# TITLE

Who is in the Transition Gap? Transition from CAMHS to AMHS in the Republic of Ireland <sup>1,2, 3</sup>McNicholas F, <sup>1</sup>Adamson M, <sup>4</sup>McNamara N, <sup>2</sup>Gavin B, <sup>5</sup>Paul M, <sup>6</sup>Ford T, <sup>7</sup>Barry S, <sup>1</sup>Dooley B, <sup>8</sup>Coyne I, <sup>9</sup>Cullen W, <sup>4</sup>Singh SP

<sup>1</sup>University College Dublin, Ireland; <sup>2</sup>Lucena Clinic, Ireland; <sup>3</sup>Our Lady's Hospital for Sick Children, Crumlin, <sup>4</sup>University of Bedfordshire, UK; <sup>5</sup>University of Warwick, UK; <sup>6</sup>University of Exeter Medical School, UK; <sup>7</sup>Cluain Mhuire Adult Mental Health Service, Ireland; <sup>8</sup>Trinity College Dublin, Ireland; <sup>9</sup>University of Limerick, Ireland

# ABSTRACT

**<u>Objective</u>:** The ITRACK study explored the process and predictors of transition between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) in the Republic of Ireland.

<u>Method</u>: Following ethical approval, clinicians in each of Ireland's four Health Service Executive (HSE) areas were contacted, informed about the study and invited to participate. Clinicians identified all cases who had reached the transition boundary (i.e. upper age limit for that CAMHS team) between January and December 2010. Data were collected on clinical and socio-demographic details and factors that informed the decision to refer or not refer to AMHS and case notes were scrutinised to ascertain the extent of information exchanged between services during transition.

**Results:** Sixty-two service users were identified as having crossed the transition boundary from nine CAMHS (HSE Dublin Mid-Leinster (n=40, 66%), HSE South (n=18, 30%), HSE West (n=2, 3%), HSE Dublin North (n=1, 2%). The most common diagnoses were ADHD (n=19, 32%), mood disorders (n=16, 27%), psychosis (n=6, 10%) and eating disorders (n=5, 8%). Forty-seven (76%) of those identified were perceived by the CAMHS clinician to have an 'on-going mental health service need' and of these 15 (32%) were referred, 11(23%) young people refused and 21(45%) were not referred with the majority (12, 57%) continuing with CAMHS more than a year beyond the transition boundary. Young people with psychosis were more likely to be referred ( $\chi^2$  (2, 46)= 8.96, p=.02) and those with ADHD less likely ( $\chi^2$  (2, 45)= 8.89, p=.01). Being prescribed medication was not associated with referral ( $\chi^2$  (2, 45) = 4.515, p =0.11). In referred cases (N=15), there was documented evidence of consent in 2 cases (13.3%), inferred in

another 4 (26.7%) and documented preparation for transition in 8 (53.3%). Excellent written communication (100%) was not supported by face to face planning meetings (n=2, 13.3%), joint appointments (n=1, 6.7%) or telephone conversations (n=1, 6.7%) between corresponding clinicians.

**Conclusions:** Despite perceived on-going mental health need, many young people are not being referred, or are refusing referral to AMHS, with those with ADHD being most affected. CAMHS continue to offer on-going care past the transition boundary, which has resource implications. Further qualitative research is warranted to understand, in spite of perceived mental health need, the reason for non-referral by CAMHS clinicians and refusal by the young person.

#### **Introduction:**

Adolescence is a time of increased risk for many mental health (MH) disorders and the importance of an effective and well managed transition between Child and Adolescent Mental Health Services (CAMHS) and Adult Mental Health Services (AMHS) has been increasingly recognised (Paul et al., 2013; McNamara et al., 2013; Singh et al., 2010). For many adolescents the presentation of MH difficulties continue and persist into adulthood (Patton et al., 2012) and as such they will frequently require long-term engagement with health services and require transfer of care from CAMHS to AMHS. Continuity of care in MH services is therefore a key aspect of service provision. Problems in transition typically disrupt continuity of care and may have a serious impact on service users, on their carers and on the effectiveness of MH services in providing quality care (Singh et al., 2010).

Shortcomings in transition have been highlighted in a UK report by the Health Select Committee (House of Commons, 2000) and by Singh and colleagues (2010). These include arbitrarily drawn service boundaries, poor communication between agencies, a shortage of in-patient units for adolescents and the need for early intervention services. The findings of the CAMHS Report (Health Service Executive, 2013) which audited all 60 CAMHS in Ireland reflects the lack of standardised practice nationwide regarding service provision for 16 and 17 year olds. The report indicated that only 19 teams nationwide accept all new cases up to and including 17. Thus while a Vision for Change recommends that the upper age for CAMHS is 18, it is clear that the transition boundary (i.e. the age boundary between CAMHS and AMHS) in reality varies between 16 and 18 years. As a result some young people face difficulties accessing appropriate

services. At present there is limited information about the process of transition in Ireland (McNamara et al., 2013).

Although mental health policy in Ireland, *A Vision for Change: The Report of the Expert Group on Mental Health Policy* (Department of Health & Children, 2006) has emphasised the importance of improving both the quality and continuity of treatment within MH services, information on this area has so far been lacking. This Irish study of transition policy and practice, ITRACK, is the first to explore the specific arrangements for transition between CAMHS and AMHS. The critical gaps between operational practice and best practice guidelines have previously been published (McNamara et al., 2013). In this paper, we describe the cohort of young people reaching the transition boundary and their outcome.

# Methods:

A comprehensive list of all consultant psychiatrists from child and adult MH services in urban and rural areas throughout Ireland was generated from the HSE website and by making telephone contact with each clinic. Ethical approval was received from the research ethics committee of each participating clinical service. Clinicians were advised about the study and invited to participate. Consenting child psychiatrists were asked to retrospectively identify all cases who had reached the transition (age) boundary during January and December 2010. Specifically, clinicians were asked to draw up a list of all young people whose cases were open when they reached age X between January 1<sup>st</sup> and December 31<sup>st</sup> 2010 (where X is the last chronological year of age for which they should be seen by CAMHS as defined by that service/team).

Following clinician identification of potential cases, clinical team members retrieved the relevant data from the case notes using the data extraction tool used in the UK transition study, TRACK, with minor modifications for the Irish setting (i.e. removing references to NHS Trust and NHS Patient ID number) (Singh et al., 2010). Fully anonymised data was provided by clinicians to the research team for analysis. In some instances, the consent of the young person was given for the research team to access the case notes directly to extract data. Information collected included: suitability for referral to AMHS; young person's clinical & socio-demographic details; parental engagement, outcome of referral; time from referral to assessment (if referred); time from referral to acceptance by AMHS; documented evidence of hand-over planning; quality of information transfer; nature and frequency of joint working during transition (between CAMHS and AMHS); problems documented during transition; contact frequency, types of contact and contact details; and admissions, discharges, referrals to other services and evidence of documentation of other transitions within the previous year. For potential referrals (those who crossed the transition boundary but were not referred), information was collected as above but also included: current status, current management plan, and factors accounting for the decision not to refer to AMHS. The diagnosis given by CAMHS was recorded on two occasions, at the time of initial presentation to CAMHS (D1) and at time of reaching the transition boundary (D2). Data were entered into SPSS, where cases were categorised as being either referred to AMHS, refused referral by the young person and / or parent or not referred. Descriptive statistics were initially derived for all variables and Pearson  $\chi^2$  tests (Fishers exact tests where appropriate and Phi or Craemer's V noted for strength of association) were used in order to determine significant associations (p<0.05). Using Bonferroni principles, correlations with a significance value of p<.01 are considered significant.

# **Results:**

From the 60 CAMHS teams contacted, 9 responded from the four Health Service Executive (HSE) service areas covering a population of 4.6 million and 1 CAMHS was ineligible as their cut off was age 12/13, transferring care to another CAMHS. From these clinics, 62 service users were identified by the child psychiatrist as having crossed the transition boundary, with the majority of cases from HSE Dublin Mid-Leinster (n=40, 66%), HSE South (n=18, 30%), HSE West (n=2, 3%) and HSE Dublin North (n=1, 2%). Clinical and socio-economic details are listed in table 1. The mean age at initial referral to a CAMHS service was 13.3 (SD 3.68, Range 4-17.5) and mean age of transition was 17.7 years old (SD .75, Range 16-19). Attendance by either parent was very common, with most mothers attending regularly (n=45, 73%) and both parents in 9 cases (20%). In cases where the information was documented (n=51) there was a very high rate of MH problems present in either parents (n=22, 43%), sibling (n=12, 19%) or second degree relatives (n=19, 37%). A Chi-square test for independence (with Yates Continuity Correction) indicated a significant association between mothers with a MH history and regular attendance ( $\gamma^2$ (1,43)=7.87, p=.012, phi=.43). Young people who had a family history of MH problems had mothers who were less likely to attend.

As might be expected diagnoses changed over time, highlighting the temporal instability of MH diagnoses. The most common diagnoses at time of initial presentation (D1) to CAMHS were mood disorders such as anxiety or depression (n=23, 37%) and ADHD (n=19, 31%). Less common were eating disorders (7, 11%) and psychosis (5, 8%). Over time (D2) mood disorder frequency decreased (16, 26%), ADHD increased (19, 31%) and psychosis (n=6, 10%) and OCD (n=4, 7%) featured more frequently, although still in a limited number of cases. Five young people had an eating disorders (8%) and 3(5%) PDD. Comorbidity was common among many of

the service users, with 42 (70%) experiencing multiple MH difficulties at some point during engagement with CAMHS

In addition to general support and psycho-education, specific interventions following initial consultation included medication (39, 64%), individual therapy (25, 41%) and parenting support (12, 20%). At the time of transition most young people were receiving general psychological support (n=47, 77%) and medication (34, 56%) with fewer individuals receiving individual therapy as the primary intervention (n=12, 20%). In the majority of cases the identified lead clinician was a Psychiatrist (n=19, 58%) followed by a Nurse (n=10, 30%) and Psychologist or Social Worker (n=2, 6% respectively).

### **Transition Pathways**

Transition pathways were determined for each case in the sample that made the transition. Out of a total sample of 62 cases, 47 (76%) were perceived by the CAMHS clinician to have 'on-going MH service needs' (referred to subsequently as 'MH need') at the time of transition while 15 (24%) did not (No MH need). Of those with 'MH need', the majority were not referred. 15 (32%) were referred, 21 (45%) were not and a in a further 11 (23%) cases, referral was refused by the young person. Conducting Chi-square test revealed few associations between those considered to have a MH need and those not. Specifically, diagnostic group or a family history of mental illness were not significantly associated with MH need. Being on medication ( $\chi^2$  (1, 61)= 6.81, p=.015, Phi=.334) or having a mother who attended CAMHS regularly ( $\chi^2$  (2, 45)=5.26, p=.044, Phi=.312) showed a trend to significance, but using Bonferroni corrections, were also not significantly associated.

#### Young people with on-going mental health needs

Forty-seven young people were considered to have MH need at the time of crossing the transition boundary, with a range of diagnosis (16 ADHD, 10 mood, 6 psychosis, 4 ED, 4 OCD and 1 autistic spectrum disorder). Of these, a third were referred (15, 32%) (1 ADHD, 5 mood, 5 psychosis, 2 OCD, 2 no Axis 1/2 diagnosis given). Most were deemed to be urgent referrals (n=10, 71%) with the mean wait time to AMHS decision of 7.9 weeks (SD 5.49, Range 0-15). One referral was not accepted, where AMHS perceived the person to have a primary substance abuse problem comorbid with depression. Nine clinicians gave specific reasons for referral, these included being on psychotropic medication (6 reports) and referral for specific interventions; dialectical behavioural therapy (1), CBT (1) and bereavement counselling (1).

Almost half (21, 45%) of those with MH need were not referred. 12 (57%) of these continued with CAMHS beyond the transition boundary for a mean number of 59 weeks (SD 30.62, Range 2-111) attending on average six times (Mean 6.4 sessions, SD 7.49, Range 0-24). Nine young people (43%) were discharged back to their GP. A smaller number of clinicians gave reasons for non-referral despite MH need. Six clinicians stated the person would not meet AMHS referral criteria (2 ADHD, 2 PDD, 1 learning difficulty and 1 mood disorder) and 7 perceived that AMHS did not have the appropriate or necessary services that the young person in question needed. Of these, four of the young people were on medication; two were receiving individual therapy in addition to general support. The disorders ranged from ADHD (3), Mood (2), Eating Disorder (1) and child protection issues (1). One young person was referred to private psychology service to better meet their needs.

Lastly, for the remaining 11 (23%) cases with MH need, the clinician considered them suitable for referral and the evidence from the case notes indicates they wanted to make the referral, but the young person and in 3 cases also the parent, refused the referral to adult MH services. Six (55%) of these cases continued in CAMHS beyond the transition boundary for 49 weeks (SD 2.51, Range=0-7) before the young person either disengaged (n=5, 83%) or was discharged to their GP (n=1, 17%). Three (27%) young people were discharged directly to their GP at transition and a further two (18%) after a period of non-attendance at CAMHS. The disorders ranged from ADHD (7), Mood (2), OCD (1) and SUD (1).

#### Comparisons between referred, not referred and refused

A comparison between clinical features of those referred and not referred, along with those who refused are given in table 2. The main differentiating features are that those with a diagnosis of psychosis are more likely to be referred ( $\chi^2$  (2, 45) = 8.96, p=.02, V =.45) and those with ADHD more likely to refuse transfer ( $\chi^2$  (2, 45) = 6.81, p=.01, V =.44), only the latter reaching statistical significance at p=.01.

Interestingly, being prescribed medication was not associated with the patient's outcome with respect to referral status ( $\chi^2$  (2, 46) = 4.515, p =0.11). This may be explained by the high proportion of patients with ADHD who were either not referred or refused the referral, who would be expected to be on medication. Individual therapy and parenting support were also more frequent among the referred group, but this did not reach statistical significance ( $\chi^2$  (2, 46)=4.485, p=0.12 and  $\chi^2$  (2, 46)=5.916, p=0.08 respectively).

#### **Case Management around Transition**

With respect to the 15 young people who were referred, there was documented evidence from the case notes that the young person consented to transition (n=6, 40%) and was prepared for the process (n=8, 53%). There was written communication between CAMHS and AMHS with respect to transition in all cases, with a referral letter being consistently sent (n=14, 93%). However, less evident from the notes were the occurrence of planning (n=2, 13%), joint appointments (n=1, 6%) or telephone conversations (n=1, 6%) between corresponding clinicians.

#### **Discussion:**

At initial assessment, many of the children attending CAMHS had comorbid MH diagnosis and had family members with difficulties. Over time and with treatment, their needs may change. MH difficulties may resolve to the point where they no longer require specific MH interventions and they can be discharged back to their GP, as occurred in 15 cases in this study, or they may be referred to other community psychological services to provide on-going support, as in the case of one young person. For others who have severe and enduring mental illness, they will require continued care from specialised MH services. The age at which that decision arises is dictated by service configurations and idiosyncratic practice. This one year cross sectional review of CAMHS attendees revealed that upon reaching this transition boundary the fate and care pathway for young people with perceived MH needs, especially neurodevelopmental disorders (ADHD), and eating disorders is far from clear. It has been previously reported that the lack of standardised practice nationwide regarding service transition boundary, coupled with an absence

of written policies and minimal formal interaction between child and adult services, contribute to the on-going ambiguity in service provision (McNamara et al., 2013).

In this study, less than a third of those with perceived MH need are in fact being referred, despite the fact that all but one of referrals made were accepted readily and within a short time frame by AMHS. This rate of referral is significantly less than the 58% found in the UK transition study (Singh et al, 2010). Referrals that were made were generally urgent, co-morbid and had typical diagnosis expected to be managed within an AMHS setting. Similar to the UK study, those with psychosis or a mood disorder were somewhat more likely to be referred to AMHS, compared to ADHD or eating disorders (Singh et al, 2010).

Equally concerning was the finding that 11 (23%) young people refused referral. The reasons elicited from the case notes suggest that there were both clinician and youth factors accounting for this.

It seems from the data that CAMHS clinicians are not necessarily considering diagnoses such as ADHD or eating disorders to have 'on-going MH need'; neither did they believe they would be accepted or appropriately managed by AMHS. None of the young people with an ED were referred, despite 4 remaining in CAMHS services beyond the transition boundary. It is recognised that the treatment of choice for an eating disorder in adolescents is family based treatment (Lock et al., 2010), and that transfer of care midway in treatment, especially to a different treatment style, may have poorer outcomes, both which may have discouraged onward referral. In fact, the dearth of services acknowledged nationally for ED across all age groups compounds that perception (Maher & Nwachukwu, 2012). Given that almost half (43%) of cases with an ED present between ages 16-20, and that for many the disorder is protracted, it is very

likely the management of ED will require on-going care through the period of adolescence into early adulthood, requiring close collaboration between adult and child services (Birmingham & Treasure, 2010). The proposed national clinical care programme for eating disorders shares this vision of shared therapeutic style and responsibility (Department of Health & Children, 2011).

Only 1 person with ADHD was referred, 7 young people with ADHD refused referral and in another 9 cases, the clinicians chose not to refer. These findings are similar to those of Singh and colleagues (2010) who found that neurodevelopmental disorders were less often referred. Given that up to 60% of children with ADHD continue to meet diagnostic criteria in adulthood (Faraone & Biederman, 2005) there is an urgent need to develop adult ADHD services. One Irish study screened attendees at AMHS and found 24% met criteria for ADHD but none had been recognised by their treating clinician (Syed et al., 2010). (Kooij, et al, 2010). Lack of belief in the validity of ADHD or expertise in its management have been linked to paucity of services or lack of recognition (Fitzgerald, 2001; Young et al., 2011; Swift et al. 2013; Hall et al. 2013; Asherson et al., 2010; Moncrieff & Timimi, 2010). With increasing awareness of the persistence of ADHD into adulthood, the associated impairment and the continued efficacy of treatment, perceptions seem to be changing. Although there are some country specific differences, most European and Irish clinicians now accept the biological nature of the disorder, and a willingness to treat (Fitzgerald & McNicholas, 2014, Beirne et al 2013). This suggests that CAMHS clinicians' views of AMHS not accepting ADHD referrals need to be reconsidered. Better communication between AMHS and CAMHS would improve knowledge of what services were available in AMHS and more joint working between teams might address the knowledge gap present, both of which may be responsible for the low rate of referrals and the poor uptake of services. Whether this belief, that AMHS will not accept or adequately manage the cases, is responsible for the refusal of many young people to be referred needs further exploration.

Many cases (45%) with perceived MH need were eventually transferred back to their GP. The expectation that GPs are willing and able to provide the necessary MH support needs to be considered. Whilst many GPs do indeed provide such support confidently either alone (Lamont et al., 2009) or with support from a specialist MH nurse (Taylor et al., 2010) other studies highlight GPs reluctance to do so, particularly around ADHD and eating disorders, both found in this study to remain either in CAMHS or be discharged to their GP. Studies have identified barriers such as inadequate training, poor screening tools and insufficient time and resources (Young et al., 2011; Ghanizadeh & Zarei, 2010; Currin, 2009; Hagelstamp, 2005; Boule, 2002). Prescribing rates amongst GPs in ADHD are known to precipitously drop after age 16, despite on-going impairment, even allowing for remission with developmental maturation, this suggests that many are not receiving appropriate care. (McCarthy S et al, 2013). A qualitative follow on from the same authors found that adults with ADHD experienced the pursuit of treatment and adult care as an 'uphill struggle' influenced by the 'sceptical and negative attitudes towards ADHD by healthcare professionals' (Matheson et al, 2013).

Tantam (2005) points to the importance of the clinician engaging with the young person with respect to referral to AMHS and it is reassuring that many young people in this study were consulted about the transition process, involved in the decision-making and referral plans. This is in line with what is considered to be a good standard for transition (Lamb et al., 2008). It is important to go further than enquire about wishes, but to tease out any possible misconceptions

that would otherwise limit transfer options. Young people (16-24) attending AMHS reported finding this stigmatising, believed the service catered for a much older cohort of patients, and excluded family and parents (Davis & Butler, 2002; Jivangee et al., 2009, Jivangee & Kruzich, 2011). The Health and Social Care Scrutiny Commission (2014) suggest that as well as a fear of stigmatisation around mental illness, young people lacked information of MH services and treatment which led to misconceptions and misinformation resulting in mistrust and anxiety. In our study, although not explored, these attitudes may well have explained the large numbers not consenting to referral.

These concerns and barriers are not unique to psychiatry services, and similar themes emerge when transitioning between paediatric and adult medical settings. Young people express anxiety and negative opinions of adult medical services including concerns over lack of familiarity with the new service and the necessity to start over with a new team, in addition to beliefs that they will be more formal, less friendly and have a broad-age range of other patients (Viner, 1999; Soanes & Timmons, 2004; Tuchman et al., 2008). For both MH services and medical services these negative perceptions and worries may be diminished by providing adequate information about the service, staff and treatment approach beforehand, ensuring that family members are included in the treatment settings, and clustering same age patients together.

The possibility also exists and must be considered that automatic transfer to AMHS even in the presence of enduring MH may not be in the young persons' best interest and other models of care may be more appropriate. For milder cases, proactive creative strategies such as youth MH cafes and community drop-in psychological services may provide a safe, accessible and non-

stigmatising space for young adults (Illback, R. J., & Bates, T. 2011, Illback et al, 2010). For more severe cases, increasingly there are calls for MH services that span the age group of 16-24, covering typically occurring disorders such as psychosis, mood disorders, ADHD and eating disorders (Smith & Leon, 2001; Young Minds, 2006).

Relative to total numbers of cases discharged form CAMHS, both this study and the HSE annual reports concur that transition numbers are generally not high, and not the source of large volume of work for AMHS (Health Services Executive, 2011). Between Oct 2012 and Sept 2013, 189 cases were transferred to AMHS nationally, representing only 2% of all closed cases (Health Services Executive, 2013). This may be appropriate in that the young person may have recovered sufficiently not to need on-going services. It also may suggest that CAMHS are only referring severe cases to AMHS. There were 1,450 open cases in CAMHS aged over 16 and 137 remained in CAMHS over age 18. (Health Services Executive, 2013). However given the recognised barriers identified, further research needs to be carried out to establish the validity of discharge to GP, or keeping within CAMHS beyond the transition boundary. Given that the cases referred by CAMHS to AMHS are indeed readily accepted and engaged well, on-going work between services around expected needs should help ensure that those in most need are in fact receiving appropriate services. It may also be necessary in the current economic climate that CAMHS clinicians hitherto practicing autonomously, idiosyncratically and flexibly, with the liberty to extend youth attendance and continue care well beyond the transition boundary when deemed fit, may no longer be able to do so, being curtailed by austerity measures.

Limitations: This study faced significant methodological challenges. The lack of centralised patient databases almost certainly had adverse effects on clinician recruitment and case ascertainment. While some teams had such databases, most teams did not and it is likely that this contributed to a relatively low response rate to requests for participation in the research. Suitable cases for inclusion on this study may have been ultimately identified by clinician recall thus lending itself prone to recall bias, despite efforts to minimize this by manual review of all records. This might suggest that cases that were particularly difficult, complex, or had adult psychopathology were more likely to be included. Furthermore, in compliance with data protection and the need to use only anonymised data, unless explicit patient consent was given, clinicians acted as gate keepers and were constrained by time pressures. This limited the numbers enrolled into the study and may have introduced some bias in data retrieval in cases where the independent researchers were unable to personally and independently retrieve the information. Future qualitative research is warranted to understand, in spite of perceived MH service needs, the significant non-referral by CAMHS and refusal by the young person. The authors are currently conducting qualitative interviews with clinicians and service users in this regard. This study includes interviews with young people who have made the transition from CAMHS to AMHS and will provide greater insight into the facilitators of and barriers to a successful transition.

#### REFERENCES

#### Asherson P, Adamou M, Bolea B, Muller U, Dunn Morua S, Pitts M, Thome J, Young S

(2010). Is ADHD a valid diagnosis in adults? Yes. British Medical Journal. 340, 549.

**Beirne M, McNamara N, O'Keeffe G, and McNicholas F** (2013). Survey examining the views of Adult Psychiatry Consultants and Senior Registrars regarding ADHD. *Irish Journal of Psychological Medicine* 30, 197-203

**Boule C & McSherry J** (2002) Patients with eating disorders: How well are family physicians managing them? *Canadian Family Physician* 48, 1807-1813

**Birmingham C & Treasure J** (2010). *Medical Management of Eating Disorders*. 2nd Edition. Cambridge University Press. New York.

**Currin L, Waller G, and Schmidt U** (2009). Primary care physicians' knowledge of and attitudes toward the eating disorders: do they affect clinical actions? *International Journal of Eating Disorders*. *42, 453-458* 

**Davis M & Butler M** (2002). Service system supports during the transition from adolescence to adulthood: parent perspectives. National Technical Center for State Mental Health Planning. (http://www.umassmed.edu/uploadedFiles/cmhsr/Products\_and\_Publications/reports\_papers\_ma nuals/servicesystemsupports.pdf) Accessed 11 July 2014.

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

**Department of Health and Children** (2010) *Youth cafes in Ireland: A Best practice guide.* Dublin. Government Publications Office. Department of Health and Children (2011). National Mental Health Programme

Plan.(http://www.dohc.ie/publications/vision\_for\_change\_6th/Progress%20Reports/National\_Me ntal\_Health\_Programme\_Plan\_Nov2011\_draft.pdf) Accessed 3 July 2014.

**Faraone SV & Biederman J** (2005) What is the prevalence of adult ADHD? Results of a population screen of 966 adults. *Journal of Attention Disorders*, 9(2), 384-91.

**Fitzgerald M** (2001). Does adult Attention Deficit Hyperactivity Disorder exist? *Journal of Psychiatry and Neurosciences*, 2, 1, 114 – 116.

**Fitzgerald M & McNicholas F.** (2014) Attitudes and practices in the management of ADHD among healthcare professionals who r4esponded to a European survey. *Irish Journal of Psychological Medicine* 31, 31-37.

**Ghanizadeh A & Zarei N** (2010). Are GPs adequately equipped with knowledge for educating and counseling of families with ADHD children? *BMC Family Practice*. 11, 5

Hagelskamp C, Lucas H, Scammell A (2005). How do GP registrars feel about dealing with mental health issues in the primary care setting? A qualitative investigation. *Primary Health Care Research & Development* 6.

Hall, C. L., Newell, K., Taylor, J., Sayal, K., Swift, K. D., & Hollis, C. (2013). 'Mind the gap' - mapping services for young people with ADHD transitioning from child to adult mental health services. *BMC Psychiatry*, 13(1), 1-8.

Health and Social Care Scrutiny Commission (2013). Mental Health Transition (16-24 Years). (http://www.newham.gov.uk/Documents/Council%20and%20Democracy/ScrutinyMentalHealth In-depthReview.pdf) Accessed 11 July 2014.

Health Service Executive (2008). Child and Adolescent Mental Health Services Report. (http://www.hse.ie/eng/services/news/camhs2008.pdf) Accessed 11 July 2014

Health Service Executive (2011) Child and Adolescent Mental Health Services Report.

(http://lenus.ie/hse/handle/10147/200893) Accessed 11 July 2014

Health Service Executive (2013) Fifth Annual Child and Adolescent Mental Health Service

Report. (http://www.hse.ie/eng/services/publications/Mentalhealth/camhsrpts/CAMHS12,13.pdf)

Accessed 26 October 2014

House of Commons (2000) Health Select Committee Report.

(http://www.publications.parliament.uk/pa/cm199900/cmselect/cmhealth/cmhealth.htm) Accessed 11 June 2014

**Illback, R. J., & Bates, T**. (2011). Transforming youth mental health services and supports in Ireland. Early intervention in psychiatry, 5(s1), 22-27.

Illback, R. J., Bates, T., Hodges, C., Galligan, K., Smith, P., Sanders III, D., & Dooley, B. (2010). Jigsaw: Engaging communities in the development and implementation of youth mental health services and supports in the Republic of Ireland. Journal of Mental Health, 19(5), 422-435.

**Jivangee P, Kruich J & Gordon L** (2009). The Age of Uncertainty: Parent perspectives on the transitions of young people with mental health difficulties to adulthood. *Journal of Child and Family Studies* 18, 435-446

**Jivanjee P & Kruzich J** (2011). Supports for Young People with Mental Health Conditions and Their Families in the Transition Years: Youth and Family Voices. *Best Practice In Mental Health*, 7(1), 115-133.

Kooij, S. J., Bejerot, S., Blackwell, A., Caci, H., Casas-Brugué, M., Carpentier, P. J. et al (2010). European consensus statement on diagnosis and treatment of adult ADHD: The European Network Adult ADHD. BMC psychiatry, 10(1), 67.

Lamb C, Hall D, Kelvin R, Van Beinum M (2008). Working at the CAMHS/Adult Interface: good practice guidance for the provision of psychiatric services to adolescents/young adults. Royal College of Psychiatrists. (https://www.rcpsych.ac.uk/pdf/Transition\_2008.pdf) Accessed 11 July 2014.

Lamont E, Harland J, Atkinson M, White R (2009). *Provision of mental health services for care leavers: transition to adult services*. LGA Research Report. Slough. NFER.

Locke J, Le Grange D, Agras WS, Moye A, Bryson SW, Jo B (2010). Randomized clinical trial comparing family-based treatment with adolescent-focused individual therapy for adolescents with anorexia nervosa. *Archives of General Psychiatry* 67, 1025-1032.

Maher C & Nwachukwu I (2012). The Challenge of Managing Severely Ill Patients with Anorexia Nervosa in Ireland. *Irish Journal of Psychological Medicine* 29, 69-71.

Matheson, L., Asherson, P., Wong, I. C. K., Hodgkins, P., Setyawan, J., Sasane, R., &
Clifford, S. (2013). Adult ADHD patient experiences of impairment, service provision and
clinical management in England: a qualitative study. BMC health services research, 13(1), 184.
McCarthy S, Wilton L, Murray M, Hodgkins P, Asherson P, Wong I (2013) Management of
adult attention deficit hyperactivity disorder in UK primary care: a survey of general
practitioners. Health Qual Life Outcomes, 11(1):22.

McNamara N, McNicholas F, Ford T, Paul M, Gavin B, Coyne I, Cullen W, O'Connor K, Ramperti N, Dooley B, Barry S and Singh, S (2013). Transition from child and adolescent to adult mental health services in the Republic of Ireland: An investigation of process and operational practice. *Early Intervention in Psychiatry*. doi: 10.1111/eip.12073 Moncrieff, J & Timimi S (2010) Is ADHD a valid diagnosis in adults? No. *British Medical Journal*. 340, 547.

Patton G, Coffey C, Cappa C, Currie D, Riley L, Gore F, Degenhardt L, Richardson D, Astone N, Sangowawa A, Mokdad A, Ferguson J (2012). Health of the world's adolsecents: a synthesis of internationally comparable data. *The Lancet* 379, 1665 - 1675.

**Paul M, Ford T, Kramer T, Islam Z, Harley K, Singh S** (2013) TRACK: Transfers and transitions between child and adolescent and adult mental health services. *British Journal of Psychiatry* 202(S54), s36 - s40

**Soanes C & Timmons S** (2004) Improving transition: a qualitative study examining the attitudes of young people with chronic illness transferring to adult care. *Journal of Child Health Care.* 8, 102-12

Singh S, Paul M, Ford T, Kramer T, Weaver T, McLaren S, Hovish K, Islam Z, Belling R, and White S (2010). Process, outcome and experience of transition from child to adult mental healthcare: multi-perspective study. *British Journal of Psychiatry* 197, 305-312.

Smith, K., and Leon, L. (2001). Turned upside down: developing community-based crisis services for 16-25 years olds experiencing a mental health crisis. Mental Health Foundation. London

Swift, K. D., Hall, C. L., Marimuttu, V., Redstone, L., Sayal, K., & Hollis, C. (2013). Transition to adult mental health services for young people with Attention Deficit/Hyperactivity Disorder (ADHD): a qualitative analysis of their experiences. *BMC Psychiatry*, 13(1), 1-11.

**Syed H, Masaud TM, Nkire N, Iro C, Garland M.** (2010) Estimating the prevalence of adult ADHD in the psychiatric clinic: a cross-sectional study using the adult ADHD self-report scale. (ASRS) *Irish Journal of Psychological Medicine*, 27(4).

Tantam D (2005). Pathways into adult care. Psychiatry. 4, 141-144.

**Taylor N, Fauset A, Harpin V** (2010). Young adults with ADHD: an analysis of their service needs on transfer to adult services. *Archives of Diseases in Childhood*. 95. 513-517.

**Tuchman, L. K., Slap, G. B., & Britto, M. T.** (2008). Transition to adult care: experiences and expectations of adolescents with a chronic illness. Child: Care, Health & Development, 34(5), 557-563.

**Viner R** (1999). Transition from paediatric to adult care. Bridging the gaps or passing the buck? *Archives of Disease in Childhood*. 81, 271-275.

**Young Minds** (2006) A Call to Action: Commissioning Mental Health Services for 16-25 yearolds. Stressed Out and Struggling Project.

(http://www.youngminds.org.uk/assets/0000/5391/SOS\_YM\_Call\_to\_Action.pdf) Accessed 11 July 2014.

**Young S, Murphy CM, Coghill D**. (2011) Avoiding the 'twilight zone': recommendations for the transition of services from adolescence to adulthood for young people with ADHD. *BMC Psychiatry*, 11, 174.

Demographics at transition boundary	Ν	%	Total N
Gender: Female	34	55	62
Caucasian Irish	58	98	59
Living in parental home	45	73	62
In formal education	47	84	56
Parents married and/or cohabiting	34	58	59
Family history of mental health problems	33	65	51
Mother attends CAMHS regularly	45	83	54
Father attends CAMHS regularly	9	18	49
Comorbidity during CAMHS	42	70	60
Given a statement of special educational needs	16	28	56
On child protection register	3	5	57

# Table 1: Demographic Details (Total sample, n=62)

			Refused								
					by						
			Not		young						
	Referred		referred		person						
	(n=15)		(n=21)		(n=11)						
				-							
							Total				Cramer's
DEMOGRAPHICS	N	%	N	%	N	%	Ν	$\chi^2$	р	df	V
Female	11	73	13	62	3	27	47	5.82	0.06	2	.35
Living in parental home	12	80	16	76	7	64	47	0.95	0.69	2	.14
In education	11	73	15	83	11	100	44	3.39	0.19	2	.28
Parents married and/or											
cohabiting	12	80	11	52	2	22	45	7.77	0.02	2	.42
Family history of mental											
health problems	10	67	11	69	5	71	38	0.05	1.00	2	.04
Mother attends CAMHS											
regularly	13	100	14	93	8	73	39	5.16	0.09	2	.36
Father attends CAMHS											
regularly	4	33	3	20	0	0	38	3.01	0.27	2	.30
Comorbidity	12	86	14	70	7	64	45	1.74	0.47	2	.20

 Table 2: Demographic and Clinical Details (Young people with MH need, n=47)

DIAGNOSIS											
Mood disorder	5	36	3	14	2	18	45	2.18	0.34	2	.22
Psychosis	5	36	1	1	0	0	45	8.96	0.02	2	.45
ADHD	1	7	8	40	7	64	45	8.89	0.01	2	.44
Eating Disorder	0	0	4	20	0	0	45	5.49	0.11	2	.35
PDD	0	0	1	5	0	0	45	1.28	0.53	2	.17
INTERVENTIONS											
Medication	13	87	11	55	6	55	46	4.52	0.11	2	.31
Individual therapy	5	33	4	20	0	0	46	4.49	0.11	2	.12
General Support/Follow up	11	73	17	70	10	91	46	1.80	0.41	2	.20
Family therapy	1	7	4	20	0	0	46	3.34	0.19	2	.27
Parenting Support	4	27	1	5	0	0	46	5.92	0.05	2	.36

