inbetweeners

The InBetweeners

Identifying and quantifying the unmet mental health needs of children and adolescents in Tallaght

Dr Elizabeth McCarthy Quinn and
Professor Catherine Comiskey

December 2019

"Like we have a year-long waiting list.
Sure it is useless! Young people need
something the day they need it. We
need 24/7 services. We need services
at weekends".

(Healthcare Professional)

CHILDHOOD DEVELOPMENT INITIATIVE CDI

TUSLA An Ghníomhaireacht um
Leanaí agus an Teaghlach
Child and Family Agency

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

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Glossary

ADD	Attention Deficit Disorder
ADHD	Attention Deficit Hyperactivity Disorder
AON	Assessment of Need
AS	Asperger's syndrome
ASD	Autism Spectrum Disorder
CAMHS	Child and Adolescent Mental Health Service
CDI	Childhood Development Initiative
CHAT	Cultural Historical Activity Theory
CHO	Community Health Office
DCYA	Department of Children and Youth Affairs
DEIS	Delivering Equality of Opportunity in Schools: national programme to address the educational needs of children and young people in disadvantaged communities
EWS/EWO	Education Welfare Service/Education Welfare Officer
GDPR	General Data Protection Regulation
GP	General Practitioner
HP	Health Professional
HSCL	Home School Community Liaison
IA	Internet Addiction
NEPS	National Educational Psychological Service
NOSP	National Office for Suicide Prevention
NVR	Non Violent Resistance
OCD	Obsessive Compulsive Disorder
PCT	Primary Care Team
PIU	Problematic Internet Use
PLE	Psychotic-Like Experiences
SCP/SPO	School Completion Programme/School Completion Officer
SPHE	Social, Personal and Health Education
TA	Thematic Analysis
YoDA	Youth Drug and Alcohol Service

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Foreword

South Dublin Children and Young Peoples Services Committee (CYPSC) is one of the longest established CYPSCs in the country, and it has a demonstrable track record in effective engagement, positive collaboration and innovative responses. Tasked with providing a forum for joint planning and coordination of activity at local authority level, CYPSC s have the very real potential for ensuring that children, young people and families receive improved and accessible services. By harnessing local expertise, listening to what's happening at community level, and fostering meaningful interagency partnership, the Committee is a central aspect of national efforts to improve outcome for children.

Youth mental health is significant issue nationally as well as within South County Dublin. There is a perception amongst both service providers and parents that many children and young people are being exposed to increasingly complex stressors and that the range of influences on their wellbeing are a growing challenge. Whether this is the case or not, we do know that services are under pressure to respond effectively, quickly and appropriately.

The Inbetweeners Report is the result of strong inter-agency working, bringing together statutory services with the community and voluntary sector, engaging with hospitals and community based providers, and offering an opportunity for a number of disciplines and services to share their collective wisdom and insights to better understand local dynamics. These processes underpin the best of CYPSPC approaches and help to strengthen the connections within the community.

As Chair of South Dublin CYPSC, I welcome this report as a further mechanism to enable us to better understand and respond to the needs of children and young people in our area, and so to collectively work to improve their outcomes.

Audrey Warren,
Chair,
South Dublin CYPSC.

Acknowledgements

Executive Summary

Despite international evidence showing that young people aged 12 to 25 years have the highest incidence and prevalence of mental illness, their access to mental health services is the lowest of all age groups. Globally, young people's mental health is of serious concern, with 20% of young people expected to experience at least one mental health disorder in any year and suicide deemed to be the third leading cause of death in young people worldwide. Within Ireland, similar rates have been observed, with 20% of young people experiencing severe emotional distress. As only a small number of these young people are in contact with an agency that can assist, there is known to be a hidden cohort of young people who are not visible to the health services. Furthermore, Ireland is known to have the fourth highest youth suicide rate in Europe.

The aim of this report was to explore the unmet mental health needs of adolescents aged from 12 to 18 years in the Tallaght region.

The objectives were:

- to use indirect statistical methods to provide a preliminary estimate of the number of young people who potentially will have difficulty accessing mental health services in the region;
- to consult with service providers on the referral processes and criteria for accessing youth mental health services from the region;
- to explore the experiences of parents of young people aged 12 to 18 years and to provide an outline profile of these young people;
- to make recommendations based on the findings.

To achieve these objectives, the research used a concurrent multiple methods design with both qualitative and quantitative approaches. The qualitative method consisted of 23 semi-structured interviews (11 parents and 12 service providers). While 11 children were the focus of the interviews, some parents had more than one child with a diagnosis. Four of the eleven children were deemed to be suicidal and had engaged in self-harm, and three of these had a diagnosis of Asperger's syndrome (AS). Two were mainly presenting with substance use and associated behavioural issues, four were suffering from anxiety, and one was suffering from severe depression. There were a total of 26 children in the 11 families potentially affected.

The quantitative method used a multiplier benchmark prevalence estimation of the number of young people in the Tallaght region at risk of mental health challenges. Benchmarks were obtained from localised census data and multipliers were obtained from national surveys. Multipliers were corroborated with additional references. Confidence intervals for the prevalence estimates were also provided. All results prior to finalisation were reviewed, discussed and validated by the full research team. Cultural Historical Activity Theory (CHAT) was used as a guiding framework for the discussion of the results described within the findings (Appendix N – Cultural Historical Activity Theory (CHAT) in the Context of This Study).

In terms of the prevalence of 12- to 18-year-olds at risk of mental health difficulties it was found that:

- the range in the estimates was from 3,552 suffering from anxiety to 550 young people suffering from severe stress;
- between 3,181 to 3,434 of 12- to 18-year-olds were estimated to have suffered from some form of depression and 804 to 958 of these experienced severe depression;

- between 3,390 and 3,654 suffered anxiety and 1,123 to 1,299 of these experienced severe anxiety;
- in terms of stress, between 1,981 and 2,201 suffered from stress and of these between 495 and 616 experienced severe stress.

In terms of the experiences of service providers and parents, two overarching themes were identified at the macro level. One of these themes could be considered structural and summarised as challenges with pathways into services. The other could be considered environmental and summarised as cultural challenges.

Within the challenges to pathways, three lower level or meso themes were found:

1. **Diagnosis not being a gateway to services.** Within this finding, both service providers and parents noted that an assessment of need (AON) did not necessarily lead to a subsequent service. Both also noted that an indication of self-harming was more likely to result in services being provided. Often children received support by proxy, as the supports engaged with parents rather than children.

2. **An uncertain first port of call.** Both service providers and parents expressed a lack of knowledge of services available. Both also highlighted the public versus private healthcare access debate. Parents spoke of doing their own research on services and professionals working in the services. They also spoke of the need for a drop-in service that would be known by and available to all.

3. **School as a gateway.** Both parents and professionals spoke of school as a gateway, and specifically 'refusal to attend school' as a gateway for additional and targeted services.

Within the cultural challenges, three lower level or meso themes were found. These were:

4. **Family, culture and community.** Both parents and health professionals highlighted the influence on the service access process of family, peers, fear and stigma. Both spoke of the impact on the family of intergenerational trauma and disability. Parents in addition spoke of the impact on other immediate family members and of fear of their own child.

5. **New emerging issues.** Both parents and professionals spoke of challenges with social media, social anxieties and waiting lists. Professionals spoke of challenges with homelessness and ethnic minorities.

6. **Service quality and availability.** Both parents and professionals spoke of the medicalised model; the location of services; the need for quality and training in counselling; services having a youth focus; resourcing; professionalism of staff; impacts on parents; and costs to the family.

Recommendations

Recommendations can be summarised into four main areas: resources, communication, models of intervention, and research.

Resources

Given that the average overall estimates of the numbers suffering from depression, anxiety or stress in the Tallaght area was 1,486 individuals, and the likelihood of these being underestimated, it would be prudent for planning purposes to plan services for the mental health needs of approximately 1,500 to 2,000 young people. The HSE needs to consider the quantum and diversity of required services to meet the needs of the anticipated number of young people in the Tallaght area whose mental health needs are not currently being met. Service planning needs to include the expansion of existing services that are working well and the development of a new model of intervention to address current gaps.

This calculation of required service provision should be replicated at a national level in order to determine the quantity of services required to meet the mental health needs of all young people.

Waiting lists should be reduced or eliminated: a maximum waiting list time for someone who appears to meet the criteria for a mental health assessment should be two weeks. This will require a 'triage' system. This triage system needs to be able to effectively access a range of local services and refer young people and their carers to these services. Services for young people who are homeless need to be targeted at these young people and located in appropriate settings that enable engagement.

Communication

CAHMS services should have clear, consistent, and transparent referral criteria.

Engagement between CAHMS and other professionals should be collaborative in order to maximise better outcomes for young people.

All health professionals should have access to comprehensive, up-to-date information on local service provision, referral pathways and delivery. Ideally, the local Children and Young Peoples Services Committee (CYPSC) will support this process.

The Joint Protocol for Interagency Collaboration between the HSE and Tusla, which was finalised in 2017, should be implemented in full, including an appropriate monitoring and standards process.

Given the confusion experienced by both health professionals and parents in relation to the pathway into services, a single drop-in, one-stop, 24-hour shop/service would be of benefit to the whole community. This would be a local centre/focus for expertise on challenges experienced, including challenges around referral pathways. It would include options for emerging challenges such as homelessness. This could be located in an existing hospital service but needs to be part of the wider community in terms of its stakeholders and governance. Interventions and processes to enable access, and support families and young people should be designed, initiated, and evaluated on a pilot basis using an implementation science approach.

Models of intervention

This report indicates that while there is effective work happening with some young people experiencing mental health issues, many more of them are isolated. There is a need to identify proven models to address the service gaps and/or develop new approaches and service delivery mechanisms. Crucial aspects will include accessibility, early intervention, ability to quickly assess and refer young people, and the provision of supports for family members.

There are a number of recommendations relating to the enhancement of schools as a gateway for mental health needs for children:

The adoption of universal support that is integrated into schools and community systems could assist in reaching young people who may be reluctant to seek individual assistance. This would also assist in normalising and naming emotions and feelings that all humans experience in life.

The range of mental health promoting programmes and activities should be continued, with an aligned monitoring and evaluation strategy.

Counselling services should be provided in venues which minimise stigma, maximise early intervention, reduce the amount of time out of school for those attending specialist services, and keep costs at a minimum. The provision of resources for counselling services in schools where children are already attending would assist parents who might struggle to pay for private services if their child required this.

The above two recommendations of Universal Support and Counselling could be integrated into, and take advantage of, the new school wellbeing strategy.

Parents attending services which they perceived to be youth-focused and representative of a whole family holistic model similar to Jigsaw highlighted a preference for such services over those underpinned by a 'medical model'.

There is a need to identify effective models of children's mental health services for this cohort of 12- to 18-year-olds, but particularly 16- to 18-year-olds.

Young people who are disengaged from school and other services need outreach supports from mental health professionals.

There needs to be greater clarity on the age of informed consent in relation to the 16- to 18-year-old cohort. Healthcare professionals differed in their understanding and interpretation of the age of informed consent.

Research

Ethics approval processes need to be streamlined to make it easier for researchers to carry out research on children and young people more effectively and in a shorter time frame. A central committee that would cover the health services generally with universal standards, forms and requirements is needed rather than individual research ethics committees with different formats and systems.

The National Research Ethics Committees legislation should progress and be enacted, with expansion to include all social research.

Further research is required to identify existing models of intervention that could be replicated in Tallaght and other parts of Ireland to address the unmet needs of young people and to effectively support their families. Future research should engage directly with young people to ensure that their experiences and insights inform the development of policy and practice.

Research should be undertaken to identify the mental health needs of children aged under 12 years of age.

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Chapter 1

Chapter 1

1.1 Introduction

Despite international evidence showing that young people aged 12 to 25 years have the highest incidence and prevalence of mental illness, their access to mental health services is the lowest of all age groups (McGorry et al., 2013). The current provision of mental healthcare for young people is considered inadequate to meet the unique developmental and cultural needs of young people, and youth-focused, evidence-based mental healthcare that is accessible and acceptable to young people is urgently needed (McGorry et al., 2013).

Globally, young people's mental health is of serious concern, with 20% of young people expected to experience at least one mental health disorder in any year and suicide deemed to be the third leading cause of death in young people worldwide (Byrne et al., 2015). A report by the United Nations Children's Fund (UNICEF) notes that suicide rates for 15- to 19-year-olds, both male and female, account for 17.6% of all deaths in 37 countries of the Organisation for Economic Co-operation and Development (OECD) and the European Union (EU). Ireland was joint fourth highest, along with Chile, at 10.3%, with the country average being 6.1% (UNICEF, 2017, p. 22). The majority of countries surveyed had an increase in self-reports of mental health issues by adolescents between 2010 and 2014, with a quarter of adolescents experiencing two or more psychological symptoms at least twice weekly (UNICEF, 2017).

With about 20% of young people in Ireland experiencing severe emotional distress and only a small number in contact with an agency that can assist, it is apparent that there is a hidden cohort of young people who are not visible to the health services (Dooley and Fitzgerald, 2012).

It is also recognised that poverty increases the incidence and severity of mental health difficulties (Samaritans, 2017). Therefore, the proportions noted above are very likely to significantly underestimate the prevalence of mental health difficulties in a community with high levels of disadvantage, such as Tallaght.

In 1992 the Irish government ratified Article 24 of the UN Convention on the Rights of the Child which states that:

> *The State shall recognise the rights of a child to the enjoyment of the highest attainable standard of health and to facilities for the treatment and rehabilitation of health, and shall strive to ensure that no child is deprived of his or her right of access to such health care services. (UNHRC, 1989)*

In addressing Article 24, the Mental Health Act (Government of Ireland, 2001) extended the age of childhood to 18 and addressed specific issues relating to severe mental illness and involuntary admission for children. The issues of age, competency and autonomy are ambiguous for the 16- to 18-year age group, and the National Consent Policy (HSE, 2013) acknowledges that the legal position is unclear in relation to 16- and 17-year-olds giving consent to treatment without parental/legal guardian consent.

According to the National Model of Care for Paediatric Healthcare Services in Ireland (RCPI, 2015), paediatric emergency departments are intended for children under 16 years, while 16- to 18-year-olds are required to attend adult general hospitals, where it is acknowledged there is little or no child psychiatry cover. This child psychiatry cover has also been identified as urgently required in the Health Service

Executive (HSE) Community Health Office (CHO7), which includes the Tallaght area (Children's Health Ireland, 2019).

The issue of mental health provision for young people with learning disabilities was addressed by the College of Psychiatrists of Ireland in its Position Paper on Mental Health Provision for Children with a Learning Disability (College of Psychiatrists of Ireland, 2011). That paper provided a rationale for a separate service for children experiencing disorders such as Attention Deficit Hyperactivity Disorder (ADHD), Autism Spectrum Disorder (ASD) with associated mental illness, Tourette syndrome and behavioural phenotypes (Lesch-Nyhan syndrome, Prader-Willi syndrome), along with pre-term or very ill babies at risk of attachment disorders (RCPI, 2015; College of Psychiatrists of Ireland, 2011). The paper also acknowledged that young people with multiple issues require lengthier assessment and a high degree of interagency collaboration than appears to be happening in reality (RCPI, 2015; College of Psychiatrists of Ireland, 2011).

The World Health Organisation (WHO) (2003) document on caring for young people with mental disorders warns that the safety and productivity of societies may be reduced by the current lack of attention to the needs of these young people, which may lead to long-term consequences. In Ireland 74% of 26-year-olds with mental illness reported experiencing issues prior to age 18, and 50% of this group experienced mental health difficulties prior to age 15 (RCPI, 2015).

A Vision for Change, the Report of the Expert Group on Mental Health Policy (Government of Ireland, 2006) was a response to growing concern about the high rates of suicide and self-harm among young people, along with antisocial behaviour, school absence and substance misuse (McGorry et al., 2013). A Vision for Change recommends that 'all individuals should have access to a comprehensive range of interventions and care for disorders that do not require specialist mental health services' (Government of Ireland, 2006, p. 61). The government has provided ring-fenced additional funding to the Health Service Executive (HSE) for mental health in line with the Programme for Government commitments, and a new HSE Mental Health Directorate was established in 2013, with full financial and operational responsibility for the delivery of A Vision for Change (Government of Ireland, 2006).

Deputy Jim Daly, Minister of State at the Department of Health with special responsibility for Mental Health and Older People, stated that the Report on Children's Mental Health Services showed a 'need for better transition arrangements for those leaving CAMHS [Child and Adolescent Mental Health Service] and the need to promote more seamless care for those aged 18 to 25 into adult services'. However, while about 18,000 CAMHS referrals are expected in 2019 – an increase from 12,800 in 2011 – short-term initiatives to reduce these are not being implemented, and long-term solutions are being prioritised (Houses of the Oireachtas, 2019).

The National Model of Care for Paediatric Healthcare Services in Ireland outlines the mental healthcare provision for children, acknowledging that 2% of children will require specialist mental health expertise at any one time (RCPI, 2015). It details a comprehensive model of mental health service provision for Ireland: a framework for building and fostering positive mental health across the entire community and for providing accessible, community-based, specialist services for people with mental illness.

The current service provision for children's mental health includes health promotion and early intervention programmes, primary and community care services, and specialist services for serious mental health issues (RCPI, 2015).

1.1 1 Health promotion/early intervention

Prevention and early intervention is an important aspect of any strategy to improve the mental health of our young people, and there are a multitude of approaches, programmes and supports in place to enable this.

Schools are largely deemed to be the main focal point for promoting positive mental health among children and young people, often looking to integrate anti-bullying measures as a key element for 5- to 12-year-olds in particular. Adolescents receive the Mental Health Matters programme as a stand-alone programme or in conjunction with the Social, Personal and Health Education (SPHE) curriculum (RCPI, 2015). More recently, the Wellbeing Policy Statement and Framework for Practice 2018–2023 (DES, 2018) acknowledges the vital role both schools and centres for education play in the promotion of wellbeing and supporting all aspects of a young person's development. This framework acknowledges that wellbeing is not just the absence of stress or mental health difficulties, but involves developing and nurturing the skills needed to negotiate the different stages of life in the context of the definition (WHO, 2001):

> *Wellbeing is present when a person realises their potential, is resilient in dealing with the normal stresses of their life, takes care of their physical wellbeing and has a sense of purpose, connection and belonging to a wider community. It is a fluid way of being and needs nurturing throughout life. (DES, 2018, p. 10; WHO, 2001)*

1.1.2 Primary and community care services and specialist services

Prevention and early intervention approaches are not always sufficient, and we know that a significant cohort of young people experience difficulties so significant that they need targeted and tailored supports, up to and including specialist therapeutic services. The range of services available is illustrated in Figure 1 below.

Figure 1: Model of child and adolescent mental health services (RCSI, 2015)
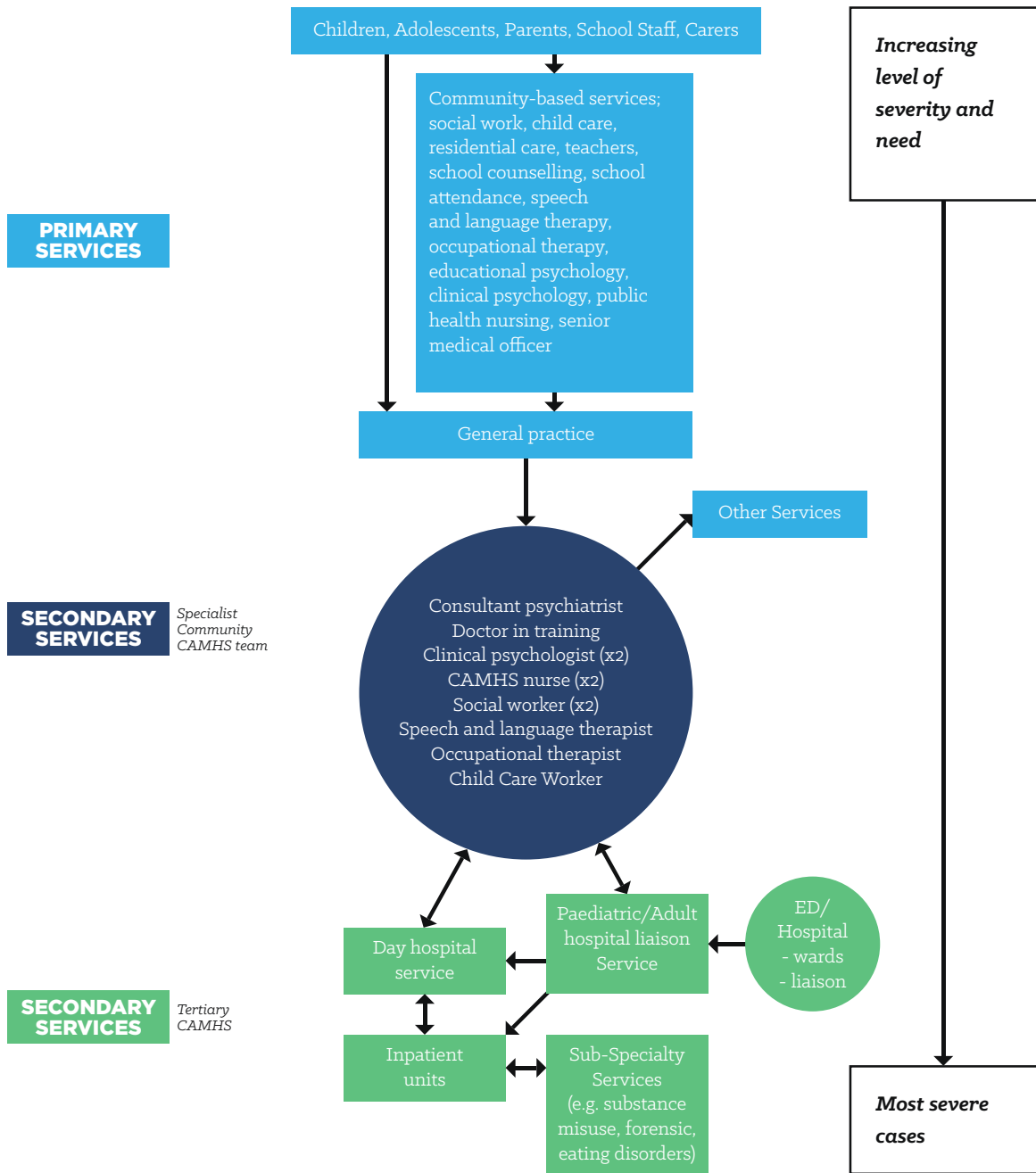
The multifaceted nature of these services can result in them being experienced as inaccessible, complicated and confusing, as suggested in Figure 2 below.

Figure 2: Agencies recommended for referral for the predominant difficulty presenting (RCSI, 2015, Figure 13.3, p. 6)
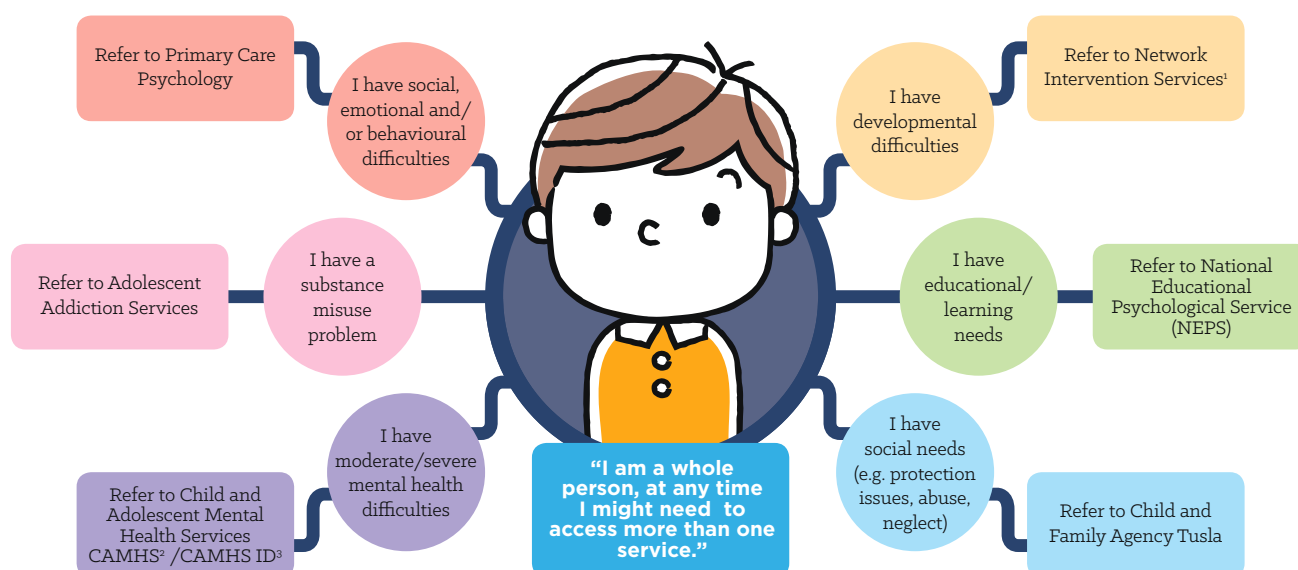
Guidelines for GPs and primary care teams are to refer young people with social, emotional, behavioural and developmental difficulties to the agency best suited to respond to the predominant difficulty (RCPI, 2015). However, as Figure 2 highlights, the young person is a whole person and cannot be divided into distinct parts. They may have difficulties that interact with and are affected by other difficulties and therefore require an interagency and multidisciplinary approach. In 2019 key performance indicators (KPIs) were set for child/adolescent referrals in the mental health services (Appendix 3, MH43) (HSE, 2019f). A draft report, the Children's Health Ireland Delivery Plan 2019, outlines the vision to have healthier children and young people throughout Ireland through a commitment to:

> *Promote and provide child-centred, research-led and learning-informed healthcare, to the highest standards of safety and excellence, in partnership with each other, with children, young people and their families through a network of children's services in Ireland.*
> *(Children's Health Ireland, 2019, p. 2)*

This plan reiterates the need to make urgent progress with an integrated healthcare system as part of the National Paediatric Model outlined above (Children's Health Ireland, 2019). One of the key observations in this report relates to the number of young people with mental health issues being 'inappropriately cared for in the acute hospital setting' (Children's Health Ireland, 2019, p. 7).

An Irish review of the evidence has found that psychotherapy, either alone or in combination with other treatments/support, is effective for a wide range of mental health diagnoses in adults, young people and children (Martin et al., 2006).

1.2 Aims/objectives

This study aims to better understand and estimate the unmet mental health needs of children and adolescents in Tallaght. A number of organisations with commitments to and responsibilities for healthcare provision throughout Tallaght have come together to maximise the utilisation of resources, expertise and local knowledge through a collaborative process. Changes in the national model of paediatric care, facility

developments and established relationships all contribute to a unique and potentially powerful synergy, which the partners are anxious to explore.

Aim:

The aim of this report was to explore and estimate the unmet mental health needs of adolescents aged from 12 to 18 years in the Tallaght region.

Objectives:

- to use indirect statistical methods to provide a preliminary estimate of the number of young people who potentially will have difficulty accessing mental health services in the region
- to consult with service providers on the referral processes and criteria for accessing youth mental health services from the region
- to explore the experiences of parents of young people aged 12 to 18 years who have chronic mental health issues and to provide an outline profile of these young people
- to make recommendations based on the findings

1.3 Service providers referred to in this study

The following provides a brief description of each of the services that participated in this research or were referred to in the interviews.

Child and Adolescent Mental Health Service (CAMHS)

Child and Adolescent Mental Health Services (CAMHS) is a specialist service, delivered through a multidisciplinary team, for people under the age of 18 with mental health difficulties. These difficulties may include severe depression, anxiety, eating disorders, psychosis and ADHD. Signs of mental health difficulty may be evident through persistent feelings of sadness, worry, stress, concentration issues or self-harm. Referrals are made to CAMHS primarily by GPs, but also other health professionals such as public health nurses, social workers, speech and language therapists or educational psychologists (HSE, 2019b).

Some CAHMS are delivered directly by the HSE. Others are funded by the HSE and delivered by not-for-profit organisations. They can vary in their referral processes and approaches.

CAMHS – Linn Dara

Linn Dara is a CAMHS inpatient unit in Cherry Orchard for young people aged under 18 who are struggling with their mental health, have become isolated, or are finding it difficult to cope with everyday life. Linn Dara is set up to be a supportive, structured and therapeutic environment and addresses mental health difficulties such as anxiety, depression, psychosis or eating difficulties, or where the young person is struggling but doesn't know what the problem is (HSE, 2019d).

Child Psychology Service

The Child Primary Care Psychology service operating within the HSE provides for children aged 0 to 18 years and their families in the Dublin south area, with referrals for teenagers made to the Teen Counselling service if considered appropriate. Some of the reasons include thinking, learning, behaviour and relationship difficulties; social skills and emotional issues; trauma; and issues with toileting, sleeping and food. However,

according to the HSE, children who are either attending or eligible for a specialist service such as CAMHS are not considered suitable for referral. This is where young people may fall between the cracks and do not have any services (HSE, 2019c).

The Child Primary Care Psychology service website provides information on the services available in Tallaght (HSE, 2019g). While there are several counselling services mentioned, only one specifically refers to counselling for young people. The online link is for a 'low-cost' counselling service (My Mind) for all age groups, with fees from €20. Another link needs to be selected on face-to-face counselling, which then informs the reader that the full rate of €50 applies to child and adolescent sessions. Locating this information does not appear to be an easy process, and the low-cost rate may still be prohibitive. The Village Counselling teen service is not referred to, and the information on the Jobstown Family Centre was also difficult to obtain (HSE, 2019g).

Counselling in Primary Care

Counselling in Primary Care (CIPC) is a short-term counselling service providing up to eight counselling sessions with professionally qualified and accredited counsellors or therapists. It is considered suitable for people with mild to moderate psychological difficulties such as depression, anxiety, panic reactions, relationship problems, loss issues and stress. However, it is intended for people aged 18 years and over who have a medical card, and is, therefore, not suitable for the young people aged 12 to 18 years in this study.

Department of Children and Youth Affairs (DCYA)

The Department of Children and Youth Affairs (DCYA) is a dedicated department that consolidates key areas of policy and services for children, young people and their families and includes a remit for Tusla and the Office of the Ombudsman for Children (DCYA, 2019a). The report Better Outcomes, Brighter Futures: the national policy framework for children and young people, 2014–2020 provides the means to inform the DCYA's work in implementing policies that are evidence-based (DCYA, 2019b). This policy document, published in 2014, 'seeks to ensure that no young person falls through the cracks because of fragmented services' (DCYA, 2014, p. xi). Children and Young People's Services Committees (CYPSCs) have been created at county level across Ireland as part of 'interagency working' (CYPSC, 2019; DCYA, 2019a). Interagency working is defined as more than one agency working together in a structured and formal way, although Statham (2011) maintains that in Ireland committees have adopted a 'collaborative' way of working, where services address gaps, duplication and overlaps in services to achieve common outcomes.

Foróige

Foróige is the leading youth organisation in Ireland working with young people aged 10 to 18 years. It operates in each county in Ireland and works closely with the DCYA. There are volunteer-led clubs and staff-led projects, youth cafés and targeted services such as Teen Parent support, Neighbourhood Youth, and Garda Youth Diversion projects. It includes children and young people in decision-making processes and in providing support, information and training to staff in other organisations (DCYA, 2015b).

General practitioners (GPs)

GPs are the 'gatekeepers' of mental health services and are often the only health professionals involved in managing a wide range of mental health problems, with medication being the usual treatment. GPs and their patients express the desire for other treatments such as psychological therapies instead of or in

conjunction with medication (Government of Ireland, 2006). However, while GPs are deemed to be the first point of care in the Irish healthcare system for accessing mental health services and a primary source of help according to young people, fewer than 20% of young people with mental health difficulties access GP services (Byrne et al., 2015).

While the role of GPs in the area of mental health is to detect and treat mental health issues, they may wish to refer on to other agencies. However, specialist, multidisciplinary assessment and treatment for children and adolescents is either scarce or not available, leaving GPs and patients frustrated (Government of Ireland, 2006). A Vision for Change recommended a single point of entry for mental health services for all (Government of Ireland, 2006), but this has not yet occurred. In the meantime, most GPs in Ireland have not had specific training in mental health (68%), and any training that has been provided has been limited to specialist mental health services, which do not cover the mental health issues and social issues generally experienced in primary care situations (Government of Ireland, 2006).

Human Givens approach

The Human Givens approach to counselling and psychotherapy uses tested techniques and approaches from a variety of associated disciplines. It is a brief, solution-focused psychotherapy based on a strengths model, drawing from person-centred counselling, motivational interviewing, cognitive behavioural therapy, psycho-educational approaches, interpersonal therapy, imaginal exposure and hypnotherapy (https://amarach.com/news-blog-articles/mental-health-and-wellbeing.html).

The underlying philosophy or premise is that everyone has emotional needs. When these needs are met, mental wellness is achieved. Each person has innate psychological needs and mental resources called 'givens' that can be utilised. Therapy focuses on understanding the issue, identifying resources, and supporting the client to use their resources more effectively (https://health.gov.ie/wp-content/uploads/2017/05/26-The-Human-Givens-Institute.pdf).

In Ireland the South-East Health Service Executive (HSE) adopted the Human Givens approach in 2012, integrating the programme into nursing, addiction counselling, palliative care and psychology services training.

Jigsaw

Jigsaw is an early intervention support service for young people aged 12 to 25 years with mental health concerns. Young people can self-refer to Jigsaw and seek mental health support or advice for another young person they are concerned about. Parents or guardians, health professionals, or any concerned adult may also refer. Jigsaw, according to their website, is not a crisis service and deals with low to moderate levels of mental health difficulty (National Centre for Youth Mental Health, 2019). Jigsaw also delivers workshops to young people and adults supporting young people, to give them the skills and confidence they need to support youth mental health in their community. All Jigsaw clinical staff are qualified mental health professionals.

National Educational Psychological Service (NEPS)

Psychologists in the National Educational Psychological Service (NEPS) are assigned to a group of schools at both primary and post-primary level, offering a range of services aimed at meeting the needs of students in relation to learning, behaviour and social and emotional development (DES, 2019a). The service uses

a consultative model, focusing on empowering teachers to effectively intervene with young people. Psychologists only become directly involved when intensive interventions are required for individual children (DES, 2019b).

Pieta House

Pieta House provides a freely accessible and professional service to people experiencing suicidal ideation or engaging in self-harm. It also runs Suicide Bereavement Counselling centres, providing free counselling, therapy and support to individuals, couples, families and children who have been bereaved by suicide, along with a Suicide Bereavement Liaison Officer (Pieta House, 2019).

Primary Care Teams (PCTs)

Primary care is often used to refer to 'general practice', but it encompasses a much broader range of healthcare professionals along with social workers, community welfare officers and many others (Government of Ireland, 2006). A Primary Care Team (PCT) is a multidisciplinary group of health and social care professionals working together to deliver locally accessible health and social services to a defined population (7 to 10,000) as a 'primary' or first point of call. The population serviced is geographically determined along with the population of participating GPs. A typical PCT includes GPs, nurses, home helps, physiotherapists and occupational therapists. Sharing of information and skills is designed to ensure patients receive appropriate, timely and coordinated care, preferably in the same building (HSE, 2019a).

Village Counselling Tallaght

The Village Counselling Service is funded by Tusla, the HSE and the NOSP. It is staffed by over 160 volunteer counsellors offering over 500 hours of counselling weekly. A cognitive-behavioural, client-centred, integrative approach is adopted, which addresses the reality of a multicultural society. The Village provides a low-cost counselling service from 9 a.m. to 10 p.m., Mondays to Fridays. It addresses issues such as depression; relationship problems; chemical dependency; loss and bereavement (including working with those who have been affected by suicide); stress; low self-esteem; sexual, physical and emotional abuse; and family concerns. The Village works in collaboration with other agencies and provides adolescent counselling, recognising that this differs from adult counselling because of the developmental stages and distinct challenges in the transition from child to adult for young people aged 13 to 18 (The Village Counselling Service, 2019).

Youth Drug and Alcohol Service (YoDA)

The Youth Drug and Alcohol Service (YoDA) is based in Tallaght. It provides assistance and treatment to young people under 18 experiencing difficulties related to their drug or alcohol use. The service provides expert treatment based on the individual needs of the young person, working collaboratively with other agencies to ensure best possible outcomes. A harm-reduction approach is adopted, and evidence-based interventions of an international standard are used with families, who are also provided with support and guidance in trying to assist the young person address their drug or alcohol use. In addition to assessment, therapy and support for young people and their families, YoDA has a remit to educate teenagers who are at a high risk of developing drug problems (HSE, 2019h).

Tusla

Tusla is the Child and Family Agency established in 2014 comprising HSE Children and Family Services, the

Family Support Agency and the National Educational Welfare Board. It also incorporates some psychological services and a range of services responding to domestic, sexual and gender-based violence. Tusla is the dedicated State agency responsible for improving wellbeing and outcomes for children. Its remit includes child protection and welfare services, educational welfare services, alternative care, early intervention, early years services, and family and locally-based community support services (Tusla, 2019f).

The following are summaries of specific services and/or approaches delivered by Tusla personnel:

Child Protection and Welfare

The term 'Children First' came from the National Guidelines for the Protection and Welfare of Children (1999, last updated 2017), which outlined non-statutory obligations for all those in contact with children. The Children First Act 2015 (DCYA, 2015a) sets out additional statutory obligations for defined categories of people and organisations (Tusla, 2019g). Social workers provide frontline services for children and families where there are concerns about children's welfare or safety.

Education Welfare Service (EWS)

Education Welfare Officers (EWOs) work closely with Home School Community Liaison Teachers (HSCL) and the School Completion Programme (SCP) to secure better educational outcomes for children and young people. Schools may contact an EWO in relation to a student's school attendance. After discussing the concerns with the school principal or designated school staff member, the EWO may make a home visit to the family to identify any underlying problems or issues. The EWO can then seek to address the family's unique set of circumstances in conjunction with school staff and other local support services as necessary (Tusla, 2019b).

Family Support

Tusla describes its Family Support services as an early intervention approach that aims to promote and protect the health, wellbeing and rights of all children, young people and their families, particularly those who are identified as vulnerable or at risk. It is aimed at supporting families in difficult circumstances to try to prevent situations escalating to a point where social workers may need to intervene (Tusla, 2019a).

Home School Community Liaison (HSCL)

The Home School Community Liaison (HSCL) Scheme is central to the Department of Education and Skill's DEIS (Delivering Equality of Opportunity in Schools), An Action Plan for Educational Inclusion, which aims to combat educational disadvantage and improve educational outcomes for children. It is viewed as preventative, seeking to promote and develop partnership between parents, teachers and communities to improve attendance, participation and retention in the education system.

The service is incorporated into the EWS. All DEIS Urban Primary and DEIS Post Primary schools are currently included in the HSCL Scheme. Full-time HSCL Coordinators are teachers who work primarily with the adults in the young person's life, empowering them to support their children to attend school, participate in education and develop positive attitudes to life-long learning. The range of interventions used are tailored to individual need and are evidence-based, focused and structured. HSCL Coordinators work in an integrated way with other support services such as the SCP and EWOs. The HSCL Scheme is managed and coordinated by a national leadership team within the Senior Management Team of Tusla's EWS (Tusla, 2019c).

Meitheal

Meitheal is a National Practice Model described as an early intervention, multi-agency response tailored to the needs of young people. According to Tusla, the needs and strengths of children and their families are effectively identified, understood and responded to in a timely way for families needing experienced services that are easily accessible and integrated in their own communities (Tusla, 2019d).

School Completion Programme (SCP)

School Completion Programme (SCP) Officers provide educational supports including transfer programmes; breakfast and lunchtime supports; after-school and homework support; learning support; personal development programmes; therapeutic supports; holiday revision; summer camps including summer literacy camps; attendance tracking and rewards; staff development; and sports, cultural, drama, dance and music programmes (Tusla, 2019e).

Chapter 2

Methodology

Chapter 2 – Methodology

2.1 Research Design

This research used a concurrent multiple methods design with the qualitative aspect consisting of 23 semi-structured interviews (11 parents and 12 service providers) and the quantitative aspect consisting of a prevalence estimation of the number of young people in the Tallaght region at risk of mental health challenges.

2.1.1 Semi-structured interviews

Service providers: Twelve key service providers/gatekeepers in the Tallaght region participated in this study. Key personnel participated in semi-structured interviews (N = 14). These interviews explored the referral processes and criteria for accessing youth mental health services. This number was considered sufficient given the time frame, costs and services in the area.

Parents: Parents of children aged 12 to 18 whose children are attending services or whose children's mental health needs are not currently being met by existing services were interviewed (N = 11).

2.1.2 Inclusion criteria

Service providers: must be employed in a mental health or support organisation in Tallaght for which ethical approval has been given and must give consent to taking part in the study.

Parents/guardians: must be a parent/guardian of a child aged 12 to 18, with mental health concerns/ behavioural issues; determined to be at risk of mental health concerns/behavioural issues; not eligible for mental health services and support from other key organisations; and give consent to taking part in the study.

2.1.3 Exclusion criteria

Service providers: not employed in a mental health or key support organisation in Tallaght or in a service for which ethical approval has not been secured; or who did not give consent to taking part in the study.

Parents/guardians: not being a parent/guardian of a child aged 12 to 18 who presented with mental health concerns/behavioural issues; who had been determined to be at risk of mental health concerns and behavioural issues; and who was not eligible for mental health services and support from other key organisations.

2.1.4 Recruitment

The InBetweeners Research Team had permission from 12 services to contact parents, with the services acting as 'gatekeepers'.

Potential participants were made aware of the study by the 'gatekeeper' (service provider), who informed them of the study, distributed information leaflets, and displayed posters informing people of the research taking place. These posters and information leaflets were provided to each service by the research team at Trinity College Dublin and to service providers/parents/guardians who had made contact directly with the researcher to indicate willingness to participate (Appendices).

Participation was by self-selection. If a potential participant was interested in taking part, the contact details for the TCD researchers were available on the poster and the information leaflets. Once contact was made, the researcher followed up with each interested participant to discuss any queries and to provide the interested participant with a consent form. Participants had seven to ten days to decide if they wished to take part.

Service providers or steering committee members were not aware of who had consented to participate in the study, as these details were anonymised and confidential. Organisational consent and ethical approval processes were known to the steering committee.

2.1.5 Informed consent

Informed consent was ensured by giving all participants a Participant Information Leaflet (Appendix B, C) in advance of the interview and again at the time of the interview, along with a Participant Information Consent Form (Appendix E, F and G) being read through at the interview and any clarifications provided before the participant signed to give consent.

For parents/guardians in particular, the study was explained to ensure that they were given ample opportunity to understand the nature and purpose of the project. They had seven days from contact to consider their participation. Participants were advised that if they wished to withdraw from the study at any time, this would be fully respected and adhered to, with participants able to tell researchers on the day of the interview, if necessary, that they did not wish to participate.

The wording of all information booklets, consent forms and other miscellaneous materials aimed at parents and other community participants was carefully considered to maximise accessibility.

2.1.6 Confidentiality

A number of measures were taken to ensure that confidentiality was maintained. A personal identification number was generated for each participant in order to (reversibly) anonymise the data. With the exception of the document that contains the participant's personal information, all other information was identified using this number in order to protect the confidentiality of participant data. The document containing the participant's personal information was stored and accessed separately from the anonymised data. Access to data with the participant's personal information and identifying material was restricted to the Principal Investigator and was password protected from all others to preserve confidentiality.

A voice recorder W550M was used for recording the interviews, with the majority of interviews occurring in Office 9, Floor 6 of the Institute of Population Health, Tallaght. Four interviews took place at a location convenient to the participant(s). All appropriate care was taken to ensure the safety of this recording device, with interviews deleted from the device as soon as the file was uploaded to the secure folder managed by Trinity College Dublin on the desktop.

2.1.7 Child protection

The InBetweeners research team did not envisage child-protection-related ethical issues or problems arising, as there was no direct contact with any children under 18. However, it was considered possible that in a project of this nature some child protection issues might emerge either directly or indirectly in the course of the study. The procedures for dealing with any such issues were explained to interviewees, and interviewees

were assured that any issues would be dealt with sensitively, promptly and in line with established guidelines for the protection of children (such as Children First, 2017; Children First Act, 2015; and Our Duty of Care, 2002), with referral, where appropriate, to a relevant agency. No issues of this nature arose.

2.1.8 Debriefing

All data were collected by the research interviewers in a sensitive and confidential manner. The InBetweeners research team did not anticipate any adverse outcomes. However, all participants were given a debriefing sheet containing contact information for services such as ChildLine, Pieta House, the Samaritans, Aware and the HSE Primary Care Psychology Service (see Appendices).

2.2 Data Collection

2.2.1 Qualitative data

As previously outlined, semi-structured interviews were conducted with both service providers and parents/guardians. The list of questions for service providers (Appendix I) and parents (Appendix H) were different, so that the different experiences of service providers and parents could be addressed.

Fourteen service providers participated from the different agencies across Tallaght. They covered a wide variety of roles: youth service workers, GPs, social workers, family support workers, a psychiatrist, a nurse, a psychotherapist, managers, and a psychologist.

All 11 parents who participated were mothers, with the young person they were concerned about ranging in age from 12 to 18. In total, there were 11 young people experiencing difficulties across the families. Including siblings, there were 26 young people affected by the difficulties experienced. In two cases, the young person was the only child in the family.

Table 1 outlines details of the participants:

Table 1: Details of service providers and parents who participated

Service Provider	Position
Foróige	Youth worker
Foróige	Youth service manager
GP	GP
GP	GP
Primary Care Social Worker, HSE	Social worker
Family Support Tusla	Family support worker
Family Support Tusla	Family support worker
YoDA	Psychiatrist
YoDA	Nurse, therapist
SCP	SCP Officer
Jigsaw	Occupational therapist
Psychotherapist	Human Givens psychotherapist
EWO	Manager
HSE	Psychology manager
TOTAL	14

Parent or Guardian	Young person	Young people in family	No.	Diagnosis
Mother	Girl 14	Girls 12, 14	2	Asperger's, dyspraxia
Mother	Girl 12	Girl 12, Boy 9	2	Suicidal
Mother	Girl 18	Girls 18, 29; Boys 28, 34	4	Suicidal
Mother	Girl 17	Girl 17; Boys 8, 13	3	Asperger's
Mother	Boy 18	Girl 22, Boy 18	2	Cannabis use, school refusal
Mother	Girl 12	Girls 12, 20, 23	3	Asperger's, ADD, diabetic, suicidal
Mother	Boy 16	Boy 16	1	Cannabis use, challenging behaviour
Mother	Girl 17	Girl 17; Boy 15	2	Anxiety
Mother	Boy 13	Boys 13, 22, 24	3	Anxiety
Mother	Boy 15	Boys 11, 13, 15	3	Anxiety, depression
Mother	Girl 15	Girl 15	1	Anxiety
TOTAL	11		26	

2.2.2 Quantitative data

The aim of this section is to provide an indirect estimate of the number of young people in the Tallaght region at risk of mental health challenges in order to inform mental health service planning and coordination. To accomplish this, working definitions of the Tallaght region, the ages of young people, and

the concept of mental health must also be identified. Mental health challenges mentioned by parents and service providers in interviews included suicidal ideation, self-harming, mild to moderate to severe anxiety, Asperger's syndrome (AS), obsessive compulsive disorder (OCD), dyspraxia, attention deficit disorder (ADD) and drug use. Details of these are provided in the findings from the one-to-one interviews.

The benchmark multiplier method was used to provide an indirect estimate of prevalence. This method has been well documented internationally and has the added advantage of having been used previously in the Tallaght region within a different application. Galligan and Comiskey (2019) successfully used the method to indirectly estimate the unknown number of children in the region who had a parent with a drug or alcohol use problem. The method involves applying a 'multiplier' to a 'benchmark'. The formula is as follows: $R = B/M$, where R is the number of young people estimated to be at risk of mental health challenges, B (the benchmark) is the known number of young people of a defined age in a defined time period and a defined region, and M (the multiplier) is the estimated at risk rate, that is, the percentage of young people believed to be at risk of mental health challenges. This may be estimated from surveys or other related publications. For example, if we know that we have 1,000 unique young people in a region (B = 1000) and if we know from surveys that 25% (M = 0.25 or 1/4) of young people are at risk, then $R = B \times M = 1000 \times 0.25 = 250$.

It may also be possible to provide statistical confidence intervals for the estimate as described by Comiskey et al. (2011).

2.3 Qualitative Data Analysis

2.3.1 Thematic analysis

The analysis for the qualitative aspect of this study was conducted using thematic analysis (TA) with a six-phase process as follows: familiarisation with the data; generating codes; identifying potential themes; reviewing themes; defining themes; and writing up the narrative for each theme (Clarke et al., 2015; Braun and Clarke, 2006). The steps used were mainly sequential; however, the analysis was a recursive process. The interviews were transcribed verbatim. TA emphasises the active role of the researcher and advocates an organic approach to coding of data and identification of themes (Clarke et al., 2015). It also assisted in the consideration of emerging themes through the theoretical lens of Cultural Historical Activity Theory (CHAT).

2.3.2 Theoretical framework – Cultural Historical Activity Theory

Cultural Historical Activity Theory (CHAT) (Engeström, 1987; Engeström, 2015) is used as the theoretical framework for this report, which aims 'to address the unmet mental health needs of children and adolescents in Tallaght'. A CHAT approach incorporates cultural, historical, situational and contextual features in the research process: the emphasis is on the study of objectives and the actual outcomes, which may or may not have been expected, and identifying possible areas for change (Engeström and Sannino, 2010; Engeström, 2009a). This is relevant to the aims of this study in seeking to explore the unmet mental health needs of young people where both the young people and their parents are influenced by their culture but also need to negotiate their way through cultural practices.

2.4 Quality in multiple methods design

Service provider interviews were transcribed and coded first, with the codes identified then used as the basis for the parent coding process.

2.4.1 Rigour – qualitative aspect

Morgan and Drury (2003) maintain that validity, generalisability and reliability are not strictly applicable to qualitative research, as researchers are trying to understand the meaning of phenomena and interpret them. However, researchers still need to outline the processes and procedures used to help them make connections and construct meaning, creating a coherent narrative and explanation (Morgan and Drury, 2003).

In order to create trust and confidence in the findings of a research study, rigour must be established (Thomas and Magilvy, 2011). Rigour is described by Morse (2015, pp. 1214, 1220) as having 'demonstrable checks and balances' in place to provide 'proof' of a rigorous inquiry so that other social science researchers may comprehend and respect the research.

Guba and Lincoln (1994) propose criteria to ensure that trustworthiness in the data and procedures is established. Trustworthiness is ensured if credibility (internal validity), transferability (external validity), dependability (reliability), confirmability (objectivity) and authenticity are established (Guba and Lincoln, 1994).

2.4.2 Credibility

Credibility refers to how faithfully participants' views are interpreted and represented by the researcher (Koch, 2006; Polit and Beck; 2010; Cope, 2014). Credibility is usually achieved by returning transcripts or preliminary findings to participants for review (Lincoln and Guba, 1985). This process is known as member checking (Birt et al., 2016) or respondent validation (Barbour, 2001). Researchers have questioned the appropriateness of this technique, citing constraints on the qualitative researcher that may be counterproductive (Sandelowski, 1986; Morse, 2015; Birt et al., 2016; Barbour, 2001), as feedback may lead to researchers amending or disregarding their original interpretations (Barbour, 2001).

The researcher, an experienced interviewer, conducted all the interviews and transcriptions in order to remain close to the data and provide descriptions of parents' experiences of mental health services in as faithful a manner as possible. Credibility was achieved by checking and rechecking transcripts and coding with the research assistant, who has considerable experience in the field of young people and their mental health.

2.4.3 Transferability

This term refers to the degree of similarity between two contexts so that the findings of this study could be applicable to a different sample or cohort (Koch, 2006; Sandelowski, 1986). According to Morse, one strategy used is 'thick description'. This refers to a rich data set, representing phenomena easily recognised by others (Morse, 2015, p. 1218). Carlson (2010) maintains the main functions of 'thick description' are to demonstrate in-depth understanding of common themes and provide detailed descriptions of participants, setting, data collection and data analysis procedures. These principles were considered throughout the data analysis.

2.4.4 Dependability

A research study may be viewed as dependable when the process is recorded in a clear and rigorous way that could then be audited by another researcher who could arrive at similar conclusions (Sandelowski, 1986; Koch, 2006). Therefore, a clear audit trail was recorded and notes were maintained to track the analysis processes as the data evolved.

2.4.5 Confirmability and authenticity

Confirmability is established through the achievement of credibility, transferability and dependability, as outlined above, requiring references throughout the study to how interpretations were arrived at (Guba and Lincoln, 1989; Koch, 2006; Thomas and Magilvy, 2011). Interpretation of data, however, can be influenced by bias, which is defined as prejudice for or against a person or group in an unfair way or concentrating on a particular subject to the neglect of others (Smith and Noble, 2014; Oxford University Press, 2018). All researchers have biases that can be ameliorated through disclosure (Carlson, 2010; Smith and Noble, 2014). Along with researcher reflexivity, a self-critical attitude about how bias can influence interpretation leads to greater trust in the findings (Thomas and Magilvy, 2011).

In this study, self-awareness and reflexivity were enhanced by use of field notes, contemporaneous notes during interview sessions, reviewing of coding, and interpretation of codes with other academics in the field to maintain objectivity. Using the journal during the coding process provided a decision trail and means to establish 'audit trail linkages' as outlined by Koch (2006).

2.4.6 Reliability

In this study, where one person is the principal coder, reliability can be established through inter-coder reliability (two equally capable coders independently selecting same codes for same text) and inter-coder agreement (coders meeting to reconcile any differences through discussion and agreement) (Campbell et al., 2013; Creswell, 2013).

This two-pronged approach was used in this study through independent coding of two transcripts line by line by the researcher and the research assistant, with both then meeting to collate the coding, identify common codes and agree on additional codes. There was a high degree of agreement and reliability in this study.

2.4.7 Ethical considerations

Ethical approval for this study was obtained from the Faculty Research Ethics Committee (FREC) of Trinity College Dublin (Appendix M) along with ethical approval from Tusla, Jigsaw and the HSE. It was not possible to obtain ethical approval for some key stakeholders, within the study timeframe, and this limited the consultation process. Specifically, this relates to Saint John of God Services and Tallaght University Hospital.

The research was all fully compliant with the General Data Protection Regulation (GDPR).

Further ethics related issues, including the role of the researcher, are discussed in Appendix O.

2.4.8 Confidentiality

Study participants' right to privacy and the protection of their data is a key principle of ethical research (Polit and Beck, 2010). Data were stored in line with the Data Protection Act 2018 (Government of Ireland, 2018).

Chapter 3

Data Analysis

Chapter 3 – Data Analysis

In this chapter the findings for the service providers and the parents are outlined separately, with Section 3.1 outlining the former and Section 3.2 the latter.

Analysis of the data identified six main themes that were common to both the service providers and parents:

1. Diagnosis not being a gateway to services

2. First port of call

3. New issues emerging

4. Family, culture, and community

5. School as a gateway

6. Service quality and availability

Within these six main themes, there were 24 sub-themes identified for service providers and 24 sub-themes for parents (Table 2). While many of the sub-themes were common to both service providers and parents, parents tended to focus on the mother's role in obtaining services for her child; the response of the services to her concerns; the impact on the health and wellbeing of the other children in the family; and the cost incurred by parents in securing assistance. In contrast, service providers focused on assessment of need not leading to services; drop-in centres; homelessness; and ethnic minorities. The difference in focus between service providers and parents is highlighted in Table 2 and in the diagrams in Chapter 4, Section 4.1.

Table 2: Six themes and sub-themes identified

Theme	Sub-themes – service providers	Sub-themes – parents
Diagnosis not being a gateway to services	16- to 18-year-olds most vulnerable Assessment of Need (AON) not leading to services Dual diagnosis and referral pathways Self-harm Support by proxy	Assessment of Need not leading to services (different focus) Dismissal of mother Dual/late diagnosis Referral pathways Support by proxy
An uncertain first port of call	Health professional (HP) lack of knowledge of services Public versus private Drop-in centre	Health Professional lack of knowledge of services Public versus private Own research
New issues emerging	Social media and internet Social anxiety Waiting lists Homelessness Ethnic minorities	Social media and internet Waiting lists
Family, culture, and community	Influence of family Stigma Parental fear Inter-generational trauma and disability	Influence of family and peers Parental fear and stigma Fear of child Inter-generational trauma and disability
School as a gateway	Gateway for services School refusal	Gateway for services Lack of resources
Service quality and availability	Medical model Location and convenience Counselling quality and training Youth focus Staffing and resources – impact on referral	Medical model Location and convenience Counselling quality and training Staffing and resources – impact on child Youth focus

3.1 Findings – service providers

This section will present the findings for service providers and will be followed in the next section with findings for parents.

3.1.1 Diagnosis not being a gateway to services

16- to 18-year-olds most vulnerable

Health professionals were confused about the age of consent, as both the hospital services and Child and Adolescent Mental Health Services (CAMHS) tend to treat 16- to 18-year-olds as 'adults', which is not considered appropriate by GPs in particular:

> *I can't remember exactly what rules apply in the different services … I am sure there is the paediatric ED may only take patients up to 16 actually? CAHMS is up to 16. Over 16, the adult services would see them. (GP 2)*

> *The issue around 16- to 18-year-olds and who is Child Psych and who is Adult Psych and what do you do with the children in the middle of that … that has to be ironed out by the psychiatry services themselves. Who is responsible for these transitionary patients? (GP 1)*

There also appeared to be differing interpretations among health professionals and service providers about the age at which young people could self-refer and give consent to treatment. Some considered that 16- to 18-year-olds were capable of giving consent:

> *If a young person wants to attend our service, wants to address their drug use, but doesn't want their parents involved, or doesn't want their parents to know … our interpretation of the HSE guidance on this is that 16-year-olds can consent to treatment on their own behalf and we are inclined to go with that. [Drug Misuse Agency 1)*

GPs, who are the main referrers to CAMHS, also noted inconsistencies on consent age across service providers as being a barrier to providing timely and appropriate referrals, particularly when they have seen a young person aged 16 on their own without parental consent or knowledge:

> *I thought 16- to 18-year-olds had autonomy and they could sign for themselves with counselling services, but actually one or two of them said no you can consent to medical procedures at 16. (GP 1)*

There was a recognition that young people aged 16 and over were particularly vulnerable, with no clear pathway for referral to appropriate services:

> *Having a pathway for the 16 pluses. Possibly up until, well, this is my own opinion but you know even up to 21 I think people are actually … They are still a bit away from adulthood, particularly when it comes to psychiatric issues. (GP 2)*

Assessment of Need (AON) not leading to services

Completing an AON process is required in order to subsequently access services. However, parents have difficulty getting a timely assessment, and support is not always readily available subsequently:

> *You would often be directing parents to the Assessment of Need (AON) process as well but again, that is entirely stalled at the moment and that's more for an assessment rather than health support. (GP 1)*

Even if the AON process is completed and therapy allocated, therapy may not be sustained, leaving both service providers and parents frustrated:

> *They do the Assessment of Needs and then they have to fight tooth and nail to keep onto the hours, like sharing a child's hour with another child. (Family Support 1)*

Dual diagnosis and referral pathways

A situation where a child may have both behavioural and mental issues or a 'dual diagnosis' can lead to difficulties in accessing services such as CAMHS, which accept those cases they consider to be 'mental health' rather than behavioural, leading to delays or even lack of therapy:

> *The children fall between two stools because in CAMHS opinion may be that behavioural issues are due to intellectual disability and not actually to a medical health issue … so difficult or challenging behaviours can continue and escalate and trying to distinguish, trying to tease out what is a purely mental health issue. (GP 2)*

Young people who have had mental health issues and accessed treatment for drug misuse can experience significant barriers to securing mental health services on referral from the drug treatment agency:

> *There is substance use in the equation, then all mental health symptoms can be viewed as having their origins in that, even oddly enough if someone has had a previous history of linking in with the service, with the CAHMS team at a younger age before there was ever any substance use. (Drug Misuse Agency 2)*

In contradiction to this, CAMHS often refer clients to the Youth Drug and Alcohol Service (YoDA) if the young person is considered to have a primary diagnosis of mental health with a 'minor' substance misuse issue. This poses difficulties for YoDA, which has the ability to respond to both mental health and drug use issues, but is concerned that the young person may have subsequent difficulties linking back in with CAMHS at a future date:

> *We would be very conscious of not wanting them to lose their connection [with CAMHS] because they may very well need that connection for longer than they need our service. (Drug Misuse Agency 2)*

In order to redress this, service providers suggest that agencies may need to be aligned, which would involve a reorganisation of existing services:

> *I would like to see the services more aligned and ideally falling under the one governance structure so you wouldn't get these issues whereby … we say it is a mental health problem and CAMHS are saying no, it's an addiction issue and we can end up in a disagreement. (Drug Misuse Agency 1)*

In the absence of guidelines on referral pathways, service providers have adopted their own pathways, often based on relationships between individuals in services rather than on formal policy or protocols. This can have implications when staff relocate (see staffing and resources):

> *There are kind of informal referral pathways and there are more formal … some of the more targeted services would have some very formalised kind of pathways [but] a lot of it is based [on] another person in the service knowing the person in our service and being able to ring up or even get advice in terms of what's an appropriate referral. (Youth Organisation 1)*

Self-harm

Many service providers are aware of one organisation, in particular, having had parents commend it for its provision of some level of support:

> *It's a mental health service … we provide brief solution-focused intervention … it's up to eight sessions of support for young people who are experiencing mild to moderate mental health concern. (Youth Service)*

However, while they receive self-referrals from young people as well as parents, primary care and other services, their services are limited:

> *If somebody was experiencing self-harm and suicidal ideation at the same time, they probably would be beyond our scope. (Youth Service)*

On trying to link in with a more appropriate service, a lack of coordination between agencies and a lack of information sharing has led to difficulties for young people who need multidisciplinary support for mental health issues. Youth work assessments are often not accepted, leading to frustration at having to repeat information and at the subsequent lack of service:

> *Our assessments are pretty comprehensive, and we are trying to share the information we have, then that is not accepted. And then the young person has to go and repeat everything to another service. (Youth Service)*

Difficulties with sharing of information emerged in several service provider interviews, with staff frustrated that their referral to other agencies often led to fragmentation and possible overlap of service because of lack of information:

> *The person is happy for me to be involved but what I have discussed with that person you are not willing to share with me? You are asking me to go back to that person, get information and have it recorded and I will ring you back – it is just frustrating. (Social worker)*

Service providers differed in their interpretation of guidelines on the age of consent for treatment and therapy, which had possible negative implications for children aged 16 to 18 who may not have had the support or input of their parents. There was also confusion among services over who was responsible for provision. Assessment of Need reports are considered necessary in order to access services, but unfortunately, they do not always result in services being activated. A dual diagnosis or indications of self-harm can also lead to a child either not getting any services or getting very delayed services because of disagreement among service providers over who has responsibility for treatment.

3.1.2 An uncertain first port of call

The GP is viewed by many service providers as the first point of service for all issues: mental, behavioural and physical. This puts a lot of pressure on the GP service:

> *So for the primary care, the referral process is the GP. The GP really is the link for everybody. (Psychologist)*

The young person, however, may never actually be seen by the GP. The GP may often see the parent, who is stressed as a result of their concerns about their teenager:

> *Oftentimes the parent would have an issue, come on their own, describe their concerns about the child and then subsequently we would ask to bring them in … Sometimes, you mightn't ever see the child. (GP 1)*

Statutory service providers tend to refer primarily to the GP as their 'first port of call' even if a non-statutory service may be more accessible:

> *We have found that, whether we might know of services ourselves, we have taken the line to - we would expect you to go to the GP and if the parent is really struggling however, we*

> *might give the name of a local drop-in service but we really take the route of the GP.*
> *(School Completion Officer)*

Health professionals' lack of knowledge of services

GPs have acknowledged that they do not have information on all the services available in their area. With limited time for consultations, they need a 'one-stop shop' and central interface they can access, with information on appropriate locally based services:

> *A coherent interface. Somewhere you can access the services that's identifiable, that*
> *everybody knows how to get to it. Because I know there is way more out there then I am*
> *aware of. (GP 1)*

Even if a GP is aware of a suitable service locally, the individual's postal address can often dictate if they are eligible or will be accepted into a specific service rather than availability being based on need or proximity to the GP practice:

> *The address thing is a huge issue … with primary care centres and access to services in*
> *general and which CHO you are in or which bit of the CHO you are in and GPs did advocate*
> *at one point that if I am in a primary care centre and there are services in the PCC, then any*
> *patient attending my practice should be able to access those services. (GP 1)*

Some service providers such as drug misuse agencies acknowledge that young people don't tend to access their GP, resulting in low referrals from that source:

> *GP aren't a big referrer to us. If they [teenagers] have got a drug problem, they are not*
> *going to go, 'Oh, I will go to the GP' … So the GP is often left out of the loop in terms of the*
> *referral process … So we have to work pretty hard at linking in with potential referrers to*
> *remind them that we exist and what we do. (Drug Misuse Agency 1)*

Public versus private

While there are no financial barriers to patients who have a medical card in accessing the GP service (GP 2), families with or without a medical card may need to access private counselling services in the absence of timely and appropriate statutory services in the community:

> *You need much more community-based services. You need to be able to go to the GP*
> *practice or the local community and meet a psychologist or mental health worker there, so*
> *you don't have to travel. (Psychologist)*

Private counselling has cost implications for families, with service providers tending to use counselling services that have low-cost options and varying levels of training:

> *Pieta House we often use … we would use Beacon of Light or Village Counselling in*
> *Tallaght so kind of low-cost counselling services … is counselling support that somebody*
> *needs, we tend to kind of suggest those as first options really. The low-cost and the clinical*
> *government structures in those organisations [are important]. (Youth organisation)*

Drop-in centre

Service providers noted that parents who are concerned about their young person's mental health need to be able to access one place that can direct them to the appropriate service:

> *I think it needs a one-stop shop … 'I don't know what to do with my child' [parent] …*
> *someone who is trained … so they can quickly go – this is the service that is needed.*
> *(Youth Organisation 1)*

Providers suggested that existing services could be adapted for this. Several recommend a service like Jigsaw that could deal with a wide range of issues from mild to severe:

> *Some services could adapt – you know that there is a drop-in where parents can just drop*
> *in and ask questions. If there was one thing I would like to see happen in Tallaght would be*
> *a service that would have a remit – a level that young people with mental health issues –*
> *between Jigsaw and Tallaght Hospital. (Youth Organisation 2)*

Health professionals acknowledge that they are not aware of all the services available in their area, particularly in the private arena, and would appreciate the facility of a drop-in centre where families could receive immediate assistance. Long waiting lists may lead health professionals to suggest private counselling services, with cost implications for families.

Support of child by proxy

The GP service in particular is patient led, but as has been mentioned already, it is often a parent who will highlight the issue first and the child might never be seen by the GP or will be brought in later:

> *Often times the parent would have an issue, come on their own, describe their concerns*
> *about the child and then subsequently we would ask to bring them in … Sometimes, you*
> *mightn't ever see the child. (GP 1)*

Some service providers find that in cases where children may not engage directly or cease engagement, the service provider will continue to provide support to the parent as a form of 'proxy' support to the child by passing on strategies and skills for the parent to deal with the problem:

> *The older ones tend to refuse … we will work with the parent and the aim is not necessarily*
> *to support the parent in the difficulty that they are experiencing, the aim is to treat the*
> *problem. (Substance Misuse 2)*

3.1.3 New issues emerging

Social media and internet

Several service providers cited the increasing use of the internet and social media, noting that both physically and through the content it provides it can create new issues for young people and their parents that will need to be tackled in the future:

> *There is a lot coming our way that we are not prepared for. (School Completion Officer)*

The use of technology, social media and the internet has been identified as creating new parenting challenges that neither parents nor service providers have the skills to address. This new challenge may lead to mental health difficulties:

> *It is so invasive … 'back in the day' you went to school … so home was a place of rest …*
> *the social media is so pervasive and there isn't any escape. Like I know you can turn the*
> *phone off, but kids don't. (NGO)*

Even when aspects of the internet claimed to assist young people, the language used around mental health issues on social media is viewed by some service providers as leading to anxiety, self-diagnosis or diagnoses by parents, possibly 'pathologising' normal youth behaviour and feelings:

> *YouTubers in particular who young people kind of talk to us about who are very much invested in kind of medicalised language around mental health and young people very much identifying with that. (Mental Health Professional)*

Social anxiety

Social anxiety was mentioned by several service providers as having an impact on children's engagement in 'normal' activities such as attending school and youth activities. This can be manifested in children staying in their bedrooms and having fear of going out:

> *They are not always the challenging behaviour children with ASD, they are more the stay-in-their-room children. (Educational support)*

Engaging children who have become socially isolated as a result of anxiety has created significant problems for a number of agencies:

> *Another barrier that I am seeing is socially isolated [teens] ... they are not even leaving the front door and how do you get them from there to here … a challenge getting young people to [engage]. (Family Support Worker 2)*

One of the major issues for children who have social anxiety and who stay in their rooms is that they don't meet the criteria for mental health services:

> *One of the barriers for me is that they [troubled young people] don't fit into whatever is the threshold for services in terms of their mental health … they don't want to come out, they just want to stay indoors, curtains closed, they probably have depression or something. But there is no service. (Family Support Worker 1)*

Waiting Lists

Service providers are keenly aware that their services are not meeting the mental health needs of young people, particularly in urgent cases, because of long waiting times even for an initial assessment:

> *Like we have a year-long waiting list. Sure it is useless! For young people, young people need something the day they need it. We need 24/7 services. We need services at weekends. (Psychology Service)*

The lack of a responsive service then tends to put increased pressure on the emergency department in the hospital. This also has very long waiting times, particularly for children in acute distress who may be unable to wait to receive attention:

> *You have to use the ED then as the place to go, but then that is very far from ideal because it's, they are left hanging around for a long period of time. They will often go with their feet and exit. (Drug Misuse Agency 1)*

Lack of resources has led to the existing criteria or thresholds for services being raised and long waiting lists leaving children at risk, particularly those in considerable distress:

> *Lack of resources, the waiting list, the services are overstretched. As a result of that, they*

are upping the threshold for certain referrals. (Family Support 1)

Now I accept that the CAHMS teams have finite resources and they have to manage those and it is a consequence of that, but it is deeply unsatisfactory I think, a max waiting list for someone who is genuinely has, appears to meet the criteria for a mental health assessment, should be two weeks in an ideal world. (Drug Misuse Agency 1)

Homelessness

Homelessness emerged as one of the major new issues for mental health, as it relates to geographical location and eligibility for services that are location based:

I had a huge issue with a CAMHS referral where the child had been resident one place, they were using the granny address for correspondence, now they were living in a family hub somewhere and CAMHS are going, oh no that's not in our catchment area. (GP 1)

The stigma that is attached to being homeless along with the invisibility of this population is viewed by service providers as leading to families not presenting themselves to the appropriate services when in need. This may have long-term implications, particularly for young people:

No young boy or girl is going to say that I am in a hostel with my mum, I have nowhere to live … the stigma attached to that alone … young homeless people that have never went through the services … I would say they would be the people that would be slipping maybe through the net. (Family Support 2)

Ethnic minorities

One of the key new areas identified is ethnic minorities, where there is a lack of resources and schools in those areas where ethnic minorities are being housed:

It is when you leave West Tallaght, when you go to parts of East Tallaght or some of the newer communities where they don't actually have a full-time SCP [School Completion Programme Officer] or Home School Liaison. That really presents challenges for the school community and also then for us, as well, trying to build things with those new communities [ethnic minorities] or new schools. (Youth Organisation 1)

In summary, service providers frequently alluded to the 'new' issues that have emerged in recent years that will have long-term implications for children and families, such as the rise in the use of social media, social anxiety, long waiting lists, homelessness and ethnic minorities.

3.1.4 Family, culture, and community

Influence of family – support and denial

Service providers often experience difficulties in securing support for a young person if there is resistance from the extended family. Mothers are often the primary instigator in seeking assistance, but they may not be supported either:

It is the motivation of the family … you give the information, and maybe they don't have the literacy or the capability or … maybe there is huge resistance within the family if there is not a united front and the mum is trying to push something and nobody else will support her. (GP 1)

Stigma

Service providers acknowledge that young people don't seek help because they fear being stigmatised by others in their community:

> *I think there is stigma as well for young people, especially in working class areas … it is seen as if there is something wrong with you if you have to [seek help], and it is a pressure on them not to meet, not to seek out help. (Family Support 1)*

Fear of services and of the services judging their family may also cause parents to actively hinder their young person in getting assistance:

> *There are some parents who don't want their young people to access services … a fear of services … like mental health services, like counselling … they don't want their young person to actually get those services. (Youth Organisation 2)*

Service providers expressed concern that parents may not consult their GP about their child's substance misuse or mental health difficulties because of concern about data retention and information that may have implications for the future:

> *It is usually the parents that will have this worry … the GP might have to do a letter for my son's mortgage approval in 10 years' time and I don't really want them to know about, the GP to know about their drug use. (Drug Misuse Agency 1)*

This parental concern is acknowledged by GPs as being a legitimate one and poses difficulties for them in providing a full service to their patients – both parents and children:

> *We would look after patients for a long period of time … their childhood GP becomes their adult GP and they are applying for a mortgage and they need life assurance and they have to get a PMA done with us … and they have got this suicidal ideation when they were a 14-year-old on their record and it is a reasonable [emphasis] concern of parents. (GP 1)*

Fear about the services or what the young person may disclose about the family to 'outsiders' may also cause parents to prevent their young person from seeking help:

> *I think there are a certain cohort of parents that will actually block the young person from accessing services because I suppose this fear of what young people may disclose … They don't want outside services to have inside knowledge of what's happening in the house. (Youth Organisation 1)*

Service providers observed that intervention is preferable at an early stage to prevent issues escalating, but that resources are often limited or thresholds too high for services to intervene:

> *It would be fantastic if we had … more low-grade interventions, that were very structured … but more low-grade interventions before it escalated into something where someone is 'labelled' if you like to having a mental health difficulty per se. (NGO)*

Family support workers in Tusla view their work as early intervention to prevent problems escalating and requiring full social worker intervention. However, they feel hampered by the negative perceptions attached to the Tusla organisation:

> *Oh, yes [parent says] everything is fine, we don't need you, it's just once off, we are fine. Even though we are there to prevent things from escalating. (Family Support Worker 1)*

According to some service providers, Tusla is viewed in a negative way by parents and the community in general. There is a lack of understanding of what the service entails and parents are fearful of Tusla being involved (see Parents, Section 3.2.4 also):

It can be linking with families who have mental health problems, it can be supporting them to get back life skills, schools, hospital appointments, general making life a bit easier for them. (Family Support Worker 2)

Parental fear

Service providers in the area of substance misuse have reported that they have had to institute a skills programme for parents who are afraid of confronting or disciplining their children because of the abuse the parents experience from their children:

A lot of parents in relation to substance misuse, particularly cannabis use, are experiencing child–parent violence. It's a somewhat recent phenomenon. We have been including the non violence resistance model in our work with the parents in the last six years … we have added that in so it is an active treatment approach to what's going on at home to the struggles parents are encountering. (Drug Misuse Agency 2)

Inter-generational trauma and disability

As previously mentioned, a dual diagnosis poses difficulties in securing appropriate services for the young person. Sometimes this results in the young person not receiving any service at all. Several service providers commented that physical and mental health cannot be separated and need to be combined in order to address young people's difficulties appropriately:

The overlap between disability and mental health services actually needs to be dealt with and not dealt with in two separate silos … inter-disciplinary teams who will manage that overlap. And we are so behind looking after the disability side that that is adding to the pressures on the mental health side. (GP 2)

Service providers also observed that disability and mental health difficulties can have deeply-rooted factors:

We have inter-generational disability which is very clearly associated with firstly, the deprivation and the kind of chronic underinvestment, under-resourcing of both of these services [physical and mental health]. (GP 2)

Some parents have become so overwhelmed and stressed that service providers have noted an increase in parental mental health issues. These can have tragic consequences for families and young people:

Some of the mothers are at their wits end. Like we had a spate in the last year-and-a-half of young parents committing suicide! (Psychology Service)

Service providers have recognised that some of the young person's issues may stem from difficulties in the home and wider family, with support needed for the whole family and not just the young person:

Young people have high levels of distress and complexity in their family lives and maybe it's not purely a mental health issue or it's not purely located in the young person but it is more systemic. There is not a huge amount of systemic family support for young people. (Youth Organisation 1)

Service providers suggest that providing support for the whole family may prevent future generations of that family experiencing the same traumas and difficulties:

The parents who don't have those resources, the parents who don't, like has an appointment who never turned up; why did they not turn up … break that generational cycle? Those young people, they will become parents and how can we break that cycle?
(Youth Organisation 2)

Service providers observed that the extended family and community had considerable influence on whether a child would receive treatment or not. Mothers were the main instigators of seeking support. Fear of stigma prevented both children and parents accessing support, with parents often concerned about the long-term implications for their child of having a recorded history. Service providers also acknowledged the need to address the impact of inter-generational trauma and disability on subsequent generations.

3.1.5 School as a gateway

Gateway for services

The school was viewed by service providers as a key contact point, not only for education but also for support, as most teenagers attend school at some point:

I would see the schools as … very important … most young people, the vast majority are in schools and if not in schools, then potentially they are in Youthreach and then there is a much smaller cohort that aren't actually engaged in anything. (Youth Organisation 2)

In West Tallaght particularly, all schools have DEIS (Delivering Equality of Opportunity in Schools) status. This status means the schools have additional support staff such as School Completion Programme Officers (SCP) and home–school liaison staff. Service providers referred to the need for 'universal' support for young people that includes coping skills and life skills that may both empower young people and pre-empt difficulties they may encounter at different stages in the life course:

Young people are empowered more to take care of their own mental health rather than it being something that the doctor or the psychiatrist, or the doctor, or the nurse manages or whatever. (NGO)

What we call universal support so that might be that I … went into a classroom to run a [life skills] programme with a class … We call that universal. So the whole class got the same input from SCP. (SCP)

The adoption of universal support that is integrated in the school system may assist in reaching students who might be reluctant to seek individual assistance, but also assists in normalising and naming emotions and feelings that all humans experience in life:

If you are outside the door, and there is a sticker on the door … then that young person is waiting, she is feeling funny, that's stigma. (Family Support Worker 1)

That they need to be educated about how their mind works … in England they run … a wholeness service on the Human Givens approach … you are getting people to understand and access their own resources ... Educate them in what's happening … what a relief is that and how empowering is that? 'I just need to understand how my brain works'. (NGO)

School refusal

School refusal can be an important indicator in identifying young people who may be experiencing mental health difficulties. Service providers note that there are increasing numbers of young people who are not attending school for various reasons. These include anxiety, tiredness or gaming:

Sometimes to get them to go to school, too … my [experience] is that they are up all night on their computers, their parents have given up, they are totally addicted and it is the breakdown. (Family Support Worker 2)

The difficulties parents are experiencing in parenting, creating boundaries for their children, or managing challenging behaviours may also result in school refusal:

They are gaming half the night and then they are asleep all day … parents are saying they can't get them to school – it's quite permissive parenting … Now that's a big judgement call I am making … it just seems to be a battle … they are living in a virtual world, they are very afraid of the real world. (School Completion Officer)

It is not just as simple as not going to school, it is a lot about … a result of what the parents are doing … we don't have enough family support at a time, and these are the young people who are slipping through the net. (Family Support Worker 1)

Educational Welfare Officers (EWOs) are employed to support young people and their families who are experiencing difficulties with school attendance. However, EWOs are attached to Tusla, and the EWO's work is often hampered by negative perceptions of Tusla (previously referred to above):

Tusla, that is all people see and for the Educational Welfare Service, is probably the negative that they see and in fact, a huge amount of the EWO's work is the support, challenging schools and challenging systems. (Educational Welfare Officer)

In summary, schools were viewed as an important resource in terms of both early identification and point of access to young people. Therefore, they hold a central role in addressing youth mental health on both a universal and individual scale, as most children attend schools. School refusal was often an indicator of and/or precursor to mental health and family issues.

3.1.6 Service quality and availability

Medical model

Service providers spoke of their concern for parents who did not know how to access assistance for their children and who find the medical model of care both frightening and not necessarily appropriate or helpful for their child and the family, often leading to further distress:

I would say a lot of people are falling through the cracks, they are bewildered. They don't know where to go. And when they do go, it is a medical model in CAHMS. People get disillusioned quite quickly … some of the mothers are at their wits' end! (Psychology service)

The criteria or threshold levels for accessing services can be quite high, and service providers have expressed frustration with accessing CAMHS for young people with significant distress but without a diagnosis:

For the CAHMS service, they would need to have a … diagnosable mental health difficulty so what is called Access 1 or Access 2 … significant levels of anxiety, depression … sometimes you would get early onset psychosis at that age … significant mental health …

significantly impairing function (Psychology Service)

Services under CAHMS also differ in terms of criteria and referral protocols, which can have serious implications for young people who are considered to be in need of a professional assessment and timely service:

In terms of CAHMS, it's different in different areas. So in Clondalkin … we have Linn Dara CAMHS, and we would make a direct referral to them … And they are very responsive. In Tallaght it is Lucena CAHMS … they won't accept referrals … and they won't accept information … they have not adapted the standard operating procedures that CAHMS have in place, unfortunately. (Youth Service)

Location and convenience

Community-based services are acknowledged as key to engaging with young people and their families, particularly in terms of access in a large geographical area like Tallaght:

A lot of the evidence would say that having a lot of agencies community based is a much better approach to actually getting those parents and young people – that don't have the resources or the skills to navigate those systems – having it more accessible to them is a better way to get them to engage. (Youth Organisation 2)

However, service providers express frustration that the young person's address can have a negative impact on their ability to access certain services considered more appropriate to their needs:

And because the young person is not living in that area, they all, the geographical piece can come into it as well and then we are left holding the risk. (Family Support 1)

Counselling quality and training

Non-statutory agencies are viewed by some service providers as 'filling the gap' that statutory services are not currently providing:

In Tallaght … we have Village Counselling service and their training standards are nationally – they are complying with national guidance and that they run a Masters in child and adolescent counselling and so they have probably a lot of experienced therapists who are going to specialise [in teen counselling]. (Drug Misuse Agency 2)

Service providers who cannot access statutory services expressed concerns about the quality of some services available to them in the voluntary or non-statutory sector, but feel a duty of care to provide a link to some service rather than none at all:

Quality, counselling can be quite unregulated and so, some of the low-cost services who provide brilliant service in the absence of any funded services, there is variable quality. (GP 1)

Youth focus

All service providers indicated that current service provision needs to be youth focused and recognise that young people are still developing. Early and timely treatment is more likely to result in good outcomes and prevent current issues escalating:

It seems ridiculous to me that we have longer waiting lists in the adolescent age range than we do in the adult age range … to leave them [young people] on an unhealthy developmental trajectory for an extra six months when you should be able to respond in a couple of weeks seems to be wholly inappropriate in an ideal world. (Psychology service)

Jigsaw is recognised by many service providers as being youth focused and appropriate for young people aged 12 to 18 for mild to moderate levels of mental health needs. (It actually provides services for 12 to 25 year olds). The gap in services occurs when the difficulty is more serious, as Jigsaw works with young people who only need a short-term intervention (see Self-Harm above):

Jigsaw is very good for a certain cohort, but they are more mild really. (Psychology Service)

So Jigsaw are not a comprehensive mental health service so they … I can't remember exactly what their criteria were, but particularly if there is any kind of active suicidal ideation. (GP 2)

I know for Jigsaw, they would all say that if a child has serious mental health difficulties, they do not have the specialist training to manage that so they don't take them on. (Social worker)

Service providers acknowledged that the medical model was not necessarily helpful for children experiencing difficulties. Services needed to be both local and convenient for families. The quality of counselling services, particularly in the private sector, was questioned by health professionals. Nevertheless, health professionals felt obliged to pass on details when significant distress was evident and waiting lists were a barrier to assessment and treatment. Staff turnover creates difficulties for service providers who have built up relationships with individual staff members, as they lose that link with them to access services for young people and their families in the absence of referral pathways. Service providers consider it important for services to be focused on youths aged 12 to 18 rather than having to link in with either child or adult services, neither of which are considered appropriate for this age group.

Staffing and resources

Service providers acknowledge that inter-agency relationships and cooperation are good in the Tallaght area. However, this can often be negatively affected by staff turnover:

So we have to work pretty hard at linking in with potential referrers to remind them that we exist and what we do. Staff turnover, a lot in social work departments or in some of the youth services. (Drug Misuse Agency 1)

Staff changes can be an issue where there may be staffing gaps, so there is not someone currently in post who can take the referral or somebody new and they are trying to find their feet and they are not happy, at that stage, to take on large volumes of referrals. (Youth Organisation 2)

While providers acknowledge that there is a lot of community infrastructure in the Tallaght region, there is a lack of personnel to provide the services:

There is a community centre in almost every community in Tallaght … But it is not a lack of venues or community services – lack of staff. (Youth Organisation 1)

Staffing and resources are an issue across the mental health services, which in turn leads to long waiting lists and thresholds being increased in order to maintain existing services:

I think there is a deficit in mental health professionals as well. (GP2)

In an ideal world, like, I think staffing and funding for the mental health services [required] – like they do not have enough personnel so they tend to be defensive … they don't even have the psychologists. (Social Worker)

Specific purpose funding, with the resulting strict accountability for the multitude of organisations in the Tallaght area, is viewed by service providers as a limitation that leads to less flexibility and a restriction of services based on need rather than availability:

Everyone is funded now for a very specific purpose … you are more accountable in terms of the numbers of people you are working with, the rationale for why you have accepted them onto your services … that there is less flexibility … in terms of being able to go outside of that remit … this does constrict the services. (Youth Organisation 2)

3.2 Findings – parents

This section presents the findings for parents. The same overall themes were identified, with sub-themes including: Assessment of Need (AON); dismissal of the mother's views and observations by health professionals; mothers doing their own research; impact of the young person's difficulties on other children; cost of private services; and staff changes. Homelessness and ethnic minorities did not feature for parents.

Eleven parents were interviewed, all of whom were mothers despite all parents being invited to participate. While eleven children were the focus of the interviews, some parents had more than one child with a diagnosis or had other children negatively affected by the 'focus' child. Four of the eleven children were suicidal and had engaged in self-harm, with three of these having a diagnosis of Asperger's syndrome; two were mainly presenting with substance abuse and associated behavioural issues; four were suffering from anxiety; and one was suffering from severe depression. Therefore, 26 children in 11 families were affected in total.

Table 3: Semi-structured interviews with Parents (N = 11) – family details

	Children	Focus Child	Conditions diagnosed	No. children in family
1	Girls 12, 14	Girl 14	Suicidal, Asperger's, depression, self-harm	2
2	Girl 12, Boy 9	Girl 12	Suicidal	2
3	Girls 18, 29 Boys 28, 34	Girl 18	Suicidal, self-harm	4
4	Girl 17, Boys 8, 13	Girl 17	Suicidal, Asperger's, [rare condition], epilepsy	3
5	Boy 18, Girl 22	Boy 18	Cannabis, school refusal	2
6	Girls 12, 20, 23	Girl 12	Asperger's, ADD, diabetic, severe depression	3
7	Boy 16	Boy 16	Cannabis, behaviour	1
8	Girl 17, Boy 15	Girl 17	Anxiety	2
9	Boys 13, 24, 22	Son 13	Anxiety	3
10	Boys 15, 13, 11	Boy 15	Anxiety, depression	3
11	Girl 12	Girl 12	Anxiety	1

3.2.1 Diagnosis not being a gateway to services

Assessment of Need (AON) not leading to services

Mothers expressed frustration at not being able to get a diagnosis which could have led to earlier intervention for their child's issues:

> *It has taken such a toll on our family, to not get that diagnosis, at that age. Because when you get the diagnosis at least you have the option to either educate yourself or not. (Rosie)*

The AON, considered necessary by service providers, does not necessarily lead to therapy or treatment, and the long waiting lists lead to delays that negatively impact on young people's education and development:

> *The assessment of need is that she requires occupational therapy, speech and language therapy and psychology … the service statement when I got it was 33 months' wait … now increased to 44 months and that means she will be 17 … no support given for the whole of her schooling. (Rosie)*

> *I am waiting for another Assessment of Needs in Chamber House now – I think I am 8 months now waiting for this? Because she has really bad sensory. (Marie)*

A diagnosis or official report of some kind was viewed by some mothers as a gateway to access services:

> *So that Ed Psych Report was an official document that seemed to tick a few boxes and open a couple of possible opportunities or avenues. (Teresa)*

In an apparent contradiction, mothers also reported that they primarily wanted practical 'help' rather than a diagnosis:

> *They [the service] kinda wanted to diagnose [child] immediately with Asperger's, which I wasn't happy about, I wanted help, I didn't want a diagnosis, as we already had this big diagnosis beforehand [rare physical syndrome]. (Norah)*

Parents didn't want their child to be labelled, but seemed to consider that young people need a 'diagnosis' to obtain the services the child and family needed:

> *I didn't want a label, I wanted help … that disappointed me … the neurologist … said, 'Look that means nothing, that label does not mean anything, she is still who she is. But if it means that, you take that and put it in your back pocket to get the help she needs and the services'. (Norah)*

Despite obtaining an AON, mothers found that there was no assistance for mental health issues if a child was diagnosed with Asperger's syndrome or Autistic Spectrum Disorder (ASD):

> *There is no help for the mental, there is more help for the physical. (Marie)*

Dismissal of mother by health professionals

Mothers reported feeling dismissed by health professionals (HPs) at an early stage when they had initial concerns about their child, with their own observations of their child's behaviour not being listened to or respected:

> *So it's really difficult because it's like you're getting 'no' even from the professionals, who know and from the people who don't know. You're in the know, but you seem to be the least important person in the whole scheme of things. (Rosie)*

> *But even though as a parent I seen the change, and I am around her 24/7 and I can sit down and tell them, they still would question everything I am saying to them. So I felt like I was trying to pull teeth. Like you are not getting me. (Marie)*

Dual and late diagnosis

Some mothers who did their own research when they were initially concerned about their child's health and behaviour and whose 'diagnosis' and concerns were dismissed by health professionals subsequently had a very late diagnosis, which appeared to confirm their views and lead to anger and frustration at the loss of valuable time:

> *Asperger's first … and the following year ADHD at the age of 17 … it's been very difficult and I am very angry with the services … 12 years later then, they were saying, 'She does have ADHD, because these are the three things that signify it.' They are the exact things she came in with [service] at age 4. (Rosie)*

> *She was late getting diagnosed. She was 12 getting diagnosed and she has been in [service] on and off since she was 7. (Marie)*

Referral pathways

Substance misuse was reported by some parents as providing a gateway to other services that they may not have been able to access otherwise:

> *At least it means I can get into YoDA and stay there and I can get ... use them as a sounding board ... because again all of these services are interlinked but not in an obvious way.*
> *(Teresa)*

Agencies that focused on drug and alcohol misuse provide services for the family as well as the young person. Parents found these services very helpful in dealing with challenging behaviour and with their own resulting mental health issues:

> *We did family mediation but none of that is mental health … We have found it very easy to put our hands on a service that we needed. Now whether it was because [family member] was linked into to the addiction services and they all marry on from one another. (Lorna)*

Support by proxy

In some cases, the service provider provided support for the parent when the child refused to engage, with mothers reporting that they were able to use the skills gained in helping their child:

> *He refuses to engage and I have been attending instead. So he is getting vicarious help.*
> *(Teresa)*

3.2.2 An uncertain first port of call

HPs lack of knowledge of services

Parents expressed concern that they needed to do their own research about available services because of the lack of correct, up-to-date information from HPs in statutory services:

> *He [assessor] put together a packet and he gave me a load of leaflets about where I could get family support … Some of it turned out not to exist … which I thought that is a bit worrying. If they are giving out information that is bogus … That there is obsolete information which makes you panic. (Teresa)*

GPs in particular were criticised for not being able to recommend services or have knowledge of their effectiveness:

> *[GP] said, 'Oh yes, I have a list', and she gave me a lot of them that were on the IACP list in the area, but again, she said I can't recommend them because I don't actually get any feedback from patients so I don't actually know. (Lucy)*

Mothers reported getting their information on available supports and services through mother-to-mother support face to face and online rather than from HPs:

> *By meeting mums and pages [Facebook] and not even like OTs or anything told me this. By talking to mums on Facebook or at school, word of mouth, it was literally word of mouth.*
> *(Marie)*

Public versus private

When mothers had concerns that were dismissed by the HPs and could not access an assessment, some opted to pay for an assessment privately, which often led to a late diagnosis:

She only got diagnosed with dyslexia in second year. That was my own private. I brought her privately to get assessed. Because she didn't fit the criteria. She was 13 then. (Norah)

The cost of accessing private counselling is onerous for parents; it impacts negatively on the household budget and is not sustainable:

Like [child] went … there was a service … it was 100 euro a session … seriously, a 100 euro a week is just unrealistic. (Marie)

Own research

A lack of information from HPs and the health services leads mothers to do their own research. While there appears to be lots of information about services for serious mental health issues, there is little or no information for parents on where to go for mild to moderate issues where there are no waiting lists:

I think it is very much up to the parent to find something … your GP and your school give you a list and then it's up to you whether you go private or public and where you go. And as I say for urgent mental stuff, there's lots, but there doesn't seem to be that kind of in-betweenish sort of young teens up, or if there are, they certainly don't advertise themselves. I couldn't find one. (Lucy)

3.2.3 New issues emerging

Social media and internet

Parents were very concerned about the influence and impact of social media and the internet on their child's health and wellbeing. Some of them tried to counteract any negative impacts by setting limits on their use:

Life is so hard for them now and I know everybody says it was the same when we were growing up and stuff. But the whole phones, social media, everything is ridiculous. I am very restrictive with it … they are not allowed their phones in their rooms. They go off at 9 p.m. at night. (Annie)

In some cases, the young person voluntarily limited their own use of social media to avoid being pressured to behave in certain ways by their peers:

You used to be able to close your door to keep your kids safe, it's intrusive now … my daughter doesn't have Snapchat. She made that decision herself because she couldn't handle what was going on in the groups. (Michaela)

Waiting lists

Mothers report very long waiting lists for services, even when the child is deemed to be in need of an urgent appointment:

So he said he has a clinical psychologist, but the waiting list is over a year long … but he said she really does need to see somebody like that. (Sandy)

I want to get [child] into counselling at the minute and I rang the … [named] counselling services. They are good. I have been to them for myself … there is a waiting list probably for over a year. (Marie)

3.2.4 Family, culture, and community

Influence of family and peers

Parental difficulties such as separation, addiction or depression were linked by parents to their children's difficulties:

He [child] would get up, get ready for school, all the normal. Get to the school gates, brakes went on, could not go in. Kick, scream, cry … I think that's where his problems started. We were probably eight or nine months into the separation. (Lorna)

Parental fear and stigma

Mothers were reluctant to bring their child to statutory services, preferring to go the unofficial or counselling route first:

No, we haven't gone to the GP, we haven't gone to CAHMS, and we haven't gone to A and E. I just, I suppose I am in denial probably, she hasn't done anything, she hasn't acted out on any of the threats that she said. (Michaela)

The reluctance for this mother seemed to be related to medications and the possible negative implications for a young person taking them:

I want that [medications] to be the last resort for the simple reason that at this age group, I am petrified [emphasis]. I know of a case where a child was given Prozac … and he took his own life. (Michaela)

However, another parent spoke positively about medication helping her daughter to cope, which in turn helped the parent to cope with her daughter's anger and pain:

Very angry and just fighting a lot and arguing with me … she was just not a happy girl at all. Until she got on the tablets and then I seen a dramatic difference in her. Much calmer and happier and more content, just much nicer … she was just in so much pain … But it gets to the point where you are like, 'Jesus Christ just somebody help us'. (Sandy)

Again, mothers felt that their fears and concerns were dismissed by the HPs. Several mothers had done their own research in advance regarding medications and their side effects, which suggested a lack of trust in the advice and judgement of HPs:

I asked the psychologist about the side effects. She goes, 'There are no side effects', and when I got the medication I read the side effects. They were all leaning towards depression and suicidal thoughts and all that sort of thing … not to even say, well be careful of her mood … I just don't understand it … They are the profession of mental health. (Rosie)

A social worker is needed to access respite services, but parents were fearful of the stigma attached to engaging with Tusla, worried that their children would be taken away from them. This reinforces the negative connotations of the Tusla name previously referred to:

Yes, you need a social worker [for respite]. Not that I wanted anyone involved in my family, because my family are good, do you know that way? But there should be somebody out there that doesn't do with taking kids away just to help kids that are in need for extra support and there isn't … So basically my family have to be really bad to get help. (Marie)

Fear of child

Parents also expressed fear of their own child in terms of physical aggression, and some mothers felt ill-equipped to handle this:

A couple of weeks ago she like had a really bad meltdown … flying off the handle to the point where she was nearly getting a bit aggressive towards me ... physically aggressive. (Norah)

She would never hurt me or anything. She might go up and wreck her room. She would be all right after that. She would just get it all out. Like that's all gone now. When she gets the help. You just wonder how many kids are out there going through that, they just need some … they really do need some meds. (Sandy)

Agencies like YoDA, with their Non Violent Resistance programme (NVR), equipped some mothers with the skills to address violence:

I've made a statement against my son for assault [against me] … it has happened before but this time I am … actually going to go through with it. And that is going to necessitate [son] having to make a statement. (Teresa)

Services such as Lucena did provide useful assistance for parents in coping with their child's behaviour, including strategies that ran counter to the parent's instincts, particularly when the parent was fearful the child might hurt herself:

She didn't see a way out and I had to learn to, because when she was like that I used to follow her and like nearly … I don't mean chastise her but nearly trying to want to talk to her immediately … you know … break it down. Where I had to actually through Lucena Clinic … they advised me just … back off. (Norah)

Inter-generational trauma and disability

Some mothers were aware that their child's anxiety may have been induced by their own anxiety:

She doesn't want to talk about everything, some of her worries are because of me. So like she worries about money, she worries about my health, she worries about everything and that's just the tip of the iceberg … and that can be a normal thing to have those worries. (Michaela)

Parents expressed frustration at not knowing what services were available to them and how to access them:

It's word of mouth. I swear to God unless my kids had been diagnosed, I wouldn't have had a clue what services are out there. They are not advertised … I had no idea, even about carers and the payment. (Marie)

Parents reported feeling inadequate and in need of support themselves in meeting the challenges of dealing with their child's issues:

> *Feel out of my depth, I feel that I am walking on eggshells, I don't know what's hormones, what is actually her, her ill health and she couldn't really offer me anything which is fine, she [counsellor] is there for my daughter, and that is what is most important. (Michaela)*

However, some parents referred positively to the influence of their own parents on their parenting style in helping them to cope with their child's challenging behaviours:

> *I feel privileged to have the upbringing that we did and we had two very strong parents who set the ground rules and you left school, you worked … you worked and you paid your own way always and you had the strong ethics there. (Annie)*

Impact on family

A child in crisis or with ongoing difficulties had an adverse effect on the rest of the family, with other children affected:

> *When you are in a crisis and you want the best for your kid and for your family, it's difficult, as you are ringing people and no one's responding to you. (Norah)*

> *I was very angry with how they conduct their business. They don't seem to realise the effect it is having on families, over the long haul. (Rosie)*

Parents spoke about how the difficulties experienced by one child negatively affected other children in the family, which in turn affected their own health, wellbeing and ability to cope:

> *My son then, he didn't really … understand what was going on … and he broke down, [daughter] said in front of him [son], 'I want to kill myself' and his face, if you physically see somebody's heart break, his heart broke … all I can do is love them and keep them safe, but there is nowhere for me to go with him, I feel, at the minute. (Michaela)*

3.2.5 School as a gateway

Gateway for services

Parents found that school programmes such as Transition Year were very helpful in providing universal support to students without singling them out for special attention. For this child who had multiple issues such as autism, dyslexia, epilepsy and suicidal thoughts, this programme was very engaging:

> *They do a lot in school on self-awareness, wellbeing, self-defence. All those things, really kind of, helped her. Transition year really suited her. (Norah)*

The school also provided a vehicle for some mothers to do further research on particular topics, especially for those who were on parents' committees:

> *I volunteered in the school and we just gathered information, did some brainstorming. So my part in it was I went off to research all of these groups. (Michaela)*

Parents also appreciated the interest and concern of teachers for the students' welfare:

> *All these people [voluntary and school] really do want to help and their hands are tied … They are just really trying their best. (Sandy)*

The secondary schools in particular provided student support and a buffer to students, especially for cases of bullying. This support was appreciated by parents:

In first year kind of had a rough ride with friends and they were hassling him and they were his friends throughout primary school ... They dealt with it really, really well and they have a student support network in there. (Annie)

Teachers were often the first people to identify issues and organise assessments, resulting in additional supports being provided both in school and at home:

Teacher copped she had dyspraxia before I copped her. I am watching her [but] that's where she [teacher] … seen different things like her balance and coordination and stuff like that and she is the one that got her assessed for me. (Marie)

Lack of resources

Mothers reported that schools were not able to deal with behavioural issues, resorting to school expulsion, which left the child without an education. While some of the schools did have a 'relaxation' room for children with sensory issues, there seemed to be a lack of facilities for disruptive children to take time out:

In secondary school they need to find a way of disruptive children … instead of expelling them, suspending them, throwing them out of the class … When he started there in 1st year he used to talk about the relaxation room. (Lorna)

Some parents mentioned that schools were a good place to provide resources like counselling, as children were already attending and costs could be kept to a minimum, which would assist parents who would struggle to pay for private services:

Engage the services of maybe a trained counsellor even to come in even once a month … at maybe low cost where you are in the familiar environment but you are still able to chat away. It seems to be needed in a lot of schools, but I don't know any actual schools that have an actual onsite counsellor. (Lucy)

Individual staff were singled out for particular praise, but if they moved away from the school, went on maternity leave, or took a career break, this service was lost, as it depended on individual staff being interested and/or trained:

The school, it hasn't been great. They had a counsellor there … who was an amazing [emphasis] soul, who went above and beyond her role … and unfortunately went on career break. (Michaela)

3.2.6 Service quality and availability

Medical model

Parents expressed a preference for attending services that were not perceived as related to the 'medical model':

When I spoke to the nurse in [service] I felt that it was very extreme. I felt that she didn't … me personally I thought we could get her some counselling maybe, but I didn't feel that she needed to see … nearly be … they felt she should nearly need to be admitted. (Norah)

Location and convenience

Parents want to obtain established services that were 'local' and 'convenient' to them, youth focused, and with a good reputation. However, services were not always available or appropriate for the particular issue:

I think it is a brilliant resource that we have locally, so I was very upset … they [service] kind of have their fingers in so many pies but when my daughter was so low, her self-esteem was crushed, I felt that would be a positive place for her to go. It didn't [wasn't]. (Michaela)

We did try to get into Jigsaw in Tallaght, but they are actually gone, they are rebuilding, they are joining with Clondalkin? … I knew they were brilliant … so we just went to a local counsellor who was quite good. (Lucy)

Counselling quality and training

In the absence of counselling being available through state-funded services, some parents opt to pay for private counselling. However, they are not always confident about their effectiveness:

It is a stab in the dark like, for instance, some of them are not registered to … Some of them are registered to the IACP which is fine, but again, it is sort of hit and miss as to what you get. (Lucy)

Staffing and resources

Parents report that frequent staff changes lead to a gap in continuity of service for their child, which can increase the child's anxiety and distress:

She goes and gets more depressed after she explains everything she has been through. Then it is left for ages and then she has to go to talk to somebody else and tell them the exact same thing. (Sandy)

A child takes a long time to get comfortable with somebody and the minute they feel comfortable … that doctor is gone and somebody else is replacing her and they close back down, shut down, not talk. (Marie)

Youth focus

Parents were not comfortable about attending the Emergency Department, even when their child was suicidal and wanted to be able to access a youth-focused centre rather than an adult-appropriate one:

I think you should have somewhere to ring and not be told to go to A&E, that's all you're told go to A&E, if you think she is suicidal, bring her to A&E. There should be a clinic definitely for that age group. (Sandy)

Several parents said that they wanted to be able to attend Jigsaw with their child regardless of the severity of the issue, as that organisation was youth focused. However, Jigsaw does not deal with cases where self-harm is involved and this mother did not know that her daughter had self-harmed, leaving her without any support for herself:

> When we went to Jigsaw they weren't able to help us … because I was bringing this child … broken child home, who just disclosed to a girl that she had self-harmed and I didn't know what to do. I actually went into complete and utter panic mode … I had not realised … I think there was a questionnaire, have you ever self-harmed? And [child] said yes. And that's when the meeting had to stop. (Norah)

Several parents were critical of the lack of services that were youth focused, expressing disappointment that Jigsaw, in particular, was not able to provide a service for their child and did not accept the referral by a mother:

> They [Jigsaw] basically said that they wouldn't take my daughter in unless it was prescribed as a course of treatment for her or is something that somebody else felt was necessary for her and I was so devastated, because I would be a big advocate for Jigsaw. We don't have specialised, focused on the children. I thought Jigsaw was it to be honest! (Michaela)

3.3 Quantitative data analysis

3.3.1 Prevalence

In order to compute the estimated number of young people impacted by mental health issues, the region and the age group needs to be defined. It is also important if possible that the timing or year of the estimate is set. Given related work in the region, it was decided to define the region broadly and align it to work completed on young people by the Tallaght Local Drug and Alcohol Task Force. The boundary of the task force was previously defined as the 13 core Electoral Divisions (EDs) of Tallaght, along with 6 others that the task force services (Comiskey et al., 2017). The population size of young people aged 12 to 18 for these regions in provided in Table 4 below.

Table 4: Population of Tallaght area (CSO, 2017): Aged 12 to 18

Tallaght EDs	Males aged:								Female aged:							
	12	13	14	15	16	17	18	Total	12	13	14	15	16	17	18	Total
Firhouse-Ballycullen	74	56	61	53	64	77	66	451	61	62	72	75	69	65	66	470
Firhouse-Knocklyon	18	26	11	17	13	19	27	131	12	11	16	18	11	25	19	112
Firhouse Village	103	94	104	102	77	105	95	680	84	73	90	92	80	87	74	580
Saggart	20	15	25	18	20	15	19	132	27	26	18	14	13	16	18	132
Tallaght-Avonbeg	13	9	12	9	13	14	10	80	9	12	11	14	9	10	11	76
Tallaght-Belgard	10	8	5	5	8	9	6	51	7	7	10	6	10	6	8	54
Tallaght-Fettercairn	84	90	93	89	77	89	84	606	83	71	88	96	74	68	67	547
Tallaght-Glenview	4	7	6	4	8	4	11	44	15	12	5	6	8	10	8	64
Tallaght-Jobstown	187	177	191	159	168	144	114	1140	174	170	171	143	154	116	115	1043
Tallaght-Killinardan	37	34	40	47	46	43	46	293	24	30	29	41	30	34	31	219
Tallaght-Kilnamanagh	17	21	21	18	22	23	23	145	25	17	12	19	25	28	15	141
Tallaght-Kiltipper	64	64	64	61	74	74	64	465	93	68	72	66	66	57	61	483
Tallaght-Kingswood	21	16	20	18	11	10	20	116	15	22	11	19	16	18	12	113
Tallaght-Millbrook	17	10	10	25	18	20	12	112	13	20	11	13	13	20	14	104
Tallaght-Oldbawn	23	20	30	28	21	27	25	174	22	15	19	32	19	16	21	144
Tallaght-Springfield	58	48	48	45	53	51	51	354	57	60	46	45	42	36	40	326
Tallaght-Tymon	36	39	34	29	36	32	24	230	25	35	36	23	24	32	30	205
Ballyboden	28	33	26	28	28	35	29	207	29	33	21	38	36	35	39	231
Edmondstown	51	34	35	36	41	45	50	292	39	32	41	33	29	40	46	260
Total	865	801	836	791	798	836	776	5703	814	776	779	793	728	719	695	5304

A graph of this population by gender and age is provided in Figure 3 and a graph by gender and region is provided in Figure 4. From Table 4 we can say that B (the known total number of young people in our estimation formula above) is given by the number of males aged 12 to 18 plus the number of females aged 12 to 18. We have B = 5,703 males + 5,304 females = 11,007 known young people in the defined Tallaght region in 2016.

Figure 3: Population of young people by gender in each age group (CSO, 2017): Aged 12–18
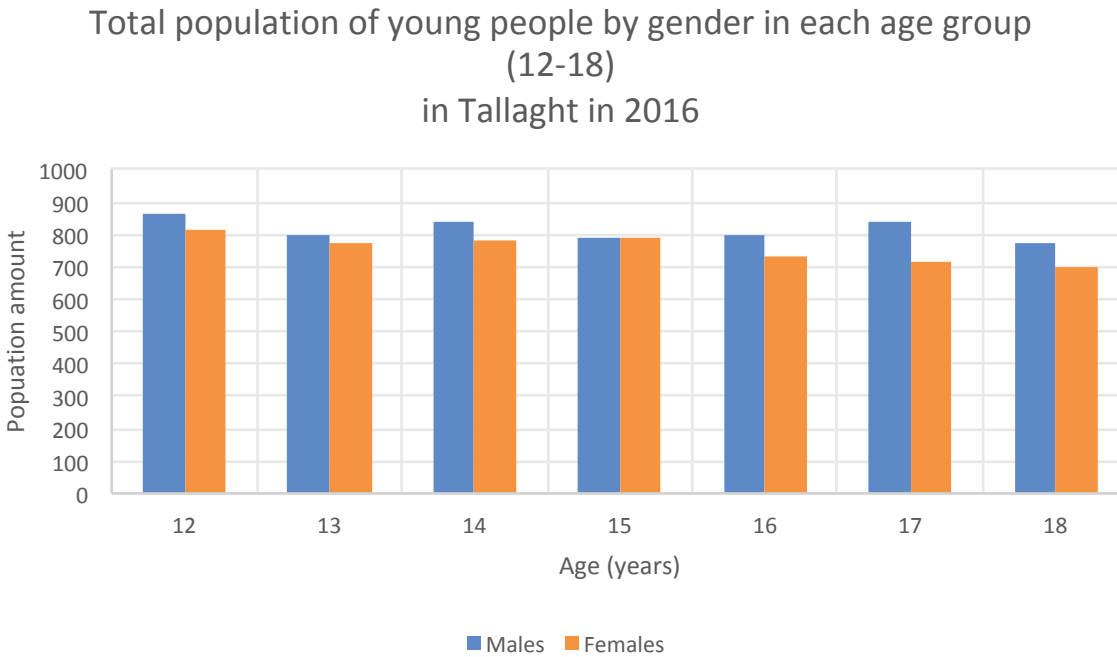

Total population of young people by gender in each age group (12-18) in Tallaght in 2016

Figure 4: Population of young people per region (CSO, 2017): Aged 12–18

Population of young people aged 12-18 per region in 2016
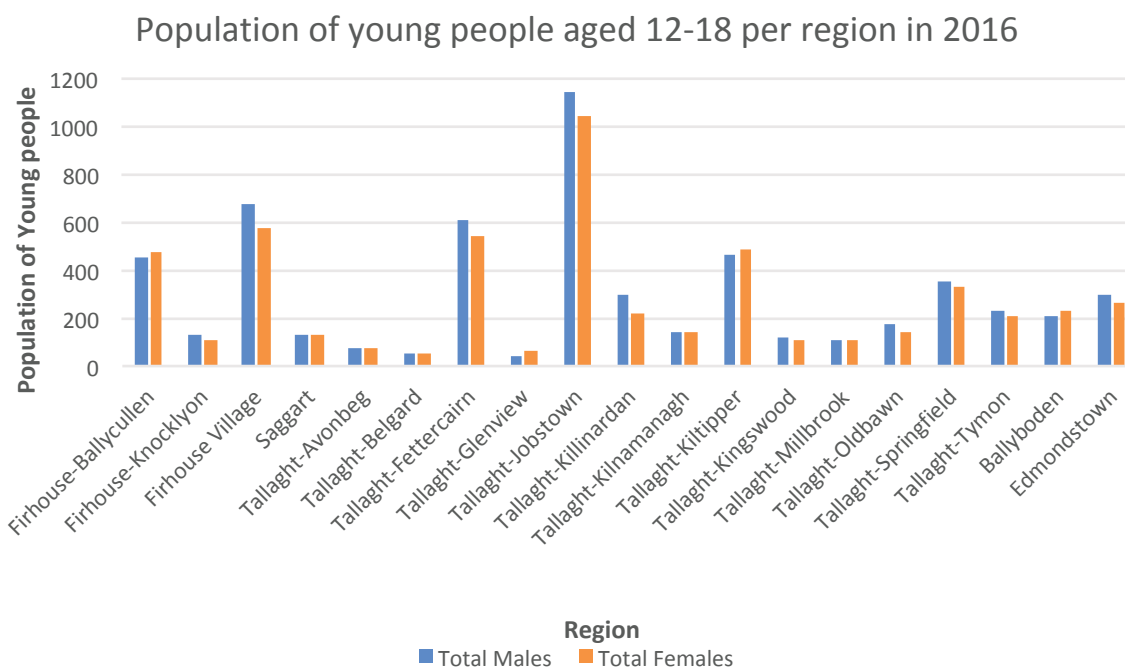
Risk of mental health challenges (estimating M)

The World Health Organisation (WHO) defines mental health as a state of wellbeing in which every individual realises his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community (WHO, 2001; WHO, 2005a; WHO, 2005b). Working with this definition, we can use general population surveys among young people to provide an estimate of the proportion of young people experiencing mental health challenges. One such survey is the My World Survey (Dooley and Fitzgerald, 2012), which states that the number one health issue for young people is their mental health. About 70% of health problems and most mortality among the young arise as a result of mental health difficulties and substance-use disorders and almost 75% of all serious mental health difficulties first emerge between the ages of 15 and 25.

The My World Survey, conducted in 2010, also defined mental health as a state of wellbeing in which the individual recognises their own abilities and is able to cope with normal daily stresses in life (Dooley and Fitzgerald, 2012). A total of 72 second-level schools, randomly selected from the Department of Education and Skills (DES) database, participated, with 6,085 adolescents completing the survey. Ages ranged from 12 to 19 years (mean = 14.93), 51% were females, and all school years were represented in the study. A further 8,221 older participants were drawn from samples of young adults in third-level education, enrolled on national training courses/schemes, unemployed and employed. Ages for this older group ranged from 17 to 25 years (mean = 20.35), and 65% were females. Data were collected from young people in second-level education in each of the 26 counties, and from every university in the Republic of Ireland, giving a sample size of nearly 15,000 young people. Only 14,306 were included in the final report, as approximately 600 respondents were excluded because they were not permanent residents in Ireland.

Table 5 below sets out the prevalence of a range of mental health issues as identified in the My World Survey, along with additional corroborative research.

Table 5: Estimates of proportions experiencing mental health challenges as reported in the My World adolescent school surveys of 12- to 19-year-olds

Mental Health Symptom	Estimates of the Multiplier M (My World, 2012)	Validating/Corroborating References
Depression*	Mild 11%; Moderate 11%; Severe or very severe 8%	Lynch et al.(2005) screened 723 young people aged 12 to 15 in Dublin and **found that 1 in 5 were 'at risk' of developing a mental health disorder**. While 16% met the criteria for a current diagnosis, of these, few had come to the attention of CAMHS.
Anxiety*	Mild 7%; Moderate 14%; Severe or very severe 11%	
Stress*	Mild 7%; Moderate 7%; Severe or very severe 5%	
Formal help sought for depression, anxiety or stress in the last year	9% reported 'some' but did not seek professional help even though they felt they had needed it; 6% reported that they had problems and sought professional help for them.	Martin et al. (2006) examined the prevalence of psychological disorders among 3,374 children and adolescents aged 18 years and under in the south-east of Ireland. **The study reported that about 19% met the criteria for at least one psychological disorder** (21% for those aged 12 to 18). Of these, 43% **(9% overall) were identified as having an anxiety disorder**. One-fifth of individuals had symptoms or problems associated with clinical risk. Most of those identified as either being at risk or meeting the criteria for a psychiatric disorder were receiving no professional help, and fewer still had contact with CAMHS.
Suicidal ideation (My World young person survey ages 17 to 25)	Approximately 43% reported that they had thought that their life was not worth living at some point. A third of participants (33%) reported that they had thought this within the past year. Just over half the sample (51%) had thought about taking their life though they 'would not do it'. Of these, 35% indicated that they had thought about it within the past year.	In Sullivan et al. (2004) almost 4,000 students aged 15 to 17 were screened in the Cork and Kerry region. **Serious personal, emotional, behavioural or mental health problems were experienced by 27% of adolescents.** A higher proportion of females displayed signs of depression (8%) and had an emotional disorder (13%) than males (5% and 6% respectively). **A lifetime history of deliberate self-harm was reported by 12%.**

***Depression, Anxiety and Stress Scale (DASS-21)** The DASS-21 is a self-report measure in which participants rate the frequency and severity of experiencing negative emotions over the previous week. The scale contains items on depression, anxiety and stress. Using recommended cut-off scores (Lovibond & Lovibond, 1995), adolescents are classified as displaying normal, mild, moderate, severe or extremely severe symptoms of depression, anxiety or stress. ****Suicidal behaviours.** Four questions on suicidal ideation, self-harm and suicide attempt were used. Each question measured lifetime rate and frequency in the past year.

Indirect estimate of the number of young people aged 12 to 18 at risk (Estimating R)

Given the benchmark multiplier formula provided above along with the estimates of the number of 12- to 18-year-olds in the wider Tallaght region as defined in Table 4 and the multipliers on the proportions of young people at risk as estimated by the My World Survey (Dooley and Fitzgerald, 2012) and corroborated by additional references, a range of indirect estimates can be derived. These are provided below, along

with their 95% confidence intervals (CIs). The usual Wald CI for a proportion was used to provide CIs for the estimates of the multipliers for depression, anxiety, stress and suicidal ideation. The simple confidence interval for a sample proportion is given by:

$$\hat{p} \pm z\sqrt{\frac{\hat{p}\,(1-\hat{p})}{n}},$$

where z = 1.96 for 95% confidence interval, $\hat{p}$ is the proportion experiencing the mental health symptom and n is the sample size. For the calculations in this report, a combination of Excel and the calculator available at http://www.sample-size.net/confidence-interval-proportion/ was used to compute the confidence intervals for the estimates.

Table 6: Indirect estimates of the number of 12- to 18-year-olds in the wider Tallaght region at risk of experiencing mental health symptom

	Multiplier, M	Benchmark, B	Estimate, R	z	N for Multiplier	Lower CI for M	Upper CI for M	Lower CI for R	Upper CI for R
Depression									
Overall	0.3	11007	3302	1.96	6085	0.289	0.312	3181	3434
Mild	0.11	11007	1211	1.96	6085	0.102	0.118	1123	1299
Moderate	0.11	11007	1211	1.96	6085	0.102	0.118	1123	1299
Severe	0.08	11007	881	1.96	6085	0.073	0.087	804	958
Anxiety									
Overall	0.32	11007	3522	1.96	6085	0.308	0.332	3390	3654
Mild	0.07	11007	770	1.96	6085	0.064	0.077	704	848
Moderate	0.14	11007	1541	1.96	6085	0.131	0.149	1442	1640
Severe	0.11	11007	1211	1.96	6085	0.102	0.118	1123	1299
Stress									
Overall	0.19	11007	2091	1.96	6085	0.18	0.2	1981	2201
Mild	0.07	11007	770	1.96	6085	0.064	0.077	704	848
Moderate	0.07	11007	770	1.96	6085	0.064	0.077	704	848
Severe	0.05	11007	550	1.96	6085	0.045	0.056	495	616
Suicidal ideation									

Approximately 43% reported that they had thought that their life was not worth living at some point (My World Survey ages 17 to 25) (Dooley and Fitzgerald, 2012).

Relevant estimates for suicidal ideation could not be provided for those under 18, as the relevant question was not asked of the adolescents aged 12 to 18 within the My World Survey (Dooley and Fitzgerald, 2012). However, some details were available for over-18s. Approximately 43% reported that they had thought that their life was not worth living at some point. A third of participants (33%) reported that they had thought this within the past year. Just over half the sample (51%) had thought about taking their life though they 'would not do it'. Of these, 35% indicated that they had thought about it within the past year.

In terms of seeking formal help for depression, anxiety or stress in the last year, 9% reported 'some' but did not seek professional help even though they felt they had needed it; 6% reported that they had problems and sought professional help for them.

We can see from Table 6 that the overall range in the estimates is from 550 young people suffering from severe stress to 3,552 overall suffering from anxiety. The mean estimate over all estimates was 1,486 individuals and the median estimate was 1,211 individuals. However, for planning purposes, given the range of estimates, it would be prudent to plan services for the needs of approximately 1,500 young people.

Chapter 4

Discussion &
Recommendations

Chapter 4 – Discussion And Recommendations

4.1 Discussion

Cultural Historical Activity Theory (CHAT) as outlined in Chapter 2 was used as the theoretical framework for design and analysis of this research and will be referred to throughout.

As previously outlined, six main themes were identified that were common to both service provider and parent interviews: diagnosis as not being a gateway to services; an uncertain first port of call; new issues emerging; parents and family; school as a gateway; and service quality and availability. Parents tended to focus on their own role in obtaining services for their young person; the dismissal of the services of their concerns; the impact on other children in the family; and the cost incurred by parents securing assistance privately. Service providers focused on the lack of treatment despite having an assessment or diagnosis; a one-stop shop for services; and the new issues of homelessness and ethnic minorities. The difference in focus between service providers and parents is outlined under the six main themes. Sub-themes common to both service providers and parents are represented in blue, the parents-only focus is represented in green, and the service provider-only focus is in orange.

4.1.1 Diagnosis not a gateway to services

**Figure 5: Diagnosis not being a gateway to services?**
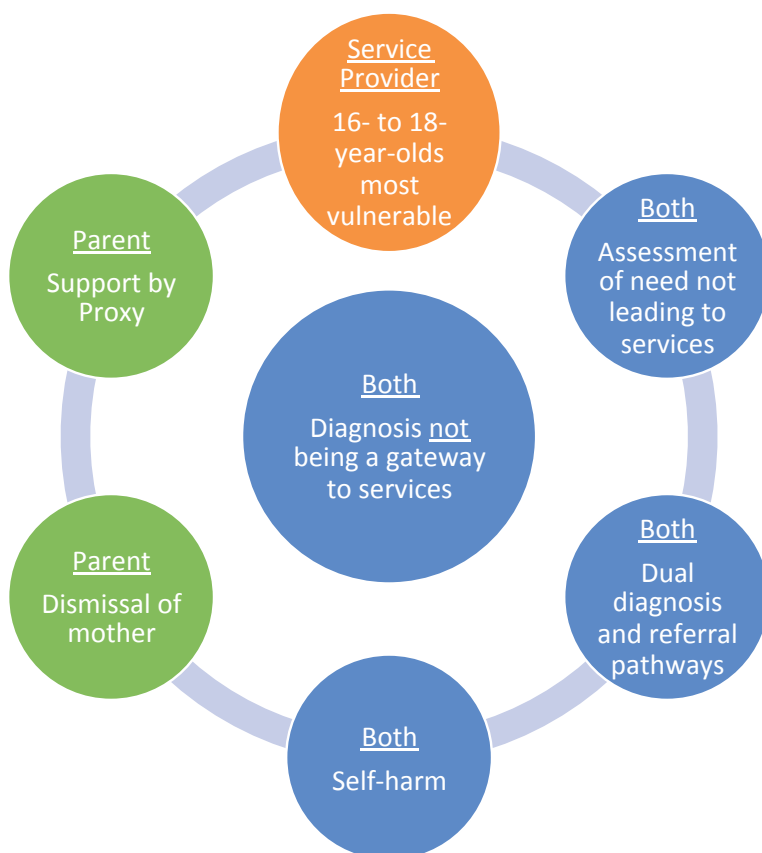
Both service providers and parents mentioned that diagnosis was important, if not essential, to secure services for a child. However, the group aged 16 to 18 years of age seemed to be particularly vulnerable, as neither children nor adult services are currently set up to deal with the unique and special needs of this

cohort, as acknowledged previously by RCPI (2015). In this study GPs were concerned that adult services were not appropriate for young people. GPs were therefore very reluctant to refer young people to adult services.

Additionally, GPs treated 16-year-olds on their own and without parental consent or knowledge for many issues, but other service providers varied in practice as to whether or not a young person aged 16 could self-refer and get treatment. Dual diagnosis was an area of particular concern for both service providers and parents, with both expressing surprise and frustration that once there was a dual diagnosis it often resulted in no service at all. One service provider referred to this as a 'silo' mentality (GP2). Staff roles and services, along with criteria for treatment, need to be urgently addressed in practice rather than in theory, to decide who does what, when, and with whom, whilst maintaining flexibility. Figure 2 (Chapter 1) amply confirms this point with its illustration of the young person as a 'whole person' (RCPI, 2015).

4.1.2 An uncertain first port of call

Figure 6: An uncertain first port of call
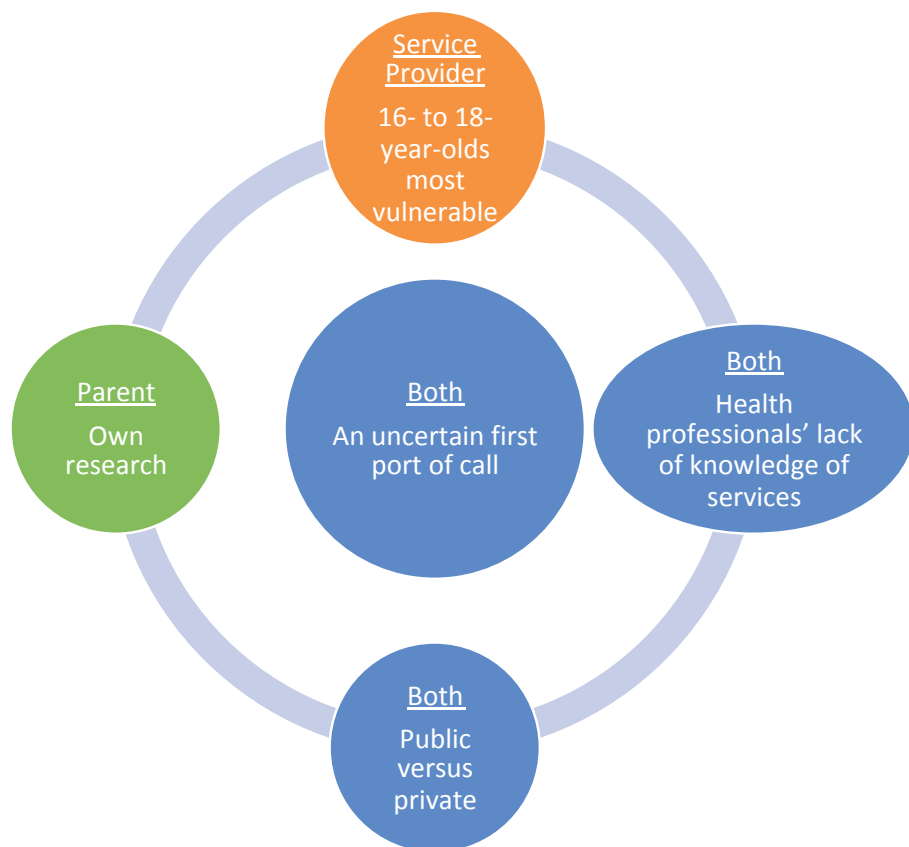
Findings clearly show that GPs are considered the first port of call by both themselves and other service providers in line with previous research (Byrne et al., 2015; UNICEF Ireland, 2011), yet fewer than 20% of young people with mental health difficulties access the GP services (Byrne et al., 2015). Other research findings indicate that depressed and suicidal adolescents are unlikely to seek help from any source, while those who do seek help prefer peer support (Chambers and Murphy, 2011; Sullivan et al., 2004). This lends credence to the view that there are large numbers of young people suffering without support.

A contradiction in the findings is that while health service policy documents maintain that services are becoming more integrated (Children's Health Ireland, 2019), the service providers and parents are not experiencing this on the ground.

4.1.3 New issues emerging

Figure 7: New issues emerging
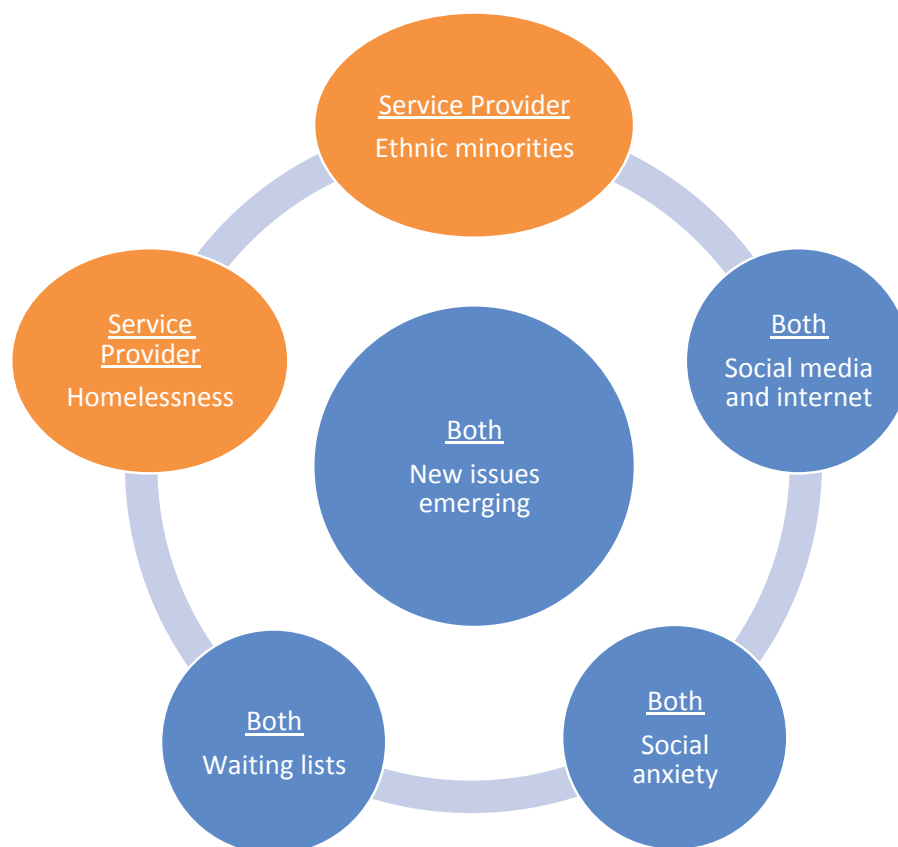
The findings were that two new issues have arisen over the last few years that have created difficulties for parents, schools, young people and society, although service providers and parents emphasised different aspects of these emerging trends.

Service providers were acutely aware of the pressures the use of social media and technology placed on parenting, but also on the provision of services itself, as staff expressed concern that they are not prepared for future negative outcomes caused by the current use of social media and technology by young people – 'there is a lot coming our way that we are not prepared for' (School Completion Officer). Service providers used words like 'invasive' and referred to the 'medicalised language' used on social media that may be leading to pathologisation of normal youth behaviour and feelings (Youth Service).

An interesting finding was that parents seemed to mention technology, social media and the internet as if they were an 'object' that could not be controlled rather than relating to boundaries that parents have to establish. However, service providers frequently referred to gaming as a significant issue that leads to anxiety, lack of sleep, tiredness and school refusal. The service providers seemed to attribute this to parents feeling unable to deal with gaming or to lay down boundaries without fear of repercussions:

They are gaming half the night and then they are asleep all day … parents are saying they can't get them to school – it's quite permissive parenting. (SCP)

This strongly suggests that parents need support to support their children. This was also mentioned by the GPs, the drug substance misuse service, and a parent supporting the child by proxy. With GPs often seeing the parent and never the child (GP1), and young people refusing to attend services for drugs misuse, service providers find themselves providing support for the parent and possibly other family members in the absence of the young person at the centre of the concern. The cost to both individuals and the wider society can be considerable as a result of poor health, long-term social maladjustment, high use of child and adults services through a lifetime, and the associated final implications for both families and the health services (Goodman et al., 2011). From a CHAT perspective, individuals cannot be separated from their community; the boundaries are not fixed, with groups of people having shared objects such as positive relationships and harmonious living. As previously mentioned, parents and their children are inextricably linked, with one person's difficulties and experiences impacting on other family members, but also that person's difficulties a possible result of their family experiences. A family is a small community, with communities constantly being constructed and constantly changing (Taylor, 2009).

These findings are supported by Health Service Executive (HSE) data. Figures for individuals discharged from hospital with 'anxiety' as the principal diagnosis doubled over the last 10 years, with the under-16 rates specifically having tripled over that period (Flynn, 2019; Houses of the Oireachtas, 2019). The Adolescent Brain Development Study found that anxiety disorders remain the most common lifetime disorder type for 11- to 13-year-olds, with 1 in 20 meeting lifetime criteria for generalised anxiety disorder (5.5%), social phobia (5.1%) and separation anxiety (4.7%) (Cannon et al., 2013). The figures reflect the finding that social anxiety seemed particularly prevalent in the young people in this study. According to Kim-Cohen et al. (2003), adolescence is a critical period for mental health, with the start of about half of all lifetime mental conditions such as anxiety and depression occurring by 15 years of age, and anxiety and major depressive disorder often co-occurring.

According to Kochel et al. (2012), anxious and depressed youths are more likely to experience disrupted peer relationships. However, poor peer relationships may also precipitate depressive symptoms, with both poor peer relations and depression reciprocally associated across time (Kochel et al., 2012). Kochel et al. (2012) also conclude that depressive symptoms and youth psychological dysfunction leave lasting damage that can undermine normal development of key skills and milestones, with lifetime implications. It is critical, therefore, that young people receive the support they need when they need it.

Colver and Longwell (2013) also acknowledge the growing influence of peers in adolescence, which along with rapid neurobiological changes associated with novelty and reward seeking, impulsivity and risk-taking, can lead to very difficult experiences for both adolescents and their families. The vulnerable period of brain development and social re-orientation coincides with other complex development situations such as attending school and entering further education or employment as young people also seek increasing autonomy (Pao, 2017).

While waiting lists are not a 'new' issue, the HSE National Service Plan has prioritised the reduction of Child and Adolescent Mental Health Services (CAMHS) waiting lists and provision of appropriate mental health interventions to children and young people (Houses of the Oireachtas, 2019; Children's Health Ireland, 2019). In June 2019 the total number of children waiting to be seen by CAMHS was 2,440 nationally,

with 177 (7.3%) waiting in the CH07 area (HSE, 2019e) and none waiting over 12 months. In total there were 2,567 child/adolescent referrals received by CAMHS in 2018 in the CH07 area compared with 18,650 nationally (HSE, 2019e).

From a CHAT perspective, interacting activity systems may have different goals with similar outcomes (Engeström and Sannino, 2010). For example, a GP may focus on the parent's source of stress and identifying the 'real' issue presenting, whereas the parent may want outside help to get the child to attend school and be less anxious. If the two systems interact and support each other, the differing objectives may result in a joint objective (Object 3 in Figure 8) such as referral for a child to an appropriate service. This may then have the possible outcome of the child being referred appropriately and the parent being less stressed.

Figure 8: Interacting Activity System: parent and health professional (GP)

Rules	Community	Division of Labour	Division of Labour	Community	Rules
Referral criteria	GP	Parent	GP service	Child	Criteria for
Medical card	Family	Child	HSE and TUSLA	Parent	services
Age of consent	Local services	Family	CAMHS	HP colleagues	Referral pathway?
	School	Services	School	Local services	Age of consent
		School	Community services	Family	Available services
			Hospital	Practice nurse	

4.1.4 Family, culture, and community

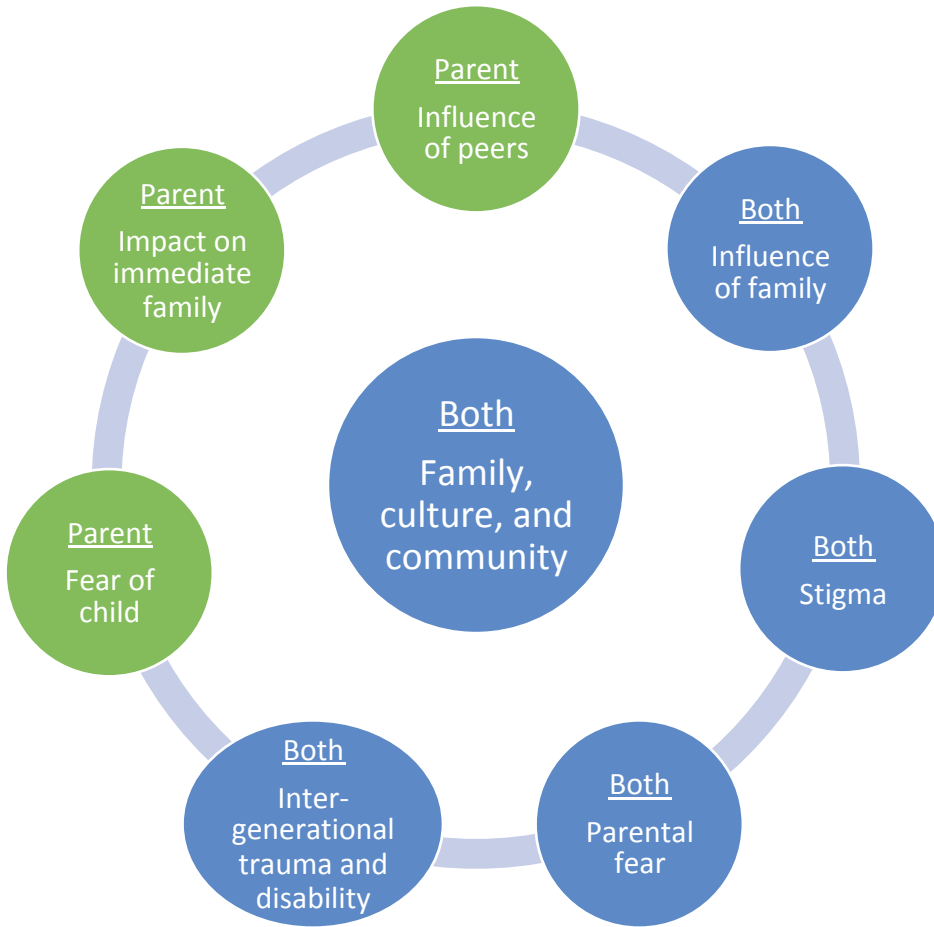**Figure 9: Family, culture, and community**

Table 3 demonstrates that for 11 parent interviews focusing on 1 child with mental health difficulties, 26 young people were affected in total. From a CHAT perspective, this also highlights an outcome that may or may not have been considered or expected. While parents seem to be very aware that the other children in the family are being negatively affected by the young person's difficulties and/or lack of appropriate service provision, without a whole family holistic approach from service providers, the outcome could be seriously damaging to the family as a whole.

The 'successful' transition from child to adult is deemed to be contextually and culturally dependent. Researchers propose that parents, schools, health professionals and policymakers need to be aware of their assumptions and key role in these processes (Pao, 2017). However, the concept of what is 'successful' is not clear and varies between and among cultures (Pao, 2017, p. 191). Allen (2013, p. 40) maintains that while 'normal adolescence' is accepted in Western societal culture as a 'biologically driven phase characterized by emotional turmoil and irrational behavior', it is a socially constructed concept that is used to explain the contradictions that are inherent in societies at this stage of life development. Colver and Longwell (2013) acknowledge the debate about whether the period of development between 11 and 25 years of age (or 'adolescence') should be treated as a special period at all, despite new imaging techniques showing striking changes. In many cultures, adolescent 'exuberance and creativity' are accepted as normal. In such cultures young people are able to explore in relative safety, bounded by their communities (Colver and Longwell, 2013). The concept of what is 'normal' development for young people, according to anthropological and

historical research, shows that this varies between cultures and in different historical periods (Colver and Longwell, 2013).

Service providers in this study reported that in working class communities the fear of being stigmatised by others for having mental health issues prevented young people from seeking assistance. As the literature shows, fear of negative reactions from peers is a common reason given for not seeking help (Barney et al, 2006). Yet contradictorily, young people are more likely to seek information and support from their peers (Byrne et al., 2015).

For parents, stigma seemed to be driven by parental fear of engaging with healthcare professionals and service providers, possibly arising from fear of a formal diagnosis and medications, and also a fear of compromising their child's future prospects by having a diagnosis on their health records. Service providers did acknowledge that parents had legitimate concerns with regard to medical records (GP1, Drugs Substance Misuse 2) and that some children may not receive appropriate services because parents do not seek assistance from formal referral pathways. For example, if a child were seeking a mortgage or life assurance as an adult (see Parental Fear, Section 3.1.4), the GP may be required to disclose the young person's health records, including any mental health difficulties.

For both healthcare providers and parents, agencies that are viewed as youth focused may be more appropriate sources of support and information than statutory services, which are either child focused or adult focused. While service providers were complimentary about youth-focused organisations such as Jigsaw, there was a perception that such organisations were not comprehensive mental health services (GP2) and were suitable for 'mild' issues rather than more serious ones (Psychology Service, Social Worker). Most service providers considered that a service that focused on young people aged 12 to 18 is required rather than a binary child or adult service. Some parents who had accessed youth-focused drug substance misuse agencies were particularly satisfied with the service they received, which they perceived as 'youth focused', timely and interdisciplinary in nature, and also providing a gateway to other services (Teresa, Lorna).

Parents were very reluctant to go to the GP or Accident and Emergency Department, preferring to take the unofficial or voluntary group route, sometimes from fear that their concerns about their child were actually justified or that medication might be necessary. Similarly, service providers were reluctant to refer to Accident and Emergency (GP2) because of the inappropriate nature of acute adult services for 16- to 18-year-olds. In particular, they acknowledged that an integrated child/teen/adult service is urgently required to avoid inappropriate care, as also outlined in the Children's Health Delivery Plan 2019 (Children's Health Ireland, 2019).

In some cases, parents' fear of stigma in their community or judgement by services resulted in them preventing their young person from getting help. There were clear findings that Tusla was viewed negatively by parents and their communities and that parents were unwilling to have any contact with Tusla, even with the family support workers, whose job it is to provide support to prevent difficulties escalating to social worker level.

4.1.5 School as a gateway

Figure 10: School as a gateway
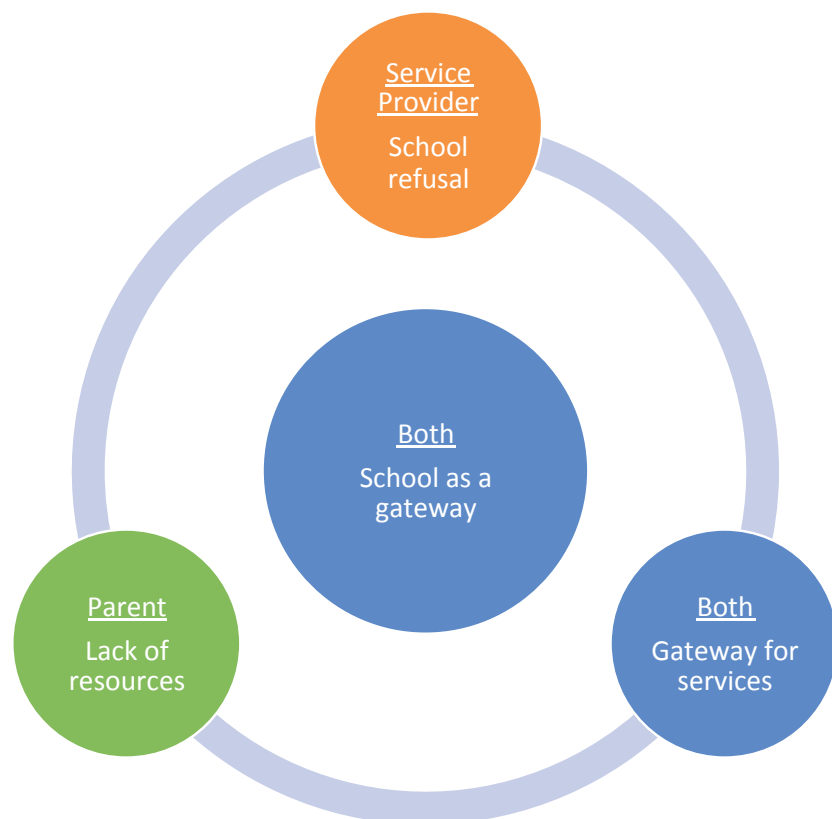
Service providers referred to the need for 'universal' support in addition to one-to-one support, particularly in the school sector, which most children attend daily. Service providers talked about empowering young people to 'take care of their own mental health' (NGO) rather than relying on services such as the School Completion Programme (SCP) that provides life-skills programmes in some schools. Governmental reports and other literature have acknowledged the vital importance of schools in providing an environment that is conducive to the promotion of wellbeing and the development of children and young people's social and emotional competence (DES, 2018; O'Brien and O'Shea, 2017; Werner-Seidler et al., 2017; HSE and DES, 2013b; HSE and DES, 2013a).

This is reflected in the literature on 'mental health literacy', defined as 'knowledge and beliefs about mental disorders which aid their recognition, management, or prevention' (Jorm et al., 1997, p. 182), along with knowledge and attitudes regarding sources of appropriate help (Jorm, 2000). Mental health literacy in the wider community is suggested as leading to more appropriate and supportive interactions with individuals experiencing mental disorder, particularly young people in need for the first time (Byrne et al., 2015).

Parents' experiences were primarily positive in relation to school support for young people's mental health. Some parents found that Transition Year (Norah) and the interest and skills of individual teachers (Marie, Annie, Michaela) led to good outcomes for their children. However, other parents referred to children who had behavioural difficulties that led to expulsion rather than school services being put in place to address the underlying issues (Lorna). It was subsequently very difficult to get an alternative school place, leaving the young person without any schooling at all or parents having to seek private education, which placed a considerable financial burden on the whole family (Lorna).

Schools have been proposed as a 'convenient intervention setting' for young people experiencing mental health problems in general, and particularly for those who are not willing or able to access mental health services (Brown et al., 2019). Additionally, reports have focused on schools providing the means to promote positive mental health encompassing the whole school environment (DCYA, 2014; DES, 2018), with responsibility now placed on the Department of Education (DES) to develop school-based initiatives in Connecting for Life – Ireland's National Strategy to Reduce Suicide (2015–2020) (Department of Health, 2015).

School refusal was mentioned by several professionals in Tusla as being indicative of mental health issues generally and also relating to the issue of social media and internet use (see Sections 3.1.3 and 3.2.3), with increasing numbers of young people experiencing tiredness and anxiety caused by gaming. The parents' focus was more on the unrelenting nature of technology. Young people were unable to 'switch off' at home and during the night, leading to challenging behaviour and refusal to attend school.

Problematic Internet Use (PIU) and Psychotic-Like Experiences (PLEs) are deemed to be common in adolescents, with one study finding that PIU and negative life experiences were significantly associated with PLEs in this age group (Lee et al., 2019). Few studies have looked at Internet Addiction (IA) in adolescents in relation to personality traits, but one study found that certain personality profiles were associated with PIU, with low self-esteem and family, school and behaviour problems as risk factors (Munno et al., 2017). Studies have also found that the risk of development and continuation of PIU in later adolescence is related to insecure attachment and that avoidance behaviours and anxiety are possible contributing factors (Schimmenti et al., 2012; Schimmenti et al., 2014; Munno et al., 2017).

4.1.6 Service quality and availability

Figure 11: Service quality and availability
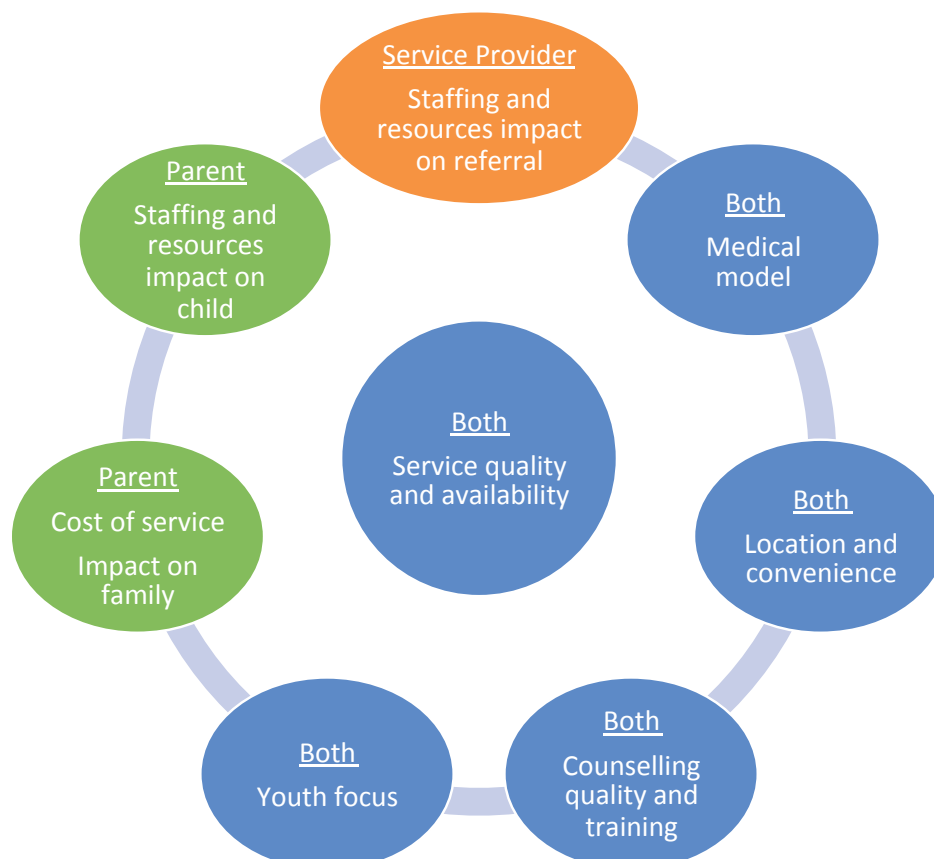
Both parents and service providers referred to the medical model and its limitations. Service providers were acutely aware that parents found the medical model frightening and bewildering, possibly adding to the distress families were experiencing, as it was not the service they wanted for their children. Parents seemed to want a softer or gentler approach at the beginning, in a less formal setting. They did not necessarily want their children admitted, but wanted quick and timely access to support. This tension between the expectations of the parents and the actual provision of services is particularly relevant to 16- and 17-year-olds, who seem to fall between child services and adult services despite being specifically included in CAMHS in the Vision for Change policy (Government of Ireland, 2006; RCPI, 2015).

The College of Psychiatrists of Ireland (2011) use the Rutter et al. (1970) definition of a 'psychiatric disorder' as:

> *The presence of abnormalities of behaviour, emotions or relationships which are developmentally inappropriate and of sufficient severity and duration as to cause persistent suffering or hardship in the child, or distress or disturbance in the family or community.*
> *(College of Psychiatrists of Ireland, 2011, p. 18)*

Mental health problems are defined as:

> *The presence of abnormalities of behaviour, emotions or relationships of sufficient severity to require professional intervention which may not be a psychiatrist. (College of Psychiatrists of Ireland, 2011, p. 18)*

The College of Psychiatrists of Ireland refers to behavioural phenotypes as abnormalities that may constitute psychiatric disorders 'consistently associated with a biological disorder' (College of Psychiatrists of Ireland, 2011, p.18).

As autism, ADD, anxiety and mood and rumination disorders are included among the common psychiatric disorders associated with children that have an intellectual disability, for example, this causes difficulties for both parents and service providers where the medical model takes precedence. For example, the medical model emphasises the impairment the individual has and focuses on helping the individual reduce or live with the impairment, whereas a social model looks at managing the social and/or physical environment and changing attitudes. The bio-psycho-social model combines both, which is deemed to be more appropriate.

The Vision for Change policy (Government of Ireland, 2006) recognised the bio-psycho-social model as being appropriate for children's services. It acknowledged that service users in their consultation process expressed concern at the over-emphasis on the medical model or 'bio' part of the bio-psycho-social model compared with the psychological and social parts. They also acknowledged that those consulted rejected the biological approach when it was presented as the only available option. While it is acknowledged that the adoption of the bio-psycho-social model was constrained by lack of resources, lack of multidisciplinary perspectives and lack of therapies back in 2006, it seems that this has not changed in 2019.

The theme of 'youth focus' was previously alluded to in Section 4.1.4, where both service providers and parents placed emphasis on the need for youth-focused services as more appropriate for children and young people. Particularly, parents wanted to be able to attend a service dedicated to youth where both they and their children would feel comfortable, regardless of the severity of mental health distress. However, youth-focused mental health services do not engage with children who have self-harmed, which then necessitates going through CAMHS or the hospital emergency department. This is stressful for all family members.

Despite the emphasis on increased resources, health and wellbeing, and on prevention and early intervention rather than crisis intervention in relation to youth mental health (DCYA, 2014), parents spoke about the cost to families when services are not readily available. The resourcing within services and the negative impact of personnel change and/or reductions in staffing were highlighted by service providers as being a particular issue at the moment. However, as the Better Outcomes, Brighter Futures policy also emphasises, in addition to resources, better planning and communication along with cultural change are required to support parents, intervene and prevent, listen to young people, ensure quality services, strengthen transitions, and increase interagency collaboration (DCYA, 2014).

4.2 Limitations of this research

This research was carried out during a time of transition to incorporate the new General Data Protection Regulation (GDPR) guidelines and health regulations. This placed considerable strain on ethics committees and limited the scope of this research.

Unfortunately, because of the limits of time and ethical considerations, young people were not involved directly in this study, and it is acknowledged that their participation would have added a more complete and rounded aspect to the findings. This research is confined primarily to the qualitative data and findings from the semi-structured interviews along with a statistical analysis of prevalence. Future research needs to include a more extensive literature review and a review of effective models of practice for this cohort of young people and their families.

4.3 Recommendations

Recommendations can be summarised into four main areas: resources, communication, models of intervention and research.

4.3.1 Resources

Service planning

Given that the average overall estimates of the numbers suffering from depression, anxiety or stress in the Tallaght area was 1,486 individuals, and the likelihood of these being underestimated, it would be prudent for planning purposes to plan services for the mental health needs of approximately 1,500 to 2,000 young people. The HSE needs to consider the quantum and diversity of required services to meet the needs of the anticipated number of young people in the Tallaght area whose mental health needs are not currently being met. Service planning needs to include the expansion of existing services that are working well and the development of a new model of intervention to address current gaps.

This calculation of required service provision should be replicated at a national level in order to determine the quantity of services required to meet the mental health needs of all young people.

Waiting lists

Waiting lists should be reduced or eliminated: a maximum waiting list time for someone who appears to meet the criteria for a mental health assessment should be two weeks. This will require a 'triage' system. This triage system needs to be able to effectively access a range of local services and refer young people and their carers to these services. Services for young people who are homeless need to be targeted at these young people and located in appropriate settings that enable engagement.

4.3.2 Communication

Clear and consistent referral pathways

CAHMS services should have clear, consistent, and transparent referral criteria.

Engagement between CAHMS and other professionals should be collaborative in order to maximise better outcomes for young people.

All health professionals should have access to comprehensive, up-to-date information on local service provision, referral pathways and delivery. Ideally, the local Children and Young Peoples Services Committee (CYPSC) will support this process.

The Joint Protocol for Interagency Collaboration between the HSE and Tusla, which was finalised in 2017, should be implemented in full, including an appropriate monitoring and standards process.

One-stop shop

Given the confusion experienced by both health professionals and parents in relation to the pathway into services, a single drop-in, one-stop, 24-hour shop/service would be of benefit to the whole community. This would be a local centre/focus for expertise on challenges experienced, including challenges around referral pathways. It would include options for emerging challenges such as homelessness. This could be located in an existing hospital service but needs to be part of the wider community in terms of its stakeholders and governance. Interventions and processes to enable access, and support families and young people should be designed, initiated, and evaluated on a pilot basis using an implementation science approach.

4.3.3 Models of intervention

This report indicates that while there is effective work happening with some young people experiencing mental health issues, many more of them are isolated. There is a need to identify proven models to address the service gaps and/or develop new approaches and service delivery mechanisms. Crucial aspects will include accessibility, early intervention, ability to quickly assess and refer young people, and the provision of supports for family members.

There are a number of recommendations relating to the enhancement of schools as a gateway for mental health needs for children:

Universal support

The adoption of universal support that is integrated into schools and community systems could assist in reaching young people who may be reluctant to seek individual assistance. This would also assist in normalising and naming emotions and feelings that all humans experience in life.

The range of mental health promoting programmes and activities should be continued, with an aligned monitoring and evaluation strategy.

Counselling

Ccounselling services should be provided in venues which minimise stigma, maximise early intervention, reduce the amount of time out of school for those attending specialist services, and keep costs at a

minimum. The provision of resources for counselling services in schools where children are already attending would assist parents who might struggle to pay for private services if their child required this.

The above two recommendations of Universal Support and Counselling could be integrated into, and take advantage of, the new school wellbeing strategy.

Youth-focused and 'whole family holistic model'

Parents attending services which they perceived to be youth-focused and representative of a whole family holistic model similar to Jigsaw highlighted a preference for such services over those underpinned by a 'medical model'. Young people who are disengaged from school and other services need outreach supports from mental health professionals.

Identification of effective model

There is a need to identify effective models of children's mental health services for this cohort of 12- to 18-year-olds, but particularly 16- to 18-year-olds.

Clarify the age of informed consent

There needs to be greater clarity on the age of informed consent in relation to the 16- to 18-year-old cohort. Healthcare professionals differed in their understanding and interpretation of the age of informed consent.

4.3.4 Research

Ethics approval processes

Ethics approval processes need to be streamlined to make it easier for researchers to carry out research on children and young people more effectively and in a shorter time frame. A central committee that would cover the health services generally with universal standards, forms and requirements is needed rather than individual research ethics committees with different formats and systems.

The National Research Ethics Committees legislation should progress and be enacted, with expansion to include all social research.

Future research on effective models of intervention

Further research is required to identify existing models of intervention that could be replicated in Tallaght and other parts of Ireland to address the unmet needs of young people and to effectively support their families. Future research should engage directly with young people to ensure that their experiences and insights inform the development of policy and practice.

Research should be undertaken to identify the mental health needs of children aged under 12 years of age.

inbetweeners

Appendices

Appendix A – Letter to Gatekeepers

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Letter to Gatekeepers

> **The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght**

I am contacting you in relation to the research study being conducted by School of Nursing and Midwifery, **Trinity College Dublin** on behalf of the **Childhood Development Initiative in Tallaght.**

This study aims to address the unmet mental health needs of children and adolescents in Tallaght. A number of organisations with commitments to, and responsibilities for health care provision throughout Tallaght, have come together to maximise the utilisation of resources, expertise and local knowledge through a collaborative process. Changes in the national model of paediatric care, facility developments and established relationships all contribute to a unique and potentially powerful synergy, which the partners are anxious to explore.

The Childhood Development Initiative (CDI) wishes to commission research into mental health among children and adolescents in Tallaght. The research will include the following:

- To consult with services in Tallaght to describe referral processes and criteria for accessing youth mental health services
- To use indirect statistical methods to provide an estimate of the number of children and adolescents in the Tallaght Area who have difficulty accessing mental health services and to provide a profile of this cohort
- To review existing models of intervention and identify potential mechanisms to address local unmet needs
- To make recommendations regarding delivery and structural issues
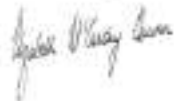
The research will include a consultation process with the following target groups in relation to this:

- Service providers in Tallaght
- Parents of young people (i.e. aged 12 to 18) whose mental health needs are not currently being met.

To achieve this, we need your help to provide us with access to participants. Access is required to enable researchers from Trinity College Dublin to carry out focus groups and interviews with service providers, and interviews with parents of young people aged 12 to 18, whose mental health needs are not being met. At all stages, consent from the participants will be sought for all aspects of the research. An information sheet about the study is included with this letter.

1 of 2

If you approve of us proceeding with this research, and/or you have any questions, you can let me know via my email below and/or by telephone contact. Ethical approval for this study has been received from Trinity College Dublin ethics board.

Kindest Regards,

Dr. Elizabeth McCarthy Quinn,

Elizabeth McCarthy Quinn, PhD, Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone: 01 8961846
Mobile: 086 3192992 (text or message only)
Email: quinne12@tcd.ie

Appendix B – Parent/Guardian Information Leaflet

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

What do you need from the Mental Health Services in Tallaght?
Parent/Guardian - Participant Information Leaflet

The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght

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About this Study

This research aims to identify the unmet youth mental health needs in Tallaght and provide recommendations to mental health services in the region, based on the findings from the current study. Researchers from Trinity College Dublin have been asked to help with this. If you wish to take part, you will be asked questions about your child's mental health needs and experience of accessing mental health services. This will help us understand their health needs. We will use this information to help to make recommendations to mental health services in the Tallaght region.

How Can I Help?

To help with this study, you could take part in an interview with a researcher as a parent/guardian of a young person. Your child will not be interviewed or be present at the interview.

How long will it take?

The interview will last about 30 to 40 minutes. You have the right to end the interview at any stage.

Where will it take place?

The interview will take place at the School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. All interviews are completely confidential and your information will be stored securely.

When will it take place?

The interview will take place on a date and time that suits you.

How can I take part?

If you are interested in taking part, you can contact Elizabeth (researcher) whose details are on this leaflet. A consent form is also provided with this information leaflet. You have 7-10 days to make up your mind. If you need more information, you can contact us. If you decide to take part in this study, sign the consent form and return it to the researcher.

What are my rights?

You can decide to stop being a part of the research study at any time. You will not have to explain why. You have the right to ask for all of the data you provided to be withdrawn or destroyed. If you are uncomfortable with any question asked during the interview, you do not have to answer. If you have trouble reading or understanding any information given, the researcher will explain it to you. Consent will not be taken if you do not understand any of

1 of 2

the information given. Data will be kept in Trinity College for 5 years in a secure password-protected computer folder.

Benefits of taking part:

You will get a chance to outline your experiences and your child's experiences of the mental health services and whether they have met your child's needs. This information will be provided to the mental health services along with recommendations from the Research Team so they may be in a better position to improve their services.

Privacy:

Your name will not be used in any reports. Some information such as contact details are needed to arrange interviews. This information will be stored in a password protected computer folder at Trinity College.

Only researchers will have this information. We will take great care to ensure that you cannot be identified in reports. If a service user wishes to leave the study at any point, the researcher will be able to delete your details. At any point you or the researcher has the right to end your involvement in this study.

Contact details:

If you are interested in taking part, please contact the researcher:

Elizabeth McCarthy Quinn, PhD, Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone:	01 8961846
Mobile:	086 3192992 (text or message only)
Email:	quinne12@tcd.ie

Appendix C – Service Provider Information Leaflet

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

What do young people need from the Mental Health Services in Tallaght?
Service Provider - Participant Information Leaflet

The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght

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About this Study

This research aims to identify the unmet youth mental health needs in Tallaght and provide recommendations to mental health services in the region, based on the findings from the current study. Researchers from Trinity College Dublin have been asked to help with this.

How Can I Help?

To help with this study, you could take part in a Focus Group [OR one-to-one interview] with a researcher.

How long will it take?

The Focus Group will last about 1 hour [interview option 30 to 40 minutes]. You have the right to end your involvement in the focus group [or interview option] at any stage.

Where will it take place?

The Focus Group [or interview option] will take place at the School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. All information gathered through the Focus Groups [or interview option] are completely confidential and your information will be stored securely.

When will it take place?

The Focus group/interview will take place on a date and time that suits you.

How can I take part?

If you are interested in taking part, you can contact Elizabeth (researcher) whose details are on this leaflet. A consent form is also provided with this information leaflet. You have 7-10 days to make up your mind. If you need more information, you can contact us. If you decide to take part in this study, sign the consent form and return it to the researcher.

1 of 2

What are my rights?

You may decide to stop being a part of the research study at any time. You will not have to explain why. You have the right to ask for all of the data you provided to be withdrawn or destroyed. If you are uncomfortable with any question asked, you do not have to answer. If you are uncomfortable being part of the Focus Group, you may withdraw at any time. If you prefer to do an individual interview, then this will be facilitated. If you have trouble reading or understanding any information given, the researcher will explain it to you. Consent will not be taken if you do not understand any of the information given. Data will be kept in Trinity College for 5 years in a secure password protected computer folder.

Benefits of taking part:

You will get a chance to outline your experiences and make suggestions for improving the mental health service in the Tallaght region for children. The information you provide may result in an enhanced service for children and may result in meeting their needs more appropriately.

Privacy:

Your name will not be used in any reports. Some information such as contact details are needed to arrange interviews. This information will be stored in a password protected computer folder at Trinity College.

Only researchers will have this information. We will take great care to ensure that you cannot be identified in reports. If a service user wishes to leave the study at any point, the researcher will be able to delete your details. At any point you or the researcher has the right to end your involvement in this study.

Contact details:

If you are interested in taking part, please contact the researcher:

Elizabeth McCarthy Quinn, PhD, Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone:	01 8961846
Mobile:	086 3192992 (text or message only)
Email:	quinne12@tcd.ie

Appendix D – Flyer for Parents

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The university of Dublin

Do you have concerns about the mental health of your young person aged 12 to 18?
Are their needs being met?

The InBetweeners Project: what are the unmet mental health needs of young people 12-18?

If you would like to help with this study, you could take part in an interview with a researcher as a parent/guardian of a young person. (Your child will not be interviewed or be present at the interview).

You will be asked questions about:

- your child's mental health needs
- your experience of accessing mental health services
- your thoughts on how things could be improved or changed

The information you provide will help in making recommendations to mental health services in the Tallaght region
All interviews are completely confidential and your information will be stored securely.

If you are interested in taking part, please contact the researcher:
Elizabeth McCarthy Quinn, PhD, Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74. **Telephone: 01 8961846,** **Mobile: 086 3192992 (text only), Email:** quinne12@tcd.ie

Appendix E – Parent/Guardian Consent Form

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Parent/Guardian Consent Form

The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght

PRINCIPAL INVESTIGATOR:
Dr. Elizabeth McCarthy Quinn, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, quinne12@tcd.ie

RESEARCHERS: Professor Catherine Comiskey & Dr Emma Murphy, School of Nursing & Midwifery, D'Olier Street, Trinity College, Dublin 2. Ms. Marie Hyland, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, hylandm3@tcd.ie

This research aims to identify the unmet youth mental health needs in Tallaght and provide recommendations to mental health services in the region, based on the findings from the current study. To address those unmet needs, you are invited to take part in an interview with our team.

By participating in this study, you are agreeing to be asked questions about your child's mental health needs and experience of accessing mental health services. You are invited to take part in an interview to share your experience and views of mental health services. The interview is expected to take approximately one hour. This will take place at the School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, quinne12@tcd.ie to ensure confidentiality.

The interview will be tape recorded and later transcribed for analysis by the Research team. Any information provided by you will be held in the strictest confidence and will only be used anonymously for the purposes of the research study. Your name will not be published or disclosed to anyone outside the Research team. Access to any information you give will be fully accessible to you upon request. Participation is voluntary and you are free to withdraw from the study at any time if you wish to do so. If the interview causes you any distress, efforts will be made to help you to access the relevant services.

Parent/Guardian Declaration:

I have read, or have had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study. I understand that participation or non-participation will in no way affect the receipt of services to my child. I understand that I may withdraw from the study or withdraw our information from the study at any time without penalty and have received a copy of this agreement.

1 of 2

Please sign below to indicate that you are willing to support this study by agreeing to participate in the interview. If you are agreeable to taking part, you may also be contacted by phone by the researcher.

I voluntarily give my agreement to participate in this study without prejudice to their legal and ethical rights. I also agree to be contacted by a researcher at a time that is convenient for me.

YOUR NAME: ....

YOUR CONTACT DETAILS:
Phone number:..

Email address if any: ....

Other Contact Details:..

PARTICIPANT'S SIGNATURE: ....

Date:................................

Researcher Contact details:
Dr. Elizabeth McCarthy Quinn (Researcher), Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone: 01 8961846
Mobile: 086 3192992 (text only)
Email: quinne12@tcd.ie

Appendix F – Parent/Guardian Consent Form – Tusla

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Parent/Guardian Consent Form

The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght

PRINCIPAL INVESTIGATOR:
Dr. Elizabeth McCarthy Quinn, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, quinne12@tcd.ie

RESEARCHERS: Professor Catherine Comiskey & Dr Emma Murphy, School of Nursing & Midwifery, D'Olier Street, Trinity College, Dublin 2. Ms. Marie Hyland, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, hylandm3@tcd.ie

This research aims to identify the unmet youth mental health needs in Tallaght and provide recommendations to mental health services in the region, based on the findings from the current study. To address those unmet needs, you are invited to take part in an interview with our team.

By participating in this study, you are agreeing to be asked questions about your child's mental health needs and experience of accessing mental health services. You are invited to take part in an interview to share your experience and views of mental health services. The interview is expected to take approximately one hour. This will take place at the School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, quinne12@tcd.ie to ensure confidentiality.

The interview will be tape recorded and later transcribed for analysis by the Research team. Any information provided by you will be held in the strictest confidence and will only be used anonymously for the purposes of the research study. Your name will not be published or disclosed to anyone outside the Research team. Access to any information you give will be fully accessible to you upon request. Participation is voluntary and you are free to withdraw from the study at any time if you wish to do so. If the interview causes you any distress, efforts will be made to help you to access the relevant services.

Parent/Guardian Declaration:

I have read, or have had read to me, the information leaflet for this project and I understand the contents.	
I have had the opportunity to ask questions and all my questions have been answered to my satisfaction.	

1 of 2

I freely and voluntarily agree to be part of this research study.	
I understand that participation or non-participation will in no way affect the receipt of services to my child.	
I understand that I may withdraw from the study or withdraw our information from the study at any time without penalty and have received a copy of this agreement.	
If during the interview, the researcher becomes aware that a child has been harmed, is being harmed, or at risk of being harmed, then this information will be passed on to the relevant service (in line with the Children First Act 2015).	

Please sign below to indicate that you are willing to support this study by agreeing to participate in the interview. If you are agreeable to taking part, you may also be contacted by phone by the researcher.

I voluntarily give my agreement to participate in this study without prejudice to my child's legal and ethical rights. If I decide not to participate, this will not affect any services for my child as this research is confidential and they will not be informed. I also agree to be contacted by a researcher at a time that is convenient for me.

YOUR NAME: ....

YOUR CONTACT DETAILS:
Phone number:...

Email address if any: ....

Other Contact Details:...

PARTICIPANT'S SIGNATURE: ....

Date:.................................

Researcher Contact details:
Dr. Elizabeth McCarthy Quinn (Researcher), Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone: 01 8961846
Mobile: 086 3192992 (text only)
Email: quinne12@tcd.ie

Appendix G – Service Provider Consent Form

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Service Provider Consent Form

The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght

PRINCIPAL INVESTIGATOR:
Dr. Elizabeth McCarthy Quinn, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, quinne12@tcd.ie

RESEARCHERS: Professor Catherine Comiskey & Dr Emma Murphy, School of Nursing & Midwifery, D'Olier Street, Trinity College, Dublin 2. Ms. Marie Hyland, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, hylandm3@tcd.ie

This research aims to identify the unmet youth mental health needs in Tallaght and provide recommendations to mental health services in the region, based on the findings from the current study. To address those unmet needs, you are invited to take part in a focus group or one-to-one interview session with our team. Researchers from Trinity College Dublin were invited to help with this.

Participation will involve a one-to-one confidential interview with a researcher from Trinity. The interview will last 15-40 minutes depending on time availability of client. The interviews will take place at the Institute of Population Health of Trinity College Dublin, in the Russell Building, Tallaght Cross West, D24 DH74, to ensure confidentiality. The interview will be recorded with your permission using a digital recorder.

All information, audio and written, will be anonymised and securely stored for the duration of the research project. All views shared will be treated confidentially and all comments will be reported anonymously. You will have access to your interview information, and anything deemed to be revealing about personal information or otherwise may be removed. At any point the service user or researcher has the right to terminate.

DECLARATION:
I have read, or had read to me, the information leaflet for this project and I understand the contents. I have had the opportunity to ask questions and all my questions have been answered to my satisfaction. I freely and voluntarily agree to be part of this research study, and not affecting my legal and ethical rights. I understand that I may withdraw from the study at any time and I have received a copy of this agreement.

1 of 2

PARTICIPANT'S NAME: ....

CONTACT DETAILS: ....

Phone number:...

Email address:...

PARTICIPANT'S SIGNATURE: ....

Date:...............................

Statement of investigator's responsibility: I have explained the nature and purpose of this research study, the procedures to be undertaken and any risks that may be involved. I have offered to answer any questions and fully answered such questions. I believe that the participant understands my explanation and has freely given informed consent.

INVESTIGATOR'S SIGNATURE:.............................

Date:.......................

Researcher Contact details:
Dr. Elizabeth McCarthy Quinn (Researcher), Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone:	01 8961846
Mobile:	086 3192992 (text only)
Email:	quinne12@tcd.ie

Appendix H – Interview Questions for Parents

Questions for parents

1. Is your child currently attending mental health services?

2. Has your child attended mental health services in the past?

3. If your child is currently accessing a service, is it meeting their needs?

4. What has your experience of accessing mental health services been like?

5. Have you faced any difficulties in accessing mental health services in your area?

6. To what extent have the existing services been able to provide the support your child needs in relation to their mental health?

7. Are there aspects of your child's mental health or social/behavioural concerns which services have not been able to help you with?

   a. If so, can you tell us about them?

8. What are the unmet needs in relation to accessing mental health services for your child?

9. What changes would you like to see happening in relation to accessing mental health services?

   a. What do you think could be improved/ done differently?

Contact: Dr. Elizabeth McCarthy Quinn, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. Office: 01 8961846, Mobile: 086 3192992, quinne12@tcd.i

Appendix I – Interview Questions – Service Providers

Interview Questions for Service Providers

1. What are the criteria for young people accessing your mental health service?

2. Can you please describe the referral processes for accessing your service?

3. What in your opinion are the current barriers and enablers for accessing your service?

4. In the case where a young person was not eligible for your service, what are the main reasons why the service was not suitable?

5. For young people who are not suitable for your service, what are the referral processes for linking the person with an appropriate service?

6. From your experience, what are the barriers and enablers of linking/referring a person into an appropriate service?

7. What do you think are the unmet needs in relation to accessing suitable mental health services for young people in the area?

8. What changes would you like to see happening in relation to accessing mental health services?

9. What do you think could be improved/ done differently?

10. Do you record data in relation to the numbers of young people who attend your service?

    a. If you answered Yes to the above, would you be willing to provide data (anonymised) to the researchers in relation to numbers attending your service?

11. Do you record data in relation to the number of young people who were not eligible for your service?

    a. If you answered Yes to the above, would you be willing to provide data (anonymised) to the researchers in relation to numbers not eligible for your service?

12. Any concluding comments?

Contact Details:

Dr. Elizabeth McCarthy Quinn,

School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74.

Office: 01 8961846, Mobile: 086 3192992, quinne12@tcd.ie

Appendix J – Parent/Guardian Debriefing Sheet

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Parent/Guardian Debriefing Sheet

The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght

Dear Participants,

The In-Betweeners Research team would like to thank you for taking part in this research; your participation is greatly appreciated. If you feel you need any mental health/wellbeing and confidential support after taking part in this study, please see supports you can access below. If you would like to gain further information about this research study, you can contact us on the information provided below. Once again, we would like to thank you for your participation.

Best wishes,
Dr. Elizabeth McCarthy Quinn,
Principal Investigator
School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, quinne30@tcd.ie

Samaritans	https://www.samaritans.org/your-community/samaritans-ireland-scotland-and-wales/samaritans-ireland Call Freephone: 116 123 Text: 087 2 60 90 90 (standard text rates apply) Email: jo@samaritans.ie (RoI) Email: jo@samaritans.org (NI)
Aware	https://www.aware.ie/ 1800 80 48 48 Available Monday to Sunday from 10am to 10pm supportmail@aware.ie Email at any time. You can expect a response within 24 hours. Support & Self-Care Groups Aware Support & Self Care Groups offer a unique opportunity to talk openly about depression or bipolar disorder and its impact. (www.aware.ie)
Pieta House	https://www.pieta.ie/ 1800 247 247 Pieta House Dublin South First Floor, Greenhills Retail Park Greenhills Road, Tallaght Dublin 24 D24 RH59 Phone: 01-4624792 Contact Person: Centre Manager - Leigh Kenny Opening Hours:

11/04/2019

1 of 2

	Monday to Thursday: 9am to 9pm Friday: 9am to 7pm Saturday: 9am to 2pm
Dr Hestor O'Connor	Primary Care Psychology Service Last day of each month Russell Building, Tallaght Cross West, Dublin 24

Researcher Contact details:

Dr. Elizabeth McCarthy Quinn (Researcher), Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone:	01 8961846
Mobile:	086 3192992 (text only)
Email:	quinne30@tcd.ie

Appendix K – Service Provider Debriefing Sheet

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Service Providers Debriefing Sheet

The InBetweeners Project: Identifying the unmet mental health needs of children and adolescents (12 to 18 year olds) in Tallaght

Dear Participants,

The In-Betweeners Research team would like to thank you for taking part in this research; your participation is greatly appreciated. If you feel you need any mental health/wellbeing and confidential support after taking part in this study, please see supports you can access below. If you would like to gain further information about this research study, you can contact us on the information provided below. Once again, we would like to thank you for your participation.

Best wishes,
Dr. Elizabeth McCarthy Quinn,
Principal Investigator
School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, Office 9, Floor 6, Russell Centre, Tallaght Cross West, D24 DH74. 01 8961846, quinne30@tcd.ie

Samaritans	https://www.samaritans.org/your-community/samaritans-ireland-scotland-and-wales/samaritans-ireland Call Freephone: 116 123 Text: 087 2 60 90 90 (standard text rates apply) Email: jo@samaritans.ie (RoI) Email: jo@samaritans.org (NI)
Aware	https://www.aware.ie/ 1800 80 48 48 Available Monday to Sunday from 10am to 10pm supportmail@aware.ie Email at any time. You can expect a response within 24 hours. Support & Self-Care Groups Aware Support & Self Care Groups offer a unique opportunity to talk openly about depression or bipolar disorder and its impact. (www.aware.ie)
Pieta House	https://www.pieta.ie/ 1800 247 247 Pieta House Dublin South First Floor, Greenhills Retail Park Greenhills Road, Tallaght Dublin 24 D24 RH59 Phone: 01-4624792 Contact Person: Centre Manager - Leigh Kenny Opening Hours:

11/04/2019

1 of 2

	Monday to Thursday: 9am to 9pm Friday: 9am to 7pm Saturday: 9am to 2pm
Dr Hestor O'Connor	Primary Care Psychology Service Last day of each month Russell Building, Tallaght Cross West, Dublin 24

Researcher Contact details:

Dr. Elizabeth McCarthy Quinn (Researcher), Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone: 01 8961846
Mobile: 086 3192992 (text only)
Email: quinne30@tcd.ie

Appendix L – Letter to Psychologist

Trinity College Dublin
Coláiste na Tríonóide, Baile Átha Cliath
The University of Dublin

Letter to Dr. Hester O Connor, Principal Psychology Manager (Dublin South West/Kildare West Wicklow), regarding welfare of proposed participants.

Dear Dr. O Connor,

I am contacting you in relation to the research study being conducted by School of Nursing and Midwifery, **Trinity College Dublin** on behalf of the **Childhood Development Initiative in Tallaght.**

As you are aware, this study aims to address the unmet mental health needs of children and adolescents in Tallaght. A number of organisations with commitments to, and responsibilities for health care provision throughout Tallaght, have come together to maximise the utilisation of resources, expertise and local knowledge through a collaborative process. Changes in the national model of paediatric care, facility developments and established relationships all contribute to a unique and potentially powerful synergy, which the partners are anxious to explore.

The Childhood Development Initiative (CDI) wishes to commission research into mental health among children and adolescents in Tallaght. The research will include the following:

1. To consult with services in Tallaght to describe referral processes and criteria for accessing youth mental health services using focus groups for service providers and semi-structured, one-to-one interviews with parents of young people aged 12-18.

2. To use indirect statistical methods to provide an estimate of the number of children and adolescents in the Tallaght Area who have difficulty accessing mental health services and to provide a profile of this cohort;

3. To review existing models of intervention and identify potential mechanisms to address local unmet needs

4. To make recommendations regarding delivery and structural issues.

To achieve this, we need to provide support for the welfare of proposed participants who take part in the research should the need arise. In this letter, we are enquiring as to whether the psychology service based in the Institute of Population Health at the Russell building in Tallaght can provide this support for us. Your participation would involve facilitating access to a psychologist to participants should support be required. At all stages, consent from the participants will be sought for all aspects of the research. An information sheet

11/04/2019   1 of 2

about the study is included with this letter. Ethical approval for this study has been applied for from the Faculty of Health Sciences Research Committee at the School of Nursing and Midwifery and we are awaiting approval.

If you approve of this request, and/or you have any questions, you can let me know via my email below and/or by telephone contact.

Thank you for your time and interest,
Kindest Regards
Dr. Elizabeth McCarthy Quinn, School of Nursing and Midwifery, Institute of Population Health, TCD, Office 9, Floor 6, Russell Building, Tallaght Cross West, D24 DH74 Tel. No: 01 8961846, quinne30@tcd.ie

Please note that this letter was sent to Dr. Hester O'Connor who has confirmed her participation and availability.

Researcher Contact details:
Dr. Elizabeth McCarthy Quinn (Researcher), Office 9, Floor 6, School of Nursing and Midwifery, Institute of Population Health, Trinity College Dublin, University of Dublin, Russell Centre, Tallaght Cross West, D24 DH74.

Telephone: 01 8961846
Mobile: 086 3192992 (text only)
Email: quinne30@tcd.ie

Appendix M – Ethical Approval

Coláiste na Tríonóide, Baile Átha Cliath
Trinity College Dublin
Ollscoil Átha Cliath | The University of Dublin

Dr Elizabeth McCarthy Quinn
School of Nursing & Midwifery,
Institute of Population Health,
Trinity College Dublin, Office 9,
Floor 6, Russell Building,
Tallaght Cross West,
D24 DH74

8th March 2019

Ref: 181010

Title of Study: The Inbetweeners Project: Identifying the unmet mental health needs of children and adolescents in Tallaght

Dear Elizabeth,

Further to a meeting of the Faculty of Health Sciences Ethics Committee held in October 2018. We are pleased to inform you that the above project has ethical approval to proceed.

As a researcher you must ensure that you comply with other relevant regulations, including DATA PROTECTION and HEALTH AND SAFETY.

Yours sincerely,

Prof. Brian O'Connell
Chairperson
Faculty Research Ethics Committee

Dámh na nEolaíochtaí Sláinte   Faculty of Health Sciences   www.healthsciences.tcd.ie
Foirgneamh na Ceimice,   Chemistry Building,
Coláiste na Tríonóide,   Trinity College Dublin,
Ollscoil Átha Cliath,   The University of Dublin,
Baile Átha Cliath 2, Éire.   Dublin 2, Ireland

Appendix N – Cultural Historical Activity Theory (CHAT) in the Context of This Study

A basic principle of a Cultural Historical Activity Theory (CHAT) approach is that human beings have both the need and ability to mediate their interactions with other humans and the non-human world through culture (Cole, 1998). Culture is described as 'social inheritance' embodied in 'artefacts' which can be material and symbolic, such as objects, words, rituals and other cultural practices (Cole, 1998, p. 291), along with signs, architectural arrangements, social institutions or all artefacts accumulated over the history of any social group (Cole and Packer, 2015). The individual cannot be understood without reference to their cultural context, and society cannot be understood without individual agency and the individual's use and production of mediating artefacts.

Activity theory is drawn upon because of its concern with everyday work practice and the recognition of practical activity as a shared enterprise such as between young people, their parents and service providers, with an overall outcome or new form of activity (Engeström, 2001). Practice is defined as 'a group of human beings conducting a collective activity with a specific object or goal' (Bødker, 1989, p. 179). In this study there are different activity systems all engaging with each other: children, parents, families, schools, health services and the wider community.

The framework facilitates a multidimensional, systemic approach by studying psychological motives, tools, culture, tensions and history through focusing on three main areas, according to Foot (2015):

1. Humans act collectively, learn by doing, and communicate through their actions.

2. Humans create, use and adapt tools to learn and communicate.

3. The concept of 'community' is central to meaning making and interpretation and all forms of learning, communicating and acting (Vygotsky, 1978).

This is pertinent to this study, where young people and their parents are trying to get help for their mental health needs.

The term 'activity' in CHAT describes a contribution to satisfying collective needs rather than a task that keeps an individual busy and oriented to maintaining the human species by providing basic needs (Roth, 2007). The basic unit of analysis in CHAT is the 'activity system', defined as a group of people sharing a common object or objective over time along with a wide range of tools they use together to realise their objective and achieve satisfactory outcomes (Engeström et al., 1999). The emphasis is on activity driven through collective objects and motives but realised through goal-oriented individual and group actions (Hasu and Engeström, 2000). The main elements of activity are subject, object, mediating artefacts, community, rules and division of labour (Hasu and Engeström, 2000; Engeström, 1987).

Mediated action can be carried out by small groups, large groups or individuals and may be both external and internal, with a sociocultural approach focusing on human action but not restricted to individual or social processes (Wertsch, 1998). In this study young people, their families and the service providers' experiences of the health service system are the activity system, and young people and their parents are the subjects engaged in the activity of seeking mental health support. Mediating artefacts could be physical

tools such as phones, written material and computers; conceptual tools such as language, meetings, online forums, social media and social others; or prior knowledge that contributes to the subject's mediated action experiences within the activity.

The object (objective) in this study is the goal or desired outcome of the activity: getting support for mental health needs. However, the actual outcome may or may not be as expected.

In designing the study and formulating the questions for Phases 1, 2 and 3, Table 7, adapted from Mwanza (2001), was used.

Table 7: CHAT informing study design and survey questions (adapted from Mwanza, 2001)

Activity	What sort of activity am I interested in?
Object (objective)	Why is the activity taking place?
Subjects	Who is involved in carrying out the activity?
Tools	By what means are the subjects performing the activity?
Rules and regulations	Are there any cultural norms, rules or regulations governing the performance of the activity?
Division of Labour	Who is responsible for what when carrying out the activity, and how are those roles organised?
Community	What is the environment in which this activity is being carried out?
Outcomes	What is the desired outcome from carrying out this activity?

Source: (Mwanza, 2001)

An individual engaged in one activity system is simultaneously influenced by other activity systems across their communities, with social action determined by history, culture and differing power relations that influence meaning, production and shaping of human activity (Plakitsi, 2013). In relation to this study, young people and their parents are influenced by the health services activity system in conjunction with other activity systems. For example, hospital staff, GPs, family members and schools can induce conflict within the parent; however, this can provide a positive context for development and change (Plakitsi, 2013; Vygotsky, 1998; Engeström, 1999).

There are five central principles to CHAT, according to Engeström et al. (1999), which are outlined in Table 8 and have been adapted for this study.

Table 8: Five central principles of CHAT (Engeström et al., 1999)

Activity system as unit of analysis	Goal-directed, individual or group actions and automatic operations: subordinate units of analysis
Multi-voicedness of activity	Multiple points of view, traditions, histories, and interests
Historicity of activity	History of activity and objects needs to be studied over time
Contradictions as driving force of change in activity	Sources of change and development
Expansive cycles as possible form of transformation in activity	Who is responsible for what when carrying out the activity, and how are those roles organised?
Individuals questioning and deviating from established norms lead to collaboration and collective effort effecting change.	Change takes place over long period; Individuals questioning and deviating from established norms lead to collaboration and collective effort effecting change.

Source: Engeström et al., 1999

Activity system as unit of analysis

In this research, there are multiple activity systems in operation. There is the young person, the parent, the other family members, the health professional and community organisations. The parent is engaged in goal-directed and object-oriented individual action in choosing to seek out support to aid them in achieving the objectives of seeking appropriate assistance for a child in need.

The individual parent acts at an individual level in accessing support but may not be fully conscious of their objectives and motives because of the Division of Labour concept. The total activity of the community with all its members and roles controls the individual rather than the individual controlling the activity, according to Engeström (1987). It is important, however, to realise that human practice does not consist of a series of actions by individuals but of 'shared object activity' which Mescheryakov, a student of Leont'ev, calls the unit of analysis or the activity system (Meshcheryakov, 1979).

Multi-voicedness of activity

An activity system may comprise an individual or a community of different points of view, traditions and interests, with the Division of Labour concept creating different positions for participants (Engeström, 2001), all of whom have their own diverse histories. This can be a source of challenge for parents and young people in the mental health system who must translate and negotiate their way in this new group that has its own history, artifacts, rules and conventions.

Historicity of activity

Activity systems are shaped and transformed over long periods of time, with any challenges being understood only by looking at the history of the organisation and its development set against the global history of the activity through its interaction with the health services and community, for example.

Contradictions as driving force of change in activity

A key component of the CHAT framework is the issue of contradictions or 'breakdowns', which are not viewed as negative but seen as new opportunities for change and learning (Turner and Turner, 2001; Engeström et al., 1999) and development. When an activity system adopts a new element from outside – for example, social media – the old ways and the new may collide, generating disturbance but also resulting in innovation in changing the activity. This is directly relevant to this study, whereby the use of social media and the internet has changed the ways in which people access support.

While individuals experience the results of contradictions and difficulties in activity systems, the solutions can only be arrived at through collective action (Blackler, 2009). In CHAT the term 'boundaries' is used in relation to the form of contradictions arising between activity systems (Roth and Lee, 2007; Akkerman and Bakker, 2011). Some representations of the activity system incorporate arrows, used to represent the complex interactions between individuals and their community (Engeström, 2001), but also to highlight secondary contradictions between key components of the activity system under review (Lim and Hang, 2003) (Figure 12). For example, a parent may want to include close family members in seeking support for her child but may have to keep a distance from them if they have different views in order to avoid conflict and further distress.

Figure 12: Source: Secondary inner contradictions example from Lim and Hang, 2003
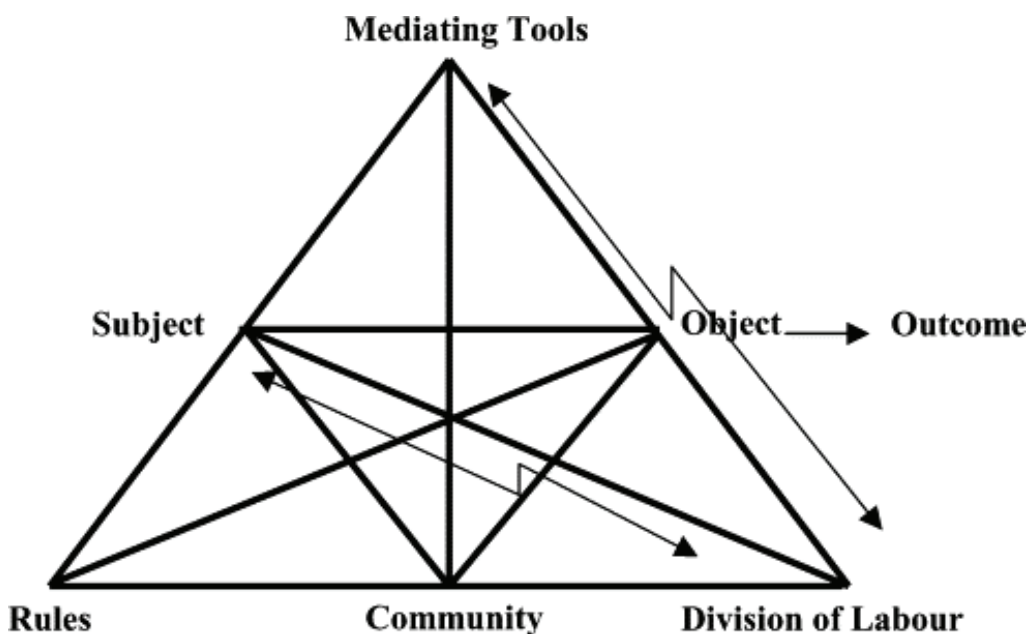
## Expansive cycles as possible form of transformation in activity

With activity theory acknowledging the individual's action and experiences, the individual cannot be separated from their social group or culture (Engeström, 1996). The notion of 'expansive learning', as proposed by Engeström (1996), starts with individuals questioning or challenging accepted practice and gradually coming together on a collective journey, resulting in transformation of practice. This aspect of CHAT could well be applied to the parent's and young person's journey.

CHAT builds on the interaction of multiple interacting activity systems focusing on an object partially shared (Engeström, 2009b; Engeström, 2001). Engeström (2005) suggests that studying interacting activity systems may help researchers to understand societal practices or activities which are developed and transformed

across boundaries of activity systems. In this study there are multiple interacting activity systems – young people, parents, family and communities – whose partially shared object may be to ensure best outcomes for the young person but with different emphasis or focus. For example, a parent and health professional may have a partially shared objective such as a young person's wellbeing. The parent's main focus may be on obtaining counselling, while the health professional may be primarily focused on referral pathways and a diagnosis, with the mode of therapy being secondary (Figure 13).

Figure 13: Interacting activity system – parent and health professional (adapted from Engeström (2001); Engeström 2001, p. 136)
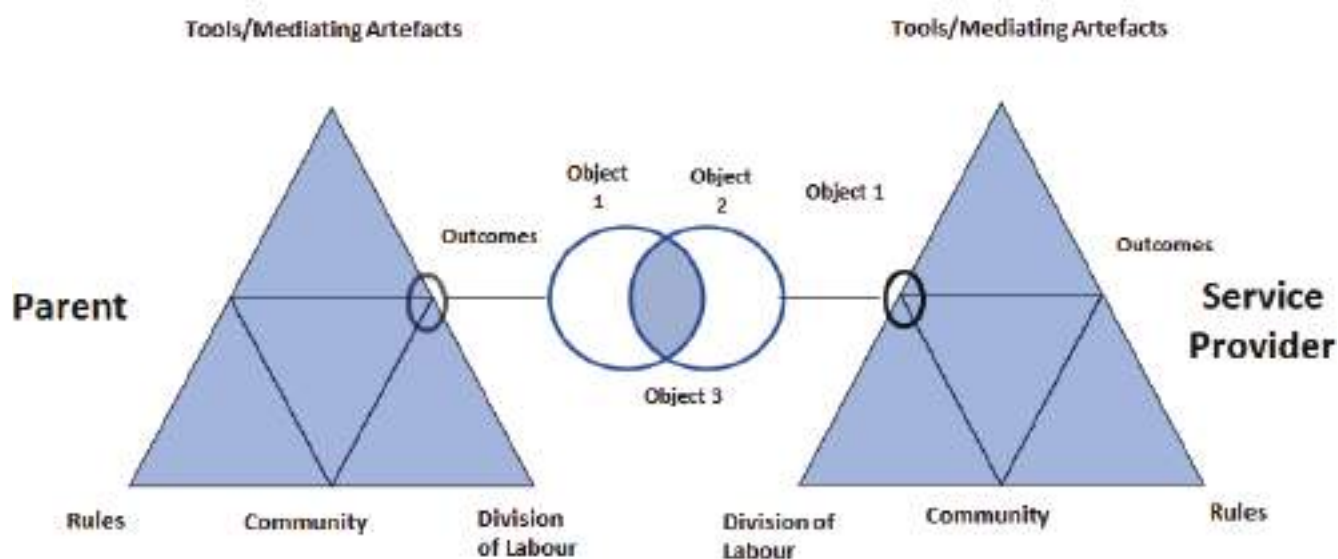
The interacting activity systems could potentially be those of the young person, parents, the informal networks and the health services along with extended family and friends.

Appendix O: Role of the researcher

Researchers have the responsibility to ensure that participants' rights and interests are protected throughout the research process (Polit and Beck, 2010). The Belmont Report (United States National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research, 1978) outlines three fundamental ethical principles to be incorporated into research guidelines: beneficence, respect for human dignity and justice. These principles are incorporated into this study.

Beneficence requires researchers to minimise harm and maximise benefits for participants and even society (Polit and Beck, 2010). This principle applies to both quantitative and qualitative research, but particularly for the qualitative aspect, especially in relation to sensitive, personal information. In this study it was not expected that the interviews would cause stress to participants. However, steps were put in place such as the provision of a debriefing sheet in the event that any individual became distressed (Appendix J, K).

An individual's right to self-determination and full disclosure, with participants having the right to decide whether to participate, ask questions, not give information and withdraw from the study without penalty, is a key facet of research (Polit and Beck, 2010). Participants were made aware of this, prior to the interviews, through the Parent/Guardian Information Leaflet and the Service Provider Information Leaflet (Appendix B, C).

Participants must be selected based on research requirements, but with full knowledge and understanding of their participation (Polit and Beck, 2010).

2.4.10 Role of the researcher and reflection

The role of the researcher, according to Hakkarainen (2004) first relates to the study itself and second to a researcher's 'being' and background, particularly with qualitative research.

Flyvbjerg (2001, p. 156) maintains that researchers need to conduct "socially-responsible research" and transmit their findings outside of the academic arena to those affected by or concerned with the area under study. Hakkarainen (2004) concurs, proposing an ethical responsibility to disseminate results in an accessible way as recognition and respect for participants and to 'target communities' for their cooperation with us as researchers.

However, Miettinen (2004) cautions that rather than expecting relevant social actors to effect change on simply accessing this information, the research results should be operational and practically useful to all interested parties.

A researcher's background influences many decisions such as the research topic, methodology, theories and research questions. In the interests of transparency and credibility, it is important to explain these (Hakkarainen, 2004). This approach requires movement from an objectivist position to an inter-subjectivist one including social properties, personal experience and self-awareness of the researcher (Boucher, 2004). Boucher (2004) concedes that researchers influence their work, but by using methodological approaches that require continual peer review and ongoing reflexivity, this influence can be reduced to tolerable levels.

Reflexivity refers to critical reflection of the researcher's own role and subjective responses in the process of research on a continual basis (Finlay, 2002; Braun and Clarke, 2013). Finlay (2002) argues against looking in, instead inviting research to dispassionately look outwards at interactions, discourse and shared meaning.

Guba and Lincoln (1994) propose the role of the researcher as 'passionate participant', facilitating the multi-voiced reconstruction of the participants, as well as the researcher's own construction, which facilitates change. This point is directly relevant to one of the five principles of CHAT, which is 'multi-voicedness' (Engeström, 2001).

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