



'STILL WAITING'

**A Rights Based Review of Mental Health
Services and Support for Children and
Young People in Northern Ireland**

Summary Report

September 2018

NICCY
PROMOTING THE RIGHTS OF
CHILDREN & YOUNG PEOPLE

How to get Help

If you are a young person reading this report and need support with your mental health talk to your parents/guardians, GP, teacher or another trusted adult.

You can also contact the following organisations:

Childline

0800 1111

www.childline.org.uk

Childline provides a 24 hour free telephone advice line and online 1-2-1 chat advice for any child or young person who has a concern.

Samaritans

116 123

www.samaritans.org

Samaritans offers a confidential hotline which is free to use by anyone who needs help. They also have branches across Northern Ireland.

Contact NI

0808 808 8000

www.contactni.com

Contact NI runs school based, community based and specialist counselling services free of charge. They also run the lifeline helpline.

For more detailed information on this report or support for Children and Young People please see our website www.niccy.org

Artwork Acknowledgement

We thank the children and young people from the Upper Springfield Youth Team in West Belfast who kindly allowed us to use their artwork on the front cover, back inside cover and Executive Summary page. It was created as part of a project in which they explored the issues impacting on local young people's mental health.

We thank Aaron Fox's parents, Paul and Sarah, who kindly allowed us to use Aaron's artwork on the inside cover. Aaron created this as part of his GCSE Art and Design in 2016.

We thank the young people from Bloomfield Youth Safety Partnership in East Belfast who kindly allowed us to use their artwork on the back cover. The project's aim was to raise awareness and reduce the stigma of mental health for young people and to signpost those affected by mental health issues to direct services that are available in the community.



Foreword

I became Northern Ireland Commissioner for Children and Young People in March 2015, and at that time I announced priorities that my office would focus on during my term in office. One of those priorities was the emotional well-being and mental health of children and young people. At that time I under-estimated how important an issue it would be, I do not under-estimate it any longer.

The United Nations Convention on the Rights of the Child (UNCRC) is the framework that guides the delivery of law, policy and services for all children and young people. The Convention is not an aspirational set of ideas, but a set of basic minimum standards which should be upheld for the promotion, protection and realisation of the rights of all our children. This Review is underpinned by the UNCRC and based on the experiences of children and young people, services and the system. We hope we have demonstrated how child and adolescent mental health services (CAMHS) can be 'rights compliant'.

In 2016, the Committee on the Rights of the Child published General comment No. 20, on the implementation of the Rights of the Child during Adolescence:

“States should adopt an approach based on public health and psychosocial support rather than over medicalization and institutionalization. A comprehensive multi-sectoral response is needed, through integrated systems of adolescent mental health care that involve parents, peers, the wider family and schools and the provision of support and assistance through trained staff” (UN 2016, Para 58).

A children’s rights compliant mental health system, is one which is responsive to children and young people as their needs arise. It is integrated and takes a whole-system, end-to-end approach, extending from prevention through to inpatient services.

A lot of work has already been done in reviewing and reforming the child and adolescent mental health system in Northern Ireland, which I commend. However, the pace of reform has been glacial, which is only partly due to insufficient resources. My office spent a considerable amount of time in the course of this Review talking to young people, their parents/carers, and professionals from across all sectors. It became apparent some issues still require further scrutiny, namely understanding children and young people’s access to services, particularly within statutory CAMHS. We heard from parents and practitioners that young people with learning disabilities, and those with drug and/or alcohol problems, were not receiving the services they required.

As Commissioner for Children and Young people, I have a range of duties and powers in relation to statutory authorities, and for this reason we concentrated on the statutory system’s services. However, it is clear from the findings of the Review that this system cannot function without the vital input of the voluntary and community sectors. Children and young people were very clear that the services provided by voluntary and community sector organisations, were just as essential in

meeting their mental health needs as those provided by the statutory system. Reform and developments cannot focus on one aspect of the system alone.

On reading this report you will quickly discover why *“Still Waiting”* can be its only title. Young people wait to seek help, and they wait to access the help they need. Despite the plethora of reports recommending reform, Northern Ireland still waits to see the necessary legislative, policy and system changes being fully implemented.

My intention is that the recommendations we have made will be helpful to a system that is still in development. It will be clear as you read *“Still Waiting”* that an enormous amount of work has gone into it, however that is only part of the process. We now have a greater understanding of children’s experiences of services, of the data collected and held by the system, and some of the resources expended. We have assessed this information against the UNCRC and other human rights standards, and have found the system wanting in particular areas, and have made recommendations to address these.

“Still Waiting” shines a light on the positive changes that have been made to date, as well as changes urgently needed. NICCY’s work in the coming period will be to ensure that the entire children’s mental health system responds to my calls, and makes the changes necessary.

We were determined that this work would be undertaken by the NICCY team, so that we could engage with the system and with children and young people directly throughout the process. This decision was the right one and we have learnt a lot from this approach.

We are deeply grateful to two Advisory Groups – firstly the professional group who were incredibly generous with their time, knowledge and expertise. Their support was

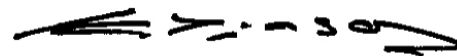
invaluable. Secondly, the NICCY Youth Panel who advised throughout the process and were amazing when it came to the survey development, the publicity materials and of course the final reports.

This Review contains a significant amount of data and financial information, and we thank our colleagues in the relevant statutory authorities for their assistance.

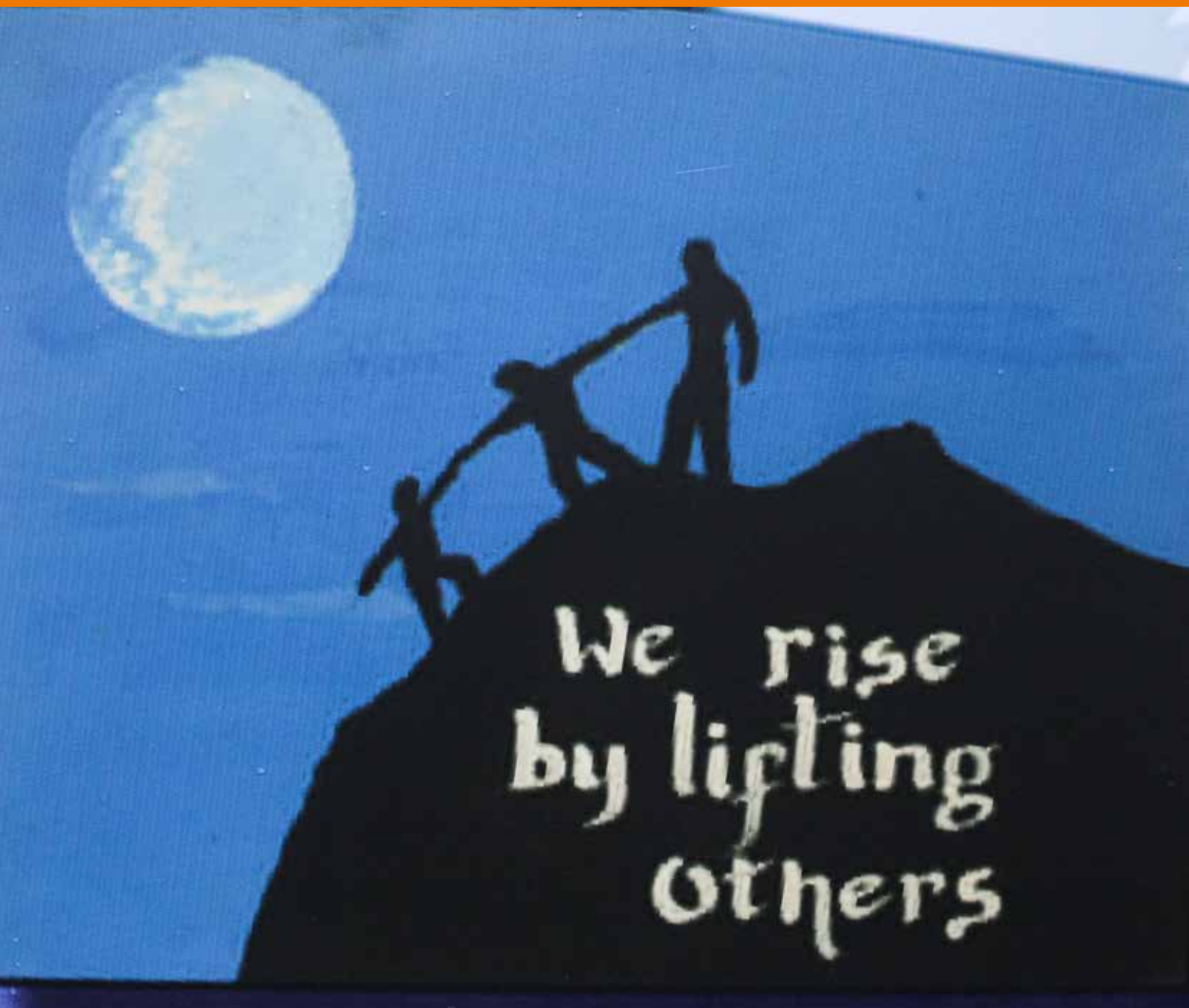
The partnership with Mencap, Start 360 and Dunlewey Addiction Services ensured that the young people with whom NICCY engaged in the course of the Review, were prepared and supported to share their experiences through interviews.

The NICCY team have been remarkable and very resourceful. They have not only risen to, but exceeded the challenge. I am in awe of their professionalism and commitment to this work.

To the hundreds of young people who participated in this Review, by sharing your experiences, completing the survey or participating in interviews, I am honoured that you trusted us with your stories and experiences. We are mindful this is a privilege and we will not let you down. My office will work to ensure that the next generation of young people will not have to wait for their rights to be met, in the way some of you did. Therefore it is with enormous pride and determination that I present *“Still Waiting”*.



Koulla Yiasouma
**Northern Ireland Commissioner for Children
and Young People**
September 2018



EXECUTIVE SUMMARY AND RECOMMENDATIONS

This is a summary report from a Rights Based Review that NICCY has undertaken on mental health services and support for children and young people in Northern Ireland. You can view the full version of the report on NICCY's website at www.niccy.org/StillWaiting, along with a Young Person's report and an Easy Read version.

This Report is the culmination of a Rights Based Review of Mental Health Services and Support for Children and Young People in Northern Ireland, carried out by the Northern Ireland Commissioner for Children and Young People (NICCY), in accordance with its functions under Article 7(2) and 7(3) of The Commissioner for Children and Young People (Northern Ireland) Order 2003. The aim of the Review was to assess the adequacy of mental health services and support for children and young people, using a children's rights framework. A central focus of the Review was to enable children and young people (and their parents and carers) to share their direct experiences of accessing, or trying to access, mental health services or support; identify barriers preventing children and young people accessing adequate support; highlight good practice and make recommendations for improving services. In doing so we also wanted to increase public awareness of the rights of all children and young people to good quality mental healthcare.

The Stepped Care Service Model for Child and Adolescent Mental Health Services

(CAMHS) is the preferred regional model for the organisation and delivery of mental health services and support for children and young people in Northern Ireland (DHSSPS, 2012). The Model applies a broad 'whole system' approach to services, and contains 5 Steps of support which includes: prevention, early intervention, specialist intervention services, crisis intervention and inpatient and regional specialist services. This Review examined children and young people's experiences of mental health services and support, using the Stepped Care Model as the service framework. It also examined available operational and budgeting data relating to mental health services in Northern Ireland. The Review has given a particular focus on Steps 3 – 5 of the Stepped Care Service Model for CAMHS, which includes statutory community out-patient, crisis intervention and inpatient care. **(Main report: Section 1)**

A mixed methods approach was adopted in carrying out the Review, which included gathering the views and experiences of children and young people who had accessed or tried to access mental health services and support. This involved carrying out a survey with 11-21 year olds- 604 young people started the survey, however, not all young people had experience of every service covered, for this reason the sample size varies for each service. The survey gathered experiences of seven key services across all steps of the Stepped Care Model, from GP services (n=246), through to inpatient provision (n=28). In addition, face-to-face interviews were carried out with two groups of young people at higher risk of developing mental health problems - young people with a learning disability (n=15), and young people with drug and/or alcohol problems (n=17). **(Main report: Sections 3 & 4)**

A mapping and analysis exercise of available operational and budgetary data on mental health services and support available to children and young people was carried out. NICCY also engaged with a range of professionals in the course of the Review on an ongoing basis, and carried out two practitioner focus group workshops in Derry/Londonderry and Belfast which engaged with 68 professionals.

(Main report: Sections 3 & 7)

The Review found a system under significant pressure, finding it difficult to respond to the scale of need, and the complexity of issues children and young people are presenting. It is clear that the core budget for children and young people's mental health services has not changed significantly enough to meet its ambitions for system reform. It also found chronic under-investment, historical patterns of funding allocations which are not based on known mental health needs, and a very mixed experience from young people on the availability, accessibility and quality of services provided. **(Main report: Sections 4-6 & 8).**

Alarming gaps were found in the collation of vital disaggregated, basic operational data required to efficiently plan, commission and deliver CAMHS. We acknowledge that during the period of this Review important steps were being taken to fill gaps in service level data through the implementation of the CAMHS Dataset, and the commissioning of the first population wide prevalence survey on children and young people's mental health which will provide essential information on the extent of mental ill health of children and young people. Comprehensive information monitoring systems must be established and maintained. **(Main report: Sections 3.7 & 7)**

The Review Team engaged with many practitioners committed to improving the mental health and well-being of children and young people. It spoke to Voluntary and Community Sector (VCS) organisations who were supporting young people with mental health needs of a much more serious nature than they should be working with, because of waiting times or other problems young people have with accessing specialist statutory services. We heard from Health and Social Care Trust (HSCT) CAMHS teams who are developing innovative practices in order to try and meet the challenge of increasing need, without an increase in the core budget. A range of stakeholders also talked about the benefits and opportunities of statutory and VCS service providers working closely together to support young people. **(Main report: Sections 9.4 & 9.6)**

We were fortunate to have such a large number of courageous and resilient young people who shared their experiences of accessing, or trying to access, support for their mental health. Overall there were very mixed views of the availability, accessibility and quality of support, but one consistent message was the hope that their experiences would help to improve the system for other young people. **(Main report: Sections 4-6)**

The Review found a lack of recognition of the Stepped Care Model for CAMHS among non-mental health professionals, as being a relevant, overarching policy in their area of work. This disconnect was particularly apparent as Accident and Emergency (A&E) does not have a clear strategic position within the Stepped Care Model, even though it is a key service which comes into contact with young people with mental health problems. The Review found delays in the implementation of the Managed Care Network (MCN), which has been designed to ensure better integration and co-ordination of acute CAMHS. It also found the inclusion of only health and social care CAMHS providers within the MCN. **(Main report: Section 9.3)**

Mental Health Pathways and Thresholds for Accessing Services. **During the professional workshops**, both VCS and statutory practitioners described children being 'referred on' from service to service within the Stepped Care Model, due to a lack of capacity within services. Within the survey and during the interviews, young people themselves talked about having to speak to multiple professionals, across a range of services before getting access to appropriate support, a situation which is contrary to one of the main aims of the Stepped Care Model, which is to 'simplify patient pathways'. The Review found young people having to wait too long to access services, and the perception that in practice, if not in policy, thresholds to access Step 3 CAMHS had increased. Single point of entry and triage systems aim to ensure that children and young people are directed to the most appropriate support as quickly as possible, however they also rely on sufficient capacity in the services or support identified. The evidence NICCY has gathered shows that services across the Mental Healthcare System are struggling to meet demand. **(Main report: Sections 4-6 & 9)**

In practice, it appears that a significant proportion of referrals to Step 3 CAMHS

come from GPs, this is despite a number of other 'accepted referral agents' being included in the regional referral guidelines for Step 2 and 3 CAMHS.¹ GPs expressed a need for training in children and young people's mental health, resources to allow them access to a greater range of self-help supports to offer young people, better communication between primary care and statutory CAMHS, clarity on referral criteria and pathways, stronger links between mental health experts and GP surgeries, and more robust and efficient feedback mechanisms where statutory CAMHS referrals are not accepted. **(Main report: Section 9.4)**

During the Review a range of stakeholders including GPs, VCS representatives and children and young people, said they would like referral pathways to be opened up to allow a greater range of professionals to make referrals to statutory CAMHS, and to ensure 'accepted referral agents' knew they could do so. This was particularly the case where young people had already been engaging with a VCS organisation, school counselling service or Self Harm Intervention Programme (SHIP). **(Main report: Sections 4.7 & 9.4)**

A key part of this Review has been about gathering a detailed understanding from young people themselves, about the stages or events between the first symptoms of their mental health problems emerging, and accessing professional support. It has become apparent that for many young people this process can be an unacceptably long time. It is concerning that, on average, just under half (49%) of the young people who had experience of services covered in the online survey, said they were able to access help when they needed it. Many young people are also delaying seeking help, only asking for help when they can no longer cope.

This makes it vitally important that they are enabled to seek help earlier, and that when they do seek help, the pathways to access support are straightforward, responsive and effective. **(Main report: Sections 4, 4.2, 5.8, 6.4, 9.4 & 9.6)**

In terms of Step 3 CAMHS, the Review found that between 2013/14 and 2015/16 the percentage of referrals not accepted ranged between 33% and 42%. There is no regional monitoring of the reasons for referrals not being accepted, and the review has raised concerns about how adequately young people, not accepted for Step 3 CAMHS, are supported to find other more appropriate help. The 9 week waiting time target for Step 3 CAMHS is calculated from the date of acceptance of the referral to the time the patient is seen, and assessed at their first appointment. There is policy and clinical guidelines but no monitoring of the waiting times at critical points of young people's care – between first appointment and review appointments, the waiting time between the referral being made to Step 3 CAMHS, and the decision being made about whether they are accepted. Nor is there monitoring of waiting time targets relating to access to psychological therapies for children, despite the existence of statutory 13 week waiting times, which apply to children and adults. Very vulnerable young people talked about their mental health deteriorating, for some to a crisis point, as a direct result of the delay in being able to access services, and being dissuaded from seeking services in future due to a lack of timely interventions. **(Main report: Sections 4, 5.8, 6.4, 7.1 & 7.2)**

There are a range of extremely concerning findings relating to **access to crisis mental health support**. The development of Crisis Assessment and Intervention Teams (CAIT) are a very welcome addition to the support

¹ Accepted referral agents include: GP, Child and Family Social Services, Paediatric Services, Child Health Services, Education Welfare Services including the Independent Counselling Service for Schools (ICSS), voluntary agencies within the Stepped Care Model and Family Support Hubs (HSCB, 2018:2).

and services available to young people, who require urgent intensive community intervention, to meet their needs and prevent hospitalisation. The introduction of CAIT services may have contributed to the overall reduction in the numbers of young people admitted to adult mental health wards, reported between 2014/15 (n=21) and 2017/18 (n=6). However, the Review also found considerable variances in the service coverage across HSCTs, which means that not all young people have access to the same level of support. Crises for a lot of young people happen outside of normal 9am-5pm working hours of services **(Main report: Sections 7.5 & 9.5)**

Accident and Emergency (A&E) is a regional medical emergency service available 24 hours a day, 7 days a week. When specialist crisis mental health services are not available or easily accessible to young people, or when medical intervention is required, young people are likely to present to A&E. A quarter (23%) of young people surveyed, and three quarters (75%) of young people interviewed with alcohol and/or drug problems, had experience of using A&E during a mental health crisis. The experiences shared by young people have highlighted significant problems with the support that is available for young people who are suicidal, and also with the aftercare support for those who have attempted suicide. 60% described the help they received in A&E as unhelpful. Young people did not think staff in A&E were adequately trained to support them or help them to access appropriate support. Over half (54%) reported feeling uncomfortable and unsafe when accessing A&E for their mental health issues, and many described a lack of follow-up support in the hours and days following presentation to A&E. Suicidal young people described leaving A&E without seeing a mental health professional, which in some cases led to an escalation in their crisis situation, due to the delay in being able to access appropriate and timely help. This

Review has found no evidence of a central monitoring system to track young people who attend A&E with mental health problems as a presenting need. Nor is there any systematic regular review of A&E facilities, regarding how they respond to children with mental health needs. The pathways from A&E to other more appropriate support need to be quicker, clearer and more robust. **(Main report: Sections 4.12, 6.4 & 9.5)**

A recurrent issue raised by young people was that they would have liked more **support at different stages of accessing Step 3 services**. Young people were more positive about their experience of Step 3 CAMHS when they could access 'wrap around support', often from a VCS organisation, between clinical appointments. Young people and practitioners agreed that a collaborative approach, which included support from both statutory (clinical) and VCS organisations (practical) was effective in aiding young people's journey through the mental health system, and in achieving better mental health and well-being outcomes. It was noted however, that availability of such multi-sectoral collaborative approaches are patchy. Young people also reported that self-help support such as coping strategies or online resources, would be useful while waiting for a Step 3 CAMHS appointment. Practitioners suggested the provision of a statutory CAMHS 'on call' telephone line for young people, parents/carers and health professionals to get advice, whilst waiting for a referral or between appointments. Some young people spoke about not being able to access support while waiting for a Step 3 CAMHS appointment, including schools' counselling (ICSS). Also, young people waiting for Autism/Autism Spectrum Disorder (ASD) assessments reported not being able to access Step 3 CAMHS. **(Main report: Sections 4, 5.8, 6.4 & 9.6)**

Many young people talked about difficulties they faced with **making and attending mental health appointments**, many of which related to

the symptoms of their mental health problems. In the survey, 42% of young people reported having to cancel or not being able to attend a mental health appointment. The Review also found that substantial and persistent regional rates of Did Not Attend (DNA) or Cannot Attend (CNA) for first appointment and review appointment for Step 3 CAMHS. For the 3 year reporting period provided, rates of DNA and CNA have remained at 15–16% for first appointments, and 24% for review appointments. The reasons for non-attendance are not monitored by the Health and Social Care Board (HSCB) and there are no plans to. For the purposes of this Review, there was no data available on the number of young people being discharged from the statutory CAMHS system, due to DNA/CNA. Young people and a range of health professionals referred to a lack of follow-up on support being arranged after discharge from mental health services. Nine GPs talked about young people being discharged from Step 3 CAMHS without their knowledge, which indicates a potentially significant issue with compliance with the regional IEAP guidelines, which requires that: *“if a patient / client DNA / CNA their appointment, a review of the risk factors should be undertaken in partnership with the patient / clients General Practitioner (GP) and a second appointment offered, if required. Any decision to discharge should be fully documented and the patient / client informed in writing.”* (HSCB, 2010, para 7.6; HSCB, 2018:2) **(Main report: Sections 7.3 & 9.6)**

Young people, particularly those with co-occurring mental health and drug and or alcohol problems, spoke about needing intensive support to make and attend appointments. During the Review, young people identified a range of practical changes that would help with making and attending appointments, this included online booking systems and appointment slots outside of school hours. Young people with anxiety or depression said that being able to attend appointments at home, or closer to home, may

have helped them to keep their appointments. **(Main report: Sections 4.15, 6.4 & 9.6)**

Young people reflected on poor **co-ordination and communication between services**, particularly regarding relevant information about their circumstances, needs and support arrangements e.g. school, social services and statutory CAMHS. Young people talked about feeling exhausted and re-traumatised having to repeat their ‘story’ or circumstances, to a range of different professionals. They also talked about difficulties they faced when a course of treatment ended and no follow-on support was provided. Young people highlighted ‘follow on support’ as vitally important in helping them to recover. In fact young people, parents/carers and professionals were unanimous in agreeing that more intensive community based mental health support is required for children and young people. They highlighted the practice of professionals ‘signposting’ young people on to another service without support to navigate through the complexities of the mental health system, as very unhelpful and overwhelming for some. There is currently no system in place to track young people moving between different services or support within the Stepped Care Model for CAMHS, and many young people were identified in the course of the Review who had ‘fallen through the gaps’. A lack of handover between services, including challenges with transitioning between statutory CAMHS and Adult Mental Health Services (AMHS), were highlighted as particular problems. **(Main report: Sections 9.6 & 9.12)**

With regard to the **effectiveness of treatment and support**, young people commonly referred to a lack of choice in the support or treatment available or involvement in the decision making. They wanted to have a greater range of psychological therapies or alternative therapies available to them. NICCY was unable to obtain regional information on the range of psychological or alternative therapies

'available', or being 'used' with children and young people in the course of this Review. Many of the young people engaged with through the Review had experience of taking prescribed medication in 2017, 12,765 prescriptions of anti-depressants were given to under 18 year olds in Northern Ireland, a proportion of which were to under 12 year olds, and there has been a year on year increase in prescriptions since 2014. This is a worrying pattern in itself, but, it is extremely concerning that statistics show that some types of anti-depressant medication prescribed to young people are not recommended for children and young people by NICE guidelines.

(Main report: Sections 4.2 & 9.7)

Young people with co-occurring **drug and/or alcohol and mental health problems** spoke about their frustration at medication being the main form of support available to them, and expressed their reluctance in taking medication because of their problems with substances. Young people wanted to have a greater range of support options available to them. The engagement with young people also raises concerns about the extent to which appropriate supervision and support are available to this group of young people to ensure that prescribed medication is being taken as directed. **(Main report: Sections 6.4 & 9.15)**

Young people were unanimous in the need for the **root cause of poor mental health** to be addressed as part of their overall care. They identified a range of factors as contributing to their poor mental health and many young people, particularly those with drug and/or alcohol and mental health problems, described dealing with multiple adversities and toxic stress. These included child sexual exploitation, neglect, physical abuse, domestic violence, substance abuse in their family and bereavement. It was clear that a failure by the system to deal with these issues when they arose, or since, was compounding

the young people's problems. The review found that mental health problems for young people with a learning disability are often caused, or exacerbated by, the barriers and discrimination they face in day to day life. **(Main report: Sections 4.4, 5.8, 6.4 & 9.14)**

The critical **role of a significant adult** was a key theme raised by all the young people engaged with as part of the Review. Young people were clear they confide in adults about their mental health based on who they can trust, and not on mental health competency: the main people being family and friends, GP, CAMHS, A&E, Hospital, School Counsellors, and Teachers. The Review identified a need for a whole population approach to children's mental health needs, in order to respond in a timely and sensitive manner. **(Main report: Sections 4.5, 5.8, 6.4 & 9.8)**

With regard to **participation and feedback**, when young people were asked to rate the quality of their care, on average, across all seven services young people were asked to share their experiences on, 73% agreed they were spoken to in a way they could understand, and 57% felt listened to and respected. Only 42% agreed they felt involved in the decisions being made about their care (ratings for different services varied between 16% and 75%), and 40% agreed they were given a choice of treatment and support, this was lowest for in-patient care (19%) and A&E (23%) as opposed to VCS (67%). **(Main report: Sections 4.2 & 9.9)**

Regarding **outcomes**, the Review found that on average, across all seven services young people were asked to share their experiences on, just under half (49%) of young people did not find the services they accessed helpful. A number of services rated below average – GP (44%), Community CAMHS (45%), In-Patient Care (39%) and A&E (34%). Young people and their parents also expressed a lack of knowledge on how to make a complaint about a mental health service. The information from

this Review highlights the absolute necessity of embedding feedback mechanisms into the system, to inform the planning and delivery of services. It is also essential that the outcomes measured are not solely clinical and include those that are defined by, and important to young people. **(Main report: Sections 4.2, 4.17 & 9.10)**

The young people who engaged in the Review gave their views on **The key characteristics of a good mental health service**. They talked about the need for a professional, relaxed, non-judgemental, non-clinical, age-appropriate approach. Clear and consistent boundaries of confidentiality are vitally important to young people. Services should be flexible and operate outside of Monday to Friday 9–5pm hours. The physical environment should be non-clinical and informal, with appointments in places familiar to the young people. Young people want to be able to access clinical and practical support at the same time, which may be why they tended to be most positive about the mental health support they received when it involved both statutory CAMHS and VCS organisations. **(Main report: Sections 5.8, 6.4 & 9.11)**

Many young people (54%) when speaking about the **transition from CAMHS to AMHS**, highlighted a lack of support in transitioning, which had negatively affected their longer term treatment and recovery. They highlighted the need for more preparation and support before, during, and in the period after moving from child to adult services, and reflected on the importance of better communication between CAMHS and AMHS. Young people also mentioned the value of a bridging service for young people aged 16 to 25, which would allow for a smoother transition from child to adult services. Other issues raised include, long waiting lists for adult mental health services, the loss of relationships with trusted health professionals when moving from CAMHS,

and young people not meeting the threshold for adult services on discharge from CAMHS. **(Main report: Sections 4.14 & 9.12)**

The Review found varying levels of **mental health awareness and literacy** across young people. A lack of awareness was particularly apparent among young people with a learning disability. A lack of support exists for young people (and their parents/carers) to develop awareness and literacy around emotional well-being and mental health, and age appropriate and effective ways to address stigma and fear around talking about mental health problems. The adoption of a consistent regional approach to educating children, and normalising conversations about mental health and emotional well-being as vital parts of a system in which prevention and early intervention are prioritised. Strategic oversight and resourcing to ensure this is happening for all young people is essential **(Main report: Sections 4, 5.8, 6.4 & 9.13)**

With regard to **young people with a learning disability**, current models of mental health services available for children and young people with a learning disability vary across Health and Social Care Trusts. There is no regional specialist service model for young people with a learning disability. The Southern Health and Social Care Trust (SHSCT) operate an Intellectual Disability CAMHS (ID-CAMHS) service. In the remaining HSCTs young people with a learning disability are signposted to generic CAMHS, or to learning disability services, and the decision regarding which service young people are directed to, tends to be determined by their IQ level. There is no regional policy on this practice, and therefore each HSCT sets its own IQ cut off point. Generic CAMHS is generally not accessible to children with severe learning disability. However, young people with a mild learning disability or borderline IQ are at risk of having difficulty with accessing either service because they 'sit around' the cut-off point between services. The

separation of CAMHS and learning disability services results in a lack of professionals with expertise or experience in working with children who have a learning disability and mental health problems. The IQ based referral system is extremely concerning, reported to be flawed if used on its own to determine the best service for a young person, and potentially discriminatory, if an equivalent service is not available to young people denied access to generic CAMHS. This Review has also found a high proportion of admissions to the Iveagh Centre are on the basis of detention, and highlighting the potentially inappropriate use of detention as a way of permitting staff to use restrictive practice.

(Main report: Sections 5 & 9.14)

With regard to **young people with alcohol and/or drug problems**, the Review found that drug and alcohol services and mental health services do not always work in an integrated way, nor is there adequate resources to meet the needs of young people requiring different levels of intervention. Gaps in services were particularly apparent for young people with the most complex needs, which would require intensive rehabilitation care in the community, or specialist inpatient care (Step 4 – 5). Many of the young people engaged with through this Review reported that substance misuse was a form of ‘self-medication’, to cope with the symptoms of their mental health problems. There is a need for a service approach which can support these young people in a holistic way, which includes responding to substance use and mental health problems simultaneously. Detention under existing mental health legislation (the Mental Health (NI) 1986) is not possible when a young person is under the influence of alcohol and/or drugs. Mental State Assessments can’t be complete either. This means that some extremely vulnerable young people are unable to access specialist mental healthcare, including inpatient care. A high proportion of the young people interviewed had attended A&E during a mental health crisis, and many

described a poor response from the service.
(Main report: Sections 6, 9.5 & 9.15)

Regarding the **operational data** requested and sourced as part of the Review, NICCY was extremely surprised by the lack of basic operational data collected regionally on children and young people accessing, or trying to access statutory CAMHS services (Step 3 – 5). The Review found alarming gaps in the collation of vital disaggregated, basic operational data required to efficiently plan, commission and deliver CAMHS. Data was not available on the demographic make-up of children in contact with statutory services, their presenting need or diagnosis, the types of treatments received, or the outcomes from these. While some of these data gaps will be addressed through the children’s mental health prevalence survey, and through the implementation of the Regional CAMHS dataset, some will not. Very little data is currently in the public domain, the new datasets must be made publicly available.

(Main report: Section 9.16)

There is general agreement that the **investment in emotional and mental health services for children and young people** is inadequate, however there has been little understanding of the levels of funding for services across different bodies and agencies. This is essential in determining how additional resources should be allocated. One element of the Review was an analysis of how emotional and mental health services for children and young people are resourced, using a fund mapping methodology. NICCY received data sheets from the Public Health Agency (PHA), HSCTs and the Education Authority (EA), providing information on the allocation of more than £31 million on 93 services provided to support children and young people’s emotional or mental health and well-being. While statutory agencies delivered all the services from Step 3 to Step 5, many of the early intervention and prevention services in Steps 1 and 2 were delivered by VCS

organisations. The Review has identified a need for a renewed focus on the coordination of services, as per the Children's Services Cooperation Act 2015, which places a statutory duty on all 'Children's Authorities' to cooperate in improving children's well-being, and to 'pool resources' for this purpose. The Review has also found that in the case of children's mental health, substantial additional and sustainable funding is required, to ensure the needs of children and young people are being met at the earliest opportunity, and in the most effective way. **(Main report: Section 9.17)**

This Review has concluded that if there is to be a significant and sustainable improvement in the quality and accessibility of mental health support for children and young people, it must become a regional health priority. Further progress can only be achieved if all the partners involved in the Regional Stepped Care Model work together, in a meaningful and genuinely collaborative manner. All services whether statutory or non-statutory, specialist mental health or focused on broader well-being are important parts of a whole system approach. Mental health services and support must be available and responsive to children's needs. Despite the barriers and challenges that young people faced whilst seeking help or receiving services, the vast majority stated that they would advise others to seek help for their mental health if they needed it. But there is significant room for improvement and the contributors to this Review have identified what needs to be done

Recommendations

A system-wide response is required to the challenges outlined in this Review. All relevant agencies and sectors must engage together, cooperating to improve children and young people's emotional and mental well-being. This is reflected in how the recommendations are articulated; in most cases this report does not specify any one agency or department against individual recommendations.

The Regional Model for the Delivery of CAMHS

1. NICCY recommends the establishment of a high level multi-agency, multi-sectoral project board that is tasked with the development of a comprehensive, adequately resourced action plan for taking these recommendations forward. This work should be embedded into the existing transformation agenda, and should include:
 - a) The development of a Children and Young People's Mental Health Transformation Fund to drive the change required. This should be a long term and sustainable 'funding and practice partnership model', which takes account of the investment required across all key services and sectors included in the Stepped Care Model;
 - b) The use of the fund mapping methodology and analyses of need, to map increases in spending on emotional and mental health services over time, and to demonstrate how additional resources are being effectively and efficiently allocated to meet the needs of children and young people;
 - c) Formalisation of the relationship between Statutory CAMHS and the Voluntary and Community Sector

(VCS), through the development and implementation of clear strategic policy direction;

- d) The development of a culture and practice of multi-disciplinary and multi-sectoral team working; and
- e) Full implementation of the Managed Care Network (MCN) as a matter of urgency, and review of its potential as a mechanism for co-ordinating and operationalising a whole system approach to the delivery of human rights compliant mental health services for children and young people.

Pathways and Referral Processes

2. The Department of Health (DoH) should review the implementation of the Regional Referral Criteria for Step 2 and 3 CAMHS to:
 - a) Develop a comprehensive training and awareness raising programme, to ensure that all 'referral agents' are aware of the referral process and their role within it;
 - b) Develop regional protocols which allow a broader range of VCS organisations working with young people with mental health problems, to make a direct referral to Step 3 CAMHS or with the support of a GP (fast track process via GP); and
 - c) Introduce multi-disciplinary and multi-agency decision making processes in individual care planning, to ensure that support pathways for young people are direct and effective.
3. Steps must be taken by the HSCTs and the HSCB to address the reasons why young people referred to Step 3 CAMHS are not having their referrals accepted.
4. Progress the development, implementation and monitoring of service specific integrated care pathways, such as those

involving A&E, CAIT and SHIP. These must be informed by the staff and professionals working across the agencies involved.

Professional Support

5. Introduce a mandatory programme of mental health training for all professionals likely to come into contact with young people with mental health problems, this must include GPs. The training needs to develop core professional competencies to respond to young people in a sensitive, competent and age appropriate way. This should include refresher training every 3 years.
6. Designated mental health practitioners, trained to work with young people, should be attached to every GP surgery, and statutory mental health professionals should also be available to every primary and post primary school in Northern Ireland.
7. Introduce Community Mental Health Fora across Northern Ireland, which bring GPs and VCS organisations together to develop local relationships and exchange local knowledge.

Support for Young People at Different Stages of Accessing Step 3 Services

8. Review appointment systems and consider the introduction of:
 - a) An online booking system so young people and carers have more control over the appointment time given;
 - b) Appointment slots available outside of school hours;
 - c) The option of appointments being held in their own home or close to home;
 - d) Reminder texts about appointments; and
 - e) The option of making remote contact with a trained mental health counsellor between appointments i.e. telephone, text.

9. Introduce a Mental Health Passport Scheme that contains key information on young people, which they want professionals involved in their care to be able to access.
10. Introduce a dedicated telephone advice line for statutory CAMHS, which professionals, parents/carers and young people could use as a way of improving the communication and support offered by services, whilst young people are waiting for an appointment or between appointments.
11. Develop a children and young people specific Regional Integrated Elective Access Protocol (IEAP).
12. A range of community based after care supports must be available to young people discharged from Community CAMHS or inpatient care.
13. Provide resources to GPs to allow them access to a greater range of self-help supports to offer young people.

Care Planning and Treatment

14. The administration of prescription medication for young people must comply with NICE guidelines. Where medication is prescribed to a young person with a history of alcohol and/or drug problems this should be risk assessed and appropriately supervised. HSCB must monitor prescribing data to ensure compliance with NICE guidelines.
15. The complete range of evidence based, effective psychological treatments and alternative therapies should be made available to children and young people. Targets for accessing such treatments should be set in the best interests of children and young people, met, closely monitored and reviewed.

16. Joint care planning processes should be developed and reviewed, to ensure that key services work collaboratively and in a co-ordinated manner to support young people to address the biological, psychological and social factors that are causing or contributing to their poor mental health.
 17. The practice of admitting children onto adult mental health wards should end. Children and young people requiring inpatient mental healthcare should receive it separately from adults.
 18. Children should receive the most appropriate and effective inpatient care for their mental health. This should be tailored and appropriate to the level of need, and include the provision of inpatient intensive care where necessary.
 19. Reasons for the increase in the number of young people being detained in Beechcroft need to be urgently interrogated. Similarly, an examination of the variances in referral rates to Beechcroft by HSCTs should be carried out. A clear policy response and actions should be taken forward as a result, in the best interests of children and young people.
 20. The reasons for Extra Contractual Referrals, treatment received and outcomes for children and young people should be closely monitored. Services which are not currently available in Northern Ireland should be provided, so that all young people who require treatment for mental health problems can receive it close to their family and community. This should include secure forensic mental health provision and complex eating disorder treatment.
- ### Access to Crisis Mental Health Support
21. Implement RCPCH 'Minimum Care Standards for Children and Young People in Emergency Care Settings who Present with Mental Health Problems' (RCPCH, 2018).
 22. The DoH should enhance the statutory framework, requiring RQIA to routinely inspect A&E Departments against the 'Minimum Care Standards for Children and Young People in Emergency Care Settings who Present with Mental Health Problems' (RCPCH, 2018). This should include appropriate, robust enforcement powers and the provision of sufficient resources to carry out this role.
 23. Crisis intervention support for children and young people should be available 24 hours a day, all year round, in all HSCTs.
 24. Include a Clinical Decision Unit, or equivalent service model, as part of every A&E Department in Northern Ireland. This would be useful for young people who may require a period of observation, further investigation or other interventions which cannot be completed within the four hour timeframe within A&E Departments.
 25. An evaluation of the compliance with, and effectiveness of, the Card Before You Leave scheme (CBYL) for children and young people in A&E should be carried out.

Participation and Feedback from Young People

26. Development of an action plan to strengthen advocacy, enhance peer support, and develop practice standards to evidence the involvement of young people in service development, and in their own care planning.
27. Revise and establish fora in each HSCT to support the active engagement of children young people and their parents/carers, to inform both acute and community care. Views expressed through this engagement should be considered at the practice based meetings, where day to day issues are raised and discussed.
28. Develop user-friendly guidance for young people and parents/carers which explain their right to complain, and sets out the minimum standards of care they should expect.

Transition from CAMHS to AMHS

29. A Regional Transitions Policy and Procedure which is compliant with NICE Transition Guidelines should be developed and implemented, to ensure that all young people transition smoothly between CAMHS and AMHS.
30. Specific attention should to be given to meeting the support needs of children and young people who do not meet the transition criteria for adult mental health services.
31. Develop a mental health 'bridging service' for young people aged 16 to 25 years old, that allows for a smoother, flexible and young person centred transition between services.

Mental Health Awareness and Literacy

32. Comprehensive mental health and wellbeing education for pupils should be provided as a core part of the education curriculum. This should ensure that all young people have sufficient vocabulary to talk about their emotional well-being and mental health, know how to look after their mental health, have an understanding of the help available and how to access it.
33. Education and mental health service providers should develop formal partnerships in order to holistically meet the needs of children in education at all levels, and for those children and young people receiving their education 'other than at school'.
34. Equal emphasis should be placed on the measurement and improvement of the well-being of children and young people in education, as on academic attainment. Schools should be inspected by ETI on their ability to develop the conditions required to nurture young people's well-being.
35. Information, guidance and training should be provided to parents, carers and children at key stages and transition points across childhood.
36. A programme of public awareness and community capacity building on mental health and emotional well-being should be developed, and regionally implemented with a specific focus on geographical areas, and groups with the highest risk factors for poor mental health.

Young People with a Learning Disability

37. A comprehensive and integrated mental health service model across Northern Ireland for children and young people with a learning disability should be agreed and implemented. This model must ensure that young people with a learning disability can access comparable services and support as young people without a disability.
38. Assess how widespread the practice of determining eligibility of access to specialist mental health services (CAMHS) solely or mainly on the basis of IQ is, and take all necessary measures to ensure that access to services is always on the basis of need.
39. A comprehensive review of community based emotional, mental and behavioural support services for young people with a learning disability should be carried out without delay.
40. Immediate steps must be taken to ensure that all detentions of children and young people in the Iveagh Centre under the Mental Health (Northern Ireland) Order 1986 is proportionate and appropriate.

Young People with Alcohol and/or Drug Problems

41. Statutory CAMHS should adopt a 'harm reduction approach' to ensure that young people can access mental health support whilst withdrawing from substances. Appropriate levels of supervision and support for young people withdrawing from substances should be provided.

42. Universal and timely access to Drug and Mental Health Services (DAMHS) should be available across Northern Ireland. DAMHS should be closely aligned to CAMHS, and closely linked to Step 2 commissioned drugs and alcohol services.
43. Step 4 specialist intensive community based support and interventions for young people with drug and/or alcohol and mental health problems should be expediently developed, and provided across Northern Ireland. This should include day treatment programmes and age-appropriate interventions.
44. Inpatient care and treatment should be provided for young people with co-occurring drug and/or alcohol and mental health problems, who cannot be safely and effectively supported within the community. This provision should take a holistic approach to need, provide a range of interventions and be fully integrated into the Stepped Care CAMHS service model.

Data and Monitoring

45. The DoH should develop a universal health information system linked to every individual child, to inform every health professional coming into contact with a child and/or their parents/carers. This should link to other information systems, such as UNOCINI. 'Patient level' data should be integrated into statistical reports as part of a transparent and accountable information reporting system, so that the impact of services on outcomes for children and young people can be tracked.

46. Government should ensure that the first Northern Ireland Prevalence Survey of children and young people's mental health is completed by year end 2019/20, and published soon thereafter. Further prevalence surveys should be repeated every 3–5 years.
47. The CAMHS Dataset should be fully implemented across each HSCT. Adequate resources should be provided to establish and maintain the system. Data should be published on a regular basis, in line with other health statistical reporting. The Dataset should be augmented to include additional basic information and data, required to monitor services and effectively plan CAMHS. These include:

Outpatient

- a) Information on young people who are accessing emotional well-being and mental health services through Learning Disability Teams/Disability Teams;
- b) The specific reasons for referrals not being accepted to Step 3 CAMHS; and
- c) Track young people moving between services within the Stepped Care Model for CAMHS. This would help to monitor the length of time and the pathways required for young people to access support. This must include young people who are not accepted for referral to Step 3 CAMHS.

Waiting Times

- d) Collection and monitoring of additional waiting time statistics:
 - i) Waiting times for services beyond Generic Step 3 CAMHS, to include key services across Steps 2 – 5 and waiting times for urgent and emergency appointments to Step 3 CAMHS;
 - ii) Waiting times between referral being made and referral being accepted or not accepted;
 - iii) Waiting times for second appointment to Step 3 CAMHS;
 - iv) Waiting times for access to psychological therapies; and
- e) Data on the types of psychological therapies and alternative therapies used as part of young people's treatment plan.

Attendance at Appointments

- f) The reasons for DNAs/CNAs should be recorded and monitored. Specific attention must be given urgently to addressing the reasons for non-attendance; and
- g) Record the numbers of young people who are discharged from CAMHS due to DNA/CNA and monitor compliance with IEAP guidance.

Inpatient

- h) Record and monitor referrals not accepted to Beechcroft inpatient unit.

Adult Wards

- h) Discharge destinations of young people admitted to adult mental health wards should be recorded and monitored.

Demographics

- i) A greater range of demographic information for specific groups of young people should be collected e.g. those with a physical, learning, sensory disability, looked after children; LGBT children; Newcomer and Separated Children.

Outcomes

48. A greater depth of information regarding patient experiences and outcomes should be collected and monitored, including outcomes defined by, and important to young people e.g. improvements in relationships with friends and family - in addition to psychometric scores of mental health.
49. Universal health services, such as GP and A&E, should agree on and implement a set of standardised information system codes, to record and monitor the numbers and profiles of young people with mental health problems and/or drug and alcohol problems accessing their services.
50. When a young person is admitted to a general paediatric bed for mental health treatment or care, the DoH should request that RQIA are notified, and provided with information on what care and treatment is being provided.

The Northern Ireland Commissioner for Children and Young People commits to monitoring the implementation of these recommendations, and will engage with all relevant agencies to ensure improved outcomes for children and young people. NICCY will publish monitoring information on an annual basis.





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Please contact the communications team at NICCY if you require an alternative format of this material.

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