

## Still Waiting: Status Update Report

### Introduction

The Northern Ireland Commissioner for Children and Young People (NICCY) was established under the Commissioner for Children and Young People (NI) Order 2003 with a principal aim to safeguard and promote the rights and best interests of children and young people in NI. In exercising her functions, the Commissioner must have regard to all provisions of the United Nations Convention on the Rights of the Child (UNCRC).

In September 2018, NICCY published a Rights Based Mental Health Review - '**Still Waiting**' this report was produced in accordance with the powers and functions set out in the NICCY Order. These included our duties to keep under review the adequacy and effectiveness of law, practice and services provided for children and young people by relevant authorities; to advise Government and relevant authorities; and to encourage children and young people and their parents / carers to communicate with the Commissioner.

### NICCY's Report

The Review assessed the adequacy and effectiveness of mental health services for children and young people and highlighted good practice and identified barriers which prevent them from fully realising their right to the highest attainable standard of mental health (Article 24 of the UNCRC). The Review included a rights based framework in better understanding the provision of services and support; more specifically this looked at availability, accessibility, and quality of services and young people's participation in their own care planning and in the planning and delivery of services.

The methodology for the Review was structured around 3 strands of work: (1) children and young people's experiences of mental health services and support, (2) a mapping and analysis of service level data and (3) a mapping and analysis of budgeting information.

The Report of the Review, entitled '**Still Waiting**' was published in September 2018 and provides a breadth and depth of information on the experiences of children and young people who have accessed or attempted to access mental health services which has not been collected before. It draws on over 600 children's and young people's direct experiences of a range of 'services or support' from GPs' Practices, VCS services to Community CAMHS and In-Patient Care.

As such, 'Still Waiting' provides a vital insight into the child and adolescent mental health system from the point of view of the service user, and is of particular relevance and value to those responsible for policy decision making, as well as those involved in the planning and commissioning of services. It identifies significant failings in parts of the system that require urgent attention, including the A&E response to suicidal young people, the access and quality of services for young people with a learning disability and for young people with co-occurring alcohol and/ or drug and mental health problems requiring highly specialist support.

The title, '**Still Waiting**', was chosen to reflect one of the key findings from the report that children and young people are:

1. waiting too long to ask for help;
2. waiting too long to get the right support when they ask for it; and
3. waiting too long for systems/services to change to effectively meet needs.

An overarching conclusion of the report is that to drive real, positive and sustainable change in the availability, accessibility and quality of mental health services and support available to young people, child and adolescent mental health must become a **regional priority**, with sufficient investment to reflect this.

Child and adolescent mental health is a **cross cutting issue** that can only be comprehensively addressed if all services, statutory, non-statutory, specialist mental health and services focus on broader mental and emotional well-being, co-operate and collaborate as equal partners. Children's lives cannot be compartmentalised; to best meet their needs, we need a system that takes a holistic approach to these.

We engaged with political parties and obtained their support for the implementation of the recommendations; a letter signed by each endorsing these was sent to the Permanent Secretaries of the Department of Health, Department of Education, Department of Justice and Department for Communities.

## **'Still Waiting' Recommendations**

In total, the Report contains 50 recommendations that encompass the entirety of a young person's journey with accessing or attempting to access mental health services and support. The recommendations can be grouped into eight areas as outlined below.

1. Working Effectively	5. Moving from Child to Adult Services
2. Accessing Help	6. Flexible Treatment Options
3. Support for Adults working with Children and Young People	7. Mental Health Awareness & Literacy
4. Specialist Support	8. Young People with Additional Needs

### Implementation of Recommendations and NICCYs Monitoring Process

Since the publication of Still Waiting, NICCY has engaged on an ongoing basis with all the relevant authorities responsible for delivering on the recommendations to provide advice on, and monitor progress on their implementation. This 'status update' provides an overview of actions taken over the previous 12 months since publication.

#### Establishment of the Inter-Departmental Project Board.

NICCY's first recommendation called for 'the establishment of a high level multi-agency, multi-sectoral project board tasked with the development of a comprehensive, adequately resourced action plan for taking these recommendations forward.'

This implementation of this first recommendation was required before the others could be progressed, and so NICCY focussed on engaging with all the relevant agencies to encourage them to work together in delivering on Still Waiting. The following organisations attended a NICCY roundtable meeting on 30 January 2019 to discuss implementation of the report recommendations:

- Department of Health,
- Health and Social Care Board,
- Public Health Agency,
- Department of Education,
- Education Authority,
- Regulation and Quality Improvement Authority,
- Royal College of General Practitioners NI,
- Royal College of Paediatrics and Child Health,
- Department of Justice and four of the five Health and Social Care Trusts.

At this meeting, each representative recognised the role their organisation needed to play in implementing recommendations, and the steps they or others needed to take to facilitate this. The Department of Health had already proposed that they lead on this work and also proposed to co-ordinate an inter-departmental written response to the report recommendations. The IDG

first met in February, 2019 to discuss government response to Still Waiting. Since that time there has been an on-going dialogue between NICCY and all stakeholders particularly the DoH which resulted with response to the recommendations being provided to NICCY in August, clearly which recommendations were accepted and which were not. A total of 35 recommendations (or sub recommendations) were accepted, including:

- Designated mental health practitioners, trained to work with young people, to be attached to every GP surgery;
- Using fund mapping and need analyses to map increased in spending on services over time;
- An online booking system for mental health appointments to give young people and their carers more control over the appointment time;
- Ensuring the availability of community based after care supports for young people after they are discharged from Community CAMHs or inpatient care;
- Crisis intervention support for children and young people being available 24 hours a day, all year round, in all Trusts; and
- A comprehensive and urgent review of community based emotional, mental and behavioural support services for young people with a learning disability.

It is important to recognise that many of the recommendations accepted by the IDG require significant actions and will play an important role in transforming the provision of emotional and mental health services to children and young people in Northern Ireland.

A further 18 recommendations (or sub recommendations) were accepted 'in principle'. In general, the acceptance of these was limited by the additional resources required for their implementation,<sup>1</sup> for example:

- The development of a long term, sustainable children and young people's Mental Health Transformation Fund taking account of the investment required across all services and sectors in the Stepped Care Model;
- A mandatory programme for mental health training for all professionals working with children and young people;
- Statutory mental health professionals available to every primary and post primary school in Northern Ireland;

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<sup>1</sup> While financial resources are critical in delivering several recommendations, staffing resource and capacity to undertake some of the actions are also important, and currently constrained. These need to be addressed to ensure progress.

- Services which are currently not available in Northern Ireland established, to ensure that children and young people receive mental health treatment close to their family, and not through Extra Contractual Referrals i.e. outside NI; and
- Comprehensive mental health and wellbeing education for pupils provided as a core part of the education curriculum.

While NICCY recognises that additional resources are required to fully implement some of these recommendations, in most cases progress can be made without further resources but rather change in practice. We also have an expectation that the relevant Departments will proceed to calculate the investment required to deliver on these recommendations and to bid for these to ensure that the additional funds are allocated. Moreover, it is critical that concerted action is taken to ensure that a sufficient and suitably qualified workforce is in place to deliver services as required to meet the recommendations.

Eleven recommendations were indicated to be ‘still under consideration’, for a range of reasons. In some cases, where a particular delivery mechanism was proposed, the IDG stated that it could progress this through an alternative, existing mechanism. An example of this is the recommendation proposing the introduction of Community Mental Health Fora across Northern Ireland, bringing GPs and VCS organisations together to develop local relationships and exchange local knowledge. The IDG suggested that the existing Integrated Care Partnerships (ICPs) and Local Commissioning Groups could play this role, but it is not clear that these are appropriate fora.

Given the difficulties experienced in seeking administrative data to inform Still Waiting, the recommendation relating to the full implementation of the CAMHS Dataset across each Health and Social Care Trust is particularly critical and it is a matter of concern that this was marked as ‘Still considering’. The DoH informed NICCY that the Transformation / Confidence and Supply funding that had been allocated to this in 2018-19 was non-recurrent and had not been reallocated in 2019-20.<sup>2</sup>

Only one recommendation was rejected: ‘Develop a children and young people specific regional Integrated Elective Access Protocol (IEAP).’ The IDG agreed to consider changing the existing general IEAP to address issues raised in the report specific to young people. On

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<sup>2</sup> A letter from the Permanent Secretary of DoH, Richard Pengelly, to the Commissioner on 17 June 2019 clarified that, while a large amount had been allocated from the Transformation Fund in 2018-19, due to challenges in recruiting staff in the timeframe available only £0.451m was spent. The funding allocation of £0.666m allocated to CAMHS Transformation projects in 2019-20 did not include funding for the CAMHS dataset or the Managed Care Network.

discussion, it was agreed that this then had not been rejected, but would be implemented through an alternative approach.

### **The IDG Action Plan**

As the IDG was developing its Action Plan, NICCY was asked to identify priorities that should be implemented first. In recognition of the fact that recommendations may need to be addressed on a phased basis, we outlined those that we would advise prioritising at this stage with reasons for choosing these.

#### Data and Funding – Sub group 1: Working Together (Rec 1 and 47)

- Addressing gaps in data and funding alongside the establishment of the Inter-Departmental Group are core pillars required for the successful delivery of the other recommendations.
- Public access to CAMHS data and funding information is necessary for transparency and accountability in monitoring progress in the availability, accessibility and quality of services available for children and young people's emotional wellbeing and mental health and for the planning, commissioning and delivery of services.

#### Referral Pathways to include Role of Voluntary and Community Sector (Rec 2-7)

- Addressing problems with the length of wait and ensuring young people are navigated to the most appropriate service in the first instance is critical to quality of care and service user's outcomes, and is likely to have very positive knock on effects on the efficiency and effectiveness of services across system when addressed.

#### Accident and Emergency (Rec 21&22) and Alcohol and Drugs (Rec 41-44)

- Still Waiting highlighted very serious concerns about the quality of care provided to young people presenting to A&E in mental health crisis, including those suicidal or having attempted suicide. These are potential right to life issues that require urgent attention.
- Addressing this recommendation is timely with the DoH review of urgent and emergency care underway and RCPCH Audit of ED against minimum care standards that includes those references in Still Waiting Rec: 21&22, calls for improved standards in A&E and better working together in the recent 2017/18 Self Harm Registry report and concern raised via HSCT CAMHS & A&E Interface Group Meetings.

- There is a significant correlation between young people presenting to A&E in a mental health crisis with alcohol and drug problems. Therefore, we would advise that recommendations that relate to A&E and intensive community / in-patient alcohol and drug support services are considered together. These are issues identified in the Review of Regional Facilities and therefore there is potential to work together with this team to achieve progress on these recommendations.

#### Children and young people with a learning disability (Rec 37)

- We understand from the IDG response to the Still Waiting recommendations that “ID CAMHS is a priority area targeted for investment and development of service provision that ensure greater consistency across the region.” We agree with this assessment and due to the substantial amount of work required to ensure service provision for this group is comparable to those available to children without a learning disability, this work should begin as a matter of urgency.
- Addressing Rec 37 would have positive knock-on effects to Rec 38-40.

#### The role of the education system (Rec 32-35)

- Still Waiting found lots of untapped potential in the education system when it comes to educating young people about their emotional and mental health development and significant room for improvement in the co-ordination and communication between Health and Education. These challenges are practical ones, which relate to improving standards and effectiveness in what schools should already be doing, and should not be cost prohibitive to address now. ETI are currently reviewing their model of inspection - there is potential to strengthen the focus they give to this aspect of the curriculum.
- Improvements in mental health and wellbeing education in schools will benefit all children and young people and has the potential to reduce poor mental health developing, improving outcomes for children & young people and reducing the numbers requiring specialist CAMHS.

In September, following a series of meetings and shortly after receiving NICCY’s advice on priority recommendations, the IDG shared with NICCY its Action Plan for taking the recommendations forward.<sup>3</sup> This is structured using the eight themes, i.e.:

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<sup>3</sup> The IDG Action Plan is available on the Department of Health website.

1. Working Effectively and Collaboratively;
2. Accessing Help;
3. Supporting adults working with children and young people;
4. Specialist support;
5. Moving from child to adult services;
6. Flexible treatment options;
7. Mental health awareness and understanding; and
8. Young people with additional needs.

The Action Plan has a logical structure, outlining clear objectives, associated actions, measures, outcomes, responsibilities and timeframes. It goes beyond the priority areas proposed by NICCY and the link to NICCY's recommendations are also indicated for each action.

NICCY warmly welcomes this Action Plan, as it indicates the seriousness with which relevant Departments and Agencies are responding to the Still Waiting recommendations. It is clear that these have been given careful consideration and a great deal of work has gone into translating them into a practical and workable action plan.

The IDG have flagged up in the Action Plan that a significant number of the actions will require Ministerial approval. 'Still Waiting' showed that the current system is failing to meet the needs of children and young people with mental health needs and there is a need for a rapid overhaul of the system to properly address these. The actions set out will go some considerable way towards improving the current system and giving children and young people with mental health needs the help and support they deserve. We hope therefore that Ministers will support the recommendations in 'Still Waiting' and the resultant actions set out. The Commissioner stands ready to discuss this programme of work with Ministers.



## Moving forward

Over the next three months we will continue to engage with the IDG in clarifying aspects of the Action Plan and to provide suggestions for its improvement. Some initial areas for discussion will be:

- Providing further clarification on how best to secure an increase in funding for statutory CAMHS services. We hope this will lead to a concrete target to which we can then work;
- Providing further information on the funding required for key recommendations, and ensuring that sufficient resources are allocated and spent;
- Clarifying the purpose of the scoping and mapping exercises contained in the action and making sure that actions follow from these;
- Ensuring that specific actions take full and proper account of children's statutory rights;
- Ensuring that there are more practical solutions contained in the action plan, including greater outreach to those working directly with children and young people in services; and
- Establishing mechanisms by which the IDG engages a broader range of stakeholders on the development and implementation of its Action Plans.

We will engage with the IDG to ensure that the priority areas are fully addressed in this initial phase of delivery, but that all recommendations are directly reflected in the Action Plan in a phased basis. The timeframes in the Action Plan are largely short term, with most due for completion in 2020, and only a few extending to 2021. We understand that this Action Plan reflects the initial actions over the first phase of delivery, and will discuss with the IDG the timeframe for subsequent Plans. We will also seek to reach agreement with the IDG on a set of indicators by which we can measure the outcomes of their work to implement the Still Waiting recommendations.

The IDG have agreed to provide a report on its progress on implementing its Action Plan in December, and in February 2020 (to coincide with Children's Mental Health Week) we will subsequently publish a Monitoring Report containing our analysis of the IDG response to the Still Waiting recommendations. Reflecting our commitment to this work, this will be the first in a series of four annual Monitoring Reports on the implementation of Still Waiting, culminating in the final report in February 2023.

These reports will provide an independent assessment of progress made against the recommendations set out in the report, and we will engage with a wide range of stakeholders to inform this monitoring process, including children and young people

themselves. The final Monitoring Report will provide a more in-depth review of progress, and will also be informed by children and young people who have sought to access support for their emotional and mental health.

Ultimately, the success or otherwise of any strategy / action plan should be judged on its outcomes – in this case the extent to which it has made a tangible difference to the availability, accessibility, quality and participatory nature of mental health services and support for children and young people.

### **Young People's Engagement**

The experiences of young people accessing services was the core of Still Waiting and our work to ensure implementation is centred on our commitment to honour their words and views. This includes informing children and young people of our findings and supporting them to have their voices heard in relation to the provision of emotional and mental health services.

The NICCY Youth Panel group on mental health continues to meet to support the implementation of the Review. They are currently working in partnership with young people from 'Elephant in the Room' to develop a campaign resource 'Tool Kit' which will be made available to children and young people across Northern Ireland to support their engagement with Government in delivering on their Article 24 Right to the highest attainable standards of mental health.

### **Conclusion**

When writing the recommendations for 'Still Waiting', the intention was that they should be as practical as possible and helpful to a system that was still in development. We heard directly from children of their experiences seeking to access services, reviewed data from service providers and analysed the resources expended. The Commissioner was clear that this was not a report that should remain on a shelf, but rather one into which we would put as much effort and energy engaging relevant authorities in implementing the report, as we had done in writing it. One year on, while the Commissioner would have liked to see quicker progress, we are nevertheless pleased at the responses we have received from the key departments and agencies - particularly in establishing the IDG and producing its recent Action Plan. This reflects a recognition of the importance placed on providing high quality, emotional and mental health services for children and young people in Northern Ireland. The Commissioner sincerely welcomes this and looks forward with optimism to reporting on progress in February 2020.