THE NEMASKET GROUP

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## Family Connections Center

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We are happy to announce that The Nemasket Group will be moving to The Pines in Mattapoisett by this fall.



Being unsure where we will be in August, we have made the difficult decision to cancel this years' Summer Sizzler.

However, rest assured that there will be other opportunities to gather together as we are planning an "Open House" and possibly other events before the end of the calendar year.

Stay tuned!

Dustin Green
Executive Director

# Food for Thought

Maria, the mother of 7-year-old Sophie, was livid about the school's proposed IEP (Individualized Education Plan) for her daughter: Sophie would be in an elementary school Life Skills class with other children aged 6-10, where the students would spend time learning to make

### Daily Living/ Life Skills

by Kathie Snow www.disabilityisnatural.com

beds, fold towels, sort recycling, and other activities (of questionable value). Little time would be focused on reading, math, or other academics.

What, exactly, are Daily Living and/or Life Skills? Is there a universally-accepted definition? Similarly, is there a standard "curriculum" (not just "programs" that are sold to school districts)? I've asked these questions of many professionals, teachers, and parents of children and adults with disabilities, and there is no specific, commonly agreed-upon definition.

Yet, ensuring that children and/or adults with disabilities "achieve" or "master" Daily Living/Life Skills is high on the list of many parents, teachers, service providers, and others in the disability arena.

I've met thousands of people over the past 25-plus years while doing presentations across the country. When I've had conversations with others on this topic, here's a potpourri of what they say Daily Living/Life Skills include: shoe-tying, bed-making, cooking, washing dishes, money skills, personal hygiene (bathing, dressing, hair-combing, etc.), and much, much more.

Search the internet and you can find a variety of websites that sell curricula on the subject, as well as websites that list Daily Living/Life-Skills activities for students and/or adults with developmental disabilities. One website, to remain unidentified, listed "mopping (school) cafeteria floors, setting up (cafeteria) tables," and other activities for students.

Several websites noted that (I'm collectively paraphrasing): students with disabilities must be taught these skills *at school* because school is the only resource that can help them transition from being student to being productive adults. Interestingly, I found no reference that these same

Life Skills were needed by students without disabilities.

This entire concept is rife with the presumption of incompetence of children/adults with disabilities and their families. First, why would anyone hold the belief that parents are incapable of helping their children with

disabilities learn ordinary skills, but they're somehow capable of helping their children *without* disabilities learn these ordinary skills? (And let's recognize that these *are* ordinary skills.) As a parent myself, it's insulting that "professionals" assume I'm incompetent to teach my son the same things I teach my daughter (who doesn't have a disability).

Other parents, however, may not feel insulted. They may, in fact, feel incompetent, while others may feel it's not their responsibility to teach to their children. And how does this come about? When the parents of a very young child with a disability begin receiving early intervention (EI) services when the child is between birth and age 3, they may be overwhelmed with anxiety and even fear, based on the negative prognoses most receive from physicians when the child is diagnosed. This is followed by the swarm of EI professionals (service coordinators, therapists, etc.) who descend on the family's home for regular home visits, access the child, write goals, and so forth.

Under these circumstances, and despite EI practices that are supposed to be family-focused, culturally sensitive, and more, the message to the parents is often very clear: you are incapable of raising your child without professional intervention, and your child/family is entitled to all kinds of professional help, now and probably for the rest of your child's life.

Some parents are able to accept this help and maintain their parental autonomy and authority. Others, however, are not. They do feel incompetent ("I'm just a parent, what do I know; surely the professionals know best...") and/or they're relieved that others ("experts") will bear some of the increased responsibilities that may

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come with raising a child with a disability. In either case, these parents relinquish some of their authority and responsibility, and the school system, not the family, assumes the role of the third parent, taking the responsibility for teaching the child Life Skills (but not academics).

Second, why do we assume children with disabilities are incompetent to learn Daily Living/Life Skills like their brothers and sisters do, from the ordinary experiences of daily family life? I didn't spend a great deal of time with daughter on specific Life Skills. Most parents don't. For example, you help your child learn to cook when she's interested in it, knowing that when you left your family home, you probably didn't have A+cooking skills. You knew enough to get by, and you learned by doing for yourself. Or maybe you didn't learn, and at some point, your spouse/partner made up for your lack of skills!

Why would we assume, as more than one website proclaimed, that a student with a disability can learn these skills *only* in a school setting? Are parents and children all presumed to be inherently

incompetent? Where does this arrogance come from?

Third, why do we assume that a Life Skills education is more valuable than academics? We're all aware of the horrendous and shameful unemployment rate of adults with disabilities (75-90 percent). How is learning to tie your shoes going to get you a job? Are there any shoe-tying jobs? What about bed-making? That may be an important skill if one is to be a hotel housekeeper one day, but I doubt if

"bed-making" is a *requirement* for being hired as a hotel housekeeper. No doubt the hotel will train its staff on how to make beds *per the hotel's* standards.

I was recently given a tour of a high school's "transition program." The assistant principal proudly shared how the students (aged 16-22) were learning how to sort things into bins so they'd be ready to move into a sheltered workshop when they aged out of special education.

A Life Skills education isn't going to lead to a paying job or to post-secondary education. Despite the Americans with Disabilities Act, employment discrimination exists. In any ordinary

If you accept the expectations of others, especially negative ones, then you will never change the outcome.

Michael Jordan

job, a person with a disability is competing against people without disabilities. Thus, children with disabilities *need a great academic education* to prepare them for a real job and/or vocational or post-secondary education.

When my son, Benjamin, was very young, educators said he would be in the Ortho Class ) for children with physical disabilities) when it was time for kindergarten. (I had already elected not to send him to the segregated special ed preschool.) They were proud of the Ortho Class where (they said) my son's needs would be met: lots of physical and occupational therapies, a focus on "functional" (physical) skills, etc. Unlike a general ed classroom, there were no shelves of books. Instead, the room was filled with therapy equipment, a television set (time for lots of videos in this classroom), mats for therapy and for naptaking, etc. Thanks, but no thanks. We moved to a school district where Benjamin and other students with disabilities were all included in general ed classrooms where they received a quality academic education. Today, as a recent college graduate, Benjamin is on the job-hunt.

My son does not write with a pencil and he needs assistive technology, accommodations and supports. He earned a Master's degree. This would not have been possible with a Life Skills education.

Why aren't we ensuring children and adults with disabilities have the assistive technology, supports and accommodations they need to succeed, instead of consigning them to a lifetime of lost opportunities, segregation, poverty, and second-class citizenship?

For adults with disabilities, why are service providers wasting time with Daily Living/Life Skills goals for cooking, bed-making, etc., instead of assisting the person with skills that will lead to a real job for real pay?

What hope is there is parents and/or educators have such low expectations for students with disabilities? If we, as responsible adults, do not ensure children with disabilities are given the same opportunities as children without disabilities to learn, grow, and succeed, we have failed them, miserably and perhaps totally, for life. How can we live with ourselves? It's time to start the conversation.

# Wanted: Playground Buddy

Need a Friend?
Sit on the Buddy Bench!



AT VERNFIELD ELEMENTARY, a school in the exurbs of Philadelphia, a first-grader named Brooke Sturm found herself alone at recess. So she sat on a bench next to the playground.

Two other first-graders, Kendal Hoover and Roisin McNamara, noticed her about a minute later. They ran across the play yard and invited Brooke to play tag.

"I just saw her, and she was my friend, and I wanted to play with her," explained Kendal, age 6. She and Roisin knew what to do because Brooke was sitting on one of Vernfield's two Buddy Benches, a playground installation where kids sit when they feel lonely, signaling other kids to ask them to play.

At least 1,000 elementary schools on six continents have installed Buddy Benches on their playgrounds. The popularity of Buddy Benches in the United States is credited to then-first-grader Christian Bucks, whose family was planning to move to Germany for his father's job. When Christian was looking at German schools online, he saw a similar bench on one of its playgrounds. He liked the idea and shared it with the principal of his school, Roundtown Elementary in York, Pennsylvania. Christian's family ultimately stayed in York, so after Christian started second grade in 2013, he introduced the Buddy Bench to his school during an assembly.

"Let's say their best friend is absent. They can sit there," explains Christian, now in fourth grade. "Kids are getting to know more people, and friends are being made."

After a local newspaper published an article about Roundtown's Buddy Bench, the story spread to media outlets like Today and The Huffington Post. Since then, the idea has spread through social media and word of mouth. Kids and educators at some schools have contacted Christian and his mother, Alyson Bucks, for advice. She maintains a website, Christian's Buddy Bench, with a map of the benches she's learned about through tools like Google News.

At Vernfield Elementary School, a parent saw one of those news stories after Vernfield merged with another school. Principal Jonathan Graf thought the benches would help students from the two schools connect.

"You don't want any child in the school to feel disconnected from their school community," Graf says.

The fifth-graders of the student body agreed and, in 2014, chose the benches as their class gift.

#### A Place for Every Child

When children feel excluded, "it's painful, lonely and confusing," says Ellen McCarty, who runs the Georgia operations of a nonprofit organization called Playworks. The group staffs low- income elementary schools with recess coaches who teach kids cooperative games, inviting all to participate and increasing their social emotional learning. The goals of Playworks and Buddy Benches are complementary: They aim to promote friendships and ensure every child has a place on the playground.

A Buddy Bench, by itself, can't create a more positive place for kids. It must be part of a coordinated effort to create an inclusive school climate. Assessing the current status of a school's culture is key to determining how to accomplish this goal, says consultant Nancy Mullin, director of Bullying Prevention Solutions.

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"Schools that are trying to address bullying need to have a comprehensive plan," she says. "The first step should be, 'Let's see what we've got going on here.'"

Educators should study incidents of bullying that have taken place and look for patterns, Mullin adds. Staff must

consistently show they will always respond to and intervene with bullying.

Christian credits Roundtown's counselor, Susan Landis, with helping make the school a welcoming place.

Landis says the school's ability to be responsive is influenced by the Green Circle curriculum, which has three parts: caring, sharing and respect. Green Circle is referenced throughout the school year in lessons about how all people are different and how they may make friends differently too. The curriculum is used district wide.

Harbour View School in suburban Los Angeles has a Buddy Bench on its main playground and Buddy Chairs in its kindergarten play area. The idea came from a second-grader at Harbour View who learned about Roundtown's bench. Principal Cindy Osterhout says the bench and chairs enhance the school's use of Positive Behavioral Interventions and Supports, which emphasizes how to act respectfully rather than telling kids what not to do.

Educators who have used Buddy Benches effectively introduce the benches and their purpose during assemblies at the beginning of the year and continue to talk about the benches all year in conjunction with other effortsto promote a friendly school community. Each new student at Harbour View is paired with a fourth- or fifth-grader who helps the child collect stamps on a "passport." Along with stops at the library and principal's office, the tour includes sitting with the partner on the Buddy Bench during recess.

The website for Christian's Buddy Bench suggests these rules.

- Before you sit on the Buddy Bench, think of something you would like to do. Ask someone else to play with you.
- The bench isn't for socializing. Only sit there if you can't find anyone to play with.
- While you're sitting on the bench, look around for a game you can join.
- If you see something you want to do or a friend you want to talk to, get off the bench!
- When you see someone on the bench, ask that person to play with you.
- If you're sitting on the bench, play with the first classmate who invites you.
- Keep playing with your new friends!

#### A Child-Friendly Approach

While some might think sitting on the bench would invite bullying of a lonely child, kids at schools that have them say that doesn't make sense.

"They just think it's sad to not have anyone to play with," says Zoey Ricigliano, a second-grader at Yardville Elementary in Trenton, New Jersey. "Our school isn't just teaching us math and writing, but how to be nice."

Students point out other benefits of having a Buddy Bench. Kids might be alone at recess because they're in timeout for poor behavior, or they want some time to think. But a child on the bench clearly wants a friend.

In Pennsylvania, Graf speaks with students in terms of the Vernfield Vision, a mission statement that includes the line, "I will take care of other people, myself and my school." He says Buddy Benches are another way to care for people.

"I think we're doing a good job with them," says fifth-grader Julia Vizza. "When I look over to them they're usually empty."

VanderMeulen is a freelance writer who specializes in education. She is currently working toward a master's degree in school counseling.



#### **Exceptional Lives How-to Guides**

Exceptional Lives just released the newest versions of its free online Guides for parents of children or adults with disabilities. Exceptional Lives Guides help parents navigate through difficult processes such as how to:

- Access SSI and other government benefits
- Find out if a child qualifies for special education
- Create an effective IEP
- Obtain guardianship or explore alternatives
- Optimize their child's health insurance



These Guides now have improved ease-of-use and new features that were driven by parent feedback - such as an interactive to-do checklist. We hope they make it even easier for parents to access services for their exceptional family member. These guides can be found at: http://info.exceptionallives.org/our-guides

### PCA Overtime - Public Hearing

The U.S. Department of Labor recently enacted a requirement to pay PCA's overtime. This requirement will cost the state additional money with current policies so MassHealth has proposed some new rules. MassHealth plans to restrict use of overtime by PCAs starting September 1. Unfortunately, these new rules will affect many consumers of PCA services.

Consumers most impacted by these changes use one PCA for more than 40 hours per week, and/or use a PCA(s) who work over 40 hours per week. Each piece of the proposal has its own complexities and issues - we strongly encourage all PCA users affected to weigh in with your needs, and why these changes might affect you adversely. As the state develops its exemption policy and implementation plan-which will be vital if the changes are enacted- it plans to consult a working group. People interested in joining this working group should contact PCA Program Manager Betsy Connell at MassHealth, at <a href="mailto:Elizabeth.Connell@MassMail.State.MA.US">Elizabeth.Connell@MassMail.State.MA.US</a>.

You can submit formal comments on the proposed regulations to the Assistant Secretary for MassHealth, EOHHS, One Ashburton Place, Room 1109, Boston, Massachusetts 02108, or e-mail them to masshealthpublicnotice@state.ma.us. E-mailed comments should contain the sender's name, mailing address, and organization or affiliation, if any. Comments will be accepted through 5:00 p.m. on Friday, July 8, 2016. The proposed regulations - 130 CMR 422.000: Personal Care Services - are available at mass.gov website.

## THE START OF A NEW DAY FOR STUDENTS WITH DISABILITIES

The path that leads a young man or woman from being a student into becoming an adult is not an easy road to travel. For people with significant disabilities it is even more challenging. For most students, turning eighteen and graduating from High School represents the start of something new and exciting. It is a time for starting a career, continuing one's education at a local college or university or moving into their own apartment. For young men and women with significant disabilities the path is not as clear and the opportunities that exist for a typical teenager do not always exist for those with special needs.

The Building Futures Project has been providing highly customized services and supports to school aged youth (14 - 22) from local public school systems since 1999. Specific focus is on helping students develop a foundation of experiences and skills that will need for when they

leave the school system. The Building Futures Project provides individualized supports in career exploration, finding paid employment, developing friendships, auditing College classes, learning practical life-skills and person centered planning.

One area we focus on is job exploration and finding meaningful paid employment. There are many reasons why people work. Naturally, there is a lot of excitement when payday comes around and the person opens their pay check. The satisfaction of making new friends, doing something productive in a job that is valued and meaningful, as well as learning new work skills all contribute towards preparing a person for the future.

There is a growing awareness among employers about the value of hiring a young man or woman with a disability. It is not uncommon to find students with special needs working in after

# HOW CAN BUILDING FUTURES HELP YOUR CHILD?

By offering customized supports to students with disabilities in local school systems.

We recognize that young people with disabilities and their families have dreams and visions for the future. It does require thoughtful planning and commitment to ensure that students with special needs have the same opportunities as other teenagers to work, have friends, to further their education and to be fully active members of their own communities.

school, weekend and summer jobs. There are however, several steps that need to take place before they start working. There needs to be planning and preparation with the person as to what they would like to do for work. Often a student likes the idea of working and making money but does not have the information as to what types of jobs are available. To introduce students to the "world of work" going on tours of local businesses, attending informational interviews, doing internships and volunteer work are all different ways for a person to learn about the range of jobs that exist. With this information the student is in a better position to make a more informed choice as to what he or she may want to do for work.

For young people with disabilities this job exploration should be seen as the start of the process of discovering one's talents, strengths and interests. A support person provided through the Building Futures Project works with the student to ensure that they find a job that they like and then provides the support to learn and maintain the job. For more information please contact Ross Hooley, Director of the Building Futures Project at 508 999-4436 ext 162.

## FREE FUN FRIDAYS!

#### 8 SITES OPEN FOR FREE EACH FRIDAY

10 FRIDAYS. 100% FREE.

**Tanglewood** 

Lyric Stage Company of Boston

Clark Art Institute MASS MoCA

Worcester Art Museum

Children's Museum at Holyoke International Volleyball Hall of Fame

The Mount: Edith Wharton's Home

Boston Children's Museum

The Sports Museum

Heritage Museums & Gardens

Falmouth Museums on the Green

Cape Cod Maritime Museum

Amelia Park Children's Museum

Jacob's Pillow Dance Festival

Wenham Museum

Museum of Fine Arts, Boston

Plimoth Plantation

Peabody Essex Museum

Cape Ann Museum

Buttonwood Park Zoo

Children's Museum in Easton

The Hall at Patriot Place

Provincetown Art Association and Museum

Edward M. Kennedy Institute

**Boston Athenæum** 

Larz Anderson Museum

Cape Cod Children's Museum

**Edward Gorey House** 

Danforth Art Museum\School

Spellman Museum of Stamps & Postal History

Fitchburg Art Museum

Boston Harbor Islands National and State Park Arnold Arboretum of Harvard University

**New Bedford Whaling Museum** 

Cape Cod Museum of Art

Pilgrim Hall Museum

The Eric Carle Museum

Fruitlands Museum

Museum of Russian Icons

John F. Kennedy Presidential Library & Museum

Commonwealth Museum

**Battleship Cove** 

Marine Museum at Fall River

Sandwich Glass Museum

Nantucket Whaling Museum

**Tower Hill Botanic Garden** 

Commonwealth Shakespeare Company

Harvard Museum of Natural History

The Old State House

The Greenway Carousel

Springfield Museums

**Historic Deerfield** 

Hancock Shaker Village

The Old Manse, The Trustees

Worcester Historical Museum

MIT Museum

The Museum of the NCAAA

**Concord Museum** 

Garden in the Woods

Mahaiwe Performing Arts Center

Naumkeag, The Trustees

**Emily Dickinson Museum** 

The Metropolitan Waterworks Museum

The Institute of Contemporary Art/Boston

**USS Constitution Museum** 

The Discovery Museums

**EcoTarium** 

The Children's Museum of Greater Fall River

**New England Historic Genealogical Society** 

**Fuller Craft Museum** 

Griffin Photography Museum

Franklin Park Zoo

Old Sturbridge Village

Freedom Trail Foundation

Museum of African American History

Norman Rockwell Museum

Berkshire Museum

Ventfort Hall Mansion and Gilded Age Museum

Cape Cod Museum of Natural History



# See More Summer



Please visit HighlandStreet.org or call 617.969.8900 for more information.







#### Wrightslaw Special Education Law and Advocacy Conference with Pete Wright, Esq.

#### Thursday, October 27, 2016

Wrightslaw Special Education Law and Advocacy Conference, a <u>Wrightslaw training program</u> featuring <u>Pete Wright, Esq.</u>, is being sponsored by the <u>HMEA Autism Resource</u> Central.

The program will be held at:

Sturbridge Host Hotel Conference Center 366 Main Street Sturbridge, MA 01566

#### **Program Description**

One-day special education law and advocacy programs focus on four areas:



- special education law, rights and responsibilities
- tests and measurements to measure progress & regression
- SMART IEPs
- introduction to tactics & strategies for effective advocacy

<u>Wrightslaw programs</u> are designed to meet the needs of parents, educators, health care providers, advocates and attorneys who represent children with disabilities regarding special education. The program is not disability specific.

Conference fee includes Continental Breakfast, lunch, PM snack, a Wrightslaw highlighter pen and the three Wrightslaw books which retail for **\$62.85** - <u>Wrightslaw: Special Education Law, 2nd Edition</u>, <u>Wrightslaw: From Emotions to Advocacy, 2nd Edition</u>, and <u>Wrightslaw: All About IEPs</u>.

For more information and to register go to: http://www.autismresourcecentral.org and click on "what we offer"

## nemasket group

NON PROFIT ORGANIZATION US POSTAGE PAID NEW BEDFORD, MA PERMIT NO. 651

#### **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



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

