

# FAMILY CONNECTIONS

The Nemasket Group



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NEWSLETTER

## Why is it important to have a vision? *By Dianne Huggon*

Often I hear the question directed to children, “So, what do you want to be when you grow up?” Immediately the child will respond, “I want to be.....” The response will certainly indicate the child’s great interests, hobbies, and talents, also known as their “dreams”. Children are encouraged to share the dreams and visions they see for their future. Even before a child is born parents begin dreaming and creating a vision for their baby. But when a parent is faced with raising a child with a disability or chronic illness, we can easily forget about those dreams or worse, believe that they are forever shattered.

My son Jonathan (Jonny) has multiple disabilities as the result of a virus, which struck him at two weeks old. Jonny was about three years old when I was asked, “What vision do you have for your child?” I went home and sat with my husband and we discovered our dreams for our son had been buried by the demands that came with caring for him. We also realized that if we did not focus on or share those dreams, we had no direction nor would we really know what we were advocating for. Recently, we updated Jonny’s vision, which is also included in his current IEP. The vision statement was written with input from Jonny, his parent’s, brother, sister, grandparents, aunts, uncles, cousins and closest friends. We want for anyone who reads this vision to know what our son enjoys or is capable of doing **and** what his hopes and dreams are.

*All things are possible for those who believe!*

### *Jonny’s Vision Statement:*

Jonathan initiates and joins in conversations with his family, friends and teachers. He expresses his likes and dislikes, preferences, choices, opinions (even if someone doesn’t ask for it) with clarity for all to understand him. He communicates his wants, needs and desires when they happen. The visibility of an augmentative communication device attached to his wheelchair invites people of all ages to initiate conversation with Jonathan. They feel comfortable to freely ask Jonathan questions and his responses lead to a more in depth conversation.

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### Why is it important to have a vision? *(Continued)*

Jonathan is able to ask for help to assist him with needs, such as, repositioning of his body for best posture and comfort, hygiene and grooming. His independence gained from use of an augmentative communication device allows him to take control of his bodily functions by letting someone know when he needs assistance. He is able to communicate his feelings, both emotionally and health related.

Jonathan has a circle of friends who live in his community. These friends are the kids he hangs out with in and out of school. They go to the movies together, bowl, hang out at school dances, attend school and community sports to support their favorite teams and share secrets that only teenagers can understand.

In school Jonathan has easy access to the general education curriculum using assistive technology, i.e., Kurzweil or WYNN program. By the end of his 7<sup>th</sup> grade year, testing results will indicate to the educational staff involved in his education consistent gains in his academics. He will freely write essays, reports, poems, letters and any other document that requires sentences and paragraph form.

Jonathan writes and tells his own jokes that express his great sense of humor. This developed skill leads him to participate in school or community drama clubs. His love for music allows him to learn music notes leading him to compose his own music and get involved by participating in supporting the school band or chorus. His love for music also leads him to take part in disc jockeying using high tech assistive technology.

Jonathan is an active member of the student council at the middle school and high school level. He is a role model for his peers and acts as a peer mediator. There is little motivation needed for Jonathan to engage in academics and/or physical activity. Instead of others motivating Jonathan, he is the one to motivate them.

Jonathan navigates his way in school, at home and in the community independently using his power chair. His mobility is not limited to the use of a wheelchair. He is able to use a walker to assist him in taking steps with little assistance, which allows him change of position and physical exercise. Jonathan participates in sports using adaptive physical education, such as floor hockey, bowling and kickball.

The use of augmentative communication is not only activated by the use of a head switch, but also with using his hands, arms or legs. Jonathan's increased range of motion throughout his whole body allows him to reach and grasp, to reach out and hug or to physically play with his siblings or friends.

Jonathan enters a high school where he continues to have easy access to the curriculum and he is known to other students and staff for who he is as an individual....**Jonathan "Jonny" Paulo Huggon**, an intelligent, outgoing, outspoken, humorous, yet sensitive Leader.



*Jonny Huggon with brother Adam, sister Paige and dog Sandy*

## Frequently Asked Questions About Creating a Vision Statement

“The vision statement focuses the Team on the future of the student. The Team steps back from the here and now to take a broader, long-range perspective as it looks to where this student is headed in the future. Developing the vision statement helps the Team balance between the immediate concerns and the hopes and dreams for the future. Teams must remember the ultimate goal for all students with disabilities is independence and productive lives.”

*-IEP Process Guide, Massachusetts Department of Education, 2001*

### **Do you experience the “FEAR FACTOR” when trying to put into words your vision for your child with a disability?**

When writing your child’s vision statement for the IEP, you, like many parents may experience the “FEAR FACTOR”! Fear of the unknown? Fear of reaching too high? Although wanting to think creatively and progressively, we as parents sometimes get sidetracked by the “disability”. We must focus on our child’s abilities and dream new dreams.

Your vision will be filled with high expectations so that your child will be provided opportunities that allow him/her the dignity to try, the opportunity to reach for the stars and the dignity to succeed or fail just like everyone else. You may find it challenging to express your and your child’s vision to others who see closed doors where you see open windows. Do not let this hold you back.

### **What could happen if the “FEAR FACTOR” prevents me from explaining our vision to school staff?**

-Without a vision you can end up in a place that you don’t recognize! A place that was not part of what you expected.

-Your child’s vision could be written by professionals who have an understanding of the disability characteristics but do not have a full understanding of how the disability affects your child.

-If the vision is written only by the professionals it may not match your outcome expectations for your child’s future.

### **Does our Vision have to be “Realistic?”**

Dare to Dream! The important piece about vision is that it is a description that draws a picture of what your child’s desired outcomes will be for the future. Is it realistic? Is it really possible? Children, teens and young adults will discover their passion, interests, skills and preferences along the way. School is a time of self discovery for all children, with and without disabilities.

**FAQ's on Creating a Vision** *(continued)*

*Let not our NEED determine OUR DREAM; But let our DREAMS DETERMINE our NEED.--Colleen Tomke*

Think back to when you were 10, 12, 16 or 17. What did you want to do? Was it realistic for you? Are you doing that? Most would answer “no!” Remember that your family’s vision should not be viewed as binding. Your vision can change and mature over time as your child’s interests change and mature.

**As a parent what do I bring to the vision?**

- A rich history and unique perspective.
- A life time of support for your child.
- A deep understanding of the nature of the disability.
- The passion of your child’s heart and how that might translate into outcomes for the future.

**Why is our vision important to the process of developing an Individual Education Program (IEP)?**

Your vision should guide the Team throughout the entire IEP development process in order to create a program that will bring your child closer to that vision in a meaningful way. This includes the planning of your child’s schedule at school and choice of classes, as well as the planning of supports and services for access to academic and non-academic activities.

**How do I develop a vision for my young child going from Early Intervention to the Public School?**

When your child is only 3 or 4 years old you are asked; “What is your vision?” The question can be very confusing because you may be just learning about the disability and how the disability will impact your child’s learning and communication style. Think about what you would like to see your child being able to do five years from now. Keep in mind that important skills to build at this age are in the areas of communication and social/emotional development.

**How do I develop a vision for my child entering elementary school?**

As your child enters elementary school your vision may list a desire to gain skills needed to be successful in academic and social environments. If your child is provided the supports to gain knowledge of facts and figures along with a successful communication style with their same age peers, he/she will be well on their way to a full and meaningful life after school.

**FAQ's on Creating a Vision** *(continued)***How do I develop a vision for my child entering middle school?**

As your child prepares to enter middle school you may want to take some time to summarize your journey thus far. Asking your child and yourself, "What have we learned about his/her learning style, talents, and interests?" Does your child understand how the disability impacts learning or assessments? Would middle school be a time to explore that further?

**How do I support my child in developing their vision when entering high school?**

Upon reaching high school the vision focus should largely be planned and voiced by your student. This will be a fluid process if they have been included in your vision planning from the start. All students entering high school begin to think about their future and what it will look like. Your child may ask themselves: Where will I live? Will I attend college? Where will I work? Who will help support me? What kind of community membership and or activities will I participate in? What will I do for fun?

Your child is beginning to identify their passions, interests, learning style and preferences based on life experiences. In high school your child's success will depend on his/her ability to explain these to teachers, friends and future employers.

**What law supports vision with high expectations for individuals with disabilities?**

Individuals with Disability Education Act or IDEA 2004 H.R. 1350 Subpart 4 Sec.682 © (1) states:

*Improving educational results for children with disabilities is an essential element of our national policy of ensuring quality of opportunity, full participation, independent living and economic self sufficiency for individuals with disabilities.*

IDEA 2004 Proposed Rules Subpart A Sec. 300.1 (a) continues by saying:

*...To ensure that all children with disabilities have available to them a free appropriate public education that emphasizes special education and related services designed to meet their unique needs and prepare them for further education, employment and independent living...*

**How can our "Vision" be weaved through the entire IEP?**

**IEP page 1:** Student Strengths and Key Evaluation Results Summary. This is a great opportunity to share your child's interests, preferences and personal accomplishments.

**IEP page 1:** Vision Statement is designed by you and your child. It is a description of what the desired outcome for the future can hold. It is written with high expectations with the hope of fruition.

**IEP page 2:** Present levels of Education Performance A; General Curriculum. Think of how your child is assessing the general education curriculum and how the general curriculum can support the designed vision outcome. Share accommodations that can be used in a variety of settings.

**FAQ's on Creating a Vision** *(continued)*

**IEP page 3:** Present levels of Education Performance B; Other Educational Needs. Check all considerations that could support the vision outcome. Be sure to look at extra curricular activities, non-academic activities, behavior needs, travel training or other related services.

**IEP page 4:** Current Performance Levels/Measureable Annual Goals. Think about the skills your child needs to build in order to achieve the goals set in their vision and how your child could be supported through measureable goals in the least restrictive environment.

**IEP page 5:** Service Delivery. Make sure the service delivery page reflects the support services and personnel expertise that is imperative for a positive vision outcome for your child.

**IEP page 6:** Schedule Modification. Does your child's vision outcome require a shorter school day, longer day, shorter school year or longer year?

**IEP page 7:** State or District-Wide Assessment. How will your child take standardized tests including MCAS? Your child can take MCAS three ways; without accommodations, with accommodations or through a portfolio of your child's best work.

**IEP page 8:** Additional Information. Any part of the vision outcome that was not supported in another part of the IEP document can be added here i.e.; Assistive Technology, Common planning time, Communication log...

**How can related services support our vision?**

Your Vision can be supported through the IEP and it can be embraced in related services (IEP page 3). For example: related services can support "friendships" which could translate into social pragmatic groups, social skills support and extended day services (IEP page 6).

Listed Below are other related services that are supported by the law and could be incorporated into a vision and supported by the school:

Parent Training	In Home Training
Speech/Language Pathology	Occupational Therapy
Physical Therapy	Music Therapy
Counseling Services	Medical Services (diagnostic & evaluation purposes only)
Audiological Services	Vision Therapy
Psychological Services	Recreation (including therapeutic)
Adapted Physical Education	Rehabilitation Counseling Services
School Nurse Services	Art Therapy
Social Work Services in School	Transportation Services
Early Identification	Orientation and Mobility

## **FAQ's on Creating a Vision** *(continued)*

### **Can we change our vision?**

Visions are living, breathing statements that can take on many forms throughout the years. The important thing is to create a meaningful vision with high expectations for success?

### **Where can I get more information on how to develop our vision into reality?**

<http://www.fulllifeahead.org>

<http://www.ric.edu/uap/publications/MAPS.pdf>

<http://www.inclusion.com/maps.html>

[http://www.communityinclusion.org/publications/fulltext/mti\\_html/index.html](http://www.communityinclusion.org/publications/fulltext/mti_html/index.html)

<http://www.youthhood.org/youthhood/index.asp>

<http://www.inclusion.com>

<http://www.ncset.org/publications/essentialtools/teams/default.asp>

*{Produced by the Parent Training and Information project at the Federation for Children with Special Needs, supported in part by grant # H328M990025 from the U.S. Department of Education, Office of Special Education Programs.}*

### **A Parent's Guide to Special Education.**

Written by the *Federation for Children with Special Needs* in collaboration with the *Massachusetts Department of Education*, the Guide is meant to serve as a resource for parents, and the organizations that serve them. The Guide contains the most current and accurate information available regarding the special education system in Massachusetts. It is the hope of the Federation that this publication will assist families in obtaining the supports and services that their children with disabilities need to succeed in school.

To obtain a copy of the guide, go to:

[www.fcsn.org](http://www.fcsn.org) and click on the "publications & resources" tab.

### **Lifespan Respite Act Approved by Senate**

Lifespan Respite Act went to the President's desk on 12/8/06 to be signed into law in Washington DC– Senator Hillary Rodham Clinton (D-NY) announced unanimous Senate approval of the Lifespan Respite Care Act. The Act provides \$30 million in the first year and almost \$300 million over five years for competitive grants for states and local bodies to increase the availability of respite care services for family caregivers of individuals with special needs regardless of age. The bill also promotes a coordinated system of accessible respite care at the state and federal level. The announcement comes just days after the House of Representatives passed its version of the bill sponsored by Representative Michael Ferguson (R-NJ) and Jim Langevin (D-RI). The bill now goes to the President's desk to be signed into law.

### **Save The Date!**

Massachusetts Developmental Disabilities Council And The Arc of Massachusetts

29<sup>th</sup> Annual Legislative Reception

Wednesday, March 21, 2007 10:30am to 12:00 noon

Grand Staircase Hall The Statehouse Boston

## What is Family Support ?

Family support means different things to different families. Since the early 1980's, an increasing number of states have begun to offer at least some services to families of people with disabilities. And now, more progressive states deliver a wide array of supports and services that are:

- *Family driven:* Each family leads the decision-making process concerning the type and amount of support they receive;
- *Easy to use:* Families are not overwhelmed by paperwork and red tape; and

*Flexible:* Families can choose supports and services based on their individual needs and preferences.

These family support programs make use of structures, services and supports, as well as informal or natural supports in the community. The idea is to provide *whatever it takes* for families of people with disabilities so that they can live as much like other families as possible. The supports that families receive need to be determined by the individual family based on their culture, values, preferences and specific needs at any given time.

Providing useful support can involve any number of types of services and/or support. These supports might be aimed not only at the person with a disability, but at other family members as well. Also, it is important to remember that *it is not just what is offered to families, but how it is offered.*

### The main goals of family support are:

- To keep families together until the person with a disability chooses to live independently;
- To enhance a family's ability to meet the many needs of their family member with a disability;
- To improve the quality of supports to families while minimizing the need and the cost of out-of-home placement;
- To allow the family to participate in integrated leisure, recreational, and social activities; and
- To make a positive difference in the life of the person with a disability as well as the lives of all family members.

### Quality family support programs should:

- Focus on the entire family;
- Change as the family's needs, roles, and ages change;
- Encourage families to express their own needs and decide how their needs will be met;
- Treat people with disabilities and their families with dignity by respecting their individual choices and preferences;
- Respect cultural, economic, social, and spiritual differences;
- Encourage families to use the natural community resources; and
- Provide supports and services that are easy to find and easy to use

## What is Family Support ? (Continued)

### Potential Family Supports

#### Centered Around the Person with Disabilities:

- Diagnosis and assessment
- Therapeutic services
- Medical/dental services
- Home health care
- Recreational opportunities
- Special clothing and diets
- Transportation
- Adaptive equipment
- Housing adaptations
- Adequate health insurance

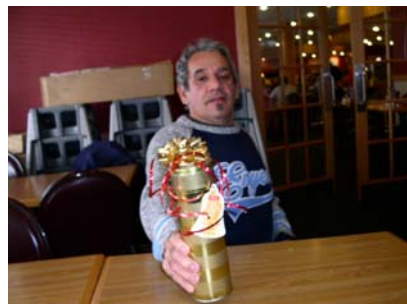
#### Centered Around Family Members:

- Information and referral
- Service coordination
- Temporary relief/respite
- Family counseling
- Parent/sibling education
- Day of family member care
- Financial assistance
- Future financial planning
- Mutual support groups
- Housing modification

## ***Family Connections' Hispanic Family Support Group***

On December 21, 2006 we gathered at the Old Country Buffet Restaurant in Dartmouth, where we were able, as a group to share and celebrate the happy, as well as, sad times of this year. It was a wonderful way for families to share their experiences and hopes and visions for the new year. To the families who attended, we would like to take this opportunity to say thank you for your participation and for allowing us to serve you. Approximately 21 people were in attendance which included one new family being welcomed to the group. We are always happy to include new families who want to participate. Our group meets bi-monthly and is open to newcomers (parents of children with developmental disabilities) from the Hispanic community. The Hispanic Support group offers opportunities for learning with guest speakers and the support of other families sharing the experience of raising children with disabilities.

If interested, please call Gloria Villalobo or Jorge Pagan at 508-999-4436.



## Combating Autism Act of 2006

"For the millions of Americans whose lives are affected by autism, today is a day of hope. The Combating Autism Act of 2006 will increase public awareness about this disorder and provide enhanced federal support for autism research and treatment. By creating a national education program for doctors and the public about autism, this legislation will help more people recognize the symptoms of autism. This will lead to early identification and intervention, which is critical for children with autism. I am proud to sign this bill into law and confident that it will serve as an important foundation for our Nation's efforts to find a cure for autism."

- President George W. Bush, 12/19/06

On December 19, 2006, President Bush Signed The Combating Autism Act Of 2006. This Act authorizes expanded activities related to autism research, prevention, and treatment through FY 2011. There are more than 1.5 million cases of autism in the United States.

Since The President Took Office, National Institutes Of Health (NIH) Funding For Autism-Related Research Has Increased By Over 80 Percent From \$56 Million In FY 2001 To An Estimated \$101 Million In The FY 2007 Budget, Including Support For Autism Centers of Excellence. In addition, the Budget includes approximately \$15 million at the Centers for Disease Control and Prevention (CDC) for autism surveillance and research, including five regional Centers of Excellence for Autism and Developmental Disabilities Research and Epidemiology. In October, CDC initiated a \$5.9 million study to help identify factors that may put children at risk for autism spectrum disorders and other developmental disabilities.

The Combating Autism Act Enhances Research, Surveillance, And Education Regarding Autism Spectrum Disorder.

The Act Authorizes Research Under NIH To Address The Entire Scope Of Autism Spectrum Disorder (ASD). Autism, sometimes called "classical autism," is the most common condition in a group of developmental disorders known as the autism spectrum disorders (ASDs). Other ASDs include Asperger syndrome, Rett syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified (usually referred to as PDD-NOS).

The Act Authorizes Regional Centers Of Excellence For Autism Spectrum Disorder Research And Epidemiology. These Centers collect and analyze information on the number, incidence, correlates, and causes of ASD and other developmental disabilities. The Act also authorizes grants to States for collection, analysis, and dissemination of data related to autism.

The Act Authorizes Activities To Increase Public Awareness Of Autism, Improve The Ability Of Health Care Providers To Use Evidence-Based Interventions, And Increase Early Screening For Autism.

## **Combating Autism Act of 2006** *(Continued)*

The Act authorizes the Secretary of Health and Human Services to:

Provide information and education on ASD and other developmental disabilities to increase public awareness of developmental milestones;

Promote research into the development and validation of reliable screening tools for ASD and other developmental disabilities and disseminate information regarding those screening tools;

Promote early screening of individuals at higher risk for ASD and other developmental disabilities as early as practicable;

Increase the number of individuals who are able to confirm or rule out a diagnosis of ASD and other developmental disabilities;

Increase the number of individuals able to provide evidence-based interventions for individuals diagnosed with ASD or other developmental disabilities; and

Promote the use of evidence-based interventions for individuals at higher risk for ASD and other developmental disabilities as early as practicable.

The Act Calls On The Interagency Autism Coordinating Committee (IACC) To Enhance Information Sharing. The IACC provides a forum to facilitate the efficient and effective exchange of information about autism activities, programs, policies, and research among the Federal government, several non-profit groups, and the public. The Combating Autism Act requires the IACC to provide information and recommendations on ASD-related programs, and to continue its work to develop and update annually a strategic plan for ASD research.

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### **Tools for Tomorrow (By The Arc of Massachusetts)**

One of the most difficult questions families and individuals face is where they want to live and what kind of life they want to have. This workshop helps individuals and their families think about the kinds of support, services, living arrangements and environments they want and need, and provides steps to achieve the best possible outcomes. Tools for Tomorrow aims to help build the futures of individuals and their families.

**When:** February 10, 2007 Full Day

**Where:** Plymouth Public Library-Plymouth Mass.

**Fee:** \$75 (Group Discount Available)

For More Information

Contact: Beth Rutledge

781-891-6270 x101 Email: [arcmass@arcmass.org](mailto:arcmass@arcmass.org)

Note: Scholarships Available-Contact your local chapter. (Special accommodations-requests must be received 2 weeks prior to workshop.)

## GOVERNOR PATRICK WILL REVERSE ALL OF ROMNEY'S MID-YEAR BUDGET CUTS!

All of the \$383 million Former Governor Mitt Romney trimmed from this year's state budget will be restored according to Governor Deval Patrick's aides – pleasing legislators and the recipients of state funds.

Romney's cuts sparked outcries last month from a wide array of state-aided providers, including public higher education institutions, HIV/AIDS prevention and treatment, human service agencies and the Massachusetts Water Resources Authority. Some legislative Democrats alleged that several of the cuts exceeded powers assigned to the executive branch under Section 9C in Chapter 29 of the state's General Laws. Others said Romney was prematurely exercising budget powers typically triggered in more desperate times.

Deval Patrick's plan to restore the cuts sends the message that he will not play politics with the lives of poor and disabled people. As mentioned in the last newsletter, the cuts were devastating to families and individuals receiving services from the Department of Mental Retardation. The cuts remaining to be restored by Governor Patrick include line items in Family Support, Autism Services, the Salary Reserve for Human Service workers, residential rates and the DMR regional and area office.



### Family Connections

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Creating a network of family support

For individuals with developmental

Disabilities and their families