

Executive Summary

Following consultation with members of Children in Hospital Ireland, three key areas were identified for specific attention in our submission: enhanced integration of care for children with complex health needs, further development of play for children in hospital, and enhanced mental health services for children and adolescents.

There are many challenges within the infrastructure of primary care that impacts on service delivery to children and their families, compounded by advances in technological innovation, and population demands. It is acknowledged that some initiatives are beginning in this area in the Irish context, however, there remain extensive challenges. The extent to which this requirement is met in practice by national health care systems, varies considerably among the countries of Europe, and is the core purpose of the Horizon 2020 funded project Models of Child Health Appraised (MOCHA), running from 2015 to 2018 (MOCHA Project 2016). In the meantime there is a need for: development of specialist community posts, enhanced clinical governance, increased equity of access and a comprehensive digital clinical information system.

For the child in hospital the absence of an appropriate means to process and cope with care delivery can lead to initial mild stressors progressing to a toxic level, which have been shown to have adverse effects on a child's health, well-being, growth and development. This has the potential to lead to negative long-term consequences ranging from psychological discomfort and distress to the child's failure to achieve developmental milestones. To date the need to assess and facilitate play in hospital has not received any particular attention of note in Irish Government policy. Given the firm evidence of the value of play in hospital it is important to recognize the skills and value of Hospital Play Specialists and play volunteers, to ensure funding for the enhanced delivery of this service and to provide a funded play service in every children's unit throughout the country.

Ireland's poor track record in addressing the mental health needs of children and adolescents was highlighted again in the recent UN Committee on the Rights of the Child (2016) which identified significant deficits in the State response to mental health issues in children. It is estimated by Cannon *et al.* (2013) that by the age of 13 years almost 30% of young Irish people will have experienced some form of mental disorder and by the age of 24 years, over 50% of young Irish people will have experienced a mental disorder. The gravity of the current situation requires immediate action on what is already known, and promises already made, including: reducing access time to mental health support, enhanced early diagnosis and intervention programmes for children with behavioural /mental health problems and an increase in dedicated mental health care facilities for children and adolescents to ensure they are provided with expert care by staff who are appropriately qualified to care for them.

List of Recommendations

Improving Integrated Care

- Specialist community based posts, including care coordinators and nurses with specialist training to support the transition of these children from acute setting to home, and to support their ongoing care in the community.
- Agreement and direction at policy level on the criteria for competent care delivery and clarity in the responsibility and regulation of training and education of nurses and healthcare staff caring for these children.
- A clinical information system that will transcend organisations to enhance information flow and integration of care delivery for children with complex care needs and their families.
- Address any inequity of access to care provision in the home to ensure care provision is not influenced by post code.
- An initial funded pilot project of a defined model of integrated care for children with complex care needs, prior to national implementation.

Enhancing the Provision of Play

- Recognition of the skills and value of Hospital Play Specialists (HPSs) and play volunteers for children in hospital.
- Further education and training of HSPs and the provision of a funded therapeutic play service in every children's unit throughout the country as an essential member of the multi-disciplinary team.
- Funding of CHI to continue to recruit, train and support volunteer teams and around the country.
- Action recommendations from *Ready, Steady, Play!* (National Children's Office 2004), with a dedicated budget line for the provision of ongoing development in this area.
- Establish community play specialist roles to enhance the care of children with chronic illness across the acute – community care interface.
- Establish developmentally appropriate programmes of play and distraction for children with special healthcare needs in hospital.

Enhancing Mental Health Services for Children and Adolescents

- Reduce access time to mental health support as a priority.
- Early diagnosis and intervention programmes for children with behavioural /mental health problems.
- Increase awareness of supports available, and how to access them, for children, adolescents and their parents / guardians.
- Increase psychological support for children and families in acute settings following traumatic injury.
- Increase dedicated mental health care facilities for children and adolescents to ensure they are provided with expert care by staff who are appropriately qualified to care for them.

INTRODUCTION

CHI is a voluntary organisation committed to promoting and ensuring the welfare of all children in hospital and their families, and functions as part of a wider European network. For 41 years the organisation has been directly working

with sick children to bring them fun and support and it uses its expertise to deliver unique daily and weekly play sessions that support child patients, parents and staff in 20 hospital wards and playrooms nationwide. CHI has a strong profile in child advocacy in Ireland and internationally, demonstrated through: experience in supporting parents/guardians and children; input in to key hospital and paediatric unit developments; and a record of delivering, and contributing to the development of play and therapeutic services for children in hospital through a variety of salient activities. Following consultation with members three key areas were identified for specific attention in our submission: enhanced integration of care for children with complex health needs, enhanced mental health services for children and adolescents and further development of play for children in hospital.

IMPROVING INTEGRATED CARE

There are many challenges within the infrastructure of primary care that impacts on service delivery to children and their families, compounded by advances in technological innovation, and population demands. This challenge is particularly noteworthy for children with complex healthcare needs, children who have substantial healthcare needs as a result of one or more chronic conditions, with functional limitations that often require technology assistance and need to access multiple health support services (Elias & Murphy 2012). Population prevalence estimates by the World Health Organisation (WHO) suggest that one in every 33 infants is born with a congenital malformation (WHO 2012). While a relatively small proportion of the population, the cost of healthcare for this group is very high; figures from the United States show that children with complex health needs account for as much as one-third of healthcare spending for all children (Berry *et al.* 2014). Although the provision of care closer to home for such children is a policy objective internationally (Peter *et al.* 2011), integration of health services is insufficient with wide variation in systems of care for these children. Progress towards achievement of this goal has been slow despite growing evidence that homecare: provides a means of mitigating the barriers and isolation children and their families experience during the transition from hospital to home, can significantly reduce hospital utilisation, and reduces the cost of care for children with complex care needs (Long *et al.* 2013, Parker *et al.* 2013).

Key constituents for a successful transition to home for such children were identified by Noyes *et al.* (2014). It is acknowledged that some initiatives are beginning in this area in the Irish context, however, there remain extensive challenges. These include communication of a child and family's needs at the acute-community interface, lack of clarity regarding the roles, scope of practice, responsibilities, supervision and monitoring of nurses, trained carers and parents; confusion over eligibility for services and the process for seeking funding for home care packages; and no defined system of documenting care needs and care delivery in a manner that can be accessible for the family and the multi-disciplinary team (Brenner *et al.* 2015). Furthermore, there is inequity of access depending on geographical location and the governance of care for children with complex care needs in the community in Ireland is often unclear and is compounded by the fragmented nature of health service delivery to this population. This

approach requires direction and support at the level of health service policy and is compounded by the absence of nationally-agreed standards for the care of children with healthcare needs in hospital or in the community in Ireland. This problem is not unique to the Irish setting. It is consistent with the diverse approach to the education preparation of nurses and healthcare professionals who care for these children and their families across Europe.

Many children with complex health issues are also living well into adulthood. For example, children with diseases such as cystic fibrosis and sickle cell, who would not have been expected to reach adulthood in the 1970s, are now living into their 40s and 50s (Bourke *et al.* 2009, DeBaun & Telfair 2012). Despite advances in life expectancy, maintaining

their quality of life during the transition period remains problematic and coincides with the period in their life where there is a reduction in parental responsibility and a peak in the influence of peer risk-taking behaviour (Holtlander *et al.* 2012, Helgeson *et al.* 2014). The challenge then is to identify a suitable programme for this time in a young adult's life that will accommodate care continuity, support for greater responsibility and compliance with treatment. One example of such a support is the Stepping Up programme launched in 2013 ([www. SteppingUp.ie](http://www.SteppingUp.ie)).

Models of care in some European countries appear to be more facilitative of these healthcare demands than others, such as the multi-professional primary care teams in Sweden and the Netherlands. However, little is understood about the specific processes and procedures that contribute to the success or failure of such models for this group, which varies considerably among the countries of Europe, and is the core purpose of the Horizon 2020 funded project Models of Child Health Appraised (MOCHA), running from 2015 to 2018 (MOCHA Project 2016). This study is embedded in the various peculiarities of national healthcare systems and the ethical and legal concerns bound to the linkage of child health data. One aspect of the MOCHA project, led by Dr Maria Brenner, is to provide an updated comprehensive analysis of the current approach in each EU and EEA Member State to managing the care of children with complex care needs, with particular regard to the integration of care at the acute/community/primary interface. The outcome of the study therefore has the potential to make a wide contribution to individual countries of the EU/EEA to understand their own level of integration of services mapped against responses from other member states. Further work, using the same surveys will be used within the project to map the EU/EAA picture against that in the United States for children on long-term ventilation and against that in Australia for children with enduring mental health conditions. Early results are expected towards the end of 2016.

ENHANCING THE PROVISION OF PLAY

It is suggested that healthcare-related stress and anxiety in children ranges from positive, to tolerable, to toxic (Middlebrooks & Audage 2008). Positive and tolerable stress may produce minor short lived physiological and psychological discomfort which the child can tolerate and overcome if appropriate support is provided by an adult carer or a healthcare professional. However, if support is not provided or if there is long-term multiple exposure, these mild stressors can progress to a toxic level, which have been shown to have adverse effects on a child's health, well-being, growth and development with potentially negative long-term consequences (National Child Traumatic Stress Network 2014). Consequences range from unnecessary psychological discomfort and distress to the child's failure to achieve developmental milestones. Children with chronic illnesses may be particularly at risk of adverse outcomes where ongoing intrusive and painful interventions are required (Schumacher & Meleis 2010, Ekra & Gjengedal 2012). Strategies such as the use of therapeutic play, toys, video games, painting and music, among others, have been reported in the literature to achieve a lower level of anxiety and stress both in hospital settings and in general (Guo *et al.* 2012, Ladouceur *et al.* 2013, Rosen *et al.* 2013). Behavioural and distraction methods have also been identified as an efficient way of reducing paediatric anxiety compared to medications (Golan *et al.* 2009, Ni *et al.* 2012).

It is widely acknowledged that these benefits go beyond reducing stress and fear during a clinical procedure; specifically these benefits include boosting a child's confidence and self-esteem, providing an outlet for emotions, facilitating communication, and assisting in diverting a child's thoughts from aspects of their clinical care (Jun-Tai 2008, Kline *et al.* 2010, Weiss *et al.* 2011). Research on therapeutic play for the child in hospital has focused on identifying and understanding the optimum delivery of therapeutic and specialised play to help a child cope with being in hospital. This includes studies on the impact of play prior to clinical procedures and the benefit of play during clinical procedures (Kline *et al.* 2010, Weiss *et al.* 2011). For example, Jun-Tai (2008) focused on the impact of play on children prior to wound dressings, in which children of varying ages were afforded the opportunity to relax in a tranquil environment to instill a sense of calm prior to having a change of wound dressing. The intervention resulted in children being more relaxed at the start of the procedure, and being more co-operative during the procedure. This was beneficial in decreasing the length of time required to perform the procedure and improved the child's experience of having a clinical procedure in hospital.

Play constitutes an important parameter of a child's normal development and collectively these studies support the value of play in increasing the child's ability to cope with the demands of hospital. Though the use of play, children have the chance to gain control in many situations, thus supporting the child's interaction with healthcare into a more positive experience, enhancing their potential to continue engaging with their healthcare providers (an exceptionally important issue during adolescent transitions to self-management). To date the need to assess and facilitate play in hospital has not received any particular attention of note in Irish Government policy. Instead the

value of play for children has focused on the provision of play facilities in communities (National Children's Office 2004). In contrast, the work of Hospital Play Specialists (HPSs) and the voluntary play service largely goes unrecognised, and they are not referred to in the National Clinical Programme for Paediatrics and Neonatology (2016).

HSPs are skilled in the use of play in a variety of therapeutic and specialised ways, across all clinical settings, to minimise stresses on children in hospital. They use play as a distraction, for education and preparation about procedures that the child might have to experience, and they also use play post-procedurally to support a child to understand what has happened to them. Due to the limited professional play service available much of the play support in Ireland is provided by voluntary recruits who are trained by CHI. Volunteers provide familiar and normalising play, the everyday activities children would experience in their everyday lives. This in itself is therapeutic for the children but the intention is to give them the opportunity to engage, socialise, play and above all, have a bit of fun. The volunteers work under the direction of the HPS, where there is a HPS on staff. Given the firm evidence of the value of play in hospital it is important that the skills and value of HPSs, and play volunteers, are recognised and supported in future health service planning for children's health services throughout the country.

ENHANCING MENTAL HEALTH SERVICES FOR CHILDREN AND ADOLESCENTS

In Ireland, the current government health strategy has made many recommendations in response to the UN Convention (United Nations 1989) including the establishment of out-of-hours social services as a priority, early intervention programmes for children with behavioural or intellectual disabilities, the expansion of mental health services for children and adolescents, and a national integrated programme for child health. However, to date little progress has been made on most of these recommendations. For example, out of hours access to social services continues to be a considerable problem and intervention programmes for children with disabilities is insufficient in meeting the demand. In recent years, despite the publication of a Vision for Change (Department of Health & Children 2006), mental health services for children have not shown any notable improvement. The most recent epidemiological study (Cannon *et al.* 2013) surveyed 1,131 young people and conducted 453 diagnostic clinical interviews with young people to assess them for the presence of mental disorders and to examine their overall level of functioning. The study found that young Irish adolescents in the 11-13 year age range have higher current rates of disorder (15.4%) than similarly-aged young adolescents in both the USA (11.2%) and the UK (9.6%). The study estimates that by the age of 13 years almost 30% of young Irish people will have experienced some form of mental disorder and by the age of 24 years, over 50% of young Irish people will have experienced a mental disorder.

The Children's Mental Health Coalition (2015) make a number of salient recommendations, based on a thorough review of the literature on child and adolescent health needs, which we support. These include the need to: build capacity in primary care services to effectively prevent, detect and appropriately treat child and adolescent mental health difficulties and disorders; ensure accessible, community based, evidence-informed and outcomes-monitored child and adolescent mental health services; develop accessible, inclusive, developmentally appropriate specialist inpatient care for children and young people with complex mental health needs, along with local, evidence-informed services. In addition it is important to highlight that care of children with mental health issues in acute adult medical facilities continues to occur due to the absence of appropriate care facilities. This repeatedly goes against best practices internationally, with staff not qualified or equipped to address the specific needs of such children and their families. All of these concerns were again brought to the fore internationally in the UN Committee on the Rights of the Child (2016) which identified significant deficits in the State response to mental health issues in children. While the recent initiative by Helen McEntee TD, Minister of State for Mental Health and Older People, regarding the National Taskforce on Youth Mental Health is welcomed, the gravity of the current of deficits in mental health services for children requires immediate action on what is already known and promises already made.

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