

NATIONAL & INTERNATIONAL LITERATURE REVIEW OF GOOD PRACTICE IN CHILD & ADOLESCENT MENTAL HEALTH SERVICES

Researched & Written by Lorna Kerin Independent Research Consultant



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Introduction to this Literature Review

Background to this Research

This brief literature review was commissioned by Mental Health Reform (MHR) to provide the Children's Mental Health Coalition (CMHC) in Ireland with an overview of some of the findings from recent national and international research on good practice in the delivery of child and adolescent mental health services, including primary care.

Lorna Kerin¹ was contracted as an independent research consultant to conduct the literature review, to synthesise the findings and to write this report. The purpose of this report is to present these key findings to the Children's Mental Health Coalition with the aim of informing discussion in the process of developing a position statement for CMHC.

Report Structure

This literature review is divided into three sections which cover the three main tiers of CAMH services in Ireland. Each section contains an executive summary and a detailed discussion of key messages identified in the literature. The report has a total of twenty-four key messages.

Section 1 contains eight key messages synthesised from the literature reviewed about good practice in the integration of child and adolescent mental health services into primary care, or Tier 1 CAMH services.

Section 2 contains eight key messages synthesised from the literature reviewed about good practice in the delivery of community-based, multidisciplinary services, known as Tier 2 CAMH services.

Section 3 contains eight key messages synthesised from the literature reviewed about the delivery of specialist services including inpatient care for children and young people with complex, acute mental health needs, known as Tier 3 CAMH services.

Research Methodology

The methodology chosen for this review was a 'quick scoping review' which is a relatively new but increasingly common approach for mapping broad topics in short timeframes². The benefit of a quick scoping review³ is that a rapid overview of research can be undertaken to provide a summary of what the evidence indicates. However inherent limitations of this methodology are that scoping reviews are not systematic due to time constraints, search sources are limited to a couple of journal databases, and research is mapped providing only simple description with limited analysis⁴. See Appendix 1 for further details of research activity conducted for this report.

¹ Lorna Kerin (BA, H.Dip Pysch., MCAT) is a qualified Social Researcher since 1995 and a member of SRA, IEN and CRNINI. Lorna specialises in evidence-informed interventions to develop child and youth wellbeing. See <u>ie.linkedin.com/in/lornakerin</u> ² Alexandra Collins, James Miller, Deborah Coughlin and Stuart Kirk. (2014). *The Production of Quick Scoping Reviews and Rapid Evidence Assessments: A How to Guide*. The Joint Water Evidence Group (Beta Version 2), DEFRA.

³ Miler, J. (2012.) *Guidance document for the production of quick scoping reviews and rapid evidence assessments* (Beta Version 8), DEFRA.

Current Child and Adolescent Mental Health Services (CAMHS) in Ireland – Staffing, Service, Need & Structure

The term 'CAMHS' in Ireland refers specifically to the HSE Child and Adolescent Mental Health Services that work to provide specialist mental health treatment and care to children and young people " with the most severe and complex problems and with other services engaged with children and young people experiencing mental health problems."

Mental health services are offered either as an outpatient community mental health service or through inpatient services. The CAMHS Community Mental Health Teams (CMHTs) are staffed by multidisciplinary professionals, led by a consultant psychiatrist. In 2013 CAMHS in Ireland consisted of 60 community teams, 3 day hospital teams and 3 paediatric hospital liaison teams staffed by 531 wholetime staff working with 17,116 children and adolescents.

There is increasing demand for CAMHS in Ireland with 2,541 children and adolescents waiting to be seen at the end of September 2013, which represented an increase of 24% from the total number waiting at the end of September 2012 (2,056).

This demand for child and adolescent mental health services, along with the need for youth specific mental health services aged 14-24, can reasonably be expected to increase, as evidenced by the latest findings from the first report of the Psychiatric Epidemiology Research across the Lifespan (PERL) Group Dublin at the Royal College of Surgeons in Ireland⁵:

- By the age of 13 years, 1 in 3 young people in Ireland is likely to have experienced some type of mental disorder. By the age of 24 years, that rate will have increased to over 1 in 2.
- The experience of mental ill-health during adolescence is a risk factor for future mental ill-health and substance misuse in young adulthood, and is associated with an increased risk of unemployment during early adult years.
- High numbers of young Irish adults aged 19-24 years are engaged in the misuse of alcohol and other substances, with over 1 in 5 meeting criteria for a diagnosable substance use disorder over the course of their lives.
- Significant numbers of young people are deliberately harming themselves and by the age of 24 years, up to 1 in 5 young people will have experienced suicidal ideation.

However CAMHS in Ireland is severely and chronically under-resourced to meet this need, operating with only 44.6% of the staffing level⁶ recommended by the national Vision for Change policy (2006). Many of the recommendations of A Vision for Change concerning inpatient services, mental health intellectual disability teams, substance misuse, eating disorder and forensic services for young people remain yet to be implemented.

⁵ Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I (2013). *The Mental Health of Young People in Ireland: a report of the Psychiatric Epidemiology Research across the Lifespan (PERL)*. Royal College of Surgeons in Ireland, Dublin.

⁶ Health Services Executive (2014). *Fifth Annual Child and Adolescent Mental Health Service Report.* HSE, Dublin.

CAMHS Delivery Structure

Current CAMHS delivery in Ireland is best conceptualized in the following three tiered model.

Tier 1 Services (CAMHs in Universal and Primary Care Services)

Tier 1 child and adolescent mental health services (CAMHs) are community based services that provide a first line of response if children or young people start to show mild mental health difficulties that cause minimal or occasional distress, without significant risk of harm. Resources such as information, advice, general support and simple medical or psychosocial interventions are offered to the child, young person, family, carers and wider community.

Tier 1 CAMHs include teachers, school counselling, school attendance, social work, childcare, residential care, child protection, speech & language therapy, community occupational therapy, educational psychology, clinical psychology, community psychology, area medical officers and public health nursing, and early intervention services for children with developmental delay.

According to the draft iCAMHS guidelines, it is the role of Tier 1 services to "*identify when a child or young person needs more specialist mental health care, and to make the appropriate referrals or ask for specialist advice or support.*"⁷

Referrals to CAMHS in Ireland must be made through General Practioners (GPs) who are currently the interfacing primary care service between Tier 1 services and specialist Tier 2 CAMHS. According to the draft iCAMHS guidelines it is the role of GPs "to recognize risk factors for mental health disorders, to provide treatment or advice where appropriate, and to refer to more appropriate community care personnel or specialist services when this is indicated". Please see **Appendix 2** of this report forguidelines issued to GPs on the referral of children and adolescents to CAMHS in Ireland.

A central finding of this literature review is that there is an **urgent need to build capacity of the primary care sector** to respond effectively to children and adolescents at risk of mental health problems. Additionally **clear pathways of collaboration and referral** need to develop between mental health services (Tier 2 and Tier 3 CAMHS) and primary care/community resources (Tier 1 CAMHs) to coordinate appropriate service provision for children and adolescents at risk of mental health problems. These and other findings are more fully discussed in Section 1 of this report.

Tier 2 Services (Community or Outpatient Specialist CAMHS)

This is the first line of specialist services for children and young people with mental health problems in Ireland. Children/young people are assessed by a multidisciplinary Community Child and Adolescent Mental Health team, under the clinical direction of a consultant child and adolescent psychiatrist. This community CAMHS should be multidisciplinary to ensure that children and adolescents are offered care and treatment for complex problems that require a range of disciplines, skills and perspectives. The multidisciplinary team should include junior medical staff, two psychologists, two social workers, two nurses, a speech and language therapist, an occupational therapist and a child care worker. According to

⁷ CAMHS Specialist Child and Adolescent Mental Health Service Advisory Group (2013). *Irish Child & Adolescent Mental Health Service (iCAMHS) National Quality Guidelines Document*. Unpublished draft pending HSE approval and progression since October 2013.

the draft iCAMHS guidelines "the assessment and intervention provided by such a team is determined by the severity and complexity of the presenting problem(s)."⁸

A central finding of this literature review is that families find it **difficult to access community CAMHS in Ireland** due to a lack of information, restrictive referral criteria and pathway, lengthy waiting periods and a lack of out of hours/crisis service. There also appears to be a **lack of standardized outcome monitoring** and a **lack of published, service quality guidelines**. These and other findings along with recommended good practice to increase equitable access to **evidence-informed** CAMHS is identified and discussed in more detail in Section 2 of this report.

Tier 3 Services (Inpatient CAMHS)

This is the second line of specialist services for children and young people with mental health problems in Ireland. This comprises of intensive community based care and inpatient care through specialist mental health inpatient services. Tier 3 services provide specialist mental health services for those children and adolescents who have complex and severe mental health problems, and/or who are at high risk of harm.

A central finding of this literature review is that there is a **lack of service user and outcomes based research** on the experiences of children and young people attending Tier 3 services. One study documents concerns about **lack of local services, the long waiting list, the stigma of attending psychiatric wards**, and the **distress and isolation** experienced by young people placed on adult or paediatric wards.⁹ Section 3 of this report details this research and discusses the **good practice need** to provide timely referral, assessment and access procedures to safe, developmentally appropriate care in a supportive environment, and to incorporate young people's and their families' views into service planning and delivery.

Tier 4 Services (UK & Northern Ireland)

There are four tiers to CAMHS in the UK and Northern Ireland. The extra capacity appears to be at Tier 2 which consists of individual practitioners offering interventions for mental health problems at early intervention stage and supporting universal and primary care services to respond to the mental health needs of children and young people in their care. Please see **Appendix 3** for further details.

The difference between CAMHs and CAMHS

A wide range of statutory, community and voluntary services also support the mental health of children and adolescents so for purposes of this literature review, the term 'child and adolescent mental health services' or 'CAMHs' will refer to the provision of these community-based and primary care services and the term 'CAMHS' will refer to the HSE specialist services.

⁸ CAMHS Specialist Child and Adolescent Mental Health Service Advisory Group, (2013), *Irish Child & Adolescent Mental Health Service (iCAMHS) National Quality Guidelines Document.* Unpublished draft pending HSE approval since October 2013. ⁹ Buckley, S et al (2012). *Mental health services: the way forward. The perspectives of young people and parents.* StPatrick's University Hospital, Dublin

Executive Summary Findings on CAMHs in Primary care, Community CAMHS & Inpatient CAMHS

This literature review is divided into three sections to reflect the three tiers of Child and Adolescent Mental Health services (CAMHs) currently delivered in Ireland through primary care settings (tier 1), specialist CAMHS services in the community (tier 2) and inpatient CAMHS (tier 3) for complex/acute mental health needs. This 5 page executive summary condenses the findings contained in the report as per section.

Executive Summary of Section 1: CAMHs in Primary Care

Section 1 of this report reviews the national and international literature on good practice in the delivery of **CAMHs (Tier 1) in primary care settings**. The overall recommendation is to build capacity in primary care services to effectively prevent, detect and appropriately treat child and adolescent mental health difficulties and disorders. Key messages include the following:

The delivery of child and adolescent mental health services in primary care settings is **internationally acknowledged best practice**¹⁰. Along with the family home and the school, primary care provides an accessible, non-stigmatising community setting to prevent, detect, treat and support child and adolescent mental health issues. The psychiatric literature evidences the 'primary care advantage' of a trusting, longitudinal relationship between the service provider and family as a therapeutic alliance that predicts both engagement and "*favourable care outcome over and above any specific treatment including medications.*"¹¹

Internationally, there is a problem of **high prevalence rates yet low rates of detection and treatment** of mental health disorders among children and young people in primary care services. Findings from the most recent epidemiological study¹² in Ireland is that young Irish adolescents in the 11-13 year age range have higher current rates of disorder (15.4%) than similarly-aged young adolescents in both the USA (11.2%) and the UK (9.6%). However there appears to be a significant **lack of data and research** on child mental health presentations in primary care settings in Ireland, which is problematic for responsive service planning, workforce training, effective delivery and rigorous evaluation.

Adequate **financial and human resource investment** is one of the key 'non-negotiable' conditions critical to ensure successful integration of first line mental health services into primary care. Primary care clinicians must be reimbursed for the investment of their time on restructuring services to encompass child mental health, as well as their time spent in the development of collaborative clinical relationships with mental health specialists¹³. The **lack of reimbursement** for GPs in Ireland for their participation in the current Irish shared care system¹⁴ is identified in the literature as a fundamental barrier, among others, to the efficacy of an accessible, collaborative model that could improve child and adolescent mental health services in primary care¹⁵.

¹⁰The World Health Organisation. (2008). *Integrating Mental Health into Primary Care: A Global Perspective*. WHO, Geneva ¹¹Meschan, J. (2010). *Enhancing Pediatric Mental Health Care: Algorithms for Primary Care*. American Academy of Pediatrics Task

Force on Mental Health

¹² Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I. (2013). *The Mental Health of Young People in Ireland:* a report of the Psychiatric Epidemiology Research across the Lifespan (PERL) Group Dublin: Royal College of Surgeons in Ireland.

¹³ American Academy of Pediatrics, Task Force on Mental Health. (2007). Strategies for System Change in Children's Mental Health: A Chapter Action Kit. Elk Grove Village, IL: American Academy of Pediatrics.

¹⁴ The Irish College of General Practitioners. (2011) *Primary Care Teams - A GP Perspective*. ICGP, Dublin.

¹⁵ American Academy of Pediatrics Task Force on Mental Health. (2009). *Improving mental health services in primary care: reducing administrative and financial barriers to access and collaboration*. Pediatrics. 2009;123(6):1611].

The literature highlights the need for **collaborative engagement** with key stakeholders to build primary care service capacity to respond effectively to child and adolescent mental health needs. Good practice service examples identified in Ireland include 'Ready, Steady, Grow', an area based infant mental health strategy in Ballymun, Dublin and 'Jigsaw', a national youth mental health systems change initiative with service delivery in ten communities to date. International good practice service examples identified include the regional initiative in Ontario, Canada where over 200 'Family Health Teams' have embedded an interprofessional, collaborative team approach to primary care, and a local initiative in the urban area of Macul, Chile where existing resources were leveraged to establish a multidisciplinary family health clinic with a particular focus on child and adolescent mental health.

It is a critical necessity to **support primary care providers through access to specialist mental health** staff. Structures to enable this include facilitating primary care access to specialised mental health consultation, co-location of mental health staff in primary care settings, the creation of 'tier 2' primary mental health care workers and appropriate training programmes for primary care providers in child and adolescent mental health.

Finally, international evidence-informed **good practice guidelines** on the assessment, diagnosis and treatment of children and young people in mental health distress are available from the World Health Organisation, the American Academy of Pediatrics Task Force on Mental Health, and the National Institute for Clinical Excellence in the UK. Irish guidelines for GPs on the diagnosis and referral of child and adolescent mental health in primary care settings have also been issued by the Irish College of Practitioners (ICGP).

Executive Summary of Section 2: Community CAMHS

Section 2 of this report reviews the national and international literature on good practice in the delivery of **specialist CAMHS (Tier 2) in community settings**. The overall recommendation is to ensure accessible, community based, evidence-informed and outcomes-monitored child and adolescent mental health services. Key messages include the following:

There is a clear social, economic and rights based **imperative to provide fully accessible CAMH** services to children and adolescents. A key standard of the Mental Health Commission's Quality Framework for Mental Health Services in Ireland is that "*mental health services must be accessible in the community*" and that "*quality service is dependent on access to that service*".¹⁶ However **many factors predict successful service access and engagement**¹⁷ and these present challenges at policy, service and provider level.¹⁸

It appears that **accessing CAMHS (Tier 2) is challenging for families in Ireland** due to a '*knowledge deficit, a lack of information and a limited availability of specialist services*'.¹⁹ Concern is expressed about the restrictive referral criteria to access community based CAMHS, the lengthy waiting period, and the lack of information about what to do during the waiting period. "A total of 2,541 children and adolescents were waiting to be seen at the end of September 2013. This represented an increase of 485 (24%) from the total number waiting at the end of September 2012 (2,056)."²⁰ However, staff capacity of

¹⁶ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHR, Dublin.

¹⁷ Garland, A. et al (2013). *Improving Community-Based Mental Health Care for Children: Translating Knowledge into Action*. Adm Policy Ment Health. 40(1): 6–22

¹⁸ World Health Organisation. (2005). Mental Health Policy and Service Guidance Package: CAMH policies and plans. WHO, Geneva.

¹⁹ Coyne, I. et al (2014). Adolescents and parents' experiences of attending child and adolescent mental health services (CAMHS) in *Ireland: The report.* TCD, Dublin.

²⁰ Health Services Executive (2014). *Fifth Annual Child and Adolescent Mental Health Service Report*. HSE, Dublin

CAMHS in Ireland is only at **44.6% of the staffing level as recommended** in A Vision for Change.

International and national **good practice guidelines advise** on how to remove barriers to timely access, to inform and support service users through the referral and waiting list process and how to enable equitable service access. This includes the provision of clear and easily accessible service information. Irish research evidence indicates that digital media could be a particularly effective communication channel to disseminate service information²¹.

Equitable access to CAMHS is facilitated by a range of **local service referral pathways** for needs based assessment and possible CAMH service. The current **restrictive referral criteria in Ireland** where only a medical doctor can refer a child or young person to CAMHS is flagged as highly problematic in terms of equity of access. Recent Irish research indicates that "*many young people experiencing mental health problems do not consult with their GP*"²² and that young people in Ireland may be "*least likely to seek help from a GP*"²³. The Choice and Partnership Approach in the UK and Australia is cited as a good practice example CAMH service model that is needs based and that enables early access through referral relationships between CAMHS and other child and family service agencies.

Clear, accessible routes to **'out of hours' and 'crisis' CAMHS** is also described in Irish and international guidance as essential to facilitating access to CAMHS. However Irish guidance for GPs on referrals to CAMHS²⁴ along with the documented views of service users and family members²⁵ indicate that the lack of 'out of hours' crisis CAMHS services, lack of standardized services, and lack of clarity about what age to refer adolescents to paediatric versus adult services is affecting both the equity and accessibility of mental health services for children and young people in Ireland. Good practice guidelines on the provision of 'crisis' CAMHS have been developed by the Quality Network for Community CAMHS Standards (2011, UK)²⁶ and are offered here as sample good practice.

Facilitating **children's**, young people's and their families' participation in service design, care plan delivery and service evaluation is also detailed as critical to good practice in the literature, as is the need to ensure **vulnerable children and young people** at higher risk of mental health difficulties are targeted and included in CAMHS service provision. Evidence informed guides and examples of good practice from the UK are cited in this review, including good practice in-service provision for children and young people with learning disabilities.

The importance of the provision of **evidence-informed CAMH services** to ensure children and young people can access quality CAMHS is discussed. Good practice guidelines and findings from the newly developing field of implementation science include fostering CAMHS organisations that are conducive to change through leadership, addressing the inevitable organisational resistance to change and supporting practitioners to access the evidence base and to engage in reflective practice.

A **quality improvement process** is essential good practice for CAMHS to measure whether "services increase desired mental health outcomes and whether they are consistent with current evidence based practice". There is promising international evidence that "**outcome monitoring systems**" demonstrate a

 ²¹ Millward-Browne, L (2009). Young People and Mental Health: A National Survey. Dublin. National Office Suicide Prevention.
 ²² Buckley, S et al (2012). Mental health services: the way forward. The perspectives of young people and parents. St Patrick's

University Hospital, Dublin. ²³ Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I (2013). The Mental Health of Young People in Ireland: a report of the

Psychiatric Epidemiology Research across the Lifespan (PERL) Group Dublin: Royal College of Surgeons in Ireland

²⁴ O'Keefe et al (2013). Child and Adolescent *Mental Health Diagnosis and Management*. CAMHS Quality in Practise Committee, Irish College of General Practitioners (ICGP), Dublin.

²⁵ Buckley, S et al (2012). Ibid.

²⁶ Barrett et al (2011). *Quality Network for Community CAMHS Service Standards*, 3rd Ed. 2011. QINMAC. The Royal College of Psychiatry, London.

positive impact on treatment effectiveness and efficiency for child/family mental health services.

However it appears that the **effectiveness of CAMHS treatment or intervention is not being routinely measured** in Ireland. Although the specialist, multidisciplinary CAMHS advisory group developed operational guidelines based on the Mental Health Commission's Quality Framework, these draft guidelines were sent to the HSE for approval and progression over a year ago in October 2013 and have not yet been progressed. This **lack of documented quality guidelines for CAMHS** in Ireland is not aligned with good practice in the provision of CAMHS as advised by the World Health Organisation²⁷.

Executive Summary of Section 3: Inpatient CAMHS

Section 3 of this report recommends that children and young people with complex or acute mental health difficulties need accessible, developmentally appropriate specialist inpatient services, along with local, evidence-informed, alternative services that meet their complex needs.

Children and young people have a right to access levels of healthcare that are appropriate to their needs.²⁸ In Ireland 'Tier 3' CAMHS provide intensive community based care and specialist mental health inpatient services for children and adolescents who have complex and severe mental health problems, and/or who are at high risk of harm.²⁹

There is a stark **lack of service user and outcomes based research** on the experiences of these children and young people attending Tier 3 services in Ireland and whether their needs are being met. Buckley et al (2012) report young service users' and some parents' concerns about the lack of local services, the long waiting list, the stigma of attending psychiatric wards and the distress and isolation that has been experienced³⁰. The report recommends the need to provide accessible, appropriate, de-stigmatised care in a supportive environment, and to incorporate young people's views into service planning and delivery.

Good practice in CAMHS inpatient care identified³¹ includes **timely referral**, **assessment and access procedures to inpatient services**. Inpatient bed provision should be based on a needs assessment and gaps should be identified through monitoring referral outcomes. Children and young people should not be placed inappropriately in adult or paediatric wards as this may expose them to safety and health risks and care may not be effective in meeting their needs. If emergency beds are not available, there must be **clear service protocols** for community CAMHS to follow and children who are initially placed in adult wards must be swiftly transferred to appropriate services.

However the literature notes that inpatient services are not necessarily the most effective environment for managing children and young people with complex mental health needs.³² Good outcomes result when there is better access to inpatient services along with the delivery of more **locally-based services, with multi-agency collaboration.** Additional and/or **alternative CAMH services** are

²⁷ World Health Organisation (2005). *Mental Health Policy and Service Guidance Package: CAMH policies and plans*. WHO, Geneva.

²⁸ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHC, Dublin.

²⁹ In 2012 there were 438 admissions of children and adolescents up to the age of 18 years to inpatient units in Ireland, according to the HSE 2013-2014 CAMHS service report.

³⁰ Buckley, S et al (2012). Mental health services: the way forward. The perspectives of young people and parents. StPatrick's University Hospital, Dublin

³¹ Quality Improvement Network for Multi-Agency CAMHS (QINMAC) & Quality Network for Inpatient CAMHS (QNIC). *Improving access to inpatient CAMHS and appropriate alternatives* (2010). The Royal College of Psychiatrists, London.

³² Green J, Worrall-Davies A (2008). *Provision of Intensive Treatment: inpatient Units, Day Units and Intensive Outreach*. Pp. 1126-1142 In: Rutter's Child and Adolescent Psychiatry, 5th edition. Edited by Rutter M. et al. Blackwell Publishing

also essential to meet children's and young people's complex mental health needs and there is significant evidence from the UK and the USA for the efficacy of a number of approaches.

Relationship building with the child or young person with complex needs is associated³³ with the effectiveness of service delivery. This has service implications in terms of ensuring adequate time, staff support, supervision, flexibility and interagency collaboration to develop recovery-focused relationships that meet the complex mental health needs of children/young people at their changing developmental stages.

Specific CAMH care pathways need to be developed for vulnerable groups of children and young people who have complex needs, such as children and young people with **learning disabilities**, who have far higher rates of mental health problems. However "there is currently no recognised, fully staffed team forchildren with mental illness and learning disability"³⁴ in Ireland despite the clear recommendations in A Vision for Change. An evidence-informed good practice guide from the CAMHS Evidence Based Unit in the UK on **developing a care pathway** is described.

Good practice on **managing the transition from CAMHS to adult mental health care** is recommended however the literature notes that the current cut off of a young person from the CAMH service based on age is highly problematic³⁵. National epidemiological research evidences the public health crisis of acute youth mental ill-health and recommends a **youth-specific specialist mental health service** which could better target care for young people aged 12 -25. McGorry recommends including "*access to integrated mental health care, substance use and vocational-recovery services*"³⁶. Purcell et al note this is " *an urgent and achievable goal if we are to deliver appropriate, acceptable, and effective care in the twenty-first century*."³⁷ The Orygen Youth Project (OYP) in Australia is cited as a good practice service example.

END of Executive Summary

³³ Kurtz, Z (2009).The Evidence Base to Guide Development of Tier 4. National CAMHS Support Service, Dept. of Health, UK.

³⁴ Irish College of Psychiatrists. (2013). *Pre Budget 2014 Submission Re Mental Health Services*. ICP, Dublin.

³⁵ Singh et al. (2010).*Process, Outcome and Experience of Transition from Child to Adult Mental Healthcare: A Multiperspective Study*. British Journal of Psychiatry.

³⁶ McGorry, P.D. (2007) *The specialist youth mental health model: Strengthening the weakest link in the public mental health system.* Medical Journal of Australia, 187(Suppl. 7), 53–56.

³⁷ Purcell, R. et al. (2011) *Toward a Twenty-First Century Approach to Youth Mental Health Care: Some Australian Initiatives.* International Journal of Mental Health, vol. 40, no. 2, Summer 2011, pp. 72–87.

Summary of 24 Key Messages on Good practice in the Delivery of CAMHS

The following key messages have been extracted from the national and international literature on good practice in the delivery of Child and Adolescent Mental Health Services with regard to the provision of CAMHs in primary care, specialist community CAMHS and specialist inpatient CAMHS for complex mental health needs. Each of these 24 key messages is discussed with reference to the supporting literature in the body of this report.

Section 1: Build capacity in primary care services to effective prevent, detect and appropriately treat child and adolescent mental health difficulties and disorders.

Key Messages in Section 1:

- 1.1 There is a high prevalence but a low detection rate of child and adolescent mental health difficulties and disorders in primary care settings
- 1.2 The delivery of CAMHs in primary health care is internationally recommended as good practice
- 1.3 There are national and international good practice examples of integrated mental health services into primary care for children and young people
- 1.4 Financial and human resources are critical enablers of the integration process
- 1.5 Capacity needs to be built to collaboratively embed mental health services in primary care
- 1.6 Primary care providers must be supported with access to specialist CAMHS consultation
- 1.7 The capacity of primary care workers to deliver child and adolescent mental health services must be developed through training, supervision and support
- 1.8 Existing good practice guidelines should be considered in the assessment, diagnosis and treatment of children's and adolescent's mental health in Primary Care

Section 2: Ensure accessible, community based, evidence-informed and outcomes-monitored child and adolescent mental health services.

Key Messages in Section 2:

- 2.1 Service information about CAMHS should be clear and accessible prior to & during service use
- 2.2 Access to CAMHS should be needs-based, timely and facilitated by a range of local service referral pathways
- 2.3 Appointments should be provided in accessible, confidential environments with consistent staff
- 2.4 Clear, accessible routes to 'out of hours' and 'crisis' CAMHS should be provided
- 2.5 Children, young people and their families should be involved at all stages of service & care plan development, delivery and evaluation as key stakeholders
- 2.6 CAMHS information, referral criteria and access pathways should consider how to reach vulnerable children, young people and families who are at higher risk of mental health difficulties
- 2.7 Evidence informed practice should be embedded in the delivery of CAMHS to ensure high quality service provision
- 2.8 Incorporate accountability for CAMHS outcome monitoring at policy, funding and organisational level

Section 3: Develop accessible, inclusive, developmentally appropriate specialist inpatient care for children and young people with complex mental health needs, along with local, evidence-informed services

Key Messages in Section 3:

- 3.1 Inpatient care has advantages and disadvantages but is not effective for some mental health disorders
- 3.2 Prompt assessment and timely access to inpatient CAMHS is crucial for children and young people in need of care
- 3.3 Children and young people should not be placed inappropriately in adult or paediatric wards
- 3.4 Additional and/or alternative CAMH services to inpatient care are essential
- 3.5 Evidence informed alternative approaches to inpatient care for children and young people with complex mental health needs
- 3.6 Relationship building with service users & support for staff are central to effective CAMH service provision
- 3.7 Specific CAMH care pathways should be developed for children and young people with intellectual and learning disabilities
- 3.8 The transition from child to adult mental health services should be effectively managed but a fundamental system change is urgently required to meet the needs of youth mental health care

Section 1: Build capacity in primary care services to effectively detect, treat and appropriately refer child & adolescent mental health difficulties and disorders.

Key message 1.1 There is a high prevalence but a low detection rate of child and adolescent mental health difficulties and disorders in primary care settings

High international prevalence

International research indicates that there is a high prevalence of children and young people attending primary care services with significant mental health issues. Child and adolescent mental health disorders regularly seen within primary care include attention-deficit/hyperactivity disorder (ADHD), conduct disorder, delirium, generalized anxiety disorder, depressive disorders, post-traumatic stress disorder (PTSD), and separation anxiety disorder.³⁸

According to the World Health Organisation, as many as 25% of children attending primary care services meet criteria for at least one mental health disorder diagnosis, and as many as 40% have clinically significant functional problems (Bernal et al. 2000; Briggs-Gowan et al. 2000; Costello and Shugart 1992).

National Prevalence

Although the Irish policy A Vision for Change (2006) recommended that data be collected on mental health presentations in primary care⁴⁰, this brief literature review for the Children's Mental Health Coalition could not locate data relevant to the presentation of children with mental health issues in primary care in Ireland. However a range of validated Irish research studies persistently indicate the high prevalence of mental ill health among children and young people.

The most recent epidemiological study (PERL, 2014), the 'Adolescent Brain Development Study' surveyed 1,131 young people and conducted 453 diagnostic clinical interviews with young people to assess them for the presence of mental disorders and to examine their overall level of functioning.⁴¹ Findings were that young Irish adolescents in the 11-13 year age range have higher current rates of disorder (15.4%) than similarly-aged young adolescents in both the USA (11.2%) and the UK (9.6%).

The PERL (2014) study estimates that by the age of 13 years almost 30% of young Irish people will have experienced some form of mental disorder and by the age of 24 years, over 50% of young Irish people will have experienced a mental disorder.

 ³⁸ The World Health Organisation. Integrating Mental Health into Primary Care: A Global Perspective. 2008. WHO, Geneva.
 ³⁹ Ibid.

⁴⁰ The primary care team is defined in the Irish Primary Care strategy as including GPs, nurses, physiotherapists, occupational therapists, social workers, home helps and administrators. Each team would in turn be supported by a wider 'network of primary care professionals' which includes speech and language therapists, dentists, dieticians, pharmacists, community welfare officers, chiropodists and psychologists (Primary Care: A New Direction, 2001, HSE)

⁴¹ Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I. (2013). *The Mental Health of Young People in Ireland: a report of the Psychiatric Epidemiology Research across the Lifespan* (PERL) Group Dublin: Royal College of Surgeons in Ireland.

These findings are consistent with the first national baseline of adolescent and young people's mental health ('My World', 2012) which found approximately 30% of the nearly 14,500 surveyed adolescents and young adults self-reported levels of depression and anxiety which fell within the mild to severe range.⁴² Headstrong, the national centre for youth mental health cites the following figures from this study:⁴³

- (1) 8% of adolescents and 14% of young adults had depressive symptoms classifiable as severe or very severe, and an additional 22% of adolescents and 26% of young adults experience mild to moderate depression
- (2) 11% of adolescents and 14% of young adults had anxiety symptoms classifiable as severe or very severe, and an additional 21% of adolescents and 23% of young adults experience mild to moderate anxiety
- (3) 21% of young adults report that at some point in the last year they have deliberately hurt themselves without wanting to take their life (deliberate self-harm)

A large prevalence study in 2006 of 3,374 children screened in the Clonmel Community Care district, Co. Tipperary, estimated that nearly 15% of under 5 year olds, 18.5% of 6-11 year olds and 21% of 12-18 year olds met the criteria for at least one psychological disorder⁴⁴. It is critical to note that 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 the child and adolescent mental health services.

Finally the 2012 report on the national data set Growing Up in Ireland finds, according to mother and teacher reports using the standardized instrument 'Strengths and Difficulties Questionnaire', that 15%-20% of 9 year old children were displaying 'significant levels of difficulty'⁴⁵.

This range of epidemiological and longitudinal research indicates that the prevalence of mental health disorders among children and young people in Ireland is high. However the clear research gap on the presentation, detection and treatment of mental health difficulties and disorders at primary care level in Ireland should be noted. Without this quantifiable data, it is extremely challenging for local and national services to plan and resource appropriate responses.

Nonetheless, given the international and national prevalence rates, it is imperative that primary care services consider how to best detect mental health difficulties and how to provide mental health services that meet the identified mental health needs of the child and youth population.

Low detection rates & under-treatment in primary care

International research indicates that there are very low detection rates of mental health difficulties and disorders in primary care. Studies in the US and UK suggest that paediatricians and general practitioners identify only 25% of children and adolescents with mental health problems (Kramer and Garralda 1998; Horwitz, et al. 2003).

⁴² Dooley, B., & Fitzgerald, A. (2012). *My world survey: National study of youth mental health in Ireland. Dublin, Ireland:* Headstrong - The National Centre for Youth Mental Health, UCD School of Psychology.

⁴³ Summary data from a 'Summary Document', September 2014. Submitted by Headstrong to this literature review. See Appendix 4

⁴⁴ Martin, M., Carr, A. (2005).*Mental health service needs of children and adolescents in the South East of Ireland: A preliminary screening study*. Health Service Executive Southern Area, Reference 08-05-0035.

⁴⁵ Nixon, E. (2012) *Growing Up in Ireland: How families matter for social and emotional outcomes of 9-year-old children-Executive* Summary [Online]. Available from: http://www.thehealthwell.info/node/113121 [Accessed: 21st September 2014].

The epidemiology⁴⁶ of child mental health complicates detection and treatment in primary care. Even when cases are detected in primary care, problems may be under-treated. For example, Wissow et al (2009) note that:

- There is a high incidence of co-morbidity that can go undetected. Over 30% of the children who meet diagnostic criteria for a single condition also meet criteria for another (Briggs-Gowan et al. 2000).
- Parents, teachers, and children often fail to agree regarding child mental health symptoms and impairment and this complicates the diagnostic process (Brown et al. 2006).
- For every child diagnosed with a specific mental health disorder, there are twice as many children who have significant problems with functioning but who do not meet diagnostic criteria (Costello and Shugart 1992; Briggs-Gowan et al. 2003).
- There are also potentially twice as many whose parents have concerns about their child's behaviour or mood (Blanchard et al.2006). Children and young people may receive minimal follow-up from a primary care provider or specialist (Gardner et al. 2003).

Of particular note is the research indicating that twice as many young people as those diagnosed may have functional problems related to behaviour or feelings but they do not meet the criteria for diagnosis for a mental health disorder. For example Wang et al (2005) found that 75% of adults with anxiety disorders report the onset of their condition as before age 21 and their median time from onset to first treatment contact ranges from 9 years old to 23 years, depending on the disorder.⁴⁷ These problems often go untreated, with lifetime consequences⁴⁸.

⁴⁶ Epidemiology is the study of how often diseases occur in different groups of people and why. Epidemiological information is used to plan and evaluate strategies to prevent illness and as a guide to the management of patients in whom disease has already developed. Source: www.bmj.com

⁴⁷ Angold, A., Costello, E.J., Erkanli, A. (1999). *Comorbidity*. J. Child Psychol. Psychiatry 40, 57–88

⁴⁸ Wang et al. (2005). *Twelve-month use of mental health services in the United States: results from the National Comorbidity Survey Replication*. Arch Gen Psychiatry. 2005 Jun;62(6):629-40.

Key Message 1.2The delivery of CAMHs in primary health care is recommended
internationally as good practice

Primary care for mental health (PCMH) refers specifically to mental health services that are integrated into general health care at a primary care level. Primary care for mental health includes all diagnosable mental disorders, as well as mental health issues that affect physical and mental well-being. The World Health Organisation states that *"integrated primary care for mental health is not only the most desirable approach; it is also a most feasible approach."*⁴⁹

The international literature⁵⁰ details that good practice in the delivery of CAMHS includes increasing the accessibility and effectiveness of child and adolescent mental health services through the involvement of primary care professionals and the delivery of interventions in the primary care setting⁵¹. Mental health care, when provided in the primary care or school health clinic setting, is often perceived favourably by families and offers the added advantage of integrated care with the child's other healthcare needs.

Of particular note in the international literature is the 'primary care advantage' which is the opportunity for longitudinal, trusting relationships with children and families which provide a safe space to raise difficult issues and which provide clinicians the insight necessary to note changes or concerns of their own. According to the American Academy of Pediatrics Task Force on Mental Health (2010), the "*psychiatry literature validates that this trusting therapeutic alliance predicts a person's engagement in care for mental illness and a favorable outcome of that care over and above any specific treatment including medications.*"⁵²

Mental health care in primary care can also remove common obstacles to accessing care such as family engagement, service fragmentation and stigma. According to Eapen & Jairam (2009), "providing assessment, early intervention and continued monitoring at the primary care level, with a coordinated management plan including primary care clinicians, mental health professionals, school personnel, and others involved in the care of the child, offers the unique opportunity to engage families and maintain young people in treatment without stigma." ⁵³

However systematic review research⁵⁴ notes that it is a global challenge as to how to effectively provide mental health services in primary care settings in a cost efficient, clinically effective way. Wissow et al (2008) note that difficulties of detection and diagnosis are not surprising in the context of the current structure of paediatric primary care⁵⁵. The researchers identified contributory factors from the literature they reviewed as including the following:

• Visits are short with many competing concerns (Epner et al. 1998).

 ⁴⁹ World Health Organisation. (2008). Integrating Mental Health into Primary Care: A Global Perspective. WHO, Geneva.
 ⁵⁰ Ibid.

⁵¹Eapen, V. & Jairam, R. (2009). *Integration of child mental health services to primary care: challenges and opportunities*. Ment Health Fam Med. Mar 2009; 6(1): 43–48.

⁵² Meschan, J. (2010). *Enhancing Pediatric Mental Health Care: Algorithms for Primary Care*. American Academy of Pediatrics Task Force on Mental Health.

⁵³ Eapen, V. & Jairam, R (2009). *Integration of child mental health services to primary care: challenges and opportunities*. Ment Health Fam Med. Mar 2009; 6(1): 43–48.

⁵⁴ Bower P, Garralda E, Kramer T, et al (2001) *The treatment of child and adolescent mental health problems in primary care: a systematic review.* Family Practice 2001;18:373–82

⁵⁵ Wissow et al (2008). A Common Factors Approach to Improving the Mental Health Capacity of Pediatric Primary Care. Adm Policy Ment Health. 2008 July ; 35(4): 305–318. doi:10.1007/s10488-008-0178-7.

- When problems are found, consultation and referral sources are limited (World Health Organisation 2005).
- Paediatric providers report that they lack the skills and knowledge to manage most mental health problems (Olson et al. 2001).

Internationally governments and health services all over the world vary widely in determining the best solution to this issue. However, according to Eapen & Jairam (2009), what is clear is that "culturally sensitive assessments and intervention methods, and creation of age-appropriate services within the primary care and school health setting should take priority. The unique strengths of the primary care physician and opportunities available in the primary care setting should be utilised to address the unmet child mental health needs of the community."⁵⁶

In the next section, some examples of mental health services for children and adolescents in primary care settings are identified.

⁵⁶ Eapen, V. & Jairam, R (2009). *Integration of child mental health services to primary care: challenges and opportunities*. Ment Health Fam Med. Mar 2009; 6(1): 43–48.

Key Message 1.3There are international and national good practice examples of child
and adolescent mental health services integrated into primary care

The WHO (2008)⁵⁷ recommends that 'first line' mental health treatment and care services can be provided to children/young people and parents/carers through community- based primary care centres. Recommended services at this level could include:

- ✓ Promotion of mental health
- ✓ Primary prevention of mental disorders
- ✓ Parental and youth education about general health and mental health issues
- ✓ Screening for mental health problems (including suicidal tendencies)
- ✓ Identification of young people at risk of mental health problems
- ✓ Short-term counselling services for young people and their families
- ✓ Basic management of behavioural disorders
- ✓ Follow-up and support for young people with chronic conditions

Example of good practice 1– Macul Primary Health Care in Chile

An example of good practice that demonstrates integrated CAMHs in primary care is a family health centre (FHC) in the urban municipality of Macul in Chile. The following description of this approach is drawn from the WHO report (2008).⁵⁸

In this centre, general physicians diagnose mental disorders and prescribe medications where required; psychologists provide individual, family and group therapy; and other family health team members provide supportive functions. A mental health community centre provides ongoing support and supervision. Clear treatment pathways, with lines of responsibility and referral, assist all members of the multidisciplinary family health teams.

This centre undertook primary care integration in the form of creating a family health model. The model was characterized by:

- Prioritisation of the family, rather than individuals, as the focus of health attention
- Multidisciplinary family health teams (general physician, dentist, nurse, obstetric nurse, nutritionist, social worker, psychologist, and nursing aide)
- Emphasis on patient health education and self-management support
- Prioritisation of early detection of risk factors, as well as early diagnosis and treatment
- Inclusion of rehabilitation and palliative care as part of family health service
- Regular monitoring of users' satisfaction

The family health centre had a particular focus on child mental health including:

- Child physical abuse
- Conduct and emotional disorders
- Attention-deficit/hyperactivity disorder
- Life skills for 1st and 2nd grade schoolchildren

Adolescent mental health was also targeted including:

- Alcohol and drug problems
- Child physical abuse and domestic violence
- Mood disorders

 ⁵⁷ World Health Organisation (2008). Integrating Mental Health into Primary Care: A Global Perspective. WHO, Geneva.
 ⁵⁸ Ibid.

Workshops on integrating mental health were targeted at multidisciplinary teams and included topics to support better CAMHs practice such as interviewing skills; family interventions; domestic violence; child sexual abuse; child behavioural problems and diagnosis of attention-deficit/ hyperactivity disorder; depression; bipolar disorders; panic attacks; and personality disorders.

Training on mental health tools for primary care also targeted nursing aides and administrative staff and taught the principal features of mental health problems in adults and children; to develop skills to deal with "difficult patients", to resolve conflicts and to work in a team; and to apply self-care and stress prevention strategies.

Community mental health group programmes were held on emotional disorders (anxiety and depression) and on alcohol problems which included an educational intervention that lasted a few months or treatment for two years with medication, group therapy and support groups.

Positive service outcomes include health service data that shows that, over time, more people with mental disorders have been identified and successfully treated at the family health centre, and user satisfaction also greatly improved.

Positive system change can also be seen in that the Family Health Center has been influential in placing mental health as one of the priorities for the Macul municipality. The FHCs and the Mental Health Community Centre now jointly design the annual mental health programme as part of the Macul health plan. This has created greater efficiency and solidarity in the use of public mental health resources, and has facilitated the inclusion of psychosocial factors as part of the municipality's health promotion work.

This example demonstrates in practice that integrated primary care for child and adolescent mental health is attainable and affordable and that scaling-up of provision of services can be achieved leveraging existing resources.

Key Message 1.4 Financial and human resources are critical enablers of the integration process.

One of the key 'non-negotiable principles' from worldwide research on successful integration of mental health into primary care is that although primary care for mental health is cost effective, financial resources are required to establish and maintain a service⁵⁹. The theme of lack of reimbursement as a barrier to providing mental health care by primary care providers is one of the most commonly cited, although not necessarily the leading obstacle to quality service provision.⁶⁰

The American Academy of Pediatrics Task Force on Mental Health (2010) advises that in order to achieve better outcomes for mental health in primary care, system change needs to first occur in terms of reimbursement for primary care clinicians for the investment of their time on restructuring services to encompass child mental health, as well as their time spent in the development of collaborative clinical relationships with mental health specialists.

This message is validated by Irish GPs who cite financial disincentives as a barrier to full engagement in the primary care teams. The Irish College of General Practitioners (2011)⁶¹ notes that all other members of the team are being paid or receive time in lieu for both their attendance and their travel time at Primary Care Team meetings. However GPs in Ireland, who essentially operate as self-employed small business owners, are not reimbursed for their time out of their practice to attend primary care meetings. The example given by the ICGP is that a GP with patients in three or four primary care areas cannot attend three or four primary care meetings per month as it disadvantages their practice financially and negatively impacts on the level of clinical service they can provide to their patients.

In their analysis of challenges and opportunities in terms of integrating child mental health into primary care, Eapen & Jairam strongly recommend that both "administrative and financial barriers that hinder integration should be addressed and, where appropriate, mental health resources should be restructured to include primary care clinicians."⁶² This is a recommendation also endorsed by the Irish College of General Practitioners which notes "Clerical support is essential otherwise team members can spend up to 50% of their clinical time doing administration – appointments etc. rather than seeing patients"⁶³. The ICGP report also highlights the "lack of IT infrastructure as a major block to team communications" since the lack of secure email places patient confidentiality at risk, and a number of other obstacles including the need to develop "clear lines of management for team members".⁶⁴

In the Mental Health Commission's analysis of the implementation of A Vision for Change, they note: "There can be little progress in the provision of high quality recovery focused mental health services without.... incentivising quality (e.g. supporting evidence-based clinical practice).....There is a need to start using existing, mainstream community resources in a more proactive way, to move away from the costly and unsustainable model of mental health services providing 'everything'."⁶⁵

⁵⁹ The World Health Organisation (2008). Integrating Mental Health into Primary Care: A Global Perspective. WHO, Geneva

⁶⁰ American Academy of Pediatrics, Task Force on Mental Health (2007). *Strategies for System Change in Children's Mental Health: A Chapter Action Kit*. Elk Grove Village, IL: American Academy of Pediatrics.

⁶¹ The Irish College of General Practitioners. (2011) *Primary Care Teams - A GP Perspective*. ICGP, Dublin.

⁶²Eapen, V. & Jairam, R. (2009). Integration of child mental health services to primary care: challenges and opportunities. Ment Health Fam Med. Mar 2009; 6(1): 43–48.

 ⁶³ The Irish College of General Practitioners. (2011) *Primary Care Teams - A GP Perspective*. ICGP, Dublin.
 ⁶⁴ Ibid.

⁶⁵ Mental Health Commission. (2009). From Vision to Action? An Analysis of the Implementation of A Vision for Change. MHC,

It is therefore clear from the literature that one of the first, sequential steps in successfully incorporating child and adolescent mental health services in primary care is to reduce administrative and financial barriers to service provision and collaboration. For additional literature sources on the 'how to do this', an evidence informed guide has been published by the American Academic Pediatrics Task Force on Mental Health.⁶⁶

Dublin.

⁶⁶ American Academy of Pediatrics Task Force on Mental Health. (2009). Improving *mental health services in primary care: reducing administrative and financial barriers to access and collaboration*. Pediatrics. 2009;123(6):1611].

Key Message 1.5 Capacity needs to be built to collaboratively embed mental health services in primary care

The current challenge for collaboration between primary care and mental health services in Ireland

The policy A Vision for Change recommends that clear links be "developed between mental health services and primary care/community resources, to coordinate appropriate service provision for children and adolescents at risk for mental health problems."⁶⁷ However, the literature reviewed on primary care in Ireland for this report indicates that, although some advances have been made on the development of a 'shared care' collaborative primary care system⁶⁸, current levels of collaboration between primary care and specialist mental health services care appear to be problematic.

For example, findings from a survey of GPs conducted in 2011 by the Irish College of General Practitioners were that 41.6% (of 423 GP respondents) were not part of a Primary Care Team (PCT), and that the 64.5% of the 195 GPs who were part of a PCT reported it as being '*poorly functioning*'.⁶⁹ It appears that primary care communication with secondary services has been challenging, with GPs highlighting lack of notification of admissions and discharges, and lack of clarity about management structures and plans, and psychiatrists raising the issue of a lack of information from GPs⁷⁰. GPs have also noted their need for more information on community based referral services such as voluntary agencies and self-help groups.

Findings from a 2012 survey of collaborative working amongst primary care and mental health service practitioners conducted by the Vision for Change Primary Care and Mental Health Sub-Group showed that "the level of integration between the mental health services and primary care is inadequate in relation to what is necessary to best facilitate the patient's journey and to support the professionals providing care for patients."⁷¹

In 2012 the HSE National Vision for Change Sub-Group on Primary Care and Specialist Mental Health Services⁷² made a number of recommendations on good practice in the delivery of effective shared mental health care services. McHugh & Byrne⁷³ used a survey method to examine the extent to which mental health teams in Ireland were achieving these recommendations. Their findings included poor overall levels of coordination and liaison with primary care, with approximately half of mental health teams having agreed referral (53.8%, n = 21) and discharge protocols (43.6%, n = 17). Support for primary care teams was also low, with a minority of mental health teams providing consultation (41%, n = 16) or training (25.6%, n = 10). Only a minority of teams provided GPs/primary care teams with service users' care plans.

73 Ibid.

⁶⁷ Department of Health. (2006). A *Vision for Change: Report of the Expert Group on Mental Health Policy.* Government Publications Office, Dublin.

⁶⁸ Some examples are cited in the *National Vision for Advancing the Shared Care Approach between Primary Care and Specialist Mental Health Service,* 2012, HSE. This guidance document also makes a number of recommendations on delivering effective shared care.

⁶⁹ The Irish College of General Practitioners. (2011) *Primary Care Teams - A GP Perspective*. ICGP, Dublin.

⁷⁰ Kierans, J. & Byrne, M. (2010). A potential model for primary care mental health services in Ireland.. Ir J Psych Med 2010; 27(3): 152-156

⁷¹ HSE (2012). National Vision for Change Advancing the Shared Care Approach between Primary Care and Specialist Mental Health Services. Health Services Executive, Dublin.

⁷² McHugh, P. & Byrne, M. (2013). *Profile of the Shared Care Teams in Mental Health Care*. Mental Health in Primary Care Implementation Subgroup. HSE.

McHugh and Byrne note that: "*in order to facilitate recovery within the community and provide service users with a continuum of care, a high degree of coordination and collaboration is needed between primary care teams and secondary care mental health teams.*"⁷⁴ McHugh and Byrne recommend that to improve good practice and better outcomes, there is the clear need for greater collaboration between mental health and primary care team members with regard to the management of specific cases, including formulating care plans, discharge planning, clarifying clinical responsibility, and greater support from mental health teams for primary care to manage mental health difficulties in primary care.

The Centre for Effective Services in Ireland conducted an international literature review to describe approaches to interagency working in children's services and cited evidence for their efficacy. The report cautions that although there are many evidenced benefits to interagency working, it is "*not inherently a good thing – only if it is done properly and implemented well*".⁷⁵ The review notes that the experience of other countries offers "*many lessons about the factors that promote the adoption of interagency approaches to needs assessment."* The following factors listed are cited directly from the conclusion section of this CES review:

- clarity about the purpose of common assessments and when they should be undertaken
- well-communicated 'vision'
- good organisational support
- high-level commitment
- sense of ownership at all levels
- inter-professional training
- guidance on use of standardised forms
- time for practitioners to develop trusting relationships across agencies

International good practice strategies on effective collaboration on children's mental health in primary care With regard to effective collaboration specifically on children's mental health in primary care, the American Academy of Pediatrics Task Force on Mental Health has published evidence informed strategy for preparing both a primary care practice, and for preparing a community for effective collaboration in a "partnership of primary care providers, families, mental health professionals, developmental, behavioral and adolescent specialists, educators, and agency personnel in both the assessment and care processes"⁷⁶. Some of the key community-primary care collaboration recommendations include

- taking a 'population perspective' to understand the child's environment
- developing an inventory of community resources
- aligning with community service providers to address children's mental health needs through primary care
- developing protocols for managing psychiatric emergencies
- addressing stigma through public education

⁷⁴ Ibid.

⁷⁵ Statham, J. (2011). Working Together for Children: A review of international evidence to inform the development of children's services committees in Ireland. Retrieved from <u>www.dcya.gov.ie</u> on 08/09/2014.

⁷⁶ American Academy of Pediatrics, Task Force on Mental Health. (2010). *Enhancing pediatric mental health care: strategies for preparing a community*. Pediatrics.125(3 suppl):S75–S86

Strategies offered⁷⁷ for preparing the primary care practice itself for provision of enhanced mental health care services include

- incrementally applying 'chronic care' principles to the care of children with mental health and substance abuse problems (just as primary care clinicians apply them to the care of children with chronic medical conditions such as asthma)
- determining the sequence of practice change by the needs of children and families whom the practice services and according to the capacity and resources of the practice.

Ready, Steady, Grow: An Irish good practice example of primary care service collaboration in infant mental health services

A good practice example of local primary care service collaboration in Ireland is the Ready, Steady, Grow (RSG) infant mental health strategy in Ballymun. This joint initiative between primary care and the area based childhood initiative known as 'youngballymun' was awarded the HSE National Prize for Excellence in Primary Care Provision in 2014.

The focus of RSG is on increasing the capacity of those who directly influence the mental health and development of infants and toddlers, including parents and practitioners. RSG seeks to promote the capacity of parents through the provision of the Parent-Child Psychological Support Programme (PCPS). This service is a universal, primary care centre-based programme consisting of six programme visits which is offered to all children in the catchment area who are aged 0-18 months. The mental health development of the infant and toddler, as well as their physical development, is assessed and supported in the centre.

Service delivery has grown since programme inception in 2010 and now includes an enhanced ante-natal course with the primary care team including a focus on psychological and emotional preparation for becoming a parent; baby massage; a parent & toddler group where parental relationships are in need of more support; a programme to support infanst and toddlers with language delay; and a parent-child therapeutic support programme which provides individualized, home based support. Parents are linked into additional local services according to need.

The core service delivery team is made up of HSE primary care staff, including public health nurses and speech & language therapists, who have been trained in infant mental health. Additional support staff are provided by youngballymun. A HSE primary care psychologist is available for collaborative input on complex cases. Co-working with staff from adult mental health services has recently developed as part of the individualized home based support service for parents who are experiencing mental health difficulties impacting their relationship with their baby or toddler.

In an independent evaluation of the service, a key finding was that a high number of stakeholders indicated that "*RSG has contributed well to the early identification of and intervention with children with Infant Mental Health risks*" including developmental challenges and disturbed, parent-infant relationships and that "*the collaborative work of RSG is facilitating collaboration between organisations*."⁷⁸

⁷⁷ Ibid.

⁷⁸ UCD Geary Institute & UCD School of Psychology. (2013). *Evaluation of the overall success and impact of Ready, Steady, Grow. Summary Report*. youngballymun. Dublin.

Jigsaw: An Irish good practice example of youth primary mental health service provision & interagency collaboration

The Mental Health Commission notes in its analysis of the implementation of A Vision for Change (MHC, 2009) that Jigsaw is a "new model of providing recovery focused, cost-effective youth mental health supports that achieves integration between primary and secondary services".⁷⁹ Developed by Headstrong, the national centre for youth mental health, Jigsaw aims as a systems change initiative to provide highly accessible, community based youth mental health services, to build capacity in local service providers to meet youth mental health needs and to facilitate interagency collaboration to achieve better outcomes for youth mental health.

According to Headstrong service provision data, in 2013 a total of 2,400 young people received support from one of the 10 Jigsaw services in Ireland. The highest proportion of young people engaging with Jigsaw were 15-17 year olds. The top referral pathways were parents (33%), self (21%), general practitioner (10%), school/higher education institute (8%) and adult mental health services (5%). The majority of young people did not need an onwards referral (71%) but where young people were directed to another service, most onward referrals were to CAMHS (6.7%), GPs (5.6%), and adult mental health services (4.9%). Of those who consulted with Jigsaw or were not suitable for the service, 18.7% were signposted to GPs, 14.8% to community organisations, 10.4% to adult mental health services, 10.4% to CAMHS, and 7.1% to youth services.⁸⁰

In terms of evaluation⁸¹ Jigsaw uses service outcome measures including standardised psychometric scale, a goal attainment scale, a follow up interview, a satisfaction survey and an inter-organisational collaboration survey. Recent organisational analysis of this data from service users in 2013 found:

- 89% of young people presented to Jigsaw with clinical levels of psychological distress, with 52% reporting high levels of distress. The most common presenting issues were anxiety, tension, worry (17%), anger (11%), family problems (10%), feelings of depression (10%) and isolation from others/withdrawal (10%).
- However, 85% of 17-25 year olds and 67% of 12-16 year olds showed a reliable reduction in
 psychological distress after getting support in Jigsaw. The most popular goals were
 emotional/mood regulation (33%), behaviour self-management (16%) and cognitive restructuring
 (15%). 92% of the goals set by young people were achieved.
- 95% said they got the kind of support they wanted in Jigsaw and 94% stated that they would recommend Jigsaw to a friend. Comments suggested that Jigsaw is viewed as a welcoming and unique place to get support, and has a positive impact on young people's lives. In particular, young people talked about how staff in Jigsaw were friendly, non-judgemental and supportive. This highlights the importance of young people having 'one good adult' to talk to when they are experiencing difficulties.

An international example of good practice in primary care collaboration: Canada's Family Health Teams

In Canada, over 200 inter-professional Family Health Teams (FHTs) have been established in Ontario since 2005 to improve primary care. This radical system change to embed a collaborative team approach in primary care has been shown to be successful in the prevention and management of mental health conditions and chronic diseases, contributing to improvements in health status and quality of life⁸².

⁷⁹ Mental Health Commission. (2009). *From Vision to Action? An Analysis of the Implementation of A Vision for Change*. MHC, Dublin.

⁸⁰ The service data for this section on Jigsaw was kindly provided directly to this literature review by Headstrong upon request. See Appendix 4: A Summary Document of Jigsaw Youth Mental Health Services in Ireland, September 2014.
⁸¹ Ibid.

⁸² Barrett, J., Curran, V., Glynn, L., & Godwin, M. (2007). *CHSRF synthesis: Interprofessional collaboration and quality primary healthcare*. Ottawa, ON: Canadian Health Services Research Foundation.

Prior to that, the majority of primary healthcare in Canada was delivered by family physicians alone. However a national goal was established in 2004 to provide 50% of Canadians with 24/7 access to primary healthcare, delivered by a multidisciplinary team, by 2011. With only 10% of Canadian family physicians working in multidisciplinary practices in 2002, considerable efforts were needed to achieve this target.⁸³ New models were therefore designed to replace solo primary care practices.

These new models offered shared work environments for family physicians with an opportunity for information exchange and collegial support with physicians, nurses, pharmacists, psychologists, psychiatrists, mental health nurses, and health educators among many other health professionals working side by side in clinical practice. They also offered patients enhanced access, safety, and quality of healthcare.⁸⁴

Findings from a comprehensive literature review indicate that although the transition to an interprofessional team model of care has been challenging to achieve, both patients and providers described improved healthcare access, greater satisfaction, and enhanced quality of healthcare using a FHT approach.⁸⁵ Patients also described enhanced health knowledge, skills, and self-care strategies.

Collaboration was fostered by effective leadership, communication, outcome evaluation, and training for both professionals and patients alike. Several key attributes to effective inter-professional collaboration have been identified including: the engagement of two or more professionals from different disciplines who share a common goal, shared knowledge, multiple interactions over time, an understanding of each professional's role, inter- dependence among professionals, symmetrical power, and a supportive organisational environment.⁸⁶

The overall evidence indicates that multidisciplinary teams can successfully work collaboratively in a community based primary care setting to improve healthcare access, resource utilization, and efficiency of services, outcomes and costs.

⁸³ Nolte, J., & Tremblay, M. (2005). *Enhancing interdisciplinary collaboration in primary health care in Canada*. Ottawa, Enhancing Interdisciplinary Collaboration in Primary Health Care Initiative. Ontario.

⁸⁴ Mulvale, G., Danner, U., & Pasic, D. (2008). Advancing community-based collaborative mental health care through interdisciplinary family health teams in Ontario. Canadian Journal of Community Mental Health 27, 55–73.

⁸⁵ MacKean, G. et al. (2012). *Advancing Family-Centered Care in Child and Adolescent Mental Health: A Critical Review of the Literature.* Healthcare Quarterly. Vol.15. Special Issue.

⁸⁶ Ibid.

Key Message 1.6Primary care providers must be provided with access to specialist
CAMHS consultation

Secondary care services that support the primary care workers in terms of referrals, support and supervision are essential. According to the World Health Organisation, a key 'non-negotiable' principle to successful integration of mental health services into primary care is that specialist mental health professionals and facilities must be available to support primary care.⁸⁷

There is evidence that this secondary care specialist child and adolescent mental health support can come from a variety of services, e.g. community mental health centres, secondary-level hospitals, or skilled practitioners working specifically within the primary care system. This support can be organised in a number of different ways.

For example, there is evidence that treatment by specialist staff working in primary care can be effective.⁸⁸ A model of a joint clinic, run by the GP or paediatrician together with the child and adolescent psychiatrist in the school or primary health clinic has found success in some settings.⁸⁹ Following assessment and initial intervention in such a setting, those children who either do not respond or whose needs cannot be met at the primary care level can be referred for specialised services.

There is also evidence that facilitating primary care providers' access to specialised consultation can support clarifying problematic diagnoses and making treatment decisions as cases become more complicated or severe⁹⁰.

An international good practice example - Massachusetts Child Psychiatry Access Project

One example of good practice in this area is the Massachusetts Child Psychiatry Access Project (MCPAP)⁹¹. This was a publicly funded project with 6 regional consultation teams who provided 1,341 Massachusetts paediatric primary care clinicians (PCCs) in 353 practices with rapid access to child psychiatry expertise, education, and referral assistance. These practices covered 95% of the young people in Massachusetts and served 10,114 children. The main reasons that Primary Care Clinicians contacted the MCPAP were for diagnostic questions (34%), identifying community resources (27%), and consultation regarding medication (27%).

Outcomes included improvement in ratings of access to child psychiatry. There was a massive increase in the rate of PCCs who reported that they are usually able to meet the needs of psychiatric patients. This rate increased from 8% to 63%. Consultations were reported to be helpful by 91% of PCCs. This good practice example indicates that primary care providers' ability to meet the needs of children and young people with mental health care needs can be substantially improved through public health interventions that promote collaboration between PCCs and child mental health specialists.

⁸⁷World Health Organisation (2008). Integrating Mental Health into Primary Care: A Global Perspective. WHO, Geneva.

⁸⁸ Williams J, Shore SE, Foy JM. (2006). *Co-location of mental health professionals in primary care settings: Three North Carolina models.* Clinical Pediatrics (Philadelphia). 45(6):537–543.

⁸⁹ Eapen V, Al-Gazali Al, Bin-Othman S, et al (1999). *Child psychiatric disorders in the United Arab Emirates: functional status and implications for service provision*. Primary Care Psychiatry 5:25–9

⁹⁰ Garland et al (2013). *Improving Community-Based Mental Health Care for Children: Translating Knowledge into Action*. Adm Policy Ment Health. 40(1): 6–22.

⁹¹Sarvet B. et al (2010). *Improving access to mental health care for children: the Massachusetts Child Psychiatry Access Project.* Pediatrics. 2010 Dec;126(6):1191-200.

Finally there is some evidence^{92, 93} that creating the specific role of 'primary care mental health worker' to coordinate patients' care across health and service settings can build mental health capacity in primary care services and promote mental health in the community.⁹⁴

The World Health Organisation notes that Primary Care workers in Mental Health (PCMH) can perform a number of key functions that could result in increases in good mental health outcomes for children, young people and families.⁹⁵ The functions recommended include community mental health promotion, parenting support, managing comorbidity, case coordination, crisis intervention, treatment adherence, trauma reduction, referral to specialist mental health services and/or community agencies.

The UK has significantly invested in creating and expanding this role of Primary Mental Health Workers (PMHWs) in the workforce to bridge the gap between primary health care and secondary mental health services. A comprehensive discussion, evaluation findings and core competencies for primary mental health workers are published in the UK national CAMHS review (2008).⁹⁶

⁹² Lester, H. et al. (2007). Cluster randomised controlled trial of the effectiveness of primary care mental health workers. Br J Gen Pract. 2007 Mar;57(536):196-203.

⁹³ Harkness EF & Bower PJ. (2009). On-site mental health workers delivering psychological therapy and psychosocial interventions to patients in primary care: effects on the professional practice of primary care providers. Cochrane Database Syst Rev. 2009 Jan 21;(1)

⁹⁴ Garland et al. (2013). *Improving Community-Based Mental Health Care for Children: Translating Knowledge into Action.* Adm Policy Ment Health.40(1): 6–22.

⁹⁵ World Health Organisation (2008). *Integrating Mental Health into Primary Care: A Global Perspective.* WHO, Geneva.

⁹⁶ Department of Health (2008). *Children and Young People in Mind: The final report of the national CAMHS review*. NHS, UK.

Key Message 1.7 The capacity of primary care workers to deliver child and adolescent mental health services must be developed through training, supervision and support

According to the World Health Organisation, pre-service and/or in-service training of primary care workers on mental health issues is an essential prerequisite for mental health integration. Professor Chris van Weel, World President of the World Organisation of Family Doctors (WONCA) states: "We need education and training on mental health care for all students and health professionals training to work in family medicine and other areas of primary health care".⁹⁷

In a paper summarising findings for the European Region of the WPA Task Force on 'Steps, Obstacles and Mistakes to Avoid in the Implementation of Community Mental Health Care', Semrau et al (2011)⁹⁸ note insufficient training for primary care staff frequently results in mental health problems either not being recognised or in treatment methods being unknown.⁹⁹

Training and Professional Development

The American Academy of Pediatrics Task Force on Mental Health in Primary Care (2010) also advises that primary care clinicians need to achieve mental health competencies⁴ through training that can build on the unique skills of the primary care clinicians and the specific opportunities of the primary care setting.

This training need has also been identified at European level. For example, Puras and Sumskiene conducted research on best practice in child and adolescent mental health in Europe, and one of their key recommendations¹⁰⁰ of good practice is the need to include professional development units on CAMH training in diverse and relevant professions such as public health professionals and teachers, as well as to introduce national curricula training in prevention and promotion in relevant higher education degrees.

In Ireland, the guidance document issued by the Vision for Change Working Group on Mental Health in Primary Care notes that there is a need to "ensure that sufficient numbers of professionals within primary care teams have the required skills and knowledge to work effectively with patients with mental health related difficulties of a mild to moderate nature that do not require referral to secondary mental health services."¹⁰¹

One of the report's key recommendations is that professionals are facilitated to attend a module run by DCU called 'Team Based Approaches to Mental Health in Primary Care module'. However there is no specific focus on child and adolescent mental health in this DCU professional development module, and therefore this appears to be a clear gap in the provision of training for primary care professionals in child and adolescent mental health care in Ireland.

⁹⁷ Integrating Mental Health into Primary Care: A Global Perspective. 2008. World Health Organisation, Geneva.

⁹⁸ Semrau, M. et al. (2011). *Lessons learned in developing community mental health care in Europe*. Institute of Psychiatry, King's College London, UK. World Psychiatry 2011;10: 217-225

⁹⁹ World Health Organization. *Mental health: facing the challenges, building solutions: report from the WHO European Ministerial Conference.* Copenhagen: WHO Regional Office for Europe, 2005

¹⁰⁰http://ec.europa.eu/health/mental_health/eu_compass/policy_recommendations_declarations/camhee_development.pdf

¹⁰¹ HSE National Vision for Change Working Group (2012). Advancing the Shared Care Approach between Primary Care and Specialist Mental Health Services: A Guidance Paper. Health Services Executive, Dublin.

Develop primary care clinicians' 'common factor' competencies

Interestingly there are a number of evidence-based 'generic' or 'common-factors' interventions that a significant body of research¹⁰² has identified as key to effective mental health interventions and improving mental health services¹⁰³ for children and adolescents¹⁰⁴. It appears from the research that one of the most important of the primary care opportunities may be the primary care clinician's capacity to have a positive impact on a child's mental health problems without needing to know exactly what the child's diagnosis is.¹⁰⁵

For example, one of these competencies is 'effective communication techniques'. Research on training paediatric primary care clinicians in communication techniques demonstrates that patients seeing such clinicians are more likely to report family violence, emotional and behavioral symptoms, and other family concerns¹⁰⁶. Moreover, children and young people interacting with clinicians trained in such techniques may have improved outcomes in subsequent assessments¹⁰⁷.

Wissow, et al suggest that training primary care providers in this competency based way "may provide an answer to the volume of specialized knowledge that primary care providers would need to learn if they were to implement diagnosis-specific treatments for many commonly occurring mental health problems."¹⁰⁸ Instead, the authors note that primary care providers would try to master a core set of skills and interventions applicable to all emotional and behavioural problems. Next, they would learn 'practice elements' common to a few broad categories of conditions. Finally, they would also need a means of identifying a smaller set of conditions that require more specific evaluation or referral onto specialist mental health services.

Wissow et al cite evidence that some 'common factor' skills can be readily taught and maintained over long periods of time¹⁰⁹ and note that at least one trial has suggested that a core set of skills can be taught with a minimal time commitment (4 hours spread over several weeks).¹¹⁰

¹⁰² Grencavage LM, Norcross JC (1990). Where are the commonalities among the therapeutic common factors? Prof Psychol Res Pr. 21(5):372–378

¹⁰³ Bickman L (2005). A common factors approach to improving mental health services. Ment Health Serv Res. 7(1):1–4

¹⁰⁴ Chorpita BF, Daleiden EL, Weisz JR (2005). *Identifying and selecting the common elements of evidence based interventions: A distillation and matching model*. Mental Health Services Research. 7(1):5–20.

 ¹⁰⁵ Castonguay LG, Beutler LE (2006). Principles of therapeutic change: a task force on participants, relationships, and techniques factors. J Clin Psychol. 62(6):631–638
 ¹⁰⁶ Wissow LS, Gadomski A, Roter D, et al (2008). Improving child and parent mental health in primary care: a cluster-randomized

¹⁰⁰ Wissow LS, Gadomski A, Roter D, et al (2008). *Improving child and parent mental health in primary care: a cluster-randomized trial of communication skills training*. Pediatrics. 121(2):266 –275

¹⁰⁷ van Os TW, van den Brink RH, Tiemens BG, Jenner JA, van der Meer K, Ormel J(2005).*Communicative skills of general* practitioners augment the effectiveness of guideline-based depression treatment. J Affect Disord. 84(1):43–51

¹⁰⁸ Wissow et al (2008). *A Common Factors Approach to Improving the Mental Health Capacity of Pediatric Primary Care*. Adm Policy Ment Health. 35(4): 305–318. doi:10.1007/s10488-008-0178-7.

¹⁰⁹ Wissow LS, Gadomski A, Roter D, et al (2008). *Improving child and parent mental health in primary care: a cluster-randomized trial of communication skills training.* Pediatrics. 121(2):266 –275

Key Message 1.8Consider good practice guidelines in assessment, diagnosis and
treatment of children's and adolescent's mental health in Primary
Care

During the course of this literature review for MHR/CMHC, several relevant 'good practice' guidelines on assessment, diagnosis and treatment of children's and adolescent's mental health in primary care were identified. Key points from these sources are briefly summarized below.

World Health Organisation Guidelines

According to the World Health Organisation¹¹¹, primary care workers must undertake two key functions to provide good-quality primary care for mental health:

- 1. assessment and diagnosis of mental disorders
- 2. treatment, support, referral, and prevention services

However the World Health Organisation notes that assessing mental disorders in primary care is dependent as much upon health workers' attitudes towards patients as it is upon their diagnostic knowledge. The key to successful diagnosis is a combination of technical knowledge of signs and symptoms, combined with an attitude in which the world of the patient is understood, welcomed, and respected. Without either of these requisites – knowledge of signs and symptoms on the one hand, and understanding of the patient's world and beliefs on the other – useful assessments cannot be made.

Moreover the World Health Organisation notes that continuity of care is a core element of effective primary care, and where there is an ongoing relationship between an individual health worker and patient, the quality of assessment and diagnosis is likely to be enhanced.

The WHO notes that the overall aims of assessment of children and adolescents are similar to those for adults, and recommends that health workers should identify the presenting problem and obtain information about its onset and course; take a history of the child or adolescent's developmental functioning; assess the nature and extent of behavioural difficulties, functional impairment, and/or subjective distress; and identify potential individual, family or community factors that may pre-dispose, maintain or ameliorate the problem.¹⁰

However the WHO recommends that special issues in the assessment of children and adolescents should be considered, including the following:

- Children's and adolescents' ability to conceptualize and communicate about their mental health is influenced by their level of cognitive, language, and moral development.
- Children's and adolescents' functioning should be assessed, and compared to what would be expected in relation to their age and phase of development.
- Children and adolescents are more changeable from day to day than adults: they respond more extremely to tiredness, hunger, and lack of familiarity with the circumstances. This necessitates multiple interviews before assessments can be finalized.
- The age of the child may influence the presentation of certain symptoms such as anxiety and depression.
- As with adults, children and adolescents should be screened for the use of alcohol and illicit drugs.
- The well-being of children and adolescents is dependent largely on the environments in which they live, such as their family, school and community.
- The family member's or educator's reasons for referral, as frequently they are most troubled by

¹¹¹ World Health Organisation (2008). Integrating Mental Health into Primary Care: A Global Perspective. WHO, Geneva.

the presenting problem as opposed to the children or adolescents themselves.

The WHO also recommends that specific information should be obtained from the primary caregiver in the assessment of children including reason for referral, details of the present complaint, assessment of family community background as well as the child or young person's development in the context of the family. This could include:

- Circumstances of conception, pregnancy, adoption, infancy
- Physical development and medical history
- School functioning
- Family relationships
- Conscience and values
- Unusual or traumatic circumstance
- Emotional problems and temperament
- Peer relationships
- Assessment of family and community background

Irish Guidelines to GPs on Diagnosing Common Mental Health Disorders (and referring to CAMHS)

A set of guidelines for GPs in Ireland has recently been developed by the Irish College of General Practitioners with CAMHS input that offers guidance on common mental health issues for children and young people, when to refer to local community CAMHS and contact details for community and voluntary support services.¹¹²

While these guidelines are a positive development in clarifying access to CAMHS, the highly restrictive nature of the referral process to community CAMHS in Ireland is noteworthy. For example, CAMHS will only accept routine referrals from a medical doctor: *"the child must be referred by a medical doctor (GP, Medical Officer or Paediatrician*)." This excludes direct referrals from parents, early years services, schools, community based services or other primary care services.

The ICGP guidelines note that "referral of Children and Adolescents to local Child and Adolescent Mental Health Services (CAMHS)... is reserved for children and adolescents who have been diagnosed with a psychiatric (Axis 1) disorder." This referral criteria excludes children and young people with autistic spectrum disorders, emotional difficulties, behavioural problems, developmental difficulties and intellectual disabilities unless there is a clear mental health component.

The ICGP guidelines advise that "many children, however, present with emotional difficulties, which do not constitute Axis 1 disorders but are significantly debilitating to require referral to other services." These referral options are also discussed in the guidelines. The guidelines note that if a child is referred, then the child is placed on the CAMHS waiting list for assessment. Urgent cases (such as children who are suicidal or psychotic) are prioritised. These guidelines are detailed in **Appendix 2** of this report.

$\label{eq:constraint} The critical need to assess perinatal depression in primary care$

There is a significant public health crisis in Ireland of maternal perinatal depression, according to Leahy-Warren (2007), who notes that the most recent systematic review suggests a post-natal depression prevalence rate of 13%.¹¹³ Despite this significant clinical issue for nurses and GPs providing postnatal

¹¹² O'Keefe et al (2013). *Child and Adolescent Mental Health Diagnosis and Management*, CAMHS Quality in Practise Committee (ICGP). Dublin.

¹¹³ Leahy-Warren, P; McCarthy G (2011) *Postnatal Depression in first-time mothers: Prevalence and Relationships between* functional and structural social support at 6 and 12 weeks post-partum. Archives of Psychiatric Nursing, 25(3)

care for mothers¹¹⁴ and their infants, post-natal depression in Ireland is *"underassessed, misunderstood, and very often poorly treated."*¹¹⁵

Infants' mental health must be considered in relation to their mother's mental health as infants and and young children of perinatally depressed mothers are more likely to have a difficult temperament, as well as cognitive and emotional delays. If depression continues post-partum, there is an increased risk of poor mother-infant attachment, delayed cognitive and linguistic skills in the infant, impaired emotional development and risk for behavioural problems in later life.¹¹⁶

However, the NHS in the UK acknowledges that General practitioners (GPs) and other primary care professionals *may "inadvertently prevent people with perinatal mental health problems from accessing psychological therapies services"*¹¹⁷as primary care practitioners may:

- Have time constraints in their surgeries which prevent them from diagnosing mental health problems effectively
- Recognise symptoms of depression or anxiety but fail to recognise that they can be treated with psychological therapies
- Believe that treating physical health problems is a higher priority than treating mental health problems, and consequently not refer patients to psychological therapy services
- Mistakenly believe that psychological therapies do not work
- Not have the skills to identify and manage perinatal mental health problems

However the literature reviewed for this MHR/CMHC report notes that primary care GPs and public health nurses are particularly well suited to initiate, carry out and evaluate the effectiveness of interventions designed to prevent adverse outcomes of maternal perinatal depression on mother and child wellbeing.^{118 119} For example, Muzik & Boroska (2010) note that "primary care holds a crucial role for detecting, treating or, if necessary, providing referrals to mental health care for women with perinatal depression."¹²⁰

They advise that recommended practice for primary care is to include screens for maternal depression as well as screens for infant depression and the dyadic relationship and note the following:

- Maternal depression can be quickly assessed in the clinic using the ten-question Edinburgh Postpartum Depression Scale (EPDS), the two-question Patient Health Questionnaire-2 (PHQ-2) and the nine-question PHQ-9. All three scales are free of charge and easily found on the web. The Beck Depression Inventory, Second Edition (BDI-II) is also a user-friendly and valid screening option for perinatal depression, but is not free of charge.
- Evaluation of infant depression can be found in the DC: 0–3.
- The dyadic relationship can be assessed using the Postpartum Bonding Questionnaire (PBQ).

Detecting and treating children's mental health aged 0-5 Years in primary care

No guidance is given to GPs in the ICGP guidelines on CAMHS regarding mental health detection, diagnosis and treatment options for infants and children in their early years. This lack of guidance may contribute to a lack of awareness and recognition of early childhood mental health issues presenting in

¹¹⁴ Leahy-Warren, P; McCarthy G (2011) Ibid.

¹¹⁵ Leahy-Warren, P; McCarthy G (2011) Ibid.

¹¹⁶ Muzik. M. & Borovska. S (2010). *Perinatal depression: implications for child mental health*. Ment Health Fam Med. 7(4):239-¹¹⁷ NHS (2009). *Perinatal Positive Practise Guide*. Improving Access to Psychological Therapies (IAPT), UK.

¹¹⁸ National Institute for Health and Clinical Excellence (2007). *Antenatal and Postnatal Mental Health: Clinical Management and Service Guidance,* London, NICE

¹¹⁹ Leahy-Warren, P. McCarthy, G. Corcoran, P (2012). 'First Time Mothers: social support, maternal parental self-efficacy and postnatal depression'. Journal of Clinical Nursing, 21(3-4):388-397

¹²⁰ Muzik. M. & Borovska. S (2010). *Perinatal depression: implications for child mental health.* Ment Health Fam Med. 7(4):239-

primary care. It is noteworthy that currently less than 1% of CAMHS caseload is under 4 years old.¹²¹ This would appear to be a critical service and guidance omission given both the prevalence of perinatal depression¹²² detailed in the section above and the severe impact that untreated attachment and relational disorders can have on infant and early childhood mental health.

While HSE primary care psychology accepts referrals for children with an emphasis on early intervention for clients experiencing mild-moderate social, emotional, or childhood behavioural difficulties, it was not possible for this brief literature review to clarify data around referrals of children under 5 to the primary care psychology services, if referrals onwards to CAMHS is now possible, and if so, the number of referrals accepted by CAMHS, the main reasons for referrals being rejected and where referrals might be sent after a CAMHS rejection.

It is useful to consider Foy and the American Academy of Pediatrics Task Force on Mental Health (2010) clear, detailed and evidence informed pathway guidance¹²³ for primary care clinicians in assessing and responding to social- emotional problems in children younger than 5 years of age and disturbances in parent-child relationships. This guidance includes indications for referral to a developmental-behavioral paediatrician, to a mental health specialist with expertise in early childhood, to a therapist for the parent or the parent-child dyad, to a specific professional (e.g., speech & language therapist), to a developmental evaluation team, or to other community resources.

Guidelines to assess the mental health of children aged 5 -21 Years in primary care

With regard to children aged 5 to 21 years old presenting with mental health difficulties in primary care, Foy and the American Academy of Pediatrics Task Force on Mental Health (2010) advise that primary care clinicians with requisite competencies can effectively assess children with mild-to-moderate levels of functional impairment associated with specific symptom clusters.¹²⁴ Tools developed outline primary care assessment of children with symptoms in each of these clusters and suggest specific indications for specialty referral of children who experience symptoms in that cluster. These clusters include: anxiety; inattention and impulsivity; disruptive behavior and aggression; depression; substance use; and learning difficulties.

Additional specific guidelines from this taskforce include the ADHD guidelines, guidelines for adolescent depression in primary care¹²⁵, as well as treatment recommendations for the use of anti-psychotics for aggressive young people^{126, 127} and good practice parameters for the assessment and treatment of children and adolescents with anxiety disorders.¹²⁸

A number of evidence informed guides for clinicians and primary care service providers on the diagnosis and treatment of child and adolescent mental difficulties and disorders, as well as promotion of good mental health by the National Institute for Clinical Excellence in the UK. See <u>www.nice.org.uk</u> for further

¹²¹ Health Service Executive (2014). *Fifth Annual Child and Adolescent Mental Health Service Report*. HSE, Dublin

¹²² O'Hara, Michael W., Swain, Annette M (1996). *Rates and risk of postpartum depression--a meta-analysis*. International Review of Psychiatry, 09540261, Vol. 8, Issue 1

¹²³ Foy, J (2010). *Enhancing Pediatric Mental Health Care: Algorithms for Primary Care.* The American Academy of Pediatrics Task Force on Mental Health Pediatrics 2010;125;S109

¹²⁴ Ibid.

¹²⁵ Zuckerbrot et al (2007). *Guidelines for Adolescent Depression in Primary Care (GLAD-PC):* I. *Identification, assessment, and initial management. Pediatrics.* 2007;120(5). Available at: www.pediatrics.org/cgi/content/full/120/5/ e1299

¹²⁶ Schur SB et al (2003). Treatment recommendations for the use of anti-psychotics for aggressive youth (TRAAY). Part I: a review. J Am Acad Child Adolesc Psychiatry. 42(2):132–144

¹²⁷ Pappadopulos, E. et al (2003). *Treatment recommendations for the use of antipsychotics for aggressivey outh* (TRAAY). Part II. J Am Acad Child Adolesc Psychiatry 42(2):145–161

¹²⁸ American Academy of Childand Adolescent Psychiatry (2007). *Practice parameter for the assessment and treatment of children and adolescents with anxiety disorders*. J Am Acad Child Adolesc Psychiatry. 46(2):267–283. Available at: www.aacap. org/galleries/PracticeParameters/JAACAP_____Anxiety_2007.pdf

details.

Guidelines for Youth Friendly Primary Care Services

Although General Practice is acknowledged in the literature as the place where most mental health problems are identified and treated^{129,} the international evidence is that young people experience a range of barriers to accessing mental health support in primary care¹³⁰. These barriers range from organisational barriers such as service design or service delivery in ways that young people don't want to engage with, or attitudinal barriers, such as the fear of being stigmatised for having a mental health problem.

One of the key recommendations from the Psychiatric Epidemiology Research across the Lifespan (2013) report on youth mental health in Ireland in response to the high prevalence of youth mental health disorders is to: *"Ensure that, when young people do seek help, quality, youth-friendly mental health services and supports will be available and accessible to them."*¹³¹

A useful good practice guide has recently been developed in the UK¹³² to help GPs and other primary care practitioners to develop youth-friendly practice, and to better identify and address the mental health needs of the young people who come to see them. The guide was developed¹³³ as a result of research with over 170 young people on the topic of their experiences of using primary care service.

Links are also included to other innovative projects such as the 'Doc Ready' website and app that helps young people experiencing mental health concerns to get the most out of their GP appointments, <u>www.docready.org</u>, and the GP Champions for Youth Health projects.¹³⁴

 ¹²⁹ World Health Organisation (2012). *Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors*. WHO, Geneva.
 ¹³⁰ Gulliver A, Griffiths KM & Christensen H (2010). *Perceived barriers and facilitators to mental health help-seeking in young people: a systematic review*, BMC Psychiatry 2010, 10:113
 ¹³¹ Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I (2013). *The Mental Health of Young People in Ireland: a report of the*

¹³¹ Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I (2013). *The Mental Health of Young People in Ireland: a report of the Psychiatric Epidemiology Research across the Lifespan* (PERL) Group Dublin: Royal College of Surgeons in Ireland

¹³² Woodhouse, A (2014). *How to Promote Young People's Wellbeing within Primary Care*. Paul Hamlyn Foundation and The Mental Health Foundation. London.

¹³³ This guide was developed by 'Right Here', a £6 million programme that aims to develop effective new approaches to supporting the mental health and wellbeing of young people in the UK aged 16–25.

¹³⁴ www.youngpeopleshealth.org.uk/5/page/71/gp-champions-project

Section 2: Ensure accessible, community based, evidence-informed and outcomes-monitored child and adolescent mental health services

Key Message 2.1 Service information about CAMHS should be clear and accessible prior to and during service use

The Quality Framework for Mental Health Services in Ireland (2007) states that: '*Members of the general public, primary care services, service users and families/chosen advocates, receive information about:* What services are available; How they work; How to access them, especially in a crisis'.¹³⁵

However a key finding from Coyne et al (2014), who interviewed 32 parents and 15 adolescents attending three CAMHS services in Ireland, was that accessing mental health services in the first place was difficult for both parents and adolescents, and was one of the most challenging parts of the process for families engaging with child and adolescent mental health services in Ireland. This appeared to be mainly due to a *'knowledge deficit'* and *'a lack of information'*.^{/136}

This apparent lack of public knowledge in Ireland about what CAMH services are available for young people experiencing a mental health problem appears to be both among parents and young people. For example Coyne et al (2014) note "*There appeared to be a lack of knowledge among some parents regarding the existence of CAMHS with GPs often suggesting a referral rather than parents requesting a referral.*" Buckley et al (2012) who found in their interviews with 18 transition year students that "*Nonservice user participants expressed uncertainty on what to do and where to go should they experience a mental health problem*".¹³⁷

The Quality Network for Community CAMHS Standards (2011, UK) advises as good practice that CAMHS providers publish and disseminate referral guidelines and pathways for access to their services in easy to understand formats through leaflets, advertisements and online.

Indeed, one of the key recommendations made by Coyne et al (2014)¹³⁸ was that each CAMHS service in Ireland should provide information leaflets, including separate leaflets using language appropriate for parents, children and young people, to describe the local CAMHS service, what happens there and who to contact if in need of support. The authors suggest these could be usefully distributed through General Practitioners in the area.

However according to Cannon et al (2013) young people in Ireland may be *"least likely to seek help from a GP and may be more likely to go to their friends and family for personal and emotional problems than from any other source"*¹³⁹, so it may be advisable to target mental health promotion and service information also at peers and families.

¹³⁵ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHR, Dublin.

¹³⁶ Coyne, I. et al (2014). *Adolescents and parents' experiences of attending child and adolescent mental health services* (CAMHS) in Ireland: The report. TCD, Dublin.

¹³⁷ Buckley, S et al (2012). Mental health services: the way forward. The perspectives of young people and parents. St Patrick's University Hospital, Dublin

¹³⁸ Ibid.

¹³⁹ Cannon. M, Coughlan. H, Clarke. M, Harley. M & Kelleher. I (2013). *The Mental Health of Young People in Ireland: a report of the Psychiatric Epidemiology Research across the Lifespan* (PERL). Royal College of Surgeons in Ireland, Dublin.

Moreover, the nature of common mental health problems experienced by young people such as depression, anxiety and substance abuse are characterised by social withdrawal and therefore can counteract their help seeking behaviours. Since the popularity of e-health applications with anxiety and depression is rising¹⁴⁰ this may indicate opportunities about the effective use of the internet by community based mental health services to promote mental health.

Recent Irish research indicates that internet and mobile application to provide accessible information about mental health and available services could be an effective and important communication channel. For example, in the recent 'My World' national study of mental health in Ireland, 77% of young people reported that they would obtain information or support from the internet for their mental health. The Young People and Mental Health National Survey (2009)¹⁴¹ in Ireland found that there is near universal use of the internet by young people with their usage focused on video and social networking and online chat.

Consideration must also be given to how information is made fully available to all groups of children and young people. The iCAMHS guidelines note that "*Information is available in ways that are accessible to everyone including refugees, asylum seekers, homeless persons, travellers, persons with sensory impairments and persons who have literacy difficulties.*"¹⁴²

Provide information while waiting for an initial appointment

Recent research conducted by Coyne et al (2014) found that the service users in their study, 15 adolescents and 32 parents who were purposefully sampled, report that their experience of waiting for CAMHS with no advice on what to expect from the service, or what support strategies are advised while waiting for an initial appointment, exacerbates stress and anxiety about accessing the service. For example, adolescent participants in Coyne et al's 2014 research¹⁴³ reported feeling uninformed and unprepared prior to commencing treatment. Parents in this study suggested that being provided with information on the service and its operation might help alleviate some of this anxiety and also help parents to know what to expect from the process.

The Quality Network for Community CAMHS Service Standards (2011)¹⁴⁴ advises that young people and their parents (where appropriate) should be fully involved in and informed during the process of referral so they know what to expect. They suggest that CAMHS staff provide young people and their parents/carers with written information about the service prior to or during their first attendance. Guidance is that this might include the distribution of leaflets and web addresses to referrers and linked services.

The standards advise that CAMHS should keep referrers aware of what is going on with the referral, and request that referrers ask young people and their parents/carers whether they understand the reasons for the referral and what will happen next. This could be included in a service information

¹⁴⁰ Christensen, H. et al (2011). *The use of e-health applications for anxiety and depression young people: challenges and solutions.* Early Intervention in Psychiatry, 5, 58-62.

¹⁴¹ Millward-Browne, L (2009). *Young People and Mental Health: A National Survey*. Dublin. National Office for Suicide Prevention. http://www.nosp.ie/young_people_09.pdf

¹⁴² CAMHS Specialist Child and Adolescent Mental Health Service Advisory Group (2013). *Irish Child & Adolescent Mental Health Service (iCAMHS) National Quality Guidelines Document*. Unpublished draft pending HSE approval and progression since October 2013.

¹⁴³ Coyne, I. et al. (2014). Adolescents and parents' experiences of attending child and adolescent mental health services (CAMHS) in Ireland: The report. TCD, Dublin.

¹⁴⁴ Barrett, R. et al (Eds) (2011). *Quality Network for Community CAMHS Service Standards*. 3rd Edition. Royal College of Psychiatrists, UK.

leaflets or referral forms disseminated to referrers from CAMHS, along with points of contact to access help.

The Quality Network for Community CAMHS Service Standards (2011)¹⁴⁵ advises that youngpeople should be kept informed about the progress of their referral and estimated wait for the first appointment, through a letter, leaflet or telephone call. CAMHS should also provide information about how young people on the waiting list can access help while they wait for an appointment.

Finally, the Quality Network for Community CAMHS Service Standards guidelines suggest that those young people and families who are offered an appointment with CAMHS should be able to contact the service easily and promptly through up-to-date contact information and sufficient staff to relay telephone messages. The expected CAMHS response to routine queries in the UK is recommended to be by the next working day.¹⁴⁶

¹⁴⁵ Ibid. ¹⁴⁶ Ibid.

Key Message 2.2Access to CAMHS should be needs-based, timely and facilitated by a
range of local service referral pathways

Provide a needs based and timely CAMHS service

The Quality Network for Community CAMHS Standards (2011, UK) recommends as good practice that that *Young people and their parents/carers can access CAMHS easily and according to their need*¹⁴⁷ However current referral and therefore access to CAMHS in Ireland appears to be restricted to children and young people who are experiencing psychiatric (Axis 1) disorders only, and children and young people who have engaged in deliberate self-harm. See Appendix 2 of this report for CAMHS referral criteria issued to GPs.

This referral criteria issued to GPs in Ireland notes that children and young people with autistic spectrum disorders, emotional difficulties, behavioural problems, developmental difficulties and intellectual disabilities should not be referred unless there is a clear mental health component.¹⁴⁸ It appears unlikely however without specialized training that GPs would be in a position to recognize and therefore refer comorbid mental health components presenting in children with the aforementioned difficulties.

Headstrong, the national centre for youth mental health notes that unfortunately the referral criteria to access CAMH services can "serve to exclude young people in distress. For example, if a young person has a mild intellectual disability, a history of substance misuse, a diagnosis of a personality disorder, is homeless or between the ages of 16-18, they are prone to "fall between the cracks"."¹⁴⁹

An example of an international needs-based clinical system to improve access and quality of service that is being widely implemented across CAMHS services in the UK, New Zealand and parts of Australia is the Choice and Partnership Approach (CAPA). This approach aims to place the needs of the child/young person and the family at the centre of the consultation, with the CAMHS service provider as a partner with the family, rather than as the expert specialist. The child/young person and family are acknowledged as the experts on their needs, strengths and vulnerabilities.

The CAPA process of identifying and responding to needs is as follows: Once a referral is made, new CAMHS users and their families are invited to an initial meeting, or 'Choice appointment' which aims to identify what the child/young person/family want help with, to reach a shared understanding of the problems and to identify a range of alternatives including "other services, strategies they can use to help themselves, and any appropriate specialist CAMHS interventions. If the service user and family choose to be seen for further appointments within the service, then they are invited to book 'core Partnership appointments'. Here, the families will aim to work in partnership with the CAMHS professional."¹⁵⁰

A national evaluation of CAPA which involved 253 CAMHS staff on 53 CAMHS teams in the UK found the benefits reported included:

¹⁴⁷ Quality *Network for Community CAMHS Service Standards*, 3rd Ed. 2011. QINMAC. The Royal College of Psychiatry, London.

¹⁴⁸ O'Keefe et al (2013). *Child and Adolescent Mental Health Diagnosis and Management*, CAMHS Quality in PractiseCommittee (ICGP). Dublin.

¹⁴⁹ Headstrong (2013). Conceptual and Empirical Underpinnings of Community-Based Early Intervention and Prevention in Youth Mental Health. The Evidence Base for: Early Intervention & Systems Design in Youth Mental Health.

http://headstrong.ie/wpcontent/uploads/2014/01/Early_Intervention_and_Prevention_in_Youth_Mental_Health updated_23-7-13_1.pdf. Accessed 11/10/14

¹⁵⁰ The Mental Health Foundation (2009). *Evaluation of the Choice and Partnership Approach*. National CAMHS Support Service, UK.

- Improved access and reduced waiting times for families entering the service.
- Reduced demands on the service due to improved partnership working with community services and improved flow of families through the service.
- More efficient and more formalised mechanisms of team working.
- Less referrals and bottlenecks to specialist clinics.
- Improved clinician skills through joint working.

However potential challenges identified included:

- There needs to be active planning, monitoring and reviewing for families with complex needs
- Families may wait for long periods of time in between having a Choice appointment and a Partnership appointment if there is not enough service capacity or if systems are not in place
- Managers need to be trained in capacity planning in order to implement CAPA effectively, and robust service monitoring and a flexible workforce who are willing to extend capacity and roles where necessary are required.

Enable referral pathways via a range of local services

The Quality Network for Community CAMHS Standards (2011, UK) also recommend as good practice that there are "*documented, up-to-date referral pathways into CAMHS via a range of local services.*"¹⁵¹ Their guidance is that these local services could include GPs, emergency departments, schools, social services, paediatric services, youth offending teams, substance misuse services, etc.

However currently in Ireland, 'for routine referrals to most CAMHS in Ireland, the child must be referred by a medical doctor (GP, Medical Officer or Paediatrician). The child is then placed on the waiting list for assessment.'¹⁵² This restriction of referral by a medical doctor only appears to be in contrast to international good practice guidelines¹⁵³ as it prohibits referral by the range of services involved in observing and supporting children's and young people's mental health in diverse settings. It also prevents parental referral and young person self-referral.

¹⁵¹ *Quality Network for Community CAMHS Service Standards*, 3rd Ed. 2011. QINMAC. The Royal College of Psychiatry, London.

¹⁵² O'Keefe et al (2013). *Child and Adolescent Mental Health Diagnosis and Management*, CAMHS Quality in Practise Committee (ICGP). Dublin.

¹⁵³ World Health Organisation (2012). *Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors*. WHO, Geneva.

The current restriction of referral into community CAMHS in Ireland by a medical doctor only is also concerning regarding equity of access. There is compelling research evidence in Ireland that manyyoung people simply do not attend their GP for mental health difficulties.¹⁵⁴ For example, Cannon et al (2013) found that young people in Ireland may be *"least likely to seek help from a GP"*.¹⁵⁵ Buckley et al (2012) also note that *"Many young people experiencing mental health problems do not consult with their GP (Potts et al, 2001)"*.¹⁵⁶ Additionally, the cost associated with a GP visit could be a significant barrier for some young people in need of referral to CAMHS.

In contrast is the good practice in the UK of facilitating referral to CAMHS from a range of professionals in different agencies working with children.¹⁵⁷ So too, the Government of Victoria, Australia has prioritized earlier access to CAMHS expertise through facilitating referral relationships between CAMHS and other services involved in caring for children.¹⁵⁸ The policy in Victoria has been that professionals working in other agencies can refer to CAMHS, including: school professionals, general practitioners, government agencies such as Child Protection and Juvenile Justice, nurses, other private practitioners and specialists.¹⁵⁹

Provide timely access to CAMHS to improve service user satisfaction and outcomes

According to Garland et al (2013) swift and easy access to CAMHS must remain an "*important aspiration because it is a key factor in improving service user satisfaction and outcomes*" ¹⁶⁰ since service access predicates outcomes. Barriers to swift access to services identified by Garland et al include geographic variation in access to services, procedures for accessing services which may be confusing for some families, a lengthy waiting list and a lack of specialist CAMHS services that can meet specific needs.

Research conducted with service users in in Ireland has found that timely, accessible support to CAMHS is one of the key elements of a satisfactory service for service users.¹⁶¹ However according to Buckley et al, who conducted interviews and focus groups with 24 young service users and two parents in Ireland:

"The perceived quality of care received was influenced negatively by the length of waiting time and initial experiences of participants in the support service environment. Long waiting times prior to accessing support services were recalled by a number of participants, often aggravated by a lack of service locally."¹⁶²

Regarding the waiting list in Ireland, the iCAMHS Quality Service Provision Guidelines (unpublished) recommend that "*The CAMH service responds to referrals in a timely way. All accepted referrals are*

¹⁵⁴ Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I (2013). *The Mental Health of Young People in Ireland: a report of the Psychiatric Epidemiology Research across the Lifespan* (PERL) Group Dublin: Royal College of Surgeons in Ireland. ¹⁵⁵ Ibid.

¹⁵⁶ Buckley, S et al (2012). Mental health services: the way forward. The perspectives of young people and parents. St Patrick's University Hospital, Dublin.

¹⁵⁷ Department of Health. 2004. CAMHS Standard, *National Service Framework for Children, Young People and Maternity Services*. UK: Department of Health.

¹⁵⁸ Department of Human Services, Government of Victoria (Australia). 2006. *CAMHS in Communities: Working together to provide mental health care for Victoria's children and young people*. Melbourne, Australia. ¹⁵⁹ Ibid.

¹⁶⁰ Garland, A. et al. *Improving Community-Based Mental Health Care for Children: Translating Knowledge into Action*. Adm Policy Ment Health. 2013 January ; 40(1): 6–22.

¹⁶¹ Buckley, S et al. (2012). Mental health services: the way forward. The perspectives of young people and parents. St Patrick's University Hospital, Dublin.

¹⁶² Buckley, S et al *(2012)*. Ibid.

seen within twelve weeks of receipt."¹⁶³ However data on the CAMHS waiting list¹⁶⁴ from the HSE is that for the 12 month period October 2012 to September 2013 18% of new cases waited more than 12 weeks, with an additional 11% not attending at all. This is unsurprising given that staff capacity of CAMHS in Ireland is only at 44.6% of the staffing level as recommended in A Vision for Change.

The waiting list and service need is escalating, as can be seen by the 2013 service statistics. "A total of 2,541 children and adolescents were waiting to be seen at the end of September 2013. This represented an increase of 485 (24%) from the total number waiting at the end of September 2012 (2,056)."¹⁶⁵

Finally, with regard to geographic equity of access to CAMHS, the Irish College of General Practitioners (ICGP) notes, in its guidelines to GPs on the diagnosis and referral of child and adolescent mental health issues, that *"The availability of services can vary throughout the country.*¹⁶⁶. In another report the ICGP notes the *"wide variation in access to ancillary services both within and outside PCTs which can be frustrating for GPs and hinders quality of patient care"*¹⁶⁷. They advise that to remedy this variance the development of *"secondary care services ….should be a top priority for development in health service that seeks to be primary care led and mindful of resources"*

¹⁶³ CAMHS Specialist Child and Adolescent Mental Health Service Advisory Group (2013). *Irish Child & Adolescent Mental Health Service (iCAMHS) National Quality Guidelines Document*. Unpublished draft pending HSE approval and progression since October 2013.

¹⁶⁴ CAMHS Specialist Child and Adolescent Mental Health Service Advisory Group (2013). Ibid.

¹⁶⁵ Health Services Executive (2014). *Fifth Annual Child and Adolescent Mental Health Service Report*. HSE, Dublin

¹⁶⁶ O'Keefe et al (2013). *Child and Adolescent Mental Health Diagnosis and Management*. CAMHS Quality in Practise Committee, Irish College of General Practitioners (ICGP), Dublin.

¹⁶⁷ Irish College of General Practitioners (2011). *Primary Care Teams: A GP Perspective*. ICGP, Dublin.

Key Message 2.3 Appointments should be provided in accessible, confidential environments

The UK Quality Network for Community CAMHS Service Standards advises that service appointments should be flexible and responsive to the needs of young people and their parents/carers. The example guidance given is to offer young people and their parents/carers the choice of a suitable appointment time, appointments out of school or college hours and home-based or school-based treatments where appropriate. The UK Standards also advise that meetings should be young-person friendly (including the language used, timing of meetings, location of venues, who is in attendance, and possible need for interpreters)¹⁶⁸.

Parents and adolescents in Ireland indicate that the physical environment of CAMHS is important to them. However some adolescent service users have commented on how being given appointments that clashed with their school timetable subsequently provoked intrusive questioning from teachers and peers and therefore worsened their struggle with the stigma of having a mental health difficulty or disorder.¹⁶⁹

The importance of a confidential environment with consistent staff

The Quality Framework for Mental Health Services in Ireland (2007) Irish standards relating to mental health facilities recommends that 'Service users receive care and treatment in settings that are safe, and that respect the person's right to dignity and privacy' (4.1) Coyne et al (2014) found that, with regard to privacy, Irish adolescents and parents wanted to speak with the CAMHS professional separately and confidentially at times rather than be in a situation where they might need to say something that could potentially upset their parent or child.¹⁷⁰ The authors recommend that given that most adolescents would like to be interviewed alone, each clinic should try and offer this. A caveat that Coyne at al offer is that "appointments should be individualised to what best suits the families' needs as, for example, younger children may not like to be seen alone."¹⁷¹

The adolescents and parents interviewed by Coyne et al also raised the issue of confidentiality with regard to the design of the CAMHS waiting area and the scheduling of appointments. Some parents and children reported that they did not want to have to meet neighbours or other community members for fear of stigma. This theme of young people's concerns around confidentiality and stigma affecting young people accessing appropriate help is also observed by Buckley et al (2012) in their report on the perspectives of young people and parents attending CAMH services¹⁷².

The Quality Framework for Mental Health Services in Ireland (Mental Health Commission, 2007) notes that 'A quality physical environment that promotes good health and upholds the security and safety of the service users'.¹⁷³ The rationale given is that stakeholders see the quality of the physical surroundings as having a strong impact on those using mental health services and on their recovery processes.

¹⁶⁸ Barrett, R. et al (Eds) (2011). *Quality Network for Community CAMHS Service Standards*. 3rd Edition. Royal Collegeof Psychiatrists, UK.

¹⁶⁹ Coyne, I. et al (2014). Adolescents and parents' experiences of attending child and adolescent mental health services (CAMHS) in Ireland: The report. TCD, Dublin.

¹⁷⁰ Coyne et al (2014), Ibid.

¹⁷¹ Coyne et al (2014),Ibid.

¹⁷² Buckley, S et al (2012). Mental health services: the way forward. The perspectives of young people and parents. St Patrick's University Hospital, Dublin

¹⁷³ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHR, Dublin.

Recommendations made by service users of community based CAMHS who participated in Coyne et al's research (2014) noted that the provision of waiting room games or something to pass the time would alleviate stress and anxiety.¹⁷⁴

Consistent staff

Young Irish service users value consistency in personnel and note that a therapeutic relationship takes time to form. According to Coyne et al (2014), the frequent staff changes make it difficult for young people to developing trusting relationships with staff and therefore CAMHS should aim to have a permanent staff member as a key worker to ensure some continuity, should inform and prepare service users prior to any staff changeover and should minimize staff changes.

These messages were echoed in a synopsis of the themes identified by young people with respect to mental health services published by the National Bureau of Scotland.¹⁷⁵ Key themes included that

- ✓ Relationships need to be given time to develop between staff and young people
- ✓ Staff need to be skilled in working with young people
- ✓ Mental health professionals need to value young people's need to consent, their right to confidentiality and their need for privacy

¹⁷⁴ Coyne, I. et al (2014). Ibid.

¹⁷⁵ The National Bureau of Scotland (2004). *Mental Health Services: What Young People Want*.

Key Message 2.4 Clear, accessible routes to 'out of hours' and 'crisis' CAMHS are necessary

Lack of access to out of hours CAMHS in Ireland

The Quality Framework for Mental Health Services in Ireland states that the 'mental health service should be available on a 24-hour basis, seven days a week'¹⁷⁶. The Irish (unpublished) iCAMHS Quality Service Guidelines also recommend that the "service user has information on how to access to an emergency mental health service on a 24 hour basis seven days a week."¹⁷⁷

However, the Irish College of General Practitioners notes in their guidelines to GPs in Ireland that provision of 'out of hours' CAMHS is still not available nationwide. Therefore, they advise that in the case of an emergency outside of usual working hours (9am -5pm, Monday to Friday), referral of children and young people to the local Accident and Emergency Department may be warranted.¹⁷⁸ The ICGP guidelines on referral to CAMHS note:

"If queries arise regarding the potential need to certify a person under the age of 18 years old, the local Child and Adolescent Mental Health Service should be contacted for advice....[However] the provision of 'out of hours' CAMHS is still not available nationwide. Therefore, in the case of an emergency outside of usual working hours (9am -5pm, Monday to Friday)....and where there are concerns about the young person being an acute risk, the GP is advised to refer the young person to their local Accident and Emergency Department."¹⁷⁹

Additionally the age at which children or adolescents should be referred to which service is unclear, according to the ICGP: *"To date, there are no nationally agreed protocols with regard to the definition of the appropriate age at which to refer a child or an adolescent to a paediatric versus an adult Accident & Emergency service..."*¹⁸⁰

This lack of standardised services, lack of clarity about what age to refer adolescents to paediatric versus adult services, along with the lack of 'out of hours' crisis CAMHS services, affects both the equity and accessibility of mental health services for children and young people in Ireland.

Good Practice Guidelines for Crisis CAMHS Provision from the UK

The Quality Network for Community CAMHS Standards (2011, UK)¹⁸¹ recommends as good practice that CAMHS have documented, up-to-date procedures and response times agreed with other agencies for: (1) routine referrals, (2) specialist referrals, and (3) emergency referrals. Detailed guidelines for a crisis or intensive CAMHS have recently been developed by QINMAC, The Quality Network for Community

¹⁷⁶ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHC, Dublin.

¹⁷⁷ CAMHS Specialist Child and Adolescent Mental Health Service Advisory Group (2013). *Irish Child & Adolescent Mental Health Service (iCAMHS) National Quality Guidelines Document.* Unpublished draft pending HSE approval and progression since October 2013.

¹⁷⁸ Barrett, R. et al (Eds) (2011). *Quality Network for Community CAMHS Service Standards*. 3rd Edition. Royal College of Psychiatrists, UK.

¹⁷⁹ O'Keefe et al (2013). Child and Adolescent Mental Health Diagnosis and Management, CAMHS Quality in Practise Committee (ICGP). Dublin

¹⁸⁰ O'Keefe et al (2013). Ibid.

¹⁸¹ Barrett, R. et al (Eds) (2011). Ibid.

CAMHS in the UK.¹⁸² The following recommendations are directly cited from the guidelines and indicate a service that is planned according to need, responsive, flexible and appropriately staffed.

- Full availability: Young people in need can access a crisis response from CAMHS at any time (24 hours, 7 days a week, including out of hours); the service has a procedure, which may include a risk assessment process
- **Rapid response:** Within an agreed time-frame, the CAMH crisis service responds promptly to referrers with a decision about the plans for a crisis response or to offer advice, including when a referral does not meet the agreed criteria for the service. CAMHS respond to all requests for a crisis intervention or advice within locally agreed time-frames. Some services report response time-frames of 30 to 90 minutes for phone requests, and same day response for an immediate intervention
- **Referrals**: CAMHS work with all potential referrers and other local CAMHS, to ensure appropriate requests for a crisis response are received. Clear referral criteria to all relevant referring services (including frontline services) are in place for eliciting a crisis response. There is a well-publicised phone-in system for referrers (including frontline services) to access CAMHS for advice or to discuss a young person's need and suitability for an immediate CAMHS assessment and crisis intervention
- **Staffing:** There is an on-call rota system in place to ensure a crisis response from CAMHS is available at all times. This includes a list of named professionals who are first and second 'on-call' duty to ensure the service is not affected by absences or sickness issues. Guidance: The core hours for a crisis response within CAMHS are based on an audit of periods of greatest activity and demand for that type of response
- Available psychiatrist or professional: The on-call system includes access to a CAMHS psychiatrist or appropriately trained professional who is available for staff to contact if there is a need to:
- 1. Provide advice about an emergency assessment or Mental Health Act assessment
- 2. Assess a child or young person who has been detained by the police under section 136 [of the UK's mental health legislation]
- 3. Consider if inpatient treatment is appropriate
- **Care Case Management:** Referral procedures specify what action is to be taken for children and young people in need of a crisis response, taking account of whether: They are known to CAMHS and have a mental health care plan (e.g. young person's care co-ordinator is quickly identified and contacted); or (b) they are *not known* to CAMHS, but present in a crisis and require an urgent mental health assessment

¹⁸² *Quality Network for Community CAMHS Service Standards*, 3rd Ed. 2011. QINMAC. The Royal College of Psychiatry, London.

Key Message 2.5Involve children, young people and their families at all stages of
service & care plan development, delivery and evaluation

The importance of children and young people having a chance to feed back their views, having choice and participating actively in their health care is accepted internationally as not only good practice¹⁸³ but imperative for service accountability. According to the WHO 2013-2020 global plan "Persons with mental disorders and psychosocial disabilities should be empowered and involved in mental health advocacy, policy, planning, legislation, service provision, monitoring, research and evaluation."¹⁸⁴

In Ireland, service user participation was one of the key recommendations of A Vision for Change in 2006.¹⁸⁵ However it appears that it was not until 2012 that data was first gathered from young service users as to how they experience current mental health services and their recommendations as to how services can best be delivered to be accessible and responsive to adolescents and young people.

Findings from Damodaran and Sherlock's (2012) research found that Irish adolescents' right to assenand participation in decisions made in their engagement with CAMHS were not often upheld¹⁸⁶.

Buckley et al (2012) conducted interviews and focus groups with 24 young service users and 3 parents with the aim of reporting the "experiences and views of a group of young people as to how services need to adapt to meet the needs of the population they serve." ¹⁸⁷ As a result of their consultation, the authors make a key recommendation that a "national advocacy service" for young people with mental health problems in Ireland should be "addressed as a matter of urgency as it would help young people express their views about their treatment and help them advocate for better quality services." ¹⁸⁸

Larger international studies have found that it is important that both young service users and their parents or caregivers are engaged with in a participatory process as there is significant difference between young people and their caregivers regarding the criteria by which CAMH services are evaluated and the aspects of the CAMH services that are valued most highly. For example, in Aarons et al (2010), 251 young people and 275 caregivers were interviewed in the USA and noted the following findings:

"Youths' positive comments primarily focused on treatment outcomes while caregivers focused more on characteristics of the program and provider. Youths' negative comments reflected dissatisfaction with the program, provider, and types of services offered while caregivers expressed dissatisfaction mainly with program characteristics. Results support the importance of assessing both youth and caregivers in attempts to understand the factors used by consumers to evaluate youth mental health services."¹⁸⁹

 ¹⁸³ Coad, J.E & Houston, R (2007). Involving Children and Young People in the Decision-Making Processes of Health Care Services.
 A Scoping of the Literature. London: Action for Sick Children.
 ¹⁸⁴ World Health Correspondence (2012). Marcula Marcula Children.

¹⁸⁴ World Health Organisation (2013). *Mental Health Action Plan 2013-2020*. WHO, Geneva.

¹⁸⁵ Department of Health (2006). A *Vision for Change: Report of the Expert Group on Mental Health Policy.* Government Publications Office, Dublin.

¹⁸⁶ Damodaran, J & Sherlock, C (2013). *Child rights and Child and Adolescent Mental Health Services (CAMHS) in Ireland*. Irish Journal of Medical Science. Volume 182, Issue 4, pp 723-727

¹⁸⁷ Buckley, S et al (2012).Mental health services: the way forward. The perspectives of young people and parents. St Patrick's University Hospital, Dublin.

¹⁸⁸ Ibid.

¹⁸⁹ Aarons GA et al (2010). *The eye of the beholder: youths and parents differ on what matters in mental health services. Adm Policy Ment Health.* Nov: 2010 Nov;37(6):459-67.

In Ireland, Coyne et al (2014) conducted interviews with 32 parents and 16 adolescent service users on their experiences of attending CAMHS. The clear message from their research on adolescents and parents is that *"there needs to be a major cultural shift in CAMHS to facilitating greater involvement of children, adolescents and parents in planning, design and evaluation of services"*¹⁹⁰. They report the following findings, which are reflective of international research findings:

- Young service users in Ireland want their views and their parents' views to be included in planning, developing and delivering youth mental health services as they are the key stakeholders
- Both parents and adolescents want to be included and their opinions sought in all discussions about their care and treatment plans
- Participants advised that care plans need to be communicated and discussed with parents, young service users and with the greater team so that there is agreement on and consistency of care
- Young service users in Ireland want to be communicated with effectively, in ways that are age appropriate and lead to the development of trusting, positive, care relationships
- Parents and adolescents want to have the opportunity to communicate their concerns and to have a structure in place that allows both complaints and positive feedback to be communicated routinely to service providers
- Young service users in Ireland advise that services should seek continuous feedback and act on the knowledge of service user's experiences to improve the standard of care for young people

These messages are also reflected in a number of international standards and reports on good practice, including the UK's Children's National Service framework (NSF) which identifies a range of *'markers of good practice'*¹⁹¹ such as practitioners having the requisite skills to communicate openly and directly with children and young people, and the involvement of users in decision-making. There is a wealth of evidence informed literature^{192, 193} and guides¹⁹⁴ on the how services can best facilitate the meaningful participation of service users, including children, young people and their caregivers.

Although the literature identifies a lack of CAMH services actually adapting to be more responsive to their service users' views and needs¹⁹⁵, Buckley et al (2012) cite some examples of good practice in UK of CAMHS service models who "*successfully worked in partnership with young people to inform service planning*"¹⁹⁶ e.g. the London Borough of Chelsea and Kensington. (Teggart & Linden, 2006). Buckley et al (2012) note that it is important that feedback from their study of the views of young CAMH service users is both reported and acted on. They recommend that "*including service users' views and working collaboratively with them is the way forward*."¹⁹⁷

¹⁹⁰ Coyne, I. et al (2014). Adolescents and parents' experiences of attending child and adolescent mental health services (CAMHS) in Ireland: The report. TCD, Dublin.

¹⁹¹ Day, C (2008). *Children's and Young People's Involvement and Participation in Mental Health Care*. Child and Adolescent Mental Health Volume 13, No. 1, pp. 2.

¹⁹² Coad, J.E. & Houston, R (2007). *Involving Children and Young People in the Decision-Making Processes of Health Care Services. A Scoping of the Literature*. London: Action for Sick Children.

¹⁹³Day, D (2008). *Children's and Young People's Involvement and Participation in Mental Health Care.* Child and Adolescent Mental Health Volume 13, No. 1, pp. 9–15.

¹⁹⁴ Young People's Health Special Interest Group (2010). *Not Just a Phase – A guide to the participation of children and young people in health services*. The Royal College of Paediatrics and Child Health.

¹⁹⁵ Worrall-Davies, A. & Marino-Francis, F (2008). *Eliciting Children's and Young People's Views of Child and Adolescent Mental Health Services: A Systematic Review of Best Practice.* Academic Unit of Psychiatry and Behavioural Sciences, Institute of Health Sciences Child and Adolescent Mental Health Volume 13, No. 1, pp. 2–8

¹⁹⁶ Buckley, S et al (2012). *Mental health services: the way forward. The perspectives of young people and parents.* St Patrick's University Hospital, Dublin.

¹⁹⁷ Ibid.

Key Message 2.6 CAMHS information, referral criteria and access pathways must consider how to reach vulnerable and minority groups of children, young people and families

The international literature recommends that vulnerable and minority groups must be considered with regard to making service information and referral pathways as accessible as possible to all children and young people who are in need of CAMHS. The World Health Organisation uses the term "vulnerable groups" to refer to *'individuals or groups of individuals who are made vulnerable by the situations and environments that they are exposed to (as opposed to any inherent weakness or lack of capacity)*^{'198}.

Vulnerability risk factors for poor mental health

The research literature consistently notes a number of key risk factors which strongly hinder successful development and therefore may contribute, to varying degrees, to children's vulnerability. These can be most usefully employed as indicators by policy makers and service providers to identify groups of children who are likely to be vulnerable and in need of effective prevention and early intervention services.

Quality Service Guidelines on inclusion of vulnerable groups

The Quality Framework for Mental Health Services in Ireland (2007) notes that mental health services should ensure that:

"Information is available in ways that are accessible to people from minority groups including refugees, asylum seekers, homeless persons, travellers, and persons who are deaf¹⁹⁹ (5.1.3), and that the mental health service ensures 'equality in accessing a service regardless of the service user's gender, marital status, family status, sexual orientation, religion, age, disability, ethnicity, membership of the traveller community or social class."²⁰⁰ (Criteria 5.1.1.)

The UK's CAMHS Standard under the National Service Framework for Children, Young People and Maternity Services (2004) states that:

"Both the commissioning and delivery of services should be informed by a multiagency assessment of need that is updated regularly. This should incorporate ... an assessment of the needs of particular groups of children and young people in the locality who are vulnerable or at risk."²⁰¹

The UK Quality Network for Community CAMHS Service Standards (2011) advise the CAMH service to identify where difficulties exist for particular groups to access the service and to implement and monitor strategies to address these difficulties. The guidance is that "depending on the locality, this may include strategies to address the needs of black and minority ethnic and newly arrived groups; young people on the autistic spectrum and with multiple health conditions; school non- attendees; and young people in transition such as asylum seekers, Travellers, and those without secure accommodation." ²⁰²

¹⁹⁸ World Health Organisation (2013). *Mental Health Action Plan 2013-2020*. WHO, Geneva.

¹⁹⁹ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHC, Dublin.

²⁰⁰ Ibid.

²⁰¹ Department of Health (UK) CAMHS Standard, *National Service Framework for Children, Young People and Maternity Services*. 2004.

²⁰² Barrett et al (eds) (2011). Quality *Network for Community CAMHS Service Standards*, 3rd Ed. 2011. QINMAC. The Royal College of Psychiatry, London.

Further advice is that "In service transformation, providers, commissioners and policy makers need to focus on those who are traditionally most likely to be left out. Often this will mean making specific adjustments to ensure their particular needs are met."²⁰³

For example, with regard to 'do not attends' or missed appointments (DNAs), the Quality Network for Community CAMHS Service Standards (2011) advise failure to attend a CAMHS appointment can be an indicator that a service is difficult for families to access or considered inappropriate, and requires reviewing. Data on referrals and missed appointments/early disengagement is compared with local population statistics (for example, national census data) to help identify where access difficulties may exist.²⁰⁴ Staff follow up on missed appointments with a telephone call. This ensures good practice of proactive, assertive engagement, particularly with young people at higher risk.

In Ireland CAMHS service data from the HSE is that for the 12 month period October 2012 to September 2013, 11% of 'new cases' of children and young people did not attend their scheduled first appointment.²⁰⁵ Data on the percentage of missed appointments by young people and/or parents and data on early disengagement did not appear to be provided in the report.

Learning disability and mental health guidelines

The Quality Network for Community CAMHS Service Standards (2011)²⁰⁶ advise that CAMHS and partner agencies should share a list of common terms and definitions regarding learning disability and mental health to ensure that appropriate assessment and intervention takes place.

The CAMHS Evidence Based Unit in the UK has published excellent guidelines specifically for mental health care pathways for children and young people with learning disabilities.²⁰⁷ Regarding access, these guidelines advise:

- Good practice involves agreeing clear referral criteria and processes across provider services to ensure new cases get to the most appropriate service to meet their needs
- Agreements are made within the overlapping agency network about how to deal with children and young people who do not fit current criteria or are at risk of being bounced between services (e.g. CAMHS/LD services/local authority children's services/special schools/challenging behaviour teams)

First contact is made, ideally with both caregivers and referrer, to clarify referral expectations and what is possible (i.e. within team competencies). Ideally contact takes place at home or ina setting relevant to the child (e.g. school/short break care setting)

Key Message 2.7 Embed evidence-informed practice and service evaluation in CAMHS to ensure high quality service provision and accountability for outcomes.

Evidence-based practice is one of the six cross cutting principles identified by the World Health

²⁰³ Barrett et al (eds) (2011). Ibid.

²⁰⁴ Barrett et al (eds) (2011). Ibid.

²⁰⁵ Health Services Executive (2014). Fifth Annual Child and Adolescent Mental Health Service Report. HSE, Dublin.

²⁰⁶ Barrett et al (eds) (2011).Ibid.

²⁰⁷ CAMHS Evidence Based Practice Unit (2007). *Mental Health Care Pathway for Children and Young People with Learning Disabilities*. University College London & the Anna Freud Center, London.

Organisation which recommends "*Mental health strategies and interventions for treatment, prevention and promotion need to be based on scientific evidence and/or best practice, taking cultural considerations into account.*"²⁰⁸ The Mental Health Commission's Quality Framework states: "*The mental health service is delivered in accordance with evidence-based codes of practice, policies and protocols.*"²⁰⁹ The consultation process that fed into the development of the Quality Framework informed the development of this standard through the rationale that all mental health "*services should be striving towards evidence-based codes of practice.*"²¹⁰

Both the National Institute for Health and Clinical Excellence (NICE), and the CAMHS Evidence Based Practice Unit (EPBU) in University College London disseminate evidence based guidelines for professionals, clinicians and services working with children with mental health difficulties and with clinical mental health conditions.

However Barwick et al (2005)²¹¹ note that the evidence is that distilling research knowledge into practice guidelines and making these available is not actually sufficient for creating practice change. The relatively recent and interdisciplinary field of 'implementation science' focuses on how to implement evidence-based practice into a variety of contexts catering to multiple client groups. Barwick et al (2005) note that a key research finding from this field is that it is not sufficient to transfer evidence-based practices to the field in the absence of understanding what is needed to prepare organisations and practitioners to receive and implement this new knowledge. The authors recommend "Assessing readiness for change is integral to the success of knowledge implementation and adoption of new knowledge or practices."²¹²

Some key recommendations from Barwick et al's seminal literature review on how to successfully embed evidence based practice in child and adolescent mental health services are as follows:

- Foster CAMHS organisations that are conducive to change. Barwick et al note "Change is complex and requires planning and strategizing Change requires 'buy-in' and engagement from a critical mass of people; the challenge is to create a 'tipping point'—the dramatic moment when something unique becomes common practice"
- Recognise and address the inevitable resistance to change from the system, the leaders, and the practitioners. Barwick et al note that "A better understanding of practitioners' attitudes toward evidence-based practice is needed to address skepticism, distrust, and resistance."
- **Support practitioners to access the evidence base.** Barwick et al note that practitioners need "better access to the research base such as library resources as well as venues at which they can share their tacit knowledge with others, including research scientists and decision-makers."
- **Support practitioners to engage in reflective practice.** Barwick et al observe that "The move toward the greater use of evidence-based practice in children's mental health system will require practitioners to develop the capacity for life-long learning and reflective practice."

²⁰⁸ World Health Organisation (2013). *Mental Health Action Plan 2013-2020*. WHO, Geneva

²⁰⁹ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHC, Dublin.

²¹⁰ Mental Health Commission (2005). *Quality in Mental Health: Your Views: Report on Stakeholder Consultation on Quality Mental Health Services.* MHC, Dublin.

²¹¹ Barwick, M.A et al (2005). *Knowledge Transfer and Evidence-Based Practice in Children's Mental Health*. Children's Mental Health Ontario, Toronto.

²¹² Barwick et al (2005). Ibid.

Evidence based practice and research should not exclude other interventions and methodologies

Friedman (2011) warns that evidence based practices should not be an effort to establish 'one-size fits all' type of interventions that are expected to be applied to all populations under varying conditions. He notes that particular interventions are not 'the final answer' to particular needs as knowledge is not static and interventions must be studied and understood in a context taking into consideration such factors as characteristics of the population to be served, the community, and the system. Friedman recommends that evidence based practice be considered as a *"useful complement and enhancement to systems of care and individualized care that can provide important information and choice to children and families, and to entire treatment planning teams"*.

Friedman (2011) also cautions against the growing trend for research and policy to priortise 'evidence based research' as one approach to research to the exclusion of others. He notes instead that evidence based practice should be an effort to encourage a culture within a system of care to focus on a variety of data-based approaches.²¹³ A similar note of balance is struck by Sir Michael Rawlins, chair of the National Institute for health and Clinical Excellence (NICE) who recommends against hierarchies of evidence where service user experiences are often placed on the lowest rung of 'valid' data. Rawlins notes:

"Hierarchies of evidence should be replaced by embracing a diversity of approaches. This is not a plea to abandon RCTs and replace them with observational studies. Rather it is a plea to investigators to continue to develop their methodologies; to decision-makers to avoid adopting entrenched positions about the nature of the evidence; and for both to accept that interpretation of evidence requires judgement."²¹⁴

²¹³ Friedman, R (2011). *Evidence-Based Practices, Systems of Care, and Individualized Care: (2011) What They Are Not and What They Should Be.* The Research and Training Center for Children's Mental Health, University of South Florida.

²¹⁴ Rawlins, M. (2008). *De Testimino: On the evidence for decisions about the use of therapeutic interventions: The Harveian Oration.* Delivered before the Fellows of The Royal College of Physicians of London, Thursday 16 October 2008. Quoted in *Kurtz et al (2009). The Evidence Base to Guide Development of Tier 4. 2009. NHS, UK.*

Incorporate accountability for CAMHS outcome monitoring at policy, Key Message 2.8 funding and organisational level

Most children receiving mental health treatment in the USA do not clinically improve

An extraordinary finding from literature in the USA²¹⁵ is that although millions of children receive treatment for mental health disorders, "studies indicate that the majority of children receiving *community-based usual care (UC) do not show clinical improvement.*^{"216} Serious concerns have been flagged for over a decade now in the USA about the ineffectiveness of usual mental health care (UC) for children and these concerns are underpinned by rigorous research.

For example, Garland et al²¹⁷ cite the large meta-analytic review conducted by Wisz et al (2004) which reported few differences between UC treatment and control groups, and reported effect sizes near zero. Manteuffel et al (2008) found that, following community based outpatient mental health treatment, an average of 50 % of young people exhibited no reliable change, 36 % of young people improved, and the remainder (14 %) exhibited poorer outcomes.²¹⁸ Bellamy et al (2010) concluded that community based outpatient mental health services did not result in any improvement on a national sample of children who had experienced long-term foster care in children's behavioral health.²¹⁹ According to Garland et al:

"the bottom line is that there is no convincing evidence of a strong aggregate clinical impact of usual community-based care for children and families. Given the numbers of children in need of care, as well as the short and long term consequences of mental health problems and the resources devoted to this care, this represents a public health crisis."

The clinical outcomes for children attending CAMHS in Ireland appear to be unknown

It is not possible to comment on how similar or different the situation regarding the efficacy of CAMHS treatment may be in Ireland as there appears to be a dearth of published data or research on clinical outcomes for children and young people attending CAMHS. Although the standards developed for Irish mental health services state that the 'care and treatment provided by the mental health service is outcomes-focused',²²⁰ the data recorded in the CAMHS Annual Report 2012-2013 does not appear to include service user clinical outcomes which may indicate that the effectiveness of CAMHS treatment or intervention is not being routinely measured in Ireland.

Clearly measuring treatment and intervention efficacy should be part of CAMHS quality service provision. According to Coyne et al (2014), the new iCAMHS National Quality Guidelines will be "very useful" as they will help CAMHS to audit and evaluate services provided and "aid the development of action plans to address potential deficits."²²¹ However these quality guidelines have not yet been published by the HSE

²¹⁵ Warren JS et al (2010). Youth psychotherapy change trajectories and outcomes in usual care: Community mental health versus managed care settings. Journal of Consulting and Clinical Psychology. 2010; 78:144–155.

²¹⁶ Garland et al (2013). Improving Community-Based Mental Health Care for Children: Translating Knowledge into Action. Adm Policy Ment Health. 2013 January ; 40(1): 6–22.

²¹⁸ Manteuffel B (2008). *Characteristics, service experiences, and outcomes of transition-aged youth in systems ofcare:* Programmatic and policy implications. The Journal of Behavioral Health Services Research. 35:469–487.

²¹⁹ Bellamy JL et al (2010). A national study of the impact of outpatient mental health services for children in long-term foster care. Clinical Child Psychology and Psychiatry. 15:467–479.

²²⁰ Mental Health Commission (2007). *Quality Framework for Mental Health Services in Ireland*. MHC, Dublin.

²²¹ Covne, I. et al (2014). Adolescents and parents' experiences of attending child and adolescent mental health services (CAMHS) in Ireland: The report. TCD, Dublin.

and it appears that these guidelines have been pending HSE approval and progression for over a year now, since October 2013.²²²

There also appears to be scarce qualitative data about service user outcomes from the service user perspective. Coyne et al (2014) note that 12 out of the 15 adolescents interviewed about their experience of attending community CAMHS in Ireland *"stated that they believe their treatment has been effective to some extent"*. However what constitutes 'effective' is not defined in any way, and no objective treatment outcome data is mentioned by the participants or by the researchers in the study to support this subjective finding. Moreover, even though it is clearly good practice to seek client feedback, there is some international evidence indicating that client satisfaction data does not actually appear to be a strong indicator of clinical effectiveness for mental health care.^{223 224}

Outcome monitoring systems positively impact on treatment efficacy

What the literature does clearly document is that "*outcome monitoring systems have demonstrated a positive impact on treatment effectiveness and efficiency for adult and child/family services.*"²²⁵ Garland et al (2013) note that in the past decade, there has been:

"considerable progress in the development of potentially effective and efficient outcome measurement systems that have been utilized at the state or county level by public service systems and provider organisations."

For example Bickman et al (2011) found that clinical outcomes for children in usual community-based care were better when providers had access to weekly feedback on a standardised assessment of children's symptoms and functioning.²²⁶ Warren et al's research (2012) found that outcome monitoring "warning" systems can accurately identify young people who are at-risk for treatment failure²²⁷. Hawaii's child and adolescent mental health system is cited by Garland et al (2013) as a good practice CAMH system which since 2008 has used a feedback system whereby agencies receive semi-annual reports documenting client outcomes on the Child and Adolescent Functional Assessment Scale (CAFAS) and Monthly Treatment Progress Summary (MTPS).

Garland et al (2012) note that there is therefore great "*potential utility for measurement systems that can be used to assess treatment progress (or lack thereof).*"²²⁸ However the selective review observes that there is an international need for improvement and training in the utility and value of outcome accountability in child and adolescent mental health services. ²²⁹

Developing a quality improvement process for CAMHS

The World Health Organisation observes that "Quality is a measure of whether services increase the probability of desired mental health outcomes and whether they are consistent with current evidence-

²²² Researcher's personal communication with Dublin North City & County CAMHS, October 2014.

²²³ Garland AF et al. (2003). *Clinicians and outcomes measurement: What's the use?* Journal of Behavioral Health Services and Research. 30(4):393–405.

²²⁴ Lambert W et al (1998). *Clinical outcome, consumer satisfaction, and ad hoc ratings of improvement in children's mental health.* Journal of Consulting and Clinical Psychology. 66:270–279

²²⁵ Garland et al. (2013). *Improving Community-Based Mental Health Care for Children: Translating Knowledge into Action.* Adm Policy Ment Health. 2013 January ; 40(1): 6–22.

²²⁶ Bickman L, et al. (2011). *Effects of routine feedback to clinicians on youth mental health outcomes: A randomized cluster design*. Psychiatric Services. 62(12): 1423–1429.

²²⁷ Warren JS et al (2012). *Predicting patient deterioration in youth mental health services: Community mental health vs. managed care settings.*). Journal of Clinical Psychology. 68:24–40.

²²⁸ Garland et al. (2013). *Improving Community-Based Mental Health Care for Children: Translating Knowledge into Action.* Adm Policy Ment Health. 2013 January ; 40(1): 6–22.

*based practices.*²³⁰ The WHO advises that child and adolescent mental health services should engage in a quality improvement process as an ongoing, iterative process, and offer the following eight step process for countries to develop a quality improvement system for CAMHS.

- (1) Align policy for CAMHS quality improvement through consultation, partnerships, legislation, funding and planning
- (2) Design CAMHS standards against which services can be measured
- (3) Establish an accreditation process for CAMHS
- (4) Assess the quality of care for different types of CAMH services
- (5) Monitor the quality of care in CAMHS through the quality processes
- (6) Integrate the quality standards into the management of the CAMH services
- (7) Improve CAMH services as indicated
- (8) Modify and review mechanisms for quality CAMHS

Additional useful reference standards to consider in the development of a quality improvement process may be the Quality Network for Community CAMHS Service Standards in the UK. These recommend that outcomes measures are routinely taken, that resources are available to support the routine evaluation of outcome and that clinical outcomes are monitored using validated outcome tools where appropriate and relevant. The standards note that outcomes should be evaluated from the perspective of staff, young people and parents/carers at a minimum.²³¹

Finally the World Health Organisation advise that countries should invest in outcome research of CAMHS treatment, prevention and promotion. The WHO advises that outcomes based research on the following has the potential to greatly contribute to CAMH service improvement:

"Efficacy and effectiveness of pharmacological and psychosocial interventions; Factors affecting treatment adherence, including family factors; Implementation or dissemination research which examines the uptake of effective interventions; Efficacy and effectiveness of various models of school-based mental health services."²³²

 ²³⁰ World Health Organisation (2005). Mental Health Policy and Service Guidance Package: CAMH policies and plans. WHO, Geneva.
 ²³¹ Barrett et al (eds) (2011). Quality Network for Community CAMHS Service Standards, 3rd Ed. QINMAC. The Royal College of Psychiatry, London.

²³² World Health Organisation (2005). Mental Health Policy and Service Guidance Package: CAMH policies and plans. WHO, Geneva.

Section 3: Children and young people with complex or acute mental health difficulties need accessible, specialist inpatient units, along with local, evidence-informed, developmentally appropriate services

Key Message 3.1 CAMHS Inpatient care in Ireland is under-researched and is in need of a more child and youth-centred, participatory approach

Inpatient child and adolescent mental health services in Ireland

International literature acknowledges that at times, children and young people with severe and/or complex mental health problems may require very intensive or emergency care which may necessitate admission to an inpatient child and adolescent mental health unit.²³³

In Ireland in 2012 there were 438 admissions of children and adolescents up to the age of 18 years to inpatient units. According to the CAMHS Annual Report:

"Inpatient psychiatric treatment is usually indicated for children and adolescents with severe psychiatric disorders such as schizophrenia, depression, and mania. Other presentations include severe complex medical-psychiatric disorders such as anorexia / bulimia. Admission may also be required for clarification of diagnosis and appropriate treatment or for the commencement and monitoring of medication."²³⁴

The CAMHS Annual Report also states that the aim of admission to a child and adolescent inpatient unit is to:

- Provide accurate assessment of those with the most severe disorders
- Implement specific and audited treatment programmes
- Achieve the earliest possible discharge of the young person back to their family and ongoing care of the community team

However there appears to be an extraordinary dearth of literature on both the experiences of, and the outcomes for, young people in Ireland attending CAMHS inpatient services. This lack of data is striking in light of the extensive international²³⁵ and national policy²³⁶ on children's rights to participation and the international literature on the importance of facilitating young people's participation as service users to shape future service development.

Damodaran and Sherlock (2013) note that "*in the absence of asking questions of children and youth some questions, rights can be violated*", note that the disparities in current practice in Child and Adolescent Mental Health Services "*result in questions about human rights*" and recommend that contemporary CAMH service changes to incorporate a more "*child-centered*", "*participatory and collaborative approach*".²³⁷

²³⁶ National Children's Office, (2000), National Children's Strategy (Our Children- their Lives);

The Minister for Children and Youth Affairs, the National Children's Strategy Implementation Group and the Children's Services Committees (2011), *Governance Framework for the Working Together for Children Initiative*; the Department of Children and Youth Affairs (2014), *Better Outcomes, Brighter Futures: the National Policy Framework for Children and Young People 2014-2020*

²³³ World Health Organisation. *Integrating Mental Health into Primary Care: A Global Perspective*. 2008. WHO, Geneva.

²³⁴ Health Services Executive (2014). Fifth Annual Child and Adolescent Mental Health Service Report. HSE, Dublin.

²³⁵ Article 6 of the United Nations Convention of the Rights of the Child (1989) states '*Children's view must be considered and taken into account in all matters*'.

Office of the Minister for Children and Youth Affairs (2007), The Agenda for Children's Services;

²³⁷ Damodaran, J & Sherlock, C (2013). Child rights and Child and Adolescent Mental Health Services (CAMHS) in Ireland. Irish

Just one published study involving young service users of the CAMH inpatient service in Ireland was identified by this literature review for the Children's Mental Health Coalition. This study was conducted by Buckley et al (2012) who met with 24 young service users, some of whom had been in an adolescent ward, others aged under 18 had been admitted to adult wards, some who had been in secure care as well as in locked adult wards.²³⁸ A small group of parents were also interviewed to contribute their perspective on their family's involvement with the mental health services.

The following findings are cited directly where possible from the report by Buckley et al (2012) to preserve the integrity of the author's findings and the young people's lived experience of CAMHS inpatient services in Ireland:

- The stigma and 'distress' of attending a psychiatric ward, as well as concerns over confidentiality were barriers to access services for some young people
- The majority of the participants agreed on the need to lower the age of consent from 18 to either 14, 15, 16, or 17 years old to access mental health support services
- A mediator or advocate role is recommended to ensure that young people can avail of the support they need, to provide support and information to both parents and child and to assist in situations where the service user might be passing through foster care
- The length of the waiting time and the initial experience of participants in the support service environment negatively influence perceived quality of care received
- The "lack of service locally" meant that some parents who could afford to used private, fee paying options, others felt they had to "bully their way into receiving support" and one parent commenting on her feelings of isolation and hopelessness in seeking help for her child stated that "the help is not out there"
- Young service users recalled feeling 'scared', 'traumatised', 'disorientated' and 'anxious' when first admitted to the service
- These feelings were heightened by "not knowing what was taking place" and not being included in decision making processes regarding their own care
- Experiences of isolation in children and adult wards were common across participant groups. This was magnified by a lack of support peer group, a lack of suitable activities for young adults and being among non-peer groups
- Young people place on adult wards and those placed in locked facilities recalled feeling traumatised with fears about their safety
- Young people were concerned about the overemphasis on mediation in CAMH support services, the side effects of medication on them and the lack of information about other alternative approaches available

Recommendations to improve the quality of inpatient CAMH service provision by service users included:

• A more sensitive approach to the needs of young adults at the time of admission, taking into consideration their feelings of isolation and fear and their understanding of mental health problems

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²³⁸ Buckley, S et al (2012). Mental health services: the way forward. The perspectives of young people and parents. St Patrick's University Hospital, Dublin

- Staff specifically trained to deal with young people
- Separate admissions and ward environments for young adults
- An inpatient service for young people aged 16 to 26 years old
- Communicating appropriately with young people
- Informing and consulting young people about their treatment and medication plan, and including alternative approaches to medication
- Giving young people a say in everyday activities during hospital placement
- Access to a key worker as an inpatient to reduce isolation and enhance support

Key Message 3.2Prompt assessment and timely access to CAMHS is crucial for children
and young people with complex and/or acute mental health needs

Prompt assessment and treatment, if necessary, is crucial to improving outcomes for children and adolescents with multiple needs and complex and/or severe mental health disorders. Prompt 'early intervention' also reduces the chances of chronic mental health problems developing.

Good practice guidelines on the provision of inpatient CAMHS(UK)

Good practice guidelines on the provision of inpatient CAMHS have recently been issued by the Quality Network for Inpatient CAMHS (QNIC) and the Quality Improvement Network for The Multi-Agency CAMHS (QINMAC) supported by The Royal College of Psychiatrists in the UK. A key standard is that "Young people who are referred to inpatient CAMHS do not experience delay in assessment or treatment that leads to a deterioration in health".²³⁹ The guidelines recommend that a young person should be managed as close to home as possible or in a local community service. However if this is not possible, then a residential service may be necessary.

The QNIC-QINMAC standards note that in order to facilitate prompt assessment and timely access, inpatient bed provision should be planned and referrals should be monitored to inform service development. The standards recommend that the actual number of inpatient beds provided should be based on a comprehensive needs assessment for inpatient bed provision, taking into consideration the availability of alternative provision such as crisis response and intensive home treatment.

The QNIC-QINMAC standards recommend as a minimum that there should be between 20–40 inpatient CAMHS beds commissioned for young people aged up to 18 years per 1 million total population. With Ireland's young demographic of 33% of the 4.5 million population under 24 years old, this could indicate that the bed provision should be in the upper range of 180 beds. However, current provision in Ireland according to the 2012-2013 CAMHS Annual Report is 60 beds.²⁴⁰

The QINMAC-QNIC guidelines suggest that bed occupancy in inpatient CAMHS should be at 85% to ensure availability of emergency beds. Additionally, service managers in community CAMHS should monitor the outcome of referrals to inpatient CAMHS to identify inadequacies in the availability of appropriate and timely inpatient provision and alternatives to inpatient service provision such as crisis response and intensive home treatment.

²³⁹ Quality Improvement Network for Multi-Agency CAMHS (QINMAC) & Quality Network for Inpatient CAMHS (QNIC). *Improving access to inpatient CAMHS and appropriate alternatives* (2010). The Royal College of Psychiatrists, London.

²⁴⁰ Health Services Executive (2014). Fifth Annual Child and Adolescent Mental Health Service Report. HSE, Dublin.

Key Message 3.3 Children and young people should not be placed inappropriately in adult or paediatric wards.

Lack of access to appropriate CAMH services can lead to lack of treatment, to an escalation of a child or young person's mental health difficulty to the point of crisis and to inappropriate, unsafe placement of children and young people with crisis or chronically severe mental health needs in adult wards.

Evidenced risks to children of co-location on adult wards

The limitation of using paediatric and adult psychiatric wards for the care of under 18s is now well documented²⁴¹ and it is acknowledged that these wards are not considered to be safe for young people and that care may not be effective.²⁴² Evidenced risks to children of co-location include:²⁴³

- The rights of children and young people are not respected
- Physical, psychological or sexual harm from other patients, staff or visitors
- Compromises in quality of care for children/adolescents if care is provided by staff without education and training in the care and treatment of children and young people or if the available equipment is inappropriate in size or design
- Inadequate or inappropriate parent/carer and family support and involvement in care
- Interruptions to normal development if opportunities for play, leisure and education are not provided
- Unnecessary trauma from witnessing distressing sights and sounds
- Compromises in the care of children/adolescents when paediatric staff and resources are diverted to provide care for adult patients
- Compromises in quality of care for adults if adults feeling ill are disturbed by either noisy children or the continued presence of the child's family, which is a key component of family-centred care

Admission of children to adult inpatient units in Ireland 2012-2013

However during 2012-2013 in Ireland, 25% (109) of the 438 admissions of children and adolescents initially admitted to inpatient units were admitted to adult inpatient units. Females accounted for 62% of those admissions to adult wards. Of those admissions to adult units, 36% were discharged within 48 hours of admission, and 65% within one week.²⁴⁴ This data may indicate that adult wards are being used

²⁴¹ Office of the Children's Commissioner (2007). *Pushed into the Shadows - Young People's Experience of Adult Mental Health Facilities*. The Children's Commissioner for England.

²⁴² Royal College of Psychiatrists (2006). *Building & Sustaining Specialist CAMHS*. Council Report CR137, Royal College of Psychiatrists, London. www.rcpsych.ac.uk/publications/collegereports/cr/cr137.aspx

 ²⁴³ Royal Australasian College of Physicians (2008). Standards for the care of children and adolescents in health services. Pediatrics
 & Child Health Division, Royal Australasian College of Physicians, New South Wales. www.racp.edu.au

²⁴⁴ Health Services Executive (2014). Fifth Annual Child and Adolescent Mental Health Service Report. HSE, Dublin.

as emergency accommodation for children and adolescents in Ireland with crisis or emergency mental health needs.

Guidelines for when a young person is placed on an adult mental health ward or paediatric ward

The QINMAC-QNIC guidelines note that where the young person is placed on an adult mental health or paediatric ward there should be an agreed protocol between CAMHS and AMHS/paediatrics that defines the required environment (age-appropriate), safeguarding arrangements, level of ongoing involvement of CAMHS in the care, the frequency of clinical / observation reviews, family visits, access to advocacy and discharge planning.²⁴⁵

The swift transfer of children from adult wards to CAMHS wards is imperative to reduce risks associated with a child/adolescent in a vulnerable state of mental distress being accommodated on an adult ward. The QINMAC-QNIC standards recommend that young people admitted to adult wards in an emergency with an overriding need should be transferred to a CAMHS unit within 48 hours.

However, in Ireland, only 36% of child and adolescent admissions to adult units were discharged within 48 hours of admission; 65% were discharged within one week.²⁴⁶ This lengthy transfer time heightens the risks that children and adolescents are exposed to an adult ward.

The issue of inappropriate placement of children and young people onto adult psychiatric and paediatric general wards due to a lack of inpatient CAMHS service capacity is not an issue unique to Ireland.²⁴⁷

The Quality Improvement Network for Multi-Agency CAMHS (QINMAC) note that if there are not clear procedures for community CAMHS to follow when inpatient beds are not available, those caring for a young person in the community are being left unsupported; whilst clinical staff can spend many hours 'ringing round' to find a suitable bed.²⁴⁸

QINMAC therefore recommend that Managers in CAMHS should

- •develop clear procedures agreed by all key agencies including all adolescent units commissioned to provide services for the local area, adult mental health services and paediatric services
- •make these procedures available to key staff to follow when an inpatient bed is required
- •include the steps to follow if the first choice of inpatient bed is not available
- •include the steps to follow where a bed need to be secured from an inpatient unit not identified within the joint agreement
- •develop procedures for situations when inpatient beds are required but are not immediately available within the relevant service²⁴⁹

²⁴⁵ Quality Improvement Network for Multi-Agency CAMHS (QINMAC) & Quality Network for Inpatient CAMHS (QNIC) (2010). *Improving access to inpatient CAMHS andappropriatealternatives* (2010). The Royal College of Psychiatrists, London ²⁴⁶QINMAC & QNIC (2010). Ibid.

²⁴⁷ Data from the Quality Network for Inpatient CAMHS (QNIC) in the UK indicates that 57% of member units reported that they did not have sufficient beds to meet clinical need.

²⁴⁸ QINMAC & QNIC (2010). Ibid.

²⁴⁹ QINMAC & QNIC (2010). Ibid.

Key Message 3.4 Additional and/or alternative CAMH services to inpatient care are essential

Psychiatric inpatient care is not necessarily the most effective care

The Mental Health Commission's Quality Framework for Mental Health Services in Ireland states that children and young people have a right to access levels of healthcare that are appropriate to their needs. According to Kurtz, *"Inpatient environments have recently come to be regarded as neither necessary nor always the most effective for managing young people with complex mental health needs."*²⁵⁰ Kurtz notes that:

"For acuteriskmanagement—in cases of harm to self and others — it can be questioned as to whether psychiatric inpatients is needed or even best for this. Somethinglike a safe house near to the child's home is what is needed although highly specialist assessment may well be required from the staff team of an inpatient unit."²⁵¹

Kurtz notes the importance of comprehensive pre-admission evaluation of the child's suitability for treatment in a psychiatric inpatient setting and states that is important that this evaluation focuses on the child's strengths and strengths in the family environment.

UK evidence on some of the advantages and disadvantages of inpatient and day care units for children and youth

In a summary of the research evidence on the effectiveness of intensive treatment, inpatient units, day units and intensive outreach CAMHS which is known as 'Tier 4 CAMHS' in the UK, Kurtz cites252 the advantages of inpatient CAMHS from Green and Worall-Davies(2008)²⁵³ discussion as follows:

- Inpatient admission allows detailed assessment in a controlled environment and away from the family. The individualised assessment and intensive educational input possible within the inpatient unit can make a major impact with young people, whose social adaptation within their community has often broken down and who have a history of school failure.
- The individualised assessment and intensive specialist treatment in an inpatient unit can at the very least lead to more effective use of other services post-discharge.
- Removal from social difficulties in the external environment and exposure to the inpatient milieu can produce rapid gains in functioning (socialisation and academic achievement) and self-esteem.
- Nevertheless, young people with significant social impairments may not be able to make effective use of such a socially orientated therapeuticenvironment.

Kurtz also cites the evidenced disadvantages of inpatient care as including:

• Loss of support from the child's local environment

²⁵³ Green J, Worrall-Davies A. (2008) Provision of Intensive Treatment: inpatient Units, Day Units and Intensive Outreach.Pp.
 1126-1142 In: Rutter's Child and Adolescent Psychiatry, 5th edition. Edited by Rutter M. et al. Blackwell Publishing

²⁵⁰ Kurtz, Z (2009).*The Evidence Base to Guide Development of Tier 4*. National CAMHS Support Service, Department of Health, UK.

²⁵¹ Ibid.

²⁵² This section is direct citation from Kurtz, Z (2009). *The Evidence Base to Guide Development of Tier 4*. *National CAMHS Support Service, Department of Health, UK*.

- Presence of adverse effects within the inpatient environment
- Effects of admission on family life

With regard to day units Kurtz states that they

"offer a very wide range of types of intervention, ranging from specific day programmes for young children with developmental problems as an adjunct to specialist school provision to intensive five-daya- week treatment interventions with whole families. Dayunits are often associated with inpatient units. The advantages of dayunits relate to: the flexibility of care that can be provided, management of younger children, work with the family and foster parental care and an emphasis on education"²⁵⁴

Inpatient care appears to be ineffective for some mental health disorders

However it appears from Kurtz's national evaluation of the evidence base for Tier 4 CAMHS services in the UK that there are some mental health disorders for which inpatient care seems ineffective. For example, she cites rigorous research studies as having shown the following:

- For depression, suicidality and psychosis, little beneficial effects of inpatient psychiatric care have been shown
- For obsessive compulsive disorder, poorer outcomes are found among those needing admission compared with those treated as outpatients
- High levels of aggressive, anti-social behaviour and organic symptoms, as in schizophrenia, predict poor outcome

However Kurtz points out that the evidence she reviewed notes that inpatient care may be effective with other mental health disorders. For example

- Emotional disorders have better outcomes
- For conduct disorder, multimodal day treatment for children with disruptive disorders has produced significantly greater improvement in behaviour than in a control group

Results for some mental health disorders are mixed, according to Kurtz.

- For eating disorders, there are widely differing results
- In substance misuse, research shows additional benefits from community treatment

Finally Kurtz notes that there are key variables to consider including:

- Pre-treatment family functioning is a key predictor of outcome
- Longer treatment stays are, in general, associated with improved outcome

Inpatient services need to change along with the development of new forms of community based services Research on inpatient care from regional reviews on CAMHS in the UK make it clear that "in order to optimise effectiveness, inpatient services need to change along with the development of new forms of community based services."²⁵⁵ A national UK Review in 2008 of the efforts to restructure CAMHS found that good progress was made when CAMHS focused on ensuring better access to inpatient services for young people with acute needs along with the delivery of more locality-based services.²⁵⁶

Some of these services which have which have been developed in local areas to provide alternative and complementary services to inpatient care have included:

²⁵⁴ Kurtz, Z. (2009). The Evidence Base to Guide Development of Tier 4 CAMHS. NHS, UK.

²⁵⁵ Kurtz, Z et al. (2008). *Tier 4 Child and Adolescent Mental Health Services (CAMHS) Inpatient Care, Day Services and Alternatives: An Overview of Tier 4 CAMHS Provision in the UK*. Child and Adolescent Mental Health, 13(4): 173-180

²⁵⁶ Department of Health (2008). Children and young people in *mind: the final report of the National CAMHS Review*. NHS, UK

- intensive treatment packages for children, young people and their families, e.g. to prevent family breakdown
- specialist care programmes for younger children with developmental disorders
- assertive outreach teams that provide intensive support for small caseloads on a 24-hour basis
- 'wraparound' services to help families to address their children's needs at home and at school

Regional Reviews²⁵⁷ of CAMHS in the UK have also identified a number of approaches that had been developed in different places to tackle local unmet needs. These approaches cited by Kurtz in her review of Tier 4 services²⁵⁸ include:

- AssertiveOutreach teams to prevent inpatient care
- Early Intervention in Psychosis services to reduce demand for inpatient admission and length of stay
- Crisis Intervention/Home Treatment teams to support young people on discharge from inpatient units, reduce length of stay and prevent readmission. Home Treatment teams may also be successful in engaging with groups who would not typically take up tier 4 services
- Safe houses in which comprehensive assessment may prevent a young person being diagnosed inappropriately as primarily needing psychiatric inpatient care
- Multi-disciplinary Referral Panel to reduce the level of inappropriate inpatient admissions
- An on-call service, if it is linked to an appropriate specialist team, may well prevent inpatient admission
- Peripatetic Specialist Assessment team to enable children to stay at home while ensuring that admission, if needed, is made to the appropriate service
- Community based delivery of new treatment modalities, such as Dialectical Behaviour Therapy (DBT)

 ²⁵⁷ Kurtz Z. (2007) Regional Reviews of Tier 4 Child and Adolescent Mental Health Services: Summary and Comment. NCSS and CSIP, London.
 ²⁵⁸ Kurtz Z. (2007) Ibid.

Key Message 3.5Seven evidence-informed alternative approaches to inpatient care for
children and young people with complex mental health needs

Kurtz (2009) ²⁵⁹, drawing on Green and Worrall (2008), summarises seven alternative approaches to inpatient care for children and young people that have been well evaluated and have demonstrated positive outcomes. Kurtz describes the evidence based interventions as follows: (direct citation)

(1) **Family Preservation** is a home-based intensive service for families who need additional support beyond typical outpatient services. It can be used as a transitional service for families with children returning home from psychiatric admission, or to prevent admission. The aims are to improve parenting skills, promote healthy child development, prevent out-of-home area placement of children and provide or coordinate services needed to maintain family stability.

Services are usually limited to weeks in duration. However, family contact with therapists is intensive during that time and almost double in residential units. One study – a randomised controlled trial – found at 1 year follow-up, more of the Family Preservation Group had sustained improvements in behaviour and symptom reduction than had those in the residential programme.

(2) Home treatment can be summarised as a service for young people with mental illness [sic] who are in crisis and are eligible for hospital admission. Studies have shown that only about 15% of young people can safely be diverted from inpatient to home treatment, exclusion criteria for the home treatment being severe psychosis, life-threatening eating disorders, families living more than 30 km from the therapeutic unit and risk-taking behaviour.

Home treatment was found to be as effective as inpatient treatment across diagnoses in reducing symptom scores and improving psychosocial functioning, both immediately after treatment and at 3-year follow-up. Compliance [sic] of the child with the therapeutic regime and the skill of the therapist were the most important predictors of therapeutic outcome.

(3) **Case management** encompasses a number of approaches including assertive outreach, assertive community treatment, wrap-around and intensive community treatment. It can be defined as a commonly used strategy for increasing access to and coordination of services within the care system. Case management is not a time-limited service, but is intended to be ongoing, providing clients with whatever they need whenever they need it for as long as necessary.

Most of the evidence for the effectiveness of assertive outreach is from studies with overlapping age groups of young people and working age adults. Broadly, assertive outreach is found to be effective despite concerns that fidelity to the model is not always adhered to. The key features are round the clock and daily availability of multidisciplinary team provision of services within the client's own setting. There is an emphasis on assisting the client in managing their illness, assistance with activities of daily living skills, relationship building and on crisis intervention.

(4) **Intensive case management** typically targets young people with the greatest service needs and relies more on an individual rather than team approach as in assertive community treatment. It

²⁵⁹ This section 3.5 is quoted directly from: Kurtz, Z (2009).*The Evidence Base to Guide Development of Tier 4*. National CAMHS Support Service, Department of Health, UK . pp.8-10.

focuses on family strengths and empowering families. And case managers act as advocates, brokers between services, and coordinate, plan and implement services.

Clinical case management is one of the intensive case management models but has the weakest effect of the models. A few studies have found that while it increased hospital admissions it significantly decreased length of stay. This suggests that the overall impact is positive but might result in 'revolving door' admissions. However, randomised trials have shown that full-time case manager models are perceived as more satisfactory and allow young people to access community rather than residential-based services, compared with treatment models where the primary worker or therapist also acts as case manager.

Wrap-around helps families develop a plan to address the child's individual needs at home and school. Wrap-around addresses a child's individual needs and builds on the child's and family's strengths, so the exact services vary. Research on the effectiveness of this model is still at an early stage. But findings suggest that this broker/advocacy model results in behavioural improvements and fewer days in hospital. However, a randomised controlled trial of treatment foster care versus case management (with wrap-around components) found that outcomes were better for young people in case management interventions than for treatment foster care and at one-third of the cost.

(5) **Multisystemic Therapy (MST)** was developed as an intensive family-based approach to young offenders presenting with serious antisocial behaviours and who were at risk of being placed out of their home area. Interventions are designed to promote treatment generalisation and long-term maintenance of therapeutic change by empowering caregivers to address family members' needs across multiple systemic contexts. Outcomes show that staff adherence to the treatment model correlates to strong case outcomes. It has a relatively strong evidence base.

Consistently positive outcomes are reported for young offenders compared with standard outpatient treatment (reduced offending, fewer out of home placements, less substance-related offending). It has been estimated that cost savings through this almost compensate for the increased cost of the MST treatment.

Even this highly intense form of ecologically focused care, does not substitute for the need for inpatient provision, but can reduce the need, and results in enhanced outcomes over treatment as usual.

- (6) Dialectical Behaviour Therapy is a form of Cognitive Behaviour Therapy developed by Marsha Linehan (1983) for difficult to engage individuals who have problems controlling their emotions and behaviour. DBT is currently the recommended treatment for borderline personality disorder and deliberate self-harm (National Institute for Clinical Excellence, 2004). In 2007, Alec Miller and colleagues adapted this standardised programme to work with young people with multiple problems.
- (7) Treatment Foster Care (TFC) comprises structured therapy within a foster family setting for young people with emotional or disruptive disorders. The evidence base comes from two well reported randomised controlled trials. Outcomes, such as improved behaviour and reduced offending behaviour, for both psychiatrically ill and offending young people were significantly better for those who received TFC than group home or hospital care. Outcomes were dependent on four main factors:
 - \checkmark the amount and type of supervision received by the young person

- \checkmark the consistency of parental discipline
- \checkmark the presence of a close confiding relationship with a trusted adult
- ✓ not being closely linked with delinquent or deviant peer

Relationship building with service users & support for staff are central Key Message 3.6 to effective CAMH service provision

Good relationships can create a positive service experience and enhance treatment efficacy

According to Kurtz's review of the evidence (2009)²⁶⁰ of what works in CAMHS Tier 4 level, dealing with mental health problems is more effective if the child's strengths, self-efficacy and resilience are promoted. This is dependent upon a reliable trusted relationship between therapist and child and also upon help from the child's family, schoolandpeers.

These messages were echoed in a synopsis of the themes identified by young people with respect to mental health services published by the National Bureau of Scotland²⁶¹. Key themes included that

- ✓ Relationships need to be given time to develop between staff and young people
- ✓ Staff need to be skilled in working with young people
- ✓ Mental health professionals need to value young people's need to consent, their right to confidentiality and their need for privacy

Irish young service users report the centrality of relationships in CAMHS to them

The Irish literature reviewed also notes the crucial importance of relationships to young people attending CAMHS. Buckley et al note that "Positive relationships with staff contributed to participants' favourable *experiences of the support provided*" ²⁶² whereas negative relationships had the converse effect. Buckley et al note: "Unfavorable contributing factors included a lack of time and available opportunities to meet with staff and a lack of sensitivity from staff to the patient's needs and requirements."²⁶³

Coyne et al (2014) also note the centrality of relationship to young people attending CAMHS and warn that "frequent staff changes in CAMHS make it difficult for young people to develop trusting relationships with staff."²⁶⁴ The report recommends CAMHS should aim to have a permanent staff member as a key worker to ensure continuity, inform and prepare service users prior to any staff changeover and minimize staff changes. This may result in a trusted service provider to a child or young person being available during a crisis and being familiar with what other relationships could be leveraged to support recovery.

CAMHS staff need to be supported in developing positive, effective relationships

Kurtz (2009) notes that

"effective interventions depend above allon the staff who deliver them. Staff need support in working with children with severe and complex problems. They need reflective opportunities, consultation with relevant others and appropriate supervision of their work."²⁶⁵

Kurtz notes that this importance of investing in sporting staff to develop effective, positive relationships with young service users has implications for service organisation and management, and recommends that services consider the best practice implementation guide called 'New Ways of Working'. This guide

²⁶⁰ Kurtz, Z (2009). The Evidence Base to Guide Development of Tier 4. National CAMHS Support Service, Department of Health, UK. ²⁶¹ The National Bureau of Scotland. (2004). *Mental Health Services: What Young People Want*.

²⁶² Buckley, S et al (2012). Mental health services: the way forward. The perspectives of young people and parents. St Patrick's University Hospital, Dublin ²⁶³ Ibid.

²⁶⁴ Coyne, I. et al (2014). Adolescents and parents' experiences of attending child and adolescent mental health services (CAMHS) in Ireland: The report. TCD, Dublin

²⁶⁵ Kurtz, Z. (2009). Op. Cit., p.13.

was originally developed to enhance interagency collaboration and improved service outcomes for mental health services for adults $^{\rm 266.}$

²⁶⁶ Department of Health (2007). *Mental Health: New Ways of Working for Everyone: Developing and sustaining a capable and flexible workforce: Progress Report.* CSIP/NIMHE, London.

Key Message 3.7Specific CAMH care pathways need to be developed for children and
young people with intellectual and learning disabilities.

Children with intellectual and learning disabilities are at high risk of developing mental health difficulties

According to the World Health Organisation (2005), an essential requirement for CAMH services is to be responsive to the needs of vulnerable and marginalised groups in society.²⁶⁷ One such vulnerable group is children and young people with learning difficulties. Research by the CAMHS Evidence Based CAMHS Unit in the UK indicates the following:²⁶⁸

- Children and young people with an IQ of below 50 have a 1 in 2 chance of experiencing mental health/behavioural difficulties
- Mental health problems are two to four times more common in children and young people with learning disabilities, with 30%-50% (approximately 4 out of 10) having a mental health problem, compared to 1 out of 10 without a learning disability
- While all mental health problems are over-represented in children and young people with learning disabilities, autism and hyperkinetic disorder are particularly increased

The provision of CAMH services to children and young people with intellectual disabilities is particularly complex, as the CAMHS Evidence Based Unit notes:

- "Children may have complex needs that require support from other agencies that may not be readily available in CAMHS, such as speech and language therapy, physiotherapy, occupational therapy, specialist teachers, psychiatric social workers, learning disability specialist support, good access to primary care and child healthcare.
- Children and young people with a learning disability may receive mental health services in a variety of settings, including not only traditional CAMHS but also community paediatric services, child development centres, specialist Learning Disability services and special needs educational services.
- The co-ordination of care between these services is highly variable and can be complex."²⁶⁹

However the CAMHS Evidence Based Unit note that provision of mental health care for children is fundamentally a human rights issue:

"children and young people with mental health problems and learning disabilities are children and young people first and foremost, and therefore should have access to children's services. It could be argued that it is a breach of human rights to discriminate on the grounds of IQ, and therefore children and young people with learning disabilities must have the same access to mental health services as those without learning disabilities."²⁷⁰

²⁶⁸ Pote, H. & Goodbar, D (2007). A Mental Health Care Pathway for Children and Young People with Learning Disabilities: A *resource pack for service planners and practitioners*. CAMHS Evidence Based Practice Unit, University College London & the Anna Freud Center, London.

²⁶⁷ World Health Organisation. (2005). Mental Health Policy and Service Guidance Package: CAMH policies and plans. WHO, Geneva.

²⁶⁹ Pote, H. & Goodbar, D (2007). Ibid.

²⁷⁰ Pote, H. & Goodbar, D (2007). Ibid.

Ireland has no fully staffed mental health team for children with learning disabilities

In Ireland, the recommendation by A Vision for Change was that thirteen consultant-led, multidisciplinary teams for children and adolescents with mental illness and learning disability were required to meet population needs.²⁷¹ However the Irish College of Psychiatrists (ICP) note that "there is currently no recognised, fully staffed team forchildren with mental illness and learning disability".²⁷² The HSE's CAMHS Annual Report notes that just 2% of the children and young people supported by CAMHS in 2013 were children and young people with intellectual disabilities.²⁷³

The Irish College of Psychiatrists states that "The singular lack of progress in the implementation of the recommendations of A Vision for Change in relation to Mental Health Services for both children and adults with a learning disability remains a serious concern."²⁷⁴ The ICP has developed a position paper on what is required for children and adolescents with learning disabilities.

A good practice guide to develop a mental health care pathway for children with learning disabilities (UK) Expert clinicians and academics in the UK acknowledged that current mental health service access for children with learning disabilities was inadequate in the UK and collaborated to create a good practice guide²⁷⁵ as a resource pack to help CAMHS partnerships and providers to plan care pathways and put them into practice. A number of good practice principles are outlined in the guide to developing a care pathway. These include: consider a child's needs holistically; use a developmental framework; multiagency referral; inclusion and equality of access; pro-active problem-solving; co-operatively share information and communicate well; encompass diversity; engage in child centred planning; provide quality therapeutic services.

Please see Appendix 5 for more details on this guide, the Quality Standards for Mental Health Care Pathway for Children and Young People with Learning Disabilities (2007).

²⁷¹ Department of Health (2006). A Vision for Change: Report of the Expert Group on Mental Health Policy. Government Publications Office, Dublin.

²⁷² PreBudget 2014 Submission Re Mental Health Services. September 2013. College of Psychiatrists.

http://www.irishpsychiatry.ie/Libraries/External_Events_Documents/CPsychl_Pre_Budget_Submission_FINAL_2_4.sflb.ashx Health Services Executive (2014). Fifth Annual Child and Adolescent Mental Health Service Report. HSE, Dublin.

²⁷⁴ PreBudget 2014 Submission Re Mental Health Services. September 2013. College of Psychiatrists. http://www.irishpsychiatry.ie/Libraries/External Events Documents/CPsychl Pre Budget Submission FINAL 2 4.sflb.ashx

²⁷⁵ Pote, H. & Goodban, D (2007). Ibid.

Key Message 3.8 The transition from child to adult mental health services should be effectively managed but a fundamental system change is urgently required to meet the needs of youth mental health care

Transitioning young people from CAMHS to AMHs is problematic

The current arbitrary cut off of a young person from the CAMH service because they have reached a certain age (usually 16, but in some services 17 and in others 18 years old) is highly problematic²⁷⁶. Chronological age alone is not an appropriate reason to transfer young people from the Child and Adolescent Mental Health Services (CAMHS) into the Adult Mental Health Service (AMHS) given that systems transition can involve stressful change for the young person as a service user because the adult system has significantly different care teams, care plans, policies, regulations, stakeholder agencies, welfare and funding arrangements. In fact the literature indicates that improvements gained during earlier treatment may not be sustained during the difficult transitional period from child to adult provision.²⁷⁷

Recommended good practice to manage the transition effectively

However there are recommended good practices during the transition from child to adult mental health care to manage the transition as effectively as possible. The Social Care Institute for Excellence in the UK has synthesized the evidence around good practice in this area. While they have drawn some conclusions, they note that "many practice developments and service models for improving transitions are at an early stage of development, and there are few robust effectiveness studies currently available."²⁷⁸However several key messages directly cited from this research include:

- (1) Service transition is a *process* [original emphasis], and good practice needs to take account of the wider context of young people's lives, including education, employment, housing and overall health needs.
- (2) Young people, their families and carers want their views to be taken seriously and to participate actively in the process of transition.
- (3) Good practice is the provision of good information, consistent support from a key worker and flexible, non-stigmatising community-based services appropriate for their age group.
- (4) Good practice also involves collaborative flexible working between agencies, clear protocols and transparent planning meetings.

A systematic review of the literature and a synthesis of the evidence on good practices that address continuity during transition from child to adult care was conducted by While, A et al. Their findings suggest core principles which they used to create a useful framework for a service development cycle in transition planning.²⁷⁹ The key steps recommended are:

²⁷⁶ Singh et al. (2010). *Process, Outcome and Experience of Transition from Child to Adult Mental Healthcare: A Multiperspective Study*. British Journal of Psychiatry.

²⁷⁷ Royal College of Paediatrics and Child Health (2003). *Bridging the Gaps: Health Care for Adolescents*. London: RCPCH.

²⁷⁸ Sainsbury, M & Goldman, R (2011). *Mental Health Service Transitions for Young People: Children's and Familie's Guide.* Social Care Institute for Excellence, London.

²⁷⁹ While, A. et al (2004). *Good practices that address continuity during transition from child to adult care: synthesis of the evidence*. Child: Care, Health & Development, 30, 5, 439-452

- 1. Identify care group/user population
- 2. Identify the key dimensions of transition
- 3. Bring stakeholders together
- 4. Identify transitional needs
- 5. Transitional planning and agreement
- 6. Identify/provide resources
- 7. Audit and Evaluation

Additionally, practical, online good practice guides have been developed to support successful transition from CAMHS to AMHS has been developed by youngminds for both young people and their parents.²⁸⁰ These are available at

http://www.youngminds.org.uk/for parents/services_children_young_people/transition_to_adult_service_es/difficulties_moving_adult_services

The current mental health system is weakest when young people have most need

16 years old onwards, an age when most young people are transferring into adult mental health services, is a time of heightened mental health vulnerability.²⁸¹ Patrick McGorry, founder of Headspace in Australia, has noted that

"public specialist mental health services have followed a paediatric–adult split in service delivery, mirroring general and acute health care. However, the pattern of peak onset and the burden of mental disorders in young people means that the maximum weakness and discontinuity in the system occurs just when it should be at its strongest".²⁸²

McGorry further notes that the evidence is that early adulthood (16-23) is actually a period "where mental health issues are beginning to peak and other supports are diminished. Therefore continuity of care, or at least an effectively managed transition, is paramount at this time."²⁸³

Recent Irish epidemiological research indicates high numbers of young people are suffering from mental ill health

Irish research supports this assertion. For example, findings from the first report of the Psychiatric Epidemiology Research across the Lifespan (PERL) Group Dublin at Royal College of Surgeons in Ireland illustrate just how vulnerable to mental ill-health young people are.

This recently published research²⁸⁴ provides some of the only epidemiological and longitudinal data on rates of mental disorder, substance misuse, suicidal ideation and deliberate self-harm among young people in Ireland young adults aged 19-24 years. These young people were a representative cohort of 169 young people from North Dublin City who had previously taken part in a study known as the 'Challenging Times Study' when they were aged 12-15 years.

 ²⁸⁰http://www.youngminds.org.uk/for_parents/services_children_young_people/transition_to_adult_services/difficulties_movin g_adult_services Accessed on 11/10/2014.
 ²⁸¹World Health Organisation (2012). *Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors*. WHO, Geneva.

 ²⁸¹ World Health Organisation (2012). *Risks to Mental Health: An Overview of Vulnerabilities and Risk Factors*. WHO, Geneva.
 ²⁸² McGorry, PD (2007). *The specialist youth mental health model: strengthening the weakest link in the public mental health system.* Med J Aust. 1;187(7 Suppl):S53

²⁸³ While, A. et al (2004). *Good practices that address continuity during transition from child to adult care: synthesis of the evidence*. Child Care, Health & Development, 30, 5, 439-452

²⁸⁴ Cannon M, Coughlan H, Clarke M, Harley M & Kelleher I (2013). *The Mental Health of Young People in Ireland: a report of the Psychiatric Epidemiology Research across the Lifespan (PERL) Group Dublin*: Royal College of Surgeons in Ireland, Dublin.

The findings are stark in demonstrating what would appear to be a public health crisis of youth mental ill health :

- By the age of 13 years, 1 in 3 young people in Ireland is likely to have experienced some type of mental disorder. By the age of 24 years, that rate will have increased to over 1 in 2.
- The experience of mental ill-health during adolescence is a risk factor for future mental ill-health and substance misuse in young adulthood. It is also associated with an increased risk of unemployment during the early adult years.
- High numbers of young Irish adults aged 19-24 years are engaged in the misuse of alcohol and other substances, with over 1 in 5 meeting criteria for a diagnosable substance use disorder over the course of their lives.
- Significant numbers of young people are deliberately harming themselves and by the age of 24 years, up to 1 in 5 young people will have experienced suicidal ideation.
- Risk factors that are associated with the experience of mental ill-health among young Irish people include the experience of health, work and relationship stress, family difficulties, the experience of being in an abusive intimate relationship and having a bisexual or homosexual orientation.

These findings confirm earlier research conducted in Ireland by Dooley & Fitzgerald (2012) which record a peak in mental health difficulties in the late teens and early twenties "accompanied by a significant decrease in protective factors such as self-esteem, optimism and positive coping strategies." 285

A different, specialist youth mental health system is needed in Ireland

One of the four key recommendations that Cannon et al (2014) make in light of the mental health vulnerability that young people in Ireland aged 19 to 24 experience, along with poor access and utilization of mental health services, is that Ireland develops "comprehensive, specialist youth mental health services that provide continuous care through the adolescent and emerging adult years."

In a review of the development of Jigsaw services in Ireland, Illback et al (2010) also argue for a *"transformation of mental health care and support"* in light of the high prevalence and onset of mental health disorders in adolescence²⁸⁶. Purcell et al note that *"The construction of a third component of the specialist mentalhealthsystem, namely a youth mental health stream, sitting between child and older adult psychiatry is an urgent and achievable goal if we are todeliver appropriate, acceptable, and effective care in the twenty-first century."*²⁸⁷

This recommendation has also been made directly by young people who have recently used CAMH services in Ireland. Buckley et al note that in their research with young Irish services users:

"There was wide consensus on the need for a specific adolescent/young adult's service that involves being among one's peers and provides a service that does not terminate at age 18 years,

 ²⁸⁵ Dooley, B., & Fitzgerald, A (2012). *My world survey: National study of youth mental health in Ireland. Dublin, Ireland:* Headstrong - The National Centre for Youth Mental Health, UCD School of Psychology.

²⁸⁶ Illbach, R., 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

²⁸⁷ Purcell, R. et al. (2011) *Toward a Twenty-First Century Approach to Youth Mental Health Care: Some Australian Initiatives*. International Journal of Mental Health, vol. 40, no. 2, Summer 2011, pp. 72–87.

but instead provides a continuum of support from mid-teenage years to the mid-twenties, followed by post-discharge access to services and therapeutic support."²⁸⁸

Good Practice Service Model – Orygen Youth Project, Melbourne, Australia.

Good practice service models of *"easily accessible and responsive"*²⁸⁹ services are cited in Buckley et al as being the Orygen Youth Project in Melbourne, Australia and The Zone in Plymouth, UK.

Purcell et al (2011) detail the development of the Orygen Youth Health (OYH) in Melbourne, Australia which has developed of early intervention models of care for young people. Initially this was done through the Early Psychosis Prevention and Intervention Centre (EPPIC) program²⁹⁰ and in recent years through the "evolution and re-engineering of a full spectrum specialist public mental health service for young people with emerging potentially serious mental disorders of all types."²⁹¹

Purcell et al (2011) describe some of these specialist services for young people with complex or severe mental disorders which have been developed by Orygen Youth Health to include the following:

- triage and assessment services;
- extended hours mobile multidisciplinary teams providing intensive community based crisis response and home treatment;
- mobile youth intensive case management services for young people with complex needs who are difficult to engage in office-based care;
- psychosocial case management and therapeutic individual and family services;
- specialist services for young people with severe personality disorders, mood disorders, and psychoses;
- consumer and carer peer support programs;
- group-based personal, social and vocational recovery programs;
- a specialist youth inpatient unit

Purcell et al (2011) comment that although the model at OYH is evolving as:

"a work in progress..... it is increasingly demonstrating that in other disorders, particularly the mood and personality disorders as well as the psychotic illnesses, early intervention is clinically effective, as well as cost effective, and is highly valued by young people and their families"²⁹²

²⁸⁸ Buckley, S et al (2012). *Mental health services: the way forward. The perspectives of young people and parents. St Patrick's* University Hospital, Dublin

²⁸⁹ Buckley et al (2012). Ibid.

²⁹⁰ McGorry, PD et al. (1996) *EPPIC: An evolving system of early detection and optimal management.* Schizophrenia Bulletin, 22(2), 305–326.

²⁹¹ Purcell et al. (2011) Ibid.

²⁹² Ibid.

Appendix 1: Details of Research Activity Engaged in for this Literature Review

Prior to this review, Mental Health Reform had compiled links to 103 research articles on CAMHS. Researcher Lorna Kerin screened these by reading the abstract or first paragraph in order to identify literature that could be used further in the evidence extraction and synthesis stages. A total of 46 articles were selected for inclusion and thematic headings emerging from the literature were created.

Additionally a keyword search was conducted in August by the researcher, using databases PsychInfo and ERIC. Key terms such as 'CAMHS', 'Good practice', 'Service Delivery', 'Evidence Informed', and Boolean operators 'AND', 'OR', and 'NOT' were used to ensure inclusion of similar concepts e.g. 'evidence informed', 'best practice', 'service innovation'. Over 1,300 articles were identified so further search limits were imposed which reduced findings to 389. These were briefly scanned to assess suitability for further reading. 124 articles were downloaded and read. Of these, 54 were assessed to be of direct relevance. These were reviewed and thematic headings emerging from this literature were created.

A considerable amount of the journal articles sourced dealt with a single aspect of good practice in CAMHS e.g. good practice in eliciting views of young people or e.g. evidence informed infant mental health programmes for a specific population or disorder. Therefore, in order to focus more broadly on systemic, organisational and policy approaches to the effective delivery of CAMHS, grey literature such as organisational reports, policy papers and submission documents from relevant bodies were searched. This resulted in over 50 relevant papers which have been synthesised in the key messages in this report where relevant.

The researcher also sought key practice documents and/or service information from the following key informants who kindly made recommendations or sent information. All suggestions were subsequently followed up and considered for inclusion.

- Prof. Agnes Higgins (TCD) on Maternal Mental Health
- Dr John Sharry (Mater CAMHS) on CAMHS Practice Guidance
- Dr Gemma Cox & Mary Fanning (youngballymun) on Infant Mental Health RSG service
- Catherine Joyce (Barnardos) on Parental Mental Health
- Dr Orla Doyle (UCD) on Perinatal Mental Health (Preparing for Life Programme)
- Dr Tony Bates (Headstrong) on Youth Mental Health
- Dr Lynsey Rose O'Keeffe & Dr Aileen O'Reilly (Headstrong) on Service Evaluation
- Dr Michael Drumm (North Dublin City County CAMHS) on service quality guidelines
- Valerie Moffatt (Psychology Dept., HSE Dublin North City) on Psychology in Primary Care
- Dr Liam MacGabhann & Dr Denise Proudfoot (DCU) on professional development for mental health professionals in leadership and in primary care.

Appendix 2: A four tiered CAMHS framework outlined by the Bamford Review (2006)

The Bamford Review in Northern Ireland engaged in an extensive literature review as to which systems and model of service delivery could best support development and access to a holistic and integrated mental health service for children and young people. The review concluded that the '4 Tier model' was highly suitable to bring together the diverse number of services from which children and young people might receive help.

These services range from primary care, paediatrics, clinical psychology to specialist community services and highly specialist inpatient units. The model also has the flexibility to encompass services outside health and social services such as education, youth justice and the voluntary & community sector who play a key role in prevention and early intervention, and who also have developed expertise in working with vulnerable populations of children and youth.

The '4 tiered mode' is in current use in CAMHS services in the UK and Northern Ireland and services three main purposes: as a strategic and planning tool, as a communication tool between services and as a blueprint for how services are practically delivered in the group.

This framework may be useful for the Republic of Ireland to consider as a fundamental, structural issue with regard to the organisation of CAMHS across the whole range of service providers and in terms of developing a common accessible language for services working across different disciplines and sectors. Therefore a detailed note on the structure of the model is given below. The material in this appendix below was sourced and is directly cited from the Bamford Review (2006).

The 4 tiered model

There will be some children and young people that may require services from a number or even all of the Tiers at the same time. However it is useful for planning, communication and service delivery to categorise CAMHS services into the following four distinct service tiers.

Tier 1

Tier 1 offers interventions to children with **mild to moderate mental health problems**. Many of these are self -limiting but may cause considerable distress in the child or family and disruption to the child's learning. This Tier should be **universally accessible** as when children with these problems present to services and when they do present problems, they are frequently missed. The professionals will need generic training at this level.

Tier 1 services are usually the first point of contact between a child and family with primary care, Education and/or voluntary and community agencies. Tier 1 staff includes GPs, other primary healthcarers, staff of child health services, school staff (teachers and counsellors), non-specialist children's social workers and many non-statutory sector workers. Services provided at this level will include:

- ✓ health promotion to prevent or interrupt the development of mental health problems;
- ✓ identification of mental health problems early in their development with early intervention;
- ✓ advice, and in some incidents treatment for less severe mental health problems (including emotional and behavioural problems);
- ✓ provision of support to enable families to function in a responsive manner to behavioural cues;
- ✓ enable families or carers to resolve parenting difficulties effectively;

- \checkmark enable children to resolve their own emotional and or behavioural problems
- ✓ inclusion of children, young people and families as partners in the intervention process.

Tier 2

Tier 2 is the first line of **specialist** services. The staff include members of health-provided specialist CAMHS, community paediatricians, educational psychologists, specialist teachers, specialist children's social workers and some staff of voluntary organisations. They will need to have completed a dedicated training in the **assessment and treatment of a range of mental health disorders**.

Tier 2 workers operate as individual practitioners, offering interventions for mental health problems and mental disorders. Sometimes staff will work as members of teams to which they may refer. Together, the functions delivered at Tier 2 are those required in each locality.

According to the Bamford review, Tier 2 workers should be in a position to:

- ✓ enable children and their families to function in a less distressed manner
- ✓ promote services and activities to facilitate children to address and manage their mental health problems
- \checkmark assessment and intervention for children and their families with mental health problems
- ✓ contribute to training, advice and consultation for people working at Tier 1 and 2
- ✓ assessment and appropriate referral to a range of other services
- ✓ inclusion of children, young people and families as partners in the intervention process

Tier 3

Tier 3 services are more specialised. Interventions are offered by professionals working in **specialist multidisciplinary teams**. They provide specialist services for more severe, complex and persistent mental disorders and illness. They are staffed by specialist CAMHS professionals from Tier 2 who become Tier 3 workers when they function together as teams for particular children and families. This group of professionals require specialist training opportunities.

This service should be accessible at a number of centralised sites to provide:

- ✓ assessment and treatment of child and adolescent mental health disorders working with children and their families or carers
- ✓ contribute to the training, advice and consultation to Tiers 1, 2 and 3
- ✓ advice and education for families
- ✓ feeding and Eating Disorder service
- \checkmark signposting to a range of other services
- ✓ participation in research, development and audit projects
- ✓ co-ordinating transition of children, adolescents and families to other Tiers
- ✓ inclusion of children, their families or carers and other agencies as partners in the process.

Tier 4

Tier 4 services deliver **very specialised interventions and care** for the most complex or uncommon disorders or illnesses. They include very specialised clinics that are only supportable on a regional or national basis, inpatient psychiatric services for children and adolescents, residential schools and very specialised residential social care. Partnership between education, youth justice, health and social services is essential at this level. This group of professionals require specialist training.

These services will normally have the same profile of professionals as at Tier 3 and the range of services delivered may include:

- ✓ child & adolescent inpatient and day-patient services
- \checkmark secure and forensic services
- ✓ feeding and eating disorder service
- ✓ specialist team for neuro-psychiatric problems
- ✓ specialist service for sensory impaired young people
- ✓ specialist service for gender identity disorders
- ✓ inclusion of children, their families or carers and other agencies as partners in the process
- ✓ contribute to training, advice and consultation to Tiers 1,2,3 and 4

Appendix 3: Referral Criteria for CAMHS and Other Services by a Medical Doctor

The following guidelines from the Irish College of Irish Practitioners is included in this brief literature review for MHR/CMHC to clarify what is the latest guidance that primary care practitioners in Ireland have received from CAMHS with regard to the referral system to CAMHS. Please note the following is direct citation²⁹³ and the researcher Lorna Kerin has created headings and emphasis to order it for the purposes of this document.

Referral to CAMHS

For routine referrals to most CAMHS in Ireland, the child must be referred by a medical doctor (GP, Medical Officer or Paediatrician). The child is then placed on the waiting list for assessment. Urgent cases (such as children who are suicidal or psychotic) are prioritised.

Referral to the local Child and Adolescent Mental Health Service (CAMHS) is generally reserved for children and adolescents who have been diagnosed with a psychiatric disorder known as an 'Axis 1 disorder'. These include all psychiatric conditions except personality disorders or intellectual disabilities. The clinical conditions include the following:

- Adjustment Disorder
- Anxiety Disorders
- Panic Disorder
- Posttraumatic Stress Disorder
- Obsessive Compulsive Disorder
- Specific phobia
- Social phobia
- Agorophobia
- Separation Anxiety Disorder
- Attention Deficit Hyperactivity Disorder/ Attention Deficit Disorder
- Dissociative Disorder
- Eating Disorders (Anorexia Nervosa / Bulimia Nervosa)
- Factitious Disorders
- Gender Identify Disorder
- Mood Disorders (Major Depressive Disorder / Bipolar Affective Disorder)
- Psychotic Disorders
- Somatoform Disorders
- Substance Related Disorders
- Sleep Disorders
- Tic Disorders

Out of Hours CAMHS

The provision of 'out of hours' CAMHS is still not available nationwide. Therefore, in the case of an emergency outside of usual working hours (9am -5pm, Monday to Friday), referral to the local Accident and Emergency Department may be warranted. To date, there are no nationally agreed protocols with regard to the definition of the appropriate age at which to refer a child or an adolescent to a paediatric versus an adult Accident & Emergency service. There are however, local protocols in place; thus, GPs should refer the young person to their local Accident and Emergency Department, as per local protocols.

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[•] O'Keefe et al (2013). Child and Adolescent Mental Health Diagnosis and Management. CAMHS Quality in Practise Committee, Irish College of General Practitioners (ICGP), Dublin.

In the event of a situation occurring 'out of hours' and where there are concerns about the young person being an acute risk, the GP is advised to refer the young person to their local Accident and Emergency Department.

Referral to other services

Many children and adolescents present with emotional difficulties which do not constitute Axis 1 disorders (and thereby do not require specialist CAMHS intervention) but which are significantly debilitating to require referral to other services. Examples of these referral options given by CAMHs are listed below. In some cases, children may present with both psychiatric and non-psychiatric mental health disorders requiring referral to several services including CAMHS. Any children or adolescents who have a co-morbid psychiatric disorder should be referred to the local CAMHS.

School based problem:

If problems are primarily school based (in the absence of mental health difficulties) parents should be advised to seek a consultation with the **National Educational Psychology Services** (N.E.P.S.) Social Communication Difficulties including speech and language difficulties and Autistic Specturm Disorders (ASD)

Children and adolescents with speech and language difficulties should be referred to the local **Speech and Language Therapy Services** in the community. ASD is no longer considered to be primarily a psychiatric disorder. Early intervention and assessment services for children with ASD should include comprehensive multidisciplinary and paediatric assessment. If a child with autism has a comorbid psychiatric condition i.e. an Axis I diagnosis, then consider referring the child to the local Child and Adolescent Mental Health Service.

Developmental delay

Children who present with a history of developmental delay should be referred to the local **paediatric service**.

Behavioural difficulties

In cases of behavioural difficulties, where there is no mental health component, **community services** such as Parenting Courses should be considered.

Aggressive behaviour

In cases where individuals have a history of aggression or risk taking behaviour which cannot be contained by parents, referral to local community services which offer parenting courses should be considered. Children and adolescents can also be referred for support through local **child welfare services**.

Child Protection Concern

If there is a suspicion that a child is being abused (emotional, physical or sexual abuse) or neglected (emotional or physical) or is at risk of abuse, the practitioner has a statutory duty to report any concerns about a child's welfare and safety to the Child Welfare and Protection Services of the HSE.

Appendix 4 : Summary document of Jigsaw Youth Mental Health Service 2014

(Note: The following information was kindly provided to this literature review upon request from Headstrong, the National Youth Mental Health Centre in Ireland)

Summary Document

Several studies (Dooley & Fitzgerald, 2012; Martin, Carr, Burke, Carroll, & Byrne, 2006; Lynch, Mills, Daly, & Fitzpatrick, 2006; National Office of Suicide Prevention, 2012) and extensive needs analyses (Illback et al., 2010; Illback & Bates, 2011) document that there is considerable mental ill-health among young people in Ireland (age 12-15 years) and a consequent need for early intervention. The most compelling recent evidence regarding the mental health needs of young people in Ireland came from Headstrong's *My World Survey (MWS)*, administered to a stratified and representative sample of young people in Ireland in 2011 (Dooley & Fitzgerald, 2012, 2013; Fitzgerald & Dooley, 2013).

Some of the most striking findings from this survey are that (1) 8% of adolescents and 14% of young adults experience depressive symptoms classifiable as severe or very severe, and an additional 22% of adolescents and 26% of young adults experience mild to moderate depression, (2) 11% of adolescents and 14% of young adults experience anxiety symptoms classifiable as severe or very severe, and an additional 21% of adolescents and 23% of young adults experience mild to moderate anxiety, and (3) 21% of young adults report that at some point in the last year they have deliberately hurt themselves without wanting to take their life (deliberate self-harm).

Jigsaw constitutes Headstrong's response to the challenge of transforming how young people in Ireland access mental health support and attain positive developmental outcomes. The core objectives of *Jigsaw* are as follows:

- 1. To ensure access to youth friendly, integrated mental health supports when and where young people need them in their community
- 2. To build the confidence and capacity of front line workers to directly support young people in their mental health and wellbeing and connect them with *Jigsaw*
- 3. To promote community awareness around youth mental health in order to enhance understanding of young people and the risk and protective factors that contribute to their mental health and wellbeing.

As of June 2014, ten communities with population catchment areas of 150,000 to 250,000 have opened *Jigsaw* programmes and are providing a range of early intervention services and support for young people. Each is at a different stage of development, with initiation dates ranging from 2008 through 2013, but all are fully operational, and nearly 8,000 young people have been served to date in *Jigsaw*.

Information about young people who engage with *Jigsaw* is captured using the online Jigsaw Data management System (JDS). This includes information gathered using individual outcome measures, as evaluation of *Jigsaw* includes a number of outcome measures. The first of these is the **CORE**, which is a standardised psychometric scale that measures psychological distress. It is administered to young people engaging with *Jigsaw* at their initial and final session to examine whether there are any changes in levels of psychological distress. The second outcome measure is the **goal attainment scale**, which is a person-centred method of scoring the extent to which a young person's individual goals are achieved during their

engagement with *Jigsaw*. The third outcome measure is the **follow-up interview**, which is conducted six weeks after a young person ends their engagement with *Jigsaw* to see whether any improvements made by a young person as a result of attending *Jigsaw* have been sustained overtime.

In addition, young people who have engaged with *Jigsaw* are invited to complete a short **satisfaction survey** which captures their reactions to the services they receive. Young people can complete this survey online or by using a paper version of the questionnaire available in *Jigsaw* hubs. The final outcome measure is the *Jigsaw* collaboration survey. This is a measure of inter-organisational collaboration that is administered to all organisations that are serving young people in a community. The survey is administered at baseline and on an annual basis thereafter as a means of tracking *Jigsaw*'s progress towards developing better links between organisations that serve young people in an area and facilitating outreach to educate a community about early identification and intervention.

Some key findings to emerge from analysis of data gathered in 2013 are:

- 2,571 young people engaged with *Jigsaw*. This comprised 929 case consultations (36%), 395 brief contacts (15%) and 1,247 brief interventions (49%)²⁹⁴
- 57% of young people engaging with *Jigsaw* were female and 43% were male
- The highest proportion of young people engaging with *Jigsaw* were 15-17 year olds, while 16 years was the most common age
- Young people were referred to *Jigsaw* from a variety of sources. The top referral pathways were parents (33%), self (21%), general practitioner (GP; 10%), school/higher education institute (8%) and adult mental health services (5%).
- Young people presented to *Jigsaw* with a range of different problems. The most common presenting issues were anxiety, tension, worry (17%), anger (11%), family problems (10%), feelings of depression (10%) and isolation from others/withdrawal (10%).
- Analysis revealed 89% of young people presented to *Jigsaw* with clinical levels of psychological distress, with 52% reporting high levels of distress
- However, 85% of 17-25 year olds and 67% of 12-16 year olds showed a reliable reduction in psychological distress after getting support in *Jigsaw*
- All young people who engage with *Jigsaw* for support are encouraged to set goals. In 2013, the most popular goals were emotional/mood regulation (33%), behaviour self-management (16%) and cognitive restructuring (15%). 92% of the goals set by young people were achieved.
- Analysis of data gathered through satisfaction surveys revealed young people were very satisfied with the service they received in *Jigsaw*. For example:
 - 95% said they got the kind of support they wanted
 - 93% felt *Jigsaw* met their needs
 - 94% stated that they would recommend *Jigsaw* to a friend
- The key themes that arose from their comments on this survey suggested that *Jigsaw* is viewed as a welcoming and unique place to get support, and has a positive impact on young people's lives. In particular, young people talked about how staff in *Jigsaw* were friendly, non-judgemental and

²⁹⁴ Case consultations were engagements with parents, teachers and others about a specific young person with mental health needs. They involved indirect support of a young person through meetings or telephone support, signposting and/or collaboration with other providers. Brief contacts were direct engagements with a young person aged 12-25 years who sought support for a mental health issue, but did not need (or choose to seek) more extensive support (typically lasted 1-2 sessions). Brief interventions were goal-focused face-to-face engagements with a young person (12-25 years), and typically lasted 1 to 6 sessions

supportive. This highlights the importance of young people having one good adult to talk to when they are experiencing difficulties.

Quotes from Young People About *Jigsaw*:

- I loved going to *Jigsaw*, from my first session I was made feel very comfortable and like I would be listened to no matter what I had to say which was exactly what I needed
- It is a brilliant service, it helped me to get through a very difficult time & make changes that I can use for life. I can't think of anything I would change
- Very nice atmosphere. Both the staff and the rooms give a sort of 'homely' feel and make it easier to talk. Very relaxing. The staff were interested in what I had to say ... It was amazing to be listened to.
- It's amazing. I honestly couldn't think of a better place to go. It's bright and open, not like a normal place for counselling and it's filled with people who are the nicest people you will ever meet in your life all willing to donate their day to help makes yours better

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Appendix 5: The Quality Standards for Mental Health Care Pathway for Children and Young People with Learning Disabilities (UK, 2007)

The Care Pathway has six quality standards which can usefully guide the development and evaluation of services for children with co-morbid mental health difficulties and intellectual disability. The below table is cited directly from the guide as a sample of good practice standards for creating good care pathways for children and young people's access to mental health services.

Pre-referral	Agree clear referral criteria and processes are agreed across provider services to ensure new cases get to the most appropriate service to meet their needs.	Agreements are made within the overlapping agency network about how to deal with children and young people who do not fit current criteria or are at risk of being bounced between services (e.g. CAMHS/LD services/local authority children's services/special schools/challenging behaviour teams)
Referral	First contact is made, ideally with both caregivers and referrer, to clarify referral expectations and what is possible (i.e. within team competencies).	Ideally contact takes place at home or in a setting relevant to the child (e.g. school/short break care setting).
Assessment	Assessments should be holistic and consider the child's mental needs of the child and their family, taking into account their age, developmental level, and culture.	
Interventions	Interventions should be individually tailored to meet the holistic needs of the child. Consider interventions within the context of other interventions (social, educational, physical) which the child is receiving. Services should develop effective inter-agency co-ordination to achieve this.	Emotional and behavioural interventions should be available at all levels of service delivery (tiers 1-4) from a variety of psychological models (behavioural, systemic, cognitive, psycho- dynamic and humanistic) in a variety of formats (direct individual, group or family therapy, and consultation), always being mindful of the needs for evidence-based practice and cost efficiency.
Discharge & re- referral	Discharge from mental health input should be clearly co-ordinated between agencies using existing review procedures.	Re-referral : When considering re- referrals, there should be clear definition of agency roles in relation to new concerns, and an agreed
Implementing the Care Pathway	Local CAMHS partnerships (or multi- agency caregroups) should take a significant lead role in implementing pathway the guidance provided in this pathway, to develop local protocols for children and young people with learning disabilities and mental health needs.	

Adapted from *Mental Health Care Pathway for Children and Young People with Learning Disabilities* by Helen Pote and David Goodban. London: CAMHS Evidence Based Practice Unit, 2007.

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