

# Practice examples of collaboration between children and young people's health and voluntary sector services



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## Introduction

In NCB's role as Health and Care Voluntary Sector Strategic Partner, we aim to support collaborative working between health and voluntary sector services and the sharing of ideas and knowledge across all relevant sectors.

In 2014, we put out a call for examples of promising collaborative work between health and voluntary sector services to improve health and wellbeing for children and young people with the aim of disseminating them widely so that others might learn about and take lessons from them.

Using specific case examples, this brief document shows how health and the voluntary sector can work together to develop and deliver effective services for children and young people. It has been updated with an additional case study in 2015.

### ***What is the benefit of collaboration between health and the voluntary sector?***

The changes introduced by the Health and Social Care Act 2012 constituted the largest reorganisation in the history of the NHS. Responsibilities for protecting and promoting the nation's health transferred to new statutory organisations at national, regional and local levels.

The health reforms presented a range of challenges and risks for the voluntary and community sector. They came at a time when public services were subject to significant financial constraints, and when changes in population and lifestyles have been putting ever-increasing pressure on the nation's health and social care system. With changes in commissioning roles, established relationships and contacts have been lost. Requirements for VCS providers to evidence their impact have increased, whilst available funding has diminished.

However, the changed environment also presents VCS providers with opportunities. Commissioners need to consider new ways of working, and a number of principles are high on the agenda within the health system:

- localism
- innovation
- integration
- patient experience
- self-management
- choice of service provider
- co-production in service design.

Voluntary and community sector providers will often be well-placed to help commissioners realise these principles, working within local communities and often using holistic approaches. Many work with and are trusted by groups and communities who experience particular health inequalities. According to Dr Michael

Dixon, Chairman of the NHS Alliance, and Sir Stephen Bubb, Chief Executive of ACEVO (the Association of Chief Executives of Voluntary Organisations):

*A key attribute of these organisations, whether they operate at the local, regional or national level, is their close links to the beneficiary groups that they serve. Consequently, the voluntary and community sector is well-placed to support the development of tailored services which improve health outcomes and create a wider range of choices for commissioners, as well as service users.<sup>1</sup>*

### **How is collaboration important for children?**

Much of the healthcare provided to children and young people is delivered outside the services accessed by adults, in neonatal and paediatric settings. Without advocates, children also do not have a strong voice in policy and commissioning. When significant changes are made to healthcare systems and structures then, there is a risk that potential gaps in children's healthcare commissioning arise, or that pathways of care become fragmented.

Childhood is a life stage during which a large number of professionals may be involved in an individual's life, and amongst the times in a person's life when healthcare may be most frequently required. Collaboration between health and VCS providers, if it helps to deliver holistic services, can be highly beneficial in this context.

A 2014 report written by child health experts and published by the Royal College of Paediatrics and Child Health (RCPCH) and NCB, *Why Children Die*, highlights the influence of poverty upon child health:

*There are substantial differences between the UK and some other European child mortality rates. This is partly explained by the higher infant mortality rates in the UK, a high percentage of which is driven by the fact that nearly two thirds of the children who die before their first birthday were born preterm, and/or with low birthweight. [...] Rates of low birthweight are higher in less advantaged socio-economic groups, and are particularly linked to a number of negative health behaviours such as poor prenatal care, substance abuse, poor nutrition during pregnancy and smoking which are more common in these groups. [...] Inadequate nutrition can also drive low birthweights, and we know that there are increasing numbers of families being referred in the UK to foodbanks which is an urgent and growing concern.<sup>2</sup>*

Poverty and inequality are social determinants of health that play a role in health outcome for children in the UK. As explained above, VCS providers are often

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<sup>1</sup> Girach, M., Hardisty, H. & Massey, A. (2012), *A Clinical Commissioner's Guide to the Voluntary Sector*, ACEVO

<sup>2</sup> Wolfe, I., Macfarlane, A., Donkin, A., Marmot, M. & Viner, R. (2014), *Why children die: death in infants, children, and young people in the UK*, RCPCH and NCB

uniquely positioned to reach and build relationships with groups who are particularly affected by inequalities or face barriers to accessing health services. It makes sense, then, to involve the voluntary and community sector in improving health outcomes for children.

### ***The Health and Care Strategic Partner Programme***

The Health and Care Voluntary Sector Strategic Partner Programme (SPP) brings together voluntary and community sector organisations to bring the voice and experience of users and the wider public to the heart of policy making to improve health and well-being, promote equality and reduce health inequalities.

It provides a mechanism for reaching a wide range of voluntary and community sector organisations to increase capability, partnership and joint working within the voluntary and community sectors and with the Department of Health, Public Health England and NHS England and the health and social care systems at national and local levels

The programme has developed from a partnership of 11 organisations establishing a robust model for working in partnership, to 22 organisations spanning the breadth and depth of the VCS. It is estimated that through these Strategic Partners, over 300,000 organisations across the voluntary sector can be reached.

### ***Acknowledgements***

NCB would like to thank:

- Vicki Dawson, Founder of The Children's Sleep Charity
- Mandy Owen & Roz Davidson, Directors of Roman Support
- Dr Steve Welch, Chair, Children's HIV Association of the UK & Ireland (CHIVA)
- Magda Conway, Projects Manager, Children's HIV Association of the UK & Ireland (CHIVA)
- Lucy Medhurst, Strategic Manager for Kent, Artswork
- The families and partners working with each featured organisation.

### ***Contributing case studies***

Further case studies can be added to this document. If you feel you have a suitable practice example you would like to contribute, it would be greatly appreciated. Please email Emily Hamblin at [ehamblin@ncb.org.uk](mailto:ehamblin@ncb.org.uk) for information.

## Supporting families through changes and difficulties, building on their engagement with health services

### ***Roman Support has linked up with George Eliot Hospital Nuneaton to provide services for families with newborn and premature babies, and asthmatic children.***

Roman Support is a recently established social enterprise run by Mandy Owen & Roz Davidson, experienced Nursery Nurses and Family Support Workers who are developing a range of services in Warwickshire and Leicestershire. Through providing home, community, and in-house flexible floating support, Roman Support aims to support the families of newborn babies and asthmatic children around issues that create social, emotional and health problems, and hospital re-admittances. Issues may include health diagnoses, parenting difficulties, and financial or housing-related problems. With families of newborns, services focus on the stresses involved in becoming a parent, birth experiences and post-natal depression. Roman Support aims to build a self-supporting community of parents, helping others succeed and creating confident families.

Roman Support is currently working on a six-month trial and evaluation with the Special Care Baby Unit and with a Paediatric Asthma Consultant at George Eliot Hospital in Nuneaton. Its community business plan is based on expanding in its first two years to provide ongoing structured support.

Around 2,400 births per year are delivered at George Eliot Hospital in Nuneaton. Mandy and Roz have established links with staff in the hospital's maternity services and Special Care Baby Unit (SCBU), providing weekly 'meet and greet' sessions with parents. This session gives parents time to talk about their experiences or worries, whilst freeing up valuable time for staff. Roman Support also runs an outreach support group in Nuneaton for all families of newborns; a premature baby group in the Nuneaton community to support parents after babies have left the SCBU; and a five-week post-natal home help programme, providing isolated families with tailored support to increase their confidence.

Mandy and Roz also have established links with the Paediatric Asthma Consultant at the hospital, who has highlighted a need for a support group aimed at families with asthmatic children. The group aims for children to be able to continue their education with the right support, taking their medication correctly, and for parents to have the correct information. This will help prevent re-admittance to hospital, thus cutting costs and time out of education, as well as promoting better quality of life, confident parenting and wellbeing.

Working in collaboration with NHS services has enabled Roman Support to create a nurturing environment for all families experiencing trauma, health changes, and life issues that arise in everyday life. The partnership approach has also allowed Roman Support to reach potential clients that may have otherwise slipped through the net, and to intervene early when health problems arise, giving parents a safety net to express their individual needs, seek the right advice and tackle future issues. They

have been able to signpost and facilitate access to relevant agencies, making positive connections with mental health, the local Healthy Living Network and dietician services, and midwives and consultants connected to the support group.

Mandy and Roz report seeing families gain valuable knowledge on how to be self-supporting. One parent accessing Roman Support's premature baby service was able to discuss her experiences and feelings and make decisions within a nurturing environment. She is now a very confident mum around breast/bottle feeding, weaning and baby development, and back in her work after six months.

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## Building creative partnerships to improve health and wellbeing

***Artswork and Royal Opera House Bridge have worked with Kent County Council and partners to use arts and culture as a vehicle for improving outcomes for children and young people.***

Artswork and ROH Bridge aim to place the arts and cultural practice at the heart of work with, for and by children and young people – particularly those deemed to be at risk – and to champion, lead and facilitate high quality work led by artists and arts and cultural organisations. Nationally, 10 organisations support the Arts Council's strategic work with children and young people and aim to strategically provide a direct 'bridge' between the work of arts and cultural organisations, schools and communities. Artswork is the Bridge Organisation for the Arts Council in South East England. Royal Opera House Bridge is the Bridge organisation for Essex, North Kent, Hertfordshire and Bedfordshire.

In 2014 Kent County Council's (KCC) Arts and Culture Service developed and managed a pilot commission in partnership with Royal Opera House and Artswork in their roles as Bridge Organisations, and KCC's Public Health department. The pilot aimed to deliver improved wellbeing for young people using creative interventions, and capacity building for cultural organisations to prepare the sector to become commission-ready. It also aimed to support the wider sector on a national level to engage with commissioning.

Six arts organisations in collaborative partnerships were contracted as service providers. The organisations/consortia were Turner Contemporary and Pie Factory Music, Rhythmix and Soundhub, Dover Arts Development and Jasmin Vardimon Company, LV21 with Cohesion Plus and The Gr@nd Healthy Living Centre, Icon Theatre, and Ideas Test (Creative People and Places) with Swale CCVS.

A bespoke support package was devised to help the providers through the journey. They were expected to deliver creative interventions with young people at risk of mental health issues to improve their wellbeing and to disseminate the Six Ways to Wellbeing messages amongst the wider population via festivals or events.

Across six Kent districts, 904 young people aged 5–19 took part in interventions, with 182 achieving Arts Awards and 20,038 members of the wider public attending the festival events. Of the young people who participated, 813 developed better understanding of the Six Ways to Wellbeing and 156 became wellbeing champions. Interventions took place in targeted areas of deprivation with vulnerable groups of young people.

The pilot resulted in the Arts & Cultural Commissioning Toolkit (ACCT), an animated online resource for the UK cultural sector as providers, and the people who might commission them.

The time-consuming nature of the work was a challenge, in particular the creation of the commissioning toolkit to benefit the wider sector.

The journey between the partner organisations began in 2012 supported by capacity building and knowledge sharing sessions led by specialist Linden Rowley. This was the first time that KCC Public Health had engaged with the arts and cultural sector in a meaningful way. The unfamiliarity of the commissioning process and procurement rules to partners and providers posed some challenges, as did communication between the stakeholders at times. Measures taken to address these challenges included engaging Linden Rowley to support the six providers through the commissioning journey, and evaluator Mandy Barnett. Mandy developed a theory of change with all partners and worked across partners and providers to ensure that learning was captured and recommendations made, with mechanisms for follow-up.

New partnerships between KCC and the voluntary and community sector led to much stronger interventions and in some cases, a change to organisational business plans and improved ways of working. The success of this partnership and pilot opened the door for KCC to work with New Economics Foundation as part of the national Cultural Commissioning Programme. KCC has continued to work with ROH Bridge and Artswork and are seeking to develop best practice in commissioning the arts across the Council.

This partnership has led to a strong relationship with KCC's Early Help and Preventative Services, who would like to see arts and culture become part of their mainstream provision. This will have a huge impact upon the lives of children and young people in Kent who will have greater access to arts and culture as a vehicle for improving health and wellbeing. Vicky Tovey, Commissioning Manager, Public Health, said that 'working with the Bridge Organisations was a really positive experience and the pilot project provided a great example of how arts and culture can deliver public health outcomes.'

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## Working with families to provide long-term resolutions and avoid the need for medical treatment

### ***The Children's Sleep Charity is working with health services in Doncaster and Sheffield to support families struggling with sleep issues***

The Children's Sleep Charity aims to address the lack of support for sleep difficulties for families in England and Wales. Up to 40% of children will experience a sleep problem at some point in their childhood, and for children with special needs, the figure is 86%. Poor sleep patterns in children can impact on learning and cognitive ability, and parents who are sleep deprived are more at risk of family break up. The Children's Sleep Charity uses a cognitive and behavioural approach to address sleep issues in children over 12 months of age, on the basis that many sleep problems can be remedied by behavioural interventions rather than the use of medication. The charity can provide sleep workshops, online advice and one-to-one sleep clinics anywhere in the country. In Doncaster, the local authority and clinical commissioning group have commissioned the charity to train professionals in the area to offer sound sleep advice.

The Children's Sleep Charity generates most of its own income by providing services commissioned by various organisations including the health service, local authorities, other charities, and children's centres. A proportion of its funding comes from the Children's Hospital Charity, which supports Sheffield Children's Hospital. However, to meet demand, the Children's Sleep Charity also raises other funds. This is a challenge that the charity aims to meet by clearly demonstrating the impact of its provision.

The charity works in partnership with Sheffield Children's Hospital. Collaboration with the hospital has allowed the charity to deliver a sleep practitioner programme for professionals, because doctors give lectures as part of the programme. The charity and the hospital also work together to ensure that families receive the most appropriate services. Sleep practitioners can signpost families whose children's sleep issues are medical to the hospital, ensuring a clinically safe way of working. Likewise, the hospital refers patients to the Children's Sleep Charity workshop so that behavioural issues around sleep can be eradicated before medical issues are explored. This approach helps to avoid unnecessary prescriptions of melatonin for children. The long-term effects of melatonin use are not known, and despite it being recommended for short term use only, many children take it for significantly longer.

For one child whose sleep patterns improved after using the charity's services, her resultant growth meant that she did not require hormone treatment. Another child had long-lasting difficulties with sleep, but after the charity's workshop helped to address these, medical investigations that were due to happen were no longer needed. Parents have reported a better quality of life for themselves and their children after receiving support from the Children's Sleep Charity, and a number of these stories have appeared in the national press.

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## Working from a basis of collaboration

### ***Collaboration between health and voluntary sector professionals is embedded in the structure of the Children's HIV Association and across its activities***

The Children's HIV Association of the UK & Ireland (CHIVA) has partnership working between health and the voluntary sector rooted in its structure, and has developed organically, informed by a legacy of pioneering patient involvement in the HIV sector. CHIVA functions both as a network for health and social care practitioners supporting children and families living with HIV, and as a service provider working directly with this group. There are around 1,000 children and young people in the UK and Ireland who are living with HIV, which comes with a deeply felt stigma and some complex family and social implications.

CHIVA was established in 2002 as a network for people providing health care for children and young people with HIV in the UK. In 2008 CHIVA became a registered charity and expanded its work for professionals. In 2010, the first CHIVA Support Camp heralded a new era in which CHIVA would undertake much more direct work with young people. It also established the CHIVA Youth Committee, a group of young people who give a voice to HIV positive and affected children and young people in the work of CHIVA and in the public domain.

All of CHIVA's work is overseen by an Executive Committee. This largely comprises paediatric HIV healthcare professionals, but also includes voluntary sector representatives. An external organisation provides secretariat and conferencing services, focusing solely on CHIVA's function and external face as a professional association. The other arm is the CHIVA Projects team, which leads all CHIVA's direct work with young people and non-clinical practice development.

CHIVA's structure enables it to effectively champion multidisciplinary working; makes it uniquely positioned to involve and advocate for children, young people and families affected by HIV; and allows relevance and reach across the whole children's HIV sector. It also enables CHIVA to consider children, young people and families' clinical and psychosocial needs holistically across the range of its activities. This is exemplified by CHIVA's website, an online information hub for professionals, parents and young people.

Specific examples of how health and VCS professionals come together within CHIVA, and how CHIVA as a voluntary organisation is recognised in formal health structures, include:

- The allocation of places on NHS England's HIV Clinical Reference Group to CHIVA Projects' Participation Officer and an Executive Committee member who works as a paediatric HIV consultant
- The use of CHIVA Standards of Care and clinical guidelines in paediatric HIV commissioning and service delivery

- Conferences featuring presentations from health, social care and voluntary sector practitioners, as well as young people living with HIV (who are frequently cited in evaluation forms to be a highlight)
- Involvement of health professionals in CHIVA's Support Camp, 'Freedom To Be'.

'Freedom To Be' or 'F2B', in its fifth year in 2014, brings 100 HIV positive young people aged 13-17 together over five days. It is supported by a team comprised of young and older adults living with HIV, health and voluntary sector practitioners working in HIV, and other volunteers. Practitioners collaborate across disciplines to deliver workshops that provide accurate information about HIV using methods that engage young people. Camp referrals are made via health professionals, and volunteers experienced in paediatric HIV nursing check each young person's medication in and out at camp and can obtain emergency supplies for individuals arriving without medication, via the young person's health team. Camp volunteers record young people's medication taking during camp, for the reference of healthcare teams and to help identify potential adherence issues. This collaboration between camp organisers, volunteers and health professionals is crucial, because treatment adherence is a key challenge for people living with HIV, and even missing one or two doses per week can allow drug resistance to develop.

There have been challenges for CHIVA in operating with a multidisciplinary approach and a bipartite structure that has developed organically over time. These include coordination, getting the right mix of skills and working cultures, and reliance on a relatively small pool of individuals working in a highly specialised area to volunteer their time and expertise. However, the principle of bringing health and voluntary sector professionals together to lead CHIVA, deliver services, develop best practice and involve young people has informed the organisation's achievements and is highly valued by all involved. As a result, children and young people living with HIV and their families can access care and support that is more holistic and responsive than it would have otherwise been.

An independent evaluation of the first camp in 2010 found that 'F2B was regarded by almost all participants as an exceptionally positive, esteem-boosting, beneficial experience, and this perception was maintained if not increased when young people were contacted three months later.'<sup>3</sup> CHIVA also conducted a survey of health professionals who referred young people to F2B in 2010. Responses were received from ten health professionals who, between them, worked with over half of camp attendees. Eight respondents reported a higher level of self-esteem in their patients. Professionals reported an increase in their patients' knowledge of key HIV topics, e.g. 60% felt that F2B had increased their patients' knowledge of adherence to medication, and nine stated that the young people in their care are more inquisitive in regards to their health care after attending F2B. Findings from subsequent camp evaluations are consistent with 2010.

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<sup>3</sup> Dodds, C. (2011) *Freedom To Be (F2B) summer camp: outcome evaluation*, Sigma Research

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## Conclusion

The case studies shared in this document represent different types of collaboration: new and long-established partnerships; health organisations commissioning VCS providers; local authorities recognising the potential contribution of VCS arts and culture organisations to public health; services delivered in health settings and in the community; and an organisation with collaboration between health and VCS professionals at the heart of its structure and functioning. All aim to improve the health and wellbeing of children, young people and families. This requires significant individual commitment from those in both health and VCS organisations, as well as learning from mistakes. Contrasts in working cultures may need to be understood and accommodated.

In trying to measure their impact, the organisations above are finding that health and VCS providers working together can be more than the sum of their parts in terms of what they are able to deliver. Collaborations of this nature are increasing services' ability to adapt to a challenging economic environment, address the key health challenges in our society, and respond effectively to the needs of children, young people and families.

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The National Children's Bureau: working with children, for children

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