

What about children with special needs?

Between 5 and 20% of children have special needs. The disability may range from a physical disability through a specific medical condition or illness, to a developmental delay or a mental disorder. The disability may be visible or invisible (e.g. epilepsy). It may be apparent at birth or emerge as the child grows older. Or it may come later as a result of an injury or illness. Its cause may be known (e.g. genetic) or as is the case with many children with developmental problems, its cause may be speculative (e.g. environmental) or unknown.

What's involved in parenting a child with special needs?

The demands on parents vary according to the nature of the disability. Many parents of children with special needs say the experience has enriched their lives in many ways. Nonetheless most parents with special needs children face additional challenges to those faced by parents raising children without special needs. These include:

Day to Day Care - Children with disabilities may require more physical care and for a longer period. Parents must take on multiple roles of therapist, teacher, playmate, and advocate. They may also struggle with behavior problems, greater susceptibility to illness, sleep disorders, and medical emergencies. The result can be physical and emotional exhaustion for the parent(s). It can also strain relationships with spouses and other family members. The additional cost of raising a child with a disability can cause financial strain. The needs of the child may force one parent to quit their job or seek part-time and/or less demanding work. Single parents face even greater challenges.

Services - Parents often have to work hard to find, access, and sustain services for their children. Most parents spend many hours both on the phone and taking their child to appointments. With current cutbacks in services, they may face long waiting lists, or depending on where they live, having to travel substantial distances. Some needed services are not available.

Childcare - Accessible, affordable childcare is an issue for many families with young children. It is usually an even larger issue for parents of children with special needs. Although some childcare centres will do everything they can to accommodate children with disabilities, others will refuse them. While the issue of childcare disappears for most children as they get older, it remains a key issue for children with disabilities over 12 who still need care.

Education - Parents of children with disabilities cannot take for granted that their child will be educated at their local school and many will have to fight for this if this is what they want. Despite the fact that there is greater acceptance of the idea of inclusion, there are not always the supports in place, or teacher willingness and ability, to make it work. Current cuts to special education funding pose a threat to the education of many children with special needs.

What is "inclusion" and why is it important?

Inclusion means removing barriers and providing supports in order to allow children with disabilities to participate in all aspects of life to the best of their abilities. This is important because:

- All children need a sense of belonging in their communities for self-esteem and healthy child development
- Being with other children helps children with disabilities to learn social skills
- Inclusion contributes to children leading active and independent lives.
- Inclusion helps make other children more aware, sensitive, and compassionate.
- Inclusion is a basic human right.

What can friends, extended family, neighbours do?

- Ask the family what you can do to help
- Be sensitive to the additional pressures that families with special needs children face
- Be accepting of the child, recognizing the child's strengths and special gifts
- Include the child whenever possible (e.g. birthday parties, informal invitations)

What can professionals do?

- Be sensitive to the feelings of parents, and the challenges they face. Try not to add to their stress
- Don't withhold information
- Make sure families have information about other services, financial support (e.g. respite care)
- You have expertise but only the parents know what it's like to live with their child
- Remember that parents have many appointments to attend, and often must coordinate them with work schedules. Be flexible as possible. Try not to keep parents waiting
- Be aware that parents may be overloaded with "homework" they have been instructed to do by other professionals. They may be too exhausted to do any of it.
- Don't overwhelm parents with the bad news. Emphasize the strengths of the child.
- Give parents credit for successes. Acknowledge their efforts.

What can employers do?

- Be understanding of employees with children with special needs.
- Be flexible.
- Implement work/life policies that benefit all employees.
- Use benefit plans that can be extended according to need; set up a special fund.
- Encourage employees to volunteer for agencies that work with disabled children.

What can governments do?

- Provide adequate levels of funding for services (e.g. respite care), special education, integrated child care and health care.
- Ensure access to rehabilitative services across the province.
- Provide adequate financial support to single parents unable to work due to their child's disability.
- Ensure appropriate legislation is in place to protect the rights of children with disabilities.
- Consider the impact of policy decisions on disabled children.
- Avoid policies/procedures/practices that force parents to fight for every entitlement.
- Listen to parents.

To think about:

"This experience we did not choose, which we would have given anything to avoid, has made us different, has made us better. Through it we have learned the lesson of Sophocles and Shakespeare that one grows by suffering. And that too is Jessie's gift. I write now what 15 years past I would still not have thought possible to write; that if today I was given the choice, to accept the experience, with everything that it entails, or to refuse the bitter largesse, I would have to stretch out my hands – because out of it has come, for all of us, an unimagined life. And I will not change the last word of the story. It is still love." (Park, 1988)