

Caregiving for persons with intellectual disabilities

by Sheila Landry



Caring for someone with intellectual disabilities involves love, affection, worry, guilt, stress and sometimes a sense of loss, similar to other caregiving roles. However, this type of caregiving often begins at birth and may last a lifetime. This long-term commitment brings unique challenges and perspectives for caregivers.

For parents and family members, caregiving is a lifelong responsibility. This role brings distinct challenges, from navigating complex systems and combating stigma to dealing with social isolation and managing everyday tasks. And while many caregivers face these hurdles, those caring for people with intellectual disabilities often have specific needs that require additional planning and support.

With the right tools, support and mindset, caregivers can not only survive, but thrive. Here are some key strategies for caregivers of people with intellectual disabilities.

Identifying needs: a person-centered approach

The caregiving journey starts with identifying your loved one's needs. A person-centered approach places the person receiving care at the core of all plans and decisions: their needs, preferences and aspirations guide all caregiving strategies.

For caregivers, this means taking the time to understand the specific challenges and strengths of the person you are caring for. Shifting the focus from the diagnosis to the person as an individual - their personality, interests, goals and what makes them feel empowered. This information will help you advocate more effectively for them, ensuring that their rights, dignity and desires are prioritized.

As a caregiver, you often serve as their voice, advocating for inclusive education, navigating the healthcare system and ensuring access to accessible services in your community.

Creating a support circle

A support circle is a group of people who support the person receiving care. This includes family, friends, healthcare professionals, teachers, community members and the person themselves. The key to a person-centered support circle is making the person receiving care an active participant in all decisions.

Regular meetings will allow the support circle stay aligned on goals, dreams and challenges, always centering on the care recipient's progress, desires and input. This empowers the care recipient and allows them to actively contribute to the planning process.

Through a person-centered support circle, caregivers can identify both short-term and long-term goals, identify resources and opportunities and help create an environment where the person receiving care can grow and succeed.

Advocating: empowering through action

Advocating for your loved one is crucial. As a caregiver, you play a key role in accessing services, resources, opportunities and accommodations that help your loved one thrive.

Advocacy often includes seeking out services, advocating for inclusive educational settings, ensuring the health providers understand your loved one's needs and securing funding for specific services or equipment that improve quality of life. Advocacy can extend to breaking down the stigma that surrounds people with intellectual disabilities.

In Nova Scotia, the Disability Support Program (DSP) can connect you to several organizations that help individuals live more independent and integrated lives. Nova Scotia Residential Services Association (NSRSA), L'Arche Nova Scotia, Directions Council and Inclusion NS offer valuable resources on housing, education, employment and community inclusion.

Planning ahead

Planning proactively ensures your loved one is ready for greater independence and a fuller integration into society. Think about your loved one's future, the goals they want to achieve. This could include living independently, getting a job or engaging in community activities. It's essential to create opportunities for your loved one to build skills and foster relationships.

This also means ensuring that the community is ready to support their inclusion. Identifying suitable housing, employment and social opportunities is an important step. Support from organizations like Inclusion NS and local advocacy groups can help you navigate available resources and help prepare your loved one for life outside the family home.

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Self-care: you matter

As a caregiver, it's easy to forget about your own needs when you're focused on caring for someone else. However, self-care is essential for long-term caregiving.

By prioritizing your own well-being - through hobbies, maintaining friendships and rest - you improve your ability to support your loved one. Maintaining your physical, mental and emotional health helps you better navigate the challenges of caregiving.

Remember, you don't have to do it all alone. Delegating tasks to other members of your support circle makes caregiving manageable and sustainable, helps you recharge.

Joining a caregiver support group can provide both emotional support and practical advice.

Thriving through a person-centered approach

Caregiving for a person with intellectual disabilities is a lifelong journey - one filled with challenges but also with immense potential for growth and success.

By focusing on a person-centered approach, caregivers can ensure that the needs, preferences and goals of the individual are always prioritized. Building a strong support circle, advocating for opportunities and planning ahead are all important steps in ensuring a fulfilling life for both you and your care recipient.

Self-care is equally important. The caregiving journey is best navigated when you are healthy, supported and empowered.

Remember, you are not alone in this journey. There is support, there are resources and there is always hope for a brighter, more inclusive future.