

A Thesis Review: Exploring the Barriers and Facilitators to Youth Eating Disorder Services in Atlantic Canada

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Context

- * Eating disorders have a huge negative impact on quality of life, affecting psychological and physical aspects of health¹
- * Anorexia nervosa (a type of eating disorder) has the highest mortality rate of all psychiatric conditions, with 10% of individuals dying as a result of this disorder²
- * Less than 20% of individuals with an eating disorder will be treated by a mental health professional³
- * In Canada it has been estimated that there are 424,767 individuals at risk of having an eating disorder, with 31,987 of these individuals living in Atlantic Canada⁴
- * In Newfoundland and Labrador there is a provincial adolescent eating disorder service (the Adolescent Medicine Program at the Janeway), and an outpatient program (The Hope Program). There is also a local eating disorder advocacy organization (the EDFNL), which is involved with supporting families and in providing education surrounding eating disorders
- * The current study is a sub-study of a larger Canadian Institutes of Health Research (CIHR) funded Atlantic Canadian project, referred to as the ACCESS-MH project⁵

Objective

- * To explore barriers and facilitators in youth and family eating disorder journeys in both a) access and b) care in the health care system in Atlantic Canada
- * The guiding research question was: ***What are the significant barriers/facilitators to accessing services related to eating disorder care in Atlantic Canada?***

The Set Up

- * Sample of Youth and Parents in an Atlantic Canadian Province:
 - A. Youth (15-24 years old)- Accessed the provincial health care system with a self-reported diagnosis of anorexia nervosa or bulimia nervosa
 - B. Guardians- of these youth who reported a diagnosis of an eating disorder
- * Narrative journey interviews with the opportunity for participant brought visuals and/or use of journey mapping

The Design

- * Face sheet- Demographic information
- * Narrative interviews-
 - * 40-150 minutes and were audio-record
 - * Guided by a developed interview protocol: early signs (retrospective); entering the system (or not); exits and returns; and recommendations and directions (prospective)
- * Brief description of analysis

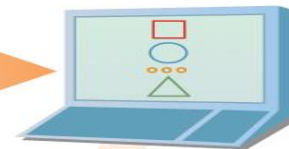
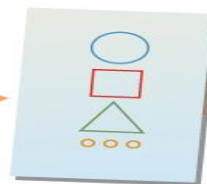
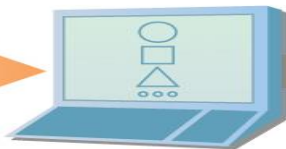
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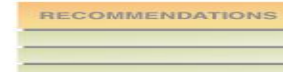
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The Findings

Table 1. Facilitators to Access and Care from Participant Interviews

Eating disorder advocacy organization- Parents support and educational group, and emotion focused family therapy
Adolescent eating disorder service
Outpatient program (p)- Psychologist (p), and making friends through services
Family physician (p)
Parental advocacy
Compassion/empathy in care and “good” providers
Art, music and writing therapy
Family support
Multidisciplinary approach
Dietician
Psychiatry unit (p)
Individualized care
Willingness/motivation to get better and self-recognition of an issue
Internet

Table 2. Barrier to Access and Care from Participant Interviews

Psychological services (p)- Accessibility, and Lack of public coverage
Family physician (p)- Lack of eating disorder knowledge, and not taking concerns seriously
Lack of staff and family education- making insensitive comments
“Bad” health care providers- A lack of empathy, and not acting professionally
Hospital- Internal medicine unit, Psychiatry unit (p), and Emergency unit
Lack of resources/capacity- Waiting period for places in hospital ward, and lack of “appropriate” food in hospital
Lack of coordination/communication- Amongst different service providers, and transitions
A lack of awareness- Eating disorder symptomology, and services available
Program/clinic timing-During work/school hours
Stigma
Outpatient program (p)
Geographical location- All specialized services only available in the capital city

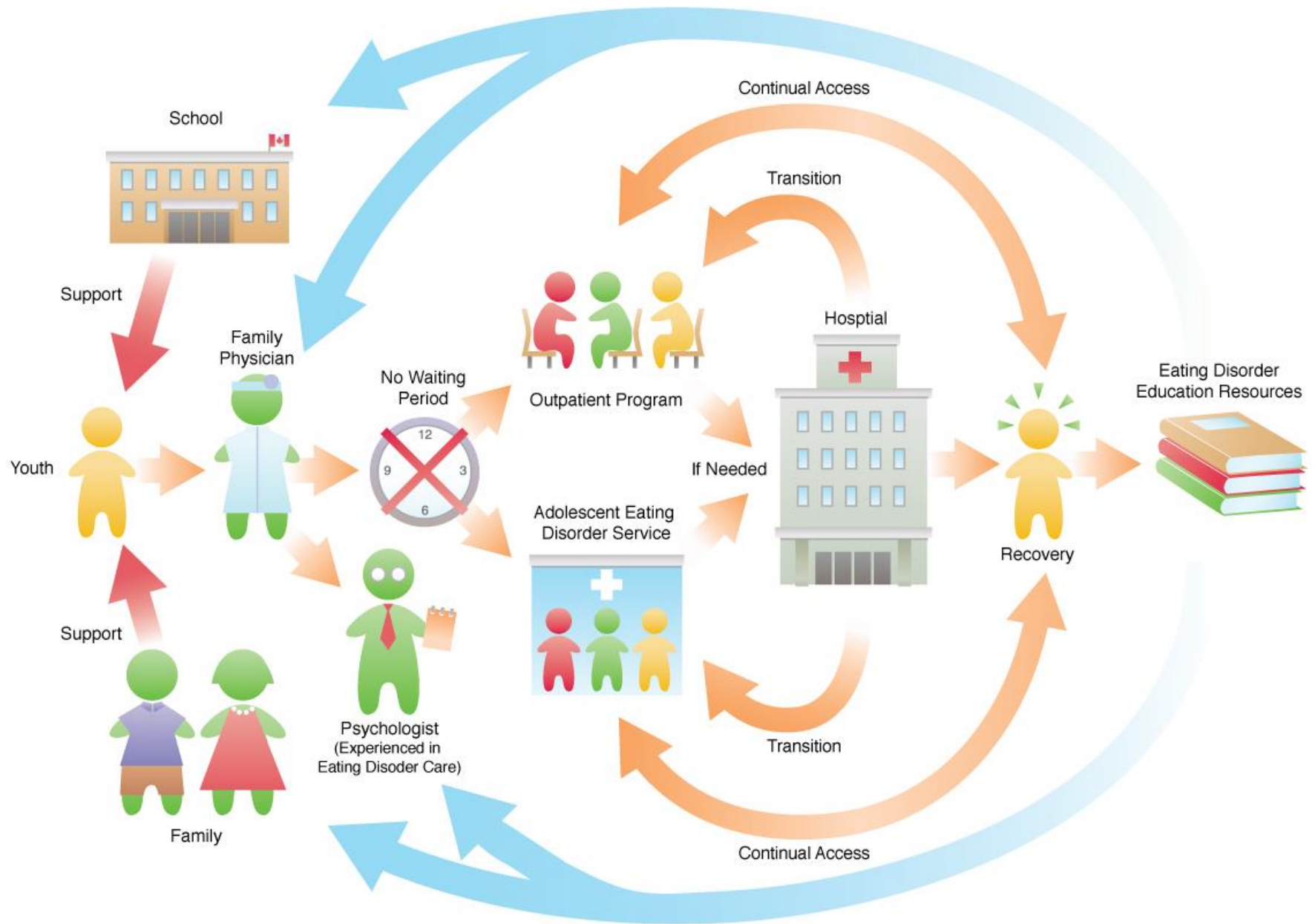


Figure 3. Composite Ideal Journey through Eating Disorder Services

Multiple Voices

- * A unique component in the current study was in the collection of the lived experiences from three different groups: youth, parents, and dyads of both youth and parents
- * In continuing interpretation within and across these groupings there was some overlap and some differences in perspectives
- * Similar:
 - * 1. Flow of the narrative (discussion of early life, accessing a service or services, events throughout this service, discussion of school)
 - * 2. Similar recommendations (increasing transition measures between services, and education surrounding eating disorders for health care providers and the general public)
- * Differences:
 - * 1. Details apparent in one journey that were absent in the other (turning points)
 - * 2. Different factors that attributed to access and recovery (coverage, therapies)

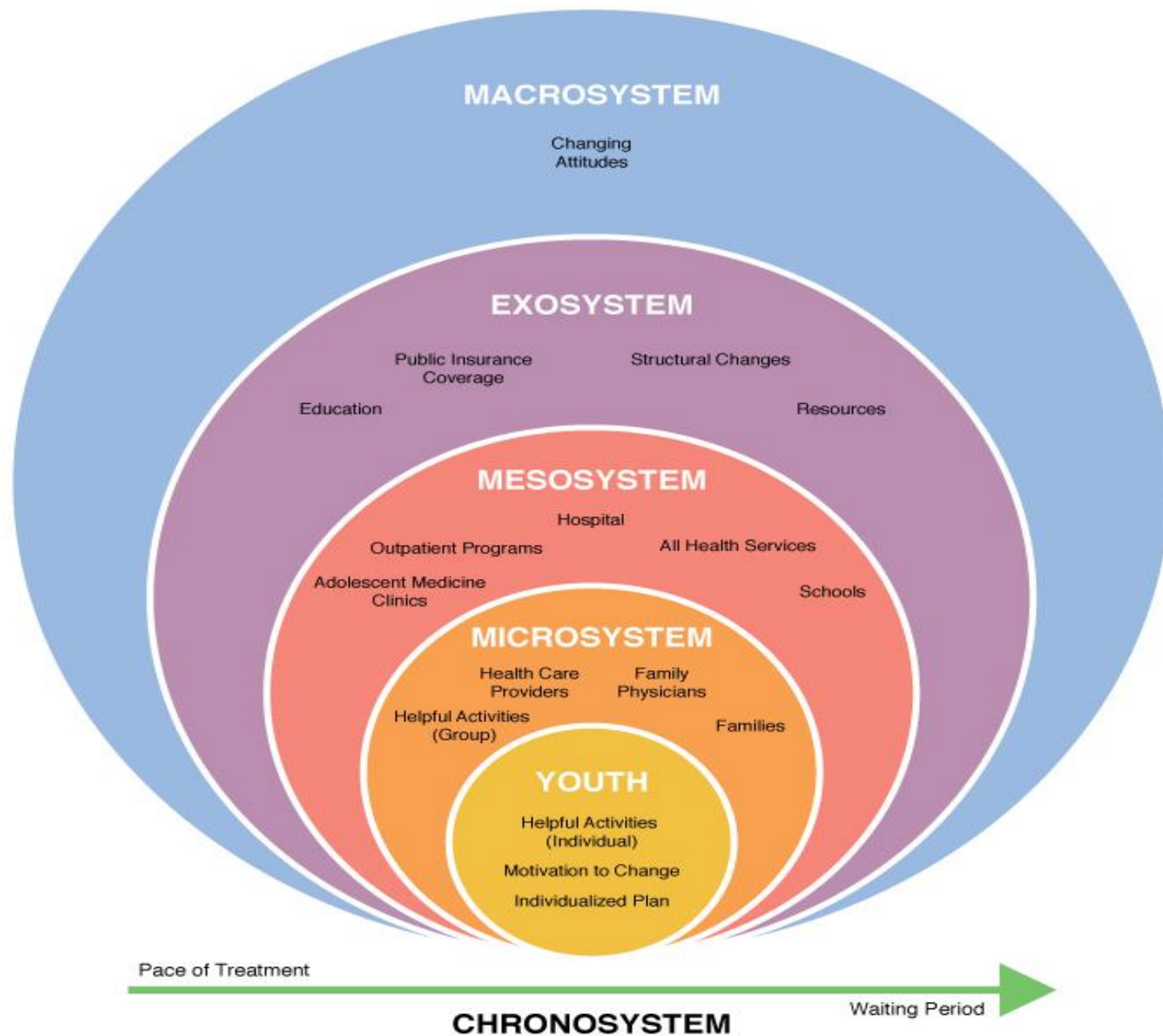


Figure 4. Recommendations From Participants: Complex Culture Nesting Model

Table 3. Recommendations for the Youth

Helpful activities (individual)	Motivation to change	Individualized plan
Sharing story publicly can be empowering	Drives recovery	Everyone needs a unique treatment plan to accommodate for his or her specific journey
Art, music, and writing as therapies	Self-awareness when struggling	

Table 4. Recommendations for the Microsystem

Helpful activities (group)	Health care providers	Family physicians	Families
Group therapy can be helpful if offered in right environment	Need to provide more compassionate and sympathetic care	Need more awareness of eating disorder services available	Need an integrated family approach to treatment- parents receive eating disorder education right away
Emotion focused family therapy was useful for parents	Need more education and awareness on insensitive comments	Need more education on eating disorder recognition	Need to take time to speak with child and listen to concerns
	Need to provide more specific practical advice and guidance to youth and family	Need more serious proactive discussion with teenagers about body image and eating status	Need to connect with eating disorder advocacy organization-to get resources, guidance, and support
		Need to refer patients that they even suspect have an eating disorder	Parents need to continue to advocate for better services and access for their child
			Families should provide opportunities for their child to regain autonomy- may result in turning points

Table 5. Recommendations for the Mesosystem

Adolescent eating disorder services	Outpatient programs	Hospitals	All health services	Schools
Multidisciplinary team is very helpful-increases quality of life with all service providers in same location	Difficult for youth and family to constantly access program during the day time hours-need to consider alternative program hours	Need better communication with family in emergency department	Need access to services in recovery stage	Need to be more accommodating-helping to supervise recess and lunch meals
Need at least one but ideally more psychologists as a member of this service	Recommended for youth, especially for the psychological support	Need to provide more specific practical advice and guidance to parents	Need more education and awareness on insensitive comments	Participants mentioned more empathy from the school in listening to their story and situation would help
Recommended for youth and parents	Three-week interview process is long- need to consider a way to streamline this process	Need an eating disorder protocol in all hospitals, and patient should be placed on this without parent having to advocate	Difficult for youth and family to constantly access programs during the day time hours- need to consider alternative program hours	It would be helpful if the school could be reorganized to help reduce social anxiety, and make the setting more familiar to youth
Difficult for youth and family to constantly access program during the day time hours- need to consider alternative program hours	Need more resources- increase capacity of program, and awareness	Need more eating disorder specific training, especially in internal medicine ward	Need a more multidisciplinary approach in all services, as this has been voiced as the best way to help individuals	Need more education on mental health led by professionals in the school for staff and students
		Need more appropriate food for eating disorder patients	Need more early intervention support from primary care providers	Need equal focus on mental and physical health in school
		Need improved organization amongst different health care providers in emergency room	Need to minimize transitions in care, and if not possible need to have transition protocol/programs in place to ease the transition	Need more support and guidance from guidance counsellors
		Need more capacity in psychiatry unit	Need to explore the feasibility of a more intensive day treatment and a drop-in service options	Need more guidance counsellors in the school
		Staff in psychiatry unit need to be more diligent in watching patient	Need more eating disorder specific training	
		Activities and therapies offered in psychiatry unit were seen as helpful		
		To not show discharge video to patients as it is seen as inappropriate in the Psychiatry unit		

Table 6. Recommendations for the Exosystem

Education	Public insurance coverage	Structural changes	Resources
Physical education needs to focus more on well being, staying healthy, and positive body image	Out of province residential coverage needs to be clearly written out and articulated for parents travelling with their child prior to accessing this support	Need more transition programs between services	Need more psychologists- publicly and privately
Schools- need more focus on mental health, provided through workshops by professionals	Coverage for out of province residential treatment should not be isolated to a single treatment centre- may not be the appropriate for everyone	School systems – need to stop isolating teenagers (junior high)	Need more psychologists who are trained in eating disorder care
School prevention programs should be mandated within the provincial curriculum	Need coverage for private psychological support- especially when access to an appropriate publicly funded psychologist is not possible	Program timing- feasibility of alternative hours for services	Need easier access/a lessened wait time to see a psychiatrist
Health care staff need more education on eating disorder care, and what topics to avoid openly discussing		Need to reduce waiting periods to the outpatient program and accessing the adolescent eating disorder service	Need more capacity in the outpatient program
Nursing, medicine, and social work programs- students should listen to youth eating disorder stories to provide the students with context for future care			Need more guidance counsellors in the school, and an increase in safe space for students to utilize
Psychologists need more specialized training for eating disorder care			Need more adequate, and appropriate food for refeeding of individuals in hospitals
Primary care providers need to learn more about eating disorders, and available services, perhaps a reinvigoration of the community capacity program			More awareness for current services to treat depression and anxiety- common in eating disorder patients
Needs to be more awareness and education in the general public around mental health and eating disorders- educational programs at the community level and more pamphlets in doctors and dentist offices			Need more capacity in the pediatric psychiatry unit, with more specific training/resources to treat eating disorders
More emphasis on the prevention side- create a culture of good mental health through awareness campaigns such as http://www.understandnow.ca/			Need to focus resources on education of staff and students towards mental health and eating disorders in school
Credible Internet sources need to be provided to families and youth			Explore offering eating disorder services in other parts of province- difficult for individuals in rural areas to access services
			Need to expand the use of technology to help individuals across the province access supports

Table 7. Recommendations for the Macrosystem and Chronosystem

Changing attitudes	Waiting period	Pace of treatment
Eating disorders can be sensationalized and romanticized in the media-need more education in the public to inform about the realities of eating disorders	Outpatient program- needs to look at possibility to streamline their interview process	Every journey is unique and requires special attention to best suit the individual
Stigma associated with having an eating disorder acted as a barrier to help seeking for some youth-need an increased awareness and education to target stigma; understand what eating disorders are and who they affect, and treatment options	If primary care providers even suspect an eating disorder- they should refer youth on to more specialized providers	Treatment goals must not be rushed- each person will have different triumphs and challenges, which will affect the speed of their recovery
Attitudes concerning obesity, body image, and “beauty” must also be addressed- youth felt that seeing their parent’s on a diet, or never complimenting themselves can be detrimental to how young people perceive themselves	More communication from emergency department workers may help in keeping families informed as to why they must keep returning for care, or have to wait several hours to be seen	Recovery must occur at a pace that the individual is comfortable with, and in a healthy manner
	While youth are waiting for their initial adolescent eating disorder service appointment perhaps family physicians can provide them with more resources and guidance so they can learn more about eating disorders, and reduce their anxiety in the waiting period	

To Conclude

1. Focus on increasing the number of eating disorder experienced clinical psychologists in the province
 2. Provide family physicians with more education about eating disorders (care, guidance for families, quicker referrals to specialists)
 3. Changing hospital policy (improving the food being offered to youth in hospital, Improving some staffing concerns such as specific training: guidance and comments)
 4. Increasing the scope of public health insurance coverage (for more psychological support)
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1. Increasing resources for various eating disorder programs/organizations (capacity and increasing advocacy)

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