



*Parent Resource Roundtable
FASD/Special Needs
Challenges and Solutions*

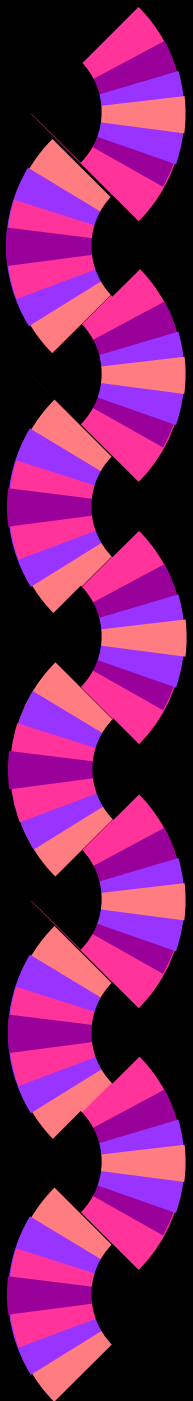
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Children are our future.

*They are the joy for us today and the
hope for us tomorrow.*



- ◆ First Nation children are the fastest growing segment of the Aboriginal population in Canada
- ◆ Life expectancy at birth is 7 to 8 years less for registered First Nations persons than for Canadians generally.



FASD/Special Needs

- ◆ FAS rates are 30 times the general population and the cost of meeting the needs of someone severely affected by FAS over a lifetime is \$1 to \$1.5 million (RCAP 1996)



What is Considered Special Needs

Children are considered to have *special needs* if they require services and supports (in order to participate with their peers) beyond what is provided through regular developmental programming.



Special Needs Requirements

- ◆ Children with special needs may require a wide range of health related services and support such as: pediatricians, physicians, nurses, behavioral, speech, clinical social workers, psychologists, psychiatrists, etc.
- ◆ Children with *special needs* may also require transportation, pharmaceuticals, medical supplies and equipment.



Special Needs and Poverty

- ◆ Aboriginal people living in urban areas are more than twice as likely to live in poverty as non-Aboriginal people (52.1%), and children with disabilities (23%) age 10-14 are more likely to be poor.
- ◆ Aboriginal children age 0-6 are the most extremely vulnerable population. (Canadian Council on Soc. Dev.)



Children Who live in Persistent Poverty

- ◆ *Are less likely* to be included in aspects of society that are critical to their healthy growth and development
- ◆ they are *twice as likely* to live in a dysfunctional family
- ◆ *twice as likely* to live with violence and
- ◆ *three times likely* to live with a depressed parent (Canada's Creeping Economic Apartheid)



Special Needs Children face conditions characterized by:

- ◆ Inadequate nutrition
- ◆ substandard housing and sanitation
- ◆ unemployment
- ◆ poverty
- ◆ discrimination and racism
- ◆ violence
- ◆ inappropriate or absent services



Special Needs Children face conditions characterized by:

- ◆ High rates of physical, social and emotional illness
- ◆ injury
- ◆ disability
- ◆ premature death



Special Needs Children Especially Need

- ◆ *Early diagnosis and assessments* to ensure early identification of special needs conditions that if treated at an early age can be less disabling as the child ages.
- ◆ Children with special needs also require medical supplies, equipment, transportation and pharmaceuticals depending on severity of their disability



Challenges for Families of children with Special Needs Include:

- ◆ Education about special needs
- ◆ Disability awareness
- ◆ Knowing their rights
- ◆ Being respected and heard
- ◆ Getting proper support and linkages in terms of programs and services
- ◆ Having the proper information to make informed decisions



Challenges for Families of children with Special Needs Include:

- ◆ Communicating with service providers
- ◆ Waiting lists
- ◆ Transportation and the cost of travel
- ◆ Lack of resources
- ◆ Lack of collaboration between agencies
- ◆ Poor linkages with local physicians



As a Result Families feel:

- ◆ isolated
- ◆ like they always have to fight for everything
- ◆ unsupported as families
- ◆ unsupported by the school system
- ◆ not included as part of the educational team
- ◆ lacking in proper education for their children
- ◆ wanting people who understand



As a Result Families feel:

- ◆ that their children are not respected or valued
- ◆ there is no sibling support
- ◆ there is a lack of necessary occupational, speech therapy or physiotherapy or other such services



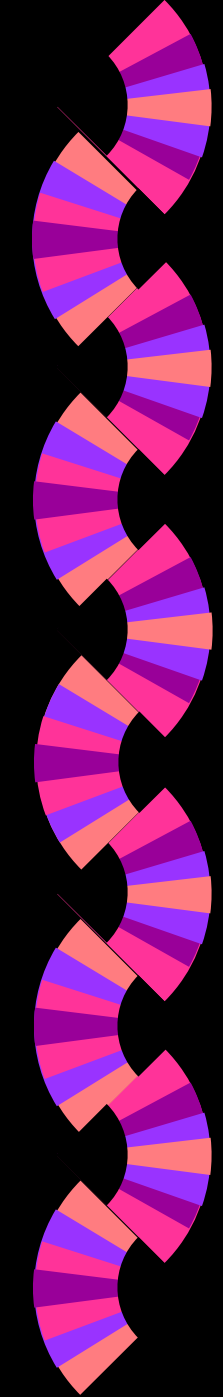
Barriers to Service delivery for Families with Special needs

- ◆ Funding and program constraints
- ◆ attitude of staff
- ◆ insufficient funding
- ◆ limited time of staff
- ◆ lack of information about disabilities
- ◆ distance and isolation



Barriers to Service delivery for Families with Special needs

- ◆ parental denial and attitudes
- ◆ general lack of services
- ◆ staff and training needs (FAS/FAE)



Social Inclusion and Embracing the needs of our children means

- ◆ When you're there you care
- ◆ sharing and caring brings true unity of belonging
- ◆ dignity is diversity
- ◆ embracing differences
- ◆ being treated equal even if we are all different
- ◆ making the world more accessible



Essential Requirements of Children with Special Needs

Families do not access programs and services because of lack of understanding, knowledge, fear and uncertainty and because of reluctance to deal with outside agencies.



What Needs to Happen

- ◆ Programs for children with special needs must be safe places where families are comfortable to communicate their needs
- ◆ Programs must have quality staff that are well trained, certified and knowledgeable about special needs.
- ◆ Parents need to feel that their child is valued and their needs are asset based/



What Needs to Happen

- ◆ Programs need to be multi-disciplinary and based on an inclusion philosophy.
- ◆ Multi-disciplinary staff must consist of teams of: teachers, specialists, health and nutritional workers, therapists, etc.
- ◆ There needs to be early partnering and holistic planning based on collaborative mobilization of resources and supports.



Fundamental Principles for Special Needs Service Delivery:

- ◆ Must be First Nation driven
- ◆ Must include First Nation people with disabilities
- ◆ Children must come first
- ◆ Must be culturally appropriate
- ◆ Must focus on strengths
- ◆ Inclusion/equality/universality are essential



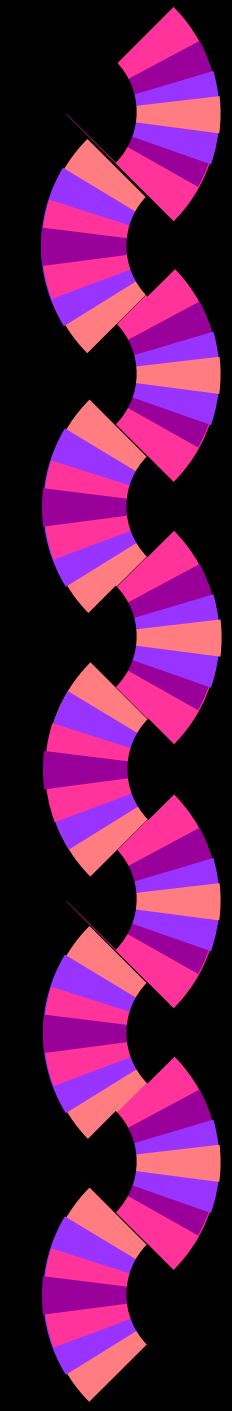
Fundamental Principles for Special Needs Service Delivery:

- ◆ Must be local capacity focused
- ◆ Must include parental and community
- ◆ Delivery is by well trained and certified First Nation people
- ◆ Service delivery is holistic and community based
- ◆ There are partnerships and shared responsibility for program and service delivery



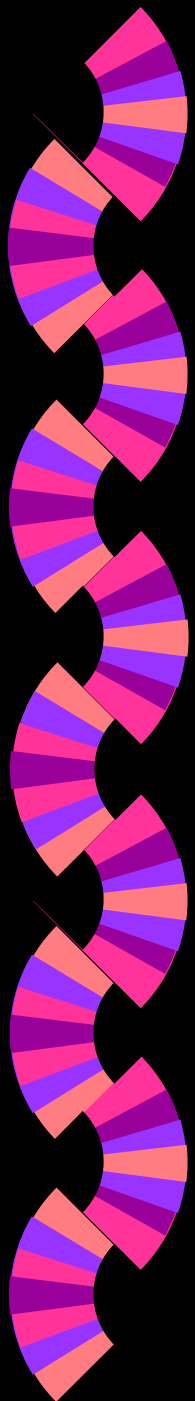
Fundamental Principles for Special Needs Service Delivery

- ◆ Prevention and early intervention is required
- ◆ Focus is proactive versus reactive
- ◆ there is financial transparency and accountability
- ◆ OCAP - ownership, control access and possession.



The greatest success stories are those people who, having recognized a problem, transformed it into an opportunity.

We now have the opportunity to make a difference in our communities and that is our challenge here today and for the future



Without healthy, socially developed children and youth we will have not future. We will have no guarantee for tomorrow without them.



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