SPECIAL NEEDS • MOVING ON

member to member

connection

Breaking through barriers for workers who have children with special needs

N° 48 Summer 2024

I am so happy to tell you my news:

When our son Basti was 3 years and 10 months old, he received a diagnosis of Autism Spectrum Disorder (ASD) and Global Developmental Delay (GDD). The beginning years presented major obstacles. He faced challenges with eating, had sensory meltdowns due to lights and sounds, resisted changing clothes, and had trouble expressing his needs, getting upset when someone touched his toys. He displayed actions such as arranging chairs in a line and tossing objects. These challenges developed as time went on.

Recognizing the situation was difficult, as well as explaining it to family members. Challenges emerged in identifying the suitable interventions, therapists, and treatments. Balancing our job with parenting our children was a difficult task. Basti always motivates us to better ourselves as parents. Raising a child with autism has given me a fresh perspective, emphasizing the importance of kindness, patience, empathy, active listening, and respect.

Currently, Basti is attending Kindergarten and will celebrate his 6th birthday in November. He is intelligent, talkative, energetic, and sociable. He enjoys eating spaghetti, mac & cheese, soup, and cake as his top food choices. Having a good time with his friends at daycare and school. He has various types of small and portable fans. He dreams of becoming a police officer like Sheriff Labrador and loves watching BabyBus Kiki & Miu Miu.

After undergoing various therapies and interventions, he has shown notable progress in his social skills, daily habits, communication, and behavior. We are extremely grateful for all the progress he has achieved, and we are immensely proud of him. We desire for him to always be aware that he is loved and supported.

We highly appreciate the support and assistance provided to our son by the Special Needs Program.

The Perez family lives in Saskatoon

Hello,

My name is Arron Andres. I am 7 years old. Grade 2 student. I just to say a great big, massive thank you! To Special Needs Projects for supporting me to my tutoring and my swimming program. I am trying my best to building my handwriting and drawing hoping that you like it.

Many thanks.

My daughter Natalie was born with half a heart. She went into cardiac arrest at 2 days old. She was on life support, then waited in critical care for 5 months, for a new heart. March 5, 2017 she received a new heart at 5 months old. She finally got to come home!

She came home on 16 different meds, addicted to morphine and trying to catch up to missed milestones. She had many therapies going on as well as tube feeds.

I was not aware of this program at this time so spreading awareness among co-workers is important. Once we did learn of the program, we are so grateful for the extra support.

Funding for tutoring, as the brain bleed she experienced during her cardiac arrest has affected her learning. We also make the 2-hour trip to sick kids frequently. Heart transplant clinic, eczema clinic, allergy clinic, haematology and respirology.

This program has been such a lift of support for us !

COMMUNICATING WITH YOUR CHILD'S TEACHER

Back-to-school season is almost upon us! Here are some tips for effective communications between parents and teachers throughout the year.

1. Contact the school before the start of the school year and ask if you and your child can visit the classroom and meet the teacher.

2. As the school year begins, inform the teacher of your child's strengths and weaknesses, their goals and needs, as well as effective tools and learning strategies that work with your child.

3. The best times to speak with the teacher are before the school year starts, after the winter break and in early spring. Whether attending a scheduled appointment or a parent/teacher interview, it is important to come prepared with clear and concise questions and/or concerns.

4. Think of your interactions with the teacher as part of a team effort with the goal being best outcomes for your child's development. Approaching matters from the perspective of your child will show you have your child's best interests at heart. Working together with the teacher also ensures that your child knows there is cooperation between school and home.

5. Take the time throughout the year to let the teacher know that you appreciate the job they are doing. If there are concerns, make sure to note positive efforts as well. Good will goes a long way.

(1) Care. - https://www.care.com/c/back-to-school-special-needs-kids/

(2) Additude - Meet the Teacher: 5 Ways to Improve Back-to-School Communication by Cindy Goldrich, Ed.M. For the full article visit: https://www.additudemag.com/meet-the-teacher-school-communication-adhd/

(3) Scholastic - https://www.scholastic.com/site/pam-allyn/5-easy-to-steps-to-great-communication-with-your-child-s-teacher.html

Marisa has been excelling with theatre and her singing. Her confidence has grown, although she still struggles with her academics, and now a new diagnosis of autism.

Just wondering if there are any families I can connect with who are experiencing adolescent struggles and now transitioning past high school into post-secondary learning?

M.C.

THERE ARE BIG CHANGES COMING!

The Special Needs Project staff and CUPW Child Care Coordinator have been working with Eviance (Canadian Centre on Disability Studies) over the past few years to make sure the projects continue to meet the needs of members, and that we continue to administer them well. And we want to let you know about some of the changes we are implementing coming out of this work.

Receipts

We have adapted the need for receipts. In addition to what has been required previously we will now require receipts for the first full year a member comes onto the project. Subsequent years the SNP staff will do “spot checks” for receipts to validate spending.

Cost Threshold

The SNP was originally designed for members who had at least $100 in eligible expenses per month for their child. Since the early days of the program, however, it has become clear that some members who spend less than $100 per month would still like to remain on the projects. We know some members want to be affiliated with the SNP even though their disability-related expenses are low because they appreciate the support they receive from their Advisor.

Moving forward these members will remain on the projects for an additional year at a reduced level of funding, after which the member’s needs and the programs’ commitments will be reassessed. After the year, if member’s do not qualify for funding, they will have the option to be eligible for Advisor Support Only (ASO).

These members will continue to do the interviews with their advisor through ASO support contracts. A new SNP member who doesn’t appear to have eligible expenses can be enrolled for funding for 3 periods. This will provide them with advisor support, and to determine if their child has needs that aren’t being met. If they are eligible but still have no expenses at the end of three periods, they can be offered ASO.

Shorter Check-in Interviews

We heard loud and clear that members find the semi-annual check-in interviews long and tedious. These interviews will be shortened, and we will reduce repetitive questions.

Reasons for Reassessment

There are some diagnoses, particularly in young children, which can improve over time. For these children a reassessment of their diagnosis will be required. The types of diagnoses in questions can include - various language delays, asthma or allergies in young children, and some learning challenges. Based on program experiences, the typical duration of such conditions from diagnosis to improvement will be documented and help us to determine how often reassessments will be required. Such information may suggest that some conditions could warrant reassessment after two or three years, and others after a longer period.

There will also be times when a reassessment will be asked for when children's diagnosis seems to be changing.

In addition, the experiences of professionals engaged in supporting a young person will be considered and accorded due weight in assessing a child's current needs. For instance, if a child's teacher provides written confirmation that they consider the child still needs remedial attention because of a learning difficulty, a formal reassessment by a psychometrist will not be required.

Recreation Programs

There has been concern about recreation programs. The SNP staff work hard to stay true to the mission of the projects - to provide financial support for children with disabilities that are "above costs" for typical children of the same age.

Regular recreation programs will be considered if there are other expenses directly related to the child's special need or disability. If there are no other expenses and it cannot be established that the recreation program has specific policies and established practices of including children with disabilities the project will not cover this expense.

The SNP cannot support costs for recreation programs that are elite, competitive, or professional in nature, i.e., geared towards exceptional skill development rather than participation with age peers.

Tracking How the Projects Support Diversity

Responding to one of the recommendations by Eviance the projects will collect member demographic information. This will help us track the extent to which the programs are reaching equity seeking groups within CUPW and UPCE/PSAC (people of colour, racialized, gender non-binary, etc.)

The SNP continues to improve how we work and how we support members on the project.

Hi, my name is Meaghan Fitzgerald, and I am the newest staff member to join the team. I replaced Benita on May 6th, 2024 in the Administrative Coordinator position. I will likely be the first English voice members will hear when they call the office.

I have 5+ years of experience working in administrative, not-for-profit settings, 4 of which have been in the health care field at Victoria County Home Support Services. I achieved my Bachelor of Arts (Major in Psychology) at Cape Breton University, and I am also currently collaborating with CBU Professor Dr. Bishakha Mazumdar as a Research Assistant for the Adding Lives to Years Project.

I am from Baddeck and have lived here all my life, and I am happy to contribute support to members from my desk in the Baddeck office.

Dorothy and Brenda are delighted to have Meaghan join our team and look forward to working together into the future

Canada Disability Benefit Act

In 2020 the Federal Government announced its intention to implement the first of its kind, federal legislation for a guaranteed monthly income supplement for working-aged people living with disabilities. On June 2, 2022, the Government introduced the Canada Disability Benefit Act (Bill C-22) in Parliament. It received Royal Assent on June 22, 2023.

The announcement was met with mixed reviews across the country with many saying the $200 dollars per month (about $6.66 per day) falls far short of covering the true cost of rising housing and grocery costs. Others were clear that accessibility isn’t possible without income security. Many felt the announcement was far too little and much too late to come anywhere near lifting persons with disabilities living in poverty, out of it. By the time the money starts to roll in 2025 inflation will have eaten that up.

Despite these concerns there was recognition that federal action is needed to support those living with disabilities to attain economic security. The preamble of the Act notes that working-age persons with disabilities are more likely to live in poverty than other working-age Canadians. It notes that they often face barriers to employment. It also outlines Canada’s framework of laws to address the financial and social barriers that persons with disabilities face.

This framework includes:

- the Accessible Canada Act
- the Canadian Charter of Rights and Freedoms
- the Poverty Reduction Act

The preamble also notes that progress in reducing poverty helps Canada to:

- realize international obligations under the United Nations Convention on the Rights of Persons with Disabilities, and
- reach the United Nation’s Sustainable Development Goals

To address the financial and social barriers that persons with disabilities face, the Act recognizes the importance of engaging with the disability community, in the spirit of “Nothing Without Us”. It also recognizes persons with disabilities may face additional barriers because of their gender, racialized or Indigenous status or other intersecting identities.

The Act also recognizes importance of engaging with provincial and territorial governments when developing income supports and other services. They are important because they already provide many supports and services to persons with disabilities.

https://www.canada.ca/en/employment-social-development/programs/disabilities-benefits/bill-summary.html

CHILD'S PLAY

CUSTOM THERAPY DOLLS—ADAPTED FOR ANY CHILD

BY KYLIE MCKENZIE. Taken from the Abilities Magazine issue 134/Fall 2023.

A Jerusalem firm is having great success making dolls for children living with disabilities that actually mirror their real-life situations.

When Tami Gutman, a special education teacher at ADI Jerusalem, (ADI stands for ability, diversity, inclusion), a rehab care facility for some 220 children and young adults, realized there were not suitable toys at neighbourhood stores, she set about adapting a few soft dolls into playtime twins.

Now, Gutman's Toy's Like Me project can personalize dolls by adding gastro lines, glasses, hearing aids, respiratory lines or even a tracheostomy cannula in their neck. As ADI's Director of Education says, Gutman's project is more than making dolls, it's based on a philosophy to make every child feel like any other child no matter what his or her needs might be. "By providing children with a standard doll alongside a doll that's customized with adaptive or medical apparatus, ADI kids get the message that there are other children like them and model the ideal of typically-abled and differently-abled kids playing together."

I wanted to share some of my autistic son Segio story.

He is now 32 years old. Looking back, I can say we always did our best to give him as much help as we could get and maybe we were lucky, some of the workers we had for him, really made an excellent job helping him to improve his communication skills and life skills.

At the beginning one of them used picture cards to enrich his language and vocabulary. Also, when he started school, he had very committed educational assistants, and little by little he has progressed in different areas. Most importantly he has been a happy person most of the time.

Now we are trying to get him to practice in some employment, but still looking for a good match.

I also wanted to express my gratitude to the Special Needs & Moving On Project for the support they have given us throughout these years. It made us feel less lonely in this quest for a better future for our son.

I will be retiring not long from now, so I will miss the phone calls and the support.

Thank you for all that.

"The Access 2 Card program reaches over 100,000 Canadians living with disabilities."

The Special Needs and Moving On Project continues to encourage members to contact our Support Navigator, Isabelle Tanner, when they are in need of assistance in finding resources and supports. Isabelle is bilingual in both English and French and is available to assist project members across the country.

Our Support Navigator works on a part-time basis for the projects but she can be reached at any time by email or by leaving a voicemail. Isabelle will get back to you as soon as possible.

Contact information for the Support Navigator is as follows:

Phone: 902-295-1645
Email: supportnavigator@specialnedsproject.ca

You can provide a brief description of what resource it is you need help finding, the age of the child concerned, your province of residence and your contact information. If the Support Navigator needs more information, she will contact you. Otherwise, you can expect a response with information on the resources you are seeking within a few days of your request.

To date, some of the resources that Isabelle has found for members includes speech therapists, behavioural therapists, autism and ADHD/LD resources, tutoring agencies, recreational activities and day/summer camps, activities for families and respite for parents.

Other resources include 211.ca and the CUPW/UPCE-PSAC Disability Supports website portal.

Please feel free to make use of these valuable resources at your disposal. If you have any questions, you can ask the Support Navigator.

Enjoy Summer Fun with the Easter Seal's ACCESS 2 Card

The Access 2 Card is for people of all ages and types of permanent disabilities who require the assistance of a support person.

Easter Seals Canada's Access 2 Card program was launched in 2004 with support from Cineplex Entertainment and a group of national disability organizations. The Access 2 Card program helps to ensure that entertainment, cultural and recreational opportunities are more available and accessible to all.

Managed and administered by Easter Seals Canada (located in Toronto), the Access 2 Card program has grown to reach over 100,000 Canadians who are living with disabilities and includes over 500 participating partner venues across the country.

For more information go to: https://access2card.ca/

Digital Newsletters

If you want to read or share a digital version of the newsletter you can find it at the address below.
To view past copies of the newsletter click the "Downloads" button on the top right corner of the page. Enjoy!
https://membertomemberconnections.com

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is the newsletter of the *Special Needs* and *Moving On Projects*. It is produced by the Canadian Union of Postal Workers and the Union of Postal Communications Employees-Public Service Alliance of Canada.

The Child Care Fund is administered by the Canadian Union of Postal Workers and financed by the Canada Post Corporation.

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