

Results from World Eating Disorders Day
Community and Advocacy Survey
April 2016

Executive Summary

World Eating Disorders Action Day was begun as a kernel of an idea amongst a handful of parent and affected people activists from the virtual advocacy group International Eating Disorders Action in November 2015 and quickly gained support and interest across the globe. The small group decided that there was a need for ONE DAY across the globe to raise awareness about eating disorders, dispel myths and 'change the face' of eating disorders by embracing the diverse groups who are affected and unite activists on a shared platform across the globe. Within a matter of weeks World Eating Disorders Action Day was born!

World Eating Disorders Action Day is a 100% volunteer, grassroots collective. To ensure a consultative and representative approach, a purposive selection of leaders from diverse populations and communities was proposed to make up the Steering Committee of the first World Eating Disorders Action Day. The collective does not receive funds from any organization; volunteers from non profit groups or individual activists make up the Steering Committee. The Steering Committee has guided the major decisions around World Eating Disorders Day, with extensive input from the 100s of activists who are part of the Facebook 'team' managing the activities. We chose the date of June 2, 2016 for World Eating Disorders Action Day, collectively developed guiding principles, a Mission and Vision, Key Messages, branding, and determined the key activities. See www.worldeatingdisordersday.org for Key Messages and information.

World Eating Disorders Action Day now boasts close to 200 organizations from 40 countries with groups requesting to join daily. We have presence on Facebook, Twitter, Instagram, LinkedIn and YouTube and a vibrant website with detailed information about the Day and how to Get Involved. We have published over 40 blog posts from leading thinkers in the field, showing state of the art research and program findings, culturally and globally diverse experiences of eating disorders and hopeful personal stories.

On June 2, 2016 our aim is to 'trend' the hashtag #WeDoAct on Twitter and massively increase our social media following across all platforms. We will launch a celebrity PSA, hold 30 hours of 'Around the Clock' Tweetchats hosted by a diverse group of global leaders and hold local events led by in country teams. We will also share a collectively developed manifesto for change, "NINE GOALS" that can be used nationally and internationally to advocate for change. To gather data to assist in developing the NINE GOALS the Steering Committee carried out a short survey available online to all.

The World ED Day community survey was developed by several members of the Steering Committee and launched in April 2016. Herein are the results of the survey. We thank Kristine Vazzano, World ED Day Steering Committee and AED Advocacy Committee representative for developing and managing the survey implementation and Rachel Presskreischer from National Eating Disorders Association (NEDA) for doing the analysis and pulling the results together. The results will be used to help develop the overarching NINE GOALS statement that will be released on June 2, 2016.

The following includes summary data and fill-in answers from the 10 question survey posted on the World ED Day website. There are tables and graphs of the quantitative data followed the write in answers. After reviewing the responses, 92% came from the United States (61%) and the UK/ some Commonwealth countries. This makes sense given we have heavier presence in these countries, and that the survey was written in English. In order to give some broader meaning to the numbers, the tables include breakdowns by number of respondents from one of the aforementioned countries and

Mexico (the other largest responding country). The graphs were generated using the total number of responses.

Although the dominance of answers from the United States does skew the responses, it is exciting to see that there were respondents from over 30 countries.

For the fill-in answers answers are groups thematically. For one of the questions there were 500+ responses, thus a keyword search pulled out some of the most commonly occurring terms, those numbers are included. The qualitative responses to the survey are also very powerful and presented here in total.

Some of the major themes in the qualitative responses to Question 9 What is the number one ISSUE/NEED related to eating disorders in your country/region are around families accessing early treatment, family based treatment support and training, weight stigma and the very real challenges of ensuring providers can properly diagnose and manage eating disorders. Many people mentioned the need for education of providers and community. Many mentioned the challenges of finding adequately trained professionals.

The results cannot be truly generalized as the respondents are a self selected group, those with internet access and use Facebook or Twitter and thus saw the advertisement, and those generally already interested in the eating disorders advocacy world.

Thank you for your participation and we hope you find the results interesting and helpful.

Steering Committee World Eating Disorders Action 2016

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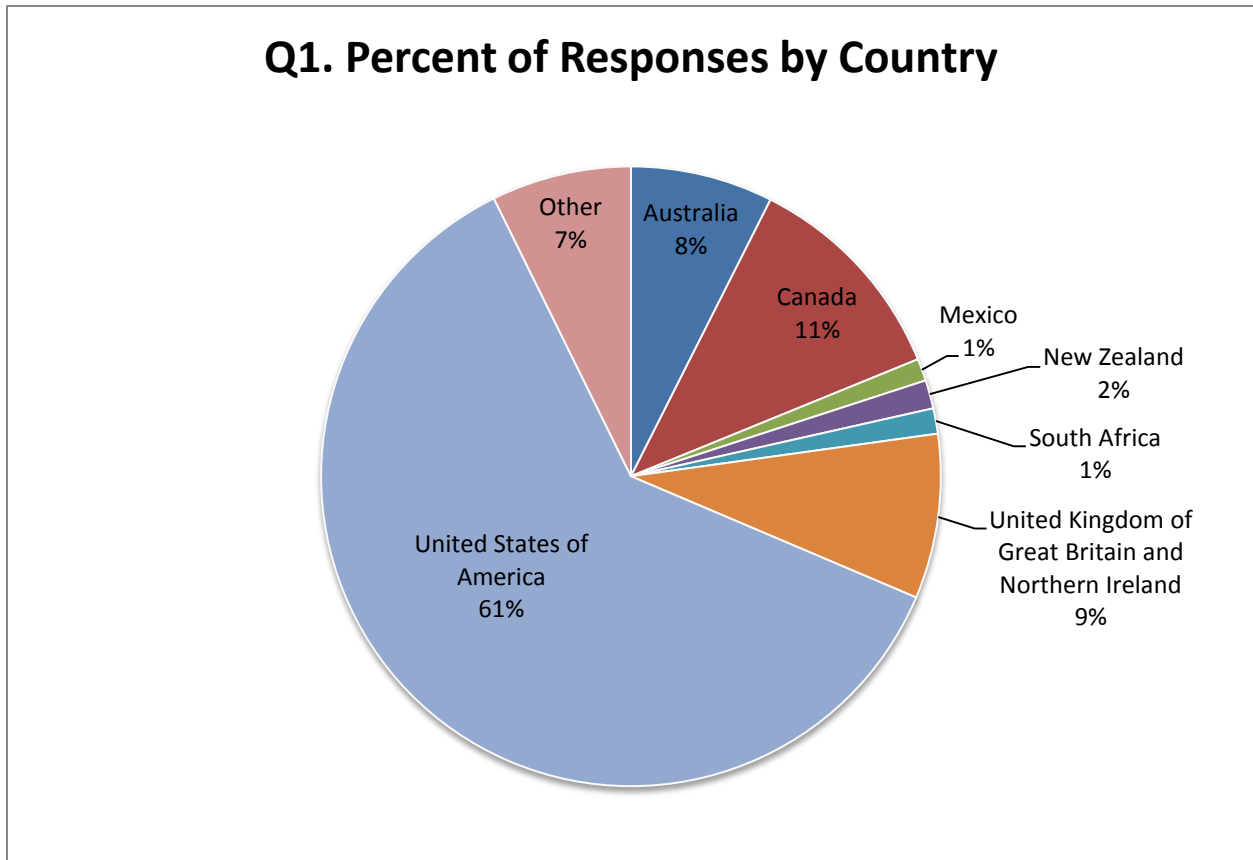
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SURVEY RESULTS:

Q1. In what country do you live?

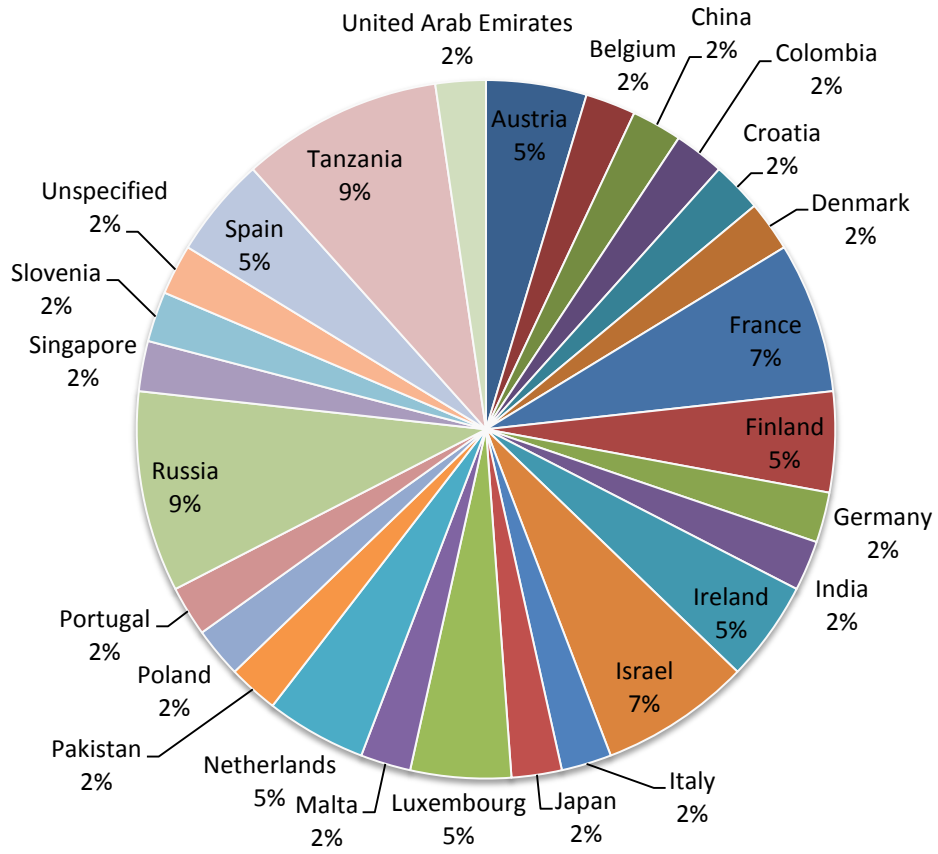
	Response Percent	Response Count
Australia	7.4%	45
Canada	11.4%	69
Mexico	1.2%	7
New Zealand	1.5%	9
South Africa	1.3%	8
United Kingdom of Great Britain and Northern Ireland	8.6%	52
United States of America	61.3%	371
Other	7.3%	44
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Answered question		605
Skipped question		4



Breakdown of "Other" Answers

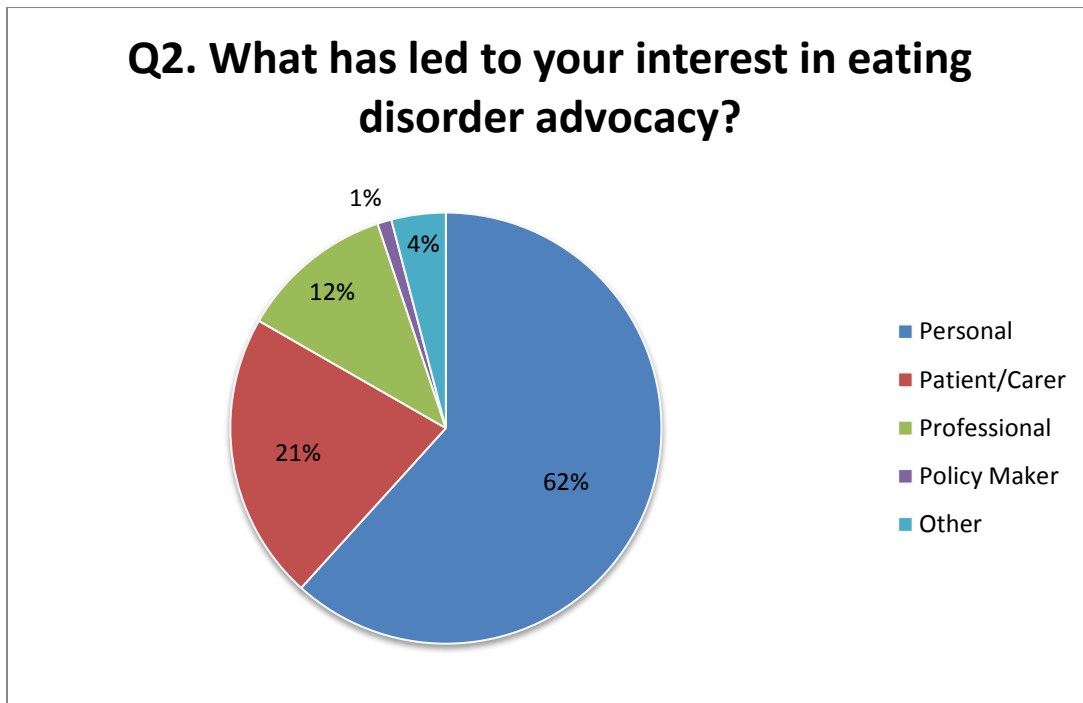
	Response Percent	Response Count
Austria	4.65%	2
Belgium	2.32%	1
China	2.32%	1
Colombia	2.32%	1
Croatia	2.32%	1
Denmark	2.32%	1
France	6.97%	3
Finland	4.65%	2
Germany	2.32%	1
India	2.32%	1
Ireland	4.65%	2
Israel	6.97%	3
Italy	2.32%	1
Japan	2.32%	1
Luxembourg	4.65%	2
Malta	2.32%	1
Netherlands	4.65%	2
Pakistan	2.32%	1
Poland	2.32%	1
Portugal	2.32%	1
Russia	9.30%	4
Singapore	2.32%	1
Slovenia	2.32%	1
Unspecified	2.32%	1
Spain	4.65%	2
Tanzania	9.30%	4
United Arab Emirates	2.32%	1
Total		43

"Other" by country



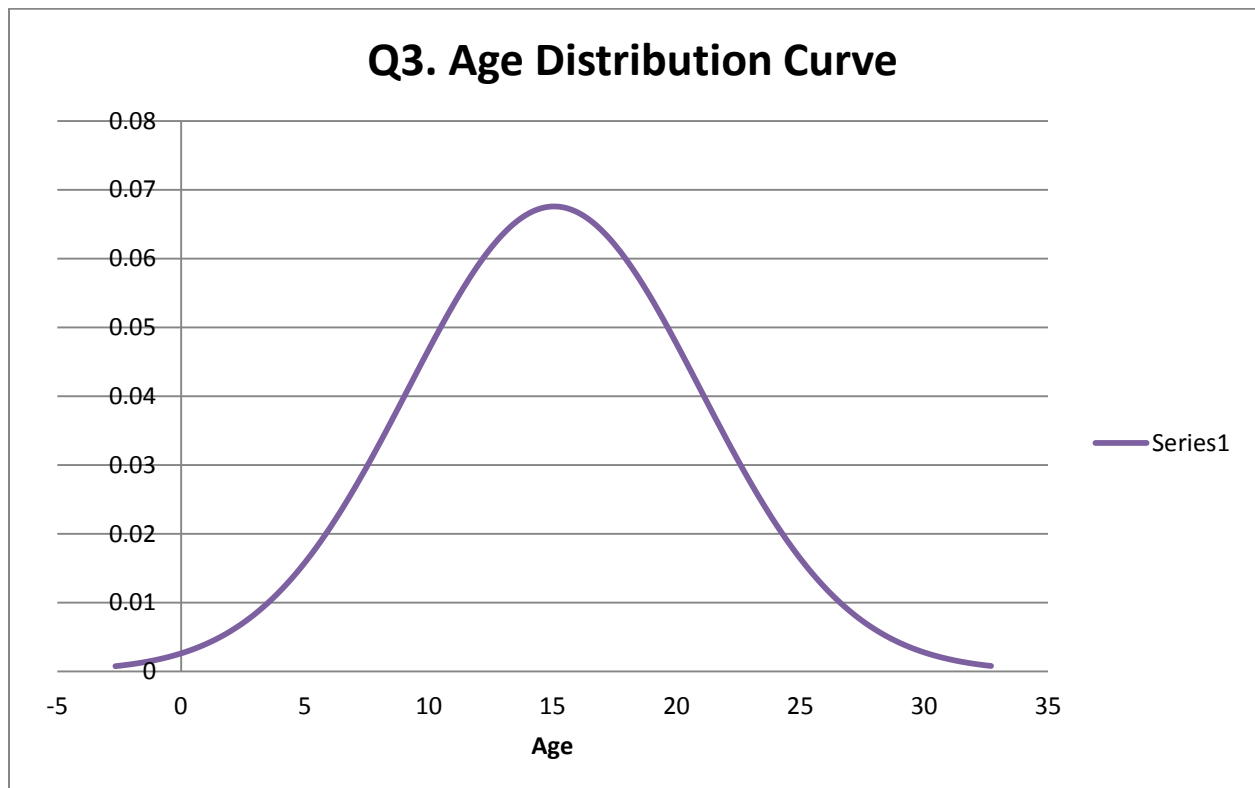
Q2. What has led to your interest in eating disorder advocacy?

	Personal	Patient/Carer	Professional	Policy Maker	Other
Canada	48	23	13	3	
USA	304	89	49	2	
United Kingdom	39	20	3	0	
Australia	30	12	7	0	
Mexico	1	1	6	1	
South Africa	4	4	1	0	
New Zealand	6	2	0	0	
Other	37	13	9	2	
Total	469	164	88	8	31



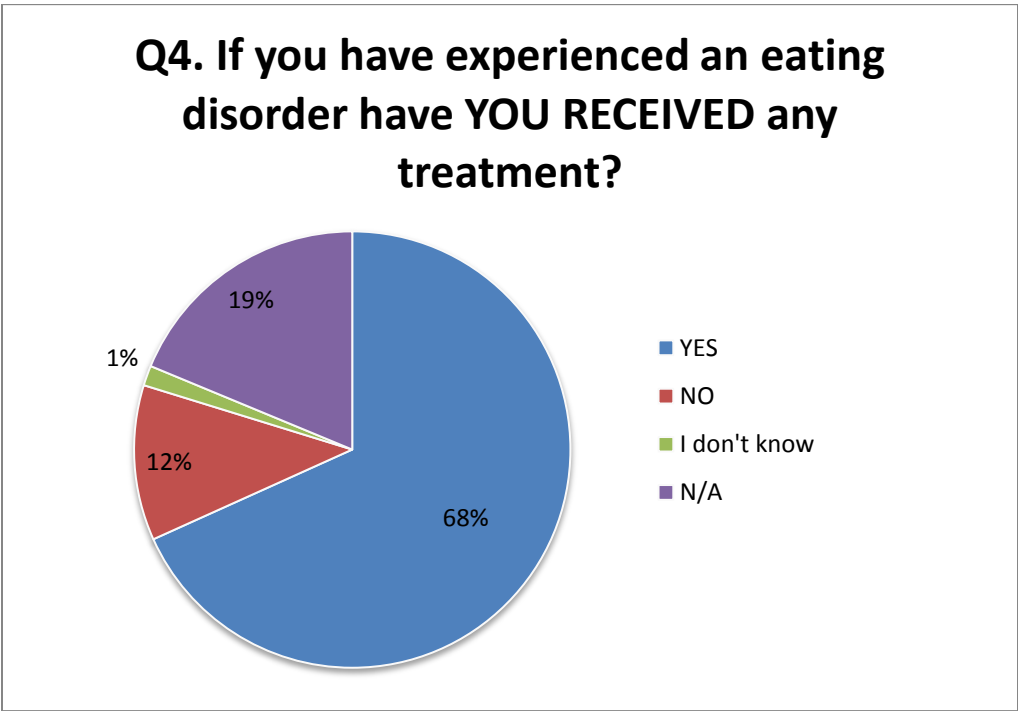
Q3. If you have experienced an eating disorder, at what age were you when symptoms developed?

Mean	15.06
Median	14
Mode	13
Range	56
Highest	58
Lowest	2
StdDev	5.90424993



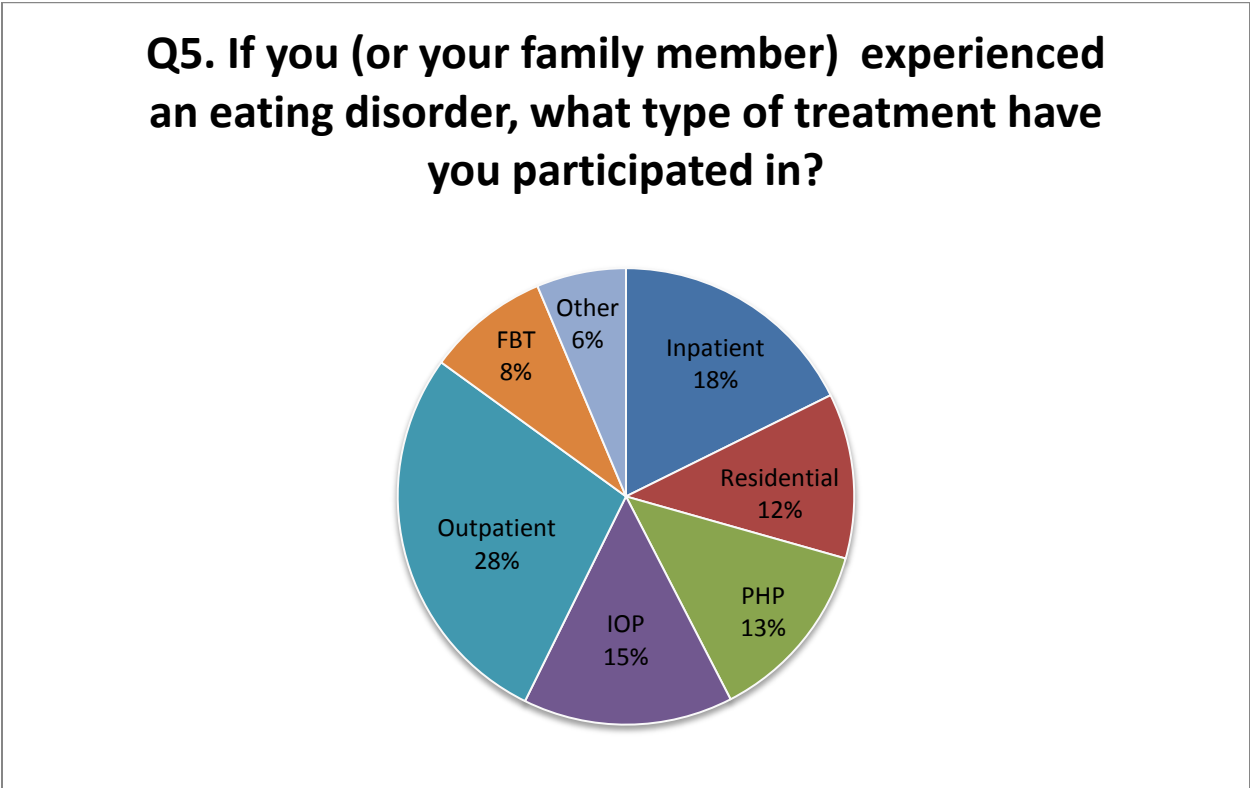
Q4 If you have experienced an eating disorder have YOU RECEIVED any treatment?

	YES	NO	I don't know	N/A
Canada	40	11	0	18
United States	266	41	9	55
United Kingdom	38	5	0	9
Australia	31	3	0	11
Mexico	1	0	0	6
South Africa	3	2	0	2
New Zealand	5	1	0	1
Other	31	7	0	12
Total	415	70	9	114



Q5 If you (or your family member) experienced an eating disorder, what type of treatment have you participated in? TICK all that apply.

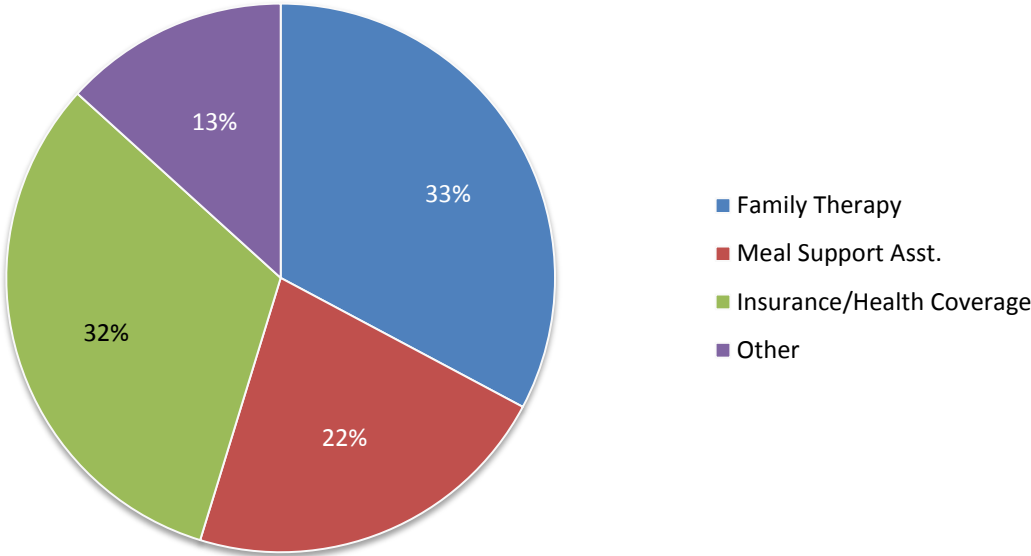
	Inpatient	Residential	PHP	IOP	Outpatient	FBT	Other
Canada	36	16	15	19	35	16	
USA	149	125	160	153	264	69	
United Kingdom	21	6	0	14	33	15	
Australia	19	4	2	10	23	11	
Mexico	1	2	0	0	3	3	
South Africa	0	3	0	1	2	1	
New Zealand	0	2	0	2	4	3	
Other	25	8	8	12	29		
Total	251	166	185	211	393	123	90



Q 7. If you are a CAREGIVER (parent, spouse, family or community member) what services and/or support do you most need?

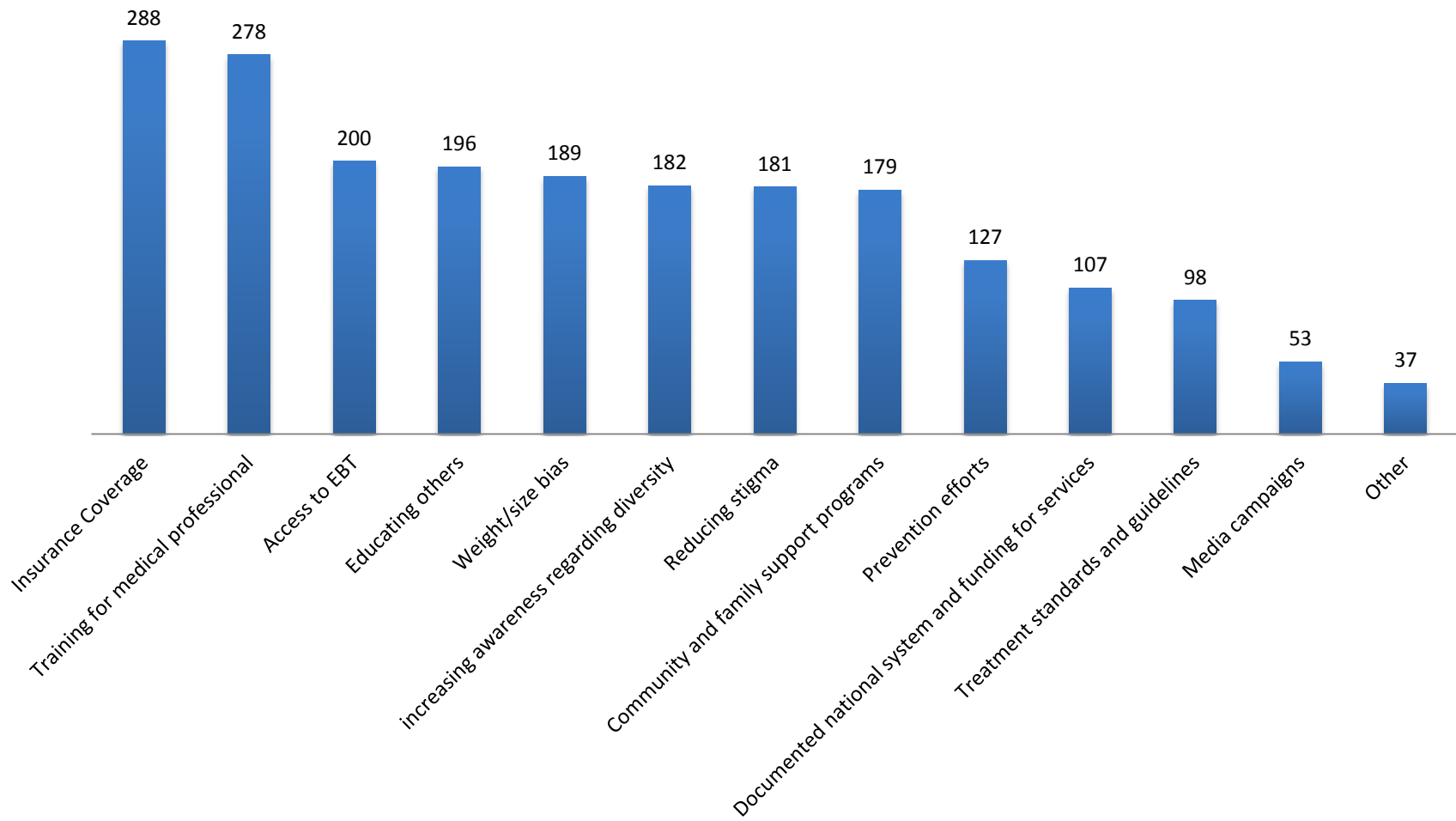
	Family Therapy	Meal Support Asst.	Insur/Health Cov.	Other
Canada	20	11	16	
USA	54	42	82	
United Kingdom	15	9	2	
Australia	9	7	6	
Mexico	4	1	3	
South Africa	5	4	2	
New Zealand	2	2	1	
Other	12	5	6	
Total	121	81	118	49

Q7. If you are a CAREGIVER (parent, spouse, family or community member) what services and/or support do you most need?



Q 8. In your region, what are the top THREE ISSUES related to eating disorders are in the most need of change?													
	Insurance Coverage	Access to EBT	Weight/size bias	increasing awareness regarding diversity and eating disorders	Reducing stigma	Educating others	Training for medical professional	Community and family support programs	Prevention efforts	Documented national system and funding for services	Treatment standards and guidelines	Media campaigns	Other
Canada	13	38	13	18	17	21	46	37	17	26	19	8	
USA	250	97	115	97	105	111	157	91	73	47	46	24	
United Kingdom	0	18	30	18	15	17	23	14	9	5	13	6	
Australia	7	23	14	20	15	18	22	13	7	10	3	3	
Mexico	2	2	1	4	2	1	4	1	2	1	0	1	
South Africa	3	3	2	3	5	1	2	6	2	1	1	1	
New Zealand	0	4	3	4	0	4	4	2	0	3	1	0	
Other	13	15	11	18	22	23	20	15	17	14	15	10	
Total	288	200	189	182	181	196	278	179	127	107	98	53	37

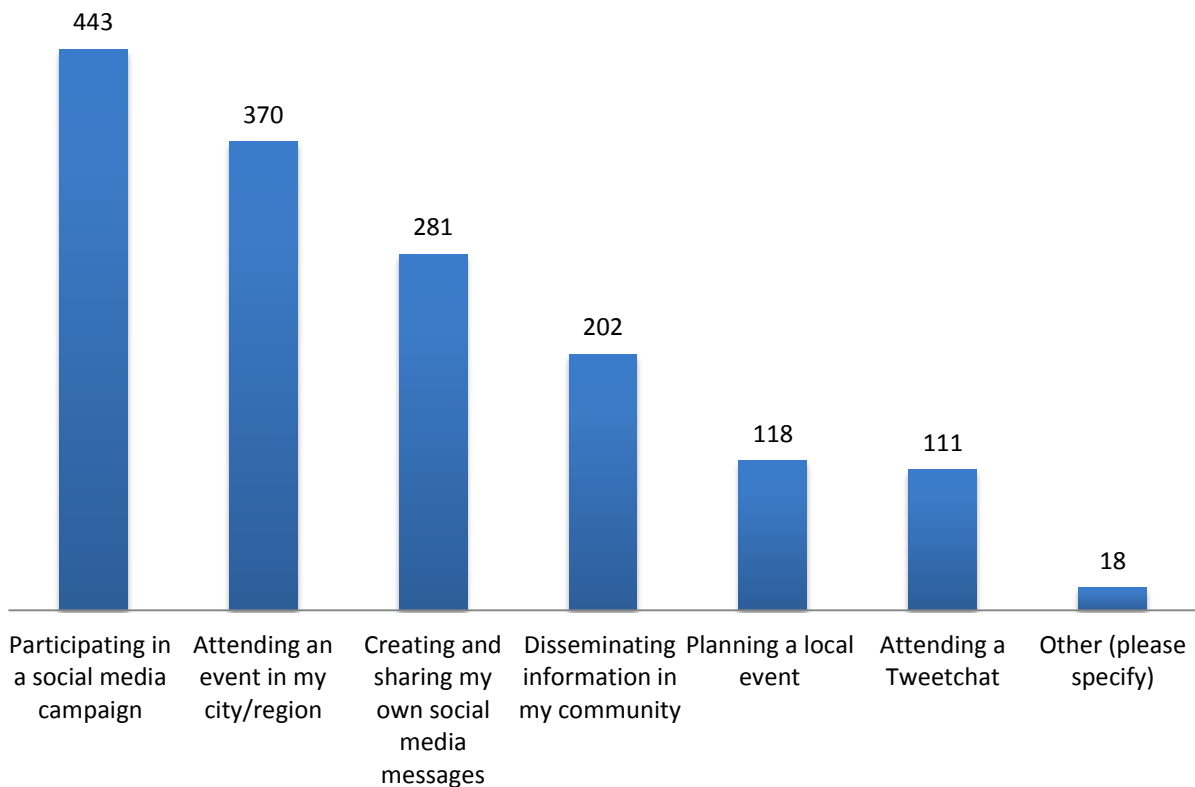
Q8. In your region, what are the top THREE ISSUES related to eating disorders are in the most need of change?



Q10. What actions would you be most committed to participating in for World Eating Disorders Action Day?

	Participating in a social media campaign	Attending a Tweetchat	Creating and sharing my own social media messages	Attending an event in my city/region	Planning a local event	Disseminating information in my community	Other (please specify)
Canada	55	14	29	38	15	26	
USA	267	68	181	238	67	118	
United Kingdom	38	11	20	25	5	15	
Australia	32	4	20	25	7	8	
Mexico	6	1	2	5	4	4	
South Africa	5	1	4	5	3	2	
New Zealand	6	1	4	5	3	3	
Other	34	11	21	29	14	26	
Total	443	111	281	370	118	202	18

Q10. What actions would you be most committed to participating in for World Eating Disorders Action Day?



"Other" Answers from Q2. What has led to your interest in eating disorder advocacy?

Family/Friend - NOT primary care giver (9)

Advocate (4)

Student (3)

Parent who lost child (2)

Parent (3)

Professional (4)

- I run an international support group for people in recovery, and write a tumblr blog about this topic. I am also involved in community education.
- I have an Eating Disorder
- My Daughter has been sick for 20yr. Knowledge of how to help at home was non existent when she was first hospitalized. Last year she went down to BMI of 9.2..We nearly lost her and they were going to send her home to die..
- mental health advocate
- Personal advocate/activist
- I have a friend whose daughter has an eating disorder
- Executive Director of ED charity
- Alyssa, our Daughter passed away in Aug. Of 2002. I advocated during her 12 year journey to get more ED services.
- Family member of someone with an eating disorder
- Family member had an eating disorder
- Psychology
- we have association for aiding persons with eating disorders
- my friend battled with an eating disorder
- I'm a woman who has to constantly tell myself its okay to look the way I look and not berate myself for nourishment. Like many.
- Work at Recovery Warriors
- I am involved in the field to help people with eating disorder
- As a friend, colleague and fellow activist
- I had anorexic/bulimic tendencies as a teen and as an adult, starting Compulsive OVER eating. My life has been one of anxiety, isolation and shame because of it.
- Miss Scott County
- And my sister had one but I didn't know what to do to help
- friend
- My daughter has ED
- Currently in college hoping to become a professional in the eating disorder field
- Dietetics student hoping to work in eating disorder treatment
- I am a friend of someone who has an eating disorder.
- I am an advocate with the ED Coalition (since 2007)
- I'm an ed recovery advocate
- I am also a blogger
- Grand parent of ill child with eating disorder
- My daughter ended her life and battle with Bulimia
- Parent of 2 children with ED

- I grew up watching my sister struggle with an eating disorder

"Other" Answers from Q5. If you (or your family member) experienced an eating disorder, what type of treatment have you participated in? TICK all that apply.

CBT - individual/group (7)

DBT - individual/group (6)

Medication (4)

Support Groups (7)

Therapy - family, individual, group etc. (22)

Nutritionist (11)

- None
- Individual therapy
- Therapy, Cognitive behaviour therapy
- Clinical Psychological Therapy
- Pychiatrist, dietitian and counselling
- My friend did not receive treatment, it was kept secret and she self manages to maintain a healthy weight, but does not have a healthy mind.
- Day program
- Cognitive Behavioural Therapy
- private therapy
- CBT group, long term psychotherapy
- Emotional focused family therapy
- Medication!
- Self guided recovery and therapy
- Sub-clinical criteria and age made my son ineligible for existing programs.
- DBT group and individual therapy
- Unable to get my loved one into care as they are old enough to refuse it.
- Private ED Therapy
- waiting for inpatient hospitalization
- counselling
- paroxetine, seresta, ...
- it is only possibility in Croatia for patients
- None
- Yet to be treated.
- Several unsuccessful psychotherapies
- (hospital setting for eating disorders only)
- General therepist
- Skill groups (dbt and cbt)
- Family therapy
- None. I recovered by myself.
- Cognitive behavioural therapy, nutritionist appointments
- All in the US.
- DBT
- Support groups, online support

- Medical admissions
- regular check ups with CAMHS
- Self none. Child - general inpatient hospital (none ED) . FBT self researched, not via therapist.
- Therapy from a clinical psychologist - waste of time, she was clueless. Also counselling which was ok, EMDR for trauma which led to ED. Plus nearly 18 years as a member of Codependents Anonymous dealing with the relationship trigger. No longer have ED.
- Community treatment with cahms who are useless
- Books (Lock n LeGrange) with support from FEAST forum
- Professional Counseling
- Compulsive over eating doesn't get any attention and is often left out of any real "treatment" plans. I have dieted and gone to 'spa-retreats' being the largest person among thin fit people. It was humiliating.
- CBT and ACT therapy
- Cognitive Behavioral Therapy
- Therapist, nutritionist
- Group support
- CBT talk therapy
- therapist
- Group
- Outpatient therapy
- Starting to see a dietitian.
- Therapy with an eating disorder specialized therapist in conjunction with my normal therapy as well as work with a nutritionist who also specializes in eating disorders
- One on one therapy
- Therapy/ Nutritionist/ EDA
- Nutrition Therapy
- Group home
- Therapy
- support group
- None
- Counseling
- CBT
- weekly counseling sessions
- Counseling
- Therapeutic yoga designed for ED patients
- family therapy and group therapy
- Nutritionist that specializes in eating disorders
- through counselor and nutritionist at college
- 12 step group - Eating Disorders Anonymous
- Talk therapy & hospital nutritionist (no hospitalization)
- Nutritional counseling, medication
- Self recovery with family support along with some check ups with a doctor.
- Equine Therapy, Support group, closed therapy group
- DBT
- support of family and child with ED
- DBT

- Medication
- ER (ICU) therapist was a disaster
- I couldn't find help and had to recover from anorexia on my own
- DBT
- home refeeding with non-FBT team
- none. my sister changed her eating habits after a super stern talk with our dad. No doctors, hospitals, treatment centers, medicine, anything (not even therapy) was involved.
- I can't afford treatment. My copay's and deductible are too high along with my monthly ins premiums.
- Madusley
- CBT
- Talk therapy
- The only treatment I've gotten is reading related books and talking to people on the internet.
- Self treated
- Enhanced Outpatient Services (EOS)
- All treatment in the U.S. while I was a student there as treatments in Japan is such a rabish.

"Other" Answers from Q6. If you are a CARER or PARENT of someone with an eating disorder how long was it before the person received Treatment?

- 10years
- I have an 8 year old girl who was diagnosed as being in the ED prodrome and my husband and I modified FBT techniques to suit her case.
- Did not receive treatment, self manages.
- In many ways I had to be own Carer...18 years passed before accessing health service
- The first treatment (counseling) was after two years, but she had to travel 800 km to acc SD it. It was ineffective.
- They refuse to acknowledge they have a problem (Lack of Insight)
- I was 17 when my eating disorder developed, but no one knew until I was in my 30's
- on wait list diagnosed 2+m ago
- 13 years
- Ellen West provided inpatient treatment since 1998
- my daughter, before 9 years
- More than 5 years
- Awaiting treatment.
- I am the symptom bearer
- Still ongoing after a year
- My son will not admit he has an eating disorder. He eats, but very little. I struggle with just the opposite....
- 6 years.
- Not until recently, as an adult
- 16 years
- for me it was different each time, from 4 months to years
- I can't answer that I'm the one with the eating disorder
- Not a parent or carer

- Once we realized the extent of our daughters issue it took 1-4 months. We didn't really seek treatment before that.
- Not yet
- My daughter stopped eating at 10 months old. I fought doctors to get her help her entire life. Finally 10 years later, she received help. She has since been receiving help with 4 times in treatment in 2 different centers and types of treatment. She is now 15.
- when we found out my daughter had an ED she was on a plane to a treatment center after one week otherwise she would have needed hospitalization.
- not a parent, 2 years after i said something / expressed concern
- immediately
- Immediately
- 2 weeks following diagnosis
- 13 yrs before accurate diagnosis of ARFID as she became medically compromised at that time.

"Other" Answers from Q7. If you are a CAREGIVER (parent, spouse, family or community member) what services and/or support do you most need?

More Support (support groups, connection with other families etc)

Relief care (someone to help so carer could take a break)

- Education.
- knowledge
- GP that understands Eds to monitor recovery and related medical issues like osteoporosis in those with eating disorders
- School support (supervision, academic support etc)
- Peer support
- Parental coaching
- Nova Scotia's Mental Health Act/IPTA seldom is applied to adults with Eating Disorders. It is still believed the patient must accept care voluntarily even when they have lack of insight and meet the criteria for MH Act
- ED Treatment Programming - nothing when Alyssa was alive in our Province
- respite for care givers. For the sufferer to be taken out our home for a few hours at least 3 days a week. She needs supervision and does not drive. She needs time out of the house to delay B/P behaviour.
- Timely treatment no waiting list for inpatient especially when in need of re feeding
- in Canada it would have been nice to get income our govt for carer support as I had to take a leave from my job 2.5 years
- more specialized professionals and treatment centers
- Eating disorder clinic that will accept under 14
- Mum and dad have said they wished they'd have had more support, had been listened to and not shut down every time they expressed their concerns. For example, a GP told my parents that it was a phase, lots of girls went through it, he'd seen loads of girls like it when he worked at a uni, not to pay attention to it because that will make it worse and draw attention to it. They told my parents that they shouldn't interfere because they'd make me worse, yet they knew that I was getting worse as time went on. They were put in a horrible position and the thing is, it hasn't changed over 12 years on!!!! This area is outdated, my parents are still being ignored.
- Family therapy body image therapy cbt for ocd and anxiety

- Long term, effective help and support
- Access to properly-trained FBT practitioners (NOT family systems therapy)
- My young adult son suffers from UNDER eating and I from Overeating. Eating disorders can be a family affair. Please give more attention to this.
- Centers that treat individuals not a lump group. And insurance that doesn't drop mental health contracts with those who can and do help.
- access to treatment support appropriate for motivated friends
- Support group
- Thankfully our treatment needs are covered.
- Support groups
- Nutritionalist
- Professionals who were knowledgeable and trained with eating disorders
- Support and friendship with other parents/caregivers
- Public understanding would have gone a long way in alleviating some of the misery. Calories on menus, front of packaging, and people's attitude that it was a choice made recovery harder by far.
- Respite so I can get a break while my child is with a safe, trained caregiver
- Medical backup for ANY refused food
- We are lacking FBT in our city/region, especially for adults
- Respite
- Availability to ED only RTC and PHP. None exist in my state.

"Other" Answers from Q8. In your region, what are the top THREE ISSUES related to eating disorders are in the most need of change?

- under-developed treatment facilities
- Increased health professionals with adequate knowledge and skills in treating and managing eating disorders
- Weight/ size bias particularly in regards to once weight restoration has been achieved. It's very disheartening to see how much more a person's issues and concerns are trivialised once they are weight restored (in general), and it only fuels the belief that you need to be severely physically unwell to seek treatment/ be honest about your own struggles
- Funding for state specific services to ensure equity of access
- Awareness by professionals that treating the mental issues can't happen till the patient is weight restored. Therefore not releasing them when underweight..
- Hard question! All of the above need to be addressed!
- Lack of Government funding for Treatment Programs, Training of Medical Drs., Nurses etc. Education and Awareness activities
- No waiting lists especially for inpatient and especially when health is compromised
- The establishment of treatment facilities in Europe
- Faster and less complicated access to treatment
- Almonte Just Treatment for rich people
- access to specialized affordable treatment
- here we have nothing
- Community assistance for activities of daily living
- more possibilities of day care hospitalisation

- more funding for services:UK. Treatment standards, stigma reduction, education, medical professional education both UK + Germany.
- Long waiting list for treatment
- Research funding
- Waiting time for treatment, number of staff available
- Waiting times
- Training but by people with lived experience. Not people who have a degree
- I am in UK, most people have to rely on NHS which has no money. Any worthwhile treatment, aside from Codependants Anonymous, has come via our personal health insurance, which most people don't have. Coda has really helped - way more than Overeaters Anonymous. NHS clinical psychology was awful!
- Education for school staff should be a priority
- More attention needs to go to people who have multiple eating disorders and or compulsive eating and the health dangers that goes with it.
- Lack of physicians, nutritionists, treatment facilities, etc. that specialize in the treatment of eating disorder
- Education in schools for All staff members to know signs, symptoms and ways of helping so no one slips through the cracks.
- Lack of programs in our area
- FBT knowledge dissemination
- I think raising awareness which can lead to earlier detection is a very critical piece.
- Greater attention to BED
- Really all of the above, I am in new Mexico and there is literally no help
- Enforcement of MH parity laws
- Lack of access to help for those on Medicare and Medicaid
- Obtaining and maintaining effective treatment at all levels for as LONG as needed for full recovery
- Doctors, pediatricians and therapists need to be educated in the latest research on EDs. Peds are often the first professionals who see a kid with an ED, and so often the symptoms are dismissed. "Prevention" efforts (I'm not sure EDs can be prevented--we might want to rephrase that as 'early intervention') should be aimed at pediatricians and family doctors. The parents usually already suspect there is a problem--they don't need the education. It's the docs who could act early but don't recognize the symptoms or the dangers of EDs, but allow their patients to get sicker before taking action, who really need the education.
- Not enough treatment facilities, group therapy and intensive outpatient programs
- Affordability
- it would be nice to have more support groups for adults with eating disorders this doesn't just pertain to children like so many assume I couldn't get treatment so I gave up.

Answers to Q9. What is the number one ISSUE/NEED related to eating disorders in your country/region? Why?

Number of occurrences of each word

Stigma (34)

Education/Educating/Educate (58)

Treatment (170)
Training/Training (35)
Insurance (95)
Weight bias (9)
Size Bias (11)
Afford (13)
Cost (11)
Cover (87)
Prevent/Prevention (22)

- Education. Eating disorders are glamourised
- prevention
- We only have 1 service and most people don't get accepted for treatment
- reducing the stigma
- Reducing stigma because that keeps people from seeking help
- Access. Minimal to no services.
- Affordable ongoing support!
- Limited access to treatment. Treatment is expensive and hard to access. Very limited resources in regional areas and few health professionals with adequate skills and knowledge to treat eating disorders in adults
- The intense focus on weight and numbers by medical professionals.
- weight bias
- More places to get help and recover because there are very few at the moment.
- Specialised treatment
- Trained professionals
- Recognising their prevalence and responding to it promptly. We are an obesogenic nation, with policy being rolled out to prevent this and this is pushing the level of low calorie dieting up - which is of course a trigger for ED, and is itself a predictor of obesity. We need to see a radical change in our understanding of the way that restriction contributes to obesity and also to the demonising of obesity and overweight that is currently very topical. As well, obesity is mistakenly seen as a causal factor for many diseases - whereas medically this is not the case.
- Access to treatment for young adults
- Stigma - sufferers are afraid to speak out and discriminated against in the workplace.
- specialised inpatient services
- lack of resources/treatment facilities.
- reduced stigma and access to inpatient/outpatient services
- Not enough treatment facilities
- Limited GP knowledge
- More Beds not enough in the public system most get turned away or a waiting list by then it could be too late
- lack of available and affordable services. very difficult to access government-funded or rebatable services.
- Access to appropriate treatment
- Funding for early intervention.... most funding is aimed at adult inpatient services, which have limited efficacy, whilst little funding is aimed towards interventions with children and adolescents - who have the best chance of recovery

- No facilities available - very weight discriminating because of limited amount of help
- Access to treatment
- Education...educating health profession, educating families and communities, educating media, educating people who develop an ED or who are vulnerable to developing an ED
- Unless you have private health insurance treatment is extremely limited. There are only 9 adult Ed beds in NSW and 3 of these only accept patients in the local catchment area. Patients who are seriously unwell present to emergency departments with low BSLs, electrolyte imbalances or cardiac problems. They are patched up and discharged into the community with no support only to deteriorate again and need to re-present in the near future. No support is offered or attempt at addressing the cause of the acute medical problem. All too often the stigma and disrespect Ed sufferers experience in emergency is awful and actually feeds into the Ed and all the negative perceptions and beliefs the sufferer has about themselves. Often 'professionals' have made comments that as a patient is not emaciated, they can't have a serious Ed which is totally untrue. It is very dangerous for a sufferer to hear something like this especially from a professional who they are meant to be able to trust. The treatment I have seen given to Ed sufferers including myself and friends I have been with in various emergency departments, has been far from adequate. Failing to take basic observations such as BSL's when someone hasn't eaten for 3 days, refusal to give fluids when someone is acutely dehydrated because they obviously didn't want to keep them any longer than they had to, I could go on.
- Easy, stigma free access to healthcare.
- More beds in Eating Disorder Units. More Eating Disorder Units. So patients are not released before they should be.
- Education
- Access to evidence based treatment
- Increasing awareness - because it's not just anorexia
- Access to treatment - no residential treatment centres, very little treatment options that are cost effective.
- ignorance/lack of education particularly relating to boys due to stigma
- Outpatient treatment
- Media creating unrealistic perceptions of weight
- Coordinated response to early identification, access to treatment, ongoing support, peer support
- Acceptance of its legitimacy and treatments put in place as a result.
- Knowledge of and access to appropriate treatment
- Resources for education of professionals, treatment of individuals, and research on a variety of subject areas
- Access to individual evidence based treatment. You should not have to choose between group therapy or no therapy. People with an eating disorder should have access to a psychologist who specializes in eating disorder treatment. Too many times have I seen friends see a counsellor and it has made the situation worse.
- Lack of services
- Lack of access to all levels of care. Criteria for existing programs is often a barrier as well as long wait lists for existing programs. Example: In British Columbia, most can only access an outpatient program weekly with group therapy/individual counseling. But there is only ONE specialized inpatient unit and ONE residential program for adults with EDs for the entire province which not everyone can access due to program criteria. If you are too sick for an outpatient program but are not sick enough to be medically hospitalized, you will not meet

criteria for the specialized ED unit yet also won't be able to access the residential program either due to a long wait list (months to years), and again program criteria where you have to be a stable weight/above a certain BMI. That leaves some people with NO treatment. There is an overall lack of programs for all levels of care in Canada.

- Accessibility! It can take up to one year to receive specialized treatment. Where do people go? There are very little trained professionals in the community to help those touched by eating disorders.
- not taken seriously as for example depression
- long waiting times. this is a health risk to patients in need of care because they could become more ill during the wait.
- Individualized treatment for chronic older patients/survivors
- Accessible treatment
- Access to treatment programs (geographically, financially, spaces in programs, etc.)
- better access to treatment. I had to wait until I was in my 30's and could pay for therapy myself to receive proper care. Making my disorder span two decades plus.
- Eliminating weight/size bias, particularly in healthcare.
- education
- Stigma/no education/those who recovered do not speak up
- Training for medical professionals
- adults expected to be motivated to choose recovery and navigate medical system themselves
- Training for medical professionals
- The stigma re: eating disorders related to the belief that they are merely self-control issues.
- More treatment options. We were lucky to access treatment quickly, most people aren't. We also need a variety of treatment options, including residential care.
- Funding. Publicly-funded care is minimal/inflexible and private counselling is too expensive for most people.
- No support groups
- Treatment programs too focused on weight and not individualized to the WHOLE person and underlying issues (programs too rigidly structured)
- Not enough resources. Lack of inpatient beds available
- Inpatient support , there isn't much in Newfoundland
- Access to treatment
- Community and family support programs because we have none
- Access to treatment/wait times
- Patient beds
- Education for medical professionals
- Lack of quick access to treatment
- Availability of treatment is terrible
- what it is no one gets it
- acces to treatment
- Having a program for transitional ages, not just child & adolescent or adult
- We have only 6 beds for the entire province of Quebec.
- Very little resources are allocated towards screening, diagnosing and treatment of ED's. Lack of awareness, silos in the medical community and a lack of funding contribute to this problem.
- Educating doctors about the severity of eating disorders. I was privileged to see an eating disorder-specialized doctor for all of high school. Now that I have been done for a year, I had to

switch to my GP, who not only made ridiculous comments, didn't care about health concerns other than weight, but also had a lack of general understanding. She would ask me if I ate breakfast, and when I lied and said yes, she told me I was doing well. In fact, my health was digressing.

- Long waiting lists due to not enough programs
- Access to treatment. Waiting lists for programs are incredibly long.
- Training for health care professionals to diagnose asap signs and symptoms to prevent ED developing and to catch it early .
- lack of available trained professionals, and if needed to go to treatment - long wait times, weight-based, not enough beds
- waiting lists for treatment
- Access to evidence based treatment for early stages of the illness, and training for medical professionals, teachers, and other people to recognize the early signs so that people can access the treatment early.
- Lack of integrated services
- lack of care
- Inpatient Treatment because we have none.
- Having multiple evidence based approaches because one treatment does not work for all.
- Access to therapists who specialize in EDs. Counselling is only available for adolescents.
- Support system is very important
- more tx facilities for less wait times
- Stigma
- Waiting times no access to residential or hospital treatment wait times are over a year for inpatient
- Treatment standards and guidelines
- Lack of access to programs
- Education. In order to receive formal treatment we are required to move 750km away.
- we need more services
- long wait list, not many RTC here in Canada
- Reducing stigma - seen as a 'choice' rather than an illness
- We need to talk about it more
- prevention
- There are not enough centers for treating eating disorders. Also, insurance coverage- too many people are unable to receive treatment for their eating disorder or are forced out of treatment because insurance denies further coverage- primarily because someone's weight reaches a healthy BMI.
- We need more therapists to work together with insurances, because there are not enough. When you want to go to an other therapist, you have to prove the insurance that 'their' therapists don't have free spots right now. It takes forever and is too much work for a person who is potentially really sick and depressed.
- Awareness of the seriousness of the condition, both for professionals and general public
- Lack of treatment (inpatient and outpatient)
- only one ward for adults with ed. very unprofesional and uncaring.
- more placs to find support
- funding for the whole gamit of levels of care. There is too much relapse because of its lack.

- We need a system suitable for children. In my region we have just one hospital that can treat patients under 14 and it does not have a dedicated unit
- Treatment and government programs
- Treatment coverage and training
- Weight and size bias
- Access to evidence based treatment, because several clinics doesn't have training for medical professionals
- The lack of knowledge of the eating disorder who both have the disease and their family for early detection .
- Information related to eating disorders/campaigns
- access to specialized treatment because of lack of specialists and of information
- over 100.000 patients in Croatia
- Implementation of FBT; in Finnish treatment guidelines, it is knowledged to be the most effective way of treating adolescents, but only few clinics in Finland offer FBT - the need is urgent!
- Bias: women should be small
- Self confidence
- Specialist services. They are so few.
- Reducing stigma and tabu
- Greater awareness
- professional help and caring treatment centres. many are money making businesses
- More treatment facilities and community based support groups. More professionals who deal specifically with eating disorders.
- Social pressure
- Support and awareness - it is still not recognised as a legitimate illness/disease.
- Understanding
- Emotions
- Not enough qualified specialists
- More comprehensive ongoing services for families.
- Stigma and 2.) standardised treatment, both countries.
- Treatment standards and guidelines
- funding as the eating disorder services receive very little
- training for medical professionals
- Prevention of conflicting dieting advice from non-qualified quacks.
- Better specialized treatment options/providers
- Educating others. Many people don't know much about ED.
- informing people about eating disorder and way to help them
- Not enough IP beds available which causes long waiting lists
- Awareness that eating disorders affect everyone because most people thought it affected only to very skinny people.
- Education - misconceptions of ED, prevention efforts
- It's very hard to get into treatment. The ones who get into treatment are often the sickest individuals. The ones with a higher BMI (than 14) and still struggle and want help, may have difficulties to get into treatment because of the strict bureaucracy and high stigma.
- Funding
- Professionals to treat ED

- We need clinics to accept children
- Research funding
- Communication between professionals
- Educating people and professionals on the reality of eating disorders. It's very difficult to get the treatment we need or get taken seriously by anyone... ANYONE, especially when at a healthy weight, making it so so hard to get better
- funded national system National systems
- Documented national system and funding for services. Because ED are very unknown and there are many wrong ideas about them
- Training for medical professionals
- Media campaigns as not many people are aware of the signs of ED's
- Reducing waiting times
- Increasing awareness and reducing the weight and size bias
- We need MORE services and in rural areas (evidence based and without weight stigma)
- I think weight bias needs to be tackled. I was weighed regularly in treatment, and although I was already doing this beforehand and I found it reassuring, it's become one of the habits of my ED that I can't break. Along with BMI being so valuable in order to define diagnosis. I understand that professionals need a diagnosis in order to best treat the individual, and weight needs to be taken into account if it is putting the individual's life in jeopardy, but ultimately weight and BMI can be unreliable and increasingly stressful when it is being used as an aspect to monitor how "well" or "unwell" you are. I don't really think muscle mass is taken into consideration either.
- The lack of knowledge from others
- Not enough awareness
- Recognition that eating disorders are psychiatric illnesses, not 'quirks'. This is because disordered eating behaviour is seen as praiseworthy, rather than dangerous.
- Access and waiting time for NHS service.
- Focus on weight, weight is a side effect. It's a MENTAL illness not a PHYSICAL illness and people don't seem to understand this often
- Prevention efforts. Because prevention is better than cure.
- Increasing the specialisation/competence of treatment providers
- Protecting and educating our younger generation
- More funding, so people can get early intervention treatment
- access to treatment
- Weight bias, often your weight is used to determine severity of ED and how quickly you can access treatment
- Adult support. No help for perceived chronic condition.
- It's hard to pick one, I wanted to tick the majority of the options above! If the medical staff were trained a little better then that would lead to earlier diagnosis and intervention, which would need evidence based treatment in order to treat people before they become chronic. However, they work on BMI criteria. So, you need to be a very low BMI in order to access the eating disorder services which tends to mean it's quite entrenched by the time treatment is offered. It'd be nice if they didn't view it based purely on BMI. I've had anorexia since 2003, it took till 2006 to get a referral to a therapist. Now, 2016 the services have altered and the eating disorder team is separate to the community mental health team, and they won't even look at my case because my BMI is 15.something, they use a BMI limit of 15... Also because I feel they've given up on me, they just tell me I manage well, I'm good at self management and I'm independent. I spend every day battling my mind and body, I have OCD, emetophobia, anxiety, depression and

PTSD (following an accident we witnessed) and obviously anorexia. I feel mentally and physically exhausted, desperately hopeless and like I am stuck because they've given up on me and written me off - 'maybe you need to accept this is how you are, that this is recovered for you...' They also use rather low BMI as a recovery point, I was confused when I was told a BMI of 17 would be fully recovered body and mind... Obviously this also goes for camhs, a young friend was under them a couple of years ago and I became increasingly concerned about her and the lack of intervention she was receiving. They moved to a different area and within 2 days of being there, she'd been put on bed rest, IV fluids, heart monitor and other medical equipment as she was so poorly. She then went onto an NG tube for several months and spent the best part of a year in a unit - she is now back at school and managing quite well. Had she of stayed here, well, she was still waiting for a peadiatric appointment and camhs were seeing her every week or fortnight but that was it. I'm not convinced she'd still be around had they not of moved, it really was scary and shocking. So,there isn't one thing I'd change, it's the whole system and even though some of the staff working within the field are awesome, they have their hands tied as they have to stick what they have been told they can do by those on high. Sorry I've rambled, I hope it makes some kind of sense, it's difficult to answer when things feel so desperate personally...

- to educate everyone on eating disorders
- No where to turn if you feeling troubled so people build up emotions, also people being turned down for treatment
- focus on weight/food not underlining issues and ought mental health problems
- Awareness
- Inpatient treatment
- Awareness of eating disorders other than anorexia i.e. The knowledge that you can be overweight and have an eating disorder.
- Funding
- Inpatient wards don't give the support promised at the beginning of treatment
- Size bias
- Treatment and awareness of eating disorders other than anorexia nervosa
- Better access to treatment
- Training for medical professionals
- stop only offering treatment based on bmi, and forcing those of a higher bmi to assume they have to get sicker to recieve treatment
- Family support is lacking a lot!
- Funding for services
- Earlier intervention with evidence based treatment that includes family support.
- getting treatment based in how much you weigh because the lower in weight you get the harder it is to recover.
- Funding. There isn't much at all, and the wait for specialist treatment is very long.
- Treatment in community meal support and day patient facilities are a post code lottery
- Training for medical professionals as ED so in the dark regarding treatment availability and understanding of ED's
- quicker access to treatment
- Access to support, waiting lists dangerously too long
- Access to treatment without being at a dangerously low weight
- Evidence based treatments
- Consistent, evidence-based approach

- Access to services is different across regions and there is definitely a weight bias in gaining diagnosis and access to treatment
- Evidence based treatment
- Media/Society
- Need more treatment centers
- Educating the public about different types of eating disorders. I have BED and people think I'm making it up because it's not as common as anorexia or bulimia. They do not realize how it controls my life and they all assume I can just stop myself from eating so much.
- Insurance coverage /help
- Again, a person who is compulsively OVER-eating has many emotional and physical problems. A person is either told go on a diet, likely denied the option of weightloss surgery and or NO other options exist such as those that address both mental and physical symptoms of those with Compulsive overeating problems.
- Prevention and early interevention education
- Lack of funding for treatment. Insurance rarely covers anything and if it does, it does not cover adequate time for treatment.
- insurance understanding
- accessible evidence based treatment
- Michigan: insurance coverage to appropriate level of care
- More resources/help
- Insurance Coverage
- Insurance coverage, I've been denied coverage on more than one occasion and the cost when I am covered is still high
- Insurance coverage
- affordable treatment and better insurance coverage
- Social Media.
- Bias due to size, weight, race, and gender
- Training for medical professionals... I have been told by numerous therapists and doctors that eating healthy and exercising would keep me from gaining the weight I was gaining in recovery....
- accessibility to treatment
- Education- there are still many people who misunderstand eating disorders or do not realize how diverse they are.
- Recognizing that minorities suffer from ED too
- Insurance coverage because good treatment is expensive!
- eradicating the stigma behind ED
- People with eating disorders come in many shapes and sizes. Someone doesn't have to be underweight to have an eating disorder.
- Insurance not covering it because treatment is too expensive for them "just to eat".
- The idea that if you're overweight, you couldn't possibly have an eating disorder.
- Public awareness about the causes of eating disorders, and the importance of treatment. Re-education of the public about eating disorders (not just about wanting to be skinny) and on a higher level, a better definition of the disease. From about 6, I began seeking comfort in food, but by 8 was hiding food and dieting. By 12 was skipping all meals, and then by 16, was bulimic. At 20, I was back to skipping meals and modeling, and by 26 I was much more bulimic with binging and purging. Even though I was hospitalized several times before seeking treatment, top

hospitals either missed that I had an eating disorder, or were too uncomfortable to confront me on it. Additionally, there is a strong misconception that EDs are about weight, because that's an easy way to understand a very complex disorder.

- Access to treatment in rural states because where I live, I would essentially have to go out of the state for residential/inpatient treatment and just OP/PHP/IOP is scarce here.
- Awareness
- Empowerment/ prevention
- lack of insurance benefits
- Use of evidence based treatments
- Education and Treatment
- Weight/size bias- recovery is very difficult when all around you, people are talking and thinking about weight
- Awareness
- ending stigma through research and education
- Education
- More free community support programs for after treatment.
- Denials of treatment by insurance companies
- Medical training for the professionals caring for Ed patients.
- Body image is a major issue because there are certain expectations that women are expected to reach.
- Training of medical professionals, nutritionists, coaches, teachers any one with access to other people
- insurance not following parity laws, discontinuing tx before completed.
- Insurance
- Lack of treatment centers nearby
- Training for medical professionals on the topic of eating disorders. They are incredibly clueless.
- Stigma and the information that is most readily accessible to the public makes eating disorders sound vain and that there is a simple fix.
- Insurance coverage- I know many people who have had to leave treatment before they should have, because their insurance would let them finish treatment
- Insurance coverage. So many lives could have been saved. I've seen friends who WANT treatment and they can't afford it.
- Treatment professionals in my area
- local treatment options
- insurance coverage
- Access to evidence-based treatment
- The need to be thin which is portrayed in models and actors
- Group support for the eating disorder person
- Access to care
- Insurance coverage
- Insurance companies and doctors not seeing how bad it is until they notice physical changes
- educating the medical community because they don't know how to identify ED and how to communicate with ED patients
- Education
- Lack of knowledge
- Education

- open support groups
- Training for medical professionals because I live in Michigan and there is NOT a single eating disorder specific residential treatment center in the whole state. So I had to go 10 hours from home for treatment.
- Access to treatment
- More facilities and providers.
- Weight bias. People believe/acknowledge anorexia as being the only eating disorder so if you're not sickly thin then you're fine. This is seen playing out with insurance companies who feel that physical health is superior to mental so they will only cover so much or nothing at all (example - if in treatment, once you reach a healthy weight they will no longer cover your care, ignoring the fact that chances are the problem isn't tak
- Staying in recovery
- Insurance coverage and if you're not at a 60 or 70 wait then they don't consider you severe enough that they won't cover you
- Treatment availability
- Insurance coverage for eating disorders is a wide-spread problem. Insurance companies are reluctant to cover the costs of treatment; the majority of the time, this is due to obvious lack of education in eating disorders.
- Prevention - because disordered eating is starting to affect children at younger and younger ages
- Having the "perfect" body.
- insurance coverage
- social media
- Stigma reduction along with education about how to help connect to resources or access resources... And positive outcome stories from people who sought help
- Insurance- I'm leaving IOP and can't find an individual outpatient people who take my insurance and specialize in eating disorders
- Need more certified ed specialists
- The stigma surrounded by eating disorders due to the media's take on what is beautiful
- Mental illness insurance coverage
- Media campaigns because it is the media that portrays these unobtainable bodies and images
- Insurance to cover mental health services
- It needs to be understood that eating disorders are primary illnesses and can be deadly if untreated. Also, They are not merely about balanced eating. The disease is in the thinking and the rituals around food which stem from mental illness.
- Prevention! Using the words, fat, bad foods, good foods, clothing sizes and #'s on the scale are contributors. We need to ban, good food, bad foods and having been "bad" when eating particular foods.
- Education for treatment and prevention of disordered eating because so many people are suffering without anyone noticing.
- Support groups. There are no support groups to attend for extra help outside of therapy and treatment.
- Prevention and education
- Insurance coverage of eating disorder treatment--there are very few treatment options locally, yet insurance companies rarely cover the cost for eating disorder treatment out-of-state.
- Education and access to resources in rural areas - mental health care as a whole

- Access to providers who specialize. I live in Wichita Falls, TX and there is no access to specialized care. I must drive at least 1.5 hours to receive it. My town has a lot of other psychiatric services and in the past had therapists with serving dietitians who specialized, but there are none now.
- Education. We lack education and therefore we lack resources for people with eating disorders to get help. For myself, I had to drive nearly 2 hours in order to reach my therapist.
- N/a
- Educating medical professionals and insurance
- Insurance coverage - nothing is covered
- Professionals informed on ED. Although we have a great team, they are learning the steps with us. Lucky they all work great together.
- correlating weight with severity
- Access to care for those in rural communities
- Prevention efforts. It is not talked about openly enough and so many are uneducated or unaware of triggers and deeper issues
- Insurance Coverage - Insurance Companies do not allow patients enough time in inpatient, residential, day treatment programs to be successful in recovery. Weight restoration is important but without more time and support to deal with the changes as well as the underlying issues, it is hard to not lose the progress you have made.
- social media and the 'need' to be 'skinny' to fit the 'norm'
- Educating Others
- Support programs/education about eating disorders as a illness, not a lifestyle choice
- lack of insurance coverage
- Social media & Education
- Education of everyone, including doctors and teachers. If more people are aware of the issue, more support (financially and treatment opportunity) will become available.
- insurance coverage
- more treatment options. many mental health professionals don't specialize in them and the ones that do still have a lot to learn.
- Education about eating disorders. There are so many misconceptions about eating disorders and it causes problems with
- weight/size bias. Most members of my family have traditional values and still believe in the norms deriving from media that they grew up with in a foreign country.
- Prevention is the most important issue because americans are so absorbed in the ideal body type, and people will go to the extreme in order to fit societal norms.
- The unconscious messages from the media about the perfect body size.
- More education about who is effected and why. Education will lead to decrease in stigma which would hopefully lead to providing a way to implement systems to aide recovery and prevention.
- Unsure. Both my daughter and I have or had eating disorders
- Insurance companies that dictate patient's treatment regardless of treatment recommendation, particularly when insurance companies base their approvals off stats on a piece of paper rather than actually meeting with the patient.
- Reduction of stigma and education
- training for medical professionals
- Access to support
- Reducing Stigma

- Continuum of care and lack of specialists. Many people in my area go from PHP to outpatient quickly or no outpatient at all which causes relapses and repeat admissions to PHP and hospitals
- School education for students AND staff. The more we know, the better everyone is at fighting in the battle. Stigma will disappear and help in all forms and for all involved will arise.
- Better understanding. So many people still have so many misconceptions about the severity of this disorder
- Prevention based on a shift in societal standards
- Doctors not taking patients seriously, especially in terms of lifestyle (Veganism) I eat vegan for ethical reasons, not because it's to rule out certain foods
- Lack of awareness
- finding a treatment facility that accepts my insurance. most places only take certain insurances.
- Lack of education in realistic signs/symptoms to look out for
- Educating people
- Lack of insurance coverage. So many people are dying too young because insurance will not cover treatment
- Weight bias
- Prevention
- Although this isn't something I experienced personally, the cost of in-patient treatment is prohibitive for most, and yet it's critical to so many seeking recovery.
- Prevention/education because I didn't even know what classified an eating disorder until I was 16
- Trained professionals
- Insurance
- weight/size bias - too many people think weight is the only determinant of ED
- Educating everyone. Many still think this is a "rich, white girl" disease and is used to become thin.
- Insurance dropped too early and I had to return to high levels of care very soon after. Insurance is hands down the biggest problem with receiving adequate treatment (in level of care and length of treatment).
- Access to appropriate medical care for eating disorders. There is an alright amount of mental health practitioners and treatment centers nearby. However, the number one concern is the poor medical care for our clients, especially at the outpatient level.
- Educating others
- Education. People need to be educated about the truth of eating disorders. Lack of education is at the root of almost all of the issues.
- Reducing stigma
- There are not enough qualified programs in the U.S. We had to send our daughter out of state for residential program. Insurance coverage is not adequate. They look at BMI, weight gain and NOT the mental component therefore treatment is cut short before optimum treatment is achieved.
- Insurance coverage bc treatment is expensive!
- Reduced stigma so that we don't have to be ashamed of our eating disorders.
- More support groups. There are only a couple in NJ and none of them are close to where I live. Online groups exist, but in person settings would be more beneficial.
- Understanding
- Support

- Getting people who need help, help faster
- Access to affordable treatment
- Stigma associated with it
- Support groups
- Insurance coverage. Many people are not able to stay in inpatient treatment long enough because their insurance does not cover it
- Insurance coverage, because treatment is hella expensive
- Confidence
- Insurance coverage
- The assumption that someone with a "normal" BMI isn't in need of help. It's incredibly difficult to be taken seriously and get a correct level of care if one doesn't "look sick."
- Access to qualify programs--we drive 3 hours round-trip to visit ours
- Parents not having enough support because it's difficult them to grasp what's happening to their children
- Weight/size bias because I didn't receive treatment for years until I "looked" like I had an eating disorder.
- prevention efforts
- Reducing stigma -- many people who have a problem do not seek treatment for this reason, and it also makes it more difficult to maintain recovery post-treatment.
- Access to trained medical professionals--few and far between, many mental health professionals unable or unwilling to work with ED patients
- Access to Care. limited insurance coverage and limited ED professionals accepting insurance of any kind, but especially Medicaid.
- Proper treatment and support
- Insurance coverage because they tend to refuse coverage especially when people are not underweight (thus not sick enough).
- People not understanding
- Unlinking the assumption that all eating disorders are caused by body image concerns and/or the media -- it creates horrible stigma, promotes the idea that EDs = vanity, and completely invalidates the majority of people who suffer from eating disorders
- Insurance coverage that recognizes that eating disorders come in many forms and sizes and that people need help based on mental challenges just as much as physical health challenges.
- insurance for any kind of treatment including registered dietitians.
- Not one support group where I live
- Financing treatment - especially for low-income and the uninsured
- Weight bias (that only thin people can have EDs)
- Insurance Coverage-State Insurance will not cover treatment centers outside of the state. Yet when there's only 1 hospital for in patient care, and they still deny treatment to that person, what do you do? They wonder why people give up and die from this disease??
- More support and aftercare
- Access
- my insurance won't pay until I get sicker, even though I've been sick for a decade and I can't finish school or hold a job or make any friends
- Education
- reducing stigma by allowing people to own this issue.

- Access to treatment. I live in South Georgia. There is one eating disorder treatment center 90 minutes away that I visited one time. I will not go back. Other psychiatrists and therapists I have seen do not seem to understand and will not focus on my eating disorder.
- Insurance coverage
- Better insurance coverage - so many people try to get treatment only to get denied adequate coverage
- community support
- **BETTER HEALTH EDUCATION FOR PREVENTION OF ALL EATING DISORDERS!!**
- My biggest problem in receiving treatment inpatient and outpatient has been insurance. I didn't have too much trouble while I was in treatment but now most of my outpatient treatment team is out of network so I end up paying \$600 per month for outpatient treatment out of pocket
- EDUCATION...stop the obesity madness, educate on matters of life and death
- Lack of affordable treatment
- Awareness. With awareness will come early detection, reduced stigma, better access to treatment, etc..
- Not enough access to treatment because of cost and insurance not covering long enough residential
- That many people people that disordered eating is Normal.
- Reducing weight stigma. The pressure to get thin and misconception that thinness=health was the top contributing factor in my developing an eating disorder.
- Overexercise because it is praised and most do not realize when it is disordered.
- Doctors, therapists, dietitians, psychiatrists who specialize in treating eating disorders
- Access to treatment. There are treatments that work in the US, but accessing them is impossible for a lot of people for various reasons. 1. It is cost prohibitive 2. It is not located in an accessible place 3. It is only offered during work hours 4. Treatment options available do not meet the needs of the individual person
- Funding for adequate treatment at all levels of care
- Greater attention to BED, because anorexia and bulimia are the only thing that get discussed, which is likely the result of fat phobia in this culture.
- Training for medical professionals
- Insurance for residential care, etc. educating professionals- I didn't learn I had an eating disorder until I was 47, forty years late.
- country - insurance
- Insurance coverage
- full insurance access for ALL levels of care
- I am unsure.
- Weight/size bias and diet culture, because I believe these are some of the biggest reasons people develop eating disorders in my country.
- Insurance companies not wanting to pay or treatment costs
- Lack of education among medical professionals
- There are no doctors with any real knowledge of eating disorders. I have searched high and low and no medical Dr will see me.
- lack of knowledge and affordable resources for people with no insurance or minimum coverage
- training medical professionals because they should be an advocate for pt's recovery, not for their eating disorders. I have been told on two separate occasions by medical doctors (upon returning from residential treatment) that I don't look like I have an eating disorder)

- Lack of trained professionals
- Lack of services
- Unrealistic body size expectations. Media, magazines, models show bias toward size 2
- Training for medical staff. So they can identify and start a dialogue with patients early so more people would get help.
- Access - it's like therapists are living in caves, people think it's so impossible to get in touch...
- I'm a researcher looking at the relationship between EDs and sexuality, and I think that's one place where there is hardly any attention given. I would love for ED programs to care more about how EDs intersect with sexuality.
- Availability of providers (including dietitians) who specialize in ED treatment.
- Weight bias within the treatment community.
- current treatment modalities are largely ineffective (especially for the chronic population); relapse is far too common and people end up going in and out of treatment their entire lives; this is solid proof that current treatment protocols are not effective for lasting recovery
- Affordable treatment options for everyone regardless of financial standing.
- insurance coverage - it's really hard to get coverage for eating disorder treatment and when you finally do they kick you out so quickly
- People think it's a choice/don't know how bad it can actually get.
- Local inpatient and PHP for 14 and under
- Unbiased, affordable, accessible treatment
- Better insurance coverage!
- Insurance coverage
- Insurance coverage - I've had a lot of peers kicked out of treatment too soon
- Lack of awareness of how deadly they are and of the fact that they are an illness rather than a choice.
- Training for medical professionals because a great disservice has been done in my life due to my not losing enough weight quick enough for my doctor to take things seriously. By the time they were serious to her, I was too far gone to benefit from much help.
- Enforcement of MH parity laws
- How Eating Disorders are viewed in the United States. As fake, as a joke...not a real illness...not taken seriously...
- Support Groups, in relation to my state of Iowa. I am a student back home I feel like I have plenty of resources thankfully but here it is hard to find anything. The closest support group is almost an hour and a half away.
- Insurance-so many can't get treatment covered
- Insurance coverage because it's often denied based on weight when weight is only a small factor to a person's health or struggle
- Insurance coverage is severely lacking
- Insurance.. Treatment is too expensive
- limited insurance coverage
- Insurance parity
- Prevention. Everything boils down to this. In the United States of America, we are fortunate to have somewhat decent insurance coverage and are changing with body weight/size bias, but we still have a long way to go. However, despite these developments, the key way to help future eating disorder related issues is to focus on prevention.
- Insurance coverage

- Lack of access to help for those on Medicare and Medicaid; treatment facilities are so greedy and the paperwork is so daunting that it is not worth their resources to take those forms of payment. And it is my eating disorder that led me to need that coverage.
- Paying for treatment
- Those who haven't lost a significant amount of weight don't get proper treatment
- Educating doctors about ED because of miss diagnose of it because they thought it was hormones thyroid ect
- Only one treatment facility
- Intensive and lower level Treatment options
- Weight/size bias, because a FULL recovery requires size acceptance
- Insurance coverage needs to stop denying patients/dropping coverage when the patient becomes physically stable because that is when the real work begins.
- Male eating disorders are left untreated and there are very limited treatments overall.
- Insurance. All insurance companies make it hard to get the help you need until you are a certain weight when in reality anyone who has an eating disorder can be any weight. Also to allow more time in hospitals, and not go by weight but by mental health
- Insurance coverage; parity is still not nationwide for all insurance companies.
- standard parity with insurance held to conformity
- Insurance removal from program before healthy
- psychaitrists trained in ED's with insurance coverage for patients
- Insurance denial of coverage
- Insurance coverage
- Cost/ coverage
- Better insurance coverage so an individual can get the needed and appropriate treatment
- We are lacking overall treatment for adults with eating disorders in my community including basic medical care. We do not have gp's comfortable or trained to treat adults with ed's. We also do not have any local inpatient option for adults leaving those in need of higher care on their own as many local therapists will also drop patients if their weight drops below a certain percentage. The local emergency departments are also not trained in what to look for or what tests to run for ed patients.
- Support groups
- Reducing stigma and education
- Hard to choose...insurance coverage for sure but also training for medical personel
- Medical field need to be more knowledgeable.
- Proper treatment. In America it is rather rare for people to get the help they need.
- Let's stop teaching kids that being fat is the worst thing that can happen
- Refusing treatment until they're dying, and then when a program starts working, and they're physically starting to improve, they kick them out and start a cycle that is harmful to health, and very costly financially.
- The medias ideas of beauty, doctors not taking patients seriously because they aren't emaciated
- Insurance--fight for parity!!
- Training for medical professionals
- National systems
- Access to quality, evidence-based treatment
- Faster time. Had to wait three months for appt with Drs who know FBT before that Drs just told my d to eat more

- More evidence based RTC and PHP\IOP
- Insurance coverage
- Insurance coverage. I get calls from people who cannot get treatment they deserve because they have Mass Health or Medicare.
- Education
- Educating Medical professionals in medical hospitals and clinics
- cohesive services--ours are fragmented and not strong
- Insurance coverage
- Insurance Coverage for treatment
- Obtaining and maintaining long term effective care treat to full recovery. Treatment coverage is pulled way to soon perpetuating the chronicity of this terrible illness
- Lack of training
- Lack of experienced professionals
- Insurance coverage, costs money to treat
- Trained professionals
- It's important to undo the past 50 years of parent blaming, and recognize instead that parents/families are the best source of hope for recovery for a loved one with ED. ED is very hard to deal with. Parents need support--medical backup, therapeutic backup, etc. They are doing heroic work. They DON'T need additional guilt or blame for something they didn't do!
- Affordability and availability of treatment.
- Insurance coverage for treatment that will not cut out when a patient is merely medically stable.
- Lack of insurance coverage
- Early accessible treatment instead of acute only
- Up to date practices
- diversity. Right now in the USA, eating disorders are a disease that "only affects white girls" because even when people preach that eating disorders don't discriminate, the evidence isn't there that there are people of color and people that aren't white that have eating disorders too. More diversity needs to be visible.
- Access to evidence based treatment
- access to treatment
- Lack of trained professionals/team for ED
- Not enough resources for children with eating disorders
- Small town/rural outpatient Trained professionals
- Affordability. After I pay for my expensive monthly Obama care premiums u can't afford care. I will die from anorexia.
- Funding
- Support and appropriate treatment
- better inpatient facilities
- Prejudice and discrimination based on body size and weight
- Weight bias
- insurance coverage
- Fat shaming resulting in people beginning severe diets leading to disordered behavior.
- Insurance coverage. Time and time again I hear of people not being able to receive treatment, or if they have insurance cuts out so fast. Personally, both time I went to intensive treatment I was only able to stay for ONE MONTH. I believe this is because I had gained the weight back...but obviously that did not mean in any way that I was better.

- body images
- Weight size/bias.
- Not enough treatment facilities available. Not able to afford the one that is available. Insurance coverage sucks. Had to leave facility after 1 day was sent to another facility that was daytime only.
- Education
- Lack of ED clinicians and no inpatient or residential
- Approval for residential treatment by ins companies. Many, many parity violations occur. We have consistently found that those who review requests at ins companies are not up to date with EDs and treatment.
- Educating all medical professionals, dietitians, therapists, and the public.
- Insurance for treatment
- access to treatment
- evidence based treatment
- Need affordable treatment!
- Stigma and lack of awareness
- Lack of understanding esp. by medical professionals.
- Increased treatment options for Medicare and Medicaid patients

"Other" Answers to Q10. What actions would you be most committed to participating in for World Eating Disorders Action Day?

- We would be committed in doing anything and everything to create awareness of this day!!! . This is such a great initiative!!!!
- Anything to bring about awareness & change
- Blogging
- Sharing my story
- Meeting with Politicians
- Awareness to long wait lists
- here we have nothing of possibility and medical treatments
- I could use my website/newsletter/media presence to disseminate education.
- Working with local professionals to reach out to parents in need.
- All :)
- I can't do much this year, however I would love to be more involved in coming years in community events on this matter.
- Volunteering anywhere
- Due to stigma, my daughter who is recovering from anorexia wants me to keep my advocacy efforts to a minimum, so I must respect her wishes for now.
- I would love to plan a local event but am not sure how.