voluntary sector support

LINks' involvement of children and young people

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An exploration of
Local Involvement Networks' (LINks)
efforts to involve chidlren and young people
in their work and in local health and social care issues.

LINks and HealthWatch

Getting it right for children and young people

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Summary

Local involvement Networks (LINks) were established in England to provide local individuals, groups and organisations with a say in improving local health and social care services.

This research was commissioned by the National Children's Bureau (NCB) to investigate the extent of LINks' involvement of children and young people.

Both quantitative and qualitative methods were used: a survey of all 150 LINks, which received 52 valid responses; in-depth interviews with 10 LINk workers; and analysis of the feedback from events run for LINks by NCB.

The LINks who responded were hosted by a range of voluntary and community sector (VCS) organisations and in a small number of cases by the children and young people's VCS. Membership numbers ranged substantially from 51 to 1700 members, with a median of 387. However the reliability of some of the returns was questionable. The most salient findings about the membership was that numbers had generally increased over time, members were predominantly older people and aspects of diversity were rarely systematically recorded. Besides the substantial variation in size of membership, these LINks were found to also vary in terms of staffing and the focus given to working with children and young people. For some this was a full-time post, while for others it was a small part of one person's time and for others it was not a priority.

Various efforts had been made to recruit children and young people to LINks, typically via VCS organisations, local authorities, schools, colleges and health agencies. Many barriers and enablers to engaging children and young people with LINks were found.

The main barriers reported were:

- Confusion regarding the concepts of 'LINks' and 'health and social care'.
- The older membership and the skewing of LINks' work towards issues affecting older people.
- Meeting times, locations and agendas that excluded children and young people.
- Limited staff capacity to specifically engage with younger people and often lack of expertise with this group.
- The current focus on the transition to HealthWatch.
- The need to work through gatekeepers and ensure safeguarding.
- The conflict with other demands on children's and young people's time.

- The greater effort required to maintain group stability as young people commonly moved on.

In addition many LINks were said to believe that work with children and young people was outside their official remit. No one source for this misconception was found, but it was thought to stem from the limitations on LINks' ability to 'enter and view' social care establishments inspected by Ofsted, which is one aspect of LINks' role. But even LINks who worked with children and young people often operated different age limits, most typically excluding younger children. Also those surveyed and interviewed were found to concentrate mostly on health rather than social care matters.

Numerous enablers to engaging with children and young people were also mentioned, such as:

- Being creative and flexible.
- Fitting in with children's and young people's agendas and time constraints.
- Encouraging children and young people to identify the issues of importance to them.
- Providing incentives and rewards for their input and time.
- Positive attitude and drive to working with this age group by staff.

This research was particularly interested in the extent to which LINks used the VCS to help engage children and young people. The findings show that LINks found it useful to work with both the VCS and the statutory sector and did not differentiate much between the two. Most typically they worked through local authority youth workers and youth groups, health bodies, schools and colleges as well as local VCS bodies. They reported that each offered different strengths and advantages and in-roads to contacting different groups of children and young people.

Being hosted by VCS infrastructure organisations, such as Voluntary Action or local Councils for Voluntary Services (CVS), was seen to make it substantially easier to develop effective working relationships with both voluntary and statutory agencies and build on existing reputations and skills. LINks hosted by children's VCS bodies believed that this boosted their work with children and young people enormously, as they already had established contacts, understanding and expertise to work with this group more effectively.

This research found that LINks had involved children and young people in different types of projects but most typically consultations, peer research and developing information materials, often in DVD format. However in terms of degrees of participation, only a few LINks enabled children and young people to be officially involved in decision-making, either by having their own sub groups or by sitting on LINks' steering groups. In the main,

ideas and issues identified were fed into the LINk by the member of staff involved. All those interviewed expected to continue and expand their work with children and young people. Survey responses indicated that those already working with this age group were most likely to continue to do so in the future.

Numerous positive outcomes were identified for both LINks and children and young people from their involvement. These included:

- Increased awareness of the issues important to younger people across LINks and local health service providers, which in turn had a positive impact on attitudes to future work with this age group.
- A broader range of contacts and working relationships for these LINks, most notably with other relevant organisations, professionals and children and young people's groups.
- Increased information around several mainly health issues and services, arguably in more accessible formats, for children and young people.
- A number of improvements in local services.

Many concerns emerged regarding the expected transition to HealthWatch, not least the lack of clarity about its specific role and configuration. It was feared that children and young people and their issues would become even more sidelined in the new system and that much of the knowledge, expertise and relationships built up by LINks would be lost when the new HealthWatch bodies were created.

The support provided by the NCB project was deeply appreciated, especially the opportunity to pick up information and ideas and to network with others. Those relatively new to working with children and young people in particular felt that LINks needed more opportunities to share practice ideas with each other, as well as training from experts in the field.

Introduction and background

Local involvement Networks (LINks) were established under Part 14 of the Local Government and Public Involvement Act 2007, to replace Patient Forums and the Commission for Patient and Public Involvement in Health. LINks were set up to enable local individuals, groups and organisations to have a say in improving local health and social care services and since April 2008 have been operating in each of the 150 English local authorities with social services responsibilities.

> **"The primary role of a LINk is to provide a stronger voice for local people in the planning, design or redesign, commissioning, and provision of health and social care services."**[1]

Each LINk is 'hosted' by a non-statutory organisation, through which the funding is channelled. Although no precise blueprint was set out, LINks were expected to be inclusive and participatory and involve a wide range of local people. LINks were given a number of specific powers regarding health and social care services, such as making reports and recommendations; entering and viewing health and social care premises; and reporting to the Overview and Scrutiny Committees within local authorities. At the time of writing, under the Health and Social Care Bill, LINks will be replaced by new 'Local Healthwatch' bodies, which will champion patient and public involvement and provide support for patients making complaints about health and social care services. Primary Care Trusts' Patient Advice and Liaison Services (PALS), which currently provide complaints advocacy, will be abolished, however many NHS Trusts are expected to continue to have their own PALS services[2].

In April 2010 the National Children's Bureau (NCB) set up a three-year project, funded by the Department of Health, to augment LINks' engagement with children and young people and to increase LINks' engagement with the children's voluntary and community sector (VCS). This research was commissioned by that NCB project to investigate the extent of LINks' involvement of children and young people.

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[1] Getting ready for LINks, *Planning your Local Involvement Network;* Department of Health, August 2007

[2] HealthWatch Transition Plan, Department of Health, 2011

Research aims

1. To inform policy at the time of transition to HealthWatch.
2. To inform the second year of the NCB project.
3. To identify emerging good practice.

Key research questions

The key research questions were:

- To what extent are LINks engaging with the children's voluntary and community sector (VCS) in order to reach children and young people?
- What are the barriers and enablers to engaging with the VCS?
- How effective is the VCS in supporting LINks to access children?
- What other routes are used to access children, and why?
- What support have LINks received, how effective has this been and what is still needed?
- What are the issues and support needs in relation to the transition to HealthWatch?

Methodology

A mix of quantitative and qualitative approaches was considered most suitable for this study and to maximise the reliability of the findings

Online survey

An online survey, using both open and closed questions, was sent to each of the 150 LINks in the summer of 2010. Fifty two valid responses were received, a response rate of roughly one-third. Responses were received from LINks in each of the English Regions. But these were not evenly spread. As can be seen in the Table 1 below, over two-thirds came from four regions (London, South West, West Midlands and Yorkshire and Humberside). As LINks can vary in many ways and the respondents were self selecting, the results should be seen as more illustrative than representative. Statistical analysis was done with SPSS statistical analysis software and Excel. Qualitative responses were analysed thematically and in some cases also re-coded into quantitative variables.

Table 1: Survey responses by region

Region	Number of LINk responses
East of England	3
East Midlands	2
London	9
North East	4
North West	5
South East	2
South west	10
West Midlands	9
Yorkshire and Humberside	8
TOTAL	52

Qualitative interviews

Qualitative, telephone, interviews were conducted with representatives from ten LINks that had responded to the survey and aimed to explore relevant issues in more depth. Interviewees were selected to represent different regions and were mostly from LINks reporting relatively higher levels and different types of involvement. About one fifth of the survey respondents and seven of the interviewees had also attended NCB LINks events. Interviews were digitally recorded, transcribed verbatim and analysed by the researcher using a Framework approach[3].

Feedback from events

Analysis was undertaken of the feedback forms completed by participants who attended events organised by the NCB project.

Definitions

Age limits	No age limits were given to define what was meant by either 'child' or 'young person' in the survey. Neither have these terms any strict, universally accepted, definitions. However in legislation and practice 'young person' can include those up to the age of 25, although sometimes limited to 18 or 21. While respondents and interviewees mostly used the term '*children and young people'*, occasionally they only mentioned 'young people'. The full phrase is used throughout this report, unless a respondent or interviewee specified one or the other group.
VCS	Stands for voluntary and community sector organisations.
Involvement	The term used in the survey questions. In this context it can have at least two meanings: 1. Recruiting numbers of children and young people to be members. 2. A more active participation in LINk activities. Both meanings are covered in the report and levels of participation are discussed on page 19.

[3] Framework is a method of analysing qualitative date, developed by NatCen (http://www.natcen.ac.uk/about-us/our-approach/framework). Qualitative data is summarised and inputted into charts, structured according to subjects & themes.

Findings

1 Profile of LINks' membership and recruitment of children and young people

1.1 Host agencies

All LINks are 'hosted' by other organisations which cannot be statutory health bodies or local authorities. The LINks which responded to the survey were hosted by a range of agencies, reflecting the national spread of host organisations previously reported by the Department of Health (DH)[4]. Across those responding, hosts were most commonly local voluntary umbrella agencies, such as local Councils for Voluntary Services (CVS). Other hosts included national disability agencies, such as the Shaw Trust; social enterprises promoting community care; nationally spread VCS agencies, such as Age Concern and children's and young people's organisations such as Barnardo's; and three private firms. Of the ten LINks interviewed, five were hosted by an infrastructure promoting VCS, such as a local council for voluntary services or Voluntary Action and five by a range of other, mainly regional voluntary agencies. One LINk had three hosts, one of which was a national children's VCS agency.

1.2 LINk membership

LINks were set up to have 'members', who can be individuals or agencies and who commit to being regularly active and involved; and 'participants' who are less regularly involved[5]. NCB survey respondents were asked '*How many members does your LINk have*?" The numbers given ranged from 51 to 1700 members, giving a median of 387 and an average of 507, which was in line with the findings of the Department of Health (DH) Annual Report 2009-10. However, some reliability issues emerged, with indications that several respondents had interpreted this question differently: some gave the number of 'participants' rather than 'members', one the number of '*registered interested parties',* and another '*approximate*' numbers. Lastly the numbers may have changed since summer 2010. The DH report noted that membership had grown from previous years and the qualitative interviews done for this study also found that membership numbers had increased for many LINks since the survey.

The survey asked what "*percentage of your members are from charities, voluntary organisations and social enterprises*?" Six respondents said they

[4] Local Involvement Networks (LINks) Annual Reports 2009-10 ; Department of Health, *Sept 2010*

[5] Getting ready for LINks, *Planning your Local Involvement Network; Department of Health, August 2007*

did not know. Of the rest the answers ranged from one to 90 per cent, with over half giving figures of between ten and 30 per cent, but no particular patterns were evident. In addition to the standard model of members and participants, one interviewed LINk had developed a model of 'partnership' agreements with roughly 40 local statutory and voluntary organisations working with children and young people.

The interviews queried the numbers of children and young people who were individual LINk members. Some did not know as this data was not collated. A few reported having 70 to 100 children and young people as members, but for most the figures were said to be 'quite small' and tended to fluctuate as children and young people actively participated for time-limited periods around specific initiatives, with figures ranging from six to 30 actively involved children and young people at those times. No relationship was found with the total membership number.

Data on the diversity of membership was not available to most interviewees and it was indicated that this was just beginning to be collated systematically in many areas. Some of the LINks interviewed specifically targeted certain children and young people, most typically carers, disabled and those living in rural areas. In addition some gave examples of targeted work with young mothers, young homeless people, travellers and lesbian, gay, bisexual and transgender groups. As far as could be ascertained, no specific targeting was undertaken on the basis of race or religion.

In terms of age, most LINKs reported that their membership and work focus was skewed predominantly towards older people. Although all those interviewed worked with children and young people, further age demarcations emerged concerning the age of their younger members in general and of those most actively involved. Interviewees tended to refer more commonly to 'young people' rather than to 'children and young people' and when queried, a variety of age parameters at the lower and upper ends emerged. For instance, some worked with 13 to 18 year olds; others with 16 to 25 year olds. In many cases this mainly reflected the groups of young people who had become involved with that LINk. Latterly, interviews explored to a limited extent the scope of working with younger children and issues such as children's autonomy and the appropriateness or not of discussing issues with parents on behalf of children, which some Links had pursued for example in relation to local maternity and neonatal provision.

1.3 Recruitment of children and young people into LINks

The survey asked how LINks had recruited children and young people. Their responses show that LINks targeted children and young people directly, as well as by using intermediary organisations, which included both VCS and statutory agencies, most typically schools, colleges, health agencies and local authority departments and youth agencies.

Analysis of the interviews found that, while there had been some learning by 'trial and error' rather than random advertising, all these LINks used three main routes to focus their efforts to engage children and young people:

- Recruitment via intermediary organisations;
- Efforts by LINks to reach children and young people directly;
- Word of mouth from the children and young people involved among their peers.

Of these, using other intermediary agencies was said to be the most fruitful by far. Both statutory and VCS organisations were used as intermediaries and found to provide different advantages. The reported merits of each approach are discussed further on page 12 below.

1.4 Reported barriers to involving children and young people in LINks

Interviewees reported the following impediments to children and young people getting involved or more involved in LINks.

i) The concepts involved, specifically 'LINks', 'health' and 'social care' were said to be *'rather dry'*, *'vague'* and '*difficult concepts to explain'* and grasp. Changes over previous years (such as the abolition of Community Health Councils), as well as the expected imminent change to HealthWatch, added to the difficulties of clarifying terms and LINks' role. Moreover children and young people were reported to approach health and social care in a way that was different to what LINks were accustomed to with older members.

> "...they came back to us with issues like their peer pressure and body image and, yeah, how they view health and social care is quite different to how the LINk traditionally ... thought of health. We tended to think about it from the service provision point of view... quite different I suppose to us thinking 'oh we could go and ask them about GP services or NHS services'.

ii) The membership and perceived image of LINKs was predominantly older. This, combined with the demographics of health problems and aging, led most LINks to focus mainly on health and social care

issues which affected older people. Moreover this was felt to be self-perpetuating to some degree: new members reflected existing membership, who in turn set the agenda.

iii) It was felt that LINks were not always that welcoming to children and young people and that there was a degree of inter-generational tension. It was also suggested that it would be difficult for both younger and older members to work together as the older committee members tended to be retired professionals and very confident, with quite different experiences and life views to the younger members.

iv) LINks meetings were said to have a format, and concentrate on issues such as governance, which children and young people might not find that appealing. Meetings were commonly fixed for day times, which clashed with school and college hours.

v) Many LINks covered large geographical and high population areas. Children and young people living in rural counties were said to face additional transport problems when trying to get to meetings or activities, as they did not have their own means of transport.

vi) LINks had limited staff capacity or funding to work with children and young people and this work tended to be a small proportion of their overall LINk responsibilities. Recent service cuts had further reduced staff capacity. In some instances the LINks staff had no previous experience of working with children and young people.

> "... certainly part of my steepest learning curve has been doing this. It's also been incredibly enjoyable, but to begin with I really didn't really know how it was going to go and, so, yeah, I think that probably gets in the way."

It had taken time for the (generally older) volunteer members to become effective in their role and even more time was felt to be necessary to work with children and young people.

vii) Preparations for the transition to HealthWatch were said to consume a large proportion of LINks' time and resources currently. Staff cuts in other organisations such as youth services and Primary Care Trusts (PCTs) detracted from services and meant that nascent working relationships were lost.

viii) Group stability was said to be harder to maintain with children and young people, as their lives and commitments would simultaneously undergo many changes, such as moving on to different schools or colleges, exams, or work.

ix) Children and young people already were said to have lots of demands on their 'free' time, such as studying, caring for others, perhaps an illness or disability, as well as any personal interests such as sports which limited their availability for LINks' type work.

x) Recruiting children and young people commonly involved prior engagement with and seeking consent from 'gatekeepers', such as schools and parents. In turn this again necessitated clarifying LINks' remit and purpose. Moreover the priorities of LINks and such gatekeepers might differ at the time of contact.

> "... it's quite difficult. We find that they're sometimes so protected by other organisations and groups and it's difficult to get to those people that you want to talk to because they're so protected. But we have done some work with groups like ADHD groups and support groups and parents as carers groups and tried to get to those sides of things. But other than that it hasn't been very easy to do that. I don't know what the solution is."

This possibly perpetuated the tendency to use children and young people who were already active in other groups, such as youth parliaments. Other aspects of safeguarding were also said to be off-putting at first, such as the need to get specific parental consent for each event.

xi) In addition, trying to work through schools was said to present additionally difficulties because of the need to fit projects around term and exam times, as well as negotiating with various gatekeepers.

> "... we did think about doing a project with schools and it was just, to have the time to be able to approach the schools and to do it properly just was, with all the requirements that you would have to meet obviously to do that effectively as well. We just thought, oh it's too big a project for us to be able to take on with the time and resources that were available."

xii) It was reported that some LINks did not believe that their remit covered health and social care in relation to children and young people. Six survey respondents said they did not work with children or young people at all and one explained that as a LINk they were not allowed to work with young people under 16. The interviews sought to explore why this belief might be held.

As mentioned previously, no one age limit was found, but many LINks interviewed favoured working with older young people and some employed minimum ages, such as 11 or 13, or secondary school age. However this appeared to reflect convenience as much as anything: older young people were said to find it slightly easier to engage because of their ability to travel independently to meetings, interest in the issues and confluence with topics they were studying at school or college.

Interviewees were asked why they thought other LINks might have concluded that LINks were not supposed to work with children and young people. It was felt that organisations might shy away from such work because it was sometimes more challenging and demanding and because of the safeguarding measures necessary. It was suggested that confusion arose because LINks' powers to 'enter and view' services did not extend to premises inspected by Ofsted. The fact that children and young people were not specifically mentioned in the Department of Health guidance was also said to aggravate their invisibility.

However, most of those interviewed were surprised and thought it was short-sighted as '*children and young people become older people*'.

> "if you get YP involved now and a better understanding of health, a better understanding of social care, it can only make things easier for everybody when they're older. .... we always tend to say young people are on the edge of everything but they're not".
>
> "We're shaping future services... and the future users of those services are our young people. So our 25 year olds will be middle aged, our 11 year olds will be coming up to 20 year olds, they'll be coming up to sexual maturation, they'll be making families, they'll be requiring maternity services."

It also emerged from both sets of data that LINks had a tendency to focus mostly on health related issues for children and young people. This may also be related to the misconception about what LINks can and cannot cover in regards to social care and again for what age groups any such limitations apply.

1.5 Key enablers to involving children and young people in LINks

- It was felt important to be creative, flexible and willing to learn, especially in terms of how children and young people are targeted, how meetings or sessions are run and in methods of communication. It was strongly felt that this group needed to be offered alternative ways of interacting. However while electronic and web-based communication methods, such as Facebook and Twitter, were tried by some and proved effective to an extent in maintaining contact, these formats

were said to work best when they were well managed and used to engender discussion about specific topics across existing members, rather than used as a recruiting tool or left to run autonomously.

> "but I think we've had to really think outside the box because there's no good doing the same way because it's worked with older people, carers or whatever, they don't want that kind of method, they don't want meetings and things."

- Fitting in with children and young people, rather than expecting them to fit in with LINks was considered essential. For example it was said that initiatives and agendas should emanate from children and young people and be as peer led as possible. Children and young people were said to respond very favourably to being shown respect and being enabled to participate and take initiative. It was also considered essential to ensure that tasks and roles were clear and bounded.

> "...[they] are just enthusiastic, ... I admire their energy, and they have been really quite I think sparked by the fact that this is one way in which adults listen to them.... they feel they're making a difference."

- Some LINks encouraged their younger members to set the agenda and identify what was important to them and what they wanted to work on. They advised matching LINks' activities, or showing how these related, to what young people are already doing, for example health and social care studies at school or college.

> "It came from actually getting young people to work on what was important to young people and I think they thoroughly enjoyed the whole process. And the whole process was also linked in to all sorts of other things they were doing, maybe school work and all of that, their citizenship stuff and talking to people, communicating with people and research, that all linked together in a really good way."

- Timing meetings and activities to suit children and young people was said to be key, such as outside school hours and fitting around other fixed commitments such as exams. One LINk had organised a conference for 4pm to 8pm on a Friday afternoon. To this end LINks sometimes offered alternative ways to keep in touch and participate in discussions, such as by e-mail or Facebook. These were felt to be a efficient method for an established group to consider topics and overcome some distance and travel barriers in rural areas.
- Incentives, rewards and 'freebies' were seen as important when trying to attract young members as well as for rewarding continued engagement: '*Pizza worked well*'. Many LINks provided certificates,

structured volunteering which counted as credits for other qualifications such as citizenship studies, and wrote references based on volunteering with the LINk. Nurturing and support were also described as crucial. In terms of maintaining a group it was said to be essential to show that the children and young people and their input was valued and to give more care and nurturing than might be considered necessary for older members, as well as extra and regular contact and reminders such as by text or e-mail.

- The attitude of LINks' steering groups and staff to this issue was said to be vital. It was said that LINks may think they know what was important to children and young people, but that only direct contact and interaction with and input from children and young people could verify whether or not this was correct.

> "actually, when you come to talk to them it's the completely opposite thing ... that's important to them".

2 Involving children and young people though VCS and otherwise

This research was particularly interested in LINks' views on the usefulness of working through VCS organisations to involve children and young people.

When asked in the survey "*Have you involved children and young people in your LINk via children's charities, voluntary organisations or social enterprises?"* 45 LINks (87 per cent) reported that they had. Respondents were also asked if they had involved children and young people in other ways, besides VCS agencies, and over half, 36 (69 per cent), said they had. This included working through statutory agencies and working directly with children and young people without any intermediary organisations. Thirty four LINks (65 per cent) had used both approaches; thirteen LINks (25 per cent) either one or the other; and five (10 per cent) neither. Fewer than half the survey respondents (24) reported having some success relating to children and young people. The responses indicate a large gap between those LINks reporting both working with and successes with children and young people and those who had not worked with this age group.

Table 2: LINks' use of VCS or other organisations to contact children and young people

How involved children and young people	Number	%
Via VCS organisations	45	87%
Via other (non VCS) organisations or directly	36	69%
Via both VCS and other routes	34	65%
Though either VCS or other routes	13	25%
Neither	5	10%

> "we have been successful in building relationships with organisations and services that support young people between the ages of 11-25. These links have enabled us to work in direct contact with young people around issues and concerns they have with their health and social care services."

Connecting with other professionals in the field and using other organisations and existing groups, was reported as a key enabler in helping to reach children and young people, explaining LINks and

developing effective working relationships. Establishing personal contact and good working relationships with one or two workers was also felt to be more useful than trying to sell LINks to a whole organisation. Working with and through other agencies was described as bringing numerous benefits from LINks' point of view. These included: making the most of LINks' restricted resources; overcoming LINks' own lack of experience working with children and young people; building on the second organisation's existing work, relationships and groups and thus saving LINks from having to start from scratch; introductions by these agencies helped pave the way for LINks, helped overcome some of the barriers negotiating with gatekeepers; and last but not least it provided LINks with direct contact with children and young people.

> "We actively go and target those organisations, like youth groups and people who are working with young people and Youth Parliaments...we've really focused on the people who are working with young people... and we've made some good links with some of the local youth organisations ...And we've started to make some good links with actual individual young people who've heard about us and approached us where there's pieces of work that they might like to do."

Moreover, it was generally believed to be more beneficial and pragmatic to work through existing agencies, which already facilitated children and young people groups and employed skilled and experienced youth workers, rather than creating a new group from LINks' limited resources.

> "... because they're on the ground working with young people and, well the difficulty we find with LINk is because we have to cover everything and everybody you don't have, we don't have the expertise to work with that whole group ... It's getting the right people to do the work. We couldn't have accessed those young people with the capacity and the old fogeys that we've got, it just wouldn't have worked."

> "we're kind of like a conduit really, ... people out in the community are much better placed, so we would pay them to run a focus group, ... it's just looking at how best to run it. ... So we paid for the hall, we paid for refreshments, we paid for a member of staff to be there, much better than us coming out and running something. So we put the resources into the experienced people in the community."

The other agencies were also said to have benefitted, in particular by widening their agendas for example by looking at health issues for the

first time, and by LINks enabling a range of organisations to work together, which they felt might not have happened otherwise.

LINks clearly found it mutually advantageous to work through and with both the statutory and VCS sector and ascribed benefits to both and on the whole respondents and interviewees did not distinguish between the statutory or not for profit sector. The distinction was not considered that important as long as the organisation had a ready formed group of children or young people who might be willing to work with LINks or could help LINks with this work in some way.

Local authorities featured most prominently among the statutory sector, although a few LINks also reported working closely with health authorities, PCTs, other health projects and individual professionals. In local authorities the LINks interviewed had most commonly worked with schools and colleges; Youth Parliaments; youth workers; and council run youth facilities, predominantly youth clubs.

Working with youth workers and youth clubs were perceived as very rewarding and helpful for LINks as the groups were already formed and receptive to LINks' work and the experience of the youth workers facilitated interaction and projects. It was also felt that experienced youth workers and teachers, who knew their groups, were better skilled at drawing out the range of views in a class or group than a visiting LINk worker could.

> "[The] LINk circulate newsletters to the Participation Officer for the Youth Service in the Borough. We attend regular meetings with the service and invite them to any events we host."

> "So I think going via the youth clubs and existing groups really cut out I suppose a lot of those barriers for us because young people were already comfortable in that environment and it was quite easy to advertise for volunteers that way and to promote the project and to get people onboard. So it meant we didn't have to contact people in their own homes essentially or on the streets, whatever it was."

Opinions were divided on the pros and cons of working with children and young people already involved in local Youth Parliaments. On one hand these offered a ready formed group, clearly interested in and willing to try to influence local affairs; while others saw it as over-using the '*usual suspects*' and not providing an adequately diverse viewpoint and preferred to spread involvement beyond those already heavily engaged.

Schools and colleges were favoured because they enabled access to the largest number and most comprehensive range of local children and young people. LINks often targeted pupils studying citizenship or health and social care in the hope of being able to provide mutual benefits. While

gaining access through schools had proved challenging for some LINKs others had been quite successful, either by linking to another pre-existing initiative or by establishing a relationship with one interested teacher.

> "The local College runs a "Speed Volunteering" event every year. The idea is that students can come and visit each organisation's stall for a 3 minute period and move on to the next stand. [Our] LINk took part the last two years and has actively encouraged a small number of young people to join."

Working with health and local authority professionals had in turn helped gain access to schools. For example several LINks had 'piggy backed' on the PCT 'You're Welcome' initiative which in itself aimed to increase the involvement of children and young people in health services[6]. However PCT changes resulting from the Health and Social Care Bill had led to the demise of some of these initiatives.

All those interviewed had used VCS agencies to some extent to help get in touch with children and young people and felt that this provided a '*good conduit*' to reach them. As well as targeting existing generic children and young people's groups, LINks had also approached young carers groups and local disability groups for children and young people.

Many of the LINks interviewed were hosted by VCS infrastructure and capacity building organisations, such as local Voluntary Actions or Councils for Voluntary Services. Having such hosts in itself was said to bring numerous benefits on which LINks could build. For a start such hosts had a comprehensive database of, and established reputations and contacts with, local VCS agencies, including those working with children and young people. This was seen as providing a '*terrific boost*' to reach other VCS organisations.

In addition some of these hosts already had staff experienced in increasing the participation of children and young people in local initiatives as well as strong working relationships with other professionals in this field. One of the hosts was the children's VCS, Barnardos, which brought even greater benefits in terms of experience of working with children and young people and an established reputation and relationships in this work.

While on the whole LINks were keen and happy to work with both statutory and VCS agencies and described different advantages to both, the one additional edge ascribed to the VCS organisations was that they could be more flexible and creative and as a result slightly quicker to be receptive to LINks' ideas and initiatives.

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[6] *Department of Health: 'Quality criteria for young people friendly health services' April 2011; available on* http://www.dh.gov.uk/publications. (accessed on 6/6/11)

3 The type and extent of children's and young people's involvement

3.1 Data from the survey

LINks which had worked with children and young people had engaged with them in different ways and the vast majority (78%) of those reporting success in working with children and young people had used more than one approach. It was also clear from the data that those who involved children and young people most had also done most in terms of different degrees of involvement and diversity of types of activities.

A number of LINks had produced information for or about children and/or young people, such as an anti-bullying DVD, which was sent out to local schools and youth organisations.

> "[Children and young people] attended groups and meetings regarding DVD. They planned, organised, and acted in the DVD. Wrote scripts, filmed, and edited the films. One of the films is now being put forward as part of a film competition."

Consultations with children and young people were common. These included meetings with, and targeted surveys and consultation events among, young people in the area.

> "As well as circulating information about the LINk to relevant young peoples' organisations we are involving three local organisations in our current projects, listening to communities and Community Health Champions. We hope that this will encourage young people in [area] to have their say."

> "We spoke to young people in a street survey about healthy living".

> "[We] have also involved CYP groups in surveys and consultations."

> "A group of up to 17 young people aged 17-21 are participating in consultation exercises, devising ways of gathering the views of other young people many of whom would not otherwise have a voice."

Many LINks undertook specific policy work, lobbying, or campaigns for children and/or young people, mostly around issues raised by children and young people. Examples included:

- Work with a young carers group to highlight their circumstances;
- Lobbying for increased spending for disabled children and young people and for improved access to local health facilities;

- Joint campaigning with other agencies for the re-instatement of local chlamydia screening facilities.

> "We have attended young carers' groups, and youth groups aimed at BME, LGBT and disabled young people. We have written reports from these meetings including the views of young people on health."

> "Children and young people have been involved with developing posters for the LINk, they have designed a leaflet that [local] NHS Hospital give to children who are discharged from hospital after having a head injury."

> "We are currently running a young person's survey to enable us to collate information countywide on the services young people currently use and what services they feel they would like to connect with in their communities."

Working with children and young people to conduct peer research was widespread. The results were shown in DVD and other formats.

> "We also worked with ... a group of young people ... who created a film based on their views on how health services can improve. This is now on our website. We will also be working with the same young people, plus a few others from another area, to design a leaflet and poster to attract young people to the LINk. We hope to work more closely with the 'You're Welcome' initiative. I will be going to a school for children with additional needs in July to ask for their views on health."

A small number of LINks had tried to involve children and young people in the LINk decision-making, to varying extents. Examples included deliberately recruiting younger people to be active LINk members and setting up a young person's sub-committee within the LINk.

> "I have currently got one young person volunteering for [named] LINk- trying to set up a young person's group... connecting with agencies and outreach when we go out to meet young people in the community and at young people's groups across the county."

> "Our Children and Young People Subgroup meets quarterly to discuss the outreach work and identify any areas where we feel work needs doing. Young members of the ... subgroup helped design the layout of the website."

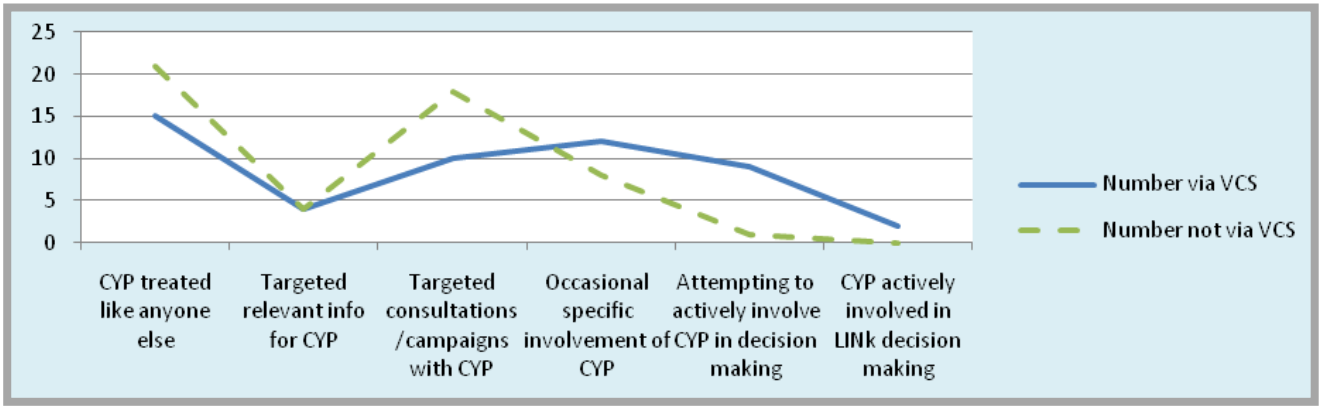
The survey responses were further analysed to reflect the degree and type of involvement. As can be seen in Table 3 below this ranged from relatively passive forms of engagement, such as being sent general literature, to children and young people having a clear role in agreeing priorities and decision-making. The table also shows whether these were recruited and involved via VCS agencies or otherwise.

Table 3: Type of involvement of children and young people

Reported involvement of children and young people	Involved via VCS agencies		Involved in other ways as well	
	No.	%	No.	%
Children and young people are treated like anyone else, e.g. may receive general literature or information	15	29%	21	40%
Targeted relevant information created about and/or distributed specifically to children and young people	4	8%	4	8%
Targeted consultations and campaigns with children and young people	10	19%	18	34%
Occasional involvement on specific tasks such as children and young people conducting peer research	12	23%	8	16%
Attempting to actively involve children and young people in agenda setting, decision-making and planning	9	17%	1	2%
Children and young people actively involved in processes, agenda setting and LINk decision-making, such as young person's sub-committee or panel.	2	4%	0	0
TOTALS	**52**	**100%**	**52**	**100%**

The above data was also put into Chart 1 below. There is a trend towards targeted consultations and occasional involvement and indications that those engaged via VCS agencies were slightly more involved in decision-making.

Chart 1: Type of involvement of children and young people



3.2 Findings from the qualitative interviews

Interviews explored the type and extent of involvement in more detail. The two most popular activities in which children and young people were engaged were peer consultations and developing DVDs.

The original ideas for consultations were said to emanate from both young people and LINks' staff. Typically the children and young people were involved in developing ideas and questions, tools and methods, drafting questions and using them to collect data. Consultations and surveys were conducted with their peers, in public; or within existing groups; or through online surveys. Group discussions were used as well as individual questionnaires.

> "I worked with a couple of young people's groups to design a survey to put out across the county at outreach events. ... I took volunteers with me to [ ] Festival to help me complete the survey. And the survey was to gauge what services were being used in what areas and how young people found that interaction with those services and whether they feel they had enough services and the right services in their area. So that's what the report is based on, it's all the statistical data gathered from that. So it's quite unique information out of that."

> "[After hearing anecdotally about inadequate counselling services] we went to the Young Advisors' Group (local youth parliament). We told them what our findings were and they told us what their views were from all their different backgrounds. We then drafted a questionnaire and we took the questionnaire to the Young Advisors again ... they had lots to say, lots to change, and we changed it and everything. And then some of them took a role in actually promoting it in their own areas, they went to a youth club or whatever, and they could complete it themselves. And then ... we worked with ... the professional at the

> groups and we ran some small focus groups ... so that we weren't strangers coming in really."

In one area the LINk invited other agencies to come forward with proposals in this field. They then selected a few projects, including supporting and funding a local youth organisation to canvass young people for their issues and priorities. The feedback was then converted into a survey.

> "[The youth organisation] said to the young people, 'what do you think is important to you?' And they said 'we want to do a piece of work on sexual health'. So then they went away and they had various groups who designed surveys... and did interviews and all sorts of things and canvassed all their peer group around sexual health. Because it was especially rurality issues about young people not being able to get to clinics and GPs, transport and all sorts of issues that we have in [area], that it's not easy to access some services. .. they got, I think it was 500 responses in the end."

DVDs proved popular as both a consultative tool to gather views from other children and young people, and as a means to report on issues important to them, from their own perspectives. Different formats were employed. For instance, in one area a series of short films were created on discrete topics and in each one young people followed scripts to act out different story lines. In others, young people were filmed being interviewed about topics and concerns of interest to them. In most examples given, health issues and services featured rather than social care issues, apart from young carers who covered both. The DVDs were said to have been used to train staff, and convey issues both to other LINks members as well as to local health authorities.

> "... they've got a film company, helping them put a presentation together. And then we're going to help them to put that presentation out to an event and invite the local commissioners and providers of those services to come along to the event and actually see those results and then challenge them to say, 'what are you going to do about it?' ... And it's all driven from the young people, which was really great."

Other activities in which children and young people were involved included

- Writing reports
- Developing a photographic exhibition by young carers

- Creating advice materials
- Running conferences for and with children and young people.

In one area the initial DVD project had identified young carers as facing particular problems, which prompted the LINks to run a photography competition for local young carers to record their views. The photographs were subsequently exhibited at the LINK AGM, prompting interaction and discussions with older LINk members.

> "... we asked them what it was that they wanted to do, and ...they decided on a photo competition ... And then they identified respite as ... their main health and social care concern as young carers. And then they took photos of what respite means to them, so they took photos of skateboarding, reading, computers, open spaces. And they took some photos of their friends and things like that as well ... And then, as part of our AGM last summer we had, we exhibited the photos"

In most cases the LINk staff who worked with children and young people saw it as part of their role to relay upwards any messages from younger members, rather than formally incorporating children and young people into the LINk decision-making, or establishing prescribed routes for the issues arising to be taken up by the main LINk decision makers. However a couple of these LINks created more formal routes. One LINk had established a young person's sub group, was equal to the other LINk sub groups. Several LINks had young people sitting on their steering groups and also encouraged their younger members to sit on the different LINK's subgroups.

The extent of young members' involvement in the more formal LINk activities, such as enter and viewings, reports and recommendations, and reports to the Overview and Scrutiny Commissioner, emerged as being generally low. Much of the work reported centred on gathering views and input in a more general way.
Notably however, some LINks had developed more formal routes and roles, for instance: enabling children and young people to feed ideas and comments into other mainstream LINk reports and recommendations; training young people in 'mystery shopping'; and ensuring that the findings from consultations and surveys were presented as formal LINk reports and recommendations. One survey respondent said they were '*training to become young health assessors'.*

3.3 Reasons why these initiatives were selected and pursued

The interviews found that initiatives often emanated from the LINks' professionals who had identified two main gaps: the older demographics of LINks' membership and focus, in that the LINks mainly worked with older people and within that most often with people over pension age;

and that their LINk did not actually know what the issues were for children and young people. While for some interviewees working with children and young people was seen as an intrinsic part of LINks' brief, on the whole this was a relatively new target group.

In some cases, the specific prompts had emanated from an existing group of children and young people, such as a young carers' group or a group of disabled young people. In one instance a piece or work with travellers had been stimulated by another professional who invited LINks to work with them. Usually, the format or design of the projects came from the children and young people, such as making a DVD or designing a survey.

The aims and desired outcomes from these projects were found to be mainly either LINks orientated or service orientated; or in other words aimed at increasing the mutual awareness, profile and voice of children and young people within LINks, and/or at improving local services.

Directed at improving LINks:

- Provide children and young people with a voice both within LINk and vis-a vis local services;
- Make LINks more aware of children and young people and how to engage with them and increase their membership and make children and young people more aware of LINks and their potential;
- Explore methods and improve resources to better engage children and young people and discover their priorities;
- Establish a strategic route for children and young people within the LINk, such as a young sub-group or 'mini LINk', or a quota of places on the steering group, so that they have a voice in commissioning.

Directed at improving services

- Show both LINk members and others what health and social care issues matter to local children and young people;
- Demonstrate the need for specific services in an area, either generally or for particular groups, such as new or continued mental health services for children and young people, or services for young disabled people or young carers;
- Improve services locally for this age group by getting their input and ideas;
- Improve the information available to children and young people on relevant health and social care issues.

3.4 Resources

The costs given for the specific projects discussed with interviewees ranged from £23 to £10,000, but were most typically about £2000, excluding any staff costs. On the whole work with this age group comprised a small proportion of interviewees' overall responsibilities,

although a few were employed full-time to work with children and young people, and many of the interviewees thought that was necessary.

3.5 Reported outputs and outcomes

Only one of the LINks interviewed had done a full-scale evaluation of their work with children and young people, although several of the others planned to do so and some had sought feedback informally from the children and young people involved.

The reported outputs included:

- DVDs
- Reports
- Survey
- Peer research and consultation tools and responses
- Workshops
- Conferences
- Presentations and public speaking to local politicians and health service commissioners
- A photographic exhibition
- Information materials
- A booklet about working with young people.

A number of concrete outcomes were reported to have been achieved, including:

- Increased awareness of issues affecting children and young people, albeit mainly concerning health, across LINk workers and members, local health bodies, GP consortia, Children's Trusts, professionals and local politicians.
- Within LINks this work was seen to have increased awareness among LINk members of why it was worthwhile to work with children and young people, '*have learnt so much'*; increased membership of young people; changed attitudes to working with them and their issues; reduced the bias towards older people; and provided '*a whole new set of priorities'*, as well as an impetus and encouragement to work with other '*easy to ignore'* groups, such as homeless people and travellers.
- This work was said to have produced a new set of contacts and relationships for LINks, who also felt more able to work with children and young people and related organisations on more issues in the future.
- For some the different ways adopted to working with children and young people had led to a change in their approach to working with older volunteers as well.

- Across health professionals, the projects were said to have created or increased a desire to work and communicate with children and young people and to do so directly rather than only via their parents. In some areas health authorities had begun initiating contact to seek the views and input from children and young people.

> "It's highly unlikely that health people would have included young people or that young people have known about health event. And young people got experience of presentations."

- These initiatives were said to have resulted in a number of improvements in local services for children and young people. The examples given were changes to local mental health and sexual health services, including opening times to fit around education and travel times; a housing improvement for teenage mothers; speech and language therapy service changes; and some better services for young carers. Most of the DVDs produced were taken up by local health bodies and used for staff training. Areas which were pathfinder areas for HealthWatch felt that the findings demonstrated by the young people would help influence HealthWatch development.
- By indirectly publicising existing young groups and highlighting their needs, LINks work with them had provided leverage for some of these to get funding.

3.6 Plans for future involvement

All the interviewees hoped to continue or even expand their work with children and young people. The vast majority of survey respondents (47, or 90 per cent) reported plans to involve children and young people more in the future. However it was not possible to assess how realistic such plans were, or what actually transpired. Moreover some of this might be as a result of the research: the effect of being asked about this issue may have prompted more interest.

Recoding of reported plans by survey respondents (see Table 4 below) indicated a degree of interest in pursuing more collaborative work with children and young people, especially in terms of more targeted consultations and campaigns, and in increasing the level of children and young people's involvement. The slight shift to increased consultations is also illustrated in Chart 2 below. However the plans mentioned in the survey again indicated a quite limited role for children and young people in designing the consultations and/ or in the LINK's decision-making. It was clear that those already working with children and young people, or who reported some success already in this area, were also the most likely to have plans to involve children and young people in the future, and generally with an increase in the degree of that involvement, especially in

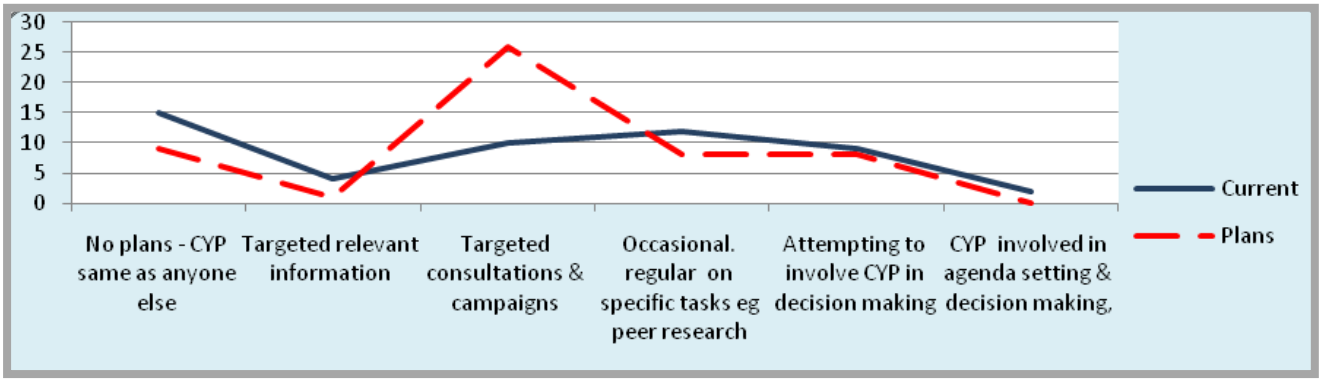
peer consultations and research. The issue of participation is discussed further below.

Combined with the other findings reported above, these indicate a split: some LINks involve children and young people quite a bit and plan to continue doing so; while others do very little in this area. It is also possible, but obviously we have no way of knowing, that those voluntarily responding to this survey were already the more active LINks in this field.

Table 4: Plans to involve children and young people in the future

Types of involvement of children and young people	Number of LINks	% (n=52)
Children and young people are treated like anyone else	9	17%
Targeted information for a particularly relevant issue or targeted specifically for children and young people	1	2%
Targeted consultations and/or campaigns with children and young people	26	50%
Occasional – regular involvement of children and young people, such as occasional recruitment to conduct peer research	8	15%
Attempting to actively involve children and young people in agenda setting, decision-making and planning	8	15%
Total	**52**	

Chart 2. Plans to involve children and young people in the future compared to current work



3.7 Examining involvement along models of 'participation'

Given the differences found in the type and extent of how LINks had involved children and young people, the survey data was also analysed under models of 'participation'. Over about 40 years there has been growing interest in the participation of the general public and children and young people in the policy areas and decision-making which affects them (eg Arstein 1969[7]; Hart 1992[8] and Kirby et al 2003[9]).

One classic view of participation is on a ranked scale or ladder, such as those devised by Arnstein (1969) or Hart (1992) and illustrated in the diagrams below. The 'Ladder of Participation' grades the degree and type of participation, with activities done to or for people ranking at the bottom and sharing agenda setting and decision-making at the top.

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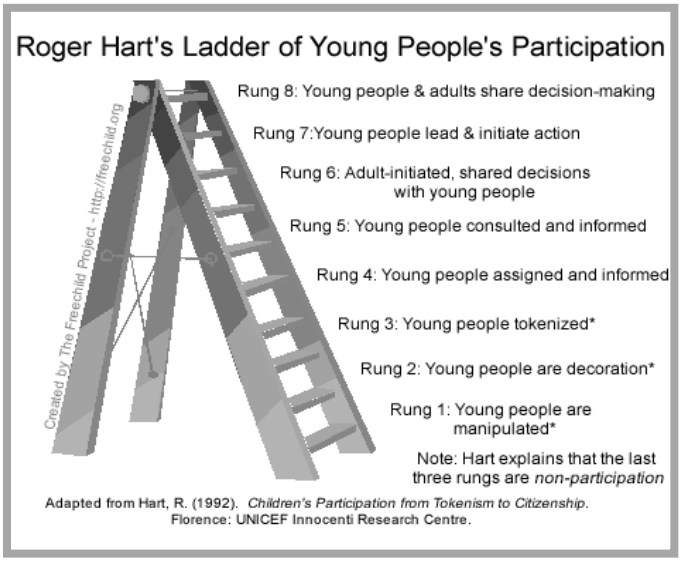
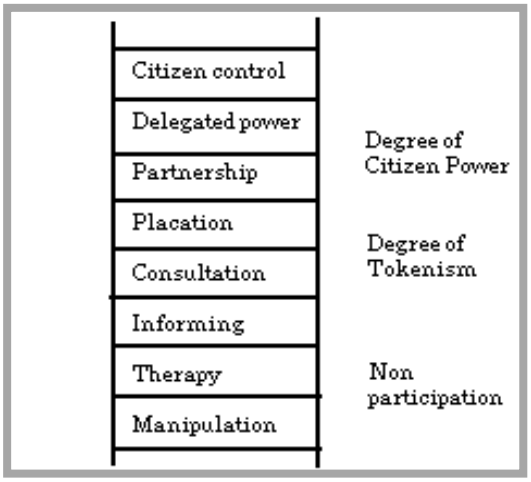
[7] SR Arnstein, 'A Ladder of Citizen Participation' can be found at http://lithgow - schmidt.dk/sherry- arnstein/ladder-of-citizen-participation.html; accessed 6/6/11

[8] Roger A Hart, 'Children's Participation: From tokenism to Partnership'; Unicef Innocenti essay 1992, No.4; http://www.unicef-irc.org/publications/pdf/childrens_participation.pdf (accessed 2/6/2011)

[9] *'Building a Culture of Participation: Involving Children and Young People in Policy, Service Planning, Delivery and Evaluation' by Perpetua Kirby, Claire Lanyon, Kathleen Cronin,& Ruth Sinclair, 2003, DfES, London*





Arnstein's model (1969)

In contrast, using case studies and other methods, Kirby et al (2003) moved away from the ranking approach to participation and proposed instead that there were different dimensions to participation.

> **"Participation is a multi-layered concept, with the same term often used to describe very different processes. Participation can be considered under the following six dimensions: level of participation; focus of decision-making; content of decision-making; nature of participation activity; frequency and duration of participation; the children and young people involved." (Kirby et al 2003)**

The authors developed a more flexible model of four types of participation: they felt that all of these four approaches were equally valid, but suited to different organisations, or departments within the same organisations, or to different activities, programmes or circumstances. They also saw a role for involving parents of very young children in order to help gather and express the views and interest of very young children. Their four-part model is illustrated below.

Types of children and young people participation: Model borrowed from Kirby et al 2003

❖ Children/young people's views are taken into account by adults and used as at least one source by decision makers

❑ Children/young people share power & responsibility for decision-making with adults (to varying extents)

◆ Children/ young people are involved in decision-making (together with adults, who make ultimate decision)

● Children/ young people make autonomous decisions (although implementation may rely on adults)

Kirby et al also hold that degrees of participation can fluctuate within an activity, according to the methods and approach of the adults involved, and that their four-part model was only a guide, as the level also depends on the way in which adults engage with children.

> "Even within an activity, power can change rapidly from task to task, from different types of decision and between individual young people. For example, adults may enable a youth forum to make certain decisions but not others, or may delegate and involve some young people (perhaps older young people) more in making decisions than others." (Kirby et al 2003)

Using this, arguably more generous, four-part model, the activities reported by the LINks surveyed and interviewed and mentioned in this report could be counted as 'participatory'

- Targeted consultations and campaigns with children and young people, (❖ in this model);
- Involvement on specific tasks, such as children and young people conducting peer research, (❖ in this model);
- Attempting to actively involve children and young people in agenda setting, decision-making and planning, (◆ in this model); and
- Children and young people actively involved in processes, agenda setting and LINk decision-making, such as young person's sub-committee or panel, (◆ in this model).

Again using this model, all the LINks interviewed could be viewed as being 'participatory' in the work they mentioned, while only 63 per cent of

NCB survey respondents could be described as being ‘participatory’ in the work they reported to date (last four rows in Table 3).

80 per cent said they planned to be more ‘participatory’ in the future (last 3 rows of Table 4).

4 The transition to HealthWatch

At the time of writing, the Health and Social Care Bill was making its way through Parliament. One of its provisions was the abolition of both LINks and Patient Advice and Liaison Service (PALS) and their replacement by a new body called 'HealthWatch', which will also operate locally. While the final details were still unknown at the time of the interviews, everyone was apprehensive about the changes and had concluded that it would become even harder to involve children and young people under HealthWatch organisations.

Interviewees found the uncertainties about the future difficult in itself, such as the shape and functions of the new HealthWatch bodies and the proposed abolition of Primary Care Trusts, as well as the lack of information about the changes, how HealthWatch was expected to develop, its capacity and precise roles. It was felt that this change on top of successive overhauls over the past eight years undermined effective working, such as the replacement of Community Health Councils with Patients' Forums and then their subsequent substitution by LINks.

Particular worries were expressed about how children and young people would fare under HealthWatch. There was a fear that the absorption of PALS work would lean HealthWatch more towards complaints, which were not expected to draw in young people and it was predicted that more complaints and issues (currently PALS work) would emanate from older people and that funding would also tend to follow older people's health and social care needs. Most feared that children and young people would become even more 'marginalised' in the new system, that their concerns would carry a much lower priority and that it would take more effort than now to place or keep their issues on the agenda, or successfully argue their case within even tighter budgets. Fears were also expressed that the agenda setting system would be more 'top down' than with LINks.

> **"I know there wasn't any particular obligation within the LINk, but it's whether or not the way HealthWatch evolves allows for children and young people to be involved in the same way."**

It was feared that much of the knowledge, expertise, momentum and resources which had been built up by LINks around working with children and young people would be lost in the transition, together with the working relationships which had been developed with other professionals and agencies. It was unclear which bodies would succeed in acquiring HealthWatch functions and there were no guarantee that a LINk would automatically become a local Healthwatch, which added to the fears of losing expertise and resources.

It was felt that it would become even harder to engage children and young people for these reasons, combined with an expected reduced capacity and greater commitments.

> "[LINks] may lose sight of young people."

Interviewees made a number of specific recommendations which they felt would help minimise the harm and smooth the changeover in relation to their work with children and young people:

- Provide more guidance about working with children and young people and remind HealthWatch staff that children and young people are also service users.
- Ensure that children and young people and their organisations (statutory and VCS) are included in HealthWatch stakeholder events.
- Maintain records, reports, resources and expertise on LINks' work with children and young people to avoid losses in the transition.
- Ensure that funding is allocated towards issues relevant to children and young people.
- Provide and fund national advertising about HealthWatch to increase public awareness.

5 Support

During its first year the NCB project organised five training, policy and information events around England, attended by a total of 68 people. These focussed on how to increase the participation of children and young people, how to improve networking across LINks and other organisations and information on the expected changeover to HealthWatch. Overall participants reported finding these events very useful and informative. A repeated theme was how each LINk worked independently and differently and developed its own priorities as well as anxieties about future changes.

Feedback collected after these events clearly showed that LINk workers wanted:

- More training, guidance, ideas and instruction on how to increase their engagement with children and young people;
- Practical examples of how other LINks approached this work;
- Assistance with networking with other LINks as well as other agencies; and
- Guidance and information on the transition to HealthWatch.

All but three of the interviewees had attended one of the NCB LINk events. Travel costs of travel had been a factor for non attendance in one case.

On the whole those who had attended had found these events helpful on a number of fronts. The opportunity to network with others in the field was valued. Interviewees felt they had gained new information and appreciated getting ideas, tips and inspiration and updates about HealthWatch. The training and information was said to be beneficial, especially for those new to working with children and young people.

Interviewees appreciated being able to access the NCB project and support and found the website useful in itself. Those without a youth work background were particularly thankful. Although a few of those interviewed were experienced in this field or had been able to access help locally to facilitate their work with children and young people, mainly from local youth agencies, most reported having no other sources of support available.

> "[For LINk workers who] don't have youth work experience, it is invaluable. Just the practical use of exercises, running the sessions ... an awareness of the potential and how it can be done and the best ways of achieving it, yeah. That support is invaluable... Unless [LINKs staff] have a youth work background, definitely."

The type and amount of other support which interviewees felt they needed varied according to their previous experience in this field and the

nature of their host organisation. But the following issues were most consistently raised:

- More money and resources were said to be needed, particularly in two key areas: employing experienced staff who had dedicated time to work with this age group; and providing transport to children and young people to enable them to access meetings and events especially in large or rural local authority areas.
- Information, ideas and training on increasing the involvement of children and young people as well as some basic training of the 'do's and don'ts of working with this age group, especially for those with little previous experience, as well as training around ethical considerations, such as when parental consent needs to be sought.
- Help to maximise the profile of children and young people across all LINks and in time across HealthWatch. Some felt that a well known 'champion' was needed to highlight the need to involve children and young people and their issues.
- Support with networking and collaborative working across LINks rather than competition. Encourage LINks to work together around both geographical and policy issues, such as children and young people's mental health.
- Encourage schools and other institutions to work with LINks and make it as easy as possible for other agencies to work with LINks and HealthWatch.
- Help to explore the potential of information and communication technology to help engagement.
- Continue to provide information around the expected changes in the structure of local health services and HealthWatch as well as how to maximise the involvement of children and young people within available structures.

Conclusion

The most noteworthy and alarming finding of the research was the misconception held by several LINks that working with children and young people was either totally outside their remit, or that they could only address health issues but not work on social care issues at all for this age group. Even those who worked with children and young people had commonly applied different informal age restrictions rather than opening involvement to all children and young people. This may reflect the age groups who had found it easiest to get involved with LINks, or those children and young people who LINks had found it easiest to engage with, rather than any specific targeting. Where LINks did involve children and young people there was significant variance in the nature of this involvement. The most common type of involvement was one-off activities such as consultations or making dvds, rather than in decision-making.

Those LINks who had involved children and young people were able to report clear advantages and benefits in terms of improvements to both LINks and local services.

The findings call into question the pursuance of diversity and the extent of monitoring by LINks. These are necessary to involving children and young people but also to ensuring that LINks' membership, focus and engagement are representative of the whole community, in particular those parts of it that are most marginalised.

The structural variations in LINks' size and staffing and how they were established, hosted and funded may in itself account for some of the differences in their approach to working with a children and young people. Hosting was found to affect the support and organisational relationships available in connection with this work and may influence priorities. Moreover the range of ways in which LINks had worked with children and young people and the type and degree of their involvement indicate considerable differences in ideas and approaches to participation and priorities. The findings that the degree of participation was highest in LINks which employed youth workers or professionals in this field and that only a few of the LINks interviewed provided a structured role for younger members, such as on sub-groups or committees, or enabled formal contribution to official reports or activities, suggests that work with this age group was still in its early days and that involvement on the same terms as older members, especially participation in relation to LINks' decision-making and priority setting is a while off.

These findings also reflect the basis on which LINks were established to identify concerns and make decisions. There is a tension between on one hand setting standardised methods and procedures across the country or, on the other, using the current 'bottom-up' approach to setting agendas.

Whilst LINks are expected to adopt the latter and follow the ideas and concerns which emanate from members, such a model relies on members being representative and on there being adequate routes and methods for all members to contribute. In this instance more official support might have helped to alert LINks that they should be working with every age group and to address the various misconceptions found about involving children and young people.

In relation to the role of the voluntary sector in facilitating the involvement of children and young people, overall the findings indicate that whilst LINks workers who worked with children and young people found it useful to work via VCS organisations to reach this target group, they used other agencies as well. Using intermediary agencies to engage with children and young people was felt to be the most productive approach by far, and LINks were found to have explored and established the most fruitful relationships wherever and however they could. Alongside VCS organisations, LINks had found statutory organisations and professionals instrumental in helping them to establish contact with and work with children and young people, as well as, if to a lesser degree, making some direct contact with children and young people. Moreover, although some LINks had worked via the children's VCS, other VCS agencies were also important, such as those working around health issues, or with carer or disability groups.

Recommendations

A clear message must go to LINks and the new Healthwatch organisations that are to replace them (through legislation, sharing best practice and/or other forms of support) that the engagement of children and young people is a central part of their remit. These organisations need clarification and support to encourage them to include working with children and young people of all ages and across both health and social care. Such input would also counteract misconceptions in this area. Particular effort is needed to get this message across to LINks who do not already work with children and young people. Ideally, support would come from both the Department of Health and NCB on this subject.

Similarly, at this critical time the advice and support relating to the creation of HealthWatch bodies needs to specifically include working with children and young people and representing their issues and concerns.

Healthwatch England – the national patient champion overseeing the work of local Healthwatch – has a role to play in driving the effective engagement of children and young people in decisions about local care services. This could include the appointment of a senior-level champion for children and young people within the Healthwatch England staff to lead on this issue nationally, oversee the collation, evaluation and sharing of effective practice with children and young people, and ensure

consideration of children and young people's needs in all Healthwatch England initiatives.

LINks/local HealthWatch need support and advice on increasing the diversity of their membership in general and in monitoring the same.

Many LINks/local HealthWatch may need extra capacity and resources to work in a meaningful way with what is for them an additional target group.

LINks/local HealthWatch need encouragement and guidance on increasing the active participation of children and young people and on how to enable them to play a meaningful role in decision-making and agenda setting.

The work and successes already achieved by many LINks require protection for the changeover to Healthwatch. Particular attention needs to be paid to maintaining established relationships and ensuring that the valuable learning, experience, resources and information accrued are passed on rather than being lost in the transition.

NCB should continue to provide information, training and stimulation to LINks and the new HealthWatch bodies about working with children and young people. These findings indicate that such initiatives for LINks/local HealthWatch need to be pitched at both basic and more advanced levels. LINks/local HealthWatch are unaccustomed to working with children and young people and need support on how best to attract, include and work with them; how to increase diversity and how best to collaborate on this issue with other agencies. At a more advanced level, support around particular issues, networking opportunities and examples of other interesting practice is required.

Government should use the new local Healthwatch pathfinders and learning sets to explore how these bodies can work effectively with children and young people and transfer and build upon learning from their LINks predecessors.

Healthwatch England should carry out or commission a review of the work of Healthwatch bodies with children and young people, one year after they are established, to assess progress in this area and identify any barriers to children and young people's involvement.

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