: Early Identification, Family Involvement, Service Guidelines, Developing an Adequate Infrastructure, Interagency Collaboration and Funding, and Training. These policy areas were discussed and further refined during two "think tank" days. The participants involved in these activities have included a diverse group of stakeholders including state agency personnel, service providers, families of young children with ASD, advocates, parent organizations, health care professionals, researchers and model developers of nationally known service approaches. From November of 1998 through the present, small stakeholder workgroups are discussing policy options and considerations for each of the policy areas above. Each policy area will include a description of the issues, policy options and considerations and state examples. NECTAS plans to begin dissemination of each policy area in the winter 1999.

## Early Identification

### *Challenges*

- Studies reported by the National Institute of Child Health and Human Development show an increased incidence of ASD and a trend toward earlier diagnosis. The stability and reliability of very early diagnosis (before age 2) is unknown. However, not all professionals are aware of the warning signs that indicate a need for a referral for an evaluation.
- Health care and other professionals are often reluctant to label young children with a diagnosis within the spectrum. There are many benefits to earlier identification not the least of which are appropriate services and supports and better outcomes for children and families.
- How to arrive at a diagnosis, by whom, utilizing which tools and by what definition is one of the complex challenges.
- Once a diagnosis has been made, linking the family to appropriate services and supports which meet the needs of young children with ASD and finding financing for those services is made more complex by philosophical differences between providers, funders, and families as to what the best course of intervention should be.
- Another challenge facing program administrators planning services for children with ASD relates to allocation of resources. Should the money be allocated for child find and increasing the public awareness of ASD versus supporting early intervention and preschool services (providing or funding services that are individually tailored and sensitive to the needs of children with ASD and their families)?
- Many young children with ASD are identified between the ages of 2 and 2 ½, the age of transition to the preschool program (Part B of IDEA). For children with ASD who react adversely to change, it is essential that issues of transition are worked out by the early intervention (Part C) and preschool program (Section 619) programs.

### *Policy Issues and Questions*

1. Some professionals are reluctant to diagnose young children with ASD. However, appropriate services may be dependent on receiving a diagnosis. How can this dilemma be addressed? Should states use an "at risk" criteria for early intervention? Should states utilize developmental delay? Should states use a categorical definition of autism?
2. How best can state and local systems increase the capacity for early identification of young children with ASD - through collaboration between public/private sectors and health and mental health professionals, specification of qualified diagnosticians, and training?
3. Should states allocate a portion of early intervention and preschool resources for early identification efforts for specific conditions such as ASD?
4. Should states recommend specific screening and assessment processes, tools and/or instruments?
5. When increased numbers of young children are identified as having ASD, how can states ensure that these children and families will have appropriate services available?
6. How can states address the issues of identification of young children with ASD close to transition to Section 619 of Part B services?

## Family Involvement

***Challenges:***

- Family involvement begins with relationship development. However, barriers such as attitudinal, administrative, financial and time constraints can inhibit family involvement and participation.
- Upon initial diagnosis, the needs of the child may be so overwhelming that families are less likely to identify their support needs.
- Individualized family-centered support does not always emphasize family priorities, culture, diversity and unique circumstances.
- Many families of children with ASD are not able to receive respite services for their child, a service perceived as an important ingredient to facilitating parent training and involvement at the policy making level.
- For some families, respite can be perceived negatively. Families may feel that if they can barely manage their child, how can they have a stranger come in and provide care.
- Many families feel that it is important to receive an early diagnosis and be allowed to select treatment options, whether traditional or alternative in approach.

***Policy Issues and Questions:***

1. With the increased numbers of children with ASD, how are states developing policies that emphasize and reflect the unique needs of families?
2. How best can state and local policies minimize barriers and actively promote family and professional collaboration?
3. How are parent networks promoting leadership skills in order to influence policy, training and practices?
4. How can local and state policies emphasize and maintain family-centered approaches/practices?

## Service Guidelines

***Challenges:***

- Clinical Indeterminacy. While there are areas of agreements among professionals in the field of ASD related to many characteristics of effective services, there is also a great deal of disagreement between respected professionals about the quality of various models, recommended frequency and intensity of services, and appropriate evaluation of early intervention/preschool services. Various services or models have different evaluation approaches and variable rigor in validating efficacy, which makes comparisons difficult.
- Service Variability. There is tremendous variability between states and among different areas or agencies within states related to the quality and amount of services available for young children with ASD. Families often find that getting appropriate services for their child involves either moving or traveling great distances on a regular basis.
- Disparate expectations about services quality. State agencies, families, and local service providers may have very different ideas about the quality and quantity of service needed for young children with ASD. Families and advocates are asking for specific models of services, while community providers may have little experience or expertise in serving young children with ASD. In addition, there are different specifications at the federal and state level for children in early intervention (Part C) and preschool services (Part B of IDEA).
- In this climate, there is a tremendous need for local, state, and federal agencies to provide guidance to service providers and families related to high quality and effective services for young children with ASD.
- As managed care and Medicaid have become important funding sources for early intervention and preschool services, there is additional pressure to define "standards of care" and the amount and types of services needed. Many state administrators hesitate to provide specific service guidelines that may be seen by local service providers as a maximum (rather than a minimum) requirement.

***Policy Issues and Questions:***

1. Should state agencies develop policies to guide program development for young children with ASD rather than develop polices that guide programs in finding relevant information, evaluating this information, and designing or modifying their programs?
2. When policies contain specific program guidelines, should they go beyond basic, appropriate services for young children with ASD and describe recommended or best practice?
3. Should state policies reflect the areas of agreement among various approaches?
4. Should compliance with service guidelines be tied with access to funding?
5. What process should state agencies or state ICC's use to develop policy and guidelines? Who should be involved and what can the nature of their involvement be?
6. How can state and local administrators assure that services are appropriate and responsive to the needs of each child and family, and achieve the desired outcomes while also assuring that the aggregate costs of services do not create an impossible fiscal burden?

## Developing an Adequate Infrastructure

***Challenges:***

- Historically, ASD has been viewed as a relatively low incidence disability. Many communities do not have access to professionals with experience and expertise related to ASD.
- Gross inequities exist between and within states in the quality and amount (intensity) of services available to appropriately serve young children with ASD and their families
- When infrastructure needs have not been addressed, service providers and families may not know where or how to access resources and expertise that is available.
- Inadequate communication among healthcare providers and the early intervention and education systems often result in delayed referrals, and families who do not know how to access services they need.
- Policy makers have recognized the need for improved infrastructure for obtaining and distributing information and resources to the agencies, children, and families who need them. The state's infrastructure must be able to support communities in developing their capacity to serve and support families and their young children with ASD.

***Policy Issues and Questions:***

1. Should states develop an infrastructure specifically to support young children w/ASD or the whole age range of people with ASD? Should they build an infrastructure to support young children with low incidence conditions? Should states incorporate supports into existing early intervention/special education systems for young children with special needs? How can interagency interests and services be captured?
2. How can state infrastructure assure that parents and providers statewide have equitable and prompt access to current information and interdisciplinary, interagency resources, including "on-call" expert support for evaluation/assessment, planning and intervention of young children w/ ASD. Should processes be developed to evaluate information and services? How does the system determine whom to include as "expert resources"?
3. How can the infrastructure assist local providers and families access and assimilate frequent changes in information about diagnosis, intervention & outcomes?
4. What technology options (teleconferencing, videoconferencing, Internet, e-mail) can be used to make information retrieval and sharing easier?

## Interagency Collaboration and Funding

***Challenges:***

- With research and experience recommending more intensive interventions, young children with ASD tend to need and receive more services than have been typical in early intervention and preschool programs.
- In order to get additional or more intensive services, children with ASD often receive services from more than one agency. Many families of young children with ASD incur large out-of-pocket expenses in seeking what they believe are necessary services for their child.
- Interagency collaboration in policies, practices, and funding is the most effective and efficient way to support the varied needs of young children with ASD and their families. True interagency collaboration is difficult to achieve.
- For states to develop policies related to interagency collaboration and shared funding, agencies must address a variety of policy issues, including different criteria for eligibility, patterns of service delivery, quality control, creative funding structures, long-term collaboration and effective interagency communication.
- A well developed, interagency funding system is required to support this collaboration and the unique package of early intervention and preschool services needed by young children with ASD and their families.

***Policy Issues and Questions:***

1. Since services for children with ASD must be highly individualized, what mechanisms can be used by communities adopt an interagency process for each child and family that commits all relevant agencies to joint planning and appropriate service delivery?
2. To address the individualized needs of each child and family, what interagency funding system can be developed across agencies to combine specific funding sources, in order to support the full array of early intervention and preschool services that may be required?
3. How will the interagency funding system provide reimbursement for services provided in a variety of settings, by a variety of appropriate provider types, and in accordance with the IFSP or the IEP?
4. When funding services for children with ASD, how can systems combine federal, state, and local government funds with resources from private agencies including, but not limited to, Medicaid, private insurance, TRICARE, and other third party payers?
5. Since children with ASD and their families receive services and supports from a variety of agencies and providers, how can effective interagency mechanisms be put in place to address all components of an interagency system including: coordination of services; sustainability of services; communication between agencies and providers; training and supervision; quality control and monitoring; and data collection?
6. How can the interagency funding system support all necessary components of the collaborative system: the identification of young children with ASD; training of different types of providers (including paraprofessionals and other non-professionals); community and family supports and education; and the integration of all funding resources and policies across government entities and private agencies?

## Training

***Challenges:***

- In many communities, service providers do no feel adequately prepared to work with young children with ASD. While a tremendous amount of information is available through written publications and Internet resources, many providers may not have access to this information. If they do have access, they may struggle in choosing and using approaches and interventions because of a lack of local clinical expertise to assist in making decisions. Some approaches may be contradictory in regard to program philosophy, practices and intensity.
- Systematic training and technical assistance at the inservice level is critical. There are pros and cons in how training should be structured and provided from a systems perspective including ongoing support.
- Another challenge is making decisions about how to build local capacity. Some providers only need an awareness or basic level of knowledge in order to identify, refer and work collaboratively with providers who have specialized skills in ASD; other providers truly need specialized skills in assessment, intervention and program design for young children with ASD.
- Local programs need support for developing program capacity, often with limited resources, including how to provide options for children with ASD and their families that is individualized in a manner that is conceptually and philosophically coherent.
- Planning for preservice education requires considerations such as whether everyone should receive a basic level of knowledge and experience with ASD and the best way to accomplished this. Institutions of higher education provide varied levels of curricular content in the area of ASD. This is influenced by state administrative structures, regulations, and policies as well as by instructional expertise, availability and experience.

***Policy Issues and Questions:***

1. Should states develop and maintain separate training and technical assistance systems and activities specifically designed to support young children with ASD rather than incorporating specialized training within existing training and TA systems for young children with disabilities?
2. Should training and technical assistance activities and systems support and encourage eclectic approaches that incorporate elements of effective programs and interventions, especially in rural areas where incidence may be lower and resources scarcer?
3. Should training and technical assistance activities and systems be developed, implemented and evaluated at the state level reflecting specific philosophies, methodologies, and practices rather than just being designed on an individual basis by local programs as needs arise? How can training be funded and provided equitably across different areas of a state?
4. Should a basic level of knowledge and skill development in the area of PDD and ASD be a required competency of preservice certification and inservice staff development for all early interventionists and early childhood special educators?
5. How should states develop and provide a mechanism for ongoing, site-based training and consultation resources to ensure available expertise to support knowledgeable supervision of child and program level interventions?

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# Services For Young Children with Autism Spectrum Disorders (ASD) And Their Families

## Forum Overview and Background

To address the national challenge of providing high quality, effective and appropriate services for young children with autism spectrum disorders (ASD) and their families (birth through five), the National Early Childhood Technical Assistance System (NECTAS) has undertaken a series of related activities known as the NECTAS Forum on ASD. This report is intended to provide an update on Forum activities and plans for continued product development efforts, for the timeframe from initiation in October 1996 until completion projected for September 1999.

NECTAS is funded through a cooperative agreement with the US Department of Education, Office of Special Education Programs (OSEP) to provide technical assistance to support the early childhood initiatives of the IDEA (Individuals with Disabilities Education Act). Our clients include: the Infant and Toddler (Part C) Programs and the Early Childhood Special Education (Part B, Section 619) Programs in all states and jurisdictions and other early childhood projects, funded by OSEP. One of the technical assistance objectives outlined in this cooperative agreement was to conduct a Forum on issues of national significance, affecting the fields of early intervention and preschool special education.

Because of numerous requests for information and technical assistance (TA) from state agencies, service providers and parents, NECTAS, with the concurrence of OSEP, has focused a national Forum on policy and service issues related to meeting the needs of young children with ASD and their families. To oversee the efforts of the Forum, a NECTAS Core Forum Workgroup was assembled (see membership below). Over the past two years, we have conducted a series of problem solving and information gathering activities, which will be synthesized as descriptive papers and recommendations to the field. The ASD Forum activities to date have included three "think tanks", multiple information generating activities and two national conferences for state teams. The participants involved in these Forum activities have included a diverse group of stakeholders, including state agency personnel, service providers, families of young children with ASD, advocates, parent organizations, health care professionals, researchers, and model developers of nationally-known service approaches.

**Technical Assistance Conferences**

In 1997, NEC*TAS conducted two national TA conferences on developing state and local capacity to serve young children with ASD and their families. The first in Denver, included teams of people from 13 states and territories; the second meeting in Clearwater, FL included teams from 18 more states. A total of 204 participants attended the conferences. State teams included interagency groups of state planners, local service providers, parents and resource people who attended substantive sessions on effective practice and other service issues, and met together to develop plans for enhancing their state and local services. Both conferences had excellent faculty, representing a variety of service approaches and research interests. Most faculty members stayed throughout the meetings making themselves available to participants and state teams. These meetings offered the opportunity to conduct focus groups of parents, local service providers and administrators. Issues, barriers, expectations and recommendations from these groups were recorded and used to inform the ASD Forum activities. State team challenges, issues and plans were also documented. The information collected via these TA conferences was organized as additional data on national needs and the status of services. It has been used to focus, clarify and prioritize Forum work and products.

**Forum Activities and Products**

To date, the Forum activities have incorporated a variety of methods, including: "think tanks", focus groups, conference calls, web-based discussion Forums, literature reviews, policy analysis, survey research and other strategies. A large body of current information with relevance for the provision of effective developmental interventions and educational services for young children with ASD and their families has been generated, collected, organized and synthesized. Continued Forum work will translate these efforts into a number of products. During 1998 – 1999 the Core Forum Workgroup (see next page) will prepare Forum products (listed below), conduct broad reviews of them and disseminate these products nationally.

1. ***NECTAS Resource Collection on Autism Spectrum Disorders (May be ordered through NECTAS Publications)***

   A collection of articles and information materials which describes resources, organizations, research, special projects and other state and national initiatives related to young children with ASD. Special pieces created via Forum activities include:
   - *OSEP-Funded Early Childhood Projects and Project Resources on ASD* that focus on serving young children with ASD & their families, contains excerpts from a database of OSEP funded early childhood projects maintained by NECTAS on our website: ***http://www.nectas.unc.edu/;***
   - An *Annotated Bibliography* of published articles and books; and
   - *National Resources on ASD in Early Childhood.*

2. Journal and Newsletter Publications

Sperry, L.A., Whaley, K.T., Shaw, E. & Brame, K. (April 1999). Services for young children with autism spectrum disorders: Voices of parents and providers. *Infants and Young Children,* 11(4), 17-34.

The perspectives and experiences of parents and service providers were examined using a focus group methodology and analyzed for emerging themes regarding service delivery systems. Areas of convergence between the two groups included issues related to finance, training, family support, early identification, collaboration, advocacy, equity and inclusion.

Hurth, J. Shaw, E., Izeman, S., Whaley, K., & Roger, S. (in press). Areas of agreement about effective practices among programs serving young children with autism spectrum disorders. (Article requested for submission for a special issue on autism scheduled for 1999.)

For more information about the journal, Infants and Young Children, please contact:
Aspen Publishers, 7201 McKinney Circle, Frederick, MD 21704
800-638-8437, Web: http://www.aspenpublishers.com

Ziegler, M. (1999, Winter). One mother's reflections: Recent readings about autism. *Early Childhood Bulletin,* 1-6 [Available from the Federation for Children with Special Needs, 1135 Tremont Street, Boston, MA 02120, 617-236-7210]

This issue of the *Early Childhood Bulletin* is written by the parent component staff of NECTAS at the Federation for children with Special Needs. Personal perspectives are provided about interesting and useful books and booklets by the author who is the parent of an adult diagnosed with autism.

Ziegler, M. (1996, Winter). Report on autism conference sponsored by NECTAS. *Early Childhood Bulletin,* 1-4 [Available from the Federation for Children with Special Needs, 1135 Tremont Street, Boston, MA 02120, 617-236-7210]

This issue of the *Early Childhood Bulletin* written by the parent component of NECTAS is a summary of the content and activities of a national conference held in Hartford, Connecticut in February 1996.

3. ***Quality Practices / Service Approaches Monograph*** (working title)

This NECTAS monograph will describe quality practices, as implemented by various intervention approaches or model programs. Its summary will provide guidance to families and local service providers about program /resource development and decision-making regarding services. Chapters will address the following topics:

- Principles and values
- Characteristics of effective programs (instructional/developmental, not medical)

- Elements of effective programs (aspects of practice common among valid program models will be described. An exploration of how different programs or models theoretically and practically address or incorporate these elements will illustrate variations in implementation)
- Closing guidance and considerations for making choices and planning services

4. ***Policy Options and Considerations*** (working title)

   This NECTAS monograph will describe the following major national issues that could be impacted by policy at the federal, state or local levels:
   - Service Guidelines/Guidance;
   - Interagency Collaboration and Funding
   - Developing an Adequate Infrastructure for State and Local Service Systems
   - Early Identification
   - Training
   - Family Involvement
   - Inclusion

   For each of the above issue / policy areas, a set of policy options will be presented, and considerations and implications discussed. In addition, examples of different approaches and activities that states are using to address these issues will be described.

**Core Forum Workgroup**

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NECTAS staff at collaborating programs: Roxane Kaufmann and Don Kates (Georgetown University, Washington, DC), Ruth-Ann Rasbold (Federation for Children w/ Special Needs of Boston), Cindy Oser (ZERO TO THREE, Washington, DC).
Core consultant: Sue Izeman, NY
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NECTAS

National Early Childhood Technical Assistance System

# Quality Practices / Service Approaches
(Working title)

## Background

A section of the Quality Practices / Service Approaches monograph will describe elements of effective programs (aspects of practice common among validated, nationally known program models). An exploration of how different programs or models theoretically and practically address or incorporate these elements will illustrate variations in implementation.

The first step in developing this section of the monograph was to bring together (during the November 1997 Developing State and Local Services for Young Children with ASD and their Families technical assistance meeting) prominent researchers, program developers and parents. The task of this group was to identify those program components that are essential in high quality early intervention and preschool programs for young children with ASD. While the group of ASD experts and families approached intervention utilizing different approaches, they came to consensus on six key program areas: 1) earliest possible start to intervention, 2) individualization for children and families, 3) systematic, planful teaching, 4) specialized curriculum, 5) intensity of engagement, and 6) family involvement. In addition, this group identified three program components that are central to some but not all high quality programs. These three components are structured environment, developmentally appropriate practices, and intervention in settings with typical children or in natural environments.

The next step in developing a paper describing quality practices was to gather information from 19 programs from around the country that serve young children with autism and their families. The final monograph developed from this information will be disseminated to state and local agencies, early intervention and preschool providers, families, and others in the field of autism.

# Areas of Agreement

## Area #1: Earliest Possible Start to Intervention

Children who begin appropriate services earlier have better outcomes. During recent years, our concept of "early" has changed dramatically. As diagnostic procedures and tools improve, identification of children with ASD occurs earlier. Research has indicated that certain observable behaviors of the infant / toddler are predictive of being "at risk" for ASD or social / communicative delays. On the average, children are being diagnosed between the ages of 2-2 ½. While children under age two may be given a diagnosis within the spectrum, the reliability of such a diagnosis is unknown. Earliest intervention may also mean that children receive services appropriate to their needs before they have received a diagnostic label.

## Area #2: Individualization of Services for Children and Families

Individualization refers to adjustments in goals and intervention strategies for each child and family receiving services. Individualization means that the child's needs, strengths, and interests along with the family's concerns, priorities, and resources determine each child's program, as well as the overall theoretical and conceptual framework of the program. Individualization for children also means that families have a decision-making role, and that each family's individual needs for support and participation are honored. Usually, individualization for children and families occurs as part of the IFSP and IEP team process.

## Area #3: Systematic, Planful Teaching

In order to address the needs of children with ASD programs and services teach new skills in a manner that is both systematic and planful. Systematic means that the instruction or intervention is carefully thought out, logical, and consistent with a conceptual or theoretical basis. A program's underlying conceptualization is used to decide what to do, and to explain why intervention choices are made and/or modified. Systematic teaching involves planning, implementing, and assessing intervention steps. Planful teaching means that each step in an intervention is intentional, coordinated with an overall approach, and builds toward meaningful goals.

Systematic, planful teaching occurs within a wide variety of program models, and can look different within different programs. For example, programs may vary in terms of how child vs. adult-directed their intervention is. However, both child-centered and adult-directed programs can be very systematic and guided by underlying conceptualization, and both kinds of programs can be eclectic and spontaneous.

### Area #4: Specialized Curriculum

While children with ASD share many instructional needs with other children, there are developmental delays and difficulties that are specific to ASD. These areas of need include the development and use of language, the development of appropriate social interaction skills, restricted interests, and repetitive behaviors. Programs serving children with ASD address these specific areas of need with core curricula. Specific instructional goals and curriculum content typically address five skill domains outlined by Dawson and Osterling, 1997: attending to elements of the environment, imitating others, comprehension and use of language, playing appropriately with toys, and interacting socially with others.

### Area #5: Intensity of Engagement

Engagement refers to the amount of time that a child is attending to and actively participating in the social and nonsocial environment. In programs for children with ASD, intensity of engagement may be expressed as the percent of enrolled time that is spent in teaching interactions. In addition, the time that a child is engaged in learning opportunities may occur both during program time and during time that the child is at home or in community settings. Engagement may be facilitated by a variety of techniques including changes in materials and environment, activity-based or incidental teaching, and direct instruction. All programs who where represented at the NECTAS meeting described above reported that children are actively engaged at least 15 hours weekly and often 20 hours or more weekly. Programs varied in where, how and who instructed or supervised a child's participation in various instructional and social interactions.

### Area #6: Family Involvement

While there is widespread consensus that family support, training, and other forms of involvement play a key role in maximizing learning and skill gains of the child, there are at least five ways that families are involved in high quality programs for young children with ASD. These are: 1) **Family involvement in their own child's program; 2) Services that are provided to families primarily because their child has ASD; 3) Services that are provided to families that are not directly related to ASD; 4) Family support and networking;** 5) **Family involvement in the overall program.**

## Areas That Are Part Of Some, But Not All Programs

Three additional program components are key parts of several programs represented at the NECTAS meeting described above, but were not common to all participating programs. These three areas are a structured environment, developmentally appropriate practices, and intervention in settings with typical children or in natural environments.

### Structured Environment

Many programs arrange the environment, instructional materials, and teaching interactions to elicit, facilitate, or support specific skill attainment or development. This structure may include use of environmental arrangements or visual cues to organize or schedule activities, to facilitate choices, and to define work, play, or rest spaces.

### Developmentally-Appropriate Practices

Many programs use teaching practices that have been designed for all young children, with and without disabilities, as the core of a program for young children with ASD. Developmentally appropriate programs are guided by information about child development and learning, each individual child's strengths, needs, and preferences and knowledge of the social and cultural contexts in which children live. Programs using developmentally appropriate practices build knowledge and skills through child-directed activities, responsive teaching, and children's active learning.

### Intervention in Settings with Typical Children or in Natural Environments

Many programs that serve young children with ASD plan for some or all interventions to occur in settings that with typical children. This may include designing fully integrated toddler or preschool settings, supporting children with ASD in community childcare or preschool settings, and providing intervention in community recreation activities. For children under 3, intervention in natural environments means providing support to children and families in the home and community settings.

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# Policy Options and Considerations
(Working title)

***Background***

The first step in the development of this draft monograph was to ask each of the 31 state teams that attended a NECTAS technical assistance meeting on "Developing State and Local Services for Young Children with ASD and Their Families" in 1997 to identify three challenges in developing services for young children with ASD. These challenges were categorized into 6 policy areas: Early Identification, Family Involvement, Service Guidelines, Developing an Adequate Infrastructure, Interagency Collaboration and Funding, and Training. These policy areas were discussed and further refined during two "think tank" days. The participants involved in these activities have included a diverse group of stakeholders including state agency personnel, service providers, families of young children with ASD, advocates, parent organizations, health care professionals, researchers and model developers of nationally known service approaches. From November of 1998 through the present, small stakeholder workgroups are discussing policy options and considerations for each of the policy areas above. Each policy area will include a description of the issues, policy options and considerations and state examples. NECTAS plans to begin dissemination of each policy area in the winter 1999.

# THE WHITE HOUSE *BULLETIN*

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MEMORANDUM FOR BRUCE REED
THE WHITE HOUSE

SUBJECT: **TODAY'S BRIEFING**

DATE: **TUESDAY, AUGUST 3, 1999**

**OFF THE WIRES:**

- **Taiwan Says China Missile Test Is Not A Threat.** Taiwanese Defense Ministry spokesman Kung Fan-ding said today that China's test-launch of a long-range missile was not a threat to the island. Kung said at a regular weekly news briefing, "This has no big effect on us." Taiwan Defense Minister Tang Fei however, criticized China for the test-launch, saying, "From the perspective of world peace, we don't think this is an act worthy of praise."

**IN THE WHITE HOUSE AND AROUND TOWN:**

- **Clinton Speaks On Welfare Reform Touting New Signs Of Improvement.** Touting new numbers showing the lowest percentage of Americans on welfare since 1967, President Clinton told a Chicago audience that he will urge businesses to hire more welfare recipients off the rolls and call for businesses to invest more in poverty-stricken areas of the country, reiterating the theme behind his poverty tour last month. Clinton was also expected to push for the states to spend their $4.2 billion in unspent welfare money, as well as ask Congress not to request a return of those funds.

  Extolling the virtues of welfare reform, President Clinton said today, "It's difficult to remember that seven years ago our country was largely out of work and out of ideas. Our economy was stagnant, burdened with a crushing debt and soaring deficits, high interest rates and high unemployment, but so was our political debate. For some, the welfare system was our last line of defense against abject poverty; to others, it was Exhibit A of America's decline. Clearly it had become a system that undermined our cherished values of work and family. ... I asked the American people to change course, to restore with all of our people the fundamental bargain that we ought to have opportunity for all in return for responsibility from all our citizens, and to include everyone in America's community. Today the bargain is being fulfilled, and our country is working again. We have the longest peacetime expansion in history, nearly 19 million new jobs; the lowest unemployment in a generation; the lowest minority unemployment ever recorded; the highest home ownership in history. From a deficit of $290 billion we are moving to a surplus of $99 billion. And this year alone, we will pay $85 billion on our national debt. And a big part of this is the decision that the American people, through their elected representatives, made to end welfare as we know it. We raised the minimum wage and passed the earned income tax credit, which says to working families, if you work full time, you shouldn't have to raise your children in poverty. We gave 43 waivers to states to launch their own welfare reform efforts when I took office, and then in 1996, as has already been said, big bipartisan majority – big majorities of both parties in both Houses reached across the divide to pass this welfare reform bill. We recognize that in addition to requiring able-bodied people to work within a certain period of time, millions of people who had never known anything but dependency, who had never even seen, many of them, their own parents have a job, could not make the transition on their own or easily. So we made sure there was extra support for child care, for transportation, for housing, and we kept the national guarantee – after

two vetoes -- but we kept the national guarantee of medical care and nutrition for the children of people on welfare, and for those moving off."

Clinton continued, "We also provided new tax incentives to encourage employers to hire people from welfare. Today I am very proud to be able to tell you that all 50 states and the District of Columbia have now met the work requirements for the percentage of people on welfare in their states that have to be in work that we set in 1996. Every single state is in compliance. The welfare rolls have been cut in half. They're at their lowest level in 32 years. And those who are on welfare today are four times as likely to work as when I took office. Now while some of the credit doubtless goes to our booming economy, the Council of Economic Advisers recently did a study for me which found that welfare reform, with its new emphasis on work, has been the single most important factor in reducing the rolls. Three quarters of the 6.8 million people have left welfare since I took office did so after welfare reform was signed in 1996. And many who left before did so under the reform efforts adopted by the states. The credit goes to all of you in this audience and people like you across our country. When we passed the law in '96, I said moving Americans from welfare to work would take the commitment of every element of our society not just government, but businesses, faith-based organizations, community groups and private citizens." Clinton added, "Members of this Welfare to Work partnership, businesses both large and small have given -- listen to this: Just the members of this partnership have given 410,000 welfare recipients the opportunity to have a job. More than eight in 10 executives report great success in hiring people off welfare rolls. They're finding these employees are a good investment. They work hard, they stay in their jobs as long or even longer than other employees. In this era of labor shortages, we must not forget that welfare recipients can be a rich pool of untapped talent, people who are good for the bottom line. I thank you for recognizing the important role you can place in extending these opportunities to all Americans."

***Boehner Links Uninsured To Unfinished Welfare Reform.*** Responding to Clinton's speech today, Rep. John Boehner said the Democratic Patients' Bill of Rights is a "poison pill" for welfare recipients because it does not address the uninsured. Many of those uninsured, according to Boehner, are former welfare recipients who have gone to work in small businesses not able to afford health plans for their employees. Boehner charged the Democratic Patients' Bill of Rights "makes virtually no effort to expand access for the uninsured" and pushed for legislation to create Association Health Plans that would allow small businesses to pool their resources in buying health insurance.

- **Gore, Democrats Urge Relief For Farmers, Blast GOP.** At a press conference this morning, Vice President Al Gore, Senate Minority Leader Tom Daschle, House Minority Leader Dick Gephardt and Sen. Tom Harkin discussed the $10 billion emergency farm assistance amendment being offered by Daschle and Harkin. Gore said farmers "are really hurting badly. There has actually been more attention in the news media to the reservoirs that are drying up than the farms that are going broke. And I think it's time that we really begin to respond quickly, with a great and appropriate sense of urgency, to the crisis in farm country." Gore continued, "We've had several factors that have all come together to create what many are now saying could turn out to be the worst crisis that our farmers have ever experienced. Prices are very low for everything at the same time. There have been times in the past where some crops were down and others were up, some livestock prices were down and others were up. It's extremely unusual to have wheat prices down, corn prices down, bean prices down, cattle prices down, pork prices the lowest since the Great Depression, and nor way for farmers to raise anything where the price they sell for exceeds the cost of their productions." Gore added, "This is a quiet crisis in farm country this time around. We haven't had the tractor convoys coming to surround the Capitol building. We haven't had the great mass demonstrations. Oh yes, there have been some, but it's not like it was in the past. The crisis, though, is deeper than it was in the '80's."

  Gore blasted congressional Republicans saying, "This year we have the biggest surpluses in the history of the world, and that bunch in control in there is trying to blow it all on a risky tax scheme while the whole farm sector of economy is on the verge of absolute bankruptcy." Gore continued, "You know, farming is different from almost any other kind of occupation. Because it's seasonal in nature, all product comes to market at the same time and you are subject to the vagaries of weather and the

unpredictable circumstances in the market when you sell your crop or your livestock. And as a result of that unique difference, ever since agriculture has existed, countries that care about their farmers and ranchers have had policies in place to ensure that their farmers survive during the hard times that are bound to come so that they and the rest of the country can prosper during the good times that also come. Well, we've had a stretch of hard years here. And yet this Congress passed the Freedom to Farm Act. Many of us said at the time, this is designed only for the good times. And we know from history and experience there will be bad times. What's going to happen then? The market will take care of it, they said. But the market's different in agriculture. If taking care of it means driving most farmers out of existence, that's not good enough, and that's why we need this amendment that is pending today. If they vote against it, then they're turning their backs on a terrible crisis in American agriculture." Gore said the Daschle-Harkin amendment "will help us meet this crisis head on. And that is why I'm proud today to announce my support for the Daschle-Harkin amendment and urge the Congress to pass it and get on with meeting this disaster head-on and helping our farmers." Gore took a parting shot at Republicans saying, "This proposal will work. The Republican response to the farm crisis in America is basically to deny that it exists, to wait it out, to pretend that market forces are going to solve the problem. Well, you know the old shop-worn cliché, 'Denial ain't just a river in Egypt.' They can't deny the existence of this problem. But any one of them that goes out there and votes against the Daschle-Harkin amendment is sticking his head in the sand and pretending that this tremendous crisis out in farm country is not taking place."

Daschle said, "Today at long last we'll have the opportunity to vote on meaningful emergency assistance to farmers and ranchers all over this country." Daschle continued, "It's important for us to pass this emergency legislation today. Democrats will be offering $10 billion in emergency aid, in an effort to offset some of these losses, in an effort to build a bridge to a better economy in the out years. There is a very big difference between what Republicans are offering and what Democrats are offering in this emergency aid package. Believe it or not, there is not one dollar of disaster assistance in the Republican package. And so it's critical that people look very closely at both the Democrat and Republican bills." Daschle added, "We want very much to help farmers and we don't care whether it's Republican or Democratic. In fact it's our view that Republicans and Democrats need to come together to do the right thing to get assistance out now. Not next September, not next October, but this month before we leave in the August recess, before the situation gets any worse."

Gephardt said, "The farm economy is in a state of crisis, which is a result of natural and man made disasters. We cannot sit idly by and watch thousands of family farmers move to the brink of fiscal catastrophe. Congress must act now to provide help." Gephardt said the 1996 Freedom to Farm Act has left family farmers "with no safety net during the freefall in commodity and livestock prices. It's time that we begin the fundamental work to repair the damage that this so-called Freedom To Farm Act has wrought. We need to start today. The farm crisis is truly an emergency and calls for emergency measures. The farm belt has been hit by one of the worst droughts in a century and an economic tidal wave caused by collapsing global prices and an Asian recession." Gephardt called the Senate proposal "a great starting point to begin the debate on safety net reform," adding, "As Tom, said, time is of the essence. And I'm thankful that Senate Democrats have had the courage to stand now for many months for real change in this program. This Congress has a miserable record of moving aid packages for natural disasters. I sincerely hope that the Republican leadership can raise the issue to the top of the agenda, not only in the Senate but in the House as well, where we need action."

***Glickman Testifies On Drought Conditions, Says Freedom To Farm Needs To Be Re-Examined.*** Testifying in front of the Senate Agriculture committee today, Secretary of Agriculture Dan Glickman commented on the drought saying, "I think emergency legislation is needed. But I also believe that it is appropriate for Congress to address the substantive issues of the current farm policy." Glickman added, "We have weak global economic growth, successive years of large global farm production -- this is the fourth year of probably worldwide record crop production -- and at the same time we've had drought and weather problems, last year in the south and southwest, this year in the mid-Atlantic region and other parts of the country as well." Glickman refused to specify how much

money he thought would be needed for farmers, saying, "I don't want to be in a position of saying you have to spend 'x' dollars or 'y' dollars."

Meanwhile, a Senate GOP leadership source said it is unclear whether the nearly $7 billion GOP bill or the nearly $10 billion Democratic bill will pass today.

- **Tax Conferees Near Agreement.** Conferees working to reconcile House and Senate passed tax cut legislation are expecting to wrap up work today, according to Hill sources. A Senate GOP leadership source said this morning that there are only about "30 minutes worth" of decisions left to be made by the principals, though much more work remains to be done by staff. The leadership source declined, however, to identify what has been agreed to and what remains to be decided. The leadership source added that the conference went until almost 2:00 am this morning as GOP leaders try to keep on schedule to pass a conference report by the end of this week in both chambers.

- **Richardson Says Lee Used Race Card.** Responding to former Los Alamos scientist Wen Ho Lee's denials on '60 Minutes' that he provided China with US nuclear secrets, Secretary of Energy Bill Richardson said today that Lee used his race to show himself as a victim after he "massively violated our security system." Commenting to reporters on Lee's assertion that he was unfairly targeted because of his Asian descent, Richardson said, "The suspect unfairly tried to use the race card. He tried to portray himself as a victim after he massively violated our security system." Richardson added, "I have little sympathy for him."

- **Republican Senators Tout High-Tech Goals.** Members of the Senate Republican High-Tech Task Force this morning held a press conference to tout their high-tech priorities, such as making the research and development tax credit permanent, and expanding the high-tech visa program. The task force includes Sens. Trent Lott, Bob Bennett, Bill Frist and Spencer Abraham. Bennett, chairman of the task force, said the group was "meeting for two reasons." First, to urge the "continuation and stability of the R&D tax credit." Bennett said members of the task force "have sent this morning to the President a letter asking the President to sign the continuation -- or the making permanent, if you will -- of the R&D tax credit." Bennett continued, "Remember what we're dealing with, Mr. President. We're dealing with investment in R&D in the part of his economy that is the most vibrant and that is making the greatest contributions to our productivity. Right now, legally, the R&D tax credit does not exist. It has to be renewed. We are calling upon you, Mr. President, in this letter not only to renew it, but to make it permanent so that the people involved in this industry need not worry from year to year as they make out their tax returns whether or not they can charge off the R&D that is so essential to their future." The "second reason," Bennett said, was to tout efforts to pass other legislation intended to stimulate the growth of e-commerce, including legislation to create legally binding electronic signatures, to expand the high-tech visa program designed to address a shortage of skilled workers, to provide tax credits to companies who donate computer equipment to schools and senior citizens' centers, and addressing abuses by "cybersquatters" who attempt to profit by seizing popular domain names.

- **Bliley Letter To Barton On Electricity Restructuring Seen By Some As Encouraging.** In a July 29 letter to energy and power subcommittee chairman Joe Barton, House Commerce Committee Chairman Tom Bliley asks Barton to hold a subcommittee vote on a bill by September 21. While some insiders view the letter as somewhat unorthodox, others see it as a positive signal that the subcommittee is back in charge of moving electricity deregulation legislation.

  One House GOP source said this morning, "We see that as very good" because "it puts the subcommittee back in charge." The GOP source noted there "was a question" in the minds of many on the subcommittee that as a result of the Bliley four-page draft outline on restructuring legislation responsibility for developing legislation "was shifting" from the subcommittee to the full committee. The GOP source said it is likely a Barton draft will be released to subcommittee members and staff before the August break, and the markup vehicle should be near completion by the time members return from the August break.

In his letter to Barton, Bliley stated, "I'm a believer in competition, plain and simple. ... In 1992, despite your reluctance, we passed the Energy Policy Act which opened the grid to nondiscriminatory national wholesale electricity markets. No one can argue that wholesale competition isn't good – it saves $5.4 billion annually. And since 1994, I've been after fair retail competition for residential consumers. Just talking about the benefits of retail competition has caused a dramatic movement toward competition in the States – up to 23 at last count. I believe the task before us now is to tie together all of these state laws in a logical fashion and pass legislation to ensure the benefits of competition by establishing a whole, national retail marketplace."

Bliley continued, "Over the past few weeks, you and I have been working diligently to develop a joint product. Much progress has been made. But there are a number of outstanding details that still need to be addressed. Joe, I think I have adopted your view that complete agreement on every single detail is not paramount at this stage of the process. At this point we shouldn't let the perfect be the enemy of the good. What is important is that we get a bill before the subcommittee members upon which you can act in short order. So, with this in mind, I'm suggesting that you put together a subcommittee mark that you can get behind and take it to a subcommittee vote, no later than September 21." Bliley concluded, "In short Joe, you are right, time is of the essence. Your efforts will be considered a priority for Committee scheduling purposes and you will have the use of Committee staff for your drafting needs."

- **Cloture Vote Tomorrow On Milk Marketing Amendment.** An aide to Sen. James Jeffords said a cloture vote is expected tomorrow morning on a milk marketing amendment introduced by Majority Leader Trent Lott on behalf of Jeffords and Sen. Patrick Leahy. According to the aide, the amendment would prevent Agriculture Secretary Dan Glickman from implementing a final rule on milk marketing on October 1. Although 61 senators last year wrote Glickman urging him to select Option 1A, Glickman instead chose Option 1B. The Jeffords amendment would prevent any rule from being implemented until Congress has an opportunity to address the dairy program. A Jeffords spokesman said implementation of Option 1B would result in "millions of dollars in lost income" for dairy farmers.

- **Riley Blasts Republican Senators For Introducing Teacher Empowerment Act.** A group of GOP senators announced this morning that they are introducing in the Senate a bill passed by the House designed to provide local education jurisdictions flexibility in improving their teaching staffs. The introduction drew a blast from Education Secretary Richard Riley.

  Riley said, "I am disappointed to see members of the U.S. Senate pretend to address the serious issue of teacher quality by introducing a thinly veiled attempt to eliminate the President's class size reduction program. As with the House's similar proposal, this bill is a flawed attempt to improve teacher quality. It not only fails to preserve the bipartisan commitment to reduce class size in early grades, but also neglects to adequately target resources to the communities most in need. This approach could in fact allow Federal funds to replace local or state support for critical education initiatives instead of increasing overall investment in schools. This measure is unacceptable, and the President has already rightly said he'd veto its House counterpart." Riley continued, "We can and must reduce class sizes and ensure well-trained teachers in our nation's schools. That's why the President has submitted a serious plan to improve education by reducing class size, supporting meaningful teacher training, expanding rigorous alternative pathways to teaching, targeting resources to the neediest students and schools, and holding states, districts and schools responsible for results. I look forward to working with Congress to pass meaningful legislation that addresses these issues and truly helps our students, teachers, parents and schools."

**LAST LAUGHS:**

**Late Night Political Humor.**

***Jay Leno:*** "Back East, man, back East, still have these drought warnings. In fact, in Washington, it is so hot and dry, Hillary has become delirious, man!"

***Jay Leno:*** "Let's see what's going on with Hillary 'The Enabler' Clinton."

***Jay Leno:*** "For the first time, it seems, in an interview, a new magazine called Talk, Hillary Clinton has spoken out about President Clinton's affair and she says that Bill's affair with Monica was a sin of weakness. Well, that's kind of an understatement, isn't it, huh? Saying Clinton has a weakness for women is kind of like saying Jeffrey Dahmer has an eating disorder, isn't it?"

***Jay Leno:*** "She blamed all of Bill's problems on troubled childhood. In fact, when he heard it, Clinton said, 'She bought it! Yes, yes!'"

***Jay Leno:*** "She says Bill told her the reason he cheated was because when he was a boy, his mother didn't get along with his grandmother. Now, men -- men, please, don't try these lies at home, okay? They won't work for you. President Clinton is a professional, okay?"

***Jay Leno:*** "You thought OJ had the lamest alibi in history? Oh, man!"

***Jay Leno:*** "And in the interview, Hillary said until the Monica Lewinsky story broke, she thought Bill had been faithful to her since 1987. You know why she didn't see it coming? Too busy watching Yankees games. You know, she's such a fan."

***Jay Leno:*** "Let's see what you have here now. You got Clinton's been fined $90,000, Linda Tripp has been indicted. You know what we should do to punish these two? Make them go on a date together, okay? Have Bill and Linda spend a couple of hours at the Olive Garden with each other. That will teach them a lesson."

***Jay Leno:*** "Today, President Clinton was a little surprised when he heard Monica Lewinsky flipped her Ford Explorer. He said, 'Car accident? I thought she was supposed to be shoved down the stairs. What happened?'"

***Jay Leno:*** "Well, that terrible drought continuing in the Midwest there. In fact it was so dry in Iowa today, listen to this, Steve Forbes actually blinked his eye."

***David Letterman:*** "Hillary Clinton, your next senator from the great state of New York. Hillary Clinton...says the reason her husband, Bill, our president, the reason Bill chases women is because of a conflict with his grandmother and his mother, you know? Oh, yeah, maternal conflict, maternal conflict. I'm telling you, that'll turn you into a philandering perjurer every time."

***David Letterman:*** "Hillary also said that it will be up to her husband to remain faithful while she's campaigning. But just to be sure, she's going to have Lo-Jack put on his pants."

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# National Contacts and Other References on ASD in Early Childhood

a part of the

*NECTAS Resource Collection on Autism Spectrum Disorders*

Kathy T. Whaley, Evelyn Shaw,
Siobhan Colgan, Laurie Sperry, &
Lisa Napp, Editors

NECTAS
National Early Childhood Technical Assistance System

IDEAs that Work
Office of Special Education Programs

This resource is part of a larger resource collection available from NECTAS on autism spectrum disorders in early childhood. Additional copies of the resource packet are available at cost from the coordinating office at:

NECTAS
137 East Franklin Street, Suite 500
Chapel Hill, NC 27514-3628
(919) 962-2001 (voice); (910) 962-8300 (TDD)
(919) 966-7463 (fax)
E-mail: nectas@unc.edu
URL: http://www.nectas.unc.edu/

July 1999

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# Introduction

This collection of national contacts was developed to help others acquire information and link to a variety of agencies, associations, and organizations. Most of the listed organizations and agencies are specific to the topic of autism. However, we have included others that are not exclusively focused on Autism Spectrum Disorders (ASD), but that have developed materials or services on this disorder that we think readers will find useful. The inclusion of a contact in this publication does not imply its endorsement by NECTAS or by the Office of Special Education Programs.

The contacts were selected after reviewing other references and conducting a search on the World Wide Web. These electronic contacts link to a large number of other resources; however, we chose to limit our selection to nationally recognized agencies and organizations. While most of these contacts are Web-based, they also are accessible via phone and mail.

Contacts are organized in the following sections:

- National Contacts on ASD;
- Other Disability and Health Contacts;
- Network of Autism Training and Technical Assistance Programs (NATTAPs);
- Network of Collaborative Programs of Excellence in Autism (CPEAs); and
- Lovaas Institute for Early Intervention (LIFE) replication sites.

We hope you find this document to be useful and timely, and we welcome your comments and suggestions.

# National Contacts on Austism Spectrum Disorders

**Aspen of America, Inc.**

P. O. Box 2577
Jacksonville, FL 32203-2577
904-745-6741
E-mail: aspen@cybermax.net
URL: http://www.asperger.org/

Aspen of America, Inc., is a national nonprofit organization formed to increase awareness of and provide information and support for individuals with Asperger's Syndrome and other related neurological disorders. Its Web site features articles and links to other sites as well as organizational goals and future activities.

**Autism National Committee**

635 Ardmore Avenue
Ardmore, PA 19003
(610) 649-9139
Fax: (610) 649-0974
URL: http://www.autcom.org/

The Autism National Committee is an advocacy organization that provides information, support, networking, advocacy in legislation and policy, the *Communicator* newsletter, a bookstore, book reviews, publications, and reviews of research and treatment issues.

**Autism Network International**

P. O. Box 448
Syracuse, NY 13210-0448
E-mail: bordner@uiuc.edu
URL: http://www.students.uiuc.edu/~bordner/ani.html

ANI is a self-help and advocacy organization run by and for people with autism. Its purpose is to share information, to provide support to peers, and to help with coping and problem solving. Membership includes a subscription to the quarterly newsletter, *Our Voice*.

**Autism Research Institute (ARI)**

4182 Adams Avenue
San Diego, CA 92116
(619) 281-7165
Fax: (619) 563-6840
URL: http://www.autism.com/ari/

ARI conducts research on preventing, diagnosing, and treating autism and other severe behavior disorders of childhood. It conducts research and other activities in collaboration with the Center for the Study of Autism *(see listing on page 2)*. ARI is developing a database to record and analyze biomedical data. Linkages among parents and researchers are facilitated with consent. ARI publishes *Autism Research Review International*, a quarterly newsletter covering biomedical and educational advances.

**Autism Resources (Web site)**

Web Site Author: Steve Cory
137 East Franklin Street, Suite 203
Chapel Hill, NC 27514
URL: http://www.autism-info.com/

This site features a map of the United States on which the user can point and click on any state to view links to that state's educational resources, planning councils, and insurance department. The site also provides links to national agencies, medical research, behavior modification resources, educational options, and on-line chat sites.

**Autism Services Center**

The Prichard Building
605 Ninth Street
P.O. Box 507
Huntington, WV 25710-0507
(304) 525-8014
Fax: (304) 525-8026

This agency operates the National Autism Hotline to provide information on autism, referral, advocacy efforts, and other resources for parents, educators, students, and others.

## National Contacts on ASD, *continued*

**Autism Society of America**

7910 Woodmont Avenue, Suite 300
Bethesda, MD 20814-3015
(800) 328-8476;
(301) 657-0881, ext. 107 or 115
Fax: (301) 657-0869
URL: http://www.autism-society.org/

ASA offers a variety of general information on autism for parents and professionals. The organization and its Web site provide links to ASA chapters and resources, discuss issues related to the Individuals with Disabilities Educational Act (IDEA), link to national resources, and provide parent perspectives and information packages. ASA publishes The *Advocate* newsletter.

**CAN (Cure Autism Now)**

5225 Wilshire Boulevard, Suite 226
Los Angeles, CA 90036
(888) 8-AUTISM; (323) 549-0500
Fax: (323) 549-0547
E-mail: CAN@primenet.com
URL: http://www.canfoundation.org/

CAN was founded by parents and is dedicated to finding effective biological treatments and a cure for autism. Its Web site provides information on autism resources and research, including the Autism Genetic Resource Exchange Project.

**The Center for the Study of Autism (CSA)**

P.O. Box 4538
Salem, OR 97302
URL: http://www.autism.org/

Disseminates information and conducts research on the efficacy of various interventions. Research is primarily conducted in collaboration with the Autism Research Institute *(see listing on page 1).* The CSA Web site discusses issues and interventions on autism and related topics and provides links to other resources on autism. Special resources for and about siblings are available.

**Indiana Resource Center for Autism (IRCA)**

Institute for the Study of
Developmental Disabilities
Indiana University
2853 East 10th Street
Bloomington, IN 47408-2601
(812) 855-6508
TT: (812) 855-9396
Fax: (812) 855-9630
URL: http://www.isdd.indiana.edu/~irca/

IRCA develops and disseminates information, engages in research activities, sponsors outreach training events, and conducts individual consultations. Its Web site discusses these activities, contains a bibliography, and posts upcoming conferences and workshops sponsored by the IRCA.

**Lovaas Institute for Early Intervention (LIFE)**

Department of Psychology
University of California at Los Angeles (UCLA)
1282-A Franz Hall
P. O. Box 951563
Los Angeles, CA 90095-1563
(310) 825-2319
URL: http://www.lovaas.com/

Information is provided on the Lovaas treatment methods, training opportunities, and behavior modification approaches. Contact information for the NIMH-funded Lovaas Institute Replication Sites is provided. *(See pages 16 and 17 for a list of the Lovaas replication sites.)*

**MAAP (More Advanced Individuals with Autism Asperger's Syndrome, and Pervasive Developmental Disorder)**

P. O. Box 524
Crown Point, IN 46307
(219) 662-1311
Fax: (219) 662-0638
E-mail: chart@netnitco.net
URL: http://ww2.netnitco.net/users/chart.maap.html

This nonprofit organization provides information on Asperger's syndrome and PDD. Opportunities for networking among families and professionals are provided as well as resource materials, training opportunities, and the quarterly newsletter *The MAAP.*

## National Contacts on ASD, *continued*

**The National Alliance for Autism Research**

414 Wall Street
Research Park
Princeton, NJ 08540
(888) 777-NAAR; (609) 430-9160
Fax: (609) 430-9163
E-mail: naar@naar.org
URL: http://www.naar.org/

This national nonprofit organization is dedicated to funding and accelerating biomedical research in autism. Its Web site provides information on research in the prevention and effective treatments of autism spectrum disorders, the *NAARRATIVE* quarterly newsletter, and reports on Alliance activities. *(Also see the NAAR editorial in the Overview section of the* NECTAS Resource Collection on ASD.*)*

**On-line Asperger's Syndrome Information and Support (OASIS) (Web site)**

E-mail: bkirby@udel.edu
URL: http://www.udel.edu/bkirby/asperger/

This site, developed by a parent for other parents seeking support and information, provides a range of information on Asperger's Syndrome. The site provides links to other sites related to Asperger's Syndrome and related disorders and to on-line support groups; lists books and articles; and discusses research, conferences, and workshops on this disorder.

**Society for the Autistically Handicapped (SFTAH) (U.K.)**

199/201 Blanford Avenue
Kettering, Northants NN16 9AT
United Kingdom
Phone/Fax: 01536 523274
URL: http://www.rmplc.co.uk/eduweb/sites/autism/index.html

Provides information on a diagnosis and assessment resource center, international references and training efforts, and provides links to information on childhood vaccines and autism.

**TEACCH**

310 Medical School Wing E
University of North Carolina at Chapel Hill
CB #7180
Chapel Hill, NC 27599-7180
(919) 966-2174
Fax: (919) 966-4127
E-mail: teacch@unc.edu
URL: http://www.unc.edu/depts/teacch/

TEACCH (Treatment and Education of Autistic and Related Communication Handicapped Children) is a statewide service system of research, training, and programming for children with autism. Its Web site features articles and information from TEACCH faculty and staff, material from the North Carolina chapter of the Autism Society of America, and other items related to autism.

**Yale Developmental Disabilities Clinic**

Yale Child Study Center
230 South Frontage Road
P.O. Box 207900
New Haven, CT 06520-7900
(203) 785-2513
Fax: (203) 737-4197
E-mail: kathy.coenig@yale.edu
URL: http://info.med.yale.edu/chldstdy/autism/

The Web site of this research and diagnostic facility provides information about autism, PDD, Asperger's Syndrome, and related conditions. It provides answers to frequently asked questions, and describes current research and clinical activities.

# Other Disability and Health Contacts

**American Academy of Child and Adolescent Psychiatry**

3615 Wisconsin Avenue NW
Washington DC 20016
(202) 966-7300
Fax: (202) 966-2891
URL: http://www.aacap.org/

This organization's Web site provides access to journal abstracts, information for families and professionals, fact sheets, and a directory to its members who are licensed child and adolescent psychiatrists.

**American Academy of Pediatrics**

141 Northwest Point Boulevard
Elk Grove Village, IL 60007-1908
(847) 228-5005
Fax: (847) 228-5097
Web: http://www.aap.org/

AAP's Web site offers access to publications and information about child health, parenting, and pediatric practices. Journal abstracts are available through a search function. Policy statements on a range of issues are available, including a policy paper on autism developed by the AAP Committee on Children with Disabilities, which can be accessed through the "Publications and Services" section of the AAP Web site.

**The American Occupational Therapy Association, Inc.**

4720 Montgomery Lane
P.O. Box 31220
Bethesda, MD 20824-1220
(301) 652-2682
Member Line: (800) 729-2682
Fax: (301) 652-7711
E-mail: praota@aota.org
URL: http://www.aota.org/

AOTA's Web site offers information on occupational therapy, publications, association conferences, and periodicals. It features a topical search function yielding information on autism, and links to a bibliographic database of AOTA journals and periodicals.

**American Psychological Association**

750 First Street NE
Washington, DC 20002
(202) 336-5500
Fax: (202) 336-5776
URL: http://www.apa.org/

The APA provides information on psychology and its different applications. PsycInfo is a search engine to the Web site's electronic database of over 1,350 scholarly journals. Access to organization publications, including journals, is available.

**American Speech-Language-Hearing Association**

10801 Rockville Pike
Rockville MD 20852
(800) 638-8255; (301) 897-5700
TTY: (301) 897-0157
Fax: (301) 571-0457
URL: http://www.asha.org/

Provides information on speech, language, and hearing disorders. ASHA provides written materials to educate consumers of audiology and speech-language pathology services about a range of related disabilities. Access to association journals through the Web site includes tables of contents and selected abstracts.

**Division for Early Childhood of the Council for Exceptional Children**

Executive Office
1444 Wazee Street, Suite 230
Denver, CO 80202
(303) 620-4579
Fax: (303) 620-4588
E-mail: dec_execoff@ceo.cudenver.edu
URL: http://www.dec-sped.org/

A nonprofit membership organization that provides information to individuals who work with or on behalf of children with special needs, ages birth through 8, and their families. The Web site offers information on services, position statements, governmental action (Children's Action Network), and two journals.

## Other Disability and Health Contacts, *continued*

**ERIC Clearinghouse on Disabilities and Gifted Education**

The Council for Exceptional Children (CEC)
1920 Association Drive
Reston, VA 20191-1589
(800) 328-0272; (703) 264-9449 (TTY)
Fax: (703) 620-2521
E-mail: ericec@cec.sped.org
URL: http://www.cec.sped.org/ericec.htm

Operated by the Council for Exceptional Children, this national information network acquires, catalogs, summarizes, and provides access to educational information from many sources.

**Family Village (Web site)**

Waisman Center
University of Wisconsin-Madison
1500 Highland Avenue
Madison, WI 53705-2280
E-mail: familyvillage@waisman.wisc.edu
URL: http://familyvillage.wisc.edu/

This project integrates information, resources, and communication opportunities on the Internet through the Family Village Web site. Information is provided on specific diagnoses, adaptive products, technology, recreational issues, education, and other disability specific resources. Numerous autism related links are available.

**Federation of Families for Children's Mental Health**

1021 Prince Street
Alexandria, VA 22314
(703) 684-7710
Fax: (703) 836-1040
URL: http://www.ffcmh.org/

This organization, operated by parents, focuses on the needs of children and youth with emotional, behavioral, or mental disorders and of their families. Information is available on SSI and managed care, and links are provided to organizations for parent support, childhood disorders, mental health, and research.

**National Information Center for Children & Youth with Disabilities (NICHCY)**

P.O. Box 1492
Washington, DC 20013
(800) 695-0285 (voice and TTY)
(202) 884-8200 (voice and TTY)
Fax: (202) 884-8441
E-mail: nichcy@aed.org
URL: http://www.nichcy.org/

NICHCY is a national information and referral center that provides information on disabilities and disability-related issues regarding children and young adults for families, educators, and other professionals. A variety of publications — including fact sheets on specific disabilities, state resource sheets, parent guides, bibliographies, and issue papers — is available.

**National Institute of Child Health and Human Development (NICHD)**

31 Center Drive, Room 2A32
Bethesda, MD 20892
(301) 496-5133
(800) 370-2943 (Clearinghouse)
Fax: (301) 496-7101
URL: http://www.nih.gov/nichd/

NICHD, part of the National Institutes of Health, administers a multidisciplinary program of research and public information on reproductive, neurobiological, developmental, and behavioral processes affecting health. Information and publications are available through its clearinghouse, including a fact sheet on secretin.

**National Institute on Deafness and Other Communication Disorders (NIDCD)**

National Institutes of Health
Bethesda, Maryland 20892
(301) 496-1804
Fax: (301) 402-7243
URL: http://www.nih.gov/nidcd/

NIDCD, part of the National Institutes of Health, conducts and supports biomedical and behavioral research in the normal and disordered processes of hearing, balance, smell, voice, taste, speech, and language.

## Other Disability and Health Contacts, *continued*

**National Institute of Mental Health (NIMH)**

NIMH Public Inquiries
Room 7C-02, MSC 8030
5600 Fishers Lane,
Bethesda, MD 20892-8030
(301) 443-4513
Fax: (301) 443-4279
E-mail: nimhinfo@mail.nih.gov
URL: http://www.nimh.nih.gov/

This NIH Institute sponsors research in the prevention, treatment, and diagnosis of mental disorders. It cosponsors, with the Library of Congress, The Decade of the Brain Project. Its publication entitled *Autism* is available through its Web-based reading room *(an excerpt from* Autism *is presented in the Overview Section of the* NECTAS Resource Collection on ASD*).*

**National Institute of Neurological Disorders and Stroke**

Office of Communications and Public Liaison
P. O. Box 5801
Bethesda, MD 20824
(800) 352-9424; (301) 496-5751
Fax: 301-402-2186
URL: http://ninds.nih.gov/

This NIH Institute is one of the lead agencies for the Congressionally designated Decade of the Brain and supports biomedical research on disorders of the brain and nervous system. Along with other information, fact sheets on autism, PDD, and Asperger's Syndrome are available.

**National Institutes of Health (NIH)**

Bethesda, Maryland 20892
(301) 496-4000
Fax: (301) 496-2443
E-mail: NIHInfo@OD.NIH.GOV
URL: http://www.nih.gov/index.html

NIH is comprised of 24 separate Institutes, Centers, and Divisions. The NIH Web site features a search utility that provides access to documents on more than 100 selected Web sites that comprise the NIH-WEB-SPACE. Each of these servers are "crawled" and indexed on an ongoing basis.

**National Library of Medicine**

National Institutes of Health
8600 Rockville Pike
Bethesda, MD 20894
(888) FINDNLM [346-3656]; (301) 594-5983
E-mail: refweb@nlm.nih.gov
URL: http://www.nlm.nih.gov/

The National Library of Medicine hosts Medline, a bibliographic database covering the fields of medicine, nursing, dentistry, veterinary medicine, the health care system, and the preclinical sciences. It contains bibliographic citations and author abstracts from more than 3800 biomedical journals.

**The National Organization for Rare Disorders, Inc.**

P. O. Box 8923
New Fairfield, CT 06812-8923
(800) 999-6673; (203) 746-6518
Fax: (203) 746-6481
E-mail: orphan@rarediseases.com
URL: http://www.rarediseases.org/

NORD is a federation of voluntary health organizations dedicated to helping locate information about rare "orphan" diseases. The organization is involved in programs supporting education, advocacy, research, and other services. This site provides access to an electronic newsletter, a rare disease database, and information about current issues.

**National Parent Network on Disabilities (NPND)**

1130 17th Street NW, Suite 400
Washington, DC 20036
(202) 463-2299
Fax: (202) 463-9403
E-mail: NPND@cs.net
URL: http://www.npnd.org/

NPND provides advocacy and information regarding federal disability policy, legislation, and initiatives such as IDEA, the Assistive Technology Act, managed care, and Medicaid. It provides congressional contact information and links to Parent Training and Information Centers.

## Other Disability and Health Contacts, *continued*

### Office of Special Education Programs (OSEP)

Office of Special Education and Rehabilitative Services
U.S. Department of Education
Mary Switzer Building
330 C Street SW
Washington, DC 20202
(202) 205-5507
Fax: (202) 260-0416
URL: http://www.ed.gov/offices/OSERS/OSEP/index.html

OSEP provides leadership and fiscal resources to assist state and local efforts to educate children with disabilities, ages birth through 21 years. Its Web site provides links to the IDEA statute and regulations and information on OSEP-funded programs.

### Pediatric Points of Interest (Web site)

Web Site Author: Christopher Lehmann
Operated through the Departments of Pediatrics at Johns Hopkins University, Baltimore, MD, and Marshall University School of Medicine, Huntington, WV
(410) 955-5976
URL: http://www.med.jhu.edu/peds/neonatology/poi.html

This searchable site links to a wide variety of information for health professionals and families. Links are organized in categories that include organizations, hospitals and physicians, electronic consultations, journals and newsletters, patient education materials, fun stuff for kids, parenting resources, e-mail discussion groups, and other medical resources.

### The Sibling Support Project

Children's Hospital and Medical Center
4800 Sand Point Way NE
P.O. Box 5371, CL-09
Seattle, WA 98105-0371
(206) 368-4911
Fax: (206) 368-4816
E-mail: dmeyer@chmc.org
URL: http://www.chmc.org/departmt/sibsupp/

This project is dedicated to the interests of siblings of people with special health and developmental needs. In addition to providing specific resources for siblings, this Web site links to a variety of resources searchable by disability or condition, including bibliographies, support groups, and organizations.

### Technical Assistance Alliance for Parent Centers

PACER Center (Coordinating Office)
4826 Chicago Avenue S
Minneapolis, MN 55417-1098
(888) 248-0822; (612) 827-2966
TTY: (612) 827-7770
Fax: (612) 827-3065
E-mail: alliance@taalliance.org
URL: http://www.taalliance.org/

This organization coordinates the national network of Parent Training and Information Centers (PTIs), which provide training and information to parents of children with disabilities and to professionals. PTIs are funded to support meeting children's educational needs under the Individuals with Disabilities Education Act.

### ZERO TO THREE: National Center for Infants, Toddlers and Families

734 15th Street NW, Suite 1000
Washington, DC 20005
(202) 638-1144
(800) 899-4301 (publications)
Fax: (202) 638-0851
E-mail: 0to3@zerotothree.org
URL: http://www.zerotothree.org/

This nonprofit organization is dedicated to advancing the healthy development of babies and young children by disseminating developmental information, training, and promoting model approaches and standards of practice and publications. Specific resources are available for parents and professionals on assessment, diagnosis and intervention, and many other topics.

# Network of Autism Training and Technical Assistance Programs (NATTAPs)

This information was updated from the June 1998, NATTAP "Networking Directory". The Directory resulted from informal meetings conducted during the 1991 and 1992 Autism Society of America conferences. It is updated annually by Cathy Pratt, at the Indiana Resource Center for Autism, and Barbara Becker-Cottrill, at the Autism Training Center, Marshall University. The programs are listed alphabetically by state and by city within state, followed by programs in Canadian provinces.

**California**

Clinic for the Behavioral Treatment of Children
Department of Psychology
University of California Los Angeles
1282A Franz Hall
Box 951563
Los Angeles, CA 90095-1563
(310) 825-2319
Fax: (310) 206-6380
URL: http://www.lovaas.com

**District of Columbia**

The Georgetown University Child Development Center
Center for Child Health and Mental Health Policy
3307 M Street NW
Washington, DC 20007-3935
(202) 687-5000
Fax: (202) 687-8899
URL: http://www.dml.georgetown.edu/depts/pediatrics/index.html
Contact: Roxane Kaufmann

**Florida**

Center for Autism and Related Disabilities
University of Miami
P.O. Box 248768
Coral Gables, FL 33124
(800) 9-AUTISM or (305) 284-6563
Fax: (305) 284-6555

The Autism Consortium of the Ralph J. Baudhin Oral School of Nova Southeastern University
3375 SW 75th Avenue
Fort Lauderdale, FL 33314
(954) 262-7100
Fax: (954) 262-1725

Center for Autism and Related Disabilities
University of Florida
Department of Psychiatry
P.O. Box 100234
Gainesville, FL 32610-0234
(352) 846-2761
Fax: (352) 846-0941
URL: http://neurosci90.health.ufl.edu/card.html

Center for Autism and Related Disabilities
Florida State University
512 Regional Rehabilitation Center
Tallahassee, FL 32306-1201
(800) 769-7926 or (904) 644-4367
Fax: (904) 644-3644
Contact: Ashley Jackson

Center for Autism and Related Disabilities
Louis de la Parte Florida Mental Health Institute
University of South Florida
13301 Bruce B. Downs Boulevard
Tampa, FL 33612
(813) 974-2532
Fax: (813) 974-6115
E-mail: card-usf@fmhi.usf.edu
URL: http://card-usf.fmhi.usf.edu/

## NATTAPs, *continued*

Miami Children's Hospital
Dan Marino Center
Outpatient Facility
2900 South Commerce Parkway
Weston, FL 33065
(954) 385-6274
Fax: (954) 385-6201
Contact: Dr. Robert Tuchman

**Georgia**
Emory Autism Resource Center
718 Gatewood Road
Atlanta, GA 30322
(404) 727-8350
Fax: (404) 727-3969
Contact: Gail McGee or Michael Morrier

**Illinois**
Easter Seals Therapeutic Day School
3424 South State Street
Chicago, IL 60616
(312) 808-0058
Fax: (312) 808-0481
E-mail: esdayschool@juno.com
URL: http://www.eastersealchicago.org/
Contact: Barbara Zawacki

**Indiana**
Indiana Resource Center for Autism
Institute for the Study of Developmental Disabilities
University Affiliated Program of Indiana
2853 East Tenth Street
Bloomington, IN 47408-2601
(812) 855-6508
Fax: (812) 855-9630
E-mail: prattc@indiana.edu
URL: http://www.isdd.indiana.edu/~irca/
Contact: Cathy Pratt

**Iowa**
Autism Services Program
Child Health Specialty Clinic
100 Hawkins Drive, Room 239
Iowa City, IA 52242-1011
(319) 356-4619
Fax: (319) 356-3715
Contact: Sue Baker

**Kansas**
Asperger Autism Resource Center
University of Kansas Medical Center
4001 Miller Building
3901 Rainbow Boulevard
Kansas City, KS 66160
(913) 588-5988
Fax: (913) 588-5942
E-mail: egagnon@kumc.edu
Contact: Lisa Gagnon

Beach Center on Families and Disability
3111 Haworth Hall
University of Kansas
Lawrence, KS 66045
(785) 864-7600
Fax: (785) 864-7605
URL: http://www.lsi.ukans.edu/beach/pbs/pbs.htm

**Kentucky**
Child Evaluation Center
Autism Training Center
Department of Pediatrics
University of Louisville
571 South Floyd Street, Suite 100
Louisville, KY 40202-3828
(502) 852-7886
Fax: (502) 852-0955
E-mail: KATC@Louisville.edu
URL: http://www.louisville.edu/medschool/KATC/
*and*
Metro Contact
Strategic Planning for Low-Incidence Metro ECSU
4001 Stemson Boulevard, Suite 201
Minneapolis, MN 55421
(612) 706-0801, ext. 109

Kentucky Autism Training Center
University of Louisville
571 South Floyd Street, Suite 100
Louisville, KY 40202
(502) 852-4631
Fax: (502) 852-7881
E-mail: rlgrau01@ulkyvm.louisville.edu
URL: http://www.louisville.edu/medschool/KATC/

## NATTAPs, *continued*

**Massachusetts**
Center for Autism and Related Disorders at the Institute of Community Inclusion
Children's Hospital on Fagan 10
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(617) 355-7971
Fax: (617) 355-4208

The Option Institute's Son-Rise Program
2080 South Undermountain Road
Sheffield, MA 01257
(413) 229-2100
Fax: (413) 229-3202
E-mail: happiness@option.org
URL: http://www.son-rise.org/

**Michigan**
Developmental Disorders Clinic
University of Michigan Health Center
3893 Taubman Center - 0390
0390 1500 East Medical Center Drive
Ann Arbor, MI 48109
(734) 764-0234
Fax: (734) 936-8907

**Minnesota**
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4001 Stimson Boulevard NE, Suite 210
Minneapolis, MN 55421
612) 706-0801 ext. 102
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E-mail: phil.sievers@state.mn.us
URL: http://www.ecsu.k12.mn.us/
Contact: Phil Sievers

**Missouri**
Judevine Outreach Services
Central Missouri Autism Project
3512 I-70 SE
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Fax: (573) 874-3880
E-mail: JudeCol@aol.com

Project ACCESS
Southwest Missouri State University
901 South National
Springfield, MO 65804
(417) 836-6755
Fax: (417) 836-4118
E-mail: shannonpotter@mail.smsu.edu
URL: http://www.smsu.edu/access/
Contact: Susan Hawkins

**New Jersey**
The New Jersey Center for Outreach and Services for the Autism Community
1450 Parkside Avenue, Suite 22
Ewing, NJ 08638
(609) 883-8100
Fax: (609) 883-5509
E-mail: njautism@aol.com
URL: http://members.aol.com/njautism/

Rutgers, the State University of New Jersey
Douglass Outreach
30 Gibbons Circle
New Brunswick, NJ 08901-8529
(732) 932-3902
Fax: (732) 932-4469
Contact: Rita Gordon

Eden Family of Services
1 Logan Drive
Princeton, NJ 08540
(609) 987-0099
Fax: (609) 987-0243
URL: http://members.aol.com/edensvcs/
Contact: Anne Holmes

**New Mexico**
New Mexico Autism Program
Center for Development and Disability
School of Medicine
University of New Mexico
Albuquerque, NM 87131
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Fax: (505) 272-5280
URL: http://cdd.unm.edu/aut/

## NATTAPs, *continued*

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Division TEACCH
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University of North Carolina
CB# 7180, Medical School Wing E
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**Ohio**
Cincinnati Center for Developmental Disorders
3333 Burnet Avenue
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Contact: Dorothyann Feldis

**Oregon**
Oregon Institute of Developmental Disabilities (OIDD)
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P.O. Box 574
Portland, OR 97207
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Fax: (503) 494-4447

**Pennsylvania**
Dr. Gertrude A. Barber Center
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URL: http://www.drbarbercenter.org/

Allegheny Intermediate Unit
Exceptional Children's Program
1400 Penn Avenue, Suite 201
Pittsburgh, PA 15222-4332
(412) 394-5750
Fax: (412) 394-5783
URL: http://www.aiu.com/
Contact: Barbara Minich

**Puerto Rico**
Proyecto De Autismo Infantil—CHRP
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San Juan, PR 00936-5067
(787) 758-2525, ext. 4102
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**Rhode Island**
Groden Center
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(401) 274-6310
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URL: http://www.state.sc.us/ddsn/
Contact: Don Sender

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South Dakota University Affiliated Program
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USD School of Medicine
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E-mail: ilene@u.washington.edu
Contact: Ilene Schwartz

## NATTAPs, *continued*

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605 Ninth Street
P.O. Box 507
Huntington, WV 25710-0507
(304) 525-8014
Fax: (304) 525-8026

The Autism Training Center
Marshall University
316 Old Main
400 Hal Greer Boulevard
Huntington, WV 25755-2430
(304) 696-2332
Fax: (304) 696-2846
Contact: Barbara Becker or
Jennifer McFarland

**Canada — British Columbia**
Provincial Resource Program for Autism
Related Disorders
4812 Georgia Street
Delta, BC V4K 2S9
(604) 946-3610
Fax: (604) 946-2956

**Canada — Ontario**
The Geneva Centre
250 Davisville Avenue, Suite 200
Toronto, Ontario M4S 1H2
(416) 322-7877
Fax: (416) 322-5894
URL: http://www.autism.net/

Muki Baum Association
265 Rimrock Road, Suite 209
Downsview, Ontario M3J 3C6
(416) 630-2222
Fax: (416) 630-2236
Contact: Dr. Nehama Baum

Autism and Related Disorders Program
Windsor Regional Children's Centre
3901 Connaught
Windsor, Ontario N9C 4H4
(519) 257-5219
Fax: (519) 257-5212

# Network of Collaborative Programs of Excellence in Autism (CPEAs)

Funded by the National Institute of Child Health and Human Development (NICHD) *(see description on page 5)*, the network of 10 CPEAs are working to learn about the causes of autism, brain structure and function, and how autism changes over the lifespan. Each CPEA focuses on some unique aspect of autism, but all use a common diagnostic system, family history, and share some aspects of procedures and protocols. The 10 CPEAs are listed below along with a brief description of the site's research focus. The sites are presented alphabetically by state.

**University of California, Los Angeles**

Marian Sigman
Neuropsychiatric Institute
760 Westwood Plaza
Los Angeles, CA 90024-1759
(310) 825-0180
Fax: (310) 825-2682
E-mail: msigman@ucla.edu

The purpose of this project is to determine the biological and environmental contributors to social communicative deficits and skills in autism. The project will investigate genetic, brain mechanisms, and environmental factors. The approaches to be used are as follows: (a) a longitudinal study of the precursors, correlates, and consequences of social communicative skills in a sample of adolescents and adults who have been followed since the age of 3 to 6 years; (b) an experimental intervention aimed at improving social communicative and play skills in very young children with autism; (c) a genetic study of individuals at risk of autism and associated social communicative deficits because of inverted duplication portion chromosome; and (d) a comparison of the neural networks associated in processes involved in communication, including recognition and response to faces, emotions, and prosody, using fMRI with adults with autism and non-autistic language impairment.

**University of California at Irvine Medical Center**

M. Anne Spence
Department of Pediatrics
101 The City Drive
Orange, CA 92868
(714) 456-8385
Fax: (714) 456-8384
E-mail: maspence@uci.edu
Contact: Judy Brown, (714) 456-3440

This research effort will explore the genetics of autism; investigate brain structure in autism using magnetic resonance imaging (MRI), especially changes in the brain in adolescence; and document "regression" in language and/or social behavior for children with autism whose early development was normal. The overall goal of the project is to identify subtypes of autism that share a common etiology (cause). These subtypes can lead us to the genes that cause autism.

**University of Colorado Health Sciences Center**

Sally J. Rogers
UCHSC Box B-148
4200 East 9th
Denver, CO 80262
(303) 871-4403
Fax: (303) 315-5641
E-mail: Sally.Rogers@UCHSC.edu

The overall goal of this project is to define more clearly what is both familial and specific in the autism phenotype at three levels of analysis — brain, neuropsychology, and behavior — through a series of converging tests. The project is designed to provide a rigorous set of converging tests of five competing neuropsychological explanations of autism: (a) a basic sensory deficit measured by means of magnetoencephalography

## Network of CPEAs, *continued*

(MEG); (b) a praxis deficit; (c) an affective deficit; (d) an inter-subjectivity deficit; and (e) a deficit in executive functions. The converging tests of the latter four, higher level deficits are as follows: (a) Does the candidate deficit(s) appear early in the development of children with autism? (b) Is the deficit(s) specific to autism? (c) Are first degree relatives in multiplex families concordant for the deficit(s)?; and (d) Is the deficit(s) correlated with the brain phenotype, either at a structural (measured by MRI scans) or functional (measured by MEG) level?

### Yale Child Study Center

Fred R. Volkmar
Yale University
230 South Frontage Road
P.O. Box 207900
New Haven, CT 06520-7900
(203) 785-2510
Fax: (203) 737-4197
E-mail: fred.volkmar@yale.edu
Contact: Kathy Koenig, kathy.koenig@yale.edu

The Yale Child Study Center is conducting a research project on multiple incidence families (families with one autistic child and another child with autism or a related Pervasive Developmental Disorder). Participation in this study involves a brief assessment and blood samples which are taken from all immediate family members. In addition, parents receive a report that includes a diagnosis and recommendations for intervention. The goal of this study is to determine whether there are specific gene(s) involved in the etiology of autism and related conditions.

### Eunice Kennedy Shriver Center

Helen Tager-Flusberg
Center for Research on Developmental Disorders
200 Trapelo Road
Waltham, MA 02254
(781) 642-0180
Fax: (781) 642-0185
E-mail: htagerf@shriver.org
Contact: Gail Andrick, (781) 642-0180 or (888) 374-4134; Gandrick@shriver.org

This project will study the behavioral genetics, psychological characteristics, developmental course, neural processing and neurobiology of autism, particularly as they related to language and social understanding. The research program will include a focus on theory of mind impairments (a potential core deficit in autistic persons' inability to communicate), innovative studies on severely impaired nonverbal adolescents with autism, structural and functional neuroimaging of language-related brain regions, and family studies focusing on the language components of the phenotype.

### Albert Einstein College of Medicine

Michelle A. Dunn
Department of Neurobiology
1300 Morris Park Avenue
Bronx, NY 10461
(718) 430-2459
Fax: (718) 430-8785

This project will examine the integrity of auditory processing in children with autism through behavioral (audiometric), physiologic, and electrophysiologic event-related potentials ERP) measures, and relate it to later language development. As such, this project may represent the most thorough assessment of hearing yet undertaken in autism.

### University of Rochester Medical Center

Patricia M. Rodier
Department of OB/GYN, Box 668
601 Elmwood Avenue
Rochester, NY, 19642
(716) 275-2582
Fax: (716) 244-2209
E-mail: rodierp@ehsct7.envmed.rochester.ed

This project involves the study of early developmental genes in human subjects

## Network of CPEAs, *continued*

characterized for behaviors related to autism: language, cranial nerve function, dysmorphology, and ophthalmology. Genetic factors identified in the human cases of autism are transferred to mice, in which their effects on the structural and functional development of the nervous system can be investigated. The responses of embryos of genetically engineered mice and embryos of normal mice to environmental factors associated with autism will be compared. Another goal of the project is to identify simple behaviors that discriminate autism from other developmental disabilities, and to apply test of these behaviors to animal models of the disorder. This research is directed at understanding the causes of the autism spectrum.

### Western Psychiatric Institute & Clinic

Nancy J. Minshew
3811 O'Hara Street
430 Bellfield Towers
Pittsburgh, PA 15213
(412) 624-0818/0819
Fax: (412) 624-0930
E-mail: minshewnj@msx.upmc.edu
*or*
autismproject@msx.upmc.edu
URL: http://www.pitt.edu/~nminshew/

This project tests the assumption that autism results from abnormal development and dysfunction of the neocortical systems. Drawing on an outstanding brain imaging and neuropsychology team, this project will examine evidence of strengths in basic brain functions and deficits in complex information processing.

### Utah State University

J. Dennis Odell
UMC 6895
Logan, UT 84332
(435) 797-1924
Fax: (435) 797-4054
E-mail: medlab@cc.usu.edu
Contact: William McMahon,
(801) 588-3384; pcwmcmah@ihc.com

This project tests the idea that autism is caused by an immunogenetic susceptibility that predisposes individuals to autism and may make infants susceptible to pathogens during pregnancy that would be harmless to others. This research is based on the immune and autoimmune abnormalities found in a large subgroup of persons with autism and/or their parents. The other studies in this project are focused on other aspects of subgroups in autism including the study of brain structure and function, particularly executive function, and a study of enlarged head sizes found in autism (University of Iowa).

### University of Washington

Geraldine Dawson
Center on Human Development and Disability
Box 357920
Seattle, WA 98195
Phone: (206) 543-1051
Fax: (206) 685-5771
E-mail: dawson@u.washington.edu
Contact: Cathy Brock, (800) 994-9701;
cbrock@u.washington.edu

The University of Washington team is seeking families with more than one child (of any age) with an autism spectrum disorder to assist in a study to discover the genetic basis of autism. Testing sites are available throughout the US. Participants in the study will receive free diagnostic and neuropsychological evaluations. All travel and hotel costs for multiplex families will be paid by the study. In addition to the genetics studies, this project will study the emergence of speech and language, and brain structure and function that underlie speech and social behavior in autism, and examine early predictors of outcome in autism.

# The Lovaas Institute for Early Intervention (LIFE)

2566 Overland Avenue, Suite 530
Los Angeles, CA 90064
(310) 840-5983
Fax: (310) 840-5987
E-mail: info@lovaas.com
URL: http://www.lovaas.com/

*Other offices:*
New Jersey: (609) 616-9442
San Francisco: (415) 785-1036
San Diego: (619) 283-1567
Sacramento: (916) 979-9398

The Lovaas Institute for Early Intervention (LIFE) is a research-based institute that specializes in teaching preschool-age children with autism, pervasive developmental disorders, and related developmental disabilities. The intervention program was developed in the psychology department at UCLA under the direction of Dr. O. Ivar Lovaas, Ph.D., and is aimed at enhancing the language, social/play, pre-academic, and independent living skills of young children so that they may take better advantage of opportunities in their communities and may require less professional attention as they grow older.

## Replication Sites

**UCLA Young Autism Project**
Assistant Director: Jacqueline Wynn, Ph.D.
Department of Psychology
Universitiy of California at Los Angeles
1282A Franz Hall
Box 951563
Los Angeles, CA 90095
Phone: (310) 840-5983
Fax: (310) 840-5987
Director: Ivar Lovaas, Ph.D.

**Central Valley Autism Project**
1201 Patterson Rd
Modesto, CA 95269
Phone: (209) 578-4271
Fax: (209) 523-0171
*and*
Clinical Director: Mila Amerine-Dickens, M.S
Director: Howard Cohen, Ph.D.
Valley Mountain Regional Center
P.O. Box 692290
Stockton , CA 95269
Phone: (209) 473-0951
Fax: (209) 473-0256

**The May Institute**
Director: Art Campbell, Ph.D., Vice President
May Center, Inc.
940 Main Street
P.O. Box 899
South Harwich, MA 02661
Phone: (508) 432-5530, ext. 211
Fax: (508) 432-3478 or 778-0076

**Community Services for Autistic Adults and Children (CSAAC)**
Director: Christine Caselles, Ph.D.
751 Twinbrook Parkway
Rockville, MD 20851-1428
Phone: (301) 762-1650
Fax: (301) 762-5230

**Minnesota Young Autism Project**
Director: Eric Larsson, Ph.D.
REM Consulting & Services, Inc.
3101 West 69th Street, #121
Edina, MN 55435
Phone: (612) 926-9808
Fax: (612) 926-4002

## LIFE Replication Sites, *continued*

**New Jersey Institute for Early Intervention**
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**Meredith Autism Project**
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Meredith College
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Fax: (919) 829-2303

**Pittsburgh Young Autism Project**
Director: Patti Metosky, Ph.D.
Intercare - Brentwood Office
2nd Floor, Suite 202
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Pittsburgh, PA 15227
Phone: (412) 881-3902
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**Autism Research Center, S.C.**
Director: Barbara Metzger, Ph.D.
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Fax: (864) 260-9099

**Converse College**
Director: Spencer Mathews, Ph.D
Department of Psyhcology
Converse College
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**Texas Young Autism Project**
Director: Gerald Harris, Ph.D
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Houston, TX 77204
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Fax: (713) 743-8633

**Northwest Young Autism Project**
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Fax: (509) 335-2522

**Wisconsin Early Autism Project**
Director: Glen Sallows, Ph.D
6402 Odana Road
Madison, WI 53719
Phone: (608) 288-9040 or 836-9131
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**Iceland Young Autism Project**
Director: Sigridur Jonsdottir, Ph.D.
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**AAkershus College (Norway)**
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Fax: (0) 011-67-11-74-01

**Barcelona Autism Project**
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Spain
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Fax: (0) 011-3493-418-4850

**P.E.A.C.H.**
Director: Diane Hayward
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London, SW13 9ZN
United Kingdom

**National Early Childhood Technical Assistance System**
137 East Franklin Street, Suite 500
Chapel Hill, NC 27514-3628
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E-mail: nectas@unc.edu
URL: http://www.nectas.unc.edu/

# OSEP-Funded Early Childhood Projects and Project Materials on ASD

a part of the
*NECTAS Resource Collection on Autism Spectrum Disorders*

Kathy T. Whaley
and Laurie Sperry,
Editors

NECTAS
National Early Childhood Technical Assistance System

IDEAs that Work
Office of Special Education Programs

Abstracts of demonstration and outreach projects that are presented on the following pages are reprinted from the NECTAS Projects Finder Database.

Projects Finder contains information on these and other early childhood projects currently funded by the Office of Special Education Programs (OSEP), U.S. Department of Education. This searchable database is available at the NECTAS site on the World Wide Web at:

http://www.nectas.unc.edu/

This resource is part of a larger resource collection available from NECTAS on autism spectrum disorders in early childhood. Additional copies of the resource packet are available at cost from the coordinating office at:

NECTAS
137 East Franklin Street, Suite 500
Chapel Hill, NC 27514-3628
(919) 962-2001 (voice); (910) 962-8300 (TDD)
(919) 966-7463 (fax)
E-mail: nectas@unc.edu
URL: http://www.nectas.unc.edu/

July 1999

# Project Abstracts

## Alaska's Autism Intensive Early Intervention Project

Demonstration Project
Grant No. H024B60061 (1996–99[99–01])
Fiscal Agency: University of Alaska at Anchorage

Todd Risley, Project Director
Cheryl Risley, Project Coordinator
2600 Denali Street, Suite 304
Anchorage, AK 99503
(907) 276-4192
Fax: (907) 276-4114
E-mail: risley@alaska.net

**Purpose:** To develop a training and consultation system for long-distance delivery of a family-based early intervention program to serve children with autism in remote locations.

**Target:** Young children, ages birth to 8 years, with autism who live in remote locations.

**Approach:** The project trains home-based teams to work with young children with autism. A designated team leader is trained on specific competencies, such as working with the child and family and team management. Team members work with the child in pairs and critique each other's techniques. Every 4 months, a video assessment protocol is used to measure the child's expressive language, social play, and engagement in activities and with other people. The child consultant trains the team in collaborative skills. Each team member provides the child with 2 to 4 hours of direct instruction each day. The team leader completes weekly team summaries; logs child progress and teaching hours; and records behavioral data, team meeting minutes, and consultation requests. The transition phase involves the parents taking over as team leaders, decreasing treatment, and integration of more community and family activities into the child's day. The child consultant supports the family in taking over this responsibility, and the team members in changing strategies to accommodate natural situations for the child. Communication is maintained from a distance via comprehensive and exportable training manuals, monitoring and tracking by speaker phones, written reports, video assessments, and regular consulting with the team and family on the child's developmental progress.

**Outcomes:** This model will increase the availability of intensive, community-based, cost-effective early intervention services to children with autism in rural locations. Children will make developmental progress through interventions provided in their natural environment. Manuals and videos will assist in training volunteers and families thereby increasing the availability of appropriate services.

## LEAP Outreach

Outreach Project
Grant No. H024D70025 (1997–00)
Fiscal Agency: Early Learning Institute

Phillip Strain, Project Director
University of Colorado at Denver
P.O. Box 173364
Denver, CO 80217-3364
(303) 556-2771
Fax: (303) 620-4587
E-mail: phil_strain@ceo.cudenver.edu

**Purpose:** To provide training in the LEAP model which features a behaviorally and developmentally appropriate practice approach for teaching young children with special needs in an integrated setting, and to develop a network of replication sites.

**Target:** Regular and special preschool educators, speech-language pathologists, occupational therapists, physical therapists, teacher assistants, and family members in preschool integrated settings and day care and Head Start programs serving young children with special needs and their families.

**Approach:** The LEAP model features: (a) a comprehensive one-week assessment for target children that results in individualized programming for 24-hour intervention; (b) a developmentally appropriate curriculum planning process that results in lessons that are applicable to groups of children from 12 to 72 months in developmental functioning; (c) a systematic method for teaching typical children to intervene successfully with the social and language skills and class deportment of their peers with autism; (d) a modularized approach to parent participation in which the learning of specific parenting and advocacy skills is evaluated at LEAP, in the home, and in community settings; (e) a systematic plan for the transition of children to regular class settings; and (f) the use of comparison group and multiple baseline designs to document the effects of specific program components.

**Outcomes:** During the first project year, six replication sites will be developed, which will include: training approximately 90 program personnel in model implementation; initiating developmentally integrated services for approximately 320 children with disabilities (primarily children with autism); and coordinating local involvement with state early childhood plans, systems change efforts, and personnel training initiatives. The project estimates that residential services can be deferred for all replication site children; that 50% of the children with autism can be placed in regular education settings within 2 years; and that 50% of these children will function within normal developmental limits within 2 years.

## Delivering Individualized Support for Young Children With Autism: Outreach for State Service Systems

Outreach Project
Grant No. H024D70040 (1997-00)
Fiscal Agency: University of South Florida

Glen Dunlap and Lise Fox, Project Co-Directors
Florida Mental Health Institute
University of South Florida
13301 Bruce B. Downs Boulevard, MHC 2113–A
Tampa, FL 33612-3807
(813) 974-4612
Fax: (813) 974-6115

**Purpose:** To assist state systems in the iplementation of components of a model demonstration program developed to provide comprehensive and effective support for young children with autism and their families.

**Target:** Children with autism aged birth to three years and their families, early intervention providers, administrators, and state systems providing services to these children.

**Approach:** The project will develop early intervention supports that result in meaningful outcomes and can be delivered through the Part H system. The model operates as an adjunctive model to build the capacity of families, early intervention providers, child care providers and communities to meet the unique and often intensive needs of young children with autism. The model provides for the development of a child's communication, social inclusion, and family support within natural contexts; through family guided developmental and ecological assessment, functional assessment of problem behavior, person centered planning, comprehensive support plans, focused and communication-based intervention, and longitudinal support for families and community inclusion. Awareness workshops, an active website, and journal articles will synthesize existing knowledge pertinent to family issues, optimal outcomes, and service integration.

**Outcomes:** Young children with autism and their families will benefit from the positive supports provided by persons trained to use this model. State agency personnel, program administrators, early intervention providers and families will increase their knowledge and practice of elements of comprehensive support and effective early intervention practices. Effective approaches in supporting children with autism and their families will be extended in multiple states. Project evaluation will provide an effective, and replicable model for providing comprehensive support for young children with autism and their families.

## First Words Project

Demonstration Project
Grant No. H324M980173 (1998-02)
Fiscal Agency: Florida State University

Amy Wetherby, Principal Investigator
Department of Communication Disorders
Florida State University, MC 1200
Tallahassee, FL 32306-1200
(850) 644-8456
Fax: (850) 644-8994
E-mail: awetherb@garnet.acns.fsu.edu
URL: http://firstwords.fsu.edu/

**Purpose:** To develop a referral and evaluation system for the early identification of children at risk for developmental disabilities, including autism, using communications measures.

**Target:** Infants, 10 to 18 months of age who have not been identified as having developmental delays.

**Approach:** This project consists of two tiers. The first tier is the early identification component and will require parent-professional and interagency collaboration to develop: a) a service coordination plan for the distribution of a referral checklist; b) materials to be used for distribution that explain the referral process and early indicators of language delays; and c) follow-up mechanisms and materials to provide information and respond to questions of families and service providers. The second tier will develop the menu of service options: a) family education and support services that may be preventative and include parent education group meetings in the community, parent education modules disseminated to families and service providers, resource and referral databases, and parent support and networking groups; b) individualized, family-guided early intervention programs for children with developmental delays to be documented by an IFSP and implemented in the child's natural environment at home or child care settings; and c) referral systems, transition planning, and transition support. The development and implementation of the second tier will require extensive involvement of families of children with disabilities as well as an interdisciplinary team of professionals.

**Outcomes:** This project will accomplish the following: a)contribute knowledge about the extent to which three measures of prelinguistic communication predict later performance on language and cognitive measures; b) provide information about the accuracy with which these measures identify children who evidence language and cognitive disabilities at age 3; and c) contribute knowledge about the extent to which specific caregiver's interaction strategies, the family's home environment, and socioeconomic status account for prelinguistic communication and later communication and cognitive functioning.

### Developmental Therapy - Developmental Teaching: An Outreach Project for Young Children With Social-Emotional-Behavioral Disabilites

Outreach Project
Grant No. H024D70035 (1997-00)
Fiscal Agency: University of Georgia

Mary Wood, Project Director
Family Service Unit
College of Family and Consumer Science
PO Box 5153
Athens, GA 30604
(706) 369-5689
Fax: 706-369-5690
E-mail: mmwood@uga.cc.uga.edu

**Purpose:** To improve competencies of children aged birth to eight years with social-emotional-behavioral disabilities and their families, and of early intervention and preschool personnel serving them.

**Target:** Children aged birth to eight years with social-emotional-behavioral disabilities, their families, and the early childhood and preschool professionals and paraprofessionals involved in providing services, as well as the state agencies responsible for coordination of service delivery.

**Approach:** The Developmental Therapy - Developmental Teaching model emphasizes enhancing adults' skills at each stage of social-emotional-behavioral development: selecting and conducting developmentally appropriate activities; designing individual objectives for increased competence; increasing interpersonal skills; strategies for team building; selecting developmentally appropriate behavior management; using assessment instruments with reliability; establishing a Developmental Therapy-Developmental Teaching criterion-referenced evaluation system; and using an observational rating inventory to measure teachers' use of specified practices. The project utilizes practices that embrace a view that learning and personality development are inseparable. The model can be used in conjunction with regular pre-academic curriculum; can be successfully implemented by families; and is applicable for children with and without disabilities because it focuses on normal developmental milestones. This outreach project focuses on various program options including inclusive and pull-out settings.

**Outcomes:** Personnel will increase their understanding of and skills to foster social-emotional development and create positive environments. Children will increase their social competence and social-emotional-behavioral development. Project findings will contribute knowledge to the field about serving young children in inclusive, pull-out, and special settings.

### A Model for Early Treatment of Toddlers With Autism

Demonstration Project
Grant No. H024B20069 *(project not on current funding cycle, most recently funded in 1995)*
Fiscal Agency: Emory Autism Resource Center

Gail McGee, Director
Emory Autism Resource Center
718 Gatewood Road
Atlanta, GA 30322
(404) 727-8350
Fax: 404-727-3969

**Purpose:** To develop, implement, evaluate, and disseminate a systematic, inclusive approach to intervention for toddlers with autism.

**Target:** Toddler-age children with or at risk for autism and their families, and typically developing toddlers as peer models.

**Approach:** The project will develop an incidental teaching curriculum that addresses the developmental goals of socially integrated groups of toddlers with autism and children without disabilities. The project will design, implement, and evaluate a replicable model for early intervention for children with autism, based on a comprehensive home- and center-based approach to education and treatment. Project information, materials, skills, and personnel will be available to improve current and newly developing service delivery systems in the state of Georgia and nationally.

**Outcomes:** By the end of the first project year, the program will be fully operational at the primary site, and incoming program evaluation data will direct the process of revision for replication. A program manual will be prepared to accompany the curriculum manual. Dissemination will take place through visitation, parent information seminars, media releases, community conferences, presentations, and publications.

## Development, Testing, and Dissemination of Nonaversive Techniques for Working With Children With Autism: Demonstration of a "Best Practices" Model for Parents and Teachers

Demonstration Project
Grant No. H024B60027 (1996-99)[99-01])
Fiscal Agency: Heartland Area Education Agency 11

Martin Ikeda and Richard Tucker, Project Co-Directors
Heartland AEA
Inter-American University
6500 Corporate Drive
Johnston, IA 50131-1603
(515) 270-9030, ext. 4494
Fax: (515) 270-5383
E-mail: mikeda@aea11.k12.ia.us
*and* dtucker@aea11.k12.ia.us

**Purpose:** To develop, implement, evaluate and disseminate approaches to prepare teachers and parents to intervene with and teach children with autism.

**Target:** Children ages birth through 8 years who are diagnosed with autism.

**Approach:** The project will develop a model program to train parents and educators in proactive strategies for teaching young children with autism. The project will field test the effects of the training program and evaluate changes in student outcomes as a function of enhanced skills of classroom personnel. Inservice preparation materials will be disseminated regionally. The project will explore managing behaviors using techniques that hypothesize the function of behavior, and teach children replacement behaviors. Interventions will enhance communication and reduce disruptive behaviors that are a function of frustration related to inability to communicate. The model will incorporate family participation, individualization of programs, and earlier intervention to promote better educational and social outcomes for children. The project will focus on teaching parents and teachers to increase communication skills within the context of age-appropriate activities. Functional analysis of behavior will promote proactive, non-punitive strategies that link assessment and intervention. This comprehensive training program incorporates components of the best of behavioral, educational, and social supports that are empirically validated.

**Outcomes:** This project will incorporate procedures to assess project effects on a variety of outcome measures, which will enable comparisons between treatment methods to be made. The project will provide important information on treatment efficacy using nonaversive strategies developed based on individual child and family needs.

## Functional Problem-Solving Skills for Children With Pervasive Developmental Disorders

Demonstration Project
Grant No. H024B60015 (1996–99[99–01])
Fiscal Agency: Washington State University

Charity Rowland, Principal Investigator
Center on Self-Determination
Oregon Health Sciences University
3608 Southeast Powell Boulevard
Portland, OR 97202
(503) 232-9154, ext. 115
Fax: (503) 232-6423
E-mail: rowland@ohsu.edu

**Purpose:** To examine the cognitive development of children with PDD as demonstrated through their relationships with objects and to develop instructional strategies for encouraging the development of functional interactions with the physical environment.

**Target:** Children aged 3 to 6 years who have a diagnosis of Pervasive Developmental Disorders.

**Approach:** Assessment and intervention strategies will help children who do not have the verbal skills and who are unable to process visual or auditory information to learn the problem solving skills necessary to function effectively and independently. Instructional strategies will provide children with a) generic skills that are necessary to solve problems that arise in the physical environment, b) the motivation to attempt to solve problems as they arise, and c) systematic problem solving experiences in a variety of generalization settings. The model will include a functional approach to the child's relationships with objects just as has already been accomplished in the realm of their relationships with the social world. The project will focus on skills such as opening containers, searching for objects, and using objects as simple tools, that are essential to independent functioning across the other skill areas necessary to succeed in inclusive early childhood settings and at home.

**Outcomes:** Children will benefit from the creation of physical environments in the classroom that encouraging development of cognitive problem solving skills in children with PDD in the contexts of regular classroom activities. Teachers in demonstration and replication sites will learn how to adapt typical classroom activities and routines to provide opportunities for the child with PDD to master the physical environment. Materials will include a manual describing a systematic approach to instruction, strategies for documenting change in environmental supports that enhance performance.

## School-Based Preschool Programs for Children With Autism: Blending Approaches to Meet Individual Needs

Demonstration Project
Grant No. H024B7009 (1997-01)
Fiscal Agency: University of Washington

Ilene Schwartz, Project Director
Experimental Education Unit
University of Washington
Box 357925
Seattle, WA 98195-7925
(206) 543-4011
Fax: 206-616-8177
E-mail: ilene@u.washington.edu

**Purpose:** To develop, implement, evaluate, disseminate, and replicate a program for young children with autism that is effective, sustainable, and acceptable to consumers (i.e., families and school district personnel).

**Target:** Preschool children with a diagnosis of autism, their families, and the professionals who teach and work with these children and families.

**Approach:** The model has five main components: a high quality, integrated preschool program; an extended instructional day; family support; staff training; and systematic collaboration, planning for generalization, and transition planning. The core of this model is a school-based high quality early childhood special education program, whose features include: (a) opportunities to interact successfully with typical peers; (b) functional assessment and evaluation strategies; (c) appropriate curriculum to meet individual child needs; (d) effective instructional strategies; and (e) strategies to program for the generalization of behavior change. The project will provide an extended program with specialized instruction, and blend the strengths of different disciplines, producing a stronger model than would come from any one of these traditions alone.

**Outcomes:** The project will provide an effective and ecologically and socially valid model to educate young children with autism in public school programs. The children served by the model program will demonstrate improved skills in multiple areas including attending, imitation, communication, play, social interaction, self-care, and cognitive skills. Families will benefit from receiving comprehensive, coordinated services, including training that will improve their ability to deal with challenging behaviors. Professionals, including students, will benefit from training and from instructional materials specific to meeting the needs of young children with autism.

### • • • ABCD: Heartland's Model for Teaching Students With Autism

*Developed by:* Heartland Area Education Agency 11; Bindy Brown, Margaret Cook, John Drinnin, Marilyn Finn, Susie Guest, Mary Humke, Martin Ikeda, Diane Penning, Richard Tucker, Lorna Volmer, and Dave Wood (June 1998, rev.)

*Format:* Print *Length:* 146 pp.

*Description:* Training manual for 5-day workshop for teachers

*Audience:* ECSE teachers

*Content is for:* Training

*Cost:* Provided to training participants

*To Obtain:*

Full manual distributed during training; 4 to 8 slots are held for out of state participants during grant period. Telephone inquiries to Project Director (Martin Ikeda) are requested.

Phone: (515) 270-9030
Fax: (515) 270-5383

### • • • Analyzing the Communication Environment (ACE)

*Developed by:* Proactive Communication Project; Charity Rowland and Philip Schweigert (1993)

*Format:* Print and Video

*Length:* 80 pp. (manual); 90 min. (video)

*Description:* The ACE provides an environmental inventory designed to reveal to what degree a specific activity encourages functional communication for a specific child, regardless of the mode of communication used by the child. After administering the new inventory, the user may read the manual and watch the videotaped examples to determine effective ways to make the activity more conducive to communication.

*Audience:* ECSE teachers, trainers, and speech-language pathologists

*Content is for:* Training and classroom curriculum

*Cost:* $99.00

*To Obtain:*

Communication Skill Builders
555 Academic Court
San Antonio, TX 78204-2498
Phone: (800) 211-8378
TDD: (800) 723-1318
Fax: (800) 232-1223

### • • • Classroom Staff Training Modules (Self-Study)

*Developed by:* LEAP Outreach: Judy Lawry, Cassandra Danko, and Phillip Strain (August 1998)

*Format:* Print *Length:* 170 pp.

*Description:* A self-help manual for teachers and staff that addresses the following: The ABCs of Behavior, Teaching Children to Follow Directions, An Introduction to Reinforcement, How to Use Reinforcement with Children, Planning Activities to Increase Desired Behaviors, Responding to Children's Undesirable Behaviors, Teaching Children New Skills, Hierarchy of Prompts, Encouraging Children to Communicate, Keeping Track of Children's Behavior, and Monitoring Group Instruction. Includes practice sheets and "Bringing It Home" activities designed to focus staff on problem solving. Geared towards 3 to 5 year olds.

*Audience:* ECSE teachers, day care providers, and specialized service providers.

*Content is for:* Training and classroom curriculum

*Cost:* $30.00

*To Obtain:*

Cassandra Danko/Judy Lawry
1444 Wazee Street, Suite 230
Denver, CO 80202
Phone: (303) 620-4082 or (303) 620-4110
Fax: (303) 620-4587

### • • • Communication Matrix

*Developed by:* Ohio State University Center on Self-Determination; Charity Rowland (1996)

*Format:* Print *Length:* 7 pp.

*Description:* The Communication Matrix is used to assess communication development in children who use any mode of communication. It covers seven levels of communicative competence from reflexive presymbolic communication to 2-symbol utterances. The profile gives a quick visual summary of development and programs.

*Audience:* ECSE teachers, trainers and speech-language pathologists

*Content is for:* Classroom curriculum

*Cost:* $5.00 ($35.00 for package of 10)

*To Obtain:*

OHSU Center on Self-Determination
3608 SE Powell Boulevard
Portland, OR 97202
Phone: (503) 232-9154 x 102
Fax: (503) 232-6423

## • • • Developing Individualized Supports for Young Children with Autism and Their Families

*Developed by:* Individualized Support Project; Lise Fox, Leigh Ann Philbrick, Pamelazita Buschbacher, and Glen Dunlap (in press)

*Format:* Print *Length:* TBD

*Description:* A replication manual that provides guidelines for the implementation of the Individualized Support Project. The Project offers an approach to early intervention that is focused on building the capacity of families and service providers to meet the individual needs of young children with autism spectrum disorders. Chapters include: Program Overview, assessment, Functional Assessment, Person-/centered Planning, developing a Support Plan, Focused Intervention, Community Inclusion and Family Support.

*Audience:* Early intervention service providers and ECSE teachers

*Content is for:* Training

*Cost:* TBD (available for purchase after August 1999; currently provided to training participants)

*To Obtain:*

Lise Fox
Department of Child and Family Studies
MHC 2113A
FMHI, University of South Florida
13301 North Bruce B. Downs Boulevard
Tampa, Florida 33612-3899
Phone: (813) 974-6100
Fax: (813) 974-6115

## • • • Developmental Art Therapy

*Developed by:* Developmental Therapy—Teaching Programs: Geraldine H. Williams and Mary M. Wood (1977)

*Format:* Print *Length:* 198 pp.

*Description:* Practical, positive approach to promoting sequences of development that foster emotional growth in children with severe social/emotional/behavioral disabilities. Based on Developmental Therapy—Teaching Programs curriculum and teaching objectives for normal developmental patterns.

*Audience:* ECSE teachers, day care providers, and therapists

*Content is for:* Classroom curriculum

*Cost:* $29.00

*To Obtain:*

The Developmental Therapy Institute, Inc.
Box 5753
Athens, GA 30604-5153
Phone: (706) 369-5689
Fax: (706) 369-5690

## • • • The Developmental Teaching Objectives and Rating Forms

*Developed by:* Developmental Therapy Teaching Programs: Mary M. Wood (1992, 4th edition)

*Format:* Print

*Length:* Users Manual — 63 pp.
Technical Report — 19 pp.

*Description:* Practical instrument assesses social-emotional-behavioral development of children, ages birth to 16 years, with and without disabilities. Establishes teaching objectives for use in assessment, placement, and planning. Includes directions for use, illustrative examples, scoring interpretation, scope/sequence analysis, and technical information.

*Audience:* ECSE teachers, day care providers, families, administrators, trainers, specialized service providers, health care providers, and other community service providers

*Content is for:* Training and classroom curriculum

*Cost:* Kit (four subscale booklets, Users Manual, Technical Report, Rating Forms) — $52.00;
Additional subscale booklets — $16.00

*To Obtain:*

The Developmental Therapy, Inc.
Box 5153
Athens, GA 30604-5153
Phone: (706) 369-5689
Fax: (706) 369-5690

## • • • The Developmental Teaching Objectives and Rating Forms — Revised

*Developed by:* Developmental Therapy — Teaching Programs; Mary M. Wood (1999, 4th edition)

*Format:* Print/Software (Mac or PC)

*Description:* Assesses social-emotional-behavioral development of children, ages birth to 16 years, with and without disabilities. Useful for assessment, placement, planning, and progress evaluation. Prints teaching objectives, management strategies, and program objectives for ISFP, IEP, and ITP.

*Audience:* ECSE teachers, day care providers, families, trainers, specialized service providers, health care providers, and other community service providers

*Content is for:* Classroom curriculum

*Cost:* Kit (booklets, user's manual, tech. rep.)—$52.00;
Software — $36.00; Kit and Software — $73.00

*To Obtain:*

The Developmental Therapy, Inc.
Box 5153
Athens, GA 30604-5153
Phone: (706) 369-5689
Fax: (706) 369-5690

### • • • Developmental Therapy – Developmental Teaching: Fostering Social-Emotional Competence in Troubled Children and Youth

*Developed by:* Developmental Therapy—Teaching Programs; Mary M. Wood with Karen Davis, Faye Swindle, and Constance Quirk (1996; 3rd edition)

*Format:* Print *Length:* 398 pp.

*Description:* Positive, sequentially ordered curriculum that fosters social-emotional-behavioral competence in children, ages birth to 16 years, with and without disabilities. It presents a framework for matching child's current skills in behavior, communication, and socialization; pre-academics for specific goals and program objectives; and management strategies for each developmental stage.

*Audience:* Administrators, trainers, specialized service providers, families, health care providers, and other community service providers

*Content is for:* Training and classroom curriculum

*Cost:* $41.00

*To Obtain:*

PRO-ED
8700 Shoal Creek Boulevard
Austin, TX 78757-6897
Phone: (800) 897-3202
Fax: (706-369-5690
URL: http://www.proedinc.com/

### • • • Developmental Therapy for Young Children with Autistic Characteristics

*Developed by:* Developmental Therapy – Teaching Programs; Ann Bachrach, Ada Mosley, Faye Swindle, and Mary M. Wood (1978; 4th printing in 1986)

*Format:* Print *Length:* 185 pp.

*Description:* Describes a program for young children with autistic characteristics who are functioning developmentally at birth to 3 year levels. It includes examples of management techniques, materials, routines and environments, activity periods, learning experiences, and home programs.

*Audience:* ECSE teachers, day care providers, families, and specialized service providers.

*Content is for:* Training and classroom curriculum

*Cost:* $34.00

*To Obtain:*

PRO-ED
8700 Shoal Creek Boulevard
Austin, TX 78757-6897
Phone: (800) 897-3202
Fax: (706-369-5690
URL: http://www.proedinc.com/

### • • • Developmental Therapy – Teaching Programs: Documenting Effectiveness

Developed by: Development Therapy—Teaching Programs; Karen Davis, Mary M. Wood, and Faye Swindle (1998)

Format: Print Length: 33 pp.

*Description:* Summarizes recent research evidence of program effectiveness at five sites serving 58 children ages 2 to 12 yeares with speech/language, developmental, or emotional/behavioral disabilities. Results show statistically significant gains in social-emotional competency during a 6-month intervention period, whether in full inclusion, partial inclusion, or special education classes.

*Audience:* Administrators, program evaluators, and program supervisors

*Content is for:* Policy/Administration

*Cost:* $2.00

*To Obtain:*

The Developmental Therapy Institute, Inc.
Box 5153
Athens, GA 30604-5153
Phone: (706) 369-5689
Fax: (706) 369-5690

### • • • Developmental Therapy – Teaching Programs: Rating Inventory of Teacher Skills (DT/RITS)

*Developed by:* Developmental Therapy – Teaching Programs; Stafford Robinson, Mary M. Wood, Carolyn Combs 1982 (reprinted 1998)

*Format:* Print

*Length:* 63 Pages

*Description:* This booklet contains the instrument proven to be valid, reliable, and useful in staff development to guide adults in acquisition of needed skills for Developmental Therapy – Teaching in inclusive, pull-out or special settings. Four forms adjust practices to different stages of intervention. Instrument development, research findings and applications are also described.

*Audience:* ECSE teachers, administrators and program evaluators and supervisors

*Content is for:* Training and supervision

*Cost:* $2.00

*To Obtain:*

The Developmental Therapy Institute, Inc.
Box 5153
Athens, GA 30604-5153
Phone: (706) 369-5689
Fax: (706) 569-5690

## • • • Hand in Hand Parent Training

*Developed by:* Heartland Area Education Agency 11; Bindy Brown, Margaret Cook, John Drinnin, Marilyn Finn, Susie Guest, Pat Hollinger, Mary Humke, Martin Ikeda, Diane Penning, Richard Tucker, Dave Wood (June 1998)

*Format:* Print *Length:* 44 pp.

*Description:* Materials for use with parents in explaining Autism and setting up their homes for supporting youngsters with Autism

*Audience:* Families

*Content is for:* Training

*Cost:* Free

*To Obtain:*

Please contact Project Director, Martin Ikeda, with inquiries at:
Phone: 515-270-9030
Fax: 515-270-5383

## • • • Parent Trainer Modules (outline for teaching parenting classes)

*Developed by:* LEAP Outreach: Judy Lawry, Cassandra Danko, and Phillip Strain (August 1998)

*Format:* Print *Length:* 194 pp.

*Description:* A trainer's manual for teaching parenting classes focusing on: The ABCs of Behavior, Teaching Children to Follow Directions, An Introduction to Reinforcement, How to Use Reinforcement with Children, Planning Activities to Increase Desired Behaviors, Responding to Children's Undesirable Behaviors, Teaching Children New Skills, Hierarchy of Prompts, Encouraging Children to Communicate, Keeping Track of Children's Behavior, and Monitoring Group Instruction. Geared towards 3-5 year olds.

*Audience:* ECSE teachers, trainers, specialized service providers and other community Providers

*Content is for:* Training

*Cost:* $30.00

*To Obtain:*

Cassandra Danko/Judy Lawry
1444 Wazee Street, Suite 230
Denver, CO 80202
Phone: (303) 620-4082 or (303) 620-4110
Fax: (303) 620-4587

## • • • Parent Training Modules (Self-Study)

*Developed by:* LEAP Outreach; Judy Lawry, Cassandra Danko, and Phillip Strain (August 1998)

*Format:* Print *Length:* 137 pp.

*Description:* A self-help manual for parents that covers the following: The ABCs of Behavior, Teaching Your Child to Follow Directions, An Introduction to Reinforcement, How to Use Reinforcement with Your Child, Planning Activities to Increase Appropriate Behavior, Responding to Undesirable Behaviors, Deciding What to Teach Your Child, Teaching Your Child New Skills, and Encouraging Your Child to Communicate. Includes practice sheets for parents.

*Audience:* Families

*Content is for:* Training

*Cost:* $30.00

*To Obtain:*

Cassandra Danko/Judy Lawry
1444 Wazee Street, Suite 230
Denver, CO 80202
Phone: (303) 620-4082 or (303) 620-4110
Fax: (303) 620-4587

## • • • Social Skills Training Curriculum for the Classroom

*Developed by:* LEAP Outreach; Judy Lawry, Cassandra Danko, and Phillip Strain (August 1998)

*Format:* Print *Length:* 66 pp.

*Description:* Ideas for increasing social interactions between children in the classroom. Includes the social skills curriculum comprised of five skills: Getting Your Friend's Attention, Shares, Share Requests, Play Organizers, and Compliments. Activities, props, and suggestions are provided. Especially helpful for preschool-age children.

*Audience:* ECSE teachers, day care providers, trainers, specialized service providers

*Content is for:* Training and classroom curriculum

*Cost:* $15.00

*To Obtain:*

Cassandra Danko/Judy Lawry
1444 Wazee Street, Suite 230
Denver, CO 80202
Phone: (303) 620-4082 or (303) 620-4110
Fax: (303) 620-4587

## • • • Tangible Symbol Systems

*Developed by:* Tangible Symbol Systems Projects; Charity Rowland and Philip Schweigert (1996)

*Format:* Print and Video

*Length:* 61 pp. (manual): 75 min. (video)

*Description:* Tangible Symbols are pictures and objects that are used as symbols. They are useful for children with autism, deaf-blindness, and multiple disabilities, and often serve as a bridge to the acquisition of abstract symbol systems. These products describe a systematic instructional approach and include five case studies.

*Audience:* ECSE teachers, trainers, and speech-language pathologist

*Content is for:* Training and classroom curriculum

*Cost:* $79.00

*To Obtain:*

Communication Skill Builders
555 Academic Court
San Antonio, TX 78024-2498
Phone: (800) 211-8378
TDD: (800) 723-1318
Fax: (800) 232-1223

**National Early Childhood Technical Assistance System**
137 East Franklin Street, Suite 500
Chapel Hill, NC 27514-3628
(919) 962-2001 (voice) ❖ (919) 962-8300 (TDD)
(919) 966-7463 (fax)
E-mail: nectas@unc.edu
URL: http://www.nectas.unc.edu/

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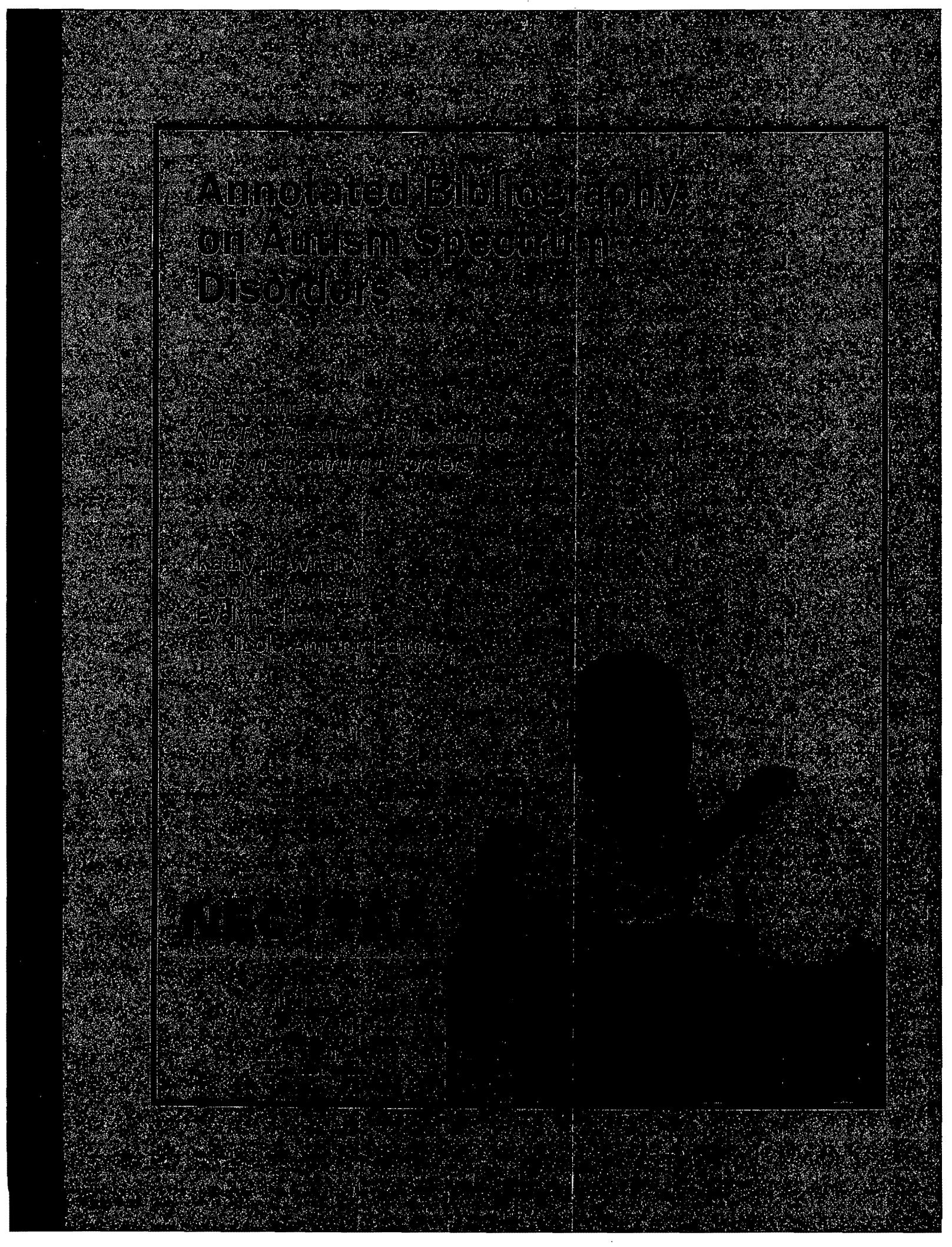
# Annotated Bibliography on Autism Spectrum Disorders