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EXPLORING AND MANAGING PARADOXICAL TENSIONS WITHIN SOCIAL NON-
PROFIT ORGANISATIONS IN THE HEALTH CARE INDUSTRY

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Abstract

Purpose – Health care is complex and expensive; the industry is struggling in varying degrees to maintain financial sustainability in an uncertain and changing environment. Mental health illnesses have increased significantly, yet even more by the impact of the covid-19 pandemic. Around the globe about one billion individuals are affected by mental disorders, nonetheless mental health is one of the most neglected areas of public health care. Non-profit organisations aim to bridge the gap in public health care service, while facing paradoxical tensions. The purpose of this study is to examine paradoxical tensions and management approaches within NPOs in the field of mental health (eating disorders), in order to deepen the understanding of these organisations and to improve their ability of managing paradoxes in a more efficient way.

Methodology – This in-depth, descriptive case study consists of an inductive approach aimed at exploring paradoxical tensions and their relations with another. The author collected data primarily via interviews, in order to perform a qualitative content analysis.

Findings – Health care NPOs in the field of mental health are rife with paradoxes, most of them already have been discovered in paradox literature and can be easily allocated to the four types of paradox: learning, organizing, performing, belonging. Whereas others, are absolutely unique and sector specific. The umbrella paradox (financial sustainability – social responsibility) and further sub paradoxes are interlinked with one another and build a complex system. For managing paradoxical tensions, NPOs highlight the importance of communication, transparency and the value in both/and thinking, in order to balance between opposing poles of paradox.

Value – This study will contribute to the organizational literature on paradoxes by empirically examining the essential but under-researched theoretical link between paradox and non-profit organisations in the health care sector. Moreover, to provide management-assistance for non-profit organisations by introducing a tool to assess and maintain a complex and dynamic system of interwoven paradoxes.

Keywords – Paradox Theory, Polarity Mapping, Non-Profit Organisations, Healthcare Industry, Eating Disorders

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List of Abbreviations

NPOs	Non-Profit-Organisations
EDs	Eating Disorders
WHO	World Health Organization
AN	Anorexia Nervosa
BN	Bulimia Nervosa
BED	Binge Eating Disorder
OSFED	Other Specified Feeding or Eating Disorders

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1 Introduction

Almost everywhere around the globe, mental health illnesses are still a taboo amongst communities even though approximately one billion individuals are affected by mental disorders, emotionally and financially. In fact, mental health is one of the most neglected areas of public health care systems, which has a major impact on society as a whole as well as the economic development (WHO 2020).

“What mental health needs is more sunlight, more candor, and more unashamed conversation.” — Glenn Close

The quotation above expresses the need for a change towards a combination of well-targeted treatment and prevention programs, in order to avoid years lived with disability and death, reduce the stigma attached to mental disorders and promote economic development (WHO 2003).

Excessive demands on health care services create tremendous pressure within the health care industry, therefore non-profit organisations (NPOs) play an increasingly important role all around the world, in helping to bridge the gap in public health care services, hospitals and community health centres. However, NPOs are also exposed to massive tensions, as these need to fulfil multiple, conflicting demands and interests of various stakeholders as well as steadily keep the balance between financial sustainability and social responsibility. By adopting a paradox perspective, competing forces resulting in evolving tensions will be examined within health care NPOs in the field of eating disorders (EDs), in order to understand the functioning of an interwoven and complex organizational system. In alignment with the overall objective, to assist health care NPOs in managing paradoxical tensions more effectively, so as to achieve an increase in productivity and effectiveness within the organisation and as a consequence also in the health care industry.

2 Background and Theoretical Framing

Health care is a large, complex and expensive industry, which is steadily evolving by facing an ever-increasing demand for services. In recent years, many of the world's public and private health systems are struggling in varying degrees to maintain financial sustainability in an uncertain and changing environment. Contributing factors include enlarging and aging populations, expensive infrastructure and medical technology investments, growing labour costs and staff shortages and rising numbers of people with chronic long-term conditions (Allen 2020; Forehand 2000). The World Health Organisation (WHO) raised the concern, that one in four people in the world will be affected by neurological or mental disorders throughout its life (2001). Mental health as an integral part of health and well-being can be affected by a range of socioeconomic factors, therefore health systems all around the world pay increased attention to frameworks that encompass not only treatment but prevention of mental health problems in well and at-risk populations. People with mental health conditions often face human rights violations, discrimination and stigma (Boyle et al. 2007; WHO 2001). The current global covid-19 pandemic provides a powerful example of a macroeconomic factor leading to cutbacks in funding despite a concomitant need for more mental health and social services, due to greater rates of mental disorders and suicide. Nevertheless, health systems all over the world have not yet adequately responded to the exposure of mental disorders, resulting in a large gap between the need for treatment and its provision (WHO 2013).

EDs fall within the scope of mental illnesses, since they are often described as psychosomatic diseases, linked with abnormal eating patterns, disrupted physical and psychosocial abilities, indigent life quality and suicidal tendencies (Bhargava, Motwani, and Patni 2013; Lourenço et al. 2018). EDs can be categorized into four main groups: Anorexia Nervosa (AN), which is characterized by the desire to reach a very low weight most often through food restriction and exercise. Bulimia Nervosa (BN), that encompasses the consume of large amount of food in a

discrete time period and inappropriate compensatory behaviours such as vomiting. Binge Eating Disorder (BED), is similar to BN, but without any regular compensatory behaviours and Other Specified Feeding or Eating Disorders (OSFED), encompasses subthreshold cases of AN, BN and BED (American Psychiatric Association 2013; Bardone-Cone, Thompson, and Miller 2020; Garrido-Martínez et al. 2019). The majority of people affected by an ED do not seek or receive appropriate treatment (Hart et al. 2011), less than 45% ever receive treatment and only 17% of those identified as at risk for an ED seek for help. The significant number of individuals who do not receive treatment, in combination with the stigma from being perceived as an ongoing voluntary behavioural choice, indicates the need for social NPOs within this field (Cachelin and Striegel-Moore 2006; A. Becker et al. 2004; Easter 2012). At the present time the organisations provide community-based and evidence-based support services, awareness events to reduce stigma, while bringing change to the culture and break down systemic, financial and healthcare barriers. NPOs have a potentially important, but widely untapped role in this field (Korff et al. 1997), even though the competition within the market is increasing. NPOs contribute to society through its social value creation, while operating in an increasingly turbulent context where building sustainable organisations has emerged as a pressing need (Weerawardena, McDonald, and Mort 2010).

2.1 Organisational Theory of Paradox

Organisations represent a complex and ambiguous system and involve different but interdependent stakeholders with persistent demands, interests and perspectives, which is likely to result in multiple paradoxical tensions (Smith and Lewis 2011), such as collaboration and competition (see Murnighan and Conlon 1991), development and change (see Evans and Doz 1992; Quinn and Cameron 1988; Westenholtz 1993), exploitation and exploration (see Smith and Tushman 2005; Andriopoulos and Lewis 2009) and profit and social responsibility (see Margolis and Walsh 2003). Lewis describe tensions as a double-edged sword, potentially

sparkling effectivity and peak performance but also spurring anxiety, dissonance and stress (Lewis 2000; Miron-Spektor et al. 2018). Hence, tensions generate permanent challenges for organisations and are considered as a source of paradox, which has been defined as “contradictory, mutually exclusive elements that are present and operate equally at the same time” (Quinn and Cameron 1988, 2). Further, has been adopted more recentl to “contradictory yet interrelated elements that exist simultaneously and persist over time” (Smith and Lewis 2011, 382). Contradiction highlights the conflicts and inconsistencies between dual elements, as in the opposing black and white loops in the Yin and Yang.

The major increase in the paradox literature results in confusion with similar tension-oriented synonyms such as contradictions, dualities, dialects, dilemmas and polarities (Andriopoulos and Gotsi 2017). Those are all bipolar concepts with two distinct and indissoluble parts, but have slightly different meanings (Quinn and Cameron 1988). Therefore, it is vital to delineate clearly between notions in empirical paradox studies, even though some researcher treated them as substitutable. Putnam, Fairhurst, and Banghart (2016) determined contradictions as mutually exclusive as well as bipolar opposites that potentially negate each other. Whereas, dualities have the most general meaning, which are independent opposites in a ‘both/and’ relationship (Janssens and Steyaert 1999). Furthermore, dialectics are specified as an ongoing process of resolving tensions through an interplay of thesis and antithesis in the interdependence and contradictory of opposites, that is merged into a synthesis (Smith and Lewis 2011; Putnam, Fairhurst, and Banghart 2016). Dilemmas present ‘either/or’ situations, where each competing alternative has clear advantages and disadvantages, leading to the selection of the most attractive alternative (McGrath 1981; Cameron 1986). Lastly, Barry Johnson introduced the synonym polarities in 1992 as an energy system, which consist of interdependent pairs that depend on each other over time. As well as unavoidable, indestructible and unsolvable, which indicates that choosing one pole of the pair as a solution to the neglect

of the other is not a sustainable solution (Barry Johnson 2020). This research sharpen the focus on the enrichment of a paradox meta-theory by reinvestigating conceptual roots and leveraging on the potential of paradox, in order to understand complex dynamics of organizational functioning (Jonathan Schad 2017).

Based on 360 studies within a 20 years' timeframe with special attention being paid to inductive action research of Lewis 2000 and Lüscher and Lewis 2008, Smith and Lewis 2011 categorized paradoxes in a "dynamic equilibrium model of organizing". According to their theory it consists of learning, where innovation and change foster tensions between stability and dynamic. Organizing, where leading and structuring causes tensions for instance between collaboration and competition. Performing, where multiple and competing objectives need to be managed in order to achieve divergent organizational success. Lastly, belonging, where identity raises tensions between the individual and the collective. This model serves as a basis and is constantly applied within the theory of paradox (Smith and Lewis 2011).

Early advocates of the paradox lens claimed that the most effective organisations are those characterized by paradox, since being able to manage tensions simultaneously leads to peak performance in the present that enables long-term success in the future (Smith and Lewis 2011; Smith, Binns, and Tushman 2010; Cameron 1986). By using paradoxical frameworks scientists attempt to answer how organisations manage tensions in an effective way. Similar to definitions, management approaches are a persistent theme and differ widely: some researchers recommend to "work through" (Lüscher and Lewis 2008, 227), to accept, to embrace or to "live with" (Poole and van de Ven 1989, 566) paradoxes as persistent and unsolvable puzzles, rather than encourage defensiveness (Smith and Lewis 2011). Related to that, Clegg, da Cunha, and Cunha 2002 rises concerns of the attempt to eliminate paradoxes and describes it as oversimplifying and as a disservice to organization theory. While others emphasize resolution of paradox either by introducing integration strategies, which seek to address both oppositional

elements simultaneously or separation strategies, such as splitting paradoxical elements in time, space or level (Bengtsson and Raza-Ullah 2017). A further approach is taken by Barry Johnson who highlights that organisations need to distinguish between a problem to solve and a paradox to manage (Barry Johnson 1998). Therefore, organisations are advised to utilize both thinking competencies, for solvable problems ‘either/or’ thinking and for unsolvable, but leverage-able paradoxes ‘both/and’ thinking. (Kayser, Seidler, and Barry Johnson 2017).

2.2 Paradox Theory within the Health Care Sector

The paradox lens is gaining increasingly attention in the healthcare sector, more and more scholars strive to understand the underlying phenomenon by uncovering and utilizing contradictions within various types of healthcare institutions. Erthal, Frangeskou, and Marques 2021 explored the interplay of lean implementation and organizational culture in a private specialized hospital by using a paradox theory lens. Furthermore, Gastaldi et al. 2018 extend the paradox literature by proposing three complementary paths to leverage on digital transformation in healthcare organisations by balancing exploratory and explicatory efforts. In addition, it was found that service and training in general surgery cannot be separated when the four known types of paradoxes (see section 2.1) are examined (Cleland et al. 2018). Moreover, El Enany, Currie, and Lockett 2013 investigated within an in-depth long term case study the process of user involvement in mental health services as an important dimension of service development. The study reveals that through a combination of self-selection and professionals actively selecting users unrepresentative involvement occurs.

Paradoxical frameworks and thinking have been explored in various organisational contexts, however, only few conducted empirical studies on NPOs. To cover social and sustainability contexts the focus has been primary on examining social enterprises, also called hybrid organisations. For instance Smith et al. 2012 developed a paradoxical leadership tool for social entrepreneurs to manage social and commercial demands. Further Park 2020 built on the

previous by exploring management methods of paradoxes within social enterprises as hybrid organisations. Furthermore, Ismail and Brendon Johnson 2019 examined management practices of hybrid social enterprises in the Middle East and North Africa (MENA) region. As stated above, the number of empirical studies on paradoxes is increasing in the health care industry. However, NPOs in the field of ED have not been considered yet in the current literature. A paradoxical perspective can illuminate potential tensions and problems within NPOs, which might indicate that their dynamic processes and organisational functioning are paradoxical in nature. Therefore, this study will contribute to the organizational literature on paradoxes by empirically examining the essential but under-researched theoretical link between paradox and non-profit organisations in the healthcare sector. It aims to fill the gap by asking: Is it all about profitability and social responsibility? What kinds of paradoxical tensions do NPOs in the field of EDs face? How successful do members manage those tensions and what kind of tool can NPOs use to balance paradoxical tensions more efficiently?

3 Research Strategy

First, a list of potential organisations were compiled from online databases, internet searches and referrals, based on four sampling criteria (Child 2020). NPOs in the field of EDs or mental health either in the private or public market, provider of information, recovery / treatment programs and educational / prevention programs. The initial contact was made to selected organisations via e-mail or online contact forms (appendix A). The limited number of organisations in the EDs market led to a global orientation of the study. Hence, in total 47 organisations from 12 countries have been contacted, leading to a detailed overview of the sector with regard to cross-cultural and economic differences. In case of a positive confirmation for participating, the participant received a declaration of confidentiality (appendix B) as well as an interview protocol (appendix C), which provided an in-depth view of the study including definitions and the four central questions. Those were based on the paradox and polarity theory:

what are the most significant paradoxical tensions within your organization? What are the upsides/values and downsides/fears of each pole of the paradox? How do you handle those tensions and why? Do you have a specific system or strategy for the recognition of tensions? The decision to share the questions prior to the interview was made since the paradox theory requires a thorough understanding and time to examine internal processes.

3.1 Methodology and Data Collection

Ten interviews from four different countries served as a primary source for developing an in-depth, descriptive case study and were conducted over a three-weeks period (End of February until Mid of March 2021). Internal and external factors increased the number of refusals to participate in the study. A generally poor level of capacity in NPOs, which has been exacerbated by the pandemic due to a significant rise of persons affected and the preparation for the international awareness week for EDs, which takes place each year in the last week of February or the first week of March. Overall ten individual online video interviews were executed through a comprehensive video conferencing platform. Each semi-structured interview lasted between 25 and 43 minutes, leading to approximately 320 minutes of interview material in total. It was the organization's responsibility to find an appropriate and knowledgeable interview candidate, who was asked to give strong and profound reflection on the organization's activities and behaviours to identify tensions by the occurrence of paradoxes. Therefore, the professional positions of the interviewees were different between the organisations, such as CEO, Donor Relations Manager, Program and Outreach Coordinator (appendix D). A set of secondary sources were used, including research papers and reference books, information and commentaries on websites / social media accounts and additional documents shared by the interviewees.

3.2 Analytical Strategy and Data Analysis

A qualitative content analysis was performed using an inductive approach. Although presented as sequential, all phases were iterative and cyclical: starting with the data preparation by transcribing all interviews verbatim (appendix E), highlighting relevant passages and store key findings. Followed by forming an organized interpretation of the data (Uzzi 1997), a template based on the polarity map (Barry Johnson 1992) was created in order to link those initial findings with existing theory frameworks (appendix F). This ensured a better understanding of the nature of each paradoxical tension. All related findings were entered and visualized in a spreadsheet as first-order codes, reflecting on the background of the paradox, as well as upsides and downsides of each pole (appendix G). By using a “snowballing technique” (Andriopoulos and Lewis 2010, 106), the document served as a fundamental communication instrument. The interviewees reviewed and verified the data, filled gaps and provided deeper insights if needed. With a detailed examination of the interviews 38 paradoxes were identified, whereby 11 are core paradoxes with over 180 relevant passages. Moreover, all core paradoxes are assigned to four categories depending on the reach of its influence. The table 1 below shows all identified paradoxes together with its characteristics:

Table 1: Overview of the Paradoxes and Characteristics

Paradox	Incidence	Categories
Financial Sustainability – Social Responsibility	9	Industry
Individual – Collective	5	World
Cooperation – Competition	5	Industry
Collaboration – Control	3	Organization
Awareness – Medical Service	3	Industry
Clinicians – Non-clinicians	3	Industry
Traditional – Innovative	3	Organization
Productivity – Selfcare	3	Individual/Org.
Flexibility – Efficiency	2	Individual/Org.
Evidence-based Support – Alternative Support	1	Industry
Responsive – Reactive	1	Individual/Org.
11	38	4

As the next stage, a cross-case analysis was conducted to compare and merge findings of each organization, while concurrently creating second-order codes for each core paradox. After, explicit and implicit relations were explored and distinguished between six

classifications. Lastly, a model for NPOs in the health care sector was developed to manage paradoxical tensions more efficiently by traveling back and forth between data and theory (Uzzi 1997).

4 Findings

The analysis revealed that NPOs in the healthcare industry are rife with paradoxes. The business model itself is built on a paradox since it constantly pulls in opposing directions to fulfil its social responsibility while simultaneously attain financial sustainability. Many of the named tensions overlapped, whereby a few were directly associated to a unique context within a specific organization.

4.1 An umbrella-paradox: Financial Sustainability – Social Responsibility

Besides the paradoxical structure of the business model, nine out of ten organisations mentioned tensions while pursuing a financially viable and sustainable mission. Moreover, informants described it as the “*biggest*” and “*hardest*” paradox to manage since there is a need to “*constantly balance and try to figure out where it is right or where it feels right to [...] fall between profit and social responsibility*”.

NPOs are compelled to constantly pursue for highly competitive grants, collaborations, sponsorships and financial donations, due to the reasons that the EDs field is in general publicly and privately poorly funded. Currently even more, as a result of the weak economic situation. In addition, the small size of the community leads to a lower number of investors, which is as well related to the social stigma attached to EDs (Touyz, Lacey, and Hay 2020). Some of the organisations are tied to diverse prospects and claims of multiple stakeholders (e.g. donors, investors, beneficiaries, cooperation partners), whereas others receive unrestricted monies, that allow autonomy, freedom of action and alignment with its social mission.

Emerging tensions may depend on the structure of the NPO, which can be distinguished between: private, public and voluntary.

Private NPOs need to make informed decisions on the selection process of the funders to ensure that their corporate values and ethical principles are aligned with the organisation's purpose. In this context each organisation pursues a different approach, which can be controversial: one organisation considers and accepts funding from a corporate investor, that might have *“racist hiring practices”* and in order to compensate, the organisation implements *“support groups for people of colour with EDs”*. Contrary, another organisation argues that accepting *“money from a company or an organisation that feels counteractive to our mission, just does not feel good.”* While others consider it as a structural and insurmountable incident, i.e. organisations are aware that companies are *“upheld by capitalism”* which *“might relate to the privatisation of healthcare, diet culture, racism or sexism, [...] however, the organisation also relies on capitalism to fund its programs”*.

Public organisations face various stress factors, depending upon the forms of government and types of political systems. The risk of losing the funding is seen as the most *“significant threat to the organization's survivability”*. Hence, a sensitive and respectful interaction in combination with an open and trustful style of communication is essential, especially while advocating for change within the public health system. The relationship of dependency stands out even more in case of unpredictable and tumultuous economic developments, which may cause that previously assured funding is *“diverted in another service to make up a gap”*. This may also be related to who is responsible for making decisions, i.e. organisations claim that decisionmakers often do not have a personal connection or lived experience, which usually results in dismissing *“the call for help”*.

Voluntary-based organisations benefit from flexibility by *“not [being] constrained to internal bureaucracy”*, but rely on external resources and support, for instance professionals who are willing to give lectures or partner organisation to run new projects. This is reflected in

a high degree of interdependence, since its social impact creation can easily be affected in both directions – positively and negatively.

To examine the umbrella-paradox to its full extent, insights about employees and volunteers are of great importance, since the system would collapse without its passionate members. They aim to “*help people and to save life’s*” in line with the organisation’s objective of “*providing accessible support for everyone*” by “*trying to create the biggest impact possible with the received funding*”. In turn, scarcity of resources raises the risk of not fulfilling its social responsibility and might be harmful for the employee’s well-being: “*caring too much [...], [while] forgetting to think about themselves*”.

4.2 Sub-Paradoxes

The umbrella-paradox is influenced by further sub-paradoxes, which will be discussed neutrally in the further process of the study. In some cases, several paradoxes were bundled due to intersections.

4.2.1 Individual – Collective

Organisations witness tensions between individual and collective approaches in diverse surroundings, which need to be examined from a variety of angles: treatment, culture and organization structure.

In the context of treatment, EDs are multifaceted and consist of unique elements which makes it strenuous to “*balance between providing individual care and collective care*”. Individual care focuses on individual health needs for instance with one-by-one counselling. In contrast, collective care focuses on the welfare of the community with the orientation towards the larger whole. However, most of the organisations follow an ‘either/or’ rather than an ‘both/and’ approach by offering mainly individual treatment approaches. Even though, some recognize the need for change and aim to establish new opportunities by tapping the lack of community-based care in the broader ED field. “*The recovery process from most of our history*

[...] has been really centred on helping individual, which on the surface [...] is not a bad thing. What we are learning [...] and incorporate in our values [...] is shifting the centre of the needs of the collective – meaning zooming out and seeing and meeting the needs on the community at large". While others query the effectiveness of the collective approach due to the gap in research about community-based care.

This relates to the context of culture, the shift from an individual to a collective perspective is highly ambitious for NPOs which are grounded in an individualistic society (for instance North America), that emphasise individual needs over the needs of the community as a whole. In this sense, one organisation recommends stepping out of the individual experience and promotes a *"more culturally informed lens"*. *"EDs are often perpetuated by cultural systems, which provide treatment mainly for a specific stereotype, represented by "white middle to upper class people"*. This is a *"reflection of [...] inequities and sub broken systems around healthcare and beyond."*

In the context of organization structures, several organisations have been established by individuals in response to personalized lived experience. As the organization grows, tensions arise commonly between the original founders and the board of directors, since expectations to be a sustainable and better controlled organisation might be diversified. To meet the challenge and pursue a peaceful outcome, both sides need to respect each other and rise constantly the question: *"How [to] balance [...] what the original founders wanted to establish [...] with that of the guidance provided by the board of directors"*. Building trust between founders and the board can lead to collective change, additional resources and growth. Besides that, comparable tensions might flourish when employees or volunteers have individual objectives, which mismatch the collective purpose of the organisations. To minimize nested tensions between different parties, an interviewee recommends to *"involve all members with all levels within the*

organisation [...] to clarify the organisational objectives [...] and the goals of each individual within the organisation”.

4.2.2 Cooperation – Competition | Collaboration – Control

The organisations named a wide range of positive attributes while speaking about national and international cooperation’s, such as: *“combined strength, knowledge exchange, gaining and building trust within the community, serving greater and better the common good and a diverse population”*. Besides the positive characteristics, some organisations draw attention to the flipside by mentioning that *“when there are several organisations in the picture [...] it is not always easy to make decisions that completely satisfy everybody”*. Further, connecting activities result in duplication of services, which potentially leads to a loss of clients. And the risk of stepping *“on someone’s toe”* while covering similar needs is always present. Competition between NPOs brings also advantages and disadvantages. On one hand it keeps everyone accountable, provides resources which leads to business growth, helps the organisations to find its identity and to fill gaps in services. On the other hand, it can lead to confusion towards decisionmakers when every organisation speaks for themselves, rather than having *“one voice”*. To prevent this, some of the organisations established or become a part of an alliance, where organisations join forces to collectively advocate for change. In the organisational paradox theory this paradox is defined as “coopetition” and has been examined in various organisational settings (Bengtsson and Kock 2000, 2014).

Furthermore, other NPOs feel opposing forces between collaboration and control accompanied with two examples. The first one shows that internal paradoxical tensions might occur within the team, when too many people are involved combined with poorly defined roles and responsibilities. Others experience these tensions more by interacting with external investors, such as the public health care system. The trade-off between being a part of the public health system by offering treatments and services, while simultaneously advocating for change

within that system, in order to represent a fundamental ethical position of the organisation. Therefore, the organisation meets the challenge “*to be part of the system but also sign the system as not adequate*”.

4.2.3 Awareness – Medical Service

Globally, a “*lack of understanding that EDs are a physical and mental illness*” exists, due to the persisting stigma around the illness, the spread of inaccurate information by non-professionals and professionals in relation to the research gap and the fact that EDs slides commonly into oblivion even in the field of mental health itself. Nonetheless, the understanding has grown in recent years mainly through the work of social NPOs with activities such as: organising awareness events to activate people for change, humanising the illness within public interviews and improving the level of research as well as education to raise productivity and growth in the wider economy. These activities are still overshadowed with incomprehension, which is manifested in the way of public “*criticism on social media*” or even in person by proclaiming per example that “*awareness is not necessary*”, rather to fulfil the desire of more medical support options. These tensions between the organisation and its stakeholders are challenging and frustrating for the employees and might lead to a decrease of performance and achievement of objectives.

4.2.4 Evidence-based Support – Alternative Support | Clinicians – Non-Clinicians

Evidence-based support includes cognitive-behavioural, interpersonal and family-based therapies (Peterson et al. 2016), whereas alternative support includes “*body-awareness*”, “*arts*” and “*lived-experience*” support groups. Similar to previous paradoxes, some of the organisations are still following an ‘either/or’ approach, but it seems that the field is in transition, since more and more NPOs are shifting to an ‘both/and’ approach while recognizing advantages and disadvantages of each side. Experience has shown that clients in support groups have different preferences, some prefer evidence-based while others favour alternative support.

Although, assessment and impact measurement methods for both alternatives are not yet sufficiently developed.

In reference to the previous paradox, one of the interviewees with more than 30 years of experience in the field of EDs shared, that NPOs have difficulties to become a part of the mental health community for the reason that it is challenging to gain the respect of professionals (i.e. doctors, psychologists, nutritionists). Although, those tensions decline with time, they may never disappear completely. This paradox is highly unique and hinges on external factors, such as the location of the NPO and the culture within the country. As another interviewee argues: *“it is generally understood that lived experience is a critical component of any kind of system design”*, since it *“is quite powerful”* by pointing out that *“both sides [professionals and non-professionals] mean to get a better result”*. In addition to this essential point, benefits are also seen in the work culture of NPOs, as offering both might enhance a diverse hiring process.

4.2.5 Traditional – Innovative

NPOs started to integrate an educational division, in order to enhance the knowledge in the field of EDs and to achieve sustainable success. In this context internal tensions emerge, since the new established division strives for innovation and transforming ways of working to engage even better with clients and to stay competitive in the market. Whereby the pre-existing division promotes traditional proven approaches, *“which are known to be successful”*. But on the other side, these are also seen as an *“outdated technology”*, which might lead in an ever-changing environment to a loss of clients. An interviewee declared: *“It is not a tension that is [...] entirely negative, [...] it keeps both [...] growing, but grounded in a way. When both sides are communicating, some of the fractions come up, where we [...] have to work through”*. The pandemic also brought a structural change for health care NPOs, initially accompanied by fear and uncertainty about the loss of efficacy and safety for employees and clients while providing services online rather than in person. On one hand, organisations extend its reach by providing

digital services and offer more flexibility by working from home. On the other hand, many adjustments had to be performed and the amount of work as well as the pressure increased significantly, since the pandemic forces public lockdown measures which lead to isolation and consequently, that people are more exposed to mental illnesses. Working from home can be another source of stress and might not represent a safe environment for employees and even other cohabitants due to the exchange of highly sensitive personal data. Organisations try to counteract this by providing flexible work schedules, reducing the work volume and redistributing tasks within the team.

4.2.6 Productivity – Self-care | Responsive – Reactive | Flexibility – Efficiency

In the field of EDs it is common that people with lived experience want to become a part of NPOs, in order to guide and support others in the healing process. Among the benefits of the integration, which were introduced in the section 4.2.4, it may create some tensions in relation with three different paradoxes.

In regards to productivity and self-care, NPOs in the field of EDs have in general high-performance expectations due to its social responsibility toward its community, but simultaneously bear a heavy accountability towards its employees. Working with vulnerable patients can be demanding and jeopardising; sharing personal experience can lead to an acute deterioration of the health status for both, patient and caretaker. Therefore, the implementation of an effective volunteer/employee screening tool is crucial. However, the hiring process may pose a challenge for these organisations, since there is a need to assess the current state of health of each applicant without violating the labour protection law. Most organisations recommend its applicants to be in a strong recovery process for at least one or two years regardless of the type of the mental illness. Furthermore, organisations are trying to establish a results-oriented and attentive infrastructure with possibilities of “*stepping back*”, to regenerate and “*keep doing the work for the long run*”. It is a challenge for both, supervisor and employee, to investigate

whether the employee is emotionally and mentally capable to perform successfully, but it is “culturally a part of the priority” to ensure “everybody is safe”. Moreover, social workers may strengthen employee’s psychological well-being and create a stress-reducing working atmosphere.

In this context, an interviewee mentions an additional paradox, which has a focus on the balance between being responsive and being reactive. The latter, lies in the human nature, when trying to solve something as quickly as possible. By contrast, being responsive means moving “intentionally and sustainably”. According to circumstances employees and volunteers have to take the decision consistent with self-protection and its duty of care.

The paradox of flexibility and efficiency affects mainly volunteer-run organisations, since those provide highly flexible work concepts by offering self-determined work schedules. That might lead to be “more efficient as an organisation in achieving [...] objectives when [its employees] are not tied to traditional ways of working”, but can be challenging for volunteers to maintain a steady work-life-balance.

4.3 Managing paradoxical tensions within NPOs

All NPOs experience and acknowledge tensions, even though under different labels, which arise out of internal and external paradoxical interventions. Tensions do not represent obstacles for those organisations rather “provide opportunities to learn and grow”. To exploit these prospects paradox management is crucial, in order to reduce or to keep paradoxical tensions on an acceptable level. By doing so, NPOs establish various management approaches which are presented along with associated quotations in the table below:

Table 2: Overview of current Management Approaches

Management Approaches	Associated Quotation
Balancing	~“we talk about how we balance these things [...] in different ways, but we never label them as tensions [...] the language what we use might be a bit different, but kind of in the essence the same”

	<p>~"to balance those"</p> <p>~"we are constantly balancing and constantly trying to figure out where it is right or where it feels right to kind of fall between"</p> <p>~"how can we balance them, rather than trying to decide who we have to choose between"</p> <p>~"constantly trying to balance"</p> <p>~"definitely in our strategic plan about how we balance some of the tensions"</p>
Both/And Thinking	<p>~"we try to do both [...] there is value in both"</p> <p>~"but also"</p> <p>~"thinking in a way, it is not focusing on profit or social responsibility, but how can we focus on both."</p>
Communicating	<p>~"transparency is a really big thing in terms of the way we approach it. These communications are important on both sides and it is important to balance."</p> <p>~"circles back or checks back"</p> <p>~"ok, there are tensions, but communication is key"</p> <p>~"my colleague [...] would be the best person to fuel this question. I won't be able to say from my own experience"</p> <p>~"She has kind of both doors open, but it is also not fair to put all that communication on one person to bring all this kind of information"</p>
Holding	<p>~"how are we going to hold that"</p> <p>~"we try to hold both on a really intentional but transparent way"</p> <p>~"how can we maintain them"</p>
Understanding	<p>~"we have been realizing [...] learning more about it and understanding more about how all of this is present"</p> <p>~"from time to time we do a formal review [...] what we need to manage and understand and then on an ongoing basis, because [...] it is built into our plan we should sort of understand what we are doing to minimize the negative side of those tensions"</p>
Shifting	<p>~"we are trying to shift that lens view"</p>

NPOs try to communicate openly, be transparent and represent different voices and views. Furthermore, the majority of the organisations have already supplemented 'either/or' with 'both/and' thinking, due to the recognition of value in both sides of paradoxes. Instead of choosing one side, the organisations are trying to "constantly balance" or "holding" both sides. One of the interviewees highlighted the need to understand, manage and "minimize the negative side of [paradoxical] tensions" on an ongoing basis by integrating them in the organisation's strategic annual plan.

5 Discussion

The main purpose of this study was to investigate competing forces and evolving tensions within NPOs in the field of EDs by capturing contradictory interests and demands of various stakeholders. The findings demonstrate that NPOs in the healthcare sector are covered with paradoxical tensions and can therefore be successfully placed in the organisational paradox

theory. Further, most of the exposed paradoxes can be allocated to the four main types of paradoxes introduced in the dynamic equilibrium framework by Smith and Lewis 2011, which represent grounded core activities and elements of organisations. Starting with the first type, the learning paradox is reflected in the opposing forces between tradition and innovation. Followed by the second type of organizing, which relates to the organisation's structures and cultures. In addition, it finds expression in two stated paradoxes: 'cooperation – competition' and 'collaboration – control'. The performing paradox includes the umbrella paradox 'financial sustainability – social responsibility', expressed by Lewis as a double bottom line where performance of organisations depends on both: financial and social goals. Moreover, paradoxes as 'productivity – selfcare', 'flexibility – efficiency' and 'responsive – reactive' fall within the type of performing. Lastly, the belonging paradox describes tensions of identity, thus relates to the paradox of 'individual and collective' (Smith and Lewis 2011). Apart from these findings, three paradoxes cannot be allocated to any of the preceding categories, as these can be seen as sector-specific paradoxes: 'awareness – medical service', 'clinicians – non-clinicians' and 'evidence-based support – alternative support'.

Researchers commonly explore complex and diverse paradoxes by centring on an individual paradox (Bengtsson and Raza-Ullah 2017; Andriopoulos and Lewis 2009; Audia, Locke, and Smith 2000). In the field of social businesses, the focus is primarily on investigating the core paradox between profit and social responsibility from a variety of perspectives or environments (Jay 2013; Smith, Gonin, and Besharov 2013). By contrast, this case study aims to place greater emphasis on the relatively under theorised interplay between paradoxes in social NPOs (Kets de Vries 2001; Andriopoulos and Lewis 2009; Jarzabkowski, Lê, and van de Ven 2013; Sheep, Fairhurst, and Khazanchi 2017), in order to disclose a complex and interconnected web of organisational paradoxes. The in-depth analysis revealed that the umbrella paradox can be directly influenced by all sub-paradoxes (appendix H), which were discussed in the previous

chapter. The table below displays the outcome of well-balanced sub-paradoxes, which might have an affirmative or negative effect either on one side of each pole or on both poles: financial sustainability pole (FS pole) and social responsibility pole (SR pole):

Table 3: Sub-paradoxes affect the umbrella-paradox directly

Paradox	Balance of	Leads to	FS pole	SR pole
Individual Collective	Individual <u>and</u> collective care	Inclusion of people with different backgrounds (race, gender, sexual orientation, religion)		+
	Objectives of original founders <u>and</u> board; organisation <u>and</u> employees	Conflict and risk reduction, results in a better performance of the organisation	+	+
Cooperation Competition	Cooperation <u>and</u> competition with other organisations in the field of ED	Increase or decrease of resources	+/-	+/-
Collaborative Control	Collaborating with the public health system <u>and</u> advocating for change	Securing of stable grants and innovation in health care system	+	+
Awareness Medical Service	Raising awareness in the society <u>and</u> providing medical service	Reach a higher number of people Increases the probability of receiving more grants		+
Evidence-based Alternative Support	<u>Both</u> treatment options	Reach a higher number of people May imply higher costs Increases the probability of receiving more grants	+/-	+
Clinicians Non-Clinicians	Clinicians knowledge <u>and</u> non-clinicians knowledge	Reach a higher number of people		+
Traditional Innovative	Traditional <u>and</u> innovative ways of working	Reach a higher number of people Increases the probability of receiving more grants (offering educational programs)	+	+
Productivity Self-care and Responsive Reactive	Performance expectations by the employer <u>and</u> self-care of the employees	Goal-oriented management strategy Sustainable working environment	+	+

In reverse, out-of-equilibrium sub-paradoxes can negatively influence or endanger the umbrella paradox. However, this flow can be carried out in two directions, meaning that positive or negative occurrences within the umbrella-paradox might affect one or even several sub-paradoxes. For instance, financial cutbacks might lead to an increase in competition and a decrease in innovation, since the organisation has to combat for financial support, while setting

internal innovation projects on hold. The paradoxical web is further expanded by the interrelations of sub-paradoxes among each other (appendix I), which can exert indirect impacts (positive/negative) on the umbrella paradox. For instance, balancing between individual and collective care implies the support of people with different backgrounds (e.g. race, gender, sexual orientation, religion), which might lead to a better balance between providing medical service and raising awareness in the society. Moreover, offering both evidence-based and alternative care might result in a more diverse culture by hiring both professionals and non-professionals.

These findings indicate to immerse an interwoven, dynamic and polarising system, rather than focusing exclusively on the paradox between financial sustainability and social responsibility. Only a few pioneering researches conducted research on this topic by introducing interwoven paradoxical tensions, which can be nested across multiple levels within an organisation (Cunha et al. 2019, 232). Furthermore, Sheep, Fairhurst, and Khazanchi 2017 specified tensions as evolving and constructed within a complex system of “tensional knots” (Sheep, Fairhurst, and Khazanchi 2017, 468). Those dynamic interconnections between paradoxes within NPOs need to be integrated in the management process by shifting the lens to capture a macro perspective of the complex system. The importance of managing paradoxical tensions was recognized at an early stage of the organizational paradox theory. Hence various management approaches were identified, critically analysed and further developed in theoretical and empirical research. The analysis of dealing with tensions in NPOs (see 4.2.7) is in alignment with existing research, since those organisations accept, “*work through*” and even embrace paradoxes. Surprisingly, all organisations are skilled in paradoxically thinking, also known as “transcendence” (Lewis 2000, 764) and follow an integration approach by addressing both oppositional elements simultaneously (Bengtsson and Raza-Ullah 2017). Even though none of the organisations seems to have a continuous paradox-specific management approach,

only two organisations integrate challenges related to paradoxical tensions in their strategic annual plan or broach them in board meetings. Furthermore, the management findings (‘balancing’, ‘both/and thinking’, ‘communicating’, ‘holding’, ‘understanding’, ‘shifting’) and impressions such as “*talk a little*” and “*learning more about them*” leads to the assumption that NPOs in the field of ED respond more loosely and informal to paradoxical tensions. These insights support the case study of managing organizational paradoxes in social enterprises from the MENA region by Ismail and Brendon Johnson 2019, who introduce “a trend of informality” and a “recurring process of identification and response” rather than a unique management technique (529). This could be rooted in sector-specific settings: one of the major factors might be the limited capacity of NPOs, since those often lack on time and human resource. Closely related to this, is the lack of management know-how since employees with different professional backgrounds may not have management capabilities. Unlike Ismail and Brendon Johnson 2019, another factor could be the small size of NPOs including a lack of adequate structures and responsibilities, even though most of them have existed for many years. Considering the above mentioned, the aim of this research is not only adding to academic paradox research, but also offering practical implications. For this purpose, a management tool for employees and executives of social NPOs in the field of EDs is introduced below, visualized in the appendix J and is based on valuable insights of key informants and already existing management instruments (Polarity Map® and the five step SMALL process by Barry Johnson; “Layers of parts and wholes of sustainability” by Jason Jay et. al.). The tool has been designed to assess and maintain the complex and dynamic system of interwoven and mutual paradoxes in order to reduce tensions within NPOs. It aims to support employees to understand, structure and monitor transforming paradoxical tensions and respond to the three sector-specific pain points by providing management-assistance, enhancing organizational structure and distributing responsibilities and saving time. Each employee should be familiar with the eight-

step-tool, which supposed to be utilized on a permanent basis. The first two steps serve to improve understanding of paradoxes by providing common examples such as ‘inhale and exhale’ and ‘active and rest’. Further, multiple questions assist in distinguishing between unsolvable paradoxes and solvable problems. This is followed by mapping paradoxes, in order to recognize positive and negative effects on each side of the pole, which may represent risks and opportunities for the future development of the organisation. Based on the findings of this research and the great relevance of interrelations, connections between paradoxes (umbrella / sub-paradoxes) will be determined in stage four. Further, they will be visualized and divided in three categories: independently, directly or indirectly related with the umbrella paradox. The results generated in this phase form the basis to the next phase, where each paradox is zoomed in and simultaneously zoomed out to capture the paradoxical web in a wider perspective. Then, the paradoxes will be assigned to six common categories, namely: individual, department, organisation, industry, nation, world. This classification is relevant for the subsequent stage where responsibilities are defined within the organisation or even beyond. For the penultimate step the four main interrogatives need to be addressed: Where? NPOs need to establish a basis for communication and management of paradoxes (e.g. regular meetings, documentation platform). How? NPOs need to identify points of optimization within each paradox in respect of the dynamic web. Who? NPOs need to define responsibilities, which depend on the classification in step six. For instance, paradoxes within the categories of individual, department or organisation will be allocated to the person in charge within the organisation who has the most points of contact with the specific paradoxes. For the remaining three categories, industry, nation and world will be a lessons-learned forum established between organisations that serves for knowledge exchange. The last step is to define a frequency for the model use, meaning that organisations are advised to use the model on an ongoing basis with a frequency adapted to their own specific circumstances.

6 Conclusion

This research reflects turbulent challenges for the health care industry and highlights the complex nature of organizational life by applying a paradox perspective with the combination of existing knowledge and new perceptions. NPOs are under constant exposure to tensions, while maintaining a balance between social responsibility and financial sustainability in respect of the divergent demands and interests of internal as well as external stakeholders. This study leverages and extends previous understandings of well-known and well-researched paradoxes, for instance cooptation. In turn, the findings provide insights of untapped paradoxes specifically related to the field of mental health (EDs) and highlights the necessity to capture a complex and interconnected web of organisational paradoxes as a whole by zooming in and zooming out. Moreover, the paper gives an indication for the need to provide guidelines and management assistance for health care NPOs, given the fact that these pursue rather informal identification and response processes. The presented tool aims to support NPOs in gaining competitive advantages and increase productivity by managing paradoxical tensions more efficiently. However, this research is subject to some limitations. The small sample size and the choice of examining a border area of mental health (EDs) questions the generalizability. Besides that, participants and researcher might be biased, meaning that the responses of participants are rather based on social acceptance than on actual feelings. Whereas, the researcher perhaps asks leading questions that prompt a specific response. Nevertheless, the hope is that this work provides extensive opportunities for future empirical studies to uncover paradoxical tensions within NPOs in the healthcare sector or even beyond. Further research might consequently focus on a wider range of NPOs in health care, increase the sample size and perform group interviews as well as conduct long-term studies to validate the functionality of the tool.

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Appendices

Appendix A: Initial Contact Template

Hello,

I hope this email finds you well. I would like to briefly present myself and the reason I am reaching out to you.

My name is Sonja Wickel, I am a student from the Nova School of Business and Economics in Lisbon, Portugal and I am currently writing my Master Thesis. Originally, I am from Germany but decided to complete my master's degree in Management abroad. Instead of focusing purely on management related themes I intended to combine psychology and management by examining social business in the health industry specialized on eating disorders.

I suffered myself for years from an eating disorder, therefore it is very much a matter of heart to contribute to raising awareness in our society. With my thesis I would like to examine what tensions social organizations (including charities or other social institutions) face while raising awareness for eating disorders and how to overcome those tensions by means of a paradoxical approach.

While searching for organizations worldwide the web presence and activities of your organization caught my attention. Therefore, I kindly ask you to participate in my international study, for which I would like to interview you. The interview will take approximately 30 min and all information that you provide will be treated confidentially.

My supervisor Anibal Lopez recommended me to complete all interviews as soon as possible, therefore I would appreciate if we can arrange a meeting in the near future.

I am looking forward to your reply.
All the best from Ericeira,
Sonja

Appendix B: Confidentiality Agreement



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 856688



European Forum on Paradox and Pluralism

Nova SBE Twinning Project

Informed consent: If you take part in this study, I will record our interview and use its content for research and publishing purposes only. The audio track will then be transcribed and stored safely. The interview transcripts can only be accessed by authorized Nova School of Business and Economics research staff. At the end of the process you will receive a copy of the research results.

Confidentiality Statement

1. I confirm that I have read and have understood the information about the study (please see the document 'interview protocol'). I have had the opportunity to consider the information, ask questions and have had these answered satisfactorily.
2. I understand and agree that my participation will be audio or video recorded and I am aware of and consent to your use of these recordings for the following purposes: Transcribing and analyzing the provided content.
3. I understand that my participation is voluntary and that I am free to stop taking part and can withdraw from the study at any time without giving any reason and without my rights being affected.
4. I understand that I am free to decline to answer any particular question or questions.
5. I understand that I can ask for access to the information I provide, and I can request the destruction of that information if I wish at any time prior to anonymization.
6. I understand that signed consent forms and original audio/video recordings will be retained on the researchers computer until 30/06/2021.
7. I understand that my responses will be kept strictly confidential and in line with data protection requirements at the Nova School of Business and Economics. I give permission for members of the research team to have access to my fully anonymized responses. I understand that my name will not be linked with the research materials, and I will not be identified or identifiable in the report or reports that result from the research.
8. I understand that confidentiality and anonymity will be maintained, and it will not be possible to identify me in any publications
9. I agree to take part in the above study.

Participant Name:

Date:

Signature:



This project has received funding from the European Union's Horizon 2020 research and innovation programme under grant agreement No 856688

Appendix C: Interview Protocol

<i>Organization:</i>	<i>Date:</i>
<i>Type:</i>	<i>Country:</i>
<i>Interviewee:</i>	
<p><i>Information about the research:</i></p> <p>This interview is part of my master thesis. My interest is to understand which tensions social healthcare businesses face while raising awareness for eating disorders and how to overcome those tensions.</p> <p>Tensions are defined as contradictory yet interrelated elements that exist simultaneously and persist over time.</p> <p>Examples: collaboration-control, cooperative-competitive, flexibility-efficiency, individual-collective, profit-social responsibility</p> <p>Tensions between various aspects seem logical in isolation but absurd and irrational when appearing simultaneously.</p> <p>Examples: Managers want to stimulate individual and autonomous performance from their employees; however, they also expect that their employees work as a team. Asking for those behaviors in isolation seems logical, while asking simultaneously seems contradictory and irrational.</p>	
<p><i>For further questions you can get in contact with:</i></p> <p>Sonja Wickel 43475@novasbe.pt +4917647969922</p> <p>Supervisor: Anibal Lopez anibal.lopez@novasbe.pt</p>	
<p><i>Question 1:</i></p> <p>Please introduce yourself and your function within the organization and give me a brief overview of the organizations' activities to raise awareness for eating disorders.</p>	
<p><i>Question 2:</i></p> <p>Based on the definition of tensions (mentioned above), what are the most significant tensions within your organization? Please think about upsides, also called values and downsides, also called fears of each pole of the tension.</p>	
<p><i>Question 3:</i></p> <p>Based on the tensions you have mentioned before, how do you handle those tensions? What is your approach and why?</p>	

<p><i>Question 4:</i></p> <p>How do you recognize tensions? Do you have a specific system or strategy for the recognition of tensions?</p>

Appendix D: Professions of the Participants

Profession	# Professions
Donor Relations Manager	1
Training Education Coordinator	1
Communications Officer	1
CEO	1
Founder Member	1
Senior Director of programs	1
Newsletter coordinator and special project lead	1
Executive Director	1
Chief Officer	1
Program and Outreach Coordinator	1

Appendix E: Transcripts with highlighted Passages

- Financial sustainability – social responsibility
- Individual - Collective
- Cooperation - Competition
- Traditional - Non-traditional
- Collaboration - Control
- Awareness - Society's understanding
- Clinicians - Non-clinicians
- Research Future - Research Status quo
- Productivity - Self-care
- Flexibility - Efficiency
- Responsive - Reactive
- Evidence-based support - Alternative support
- Research (future) – research (status quo)

Strategy – how to deal with tensions

Profession

Covid

Theory

Interviewer

Interviewee

Interview 1 – 16/02/2021

First of all, I want to thank you that you take the time to participate in my study and I thought it might be good to start with a brief introduction and after that we can already start if you do not have any further questions.

So, my name is Sonja I study at the moment in Portugal and I took some courses which were related to social businesses, due to that I realized that I am interested in researching in this area. Therefore, I applied for the master thesis in the field of social entrepreneurship. Additionally, as I wrote in my e-mail, I have been infected by an eating disorder and that is why it is so important to me or I feel the need to change something in our society. That's why I thought this would be an interesting topic for my master thesis, my supervisor Anibal Lopez have been convinced as well. Together we tried to figure out how to connect this topic with a research topic and my university is researching about paradoxes. Anibal suggested to me to interview different organization over the globe to figure out what kind of tensions those kinds of organizations have. And that is the reason why we are here today. I tried to explain it to you in the interview protocol I have sent to you. Tensions can be seen as yin and yang, so guess the best example for social organizations is actually that they on one hand want to follow a social mission and on the other that they want to stay profitable.

I guess that would be my brief introduction, if you have any questions so far please feel free to ask them otherwise, we could start with your part.

I am ready to start.

Ok, perfect, then I would kindly ask you to start to introduce yourself and your function within the organization and give me a brief overview of the organizations activities to raise awareness for eating disorders.

Yes, my name is xxx and I am the communications' officer for xxx, that is the eating disorder association of Ireland. I have been with the organizations since 2012 and in my role, I do various tasks like updating the website, making changes and manage all of our social media accounts as well. I work on various different projects, I work on online safety, I work with Facebook, Twitter and Instagram in relation to [...]and [...] disorders as well and I also speak to the media, do interviews on the radio, do interviews for print media, online media or podcasts as well. That is some parts I do and I am involved in different groups, so I recently joined, one called, there is a group called men's health Ireland, so they have a campaign every year to raise awareness for men's health and I am currently also the coordinator of xxx, it's called the [...] group and it is in relation to eating disorders in sport and also RED-S that relative energy deficiency in sports, which is the successor to, you might have heard the female athletes triad. So RED-S is the successor to more up to date [...] term for relative energy deficiency in sport. The simple explanation is, they are not feeling enough [...] their needs of their sporting performance under training, so they develop problems like stress fractures and [...], so there is a lot of mental health and physical consequences to that and currently part of a project with sport psychologists, sports [...] and ask with personal experience as well.

Okay, that sounds highly interesting, you are doing a lot. Okay, I think then we can already carry on with the next question, if you don't mind. Regarding to what you have just explained, what kind of tensions does the organization face? Can you imagine any tensions which challenges you?

*When people talk about awareness in Ireland, we don't have all of the services we need in the medical system for eating disorders. So, some people with personal experience would say we don't need awareness, we need services, we need special treatment. So, every year there is a campaign called Eating Disorders Awareness Week in the end of February or March and it is the same in the UK, so the challenge is to come up with new ideas and information each year and images and posters. So here is one, this is one from last year per example. There are different ones for each year. So, we try to do something different. We also have these here, these are more information and statistics. So, each year it's the try to come up with new ideas, because xxx is the ONLY national volunteer association in Ireland. Outside of the health system that has the focus for eating disorders. The tension I suppose is that we sometimes get criticism on social media, we don't need this, so I think it is important to say, there is a big information what I call it is an information gap regarding eating disorders. 200.000 studies have been published on depression, only 15.000 has been published on eating disorders. **There is a big gap, we just don't know a lot of the field and that effects everything we do, it effects the front line, it effects research, also treatment can be made available.** That is one aspect and then less than one percent of all eating disorder research has been made on men, there are no medical guidelines for men with eating disorders. So, when people criticize awareness, there are other things, we know there is a relationship between eating disorders and autism for example and in the UK they say its [...], so [...] woman with an eating disorder may also be autistic. So, when I hear criticism of awareness week, yes I do think it is valid and people are welcome to criticizes us, but it is also by addressing some things that people don't know and whenever I go on the radio, well I think it is really important: You have to humanize the illness, as well, I feel that is part of my job. I cannot talk just about signs and symptoms; I don't think that is very interesting. I have to put a kind of human frame around what it is like, and that is what I am trying to do while speaking on the radio.*

Ok, that is definitely a point, so you mean one of the tensions is that people criticize awareness, so it is kind of an external tension?

Yes, people come up to our Twitter page, or in Facebook and that kind of thing.

Ok, and if they go on the webpage or Twitter and post something negatively, how are you dealing with it? Do you have any system behind it?

*Sometimes I response, sometimes I don't. It depends, **we are in a very difficult position in one sense because we get funded by the health service so we cannot publicly criticize them, because that is where our funding comes from. We cannot get to in a public disbud because their fund our organization – that won't work.***

Ok, but does that mean that this is another tension, that it depends on your funders, would it be easier if you have other financial resources?

*Most of our funding comes from the health service, **you might know yourself from your own experience, that public sympathy is not generally on the side of eating disorders,** people will fundraise for other things, like suicide prevention and those kinds of things. **People who don't have a personal connection to eating disorders still see it as a lifestyle choice unfortunately.** That's not say we don't get people who do fundraise, we do get people doing runs and walks. There is one man he is doing a trip across the United States in September, he is travelling coast to coast and he is cycling. **Lot of people come to us with fundraising ideas, they have enough***

personal experience. Just to give you the bigger picture, in Ireland we unfortunately have been funding difficulties within the whole eating disorder program in Ireland, so between 2018, 2019 and 2020 the funding was not used, ours was diverted in another service to make up a gap in another service. That is public record, it is in the news, privately that has been a great disappointment to us. But I can't go to the radio and say this is completely wrong I have to say 2021 is looking better, they have committed that they will fund us and **the problem is when there is no funding is they can't recruit staff, it slows everything down.** What they did in 2018, they launched it is called the clinical program and it is designed to create 16 teams, meaning 8 teams [...] lessons and 8 for adults in different places in Ireland, who have all the specialized skills for eating disorders. So, there are only three teams now and they haven't moved since the funding was not available. Unfortunately, there are people in Ireland they have to be sent over the country to get treatment, because there are so unwell, sometimes they have to go to the UK. That is highly difficult for the person and also for their parents as well.

Of course. Ok, just to clarify. A second tension would be the funding. Because you said, if you don't get the funding it is really hard to get the resources and you have instead of 16 teams only three. And therefore, it is quite hard to raise awareness and provide support in the whole country.

Yes, I can send the link about the funding, I guess that will help. If you want?

Yes please, that would be great. And about geographical situation, that is also an issue? So is there is no space for treatment available they have to go even to the UK. Wow, okay, I expected actually that the funding would be easier – but it is not.

It is politics unfortunately, I think the tension for me is that the people who make the big decisions in funding, they are never named, there is no accountability. They never go on the radio to defend us. So, it is a little hidden and very disappointing. But I think 2021 is looking better because they know there has been such an increase with the pandemic, as you probably know. **There has been a big increase due to the pandemic.**

Yes, I have read that a lot and also other organizations named that as a reason to not be able to do the interview with me, because the cases have risen so much that they don't find the time for it. That why I think now, it is even more important than ever to change something.

As I told you I am from Germany and of course I checked also there for organizations which work in the field of eating disorders and I found only a few organizations. I think all countries have the issue, that on eating disorders is not the focus yet.

You mentioned so far three tensions, do you have something different in mind, what effects your organization?

Yea, **I guess the funding is probably the hardest.**

Okay, understandable. What did you do regarding this, did you maybe contact other organizations in other countries to figure out how they deal with this issue?

So, what we can do is to contact the parliament, the politicians to ask questions on the record. So, here there are called parliament questions and then a member of the opposition party will then generally will ask a question. Someone ask the question the other day from the social democrats, where is the funding and that puts it on public record. Sometimes there is an answer, sometimes there is not. Sometimes the answer gets referred back to the health service. Sometimes the minister of health will answer, I will send you the links. So, you might see.

Yes, that would be great, but I can imagine that must be quite frustrating, since you aim to help and to change something in society and then there is no help from the parliament. But since you said that the funding comes mainly from the public/from the parliament, have you tried to find

other resources for funding? Do your events to raise awareness help to find investors, like private investors? Or is it difficult to find?

That is very hard with commercial companies or those kinds of things. Sometimes unfortunately we do get notice that someone had died from an eating disorder and then money is donated by their family to us, which is very generous and thoughtful, and it happened a couple of times over the years so that, it is very hard to imagine to what it is to be like to be grieving to make a donation to an organization who works in that area. We have to be very gentle with those kinds of situations.

Sure, I can imagine. But I am a bit surprised, since you said, that it doesn't happen that you get funded by them. Because I think also employees who work for those companies can get affected by eating disorders, since it can also influence also different kind of mental health issues. So, I was expecting that they would like to support prevention in this field.

I think it is really hard, I think you know the stigma. Even sometimes when I have been to conferences and people asked me where I work, they will say things that aren't correct. There are a lot of stereotypes and kind of misconceptions about eating disorders.

I am just checking my notes, yea I think that's it. Just to sum up, you think that the main tension is the funding and the other one would be related to the awareness criticism.

And the other thing that comes up sometimes is, hospital beds. So, the number of hospital beds in Ireland is very low and that leads to a lot of criticism as well. So, that robs of [...] sometimes on my organization, it is mostly a criticism of the health system service. When people are in need to go for an impatient hospital that there are enough specialized eating disorders beds in Ireland.

Okay, I understand, but are you also trying to provide more beds, do you discuss with hospital the number of available beds. Is that a responsibility of your organization?

So, at the moment the new children's hospital is being build, there should be more eating disorder beds in that new children's hospital. Back to what I was saying earlier about the program, they launched in 2018, is that they want to get a situation where eventually they want not as many people will be so thick, there will not be a huge need for bed, but that people can be treated sooner. So, that they don't become pass sick that they need the beds. It's called, what they say is a stepped model of care, level 1 that your gp, general practitioner, your family doctor and then patients are treated on an outpatient basis, day-hospital or day retreatments and then all the way up to impatient. So, if people are treated earlier in the stepped model of care then that reduces the need of beds. This is all in theory kind of on paper, that is what they would like to see, people are not getting so chronically ill, that there get so sick that they need an impatient bed. More beds would be welcoming certainly.

Regarding the stepped model of care, the first step is to see their family doctors. I was reading a lot about the issues that professionals as the gp's are not very well aware of eating disorders. So sometimes they don't even see the symptoms, but even when they see them, that they don't do the correct treatment.

I guess people have very mixed experiences, some very good doctors or gp's some have so little training and make very offensive comments to people in their clinic. That is something you will see and I see it sometimes on social media as well, people have gotten to their gp and then the gp has not been very helpful and equally seen the opposite the gp, those have empathy, those have kindness and doesn't judge. We would call it, the clinical group, so pharmacists need training, dentists need training, we have worked with college of gps here, we have worked with pharmacies regularly and the dentists association. They still need, I think people who are

medical students who need specific medical training for what to do and what to look out for when someone comes to their gp practice with a possible eating disorder.

So, do I understand correctly, that some of the professionals are already more open to those kinds of trainings? That they realize the need for the additional education, and some are blocking points?

I think they all want, and they are all interested.

Ah, okay, they are.

Their representors or their staff, where we see people with bad practices, that they don't have a lot of training, therefore they make those offensive comments and it leads to a bad appointment for that person.

So that leads again to the tension of the missing resources, if there would be more recourses available, there would be more training and would increase the impact. So, the lack of people. *I don't have a source for that, but when I first started, I was told, that gps get only have an hour of training. I can't tell where that is coming from, I hope that is still not true, but it is very little time obviously for any medical student to guess (27.57) an eating disorder. I attended the [...], so they had a conference in January and their team are doing training the UK with gps and medical students. The gp logs in, it's kind of a role play situation and they are giving training on how to approach patients with an eating disorder. So that it is really important.*

Yes, that is true. Okay, I guess I don't have any further questions so far, but in case I do have some while listening to the record, would it be ok to get in contact with you again?

Yes, absolutely.

Thank you, that is kind of you. And also, could you please send me the pages you have mentioned before, that would be helpful.

Yes, for sure.

Perfect, then have a good day and thank you very much.

Thank you, bye bye.

Interview 2 – 18/02/2021

Thanks for being here today.

Yea of course, thanks for reaching out that is so cool for being involved in an international project.

Yes, thank you. So, I thought I give you a short introduction on how I would like to structure the interview, I would start to introduce myself and the purpose of my research, after that I would explain the theory of paradoxes / tensions and after that it would be your turn and go through the questions I have prepared. Would that be fine for you?

Yes.

Perfect.

[Introduction]

I would like to ask you to introduce yourself, the function in the organization and the organizational activities to raise awareness. That would be great.

Yes, perfect. I am xxx and I am a social worker; my title is program and outreach coordinator at xxx. So, I have been working there for almost 2 and ½ years and I was actually a volunteer before then, so I am involved since 2015 for the organization.

So, xxx is a community mental health charity or also non-profit and we provide group-based support for people with eating disorders and disordered eating, as well as family friends and loved ones of people with eating disorders. So, we don't do treatment or individual therapy, so everything we offer is group based and we have many different types of groups we provide. There are five main categories, like general support groups and we have many different types, so some are really open, some are demographic specific, for people with Bing eating disorder or half a people who identifies trends [...], half identifies [...], people of colour. So, we have quite different support groups in that category, we also have expressive arts groups, body image groups, skill building groups and nutrition groups. I mean of course there are some overlaps between them, but there are generally in those categorize. We are offering everything online right now, because of the pandemic, but before we were running all in person out of an old house, which was converted kind of into an organization. It is not very big, we have 7 full time staff and then other mental health professionals, who are hire on contract to run those groups. So, they come in an do their groups weekly, we also do. So, my role as a social worker I run some of those groups and then I also do our outreach and education. So, that involves workshops and trainings and presentations for various community groups, so could be like high school students or university or college students or like medical teams, mental health professionals. Kind of either to learn, so for like younger people it would be about body image and developing a healthy relationship with food. And then for people who are more helping or caring professions how to support people, who may have eating disorders or disordered eating, since it is an area where I am sure you know where not a lot of people will know a lot about. Yea so, we try to raise awareness and reduce stigma through region education as well. So those are the main things we do and that I do in the organization.

Okay, thank you, that sounds highly interesting and it is a lot what you are doing. Yea, I think based on that we can already go to the next question, because this is where I would like to focus on. So, based on what you told me do you have any tensions in mind?

So, I have a couple of ideas and I hope these are what you had in mind. So, I should just mention before that we offer everything for free, so there are no costs associated and we don't require diagnoses or referral of people who access this service. So, this will be relevant in what I share next.

The first tension is around like if it's a term you are familiar with, but the non-profit industrial complex. So, there is that idea. So, in Canada although our health care system is public and run by the government, so, we get free healthcare however it is very limited in a lot of ways. So, for example that eating disorders retreatment programs, they exist in the hospitals, which are funded by the government, however there are very, very few spaces or beds for people to get treatment and so the waitlists are really, really long. A lot of people will never even qualify for treatment, because they don't meet the criteria and so a lot of people have to go and get private treatment and pay a huge amount of money for that. Essentially, we at xxx we don't get government funding, we rely totally on private donations from a lot of cooperation's and companies. So, this is this kind of tension where I think it is really specific to eating disorders as well, you know where a lot of things like the privatization of health care or diet culture or phagophobia, racism, sexism, all these things are kind of [...] in a sense by a lot of big cooperation's, which files eating disorders in a lot of ways. However, we rely on those cooperation's to give us money to run our programs. Does that make sense, I am feeling that I am not making a lot of sense?

No, no, not at all it makes sense.

So, like specifically to look at diet industry for example, that is a million-dollar industry and it is not responsible for eating disorders, but it definitely fuels or [...] eating disorders or disordered eating for so many people. Not that we would directly take money from a diet company, you know for a program, **but it is still complicated that so many things like diet culture and sexism or racism or transphobia or those things upheld by capitalism in a sense. And we also rely on capitalism to fund our programs.** So, there is kind of the weird tension, like where do we, like we have to accept money from people in order to provide support, **but who are we going to accept money from. So, yea, that feels like a tension in eating disorder field and also mental health merger.**

Yea definitely, it is super interesting. Because I was, before I started with the interviews, I was also thinking about tensions, what could affect the companies, but about this tension I haven't even thought about it. It makes sense. But do you have, or did you find a way to overcome this tension? Did you try to reach out to different companies or the government?

Yea I mean it is an ongoing process, **we have applied for government funding, many times, but it is really competitive, and it is really hard to get it.** We got a little bit of Covid relief kind of money from the government, but other than that we haven't received money from them in a long time. We also, like I said, we don't approach companies that would be very obviously accoutering our values, so we get a lot of money from telecom companies and things that are more unrelated to food and eating and eating disorders, but still like it is not perfect. We also typically the money we get is unrestricted most of the time, which means that we can use the money that we get in any way that we want, which is great, because then **we are not limited to what the company or the donor wants us to use the money for in their values. We can say even if this company has racist hiring practices, or they [...] sexism, we can use that money to implement a support group for people of colour with eating disorders.** So, we have a lot of freedom with how we can use the money to work with in line with our values, which helps to address that. Also, we do a lot of advocacy as well, we partner with other organization and acuity to the government for more recognition of eating disorders as serious as a health challenges, so that they can get more support. It is a different awareness and advocacy efforts as well.

Okay thank you, I have one more question, because you mentioned you do also workshop's in schools and universities. But I am not sure, how it is in Canada actually if it's all private.

Because for us, in Germany, the schools are mainly public and also the universities and then I would imagine if you do workshop's for public institutions that you get some money from them? Or do you provide this service also for free?

That is a good question, so we ask first for donation in exchange for the presentations, but it is not a main source where we get our money, it is like a little nice amount of money that comes in, but it is more for them to acknowledge that we are doing this and not as a fee for a service kind of exchange. And universities here are interesting, they are public but people, it is like a weird combination, so the government subsidizes most universities, but people still have to pay more than they actually would need to go to university. So, it is not as bad as the US, like it is a lot cheaper, but it is still a combination. And then high schools are both, they are public schools and private schools. So, we have gone to both.

Okay, cool thank you. I guess I will think about further questions, but for now I am good. But you mentioned you thought about several tensions. Can we speak about another one?

*There is one more, that I thought of. So, this is more related to the actual groups that we provide and the type of support we provide. So, there is this tension kind of in the mental health world of implementing **evidence-based** practices. So, hiring people with specific degrees to run specific programs that have research and evidence in support of them. It is like different therapy modalities, cognitive behavior therapy, dialect behavior theory, so these things that are very popular and **evidence based and on the other hand there is a lot of value in the more alternative healing methods as well**, like the arts for example and so balancing, like we are always asking our, the people who are accessing our services, asking them what do you want, what kind of groups do you want, what would be helpful for you, because for the people who are going through eating disorders are, oh and people always say it, arts groups, body-awareness and things that are more alternative and less evidenced based as well. So, trying to balance a sort of like, **bring in experts and people with degrees and credentials to run these programs and also feeding the needs of the people who are living with eating disorders, valuing their lived experiences and not just what's the experts say we need to do.** Does that make sense?*

It does make sense and that's why you also provide different kind of groups, right? Because you mentioned in the beginning all the different types of the groups. It seems like you try to cover both sides, so you are trying to balance this tension within your organization.

Yes, exactly, we try to do BOTH and that also ties into funding and money, because donors want to see that you are doing things that are evidence-based and there is VALUE IN BOTH. So, we try to bring in both when we can. So, there is also from what we are looking at, which group [...] is higher. Like people who have the highest degrees are often let's say white, or people who are like heterosexual because of the discrepancies in getting those degrees and getting access to those things. If we want to make sure that we hiring in an accurate way, we obviously want to pick people who have the most experience and the most degrees, but also, we want to make sure that we are hiring like a diverse group of people. So that is related as well, but yes, we try to do both.

Okay, but when you hire people does it also happen that you hire people who suffered by eating disorders? Because I heard as well that this can sometimes raise problems within the organization. Because you and also themselves do not know if they/them can handle it to work in that field?

*Yea, that is actually a tension as well. We do hire people who have experience, we don't ask people to disclose that. So, after we hire people they might say, oh yea I had an eating disorder, but we are not allowed to ask them when hiring them. Something we do when we bring on students, like to do their students placements we say: **We are not asking you to disclose your***

mental health history, but we do need to make sure that you have the appropriate supports in place. So, can you tell us if you have the appropriate mental health supports in place and we also say, again we not asking you to share anything about yourself, but we do need our stuff, students have been in recovering from an eating disorder for at least a year for working for the organization. So, can you confirm for us that this is the case. And if they say no, then we will have a conversation about that. So, we do kind of ask that, but it is subjective what recovery even means. We have had situations where we hired people where they started working, students have had started working and they have been like: You know what that is too much. I thought I was ready, but I am not, so I going to step back.

Okay, but I can imagine that it must be hard, also that it takes time to find appropriate people and also to hire again and again.

Yes, it is.

But I need to go back for one more question to the research topic. Because I was also checking the comparison between research which was done in the field of eating disorders and research, which was done for depression. So, you mentioned before, that you tried to implement your service based on evidence and research, but do you try to push forward research, since you said you cooperating with universities? Does there exists a program in order to extend the research to find better ways to raise awareness or also treatment?

So, in the past we have done a little bit of research or supporting people who are doing research, but in the last three years we haven't, simply because of capacity. So, because we do not have so many people, you know no professors or universities are running a study, we recruit people, put up the posters and send out the information to the people who participate, but we haven't been directly involved for research for a while. Because, like you said, there are so little research about eating disorders and of the research that exists it is mostly about young, white woman. So, that is the main sample of all the research, however as we know eating disorders affect all types of people and so we really don't have much information about eating disorders among man or nonbinary people, or people of different races or ages even. So, that is also another WEIRED TENSION where we use the research, but the research doesn't apply to so many people with eating disorders.

Exactly, I think that is also one of the main problems. And related also to that, because you mentioned that you do workshop at school and universities, do you have a system to measure your impact. So, how do you know that you are going in the right direction with these workshops, do you get feedback? How do you know when change is needed, that would be also interesting for me to know.

Yes, we do collect that information, all of our groups are 10 weeks long and so at the end of the 10 weeks we ask people to complete a survey that is anonymous. So, they can share their, there are a lot of different matrixes on it not so much related to their eating disorders symptoms, but more around, did you feel supported in this group, did you feel connected to other people, like did you learn new skills. So, kind of proxy measures how their eating disorder is and then also qualified feedback, what did you like about the group, what could be improved. And then more generally, like programs do you want to see more of at xxx, so we always collect that information and simultaneously with the outreach presentation collect information around what was helpful, what did you learn, what could be improved. The problem with that is that we are not capturing the people who didn't make it to the end of the 10-week group, or who didn't make it to send end of the workshop. Cause it is a little bit biased as if people stayed to the end of the 10-week group, they probably like it enough. So, that is always an issue with collecting data as well.

Ah okay, but does it happen a lot, if I may ask that, that people drop out earlier?

Yea, it is pretty common, we have done some attrition surveys in the past, just to try to get a sense of why people only came to one or two groups. So, why didn't you coming back and often what people will say, the most popular reasons are mood and anxiety, so, because depression and anxiety is so common with eating disorders. People are often just not feeling up to it, they are too anxious, not ready and also like scheduling conflicts and changes. They maybe signed up, but then something else came up, so they couldn't come. Some other people would say, oh I just went, and I was not ready to talk to other people. So, I felt triggered. So, we try, but it is hard to collect that information.

Yea, I can imagine. Okay so, half an hour is almost over. I was wondering, since I already had some interviews and while transcribing them, I figured out that I have sometimes further, more in deep questions. Would it be possible to reach out to you again via e-mail, in case I have some further questions? That would be very helpful.

Yes definitely.

Okay, cool! Do you have any questions?

I don't think so. I think this is a very interesting conversation, normally when people, we often get students asking me, but it is not usually for a master thesis or a specific big project like this, it is more an information interview. So, this is really interesting, and I appreciate how unique it was. So, I hope your thesis goes well and that you get all the information you need.

Thank you so much, I hope so too. If you want, I can share my work when it is finished, so you can have a look at it.

Yea, definitely. Love that.

I have one last question, can you recommend me any other organization who are working in the field of eating disorders, that I could interview as well?

Yea, I know a few, would it be helpful if I send them through an e-mail?

Perfect, that would be great!

Yea, I have lots of lists of that. So, I can easily just send them over.

Nice, then thank you so much for your time. It was super interesting.

Yea, it was really nice to meet you. Good luck and please follow up if you need any further information.

Perfect, thank you so much. Have a good day.

Bye.

Interview 3 – 01/03/2021

[...]

First of all, thank you for taking the time I really appreciate that.

Of course, I hope I am able answer this, because I am not sure if I am the right person for you, but we give it a go and see what happens.

Exactly, I think it will be perfectly fine.

First of all, I would like to give you a brief overview about how I would like to structure the interview. I would start to briefly introduce myself, I already did it in my e-mails, but just to give you a brief overview. After that I would like to speak about paradoxes or tensions, just to make clear that we are on the same page.

Exactly, that would be good, because I am not sure I got a grasp of it, but let's see.

Okay, perfect and then I think we can start already with your part, that you introduce yourself and your function and the other questions I have prepared before. Is that ok for you?

Yea, yea. Fine.

[...]

Do you have any questions?, please feel free to ask them.

*No no, I think I understood it a bit better, I mean hopefully I will be able to contribute. We are talking about social organizations and charities, you know the funding tension is always there. If we don't have any funding, the organization is not there. So, we are more a mental health charity, we are funded, we get a grant by the department of health care and then we have to find the other funder by ourselves, make ourselves independent, that we are not dependent on the government. The other tension is that, you know for us as a mental health charity and most of us, in fact all of us had some experience with an eating disorder, me as a carer and most of us as workers or part timeworkers have had personal experience. We are not qualified in any way to practice counselling or anything of that. **A tension was, and is still be there, is that the professional's services for mental health is against the charities.** There is a kind of tension there, the professionals would say: **They don't have any qualifications, so I guess that counts for every kind of charity, that there is a tension between the professional's and the peer support and the people with personal experience who have created charities. That is one of the biggest tensions for us.***

Yes, I can imagine that. Can you think about any other tension or can you think about the tension you have just explained; can you name me upsides and downsides for those tensions?

*Yes, downside that is, once you have recognized that there is a tension there. I have occasion to make with them you could say that then they could ask my opinion on things, they talked amongst themselves, you know the psychologist or therapists or the mental health nurses – they look them out. The upside is you find somebody in that group, you get to know and you make your best to get to know them and over time if you continue with the work, because we began in 1992, so we have been there for a very, very long time. **So, there is a certain amount of respect that comes in, a little bit.** And we also have a position, if a family is struggling, that we have contact to the professionals we can follow [...]. So, it enables us as an organization for families that are struggling with young people with eating disorders. They have to work to get to that.*

Okay, when you said, once you recognize the tensions, so what is your way of getting aware of those tensions? Do you have any system?

Well In my case it just came up, because eating disorders doesn't have any services when I began. There was no special service, so we were starting from the beginning and I realized the tension that was there [loss of connection], the health nurses, professionals and then me form the eating disorder association. **I kind of get a sense you know they were there and they didn't include me in the discussions. I had to make my own way into the discussions and that's how I realized from the very beginning, that there was some work to be done by us, as a volunteer organization and trying to earn the respect of those people in the community.** I would say Sonja, **that this tension is still be there, not as much, but there would be still people in the health service, who wonder who are those people where do they come from.** But because we are groundage by the department of health, they give us help with our funding, that gives us a bit of [...] as well, and that they **recognize if the department of health give them groundage, they must be ??, they must be ok.** But it is still be there.

When you mentioned the funding, you are not only funded by the health department?

Yes, we have to look for other grands, maybe for a particular project. We have to go to the xxx bank, who do very good work here in Northern Ireland, various charities they found. So like other charities, we would have quite a lot of money to top of some money that we get from the department of health and it is difficult because all kind of charities are doing good work and eating disorders is, and it surprised me when you mentioned how it is in Germany, but in northern Ireland it is quite open and as an organisation we have done our repack to do that, so eating disorders it is very much talked in northern Ireland. But having said that it is still, the numbers of woman and man are growing, it is still a very small number and the other thing is, that there isn't enough research, because of the small numbers and the specialist area of mental health and there is not enough interest in picking it up.

So, when we come to get to deploy the xxx bank, for a grant, the decisions would be made by business people and money people and obviously the people who are employed there, there wouldn't be a lot of people in there who experienced by themselves an eating disorder. When they making a decision, they making them on what they have heard on the news or related to depression or other mental illnesses or those kinds of circumstances you can be sure, there would be a few people with absolutely no difficulties with mental health issues in the family, but if, it affects the whole family.

So, eating disorders is, there is a big struggle to get funding for what we do and I think the cause of that is the lack of understanding that it is a physical and a mental illness. So yes, the mental illness, it is hard for the recovery but also, going alongside that someone who is restricting or someone who makes themselves ill, that they are doing themselves some serious physical damage as well. So, dealing with a child and their families, we have seen a lot more families since the lockdown. I think the lockdown is triggering and these families are [...] They watching their son or daughter just not eating and they say, I know that since I had the own experience with my daughter, they start to panic and think my child to die here. And you can't say, oh no she / he won't, you now have to find a way of saying she will find some help. I think there is a total lack of understanding by the absolute despair the families have when their children are not going to eat anymore. And sometimes, in the early days when I started, a parent would say, **well my daughter has bulimia, but I don't think it is as bad as anorexia, cause at least she is eating.** Although, she makes herself sick, and then you have to educate them, no, that bulimia can do more physical damage in a shorter time that can be live long problems and so there is and still is and even when we talk a lot especially next week during the eating disorder awareness week, we still have a long way to go, when it comes to funding and the trust and foundations.

In the south of Ireland, there is a foundation called xxx, they have interests what happen in the north and we are interested what happens in the south. They are very well founded by the health department, they don't have any fundraisings by themselves. It is good to see that side of Irelands recognizes the difficulties of fundraising and the wider trust for those organizations. We have special circumstance, since the people think there is not so many people affected.

But as you said, the number is raising, because of social media and the pandemic. Therefore, there need to be a focus on that topic. And it happened to me as well, when I told my family they didn't know much about this sickness. They had to do research about it. Compared to depression, it is a very well-known mental illness, everyone has heard or read about it and for eating disorders it is quite different.

*Yes, that's why it is so hard to get your head into something that is so pleasurable, you know everyone loves to eat and celebration are eating, like Christmas or a birth of child. It is, even when I am for quite a long time in this area, I wonder myself why they can't eat. It is hard to get your head, you know who can someone physical do that. The behaviour of people who just can't eat, it is just very hard to understand. So, everyone is like, why would anyone want to do that. So, it is a very interesting subject and I am glad you study it, because I think it needs more people to push it up in the agenda of the government. It has to be properly founded, that very poorly founded in the north of Ireland. You know there has been recently a woman elected as a mental health champion in Northern Ireland, her name is xxx and she is looking in all the mental health areas for Northern Ireland. And she, I saw the draft of a statement, that she wants to provide on the eating disorder awareness week, she was saying highly underfunded and under resourced. And what Northern Ireland needs is a regional service, but Northern Ireland has a regional service and whatever kind of investigation she is doing, she misdid there is actually a regional service for the north, east, south and west support teams for eating disorders. It is just they haven't got the resources and they are not working, it is not that there is any service, like when my daughter was ill. They do have the structure set up as a regional service, it is just, the government feeding the money that it needs. So, the number of psychologists, they could double the doctors, but they haven't got the funding. So, I find it interesting that a woman, who has been set up as a metal champion, that she obviously hasn't find anything that tells her: Oh yes, we do have a service, we just have to look at why it is not working properly. So, she has to change her [...], because if they see that, they will say, oh yes, we do have a service. You just say, we need to set up a service, but we do have a service. **She dismissed her request for help.***

But do charities have the opportunity to speak to this woman?

*Yes, that is exactly what I did, I haven't met her personally, but my colleague has. So, I contacted her immediately and said she needs to [...]. That might give them the excuse to dismiss that call for help, by saying she doesn't even know we have a service. What she should be saying is, that there may be a service, but it is obviously not working. It is not properly resourced, so more money needs to go into and more people need to be employed in that area of mental illness. Hopefully, she will do that. **I was just giving you that example, to show even someone who is totally involved in mental health in Northern Ireland has not really been paying attention to what is going on in eating disorder of mental health.***

Yes, that is shocking. Thank you that was a really good example. Unfortunately, we are coming to the end of this interview, but it has been so far highly interesting. Thank you so much.

The background of our organization you can find on our website, Sonja.

Yes, I will check your website again, thank you. But would it be possible, that you just quickly introduce yourself and your function within the company?

Yes, my name is xxx and my oldest daughter became very ill with anorexia in 1991, quite long time ago and she was only 17 and she became very, very ill, very quickly. And I couldn't even get her GP to recognize that she has a problem, because she was a serious runner at that time, so her doctor, just said she is doing too much exercise and so I couldn't, it was really a terrible year and I thought she was going to die. I got as much information as I could, I have some friends in America and read and researched and we battled through it. And I realized then when she started to recover, that families needed to be informed what is going on with eating disorder. Because their part of the recovery, they needed to know right away, what do I say what to say when they are sad. So, I started my support group of helping parents, but very quickly we got people disorders coming for help, and we had no other place to send them. We became quickly a charity who is helping people with eating disorders and their families. We have some great long-term volunteers.

Amazing story, very sad that you had to experience it, but I it is so nice to hear that people like you exist, that say okay hands-on, we have to change something.

Yes, I have quite a lot of information regarding this, I am happy to share that with you.

Wow, thank you so much, that would be amazing.

If I have more questions, since I will transcribe the interview, there might come up more questions, is it fine that I will contact you again?

Yes you have my number, that is my office number, but it transfer to my mobile. Just leave me a
message.

Perfect, thank you so much.

You welcome, take care.

Bye.

Interview 4 – 02/03/2021

I am good as well, I am excited it is rare that we get to do an interview that goes beyond the basic questions related to eating disorders.

That is great, I am also excited, for me it is highly interesting to interview the organisations. So, thank you so much you are helping me a lot with your participation. I think if you don't have any questions before, we can already start.

[Introduction]

Do you have any questions, or is it clear so far?

No, it is clear so far.

Okay perfect, then I would like to ask you to briefly introduce your organization, yourself and your function within the organization.

Sure, my name is xxx and I serve as our chief officer for xxx, what that means is I oversee and sit to improve and make better or more efficient, or policies or practices how we work. I also oversee all of our programming from our support services to our connection to clinical treatment and as well as our educational programming and again really looking over all of our purposes and how we operationalize how we systemize those things, so that we can create a bigger impact. We also still working really sustainably – ideally. So that is my role.

Okay, perfect, thank you so much. I think then we can already dive into the next question, could you find the time to brainstorm about any tension within your organization? And also mention, what upsides or downsides relate with this tension?

*Yes sure, I wrote down a few because I didn't want to forget. So, one, I think was listed as an example was **collaboration vs. competition**. You know what I think, it is really interesting that eating disorder, I don't know if inherently is the right word, but what we see a lot of times is folks who are struggling with eating disorders, **also struggle with these really competitive tendencies and the more one is struggling with that inner eating disorder voice, the more that competitive nature comes out** and it shows that with food and with relationships. It shows up with our behaviors, we are competing with our selves, right. And so, we are kind of up against that, while and as an organization we recognize, right it is important that some people are challenging that (07:49) true collaboration and relationship building and community building that we are able to heal from something like an eating disorder. But there is definitely a tension there, because when someone is struggling and the eating disorder voice is sort of on loud, that competitive piece is really hard to break free from and so that is definitely a tension. As far as what is the upside and the downside. I think the upside is that tension provides opportunity to learn and grow and go deeper what is recovery is all about anyways, it is about understanding our own interwork being and figuring out how to heal and involve through those. The downside is obviously that often makes recovery so hard and so long draw out process is that there is that inner battle at play often during the entire process.*

*So that was one of the tensions I wrote down, one of the others was, you know eating disorders are at least what I checked the mental illness with the second highest mortality rate. Since [...] addiction and so what often happens is folks end up in crisis, they are so deeply struggling their bodies are extremely compromised and there mental [...]is extremely compromised. So, to operate from as an organisation we **always want to be operating from a sustainability perspective and trying to again really centre working intentionally, creating the biggest impact possible we can with the resources we have and for us that means we need to slow down and we need to be responsive vs. reactive**. But the tension there is when someone is in crisis is **kind of in human nature to want to react really quickly trying to solve the problem**.*

Right and that is often one of the things, we are always working on trying to figure out how can we support this person or this group of people or this family who is struggling when we feel there is a sense of crisis and struggle, **but what we really need to move also intentionally and sustainably so that we are not burning ourselves out in the process and also that we are acting or responding from the most impactful place.** If that make sense.

Yes, it does.

Another one I think is we are continually playing with is the **individual vs. collective** and again **eating disorders are a very individualized experience or at least that is they show up in our culture in the United States and I think in many western cultures is that very individualized internalized experience and so the recovery process from we have seen and been a part of from most of our history has been really centred on helping individual, which on the surface on would argue it is not a bad thing. What we are learning more and more and really incorporate in our values in the ways that we work is shifting the centre of the needs of the collective, meaning zooming out and seeing and meeting the needs of the community at large. Knowing and trusting that we can do that is also good, helpful and beneficial for individuals.** But really shifting the priority there and that feels so hard, because in the States we are very individualistic society definitely compared to other cultures and **we kind of up against the culture norm.** As well as again that very individualistic experience, even when we have a digital course that people to learn more about eating disorders and how they can create change. So, a lot of times folks who take this course have their own experience with an eating disorder or even still in recovery. And a lot of times what we see or hear is I want to get myself better, so I can help others and we really trying and again on a surface it is not a bad thing, **we are trying to shift that lens view of I want to create change in the world, I want to heal this community from this struggles from this disease and we all need be better for that. Again, it is just a really hard shift serving, you know the opposite has been normalized in our culture.**

Yes, can I ask you one question related to that. For me it is interesting to know how did you recognize that you need to shift? How did you feel the need to change from the lens of an individual to a broader spectrum?

Yea that is a great question, I think part of it is just in our own learning within leadership in our organization and understanding from a more culture competent perspective. I think a big thing we are really working on, over the last three years, is again kind of a company that shift to the collective lens is looking at and helping other people to understand that eating disorders are often perpetuated or even creative by systemic forces, cultural forces. Yes, genetics plays a part, yes trauma plays a part, absolutely. The systems that we are live in or operate all takes a really big impact. So, something like phobophobia is a functional racism until blackness in particular. So, in our own learning as an organization, we really working to help other people understanding you know your fear of gaining weight is [...] actually an anti-blackness and we need to address that, right. It is really hard and really scary for a lot of people to dig into, cause it is hard internal work. **So, we have been realizing as we been under, like learning more about it and understanding more about how all of this is present, like inter connect and intersect with eating disorders.** The need to help people to step out of their own individual experience is greater because of if you are a white person, you not going to understand from the receiving and enter blackness, you know from your own experience. We can subsidize it we can emphasize it, we can shift our behaviours and our attitudes around it, but we will never have that experience. **So, from that simply, I have to approach it more from that collective standpoint, because that is not my own individual experience. Part of it, it is just the evolution of your own understanding in our desire to help other people to understand that eating**

disorders are often perpetuated by these cultural systems and so if we want to change those systems we have to take a different approach. Because most of the time, I mean if we look at the eating disorder population again in the states a least often that we see represented is mostly thing white middle to upper class people who receive treatment. That is our reflection of our own inequities and sub broken systems around healthcare and beyond, right. And so really again wanting to change, not even the make-up population, but just how that population is understood, because it is not representative. The way the eating disorder population is represented is not represented of the actual people who struggle. I feel that I really wanting to help people understand from this more culturally informed lens. I think kind of a long the way we found ourselves trying change to a more collective lens.

Okay, thank you so much for this explanation. I have one more question, because you have said that people come to you, they would like to help. Those people were them most of the time also effected by an eating disorder? Can that also become a tension within your organization?

*Yes, I would say that is a great point and I would say yes, most people who say I would like to volunteer, they have either struggled individually or had daughter partner, somebody really close to them in their lives who struggled. So, they want to learn how they can be a better support person or create change. Specifically someone has struggled or currently is still struggling with an eating disorder, it can be really tricky, because often times when we are struggling we don't realize we also projecting onto others, **we potentially triggering others by sharing too much of our own experiences or own behaviours** and I think what is hard you know we act through stories and shared experience and you know when we struggle arguable we want to share that with others too, that is a part of healing. And that is why support groups basis can be so helpful because we can have a community who also kind of get it, **from the lens of educate others or spread awareness it can become a little bit, I don't know if dangerous is the right word, unsafe maybe, because if someone hasn't worked through all of their own healing and arguably there is no finish line. The work is never done, when someone is really early on in that process, they often don't recognize the things that they are still struggling with and that those trigger for somebody else. It can be just really harmful for somebody else to hear and so again I think we can tie that back to shift that a little bit from that individualistic to that collective experience.** It is really helpful when someone is approaching, you know wanting to spread awareness, wanting to educate and get involved from that collective lens because then they kind of stripping back their own individual experience a little bit away from showing up in that space.*

Okay thank you, do you have other tension in mind?

I think that was it, I think I covered all of it.

No, it is already a lot actually, so thank you! But can I ask you a few more questions about what you have just mentioned?

Sure.

Is the sustainability tension you have mentioned early related to funding as well?

*Yes, I think from two perspectives, so one funding and just resources in general. Right, like we are a non-profit, so funding is limited and we always **trying to think of how we can we make the biggest impact with the funding we receive** and then the other piece we that really value keeping a pulse on and checking in with as an organization is that understanding that to do this work with folks who are struggling on a regular basis to also be so deeply invested in understanding to working to this mental system of oppression that is really hard work. And it can take its whole and often leads to burn out and so really wanting to help our team and our staff work from a more grounded and centred space, so that they are not just like at a 120% all*

the time and end up feeling really burned out. That is something I think in our field, in the health care field and social justice work in general it is really common is that we care so much, that we put our whole hearts into it and then we end up forgetting to think about ourselves on the way. And that is also part of the sustainability piece. To figure out, how do we do this work to keep doing this work for the long run.

That is super interesting, I haven't heard this perspective yet and I haven't thought about it by myself. So that is really interesting. Okay so that was one part and the second part.

Oh, sorry that was that two, so the funding and then the personal burn out.

Regarding the funding, are you funded mainly by the government or mainly from private donors?

So, a little bit of lots of different places, we are funded in part by our café which is our social enterprise, this are funds about 20ish. It used to be more before Covid happened, so right know its support 20% of our budget annually. We are supported by government grants, probably 10 to 15% our budget is made up by that. It changes a little every year, but private grants from foundations we probably get 20% from our funding from them, probably 15-20% from private donations from individuals and then the rest is made up by fundraising efforts.

Okay, thank you. I will quickly go through my notes if I have more questions.

One more questions regarding the funding, since I was speaking to other organisations already they told me that they experience some tensions regarding their funds from which companies they receive the money. Because some companies might be active in the diet industry and then it can occur an ethical tension, does that happen to your organisation as well?

*Yea, my ego wants to know so badly who those organisations are, but I can guess. No, we do not accept funding from any kind of diet companies or something like that. I think one of the things we are really trying to bring light to and to do on [...] with our funding, even from like private donors. Is helping whether it is a great grant from a foundation or a donation from an individual is helping our people or audience understand our values and our politics. So that they know exactly where they are giving money to and if they don't feel they align with us. This is hard right, because we just trust them that we needed where we get that funding from doesn't mean we are operating on a shoestring budget – yes. **But I think you know for us to accept money from a company or an organisation that feels counteractive to our mission, just doesn't feel good.** And I think it would even limit us to do in education programming and awareness efforts. We don't want to be tied down to that.*

No, for sure. I think I have one last question. Does Covid impact your organisation, does it create tensions?

Quite a bit on the Café site, you know the food industry was hit so hard we have pretty strict restrictions, about how many people could be in the café at once, you know social distancing guidelines. All of that, and I think all of that was or is necessary to keep people safe. But it definitely impacted business, which means the amount the café is able to donate back to Ophelia's Place is impacted. Before Covid the café contributed about 45% of our budget, so now it is around 22%, we had to adopt and change our model a bit, we had to decrease our team size. So, it was definitely a big impact on the Ophelia's place, most of our programs have been already digital, so that was really helpful. We had to shift all of our support groups online and that we have found is working actually great and lots more people to join them. So, we just probably keep them virtual going forward. I think the biggest impact on Ophelia's Place, I mean we are an all-woman team and most of us are mothers, so that has been difficult with managing not having childcare and also working, so again it come back to the capacity of our team has felt a little bit limited, because of all of that life changing that came along with Covid.

Definitely, then I thank you even more, that you took the time for this interview. I guess it is very stressful at the moment. I think I don't have any more questions; do you have any questions for me?

No, I am grateful to get to play part of your research and I be looking forward, will this be shared when it is all published or

Yes definitely, I am happy to share my work as soon as it is done. Is it possible that I can get in contact again, if I have further questions after transcribing the interview?

Yes, sure.

Perfect thank you so much for your time.

Thank you, you too. Take care.

Interview 5 – 02/03/2021

Hello, how are you?

Good thank you, and you?

Doing okay, thank you.

Great, first of all thank you so much for participating in my study, it is really a pleasure for me – you help me a lot!

Absolutely, yes. So, I am excited to hear about your study and what I can do to help you.

Perfect, thank you. Then I would already start with how I would like to structure the interview. As you said, I will start by introducing myself very briefly and also the research topic and then I will dive a bit into the topic of paradoxes or also called tensions. Just to see, if we are on the same page. Yea and after that we can already start with your part, that you introduce yourself and the function you have within the organization and that we go through each question I have prepared before. Do you have any questions beforehand?

I don't think so.

Perfect. So, as you know my name is Sonja I study at the moment in Portugal and the last two semesters I had the opportunity to take different courses related to social businesses and positive organizations and I realized that I am highly interested in these topics. And as I also already mentioned in my e-mail I suffered by myself from an eating disorder for quite a long time and then I started to think about in what kind of direction I want to go with my master thesis. I think it might be similar in your country, but I started to do some research and I realized quite soon that it is not a topic where a focus is on and I think that needs to be changed. I started to research about your organization and other organizations around the globe and I think all of you are doing a really great job. Therefore, I applied for my master thesis by my supervisor Anibal Lopez, because he has a background in psychology and he also research a lot in the field of social enterprises. We tried to figure out how we can approach that and he suggested me to have a look into paradox theory, because our university is integrated in an so called impact lap, in which different organization, universities and people participate who research about paradoxes. And that is exactly what I would like to figure out about your organization.

To speak a bit about tensions, for me it was the easiest way to picture yin and yang. Both sides interrelate with each other, if one exists the other has to exist as well. One example I can give you is, that organisations strive to stay traditional and on the other hand try to become innovative to stay competitive. And also, just to give you another example, leaders aim that their employees are on one hand very good at working individually and on the other hand that they function quite good in a team.

Yea I think that is already everything from my side so far, do you have any questions?

I was curious who else are you interviewing for this project, are you interviewing anyone else?

Yes, I do. At the beginning of my project I was quite ambitious and thought it will be possible to interview around 20 organizations, but I quickly realized, and also my professor told me that it would be super if I can interview 10 organizations. I guess here you can see the experience difference. I interview organizations around the world, in Canada, in Australia, in the US, in Europe. And so far, I have interviewed 4 other organizations, but I found 10 organizations in total who are willing to participate. That makes me happy, even though I hope I can find a bit more than 10. Many organizations coming back to me and letting me know that they don't have enough resources and I have the feeling that my timing to get in contact was a bit bad, since it is the busiest time of the year and also regarding the awareness week. So, I think I was also a bit unlucky.

Yes, I think so, the awareness week last week was just a busy time, we had so many things going on. But I am happy to connect. Have you talked to any other United States based organization? Not yet.

Are you talking to any other?

Let me check. If you have any recommendations for me, which organization I could still contact, please let me know.

In the US I was also in contact with other organizations, but they are mainly from other countries.

That is great to hear, I am curious what kind of feedback you get from across the world. If it is different in different regions or different in different countries. I guess that would be interesting.

Yes, I have to admit that I was already surprised from the answers I have got so far, since each organization named different tensions, of course each named the tension related to funding, but besides that it varied.

Well, I am ready whenever you are.

Sure perfect, so I kindly ask you to present yourself and the function within your organization. *My name is xxx and I am the donor relations manager at xxx, we are a national organization based out of west beach Florida, but we serve folks all across the United States and actually across the world since now that we are offering virtual service.*

That is impressive. Okay, that was everything related to the first question?

So, yea as far as what the organization does do you want me to speak about that now.

Yes, that would be great.

Here at xxx we provide tangible assessable services for individuals who experiencing any kind of eating disorder, as well as their loved ones. I will tell you about several of our programs, so what we have. So, one of our programs is called Find ED help, it is the nation's largest and most comprehensive referral database. So, if folks need help finding treatment provide, if the need help finding any kind of eating disorder care, they are able to call our helpline, to go to our website or to download or app and we will help them find an eating disorder specialist clinician. We have free therapist support groups, we are the largest national organization to provide free therapist support groups. Currently we have 5 free weekly virtual groups, because of the pandemic we had to close all our in-person groups. So, we are meeting right now virtually, which is great because lots of folks from across the world has been able to join us. So, it's been existing and, in some way, the virtual space has allowed us to reach even more people. We also have education; our education is done by licensed therapists who are specialised in eating disorders and we do education to the in-specialist providers. So, there are all the other organizations out there, that are providing eating disorder specialist training to therapist to dietitians. We are helping those, that they are specialist, so anything from schools, talking to young children, doing presentation at the college and higher educational levels. Working with other providers, working with homeless populations or other organizations that serve women, organizations that serves women who has been victims by violence, so on and so forth. Because we know there is so much overlapping and intersection between different populations. We also do advocacy, we work with our elective officials at our national capital to expand eating disorder awareness to make sure that eating disorders are covered by health insurance, just insurance covers your physical health that should also covering your mental health. So, we are making sure that this gets done. So, yea, those are our main programs and main activities that we do.

That is really amazing! I am impressed, I think you are doing a lot. And especial those points, some people don't even think about that some people can't effort to get help and therefore I guess it is super good, that you also cover the topic with the health insurance. And also of course the educational part in order to raise awareness. Thank you!

Then I would say we can already dive into the second question and for me that is the most important one to speak about tensions. I don't know if you had already time to brainstorm a bit what kind of tensions do exist in your organization? And also, if there exist any down or upsides from those tensions?

Is that specifically within our organization only, or with our organization interacting with other organizations?

Both is fine.

Okay, yea based on the definition of tensions you provided I definitely thought a lot about that. I am going to go through them one by one I think. As far as collaboration and control I think that here at xx we were very lucky that we have an amazing team. We have about 10 full time staff members and about 30 clinicians to be contract to run our support groups. So, we are a fairly small team and we are here day to day making all the stuff happen. So, there is definitely a lot of collaboration that is required. Just because no person only does one single thing at our office. Now to your point about tensions, of course the opposite of collaboration is the control and I think where the tension arises is we are all perfectionists, we all want to do the best that we can for the folks that we serve. So, I hate to even say control because it is not coming from a negative or hateful place, but sometimes when you have so much collaboration and you have so many hands in the same pot, or so many cooks in the same kitchen. You know it is an American saying. Sometimes that can just, you know things get lost or you assume that someone is doing something and this someone assumes not.

As far as flexibility and efficiency I would say we are pretty good with among our staff, we definitely all have a good set of communication and a good sense of trust, which I think is really important. That you know if I helping my colleague with something I don't feel the need to check in and need an approval for every little thing, because that would slow down productivity and slow down time, but that is only build because of the trust my colleague has in me and vice versa. So, I'd say that is a big part.

As far as profit and social responsibility as a non-for-profit organization we can't have a profit that comes to our staff, so if we raise more funds in a particular year that we spend, because we are a non-profit organization by nature, those extra funds are going back into our programming for the following year. So, it is not that anybody is getting rich here of the work we are doing, that is not why we are working here, we are here to save lives, we are here to help people recover from their eating disorders.

Then as far as our interaction with outside of our organisation, I think that is where things are getting a bit more interesting. I think if we are looking at the mental health help space as a whole. There is sometimes that collaboration there, unfortunately eating disorders are still shrouded in a lot of secrets and a lot of stigma. So, there is even a lot of general mental health organizations out there that focus on mental health that focus on their mission that don't want to talk about eating disorders, because eating disorders, it is still seen as a choice or something you can just get better from or something that is not that big of a deal. And meanwhile we know that eating disorders are the second deadliest illness, somebody dies every 50 min from an eating disorder. Not that we have to justify, how sick people are, for others to take it seriously, but sometimes we do. So, I would say, sometimes there are, you know based on your definition of tensions, sometimes it is frustrating. Like you said when we got first onto that call, last week

we were swamped since it was eating disorder awareness week and we have to take advantages of that. So, you know that is when all the other organizations don't focus on eating disorders or spotlighting eating disorders. So, we have to pack as much as we can into one week, because now that is March they have moved on to other mental illness. And don't get me wrong, other illness deserving as much as attention, of help, of all of that. And sometimes eating disorders are left by there side. I have been in conversation with elective officials with leaders with other mental health organizations or community-based organizations and say really hurtful and inaccurate things about people that have eating disorders or how they should just get better or how it is no longer a problem. So sometimes to getting people to understand, that eating disorder is a significant mental illness is just the first part of the conversation. Once we get them to understand that yes that is in fact a problem, then we can go on to other ways to collaborate. **But I say just the stigma about eating disorders and the misunderstanding and the lack of attention that is put on them you know globally. You know it definitely causes some tension, it causes harder to do our jobs.** Again, I want to make clear that I think all mental illnesses deserving of attention, deserving of funding and research and recovery and all of that. I have seen it, having worked with other mental illnesses or other health related topics, eating disorders is definitely a tough one for some people to rap their minds around.

Yes, I think so too. Definitely. Thank you for all this input, it is perfect and highly interesting. Just related to this topic about the awareness and the stigma. Do you think it is also a tension that the research in this field is lacking? I read that the research is very limited, especially compared to other mental illnesses. Are you also active in this field, that you try to close this gap?

So as far as formal research that is done, you know preventive articles that is something xxx does, we definitely collaborate with the other organizations in the field that are more researched based and do a lot of that very [...] data collection. When there came out, last fall, it was released by Harvard, by Deloitte economics and it looked at the financial impact of eating disorders in the United States and that was really interesting because before that study came out, research previously told us that a life was lost every 62 minutes, based on this new research we see that it is actually 52 minutes and that was the first time that I was aware of a study was done on a national scale to say this is how much money eating disorders cost us in direct healthcare cost and that is how much productivity is lost in the American economy because of it. We are talking not only about insurance bills and hospitalization bills and things like that. How much time are people out of work, how much time are sick or misdiagnosed or running around in circles trying to get help for something that we know is real, but that some health care providers are not able to recognize or choose not to recognize. So, well, we don't personal do the research, but we definitely appreciate, collaborate with the other organizations who are out there doing the research. As far there is not enough research, absolutely. And I think that goes back to the stigma, that some people mistakenly think that eating disorder is a choice or believe that those are no longer exist or that are not a real health issue. And I think there are similar tensions that are arise with the substance use field, I see people say that substance use disorders are not really a mental health issue, it is an addiction that is different. We personally don't believe that, we believe that substance use is a mental illness and it is actually highly correlated with eating disorders. To going back to the tension, that is one place we are looking for more collaboration with other organizations that focus on that other illnesses, such as substance use, suicide, depression and OCD, because we know that to help people you cannot just treat one thing or one diagnoses. We believing in treating the whole person, which makes eating disorder treatment that more complicated, because rarely you are

only dealing with an eating disorder it is just the tip of the iceberg. It is all other stuff under beneath. So, we addressing lots of sexual trauma, we addressing deep seated stuff that folks have dealing with a long time and yea it is really interesting work. I think more research would be amazing to help us know of how big that kind of a problem it is and how successful programs like ours are and I am not holding my breath, here at xxx something what we say is: Get stuff done. So, while we are hoping that there gets more research, that there will be more studies. In the meantime, we are just getting stuff done. In the meantime, people are dying and while we are appreciating that there are organizations that focusing on awareness, focusing on studies, we are here to provide tangible assessible support for our people. And again, not to say that one is more important or more needed than the other, but that is our bread and butter, is providing those support groups providing care. So, I hope that answers your question.

Yes, definitely and I think you are right, both is very important. I spoke with another organization and she told me that her daughter had anorexia and almost died from it in the 1990's and she said nothing existed around that time. Therefore, I think it is also highly important that organizations like yours exist that people get help.

That just reminded me on something, can I just quickly: So, we were founded 20 years ago by our founder, CEO xxx exactly because of what you have just said. xxx lived in, she was not in an upper-class family, but the folks she was surrounded were a lot of upper class, she light female, had access to care couldn't afford it and she knew how dramatical that was to her recovery. So that's why she founded xxx to bring our communities together in alliance with each other to help provide this care, because so many doors are closed on people. When people showing up and say, hey I have a problem I might need help, there shouldn't be doors closed in their face. Insurance shouldn't be saying money shouldn't be an issue, finding a provider what they are talking about, that would be an issue and it is, that's what we are doing here every day. We are here to help to find those clinicians, who do know how to treat eating disorders, we are here to help people to find health insurance covers, we are here to provide them with free support groups. No matter what they can at least log on to our support groups and have the safety of our therapists in the virtual space. So, we were founded because of that inequality to access to care and that is what I most appreciate about this organization is not matter what, we don't lose what we are working for. We are working for the people who are out there suffering. We are not working for anyone else, we are not working for; so not one more mum has to make that phone call, that her child has passed away. Or not one more spell that doesn't know how to help their partner go through what they are going through. Last weekend we had our NOT ONE MORE weekend, which is our three-day event, what is making sure that not one more live is lost to an eating disorder and during our program and also during our rally for recovery we did have a short section to reflect upon the lives that were lost. I know there are some others in the eating disorder field who feel it is too triggering or too depressing to talk about the lives that were lost. Our belief is we are here to prevent that from happening, to one more life, to one more person. And to one hand we want to honour those lives who has been lost, who's have been taken too soon by this disease, we want to honour their families who are still working so hard to make sure that doesn't happen to somebody else. So, I will send you a link to watch the celebration of live, it was beautiful, it is tough to watch, you know reflecting upon those individuals and seeing them as people. And knowing we are here to make sure that doesn't happen to somebody else it is really special to us.

I can imagine, I guess this is a completely different work and you really do some thing good of people and our society.

I have one more question, because as you said when we were speaking about your research in your programs. Do you have any systems to measure your impact or programs? I can imagine because its barley exists research, how do you know that you are going in the right directing with you programs or being effective?

So, that is tough. So, let me kind of break it up in the programs we have. So, for our education and training, so, when we go into the community and training and talk to a group of physicians, we have them fill out a survey, to know did you learn anything, will you be able to apply that to your everyday practice and overwhelmingly, thankfully we have this such a great team, that our education we provide is helpful. We also looking always for feedback to pivot everything we are providing to what is needed in the community. For example, here in the United States, I don't know if that is the case in other places the idea of trauma and trauma informed care has been a hard topic were a lot of folks in the mental health field are realizing the significant impact that trauma from younger years or previous generations can have on individuals. So, we launched a whole new program where we training folks on the impacts on trauma and eating disorders. So, we have been working a lot with domestic violence serving organisation, a lot with organizations that serve homeless, even some kind of colleges offices to help them identify if their clients or patient has experiences trauma, how I can help them to screen for eating disorders and then what there is to do about it if there is an eating disorder present. Otherwise we measure our impact. So, one program, that I didn't mentioned early is called our psychological services. It is the only program in the nation where individual who don't have insurance or having insurance that is unaffordable, are able to come to xxx and get outpatient care for less than 5 dollars a session. And I am sure you know how much our patient care normally is, so individuals, we do that based on evidence-based practices. So, it is not like a lot of mental health clinics they will see a patient five times and then they are done. We treat people to completion. So, they are able to stay with us in our program for as long as it is needed. We opened the program in 2018 I think and some of our clients are still with us. From a business stand point of view, it is not that we are a business, but some folks would say how are you treating the same client for years at 5 dollars a session, where is your return on investment? We are here to helping to get the person better, and if it takes 3, 4, 5 years and seeing that person 3 times a week, for 5 dollars a session that we are here for to do. And we are very lucky that our community allows us to do something like that. So, to your point about assessments, before and after each therapeutically appointment the clients take the eight-corner assessment, which is an assessment based on eating disorders mentality. So, the therapist is able to get in real time a snapshot about how they are feeling before the session and after the session and they are able to look at that data. This program itself is a post-doctoral program, so it is a teaching program for students who have graduate from their PhD's which are not fully licenced yet. So, they get lots of supervision from two clinical supervisors who have a combined 70 years of experience in the eating disorder field. The post doctoral fellows are also licenced with our others staff, so they are doing community presentations, they are running our support groups. So, they are really getting an idea of how to treat folks holistically. So, I would say, those are our two programs that we measure numerically, where we measure the impact.

Okay, perfect. Thanks, do you have any other tensions in mind?

As you can tell, we are very passionate about this. I think the main tension is getting people to understand that mental illnesses is real, that eating disorders are a mental illness and most importantly recovery is possible. We see folks every day to living their day on an eating disorder, who are living a fulfilled and meaningful live and they are giving back to others. And I think the biggest tension is just society as a whole. I think we have come a long way in the

mental health fields. I think a lot more folks, have understand that mental illness does exist and it is not fake, but eating disorders still have to catch up where the rest of the field is. Just because there is so much stigma. But I think we are really excited and well equipped to do what we can do to make an impact. You know we have already 4.000 people on our support groups this year and it is only march second. So, we are growing. It is a lot, last year we had about 9300 people all year in our support groups now we are already to have of that and we are only two months of the year. So, we are growing and we are doing the work, people deserve care and that is what we are here to do.

Exactly and I think that is important even more nowadays, because of all the social media and also now with Covid, I think that pushes people even more in these kind of sicknesses.

Yes, I am glad you brought that up. Before I talked a little bit about culture and all that but Covid is another tension. Because as you know eating disorders thrive in isolation and when people cannot connect with their support networks and they can't even leave the house. People are very sick right now. A lot of treatment centre's we are working with have long waits, weeks until people can get treatment. It is not good. So just to say, world affairs are definitely a tension. I think everyone is being impacted by Covid in negative ways. So, I don't want to think that we are the only people dealing with that, but it definitely changed a lot, it has changed the acuity and the level of sickness people are experiencing and on the flip side because Covid forced us to stop providing services in person and shift everything to virtual, we have been able to connect to so many more people. We were able to welcome people from Dubai from Ireland from Australia, New Zealand. We were able to welcome all those to our support groups, which we weren't able before because our support groups were in person in the united states. So far, Covid has been a horrible horrible a global event for many reasons and we have to look at one positive thing that comes out of it. I think it is our ability to provide more services across the globe.

Okay, can I ask you, I know we are already a bit over the time, is that okay?

Yes sure, I have a few more minutes yes.

Okay, perfect! Thank you so much. Because you mentioned before, that you had the possibility due to Covid to offer everything online. But before that, were you a more traditional organization? Wasn't it in the first moment when Covid appeared a tension for your organisation? Because I imagine, to do from today to tomorrow everything online especially in that field must be very tough.

It was scary. So, I remember, it was a Wednesday night and we were all at the office like normal. And the news was telling us that virus is coming, ah no it was a Friday night and we all were leaving the office and go home for the weekend and I packed my stuff and said, we are not coming back on Monday. No one else, they all said I was crazy. Over the weekend was when things really explode the numbers started to explode here in the US. So that weekend our CEO and clinical director were on the phone how are we doing support groups, we had support groups in person, how do we do this? And we were scared, can we do this online, is it safe, does it feel the same, is it effective, will anyone show up? And again, as I am sure you know folks in the eating disorder field, people that have had experience with eating disorders we don't deal very good with that grey, we deal better with the black and white. So, thinking over the weekend, how do we go from offering 24 groups in person to nothing, we can't do that to people. But we don't know what virtual is going to be like, will I work. So, it was a tension, it was a lot of conversation between our staff, it was a lot of conversations with our community asking them will they even show up and we took a leap of faith and luckily, it's been beyond our wild of imagination of how successful it has been. And it has been successful, since we have such an

amazing clinical team that makes sure it stays safe I formal believe if we did not have our clinical director we did not have licenced therapists on staff we could not do this. I don't believe that eating disorders are a thing that can be treated solely with peer support. I personally believe that it is important to have medical professionals and clinicians present and I think because we have that clinical insight, that we felt comfortable offering this service and continuing this service virtually. **So yea it was Covid and the decision to make things virtually has definitely been a tension. It is definitely something we had to learn and now almost a year into it we are so thankful that we took that leap faith. And we are still learning, still growing and we are looking at what happens next. What happens when things are start to getting back to normal, what benefits do we get from virtual vs. what benefits do we have in person, is there a way to do BOTH?** So, we are exploring a lot right now and we will see. I think all of us across the world are kind of waiting to see what will happens. But we are prepared and excited for that.

Okay, that is nice to hear. I can really imagine, that it has been really tough in the beginning. So, I would have one last question, if you would allow me? So, you said that the work together with health care professionals is very important for you, but was it always easy? Because I was speaking to another organization and they told me that there has been always been tensions between health professionals like clinicians and the non-profit organisations. Does that occur also to your organization?

Do you mean working with other professionals in the mental health field? Because I am not a clinician, so me working as a non-clinician. So why am I in this kind of field?

Exactly, that is what she meant. Of course, it is important that you get the support from clinicians or also psychologists. She told me that they as an organization struggled sometime to get their support. Because it happened that they don't value the work of their non-profit organization?

Got ya', I think I understand. I personally don't do our education and training. So, if there is a doctor's office or another organisation that wants us to train their staff on eating disorders, we employ two licence therapists. xx who is a psychologist and xx who is a licenced health canceler, so we have two folks who are specialized therapists who provide our education for that purpose not only that they are much more educated then I am on eating disorders and the treatment and the cause, but it helps having this appear. While having someone on the same level, a doctor speaking to a doctor saying this is what eating disorders can present this is why you should attention to. So, we definitely believe in employing clinicians and employing therapists that are experts to deliver those programs. Of our staff that is not clinicians a lot of our staff has lived experience, so they identify our folks to recovered from eating disorders. So, we try to [...] break down [...] from other clinicians to have those degrees and know who to treat those patients and then also the lived experience. The people on our staff, who say I have been there I have done that. Cause we all know that sometimes when you are sitting in support groups people don't want to hear from the therapists they want to hear from someone else who is recovered. So, we always have the therapist there to make sure it is safe and appropriate but we also have people with lived experience to say hey you can do this too.

Okay, great. Thank you so much for answering all my questions. Sorry that it took a bit longer than planned, but it was just so interesting for me to speak to you.

Absolutely.

Do you have any more questions for me?

Yes, are we able to see once you are done with this, what you have been doing?

Yes, of course. I will share my work, I think it will take until June this year, but after that I am happy to share my work with you. I hope it is going to be good, but with all the input I have got so far, I think or hope it's going to be good.

Yea I am sure it will be. I will definitely forward you some information so you can see the video from this weekend and a little bit more about what we do. So, if you have any questions feel free to reach back out to me.

Thank you, that would be amazing. Actually, that would have been my next question, since as I told you before I record the interviews and transcribe them afterwards, usually there arise some more questions, so I am thankful that I can still reach out to you again.

Awesome, well thank you.

Thank you so much, have a good day.

Have a good one. Bye.

Bye.

Interview 6 – 03/03/2021

[Introduction]

If you are ready I think we can already start with the first question, so I would like to ask you to briefly introduce yourself and the organisation and your function within the organisation.

Sure, I am xx the Senior Director of Programs at the xxx, what xxx does is we are the largest eating disorder non-profit organisation in the United States serving individuals and families and really gear towards accessing treatment and providing information and tools to connect people to care.

Okay, thank you. That is everything you want to share?

I mean I can tell you a little bit more about the different programs that we have, you know all of our programs go back to serving the mission. So, we have some different branches I would say. We have our helpline which is one of our biggest programs, it really serves the need for anyone who is affected by eating disorders. We have volunteers who staff that line for extant and supervised by staff members. They directly have conversations through a number of different contact methods, chat, phone, e-mail and texting. And they be able to be the first step in the conversation that somebody may have, either a family member or an individual who thinks they might be struggling or friends who are worried about a loved one. And discussing with them what information am I need to make the next step in that process. Often it looks like connecting to professional help, sometimes it looks like finding support for themselves, if they supporting an individual who is struggling with an eating disorder and sometimes it can be just basic education what is an eating disorder, what is eating disorder treatment look like, what kind of options do I have. And then we walk them through that kind of process and then if they need to find a treatment option. In the United States particular it is super complicated, there is not a clear structure from who is able to get treatment and how and where. It really depends on insurance coverage, if they have insurance and then out of pocket expenses, as well as the level of care and what is available in that area. There are a number of different factors. Then we also have programming for prevention, it is based on research that has tried to reduce the risk of eating disorders. We have a couple of different programs that are geared towards that serving parents of early childhood. We have another prevention program geared towards health high school college each girls with some pilot programs related to man and like young man and boys and some kind of additional of [...] of that and then we also have a research component as well in our organization where we have a fund that grants research funding to some different opportunities within the field to play a role and progression treatment in that area. As well as promoting new information and progression in the field overall. We also have community sort of events and awareness campaigns, we just wrapped up our eating disorder awareness week last week and that takes place every year of the end of February. We also have a stigma awareness week, which takes place at the end of September. As well as sometime we take place in some of the other international awareness campaigns as well, there is a globally eating disorder day, as well as a no diet day. There are some other once where we partner with others organizations with as well. But I would say that the two kind of largest events, the eating disorder awareness and the stigma awareness campaigns and that is an opportunity to both educate the larger public, as well as get our community involved or engaged. Often eating disorder awareness week is to celebrate [...]or to share some experiences of others to educate the public and make aware of how basic eating disorders are. We have used in particular the last years the platform to talk about who is traditionally locked out of those conversations. So, we know that eating disorders do not discriminate they can affect people from all different kind of backgrounds

[Connection break down]

Sorry could you repeat that please, I think the connection crashed down for a few seconds, thank you.

*Sure, so we use this platform to, in particular in the last few years, to have better communications with community members who have been typically left out of the conversations. **I think there is a stereotype, at least in the united nations, that states that eating disorders affect like young, white woman, we know that this is not the case, however a lot of people are the ones have access to treatment. So, trying to change that and educate people kind of across the country that eating disorders can affect anyone, there is not just one look for somebody.** As well as, what are the obstacles that people have to be able to access care. And really tackle this conversation by start those conversations to challenge and the field, the medical field, just general awareness of eating disorders in recognizing that everyone is deserving of care. And about the stigma week, similar to the awareness week, recognizing what stigma is, how it affects our society in general. As well as really just building education and awareness across our community as well as the broader country of what that looks like and **how to make themselves aware and ourselves aware of the challenges and how it looks like, kind of activate people to be able to make a difference.***

Okay perfect thank you so much for all the insights, I think you offer quite a lot. If you are fine it, we can already dive in the second question since it is the most important question for me. Maybe you had some time to brainstorm beforehand about some tensions which might exist in your organization.

Yea you know I am not a 100 percent sure exactly you want to go by answering this question, there are a lot of different ways I think there can be tensions. Within the organization we serve a very large group of people who are affected by eating disorders, so there can be some conflicts in terms of who we are serving and how we are serving them. We are talking about different stages the eating disorder as well as who are we serving and are we reaching the whole kind of spectrum of the eating disorder progression starting from you know the first recognition, through actively dealing with the eating disorder through treatment or support and also afterwards, what kind of support is available and do we truly offer something for everyone in every stage and then additionally I think in particularly how we are challenging those conversations in raising awareness, who is affected by eating disorders and are we able, do we have the resources the support to be able to talk about the new once, because what is available for treatment options may not actually serve everyone and how we are handling that by providing support for those who might not have the right access to care available.

Yes, that is definitely a tension. So, just to wrap up the first tension you say on one hand the treatment you provide and on the other to make sure that these treatment serves anyone?

Yea I think that is one of the constant conversations about how we can do better to grow and to improve us, we do grow and recognizing our responsibility in serving the whole large country. And how that's look like that doesn't look like one particular case, there is many different elements there and so many different unique stories and finding ways to support all of that areas.

Do you think this tension is also related to the tension you mentioned before, of the lack of research? Because as you said, the broader field expect that it is always a young, white women. I read lots of articles which described that about other mental illnesses exist a lot of research compared to eating disorders.

Yes, I think for sure, I think that there is a large part of that the field itself does not have necessarily enough research behind it [...], at least our community would like them or really

*need them to be able to get the help what they need. That is certainly a barrier for **traditional treatment** where questions are being ask who is being researched about. You know in particular we know for research a lot of times there is a specific group of people that have been researched and other people have not been part of that may not be responding the same way to treatments and that can certainly affect the outcomes and the access to care.*

Yes definitely, okay great. Do you have any other tensions in mind?

*Let me think, I think there is also. I think that is the large picture of things, I think that also depends on recognizing the ways on how you approach people in different places of their recovery can look different and that is, that can be challenging. To make sure that is very clear which particular piece of program is interactive [...] to who and **making them feel welcome rather than excluded and safe rather than unsafe**. Recognizing there are conversations that are appropriate and necessary to have at one stage that is may not be appropriate and necessary on other stages than that.*

And do you think you have also internal tensions, like within your organization? Let's see Covid as an example, since I guess your support groups has been before in-person support groups and then everything had to be shifted to virtual groups. Can you relate with that?

*We have been very lucky that we have been to move towards that doing things anyway for a number of years and actually our helpline went fully virtual at the end of 2019, which was perfect timing. So, we were very well set up in 2020 in March when we had to go virtual anyways. Already all of our volunteers were not all in one spot, we already accessing tools from home and things like that and the company culture and is also been virtually already before Covid. So, we felt very lucky that there is definitely growing challenges in terms of **internal communication and not be able to meet in person to be able to brainstorm in the same way we have been be able to before**. And I think that is something I know that organization has across the world that we all had to change the way of communicating as a group, however we have been very lucky that we already had a lot of tools set up to be successful as a company, that that structure was there. It was more the culture than anything. You know Covid put a lot of pressure on everything being online so all messaging was online, everything was absorbing it and accepting very rapid greed's. Certainly, our work was different and the expectations of our work was very different. So that certainly had an effect on the way that we produce somethings. I don't know if you asking this, **but certainly we had a lot of people were forced, were home with their kids who could not work the same way that they could have before and some of the content we have that we are sharing may not be a 100 percent care appropriate. So, having conversations where was a little bit different just of terms in having those safe environments employees to be able to do that.***

But could you figure any approach to overcome this tension, to change and improve that?

*Some of them having different meeting times, so having them when their kids were occupied or asleep. Some of them just meant understanding that the work volume had to change. So, in some programs it happens just slower than in an office for 8 hours a day, or we redistributed to people who could do those jobs in a different way. We also had some additional support groups to **took into place**, which certainly put pressure onto our team but in a positive response way or we had regular live Facebook, we call them leader connection, but regular 15 min conversations with a number of people from within our community as well as partners outside of our community to be able to give our community members to be more in touch with us since we couldn't visit them in person. So we were supposed to have a conference that was in person I believe it was supposed to be in March and that obviously was rescheduled to became virtual in May and that was very much impacting, because there were people who were supposed to*

present but could not present anymore because their schedules was different, they were with their families and working remotely so their hours and abilities were quite different, so there were no longer available for the remote version.

So even just the ability to connect, also the other programs that I didn't mention before but it is another community building aspect is in our walks in person, those happen through our all of our country across over the year and we have set many of them in the spring, which were cancelled. So, people were really missing this in person meeting to connect with our community. As well, so that was with the connection to online, helping was also giving to somehow connect with people certainly it is very different than face to face in person opportunities I think also the other piece that might be part of this the conflict with, you know even video chatting was never a thing we did before as usual phone calls or we talked to people and go see them and now most of our conversation are via zoom or another platform, even with people in the office working together. It is certainly just a completely different way of doing things that we ever did before.

Yes, I can imagine, does this also raise more tensions within the team? Because so far you have mainly raised tensions with external factors. Can you think about other tensions, even not related to Covid?

You mean Covid specifically or just generally?

Generally.

I think there has always has been some conflicts with people who have personally struggles with eating disorders, whether or not they are still struggling or you know mental health is supposed to be a focus in general in our community and it is still business life. There is certainly been a conflict of what level is the culture is supposed to be supportive and loveable I am sure this is pretty American, but was enabling [...], I don't like saying this because I think it is not fair, but it is certainly been a conversation of a business perspective that has happen of wanting to give people time and space in particular with students with stress, but also recognizing that there are deadlines and there is work that needs to be done and we have a high performance expectation, because we have a responsibility to our community and sometime in particular, since we are a non-profit organisation, that means that it is not like you going to be compensated in the same way as in a profit organization. So, you know work life balance is different and there can be some different expectations of that when people come in this experience. They thinking the workload might be easier and there are a lot of high-pressure times and for people who may have experience with mental health issues to have not found a way to healthy mat (41:47) healthy manage that or have not encountered that in particular experience to have the tools it can be both challenging as a supervisor and the individual. So, figure out how that work.

Could you give me some examples how you proceed with it, if you realize that some people are really struggling in any kind of way?

Yes, so it depends. So, there happen periods of times I can talk about, there are some different examples. One would be for volunteers we are very clear about their boundaries, if you feel this is too hard for you or the work is too triggering. We general recommend that you need to be two years of strong recovery to be able to volunteer. Legally we cannot have that requirement for individuals in our work force, because that is illegal, but that is a recommendation for volunteers, for their own safety. And we have seen that, even when people are in strong recovery that they encounter situations that are very harm especially when they had personal experience in particular. And so, giving them space to be able to back away from that to say it is okay you don't have to be involved or you can take some time away. Has been something we have set up

as kind of no penalty if you will situation, they are encouraged to be honest with us and let us know if they can't take on this work what we want and so they take a little step away to help themselves first.

For employees it is a little bit different and I think that is really challenging, we certainly make space for people to attend regular appointments within the workday if needed so that they can be flexible on having access to those opportunities since scheduling this outside of work can often be very hard a lot of times because such appointments have to be in the middle of the day. So **we give people the space** to do that, leave earlier or come later to work to be able to make that happen has been something that **has been part of our culture** and encourages first supervisors [...] if possible we allocating those tasks to someone else to back that on is generally what we try to do **and if needed to have a conversation about whether or not if that is the right position for them**, when it is not healthy for them. **Having that is quite challenging because there are lots of employ regulations in place, so having this conversation can be really difficult, but figuring out how to support them is culturally a part of the priority.**

Okay, thank you for answering my question. I think I have no more questions so far; do you have any other things to mention or other tensions in mind? Do you feel any tensions within your community or also with other organisations or professionals from healthcare centres?

Yea, I think all of them have some kind of dynamic there, certainly we are one of the biggest eating disorders non-profit organizations, but there are certainly some other smaller organizations within our field in the United States. So, we work very really closely with international organisations and have strong partnerships. The organisations that are in our country end up being a little bit different, because sometimes they have started in a smaller capacity and doing some other things and **finding a way to be not competitive and be collaborative can be a little challenging**. We do try as much as possible to not have competition. Like the perspective I always had and also the organization as a whole had had that, whatever possible **to collaborate rather to competing over resources is like intelligent and serves greater and better our community**, but certainly their personal is very strong and people who have really done hard work on their own who have decided to want to do it better or have felt we were not serving them so they have started to build organizations themselves or were not aware of us so their started other organizations. That can be hard to work with and figure out if they need support without [...].

Okay for sure I can understand that, but I guess on one hand you are totally right it is not good to be competitive, but on the other hand it means more service for people who need help? So, you would rather like that your organisation grows instead of other starting new organizations? Yes of course we always want to grow, but also working in collaborations with the other organizations is ideally the way to go. So that there is no competition whether they doing that they are doing what we are not doing well. I think that is ideally when organizations speak to us and say your organization is not doing good in xyz, therefore we are doing this and then we will step back and do not anything on that, because we can refer people to you for that work. However, there might be organizations that might be really complementary that also do want to grow themselves and sometimes that looks like taking on programs we also may doing and that can look like conflict. **There is a perception there is scarcity of resources even effects the audience waning that people come to them instead of to us**. Can be something that can happen, as much as possible we try to avoid that, but people have done really good work themselves and work really hard and feel like mentioned before, that they think they are doing something we haven't done as they want us to do, so they just do it themselves. And certainly, that can look like competition.

I think I have one last question, because I see our time is already over or do you need to go?

I have extra time.

So just as you have mentioned you are not a profit organization do you have also tensions related to funding.

Oh yes, absolutely. This was a very hard year for fundraising, this last year we had to lay off several people from our team at the end of last year in particular the funding was challenging our in-person events, like our walks could not take place, past march is when they usually start, because they are usually in the spring and in the fall, cause these are the warmer seasons and people are in schools and not traveling and things like that. So those could not take place and those are the largest fundraising events we have or gala generally takes place I think it was supposed to be in May and that was cancelled and it was not safe in person and that is usually a big fundraising event too. So, it took a large cut for us and did affect our donations and our ability to the funds that we had had to scale down for programming and so we still allocated what work to stand, some programs had to be on hold or scheduled for the next year. Well we look at new opportunities and hope that we have a vaccine.

But that means that your organization is mainly funded by private donors rather than the government?

Right, we do not have government funding, we have a few private grants and we have larger private donors.

Okay, perfect I think that is all from my side. Thank you for taking the time, the last question I have, because as I said I will record and transcribe the interview, while doing that sometimes more questions pop up, do you mind if I contact you again via e-mail if that is the case?

Sure!

Perfect, thank you so much.

Take care.

You too, bye.

Interview 7 – 05/03/2021

[Introduction]

No, I don't think I have any questions, I have been looking over the stuff you have sent, very excited to talk about this. I think tension, yea we talk a little bit about them, but we do not necessarily call them tensions. So, it was interesting to kind of think about them a little bit and which things we are facing in that way. So, it was actually really exciting to think about it.

Thank you so much, that is even better that you had some time to think about it. If you are fine with it, we can already start with your part, therefore I would like to ask you to briefly introduce yourself, the organization and your function within the organization.

Yea, my name is Erin Huston I am the training education coordinator with xxx, so I have been with the organization since January 2019. I started as a master student doing a replacement there and then I was just on a contract to do some of their stuff with their conference for another year and a half and then I just started fulltime in January working with them as a training education coordinator. So, I have been in this role fairly for a few times, but been with xxx for a couple of years. I think the official beginning with body brave was in 2017. So, I have been there for half its life, which I hopefully can provide enough context in detail for the work you are interested in at. In terms of the work that we do, we kind of work in two separate wings, there are kind of two separate columns to xxx, so one is the clinical side, where we do actual treatment and support for people with eating disorders. So, we have groups or offer different kinds of one-in-one therapy whether that is with a psychologist's therapist or dietician or family thing or any kind of this thing and working with clients and proving workshops, groups therapy and all this kind of things. And then we have, we just call them non-clinical side, which is more about the education and awareness and those kind of aspects, government advocacy and those kind outward facing things. That is where I spent the most of my time in kind of awareness or education work that we do. We are kind of primarily focus on not necessarily in initial awareness more of deepening understanding of to those who maybe already know that eating disorder exist, but don't know that much about them, so like doctors, dieticians, social workers, those people who kind of know that eating disorders are out there, but maybe don't have the language or the tools or the understanding of the complexity of eating disorders and really providing education and increased awareness to those populations.

Okay, perfect thank you. I think it is interesting that you split into those two parts. If you covered everything to the first question I would like to ask you the second question, these is the most important question for me, since it is related to tensions. It would be great if you can tell me, what kind of tensions does your organization face. And it would be good if you can think also about the up- and downsides of those tensions.

Yea, sure. Looking, yea like I said we kind of talk about how we balance these things, but we never label them as tensions. With the examples, I was kind of going through them like we kind of touch on this or we kind of talk a little how we balance these things in different ways. The language what we use might be a bit different, but kind of in the essence is the same. So, I think definitely like the individual vs. collective tension is one that we face, kind of in terms of providing support. So, what is the best way to provide support is it on an individual basis OR like group support and there is a lot of evidence for inpatient kind of approaches or like one in one counselling, but there is a lot less research about community-based care which is more where we sit. So, what is that balance between providing individual care AND providing collective care. I think in that same vein working with other eating disorder organisations it is like that tension of trying to have our own identity and the work we do as xxx, but then also want to working with other organizations to make larger government or collective change. And

how ARE WE GOING TO HOLD THAT, to stay true to what we believe and the boundaries we have as an organization, BUT ALSO work with others and see the value in that. I think definitely profit vs. social responsibility is a big one, especially for us. With our two columns, like the support and the clinical side, we want to continue to be able to provide free of charge to people. People don't pay for the services at xxx. You have the option to donate, but they are entirely financially assessable for anyone and so because of that, because we are offering like work with a therapist or a dietitian or all of this things free of charge we do need so supplement that and so that *with training and education we do often charge* for those things for the training for dieticians or the training we do for different organisations and that kind of stuff we do charge for those. *And it is kind of to balance those. We want to be able to provide as much education for everyone and try to be really accessible, but at the same time we need to have something to supplement like the support that we are giving also really needs to be accessible. And that is one we are constantly balancing and constantly trying to figure out where it is right or where it feels right to kind of fall between profit and social responsibility for sure.*

Yes, thank you. I can understand that. But what is your approach, because you said that you are always trying to balance those two things. What ways do you try to follow?

Yea that is kind of why the training and education piece is growing so much, because that is kind of our way of balancing it. So, we want our support entry free, we also want to pay our staff well and make sure that our staff is healthy and can care for their families and that is where we kind of brought in our training and education piece and that is kind of our tool to help supplement that balance. So, bringing in that can bring us a little bit more revenue and make it easier for us to continue to provide our services that we do. For the training and staff, we applied for a lot of grants, trying to get a lot of funding, so that we can still offer them at a fairly accessible rate for people. So, that the training isn't absurd expensive. *Trying to find ways to bring in money, whether it is grants or donations all of those kinds of things. Is kind of the tool, we are trying to balance profit vs. social responsibility, because the profit is right going into the social responsibility asset. If that makes sense.*

Yes, it definitely does make sense. But just to make sure that I understood everything correctly. The people you educate, like doctors, dietitians etc. they pay a small fee, but additionally you raise funds or grants to do the education programs and especially cover the clinical side?

Yes exactly, we kind of get grants to help us put together the trainings and we have them available on a virtual platform that we have built and continue to maintain. So, it takes money to keep that afloat and in terms of marketing and that kind of stuff. We like our trainers accreditive so there is value for the people who are doing them and that also costs money, but we try to get as many grants to help us that our trainings are good and sustainable and all these kinds of things. We do have people pay a fairly rate to be able to access those trainings.

Okay, cool thank you. Since I didn't want to interrupt before, when you were speaking about the tension individual vs. collective why is that your approach? Because I remember that you have said, that you aim to shift it more to the collective perspective rather to the individual one. How did you figure out, why the collective perspective is also important?

Yes, absolutely. We have kind of come to find a new process in that, if a patient or client comes to xxx and is interested in any of our services or anything. We do an in-tick-process, through our in-tick-process we figure out what would be the best for them. So, first for some people, groups is just not helpful that is not what they need, for others it is a great tool. So being very, very intentional a better in-tick process and figuring out what works best for each individual person and sometimes you know, if we don't have the resources support for that person based on a number of things, we are very happy to offer them additional resources or point them in

the right direction. So, we only provide support for people 17 or older just based on legality issues and what we are able to do capacity wise, but often we get parents who are concerned about their children and therefore we kind of give them support resources. We are not afraid to send people to other resources we know about. So that is very based on each person and what we think is best for them. But in terms of what we are tend to provide more is the group and the community-based care, because that is definitely lacking kind of in a broader eating disorder context, at least in Canada at least. We kind of work from the [...] collective approach because that is the spot that is more missing and we are kind of trying to fill that gap in care. Perfect, have you thought about any other tensions?

Mhh, I am trying to think.

Just to let you know that these both examples were already perfect.

Okay perfect, I am glad. I think **cooperation v. competition** is one early on we kind of struggled with a bit. When xxx was trying to find their identity and you know where we fit with all other eating disorder organizations and what gap we are filling. **We definitely moved from feeling more in a competition space to a more collective space.** Because in the beginning we were not taking as seriously and that kind of things as a natural being an organisation that was community based and with based and lived experience and so we saw things more in a competitive way, but now we definitely **hold a more openness-cooperative approach.** So, we are work with a lot of eating disorder organizations across Canada and we have province or nationwide meetings where all organizations come together and talk about what work they are doing or things that are coming up that are really exciting for them and so we are definitely shifted that more in a cooperative space, which I think is really good. I think early on that was more a tension, when we were trying to figure out how are we the same people or how are we different, what do we provide? Across the organization that less the tension in our day to day. Okay, cool. That is interesting to hear, because I expected actually that it would be the other way around. So that means you definitely see more upsides in collaboration than in competition?

Yes, absolutely and we had meetings, especially province wide, where. Like recently we have doing a bit more advocacy with the government and we all have kind of all the different organisation come together and figure out like okay **what do eating disorder organizations across the board all need. Like whether the money goes to you or to me, so it doesn't matter, so what do we need more as support.**

So, it gives you more strength?

Yes, absolutely. And it definitely has become more community where we are **looking out for each other, we are really excited to promote the work that others are doing.** And they are really existed to do the same with our work and that kind of stuff. And so I think it is about building trust, building trust with other organizations that we are arguing [...] good work and that we are not causing harm to the community that they are trying to get [...]. Because I think that is a very valid reason for someone to feel closed of to that kind of collaboration, but we are doing that kind of trust building process, working with these organization that have been around for log time and gaining their trust is definitely much more collaboration, which we are really grateful for. **We work with a lot of organizations and we kind of all do similar work but do all kind of different work at the same time.** So, it is actually really exciting to hear what other people are doing and working on and talk about ideas and all that stuff.

Okay, but when you say you are doing kind of the same, but also quite different. Do you cover with that only organizations within the same industry or do you also have cooperation's with

other organisations who serve like completely different industries or are not even non-profit organisations?

I think most of us, yes, are non-profits kind of within the same industry, but we still do really kind of different work. So, some are really focused on providing information and being a kind of resource hub, providing resources to care givers or people who are struggling and making those kinds of tools. Others are specifically focused on providing groups for people in groups peoples for men who are struggling or trans people who are struggling and providing support in that way. There is others where

[connection broke down]

Sorry, could you please repeat that, because the connection broke down.

Okay, no that is okay. Others who are doing peer support and building up a peer support community in their area and so we are all non-profits in the eating disorder space, but we still are doing all very different things. And yea, it is a space where you might expect there to be more competition, but I think we just all know that the reality in eating disorders is just grim, it is more like an ordinary, we can't get frustrated of this other organizations out there because so many people need help. And so, I think we all come from that mentality field, that we are looking out for each other, which is different from other non-profit spaces, but we are very, very lucky.

That is great to hear. Okay just one question do you have any internal tensions related to your team per example?

The nature with xxx with the clinical vs. the non-clinical, there is just often we kind of do work in silence we don't know exactly what is going on in the other side or. I know their spring groups are starting soon, I don't know when they start or what they are. And they know some of the stuff we are working on, but not when it is coming out or when our next training is or that kind of stuff. So, we know what is going on, like we don't know always the details and that is something we are actively now trying to really work on. And I think part of that is, we have grown really quickly over a short period of time. So, we have a small staff, but often have like 20 to 30 students doing placements with us and on top of managing or core team, we also managing these students and then managing our project. And so, we just started doing monthly meetings with just the core team, so that we can kind of each other updated on stuff. So, I don't know if it would be a kind of clinical vs. non-clinical tension, or what kind of tension it would fall under, but this is definitely something we are struggling with and not because one side thinks we are more important or I think there is just a lots things going on and we are trying to balance all these things and make sure we are focused on our main goal and that information is getting passed. So, we want to inform the stuff on the clinical side the trainings that we are doing and making sure that a lot of people are struggling with this thing or that a doctor has said X to someone, that we can have that information in our trainings, so we can educate people to [...]. Trying to find these avenues of communication and I think that is one of the main tensions.

Just one quick question related to this topic, so that means that in the non-clinical part are non-professionals, don't get me wrong, I mean no health professionals are included?

Yes, we have xxx is the medical director and she is the one who has kind of one slip in each side. So, she does groups and support and is the physician of the team, but she also does a lot of the professional trainings and looks over the trainings and makes sure that they are how they need to be. She has kind of both doors open, but it is also not fair to put all that communication on one person to bring all this kind of information. So, we have some overlap,

but it is not as clear as we like it to be and as open we like it to be. That is something we are actively working on right now.

Okay, and you have already mentioned a few upsides, that you have more meetings together and so on.

Yes, we have like a monthly meeting together, were we get all together and talk about what is going on over there and this is what's going on over here. Nothing like strategic and intense, but information sharing, which I think is important just to know what's going on and to see each other.

But can you think also about some downsides of going more in that direction?

*Mh, I think there can be disagreements in the tools that we use. How can I explain that in a proper way? So, on the education, training or non-clinical side we are looking on different ways, like engaging with people or engaging with our clients and there is a lot of cool research that you can use to community with clients and different ways working with our clients. We can see those or we have conferences or talking to different people. Where the clinical side, they are good and that works. Maybe that is kind of a **traditional vs non-traditional tension**, that kind of comes up there, which like both sides very much respect. **It is not a tension that is like entirely negative, I think it keeps both of us growing, but grounded in a way.** So that kind of wanting to innovate and do things that are new and exciting, but also wanting to you know if something works then don't fix it, we have those tools and they work great. **So, when both sides are communicating I think some of the fractions come up, that we kind of have work through.***

Yes okay, thank you. I just see that our time is almost over.

Oh no that is okay.

Okay, cool perfect. Do you have any other tensions in mind?

*I don't think so. Over all I think the profit vs. social responsibility is the one that we face more on a daily basis and thinking about lot more and then individual vs. collective is more us in a broader community. **I think definitely profit vs social responsibility is the one we are constantly trying to balance.***

Can you quickly give me some time so I can go through my note to check if I have any further questions?

Of course. I have until three thirty, so I have so much time.

That's perfect, thank you so much.

No problem.

I think I don't have any specific questions to the tensions you have mentioned, but in the beginning I remember that you have said that you new what I have meant with tensions and that you always trying to balance these things. But how do you get aware of those tensions in your daily work?

Do you get in contact with you supervisor, or who actually pushes for the change in case it is needed? Or on what side does it make sense to put more weight on?

*Yes, I think part of it is xxx the CCO does very, very well, bringing in people with a lot of different ideas, different kind of priorities. So, I am a very grants-oriented person, if I could make things free for everyone I would I don't know so much about profits. But there are other people who know a lot about that and that is important that we know that we can speak to them. **And I think part of it is bringing in those different voices into the organisation and then not shying away from those kinds of conversation.** That is something which I think xxx has done very well, bring in those people strategically that have different voices. So, I can say that this education for care givers we should make free, because a lot of care givers do not won't necessarily have access to income or maybe we can give them an option to donate after the*

training or something vs someone is coming in and saying, this is the budget, this is the grants coming up, but we have this gap what we need to fill. How can we do that. When the training would cost 50\$ would this work? Or 10\$ would that work. I think having those conversations and having them very openly. I think, yea, transparency is a really, really big thing in terms of the way we approach it. These communications are really important on both sides and it is really, really important to balance. Thinking in a way okay it is not focusing on profit OR social responsibility, but how can we focus on BOTH. And so, we try to hold both on a really intentional but transparent way. When people donate we want that they know where their money is going or when people pay for a training they want to know okay this much is going to making sure that people who are signing up on therapy are not on long waiting lists and that kind of stuff. And being really open about that with the community, so even the profit side even feel gross or doesn't feel like an issue. Kind of bringing social responsibility to all of that. So more to hold them, how can we maintain them, how can we balance them, rather than trying to decide who we have to choose between. Yea I think definitely transparency is the big thing that we practice at body brave that we hold those.

Very interesting, okay. Then I think I don't have any further questions. Do you have any questions?

I don't think so, much more about how is it going where are you at and the process and what is the next steps going to look like for you

[private chatting]

Interview 8 – 08/03/2021

Hi

Hello, how are you?

Good, how are you doing?

Good, thank you and thank you so much for participating in my research, you really help me a lot.

Did I tell you, so I have a daughter she is probably in the same age as you and she just did her masters and was interviewing people and I thought I know when she was trying to find people it was hard to do that, so I was happy to help you out.

Ah, that is good to hear, perfect.

So, you are in Germany?

No, at the moment I am in Portugal, because I study in Lisbon, but originally, I am from Germany. Have you been here?

No!

I can recommend it, it is super beautiful.

Yea I d' love to.

[Introduction]

Do you have any questions so far?

No, I don't. Sorry I was just checking something.

No problem, then I would say we can already start with the first question where I kindly ask you to briefly present yourself and the organization.

So, my name is xxx I work at the xxx, I am in the Executive Director position with xxx. I officially checked that role on in October, so it has been only about 5 months however, prior to that I have been volunteering for the organisation about 5 years. And I guess most of my professional experience is probably not important to you, but I did work in the federal government in Canada in a strategic policy and human resources role.

So, xxx, we are a non-for-profit national organisation that exists of, who are dealing with people impacted by eating disorders including the sufferers and caregivers as well. We do a lot of work in this area. We do this by developing educational materials and resources to assess socially (11:03) recovering oriented resources really related to prevention and treatment. We undertake a lot of initiatives and projects design to I guess raise awareness about eating disorders amongst the general population within Canada. Healthcare providers as well, we are currently working with the [...] government in our province to try to raise awareness and understanding to get additional funding for in evidence-based treatment for eating disorders. We also play a catalyst role within the Canadian Eating Disorders Community, we are an organisation that really focuses on bringing other organisations together to address issues for example we are provided leadership to the development to the Canadian eating disorder strategy a few years ago. So, Canada does now have a strategy for eating disorders, we are just looking now on bringing organisations together to do an economic impact study. So, what is the economic impact cost for Canada.

That is amazing

I can see you are smiling.

Yea I am positive surprised, because I guess many countries are not as far as you are. To provide a strategy for whole Canada is amazing and necessary.

It is, but it is a challenge. To get everyone to recognize this strategy, which is officially not recognized by the Canadian Government, but we are really working grassroots moving things

up and trying to get attention, but if you can get everyone on the same page it helps to make the case to move forward. So, that is really what we are doing.

Thank you for your answer.

You welcome.

I think then we can already move on to my second question, which is the most important one for me. So, that we talk about what kind of tensions your organisation face. I am not sure if you had time to brainstorm a bit beforehand.

I did.

Oh, perfect.

Yes, I did, I spend some time this morning and really thinking about what you were asking and how I could best response to those questions.

That is great! If you are ready you can already share with me your first tension.

*So, I have looked at the examples you have provided, the five and I think there is a few of them which are quite applicable to our organisation. But the one that stood out was the **individual – collective tension**. And I would say that because I think as a non-for-profit or charitable organisation, you know using our organisation as an example. It was really needles established by an individual, two individuals in response to personalized lived experience and to a response to a need that they saw. So, they saw that there was a social issue that needed to be addressed and that was eating disorders and access to treatment. So, I think the tension arises is that with over time the organisation grows. There is tension between the I guess the objectives and the mission and maybe the mandate of the founders and those of the board of directors and the executive. So, **how do you balance that of what the original founders of xxx wanted to establish and wanted to do at the time in response to their own personal experience with that of the guidance provided by the board of directors by the executive team that is put in place and then I guess by emerging needs as a whole**. So, I think some tensions can really develop there and how do you continue to move forward to without too much conflict, while **respecting what the original founders wanted, but also to be us a sustainable organisation with a board of directors with its strategic plan with annual reports** etc. So that is where some of the challenges can arise. And I think that touches on control as well. Right, that the individual founders at what point did they start to relinquish I think some control to the board of directors and to the executive comity.*

*I was also thinking about that volunteers play an important role at xxx. We are a volunteer run organisation, many people who come to xxx to offer their services, come for individual reasons. So, maybe they had a lived experience, that they have been someone who had suffered from an eating disorder themselves, they are the caregiver or parent and they want to find a way to give back. So, they really bring in their **individual needs to the organisation and their individual objectives**, so, what they want to achieve and I think where the tension arises is that **how do you kind of match that with the collective goal of the organisation and that can be challenging**. I think what we really need to is to **ensure that we have really strong volunteer screening policies in place and when we are bringing the staff members on board, just really digging deep to find out why did they want to join the organisation**. Canada works as a team to move things forward, while still respecting their individual needs, like as you said being autonomous driving their own performance but respecting what we need to do at the broader level. And I think that goes to the individual collective goes to the board members as well. Lots of our board members have very individual reasons for wanting to join the board of directors, but to ensure that they are caring out their work but at the same time supporting the collective work of the organisation.*

I can imagine, I think that is a really good tension.

I am glad.

Yes, it is. I haven't heard it before. But what kind of approach do you have, to tackle this tension? Do you have regular meetings to discuss?

I think one of the things is the strong staff and volunteer screening processes, but I also think as part of our annual strategic operational planning process that we need to involve all members with all levels within the organisation, the executives, the volunteers and the board members as well and really clarify what are the organisational objectives, what are the key points in our work plan, what are the goals of each individual within the organisation. And if we can do that then it helps to reduce the level of tension between the individual and the collective. I think it is really important to be clear at all points, you know whether we need to achieve when we agree that. I guess it is about showing also that the executive team always kind of circles back or checks back to our mandate and our vision and our work objectives, before we take on anything new. So, if an individual per example wants to start a new eating disorder treatment centre in one of the provinces and they want xxx to be involved in doing that, instead of on the surface it can sound like a wonderful idea, but is that really part of our mandate and what we need to archive as an organisation, to move forward. So always circling back and checking back, yea that sounds really good, but does it fit in within our organisation objectives and what we need to do. And I think that is a real challenge and establishing partnerships as well. Or partnerships with other organisations that are doing work in the field of eating disorders or partnerships with universities who are doing research. You know we need to look at the level of investment what we are going to making in terms of time, because we do have limited resources in terms of people to do the work we all bring a passion to the table, we are all interested in this field. So, in order to reduce tensions, it is about, okay reality check: Do we have the people to do this, does the support or organisational mandate or is it something maybe we can't do down the road or are we not able to do that.

Okay, just to make sure I understood correctly, does that tension already touches the next tension regarding resources?

Yes, that touches the problem of resources. Yes. It is a tension within our organisation we are just in the process of developing a gesture, we try to get charitable starter in Canada, so that we can do more fundraising. We do some now but it is definitely a tension, we have individuals on our board who really, really to become us, to get charitable starters and that has tax implications, where others want us to stay a non-profit. So that we don't have as much paper work and other government process. So, that can definitely create some tensions as well.

Okay.

I had another one tension the cooperative or competitive, I think that people who are working with our organisation are very committed to the cause, we really want to do a difference. I think there is some a little bit of competitive nature. So, at what point is it better to cooperate, it is always better to cooperate together, but I guess how do you kind of harness the competitive nature of individuals who want to make a difference to the collective good, so they cooperate better together.

But do you mean within your internal team or is it related to other organisations within the same field?

I would say, I guess that is probably more related to other organizations. It is a little bit within our team, but I am not sure if you are interested in the relation with other organisations, there is definitely a tension there who does what sometime I find that our mandates often overlap. Everybody individually as organisations want to do their very best and as individuals. Some

organisations get more facetime, like more attention than others do, so I think that is a tension between organisations.

The only thing I am always wondering about is that lots of people suffer from eating disorders, lots of people need help and I always thought, that it would be the best that as many organizations as possible exist. But still there is the competitive thought, if new organisations pop up or get established, and they offer similar programs.

Yes, and I find that our organisation, just because of the initial founders of xxx, the people who established like I think nine years ago. They really established individual relationships with other organisations and with the [...], so it is our provincial government here and because of that and because we do not receive government funding we have the opportunity to have a voice at the table of the government sometimes. Whereas other organisations don't necessarily, so that can create some tensions between us and them.

Okay, but in the beginning I remember that you have said that you also try to work as an organisation that brings all other organisations together. So that means you see an upside in that tension, that you would rather strive to go in the collaborative direction than in the competitive direction? In order to create a bigger impact all together, did I assume right?

Definitely yes, that is right. So, I think the reputation our organisation has established across the country that we do have the ability to bring organisations together for the collective good.

That is good to hear. Since you said you are not government funded. Could that be also a tension for your organisation that you do not get enough funds or grants, so that you do not receive enough resources or is it not an issue at all. So, per example a tension between profit and social responsibility?

Yes, it does impact our organisation, we don't we get very little funded. We don't get any government funding at this point and we get very little funding from other resources from other sources. So, we are really a volunteer-run organisation and with people volunteering on a fulltime basis to make a difference.

Okay oh wow. I never heard this before. That is incredible, especially nowadays that people can effort financially and have the time to volunteer fulltime.

*Yes, and I think because of that on the positive side of that, we are not constrained by government regulations, well we are, we follow the rules **we are not constrained by internal bureaucracy within our organisation.** We do have a board of directors, but we are very professional organisation. So, the board of the directors trust the work what we are doing and they want to be kept informed, but because when it comes to financial tensions and pressures. **When we do bring other organisations together to address an issue or develop a strategy or the economic impact study we do not have the money to fund those, so we rely on other organisations to come up with the money to provide leadership or to those.** That crates, that has an impact as well the funding issues on the work that we can do internally. **And sometimes the process pressures as part of our team and what we can actually take on when we don't have the funds to bring other people in. So, that can be challenging.***

Okay, yes, I can that imagine. Do you have any other tensions in mind?

*Yes, I was thinking about **the flexibility – efficiency tension.** So imagine we are leading voice-feeding-disorder in Canada, we have a strong reputation, very results oriented, but we are a volunteer-based orientation as I said, so our members, our employees, we are not expected to work on a nine to five capacity, we don't have set hours of work and I think what I have seen, **so individuals set our own schedules, we know what needs to be done and because we are all passionate we get the work done, but I think that is a real positive, because we are so much more efficient as an organisation in achieving our objectives when we are not tied to***

traditional ways of working. We are not focused on, okay I need to be at my desk from nine o'clock to five every day.

Okay that means that people really know this has to be done and they can choose whenever they would like to do it, but then it will be done, just because they know it is important.

Yes, exactly. But as an organisation really our ability to achieve so much and be results oriented comes from the drive of the individuals and from the culture that we have created within our teams. So, we are extremely efficient due to what we have to achieve our mandate.

I going to ask the next question out of my own curiosity, maybe you have some volunteers who work already for a long time for your organisation, but when they leave per example, do you have any struggle to find replacements?

We have a really strong social media and communications team, so in terms on that side we have no problems to get volunteers and we have continued applicants. Prior to covid we run like 70 in person symposiums, whether with speakers, workshops and things like that, like just three-hour events and we never had any issues getting medical professionals, psychologists, doctors, people with lived experience to volunteer to help set up the events. **I think the challenge is sometimes that finding the people with the right skills.**

Yes, I can imagine that.

And as I mentioned before with the volunteer screening is really important because as you may know people, when you are recovering from an eating disorder I think people want to jump in give back and make a difference right away, but people are not necessarily ready for that. So, we need to be careful that people are ready and that is not going to be triggering for them to work for this organisation. So, maybe that is a tension as well, to make sure that people are ready to work in this capacity, we have a lot of parents or adults who come to us and you know that is how I came to xxx as well, my daughter was just recovering, I want to do something I want to make a difference I want that people have the resources, that I never had, but really at the beginning I was told maybe I need to give it some time. So, I think that is the tension that exists in a lot of organisation, like non-profit that an eating disorder organisation, that people come too soon sometimes.

But what is your approach to coop with this? If you realize that a person is struggling?

We do have a volunteer-screening tool, like a checklist and that applies to any speakers as well and anyone who is going to do work with the organisation, we also have a social worker, who will make sure especially if someone is going to speak up on an event or showing their story, someone who can have a conversation with them ahead of time to make sure they're going to be okay, doing that. Because we don't want to put anybody at risk by having them working with us.

But this all happens in the beginning of the hiring process right, but do the employees or volunteers have the possibility to get this support after a while they have worked with you.

Yes definitely, and you know if someone had to step back for a while or they were not ready, we can always welcome them back, once they were. We want to make sure, that everybody is safe while working with us.

Great, one last question, because I think we are already getting to the end, unfortunately.

No, I am talking too much, I am sorry.

No not at all, but sometime people expect to be done after 30 minutes since I gave that as an estimate. Do you have internal tension, which relates to the team maybe?

I think within our media core team at xxx, our executive team. I am trying to think what to say, we work very, very well together as an organisation as a team. I think because we are all volunteers, I mean when I say volunteer we are all working 5, 6, 7 hours a day. It is not

volunteering in that way. I think the tensions may come with some people they feel they take on more responsibility than others do. So, because the way that we are functioning we don't have a boss, as I was used to when I was working for the federal government. I need this, I need you to do this, we really have to figure it out together as we go, what we are need to do and who is going to do what.

Oh, that means a lot of communication or?

Yes, it does mean a lot of communication.

So that means it is not more like a structure, that people are not responsible for a specific thing, it is more like that things are coming up and then you figure out together how you deal with them?

We do have a real structure, we have different committees, which are responsible for different things, like our education committee and our social media committee and communications committee for example and we also have our executive committee which really provides leadership under a board of directors. What I guess what I mean we don't have a formal structure that would be established like an org chart within our organisation, like who reports to you, we still kind of report to each other, but it is very different. Okay, there are tension, but communication is key. [...]

Interview 9 – 10/03/2021

[Introduction]

Okay, perfect. So, if you agree we can already start with the first question, where I kindly ask you to introduce yourself, the organisation and your function within the organisation.

Sure. So, my name is xxx, I work for the xxx or xxx, which is a non-profit organisation in Canada, based in Toronto but serving all of Canada. That was established in 1995 to provide information resources and support for people living with or affected by eating disorders and my position at xxx is special project lead, but like a number of colleagues, since I carry out all reflected out in my job title, like some of my colleagues spend time on the xxx's helpline. So, in addition to focusing on other aspects of our organisations programming I do also spend some time be some of the people who answers inquiries for information, resources, referrals and support through xxx's helpline which includes, like a telephone line, like an instant chat service and I coordinate the production xxx, which is all the bulletin and the lead for different projects. I guess that is a summary of what I do.

Okay, great, sounds that you do quite a lot and that it is very various.

Yes, I think all of us have a variety of different roles even if we have a short title, it doesn't necessarily incoop the vary things that we actually do on a day to day basis.

Okay, I think that is quite normal, but probably even more when you work for a social business.

Okay, if that is everything related to the first question, I think we can already dive into the second one and for me this is the most important one, because it is related to the tensions. So, maybe if you had time before to brainstorm a bit otherwise it is also fine to do it here. Do you have any tensions in mind which relates to your organisation? Within the organisation, but also with other organisations?

Did I miss something about xxx's work and what, we do in terms of awareness raising?

Oh yes, you can also tell about this, sorry.

Okay, because I did write some notes to be able to, I thought that I don't forget anything. So, I am happy to talk about that. There are a number of ways in which we at xxx carry out our cems ?? for raising awareness of eating disorders and stemming information about eating disorders to be public. Even if I would say that awareness raising isn't as a prominent activity as it has been maybe in years past. One of the ways we do raise awareness though is, like coordinating eating disorders awareness week activities. So here in Canada we actually recently celebrated eating disorders awareness week, which takes place annually from February first to seventh and so, we worked with other eating disorder organisations across Canada to create themed social media posts and so, across the country there was consistency in the messages that we are being communicated to the public. And in the previous years we created posters that where send to health centres and other such places across Canada and organized local in-person events. Of course, in-person events weren't possible this year. So, pretty much everything was online and planning for eating disorder awareness week is actually quite a big undertaking and considerably part of our outreach and education role. In terms of planning that has to start many months in advance. Another thing in terms of awareness raising is in participating in the international no-diet-day which is in May and the eating disorder action day which is in June. So, those are two other key annual events for us and there are various days throughout the year dedicates of others mental health concerns or mental health in general. In which kind of make sense to also highlight eating disorder. So, we do that, we do a lot of social media posting on those types of days. In our outreach and education team participate in a variety of community-based events, health and wellness fares, which are opportunities to engage with people in the community and drag their attention to importance of being aware of eating disorders.

Perfect, thank you for reminding me, that I missed that information. But now you have covered everything which relates to the first question?

[nodding]

Okay, thank you so much.

Moving on to tensions then, well as an organisation with very limited resources, both in terms of staffing and financial resources, but that does serve all of Canada, which is a large country covering large [...] collaborations with other organisations is absolutely essential and not only being a large country, Canada has also a very diverse population. Collaborating enables us to raise awareness and diverse needs are much more effectively than doing everything on our own or by ourselves. I think we enjoy working with other organisations, we really do have some strong relationships with other organisations. But of course, there are challenges in collaborations, perhaps when there are several or many organisations in the picture it is not always easy to make decisions that completely satisfy everybody. And we want to collaborate with other groups or communities when there is a fit, but that also does present various challenges an example maybe is: We have in the past tried to work with dance and yoga studios where their leadership was interested in raising awareness in eating disorders in their settings and wanting to support those stuff to help a client or a member who seems to struggling with their body image or eating issue, but sustained collaborative our relationship really come out of this [...], be focused on parents and the weight bias can be very throng in these settings can make it difficult to find enough alignment in our philosophies to work affectively as partners.

Sorry for interrupting, but you did partner with them or you haven't since you realize the expectations are too different?

So, we have explored working together, but we don't have those longer-term types of relationships where we work together on an ongoing basis.

Ah, okay, thanks.

Mh, that's it. Collaborating presents also opportunities to grow and learn, well we do have an expertise in eating disorders and related issues, we of course don't know everything there is to know and this means consulting with others and allowing others to take the lead at times. An example of this is our collaboration with a member of the two LGBTQI+ community. So, we are working on developing an informational resource focusing on eating disorder issues among that community, but we don't have the lived experience expertise internally and so at the outside we recognised it was important to take more of the listening and learning role and developing this resource and not being the once who setting the agenda and directing the work. And at the same time, we have to stay true to our style. So, unless we can feel that stand behind a piece of work that we created with a partner, we can't publish and put our name on it a situation might call for us to a cert more control to participate. So, there is that tension there.

Okay, so just to make sure that I understood right. So, you mean on one hand it is very important for you to collaborate, but sometimes when you feel it doesn't make sense or it doesn't go in the right direction with your values / mission, then you would rather go more in the direction of being competitive?

So, I am not saying that it is competitive necessarily it is more to not deciding to peruse further collaboration or maybe to having to readjust the level of like direction that we are maybe taking within a or providing within a collaboration. If that makes sense.

Yes, it does make sense. Thank you. One more question, since you said you had to change the way of working, as you dived into another topic where you did not have the lived experience. So, you swopped to the role listening and learning. But did this process took a long time, was it challenging, how did you figure out to take another approach instead of being the one who

gives the direction rather being the one to step back and learn something new? Do you understand what I mean?

If I understand your question, I think from the very beginning we recognized our limitations, so, it wasn't necessarily difficult to say we really value your expertise with your lived experience and so, actually we don't want to be the ones making decisions or not that we won't do decisions, but being very descriptive in how the project would be carried out. But as we received the sort of draft, we saw that there would have to be some significant changes to the draft to make it consistent with our style of resources.

Okay thank you. Is that everything related to the first tension?

*Mhh, I can also talk about the tension between **cooperating and competing**. So, we ?? with other organisations asking to support each other to make the most of limited resources. So, while we are seeking [...] **in connecting activities, that would result in duplication of services and potentially directing clients away from us with xxx and towards them**. That is tricky. And we also have to maintain transparency with the other eating disorder organisations across the country. So, that we don't attract attention away from them and the great work what they doing in their region. As we carry out our public outreach and education activities. So, we are based in Toronto, but we may be invited by an organisation let's say in another province where there is already one of our fellow eating disorder organisation, that is well established and doing very great work there and so we want to be transparent that if we are going out to these other regions in our country and doing our work that it is not that we are trying to step on anybody's toe when we do that.*

Okay, for sure. But how can I imagine do you get in contact with these organisations and speak about, okay is it possible to go there, since we might cover this topic in a better way than you do? Or does this transparency work?

Yes, sometimes it means getting in touch and say heads up we have been invited to dadadada. But does it also happen that you get a bad reaction, is it mainly that the organisation behaves the same way as you do? Or does it happen that they are super competitive and do not want the collaboration?

Well to be honest my colleague the outreach and education manager would be the best person to fuel this question. So, I won't be able to say from my own experience, because I am not the one who is managing those relationships.

Oh yes, for sure. Sorry for being so detailed.

No, you didn't know. So, can't fault you with that.

True, but thanks for letting me know.

Okay, I just go through my notes.

*Well I can also talk about how the reality of the eating disorder field **very underfunded by the public sector, that means that organisations such as ours have to be constantly pursuing grants and sponsorships and financial donations** and so that means to really having to be mindful and respectful of when I would say local eating disorder organisation are holding fundraising events. So that we aren't having events to close each other or detracting attention away from them. As well as being aware of the other organisations when there is a risk their activities avert financial support for xxx. The eating disorder community is small, it is a small pool to draw from. Right, there is not going to be these huge numbers of members who have that great interested in supporting eating disorder work and so we have to be mindful of each other and balancing that cooperation and competitiveness. It doesn't benefit any of those us in the field to never cooperate never with members and also balance the competitiveness which*

seems to be inherent the nature of having not that many options when it comes to this grants and sponsorships or opportunities.

So, this tension what you have just described it goes or it belongs kind of still to cooperating and competing tension. But is it also a tension in itself? Because you said it is really hard to get grants or funding etc. I think it must be really hard on one hand to be profitable to carry out your programs, but also on the other hand to fulfil the social responsibility? Is that correct?

[Pause]

Because you have said, you have different programs and then you are in a really small community and trying to offer not the same things as other organisations within this field. So, I imagine at least, maybe I am wrong, that it is quite hard you fight for the same grants to have money within the organisation, but on the other hand you have to have this money to fulfil your mission as an organisation, to support people, to raise awareness, all these things you have mentioned in the beginning. Is that also a tension, that you always have to find ways to get financial resources, but at the same time to fulfil a social mission?

So, *having to do a lot with a little?*

Exactly, in very consist terms. Yes, I guess you can say that. Again, we are a small organisation and yes, we are operating a helpline across all Canada, we are offering outreach and education programming. Delivering presentations and workshops to lots of different community groups and organisation across the country. Though, you can say that.

Yes, it seems that you have to do, as you have said, a lot with a little resource.

Okay, thank you. Do you have any other tensions in mind you would like to speak about?

I think it would be the two of top of mind ones.

[Ending]

Interview 10 – 10/03/2021

[Introduction]

Do you have any questions so far?

No, no that is fine, I think I can see a few that apply to xxx and the work we do. I am happy to sort of roll into it.

Okay, that is perfect. Cool then I think we can already start with the first question where I kindly ask you to introduce yourself the organisation and your function within the organisation.

Alright. My name is xxx, I am the CEO of the xxx organization, which obviously makes me overall responsible for that organisation and any subsidiaries.

Do you wanna know a little bit about what Butterfly does, before we kick off?

Yes, that would be amazing actually.

We are a non-for-profit organisation, we have slightly over half of our funding coming from government. We work in the areas of prevention, sort of school programs, school interventions around body image and treatment. So, we run face to face, but now online or virtual outpatient programs and we run the national helpline for eating disorders, which is a 8 am to midnight 7 day a week service for those who wanna call or with chat if needed [...] support. And then we have also built a [...] for eating disorders as well. And then we provide support both online and face to face for parents. We are about 70ty people in our organization across different cities.

Okay, thank you for this information.

Then I think we can already start with the second question and that is the most important one for me, just that to tell me what kind of tensions does your organisation mainly face? And additionally, it would be great to hear about upsides or downsides of those tensions.

Yea, perhaps the one that is most obvious is cooperate vs. competitive. So, we work in a non-for-profit space where there is a defined amount of money that is donated and it comes from government. Usually and we are a national or federal charity, but in each of the states, so, in the main states there exists similar organisation that are funded parsley by state governments and also by [...]. In Victoria there is xxx and in Queensland there is xxx, we are sort of the national voice, but none of these groups report to us. But when it comes then to funding for resources you know we find ourselves sometimes in competition as a [...] to often needing to sort of collaborating for the graded good. So, one of the questions is how do you deal with that I guess that is the question three. I think upsides, you know if it is a competitive world that means as a charity you need to be looking at measuring outcomes of what you do, as supposed just of outputs. So, for examples if you work for within schools you can measure the number of programs you run, but are you also measuring the impact that heads on the students and the teachers in terms of attitudes or [...] a like. I think the positive of a competitive environment is that it keeps everyone being [...].

I think the downside is that if you are all competing for funding sometimes you don't have the same voice to government or decisionmakers and that can confuse and can split resources or duplicate resources. So, there is a few observations from that area. I guess I can talk about how we manage that you know in question three.

The other tension that really, really stands out is I guess you got profit vs. responsibility. So, for us we are a non-for-profit organization, but of course we need to remain solvent and we need to have a positive cashflow. So, often therefore we are needing to rise funds in the community and from government. I think this challenge really relates to our government funding. So, we are about 50 percent funded by the federal government and we need to advocate for a change and that may upset the federal government and so the tension is how do you [...] and do you advocate for those in need where by the same time understanding that if they were

would withdraw their funding it would be a significant threat to the organization's survivability.

So that is a bit of a tension, the upside of this is it really recuse you to have absolute clarity about what battles you want to fight, so, you know there are many things you want to change in the world and you know you can't change them all and so, you need to pick the battles that you wanna fight with the federal government and the hand that pays you on occasion. That is one other one.

And I guess the third it was **collaborating and control**. So, **we offer treatments and services, so we run outpatient programs and like, which sort of makes us part of the system of care but at the same time as the ethical of the organisation we are advocating for change in that system so for us the challenge is how can you be part of the system but also sign the system as not adequate**. So, there is a bit of the tension between what role do you actually play. For us the positive here is, we need to ensure that we are innovating in terms of treatment and in many cases we would do so where it is not financially viable for privily organisations to do so. So, for us it is about proving certain models of care might work and trying to create the conditions of success from a funding perspective to [...] other organisations to deliver. So, that probably are the three biggest tension that we are have as an organisation. So, I happy to get a question ready if you wanna talk about how we manage those.

Yes, I think you can keep going and tell me how you manage those, what is your approach or do you have specific system. And then I will ask my questions later.

Okay, in terms of how we manage those, if I take the cooperate competitive, which was the different state-based organization vs. a national organization. What we have done in recent time we formed a alliance between those organisations, where they [...] of understanding. And what enables us to do is meet together regularly talk about what we might jointly advocate for and then agree that we might at a state or federal level or pursue different agendas, but at least we have one voice to the government in certain areas. So, we work to pick which we might make the most difference and then we have a united voice, which perhaps a recent example would during covid. You know the supermarkets were very restricted in terms of food, there was a lot of hording going on. So, we fought at the alliance that people with eating disorders could be prioritized with shopping hours and a like there weren't subjected to some of the conditions as others in the community were. So, I guess coming together as groups and understanding how each other want to work and to focus.

From a profit – social responsibility, that is the tension with governmental funding we meet regularly every forth night with the federal department of health. So, it is very clear what kind of agenda we are pursuing. In or contract we agree on a workplan. So, we agree jointly this is what we are do. It could be seeking advice from lived experience, it could be sitting on technical advice for groups or likewise. So, for us it is about prices. So, if we going to educate for something to change the only tent to give the government to give prewarning, so they can get ready to respond. So, we still get our point to cross, but we do so I guess in a respectful way.

And the third one I have talked about collaborate vs. control, **I think that is a hard one for us to navigate, because we feel the need to be part of the system to understand the system of care, but that does create a tension**. So, it is really frustrating about communication that people know what we are doing, why we are doing it and we are not I guess communicating, what they do is bad it is more that there might be a gap in the system and you know we think that gap needs to be filled. And I think the other area is that we have our lived experienced network. So, a group of people that we can call on that have had their lived experience and they can look at issues and can form related opinion and that gives us the possibility to say, **it is not just our**

organisation it is the voice of the people we represent, which is quite powerful. That is probably about the areas I would say we are used to manage.

Okay, thank you. I have just a question about the last one, because you have said you also have people who have lived experience. So, do you employ both, professionals and non-professionals, like people with lived experience?

Yea, it is a mix of both, within our organisation we have, you know qualified psychologists and clinicians and we also have people with lived experience. So, we felt that was not enough, so, we also have a formal network and a lived experience advisory group, which consists of 14 people across Australia. They are not employees, but we pay them a consultant fee. So, if they do work for us or attend a meeting or respond to a question there is a contract that has an outlay right. And that seems to be what is traditionally done here in Australia, which is in order to restrict [...] their voice we can't do it free of charge all the time. They do not get paid a lot, but it is enough just offset their time.

Okay perfect thank you. And one more question, do you also face like internal tensions within your team? Maybe between professionals and non-professionals? Do you face tensions like that as well?

Mhh, yea I think broadly there is tensions because in organisation like ours it is small, but not that small, so we have a variety of different backgrounds so sometimes there is a debate and discussion about lived experience, which is one person's personal perspective vs. someone's professional knowledge. That could be challenging at times, could be also be beneficial because as you argue both sides of the point mean to get to a better result. So that does occur. I think if you look at the national standards, you know quality health care and service delivery in Australia, it requires that all treatment programs have [...] design with lived experience present, because that needs to be reflected in order to ensure that you have a qualified system. So, I think it is just generally understood that lived experience is a critical component of any kind of system design. And so, I think you are right there is tension, but it is manageable, as long as the individuals understand the roles that they are playing and that they respect each other's opinion.

Okay, that is good to know. I have just one more question regarding what you have said. Because I am not sure if I understood right, you said that you are the national organisation and that there exist different organisations within different areas, but they do not belong to you. Is that correct?

Yes, that is right. You often call us a pig body, but the other state-based organisations don't report to us. So, they are usually funded by state government and they might deliver services at a state-level, but nothing nationally. We are funded by the federal government and we provide kind of the helpline services, across the whole of the nation. So, we probably call ourselves a pig-voice for eating disorders. So, we touch a lot of the states in this country, but we do so more at a national level. That does create a bit of tension of course, because you know if you are doing work in someone else's state you need to make sure that you sort of not overlapping or stepping on each other's toes.

Yes, but does it happen that organisation that they feel that you step on their toes? Or do you always find a good way of collaboration?

Well I think, well I have been with xxx about two years from now and I think it happens every now and then, historically and xxx has been established 17 years ago, so, on occasion it does happen and often it is just misunderstanding or a lack of communication. But I think by forming the alliance to inform all the associations the communication is much better now.

Okay, that is good, perfect thank you. And then regarding the last question I was just wondering does this topic comes up in the daily business, or do you have a system how you recognize the tensions and is it always on the table that you try to balance those tensions? Was it surprising that I asked especially for the topic tensions?

So, not surprising I think you just gone through a strategic planning process for the next three years and as part of that we did a lot of stakeholder interviews. So, we went out to other associations, lived experience to clinicians in the field, to donors and so on, just asking them about the role we play and in the number of cases they would raise those tensions. As thing that need to be considered in our strategic plan. So, I think from time to time we do a formal review you know what we need to manage and understand and then on an ongoing basis, because you know it is built into our plan we should sort of understand what we are doing to MINIMIZE THE NEGATIVE SIDE OF THOSE TENSIONS. You know some days more different to others, you know sometimes we are dealing with quite a lot of tensions and on other times it doesn't come up for a month or so that it is definitely in our strategic plan about how we balance some of the tensions we have talked about.

Okay, interesting. Thank you.

I just go quickly throw my notes, if I have further questions. Actually, I think from my side everything is clear so far. Do you have any questions?

No, no, no. That's fine, it has been good to chat half around the world. What time is it for you over there?

[Ending]

Appendix F: Polarity Map Template

Analysis Polarity Thinking



Organisations' name	
Interviewee	
Interviewees' profession	
Location	
Target Group	
Organisations' main activities	

Paradox / Tension		
Explanation		
Upsides / Values		
Downsides / Fears		
How to deal with the tension		

Appendix G: Polarity Map for each NPO inclusive Feedback

Organisation 1:

Tension 1	Awareness	Understanding / Medical Service
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Trying to close information gap with different events, projects and tools, like conferences and webinars - Information spreading, especially with information people might not be aware of 	<ul style="list-style-type: none"> -Humanising the illness is about highlighting more than signs and symptoms, it's about showing the consequence for the person and all of the aspects of someone's life that it impacts, that it's not really about food or weight, it's not about vanity or attention seeking.
Downsides / Fears	<ul style="list-style-type: none"> - Some people have the opinion that awareness is not necessary, rather that treatment is needed - The staff needs to be highly creative, to come up with new ideas for the awareness events each year; it is a challenge - Organization gets sometimes criticised by people with ED, parents or the public via social media, or in person (before Covid), email or phone 	<ul style="list-style-type: none"> - Big information gap; 200.000 studies about depression in comparison to 15.000 about ED - People without lived experience see it as a lifestyle choice - Stigma arises: Stereotypes, misconceptions and spread of incorrect information - Correlates with the problem of the gap of research; it exists mainly research about the stereotype -this can be superficial because they don't really understand an eating disorder, unless it's affected them personally or been in the family.
How to deal with the tension	The organisation provides information, support and understanding and also educating programs	

Tension 2	Financial Sustainability	Social Responsibility
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Many people have suggestions for new fundraising ideas/events - The organisation has the possibility to contact the parliament; issues get public recorded - Organisation receives sometimes donations from families, which had a loss in their families due to an ED 	<ul style="list-style-type: none"> -Part of the role is to ensure that the issue of eating disorders does not fall off the agenda, the organisation advocate for health services that are specialised and well-resourced. Those services work well, where they are available.
Downsides / Fears	<ul style="list-style-type: none"> -Public sympathy is small; people usually fund for other mental illnesses - Depended on the health service (HSE), since the organization is funded by the HSE, therefore they do not get into a public disagreement with the HSE. - Organisation does not receive their promised funds, which slows down its processes - Funding relates to politics, therefore it is often not accountable 	<ul style="list-style-type: none"> -The health service established a so called "clinical team" in order to provide more service for ED, the program is not successful, since it does not provide the promised resources (Part of the Model of Care is to create 16 teams, 8 for children and adolescents and 8 for adults. There are 3 teams at the moment, they hope to create 3 more by the end of 2021)
How to deal with the tension		

Organisation 2:

Tension 1	Funding	Social Responsibility
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Receive funding from various organisations in different sectors -Received Covid-relief-funds from the government 	<ul style="list-style-type: none"> -The money the organisation receives is mainly unrestricted, which means the organisation can freely decide on how to use the money to work in line with their values & its social mission
Downsides / Fears	<ul style="list-style-type: none"> -Companies who provide money for the organisation might relate to the privatisation of healthcare / diet culture / racism / sexism etc. - those things upheld by capitalism & perpetuate eating disorders; however, the organisation also relies on capitalism to fund its programs -Government funding is highly competitive 	<ul style="list-style-type: none"> -Rely on those funds to pursue its social mission
How to deal with the tension	<ul style="list-style-type: none"> -Outreach & education activities directly discuss impacts of diet culture, poverty, racism, etc. on the development of eating disorders -Engaging in activism efforts to advocate for more accessible eating disorders treatment in the province/country (e.g. letter writing & petitions, meeting with government officials) 	

Tension 2	Evidence-based Support	Alternative Support
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Providing therapy modalities, cognitive behavior therapy, dialect behavior therapy -Providing experts / people with degrees and credentials 	<ul style="list-style-type: none"> -Providing art-groups -Providing people with lived experience -The organisation aims to hire a diverse group of people
Downsides / Fears	<ul style="list-style-type: none"> -While hiring professionals they want people with the highest degrees, but those are most of the time white and heterosexual people, because of the discrepancies in getting those degrees (bias) 	<ul style="list-style-type: none"> -Donors like to see most of the time evidenced-based support
How to deal with the tension	<ul style="list-style-type: none"> -Establishment of a good hiring process -Incorporate both evidence-based and alternative support programs -Organization of panels & events that highlight the importance of lived experience (not just professional expertise) -Engaging in group facilitation practices to minimize the power imbalance between service users and service providers (asking for & incorporating group member feedback, using invitational language, avoiding assumptions and judgments) 	

Tension 3	Productivity	Self-care
Explanation		
Upsides / Values		<ul style="list-style-type: none"> - While hiring the organisation is very sensitive and sympathetic
Downsides / Fears	<ul style="list-style-type: none"> - It is difficult to find appropriate candidates and it is time-consuming 	
How to deal with the tension		

Organisation 3:

Tension 1	Profit	Social responsibility
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Do not receive much government funding; which means the organisation is independent from the government 	<ul style="list-style-type: none"> -Tries to get political attention, which pushed the government to create a mental health champion in Northern Ireland
Downsides / Fears	<ul style="list-style-type: none"> - The area ED is in generally poorly founded in Northern Ireland -Competition with other organisations/charities, therefore it is difficult to receive funding -There exist not enough interest in picking the topic ED up; through the lack of research, information and the small number of affected people - Decision makers are often "business people" or "money people", who never experienced themselves an ED; connected to the lack of understanding that ED is a mental and physical illness - Trust issues 	<ul style="list-style-type: none"> -The health champion dismissed the request for help; which means people are responsible even when they are not aware about the topic -Not enough resources (staff, people, etc.) to provide or fulfil social responsibility
How to deal with the tension		

Tension 2	Competition	Cooperation
Explanation		
Upsides / Values		<ul style="list-style-type: none"> -The longer the organization is in the field of ED the better the integration -Charity function as a link between professionals and people / families who are struggling -Due to the fact that the charity receives governmental funding it gives them a good reputation within the ED sector
Downsides / Fears		<ul style="list-style-type: none"> -Does not receive the respect of professionals -Does not get asked for their opinion -Does not get integrated in the discussion
How to deal with the tension	Establish good and lasting relationships	

Organisation 4:

Tension 1	Reponsive	Reactive
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Trying to work intentionally -Operating from a sustainable perspective -Slowing down and creating the biggest impact possible with the available resources 	<ul style="list-style-type: none"> -Aim to solve problems as quickly as possible (related to the support of clients)
Downsides / Fears	<p>"It can often feel like we're not moving fast enough, doing enough, helping enough people... this takes a lot of time to continually work through and remember that it's okay to move more slowly than capitalism demands"</p>	<ul style="list-style-type: none"> -burn out of employees -acting in ways that actually cause harm to our staff or community because we're not being thoughtful enough -contributes to upholding capitalism
How to deal with the tension	<p>We spend a lot of time prioritizing (and re-prioritizing) care and rest. Usually when one or many of us are feeling burnt out, it's a sign that we're moving too quickly. Rest for us is intentional... it's not just checking out and watching Netflix, it's about re-wiring about what 'work' can look like. It can look like connecting with community, learning through books and podcasts, etc.</p>	
Tension 2	Individual	Collective
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Providing support on an individual level -Recognized that providing collective good is also beneficial for individuals 	<ul style="list-style-type: none"> -Zooming out to meet the needs of the community at large -Trying to step out of their own individual experience -Employees spread awareness, educate and get involved from a collective lens
Downsides / Fears	<ul style="list-style-type: none"> -Employees/Volunteers have often the individual lens, rather than the collective lens -Does often miss cultural differences, racism, etc. due to a stereotype: "We can emphasize and shift our behaviours/attitudes, but will never have that experience" -Employees/ Volunteers who have lived experience can potentially trigger others by sharing too much of their own experience/behaviours 	<ul style="list-style-type: none"> -The shift from an individual to a collective perspective is quite difficult, since it is grounded in the individualistic society (USA). -The way Eds population is represented is not represented of the actual people who struggle
How to deal with the tension	<p>"Evolution of our own understanding in our desire to help people"</p>	

Tension 3	Funding	Social Responsibility
Explanation		
Upsides / Values	-Align the organisations' values and policies with the funders expectations	-Trying to create the biggest impact possible with the received funding -Deeply investing in understanding to working to this mental system of oppression -Organisation aims that their staff works from a more grounded and centred space
Downsides / Fears	-Funding/Resources are limited -Due to Covid it is even harder to receive funding	-Leads to burnouts of the employees -"Employees care too much, they put their whole hearts into it, forgetting to think about themselves"
How to deal with the tension	Trying to find an approach to keep doing this work for a long time	

Tension 4	Productivity	Self-care
Explanation		
Upsides / Values		- Sharing own experience
Downsides / Fears	- By sharing too much of their own experience it can potentially trigger others (unsafe)	
How to deal with the tension		

Organisation 5:

Tension 1	Collaboration	Control
Explanation	Within the team collaboration is needed, since the responsibilities do not have a clear structure. "Many cook's in the same kitchen"	
Upsides / Values	Collaboration with other organisations in the field of eating disorders can close gaps. The organisations trying to cover different topics, such as research or even other mental illnesses	Staff's flexibility allows us to quickly shift focus to whatever needs to be prioritized at the moment
Downsides / Fears		Sometimes projects may be slowed down due to too many staff involved
How to deal with the tension	More-clearly delineate who needs to be included in projects, and at which point	

Tension 2	Flexibility	Efficiency
Explanation	That you know if I helping my colleague with something I don't feel the need to check in and need an approval for every little thing, because that would slow down productivity and slow down time, but that is only build because of the trust my colleague has in me and vice versa.	
Upsides / Values		
Downsides / Fears		
How to deal with the tension		

Tension 3	Financial sustainability	Social Responsibility
Explanation	"We are NON-PROFIT organization and all monies earned must be re-invested in the organization's programming and services. Commitment to social responsibility can sometimes make it difficult to focus on raising enough funds.	
Upsides / Values	<ul style="list-style-type: none"> - The received funding goes directly into the programs, which the company provides - The organisation can offer therapy sessions for less than 5\$, therefore the service is quite accessible 	<ul style="list-style-type: none"> - Employees work for the organisation, since their objective is to help people and to safe life's - Through there service, less people get infected by an ED
Downsides / Fears	The employees' salary is low	Employees' concern with clients' well-being.
How to deal with the tension	Raise more funds from diverse funding sources.	

Tension 4	Awareness	Medical Service / Understanding
Explanation	"There are many preconceptions about how develops EDs, what they "look" like, etc."	
Upsides / Values	<ul style="list-style-type: none"> - Organize different events to raise awareness, for instance the eating disorder awareness week in February 	<ul style="list-style-type: none"> - The understanding has grown over the past years, due to the work of social institutions "We have come a long way in the mental health field and made a big step forward"
Downsides / Fears	<ul style="list-style-type: none"> - Influences the attention for other mental illnesses in a negative way - Pushing awareness in the field of ED can be frustrating for the employees "Makes it harder to do our job" 	<ul style="list-style-type: none"> - Organisations who belong to the mental health care sector do not cover ED, since it is seen as a lifestyle choice. - Spread of inaccurate information from non-professionals and professionals; therefore a wrong image develops - Lack of attention and research - Misunderstanding of ED
Approach of how to deal with the tension	Increase awareness of eating disorders and work to change diet-culture from a systemic and cultural level.	

Tension 5	Research (Future)	Research (Status quo)
Explanation	Current research on eating disorders is lacking, especially considering it is a mental illness experienced by millions of people worldwide each year.	
Upsides / Values	<ul style="list-style-type: none"> - Increases the success of the programs / services - Raise the productivity of the economy, since more research would provide better treatment options 	<ul style="list-style-type: none"> - ED organisations make the best of the current situation / available research "Organisations getting stuff done" - The organisation collects data via surveys to measure the satisfaction of clients (8 corner assessment)
Downsides / Fears	<ul style="list-style-type: none"> - Lacking - without research, funding does not get appropriated to treatment, or other important resources 	<ul style="list-style-type: none"> - Difficult to measure the efficiency of the services - Inequality to treatment
Approach of how to deal with the tension	Increase awareness of EDs among academic, those funding research, and those treating mental illnesses.	

Tension 6	Traditional	Innovation
Explanation	Related to Covid-19	
Upsides / Values	<ul style="list-style-type: none"> - Personal connection 	<ul style="list-style-type: none"> - Able to provide more services across the globe through digital services, which leads to growth of the business
Downsides / Fears	<ul style="list-style-type: none"> - Fear about the change "Can we do this online, is it safe, does it feel the same, is it effective, will anyone show up?" 	<ul style="list-style-type: none"> - Thrives people even more in isolation and changes the level of sickness, which leads to an increase of work
Approach of how to deal with the tension	Plan to provide a blend of virtual and in-person services, once it is safe to return to in-person services. We may also implement temperature checks and mask policies.	

Tension 7	Clinicians	Non-clinicians
Explanation	employs a mix of clinicians (LMHC, PsyD, etc.) and non-clinicians	
Upsides / Values	<ul style="list-style-type: none"> - Professional experience - Enables the organisation to provide evidence-based practices - Represent a safe and appropriate environment in support groups - Education Training: Same level of profession, can create a higher impact / better communication 	<ul style="list-style-type: none"> - Sometimes non-clinicians reach better to patients, since they want to be supported by someone with lived experience
Downsides / Fears	<ul style="list-style-type: none"> Sometimes non-clinicians lack an understanding of eating disorder treatment knowledge 	<ul style="list-style-type: none"> sometimes clinicians lack an understanding of operations / non-profit organization knowledge.
Approach of how to deal with the tension	Increase cross-training of basic knowledge amongst departments through short, staff trainings	

Organisation 6:

Tension 1	Individual	Collective
Explanation	Does the organisation serves everyone; who are they serving and how	
Upsides / Values	Ideally everyone feels that they have a place to connect with others in whatever place they are in.	<ul style="list-style-type: none"> -Aim to serve anybody at any stage of the illness -Organisation grows by serving the whole country - Promotes integration
Downsides / Fears	-ED consist of many different elements and very unique stories, this makes is difficult to serve individuals, but also the community	<ul style="list-style-type: none"> -Status quo: Available treatment options may not serve everyone, due to the gap in research and traditional treatment. Makes it more difficult for the organisation to shift from an individual to an collective approach
How to deal with the tension	Constant conversations about improvisation and growth	

Tension 2	Traditional	Innovative
Explanation	Covid	
Upsides / Values	<ul style="list-style-type: none"> -Personal connection with the community, for instance the walks in person 	<ul style="list-style-type: none"> -More flexible by working from home -Providing additional support groups -Establishment of live Facebook conversations called "leader connections", in order to stay in contact with colleagues
Downsides / Fears	Not all opportunities were accessible for folks. They may not have been able to participate in person and/or at a particular time.	<ul style="list-style-type: none"> -Seeking treatment is risky for some individuals: it does not represent a safe environment, due to the working hours and the presence of their loved ones -Additional support needs for the community put pressure on the team -No personal visits possible and in person events had to be rescheduled -Different way of working, adaptations were needed
How to deal with the tension	-Change of work volume, meeting times and redistributions within the team	

Tension 3	self-care	productivity
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Organisation gives employees / volunteers with stress time and space -Provides the possibility to step back -Aims to create a "honest" culture -Flexible working hours; employees / volunteers can regularly attend personal appointments -Open conversations 	<ul style="list-style-type: none"> -High performance expectations due to its responsibility to its community -Internal business deadlines
Downsides / Fears	<ul style="list-style-type: none"> -The expectations from employees / volunteers and organisation can differ; such as work-life-balance -Legal regulations -Having those conversations can be challenging for employee/volunteer and supervisor 	<ul style="list-style-type: none"> -People in a non-profit-organisation do not get compensated in the same way as in a profit organisation -Expectations can differ regarding the workload -Employees/Volunteers with lived experience in mental health are not always able to manage high-pressure times well, which is for both (Employee/Volunteer and supervisor) challenging
How to deal with the tension	Recommendation for employees / volunteers: At least two years of strong recovery	

Tension 4	Competitive	Cooperation
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -People establish new organisations in order to make it better or fill a gap -Business growth 	<ul style="list-style-type: none"> -international collaborations / partnerships -serves greater and better our society -Integrating of new opportunities in the field of ED, even when that means that the organisation has to step back in a specific service
Downsides / Fears	<ul style="list-style-type: none"> -Fighting for resources -Overlapping of services/programs, which creates conflicts -Scarcity of resources has also effects on the audience 	
How to deal with the tension		

Tension 5	Awareness	Understanding
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Trying to bring change and education that ED can affect anyone - Activate people to be able to make a difference 	
Downsides / Fears		<ul style="list-style-type: none"> - Stereotype
How to deal with the tension		

Organisation 7:

Tension 1	Clinical side	Non-clinical side
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Evidence-based <u>treatment</u> and support for people with ED - treatment that is trauma-informed, culturally relevant which can be hard to find 	<ul style="list-style-type: none"> - Education and awareness in society - Provide information for those who are aware of ED, such as doctors, dieticians, social workers
Downsides / Fears	<ul style="list-style-type: none"> - Communication; no information about the non-clinical side - Lack of transparency 	<ul style="list-style-type: none"> - Communication; does not have a lot of information about the clinical side; therefore important information is not integrated in their programs - Lack of transparency
How to deal with the tension	Increasing communication between the two sides, ensuring that both sides are informed by the other rather than as two separate silos	

Tension 2	Individual	Collective
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Evidence-based impatient approaches / one-by-one counselling - Established their own identity as an organisation - Stay true to the companies' beliefs, ethics and boundaries 	<ul style="list-style-type: none"> - Working with other organisations to create larger government or collective change; obtaining more power - Provides additional resources for clients - Establishes new opportunities, since community-based care is lacking in the broader ED field
Downsides / Fears	<ul style="list-style-type: none"> - traditional approaches to treatment can be harmful/dismissive - often not patient-centred 	<ul style="list-style-type: none"> - Not enough research about community-based care available; therefore it is questionable if the collective approach is effective
How to deal with the tension	-supporting clients to find what approach works best for them, offer collective/community based supports but acknowledge the place for individual/traditional treatment approaches	

Tension 3	Financial Sustainability	Social responsibility
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Possibility to donate - Charging for educational programs (non-clinical side) - Education programs enables the organisation to apply for more grants 	<ul style="list-style-type: none"> - Providing free of charge support / treatment, which makes it accessible for everyone - sustainable programs - The organisation aims to provide a healthy work environment for its staff
Downsides / Fears	<ul style="list-style-type: none"> - Running costs; such as the virtual platform - Accreditive trainers are costly - Marketing expenses 	<ul style="list-style-type: none"> - The support is dependent on the capacity of the team, which is dependent on the funding
Approach of how to deal with the tension	<ul style="list-style-type: none"> - Shift focus from tension between the two to how one supports the other, accepting their education side as being profit based, and their treatment side as doing their social responsibility to be accessible for all 	

Tension 4	Cooperation	Competition
Explanation		
Upsides / Values	<ul style="list-style-type: none"> - Working with other organisations across Canada; knowledge exchange - Province and national meetings - Advocacy with the government - Combined strength - Promoting work from other organisations and vice versa - Gaining and building trust within the community - Reducing duplication in the service 	<ul style="list-style-type: none"> - Finding the organisation's identity and filling gaps - Trying to be different
Downsides / Fears	<ul style="list-style-type: none"> - Organisations might be afraid to get harmed 	<ul style="list-style-type: none"> - Duplications in services
Approach of how to deal with the tension	<ul style="list-style-type: none"> - Support other groups and offer resources as they are able, use other organizations as tools to learn from each other rather than has competition 	

Tension 5	Traditional	Innovative
Explanation	Related to Covid-19	
Upsides / Values	<ul style="list-style-type: none"> - Using system which are known to be successful - Be grounded 	<ul style="list-style-type: none"> - Innovative, provides new ways of working - Engaging even more with clients - Creates growth
Downsides / Fears	<ul style="list-style-type: none"> - Outdated technology, which can lead to a loss of clients - Less competitive within the market 	<ul style="list-style-type: none"> - Limited resources/access to funding to support these approaches
Approach of how to deal with the tension	- Have voices within the team that appreciate both sides and work on a more case by case basis rather than choosing one approach or the other.	

Organisation 8:

Tension 1	Individual (Founders)	Collective (Board/Executive)
Explanation	Respecting what the organisations' funders wanted to achieve, but at the same time be a sustainable organisation with a strategy plan and annual reports	
Upsides / Values	<ul style="list-style-type: none"> -Organisation has been established by two individuals in response to personalized lived experience with the aim to solve a social issue 	<ul style="list-style-type: none"> -Better controlled
Downsides / Fears	<ul style="list-style-type: none"> -Founders missed that the organisation is growing -Different expectations than board/executive can arise tensions (mission/objective/mandate) 	<ul style="list-style-type: none"> -Different expectations than founders can arise tensions (mission/objective/mandate)
How to deal with the tension	Engage founders and board members in strategic and operational planning. Co-development should lead to a shared understanding of the steps required to ensure organizational sustainability.	

Tension 2	Individual (Employees)	Collective (Organisation)
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Volunteer-run organisation -Individuals respecting the need for the broader need 	<ul style="list-style-type: none"> -Providing a social worker -Established a volunteer-screening tool -Tries to establish a safe work environment -Employees/Volunteers have the possibility to step back for a while and the organisation welcomes those back -Respecting the need for the individual
Downsides / Fears	<ul style="list-style-type: none"> -Sometimes employees struggle to handle the work -Volunteers/employees individual objectives to the organisation, which sometimes does not match with the collective goal of the organisation 	<ul style="list-style-type: none"> Can be difficult to achieve objectives when volunteers leave the organization and/or are become less engaged over time partially due to fact that aren't being paid. The lack of funding for paid positions impacts long-term sustainability.
How to deal with the tension	<ul style="list-style-type: none"> -Established strong volunteer screening policies and an annual strategic operational planning process, which involves all members with all levels within the organisation. Clarifying organisational objective, determine the key points in the workplan and consider individual and collective goals -Organisations' board cycles back to the mandate, vision and work objective while making decisions - "Reality check: Do we have the people to do this, does the support or organisational mandate or is it something maybe we can it down the road or are we not able to do that" 	

Tension 3	Cooperative	Competitive
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Established good relationships -Have a voice at the table of the government -The reputation of the organisation has established across the country, it has the ability to bring organisations together for the collective good 	<ul style="list-style-type: none"> -Organisations want to do their very best as individuals
Downsides / Fears	<ul style="list-style-type: none"> -Competitive nature in the ED field -Mandates often overlap 	<ul style="list-style-type: none"> -Tensions can arise when an organisation gets more attention than others do
How to deal with the tension	<ul style="list-style-type: none"> Build relationships with through on-going communication with other organizations in the ED field. Follow-through on commitments to other ED organizations so that trust is built. Take deliberate action to share information with other ED organizations so that transparency is maintained. Ensure that organizational mandate is clear and avoid duplication of roles to the extent possible. 	

Tension 4	Financial sustainability	Social responsibility
Explanation		
Upsides / Values	-Organisation does not receive any funding, therefore it is not constrained by internal bureaucracy within the organisation	Volunteer-run organisation, every member works with its heart
Downsides / Fears	-Does not receive any government funding -Rely on the money of other organisations, in order to develop a strategy or the economic impact study -Do not have funds to bring in other people in the organisation, relates to the impact creation	-Rely on the money of other organisations
How to deal with the tension	As a volunteer-based organization, we need to focus on our programs, and finding the resources (people and financial) to fulfill social responsibility commitments can be challenging. In response to this challenge, we are in the process of developing a giving-back program.	

Tension 5	Flexibility	Efficiency
Explanation		
Upsides / Values	-Individuals set their own schedules -Not tied to traditional ways of working -Have continued applicants as volunteers	-All members are passionate about ED and work efficiently -Results-oriented culture, which is driven by the individuals
Downsides / Fears	The main fear is that volunteers take on too much work and are at risk of burnout. Some members of our executive team work 30-40 hours per week (unpaid work). Given that people set their own schedules, it can be challenging to differentiate between work and personal time.	-It is challenging to find people with the right skills
How to deal with the tension	Regular discussions with employees to ensure that they're doing okay, and that they aren't feeling overwhelmed by the amount of work. Learning to set boundaries is also important - specifically, saying that won't be able to carry out a task until another one is completed.	

Organisation 9:

Tension 1	Collaborative	Control
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -Essential to serve the whole country -Serves a diverse population -Enables to raise awareness and diverse needs -More efficient, rather doing it on their own -Present opportunities to grow and learn -In case the expertise within the organisation is missing, it is needed to consult with other and allowing others to take the lead -Developing resources by taking the listening and learning role 	<ul style="list-style-type: none"> -Stay true to themselves and their style
Downsides / Fears	<ul style="list-style-type: none"> -Some decision might not satisfy everyone -Sometimes it is difficult to find enough alignment in their philosophies to work affectively as partners -Sometimes readjustment is needed to make the collaboration efficient or suitable 	<ul style="list-style-type: none"> -More difficult to reach and engage people in their target audience, especially those in other regions of the country, without partnerships
How to deal with the tension	Ongoing assessment as opportunities arise and circumstances evolve; sometimes it makes sense to collaborate and others times it does not	
Tension 2	Cooperating	Competing
Explanation		
Upsides / Values	<ul style="list-style-type: none"> -The organisation respects the work and effort of other organisations -Rather cooperates than competes 	<ul style="list-style-type: none"> -Promotes public awareness of their organization and helps ensure that the public understands the unique role that they play in the ED field in their country
Downsides / Fears	<ul style="list-style-type: none"> -Connecting activities might result in duplication of services and potentially directs clients away -No transparency leads to overlapping -Risk to step in someone's toe 	<ul style="list-style-type: none"> -Fighting for funding
How to deal with the tension	Communication is key, if necessary reach out to the other organisations	

Tension 3	Financial sustainability	Social responsibility
Explanation		
Upsides / Values	-Every organisation tries to be mindful to not detracting attention of other organisations	"Doing a lot with a little"
Downsides / Fears	-In generally the ED field is underfunded by the public sector -Needs to constantly pursuing grants, sponsorships and financial donations -ED community is small, not a huge number of members who have that great interest in supporting ED work	-Risk of burnout; the work can be emotionally taxing, and yet they are carrying it out with very limited resources
How to deal with the tension	Make thoughtful decisions that considerate of the needs of their organization, the wellbeing of the people within the organization, and the wellbeing of the clients that they serve	

Organisation 10:

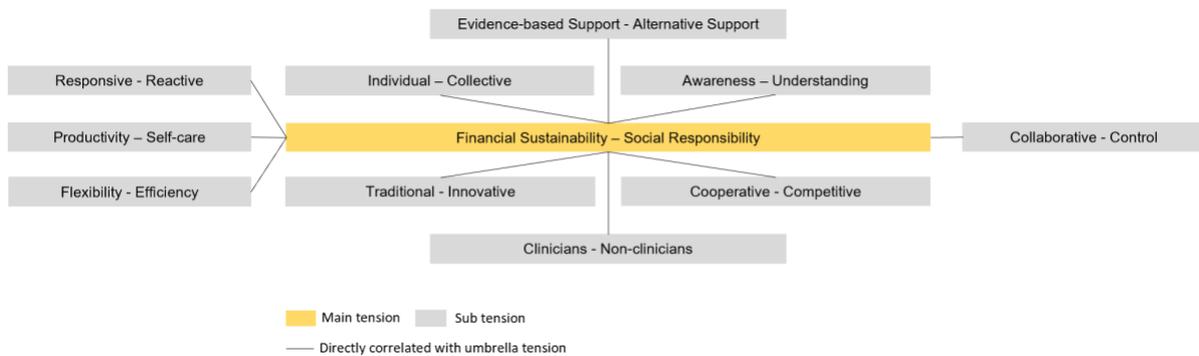
Tension 1	Cooperative	Competitive
Explanation	- Butterfly is a national or federal charity, but in each of the states exist similar organisations, which are funded by state governments.	
Upsides / Values	-Collaborating for the common good	-Receive resources -Keeps everyone accountable -Serve the whole nation
Downsides / Fears	- A split with state/local organisations can result in a fractured vice for change, risking government confusion in terms of areas to assist/invest	- "The voice" of the organisation is different to government / decisionmakers - It can get confusing, if all organisations speak for themselves - Duplicate resources - Organisations might step on each other's toes - Lack of communication and misunderstanding
How to deal with the tension	- Formed an alliance between organisations, including regular meeting - Generated "unit voice" to government and decisionmakers - Measuring their outcomes/outputs (Example: Measure the impact on students/teachers in terms of attitudes while running a project at schools)	

Tension 2	Financial Sustainability	Social responsibility
Explanation	The organisation needs to have a positive cashflow, therefore it needs to raise funds in the community and the government, in order to fulfil their social mission	
Upsides / Values	-There is community understanding that charities need funds to do well	-A strong relationship with Government enables change to occur when you have a trusted partnership
Downsides / Fears	- 50% funded by the federal government: To advocate for change within the health system upset the federal government, which leads to the risk of losing the funding	- Risk of been seen as not advocating for change enough, or "pulling punches" on key issues with the Government
How to deal with the tension	<ul style="list-style-type: none"> -The organisation needs to be absolutely clear about what "battle" it wants to fight -Regular meetings with the federal department of health; make clear what agenda the organisation is perusing - Provide information for the federal department of health on an early state 	

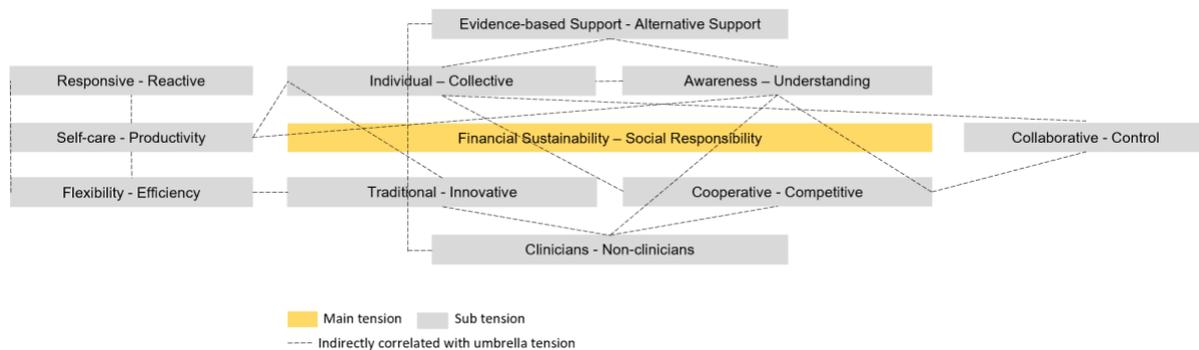
Tension 3	Collaborate	Control
Explanation	The Organisation is part of the system of care by providing treatment and services (outpatient programs), but at the same time advocating for change in that system.	
Upsides / Values	- It is generally understood that lived experience is a critical component of any kind of system design	<ul style="list-style-type: none"> - The organisation thrives for change and innovation in terms of treatment - The organisation is financially able to do so, compared to other organisations - Tries to provide certain models of care
Downsides / Fears	- Be part of the system and to follow their "rules"	-The organisation might risk to loose the support of the department of health care, in case the organization is too critical
How to deal with the tension	<p>Most difficult tension to manage</p> <ul style="list-style-type: none"> -Established a lived-experience network; which represents the peoples' voice (quite powerful tool) 	

Tension 4	Clinicians	Non-clinicians
Explanation	Yea, I think broadly there is tensions because in organisation like ours it is small, but not that small, so we have a variety of different backgrounds so sometimes there is a debate and discussion about lived experience, which is one person's personal perspective vs. someone's professional knowledge. That could be challenging at times, could be also be beneficial because as you argue both sides of the point mean to get to a better result. So, I think it is just generally understood that lived experience is a critical component of any kind of system design.	
Upsides / Values		
Downsides / Fears		
How to deal with the tension		

Appendix H: Direct Relations with the umbrella paradox

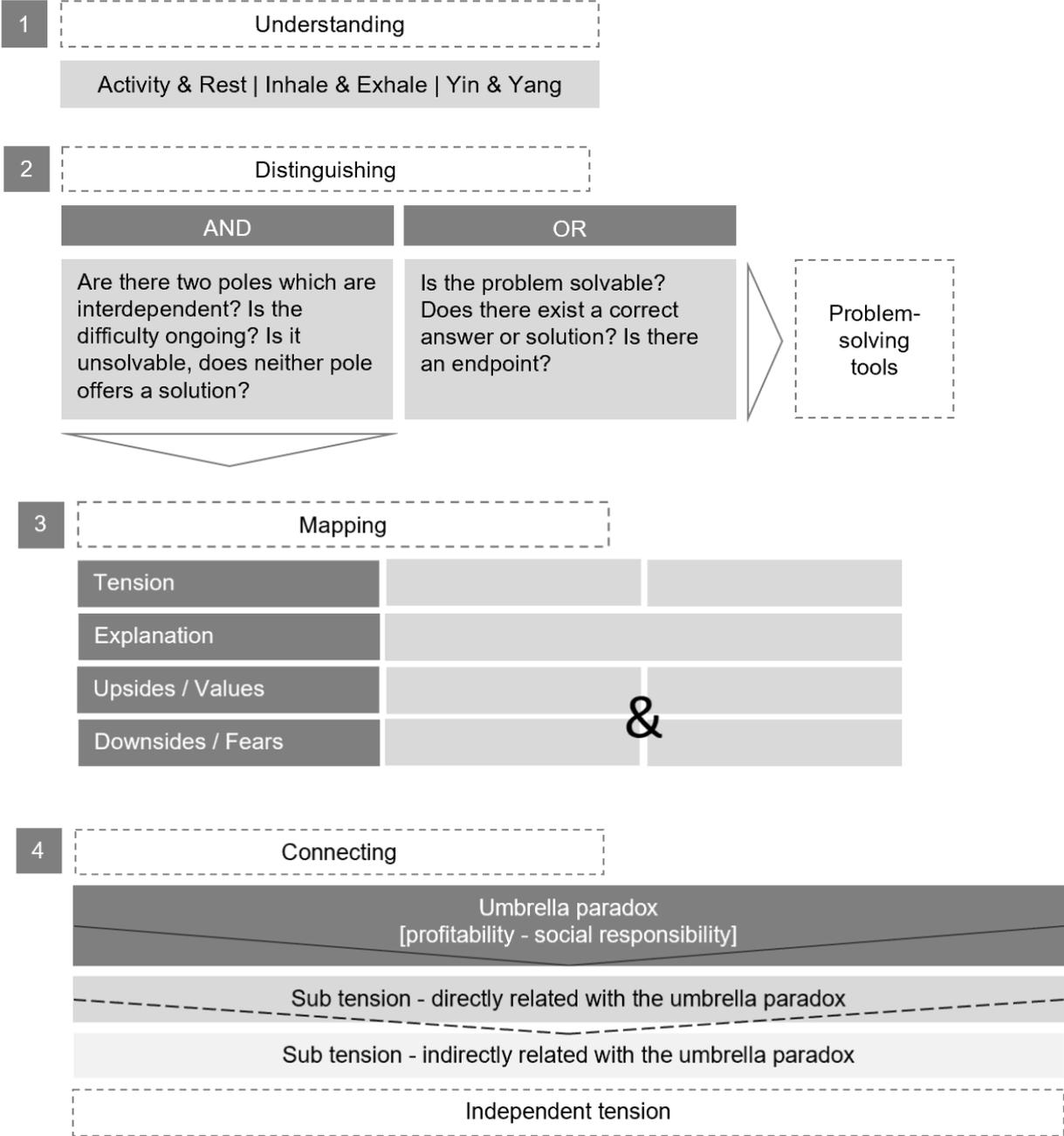


Appendix I: Indirect Relations with the umbrella paradox

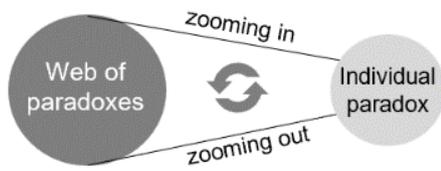


Appendix J: Management Tool for NPOs

The model is based on already existing practice tools and figures: Polarity Map, five-step “SMALL” (Barry Johnson 2020, 13-19, 223; Kayser, Seidler, and Barry Johnson 2017, 684), layers of parts and wholes of sustainability (Jay, Sonderstrom, and Grant 2017, 456)



5 Zooming



6 Classifying



7 Assessing & Action



8 Looping

