

## **Terms of Reference**

### **Right Based Review of Children and Young People's Experiences of Mental Health Services**

#### **Introduction**

The Office of the Commissioner for Children and Young People (NICCY) was created in accordance with 'The Commissioner for Children and Young People (Northern Ireland) Order' (2003) to safeguard and promote the rights and best interests of children and young people in Northern Ireland. In carrying out these functions, paramount consideration must be given to the rights of the child or young person, having particular regard to their wishes and feelings and to all relevant provisions of the United Nations Convention on the Rights of the Child (UNCRC).

NICCY plans to carry out a review of children and young people's experience of accessing or trying to access mental health services or support. We are interested in hearing children and young people's individual stories about the type of mental health supports they have accessed or attempted to access and the impact that has had. The review wishes to include the experiences of those who have transitioned between child and adult mental health services, therefore the target age range for the review will be up to 21 years old.

In 2012 a regional model for Child and Adolescent Mental Health Services (CAMHS)<sup>1</sup> was agreed in order to move towards a system in which there were a comprehensive range of services available across all Trust areas which covered prevention, early intervention, specialist intervention, crisis care and inpatient and regional specialist services. The need to focus on specific groups of children and young people who are most vulnerable and marginalised was highlighted as an important aspect of the implementation of the model:-

*"The needs of children and young people who are vulnerable and marginalised, in line with Section 75 and UNCRC obligations, need to be prioritised and given targeted support in order to reduce the likelihood of developing lifelong mental health problems"*<sup>1</sup> (para 4.6)

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<sup>1</sup> A full detailed breakdown of services offered at each step, is available from the CAMHS regional model document (pg 24) <https://www.health-ni.gov.uk/publications/child-and-adolescent-mental-health-services-service-model-july-2012>

The model contains 5 different stages of support which are outlined below. The establishment of the regional CAMHS model is not complete, different Trusts are at different stages of implementation, which perpetuates the fragmentation and unequal access to services.

Step 1	Targeted Prevention	GP, school nursing, maternal care services, school nursing, health visiting, public health education, community / voluntary development, youth services, education, independent sector.
Step 2	Early Intervention	Primary mental health services, paediatric care services, child development services, infant mental health services, family support and social care, LAC Therapeutic services, community led mental health services, youth counselling, children's disability teams.
Step 3	Specialised Intervention Services	Elective CAMHS teams, eating disorder, addiction services, specialist autism service, safeguarding services, Family Trauma Services, Behavioural Support for Learning Disability Services,
Step 4	Integrated Crisis Intervention Child and Family Services	CAMHS resolution and home treatment teams, crisis residential care, intensive day care support services.
Step 5	Inpatient and Regional Specialist Services	Paediatric intensive care unit (PICU), acute inpatient care, Secure care, forensic CAMHS.

## Background

As a signatory of the UNCRC, NI as a devolved nation of the UK has ratified all articles of the UNCRC. These articles are based on the fundamental premise that children and young people are entitled to 'special care and assistance' because of their age and evolving capacity. Article 24 in particular builds on the fundamental right to life as articulated in Article 6, and sets out the right of every child to the highest attainable standard of health, facilities for treatment and rehabilitation, and to ensure that no child is deprived of access to health care.

*24 (1) States Parties recognize the right of the child to the enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and*

*rehabilitation of health. States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services.*

General Comment 15 provides further guidance to duty bearers in the interpretation and practical considerations for the implementation of Article 24, and sets out the broad scope of children and young people's right to health to include the timely and appropriate prevention, health promotion, curative and rehabilitative services<sup>ii</sup>.

Furthermore, the Committee on the Rights of the Child reminds all State Parties that when developing and implementing policy, practice and services that affect the lives of children and young people, a number of overarching general principles need to be applied.

These General Principles are:

- to protect the rights of all children not to be discriminated against (Article 2);
- to have their best interests upheld (Article 3);
- to be supported to develop to their maximum potential (Article 6); and
- to be enabled to meaningfully participate in all aspects of their lives (Article 12).

It is vitally important that the principles of human rights, social justice and equity are translated into all legislation, policy and practice. Every 6-8 years the UK and devolved governments' compliance with the UN Convention on the Rights of the Child is examined by the Committee on the Rights of the Child. The most recent examination was in May 2016<sup>iii</sup>, and the Committee made a number of specific recommendations regarding mental health support and services. The recommendations are set out in full below, in summary, this included very strongly worded advice to the State Party to rigorously invest in child and adolescent mental health and to develop strategies to ensure services are provided on a child rights compliant basis, and for these plans to focus on providing measurable indicators, disaggregated data and addressing key underlying determinants of poor mental health.

*60. (a) Regularly collect comprehensive data on child mental health, disaggregated across the life course of the child, with due attention to children in vulnerable situations, and covering key underlying determinants.*

*(b) Rigorously invest in child and adolescent mental health services and develop strategies at national and devolved levels, with clear time frames, targets, measureable indicators, effective monitoring mechanisms and sufficient human, technical and financial resources. Such strategy should include measures to ensure availability, accessibility, acceptability, quality and stability of such services, with particular attention*

*to children at greater risk, including children living in poverty, children in care and children in contact with the criminal justice system.*

- (c) Expedite the prohibition of placement of children with mental health needs in adult psychiatric wards or police stations, while ensuring provision of age-appropriate mental health services and facilities;*
- (d) Support and develop therapeutic community-based services for children with mental health conditions;*
- (e) Review current legislation on mental health to ensure that the best interests and the views of the child are taken duly into account in cases of mental health treatment of children below the age of 16, in particular with regard to hospitalization and treatment without consent.*

*62. The Committee also recommended that the State party:*

- (b) Ensure that prescription of drugs is used as a measure of last resort and only after an individualized assessment of the best interests of that child, and that children and their parents are properly informed about the possible side effects of this medical treatment and about non-medical alternatives*

NICCY takes cognisance of a range of international human rights instruments and standards when considering the rights and needs of children and young people; this includes the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD). With respect to child and adolescent mental health there are a number of articles of the UNCRPD that have particular relevance to this Review, these are Article 25- highest attainable standard of health without discrimination on the basis of disability, Article 7- which refers to the right of children with disabilities to enjoy all human rights and fundamental freedoms on an equal basis with other children, Article 12 which states that the aim of the UNCRPD is full and equal legal capacity for everyone and Article 21 - freedom of expression and opinion, and access to information. These right based international treaties will act as the framework upon which this review will be undertaken.

During 2016, NICCY carried out a scoping exercise<sup>iv</sup> to better understand the prevalence and nature of poor mental health within the population of children and young people, and to review the operational aspects of the CAMHS system, such as service usage, need, outcomes, and budgetary spend. From the evidence that was available NICCY has identified a number of key concerns with regards child and adolescent

mental health services; this includes significant issues regarding the availability and accessibility of services. These issues include:

- unequal availability and accessibility of services across NI- in particular, fragmented availability of community provisions that includes out of hours / crisis support services;
- gaps in availability of specialist services which include children with dual diagnosis or requiring specialist in-patient care;
- limitations to access or choice of therapeutic supports;
- unacceptably long waiting lists across the system;
- rising thresholds and criteria for accessing services;
- poor transitional planning arrangements for those moving between child and adult mental health services and;
- a lack of joint working and integration of CAMHS with other services and sectors.

This scoping process also identified a significant lack of publically available robust, disaggregated, regional data, monitoring, or analysis on key operational aspects of the CAMHS system. It also established that there is no official prevalence data collected on the scale of mental health needs in under 18's. This lack of information makes it very challenging to fully review the adequacy and effectiveness of current provisions, with respect to children and young people's rights and best interests or to advise relevant authorities in a fully informed way.

Furthermore, although there have been a range of recent and on-going system reviews and implementation plans being undertaken in CAMHS, which are welcomed, they do not take sufficient account of whether current services across CAMHS are meeting fundamental rights principles such as children and young people's rights to equal access to high quality mental health services. Neither is there evidence that sufficient account is being taken of the direct experiences from a range of children and young people requiring CAMHS. Children and young people have a right to have their needs understood and responded to as early as possible in their own care planning. They also have a fundamental right to be listened to and have their views fully considered when decisions are being made about services that affect them.

NICCY has decided to carry out a rights based review to examine children and young people's experience of accessing or trying to access care and treatment from mental health services. Applying a child rights perspective to the area of mental health, and in particular, access to adequate mental health services will set child and adolescent mental health policy and practice within a rights based framework. The aim of which is

to better understand the health and social care systems capacity to safeguard and promote the rights and best interests of children and young people.

This review is being conducted in accordance with NICCY's functions under Articles 7 (2) and (3) of the Commissioner for Children and Young People (NI) Order 2003 which includes a duty to 'keep under review the adequacy and effectiveness of law, practice and services provided for children and young people by relevant authorities.' It is also in line with the Commissioner duties under Article 7 (5) (b) & (d) to encourage children and young people to communicate with the Commissioner, and for the views of children and young people, and their parents, to be sought whilst carrying out her functions. Furthermore, under Article 7 (4) (b) NICCY has a duty to advise relevant authorities and or Executive Committee of the Assembly on issues concerning the rights and best interests of children and young people identified during the Review.

## A Rights Based Service Review

As a rights based review a central aim of this piece of work will be to explore the challenges to realising children and young people's rights with respect to mental health services and where possible identify solutions or recommendations for removing or reducing these obstacles. In compliance with international obligations, the Review will endeavour to hear from children and young people directly, or where appropriate with a trusted adult i.e. parent, guardian or advocate. It will also seek the views of a range of professionals who work within the CAMHS system or who have a role in supporting children and young people in accessing CAMHS.

The information gathered through this review will be used to develop a set of recommendations for all those responsible for commissioning, planning and delivering child and adolescent mental health services. It is also the intention that this work will provide guidance that the health and social care system can use to deliver on its obligations as set out by the UNCRC and to positively address issues raised by the Committee on the Rights of the Child in relation to Northern Ireland's compliance with the Convention.

The piece of work will focus on assessing children and young people's experiences of accessing or trying to access child and adolescent mental health services against 6 key standards set by the UNCRC<sup>2</sup>:

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<sup>2</sup> General Comment 15 of the UNCRC, in particular section 6: Framework for implementation and accountability (pg 19) and guidelines developed by the Council of Europe on child-friendly health care.

**1. Availability:** whether there are adequate facilities and services in place to meet the needs of children and young people with mental health problems.

**2. Accessibility:** there are a number of aspects by which accessibility will be considered:

*Non-discrimination:* whether there is equal access to mental health services for all children without discrimination of any kind, and irrespective of where live, who live with, age, gender, ethnic background, or circumstances.

*Physical accessibility:* Whether health facilities are within accessible distance for all children and young people and that additional measures are taken to ensure the needs of children with disabilities are met and those living in under-served areas.

*Information accessibility:* whether information on health services, health status and treatment options are provided to children and their care givers in a way that is accessible and understandable.

**3. Acceptability:** whether mental health facilities and services are designed and delivered in a person-centred way i.e. respectful of children's needs, expectations, views, cultures and languages.

**4. Quality / Impact:** whether children and young people are offered a quality of service which adequately meets need, is appropriate and which improves well being. This includes whether choices with regards to evidence based treatments and interventions and adequately skilled and trained staff to offer child specific support.

**5. Participation:** whether the views of children and young people are gathered, seriously considered and taken into account in their own care planning and in the development of policy and services.

**6. Co-operation:**<sup>3</sup> whether there is timely and appropriate co-operation and integration of services to ensure a holistic approach is taken to need. This includes looking across tiers of CAMHS, interfaces between CAMHS and other disciplines such as primary care, social services, justice, education and between the NGO and Statutory Sector.

## Service Review Aims

The aims of this review are to:

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<sup>3</sup> This is particularly important now given the new statutory duties to co-operate set out in the Childrens Services Cooperation (NI) Act 2015.

- Enable children and young people (and their parents, guardians and advocates) to share their direct experiences of accessing or trying to access child and adolescent mental health service and the impact of that journey;
- Identify barriers which prevent children and young people from fully realising their rights to the highest attainable quality of health and access to CAMHS;
- Identify good practice and produce a range of recommendations for improving services, which are informed by children and young people, and directed at key government departments and agencies; and
- Increase public awareness of children's rights and in particular children and young people's rights to health and to access to health services.

## **Methodology**

The key strands of the review are set out below.

1. An online survey will be used to capture children and young people experience of accessing or trying to access mental health services or support. It is anticipated that this engagement may require the support of parents or guardians or for the Review to engage with parents / guardians as a proxy.
2. A series of thematic interview cycles (waves) will be conducted with specific groups of children and young people that are particularly vulnerable to discrimination in access to health services because of their particular condition or circumstances will be undertaken.
  - 2a. Wave 1: children and young people with co-morbid conditions i.e. mental health problems and a physical, learning or sensory disability.
  - 2b. Wave 2: children and young people with mental health and an addiction disorder (dual diagnosis).

There are a range of other conditions and circumstances that increase a child or young person's risk of poor mental health and vulnerability to discrimination to access to services and support. These include those in the care system, justice system, secure care, living in rural areas or an area of multiple deprivation, those part of a minority groups and those from the LGBTI community. The communication strategy for the survey will endeavour to target these groups of young people not specifically included in the interview waves, and it is likely that some young people included in the interviews will also have these

characteristics.

3. Thematic workshops with parents / guardians whose child has experience of accessing mental health services or support. The workshops will be aligned to interview cycles.
4. Thematic workshops and an online survey with professionals and practitioners who provide direct support to children and young people. Professionals and practitioners will include those who work within the CAMHS system or support children and young people who require the support of CAMHS, i.e. clinicians, NGO's, youth organisations, advocates and advisers.
5. Carry out an analysis and mapping exercise of available official statistical information on the operational aspects of CAMHS and a detailed breakdown of budgetary spend on CAMHS. NICCY's procedures for requesting information from relevant authorities will be followed.

### **Ethical Considerations:**

NICCY's Ethical Procedures and Guidelines policy will be followed, this involves completion of an ethical approval process in which external ethics reviewers provide advice and support before the review begins.

### **Time Frame**

Key milestone dates for the review are set out below:

March- April 2017	Meetings with key stakeholders to finalise the methodology.
June- Nov 2017	Programme of engagement and evidence gathering with children and young people across Northern Ireland.
May- Nov 2017	Call for evidence from professionals and practitioners.
Dec 2017–Mar 2018	Interim findings produced.
June 2018	Final report completed.

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i DHSSPS (2012) Child and Adolescent Mental Health Services: A Service Model, available from <https://www.health-ni.gov.uk/publications/child-and-adolescent-mental-health-services-service-model-july-2012>

- ii CRC/C/GC/15 (2013) General Comment No. 15 on the rights of the child to the enjoyment of the highest attainable standard of health.  
[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=5&DocTypeID=11](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=5&DocTypeID=11)
- iii CRC/C/GBR/CO/5 (2016) Concluding observations on the fifth periodic report of the United Kingdom of Great Britain and Northern Ireland, July 2016, available from  
[http://tbinternet.ohchr.org/\\_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=5&TreatyID=10&TreatyID=11&DocTypeID=5](http://tbinternet.ohchr.org/_layouts/treatybodyexternal/TBSearch.aspx?Lang=en&TreatyID=5&TreatyID=10&TreatyID=11&DocTypeID=5)
- iv NICCY (2017) Child and Adolescent Mental Health in NI: A Scoping Paper (due to be published end of April)