

NICCY Response to the Patient and Client Council on Draft Corporate Plan for 2017-2021.

10 January 2017

Thank you for the opportunity to respond the Patient and Client Council (PCC) draft corporate plan for 2017-2021.

The Office of the Commissioner for Children and Young People (NICCY) was created in accordance with 'The Commissioner for Children and Young People (Northern Ireland) Order' (2003) to safeguard and promote the rights and best interests of children and young people in Northern Ireland. Under Articles 7(2) and (3) of this legislation, NICCY has a mandate to keep under review the adequacy and effectiveness of law, practice and services relating to the rights and best interests of children and young people by relevant authorities. Under Article 7(4), NICCY has a statutory duty to advise any relevant authority on matters concerning the rights or best interests of children and young persons. The remit includes children and young people from birth up to 18 years, or 21 years, if the young person has a disability or has been/is in the care of social services. In carrying out these functions, paramount consideration must be given to the rights of the child or young person, having particular regard to their wishes and feelings and to all relevant provisions of the United Nations Convention on the Rights of the Child (UNCRC).

As set out by the Order the UNCRC is the guiding framework by which NICCY carries out its work and along with views of children, young people and their parents provides the checklist for everything that we do. The key statutory duties of the Commissioner fall into three categories i.e. advising, promoting and monitoring and it is with these duties in mind that we make this response.

NICCY recognises the important statutory role that the PCC have in providing an impartial, independent voice regarding health and social care services for patients, clients, carers and communities in Northern Ireland. Information gathered by the PCC is one of the main mechanisms for capturing the views of health service users with the findings from reports shaping the PCC's subsequent business plans, along with the Commissioning Plans for the Health and Social Care Board (HSCB), Public Health Agency (PHA) and Local Commissioning Groups (LCGs)¹. Moreover, the PCC have a key statutory role in encouraging and supporting individual young people to seek redress when breaches occur.

¹ The People's Voice: A summary of the work of the Patient and Client Council 2009-2016 (2016) pg, 9

We wish to highlight the specific role of the PCC in being a key statutory advocate for children and young people using health and social care services. We recognise the commitment outlined by the PCC in its draft corporate plan *‘to ensure the most vulnerable in our society, including children and adults at risk of harm, are looked after effectively across all health and social care services.’* Children and young people have an innate vulnerability because of their age and evolving capacity. In the context of the work of the PCC this means that specific measures need to be considered in order to ensure that children and young people are facilitated in having their statutory rights met. Children and young people are one of the groups most vulnerable to being discriminated against with regard to access to health care services and likely to have most difficulty in using complaints systems. In both cases this is often because services and systems are developed by adults, for adults. It is well understood that services are more effective when they are shaped by the people using them.

Relevant Articles of the UNCRC

As the main Human Rights Institution for children and young people in Northern Ireland, have a duty to promote awareness of their right, having due regard to the UNCRC.

Article 4 of the UNCRC stipulates that all State Parties, which includes government departments and their agencies, must take measures to ensure that all convention rights are fully reflected in the work that they do: *“States Parties shall undertake all appropriate legislative, administrative, and other measures for the implementation of the rights recognized in the present Convention.”*²

There are four guiding principles³ of the UNCRC which provide the basis for all other rights, including the right to health (Article 24).

Article 2, in the context of health, requires State Parties to recognise every child’s equal right to the best possible health and access to health services without discrimination.

Article 3 places an obligation on State Parties to ensure that the best interests of the child are assessed as a primary consideration in all actions affecting the child. The Committee urges State Parties to place children’s best interests at the centre of all decisions affecting their health and development, including the allocation of resources, and the development

² CRC/GC/2003/5- General Comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child

³ UNICEF Handbook

and implementation of policies and interventions that affect the underlying determinants of health.

Article 12 emphasises children's right to participation, including in health promotion and the need to respect the views of the child in decisions made about their own health care and in the planning and provision of health services.

Article 6 sets out a child's rights to survival and development and is the foundation for Article 24 which sets out the right of every child to the highest attainable standard of health and for facilities for the treatment of illness and rehabilitation of health; and that States Parties shall strive to ensure that no child is deprived of his or her right of access to such health care services. (Article 24 (1))⁴

NICCY wishes to comment on a number of key areas referred to in the Corporate Plan; in large part these relate to how the corporate goals can deliver for children and young people and in particular how PCC can ensure that through its work, it promotes and protects children's rights.

The current Executive has placed a very strong emphasis on gathering user experiences of health and social care services - we very much welcome this commitment as it is only by doing this that key child rights principles can be met. The Health Minister has recently outlined her commitment to establishing effective mechanisms for listening to those with experience of using the health system and to use that information to shape services which meet their needs and expectations⁵.

Investing in a range of feedback mechanisms is a necessary way of ensuring that people who are at risk of discrimination, or experiencing poor treatment or care, have a vehicle through which they can have their voices heard. It also benefits service providers and commissioners who can ensure that the HSC system provides interventions that support patients as early as possible and which are meeting minimum quality standards.

It is very important that the views of children and young people are collected as part of any process and where possible this should be the direct feedback from children and young people and not through a 'proxy'. This is a right that all children and young people aged 0-18 years old have under both domestic and international law e.g. Personal and Public Involvement obligations set out in the Health and Social Services (Reform) Northern Ireland Act 2009, Section 75 of the Northern Ireland Act 1998 and UNCRC (Article 12).

⁴ <http://www.ohchr.org/Documents/ProfessionalInterest/crc.pdf>

⁵ Health and Wellbeing 2026- Delivering Together, Department for Health, October 2016.

There is currently very little visible evidence of feedback processes within the HSC system being tailored to ensure that children and young people are facilitated and encouraged to give their experiences and views i.e. policy or service development. Neither is there evidence of where information collected from children and young people has influenced or shaped health and service policy or practice. This is particularly evident for those aged under 16. The PCC have an important role in monitoring each of the Health and Social Care Trust's delivery of this statutory duty and indeed of facilitating young service users input to the planning and delivery of these services.

Programme for Government

We fully support the Patient and Client Council's intention to align its work with the Executive's Programme for Government 2016-2021 (PfG) objectives. NICCY has provided a range of advice to the Executive on its draft Programme⁶, this includes the overarching necessity for the PfG to fully reflect the current strategic legislative and policy context in relation to delivery for children and young people in Northern Ireland. In particular it should reflect the statutory obligations on children's services providers as set out in the Children's Services Co-operation Act (Northern Ireland) 2015 (CSCA), and the related development of the next Children's and Young People's Strategy for Northern Ireland. When one compares the current PfG indicators against the eight CSCA well-being measures, it is clear that there are gaps and omissions in relation to its compliance with these legislative requirements. NICCY has been advising the Executive that in order to fully comply with this obligation, it is essential that the Children's and Young People's Strategy is regarded as the delivery vehicle for Outcome 14 and indeed all additional 13 outcomes areas as they relate to children and young people.

In our response to the NI Executive's consultation on the Programme for Government we welcomed outcome 11 - 'We Have High Quality Public Services -% of people who are satisfied with health and social care' which is aimed at starting to gather some aspect of users' experiences of HSC services. This outcome clearly aligns with the work of the PCC and in the remainder of our response we have made specific comments on how we think the PCC can develop its engagement with children and young people. It is only through such engagement that it can fully and accurately represent the interests and views of children and young people, and by so doing ensuring that the design, commissioning and delivery of health and social

⁶ Advice to the Northern Ireland Executive on its Draft Programme for Government, <http://www.niccy.org/publications/2016/december/23/programme-for-government-pfg/>

care services result in high quality services which are meeting needs and achieving improved outcomes.

CSCA

The new Children's Services Co-operation Act (Northern Ireland) 2015 (The Act) is a significant legislative development which aims to improve the well-being of children and young people in a manner which realises their rights. The Act⁷ in addition to providing a legislative basis for the Children's and Young People's Strategy, also places a statutory duty on government departments and their agencies to work together with other 'children's authorities' and with 'other children service providers' to deliver on the eight 'wellbeing' outcomes for children. These outcome areas include physical and mental health, equality of opportunity and good relations and making a positive contribution to society (which includes a child's right to participation). In order for the PCC to discharge its statutory function, collaboration is necessary with a range of health and social care services the public access. This new legislation provides a useful tool the PCC can use to obtain better co-operation between different parts of the health and social care system.

PCC engagement with children and young people

We welcome the specific reports published by the PCC that focus on the views and experiences of young people using the health system. For example, the Young People's Priorities Report published in 2012 that included the views of over 1200 young people aged 16-21 on Health and Social Care. In fact, the PCC was recognised by NICCY through our Participation Awards in 2013 for creating a space for young people to be involved in decision making.

Unfortunately to our knowledge, few substantial reports have been produced since that time, which focus specifically on young people or which include a representative sample size. Furthermore, we note that the majority of the research done by the PCC is with 16+ year olds and therefore, in the main, excludes those aged under 16 years old. As children under 16 years old will also use health and social care services, it is important that their experiences are gathered; where possible, this should be taken from them directly, or alternatively, through an advocate.

Key articles of the UNCRC including Article 13, on the right to freedom of expression, and article 17, on access to information and Article 12, on the right to be heard, establish that '*all children are right holders and are entitled to exercise those rights on his or her own behalf, in*

⁷ <http://www.legislation.gov.uk/nia/2015/10/contents/enacted>

accordance with her or his evolving capacities.’ The Convention does not establish an arbitrary age upon which capacity is met, rather it asserts that, *‘children who are capable of forming his or her own views should have the right to express them and for them to be given due weight in accordance with the age and maturity of the child’*. We also recognise that in some cases it is not possible to seek the view directly from children and young people, i.e. babies, very young children, children with severe learning disabilities. In these cases, parents, carers or advocates should be encouraged and supported to speak on their behalf.

Addressing barriers to involving children and young people

NICCY recognises that there are a range of issues which need to be taken into consideration when engaging with children and young people, this includes suitable times for meeting, transport to/from meetings, ethical considerations such as consent and confidentiality, and developing age appropriate forms of engagement. We also acknowledge budget constraints the PCC works under; however, there are equally specific issues and additional support requirements with engaging with other health service user groups i.e. people with a learning disability or mental health problem.

In order to ensure that there is appropriate allocation of resources to children and young people, we would recommend that the PCC set specific targets for engaging with children and young people - reports, membership scheme, and complaints. The resource allocated should be commensurate with the level of usage of the health and social care system by children and young people, but also take account of the fact that communication methods and engagement strategies often need to be different to those required for adults.

Disaggregation of Information

In general, NICCY is concerned about the lack of regional, easily accessible and transparent data on health and social care services used by children and young people. The lack of a regionally robust system for collecting and analysing patient and client experience data is a serious issue which should be addressed as a matter of urgency. The UN Committee in General Comment 5 reminds State Parties that *‘the collection of sufficient and reliable data on children, disaggregated to enable identification of discrimination and/or disparities in the realization of rights, is an essential part of implementation.’*⁸ Furthermore, the Committee on the Rights of the Child in its recent examination of the UK State Party (which includes NI as a devolved region) reiterated the need for disaggregated data on health for *‘planning and monitoring purposes’*.

⁸ CRC/GC/2003/5- General Comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child, para 48

We recommend that all reports produced by the PCC include a demographic breakdown of the respondents/participants e.g. by age, ethnicity and disability etc. This includes all evaluation / research reports, specific projects, annual complaints reports, and monitoring of PCC membership. Providing this level of demographic detail is necessary to understand the level of involvement of children and young people in the strategic policy work PCC do and in accessing individual legal support through the complaints service. The annual complaints reports do not provide an age breakdown of those accessing the service or the age of the person on whose behalf the complaint is being made.

Child Friendly Complaints System

One of the four statutory functions of the PCC is to provide assistance to individuals making or intending to make a complaint relating to HSC services. The PCC complaints support role is specifically defined in the HSC Reform Act 2009 as *'providing assistance (by way of representation or otherwise) to individuals making or intending to make a complaint relating to health and social care for which a body to which this section applies is responsible'*.

Alongside domestic legislation, the UNCRC is very clear that child friendly complaints systems are an important way for children and young people to have their rights realised. More specifically, good complaints processes help ensure their rights to non- discrimination (Article 2), that their best interests are a primary consideration in actions concerning them (Article 3) and to have their voice heard and taken seriously (Article 12). As a consequence, the realisation of these rights ensures that service providers are developing practice in partnership with health service users that is responsive to need.

The UNCRC general comments provide additional information on the right of children to access an appropriate complaints system. General Comment 5 sets out a range of general measures to ensure the full implementation of children's rights.⁹ This includes the importance of effective remedies for redressing rights violations that include independent complaint procedures. Furthermore, it highlights the need for child sensitive procedures for children and their representatives due to their special and dependent status which creates difficulties for them in pursuing remedies for breaches of their rights.

For rights to have meaning, effective remedies must be available to redress violations. This requirement is implicit in the Convention and consistently referred to in the other six major international human rights treaties. Children's special and dependent status creates real difficulties for them in pursuing remedies for breaches of their rights. So States need

⁹ CRC/GC/2003/5- General Comment No. 5 (2003) General measures of implementation of the Convention on the Rights of the Child (arts. 4, 42 and 44, para. 6)

to give particular attention to ensuring that there are effective, child-sensitive procedures available to children and their representatives. These should include the provision of child-friendly information, advice, advocacy, including support for self-advocacy, and access to independent complaints procedures and to the courts with necessary legal and other assistance. Where rights are found to have been breached, there should be appropriate reparation, including compensation, and, where needed, measures to promote physical and psychological recovery, rehabilitation and reintegration, as required by article 39. (Para 24)

General comment 12 also highlights the importance of ensuring any complaints system is accessible, flexible and age appropriate:- ¹⁰

(...)Children need access to information in formats appropriate to their age and capacities on all issues of concern to them. This applies to information, for example, relating to their rights, any proceedings affecting them, national legislation, regulations and policies, local services, and appeals and complaints procedures. (para 82.)

In view of the fact that the PCC receive no complaints from or on behalf of children and young people, we would welcome further information on any assessment the PCC have made on why this is the case, including plans you have to rectify this issue, including reaching out to children and young people and their parents / guardians to promote your services and ensure they are set up in a way that is approachable and young person friendly.

Bamford Monitoring Group

The Bamford Monitoring Group does not appear to be an effective mechanism for feeding the views of children and young people into health and social care service planning and delivery. It is our understanding that group membership is limited to those aged 16 and over but in reality members tend to be aged 18 years and over. Mechanisms must be put in place for gathering the views of children and young people, including under 16's, who have experiences of accessing health and social care services.

The Bamford Programme Project structure will be changing with dissolution of the HSCB. This review represents an opportunity to improve engagement with health service users by developing more age appropriate communication methods. The PCC have an important statutory responsibility to ensure that all groups within society are fully represented on these groups - this includes children and young people.

¹⁰ CRC/C/GC/12: General Comment No. 12 (2009) The right of the child to be heard

The current prioritisation of partnership working with patients, service users, staff and politicians in service planning and delivery outlined in the Bengoa Report and the focus in the Programme for Government on developing systems that measure patient satisfaction, provides a real opportunity to embed, strengthen and promote the involvement of children and young people in decision making throughout the health and care system. As the PCC is the statutory body for providing an independent voice for the public in health and social care issues, we respectively remind you of your duties to fully and accurately represent the experiences and views of children and young people, and by so doing ensure that the design, commissioning and delivery of health and social care services are providing high quality services which are meeting their needs and achieving improved outcomes as stated earlier

NICCY recognises that the PCC have endorsed NICCY's Participation Policy Statement of Intent (PPSI), which calls for appropriate consideration to be given to engagement and participation of children and young people in policy decision making. The PCC were also represented at a recent NICCY roundtable which involved statutory sector partners who have specific responsibilities to engage with children and young people in their work. This was very encouraging and demonstrates your commitment to ensuring that the PCC exercises its statutory duties on in relation to children and young people. We look forward to continuing supporting you in this and in seeing the out-workings of the corporate plan in the time ahead.

Thank you again for the opportunity to respond to the PCC draft corporate plan. We hope that you find this response useful and would be happy to discuss any of the issues raised with you in more detail.