NCB and Council for Disabled Children response to *No decision about me, without me: Further consultation on proposals to secure shared decision-making*

"It's managing my way … this is how I want to live my life … it's not only doctors' appointments, it's not only how I can control my condition …. It's about how I can live with my condition but still have a good time and just be a young person."[1]

Summary

- Evidence suggests that children and young people want to share in decisions and that it can benefit them
- The main barrier to this relates to communication with, and the attitudes and skills of, health professionals. This is particularly true for disabled children and those with complex needs, who, although they may face additional challenges, want just as much to participate in shared decision making
- We are concerned that the consultation document and accompanying documents do not show evidence that the impact of the proposed policy on children, or how it will be implemented in ways that benefits them, has been considered
- The consultation appears to conflate shared decision-making with choice of provider. We are concerned about this as action on much broader issues, such as information and communication with health professionals, are more relevant for securing shared decision making for children and young people
- Government, along with local and national health bodies, should take steps to secure shared decision making for children and young people including:
    - Steps to support professionals to better communicate with and engage children and young people in decisions about their health
    - Monitoring and reviewing the extent to which shared decision making is being achieved for children and young people in all health settings.

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[1] Disabled Young Person's view recorded at a focus group for the Council for Disabled Children's Managing My Way Project. See the full research report at http://www.councilfordisabledchildren.org.uk/what-we-do/work-themes/health/practice-and-projects/managing-my-way/research-report

About NCB

The National Children's Bureau is a leading research and development charity working to improve the lives of children and young people, reducing the impact of inequalities. We work with children, for children to influence government policy, be a strong voice for young people and front-line professionals, and provide practical solutions on a range of social issues.

For more information visit www.ncb.org.uk

About the Council for Disabled Children

The Council for Disabled Children (CDC) is the umbrella body for the disabled children's sector in England, with links to the other UK nations. CDC works to influence national policy that impacts upon disabled children and children with special educational needs (SEN) and their families. CDC promotes the active participation of disabled children and young people, making sure their voices and success stories are heard.

CDC membership is drawn from a wide range of professional, voluntary and statutory organisations and agencies. CDC's membership and extensive networks give a unique overview of current issues.

Introduction

NCB and CDC welcome this opportunity to comment on progress towards making shared decision making a reality in health services, although our response does raise concerns about the limited scope of the proposals set out in this consultation. As the current round of reforms of the health service have been developed and implemented, we have been calling for better involvement of children and young people in decisions that affect their health, both in decisions made at a strategic level about service provision and in decisions about their individual care, treatment and support. Our response is informed by what children and young people themselves have told us about their experience of health services. It sets out why being involved in decisions about their care is important to them, what shared decision making looks like, the evidence on the extent to which this is being achieved, and suggestions for how the situation may be improved.

Children and young people want, and can benefit from being involved in decisions about their health

A recent review of the evidence on children's views of health provision carried out by NCB's Research Centre found evidence of positive outcomes when children and young people were listened to and played an active role in the management of their care.[2] Children and young people want to engage in shared decision making and government should consider the barriers they experience to achieving this, alongside good practice, and children and young people's own suggestions for improvements.

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[2] Ivana La Valle and Lisa Payne with Jennifer Gibb and Helena Jelicic (2012) *Listening to children's views on health provision: A rapid review of the evidence*, p6

Over the last two years the National Children's Bureau has supported children and young people to have an input into emerging health policy in England. Through a series of dedicated events[3] children and young people have given their views on a range of topics including the principle of 'no decision about me without me'. The key messages were that children and young people:

- Should have a say in decisions about our health and be allowed to take the lead where they are capable
- Want better health information and better ways of communicating with health professionals to enable them to do this
- Would be willing to train GPs and other health professionals. (The involvement of young people in the development of training was also suggested by the NHS future forum[4])
- Value the support and advice of our parents when making big health decisions.

A review of 31 research studies found that one of the things that children and young people want from health provision and health professionals is to be allowed to be active partners in their care, to be able to express their own views and needs.[5]

A study with hospitalised 13-16 year olds[6] found that:

- Being informed and involved was described by the young people as helpful because otherwise they would have felt more worried and anxious
- Being given information and explanations helped young people feel included in decision making about their care
- Effective communication at an appropriate level was important. In cases when staff only spoke to the young people to *obtain* rather than provide information, or just spoke to a parent, young people felt less in control, less able to trust carers, and more upset.

Support for disabled children and young people to be involved in decisions about their health is vital in helping them develop an understanding of their condition and its affect on their life, and take on greater responsibility for its management as they get older. Failure to do this can have significant implications for a disabled young person's transition to adult services and their long term health outcomes.

Studies of children and young people with cancer have also highlighted the link between involvement in the management of care and positive outcomes, such as avoiding

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[3] See www.ncb.org.uk/ourhealth

[4] Education and Training – next stage A report from the NHS Future Forum p17

[5] Robinson, S. (2010). "Children and young people's views of health professionals in England." Journal of Child Health Care **14**(4): 310-326, cited from *Listening to children's views on health provision*

[6] Kelsey, J., N. Abelson-Mitchell, et al. (2007). "Perceptions of young people about decision making in the acute healthcare environment." Paediatric Nursing **19**(6): 14-18, cited from *Listening to children's views on health provision*

diagnostic delay and negative psychological effects[7], and preparation for making informed decisions about their treatment and other health choices in adulthood. [8]

Considering the application to, and impact of, policy on children and young people

We are concerned that the consultation document does not explore how the policy proposals would apply to children and young people. With all proposals relating to shared decision making, choice and control, and information, it is vital to consider how children and young people will benefit from this. All children and young people, regardless of age and comprehension have a right to have their views heard on all issues that affect them. This right is enshrined in Article 12 of the UN Convention on the Rights of the Child. The relevant UN Committee has set out in its comments what this means in terms of healthcare. This includes a statement that:

> "Children, including young children, should be included in decision-making processes, in a manner consistent with their evolving capacities. They should be provided with information about proposed treatments and their effects and outcomes, including in formats appropriate and accessible to children with disabilities."[9]

How this is realised will always require careful consideration, not least due to children and young people's legal capacity to consent and their relationships with their parents.

GMC guidance on consent[10], for example, reflecting the Mental Capacity Act, prescribes that the ability to make decisions can be presumed from age 16 and that younger children may have capacity depending on their maturity and ability to understand what is involved. In most cases parents will play a key role in decisions but it should not be assumed that they exercise children's rights on their behalf. Many vulnerable children, including those that are looked after, may lack the parental support that others have.

While they do not always make decisions for themselves regarding their health, it is vital that they are offered appropriate opportunities to be involved in decisions, and to be supported where they are able to make decisions independently. Children who are deemed to be not 'Gillick Competent' will not have the capacity to control their healthcare, but should not be denied the opportunity to participate at the level at which they are able.

How proposals relate to such issues needs to be considered from an early stage to ensure that from the point of implementation, children and young people are as aware of and able to exercise their rights as everyone else.

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[7] Gibson, F., S. Pearce, et al. (2009). Cancer in young people: a narrative study to explore their experience from first symptoms to the diagnosis of cancer, CLIC Sargent, cited from *Listening to children's views on health provision*

[8] Gibson, F., S. Aldiss, et al. (2010). "Children and young people's experiences of cancer care: A qualitative research study using participatory methods." International Journal of Nursing Studies 47(11): 1397-1407, cited from *Listening to children's views on health provision*

[9] Committee General Comment 12 on Right to be Heard:
http://www2.ohchr.org/english/bodies/crc/docs/AdvanceVersions/CRC-C-GC-12.doc

[10] General Medical Council (2008), *Consent guidance: patients and doctors making decisions together,* p23

We are particularly concerned at the choice of language in paragraph 4 stating government's ambition to "ensure that everyone has access to the best possible public services... by treating people like grown-ups". This is inappropriate as it may imply that those that are not "grown up" are somehow less entitled to the best public services or that being able to secure the best possible public services should be dependent on presumed capacity to make independent decisions.

The Department of Health and all of the agencies in the new health system, as public bodies, are subject to the Public Sector Equality Duty[11]. This means that, as part of a general equality duty, they have a duty to have due regard to the need to advance equality of opportunity between people of different ages. EHRC guidance is clear that understanding the effect of your policies and practices on people with different protected characteristics (e.g. of different ages) is an important part of complying with the general equality duty.[12]

The equality analysis published by the Department of Health alongside this consultation, when considering the protected characteristic of age only refers to the needs of older people[13]. We also note that the study by the Kings Fund referenced several times in the impact assessment to demonstrate the rationale for the policy only considered the view of those age 16 and up in its patient survey.[14]

The Children and Young People's Health Outcomes Forum[15] has produced recommendations that children and young people's voices are heard at every level of the health system, and that the NHS Commissioning Board fulfils its duty to act in a way that enables patients to take choices about their healthcare:

> "It is essential that the development of choice in healthcare includes exploration about how choice can be extended to children and young people. This may be more complex than for adults, as it requires relevant information to be presented in ways appropriate to the level of development and capacity of the child or young person."[16]

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[11] Section 149 of the Equality Act 2010. Although there are exclusions applicable to other parts of the Act, the part of the general equality duty discussed here applies equally for those aged under 18 in relation to the protected characteristic of age.

[12] Equality and Human Rights Commission (2012), *Meeting the equality duty in policy and decision-making: England (and non-devolved public authorities in Scotland and Wales)*

[13] Department of Health (2012), Liberating the NHS: No decision about me without me Further consultation on proposals to secure shared decision making - Equality Analysis, p16

[14] Dixon et al (2010) Patient *choice: How patients choose and how providers respond*, the King's Fund, p170

[15] The Children and Young People's Health Outcomes Forum was established by the Secretary of State to review how children and young people are supported by the NHS and Public Health Outcomes Frameworks and produce a strategy making recommendations set out the contribution that each part of the new health system needs to make in order that these health outcomes are achieved.

[16] Report of the Children and Young People's Health Outcomes Forum (2012), p24

What does Shared Decision Making mean for children young people?

Choice of provider is one small part of shared decision making. This distinction between choice and involvement in decisions is reflected in the *separate* general duties placed on clinical commissioning groups and the NHS Commissioning Board by the Health and Social Care Act 2012[17]. We share the concern highlighted in a response from National Voices that the confusion of provider choice with shared decision making may create an additional block in addressing the cultural and behavioural changes necessary to realise the Government's vision of 'no decision about me without me'. The conflation of these two concepts is particularly problematic for children and young people who will benefit from different types and levels of involvement in decisions about their health depending on their ability and maturity. Shared decision making for children and young people is not just about exercising choice but also having the information they need, understanding what is happening, being able to ask questions and having their views taken into account.

For children and young people to be able to effectively participate in shared decision making they need to be respected, and informed and supported in a way appropriate to their individual needs. Participation is not a single process or standard that a child or young person must reach, rather it is a spectrum of activity underpinned by a commitment to the principles of listening to and respecting the views of children and young people. These processes encompass:

Children and young people being informed and having information that is accessible to them: Health professionals provide children and young people with information and support appropriate to their understanding and circumstances.

Children and young people's views are taken into account: children's views are taken into account if their rights are to be respected under the UNCRC. The information children provide is one source, amongst others, that health professionals use to make a decision.

Children and young people are involved in decision-making: at this level children are actively and 'directly involved in the point where decisions are made' Children and adults share views and discuss issues together. Health professionals still hold ultimate responsibility for deciding the course of action, but children will be involved in steering that.

Children and young people share power and responsibility for decision-making: this requires a commitment by the health professional to share power and to undertake joint decision-making with children through negotiation and consensus.

Children and young people make autonomous decisions: Children make autonomous decisions while recognising that often the implementation of these decisions will require input from health professionals and is ultimately dependent on adult structures, responsibility and power.

(Taken From: Perpetua Kirby, Claire Lanyon, Kathleen Cronin and Ruth Sinclair (2003) *Building a Culture of Participation*, Department for Education and Skills, p 22)

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[17] Sections 13H and 14U of the National Health Service Act 2006 (as amended) refer to the involvement of each patient and sections 13I and 14V refer to choice

It will be vital that attention is paid to all of these processes, in order to move towards ‘no decision about me, without me’ for all children and young people. Children and young people must be supported to participate in whatever way they are able and their perceived ability to, for example, make autonomous decisions, should not affect any entitlement to be kept informed about their health. Disabled children and young people in particular need additional support prior to, during and after health consultations to ensure they understand and contribute to the process in an appropriate way for them. Professionals will also need to be aware that for children with severe impairments the contribution that they make in terms of giving information may be non-verbal and have to be inferred from behavior rather than directly communicated.

While government must ensure that any policy on extending choice must benefit children and young people equally to adults, their views should also be considered when assessing the relative priority such measures should be given in the quest for shared decision making. For example, the youngest group (16-35 year olds) surveyed by the Kings Fund study on patient choice, used in the impact assessment, displayed significantly lower awareness of the availability of choice than older groups.[18] This may suggest that they are less likely to access the extended choice proposed by this consultation.

Disabled children and young people will often be involved with a range of health professionals in addition to education and social care professionals. The coordination of this complex package of care, and the potential negative impact on their lives, is one of the most significant issues raised by disabled children and their families. The proposals outlined in “Support and Aspiration: A new approach to special educational needs and disability” Green Paper and Next Steps documents make clear the government’s commitment to a more integrated assessment and care planning process for disabled children and young people by putting together an integrated care package that meets the child’s need across the range of services. For the Education Health and Care Plan to succeed, health services have to be part of the shared decision making and personalised planning process, rather than just offering choices about services in isolation.

It will also be important to consider the needs of those children, for example those with low incidence needs, for whom access to a single provider of an appropriate service is a challenge. In such cases the uniqueness of the child’s needs may mean that there is not a sustainable market within which to make such choices, but they should still be involved in decisions about their care in the ways described above.

We welcome the recognition in chapter 2 of the consultation document that information will play a key role in shared decision making. We are concerned, however that the Information Strategy that is intended to secure the requisite improvement in this area does not adequately address children and young people’s information needs.[19]

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[18] Dixon, A., Robertson, R., Appleby, J., Burge, P., Devlin, N., Magee, H., Patient Choice: How patients choose and how providers respond The Kings Fund (2010) p25

[19] See NCB’s sector briefing on The Power of Information at http://www.ncb.org.uk/health/resources-and-publications/policy-briefings

With regards to good health information, children and young people tell us[20] that they want

- to be able to access confidential advice, easily, quickly and at no cost
- to have access to information about consent and their legal rights
- information that can be seen as trustworthy, credible and age-appropriate
- a variety of information sources, including traditional and social media, and from individuals giving them information face to face and in confidence as well as though sources in the public domain
- clear and concise resources that are not wordy and full of jargon
- to be able to feedback information to improve services for others

The consultation document is right in its statement that "Shared decision-making involves a patient and their clinician(s) working together to clarify options and goals for their care, treatment and self-management, sharing information about those options and aiming to reach agreement on the best course of action." Securing this, however, particularly for children and young people, will require a model that goes far beyond the proposals on provider choice set out by this consultation.

Children and young people's experience of health decisions

The most significant barriers to shared decision making children and young people face are related to a lack of information and the communication skills and attitudes of health professionals. It is vital that addressing these issues is not sidelined to focus solely on extending choice of provider.

We are concerned that the consultation document appears to underestimate such issues and does not reflect the experience of children and young people. The GP survey cited in paragraph 3.11, for example, only records the views of those aged 18 and over, and the positive conclusions drawn from it about the relationship between GPs and patients are at odds with evidence about the experience of children.

NCB's review of the evidence[21] found a number of studies and consultations highlighting consistent themes in relation to children and young people's experiences of primary health and hospital care, including:

- Failure to consistently involve children and young people in decisions about their care
- Poor communication from health staff who tended to communicate with parents and spoke in a way that children and young people could not really understand
- Some health staff being unfriendly and not treating them with respect

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[20] NCB (2012) Technology, Feedback and Health, Young people's opinions about health and information: What works, what needs to change and ideas for the future http://www.ncb.org.uk/ourhealth

[21] Ivana La Valle and Lisa Payne with Jennifer Gibb and Helena Jelicic (2012) *Listening to children's views on health provision: A rapid review of the evidence*, pp5-6

- Communication difficulties highlighted above could be even more severe for children and young people with speech, language and communication needs if health staff did not know how to communicate with the
- For children and young people who lacked parental support (e.g. in care or secure accommodation) a key issue was the lack of information and advice on health issues and accessing health services.

CDC's research[22] into disabled children and young people's experience of participation in their own health care found two overarching themes:

- The importance of getting interactions, communications and relationships between professionals and young people right
- The importance of developing young people's ability, confidence and independence around managing their own care.

Children and young people with disabilities often face a number of complex challenges at every stage of their health care, from primary care to treatment after diagnosis, that are not recognised in the consultation.

Many GPs are not confident in dealing with disabled children and young people. This stems from a lack of adequate training in both mainstream paediatrics' and particularly training in communicating with children and young people with speech and language difficulties and additional communication needs. This means for a significant number of disabled children and young people GPs do not play the central role in managing their care, rather specialist services take the lead role.[23]

This lack of confidence and experience, in addition to cultural expectations, can result in the health service not listening to and valuing disabled children and young people's own knowledge and experiences as part of the diagnosis and assessment process. This, as well as excluding disabled young people from the process, can also result in diagnostic delay

Suggested actions to help secure shared decision making for children and young people

Addressing all of the issues that have been raised above will require changes to the culture and range of skills that exist in many health settings. This can be tackled through improving education and training for health professionals and empowering children and young people with better information, as well as paying closer attention to children and young people's experiences so that training can reflect this and services can be held to account. We recommend the following as examples of actions to secure shared decision making for children and young people:

- Implement the recommendation of the Children and Young People's Outcomes Forum to incorporate the views of children and young people in patient surveys in all settings, including their experience of involvement in decisions about their

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[22] Council for Disabled Children (2012), Managing My Way, p4

[23] Every Disabled Child Matters (2009), Disabled Children and Health Reform, p20

care[24], and ensure that this information is used to hold providers and commissioners to account

- Review the extent to which agencies are helping to secure shared decision making for children and young people, perhaps linked to a review of the effectiveness of Healthwatch already agreed to by government[25], as part of a wider review how the patient participation and involvement agenda is moving forward for children and young people
- Implement the Information Strategy for health and care in such a way that takes into account childrens views and provides them with information to get more engaged in decisions about their health; including on their rights in health settings, and to information about their health and care
- Make significant improvements to the training of health professionals in communicating with children and young people, including implementing the relevant recommendations of the Children and Young People's Health Outcomes Forum[26], and involving young people in the development of training
- Support the adoption of a recognised standard for young people's participation in decisions about their healthcare. This should build on suitable aspects of existing participation standards and toolkits, including those within the Department of Health, the You're Welcome Standards[27] and those developed by the Voluntary sector[28], and support the Children's Health Charter recommended by the Children and Young People's Health Outcomes Forum[29].

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[24] Report of the Children and Young People's Health Outcomes Forum, pp29-30

[25] See Baroness Northover's response to issues raised at report stage of the Health and Social Care Bill on 8 March 2012: Hansard: HL Deb, 8 March 2012, c1969

[26] Report of the Children and Young People's Health Outcomes Forum, pp54-55

[27] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126813

[28] http://www.participationworks.org.uk/npf/nationalparticipationstrategy and http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_126813

[29] Report of the Children and Young People's Health Outcomes Forum, p25