



# Long Island Sounds

2008 – 2009

## Findings and Recommendations for People With Developmental Disabilities

Submitted by

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**UJA-Federation of New York/ F.E.G.S  
Developmental Disabilities Listening Groups**

**Summary of Findings**

**LONG ISLAND SOUNDS BACKGROUND**

The Long Island Program Services Cabinet (LIPSC) of UJA-Federation of New York has established *Long Island Sounds* as part of our comprehensive planning strategy to gain a clearer understanding of the needs of the Jewish community. *Long Island Sounds* is a series of listening groups that complement our other strategies to gather information, which include surveys, analysis of census data, review of literature, and speaking with experts in the field.

Qualitative data derived from listening groups is extremely valuable when vivid and rich descriptions are needed. Listening groups are in-depth, qualitative interviews with a small number of carefully selected people brought together to discuss a host of topics. In contrast to the one way flow of information of individual interviews, listening groups allow participants with similar challenges to interact and provides dynamic and richly descriptive feedback about what they think through the give and take of group discussion.

The first round of *LI Sounds* focused on issues relating to the service needs of older adults. Through the process, we identified community stakeholders connected to aging and sought their perspective on the major issues confronting Jewish older adults of Long Island. The report was circulated to lay leadership of the Caring Commission and the professional staff of all four Commissions at UJA-Federation. It informed the Caring Commission's work with regard to the decision to develop and release an RFP for new Partners in Caring programs for isolated adults, as well as developing the content. Additionally, the Caring Commission used the report to help foster collaborations among select Long Island network agencies serving the aging.

Given the success of the *LI Sounds: Aging* report issued in February 2005, LIPSC began the *LI Sounds* series. The second in the series focuses on women's health issues. Modeled after *LI Sounds: Aging*, the *LI Sounds: Women's Health* gathered community stakeholders to identify the most pressing health issues for women and the challenges they face with the health care system. The report was used to assist the Caring Commission to identify, frame, and prioritize the most important issues regarding women's health.

The third in the *LI Sounds* series engaged rabbis. With over 170 synagogues on Long Island, rabbis are critical to understanding and serving the Jewish community. Through a series of five listening groups, *LI Sounds: Rabbis* brought together rabbis from across Long Island to help develop a fuller understanding of the entire Jewish community. This report provided rabbis and UJA-Federation the information needed to collaborate and better serve the needs of the Jewish community.

UJA-Federation of New York, in partnership with F-E-G-S, has established *Long Island Sounds: Developmental Disabilities* to assess the needs of parents and caregivers of individuals with developmental disabilities, increase awareness of existing programs, and improve programs and services where needed. Parents and caregivers of people with disabilities struggle throughout their lives to provide the services and care they need. From detection and early intervention to entering the school system to transitioning into the work force, higher education, or a group home, children with special needs need access to systems offered by their school system, medical service provider, and community. As the life expectancy of individuals with developmental disabilities increases, needs of the community are changing. While the system of programs and support is growing, there are still those who fall through the cracks and parents and caregivers who do not know where to access these services.

*Long Island Sounds: Developmental Disabilities* hosted a series of six listening groups consisting of two parent groups, agency service providers, educators, medical professionals, and government employees. These groups focused on the challenges of transitioning individuals with developmental disabilities throughout their lifetime. Through these listening groups, we gathered information in answer to the following questions:

1. What are the challenges facing parents of children with disabilities:
  - In their early years?
  - Upon identification?
  - Within the school system and when school is not in session?
  - Upon transition out of the school system?
2. Where are the gaps in programs and services from birth to adulthood?
3. How is information and knowledge shared between parents, educators, agencies, and medical professionals?
4. Where do parents go to find information and gain access to existing services?
5. What happens when the parent is no longer able to care for their child?
6. What is the school's role in:
  - Developing a working relationship with parents?
  - Working on transition planning with students and parents?
7. What resources are available to schools and students in preparation for transition?
8. What are the school's main concerns about the transition process?
9. How do students graduating from high school become known to government agencies that provide services to individuals with special needs?

## Themes and Findings

The following themes and issues emerged from the listening groups.

### ➤ **Early Identification**

The early years of a child's life are very important. This is the time that a child experiences rapid growth and development. For families who face the challenge of a child who is not developing typically, early identification of developmental delays is essential in order to access needed and appropriate services as early as possible. In New York State, the Department of Health is the lead agency responsible for the Early Intervention Program. The responsibility is then assumed by each county. The county is charged with "finding eligible children". Children can be referred for early intervention by their parents or by a health care provider, with the parents' consent. However, pediatricians lack the necessary training to correctly diagnose developmental disabilities. Dr. Joel Bregman (North Shore-Long Island Jewish Health System) states "This dearth of training leads to inaccurate diagnosis and missed opportunities for the early and most successful intervention."

In the same vein, most day care and preschool staff are ill-equipped to identify presenting symptoms of young children. The turnover of staff in early childhood is great. Often you find the most inexperienced and/or least educated teachers in the early childhood arena. Therefore, parents who are inexperienced in disabilities feel like "pioneers" exploring uncharted waters. If they suspect their child has a disability, many are unaware of how to get or where to go for an assessment.

Parents are also unaware of how to answer the Vineland Adaptive Behavior Scales (VABS) and often describe their children as higher functioning than they really are. (The VABS provides data for diagnosis or evaluation of a wide range of disabilities, including mental retardation, developmental delays, functional skills impairment, and speech and language impairment. It is also an accurate resource for predicting autism and Asperger Syndrome.) If hopeful parents describe their children as too independent, it limits access to accurate identification and services. Day care and early childhood teachers also need to be trained on the Vineland Adaptive Behavior Scales in order to help accurately identify young children with developmental delays.

### ➤ **Childhood and the Educational System**

Educators feel that parental needs are endless. The two core needs identified are information and respite. The special education process, particularly legal rights and entitlements, is often confusing and adversarial. Dennis Feuerstein (parent and also professional in the field) said "You must fight the school district to get what you need." Parents find the Committee on Special Education (CSE) intimidating. The meeting is conducted with educational jargon, a language they don't speak. The onus is on parents to learn the jargon and the range of services and resources to which their child is entitled; they must quickly become strong and educated advocates for their children.

Furthermore, schools need to be pushed into providing services required by law.

Although information and respite were noted as primary problems of parents with school age children, other issues were discussed, particularly gaps in insurance coverage/benefits and entitlements and the difficulty of finding quality special educators. Parents whose children do not meet the requirements to qualify with the Office of Mental Retardation and Developmental Disabilities (OMRDD) and for Medicaid entitlements often have trouble finding services for their children covered by their insurance company.

Regarding educator qualifications, certification in special education requires extra coursework beyond that of general education teacher certification. This, coupled with relatively low teacher salaries, makes it difficult to find and retain qualified teachers. There is also a lack of continuing education opportunities once educators have been working in school.

### ➤ **Respite**

Respite, temporary relief for a caregiver taking care of an individual with developmental disabilities, is critical to help preserve the family unit. Because there is no centralized place for parents to get information, they spend enormous amounts of time researching. Sherry Rubin (parent) said “You have to do it all yourself.” This can be overwhelming and can take away from time needed for spouses and siblings. Educators report that respite care for families of children with developmental disabilities is crucial. A government survey found that home respite care was the number one need of families with children with developmental disabilities, followed by out of home respite. Despite the support for family stability and well-being respite can provide, it is hard to access. Respite can cost more than a family can afford and is usually not covered by insurance. When respite is available the caregivers are often not adequately trained.

### ➤ **Transition Planning**

Transition planning, an outcome-oriented process which guides the movement of a student from school to post school activities, is supposed to be part of the Individual Education Plan (IEP) from age 14. Transition planning is based on a student’s needs, preferences and interests and includes instruction, related services, community experience, development of employment and post school adult living objectives, as well as appropriate daily living skills and functional vocational education. Although Individuals with Disabilities Education Act 9 (IDEA) mandates the school to be the director of the transition plan, it is often a service provider who begins the discussion about transitioning the year before graduation. Many times, this is too late to get a child into a beneficial program. (School districts do include the transition plan in the IEP. However, the IEP is not a user or reader friendly document and most parents do not understand exactly what the transition plan is.)

Many parents of both listening groups were surprised to find that transition planning as part of the IEP was their right. There is no centralized information or available resources for transitioning. Parents are clamoring for training and support during transition, and educators concur. Dr. Lou Gallagher (Suffolk County Division of Community Mental Hygiene) said parents must become strong advocates for their children or the transition planning will be inadequate.

There is also a need for life skills training. Stacy Ezor (parent) said “Schools have to understand that there is more to school than academics. They need to prepare kids for life.” State government has made it a priority to have adults with developmental disabilities remain at home. However, vocational training programs are limited or nonexistent. Planning is further complicated by the lack of communication from the variety of caregivers – medical professionals, educators, parents, and agency employees. Parents must collect information and input from a variety of sources and synthesize a plan.

Even the age of 14 is often too old to plan for all of the transitions needed. Dr. Michael Gruttadauria (medical professional) said “There is an explosion of children in need of adult services who will soon be aging out of children’s services. There are not nearly enough beds in group homes.” For this reason, parents must put a child on a waiting list for a group home almost from birth in order to secure a spot. They are often unaware or emotionally unable to plan for transitioning at this early stage.

### ➤ **Adulthood**

Parents fear what will happen to their children when they are no longer able to care for them. They often do not plan adequately or far enough in advance. Some parents thought that the abled sibling would take over care, while others would want anyone but that sibling to care for the sibling with developmental disabilities. A few parents have realized that there will be a cost to providing care after they are unable to and have set up trusts to meet those financial needs. Most have not begun to think about what will happen because they are dealing with day to day crises and issues. Educators recognized that parents need help in planning to care for the adult child.

Adults with developmental disabilities are aging and living longer. Additionally, supportive services are needed for higher functioning young adults. Integrated health care for adults living at home is critical to longevity.

## **Recommendations of Directions to Explore**

Throughout the listening groups, participants were educated about the plethora of services for people with developmental disabilities provided by UJA-Federation agencies. Participants were appreciative of the significant programs put forth to service families and address their needs. The impact of the services and the increasing needs are so great that the participants ask for further expansion of the following areas of services currently being addressed by UJA-Federation's Caring Commission. Additionally, they raised new areas for your consideration.

### Areas of Further Expansion:

#### 1. Family Services:

- a. Advocacy training for families needs to be offered locally, utilizing both parents and professionals to help walk new families through the CSE process.
- b. Increase respite services.
- c. Transition training and support for parents.
- d. Social skills groups.
- e. Support for siblings.
- f. Parent education and training.
- g. Fostering of inclusion in communal agencies and institutions which will require support from leadership, as well as providing sensitivity training for members.

#### 2. Personnel/Training:

- a. Professionals who work with families should be trained to value family needs and help families maintain control over supports and services.
- b. Work to attract more qualified personnel at day care centers as well as residential centers for adults with disabilities.
- c. Professional training for agency staff and educators needs to be expanded. For example, early childhood staff and parents should be trained in the Vineland Adaptive Behavior Scales.
- d. Community services staff development for school personnel.

## New Opportunities:

1. To deal with the increase in children who need adult services, group homes should be expanded or more should be created. Explore the development of housing options, in addition to group residences, particularly for those in need of some supports, who do not qualify under the Office of Mental Retardation and Developmental Disabilities (OMRDD).
2. Create a system of coordination of services:
  - a. Care managers – A care manager could be someone to call at a human service agency who would work with the family over the course of the services.
  - b. Create a centralized website where parents can go to find support and services. It should include a listing of medical professionals who are qualified to assess and deal with the unique issues of special needs children, a “parents helping parents” section to provide a place for discussion and support, an Ask the Expert section, where parents can find expert advice, and a comprehensive listing of services available to them.
  - c. Structure a continuum of services by district so each neighborhood has one continuum to seek assistance.
  - d. Advocate to government to coordinate the care and communication among its various agencies that service people with developmental disabilities.

## **Developmental Disabilities Service Providers**

On November 21, 2006, 17 UJA-Federation network agency service providers met to discuss the challenges individuals with developmental disabilities face during times of transition over the course of their lives. The discussion included the services they currently offer and the gaps in provided services.

The group unanimously agreed that there is a tremendous need in the community for information and assistance with transition planning for parents and older teens exiting the school system. Various agencies, such as The Sid Jacobson JCC, Jewish Child Care Association, and Kulanu (a local private school) offer parent support groups, self advocacy programs, and advocacy training for families. However, there are not enough of these kinds of programs to service the population. Elise Hahn-Felix (JCCA) said that parents are in need of organized information about transition planning and programs. Anita Altman (UJA-Federation of New York) stated that a regional approach to school districts on transition planning and assisting parents with the process would make services more accessible.

The JCCA Compass Program finds that the greatest need for people exiting the school system is for training in independent living skills. F·E·G·S works with the Compass Program to provide informational workshops to college students and to recruit mentors to provide job shadowing opportunities. Jeri Mendelsohn (Samuel Field YM & YWHA) stated that higher functioning young adults who require assistance to live independently could tremendously benefit from this kind of service but are often left out because of the rigorous OMRDD qualifications. Jeri suggested training staff in understanding and administering the Vineland Adaptive Behavior Scales would help to increase the numbers of children qualifying to meet the OMRDD criteria. Cara Green (Sid Jacobson JCC) stated "Parents don't know what they will do when their kids turn 21."

Agency representatives also voiced a great deal of concern about the challenges around staff recruitment and retention issues. Low pay and limited staff training have an impact on the quality of programs. Robert Greenberger, F·E·G·S Associate Vice President, said, "Incentive programs to attract and retain staff are important." Since turnover is rapid, training is always needed for beginners and ongoing training is needed for all, especially in the area of behavior. As program participants get older, their behavioral needs change.

The following list summarizes the key needs expressed by agency representatives:

1. A regionally organized listing of transition services.
2. Increase in vocational programs, parent support groups, self advocacy programs, and advocacy training for families.
3. Independent life skills programming for higher functioning young adults.
4. Incentive programs to attract and retain staff.
5. Staff training, including administering the Vineland Adaptive Behavior Scales.
6. Recruitment of job mentors.

## **Developmental Disabilities Medical Professionals**

On January 25, 2007, ten medical professionals, doctors and administrators met to discuss the needs of the population with developmental disabilities. They focused on health care, diagnoses and intervention, and training of medical personnel.

Dr. Richard Kessler, D.O. (Medical Director, Adults and Children with Learning and Developmental Disabilities, Inc.) reported that studies have shown that de-institutionalization has led to higher mortality rates for persons with developmental disabilities. It is suspected that this is caused by a lack of integrated medical care. It is vitally important to create critical service teams to ensure standards of care are being met; i.e., routine screenings such as pap smears, PSA tests and mammograms. There was a consensus that the population needs integrated care, and it has become less possible to do this. Karen Breitingner, LCSW (Schneider Children's Hospital) and Richard Kessler, D.O. (ACLD) said "Many people with developmental delays do not qualify for OMRDD and Medicaid entitlements and are unable to receive needed health care."

The training that medical students and other professionals receive in diagnosing and intervening in the area of special needs is inadequate. Dr. Joel Bregman (The Linder Center of The North Shore-Long Island Jewish Health System) states that a lack of training leads to inaccurate diagnoses and missed opportunities for early intervention. He also believes that even special education teachers are not adequately trained. Bernice Polinsky (Asperger's Syndrome and High Functioning Autism Association) said that an additional problem stems from the fact that many people with special needs cannot speak for themselves. Therefore, the doctors are not more proactive. Parents also need training in how to advocate and discuss their children's issues so they do not over-rate their children on the Vineland Scales and disqualify them from receiving services.

Dr. Michael Gruttadauria said there will be an explosion of children in need of adult services and there are not enough spaces in group homes. Furthermore, all providers agreed that parents are often ill-equipped to plan for life stage transition because they are dealing with the imminent day to day crises, and it is difficult to plan for their children's futures. They need to know that their children will be going to a safe place where a full spectrum of care will be provided.

Summary of needs expressed by medical professionals:

1. Integrated health care for those adults who remain with their families.
2. Tremendous need to accommodate children aging out of youth programs in group homes for young adults.
3. Training for medical personnel on diagnosis and intervention.
4. Training for parents in advocacy and strategically and accurately evaluating their child with Vineland evaluators.

## Developmental Disabilities: Parents

On March 7, 2007 and May 17, 2007, parent listening groups were held. On March 7<sup>th</sup> three facilitators met with 14 parents of children with developmental disabilities including those with diagnoses of Autism Spectrum Disorders (ASD), mental retardation, Asperger's Syndrome, Cerebral Palsy, Sturge Weber Syndrome, and learning disabilities. On May 17<sup>th</sup> two facilitators met with eight parents of children with developmental disabilities which included diagnoses of ASD, Asperger's Syndrome, legal blindness, and other health impairments. These listening groups focused on the needs of individuals with disabilities and their families as they relate to life transitions.

Each parent group agreed that having a child with special needs puts enormous demands on the parents' time. The children's needs have directly affected some parents' career paths. Some mothers quit their jobs because of the multiple demands of caring for their children. Susan Yellin (mother of a 17 year old) resigned from practicing law to create The Center for Learning Differences. Sherry Rubin authored the book *Finding Marisa - A Mother's Story* on raising a child with autism. Aviva Guttmann (social worker and mother of a 15 year old) said, "You have to be involved with everything." The lack of income, coupled with burdensome medical bills, puts many families in financial difficulty.

Respite is also a critical need, expressed by all parents in the listening groups. It allows the family to focus on each other and connect with people outside of the family structure. It is also vital for re-building the energy and patience needed to meet the multiple and challenging demands of sustaining a family with children with special needs.

Every parent felt like they were "pioneers" in the field of developmental disabilities. When their children were first diagnosed, there was no centralized and accessible route to finding the information they needed. Many of the people who helped them were other parents who had children with similar disabilities. Although many parents have formed informal networks, many remain "invisible" and find themselves struggling to access what they need for their child. There seem to be four distinct systems that parents have the greatest difficulty navigating: government, school systems, and for profit, and not-for-profit providers. There is limited coordination among and between these sectors and many challenges result for parents trying to get all they are entitled to for their child(ren). It was suggested that one website be created for all organizations to disseminate information.

Consistent with the feedback from agency representatives and medical professionals, parents also noted the lack of adequate training among pediatricians and early childhood school personnel in the identification and diagnoses of developmental delays. This training is critical to ensure that children will receive appropriate and timely (early) intervention. Often, parents will raise concerns about their child(ren) to their pediatrician, and the response is typically, "the child will grow out of it". Brenda Hamby (mother of a 45 year old) believes her son was continually misdiagnosed starting at age 4. This misdiagnosis led him into drug abuse and severe depression. Similarly, many

teachers (importantly, those in day care and early childhood education settings) do not have the education or training to identify signs of developmental delays.

The school district has a great deal of control over, and responsibility for, administering the services a student with developmental disabilities receives and to which they are entitled. Parents often feel like they have an adversarial relationship with their school district. Stacy Ezor (mother of a 12 year old) said, "My job is to be a pain in the neck to the school system." Sandra Gumerove (mother of a 26 year old) said, "It's all about money with the schools." Dennis Feuerstein (father) said, "You must fight school districts to get what you need." Susan Yellin said, "I negotiated for a living, and couldn't do that for my own kid."

Many parents are shocked to learn that transition planning for their child with developmental disabilities is their legal right. Even the parents who are aware of the right to expect and have access to an Individual Transition Plan (ITP) as part of their child's Individual Education Plan (IEP) have been dissatisfied with the scope and nature of the goals included. Life skills, including sexuality, driving, and financial planning, so needed for adult independence, are not necessarily addressed. Karen Spector (mother of a 13 year old) would like resources to be provided for these areas. Stacy Ezor feels that the schools do not see "life after high school". Furthermore, if the child is not eligible for state-funded services, the parent is on his/her own. Stacy would like to see a booklet about transition services for parents. Laura Wagman (mother of a 15 year old) said there is a need for parent training and support during transition.

When asked, "Who will physically care for your child when you can't?" the silence in the room was deafening. Many parents said it was the challenge they feared most. The two most common answers are in opposition to each other; a sibling of the child with developmental delays, or anyone but the sibling of a child with developmental delays. Brenda Hamby (mother of a 45 year old) shared her fear of what her son's future will be when she and her husband can no longer care for their son or are no longer alive. Some families have set up trusts to deal with the financial burden of caring for an aging adult with developmental delays. Sherry Rubin (mother of 16 and 29 year olds) has a daughter in a group home. She says, "The most important thing for my daughter is to be happy. She is happiest living among her peers and being engaged in group activities with her peers."

The following list summarizes the key needs expressed by parents:

1. Respite for caregivers and siblings.
2. Centralized information for parents on CSE, transitioning planning, and other available services/benefits and entitlements.
3. Increased training for pediatricians and school personnel in early identification of developmental delays and early intervention.
4. Stronger partnerships between parents and school systems, and better coordination between government, school systems and the provider sector.
5. Training for school personnel on interacting with parents of children with developmental delays.
6. Goal driven transition planning.
7. Life skills training for students with developmental disabilities.

8. Help for parents to plan the care for their adult child, when they are no longer able.
9. Parent training and support on advocacy, transition, entitlements and how to access the range of available services.

### **Developmental Disabilities: Educators**

On June 6, 2007 a school psychologist, a religious school director, and a social worker met with two facilitators to discuss education, transition, and parental needs as they relate to children with developmental disabilities. Of the five women, four have their own children with special needs.

Elizabeth DeFazio-Rodriguez (School Psychologist) receives many requests from parents for advice on navigating the Committee on Special Education (CSE). Marily Trujillo (Behavioral Consultant) reported that, at CSE meetings, parents often seem intimidated and uninformed of their children's rights. Furthermore, most parents do not realize that the school is responsible for creating an Individual Transition Plan (ITP) as part of the Individual Education Plan (IEP). Typically, it is a service provider (social worker, therapist, etc.) who raises the idea of transition planning when students are a year from graduation or aging out of the school system (IDEA mandates that an ITP be in place by age 14). Ideally, the ITP would include community services. However, school personnel have little knowledge of what is available.

The delay of a student's graduation (a child can stay in school until age 21) may raise emotional and social challenges. Many students will drop out of school. Elizabeth DeFazio-Rodriguez recommends support groups for students not graduating on time.

Finding quality special education personnel is very difficult. For day care centers, with their relatively low salary scale, finding and retaining quality staff is even more challenging. Therefore, the staff is ill-equipped to identify presenting symptoms of young children at the most important stage of diagnosis and intervention.

Consistent with feedback from other groups, the educators identified some core needs of parents: information about available services, benefits and entitlements, advocacy training, and respite. Parents are unaware of services available to their children and unknowledgeable about how to access the services about which they are aware. The parents spend enormous amounts of time researching and learning. This, coupled with all the other responsibilities faced by parents (other children, work, finances, etc.) makes the need for respite a top priority.

In addition to these areas, educators feel that parents need training about how to best support, interact with, and discipline their child. A parent, trainer or coach would help teach the parents how to most effectively interact with their child as well as offer guidance and support to the entire family unit.

The educators also echoed the concerns of other groups, by fearing that parents don't plan well enough or far enough in advance for how their child(ren) will be cared for when they are no longer able to do this on their own. One member of this listening group, who is also a parent of a child with special needs, put her child on a waiting list for residential housing, as well as put money away to help buy into a group home with like children. Many parents don't do this kind of planning and preparation.

The following list summarizes the key un-met needs expressed by educators:

1. Parent training on CSE meetings, IEPs and ITPs, including overview of rights and advocacy skills.
1. Support groups for students aging out of the school system.
2. Staff development for secondary educators on community based services.
3. Day care and early childhood teacher and staff training in early diagnosis and intervention.
4. Respite for families of children with developmental disabilities.
5. Centralized information with easy access for parents.
6. Parent training and coaching to improve support and interaction with their children with developmental delays.

## **Developmental Disabilities Government Agency Representatives**

On September 26, 2007 seven government agency representatives participated in a listening group to discuss the needs of the population with developmental disabilities and their caregivers. The discussion was focused on service needs and the gaps in provided services. Topics discussed included transition planning, parent or caregiver respite, and residential services.

One of the most overwhelming causes of problems in adequately meeting the needs of students with developmental disabilities seems to stem from the fractionalization of Long Island's school system; there are 124 school districts across Nassau and Suffolk Counties, each with their own governing body. This makes service coordination and access very difficult and many students fall through the cracks. Dr. Lou Gallagher (Suffolk County Division of Mental Hygiene) and Art Fleisher, LCSW (Suffolk County Division of Mental Hygiene) believe that stronger mandates must come from the State (New York State Education Department) to the school districts. The districts do not coordinate with each other nor with the government agencies to adequately plan for and meet the needs of students with developmental disabilities facing transitions. Schools often avoid their responsibilities because of the high cost and time involved in delivering the range of services and planning which they are mandated to provide. Parents must become strong advocates for their children or the transition plan will not be timely or adequate. Parents are often unaware of the agencies that assist with advocacy and also help coordinate adult services.

Bob Lopez (Deputy Director Community Services LIDDSO- Bi-county) advocates having BOCES work with the school districts to provide transition services. As the general education students are given access to information about higher education opportunities (including college fairs, campus visits, and applications and catalogues in the guidance office), students with developmental disabilities should have access to visits to day programs, sheltered workshops, and higher education options. Furthermore, while there is attention given to students with developmental delays during the school day, there are very few after-school recreational opportunities for children with developmental disabilities.

In addition to problems with transition, access to residential and day program services is limited. The number of persons needing these programs has increased due to advances in medical technology which have significantly reduced the mortality rate of premature infants, but ultimately often lead to developmental challenges in these children. These numbers are difficult to quantify.

The New York State CARES Registry is the official residential placement waiting list. Children do not go on this list, but parents complete a DDP4 form to make them known in the system. Bob Lopez states that parents completing this information seem to downplay their children's disabilities out of shame and pride, actions which then jeopardize their access to benefits and entitlements and their access to appropriate placement as they transition to young adulthood. To ease the congestion within the system, the state has made it a significant priority to enable those who can stay at home, to stay at home with assistance.

A survey which drew 1,000 responses from families with children with developmental disabilities concluded that in-home respite was the number one need, followed sequentially by out of home respite, non-Medicaid service coordination, and recreation. The need for respite and additional community based residential opportunities are critical for aging parents who are caring for adult children at home, particularly with increasingly longer life expectancies of those with developmental disabilities. As the population of adults with developmental delays ages, group homes need more funding for modifications. Chris Long (F·E·G·S, VP of MRDD Residential Services) said "As the population of individuals with developmental delays ages, the residences need modifications to accommodate the elderly and medically frail."

Dr. Lou Gallagher (Suffolk County Division of Mental Hygiene) brought up the unmet need of forensic services for people with developmental disabilities who are under the purview of the Department of Justice. The police, probation and parole officers receive inadequate training for transitioning the population with developmental delays back to the community, and on mitigating recidivism.

The following list summarizes the key needs expressed by government agency representatives:

1. Centrally coordinated transition services for all students with developmental delays.
2. Increased access to school-based transition services.
3. Training for parents on transition and advocacy in accessing benefits/entitlements.
4. Better identification procedures for those who will need residential or day programs.
5. Additional and modified residential facilities.
6. Increased support, especially, respite for families caring for a person with developmental disabilities at home.
7. Training of criminal justice personnel.

UJA-Federation of NY/ F·E·G·S  
*LI Sounds: Developmental Disabilities*  
APPENDICES

1. List of Participants in Each Listening Group
2. Questions for Long Island Sounds: Developmental Disabilities  
PHYSICIANS listening group
3. Questions for Long Island Sounds: Developmental Disabilities  
PARENTS listening group
4. Questions for Long Island Sounds: Developmental Disabilities  
AGENCY SERVICE PROVIDERS listening group
5. Questions for Long Island Sounds: Developmental Disabilities  
GOVERNMENT PROVIDERS listening group
6. Questions for Long Island Sounds: Developmental Disabilities  
EDUCATORS listening group

RECOMMENDED READING

1. Article: Providing the Best for Families: Developmentally  
Appropriate Home Visitation Services by Edith Anne  
Bouhebent. *Young Children*. March 2008.
2. Progress in Providing Services to Young Children with Special  
Needs and their Families: An Overview to and Update on the  
Implementation of the Individuals with Disabilities Education Act  
9 (IDEA) by Pascal L. Trohanis. *Journal of Early Intervention*.  
March 2008.
3. Article: Communication Made Easier: Facilitating Transitions for  
Students with Multiple Disabilities by Steven Peck, *Teaching  
Exceptional Children*. June 2004.

*Long Island Sounds: Development Disabilities*  
List of Participants in Each Listening Group

**November 21, 2006: Network Agency Service Providers**

Ann Dorman Adler  
Jonathan Cooper, Kulanu Torah Academy  
Robert Greenberger, F·E·G·S  
Cara Greene, Sid Jacobson JCC  
Elise Hahn-Felix, Jewish Child Care Association (JCCA)  
Christopher Long, F·E·G·S  
Jeremy Melnick, Sid Jacobson JCC  
Jeri Mendelsohn, Assistant Executive Director, Samuel Field JCC  
Alyse Middendorf, Kulanu Torah Academy  
Naomi Nadata, Communities Acting to Heighten Awareness and Learning (CAHAL)  
Debby Perelmuter, JCCA  
Chana Pfeifer, JCC of the Greater Five Towns  
Nancy Leipzig Powers, UJA-Federation of NY  
Beth Raskin, Kulanu Torah Academy  
Eileen Schneyman, Suffolk Y JCC  
Sue Schwaber Tregerman, Mid-Island Y JCC  
Sheryl Smith, Barry & Florence Friedberg JCC  
Kathy Rosenthal, F·E·G·S (Facilitator)  
Laura Wagman, F·E·G·S (Facilitator)

**January 25, 2007: Doctors Listening Group**

Susan Bender, Sid Jacobson JCC  
Joel Bregman, Fay J. Lindner Center--North Shore LIJ Health System  
Karen Breitinger, Schneider Children's Hospital, Pediatric Social Services at Hillside  
Dennis Feuerstein, Sid Jacobson JCC  
Mindy Gruttadauria, Sirri Center  
Zinoviy Gutkovich, Zucker Hillside Hospital  
Richard Kessler, D. O., Medical Director, Adults and Children with Learning and Developmental Disabilities, Inc. (ACLD)  
Bernice Polinsky, Adult Issues, Asperger's Syndrome and High Functioning Autism Association (AHA Association)  
Nancy Leipzig Powers, UJA-Federation of NY  
Kathy Rosenthal, F·E·G·S (Facilitator)  
Pat Schissel, President, Asperger's Syndrome and High Functioning Autism Association (AHA Association)  
Elihu Turkel, Zucker Hillside Hospital  
Laura Wagman, F·E·G·S (Facilitator)

*Long Island Sounds: Development Disabilities*  
List of Participants in Each Listening Group

**March 7, 2007: Parents Group [#1]**

Ann Dorman Alder  
Stacy Ezor, F·E·G·S  
Saundra Gumerove  
Aviva Guttman  
Lori Hason  
Marcy Klein, LCSW  
Debbie Levine  
Linda Mograbi  
Nancy Leipzig Powers, UJA-Federation of NY  
Karen Spector  
Dena Stein, President, SULAM  
Marily Trujillo, LMSW, Social Worker/Behavior Consultant  
Laura Wagman, F·E·G·S (Facilitator)  
Ian Weinberg  
Cindy Wittels  
Susan Yellin, The Center for Learning Differences

**May 17, 2007: Parents Group [#2]**

Stacy Ezor, F·E·G·S  
Dennis Feuerstein, Sid Jacobson JCC  
Ilene Fishbein  
Aviva Guttman  
Brenda Hamby  
Nancy Leipzig Powers, UJA-Federation of NY  
Sherry Rubin  
Karen Spector  
Laura Wagman, F·E·G·S (Facilitator)

*Long Island Sounds: Development Disabilities*  
List of Participants in Each Listening Group

**June 6, 2007: Educators Group**

Elizabeth Defazio-Rodriguez, School Psychologist, Long Island Parent Technical Assistance Center

Ellen Marcus, Religious School Director

Nancy Leipzig Powers, UJA-Federation of NY

Marily Trujillo, LMSW, Social Worker/Behavior Consultant

Laura Wagman, F·E·G·S (Facilitator)

**September 6, 2007: Government Group**

Art Flescher, Suffolk County Division of Community Mental Hygiene Services (SCDCMHS)

Lou Gallagher, Suffolk County Division of Community Mental Hygiene (SCDCMHS)

Christopher Long, F·E·G·S

Lois Kilkenny, Community Services Administrator, Long Island Developmental Disabilities Services Office (LIDDSO)

Bob Lopez, Developmental Disabilities Program Specialist IV, Long Island Development

Disabilities Service Office (LIDDSO)

Nancy Leipzig Powers, UJA-Federation of NY

Kathy Rosenthal, F·E·G·S (Facilitator)

Michelle Zoldak, Self Determination/Self Advocacy, Long Island Developmental Disabilities Services Office (LIDDSO)

Questions for Long Island Sounds: Developmental Disabilities  
PHYSICIANS listening group 1/ 25/07

1. What types of care or services do you provide for individuals with developmental disabilities?
2. What issues come up in providing care for these individuals that are unique to them as a population?
3. What are the most challenging transitions that face your patients?
4. How do you intervene/assist your patients with these transitions (e.g. school to community, aging and so on)?
5. What community living situations are most beneficial for this group of patients?  
What are the barriers in terms of these living situations?
6. How do you see your role in communicating with parents and with organizations involved in assisting your patients (schools, for example)?  
In your experience, is there a “team” approach on the part of everyone involved and, if so, is it a formal arrangement or is it informal? What is the ideal model for communication?
7. From your vantage point as a physician, what would you say are the biggest challenges in providing health care to your patients?
8. Have you seen an increase in patients who are diagnosed as being on the autism spectrum? If so, to what do you attribute the increase?
9. What would be your “wish list” for services that might assist your patients?

Questions for Long Island Sounds: Developmental Disabilities  
PARENTS listening group

Parent Concerns about Services and Programs for Their Children

1. What are the challenges facing parents in the early years of a child's life when they suspect -- or perhaps have been told -- that their child has a special need? Do parents know where to seek assistance? What types of supports can parents benefit from?
2. To what extent are there gaps in programs and services for children from birth through pre-K?
3. When a child with identified or suspected special needs enters elementary school, parents find themselves dealing with the Committee on Special Education (CSE) in their district to obtain educational programs and services for their children. To what extent are parents informed about the CSE process? What are the obstacles that come up in this process? What are the supports available for parents?
4. For the school-age child, what programs are important when school is not in session?
5. The transition planning process for youngsters with disabilities, from age 14 and up until they graduate or age-out of high school and enter the community, can be very trying for parents. What are your experiences and those of other parents in transition planning with the school district? What might make the process as smooth as possible for the parents?
6. What are the needs older teens and young adults have post-high school age? What are the obstacles in meeting the needs of these young people in the community? What would help parents with these issues?

Questions for Long Island Sounds: Developmental Disabilities  
PARENTS listening group

Questions for Parents Second Meeting – May 17, 2007

1. Transition to the community after high school is a huge change for students and parents. Once a student is post-high school, (s)he is in the world of adult programs and services, a major change from dealing with the special education system. What guidance, experience, opportunities do the students need during high school in order to make the best transition into the community? What is available to them and what is needed?
2. What assistance can parents use in fostering their child's independence during and after high school?
3. Family relationships are often complicated. In the case of parents who have children with special needs, what are the considerations in relying on other family members, including siblings, as time goes on?
4. Current and future financial considerations are a major area of concern in parenting. What are some of the considerations with which parents grapple? What roles do government entitlements play?
5. The transition planning process for youngsters with disabilities can be very trying for parents. What have been your positive and negative experiences and those of other parents in transition planning with your school district?
6. What additional information, guidance or support could make the process as smooth as possible for parents?

Questions for Long Island Sounds: Developmental Disabilities  
AGENCY SERVICE PROVIDERS listening group

**Concerns About Serving Individuals Transitioning Into the Community**

**Target Group: UJA-Network Providers on Long Island**

1. To what extent are you able to develop a working relationship with school districts and BOCES programs prior to transition of young people into adult services?
2. From your knowledge, to what extent are the school districts prepared to inform parents of the community life options and service system prior to transition?
3. **What are the challenges in working with the school districts on transition planning?**
4. What are the main concerns you have about preparation of staff working with young men and women transitioning out of the local school districts or BOCES programs?
5. What training topics would be best to focus on as we prepare to provide services to the men and women transitioning out of the districts?
6. What are the greatest needs of young people transitioning out of the special education system?
7. What are the gaps in services to meet those needs?
8. What are ways in which we can work together to address these gaps?

Questions for Long Island Sounds: Developmental Disabilities  
GOVERNMENT PROVIDERS listening group

September 26, 2007

1. Transition Planning

Schools/districts don't always do what they are mandated to do. What is government's perspective and/or role in the area of transition planning?

What can providers do in collaboration with government? What resources can be tapped to assist families?

2. What are the priorities for family support dollars?

3. What is the size of the waiting list for children aging out in need of residential and day program services?

What is the composition of the list vis-a-vis types of disabilities?

4. What is government's perspective on children's residential services? Unmet needs in this area?

5. What is the government perspective on adults with developmental disabilities living with aging parents? What are the resources to assist?

6. What is the government perspective on individuals with adaptive deficits / those who fall through the benefits crack? How do we assist?

Questions for Long Island Sounds: Developmental Disabilities  
EDUCATORS listening group

Educators' Concerns About Transition for Teens Into the Community  
**Target Group: Special Education Teachers, Guidance Counselors,**  
**Committee on Special Education Chairs at Various Schools on Long**  
**Island**

1. Describe your role, if any, in working on transition planning with students and with parents?
2. What are the main concerns you have about the process?
3. To what extent are you able to develop a working relationship with parents?
4. What is your understanding of "what is out there" for youngsters who are in special education in terms of opportunities for community life?
5. What are the challenges in working with adult service agency referral sources?
6. What resources could you use in the transition planning process?
7. What community resources do students access as part of preparation for transition?