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Waiting for What?

An inquiry into the fundamental questions of how to fix adolescent mental health care

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Abstract

Improving the effectiveness of mental health and substance abuse care for young Canadians is a complex and pressing issue. Currently, there is a focus on reducing wait times and facilitating “system integration” as proposed solutions to the crisis in mental health care. As resources are being allocated toward pursuing those two solutions, the authors argue that the more fundamental challenge to addressing the crisis in mental health care for Canadian adolescents is to urge treatment providers and agencies to clearly define the goals and mechanisms of treatment while evaluating program impacts in order to generate knowledge about effective approaches to treatment. In essence, the authors suggest asking two fundamental questions: What are we treating? And what works?

Drawing from insights gained through the creation of a mental health treatment centre at Pine River Institute and the development of subsequent collaborations with various clinical and research communities, the authors outline the importance of clarifying the goals and mechanisms of mental health treatment and creating better definitions and measures of treatment success as a strong foundation for moving toward decreasing wait times and increasing system integration. More specifically, they suggest that the government’s most effective role is to increase system capacity by setting standards for excellence. The government can increase system capacity by requiring accountability through

accreditation and outcome evaluation; increasing resources for program evaluation; and encouraging innovation by funding research into potentially effective treatment that can contribute evidence to the field of adolescent mental health and substance abuse treatment.

We have heard countless personal stories from desperate parents about what it is like to watch their child in a downward spiral marked by issues with mental health, substances and life-threatening behaviour. Their stories are compelling, real and terrifying, and they put the issues of adolescent mental health care in perspective. These families run from psychiatrist, to family doctor, to addiction counsellor, to foster home, to police station and to youth shelter. Parents prowling through back alleys in the middle of the night, in –20°C weather, hoping to find their child alive. They resort to begging youth court judges to hold their child in a detention centre so at least they know the child is safe. They implore gatekeepers of secure psychiatric units to keep their child until they can find some follow-up treatment that will provide the containment required to allow time for healing. No one holds the hands of these parents while they weave through the confusing maze of treatment options, and there is little support while they are waiting for access to care.

There is no question that the “system” of mental health care for young Canadians is in dire need of improvement (Kirby

2006). The statistics tell us that one in five Canadians will experience a mental illness in any given year (Health Canada 2002); the majority of mental illnesses begin during adolescence and young adulthood (Health Canada 2002); and in 2007–2008, \$14.3 billion of public expenditures was spent on mental health services and supports in Canada (Jacobs et al. 2010). For those families who do access treatment, current approaches include brief intervention, outpatient treatment, limited residential treatment, psychopharmacology, substance substitution, brief incarceration or brief hospitalization. Still, there is very little evidence about which treatment modalities work (Brannigan et al. 2004; Hair 2005; Hoagwood et al. 2001; Plant and Panzarella 2009; Williams and Chang 2000) and very little consensus and understanding about the purpose of different treatment approaches or the effectiveness of currently used approaches. Many professionals and policy makers – like the desperate families they wish to serve – are reacting to the challenges of simply accessing treatment without pausing to evaluate what we propose are more fundamental and critical questions: What are we treating? And what works?

Access Is Not a Sufficient Measure of Success

The response to the crisis in mental health care from those who contribute to mental health policy is currently on improving timely access to assessment and treatment by *reducing wait times* and increasing system integration by making *every door the right door*. Although such changes would be welcomed, they are premature if we cannot answer the questions of what we are treating and what works. A component of access is the ability to receive quality treatment, with demonstrated effectiveness. A helpful analogy might be to imagine a patient with acute appendicitis. Let’s say that there is centralized access and the patient is referred to one of five hospitals, each with a different conceptualization of appendicitis, and each with a different treatment approach and no evidence of treatment effectiveness. What would the rationale be for referring the patient to any particular hospital unless the medical problem is clearly understood and the particular hospital’s treatment approach is explicit and supported by evidence?

Now consider the problem with an adolescent struggling with severe substance use, who is likely in the midst of a global breakdown that includes chaotic family relationships, compromised physical and mental health, running away, hospitalizations, trouble with the law, declining or abandoned academic careers and a consistent problematic substance use. Referring agents are faced with varied treatment programs, each with a host of elements that differ on treatment approach, duration, location, family involvement, academic involvement, medical involvement and so on. Without clear specification of what is being treated or evidence of treatment success, what rationale does the referring adult – parent or professional – have to place

faith (and the health of the adolescent) in a program, or to make a choice among programs?

Imagine the variety of responses if the following list were circulated to all professionals who treat these young people, asking the question, “What is being treated in an adolescent struggling with severe substance use?”

- Drug or alcohol toxicity
- A bad habit
- Chronic, incurable disease
- Addiction, a disease marked by relapse
- Developmental disruption/immaturity
- Depression
- Anxiety
- Post-traumatic stress disorder/trauma
- Obsessive compulsive disorder
- Oppositional defiant disorder
- Substance use disorder
- Adolescent-limited addictive behaviour
- Family dysfunction
- Homelessness
- Genetic disease
- Attention-deficit disorder/attention-deficit/hyperactivity disorder
- Juvenile delinquency
- Criminality

Now ask them the question, “What is your mode of treatment?”

- Detoxification
- Breaking bad habits
- Brief intervention
- 12-step program
- Psychopharmacology
- Substance substitution (e.g., methadone)
- Cognitive behaviour therapy
- Dialectical behaviour therapy
- Psychotherapy
- Psychoanalysis
- Recreation therapy
- Art therapy
- Music therapy
- Adventure-based therapy
- Life skills education
- Developmental opportunities
- Health education
- Academics
- Behaviour modification
- Family therapy
- Family program
- Self-help group, peer mentoring
- Group therapy
- Motivational interviews

The decision about where to refer an adolescent and family in need of care is difficult to make unless there is a clear conceptualization of the problem to be addressed and reliable information about which method(s) of treatment are most effective for the identified problem. Only with clear conceptualization of the problem can the best mode of treatment be determined. Efforts to shorten wait times will not address issues that arise when adolescents are placed in programs that are not effective in treating an identified problem. Shortening the wait time or smoothing the path from one facility to another through system integration is

not likely to improve the treatment outcome. While access to treatment may be one measure of success for a system, *it is not a sufficient measure of success* when evaluating the effectiveness of mental health treatment from the client or patient perspective.

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Basis for Success

Success is based on defining the problem of what we are treating, defining measures of success (i.e., outcome indicators) and measuring outcomes. Process measures (e.g. number of clients served, how quickly and at what cost) are the only measures that are currently required in Ontario's performance evaluation of mental health care and addiction treatment agencies. These measures serve as predictors and potentially surrogates for ultimate outcome measures. These are the only measures that are currently required in Ontario's performance evaluation of mental health care and addiction treatment agencies. Outcome measures that are patient-centred would include measures of clients' ability to function, their mental health and the robustness of their response to treatment. This article proposes that the most important contribution to improving mental health and substance abuse treatment programs will be achieved by policy and resources that encourage programs to measure their outcomes, evaluate what works and introduce change and innovation that improves treatment outcomes. The case study that follows is based on the experience of only one program, and is offered as an example that we hope will influence other programs to evaluate their outcomes, share knowledge of what works and contribute to the advancement of this field.

An Example from the Field: Pine River Institute

In the past decade, professionals at the Pine River Institute (PRI) have talked to thousands of parents who have hit the wall – parents wondering how they should intervene when their 14-year-old moves in with a drug dealer; when their 17-year-old falls down the stairs dead drunk; when their 16-year-old cuts herself, steals from them and crashes the car; when their 13-year-old flies into a rage at the slightest provocation, and the babysitter says he is dealing drugs from the basement.

The need for more effective services for these adolescents and families was the impetus for establishing PRI, a residential treatment centre developed to respond to the gap in treatment for adolescents struggling with mental health and specifically substance abuse. The challenge to “raise rock bottom” and improve the system of care for these youth led the founders of PRI on an international search for treatment options and literature on best practices. Innovative programs in other juris-

dictions where Canadian youth were being sent by parents who could afford the cost of these private programs were included in the review. By 2001, the Ontario government began to provide financial support to families on a case-by-case basis through the out-of-country program to these same programs. Early on, the founders learned that there is little consensus in Canada on approaches to the problem and its treatment. Canadian “best practice” guidelines drafted in the late 1990s are based on limited literature reviews and consultation (Health Canada 2001). The evidence-based literature in this field remains sparse (Hoagwood et al 2001; Plant and Panzarella 2009).

Extensive research and consultations informed the development of the current PRI model, a multi-component developmental-systemic approach to adolescent substance abuse, where substance use is conceptualized as a symptom of individual and family system challenges that have consequences for healthy development. Additionally, a commitment to outcome evaluation and research was established early on.

The PRI model addresses adolescent substance use problems within the broader context of impaired functioning across multiple domains. Complex interactions among biological (neurodevelopment, genetic vulnerability), psychological (trauma, mental illness, learning disability) and social (family and peer dynamics) domains are seen as contributing to adolescents' impaired functioning, substance use and failure to advance developmentally.

This treatment approach provides a context for accelerated development within which adolescents can increase multiple capacities, including emotional and behavioural regulation, abstract thought, pragmatic future orientation, empathic healthy relationships, individuation and social ethics. Such important developmental achievements facilitate and sustain desired treatment gains including decreased substance use, increased functional living and improved quality of life.

What Are We Treating?

From the beginning, the leaders at PRI have attempted to explicitly define and articulate the core conceptualization and assumptions regarding the focus of treatment. The PRI model is based on the conceptualization of the adolescent as existing within a complex system along a developmental trajectory. The model is based on the assumption that significant problematic substance use and the behaviours often associated with it cause development to essentially “arrest” in many areas of the child's life, including emotional, social, academic (intellectual) and even physical development (consider the impact of poor nutrition, school dropout/disengagement, poor sleep habits, numbing of emotions and failure to engage in healthy relationships). The developmental systemic frame for conceptualizing adolescent substance use is based in part on the works of Drs. John McKinnon and John Santa, clinicians and researchers in

the United States who are encouraging the leaders of American treatment programs to reflect on the assumptions that inform their definitions of successful treatment outcomes (McKinnon 2008 and 2011; Santa 2009).

The PRI model is also informed by neurological research indicating that the brain is plastic and that neurological changes caused by substance use may be part of the explanation about why it is hard to quit an addiction (Doidge 2007). Because recent research has revealed that the brain undergoes a marked period of re-pruning, development and growth during adolescence, the potential impacts of any experiences during those years may have significant effects on the actual structures and functions of the brain (Dahl 2004; Lubman et al. 2007). In fact, due to the accelerated rate of brain development, any impacts (positive or negative) are augmented proportionately to the rate of growth. Thus, although prolonged and chronic substance use will likely have augmented negative effects on brain development, the phenomenon of neuroplasticity coupled with the increased rate of brain development during adolescence means that “healing,” as a result of stopping substance use and improving nutrition and other healthy behaviours, can actually occur (Chambers et al. 2003; Weisz and Hawley 2002).

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At the systemic level, substance use is conceptualized as a manifest symptom and maladaptive coping strategy to deal with individual- and systems-level problems. More specifically, substance use is viewed as a strategy being employed by the adolescent to cope with individual-level problems (e.g., depression, trauma, attention-deficit/hyperactivity disorder or other mental illness) and/or dysfunction within the system (e.g., family dysfunction, victimization at school). The many complex factors that exist in the life of adolescents (biology/genes, personality, immediate family, peers, school environment, community, broader social culture and media), including their relationship to the various parts of the system, are considered when formulating individual approaches to treatment.

What Works?

The treatment goal at PRI is to help each adolescent and family identify and address systemic factors that may contribute to the young person’s desire to use substances, while teaching the youth and family alternative ways of coping with the identified problems at both the individual and systems levels. Additionally, because engaging in a lifestyle of problem substance use can result in disrupted and delayed development, adolescents at PRI are

provided with the opportunities they need for “accelerated” development across the spectrum of areas affected (McKinnon 2011).

The PRI approach assumes that accelerated development can best be accomplished through carefully considered therapeutic experiences coupled with guidance from professionals who are trained in promoting child development and dealing with the challenges that these youth face in “catching up.” Treatment for these young people goes beyond relieving symptoms. In other words, in addition to addressing the substance use and underlying issues, these adolescents need opportunities, guidance and time to mature.

Because so little is known about “what works” for these young people, PRI’s core structure was designed to include program and outcome evaluation, with a strong commitment to building a culture of integrated research and practice. An international Research Advisory Committee brings expertise from universities, research centres and other programs, and participation in an international research consortium out of the University of New Hampshire allows for collaborative research.

The process of identifying indicators for treatment success forced leaders at PRI to more clearly and explicitly address the question, what are we treating? PRI treats substance use, individual- and systems-level problems and relative immaturity. The definition of success is based on functional living and quality of life of youth and families who participate in the program. As a result, outcome evaluation is based on a range of functional living and quality-of-life indicators, including substance use, academic status, crisis behaviour, future orientation and family participation, among others.

PRI’s leadership and staff are committed to making a meaningful contribution to the limited research on evidence-based treatment for this population. Process and outcomes are measured on an ongoing basis through careful documentation, reflection and review, and data have been analyzed every six months since the program opened in 2006 (PRI 2010). The PRI treatment model remains dynamic and continues to evolve, responding to the results of the ongoing outcome and process evaluations, and developments in the field, in an effort to answer the question of what works in assisting young people and their families as they transition to healthy adulthood.

Proposed Solutions

Enforce Basic Safety Standards: Licensing and Accreditation

Requiring accreditation by nationally or internationally recognized accreditation agencies would contribute to ensuring a basic level of performance and risk management in child and youth residential treatment programs. Increasingly, these programs demand evidence of “performance quality improvement” and encourage program and outcome evaluation on an ongoing basis. They also require an explicit statement of

treatment models and assumptions. Government's role is not to accredit but to encourage and require accreditation and to provide agency funding to support this process.

Treatment Success Needs to be Based on Constantly Evaluating Goals and Outcomes

The developmental-systemic construct, which goes beyond a narrowly defined medical construct, is not broadly held as a way to think about adolescent mental health and addiction treatment. The recent trend in research funding at the National Institute of Mental Health indicates that there is interest in advancing adolescent mental health research that takes a developmental-systemic approach in a field that currently relies predominantly on outpatient, short-term, symptom-targeted psychiatric and psychopharmacological interventions (NIMH 2008). Treatment success and knowledge about what works can only be based on ongoing outcome evaluation and research that is grounded in a clear definition of what is being treated and the corresponding indicators for success.

Payers and Regulators Should Expect Outcome Evaluation

Recent documents outlining Ontario's 10-year strategy for mental health and addiction articulates the need for promoting accountability at the leadership level (Ministry of Health and Long-Term Care 2010; 2011). Only with reliable treatment outcome studies will payers and regulators (i.e., government) be able to make informed decisions about how best to invest resources toward effective mental health treatment. Additionally, ongoing evaluation of treatment goals and outcomes is the process through which treatment innovations can be transformed into evidence-based practices and policies.

Payers and Regulators Also Need to Understand That This Process Takes Resources

There was no government funding in the initial stages of PRI's development, so private donors and foundations contributed the funds to allow the start-up of a small and innovative operation, including basic evaluation research. Government funding for a pilot project was provided a year after opening, with early results from outcome evaluations indicating that clients were responding to the treatment provided. This pilot funding allowed PRI to build service capacity by making services accessible to a larger number of young people and their families. In addition, the Ontario Centre of Excellence on Child and Youth Mental Health provided some funding and technical assistance to build outcome evaluation capacity. Only with support from the government and community did PRI have the capacity to develop and evaluate an innovative service in Canada. Government must be prepared to dedicate resources to support program evaluation capacity in mental health treatment programs.

Only After Knowing What Works Can We Get into the Business of Dealing with Access Issues

PRI staff have been joined by other Canadian colleagues in an interdisciplinary dialogue among researchers, practitioners and policy makers to deepen the conceptual framework that informs our assessment, intervention and evaluation of adolescents struggling with mental health and addictions (Pine River Institute and The Hospital for Sick Children 2010). What are we treating? How do we measure success? What works? The shared goal is to learn ways to promote the increased uptake of outcome evaluation in adolescent mental health and addiction treatment, and a dialogue has been initiated that includes the Canadian Centre on Substance Abuse, the Ontario Centre of Excellence on Child and Youth Mental Health, SickKids Hospital, the Centre for Addiction and Mental Health, Hincks Dellcrest and PRI. Knowing what works is the necessary foundation for effective solutions to access issues.

The voices of parents, youth, professionals and policy makers are calling for a fundamental change of approach to remedy the critical lack of support for troubled teens who are at risk of not making it to adulthood.

Conclusion

Introducing innovation for a more robust system of care for child and adolescent mental health must be based on a carefully considered conceptual framework. Any responsible interventions in the children's mental health field will be based on this foundation. Taking accountability for articulating our frameworks, identifying what success looks like and measuring the outcomes are the building blocks for system change. Reducing wait times or attempting to create system integration would be the next steps, but not the first. *If you don't know where you are going, any road will take you there.* The voices of parents, youth, professionals and policy makers are calling for a fundamental change of approach to remedy the critical lack of support for troubled teens who are at risk of not making it to adulthood. We are optimistic that the demand for change has become a productive one that calls for accountability and excellence, not just more of the same. And we are heartened when our colleagues in well-established institutions are calling for standards of excellence that will build robust and meaningful system capacity.

The most appropriate role of government in this venture will include ensuring that all treatment programs that they fund are licensed or accredited by a nationally or internationally recognized accreditation organization. While government cannot take on the task of measuring outcomes of the programs and services it funds, it can contribute to building system capacity to define

treatment models and outcome indicators and to measure the results. While these fundamental actions are taken for granted in physical medicine, they are not widely practised in child and youth mental health and addiction treatment. Only when we understand what we are doing and how well we are doing will it make sense to tackle system integration and wait times. In the meantime, raising the bar for excellence will save more lives than any process reforms, by addressing the fundamental challenge of defining what we are treating and by evaluating our outcomes.

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