Parental Experiences of Autism Diagnostic Services in Ireland

Anna O Brien

X18327751

National College of Ireland

BA (Hons) Psychology

Supervisor: Dr. David Mothersill

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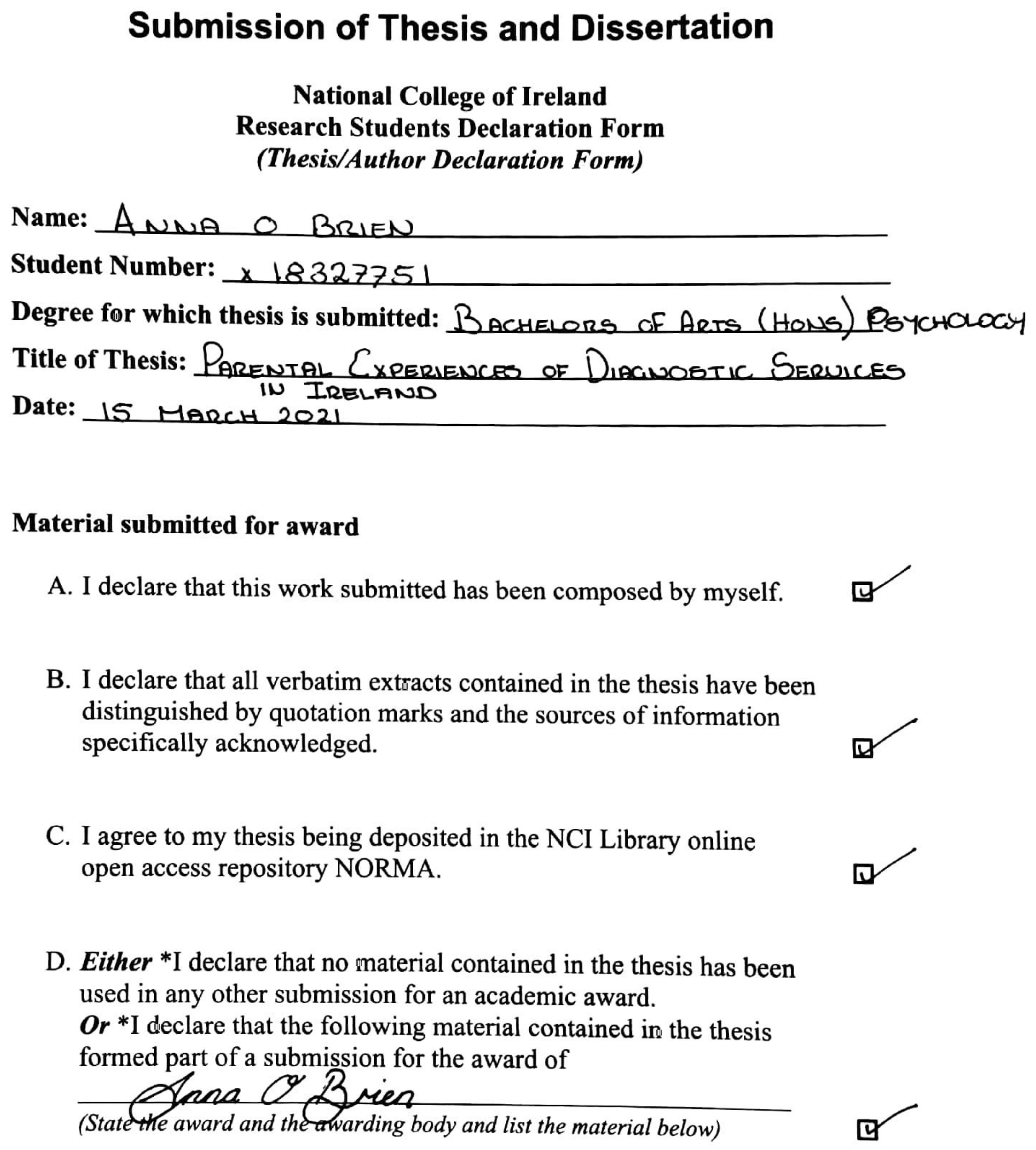

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Contents

Abstract

Autism is present in all cultures and societies and is increasing in prevalence, and research into the experiences of parents going through autism diagnostic services for their children is vital. However, to the author’s knowledge, research in this area is limited in Ireland. This study aimed to access five factors of autism diagnostic services in Ireland (information received, stress, professional manner, post-diagnostic support, time period of the diagnosis, and child’s age at diagnosis) and investigate if they have an effect on parents’ overall satisfaction levels with the diagnostic process, including an analysis determining if there is a difference in satisfaction levels between private and public service providers. This study contained 211 participants, collected through non-probability convenience sampling, and used hierarchical multiple regression analysis. The key findings were that low ratings of the quality of the information parents received, professional manner, and post-diagnosis support, as well as high levels of stress, were all indicative of lower satisfaction scores for the diagnostic process as a whole. This research could help improve services by providing practitioners insight into parent’s experiences, which in return could help parents have a better experience and increase satisfaction ratings of autism diagnostic processes.

Introduction

The focus of this study is to access factors of autism diagnostic services in Ireland and analyse how they affect parents' overall satisfaction score with the process. Research on this topic in Ireland is observed to be scarce. In the UK, Crane et al. (2016) performed a study that found significant indicators for negative experiences such as stress and dissatisfaction for parents seeking autism diagnosis and highlighted the need to improve parental experiences and perceptions of the diagnostic process. With a continually increasing prevalence rate of autism in Ireland (Boilson et al., 2016; Department of Health, 2018; Roddy & O'Neill, 2020; World Health Organization, 2018), the need for research into this area is key to ensure the best quality care for families (Crane et al., 2016). This literature review will look at autism and factors of autism diagnostic processes that have an effect on parental experience and satisfaction.

What is autism?

Autism is a neurodevelopmental disorder that materialises in unique ways, such as difficulties with social communication, interaction, relationships, and relating to peers, as a result of struggles with non-verbal communicative skills that can be very common with autism. People with autism often have different ways of thinking than typically expected and can engage in behaviours considered unusual to an individual who has not encountered autism previously, such as repetitiveness, rigidness in routine or method, lack of/fixated attention, and hypo or hyperactivity to sensory stimuli. Autism can present with significant clinical impairment in occupational and basic functioning (American Psychiatric Association, 2013; World Health Organisation, 2020) and can be difficult to manage for parents of young children with autism (Bonis, 2016). However, having a child with a disability or disorder such as autism can be a heart-warming and fulfilling experience, highlighting the importance of making the diagnostic process as positive as possible for parents, promoting a positive outlook from the very beginning (Markoulakis et al., 2012; McConnell et al., 2015).

Prevalence rates of autism and autism service demand

Children are being diagnosed with autism at much higher rates than previously due to the broadening of diagnosis criteria (American Psychiatric Association, 2013; Roddy & O'Neill, 2020; World Health Organisation, 2020), which is increasing the demand for related services as well as delaying the diagnostic process (Department of Health, 2019). According to the DSM-V, autism has reached a prevalence of 1% in the United States and non-US countries (American Psychiatric Association, 2013). More recent research showed that prevalence rates of autism diagnosis are as high as 1 in 100 people in Ireland (Staines, 2014). Parents often wait long durations to initiate the diagnostic process (Chiri & Warfield, 2012; Liptak, et al., 2008), which can severely impact their overall satisfaction of the services provided to them (Crane et al., 2016; Rogers, 2016). Difficulty obtaining a diagnosis, as well as prolonged waiting times, can increase stress for the family (Crane et al., 2016; Eggleston, et al., 2019; McMorris, 2013). Other countries have gained valuable insight from researching these topics, however, to the author's knowledge, this is scarcely researched within Ireland.

Parental stress

Child autism diagnoses can be a stressful experience for parents (Keenan, 2010), who are susceptible to significantly higher stress than those with other developmental disabilities or the general population (Argumedeset al., 2018; Benson & Karlof, 2009; Weiss, 2002). Although awareness of autism is on the rise in our communities (Dillenburger et al., 2015), parents are faced with daily criticism and stigma about their child's diagnosis and behaviours (Altiere & von Kluge, 2009; Farrugia, 2009; Recio et al., 2020). This can cause them stress (Farrugia, 2009) and can be detrimental to parents' self-esteem (Recio et al., 2020), which can subsequentially be detrimental to the autistic child's prosocial skills and behaviour management (Templeman, 2019). It can also affect their ability to manage their child’s behaviours (Bekhet et al., 2012; Osborne et al., 2008). Evaluating factors affecting parental stress may be a very important step in improving the services provided to families and increasing overall satisfaction rates for the diagnostic process (Moh & Magiati, 2016). Many variables can influence stress for parents of autistic children, such as information provided at the time of diagnosis, the manner of the professional giving the diagnosis, the stress associated with the diagnosis, and the satisfaction with post-diagnostic support (Crane et al., 2016). Assessing these factors and identifying problem areas can improve services and aid in establishing a parent/client-centered model for autism diagnostic services (Crane et al., 2016; Siklos & Kerns, 2007).

Manner of the professional

Communication and collaboration between parents and health professionals is a vital art of the diagnostic process in order to successfully meet the needs of autistic children (Straus et al., 2019). Navigating autism services can be difficult (Keenan, 2010), and can foster increased stress as parents have reported feeling isolated and ignored by professionals (Byrne et al., 2018; Legg & Tickle, 2019). Parents who reported higher professional partnership satisfaction sequentially reported higher prosocial levels and fewer behaviour problems for their children (Templeman, 2019). This an extremely important statistic hugely impacting the quality of life for an autistic child and their family (Totsika et al., 2015). A positive professional relationship can be beneficial (Casagrande & Ingersoll, 2017); highlighting the importance of professional/parent communication and providing necessary information (Coussens, et al., 2020).

Information given throughout the diagnostic process

Giving parents sufficient and good quality information throughout the diagnostic process can positively impact their overall satisfaction with autism diagnostic services

(Mansell & Morris, 2004), and feedback from parents should be a valued resource (Resch, 2010). Previous research has shown that parents find it challenging to find professionals who are knowledgeable, helpful, and qualified to assess their child and who understand the challenges autism (Silva & Schalock, 2012), this may be a similar pattern could be assumed for autism diagnoses in an Irish context. Many parents struggle to find the appropriate support, resources (Finnegan et al., 2014), and information (Mitchell & Sloper, 2002); and these parents need to be facilitated. Giving parents suitable information could significantly ease their stress related to understanding autism and the diagnostic process, as well as aid a harmonious lifestyle and help them deal with challenges (Crane et al., 2016).

Post-diagnostic support

Support for parents post-diagnosis is crucial as they often struggle to find, manage, and balance autism services (Ludlow, 2012; Nealy et al., 2012). Autistic children have a greater need for medical and therapeutic support creating further stress for parents (Hoogsteen & Woodgate, 2013). Families can also struggle to determine which services and supports they require, and how to gain access to them (McLennan et al., 2003). Raising awareness of the need for more services could permit the provision of better services for the child and support for their family (Hoogsteen & Woodgate, 2013). Lack of post-diagnosis support can be very stressful (Rabbitte, Prendeville, & Kinsella, 2017); it is essential that informing parents of the post-diagnostic supports available to them is part of the diagnostic process (Crane, et al., 2018). It can help mitigate the negative effects that stress can have on the health of parents (Zablotsky et al., 2010) and greatly impact their satisfaction with diagnostic processes (Doherty et al., 2000), as well as improve prosocial behaviour in autistic children (Templeman, 2019).

Experiences of parents

Giving parents a voice and assessing their individual experiences is critical in improving services (Raina, 2005). Receiving feedback from parents and listening to their concerns can reduce their stress, improve overall life satisfaction, ease anxiety (Ryan & O'Connor, 2017), as well as improve their experience and prevent future disservices (Resch, 2010). There is little observed research assessing the lived experiences of Irish parents going through an autism diagnosis for their children. Other countries have benefitted from analysing parents’ experiences concerning receiving a diagnosis, the support and education they were given, and helping them avail of the services available is a vital step in reducing stress and difficulties parents experience when seeking autism services (Moh & Magiati, 2016; Tehee et al., 2009). Previous studies have shown that parents often have unmet needs for their autistic child (Bromley et al., 2004; Chiri & Warfield, 2012; Lindly et al., 2019), this could be an unknown problem within Irish healthcare. Inspecting parental satisfaction of services and ensuring quality care is vital to reduce stress for both the parents and their child. It can also give the autistic child the best possible chance to reduce difficulty and stress throughout their lifetime and be provided with the best care (Plant & Sanders, 2007; Siklos & Kerns, 2007).

Private vs Public Healthcare

Public and private healthcare systems can often differ in experiences reported by the service users, with private healthcare often having higher satisfaction ratings (Owusu-Frimpong et al., 2010), and those in public healthcare having poorer access to services (Miller et al., 2014). Comparative studies between private and public healthcare is a major gap in the literature for autism diagnostic services, a study including this aspect has yet to be completed in Ireland which the current study aims to address.

Previous research

The current study is based on the Crane et al. (2016) study which examined the experiences of parents who had gone through autism diagnoses for their children within the UK. Their questionnaire was constructed to be in accordance with the DSM-IV (American Psychiatric Association, 2013) and adapted from the Howlin and Moore (1997) study that was conducted 15 years previous, and further adapted and researched by Brogan and Knussen, (2003) and Siklos and Kerns (2007). With such high sample sizes, ranging from 56 to 1200, these studies produced reliable results and provided in-depth insight into parental experiences throughout the UK. Crane et al. (2016) used hierarchical multiple regression analysis to analyse the data along with descriptive statistics and qualitative information. They also provided clear aims and emphasised parental experience both during and after their child's diagnosis, and these correlated to the goals for the current study and provided a clear process. The development of the questionnaire throughout the three studies provides strong validation and gave the current study a confident base. The data Crane et al. (2016) produced can serve as models for best practise in diagnostic services in the UK, this is a valuable asset and can be greatly utilised in an Irish setting.

The current study

The limited research available for Irish contexts has shown that diagnostic processes in Ireland are emotional and difficult journeys (Rabbitte et al., 2017), parents can often present with high stress levels and susceptibility to psychological difficulties (Doherty et al., 2000). Efforts to identify and reduce stress at diagnosis would be beneficial for service satisfaction and parents' optimism for their child's future (Myers, 2009). Providing parents with support services and education can improve satisfaction with the diagnostic process (Renty & Roeyers, 2006).

Research conducted in other countries has provided a solid foundation to build the current study on. Stress for parents, waiting times for diagnosis, satisfaction levels of services, information, and support parents receive as well as giving parents a voice are all crucial aspects in assessing the services provided to parents of children with autism (Crane et al., 2016; Crane et al., 2018; Eggleston et al., 2019; Moh & Magiati, 2016). Ireland's health system and care providers could benefit from the insight provided by the current study, such as identifying which factors are strong predictors of low satisfaction and high stress. These factors can then be analysed in further detail and possible solutions could be rendered. The current study adopted the questionnaire and analyses used by Crane et al. (2016) to be used within an Irish context, with an added analysis assessing the differences between private and public healthcare providers (see appendix D for the current study's questionnaire).

The health system is engaged with the development of processes to support clinical decision-making at a local, regional, and national level as part of the quality improvement process (Hse.ie, 2020). These processes involve the development of policies, protocols, and guidelines (Hughes, 2008; National Clinical Effectiveness Committee, 2015). Previous research has identified the need for focus on new models and strategies in autism diagnoses to cater to the needs of families (Russa et al., 2015). The insight provided in the current study could be extremely beneficial in forwarding the development of services and increasing their quality. The progress of children and the outcomes they achieve is strongly related to family engagement, and to improve family experience and outcome, it is vital that professionals continually increase their knowledge and utilise supports that are comprehensive and beneficial for families (Russa et al., 2015).

Hypotheses. For the current study, the hypotheses were based on Crane et al (2016) study, with the final hypothesis being unique to the current study:

Hypothesis one. Shorter time frame between first seeking help and receiving a diagnosis, as well as age at diagnosis, will significantly predict higher ratings of overall satisfaction, in an Irish sample of parents of a child with Autism Spectrum Disorder (ASD). Directed by Crane et al. (2016), on the basis that previous studies have shown that short wait times between first seeking help and receiving a diagnosis have been correlated with higher levels of overall process satisfaction (Brogan & Knussen, 2003; Hasnat & Graves, 2000; Howlin & Moore, 1997; Smith et al., 1994; Osborne et al., 2008; Mansell & Morris, 2004).

Hypothesis two. Higher ratings for information received at diagnosis predict significantly higher ratings of overall satisfaction, in an Irish sample of parents of a child with Autism Spectrum Disorder (ASD). Directed by Crane et al. (2016), on the basis that previous studies have shown good quality information can have positive impacts on parents' experiences (Mansell & Morris, 2004; Mitchell & Sloper, 2002)

Hypothesis three. Higher ratings of the manner of the professional delivering diagnosis predict significantly higher ratings of overall satisfaction, in an Irish sample of parents of a child with Autism Spectrum Disorder (ASD). Directed by Crane et al. (2016) and Coussens et al. (2020), on the basis that previous studies have shown that parents who report better professional relationships experience higher levels of prosocial behaviour and fewer behavioural problems for their child with autism (Templeman, 2019), in addition to positively impacting the child's quality of life (Totsika et al., 2015).

Hypothesis four. Post-diagnostic support significantly predicts higher ratings of overall satisfaction in an Irish sample of parents of a child with Autism Spectrum Disorder (ASD). Directed by Crane et al. (2016), on the basis that previous studies have shown lack of post-diagnostic support can increase levels of stress (Rabbitte et al., 2017), positively impact satisfaction levels (Doherty et al., 2000), and increase prosocial levels in autistic children (Templeman, 2019).

Hypothesis five. Lower levels of stress significantly predict higher ratings of overall satisfaction in an Irish sample of parents of a child with Autism Spectrum Disorder (ASD). Directed by Crane et al. (2016), with supporting studies highlighting the negative effects of parental stress on satisfaction levels (Moh & Magiati, 2016)

Hypothesis six. Private and public services provided in Ireland will differ in the ratings of satisfaction and stress levels of the diagnostic process. Previous studies have shown a difference in the quality and satisfactory levels of the services they provide (Owusu-Frimpong et al., 2010; Miller et al., 2014). This is a scarcely researched topic within autism services in Ireland, the current study aims to address this gap in the literature.

Methodology

Participants

The current study consisted of a research sample of 211 participants with a mean age of 41, which comprised of all females, except for one male participant. Participants were recruited through non-probability convenience sampling using the EPT Clinic client database, EPT Clinic social media (Facebook and Instagram), and Facebook support groups. The required sample for statistical analyses was calculated using G* power (3.1) which rendered a required sample of 31 participants with a 95% power to detect large (.95) effect sizes. The use of multiple platforms for recruitment ensured a vast range of participants were recruited and worked towards a varied sample of participants who went through both private and public service providers, and participants who attended different clinics and professionals to ensure a diverse and rounded sample. No incentives were used in recruiting participants.

To participate in the study, participants had to meet a set of inclusion criteria. This included being a parent/guardian of a child diagnosed with Autism Spectrum Disorder, must be 18 years or older, and obtained this diagnosis through certified Irish services. A total of 225 responses were gathered, and after analyses, 14 responses had to be eliminated due to incorrect fulfilment of the questionnaire.

Measures/Materials

The variables in this study were measured through a questionnaire that was adapted from Crane et al.’s 2016 study. As this study was conducted in the UK, necessary adaptions were made to enable the study to suit an Irish context. “Where in the UK were you living at the time you sought a diagnosis?” was changed to “Where in the Republic of Ireland were you living at the time you sought a diagnosis?” and the subsequent answer options were changed to Leinster, Munster, Connacht, and Ulster. Ethnicity was removed from the demographics sections as it was not required for this analysis. The questions requiring participants to put their child's age down was changed from a grouped answer (Under 36 months) to numeric answers (enter your answer: e.g., 4 years and 6 months), this was done to better specify the time between the first appointment and receiving a diagnosis. A question asking whether the participant obtained the services through private or public healthcare was also included in each section. This was used to assess hypothesis six. Some minor alterations were made to answer options to better suit an Irish context (e.g., portage working from professional type was removed along with some similar minor changes).

The questionnaire was constructed using the platform 'Microsoft Forms' and consisted of 11 sections, which included the Participation Information Leaflet (see appendix A), Informed Consent Form (see appendix B), and Debriefing Form (see appendix C). The reliability for satisfaction and stress rating questions produced a Cronbach's alpha of .74 which indicates a high level of internal consistency for the scales. Participation in the study took on average 15 minutes to complete.

Questionnaire sections. (adapted from Crane et al. (2016))

Information about the parent and child. Parents' demographics were recorded (age, gender, location, parent autism diagnosis, level of education, if they currently attended support groups). Parents were also asked to give information about their child (current age, gender, age at initial concerns, and nature of these concerns).

Diagnostic process. Parents were asked to give the age of the child at the initial appointment with a health professional, did they go through a public or private service provider, what this professional was (psychologist, GP, etc), what happened at this appointment (diagnosis made, referred, etc).

Subsequent referrals. Information was collected on each of the subsequent referrals that parents attended (how they got the referral, private or public service, professional, age of the child, what happened at referral).

Disclosure of diagnosis. Age of child at final diagnosis was asked, along with what this diagnosis was, and if they had any other diagnosis, the professional who gave this diagnosis.

Support post-diagnosis. Parents were asked if they received a written report or a follow-up appointment. they were also asked what post-diagnostic support they were offered if any.

Satisfaction with the diagnostic process. They were asked to rate their satisfaction on a 5-point Likert scale (‘very dissatisfied’ to ‘very satisfied’) with the manner of the professional that gave the final diagnosis, the information they received at the final diagnosis, the post-diagnostic support they received/were offered and then the diagnostic process as a whole.

Stress. Parents were asked to rate their stress levels during the diagnostic process on a 4-point Likert scale (‘not at all stressful’ to ‘very stressful’).

The questions that involved Likert-scales were scored as one to five or one to four appropriately. One being the lowest score (very stressful /very dissatisfied) and four/five being the highest (not at all stressful/very satisfied). For the full questionnaire, see Appendix D.

Study Design

The current study adopted a cross-sectional quantitative approach to assess satisfaction scores by analysing the collected data through inferential statistics. A previously established and validated questionnaire was used, Crane et al. (2016), this assessed factors relating to the diagnostic process for children with autism (Crane et al., 2016; Howlin & Moore, 1997; Siklos & Kerns, 2007). The original study conducted by Crane et al. (2016) included qualitative data collection in addition to quantitative data, to ensure the validity of the questionnaire, the qualitative questions of the questionnaire were included in the current study with the aim of analysing and interpreting it in a future paper through thematic analyses (Braun & Clarke, 2013), for submission to a peer-reviewed journal. This study was conducted in collaboration with the Education, Psychology, and Therapy Clinic Kilkenny (EPT Clinic).

In the current study, the dependent variable for all hypotheses was satisfaction with the diagnostic process as a whole, while the predictor variables were as follows: 1) time period between first seeking help and receiving a diagnosis, and child's age at diagnosis, 2) ratings for information received at diagnosis, 3) ratings of the manner of the professional delivering diagnosis, 4) ratings of post-diagnostic support, 5) levels of stress, and 6) public versus private service providers.

Data Analysis

Hierarchical multiple regression was used to analyse the quantitative data through the use of SPSS software. Collected data was analysed by the researcher to ensure data was entered correctly by participants. Any incorrect responses resulted in the removal of that participant's data. A total of 12 participants were removed from the study as a result. Location was converted into three dummy variables (Connaught, Munster, and Ulster), as it was a variable with more than two categories which is incompatible with hierarchical multiple regression.

Participants were asked at each section of the questionnaire if they went through a private or public service provider. In order to get a valid assessment of the differences between the two services, participants who reported a switch between private or public services were excluded from the hierarchical regression analysis. Participants who obtained solely private or solely public providers included.

Data Collection

The collection of data began on the 27th of November 2020 and ceased on the 18th of December 2020. All data was collected anonymously. There were four methods of data collection in this study: direct contact through EPT Clinics client database, EPT Clinic's social media (Facebook and Instagram), researchers' social media (Facebook), and through Autism special interest group of PSI.

Recruitment through EPT Clinic's client database. This involved analysing the consent forms parents signed upon obtaining services through the EPT Clinic. These consent forms consisted of clients' consent to contact them for future research being conducted through the EPT clinic. Potential participants were first contacted via phone call, which included an introduction to the researcher, a brief description of the study, and were then asked if they would be interested in participating. If the client expressed interest in participating, an email containing the survey link was sent to them. This included an introduction to the researcher and the study, along with a link that would bring them to the survey containing the participation information leaflet and the informed consent form. This was compliant with EPT Clinic's GDPR and ethics policies (see appendix E).

Recruitment through social media. A social media advertisement poster was designed for recruitment (see appendix F). This poster contained an introduction to the researcher, a brief description of the study, and their participation in the study, along with a link that would bring them to the survey. Groups specific to parents of children with autism were also used for recruitment. The administrators of these groups were contacted and asked if they were willing to distribute the recruitment poster and survey link on their platform, and the study advertisement was then posted within these groups: Autism Mammaí, Friends of Liam Foundation, Autism Parents Ireland, and Irish Autism Mammys.

Psychological Society of Ireland Autism Special Interest Group. PSI Autism Special Interest Group (SIG) was contacted by email which included an introduction to the researcher along with a brief description of the research and the survey. This email also requested assistance to share the survey through their social media platforms. PSI Autism SIG responded and was eager to help. They shared the recruitment poster along with the link to the survey on all of the PSI Autism SIG social media platforms.

Procedure

After the initial communication and provision of the link to the survey (phone call and email or social media advertisement), those who chose to follow the link to participate were brought directly to the questionnaire. The first section of the survey contained the Participation Information Leaflet, and in order to proceed, participants had to state that they had read through this leaflet fully and understood its contents. This then led them to the Informed Consent Form, after reading this form, participants were asked “Do you want to participate and give your informed consent to do so?”, if participates answer “yes”, they were brought to the start of the survey. If they answered “no”, they were brought to the “participation declined” section, where they were asked to exit the survey or submit it as a blank document.

Participants were brought to the Debriefing Form (see appendix C) upon completion of the survey. Here, they were thanked for participation, given a brief description of the significance of their contribution, and provided with support services if they had negative emotions or adverse feelings upon completion of the survey.

Ethical considerations

The National College of Ireland Ethics board granted ethical approval for this study, in addition to this, the EPT Clinic Clinical Director also granted permission (see appendix E). The study was conducted in conjunction with the GDPR guidelines and policies of EPT Clinic as well the ethical guidelines of NCI. The benefits and risks were clearly outlined to participants before they gained access to the survey, participants were not given incentive to take part. Informed consent was required from the participants in order to gain access to the questionnaire. It was considered that parents may have felt obliged to complete the survey if they were receiving services from EPT Clinic, this was addressed by clearly stating to each potential participant contacted through EPT Clinic that the survey was completely anonymous and that there was no possibility of identifying if the participant took part. The possibility of parents becoming distressed during or after the completion of the survey was considered, this was addressed by clearly stating in the information leaflet and debriefing sheet that if the participant did feel distressed, that they should contact one of the organisations that were provided along with their contact details. Before gaining access to the survey questions, participants were asked to give their informed consent (if they did not provide informed consent, they could not access the survey). Permission was obtained from group administrators for all social media group platforms used for recruiting. A set of inclusion criteria was outlined.

Results

Demographics

The age of parents who participated ranged from 23 to 60, with a mean age of 40.8, a standard deviation of 7.36, and a confidence interval of 39.8 to 42.8. The majority of participants were female, with one male participant. 2.4% of the parent population had an ASD diagnosis themselves. The sample was skewed geographically, with 49.8% of participants from Leinster, 34.6% from Munster, 10.4% from Connacht, and 5.2% from Ulster. This could be due to the fact that the first stage of recruitment taking place in the EPT clinic which, although not limited to, is based in Leinster. 75.4% of the sample reported being a member of a parent support group. 66.8% of parents reported having third level or above education, 24.6% reported having Leaving Cert level, 6.2% Junior Cert Level, and 2.4% reported having no official level of education.

The gender of children of the parents participating in this study showed a higher number of males with ASD (73%) than females (25.1%), with four parents reporting their child’s gender as other (1.9%). However, through manual analysis of both quantitative and qualitative data gathered by the questionnaire, it was decided to remove these participants’ data from the analysis as they were answering for more than one child rather than a child who identified their gender outside of male or female (i.e. instead of one child and answering male, they were reporting for two children, one male, one female, hence answered other). This was determined through the qualitative data that was collected. The mean age of the children at the time the questionnaire was filled out by their parents was 10.04 years, with a range of 2.17 to 25 years (SD= 5 years). The diagnosis of the participants’ children took place a mean of 4.17 years previous to the study being conducted, with a standard deviation of 3.8 years and a range of 0 to 20.7 years (SD= 3.82). The mean age of children at diagnosis was 5.86 years (SD= 3.49), ranging from 1.17 to 17 years.

From the time of their first appointment with a professional about their concerns for their child, it took parents a mean of 2.9 years to obtain a diagnosis, with a range from 0 to 17 years, with a standard deviation of 2.6 years. It took female children longer to get diagnosed with an average of 3.4 years (SD= 2.9) compared to males (M=2.7 years, SD= 2.22). Parents first noted their concerns for their children around the average age of 3.02 years, this ranged from .08 months to 19 years (SD= 3.04), they sought their first appointment with a professional for these concerns at an average of 3.39 years of age, this ranged from .25 months to 14 years (SD= 2.51).

Support Services

53.1% of parents reported that they were not offered any follow-up appointment with their diagnosing professional. After the diagnosis of their child, 21.8% reported that the professional from whom they obtained the diagnosis gave them direct help or support. 37% stated that they were only signposted towards help, and 37.9% stated that they were offered no help or support from at all from their diagnosing professional.

Predictors of Satisfaction of the Diagnostic Process as a Whole

A hierarchical multiple regression was performed to investigate the seven predictor variables for satisfaction with the diagnostic process as a whole (ability of time frame between first seeking help and receiving a diagnosis, quality of information received at diagnosis, rating of the manner of the professional delivering diagnosis, ratings of post-diagnostic support, levels of stress, and service provider). This regression controlled for parent and child demographics (child gender, education level, child age at the time of questionnaire, if they attend a support group, parents' age, location).

Preliminary analyses were conducted to ensure no violation of the assumptions of normality, linearity, and homoscedasticity. Additionally, the correlations amongst the predictor variables were examined and these are presented in Table 1. Correlations ranged between r = -.185 to .650. Tests for multicollinearity also indicated that all Tolerance and VIF values were in an acceptable range. These results indicate that there was no violation of the assumption of multicollinearity and that the data was suitable for multiple linear regression analysis.

Table 1

Correlations between variables included in the model.

Variable	1.	2.	3.	4.	5.	6.	7.	8.	9.	10.	11.	12.	13.	14.
1.Satisfaction/whole diagnostic process	-													
2.Child gender	.048	-												
3.Child age at present	-.185**	.149*	-											
4.Parent Support group	.004	-.066	-.046	-										
5.Parent age	-.109	.168**	.640***	-.051	-									
Location														
6.Munster	.027	.018	.102	.046	-.049	-								
7.Ulster	.072	-.094	-.077	-.113**	-.098	-.171**	-							
8.Connaught	.005	-.011	-.050	.015	.073	-.248***	-.080	-						
9.Quality of information	.513***	-.083	-.154	-.032	-.044	-.038	.089	.055	-					
10. Professional manner	.510***	-.012	-.078	-.012	.001	-.070	.043	.052	.632***	-				
11.Support post-diagnosis	.339***	-.007	-.087	.011	.042	.026	-.033	.016	.271***	.308***	-			
12.Levels of stress	.390***	.004	-.077	.013	-.093	.119*	-.112*	.025	.151	.202**	.217**	-		
13. Diagnosis time period	-.103	.170**	.380***	-.016	.227***	.005	.032	-.079	-.003	.022	-.011	-.042	-	
14.Child age at diag	-.074	.293***	.650***	-.051	.401***	.091	-.035	-.018	.010	.062	-.006	.010	.655***	-
15.Public vs private	-.169*	.167*	.306***	-.009	.321***	-.082	.052	.097	-.129	-.049	-.097	-.154**	.263***	.133**

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

In the first step of the hierarchical multiple regression, five predictors were entered: child gender, education level, child age at the time of the questionnaire, if they attended a support group, parents' age, and location. This model was not statistically significant F (7, 169) = 1.220; p = .295 and explained 4.8% of the variance in Satisfaction levels with the diagnostic process as a whole (see Table 2 for full details). Step two of the regression included the time frame between first seeking help and receiving a diagnosis, ratings for information received at diagnosis, rating of the manner of the professional delivering diagnosis, ratings of post-diagnostic support, levels of stress, and public vs private. At Step 2 the total variance explained by the model was 45% (F (7, 162) = 9.543; p < .001). The introduction of block two variables explained an additional 40.4% variance in satisfaction levels with the diagnostic process as a whole, after controlling for parent and child demographics; a change that was statistically significant (R2 Change = .404; F (7, 162) = 9.543; p < .001).

In the final model, five PVs uniquely predicted Satisfaction levels with the diagnostic process as a whole to a statistically significant degree, all of which were positive predictors. Quality of the information received (β = .28, $p < .001$) and levels of stress (β = .26, $p < .001$) were the strongest predictors (see Table 2 for full results), followed by ratings of professional manner (β = .24, $p = .002$), and ratings of post-diagnostic support β = .13, $p = .04$), and finally, child gender (β = .13, $p = .04$).

Table 2

Hierarchical multiple regression for analysis of hypothesised predictor variables for satisfaction levels of the diagnostic process as a whole.

Variable	*R*	R^2	R^2 *Change*	*B*	*SE*	*β*	*T*
Step 1	**.219**	**.048**					
Child gender				.24	.22	.08	1.08
Age at present				-.06	.03	-.21*	-2.11
Parent Support group				.02	.25	.01	.09
Age				.004	.02	.02	.21
Location							
Munster				.19	.24	.07	.82
Ulster				.49	.49	.08	1.02
Connaught				.08	.36	.02	.21
Step Two	**.672**	**.452**	**.404**				
Child gender				.37	.18	.13*	2.06
Child age at present				-.001	.03	-.003	-.03
Parent Support group				.07	.19	.02	.37
Parent Age				-.004	.02	-.02	-.29
Location							
Munster				.09	.19	.03	.49
Ulster				.55	.39	.09	1.43
Connaught				-.06	.28	-.01	-.22
Quality of information				.32	.09	.28***	3.66
Professional manner				.25	.08	.24**	3.12
Support post-diag				.15	.07	.13*	2.03
Stress				.49	.12	.26***	4.26
Time period for diag				-.02	.04	-.05	-.55
Age-diag				-.03	.04	-.08	-.80
Public vs private				-.17	.19	-.06	-.86

Note: Statistical significance: **p* < .05; ***p* < .01; ****p* < .001

Additional descriptive statistics for other data collected in the current study can be found in Appendix G.

Discussion

In the current study, the key findings reveal that the quality of the information received, levels of stress, rating of professional manner, and satisfaction with post-diagnostic support are all important aspects of the diagnostic process and can significantly impact the experience of parents and their satisfaction with the services they were provided. The findings of this research supported four out of the six hypotheses outlined. The aims of this study were to investigate the experiences of parents who have gone through autism diagnostic services in Ireland, analyse the different factors associated with autism diagnostic services, and investigate their impact on parents' experience and satisfaction ratings with the services.

Hypothesis one was rejected by the results of the hierarchical multiple regression, demonstrating that the time period parents experience waiting for a diagnosis and their child's age at the time of the diagnosis did not have a significant effect on satisfaction levels with the diagnostic process as a whole. However, the results of this study support hypothesis two, as it was found that better quality of information was able to predict higher satisfaction with the diagnostic process as a whole. When analysing the predictive relationship between ratings of the professional manner and parent satisfaction with the diagnostic process as a whole, it was found to have a significant relationship, implying that parents who reported higher ratings for professional manner subsequently had higher satisfaction levels for the diagnostic process as a whole, which is supportive of hypothesis three. The results of this research provide evidence that supports hypothesis four, showing that parents' satisfaction with the diagnostic process as a whole was significantly influenced by the support they received after obtaining a diagnosis for autism. When investigating levels of stress and their role in levels of satisfaction for the diagnostic process, a significant result was found to indicate that higher levels of stress are predictive of lower levels in parent satisfaction of the diagnostic process, which demonstrates support for hypothesis five. The current study's analysis did not find evidence to support hypothesis five, as whether parents obtained their services through private and public service providers did not predict levels of satisfaction for the diagnostic process as a whole, this hypothesis was therefore rejected.

It is also important to consider other relevant results of this analysis. The hierarchical multiple regression controlled for five variables (child's gender, child's present age, parent's support group, parent age, and location), of which, the child's age at present showed to be a significant predictor. This demonstrated a negative relationship, indicating that the younger a child was at the time of the questionnaire correlated with higher levels of satisfaction with the diagnostic process as a whole. After controlling for these variables, the child's gender also had a significant effect on satisfaction levels of the diagnostic process. It is also relevant to note that many studies have found that males are diagnosed at higher rates than females, resulting in higher prevalence in the male population (Campbell et al., 2014; Halladay et al., 2015; Whiteley et al., 2010). The current study reflects these findings, as parents reported more male children with autism than female children. This relationship also highlights the emerging theories in literature around gender differences in autism diagnostic services, identifying that parents of female children rate services with lower satisfaction (Zamoraet al., 2014). This could be a result of gender differences in core symptomology in autism (Rivet & Matson, 2011), and the delay females with autism often face when seeking a diagnosis (Begeer et al., 2013). The non-significant result of location as a predictor may demonstrate an equal availability of services throughout Ireland; this can be important for satisfaction levels as travelling long distances for services can be an impacting factor (Martinez et al., 2018).

Findings in relation to previous literature

Diagnosis time period and child's age at diagnosis: The current study found the age of the child at the time of diagnosis and the time period taken to receive a diagnosis did not significantly predict satisfaction levels for the diagnostic process as a whole. Contrastingly, Crane et al.'s (2016) found a significant relationship between the time period taken to get a diagnosis and satisfaction levels for the diagnostic process. However, when comparing our results to those of Crane et al. (2016), it must be noted that the current study presented a wait time to receive a diagnosis as lower (2.6 years) than that of Crane et al (3.5 years) indicating shorter wait times in Ireland for autism diagnoses compared to the UK. This could be a contributing factor to the difference in results between the two studies. Lengthy wait times can negatively impact parental experiences of the diagnostic process (Chiri & Warfield, 2012); it is possible to interpret this result as parents in Ireland feeling they have not experienced long wait times in comparison to those in the UK.

Quality of information received by parent: The findings for this variable are directly in line with previous findings from Crane et al. (2016) study, in addition to findings from other relevant research (Mansell & Morris, 2004; Silva & Schalock, 2012). Receiving appropriate and quality information is an area of great importance for parents when navigating diagnostic services for disabilities (Mitchell & Sloper, 2002).

Manner of professional delivering diagnosis: The results of the current study ties well with those of Crane et al. (2016) wherein high ratings for professional manner had a predictive relationship with satisfaction of the diagnostic process as a whole. The importance of the parent and professional relationship has been highlighted in many studies as a crucial factor of parents' positive experience of autism diagnostic services (Casagrande & Ingersoll, 2017; Coussens, et al., 2020; Straus et al., 2019).

Post diagnostic support: Similar to research by Crane et al. (2016), the present study found a significant result for the ability of higher ratings of post-diagnostic support to predict higher levels of satisfaction with the diagnostic process as a whole. This also reflects previous research performed in Ireland by Doherty, Fitzgerald, & Matthews (2000).

Stress: The current study mirrored the relationship produced by Crane et al. (2016) for the predictability that levels of stress have on the satisfaction of the diagnostic process as a whole. Other previous research has also found that stress is a prominent factor when going through the diagnostic process for autism (Keenan, 2010; Moh & Magiati, 2016).

Public vs private service providers: Contrary to the findings of Owusu-Frimpong et al. (2010), which found private services providing better parental satisfaction with their diagnostic process and lower stress related to the process, this study did not find a significant difference between the satisfaction levels of the diagnostic process as a whole and the type of service provider (public and private) parents used. This may be indicative that Irish services are non-discriminatory towards parents who seek their services privately or through public providers.

Contribution to the existing literature

The current study provides insight into the experiences of parents who have gone through autism diagnostic services for their children. It highlights areas that have an impact on satisfaction ratings of parents (quality of the information received, the manner of the professional involved, the post-diagnostic support, and stress levels) as well as investigating the potential differences provided by public and private healthcare providers for parents seeking services. Acknowledging the opinions of parents and giving them a voice is a key role in enabling improvement of the services provided to parents for their autistic children and ensuring families get the best possible care and to help parents have a better experience and increase satisfaction ratings (Moh & Magiati, 2016; Tehee et al., 2009). The current study has also provided research to address an evident gap in the literature comparing private and public service providers. It would be beneficial for future studies to research into this factor with more in-depth analysis to provide greater knowledge and validity or the differences between private and public service providers in healthcare.

Limitations and Strengths

This study is reliant on the participants who fill out the required survey, and it cannot be established whether the participants who completed the survey represent non-respondents as well, as it is a self-selecting sample. Although the current study is based on the research performed by Crane et al. (2016), some results did not correlate with theirs. These differences could be down to cultural and/or country differences, however, it can also be down to sample size. Crane et al. (2016) had a sample size of 1000, whereas the current study contains 211 participants. Although this is a large sample size and in accordance with the estimated sample size needed to obtain similar effect sizes, the large sample size of Crane et al. (2016) study could mean a better representation of parents with a more diverse experience. The majority of participants in this study reported being based in Leinster, therefore, the four provinces of the Republic of Ireland have not been equally represented and it cannot be determined if services are equal as such. Future studies should aim for larger and more diverse samples to better analyse what factors are due to culture/county or sample in comparison to the Crane et al. (2016) study.

Although participants may report being based in one province, this does not determine if this is the province that they received their services from. Participants may have travelled far or to multiple locations to obtain services, therefore, results cannot be assessed on a regional basis. When examining the differences between public and private services, it is important to note that the majority of responses report having sought their services through public service providers, resulting in an under-representation of private services. It may prove beneficial to take this into account for future studies to attempt to collect an even ratio of public and private service provider users when collecting data. This sample population in this study is dominantly represented by females (mothers). It was also not noted on responses whether parents had one or more children with ASD and whether their response reflects their combined experiences or a singular experience. This may also affect their satisfaction levels, as parents who have previously been through an autism diagnostic process may be better informed and less susceptible to stress/worry than parents who have not. Future studies should include questions to address these limitations in their survey to assess whether they are contributing factors to the results produced. The current study found that many categorical variables were used in the questionnaire provided by Crane et al. (2016), this produced difficulty when conducting inferential statistics for the current study's data. Future studies may benefit from gathering continuous data and avoiding categorical variables where possible, as continuous variables are more robust and practical to use when conducting an analysis. Regardless of the limitations, this study obtained a large and rounded sample of participants. The measures used were from a reliable and previously tested source. The age of participants' children was diverse and a wide time period for when diagnoses took place was covered.

Clinical Implications

The contributions of this research can be widely applied; it presents reliable results and the relationships found within it provide valuable insight and information into the experiences of parents. The findings from this research can provide professionals in the field of autism with an increased awareness of the factors that negatively impact a parent's experience. It expands the knowledge of services from a parental perspective and provides navigation towards improving services which in turn will improve the experience of families and their outcomes.

Specifically, this research can be used to target specific areas of the diagnostic process that influence parent satisfaction. Professionals working with parents of children going through an autism diagnosis can implement strategies to better address the concerns of parents and provide them with ample and adequate information to ensure they leave the professional feeling informed, with an understanding of their child's potential diagnosis and what that will mean for their family. Implementing strategies to achieve this is simple and cost-effective but can make a significant difference to parents. The findings of this study highlight the fact that clinicians can benefit from future research into the causes of stress for parents going through an autism diagnosis for their child, as reducing parents' stress levels may help improve their satisfaction. Educational psychologists who diagnose autism can improve parents' experience by providing them with direction for support post-diagnosis; the current research identifies this area as an impacting factor in overall parents' satisfaction, this could be addressed by clinicians by developing post-diagnostic support programmes for parents. Multi-disciplinary teams in educational clinics are of extreme benefit to clinic directors, in addition to parents. It can provide clinics with additional in-house referrals and increasing client intake. This enables clinicians to introduce parents to other professionals within the clinic who can help them on their child's journey with autism (e.g. speech and language therapists and occupational therapists), in addition to professionals that can help the parents' wellbeing (e.g. counsellors or psychotherapists). This can provide them with tools to help their child develop and direction to support services (e.g. support groups, child emotional regulation programmes). Furthermore, interprofessional collaboration using a multidisciplinary approach can have significant positive effects on the outcomes for children with autism (Strunk et al., 2017).

Conclusion

The current study has given parents a chance to use their voice, express their experiences, and give others an understanding of what they went through when they sought autism diagnostic services for their children. These parents have shone a light on the key areas that affect their overall satisfaction with diagnostic services. The results from this study found that low ratings of the quality of the information parents received, low ratings of the professional manner, low ratings of post-diagnosis support, and high levels of stress were all indicative of lower satisfaction scores for the diagnostic process as a whole, in addition to child gender and the child's age at the time of the study also being a significant predictor. It is concerning to consider that something as small as providing parents with quality information and a professional that addresses their needs and helps them navigate the services they need for their children is a problem area for parents. The knowledge that parents are then left feeling unsupported after they receive the diagnosis is troubling as this is the time when they are adjusting to their child's diagnosis and need help and support to give their child the best possible care to aid their development. This study also assessed differences in satisfaction between public and private service providers, which found no significant differences when comparing public and private service providers, a research question that has not been studied in Ireland by previous research. These findings have highlighted the importance of parents' experiences and giving parents a voice for the services that they rely on to help their children and provide the best possible care. This can provide direction for practices that wish to further improve their services and utilise this study as a tool to do so. Professionals in the field of autism have a considerable responsibility to provide adequate and appropriate services to children with autism. Further research could provide more in-depth insight into the factors affecting parents' experience and satisfaction levels of the services provided to them, in addition to increasing the reliability of the results by replicating this study, widening the sample size, and reducing any limitations that were addressed.

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Appendices

Appendix A

Participation Information Leaflet: A study of parent's experiences with autism diagnostic services.

You are being invited to take part in a research study. If you have any questions about the information provided, please do not hesitate to contact me using the contact details provided at the end of this leaflet.

What is this study about?

I am a final year BA of psychology student in the National College of Ireland. As part of my degree, I am to conduct an independent research project. For my project, I have decided to examine the experiences of parents of services they received during the diagnostic process for Autism Spectrum Disorder. This study aims to give parents a voice and means to express their experiences. This project is being supervised by Dr David Mothersill of the National College of Ireland as well as clinic manager of EPT Clinic Kilkenny, Lorraine OB Madden.

What will taking part in this study involve?

If you decide to take part in this study, you will be asked to answer an online questionnaire regarding your experiences of the services provided to you during the autism diagnosis. The questionnaire will take approximately 8 to 15 minutes to complete. After this questionnaire is complete, your participation in the study is finished, nothing further will be asked of you. You are more than welcome to contact me before or after your participation to relate any queries you have about the research or your participation in it.

Who can take part?

You can take part in this study if you (the parent/guardian of the child) are over the age of 18 and have a child that has a diagnosis of Autism.

Do I have to take part?

Participation in this research is completely voluntary, deciding to participate or not to participate in this study will have no effect on the services being provided to you by any practise in the present day or services you seek in the future. You can withdraw from the study up until you have submitted your questionnaire. This can be done by simply leaving the questionnaire webpage or submitting a blank questionnaire.

What are the possible risks and benefits?

The information gathered from your participation will contribute to research helping us to understand the experiences had by parents of children with autism and help further and possibly improve the experiences of others who will go through these services in the future.

There is a small risk that some of the questions contained in the questionnaire may cause some distress for some participants. If you experience any distress, you are free to discontinue your participation and exit the questionnaire at any time. Contact for relevant support services are also provided at the end of the questionnaire.

Will taking part in this survey be confidential?

Participation in this study will be strictly anonymous. There will be no method of identifying who participated in the survey or linking the questionnaire you submit to your person.

What will happen to the results of the study?

The results of this study will be presented in my final dissertation, which will be submitted to the National College of Ireland. The results may be presented at a conference and/or submitted to an academic journal for publication.

Who should you contact for further information?

Anna O Brien

National College of Ireland

X18327751@student.ncirl.ie

Dr David Mothersill

National College of Ireland

David.mothersill@ncirl.ie

Lorraine Madden

EPT Clinic, Clinic Manager

info@eptclinic.ie

Appendix B

Informed Consent

Study Title: A study of parents' experiences during autism diagnoses in Ireland.

Researcher: Anna O Brien.

Academic Supervisor: Dr David Mothersill.

In order to participate in this research study, it is necessary that informed consent in given. By agreeing to participate you are indicating that you understand the nature of the research study and your role in the research and that you are agreeing to participate in the research.

Please consider the following points before giving your informed consent:

- I understand that all information I provide is confidential and my participation is anonymous.
- I understand I have been given contact details and support services I can contact and avail of if any distress is to come from participating in this study.
- I understand that participation in this study is not required and is voluntary, that I may refuse participation without penalty.
- I understand that my participation or lack of participation will not affect any services, either current or future, that I might avail of through service providers.
- I understand that I have the right to withdraw my participation from this study at any point up until I have submitted the questionnaire.
- I understand that the results will be presented in a dissertation to The National College of Ireland and may go further to be presented in conferences or published in research journals.

By continuing to participate in this study I am stating that I am over 18 years of age and have a child that has been

professionally diagnosed with Autism Spectrum Disorder, I understand the information outlined above and consent to

participate in this study being conducted by the researcher through EPT clinic and The National College of Ireland.

Do you want to participate and give your informed consent to do so?

☐Yes

☐ No

Appendix C

Debriefing Form

Project Title: A study of parents' experiences of services for their children with Autism Spectrum Disorder.

Researcher Information: Anna O'Brien
National College of Ireland
X18327751@student.ncirl.ie

Thank you for participating in this research project! Your participation and opinion are vital, and this study aims to better the services provided to parents of children with Autism. This study's ambition is to give parents a voice and a way to project their experiences to better their own future experiences and the experiences of parents navigating their own way through an Autism diagnosis, while also comparing public and private services.

Autism effects every 5 in 10,000 people in Ireland. It can be difficult for parents and families to manage and navigate a diagnosis of autism. Assessing the quality of the services provided to these parents, both during diagnosis and post-diagnosis is of vital importance to progress and improve these services. Ensuring quality care and satisfactory services is essential to reduce the stress parents may feel and give the best possible care.

If you have any questions or comments, please feel free to contact the researcher, Anna O Brien via email (provided below). If this study has caused any form of distress for you, please contact the researcher or the support services given below:

- Your GP or local HSE service

- Irish society for Autism
  www.Autism.ie
  +353 1 874 4684

- Enable Ireland
  www.enableireland.ie
  +353 (0) 1 8727155

- As I Am.ie
  www.asiam.ie

- Middletown centre for Autism
  www.middletownautism.com
  +44 28 3751 5750

Other relevant contacts:

- Dr David Mothersill
  National College of Ireland
  David.mothersill@ncirl.ie

- Lorraine Madden
  EPT Clinic, Clinic Manager
  info@eptclinic.ie

Once again, thank you for your participation!

All the best,

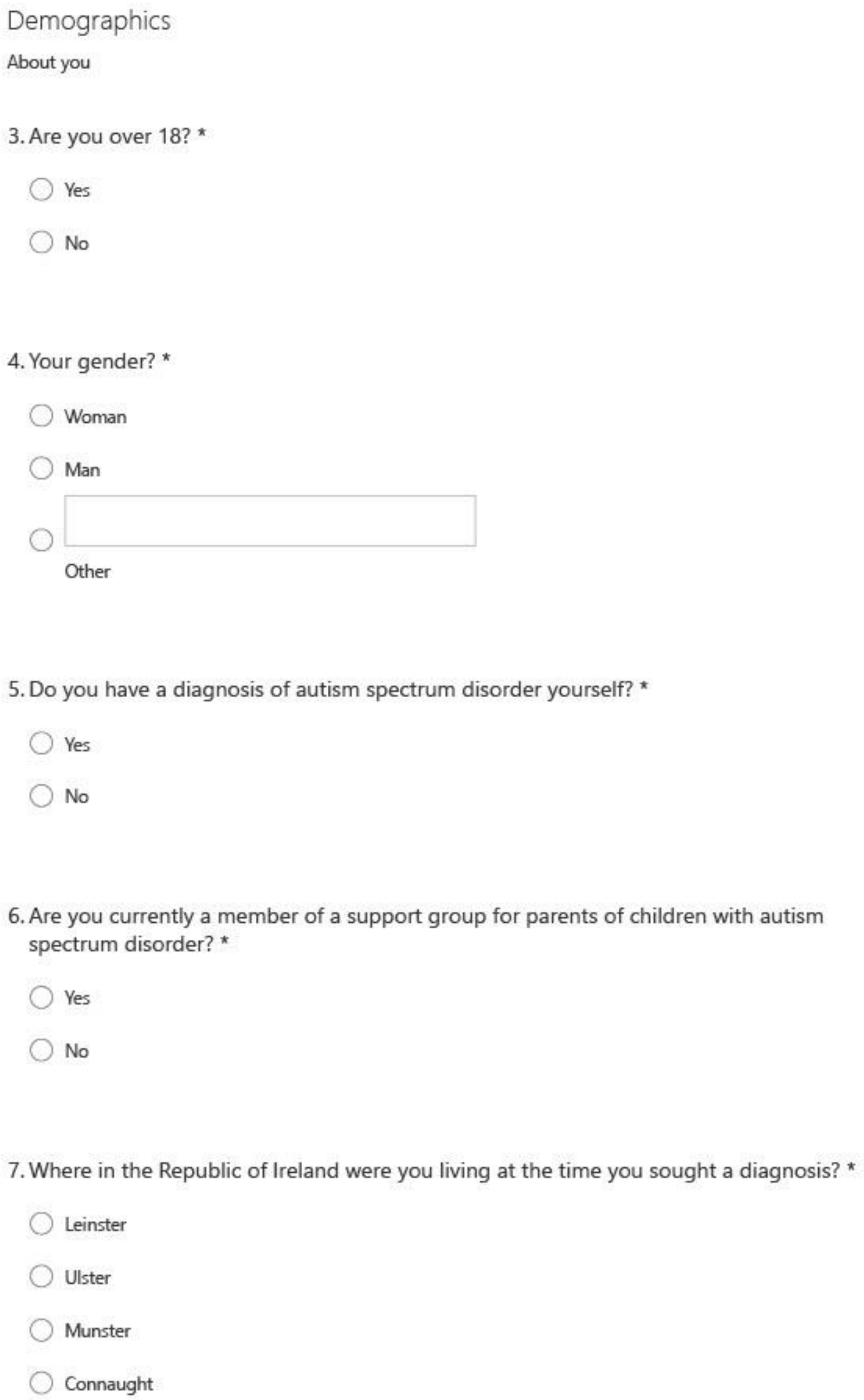
Anna O Brien.

x18327751@student.ncirl.ie

National College of Ireland.

Appendix D

Questionnaire Form



Demographics

About you

3. Are you over 18? *

○ Yes

○ No

4. Your gender? *

○ Woman

○ Man

○ Other

5. Do you have a diagnosis of autism spectrum disorder yourself? *

○ Yes

○ No

6. Are you currently a member of a support group for parents of children with autism spectrum disorder? *

○ Yes

○ No

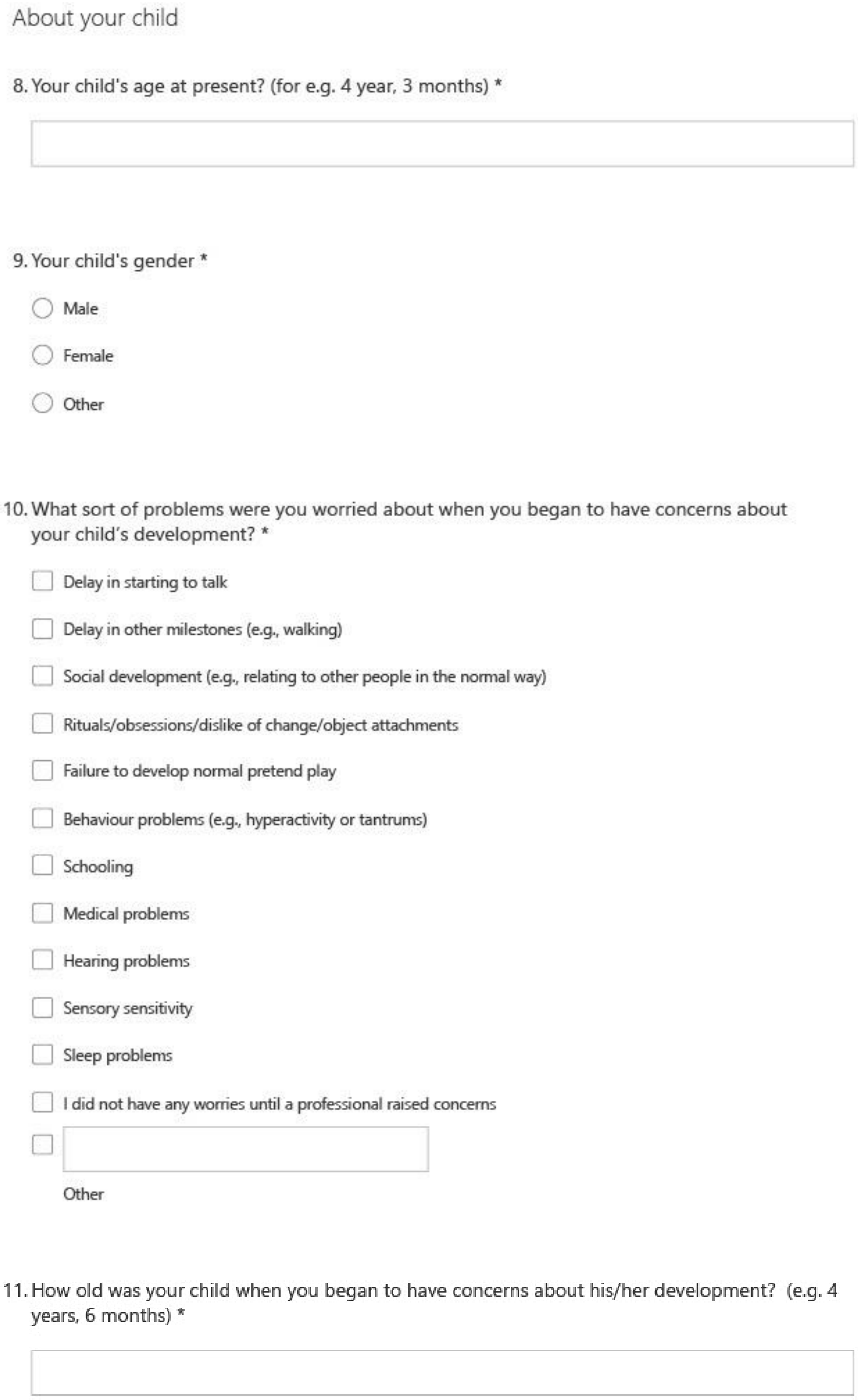
7. Where in the Republic of Ireland were you living at the time you sought a diagnosis? *

○ Leinster

○ Ulster

○ Munster

○ Connaught



About your child

8. Your child's age at present? (for e.g. 4 year, 3 months) *

9. Your child's gender *

○ Male

○ Female

○ Other

10. What sort of problems were you worried about when you began to have concerns about your child's development? *

☐ Delay in starting to talk

☐ Delay in other milestones (e.g., walking)

☐ Social development (e.g., relating to other people in the normal way)

☐ Rituals/obsessions/dislike of change/object attachments

☐ Failure to develop normal pretend play

☐ Behaviour problems (e.g., hyperactivity or tantrums)

☐ Schooling

☐ Medical problems

☐ Hearing problems

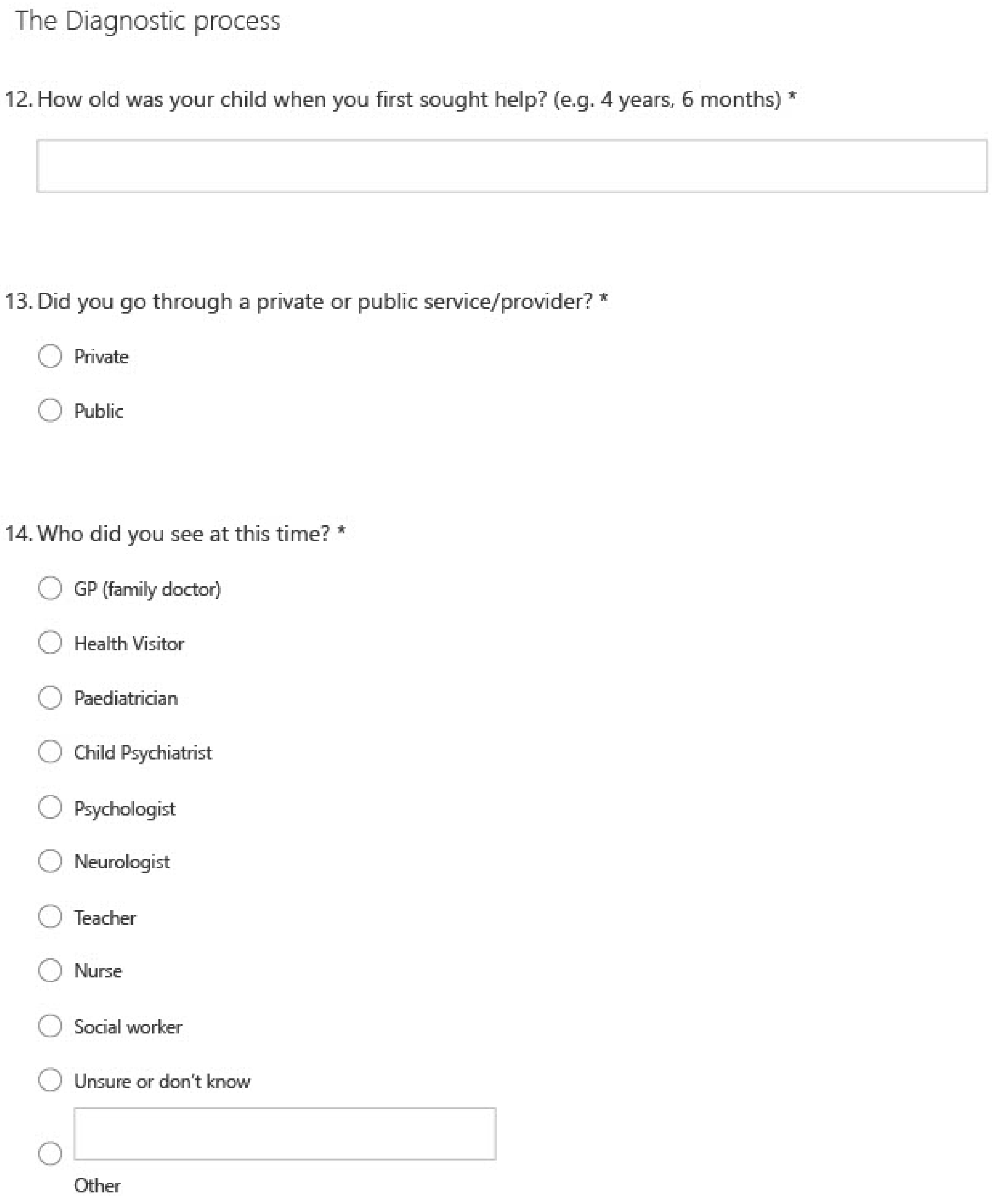
☐ Sensory sensitivity

☐ Sleep problems

☐ I did not have any worries until a professional raised concerns

☐ Other

11. How old was your child when you began to have concerns about his/her development? (e.g. 4 years, 6 months) *



The Diagnostic process

12. How old was your child when you first sought help? (e.g. 4 years, 6 months) *

13. Did you go through a private or public service/provider? *

○ Private

○ Public

14. Who did you see at this time? *

○ GP (family doctor)

○ Health Visitor

○ Paediatrician

○ Child Psychiatrist

○ Psychologist

○ Neurologist

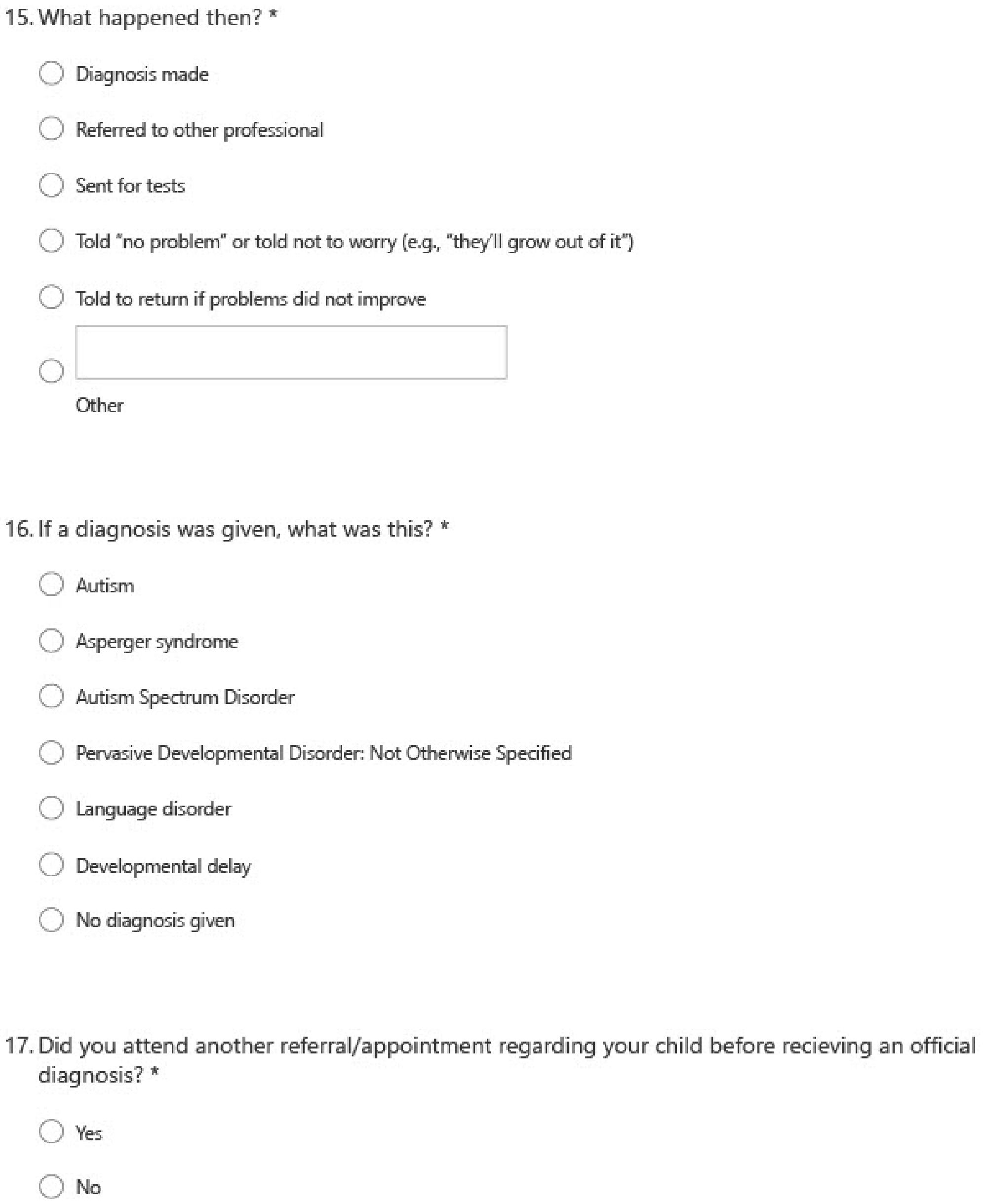
○ Teacher

○ Nurse

○ Social worker

○ Unsure or don't know

○ Other



15. What happened then? *

○ Diagnosis made

○ Referred to other professional

○ Sent for tests

○ Told "no problem" or told not to worry (e.g., "they'll grow out of it")

○ Told to return if problems did not improve

○ ☐ Other

16. If a diagnosis was given, what was this? *

○ Autism

○ Asperger syndrome

○ Autism Spectrum Disorder

○ Pervasive Developmental Disorder: Not Otherwise Specified

○ Language disorder

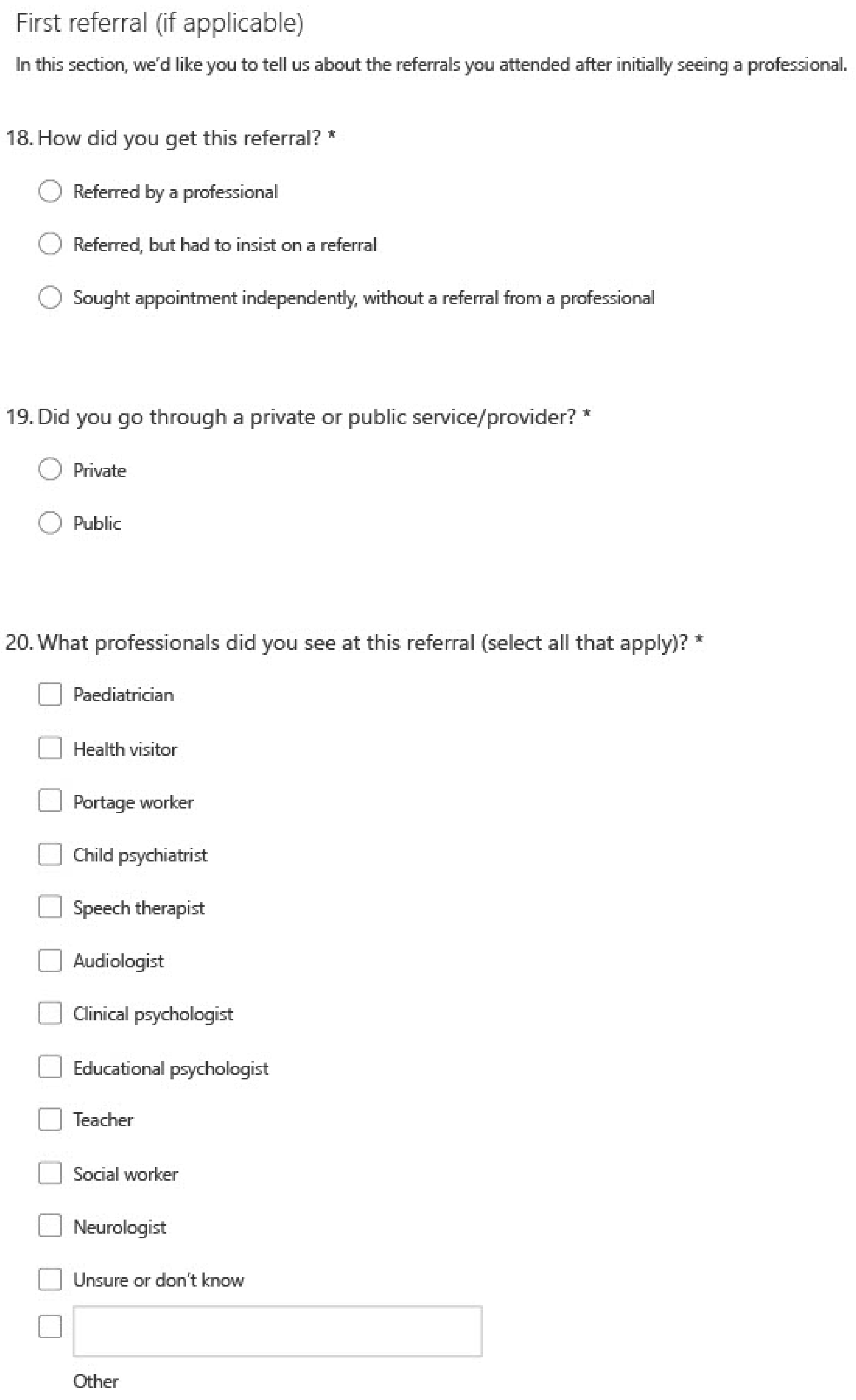
○ Developmental delay

○ No diagnosis given

17. Did you attend another referral/appointment regarding your child before recieving an official diagnosis? *

○ Yes

○ No



First referral (if applicable)

In this section, we'd like you to tell us about the referrals you attended after initially seeing a professional.

18. How did you get this referral? *

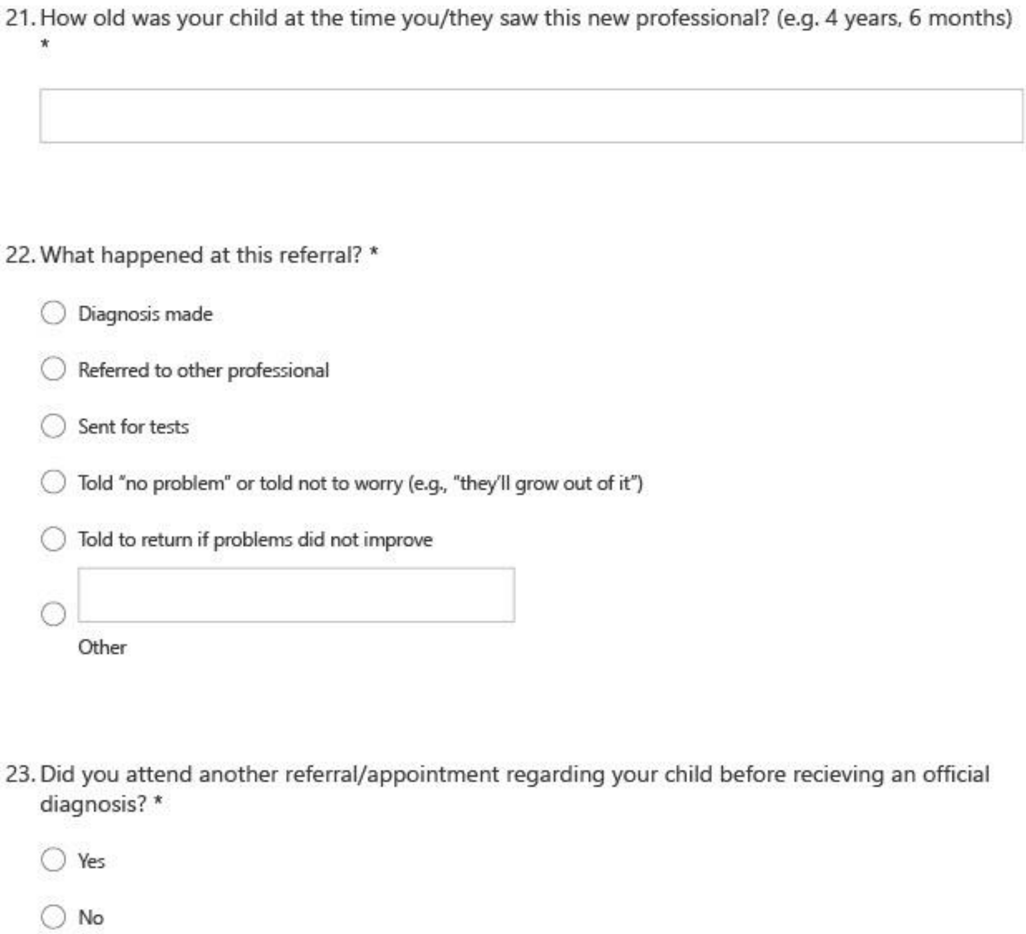
○ Referred by a professional
○ Referred, but had to insist on a referral
○ Sought appointment independently, without a referral from a professional

19. Did you go through a private or public service/provider? *

○ Private
○ Public

20. What professionals did you see at this referral (select all that apply)? *

☐ Paediatrician
☐ Health visitor
☐ Portage worker
☐ Child psychiatrist
☐ Speech therapist
☐ Audiologist
☐ Clinical psychologist
☐ Educational psychologist
☐ Teacher
☐ Social worker
☐ Neurologist
☐ Unsure or don't know
☐ Other



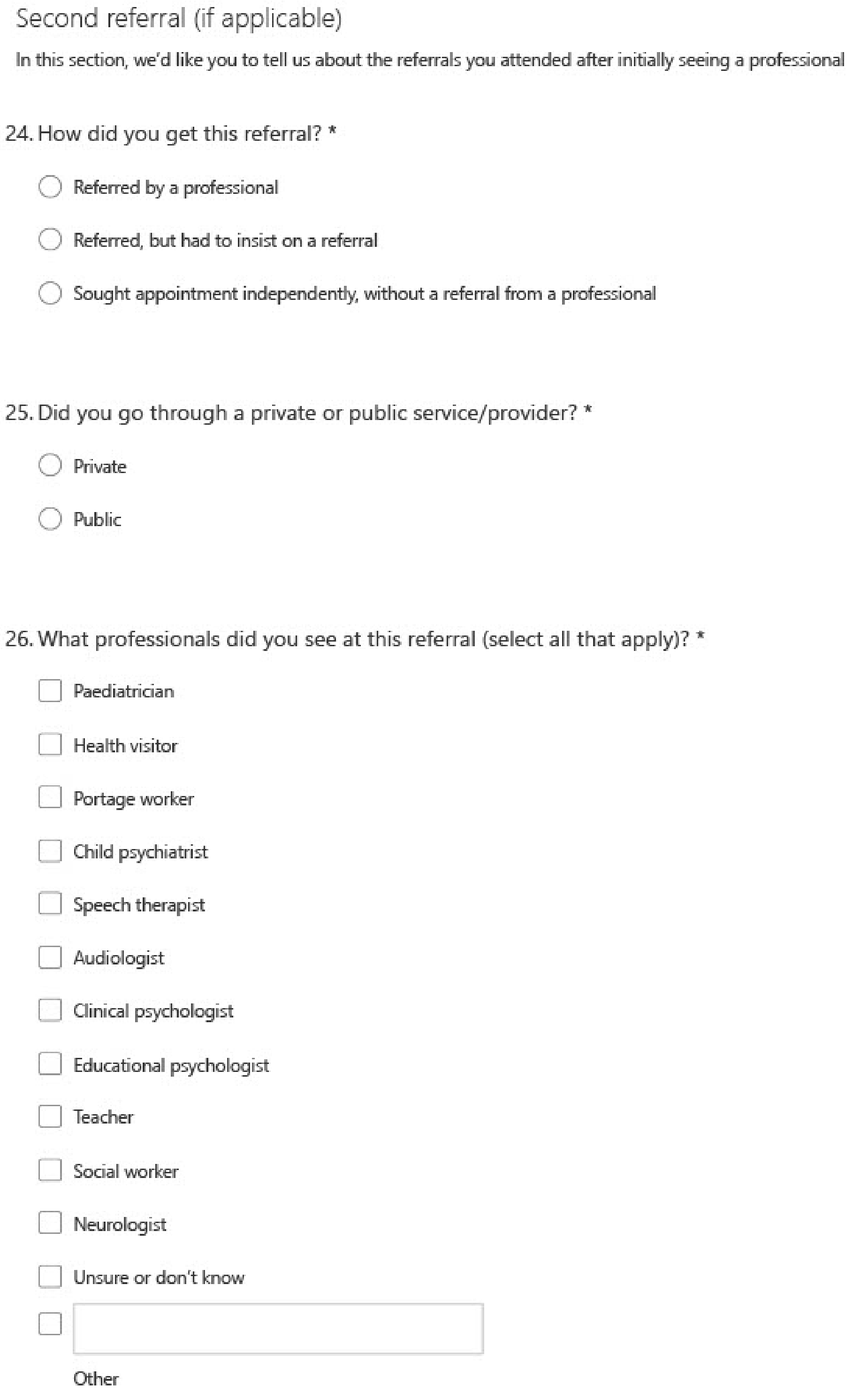
21. How old was your child at the time you/they saw this new professional? (e.g. 4 years, 6 months) *

22. What happened at this referral? *

○ Diagnosis made
○ Referred to other professional
○ Sent for tests
○ Told “no problem” or told not to worry (e.g., “they'll grow out of it”)
○ Told to return if problems did not improve
○ Other

23. Did you attend another referral/appointment regarding your child before recieving an official diagnosis? *

○ Yes
○ No



Second referral (if applicable)

In this section, we'd like you to tell us about the referrals you attended after initially seeing a professional

24. How did you get this referral? *

○ Referred by a professional

○ Referred, but had to insist on a referral

○ Sought appointment independently, without a referral from a professional

25. Did you go through a private or public service/provider? *

○ Private

○ Public

26. What professionals did you see at this referral (select all that apply)? *

☐ Paediatrician

☐ Health visitor

☐ Portage worker

☐ Child psychiatrist

☐ Speech therapist

☐ Audiologist

☐ Clinical psychologist

☐ Educational psychologist

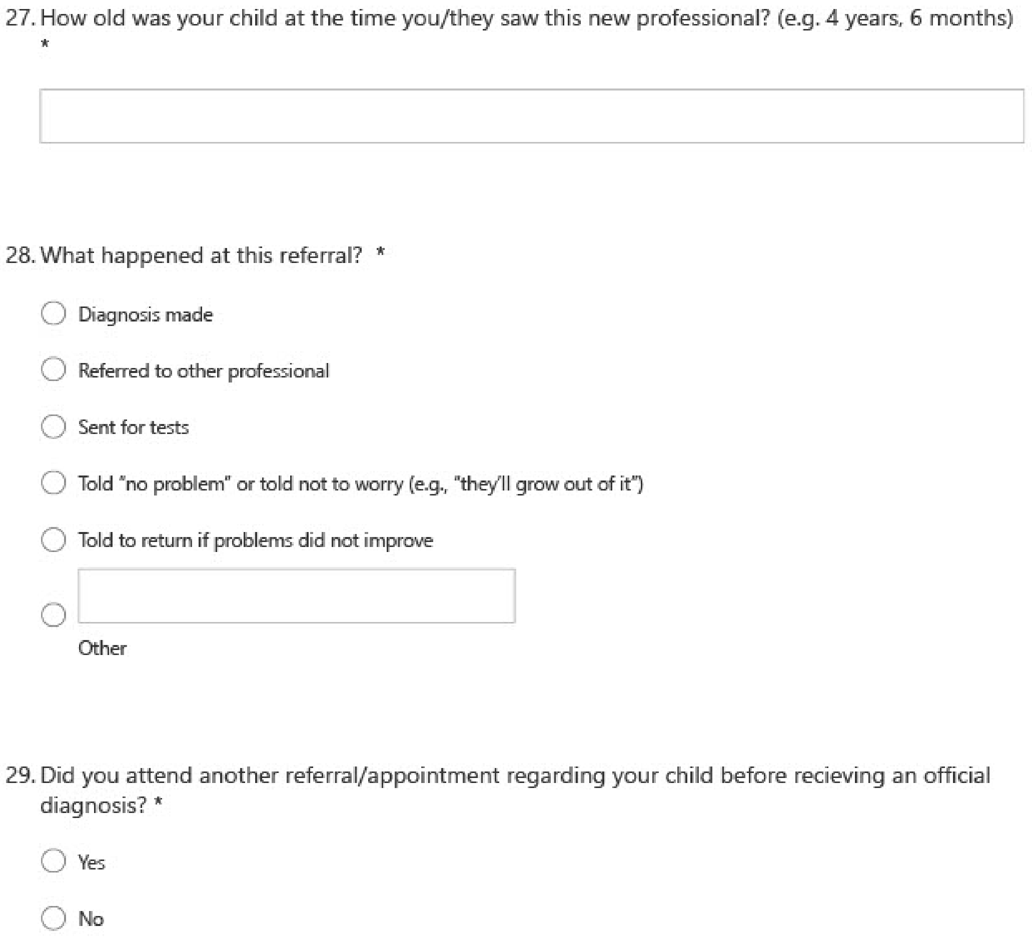
☐ Teacher

☐ Social worker

☐ Neurologist

☐ Unsure or don't know

☐ Other



27. How old was your child at the time you/they saw this new professional? (e.g. 4 years, 6 months) *

28. What happened at this referral? *

○ Diagnosis made

○ Referred to other professional

○ Sent for tests

○ Told "no problem" or told not to worry (e.g., "they'll grow out of it")

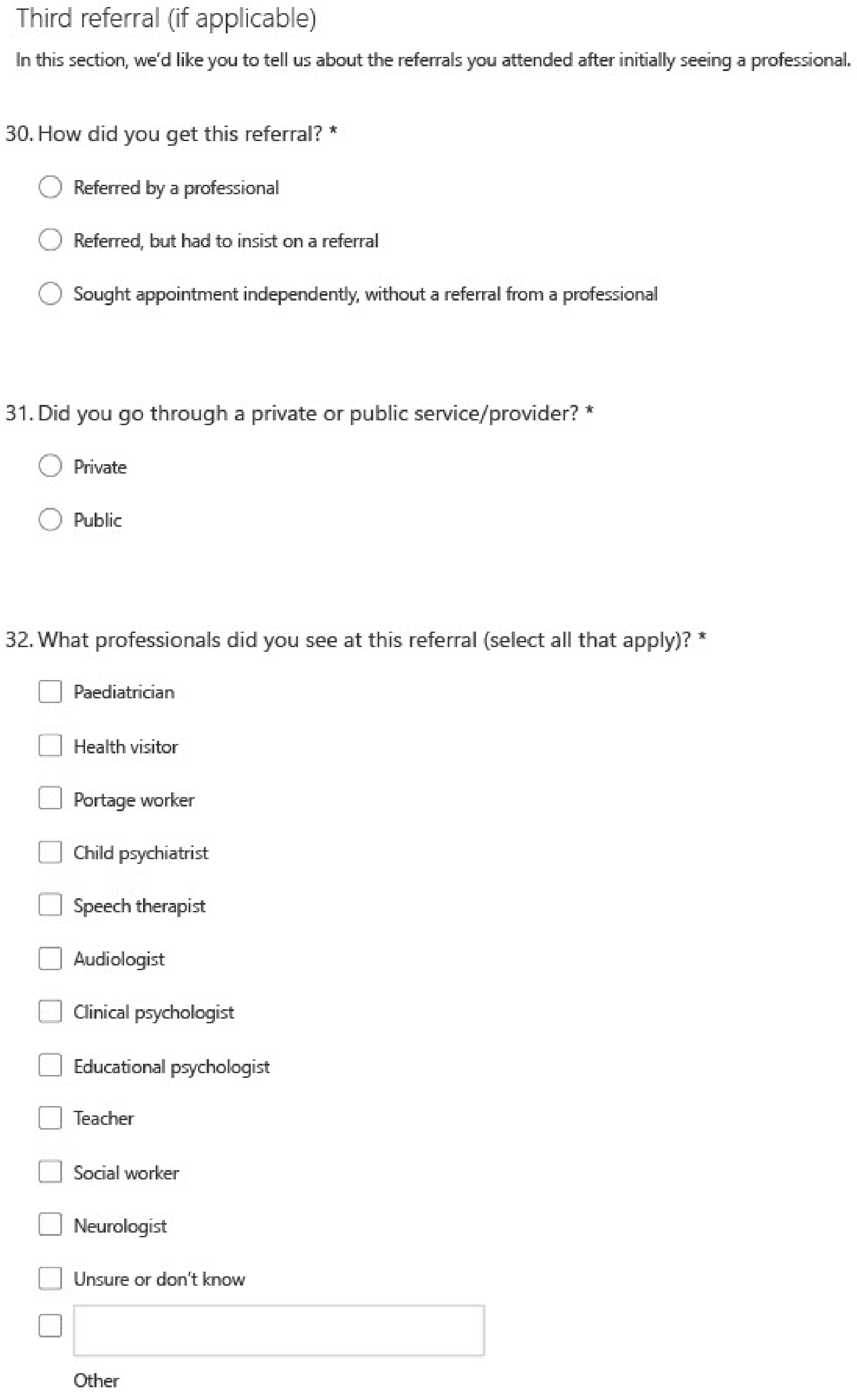
○ Told to return if problems did not improve

○ Other

29. Did you attend another referral/appointment regarding your child before recieving an official diagnosis? *

○ Yes

○ No



Third referral (if applicable)

In this section, we'd like you to tell us about the referrals you attended after initially seeing a professional.

30. How did you get this referral? *

○ Referred by a professional

○ Referred, but had to insist on a referral

○ Sought appointment independently, without a referral from a professional

31. Did you go through a private or public service/provider? *

○ Private

○ Public

32. What professionals did you see at this referral (select all that apply)? *

☐ Paediatrician

☐ Health visitor

☐ Portage worker

☐ Child psychiatrist

☐ Speech therapist

☐ Audiologist

☐ Clinical psychologist

☐ Educational psychologist

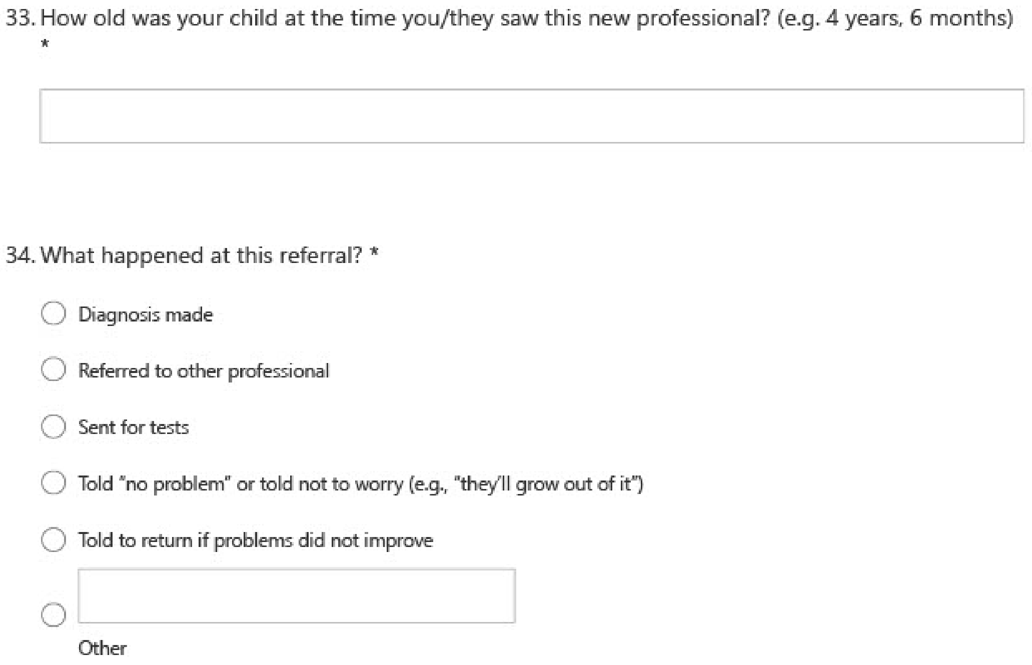
☐ Teacher

☐ Social worker

☐ Neurologist

☐ Unsure or don't know

☐ Other



33. How old was your child at the time you/they saw this new professional? (e.g. 4 years, 6 months) *

34. What happened at this referral? *

○ Diagnosis made

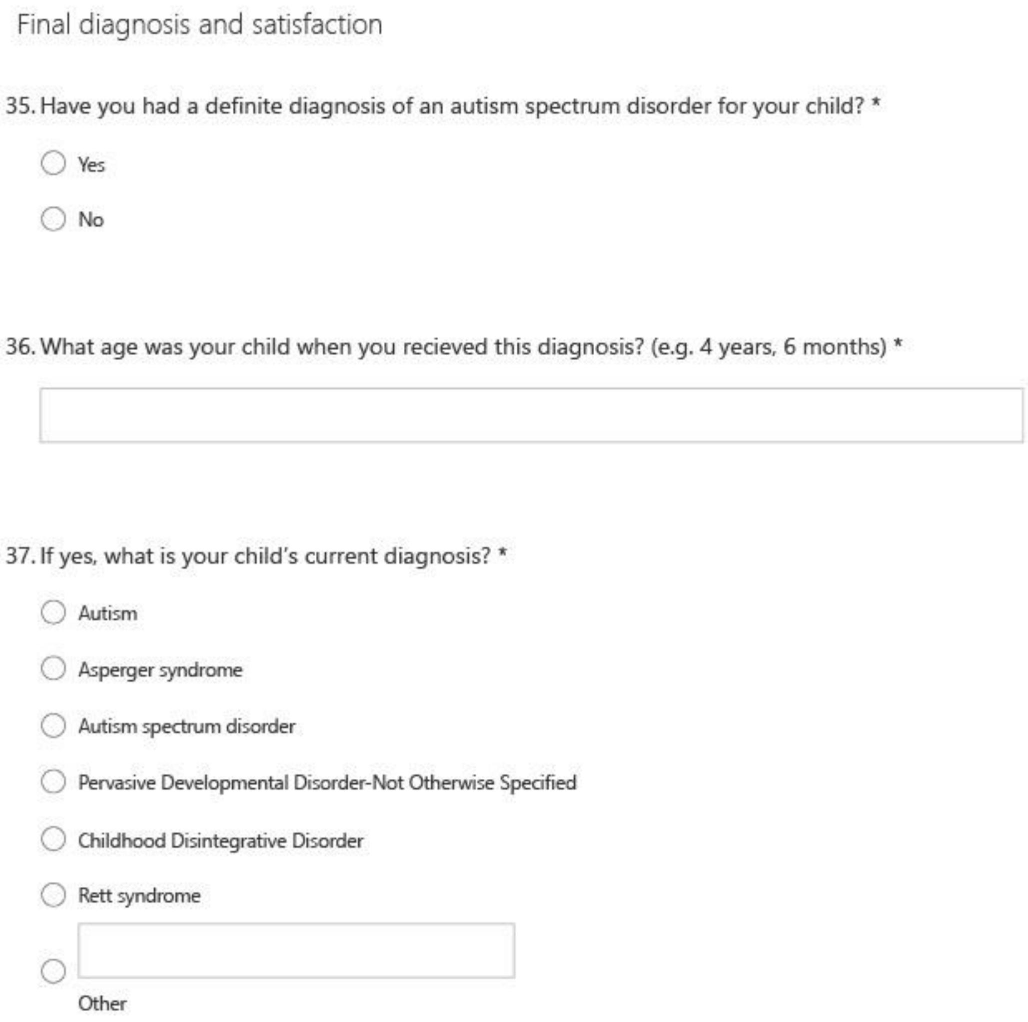
○ Referred to other professional

○ Sent for tests

○ Told "no problem" or told not to worry (e.g., "they'll grow out of it")

○ Told to return if problems did not improve

○ Other



Final diagnosis and satisfaction

35. Have you had a definite diagnosis of an autism spectrum disorder for your child? *

○ Yes

○ No

36. What age was your child when you recieved this diagnosis? (e.g. 4 years, 6 months) *

37. If yes, what is your child's current diagnosis? *

○ Autism

○ Asperger syndrome

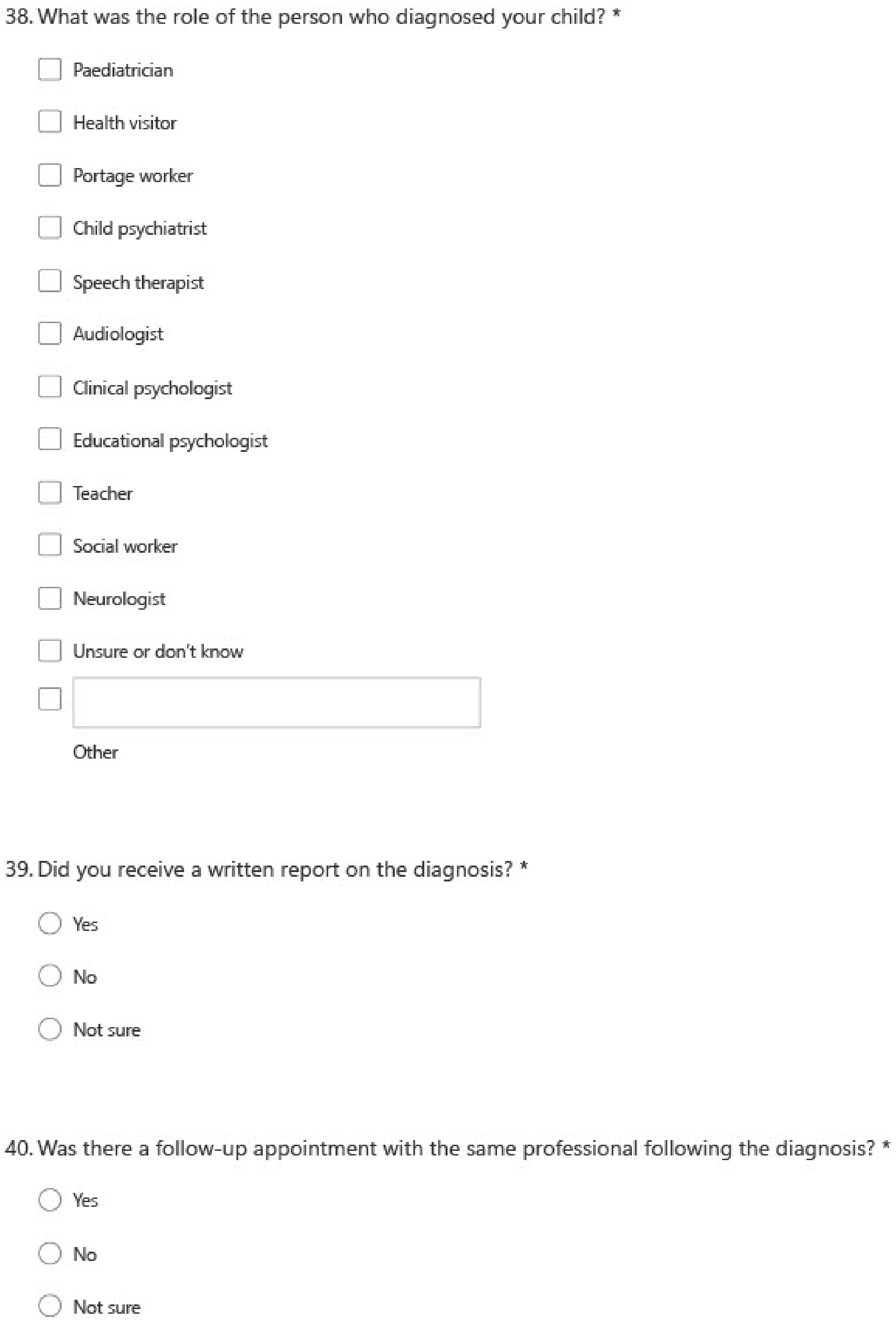
○ Autism spectrum disorder

○ Pervasive Developmental Disorder-Not Otherwise Specified

○ Childhood Disintegrative Disorder

○ Rett syndrome

○ Other



38. What was the role of the person who diagnosed your child? *

☐ Paediatrician

☐ Health visitor

☐ Portage worker

☐ Child psychiatrist

☐ Speech therapist

☐ Audiologist

☐ Clinical psychologist

☐ Educational psychologist

☐ Teacher

☐ Social worker

☐ Neurologist

☐ Unsure or don't know

☐

Other

39. Did you receive a written report on the diagnosis? *

○ Yes

○ No

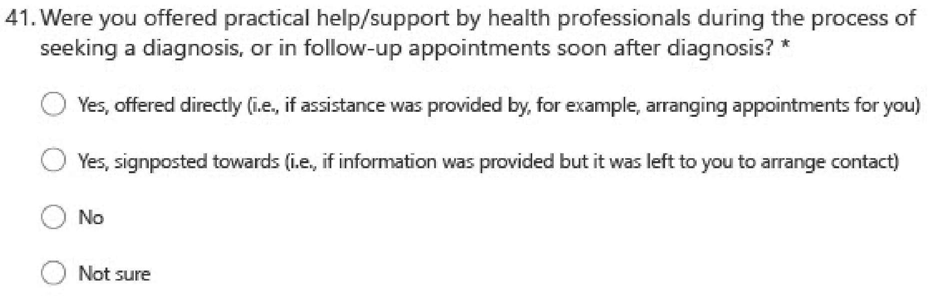
○ Not sure

40. Was there a follow-up appointment with the same professional following the diagnosis? *

○ Yes

○ No

○ Not sure



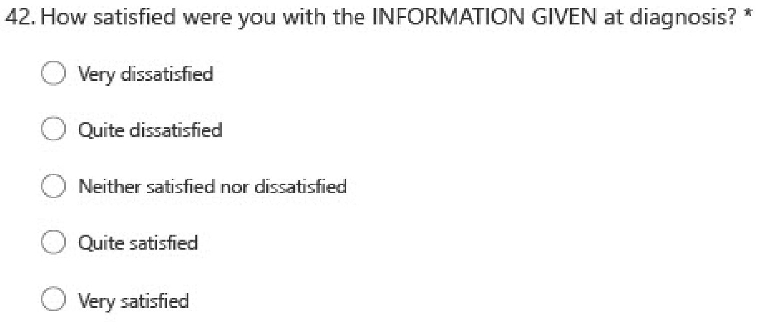
41. Were you offered practical help/support by health professionals during the process of seeking a diagnosis, or in follow-up appointments soon after diagnosis? *

○ Yes, offered directly (i.e., if assistance was provided by, for example, arranging appointments for you)

○ Yes, signposted towards (i.e., if information was provided but it was left to you to arrange contact)

○ No

○ Not sure



42. How satisfied were you with the INFORMATION GIVEN at diagnosis? *

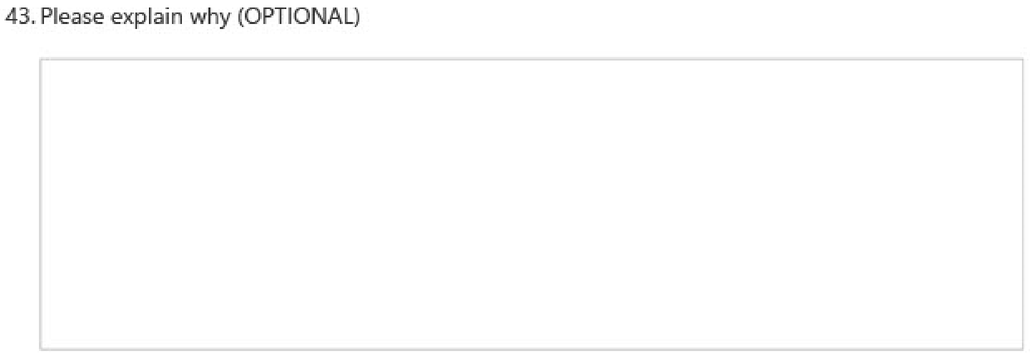
○ Very dissatisfied

○ Quite dissatisfied

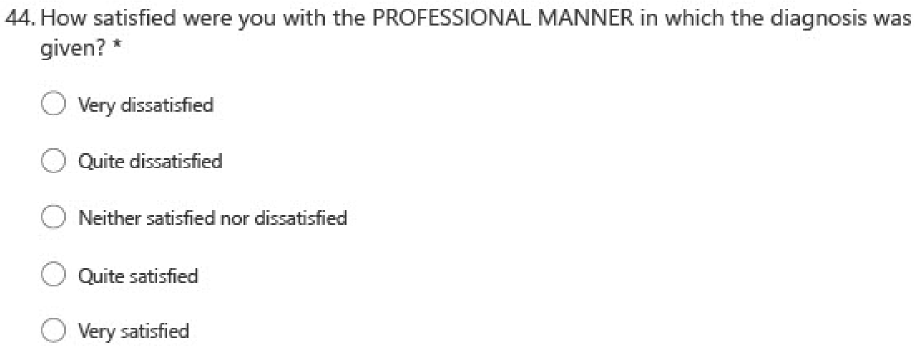
○ Neither satisfied nor dissatisfied

○ Quite satisfied

○ Very satisfied



43. Please explain why (OPTIONAL)



44. How satisfied were you with the PROFESSIONAL MANNER in which the diagnosis was given? *

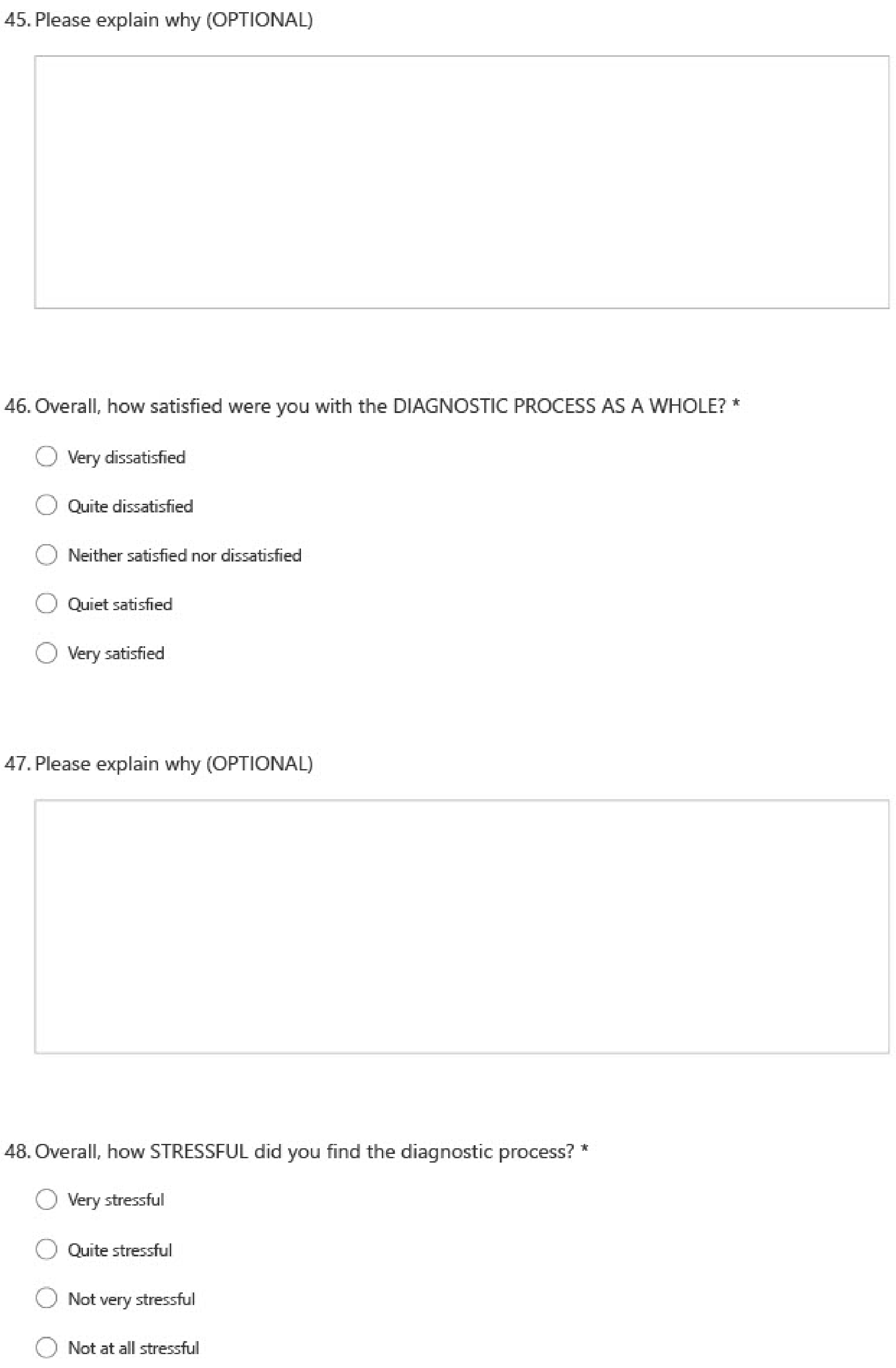
○ Very dissatisfied

○ Quite dissatisfied

○ Neither satisfied nor dissatisfied

○ Quite satisfied

○ Very satisfied



45. Please explain why (OPTIONAL)

46. Overall, how satisfied were you with the DIAGNOSTIC PROCESS AS A WHOLE? *

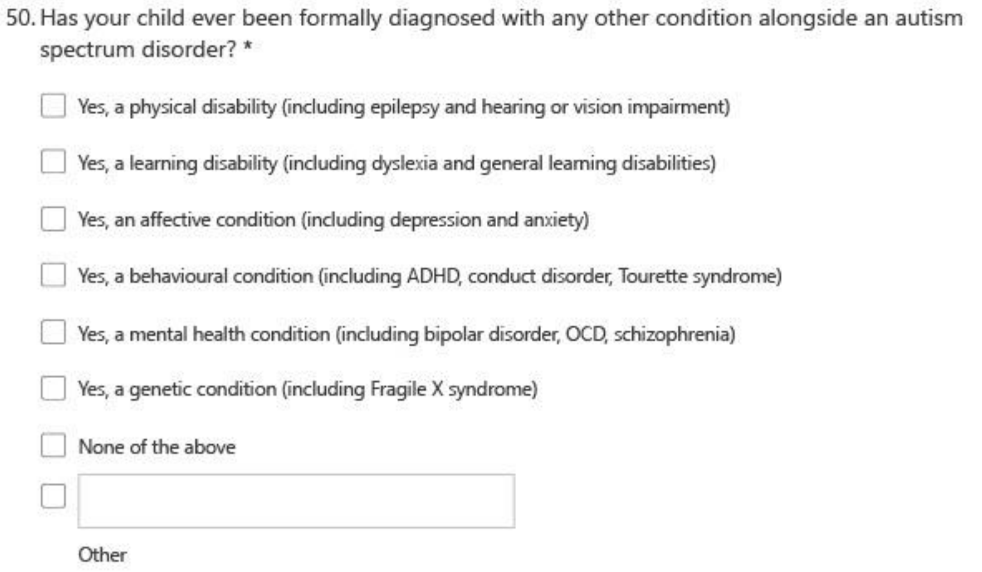
○ Very dissatisfied
○ Quite dissatisfied
○ Neither satisfied nor dissatisfied
○ Quiet satisfied
○ Very satisfied

47. Please explain why (OPTIONAL)

48. Overall, how STRESSFUL did you find the diagnostic process? *

○ Very stressful
○ Quite stressful
○ Not very stressful
○ Not at all stressful

49. Please explain why (OPTIONAL)



50. Has your child ever been formally diagnosed with any other condition alongside an autism spectrum disorder? *

☐ Yes, a physical disability (including epilepsy and hearing or vision impairment)

☐ Yes, a learning disability (including dyslexia and general learning disabilities)

☐ Yes, an affective condition (including depression and anxiety)

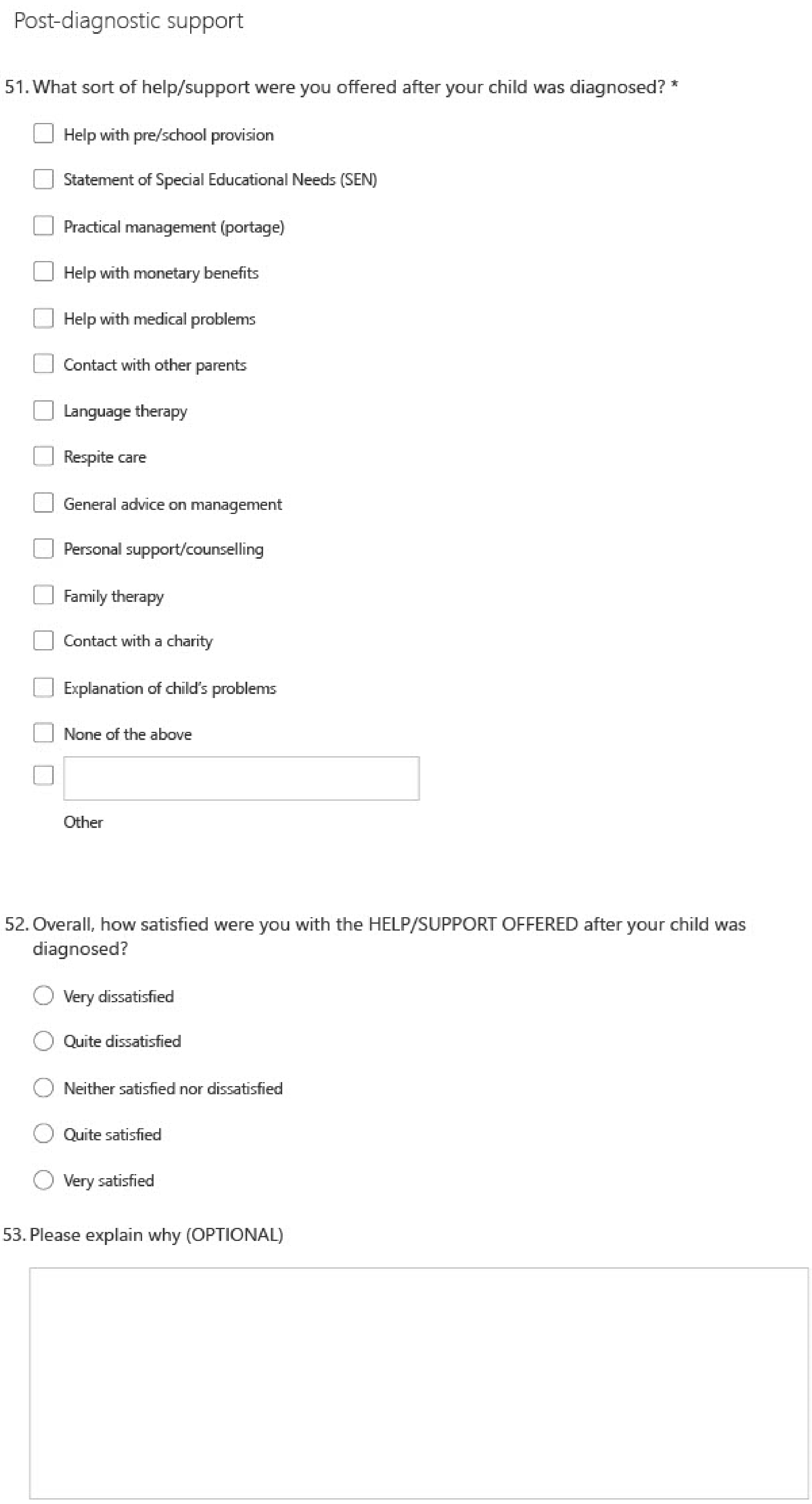
☐ Yes, a behavioural condition (including ADHD, conduct disorder, Tourette syndrome)

☐ Yes, a mental health condition (including bipolar disorder, OCD, schizophrenia)

☐ Yes, a genetic condition (including Fragile X syndrome)

☐ None of the above

☐ Other



Post-diagnostic support

51. What sort of help/support were you offered after your child was diagnosed? *

☐ Help with pre/school provision
☐ Statement of Special Educational Needs (SEN)
☐ Practical management (portage)
☐ Help with monetary benefits
☐ Help with medical problems
☐ Contact with other parents
☐ Language therapy
☐ Respite care
☐ General advice on management
☐ Personal support/counselling
☐ Family therapy
☐ Contact with a charity
☐ Explanation of child's problems
☐ None of the above
☐ Other

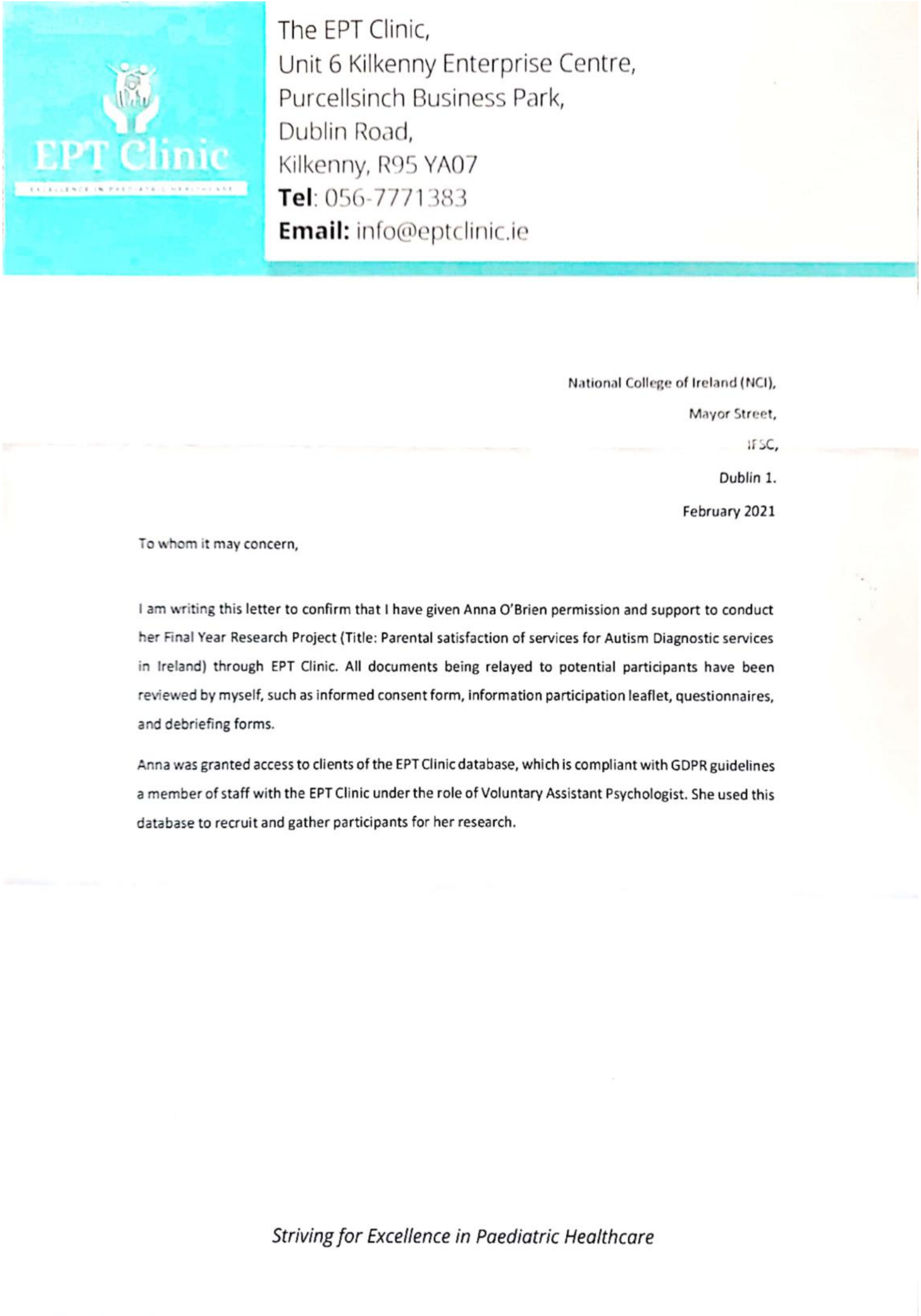
52. Overall, how satisfied were you with the HELP/SUPPORT OFFERED after your child was diagnosed?

○ Very dissatisfied
○ Quite dissatisfied
○ Neither satisfied nor dissatisfied
○ Quite satisfied
○ Very satisfied

53. Please explain why (OPTIONAL)

Appendix E

The EPT Clinic Letter of Approval



EPT Clinic

The EPT Clinic,
Unit 6 Kilkenny Enterprise Centre,
Purcellsinch Business Park,
Dublin Road,
Kilkenny, R95 YA07
Tel: 056-7771383
Email: info@eptclinic.ie

National College of Ireland (NCI),
Mayor Street,
IFSC,
Dublin 1.
February 2021

To whom it may concern,

I am writing this letter to confirm that I have given Anna O'Brien permission and support to conduct her Final Year Research Project (Title: Parental satisfaction of services for Autism Diagnostic services in Ireland) through EPT Clinic. All documents being relayed to potential participants have been reviewed by myself, such as informed consent form, information participation leaflet, questionnaires, and debriefing forms.

Anna was granted access to clients of the EPT Clinic database, which is compliant with GDPR guidelines a member of staff with the EPT Clinic under the role of Voluntary Assistant Psychologist. She used this database to recruit and gather participants for her research.

Striving for Excellence in Paediatric Healthcare

Yours sincerely,

Lorraine OB Madden 26th Feb 2021

Lorraine O.B Madden C. Psychol., Ps.S.I M6672 M.A. B. Ed.

Psych.Ad.Dip.

Clinical Director of EPT Clinic and Chartered Educational Psychologist

Chairperson of the Kilkenny/Carlow Infant Mental health Group

Committee Member of the Autism Special Interest Group, PSI

The Education, Psychology and Therapy (EPT) Clinic,
Unit 6 Kilkenny Enterprise Centre,
Purcellsinch Business Park,
Dublin Road,
Kilkenny R95 YA07
www.eptclinic.ie
Info@eptclinic.ie
056-777-1383

Appendix F

Recruitment Poster

National College of Ireland

EPT Clinic

Education Psychology and Therapy

Parents of children with Autism

We want to hear your voice!

I am a final year psychology student of the National college of Ireland and I am currently conducting research as part of my thesis on parental experiences of autism diagnostic services in Ireland.

I would love to hear the voices and experiences of as many parents as possible, every voice matters!

The questionnaire takes 8 to 15 minutes to complete and is completely anonymous to take part!

To Take part, follow the link!

For more information, contact Anna O Brien:
x18327751@student.ncirl.ie

www.eptclinic.ie

Appendix G

Table 1

Outcomes at each stage of diagnostic process.

	Diagnosis given	Referred to another professional	Asked to perform tests	Told "no problem" or told not to worry	Told to return if problems did not improve
At 1st appointment (*n*= 211)	37.4	49.8	12.8	19.9	5.2
At 2nd appointment (*n*=131)	34.1	15.2	6.6	2.8	3.3
At 3rd appointment (*n*=63)	19.4	6.6	1.4	0.5	1.9
At 4th appointment (*n*=26)	8.5	2.4	.5	0	.9

Above percentages are valid percentages for number of participants in each category.

Table 2

When seeking a further appointment or referral for their child after the initial appointment.

	Referred by a professional (%)	Referred, but had to insist on a referral (%)	Sought appointment independently, without referral (%)
When seeking 2nd appointment (*n*= 131)	59.5	22.9	17.6
When seeking 3rd appointment (*n*=63)	65.1	11.1	23.8
When seeking 4th appointment (*n*=26)	57.7	19.2	23.1

Above percentages are valid percentages for number of participants in each category.

Table 3

Group differences between Private and Public for satisfaction scores and levels of stress.

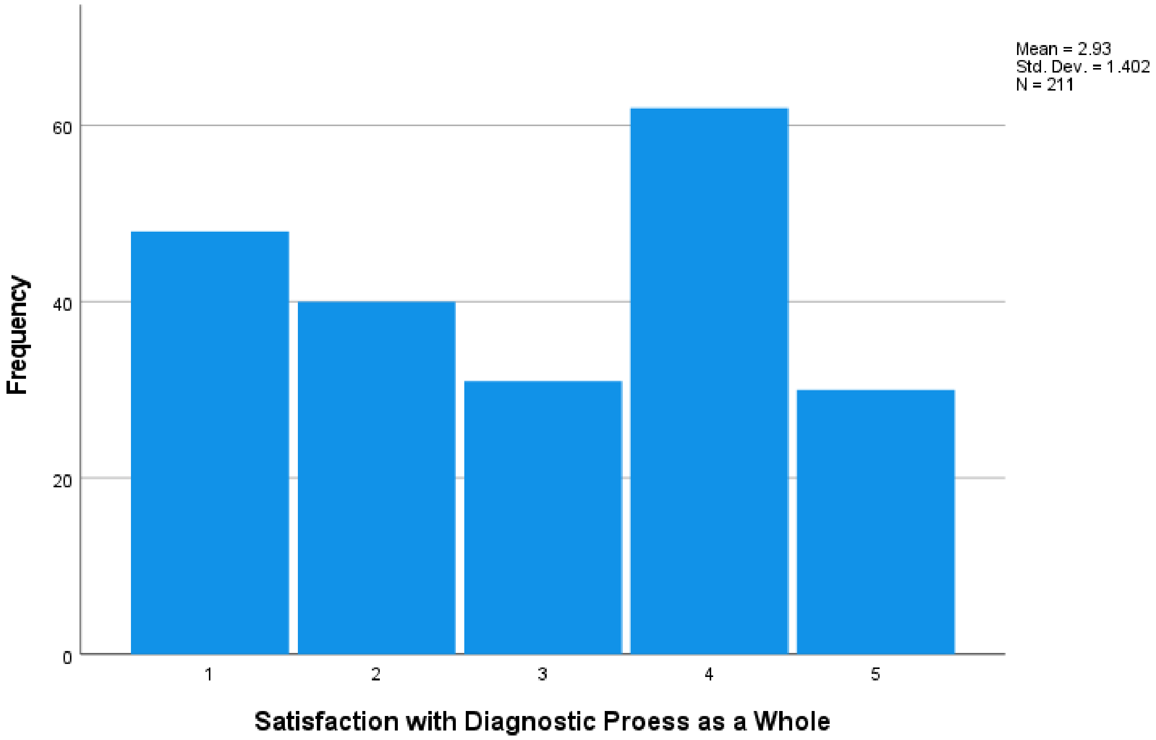
	Private			Public		
	M	*SD*	*n*	*M*	*SD*	*n*
Sat/Diagnostic process	3.28	1.47	65	2.79	1.33	113
Ratings/information given	3.31	1.36	65	2.96	1.23	113
Ratings/professional manner	3.58	1.49	65	3.44	1.35	113
Levels of stress	1.71	.81	65	1.48	.66	113
Ratings/help post-diagnosis	2.28	1.27	65	2.02	1.23	113

Note: CI = confidence interval for mean difference

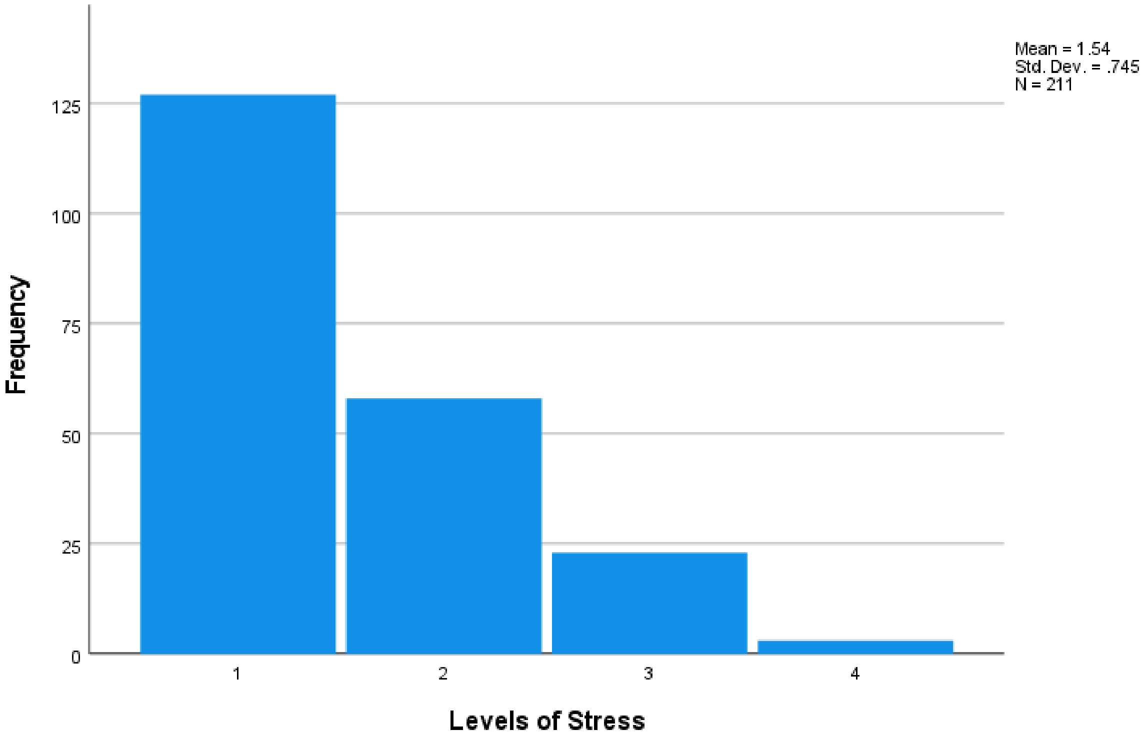
Table 4

Descriptive statistics for satisfaction and stress rating.

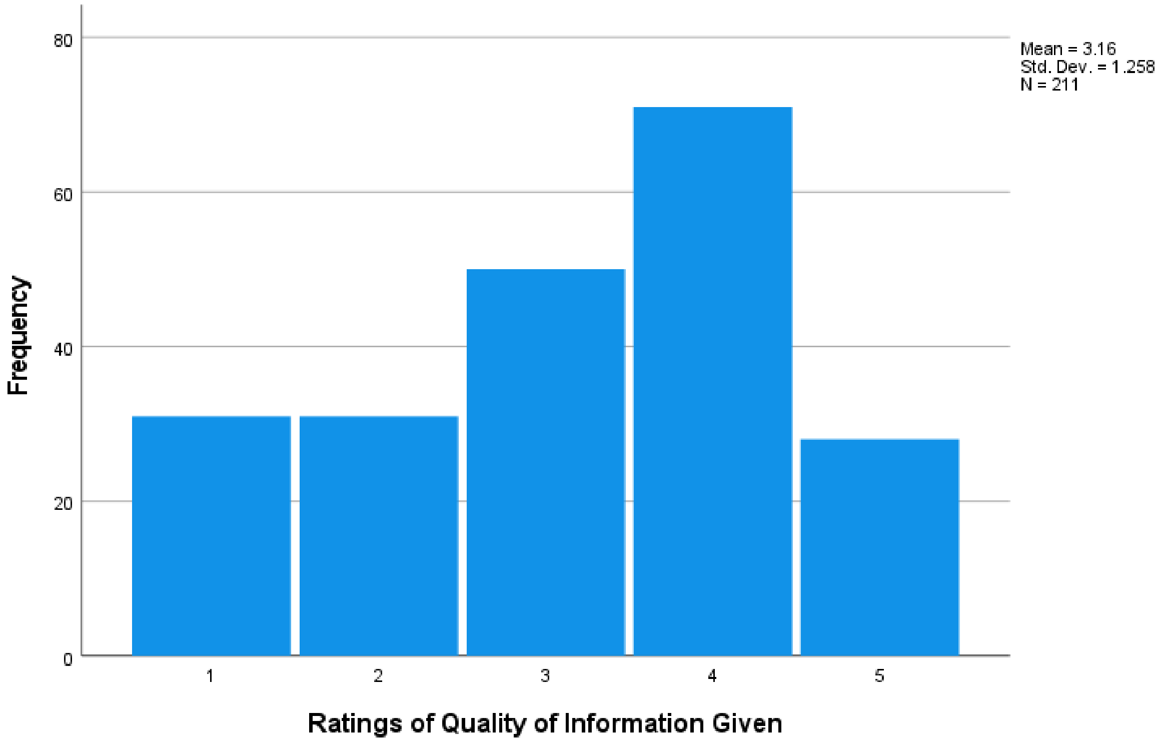
	M	*SD*	95% CI
Sat/Whole diag process	2.93	1.20	2.74, 3.12
Rating/information given	3.16	1.26	2.99, 3.33
Rating/professional manner	3.57	1.35	3.39, 3.75
Levels of stress	1.54	.75	1.43, 1.64
Rating/help post-diagnosis	2.08	1.21	1.92, 2.25



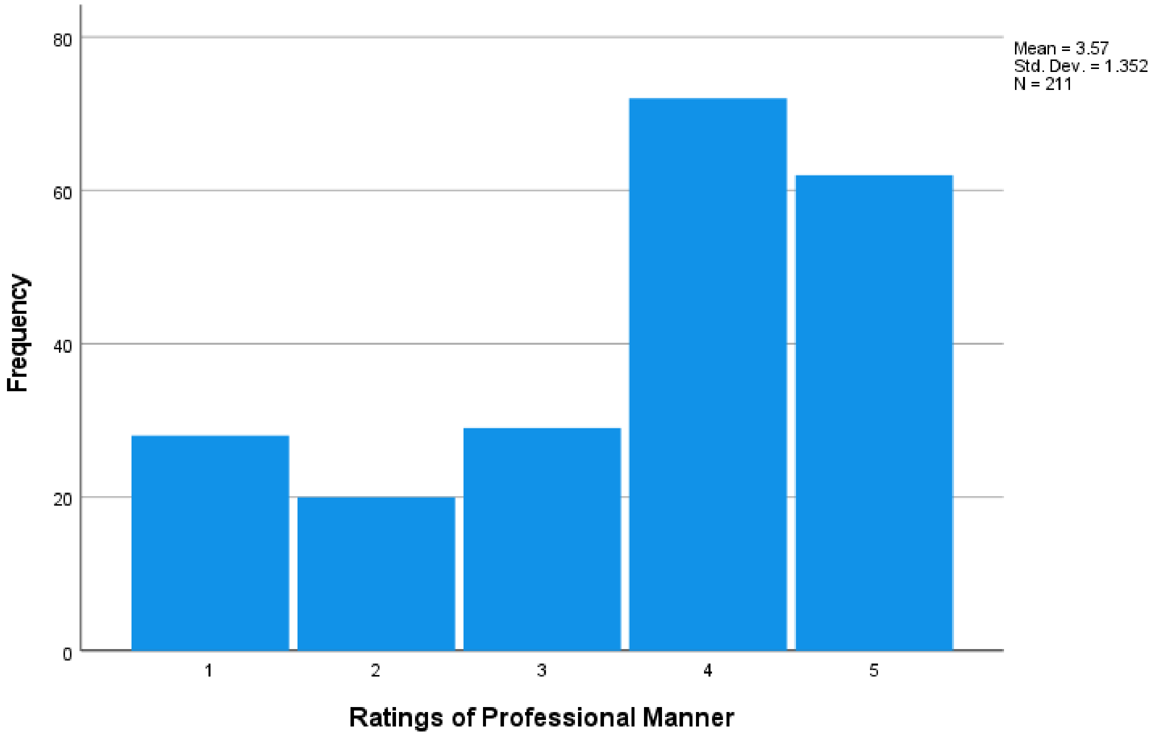
Note: 1- Very Dissatisfied, 2- Quite Dissatisfied, 3- Neither satisfied nor Dissatisfied, 4- Quite Satisfied, 5- Very Satisfied



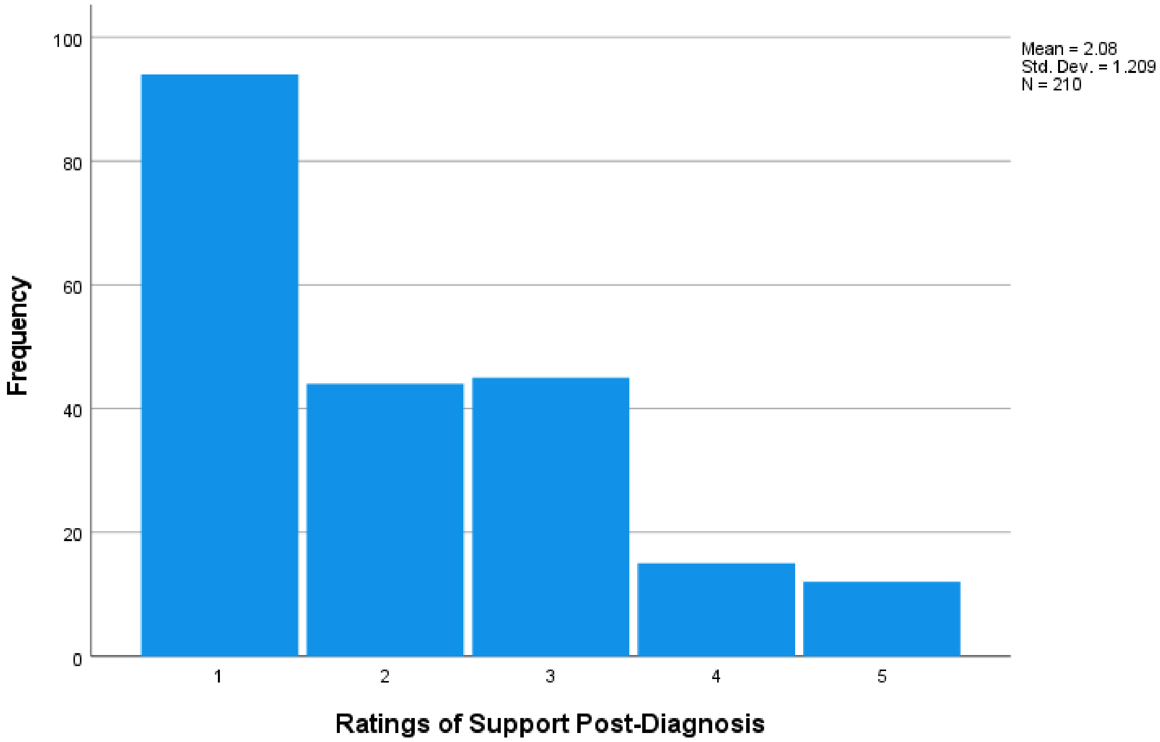
Note: 1- Very stressful, 2- Quite stressful, 3- Not very stressful, 4- Not at all stressful



Note: 1- Very Dissatisfied, 2- Quite Dissatisfied, 3- Neither satisfied nor Dissatisfied, 4- Quite Satisfied, 5- Very Satisfied



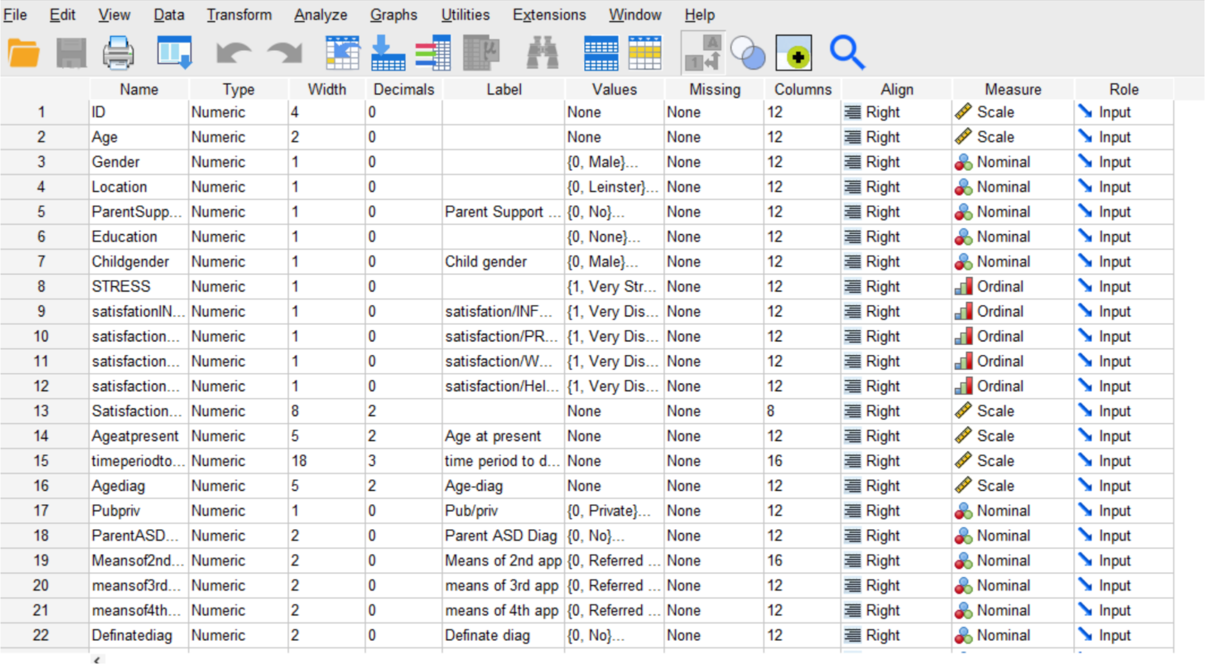
Note: 1- Very Dissatisfied, 2- Quite Dissatisfied, 3- Neither satisfied nor Dissatisfied, 4- Quite Satisfied, 5- Very Satisfied



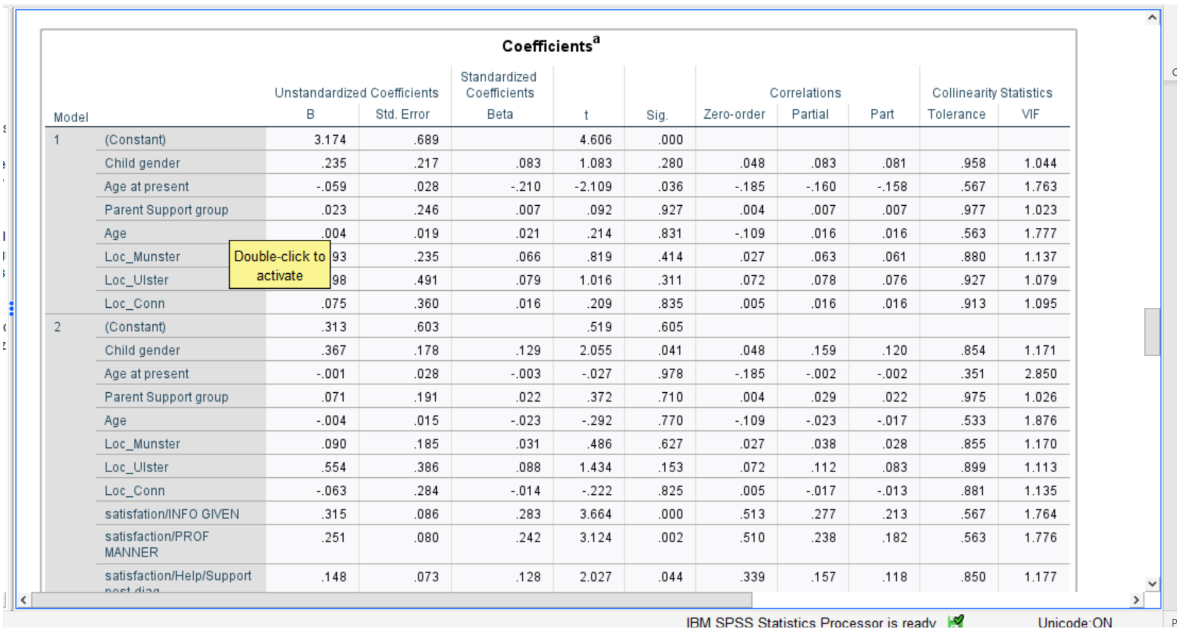
Note: 1- Very Dissatisfied, 2- Quite Dissatisfied, 3- Neither satisfied nor Dissatisfied, 4- Quite Satisfied, 5- Very Satisfied

Appendix H

Evidence of data and SPSS output



	Name	Type	Width	Decimals	Label	Values	Missing	Columns	Align	Measure	Role
1	ID	Numeric	4	0		None	None	12	Right	Scale	Input
2	Age	Numeric	2	0		None	None	12	Right	Scale	Input
3	Gender	Numeric	1	0		{0, Male}...	None	12	Right	Nominal	Input
4	Location	Numeric	1	0		{0, Leinster}...	None	12	Right	Nominal	Input
5	ParentSupp...	Numeric	1	0	Parent Support ...	{0, No}...	None	12	Right	Nominal	Input
6	Education	Numeric	1	0		{0, None}...	None	12	Right	Nominal	Input
7	Childgender	Numeric	1	0	Child gender	{0, Male}...	None	12	Right	Nominal	Input
8	STRESS	Numeric	1	0		{1, Very Str...	None	12	Right	Ordinal	Input
9	satisfationIN...	Numeric	1	0	satisfation/INF...	{1, Very Dis...	None	12	Right	Ordinal	Input
10	satisfaction...	Numeric	1	0	satisfaction/PR...	{1, Very Dis...	None	12	Right	Ordinal	Input
11	satisfaction...	Numeric	1	0	satisfaction/W...	{1, Very Dis...	None	12	Right	Ordinal	Input
12	satisfaction...	Numeric	1	0	satisfaction/Hel...	{1, Very Dis...	None	12	Right	Ordinal	Input
13	Satisfaction...	Numeric	8	2		None	None	8	Right	Scale	Input
14	Ageatpresent	Numeric	5	2	Age at present	None	None	12	Right	Scale	Input
15	timeperiodto...	Numeric	18	3	time period to d...	None	None	16	Right	Scale	Input
16	Agediag	Numeric	5	2	Age-diag	None	None	12	Right	Scale	Input
17	Pubpriv	Numeric	1	0	Pub/priv	{0, Private}...	None	12	Right	Nominal	Input
18	ParentASD...	Numeric	2	0	Parent ASD Diag	{0, No}...	None	12	Right	Nominal	Input
19	Meansof2nd...	Numeric	2	0	Means of 2nd app	{0, Referred ...	None	16	Right	Nominal	Input
20	meansof3rd...	Numeric	2	0	means of 3rd app	{0, Referred ...	None	12	Right	Nominal	Input
21	meansof4th...	Numeric	2	0	means of 4th app	{0, Referred ...	None	12	Right	Nominal	Input
22	Definatediag	Numeric	2	0	Definate diag	{0, No}...	None	12	Right	Nominal	Input



Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	t	Sig.	Correlations			Collinearity Statistics	
		B	Std. Error	Beta			Zero-order	Partial	Part	Tolerance	VIF
1	(Constant)	3.174	.689		4.606	.000					
	Child gender	.235	.217	.083	1.083	.280	.048	.083	.081	.958	1.044
	Age at present	-.059	.028	-.210	-2.109	.036	-.185	-.160	-.158	.567	1.763
	Parent Support group	.023	.246	.007	.092	.927	.004	.007	.007	.977	1.023
	Age	.004	.019	.021	.214	.831	-.109	.016	.016	.563	1.777
	Loc_Munster	93	.235	.066	.819	.414	.027	.063	.061	.880	1.137
	Loc_Ulster	98	.491	.079	1.016	.311	.072	.078	.076	.927	1.079
	Loc_Conn	.075	.360	.016	.209	.835	.005	.016	.016	.913	1.095
2	(Constant)	.313	.603		.519	.605					
	Child gender	.367	.178	.129	2.055	.041	.048	.159	.120	.854	1.171
	Age at present	-.001	.028	-.003	-.027	.978	-.185	-.002	-.002	.351	2.850
	Parent Support group	.071	.191	.022	.372	.710	.004	.029	.022	.975	1.026
	Age	-.004	.015	-.023	-.292	.770	-.109	-.023	-.017	.533	1.876
	Loc_Munster	.090	.185	.031	.486	.627	.027	.038	.028	.855	1.170
	Loc_Ulster	.554	.386	.088	1.434	.153	.072	.112	.083	.899	1.113
	Loc_Conn	-.063	.284	-.014	-.222	.825	.005	-.017	-.013	.881	1.135
	satisfation/INFO GIVEN	.315	.086	.283	3.664	.000	.513	.277	.213	.567	1.764
	satisfaction/PROF MANNER	.251	.080	.242	3.124	.002	.510	.238	.182	.563	1.776
	satisfaction/Help/Support	.148	.073	.128	2.027	.044	.339	.157	.118	.850	1.177

IBM SPSS Statistics Processor is ready

Unicode:ON