

Connecting with Autism:
A BLUEPRINT FOR
LIFETIME SUPPORT



Autism™
NEW JERSEY

**Do I have
autism?**



**How can
I help?**



**Will I ever
learn to talk?**



**Who will
take care
of my adult
son when
I die?**



**Why do
they think
I'm weird?**



**What will my
friends think?**

**Where
will I live?**

This process started with a question:

How can we better meet the needs of individuals with autism?

Who better to guide us to answers than those stakeholders most affected by autism? So what did we do? We listened. We really listened. In a significant step forward in our mission to serve the needs of the entire autism community, we conducted hundreds of face-to-face interviews. We heard a great deal. Now, it's our chance to tell you what we learned.

This seminal document identifies the critical goals and activities that will lead to an improved quality of life for one of New Jersey's most vulnerable, and frankly, most underserved populations. Residents of New Jersey who are concerned with autism now have a plan. This document outlines how we can collectively address this urgent public health concern. Make no mistake, autism is prevalent and complex.

Achieving these visionary images of the future will require all New Jersey citizens, public and private organizations, service providers, and state, county, and local governments to align their respective policies, practices and areas of expertise in support of the vision set forth in this report. You can make a difference.

Start today. As you read this report, use it as a catalyst to determine what part of the change, big or small, you can achieve on behalf of individuals with autism.

Please complete the *From Vision to Action* feedback form on page 25 to express your thoughts and actions. We're still listening.

Sincerely,



James A. Paone II, Esq.
President



Linda S. Meyer, Ed.D., MPA, BCBA-D, CPT
Executive Director

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“My older brother has autism. He doesn't play with me and my toys the right way. He can't talk or even tell my mom when his stomach hurts. Sometimes he cries and screams and we don't know why. We can't always go out when I want to. My mom and dad are really worried about him.”

- A 9-year-old's description of his brother with autism

Autism spectrum disorders (ASDs)* affect approximately 1% of New Jersey's citizens. ASDs know no racial, ethnic, or societal boundaries. ASDs are developmental disorders that limit a person's social interaction and communication. Individuals with ASDs also have a restricted range of interests and often have difficulty learning how to perform everyday activities. Autism, Asperger's Disorder and Pervasive Developmental Disorder Not Otherwise Specified (PDDNOS) fall under the umbrella of Pervasive Developmental Disorders and are commonly referred to as “autism spectrum disorders.”

**For the remainder of the document, autism spectrum disorders will be referred to as autism.*

To learn more about what life with autism is like, visit www.autismnj.org.





AUTISM NEW JERSEY

Autism New Jersey is the state's leading source of information, support, advocacy and public policy for parents of individuals with autism and the professionals who support them. Considering that the national prevalence rate of autism spectrum disorders is approximately 1% of the population, Autism New Jersey is needed now more than ever to serve the critical needs of the autism community.

OUR VISION

Autism New Jersey is GROUNDED in science, STRENGTHENED by knowledge, and DEVOTED to creating a society of compassion and inclusion for all those touched by autism.

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BACKGROUND FOR THE LISTENING TOUR

In March 2008, Autism New Jersey's Board of Trustees and its executive staff conducted a strategic planning retreat that included individuals with autism, families, professionals, service providers and other autism experts. The retreat was preceded by an external survey that ascertained the needs and desires of Autism New Jersey's membership. The primary question and the focus of this strategic planning retreat was: **How might we better serve the needs of individuals with autism?**

One of the initiatives that emerged from the strategic planning process was that Autism New Jersey should develop a "blueprint for lifespan services for individuals with autism." It was envisioned that this the blueprint would serve two purposes. First, it would guide the delivery of Autism New Jersey's services. Second, it would serve as a guide to government decision makers and service providers. In December 2008, the Board of Trustees and the Executive Director launched a process to develop such a blueprint for lifespan services.

THE PROCESS FOR DEVELOPING THE BLUEPRINT

Giving Voice to the Autism Community

There were several strategic choices that guided the way the Blueprint was developed:

First, include the entire autism community.

Autism New Jersey believed it essential that the entire autism community in New Jersey be engaged in the process of developing the blueprint. Autism New Jersey therefore looked beyond its membership base to include non-members, individuals, families, professionals and experts. Autism New Jersey also planned a Listening Tour to hear the hopes and dreams of the broader autism community in New Jersey.

Second, listen to everyone and stay positive.

Autism New Jersey wanted the process and its eventual result to be positive, strength-based and visionary. Much has been documented and discussed about the obstacles, and even barriers, individuals and their families confront in accessing much needed autism services and supports. Rather than add to the chorus of much deserved criticism, Autism New Jersey chose instead to listen to not only the needs, but the hopes and dreams of the autism community. The goal was to create a vision of a service delivery and support system that meets their needs when needed, as needed.

Third, stay true to our evidence-based approach by gathering data to determine the content of the Blueprint.

Comprehensive and effective strategic planning begins with the gathering of data. To develop Autism New Jersey's strategic plan, we went to the direct source: the autism community. The ideas outlined in this report were repeatedly expressed by those interviewed.

"My son brings great meaning to my life. He's made me a much better and more loving person. People often only see his needs, but he's given our family so much and has taught us what is possible when we work together."



The Listening Tour Core Planning Team develops questions.

"Sometimes even my family uses that 'I'm so sorry face' with me. I try to remind them that our son is a happy little boy who brings me joy."

In addition to individuals with autism and their families, some of the professions included in the interview process were:

Medical: including pediatricians, family practitioners, specialists, dentists, psychiatrists and nurses

Clinical: including psychologists, behavior analysts, speech and occupational therapists

Educational: including preschool teachers, administrators, early intervention specialists, special education teachers, teaching assistants, in-district speech pathologists, K-12 teachers and advocates

Vocational: including labor and workforce development, such as employment specialists, job coaches, and supportive employment providers

Service providers: including adult day care workers, case managers, family support specialists, social workers, support group facilitators and residential staff

Legal: including attorneys who specialize in supporting individuals with autism and their families

Religious: including pastors, rabbis and representatives of various religious communities

A Positive Interview Process to Discover the Needs of the Autism Community

Autism New Jersey and its planning team collaboratively developed the interview guide. The interview questions were designed to identify those aspects of the service delivery system which succeed in serving the needs of individuals with autism. Autism New Jersey's goal is to magnify, expand and replicate those effective services and supports.

The questions also sought to elicit the people's hopes and dreams for a service and support system that would make the lives of individuals with autism and their families better.

Listening to the Diverse Voices within the Autism Community

Following an interviewer training session, 58 volunteer interviewers conducted 537 face-to-face interviews for approximately 2,000 hours over the course of eight months traveling across the state. The results of the interviews were entered into a secured data management system.

Listening Tour interviews represent a diverse cross section of the autism community, including:

Every county in New Jersey representing people from **rural, urban, and suburban** areas

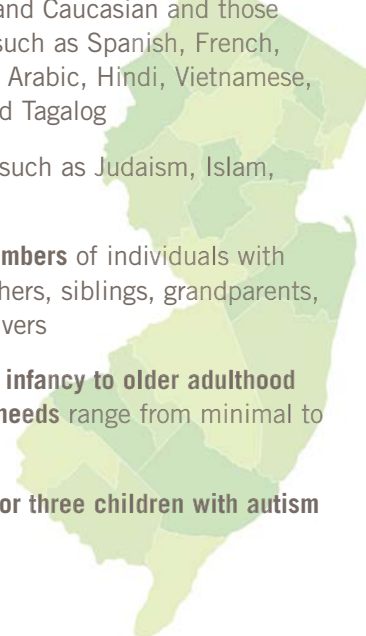
Various ethnic and racial backgrounds, including Asian, African American, Hispanic and Caucasian and those who speak **other languages**, such as Spanish, French, Chinese, Italian, Portuguese, Arabic, Hindi, Vietnamese, Bengali, German, Filipino and Tagalog

Various religious affiliations, such as Judaism, Islam, Buddhism and Christianity

Self-advocates and **family members** of individuals with autism, such as mothers, fathers, siblings, grandparents, guardians, friends and caregivers

Individuals with autism from **infancy to older adulthood** and whose **care and support needs** range from minimal to moderate to significant

Families who have **one, two, or three children with autism**



Engaging the Autism Community in Interpreting and Deriving Meaning from the Interview Data

On June 20, 2009, Autism New Jersey conducted a one-day “Blueprint for Lifespan Services” Summit in Newark, New Jersey. More than 200 people participated in the Summit. Once again, they represented a cross section of the autism community: individuals with autism and their families, educational and medical professionals, service providers, government officials and advocates. The participants spent the day reviewing, analyzing, interpreting and deriving meaning from the interview data, particularly as it related to the hopes and dreams of the autism community.

“I'd like my child to live, go to school, play and eventually work in a community surrounded by people who understand and accept him, where he can just 'be' and feel valued.”



Summit participants analyze Listening Tour interview responses.

From the 537 interviews and the work conducted at the Summit, the overarching theme and five goals emerged:



The remainder of this report expands on each goal.

Image of the Future: This section captures the interviewees’ hopes and dreams.

Key Activities: These suggested activities were generated from the interviewees and the core planning team’s subsequent discussions. They are representative of the ideas and work necessary to achieve the goals.

Success Indicators: These suggestions offer a means of evaluating the key activities and progress toward the goals.

GOAL: LIFETIME ACCESS TO INDIVIDUALIZED SERVICES

Image of the Future

All individuals with autism have timely access to diagnostic evaluations and a lifetime of reliable and effective services that are sensitive to the individual's and family's preferences. These services emphasize social skill development and crisis intervention services that lead to long-term improvement in the individual's abilities and quality of life. Adults with autism have a safe place to live, are gainfully employed with appropriate supports and are engaged in meaningful relationships and daily activities. Family services include crisis services and respite so that they are empowered and supported through the challenges of autism. Researchers have identified the cause(s) of autism, making the prevention of and the cure for autism an option.

"I would love to find skilled, compassionate providers. It would be great to have a website to plug in services and get a big list with no waiting, saying 'Come on down, we're ready for you!'"

"If a family is not educated on what services are available for their child, they are not likely to receive them. Connections can help, but even connections won't guarantee you good services."

INITIATIVE A: SCREENING AND REFERRAL

Key Activity

1. A comprehensive electronic reporting mechanism to determine if providers are utilizing autism screenings and making appropriate referrals is collaboratively developed by healthcare providers, relevant state agencies and autism organizations.

Success Indicator

- A. Families report timely access to screening and referral services for early diagnosis.

INITIATIVE B: SERVICES ACROSS THE LIFESPAN

(Children and adolescents are referred to as children)

Key Activities

1. Early intervention, education and adult services are delivered as immediately and intensively as necessary to maximize developmental progress and fully support functional abilities, meaningful relationships, employability and quality of life.

These services:

- Incorporate individualized goal selection, motivational systems and accountability measures (e.g., all goals are written in observable and measurable terms; direct observational data are collected and analyzed to inform programming decisions).
- Occur in settings that are most conducive to the achievement of the goals. (These settings include homes, schools, communities and residential facilities.)

- Emphasize social skill development, a core deficit in autism.
 - Include crisis assessment and intervention to minimize the adverse effects of severely challenging behavior.
 - Include recreation and leisure skill development to increase the individual's ability to engage in enjoyable independent and group activities.
 - Include vocational readiness skills and training to increase the individual's chances of securing and maintaining employment.
 - Utilize best practices as a standard of care. Best practices include evidence-based and effective interventions as described in peer-reviewed literature (e.g., Applied Behavior Analysis [ABA]). When non-evidence-based interventions are implemented, additional accountability measures are used to determine effectiveness.
 - Are implemented by professionals who are compassionate and knowledgeable about autism and skilled in how to deliver effective intervention. State departments, early intervention providers, educational and adult programs employ a sufficient number of competent and credentialed individuals to direct programming and, when appropriate, publicly disseminate information.
2. A continuum of educational, residential, employment and day service options are available through the development, expansion and improvement of public and private programs. Information on the availability and quality of all such programs is publicly available.
 3. Transportation necessary to access services is available and funded.
 4. All relevant state departments write plans to improve the availability, quality, and accountability of services for individuals with autism. A protocol (e.g., NJ Department of Education's Autism Program Quality Indicators) for conducting quantitative and qualitative audits of all programs is developed, utilized and enforced.
 5. Medical services are accessible and delivered by physicians who are knowledgeable in autism spectrum disorders and represent the full range of specialties (e.g., family, internal and emergency medicine).
 6. A comprehensive research agenda is implemented to identify the cause(s) and advance the treatment of the debilitating behavioral features of autism.
 7. The expertise and experience of individuals on the spectrum is used to inform service delivery and research.
 8. Parent, child, staff and other consumers' responses on satisfaction surveys are used to make systematic program improvements.

Success Indicators

- A. Every child, adolescent and adult is given the fullest opportunity to achieve his/her potential.
- B. Services are accessible and high-quality.
- C. Individuals with autism participate in the type and amount of intervention necessary to lessen and, whenever possible, eliminate the adverse symptoms of autism.
- D. Intervention maximizes individuals' functional abilities through state-of-the-art methods and a community of supports.
- E. All professionals utilize evidence-based interventions and regularly evaluate the effectiveness of these interventions.

"We need more and QUALITY residential placement options in our state. Why should residential housing only become available for my son when I get ill or die?"

"If my son can't work after he turns 21, I will have to provide supervision for him. That means I can't work. What are we going to do for income? What will our life be like if I can't work?"

INITIATIVE C: EXPANDED ADULT SERVICES AND SUPPORTS

Key Activities

1. The availability of and access to employment services are expanded.
 - An educational campaign designed to promote the talents and resources available in the pool of employees with autism is developed and marketed to employers, Workforce Investment Boards and Business Leadership Networks.
 - The autism community promotes the use of video resumes, customized employment, and job sharing as methods for creating employment opportunities.
 - The autism and business communities explore the potential use of tax credits and other incentives to businesses.
 - The autism community considers a certification program and mandatory continuing education for job coaches and developers.
 - Strategies and resources to increase opportunities for individuals with autism to attend college are developed and promoted.
2. The availability of and access to day services are expanded.
 - High-quality day programs offering activities and experiences meaningful to the individual with autism are developed to meet the needs of adults who are not employed on a full-time and permanent basis.
3. The availability of and access to residential services are expanded.
 - There is a continuum of residential options representing and respecting the culture and values of the individual and his/her family.
 - New Jersey institutions of higher education establish a college-level curriculum for residential "Life Coach" certification for direct care professionals. Measurable standards include areas such as knowledge of autism, safety skills, assessment and interventions for challenging behavior and community integration.

4. Parent, adult, staff and other consumers' responses on satisfaction surveys are used to make systematic program improvements.

Success Indicators

- A. All adults with autism have access to high-quality residential, employment and day service options and participate in the amount of intervention necessary to maximize their functional abilities, meaningful relationships and employability.
- B. Vocational and daily activities match interests and abilities.
- C. Adults with autism make a substantial contribution to society.
- D. All personnel who work with adults with autism utilize evidence-based interventions and regularly evaluate the effectiveness of these interventions.

"The best part was having him start a vocational program that he loves where he can earn a paycheck. I think he feels more like an adult, even though he can't express it in those words."



For more information on Adult Services, see Autism New Jersey's
Meeting the Needs of Adults with Autism: A Blueprint for the Future.

**Call toll-free 800.4.AUTISM
or visit www.autismnj.org.**

"When my son was aggressive with us, I used to take him to the ER. There was nowhere else to go. But now, I don't even take him there. They just don't know how to help us in the long run."

INITIATIVE D: CRISIS INTERVENTION

Key Activities

1. High-quality, local, inpatient and outpatient behavioral crisis services are developed and available on a 24/7 basis for individuals with autism, including a call center, home visits, designated "urgent behavior/medical care facilities" and hospital-based behavioral stabilization units.
2. Family members, individuals with autism, staff and other consumers' responses on satisfaction surveys are used to make systematic program improvements.

Success Indicators

- A. Families have access to professionals with behavioral and medical expertise who design and oversee behavioral intervention plans that address the families' needs before, during and after a crisis.
- B. Families receive support to implement behavior intervention plans at home and in the community. When maintaining the individual's and family's safety at home is not possible, a range of high-quality medical, behavioral, clinical and residential services are easily accessed.

INITIATIVE E: RESPITE

Key Activities

1. Respite services are developed and expanded in settings and at times that meet families' needs (e.g., home-based, community-based and before and after school).
2. Creative partnerships are fostered to expand the pool of respite providers, while still maintaining quality through background checks and ongoing training.
3. Creative funding mechanisms such as flexible spending accounts and cash stipends to families are developed in order to finance local and family-friendly respite arrangements.
4. Parent, child, staff and other consumers' responses on satisfaction surveys are used to make systematic program improvements.

"My child means everything to me but I don't seem to be able to give her what she needs and take care of the rest of our lives, too. It takes so much effort and time and is completely overwhelming. It is exhausting to live in our house."

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Success Indicator

- A. Respite is readily available when families need it and provided by people who are trustworthy, knowledgeable in autism and skilled in implementing effective support strategies.

GOAL: COLLABORATION AND PARTNERSHIPS FOR LIFETIME PLANNING

Image of the Future

Collaborative partnerships support lifetime planning for individuals with autism and their families. Core components of lifetime planning include family input and respect for the dignity and value of the person. A coordinated, collaborative approach to lifetime planning includes interdisciplinary expertise, honesty and the sharing of accurate and reliable information. All components of lifetime planning are grounded in evidence-based practices.

INITIATIVE A: LIFETIME PLANNING MODEL

Key Activities

1. The autism community and relevant state agencies design a lifetime planning system for individuals with autism.
2. State departments enhance intradepartmental and interdepartmental communication, coordination of information sharing, and the elimination of conflicting policies and procedures.
3. State departments communicate streamlined information to families, service providers and self-advocates.

Success Indicators

- A. Lifetime planning for individuals with autism and their families is the norm rather than the exception and features continuous collaboration among service providers (e.g., medical, psychological, behavioral, educational, vocational, residential).
- B. The lifetime team-based planning model incorporates regular communication regarding evidence-based practices, available resources and creative solutions to meet the individual's needs.
- C. Parents and self-advocates report that case managers take initiative and are responsive, knowledgeable and helpful.
- D. Parents and self-advocates report that the members of the treatment team are communicating, collaborating and working in the best interest of the individual.

"I am thinking about the essential services and support my child will need throughout his lifetime... everything that a mother does for a child... who will do that when I am no longer near?"

"The state should provide families with a 'Family Partner' who, from diagnosis on, is there every step of the way to help families navigate the system. Wouldn't it be great to have someone like this in your corner?"

GOAL: SKILLED AND COMPASSIONATE PEOPLE

Image of the Future

As a result of the rapid advance in effective treatment for autism, a multitude of training programs are available on statewide and local levels which are monitored and enforced. Professionals, including all school personnel, home- and community-based providers, medical staff and first responders are knowledgeable, effective and compassionate in the delivery of services. Professionals receive ongoing, evidence-based training. All trainings have an emphasis on relationship-building, compassion and sensitivity toward individuals with autism and their families. Parents and siblings are also provided with training to best support their loved one with autism and their family's quality of life.

"I wish that the people in my daughter's life—her teachers, doctors and other professionals—not only know what they are doing but are sensitive and compassionate. We can't wait for this; we need to make it happen now."

INITIATIVE A: TRAINING PROGRAMS FOR PROFESSIONALS

Key Activities

1. The autism community, service providers and relevant state departments collaboratively identify and/or develop comprehensive training programs for professionals.
2. Training programs on professionalism, sensitivity, and ethics are available for all professionals (e.g., early intervention, educational, vocational, residential) to enhance their awareness of individuals' rights and families' needs.
3. Training programs and ongoing consultation on evidence-based practices are available for all professionals (e.g., early intervention, educational, vocational, residential) to enhance their skills to teach and positively manage behavioral challenges.
4. State agencies mandate rigorous training standards. They employ appropriately credentialed and skilled professionals and utilize accountability measures to ensure that state-of-the-art practices are implemented.
5. Private service providers have access to standardized training models and adapt them as appropriate to maintain state-of-the-art service delivery.
6. Day care and preschool providers participate in training on identifying the symptoms of autism and appropriate referral resources as a mandatory component of facility licensing.

7. General education, special education and child study team personnel participate in mandatory trainings to recognize the symptoms of autism. The symptoms of “high-functioning” autism are given particular attention as these typically become more noticeable in the elementary and secondary grades.
8. Professionals are provided with information to educate peers on the strengths and needs of individuals with autism and how to respectfully promote meaningful and helpful interaction with them.

Success Indicators

- A. Parents report that they and their sons and daughters are treated with dignity and respect.
- B. Self-advocates report that they are treated with dignity and respect.
- C. Professionals feel confident and are effective when teaching and managing challenging behavior.
- D. Professionals address crisis situations in ethical, effective and clinically-sound ways.
- E. Professionals are supported with ongoing professional development and expert consultation as needed.
- F. Programs and service providers meet mandatory minimum training standards prior to opening for service delivery.
- G. State agencies report compliance with training standards.
- H. Professionals feel confident in their ability to recognize early symptoms of autism, discuss their general concerns with families and make appropriate referrals.
- I. Peers report an understanding of autism and have meaningful interactions with individuals with autism (e.g., classmates and neighbors).

“ Well-trained educational staff are essential to a child’s success.”

“ Continued professional development has been the key to success in my classroom. The more I know, the more I can help my students. A great example is how I learned practical strategies from so many experts and networked with other professionals and parents at Autism New Jersey’s annual conference.”

"Professionals should not only be competent but also compassionate."

INITIATIVE B: TRAINING PROGRAMS FOR MEDICAL PROFESSIONALS

Key Activities

1. Health care providers participate in training on autism, evidence-based practices, treatment decision making and management and how to best meet the family's needs.
2. Health care providers participate in training to enhance their ability to recognize and rule out possible medical causes of challenging behaviors exhibited by individuals with autism.
3. Emergency medical technicians and hospital personnel are informed about available facilities with expertise in autism and behavioral crises.

Success Indicators

- A. Health care providers are knowledgeable about autism, evidence-based practices and how to ethically and effectively handle behavioral crises.
- B. Families report competent and compassionate emergency and routine medical care.

"Now that I have been trained to do some of the ABA techniques at home, he's learning more every day because I know how to teach him. I can't tell you how life changing this is for our family."

INITIATIVE C: TRAINING PROGRAMS FOR PARENTS AND SIBLINGS

Key Activities:

1. The autism community, service providers, and relevant state departments collaboratively identify and/or develop comprehensive training programs to teach parents, siblings and extended family. These trainings provide individualized and practical strategies that the family can implement in their everyday lives.
2. Evidence-based training programs for families are available to provide them with skills to teach and positively manage behavioral challenges.
3. A comprehensive training program on the prevention and handling of crisis situations is developed for families. The primary objective of this training is to enable families to provide home-based crisis prevention and intervention that maintains the individual and family's health and safety.

4. Parents and siblings are provided with opportunities that address their needs for information, coping strategies and social supports, and they have access to professional services when necessary.
5. Parents of all children are provided with timely information about the symptoms of autism to increase their awareness and likelihood of seeking developmental evaluations.

Success Indicators

- A. Parents feel confident and are effective when teaching skills and managing challenging behavior.
- B. Parents and siblings report having access to opportunities which address their needs.
- C. Parents recognize the symptoms of autism and act upon their concerns.

INITIATIVE D: EVALUATION OF TRAINING PROGRAMS

Key Activities

1. The State of New Jersey monitors the state departments and all programs receiving state money to ensure compliance with training practices.
2. Private agencies solicit external evaluation.

Success Indicator

- A. Public and private agencies respond to feedback provided by external reviewers.

"My other kids have never known a life without autism. I can't give them the same amount of attention. Siblings need support, too."

"Professionals should practice the virtue of compassion because parents did not choose the path they are on. Parents should practice the virtue of gratitude because the professionals DID choose this path."

GOAL: CREDIBLE AND RELIABLE INFORMATION

Image of the Future

Credible and reliable information about autism (e.g., treatment options, providers, service systems) exists in the form of a comprehensive navigation system. Information seamlessly covers all ages and stages across the lifespan (including times of transition and crisis) and describes entitlements, services and supports. Information is dynamic in that it is updated as services and information change.

This navigation system is available to guide anyone affected by autism. It is instantly and easily accessible and is designed to systematically direct individuals, families and professionals through the service and support systems. Individuals can independently access information via the navigation system or with the help of an autism expert.

"I have to go to so many different workshops every year to put together my own timeline of what to do when. It's hard to keep track of everything. If only there was someone or something to help me sort through all this information."

"We need one-stop shopping. One place or person who has all the information we need for our son at each age level."

INITIATIVE A: NAVIGATION SYSTEM

Key Activities

1. Content for the navigation system is developed.
Information is solicited from relevant state agencies, such as the Division of Developmental Disabilities, the Division of Disability Services, the Early Intervention Program, the Department of Education, the Division of Vocational Rehabilitative Services, and community providers.
2. An easy-to-navigate web infrastructure is created.
3. A quality rating system is initiated to clearly define the strengths of service providers.
4. A consumer review feature is developed that preserves evidence-based standards while encouraging users to share information and referrals.
5. A call center is developed to provide expert navigation assistance.
6. Family members and professionals' responses on satisfaction surveys are used to make systematic program improvements.

Success Indicator

- A. Everyone has access to credible, reliable and current information about quality programs and services, when needed, as needed.

INITIATIVE B: ADVOCACY SUPPORT

Key Activities

1. Individuals' rights and entitlements are easily accessible or provided upon diagnosis and as needed thereafter for families and professionals.
2. Competent and collegial advocates offer in-person support for parents during interactions with professionals, especially during individualized planning meetings.
3. Parents, individuals with autism, staff and other consumers' responses on satisfaction surveys are used to make systematic program improvements.

Success Indicator

- A. Families easily navigate service systems independently or with the assistance of advocates and assertively address their children's needs, entitlements and procedural safeguards.

"We have to work so hard to get our kids the services they need. We shouldn't have to fight for every hour of therapy when they have a neurological disorder."

"My hope is that the ability to access necessary information, training, and support within my community for my son will one day be as easy as dialing 2-1-1 and not having to get ten different people to offer me what they think I need."

GOAL: COMMUNITY-BASED INCLUSION

Image of the Future

Individuals with autism are valued members of a vital community that thrives on mutual support. Community-based inclusion and integration is achieved through public awareness within all facets of community life, including education, employment, recreation, leisure and faith congregations. Training, choice and support structures result in community understanding, acceptance, and inclusion throughout the individual's life.

"I wish for more informed, educated, and sensitive people within our greater community who recognize and understand the supports needed by persons with autism and offer to assist in making sure they are fully included in the fabric of our society."

"Work is a defining part of our lives; we need to build awareness within the business community."

INITIATIVE A: LOCAL AUTISM AWARENESS FORUMS

Key Activities

1. Local community leaders are engaged in public autism awareness forums that provide the general public with information to increase sensitivity and awareness. Elected and appointed municipal officials; faith-based, volunteer, advocacy, and other community-based organizations; and educational and health institutions are included in these awareness efforts.

Success Indicators

- A. Individuals with autism are considered in all aspects of community planning.
- B. Opportunities for participation are increased in community events, education, volunteerism, employment and housing. Individuals with autism are invited to participate in local events and are supported with appropriate accommodations or modifications to programs.

INITIATIVE B: LOCAL AND REGIONAL BUSINESS ADVISORY COUNCILS

Key Activities

1. Local business networks are encouraged to include an individual with autism, a family member of an individual with autism, or an autism service provider on business advisory councils (e.g., Chamber of Commerce, Rotary or local industry associations).
2. Business advisory councils are educated on the benefits that individuals with autism can bring to their community, including employment, buying power, and inclusive services.

3. Descriptions of successful community-wide inclusion opportunities and programs are disseminated. This resource material can educate all New Jersey businesses and communities on how to better serve individuals with autism and their families.

Success Indicators

- A. Individuals with autism or their families are included in local or regional business advisory councils and are able to make positive contributions to the development of business services that offer inclusion opportunities. These services include employment, volunteer and recreational opportunities.
- B. Individuals with autism and their families report greater acceptance and involvement in their local communities.

INITIATIVE C: EXTRACURRICULAR, RECREATION, AND MEMBERSHIP ORGANIZATIONS

Key Activities

1. Information on how to support the meaningful participation of individuals with autism is disseminated to extracurricular, local recreation and membership organization committees.
2. Communities are educated and information is disseminated about the value that inclusive extracurricular, local recreation and membership organizations provide to the entire community.
3. Extracurricular, local recreation, and membership organizations provide structured and unstructured opportunities to enhance the social skills of individuals with autism when interacting with typical peers.

Success Indicator

- A. Individuals with autism are able to successfully participate in a full range of extracurricular, local recreation and membership organization activities.

"The community is a big piece of an individual's success."

"Everyone else has a choice in how they want to spend their lives—why not people with autism?"

INITIATIVE D: FAITH-BASED COMMUNITIES

Key Activity

1. Resource material is disseminated and sensitivity training is provided to faith-based communities, with an emphasis on strategies to integrate individuals with autism in all aspects of their faith communities.

Success Indicator

- A. Individuals with autism participate and are supported in inclusive, meaningful faith-based communities of their choice.

“It is good to know that Autism New Jersey is listening to our concerns and there can be hope.”

To be clear, to achieve the objectives outlined in this report will take vision, commitment and ambition. In the end, our goal for the future is quite simple: individuals with autism should enjoy a better quality of life tomorrow than they do today. To do this, we must appreciate the enormous potential each individual with autism possesses.

We recognize that great progress has already been made and that New Jersey proudly has world-renowned services for individuals with autism. The trailblazing efforts of families and professionals decades ago have set the stage for what is to follow. However, no one will dispute that the needs of the autism community are significant and to address them will take significant action on the part of all stakeholders. The responsibility lies with all of us and our public officials. We must work collectively and form effective public and private partnerships that address the needs as set forth in this report. Individuals with autism deserve to choose from a continuum of quality services. They deserve our best effort to allow them to achieve their full potential.

The following broad priorities can help focus our efforts in implementing this ambitious Blueprint. If we are all successful, the autism community in New Jersey will enjoy:

1. Easy navigation of service delivery systems
2. Respectful and compassionate service providers
3. Effective, lifelong teaching that maximizes potential
4. Support before, during and after behavioral crises
5. Respite when needed, as needed
6. Community acceptance

**We have listened.
Now is the time for action.**

CONNECTING WITH AUTISM: A BLUEPRINT FOR LIFETIME SUPPORT FROM VISION TO ACTION

Share with us how YOU are connecting to autism. We want to know what the Blueprint has inspired you to do and how you are taking steps to achieve its vision. To summarize the successes across the state, Autism New Jersey will develop a Statewide Autism Report Card to evaluate the progress made toward the initiatives in this Blueprint. Our immediate goals are to enhance and expand service delivery, connect you with others working on similar goals and publicly celebrate your achievements. Our ultimate goal is a state autism plan to coordinate and maximize resources that lead to meaningful improvements in the lives of individuals with autism.

Highlight your success! Be a part of the Autism New Jersey's Statewide Autism Report Card!
Visit www.autismnj.org

I am addressing the following goal(s):

- ☐ Lifetime Access to Individualized Services
- ☐ Collaboration and Partnerships for Lifetime Planning
- ☐ Skilled and Compassionate People
- ☐ Credible and Reliable Information
- ☐ Community-Based Inclusion

Specifically, my initiative(s) is/are:

Name: _____

Agency/Company/School: _____

Telephone: _____

E-mail: _____

Autism New Jersey may contact you to discuss your work.

Areas of need not identified in this document:

If you need additional space, please attach a separate sheet and fax, e-mail or mail to:

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We also wish to thank the following businesses and their representatives for allowing Autism New Jersey to use their space free of charge for our many planning meetings: Jean Wiegner and Eric Risberg of Merrill Lynch, Kyle Barich and Dave Rader of CDM Princeton, David Filippelli, Esq., Gibbons, PC and Claudia Sommerer of JFK Medical Center. A special thank you is also extended to Whole Foods for providing refreshments and allowing Listening Tour interviewers to meet with interviewees in their cafes throughout New Jersey.

A heartfelt thank you is extended to the North Ward Cultural Center in Newark, New Jersey for allowing Autism New Jersey to conduct its June 2009 Listening Tour Summit on its property and in its building. The hospitality of the Adubato family in accommodating nearly 200 participants was overwhelming and very much appreciated.

We thank James M. Davy of James M. Davy Associates and Tony Silbert of Innovation Partners International for expertly designing the positive, strength-based framework for our Listening Tour process and for facilitating our many meetings.

Again, we express our sincere gratitude to those mentioned above and countless others who made this initiative successful.

Most of all, we are truly grateful to those who were interviewed. You gave us your time, your expertise, and your vision. We hope you feel validated and represented in this document. Your stories were all memorable, sometimes uplifting, sometimes devastating, and always inspirational. We share your vision for a better tomorrow. Autism New Jersey is committed to making these images of the future a reality on behalf of all individuals with autism.



Get connected...
become a member of Autism New Jersey

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