Reflections on **Eating Disorder Experiences** in Ireland

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MARCH 2021

Connecting for Life

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BODYWHYS
The Eating Disorders Association of Ireland

Acknowledgements

The authors wish to thank all the participants who generously gave of their time to take part in this research. This research was conducted at the request of Bodywhys and funded by the HSE National Office for Suicide Prevention (in alignment with Connecting for Life, Ireland's National Strategy to Reduce Suicide) and Nottingham Trent University School of Social Sciences. Our thanks go to Bodywhys staff for their support in completing this report.

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EXECUTIVE SUMMARY

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1. Living with an eating disorder is a significant challenge facing many Irish people. Previous research revealed that services in Ireland were under-developed, under-resourced, and ill-equipped to provide the necessary care for people with eating disorders (PWED) and their families. The National Clinical Programme for Eating Disorders (NCP-ED) was established to address these service gaps and published its model of care in 2018.

2. A key element in the planning and provision of care for PWED is to understand the factors which contribute to positive (and negative) service user experiences, and the satisfaction factors for those who access the services. The current research, commissioned by Bodywhys, supported by the National Office for Suicide Prevention (NOSP) and conducted by Nottingham Trent University, was designed to establish a picture of service user experiences prior to the full implementation of the NCP-ED and to identify strengths in healthcare provision as well as areas for development. It is hoped that the findings detailed in this report will prove to be a valuable learning resource for all those involved in delivering care and support to PWED and their families.

3. This research employed a mixed-methods design comprising interviews and online surveys with carers and people who were receiving (or had recently received) treatment and/or support for an eating disorder. 46 people (21 carers and 25 PWED) participated in interviews and 164 people (82 carers and 82 PWED) completed online surveys. Participants reported a diverse range of eating disorder diagnoses and accessed services across Ireland (with a small number travelling to the UK for treatment in addition to receiving care in Ireland).

4. Our key findings are grouped into three main areas of enquiry:

   (1) PWED and carer service user experiences,
   (2) PWED and carer psychosocial health and well-being, and
   (3) PWED and carers' day-to-day experiences of living with an eating disorder.

5. Positive service user experiences:
    a. Across most services most carers and PWED reported being involved in agreeing treatment, receiving understandable information related to the eating disorder and treatment, and being treated with dignity and respect.
    b. Effective services were experienced as being delivered in a compassionate way by staff with specialist skills, knowledge, and experience who responded to both carers and PWED in a non-judgemental, empathic way.
    c. Carers valued health professionals' recognition of their efforts to support their son or daughter, being emotionally supported by clinical staff, and knowing staff were available to respond to their concerns. They appreciated receiving updates on their son's or daughter's progress and being allowed time to raise their concerns with clinicians during sessions.
    d. Meeting with similar others was perceived by both carers and PWED to combat feelings of isolation. Both appreciated the informational and emotional support provided by support groups/organisations.

6. Negative service user experiences:
    a. Some GPs, Emergency Departments and General Hospitals were perceived to lack specialist knowledge and training in eating disorders.
    b. PWED tended to feel excluded from having a role in agreeing treatment in CAMHS, while carers tended to feel excluded in AMHS.
    c. Mental Health Services (both CAMHS and AMHS) were perceived to be under-staffed and under-resourced. Treatments offered varied by catchment area and in some cases were reported to be withheld based on BMI.
    d. The high cost of private treatment placed a significant burden on families and PWED.
    e. Most services (except for private health professionals and support groups/organisations) were not perceived to meet the support needs of carers and PWED.
    f. Carers and PWED rarely received written copies of care plans.
    g. Carers and PWED experienced some health professionals as lacking in empathy and understanding. This hindered the ability of PWED to form trusting and collaborative therapeutic relationships with health professionals and, in some cases, was reported to contribute to disengagement from the treatment process.

7. Carer and PWED Psychosocial Health

   a. Feeling a sense of connection (or identifying) with social groups (such as family and others in recovery), was positively associated with psychological health and well-being for carers and PWED.

   b. PWED that identified more strongly with their family were less lonely and this reduction in loneliness was associated with increases in life satisfaction and fewer negative eating thoughts and behaviours.

8. Experiences of Living with an Eating Disorder

   a. Eating disorders take a significant toll on family functioning and overall health and well-being. Carers and PWED both reported considerable disruption to family relationships. Carers strongly believed that therapeutic support should be provided to families as part of care pathways.

   b. Carers noted the substantial financial cost of the eating disorder with some having to take leave from work or reduce their working hours to support their son or daughter's recovery.

   c. Stigmatisation of eating disorders constituted a barrier to support (both from health professionals and friends and family). Both carers and PWED believed that they (or the person they cared for) were the victim of commonly held stereotypes including that the ED was self-inflicted.

   d. Both carers and PWED shared an understanding of recovery as a gradual process incorporating both physical and psychological components.

9. We have proposed several recommendations based on our wider findings in the areas of: (1) service development, (2) professional training, and (3) supporting carers and PWED:

   a. Service development

      i. Specialist eating disorder service provision is needed in all catchment areas; there should not be regional variation in treatments offered. The NCP-ED should be fully funded to implement all proposed hubs across the country.

      ii. Healthcare services or specialist interventions should not be withheld based on BMI/weight.

      iii. Greater liaison is needed between medical and psychiatric supports for those admitted to general hospital wards and presenting at Emergency Departments.

b. Professional training

  i. Specific, on-going training needs for GPs, Emergency Department and General Hospital staff (including staff in Children's hospitals) should be addressed.

  ii. Training on how to appropriately communicate with families and PWED is needed across all healthcare services (except for support groups / organisations) and should form part of the NCP-ED core curriculum on 'engagement skills'. This is to ensure all those who encounter PWED and their carers understand the challenges faced during recovery (by carers and PWED) and the need for empathic communication.

c. Supporting carers and PWED

  i. Healthcare staff, particularly GPs, should ensure that they routinely signpost carers and PWED to Bodywhys as recommended by the NCP-ED so that both can access informational and emotional support for coping with an eating disorder.

  ii. Therapeutic support for families should be part of care pathways across the lifespan. The importance of preserving the family group (given its positive associations with well-being and recovery outcomes for carers and PWED) should be recognised.

  iii. The NCP-ED Model of Care should consider incorporating the assessment and treatment of family members in accordance with a family recovery model. Mental health issues affect all family members and the recovery needs of each member (and the family as a whole) should form part of the care pathway.

  iv. Consideration should be given as to the most appropriate and effective way to support family involvement in the treatment of adults with eating disorders.

  v. The PiLaR (Peer-Led-Resilience) programme for carers delivered by Bodywhys has shown to be an effective programme for carers and is a key part of the NCP-ED. PWED might benefit from a psychoeducational programme similar to PiLaR but tailored to their specific psychoeducational and support needs.

10. We hope these findings will help to inform future service developments. We recommend, following wider implementation of the NCP-ED, that a follow-up to this research is conducted to ascertain any changes to the service user experiences and outcomes for PWED and their carers.

01

Introduction

SECTION 01

Introduction

In times of heightened pressures on healthcare services, meeting the needs of people with eating disorders (PWED) and their families remains a high priority. Based on epidemiological projections, an estimated 188,895 people in Ireland will experience an eating disorder at some point in their lives. It is estimated that approximately 1,757 new cases occur in Ireland each year in the 10-49 age group[1]. PWED can face a wide range of social, psychological, and physical impacts, including a risk of mortality higher than any other diagnosed mental health disorder for people diagnosed with Anorexia Nervosa. The complex interactions between these different elements may mean that treatment pathways are complex, with risks of missed opportunities to care and support along the way. Such missed opportunities can carry personal impact for PWED and their families, but also carry a considerable economic impact in terms of costs of direct treatment, indirect healthcare costs from secondary difficulties, and the lost economic potential of individuals disabled by the consequences of their eating disorder (ED[2]).

A key element in the planning and provision of care for PWED is to understand the factors which contribute to positive (and negative) service user experiences, and the satisfaction factors for those who access the services. From recent research studies in Ireland, there is evidence that service users express preference for services in which they experience a positive, consistent therapeutic relationship with a knowledgeable provider, and which take a holistic approach (rather than an illness-based approach) to their health[3]. However, such care is not always received: parents of people with eating disorders have described their experiences of having to overcome hurdles in accessing the required specialist care, with communication between parents and healthcare professionals occasionally found to be confusing, and with concerns about the unknown nature of the treatment pathway ahead of their children[4]. Specific exploration of children's services has also indicated that young people, their parents, and healthcare providers experience many barriers to

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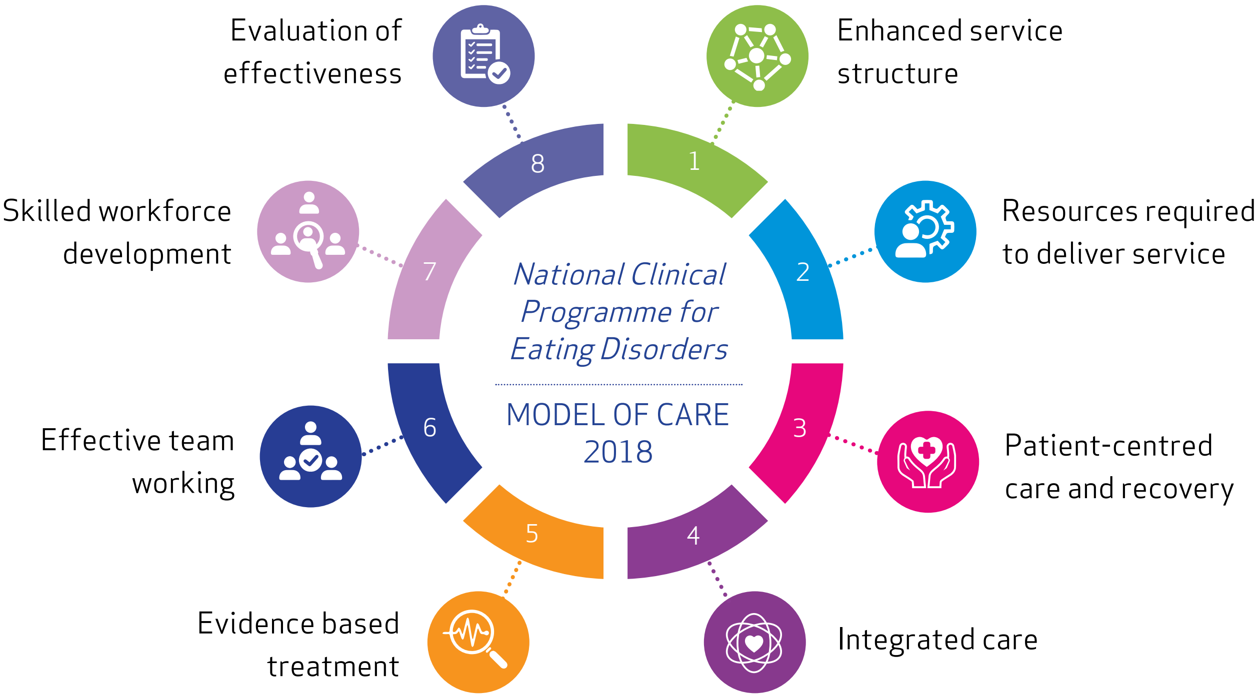
[1] Health Service Executive (2018). *Eating Disorder Services: HSE Model of Care for Ireland.* Dublin: Health Service Executive

[2] Pricewaterhouse Coopers (2015). *The Costs of Eating Disorders: Social, Health and Economic Impacts.* Norfolk: Beat Eating Disorders

[3] Sheridan, G., & McArdle, S. (2016). Exploring patients' experiences of eating disorder treatment services from a motivational perspective. *Qualitative Health Research, 26(14)*, p.1988-1997.

[4] McArdle, S. (2016). Parents' experiences of health services for the treatment of eating disorders: a qualitative study. *Journal of Mental Health, 28(4)*, p.404-409.

accessing specialist ED services, resulting in feelings of isolation and helplessness for those needing support[5]. These experiences in Ireland are not unique: studies from Europe and the United States highlight similar difficulties and dissatisfaction, with multiple barriers to information and treatment, and with difficulties that begin from first raising concerns with GPs[6]. Ireland has been engaged in the current cycle of revisioning its mental health provision since *A Vision for Change*[7] was published by the Health Service Executive (HSE) in 2006, identifying some of the problems facing the country in supporting the needs of people with mental health difficulties, as well as potential solutions to these problems. Following the publication of *A Vision for Change*, the HSE identified four priority conditions requiring National Clinical Programmes (NCP), with 'ED across the lifespan' identified as one of those four priorities. The National Clinical Programme for Eating Disorders (NCP-ED) published a new model of care in 2018, which contained 8 thematic priorities:



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[5] McNicholas, F., O'Connor, C., McNamara, N., & O'Hara, L. (2018). Eating disorder services for young people in Ireland: perspectives of service providers, service users and the general adolescent population. *Irish Journal of Psychological Medicine, 35(4)*, p.301-309.

[6] Regan, P., Cachelin, F. M., & Minnick, A. M. (2017). Initial treatment seeking from professional health care providers for eating disorders: A review and synthesis of potential barriers to and facilitators of "first contact." *International Journal of Eating Disorders, 50(3)*, 190–209.

[7] Department of Health & Children (2006). *A Vision for Change: Report of the Expert Group on Mental Health Policy. Dublin: Government Publications Office*.

Developed by an interprofessional national working group of HSE clinicians, in collaboration with Bodywhys and the Eating Disorder Clinical Advisory Group from the College of Psychiatrists of Ireland, the aim of this model is to reduce the fragmentation of care described above, and increase positive outcomes and satisfaction levels for people who use Ireland's healthcare services. *Sharing the Vision*[8], the 2020 successor to *A Vision for Change*, recommends the implementation and evaluation of the NCP-ED in the medium term.

With evaluation having been noted as one of the NCP-ED's thematic priorities (as well as being a recommended action in *Sharing the Vision*), it is essential to track how PWED and carer experiences of services change as NCP-ED is implemented and establish how well it is working to meet the needs of this vulnerable group. As such, this report has been undertaken to establish a picture of service user experiences prior to the implementation of the NCP-ED. Through interviews and surveys of PWED and carers, we present a picture of where there are currently strengths in Irish eating disorder healthcare provision, and where there are areas for development. It is hoped that this report will be a valuable learning resource for all those involved in the treatment and support of people with eating disorders and their carers.

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[8] Department of Health (2020). Sharing the Vision: A Mental Health Policy for Everyone. Available at: https://www.gov.ie/en/publication/2e46f-sharing-the-vision-a-mental-health-policy-for-everyone/

02

Method

SECTION 02

Method

2.1 Study Design

This research employed a mixed-methods design comprising interviews and online surveys with carers and people who were receiving (or had received) treatment for an eating disorder. This form of research design allowed us to collect and analyse four separate databases that were then integrated for the purposes of interpretation. Our approach assumes that neither qualitive nor quantitative data alone is enough to provide a comprehensive insight into the experiences of living with an eating disorder in Ireland. While the online surveys provided an insight into the types of treatment and support offered to carers and PWED, the interviews allowed us to gain a deeper insight into the factors that facilitated and/or hindered positive service user experiences for PWED and carers. The interviews also allowed us to explore the impact of the eating disorder on participants' daily lives.

2.2 Participant Recruitment Strategies and Data Collection

Ethical approval for the research was granted by Nottingham Trent University College of Business, Law and Social Sciences Research Ethics Committee. Data collection took place between November 2018 and October 2019. Participants were recruited for both interview and survey studies through social media, clinical networks in Ireland, and Bodywhys, who advertised the study via their website, online groups, social media pages and at events involving carers and PWED. The specific inclusion criteria were:

- Participants had to identify as living with (or recovered from) an eating disorder or as caring for someone who was living with (or recovered from) an eating disorder
- Participants were required to be 18 years of age or older
- Participants had to have previous or current experience of receiving care or support in the Republic of Ireland (or the person they cared for had to have this experience). Those who had been receiving support or treatment only in Northern Ireland (or those who cared for someone who had only been supported or received treatment in Northern Ireland) were not eligible to take part

- Participants could only take part in the online surveys if they had made contact (or the person they cared for had made contact) with a health or support service within the previous three years

Interviews were conducted by telephone, Skype, or email, at the choice of the participant. A semi-structured interview schedule was developed to capture participants' own experiences of recovering from an ED or caring for someone with an ED, and the researchers' areas of interest. Participants were asked about their service user experiences (including what aspects they found helpful and what they felt needed improvement), their insights into the development of their eating concerns (or the eating concerns of the person they care for), the impact on family life, and their understanding of what recovery from an eating disorder means/looks like. Participants were free to decline to answer any questions they did not wish to answer and were given the opportunity to talk about what was relevant to them, even if this went outside the scope of the interview schedule. Following the interviews, audio files were transcribed verbatim. Transcripts of email interviews were produced by collating all questions and responses from each participant. All transcripts were subsequently anonymised.

Separate surveys for carers and PWED were hosted online using the Qualtrics platform and included the following measures:

Service experience questions

- Contact with primary care, secondary care, tertiary care, emergency departments, and support organisations
- Contact with private health services and private healthcare professionals
- Types of treatment received from services and healthcare professionals
- Informational and emotional support received from services, healthcare professionals, and support organisations
- The extent to which participants felt they had been treated with dignity and respect by services, healthcare professionals, and support organisations
- The extent to which participants felt they were able to engage in shared decision-making with services, healthcare professionals, and support organisations

Psychosocial measures

- Identification with (1) family, (2) other people in recovery (PWED only), (3) other carers (carers only). This is a measure of the degree to which individuals see themselves as a member of each group and how close they feel to other members of those groups
- Multiple Group Memberships: the degree to which individuals see themselves as active members of lots of different groups, and how close they feel to the members of these different groups
- Perceived Personal Control: the degree to which individuals feel that they are in control of and responsible for the things that happen in their life
- Loneliness

Health and well-being measures

- Satisfaction with Life
- Eating thoughts and behaviours (PWED only)
- Eating Disorder Symptom Impact Scale (Carers only)

Demographics

- Age
- Gender
- Ethnic background
- Relationship status
- Employment status
- Educational qualifications
- Community healthcare organisation catchment area
- Diagnosis received and source of diagnosis (or if there has been no official diagnosis, which eating disorder the individual identifies with)
- Other physical and/or mental health conditions
- Illness duration
- Stage of recovery
- Stage of treatment

2.3 Participants

2.3.1. Interview Study

21 carers (18 female, 3 male) ranging in age from 43 to 74 years (average age: 53 years) participated in interviews. Most carers (n=8) were from Dublin and most reported that the person they cared for received treatment in Dublin (n=15). The remainder received treatment in the following counties: Galway (n=4), Kilkenny (n=2), Carlow (n=1), Cork (n=1), Limerick (n=1), Mayo (n=1), and Tipperary (n=1)[9]. All carers were the parent of a son or daughter with an eating disorder (19 female and 2 male) ranging in age from 10 to 34 years (average age: 19.7 years). Seven parents reported their son or daughter had received treatment in multiple locations across the country (typically involving in-patient care), including three parents who reported their son or daughter received additional treatment in the UK. The most common diagnosis reported was Anorexia Nervosa (n=13) and parents had been caring for their son or daughter between 3 months and 23 years. Of those that provided data (n=18), most felt their son or daughter was 50-65% recovered (n=8).

Interviews were also conducted with 25 PWED (24 female, 1 male) ranging in age from 18 to 62 years (average age: 30 years). Most (n=8) were from Dublin and most had received services there (n=16). However, other areas where services were accessed included: Limerick (n=4), Cork (n=2), Laois (n=3), Clare (n=1), Donegal (n=1), Kerry (n=1), Kildare (n=1), Galway (n=1), Tipperary (n=1), Wicklow (n=1), the UK (n=4), and elsewhere in the world (n=2)[10]. Of those reported receiving a diagnosis (n=24), most had received multiple ED diagnoses (n=10), followed by Anorexia Nervosa (n=8), Binge Eating Disorder (n=2), Bulimia Nervosa (n=1), ED Not Otherwise Specified/Other Specified Feeding or Eating Disorder (n=2) and Unspecified Feeding or Eating Disorder (n=1). PWED received their diagnoses between 6 months and 30 years prior to data collection and considered that they had been living with an ED for between 1 and 30 years. There was a range of experiences from across the recovery spectrum, with 28% (n=7) of participants rating themselves between 90-100% recovered, and the rest of the participants selecting either 70-80%, 50-65%, or 0-40% recovered (24% (n=6) selected each category).

2.3.2. Online Survey Study

82 carers (66 female, 4 male, 12 not reported) ranging in age from 22 to 70 years (average age: 50.17 years) participated in the online carer survey. Participants came from across all HSE catchment areas. The most common areas of residence reported were: CHO Area

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[9] PWED could have received treatment in multiple locations.

[10] PWED could access services across multiple locations.

4 (n=14), CHO Area 6 (n=14), and CHO Area 8 (n=8). Most were parents of someone with an eating disorder (n=65) and most reported that they were currently living with the person they care for (n=64). The most common diagnosis was Anorexia Nervosa (n=59). Most reported that the person they cared for was receiving treatment (n=54), followed by fully recovered (n=17), and having left treatment (n=6).

82 PWED (70 female, 1 male, 1 non-binary, 1 transgender, 9 not reported) ranging in age from 18 to 62 years (average age: 28.95 years) participated in the online survey. Responses were collected from participants across HSE catchment areas. The most common locations reported were: CHO Area 7 (n=12), CHO Area 8 (n=11) and CHO Area 5 (n=9). Of those who reported their living arrangements, 38.4% (n=28) lived with their parents, 19.2% (n=14) lived with a partner, 17.8% (n=13) lived alone, 16.4% (n=12) lived with other family members, and 8.2% (n=6) lived with friends. The most common diagnosis was Anorexia Nervosa (n=34) followed by OSFED (n=12) and AN/BN (n=11). Most participants were in treatment at the time of data collection (n=48), 19 had left treatment, and 11 considered themselves fully recovered.

2.4 Data Analysis

2.4.1. Quantitative analysis

Our analysis of the quantitative survey data begins by exploring participants' feedback on their experiences of the care and support they have received from a range of services. We then move on to consider participants' psychological health and well-being, as well as the extent to which participants' feelings of health and well-being were predicted by social factors such as feeling connected to important groups.

2.4.2. Qualitative analysis

Our qualitative analysis provides an overview of participants' positive and negative experiences relating to the range of services that they have interacted with. Following this, we explore the lived experience of people with eating disorders and carers, focusing on those aspects that were identified by our participants as being particularly pertinent.

03

Feedback on Health Services

SECTION 03

Feedback on Health Services

In this section, we report our participants' experiences with a range of health services (General Practitioners, Child & Adolescent Mental Health Services, Adult Mental Health Services, In-patient care, Private Health Professionals, and Support Organisations). The data comes from our online surveys and where relevant we include additional insights gleaned from PWED and carer interviews. Extracts from interviews are included to illustrate individuals' experiences however participants are identified by a number to protect their anonymity.

3.1 General Practitioners

3.1.1. Survey Responses

Almost two thirds (63.4%) of PWED sought help from their GP in the last three years and most carers (78%) said the person they cared for did the same. Carers indicated the most common type of GP support given to the person they were caring for was advice (51.6%) and nearly one third (32.7%) of PWED reported medication to be the most common type of support received. 12.5 % of carers and 3.8% of PWED reported receiving a referral to Bodywhys. Finally, 15.4% of PWED and 4.7% of carers reported that their GP did not take any action. A full overview of the support provided by GPs as well as the frequency with which participants attended their GP is reported in Table 3.1.

	N		%	
	CARER	PWED	CARER	PWED
Has PWED Sought GP Help in Last 3 Years?				
Yes	64	52	78%	63.4%
No	18	30	22%	36.6%
Last Time PWED Saw GP for ED Help				
In the last month	10	12	15.6%	23.1%
1-3 months ago	8	8	12.5%	15.4%
4-6 months ago	10	10	15.6%	19.2%
7-12 months ago	10	4	15.6%	7.7%
1-2 years ago	19	6	29.7%	11.5%
More than 2 years ago	7	12	10.9%	23.1%
What Support Did GP Give? (tick all that apply)**				
Advice	33	13	51.6%	25%
Guided Self-Help	5	3	7.8%	5.8%
Nutrition Advice/Monitoring	16	8	25%	15.4%
Medication	15	17	23.4%	32.7%
Referral-Individual Psychological Therapy	22	14	34.4%	26.9%
Referral-Group Therapy	2	1	3.1%	1.9%
Referral- Bodywhys	8	2	12.5%	3.8%
Referral- Another Treatment Service	29	17	45.3%	32.7%
GP Took No Action	3	8	4.7%	15.4%

Table 3.1: Overview of frequency of GP attendance and support received by PWED and carers

Most carers (78.1%) and over half of PWED (61.6%) felt involved to some extent in agreeing the treatment with the GP. PWED were additionally asked about the extent of their families being involved. As seen in Figure 3.2, those who wanted their families involved in their treatment tended to indicate that this happened to some extent (23%).

However, our results also indicate the complexities surrounding family involvement in agreeing treatment. Some participants reported that there was too much involvement from their families (9.6%) or that their families did not want to be involved (3.8%). There was also a considerable number of participants who reported that they did not want their families involved in agreeing treatment (38.5%). Whilst most carers (61%) and PWED (53.8%) reported that GPs provided information that was understandable, almost 40% of carers and almost 50% of PWED reported they either did not understand the information provided or were not given any information at all.

Q Did the GP involve you in agreeing treatment as much as you wanted?

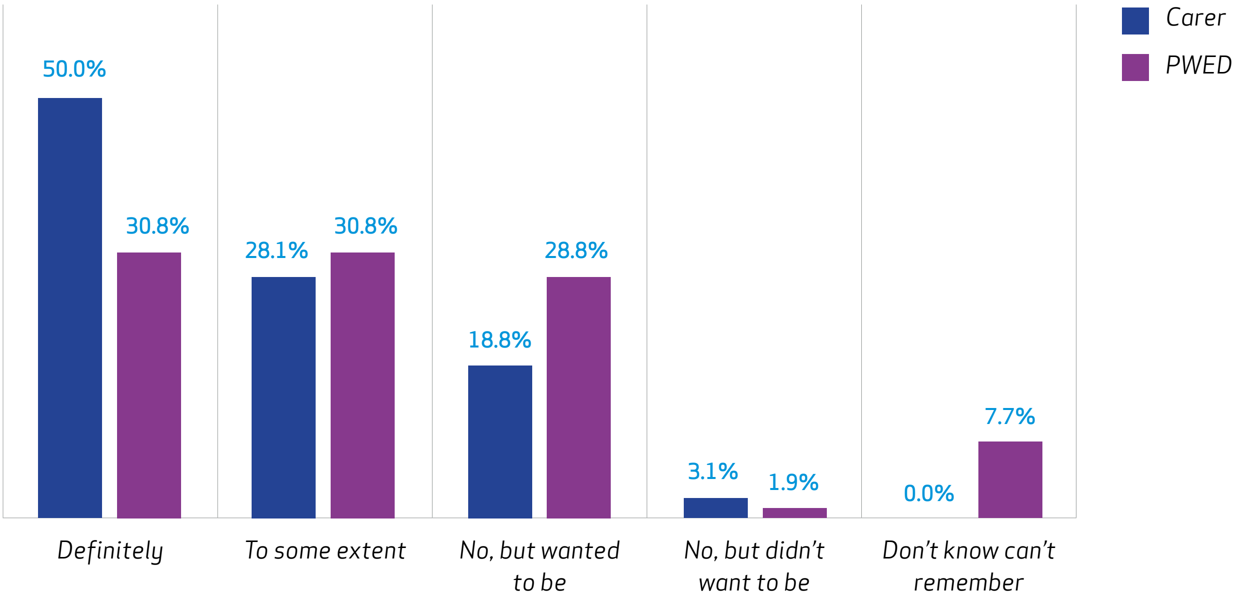

Figure 3.1 Extent to which carers and PWED felt involved in agreeing treatment with their GP

Q Did the GP involve your family as much as you wanted?

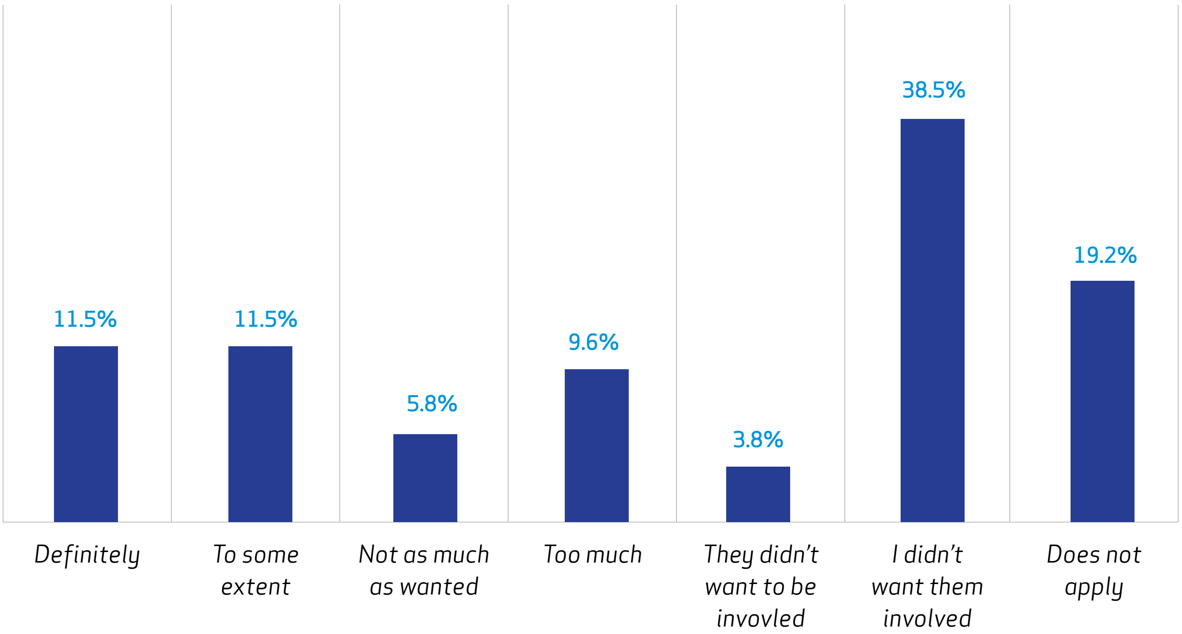

Figure 3.2 Extent to which PWED felt their GP involved their families in treatment

Q Did the GP give you information you could understand?

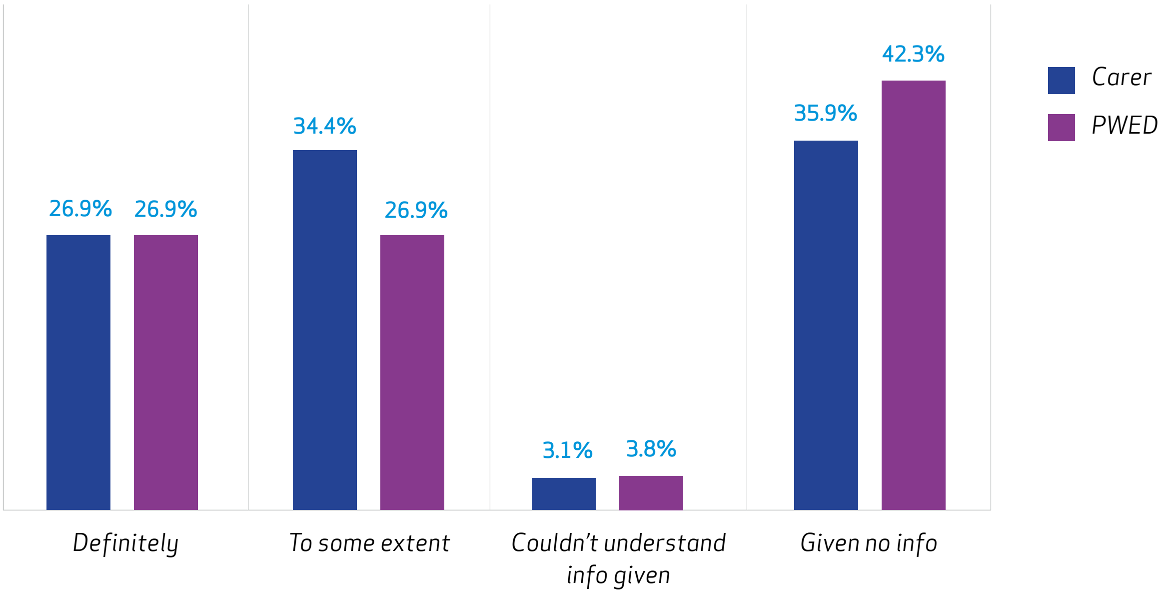

Figure 3.3 Extent to which carers and PWED felt GPs provided information that was understandable

Most carers felt that both they (87.3%) and the person they cared for (90.7%) were treated with dignity and respect by the GP. Similarly, the majority of PWED (63.4%) felt the same however, there was a sizeable number of PWED that did not feel this way (36.5%). Finally, not all PWED and carers felt their support needs were met; nearly half (48.4%) of carers and just over half (53.8%) of PWED did feel as supported as they would have liked.

Q Did the GP treat you with Dignity and Respect?

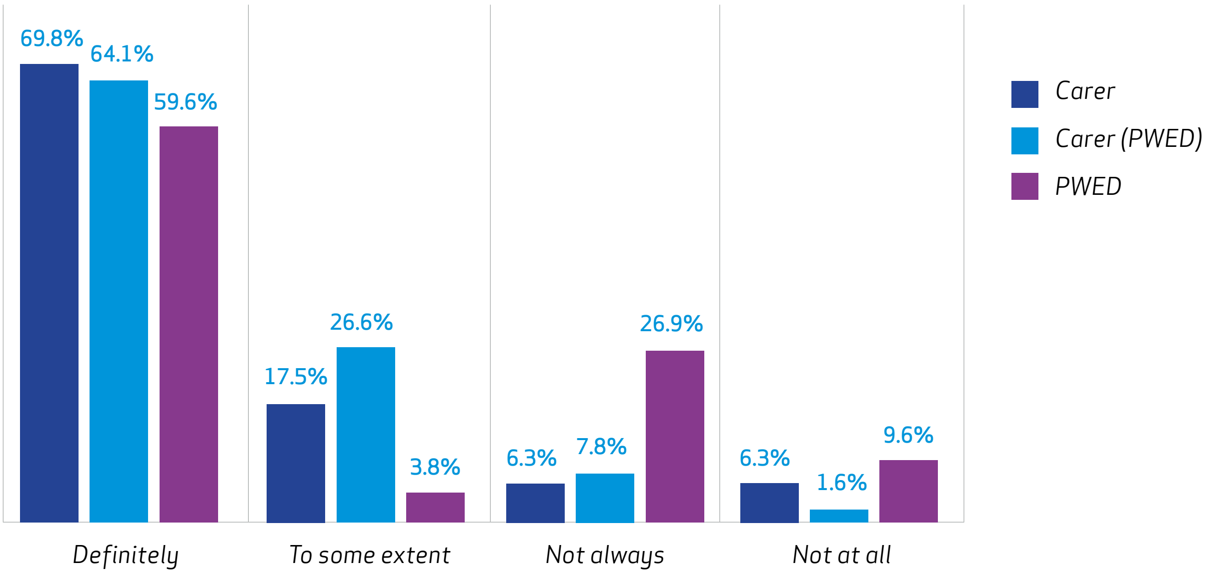

Figure 3.4 Extent to which PWED and carers felt that they and the person they care for were treated with dignity and respect by their GP

Q Did the GP meet your support needs?

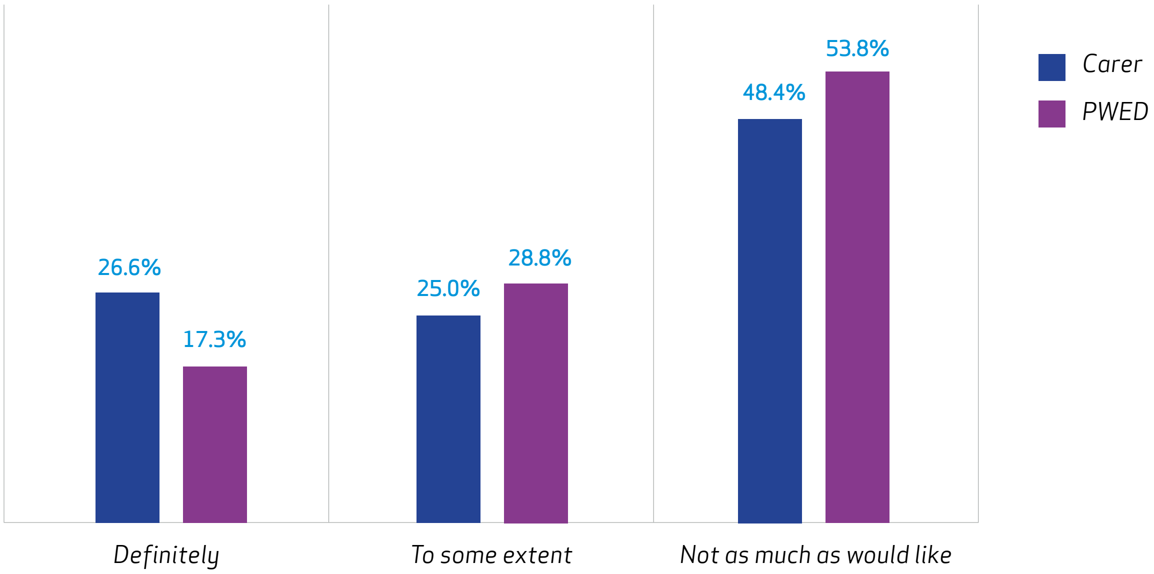

Figure 3.5 Extent to which carers and PWED felt that their support needs were met by their GP

3.1.2. Interview Insights

In interviews, both carers and PWED reported that GPs were instrumental in referring on to other treatment services. GPs were perceived to be particularly helpful when they understood mental health issues and eating disorders and were able to recognise that carers and PWEDs were dealing with a serious illness as well as, in the case of younger people, provide this information in an appropriate way.

> *[GP] was amazing with our daughter and explained it so well to her at an age appropriate level (Carer 07).*

For some PWED, it was the GP who first suggested the possible presence of an eating disorder when they visited for other reasons and so, they felt the GP was instrumental in identifying the right treatment for them.

> *I wasn't expecting [my GP] to say [I had an eating disorder], I was expecting him to say, 'alright well look, we'll try this for weight loss', when I explained my symptoms and what I do and how I feel and he said that that is a binge eating disorder that you have (PWED 15)*

Even where GPs admitted that they did not have this specialist knowledge, carers felt reassured by those who indicated a willingness to work together with them to find a solution.

> *[GP] reassured me. Kinda going, 'you're not mad, you have a problem. I can't help you myself, but we're gonna work through it together.' (Carer 01)*

GPs willingness to work with patients and carers and the ability to ask questions around the possible presence of an eating disorder is vital. Our participants revealed that they can find discussing and admitting their problems with eating to be particularly challenging, not least due to a fear of judgement from others (including health professionals). Those who felt respected by their GPs commented on how this approach facilitated disclosure of eating concerns and related issues.

> *He was fantastic. [lines omitted] He didn't judge at all, he completely understood, he was fantastic, I really have to say. I suppose I owe him my life because he was amazing. He just understood immediately. (PWED 05)*

The importance of a sense of empathy and understanding was particularly seen in its absence. PWED who reported negative experiences with GPs reported that it was their perception that a lack of understanding and empathy from GPs stemmed from low levels of knowledge of EDs. Some described feeling "patronised" and "judged" to the extent that they were discouraged from further engagement with their GP for eating-related concerns:

> *One thing I would probably do differently is not go to my GP for the first step in getting help because I felt he didn't have a good understanding of anorexia and didn't explain anything or be compassionate, which made it more difficult and confusing. (PWED 17)*

When discussing their GP's failure to provide appropriate support, carers and PWED felt that this was a direct result of a lack of knowledge. GPs were not able to talk through treatment details (e.g., the possibility of being tube-fed) and tended to focus on physical rather than psychological aspects of eating disorder recovery.

> *I felt like my GP was very good recognising it, at least physically and most of what she did for me from then on, she was like, "Right, well, what we can do is we're going to try and get you into [private unit] and in the meantime we're going to make sure your weight doesn't drop below the threshold where they won't accept you." But I can't say there was much discussion of, like, the mental aspect of it. (PWED 22)*

In some instances, carers believed they were offered poor advice (often around encouraging their child to eat more) that stemmed from a misunderstanding of the nature of eating disorders. They perceived that this absence of knowledge and training delayed access to treatment and early intervention. Some felt that their concerns were not taken seriously by GPs – and that this was another reason why action was not taken as promptly as it should have been:

> *I really feel the GP just did not have the skills or the knowledge about eating disorders, or anorexia, or whatever, particularly with such a young child. I'm not blaming the GP, but I really feel the action could have been more prompt. (Carer 05)*

3.2 Child and Adolescent Mental Health Services (CAMHS)

3.2.1. Survey Responses

Only five of our PWED survey respondents had used CAMHS within the previous three years and were able to provide their perspectives. We therefore advise caution in interpreting the numbers presented. Nonetheless, the survey results are in line with insights garnered from the interviews as well as with issues reported by carers, which gives us some confidence in the reliability of the findings.

Only five PWED (6.1%) and nearly one third of carers (63.4%) reported the person they cared for accessed CAMHS for help in the last three years. Most were seen within 1 month of referral. Carers and PWED indicated the most common type of support for was individual psychotherapy (63.5%). Most respondents indicated they were seen by CAMHS every 1-2 weeks. Table 3.2 provides more details on their frequency of attendance and support received from CAMHS as reported by PWED and carers.

	N		%	
	CARER	PWED	CARER	PWED
Has PWED Sought CAMHS Help in Last 3 Years?				
Yes	52	5	63.4%	6.1%
No	30	77	36.6%	93.9%
Last Time PWED Saw CAMHS for ED Help				
In last month	21		41.2%	
1-3 months ago	8		15.7%	
4-6 months ago	3	1	5.9%	20%
7-12 months ago	6		11.8%	
1-2 years ago	12	1	23.5%	20%
More than 2 years ago	1	3	2%	60%
What Support Did CAMHS Give? (tick all that apply)**				
Individual Psychological Therapy	33	5	63.5%	100%
Group Therapy	5	1	9.6%	20%
Advice	15	1	28.8%	20%
Guided Self-Help	8		15.4%	
Nutrition Advice/Monitoring	22	3	42.3%	60%
Medication	13	3	25%	60%
Family-Based Treatment	28		53.8%	
In-Patient Care		2		40%
Other	9		17.3%	
How Long Between Referral & Being Seen By CAMHS?				
Straight Away	11	1	21.2%	20%
Within One Month	23	3	44.2%	60%
1-3 Months	7	1	13.5%	20%
More than 3 Months	8		15.4%	
Don't Know	3		5.8%	
How Frequently Saw CAMHS?				
Every 1-2 Weeks	40	5	80%	100%
Once A Month	6		12%	
Once Every 3 Months	3		6%	
Less Than Once Every 3 Months	1		2%	

Table 3.2 Overview of frequency of CAMHS attendance and support received by PWED and carers

Most carers felt that they had a role in agreeing the treatment their child would receive from CAMHS (82.4%). PWED felt that they were not given as much of a role as they would have liked when in CAMHS, with 60% reporting that they were not involved enough in deciding their treatment. This however is not an atypical experience given the service delivery model and is an opinion often expressed by young people more generally when reflecting on their CAMHS experiences[11]. However, this also extended to feeling excluded from agreeing when treatment should end, with 40% reporting they were not as involved as they would have liked – which could have implications for transition experiences of PWED. Most PWED (80%) felt that their family was involved to an appropriate extent in their treatment. Both carers (86%) and PWED (80%) reported that CAMHS provided information that was understandable. However, most carers (78.3%) and PWED (68.9%) indicated that they did not receive a care plan or letter describing the treatment they (or the person they cared for) would receive.

Q Did CAMHS involve you in agreeing treatment as much as you wanted?

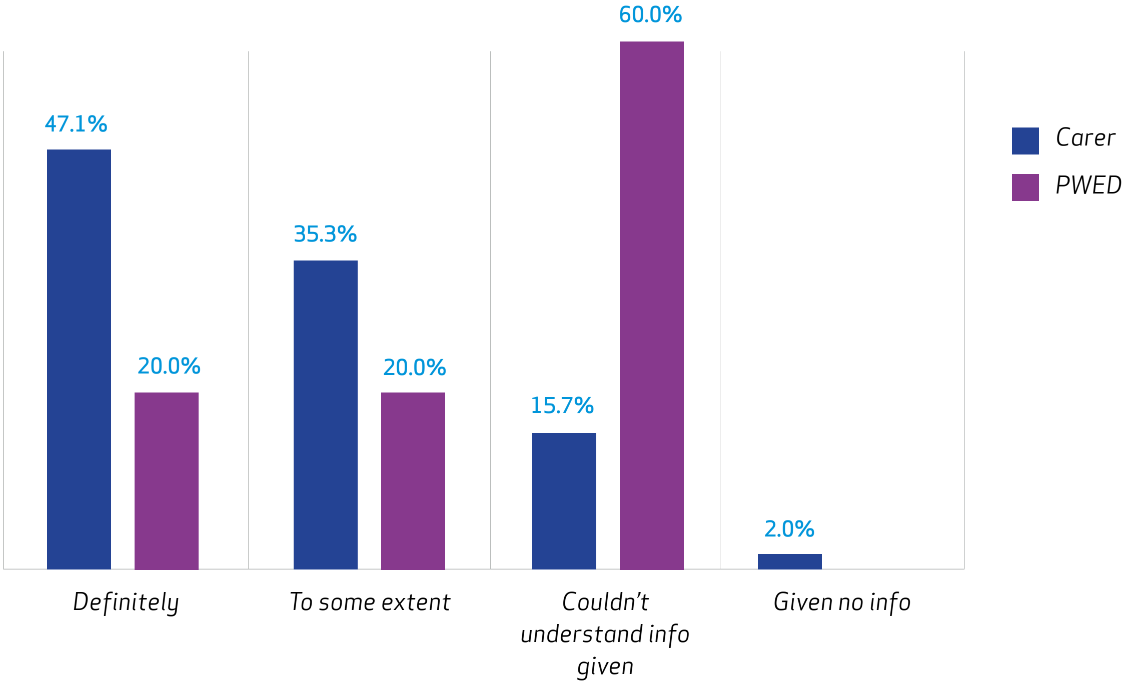

Figure 3.6 Extent to which carers and PWED felt involved agreeing in treatment with CAMHS

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[11] Coyne, I., McNamara, N., Healy, M., Beattie, C., Sarkar, M., & McNicholas, F. (2015). Adolescents' and parents' views of Child and Adolescent Mental Health Services (CAMHS) in Ireland. *Journal of Psychiatric & Mental Health Nursing, 22*, 561-569.

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Did CAMHS involve your family as much as you wanted?

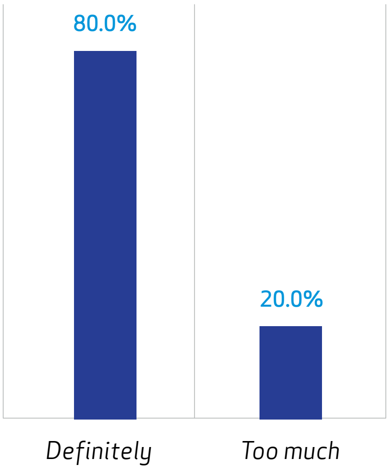

Figure 3.7 Extent to which PWED felt CAMHS involved their families in treatment

Did CAMHS involve you in agreeing an end to treatment as much as you wanted?

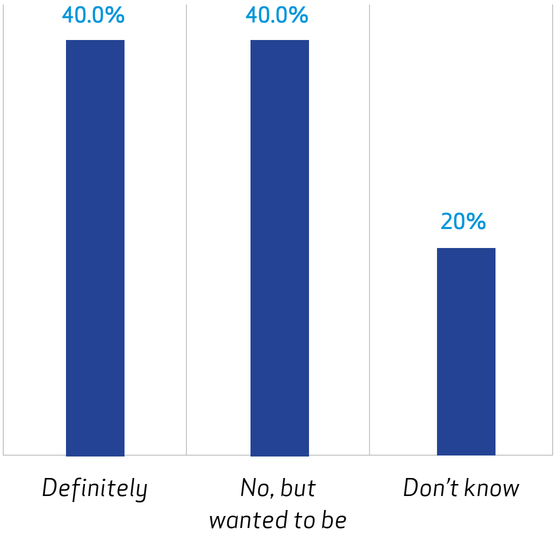

Figure 3.8 Extent to which PWED felt involved in agreeing an end to CAMHS treatment

Did CAMHS gve you information you could understand?

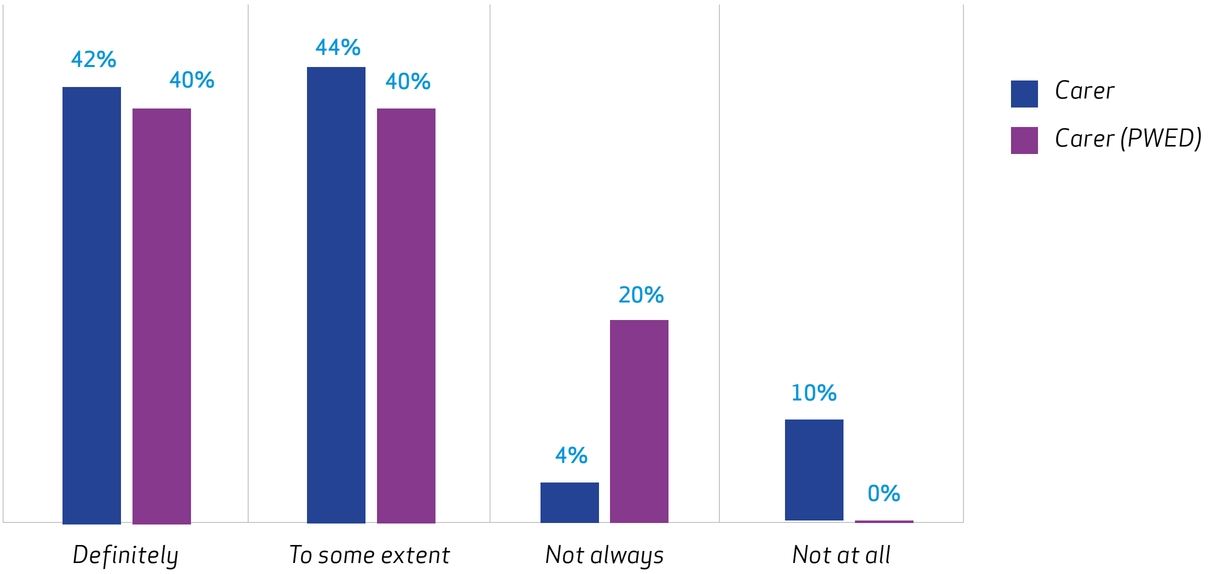

Figure 3.9 Extent to which carers and PWED felt CAMHS provided information that was understandable

Most carers felt CAMHS staff treated both themselves (72%) and the person they cared for (76.5%) with dignity and respect, at least to some extent. Most PWED (60%) did not feel this way. Just over half of carers (51%) reported that CAMHS did not meet their support needs as much as they would have liked. None of the PWED felt their support needs were adequately met by CAMHS staff.

Q Did CAMHS treat you with dignity and respect?

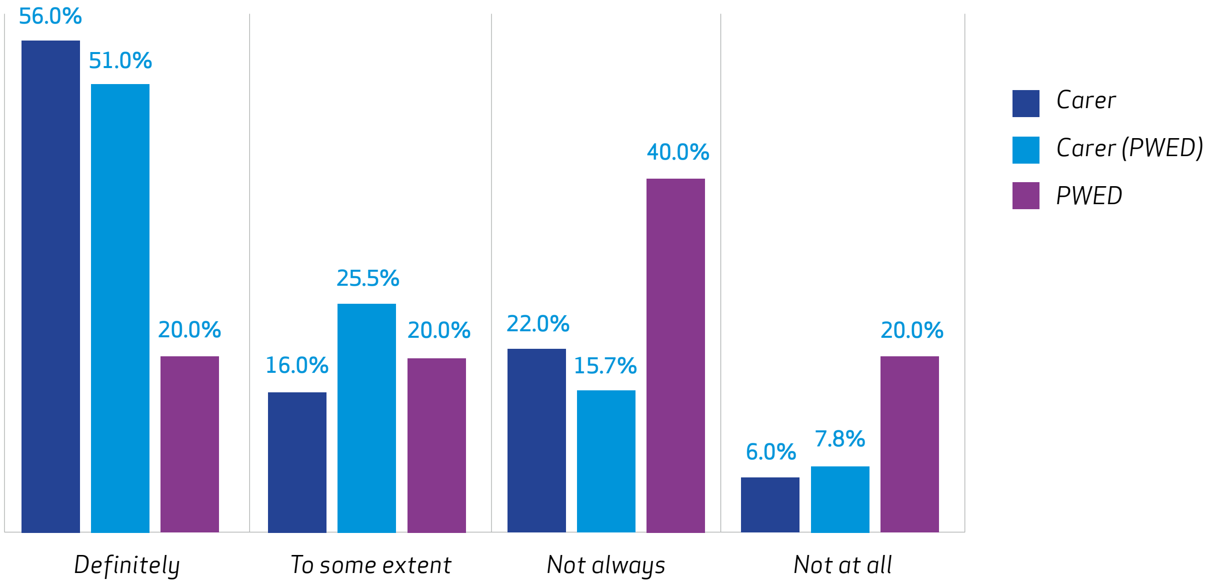

Figure 3.10 Extent to which PWED and carers felt that they and the person they care for were treated with dignity and respect by CAMHS

Q Did CAMHS meet your support needs?

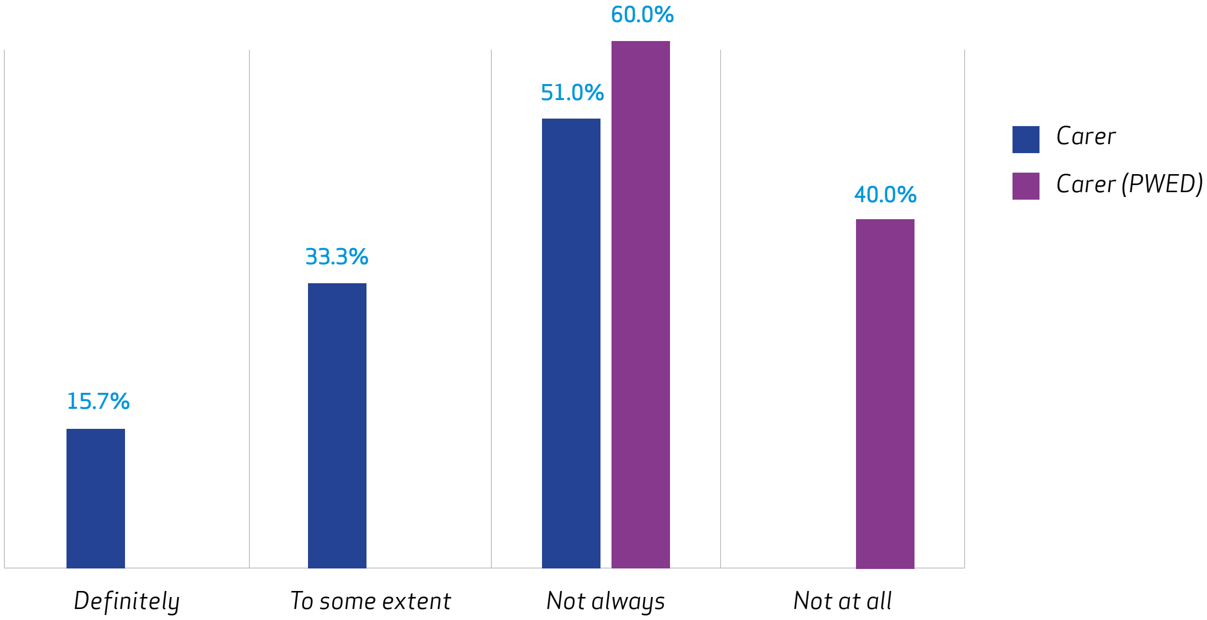

Figure 3.11 Extent to which carers and PWED felt that their support needs were met by CAMHS

3.2.2. Interview Insights

Carers perceived CAMHS to be under-resourced and under-staffed. Reflecting on their time in CAMHS, PWED could retrospectively also see that this was the case[12]. Consequently, service user experiences varied, and treatments offered differed by area (i.e., there was a lack of standardised care). Carers were keen to highlight their awareness of the constraints these services were operating under.

> *CAMHS are absolutely chocka-blocked (sic), they don't seem to have enough money or support themselves (Carer 12)*

The benefits of having a well-resourced service were clear. Carers valued the weekly meetings offered by CAMHS (particularly where the parent was offered time alone with the clinician) and a holistic approach to treatment. They appreciated being involved in their child's treatment, receiving updates on their child's progress, and being allowed time to raise their concerns with clinicians during sessions:

> *having weekly meetings was just invaluable, and that was amazing to have that service that we could go back week on week (Carer 05)*

> *We have always been included and could talk about any concerns we had and could ring at any time. They used CBT and gave us great tools to deal with her related issues at home. They also suggested support for us as parents via Bodywhys PiLaR and Maudsley courses. (Carer 07)*

One PWED who described a positive CAMHS experience also praised the inclusion of her family in treatment:

> *[The best part] was the inclusion of the family in the treatment and, you know, working with me and my mum together because I think I very much needed for someone to be able to kind of explain to my mum a little bit about what was happening to me which I found very difficult, and then also to help her to kind of be able to support me in recovery (PWED 20)*

While carers valued having a role in treatment, this could be a double-edged sword. Carers were often responsible for ensuring specific diet plans, etc. were followed in the home. Some perceived that their child's health depended solely on them. However, many felt that clinicians underestimated the difficulties faced by them in supporting their child (e.g., if the carer was supporting the child alone, if the child refused to engage in sessions, etc.).

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[12] *It should be noted that only 5 PWED interviewees had experience with CAMHS within the previous three years.*

They perceived a lack of support from clinicians in dealing with these situations and did not feel listened to by clinicians. Some carers either blamed themselves for their child's condition and/or felt that clinicians held them responsible for a perceived lack of adequate progress:

> *CAMHS I just don't feel have been there for us, at all. They, I think like, all I ever get from them is, 'Oh, your only job is to get her to eat. That's all you have to do.' And I'd be kind of going, 'oh, well she won't eat,' 'oh, but she has to eat,' 'give me some advice, she won't eat.' 'oh, no, no, she has to eat. That's her only job.' (Carer 01)*

Furthermore, carers perceived that underlying psychological issues were not addressed by some CAMHS services (with counselling/psychotherapy reported to be withheld based on BMI) and it was perceived that there was a severe lack of knowledge in CAMHS regarding how to support children under the age of 12.

> *I kept saying to Dr [name] I said [daughter] keeps telling us that she wants to talk to somebody and he kept saying 'Well, her weight is too low to talk to somebody because you have to be over a certain BMI', in CAMHS, for them to be refer you to a counsellor because they don't think you have the cognitive ability to do it when you're starving yourself. (Carer 02)*

PWED were not as involved in treatment decision-making as carers and their reports of negative experiences tended to centre around descriptions of fraught relationships with clinicians. Tensions were described as arising from what PWED perceived to be stereotypes associated with eating disorders (e.g., these illnesses are a personal choice):

> *I kind of felt sometimes the psychiatrist like they would speak as if kind of this was a choice I was making or, you know, I was doing on purpose and they would come across as quite frustrated, like literally be talking about more physical aspects where health's been damaged and kind of talked to me as if I was consciously on purpose doing this which was quite unhelpful. (PWED 20)*

Poor experiences with clinicians and an absence of trust was noted by two PWED as their reasons for refusing to engage with CAMHS:

> *I think [my parents] were also a bit annoyed with [CAMHS] because I was crying, please do not tell me my weight, and they did, they told me my weight, which was just…I was only a child. I was 16 years old, to completely just go against what I wanted. How am I supposed to work with you, if before we've even got started, you're going to be against me? So, anyway, I didn't go back to [CAMHS] (PWED 12)*

3.3 Adult Mental Health Services (AMHS)

3.3.1. Survey Responses

Approximately one third (35.4%, n=28) of carers reported that the PWED sought help from AMHS in the last three years and just over half of PWED (55.6%, n=45) reported the same. 23.1% of carers reported their loved one was seen straight away with 26.9% seen within one month. Approximately a third (31.2%) of PWED reported being seen within one month of referral, with 15.6% of these seen straight away. Carers noted the most common types of support given to the PWED they cared for was individual psychological therapy (42.9%), followed by medication and advice (both at 35.7%). Similarly, individual psychological therapy was reported to be the most common type of support with PWED participants as well as medication (both at 42.2%). 10.7% of carers and 8.9% of PWED reported AMHS did not provide them with any supported related to their eating disorder. Table 3.3 provides an overview of AMHS attendance and support received.

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Has PWED Sought AMHS Help in Last 3 Years?				
Yes	28	45	35.4%	55.6%
No	51	36	64.6%	44.4%
Last Time PWED Saw AMHS for ED Help				
In last month	12	17	44.4%	37.8%
1-3 months ago	4	8	14.8%	17.8%
4-6 months ago	3	5	11.1%	11.1%
7-12 months ago	3	5	11.1%	11.1%
1-2 years ago	2	5	7.4%	11.1%
More than 2 years ago	3	5	11.1%	11.1%
What Support Did AMHS Give? (tick all that apply)**				
Individual Psychological Therapy	12	19	42.9%	42.2%
Group Therapy	5	5	17.9%	11.1%
Advice	10	16	35.7%	35.6%
Guided Self-Help	3	8	10.7%	17.8%

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Nutrition Advice/Monitoring	8	15	28.6%	33.3%
Medication	10	19	35.7%	42.2%
Other	4	11	14.3%	24.4%
No Support	3		10.7%	
How Long Between Referral & Being Seen By AMHS?				
Straight Away	6	7	23.1%	15.6%
Within One Month	7	7	26.9%	15.6%
1-3 Months	7	12	26.9%	26.7%
More than 3 Months	4	8	15.4%	17.8%
Don't Know	2	11	7.7%	24.4%
How Frequently Saw AMHS?				
Every 1-2 Weeks	11	25	45.8%	58.1%
Once A Month	6	9	25%	20.9%
Once Every 3 Months	4	1	16.7%	9.3%
Less Than Once Every 3 Months	3	5	12.5%	11.6%

Table 3.3 Overview of frequency of AMHS attendance and support received by PWED and carers

Most carers (62.5%) did not feel that they were given the role they wanted to have in agreeing treatment and just over half of PWED (56.8%) felt that AMHS involved them at least to some extent in agreeing their treatment. We again see the complexities involved in providing a role for family in this setting. 18 PWED wanted some involvement from their family in agreeing treatment. Just over half (55.5%, n=10) reported that this was facilitated by AMHS with the remainder stating that their family were not involved as much as they would have liked. Once again, a sizeable proportion of PWED did not want their families involved in treatment. Half of the carers reported not receiving any information from AMHS and half reported they had received some form of understandable information. Just over half (59%) of PWED said they were provided with understandable information to an extent. A large proportion of both carers (92%) and PWED (88.6%) did not receive a copy of a care plan.

Q Did AMHS involve you in agreeing treatment as much as you wanted?

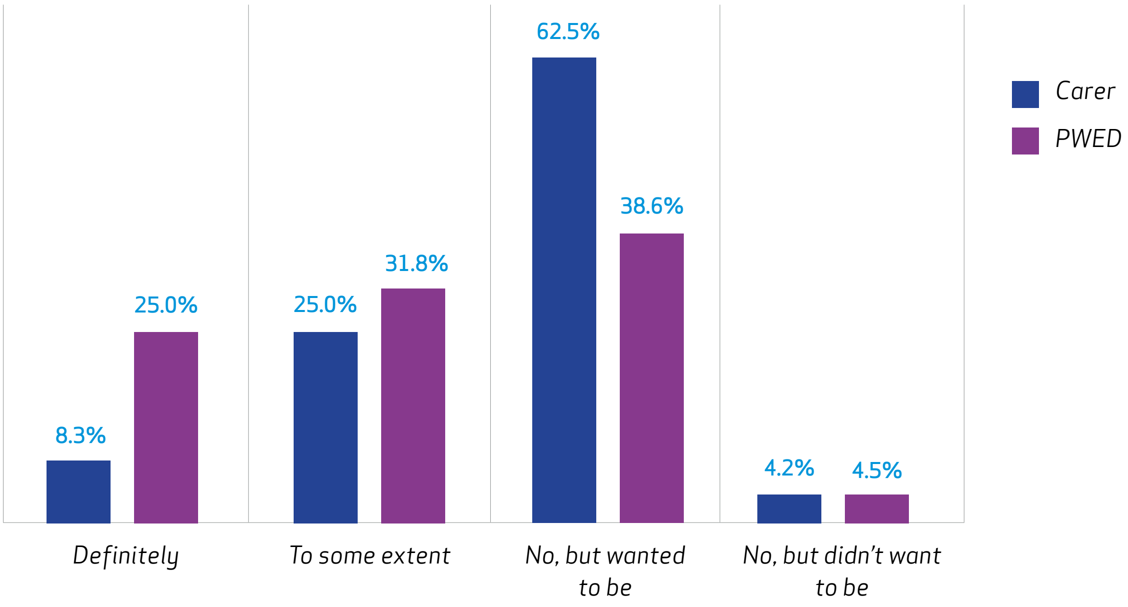

Figure 3.12 Extent to which carers and PWED felt involved in agreeing treatment with AMHS

Q Did AMHS involve your family as much as you wanted?

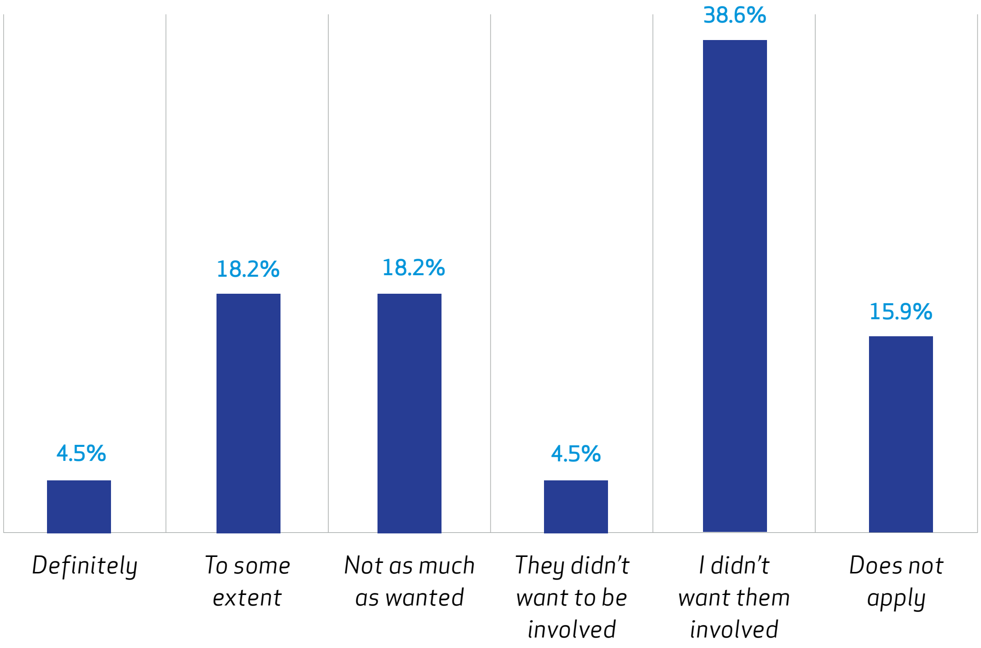

Figure 3.13 Extent to which PWED felt AMHS involved their families in treatment

Did AMHS give you info you could understand?

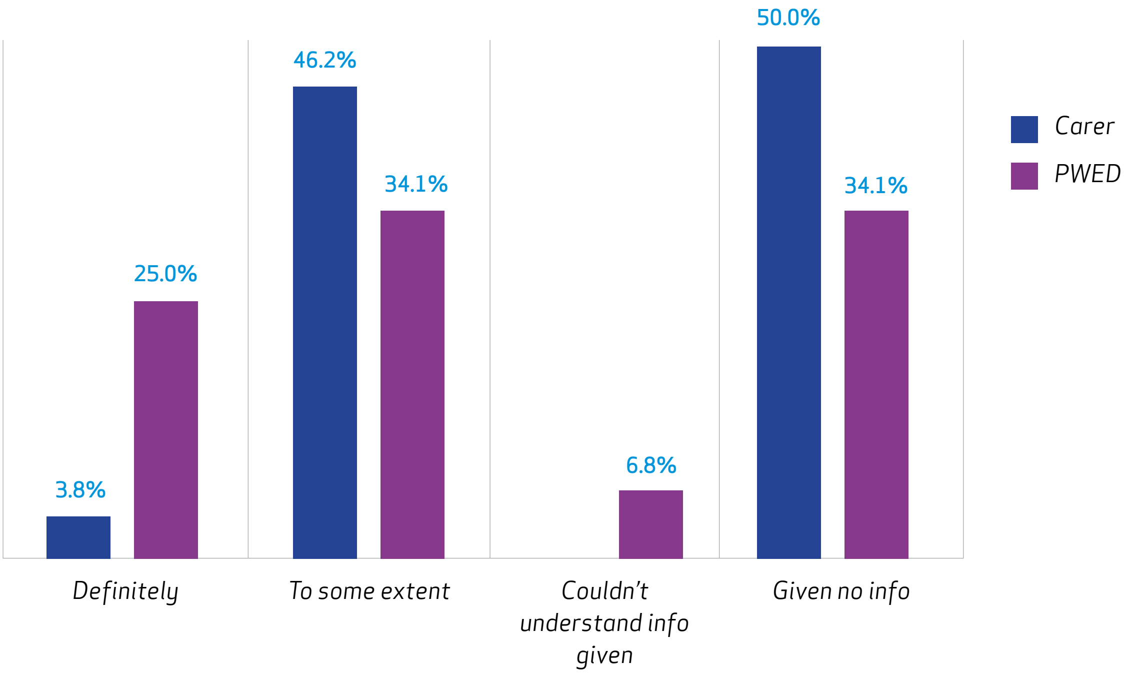

Figure 3.14 Extent to which carers and PWED felt AMHS provided information that was understandable

Most carers said the person they cared for was treated with dignity and respect by AMHS staff (82.6%) whilst just over a third of carers (37.5%) did not feel this was always true for themselves. Three quarters of PWED (75%) did think AMHS staff treated them with dignity and respect, to some extent. More than half of carers (58.3%) felt their support needs were not met and just over three quarters of PWED (76.7%) reported feeling unsupported to some degree.

Did AMHS treat you with dignity and respect?

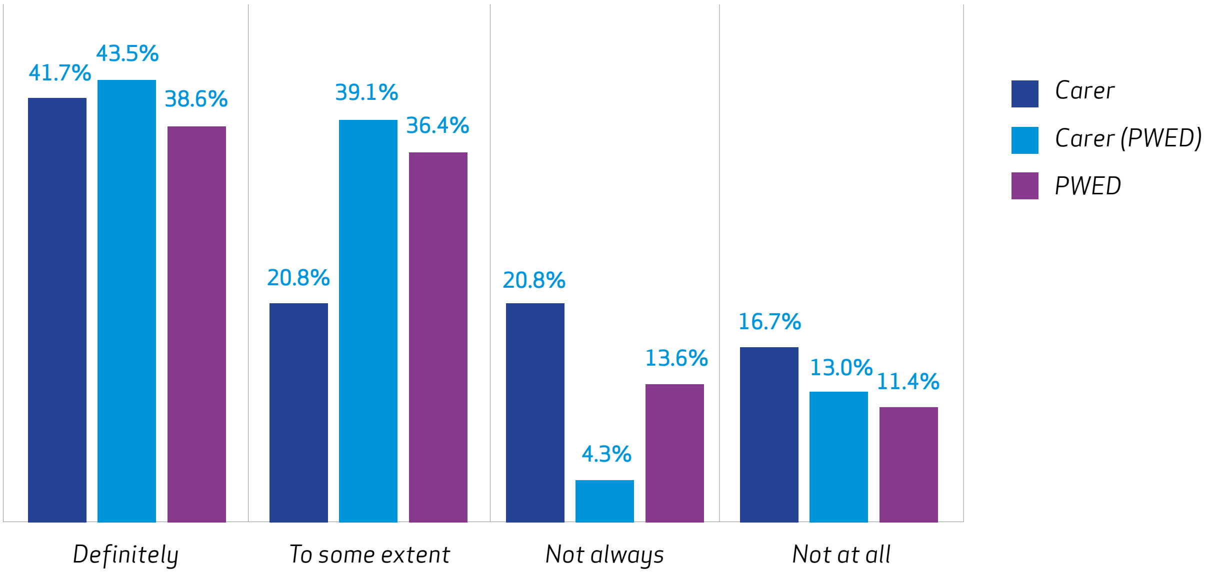

Figure 3.15 Extent to which PWED and carers felt that they and the person they care for were treated with dignity and respect by AMHS

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Q Did AMHS meet you support needs?

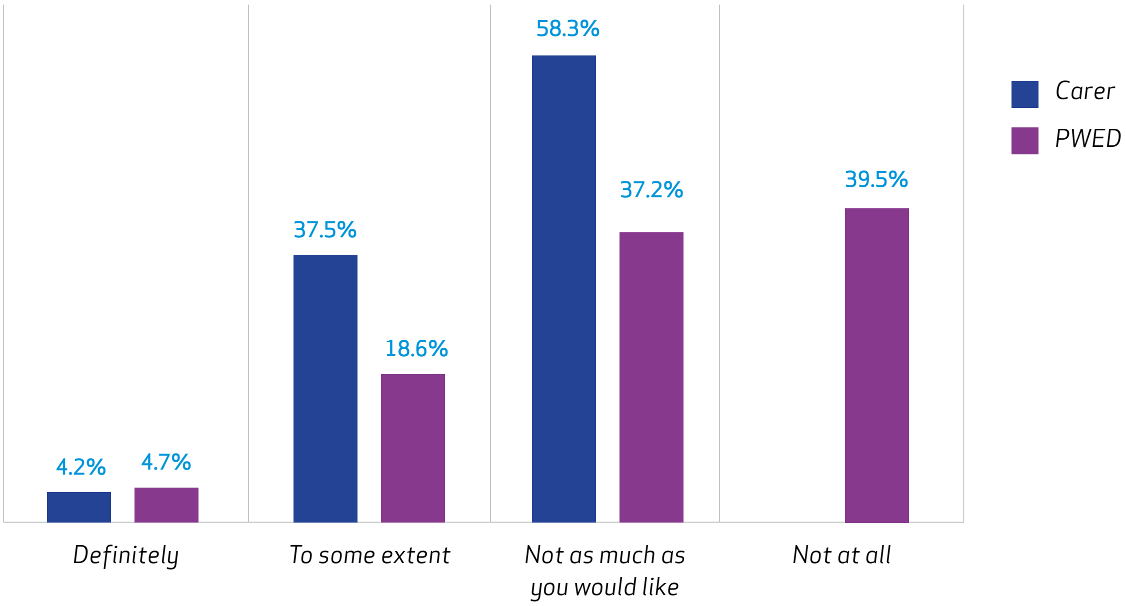

Figure 3.16 Extent to which carers and PWED felt that their support needs were met by AMHS

3.3.2. Interview Insights

Relatively few carers that we interviewed were caring for someone who was currently attending (or had recently attended) AMHS (n=4). Their experiences were predominantly negative. Carers were particularly concerned about the perceived absence of specialist interventions (which they attributed to poor resourcing of services).

> *It's very complex and involved, and you need good therapists, and you need to put the resources into, you know, we've no dietitian, there's a serious lack of dietitians, which is the basic requirement, as well as therapy, and therapy at all levels. We really need to work hard in those areas. So, those are the areas that are lacking. (Carer 06)*

One parent, whose daughter had transitioned from CAMHS to AMHS services noted that the specialist interventions provided by CAMHS were absent in the adult service. These thoughts were echoed by PWED who also felt that services were overstretched with long waiting lists. They also noted a lack of availability of specialist interventions, with some describing services having a limited focus on weight.

> *it's very, very difficult to get into the HSE psychology services in Ireland,[lines omitted] so it took over a year to get me into HSE run psychology. (PWED 05)*

> *I found nothing supportive about the appointments – which were just about being weighed and being asked what I ate [PWED 08]*

The change in service delivery model from child to adult services was perceived differently by carers and PWED. Some carers struggled with not being fully involved in their loved one's care. For example, one parent reported feeling helpless when their daughter decided to leave in-patient care. This change in role was difficult for those who had previously occupied a central role in their son or daughter's medical care.

> *I did notice a huge, like I remember when she was 17, I would go to the doctor's with her and they'd talk to me and I'd be very involved. Once she turned 18 that was it, you know, nobody could talk to me anymore and that was very frustrating. (Carer 08)*

Conversely, PWED reported that being given an active role in treatment where they collaborated with clinicians to build solutions was extremely helpful to them. However, the success of these relationships was reported to depend on the level of specialist knowledge and training in eating disorders. Talking to clinicians who understood and were sensitive to the challenges faced by those in recovery from an eating disorder helped PWED generate feelings of trust and openness. These clinicians were also seen in a more empathic light than those who did not exhibit such an understanding:

> *It took me a while to feel like I could trust the psychologist enough to open up to her and tell her things. I did find however throughout this process, she was understanding especially about how difficult it was to speak openly to her. She has a good knowledge of eating disorders in general. After a couple of months I felt I could trust her and knew she would listen without judgement. (PWED 17)*

3.4 Psychiatric In-patient Units

3.4.1. Survey Responses

Nearly half of carers (45.6%, n=37) reported that the person they care for had accessed in-patient care in the last 3 years, with 91.6% seen in Ireland. Approximately one third of PWED (36.3%, n=29) had received in-patient care in the last 3 years, with all but one (96.6%) seen in Ireland. Nearly half of the PWED that the carers cared for (47.2%) were seen in public units, 30.6% were seen in private units, and 22.2% accessed a mixture of public and private units. A third (38.9%) were seen straight away after referral, a further third (36.1%) seen within a month. 41.4% of PWED participants accessed a private unit, 27.6% were seen in a public unit, and 31% used a mixture of public and private units. Approximately a third (31%) were seen straight away after referral, 41.4% were seen within a month. Carers and PWED both noted the most common length of stay was 5-12 weeks (41.6% and 44.8%, respectively) and both carers and PWED reported nutritional advice/monitoring to be the most common type of support received in an in-patient unit (75% and 79.3%, respectively). Table 3.4 provides an overview of psychiatric patient unit attendance and supports received as reported by carers and PWED.

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Has PWED Sought In-patient Help in Last 3 Years?				
Yes	37	29	45.6%	36.3%
No	42	51	54.4%	63.7%
No. of Times PWED admitted to In-patient unit in Last 3 Years				
Once	19	9	52.8%	33.3%
Twice	7	10	19.4%	37.1%
Three Times	6	4	16.7%	14.8%
Four Times	3	1	8.3%	3.7%
Five Times		2		7.4%
Six Times	1	1	2.8%	3.7%
In-patient Unit Type				
Public	17	8	47.2%	27.6%
Private	11	12	30.6%	41.4%
Mixture	8	9	22.2%	31%
In-patient Unit Location				
Ireland	33	26	91.6%	89.7%
Ireland & England	1	1	2.8%	3.4%
England		2		6.9%
Northern Ireland	2		5.6%	
What Support Did In-patient Unit Give? (tick all that apply)**				
Individual Psychological Therapy	21	13	58.3%	44.8%
Group Therapy	21	19	58.3%	65.5%
Advice	19	15	52.8%	51.7%
Guided Self-Help	16	12	44.4%	41.4%

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Nutrition Advice/Monitoring	27	23	75%	79.3%
Medication	25	20	69.4%	69%
Re-feeding	12	10	33.3%	34.5%
Other	3	4	8.3%	13.8%
How Long Between Referral & Being Seen By In-patient Unit?				
Straight Away	14	9	38.9%	31%
Within One Month	13	12	36.1%	41.4%
1-3 Months	6	6	16.7%	20.7%
More than 3 Months	2	2	5.6%	6.9%
Don't Know	1		2.8%	
Length of In-patient Unit Stay				
1-4 Weeks	5	5	13.9%	17.2%
5-12 Weeks	15	13	41.6%	44.8%
13-24 Weeks	12	6	33.3%	20.7%
25-52 Weeks	2	2	5.6%	6.9%
53 Weeks or More	2	3	5.6%	10.4%

Table 3.4: Overview of frequency of psychiatric in-patient unit attendance and support received by PWED and carers

Most carers (65.7%) and PWED (65.5%) felt involved in agreeing treatment to some extent during their time at an in-patient unit. In addition, most of the PWED who wanted their family to have a role (55.1%) felt that this was supported by the in-patient unit. Once again, there was a sizeable proportion (20.7%) who did not want their family to have a role in agreeing treatment. A large portion of both carers (86.1%) and PWED (72.4%) reported receiving good quality information from the in-patient unit. One third of carers (33.3%) reported receiving a written copy of a care plan whereas 51.7% of PWED were not provided with a copy of their own care plan.

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Q Did the in-patient unit involve you in agreeing treatment as much as you wanted?

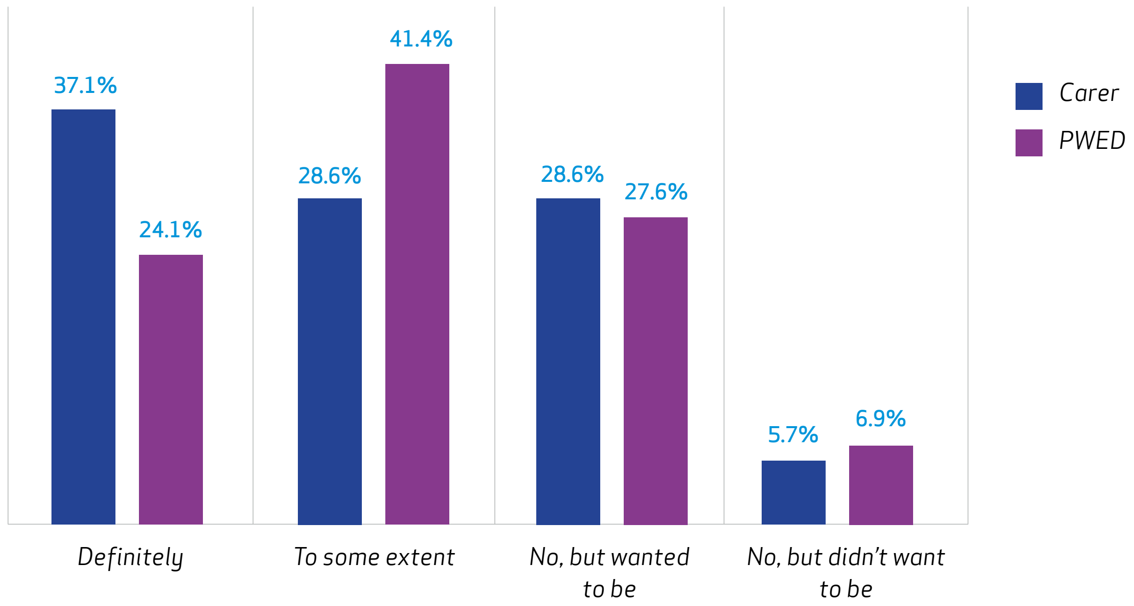

Figure 3.17 Extent to which carers and PWED felt involved in agreeing treatment with psychiatric in-patient unit staff

Q Did the in-patient unit involve your family as much as you wanted?

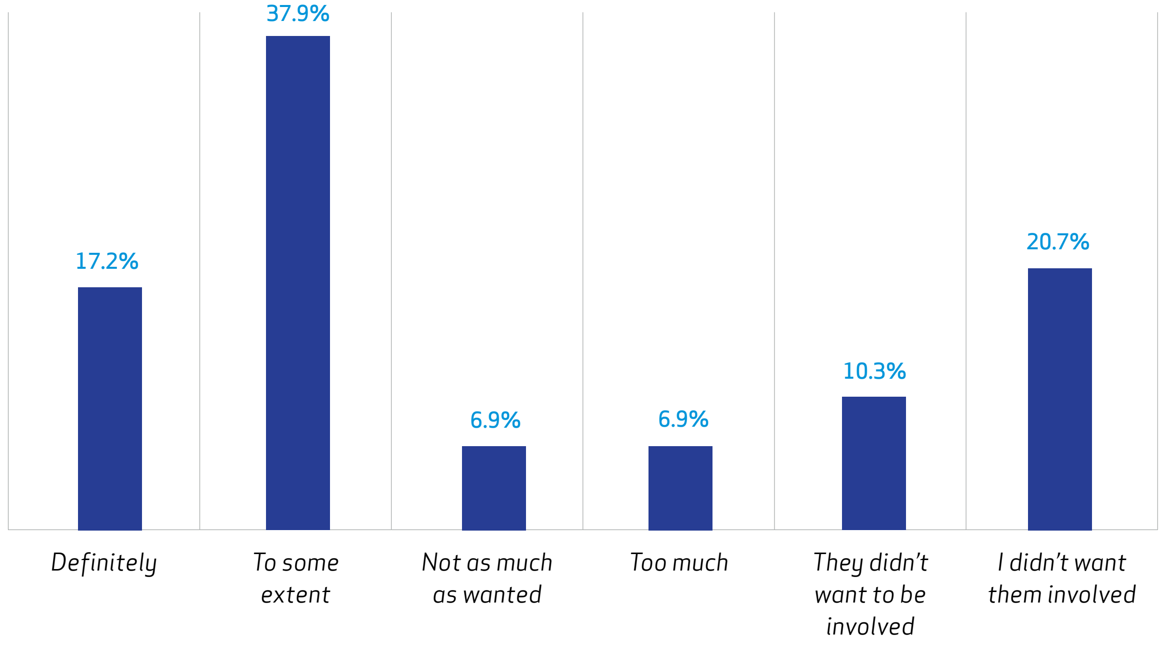

Figure 3.18 Extent to which PWED felt psychiatric in-patient unit staff involved their families in treatment

Q Did the in-patient unit give you info you could understand?

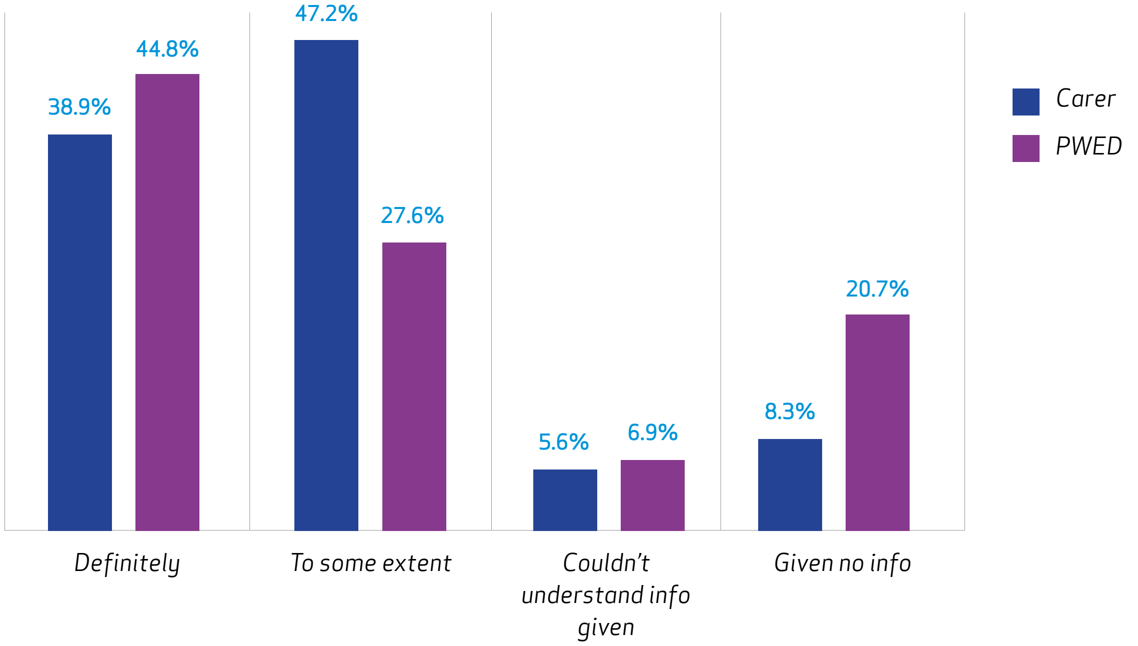

Figure 3.19 Extent to which carers and PWED felt psychiatric in-patient unit staff provided information that was understandable

Most carers felt that both they (72.2%) and the person they care for (86.2%) were treated with dignity and respect by in-patient staff. 34.5% of PWED thought they were not treated in this way. Just over half of carers (55.6%) felt their support needs were met at least to some extent by in-patient staff. 44.4% of carers and 51.7% of PWED did not feel as supported as they would have liked.

Q Did the in-patient unit treat you with dignity and respect?

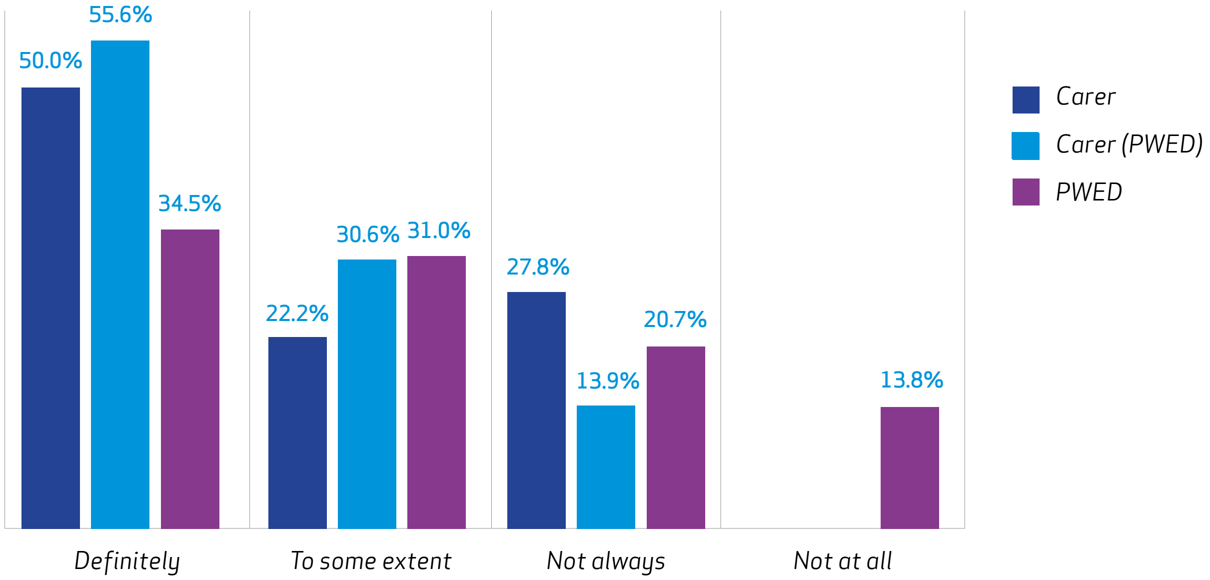

Figure 3.20 Extent to which PWED and carers felt that they and the person they care for were treated with dignity and respect by psychiatric in-patient unit staff

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Q Did the in-patient unit meet your support needs?

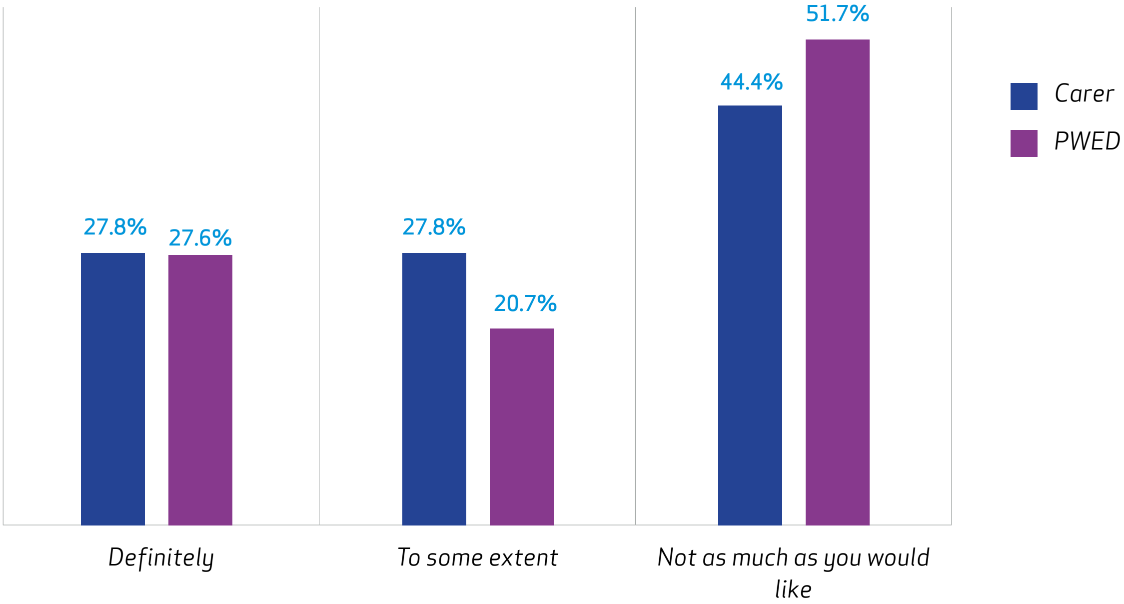

Figure 3.21 Extent to which carers and PWED felt that their support needs were met by psychiatric in-patient unit staff

3.4.2. Interview Insights

Carers praised the specialist interventions offered in in-patient units (this was true in the cases of private and some public units). It was thought that these specialist interventions made a significant difference to the PWED's recovery and carers appreciated that these addressed all aspects of the eating disorder (psychological and physical).

> *there was all different classes and they were dealing with her mental image, her body image, so they were targeting it from different angles so it wasn't just one angle, they were targeting everything and that was brilliant (Carer 18)*

Other positive aspects included the support and empathetic care offered by staff to parents in CAMHS units. Two parents noted that this support helped them to deal with their emotional distress.

> *As a family and as parents, the social worker saw us every week and just went through what was happening and my husband felt a bit, it wasn't great but I did like having someone to talk to and someone just to, you know, air my grievances to (Carer 12)*

Only four PWED interviewees had experienced in-patient care (one as a day patient). As with carers, PWED who reported positive experiences pointed to the importance of holistic care (e.g., being supported by a team) and empathic, caring staff. One participant who had been admitted during adolescence felt that the family support offered proved invaluable for her mother.

> *I really got on very well with the psychiatrist and my parents really liked her as well. I think she helped them cope quite well (PWED 22)*

Units that were not thought to offer specialist treatments were thought to be ineffective. Two PWED participants found the support they experienced to be limited and primarily weight focused. They also reported a lack of specialist knowledge and understanding on the part of some staff.

> *I feel like [dietitian] didn't really understand the psychology of [recovery]. She felt a bit like, "You guys should be able to get over it," kind of thing. Certainly, I just remember everyone complaining about her and I don't think I ever heard someone say that they found her helpful. (PWED 22)*

Some carers also felt that in-patient units did sometimes withhold treatments based on BMI and weight. They believed this to be detrimental to those they cared for.

> *we were saying when is the psychiatry going to start, when is the psychologist, when is she going to, they said look we have to, her BMI is too low, it doesn't start until the BMI goes up because she just isn't nourished enough to take in what we'll be telling her (Carer 03)*

However, one of the key concerns voiced by carers was the ability to access in-patient treatment. Some carers felt that their ability to access in-patient care depended on 'luck.' Long waiting lists often meant that parents (who had the means to do so) had to seek private treatment for their son or daughter, which came at a high financial cost. Many carers indicated that private health insurance was essential to be able to access care, particularly in-patient care, and described significant challenges faced when this cover ran out.

> *if you don't have private healthcare like we had you're absolutely screwed because your child is going to die and that's the honest to god truth, there is no help. (Carer 18)*

> *you've to [beg] the services if they're an in-patient and your VHI runs out, the public health insurance runs out, and then you've got to go back and beg and that's a huge stress on families, and you're turfed out of the these places [service1] or [service2] once your 12 weeks' allocation is gone. They just fire you out the door so, if you don't have the money. I mean, that puts a huge stress on a patient too, you know, there's no set time like for recovery. (Carer 06)*

3.5 Emergency Department

3.5.1. Survey Responses

38.5% (n=31) of carers reported that the PWED had sought emergency department help in the last 3 years and this was the case for one third (33.8%, n=27) of PWED participants. 60% of the PWED from the carers survey were admitted to hospital, 36.7% were referred to mental health services and 13.3% were given advice. Approximately two thirds (63%) of PWED participants that accessed the Emergency Department were admitted to hospital and 22.2% were referred to mental health services. There were some cases (6.7% of carers and 7.4% of PWED participant) where reports that no support at all was given when in the emergency department. Table 3.5 provides an overview of frequency of attendance and support provided by emergency departments as reported by carers and PWED. (Note: 'help' in this instance refers to help related to their eating disorder).

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Has PWED Sought Emergency Department Help in Last 3 Years?				
Yes	31	27	38.5%	33.8%
No	47	53	61.5%	66.2%
Last Time PWED Attended Emergency Department for Help				
In last month	3	5	10%	18.5%
1-3 months ago	1	5	3.3%	18.5%
4-6 months ago	6	4	20%	14.8%
7-12 months ago	4	5	13.3%	18.5%
1-2 years ago	11	6	36.7%	22.2%
More than 2 years ago	5	2	16.7%	7.4%
What Support Did Emergency Department Give? (tick all that apply)**				
Advice	4	3	13.3%	11.1%
Admitted to Hospital	18	17	60%	63%
Referral-Mental Health Services	11	6	36.7%	22.2%
Other	8	7	26.7%	25.9%

Table 3.5: Overview of frequency of emergency department attendance and support received by PWED and carers

Most carers (90%) reported they and the person they cared for (80%) were treated with dignity and respect by Emergency Department staff. Over half (55.5 %) of PWED reported that they were not always or not at all treated with dignity and respect by staff. Most carers (60%) felt that their support needs were met to at least some extent by Emergency Department staff. Most PWED (77.8%) felt the opposite and reported the Emergency Departments did not meet their support needs.

Q Did the emergency department treat you with dignity and respect?

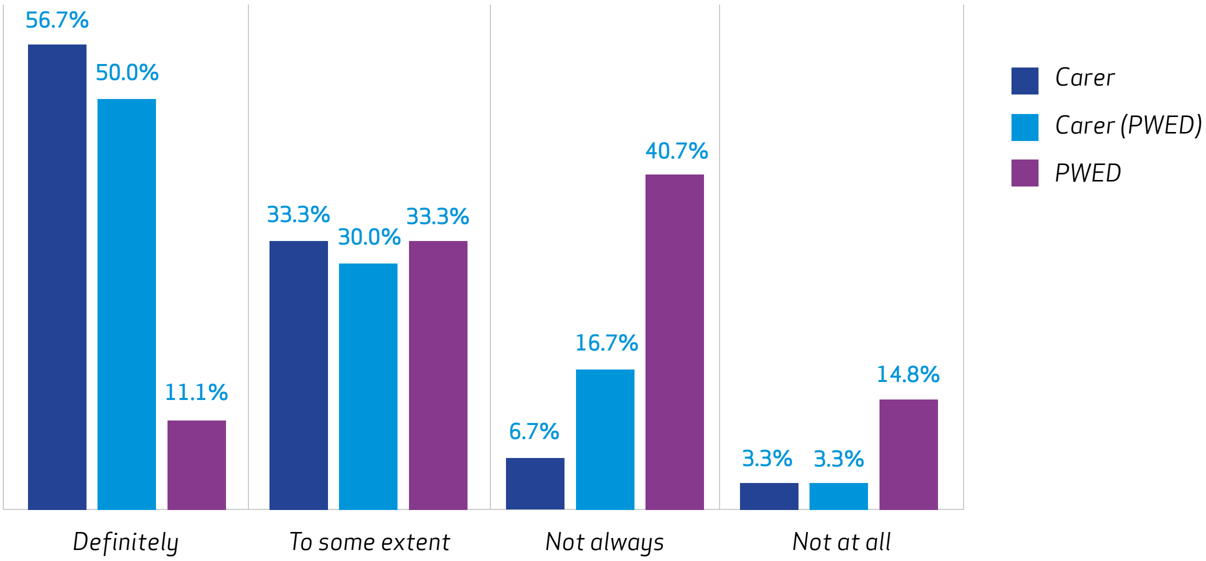

Figure 3.22 Extent to which PWED and carers felt that they and the person they care for were treated with dignity and respect by emergency department staff

Q Did the emergency department meet your support needs?

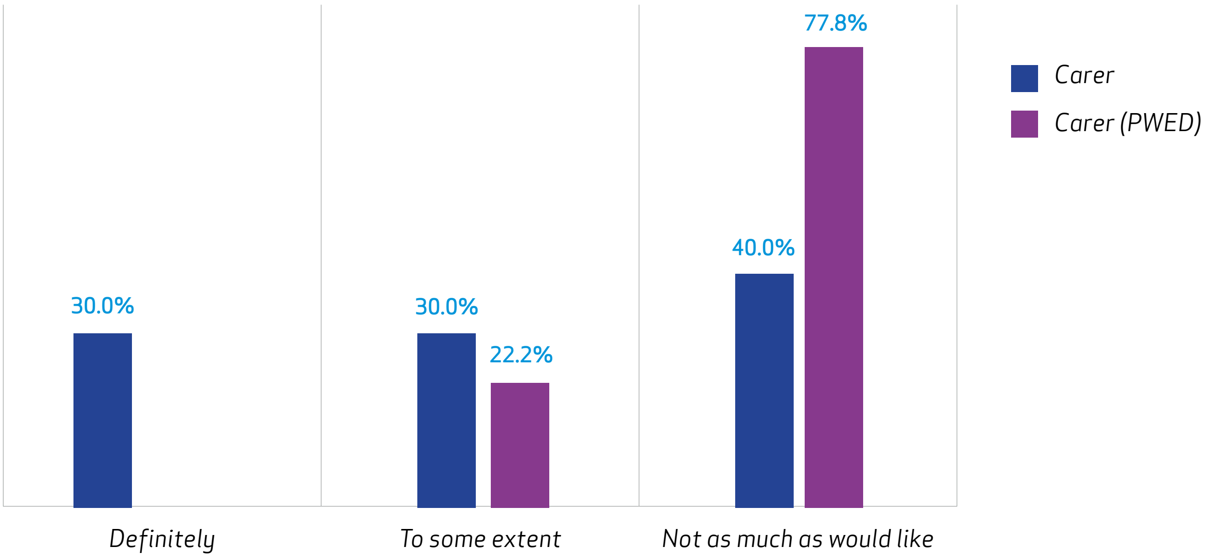

Figure 3.23 Extent to which carers and PWED felt that their support needs were met by emergency department staff

3.5.2. Interview Insights

PWED did not report any experiences with Emergency Departments in interviews conducted. Carers felt that Emergency Department staff had limited understanding of how to treat eating disorders.

> *[Daughter] started asking the doctor what's in that, you know, the drink, he said 'Oh, different nutrients and glucose and whatever', yeah but what's in it. I said, 'how many calories are in it is what she's actually asking'. It's always what she'd say, what's in it, I knew straight away what she means. And he said, 'oh, just a couple'. I said, 'I don't think there's any in it', I looked at him and he said, 'no, probably not'. (Carer 12)*

Some felt that those who attended the emergency department had to meet quite a high threshold to be offered treatment and perceived that their loved one needed to be 'sicker' to access medical support:

> *We spent the whole day there...[daughter] had blood tests, ECG and she was given fluids. Finally, they came back later in the day to say [daughter] would not be admitted as her tests came back normal even though her weight was only 37.25kg and BMI 13.5. (Carer 16)*

3.6 Medical Admissions to General Hospitals

3.6.1. Interview Insights

While this was not covered in our survey, both carers and PWED spoke of their experiences of medical admissions during their interviews. Most carers and PWED praised staff (particularly nursing staff) for their support and empathy:

> *I would be in there for eight, ten hours a day and [my daughter] would scream at me and abuse me or just not talk to me, and [the nurses] would put me out of the room and bring me some coffee and just kinda go, 'you're doing ok, and don't let her treat you like that.' They were amazing, and they were amazing to her. (Carer 01)*

> *The other Dietitians were pleasant to deal with overall. I did not find them judgemental and I cooperated as best I could with their advice while I was in the hospital and at subsequent appointments afterwards. I also found the Endocrinologist very nice to deal with. Again she was not judgemental and she had a compassionate manner. The nurses and other staff (e.g., catering staff) were also very kind. (PWED 11)*

However, both carers and PWED felt that general hospitals were ill-equipped to help those with EDs. First, they felt staff were not trained in this area and there was a severe lack of knowledge relating to the care of patients with eating disorders. General hospitals were primarily perceived to focus on medical issues. Carers perceived a clear separation of medical and psychiatric services whereby psychiatric services refused (as parents perceived it) to treat their child if there was a medical issue and medical staff were unable to address psychiatric issues.

> *[Daughter] just wanted to constantly talk, but they wouldn't, they said, no, we're not talking to her, she's not ready, she won't take anything, and I understand that a bit more now because she couldn't engage, her BMI was so low, but I felt that they were just leaving her alone, they were ignoring her. I felt that whilst she'd been fed by the tube, she needed some psychological support. They were just plugging her into this tube thing and then leaving her to deal with all her horrible thoughts (Carer 19)*

3.7 Private Health Professionals (PHP)

3.7.1. Survey Responses

62% of carers reported that PWED had sought PHP support in the last 3 years. Almost half (45.7%) of were seen straight away after referral, with a further 37% seen within a month. Two thirds (62%) of PWED sought help from a PHP in the last 3 years and approximately a half of them (48.9%) were seen straight away after referral, with a further third seen within a month. Carers indicated private psychologists and counsellors to be the most common main PHP seen, both at 36.7%, and PWED participants reported counsellors as the most common main PHP seen (15.9%). The most common type of support reported by carers and PWED participants from PHPs was individual psychological therapy (73.5% and 65.3%, respectively). Table 3.6 provides an overview of frequency of attendance at PHP practices and support received as reported by carers and PWED.

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Has PWED Sought PHP Help in Last 3 Years?				
Yes	49	49	62%	62%
No	30	30	38%	38%
Type of PHPs Approached* (tick all that apply)**				
Private Psychiatrist	7	18	14.3%	36.7%
Private Psychologist	20	19	40.8%	38.8%
Counsellor	22	22	73.3%	44.9%
Psychotherapist	13	18	26.5%	36.7%
Dietitian	27	16	55.1%	32.7%
Clinical Nurse		1		2%
Other	5		10.2%	
Main PHP				
Private Psychiatrist	3	8	6.1%	9.8%
Private Psychologist	18	9	36.7%	11%
Counsellor	18	13	36.7%	15.9%
Psychotherapist	9	12	18.4%	14.6%
Dietitian	14	2	28.6%	2.4%
Clinical Nurse		1		1.2%
Other	3		6.1%	
Last Time PWED Saw Main PHP for ED Help				
In last month	16	19	34%	42.2%
1-3 months ago	12	4	25.5%	8.9%
4-6 months ago	3	5	6.4%	11.1%
7-12 months ago	6	6	12.8%	13.3%
1-2 years ago	8	7	17%	15.6%
More than 2 years ago	2	4	4.3%	8.9%
What Support Did Main PHP Give? (tick all that apply)**				
Individual Psychological Therapy	36	32	73.5%	65.3%
Group Therapy	2	4	4.1%	8.2%

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Advice	12	21	24.5%	42.9%
Guided Self-Help	6	17	12.2%	34.7%
Nutrition Advice/Monitoring	19	15	38.8%	30.6%
Medication	3	5	6.1%	10.2%
Other	5	3	10.2%	6.1%
How Long Between Referral & Being Seen By Main PHP?				
Straight Away	21	22	45.7%	48.9%
Within One Month	17	15	37%	33.3%
1-3 Months	6	5	13%	11.1%
More than 3 Months	2	2	4.3%	4.4%
Don't Know		1		2.2%
How Frequently Saw Main PHP?				
Every 1-2 Weeks	33	35	70.2%	77.8%
Once A Month	10	6	21.3%	13.3%
Once Every 3 Months	2	2	4.3%	4.4%
Less Than Once Every 3 Months	2	2	4.3%	4.4%

Table 3.6: Overview of frequency of attendance at private health professionals' practices and support received by PWED and carers

Most carers (74.5%) and PWED (88.9%) reported being included in the planning of treatment. Over three quarters of carers (76.1%) and PWED (77.8%) reported the information they received from PHP to be understandable to some extent. However, some carers (21.7%) and PWED (22.2%) indicated that they did not receive any information at all. A third (31.1%) of PWED reported that their family was involved as much as they wanted. However, 40% of them did not want their family involved in their treatment. A fairly large proportion of carers (78.3%) and PWED (68.9%) did not receive a copy of the care plan from the PHP.

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Q Did the private health professional involve you in agreeing treatment as much as you wanted?

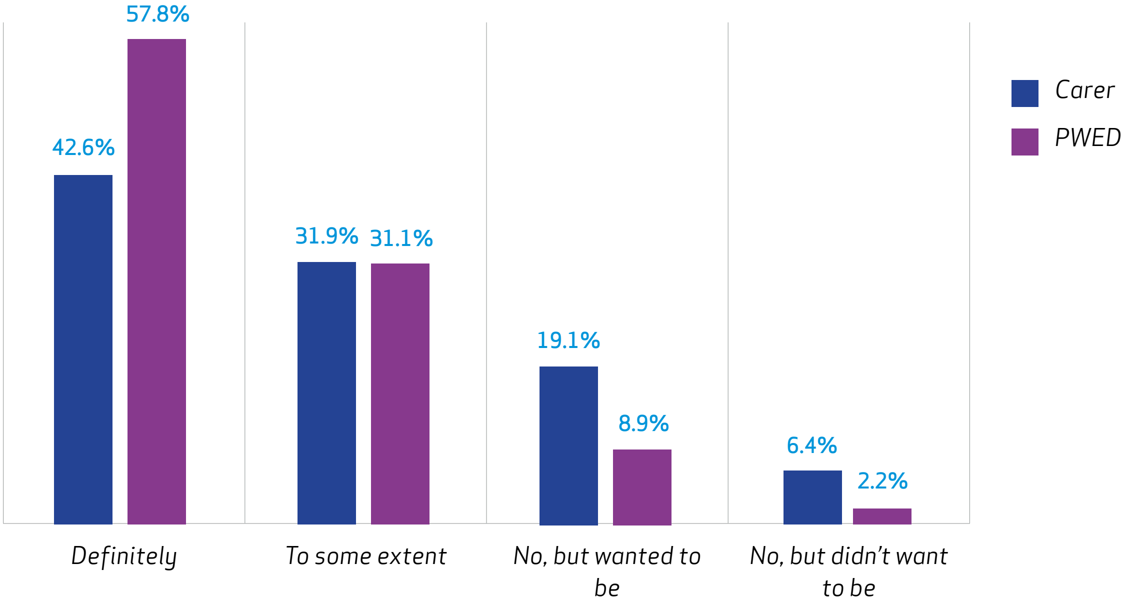

Figure 3.24 Extent to which carers and PWED felt involved in agreeing treatment with private health professionals

Q Did the private health professional involve your family as much as you wanted?

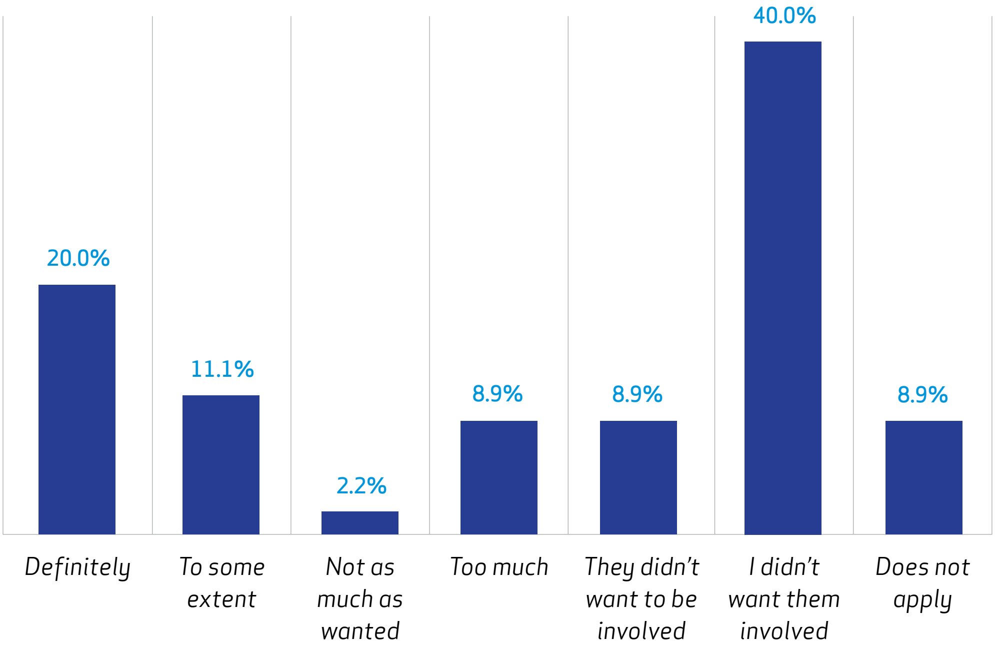

Figure 3.25 Extent to which PWED felt private health professionals involved their families in treatment

Q Did the private health professional give you information you could understand?

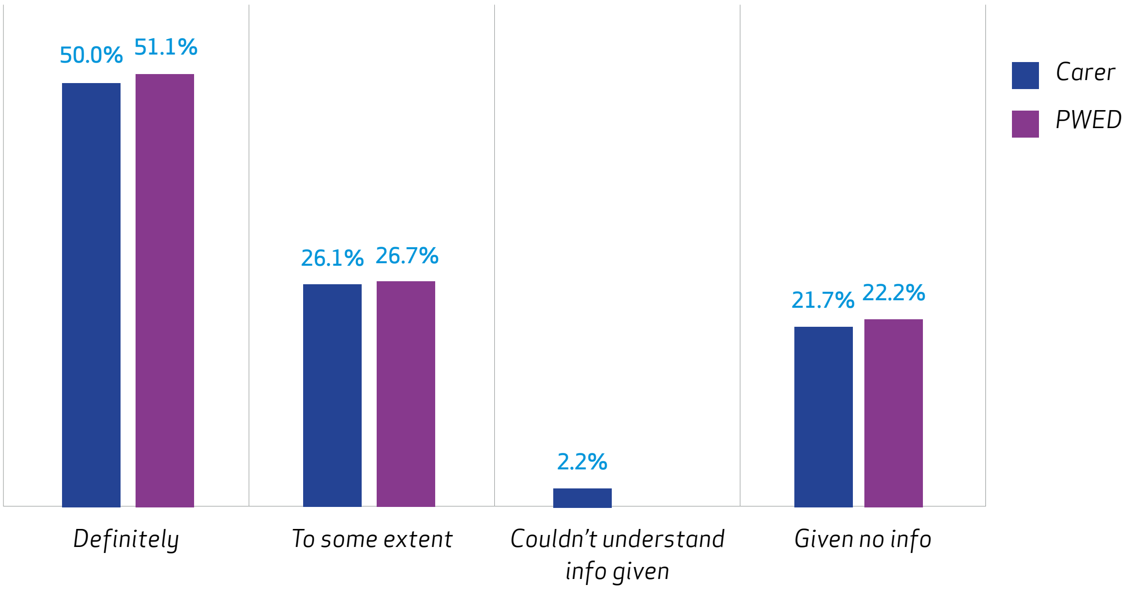

Figure 3.26 Extent to which carers and PWED felt private health professionals provided information that was understandable

Most carers felt that PHP treated them (95.3%) and the person they cared for (97.8%) with dignity and respect. PWED also largely felt respected by PHP, with 88.9% reporting that they were treated with dignity. However, PWED were split on how supported they felt by the PHP, with 60% feeling their support needs were met to some extent, and 40% feeling that they were not met as much as they would have liked. Most carers felt that their support needs were met by PHP (80%).

Q Did the private health professional treat you with dignity and respect?

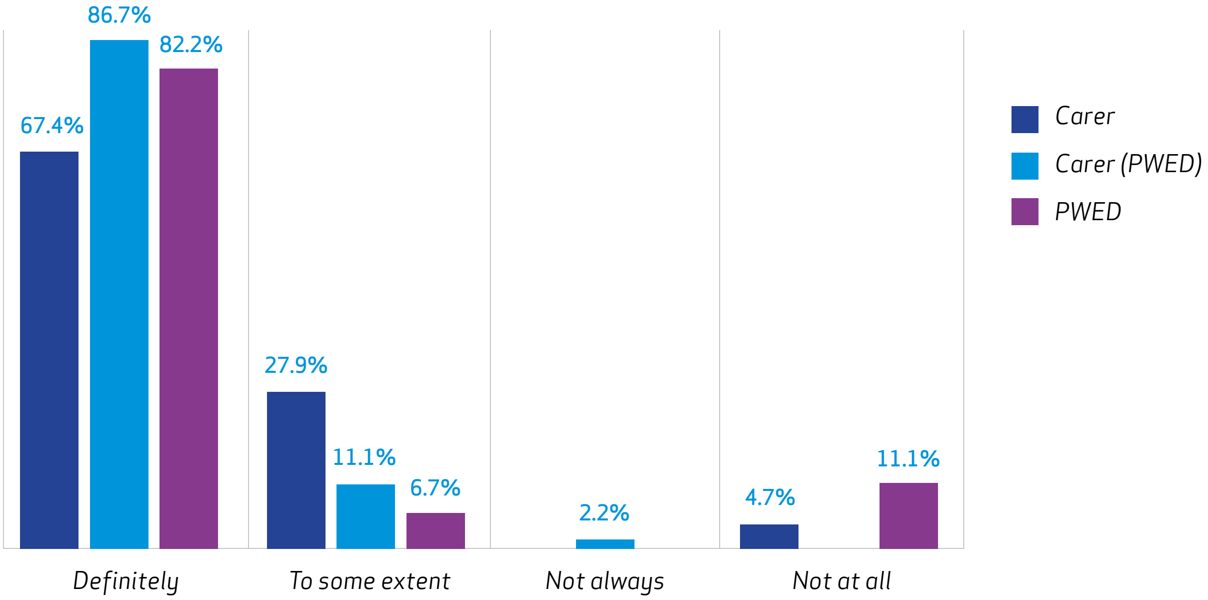

Figure 3.27 Extent to which PWED and carers felt that they and the person they care for were treated with dignity and respect by private health professionals

Q Did the private health professional meet your support needs?

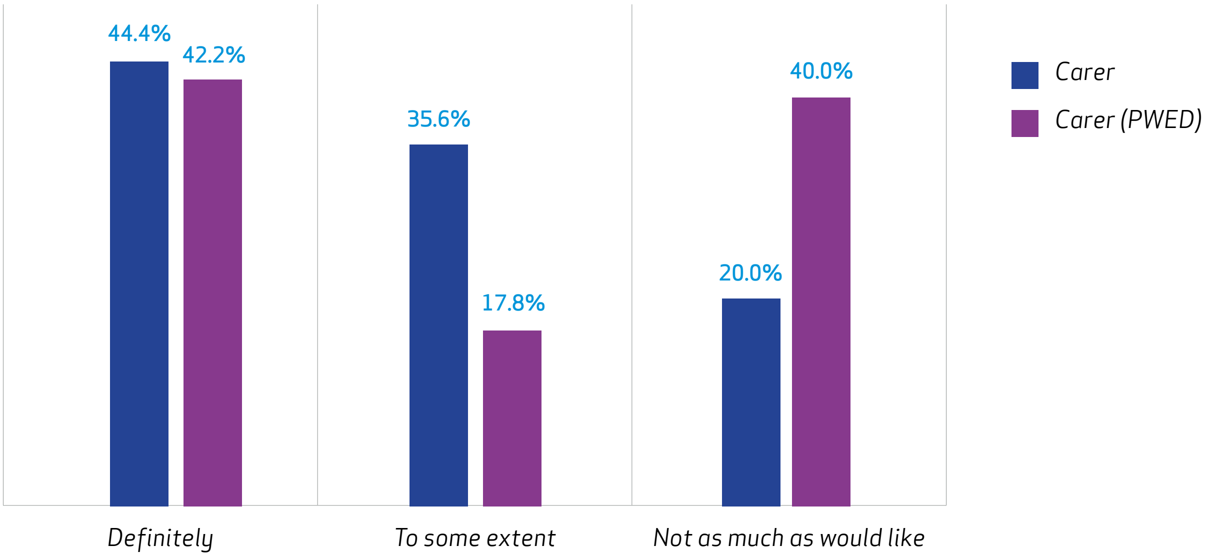

Figure 3.28 Extent to which carers and PWED felt that their support needs were met by private health professionals

3.7.2. Interview Insights

Some carers felt that the only way for them to access treatment in a timely fashion was through the private route. These carers noted exceptionally long waiting lists or the absence of public services, such as counselling, in their areas. For some, their GP advised them to pursue this route. Carers who reported positive experiences noted the value of holistic support offered by private clinics/treatment centres and working with understanding professionals:

> *She went to [professional]. I think weekly at the beginning, and came out and said, 'Mum, at last somebody can, kind of, treat me, and doesn't think it's because of some awful thing I might have', but this has happened, because basically [daughter] didn't really know why it happened to her. She felt this was somebody who really understood, and it was really working then. (Carer 17)*

Similarly, PWED noted the helpfulness of the psychological support provided by PHPs (focusing on exploring relationships, body image, etc.). Some participants reported that this helped them to understand their illness and how to move forward towards recovery. The quality of the relationship with the professional was of crucial importance. PWED valued those who had specialist knowledge, showed empathy and respect for the PWED, and worked with them to agree a direction for treatment.

> *The counselling sessions were very difficult in the beginning and usually I felt worse going in but the days after the sessions I felt the positive benefits of attending. I found the counsellors and psychologists to be very easy to deal with in the sense that they did not seem to patronise me like the doctor. (PWED 14)*

Carers who did not have positive experiences felt that this was due to a lack of specialist training and knowledge.

> *I felt the dietitian did not understand eating disorders and didn't seem to take on board that [daughter] had lost a lot of weight and had been restricting a lot in the previous weeks. She told my daughter that 'Her weight was fine'. My daughter was 'in denial' about her illness and thought I was 'over reacting' and as a professional saying that to her it reiterated to her that she was fine and as we walked from the dietitian rooms she looked at me and said 'Now mom I told you I was fine' (Carer 10)*

For PWED, the absence of trust, specialist knowledge and feeling judged by the professional tended to underly negative service user experiences.

> *I then visited about another 2 general counsellors who were completely useless. They told me to eat fruit, drink more water, hadn't a clue. (PWED 16)*

Participants also described difficulties accessing private services initially and being unsure which professional was the best person to attend or whether they had appropriate qualifications. Finally, both carers and PWED noted the high cost of treatment and the difficulties associated with this.

> *It was difficult to afford the private psychologist while I had to wait 12+ months to see the psychologist in the centre. (PWED 17)*

Carers spoke of a "two-tier system" where they felt lucky to be able to access private treatment and felt sorry for those who did not have this option. These costs however did place a significant burden on families:

> *we never made an issue of the money but the money is an issue ok, we always had to try and pretend it didn't make a difference but it was costing us a couple of hundred every week, so. We were trying, we did, we pretended it didn't make any difference but of course it did, we had a day when we didn't go and she said 'Oh, I don't need to go', we were delighted because there's a couple of hundred Euros in our pocket extra that week. (Carer 15)*

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3.8 Support Groups / Organisations (SGO)

3.8.1. Survey Responses

85.7% of carers and half of PWED (51.3%) they had sought SGO help in the last 3 years. Most carers (95.5%) and PWED (84.6%) accessed Bodywhys. 60.6% of carers and 79% of PWED had been seen in the last year, with 15.2% carers and 26.3% PWED being seen in the last month. Nearly half (45.5%) of carers were no longer in contact with the SGO and this was the case with one third (32.4%) of PWED. The most common type of support that carers access was a course for carers (56.1%) and the most common type of support PWED received (59%) was online group support. Table 3.7 provides a detailed overview of frequency of attendance at SGO and the support received as reported by carers and PWED.

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Has Carer Sought SGO Help in Last 3 Years?				
Yes	66	39	85.7%	51.3%
No	11	37	14.3%	48.7%
What SGO Was This? ** (tick all that apply)				
Bodywhys	63	33	95.5%	84.6%
Other	14	8	21.2%	20.5%
Multiple SGOs	3	2	4.5%	5.1%
Last Time Carer Saw SGO for ED Help				
In last month	10	10	15.2%	26.3%
1-3 months ago	13	8	19.7%	21.1%
4-6 months ago	8	7	21.1%	18.4%
7-12 months ago	9	5	13.6%	13.2%
1-2 years ago	23	2	34.8%	5.3%
More than 2 years ago	3	6	4.5%	15.8%
What Support Did SGO Give? (tick all that apply)**				
Individual Telephone Support	16	9	24.2%	23.1%
Individual Email Support	5	9	7.6%	23.1%

	N		%	
	Carer	**PWED**	**Carer**	**PWED**
Face-to-Face Support Group	29	11	43.9%	28.2%
Online Support Group	5	23	7.6%	59%
Advice/Information	16	14	24.2%	35.9%
Guided Self-Help	3	5	4.5%	12.8%
Course For Carers	37		56.1%	
Help For Family		1		2.6%
None		1		2.6%
Other	3		4.5%	
How Frequently Saw SGO?				
Every 1-2 Weeks	6	6	9.1%	16.2%
Once A Month	7	6	10.6%	16.2%
Once Every 3 Months	6	5	9.1%	13.5%
Less Than Once Every 3 Months	17	8	25.8%	21.6%
No Longer In Contact With SGO	30	12	45.5%	32.4%

Table 3.7: Overview of frequency of support group / organisation attendance and support received by PWED and carers

All carers reported the SGO gave them information they could understand, to an extent. 78.9% of PWED thought this was the case. 21.1% of PWED reported not being given any information at all. All carers thought they were treated with dignity and respect and nearly all PWED (94.7%) thought the same. 90.9% of carers reported their support needs were met. In terms of PWED, although despite most (67.5%) feeling supported by the SGO, a third (32.4%) of PWED reported that the SGO did not meet their support needs as much as they would have liked.

3.8.2. Interview Insights

Q Did the support group/organisation give you info you could understand?

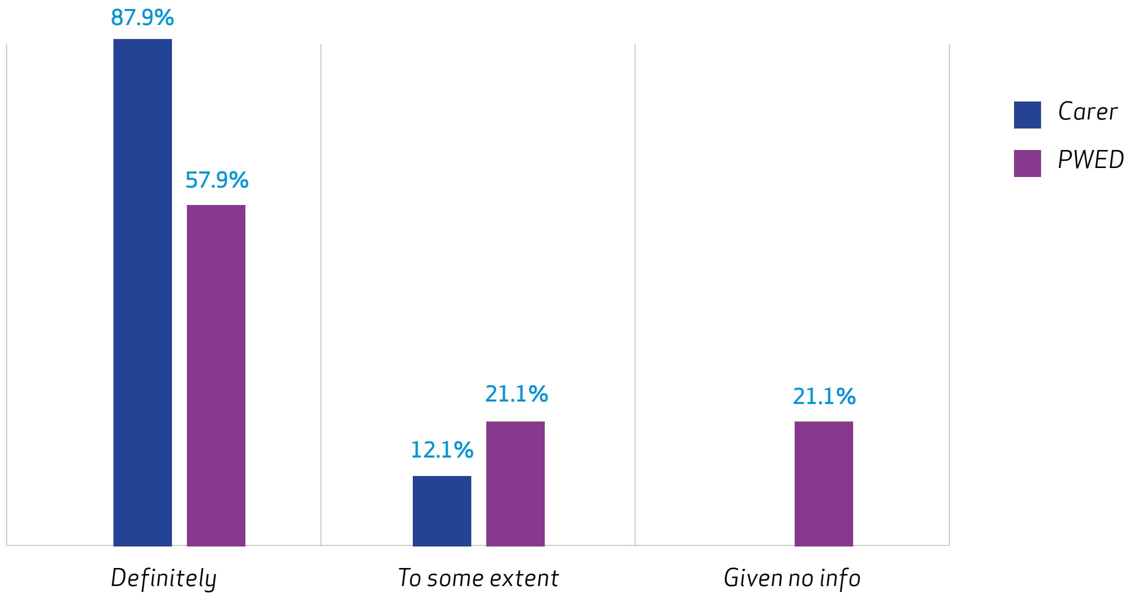

Figure 3.29 Extent to which carers and PWED felt support groups / organisations provided information that was understandable

Q Did the support group/organisation treat you with dignity and respect?

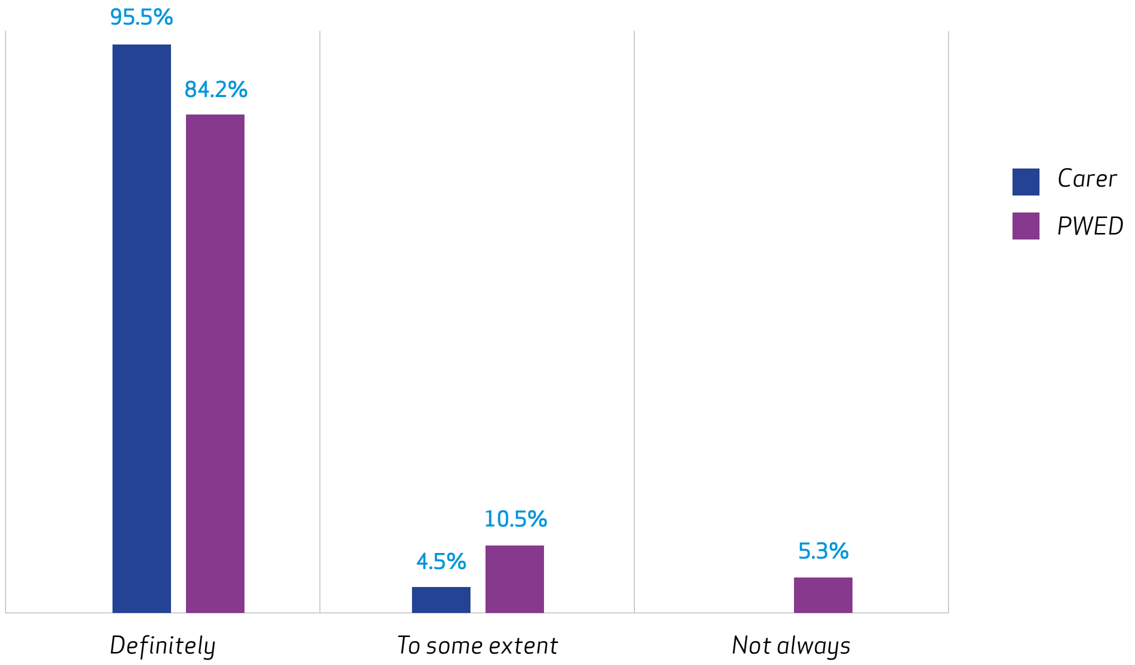

Figure 3.30 Extent to which PWED and carers felt that they and the person they care for were treated with dignity and respect by support groups / organisations

Q Did the support group/organisation meet your support needs?

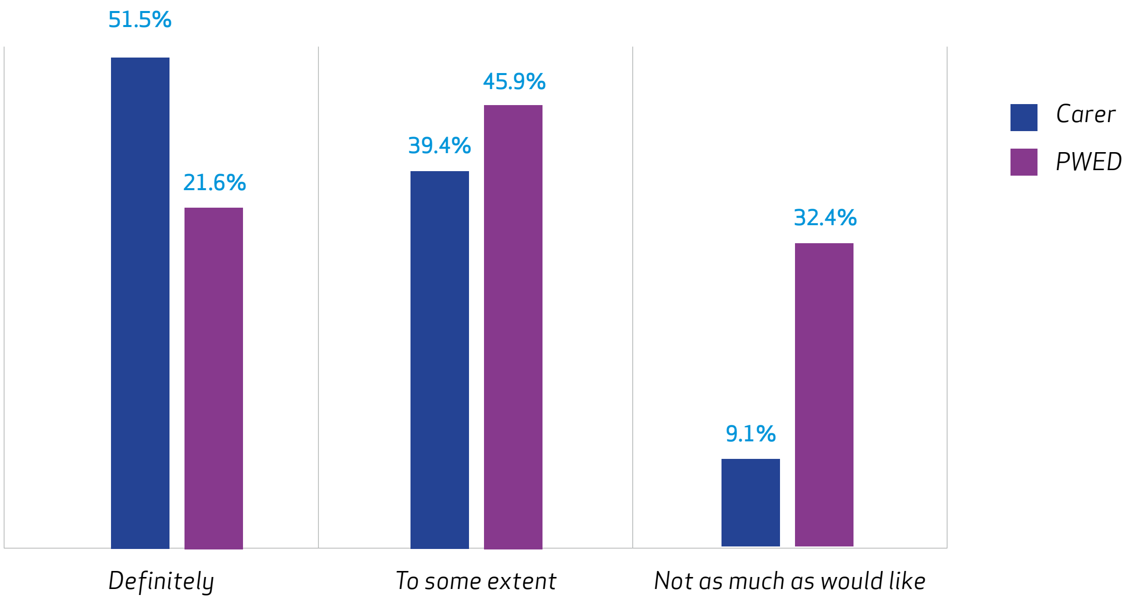

Figure 3.31 Extent to which carers and PWED felt that their support needs were met by support groups / organisations

Carers rarely spoke of needing emotional support for themselves – typically they focused on seeking help for their son or daughter and their own needs for information and knowledge to help their son or daughter recover. Carers appreciated attending courses designed to meet these needs.

> *The course was a great starting point and an eye opener for us as to what we were dealing with and it was great to meet with other parents as it took some of the isolation away. (Carer 07)*

Informational support delivered in an empathic way from experts (either professionals or experts by experience) was especially helpful. They mentioned that seeing others who have recovered inspired hope that recovery was possible for their child. They especially valued learning about the ED and the recovery process as well as how to talk to their child and understand the ED from their perspective. PWED reported accessing support via web resources, individual staff members, and support groups. Like carers, they praised empathic, non-judgemental staff and some found anonymity helpful (either when seeking online or via telephone support).

> *The doctors and hospital programmes make judgements about how I'm doing – i.e I'm resistant, I'm not ready to recover, I'm good/bad, making an improvement/ need to do more etc but it is in emailing and talking to Bodywhys that I've been able to practice taking the risk of taking care of myself – and to take that risk and learn what taking care of myself means without the distraction of punishment or judgment or expectation from an institution or 'judgemental doctor'. (PWED 08)*

Many carers mentioned that talking to/hearing from others in similar situations was helpful (in terms of feeling less isolated but also gaining additional informational support). This was true for those who were members of support groups as well as those who attended courses delivered in groups. Some carers mentioned being in contact with other individual carers and again valued the support provided by these relationships. The value of support from similar others was also highlighted by PWED who were members of support groups.

> *I'm a member of a support group. Luckily enough I had known another woman whose daughter, much older daughter, had anorexia, and she was my lifeline, she was on the phone to me the whole time whenever I needed to talk to somebody. It wasn't the doctor. You couldn't get them. (Carer 19)*

> *I used the Bodywhys online chat/support rooms. They have a set time and date for the online support group. And it feels like a safe space where I can talk to others who are going through similar difficulties. (PWED 17)*

Less positive experiences tended to occur when there was a mismatch between the support carers felt they needed and the type of support they sought from the support organisation. Often those with informational support needs were dissatisfied when they attended support groups. These carers mentioned they needed specific, tailored information on how to help their child which they felt was not suited to the format of the support group.

> *All we got was, I felt, it was, sort of, a field of names of people, and they could be anybody, and we weren't sure of what their qualification was, and from our past experience we, kind of, thought, well, we desperately want…if you want treatment you desperately want the right treatment and the best treatment. We found it hard to get that information, I suppose, and I guess we felt that it wasn't support for ourselves that we were looking for, it wasn't the right help for our child. (Carer 17)*

Two carers who had young children with an eating disorder also wanted more tailored support for their situation as they felt that support was tailored towards those with adolescent or adult children.

> *Everything was targeted around teenagers, and getting them to talk, and I was asking the questions, well, what about your 10 and 11-year-old, it's more difficult for them to articulate how they're feeling. (Carer 05)*

As with carers, some PWED felt that they would benefit from more tailored support. This differed across participants. For example, one person wanted more directive advice around which specific health professional would be the best to contact, while another wanted to talk more specifically about disordered behaviours / eating patterns in the online support group (although this latter request would potentially jeopardise the safety and recovery-oriented nature of the online group). Another participant suggested a course like that for carers but tailored towards PWED would be useful.

> *it would also be good if [SGO] did a course maybe on how to beat it and thing to do, not just meeting up with other people with the same situation because that's fine like, we can all have the same eating disorder but still, we're still like all how are we going to do this?, how are we going to beat it? (PWED 15)*

3.9 Conclusion

While carers and PWED reported some positive aspects of their interactions with health and support services, there are several areas requiring urgent attention in future service development plans. First, services are failing to adequately meet the support needs of carers and PWED (except for private health professionals and support groups / organisations). Second, there are suggestions of poor communication between health services, carers and PWED. A substantial number of participants reported receiving no information from services, and participants very rarely received a written copy of their care plan. Third, not all public services are resourced to provide specialist interventions and families are experiencing significant financial burdens in sourcing private treatment for their son or daughter. The benefits of having well-resourced mental health services (i.e., CAMHS and AMHS) was clear from participant interviews. Finally, there remains a need for specialist training in eating disorders for GPs, staff in emergency departments, and staff in general hospitals. Healthcare staff with direct and specialist knowledge are essential to positive service user experiences. It is likely that specialist knowledge and experience also supports the development of an empathic interaction style with carers and PWED. Talking to healthcare staff who understood and were sensitive to the challenges faced by carers and PWED contributed to feelings of trust and openness, which in turn is likely to facilitate treatment engagement.

04

Participant Psychosocial Health and Well-being

SECTION 04

Carer and PWED Psychosocial Health and Well-being

Contemporary research and theory in social psychology indicates that when we experience a sense of identification with others, it can have a beneficial effect upon our health and well-being in several ways[13]*. There is evidence within this area of research that such effects might be present for PWED*[14]*(although to our knowledge, these issues have not been explored with carers), and so we have explored whether this can be found within the data we have collected.*

As outlined in Section 2, our online surveys included a series of psychosocial measures exploring carers' and PWED's group memberships, their feelings of identification (with their families, with other carers, or others in recovery), as well as measures of loneliness and psychological health and well-being. In this section, we outline the key findings for each participant group.

1.1 Carer Psychosocial Health and Well-being

We statistically analysed the correlations between the different scales we used[16]. Our results indicated that carers who identified strongly with their families tended to be less lonely and tended to identify strongly as carers. Carers with a strong sense of possessing multiple social identities (i.e. belong to multiple groups) tended to experience less loneliness. Additionally, carers with higher levels of carer burden tended to experience lower levels of life satisfaction and higher levels of loneliness.

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[13] Wakefield, J., Bowe, M., Kellezi, B., McNamara, N., & Stevenson, C. (2019). When groups help and when groups harm: Origins, developments, and future directions of the 'Social Cure' perspective of group dynamics. *Social & Personality Psychology Compass, 13*, e12440. Doi:10.1111/spc3.12440

[14] McNamara, N., & Parsons, H. (2016). "Everyone here wants everyone else to get better": The role of social identity in eating disorder recovery. *British Journal of Social Psychology, 55*, 662-680.

[15] Beside each scale name, the range (lowest and highest possible values), mean (M), standard deviation (SD), and measure of scale consistency where appropriate (r/α) are stated. Correlations between each scale are also reported.

[16] In these analyses, a number is generated between -1 and 1. If the number is negative, it means that in this sample, responses to one measure are more likely to be higher when responses to the other measure in question are lower. If the number is positive, it means that the responses to one measure are likely to be higher when the responses to the other measure are higher. The further this number is from 0, the stronger the relationship is. We can then determine whether these observed relationships represent a chance occurrence, or if they are likely to be related for reasons other than chance. If $p<0.05$, this indicates that there is only a 5% likelihood of it occurring due to chance; $p<0.01$ is a 1% likelihood, and $p<0.001$ is a 0.1% likelihood.

Scale	1	2	3	4	5
1. Carer Identification (1-7; M = 5.26, SD = 1.75)	-				
2. Family Identification (1-7, M = 5.36, SD = 1.62)	.28**	-			
3. Multiple Identities (1-7, M = 4.21, SD = 1.63, r = .65)	-.12	-.05	-		
4. Life Satisfaction (1-7, M = 4.49, SD = 2.04)	-.11	.05	.16	-	
5. Loneliness (1-3, M = 1.64, SD = 0.61, a = .83)	.08	-.23*	-.26*	-.51***	-
6. Carer Burden (24-120, M = 62.25, SD = 15.26)	-.09	-.21	.01	-.41**	.46***

Note: * p < .05, ** p < .01, *** p < .001.

Table 4.1: Descriptive statistics and inter-correlations for group memberships, life satisfaction, loneliness and carer burden.

We hypothesised that carer's family identification and multiple group identities would improve their life satisfaction and decrease carer burden by reducing how lonely they felt. We tested this hypothesis using a 'mediation' analysis, which allowed us to investigate how group identities are related to life satisfaction and carer burden, and whether loneliness explains this relationship. The results showed that although family identification and possessing multiple social identities did reduce loneliness, this did not appear to predict higher levels of life satisfaction or lower levels of carer burden.

1.2 PWED Psychosocial Health and Well-being

Using the same analyses as described in Section 4.1, our results suggest that PWED who identified strongly as being in recovery tended to identify strongly with their family, feel highly satisfied with their lives, perceive themselves as having higher levels of personal control, and tended to have fewer negative eating-related thoughts and behaviours. Additionally, PWED who identified strongly with their family tended to have a strong sense of possessing multiple social group identities, feel highly satisfied with their lives, feel less lonely, perceive themselves as having higher levels of personal control, and tended to have fewer negative eating-related thoughts and behaviours. PWED with a strong sense of possessing multiple social identities tended to experience more life satisfaction and less loneliness.

Scale	1	2	3	4	5	6	7
1. Recovery Identification Others (1-7; M = 4.24, SD = 2.13)	-						
2. Family Identification (1-7, M = 4.27, SD = 1.86)	.27*	-					
3. Multiple Identities (1-7, M = 4.57, SD = 1.78, r = .70)	.08	.38***	-				
4. Life Satisfaction (1-7, M = 3.56, SD = 2.07)	.32**	.37***	.24*	-			
5. Loneliness (1-3, M = 2.29, SD = 0.63, a = .80)	-.17	-.31**	-.34**	-.56***	-		
6. Personal Control (1-7, M = 3.70, SD = 1.49, a = .73)	.27*	.23†	.18	.73***	-.52***	-	
6. Negative Eating Thoughts/ Behavs (1-6, M = 4.40, SD = 1.11, a = .94)	-.20	-.26*	.09	-.54***	.48***	-.60***	-

Note: † p = .054, * p < .05, ** p < .01, *** p ← .001.

Table 4.2: Descriptive statistics and inter-correlations for group memberships, life satisfaction, loneliness and personal control, and negative eating thoughts/behaviours.

We hypothesised that PWED who belong to multiple groups and identify with their families will feel less lonely, and therefore be more satisfied with life and have fewer negative eating thoughts/behaviours. As with the carers, we again tested this hypothesis using a 'mediation' analysis. We found that PWED that identified more strongly with their families were less lonely, and this reduction in loneliness was associated with increased life satisfaction and fewer negative eating thoughts/behaviours.

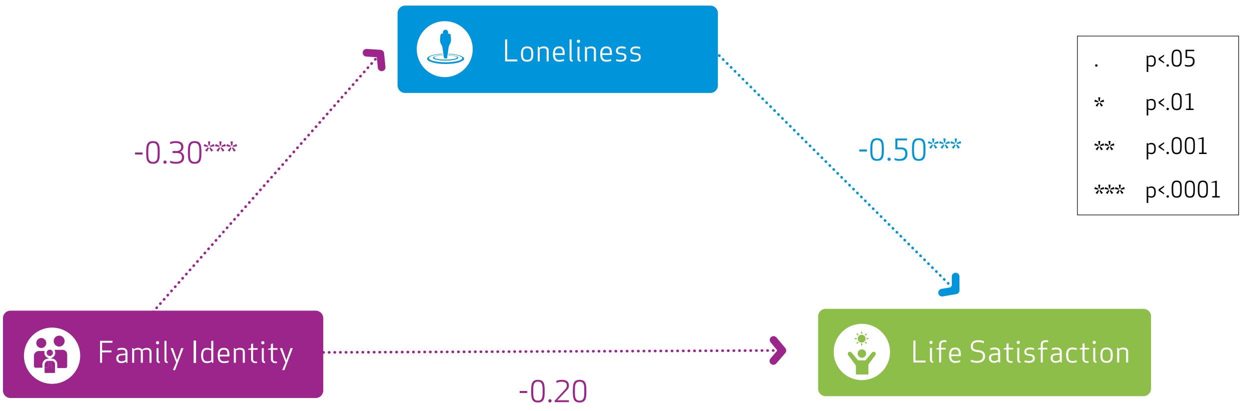

Figure 4.1. Mediation model testing indirect effect of family identity on life satisfaction through loneliness

Similarly, we found that PWED that identified with multiple groups were also less lonely, and this decreased loneliness was associated with satisfaction with life and fewer negative eating thoughts/behaviours.

1.3 Conclusion

This section provided some initial insights into the psychosocial health of carers and PWED who participated in our online surveys. Our findings illustrated the important associations between group memberships (and the social identities derived from these group memberships) and psychological health. These associations were present for both carers and PWED. Family was a particularly important group for both; greater family identification was associated with lower levels of loneliness for PWED and carers. For PWED, greater family identification was also associated with lower levels of ED symptomatology, greater satisfaction with life, and a greater sense of control. This suggests that family identification is associated not only with better well-being but also has a positive association with recovery outcomes. Possessing multiple social groups was also beneficial for well-being in both carers and PWED. Finally, we noted the importance of identifying as someone in recovery for PWED. The more PWED identified as 'in recovery', the better their well-being and recovery outcomes. We should note however that our sample sizes were relatively small and further research needs to be conducted to confirm these results.

05

Experiences of Living with an Eating Disorder

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SECTION 05

Experiences of Living with an Eating Disorder

In addition to talking to both carers and PWED about their service user experiences, we were also interested in their day-to-day experiences of living with an eating disorder. In doing so, we hoped to get a truly comprehensive insight into the impact the disorder has on their daily lives and their hopes for the future. In this section, we outline three important aspects from the perspective of our participants: (1) the impact on family life, (2) experiences of stigma, and (3) looking towards recovery.

5.1 Impact on Family

Carers and PWED spoke about the changes to family life brought about by the presence of an ED and discussed how this had impacted: (1) family relationships, (2) family mental health, and (3) family finances.

5.1.1. Family Relationships

Family life and family relationships experienced significant change following the emergence of an eating disorder in a family member. Daily life and family routines were described as centring on the PWED and their recovery. Families often had to cope with what could be quite challenging behaviour at home:

> *It does affect relationships, it definitely does. They're fine but I think she drives [sister] absolutely mad at times. There's things that we can't do as a family, we can't go out to eat, we can't go out for meals. Holidays have been awful with her, awful. So it's hard, we're all only human and it is hard trying not to say, "Oh for god's sake, [daughter], like really and truly just cop on", like it is, it's hard. (Carer 11)*

Carers, like Carer 11 above, described mealtimes as particularly tense and family activities often had to be arranged around the needs of the person with the eating disorder, placing restrictions on the family's day-to-day life. PWED also discussed the tension they felt around mealtimes. They described feeling, "overwhelmed" by food at home and withdrawing or acting out at family members as a result:

> *I feel like [my mum] didn't really understand what I was going through. I was overwhelmed by the amount of food I was surrounded by, I became upset and hid in my room to get away from it all. I think my mum took this as a personal attack on her and we ended up fighting - I was called "selfish" etc. I get that it's hard for my mum to process and that kind of behaviour isn't normal for her so I just blamed it on the fact that there is a serious lack of education when it comes to eating disorders. (PWED 03)*

As suggested by PWED 03 above, arguments between family members could develop from feelings of mutual misunderstanding. PWED sometimes saw this lack of understanding as evidence of a "hostile attitude" towards them but simultaneously recognised their own difficulties in engaging with treatment, noting feelings of ambivalence towards recovery.

Some carers described their families being "torn" or "ripped" apart. Challenging behaviours and restrictions on family life were believed to result in the disruption or breakdown of previously close bonds between PWED and their parents, between parents, and between siblings:

> *So, [Susan] and [David], [David] is my second, he's my son. There's seventeen months between [Susan] and [David], and they would have been like two twins. They got on like a house on fire, and they would have been absolutely best pals. So, [David] now really has turned to [Jessica], my youngest, and they would now, you know, they have clung together. [lines omitted] Now, they were broken hearted, they were crying, they were worried about her, but now they are, the two of them are just gelled together, and they hate [Susan] doing it. [lines omitted] their relationship with her, has hugely changed (Carer 19) ' (Please note that the names used here are pseudonyms)*

Another aspect of feeling "torn" described by parents involved their feelings of guilt at not being able to devote as much time as they felt they needed to their other children. This was compounded by their desire to "protect" their other children from emotional distress

> *in hindsight my kids would say, at the time they said they thought they'd lost their parents. So, we were, kind of, giving everything to [daughter], and leaving out, you know, we didn't realise it, but we obviously were not giving everything to our other kids, and so they felt, kind of, that we weren't there for them. (Carer 21)*

For their part, PWED also recognised the toll the disorder could have on family relationships. Those with children and spouses of their own wanted to protect their families from distress and, for some, from developing similar disordered eating patterns:

> *when I'm like that I get moody and take it out on my family and stuff like that and it just got to a point where I kind of said this isn't the right, I can't be doing this to my wife and I've got two kids, I can't let them see me acting this way and having this kind of relationship with food and all of this kind of stuff, I can't allow them to do that, it has to stop. (PWED 21)*

In summary, the eating disorder takes a significant toll and is extremely disruptive to family life. As detailed in the next section, this has considerable consequences for the health and well-being of all members of the family.

5.1.2. Impact on family mental health

Participants described the emotional toll the presence of an eating disorder takes on family members. Parents described feeling afraid for their child and worried about whether they would survive. They also reported feeling that they were to blame for the disorder. They perceived that these feelings of fear and guilt were also felt by siblings. This was described as having a significant impact on the mental (and sometimes physical health) of family members:

> *I mean, the worry and the stress of knowing that your child is dying in front of your eyes and they won't take her into the medical hospital. It's so horrendous. (Carer 06)*

> *My daughter wanted to die, every day she was talking about wanting to die, her brothers found this, especially her younger brother found this horrendous, she'd say, "just let me die" and he'd say, "I don't want you to die, you're my sister" and he was blaming himself, he said to me, "what could I have done to help her, why can't I do anything, I'm her brother?". (Carer 12)*

Many carers reported feeling "helpless and unsupported" and strongly recommended that more formal support should be made available for family members. Those who were in receipt of support from services felt that this was not enough to meet the family's needs. A number reported difficulties in engaging with family therapy which they felt was particularly challenging for siblings. One carer noted that she felt the primary function of family therapy was to support the child with the eating disorder and that additional separate supports were needed for family members:

> *Treatment should automatically include support for carers and family members where they can discuss how the situation is affecting them and learn ways of dealing with the stress/ guilt/ relentlessness of situation etc. as it can be overwhelming and very stressful. Counselling/ Family Therapy should be offered if required. (Carer 07)*

> *[Family therapy] always seemed that it was more about trying to make it right for [daughter] all the time rather than making it a family thing, you know, where she'd take responsibility and what she could do to make things better as well. (Carer 21).*

PWED recognised the impact of their eating disorder on the family, including the worry this caused their parents and other family members with some reporting that they did not discuss the illness with them in case it caused further distress:

> *because [my sister is] younger than me I felt kind of protective of her so I didn't really want to have to talk too much with her about it in case she got upset. (PWED 20)*

> *the middle brothers are 8 and 10 now but they didn't realise what was happening so we kind of kept them out that week, so they knew we were in hospital but we just kept telling them I was sick and that was it. But my older brother who is like 22 now, it hurt him a lot, like he was scared for my life basically. (PWED 02)*

At the same time however, PWED felt that not discussing the illness within the family could contribute to feelings of isolation and could create further distance between siblings who "didn't really understand why I was the way I was" (PWED06). While speaking about the disorder within the family was difficult, PWED felt that this did offer some support as described by PWED 04:

> *My family were extremely supportive and encouraging. They found it hard to understand and feared saying the wrong thing but they made sure they done everything they could for me. My extended family avoided bringing it up directly but would encourage me by telling me I looked well or healthier and by texting to check in on me. I did feel a slight awkwardness at all the attention but it was reassuring to know I had a support there and that people understood what I was going through better. (PWED 04)*

While all carers mentioned that the challenges they faced were considerable, some carers spoke about how their families became closer and that the experience of supporting their family member in recovery strengthened already close bonds:

> *I would say her diagnosis has made us closer because it has, you know what I mean, it has brought us closer because of it because we've had to sit around as a family and talk about it and she's really open, she's really open about everything, she's very open. So it's brought us closer from that point of view. (Carer 15).*

> *We supported each other as a family, we took time out with friends and extended family members so everyone got a break from it. It took over our lives for 3-4 years and none of us on our own could have done it without each other's support. (Carer 10).*

These experiences highlighted the importance of family members supporting each other; however, it is essential that families themselves are supported by services to achieve this.

5.1.3. Financial Impact

The financial impact on the family was only discussed by carers. These discussions provided insights beyond the high cost of private treatment mentioned earlier. Some carers reported that they had to reduce their hours at work or take leave to ensure that they could support their son or daughter in their recovery. This had clear financial implications for those who were self-employed or who were the sole financial provider for their family. Parents reported additional costs associated with travelling to appointments. This was particularly evident in the case of families whose son or daughter travelled to the UK for treatment. Financial implications were both direct (the costs of travel) and indirect (having to reduce working hours in order to travel).

> *I was told we had to give up work. But at this stage, I, I just couldn't. I lasted another week in work, I was trying to go to the school and sit with her for meals and do what's for her best. So, by the following week I had to give up work as well. Uhm, I think their exact words to me were, actually I know their exact words, 'what's more important? Your job or your daughter?' [Int: Really?] Oh yeah, yeah, that's what her psychiatrist said. After I explained to him I'm the sole breadwinner and have my two kids and that I'm on my own. So work was great, and I went on sick leave, so I still got paid (Carer 01)*

> *I think the cost of it, I work for myself so it's taken an awful lot of my time having to go to counsellors and you know, give [daughter] the time that she needs for herself (Carer 08)*

> *when we [went to the UK], the health care system here paid for her hospital service, but obviously we paid ourselves for our flights back and forth, and our accommodation, and all of that. Financially, that was significant. (Carer 21)*

5.2 Experiences of Stigma

The experience of stigma in everyday interactions featured in both carer and PWED interviews. Carers, who were aware of their own lack of knowledge before their family member had become ill, reported that poor public understanding was a significant external challenge that both they, and their family member, had to confront during recovery. Stereotyped views that carers encountered included other people in their social networks believing that the disorder was a choice or that their son or daughter was seeking attention:

> *Cause you'll get people who understand, but you'll get people who don't understand. Like my mother kept telling me, 'would you not bring her to Costa?' Because apparently coffee and a nice bun would solve it. And other people would say to me, 'oh well bring her out to dinner with her friends.' And people, they don't understand, they think it's an eating disorder, it's just about eating. But the eating part is just the bit that will kill you. It's, it's all-encompassing, it's so much else. And people, to find somebody who gets that, who doesn't tell you, you know, who doesn't send you a recipe because 'oh she won't be able to resist this.' It's so frustrating, you know? (Carer 01)*

A few carers reported their son or daughter having to endure derogatory comments at school regarding their weight and appearance and felt schools could do more to educate teachers and pupils/students about the nature of eating disorders and the challenges faced during recovery:

> *[Daughter] tells me she cries most days in the bathroom during the day and people make stupid remarks, people know where she's been, they know what's been wrong with her, some boys behind her one day in class said, "I can't believe she ever thought she was anorexic, like look at the size of her". Stuff like that. (Carer 12)*

There appeared to be an awareness on the part of PWED of the pervasiveness of negative stereotypes surrounding individuals with eating disorders (e.g., that the eating disorder is a choice). Some, anticipating a negative reaction from friends and family on disclosing their illness, reported this stigma as a barrier to help-seeking. Actual experiences of negative reactions following disclosure were reported to reinforce feelings of isolation and internalised stigma:

> *I told one or two of my friends but they reacted by saying things like "you don't look like you have an eating disorder" etc. This made me feel humiliated for reaching out to anyone and I felt like my diagnosis was invalid because I didn't look "sick" enough, so I stopped telling people. (PWED 03)*

Key to appropriate support from family and friends was the perception that they understood the nature of eating disorders and recovery. Some PWED reported feeling less resistant to offers of help when approached by a friend or family member who had been in a similar situation:

> *The reason I agreed to get help was because my older cousin (who works as a psychiatric nurse and is someone I am very close to and look up to) came to visit me and sat down with me and asked me did I have a difficulty/problem with food. When I told her; she explained that she knew how I was feeling because she also had similar difficulties/problems with food when she was around my age. She seemed very understanding and non judgemental towards me. (PWED 17)*

Overall, feeling a sense of empathy and understanding from others is as important in informal support settings and relationships with others as it is in interactions with healthcare professionals.

5.3 Looking Towards Recovery

Both carers and PWED talked about their understandings of recovery. It was notable that this often did not focus solely on physical aspects of recovery. Carers described recovery as a gradual process which was perceived to be longer than they anticipated when their family member first entered treatment. Some, however, felt that their loved ones would continue to battle these issues for the rest of their lives.

> *Well, for me, hopefully it would be not having the need to binge and purge, or not having the urge. I don't know whether that's ever possible certainly to the urge, maybe it's not, and being able to enjoy food, being able to enjoy sitting around a table with the family, and not having to think, and basically, a restoration of inter-personal relationships. (Carer 17)*

Recovery to most carers was more than weight restoration or eating "normally" – it meant that their family member would be able to eat freely without the accompanying negative emotions or thoughts. Recovery also meant that their family member would be able to lead a "normal", "independent" life and would learn how to cope with stressful situations/triggers without returning to disordered eating patterns.

> *She would be independent in her life, you know, have gone through college, because she'd got her college place in the university, and that she'd do her college course. She'd live independently. She'd be driving her car. She'd be going on holiday. She'd be hanging out with her friends. She'd be normal, just normal. (Carer 06)*

PWED echoed these sentiments by also describing recovery as a gradual process that involved being able to deal appropriately with challenging feelings and situations and learning self-acceptance. They mentioned that changing ingrained behaviours is psychologically challenging and several PWED reported feeling ambivalent towards recovery – simultaneously looking forward to reclaiming their lives while fearing the process of recovery.

> *Recovery now means me being able to live my life and do what I want to do in the world – it means being able to go to college. It means being willing to give up the safety of going back to using food and measuring/controlling my weight when I'm under stress. It means being able to realise that when I feel anxious and panicky about buying food that nothing bad will happen if I actually buy the food. It means being able to rest, to eat and to have relaxation time or leisure time if I want (PWED 08)*

Most PWED conceptualised recovery as representing freedom; a state where the eating disorder does not dominate their daily lives or identity, thereby allowing them to form connections and live "fulfilled" lives.

> *When I stop seeing my problems as part of my identity or dominating my life; When I can live a fulfilled and contented life without being negatively affected by them for the most part. (PWED 11)*

> *Recovery to me, means having freedom around food and to not fear food or see it as something bad. Having acceptance of my body and positive body image and not constantly trying to change it. Recovery means living life rather than just existing and being able to engage socially without disordered thoughts & behaviours interrupting. (PWED 17)*

06

Discussion and Recommendations

SECTION 06

Discussion and Recommendations

Living with an eating disorder is a significant challenge facing many people and their families in Ireland. Previous research conducted in Ireland as well as mental health service policy papers suggested that services were under-developed, under-resourced and ill-equipped to provide the necessary care for PWED and their families.

The NCP-ED was established to address these service gaps and published its model of care in 2018. It was intended that this model of care would be rolled out across Ireland over the subsequent five years. The purpose of the current research was to establish a picture of service user experiences prior to the full implementation of the NCP-ED and to identify strengths in healthcare provision as well as areas for development. While the full implementation of the NCP-ED has yet to be realised due to delays in funding[17], it is hoped that the findings detailed in this report will prove to be a valuable learning resource for all those involved in the delivery of care and support to PWED and their carers. This final section presents an overview of the key findings prior to outlining some recommendations for future service developments.

6.1 Summary of Key Findings

The following presents a summary of the key findings to emerge from this multi-method research project across our three main areas of enquiry: (1) PWED and carer service experiences, (2) PWED and carer psychosocial health and well-being, and (3) PWED and carers' day-to-day experiences of living with an eating disorder.

6.1.1. Service Experiences

Our summary of service experiences includes both positive and negative aspects of participants' experiences.

6.1.1.1. Positive experiences

- Across most services most carers and PWED reported being involved in agreeing treatment, receiving information related to the eating disorder and treatment that they could understand, and being treated with dignity and respect

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[17] Coyle, F. (2020, October 10). Stop diverting funding allocated for eating disorders to other areas. TheJournal.ie. Retrieved from: https://www.thejournal.ie/readme/eating-disorders-government-hse-funding-5219534-Oct2020/

- Experiencing services as compassionate was important for both carers and PWED. The most effective services were delivered by staff with specialist skills, knowledge, and experience
- PWED valued health professionals and support group / organisation staff who responded to them in a non-judgemental, empathic way
- Carers valued health professionals' recognition of carers' efforts to support their child, being emotionally supported by clinical staff, and knowing staff were available to respond to their concerns. They appreciated receiving updates on their child's progress and being allowed time to raise their concerns with clinicians during sessions
- For carers and PWED meeting with similar others helped to combat feelings of isolation. Both appreciated the informational and emotional support provided by support groups/ organisations

6.1.1.2. Negative experiences

- GPs, Emergency Departments and General Hospitals were perceived to lack specialist knowledge and training in eating disorders by both carers and PWED
- PWED tended to feel excluded from having a role in agreeing treatment in CAMHS, while carers tended to feel excluded in AMHS
- Mental Health Services (both CAMHS and AMHS) were perceived to be under-staffed and under-resourced. Treatments offered varied by catchment area
- Private healthcare was an alternative to public health services who were perceived to have long waiting lists. The high cost of private treatment placed a significant financial burden on families and PWED
- Most services (except for private health professionals and support groups/ organisations) were not perceived to meet the support needs of carers and PWED.
- Carers and PWED rarely received written copies of care plans
- Carers and PWED experienced some health professionals as lacking in empathy and understanding. This hindered the ability of PWED to form trusting and collaborative therapeutic relationships with health professionals and, in some cases, contributed to disengagement from the treatment process

6.1.2. Carer and PWED Psychosocial Health

- Social relationships, particularly group memberships, are positively associated with psychological health and well-being for carers and PWED
- Identifying with family is associated with better well-being for PWED and better recovery outcomes

6.1.3. Experiences of Living with an Eating Disorder

- Eating disorders take a significant toll on family functioning and overall health and well-being. Carers and PWED both reported considerable disruption to family relationships
- Carers noted the substantial financial cost of the eating disorder with some having to take leave from work or reduce their working hours to support their son or daughter's recovery
- Carers strongly believed that therapeutic support should be provided to families as part of care pathways
- Both carers and PWED shared an understanding of recovery as a gradual process incorporating both physical and psychological components. Recovery was seen as a return to normal (by carers) and as gaining freedom from intrusive thoughts and compulsive behaviours (by PWED)
- Stigmatisation of eating disorders constituted a barrier to support (both from health professionals and friends and family). Both carers and PWED believed that they (or the person they cared for) were the victim of commonly held stereotypes including that the Eating Disorder was self-inflicted

6.2 Implications of Key Findings

While this research has provided a comprehensive picture of carer and PWED experiences of eating disorder services in Ireland, we would like to highlight a number of key research findings in this section that we believe require urgent attention in the future.

First, accessing appropriate services in a timely manner remains a problem for PWED and their carers. Care remains unstandardised across Ireland with regional variation in the types of interventions offered. Many who are facing long waiting lists pursue private treatment. However, this is not a route available to all and those who do avail of it are placed under considerable financial burden. Without significant investment in mental health services, it is unlikely that CAMHS or AMHS will be able to fulfil the roles envisaged for them as part of the NCP-ED's model of care.

Second, an inability to access secondary services is likely to mean that GPs must take on a greater role in supporting and monitoring PWED. The NCP-ED model of care proposes that the role of GPs includes: "case recognition of patients, providing basic education and advice, shared decision-making, making evidence-based recommendations, monitoring of borderline or at-risk cases, and only referring where clinically needed" (p.64). While we did identify areas of excellent practice by some GPs, we also note the continuing need for specialist training to support all GPs to fulfil the role proposed in the model of care. GPs play a vital role in initiating care for PWED and this training gap, first identified in *A Vision for Change*, needs to be urgently addressed. Other arenas in which this training is also urgently needed include staff in general hospitals and emergency departments. It should be noted that while these training gaps were identified for GPs, general hospital, and emergency department staff, many of our participants remarked on their positive experiences of being involved in agreeing treatment and being treated with dignity and respect.

Finally, there remain significant unmet informational and emotional support needs on the part of carers and PWED. These needs have been highlighted in previous research conducted with adolescents and their parents[18]. Our research supports these findings and extends them to adult PWED and their carers. The findings highlight the importance of including families (where appropriate) in the treatment process. For instance, a sense of family identification is associated with positive health outcomes for PWED. It follows that services should accommodate the inclusion of family as part of the treatment process where appropriate (and particularly when requested by the PWED). Our findings suggest that the degree to which this is accommodated by services varies. In particular, there is a need to identify how to include the family as part of adult health services. However, eating disorders can disrupt family relationships and can cause significant distress in all family members. Therefore, the health and well-being of carers, parents and siblings is likely to benefit from tailored social and clinical support across services. This should be in addition to psychoeducation (or similar) provided to carers to enable them to support the recovery of their family member.

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[18] McNicholas, F., McNamara, N., O'Hara, L., & O'Connor, C. (2015). *The impact of stigma on the detection, treatment, and management of eating disorders in Ireland. Final research grant report.* Dublin: St John of God Library Services.

6.3 Recommendations

The following presents a number of recommendations for service development, professional training, and addressing support needs based on the findings of this research project.

6.3.1. Service development

- Specialist eating disorder service provision is needed in all catchment areas; there should not be regional variation in treatments offered. The NCP-ED should be fully funded to implement all proposed hubs across the country.
- Healthcare services or specialist interventions should not be withheld based on BMI/ weight.
- Greater liaison is needed between medical and psychiatric supports for those admitted to general hospital wards / presenting at Emergency Departments.

6.3.2. Professional training

- Specific, on-going training needs for GPs, Emergency Department and General Hospital staff (including staff in Children's hospitals) should be addressed.
- Training on how to appropriately communicate with families and PWED is needed across all healthcare services (except for support groups / organisations) and should form part of the NCP-ED core curriculum on 'engagement skills'. This is to ensure all those who encounter PWED and their carers understand the challenges faced during recovery (by carers and PWED) and the need for empathic communication. As recommended by Bodywhys in the NCP-ED model of care (p.91), "anyone who enters the health system to access help can benefit from a pathway to recovery that is both expert and empathic"[19].

6.3.3. Supporting carers and PWED

- Healthcare staff, particularly GPs, should ensure that they routinely signpost carers and PWED to Bodywhys as recommended by the NCP-ED so that both can access informational and emotional support for coping with an eating disorder.
- Therapeutic support for families should be part of care pathways across the lifespan. The importance of preserving the family group (given its positive associations with well-being and recovery outcomes for carers and PWED) should be recognised.

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[19] Emphasis added in the original text

- The NCP-ED Model of Care should consider incorporating the assessment and treatment of family members in accordance with a family recovery model[20]. Mental health issues affect all family members and the recovery needs of each member (and the family as a whole) should form part of the care pathway.
- Consideration should be given as to the most appropriate and effective way to support family involvement in the treatment of adults with eating disorders.
- The PiLaR (Peer-Led-Resilience) programme for carers delivered by Bodywhys has shown to be an effective programme for carers and is a key part of the NCP-ED. PWED might benefit from a psychoeducational programme similar to PiLaR but tailored to their specific support needs.

6.4 Conclusion

This multi-method study aimed to provide a comprehensive picture of the health and support service user experiences of PWED and their carers. We identified areas of excellent practice across services. Healthcare staff with direct and specialist knowledge had a positive impact on the service experiences of PWED and carers, likely due not only to their expertise in the treatment of eating disorders but their ability to understand the challenges faced by those in recovery and their carers. Across most services, most carers and PWED reported being involved in agreeing treatment, received some form of information related to the eating disorder, and felt that they were treated with dignity and respect. However, we also identified areas for improvement including the need to standardise care across the country, to roll-out on-going professional training for GPs, staff in general hospitals and staff in emergency departments, to support the involvement of the family across services (including adult services), and to address the unmet support needs of carers and PWED. The data were gathered at an early stage in the implementation of the NCP-ED and we hope these findings will help to inform future service developments. We recommend, following wider implementation of the NCP-ED, that a follow-up to this research is conducted to ascertain any changes to the service experiences and outcomes for PWED and their carers.

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[20] Family Recovery Guidance Document 2018-2020. Supporting 'A National Framework for Recovery in Mental Health 2018-2020'. Retrieved from: https://www.hse.ie/eng/services/list/4/mental-health-services/advancingrecoveryireland/national-framework-for-recovery-in-mental-health/family-recovery-guidance-document-2018-to-2020.pdf

[21] HSE National Clinical Programme for Eating Disorders (2019). PiLaR Programme – An Evaluation. Retrieved from: https://www.bodywhys.ie/wp-content/uploads/2019/02/PilarReport_web.pdf

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Appendices

Appendix 1: Participant Demographics

Appendix 2: Descriptive Statistics for Carer and PWED Health Service Experiences

Appendix 3: Psychosocial Statistics for Carers and PWED

Technical Appendix 1: Participant Demographics

Table A1.1: Participant demographics for Carer online survey

	%	n*
Gender		
Female	94.3%	66
Male	5.7%	4
Ethnicity		
White	100%	69
Relationship Status		
Married	81.4%	57
Separated	7.1%	5
Single	2.9%	2
In a Relationship	2.9%	2
Troubled Relationship	2.9%	2
Civil Partnership	1.4%	1
Widowed	1.4%	1
Employment Status		
Full-Time Employment	43.5%	30
Part-Time Employment	31.9%	22
Unemployed Looking Work	2.9%	2
Unemployed Not Looking Work	4.3%	3
Full-Time Carer	11.6%	8
Student	2.9%	2
Retired	2.9%	2
Community Healthcare Organisation Catchment Area		
Area 1 (Donegal, Sligo/Leitrim/West Cavan, Cavan/Monaghan)	4.5%	3
Area 2 (Galway, Roscommon, Mayo)	10.4%	7
Area 3 (Clare, Limerick, North Tipperary/East Limerick)	7.5%	5
Area 4 (Kerry, North Cork, North Lee, South Lee, West Cork)	20.9%	14

	%	n*
Area 5 (South Tipperary, Carlow/Kilkenny, Waterford, Wexford)	7.5%	5
Area 6 (Wicklow, Dun Laoghaire, Dublin South East)	20.9%	14
Area 7 (Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West)	10.4%	7
Area 8 (Laois/Offaly, Longford/Westmeath, Louth/Meath)	11.9%	8
Area 9 (Dublin North, Dublin North Central, Dublin North West)	6%	4
Relationship to PWED		
Parent	94.3%	65
Husband	2.9%	2
Aunt	1.4%	1
Sister	1.4%	1
Living with PWED?		
Yes	88.9%	64
No	11.1%	8
PWED's Type of ED		
Anorexia Nervosa	72%	59
Bulimia Nervosa	7.2%	6
Anorexia/Bulimia	6.1%	5
Binge Eating Disorder	4.9%	4
Avoidant/Restrictive Food Intake Disorder	4.9%	4
Orthorexia	3.7%	3
Other Specified Feeding/ED	1.2%	1
PWED Has ED Diagnosis?		
Yes	91.5%	75
No	7.3%	6
Unsure	1.2%	1

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	%	n*
Source of Diagnosis		
Psychiatrist	62.6%	47
General Practitioner	14.7%	11
Other Professional	22.7%	17
PWED Having Treatment?		
Yes	55.8%	43
Relapsed-Further Treatment	14.3%	11
Were in Treatment but Left	7.8%	6
Fully Recovered	22.1%	17

**Note that the column listing the number of participants in each category does not sum to 82 (i.e., the total number of participants who took part). Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

Table A1.2: Participant demographics for PWED online survey

	%	n*
Gender		
Female	95.8%	70
Male	1.4%	1
Non-Binary	1.4%	1
Transgender	1.4%	1
Ethnicity		
White	100%	73
Relationship Status		
Single	56.2%	41
In a Relationship	23.3%	17
Married	16.4%	12
Separated	2.7%	2
Divorced	1.4%	1
Employment Status		
Full-Time Employment	32.9%	24
Part-Time Employment	13.7%	10
Unemployed Looking Work	1.4%	1
Unemployed Not Looking Work	8.2%	6
Student	34.2%	25
Retired	1.4%	1
Other (e.g., sick leave)	8.2%	6
Community Healthcare Organisation Catchment Area		
Area 1 (Donegal, Sligo/Leitrim/West Cavan, Cavan/ Monaghan)	8.2%	6
Area 2 (Galway, Roscommon, Mayo)	9.6%	7
Area 3 (Clare, Limerick, North Tipperary/East Limerick)	6.8%	5
Area 4 (Kerry, North Cork, North Lee, South Lee, West Cork)	8.2%	6
Area 5 (South Tipperary, Carlow/Kilkenny, Waterford, Wexford)	12.3%	9

	%	n*
Area 6 (Wicklow, Dun Laoghaire, Dublin South East)	12.3%	9
Area 7 (Kildare/West Wicklow, Dublin West, Dublin South City, Dublin South West)	16.4%	12
Area 8 (Laois/Offaly, Longford/Westmeath, Louth/Meath)	15.1%	11
Area 9 (Dublin North, Dublin North Central, Dublin North West)	11%	8
Living Arrangements		
Alone	17.8%	13
Parents	38.4%	28
Partner	19.2%	14
Friends	8.2%	6
Other Family	16.4%	12
Type of ED		
Anorexia Nervosa	41.5%	34
Bulimia Nervosa	12.2%	10
Anorexia/Bulimia	13.4%	11
Binge Eating Disorder	7.4%	6
Other Specified Feeding/ED	14.7%	12
Avoidant/Restrictive Food Intake Disorder	2.4%	2
Orthorexia	1.2%	1
Overeating	2.4%	2
Diabulimia	1.2%	1
Pica	1.2%	1
Mixture	2.4%	2
Has ED Diagnosis?		
Yes	79.3%	65
No	20.7%	17
Source of Diagnosis		
Psychiatrist	73.8%	48
General Practitioner	13.8%	9

	%	n*
Other Professional	12.4%	8
Having Treatment?		
Yes	41%	32
Relapsed-Further Treatment	20.5%	16
Were in Treatment but Left	24.4%	19
Fully Recovered	14.1%	11

**Note that the column listing the number of participants in each category does not sum to 82 (i.e., the total number of participants who took part). Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

Technical Appendix 2: Descriptive Statistics for Carer and PWED Health Service Experiences

Table A2.1 Carer Experiences of General Practitioners

	n*	%
Has PWED Sought GP Help in Last 3 Years?		
Yes	64	78%
No	18	22%
Last Time PWED Saw GP for ED Help		
In last month	10	15.6%
1-3 months ago	8	12.5%
4-6 months ago	10	15.6%
7-12 months ago	10	15.6%
1-2 years ago	19	29.7%
More than 2 years ago	7	10.9%
What Support Did GP Give? (tick all that apply)**		
Advice	33	51.6%
Guided Self-Help	5	7.8%
Nutrition Advice/Monitoring	16	25%
Medication	15	23.4%
Referral-Individual Psych Therapy	22	34.4%
Referral-Group Therapy	2	3.1%
Referral- Bodywhys	8	12.5%
Referral- Another Service	29	45.3%
GP Took No Action	3	4.7%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	32	50%
To Some Extent	18	28.1%
No, But Wanted To Be	12	18.8%
No, But Didn't Want To Be	2	3.1%

	n*	%
GP Gave You Info You Could Understand?		
Definitely	17	26.6%
To Some Extent	22	34.4%
Couldn't Understand Info Given	2	3.1%
Given No Info	23	35.9%
GP Meet Your Support Needs?		
Definitely	17	26.6%
To Some Extent	16	25%
Not As Much As Would Like	64	48.4%
GP Treat You With Dignity?		
Definitely	44	69.8%
To Some Extent	11	17.5%
Not Always	4	6.3%
Not At All	4	6.3%
GP Treat PWED With Dignity?		
Definitely	41	64.1%
To Some Extent	17	26.6%
Not Always	5	7.8%
Not At All	1	1.6%

**Note that the column listing the number of participants in each category does not sum to 82 (i.e., the total number of participants who took part). Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

***Note that for this category, 100% = all participants who stated that the PWED that they care for had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.2 PWED Experiences of General Practitioners

	n*	%
Has PWED Sought GP Help in Last 3 Years?		
Yes	52	63.4%
No	30	36.6%
Last Time PWED Saw GP for ED Help		
In last month	12	23.1%
1-3 months ago	8	15.4%
4-6 months ago	10	19.2%
7-12 months ago	4	7.7%
1-2 years ago	6	11.5%
More than 2 years ago	12	23.1%
What Support Did GP Give? (tick all that apply)**		
Advice	13	25%
Guided Self-Help	3	5.8%
Nutrition Advice/Monitoring	8	15.4%
Medication	17	32.7%
Referral-Individual Psych Therapy	14	26.9%
Referral-Group Therapy	1	1.9%
Referral- Bodywhys	2	3.8%
Referral- Another Service	17	32.7%
GP Took No Action	8	15.4%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	16	30.8%
To Some Extent	16	30.8%
No, But Wanted To Be	15	28.8%
No, But Didn't Want To Be	1	1.9%
Don't Know/Can't Remember	4	7.7%

	n*	%
GP Involve Family As Much As You Wanted?		
Definitely	6	11.5%
To Some Extent	6	11.5%
Not As Much As Wanted	3	5.8%
Too Much	5	9.6%
They Didn't Want To Be Involved	2	3.8%
I Didn't Want Them Involved	20	38.5%
Does Not Apply	10	19.2%
GP Gave You Info You Could Understand?		
Definitely	14	26.9%
To Some Extent	14	26.9%
Couldn't Understand Info Given	2	3.8%
Given No Info	22	42.3%
GP Meet Your Support Needs?		
Definitely	9	17.3%
To Some Extent	15	28.8%
Not As Much As Would Like	28	53.8%
GP Treat You With Dignity?		
Definitely	31	59.6%
To Some Extent	2	3.8%
Not Always	14	26.9%
Not At All	5	9.6%

**Note that the column listing the number of participants in each category does not sum to 82 (i.e., the total number of participants who took part). Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

***Note that for this category, 100% = all participants who stated that they had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.3 Carer Experiences of CAMHS

	n*	%
Has PWED Sought CAMHS Help in Last 3 Years?		
Yes	52	63.4%
No	30	36.6%
Last Time PWED Saw CAMHS for ED Help		
In last month	21	41.2%
1-3 months ago	8	15.7%
4-6 months ago	3	5.9%
7-12 months ago	6	11.8%
1-2 years ago	12	23.5%
More than 2 years ago	1	2%
What Support Did CAMHS Give? (tick all that apply)**		
Individual Psych Therapy	33	63.5%
Group Therapy	5	9.6%
Advice	15	28.8%
Guided Self-Help	8	15.4%
Nutrition Advice/Monitoring	22	42.3%
Medication	13	25%
Family-Based Treatment	28	53.8%
Other	9	17.3%
How Long Between Referral & Being Seen By CAMHS?		
Straight Away	11	21.2%
Within One Month	23	44.2%
1-3 Months	7	13.5%
More than 3 Months	8	15.4%
Don't Know	3	5.8%
How Frequently Saw CAMHS?		

	n*	%
Every 1-2 Weeks	40	80%
Once A Month	6	12%
Once Every 3 Months	3	6%
Less Than Once Every 3 Months	1	2%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	24	47.1%
To Some Extent	18	35.3%
No, But Wanted To Be	8	15.7%
No, But Didn't Want To Be	1	2%
Treatment Finished?		
Yes	25	48.1%
No	27	51.9%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	4	16%
To Some Extent	8	32%
No, But Wanted To Be	12	48%
Don't Know	1	4%
CAMHS Gave You Info You Could Understand?		
Definitely	21	42%
To Some Extent	22	44%
Couldn't Understand Info Given	2	4%
Given No Info	5	10%
CAMHS Meet Your Support Needs?		
Definitely	8	15.7%
To Some Extent	17	33.3%
Not As Much As Would Like	26	51%

	n*	%
Receive Copy of Care Plan?		
Yes	10	19.6%
No	38	74.5%
Don't Know	3	5.9%
CAMHS Treat You With Dignity?		
Definitely	28	56%
To Some Extent	8	16%
Not Always	11	22%
Not At All	3	6%
CAMHS Treat PWED With Dignity?		
Definitely	26	51%
To Some Extent	13	25.5%
Not Always	8	15.7%
Not At All	4	7.8%

**Note that the column listing the number of participants in each category does not sum to 82 (i.e., the total number of participants who took part). Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

***Note that for this category, 100% = all participants who stated that the PWED that they care for had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.4 PWED Experiences of CAMHS

	n*	%
Has PWED Sought CAMHS Help in Last 3 Years?		
Yes	5	6.1%
No	77	93.9%
Last Time PWED Saw CAMHS for ED Help		
4-6 months ago	1	20%
1-2 years ago	1	20%
More than 2 years ago	3	60%
What Support Did CAMHS Give? (tick all that apply)**		
Individual Psych Therapy	5	100%
Group Therapy	1	20%
Advice	1	20%
Nutrition Advice/Monitoring	3	60%
Medication	3	60%
In-Patient Care	2	40%
How Long Between Referral & Being Seen By CAMHS?		
Straight Away	1	20%
Within One Month	3	60%
1-3 Months	1	20%
How Frequently Saw CAMHS?		
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	1	20%
To Some Extent	1	20%
No, But Wanted To Be	3	60%
CAMHS Involve Family As Much As You Wanted?		
Definitely	4	80%
Too Much	1	20%
Treatment Finished?		
Yes	5	100%

	n*	%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	2	40%
No, But Wanted To Be	2	40%
Don't Know	1	20%
CAMHS Gave You Info You Could Understand?		
Definitely	2	40%
To Some Extent	2	40%
Couldn't Understand Info Given	1	20%
CAMHS Meet Your Support Needs?		
Not As Much As Would Like	3	60%
Not At All	2	40%
Receive Copy of Care Plan?		
Yes	1	20%
No	4	80%
CAMHS Treat You With Dignity?		
Definitely	1	20%
To Some Extent	1	20%
Not Always	2	40%
Not At All	1	20%

**Note that the column listing the number of participants in each category does not sum to 82 (i.e., the total number of participants who took part). Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

***Note that for this category, 100% = all participants who stated that the PWED that they care for had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.5 Carer Experiences of AMHS

	n*	%
Has PWED Sought AMHS Help in Last 3 Years?		
Yes	28	35.4%
No	51	64.6%
Last Time PWED Saw AMHS for ED Help		
In last month	12	44.4%
1-3 months ago	4	148%
4-6 months ago	3	11.1%
7-12 months ago	3	11.1%
1-2 years ago	2	7.4%
More than 2 years ago	3	11.1%
What Support Did AMHS Give? (tick all that apply)**		
Individual Psych Therapy	12	42.9%
Group Therapy	5	17.9%
Advice	10	35.7%
Guided Self-Help	3	10.7%
Nutrition Advice/Monitoring	8	28.6%
Medication	10	35.7%
Other	7	25%
How Long Between Referral & Being Seen By AMHS?		
Straight Away	6	23.1%
Within One Month	7	26.9%
1-3 Months	7	26.9%
More than 3 Months	4	15.4%
Don't Know	2	7.7%

	n*	%
How Frequently Saw AMHS?		
Every 1-2 Weeks	11	45.8%
Once A Month	6	25%
Once Every 3 Months	4	16.7%
Less Than Once Every 3 Months	3	12.5%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	2	8.3%
To Some Extent	6	25%
No, But Wanted To Be	15	62.5%
No, But Didn't Want To Be	1	4.2%
Treatment Finished?		
Yes	8	29.6%
No	19	70.4%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	1	12.5%
To Some Extent	6	35.5%
No, But Wanted To Be	1	12.5%
Don't Know	1	12.5%
AMHS Gave You Info You Could Understand?		
Definitely	1	3.8%
To Some Extent	12	46.2%
Given No Info	13	50%
AMHS Meet Your Support Needs?		
Definitely	1	4.2%
To Some Extent	9	37.5%
Not As Much As Would Like	14	58.3%

	n*	%
Receive Copy of Care Plan?		
Yes	1	4%
No	23	92%
Don't Know	1	4%
AMHS Treat You With Dignity?		
Definitely	10	41.7%
To Some Extent	5	20.8%
Not Always	5	20.8%
Not At All	4	16.7%
AMHS Treat PWED With Dignity?		
Definitely	10	43.5%
To Some Extent	9	39.1%
Not Always	1	4.3%
Not At All	3	13%

**Note that the column listing the number of participants in each category does not sum to 82 (i.e., the total number of participants who took part). Instead, this column sums to the total number of participants who answered each of the questions listed, reflecting the valid percent.*

***Note that for this category, 100% = all participants who stated that the PWED that they care for had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.6 PWED Experiences of AMHS

	n*	%
Has PWED Sought AMHS Help in Last 3 Years?		
Yes	45	55.6%
No	36	44.4%
Last Time PWED Saw AMHS for ED Help		
In last month	17	37.8%
1-3 months ago	8	17.8%
4-6 months ago	5	11.1%
7-12 months ago	5	11.1%
1-2 years ago	5	11.1%
More than 2 years ago	5	11.1%
What Support Did AMHS Give? (tick all that apply)**		
Individual Psych Therapy	19	42.2%
Group Therapy	5	11.1%
Advice	16	35.6%
Guided Self-Help	8	17.8%
Nutrition Advice/Monitoring	15	33.3%
Medication	19	42.2%
Other	11	24.4%
How Long Between Referral & Being Seen By AMHS?		
Straight Away	7	15.6%
Within One Month	7	15.6%
1-3 Months	12	26.7%
More than 3 Months	8	17.8%
Don't Know	11	24.4%
How Frequently Saw AMHS?		
Every 1-2 Weeks	25	58.1%
Once A Month	9	20.9%

	n*	%
Once Every 3 Months	4	9.3%
Less Than Once Every 3 Months	5	11.6%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	11	25%
To Some Extent	14	31.8%
No, But Wanted To Be	17	38.6%
No, But Didn't Want To Be	2	4.5%
AMHS Involve Family As Much As You Wanted?		
Definitely	2	4.5%
To Some Extent	8	18.2%
Not As Much As Wanted	8	18.2%
They Didn't Want To Be Involved	2	4.5%
I Didn't Want Them Involved	17	38.6%
Does Not Apply	7	15.9%
Treatment Finished?		
Yes	19	43.2%
No	25	56.8%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	6	31.6%
To Some Extent	4	21.1%
No, But Wanted To Be	3	15.8%
No, But Didn't Want To Be	1	5.3%
Don't Know	5	26.3%
AMHS Gave You Info You Could Understand?		
Definitely	11	25%
To Some Extent	15	34.1%

	n*	%
Couldn't Understand Info Given	3	6.8%
Given No Info	15	34.1%
AMHS Meet Your Support Needs?		
Definitely	2	4.7%
To Some Extent	8	18.6%
Not As Much As Would Like	16	37.2%
Not At All	17	39.5%
Receive Copy of Care Plan?		
Yes	2	4.5%
No	39	88.6%
Don't Know	3	6.8%
AMHS Treat You With Dignity?		
Definitely	17	38.6%
To Some Extent	16	36.4%
Not Always	6	13.6%
Not At All	5	11.4%

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***Note that for this category, 100% = all participants who stated that they had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.7 Carer Experiences of In-patient Units

	n*	%
Has PWED Sought In-patient Help in Last 3 Years?		
Yes	37	45.6%
No	42	54.4%
No. of Times PWED admitted to In-patient unit in Last 3 Years		
Once	19	52.8%
Twice	7	19.4%
Three Times	6	16.7%
Four Times	3	8.3%
Six Times	1	2.8%
In-patient Unit Type		
Public	17	47.2%
Private	11	30.6%
Mixture	8	22.2%
In-patient Unit Location		
Ireland	33	91.6%
Ireland & England	1	2.8%
Northern Ireland	2	5.6%
What Support Did In-patient Unit Give? (tick all that apply)**		
Individual Psych Therapy	21	58.3%
Group Therapy	21	58.3%
Advice	19	52.8%
Guided Self-Help	16	44.4%
Nutrition Advice/Monitoring	27	75%
Medication	25	69.4%
NG Tube/re-feeding	12	33.3%
Other	3	8.3%

	n*	%
How Long Between Referral & Being Seen By In-patient Unit?		
Straight Away	14	38.9%
Within One Month	13	36.1%
1-3 Months	6	16.7%
More than 3 Months	2	5.6%
Don't Know	1	2.8%
Length of In-patient Unit Stay		
1-4 Weeks	5	13.9%
5-12 Weeks	15	41.6%
13-24 Weeks	12	33.3%
25-52 Weeks	2	5.6%
53 Weeks or More	2	5.6%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	13	37.1%
To Some Extent	10	28.6%
No, But Wanted To Be	10	28.6%
No, But Didn't Want To Be	2	5.7%
Treatment Finished?		
Yes	26	72.2%
No	10	27.8%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	9	34.6%
To Some Extent	7	19.4%
No, But Wanted To Be	9	34.6%
Don't Know	1	11.4%

	n*	%
In-patient Unit Gave You Info You Could Understand?		
Definitely	14	38.9%
To Some Extent	17	47.2%
Couldn't Understand Info Given	2	5.6%
Given No Info	3	8.3%
In-patient Unit Meet Your Support Needs?		
Definitely	10	27.8%
To Some Extent	10	27.8%
Not As Much As Would Like	16	44.4%
Receive Copy of Care Plan?		
Yes	12	33.3%
No	19	52.8%
Don't Know	5	13.9%
In-patient Unit Treat You With Dignity?		
Definitely	18	50%
To Some Extent	8	22.2%
Not Always	10	27.8%
In-patient Unit Treat PWED With Dignity?		
Definitely	20	55.6%
To Some Extent	11	30.6%
Not Always	5	13.9%

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***Note that for this category, 100% = all participants who stated that the PWED that they care for had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.8 PWED Experiences of In-patient Units

	n*	%
Has PWED Sought In-patient Help in Last 3 Years?		
Yes	29	36.3%
No	51	63.7%
No. of Times PWED admitted to In-patient Unit in Last 3 Years		
Once	9	33.3%
Twice	10	37.1%
Three Times	4	14.8%
Four Times	1	3.7%
Five Times	2	7.4%
Six Times	1	3.7%
In-patient Unit Type		
Public	8	27.6%
Private	12	41.4%
Mixture	9	31%
In-patient Unit Location		
Ireland	26	96.4%
Ireland & England	1	1.2%
England	2	2.4%
Last Time Admitted To In-patient Unit?		
In The Last Month	3	10.3%
1-3 Months	4	13.8%
4-6 Months	3	10.3%
7-12 Months	6	20.7%
1-2 Years	5	17.2%
More Than 2 Years	8	27.6%
Location Of This In-patient Unit?		
Ireland	28	96.6%
Elsewhere	1	3.4%

	n*	%
What Support Did In-patient Unit Give? (tick all that apply)**		
Individual Psych Therapy	13	44.8%
Group Therapy	19	65.5%
Advice	15	51.7%
Guided Self-Help	12	41.4%
Nutrition Advice/Monitoring	23	79.3%
Medication	20	69%
NG Tube/re-feeding	10	34.5%
Other	3	10.3%
None	1	3.4%
How Long Between Referral & Being Seen By In-patient Unit?		
Straight Away	9	31%
Within One Month	12	41.4%
1-3 Months	6	20.7%
More than 3 Months	2	6.9%
Length of In-patient Unit Stay		
1-4 Weeks	5	17.2%
5-12 Weeks	13	44.8%
13-24 Weeks	6	20.7%
25-52 Weeks	2	6.9%
53 Weeks or More	3	10.4%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	7	24.1%
To Some Extent	12	41.4%
No, But Wanted To Be	8	27.6%
No, But Didn't Want To Be	2	6.9%
In-patient Unit Involve Family As Much As You Wanted?		
Definitely	5	17.2%

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	n*	%
To Some Extent	11	37.9%
Not As Much As Wanted	2	6.9%
Too Much	2	6.9%
They Didn't Want To be Involved	3	10.3%
I Didn't Want Them Involved	6	20.7%
Treatment Finished?		
Yes	22	75.9%
No	7	24.1%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	2	9.1%
To Some Extent	8	36.4%
No, But Wanted To Be	10	45.5%
No, But Didn't Want To Be	1	4.5%
Don't Know	1	4.5%
In-patient Unit Gave You Info You Could Understand?		
Definitely	13	44.8%
To Some Extent	8	27.6%
Couldn't Understand Info Given	2	6.9%
Given No Info	6	20.7%
In-patient Unit Meet Your Support Needs?		
Definitely	8	27.6%
To Some Extent	6	20.7%
Not As Much As Would Like	15	51.7%
Receive Copy of Care Plan?		
Yes	13	44.8%

	n*	%
No	15	51.7%
Don't Know	1	3.4%
In-patient Unit Treat You With Dignity?		
Definitely	10	34.5%
To Some Extent	9	31%
Not Always	6	20.7%
Not At All	4	13.8%

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Table A2.9 Carer Experiences of Emergency Departments (E Dep)

	n*	%
Has PWED Sought E Dep Help in Last 3 Years?		
Yes	31	38.5%
No	47	61.5%
Last Time PWED Saw E Dep for ED Help		
In last month	3	10%
1-3 months ago	1	3.3%
4-6 months ago	6	20%
7-12 months ago	4	13.3%
1-2 years ago	11	36.7%
More than 2 years ago	5	16.7%
What Support Did E Dep Give? (tick all that apply)**		
Advice	4	13.3%
Admitted to Hospital	18	60%
Referral-Mental Health Services	11	36.7%
Other	8	26.7%
E Dep Meet Your Support Needs?		
Definitely	9	30%
To Some Extent	9	30%
Not As Much As Would Like	12	40%
E Dep Treat You With Dignity?		
Definitely	17	56.7%
To Some Extent	10	33.3%
Not Always	2	6.7%
Not At All	1	3.3%

E Dep Treat PWED With Dignity?	n*	%
Definitely	15	50%
To Some Extent	9	30%
Not Always	5	16.7%
Not At All	1	3.3%

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***Note that for this category, 100% = all participants who stated that the PWED that they care for had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.10 PWED Experiences of Emergency Departments (E Dep)

	n*	%
Has PWED Sought E Dep Help in Last 3 Years?		
Yes	27	33.8%
No	53	66.2%
Last Time PWED Saw E Dep for ED Help		
In last month	5	18.5%
1-3 months ago	5	18.5%
4-6 months ago	4	14.8%
7-12 months ago	5	18.5%
1-2 years ago	6	22.2%
More than 2 years ago	2	7.4%
What Support Did E Dep Give? (tick all that apply)**		
Advice	3	11.1%
Admitted to Hospital	17	63%
Referral-Mental Health Services	6	22.2%
Other	7	25.9%
How Long Wait To Be Seen?		
Straight Away	5	6.1%
Within 1 Hour	1	1.2%
1-3 Hours	8	9.8%
More Than 3 Hours	13	15.9%
E Dep Meet Your Support Needs?		
To Some Extent	6	22.2%
Not As Much As Would Like	21	77.8%
E Dep Treat You With Dignity?		
Definitely	3	11.1%
To Some Extent	9	33.3%
Not Always	11	40.7%
Not At All	4	14.8%

Table A2.11 Carer Experiences with Private Health Professionals (PHP)

	n*	%
Has PWED Sought PHP Help in Last 3 Years?		
Yes	49	62%
No	30	38%
Type of PHPs Approached (tick all that apply)**		
Private Psychiatrist	7	14.3%
Private Psychologist	20	40.8%
Counsellor	22	73.3%
Psychotherapist	13	26.5%
Dietitian	27	55.1%
Other	5	10.2%
Main PHP		
Private Psychiatrist	3	6.1%
Private Psychologist	18	36.7%
Counsellor	18	36.7%
Psychotherapist	9	18.4%
Dietitian	14	28.6%
Other	3	6.1%
Last Time PWED Saw Main PHP for ED Help		
In last month	16	34%
1-3 months ago	12	25.5%
4-6 months ago	3	6.4%
7-12 months ago	6	12.8%
1-2 years ago	8	17%
More than 2 years ago	2	4.3%
What Support Did Main PHP Give? (tick all that apply)**		
Individual Psych Therapy	36	73.5%
Group Therapy	2	4.1%
Advice	12	24.5%
Guided Self-Help	6	12.2%

	n*	%
Nutrition Advice/Monitoring	19	38.8%
Medication	3	6.1%
Other	5	10.2%
How Long Between Referral & Being Seen By Main PHP?		
Straight Away	21	45.7%
Within One Month	17	37%
1-3 Months	6	13%
More than 3 Months	2	4.3%
How Frequently Saw Main PHP?		
Every 1-2 Weeks	33	70.2%
Once A Month	10	21.3%
Once Every 3 Months	2	4.3%
Less Than Once Every 3 Months	2	4.3%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	20	42.6%
To Some Extent	15	31.9%
No, But Wanted To Be	9	19.1%
No, But Didn't Want To Be	3	6.4%
Treatment Finished?		
Yes	25	53.2%
No	22	46.8%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	11	44%
To Some Extent	5	20%
No, But Wanted To Be	6	24%
Don't Know	3	12%
PHP Gave You Info You Could Understand?		
Definitely	23	50%
To Some Extent	12	26.1%

	n*	%
Couldn't Understand Info Given	1	2.2%
Given No Info	10	21.7%
PHP Meet Your Support Needs?		
Definitely	20	44.4%
To Some Extent	16	35.6%
Not As Much As Would Like	9	20%
Receive Copy of Care Plan?		
Yes	9	19.6%
No	36	78.3%
Don't Know	1	2.2%
PHP Treat You With Dignity?		
Definitely	29	67.4%
To Some Extent	12	27.9%
Not At All	2	4.7%
PHP Treat PWED With Dignity?		
Definitely	39	86.7%
To Some Extent	5	11.1%
Not Always	1	2.2%

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Table A2.12 PWED Experiences of Private Health Professionals (PHP)

	n*	%
Has PWED Sought PHP Help in Last 3 Years?		
Yes	49	62%
No	30	38%
Type of PHPs Approached* (tick all that apply)**		
Private Psychiatrist	18	36.7%
Private Psychologist	19	38.8%
Counsellor	22	44.9%
Psychotherapist	18	36.7%
Dietitian	16	32.7%
Clinical Nurse	1	2%
Main PHP		
Private Psychiatrist	8	9.8%
Private Psychologist	9	11%
Counsellor	13	15.9%
Psychotherapist	12	14.6%
Dietitian	2	2.4%
Clinical Nurse	1	1.2%
Last Time PWED Saw Main PHP for ED Help		
In last month	19	42.2%
1-3 months ago	4	8.9%
4-6 months ago	5	11.1%
7-12 months ago	6	13.3%
1-2 years ago	7	15.6%
More than 2 years ago	4	8.9%
What Support Did Main PHP Give? (tick all that apply)**		
Individual Psych Therapy	32	65.3%
Group Therapy	4	8.2%
Advice	21	42.9%

	n*	%
Guided Self-Help	17	34.7%
Nutrition Advice/Monitoring	15	30.6%
Medication	5	10.2%
Other	3	6.1%
How Long Between Referral & Being Seen By Main PHP?		
Straight Away	22	48.9%
Within One Month	15	33.3%
1-3 Months	5	11.1%
More than 3 Months	2	4.4%
Don't Know	1	2.2%
How Frequently Saw Main PHP?		
Every 1-2 Weeks	35	77.8%
Once A Month	6	13.3%
Once Every 3 Months	2	4.4%
Less Than Once Every 3 Months	2	4.4%
Involved In Agreeing Treatment As Much As You Wanted?		
Definitely	26	57.8%
To Some Extent	14	31.1%
No, But Wanted To Be	4	8.9%
No, But Didn't Want To Be	1	2.2%
PHP Involve Family As Much As You Wanted?		
Definitely	9	20%
To Some Extent	5	11.1%
Not As Much As Wanted	1	2.2%
Too Much	4	8.9%
They Didn't Want To be Involved	4	8.9%
I Didn't Want Them Involved	18	40%
Does Not Apply	4	8.9%

	n*	%
Treatment Finished?		
Yes	18	40%
No	27	60%
If Yes: Involved In Agreeing End As Much As You Wanted?		
Definitely	11	61.1%
To Some Extent	5	27.8%
No, But Wanted To Be	2	11.1%
PHP Gave You Info You Could Understand?		
Definitely	23	51.1%
To Some Extent	12	26.7%
Given No Info	10	22.2%
PHP Meet Your Support Needs?		
Definitely	19	42.2%
To Some Extent	8	17.8%
Not As Much As Would Like	18	40%
Receive Copy of Care Plan?		
Yes	11	24.4%
No	31	68.9%
Don't Know	3	6.7%
PHP Treat You With Dignity?		
Definitely	37	82.2%
To Some Extent	3	6.7%
Not At All	5	11.1%

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Table A2.13 Carer Experiences of Support Groups/Organisations (SGOs)

	n*	%
Has Carer Sought SGO Help in Last 3 Years?		
Yes	66	85.7%
No	11	14.3%
What SGO Was This? ** (tick all that apply)		
Bodywhys	63	95.5%
Other	14	21.2%
Multiple SGOs	3	4.5%
Last Time Carer Saw SGO for ED Help		
In last month	10	15.2%
1-3 months ago	13	19.7%
4-6 months ago	8	21.1%
7-12 months ago	9	13.6%
1-2 years ago	23	34.8%
More than 2 years ago	3	4.5%
What Support Did SGO Give? (tick all that apply)**		
Individual Telephone Support	16	24.2%
Individual Email Support	5	7.6%
Face-to-Face Group Support	29	43.9%
Online Group Support	5	7.6%
Advice/Information	16	24.2%
Guided Self-Help	3	4.5%
Course For Carers	37	56.1%
Other	3	4.5%
How Frequently Saw SGO?		
Every 1-2 Weeks	6	9.1%

	n*	%
Once A Month	7	10.6%
Once Every 3 Months	6	9.1%
Less Than Once Every 3 Months	17	25.8%
No Longer In Contact With SGO	30	45.5%
SGO Gave You Info You Could Understand?		
Definitely	58	87.9%
To Some Extent	8	12.1%
SGO Meet Your Support Needs?		
Definitely	34	51.5%
To Some Extent	26	39.4%
Not As Much As Would Like	6	9.1%
SGO Treat You With Dignity?		
Definitely	63	95.5%
To Some Extent	3	4.5%

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***Note that for this category, 100% = all participants who stated that the PWED that they care for had accessed this type of help in the past three years. This means that the percentages in this category will not sum to 100%. Since participants were asked to tick all types of support received, the frequencies in this category will not sum to 82 (i.e., the total number of participants who took part).*

Table A2.14 PWED Experiences of Support Groups/Organisations (SGOs)

	n*	%
Has PWED Sought SGO Help in Last 3 Years?		
Yes	39	51.3%
No	37	48.7%
What SGO Was This? ** (tick all that apply)		
Bodywhys	33	84.6%
Other	8	20.5%
Multiple SGOs	2	5.1%
Last Time PWED Saw SGO for ED Help		
In last month	10	26.3%
1-3 months ago	8	21.1%
4-6 months ago	7	18.4%
7-12 months ago	5	13.2%
1-2 years ago	2	5.3%
More than 2 years ago	6	15.8%
What Support Did SGO Give? (tick all that apply)**		
Individual Telephone Support	9	23.1%
Individual Email Support	9	23.1%
Face-to-Face Group Support	11	28.2%
Online Group Support	23	59%
Advice/Information	14	35.9%
Guided Self-Help	5	12.8%
Help For Family	1	2.6%
None	1	2.6%
How Frequently Saw SGO?		
Every 1-2 Weeks	6	16.2%
Once A Month	6	16.2%
Once Every 3 Months	5	13.5%
Less Than Once Every 3 Months	8	21.6%

	n*	%
No Longer In Contact With SGO	12	32.4%
SGO Gave You Info You Could Understand?		
Definitely	22	57.9%
To Some Extent	8	21.1%
Given No Information	8	21.1%
SGO Meet Your Support Needs?		
Definitely	8	21.6%
To Some Extent	17	45.9%
Not As Much As Would Like	12	32.4%
SGO Treat You With Dignity?		
Definitely	32	84.2%
To Some Extent	4	10.5%
Not Always	2	5.3%

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Technical Appendix 3: Psychosocial Statistics for Carers and PWED

Table A3.1 Descriptive statistics and inter-correlations for group memberships, life satisfaction, loneliness and carer burden.

Scale	1	2	3	4	5
1. Carer Identification (1-7; M = 5.26, SD = 1.75)	-				
2. Family Identification (1-7, M = 5.36, SD = 1.62)	.28**	-			
3. Multiple Identities (1-7, M = 4.21, SD = 1.63, r = .65)	-.12	-.05	-		
4. Life Satisfaction (1-7, M = 4.49, SD = 2.04)	-.11	.05	.16	-	
5. Loneliness (1-3, M = 1.64, SD = 0.61, a = .83)	.08	-.23*	-.26*	-.51***	-
6. Carer Burden (24-120, M = 62.25, SD = 15.26)	-.09	-.21	.01	-.41**	.46***

Note: * p < .05, ** p < .01, *** p < .001.

Carers' mean values for identification as carers and as family members were both significantly above the scale mid-point of 4 (p < .001), as was their mean value for life satisfaction (p = .04), thereby indicating relatively high levels of these three variables. Participants' mean value for loneliness was significantly below the scale mid-point of 2 (p < .001), thereby indicating a relatively low level for this variable.

Carers who identified strongly with their families tended to be less lonely and tended to identify strongly as carers. Higher levels of loneliness were associated with lower levels of life satisfaction. Carers with a strong sense of possessing multiple social identities tended to experience less loneliness. Additionally, carers with higher levels of carer burden tended to experience lower levels of life satisfaction and higher levels of loneliness.

Table A3.2 Descriptive statistics and inter-correlations for group memberships, life satisfaction, loneliness and personal control, and negative eating thoughts/behaviours.

Scale	1	2	3	4	5	6	7
1. Recovery Identification Others (1-7; M = 4.36, SD = 1.88, r = .58)	-						
2. Family Identification (1-7, M = 4.27, SD = 1.86)	.31**	-					
3. Multiple Identities (1-7, M = 4.57, SD = 1.78, r = .70)	.11	.38***	-				
4. Life Satisfaction (1-7, M = 3.56, SD = 2.07)	.42***	.37***	.24*	-			
5. Loneliness (1-3, M = 2.29, SD = 0.63, a = .80)	-.17	-.31**	-.34**	-.56***	-		
6. Personal Control (1-7, M = 3.70, SD = 1.49, a = .73)	.33**	.23†	.18	.73***	-.52***	-	
6. Negative Eating Thoughts/ Behavs (1-6, M = 4.40, SD = 1.11, a = .94)	-.26*	-.26*	.09	-.54***	.48***	-.60***	-

Note: † p = .054, * p < .05, ** p < .01, *** p ← .001.

PWED's mean values for multiple identities, loneliness, and negative eating thoughts/ behaviours were all significantly above the scale mid-points (ps = .008, < .001, and < .001 respectively), thereby indicating relatively high levels of these variables.

PWED who identified strongly as being in recovery tended to identify strongly with their family, feel highly satisfied with their lives, perceive themselves as having higher levels of personal control, and tended to have fewer negative eating-related thoughts and behaviours. Additionally, PWED who identified strongly with their family tended to have a strong sense of possessing multiple social group identities, feel highly satisfied with their lives, feel less lonely, perceive themselves as having higher levels of personal control, and tended to have fewer negative eating-related thoughts and behaviours. PWED with a strong sense of possessing multiple social identities tended to experience more life satisfaction and less loneliness. Additionally, PWED who felt highly satisfied with their lives tended to experience lower levels of loneliness, perceive themselves as having higher levels of personal control, and lower levels of negative eating-related thoughts and behaviours. Meanwhile, PWED with higher levels of loneliness tended to perceive themselves as having lower levels of personal control, and experienced higher levels of negative eating-related thoughts and behaviours. Finally, PWED who perceived themselves as having high levels of personal control experienced lower levels of negative eating-related thoughts and behaviours.

The following regression and mediation analyses were all carried out in R (R Core Team, 2018). All regressions and mediations were carried out controlling for gender, age and whether the participant had an eating disorder diagnosis.

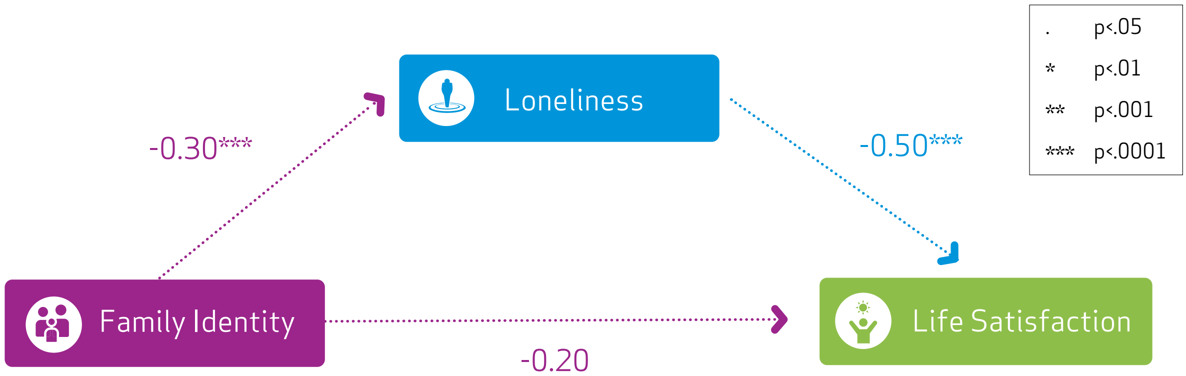

Figure A.3.1 Mediation model estimating the indirect effect of family identity on life satisfaction through loneliness.

The proposed model was tested using a series of regressions. Satisfaction with life was regressed onto family identity (β=0.36, p<0.01, 95% CI [0.13, 0.59]), loneliness was regressed onto family identity (β= -0.30, p<0.01, 95% CI [-0.53, -0.07]), and satisfaction with life was regressed onto both loneliness (β= -0.50, p<0.0001, 95% CI [-0.71, -0.29]) and family identity (β=0.19, p=.07, 95% CI [-0.02, 0.41]. The lavaan package (Rosseel, 2012) was then used with 5000 bootstrap samples to estimate the indirect effect of family identity on satisfaction with life through loneliness. The standardised indirect effect was significant at 0.16, p<.05, 95% CI [0.05, 0.33].

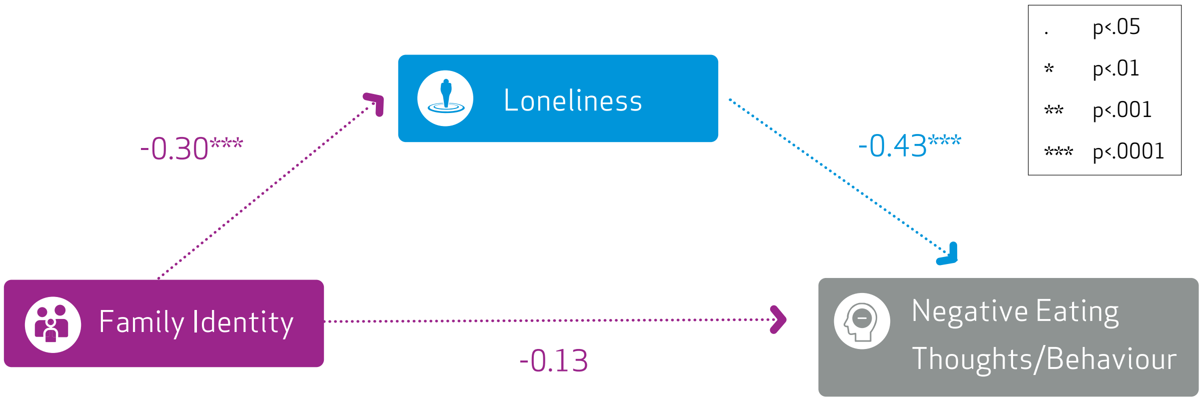

Figure A.3.2 Mediation model estimating the indirect effect of family identity on negative eating thoughts/behaviour through loneliness.

The proposed model was tested using a series of regressions. Negative eating thoughts/behaviour was regressed onto family identity (β=-0.26, p<0.05, 95% CI [-0.49, -0.02]), loneliness was regressed onto family identity (β= -0.30, p<0.01, 95% CI [-0.53, -0.07]), and negative eating thoughts/behaviour was regressed onto both loneliness (β= 0.43, p<0.001, 95% CI [0.20, 0.65]) and family identity (β=-0.13, p=.24, 95% CI [-0.35, 0.09]. The lavaan package was then used with 5000 bootstrap samples to estimate the indirect effect of family identity on negative eating thoughts/behaviour through loneliness. The standardised indirect effect was significant at -0.13, p<.05, 95% CI [-0.26, -0.03].

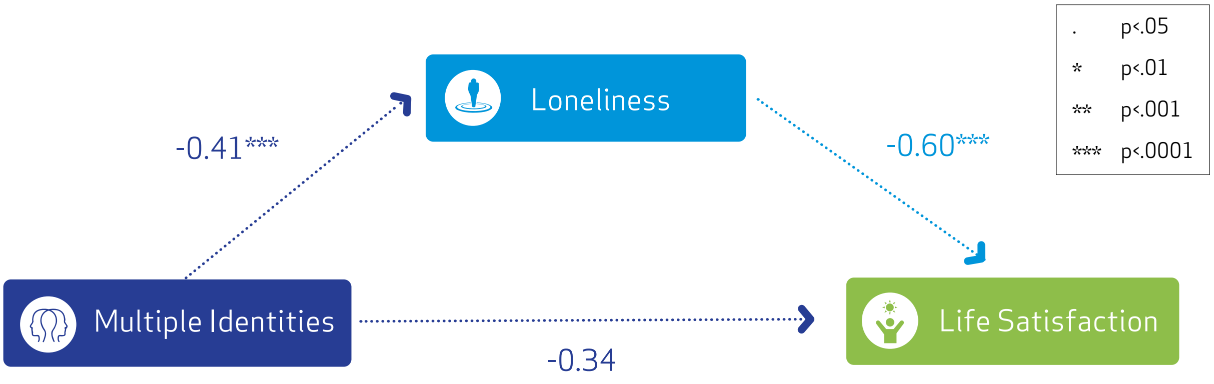

Figure A.3.3 Mediation model estimating the indirect effect of multiple identities on life satisfaction through loneliness.

The proposed model was tested using a series of regressions. Negative eating thoughts/behaviour was regressed onto multiple identities (β=0.09, p=0.49, 95% CI [-0.18, 0.36]), loneliness was regressed onto multiple identities (β= -0.41, p<0.01, 95% CI [-0.66, -0.17]), and negative eating thoughts/behaviour was regressed onto both loneliness (β= 0.60, p<0.0001, 95% CI [0.37, 0.82]) and multiple identities (β=0.33, p<.01, 95% CI [-0.22, 0.27]. The lavaan package was then used with 5000 bootstrap samples to estimate the indirect effect of multiple identities on negative eating thoughts/behaviour through loneliness. The standardised indirect effect was significant at -0.24, p<.01, 95% CI [-0.43, -0.08]. There was also a significant standardised direct effect of multiple identities on negative eating thoughts/behaviour in the opposite direction at 0.34, p<.01, 95% CI [0.1, 0.57].

BODYWHYS

Company Information

Company information as of 31st December 2019

DIRECTORS

Henry Blake
Parvez Butt
Marie Devine
Tiggy Hudson
Ann McCann
Sene Naoupu
Malachy Heffernan
Dermot Smith

COMPANY SECRETARY

Henry Blake

REGISTERED OFFICE

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Dublin 2

AUDITORS

Dillon Kelly Cregan & Co.
18 Upper Mount Street
Dublin 2

REGISTERED CHARITY NO

11961

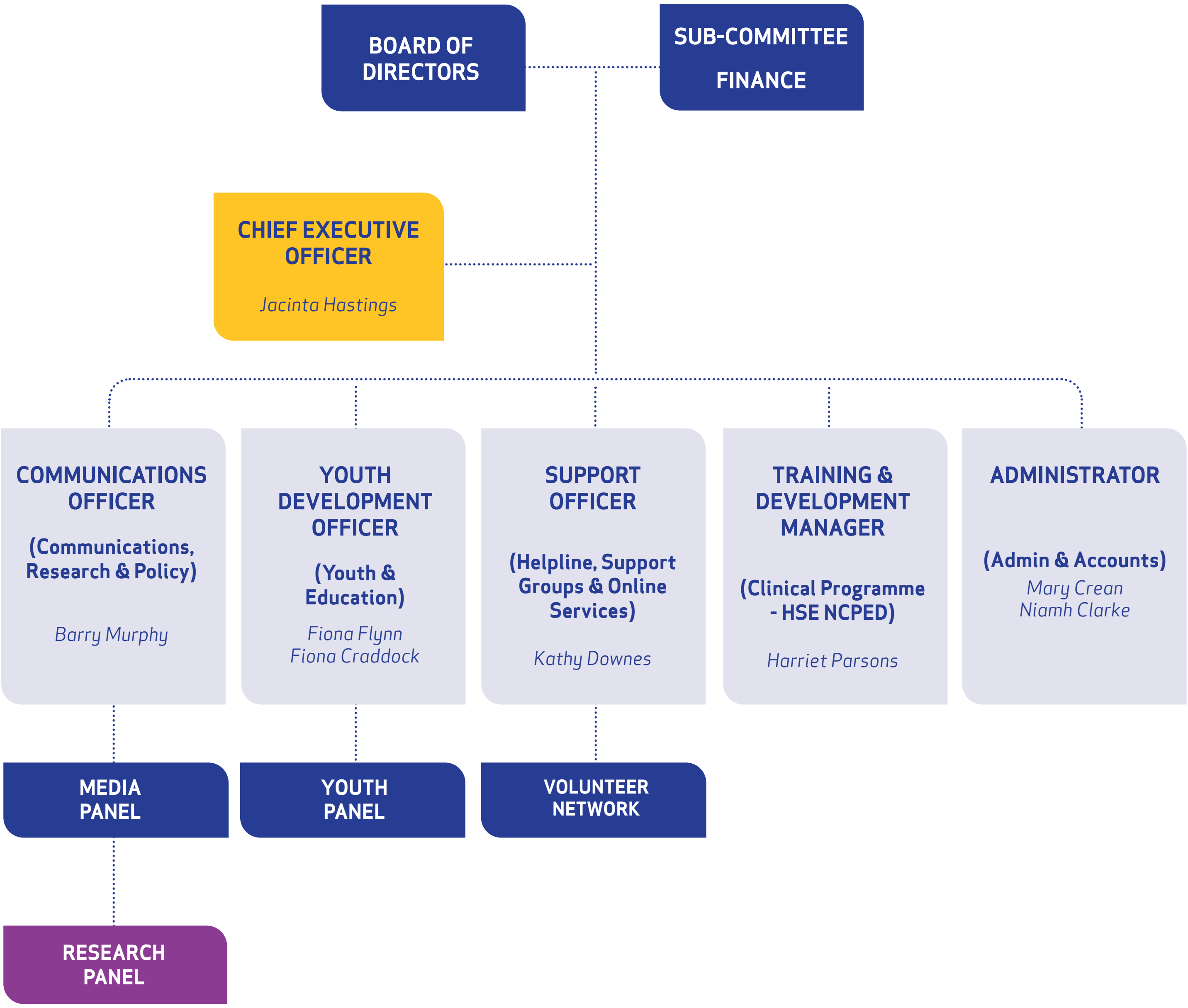
BODYWHYS
The Eating Disorders Association of Ireland

Bodywhys Team (2021)

Jacinta Hastings, Chief Executive Officer
Harriet Parsons, Training & Development Manager
Terri Coffey, Administrator
Kathy Downes, Support Officer
Fiona Flynn, Youth Development Officer
Barry Murphy, Communications Officer

BODYWHYS

Organisation Chart



BOARD OF DIRECTORS

SUB-COMMITTEE

FINANCE

CHIEF EXECUTIVE OFFICER

Jacinta Hastings

COMMUNICATIONS OFFICER

(Communications, Research & Policy)

Barry Murphy

YOUTH DEVELOPMENT OFFICER

(Youth & Education)

Fiona Flynn
Fiona Craddock

SUPPORT OFFICER

(Helpline, Support Groups & Online Services)

Kathy Downes

TRAINING & DEVELOPMENT MANAGER

(Clinical Programme - HSE NCPED)

Harriet Parsons

ADMINISTRATOR

(Admin & Accounts)

Mary Crean
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