

Saskatchewan

Communities Working Together

*Saskatchewan's Action Plan
for Citizens With Cognitive Disabilities*



**Saskatchewan
Ministry of
Health**

Healthy People. A Healthy Province.

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Executive Summary

Communities Working Together: Saskatchewan's Action Plan for Citizens With Cognitive Disabilities provides a framework for supporting individuals with cognitive disabilities who have significant behavioural and developmental challenges. The strategy is a result of a comprehensive review conducted in 2003 by an interdepartmental working group. The review was formed by information gathered from a number of sources, including Fetal Alcohol Spectrum Disorder Community Discussions in 2003.

In order to address gaps in existing services, many of the new initiatives outlined in the strategy are targeted toward those individuals with cognitive disabilities, primarily between 6 to 24 years of age, with an identified unmet need. There will be some flexibility depending on need, and circumstance.

Participating departments in the development of the strategy included: Saskatchewan Health, Community Resources and Employment, Learning, Corrections and Public Safety, Justice, Office of Disability Issues, First Nations and Métis Relations and the Saskatchewan Liquor and Gaming Authority.

In 2005-06 the Government of Saskatchewan will be committing \$1.65M dollars in funding to priority program enhancements intended to shape future policy and program direction. In 2006-07 the budget will be annualized to \$4.15M to allow for further enhancements to the initiatives. The priority enhancements for 2005-06 include:

1. Strengthening Direct Supports Based on Need;
 - i. Enhancing knowledge and skills of service providers
 - ii. Establishing flexible and individualized supports
2. Improving Access to Assessments and Diagnoses; and
 - i. Enhancing Assessment and Diagnostic Services
 - ii. Three-Year Telehealth Cognitive Disabilities Diagnostic Pilot Project
3. Strengthening Fetal Alcohol Spectrum Disorder (FASD) Prevention and Intervention.
 - i. Strengthening Prevention
 - ii. Partnership with Saskatchewan Fetal Alcohol Support Network
 - iii. Screening and Alternatives Measures Pilot Project

Along with outlining a vision, framework and priority initiatives, the strategy:

- emphasizes providing supports based on need and impact of disability;
- encourages partnerships at the local, regional and provincial levels in order to strengthen communities (build capacity);
- builds upon existing services and supports;
- supports the Government of Saskatchewan's vision of building a quality of life that supports healthy people, families, neighbourhoods, communities, and full citizenship and equal participation of individuals with disabilities;
- complements and links with other key initiatives, including: *KidsFirst*, Early Learning and Care (in development), School^{PLUS}, Building Independence, Strategy for Métis and Off-Reserve First Nations People (MOR), Healthier Places to Live, Work and Play. . . A Population Health Promotion Strategy for Saskatchewan, Youth Services Model and Saskatchewan Council on Disability Issues' Saskatchewan's Disability Action Plan.

The overall direction of the strategy puts the needs of individuals with cognitive disabilities first. Understanding how disabilities impact individuals in their daily lives and tailoring services based on individual needs, rather than a specific diagnosis, is a key focus of the strategy.

Implementation of some of the major initiatives is under way. In the meantime, it is hoped that by sharing this strategy others will find it a useful resource in their continued work assisting individuals with disabilities.

Introduction

There is growing recognition of the need for better coordination, integration, and enhancement of supports and services to people with cognitive disabilities. Because existing services are often challenged to address the impacts of cognitive disabilities, provincial government departments have been consulting with communities to discuss how best to improve services and supports.

“Full citizenship of persons with disabilities requires access to supports and the elimination of barriers to service.”

In Unison 2000: Persons with Disabilities in Canada, Human Resources Development Canada, 2000.

Beginning in 2004-05 government committed new funding to the *Communities Working Together: Saskatchewan's Action Plan for Citizens With Cognitive Disabilities*. The strategy assists persons with cognitive disabilities and their families, their communities, service providers and government departments.

The main focus of the strategy is to provide supports based on need and impact of disability. This provides more individualized and flexible services. Strengthening communities and building on existing services is an important aspect of the strategy.

The strategy provides a framework for supporting individuals with cognitive disabilities who have significant behavioural and developmental challenges, between 0 and 24 years of age. However, in order to address gaps in existing services, many of the new initiatives outlined in the strategy are targeted toward those individuals with cognitive disabilities, primarily between 6 and 24 years of age, with an identified unmet need. There will be some flexibility depending on need, and circumstance. Upon completing a review it was determined there are often gaps in services and supports for those individuals who transition from youth into early adulthood.

Key investments will be made in prevention, direct supports, assessment and diagnosis as well as specific initiatives related to Fetal Alcohol Spectrum Disorder (FASD).

The *Communities Working Together: Saskatchewan's Action Plan for Citizens With Cognitive Disabilities* will also complement and link with other provincial initiatives already underway. Examples include: *KidsFirst*, Early Learning and Care (in development), *School^{PLUS}*, *Building Independence*, *Strategy for Métis and Off-Reserve First Nations People (MOR)*, *Healthier Places to Live, Work and Play*. . . *A Population Health Promotion Strategy for Saskatchewan*, *Youth Services Model* and *Saskatchewan Council on Disability Issues' Saskatchewan Disability Action Plan*.

While each of the above initiatives has a distinct focus, approach and target group, an individual or family may be touched by a combination of strategies at any point across the life cycle. These initiatives are not designed to replace existing services or to develop a new service delivery system, but rather are designed to enhance existing supports, fill service gaps, and support front line service providers.

Defining Cognitive Disabilities

A cognitive disability is typically a long-term condition that involves significant limitations in a person's ability to learn and to process information from his/her environment (e.g. acquiring knowledge, remembering, decision making, problem solving, abstract reasoning, etc.).

This strategy will begin to address the unmet needs of individuals with cognitive disabilities who have significant behavioural and developmental challenges that impact daily functioning.

Behavioural challenges refer to limitations in an individual's social, emotional or behavioural functioning. Behavioural challenges can impact on a person's daily functioning.

Developmental challenges refer to limitations in the person's adaptation to daily living. In this context, developmental challenges may include behavioural challenges but also limitations in other areas of functioning such as self-direction, self-care, home and community living, work, leisure, safety, educational, vocational and employment activities.

Impact of disability means understanding an individual's limitations or restrictions and the supports required to participate and to be included in the community.

Wide variations in severity and levels of functioning produce varying degrees of impact of the disability on daily living. An approach based on the impact of disability allows supports to be more closely matched to individual need and circumstance.

A Framework to Guide Actions

A framework has been developed in order to guide actions to support individuals with cognitive disabilities and their families.

See *A Framework at a Glance* on the next page.

In order to support the framework, Guiding Principles have also been developed. They include:

- Services and supports are based on need.
- Independence and community strengths are recognized.
- Processes are respectful, compassionate and culturally responsive.
- Holistic, integrated approaches are used.
- Collaboration and capacity building are promoted among governments, service provider agencies, individuals, families and communities.
- Balance of services and supports across the lifespan are provided.
- Shared responsibility and accountability are recognized.
- Evidence-based planning and service delivery are provided.
- Services and supports are sustainable.

*SUPPORTING PERSONS WITH COGNITIVE DISABILITIES IN SASKATCHEWAN:
FRAMEWORK AT A GLANCE*

VISION:

A community that supports persons with cognitive disabilities so that each individual is able to participate and contribute as a full citizen in the economic and social life in Saskatchewan.

GOALS:

1. Develop and increase family, community and professional ability to support individuals with cognitive disabilities.
2. Assist individuals with cognitive disabilities to become independent and self-sufficient to the maximum of their capabilities.
3. Prevent FASD by reducing or eliminating the consumption of alcohol during pregnancy through accessible, culturally appropriate supports.

OBJECTIVES:

1. Increase awareness and understanding of the life-long effects of cognitive disabilities.
 2. Strengthen education, training and skills development, and early intervention in order to address the needs of individuals, family and community and to lessen the impact of disability.
 3. Improve access to appropriate assessments, diagnoses and other support services.
 4. Identify and link existing services for individuals with cognitive disabilities using integrated planning processes.
 5. Provide services and supports to address the impact of disability, meet identified needs, and facilitate independence.
1. Continue to raise the level of public awareness and health promotion in the general population about the risks of alcohol consumption during pregnancy.
 2. Inform all women of childbearing age about substance use during pregnancy and the help available if needed.
 3. Increase awareness of the complex social factors associated with drinking alcohol during pregnancy.
 4. Identify and target vulnerable populations through coordinated and specialized prevention early intervention programs that use non-judgmental and culturally appropriate approaches.

A Model of Support

An integrated approach involving all human services sectors (e.g. health, education and training, employment, social, justice, housing, recreational and cultural services) is necessary to meet the needs of, and improve the outcomes for, persons with cognitive disabilities and their families. Working together ensures that people receive the support they need when they need it.

Integrated planning includes a team approach with informal and formal supports to assist in identifying strengths and needs of an individual and family.

The strategy supports integrated planning processes for individuals with cognitive disabilities and their families. Where individuals or families are not connected to a network, help may be needed to develop one.

Informal supports, such as family, caregiver, friends, or volunteers / mentors, and formal supports, such as paid service providers like counsellors, social workers, teachers, medical professionals, etc., may be involved in supporting the individual and family. Informal and formal supports may be enhanced through focussing on prevention and awareness, screening, assessment, diagnosis and strengthening the knowledge, skills and other supports available in the community.

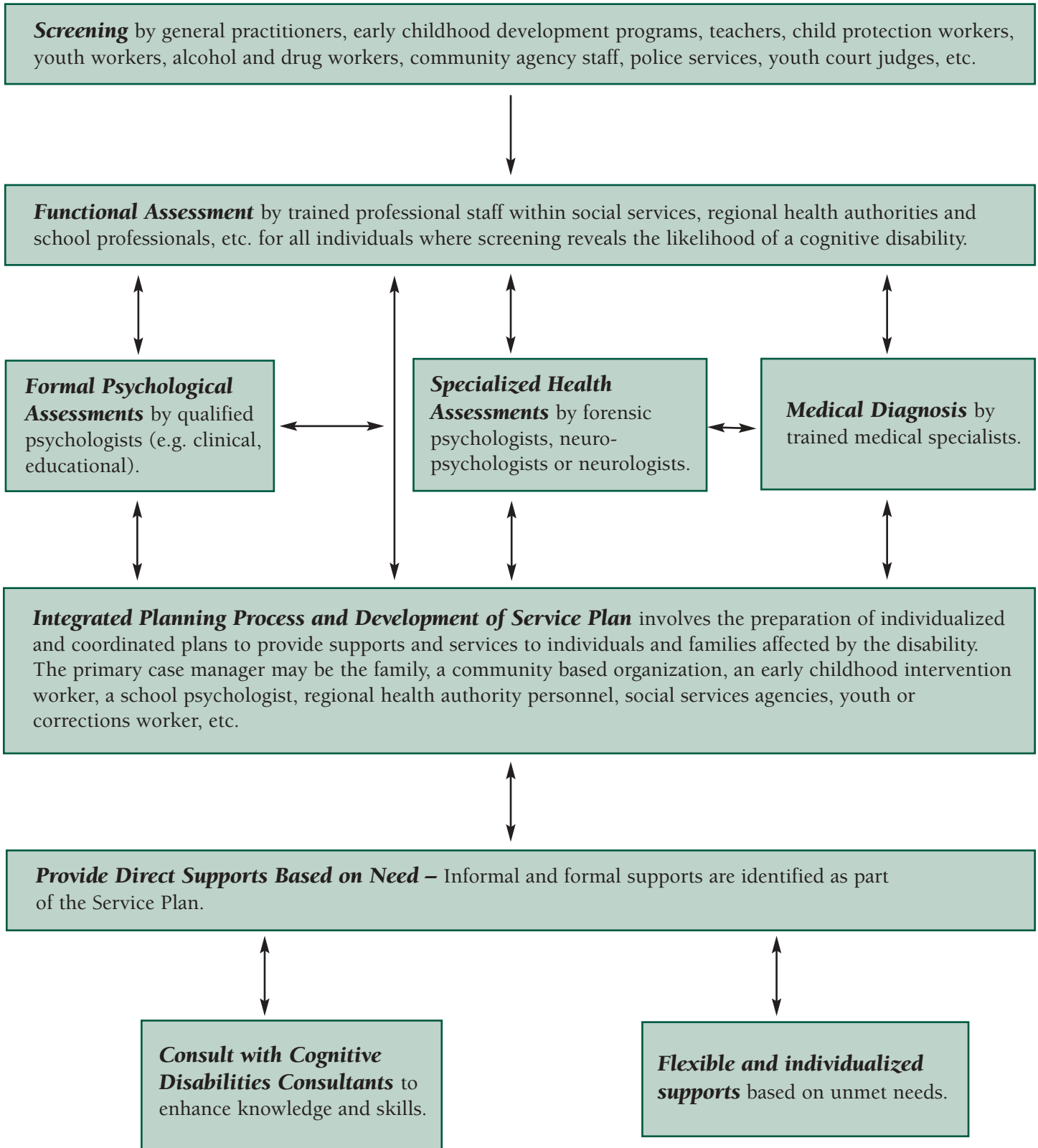
The strategy is based on a citizenship approach to disability issues. This approach was described in the Saskatchewan Council on Disability Issues' *Saskatchewan's Disability Action Plan* in June 2001. Full citizenship means the inclusion of people with disabilities in all segments of the social, economic, political and cultural life of our province. Government has endorsed the vision of full citizenship.

"There are times when individuals need support in making decisions...the individual [should] be involved in the decision making process to the full extent of his or her ability."

Saskatchewan Council on Disability Issues, Saskatchewan's Disability Action Plan, June 2001.

The model on the next page supports the vision where individuals with disabilities may achieve full and equal participation by receiving the supports they need.

*Assessing the Impact of Cognitive Disabilities Using a Community Based Approach
Identifying Needs, and Providing Supports*



Links To Complementary Initiatives

The Government of Saskatchewan is involved with a number of human services initiatives that address specific needs of citizens, particularly those who are vulnerable. While each initiative has a distinct focus, approach and target group, an individual or family may be touched by a combination of initiatives at any point across the life cycle. Many initiatives are at different stages of development, however, they complement and link with the *Communities Working Together: Saskatchewan's Action Plan for Citizens With Cognitive Disabilities*.

KidsFirst – The interdepartmental initiative is a component of Saskatchewan's Early Childhood Development Strategy (ECDS). Prevention and early intervention initiatives focus on providing targeted services to vulnerable families with children prenatal to age five. Program components include prenatal case finding, in-hospital screening, in-depth assessment, an intense home visiting program, early learning opportunities, access to child care, dedicated mental health and addictions services, community-based supports, and the prevention of FASD. These voluntary services focus on partnership with parents, their wants and needs, and their strengths and capacities. It supports high risk children and families living in targeted communities including the North, Nipawin, Meadow Lake, Prince Albert, North Battleford, Yorkton, Regina, Saskatoon and Moose Jaw.

Early Learning and Care [ELC] (in development) – As with the *KidsFirst* initiative, ELC is best seen as a component of the province's ECDS. A blended approach to early learning and care is a relatively new idea that addresses both the developmental needs of young children and the needs of parents for child care so they can participate in the labour market. It will build on the needs and preferences of families, resulting in an approach that enhances child development through early learning whether the child is at home or in another setting.

Saskatchewan is currently developing a plan for Early Learning and Child Care that will support the province's youngest children in reaching their potential. Stakeholder discussion forums across the province in May and June 2004 provided clear direction and feedback to support the development of a system-wide vision for Early Learning and Child Care that will encourage healthy child development and will assist parents in balancing their work and family responsibilities. Negotiations with the federal government are also ongoing, and it is expected these new resources will help to create a "Made in Saskatchewan" approach to child care and early learning that responds to the needs of families and communities in the province.

School^{PLUS} – The initiative is a concept that envisions schools as the centre of the community, hubs for the delivery of a wide array of services and supports for the children and families they serve. Its goal is to create the conditions where all children and young people have the opportunity and supports they need for healthy development, and success in school and life. Ensuring the well-being and success of every child is both a challenge and a shared responsibility. Working together across the province, the provincial government departments are collaborating with provincial partners, systems, Aboriginal organizations, community-based organizations, communities and families to create School^{PLUS}.

Building Independence – The initiative seeks to reduce poverty and welfare dependency for families. It is based on the belief that while social assistance can prevent destitution, it is highly ineffective when viewed as a solution to poverty. A system of supports has been structured outside the welfare system so that it is clearly economically beneficial for low-income families to work. The Saskatchewan Employment Supplement, Child Tax Benefit, Family Health Benefits, and child care subsidies are available to low-income families whether or not they receive social assistance. These mainstream initiatives encourage independence and self-reliance, and improve the quality of life for low-income people.

Strategy for Métis and Off-Reserve First Nations People (MOR) – The strategy was implemented in 2001 to address the urgent and growing needs of a young Aboriginal population. An ad hoc approach was replaced with one integrated, government-wide strategy aimed at achieving meaningful change in the lives of Aboriginal people over one generation and provide direction to address the circumstances facing urban and northern Aboriginal people throughout the lifespan. It focuses on four critical goals: success in education; work preparation; jobs and economic development; and, individual and community well-being. Principles guiding this work include respecting Aboriginal peoples' culture and rights, involving Aboriginal people in program design, delivery and decision-making, and acknowledging the federal government has constitutional responsibility for all Aboriginal people, while Saskatchewan has responsibility for all residents of the Province.

Healthier Places to Live, Work and Play. . . A Population Health Promotion Strategy for

Saskatchewan – The strategy was released in April 2004 by Saskatchewan Health. It provides a framework for population health promotion work within the province and focuses on changing conditions and environments in which people live, work and play. The Strategy defines four priority areas using a population health promotion approach: mental well-being, accessible nutritious food, decreased substance use and abuse, and active communities.

Youth Services Model – The Youth Services Model sets out to improve the way we deal with youth who offend or are at-risk to offend. The Model provides direction to all those who work with these youth. It builds on existing services that have been shown to work. Pilot sites are located in Regina and Prince Albert.

Saskatchewan Council on Disability Issues'

Saskatchewan Disability Action Plan – Released in 2001 by the Saskatchewan Council on Disability Issues, the plan is based on the principle of full citizenship for all individuals including those who have disabilities. The vision is of a society that recognizes the needs and aspirations of all citizens, respects the rights of individuals to self-determination, and provides the resources and supports necessary for full citizenship.

It is also recognized there are many existing provincial, regional and community based services across the province currently assisting individuals and families with cognitive disabilities. Examples include:

- Early Childhood Intervention Program (ECIP)
- Saskatchewan Association for Community Living (SACL)
- Autism Treatment Services of Saskatchewan
- Provincial Acquired Brain Injury Services
- Community Resources and Employment Programs
- Regional Health Authority Services and Supports
- Saskatchewan Learning (e.g. designated disabled pupil program, Diversity Recognition)

These are just a few examples. It is recognized there are many more services providing supports to individuals and families.

LINKS TO COMPLEMENTARY INITIATIVES

| | Investment in Capacity Across The Life Cycle | | | |
|---|--|---------------------|--|-----------|
| | Prenatal Birth to 6 years | 7 years to 18 years | | Adulthood |
| Saskatchewan Council on Disability Issues' Saskatchewan's Disability Action Plan | | | | |
| Healthier Places to Live, Work and Play A Population Health Promotion Strategy for Saskatchewan | | | | |
| Saskatchewan Strategy for Métis/ Off Reserve First Nations People | | | | |
| Action Plan: Citizens with Cognitive Disabilities | | | | |
| Youth Services Model | | | | |
| KidsFirst | | | | |
| Building Independence | | | | |
| School ^{PLUS} | | | | |
| Early Learning and Care | | | | |
| Early Childhood Development | | | | |

This chart provides an illustration of how the initiatives complement one another and link across an individual's lifespan. Each initiative has a specific vision statement, with common themes of inclusion and citizenship of healthy children, individuals and families. While each of the initiatives has a particular focus (from the prenatal period through adulthood), they build on each other in overlapping approaches. The goals of the initiatives can be grouped into complementary categories –learning success, participation in the labour market and community life, well being, and community/shared responsibility.

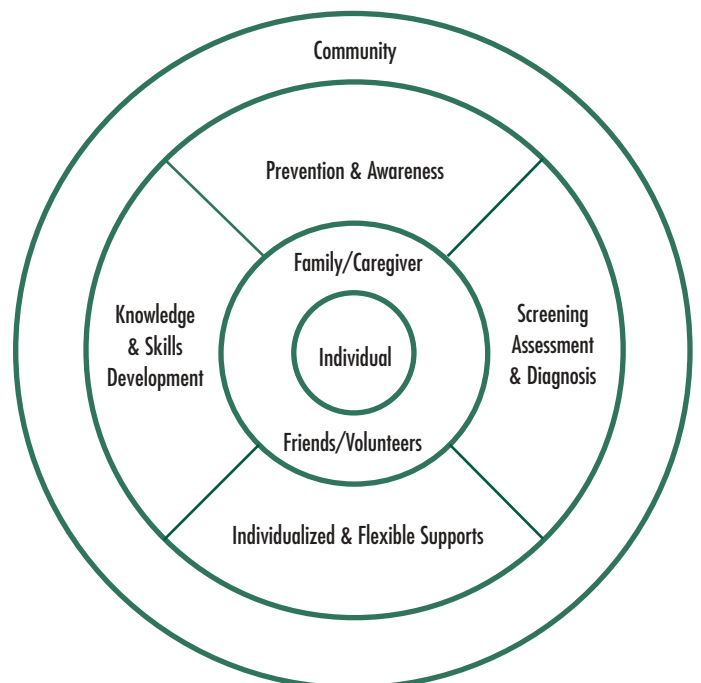
Priorities For Action

During 2005-06 a number of new initiatives will be implemented to meet the needs of individuals with cognitive disabilities and their families.

Specific initiatives include:

1. Strengthening Direct Supports Based on Need
 - i. Enhancing Knowledge and Skills of Families and Services Providers; and
 - ii. Establishing Flexible and Individualized Supports
2. Improving Access to Assessments and Diagnosis; and
 - i. Enhancing Assessment and Diagnostic Services
 - ii. Establishing a Three-Year Telehealth Cognitive Disabilities Diagnostic Pilot Project
3. Strengthening Fetal Alcohol Spectrum Disorder Prevention and Intervention.

The graphic below illustrates the circle of supports for individuals with cognitive disabilities and their families.



1. Strengthening Direct Supports Based on Need

Experience suggests that a team approach benefits individuals with cognitive disabilities who have significant behavioural and developmental challenges, and their families. Two new initiatives will assist in facilitating integrated planning processes, including:

- i. Enhancing Knowledge and Skills of Families and Service Providers; and
- ii. Establishing Flexible and Individualized Supports.

These two initiatives work together to support an integrated approach that will respond to the needs of persons with cognitive disabilities and their families.

i. Enhancing Knowledge and Skills of Families and Service Providers

Overview

Families and caregivers are often resources for individuals with cognitive disabilities. They can model, reward, encourage and assist in the development of behaviours and life skills. They can also influence the environment that leads to success that will result in preventing further complex problems, such as secondary disabilities (e.g. mental health and alcohol and drug concerns, school problems, trouble with the law, etc.).

A key element in creating a more effective response will be to enhance the knowledge and skills of families and service providers meeting the needs of persons with cognitive disabilities.

Getting Started – What's Involved?

Through collaboration between Saskatchewan Community Resources and Employment and local planning committees, four cognitive disabilities consultants will assist in strengthening communities (i.e. community capacity) by providing specialized training and information on direct interventions.

Finding ways to improve the knowledge and skills of parents, caregivers and other service providers is another key strategy in the development of a service plan and in building an overall support system.

These resources will assist with:

- improving the knowledge and skills of families and service providers regarding cognitive disabilities and effective practices in supporting individuals;
- providing specialized training on behaviour management and life-skills; and
- providing consultation on strategies to better manage behaviours of children, youth and young adults.

Implementation is under way.

Where?

Cognitive Disability Consultants will be located in Regina, Saskatoon, Prince Albert, and La Ronge, with expansion to full provincial coverage in 2006-07.

ii. Establishing Flexible and Individualized Supports

Overview

A new flexible and individualized supports initiative will provide an additional option in the planning process for individuals with cognitive disabilities and their families. This funding will be linked to the individual/family and will offer greater options in terms of choice and control of supports.

Flexibility of funding supports will ensure agencies involved can assist an individual or family to access the funding.

Getting Started – What's Involved?

Saskatchewan Community Resources and Employment will manage the Flexible Individualized Support Initiative. This initiative will provide funding for family support and supportive independent living services to individuals with cognitive disabilities who have an identified unmet need.

Eligibility for funding will be based on an assessment of impact of disability and unmet need. This funding will not replace existing supports but will be used to supplement support from existing resources to develop a shared response (e.g. social housing, home care, mental health services, employment supports, etc.).

Since this is a new approach to providing supports, further program development is needed. Implementation is expected for Spring 2005.

Where?

There will be access to individualized supports throughout the province.

2. Improving Access to Assessments and Diagnosis

People diagnosed with FASD are less likely to experience social and relationship problems if they are diagnosed early in life and raised in a stable and nurturing environment. These two factors have been associated with helping individuals escape negative experiences, including confinement for criminal violations and other reasons, trouble with the law, inappropriate sexual behavior, alcohol or drug problems and disrupted education. Accordingly, timely access to cognitive disabilities assessment and diagnosis is a priority initiative in Saskatchewan. The enhancement of provincial cognitive disabilities assessment and diagnostic services and the establishment of a telehealth cognitive disabilities diagnostic pilot project will assist with improving timely access to service throughout the province.

“These two positive factors, living in a stable environment and having an FAS or FAE diagnosis at an early age, are now documented for the first time as having a strong influence on what was previously assumed by many people to be an unchangeable situation.”

Streissguth, A.P. et al: Risk factors for adverse outcomes in fetal alcohol syndrome and fetal alcohol effects, Journal of Developmental and Behavioral Pediatrics, 2004.

i. Enhancing Assessment and Diagnostic Services

Overview

Individuals with cognitive disabilities who have unmet needs will have improved access to screening, assessment and diagnosis to better determine the impact of their disability and identify needs.

Screening usually refers to an initial step being taken and provides a preliminary evaluation. Different types of service providers and professionals use different levels and types of screening for different purposes. A referral to a professional(s) for a functional assessment usually follows.

A functional assessment assists in establishing a service plan. A functional assessment does not replace a diagnosis, but can assist in the diagnostic process. It can also identify individuals with need where diagnosis is not possible or not essential to establishing a service plan.

A functional assessment:

- determines the impact of the disability;
- identifies individual and family strengths;
- provides a basis for addressing challenges such as behavioural and learning problems; and
- helps in the development of an individualized plan.

Diagnosis identifies a specific disease, disability or condition. Only a medical practitioner, such as a doctor, makes a diagnosis of medical conditions.

In addition, Health Canada has released National Diagnostic Guidelines for FAS and its related disorders. These guidelines will assist physicians in making a more accurate diagnosis.

Getting Started – What’s Involved?

When screening indicates the individual is suspected of having a cognitive disability, they should be referred to professionals for a functional assessment. Then some individuals may need to be referred for a formal psychological assessment by a qualified psychologist (e.g. clinical, educational). In some cases it may be appropriate to refer for a medical diagnosis. Specialized Health Assessments may be required from time to time from forensic psychologists (for specialized mental health assessments of offending behaviours), neuro-psychologists (for brain-behaviour assessments) or neurologists (for neurological assessments).

“Intervention should be based on need, and should not be delayed because of waiting lists or delay in accessing definitive diagnostic services.”

Canadian Paediatric Society Position Statement: Fetal Alcohol Syndrome, March 2002.

Some cognitive disabilities have underlying medical conditions and therefore, a trained medical practitioner must make the diagnosis of the medical condition.

Where?

Provincial services will be enhanced in the Regina Qu'Appelle, Saskatoon and Prince Albert Parkland Health Regions.

ii. Establishing a Three-year Telehealth Cognitive Disabilities Diagnostic Pilot Project

Overview

Telehealth Services are being used in remote communities across our province. Telehealth allows patients and physicians in rural and remote areas to have consultations through an interactive video link with specialists in larger centres. The system is also used to deliver continuing education to health providers, and educational sessions for patients and community members.

Manitoba's positive experience using telehealth services to diagnose FAS and its related disorders in remote northern communities demonstrates the possibility of a pilot in Saskatchewan. Using existing telehealth technology, a three-year Pilot has been initiated.

Getting Started – What's Involved?

An experienced cognitive disability assessment and diagnostic team partners with a health care team in a more remote location to offer cognitive disability assessments and diagnosis through the use of telehealth technology. During the developmental stage of the project the experienced team will make several outreach visits to the remote location to facilitate team development and to ensure that all team members understand their role in the provision of assessment and diagnostic services through telehealth. Once the project progresses to service provision, residents in the remote location will have regular access to cognitive disability assessment and diagnostic services.

Where?

The Saskatoon Health Region and the Athabasca Health Authority are collaborating to offer cognitive disabilities assessment and diagnostic services through telehealth to residents of the Athabasca Health Authority.

3. Strengthening Fetal Alcohol Spectrum Disorder Prevention and Intervention

Overview

As part of the *Communities Working Together: Saskatchewan's Action Plan for Citizens With Cognitive Disabilities in Saskatchewan*, a number of specific initiatives related to Fetal Alcohol Spectrum Disorder (FASD) will be developed in order to address the specific challenges of this disability.

Exposure to alcohol before birth can sometimes affect the development of the unborn baby. FASD is a term that refers to a range of physical, developmental, and behavioural impairments. These impairments are permanent and lifelong and often lead to difficulties with learning and social skills for the person.

“Those working in human services must become more knowledgeable on FASD so that there is a planned, sensitive and helpful approach to services.”

Fetal Alcohol Spectrum Disorder Community Discussions Summary Report, February 2004.

While FASD is prevented by not consuming alcohol during pregnancy, many individuals are unaware of how alcohol use during pregnancy can affect the unborn baby and cause permanent impairments. Other areas of concern, such as addiction and problems related to poverty, lack of housing, violence, historical sexual abuse and despair, may also contribute to consuming alcohol during pregnancy.

There is no known safe time, level or type of alcohol to use during pregnancy.

Because alcohol affects each pregnant woman and unborn baby differently, the best advice for a woman who may become, or who already is pregnant, is to not drink any alcohol. That way the unborn baby will be safe from FASD for sure. If a woman is finding it hard to stop drinking, a referral to an agency that can help should be made in a local community. Early intervention using a supportive, culturally sensitive and non-judgmental approach will have long-term benefits.

Getting Started – What’s Involved?

A number of initiatives will be undertaken. They include:

- i. Strengthening Prevention
- ii. Partnering with the Saskatchewan Fetal Alcohol Support Network
- iii. Developing a Screening and Alternative Measures Pilot Project

i. Strengthening Prevention

A number of approaches to prevention and early intervention are required to address this disability. Effective prevention means:

- All women and their partners must be aware of the effects of alcohol on the unborn baby.
- Children and youth are taught at an early age the association of alcohol, pregnancy and the life-long disability of FASD.
- Specialized, concentrated efforts should be focused on vulnerable, substance abusing and chemically dependent women and their partners.
- If women are to experience successful recovery from substance abuse they must receive support and experience positive relationships and interactions.
- Some women will struggle with complete abstinence. Reducing the use of alcohol during pregnancy will reduce the harm caused by it.
- Prevention and early intervention needs to be integrated with existing programs.

Promoting a Harm Reduction Approach

“To be effective in FASD prevention efforts, we need to move from a focus on women’s alcohol use alone to increased understanding of related health and social problems experienced by women that contribute to FASD, and to provide a network of supports that directly address these contributing factors.”

British Columbia Centre of Excellence for Women’s Health Policy Series, Mother and Child Reunion: Preventing Fetal Alcohol Spectrum Disorder by Promoting Women’s Health.

Many women who are vulnerable to having babies with FASD will have a difficult struggle with total abstinence from alcohol during pregnancy. Some will have experienced the effects of multi-generational poverty and some will have grown up in families and neighbourhoods where alcohol is part of a lifestyle. In many cases, alcohol is a crutch or tool to help them ‘cope’ or ‘escape’ the pressures in their lives. Many women will experience significant pressures from their partners and others to continue using substances.

“A harm reduction approach emphasizes:

- Assistance toward improving women’s health in a holistic way.
- The right to non-judgmental, non-coercive services.
- Reducing the harm arising from use, rather than focussing on the drug itself, whether legal or illegal.
- The involvement of women who use, and their communities, in jointly coming up with strategies that will work.”

Saskatchewan Provincial Alcohol and Drug Services Working Group. Fetal Alcohol Syndrome: A role for professionals in providing early intervention and other support for women, April 2002.

It is unrealistic to believe that once aware of the effects of alcohol and being offered treatment that total abstinence will result for all women. Small steps, including reduction of alcohol consumption during pregnancy, must be recognized and supported.

Intervention approaches that are culturally sensitive must be effective in working with troubled individuals who may not always welcome intervention. No mother consumes alcohol with the intent to have a child affected by FASD. Effective practices recognize the issues with alcohol abuse and addiction. Women must be supported throughout their pregnancy to prevent FASD.

To enhance existing prevention and awareness efforts already underway, and to support the objectives outlined in the framework, a number of initiatives will be undertaken using community development approaches. They include:

- a) Strengthening prevention and awareness initiatives.

Saskatchewan Liquor and Gaming Authority have created a funding pool to enhance social responsibility initiatives related to beverage alcohol. Resources will be allocated in partnership and consultation with Saskatchewan Health, and will focus on FASD.

Further discussions with community partners will take place on an annual basis to identify priority areas.

- b) Establishing a prevention pilot project for youth and women at-risk of consuming alcohol during pregnancy in the *KidsFirst* North program.

KidsFirst is a key interdepartmental initiative designed to support vulnerable families in developing the capacity to nurture their children. The program involves a comprehensive, research-based and strategic array of prevention and early intervention initiatives that focus on providing services for pregnant women, their families, and children to age five, who are most vulnerable due to their social and economic circumstances. Emphasis is also placed on the prevention of FASD.

KidsFirst North will enhance existing services by establishing a prevention pilot project targeting additional resources to youth and women at-risk of consuming alcohol during pregnancy. This targeted funding will also support community development activities.

- c) Developing FASD Curriculum.

Saskatchewan Learning will develop sample units on topics in the curriculum relating to FASD and parenting. The sample units will provide instructional methods, student activities, assessment and evaluation strategies, and student teacher resources.

- d) Province wide intervention training strategy.

Professionals and service providers will be trained so that they have the knowledge and skills necessary to support women at risk of having an infant with FASD, and to support individuals with cognitive disabilities. Training will be offered to physicians, health professionals, police, lawyers, judges, other service providers, and families. The training will be managed centrally and involve a common set of materials with special modules for each group of professionals and service providers.

ii. Partnering with the Provincial Saskatchewan Fetal Alcohol Support Network

The Saskatchewan Fetal Alcohol Support Network (The Network) is a provincial non-profit organization that supports parents and caregivers of persons with FASD.

Over the past few years The Network has developed a number of resources, including Tip Sheets that have been very useful to parents, caregivers and professionals. They also provide information to professionals and, in partnership with the Saskatchewan Prevention Institute, have developed a Speakers Bureau that provides educational presentations to parents, professionals and community groups. The Network encourages the development of parent support groups around the province.

“It is important to take away stigma attached to FASD (both for those identified as having FASD and for the families).”

Consumer, Fetal Alcohol Spectrum Disorder Community Discussions Summary Report, 2004.

The provincial departments of Community Resources and Employment, Health and Corrections and Public Safety will provide funding to assist The Network with their continued work to address FASD.

Further information about The Network can be found at the following website address: <http://www.skfasnetwork.ca>.

iii. Developing a Screening and Alternative Measures Pilot Project

This pilot project will test a screening / assessment / case planning system designed to meet the short term and long term needs of youth affected by FASD in the justice system as defined under the Youth Criminal Justice Act.

Outcomes of the project will include:

- Youth affected by FASD are identified through a screening process;
- Youth screened as having a significant likelihood of being affected by FASD receive assessment and diagnosis (when necessary);
- Youth affected by FASD are held accountable for their offence in ways that are meaningful to them;
- Appropriate short term and long term intervention plans are developed and carried out for youth affected by FASD.

Where?

Saskatoon.



Small Steps Equals Big Gains

The time is right in Saskatchewan to address disability in a new way.

The *Communities Working Together: Saskatchewan's Action Plan for Citizens With Cognitive Disabilities* is a step in achieving a vision for the future in Saskatchewan where individuals with disabilities may achieve full and equal participation in our province. The initiatives will provide a foundation for the improvement of supports and services to individuals with cognitive disabilities.

A comprehensive approach to supporting individuals with cognitive disabilities is important. Continued discussions and collaboration by all sectors and communities are needed.

Using community development and culturally appropriate approaches will be important in the development of many of the initiatives outlined in the strategy. The Strategy will align with other initiatives currently underway.

Ongoing discussions with community partners across the province will take place in the coming months as the provincial strategy continues to be developed. Government departments will continue to play a role in providing central support to the implementation of the strategy. It is expected evaluation of initiatives will inform future service development and effective practices.

Glossary

Behavioural Challenges – refers to limitations in an individual's social, emotional or behavioral functioning. Behavioural challenges can impact a person's daily functioning.

Capacity Building – involves drawing together the resources, skills and knowledge that already exist at all levels – in families, communities, regions, governments, private industry and non-government organizations – and filling in gaps with additional training, sharing of best practices, knowledge and other resources (Health Canada: *Fetal Alcohol Spectrum Disorder – A Framework for Action*, 2003).

Clinical Psychological Assessment – typically involves the gathering and analysis of information on an individual suspected of having a disorder of behaviour, emotions or thought. Information is gathered from a variety of sources, and includes direct observation/interviewing and psychological testing of the individual; and reports from those familiar with the individual, including his/her family. The analysis is expected to lead to recommendations for the treatment and management of the individual's disorder.

Cognitive Disability – is typically a long-term condition that involves significant limitations in a person's ability to learn and to process information from his/her environment (e.g. acquiring knowledge, remembering, decision making, problem solving, abstract reasoning etc.).

Community – A group of people bound together through mutual interests and sense of shared destiny based on ethnic, racial or cultural differences. Boundaries can be geographical (such as a neighbourhood, town, city or region) or non-geographical (such as an interest group dispersed across the province, workplace, business organization, professional association, or ethnic/cultural group). (Government of Saskatchewan, *Saskatchewan Human Services: Integrated Case Management*, October 1998).

Community Development – is an educational and motivating process that engages community members and organizations and empowers them to participate actively in improving the quality of their lives. (Saskatchewan Education, *Building Communities of Hope: Best Practices for Meeting the Learning Needs of At-Risk and Indian and Métis Students*, 1996).

Determinants of Health – Physical and mental health is determined by a number of factors including: Income and social status, employment and work environment, education, social environment, natural and built environments, personal health practices, individual capacity and coping skills, biology and genetic endowment, health and social services, culture and gender. (Health Canada: *Fetal Alcohol Spectrum Disorder – A Framework for Action*, 2003).

Developmental Challenges – refer to limitations in the person's adaptation to daily living. In this context, developmental challenges may include behavioural challenges but also limitations in other areas of functioning such as self-direction, self-care, home and community living, work, leisure, safety, educational, vocational and employment activities.

Diagnosis – is a formal statement given to identify a specific disease, disability or condition. Only a medical practitioner, such as a doctor, can make diagnoses of medical conditions.

Educational Assessment – refers to a comprehensive range of methods and strategies used to gather information about a student. Information is gathered from a variety of sources including classroom-based measures, parent/family interviews, observations in a variety of settings, past student records, reports from other personnel involved with the individual and family, and formal norm-referenced assessments. This information provides insight into a student's abilities, needs, interests and progress.

Fetal Alcohol Spectrum Disorder (FASD) – is an umbrella term used to refer to a range of physical and developmental disabilities resulting from prenatal exposure to alcohol. It is not a diagnostic term. There are diagnostic terms within the FASD umbrella term including: Fetal Alcohol Syndrome (FAS), partial Fetal Alcohol Syndrome (pFAS), Alcohol-Related Neuro-development Disorder (ARND) and Alcohol-Related Birth Defects (ARBD).

Formal Resources – are those services represented by paid service providers (e.g. social workers, addiction or mental health workers, teachers, etc. (Human Services Integration Forum, *Integrative-Wraparound Process Training Manual*, April 2001).

Functional Assessment – evaluates a person's ability to perform activities of daily living (ADLs) as well as the person's ability to care for himself/herself. It considers aspects of quality of life, and physical and mental well being.

Harm Reduction – is defined as 'a policy or program directed toward reducing or containing the adverse health, social, and economic consequences of alcohol and other drug use without requiring a reduction in consumption or abstinence from substance use'. Harm Reduction allows for the 'right help at the right time'. (Saskatchewan Provincial Working Group, *Meeting the Challenges, The Saskatchewan Model of Recovery Services*, 2001).

Holistic – A definition of health that looks at the whole picture and takes all determinants of health (physical, intellectual, emotional and spiritual), including social determinants, into account. (Health Canada, *It Takes a Community: A framework for the First Nations and Inuit Fetal Alcohol Syndrome and Fetal Alcohol Effects Initiative*, 2001.)

Human Services – Services provided to individuals to help meet their physical, psychological, and/or social needs. These include health, education and training, social, justice, housing, recreational and cultural services. (Government of Saskatchewan, *Saskatchewan Human Services: Integrated Case Management*, October 1998).

Informal Supports – includes family/caregivers, friends, and/or volunteers who actively provide support to individuals and families. (Human Services Integration Forum, *Integrative-Wraparound Process Training Manual*, April 2001).

Integrated Planning Process – includes a team approach to assessing, planning, coordinating, implementing, monitoring, and evaluating individual and family needs.

Inter-sectoral Approach – evaluates a person's needs from the perspective of more than one service provider.

Intervention – activities intended to prevent or reduce the harm associated with primary and secondary disabilities. (Health Canada, *Best Practices: Fetal Alcohol Syndrome/Fetal Alcohol Effects and the Effects of Other Substance Use During Pregnancy*, 2001).

Impact of Disability – is understanding an individual's limitations or restrictions and the supports required to participate and to be included in the community. An approach based on the impact of disability allows supports to be more closely matched to individual need and circumstance.

Neurological Assessment – is completed by a neurologist or other physician and includes a physical examination that focuses on evaluating the neurological status of the individual, using specialized knowledge of the function and distribution of the nerves in a person's body.

Neuropsychological Assessment – includes specific psychological tests that determine the areas of impairment in the individual's brain and the relationship to his/her behaviour.

Screening – usually refers to an initial step being taken and provides a preliminary evaluation. A set of criteria is used to examine behaviours, physical characteristics, or other attributes that may indicate a certain disorder (e.g. use of screening tools to determine problem drinking).

Secondary Disabilities – occur after birth and may include mental health and alcohol and drug concerns, and related issues such as school problems, inappropriate sexual behaviours, and trouble with the law.

Service Plan (Care Plan) – A series of goals, interventions and responsibilities that provide a cohesive and integrated approach to address the identified strengths and needs of the client. (Government of Saskatchewan, *Saskatchewan Human Services: Integrated Case Management*, October 1998).

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