



Canadian Centre
on Substance Abuse
Centre canadien de lutte
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Systems Approach Workbook

Valuing People with Lived Experience

October 2013

Who should read this brief?

- People who have experience, either personally or through a spouse, friend or family member, with substance use problems and with accessing or trying to access the treatment system.
- Service providers or others looking for information on system change to provide to individuals with lived experience.
- Leaders and decision makers looking to support incorporating people with lived experience into system change, planning, delivery and evaluation.

Why is lived experience important to systems change?

- The voice of people with lived experience provides a unique and valuable perspective.
- The participation of people with lived experience in the planning, delivery and evaluation of services and supports can help to make sure that the system is taking a client-centred approach and better serving individuals.
- Individuals have the right to be involved in their own service planning and to be involved in decisions that impact the services to which they have access.

Overview

This brief provides:

- An introduction to how treatment is currently organized in Canada;
- An introduction to the report, *A Systems Approach to Substance Use in Canada: Recommendations for a National Treatment Strategy*, and
- A summary of the role individuals can play in improving accessibility and quality of services.

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This document was published by the Canadian Centre on Substance Abuse (CCSA).

Suggested citation: Canadian Centre on Substance Abuse. (2013). Systems Approach Workbook: Valuing people with lived experience. Ottawa: Author.

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Production of this document has been made possible through a financial contribution from Health Canada. The views expressed herein do not necessarily represent the views of Health Canada.

This document can also be downloaded as a PDF at www.ccsa.ca.

Ce document est également disponible en français sous le titre :

Manuel d'Approche systémique : Valoriser les gens qui ont une expérience pertinente

ISBN 978-1-77178-046-9



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A Brief Introduction to Treatment in Canada

The largest providers of substance use treatment services in Canada are the healthcare systems organized by the ministries of health within each province and territory. Some federal agencies also provide services to specific populations, for example, First Nations and Inuit communities, veterans and military personnel, and people in federal prisons. There are also services offered by private individuals and companies, and non-government agencies such as the Salvation Army.

Most Canadians that get help with alcohol or drug problems do so without going to a specialized service. They go to self-help groups in the community, to spiritual resources and to primary care services like a walk-in clinic or a family doctor.

Although there are many excellent services in Canada, many people who have substance use problems do not get the help they need. The challenges people face include:

- Not wanting to be stigmatized or labelled an “addict”;
- Not knowing what services are available or how to access them;
- Not being able to find a service that suits their needs in terms of age, gender or culture;
- Not having appropriate services close enough to home; or
- “Falling through the cracks” because of poor co-ordination between services.

What is a Systems Approach?

There is no single solution to substance use; people differ in their needs and experiences. Canadians require a range of services and supports broad and flexible enough to respond to these needs.

Taking a Systems Approach means looking at how the different services and other components of the treatment system should work with one another. When services work together, the overall quality of care improves and people get better results. Unfortunately, the current treatment system is fragmented and services are not well connected, making it hard for people to navigate the system.

In 2008, a group of researchers, people working in the field and people with treatment experience released [A Systems Approach to Substance Use in Canada: Recommendations for a National Treatment Strategy](#) (the Systems Approach report). This report makes 20 recommendations for improving the accessibility, quality and range of substance use services and supports in Canada.

The first two recommendations are particularly important for people who live with alcohol or other drug problems:

Recommendation 1: Increase the range and quality of services and supports available, and make it easier to access the right ones no matter where an individual starts.

Recommendation 2: Involve people with lived experience, advocates and families in planning and evaluating services, systems and policies.

The report focuses on the development of a continuum of services, represented by a tiered model that is intended to be flexible and work in a variety of contexts. The Government of Alberta, for example, has adapted the model for its 10-year addictions and mental health strategy, *Creating Connections* (Figure 1). With each tier, the level of complexity and intensity of service increases, while they overlap with one another and work together. The model also shows health promotion and prevention, the individual client, families and the community as the central focus across all tiers.



Figure 1: Alberta’s Creating Connections Model

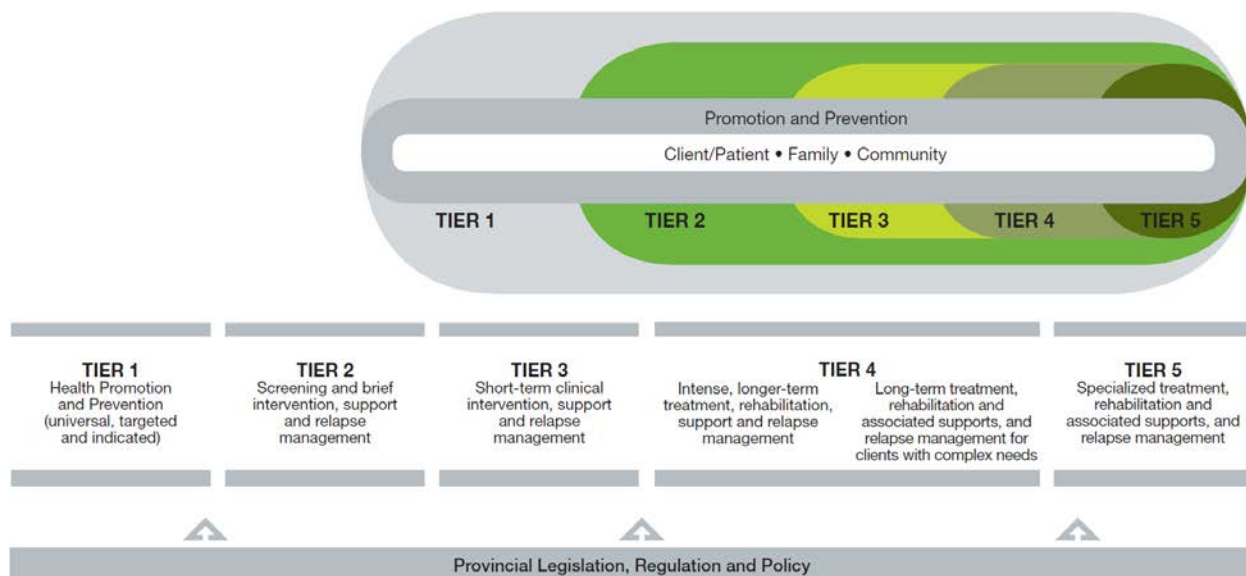


Image reproduced with permission from *Creating Connections: Alberta’s Addiction and Mental Health Strategy*, Government of Alberta.

What Difference Can a Systems Approach Make?

The Systems Approach report is the first comprehensive strategy for substance use services in Canada. It outlines the type of system that people who are at risk or are experiencing problems because of substance use should be able to access. Although system-level change can take time to have an impact on the experience individuals have of service, that is the fundamental goal. Table 1 gives hypothetical examples from two different systems, one that’s “business as usual” and one that respects the Systems Approach report’s guiding concepts.

Table 1: Using the Systems Approach Concepts and Principles to Illustrate an Improved System

Business as Usual	Systems Approach Guiding Concepts Applied
Guiding Concept 1: No Wrong Door No matter which agency I approach, they’ll help me get to the right place.	
Things were going downhill and I knew I needed help. I saw an ad for a service and called the toll free number. They asked me about my addiction and my life. I still had my job then and a supportive family. They told me I didn’t meet their criteria yet, but that I could call back when things got worse!	Things were going downhill and I knew I needed help. I saw an ad for a service and called the toll free number. They asked me about my addiction and my life. Although they told me that the service they offered wasn’t a good fit for my needs, they made an appointment for me to talk to a case manager who could connect me to any of the services in the area.
Guiding Concept 2: Availability and Accessibility I will be able to access services and supports within a reasonable distance and travel time from my home community.	
I have to drive for two hours to get to the closest doctor that prescribes methadone and I was on a waiting list for six months before I could start.	The province recently provided funding for nurse practitioners to help manage increased workload because of methadone clients. Now one of the doctors at the local health centre is working with methadone clients. I didn’t have to join a waiting list and I just have to go across town to see him.



Business as Usual	Systems Approach Guiding Concepts Applied
<p align="center">Guiding Concept 3: Matching I will be matched to services and supports that are appropriate to my needs and strengths.</p>	
<p>A close friend has a problem with alcohol and I've been trying to get him to treatment. I found an evening program offered at a local treatment centre and convinced him to go, but my friend wasn't comfortable with the group format and only lasted a few weeks. We come from a pretty tight Asian community and he wasn't comfortable talking about personal issues with people who might know his family.</p>	<p>A close friend has a problem with alcohol and I've been trying to get him to treatment. I found an evening program offered by a provincial addiction services agency and convinced him to go. We come from a pretty tight Asian community, and we really value privacy. The service understood that and offered individual rather than group sessions, and someone who spoke our own language.</p>
<p align="center">Guiding Concept 4: Choice and Eligibility If more than one service or support meets my needs, I can choose which to access.</p>	
<p>I did an intake interview at the local health centre and was put on a list for the next session for outpatient treatment. The timing didn't work for me though and I came close to missing enough sessions to get kicked out. I found out after that there was another program that was on the other side of town, but would have worked better with my schedule.</p>	<p>I did an intake interview at the local service agency. After reviewing the results, the intake worker gave me a list of the different services available, where and when they were offered, and what the differences were between them. I picked one that was further away for me, but worked with my shift schedule and was a support group, which I'm more comfortable with than one-on-one.</p>
<p align="center">Guiding Concept 5: Flexibility I can access more or less intensive services over time; I'm not tied to a set process.</p>	
<p>I got into treatment as part of my probation conditions. I was going to meetings in the community and seeing a counsellor once a week. When my probation ended successfully and everyone congratulated me on being able to move to just the community meetings. I'm having a lot of trouble without the support I had on probation though and have less incentive to stay clean.</p>	<p>I got into treatment as part of my probation conditions. I was going to meetings in the community and seeing a counsellor once a week. My probation ended just after my one-on-one sessions. The community counsellor asked if I was enjoying the freedom, but I admitted I had actually been doing worse instead of better lately. Instead of kicking me out, the counsellor transferred me to a more structured outpatient program where I've been doing well. My counsellor also told me that I can try going back to the community meetings when I feel ready.</p>
<p align="center">Guiding Concept 6: Responsiveness I can access different types of services and supports as my needs change.</p>	
<p>I've been going to the same group for a while now. I like it, but I kind of feel like I've hit a wall right now. There are things I want to do with my life—like have a family—that don't really get talked about here.</p>	<p>I've been going to the same group for a while now. Every few months, we fill out a questionnaire that asks about our substance use, what we think of the service and other things going on in our lives. I wrote in the last one that I was thinking of starting a family. When I met with my counsellor next she gave me information about another program in the community that includes skill-building for money management, nutrition and parenting. There's even child care available for people in the program.</p>
<p align="center">Guiding Concept 7: Collaboration My treatment is a partnership between me, my service providers and others in the system.</p>	
<p>First I went to my family doctor. She gave me a 1-800 number to call for addiction services. I got a referral from them and did an intake. They told me I should also get help for depression and gave me another 1-800 number to call. I got another referral there and did another intake, but I don't have time to do both at once. I feel like a ping-pong ball being bounced from one place to another.</p>	<p>First I went to my family doctor. She referred me to a community health centre. The intake worker got me into a program that's offered jointly by the mental health and substance use programs in the centre, so I'm getting help with depression as well as with my cocaine use. There's also a program to help me quit smoking that the worker can get me into if I decide I want to.</p>
<p align="center">Guiding Concept 8: Co-ordination The different parts of the system work together behind the scenes to make my treatment experience better.</p>	
<p>Every time I go to a new place it seems like I have to fill out the same forms and tell the same story.</p>	<p>I filled out an intake form and went through it and my history, goals and so on with an intake worker at the clinic. I signed a form saying that he could share the information with other service providers. Since then, each new place I've gone has asked me a few specific questions, but I haven't had to go through the whole process all over again.</p>



What Happens Next?

Change doesn't happen overnight, but it is happening. British Columbia, Ontario, Alberta and New Brunswick have released provincial addictions and mental health plans that align with the Systems Approach report's recommendations for a comprehensive, tiered continuum of services. Thanks to the Systems Approach report, Canada is now collecting data at the national level through the [National Treatment Indicators](#) project. Organizations across Canada are investing in ways to make sure that the services you access are informed by the most recent data and best research available.

What Can I Do?

The addiction field lacks powerful voices, a vacuum that has left only policy makers and health providers to speak for anonymous clients. However good their advocacy, there is no substitute for direct testimony from people who are, or have "been there." (Out of the Shadows at Las, 2006)

Client advocacy means clients acting to improve the services they access. The voices of people with lived experience are having more impact on health care than they used to. People living with HIV or mental illness and their families have played an important role in increasing awareness, reducing stigma and improving services. Organizations of people who use drugs have also had a major impact in HIV prevention in Canada and internationally.

Involving people who have experience with the treatment system is important, but we are still learning how to work with challenges like stigma, traditions of anonymity and providing meaningful support (financial, training, etc.). Examples of clients getting involved at the system level include:

- Participating in public consultations;
- Participating on advisory groups;
- Coordinating or participating in advocacy groups; and
- Assisting in training professionals (doctors and other health providers, police, youth workers and so on) by providing a lived-experience perspective.

You can make an important contribution as an individual. You have the right to be involved in your own service planning, to ask questions and expect answers, and to have an opportunity to provide feedback if your needs are not being met.

For More Information

- CCSA developed the Systems Approach website (www.nts-snt.ca) to provide more information about the Systems Approach and resources to support the implementation of its recommendations.
- The Canadian HIV/AIDS Legal Network booklet, [Nothing About Us Without Us](#), outlines the importance of involving people who use drugs in reducing the risks of HIV and hepatitis C infection, and provides a list of "dos and don'ts" for consulting with people who use drugs.
- The New Zealand National Quality and Risk Managers Group published a [Guide for Developing a Consumer Experience Framework](#) (2012). The toolkit summarizes different methods for getting input from people in the health system in a meaningful, respectful way.



- [Engaging People with Lived Experience for Better Health Outcomes: Collaboration with Mental Health and Addiction Service Users in Research, Policy, and Treatment](#) (2009) was prepared for the Ontario Minister's Advisory Group. The report summarizes a literature review, provides recommendations for increasing the involvement of people with lived experience, and describes barriers and challenges.
- The National Treatment Agency for Substance Misuse in the United Kingdom released the [NTA Policy on Involvement of Users and Family Members](#) (2008). The document provides detailed guidance on the levels of involvement, criteria and payment procedures for lived experience representatives as an example of how people with lived experience can provide input to the system.
- The Mental Health Commission of Canada recently released [National Guidelines for a Comprehensive Service System to Support Family Caregivers of Adults with Mental Health Problems and Illnesses](#) (2013). The report includes recommendations for policy makers and service providers on useful services and supports for family caregivers.

Additional Resources

Links to external websites are provided for information purposes and do not imply endorsement or authorization by the Canadian Centre on Substance Abuse. The list is not exhaustive. Additional suggestions and updates are welcome.

A Selection of Lived Experience Associations and Initiatives

- [Advocates for the Reform of Prescription Opioids](#) (ARPO, Canada and US)
- [Canadian Association of People who Use Drugs](#) (CAPUD)
- [Drug Users Advocacy League](#) (DUAL, Ottawa)
- [International Network of People who Use Drugs](#) (INPUD, Canada)
- [Patients Canada](#) (general healthcare)
- [The Alliance](#) (United Kingdom)
- [Recovery Day](#) (Canada)
- [Vancouver Area Network of Drug Users](#) (VANDU)

Information on Treatment Services

- CCSA published [Key Questions to Consider when Seeking Substance Abuse Treatment](#) to help individuals, their friends and family to ensure that they are accessing effective, evidence-based services that will meet their needs.
- Health Canada maintains the [National Native Alcohol and Drug Abuse Program Treatment Centre Directory of Services](#) for First Nations and Inuit communities.

This brief is part of the [Systems Approach Workbook](#), which is intended to assist those using the Systems Approach report as a guiding framework for improving the accessibility, quality and range of services and supports for substance use in Canada. The brief benefitted greatly from the input of people with lived experience and CCSA extends its appreciation to them for sharing their insight.