A Message to our Families

For those of you who don’t know the movie Groundhog Day, the main character, Bill Murray, is doomed to live the same day, over and over and over again. Similarly, Community Partners’ families must, every two years, repeat the cycle of going to Concord to advocate that our legislature adequately fund the services that our family members with disabilities so need to have a productive, inclusive life. What some call “The New Hampshire Advantage,” ends up pitting many deserving entities in a battle to sustain their programs because of scant resources. Intermingled at budget public hearings are stories of why substance abuse services are needed, why domestic violence programs save lives, stories of long waits in emergency rooms of local hospitals because inpatient behavioral health services are at capacity, and, of course, worried parents of individuals with developmental disabilities about potential cuts to existing programs and whether a program will even be there when their child reaches 21 and leaves school. This is not something you should ignore and hope others will deal with. As my friend, Pete Eldredge says, “Everyone does nothing, equally well.” We will be looking to parents of school aged children to become seasoned legislative advocates to fight the good fight in Concord, and Community Partners will be with you each step of the way on your journey. It can be a lot of work but you’ll get to do it with, as well as benefit, a lot of other wonderful families.

Yes, I’m Retiring...  

It was 20 years ago, April 1995, that we decided to start a quarterly Family Support Newsletter and I volunteered to be the editor. I recently looked back at issue #1 and saw that Family Advisory Council members included Karen Salter and Pete Eldredge, both of whom continue to serve to this day. The issue also urged families to apply for summer recreation and camp assistance; to sign up to go to the Family Support Conference at Settler’s Green in North Conway; and to write to their legislators over looming budget cuts. Some things haven’t changed but the fact that our good work continues is because of support we get from you, our families.

It is with both sadness and excitement that I am turning over the editorial reins to Denice Albert who will be our new newsletter editor. With her new ideas, I am looking forward to seeing how the newsletter will evolve. And since the length of tenure as newsletter editor is established at 20 years, Denice should be at the helm through the year 2035.

I know I won’t be able to meet with and say goodbye to everyone I’ve had the pleasure of working with, both currently and the past. Over the last 30 years, while working primarily as the agency’s Transition Coordinator, I’ve met and worked with hundreds of amazing students, families, educators, colleagues, and co-workers, while working in Family Support, which is clearly the best team to be a part of, here at Community Partners. And if the legislature doesn’t totally defund us, I know you will be in good hands in the future. Bottom line though, as I said in the above article, you must keep vigilant to what is happening in Concord.

I will think of you all often.

Next on my agenda is to go to my town hall and get my 2015 beach sticker. (half price—senior rates!)
Autism Awareness at StoryLand—June 27 & 28

StoryLand and Autism Speaks will cosponsor an Autism Awareness Weekend at StoryLand. It will be held on June 27 & 28, 2015. Discounted Tickets are available for $20 each. If this date doesn’t work, the tickets can also be used any time between June 1, 2015-July 31, 2015. (Tickets are not valid outside that time-frame). To purchase tickets, please visit [http://events.autismspeaks.org/StoryLand2015](http://events.autismspeaks.org/StoryLand2015).

Tickets will be mailed to you via US Postal Service. PLEASE allow 5 business days for your tickets to arrive. Tickets must be purchased online at the link above. Deadline to purchase is June 22.

Highlights:
- staff are trained to work with individuals with ASD
- information tables staffed by autism support volunteers & professionals throughout the park
- designated quiet area

Note: A portion of your ticket is a donation to Autism Speaks. Thank you for your support! For information on specially-discounted lodging options with the nearby Red Jacket Mountain View Resort & Kahuna Laguna Water Park, please contact them (603) 356-5411.

GEMSS: Genetics Education Materials for School Success

As part of the NH Leadership Series, an Action Group has formed to help promote and bring about awareness of a website that they hope you will be able to use as a resource. The aim of GEMSS is to assure that all children with genetic health conditions will succeed in school life. Children who have genetic conditions are members of neighborhood schools across the country. In fact, it has been estimated that about 1 in 20 children have a genetic condition. GEMSS are tools for schools and were developed for teachers, schools and parents, by the Education & Outreach work group within the New England Genetics Collaborative (NEGC). The NEGC is a group of specialists and providers from the six New England states: Connecticut, Maine, Massachusetts, New Hampshire, Rhode Island, and Vermont.

There are many ways in which GEMSS can help you, including: developing lesson plans, providing backup documentation for meetings, IEP Development, support for Children with challenges who are not diagnosed, Staff Training, preparing for educational and medical transitions, modifying Physical Activity/Education, support to assist children to be able to go on a field trip, and help planning for lunch room meals and snacks.

Please visit their website at:

[www.gemssforschools.org](http://www.gemssforschools.org)
Family Support Pool Party

Family Support Pool Party at the Works in March was full!! What a great way it was to pick ourselves up at the end of a long, cold winter. Here are a few pictures of families in the pool.

Spa Day 2015 - Hold the Date: 9/27/15

The next Spa Day is in the works. Partners in Health and Community Partners’ Family Support are once again hosting a spa day for caregivers. We had a great turnout last year at the Frisbie Conference Center in Rochester. Everyone enjoyed a lovely brunch, massage, Reiki, meditation and relaxation. Mark your calendars for Sunday, September 27, 2015. More information will follow as we get closer to September.

Self Directed Services Info Night: 6/18/15 @ 6:00pm

If you are considering or just want more information about Self Directed Services be sure to register for their required information nights. Self Directed Services (also known at PDMS: Participant Directed and Managed Services) is a program for individuals eligible for developmental services and who are over the age of 21. It allows the family the ability to design and oversee the services their family member receives, an option many families enjoy. This info night will give you an overview of what you can and can’t do in a PDMS program. RSVPs are required: Call Amy Cook at 516-9305 or email Amy at: acook@communitypartnersnh.org. Attending an info night is required prior to starting PDMS services and are held quarterly. The next one after this will be sometime in the fall.

       June 18th, 2015 from 6:00 to 7:30—Crosby Community Office, 113 Crosby Rd , Unit 6, Dover, NH
Parent Connections  Betsy Carroll

Just a reminder that Family Support now has a Facebook page that is just for parents in Strafford County connected with Community Partners. Friend us on Facebook at Family Support Community Forum and we will get back to you. It’s a great way to provide support as well as receive feedback for what’s on your mind. Denice posts some useful information that you don’t want to miss!

Another way to connect with other parents is to check out the Supporting Parents On-Line Training Program at www.nhfamilyties.org. It would be so helpful to have more parents in our region trained utilizing this easy on-line opportunity. My vision is to then meet with those parents who have taken the time to do this and provide an opportunity to talk about the process and answer any questions. Feel free to contact Betsy at 516-9323 if you are now in a position to support others on their journey as a parent of a child with a disability.

NH Care Path

In New Hampshire, there are many paths available to help people of all ages live better in their communities. The vision of a No Wrong Door system has been established as the go-to system for community long term services and supports. The new website, www.nhservicesandsupports.org, is designed to be a resource for people looking for information about services and supports for families, caregivers, older adults, and persons living with a disability.

Fun in the Sun at White Lake

Sunday, July 26th

Save the date for Fun in the Sun at White Lake. Please note that it says Sun and not Rain (as was the weather last year). Flyers will be going out in July.

Buddy Ball

Check out Buddy Ball at Howie’s Field of Dreams in Rochester. This might be a fun activity for spring and summer and this year they have 4 teams!

Their website is www/howiesfieldofdreams.com.
Teen Fun!

We have had 3 fun-filled teen groups since our last newsletter. On Feb. 7 the group went tubing at Gunstock. March 15 was a fun afternoon of trying out a variety of cycles with Northeast Passage. On April 17 there was a pizza and movie night (Big Hero Six) at our Crosby Community Office. What a great group of teenagers! Check out some of the pictures. Our next Teen Group will be a hike at Northwood Meadows off Route 4 in Northwood on 5/30/15. Call Betsy at 516-9323 for more information and to sign up.

What does the ADA (Americans with Disabilities Act) say about Daycare?

The ADA protects individuals with disabilities across a spectrum of locations and services. The ADA does apply to privately run as well as home day care providers. Like restaurants, schools, and recreation centers; child care providers must comply with Title III of the ADA. Even small home based child care centers that may not have to comply with certain state laws have to comply with Title III of the ADA. Only centers run by religious entities are not required to comply with the ADA.

The ADA requires that child care providers not discriminate against people with disabilities and that they provide children and parents with disabilities equal opportunity to participate in the center’s programs and services. Centers cannot exclude children with disabilities unless their presence poses a direct threat to the health and safety of others or requires a “fundamental alteration” of the program. Centers do have to provide “reasonable accommodation” but not “fundamental alteration”. Where this line is can be contentious between parents and providers.

Centers must provide appropriate aids and services for effective communication. Barrier removal is subject to the “readily achievable” standard while any new construction and remodeling must meet ADA standards.

Child Care Centers cannot just assume that a child’s disabilities are too severe for the child to be integrated into the program, rather it must undertake a “individualized assessment” about whether it can meet the child’s needs.

Adapted from the Rocky Mountain ADA Center
They say when you’ve met one person with autism, you’ve met one person with autism. Not one individual with Autism Spectrum Disorder (ASD) is the same. Sure, they may have some similar "visible" traits: the hand flapping, the vocalizing, the repetition ... but not one of them is cut from the same mold. There are so many varying degrees of ASD and I know this all too well. I live with it every day. Both of my children are autistic. They are autistic and beautiful.

People say to me all the time, "I don't know how you do it". Well, sometimes I don't either. And honestly, there are days when I feel like I can't. But I do it because it's what I do. I'm a mom with two autistic kids. Disability or no disability, they're my adorable, loving, polar-opposite children. No, I may not be able to take them both to the grocery store, to a restaurant, or even on a walk without the help of family, friends and personal care providers, but my kids are happy. Their smiles and laughter are infectious. And despite the multitude of challenges they face day in and day out, they amaze and inspire me with their resilience and their ability to adjust and adapt to a “typical” world, one where they’re seen as “different.”

Is it easy raising two kids on the Autism Spectrum? Absolutely not. Everyday is a different adventure. I need to recognize the signs of an impending meltdown, find ways to address aggression and unsafe behavior, figure out what my non-verbal daughter is trying to tell me, and why my son is all of a sudden dead-set against doing something he usually loves. The same video clip can be seen and heard hundreds of times a day (on multiple devices).

My daughter retreats to her tent in her room while my son likes to use his swing and occupy the entire living room with his toys and DVDs. A visual schedule is posted everyday so they know what (and who) to expect. The only time it’s quiet is at night when they’re sleeping, although even then my son may have his DVD player running. That’s not taking into account the nights that they actually sleep through, because that’s not always the case. Sleep is often hard to come by in our household.

Countless “learning moments” happen throughout the day. They’re learning and so am I. Some days are great and other days, not so much. Some can be downright discouraging. So many times, I’ve wished I could crawl into those brilliant brains of theirs and see, hear, touch and experience the world the way they do just so I could have a better understanding. Maybe I’d know how to be an even better Mom.

Perhaps by helping and educating others about my children, I can spread not only autism awareness but autism acceptance as well. My kids may be “different”, but they’re not less.
Need Disposable Toileting Garments?

If you are in need of disposable toileting supplies, an abundance have been donated to Family Support. Please contact anyone in Family Support at 516-9300 to make arrangements to take some! First come—first served.

**Adult Size:**
- 4 pkgs Prevail Disposable Underpads
- 6 cases Adult M tabbed-style briefs
- 2 cases Adult S/M pull ups
- 1 case Attends Super Plus Adult M pull ups
- 1 case Attends Super Plus Adult L pull ups
- 1 bag women’s XL pull ups

**Kids Size:**
- 1 bag Goodnight S/M
- 1 bag Sleepovers L/XL
- 2 bags White Cloud Training Pants 4T-5T
- 2 bags Huggies Slip On size 3
- Mystery bag of smaller sized diapers—both boys and girls prints

2015 Spring Transition Series a Hit with Families

A dozen or more families attended the 2015 Spring Transition Series held on two evenings this past April. The first night was in the Probate Courtroom where families had a chance to learn about the process of becoming a guardian, as well as the role of a guardian. The presenter was Judge Gary Cassavechia who has presided over our families’ guardianships for about 20 years. Families had a chance to get their questions answered. Thanks to Judge Cassavechia for being so available to our families. The second evening gave parents a chance to learn about Social Security Law and SpecialNeeds Trusts. These complex topics were explained by Community Partners’ Board Chair and Attorney Chris Roundy who also answered many questions families had and we appreciate his availability for our families. Thanks also go out to Liz Fowler of our Family Support Team for her help in pulling these workshops together. These workshops will likely be repeated in 2017 and will be well publicized ahead of time.

From the Institute on Disability

The Institute on Disability is looking to connect with family members and self-advocates to share two great learning opportunities:

**NH Leadership Series** – one overnight per month for seven months. Great opportunity to build leadership skills and establish lifelong connections. A Quick video will tell you more and is at: [www.nhleadership.org](http://www.nhleadership.org). Applications are being accepted but need to be sent in ASAP.

**NH LEND program** – 9 month intensive program to develop leadership, research and clinical knowledge and skills and is held at the UNH campus, with travel to various clinical and leadership sites. This program comes with a stipend. Interested people should apply very soon as trainees are being chosen soon. Parents, siblings, self-advocates, and community professionals who have a bachelor’s degree or higher are encouraged to apply.

Ann Dillon can be reached at [ann.dillon@unh.edu](mailto:ann.dillon@unh.edu) to answer any of your questions. For LEND, you can also contact Betsy Humphreys at [Elizabeth.Humphreys@unh.edu](mailto:Elizabeth.Humphreys@unh.edu), and for NH Leadership, you can contact Deborah Genthner at [deborah.genthner@unh.edu](mailto:deborah.genthner@unh.edu).
Summer is Coming Raffle

Congratulations to Jon Brown who won the gift card to The Governor's Inn. Hope you enjoyed a quiet evening of great dining. This month's Raffle is for $50.00 in Gas Cards to help with some summer family adventures. Simply return the below form to:

Denice Albert, Community Partners, 113 Crosby Rd. Dover, NH 03820

or email the below info to her at dalbert@communitypartnersnh.org. Put “Raffle” as the subject line.

Name:
Address:
Telephone: Email:

Please enter by May 29th.

This raffle only open to our eligible Family Support families who receive this newsletter through the mail or by email.