contact a family
for families with disabled children

Parent carer forum involvement in shaping health services

Contact a Family provides advice, information and support to all UK families with disabled children, regardless of the disability or health condition. Through a national helpline and family support service, we provide advice on any aspects of caring for a disabled child, including help with benefits and educational issues. We help families get in touch with others in similar situations. We have supported the development of parent carer forums across England, where parent carers work with professionals to improve how services are delivered in their local area.

Parent carer forum involvement in shaping health services

Contact a Family has been funded to support the involvement of parents of disabled children in commissioning and improving health services, through the Department of Health Innovation Excellence and Service Development Fund (2011).

This report on the result of a survey sent out to 151 parent carer forums highlights the work carried out by parent carer forums in shaping health services and the challenges forums have experienced in raising children's issues through LINks.

Our report explores the complexity of delivering public and patient involvement in the NHS and suggests ways that HealthWatch could coordinate local patient and community groups to ensure that the voices of parents of disabled children and other patient groups are not lost in the system.

Sheila Davies
Contact a Family

Contents

Summary of Findings

In the last three years under the Aiming High for Disabled Children's programme, parent carer forums for parents of disabled children developed across England to work with professionals and improve services for disabled children and their families.

Disabled children are a relatively small proportion of the population but can have complex needs and access a wide range of different health services. Parent carer forums help identify and feedback problems frequently experienced by families with disabled children and work with professionals to help them improve how services are delivered.

In July 2011, a survey was sent out to all 151 parent carer forums asking them about their work in influencing health services and their experience of Local Involvement Networks (LINk). Many parent carer forums had been successful in improving one or two local services by working with individual NHS managers, commissioners and clinicians. However, forums frequently reported difficulties in finding someone in health to work with regarding other services they were concerned about. For example one forum was successful in improving the local wheelchair service, working with the PCT, but unable to find who to approach regarding the autism service.

Local Area Involvement networks (LINks) are funded by government to support public and patient involvement in shaping local health services. Our survey shows that nearly all parent carer forums have not found LINks effective in supporting them to improve services for disabled children. services. Almost half of LINKs either did not think they had a remit to work in children's services, or were primarily focused on adult services which affected the majority of their members.

LINks mostly work in a different way to parent carer forums. LINks run consultations with their members about local services, inspect adult premises and write reports on their findings for the Primary Care Trust. Parent carer forums work directly with the people responsible for the services their children access. This allows managers/commissioners/clinicians to hear directly from families of their experience of services and how they can be improved.

Subject to the Health and Social Care Bill 2011, health services in England will be commissioned by Clinical Commissioning Groups managed by GPs working with other clinicians. Disabled children who visit a wide a range of health professionals and services benefit from a multi-disciplinary 'team around the child' approach integrated with education and social care, such as that already delivered by the Early Support programme. Recent research[1] showed that 75% of families of disabled children did not see their GP about their child's condition.

As a result of the Health and Social Care Bill 2011, local authorities are setting up Health and WellBeing Boards to work with Clinical Commissioning Groups. The Boards' remit includes making sure services are commissioned in a joined-up and integrated way that meet the needs of the local population, including disabled children and young people. Patient representation on this board will be through local HealthWatch organisations, which are evolving from LINks.

Recommendations

- The government[2] wants user involvement to be embedded at every layer of the NHS. HealthWatch could support this by linking different patient/community groups with the commissioners/managers responsible for the particular services they access.
- GP practices, Clinical Commissioning Groups, the NHS Commissioning Board, Health and Well Being Boards and service providers are all required to involve patients in shaping their work. This could lead to a duplication of consultations, public disengagement with the consultation process and, therefore, would be a waste of resources. This could be prevented if HealthWatch coordinate local consultations, make sure consultations are meaningful and target the appropriate audience and share findings of consultations across all relevant organisations.
- HealthWatch should demonstrate how the involvement of patients and the public have made a difference to local service provision. This will also be helpful in monitoring the effectiveness of their work.
- The Government should ensure that local Health and Wellbeing Boards have a defined focus on the delivery and improvement of services for disabled children.
- Health and Wellbeing Boards should be required to report on how they have involved and engaged different patient groups, including disabled children, young people and families and what difference it made.
- HealthWatch will need to carry out targeted work with the patient/community groups who require joined-up integrated services, so their experience of services is input to the Health and Wellbeing Board and joint-strategy plans.
- As part of this targeted work, HealthWatch will need to consult with disabled children and young people and their parent carers at suitable venues and at times they can attend.
- Everyone involved in public and patient involvement will need a clear understanding of both the principles involved and their role. Training resources will need to be provided to support this.

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[1] Putting families with disabled children at the heart of the NHS reforms, www.cafamily.org.uk

[2] Health Watch Transition Plan, March 2011

Introduction

Between 2008 and 2011, parent carer forums developed across England through support provided by the government funded Aiming High for Disabled Children programme. These forums were set up to support parent carer participation in shaping services provided for disabled children and their families. The aspiration was for the forums to have parent members representing a wide range of disabilities who would influence improvements in services across health, social care and education.

Disabled children frequently visit a wide range of health professionals and services, including paediatricians, physiotherapists, speech and language therapists, occupational therapists, wheelchair and equipment, continence, special feeding units, podiatry and mental health services, as well as specialist clinics, some commissioned at a regional level because of low incidence. Parent carer forums can provide a mechanism to facilitate consultations about a range of health services as well as allowing willing parents to more actively participate by representing the views of other parents on decision making boards

Contact a Family received feedback that, whereas some parent carer forums were working successfully with one or two health services, they frequently found it difficult to find professionals to work with from other services which were causing parents concern. Some parent carer forums had tried working with their Local Involvement Networks (LINks), which are funded in each local area to support patient and public input involvement in health. These forums reported they found it difficult to get issues they raised prioritised by LINks and, in some areas, LINks told forums they had no remit to work in children's services.

As a result of this feedback, in July 2011 Contact a Family carried out a survey of parent carer forums across England to gather quantitative data and find out more about parent carer forums involvement with health services. Parent carer forums were asked about their experiences of working with Local Involvement networks (LINks), and their experiences of working directly with NHS commissioners, NHS managers and lead clinicians.

This report highlights the work of parent carer forums in shaping health services, as well as the problems forums have experienced in raising children's issues through LINks. Our report explores the complexities of delivering public and patient involvement in the NHS, and suggests ways that local HealthWatch services could coordinate different patient and community groups to ensure that the voices of parents of disabled children and other patient groups are not lost in the system.

Parent Carer Forums – a brief history

Before the Aiming High for Disabled Children programme began in 2008, there were only a small number of parent carer led forums in England working across health, education and social care.

As well as funding parent participation, the Aiming High for Disabled Children Programme gave substantial funding to local authorities to develop a range of short breaks for disabled children. Local authorities were expected to involve parents in commissioning these services and consult with disabled children and young people to find out what type of short breaks they wanted. Children's service managers and commissioners found that working in partnership with parents[3] and children and young people[4] helped them make more effective use of available funding and also deliver services that better meet families' needs. Partnership work also helped parent carers understand the commissioning process.

> "Parent participation has influenced the choice and quality of the short break services we buy, by making sure we ask the right questions in applications and interviews, and influencing processes such as the entitlement framework, so I consider the local authority to have better value services as a result of an ongoing process of parent participation."
>
> **Commissioning Officer**

Additionally, having a good short breaks service also helped reduce the number of children going into care and thus saved local authorities considerable money.[5]

Parent carer forums frequently reported they also wanted to engage with health on services accessed by disabled children, but found it difficult to identify someone in health to work with on this. Some forums were fortunate in finding a contact in health willing to work with them and this proved effective. An example of how the Parent Carer Forum in Southend helped the PCT develop a service specification for a paediatric wheelchair service can be downloaded at:
www.cafamily.org.uk/professionals/parentparticipation/howwecanhelp.html

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[3] How Parent Participation and Parent Carer Forums leads to better outcomes for disabled children, young people and their families - http://www.cafamily.org.uk/professionals/research.html
[4] Is the Voice of the Child Having an Impact on the Development of Short Breaks for Disabled Children? http://www.cafamily.org.uk/professionals/research.html
[5] Impact of the Short Break Programme on the Prevention of Disabled Children Entering the Looked After System http://www.cafamily.org.uk/professionals/research.html

Survey results

In June 2011, Contact a Family sent a survey out to 151 parent carer forums across England to quantify: how many parent carer forums were working in health, their experience of working with LINks as well as trying to work directly with NHS managers, commissioners and lead clinicians. Contact a Family received responses from 78 parent carer forums, a 52% return. The areas responding were spread fairly evenly across all nine English regions.

Name of region	Number of forums replied	Number of areas in region	Percentage return for region
East	5	11	45%
East Midlands	5	9	56%
London	18	33	55%
North East	5	12	42%
North West	11	23	48%
South East	10	19	53%
South West	6	16	38%
West Midlands	9	14	64%
Yorkshire & Humber	9	15	60%
Total	**78**	**152**	

Parent carer forums awareness of LINks

LINks are meant to involve individuals and local community groups in their work, yet 24% (19) of parent carer forums had not heard of LINks and did not know what they do.

"Not sure what LINk is and what it is about.'

"Our parent/carer development worker had recently advised us about Link but most members of the forum did not know about their existence prior to this."

"Seems to have very low profile. We did not really know of its existence until very recently. I have spoken to other contacts at the LA and they agree with this."

It is possible that many LINks had not heard about the parent carer forum in their area, as parent carer forums publicity is usually directed through organisations that reach parent carers of disabled children, such as special schools, parent support groups and children's services.

Three parent carer forums reported that they had tried to make contact with their LINk but found it impossible to make contact with them.

"Could not find them"

"We phoned them to make an appointment to see them and explain who we were and I don't think anyone got back to us."

"They are inordinately bureaucratic and hard to access – we are trying to make contact through our local voluntary services umbrella."

12% (7) parent carer forums said they knew of LINks but had not tried working with them, either because influencing education or social care services was more of a priority, or because parents did not have the capacity to get involved with LINks in addition to the work they were already involved in. Some forums reported it was difficult for them to attend the local LINk meetings because of the time of day they were held and location. Parent carers can find it difficult to attend meetings because of their caring duties and needing to take/collect children from school.

"They were helpful but, due to our own time constraints, we are kept on their loop of information and don't attend meetings."

"The LINk meetings are at different venues each time scattered across the county."

"They are also usually at a time that makes it difficult to attend because of school runs, and other parent commitments."

This raises questions about how affective LINks are being in hearing the views of the wider community. If the new HealthWatch is to be more effective, they need to reach and involve patients from a broad range of experiences, including medical conditions, health services accessed, age and demographics.

Being sent our survey appeared to prompt some parent carer forums to find out about their LINk and make contact. 24% (14) of forums who knew about LINks reported they were just starting to work with them. In other areas, parent carer forums reported that the commissioners they worked with had recently suggested they make contact with LINks. This could be related to the changes being implemented in the NHS and LINks' transition to becoming HealthWatch.

> "No – as only recently found out about this service, however it is planned to invite them to local forum to discuss job role."

> "We have invited LINk to our next open forum meeting (14th July) to explain to a wider audience what their role involves."

> "Though our forum had heard of Link we did not have a clear indication to their role. However, since your communication we have now got into contact and they will be including us on their mailing list."

> "In last six months, we were linked by our children's Commissioner, who suggested they contact us about plans for developing Healthwatch."

Do LINks focus on children's services?

23% parent carer forums who proactively made contact with their LINk were told that they did not work with children's services.

> "At time of contact they only worked in adult services."

> "They are not constituted to deal with children's health or other children's issues at all."

> "The LINK doesn't have a remit for childrens services so discussion is about access to information and health services for young people over the age of 16."

> "When LINk's were approached they told us that LINk works with adult services and there is a separate pathway for commissioning of children's services."

This confusion could arise because LINks have a duty to inspect residential home for adults, but inspections for children's residential homes is handled by Ofsted. However, this lack of understanding by LINks that they are also responsible for children's health services is a matter of great concern and needs to be addressed. Clarity needs to be given to HealthWatch about their role in supporting involvement in children's services.

An additional 21% parent carer forums, reported they found it difficult to get children's issues prioritised as they were a minority voice at LINk meetings. Parent carer forums frequently reported that LINk meeting were attended by elderly people who were mainly interest in geriatric services. This could be because people concerned about residential care for the elderly would be motivated to join their LINk as they have the right to inspect these settings. Also, retired people have the time available to attend LINks meetings which are frequently held during the day.

> "The local areas of work were decided by LINk members and their agreed priorities did not fit in with the Parent Groups priorities."

> "Many of the issues LINk deals with are centred round the concerns of white and elderly members."

> "There are no parent carers on their executive group. Their working group is overwhelmingly made up of representatives from age-related disabilities. The plight of children's services is drowned over the multitude of representation by adult related issues."

Recent research[6] carried out by the National Children's Bureau also found that many LINks did not think they had a remit that included children's services and that their membership is mainly elderly and focus on services used by the elderly.

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[6] LINk's involvement of children and young people, June 2011,NCB – http://www.ncb.org.uk/pdf/LINk's_VSSreport_final.pdf

Parent carer forums experience of working with LINk's

LINks are meant to engage both with individual members of the public and community groups. Feedback from our survey shows there was frequently no obvious mechanism for groups to give feedback on issues affecting many of their members and LINks appeared more interested in increasing numbers on their database.

"The family group I attended had one family represented (a parent and her father). It was not evidence based: we offered our evidence from consultation with 1200+ parents but this was not really taken up."

"The LINk requested parents sign up as individual LINk members. We wanted to work with LINk as a distinct parent group and use it as a forum to feed issues but couldn't see how this could actually work in practise."

"There was some uncertainty as to whether the LINk could influence children's services but, if parents signed up as individuals, their experiences could possibly be used."

On the few occasions LINks had taken up issues raised by a parent carer forum, they often appeared to have been ineffective in bringing about change or communicating back to the parent carer forums what happened after consultations had taken place. It is a basic principle of good user involvement that people need to hear what, if anything, happened as a result of their input, otherwise they lose motivation to continue being involved.[7]

"LINk did take up one of the problems we put to them with regards to CAMHS (that services were being cut and leaving paediatric services in a dire state). However, there has been no response to their letter they sent to the PCT which was several months ago."

"We went to the launch of LINK some years ago and got our issues agreed as a priority. After two years of setting up, they said they were not set up for children or for disabled children."

"It was to do with issues around speech and language therapy which resulted in a consultation with all interested parties but we are not sure why the service wasn't improved dramatically."

From the survey, only one parent carer forum, Calderdale Parent Carer Council, could report a definite improvement in services as a result of support from their LINk.

"In 2009, the Forum prioritised Pads and the Incontinence service as a key issue to work on. The LINk worker, who was also a parent of a disabled child, assisted in running a focus group to gather the views from parents and raise the issue with the PCT.

This was a most successful partnership and we were able to gather the views of a wide range of parents and take a final report to the PCT. This resulted in a small working group of parents meeting with heads of the service and PCT over a number of sessions to look at ways of improving the service.

The LINk worker's role was to write the report and my role was to involve and engage with parents. She also used her own contacts within the PCT to highlight the issues riased. They were contacts we have already, but this gave us less work to do in the long run and, I feel, it speeded up the processes. It did give us a quick way in to the right people to influence."

Chair, Calderdale Parent Carer Council

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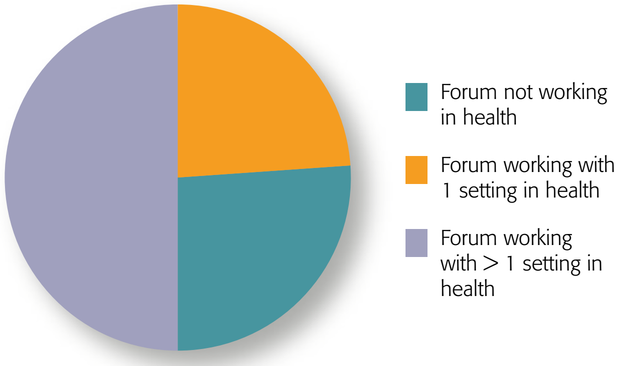
[7] Parent Participation: Improving services for disabled children, professionals guide: www.cafamily.org.uk/pdfs/ContactProf05.pdf

On this occasion, the hub worker from the LINk was successful in supporting a consultation about the service. Following this, a small working group of professionals and parents found ways to improve the Service. Unfortunately, that particular LINk worker has left and the forum has had little contact with their LINk since.

Parent carer forums' direct work with managers/commissioners/clinicians

74% (58) of parent carer forums who responded to the survey reported they had worked with health services and 50% (39) of forums were working with more than one setting in health.

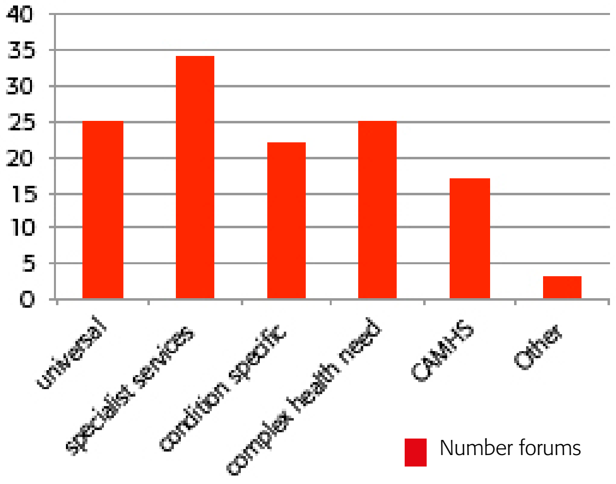
Parent forums working in health settings



Forums were asked about which health settings they had been involved in working with. The responses included:

- Universal service, for example, A&E, hospital ward, transport, outpatients
- Specialist service, for example, continence, therapy, wheelchair
- Condition specific care, for example, autism, developmental delay, visually impaired
- Services for those with complex needs requiring input from multiple professionals and services
- CAMHS (Child and Adolescent Mental Health Service)

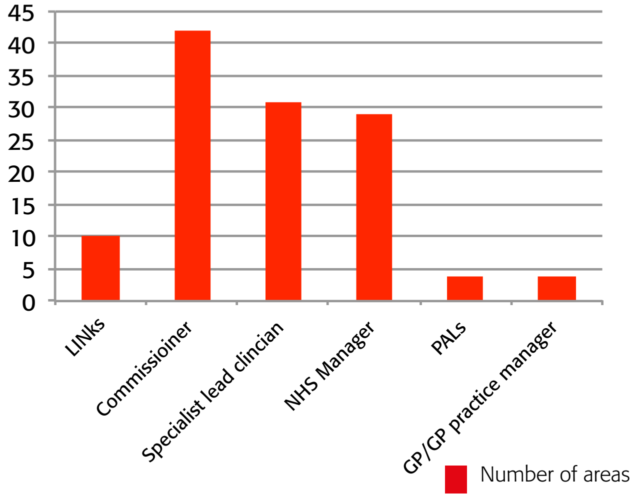
Number of forums and the services they engage with



Our survey results showed a fairly even spread across all five service areas, with specialist services and services for children with complex needs receiving the most attention. A few forums also mentioned being involved in other services, including Early Support, child development centres, community health services and GP consortia.

Parent carer forums were also asked who their key contacts were in health for their participation work.

Key contacts for forums' work



A key contact was usually a commissioner, lead clinician or NHS manager, although some forums were in contact with all three. Very few parent carer forums had used LINks or Patient Advisory Liaison Service (PALS) as their main contact.

Many forums preferred to work directly with the commissioners/managers/clinicians for the services they accessed and did not see any reason why they would want to work through their local LINk. Eight forums who had worked both with LINks and directly with service managers said they found the latter approach more effective.

"Not really needed to work with LINks – we've done well enough by ourselves so far."

"We prefer to work directly with teams on specific issues; there are not enough of us to sit on another strategic group."

"I have had contact with the LINK but as we were working directly with children's services, including health, we didn't see the need to engage with it."

"Nothing has come up where we felt we needed additional muscle!"

One parent carer forum had been successful in working with health services but was no longer able to, as the key people they were working with had left and the forum had been unable to find anyone to replace them.

"The people who we were working with have left their posts and found new jobs due to cuts in their service. We have since been unable to establish any contact with Health (which is getting frustrating!!)"

Staff turnover is a continual problem for forums, as they have to find and start building new working relationships with different professionals after the people they worked with in the local authority/health service leave.

Parent carer representatives sitting on decision making groups/bodies

46% (21) of parent carer forums that replied to the Survey said they had parent representatives sitting on at least one working group and participating in the decision making process. The type of steering groups parent carers sat on reflected the diverse number of services they access, including therapy services, palliative care services, autism services, child development centres, CAMHS groups, complex needs groups, hospital patient groups and joint service commissioning boards. Some of these working groups had been set up for a specific task for a limited time period whereas others meet on a regular basis.

"A three-year project ended last year where parent/carer members of the Disability LINk's Forum worked with professionals, including health professionals to ensure that hospital admissions for children with disabilities (planned and unplanned) are more successful."

"Parents sit on the Disabled Children & Young People's Partnership board, along with professionals from health. Also there's parent representation on other work streams such as, ADHD, Parent/family support/ first year of life, equipment & therapy, palliative care, school nursing services."

"We currently sit on the Learning Disability Forum at Chelsea & Westminster Hospital."

Some forums invite health professionals to visit their forums and hear first hand from families about the issues they face. Other parent carer forums prefer to work in small 'task and finish' focus groups, where a few professionals and parents meet to explore how services could be improved before taking their joint proposals to decision making boards.

"The children's commissioner, SALT, OT and Clinical psychologists have attended Parents Active forum meetings on a regular basis."

"We do not sit on HS groups but the professionals we work with sit on our parent/carer focus groups."

"Information from the forum is fedback to the Operational Manager for Newcastle Hospital's Foundation Trust, as they are part of the Children with Disabilities Management Partnership. They are due to come to the Forum to talk about changes to equipment services but this has not started yet."

Parent carer forums support a dialogue between families using a service and the professionals responsible for running them. It is this dialogue which helps raise awareness of service users' perspectives, identifies gaps in service provision and supports the improvement of local services that better meet families' needs.

"'Effective parent participation happens when parents have conversations with and work alongside professionals, in order to design, develop and improve services. This conversation benefits everyone.

'Working with parents helps professionals to understand what needs to happen to develop services that meet families' needs.

'Working with professionals helps parents understand the complexity involved and the challenges faced by the professionals who have to bring about that change.

'Working together and sharing knowledge enables parents and professionals to find solutions that work."

How to Guide to Parent Participation

The benefits of partnership working is described in more detail in the How To Guide on Parent Participation[8].

Having a good relationship between commissioners and parent carer forums can have other advantages, as can be seen from the example below:

"When the forum began to receive calls from parents reporting problems, they emailed all their members to find out if other parents were having similar problems. They quickly received responses from dozens of parents telling them about problems that were occurring as a result of changes to the types of nappies provided, which meant families could no longer order pull-up nappies. This was preventing parent carers from toilet training their children which had long-term cost implications for the Commissioners. The Forum contacted the commissioner who was unaware the service provider had implemented these changes. After hearing about the problems this was causing, he agreed to follow up with the service provider. Since then pull-up nappies have been reinstated and further discussions are now taking place between the Forum and service provider to try to improve parent carers experience of the service."

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[8] How To Guide to Parent Participation www.cafamily.org.uk/families/parentparticipation/e-newsletter.html

Embedding user involvement within the NHS

> "The Government's health and social care reforms are centred around the fundamental principle that patients and the public must be at the heart of everything our health and care services do. This will only happen if there are mechanisms in place to involve and engage people in every aspect of how services are planned, commissioned, delivered and monitored. In practice, this means ensuring that consumer voice is integral to the way things are done, not an add-on, an optional extra, or isolated outside decision-making and planning – but a genuine shift to putting people's views and experiences at their heart."
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> **HealthWatch Transition Plan[9], DH, March 2011**

Supporting public and patient involvement in the NHS is inevitably complex, as the NHS delivers so many different services to different people in different settings. Providing information, consulting and actively involving users in decision making are all essential components to effective public and patient involvement.

Information is needed so people are informed about what services are available, how they access them and how they can be involved in shaping them. They also need information telling them about changes to services. People can receive information from a wide range of sources, GP practices, hospitals, websites, libraries, information centres and groups within the community. Information needs to be provided to the whole community.

Consultation is needed so people can feed in their experience of services and input their views about any proposed changes to services. This can be through suggestion boxes, listening to patients' experiences, formal surveys, small focus groups and open public meetings. To be effective, consultations have to include the correct audience. This might include people with experience of a particular service, or those most affected by a proposed change to a service. This could include getting the views of patients/carers with specific conditions, those from ethnic minority groups and people living in a certain geographical area.

Participation, where patients and carers sit alongside professionals and take a more active part in decision making, can be in the form of small working groups set up for a limited time to focus on changing a specific service, or steering groups/decision-making boards that meet on a regular basis. Patient/carer representatives also need to be in touch with the views of the people they represent and their experience of services.

To achieve this, there needs to be support in place for different service users to engage with the people responsible for delivering the services they access. There is also a need to consult with people living in the geographical area about issues that affect the whole community.

The diagram on the next page illustrates the different levels required for patient and public engagement in health.

Level 1 –Planning and making decisions about services within the local area

Service Directors, commissioners and public health leads will need to consult with the community when making decisions that affect people living in the area. (for example, hospital closure, walk in centres). They will also need to consult with patient groups with more complex needs who require joined-up and integrated services, (for example, disabled children, degenerative neurological conditions, stroke, terminally ill) so their experiences of services is fed into the Health and WellBeing Board.

Level 2 – Improving services within a setting e.g. hospital, GP

Hospital managers and centre managers need to get feed-back of patient/carers who use their services; for example, on hospital food, ward cleanliness, disability access. Certain groups will need to be specifically targeted for consultation to make sure their experiences are also heard. These groups include children and young people, those with a learning disability, BME communities. Local community groups and condition-related support groups can provide people to input to this.

Level 3 – Specific services

Hospital service managers, commissioners and clinicians need to get feedback from patients/carers about their experience of care for particular conditions or specialist services and involve patient/carers who use these services in shaping them. Patients using the service and local condition-related support groups can provide people to input to this.

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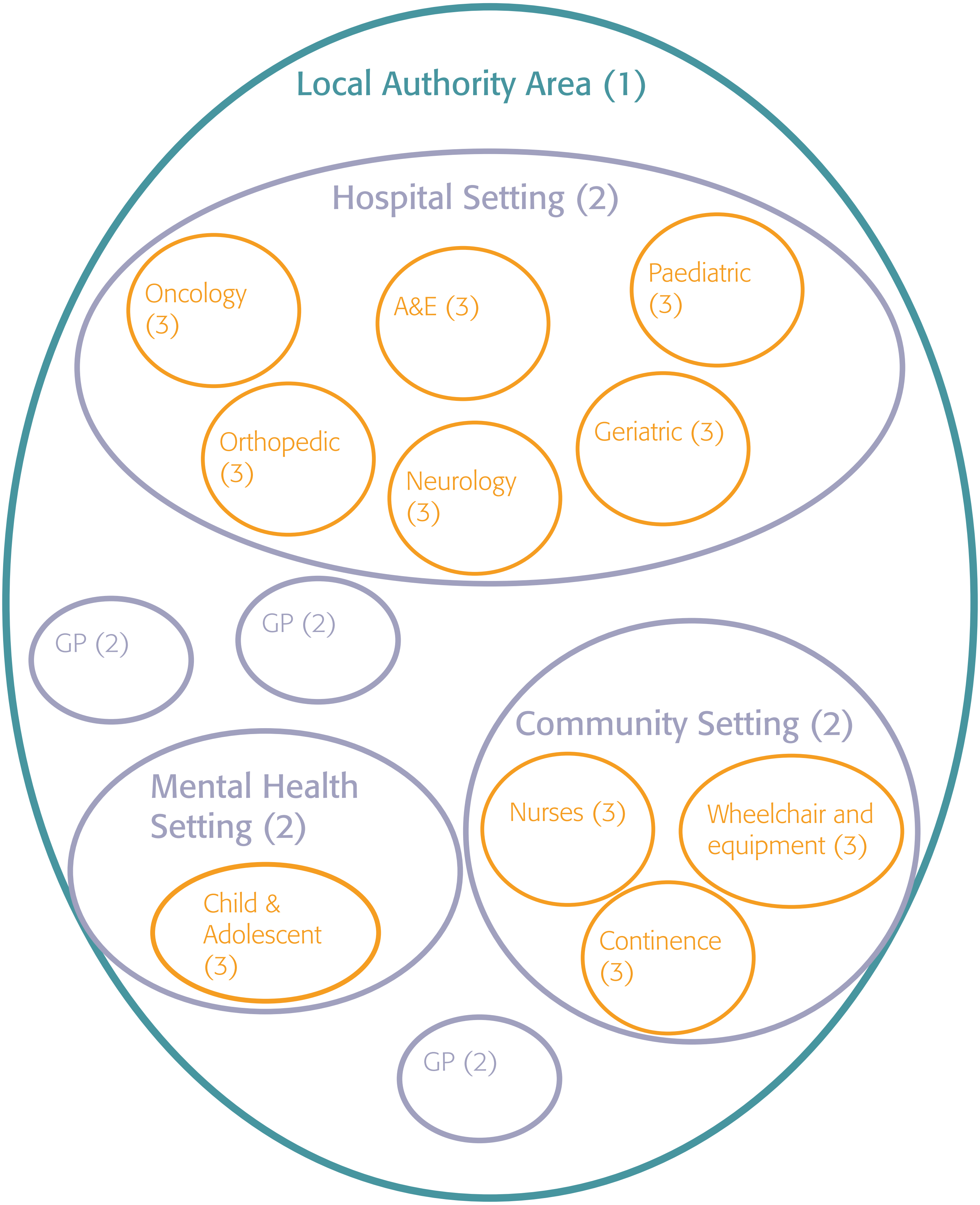
[9] HealthWatch Transition Plan , March 2011, http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_125582

Diagram illustrating different layers of health services within a local area

Patient groups need to feed their experiences into different services



Current levels of engagement

Parent carer forums have found it effective to get involved in shaping specific services (Level 3), their children access. Forums have also managed to become involved with hospital-led patient groups (level 2), looking at accessing hospital services, which is a problem for many families of disabled children. This has been achieved through working directly with health managers, commissioners and clinicians.

LINks are more often involved in running consultations affecting the whole community (level 1 and 2). Even where LINKs understood that their remit includes children services, it is likely that consultations at level 1 and 2 have taken a higher priority than consultations about specific services, as they affect more people. For example, closing an A&E Department (level 1) affects the whole community, whereas changing the wheelchair service (level 3) affects only a few.

Parent carer forums (and possibly other patient groups), have found it difficult to get their issues prioritised through LINks and become disillusioned about working with LINks. Members of the public are often motivated to get involved in participation because of experiencing a poor service. If they find HealthWatch are not interested in improving that specific service, members of the public are likely to get disheartened and disengage with patient and public involvement.

Consultations need to be targeted to appropriate service users but, at present, this does not always appear to happen. A recent example of this was the consultation to prioritise three of eight services for Any Qualified Provider, (see http://healthandcare.dh.gov.uk/any-qualified-provider/). The services listed included paediatric wheelchair services and continence service, both highly-specialised services accessed by a small proportion of the population and very important to families of disabled children.

In some areas, LINks ran this consultation by simply sending out an electronic survey to individuals registered with them asking them to choose three of eight services. This approach meant that, given the current profile of those who engage with LINKs, the vast majority people inputting to the consultation would have had no experience of using, or requirement for, these services, whilst the people who used these services did not know about the consultation and had no input to it.

In other areas in England, LINks had no knowledge of this consultation happening and the only way members of the public would have known about it would be if they regularly checked their PCT cluster website. It is likely that not many members of the public know about PCT clusters, let alone where to look for details of relevant consultations.

If parent carer forums and other patient groups are not involved with LINks, they too often miss out on important consultations that affect them. Even if they are registered with LINks parent carers are not always made aware of consultations that affect them.

How HealthWatch can support all levels of patient engagement

> “To help make this vision a reality, the Government has committed to strengthening the collective voice of patients, users of care services and the public and ensuring that voice is no longer lost in the system. One of the main ways of achieving this will be through the HealthWatch arrangements. Other ways will be through duties on commissioners and providers of health and social care services to involve and consult patients and the public”
>
> **DH HealthWatch Transition Plan**

LINks are in the process of being transformed into local HealthWatch services and will have stronger powers to work with commissioners and champion user involvement.

The changes being proposed to the NHS in the Health and Social Care Bill include embedding user involvement at every level. All GP practices now have to set up a patient representative board. Clinical commissioning groups are to involve the public in their work.

Without careful planning and coordination there is the potential for lots of consultations carried out which do not reach their target audience and, in some case, duplicate previous consultations. As well as being a waste of resources, this will lead to members of the public (and health service managers) becoming increasingly disenchanted and disengaged with public and patient involvement.

Each HealthWatch will have representation on the newly formed Health and Well Being Board which will carry out (level 1) strategic planning for the whole community and has a remit to focus on making sure services are joined up and integrated. They will need to involve users in strategic needs assessments and, to do this have to reach those patient groups most in need of joined-up, integrated services. This includes disabled children and their families who access a wide range of different services which need to be coordinated across health, education and social care.

In Parliamentary Hearings[10] on Services for Disabled Children in 2006, almost half of disabled children’s parents making submissions (48 %), and over a third of professionals

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[10] Parliamentary Hearings on Disabled Children http://www.ncb.org.uk/edcm/edcm_parlhearingsreport_full_final.pdf

(35%) described health services as 'poor'. The Kennedy Report[11] also highlighted the frustration that parents feel at the lack of co-ordination between services. For this reason, it is vital that local HealthWatch work with parent carer forums in feeding into the Health and Wellbeing Board the experiences of disabled children and their families, to inform the decision making process. There are other patient groups who also require joined up and integrated services whose views will need to be fed into the Health and Wellbeing Board, such as those affected by dementia, long-term neurological conditions and stroke.

The Health and Social Care Bill currently going through parliament states that HealthWatch must have at least one patient representative sitting on Health and Wellbeing board. Yet, it is impossible for one person to represent the diverse needs of patient groups. There needs to be a mechanism to ensure the experiences of all these different patient groups inform the decision making processes of this board. One solution would be to give local HealthWatch a role in coordinating public and patient involvement at all three levels. Healthwatch could:

1. Consult with the local community regarding issues affecting people living in the area and carry out targeted consultations with a range of patient/community groups to feed at a strategic level to Health and Well Being boards, especially those groups requiring joined-up and integrated services, for example, disabled children and young people, those affected by dementia, strokes and cancer
2. Link patient/community groups with hospital/centre managers, so they hear about the experiences of different patient groups accessing their centre, for example, the disabled, elderly and ethnic minorities.
3. Link patient groups with managers/commissioners for specific services, so they can work together.

The table below shows the patient/carer groups different settings would consult with, what they would consult about and the structures though which they could actively involve patient/carers in improving the way services are delivered locally.

Service or Setting	consult with	hear about	actively work with
Level 1 Local Authority	People living in the community taking into account local demographics and targeting particular patient/ community groups, including those requiring joined-up and integrated care.	Experience of people living in the area needing/ accessing services	Patient/carer representatives on Health and Wellbeing Board and sub-committees/ working groups
Level 2 GP practice	Patients registered with GP services, and targeting different patient groups within the practice, e.g. the elderly, children and young people, people with long term conditions, carers	Patient and carer experience of GP services, e.g. appointments, out of hours, home visits	GP Patient Reference Boards with representatives from different groups, e.g. the elderly , parents, those with long-term conditions
Level 2 Hospital	Patients, carers, relatives visiting the hospital, and targeting particular groups e.g. the elderly, children and young people, those with a learning disability	People's experiences of visiting or staying in hospital	Hospital Patient panels/ forums which include representatives from targeted groups
Level 3 Specific clinics/ services e.g. autism, wheelchair	Patients/carers who attend clinic or use the service, local support groups for specific conditions /disability	Patient and carer experiences of service	Patient/carer representatives on clinical steering groups

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[11] Getting it Right for Children and Young People, Overcoming cultural barriers in the NHS so as to meet their needs , Kennedy, 2010 http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119445

Conclusion

For user involvement to work, everyone involved needs a clear understanding of both the principles involved and their role. Only if patient/carers see the benefit of their involvement, will they be motivated to continue. When professionals understand the benefits of working in partnership with patient/ carers, they want to continue to do so.

If user involvement is not done well, people quickly become disillusioned and lose their motivation to continue. If HealthWatch is to be successful in supporting and embedding patient and public involvement in the NHS, different staff will need to have the necessary skills, training and resources to support public and patient involvement that follows the three basic principles:

Information – provide information, so members of the public know how they can influence local services and what has changed as a result of patient and public involvement.

Consultation – carry out well planned consultations, using a variety of techniques (quantitative and qualitative) which target the appropriate audience.

Participation – support active participation of patients and carers to work alongside professionals, so patient and carer's experiences of receiving services informs the decision making process.

By engaging with users effectively, real transformation of services and support to patients and carers can be achieved.

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About Contact a Family

Campaigning

We campaign for rights and justice for all families with disabled children.

Freephone helpline

Our freephone helpline for parents and professionals across the UK is staffed by trained parent advisors. It provides information and advice on a wide range of issues including welfare rights, education, short breaks, local services and local support.

Publications

We produce a wide range of publications including newsletters, parent guides and research reports, helping parents and professionals to stay informed.

Linking families

We put families in contact with others whose child has the same condition for support. We link them through existing support groups, our online social networking sites or using our one-to-one linking service.

Medical information

We produce the Contact a Family Directory – the essential guide to medical conditions and disabilities with information on over 440 conditions and UK support. Each entry provides an overview of the condition with details of support groups where available.

One-to-one support groups

We offer both practical and emotional support on a one-to-one basis to families with disabled children, through our family support service, volunteer parent representatives and through our local offices.

Local, regional and national offices

Contact a Family has a number of offices around the UK providing local newsletters, information, workshops and support.

Parent carer participation

Contact a Family supports the involvement of parents in shaping services (health, education and social care).

Getting in contact with us

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Open Mon-Fri; 9.30am - 5.00pm

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