Health and Sport Committee evidence session: Year of Young People 2018

Call for views: Healthcare Improvement Scotland response

Thank you for the opportunity to contribute to the Committee’s evidence session on the Year of Young People.

Healthcare Improvement Scotland’s core aim is better quality health and social care for everyone in Scotland. Our strategy, Making Care Better, outlines our priorities underpinning this aim, and the voice of people is threaded throughout these. As a result, we will:

- advocate for and support shared decision making through engaging with people to understand what matters to them
- ensure service redesign and improvement is informed by voices of local people
- gather and share views on what matters to people to help shape health and social care policy and services
- ensure that quality assurance is informed by the voice of local people.

In particular, the Scottish Health Council, part of Healthcare Improvement Scotland, works closely with a wide range of stakeholders in order to support and promote effective engagement in the design and delivery of health and social care.

Healthcare Improvement Scotland welcomes the Year of Young People as an opportunity to raise the profile of young people in Scotland, and to acknowledge and celebrate the importance of young people in society and in the context of public policy and service delivery. We are aware that a number of NHS boards are planning additional activities focused on young people as a result.

Healthcare Improvement Scotland’s remit covers health and social care and we have not, therefore, commented on sport policy in this response.

- How well are the views and interests of young people taken into account in health and sport policy?

Healthcare Improvement Scotland believes that the many national and local organisations which do an excellent job of representing the views and interests of young people, as well as young people themselves, are best placed to answer this question.

Whilst we have not conducted any systematic review in relation to how young people’s views are taken into account in health policy, there are a number of areas of our work that are relevant in this context.

The Scottish Health Council, which is part of Healthcare Improvement Scotland, has gathered views from young people on a number of national healthcare policy issues. This has usually involved working in partnership with third sector or other public sector organisations to design and carry out the engagement in a way that takes the needs and
wishes of the young people participating into account. Most recently this has included gathering views on issues such as organ and tissue donation and transplantation\(^1\), and on realistic medicine and shared decision making. Reports of this engagement are submitted to policy leads in Scottish Government and published on the Scottish Health Council website.

It is vital that the young people who take part in engagement on policy issues receive feedback about how their views have been listened to and acted on, and providing such feedback should be prioritised by policy-makers. There is a risk that people will not get involved in future and will lose confidence in service providers or policy-makers if they cannot see the impact their involvement has had.

In 2017, the Scottish Health Council, in partnership with Includem, commissioned a scoping study to consider the potential and feasibility of a pan-Scotland, collaborative approach to young people’s participation in the planning and delivery of health and care services. This included a literature review and engagement with relevant organisations and young people, with a survey to which 90 young people responded.

Young people who responded to the survey said that it is a good idea to get young people’s voices heard when people are planning how their health and social care is provided, because:

- it’s their right as the main stakeholders in health and social care service for young people,
- it will lead to better services with better outcomes for young people.

More than half of young respondents (58\%) who expressed an opinion considered that young voices are not being heard when health and social care services are being planned in Scotland. They said that this is because:

- they are not asked what they think when health and social care services are being planned, designed and delivered, and
- they feel ignored if they do speak up.

The full report\(^2\) is available online. The literature review noted that there is very little published evidence about the structures and processes which work well in involving young people in the planning and delivery of health and social care services, and very little published evidence that involving young people in planning and delivery of services makes any difference. This does not mean that meaningful involvement doesn’t happen – however it is not always reflected in the form of published evidence that can be used to inform future practice.

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\(^1\) This engagement is referenced in the Policy Memorandum and other supplementary documents accompanying the Human Tissue (Authorisation) (Scotland) Bill which is currently before the Scottish Parliament

Healthcare Improvement Scotland has also involved young people in various ways to inform our own work, including the following examples:

- We contribute a health perspective to joint inspections of children’s services led by the Care Inspectorate. Along with other scrutiny partners, we have contributed to the development of a revised model of inspection for children and young people that takes a more focused look at those who are most vulnerable, such as those in need of protection and those experiencing corporate parenting.

- Healthcare Improvement Scotland also worked with the Care Inspectorate and key stakeholders to develop national Health and Social Care Standards. One of the 5 key principles underpinning the Standards is about 'being included'. A range of activities were carried out to inform these Standards, including focus groups with primary school children. CELCIS (Centre for Excellence for Looked After Children in Scotland) also ran focus groups with care experienced young people to feed into these Standards. The Standards will underpin all assurance activity carried out by Healthcare Improvement Scotland and the Care Inspectorate in the future.

- The Scottish Intercollegiate Guidelines Network (SIGN), part of Healthcare Improvement Scotland, develops clinical guidelines containing recommendations for effective practice based on current evidence. SIGN is currently developing guidelines for epilepsy in children and young people. It has worked in partnership with third sector organisations to identify people, including young people, to sit on the guidelines group to ensure these guidelines address matters that are important to children and young people. A discussion session with Epilepsy Scotland’s youth group told us what young people thought about living with epilepsy.

- Our Mental Health Access Improvement Support Team aims to enable improved access to Psychological Therapy Interventions and Child and Adolescent Mental Health Services (CAMHS). The team is linking with Barnardos Scotland around alternative models of access and how it can involve young people in developing and designing services. It is also linking with mental health organisations, such as SeeMe and SAMH, who have been gathering information from young people with a lived experience of CAMHS.

- Our work on person-centred health and care, and specifically, working with the Scottish Government, NHS boards, the Alliance and See Me Scotland to promote and support participation in What Matters to You Day, has encouraged conversations between healthcare professionals and children and young people about what matters to them.

- The Scottish Health Council’s Young Voices project\(^3\) tested an approach to engaging with young people to improve services. At each test site we worked with young people and local organisations to explore issues of interest and identify areas for improvement:

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\(^3\) See [https://www.ourvoice.scot/young-voices](https://www.ourvoice.scot/young-voices) for more information about this project and the engagement tools used.
• Access to youth and young adult health and wellbeing services in Highland
• Health assessment process for looked after children in Forth Valley
• Student support and wellbeing services at St Andrews University, and
• Transition support services with young people at Includem.

The duty of Corporate Parenting, which was introduced by the Children and Young People (Scotland) Act 2014, includes a requirement on public bodies, including NHS Boards, to take account of the views and needs of care experienced children and young people, and to promote their wellbeing. Healthcare Improvement Scotland believes this duty has the potential to make a significant difference in improving services for care experienced young people, and we have collaborated with other corporate parents in carrying out this duty.

A recent example of this is when Healthcare Improvement Scotland and NHS 24 joined Who Cares? Scotland to deliver an interactive session to the Who Cares? Young Radicals Group. This is a group comprised of care experienced young people and care leavers aged between 14 to 28 who meet regularly to discuss issues important to them. The learning from this session has been shared with Healthcare Improvement Scotland staff to raise awareness of the issues highlighted by the group and inform future activity.

• What are the priorities in health and sport for young people?

Healthcare Improvement Scotland strongly believes that this question is best answered by young people themselves and the many organisations in Scotland that represent their interests. These organisations have already produced much information about what matters to young people. It is very positive to see that the Health and Sport Committee has been engaging with young people to hear directly from them about the issues they consider are important.

The following are some examples of what young people have told Healthcare Improvement Scotland they consider to be important in the context of our work.

Joint Inspections

When the Care Inspectorate engaged with children and young people about the focus of joint inspections (outlined above) their most important message was that children and young people should be enabled to experience sincere human contact and enduring relationships. They want to be able to build trust through consistent relationships with adults and they want to be supported to maintain contact with those people who are most important in their lives. HIS contributed to the methodology development and discussions about how this could considered in the inspections.

Corporate Parenting – Young Radicals Session

The Young Radicals session mentioned above invited care experienced young people to consider and explore:

• what keeps them well
• where they go for support when feeling unwell
• positive and negative experiences of accessing health and care services
• how support could be improved for care experienced young people.

Suggestions for improvement mainly focused on the building of relationships and learning more about young people’s lives and the context of their health situation. It was also proposed that staff within GP practices should be aware of the impact care experience can have on mental health, and be trained/supported to signpost/support young people who contact them regarding mental health issues, even if there are no immediate appointments in the practice. Other ideas included ways of providing care experienced young people with their own information on vaccination and immunisation, and for this information to be shared between relevant parties.

Young Voices

Whilst the Young Voices project mentioned above took place in 4 different geographical areas and engaged with young people on different issues, there were common themes in the issues they identified as being important to them. These included mental health and wellbeing, and relationships with friends, family and key staff. Other issues raised included: access to support and services; the role of education; and the importance of being taken seriously and treated with respect.

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