

FY 2010

The Autism Program of Illinois

1st Quarter Report

July 1, 2009 – September 30, 2009



Public Act 95-707

Be it enacted by the People of the State of Illinois, represented in the General Assembly:

Section 5. The Mental Health and Developmental Disabilities Administrative Act is amended by adding Section 57.5 as follows:

Sec. 57.5 Autism diagnosis education program

(a) Subject to the appropriations, the Department shall contract to establish an autism diagnosis education program for young children. The Department shall establish the program at 3 different sites in the State. The program shall have the following goals:

- (1) Providing, to medical professionals and others statewide, a systems development initiative that promotes best practice standards for the diagnosis and treatment planning for young children who have autism spectrum disorders, for the purpose of helping existing systems of care to build solid circles of expertise within their ranks.
- (2) Educating medical practitioners, school personnel, day care providers, parents, and community service providers (including, but not limited to, early intervention and developmental disabilities providers) throughout the State on appropriate diagnosis and treatment of autism.
- (3) Supporting systems of care for young children with autism spectrum disorders.
- (4) Working together with universities and developmental disabilities providers to identify unmet needs and resources.
- (5) Encouraging and supporting research on optional services for young children with autism spectrum disorders.

In addition to the aforementioned items, on January 1, 2008, The Autism Program shall expand training and direct services by deploying additional regional centers, outreach centers, and community planning and network development initiatives. The expanded Autism Program Service Network shall consist of a comprehensive program of outreach and center development utilizing model programs developed by The Autism Program. This expansion shall span Illinois and support consensus building, outreach, and service provision for children with autism spectrum disorders and their families.

(b) Before January 1, 2006, the Department shall report to the Governor and the General Assembly concerning the progress of the autism diagnosis education program established under this Section.

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Executive Summary

The Autism Program (TAP) Network continues to demonstrate a commitment to the systems development mandate outlined in its enacting legislation and is having a dramatic impact on service access and quality statewide. TAP Centers provide a variety of direct services and supports to families and providers. Moreover, TAP training initiatives and the work of TAP university partnerships are equipping and inspiring a workforce for future service.

The Autism Program at a Glance

Network Activities in Quarter 1 FY 2010	
Number of Illinois Counties Impacted by The Autism Program Service Network in Q1	85
System Development	
Contacts between TAP Network Partners and the Community (count)	11,825
Contacts with Parents and Family Members (count)	3,620
Contacts with Schools & School Personnel, Individual Providers, Community Groups, and Others (count)	8,205
Family Community Resource Room (FCRR)	
Visits to TAP Network Partner FCRRs throughout the Network (count)	1,297
Number of Learning Aids Provided at No Cost	20,432
Training Programs	
Trainings Conducted (count)	63
Participants Trained (count)	1,256
Clinical Programs	
Clients Screened (unique count within Q)	192
Comprehensive Diagnostic Evaluations Conducted (unique count in Q)	84
Children receiving direct services (Child Treatment; unique count in Q)*	203
Clinical Consultations Conducted (Educator / Family Consultation; unique count in Q)*	117

*Due to technical difficulties, information in these data points is not wholly reflective of the work done in Q1 of FY10. This data will be corrected and reflected in the Q2 report.

Comparison to prior periods: Data across several years indicates that service numbers climb from Quarter 1 to Quarter 4. This trend is related to:

1. Quarter 1 opens mid summer
2. Quarter 1 resources are often directed to contracting and hiring
3. Quarter 1 activities are often affected by delays in state funding

The Autism Program Service Network, operating under serious threats to funding and extended funding delays, continued to meet the needs in their communities, as outlined in the following narrative and outcome summaries. TAP partners performed well when compared to Quarter 1 of 2009 which was supported by similar funding. The data show an increase in several areas which is likely related to increased community outreach and the fact that TAP Centers are now established as the place to go for ASD specific services and training. This quarter TAP Partners made 3,620 contacts with parents and family members compared to 2289 for the same time frame in FY2009. Contacts to school personnel and providers rose from 6,065 to 8,205 and training events rose slightly from 60 to 63. Visits to the Family Community Resource Rooms decreased from 2424 to 1,297, but provision of free learning aides increased from 15,964 to 20,432. This pattern may be indicative of fewer open house events, and increased utilization by regular parents and providers.

Funding and Advocacy: The Autism Program Service Network and agencies serving individuals with ASD and developmental disabilities across the state are understandably concerned about the current fiscal crisis. The Autism Program continues to support services through allied grant and foundation funding—garnering over 18,000,000 in non-state dollars---and through resource sharing and collaborative programming that reduces costly duplication of effort in communities across the state.

The Autism Program Headquarters staff have completed a comprehensive analysis of potential funding streams including but not limited to: private pay options; insurance reimbursement; and Medicaid. Unfortunately, exemptions in the insurance legislation, the decided low allocation to the Medicaid waiver and the fact that the services and the appropriate services providers recommended as evidence-base or as promising practices are often not eligible for basic Medicaid coverage provides limited relief. TAP Centers are reviewing funding options to ensure that clinical and support services offered by TAP will continue to be available to all families regardless of their ability to pay.

Leadership Structure: The TAP Leadership structure including topical committees covering: Performance Management and Network Development; Research; Clinical Service; Family Outreach; and Strategic Planning, continue to inform program development and have been invaluable sources of direction in all areas including: quality assurance; funding; program development; advocacy; cultural competency and more.

Autism Program FY2010 First Quarter Highlights

With new ASD prevalence rates of 1 in 100 or 29,000 school age children with an ASD, The Autism Program's community based approach to development, implementation and evaluation of quality services is an efficient, economical and effective method for meeting the growing needs of the ASD population. Community planning has taken place in every corner of the state. Easter Seals Peoria-Bloomington (ESPB) has reconvened its steering committee and developed new work teams based on community identified priorities. Easter Seals Metro Chicago's (ESMC) Community Planning Advisory Board, consisting of 30 regional professionals, met to address: early intervention and transition into early childhood programs, transitions: life after 18, financial/futures planning for individuals with special needs, behavioral issues and recreation and leisure/ community integration. In the southern Illinois the Foundation for Autism Services Today and Tomorrow (FASTT) has deep roots within their community forging strong and diverse partnerships with their local YMCA, Southwestern Illinois College, Collinsville Memorial Public Library, and Mid America Horse Rescue. The Illinois Center for Autism has embarked on a statewide community planning process focused on adults services that has included attendance at 4 Regional Community planning meetings and the hosting of a statewide community planning conference call.

While many who work with the ASD population focus specifically on that constituent group the Autism Programs Network Partners take a more holistic approach of training and educating professionals, families and communities. Easter Seals LaSalle and Bureau County held their second annual Safety Event, inviting police, fire, and emergency medical technicians to come and demonstrate what they do and allow individuals with ASD to intern inform them. Easter Seals Rockford presented an overview of what ASD is to 40 Kiwanians as an awareness and advocacy event. Have Dreams held trainings for 72 education professionals. Trinity services provided its region with 2176 informational handouts and educational materials. The Hope center offered a Family Advisor Training to 10 parents who will implement this program with their family medical providers. TAP at Southern Illinois University (SIU) provided 20 families consultations and case management.

To better meet the need of future individuals with ASD, The Autism Program has numerous network partners working for the future through research initiatives and offering real life experiences to students/ future practitioners. Kreider trained two interns from the Clinical Psychology program at Northern Illinois University. TAP at Illinois State University (ISU) conducted intensive early intervention training for 15 pre-professionals. Through the Community Planning process of the University of Illinois Urbana Champaign (UIUC) they have identified and are working toward their communities long term goals of increasing awareness and overall training of ASD professionals in our schools and community. Charleston Transitional Facility staffs its Family Resource room with student volunteers allowing them to gain some hands on

clinic experience. Almost every TAP Center has developed or is in the process of developing collaborations with undergraduate and graduate programs in their regions.

The Autism Program Network partners have also provided their local communities and regions with some of the best ASD services possible. Charleston Transitional Facility offers a Getting Along Social Skill Program and a New Diagnosis Family Orientation where families recruit others who are actively involved in their lives to be trained to offer support to the family. TAP at SIU provided screenings for 20 children in this first quarter. The Hope Center offered music therapy to five children, ABA crisis clinic to 13 children and 12 children took part in the Social Skills open house. Krieder provided two Social Skills Groups focused at four to five year olds. Through Quarter One of FY 2010 The Autism Program and its Network Partners continued to provide all regions of the state with comprehensive high quality services while preparing for the future.

The highlights outlined above provide a quick summary of TAP Quarter One activities. The Outcome Summary in Appendix IV provides a detailed listing of all Network activities.

Consensus, Community and Coordinated Action

This quarter report follows the FY2009 Quarter 3 discussion on diagnostics as the second in a continuing series of policy discussions regarding system development for individuals with ASD. This quarter's report will focus on the inception, ongoing evolution and impact of The Autism Program's Community Planning and Network Development Initiative.

The Autism Program Service Network is solidly grounded in a community approach. The program was initiated by a community of parents, providers and legislators determined to change the system of care for individuals with autism. In FY2004 The Autism Program conducted a comprehensive needs assessment to ensure that the autism community—self advocates, parents and providers---would have a voice in the statewide system initiative. A review of the early feedback from the community and TAP's subsequent development confirms that program development has been closely aligned with the expressed community need.

“Community” evokes images of harmony, mom and apple pie. In reality, “community” involves navigating differences, resolving conflicts and working collaboratively to reach common goals. Community requires compromise, and coordinated action. There is no doubt that community and collaboration are necessary to meet the needs of individuals with ASD in Illinois. Unfortunately, the autism community has at times been paralyzed by destructive, divisions related to opposing views of autism, etiology, treatment, appropriate support and education. Illinois legislators and public policy makers have identified consensus and community as necessary to continued system development in Illinois.

Realizing the Needs: In FY2004 The Autism Program published *Realizing the Needs of Illinois Children with ASD and their Families: The Autism Project FY2004 Needs Assessment* (Appendix I), this comprehensive review was conducted to ensure that the autism community—self advocates, parents and providers---would have a voice and would be thoroughly engaged in the statewide system initiative. Quantitative and qualitative data from the report supported the following key findings:

- Access to autism-specific services is a function of geographic location. The majority of services are concentrated in urban areas
- Access to appropriate screening and diagnosis is limited by poor reimbursement, a lack of trained providers and a reluctance to provide an ASD diagnosis
- Illinois agencies do not consistently follow a best practice approach to diagnosis, treatment and/or education of children with ASD
- Families face a myriad of barriers to quality care, negatively impacting their quality of life
- Lack of public awareness contributes to stigma and isolation for families
- There is a shortage of trained providers across all service sectors
- The system is chaotic and fragmented further reducing access to scarce resources
- Life stage transitions and transitions across program areas are problematic
- Information and service for underserved and non-English speaking is severely lacking

A review of The Autism Program's service and support programs and our general development demonstrates conscientious attention to these findings. The FY2004 needs assessment, informed by surveys, TAP funded studies and interviews with parents across the state provided the basis for The Autism Program's design and for many of the program's early and existing programs.

Uniting the Community: Although we have made substantial progress toward addressing the needs identified in FY2004, there continues to be an enormous discrepancy between the breadth and depth of the need (these needs multiplied by 1 in 100 Illinoisans) and the relatively small allocation of resources to this population. The gap between the need and the resources continues to be a divisive factor in the autism community in Illinois and across the country. Factions readily develop over research or service; community living for adults or early intervention, this list goes on. These either/or questions are not appropriate. We need research and service. We need community living and early intervention. We need to expand the resources. We need to engage and equip more people. We need to harness new or reconfigure existing funding streams. This work requires consensus.

In FY2007, The Autism Program launched *Consensus for Autism: A Movement for Positive System Change*. *Consensus for Autism* (Appendix II) draws upon the work of leaders in the field to outline a few core principles including:

- Reliance on National Research Council recommendation for system development
 - Personnel preparation
 - Technical assistance
 - Applied research and program evaluation
 - Communication
 - Demonstration
 - Data Systems
 - Comprehensive Planning
- Unity across the Autism community and across the larger developmental disability community
- Integrated services with trained providers across Illinois
- Evidence-based services through statewide partnership

Consensus for Autism synthesizes the expertise of parents, clinicians, educators and researchers resulting in a statement of common beliefs and goals that are central to the majority of people within the Autism community. *Consensus for Autism* provides a common platform to support the development of governmental and community programs, effective legislation and stable funding. Consensus is a critical component of positive change. *Consensus for Autism* is an integral part of The Autism Program's system and network development and provides the foundation for a statewide Community Planning and Network Development Initiative (CPND)

Planning for Progress and Inviting Participation: The Autism Program's FY2009 Needs Assessment highlighted the tremendous regional differences in need and access to resources. Illinois is enriched by many ethnicities, by urban and rural environments, by a variety of organizations and universities. The differences in services across regions and the tremendous diversity of the population demands a regional/community approach to system development. Simultaneous with the FY2007 development of *Consensus for Autism*, the Autism Program rolled out a Community Planning and Network Development (CPND) program. CPND was piloted by TAP at University of Illinois Urbana Champaign in FY2006 and was amended to allow regional application. In FY2007 TAP, in partnership with Easter Seals Peoria Bloomington, Autism Society of McLean County, Tri-County Autism Society, Illinois State University, Baby Fold and many others rolled out to the Tri-County (Peoria, Tazewell, and Woodford) and McLean county Community Planning and Network Development Programs (CPND).

The CPND has created access to new resources by engaging new partners and harnessing new resources. CPND initiatives are led by over 12 TAP Centers across the state, but the resulting plans represent the goals and the responsibility of multiple agencies and individuals in each region. CPND also provides a ready feedback loop to evaluate TAP and community progress on a variety of fronts. It has been interesting to note the similarities and differences across community plans. Most have reinforced the findings of the FY2004 needs assessment and have endorsed the following in some fashion:

- The need for a physical space, specific people, and resources to support persons with ASD and their families.

One CPND participant likened it to the huge “Shell” signs on the interstate letting us know “you can fuel up here”. The Autism community endorses a real place letting people know “you can get autism assistance here”.

- The ongoing need for quality screening and diagnosis.

CPND has driven development of a comprehensive diagnostic protocol reviewed in last quarter’s policy discussion and is beginning to make inroads toward uniting clinical and educational diagnostic criteria in some communities. An instructional guide and a sample of an original community plan are provided in Appendix (XX).

- The need for lifespan services.

The needs outlined through CPND have erased artificial lines between child and adult provider groups as all groups recognize the benefit in development of effective transition activities and the importance of quality services for continued learning and development across the age continuum.

One of the original community planning partners made the following comment about the potency of the CPND program, “When legislators, policy makers and funders ask...Who said that this service/program/training was necessary. You can point to the community plan and say...The community represented by all of these agencies and families said so”. Appendix III contains an instructional guide outlining the general community planning process and a copy of the McLean County Community Plan created by TAP partners.

The Needs Assessment (2004) and the ongoing community planning all point to the need for increased services and supports. TAP has always added to available service directly through services at our Centers and indirectly through workforce development (training, consultation, demonstration programs). Late in FY2007, TAP leadership met to develop an economical, efficient and evidence-based approach to the continuous call for additional services. Reviewing available resources and the number of providers eager to obtain specialized expertise in ASD suggested that there was potential to expand and equip the workforce. Unfortunately, funding

streams that traditionally sustain clinical service are either unavailable or inadequate for the ASD population. Additionally, having a family member with a developmental disability often reduces the overall family earning power and increases family expenses, leaving families unable to purchase services.

In FY2007, The Autism Program created a community-based plan for service expansion that was predicated on 1) Families and providers rely upon familiar, established regional supports; 2) Existing agencies are often inundated with requests for ASD services and are frustrated by the lack of quality programs and/or supports for implementation; 3) Transition can be supported by the inclusion of agencies and providers who service both children and adults and who have solid experience in navigating the system; and 4) Building ASD specific supports and services through collaboration with existing agencies will result in an initial and in ongoing cost reductions and increased monies for services. The Autism Program Service Network is the result of response to a Request for Proposal (RFP) defining a plan for service expansion, an initial service menu and the support of the Illinois General Assembly. Due a 50% funding cut the complete plan articulated in the RFP has not been realized, but the funding provided was sufficient to fund many new partners, albeit at a reduced level. Partners slated to receive funding under the full appropriation are training their staff and are ready to implement programs with adequate funding.

Maintaining Momentum and Obtaining Ongoing Feedback: The Autism Program system development initiative has created strong links to the community through a myriad of activities including but not limited to: Needs Assessment; Consensus Building; Community Planning and Network Development; and Engaging and Equipping Community Agencies. The links to the community continue to inform program development across the state and in each region. The community links provide feedback on existing services, recommendations and resources for new services. The Autism Program's decision not to create a system from whole cloth, but to weave a network from existing providers has made good use of scarce resources and has created a system that has built in supports for growth and sustainability.

The Autism Program Service Network is committed to work with the Illinois General Assembly to achieve full funding. The program plan to the Illinois General Assembly in FY2008 and the commensurate funding of 10.2 million is still the standard for statewide services and system development. Though all TAP partners are working valiantly to meet the needs of the autism community, they have been working under a budget that represents less than 50% of the budget in the original program plan, and the budget endorsed by the Illinois General Assembly over the last several years. While understanding the very real financial constraints in the State of Illinois, TAP partners are constantly faced with the growing needs of Illinois' autism population. The Autism Program Service Network will continue to provide high quality services and will continue to work to garner the resources necessary to meet the need.

The Autism Program's Community Planning and Network Development program continues to develop. Questions regarding this initiative can be directed to The Autism Program at 217.525.8332.

Appendices

- I. Realizing the Needs of Illinois Children with ASD and their Families
- II. Consensus for Autism
- III. Community Planning and Network Development Instructional Guide, McLean County Community Plan
- IV. Outcome Summary—Quarter One FY2010
- V. Output Definitions
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Realizing the Needs of Illinois Children with Autism and their Families: The Autism Project FY2004 Needs Assessment



The Autism Project

A project funded by the Illinois Department of Human Services



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* edits made for version 1.03 are cosmetic in nature

Suggested Reference

Kelley, S. D., Grieve, A. Parker, J., Affrunti, C. L., Winson, G., Muenstermann, A., et al. (2004). *Realizing the needs of Illinois children with autism and their families: The Autism Project FY2004 needs assessment*. Springfield, IL: The Autism Project. Available online at www.theautismproject.com/Resources.asp



The Autism Project

A project funded by the Illinois Department of Human Services



LETTER OF APPRECIATION

This project would not have been possible without the immense effort and support from individuals and organizations that were willing to contribute information, data, and time to shedding light upon the many areas of need relative to improving the system of care for autistic children and their families. We would like to express our thanks to the TAP partners, Anthony Cuvo, Ph.D., Joseph E. Nyre, Ph.D., and Bennett Leventhal, M.D., and all of their staff for their contributions to this needs assessments.

We wish to express our gratitude to all of the individuals who provided us with pertinent Illinois data through our collaboration with various state partners. Their information greatly enhanced the findings of this project. A thank-you is also in order for the individuals and agencies that assisted in the collection of original data for TAP purposes. The information proved to be invaluable and an essential asset to the culmination of this project.

Our immense gratitude also goes to all of the service providers, educators, and families of children with ASD who took the time to provide us with precious feedback, guiding us in bringing to light the areas of need within the autism community.

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**Realizing the Needs of Illinois Children with Autism and their Families:
The Autism Project FY2004 Needs Assessment**

EXECUTIVE SUMMARY

Purpose

As per The Autism Project's (TAP) contract with DHS for FY2004, this needs assessment was conducted with a primary aim of informing program planning and development in the areas of autism training and services in Illinois.

Framework

Consistent with best practice standards, the needs assessment was developed together with key stakeholders (parents, providers, and state officials) who identified core areas of need to be assessed. Using these key areas as a framework, TAP sought to utilize existing sources of information, both nationally and specific to Illinois, in addition to original data collection in targeted areas. TAP intends to continue assessing needs in each fiscal year, with the intention of promoting a data-driven approach to addressing Illinois' problems and our own program development.

Major Finding

Consistent with the U.S. Surgeon General's Report and the experience of other states, one outcome of this year's needs assessment was the need for a more systematic approach to data collection, ensuring statewide coverage and inclusion of a wide variety of stakeholders. This would include an epidemiological study to gain further information on the numbers of Illinois children and families impacted by autism, which can currently only be estimated from a variety of sources.

Autism presents a national public health crisis. The increase in prevalence, the lack of services and trained providers, and the fragmented system of care have resulted in devastating consequences for children with Autism Spectrum Disorders (ASD) and their families. The state of affairs in Illinois is consistent with the larger national picture, highlighting the need for a statewide systematic response to meet the needs of children currently identified with ASD and the rising numbers of those to be diagnosed in the future. As a state, it is clear that we need to find ways to meet the needs of all children with ASD in order to promote meaningful and lasting changes in their lives and in the lives of their families.

Key Findings**

Quantitative and qualitative data in "Realizing the Needs of Illinois Children with Autism and their Families: The Autism Project FY2004 Needs Assessment" supports the following key findings:

- ❑ Access to autism-specific services often depends on where a family is located in Illinois, with the majority of services concentrated in urban areas.
- ❑ Children are not being adequately screened nor consistently referred for diagnostic evaluations, often attributed to poor reimbursement, a lack of trained providers, and reluctance to provide an ASD diagnosis.
- ❑ Illinois agencies do not consistently follow a best practice approach to diagnosis, treatment, and education for children with ASD. Of those that do, there are limited resources to support it.
- ❑ Families face a multitude of barriers to accessing care for their children that negatively impact their quality of life.
- ❑ A lack of public awareness of autism contributes to the stigma and isolation experienced by families.
- ❑ There is a shortage of trained providers across all service sectors (childcare, respite, early intervention, schools, healthcare) impacted by a lack of consistent certification standards in Illinois.
- ❑ The Illinois system is chaotic with fragmentation of care, inconsistency in referrals, lack of consensus on provider qualifications, and no accepted standards of care.
- ❑ Youth with ASD are in danger of being dropped at crucial transitions, from EI to school or school-based to adult services.
- ❑ There are few sources for information and services for underserved populations, including non-English speakers and Hispanic migrant populations.
- ❑ State monitoring and tracking systems are insufficient, with a need for a unified single point-of-entry system to maximize federal dollars and exploration of Medicaid waiver programs.

Concluding Comment

Illinois is in an excellent position to dramatically improve the quality, quantity, and accessibility of ASD services by building on pockets of excellence in autism services, ongoing state-funded projects such as The Autism Project and the Illinois Autism/PDD Training and Technical Assistance Project, advocacy efforts by family support agencies, and recently established multi-agency work groups such as the Illinois Autism Task Force. In order to meet the needs highlighted above, there is an overriding need for an umbrella autism program in Illinois, designed to inform and impact autism services across a variety of state and community programs. The state needs a recognized authority with multiple ports of entry to ensure that families and agencies know where to go for autism related services. Such regional centers would ensure that individuals, families, and service providers had easy access to training and services, as well as promoting best practices throughout the state.

** Please see full report for further detail.

INTRODUCTION

The Autism Project (TAP) was created by The Illinois General Assembly in response to the need for training, consultation, and services for the state's growing number of children with ASD. TAP is a systems development initiative designed to create and enhance community networks that promote best practice in the diagnosis, treatment and education of children with ASD. There are three sites throughout Illinois, representing geographic diversity and each linked to a university partner: The University of Chicago in Chicago, The Hope School in Springfield, and Southern Illinois University at Carbondale. Each site provides diagnostics, parent training, and consulting services as part of the larger systems development venue. The project's research and evaluation division participates in and funds research initiatives that will have a direct impact on children, families, and the system of care.

Based on an ongoing needs assessment for Autism training and services in the state of Illinois, the project seeks to augment and coordinate evidence-based practices within the system of care for families of young children with Autism. The project coordinates its efforts with existing systems, including local school districts, early intervention systems, and Illinois' Division of Developmental Disabilities networks. Specific goals include building the capacity of service providers and families through training, advancing the knowledge base through development of a consistent program of research, strengthening outreach to underserved and culturally diverse populations, and documenting project outcomes through program evaluation. Program initiatives are conducted in the following six areas: training and consultation, outreach and support to families, outreach and support to providers and agencies, resource development, site and system development, and research and evaluation.

Currently in its second year, TAP has three pilot sites representing geographically and culturally diverse areas of Illinois: Southern Illinois University at Carbondale, Rehabilitation Institute, Center for Autism Spectrum Disorders (Anthony Cuvo, Ph.D.), University of Chicago Developmental Disorders Clinic (Bennett Leventhal, M.D.), and The Hope School in Springfield (Joseph E. Nyre, Ph.D.).

TAP initiatives in FY2004 have resulted in increased capacity and coordination of qualified service providers in the fields of medicine, speech therapy, occupational therapy, education, and daycare. Through demonstration clinical services at each site and coordination with a variety of agencies throughout Illinois, more children are receiving early, accurate diagnosis and timely treatment of appropriate intensity. TAP continues to work to promote a best practice approach to assessment, treatment, and system reform in Illinois. The

TAP FY2004 Annual Performance Review is available at www.theautismproject.com/Resources.asp.

As part of its mandate, TAP has conducted a needs assessment in a variety of areas pertinent to its mission, with the goal of enhancing participation from a variety of key stakeholders and providing guidance for program development. Key stakeholders in TAP include children with ASD, their families, community providers and agencies, early intervention professionals, teachers and other school personnel, health care professionals, daycare and after school program providers, and state officials and agencies. FY2004 represents TAP's first year of systematically assessing the needs of our consumers through direct service, training and consultation, and other means.

The overarching aim for this year's needs assessment was to begin a process of linking needs assessment to program goals to evaluation of program progress and guidance for future planning and development. Thus, this is not a static document, but represents a **dynamic** process that is intended to contribute to a *learning organizational* approach whereby TAP will continue to contribute to and benefit from an increasing awareness of the needs of children with ASD, their families, and service providers in the state of Illinois.

This project could not have been undertaken without the energies of many partners, whose devotion to progress in the field of autism is unflagging. Core areas of need and specific questions were derived from consensus building with a variety of key stakeholders as mentioned above. Sources of information used for the completion of the needs assessment included national statistics and published literature, existing needs assessment and information available from sources within Illinois, and original data collection. It should be noted that this methodology was employed in answer to critical feedback from stakeholders that there already existed sufficient assessment of need in Illinois. Thus, we chose to incorporate and synthesize existing information together with targeted data collection in areas where little data were available.

SOURCES OF INFORMATION

The review of existing information was conducted in the course of business over the past year, reviewing national and state trends, published literature including peer-reviewed journal articles, state guidelines and practice parameters.

National Statistics and Published Literature

Although by no means an exhaustive review of the literature, the needs assessment was guided by information available from national organizations and published literature, particularly peer-reviewed sources. These sources are cited throughout the text.

Review of Illinois Data

The following sources were made available through TAP collaboration with a variety of state partners:

Existing Sources

Financing Services to Individuals with Developmental Disabilities in the State of Illinois (Robert M. Gettings, Executive Director, Robin Cooper, Director of Technical Assistance, and Max Chmura, Consultant, National Association of State Directors of Developmental Disabilities Services, Inc., Alexandria, VA, September 2003).

This report, developed in partnership with the Illinois Council on Developmental Disabilities, provides a detailed summarization and recommendations with regard to existing methods by which Illinois funds developmental disability services and programs, development of a policy construct for financing future services, and identification of new sources of revenue. NASDDDS gathered information from stakeholders within the area developmental disabilities and analyzed budget documents, data reports, and other documents. They also incorporated knowledge gleaned from federal Medicaid policy, as well as from other states. Findings by the team were extensive and included the establishment of single designated entity in Illinois to manage state-funded developmental disability services and strategies for revenue enhancement in both the short and long term.

Illinois Autism Project Regional Survey Results (Kathy Gould, Illinois Autism/PDD Training and Technical Assistance Project, LaGrange, IL, 2002)

Information for this study was acquired during the course of 30 Family Forums, conducted from September 2001 through March 2002, in which presentations were given with regard to the Illinois Autism/PDD Training and Technical Assistance Project. Discussion of topics such as family concerns, issues, and training was encouraged, and participants

were also given a questionnaire to complete. A total of 327 questionnaires were collected and reviewed for the purposes of this study.

Survey of Illinois Special Education Administrators (Stacey Jones Bock, Ph.D., Autism Spectrum Institute, Normal, IL, 2002)

This study was undertaken to gain knowledge about the training needs of special education administrators and districts throughout Illinois, particularly with regard to service delivery and programming for individuals with Autism Spectrum Disorders. Surveys were sent to 116 special education administrators, with 52 responding.

The Illinois Autism/PDD Training and Technical Assistance Project (Kathy Gould, Illinois Autism/PDD Training and Technical Assistance Project, LaGrange, IL, April 2004)

This was a presentation conducted at The Autism Project Town Hall Meeting in Springfield, IL in April, 2004. Information discussed included statistics related to estimates of autism in school-age youth and personnel needs for special education derived from a variety of Illinois sources including the Illinois State Board of Education.

Unmet Needs Project: A Research, Coalition Building, and Policy Initiative on the Unmet Needs of Infants, Toddlers, and Families (Ann Cutler, M.D., University of Illinois-Chicago, and Linda Gilkerson, Ph.D., Erikson Institute, May 2002)

The Unmet Needs Project, funded by the Illinois Council on Developmental Disabilities, developed a research program consisting of three separate studies. The first study, which addressed the needs of infants and toddlers not eligible for early intervention services, consisted of questions added to the Developmental Screening Surveys used in the third study. The second study investigated the needs of children and families currently taking advantage of EI services, but who need additional services not mandated by the State of Illinois. An early intervention childcare family survey, an early intervention parent survey, and parent focus groups were used to collect data. A total of 642 childcare family surveys were distributed to families, of which 126 were completed and returned. Nine EI programs distributed 493 parent surveys, and 104 were completed and returned. A total of 4 focus groups were conducted across the state, with 32 parents attending. The third study addressed the need for adequate developmental screening and mental health services for at-risk infants and toddlers. A developmental screening survey and infant mental health survey were used to collect information. Five versions of the developmental screening survey were administered to EI programs, childcare programs, public health clinics, and primary care physicians, with 603 out of 1645 surveys completed and returned, and 274 out of 661 infant mental health surveys completed and returned. All survey data for the three studies was collected between from January to December 1999.

Original Data Collection

In order to more fully explore specific issues related to review of existing sources, several means of original data collection were employed in FY2004 with a variety of key stakeholders.

Surveys, Interviews, and Focus Groups

Autism Focus Group at The Hope School (2004)

Sponsored by The Hope School, a TAP partner, and conducted by Dr. Peter Nierman, Deputy Director for the Illinois Department of Human Services – Division of Mental Health. The event was attended by approximately 50 parents of youth with ASD, staff of the school, and other key stakeholders. The goal was to create guideposts for an optimal State sponsored system of care for children with ASD and their families.

Autism Needs Interviews (2004)

Conducted by TAP staff, a series of focus groups with EI providers and key informant interviews with parents were held in all 3 TAP catchment areas. Eighteen EI providers participated in focus groups ranging from 1 to 1 ½ hours each. Six parents participated in interviews ranging from 1 to 1 ½ hours each. A semi-structured interview format was utilized for both venues. Participants were selected from a sample of convenience, consisting of individuals with whom TAP had worked over the past year.

Autism Needs Survey (2004)

Conducted by TAP staff, written surveys were collected after 4 large training events held across Illinois. Of the 262 respondents, 89% were professionals who work with children with ASD and their families, with the remaining 11% consisting of parents of children with ASD. Information assessed included training needs and needs specific to children with ASD aged 0 to 3 years, children with ASD aged 4 to 5 years, children with ASD aged 6 to 21 years, families of children with ASD, and providers and agencies who work with children with ASD.

Daycare Needs in Southern Illinois (2004)

The assessment of needs related to caring for children with ASD was conducted during the course of consultation with a daycare facility in southern Illinois by Anthony Cuvo, Ph.D. and staff from the Rehabilitation Institute at SIU-Carbondale, a TAP partner.

Early Autism Detection and Referral Program Needs Assessment (2004)

In 2004, as part of a contract with TAP, the Illinois Chapter of the American Academy of Pediatrics (ICAAP) has presented practice-based

training workshops on ASD at 31 sites in Illinois. Prior to these training programs, ICAAP distributed pretests to a total of 120 attendees, including physicians, nurses, medical students, and staff. Posttests were distributed to 43 physicians and nurses after the training, of which 15 were completed. Program needs assessment surveys were also distributed in conjunction with the training programs. A total of 7 of these surveys were completed.

Forums for Professionals in Varied Geographic Regions in Illinois (2004)

Two separate professional forums were held by TAP in central and southern Illinois, with 29 and 6 attendees respectively. Information on needs for Illinois children with ASD, their families, and providers was collected through process notes completed by staff at each meeting.

Needs Assessment for Children with Autism in Illinois Survey (2004)

A written survey was mailed and emailed to parents across the state by Laura Cellini, a parent affiliated with TAP, with data entry and analysis support from TAP staff. Surveys in English and in Spanish were sent, with 81 respondents. Information assessed included demographic data pertaining to the child, place of child's diagnosis, and type of services and community supports being received. Parents were asked to respond qualitatively to a question on what services/supports would better help the child/family in order that they would be more likely to remain in a home-based or least restrictive community or educational setting.

Survey of Autism Informational Needs for Professionals and Parents (2004)

Sponsored by TAP and conducted by Anthony Cuvo, Ph.D. of the Rehabilitation Institute at SIU Carbondale. Eighty professionals and 28 parents were surveyed regarding their autism informational needs. Most professionals surveyed were between the ages of 46 and 55 and had up to 5 years experience with ASD. The majority of parents surveyed were in the age range of 31-45 with children diagnosed with ASD who were six years old or younger.

Survey of Respite Services (2004)

Sponsored by TAP and conducted by Little Friends, Inc. with five agencies that provide respite services. The surveys took place in February and March 2004. The purpose of the survey was to obtain a better understanding of the respite services that are provided to children with autism in TAP catchment areas, and to identify these agencies' needs and obstacles for serving children with autism through respite.

Selected Original Research Sponsored by TAP

Assessing Relational Learning Deficits in Perspective-Taking in Children with Asperger Syndrome and High-Functioning Autism (2004)

Research sponsored by TAP and conducted by Ruth Anne Rehfeldt, Ph.D., BCBA, Rehabilitation Institute, SIU Carbondale. The purpose of this project was to identify modifications to enable future participants to complete the perspective-taking protocol successfully. To achieve this, scores were compared on a computerized perspective-taking protocol for children with and without high-functioning autism, and correlating those scores with scores on other standardized autism-assessment instruments. 57 trials approximately 60 minutes in duration were conducted. Eight children between six and ten years of age were run as pilot participants, 4 children diagnosed with high-functioning or mild autism, and 4 typically developing children.

Building a School Consultation Model for Children with Autism Spectrum Disorders and Their Families: Integrating Content and Infrastructure (2004)

Research sponsored by TAP and conducted by Susan Douglas Kelley, Ph.D., Georgia Winson, M.S., LCPC, and Joseph Nyre, Ph.D. The purpose of the project was to develop a model for consultation in school settings that incorporates best practice approaches in consultation, infrastructure support, content, and evaluation. The overarching aim of the project was to improve school districts' capacity for developing internal resources for consultation to improve environmental and educational supports for children with ASD. A series of focus groups were held with special education administrators in districts and cooperatives throughout central Illinois to assess needs.

Characteristics of Self-Injury in Young Children with Autism (2004)

Research sponsored by TAP and conducted by Jeff Salt, D.Clin.Psy., Department of Psychiatry, University of Chicago. The study had two main goals: first, to identify the types and severity of SIB in children under four years of age by a cross sectional study using parent report of self-injury using the ADI 'current' and 'ever' scores. The study describes the topography of self-injurious behavior in young children with Autism, as well as the severity of the self-injury reported; the second goal of the study was to compare two groups of young children, those with SIB and those without SIB, at time of assessment. The study describes risk factors associated with displaying self-injury in young children with Autism.

Evaluating Social Skills Interventions for Young Children with Autism: Comparing Social Stories to Standard Practice (2004)

Research sponsored by TAP and conducted by Karla Doepke, Ph.D., Department of Psychology, Illinois State University. This investigation used a multiple-baseline design across three individually defined social behaviors replicated across three elementary-school age children diagnosed with autism. For each child, the teacher selected three social behaviors that reportedly impacted the child's social opportunities and success in the school setting. The baseline condition provided a measure of the frequency of social behaviors as they naturally occurred in the classroom setting. Following the baseline, each child received intervention in the form of practice-with-feedback. After a stable pattern of responding was established, the social story intervention was introduced for direct comparison of additive benefits of social story interventions to the standard practice that is currently being used in these children's settings to teach them "appropriate" social behaviors.

Oral Health Needs Assessment of Children with an Autism Spectrum Disorder and Other Developmental Disabilities (2004)

Research sponsored by TAP and conducted by Ronda DeMattei, R.D.H., M.S.Ed., SIU Dental Hygiene Program and Anthony Cuvo, Ph.D., SIU Rehabilitation Institute and TAP Partner. In June 2004, Ronda DeMattei, R.D.H., M.S.Ed., SIU Dental Hygiene Program, and Anthony Cuvo, Ph.D., SIU Rehabilitation Institute, conducted a study of 55 children, from three different schools, including The Hope School, to further document the need for studies describing the prevalence of oral disease for individuals with ASD. The majority of children (42) had ASD with the remaining 15 diagnosed with a variety of developmental disorders. A questionnaire was used to examine children's behaviors, as reported by parents/guardians or caregivers, that may contribute to compromised oral health. An oral assessment was conducted to add to the body of knowledge concerning oral health needs of children with an ASD. Two registered dental hygienists conducted oral assessments on children from three different schools. Analyses were conducted to compare survey data and oral assessment data.

White Papers Sponsored by TAP

Best Practices in Early Identification of Autism Spectrum Disorder (2004)

White paper sponsored by TAP and written by Ann Cutler, Ph.D., Elina Manghi, Ph.D., both of the Department of Disability and Human Development, University of Illinois at Chicago, and Joan Ingram, Ph.D., private practice. This paper addresses issues related to the early identification of ASD and reviews current identification practices in Illinois. Recommendations are made in the areas of early identification and assessment, collateral support services, professional development, and future research based upon an evaluation of existing diagnostic tools, review of current status of early identification of ASD in Illinois, and research findings on the earliest biological and behavioral signs of ASD.

Best Practices in Functional Assessment (2004)

White paper sponsored by TAP and written by Lynette Chandler, Ph.D. and Toni R. Van Laarhoven, Ed.D., Northern Illinois University. A white paper literature review was performed to discuss recommended practices and procedures for assessing and addressing challenging behavior for your children with autism.

Best Practices in Identification of ASD in School-Age Children and Youth (2004)

White paper sponsored by TAP and written by Karla Doepke, Ph.D., Department of Psychology, Illinois State University, Linda Kunce, Ph.D., Department of Psychology, Illinois Wesleyan University, and Virginia Moody, Ph.D., Central Illinois Psychiatric Associates. The paper addresses the complex challenges in the identification of school age children with ASD, including definitions of autism, referral and screening issues, diagnostic best practices and assessment procedures. Current Illinois practices are reviewed and placed in a national context. The authors conducted a telephone survey of 10 national clinics and 9 Illinois clinics on best practices.

Best Practices in Treatment: Social Deficits (2004)

White paper sponsored by TAP and written by Karla Doepke, Ph.D., Department of Psychology, Illinois State University, Linda Kunce, Ph.D., Department of Psychology, Illinois Wesleyan University, and Virginia Moody, Ph.D., Central Illinois Psychiatric Associates. The paper identifies and considers ten best practices in the treatment of social deficits.

Outreach Programs to Culturally Diverse and Underserved Populations

Autism Migrant Worker Outreach Training (2004)

Sponsored by TAP and conducted by Elina R. Manghi, Ph.D., Department of Disability and Human Development, University of Illinois at Chicago, this project provided a one-day bilingual and bicultural outreach training workshop for Hispanic migrant families from Southern Illinois with the purpose of disseminating basic information on autism spectrum disorders. A train-the-trainer model was used to ensure dissemination of information. A total of three trainings were offered, each in an area densely populated by Hispanic migrant workers. Information was assessed related to needs expressed by Hispanic migrant workers and providers in attendance.

Outreach to Children with ASD in Culturally Diverse, Underserved Populations (2004)

Sponsored by TAP and conducted by Easter Seals of Metropolitan Chicago, this project delivered outreach information to parents, relatives, friends and service providers of children with the diagnosis of ASD in culturally diverse, underserved populations. An informational marketing campaign that combined broadcast radio, print media and CD/DVD technology was used to outreach to segmented ethnic groups on Chicago's south side and south suburban Cook County. Information on needs was assessed during the course of the project.

FINDINGS

National Public Health Crisis

Autism spectrum disorders (ASD) are increasing in prevalence, and the lack of services, trained providers and the fragmented system of care (Akerley, 1975; Bristol & Schopler, 1983) have produced devastating consequences for children and families, constituting a national public health crisis. The severity of the impairment, frequent comorbidity of medical disorders, high intensity of service needs, and costs (both human and financial), have fueled an avid search for effective treatment (USDHHS, 1999).

National Prevalence Rates

Current studies estimate the prevalence rate for people identified with autism ranges from 2 to 6 per 1,000 individuals (CDC, 2004a). The CDC differentiates 3 types of autism identified with varying prevalence rates: (1) "Classic" autism, consistent with a DSM-IV diagnosis, at 1 in 1,000 individuals, (2) individuals within the autism spectrum, including pervasive developmental disorders (PDD) at 1 in 500, and Autism Spectrum Disorders, including PDD and Aspergers, at 1 in 166 individuals. This corresponds to a prevalence rate of 0.06% (CDC, 2004a).

This is a drastic change from past prevalence rates. While we do not know why prevalence rates have increased, we do know that the number of children diagnosed with Autism has increased, as has the demand for services. Surveillance programs are needed to estimate the current incidence of ASD and to monitor changes over time (Cutler, Manghi & Ingram, 2004). According to federal education officials, in the 1992-1993 school year fewer than 20,000 of the nation's 5 million special education students, ages 6 to 21 years, were considered autistic. Ten years later the number has grown to nearly 120,000 of six million special education students with autism. This figure does not include the 19,000 children aged 3-5 years, who were receiving autism services under federal law (Gross, 2003).

Illinois Estimates

There are no true prevalence or incidence statistics available for Illinois. Washington University in St. Louis is currently generating regional epidemiological data, although not specific to Illinois. Currently, estimates of the prevalence of ASD are based on the number of children identified as such under IDEA through state early intervention or school systems. It should be noted that such statistics are generally considered to be a gross under-representation. There are some discrepancies in these numbers for several reasons, one of them being that some school districts do not count children in the autism category within a

medical diagnosis even when they do fit under the state educational definition of autism (Doepke, Kuncce & Moody, 2004b).

At the TAP Town Hall Meeting in April 2004, Kathy Gould of the Illinois Autism/PDD Training and Technical Assistance Project presented a compelling picture of Illinois needs based on data compiled from the Illinois State Board of Education (Gould, 2004). According to the 2001 census, there were 3,605,506 children aged 0 to 18 years in Illinois. If the 0.06% prevalence rate were applied, there could be as many as 21,590 children with ASD. Illinois school records for the 2002-2003 school year indicate 6,125 children aged 3 to 21 years receiving special education services under the category of autism (ISBE Annual Report, 2003 in Gould, 2004). Although there are some minor age differences, this corresponds roughly to a difference of 15,465 children who may have gone undiagnosed and who are not receiving appropriate services in Illinois. The number of children identified with autism varied by age group, with 910 from 3-5 years of age, 3374 from 6-11 years of age, 1585 from 12-17 years of age, and 256 from 18-21 years of age (ISBE IDEA Count December 2, 2002 in Gould, 2004). Projections of future prevalence rates among Illinois school-age populations are expected to be between 7,199 - 14,397 individuals.

It is clear that reliable information on the overall prevalence of ASD in Illinois is lacking, although predictions can be made on the best available national estimates. Illinois lacks a coherent, readily accessible state data base that can inform such questions as the age at which children are being diagnosed, patterns across ethnic and regional groups, and the extent to which children might be re-classified over time (Doepke et al., 2004b).

Initiatives to address the crisis in autism services have clearly identified the need for (1) early identification, (2) evidence-based practices in assessment and intervention, (3) family-centered care, (4) training and ongoing consultation to all providers of care, and (5) a coordinated system of care (Barlow, 1996; Chambless & Hollon, 1998; Rosenbach & Gavin, 1998; AAP, 2001a).

Need for Early Identification and Surveillance

National Statistics and Literature Review

In the past decade, a number of studies have documented positive outcomes for the long-term benefits of early intervention for very young children (Lovaas, 1987; McEachin, Smith & Lovaas, 1993; Ozonoff & Cathcart, 1998; Rogers, 1998; Sheinkopf & Siegel, 1998), with children being accurately diagnosed and responsive to intervention as early as 2 years of age (Stone et al., 1999; Stone, Coonrod & Ousley, 2000). Early diagnosis and treatment are catalysts for the

development of necessary supports including family training, educational planning, respite and appropriate medical care (Lovaas, 1987; McEachin et al., 1993; Ozonoff & Cathcart, 1998; Rogers, 1998; Sheinkopf & Siegel, 1998). As stated in an interview with Dr. Geraldine Dawson, an expert in autism at the University of Washington, research conducted at the University of Washington estimates that early identification and intervention for children with ASD will save 1 million dollars per person by the time the person reaches 55 years (Morgan & Shoop, 2004).

Despite the growing evidence of the importance of early identification and the critical need for early, intensive treatment, there have been few significant changes in clinical practices. A recent study of 1,300 families found that the average age of formal diagnosis was 6 years, although the majority of parents had sought medical attention for ASD symptoms by 2 years (Howlin & Moore, 1997). Few children and young adults with autism who are receiving special education services did not get early, intensive treatment, which significantly limits the effectiveness of current services (Gross, 2003).

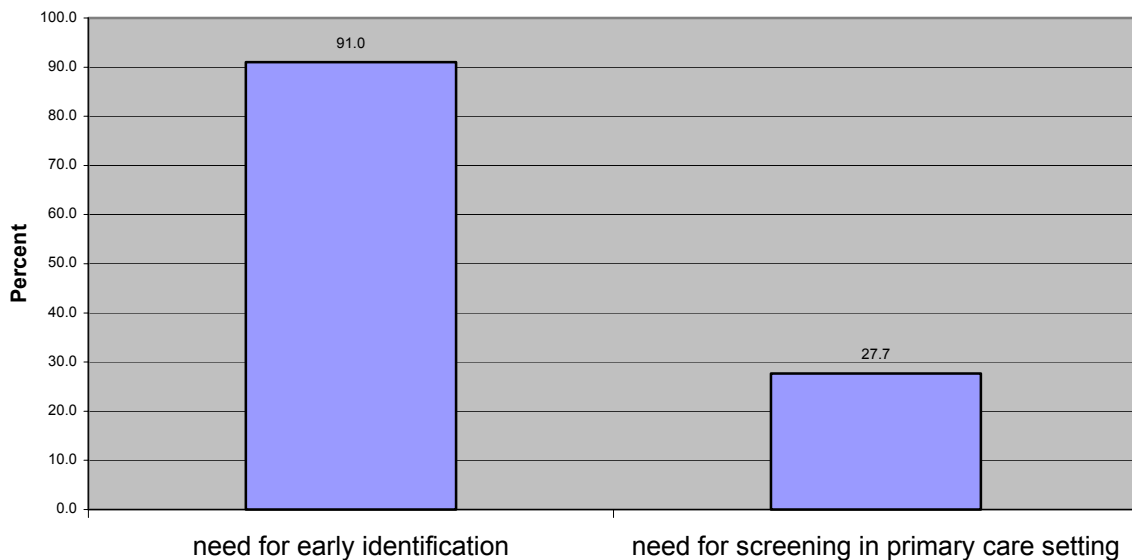
There are several barriers to the early and accurate identification of children suspected of having ASD. A consensus that came out of a major national conference focusing on the federal government's role in biomedical autism research, early screening and diagnosis, and improving access to autism services stated that there was a national crisis in adequate and timely diagnosis, driven in part by a lack of urgency on the part of the overall system (IACC, 2003). The lack of trained providers contributes to inaccurate screening and delays in diagnosis due to waiting lists for an expert evaluation. Further, it is often unclear to parents, teachers, and frontline professionals as to when or to whom a child should be referred for further evaluation. One major factor in the delayed identification of children with ASD is that the individuals who have primary contact with the child do not have the training and support necessary to identify children at the earliest possible ages (Filipek et al., 1999; South et al., 2002).

In addition, there is still a great need for more research to develop sensitive and easily used screening tools that would allow for the early identification of children who now are not able to benefit from early intervention services (Filipek et al., 1999; NIMH, 2004). Children who have high functioning autism or Asperger disorder are generally identified later due to the lack of appropriate screening tools (Filipek, 1999; Cutler et al., 2004). Good screening tools could be used to increase the rate of accurate screening in a variety of settings. For example, while physicians generally identify children with physical or neuromotor disabilities during the first year of life, they were much less likely to identify children with social-emotional or language concerns (Palfrey, Singer, Walker, & Butler, 1987). In these cases, the diagnosis was initially determined by

a non-physician 75% of the time and usually delayed until the child was in school and encountering other professionals. Nationwide surveys of pediatricians by the American Academy of Pediatrics (Sareen et al., 2001; Cutler et al., 2004) have reported little use of developmental screening tools in pediatric practices.

Review of Illinois Needs

Core Issues in the Field of Autism: Identification



In TAP's (2004b) Needs Survey (N=262), participants endorsed identification needs (81%) as the single-most important issue for children aged 0 to 3 years of age. When asked to rate issues of importance within the area of identification needs, survey participants, which included both parents and providers, overwhelmingly acknowledged needs for early identification of autism (91%) and provider training on identification issues (82.4%) as areas that deserved the most attention. Over a quarter of the respondents identified the need for screening in primary care settings as one of the top 3 issues in identification.

Delay in Identification

The number of infants and toddlers diagnosed with ASD in the Illinois early intervention system, which serves children ages 0 to 3 years, is very low (Cutler et al., 2004). Based on U.S. census data for the year 2000, there were 173,000 2-year olds in the state. In the same year, there were only 45 children identified with ASD in the Illinois early intervention system, representing approximately 0.026% of 2-year old children in Illinois. Based on a national prevalence rate of 0.06%, there may be 1,038 two-year old children with ASD in Illinois, an under-identification of over 2,300%.

The identification and diagnostic process is both distressing and unjustifiably drawn out for many families. Parents typically have concerns about their child's development but have to wait months to a year or more for diagnostic confirmation by professionals/center with expertise in diagnosing autism (Cutler et al., 2004; Doepke et al., 2004 b). A survey of national and Illinois clinics found that the demand for services exceeded the supply, and that the average wait for a diagnostic evaluation was 6 to 12 months (Doepke et al., 2004 b). For all the agencies surveyed, there was emphasized a general increase in referrals of all ages with few resources to meet the need. Other barriers to screening that have been mentioned include lack of time, lack of reimbursement, and lack of training (Cutler & Gilkerson, 2002). In TAP's Needs Interviews (2004 a), conducted with parents individually and with early intervention providers in focus groups throughout the state, the consensus was that a typical diagnosis takes anywhere from 1 to 18 months from the time a concern about the child's development is first raised. Interestingly, the shortest time experienced for a diagnosis was one month (that diagnosis was received through TAP).

Barriers to Early Identification: Reluctance to Discuss

There are multiple reasons why young children with ASD remain under-identified in Illinois, including a system-wide reluctance to talk directly about ASD. School-age children often enter preschool with a diagnosis of 'developmental delay,' despite the parents being told the child was probably on the autism spectrum, thus creating an unnecessary delay in accurate formal identification (Doepke et al., 2004b). Both providers and parents commented on the difficulty of being faced with a diagnosis of ASD, also referred to as the "A word" (TAP, 2004a). Notably, parents remarked on their desire for an earlier discussion from providers about ASD despite their fears, while some providers commented on their reluctance to broach discussions about ASD too early on. Many providers believe that families will respond negatively to a referral for ASD evaluation. Similar concerns were voiced by health care providers in Illinois, who cited the lack of parental acceptance of symptoms as a barrier to early identification (Cutler & Gilkerson, 2002). Specifically, in a survey (N=120) administered by ICAAP (2004), 91% of the providers completing the survey stated that they have encountered a situation in which parent denial served as a barrier to receiving appropriate services. A provider participating in the TAP Needs Survey (2004b) stated, "I had a few children whom we believed were children who had been diagnosed, but the parents refused to share medical info with the school. How do you discuss issues with parents whose only view of Autism is 'Rainman'?"

A lack of adequate monitoring of ASD exists in Illinois. Diagnostic information that is obtained through the EI system is not reliably captured (Mr. N. Robinson, DHS, personal communication, April, 2004 as cited in Cutler et al., 2004). For example, data obtained following medical diagnostic evaluations in early intervention is not consistently entered into Cornerstone, the data system used by the Illinois Department of Human Services. Moreover, when children are identified, EI screening and assessment in Illinois does not require tools that are sensitive or specific for ASD, nor are providers necessarily trained in ASD. These findings suggest that many changes need to be made to Illinois' system of monitoring cases of ASD, such that cases are not only properly identified, but also that providers have access to tools specific and sensitive to an ASD diagnosis.

Barriers to Early Identification: Where To Go for Diagnosis?

“It is an inconsistent and winding road to diagnosis, requiring multiple stops for assessment,” - Parent (TAP 2004a).

Parents and providers experience significant confusion within the Illinois system specific to where children should be referred for diagnosis, and what professionals are qualified to make a diagnosis. Illinois programs differ in their referral protocols for further evaluation of general developmental concerns (Cutler & Gilkerson, 2002). Prevention and public health programs refer first to Community and Family Connections (CFCs), the entry point into the early intervention system. However, physicians are most likely to refer to private providers and childcare program staff is most likely to refer to the public schools. One of the most striking findings of the study (Cutler & Gilkerson, 2002) was that 55% of infant/toddler child care programs and one-third of the primary care physicians surveyed had no knowledge of CFCs.

In addition to increased awareness of the symptoms of ASD, parents need information on where to go for help with concerns about ASD symptoms in their children (TAP, 2004a). One parent stated, “We’ve all seen *Rainman* but I had no idea what autism was.” When asked whom they contacted first regarding their concerns, it was not surprising that 5 different answers were received, from professionals (pediatrician, day care teacher, family doctor) to friends and family members.

Aside from the question about provider training and experience in ASD diagnosis, there is disagreement about what professionals are qualified to make a

diagnosis. Parents' experience of such a system is extremely frustrating. In interviews with TAP staff (TAP, 2004a), a parent recalled her pediatricians acknowledging her child's delays as consistent with ASD, but being told that he was not qualified to make a diagnosis. This contributes to parents having to make multiple stops. For instance, one parent who participated in the TAP (2004a) Needs Interviews remarked that they had to make 10 stops over the course of 12 months in order to get a diagnosis. Two other parents who participated in the same interview had to make 4 stops over the course of 6 and 12 months, respectively (TAP, 2004a). Essentially, both parents and providers need to be informed as to where a proper ASD diagnosis can be performed.

Barriers to Identification: Lack of Screening

“A step-by-step approach toward diagnosis is needed with a checklist for parents and primary referrals (physicians, service coordinators) regarding autism signs. These people need to know it is okay to obtain an evaluation (such as those given by TAP) to rule out ASD” - Provider (TAP, 2004a).

While Illinois physicians and childcare workers have ongoing access to a large number of children, they were the least likely providers to use a standardized screening instrument, preferring to use agency developed checklists or clinical judgment (Cutler & Gilkerson, 2002). Only one-third of Illinois health care providers reported using valid screening tools for general development and 7% specific to autism (Cutler & Gilkerson, 2002; ICAAP, 2004). Only one-third of 199 Illinois health care providers reported using valid screening tools for general development (Cutler & Gilkerson, 2002). Even fewer use standardized tools to screen for autism, with only 7% of XX pediatricians surveyed reporting the use of published measures rather than informal means (ICAAP, 2004). Of 7 pediatric practices surveyed, the number of children 5 years old and younger seen each year ranged from 3,000 to 17,500, with corresponding referral rates for autism diagnostic evaluations ranging from 5 to 100. Compared to the national prevalence rates of 0.06% ASD diagnosis, it would be reasonable to expect rates of children screened to be higher. While one practice had what appeared to be an appropriate rate of screening at 1.7%, the remainder of the practices had referral rates of 0.3% or below. Providing information on characteristics of autism and appropriate screening tools specific for ASD to health care and childcare professionals is imperative.

At a Glance: Need for Early Identification and Surveillance

- Barriers to early and accurate identification include the lack of urgency on the part of the overall system, lack of trained providers, the lack of a statewide monitoring system, and reluctance of both parents and providers to discuss an ASD diagnosis.
- Participants in TAP's Needs Survey indicated identification needs as the most important issue for children between the ages of 0-3 years of age.
- As many as 1,038 2-year-old children in Illinois with ASD may have gone unidentified.
- Referral protocols for an ASD diagnosis vary widely, leading to confusion for both parents and providers.
- Illinois childcare workers and physicians have ongoing access to a large number of children, yet are least likely to use a standardized screening instrument.

Need for Accessible Assessment and Intervention Services Based on Best Practices

National Statistics and Published Literature

With respect to existing services and to inform the building of a system of care, improvement of assessment and intervention strategies is necessary to facilitate adequate access to care for children with ASD and their families. Several practice parameters and state guidelines have been published to assist practitioners in identifying and treating ASD and making referrals to appropriate services (NYSDOH, 1999; Filipek et al., 2000; AAP, 2001a; AAP, 2001b; CADDSS, 2003). Priorities include enhancing the diagnostic process through collaboration across disciplines (Volkmar, Cook & Pomeroy, 1999; Filipek et al., 2000) and use of appropriate assessment tools and enhancement and increased utility of early intervention and school-based services.

However, there are a number of barriers to the implementation of evidence-based approaches in practice settings. Primarily, these consist of or are related to (1) lack of services, (2) lack of trained providers, (3) lack of standard policies for implementation, and (4) lack of research in general. For example, while developmental screening is suggested at every well-child visit (AAP, 2001c), it is limited in scope given the lack of internal resources (e.g., time, lack of reimbursement for care) and external resources (autism-trained providers in the community) (Baird & Hall, 1985; Constantino et al., 2003). These barriers need to be addressed in order to improve assessment and intervention strategies and facilitate implementation of evidence-based practices.

Lack of Trained Providers

There is substantial agreement across guidelines that the formal diagnostic process must be comprehensive (Volkmar et al., 1999; Filipek et al., 2000; NRC, 2001). Evaluators must gather sufficient information to (a) determine whether the child meets diagnostic criteria for an ASD, (b) make differential diagnosis, (c) diagnose any coexisting conditions, and (d) make meaningful intervention recommendations. Cooperation and collaboration among multiple groups is essential, meaning the diagnosis process must be interdisciplinary. It is unlikely that the local education authority will have the experience and expertise needed for diagnosis of ASD (Sparrow, 1997; NRC, 2001). Therefore, cooperation and collaboration among multiple groups is essential (Volkmar et al., 1999; Filipek et al., 2000).

In order to fully benefit from early intervention strategies, providers need mental health services for children AND parents. Also needed are consultants to train and monitor providers on an ongoing basis. Collaboration between health plans, physicians, families, and schools is essential; but interactions must be changed to promote true “community” implementation and translation of research to practice. While the prevalence of autism is rising, the number of adequately trained professionals is not. Evidence-based interventions with characteristics demonstrated to be effective, including those that are intense, flexible, coordinated, accessible, and collaborative, should be implemented. Practitioners, researchers and policy makers must support families in obtaining consistent and full information about the basic signs of autism. (IACC, 2003)

Lack of Standard Policies for Implementation

The CDC Metropolitan Atlanta Developmental Disabilities Surveillance Program for diagnosis of ASD defines a qualified professional as an educational, psychological or medical professional with specialized training in the observation of children with developmental disabilities (e.g., special education teacher, clinical/developmental/school psychologist, speech/language pathologist, learning specialist, social worker, developmental pediatrician, child psychiatrist, pediatric neurologist) (CDC, 2004a). The consensus guidelines developed by Filipek et al. (Filipek et al., 2000) take a strong stand with regard to the importance of professional expertise. Specifically they state that formal diagnosis and evaluation of ASD should be conducted only by experienced professionals with expertise in autism.

Researchers have found that clinicians with autism experience – defined in one set of studies as having evaluated 25 cases of autism – can diagnose ASD more reliably than inexperienced clinicians (Doepke et al., 2004b). In addition, the wide variability seen in children referred for autism evaluations requires considerable expertise.

Lack of Research in General

A broader issue impacting the diagnostic picture is that although there are some diagnostic tests, there is no simple test or battery of tests that can clearly delineate the diagnosis of ASD. Further research and instrument development is needed. (TAP, 2004a)

One roadblock to the improvement of early intervention services is the lack of a tested model for early intervention in children under the age of 2 (NIMH, 2004). There is wide agreement that intensive behavioral therapy, which can include breaking a simple task like hand washing into a dozen component parts beginning at the earliest possible age, is highly effective for many children. Also necessary are randomized clinical trials developed for the evaluation of the

effectiveness of early behavioral intervention and factors predicting response to intervention and multi-site randomized clinical trial implemented to identify moderators and effective ingredients (e.g. dose, intensity, mode of delivery, age of onset) of early intervention treatments.

Testing of early intensive behavioral intervention (EIBI) could include:

- The efficacy of EIBI relative to other widely used treatments
- Identification of key moderator variables
- Identification of the optimum and cost-effective intensity of EIBI and other psychosocial interventions
- Understanding the impact of the timing of onset and intensity of treatment
- Understanding the effect of early intervention on brain development (NIH/ACC, 2002).

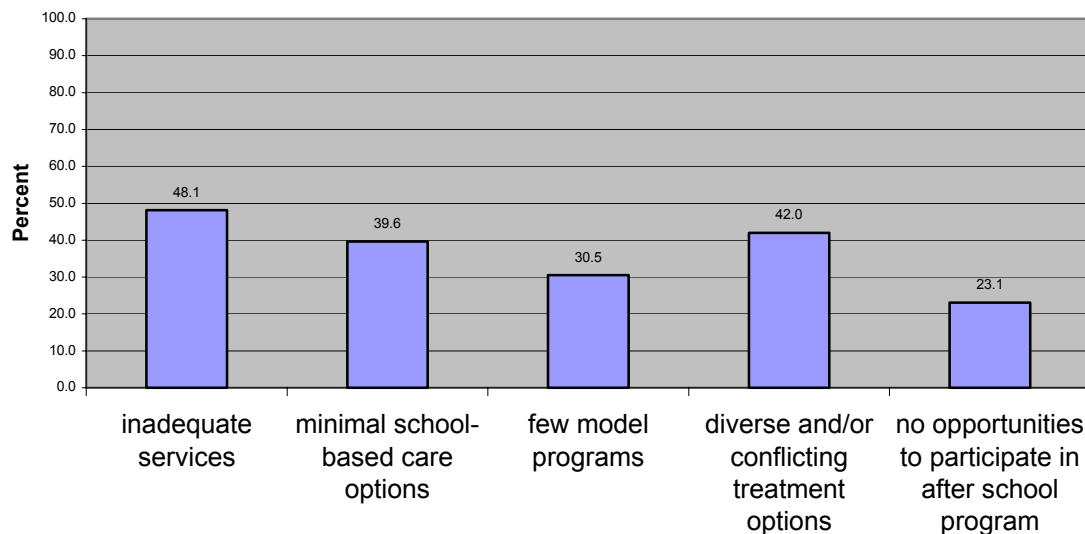
A review of the literature reveals a lack of comparable research. Therefore, we do not know which comprehensive programs are the best for children with ASD in general, much less for a specific child. Instead, we do know that research points to comprehensive, behaviorally informed, structured, and intensive programs as promoting best outcomes (Doepke et al., 2004a). Comprehensive programs (e.g., Learning Experiences, Alternative Program [LEAP]; Treatment and Education of Autistic and Related Communication Handicapped Children (TEACCH); The UCLA Young Autism Project; and the Denver Model) differ in their underlying philosophy, thus emphases vary with regard to aspects such as use of specific intervention strategies and contexts in which interventions occur. Therefore, parents, educators and state officials need to know how to build the best possible program around the common elements abstracted from all these programs, and which components are most effective for which children in what settings.

The increased focus on the need for promotion of a best practices approach to service delivery mirrors the national agenda. NIH support of autism research grew from \$22 million in 1997 to \$73 million in 2002 (NIMH, 2003), with a call for greater resources to be utilized to address this public health crisis. Propelled by the skyrocketing number of diagnoses of autism in children, federal officials have for the first time mapped out a long-term interagency plan to deal with the problem. The three-pronged plan sets goals for more coordinated biomedical research, earlier screening and diagnosis, and effective therapy. The plan demands, for the first time, collaboration between scientists, clinicians, educators, and policymakers in an array of federal agencies (Gross, 2003). "What remains a mystery is which children benefit and why, which techniques work best and whether early improvement is sustained over time," said Dr. Catherine Lord, director of the Autism and Communications Disorder program at the University of Michigan and author of the interagency plan (Gross, 2003).

Although the research in ASD is progressing, there is still confusion for those who care for people with ASD (Doepke et al., 2004 a). At a minimum, parents and providers are often confused by the competing theories and the multiple treatment options based on those theories. At the worst, parents and providers become vulnerable to misinformation and treatments that are not based on sound scientific principles. This indicates a need for a multidisciplinary approach to undertaking research efforts in order that standard guidelines and treatment options are developed.

Review of Illinois Needs

Core Issues in the Field of Autism: Treatment



Limited Access to Care

Access to care in Illinois communities is related to (1) the lack of appropriate services, (2) the lack of trained providers, and (3) the lack of funding for services (Cutler & Gilkerson, 2002). Parents and providers identified the lack of services as one of the top 5 needs in the state of Illinois (TAP, 2004a). As can be seen in the table above, almost half of the respondents, including parents and providers, endorsed inadequate services as a top priority in improving treatment for children with ASD, specifically pointing out minimal school-based options (40%) and few model programs (31%) in which to participate (TAP, 2004b). Illinois parents have few opportunities to participate in after school programs and are impacted by diverse or conflicting treatment options. Some specific areas that impact limited access to care are detailed below.

Oral Health Care Needs

There is very little information available on the prevalence of oral disease for individuals with developmental disabilities, with no information available on the status of oral health needs in children with ASD. A study of 55 children with ASD and other developmental and physical disabilities (63% with ASD as a primary diagnosis) found significant oral health needs, but little regular access to dental care (DeMattei & Cuvo, 2004). Anecdotally, in the course of conducting the study, it was noted that there were no resources available for dental care for children with such multiple disabilities in the central Illinois region. Indeed, the primary source of care was the emergency room. The majority of dental practices contacted indicated that barriers to care included the lack of reimbursement and the increased time needed for these children to be seen. Caregivers may consider preventive oral care a low priority when compared to other challenges afflicting the child with ASD; however, it is crucial to avoid serious, possibly life-threatening illness. Much more research is needed to address the oral health needs of children with ASD as well as the barriers to providing this care.

Physical Health Care

In Illinois, there are few resources for consultation on ongoing management and medication issues for children with ASD. For example, a statewide resource, the Division of Specialized Care for Children, provides extensive consultation and support to pediatricians and family practitioners throughout the state. However, autism does not qualify a child as having special needs according to Illinois criteria (DSCC, 2004). Similar to oral health care issues, health care professionals report significant barriers to care including lack of reimbursement, lengthy visits, and lack of training for working with children with ASD (ICAAP, 2004). Furthermore, some geographic regions in Illinois have a dearth of any physicians. For example, a significant problem that has been identified is the unavailability of child psychiatry in the central and southern regions of the state (Nierman, 2004). It is evident that efforts to provide easy access to health resources for both practitioners and families are necessary to improve the quality of life for children with ASD.

Self-Injury Behavior

As stated elsewhere in this report, training on behavior problems and behavior management is one of the most requested training topics in autism. A TAP funded researcher suggests that self-injury behavior (SIB), an extreme form of behavior problem, serves to reduce access to appropriate education, accommodation, services and community activities due to the danger to service providers and lack of SIB-specific training (Salt, 2004). This results in seriously diminished quality of life for the SIB inflicted youth. The most common form of self-injury behavior (SIB) includes head-banging, hand-biting and excessive

scratching or rubbing. Further study of the affliction is needed to help identify appropriate preventive interventions.

Social-Emotional Functioning

There is an urgent need to identify appropriate screening tools and assessment procedures for social/emotional concerns in children ages birth to 3, and to train providers of developmental screening, diagnostic, assessment, and intervention services in these measures (Cutler & Gilkerson, 2002). The Special Advisory Panel for Early Intervention has appointed a subcommittee on social/emotional development to examine issues related to IDEA Part C services. The subcommittee has identified appropriate screening and assessment tools for social/emotional development in the birth-to-3 population and is developing recommendations for a statewide train-the-trainer approach to disseminate this knowledge within the EI system. The information on social/emotional screening and assessment gathered for Part C services can provide much needed resources and directions for other infant/toddler settings.

There are positive developments projected in the future as long as supports remain available at local levels. For example, it is likely there will be substantial growth in social assessment in the next 10 years as tests of social language and functioning are developed and evaluated with regard to their potential usefulness with the ASD population. Also, through a TAP-funded project, a computerized assessment protocol with regard to deficits in perspective taking in children with high-functioning autism is also being developed in the hopes that these deficits will be reduced by providing the children with a background of reinforced relational responding (Rehfeldt, 2004). Another project being conducted through TAP-funded research that addresses the use of social stories as an intervention in teaching acceptable social skills and behaviors (Doepke, 2004). Funding will be required for research, such as the efforts noted above, as well as training (or retraining) of assessment professionals to increase the likelihood that the most valid methods of assessment will be used.

Access Based on Geographic Location

In Illinois, there is a need for the development of statewide service access policies that afford individuals and families across the state equitable access to state-financed services and supports (Gettings, Cooper & Chmura, 2003). This would entail the generation of extensive data on unmet needs within the state's developmentally disabled population that can be used to support requests for additional funding and map out plans for improving access in underserved areas (Gettings, et al., 2003). Because many families of children with ASD are unable to access appropriate services based solely on their geographic location, it is

important to develop and implement policies that will assist these families in gaining access to appropriate services.

Comprehensive and Multidisciplinary Diagnosis

Evaluator Experience and Expertise: Who is Qualified?

In Illinois, the lack of expert identification and appropriate treatment resources may discourage primary providers from making an ASD diagnosis even when they suspect it is warranted. For instance, participants in a survey administered by ICAAP (2004) acknowledged that the poor availability of autism spectrum treatment (44.2%) was a barrier to receiving treatment. Moreover, 2 individuals who recently participated in a survey of 10 national clinics and 9 Illinois clinics (Doepke et al., 2004b) further commented on the need for evaluator experience and expertise. Dr. Christina Corsello, intimately involved with ADOS/ADI-R training for several years and Associate Director at the University of Michigan Autism Center, emphasized the need for extensive training to develop expertise in evaluation of individuals with suspected ASD. Depending on a professional's preexisting assessment skills and autism experience, Dr. Corsello noted that advanced training in specialized autism assessment is likely to take about 6 months, with the individual participating in 2 diagnostic assessments a week, seeing children across a wide range of age and developmental levels. With respect to maintaining expertise, Dr. Peter Doehring of the Delaware Autism Program indicated that a diagnostic team needs to conduct 20 to 50 ASD assessments a year in order to provide effective and expert diagnosis across the full spectrum (Doepke et al., 2004b). As is evident, extensive training and continuing education for professionals associated with ASD is necessary to improve identification and treatment efforts.

Use of Interdisciplinary Teams and Appropriate Tools

In the survey conducted in 2004 (Doepke et al., 2004b), a selection of well-regarded clinics at the national level was found to be relatively experienced in the diagnosis of ASD. National clinic respondents indicated that community level diagnoses too often were inaccurate and insufficient, thereby resulting in a need for additional evaluation at the specialty clinic. The difference between national and state services may be that national centers always involve professionals from more than one discipline in the diagnostic process. In contrast, in Illinois centers, only 56% involved professionals from more than one discipline in the diagnostic process (Doepke et al., 2004b).

The ADOS and ADI-R are used most often for diagnosing ASD. In a study regarding best practices in identification of ASD cases, researchers analyzed data gleaned from a survey of 10 national clinics and 9 Illinois clinics (Doepke, et al.,

2004b). The premise of this study was that although there are definitive published guidelines and research that relate the general consensus on use of best practices in identification of ASD, there is a paucity of published research examining how clinics truly carry out the guidelines in practice. In talking to professionals at the clinics, use of assessment tools was determined by taking into consideration such factors as the person's expertise with a tool and certain behavioral and developmental issues present in the child. Specifically, child observations were conducted using a full or partial ADOS at 100% of the national clinics versus 56% of the Illinois clinics. Further, diagnostic interviews using a full or partial ADI-R were conducted at 70% of the national clinics versus 33% of the Illinois sites. Illinois clinics were also less likely to use standardized measures to assess cognitive functioning (56%) or adaptive behavior (44%) compared to national centers (70%) (Cutler et al., 2004). These findings are contrary to recommendations made by national clinics. Of the Illinois clinics surveyed, a broad range of assessment tools was employed, with one site reporting no use of assessment tools. (Doepke et al., 2004 b). Findings specific to the Illinois sites included

- All "reported use of a structured or semi-structured parent interview"
- All "reported use of observation as part of the diagnostic process"
- 6 sites used expressive and receptive speech and language measures
- 5 sites used "some type of cognitive assessment"
- "Less than half of the clinics reported routine use of adaptive behavior assessments."

In line with these findings, one-third of pediatricians and family physicians recently surveyed in Illinois reported using valid developmental screening tools (Cutler & Gilkerson, 2002). As research efforts already undertaken in Illinois show, implementing diagnosis and assessment methods that take advantage of expertise across multiple disciplines and employs appropriate assessment tools are essential to a comprehensive diagnosis of ASD.

Early Intervention Services

The social/emotional well being of children and families is increasingly cited as a key to healthy development in general, and as foundation for all learning, including success in school. Children vary in their risk for behavioral and emotional difficulties. While children in high-risk communities tend to be at greater risk, social/emotional mental health concerns in children occur across groups and in all communities (Cutler & Gilkerson, 2002).

How Many Individuals Does Early Intervention Serve in Illinois?

According to an October 2002 report on the status of early intervention services, which IDHS filed with the state General Assembly, in FY 2002 Illinois' EI program served 20,993 infants and toddlers. The report indicates that the national participation rate in EI programs is about 2% of children under age 3. Illinois exceeds this rate, despite the fact that the state uses stricter entrance requirements than the average state (Gettings et al., 2003).

Despite the benefits that are exhibited in the children who receive it, many children do not receive early intervention services (Cutler & Gilkerson, 2002). When a referral is to be made, it is often not always clear where a child in Illinois can go for a diagnostic work-up. The state lacks a systematic method to get children from the referral point to the appropriate professionals. Additional public awareness and coordination of services is needed. Further, 66% of communities do not have adequate services to meet the needs of children with mild developmental delays. Prevention and childcare programs do not have access to developmental specialists, occupational therapists, and other specialists to assist them in planning for or serving these children. Further, physicians, early intervention providers, and families all need training on the development and use of best practice guidelines for working with children with autism spectrum disorders. It is important that the age of identification and entry into early intervention be reduced in order to optimize child development.

School-Based Services

Educators in Illinois recently identified several barriers to conducting functional behavioral assessment and implementing assessment-based intervention strategies in school settings (Chandler & Munk, 2004). These barriers included poorly conducted functional assessments (e.g., functional assessment did not include observation in the natural environment, included too few observations, or intervention strategies did not teach appropriate replacement behavior or match the function of challenging behavior), lack of training for school staff and families, and lack of time to conduct assessment, implement intervention strategies, and provide in-class coaching and follow-up evaluation. For instance, a survey of primary care physicians and staff indicated that 33.4% of those surveyed perceived the lack of early childhood/school-based services as a barrier to the child and family receiving appropriate services (ICAAP, 2004). If functional assessment and positive behavioral interventions are to become effective, institutionalized practices in Illinois that are maintained over time, the systems that support their use must be in place. This includes staff development related to conducting functional assessment, developing positive intervention plans, and implementing specific procedures; providing a sufficient number of

staff to conduct assessments and implement intervention procedures; a team approach that includes family members as team members; time allocated for data collection, team meetings, intervention planning and implementation; and supports and strategies for evaluation. (Chandler & Van Laarhoven, 2004)

Some fear that there are not enough services, while others have expressed concerns about adequate staffing and sufficient knowledge of ABA therapy. For example, one mother would prefer a non-residential school for children with autism. Another believes that her district is poor and does not have knowledge about the diagnosis and how to work with children with autism. (TAP, 2004a)

In a focus group with parents and a variety of professionals, different experiences were expressed regarding collaboration with local school districts (Nierman, 2004). While some participants found their local schools extremely helpful in coordinating care for children with ASD, others recounted a number of problems with school-based services. Themes that emerged in the discussion included:

- Lack of accountability
- Family too dependent on a school district
- Lack of coordination with community organizations
- Lack of standards
- Inability to access “wrap-around” approach
- Insufficient teacher and workforce training
- Variability in approach and outcome

To address these problems, participants discussed the need for a community entity that would provide supports and services in coordination with the school. The organization should be consumer driven, composed of private and public agencies and providers, smaller in size, and regionally based (Nierman, 2004).

Essentially, to provide the necessary educational requirements to autistic children and to meet the needs addressed by parents, much teacher training is in order. Education professionals may be unprepared for the high level of home-school communication required for effective social intervention of children with ASD. Thus, professionals may require training on the need for and methods of collaboration. In addition, teachers, especially, require administrative recognition and resources to support them in this endeavor (Doepke et al., 2004a). Collectively, these findings suggests that teacher training and use of effective functional assessment practices, as part of a broader spectrum of improved school-based services, are necessary to ensure that all children with ASD received adequate early childhood and school-based services.

At a Glance: Need for Accessible Assessment and Intervention Service Based on Best Practices

➤ Barriers associated with access to necessary care in Illinois include the lack of appropriate services, lack of trained providers, and lack of funding for services.

➤ Through the TAP Needs Survey, 48.1% of the participants identified inadequate services as a barrier to receiving treatment; 39.6% noted minimal school-based care options was also a barrier.

➤ Collaboration across professional disciplines is essential. As evidence of this need, only 56% of the Illinois clinics surveyed by Doepke and group include professionals from other disciplines in the diagnostic process.

➤ Not all children who need early intervention services have access to them; many communities are not capable of providing services to families, as evidenced by the Unmet Needs Survey, which stated that 66% of the communities surveyed could not provide adequate services.

➤ School-based services are not meeting the needs of families for reasons that include the performance of inadequate functional assessments, lack of time to conduct assessments, and lack of school personnel trained to work with children with ASD.

Need for Family-Centered Care

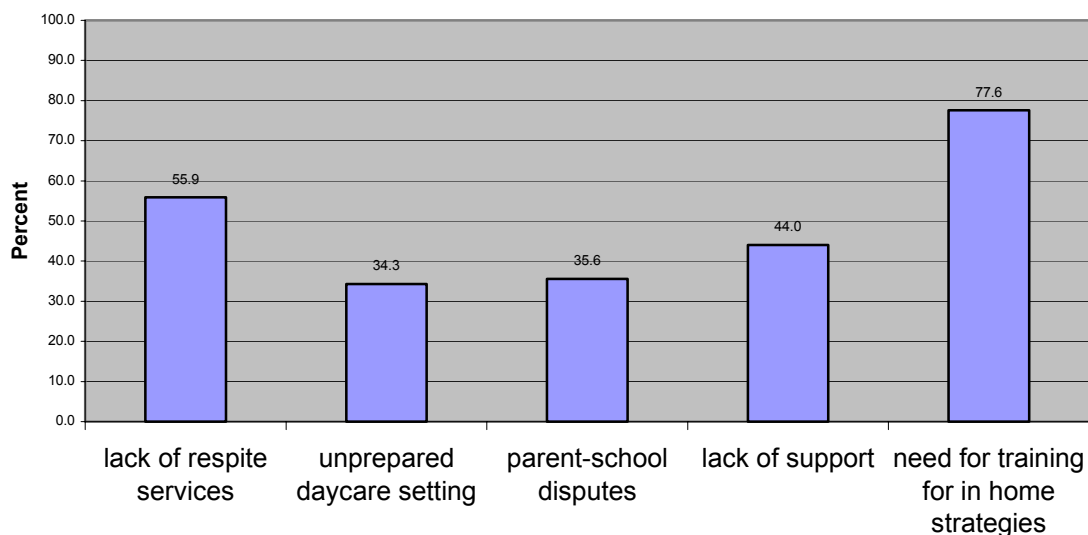
National Statistics and Literature Review

With little access to appropriate diagnosis, treatment and support, families are deeply affected by the stress of raising a child with ASD. Family stress is impacted by delays in formal diagnosis (Filipek et al., 2000; Glascoe, 2000a, 2000b) and familial reoccurrence of ASD (AAP, 2001b). Researchers have found that family members, especially mothers, experience extreme stressors when raising a child with autism. Indeed, these stress levels significantly exceed those typically found in families of children with other developmental disabilities (Hastings & Johnson, 2001; Seltzer, Krauss, Wyngaarden, Orsmond, & Vestal, 2001; Olsson & Hwand, 2002; Tobing & Glenwick, 2002).

Parental involvement is central to the child's improvement (Moroz, 1989; AAP, 1999). Education, support, and a focus on families in intervention, will result in healthy families able to create more potent therapeutic milieus for their children (Holroyd & McArthur, 1976; Bouma & Schweitzer, 1990; Dunn, Burbine, Bowers, & Tantleff-Dunn, 2001). TAP has collected data as well as reviewed other Illinois information sources to better understand the needs of these families.

Review of Illinois Needs

Core Issues in the Field of Autism: Parent Support



As evidenced by the above figure, survey participants (N=262) identified the need for training on in-home strategies (77.6%) as the most important issue in parent support. Second to this was the provision of respite services to parents

(55.9%). Participants identified a general lack of support for parents (44%) as a third key element to the core issue of parent support (TAP, 2004b).

When asked to state the top 5 needs for families of children with ASD in Illinois, themes that emerged from interviews with parents and providers included (TAP, 2004a):

- ❑ Support groups
- ❑ Parent education and information on community resources
- ❑ Improved coordination of care and prompt diagnosis
- ❑ Availability of childcare and respite care
- ❑ Sibling and family counseling
- ❑ Increased professional and community awareness

Impact on Family Functioning and Quality of Life

Illinois parents uniformly describe their children with ASD as “very loving and affectionate,” happy, with “enthusiasm to learn,” but they acknowledge the stresses involved in raising them as well (TAP, 2004a). The findings of multiple focus groups in Illinois echo the national results cited earlier (Cutler & Gilkerson, 2002; Nierman, 2004; TAP, 2004a), with family members describing being under a great deal of stress and feeling overwhelmed at times. Stressors mentioned by families included:

- ❑ Managing their child’s therapies
- ❑ Coping with the challenges of children’s behavior problems
- ❑ Difficulties with a child’s sleep and feeding
- ❑ Trying to balance work with family demands
- ❑ Dealing with the tensions of marriage and family
- ❑ Forced isolation and loss of independence
- ❑ Stigma and criticism from other community members

The stress and multiple demands placed on the parents of children with ASD are an important element to consider within the realm of improving parent support. The above findings represents this need, highlighting the importance of improving services for families related to coping with the stress of living with ASD.

“...These children [with autism] look so normal on the outside. When...[a parent]...goes to the grocery store and everyone looks at them like they have a bad kid it’s very stressful.” – Provider (TAP, 2004a).

Family Involvement, Information, and Advocacy

Illinois parents and providers have stated that families need to be more involved in all aspects of their children's care. When asked whether they felt their family's values and priorities had been involved and respected in interactions with providers, parents responded that this often was not their experience, or when it was, that it was unique to one provider (TAP, 2004a). One parent stated "No...they didn't really look at the family. They just went straight to the child and didn't interact with the family." Often when parents endorsed being actively involved in their child's treatment, they stated it was because of their own initiative, with one parent commenting, "I have to go to them, they don't seek me out" (TAP, 2004a).

Lack of family involvement is related to a strong need for greater awareness and sources of information for families, which contributes to delays in or lack of access to screening, diagnosis, and appropriate interventions (Cutler & Gilkerson, 2002; Nierman, 2004; TAP, 2004a). In one study, although the majority of parents surveyed reported satisfaction with their child's current health care provider, many parents in the focus groups reported difficulty finding a physician who understood developmental and/or behavioral issues or who understood their concerns (Cutler & Gilkerson, 2002). In addition, families cited a lack of information about many different services, from respite care to recreational programs. Families need to be provided with information about autism, names of support groups in their area, and referral to early intervention and special education (Cutler et al., 2004).

"We've all seen *Rainman* but I had no idea what autism was." – Parent (TAP, 2004a).

In addition to access to information, parents need information that is evidence-based. As one provider put it, families need a "non-judgmental ear...someone they can talk to who knows about autism" (TAP, 2004a). Specifically, families are looking for guidance in weeding through the vast amounts of information (TAP, 2004a). There is no one definitive source where parents may go to find information – the internet, other parents of children with ASD, professionals. Whether or not that information is valid and evidence-based is not clear. Most parents do not refer directly to scientific articles (2 of 5 parents), instead gaining access to scientific information on effective assessments and interventions from "trusted" websites, newspaper and magazine articles, and friends/family members who are health care providers. Only 1 in 5 parents recalled scientific information being given to them by providers.

Variety of Family Supports Needed

One participant stated that more emotional support is needed, acknowledging the “grieving process a family” goes through when the diagnosis is received (TAP, 2004b). For example, although families are not routinely offered social work or psychological support as part of the IFSP (Individual Family Service Plan) process, they feel they should have the opportunity to receive these services (Cutler & Gilkerson, 2002). Emotional support from peers is also a key need area, with families asking for peer support and mentoring to be included as a service focus (Cutler & Gilkerson, 2002; Nierman, 2004; TAP, 2004a) and from family support groups, although many families are unable to access them due to competing needs (Gould, 2002). In an informal survey of 81 families, only 42% stated that they were currently participating in a support group (Cellini, 2004). However, the benefits of family support groups seem to be significant, with families stating that they improve their quality of life (Cutler & Gilkerson, 2002).

Families of children with ASD describe their participation in extracurricular activities as limited and desire greater involvement in social activities (Nierman, 2004; TAP, 2004a). According to one parent, the benefits of peer support include stress relief as well as a place to share “understanding of bad situations and rejoicing in triumphs” (TAP, 2004a). Other supports mentioned include the need for help with transportation, safety in the home, playgroups for their children with ASD, and childcare for attendance at activities (Gould, 2002; Nierman, 2004; TAP, 2004a).

Families Want Training

“Even when ASD is identified early, parents are not directed for effective intervention...Parents often have a lack of knowledge of what is needed for effective intervention” – Provider (TAP, 2004b).

Across a majority of the data sources utilized for this needs assessment, parents emphasized the need for more training, particularly provided in the home in order to increase access and availability (Gould, 2002; Cutler & Gilkerson, 2002; Cellini, 2004; Nierman, 2004; TAP, 2004a; TAP, 2004b). Although not an inclusive list, content areas mentioned include:

- Behavioral interventions
- Socialization strategies and social skills issues
- Communication techniques, including sign language, picture exchange schedules and visual systems
- Nutritional issues

- Use of technology, such as computers
- Pointers on how to access services and advocate with service providers.

Families ask for training to be offered at a variety of times (both days and evenings, during the week, and on weekends) with training available in all areas, across all age ranges, and at all ability levels (Gould, 2002). Barriers to participation in trainings, and services in general primarily involve the logistical difficulties, such as obtaining time off work, finding child care for other children, travel distance, and transportation needs (Cutler & Gilkerson, 2002; TAP, 2004a)

Need for Respite and Childcare

Families indicated the need for more respite care as well as several barriers to accessing respite, with only 30% of 81 families surveyed stating respite as a current service received (Cellini, 2004). In the TAP Needs Interview with 5 families (TAP, 2004a), none of them had used respite care in the past 6 months. While 3 of the 5 had family support as the reason they didn't use respite care, 1 parent stated that she was unaware of any respite care available for her child. In a survey of 104 parents of children with developmental delays, 60% reported not having been informed of respite services (Cutler & Gilkerson, 2002). Of the 42% of parents who reported that they had needed respite care for an emergency, 79% reported they were not able to find services. Parents have described a lack of information about accessing respite care, concerns about adequacy of autism training for respite providers, and lack of affordability of care (Cellini, 2004; TAP, 2004a). In a survey of respite care providers (Boheme, 2004), all of the agencies surveyed stated that they wanted and needed training in autism, and do not feel equipped to deal with the behavioral and communication needs of children with autism. Two of the 5 agencies surveyed acknowledged that they couldn't serve all their referrals for respite for children with autism due to a lack of funds.

Parents stated that childcare was the most challenging issue facing a family (Gould, 2002; Cutler & Gilkerson, 2002; Nierman, 2004; TAP, 2004a; TAP, 2004b). Problems encountered included children being ejected from daycare, difficulty finding quality care, affordability, or logistical problems. A survey of parents of children with developmental disabilities found that 42% of families utilized childcare, of which 27% had childcare denied, with at least half being denied due to their child's special needs (Cutler & Gilkerson, 2002).

Childcare programs themselves have reported similar barriers to care. In a survey of 195 programs providing preventive early intervention, public health, and childcare services, over 40% of childcare programs reported having had a child removed from the program because of social/emotional behavioral problems (Cutler & Gilkerson, 2002). In another survey (N=89) administered as part of the Unmet Needs Project, only 30% of programs reported they were

adequately prepared to meet the social/emotional needs of children and families they serve (Cutler & Gilkerson, 2002). Sixty-six percent of the childcare programs reported that their community does not have enough services for children with even mild delays (Cutler & Gilkerson, 2002). The impact of the lack of childcare on families was significant, with 65% of parents reporting work, school, or job training difficulties because of problems in finding or keeping childcare, with 4% having lost their jobs.

At a Glance: Need for Family-Centered Care

- Families coping with a child diagnosed with ASD experience tremendous amounts of stress, negatively impacting their quality of life.
- 77.6% of participants in TAP's Needs Survey identified the need for training on in-home strategies as the most important issue in parent support; respite services for the parents was also acknowledged as important (55.9%).
- Families desire more evidence-based information about autism, access to support groups in their area, and information on referrals to EI and special education.
- Parents of children with ASD are very much in favor of receiving more training, preferably in-home, and offered at a variety of times.
- The impact of lack of adequate respite care and childcare is clear: 65% of parents report that the lack of childcare interferes with work, school, and job training.

Need for Ongoing Provider Training and Consultation

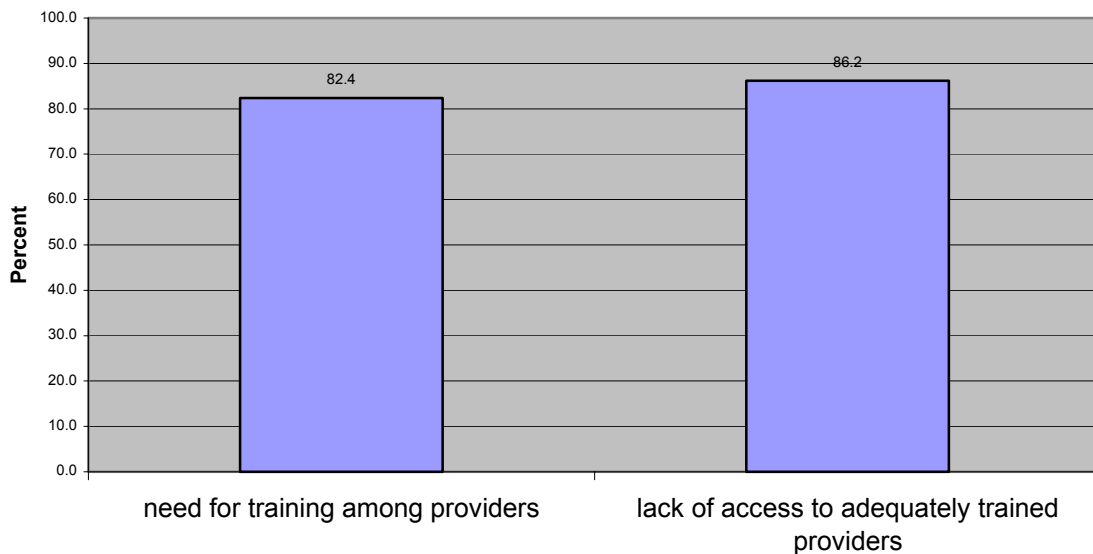
National Statistics and Literature Review

There is a great need for ongoing training and consultation to facilitate early identification, treatment, and referrals. Further, such activities must be based on evidence-based approaches, guided by data-based practices and effectiveness studies (e.g., (Barlow, 1996; Chambless & Hollon, 1998).

Training with regard to ASD would benefit not only the families of children with ASD, school personnel, early intervention providers, health professionals and allied providers, but also people in the child's extended community, including police and fire officials, library personnel, and church members (Helps, Newsom-Davis, & Callias, 1999; Doepke et al., 2004a). In keeping with this sentiment, at the Autism Summit Conference held in Washington, D.C., attendees suggested enhanced training for general education professionals, as well as special education professionals, pediatricians, and paraprofessionals (IACC, 2003). Parents could also potentially collaborate with providers as members of the educational team (IACC, 2003). National models suggest that the cost for consultation is not excessive, and that consultation is an effective means for staff development and quality improvement (Cutler & Gilkerson, 2002).

Review of Illinois Needs

Core Issues in the Field of Autism: Provider Training



Participants (N=262) in TAP's (2004b) Needs Survey identified the lack of access to adequately trained providers (86.2%) as the primary area of need within the core issue of treatment. The need for training among providers followed closely

behind, with 82.4% of the participants identifying it as a concern within the core issue of provider training.

Lack of Trained Providers

Parents want people involved in typical everyday activities with youth to have exposure and experience working with youth with pervasive developmental disabilities (Nierman, 2004). When asked what would most improve their quality of life, the overwhelming response from parents of children with developmental disabilities was the need for improved qualifications of the therapists working with their children (Cutler & Gilkerson, 2002). This includes people in primary health care. They feel there is a need for more medical professionals who know what they are doing with this population (Nierman, 2004). The need for additional training for professionals was also verbalized in the TAP (2004b) Needs Survey. Participants who completed the survey, including both service providers and parents, identified professional education and training (10.7%) as one of 5 key components of an ideal system of care (TAP, 2004b).

Not only are the families of children with ASD calling for more adequately trained providers, but also service providers and agencies themselves are crying out for additional training in order to better serve their clients. For instance, 100% of the agencies participating in the Survey of Respite Services (Boheme, 2004) indicated they wanted and needed more training in autism. In a survey of 75 childcare providers, 84% identified the need for training to identify social/emotional/mental health concerns in infants and toddlers, and 64% wanted training to initiate discussion with families about child concerns (Cutler & Gilkerson, 2002).

“...We feel staff would feel more comfortable working with individuals with autism if they knew what they were doing.” – Provider (Boheme, 2004)

Teacher training has also been identified as a key area of need within the autism community. ASD-specific teacher training is imperative to fostering an environment that is conducive to learning for children with ASD. Not surprisingly, a 2002 survey (N=116) of Illinois Special Education Administrators showed that 92% of the survey participants indicated a need for teacher training on ASD, and 86.5% indicated that the necessary training was a high priority (Bock, 2002).

Given the continued increase in identification as well as the rising prevalence rate, it is expected that the number of trained staff will need to increase greatly in order to meet the needs of children with ASD in school settings (IACC, 2003).

According to Gould's survey, currently, there are 162 full-time equivalent teachers reported as employed to provide special education services for students with autism, which corresponds to 1 teacher for every 37.8 students with ASD (ISBE, 2004). The state is behind the demand. To reach the recommended ratio of 1:8, there is a current need for 765 teachers, over 4 times the number currently employed. By 2008, at the recommended ratio of 1:8, it is estimated that Illinois will need 4,556 teachers who are trained to work with children with autism.

Focus groups with key special education administrative staff of Central Illinois school districts and cooperatives put these concerns in context (Kelley, Winson & Nyre, 2004). While most of the districts and cooperatives had a minimum level of personnel trained in ASD to conduct evaluations and develop IEP goals, none had the trained staff available to provide consultation within classrooms and to school personnel. All of the administrators identified increased staffing with training in ASD as a key need in Illinois.

Training for health care professionals in the identification and screening of children with ASD and in coordination of ongoing care with multiple agencies is a significant need in Illinois. Following an office-based training on developmental screening and referral to 44 practices throughout the state, a significant number of pediatric practices (81%) reported using valid developmental screening tools 3 to 6 months following the training, compared to only 7% who reported using the screening tools prior to the training (ICAAP, 2004). It should be noted that the training was intended to address several barriers to training, including being offered in practice sites so that all physicians, nurses, and support staff could participate. Comparisons of the pre- and post-tests indicated a steep increase in knowledge, with a 69% increase in the number of correctly answered questions. These questions pertained to knowledge vital in identification and coordination of care for children with ASD, such as an understanding that intensive intervention can enhance development (27% increase in correct answers). (ICAAP, 2004).

Lack of Systematic Certification and Standards

“This program [IDHS curriculum for childcare workers] will give continuing education credits for childcare workers, but will not be required for licensure.” – Provider (Cutler et al., 2004)

Lack of certification and licensure requirements serves as a major barrier to employing trained early intervention providers and childcare workers. This is contradictory to other professions relating to the care of children, including

teachers, physicians, and other allied health personnel. Early intervention providers can obtain credentialing to provide services without having any documented experience in working with children with autism (Cutler et al., 2004). Although not specific to autism, the Unmet Needs Project indicates the potential for development of professional standards and provider certification requirements. Parents and providers have identified credentialing as a major issue (Nierman, 2004). Improving upon the qualifications of therapists who work with children is imperative to improving the children's quality of life (Cutler & Gilkerson, 2002).

Types of Training Needed

“We need more on-the-job training for working with children with autism. We are not familiar with using things like picture systems; we really need more basic training.” – Provider (Boheme, 2004)

- According to the TAP (2004b) Needs Survey (N=262), the top 5 training needs that the participants endorsed included the need for hands-on training (82.1%), more access to experts in ASD (52.3%), case-centered consultation (35.9%), lecture-based trainings (21%), and clinical supervision (19.1%). Mirroring these findings, one provider noted “more hands-on [training] such as ‘Make it, Take it’” was needed (TAP, 2004a). Providers also voiced a need for a revolving schedule of trainings. One survey participant commented that there were “constantly new providers that need trainings” (TAP, 2004a). Special education administrators have called for pre-service programs and workshops to support teachers in increasing their expertise in ASD (Bock, 2002). Such training needs to be accessible, particularly to meet the needs of special populations such as EI providers who work with the Hispanic migrant population (Doepke et al., 2004b).

With regard to the primary means by which to conduct trainings, service providers tend to favor oral presentations over other means of presentations. The 2004 Autism Informational Needs for Professionals and Providers survey of 80 professionals indicated that 67% of the participants preferred oral presentations, with the least preferred method of presenting material being via multimedia CD-ROMs (Cuvo, 2004a). Providers did acknowledge the usefulness of working with other trained providers, with one provider noting, “most education is from co-treating with other therapists” (TAP, 2004a). Indeed, it has been found that staff best learn how to work with families and children with complex issues through ongoing supervision and consultation directly related to

the families they serve (Cutler & Gilkerson, 2002). Thus, policies are needed to specify that consultation be a component of state-support intervention programs.

Training Content

“I need to know the evidence behind treatments—extremely important because I have to prove to SDs and insurance companies, etc...that what I am doing is necessary and important.” – Provider (TAP, 2004a)

Providers have expressed a deep desire to receive more evidence-based training. Early intervention providers interviewed by TAP indicated a general consensus regarding training. Qualitative data from the TAP Needs Interviews (TAP, 2004a) showed participants generally indicated that specific evidence-based training is needed – they need to know why it works. Also, evidence is important for insurance and for parents, and for providers to be able “to prove treatment is necessary” (TAP, 2004a). Specific training for specific provider disciplines to provide consistency was also indicated as a need with regard to training content (TAP, 2004a).

Training on behavior management is requested by most providers (Nierman, 2004; TAP, 2004a, 2004 b). Such training can have quite an impact on other aspects of the system, such as access to daycare. As an example, lecture-based training on how to prevent behavior problems in the classroom and other aspects of ASD were presented to staff at a daycare in southern Illinois (Cuvo, 2004b). Following the presentation, daycare staff received weekly training on behavior management techniques over a period of a month and a half. As a result of the intensive training, daycare staff expressed that they would be willing to accept children with ASD in the future.

In addition to the need for evidence-based training, training on developmental screening and diagnosis is also necessary. Best practice standards urge the use of a standardized screening tool, which necessitates the use of training in developmental screening (Cutler & Gilkerson, 2002). As mentioned previously, after a workshop by ICAAP targeting this content area was conducted, 81% of physicians taking part in the training were using the recommended tools (ICAAP, 2004). Providers taking part in the TAP Needs Interviews (TAP, 2004a) noted that they would like more training on the use of diagnostic assessment tools, such as the ADOS and CARS. It should be noted that such training goes beyond a lecture-based setting, with the need for ongoing consultation and supervision (Doepke et al., 2004b).

Specific topics that have been endorsed as needed areas of training have been summarized in the table below (Cuvo, 2004a).

Training Topic	Percent Endorsed
Assessment, diagnosis, treatment planning	72
Characteristics, prevalence, & causes	80
Different treatment models for autism	65
Criteria to choose effective interventions	80
Promoting community integration	31
Promoting school inclusion	48
Rights, responsibilities & services for parents & children under federal & state laws & regulations	55
Individualized plans IEPs/IFSP	65
Home based programming	30
Strategies for visual learners	56
Teaching emotional recognition	48
Teaching expressive language	59
Teaching language in a social context	66
Teaching matching, sorting, imitation	40
Teaching peers & siblings to participate	54
Teaching play & other social behavior	65
Teaching receptive language	56
Discrete trial teaching	25
Establishing & maintaining motivation	58
Naturalistic teaching methods	30
Alternative/augmentative communication	44
Applied behavior analysis (ABA)	35
Sensory problems & intervention	63
Causes & interventions for problem behavior	77
Food refusal & other eating problems	37
Biological/medical interventions	39

At a Glance: Need for Ongoing Provider Training and Consultation

➤ Adequate provider training is a necessity as evidenced by the TAP Needs Survey, in which 86.2% of the participants noted that the lack of access to adequately trained providers was an area within autism in need of attention.

➤ An increase in the identification of children with ASD, as well as an increase in the rate of prevalence, indicates that a significant increase in the

number of trained providers is necessary in order to meet the needs of the ASD community.

- Providers have expressed a desire that training focus on evidence-based techniques, as well as behavior management training.

- The top 5 training needs acknowledged by participants in the TAP Needs Survey include the need for hands on training (82.1%), more access to experts in ASD (52.3%), case-centered consultation (35.9%), lecture-based trainings (21%), and clinical supervision (19.1%).

- Teacher training is also a priority; currently in Illinois, there is a deficit of 765 teachers, the number necessary to reach the recommended teacher-to-student ratio of 1:8.

- Development of systematic certification and licensure standards for early intervention and child care workers is essential.

Need for a System of Care Approach

National Statistics and Literature Review

Meeting the complex and intense needs of children with autism spectrum disorders and their families requires an effective system of care. The current system of care for children with ASD has been described as anemic and poorly coordinated. The components of the system are poorly trained and understaffed and families have little access to best practice services in diagnosis and treatment. Moreover, the linkages between system components are weak or non-existent. Access to care in rural and other underserved communities is sorely lacking (NIMH, 2003). Families and practitioners have struggled valiantly to piece together effective diagnostic and intervention services. Fragmented service coordination and lack of ongoing support and consultation present roadblocks to understanding the causes and best treatment options for autism, resulting in children being removed from their communities, family disintegration, and educational failures (USDHHS, 1999; NIMH, 2004).

Furthermore, caring for a family member with autism carries with it a lifetime economic burden. In addition to loss of personal potential, the cost of health and educational services to those affected exceeds \$3 billion each year (NIMH, 1997). Data have shown that pediatricians serving primarily Medicaid or minority populations were less likely to refer to parent support and child development programs (Sareen et al., 2001).

Transitioning children between service settings, such as EI to EC or young adulthood, has been recognized as a significant problem in autism services (Grzywacz, Lombardo & Bristol, 1999; NIMH, 2004). In New Hampshire, anecdotal data indicates that coordination of care between parents, physicians, and educators, as well as individualized programming and involvement of parents appears to improve the transition to school (Grzywacz et al., 1999). There is a lack of data on effective methods for smooth transitions, and the U.S. Department of Health and Human Services has prioritized research in the area (NIMH, 2004). This effort will involve a range of research methodologies and strategies to include intervention development; testing of efficacy and effectiveness of existing interventions in diverse community settings; determining roadblocks to implementation of, and access to, effective interventions; strategies for overcoming roadblocks to implementation of, and access to, effective interventions; and strategies for overcoming roadblocks to widespread dissemination.

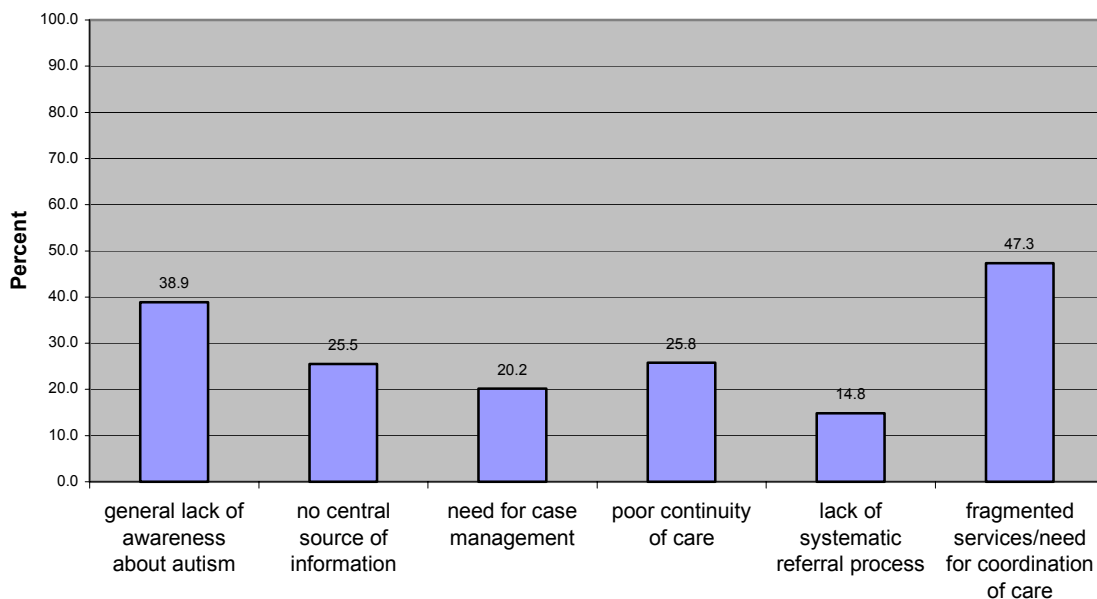
The state of Illinois, and indeed the majority of the country, lacks a systematic approach to service delivery, provider training, and system development for

children with ASD and their families. Commonly known as a system of care, this approach has been enacted in related fields, such as child mental health services. A system of care has been defined as: a comprehensive spectrum of mental health and other necessary services which are organized into a coordinated network to meet the multiple and changing needs of children and adolescents with severe emotional disturbances and their families (Stroul, 1994, 1996). A system of care emphasizes a child-centered and family-focused approach to service delivery, community-based services, and culturally competent care. The intention is to increase access, comprehensiveness, and coordination of care.

Review of Illinois Needs

Illinois families, providers, and other data sources weighed in on several relevant issues, including the need for coordination of care, lack of access to care in underserved areas, and funding and cost issues.

Core Issues in the Field of Autism: System of Care



Nearly half of all respondents (48%) in the TAP (2004b) Needs Survey (N=262) called for attention to system of care issues with regard to Illinois needs for providers and agencies. As can be seen in the table above, the primary issues were the problem with fragmented services and a general lack of awareness about autism. Confirming the lack of coordination, approximately one-fourth of the respondents indicated that there was no central source for information about autism available to professionals and families in Illinois, and that there exists poor continuity of care for children in the system. Fewer identified the need for case management and the lack of a systematic referral process as the core needs.

When posed the question of what the most ideal system of care for individuals impacted by ASD would include, the top 5 components suggested by all of the participants were early identification and diagnosis (56.9%), professional education/training (10.7%), comprehensive diagnostics (8%), parent training (6.9%), and coordination of care among providers (3.4%) (TAP, 2004b). A focus group of parents and providers (Nierman, 2004): called for a system of care that is:

- ❑ Least restrictive
- ❑ Family centered
- ❑ Parent driven
- ❑ Comprehensive
- ❑ Community based
- ❑ Culturally competent
- ❑ Evidence based
- ❑ Collaborative and coordinated
- ❑ Strengths based
- ❑ Accountable
- ❑ Financially sustainable

Coordination of Care

Transitions Between System Sectors

“What happens to kids when they turn 21 and the school system’s responsibility ends?” – Provider (TAP, 2004b).

In the core area of coordination of care, participants in the TAP Needs Survey (N = 262; 2004 b) prioritized problems with transition periods in over half (54.3%) of the responses. This refers to transitions between related parts of the system in Illinois, such as from Early Intervention to Early Childhood, as well as young adulthood issues such as transitioning from school-based services to adult services. There are few data currently available with regard to parent and provider perceptions of such transitions, so surveys, interviews, and focus groups were conducted (Cellini, 2004; TAP, 2004a, 2004b).

Parents of teenagers and young adults expressed concerns about their children transitioning into adulthood, drawing attention to the needs for in-home supports, developmental training, and other supports after age 21 (Cellini, 2004). Perceptions of the transition from EI to EC were mixed (TAP, 2004a). One parent had a good experience, stating that at her child’s first IEP meeting, the “room was packed with his therapists and everybody had copies [of his EI evaluations].” However, another parent described the transition from EI to EC as

a “scary” process. As one provider stated “When a family goes from a family-driven to an education-driven model they are no longer running the show...and it is difficult for them to transfer their responsibilities”. Parents and providers interviewed identified several barriers to a smooth transition, including:

- Parents typically don’t know what to expect with the transition
- Therapists are not paid to attend transition meetings
- No meeting held to facilitate the transition
- Apparent lack of utilization of EI evaluations in setting IEP goals
- Parental fears about the adequacy of school-based services

Suggestions for improving the process from EI to EC services included creating a “student profile” of the child to serve as an introduction to the educational team, having an overlap of services by six months to facilitate communication, promoting family involvement in the process, providing resources for parent advocacy, and improving the timeliness of the process (TAP, 2004a). One parent suggested continuing the position of the EI case manager into the school setting (Cellini, 2004).

Chaotic Referral System for Diagnosis and Treatment

Consistency of practices and coordination of services across multiple delivery systems is challenging (Doepke et al., 2004b). Professionals in Illinois appear to hold multiple and sometimes opposing expectations regarding how, when and even if children should be diagnosed with ASD. For example, for school-aged children, points of confusion include: the type of diagnosis that is needed (i.e., educational vs. clinical), the appropriate interpretation of ISBE guidelines (i.e., different schools may identify children with ASD differently), and who has the ability to diagnose ASD.

The lack of coordination among various state and regional agencies serving children with ASD and their families creates another layer of bewilderment. Evidence of the need for improved coordination of Illinois services is seen in the Illinois Public Act 093-0073 (July, 2004) which mandates a multi-agency task force to study and assess service needs of persons with autism. According to a survey of over 2,400 providers in the state, primary settings where developmental screening for infants and toddlers occurs differ greatly in their referrals for early intervention services (Cutler & Gilkerson, 2002). Prevention and public health programs refer first to Child and Family Connections (CFCs), the entry point into the EI system. Physicians are most likely to refer to private providers and agencies, and childcare program staff is most likely to refer to the public schools. One of the most striking findings was that 55% of infant/toddler child care programs and one third of the primary care physicians had no knowledge of the Child and Family Connections, the entry point into the early intervention system.

To better understand the experience of parents or providers seeking information to refer a child suspected of ASD for diagnostic exam, a phone survey of Illinois agencies listed as resources in the “Directory of Illinois Resources for Young Children with Autism and Their Families” (TAP, 2004d) was conducted (Doepke et al., 2004b). Contacts were asked whether the agency provided diagnostic services for individuals with ASD and, if not, where they would refer a parent or professional with this question. Successful contacts were made to 63 of 83 (autism=20 out of 21 and general=63 out of 83) agencies. The results were compelling:

- Only 7% (6 agencies) offered diagnostic services or direct case management/ screening services. That included help obtaining a complete assessment.
- Less than half (46%, or 38 agencies) offered specific referrals to professionals or agencies.
- One fifth (20%, or 17 agencies) made only generic referrals, with the most common being to “your primary care/family physician” (N=13) or “a pediatric neurologist” (N=4)
- Almost one fifth (19%, or 16 agencies) offered no referrals at all.
- Of those offering generic or no referrals, typically no additional information regarding “how to” obtain a diagnostic assessment was given.

What do these numbers mean when translated into a parent’s experience? Although almost half of the agencies made specific referrals, they varied substantially in quantity and quality (Doepke et al., 2004b). Some referrals were made to agencies that actually *do not* conduct diagnostic assessments or that lack professionals with autism expertise. Others were made to the Illinois “pockets of excellence” in autism diagnostics. A substantial number of specific referrals were made to agencies outside of Illinois, especially when the issue was obtaining a comprehensive ASD assessment. Only one referral was made to the Illinois Autism Society and no referrals to federally funded Illinois Parent Training and Information Centers (PTIC). There was no mention of the TAP Resource Directory and only three referrals to TAP as an organization. Better coordination between agencies, schools, health care settings, early intervention, mental health, child welfare, and recreational organizations is needed (Nierman, 2004).

Furthermore, when a specific referral was made, consistency was minimal (Doepke et al., 2004b). Of the 38 agencies providing specific referrals, approximately 40 different professionals or agencies were recommended, with little overlap (30 were mentioned only once and only 4 mentioned more than 4 times). The end result is that when families are provided with information regarding where to obtain a diagnosis, information received regarding how or

why to obtain an ASD diagnosis is negligible. Whether or not a child is identified with ASD may depend on geographical location rather than their symptoms.

Several parents and providers commented on the need for assistance in coordinating care, both from individuals and organizations in order to knit together the fragmented pieces of the system (Cellini, 2004; Nierman, 2004; TAP, 2004a). Case management, by someone serving as a coordinator or social worker, was often mentioned to help families deal with navigating the system. One provider commented that “one phone call per month should be given” to assist families in gaining access to information and resources (TAP, 2004a).

Access to Care in Underserved, Culturally Diverse Areas of Illinois

An important part of a system of care is ensuring culturally competent care. Illinois has a diversity of geographic regions, from urban Chicago, to semi-rural Central Illinois, to rural Southern Illinois. There is a great deal of ethnic diversity, from a Hispanic migrant population in Southern Illinois to the multi-ethnic population in Chicago. Poverty, geographic isolation, and cultural differences all present barriers to accessibility of services. As one of 3 specific areas of need within the core area of coordination of care, 19% of respondents on the TAP (2004b) Needs Survey endorsed attention to underserved areas as a top need in Illinois.

There is little information available on the impact of such sociocultural factors on autism services in Illinois. Therefore, TAP funded 2 outreach programs to families who have been marginalized by language, cultural or economic barriers, one with Hispanic migrant families in Southern Illinois (Cutler et al., 2004; Manghi, 2004) and the other in urban Chicago (Easter Seals, 2004). Although these programs were designed to raise awareness and increase utilization of services, they also provided a unique opportunity to assess the needs within a wide array of populations.

Autism awareness and services are less available in rural areas of the state, such as the Southern Seven counties. Hispanic migrant families, who represent a significant portion of families living in rural poverty in the Southern Seven counties, have even more restricted access for a variety of reasons. They have little information regarding normal development, and often have never heard the word autism (Manghi, 2004). Families whose primary language is not English are likely to encounter barriers to having an evaluation done in their native language or with trained interpreters to provide an unbiased diagnosis. In an outreach program to Hispanic migrant families in the Chicago area, forms were made available, but the culturally sensitive written form wasn't used. Oral comments

included a parent who stated that he had “never heard anything about autism” but had identified a child in the migrant community with similar symptoms. There is a need to work jointly with local EI providers to expand their knowledge and create connections with migrant parents.

Typically, many new immigrants and refugees maintain their traditional cultural beliefs and health care behavior, which can be very different from those practiced in this country (Easter Seals, 2004). Cultural and language barriers range from patients’ inability to understand the U.S. health care system to distrust and disrespect of physicians and western medicine. There is a rising concern about the language/cultural barriers to health care and patients’ inability to comply with medical treatment plans. There is a need for cultural competency training curricula and model programs to improve the quality and access to health care for the immigrant/refugee populations. Bilingual health education materials are needed to help the limited English-speaking immigrants and refugees understand the U.S. and Illinois health care system.

Funding and Cost Issues

Economic constraints affect who is able to obtain services. For example, access may be limited to families who (a) have medical insurance that will pay for such an assessment, (b) have the personal resources to pay for services, (c) are sufficiently educated to know how to obtain a referral from their school system, (d) live in a school district that actively and accurately identifies children with ASD, or (e) happen to live near a center that provides low cost services (Doepke et al., 2004b). Costs for diagnostic assessment range from \$600 for a basic evaluation to over \$2000 for a multidisciplinary comprehensive assessment (TAP, 2004c). Children without insurance or on Medicaid have fewer diagnostic options. In a recent national survey 12% of Illinois residents surveyed stated they did not have any kind of health care coverage (CDC, 2004a, 2004b).

Regardless of insurance issues, families and providers across the state name funding and cost issues as a primary barrier to care for children with autism in Illinois (Cutler & Gilkerson, 2002; Boheme, 2004; Nierman, 2004; TAP, 2004a; TAP, 2004b). Of 262 individuals surveyed about advocacy and funding issues, 61% identified limited sources of funding as the primary need, followed by 33% endorsing the high cost of services as the primary problem (TAP, 2004b). The need for flexible and supported funding is imperative, with specific funding streams to include Medicaid, state general revenue funds, educational funds, foundations, vouchers, and funding blended from multiple secure sources (Nierman, 2004). Parents and providers request affordable programs that are specific to autism, such as social skills groups, recreational activities, and childcare in addition to diagnostic, treatment, and educational services (TAP,

2004a). The providers are also calling for more funding for training in the area of autism in order to serve parents and children more effectively (Boheme, 2004).

Aside from data on general concerns and calls for more funding, there are no Illinois data available with respect to family and provider costs related to caring for children with ASD. However, it is informative to explore the state's financing of services for individuals with developmental disabilities for implications related to the subgroup of children with ASD. Robert Gettings and associates (Gettings et al., 2003) provided a report to the Department of Human Services, Division of Developmental Disabilities that speaks to the characteristics of the system and implications for federal dollars.

Illinois, unlike most other states, has yet to establish a unified, single-point-of-entry system for managing state-funded developmental disabilities services (Gettings et al., 2003). Such a system would consist of designated local entities located throughout the state, which are responsible for eligibility determination intake, individual program planning, service coordination and the purchase of needed services. Based on FY2002 expenditure data provided by the Department of Human Services, Division of Developmental Disabilities (DDD), Illinois expended approximately \$39.3 million on community services targeted to children aged 0 to 17 years. Only 6,695 children and adolescents under 18 years of age received services funded by the division in FY2002, representing about 15% of DDD's total fiscal year caseload.

Currently, the Medicaid recovery rate is inadequate in Illinois (Gettings et al., 2003). For example, of the \$39.3 million mentioned above, the state would collect \$19.5 million in additional federal revenue just for children's services if even half of these funds could be matched with federal Medicaid dollars. While 50% recovery seems conservative, the estimate was based on the experiences of other states and Illinois' experience with EI services. During FY2002, 58% of children enrolled in the state's EI program were Medicaid eligible and 52% of total EI program costs were being recovered through Medicaid payments.

Illinois state officials are attempting to improve the recovery rate for EI services under the state's Medicaid plan (Gettings et al., 2003). Efforts are underway to add transportation and assistive technology costs to the roster of Medicaid-reimbursable EI services. The financing of service coordinator costs also was being converted to a target management coverage under the state plan. However, without a significant reorganization of service delivery, such efforts will be limited. According to Gettings et al. (2003), one central lesson that can be drawn from the states' collective experiences over the past 2 decades with Medicaid funding of services to persons with developmental disabilities is that the ability to access and effectively use federal entitlement dollars is closely tied

to the general manner in which a state is organized to finance and deliver services. When multiple agencies are responsible for managing Medicaid dollars, as in Illinois, it is difficult to develop and implement a holistic strategy to take full advantage of the financing opportunities presented by the Medicaid program.

Furthermore, there is a great need for more data on unmet needs within the state to support requests for additional funding and map out a plan to improve access to services (Gettings et al., 2003). The authors suggest that the state analyze the merits of creating one or more Home and Community-Based Services (HCBS) waiver programs targeted to children with developmental disabilities. Such an initiative could include a family supports waiver program and a children's intensive supports waiver program. Such HCBS waiver programs are also needed for adults with developmental disabilities to promote alternative community living opportunities for persons with severe, complex disabilities. Such data and policies are needed to afford equitable access to services and supports across the state within the constraints of available public dollars.

At a Glance: Need for a System of Care Approach

- Our current system of care does not adequately address the transition of children with ASD between agencies within the system, the needs of underserved populations, or access to properly trained professionals.
- 48% of the participants in the TAP Needs Survey indicated a need for attention to the current system of care in Illinois.
- The 5 key components of an adequate system of care, as identified by TAP Needs Survey participants, include early identification and diagnosis (56.9%), professional education and training (10.7%), a comprehensive diagnosis (8%), parent training (6.9%), and coordination of care among providers (3.4%).
- As evidenced by the implementation of a multi-agency task force by Illinois Public Act 093-0073, coordination of care between providers is in need of improvement.
- Both parents and providers have acknowledged that funding is a significant barrier to accessing services for children with ASD, with a need for waiver programs targeted for children with ASD.

- The Medicaid recovery rate in Illinois is inadequate, with millions of dollars not collected.
- Contrary to most states, Illinois has yet to implement a “single-point-of-entry” system to manage developmental disabilities services that are funded by the state.
- There is a great need for more data on unmet needs within the state to support requests for additional funding and map out a plan to improve access to services.

CONCLUSIONS AND FUTURE DIRECTIONS

As per TAP's contract with DHS for FY2004, this needs assessment was conducted with a primary aim of informing program planning and development in the areas of autism training and services in Illinois. Consistent with best practice standards, the needs assessment was developed together with key stakeholders (parents, providers, and state officials) who identified core areas of need to be assessed. Using these key areas as a framework, TAP sought to utilize existing sources of information, both nationally and specific to Illinois, in addition to original data collection in targeted areas. TAP intends to continue assessing needs in each fiscal year, with the intention of promoting a data-driven approach to addressing Illinois' problems and our own program development.

Consistent with the U.S. Surgeon General's Report and the experience of other states, one outcome of this year's needs assessment was the need for a more systematic approach to data collection, ensuring statewide coverage and inclusion of a wide variety of stakeholders. This would include an epidemiological study to gain further information on the numbers of Illinois children and families impacted by autism, which can currently only be estimated from a variety of sources.

Autism presents a national public health crisis. The increase in prevalence, the lack of services and trained providers, and the fragmented system of care have resulted in devastating consequences for children with Autism Spectrum Disorders (ASD) and their families. The state of affairs in Illinois is consistent with the larger national picture, highlighting the need for a statewide systematic response to meet the needs of children currently identified with ASD and the rising numbers of those to be diagnosed in the future. As a state, it is clear that we need to find ways to meet the needs of all children with ASD in order to promote meaningful and lasting changes in their lives and in the lives of their families.

Key Needs

Need for early identification and surveillance

- ❑ Adequate, timely, and comprehensive diagnosis
- ❑ Provider training on screening and identification to ensure earliest possible identification
- ❑ Screening in primary care settings, with adequate time and sufficient staff to do screenings
- ❑ Successful models of screening practices in community settings
- ❑ Parental acceptance of delay

- ❑ Clarity for parents, teachers, and frontline professionals regarding when children should be referred for further diagnosis
- ❑ Medical community's appreciation for the value of early intervention/ability to offer other options
- ❑ A primary medical care "home" to foster early screening, detection, intervention and follow-up

Need for a best-practice approach in assessment and intervention

- ❑ Enhancement and increased utility of early intervention services
- ❑ Comprehensive, behaviorally-informed, structured, and intensive programs
- ❑ Training for physicians, early intervention providers, and families on the development and use of best-practice guidelines
- ❑ Enough professionals with autism expertise in the state to meet the growing demands of the ASD population
- ❑ Expert identification and appropriate treatment resources
- ❑ Adoption of statewide standards and certification for professionals
- ❑ Cooperation and collaboration among multiple groups and use of appropriate assessment tools is essential; diagnosis process must be interdisciplinary
- ❑ Birth to 3 programs and school districts funded to proactively lead w/intervention services
- ❑ Evidence-based interventions with characteristics demonstrated to be effective, including those that are intense, flexible, coordinated, accessible, and collaborative.
- ❑ Use of standardized measures to assess cognitive functioning or adaptive behavior
- ❑ Time allocated for data collection, team meetings, intervention planning and implementation (at school)

Need for family-centered care

- ❑ Provide families with information about autism, names of support groups in their area, reliable sources of information and referral to early intervention and special education
- ❑ Provider intervention and support with a focus on families' values and priorities
- ❑ A team approach that includes family members as team members
- ❑ More intervention training for parents, flexibly provided to accommodate family schedules
- ❑ Respite services for parents and quality, affordable, knowledgeable childcare for children with ASD

- ❑ Ancillary support for parents (family support groups, peer support, social activities, transportation, playgroups for their children with ASD, and childcare for attendance at activities)
- ❑ Mental health services for children AND parents

Need for ongoing provider training, consultation, and resource development

- ❑ Additional public awareness programs
- ❑ Childcare programs and other providers need access on an ongoing basis to developmental specialists, occupational therapists, and other specialists to assist them in planning for or serving children with ASD
- ❑ Hiring and retaining teachers with training in autism
- ❑ Training for education professionals on the need for and methods of collaboration with families
- ❑ Staff development related to conducting functional assessment, developing positive intervention plans, and implementing specific procedures
- ❑ Administrative recognition and resources for teachers
- ❑ Physicians who understand developmental and/or behavioral issues and who understand parental concerns
- ❑ Training and additional funding for respite care providers
- ❑ Therapist comfort with ASD diagnosis
- ❑ For providers: hands-on training, more access to experts in ASD, case-centered consultation, lecture-based trainings, and clinical supervision
- ❑ Funding for research as well as training (or retraining) of assessment professionals to increase the likelihood that the most valid methods of assessment will be used.
- ❑ Specific evidence-based intervention training - practical, hands-on therapy ideas
- ❑ EI providers to expand their knowledge and create connections with migrant parents

Need for a system of care approach

- ❑ Implement a comprehensive state database
- ❑ A systematic method to get children from the referral point to the appropriate professionals
- ❑ Coordination of care between service sectors
- ❑ Smooth the transition between early intervention and school-based services, and school-based services to adult services
- ❑ Collaboration between health plans, physicians, families, and schools is essential, but interactions must be changed to promote true “community” implementation and translation of research to practice

- ❑ Infrastructure should be improved to ensure that existing, evidence-based programs are available to all children who need them
- ❑ Strategies that improve accessibility of essential services, including health care, early intervention, care coordination, and program expansion to children with autism and their families, should be implemented
- ❑ If functional assessment and positive behavioral interventions are to become effective, institutionalized practices in Illinois that are maintained over time, the systems that support their use must be in place
- ❑ A community entity that provides supports and services that are coordinated between schools and families. Desirable characteristics: consumer driven, private and public, small v. larger, local or regional, and reliable
- ❑ Access to care in rural and other underserved communities
- ❑ Cultural competency training curricula and model programs to improve the quality and access to health care for the immigrant/refugee populations, including bilingual health education materials
- ❑ Comprehensive lifetime approach to intervention, comprising in-home supports, developmental training, and other supports after age 21
- ❑ Unified, single-point-of-entry system for managing state-funded developmental disabilities services
- ❑ Need for the state to match the federal emphasis on continued funding for system development, research & training
- ❑ Improve the process from EI to EC services: create a “student profile” of the child to serve as an introduction to the educational team, have an overlap of services by six months to facilitate communication, promote family involvement in the process, provide resources for parent advocacy, and improve the timeliness of the process - continue the position of the EI case manager into the school setting
- ❑ Need for an umbrella autism program in Illinois, designed to inform and impact autism services across a variety of state and community programs. Create a recognized authority with multiple ports of entry to ensure that families and agencies know where to go for autism related services. Such regional centers would ensure that individuals, families, and service providers have easy access to training and services.
- ❑ Improve the recovery rate for EI services under the state’s Medicaid plan
- ❑ Flexible and supported funding is imperative (specific funding streams to include Medicaid, state general revenue funds, educational funds, foundations, vouchers, and funding blended from multiple secure sources)
- ❑ Resolve insurance difficulties

Key Needs – Need for More Research

- ❑ Systematic epidemiological study to gain better insight into the numbers of Illinois families impacted by ASD, including age at which children are being diagnosed, patterns across ethnic and regional groups, and the extent to which children might be re-classified over time
- ❑ Further research and instrument development that would allow for early identification, emphasizing sensitivity and specificity and factors that impact utilization in a variety of settings
- ❑ How to engage pediatricians and the community at large
- ❑ Additional research examining how clinics carry out published guidelines in practice and how to promote a best practice approach
- ❑ Data on effective methods for smooth transition
- ❑ Information on the impact of sociocultural factors on autism services in Illinois
- ❑ Illinois data on funding and cost issues specific to autism
- ❑ More data on unmet needs within the state to support requests for additional funding and map out a plan to improve access to services
- ❑ Analyze the merits of creating one or more Home and Community-Based Services (HCBS) waiver programs targeted to children with developmental disabilities.
- ❑ Continued assessment of barriers to care & other needs within the state

Illinois is in an excellent position to dramatically improve the quality, quantity, and accessibility of ASD services by building on pockets of excellence in autism services, ongoing state-funded projects such as TAP and the Illinois Autism/PDD Training and Technical Assistance Project, advocacy efforts by family support agencies, and recently established multi-agency work groups such as the Illinois Autism Task Force. In order to meet the needs highlighted above, there is an overriding need for an umbrella autism program in Illinois, designed to inform and impact autism services across a variety of state and community programs. The state needs a recognized authority with multiple ports of entry to ensure that families and agencies know where to go for autism related services. Such regional centers would ensure that individuals, families, and service providers had easy access to training and services, as well as promoting best practices throughout the state.

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Appendix II: Consensus Statement

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:
 - Inclusive of all stakeholders (families, clinicians, early interventionists, researchers, educators, vocational specialists and support personnel).
 - Accessible regardless of income, geography, ethnicity, etc.
 - Coordinated across community and government programs
 - Integrated with existing services and providers, and flexible enough to ensure individual choice and to allow the entry of new services and providers
 - Trained and equipped for service
 - Effective across the lifespan
 - Supported through multiple funding streams including state and federal grants (research and services), insurance, Medicaid, and private payment options
2. Program development in education and treatment should be guided by a focus on evidence-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)
 - Not recommended (research demonstrates treatment to be ineffective or contaminated).

Additionally, treatment planning should consider the following characteristics identified as representative of effective treatments:

- Early entry into an intervention program
- Active engagement of intensive instructional programming for the equivalent of a full school day, including services offered at other sites.
- A minimum of five days a week of year-long programming
- Maximization of planned teaching opportunities – focused on frequent, but brief intervals distributed across the day
- 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, development and maintenance of a system of care will require a comprehensive initiative that is responsive to the needs of individuals and families include:
 - Personnel preparation
 - Technical assistance
 - Applied research & program evaluation
 - Communication
 - Demonstration
 - Data systems
 - Comprehensive planning

Finally, an effective system of care must be dynamic and is possible only through coordinated, collaborative efforts of families and agencies across Illinois.

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Appendix III: Community Planning and Network Development Instructional Guide,

McLean County Community Plan

Community Planning and Network Development Instructional Guide

Definition: TAP Community Planning and Network Development (TAP-CPND) encompasses a variety of activities designed to engage the community in creating, improving, and maintaining evidence-based services for individuals with Autism. TAP-CPND is a participatory process that seeks input from a broad range of stakeholders including, but not limited to:

- Parents
- Physicians
- Individuals with ASD
- Educators
- Early Interventionists
- Therapists
- Vocational and Residential Specialists
- Corporate Representatives

Desired Results: TAP-CPND should result in an integrated, actionable and dynamic community plan to support increased service and support for individuals with ASD and increased community consensus, networking, and collaborative funding.

Process and Components: TAP-CPND initiatives will vary depending upon local need and resources; however the following outlines a process and key components that have been proven useful in other communities:

Step One-Steering Committee: A successful community planning and network development initiative begins with an initial steering committee that is knowledgeable about the needs and resources in a specific area (city, county, region or state) or within a specific service population (Developmental Disabilities, Mental Illness, Aging). Steering Committees, at this stage in the process, work best if they are small (5-7 members) The primary mission of the Initial Steering Committee is to:

- Adopt a format and process for subsequent community planning
- Identify, engage and maintain the active participation of members for all relevant stakeholder groups
- Identify and train facilitators to participate in lead community planning (see enclosed PowerPoint for facilitator training)

- Coordinate invitations, venue, format and process for Initial Community Meetings
- Provide leadership to workgroups and committees

Step Two-Facilitator Training: The community plan will require between 2 and 3 community meetings. Community meetings can range from 40 to 150 attendees, therefore, planners should be prepared to split into small groups for discussion. Each group should be staffed with a facilitator who has the ability to direct group process and who has received a brief training on the Logic Model (see attached training PowerPoint and Logic Model Manual). Facilitator training should take approximately 2 hours.

Step Three-Initial Community Meetings: Initial community meetings (Two, 3-hour meetings are recommended to meet the goals outlined below) create an environment and the tools necessary to engage in comprehensive community planning including:

- Creation of an accurate up-to-date contact list for future meetings
- Resource-mapping
- Identification of: unmet needs, desired outcomes, relevant activities and overall impact
- Creation of a draft community plan

TAP-CPND initiatives across the state have found The Autism Program Guiding Principles Consensus Statement (provided) and The Kellogg Foundation Logic Model to be an effective method to organize relatively large community planning initiatives. The Kellogg model (described in full detail in attached materials) ensures that community plans realistic and grounded in identified needs and resources. The following agenda would be appropriate for the first Community Meeting:

- I. Review TAP Service Delivery Network and TAP Legislative Mandate (*During this portion of the program, leadership should introduce participants to the TAP Service Network and the TAP Legislative Mandate. This serves to create a sense of being part of a larger process and emphasizes the fact that this process is supported by a statewide program*)
- II. Review Intent of TAP-CPND (*During this portion of the program, leadership should outline the intent of the community planning process and provide a brief overview of the process*)
 - a. Definition (*See definition above*)
 - b. Desired Results (*See definition above*)
 - c. Process
 - i. Introduction of Steering Committee

- ii. Community Meetings
 - iii. Community Plan
 - iv. Workgroups
- III. Review TAP Guiding Principles Consensus Statement (*The Steering Committee may want to send this document out with the invitation to the first meeting so that participants have a chance to review prior to the first meeting*)
- IV. Review Logic Model The Guiding Principles Document and the Logic Model should be reviewed with the entire group at the first Community Meeting. (*The Steering Committee will have already trained facilitators who can support breakout groups in walking through the Logic Model Process, therefore, a brief overview is all that is needed here*)
- V. Logic Model Planning (*This portion of the program is best conducted in small groups. If the planning meeting is addressing a specific population (Early Intervention; Adolescents; Adults), the planners may want to divide participants into 4 groups dedicated to issues relevant to the specific population (i.e. Adolescents; Social Skills and Relationships; Vocational/Secondary Education; Independence; Residential). Each group will walk through the steps of the logic model with a focus on their specific area*)
- VI. Report (*This portion of the program allows each group to provide a report on their discussion. The report should follow the logic model format. A member of the Steering Committee should take clear notes and should ask group leaders for a copy of their notes*)
- VII. Next Steps (*This portion of the program should include an outline of next steps—these will depend on the progress made in the planning meeting. Possibilities include:*
- 1. *Set a date for a second community meeting to complete community plan.*
 - 2. *Set a date to review draft of the community plan*

Step Four-Draft Community Plan: Staff members supporting the Steering Committee should take the information collected at the Community Meetings and compile them into a comprehensive community plan (sample provided). The Community Plan should begin with the TAP Guiding Principles Consensus Statement followed by the specific outcomes of the planning sessions.

Step Five-Steering Committee Review: The Steering Committee should review and sign off on the 1st draft of the community plan prior to disseminating it to community members.

Step Six-Community Meeting-Review, amendment and ratification of Community Plan

Staff members supporting the Steering Committee should prepare and disseminate a draft of the Community Plan prior to the meeting. This meeting (which is usually the third time that the community has come together as a whole) will allow community members the opportunity to comment and suggest amendments to the plan. The goal is to achieve ratification of the plan and identification of workgroups.

Step Seven-Workgroups: The major outcomes identified in the Community Plan should suggest the necessary workgroups. The Community Meeting described in Step Six should include an identification of the workgroups; their membership; and a tentative schedule for workgroup meetings. Each workgroup should appoint a convener to schedule meetings and a recorder to record minutes and submit the minutes to the Steering Committee

Step Eight-Follow-up and Maintenance: The Steering Committee should stay in touch with the conveners from each workgroup; summarize and disseminate workgroup reports; and plan and host a bi-annual community meeting to review the community plan and progress made.

McLean County Community Autism Plan

The McLean County Community Autism Plan is the result of coordinated, collaborative efforts of the McLean County Autism Steering Committee and the McLean County Autism Community as a whole. McLean County families, agencies, educators and providers – working in collaboration with The Autism Program – have succeeded in developing a comprehensive plan for autism services for McLean County. This consensus statement is a product of their united efforts.

The McLean County Community Autism Plan, The McLean County Autism Steering Committee and members of the McLean County Autism Community support the guiding principles consensus statement developed by The Autism Program and articles of a joint platform for autism services developed by the McLean County Autism Community.

Guiding Principles Consensus Statement:

Discussions of autism often revolve around differences. This focus frequently eclipses the substantial, powerful commonalities that exist in the autism community. This document represents a joining of the autism community in McLean County around commonalities and shared goals. This joining of community vision and an agreed upon action plan represents a critical step toward the expansion of funding and service options for children with ASD and their families in McLean County.

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, physicians, early interventionists, educators, vocational specialists and support personnel)
- b. Accessible, regardless of income, geography, ethnicity, etc.
- c. Coordinated across community, private, public and government programs
- d. Integrated with existing services and providers and flexible enough to ensure individual choice and to allow the entry to 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 evidence-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 identified by the National Research Council (2001¹¹) 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 5 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 disabilities community.

4. Consistent with the National Research Council recommendations and ongoing needs assessment in Illinois, development and maintenance of a system of care will require a comprehensive initiative that is responsive to the needs of individuals and families.

National Research Council Recommendations for Statewide System Development

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 pre-service and in-service 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: One of the key aspects of an infrastructure is the ability to do

PLANNING: 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.

Finally, an effective system of care must be dynamic. The system of care outlined above is possible only through coordinated, collaborative efforts of families and agencies across McLean County and the state. The Autism Program, The McLean County Autism Steering Committee and members of the McLean County Autism Community acknowledge 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.

McLean County Community Autism Plan

The McLean County Community Autism Plan embraces the tenants of *The Autism Program's Autism Joint Platform and Consensus Statement*, and focuses on the entire lifespan of a person with ASD, addressing explicitly the following core areas:

1. ASD Resource Center
2. Comprehensive, Coordinated Training
3. Diagnostic & Assessment Services: Building Community Consensus Across Clinical and Educational Settings
4. Meaningful Employment

The McLean County Community Autism Plan will be undertaken with guidance from The Autism Program. The Plan will be implemented through coordinated, collaboration with neighboring communities in Illinois that are engaged in community visioning for autism spectrum disorder programs and services. Work Teams for each of the four core areas have been established to bring the McLean County Community Autism Plan to reality.

Autism Spectrum Disorder Resource Center

The McLean County Autism Spectrum Disorders Resource Center serves as a single point of entry for information, resources, advocacy, guidance, assistance and support for persons with autism and their families. The McLean County Autism Spectrum Disorders Resource Center is to be housed in a common, accessible location and is to be staffed by trained individuals (including employees, volunteers, parents, support staff, mentors and trainees) and governed by a Board of Directors with the input of a community advisory council. The McLean County Autism Spectrum Disorders Resource Center will be a source of information and resources, which may include services such as a sensory loan center, ASD toy swap and ASD information library. The Center will sponsor ASD awareness activities for the community, a 1-800 Help Line, web resource, support groups, trainings, social skills programs, recreational programs, child care co-op, as well as mentoring and support programs.

The long-term impact of the McLean County Autism Spectrum Disorders Resource Center is anticipated to be:

1. Families and persons with ASD will have a one-stop resource center available to them.
2. The resource center will be a source of information, guidance and advocacy.
3. The resource center will be a respected resource for training.
4. The resource center will provide supports, programs and services that are consistent with the needs of the community and reflective of best practices in ASD.
5. The resource center will be responsible to the community and will be represented by a broad range of community groups, agencies and interests.

6. The resource center will provide a model for duplication by other communities.

Substantial existing resources within McLean County have been identified, including, but not limited to the following:

1. Three existing libraries (ISU, Easter Seals, Normal Public Library)
2. Community awareness and educational materials
3. TAP/ASMC resource guides
4. Support groups
5. Social skills groups
6. Training
7. Recreational programs
8. TAP/ASMC websites
9. Potential physical space for Community Resource Center-Easter Seals
10. Trainees/parents willing to engage
11. Qualified professionals willing to engage
12. Advocates/mentors
13. Pool of people for advisory council and Board of Directors
14. Pool of potential support staff
15. Pool of potential administrative staff
16. Two universities and Jr. college
17. TAP Affiliate at Illinois State University
18. ASMC
19. SOAR
20. Easter Seals – Bloomington + Timber Pointe Outdoor Center
21. IL Autism Society
22. YWCA

23. Baby Fold
24. MARC/SPICE
25. Easter Seals
26. Public Schools
27. Eugene Field
28. Local SEAs

Additional identified resources and needs include but are not limited to the following:

1. Grant support
2. University endorsement
3. Subcommittee to address philanthropy and short and long-term corporate sponsorship
4. Collaboration with Early Childhood Intervention Clearinghouse
5. Investigation and direction on the following issues:
 - a. Ownership: legal advice to support receipt of funding and broad community support and involvement
 - b. Public funding
 - i. 377 MH Board and other tax dollars
 - c. United Way association
 - d. Illinois Prairie Community Foundation
 - e. Technological support through State Farm or other corporate gifts.

The McLean County Autism Steering Committee and the McLean County Autism Community as a whole will work collaboratively in the building of the McLean County Autism Resource Center.

Comprehensive, Coordinated ASD Training

Comprehensive, coordinated training across McLean County has been identified as a core area of need and a focus of the McLean County Community Autism Plan. Comprehensive, coordinated training will bring together the major training providers in the McLean County area to assure that training reflects best practices, current knowledge and is coordinated across agencies and provider groups to allow for open access, conservation of resources,

and optimization of training impact. Comprehensive, coordinated training will include training for professionals in the latest & most effective methodologies, training to physicians, educators, teacher's aides and paraprofessionals, early intervention and early childhood providers, health care providers and support personnel in McLean County. The goal of the McLean County ASD Training Committee will be to establish community-wide standards for basic ASD knowledge.

The long-term impact of Comprehensive, Coordinated ASD Training is anticipated to be:

1. All professional groups in McLean County will receive training to achieve a minimum level of ASD competence as established by the McLean County ASD Community.
2. Direct care providers will receive specialized ASD training.
3. McLean County will establish community-wide standards of basic ASD knowledge and training curricula expectations representing different levels of ASD expertise.
4. More efficient use of existing training resources

Identified initial actions include but are not limited to:

1. Obtain a list of medical providers and advertise STEPPS II training.
2. Comprehensive review existing curriculum for appropriate curriculum for teachers and teacher's aides
3. Compile a comprehensive list of existing training offered in McLean County by various groups, agencies, individuals.
4. Form Training Subcommittee that determines training areas, topics and works to create standardized training curriculum for various provider groups in McLean County.

Substantial existing resources within McLean County have been identified, including, but not limited to:

1. Baby Fold
2. ISU
3. Easter Seals
4. TAP
 - a. ICAAP Training (STEPPS II)
 - b. New Diagnostic Parent Orientation Program

- c. ADOS training
- d. School curricula

Diagnostic & Assessment Services: Building Community Consensus Across Clinical and Educational Settings

Diagnostic & Assessment Services: Building Community Consensus Across Clinical and Educational Settings were identified as core areas of intervention for the McLean County Community Autism Plan.

Comprehensive Clinical Diagnostic Services

McLean County will identify a core diagnostic protocol that is reflective of best practice guidelines and consistent across McLean County, from one diagnostic service provider to another. The plan includes early, multi-disciplinary, standardized diagnostic program and screening with funding to cover & assessment for treatment planning coupled with a short wait for services.

The long-term impact of the comprehensive clinical diagnostic services is anticipated to be:

1. McLean County will have a standard diagnostic protocol used by all agencies and providers who provide ASD diagnostic services.
2. Children will receive access to early diagnostic services and comprehensive treatment planning within a reasonable period of time from referral.

Identified initial actions include but are not limited to:

1. Utilizing existing resources for comprehensive diagnostic services provided by Easter Seals (Peoria + Bloomington) and The Autism Program, Central Illinois Regional Training and Service Center at The Hope School.
2. Identify a standard protocol for diagnostics involving a multi-disciplinary team.
3. Identify current protocols for diagnostics.

Assessment for Educational Intervention Planning & Community-wide Educational Consultation Team

McLean County will form a collaborative team of ASD diagnostic specialists and professionals who will work together in developing IFSP and IEP goals and creating an individualized education plan based on each child's unique needs and strengths. This diagnostic team may have access to ASD transitional/observational classrooms – housed in both public and private schools – and have maximum flexibility to conduct educational evaluations across school districts and settings in McLean County.

The long-term impact of the assessment for educational intervention planning and community-wide educational consultation team is anticipated to be:

1. All children in McLean County will receive a comprehensive ASD diagnosis utilizing a standard protocol that is reflective of best practice standards, regardless of what diagnostic service provider they see in McLean County.

2. All children diagnosed with ASD in McLean County will have access to a specialized, community-wide team of highly trained ASD professionals to assist their individual school districts and teachers in formulating the best educational plans to meet their needs.
3. All children diagnosed with ASD in McLean County will have access to a specialized, ASD transitional/observational classroom through which a comprehensive educational plan can be developed and evaluated.

Identified initial actions include but are not limited to:

1. Collaboration between Hammit School/Baby Fold, Unit 5, Tri-County Special Education Association, District 87 and Easter Seals on creation of a community-wide ASD evaluation and intervention-planning team.
2. Identification and adoption of a standard ASD diagnostic protocol based on best practice standards.
3. Development of a transitional/observation classroom for children with ASD in McLean County.

Meaningful Employment

Meaningful employment for persons on the ASD spectrum residing in McLean County was identified as a core issue in lifespan planning and the focal issue of initial McLean County Autism Community efforts. Meaningful employment is differentiated from competitive employment, the current goal of DRS/DHS. Meaningful employment implies a position that is rewarding, fulfilling and meaningful to the person with ASD and his/her family. Meaningful Employment for persons with ASD in McLean County would involve: job opportunities throughout the community, availability of job coaches and job teams to provide support, the availability of supported employment opportunities in every school in McLean County and vocational programming with true ASD expertise.

The long-term impact of lifespan services and supports for persons with ASD in McLean County is anticipated to be that adults with ASD in McLean County will have access to resources, appropriate housing, opportunities for socialization, leisure, higher education and employment.

Identified initial activities include but are not limited to:

1. Identify adult providers in area already providing vocational services (e.g., MARC, ODC, School-based programs)
 - a. Share this list during educational transition period
 - b. Establish further links with Employalliance for training and placement assistance

- c. Seek assistance from CISA and DHS/DRS in understanding differences between “competitive employment” – their goal and “meaningful employment” – family and child goal
2. Identify area businesses currently hiring or are willing to hire persons on the ASD spectrum
 - a. Educate and encourage major area employers to participate – State Farm, BroMenn, County Companies, ISU, IWU
 - b. Support and strengthen relationships with businesses currently providing employment opportunities--Walgreens and Marriot Corporation.
 - c. Explore federal JWOD contracts in McLean County area
 - d. Invite “Project SEARCH” in Cincinnati to share their employment process and vision/mission with area employers
 - e. Use work-study students at ISU and IWU to be job coaches for persons on ASD spectrum
3. Explore self-employment, entrepreneurial efforts, customized employment options
 - a. Encourage businesses to set aside specific tasks/contracts that could be completed by people on the ASD spectrum – in-house scanning, shredding, collating, labeling, billing up to more complex activities
 - b. Encourage the development of a business primarily staffed by people on the ASD spectrum
4. Legislation to create incentives for employers to hire and retain persons on the ASD spectrum
5. Funding from local, state and federal bodies to support the hiring of a full time person [e.g., client coordinator/case worker] to assist those on the spectrum to find and retain employment in McLean County – “honest broker” to work with client, employer, vocational providers & educational providers
6. Obtain additional funding for local vocational providers (e.g., grant, etc.)
7. Naturalized support for employment for persons on the ASD spectrum – job sharing, flex time, job clubs, social skills classes, job/life coaching, case management, etc.

Substantial resources already exist within McLean County to achieve the goals of meaningful employment for persons with ASD. These include but are not limited to:

1. MARC/SPICE
2. ODC
3. School systems
4. DHS/DRS
5. State Farm
6. ISU
7. IWU
8. CISA

Signatures below indicate support of The Autism Program Guiding Principles Consensus Statement and The McLean County Community Autism Plan. Signatories agree to abide by the tenants of The Autism Program Guiding Principles Consensus Statement, to work collaboratively with The Autism Program and to support the McLean County Community Autism Plan, taking an active role in the planning, development and sustainability of the autism-specific programs and services outlined in the McLean County Community Autism Plan.

Signature	Organization	Title	Date
_____	_____	_____	_____
Signature	Organization	Title	Date
_____	_____	_____	_____
Signature	Organization	Title	Date
_____	_____	_____	_____
Signature	Organization	Title	Date
_____	_____	_____	_____
Signature	Organization	Title	Date
_____	_____	_____	_____

Appendix IV: Outcome Summary—Quarter One FY 2010

	Report Period Ending:				Total
	Q1	Q2	Q3	Q4	
Service Volumes					
Direct Service Volumes by Children (unique count within Q)	508				
<i>Diagnostic Assessment</i> (unique count within Quarters)	84				
Hours (including report writing; duration)	1065				
<i>Screening / Intake</i> (unique count within Quarters)	192				
<i>Child Treatment</i> (unique count within Quarters)*	203				
Contacts (frequency; count)	1562				
Hours (duration)	3044				
<i>Family Treatment</i> (unique count within Quarters)*	99				
Contacts (frequency; count)	366				
Hours (duration)	628				
<i>Educator / Family Consultation</i> (unique count within Quarters)*	117				
Contacts (frequency; count)	920				
Hours (duration)	308				
Training Programs and Services					
Trainings Provided (count)	54				
Participants Trained (count)	1097				
Parents and/or Family Members Trained (count)	63				
Providers and/or Educators Trained (count)	1033				
DHS Mental Health Providers Trained (count)	1				
Child Care Trainings					
Trainings Provided to Child Care Providers / Staff	4				
Child Care Providers / Staff Trained	75				
Telehealth Trainings and Skills Spotlights					
Telehealth Consultations and Skills Spotlights Hosted (count)	5				
Providers attending Telehealth and/or Skills Spotlights (count)	84				
Resource & Referral: Parent, Family, Provider, & Community Outreach					
Parent Contacts / Requests (count)	3620				
Provider, Agencies, Other Contacts / Requests (count)	8205				
Visits to TAP Network Partner FCRRs throughout the Network	1297				
Free Learning Aids Provided	20,432				
Contact Service: Resources Provided	4567				
Contact Service: Information Shared	10,214				
Contact Service: Technical Assistance	864				
Contact Service: Make Referral	887				
Contact Service: Other Services	319				
Contacts involving collaboration (planning and /or delivery) of a joint program or service with another provider, agency, or parent group (Level three contact)	96				
Attendees to Level Three contact	1167				

The Autism Program of Illinois

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FY2010

	Report Period Ending:				Total
	Q1	Q2	Q3	Q4	
Contacts with the purpose of building a “system of care” with another agency, provider, or parent group (Level four Contact)	31				
Attendees to Level Four Contact	382				

*Due to technical difficulties, information in these data points is not wholly reflective of the work done in Q1 of FY10. This data will be corrected and reflected in the Q2 report.

Appendix V: Output Definitions

Children receiving direct services (unique count w/in Qs)

Any services delivered that directly impact the child and /or the child's family. The child is counted within each quarter only once, regardless of how many different direct services he or she may receive within that quarter.

Diagnostic Assessment (unique count w/in Qs):

An in-depth assessment, including social /clinical history, behavioral and cognitive assessments, and assessments specifically designed to capture symptoms of ASD. A multidisciplinary team meeting with the family and referral agency is held following the evaluations to discuss the results of evaluations and recommendations.

Screening / Intake (unique count w/in Qs):

Parents are interviewed regarding their child's health history and the concerns of the referring agency. If appropriate, the child is scheduled for a diagnostic assessment.

Child Treatment (unique count w/in Qs):

Any services provided for the child, where the child was present and the primary intention was treatment of the child. The same treatment hour is not counted for child and family treatment.

Family Treatment (unique count w/in Qs):

Any services provided for the family (parents, extended family, and/or siblings), regardless of whether or not the child was present. While the service may benefit the child, the primary intention for the intervention is at the family level. Examples include individual and group parent training.

Educator / Family Consultation (unique count w/in Qs):

Any services where program staff consulted with school personnel, the family, or other providers (health care providers, etc.) regarding the child, whether in person or communication indirectly. This does not include time in Team Meetings or Feedback Sessions already counted as part of diagnostic assessment.

Resource & Referral--# Parent Contacts / Requests:

Total number of parent contacts, either face-to-face, via telephone or email. As a result of this contact, the agency may have provided to the parents free learning aids, other resources, shared information, provided technical assistance, made a referral, or other service as needed.

Resource & Referral--# Provider Contacts / Requests:

Total number of provider, or other professional, contacts, either face-to-face, via telephone or email. As a result of this contact, the agency may have provided to the provider free learning aids, other resources, shared information, provided technical assistance, made a referral, or other service as needed.

Appendix VI: Budget

The Autism Project (TAP)
 Program Expenditures (Budget to Actual)
 For the 3 Months Ended September 30, 2009

	12 Months Budget July 2008 - June 2009	Grand Total	3 Months Actual July 2008 - Sep 2009
Salaries & Benefits	421,156		107,464
Indirect Support Costs	392,000		98,000
Occupancy Costs	67,852		16,191
Supplies	21,800		319
Administrative Costs	43,997		13,055
Statewide Support & Services	3,953,195		95,601
Total	<u>4,900,000</u>		<u>330,630</u>
Interest Earnings	10,000		8,490

Any program revenues, such as training revenues, offset costs