A Note from the Executive Director . . .

With another summer waning and the beginning of a new school year I wanted to take a personal approach with my note to all of you this quarter.

Today I dropped my 12-year-old with Down Syndrome off at Middle School for the first time. I have heard from fellow parents of children with disabilities who have experienced the Middle School years that these can be especially difficult years. As I walked away from the school my stomach was filled with nervous butterflies for her. I was quickly reminded of an exchange of texts from some of Sami’s wonderful teachers which emphasized without change we would never have the chance to experience something greater. Today I am embracing the opportunities change will bring to our family.

Two quick highlights from our work over the summer are the development and printing of two new guides:

- Transition Planning: A Guide for Parents of Young Adults with Disabilities
- Transitioning to Kindergarten: A Guide for Parents of Children with Disabilities

If you are interested in receiving one or both of these, contact us at (800) 870-7746 or E-mail: parentconnect@mpf.org.

We are entering the second year of our Supported Decision-Making program. If you are interested in having your family participate, we are currently looking for families of children with special healthcare needs or disabilities in grades 8 through 11. Please call or E-mail us for an application.

Some groups we are actively participating in and bring the parent voice to include:

- Preschool Developmental Grant,
- Office of Child & Family Services Advisory Group,
- Maternal Child & Health Bureau Block Grant.

Lastly, I will be speaking at the Rare Disease of New England Conference on October 26th.

May the change in season bring greater opportunities to all of you and your families!!

Kind Regards, Carrie Woodcock
What’s New in the Information Center at MPF?

Maine Parent Federation has informational packets available on more than 200 topics. These packets contain researched information, tips, local and national resources, and a list of related lending library material available here at MPF. The following information packets have recently been updated:

Disability/Disorder Related Topics:
- Bipolar
- Emotional Disturbance
- Extended School Year
- Home Schooling
- Mental Illness

If you would like to receive any of our information packets, or would like information on another topic, please contact MPF by:

- Phone: (800) 870-7746
  (Ask to speak with a Parent Information Specialist)
- E-mail: parentconnect@mpf.org
  (Please provide mailing information)

These materials are offered free of charge!

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Family Support Navigator Program

Maine Parent Federation has trained Family Support Navigators (FSN) that can help support your family at no cost to you! A FSN is an experienced parent who lives in your area and is available for one-on-one support. A FSN can help you:

- organize your paperwork.
- interview a prospective service provider.
- prepare for a meeting with your child’s doctor, school, or service provider.
- provide support at an IEP meeting.
- locate resources in your area.

To learn more about the FSN program, visit our website at www.mpf.org or call us at (800) 870-7746.

We are currently accepting referrals to the program. If you are a parent that needs help or know of a family that needs help, please contact the Regional Family Support Coordinator in your county for more information:

Androscoggin, Cumberland, Franklin, Kennebec, Knox, Lincoln, Oxford, Piscataquis, Sagadahoc, Somerset, Waldo, and York
Deborah Newcombe, (800) 870-7746, dnewcombe@mpf.org

Aroostook, Hancock, Penobscot, and Washington
Robin Levesque, (207) 538-0866, rlevesque@mpf.org.
If you parent kids with disabilities, chances are you understand how important self-care is. And if you are anything like me, self-care is often a dream easier said than done.

As parents, most of us tend to put our children and family first, leaving little time and effort to invest in us. Yet, if we do not take care of us, who will? Emotionally and physically exhausted parents are not what our kids need.

We are all unique, and self-care looks different for each one of us. Some of us need a little more than others.

Self-care does not necessarily consist of spending the day at the spa (although that would be a great day of self-care). Self-care does not always require a babysitter (although that would be ideal). Self-care can be done in small pockets of time throughout the day by doing small things that can make a big difference.

We reached out to parents in our community and asked them what self-care looked like for them.

**These were their responses:**

“Hitting the hay eight hours before I need to get up. That’s my biggest self-care move.” — Courtney C.

“Having my own space and being more independent.” — Sarah S.

“Self-care is a quiet moment alone, an extra cup of coffee, my inner voice saying, ‘you did your best and it’s OK.’” — Kristy G.

“A nap, Netflix alone in another room, time with my oldest, ordering in for supper so I don’t have to stress about a meal on an already stressful day.” — Jessica L.

“Some simple self-care things I do and that are free are a strict bedtime for all the kids, early bedtime for the kids if I’m having a bad day, nap time or rest time for kids every day so I can just veg. Get out to visit a friend for the morning, even if it means taking the kids with to play there. Taking a bath or hot shower once the kids are tucked in. Not letting the bad stuff pile on. When I feel tense and know there’s gonna be more hard stuff coming, I take the day to myself even if that means running errands all day without kids.” — Michelle R.

“Writing, journaling, blogging.” — Kelli K.

“Six years ago self-care for me was a weekly therapy session with a therapist. Too many self-care is a bath or an alone drive to Starbucks on the way home from work. If it’s been a hard week I blast music in the car, if it’s been good I go straight home to relieve my partner. In between, I try to keep my hope up and dream wildly. Having personal dreams and goals are proof that the self-care methods are working and that I’m still OK.” — Georgi S.

“The gym… I love to lift weights. I wake up at 4 a.m. to go to the gym because between my daughter, working full time and being in grad school, that’s the only time I have for myself!” — Jennifer W.

“Going to the loo by myself. Actually, having a full shower, including washing my hair, with the door closed and on my own with no interruptions. Getting dressed on my own.” — Kristen G.

“Netflix and chill — that is if my kid doesn’t have too many insomnia issues that night. Getting myself a rare coffee when I can afford it just after dropping him off at school before I have to go to work (I work from home part-time because his health makes full-time work difficult since not many employers are understanding).
Setting a price limit on birthday and Christmas gifts so there’s enough money left to buy myself something. Not answering every call or text right away — especially if the day is hectic or stressful. Quiet time with God — sometimes at night, sometimes at 4 a.m. Saying no to outings and staying home to relax. Sometimes self-care includes my child. For example, every so often we’ll cheat on his diet for one night and order take out so I can get a break from the kitchen. Self-care is so many tiny little things that add up to something super simple that might not seem like self-care to others.” — Jamie J.

“Spending time with friends is very important to me. It also makes me feel like a functional human when I can take time for my creative pursuits and engage my brain in a ‘selfish’ manner. You can’t pour from an empty cup, so keying in on what fills your cup is extremely important. It doesn’t need to be expensive or time consuming to give you a big boost.” — Kyla H.

“A shower every day, and alone time.” — Tanya S.

“Reading. Or leaving the house for a short respite somewhere local. If the above isn’t something in my reach, I hide out in my bedroom for 15 minutes with the other siblings on the watch until I return.” — Dawn M.

“A weekly Zumba class with a fellow mum of a boy with additional needs. We talk non-stop all the way in the car there and again on the way back.” — Sarah G.

“Self-care is taking a shower that’s not rushed or interrupted, lighting a candle while I enjoy a TV show and coffee, and the occasional time to craft.” — Cilla L.

“Alone time in the car with great music going or a bit longer of a shower (if I am really lucky).” — Jennifer S.

“Taking small courses on web or graphic design and practice the acquired skills in solitude at a nice cafe or restaurant. Just walking through the city or riding the subway with a good book on the phone.” — Camilla H.

“It can be a moment or two of silence, just enough to not be worried about what’s going on in the other room, little bits and pieces here and there that help me keep my sanity!” — Katrina F.

“A long shower and three one-and-a-half-hour sessions a week my daughter has with a carer. While she is asleep in the morning a quick 30-minute walk. I have an hour psychology session once every two months to talk about everything and anything.” — Tammy V.

“Self-care for me comes in a conversation with a friend. A friend who has walked this walk and understands without an explanation. Her strength is my inspiration as her child gained her wings a year and a half ago. She is my angel… and I feel as if her daughter watches over my daughter every day. I would be lost without her wisdom and guidance. We heal each other, we support each other… and I am so very thankful.” — Ally W.

“Self-care is choosing to leave my sink full of dishes one night to go to bed early.” — Heather S.

“Long baths! Naps, date nights, counseling, prayer time, walking or exercise. Doctor appointments for yourself.” — Nicole N.

“Yoga, pilates and chiropractor. Occasional/rare naps.” — Jennifer E.

“Self-care is taking the time to read, sit, walk or have a long shower when able and not feeling guilty about it.” — Sheridan P.

“Taking a bloody fantastic whole food supplement that covers for my lack of sleep, eating habits and high-stress life (and it’s doing an awesome job), bought a brilliant skin care system (including eye cream for the bags and dark circles) and use my down time (time I should probably either be sleeping, exercising, doing housework or doing more therapies with my son) to build a community with resources to support parents of children [with disabilities] to take care of their health and have goals outside of their child and build my own income stream to have my own sense of achievement and bring value to the world outside my family.” — Abigail B.

“Recognizing when I have hit my limit and allowing my partner to take over care of our daughter.” — Julia R.

“I enjoy sitting at a table and painting miniatures from popular war games. I find assembling and painting them to be very cathartic. The fine small details take a lot of focus and cause me to forget the stresses of life. Then I get to play the game with my family once the minis are all painted. I also like to play video games for some self-care. Nothing better than escaping the world for another one.” — Richard M.

“Time alone doing something I enjoy. Usually at night playing video games or watching sports.” — Andrew S.

Ellen Stumbo is the Parenting Editor at The Mighty. She is also the founder of Disability Matters, an organization with the mission to encourage every church to embrace disability.
Social Security Accelerates Decisions for People with Serious Disabilities

Agency Adds to the Compassionate Allowances List

Andrew Saul, Commissioner of Social Security, announced four new Compassionate Allowances conditions: CDKL5 Deficiency Disorder, Pitt Hopkins Syndrome, Primary Peritoneal Cancer, and Richter Syndrome. Compassionate Allowances is a program to quickly identify severe diseases and medical conditions that meet Social Security’s standards for disability benefits.

“Social Security’s highest priority is to serve the public and we are committed to ensuring Americans with disabilities receive the benefits they are eligible for,” said Commissioner Saul. “For over a decade, our Compassionate Allowances program has helped us accelerate the disability process for people who are likely to get approved for benefits due to the severity of their condition.”

The Compassionate Allowances program identifies claims where the applicant’s condition or disease clearly meets Social Security’s statutory standard for disability. Due to the severe nature of many of these conditions, these claims are often allowed based on medical confirmation of the diagnosis alone. The list has grown to a total of 237 conditions, including certain cancers, adult brain disorders, and a number of rare disorders that affect children. To date, more than 600,000 people with severe disabilities have been approved through this fast-track policy-compliant disability process.

The agency incorporates leading technology to identify potential Compassionate Allowances and make quick decisions. When a person applies for disability benefits, Social Security must obtain medical records in order to make an accurate determination. Social Security’s Health IT brings the speed and efficiency of electronic medical records to the disability determination process. With electronic records transmission, Social Security is able to quickly obtain a claimant’s medical information, review it, and make a determination faster than ever before.

For more information about the program, including a list of all Compassionate Allowances conditions, please visit www.socialsecurity.gov/compassionateallowances.

To learn more about Social Security’s Health IT program, please visit www.socialsecurity.gov/hit. People may apply online for disability benefits by visiting www.socialsecurity.gov.

To create a my Social Security account, please visit www.socialsecurity.gov/myaccount.

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Rare Caregiver Respite Program

This first-of-its-kind assistance program is designed for caregivers (parent, spouse, family member, or other significant other) of a child or adult diagnosed with a rare disorder. The National Organization for Rare Disorders (NORD) understands that caring for a loved one is a generous gift that demands significant amounts of time, attention, patience, and dedication. The Respite Program provides financial assistance to enable the caregiver a break to attend a conference, event, or simply have an afternoon or evening away from caregiving. Financial assistance will be granted up to $500 annually for those who qualify. Awards may be spread throughout the year or in a single use.

What care may be covered?

- Registered Nurse (RN)
- Licensed Practical Nurse (LPN)
- Certified Nursing Assistant (CNA)
- Home Health Aide (HHA)

(continued)
Who is eligible?

- The caregiver must be a US citizen or permanent resident of the United States for at least 6 months with evidence of residency.
- The applicant must be willing to undergo a financial evaluation of need and fall within the Program’s financial eligibility guidelines.
- The patient for whom care is being provided must have a confirmed rare disease diagnosis.

How do you apply?

- Awards are granted on a first come, first served basis to eligible individuals.
- A NORD Patient Services Representative will guide the applicant through the process, including verifying financial eligibility using the Electronic Income Verification System. The application decision process can take as few as five minutes over the telephone. Applications completed and submitted via email, fax, or US mail will be processed within three business days of receipt.

For more information about this program, contact NORD at 203-616-4328 or email caregiverrespite@rarediseases.org.

New Augmentative Language Learners Group in Dexter, Maine

The first meeting will be held at Abbot Memorial Library, 1 Church Street in Dexter on September 21, 2019 starting at 9:00 AM.

This is for all ages, students, parents, and adults. Anyone that needs to use augmentative alternative communication (AAC) to communicate, their families, and the community are welcome to attend.

If you have any questions, contact Crystal at (207) 270-0461 or E-mail: crystalannepitman@gmail.com.

Reading Corner
by Robin Levesque

A Different Kind of Perfect: Writings by Parents on Raising a Child with Special Needs
by Cindy Dowling (Editor), Bernadette Thomas (Editor), Neil Nicoll (Introduction)

This amazing book reflects on the emotional journey that so many parents take when raising a child with a disability. This book touches on everything from the grief parents feel, along with the anger, frustration, denial, and finally acceptance. This book also brings stories of empowerment, laughter and joy.

This is a must read for anyone touched by a disability in their lives, it brings comfort to read these very touching personal stories and know we are not alone.

Planet Ripple: Minnow's World
by Nicholas Anderson (Author and Illustrator)

This is a Maine Author

In this the 1st in a series of graphic novels we meet the main character Minnow who is on the Autism Spectrum and also needs prosthetics to get around. This is a great Sci-Fi book where Minnow was born into a world that is going down the drain. There are many very unique characters with an incredible story line. Minnow is a good hero who is humble, kind and assertive when needed and very open about her challenges.

Nicholas Anderson the very gifted author and illustrator who is on the Autism Spectrum himself has done an amazing job bringing awareness and understanding to the world of disabilities.

The Girl Who Thought in Pictures: The Story of Dr. Temple Grandin (Amazing Scientists) by Finley Mosca, Julia (Author), Daniel Rieley (Illustrator)

This is the first is a series (Amazing Scientists) of educational books reflecting on the inspirational lives of some amazing scientists such as Temple Grandin who is a Professor of animal Science that is on the Autism Spectrum. This book is a must read for all ages, and for people with or without a disability.

The story offers great rhymes and illustrations that make it a fun read while providing a factual interesting story that teaches diversity and helps kids see it is okay to be different.
The Greely High School Best Buddies Chapter & Maine Parent Federation are happy to host a screening of

“Intelligent Lives”

This documentary from award-winning filmmaker, Dan Habib stars three pioneering young American adults with intellectual disabilities – Micah, Naieer, and Naomie – who challenge perceptions of intelligence as they navigate high school, college, and the workforce. Academy Award-winning actor and narrator Chris Cooper contextualizes the lives of these central characters through the emotional personal story of his son Jesse, as the film unpacks the shameful and ongoing track record of intelligence testing in the U.S.

Intelligent Lives challenges what it means to be intelligent, and points to a future in which people of all abilities can fully participate in higher education, meaningful employment, and intimate relationships.

Event Details
Please join us @ 6:30 PM on October 3rd, 2019 at the Greely Center for the Arts

This event is free to the public!

For more information, contact Jodie Hall at (207) 841-4129 or Jhall@mpf.org