### Transforming mental health services for young people: A Canadian model

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#### Abstract

In most mental illnesses, onset occurs before the age of 25 and the earliest stages are critical. The youth bear a large share of the burden of disease associated with mental illnesses. Yet, Canadian youths with mental health difficulties face delayed detection; long waiting lists; inaccessible, unengaging services; abrupt transitions between services; and, especially in remoter regions, even a complete lack of services. Responding to this crisis, the Canadian Institutes of Health Research announced a five-year grant that was awarded to ACCESS, a pan-Canadian network of youths, families, clinicians, researchers, policymakers, community organisations and Indigenous communities. Using strategies developed collaboratively by all stakeholders, ACCESS will execute a youth mental healthcare transformation via early detection, rapid access and appropriate, high-quality care. The project includes an innovative, mixed-methods service research component. Similar in many respects to other national youth mental health initiatives, ACCESS also exhibits important differences of scale, scope and approach.

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## Introduction

Over 75% of mental disorders arise between early adolescence and young adulthood (Kessler et al., 2005), often initially in milder, sub-threshold forms, with increasing severity over time (McGorry et al., 2006). Emerging at junctures of life that entail significant physiological, emotional and social developments, mental disorders have serious short- and long-term negative consequences especially when untreated, treated late or treated poorly. Such consequences include school/work failure, strained relationships, hospitalisation, suicide, homelessness, legal problems, and violence (Boivin et al, 2005, Cheung and Dewa, 2007, Stephens and Joubert, 2001). Mental illnesses also inflict immense suffering on affected persons and their families and great costs on society (Mental Health Commission of Canada, 2013, Rossler et al., 2005). Yet, the accessibility of mental healthcare to the youth remains limited. Just 20-25% of Canadian youths in need get help (Wang et al., 2005) and treatment outcomes remain poor (Freeman et al., 2011, Wang, 2007).

Specialised, youth-friendly early intervention services for serious mental disorders (particularly psychosis) promise long-term benefits (Greenberg et al., 2001, McGorry et al., 2007c). Although, along with other countriess, Canada has led the early intervention for psychosis movement (Iyer and Malla, 2014, Malla et al., 2003, McGorry and Yung, 2003), its precepts have not been applied to broader youth mental healthcare. Most Canadian youths with mental health needs experience significant delays in seeking help, excessive wait times (Kowalewski et al., 2011) and long, circuitous, often traumatic pathways to care (Anderson et al., 2013, Reid et al., 2011). The unengaging nature of many conventional mental health services results in reduced youth participation, increased drop-out (30%; Canadian Mental Health Association (CMHA), 2013)

and minimal benefits (Cheung and Dewa, 2007, Freeman et al., 2011, Wang, 2007). Transitions into and out of services are often based on age and not on need. Services rarely offer effective social, psychological and biological treatments that are strongly indicated for many mental disorders. In Canada's marginalised and Indigenous communities, even basic services remain unavailable (Adelson, 2005, Kirmayer et al., 2000).

Australia, Ireland and the United Kingdom have responded to similar challenges with a radical reconstruction of youth mental healthcare (McGorry et al., 2013). In Canada, however, these issues had, until recently, remained unaddressed at the systemic level. In 2012, the Canadian Institutes of Health Research (CIHR) and the Graham Boekch Foundation announced the "Transformational Research in Adolescent Mental Health" (TRAM) grant to engender a Canadian response to the issue of unmet youth mental health needs.

#### The TRAM Initiative

CIHR's Strategy for Patient-Oriented Research (SPOR) aims to establish Canada-wide networks of federal and provincial/territorial partners to promote evidence-informed, high-quality, accountable, timely and accessible healthcare (CIHR, 2011). Launched in October 2012 as CIHR's first SPOR initiative, TRAM provides \$25 million in funds over five years, to create a pan-Canadian network to improve the identification of youths with mental illnesses and the timeliness and quality of their care. Framing the state of youth mental healthcare as a crisis meriting a paradigm shift (Handa, 1986, Kuhn, 2012), TRAM sought a network that would go beyond incremental changes to fundamentally transform how Canadian youths access and receive mental healthcare.

TRAM targeted youths aged 11 to 25 years, limited its scope to secondary and tertiary prevention, precluding primary prevention activities (e.g., better prenatal care), and prioritised bridging the science-practice divide by applying existing evidence to improve mental healthcare over the exclusive generation of new evidence. With its emphasis on philosophical and systemic change, TRAM was different from typical scientific grants, funding a project led not, as usual, exclusively by researchers, but by all stakeholders with an interest in youth mental health. After a rigorous, multi-stage application process, beginning with expressions of interest from 54 applicants in April 2013 the authors' network, ACCESS, was awarded the grant on May 22, 2014.

## **ACCESS: Detailed description**

The ACCESS network includes youth, family/carer, community organisation, service provider, researcher, and policy and decision maker stakeholder groups from six Canadian provinces and one territory. The network's vision is encompassed in its name: <u>A</u>dolescent/young adult <u>C</u>onnections to <u>C</u>ommunity-driven <u>E</u>arly <u>S</u>trengths-based and <u>S</u>tigma-free services (ACCESS). All stakeholder groups, particularly youth, embraced this name.

Committed to service and sector integration, and a youth-friendly, empowering culture that alters the language and perceptions around mental illness, ACCESS will implement, evaluate and elaborate a transformation in youth mental healthcare to:

- a) Improve stakeholder engagement with and awareness of mental health issues, leading to early need identification
- b) Offer rapid, engaging, timely access to youths seeking help

c) Provide evidence-informed, youth-friendly, appropriate mental healthcare for all severity levels and types of difficulties with needs-based transitions

The ACCESS service transformation will be implemented at 12 demonstration sites chosen to represent pan-Canadian variations in geography, culture and service availability. These include large urban sites, smaller urban and rural locations and small/remote Aboriginal communities. ACCESS will also target some particularly vulnerable youth groups (e.g., Indigenous, immigrant, minority, and homeless youth; adolescents in state care; and youth in the criminal justice system).

The ACCESS transformation will be informed by site-specific resources, needs and contexts. This is important in the Canadian healthcare system (more accurately, systems), where although basic coverage guidelines are federally outlined, healthcare is provincially administered. Healthcare for Indigenous groups is delivered via a complex system governed by federal, provincial, territorial and Indigenous jurisdictions.

Guided by local needs and contexts, ACCESS will reinforce strengths; enhance capacities through inter-sector, inter-service and inter-stakeholder collaboration; add trained staff; and deploy e-technologies. ACCESS will also create/use youth-friendly physical spaces as portals for help-seeking and venues for youth peer support activities. New staff at these spaces will include ACCESS-trained clinicians and, where possible, a peer support worker.

At each site, frontline mental health services will be supported by and connected to specialised services (e.g., for eating disorders or first-episode psychosis). Where such services are unavailable, ACCESS will deploy tele-mentoring, remote consultation with specialists or

electronically delivered specialized interventions.

Being CIHR-funded, ACCESS, in addition to service transformation, is committed from the very outset to a global, systematic research and evaluation strategy.

## Underpinnings: Stakeholder input and established evidence

ACCESS members agreed that youth mental healthcare transformation must proceed from all stakeholders' input and relevant established evidence.

#### <u>Stakeholder input</u>

Stakeholder input on barriers to seeking and providing/receiving appropriate care was sought through multiple means. Youths and families shared moving accounts of their experiences with the mental healthcare system, while, other stakeholders gave concrete examples of barriers operant at their sites. Inputs on barriers were also derived from a network-wide email exchange (over 40 pages) and descriptive site reports (over 100 pages). These materials were synthesised using qualitative analysis methods and consolidated into six key themes:

- i. Lack of knowledge about mental health, services, privacy legislation and patient rights
- ii. Limited accessibility
- iii. Services not meeting youth and family needs
- Limited skills of mental health professionals in providing generic and specialised interventions to youth
- v. Negative attitudes towards marginalised and vulnerable populations
- vi. Negative and fearful perceptions of mental illness

These barriers echo those identified in previous mental health research (Anderson et al., 2013, Gulliver et al., 2010, Yap et al., 2013). Notably, stakeholder-identified barriers pertained not only to accessibility but also to the ability of services to keep youths and families engaged. This may explain the reportedly high rates of youth mental healthcare drop-out (Armbruster and Fallon, 1994, Edlund et al., 2002). All stakeholders, particularly the youth and families, played an active role in developing ACCESS's response to the barriers and deficits that they had identified.

## Established evidence

The following sets of evidence were considered in developing the ACCESS model:

- A. Most mental disorders appear first as general distress and sub-threshold symptoms (often vague, overlapping, or not accurately indicative of future diagnosis) that may progress to syndrome-level disorders (often still with overlapping symptoms) (McGorry et al., 2007). Some youths presenting with serious complaints (e.g., hearing voices) do not necessarily develop psychotic disorders but remain vulnerable to other mental disorders (Patton et al., 2014). ACCESS will therefore provide immediate access to assessment regardless of the youth's presenting symptoms or stage of illness. Interventions will be available for a wide spectrum of disorders, be tailored to the phase of illness, and address multiple problems challenging the same individual (e.g. depression and substance abuse).
- B. Evidence supports the benefits of early identification and intervention for specific mental disorders, particularly psychosis (Malla et al., 2005b, McGorry et al., 2002, Singh, 2010).
  Such approaches have not been applied to other mental disorders, are unavailable to most youths, are generally restricted to specialised services and have not been incorporated into

policy decisions. ACCESS will expand the reach of early intervention to other mental illnesses and broader sections of Canadian youth. Early psychosis services privilege individualised intervention plans that promote engagement (Malla et al., 2005b, McGorry et al., 2013). This element will be retained and bolstered.

- C. Canadian youths needing mental healthcare often experience severe delays in seeking and/or accessing help. Treatment delays are associated with negative functional and social impacts (Sherman et al., 2009, Williams et al., 2008). Depending on their age and the nature of their difficulties, youths may first present through the healthcare, education, social service, youth protection or judicial system (Anderson et al., 2013). The disconnections between these systems can complicate and delay help-seeking. Even initial contact with primary healthcare can be a missed opportunity (Lieske et al., 2013, Vohringer et al., 2013) if it does not result in appropriate intervention or referral. Many youths access mental healthcare through crowded hospital emergency services (Anderson et al., 2010) that can seem unfriendly and traumatising. ACCESS will therefore ease youths' pathways to mental healthcare. Current knowledge of pathways to care and treatment delays will inform remedial strategies (e.g., single-point contact, multiple entry portals, youth-friendly access portals, etc.).
- D. Most youth mental health services are located in discrete, unconnected institutions (Greenberg et al., 2001); unable to engage youths; not based on best practices; prone to delays (Boydell et al., 2006, Canadian Institute for Health Information, 2012, Kowalewski et al., 2011, Reid and Brown, 2008); and likely to yield poor functional impacts (CMHA, 2013) and recovery perceptions (Scott et al., 2009). Rigid age cut-offs and administrative boundaries between paediatric and adult mental health services often result in abrupt, inappropriate transitions (Singh et al., 2010). Eighteen is a common youth service cut-off age

that has no real psychosocial basis. ACCESS will therefore focus on service and sector integration; a youth-friendly, empowering culture; and innovative strategies to increase the accessibility of appropriate, evidence-based care with needs-based transitions.

## **Organisational framework**

Our organisational framework is the Theory of Change (Center for Theory of Change, 2013), a formalised framework for identifying steps required to proceed from a starting point to a longterm goal. It can empower all stakeholders to contribute to the blueprint for change, to fully understand clearly articulated goals, and to chart a course to their achievement. The process involves stating the long-term goal, identifying preconditions required to achieve it, and backwardly mapping intermediate goals/interventions required to proceed to the preconditions. Figure 1 shows the Theory of Change framework for our long-term goal, improved youth mental health outcomes. The preconditions for achieving improved outcomes identified by all stakeholders were early identification; rapid access; and high-quality, appropriate care with needs-based transitions. Although not reflected here, Theory of Change also involves questioning the assumption that each short-term goal will lead to the next longer-term goal and using predefined indicators to evaluate the attainment of all goals. Each ACCESS site will produce its own Theory of Change grid based on its specific needs and resources, enhancing the replicability of our Theory of Change implementation model during scale-up.

## Values and Key Activities

ACCESS's transformation model stems from core values and comprises key activity components. Our core values, defined and agreed upon by all stakeholders, are listed in Table 1.

## <u>Activities</u>

ACCESS activities will be conducted in youth-friendly, stigma-reducing, hopeful cultures of care. At all levels, youths and their families/carers will be involved, as appropriate, in peer support; peer-led interventions; service planning; service evaluation; site-level transformation; outreach; participatory research; e-services development (including a central website); and youth-driven and campus initiatives. Most significantly, the youth will be included as full partners in care through menus of treatment choices, informed consent, shared decision making, confidentiality and respect.

The activities related to the three preconditions (early case identification, rapid access, and highquality care) and activities enabling transformation to be conducted at all sites are listed in Table 2-5.

## **Research and evaluation plan**

ACCESS's research and evaluation strategy, involving multiple informants and methods, has been collectively defined by all stakeholder groups in the spirit of participatory action (Baumbusch et al., 2008) and integrated knowledge translation (CIHR, 2014, Lomas, 1991, McGrath et al., 2009). A brief overview this strategy is presented below.

Our research will assess structures, contexts, processes and performance to answer the question, "How well does ACCESS work to identify youths in need and improve their access to highquality mental healthcare?" Given the diversity of our target populations and settings, we will also ask, "Among which youth and family/carer groups is the transformation most and least beneficial?" and "In which contexts is ACCESS most and least effective?"

Six ACCESS sites will participate in a community-led stepped wedge cluster randomised trial (Dreishulte et al., 2013, Hussey and Hughes, 2007). Two groups of three sites will be randomised to begin implementing the transformation at separate time points. The primary outcome of interest is the level of youth and family satisfaction (posited as a product of the entire complex of service accessibility, suitability and quality), in keeping with ACCESS's "service user-oriented" focus. Secondary outcomes in the trial design are wait-times to care and the number of help-seeking contacts before accessing appropriate care.

The stepped wedge design was chosen because our stakeholders thought it more ethical for all sites to receive the transformation rather than for some sites to serve as "controls" as in a typical randomised control trial (RCT). Like traditional RCTs, a stepped wedge trial can generate evidence that has a higher impact on practice and policy (Andersson, 2011, Dreischulte et al., 2013). Staggering the intervention roll-out allows second-stage sites to learn from and improve upon the transformational experiences of first-stage sites. It is also more feasible in resource allocation terms and facilitates easier expansion during the scale-up phase.

The remaining six sites with unique characteristics (e.g., a site serving homeless urban youth) will serve as special demonstration projects and allow us to evaluate the underlying processes and effectiveness of youth mental healthcare transformation in diverse settings.

At all sites, youth-focused outcomes like participation in education, employment, and social roles; improvements in mental health, substance use, and personal well-being; hope for the future; quality of life; satisfaction with and engagement in services; accessibility of care; etc. will be assessed for ACCESS's overall evaluation. Individual sites may append measures in consultation with their stakeholders. For instance, a site whose catchment includes many

immigrants may measure increases in the numbers of ethnic minority youths accessing its services.

An economic analysis of the benefits of the ACCESS transformation will be conducted in detail at two sites and on a more basic level at other sites. This will be critical for influencing policy and ensuring long-term scalability and sustainability. For a detailed, nuanced understanding of the barriers to and facilitators of the desired transformation, ACCESS will conduct an ethnographic study of the entire transformation process. Other components of the ACCESS research strategy include community surveys to assess unmet needs and help-seeking factors; traditional, participatory arts-based (e.g., PhotoVoice) and innovative qualitative (e.g., social media analysis) studies; and an evaluation of the impact of early identification efforts through pre- and post-transformation comparisons of administrative incidence figures of first mental health presentations among youth (Anderson et al., 2012).

### ACCESS in the context of the global youth mental health movement

ACCESS was conceived in response to a CIHR grant initiative. This is unlike Australia where youth mental healthcare transformation evolved under a national deployment strategy and unlike Australia and Ireland where purpose-built central institutions (the National Youth Mental Health Foundation in Australia and The National Centre for Youth Mental Health in Ireland) have played a critical role in youth mental health transformation. ACCESS has also been conceived with a comprehensive evaluation plan built in to the design, and as such is a large-scale pilot test of a health system redesign initiative.

Despite these differences, the values and elements of transformation that emerged from ACCESS

stakeholder inputs closely resemble those of similar initiatives in Australia, Ireland and the United Kingdom (McGorry et al., 2013). The principles of and learnings from youth mental health transformation in these countries have informed the ACCESS model. As well, ACCESS is similar to its international counterparts in recognising unmet youth mental health needs and conceding the inability of extant systems to meet such needs, they commit themselves to improving the accessibility and appropriateness of care for youths and their families. They also accord primacy to the youth voice in designing services for the youth and recognise the value of avoiding harmful transitions.

## **Concluding thoughts**

We expect to show that youths and families at our demonstration sites gain rapid access to appropriate, high-quality care via simple pathways, resulting in significant improvements in multiple outcome domains. Over time, these positive outcomes, youth and family empowerment, and services that prioritise resilience and social inclusion will together reduce the stigma of mental illness. Such timely and appropriate youth mental healthcare can reduce human and financial costs by minimising social, educational and vocational impairments; reducing morbidity; and possibly forestalling the progression of illnesses.

At this early stage, ACCESS's operational efficacy, emerging challenges and evolving opportunities remain to be seen. Nonetheless, simply creating the ACCESS proposal has sparked widespread interest in youth mental health and engendered dialogue around the youthfriendliness, appropriateness and accessibility of services. Our largest systemic effect may thus well be the bringing of youth mental health to the centre stage in Canada. ACCESS has united varied stakeholder groups from diverse geographic, cultural, economic and socio-demographic

backgrounds and powerfully mobilised existing community capacities. Another important gain has been the consensus that service transformation must create a "culture of care" that nurtures expectations among all stakeholders and meets these expectations with a highly-focused, wellconceived plan. We have also learnt that youths and families can and should have a strong voice in highlighting unmet mental health needs, demanding and driving change.

For the envisioned transformation to occur, our collaboratively conceived model must be implemented; iteratively improved upon through data-based, multi-stakeholder reflection and modification; and then scaled up. The scalability and sustainability of the ACCESS model is enhanced by its leveraging and strengthening of extant resources. However, in Canada as elsewhere, continuous advocacy for extensive policy-level support and commitment will be required for a pervasive, sustainable transformation that integrates services for all illness stages, all youth groups and all needs.

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# Tables:

Table 1 Core values of ACCESS

(A) A culture of full participation from youth and families who will shape and actively engage in the transformed system of care.

(B) A recognition that a young person in distress is a "whole person, not his/her disorder" (quoting a youth participant).

(C) The conception of services from a philosophy of hope, resilience, empowerment, and respect for personal agency. Youth participants highlighted the value of being regarded as equal partners in a nonjudgmental, respectful relationship.

(D) Flexibility, portability, and adaptability of care/services provided, and appreciation of local, personal, and sociocultural circumstances, values, beliefs and strengths.

(E) Easy, early access to a continuum of assessment and subsequent evidence-informed intervention, where, when and if needed.

(F) A sustained commitment to the integration of services and stakeholder groups.

	Activity Description
1.	Strengthen links between systems/institutions that encounter youth (schools, courts, hospitals, etc.), especially high risk-populations (youth protection, polic etc.) and consolidate partnerships with organisations tha promote mental health awareness.
2.	Increase the capacity of pertinent systems (including youth and families/carers) to identify the need for help and access. Based on local contexts and stakeholder inputs, sites will choose early case identification techniques from a menu of evidence-based strategies (academic detailing, face-to-face contact, peer support, e technology, etc. (Chong et al., 2005, Joa et al., 2008, Johannessen et al., 2001, Lester et al., 2009, Malla et al. 2005a, McGorry et al., 1996, Melle et al., 2004, Power e al., 2007, Renwick et al., 2008, Wright et al., 2006)).
3.	Create a central multilingual website with a 24×7 interactive component that recommends appropriate routes to help, provided in partnership with an organisation that has offered a similar service in Canada since 25 years (Kids Help Phone).

Table 2: Key Activities to promote early case identification

4.	Screen youths with mental health difficulties out from the criminal justice system, using a Youth Intervention Diversion model that the Royal Canadian Mounted Police have successfully deployed in Canada's Atlantic region.
5.	Target youths "not in employment, education or training" (McGorry et al., 2013) who are more vulnerable and less likely to seek help.

Table 3: Key Activities to promote rapid access

	Activity Description
1.	Provide direct, rapid access to assessment within 72 hours of help-seeking through an ACCESS Clinician. Each site's ACCESS clinician will serve as a single, well-publicised point of contact available in person or over the phone to help-seekers. Youths or others acting in their interest may seek help, without any referral, for any symptom or issue, regardless of severity. The ACCESS Clinician, a suitably trained healthcare professional who is not a physician, will be the key to rapid access.
2.	Seamlessly connect all suitable services with each site's ACCESS clinician who will conduct initial assessments, refer youths to further specialised care if necessary, introduce them to specialists and, if needed, accompany them and their families to initial appointments. The ACCESS Clinician will be supported by a peer support worker when appropriate.
3.	Create or strengthen a system of multiple online and offline access portals and deploy telemedicine technologies to facilitate rapid assessment at remote sites.
3.	Promote hope and future service engagement by conducting initial evaluations in settings preferred by presenting youths and involving families/carers in assessment when appropriate
4.	Working with youths and/or family peers to support those hesitant to seek help
5.	Forge strong partnerships with emergency/hospital services so that youths presenting there are immediately referred to the ACCESS Clinician.
6.	Contact youths who initially need no treatment or only brief counselling every six months.

Table 4: Key Activities to promote high-quality, appropriate care

Activity Description
Activity Description

1.	Offer rapid, fluid, continuous access to appropriate care. ACCESS will deploy several evidence-informed strategies (Reid and Brown, 2008, Reid et al., 2011, Vallerand and McLennan, 2013) to reduce wait times.
2.	Offer evidence-informed interventions staged by the phase of illness and level of care needed, ranging from minimal support and basic psychosocial interventions (resilience-building, brief counselling, etc.) to specific care for common and severe disorders (e.g., CBT for psychosis) (McGorry et al., 2007b, Scott et al., 2013).
3.	Foster collaboration between stakeholders, sectors, disciplines, services and modes (in-person, electronic), facilitating task-sharing and task-shifting (Gessessew et al., 2011, World Health Organization, 2007, Walsh et al., 2010) necessary to make appropriate care accessible.
4.	Provide care in youth-friendly, engaging, rights-respecting, non- stigmatising and recovery-oriented environments created and sustained via continuous youth participation.
5.	Enable transitions based on needs, not rigid age cut-offs
6.	Encourage youths to draw on their own strengths, networks of attachment (particularly family) and communities (e.g., Indigenous elders) for a sense of support, inclusion, resilience, and value.
7.	Focus on youths' own goals and recovery in active collaboration with families/carers and peer support providers. Social and educational/work improvements will be focal targets of intervention, in line with youth and family input and recovery literature guidelines (Barnett and Lapsley, 2006, Leamy et al., 2011, Windell et al., 2012).
8.	Promote care that values all expressions of diversity and is attentive to the needs of especially vulnerable populations, e.g., children in youth protection.

# Table 5: Other enabling activities conducted across all sites to facilitate transformation

	Activity Description
1.	Apply community mapping (Amsden and VanWynsberghe, 2005,
	Griffin and Farris, 2010, Lydon, 2003, Minkler et al., 1997) using
	the University of Kansas Community Tool Box (Community Tool
	Box, 2013) for identifying community assets. This exercise will
	expand the range of generic, non-stigmatising, community-based
	services and resources that youths and families/carers can access
	or be referred to.

2.	Execute a youth-centred e-mental health strategy. E-mental
2.	
	health, an extensively reviewed approach, uses information and
	communication technologies to deliver or enhance mental health
	information, services and support (Christensen et al., 2002,
	Christensen and Petrie, 2013, Lal and Adair, 2014). It can
	complement in-person care and extend its therapeutic benefits
	engagingly and cost-effectively, particularly at remote sites.
	ACCESS will use telephone, mobile and Web media to deploy
	electronic interventions.
3.	Implement a comprehensive training and knowledge translation
	plan that includes training for Access Clinicians, peer support
	providers and youth mental health clinicians and workers;
	school-based outreach; the promotion of evidence-based
	practices (Bernstein, 2013, Barth et al., 2012, Chorpita et al.,
	2011, Chorpita and Regan, 2009, Rotherman-Bous et al., 2012);
	mental health first aid and suicide prevention training; a Train-
	the-New-Trainer program; Communities of Practice (Eckert,
	2006, Stramps, 1997, Wenger et al., 2002); and training for next-
	generation youth mental health researchers and service leaders.



