

# Family Connections Center

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## Please Reach Out Again to Your Senator and Representative

*Conference committee to meet about State Budget*

Two weeks ago, the Senate finished its version of the 2014 fiscal year budget, thus the House and Senate will meet this month in conference committee to reconcile differences to send a final budget to the Governor. Both the Senate and House versions of the budget reflect positive developments for our constituents. The Senate budget included Salary Reserve one-time funding at 11.5 million dollars (\$4.5 M higher than House), 7 million dollars for Turning 22 (1 M higher than the House), Community Residential at 3M more than the House, and language in the Autism Waiver to require a posted annual open enrollment period. The House budget included \$500,000 more than the Senate for Transportation and \$500,000 more than the Senate in the Employment/Day account as well. (Two items of interest – Family Supports (51M) and the DESE/DDS Family Preservation (6.5M) accounts are the same dollar amount in both the House and Senate so are not subject to conference committee.)

You now have an opportunity to contact your senator and representative to advocate for our budget priorities, with the Senate and House Ways and Means budget committee conferences. In the coming days, please directly appeal to your senator and representative to request that they raise our priorities in writing to the budget conference committee members who will finalize the Fiscal Year 2014 budget. In addition there is a possibility that the administration will request additional residential services funding for Chapter 257. We are waiting on that news.

Budget priorities for your senator and representative to advance include:

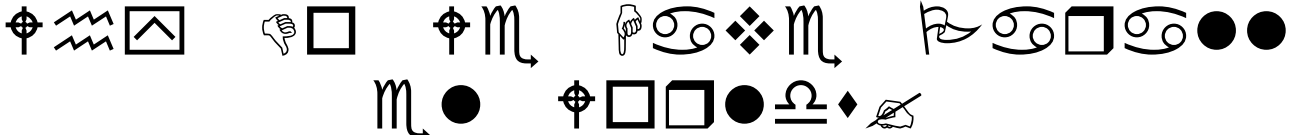
- Turning 22 – Senate (7M)
- Residential Services Funding – Senate (3M higher than House)
- Autism Waiver – Senate language
- Salary Reserve for direct-care staff – Senate (11.5M)
- Transportation – House (\$500K higher)
- Employment/Day – House (\$500K higher)

Together, we must ensure that all DDS accounts are adequately funded so that individuals get the services they need to lead fulfilling lives in the community. Do not delay in contacting your legislators and encouraging others to do so. The numbers of people who act will make a difference.

Please go to [www.arcmass.org](http://www.arcmass.org) and click on the TAKE ACTION button to send a message to your Senator or Representative.

# Food for *Thought*

## Questioning Conventional Wisdom



A 20-year-old woman moves away from home. Her parents know she still has a lot to learn. They trust she'll learn what she needs to know – through experience, just like they did, just like most young adults do.

A 35-year-old woman with a disability has lived in a group home for fifteen years. She wanted to move out on her own when she was 20, but her parents said she wasn't ready, so they put her in the group home. Now the group home staff tells her she's still not ready, and that she can't even consider living on her own until she meets the goals of her IHP (Individual Habitation Plan), which include: cook efficiently, do laundry appropriately, wash the dishes within 20 minutes of finishing a meal, make the bed within 30 minutes of getting up, and so on and so on and so on.

A 16-year-old boy applies for a job at every fast food restaurant in his part of town. His parents and friends give him a little advice on how to handle a job interview. He finds a job and begins saving money for a car. He's on his way to adulthood.

A 16-year-old boy with a disability wants to get a part-time job. But no one thinks he's ready (or able) to do this on his own. So his parents, special ed teacher, and a vocational-rehabilitation counselor convene an IEP (Individualized Education Program) meeting to talk about this issue. The voc-rehab counselor and the special ed teacher will try to get him a job; they know best. Six months later, he's still waiting.

A 10-year-old girl struggles with math and reading. Her parents give her extra help at home and they enroll her in after-school classes at a private learning center. Her classroom teacher is giving her more help at school. Everyone knows she'll catch up.

A 10-year-old girl with a disability label struggles with math and reading. Educators believe – based on her IQ score – that she'll never master either. So her IEP goals are not focused on daily living skills in the special ed resource room. Her parents are told to get their daughter on the waiting list for adult services so she'll be assured of a group home placement when she ages out of special education services at age 22.

The mother of a 3-year-old wants her child to spend time with other young children. She visits several preschools close to her home (unannounced visits), interviews the directors and teachers about the 3-year-old Tuesday-Thursday half-day class, and talks to other parents whose children are enrolled at the preschool. She's determined to find the place that's right for her child!

The mother of a 3-year-old with a disability is told which special ed preschool her child will attend. She's not crazy about putting her child on the school bus five days a week for the 45-minute ride each way (at 8:30 am and 3:30 pm), and she doesn't visit the school to check it out. She'd really like to keep her child home with her – she can't imagine her son being away from her all day (and taking naps at school). She also thinks she's been doing a good job helping him learn new things. But she figures the professionals at the segregated special ed preschool must know best.

The parents of an 11-month-old are eagerly planning the baby's first birthday party! Being first time parents, they've had some struggles, but their families and friends have helped them over the rough spots. Life couldn't be better!

The parents of an 11-month-old with a disability are nervously anticipating the IFSP (Individualized Family Service Plan) meeting coming up next month. The Service Coordinator, the therapists, and the baby's mother are concerned the baby isn't meeting all the goals. The mother is worn out from all the therapies and services, but she feels these things are important. The father is not so sure. He thinks all this is too much – birthday party plans aren't even on the horizon for his baby son – and he's ready for family life to go back to normal. The marriage is becoming strained.

Why do we have Parallel Worlds? Why are there separate Rules for people who have been labeled with disabilities, and why do so many people with disabilities and family members follow those Rules, even when they don't seem to make much sense? Why should the lives of people with disabilities be so different from the lives of people who don't have disabilities?

How can the staff at a group home impose goals for the 35-year-old that *they don't follow themselves*? When questioned, most admitted they don't always do the dishes within 20 minutes of finishing a meal, and some *never* make their beds! Further, they admitted that they don't know how to do lots of things when *they* left home so many years ago. Perhaps more importantly, *why didn't this woman's parents teach her these things as she was growing up?*

If the government mandates Rules (like writing IHP goals) for those receiving government assistance, can't we at least make the goals relevant, meaningful, and realistic? Define "cooking"! Must "cooking" mean reading and following a recipe book, or can we admit that "cooking" may actually mean pouring milk over a bowl of cereal for breakfast, making a sandwich for lunch and putting a TV dinner in the microwave for the evening meal? How many men and women who *are employed* in a group home or congregate living setting actually crack a recipe book every evening to cook a meal from scratch? If *they* don't have to do this, why should a person with a disability be required to meet this goal?

Why should a teenager with a disability wait on special educators and voc-rehab counselors to get him a job? Why shouldn't he try to get a job on

his own, with the help of parents and friend? If his parents shopped at a store that sold lousy products or had bad service, they'd try another store. Why do they continue to accept lousy service from people in The System? Why don't *they* help their son move on with his life?

Why do the parents of the 10-year-old girls with a disability depend on the special ed department for everything? Why don't *they* research other ways of helping their daughter learn academic skills, like computer programs at home, private learning centers, or even hiring a regular ed teacher as a private tutor? And why do they accept the *validity* of the school's assessments of their daughter's abilities and potential?

Why doesn't the mother of the 3-year-old with a disability take as much care investigating the special ed preschool as she would if her child *didn't* have a disability? If she's not comfortable with the services offered, why doesn't she say no? How many parents of 3-year-olds without disabilities would put their little ones on a 45-minute bus trip to a place they know little or nothing about? And why does this mother believe the experts' opinions that the only place that's appropriate for her child is a segregated environment?

Why don't the parents of the baby with a disability say no to the therapies and interventions that cause disruptions and discord in their family's life? If they truly believe their baby needs ongoing professional help, why don't they redesign the help so it's more natural and less intrusive, so they can ensure their baby lives the life of a baby, instead of a patient who needs to be "fixed" via therapies and interventions?

Yes, within the system of services for people with disabilities, sets of rules create Parallel Worlds. And too many people with disabilities and their families exist in Disability World – a surreal world that isolates and segregates them from the Real World. Disability World is created by the

service system and its rules. It continues to exist only because people with disabilities/family members choose to use The System to follow its Rules.

Service professionals are expected to enforce The Rules. Many do so, without question. Others are beginning to see the unintended negative outcomes of these Rules, and they're bending (and sometimes breaking) many of the ridiculous Rules that are hurtful instead of helpful.

Some people with disabilities and family members follow The Rules without question. Others try to bend the rules, and still others are saying no as they pack their bags and leave Disability World once and for all.

The path that's chosen – whether a person is a "provider" of services or a "recipient" of services – seems to be determined by one's belief system. If a person ("provider" or "recipient") believes people with disabilities and/or family members are needy, unable, and/or entitled, and also believes

that The System can provide all the answers, this person embraces The Rules. And amazingly, there are many people who profess to hate The System and its Rules, but they continue to *defend and protect* both.

I've met educators, for example, who dislike the segregation of students with disabilities. But they stay in their jobs as special educators (educating students with disabilities in segregated special ed/resource rooms) while they attempt to "change the system." My best friend, Charmaine – a special educator – tried this for a few years before she saw the light (or actually the dark). When she realized she could not change her school alone, she shed her "special ed teacher" label, became a second grade teacher, and made sure second-graders who had disabilities were included in her classroom.

**One overall belief  
can guide us: if it's  
not okay for  
people *without*  
disabilities, it's not  
okay for people  
*with* disabilities.**

At the other end are parents who feel they are constantly “fighting The System” (and as a result, they’re emotional and physical wrecks). Most of them are terribly unhappy with The System and its services and bureaucratic red tape, but they refuse to look into alternatives, determined to (1) get their child’s “entitlements” and/or (2) “change the system.” In the meantime, their children are in suspended animation – not getting what they really need (from any source possible), being segregated, living unnatural lives, and more.

If, on the other hand, a person believes that people with disabilities are competent, able, and “okay just the way they are,” they try to bend or break The System’s Rules so they’ll make more sense. If that doesn’t work, parents and/or people with disabilities *cut their losses and move on*, using alternative sources of assistance; and professionals change careers (as my friend did). Still others deny the validity of today’s conventional wisdom, and choose to live without The System and its Rules. My hope is that individuals and their families will begin to use The System as a last resort, instead of the first choice. I hope we’ll look to the natural supports and generic services in our communities for the assistance an individual/family might need—and go to The System, again, only as a last resort.

If we pause and ask why we do what we do, and then wonder how we can do things differently, and when we act more humanely and consider the feelings and real needs of people with disabilities, change will come. Service providers can help by providing people with disabilities the assistance they need to meet their *real* life goals instead of focusing on the achievement of “life skills” which they, as service providers, don’t always meet! And they can ask themselves, “how would I feel if someone wanted to write an IHP for *me*?” (Most, if not all, wouldn’t stand for this!) Pondering gives rise to new ways of thinking.

People with disabilities and parents can take more personal responsibility for their lives and move away from dependence on the services that

**There are no secrets.  
There is no mystery.  
There is only common sense.**

Onondaga Proverb

frequently make their lives worse, instead of better. They can and should decide what’s important and right, instead of assuming others know best.

Each of us can create community connections to ensure individuals with disabilities are included, and that they receive assistance from the natural supports and generic services in their communities. Other articles on this subject are available at [www.disabilityisnatural.com](http://www.disabilityisnatural.com), and the strategies in my *Disability is Natural* book can lead us in new directions.

One overall belief can guide us: if it’s not ok for people *without* disabilities, it’s not okay for people *with* disabilities. For example:

- If it’s not okay to make a 35-year old *without* a disability live under the supervision of others until he can cook and do laundry, it’s not okay to enforce that rule on a 35-year-old *with* a disability.
- If it’s not okay to talk about the “problems” of a person *without* a disability, in front of him, like he’s not even there, while ignoring his strengths and abilities, it’s not okay to do this to a person *with* a disability.

Consider the countless other situations in which you could apply this new way of thinking, which can help eliminate Parallel Worlds. Then spend some time pondering all The Rules (spoken and unspoken) that are applied to the individual(s) with disabilities in your life. Question if they reflect common sense – if they’re relevant, meaningful, dignified, honest, and realistic. When you do, the bustling activity of your wondering brain – and the conclusions you reach – will astound you!

# Available *Resources*

## **When Behavior Gets in the Way: Creating Caring Schools and Communities**

**The National Center on Inclusive Education Summer Institute**

### **General Info**

#### **Conference Description**

The Institute on Disability's National Center on Inclusive Education (NCIE) Summer Institute builds upon 15 years of experience presenting high quality, evidence-based conferences that serve professionals, families, and self-advocates by providing the latest information and practical strategies in the areas of inclusive education, post-secondary transition, and autism. The 2013 conference, **When Behavior Gets in the Way: Creating Caring Schools and Communities**, will provide learning experiences for families, educators, community services providers, community mental health professionals, and self-advocates who are working to promote inclusive education and transition experiences for students who have challenging behaviors.

This year, we have organized the conference into five strands over three days:

- Every Student College and Career Ready: Positive Behavioral Interventions and Supports in Schools
- The Communication & Behavior Relationship: Focus on Augmentative Communication and Students Taking the Alternate Assessment
- Inclusive Classroom Strategies that Promote Positive Relationships, Behavior, and Learning
- Youth Leadership
- Contemporary Topics

Conference participants may attend sessions in one strand or may mix and match sessions from the five strands according to their interests to create a custom learning experience.

#### **Who Should Attend**

The NCIE Summer Institute is designed for and will benefit individuals with disabilities and/or challenging behaviors, parents, educators, paraeducators, school administrators, guidance counselors, related services providers, psychologists, university students, educational teams including families, and others interested in creating more inclusive opportunities for students with disabilities.

#### **Professional Development**

All participants will receive a Certificate of Participation. The NCIE Summer Institute qualifies for 24 Staff Development Hours.

#### **Event Contact**

Name: Cat Jones  
Email: [events.iod@unh.edu](mailto:events.iod@unh.edu)  
Phone: 603.228.2084  
Website: [radisson.com/manchester](http://radisson.com/manchester)

**July 29-July 31**  
**8:00 am – 4:00 pm**

# Information to *Share*

## Parents Supporting Parents



July 11, 2013 10a.m.-12:00  
August 7, 2013 10 a.m.-12:00  
September 18, 2013 10 a.m.-12:00



### Parent/Caregiver "Walk in the Park" Support Group

Join us here at The Nemasket Group (weather permitting) for the beginning of our spring/summer Parent Support Group series. Walking is a great way to get your mind off of distressing concerns and daily pressures. Come join us for a relaxing stroll around Cushman Park.

Our goal is to create a safe & welcoming place for parents/caregivers of individuals with special needs to:

- Provide emotional and practical support
- Offer encouragement
- Reduce stress
- Develop friendships



Water bottles will be provided, please wear comfortable shoes

"You alone can do it-but you can't do it alone"

# Save the Date

Easter Seals is proud to host the **Assistive Technology Pavilion: Interact with Tomorrow's Technology Today** at the Abilities Expo, coming to Boston September 20-22, 2013.

Learn more about this dynamic conference at: [www.abilitiesexpo.com](http://www.abilitiesexpo.com)

The assistive technology that innovators have devised to bridge the divide between ability and disability is nothing short of amazing. At AbilitiesExpo, we welcome you to visit our **Assistive Technology Pavilion**, where companies and organizations are featuring the latest AT products for people of all ages with wide ranges of physical, sensory, developmental and learning disabilities. You or your loved ones will have the unique opportunity to experience how these adaptive technologies can enhance day-to-day life.



The Nemasket Group's

## Summer Sizzler



DATE: August 15, 2013

(rain or shine)

TIME: 4:00 - 7:00 pm

LOCATION: The Nemasket Group

56 Bridge Street, Fairhaven, MA 02719

Come celebrate summer with the staff and families of The Nemasket Group and the Family Connections Center. Join us for a cook-out and lots of fun!

Food and drinks will be provided by The Nemasket Group. Families are asked to bring dessert and lawn chairs.



We hope you can join us!







## *Family Connections Center Invites You To*

# SSI/PUBLIC BENEFITS FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS



JULY 31<sup>st</sup> 10-12  
 The Nemasket Group  
 56 Bridge Street  
 Fairhaven, MA 02719

This training is meant to help learn about supplemental security income (SSI), CommonHealth, Kaileigh Mulligan Home Care Program and other public benefits for children...

Presented by Gail Havelick, SSI/Public Benefits and Training and Policy Specialist Division for Prenatal, Early Childhood and Special Health Needs Bureau of Family Health and Nutrition MA Department of Public Health

*This training is free, but space is limited so please RSVP to Kathleen Amaral 508-999-4436x133 no later than July 24th*



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 The Nemasket Group  
 on Facebook!**



Like us on  
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# 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



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



## Save the Date

Monday August 26, 2013

The Louis Nisenbaum Memorial Golf Tournament  
to benefit The Nemasket Group  
at the Country Club of New Bedford



Come join us for a fun afternoon of lunch, golf, dinner, raffle  
and auction all to benefit The Nemasket Group. The cost to play  
is \$175 and includes lunch, golf, dinner, and auction and award ceremony.

If golfing is not your sport you can always join us for dinner  
and the festivities (auction, raffle and awards) after the game.

If you know of someone who would like to play in the tournament,  
sponsor a hole or donate a raffle or auction prize please contact  
Patricia Janiak at [patricijaniak@nemasketgroup.org](mailto:patricijaniak@nemasketgroup.org) or call 508-999-4436 ext.101.