



Consensus for Autism

Consensus is a critical component of positive change. There is no doubt that major, system level change is required to provide appropriate diagnosis, treatment, education and support for individuals with autism spectrum disorders (ASD) and their families. **Consensus for Autism** is an integral part of The Autism Program system development initiative. The Program is designed to build consensus through a focus on best practice and through a network or regional centers, affiliates and collaborators who are able to bring together stakeholders from across Illinois.

The Autism Program's leadership is resulting in growing unity within Illinois' autism community. The Autism Program has been a voice for consensus within a community that is all too often polarized on etiology, treatment and educational options. This fall the TAP administrative and clinical team developed *The Autism Program Guiding Principle: Consensus Statement* (LINK). This document sets the stage for ongoing system development by providing a baseline consensus statement that unites parents and providers and paves the way for change and growth.

The Guiding Principles has provided a foundation for community planning meetings. The meetings held so far are impacting more than 148,000 individuals with developmental disabilities across 7 counties in Central Illinois. Agencies, parents, school districts and providers have created community plans to build services and are serving on a variety of work groups that will create new services.

Consensus for Autism is creating positive changes in communities across Illinois. Thank you for your contribution to consensus and to your part in creating and maintaining an effective system of care for Illinois. The following agencies have already demonstrated their support for this initiative. Please contact Amy Dickenson at adickenson@thehopeschool.org if you would like to join the momentum.





Supporters of *The Autism Program Guiding Principles: Consensus Statement*

- ARC of Illinois (Approx. 70 Chapters statewide)
- Charleston Transitional Facility
- City of Chicago
- Clearbrook
- Community Alternatives Unlimited
- Developmental Disability Services of Metro East
- Easter Seals Central Region
- Easter Seals Children's Development Center Rockford
- Easter Seals for DuPage and Fox Valley Region
- Easter Seals Joliet Region
- Easter Seals LaSalle and Bureau Counties
- Easter Seals Metropolitan Chicago
- Easter Seals National Headquarters
- Easter Seals Peoria-Bloomington
- Easter Seals Southern Illinois
- Easter Seals Southwest Illinois
- Illinois Center for Autism
- Kreider Services, Inc.
- LaRabida Children's Hospital
- Little City Foundation
- Project Org & Design Studio, Inc.
- Service of Will, Grundy & Kankakee Counties, Inc.
- Suburban Access, Inc.
- The Hope Institute for Children and Families
- Trinity Services, Inc.





The Autism Program Guiding Principles: Consensus Statement

Discussions of autism often revolve around differences. This focus often eclipses the substantial, powerful commonalities that exist in the autism community. Legislators, agency representatives, and progressive advocates are calling those in the autism community to join around commonalities and shared goals as a critical step toward the expansion of funding and service options.

Drawing on the expertise of parents, clinicians, educators, researchers and public policy makers, The Autism Program has compiled a statement of common beliefs and goals that are central to the majority of people in the autism community. Together, these central beliefs and goals provide a common platform to support the development of governmental and community programs and will pave the way for effective legislation and stable funding. We acknowledge the following as central to our efforts to support individuals with autism spectrum disorders and their families.

- 1) Individuals with autism spectrum disorders can succeed with the support of a strong system of care that extends across the lifespan. A strong system of care must be:
 - a. Inclusive of all components (families, clinicians, early interventionists, researchers, educators, vocational specialists, and support personnel)
 - b. Accessible regardless of income, geography, ethnicity, etc.
 - c. Coordinated across community and governmental programs
 - d. Integrated with existing services and providers and flexible enough to ensure individual choice and to allow the entry of new services and providers
 - e. Trained and equipped for service
 - f. Effective across the lifespan
 - g. Supported through multiple funding streams including state and federal grants (research and service), insurance, Medicaid, and private payment options.

- 2) Program development in education and treatment should be guided by a focus on evidenced-based practice; however, this focus must be tempered by the realization that ASD treatment research is in its infancy. Scientists and practitioners from various fields have categorized treatments into four general areas: well-established (scientifically-based), probably efficacious (some research support, promising practice), unknown (practice having limited supporting information), and not recommended (research demonstrates treatment to be ineffective or contraindicated). Effective education and treatment should focus on interventions that have an evidence base, while encouraging further investigation of interventions that have shown promise.

Additionally treatment planning should consider the following characteristics (National Research Council 2001) identified as representative of effective treatments:

- a. Early entry into an intervention program
- b. Active engagement in intensive instructional programming for the equivalent of a full school day, including services that may be offered at different sites



- c. A minimum of five days a week of year-long programming
 - d. Maximization of planned teaching opportunities—focused on frequent, but brief intervals distributed across the day for the youngest children
 - e. Appropriate levels of one-to-one adult interaction and small group instruction focused on individualized goals.
- 3) Effective advocacy for program development and funding depends upon unity within the autism community and between the autism community and the larger developmental disability community.
- 4) Consistent with the National Research Council recommendations and ongoing needs assessment in Illinois (attached), development and maintenance of a system of care will require a comprehensive initiative that is responsive to the needs of individuals and families and includes:
- a. Personnel Preparation
 - b. Technical Assistance
 - c. Applied Research and Program Evaluation
 - d. Communication
 - e. Demonstration
 - f. Data Systems
 - g. Comprehensive Planning

Finally, an effective system of care must be dynamic and the system of care outlined above is possible, only through the coordinated, collaborative efforts of families and agencies across the state. The Autism Program acknowledges that the central beliefs and goals outlined above provide a joint platform for the development of autism programs. The Autism Program is committed to work in collaboration with individuals and agencies to advance funding and programmatic initiatives and to further advance the system of care.

Next steps for system development include active engagement and support of providers and agencies to create a structure to allow flexible, sustainable programs of service delivery that address identified gaps in service.



The National Research Council Recommendations for Support Infrastructure for Building a System of Care for Children with Autism Spectrum Disorders*

- Personnel Preparation** There is a need for a continuous flow of qualified personnel. To that end, there needs to be a series of training programs and experiences directed at preservice and inservice needs.
- Technical Assistance** Many professionals and programs run into situations related to autism that cause them to seek additional professional help. Programs of technical assistance are designed to provide consultation and short-term training to meet the needs of the requester.
- Applied Research and Evaluation** There is a strong need to be reflective about our own performance as part of a strategy of continuous improvement. Public calls for accountability stress the importance of developing the proper tools and measuring instruments and personnel to conduct effective program evaluation.
- Communication** It is important to establish a communications network so that there is continuous contact with other professionals who are working on the same or similar problems. It is a way of keeping up with the latest knowledge and practices.
- Demonstration** One of the strategies that has been often used to improve program quality is to identify outstanding programs, establish them as demonstration centers, and then urge other professionals to observe and emulate what is happening in those centers or programs that could be transferred to their own program.
- Data Systems** There are many important policy questions that cannot be answered without an organized data system. Questions such as, “How many teachers are needed?” can only be addressed if one has a data system to compile the demographics of the individuals or programs.
- Comprehensive Planning** One of the key aspects of an infrastructure is the ability to do comprehensive statewide planning and to be able to allocate resources over time and in a systematic manner to more easily reach the goals of the program.

Gallagher, J. and Clifford, R. (2000). The missing support infrastructure in early childhood. *Early Childhood Research and Practice* 2(1): 1-24.

Lord, C. (2001). *Educating Children with Autism*, National Academy Press, Washington D.C.

Simpson, R. (2005). Evidenced-based practices and students with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 20(3), 140-149.

