

Achieving impact by joining up research, policy and practice

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For those who aren't familiar with us, NCB, the National Children's Bureau, is a charity with a long history. It was founded 50 years ago, as the National Bureau for Cooperation in Child Care, in response to growing concern about the treatment of neglected children. Although our name has changed, our priorities are very similar today. We work to improve the experiences and life chances of children across the country, particularly the most vulnerable, and to reduce the impact of inequalities.

As an organisation, we work closely with both national and local government to improve policy and legislation affecting children and young people. Our recommendations are backed not only by rigorous research, but by the experience of practitioners in our specialist networks, and by the voices of the children and young people we work with, and for.

Today, we'll use three case studies to illustrate how we design and disseminate our research, in order to maximise its value for policy and practice. These case studies involve three quite different pieces of research:

- A rapid evidence review, focusing on children's views of health services
- An evaluation of an advocacy service, for young people going through child protection proceedings
- A consultation and literature review, focused on the experiences of young people living with HIV.

1. Rapid evidence review on children's views of health services

Our first example was a rapid evidence review on children's views of health services. It was funded by a body called the Children and Young People's Health Outcomes Forum (CYPHOF), which was set up by the Department of Health in February 2012 to inform their strategy for improving health outcomes.

In the space of just a few months, we undertook a literature review and a 'call of evidence', which we disseminated across the country through our networks, and which delivered further examples of local research and consultation with children and young people. The research found that:

- Although there was good practice in some cases, there was also evidence of poor communication with children and young people, and of failures to involve *them* – as opposed to their parents - in decisions about their care.
- Typically, there were no mechanisms set up to canvass children's views in relation to either the evaluation or development of health services. As a result, their perspectives were being missed, despite the fact that they want to be involved, and despite the evidence that taking account of their views can improve services and outcomes – as is already accepted in relation to views of patients and the public more broadly.

Findings of the study were reported to the CYPHOF, and the full report¹ and a four-page summary² were posted on our website and disseminated widely. The report was used as a key piece of evidence in NCB's efforts to influence health policy. It informed the recommendations of the CYPHOF, presented to the DH in July 2012, particularly around measurement of children's experience, their rights as patients, and age-appropriate settings for service delivery.

The response from government included improvements to the NHS constitution and funded work to promote it, along with moves to develop improved measurement of children's experiences. In addition, further research was funded in response to some of our key recommendations. Firstly, the DH commissioned us to help develop a health-focused survey of 15 year olds – indicating not only their acceptance of the need to canvas young people directly about their health needs and experiences in order to better inform health provision, but recognition that measures will be more effective if developed in an involving way.

We held a 2-day residential with young people, who came up with a youth-friendly name, branding, and constructive suggestions for improving the materials. With many of their ideas taken on board, it is expected that this will lead to improved response rates, and therefore gathering of (more) useful health data. Secondly, the Office of the Children's Commissioner (OCC) asked NCB to review children and young people's involvement in strategic health decisions, focusing on health and wellbeing boards (HWBs), local authorities (LAs) and clinical commissioning groups (CCGs). The research involved analysis of the national policy framework and local health plans, as well as interviews with professionals and focus groups with young people. It provided a snapshot of young people's involvement in the new health structures, demonstrating that participation in local health decision-making was mixed and fragmented, and that, typically, children were consulted at a particular (late) stage in decision-making. The report – which has been disseminated widely - provided case studies of different types of involvement, and highlighted needs for further guidance. Subsequently, NCB Practice Development staff have provided support to LAs, and are developing further training, tailored to emerging needs.

In these cases, several factors in combination maximised the impact of our research:

- The Policy team's awareness of the opportunities - and likely timeframes.
- There was a major NHS reform programme underway, and our agenda could be aligned with government policy around greater patient & public involvement.
- NCB had established relationships with policy makers, and with the funder (CYPHOF)
- Cascading the call for evidence through policy and practice networks ensured that we drew on, and disseminated, up-to-date, local experience which was meaningful to practitioners and policy makers.
- We had the specialist capacity for a rapid but rigorous response, through:
 - Our policy & research teams, supported by the NCB Information Centre
 - Our established links with groups of young people (Young NCB, YRAs)
 - Cascading the call for evidence, through our policy & practice networks
- Concerted dissemination and lobbying activity
 - Presented to the CYPHOF and disseminated online
 - Used as centrepiece evidence for NCB health policy influencing , in consultations and reports.

Ideally, we would have welcomed more time for the each piece of work. However, in the circumstances it was crucial to sift as much material as possible in a very tight timeframe. While this restricted the scope of the reviews and fieldwork, it ensured its relevance.

2. Evaluation of an advocacy service for child protection conferences

Our second example involves an evaluation of a pilot advocacy service for children and young people going through child protection proceedings, in Kensington and Chelsea. The aim of the service was to support children to express their views, and to ensure they were taken into account when decisions were made about their care. The advocacy service and the evaluation were part of an EU initiative which also funded projects in Sweden and Italy.

The evaluation itself involved analysis of child protection records (for 41 children) and data on take-up of the service, as well as interviews with children, parents, social workers, advocates and managers, including CP conference chairs.

Our findings demonstrated that:

- Advocacy helped to ensure that children's views were represented. Children could see that their views had made a difference, informing and shaping their child protection plans.
- Parents and professionals felt contributions from the child and advocate improved the atmosphere of the conference, supported constructive dialogue, and helped them focus on the perspective and needs of the child.
- Similar benefits were observed elsewhere, in other local authorities providing advocacy, but further development of services, nationally, would need a clear legislative and policy drive.

Following the launch of the report, not only was the advocacy service extended in Kensington and Chelsea, but the Minister for Children issued a letter and corporate parenting guidance highlighting the need for local authorities across the country to provide advocacy. Key facilitators in this instance were:

- Timeliness. In the context of high profile child protection failures, we were aware of a receptive audience for our findings and key messages – both in local authorities, keen to improve outcomes, and in central government.
- Our policy team's efforts to secure dissemination and lobbying opportunities.

We launched the evaluation findings³ at a series of conferences for practitioners and policy makers, alongside two complimentary reports; a review by Carolyn Willow⁴, which set our work in the context of other relevant research, and 'Time to listen'⁵, an accessible briefing summarising the key points by NCB's Policy team. All three were placed on our website, with press releases ensuring further media coverage elsewhere, for example, in *Community Care* magazine. Our Policy team arranged a special meeting of the All Party Parliamentary Group for Children (APPGC), which NCB clerks, focusing entirely on advocacy in the child protection process. Young people with experience of advocacy presented at all these events. Together, they reinforced the value of advocacy, and the need for clear legislative and policy drivers to ensure more children could benefit.

A key challenge in this case was that much of the crucial dissemination activity was unfunded. Moreover, while we pushed for children to gain a legal right to an independent advocate, such an 'ask' is subject to parliamentary process, and difficult to negotiate. Without that legal right, however, and in the context of LA cuts, even enthusiastic corporate parents may struggle to make the case locally for wider access to advocacy.

3. Consultation informing resources for young people living with HIV

Our third example is quite different from the previous ones. The Transition Project, as it was called, was grant-funded by the DH, to better understand how young people living with HIV make the transition from childhood to adulthood and, in particular, improve their experiences in moving from child to adult services. This was a new challenge in the UK, because the cohort of children born with HIV is only now reaching adulthood.

In this case, the fieldwork was carried out by staff in our Children and Young People HIV Network, led by Emily Hamblin, rather than the Research Centre, although we helped to evaluate the project and the materials it informed⁶. The first stage of the research involved a literature review which focused on current thinking around transition for young people with HIV, and other health conditions⁷. Subsequently, a series of consultations were held, involving focus groups and interviews with young people and practitioners across the country. The resulting report⁸ demonstrated:

- The diversity of experience amongst young people, in terms of circumstances, needs and access to services.
- That transition is a critical time for young people living with HIV, as they want to be treated as 'normal', and to lead ordinary lives. As they move away from home, familiar routines and services, this can make adherence to treatment and accessing support more difficult, while they face difficult decisions about who to tell, and how, about their HIV status.

The research informed a series of resources for practitioners, young people and parents. These included six leaflets for young people ('Your Life' leaflets) covering growing up; work and careers; further and higher education; independent living; rights; and talking to others about HIV, along with a 'LifeLinks' website, with a directory of links and information. There were parallel leaflets for parents, web resources for practitioners, and a series of regional practice-sharing events.

Our evaluation found that practitioners and young people welcomed the report, resources and practice-sharing events. Practitioners reported that resources were being used, both to help inform young people about their rights and sources of support, and to inform parents and practitioners about their needs during transition. This was particularly the case for staff in adult services, and in non-health settings including colleges and universities. Staff attending practice sharing events reported gaining insights that would inform their practice, in relation to: student entitlements; the need to prepare parents as well as young people for transition; the value of peer support services, and emotional aspects of disclosure of HIV status.

For this project, crucial factors which helped ensure the project's relevance included:

- Our established links with practitioners, through the HIV Network, which provided a sampling frame which would otherwise have been lacking. The project researcher was seen as willing and able to reciprocate support, and trusted to approach young people in an appropriate, sensitive way.
- That planned outputs from the project included helpful resources for young people, parents and practitioners, addressing needs identified by relevant young people & practitioners.
- That materials were designed in consultation with young people, for young people.

A key challenge was the risk of reliance on a small group of over-researched young people (in contact with services and 'engaged' practitioners) alongside more isolated ones. However, the researchers travelled and reciprocated support to minimise burdens on young people and services, tailored events to practitioners' needs, provided development opportunities for young people as well as 'thank you' vouchers, and focused on providing resources which would help even the most isolated young people, increasing awareness of the support available.

Resource constraints affecting services in the NHS and elsewhere limit the extent to which they can increase provision for young people in transition to adult services – particularly in areas where young people with HIV are a very small group. In recognition of this, the project was designed to provide outputs useful for practitioners and young people in a broad range of situations. The feedback from practitioners and young people suggests that the project did indeed fill important gaps in relation to information and support.

Conclusions: Ensuring research has an impact

As researchers, we can try to maximise the impact of our work in a number of ways, while recognising its limitations.

Firstly, the unpredictability of the policy making process means that we have to be opportunistic, and prepared to scope our research to meet difficult deadlines.

Secondly, more typical research timescales mean that the policy context can change over the life of a project.

Accordingly, rather than finalising the policy aims of dissemination at the outset, we need to review and adapt these as the research moves towards completion.

Likewise, our planned outputs need to be sensitive to real needs but also resource constraints in our targeted areas of practice.

While resource constraints clearly affect us too, we need to fund and plan policy work, relationship-building and dissemination. Dissemination is a key area that tends to be neglected, but which is critical for increasing the impact of research and utilizing its full value for policy and practice.

All three of the projects described in this summary were underpinned by work to maintain a broad focus on the needs and perspectives of young people, policy-makers and practitioners. Investing in relationships with all three groups has been essential in helping us to respond rapidly to opportunities, to conduct more efficient and effective fieldwork, and to identify gaps in knowledge and provision.

- We have established strong relationships with practitioners through our special interest groups and networks. The HIV Network is one of several such groups which bring together sometimes isolated practitioners and provide opportunities to share practice and disseminate learning.
- We have earned the respect of policy makers through our track record of partnership work, informing policy and promoting participation.
- We always seek to involve children and young people in our work. Not only is it essential to understand their perspectives, in order to improve our research, their lives and the services they use, but given appropriate opportunities, they can present their views and experiences to policy makers in a persuasive and powerful way.
- Finally, rather than taking a 'one size fits all' approach, we also tailor our reports and resources to different audiences. The links below will give you a flavour of our reports, but for more material see <http://ncb.org.uk/>

References

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- ⁶ Gibb, J and Blades, R (2013) *Children and Young People HIV Network Evaluation. 2010-2013*. National Children's Bureau. http://www.ncb.org.uk/media/1009659/hiv_network_evaluation_-_final.pdf
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- ⁸ Hamblin, E (2011) *Just Normal Young People. Supporting young people living with HIV in their transition to adulthood*. National Children's Bureau. <http://www.ncb.org.uk/media/470465/justnormalyoungpeople-hivnetworktransitionreport.pdf>