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Involving young people in the development of health services

Young people need to be in their best possible health to achieve their full potential. The Department of Health is committed to improving young people's health and wellbeing. As part of this commitment the Department funded a two-year programme to establish four 'Teenage Health Demonstration Sites' which developed innovative ways to improve young people's physical and emotional health services. Bolton, Hackney, Northumberland and Portsmouth were chosen to show how services can be developed in a wide variety of circumstances. Each area developed services for young people in health *and* community settings aiming to reach the widest group of young people. The demonstration sites gained huge experience about building and delivering sustainable services for young people.

This is the *first* guide in a series of six which present key learning drawn from the independent evaluation of the demonstration sites. The guides are:

1. *Involving young people in the development of health services*
2. Making health services more accessible to young people
3. Taking young people's health services into the community
4. Ensuring health services reach all young people
5. Working with partners to improve young people's health services
6. Planning young people's health services

About this guide

The guide is for *everybody* involved in providing young people's health services from those commissioning services to those working directly with young people.

This guide focuses on how to effectively engage young people in the development of services. It explores the reasons for involving young people and provides practical tips and resources for putting participation into practice.

"Participation of young people is central – this needs supporting and resourcing and services need to be set up to be flexible and willing to respond to the feedback and priorities of young people".

Member of frontline staff



Summary

There is great value in involving young people in a health context, including benefits for the organisation, staff and the young people involved. When thinking about how to engage young people in the development of services there are some key messages from the demonstration sites which should be built into planning:

- Participation work needs to be endorsed at all levels in your organisation
- Adequate time is required to prepare for participation work
- Monitoring and evaluation systems for the participation work need to be put in place at an early stage
- Funding sources need to be considered to ensure sustainability
- Services need to be able to adapt in response to young people's feedback
- The involvement of experts in youth participation should be considered
- Services should consider the skills and support that employees may need
- Young people with a diverse range of experience should be engaged
- Time is required to prepare young people for participation
- Suitable incentives should be provided to encourage participation
- Achievements should be recognised and celebrated

Why should we involve young people?

It's an international priority

The UK is committed to the UN Convention on the Rights of the Child which entitles young people to have a say in all matters that affect them. Article 12, **'Respect for the views of the child'**, states that when adults are making decisions which affect children and young people, they have the right to say what they think should happen and have their opinions taken into account. The article also refers to the fact that the ability to form and express opinions develops with age.

It's a national priority

The strategy for children and young people's health, 'Healthy Lives, Brighter Futures' sets out the Government's commitment to, **'Ensure that children and young people's views are given prominence in future assessments of healthcare organisations'**. It stresses that participation must be a meaningful activity which moves beyond just listening to young people to fully engaging them in design and delivery. Young people with complex needs and those from vulnerable backgrounds need to be fully engaged in this process.

From now on Comprehensive Area Assessments will: **'Assess performance of areas in achieving better health outcomes for children and young people including how the views of children and young people are taken into account in doing so'**.

To improve young people's health outcomes the Department of Health has made a commitment to World Class Commissioning which includes, **'Fully engaging with children, young people and families using creative approaches to reach vulnerable young people'**.

The new 'Healthy Child Programme: From 5-19 years old' makes recommendations for a universal service to promote health and wellbeing. It highlights the role of scrutiny by, and involvement of, children and young people and their families as 'important factors in the HCP's impact, effectiveness and success'.

The value of involving young people

Young people's participation has benefits for everyone involved.

"If young people aren't involved and adults do all the planning then it isn't as good or effective for us".

16 year old, Northumberland

"There is something about how inspiring it is to work with young people and how it grounds you in what the purpose of your organisation really is".

Manager, Northumberland

It is important to be clear about how participation will benefit your organisation, young people and other staff involved.

Some of the key benefits are summarised in the box below:

Benefits of young people's participation

For young people

- Enhances skills and competencies
- Increases confidence and self esteem
- Empowering
- Provides opportunities to influence organisations' policy and practice
- Leads to more appropriate services
- Provides new experiences

For organisations and partners

- Provides fresh perspectives and new ideas
- Improves quality of decision making processes
- Deepens understanding of the priorities of young people
- Creates more timely and user led services
- Demonstrates the quality of the service
- Meets national and international good practice standards

Putting participation into practice...

What happened at the demonstration sites?

Experience from the demonstration sites showed that given the right commitment organisations can work successfully with young people to develop meaningful participation. Staff agreed that whilst developing participation work was challenging, it was ultimately worthwhile. The evaluation found that young people's participation in the planning and development of services had increased over the two years of the programme, and that this contributed to overall improvements to services. Young people welcomed the opportunity to give feedback on the services they received and wanted their input to be listened to and acted upon.

“Teenage Health Demonstration Sites showed that with strategic endorsement, appropriate time to plan, and resources to manage the work and the recruitment of appropriate young people... participation work can be very successful”.

Teenage Health Demonstration Sites Evaluation Report (2009)

“Progress was made especially where... young people were central to planning”.

Teenage Health Demonstration Sites Evaluation Report (2009)

Hear by Right

The demonstration sites aimed to meet the standards set out by the National Youth Agency's 'Hear by Right' framework. This provides an accessible toolkit for the assessment and development of productive and sustained input from young people. The framework is designed for use in all sectors and is based on seven areas required to create organisational change which are: Shared values; Strategy; Structure; Systems; Staff; Skills and Knowledge and Style of leadership. For more information see the resources section of this guide.

Key action points

The following key action points provide practical advice for participatory work based on the experience of the sites.

Making participation meaningful

Making sure that young people's involvement is *meaningful* is just as important as making sure that young people are involved. It is important to avoid making participation tokenistic. Good sources of information about this are works by Roger Hart who has written about the varied (and not always good!) ways in which young people have been engaged in participation work (see resource section) and the 'Hear by Right framework' which provides comprehensive practical advice for participation work.

Make participation a priority

Young people's participation needs to be embedded in the commissioning process and endorsed at all levels of the organisation from the very start of an initiative. This could be by building participation into senior staff job descriptions or developing a high profile participation strategy. This approach will ensure a long-term commitment to participation work.

Ensure you have adequate preparation time

Participatory work takes time to prepare and requires thorough planning to ensure that young people's involvement is meaningful and sustainable.

Key action points (continued)

Put monitoring and evaluation in place from the start

It is important to monitor and evaluate your participation work with the young people involved. To do this effectively monitoring and evaluation systems need to be established in the very initial planning stages. These should be developed with young people to ensure that the variety of methods used are meaningful. Structured questionnaires and focus groups can be used to gather feedback from young people and can be used in conjunction.

Think about how work will be funded

Many of the points covered by this guide do not require specific funding in order to be carried out. However in some circumstances it will be necessary to secure funding, for example, if you want to bring in an agency to help develop your participation work. Sources of funds need to be identified in the early stages of setting up an initiative or service.

Be flexible enough to adapt your services

Organisations should be honest and clear about the extent of young people's power in decision making and how their views will be used to develop services. The purpose of young people's participation needs to be identified. Agreeing aims and objectives will help here. You must be realistic about what change is possible, build in enough flexibility to be able to adapt the service and work creatively to overcome barriers to change.

Use the skills of experts

Initially a number of the demonstration sites used *existing* members of staff to lead on participation but found this to be problematic. The areas came to recognise that specialist skills are needed to carry out this work and also that due to heavy workloads existing staff members may not have enough time to devote to this work. By the end of the programme all of the areas had moved to using people with specific expertise in relation to participation and as a result were seeing greater success and innovation. Think about how experts in participation could be involved in your work at strategic and operational levels.

Consider the relative benefits of commissioning participation work or employing a dedicated participation worker

The demonstration sites used two approaches:

- Commissioning support for participation as and when it was needed from statutory or voluntary agencies.
- Employing a dedicated participation worker for their area with a dual role of supporting young people in participation work and facilitating staff to integrate this into their roles.

Whilst commissioned work was used successfully during the programme and may be a useful approach for your organisation, experience from the sites

suggests that in order to implement participation work across an area, employing a dedicated participation worker as early as possible is most successful. Continued and robust participation by young people is challenging without a participation worker employed within the core team.

Case Study – Participation in Northumberland

At a hospital in Northumberland regular diabetes management sessions for young people had ceased because nurses felt they lacked the skills, knowledge and materials to deliver them. On discovering this, youth workers approached the hospital's diabetes team offering to develop sessions and materials through consultation with young people who were in contact with the diabetes team. Contact was established with young people who were waiting for appointments, and the youth workers engaged them in the development of the sessions. The new sessions were very well received, **"It went down an absolute storm"** (Youth worker). Young people continued to be involved in service development through input at regular focus group meetings and by working with staff to develop materials for other young people with diabetes. Participation was made attractive through innovative means, for example one focus group was held at a premier league football stadium where young people were given a tour of the ground.

Key action points (continued)

Employing a dedicated participation worker also provides an opportunity for staff to be trained in participatory methods which may enable them to embed participation into practice.

“Just by watching us and working with us [staff have] picked up that information and become specialists in engaging with young people”.

Youth worker, Northumberland.

Consider what support staff may need

Participation work will be new for many staff members. Organisations need to consider how to provide appropriate support for people to incorporate participation in their work. An inclusive bottom up management approach with a focus on consultation with staff at all levels as well as with young people is most likely to lead to successful participation work.

“There is immense satisfaction in seeing young people who were previously perceived as troubled, hard to reach or withdrawn, giving feedback in a constructive way, in a confident manner, on their terms”.

Manager, Northumberland

Involve young people with a diverse range of experience

View recruitment of young people as an ongoing process and use creative approaches to ensure that vulnerable young people are included. The sites found that developing health and

wellbeing services with vulnerable groups was easier when they exploited situations where community groups or statutory services were already involved. Considerable networking with frontline staff working with hard to reach communities may be necessary to establish links with these groups and engage young people in participation. Consider incentives that are particularly appealing to under represented groups and think about what might act as barriers to participation such as timing, location, transport or intimidating factors like scary buildings or staff! You should develop advertising in conjunction with young people to make participation appealing. Make sure all young people are asked to feedback on services.

Make time to prepare young people for participation

Preparing and supporting young people for participation takes time, expertise and enthusiasm. You should schedule time for young people to learn about the processes involved in participation and to build up trust and rapport. Remember that young people are volunteers, that their commitment is part-time and that progress may be slow. You should provide accessible information about what is expected from young people and consider whether they have the necessary confidence, skills, commitment and time to do what you are asking. If young people do not have these skills, think about how you can provide support so that they can attain them.

Think about suitable incentives for young people

Services should offer suitable incentives to encourage young people to participate. Incentives could include things like fun experiences, shopping vouchers or even coursework credit, ***“They devised a questionnaire that went out throughout the college, and they used the work they were doing with us as part of evidence for their files for their actual course”.*** Youth worker, Northumberland. Any costs the young people incur should be reimbursed.

Young people’s input must be both respected and acknowledged. It is likely that young people will have their own agenda which may not fit your aims, so be prepared to listen. Make sure that young people know that they have been heard, that their views are valued and how their feedback will be used.

“When young people have done stuff the chief executive’s fantastic and met with young people. And then he’s responded to the young people, you know, he’s sent them letters saying, ‘Thanks very much for what you’ve done’.”

Manager, Bolton.

Recognise and celebrate what you achieve

It is important not to have unrealistic expectations and to recognise that participation is a long term strategy with long term outcomes. Make sure that you identify your achievements and celebrate these. Recognising and celebrating success is key for everyone involved; young people, staff and the organisation!

Resources

There are many sources of support and information about participation. Below are a few resources which may be helpful for your organisation.

- **Hear by Right** Downloadable resources including 'Hear by Right Mapping & Planning Tool' and 'What's changed? Tool' available at: www.nya.org.uk/hearbyright.
- **Hear by Right for Health** – a new tool is being developed and will be available later in 2010 via NYA and AYPH.
- **You're Welcome quality criteria: Making health services young people friendly.** These criteria set out principles that will help health services become young people friendly. They cover areas to be considered by commissioners and providers of health services. Content is based on examples of effective local practice. You can access the criteria, self assessment tool and guidance at www.dh.gov.uk
- **Participation Works** is a consortium of six national children and young people's agencies that enables organisations to effectively involve children and young people in the development, delivery and evaluation of services that affect their lives. Their website includes a range of useful resources and information about events and training: www.participationworks.org.uk
- **Hart's 'Ladder of Participation'** is a model of participation through eight levels, starting from manipulation and non-participation and moving up towards equal participation of adults and children. The paper (full title below) can be accessed at: www.unicef.org/adolescence/cypguide/index_monitoring.html
Hart, R. (1992) Children's Participation: From tokenism to citizenship.
- **UN Convention on the Rights of the Child:** A useful summary of the convention entitled; 'FACT SHEET: A summary of the rights under the Convention on the Rights of the Child' can be found at www.unicef.org/crc/files/Rights_overview.pdf
- **Young Researcher Network, National Youth Agency:** supports and encourages research led by young people. The project can provide support to organisations wishing to develop their own young researchers and can provide advice on monitoring and evaluation tools. For more information go to www.nya.org.uk/youngresearchnetwork
- **Comprehensive Area Assessments:** for more information about Comprehensive Area Assessments visit the Audit Commission's website www.audit-commission.gov.uk

Contact details

For more information about this briefing and the other work that the Association for Young People's Health is undertaking to share the learning from the sites including support available for those involving young people in the development of services contact AYPH: Tel: 0207 022 1885 email: info@youngpeopleshealth.org.uk

Thank you to...

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Footnotes

This guide draws on the findings from the evaluation of the demonstration sites and also from a number of other sources some of which are found in the resource section and some of which are listed here.

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