

Family Connections Center

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With warm wishes for love, peace and many moments of joy during this holiday season!



We are so grateful for our relationship with you and the opportunity to be of service!

We look forward to continuing our work with you in the New Year!

*Sandy Jorge Kathleen
Jennifer Julia*



Food for *Thought*

Comparison: The Thief of Joy

From the www.disabilityisnatural.com E-Newsletter by Kathie Snow

"Comparison is the thief of joy," attributed to President Theodore Roosevelt and others, evokes a powerful sentiment that can be life-changing. If we compare ourselves to others, we may be left with feelings of inferiority or superiority – and neither creates an emotionally healthy human being! I'm reminded of the lines from Max Ehrmann's "Desiderata" poem, wildly-popular in the early 1970s: "If you compare yourself with others, you may become vain or bitter, for always there will be greater and lesser persons than yourself." As we mature, we (hopefully) realize the wisdom of not comparing ourselves to others.

But let's shift the conversation to children and adults with disabilities. If they're "receiving services," most are *routinely* assessed and *compared* to some "norm," and are then usually judged to be "less than." Consider the descriptors that may be used: deficient, sub-normal, below average, low functioning, severe, impaired, and so on. And once a comparison is made, it can be nearly impossible to see the person's abilities, strengths, and/or talents. In addition, we may be unable to recognize that the person is *making progress*.

Comparisons, and their harmful consequences, can also occur outside of traditional disability-related assessments. Our son, Benjamin, has cerebral palsy and other diagnoses. He and his sister attended an inclusive elementary school where students with disabilities learned in general education classrooms. It was Parents' Night, an exciting time for moms and dads to visit their children's classrooms; Emily was in second grade, Benjamin in kindergarten. When all the parents entered the kindergarten classroom, we could see our children's work – drawings of a cow – tacked up on the walls. Other parents had to get up close to find their child's name on the paper (most of the drawings looked the same). But Mark and I spotted Benjamin's drawing from 30 feet away. He had told us it was a cow and we *believed* him – it was a Picasso-like cow. His teacher approached us and said, "I'm sorry his work doesn't look

like the other children's." I responded, "Please don't ever compare Benjamin to other Children. If you do, *you* will always be disappointed. *We're* not – we *love* his work; we're *proud* of how well he's doing! But if you compare him to other children, he'll never measure up in your eyes. Please compare Benjamin only to *himself*: what is he doing *today* that he wasn't doing six minutes, six hours, six days, or six weeks ago, and then you'll see the *progress* he's making!"

I could share more personal experiences like this, but one example is enough. Unfortunately, there are millions of parents who can tell similar stories.

Yes, within the service system, assessment data may be the key that unlocks the door to "services." But let's be fair to the person and recognize that – contrary to popular belief – assessment results *do not* represent the "whole person." They are, instead, a means to an end.

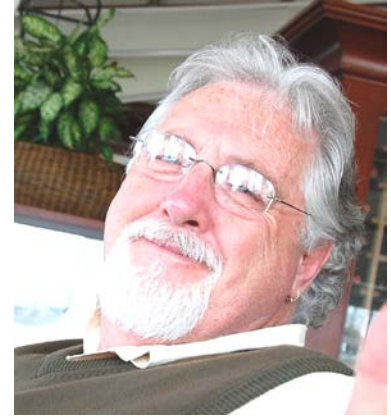
Whether a comparison is the result of formal assessments or informal observations (as detailed above), let's become vigilant defenders against the "thief of joy." Professionals must not steal the joy of parents by comparing their children to others. Ditto, professionals who work with adults with disabilities. When discussing the (usually) dismal assessment results, professionals can also detail the person's strengths and abilities!

Parents must not steal the joy of their children with disabilities by comparing them to brothers/sisters/ and/or other children. They must also not rob *themselves* of parental pride in a child's accomplishments by comparing him/her to others or allowing others to do so.

Anyone in a position of authority in the life of a person with a disability has great power, for good or ill. If we have unintentionally stolen joy by comparing, can we now, with generosity and goodness, take the time and make the effort to intentionally *restore* it?

Available *Resources*

Louis Nisenbaum



Memorial Scholarship Fund

The Louis Nisenbaum Memorial Scholarship Fund is available to family members of children/adults with disabilities. The goal of the Scholarship Fund is to grant family members the opportunity to attend conferences in which the central theme is inclusion/living in community. Applicants can submit a request to attend either national or international conferences.

For an application, interested individuals and families should visit www.nemasketgroup.org, click on "Resources" and then on Louis Nisenbaum Memorial Scholarship Fund. (Please note there is a limit of two family members who will receive funding to go to a requested conference.)

Lou's passion and commitment for people with disabilities were woven into the fabric of his being. He was fascinated by people and he truly believed we are our brother's keeper. He absolutely loved connecting people, looking for resources and sharing ideas. He also enjoyed challenging all of us to imagine better! The world he wanted to live in, and worked to create, was really all about community. It was about being there for each other. He often said, "Everyone needs someone in their lives to be unreasonable on their behalf." Lou willingly took on that role for so many people as do so many other family members.

Lou considered himself fortunate to work throughout the state, nationally and internationally. He humbly sought ideas and shared ideas always believing that he had so much to learn. He was besotted by the idea of family support and the potential of families to create change. He was instrumental in the development of our system of family support here in Massachusetts. Lou would be delighted to know that through this scholarship fund he will provide other family members the opportunity to "partake of learning" which might enhance the lives of their family members, others living with disability and our fellow community members.

Donations for this Scholarship Fund are gratefully appreciated. Please write the check to The Nemasket Group, 56 Bridge St. Fairhaven, MA 02719 with *LN Scholarship Fund* on the subject line.

"We all know that community must be the center of our lives because it is only in community that we can be citizens. It is only in community that we can find care. It is only in community that we can hear people singing. And if you listen carefully, you can hear the words: "I care for you." ~ John McKnight

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The Louis Nisenbaum Memorial Scholarship Fund

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The fund will pay for conference fees, travel expenses, hotel costs for up to two family members from the same family to attend a conference. Applications must be received and approved before the event. The Scholarship Award Committee will respond to requests based on the Scholarship Fund guidelines outline below.

If you would like to receive more information please email, call, or write to:

Email: EmilyNisenbaum@NemasketGroup.org
 Tel: (508) 999-4436 ext 153
 Fax: (508) 997-9239
 Address: Attn: Emily Murgo Nisenbaum
 Louis Nisenbaum Memorial Scholarship Fund
 56 Bridge Street, Fairhaven, MA 02719

Louis Nisenbaum Memorial Scholarship Fund Application Guidelines

The goal of this scholarship fund is to support the efforts of family members of people with disabilities to imagine and create better lives by ensuring our children live in communities that are welcoming and inclusive.

Who Can Apply?

- A family member of an individual with a developmental disability.

How Much Can I Apply For?

Considering the cost to attend a national or international conference may be prohibitive for many family members:

- The LN Memorial Scholarship Fund Council will provide a maximum of \$2000.00 for one event per family per year
- We may offer an amount less than the total needed and provide assistance to the family to find additional resources.
- A family cannot receive a scholarship in two consecutive years.

What Types of Events May I Attend?

Eligible events include:

- Conferences which emphasize inclusion, community membership, and relationship building

How Do I Apply?

- Complete the Louis Nisenbaum Scholarship Fund Application Form online or print it out and mail or fax. Please attach a copy of the brochure/application for the event and a brief summary describing how attending the conference or event will benefit you and/or others.
- Applications must be received at least 30 days prior to the event in order to be considered for approval. Applications may be submitted online, mailed, faxed, hand-delivered or emailed to emilynisenbaum@nemasketgroup.org

How Will I Be Notified/Receive Funds?

- The review committee will meet as applications are received. Decisions will be made as soon as possible after receipt of application and applicants will be notified whether approved or not.
- Funds will be disbursed after approval and with documentation of costs to be paid.

IRS Relaxes Rules For New ABLER Accounts

by Michelle Diament | November 30, 2015 Disability Scoop

The Internal Revenue Service is easing up on rules for new accounts that will allow people with disabilities to save money without jeopardizing their government benefits.

Earlier this year, the IRS laid out plans for how accounts established under the Achieving a Better Life Experience, or ABLER, Act would operate. But the agency received significant pushback from disability advocates and state officials alike who said the proposed federal requirements would be overly burdensome.

Now, the IRS is backing off. In a notice, the agency said it plans to issue final regulations with less stringent reporting requirements.

Specifically, individuals opening ABLER accounts will not need to submit medical documentation, but will have to certify under penalty of perjury that they have a qualifying diagnosis, the IRS guidance said.

What's more, the agency indicated that ABLER programs will not be required to request taxpayer identification numbers from contributors to ABLER accounts except in limited circumstances and program administrators will not have to categorize what money in the accounts is used for.

"We are very pleased with the interim guidance issued by the IRS, which will make it easier for state administrators to establish and administer ABLER programs in an expedient and efficient manner," said Heather Sachs, vice president of advocacy and public policy at the National Down Syndrome Society.

Despite federal passage of the ABLER Act last year, each state must establish regulations of their own in order to make the accounts available.

So far, 34 states have approved such legislation, according to the National Down Syndrome Society. However, these states are still working out the details for administering their programs, a process contingent on the IRS rules.

Nebraska State Treasurer Don Stenberg, who was critical of the IRS' initial proposal, said the agency's updated approach is welcome and will allow his state to make accounts available as planned next summer.

"In particular, I am very pleased that the IRS will no longer require states to obtain information about expenditures by plan participants and that states will no longer be required to seek and receive medical information about ABLER plan participants," Stenberg said. "Had those requirements remained in place, the cost of the ABLER program would have increased substantially."

ABLER accounts are expected to start becoming available to consumers next year, but the exact timetable will vary by state.

With the new accounts, people with disabilities will be able to accrue up to \$100,000 without losing access to Social Security and other government benefits. Medicaid coverage will remain intact no matter how much money is saved in an individual's ABLER account.

Modeled after 529 college savings plans, funds in the accounts can be used to pay for education, health care, transportation, housing and other expenses. Interest earned on savings in the accounts will be tax-free.

Individuals with disabilities that originated before age 26 will be eligible for the new accounts.

“If family support was truly supportive, what would it look like?”



A number of advocacy groups across Massachusetts (including Massachusetts Families Organizing for Change) are developing a campaign to increase Family Support funding in the 2017 budget.

We need your help. We know that families across Massachusetts are struggling to meet the needs of their loved one with a disability. We know that many families do not receive enough financial support, and that this can create substantial financial and emotional hardship. We know this, but our legislators do not. Which is why five statewide organizations are launching a campaign to substantially increase funding for families who are supporting individuals with disabilities in their homes.

There is a crisis facing many of the eighteen thousand families who support their loved ones at home. The families which face difficulty do not have adequate funding through the Department of Developmental Services (DDS). We can and will provide facts and figures that justify this expenditure, but the most powerful thing our legislators can hear are the life experiences of families like yours. Together, we can communicate the critical need to invest in families, and the incredible potential that will be unleashed when we do.

We are asking you to think about this question: “If family support was truly supportive, what would it look like?” It is important to capture what your life looks like now and what it could look like with more financial support from DDS. Some families have said they could get a job if they had more family support funding; some families say they could pay someone to take over during the night so they could get a full night’s sleep; other families have said they would buy adaptive equipment that would radically change the quality of their loved ones’ life.

We need your story so that we can communicate the real challenges faced by real families, and the real impact that increasing family support can have on our families and our communities.

We will be using these stories to raise awareness in the general public and in our legislature. You can choose to have your identity remain anonymous or public, and we will fully respect your choices of how we may use this information.

Please consider completing the attached survey of guiding questions, or email us your story. The survey is also online at <https://www.surveymonkey.com/r/8D2GGK9>
Together, we can make a difference!

For more information, email us at SupportingFamilies@arcmass.org. Thank You!



PEDIATRIC HOME HEALTH AIDE SERVICES

Raising a child is a rewarding yet challenging time for any family, but when children are faced with special healthcare needs, sometimes extra support is needed.

That's where we come in. Centrus Premier Homecare, Inc. is an experienced provider of personal care and home health aide programs offered in the comfort of a child's home. Our in-home services are designed to provide care and support to children who need additional assistance with activities of daily living.

Experienced, Compassionate Care

Centrus understands that finding the best in-home care is not only important, but essential to a patient's progress and well being. Our services are provided by experienced Home Health Aides (HHAs). With Centrus, children will get the assistance needed at home. Our Certified HHAs can provide the following services:

- Personal care
- Assistance with mobility
- Transfer assistance
- Meal preparation and feeding
- Companionship and supervision
- Light housekeeping (in the child's living areas)
- Entertaining (games, crafts, reading)

Our Quality is Reassuring

Centrus' clients know that they are working with an agency dedicated to their satisfaction. When you call Centrus, a representative will answer your questions and address any concerns you may have.

The Centrus Pediatric Home Health Aide Service Program

Centrus' Pediatric Home Health Aide Services are similar to the Personal Care Attendant (PCA) program. Our services are fully funded by MassHealth. Most patients can qualify for up to 35 hours per week. Some advantages of Centrus' Pediatric Home Health Aide Services as compared to the PCA program are as follows:

- Centrus' HHAs are certified and have gone through specific training to provide appropriate care in the home
- Centrus' HHAs are supervised by a registered nurse who will work with the child's physician to implement the most complete plan of care
- Centrus will recruit and screen potential caregivers
- Centrus assumes all responsibility for reimbursing our HHAs
- Centrus is on call 24/7

Call Centrus Today!

Franklin

31 Hayward Street, Suite 2F
Franklin, MA 02038
Phone: 508-528-3090
Fax: 855-696-7517
Toll Free: 855-218-7219

Needham

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Phone: 781-400-7080
Fax: 866-914-5859
Toll Free: 877-606-2946

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Fax: 877-394-4763
Toll Free: 800-698-8200

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Toll Free: 866-547-2782

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Fax: 855-696-7518
Toll Free: 866-492-5289

Worcester

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Worcester, MA 01606
Phone: 508-754-8205
Fax: 855-415-4967
Toll Free: 866-492-3734



Information to *Share*

A&E Network to Premiere New Original Docu-Series 'Born This Way' Tuesday, December 8 at 10:00 PM ET/PT (6 Part Series)

*Series Offers An Intimate Look Into The
Lives Of Young Men And Women Born With Down Syndrome*

*A&E Partnering With Best Buddies International To Raise Awareness And Encourage
Opportunities For People With Intellectual And Developmental Disabilities*

NEW YORK, NY – A&E Network is premiering the new original docu-series “Born This Way,” following a group of seven young adults born with Down syndrome along with their family and friends in Southern California. The six-episode, hour-long series from Bunim-Murray Productions premieres **Tuesday, December 8 at 10 PM ET/PT.**

Cameras follow the young men and women of “Born This Way,” as they pursue their passions and lifelong dreams, explore friendships, romantic relationships and work, all while defying society’s expectations. In their willingness and courage to openly share their lives, through a lens that is not often shown on television, we learn they have high hopes just like anyone else. The series also gives voice to the parents, allowing them to talk about the joy their son or daughter brings to their family, and the challenges they face in helping them live as independently as possible.

“We are proud to be airing this important and extraordinary series and hope it will inspire meaningful conversations about people with differences,” said Elaine Frontain Bryant, EVP & Head of Programming A&E Network. “‘Born This Way’ is a show with honesty, humor and heart that celebrates and embraces diversity.”

“There is a freshness and honesty in the way these young adults lead their lives; something we could all learn from them. We are enormously thankful to them and their families for participating in this project,” said Jonathan Murray, Executive Producer.

“I’m so incredibly proud to see ‘Born This Way’ highlight the outgoing personalities and amazing abilities of Best Buddies participants like Rachel Osterbach and Sean McElwee,” said Anthony K. Shriver, Founder and Chairman, Best Buddies International. “It is my hope that this show will demonstrate to society that individuals with intellectual and developmental disabilities are just like everyone else and should be fully included in our communities, our workplaces and our lives.”

A&E has partnered with celebrated global non-profit organization Best Buddies International and committed to an on-air PSA featuring Anthony K. Shriver and Best Buddies program participants in support of promoting opportunities and increasing awareness for people living with intellectual and developmental disabilities.

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The cast of "Born This Way" includes:

- **Rachel** – Working in the mailroom for an insurance company, she will be the maid of honor at her brother's upcoming wedding. Rachel would love to get married herself, but first she has to find the right guy.
- **Sean** – An excellent golfer and avid sportsman, Sean is a self-professed ladies' man, who is not shy about introducing himself to every eligible woman he meets.
- **John** – From a very young age, John made it clear to his parents that he craved the spotlight. A born entertainer, John is committed to his music and is pursuing a career in rap.
- **Steven** – Working as a dishwasher at Angel Stadium in Anaheim and in customer service at a local grocery store, Steven is a huge movie buff and knows the title and year of each Oscar winning film.
- **Christina** – This loving and compassionate young adult works in a middle school. In her free time she loves talking on the phone with Angel, her boyfriend of 4 years and the man she plans to marry.
- **Megan** – A budding entrepreneur, Megan has created a line of clothing she sells under the brand "Megology." She is pursuing her dream of becoming a film producer and is a proud advocate committed to spreading the word that society should not limit adults with disabilities.
- **Elena** – With a flair for the dramatic, this young woman embraces life. Elena loves to cook, dance and write poetry and takes a great pride in her independence.

According to the U.S. Census, one-in-five Americans have a disability. Currently 70 percent of working-age people with disabilities are not working – even though most of them want jobs and independence. The numbers are even worse for people with Down syndrome. There are many studies that show that people with disabilities, including those with Down syndrome, can work successfully and live relatively independently.

"Born This Way" is produced by Bunim-Murray Productions ("I Am Cait," "The Real World"). Executive producers for Bunim-Murray are Jon Murray, Gil Goldschein, Laura Korkoian and Barry Hennessey. Executive producers for A&E Network are Drew Tappan and Elaine Frontain Bryant.

SECONDARY TRANSITION WEBSITE



The Office of Special Education Planning & Policy Development (SEPP) has a new Secondary Transition website. You can find it by going to the home page, www.doe.mass.edu/sped, and then clicking on the "Secondary Transition" link in the left-hand menu.

The direct link is <http://www.doe.mass.edu/sped/secondary-transition/default.html>.

the nemasket group

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Family Connections Center

Joint Project of The Nemasket Group and
DDS (*Greater New Bedford Department of Developmental Services*)
56 Bridge Street
Fairhaven, MA 02719
Phone: 508-999-0077
Fax: 508-997-9239



United Way
of Greater New Bedford

Creating a network of family support
for individuals with developmental
disabilities and their families



Pathway to Opportunity

You can help create a Pathway to Opportunity!

The Nemasket Group invites you to participate in our "Pathway to Opportunity" Brick Program. Your personalized brick will become part of the lasting pathway at The Nemasket Group's new home to be built in the near future.

It's a unique opportunity to celebrate a special occasion, mark a special anniversary or make a dedication. Honor a friend or a loved one, or celebrate an important milestone in your life and the lives of those close to you.

There are two sizes; a 4 x 8 brick is \$125 and an 11.5 x 11.5 blue stone paver is \$250.
For more information, please call the Development Office at 508-999-4436 x 101