



**Adolescents' and parents' views of Child and Adolescent
Mental Health Services (CAMHS) in Ireland**

Journal:	<i>Journal of Psychiatric and Mental Health Nursing</i>
Manuscript ID:	Draft
Manuscript Type:	Original Article
Keywords:	User Involvement, Child and Adolescent, Qualitative Methodology, Carers/Families, Communication

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Manuscripts

Review

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3 **Adolescents' and parents' views of Child and Adolescent Mental Health Services**
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5 **(CAMHS) in Ireland**
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9
10 **Abstract**

11 **Aim:** To explore adolescents' and parents' experiences of CAMHS in relation to
12 accessibility, approachability, and appropriateness.
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15 **Methods:** Using a descriptive qualitative design, a combination of focus group and
16 single interviews were conducted with adolescents (n=15) and parents (n=32) from
17 three mental health clinics. Data were transcribed verbatim and analysed using
18 thematic analysis.
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21 **Results:** Accessing mental health services was a challenging experience due to
22 knowledge deficit, lack of information and limited availability of specialist services.
23 Participants desired more information, involvement in decision-making, single and
24 shared consultations, flexible scheduling of appointments, continuity with clinicians,
25 school support and parent support groups. Participants seem to be generally satisfied,
26 however adolescents felt less involved in decision making than they would have liked.
27 Frequent staff changes was problematic as it disrupted continuity of care and hindered
28 the formation of a trusting relationship.
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31 **Implications for practice**

32 Parents and adolescents expressed similar views of the positive and negative aspects
33 of mental health services. Their need for more information-sharing and involvement
34 in decision-making underline the importance of collaborative practice. Clinician
35 continuity contributed to trusting therapeutic relationships and was valued. These are
36 key principles that with attention, could lead to quality service provision for
37 adolescents and families.
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39 **Keywords:** Adolescence, user participation, parents, services, mental health,
40 qualitative methodology.
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Accessible summary**What is known on the subject**

- We do not know enough about adolescents and parents' experiences of attending child and adolescent mental health clinics in Ireland.
- We need to ensure that services for adolescents and parents are user-friendly, designed around their needs, accessible and effective.

What this paper adds to existing knowledge

- Lack of information and availability of services made it difficult for participants to access help for mental health issues.
- Joint appointments hindered open disclosure, with both parents and adolescents preferring time alone with professionals.
- Adolescents wanted to be included in information-sharing and decision-making, but some felt that their voices were not heard in the decision-making process.

What are the implications for practice

- Both adolescents and parents find it difficult to disclose feelings and build trust, so a consistent relationship with a professional is essential.
- Provision of flexible consultations (both single and shared), coupled with inclusion in information-sharing and decision-making would help improve the experience for adolescents and parents.

Introduction

To ensure quality care, CAMHS teams need to place the adolescent¹ and family at the heart of the service and work in partnership with them to deliver accessible and community-based mental health (Department of Health, 2008). Government departments and organisations have a responsibility to promote meaningful participation for adolescents and families (Sinclair, 2004) and to promote choice, partnership and involvement for families in child and adolescent mental health services (CAMHS) (Department of Health, 2006, James, 2007, Department of Health, 2008, Mental Health Foundation, 2009). Community child and adolescent mental health teams are the first line of specialist mental health services with adolescents the most frequent attenders (Health Service Executive, 2012). Some research suggests that parents' experiences are influenced by clinics' accessibility, level of involvement, and understanding of the services (Bjorngaard, *et al.*, 2008, Holmboe, *et al.*, 2011). Service users' participation is an essential indicator of quality of care and caregiver participation has been associated with better outcomes for adolescents (Fawley-King, *et al.*, 2013). Parents' and adolescents' satisfaction with services has been strongly linked to functional improvement, diminished symptoms (Garland, *et al.*, 2007, Ronzoni and Dogra, 2012) and completion of treatment (Oruche, *et al.*, 2014).

Although there is increasing demand for user involvement, person-centred care and participation in service development and delivery worldwide, there remains a significant gap in the evidence base (Patel, *et al.*, 2007, Day, 2008). Studies that

¹ Children' is commonly used to encompass the age range of 0-18 years. In this paper, the term 'adolescents' seems more appropriate as participants were 11-17 years. Adolescents includes the term 'young people' to avoid cumbersome phrases.

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2
3 include adolescents in the evaluation of CAMHS are relatively few (Claveirole, 2004,
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5 Dogra, 2005) and a recent review found only 13 relevant studies, mainly of poor
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7 methodological quality, and concluded that more studies were needed (Worrall-
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9 Davies and Marino-Francis, 2008). Likewise in Ireland, only two studies have
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11 examined users' experiences of CAMHS (Teggart and Linden, 2006, Damodaran and
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13 Sherlock, 2013). Structured interviews with adolescents (n=22, aged 4-16) revealed
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15 that their right to assent to treatment and participation in decisions were not often
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17 upheld (Damodaran and Sherlock, 2013). In a mixed methods study with
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19 parents/carers (n=14) and young people (n=11, aged 14-20) in Northern Ireland,
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21 participants reported frustration with service accessibility, information provision,
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23 waiting times, incomplete services, fears of stigma, and wanted more involvement in
24
25 information provisions and decision-making (Teggart and Linden, 2006). Research
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27 indicates that parents and their children have different mental health needs and
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29 evaluate services based on differing perspectives, therefore, it is vital to include both
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31 viewpoints in any evaluation of services (Garland, *et al.*, 2007, Aarons, *et al.*, 2010,
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33 Biering, 2010). Given the limited research in this area, we investigated adolescents'
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35 and parents' views of child and adolescent mental health services in Ireland. The
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37 primary objective was to identify key factors impacting both positively and negatively
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39 on participants' satisfaction with CAMHS.
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47 **Methods**

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49 Qualitative descriptive approach were used to conduct this study (Sandelowski, 2004).
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51 Interviews were seen as more suitable for accessing in-depth information rather than
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53 structured satisfaction surveys which tend to produce higher satisfaction rates (Barber,
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55 *et al.*, 2006, Bjorngaard, *et al.*, 2008). Focus groups can work well with adolescents as
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3 it can help them feel more comfortable and group format can encourage expression,
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5 aiding interactions and feeling less exposed (Day, *et al.*, 2006, Coyne, *et al.*, 2009).
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7 Focus groups may not suit all participants particularly in a mental health context, thus,
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9 we included the option of individual interviews. Ethical approval was granted by the
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11 lead institution and local health service ethics committees.
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14 15 16 ***Sample and recruitment*** 17

18 Participants from three clinics located in three regions were invited to participate by
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20 clinic staff, who explained the study and obtained verbal consent. Prior to data
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22 collection, the researchers obtained written informed consent from participants and
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24 assent from those under 18 years. Participants were advised that the care they received
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26 would not be affected by their participation and that support was available after each
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28 interview if required.
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34 The interview schedule contained open questions on services accessibility,
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36 availability, and appropriateness. Nine focus groups (six with parents and three with
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38 adolescents) and ten interviews (four with parent (s) and six with adolescents) were
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40 conducted. Interviews lasted approximately 30-90 minutes and were conducted by a
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42 psychologist/ social worker and nurse researcher. Recruitment of new participants
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44 ceased once data saturation had occurred. Final sample included 32 parents (6 male
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46 and 26 female) and 15 adolescents (6 male and 9 female). Adolescents (11-17 years)
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48 had been attending for an average of 23.57 months ($SD=23.30$, $N=14$, range 5-90
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50 months). Five had a mood disorder, three had Attention Deficit Hyperactivity
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52 Disorder (ADHD) and remaining diagnoses included impulse control, anxiety,
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54 adjustment and behavioural disorders.
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Data Analysis

Interviews were audio recorded and transcribed verbatim. Data were analysed by systematically identifying and grouping codes and categories into themes (Braun and Clarke, 2006). Transcripts were read to identify commonly occurring codes which were extracted into a table and then grouped into core categories according to similarity of content. The initial analytic framework was independently checked by two members of the team and then the remainder of data coded. The framework was refined throughout the analysis. An independent review of the final themes and process was conducted by the lead researcher to enhance the trustworthiness of the analysis (Sandelowski, 1993, Morse, *et al.*, 2001).

Results

The analysis resulted in five themes: (1) Getting help, (2) Being heard and voicing opinions, (3) Building a therapeutic alliance, (4) Impact of stigma, and (5) Meeting support needs. Table 1 displays the themes and categories supported with participants' statements.

Theme 1: Getting help

Seeking help for a child who is experiencing mental health difficulties proved challenging for parents. For many, this was their first experience and they reported being unsure where to access help. Parents mentioned consulting with family members, teachers, and other acquaintances for advice about services. General practitioners (GPs) and private counsellors were typically the first point of contact for help. Parents were critical of the length of time it took to access CAMHS, which in

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2
3 some cases extended to 18 months. Several parents had been advised that they could
4 access support much quicker by going to private services or asking their GP to write
5 an urgent referral letter. Waiting for an appointment proved to be a particularly
6 stressful time for parents. There was a perception that this concern was not shared by
7 those in the CAMHS and in one clinic, parents felt that those who made a fuss often
8 got an appointment quicker than those who stayed silent. These same concerns were
9 not evident in the adolescents' data. It emerged that many were unaware they would
10 be attending CAMHS until just prior to their first appointment, suggesting they were
11 not involved in this part of the decision-making process.
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25 **Theme 2: Being heard and voicing opinions**

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27 Some parents felt fully informed by healthcare professionals (HCPs) on all aspects of
28 their child's care and that their opinions and requests were listened to, while others
29 felt suboptimally involved. These parents felt they had to fight for their voices to be
30 heard or to obtain information on their child's progress. They did not feel empowered
31 to question their child's care, to raise specific issues and felt pressured into accepting
32 HCP's advice. Similarly some adolescents also felt at the periphery or excluded from
33 the decision-making process, and did not feel empowered to voice their views.
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45 Shared consultations were problematic. Both adolescents and parents felt it was
46 important to be heard and be able to express views during sessions. However, they
47 reported feeling inhibited speaking in front of each other and often engaged in self-
48 censorship. Parents noted that sometimes they had to say things they would rather
49 their child did not hear. They worried that speaking openly may hinder their child's
50 progress or would cause them to lose their child's trust. Consequently, they reported
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3 limiting what they shared and/or asking to speak to the HCP alone. Similarly
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5 adolescents were sometimes unwilling or unable to speak openly with a parent present
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7 and preferred separate consultations with HCPs. Some teams did provide
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9 opportunities for parents and adolescents to speak privately with HCPs; however this
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11 did not happen in all cases.
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16 **Theme 3: Building a therapeutic alliance**

18 Both parents and adolescents spoke about the importance of building a trusting and
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20 therapeutic relationship with HCPS. A non-judgemental approach was considered
21
22 very important. Some parents felt uncomfortable speaking about personal issues with
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24 strangers whilst others felt their parenting style was under scrutiny. Parents remarked
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26 that their children experienced difficulty talking openly with others and expressing
27
28 thoughts and feelings. Those that felt that the process did not connect with their child
29
30 suggested that professionals should try to establish a better rapport to encourage them
31
32 to 'open up'. Likewise adolescents also stated that at times it was difficult to talk to
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34 professionals. Some were aware that professionals were sensitive to these issues as
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36 they used different means of fostering communication, such as writing or drawing.
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38 For older adolescents though, painting or completing questionnaires could be
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40 frustrating.
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47 Staff turnover was noted as a key issue that negatively impacted on the therapeutic
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49 alliance, particularly in the case of psychiatry registrars. Participants were given either
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51 very little or no prior notice that this change would happen. Frequent changes were
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53 problematic as professionals had different approaches to care and treatment, and
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55 families had to start "from scratch" to establish a rapport with a new HCP. Parents'
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3 statements underscored the negative impact of staff turnover on adolescents'
4 participation efforts. Adolescents noted how difficult it was to 'open your heart' to
5 someone, for that person to leave, and feeling exposed 're-telling' their story to a new
6 professional.
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11 12 13 14 **Theme 4: Impact of stigma**

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16 Both parents and adolescents were sensitive to the stigma attached to mental illness,
17 which made some feel reluctant to engage with services. Some parents concealed the
18 fact that their child was attending CAMHS from friends and family members,
19 sometimes at the request of the child. Deciding to disclose to another person that their
20 child was experiencing mental health problems was not done lightly, if at all.
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24 Adolescents also mentioned a reluctance to tell others that they were attending
25 CAMHS. Stigma was perceived by parents to be most obvious within schools.
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27 Although some parents were satisfied with the support they received from their
28 children's schools (often coordinated in conjunction with CAMHS staff), others
29 complained about teachers who lacked understanding of mental health issues and a
30 unsupportive school system.
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43 **Theme 5: Meeting support needs**

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45 Most participants had very little, if any, previous experience with mental health
46 services. It was clear that there was a significant amount of anxiety and uncertainty
47 associated with engaging with mental health services. Support needs consisted of two
48 distinct categories: informational and emotional. Many parents reported not knowing
49 what to expect at the first appointment and suggested that information on the service
50 and processes would help alleviate their anxiety. The perception of not having
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3 adequate information appeared to continue past the first appointment as few parents
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5 reported having the therapeutic process explained to them and almost none reported
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7 receiving a care plan.
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11 Similarly adolescents wanted more information on what to expect before attending
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13 their first appointment. They remarked that they were given little or no information
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15 by their parent(s) prior to their appointment and their parents had not answered some
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17 of their questions. However, it is likely that parents could not provide this information
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19 as they were unaware what to expect themselves. Most adolescents reported feeling
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21 uninformed and unprepared before attending appointments which made them feel
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23 anxious. However over time, some noted that they received more information on the
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25 treatment process.
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31 While HCPs were seen as important sources of information, parents reported that they
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33 would appreciate more psycho-education, including what they could do to help their
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35 child and if there were any particular behaviours or signs of distress they should be
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37 watching for. Some had attended courses provided by CAMHS which had helped
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39 them understand their child's condition and provided them with useful behaviour
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41 management strategies and opportunities to meet other parents in similar situations.
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43 Parents remarked that their child's condition had a significant impact on their own
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45 well-being and family life and that they would benefit from additional support
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47 separate to that being provided for their child. Parents sometimes blamed themselves
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49 and felt guilty, because they felt they should have noticed their child's difficulties
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3 Adolescents identified three sources of support: HCPs, parents and particular teachers.
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5 Those who spoke positively made reference to being kept well informed, included in
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7 the decision-making processes, encouraged to participate during consultations and
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9 actively listened too by the professionals. They preferred HCP's who were friendly,
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11 warm, genuine, trustworthy, and non-judgmental. They appreciated HCPs liaising
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13 with their schools to discuss strategies and explain their conditions to teachers.
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18 19 **Discussion**

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21 The findings indicate that accessing and engaging with mental health services was a
22
23 challenging experience for parents and adolescents due to accessibility barriers, staff
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25 changes, stigma, and lack of information about services and procedures. These same
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27 factors have also been reported as negative factors worldwide (Street, 2004, Sayal,
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29 2006, Plaistow, *et al.*, 2014). Although changes are underway to improve CAMH
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31 services, a recent report (Health Service Executive, 2012) found significant variation
32
33 in the distribution and resourcing of CAMHS across regions. The scarcity of
34
35 resources for youth mental health is a serious concern as most mental disorders
36
37 emerge in adolescence and early adulthood and Ireland has high rates of youth mental
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39 health problems and suicide (Lynch, *et al.*, 2004, Illback and Bates, 2011). However
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41 the scarcity of adolescent specialist services, poor awareness of mental disorders and
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43 stigma are also major challenges worldwide (Patel, *et al.*, 2007).
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50 Although parents and adolescents expressed satisfaction with the services, they held
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52 both positive and negative views on care provision. They appreciated the therapy and
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54 help but lacked information about what to expect, the treatment process, philosophy
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56 of care and professionals' roles. They wanted information on the service structure and
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3 procedures prior to the first appointment. Parents needed more information on their
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5 child's care plan, condition, and more parenting courses on behaviour management.
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7 Some parents were satisfied with the support they received from their children's
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9 schools (co-ordinated by CAMHS staff), whilst others reported difficulty sourcing
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11 support and experienced stigma.
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16 Sharing treatment sessions was problematic for both parents and adolescents because
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18 of privacy and confidentiality concerns which is relatively under-reported (Harper, *et*
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20 *al.*, 2013). They reported feeling inhibited by each other's presence (parent or child),
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22 resulting in constrained communication. As seen earlier, most adolescents felt
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24 excluded from the initial decision to attend and reported limited involvement in care
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26 decisions. This is problematic as encouraging openness and building a sense of trust
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28 and shared goals are essential elements in building a strong therapeutic alliance which
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30 is an important predictor of treatment outcome (Day, 2008).
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36 Consistency in service provision and the quality of the relationship between families
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38 and professionals was reported to have a significant impact on both parents and
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40 adolescents satisfaction levels. Frequent staff changes were problematic as it hindered
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42 development of trust and relationship building. The importance of consistency, trust,
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44 good relationships, and professionals' interpersonal qualities are consistent with
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46 studies from Ireland (Teggart and Linden, 2006, Damodaran and Sherlock, 2013),
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48 England (Buston, 2002, Street, 2004, Day, *et al.*, 2006, Plaistow, *et al.*, 2014) and
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50 worldwide (Mitchell-Lowe and Eggleston, 2009, Gulliver, *et al.*, 2010).
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Practice implications

The format of consultations needs to accommodate both parents and adolescents' preferences to encourage free and open information exchange (Coyne, 2006, Coyne, 2008). Adolescents and parents should be offered the opportunity to be seen separately and then together. It is essential that adolescents feel enabled to share their views, and contribute to shared therapy goals. It is important that professionals are approachable, friendly, warm, non-judgemental as this positively impacts on adolescents' experiences (Kim, *et al.*, 2012). Staff turnover needs to be addressed as consistency is a critical requirement for adolescents (Harper, *et al.*, 2013). CAMHS teams need to ensure that the adolescent has a key worker. Nurses could be the key worker as they play a key role in providing increased continuity and advocacy for service users and their carers/ family members, and in health promotion in schools (Health Service Executive, 2012).

Coping with a child who has mental health difficulties affects parental well-being and the family dynamic (Harden, 2005, Oruche, *et al.*, 2012) so parental psycho-educational support is crucial. Information should be provided in different formats to prepare, assist involvement and reduce misunderstandings and anxiety (Ross and Egan, 2004). The significant impact of stigma on adolescents and parents, alongside the impact of the adolescents' mental health difficulties, indicates that information, multi-agency communication and social support are essential (O'Reilly, *et al.*, 2013).

Limitations

Participants were recruited by gatekeepers which may have biased the sample but participants did express both positive and negative experiences about services. Future

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3 studies should include larger sample of adolescents and parents, combine interviews
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5 with participatory techniques, and take a longitudinal approach.
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8 9 **Conclusions**

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12 In summary, participants desired more information, involvement in decision-making,
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14 collaboration on care plans and valued therapeutic relationships and clinician
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16 continuity. These same principles are outlined in *A Vision for Change* (Department of
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18 Health, 2006) which provides a comprehensive model of mental health service
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20 provision for Ireland, and are included in the new *iCAMHS* National Quality
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22 Guidelines (Health Service Executive, 2013) encouraging auditing and evaluation of
23
24 services, identification of service gaps and development of action plans to address
25
26 deficits. Quality service provision for adolescents and families is critically important
27
28 in light of the increasing prevalence of mental disorders in adolescents and the long-
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30 term consequences of untreated disorders. To date CAMHS annual reports have not
31
32 collected outcome measures that allow clinicians and providers to establish whether
33
34 service providers are meeting the needs of those attending. This study contributes new
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36 data on adolescents and parents' experiences and results have been shared with
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38 participating clinics and more widely. Professionals are aware of service users' need
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40 for inclusion but there is still much work to be done to promote true partnership in
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42 mental health services.
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Themes	Categories	Parents' quotes	Adolescents' quotes
Theme 1: Getting help	Long waiting lists	<i>FG3C-P3: I remember going to my own doctor crying and I said, you have to do something you know? I'm sick listening to the teachers, I've a path worn to the school, they all know there's some kind of problem and she said the waiting list is so long you're better off going privately.</i>	<i>INT-YP6C I didn't have any say in it. I didn't want to go the first time I felt nervous.</i>
	Lack of information about services		
	Feeling unprepared	<i>INT-P3C: Oh 100 % satisfied, I mean I couldn't be any happier with the help that daughter got or the help that I got because without them I don't know where I'd have been.</i>	<i>FG1A-YP1: Well I like coming here cos everybody's really friendly, like nobody's like real strict like, they're all really nice</i>
	Getting help		
Theme 2: Being heard and voicing opinions	Discussing choices	<i>FG4B-P2 I think we met with the psychiatrist first and she put some different options to us with regard to [child] and then we discussed them with her and we let her know what we were going to do'</i>	<i>INT-YP3A: I feel like everyone just kind of talks at me or about me when I'm right there and they might ask me is that ok and they ask me in such a way that I kind of feel like I don't have any other option just to agree with them</i>
	Lack of information about treatment process		
	Feeling excluded	<i>FG6B-P1 I actually think it would be a good idea if parents could have a private session just because anytime we went in there, we had [child] with us. And while I suppose we learnt how to talk about things because maybe we didn't before cos we never had to deal with it, I think for me personally, I'd have liked the opportunity to have half an hour or an hour just about how do I really feel about this? What am I supposed to be feeling? What was I doing wrong?</i>	<i>INT-YP2A Explain things better and like on your first session don't be asking such personal questions when there is loads of other people in the room cos when I was brought in there were four counsellors sitting there and a doctor who my parents met and they were asking me really personal questions that I didn't want to answer in front of my parents let alone a load of strangers'</i>
	Difficulty with shared consultations		
Theme 3: Building a therapeutic	Building trust	<i>INT-P3C: You know it didn't matter what I said or what, you know, what happened I had somebody there that I could talk to and it wasn't an issue, I wasn't fobbed aside and I wasn't ridiculed, my opinion and my feelings were of importance I felt to them, they wanted to know</i>	<i>INT-YP4A You don't feel like your judged in anything that your saying and I really like as well they remember who you are...and for example my psychologist she remembers everything that I tell her like I start to tell her something and well she still lets me talk</i>
	Building relationships		
	Frequent staff changes	<i>FG3B-YP1 You see them for two weeks then you come back and you find someone else. So it's weird and then they ask</i>	<i>FG3C-YP2: It's very hard cos you're used to them, or you're just getting used to them, and they go. It's a</i>

alliance	Re-telling personal history	<i>you the same questions the same person asked you two weeks ago and it's like, getting to know you again. It's like they don't know about you, like they can't read the file before you walk in the door. It's just like, sorry what's your name again?' It's frustrating.</i>	<i>real step you're opening your heart, you're exposing yourself and then they're gone and you're thinking God you were just getting to know them, you have to start all over again</i>
Theme 4: Impact of stigma	Fear of being labelled Keeping attendance secret Lack of support from teachers & school	<i>FG4C-P3: I have told another person that had similar problems and that probably would be the only person I've told, certainly I'd have family members told that we're getting help but I wouldn't have told them that we're going to psychiatric services to avail of help because I don't think Ireland has moved that much further even now</i> <i>INT-P2C: The last school where my son came from people gossip and stories manage to circulate so we did have trouble trying to find him a proper school and support. The school we chose has been great and I really thing that made the difference. I think the school was crucial because there was no support in his previous school.</i>	<i>FG3C-YP1: At the start I came here every week and it was every Tuesday and my friends would be like, where are you going? Cos they'd notice I was disappearing every week and they'd be like, where are you going? I'm going to a friends, leave me alone.</i> <i>INT- YP1C When I first came to the building it was mental health that was my first time so when I first came I was worried and I said to my friend does that mean that I am mad?</i>
Theme 5: Meeting support needs	Informational support needs Emotional support needs Parenting courses helpful Support from teachers & schools	<i>FG2A-P1 It's a blind journey actually, the way it is, and I don't think it has to be blind, I think there could be a bit of a road map laid out there for you. To be told, this is what we might do or that could happen or that could happen. That the options are laid out for you so it's not a case of, I wonder what we're going to do this week, you know?</i> <i>FG5C-P2 I did a parenting group and I found it was brilliant... we built up certainly a lot of stuff that we learnt on that course into our family. It helped us an awful lot'.</i>	<i>FG3B-YP1: I have no idea. I actually don't know. I don't know who any of these people are. They just come in and say hi I'm [name], I'm [name], and it's like, hey</i> <i>FG2C-YP2: If I'm having trouble in school or anything like if I'm having a bad day now, like [name], she set up something in school for me so I'd have someone to talk to about stuff so it's grand</i>

For Peer Review

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