



The Winston Churchill Memorial Trust

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To explore how innovation and collaboration can improve outcomes for people with eating disorders: USA, Canada, Scotland, and England

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2016 Churchill Fellow



REWARDING

AUSTRALIANS STRIVING FOR EXCELLENCE

The Winston Churchill Memorial Trust • ACN 008 445 707 • ABN 71 622 563 935

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EXECUTIVE SUMMARY

“A moment's insight is sometimes worth a life's experience.” *Oliver Wendell Holmes (1809-1894)*

In October and November of 2017 I was privileged as a Churchill Fellow to travel from Australia to USA, Canada, Scotland and England to discover the insights of others as I set about to explore how innovation and collaboration can improve outcomes for people with eating disorders. Not only was I poised to gain new insights of my own, but also to gather insights of others gained from their years of experience as professionals, volunteers, parents and clients of the eating disorders service system.

In particular special thanks go to the following people who gave something unexpected to my journey of learning: Dr Calum Munro (for his advice, stimulating conversation and providing a home away from home); Dr Dasha Nicholls; Claire Mysko and the team at NEDA; Chevese Turner from BEDA; Drs Jennifer Hagman and Mindy Solomon at Denver Children's Hospital; Dr Douglas Bunnell at Monte Nido; Kristin Brawn at Walden Behavioural Care; Debra Berlin-Romalis at Sheena's Place; Andrew Radford, Tom Quinn and the team at Beat; people with and recovered from an eating disorder, and their family members; and Sara Preston (UK Churchill Fellow and inspiring advocate).

There was no model of an ideal service system, nor a simple formula for quick and complete recovery from an eating disorder. Instead there were people grappling with the complexity of managing the impacts of eating disorders at individual, family and service system levels. The weeks were filled with interactions with many dedicated, creative and insightful people who shared their perspectives with me. Something novel or interesting was shared in every conversation, and often I was reassured by our common experience of facing similar challenges. The discovery made was that there are some key components required to provide holistic and compassionate care as people work to recover from an eating disorder. These have been identified and developed in many services through a process of quality improvement as people have attempted to find more supportive paths to recovery.

It is recommended that Eating Disorders Victoria, specialist eating disorders services, and the wider service system in Victoria implement the following principles as a way of enhancing our system of care towards recovery from these complex mental health illnesses.

1. Policy – an overarching framework to guide the development of a full continuum of care.
2. Motivation to change – essential for unwell people to engage with the hard work of recovery.
3. Family inclusion – necessary to support the full recovery of people with an eating disorder.
4. Person centred – therapeutic models should serve client needs first and foremost.
5. Networks – build rigorous relationships in the service system to share and learn from each other.

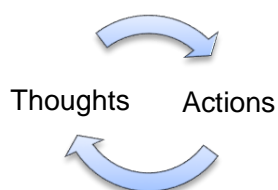
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1. INTRODUCTION

The eating disorders service system in Victoria, Australia, is often fractured and is not a system that is easy to access or navigate for many people who are concerned for themselves or a family member. There has been investment into our public services by successive Victorian governments over recent years, and there are now more specialist services available in the hospital and community health system. However, this has not resulted in the ease of access required by people with eating disorders and their families – of all ages and diagnoses. At Eating Disorders Victoria (EDV), where I have been Chief Executive Officer for almost six years, we frequently hear of the distress experienced by people who can't find services to help them which compounds a delay in treatment by months or years. Then when people do get help, it is often not the 'right' help for that person and thus begins a cycle of seeking, trying, and disengaging from services and support. Eating disorders are complex mental illnesses that have significant physical effects, and experts all agree that early identification and intervention can significantly reduce the severity and duration of the illness. It was on this basis that I sought to use my Churchill Fellowship to investigate what is happening in other countries, in particular with a focus on innovation and collaboration that improves the outcomes for people.



At the heart of my investigation was a desire to find ideas to stimulate change in Victoria and ways to implement that change – an ambitious goal that was moderated somewhat by various learnings!



Thoughts and actions form a cycle, with each element influencing the other to create a cycle of learning. We think, we act, and if we remain open-minded those actions then transform our thinking....and so it continues. Whether thinking or acting comes first is less important than the iterative process that ensues from the influential interactions that occur between thoughts and actions. The six weeks of being open minded resulted in many ideas for change, and allowed me to test our practices here in Victoria with

those abroad. Responsibility for some change and refinement falls to me in my role as CEO as EDV. I also hope that others will be inspired by the ideas to consider using the position held within their organisations to introduce and influence the change process. However, we all have an opportunity to utilise our informal authority to influence for positive change, and it is my hope that this report will inspire our collaborative efforts to improve the service system in Victoria.

Travelling around, reading, meeting different people in different environments and contexts with different opinions and views created much complexity for me. Rather than providing answers to my questions and solutions to my defined issues, in many cases the resultant information generated more questions, more possibilities and unearthed more contradictions and complexity. However, since my return home, and as I have allowed the data acquired while away to settle, the wrestling with this information has subsided into a dataset from which I can now draw some themes and, simplicity. I have had an adventure of being immersed in the unknown and I hope that readers of this report benefit from the grappling with complexity I have done and find some ideas in how I have interpreted my findings.

I would like to thank the many people who made this once in a lifetime experience possible:

- the Board of EDV, Matthew Hercus (Victorian Department of Health and Human Services) and Associate Professor Richard Newton who supported my application and design of the study tour;

- the Winston Churchill Memorial Trust of Australia for creating the opportunity, providing a rigorous application process, and bestowing the privilege of Fellowship upon me;
- the staff and volunteers at EDV, other eating disorders professionals and people with lived experience for filling my itinerary with ideas, suggestions of places to visit, and connections to people abroad;
- Kelly Edwards for stepping in and acting with skill and competence as CEO while I was away;
- the wonderfully generous people from across the northern hemisphere who shared their knowledge, experience and insights with me;
- my dear family (Damien, Lydia, Phoebe and Joanna) and friends who listened, encouraged and reminded me when I was inspired, tired or homesick, that good relationships are the foundation of a good life and home is a wonderful place.
- And a final acknowledgement to the passion, wisdom and courage of Winston Churchill whose legacy has helped many to make our world a better place.



Statue of Sir Winston Churchill in Parliament Square, London

2. PROGRAM

9th October – 21 November 2017

Denver, Colorado, USA		
Eating Recovery Center www.eatingrecoverycenter.com	Dr Susan McClanahan,	Chief Clinical Officer
	Bonnie Brennan	Senior Clinical Director
	Kathleen Reeves	Chief Operations Officer
	Ellen Broxmeyer	Quality & Safety Director
	Doug Weiss	Chief Marketing Officer
The Eating Disorder Foundation www.eatingdisorderfoundation.org	Dani Gilady	Program director
STAR Center for Sensory Processing Disorder www.spdstar.org	Dr Kay Toomey	Clinical Consultant at the Feeding Clinic
Denver Children’s Hospital Eating Disorder Program www.childrenscolorado.org/doctors-and-departments/departments/psych/programs/eating-disorders/	Dr Mindy Solomon	Clinical Program Director
	Dr Jennifer Hagman	Medical Director,
	Staff and families	
New York City, USA		
Monte Nido, Manhattan Partial hospitalisation program and intensive outreach program www.montenido.com	Rachel Pancake	Assistant Clinical Director
	Kylie Walker	Clinical Director
	Program Chef	
Monte Nido, Irvington residential program www.montenido.com	Dr Douglas Bunnell	Chief Clinical Officer East Coast
	Dr Sarah Chipps	Clinical Director
	Therapist and dietetics staff	
National Eating Disorders Association (NEDA) www.nationaleatingdisorders.org	Claire Mysko	CEO
	Lauren Smolar	Director of Programs
	Chelsea Kronengold	Manager of The Body Project
Binge Eating Disorder Association (BEDA), Conference in Brooklyn, NY bedaonline.com	Chevese Turner	Founder and CEO
The Body Project Brooklyn, NY http://www.bodyprojectcollaborative.com/	Dr Carolyn Becker	Cofounder
Boston, Massachusetts, USA		
Harvard Kennedy School	Executive education program <i>Creating Collaborative Solutions</i> 65 classmates from 17 countries	
Multiservice Eating Disorders Association (MEDA) www.medainc.org/about-meda	Beth Mayer	Executive Director
	Mitch Appelbaum	Chair of Board
	Staff	

Walden Behavioural Care www.waldenbehavioralcare.com	Dr Stu Koman	President and CEO
	Kristin Brawn	Vice President, Marketing & Community Relations
	Jane	RN on inpatient unit
Toronto, Canada		
Sheena's Place www.sheenasplace.org	Debbie Berlin-Romalis	Executive Director
National Eating Disorder Information Centre (NEDIC) www.nedic.ca	Suzanne Phillips	Program Manager
	Kelsey Johnston	Outreach and Education Coordinator
Scotland, UK		
Lothian National Health Service (NHS), Edinburgh www.nhslothian.scot.nhs.uk/Services/A-Z/EatingDisordersServicesForAdults/Pages/default.aspx www.seeds.scot.nhs.uk/SESServices/Lothian/CullenCentreOutpatientTeam/Pages/default.aspx	Dr Calum Munro	Consultant psychiatrist
	Anne Pilbeam	Dietitian
	Louise Randell	Psychologist
	Caroline Burdon-Coop	Psychologist
	Lenita Wambeek	Assistant Psychologist
	Fenella Hodgson	Art Therapist
	Dr Katharine Logan	Psychiatrist
	Cullen community team staff	
	Cullen outpatient team	
Action Group, Edinburgh actiongroup.org.uk	Lorna Patten	Home and Community Support Service Coordinator
Beat Eating disorders charity, Edinburgh www.beateatingdisorders.org.uk	Sara Preston	Senior National Officer (Scotland)
Stirling University, Stirling Food for Thought resource www.foodforthoughtproject.info	Dr Ruth Edmond	Author and academic
	Prof Samantha Punch	Author and academic
England, UK		
Great Ormond Street Hospital, London Feeding & Eating Disorders Unit www.gosh.nhs.uk/health-professionals/clinical-specialties/department-child-and-adolescent-mental-health-dcamh/national-feeding-and-eating-disorders-service	Dr Dasha Nicholls	Consultant Psychiatrist Joint Head of Feeding and Eating Disorders Service
	John Stewart	Clinical Nurse Specialist
Beat Eating disorders charity, London www.beateatingdisorders.org.uk	Andrew Radford	CEO
	Tom Quinn	Director of External Affairs
	Toby Upson	Regional Officer London & South East
	Philip Roethenbaugh	Director of Fundraising
	Katherine Pugh	Campaigns and Policy Manager
	Michaela Lodovichi	Head of National Network

	Caroline Price	Director of Services
	Sadie Miller	Corporate Fundraising Manager
Maudsley Hospital, London http://www.slam.nhs.uk/patients-and-carers/health-information/eating-disorders	Prof Ulrike Schmidt	Consultant psychiatrist in the eating disorders service at SLaM, Professor of Eating Disorders at Kings College
Men Get Eating Disorders Too, Brighton Conference mengetedstoo.co.uk	Sam Thomas	Founder and CEO
	Dave Chawner	Comedian and MGEDT ambassador
Fixers.org.uk, London www.fixers.org.uk/fixing-eating-disorders.php	Maggie Morgan	Director of Communications & Stakeholder Engagement

3. BACKGROUND

Anorexia Nervosa:

- restricted eating
- fear of gaining weight

Bulimia Nervosa:

- recurrent binge-eating episodes followed by compensatory behaviours (eg. Purging, restricting)
- may be average or above average weight

Binge Eating Disorder:

- frequently eating excessive amounts of food, often when not hungry
- Feelings of guilt, shame often follow a bingeing episode

Other Eating Disorders

- eating disorders that impair functioning but do not meet strict diagnostic criteria

Avoidant/Restrictive Food Intake Disorder

- persistent failure to meet appropriate nutritional and/or energy needs
- weight loss and psychosocial impairment
- no body image issues

An eating disorder is a complex mental illness, characterised by an unhealthy preoccupation with eating, exercise and/or body weight/shape. Eating disorders can take many different forms and include binge eating disorder, bulimia nervosa, anorexia nervosa, and avoidant restrictive feeding disorder¹. Eating disorders also have significant physical effects, and experts agree that early identification and intervention can significantly reduce the severity and duration of the illness. At Eating Disorders Victoria, we provide information, navigation, support and care to people with eating disorders and their families and friends. We also provide information and education to professionals and the wider community to help increase awareness and understanding of these debilitating illnesses to reduce stigma and facilitate help seeking. We have ongoing contact with people who are ill and those who have recovered, and seek to ensure that their experiences inform our services and supports and help us to advocate on their behalf.

As CEO at EDV, the Churchill Fellowship provided a wonderful opportunity to investigate what is happening in other countries, in particular with a focus on innovation and collaboration that results in earlier access and a continuum of care for people with eating disorders of all types and at all ages.

Louis Theroux made a documentary *Talking with Anorexia*² which was screened during my time in the UK. His comment below highlights the complexity and apparent contradictions, which create confusion for many who try to understand the effects an eating disorder has on those who suffer. These are the people for whom we seek to provide care and support for at EDV. *“(An eating disorder)is an illness associated with appearances, but in my time speaking with people with the disorder I've been struck by how much it had to do with the deepest feelings of powerlessness and lack of self-worth. It intertwines itself with positive qualities of conscientiousness and self-discipline and makes them poisonous; demanding from those who have it a daily heroism facing down an illness often indistinguishable from their own selves.”*

4. METHODOLOGY

There were two approaches undertaken to my six-week study tour. The first was to learn from academic frameworks and the experiences of others in understanding and resolving issues of public policy – this was achieved by attending a seven-day executive program at the Kennedy School of Harvard University. Teaching by Prof Mark Moore and Jorrit De Jong in the ‘Creating Collaborative Solutions’ course facilitated working in an intensive environment where 65 senior executives and government officials from 17 countries were able to learn about and interrogate the theories related to collaboration; The Strategic

¹ <https://www.eatingdisorders.org.au/eating-disorders/what-is-an-eating-disorder>

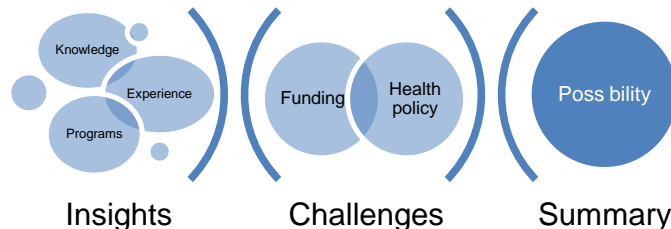
² <https://www.bbc.co.uk/iplayer/episode/b09d5nk2/louis-theroux-talking-to-anorexia>

Triangle³ provided a lens through which to consider the interaction between public value, the authorising environment, and the required resources. Application of the model was then explored through a process of case study and discussion. This week was a highlight of my time away. It served not only to provide a foundation of understanding and thinking for the field trip part of my study tour, but also provoked opportunities to think creatively as we considered the diverse array of problems that faced our colleagues.

The second aspect to my trip was the schedule of visits to a broad range of 22 clinical, nonclinical and support organisations. Over this time, I had meetings with 51 different people, and was also invited to join five different teams to participate in a regular day of activities – that is, staff meetings, case discussions, multifamily therapy groups, and client assessments. As my time progressed I found that not only was I building a picture in relation to how things are in Victoria, but also using previous conversations on my trip as a reference point that facilitated depth of investigation and cross referencing of policy contexts, practices and rationales. The picture became richer and more complex and as I neared the end of my time away some clarity began to emerge through the vast amount of information and is now distilled into my thoughts contained in this report.



Creating Collaborative Solutions: Issues in Governance



My report is a summary of the themes that emerged from my time in USA, Canada, Scotland and England. There has been much, much more that I have seen, heard, experienced and discussed than is contained herein. It has not been possible to include some information due to the complexity, or confidential nature. The report is not exhaustive, nor does it claim to be anything more than a summary of the range of services, organisational models, current issues and perspectives that were shared with me. I encourage you to contact me directly for further discussion. It has been a profound learning experience and I offer this report to you as an account of my observations. Please read with an open mind, as it may be that the insights and contradictions contained herein may challenge or inspire you, as I was regularly challenged and inspired by them myself.

³ Moore, Mark *Creating Public Value: Strategic management in government*. Harvard University Press, 1995 (pp70-76)

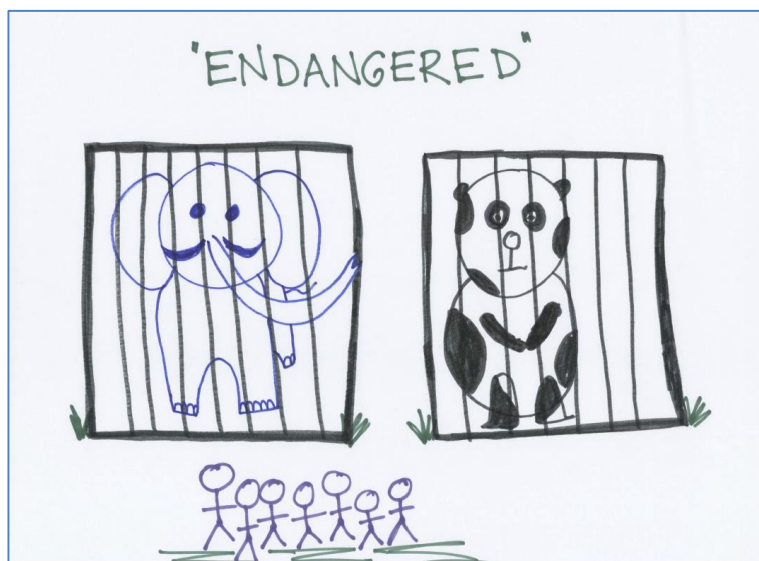
5. SETTING THE SCENE

Imagine this:

It's a sunny morning outside beyond the large windows and inside the rooms and corridors are light and airy. You're in an Eating Disorders Unit at a children's hospital that is busy with chatter in the halls and people moving between rooms. Gradually the activity subsides, and eight young people aged between 9 and 18 years congregate in a room, each with one or two of their parents. The multipurpose room is large and bright and furnished with comfort and aesthetics in mind. It's time for the multifamily therapy session supported by a handful of professionals who facilitate the work to be done before lunch.

Every person is asked to choose an animal, and explain to the group why they chose this particular animal. Following explanations, each family group is asked to draw their animals together in a scene.

M is an articulate and responsive girl in her early teens, with a sadness in her eyes. The nasogastric tube taped to her cheek is a reminder of the ongoing battle with her illness. She sits with her mother and they exchange quiet conversation as they draw. M has chosen a panda for its softness, quietness and simplicity of fur pattern and colour. Her mother draws an elephant because it is caring and reliable. However, their animals are drawn in separate cages. Trapped together but kept apart. The word above the image is 'endangered'. M describes the picture to the group and slowly her language changes from talking about the animals to talking about her mother and herself. They are trapped; they feel trapped and powerless. They want to be free, but don't know how to be freed. They don't know how to get out, are unable to help each other, and unsure of the intentions of the people standing on the outside.



Representation of M's drawing

Everywhere I went, I met people and heard of people who share the same experience. They feel trapped and isolated by their illness, and want to be free, but they don't know how to become free or even whether it will be possible.

6. FINDINGS

6.1. Organisational characteristics

Values and purpose

Across the countries, I visited a range of organisations providing a range of services. Irrespective of the organisational type and structure (hospital, university, for-profit, not-for-profit) the goal of all organisations was to make quality services accessible to enable people with eating disorders and their families to recover well. The themes of person centered care, ease of transitions, quality of life, and a recovery focus were common and widely evident. Each organisation was able to describe their role in the wider system and fidelity to their stated purpose was displayed. Similar values were declared and espoused across for-profit, not-for-profit, hospital and government organisations. These stated values inform the organisational ethos and underpin the range of services offered.



The range of prevailing system type (user pays, universal health, hybrid system) were all compatible with my experience of the cultural context of each country, and as such it is difficult to draw any conclusions about a preferable system. High demand for services is apparent everywhere and awareness of pressure to provide timely access to people seeking help, within the confines of the prevailing system. However, I was repeatedly reassured by what I saw that Victorian services are likewise well developed, informed by similar values and driven by compatible motivations.

Organisational beginnings

With some exceptions, most services were established by a founder with a lived experience of eating disorders, for themselves or a family member or in their professional role. Likewise, many staff shared of personal reasons for pursuing a professional role in working with eating disorders, and this personal commitment resulted in a tangible sense of purpose in the way they talked about their work. For a curious Australian, it was heartening that even in the many for-profit organisations, the sense of purpose and use of creativity to provide high quality and individualised care was demonstrated by clinical and management staff alike.

Volunteers

Many organisations and services make regular use of volunteers to supplement existing resources available for strategic and values based reasons. Like EDV, volunteers are included as ambassadors to share their stories to raise awareness and promote the hope that recovery is possible. Additionally, many use volunteers⁴ as program facilitators (students, professionals) including an extensive network who delivers The Body Project on behalf of NEDA in New York City. It was great to see so many examples of how volunteers are used effectively in other places – and EDV was the envy of many when I advised EDV has a staff volunteer coordinator who is a dedicated resource available for support and



⁴ <https://www.nationaleatingdisorders.org/positions/volunteer>; <https://www.beateatingdisorders.org.uk/volunteer>

debriefing for our volunteer team. By providing specific support, many EDV volunteers can utilise their recovery experience in productive ways and leverage this value for the benefit of the thousands of Victorians who call EDV every year.

Clinical organisations

While there were many similarities and common themes, there were differences between organisations providing clinical and non-clinical services. In general, clinical services are striving to provide a continuum of care to help people with early intervention right through until they have recovered. I saw some superb examples, some are mentioned later, of ways in which organisations have developed and refined their services to provide a vast array of valuable treatments and services to their clients. Each country has its own prevailing system which dictates certain constraints (user pays, insurance pays, government pays, or a hybrid of elements).

Clinical services value the role played by non-clinical services as referrers and advocates, however were unclear of other value offered. In many conversations, it seemed that clinical services would prefer to take responsibility for addressing all gaps identified by non-clinical organisations if they could, and not include the non-clinical organisations as part of the solution. Client recovery is the goal of any clinical service and so the services visited were focused on and challenged by the management of referrals and caseloads to meet outcomes and financial targets.

As I probed the issue further, clinical services were satisfied with the current scope of their involvement with the nonclinical sector, and in some cases seemed unaware of what other possibilities may exist. For example, some were unaware about how peer support could be incorporated as part of their programs, and were curious about how it might be implemented formally in a service model. I encouraged clinical service staff to initiate a conversation with the staff in their local non-clinical/support organisation about how they could find new ways to work together.



Nonclinical organisations

Non-clinical/support organisations understand their role as working closely with the clinical sector to ensure people are referred to the right place, and to advocate for relevant legislation, public policy and service development so that people can access services with ease. These services know that they have intrinsic value to people with and recovering from eating disorders and their families, because people tell them so. Feedback received from thousands of people over decades speak to their value as places of understanding and empathy when they are first concerned there may be a problem and after clinical services are no longer accessed or not used to support them through the often lengthy recovery phase.

Non-clinical services were adaptive and responsive to client needs with many examples of new programs, trails of innovative approaches, and engagement with research available to be viewed and discussed. Often it is the non-clinical organisations who provide the early information and intervention to people before they are ready to seek professional help. They provide non-judgmental and safe places for people to consider their readiness to change and explore service options. Unfortunately, the proportion of people being successfully referred on for treatment is offset by a larger proportion who are unable to access treatment (for reasons of money, diagnosis, geographic availability, sense of shame and stigma and others). These are the folks that non-clinical organisations continue to work for, calling on their sense of purpose to maintain the drive. Many services are provided free of charge which means these organisations are focused on and remain challenged by matters of sustainability related to funding year on year.



Balance of clinical and nonclinical service system

Given that it is the nonclinical organisations who fill the gaps created by inconsistent and inequitable service systems, there was a rising question developing in me. As the clinical sector looks within themselves to develop holistic models of care there may be a significant and negative consequence to the broader eating disorders sector. We most definitely need a sector that has easy access and joined up services to ease the transition stages for those with an eating disorder, it may be that in trying to address one issue, these solutions may inadvertently reduce access to services. Without a broad and variable source of income, non-clinical organisations do not have the resources to continually reinvent themselves in a market of self-contained providers. Control and choice for consumers and carers is a benefit that any well-developed system will offer to service users. It is in the interest of us all to find ways to support the unique role that the nonclinical organisation type plays, for there is value in diversity of all things – in organisational shapes and sizes just as in body shapes and sizes.

6.2. Eating disorders policy and strategy

In preparing for the Fellowship trip, many Victorian professionals asked me to find out who 'owned' or was responsible for developing and implementing eating disorders policy and service provision. While we were all hoping that there was a model of coordinated overarching policy and implementation, disappointingly such a model was not found. Support for eating disorders comes from a range of places, which varies country by country. Again, while around the world we all agree that there needs to be a coordinated approach, each country has a system that is recognised from within as flawed - reflective of its unique policy context, funding constraints and demographics. This is characterised by persistent misunderstanding and stigma about eating disorders across communities in general, and within eating disorders organisations people are doing their best with the resources available.

"Everyone wants to own it" – an unsolicited quote given by someone with her own lived experience who now works in the sector. Her view is that because of the lack of overarching policy we have a fractured system where everyone is pursuing a better future based on their own perspective and interests, to the exclusion of others.



In the **USA**, individual organisations uphold their responsibility to provide services as independent entities with voluntary connections to each other through various local and professional networks. All players in the eating disorders sector (private providers, hospitals, universities and not-for-profit orgs) provide input into ways of working together. There was no government policy direction, strategy or funding seen for any of the places visited.

In **Canada**, eating disorders organisations are sprinkled across the country. There is no national data collection or coding of visits to hospitals and emergency departments. Some not-for-profits and other advocates are self-organizing to collaboratively develop guiding documents and strategies. Like Australia, there is a large geography with diverse needs, variable resources and a range of interests that make a unified strategy difficult to achieve and even more difficult to implement. However, the participants from not-for-profit/non-government organisations aim to use collective goodwill to develop such a strategy from the ground up.



In the **UK** there are a number of well-developed policy documents and strategies. However, like Australia these are impacted by national agendas of separate health systems and a legacy funding model for hospitals and community settings. The UK has a similar approach to Australia, with national specific mental health plans that outline an aspirational framework with some specific targets for development.



In **Scotland** the *Mental Health Strategy:2017-2027*⁵ outlines the importance of a system that provides accessible services, including for young people with eating disorders.

In **England**, the National Health Service (NHS) has developed *The Five Year Forward View For Mental Health 2016*⁶ which outlines plans to provide standards of care for people with mental health problems, including stated outcomes for eating disorders, early intervention and system improvements to help people lead better lives as equal citizens.



	Policy direction/ Eating Disorder Strategy	Private services	Govt funded services	Not-for-profit organisations
USA	X	✓	X	✓
Canada	X	✓	✓	✓
Scotland	Mental Health Strategy (some eating disorders focus)	✓	✓	✓
England	Mental Health Strategy (some eating disorders focus)	✓	✓	✓

6.3. Service gaps

Equity of access to specialist eating disorders services remains a significant issue in every country visited. As a result, there are many service gaps. There are different factors impacting this, but resulting in the same outcomes of inconsistent access for residents of all countries. There is a prevailing misunderstanding in the health system about eating disorders which prevents access to care and increases the distress and impacts of the illness for people.

⁵ <http://www.gov.scot/Resource/0051/00516047.pdf>

⁶ <https://www.england.nhs.uk/wp-content/uploads/2016/02/Mental-Health-Taskforce-FYFV-final.pdf>

In **USA**, access is limited to those who have generous health insurance coverage or are able to pay for services privately. The clinical services visited provided a full continuum of care across a range of eating disorder diagnoses and ages. These consisted of outpatient, day patient, intensive out patient, partial hospitalisation, residential and inpatient programs, and supported transitions between each of the levels of care. Services are funded by insurance or privately by full fee-paying clients, leaving a huge gap in access to services for those who are unable afford the cost of such care. There is a burden of proof for all services to regularly demonstrate that the patient is achieving recovery, often with unrealistic expectations of the amount of time to achieve recovery. An underlying assumption exists by many insurance providers that people will dupe the system and that some services unwittingly undertake a role of watching people be unwell.



In **Canada**, there is significant variability due to lack of specialist staff and services across every region. I was advised there are not enough psychiatrists who see people with eating disorders, and many of these are based in and around the most populous provinces of Ontario and Quebec. Apparently due to some specialist treatment centres admitting only voluntary patients to inpatient care, there are many people who are effectively denied treatment. It was difficult to obtain a clear sense of the situation in Canada, and I suspect it is not unlike that around Australia – with some states and territories having some services available and others having nothing. Sometimes the Ministry of Health will fund people to go out of the country, to USA, for specialist services.



In the **USA and Canada**, in addition to private services, not-for-profit organisations provide affordable or free services in the community. Many group and individual programs, helpline support and psychoeducational services attempt to fill the gaps but often leave people with inadequate service and professionals with the frustration of not being able to provide the level or type of care required.

In **UK**, (both **Scotland and England**, through their local versions of the NHS) the term ‘postcode lottery’ was a frequently used phrase. While the system appears well designed to provide a continuum of care, the reality is different for many people. In some cases, inpatient care is provided in locations that are far away from home, resulting in poor transitions with little support when patients return home. It was mentioned more than once to me that the government needs to make sound policy decisions for eating disorder services so that perverse outcomes are eliminated. The current policy and funding situation results in poorly coordinated transitions from hospital to community care as each part of the system is managed and funded separately. Hospitals are funded by the national NHS and community services are funded by local NHS trusts.



In the **UK**, third sector organisations provide a range of group and individual programs, helpline support and psychoeducational services on a free or moderate fee basis.

6.4. [Advocacy and government engagement](#)

Much of the work of advocates is to provoke and support change. It requires tireless effort to be an informed voice on behalf of others and to focus the attention on eating disorders over other competing messages. However complex health issues, such as eating disorders, require government action to guide policy and facilitate beneficial conditions for positive change and all the organisations I visited undertook

some form of advocacy work to government. They engaged in formal and informal means of advocacy and awareness raising, using their perspective on eating disorders to add credibility to arguments, and to lend support to the efforts of others.

In **USA** there are advocacy efforts at both federal and state levels. At a federal level the effort has been to ensure that certain diagnoses (such as binge eating disorders) are acknowledged and recognised formally. There has also been recent success in obtaining parity of access to insurance coverage for mental health conditions as is available for physical health conditions, although this varies from state to state for eating disorders. At a state level, activity in Massachusetts has been focused on lobbying for data on eating disorders to be collected by the Centre for Disease Control (CDC). There have also been opportunities for those with lived experience to visit the State House and tell their stories to politicians as a means to create awareness and add support to the lobbying of others.

In **Canada**, various eating disorder organisations are working together to develop an eating disorder strategy. This will then be used to advise stakeholders and lobby to the national and provincial governments for the strategy to be adopted and implemented by increasing resources across the country to provide better access to specialist treatment and care.

In the **UK**, Beat recently launched the document *Delaying for years, denied for months*⁷ at the Houses of Parliament in London. I was privileged to attend this event along with a large number of Beat stakeholders, including ambassadors, family members of those with eating disorders, clinicians, academics and members of parliament. It is their second event at the Houses of Parliament and they received bipartisan support on the night and good relationships with MPs that have been developed over time. There are opportunities to hold events in both London and the Scottish Parliament in Edinburgh to raise awareness and petition for inclusion of eating disorders in policy development. The use of patient and carer voices increases the knowledge of policy and decision makers and enables the sector to unite behind clear messages. There is a mental health survey undertaken in the UK every seven years, and still there are no questions about eating disorders included. This is a long term advocacy and lobbying effort that has still to achieve success.



Secretary of State for Health, Jeremy Hunt



Shadow Minister for Mental Health, Luciana Berger



EDV CEO, Jennifer Beveridge supporting campaign for Beat

⁷ <https://www.beateatingdisorders.org.uk/news-research/delaying-years-denied-months>

An insight was shared by a couple of sources that despite the revised NICE guidelines for eating disorders ⁸ being published in 2017 perhaps the ‘moment’ for eating disorders in the UK has not yet come. MPs are being nudged further; many are interested, some are well engaged, and all require more awareness for the significant impact of eating disorders on the community to drive positive change from the top for eating disorders services. Continued persistence with a united voice may help to ensure that the ‘moment’ for eating disorders is soon.

When will it
be the
‘moment’ for
eating
disorders as a
policy issue?

6.5. Media engagement

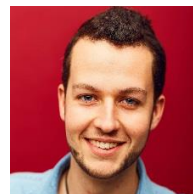
The broader media sector in the UK is actively promoting the issues of eating disorders. The Louis Theroux documentary *Talking with Anorexia* was recently screened on the BBC, Mark Austin (an ITV journalist) made a documentary for Channel 4 about his daughter’s illness *Wasting Away: The Truth About Anorexia*, comedians like Dave Chawner (www.davechawner.co.uk) are using their lived experience to break down stigma and educate people, and organisations like Fixers (www.fixers.org.uk) provide innovative ways for the voices of young people to be heard. These are inspiring messages conveyed by people who are experts at making a difference through their storytelling.



Mark and Maddy Austin



“Talking with anorexia”
Louis Theroux documentary



Dave Chawner



The Fixers

It was highlighted by many that it’s important for advocacy efforts and documents to be supported by all the voices so that the breadth and depth of experiences of eating disorders can be represented together. This requires the full range of contribution by those with lived experience, academics, clinicians and staff in nonclinical and support organisations to ensure the full extent of these complex illnesses are presented in a unified manner. More on that in the Partnerships section, however it was a quietly spoken and enduring theme throughout many conversations - that the eating disorders sector is not inclusive which often unconsciously sabotages the cause.

6.6. Health promotion and positive body image

As a sideline, it is worth mentioning here that a growing concern was expressed about the eating disorders sector participating in the ‘love your body’ movement. Is it right for us to be encouraging people to love their bodies? Is this a helpful approach, or are we creating another unrealistic goal? Should we change the conversation so that it is not about bodies at all?

⁸ <https://www.nice.org.uk/guidance/ng69>

6.7. Funding and acquittals

Various funding models have been touched on earlier in this report, however for the sake of clarity a summary is provided here. Clinical services in USA receive funding from private fee-paying clients either from their own pockets or via the insurance provider which may include a copayment. Government also contributes substantial funds to eating disorder services in Canada, Scotland and England. Acquittals of funds are reported on to the various funders according to their own set of criteria. Reporting can be frequent, especially in the case of insurance companies that may require feedback on progress on a weekly basis to agree to continue paying for treatment. The NHS has waiting time and caseload targets, which can conflict with each other as high demand caseloads and availability of specialist staff can slow the acceptance of new referrals into a system that is already under pressure.

Nonclinical services have a different set of funders, as there is almost no government funding provided for the community awareness, information provision, early access and support services roles undertaken by the not-for-profit sector. Only one organisation received any government funding which was small, and as a result are prevented from undertaking any advocacy efforts. The Victorian community is well supported by our state government, as EDV receives recurrent funding for a range of core services every year. Ongoing financial support from the Victorian government enables us to focus on developing and providing support to the thousands of people who contact us every year, rather than being distracted by the imperative to fundraise to keep the basic services available.

Most of the income for the nonclinical sector comes from donations, fundraising events, philanthropic grants and corporate partnerships. There were many examples of corporate partnerships with retail clothing, pharmaceutical and local business. Many specialist clinical organisations also sponsor the

Nonclinical sector income

Donations	✓
Sponsorships	✓
Fees	✓
Philanthropic grants	✓
Government funding	X

nonclinical organisations either directly or through their own foundations. Some have been long-term donors and sponsors of nonclinical organisations. Increasingly, clinical for-profit organisations may require greater transparency for the return on their financial investment rather than donations being made from generosity alone. There was a gentle rumble of feeling expressed that with increased numbers of not-for-profit organisations the market is becoming oversaturated and there is uncertainty regarding how much and to where donations should be given. Some nonclinical organisations earn a small income through fee for service activity, but most offer their services free of charge and rely wholly on donations for income. It seems that the issue of donations will not be resolved but rather may become a bigger problem over time.

There are some challenges for nonclinical organisations receiving corporate sponsorship. One is how to ensure that the product sold by the business is aligned to the values of the organisation. Another is that such partnerships generally require focused relationships management. This can be anathema to voluntary organisations who dislike spending money on things that don't generate a direct outcome for clients. However, there are examples of times when good stakeholder management provides benefit to both parties. In one case, through targeted engagement the corporate partner felt more connected to the organisation. Not only did they begin to support the organisation by attending events and engaging in social media activity, but there was also an unsolicited increase in the donation of more than four times the amount from the year before, taking it to a six figure donation (in Australian \$).

6.8. Outcome measures

In addition to reporting to various funding sources, organisations also have a wide range of outcome measures in place for their clients and for the organisation as a whole. Client outcomes are based on each individual and include:

- change on clinical measures
- progress over time
- family relationship improvements
- engagement in social activity and/or employment.

Some organisations have robust processes for including clients in regular evaluation of their own care and recovery. Organisations evaluate length of wait from referral to assessment to treatment, duration of treatment, length of stay and readmission rates (inpatient and residential) and client satisfaction. Workforce management is another measure regularly utilised. Staff burnout and turnover can be high due to the intensity of the work, and most organisations had solid support processes in place. Some organisations had internal systems established to track a person's engagement with the organisation as client or professional, and data analysis of conversion rates from caller to service user is regularly undertaken. This was only done by those organisations with comprehensive database systems in place, while many are still using paper based information collection and storage.

Providing the appropriate intensity of care required for treatment for eating disorders needs significant investment in resources. Executive staff highlighted the application of a balance between clinical outcomes and efficiencies result in financial outcomes. There seems to be a disconnect between the data that is collected for clinical purposes and that which is collected for financial purposes. There was only one organisation that was able to describe, in data and through their reporting, how better clinical outcomes also generated better financial outcomes.

It will also be interesting to observe what impact the new model of private equity ownership in USA will have as traditionally financial metrics are prioritised over client outcomes. Or perhaps private equity is entering a new phase and will develop a new set of outcomes that will ensure client care remains the priority.

Some organisations are working on developing a theory of change and using that framework as a tool to evaluate services and measure outcomes. It is hoped that together we could unite as eating disorders organisations and develop a set of outcomes for the range of similar works that we do in English speaking countries.



Monte Nido Residential Program, Irvington, New York

6.9. Treatment services and models

6.9.1. Pathways to and from specialist care

As mentioned earlier there are as many gaps in the service system for eating disorders abroad as there are in Victoria and Australia. When access to treatment due to cost of treatment or geography or lack of services is limited, the options are only those which people can source or create for themselves. There seemed to be no wholesale examples of smooth and easy flow between services or transition points. Ongoing support for people once they leave intensive and clinical services is patchy and depends on many variable factors. The issues faced by services abroad, for those with eating disorders, create the same frustrations and anguish as here.

6.9.2. Service delivery models

There are many therapies and intervention models being used in the field of eating disorders around the world. These will be familiar and are used regularly in practice by professionals in Australia and there are presentations at conferences, workshops and webinars. There is training here for the commonly used tools such as Cognitive Behaviour Therapy (CBT), Schema Therapy, Family Based Treatment (FBT), Acceptance and Commitment Therapy (ACT) and many others. We are also familiar with new models such as First Episode and Rapid Early Intervention for Eating Disorders (FREED)⁹, Maudsley Anorexia Treatment for Adults (MANTRA), Management of Really Sick Patients with Anorexia Nervosa (Marispan)¹⁰, and treatment¹¹ for Avoidant Restrictive Food Intake Disorder. The use of evidence based approaches is similar however the application may be different.

6.9.3. Transitions between adolescent and adult

There is universal difficulty as young people move from a paediatric service to an adult service around the age of 18 years. In organisations where there is a full continuum of care, the transition is supported and straightforward from a structural point of view. However, mostly the transition process is experienced as problematic by clients, and is difficult for services to manage. These frustrations are usually because of process or structural obstacles such as: funding, therapeutic models, staffing profiles, service targets. The Maudsley Hospital makes use of a nursing staff member who meets with the young person and their family when they are still a patient in the adolescent unit, and then assists in the transition to adult service. While acknowledged that a different model could provide a more comprehensive transition, this process has been operating well and provides an active bridge to manage expectations and provide continuity across to the adult service.



6.9.4. Non-medical service delivery

Most of the services I visited had a biopsychosocial approach to the understanding and treatment of eating disorders. This means that a number of factors are considered as part of a person's recovery – their mood and psychological wellbeing, self-awareness and cognitions, family relationships, medical status

⁹ <http://freedfromed.co.uk/>

¹⁰ <http://www.marsipan.org.uk/>

¹¹ <http://www.gosh.nhs.uk/medical-information/clinical-specialties/department-child-and-adolescent-mental-health-dcamh/national-feeding-and-eating-disorders-service-0>

and eating behaviours. A holistic view of this resulted in various tolerances for risk in relationship to medical status.

For children, young people and adults care was generally provided in a person centred, family inclusive way across a range of services, often with flexible approaches and use of hybrid models. It was acknowledged that on the inpatient units of general hospitals this can be challenging. Given the hospital system use of ward rounds with its intrinsic medical approach, it is difficult to maintain a biopsychosocial, person centred care approach for adults. It is also difficult to ensure that parents retain the decision-making responsibility for their children in FBT when the medical model prevails in a hospital setting.

In the USA where specialist inpatient services were provided as part of the integrated step-up and step-down continuum of care it seems easier to maintain a continuity of care across the staff team who are all working within the same philosophical framework, and often in buildings that are near each other such as the Eating Recovery Centre in Denver.

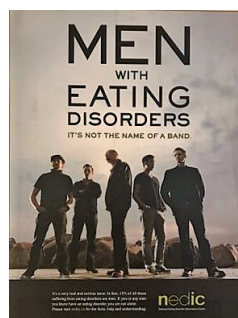


6.9.5. Early Intervention

There is widespread acceptance around the world that early intervention for an eating disorder creates the best outcomes for people. For those who seek help within the first two years of the onset of an eating disorder, full recovery is possible. As a result, there are many efforts by various means to educate people about the warning signs and the need to seek treatment immediately. These range from formal programs for emergency department staff and General Practitioners through to programs for people with disordered eating and targeted messages for the general population.



Beat, UK



NEDIC, Canada



MEDA, USA



Walden Behavioral Care, USA

Additionally, there is innovative work being undertaken that may broaden our perspective of what 'early intervention' looks like – this includes original work by Professor Samantha Punch and Dr Ruth Edmond at Stirling University in Scotland¹². They have developed some resources to assist foster carers and residential staff for children in out of home care to reflect and consider how food and eating practices may contribute to building an environment that is responsive and supportive. While not intended as a therapeutic tool for children and young people



¹² <http://www.foodforthoughtproject.info/about/>

with eating disorders, it may provide a basis from which to think differently about cohorts of people those who may be at risk and consider appropriate approaches for early intervention.

6.10. Specific cohorts

6.10.1. Males

Men Get Eating Disorders Too¹³ (MGEDT) is a charity run by and for men with eating disorders and their families. MGEDT has been a force over recent years advocating and campaigning for increased awareness



the fact that eating disorders do not affect only women and girls. They also provide information and support to males through a number of online and face to face activities. I attended the annual

conference in Brighton and sat in a room full of passionate people who shared of their negative experiences which were amplified due to gender. It's unusual to be in a room of men who feel overlooked and underrepresented. Many of the speakers spoke with enthusiasm of their advocacy and awareness raising and there were speakers presenting information and current research findings on topics such as body dysmorphia. MGEDT is an organisation that continues the hard work of the many volunteers and another example of people who are well intentioned making a difference with very few resources.



Partnerships and collaboration will be important to keep the original inspiration for the establishment of this organisation nurtured, and I feel honoured to have participated in the conference.

6.10.2. Binge eating disorder

The Binge Eating Disorder Association¹⁴ (BEDA) was established by Chevese Turner in USA in 2008, and since then she has led a team of tireless volunteers to develop awareness of binge eating disorder (BED), educate clinicians and support people who seek help.

BEDA has three continuing goals:

1. to work with the existing system to highlight the serious impact on binge eating disorder on lives
2. to address the weight stigma within the eating disorders community
3. to take the messages to a wider audience.

There was broad concern about providing services for people with binge eating disorder. Where there are resources to do so, some organisations such as the Eating Recovery Center in Denver have developed new structures and a new milieu as requested by those with BED who find it challenging being in the same space as those with other eating disorder diagnoses. The same model is used as for other eating disorders and a full continuum of care is available, however being separate provides an environment for people to belong and experience a sense of value and worth.

Others, such as Monte Nido, find that treating all eating disorder types together 'goes ok', and offers an opportunity for therapeutic exchange. These services tend to view the treatment model with an underlying philosophy that clients have a similar experience of pain and disordered behaviours is different

¹³ <https://mengetedstoo.co.uk/>

¹⁴ <https://bedaonline.com/>

for everyone and not exclusive of any diagnosis. In this paradigm clients are viewed equally, and all interactions are considered intentional or therapeutic. There was a refreshing honesty to these conversations where clinicians talked about the importance of not tiptoeing around clients, including the belief that those with BED can participate in programs with someone who has restrictive eating behaviours. Their view was pragmatic and hopeful – along the lines of ‘whatever is wrong we can repair’ and ‘how does tiptoeing help people to recover?’. Qualified staff in this service, many who have their own experience of an eating disorder, saw that they are role models in their relationship with clients and can actively use their relationship as an intervention tool. This aligns somewhat with the EDV Peer Mentoring Program where mentors use their own experience of recovery as a basis for working with clients.

However, where resources are stretched or severely limited, support and services for BED barely exist. Even within eating disorder services while referrals and programs for those with AN or BN continue at steady rates, those for people with BED are slow and services face multiple challenges to provide appropriate responses. There is much to be done to address the inequity of access to services for those with BED.

Nevertheless, BED is on the radar and becoming a priority for decision makers in services. It may well be the next frontier and as awareness and services develop further new opportunities may arise to respond in creative ways to provide care and support for this overlooked group.

6.11. Areas of Innovation

The range of services and supports I saw while travelling was a variation on a theme of what happens here in Victoria and around Australia. Along with the highlights shared below, there was great interest and acknowledgment in the innovative EDV Peer Mentoring Program¹⁵ that is being piloted in Victoria.

6.11.1. Quality of life approach

Recovery from an eating disorder is possible – this is the philosophical basis that drives the work we do. We remain focused on this as a goal, sometimes to the detriment of our clients for whom recovery seems like another unattainable ideal. While it remains an important perspective for our services there are some clients who require support and care despite a lack of progress towards recovery. This remains a topic of much discussion at conferences, in clinical supervisions, and there is ongoing debate among the ‘experts’. Yet often resolution regarding how to reconcile this as an option is elusive for those of us offering services in Australia – instead discharging patients/clients from care until they are ready to engage with the service’s philosophy to recovery.



There are examples abroad where services accept that recovery is not an appropriate goal for some clients, for a range of reasons. Rather a quality of life outcome is sought – by living at home, being engaged

¹⁵ <https://www.eatingdisorders.org.au/news/100-latest-news/1568-peer-mentoring-program>

in productive and enjoyable activities, and maintaining relationships with family and friends. Medical risk is managed but does not form the primary basis of care or services. Clinical and nonclinical¹⁶ organisations provide a range of services to clients, either directly or in partnership with other organisations¹⁷ that enable people with long term eating disorders to focus on living a life that provides them with a focus on things other than medical recovery from their eating disorder.

Of course, access to a quality of life approach to support and care is dependent on a system where such options are available. The introduction of the National Disability Insurance Scheme (NDIS) in Australia may open up new options for people with eating disorders to participate in activities that ensure quality of life without the assumed recovery focus.

6.11.2. Flexibility of the approaches to treatment

Very early on it became apparent that clinicians are creative and using the evidence base as a foundation or starting point from which to build individualised interventions and care plans to work with each unique situation for clients and their families. I did not see a manualized approach to treatment but rather a careful application of a range of evidence based approaches. Many clinicians reported that since they have incorporated a values based approach to the clinical treatment they have seen considerable benefits. Reported benefits from several organisations included: increased client satisfaction, improved family functioning, greater parent empowerment, better client responsibility for their own recovery, more satisfied staff who can see meaningful change in their clients. Many examples of hybrid models and flexible approaches were used and reported as person centred care was held up as critical to recovery.

Extended conversations revealed that many clinicians remain puzzled about what is truly required to help people recover. A common theme emerged that there seem to be three essential and precursory elements required. The first is a willingness to change by the person with the eating disorder. The second is family support, whether it be family of origin or family of choice. The third is a positive rapport and relationship between the clinician or health professional and the client, and their family. Then, on this foundation, can sit the therapeutic intervention. I

Recovery ingredients

1. Motivation to change
2. Family support
3. Positive relationship with clinician
4. Therapeutic model

wonder how often we expect people to recover because of the treatment that is being given to them, and overlook the first three factors listed. As a senior clinician shared with me, it is not possible to argue out a repeating song in your head. You have to be creative about dealing with invasive thoughts and it's not always with logic. When working with people with an eating disorder, while there is evidence available for many therapies, sometimes it helps when clinicians are flexible and curious about different methods to help behaviours and attitudes change – and not rely on logic alone.

6.11.3. Family engagement

Family engagement is assumed for people of all ages in many services. 'Family' in this context may be members of the family of origin or a family of choice – and services make continued efforts to identify key support people to engage in the treatment and recovery process. Change is difficult to achieve and

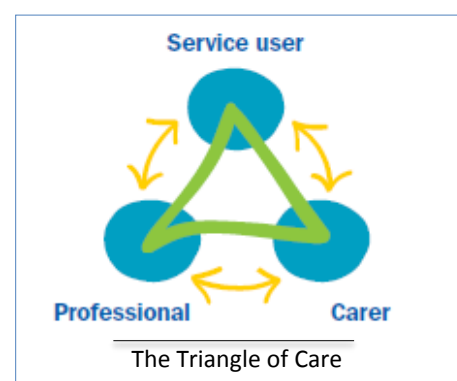
¹⁶ Eg. Cullen Community Team (Edinburgh), Sheena's Place (Toronto)

¹⁷ Cullen Community Team and Action Group (Edinburgh)

maintain without the support of others and many services actively work with clients to include family members. Treatment models for children and young people in Australia are built on the understanding that families are the key to recovery with this group. However, the same often does not apply for adults, instead family participation in Australia seems to be an optional extra. However, by establishing the expectation from the beginning with adults accessing treatment, services in USA and UK demonstrate the value of including families as a core part of the treatment and recovery process. Family therapy is provided as a component of treatment, and direct support for family members in group and individual settings is also available.

In some settings, such as the intensive inpatient and residential programs in the USA this is easier to provide due to regular visits and the amount of time spent at the treatment centre by family members. However, in outpatient and community settings in USA and UK I saw and heard of the priority given to maintaining involvement of family members as part of the 'treatment team'. Challenges and outings provided as part of weekly schedules, and evidence of the inclusion of popular concepts like the five love languages¹⁸ are built into family centred activities. Attendance at groups and activities at the treatment centres were some of the ways that families are actively engaged with, rather than excluded from, the long journey with their loved one's illness.

The Triangle of Care¹⁹ was launched in 2010 as a model to support the engagement of families and carers in the mental health care sector in the UK. The included self-assessment tool²⁰ can assist services to assess their level of inclusion and identify ways to improve existing practice. While clients may not want to include family members the importance of revisiting the idea regularly is recognised by many services and is encouraged. Family engagement in treatment and building/restoring positive relationships were goals that were stated for a number of clients during case discussions, and it was heartening to see, despite the inherent difficulties, staff striving to include families as part of their practice.



6.11.4. Meal support

Eating and meal support is considered a critical part of ongoing treatment for clients. Over and over eating as a core activity of treatment was described, whether it be full meals during day programs or a snack as part of an outpatient session. By including eating as a regular part of treatment sessions, opportunities are facilitated to change behaviour and thinking at the same time.

6.11.5. Home based services

Home based care was offered in a few places, and this too facilitates the involvement of family members. Not unlike supported meals provided as part of treatment for children and young people in FBT, meal

¹⁸ <http://www.5lovelanguages.com/> by Gary Chapman

¹⁹ <https://professionals.carers.org/working-mental-health-carers/triangle-care-mental-health>

²⁰ https://professionals.carers.org/sites/default/files/toc_self_assessment_tool_guidance_notes_-_word_version.doc

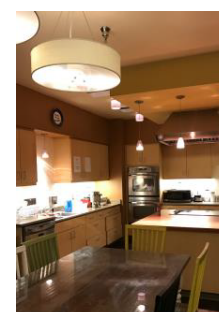
support at home for adults²¹ provides opportunities for family members to be actively involved and to utilise the professional expertise of the clinicians for their own debriefing and support. In the USA, many organisations refer to clinical home-based services²² for ongoing support, and others regularly use technology to support people to remain engaged with treatment when required. A recent example cited was during the hurricanes in the south of USA when it was considered important for treatment to continue despite the difficulties encountered to attend the treatment centre.



Furthermore, some of the clients at the Cullen Community team have been referred to The Action Group for home and community support services. Non-specialist staff have been provided with training to support people with severe anorexia to remain at home and they work as part of the multidisciplinary team who provide options for a quality life with monitoring of the medical risk according to predetermined guidelines.

6.11.6. Adjunct services to clinical intervention

Many opportunities for skills development and complementary activities were made available for clients in a range of settings. These included: art therapy, cooking classes for individuals and families, yoga, and regular outings. Some skills development opportunities such as shopping, meal preparation and challenging the eating disorder behaviours directly using approaches based on CBT and exposure therapy.



6.11.7. Online support

NHS Berkshire has developed a *clinical social networking site*²³ that provides 24/7 peer support and expert advice through our private and confidential support to young people with eating disorders, and others. The service is moderated by a range of trained people, including past clients who are trained to participate as moderators. Qualitative review of the impact has revealed a reduction in relapse rates.

6.11.8. The Body Project



The Body Project²⁴ is an eating disorder prevention program for young women that was developed by Carolyn Becker, Eric Stice and Alan Duffy. Using a group format, research has demonstrated that participation in the program has reduced the onset of eating disorders. In an energetic conversation with Carolyn we discussed a number of variations to the original program that are being developed and evaluated further, including with LGBTIQ cohorts. NEDA²⁵ has been delivering The Body Project for a number of years and delivers training regularly to those who want to facilitate the program in their local area. It was great to hear about their delivery of this program

²¹ Cullen Community team, Lothian NHS uses assistant psychologists to provide meal and other support for people with severe anorexia in an outreach capacity.

²² <https://oconnorpg.com/>

²³ <https://www.berkshirehealthcare.nhs.uk/our-services/other-services/sharon/>

²⁴ <http://www.bodyprojectcollaborative.com/>

²⁵ <https://www.nationaleatingdisorders.org/get-involved/the-body-project>

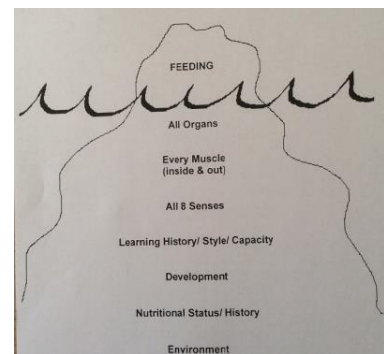
using volunteers in some of the New York City schools who would otherwise not have access to the program.

EDV launched Body Project Australia²⁶ in late 2017. It was helpful to meet with people delivering the program in USA and become part of the worldwide community for this important program. We look forward to building on the solid foundations with an Australian version.

6.11.9. Treatment of feeding and eating disorders

There is a developing awareness of possible overlap between feeding and eating disorders, especially now as Avoidant/Restrictive Food Intake Disorder (ARFID)²⁷ has been included in the DSM V. I met with some experienced clinicians who engage with complex behavioural presentations of children and utilise their skill and expertise to work with children where the cause may be unclear but there is significant difficulty with eating. Regardless of the diagnostic perspective, experts in both feeding and eating disorders address a range of factors including physical/medical, psychological and social.

It was interesting to hear how those with knowledge of sensory processing disorder²⁸ approach diagnosis and treatment at the Star Institute for Sensory Processing Disorder in Denver. While the underlying cause of a feeding disorder is different to that of an eating disorder, over time the impact of anxiety can result in behaviours that make a feeding disorder look like an eating disorder. Treatment consists of similar elements, including regularity and appropriateness of eating behaviours, and a range of cognitive, psychological and interpersonal interventions. There are opportunities for learning and synergy to occur between the two areas – for eating disorders to be reconsidered through a sensory processing lens, and those with feeding disorders to learn from the experiences of those with expertise in eating disorders.



Source: Dr Kay Toomey



A more formal arrangement has been developed at the National Feeding and Eating Disorders Service²⁹ at Great Ormond Street Hospital in London. The two specialist teams use a multidisciplinary and family centred approach and often work collaboratively to help the children and families who seek help, including joint assessments and treatment planning.

²⁶ <https://www.eatingdisorders.org.au/our-services>

²⁷ <https://www.eatingdisorders.org.au/eating-disorders/what-is-an-eating-disorder/classifying-eating-disorders/dsm-5#arfid>

²⁸ <https://www.spdstar.org/staff/kay-a-toomey-phd>

²⁹ <http://www.gosh.nhs.uk/health-professionals/clinical-specialties/department-child-and-adolescent-mental-health-dcamh/national-feeding-and-eating-disorders-service>

6.12. Collaboration

Partnerships are a reality for those working in the field of eating disorders. These consist of partnerships with clients, and their families; partnerships with funders and donors; partnerships with like services; partnerships that are local and others that are geographically diverse; partnerships with referral sources, and those to whom clients are referred; partnerships with volunteers, people who have recovered, and important stakeholders who help us with the work of advocacy. The list could continue to include schools, other health professionals, the media and so on. Therefore, without the ability to work together much of the misunderstanding would remain, people would continue to be unwell, and so would the sense of isolation and frustration of working in a context that is wracked by a lack of resources, stressed families and much complexity.

Clients
Families
Funders
Donors
Other services
Referrers
Volunteers

Across the board there were stated efforts of the importance of working together to share a common ground and find the combined strength that provides benefit to all. I saw multiple examples of effective formal partnering arrangements to provide funding³⁰, services³¹ or join forces on a project where the purpose was shared. I also saw examples of informal arrangements that were effective³² but less secure, and other partnerships that were perhaps more calculated in nature for mutual gain³³.



Some active models of partnership included the operation of consumer, parent and community provider action boards which have been established to provide feedback to the clinical services. These groups are tasked with the responsibility of seeking information from others on a regular basis and then providing this via formal processes to executive staff. The feedback obtained ensures that quality is monitored from the perspective of external sources and informs improvement plans. The staff explained that often the feedback was challenging to hear, however that over time the unique worth of receiving such collated feedback has become invaluable and led to significant changes. In many cases these changes were not something that clinicians would have identified as a priority and yet they now look forward to the reports from the action boards as a source of ideas and innovation.

Creation of new organisations

In all countries I visited, reference was made to the ongoing increase in the number of new organisations established, rather than contributing to or working with the existing organisations. This is particularly the situation for foundations and the non-clinical organisations. Some of these have been established by people with their own experience and others by organisations wanting to find new business models. Concern was expressed that while more is often seen as better this approach can be counterintuitive as it fractures an already inadequate and stretched sector.

³⁰ See Funding section for more information

³¹ Cullen Community Team (Edinburgh) working with community sector organisation (The Action Group) providing regular in home support for someone with an eating disorder, see page 28

³² Volunteer support by clinicians to convene eating disorder support groups

³³ Professional sponsorship of eating disorder support organisation for stated range of benefits, including referrals

Replication is seen to hurt the cause as people are torn about who to support. Given the high demand for services and supports there is no need for duplication, and so rather than creating new organisations, and splitting the donor base, people I spoke with were trying to explore how they could work together more effectively. They prefer to collaborate and build on the current system of organisations to develop further their purpose and passion together. This has also occurred to some extent in Australia, and creates new challenges. While there may be a valid reason for establishing something new, it does not always take a holistic view and sometimes results in more confusion for people seeking help, or increased competition for funding and competing messages. This is an area in which more collaboration would likely produce better outcomes.

Sharing of knowledge and practice

Again, as my conversations developed with people during each interview and over time, people entrusted me with thoughts and ideas that initially seemed contradictory and even controversial. However, I began to understand that they were sharing both sides of their experiences – one of generosity and openness, and the other of control, uncertainty and exclusiveness. Repeatedly I was told that despite being willing to work with others and acknowledgment of the imperative to do so, multiple barriers existed. These were mentioned as: issues of power and control; protection of own expertise; competitiveness for status, recognition and resources; professional snobbery; protection of ‘brand’ or message; internal and external politics; misunderstanding; and a replication of behaviours that are symptomatic of an eating disorder.

Some people stated that they had important contributions to certain matters, and yet their views had



often not been sought or included. Once these people had become aware of the advocacy efforts, the policy position being written or the request for new services, the time for contribution was past and the opportunity to contribute was lost. I was astonished at the number of times this was raised as an issue – by all organisation and professional types who work with people with eating disorders. Everyone had something to say about being excluded at some point when they believed they had an important contribution to make – academics about advocacy efforts, support organisations about design of family support services, clinicians about program changes.

Dynamics within the sector

Over and over I also heard the phrase ‘we don’t want to step on anyone’s toes’ stated by the same people who identified times when their contribution was not sought. It is a phrase I have heard at home too, and it puzzles me. How can one know what it means to ‘step on someone else’s toes’ when the question is not asked of the owner of said toes? How does one know that a certain action would be invasive or offensive rather than a welcome addition or an innovative solution? Would it be more useful to share ideas, test the proposition and explore how a more open collaborative approach may elevate the pitch/engagement prospects?

When I reflect on these questions regarding the value identified by the power that partnership and collaboration can bring, it doesn’t make sense. So, there is something else at play in the dynamic that is not overt and contributes to the fractured nature of our sector. The eating disorders sector does not seem to be inclusive, and in the quiet of private discussions this was admitted in all cities I visited. My summation from these discussions, as I allowed the conflicting information to settle, is that we see the

need to be open and inclusive but perhaps uncertainty, doubt and fear make it difficult. Ironically, the sector can sometimes display behaviours that are as secretive and isolating as the behaviour of an eating disorder itself. It's time to create some change within ourselves and be bold to take a leap of faith and start asking questions and challenging our own hesitations.

There were a number of people who identified themselves as 'truth tellers' and 'challengers of the status quo'. These folks accept a role to actively work to be change agents of the culture in the sector in their home cities and states – they see the need for everyone to be invited and included. It would seem that in order to improve the way we work as a sector we need truth tellers and challengers. We also need protectors of the evidence and knowledge base, developers of new ideas, experts of lived experience, connoisseur users of treatment and services, implementers of evidence into practice, authorities on public policy and service development, and many more. With all the collective wisdom and experience combined, together the sector will develop a voice that can only compel others to listen.

7. CONCLUSIONS AND RECOMMENDATIONS

Positive developments have been occurring gradually in Victoria over many years, with a number of people, partnerships and policy documents carefully guiding and producing better outcomes for people with eating disorders and their families. Simultaneously, frustrations also remain as progress towards timely access to good quality care for people is slow and inconsistent. It was reassuring to observe similarities abroad – that creative and committed people are working together, that a strong values base underpins the efforts of those in both for profit and not-for-profit organisations, and that people are willing to step into the unknown as they grapple with how to find solutions to complex issues. There have been many successes and yet there remains the need for ongoing efforts to advocate for and implement an accessible and service system.

I saw and heard of many examples of innovation and collaboration, and examples of hindrance and maintenance of the status quo. Given our collective interest of wanting to be part of a system that is easy to access, provides a full continuum of care, and helps people to fully recover, I share the following with you. These are five highlights that naturally become a series of recommendations for EDV and the wider eating disorders service sector in Victoria.

1. Government needs to invest in a state-wide eating disorder strategy that will direct the development of a full continuum of care model across all regions and services in Victoria. This includes providing strategies that enable equitable access to services from any health regions – we don't want to play the 'postcode lottery' game anymore. With our enviable health care system in Victoria, it remains the responsibility of government to ensure access to quality services is available to all.
2. We should build flexible treatment options that support people to find and maintain their motivation to change as the most significant precursor to recovery. We agree that eating disorders are complex issues and recovery can be a long and slow process. There are no simple answers to complex issues and we should be demonstrating through our behaviour that flexibility is a valuable quality when it comes to seeking help, engaging with treatment, and achieving recovery from an eating disorder.

3. Please, let's enable family inclusion (of origin or of choice) in all our services, for all people of all ages with an eating disorder. We should support people to build their significant relationships as part of their recovery rather than watch as the eating disorder symptoms poison and destroy. Using privacy law as a reason to validate exclusion of family members effectively sabotages the recovery process and we should change our practice and manage client expectations accordingly.
4. Manualised therapeutic approaches may serve clinicians well, but they don't work for many clients. The evidence base provides a solid foundation that informs treatment and by incorporating individual preferences, quality of life perspectives and family inclusion as an integral part of good quality care, clinicians will be supporting people to achieve that which we all have as our goal – helping people to recover from their illness. However, it will require staff to embark on their own journey of learning to tolerate the ensuing uncertainty and mess, and to manage for ourselves the ambiguity generated by stepping away from rigid and contained professional practice.
5. We don't know what we don't know – so we should ask others for their contribution. This would be resolved if we developed a network of relationships characterised by curiosity and honesty with each other and between our services. Formal and informal, across all disciplines, irrespective of profit and not-for-profit organisation type, clinical and nonclinical. Imagine the things we could do if we truly work collaboratively – we would learn, understand, explore, and align our advocacy efforts.

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