

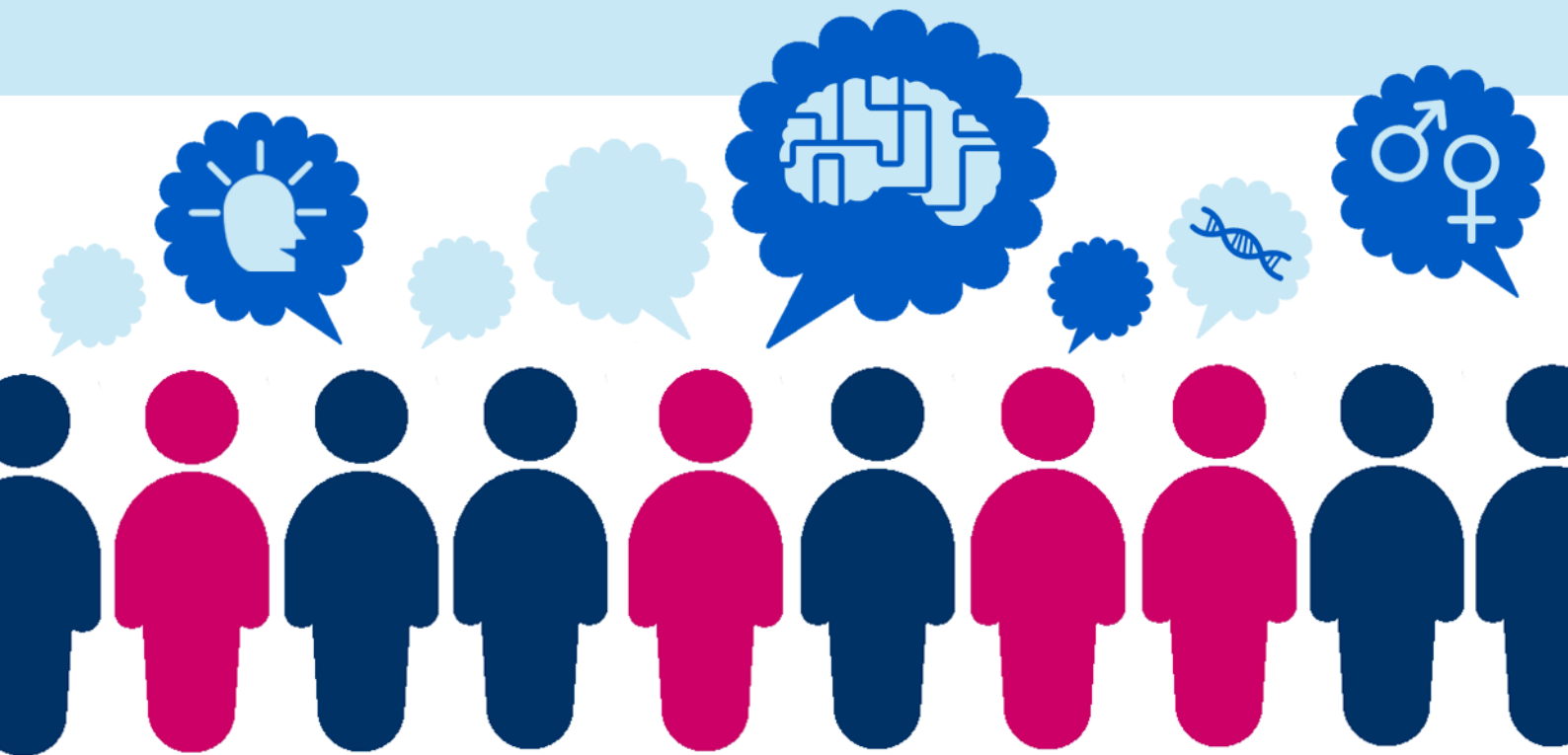


Championing Children and Young People in England

“It takes a lot of courage”

Children and young people’s experiences of complaints procedures in services for mental health and sexual health including those provided by GPs

July 2012



A Cernis report commissioned by the Office of the Children’s Commissioner.

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ABOUT THE OFFICE OF THE CHILDREN'S COMMISSIONER

The Office of the Children's Commissioner is a national organisation led by the Children's Commissioner for England, Dr Maggie Atkinson. The post of Children's Commissioner for England was established by the Children Act 2004. The United Nations Convention on the Rights of the Child (UNCRC) underpins and frames all of our work.

The Children's Commissioner has a duty to promote the views and interests of all children in England, in particular those whose voices are least likely to be heard, to the people who make decisions about their lives. She also has a duty to speak on behalf of all children in the UK on non-devolved issues which include immigration, for the whole of the UK, and youth justice, for England and Wales. One of the Children's Commissioner's key functions is encouraging organisations that provide services for children always to operate from the child's perspective.

Under the Children Act 2004 the Children's Commissioner is required both to publish what she finds from talking and listening to children and young people, and to draw national policymakers' and agencies' attention to the particular circumstances of a child or small group of children which should inform both policy and practice.

As the Office of the Children's Commissioner, it is our statutory duty to highlight where we believe vulnerable children are not being treated appropriately and in line with duties established under international and domestic legislation.

ABOUT CERNIS

Cernis, a research organisation was commissioned by the Office of the Children's Commissioner to produce this report. The two main authors, Cathy Street and Yvonne Anderson are former health professionals.

Organisational improvement is our aim, founded on the conviction that there is always scope to be better and always scope for growth. High performing organisations are always changing and developing, resulting in a happier workforce and satisfied customers or clients.

ACKNOWLEDGEMENTS

The consultant team wish to thank the many children and young people, parents and carers and the staff working with them for the time they gave to this project. In particular, thanks are due to the five organisations that helped with setting up the Discovery Groups: the Allsorts project and Bridging the Gap Teen to Adult Personal Advisors (TAPAs) in Brighton and Hove; Collingham Child and Family Centre in West London; the Young People's Advisory Service (YPAS) in Liverpool; Young Devon and Out Central, a Birmingham Youth Service Project.

A number of organisations consulted with young people, with their Independent Mental Health Advocates and with their young advisors on behalf of the team: Mancroft Advice Project (MAP) in Norwich, Action for Children, Brook and the National Youth Advocacy Service (NYAS). Their support of the project is much appreciated.

A number of young people acted as advisors to the project and these included: Annabelle Davis; Jolene Dillon and Sahar Shahid. Their feedback and suggestions on the initial findings and earlier drafts of this report have been invaluable in helping the team to develop the final recommendations arising from the investigation.

Note

Wherever possible, quotes from children and young people have been used in this report to illustrate the issues raised by them in the group meetings and individual interviews. However, in order to protect their identity and to respect their confidentiality, their names and those of the young people and families who provided case study examples have been changed.

FOREWORD

I am pleased to introduce this powerful report, ringing with the voices of young citizens some of whom are also patients prepared to reflect with us on their experiences of health services. They have not held back from describing their experiences. We should listen to them, especially if things have gone wrong and they need to complain.

As Children's Commissioner for England I have a statutory duty to consider the operation of complaints procedures for children and young people.

In all I do, I am here to promote and protect children's rights. I am bound by a duty to pay due regard to the United Nations Convention on the Rights of the Child (UNCRC), and to encourage others to do so. We ratified this UN treaty in 1991 and should pay close attention to the promises it makes to every child under the age of 18. For the purposes of this report there are four key Articles against which we should be holding health services for children and young people to account.

Article 2 (lack of discrimination): The Convention applies to every child regardless of their ethnicity, gender, religion, abilities, whatever they think or say, no matter what type of family they come from.

Article 3 (best interests of the child): The best interests of the child must be a top priority in all actions concerning children.

Article 12 (Respect for the views of the child): When adults are making decisions that affect children, children have the right to say what they think should happen and have their opinions taken into account.

Article 24 (Health and health services): Children have the right to good quality health care – the best health care possible.

My work is worthwhile and enjoyable, but there are times when what I report will challenge us all. The publication of this report, and some of the directness of children's feedback in it, represent one of those times.

This report is published at a time of large scale reorganisation and health system change and concerns have been expressed about what will happen to complaints handling with the implementation of the new Health and Social Care Act. As GPs will now take on a much larger role in the commissioning of all services, we are living through a time of considerable change. That change will be reflected in how patients obtain the services they need and how they feel about their quality, accessibility and ease of use.

The general consensus of the GPs interviewed for this research is that young people do not usually complain to them. One GP commented:

"In my ten years in this practice and the seven years that I have run my young people's clinic at the practice, I have no recollection of young people complaining about the health service they receive, and I encourage complaints."

If a central aim of the forthcoming changes is fulfilled, services will become ever more responsive, flexible and versatile, delivered ever closer to where patients live. The fact that at least one in seven users of GP services is a child means that those services should take

seriously their responsibilities to listen to and act on the views of our children and young people, including when what they have to say is uncomfortable or challenging.

The findings and recommendations in this report are a good starting point for those who seek to know what children think. They are based on the views of a wide range of children and young people as well as of professionals working within the NHS. The report looks to celebrate and highlight good practice, which places the voice of the child as a patient at the heart of continued improvement. However this research also reports that some children and young people do need to make complaints about the services they have received. The way they do so, and the responses of the services they wish to comment about, should be used as valuable feedback on which to base the design, commissioning, evaluation and decision making, and continuous improvement of health services.

Improving the complaints process in line with the advice these young people have been brave enough to give, could go a long way towards embedding the emerging NHS ethos based on the notion that a patient can and should say 'make no decision about me without me.' This is a high ideal of shared decision-making, where the patient is not done unto, but has a right to share in what is done.

Young people featured in this report say very clearly, and cogently, how they would like the system to change so that they feel this is their health, not somebody else's. Over the coming months we will continue to discuss our findings and recommendations with the key partners identified throughout this work, because we consider it is not a threat to professionalism or status, but should be used as a means of improving vital services.



Dr Maggie Atkinson
Children's Commissioner for England

EXECUTIVE SUMMARY

This report combines data from primary and secondary sources to produce compelling evidence about children and young people's experiences of complaints systems, with particular reference to sexual health and mental health services, including those delivered by GPs.

Disparate sources have been used and children and young people from a range of different settings and parts of the country have been consulted, resulting in strong, consistent messages that echo the findings of earlier work in this area.

It is a cause for serious concern that access to and use of complaints processes for children and young people in relation to mental health, sexual health and GP services is so under developed. Significant barriers need to be overcome if children and young people, or their parents and carers, are to be able to complain when they are dissatisfied with the care or treatment they have received. An important barrier is the defensive culture within health organisations which does not in any way recognise complaints as a learning opportunity and which at worst, can leave children and young people feeling mocked or viewed as 'troublemakers' when they try to raise concerns.

Children and young people say:

- They are not provided with information about:
 - their rights to complain
 - how to complain
 - confidentiality issues
 - what happens when they complain (the process).
- Complaints systems are too complicated, take too long, rely too much on written skills and are overly formal, so that very often the young person does not bother
- Staff in mental health, sexual health and GP services are not trained to be able to receive and act on complaints made by children and young people
- Staff in mental health, sexual health and GP services regard complaints as negative rather than something to learn from
- Complaints are not always treated in confidence and sometimes young people are labelled as troublemakers
- Children and young people generally do not have much awareness of advocacy and its availability is patchy.

“Young people often feel more disillusioned after making a complaint than before it.”
(Stakeholder interview: participation worker)

THE BIG 5 - ACTIONS NEEDED FOR IMPROVEMENT

In order to do justice to the wealth of knowledge so readily and openly shared with the team by young people, parents and professionals, a large number of recommendations has been generated. These are given in full in section eight alongside the essential conclusions of this project. Here they are summarised as the big five actions that must be taken on board if young people are to stop saying “nothing changes” and have a system they can believe in.

Recommendation 1: Ensure adherence to NHS statutory responsibilities

- The Department of Health (DH) should issue guidance to the NHS and local authorities on adherence to the 2009 regulations concerning complaints and take steps to improve record keeping and analysis of complaints, including the collection of national level data broken down by age
- The Health Service and Parliamentary Ombudsman (HSPO) should raise awareness of children and young people's rights to complain about NHS services
- DH should ensure that Healthwatch plays a lead role in the monitoring, reviewing and promoting of child and young person friendly complaint processes. Healthwatch should also have a clear remit to publish feedback about the handling of complaints.

Recommendation 2: Provide comprehensive support for children and young people who wish to make a complaint

- Local NHS providers need to ensure that user friendly information is displayed in services outlining the existence and purpose of NHS complaint processes and how to access them
- Advocacy services, in particular that are independent from the NHS, should be more widely provided and children and young people's access to them promoted.

Recommendation 3: Make the complaints process more ‘young person friendly’

- Local NHS providers need to ensure that the process for making a complaint is simpler, less reliant on writing things down and where use of the internet and other technology favoured by children and young people is promoted
- Services should develop complaints processes based on as short a timescale as is practical. A professional with experience of working with children and young people should act as the nominated point of contact for any child, young person, parent or carer, who wishes to complain, to prevent them getting ‘lost in the system.’

Recommendation 4: Take the necessary steps to address staff attitudes and change NHS organisational culture

- All staff working in the NHS should receive training in complaints policy and procedures and in how to handle complaints made by children and young people; this should be part of the induction, ongoing continual professional development CPD and supervision of all staff

- Providing feedback to service users, including compliments, comments and complaints, should be a routine feature of all services and senior managers should support staff in this
- Commissioners should set out in their service level agreements and contractual arrangements with NHS providers requirements for all staff to receive training in handling complaints made by children and young people, or parents and carers on their behalf.

Recommendation 5: Embed the involvement of children and young people in NHS services, at all levels

- Children and young people need to be central to the role and remit of Healthwatch arrangements and this should be laid out in the DH regulations that govern Healthwatch, both nationally and at the local level
- Healthwatch needs to engage with children and young people and to support their involvement in local health and wellbeing boards.

1. INTRODUCTION

1.1 This report

This report presents the findings of an investigation commissioned by the Office of the Children's Commissioner into children and young people's access to and use of complaints procedures within NHS services, in particular, mental health services, sexual health services and GP provision of such services. The work was undertaken by a team of six child health consultants and researchers and had a central focus on presenting the perspectives of children and young people aged between 8 and 21 years. The project ran from December 2011-April 2012, with most of the data gathering taking place between January and March.

The aim of the project is to provide a broad understanding of NHS/ health complaints processes and more specifically, to provide:

- An overview of the complaints processes available to children and young people using sexual health, mental health and GP provided services
- Analysis of the key messages from children and young people as to the need for a complaints system and what this might need to include for it to be accessible to them
- Information as to the extent to which children and young people are using current complaint systems
- A better understanding of informal and formal complaints processes/resolution mechanisms used by children and young people and the interaction (if any) between them
- Recommendations about how the current complaints system can be improved, including being made more accessible, based on the views and experiences of children, young people, parents and carers and the staff working with them.

In analysing the data gathered, the consultants were asked to consider:

- How accurately formal inspection and complaints systems reflect the views of children and young people
- Any additional safeguards or support that may be required by children and young people with additional needs, or those who find services hard to engage
- Whether there is evidence as to the provision of advocacy services improving children and young people's access to complaint procedures.

1.2 Structure

The report is made up of eight chapters with additional detail in two annexes.

Chapter 2 outlines the national policy and legislative context that underpins current complaints procedures in mental health, sexual health and GP provided services. This chapter also provides information about the proposed changes arising from the Health and Social Care Act 2012 and the implications for complaints procedures.

Chapter 3 presents the Discovery Groups and interviews undertaken with children and young people as a part of this investigation into complaints processes; as much as possible, quotes from the children and young people who took part in this project are used to illustrate the issues raised.

Chapter 4 summarises the findings of the online questionnaire that was developed for the project on www.puzzledout.com, giving young people's ideas for improving complaints systems.

Chapter 5 gives the findings from the stakeholder interviews that were undertaken with a wide range of professional groups working in health settings and children's services. These included: advocates, PALS staff, local complaints managers, service commissioners, CAMHS participation officers and GPs. The findings of the online questionnaire for stakeholders conclude this chapter.

Chapter 6 explores both national and international literature about 'good practice' in managing complaints and provides a range of examples identified during the stakeholder interviews and also via an online call for good practice that ran from January-April 2012.

Chapter 7 draws together the information gathered from children and young people as to what an 'ideal' complaints procedure for children and young people might look like.

Chapter 8 concludes the report and sets out a number of recommendations that draw on both the policy and research literature, as well as the new primary data collected through the project.

Annex I provides an overview of the literature concerning children and young people's satisfaction with services and about what research has found in terms of why they can or cannot share their views and experiences with professionals.

Annex II outlines the findings of a number of recent consultations with children and young people about their use of mental health, sexual health and GP services; the findings also discuss advocacy and young people's views of what makes a 'good' GP surgery.

Interspersed throughout the report are a number of in-depth case studies that explore the different stages young people, or their families went through in trying to make a formal complaint about a mental health or sexual health service.

1.3 Background to the project

In 2011 a House of Commons Select Health Committee reported that there continues to be “unacceptably wide variation in operation of complaints procedures within the NHS”, that reporting of complaints by Foundation Trusts remains voluntary and that the NHS has no national protocol for the classification and reporting of complaints.¹

The report goes on to state that the culture in the NHS is often defensive and needs to be persuaded to become more open. This does not bode well for vulnerable or less empowered groups, particularly children and young people who make up 22% of the population.

A recurrent theme in the research literature concerning the provision of services to promote the mental health and emotional wellbeing of children and young people, is that often the information given to them or their parents and carers is inadequate and lacks detail – as to what will happen to them and why; what will be offered and by which professional; the choices available to them and how to complain about their treatment and care if it does not meet their needs.

This situation is not peculiar to young people’s engagement with GPs, but affects community level health and mental health services more generally.² It is also apparent from many studies over the last decade, that dissatisfaction with services often leads to children and young people, or their parents and carers, disengaging or dropping out of treatment (rather than complaining) or only accessing services when they are at crisis point.

These concerns lie behind the calls for more ‘young person’ friendly services and for more flexible models of provision (e.g. assertive outreach approaches).³ However, they are also clearly pertinent to the issue of what needs to happen more specifically to improve complaints processes for children and young people using mental health and sexual health services. Furthermore, the learning that could potentially develop from an effective complaint and feedback process, cannot take place to improve services.

It is also important to consider how children and more especially, marginalised young people access advice and information in the first place and the learning from Youth Access as to how young people access social welfare advice provides some useful pointers. The 2009 report *Young people’s access to advice – the evidence*⁴ highlights the following:

- That young people’s advice-seeking differs markedly from that of the general population, it is often more haphazard and unsuccessful
- Young people are less likely to obtain advice when they need it

¹ <http://www.parliament.uk/business/committees/committees-a-z/commons-select/healthcommittee/news/11-06-28-clreopr-substantive/>

² Street, C. and Svanberg, J. (2003) *Where Next? New directions in inpatient mental health care for children and young people*. London, YoungMinds

³ Garcia, I; Vasiliou, C. & Penketh, K. (2007) *Listen Up! Person-centred approaches to help young people experiencing mental health and emotional problems*. London, Mental Health Foundation

⁴ Kenrick, J. (2009) *Young people’s access to advice – the evidence* London, Youth Access

- Mistrust of ‘the system’ is a significant factor
- Young people are more likely than other groups to take no action to resolve any problems, they are more prone to delay and to give up seeking help
- Many will try and handle their problems alone
- Many who do not access advice later regret this.

Collectively, these reports highlight the importance of having complaints procedures and processes that have been carefully designed with children and young people in mind, that are well explained, easy to access and sensitive to the worries and concerns of children and young people.

Context - reorganisation and large scale health system changes

At the time of this investigation, considerable changes to the NHS were underway, or were being considered. Significant cutbacks to services for children and young people, in particular, in the voluntary sector, were also taking place across the country.

Undoubtedly this context is impacting on access to mental health and sexual health services for children and young people, with long waiting times and/or a lack of provision being a possible reason why they or parents and carers, might be more likely to make a complaint.

On the other hand, however, and certainly indicated by some of the data gathered in the investigation, this context may actually reduce the number of complaints made by children and young people about health services – either because information about how to complain is less readily available or protocols for channelling information to health service complaints officers are disrupted (e.g. because of changes in staffing or service reorganisations). Another reason may be that children and young people are deterred from complaining, for fear that by doing so, they may lose the service they may have waited a considerable time to receive.

1.4 Approach to data gathering

The investigation involved gathering both primary and secondary data from a variety of sources and including both qualitative and quantitative material. A dedicated website for the project was created (www.listenup.org.uk) which provided project information sheets and access to two online questionnaires. The main components of the investigation were:

- **A literature and policy review** was undertaken to identify key legislation and policy relevant to children and young people’s access to NHS complaints processes; the review also examined what research has been identified about how young people communicate about their experiences of using health services, including their involvement in mechanisms for monitoring service user satisfaction.

Other topics searched for included: research about children and young people’s attitudes to and satisfaction with primary care; research concerning attitudes towards

complaints mechanisms; studies about 'young person friendly' primary care; research about what support children and young people might need for making a complaint.

- **Four Discovery Workshops plus individual interviews (instead of a group) at one further service** were offered in a variety of settings, some offering sexual health services for young people, some offering mental health primary care and some a combination of services.

One of the services had a specific focus on supporting young lesbian, gay, bisexual and transgender (LGBT) young people and in all of the group discussions and interviews, young people were encouraged to record their own data, using storytelling, interactive exercises, graffiti/post-it walls and/or journey mapping.

- **Gathering professional stakeholder views** via semi-structured telephone and face-to-face interviews; email questionnaires and an online questionnaire on Survey Monkey. Specific professional groups were targeted, including: independent mental health advocates (IMHAs); managers of advocacy services; participation workers in CAMHS and children and young people's services; Primary Care Trust (PCT) and local authority complaints officers; managers of youth sexual health services; GPs and practice managers; local Healthwatch officers and PALS (Patient Advice and Liaison Service) officers.
- **A call for good practice and a request for case studies** (as well as an invitation to take part in an interview) was disseminated across services working with children and young people, with a number of national organisations hosting information about the project on their website or distributing this via their online newsletters.
- **An online survey for children and young people** was created at www.Puzzledout.com. This also provided an opportunity for children and young people to 'tell their stories' or to send in blogs, pictures or videos.

To support the data gathering and the identification of key themes and recommendations from the information gathered, four young project advisors were recruited, three of whom had experience of using mental health and/or sexual health services and one had experience of making a complaint that had gone as far as the Health Service Ombudsman.

Table 1: Numbers of young people participating in a Discovery Group or interview

Location	Number of young people
Liverpool	7 (5 female, 2 male, all 18-early 20s). 1 interviewee also a project advisor
Devon	7 (all female, age range 18-early 20s)
Brighton	2 (2 male; age range 17-19)
London	6 (4 male and 2 female; age range 8-10)
Birmingham	6 (1 female, 5 male; age range 17-20)

Table 2a: Dissemination of project information by local organisations

- **Waltham Forest Black People’s Mental Health Association** consulted its service users
- **Just for Kids Law**, a legal centre in North London, consulted its young people project advisors
- **Coram Children’s Legal Centre** reviewed the issues on which it provided legal advice in 2011
- **Mancroft Advice Project (MAP) in Norwich** consulted young people using the service
- **The Who Cares Trust** gave out information to young people

In addition, a number of CAMHS and Children’s Services circulated the project information sheets to their local teams, in particular, to encourage children and young people to complete the online questionnaire at Puzzled Out.

Table 2b: Dissemination of project information by national organisations

- **Youth Access** circulated information to all its member Youth Information, Advice, Counselling and Support Services (YIACS); a number of YIACS helped to recruit young people to the Discovery Groups and/or offered meetings and interviews with project managers
- **Relate** put project information on its new website that offers online counselling (www.irelate.org.uk)
- **Rethink Mental Illness** disseminated information via its Time to Change Young People's Panel
- **YoungMinds** put information about the project in the CHIMAT online newsletter and also circulated materials across its VIK (Very Important Kids) participation network
- **Action for Children/ACH** consulted on behalf of the consultant team across its range of projects offering advocacy support to children and young people
- **The Peer Outreach Team** based at City Hall in London which works with the Greater London Authority and the Mayor of London to engage with young people across the capital in order to hear their opinions and consult with them about services, disseminated project information across its networks
- **The London Deanery** disseminated information across its member GPs
- **NYAS**, the National Youth Advocacy Service, consulted with its Southern Region Independent Mental Health Advocates
- **Brook** consulted with their team of young advisors

1.5 Key issues identified

“The complaints process should be an opportunity for a conversation but is too often the end of it – doors are shut and the young person is seen as trouble”

(Stakeholder interview: participation worker)

Children and young people

- Don't know about their right to complain
- Say they have no information about who to speak to, or where to go
- Fear repercussions
- Are worried about making a fuss/want to 'keep their head down' and not be singled out
- Don't feel listened to
- Feel there is mental health stigma
- Have doubts about whether they are over-reacting
- Feel it's difficult to complain about someone they have to see
- Say the system is not sufficiently independent
- Describe a 'power imbalance'
- Are aware of staff in the NHS being under pressure
- Say the complaints process is too complicated and takes too long
- Believe 'nothing happens anyway'.

Younger children highlighted a reliance on their parents to sort it out and also worried they would get into trouble.

Parents

- Are often unclear who is in charge or who they should approach
- Question the independence of the system
- Are unsure about costs (for instance of access to records)
- Feel PALS is ineffective
- Experience a drawn out process that takes a lot of time

- With older adolescents, parents feel actively excluded from their child's care and treatment.

Staff perspectives

Staff perspectives included the following concerns:

- Lack of training for staff to be comfortable and skilled in dealing with complaints
- Junior staff find it difficult to challenge senior medics (whistle blowing)
- Some issues cannot be resolved, so no feedback is given
- Complaints officers have less time to inspect therefore if a service is not getting many complaints they may feel that is a relief and they do not need to visit
- Data broken down by age is limited, therefore it is hard to assess the scale of the problem
- Complainants have limited access to advocates
- There is pressure to meet targets and growing worries about professional liability if an organisation acknowledges something has not gone well
- Good practice would be to try and deal with things at an informal stage – but what actually happens is not monitored, may not be recorded and so could be very variable
- Procedures make the process lengthy and bureaucratic.

2. NATIONAL POLICY AND LEGISLATIVE CONTEXT

2.1 Complaints mechanisms for young people – an overview

The right to complain about NHS or Local Authority services exists for all age groups in the UK. A wide body of research clearly indicates that there is a link between service uptake, levels of satisfaction with services and whether or not people complain. With regard to children and young people, studies also indicate that young people moving between children focused and adult services tend to use services less than older people and are less likely to complain. Evidence suggests that they share many of the same dislikes about services and complaints mechanisms as older people, but there may also be some additional ones.

The involvement of young people in being able to influence the nature and delivery of services, and make suggestions for their improvement, is likely to improve their service use and health outcomes. The development and design of youth friendly services and youth friendly ways of making suggestions or complaints is essential. Without these features, complaints by young people may be few, but that will not necessarily reflect service satisfaction or appropriate levels of service uptake.

Over the last two decades there has been a growing acknowledgment of the rights of children and young people to have their voices heard and express concerns about services they use.

2.2 National Policy and Legislation

UN Convention on the Rights of the Child 1989

The rights of children and young people to participate and to express their opinions was enshrined in the UN Convention on the Rights of the Child, 1989. One of the guiding principles of the Convention included the child's right to participate and children's entitlement to the freedom to express opinions and have a say in matters affecting their social, economic, religious, cultural and political life. Participation rights included the right to express opinions and be heard.

Article 12 enshrined the right of children including those with mental or physical disabilities to enjoy a full and decent life in conditions ensuring dignity, self-reliance and active participation. Article 24 enshrined the right to enjoy the highest standard of health treatment and rehabilitation.

Legislation and guidance

The following have improved the rights to an advocacy services for children and young people wanting to make representation and complaints about their service:

- The Children Act 1989 instituted this right for looked after children and children in need.
- The Children (Leaving Care) Act 2000 extended this right for young people leaving the care system
- The Adoption and Children Act 2002 gave a statutory right for looked after children, care leavers and children in need to have advocacy when making a complaint
- The Care Planning Act 2010 ensured that in care planning, placement and reviews, for children who have difficulty expressing their views, consideration must be given to them having the services of an advocate
- The Care Leavers Act 2010 resulted in an entitlement to advocacy when making complaints but also when needing to make representation about the quality of care
- Working Together to Safeguard Children 2010 stated that children and young people should be invited to their case conferences and entitled to bring an advocate, friend or supporter
- The National Minimum Standards (Department for Education 2011) extended similar rights for children and young people in fostering and residential care
- The Secure Training Centres Rules 1998 determined a right of advocacy for young people in secure training centres
- The Mental Health Capacity Act 2005 stated that young people aged 16 years and above, who had no one to support them, and no advocate, could have access to an Independent Mental Capacity Advocate
- The Mental Health Act 2007 stated that children and young people who were likely to be, or had been sectioned, had a right to an Independent Mental Health Advocate (IMHA).

Within the National Health Service, a complaints process is underpinned by statutory instruments, and the NHS constitution guarantees a patient's right to complain, the right to know the outcome of their complaint, to take a complaint to the Health Service Ombudsman if not satisfied and to make a claim for judicial review if they consider they have been unlawfully dealt with, and to be compensated for any harm.

You're welcome

In 2011 the Department of Health published 'You're Welcome': Quality criteria for young people friendly health services.

These quality criteria are designed to involve young people in service improvement, enhance the patient experience and increase young people's opportunity to share in decisions about their health. Interestingly, the main themes in 'You're Welcome' cover areas which are often highlighted in the complaints process.

The themes outlined the following: the need for services for young people to be accessible and effectively publicised; address confidentiality and consent, be provided in an environment with an atmosphere that is young people friendly, ensure that staff have the training, skills and attitude to deliver young people friendly services and that their needs are met; that services are joined up for effective delivery; acknowledge young peoples' involvement in service development, monitoring and evaluation, and address the transition as young people move from childhood into adulthood.

The Quality and Outcomes Framework

The Quality and Outcomes Framework (QOF) is the annual reward and incentive programme detailing GP practice achievement results, including the patient experience. The QOF is a voluntary process for all surgeries in England and was introduced as part of the GP Contract in 2004. QOF awards surgeries achievement points for:

- Managing some of the most common chronic diseases, e.g., asthma, diabetes
- How well a practice is organised
- How patients view their experience at a surgery
- The amount of extra services offered such as child health and maternity services.

2.3 The current system for complaints in health and social care

Health - complaints about primary care

All Trusts, both hospital and primary care, are required to have a complaints procedure and there are timescales relating to the initial informal complaint and a formal complaint that would involve the Ombudsman.

The NHS Choices website explains that the first step to making a complaint would normally be to raise the concern with the patient's GP or the practice manager at the surgery either by speaking to them or writing a letter or an email. The GP or practice manager may be able to solve the problem. However, if the matter is unresolved or the patient is unhappy with the response, the patient may wish to make a complaint, and all GP surgeries should have a written complaints procedure either at reception or on the practice website.

An alternative for patients who do not wish to raise a matter with the GP or practice manager is to complain to the local Primary Care Trust (PCT). It also states that help and advice about making a complaint can be obtained from the local Patient Advice and Liaison Service (PALS) or the local Independent Complaints and Advisory Service (ICAS).

In terms of making a formal complaint, this can be verbally or in writing to the GP surgery, and the patient should receive an acknowledgement within three days of the surgery receiving the complaint. If a patient is unhappy with the reply, then it may be possible to refer the complaint to the Parliamentary and Health Service Ombudsperson. Various structures are identified for supporting people and these include:

- **PALS** – The Patient Advice and Liaison Service (PALS) can assist patients or their carers with listening to complaints, providing information and helping complaints be resolved
- The **Independent Complaints Advisory Service** can explain options to patients or their carers and offer help and support a complainant making a complaint
- **LINKs** - Local Involvement Networks were established in England to provide individuals, groups and organisations with the opportunity to have a say in their local services.

Recorded numbers of complaints in the health system (all ages)

The new system of complaints was established in 2009 and in the first year of the new system, complaints increased by 13.4% to 101,077, with an increase in general practice and dental service complaints of 4.4%. The Health Select Committee observed that this increase could be because of an increase in demand for health care, greater consumer awareness of the ability to complain and/or deterioration in standards of care. ⁵

Statistics produced by the Information Centre for Health and Social Care for 2009-11 found the following: from 2009/2010 to 2010/2011, there had been an increase of 0.1% in complaints to general practice and dental services, an increase from 50,760 to 50,710. Of these complaints 60.7% were for the medical service area, an increase of 0.5%, and 19.2% were for general practice administration. In total 35.4% of complaints were about clinical matters, and 23.1% were related to communication and attitudinal issues.

The Health Select Committee, found that satisfaction with local resolution, i.e. stage one, had increased in the last few years with a 70% satisfaction rate in 2009/10 compared with the 45% to 56% rate in 2006/7.

With regard to complaints that reach the Parliamentary and Health Service Ombudsman, in 2010/11 the Ombudsman received 13,625 enquiries about the NHS, of which 2,581 were complaints about GPs. Their annual report commented that only a small number of these required a formal investigation. ⁶

Regarding advocacy and support for patients or carers making a complaint, the Committee observed that PALS is often not very visible in Trusts; may often be perceived as lacking sufficient independence from the Trust and can be seen as ineffective, particularly if the staff are on a lower grade to the staff being complained about.

⁵ Health Select Committee (2011) *The NHS Complaints System*

⁶ *A Service for Everyone. Annual Report 2010-11*. Parliamentary and Health Service Ombudsman.

With regard to ICAS, there is some evidence that their help makes it more likely that a complaint will be successfully taken to the Ombudsman, but on the whole, it has an even lower profile than PALS. The Committee suggested that PALS should refer more often to ICAS.

Complainant characteristics

Of the enquiries to the Ombudsman, 36% of the people who contacted the office regarding NHS complaints had a disability; 39% of all enquirers about the NHS and other governmental departments were aged between 55 and 74 years old, and 18% of total enquirers were from black and minority ethnic communities.⁷

Barriers to making a complaint

Although complaints can be referred to the Health Service Ombudsman, there are a number of criteria that need to be met: the complaint must relate to maladministration or poor service, the patient must have suffered an injustice or hardship as a result of their treatment, and there must be a prospect of a worthwhile outcome.

There has been a significant increase in stage two complaints, but only 2.3% of the complaints taken to the Health Service Ombudsman are pursued, so 98% are not investigated. The Health Select Committee was concerned that many patients were bounced back for local resolution to an organisation with whom they are already dissatisfied, and the Committee expressed concern that the eligibility criteria for referral to the Ombudsman were too demanding.

The hurdles to successfully complaining, resulted in only 5% of those dissatisfied with their NHS care making a complaint in 2008, of which 16% made an informal complaint and 79% made no complaint (National Audit Office). It appeared that this lack of resort to a complaints mechanism was due to several factors:

- Lack of confidence in the system
- Scepticism that anything would be done or the system would be sufficiently fair
- Some fear of the repercussions for a patient should future treatment be required.

The Committee considered that this particularly applied to general practice services and especially those in rural areas where there was little choice of an alternative clinician.

The Committee noted the link between quality of care and effective complaints handling; it observed that Executive Boards of Trusts tend to set a tone about expectations and culture and that under a half of Trusts systematically analyse complaints. There was also concern expressed that only a quarter of Foundation Trust Boards met in public.

⁷ Health Select Committee (2011) *Op Cit*

Local authority complaints system

Complaints about social care services are dealt with by a local authority complaints system. Local authorities have their own systems and as an example, Leicester City Children and Young People's Service has a three-stage system before referral to an Ombudsman. Stage one is local resolution by the manager nearest to the service, followed by a formal independent investigation by experienced investigators who are not employed by the city. An independent review panel of independent people may then review the stage two investigations. At that point, if a complainant is not satisfied, they can refer their complaint to the Local Government Ombudsman (there are separate Ombudsman offices for England, Scotland and Wales).

The roles of the Local Government Ombudsman (LGO) are set out in the Local Government Act 1974 (amended by the Health Act 2009) and the Apprenticeship, Skills, Child and Learning Act of 2009. The role was extended to adult social care providers in 2010. In 2010, the LGO extended its complaints handling service for parents with concerns about schools, to 14 Local Authority areas. For maintained schools outside those areas, unresolved complaints are handled by the Department for Education, as are complaints relating to independent schools. Unresolved complaints about academy schools will be handled by the Education Funding Agency from April 2012.

Figures

The Local Government Ombudsman has an advice team which handles initial contacts and in 2010/11 there were 20% more complaints compared to 2009/10, a total figure of 21,840. Of this total figure, 11,249 complaints were handled by the investigative teams, a 7.5% increase on 2009/10.

Complaints about education and children's services are the largest single category equating to 19% of all complaints received; in 2010/11, these increased by 15% on 2009/10.

Figures from the Coram Children's Legal Centre for 2011 indicate that the Centre provided legal advice to 12,753 users. Of these, 263 users were under the age of 25 and their main issues were contact, residence, education, the duties of local authorities and parental responsibility. There were no calls by young people requesting advice about how to complain about mental health or sexual health services.

Complainant characteristics

The LGO found that young people aged 24 years and under, who represent 31% of the population, are significantly under-represented in the figures of those who have made a complaint – over the last three years, only 3% complained. Men of all ages were slightly more likely to complain than women (55% as against 45%). Citizens from Black and minority ethnic groups constitute a slightly larger proportion of complainants than their numbers in the population, according to the 2001 census.

2.4 Proposed new system – Health and Social Care Act 2012

Proposals

The Health and Social Care Act 2012 makes provision for the establishment of Healthwatch as a new independent consumer champion; it will operate at the local level as local Healthwatch, and at the national level as Healthwatch England. Healthwatch England will be established in October 2012, with local Healthwatch organisations being established in April 2013.

Healthwatch England will be established as a committee of CQC, close enough to influence regulation and share information, but with sufficient independence to be a strong consumer voice. Local Healthwatch organisations will be social enterprises, contracted by the local authority, to act as the local consumer champion.

The Healthwatch role is to:

- Present views, shaping and monitoring health and care services
- Provide a strong, independent, local, consumer voice using views and experiences to help bring about better health and social care outcomes
- Monitor local health and care services and make recommendations to commissioners and providers about things that could or should be improved
- Be authoritative, credible, and influential with commissioners and providers of services
- Contribute their information about local health, care and public health services to the Joint Strategic Needs Assessment (JSNA) process and the health and well-being strategy.

It is expected that Healthwatch will have a role in signposting individuals, to help them access information about services and to empower and facilitate people to speak out, including through NHS complaints advocacy. It is further expected that local Healthwatch will have a good understanding of local, voluntary and community groups, other patient and public groups, for example, patient participation groups and Foundation Trust membership, and how these complement each other.

At a national level, Healthwatch England is expected to provide the following:

- Leadership and advice to local Healthwatch
- Advice to the Health and Social Care Information Centre on the information which would be of most use to patients to facilitate their choices about their care
- Advice to the NHS Commissioning Board, Monitor and the Secretary of State
- Advice to CQC with regard to the investigation of poor services, based on information received from local Healthwatch and other sources.

Within the proposed new structure, the role of LINKS will evolve to become local Healthwatch.

However, there is no automatic right for existing LINKs to become local Healthwatch organisations since these will be commissioned by Local Authorities who have the freedom to choose who they wish to commission the service from.

From April 2013, PALS and ICAS will no longer exist in their current form and many of their functions will move to local Healthwatch. Local authorities will have responsibility for commissioning local NHS complaints advocacy services for people requiring support to make a complaint. Complaints advocacy can be commissioned by the Local Authority from Healthwatch or any independent advocacy organisation. Additional funding will be available from the Department of Health to support Local Authorities in setting up their local Healthwatch. Local Healthwatch will have a seat on the Local Authority health and well-being board, to ensure consumer voice is integral to decision-making.

Safeguards and concerns emerging from the proposed changes

Concerns have been expressed about what will happen to complaints handling as the Health and Social Care Bill was passing through Parliament. While some of these concerns were addressed there are still concerns regarding the implementation of the Health and Social Care Act 2012.

The abolition of Primary Care Trusts (PCTs) has implications for both the handling and monitoring of complaints and feedback from patients, the public and MPs. In a submission by the NHS Confederation, it was stressed that complaints handling is particularly important in relation to primary care because there is a known reluctance amongst people to complain to their GP or other primary care provider. The submission also suggested that it is currently unclear who patients and MPs should go to when a complaint concerns several services, including primary care.

With regards to complaints monitoring, it has also be noted that if future commissioners in GP consortia and the NHS Commissioning Board are not informed about complaints and do not receive feedback on services, they will have incomplete information on which to base their commissioning decisions. As a result, there may be missed opportunities to drive up service quality.

Case study 1: N's story

Young person's own words (written, then followed up by phone)	Timeline summary
<p>Well, it all started when I was 16 in the summer of 2010. I began having fears and general anxiety around being in a room with an older male, just alone. Because of this, my GP got in touch with my CAMHS service, and asked them to make a reasonable adjustment.</p> <p>The reasonable adjustment she said could take place would be for a CAMHS support worker to sit in the room with him, or to have a female psychiatrist.</p> <p>At first, I was allowed a female worker to sit in the room, this was in the place of my case worker who oversaw all the therapy I was being given as well as the social care and psychiatry. She then started to not attend my appointments, meaning I could not attend my sessions that I have weekly with my psychiatrist. Because of this, I was getting letters to my house, from CAMHS, telling me I need to start attending my appointments... About 20 calls later, we finally sorted this out with the admin staff.</p> <p>Then, I was diagnosed with PTSD, however, for three and a half months, I wasn't told I was diagnosed with PTSD, and the medication I was put on, he said it was because of a 'low mood'. When looking back into my case file, he prescribed it for PTSD.</p> <p><i>Access to files – N asked the case worker and at first was told “it won't be best for you”. He responded by “kicking up a fuss and getting angry” then had access to the case notes.</i></p> <p>All my sessions ended up being revolved around this, and nothing around anxiety, even after repeated attempts at me telling CAMHS I need help in other places.</p> <p>One of my therapists, my general psychotherapist, who is my main therapy giver, then was stripped from me on the grounds we hadn't formed a therapeutic relationship.</p>	<p>2010 N is 16 Talks to GP about fears about being alone with male psychiatrist (Dr R)</p> <p>GP writes to CAMHS suggesting switch to female psychiatrist – or female chaperone in weekly psychiatry sessions</p> <p>Initially female chaperone sits in, then this tails off - N stops attending as a result. (It subsequently transpires that Dr R had only scheduled in the chaperone for half the appointments)</p> <p>Letters and calls with CAMHS result in weekly appointments with chaperone reinstated</p> <p>Dr R prescribes medication for “low mood”</p> <p>N reads case file and discovers Dr R has in fact diagnosed PTSD</p> <p>.</p> <p>Dr R focuses all sessions on PTSD, despite N's requests for help in other areas, e.g. with anxiety</p> <p>Following a routine case review N is informed by the case worker that the main therapy giver will no longer be working with N as they have not formed a therapeutic relationship. N disagrees</p>

Two months later, I was told I had to start seeing him again, otherwise I would be sectioned. Totally contradicting the fact that they said I would not be able to see him anymore. My case worker said “you’re not thinking straight it’s not best for you.”

Well, initially, I had a bit of a breakdown in my centre, and started screaming and they put me in hospital (voluntarily). Whilst I was in hospital, I write a letter to Julie, who is one of the CAMHS admin team. This letter was ignored.

Because it was ignored, I wrote an email to the Royal College of Psychiatrists (RCP). They said they don’t deal with matters like this, and I would have to contact the General Medical Council (GMC), however they will be happy to assist.

They forwarded my email, within three hours. I had a phone call from an outreach worker, asking to come meet me whilst I am in hospital so he can get a fuller grasp of the whole situation.

I sat with the man, for about two hours, and explained everything above. In the end, we complained on the grounds of:
A) Dishonesty, with regards to why I am on this medication, and my real diagnosis
B) Failure to examine my needs properly and respond reasonably. With regards to ignoring my anxiety at times. And being unable to make reasonable adjustments towards the disability discrimination act with regards to me needing to see a female worker (on my case file, he only scheduled her in for half of my appointments).

So, exactly seven days later, they said that they are going to need more time to investigate, as they need to interview Dr R.

Another seven days goes by, and they ask to meet with me. They come visit me in hospital, and this time, they tell me how my treatment plan is going to change, and CAMHS East are reforming as we speak in the sense

Approx three months later the case worker uses sectioning (detention under the Mental Health Act) as a threat to get compliance

N writes a letter of complaint to Dr R’s admin/PA

No acknowledgement or reply

N escalates the complaint – contacts RCP

RCP replies that’s not in its remit – then forwards the email to the GMC

Within three hours, N receives a phone call from a GMC outreach worker

After meeting the GMC rep and N agree the complaint:

1. Dishonesty about diagnosis and medication
2. Failure to meet N’s needs and respond reasonably
3. Failing to make reasonable adjustments re female chaperone

Point 3 evidenced by the case notes where it transpires Dr R had only scheduled the chaperone for half the appointments

GMC follows up by interviewing Dr R.

Change to treatment plan, N’s care is switched to the intensive care team until transition to AMHS

they are revising their policies and procedures and I will be seen by the intensive care team until I transition from now on.

With regards to Dr R, He has had a 'verbal warning'...

So that's about it...

Dr R receives a verbal warning

In summary:

It was 6-7 months intensive
N still experiences cancellations
N is now more cautious
"Glad I complained – couldn't get worse"

3. FINDINGS FROM THE DISCOVERY GROUPS AND INTERVIEWS WITH YOUNG PEOPLE

Young people from different areas of England were consulted; most were aged 16+ although one group was with younger children aged 8-11. Whilst there were some important differences between the groups, for example, in one group, all of the participants had been in local authority care, and in another, they had used mental health services only, there was a high degree of consistency in the issues and concerns raised. Furthermore, many of these issues were consistent with the concerns outlined in the studies identified in the literature review (Annex I) and in the recent consultations summarised in Annex II.

3.1 Devon Discovery Group

The participants in the Devon group came from a number of different services from across the county. There was mixed awareness across the group of their right to complain about the health services they had used, and none had ever made a formal complaint, although one young person reported that their parent had complained on their behalf, with the matter going as far as the General Medical Council (GMC).

Information from the group was collected in a number of ways including group discussion, drawing (to explore the worries and/or emotions young people may have about complaining) and a 'post-it' wall. This collated the various reasons why members of the group had not complained when they had been unhappy with the service they had received; the group voted on this to identify what are, in their opinion, the main deterrents to young people making formal complaints.

The group made a number of general observations about how difficult they thought it was to make a complaint about a mental health service and these included:

- The process of making a complaint is hard because the thing you want to complain about makes your confidence drop – so you're feeling worse than before it happened
- Many young people fear talking/speaking out; they worry about being made to look stupid and being kicked out of the service.
- If someone else is horrid to you, why would you want to complain to them? It would make things worse.

They gave the following reasons why they had not complained, when they had not been happy with the service they had received:

- *"It's difficult to complain about someone you still have to see"*
- *"People don't listen"*
- *"They don't take you seriously if you have a mental health problem, they say you're over sensitive... or they say it's just part of your illness..."*

- “If you’re in a unit it’s hard to talk to anyone outside; nobody seems to be keeping an eye on what goes on inside”
- “Your (mental) illness can make you doubt yourself and whether what seems wrong really is wrong or is just you.”

The group unanimously agreed that young people need someone who is independent and not from the NHS to make complaints to – and in this respect, they viewed PALS as insufficiently independent. QNIC visits (the Royal College of Psychiatrists Quality Network for Inpatient CAMHS) were also mentioned – these were felt to be insufficiently frequent and to not always ask the right or enough questions. The group also suggested that advocates should be made more available to support all young people using health services and that young people need adequate responses when complaints are made – “not just letters that say thank you.”

Table 3: Group voting on the main reasons young people identified as to why they do not make complaints about mental health or sexual health services

Issue	Number of votes
Stigma/want to fit in and not bring attention to myself	7
Worried about being judged/kicked out of the service	6
Takes too long/find out too late and at that point, can’t be bothered	4
Too busy trying to get help and worried about causing more delays	3
Don’t want parents to know	3
Lack of information	3
Feels awkward	2
Process not advertised so you don’t think about it	2

Young people’s suggestions for improving the complaints system

These included making the process **more visible and standardised** – for example, information on complaints that have already been dealt with should be publicised; complaints officers should be more visible – for example, information leaflets provided that include a photograph of them; time limits should be publicised and all young people making a complaint should be given a case reference number, to validate that the complaint has been received and so that their complaint can be tracked.

The group strongly emphasised that, in their opinion, the way forward is to **make more use of the internet** – for example, information about a service’s complaints procedure should be on its website and there should be opportunities for providing online feedback.

Other suggestions for what would improve complaints processes in mental health and sexual health services included:

- Having a booth to give feedback on the service – which young people could use only if they wanted to
- Training staff in how to handle young people's complaints
- An inspection process (like 'Mystery Shoppers') that includes complaints.

3.2 Birmingham Discovery Group

"There is a social stigma attached to complaining. They should have a box for us to put a remark into"

(Group participant, explaining why young people don't complain)

The six young people and two members of staff in this group raised a wide range of issues about their experiences of using sexual health and GP services. With the exception of one young person who had worked in a hospital, none of the group had heard of PALS and - nobody had been offered an advocate or been an advocate for anyone else. A number of the group were concerned about confidentiality and it would appear that there was only limited understanding of the boundaries of this.

Various comments were noted that services did not provide avenues for giving feedback including compliments or saying thank you; that staff often showed a general lack of discretion (e.g. when booking young people in) and did not apologise to young people when things went awry – for example, referral or appointment forms were lost. Some of this discussion touched on the negative connotation of the word 'complaint' and whether this made raising concerns more difficult for young people:

"We're young and we've got a bad reputation already so complaining would make it worse – maybe call it feedback not complaints."

The comment of one young person suggested that staff responses to young people's complaints can on occasion be unhelpful:

"I've seen someone cover their name badge when someone wanted to complain."

Other prominent themes emerging from the discussion as to why young people find it difficult to make a complaint were as follows:

- Staff making assumptions about young people:

"They look at you, they make assumptions about you, it's the whole stereotype because of your age."

- Young people not feeling listened to:

“I was trying to talk to my doctor – he just handed me a sheet and said ‘Try this number.’”

- Young people feeling they are treated differently to adults:

“This woman (in A&E) was so rude to us. I know I’m gonna get this rudeness when I go in so why would I complain? I’ve gone with my mum before and the experience was different”

- The importance of welcoming staff in the service reception:

“People get intimidated – at reception for instance people who are miserable and rude – I’m shocked at the things people say, I can’t imagine a 13-year old having these things said to them.”

- Not being clear that as a child or young person they could complain:

“I wouldn’t think as a 14-year old that I could complain. I’d expect my parents to do it for you.”

- Long waiting times, often accompanied by a view that nothing will happen:

“I saw a psychiatrist and I needed to get a referral and they said it would take a couple of weeks but it took months, I didn’t see the point in complaining cos I couldn’t see what it would achieve.”

- Worries about repercussions:

“I’d worry that they would give me bad service if I complain.”

- Worries about having to start again, to re-tell their story to someone else:

“The main reason I didn’t go to complain was cos I expected it to be a couple of weeks – but had I known it would be two months! We all know the NHS takes time. You wouldn’t wanna go back to your Doc if you had complained and the thing is, I don’t want to change to another doctor because I would have to tell them everything all over again.”

One of the youth workers supporting the young people in this group also noted that often young people lack confidence and that this can make it difficult for them to raise concerns about the service they have received, especially if they don’t know what to expect in the first place:

“It takes time to know what your rights are and to have the skills and not feel guilty to say what you wanted to say.”

Young people’s suggestions for what a good complaints procedure would look like

ACKNOWLEDGEMENT OF RECEIPT - e.g. ‘We will acknowledge your complaint within 24 hours.’

CLARITY - e.g. a choice of level of confidentiality: open or confidential; a video diary telling you who will help you and providing information about the system; information about the different steps.

NEUTRALITY - e.g. 'Somebody neutral, not the receptionist.'

ACCESSIBLE - e.g. touch screens in GPs and hospitals; on your mobile phone like a mobile app; an automated system on a phone. Overall, it should be an open service with lots of routes to complain and run by friendly staff.

TRACKING – so that young people can see where their complaint is in the system, as well as feedback when it is resolved.

PUBLICATION OF THE RESULTS - make complaints made by others accessible to the public.

PUBLIC AWARENESS - a campaign or project aimed towards changing how people view complaints could be helpful. Build more awareness of PALS and other similar services and give them better names. Ensure the system is bright and colourful to make it attractive to young people.

3.3 Liverpool Discovery Group

In this group, the six young people had been in care and as such, they knew their rights fairly well and appeared able to complain, verbally at least, fairly easily. The information they shared concerned mental health services. Two of the group became distressed during the session, after re-living their poor experiences, with one young person stating: *"I have had a lifetime of abuse and being in care. Staff make me feel humiliated and even more let down."*

Several of the group had used PALS, others, however, had seen PALS but did not realise that it was applicable to them. One had received the support of an advocate in relation to a Section of the Mental Health Act and they all knew about CCC⁸ – 'Compliments, Comments and Complaints' – and two had used CCC to complain.

The young people provided a range of reasons for why they had in the past either made a complaint, or had wanted to complain about the mental health services they had used. The behaviour of mental health practitioners, and in particular, their lack of compassion towards young people in distress, attracted many comments. One of the group described being discharged from A&E at 3am following an overdose; others talked of staff in A&E departments being rude and dismissive of young people's concerns and one stated that they had been told *"kill yourself or go home."*

The group also reported experiences of being labelled or stereotyped by health staff and of being pointed at and talked about. One noted that they had been labelled as a troublemaker for complaining; they described an incident following a complaint wherein a receptionist responded to a request for change of appointment with *"Who do you think you are?"* Overall,

⁸ CCC is part of their local organisation's registration with ISO 9001 – a national accreditation system for quality assurance.

the group suggested that when young people make a complaint about mental health services, this is seen as attention-seeking or trouble-making.

Other reasons why the young people had in the past wanted to complain included: being kept waiting, or promises being broken, with no information or explanation, and the use of restraint when in the opinion of young people, it was not needed.

Reasons for not complaining

“It took me a lot to complain – and then they let me down.”

(Group participant, talking about the experience)

The overwhelming reason for not complaining identified by this group, was that in most cases, they believed that ‘*nothing happens*’ and young people’s past experiences of trying to complain were clearly an important influence underpinning this perception. The group talked of occasions when they had made complaints which were never acknowledged, and/or where nothing was ever received in writing and where again, young people had felt labelled as ‘trouble makers.’ A fear of repercussions was also reported. Other reasons given included:

- Some experience to suggest it would be detrimental to them and to their care
- The form filling process was off-putting
- The conviction that it was not possible to complain anonymously, with the group talking about the services they used being too small, which would make it possible for workers to identify which young people had complained

Some important insights in to the particular vulnerabilities that may affect young people using mental health or sexual health services were also raised – that young people can lack the articulacy, or skill, or courage to make a complaint, especially against medical professionals who they see as powerful and able to influence others. Furthermore, when young people are unwell, they are even more vulnerable and disempowered. These comments echoed the themes raised in the Devon Discovery Group.

The outcomes of their complaints – what happened?

Two of the group reported a speedy and satisfactory resolution and that they were happy with both the process and the outcome, however, the rest of the group reported less positive outcomes which included: nothing happening; feeling repeatedly ‘fobbed off’ or labelled as a trouble maker; some short term effects, such as staff being suspended in serious complaints, but effects which overall, did not seem to be sustained and which “*seemed to fizzle away*”. None of the group had ever received anything in writing and one commented that it would have made her feel less unimportant if this had happened.

Suggestions for improving complaints systems

Like the Devon, and Birmingham groups, the suggestions made by young people in Liverpool centred on the need for a more **visible and standardised** complaints procedure; for **greater independence/neutrality** from the health service itself; for **simpler processes** including easier forms to fill in and the use of online avenues for both sharing information and receiving feedback and for staff to be trained in how to handle and receive complaints.

The group emphasised that complaints should lead to change and the change should be publicised and that in order to improve the situation:

- A large scale shift in culture within the mental health service system is needed – in their opinion, it is a power imbalance between staff and young people, parents and carers. The system is loaded in favour of staff who themselves seem to be afraid of complaints – so their culture, and their attitude towards complaints, also needs to change to enable them to be supported to embrace feedback.
- Organisations should learn from their mistakes - at its simplest: “You said, we did” – again indicating that a whole organisation culture change is required.

This group echoed the Birmingham group in suggesting that the word ‘complaint’ is unhelpful and that having more routine feedback options (like CCC) wherein comments, complaints and compliments have equal weight would be helpful.

A practical suggestion was that posters explaining the complaints process should be displayed prominently within all services and these should explain that it is okay to complain and that this will not in any way affect a young person’s treatment or care.

3.4 London Discovery Group

6 younger children in the age range 8-11, all of whom were resident in an inpatient CAMHS unit, provided some ideas and suggestions for what they would do if they were unhappy with their mental health care or treatment. The unit had in place a number of avenues for gathering feedback and the children commented on these. One also provided some limited feedback about making a complaint about food on the unit. None had seen a leaflet or received information about to complain and it was acknowledged that there was no information on display in the unit.

The following points were noted:

- In the first instance, if they were unhappy, the group members said that they would probably talk to a member of staff or the teacher on the unit and they would expect an apology and for something to happen.
- If this didn’t help, they would then tell their parents.

What worried the group, and possibly reflects their inpatient situation, was that quite often the things that upset them, concerned the behaviour of other children on the unit and they were worried that if they complained, they might make the other child’s parents angry or upset.

The unit offers a comments box; several of the children mentioned using this, also reporting that children on the unit would often try to disguise their handwriting in making comments because they didn't want staff to recognise the writing. They thought that being able to make comments anonymously was important, also that having advocates to support children and young people was a good idea.

Asked to rate how serious something might have to be before they would complain, or at least say something to a staff member, where 1 was 'alright' and 5 was 'really bad/serious', one of the group gave a rating of 3 and explained that before you did or said anything, you had to firstly, work out who you might talk to and if they might be in a position to do something. Secondly, you then had to weigh up the dilemma of whether it was going to be worth upsetting someone and also worth drawing attention to yourself. Other members of the group indicated their agreement with this approach.

In addition to the six children, one parent also completed a questionnaire. This indicated that they had received a leaflet about the unit's complaints procedure, however, they had not made a complaint because they were worried that it would affect their child's care; they also commented that they were:

"Not convinced it would make any difference – have been made to feel powerless in the system."

They suggested that a phone line would be helpful since it can be easier to talk rather than putting everything in writing.

3.5 Interviews with young people from Brighton

Two young people from a project supporting young LGBT people were interviewed on an individual basis; neither had received any information about how to complain and both indicated that they had no idea how to go about this, even though both had been dissatisfied with the mental health care they had received. One of the young people, asked why he thought young people found it hard to complain commented:

"Young people may be shy and maybe they don't want to hurt anyone's feelings"

He went on to say that it was difficult to complain when you saw someone different every time you went to the hospital, also that he had been referred to a service that then closed down. He suggested that there should be more information available about how to complain and that:

"I think it would be effective if young people complained, things might get better"

The other interviewee from Brighton suggested that the only way most young people hear about how to complain is by asking or talking to other young people who may have complained. However, this can be a problem if you don't want someone to know that you are using a certain service.

This young person also reported that they knew “*many people who feel that their complaints have not been listened to also that there is no point, since nothing is done.*”

Suggestions for improving young people’s access to and use of complaints processes were as follows:

“It needs to be signposted more in NHS places – like having leaflets and posters around that need to be accessible to young people. To actually know you have the right to complain. To know that something will be done instead of it being bypassed.”

3.6 Consultation with Brook young advisors (undertaken on behalf of the project team by Brook staff)

A group of Brook’s young advisors were consulted about complaints processes in sexual health services and GP-based provision and they identified young people not knowing how to make a complaint, or who to contact, as a massive barrier that deters many from even thinking about expressing dissatisfaction with a service.

They suggested that young people often feel that they are not taken seriously when they try to make a complaint; rather, they are made to feel that they are blowing things up out of proportion, they are ‘making a fuss for nothing’ and they can feel mocked by professionals. Young people can also be given false hopes that something will be resolved and then nothing happens; this makes young people feel that there is nothing that can be done.

They highlighted that a major problem is that in order to make a complaint, a young person has to tell someone else about their situation; this can be very difficult if it’s something personal and/or the young person is worried about confidentially.

With regard to comments boxes, young people worry that comments don’t get read or are simply dismissed. However, in the opinion of the Brook young advisors, a ‘comments box’ is much better than a ‘complaints box’ since if people see you putting something in, they won’t know that you are making a complaint. They also suggested that comments boxes (and paper and pens) should be in every room of a service, including the toilets, so that there are lots of opportunities to use them.

They concluded that young people worry that by making a complaint they will receive a worse service in the future – staff might hold a grudge against them or could make them feel guilty for complaining, which might lead to the young person not going back to the service.

Suggestions for improving complaints processes

Like a number of the Discovery groups, the suggestions made by the Brook young advisors included the development of web-based mechanisms, in particular, offering the facility to make a complaint anonymously and being able to text feedback to a service. Possibly going further than the Discovery groups, however, they also proposed that there should be a centralised complaints website, run by an independent third party, to ensure that all

complaints were dealt with in an unbiased manner and that a free helpline for feedback and complaints, could also be considered.

Improving the clarity of the complaints process was again suggested and the young advisors noted that services should have a clear policy on their feedback systems – for example, how comments received in comments boxes would be dealt with. It was noted that a board or poster detailing previous comments received and what was done as a result, would provide clarity and credibility to the system.

Training staff to support young people in distress more effectively and in particular, to equip them with the skills to support young people after a negative experience was noted and again echoes the themes of the Discovery groups. The young advisors highlighted the importance of continuity of support to young people, including at the point of leaving the service/after an appointment (i.e. to check they are OK and whether anything needs to be followed up), noting:

“It takes less than a minute to check-in with a young person and get feedback about their experience.”

A practical suggestion was for services to give all young people using a service a business card at the end of their appointment or session, with details of how to make a complaint if they were not happy with the service they had received.

3.7 Consultation with young people by Mancroft Advice Project (MAP), in Norwich

Young people from this Youth Information, Advice, Counselling and Support Service (YIACS) in Norwich reported that the main reason young people do not complain about mental health services is because they do not feel they will be listened to. Some had tried in the past to complain and felt this had not been taken seriously; one young person mentioned that she had been told to apologise to her mental health worker for making a complaint and stated that she felt misunderstood. Knowing who to complain to was identified as a barrier and several of the young people noted that they had spoken to their GP but that nothing had resulted from this.

Case study 2: Sarah's story

Sarah needed several stays in an independent inpatient unit when she was 16 years old. She became very unhappy at the level of care she was being offered and so she raised her concerns at her Care Programme Approach (CPA) review and also with an advocate who provided some sessions at the unit. Both she and her mother described a process of both questions and emails never being answered.

As a result of these problems, and because the complaint Sarah had raised via the advocate had not brought any improvements, Sarah's mother decided to make a formal complaint about the psychiatrist in charge of her daughter's care. In particular, she was very worried about the lack of any care being organised for Sarah in the community. An initial contact with the local PALS service then resulted in the unit's psychiatrist, during a CPA meeting, asking whether she was making a complaint – Sarah's mother described this feeling quite threatening and also inappropriate and a breach of trust.

What followed was an extremely protracted process of trying to identify who she should speak to, with little or no advice being offered as to how to make a formal complaint and it seemed, a general lack of clarity as to who was responsible for dealing with complaints about independently provided inpatient CAMHS.

The process included, amongst others, contact with ICAS, the local PALS, the Chief Executive of the local NHS Trust, the service director, a local complaints manager, the CAMHS Clinical Director, two local CAMHS Commissioners and a local councillor. Sarah's mother noted that it was only when she took this 'top down' approach that things started to happen and that from that point onwards, it did feel as if her concerns were taken seriously. However, in total, she estimated that over twenty people were involved along the way.

Sarah's mother suggested that, in her opinion, a major problem with complaints about mental health services is that although non-medical and non-therapeutic aspects of care (for example, about hospital food or physical amenities) do get addressed, it seems very hard to challenge the decisions and actions of senior clinical staff. She commented that she had found the junior staff in the inpatient unit much more supportive but not strong enough to support Sarah with her complaint and that some senior staff appeared "untouchable" and to view the complaints procedure as "laughable".

She concluded that "if you can't get to the right person at the start, you feel like you should give up." Her daughter has also never received an apology, nor any acknowledgment that her treatment could have been managed better.

4. THE PUZZLED OUT 'LISTEN UP' SURVEY

Puzzledout.com is an online consultation tool developed for the Department of Health by Cernis in collaboration with a large and diverse cohort of young people.

The Listen Up survey was widely publicised through the networks described in 1.4 above. The survey was started by 125 participants and completed by 36, equating to a 29% response rate, which is consistent with what would be expected in a survey of this type. It can be speculated that the low completion rate may reflect the findings from the fieldwork, which showed that the vast majority of children and young people do not have experience of making a complaint, even when they are dissatisfied with a service.

In addition to the survey results, four young people chose the "Tell your story" option.

Full results can be viewed on the Puzzledout site.

Survey results

34 young people gave their gender: 30 (88%) female, 4 (12%) male.

35 young people supplied their age: 20 (57%) were over 18, 15 (43%) were aged 14-17.

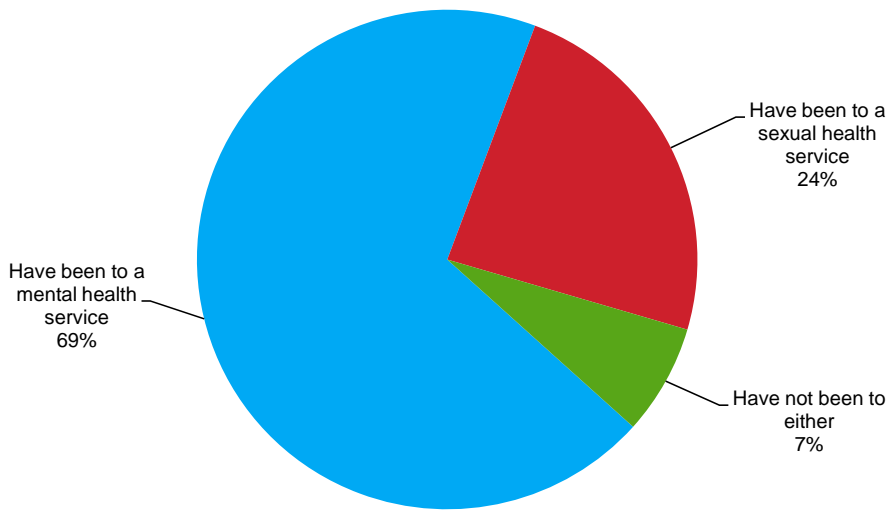
34 young people gave their ethnicity: 33 (97%) White British, 1 (3%) Asian or Asian British.

The survey also asked for young people's sexuality. The responses were:

Table 4: Sexuality of respondents

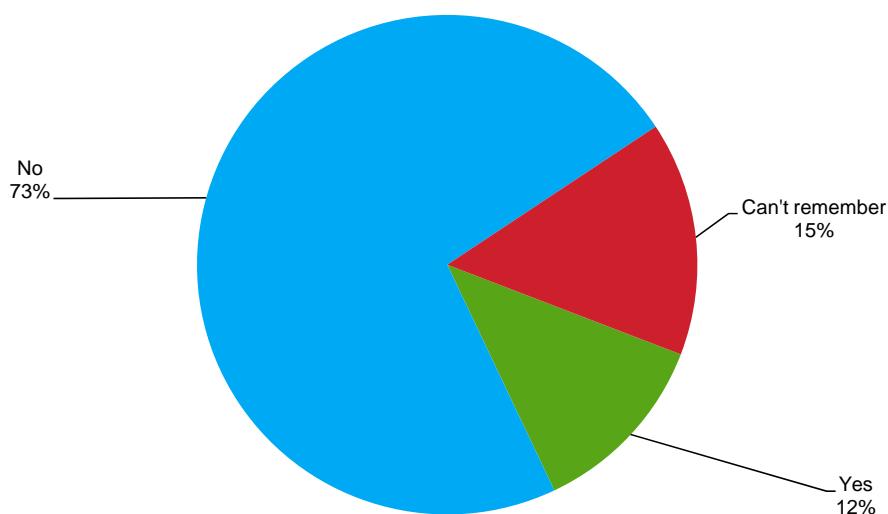
- | |
|---|
| A) Heterosexual (Man attracted to women/ woman attracted to men): 19 (54%) |
| B) Lesbian (Woman attracted to women): 3 (9%) |
| C) Gay man (Man attracted to men): 5 (14%) |
| D) Bisexual (Man or woman attracted to both men and women): 4 (11%) |
| E) Questioning (Man or woman not sure if you are attracted to men or women): 2 (6%) |
| F) Prefer not to say: 1 (3%) |
| G) Other: 1 (3%) (Pansexual) |

Figure 1: In the past year have you used a mental health service or a sexual health service?



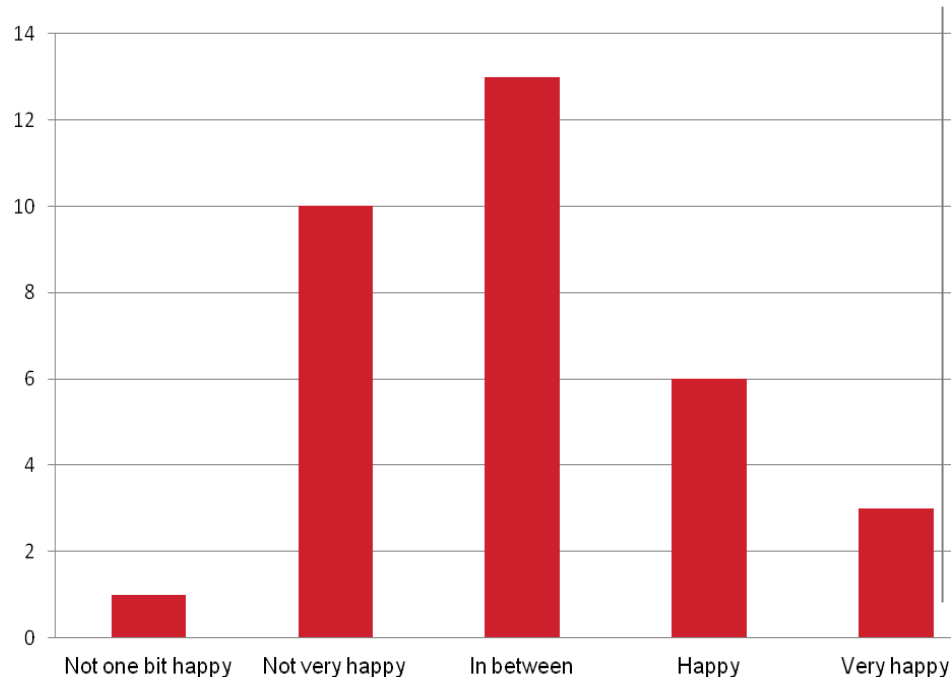
The majority of respondents had used a mental health, rather than sexual health service.

Figure 2: Were you given any information about your right to complain about the service?



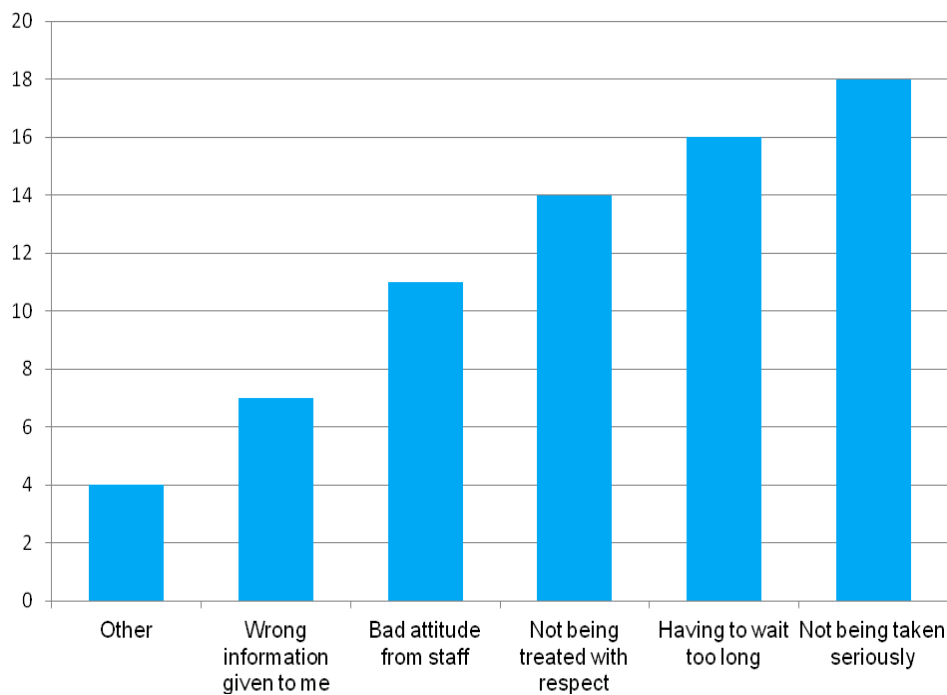
Approximately three quarters of respondents were not furnished with information about how to complain.

Figure 3: How happy were you with the service you got?



Overall the respondents were less than happy about the service received.

Figure 4: What were the things you were not happy with?

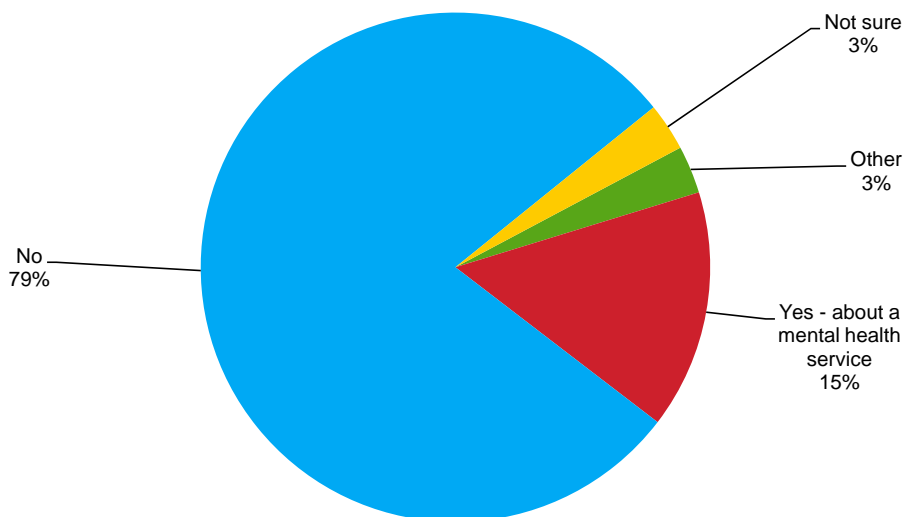


Not being taken seriously and having to wait too long were the most common reasons for being unhappy with a service.

Additional comments:

- *Appointments were made, then a text was received with a completely different time and date for said appointments.*
- *Finding it hard to get information about the options available to me.*
- *Waiting time after the appointment.*
- *Staff leaving with short notice.*

Figure 5: Did you try to make a formal complaint?



The majority of respondents did not make a complaint – only 15% complained about a mental health service.

One person said: *“I told a CAMHS person about my treatment at the sexual health clinic and she phoned up and tried to find me a different place to go.”*

The survey asked: **If you did complain what happened?**

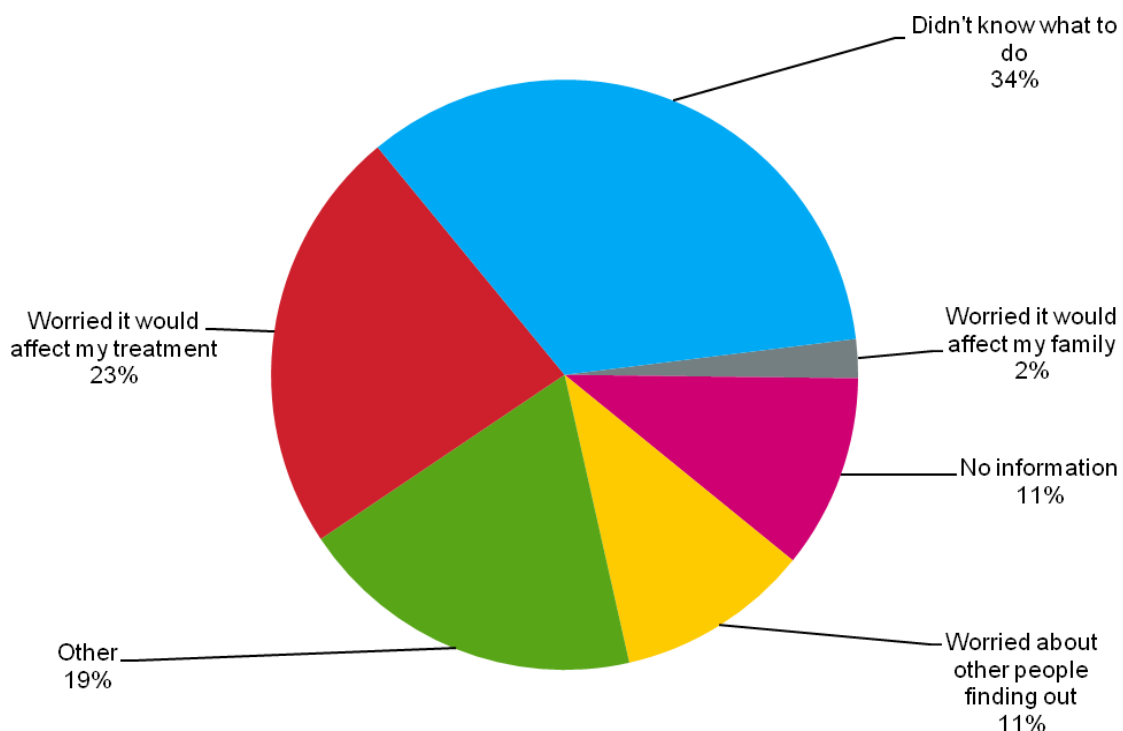
Answers included:

“Found there was no other service so just dealt with it.”

“Nothing happened, when I asked someone if they had the letter they said yes and it was brave of me to write in to them. When I spoke to them about another problem because I wasn’t happy with seeing the CAMHS worker I had been allocated they said I could see someone else and after one session told me I needed to go back to the old person because I was nearly 18 (four months away at the time).”

“I never got to make a complaint.”

Figure 6: If you were unhappy and did NOT complain, why?



The reasons for not complaining mostly involved fear of reprisals, while for some it was because of a lack of information and knowledge.

Other comments included:

“Not that bad.”

“I didn't think it would change anything.”

“I didn't know how to.”

“Afraid of offending them.”

“Knew it was the only service nearby so didn't really want to.”

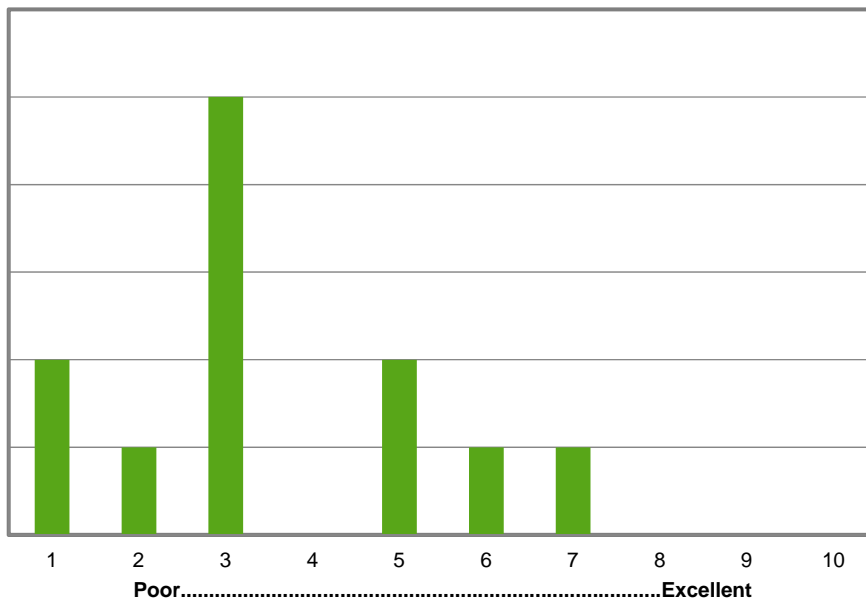
“I didn't want to complain to the sexual health clinic because they were nice people and I didn't want to upset anyone. I didn't know how to either.”

“Wondered if my expectations of the service were just out of line.”

“How I was treated when I complained informally.”

“Couldn't be bothered - my complaint won't change a thing.”

Figure 7: Overall how would you rate your experience of making a complaint?



Overall the respondents' experience of making a complaint was quite poor.

Finally the survey asked: **What suggestions or ideas do you have to make it easier for young people to complain about mental health services and sexual health services?**

This elicited 23 free text responses, more than for any other question.

The young people's suggestions emphasised the importance of information, anonymity and confidentiality, as well as the ability to give routine feedback.

Table 5: Young people's suggestions to improve complaints systems

- More information. More open minded staff that aren't so defensive and looking down on young people
- Have a complaint box
- Regular anonymous surveys asking for opinions with the option to leave contact details to follow it up. Follow up done by a different member of staff to the one you're being treated by
- Be told in the first place you have a right to complain. Be given the proper information and help so that you can do so. Be able to know you will not be judged
- Anonymous feedback boxes in the waiting room, or being able to email rather than voice it
- Clearer pathways and more support
- A discussion with those involved with your treatment once a month for so about how you feel your treatment is going as well as being given a contact number if you feel unable to tell the staff that their service isn't acceptable
- Let them know how exactly to make the complaint and who to
- A suggestion box
- Have an advocate there most of the time/on a regular basis
- Being told how to complain and forms being easy to get instead of having to ask for it
- Advertise an email for complaints
- Information given when you start using the service
- Web based informal feedback; clearer and easier to understand information about complaints procedures; advocacy support to make a complaint and help you understand your rights; clearer information about what you can expect from the service so you feel more able to complain if your needs are not being met
- Tell us how we can [complain]
- A clear guide on how you can complaint confidentiality.
- Reassurance that complaining is okay
- Know how to [complain]
- Making it more accessible. Not having incompetent mental health practitioners!
- An agency / hotline that can be called up for free or low cost where they aren't judged and the complaint is fully investigated

Tell your story responses

The three stories below are about extreme dissatisfaction with services that do not appear to have resulted in a complaint. The first two are brief extracts from very full stories which can be read on the Puzzledout site. The third is extremely disturbing and sad.

Young person A suffered such extensive damage from an undetected cyst that the majority of one ovary and fallopian tube had to be removed. Recovery took over 12 months and in response to the “appalling lack of care” she experienced, this young woman set up her own organisation to provide support, information and guidance to young women who are experiencing similar problems.

Young person B did not receive basic information about sexual health. She and her female friends all had to learn from experience: *“I don't understand why we weren't told such a simple fact at school when it's something that will inevitably happen to women. My school gave us endless contraception lessons and biology lessons on periods that I thought I was super-clued-up.”*

The young person stated she should have been told the information I needed at the very first visit.

Young person C said: *“I first went to CAMHS when I was nine with mild depression and PTSD. Now I'm 14 and I self harm, have bulimia and have bad suicidal ideation and take prozep. I asked for help again at 12 and they said I would have to wait for a very long time so I felt there was no hope so I tried to kill myself. Even now they don't listen to me. I tried to hang myself last October and before, I said I was going to kill myself and no help was given.”*

5. STAKEHOLDER PERSPECTIVES: FACILITATORS AND BARRIERS FOR CHILDREN AND YOUNG PEOPLE WISHING TO MAKE A COMPLAINT

5.1 Overview

A wide range of different professional groups have been consulted about children and young people's access to and use of complaints procedures in mental health, sexual health and GP provided services and these groups included:

- GPs
- PCT and NHS Trust Complaints Managers
- Voluntary sector complaints managers
- Independent Mental Health Advisors (IMHAs)
- Advocates
- PALS officers
- Commissioners in Children's Services, CAMHS and Specialist Commissioning Groups
- Youth service staff including service managers, education staff and operations and business development staff
- CAMHS Participation Workers
- Legal advisors and counselling managers working in Youth Information, Advice, Counselling and Support Services (YIACS)
- You're Welcome leads
- The Assistant Ombudsman for Local Government
- The Health Ombudsman.

In addition, senior staff were consulted from the various organisations shown in Table 2 on page 9 of this report.

A semi-structured interview format was used and there was also the option to complete an online questionnaire. In addition to exploring the use of complaints processes by children and young people, the stakeholder interviews sought suggestions for how to improve complaints procedures and examples of good or innovative practice.

5.1 The GP perspective (five interviews)

The general consensus of the GPs who were interviewed is that young people do not usually complain, either informally or formally about GP provision, they 'vote with their feet' if they are unhappy with a service. If complaints are made, then usually they are by parents complaining on behalf of their child.

One GP commented:

"In my ten years in this practice and the seven years that I have run my young people's clinic at the practice, I have no recollection of young people complaining about the health service they receive, and I encourage complaints."

In terms of how complaints processes are publicised, those interviewed reported a variety of leaflets and forms on their websites – but none had been adapted to be young-person specific. Some also had suggestions or comments boxes, although formal feedback systems seemed to be somewhat limited.

One reported that they had done a survey about how young people would like to give feedback which had indicated that there is no single answer, some like face-to-face, others to use social media; least popular were email or filling in a form.

Expecting young people to have a meeting with a practice manager to make a complaint was described as "unimaginable" by one interviewee. Another expressed the view that in order to go to a GP, a person has to be good at accessing services and that many surgeries do not make this easy – not least because of the "scary receptionist" and that surgeries need to take action to try and be as young person friendly as possible.

Suggested barriers facing young people

- In the experience of these GPs, young people with mental health problems and sexual health problems tend to present to GP services 'chaotically' and it can be hard for the GP to establish a rapport with them. Without trust, many young people will not express their views, positive or otherwise
- Young people can be embarrassed to come to their GP, especially if the doctor has known them or their families for many years
- Limited provision in rural areas means that young people cannot choose who to see (e.g. a different doctor to the one their parents see); limited transport also makes independent visits impossible
- Local culture – in some parts of the country, it was reported that people respect the doctor, they are socially distant from them and it would be seen as against local culture to complain about them
- Worries and confusion about confidentiality.

What's needed?

A theme in these interviews was that a message needs to go out to young people that it's safe to talk to GPs and that GPs need to look for and develop opportunities to build relationships with their young patients in order to build up trust and understanding of their needs.

Practices also need to invest in services specifically for young people and to develop young people friendly information resources, including about complaints processes. Although without a financial structure/resources, this may be problematic. Involving young people in the design of GP services would be a useful step forward.

One of the interviewees suggested that strengthening the links between community health services and GPs surgeries, including building links with voluntary sector provision (e.g. counselling and sexual health services) could help GPs to be kept more involved, thereby building young people's awareness and confidence in GPs and encouraging young people to come into the surgery if they needed to see a doctor. Work undertaken by Youth Access (the Making Tracks project) may have useful lessons to draw on in this regard.

Two of the GPs interviewed provided examples of good practice that are described in the next chapter.

5.2 Advocates and managers of advocacy services (Four interviews and consultation by NYAS on behalf of the project team with its IMHAs in the southern region)

"Everyone is very, very nervous about complaints because it is seen as a black mark and not a learning experience."

A number of advocates and advocacy managers in local services provided by the charity MIND expressed the following opinions:

- In their experience, very few young people's comments progress to a formal complaint and one reason behind this is that NHS Trusts are for complaints to be put in writing and young people are uncomfortable with the format required, especially if they cannot write well or struggle with spelling and grammar.

"It can be very blocking to have to put it down on paper."

- Young people may not consider their criticisms as a complaint, it may be an issue with a particular staff member that they are unhappy with and they just want the person to "stop doing it" rather than make a complaint about practice more generally
- Young people with mental health problems often don't feel confident or competent to complain, they fear that people won't believe them because they are mentally ill

- Young people lose the drive to complain because it takes a long time to get a resolution; many also do not see the point since they do not believe anything will change
- Young people are deterred from complaining because they are worried about what is recorded in their CAMHS notes. They may be ashamed or worried about things they have done in the past and fear that people will think that they are bad.

One of the advocates interviewed also talked of the letters that are sent in response to complaints often being full of jargon and quite far removed from what the young person who has complained, is worried about.

This interviewee went on to suggest that it could be therapeutic and empowering for young people to make a complaint, it helps to feel that they have a 'voice' in the service. However responses must not be patronising and must be in language that young people can relate to. It was also suggested that the situation could be improved by ensuring that mental health staff understood the complaints process and could support young people more proactively.

In response to this investigation for the Office of the Children's Commissioner, the Southern Regional Team meeting of the independent mental health advocates (IMHAs) employed by NYAS, discussed the barriers facing children and young people using inpatient mental health services who wish to make a complaint. They identified the following:

- Staff in mental health services lack training and knowledge around complaints. For example they are unaware that a complaint could be a way to improve a service and instead they are defensive whenever a complaint is raised or discussed
- Not all CAMHS inpatient units have advocacy services and this lack of independent support for young people can affect their ability to make a complaint
- If a complaints procedure is not transparent, young people may be wary of using it for fear of repercussions
- The process is often lengthy – for example, in many Trusts, the normal procedure is for the Complaints Manager to make contact with the young person. This may be difficult to organise due to the ward routine or the young person being unwell
- Young people often tell the NYAS IMHAs that there is a lack of feedback after they have made a complaint.

The group also identified some good practice they had seen in managing young people's complaints - this is presented in the next chapter.

One advocate working in a Local Authority service for children in the looked after system reported that often it is the less serious complaints or those that are more ambiguous, that go to the formal stage, possibly because young people feel they have not been taken seriously. More serious complaints may be dealt with more promptly and perhaps more

effectively, at an early informal stage and so are not formally proceeded with. Obviously whilst this may be commendable, a lack of systematic recording of informal complaints does mean that it is not always clear if a young person's concerns have really been addressed. This interviewee highlighted that when young people have met staff face-to-face to discuss their concerns, this has often been a positive experience, with successful informal negotiations resulting. However, they also commented that complaints going to stage two can take up to four or five months which is difficult for young people to deal with.

5.3 Youth work staff and participation workers in CAMHS and Children's Services (one group meeting with four participants and four individual interviews)

The main theme of the group meeting was that young people do not make complaints because of the requirement to write things down. There is a sense given that a complaint has no weight or currency if it is not written down – which can mean that quite serious matters are left unaddressed. It was also suggested that multi-agency meetings are disempowering for young people but also for inexperienced or more junior staff who may be offering them support. One of the participants commented that a person has to be in a 'good place' to be able to make a complaint and that good vocabulary and literacy skills are needed.

The group were of the view that many professionals want to repel complaints at all costs, they are something to hide away and are not viewed as a development opportunity. They suggested this may be related to Quality Assurance (QA) processes and the blame culture endemic in many organisations including the NHS. One consequence is that professionals are often perceived by young people as being dismissive of their views; young people can also feel pathologised for complaining and may isolate themselves from particular services they may need.

Suggestions for improving this situation included:

- That young people should go on empowerment programmes
- Services should develop more creative ways for assisting young people to complain, that are not so reliant on written formats
- Staff being supported so that complaints can be seen as a learning opportunity.

According to one of the CAMHS participation workers who was interviewed "Young people often feel more disillusioned after making a complaint than before it."

This interviewee talked of staff acting as gatekeepers who work to 'protect' the organisation, and said that the lack of information about how to complain is evident across the healthcare system and includes a paucity of information about: "What to expect with regard to mental health treatment and care; what young people's rights are, let alone how to complain."

She identified two typical responses to making a complaint often seen in young people – either “adversarial and challenging or fighting everything” or alternatively, “apathetic and disengaged” with neither being good for the young person’s care, and with the opportunity to improve the dialogue with, and understanding of, a young person’s experiences of a service being lost.

The need for better use of the IT technology that young people typically use, strengthening of the advocacy role to have a specific remit to support young people who wish to complain and developing the role of Healthwatch in the management and monitoring of complaints, were suggested improvements. Similar points were made by a worker implementing the You’re Welcome standards who also called for better information for young people about confidentiality and information sharing to address young people’s misunderstandings and worries about these issues.

A youth worker who had used both mental health and sexual health services as a university student described her experiences of wanting to complain but not doing so because firstly, she “didn’t want to be seen as someone who was always moaning”; secondly, because her illness often made her doubt her feelings, and thirdly, because she had no idea how to start the process. The importance of all staff in health services being briefed in how to respond to an approach by a young person was highlighted by her comment that:

“It takes a lot of courage to ring up in the first place – so if you then just get passed around, you drop out.”

This interviewee went on to talk about how difficult it was for young people to challenge older and experienced medical professionals whose “power puts them on a different level” and she identified stigma is a particular problem. Stigma results in many young people not wanting their family or friends to know that they are using either mental health or sexual health services and they “don’t want to be associated with it [the service] any more than they have to be.”

In her current role supporting young people with mental health problems or using sexual health services, this worker commented that she could clearly see the self-doubt that many young people feel. She felt that this is very disempowering and that young people can be worried that if they complain, they will hurt the person trying to help them. In her view, girls tend to be scared of complaining when things are not going well, whereas boys/young men are too proud to admit that they have a problem.

This interviewee concluded that what would have made a real difference to her when she was younger was having a doctor who was interested in her, who seemed to care and who could offer reassurance about her feelings. She suggested that putting the whole system in to a more positive framework – so calling it ‘comments’ rather than complaints which has a very negative connotation – would be a helpful step. Other suggestions included:

- Young people having support and staff able to reassure them and offer confirmation if concerns were valid

- Better information about how to complain, ideally online and offering opportunities to complain anonymously. Also useful would be an online database showing all complaints received and how these had been addressed and posters and other information materials in GP surgeries, other places used by young people and on TV/ via digital media
- Continuity of staff, especially in sexual health clinics, so that young people can get to know and trust them.

5.4 Commissioners and NHS Trust Complaints Managers (three interviews)

Some of the key points in these interviews concerned the length of time involved in complaints procedures, which coupled with young people's doubts that anything will happen, often leads to them not making a complaint. It was also acknowledged that by the time a complaint reaches a formal stage, the response of the service/professionals can be very defensive.

With regard to the involvement of service commissioners in complaints about services, it does appear that this is often on an ad hoc basis and that there is a need to link up the process between managers of services and those commissioning them.

Both commissioner interviewees also alluded to complex complaints raising interface issues, especially between community mental health services and inpatient provision that is commissioned through specialist commissioning groups.

The specialist commissioner who was interviewed described part of her role as undertaking unannounced visits to services commissioned by her group. She also received quarterly reports from the local advocacy services but had no link with the local PALS. She expressed concern that in the current NHS, the environment is becoming more territorial and competitive which could impact on the willingness of staff to work together to resolve difficult issues, including complaints made by children and young people.

Her suggestions for improving complaints procedures for young people echoed those of many of the other interviewees, namely, that there needs to be more creative use of IT and more proactive and positive ways of gathering feedback data; that staff need training in how to respond to complaints and be supported to appreciate that feedback can provide learning opportunities. Specifically from a specialist commissioner perspective, she identified a need for stronger links between commissioners and their provider colleagues and suggested that where a complaint spans both community and inpatient CAMHS, there should be joint investigations involving staff from both sectors.

Information gathered from the NHS Trust Complaints Officer who was interviewed indicated that in her area, it was extremely rare to receive complaints from young people about sexual health services. Where complaints about mental health services were received, these were usually made by parents and carers on behalf of young people.

This interviewee suggested that young people's embarrassment at using sexual health services probably accounted for the lack of formal complaints, and that in the case of CAMHS, it could reflect CAMHS staff's ability to work with young people in conflict and their tendency to try to resolve difficulties informally.

This interviewee described the pressures of a greatly increased workload curtailing her ability to do service visits, also that resource cutbacks had reduced the gathering of service user feedback – both of which have obvious implications for monitoring any complaints made by young people that are dealt with informally.

5.5 Voluntary Sector Complaints Managers Forum (meeting with five complaints managers all working in services for children and young people)

This meeting explored a wide range of issues, with the general consensus being that it was good practice to try and pick up complaints as early as possible and to resolve them informally. It was emphasised that even serious issues can be addressed in this way, that it is not helpful to only view a complaint as 'real' or 'serious' if it has passed to the formal stage since this misses the bulk of the problems young people may report about services.

In essence, if young people's views about services (dissatisfaction or otherwise) are to be more effectively collected, their significance appreciated and acted upon, there is a major definitional issue to be addressed so that we move away from only being worried about complaints that are recorded (i.e. focus too much on the formal end of things) and look at the 'wider picture' of all feedback, including informal complaints that are made verbally. As a result improving the monitoring and information gathering on how informal complaints are handled, and giving complaints made informally more status, are urgently needed.

The group put forward a number of suggestions for what is needed to support children and young people in being able to complain if they are dissatisfied with a service they have received and these included:

- All staff receiving training, ideally as a core component of their induction, in how to listen to and respond appropriately and sensitively to young people's complaints
- That the patchiness of advocacy provision across the country needs to be addressed, with advocates receiving training in how to work with children and young people.

Two major concerns were noted by the group. Firstly, that NHS cutbacks may mean that the issues raised in complaints made by children and young people cannot be resolved. Secondly, more widespread concerns about organisational/ corporate liabilities may make health professionals more wary of acknowledging the issues raised in a complaint in writing (including writing to apologise to children, young people and their parents or carers).

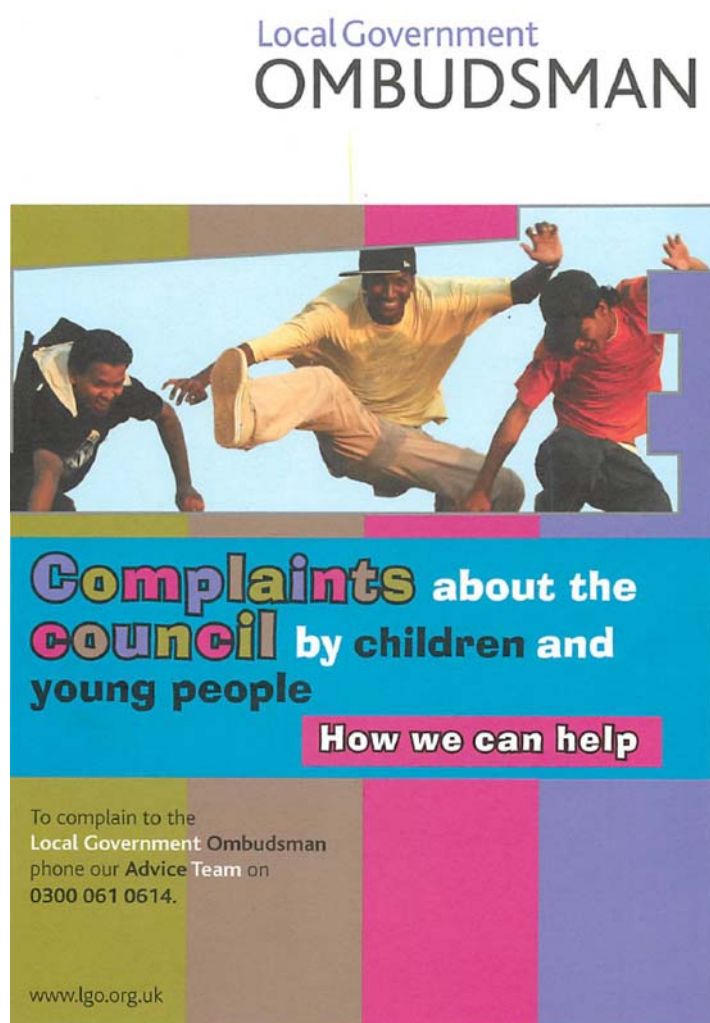
5.6 PALS

Calls at random to a selection of PALS revealed that they were not generally set up to deal with complaints concerning young people under 18. One branch suggested that they might be able to act if the complaint concerned inpatient care in a NHS Trust where there was an adolescent inpatient unit and if the young person's complaint was made via an advocate or parent. Not one of the services called said that they had acted on a young person's complaint or had any information materials or systems to provide for this.

5.7 Local Government Ombudsman and Health Ombudsman

The Health Ombudsman does not receive complaints from children and young people and when children and young people are the subject of complaints these tend to have been made by parents. Encouraging complaints by children and young people is something the Health Ombudsman would like to encourage.

The Local Government Ombudsman has taken steps to increase the number of complaints by children and young people, by producing child-friendly information (below) and training staff in working with this age group. All ombudsman staff are subject to enhanced Criminal Records Bureau (CRB) checks. Numbers of complaints from children and young people have increased slightly in recent years, but are still very low. On the fairly rare occasions that children complain they are supported by parents or foster carers. If however a young person gets through to the advice team, they will immediately be put through to an investigator. The ombudsman also has discretion in dealing with complaints by children and young people.



5.8 Findings from the online stakeholder questionnaire (four responses)

Despite a very low response rate, some useful information emerged from the four responses received:

- The four respondents reported that in their service, information about how to make a complaint was publicised via a number of avenues including posters (three respondents), leaflets (all four respondents), verbal information (three respondents) and via the service website (two respondents). However, only one of the four reported that the information had been adapted to make it young person specific
- Of the four respondents, three indicated that in their service no young people, or parents acting on their behalf, had made a complaint and that they felt this was too low.
- Two answered the question asking if young people were offered independent support, with one answering yes
- Two answered the question about the time taken for a complaint to be addressed, with one indicating it took 1-2 months and one that it took 3-6 months.
- Three respondents reported giving a time by which their service would respond to a complaint and that they reviewed the complaints they received to improve services
- Two responded to the question asking if complaints by children and young people are satisfactorily addressed, one answering yes and one answering no
- The mechanisms for gathering service user feedback included: patient surveys, informal comments, suggestions boxes, leaflets, feedback via the website (including the option to submit comments anonymously) and comments cards.

In terms of the reasons why children and young people don't complain, it was suggested that this may be because young people are unable to access the necessary information. It was also noted that the word 'complaint' is very emotive and may deter young people since it suggests a "negative emotion rather than a request for problem resolution and the provision of constructive feedback."

A key suggestion, which chimes with the messages from the voluntary sector complaints managers forum described earlier, was that the situation would be improved by engaging: "more young people in informal feedback, which in turn, will empower them to feel able to give formal feedback, especially if this happens to be a complaint."

Case study 3: Claire's story

Claire needed inpatient mental healthcare when she was 18 years old. She experienced a variety of problems with her care and treatment including being discharged from the unit with no advance warning and then receiving very little support post-discharge from the local community mental health team.

Claire's parents made two formal complaints about her care; they did this on Claire's behalf because Claire was fearful that if she made the complaint herself, her treatment might be stopped or it would negatively impact on what was offered to her. Claire describes receiving no information whatsoever about how to complain or her rights to do so from the inpatient unit, a point echoed by her parents.

The only active support Claire's parents received came via the Independent Complaints Advocacy Services (ICAS). A receptionist at Claire's community mental health team gave them a leaflet listing various avenues of complaint they could pursue and this included ICAS.

ICAS provided a named support worker who helped the family to draft letters explaining their complaint, ensured these went to the appropriate person and attended a local resolution meeting with the family.

Claire's mother describes a process of writing "letter after letter", of being "passed from pillar to post and constantly brushed off" and of waiting months for a reply.

Reflecting back on her experience, she noted that the whole process was distressing and very hard work and that she would only consider making a complaint again if something drastic happened.

She pointed out that families have to pay to see their child's health notes which can make it even more difficult to make a formal complaint and she concluded that without the support of the ICAS worker, she would have given up.

6. IDEAS FOR GOOD PRACTICE

6.1 Lessons from other countries

Interest in designing effective and accessible services and complaint systems is not unique to the UK. In terms of the key elements of complaints processes for young people, the Children Youth and Ombudsperson in British Columbia, Canada produced a document in 2010 with a number of guiding principles and key elements.

The Ombudsperson in British Columbia declared that a child-centred approach to complaints resolution should have the following guiding principles:

- It should be in the best interests of the child
- There should be meaningful participation
- There should be support and/or advocacy and there should be a request for the child or young person's cultural values
- The key elements of a process and the process need to be responsive and effective.

In terms of responsiveness, the process needs to demonstrate awareness, accessibility, timeliness, problem solving and respect for different cultural approaches. In terms of effectiveness, there needs to be fair and transparent administration and quality assurance and accountability.⁹

6.2 Findings and suggested good practice from international experience

A study in 2008 drew lessons from a number of international systems.¹⁰ This report was published by the National Audit Office to support their work with the Department of Health in consultation with the Health Services and Local Government Ombudsmen and was intended to inform plans to introduce a single comprehensive system for handling complaints in the UK in 2009.

The report looked at complaint systems in health and social care in Northern Ireland, Scotland and Wales, Australia, Canada, Denmark, Germany, New Zealand and the Netherlands; countries likely to provide relevant lessons for England. It notes:

“In all the countries surveyed complaints systems were seen as important to improve the quality and responsiveness of services and as a stimulus to service improvement. The ideal is for staff to welcome feedback and for patients/clients to feel free to complain or comment based on a clear understanding of the quality of service they should expect. Staff should feel

⁹ Joint Special report – hearing the Voices of Children and Youth. Representative for Children and Youth Ombudsman British Columbia 2010

¹⁰ Lister, G; Rosleff, F; Boudioni, M; Dekkers, F et al (2008) *Handling complaints in health and social care. International lessons for England* National Audit Office

free to apologise, resolve issues quickly at a local level, restore relationships and pass on lessons so that systems are improved. Where complaints cannot be resolved informally, complainants should be supported by local and national patient/client centred organisations through further complaints procedures that should be independent, simple, transparent and swift, leading to appropriate redress and action on professional conduct or system failures.”

A number of key themes and lessons were identified as follows:

- Organisational responsibilities should stress local front line responsibility for complaint handling as the most crucial part of the system. Complaints should as far as possible be resolved informally within the care team
- At local or organisational level respondents saw value in drawing together the functions of complaint support, quality improvement and patient/client advice and engagement
- It was essential that complaint appeals organisations were seen to be independent
- Most countries linked complaints and appeals to professional disciplinary action at regional level
- Legislation and regulation should provide a clear basis for patient/client and staff expectations, so that patients and clients are clear as to their rights and the standards that should be expected, and that providers of healthcare and users know when something must be improved, and when a complaint is justified.

Good practice service providers adopt an objective of encouraging feedback from staff and users to improve their services. The most meaningful measures of performance for complaints agencies included actions resulting from complaints such as: systems improvements and conduct enquiries, as well as timeliness. Good practice agencies also had explicit objectives of improving equity of access to complaints for vulnerable people, those with language barriers or speech problems.

Other points made:

Definitions of complaints needed to be broad but measurable and include oral comments and staff improvement suggestions.

Analysis of complaints needs to identify serious complaints or clusters of common complaints that can raise issues of principal that require policy review and action.

Processes need to be simple and avoid hand-offs between agencies. In most cases local resolution (informal and formal) supported by independent review processes (assessment, review, investigation, decision and report) undertaken by a second agency seemed appropriate.

Timescales should be as short as practical. Informal resolution and apologies should be immediate where possible and local formal resolution within 4-5 weeks. When moved on to a second stage, one of the greatest hurdles for patients and clients is the timescale.

Both complainants and people who are the subject of complaints should have access to independent **support staff** or volunteers to help them in the process.

Numbers of complaints do not reflect opinions of services. While most cases showed a gradual increase in the number of complaints in recent years it was notable that where a positive attitude was taken numbers increased rapidly – and happily. It is also apparent that some complaints do not reflect a realistic understanding of what patients/clients should reasonably expect and it is important to be able to close such complaints without overloading the system.

Attitudes of the public show that they often find it difficult to initiate complaints. Patient/client surveys identified obstacles including: the perception that the process would be long and complex, that no action would be taken anyway and/or that there might be repercussions for their care. They most often wanted an explanation, an apology and reassurance that the same thing would not happen to others.

Attitudes of staff are the most important barriers to positive approaches to complaints. Underlying staff attitudes to complaints is the fear of blame from management, professional bodies or as a result of legal proceedings. Since these are actually rational and reasonable fears they are more difficult to counter and there needs to be a more supportive management culture and greater clarity as to what can reasonably be expected to be delivered to patients and clients.

Apology remains difficult for staff and complaints mechanisms require that apology and resolution of complaints should be separated from the acceptance of liability and blame as far as possible.

Redress is emerging as a practical element of some complaints systems. No fault compensation schemes are separate from complaints systems, but small gifts and payments to recognise costs and inconvenience offer a way of recognising problems and recovering confidence, particularly when accompanied by explanation and apology.

Monitoring should occur at local and national levels and involve real examples in addition to statistics. Monitoring too often focuses on timescales, to the exclusion of other outcomes.

Learning from complaints should occur at local and national levels. Best practice at local level saw complaints support staff working closely with quality improvement teams. Where national complaint support agencies do not have a broad remit they need strong links to quality improvement and standard setting agencies.

Improvement suggestions were proposed by all respondents to increase the responsiveness and accessibility of complaints systems and their efficiency and timeliness.

Comments included calls for a positive approach to complaints, increased transparency to keep complainants informed of progress and personalised responses.

6.3 Good practice identified during the project

Example 1:

In one inpatient unit, the Trust complaints department staff make themselves known to young people by coming regularly to the unit and just being around as a 'presence'. They go to community meetings, to service user forums, etc so that young people get to know them as people and so are able to trust them.

When they comment on the service, the complaints staff say: "do you think that's a complaint?" "If so shall we take it further?" The staff will then thoroughly explain the process of making a complaint in language that young people understand and in a way that is not seen as intimidating. They then write it down for them, check with the young person that it is accurate, type it up and take it back again for checking by the young person. All this is done very quickly. They continue to support them throughout the process.

Example 2:

The Independent Mental Health Advocates employed by NYAS in the southern region reported the following:

- Young people friendly complaints information materials have been developed in a number of services in the southern region
- Some services promoting a variety of avenues for raising concerns including the use of ward rounds, community meetings, young people's opinion groups, ward debrief sessions, ward governance meetings, CPA reviews and key worker sessions
- PALS, local complaints departments and advocacy services forming good working relationships and links
- Services ensuring that both young people and the staff working with them are aware of the local complaints procedure.

Example 3:

In a South London GP practice, the emphasis is on prompt resolution at the earliest opportunity, with the process starting with the GP phoning the complainant to discuss the issue. An appointment is offered within a day or two and the young person is invited to bring someone with them if they wish. As much as possible, whatever is causing concern is dealt with on the day of the appointment. This is followed up with another personal call from the doctor. If things cannot be immediately resolved, then the purpose of the follow up call is to explain what has been done and what is planned for the next steps.

The practice philosophy is to treat a complaint/complainant as you would want to be treated yourself and to allay anxiety and distress as much as possible. All complaints are collated and passed to the PCT for monitoring.

Example 4:

In Plymouth, the You're Welcome lead has developed a short poster to be used across all sexual health services in Plymouth. This is presented below.

Complaints procedure

All staff working for (organisation name) are committed to offering a young people friendly service.

We will endeavour to:

- **Give you time**
- **Be courteous**
- **Treat you as an individual**

You have the right to let us know if you feel frustrated or upset about how you or your situation has been dealt with.

Sometimes things can and do go wrong and if you feel this has happened to you **please** let us know. We are here to help; we will try to put it right.

You may have:

- **Comments on our service**
- **Unanswered questions**
- **Suggestions for improvement**
- **A complaint about a worker, service or lack of service**

How to make a complaint:

If you feel you have been:

- **Badly treated by someone working for (organisation name)**
- **Unfairly refused a service**
- **Discriminated against because of your age, colour, disability, ethnic or national origin, gender, sexual orientation, marital status, race religion or age**
- **Or have other reasons to complain**

You can –

- **Talk to a member of staff**
- **Ask for a comments form**

You can write to us stating your complaint at the address below

Example 5:

In all Brook centres, there is a standard feedback questionnaire to find out if the service has met a person's needs and the centre publicises the name and photo of the centre director. There is an emphasis on giving immediate feedback and in every centre there is a board that says `YOU SAID....AND WE DID' which details how Brook has responded to suggestions and complaints and what changes have been made. From time to time, a variety of other methods of gathering feedback are also used – for example, one centre rented a “Big Brother” booth so that people could go in and answer some questions or give comments; masks were supplied if they wanted to use these.

Complaints procedures have been amended to be young person specific and there is regular training (including during staff induction) on how to manage complaints. Data from the different Brook branches is collated for quarterly reviews which look for any disproportionate numbers/ variations across branches.

Brook is currently exploring opportunities to further develop website possibilities for managing any complaints it receives; currently it does not have a specified timescale for complaint investigations but this is something that may be introduced in the future.

The winner of the Brook UK Sexual Health Awards 2012 (young people's sexual health service project of the year) was Sheffield Open Doors, a city-wide service providing outreach across the city and close partnership working with many Sheffield schools. The service actively tries different ways to get feedback on the service, including surveys and 'mystery shoppers'. The homepage of their website has information about how to complain:

How can you help us?

We are very keen to have your suggestions as to how we can improve our service. If you think of any way that we can improve our service or if you have any problems during your visit please let us know - you can talk to any member of staff about this or fill in a comments slip and hand it to the receptionist.

[Information on how to make a formal complaint.](#)

Example 6:

Action for Children (ACH) produces an annual report detailing feedback on all its services which is available on its website. The report is also distributed to all ACH projects as evidence that feedback is looked at centrally and that the organisation learns from any complaints. Detailed quarterly reports are also provided to the charity's operational directors so that they can address any issues that have arisen in their area.

All projects have feedback leaflets which give some information about the complaints process and ways of raising concerns.

Example 7:

Barnardo's have developed comprehensive monitoring forms, one for taking down the details of the complaint and one which sets out the actions to be taken. These are given to the young person so that they are fully involved and aware of the decisions agreed.

Example 8:

Complaints received by the General Medical Council (GMC) tend to be about systems. For an investigation they need to raise concerns about a doctor's fitness to practise. Until recently the GMC was reactive – now there has been a change in climate and in expectations. Generally now the GMC is taking a proactive role to involving local people more in doctors' professional practice, trying to raise issues early and address them through training, rather than just wait for complaints to arise. Each region has a liaison worker, whose role is to proactively involve the public, including children and young people.

The link below provides some detail as to how the GMC developed guidance for doctors around working with children and young people. It was some time ago - however they will soon be issuing guidance around child protection where they also consulted with young people and expect suitable current resources will be produced to support this:

http://www.gmc-uk.org/guidance/children_and_young_people.asp

Poster campaign aimed at young people – now dated but appropriate at the time:

[http://www.gmc-uk.org/static/documents/content/GMC_Poster_\(English\).pdf](http://www.gmc-uk.org/static/documents/content/GMC_Poster_(English).pdf)

Patients' Help, interactive site on how to complain:

http://www.gmc-uk.org/concerns/making_a_complaint/3841.asp

Leaflet for witnesses:

http://www.gmc-uk.org/Help_for_witnesses___English.pdf_33412922.pdf

Information around who the GMC may treat as vulnerable witnesses (additional support is available in these circumstances):

http://www.gmc-uk.org/concerns/hearings_and_decisions/hearing_information_glossary.asp

Example 9:

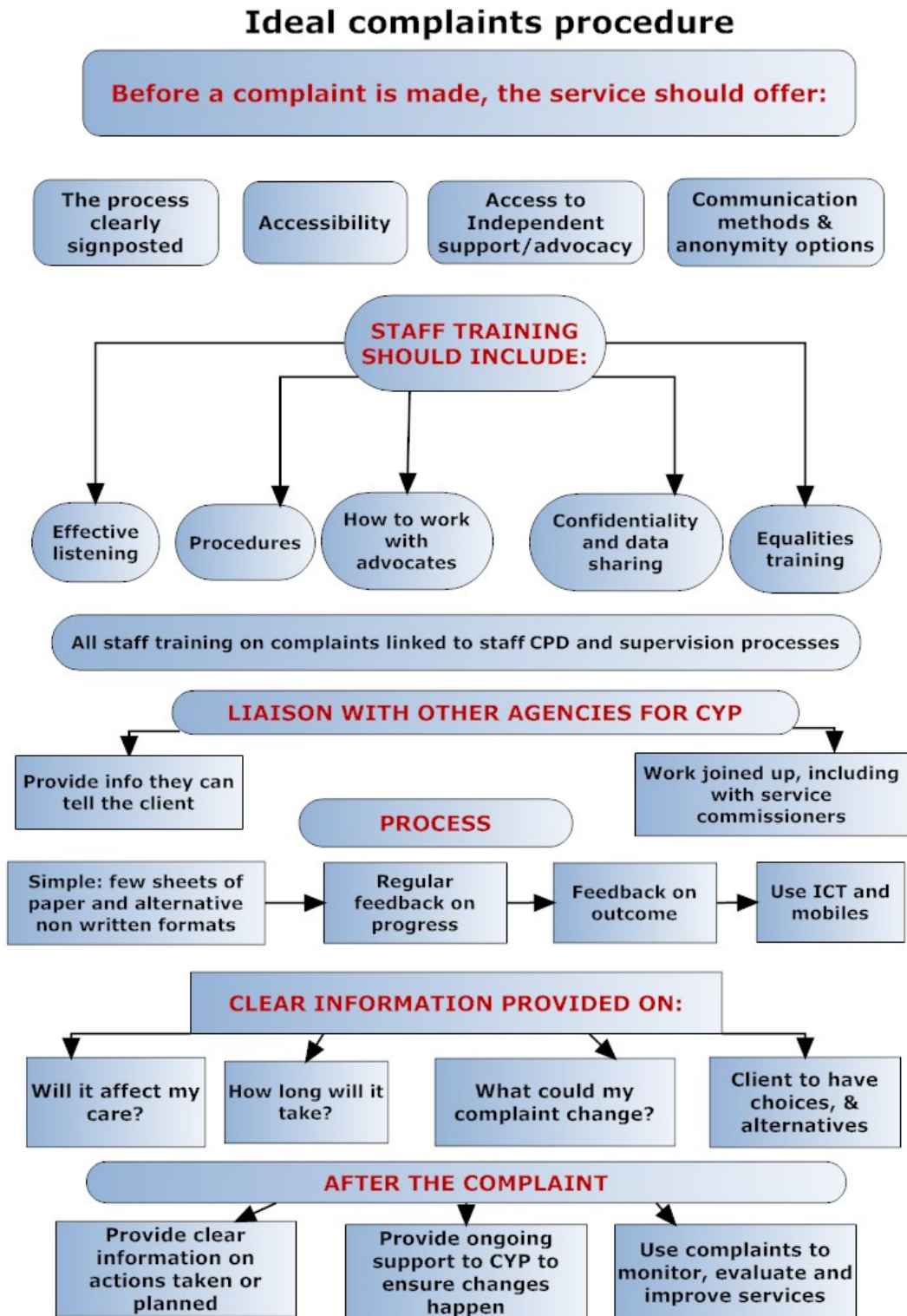
Pohwer, a user-governed organisation is among the first to develop information, advice and advocacy services. Its focus is on protected and disadvantaged groups. Pohwer provides a wide range of empowerment services including:

- The Independent Complaints Advocacy Service (across London, the West Midlands and the East of England). This service is available for children and adults who wish to complain about the care and/ or treatment provided by the NHS in England. It includes healthcare in prisons and Young Offenders Institutions (YOIs)

- Independent Mental Capacity Advocacy (IMCA) – for people over 16 in certain situations in England who lack decision specific capacity (In various Local Authority areas across London, the South East, the West Midlands and the East of England)
- Independent Mental Capacity Advocacy (IMHA) – for children, young people and adults people subject to the Mental Health Act (In various Local Authority areas across London, the South East, the West Midlands and the East of England)
- Community advocacy for children, young people and adults who need assistance to use public services (In various local authority areas across London, the South East, the West Midlands and the East of England)
- Specialist advocacy services commissioned by individual Local Authorities or organisations. We have services for:
 - Young people using child and adolescent mental health services
 - Young people and children at risk of being excluded from school
 - People on the autistic spectrum receiving specialist support
 - People who are cared for in secure settings.

7. WHAT MIGHT AN IDEAL COMPLAINTS PROCESS FOR CHILDREN AND YOUNG PEOPLE LOOK LIKE?

This diagram has been built up from the young people's suggestions.



8. CONCLUSIONS AND RECOMMENDATIONS

8.1 Overview

This project has gathered data from a wide variety of sources, children and young people from a range of quite different settings and parts of the country have been consulted. The findings indicating, to a high level of consistency, that children and young people's access to and use of complaints processes in mental health, sexual health and GP is a cause for serious concern. Furthermore, the prominent themes emerging from this investigation are very similar to a number of earlier studies of complaints processes in health and social care (described in Chapter 2).

It is apparent from the research material the consultant team has reviewed, and the new primary data that has been generated, that there are a number of significant barriers to be overcome if children and young people, or their parents and carers, are to be able to effectively complain when they are dissatisfied with the care or treatment they have received. At an overarching level, this includes tackling the defensive culture within health organisations which does not in any way recognise complaints as a learning opportunity and which at worst, can leave children and young people feeling mocked or viewed as 'troublemakers' when they try to raise concerns.

At a more practical level, improving this situation includes addressing:

- Widespread information gaps – for example, about children and young people's rights to complain; about confidentiality and about who children and young people should talk to if they wish to complain
- The often complex and lengthy systems many services have in place
- The training of staff in mental health, sexual health and GP services so that they are able to receive and handle complaints made by children and young people
- The need for complaints systems to be independent of the provider service if they are to be seen as credible and to be trusted by those wishing to make a complaint
- The patchy availability of advocacy and other sources of support for children and young people wishing to complain
- The inadequacy of complaints monitoring and evaluation processes which have a specific focus on children and young people.

8.2 Messages from national policy

The Health Select Committee¹¹ recommended that anonymity for complainants would be helpful; the establishment of a no blame culture; a shift to removing error provoking aspects of care; the need for staff training, and a welcoming, open atmosphere.

The Ombudsman's report, *Listening and Hearing 2011*, concluded that the NHS needed to listen more, that many lessons could be learnt from complaints and that there were many things that it would be easy and cheap to put right. The report commented that apologies and explanations were often all that were required, and needed to be delivered promptly. It also recommended improved record keeping and better information for NHS patients and carers on how to complain.¹²

With regard to the new systems that will be in place following the implementation of the Health and Social Care Act, the NHS Confederation has suggested that for Healthwatch to become an effective voice for patients, provision should be made to strengthen its independence and autonomy from the CQC by giving it a dedicated budget and support team and an ability to set its own agenda. It also suggests that to increase the power and relevance of its voice, a local Healthwatch should be representative of the local community or take regular and systematic steps to gather representative views from the local community including service users.

The Health Select Committee suggested that there should be one organisation with responsibility for an overview of complaints handling and thought that Healthwatch might fit this role. It observed that Commissioners needed a greater focus on complaints and that there should be a contractual duty to report on complaint action plans and the need for effective proposals for the new Commissioning Boards in primary care to address complaints satisfactorily. They noted concern that participation by Foundation Trusts remained voluntary.¹³

8.3 The principles and culture that should underpin NHS complaints

Drawing on the research literature and policy, there are a number of underlying principles for complaints systems that NHS services should be mindful of, namely that it should be in the best interests of the child or young person; there should be meaningful participation, with support and/or advocacy readily available.

The process must be **responsive** demonstrating awareness, accessibility, timeliness, problem solving and respect for different cultures. It needs to be **effective**, with fair and transparent administration, quality assurance and accountability.¹⁴ The **emphasis** should be on getting it right; being customer focused; being open and accountable; acting fairly and proportionately; putting things right and seeking continuous improvement.

¹¹ Health Select Committee 2011 *The NHS Complaints System*

¹² AA Service for Everyone. *Annual Report 2010-11*. Parliamentary and Health Service Ombudsman

¹³ Health Select Committee 2011 *The NHS Complaints System*

¹⁴ *Joint Special report – Hearing the Voices of Children and Youth*. Representative for Children and Youth Ombudsman British Columbia 2010

In terms of culture, it is important that organisations encourage routine feedback from staff and users to improve their services, with a 'no blame culture' for suggestions and complaints. Apologies and explanations, which are often all that are required, should be delivered promptly, with apology and resolution of complaints separated from the acceptance of liability and blame as far as possible.

Redress (e.g. small payments to recognise costs and inconvenience) should also be a routine consideration in the complaints process.

8.4 The organisational framework for improving the handling of complaints

Legislation and regulation should provide a clear basis for patient/client and staff expectations, so that patients and clients are clear as to their rights and standards that should be expected, and that providers of health and care and users know when something must be improved, and when a complaint is justified. Organisational responsibilities should stress local front line responsibility for complaint handling as the most crucial part of the system and as far as possible, complaints be resolved informally within the care team.

It is essential that any complaint appeals organisations are seen to be **independent**. Where this is not the case, complaints managers must be *senior* in an organisation in order to deal with complaints about *higher status* staff and the same would also apply in primary care if the practice manager was a complaints manager and a GP was the person complained about. The monitoring and learning from complaints should occur at both local and national levels with complaints support staff working closely with quality improvement teams, and with information gathering not solely focused on statistics but also providing real examples that practitioners can learn from.

An effective organisational framework needs to be underpinned by **good data collection processes**. Analysis of complaints needs to identify serious complaints or clusters of common complaints that can raise issues of principal that require policy review and action.

8.5 Complaint mechanisms for young people

As an overarching principle, complaint processes for young people need to be simple, to avoid hand-offs between agencies and to follow timescales that are as short as possible. In most cases, local resolution (informal and formal) supported by independent review processes (assessment, review, investigation, decision and report) undertaken by a second agency, should be appropriate.

Definitions of complaints need to be broad but measurable and include oral comments and staff improvement suggestions. Suggestions and complaints opportunities should be offered together in order to encourage more people to express their views and the process should allow children and young people to make suggestions and complaints anonymously, by a variety of means not only written. Complainants should be asked what they want as an outcome and within the complaints mechanism, 'young person friendly' feedback and information on how complaints were handled, and the results of complaints, should be routinely offered.

Alongside complaints mechanisms, alternative methods for involving young people more actively in services, for example a children's or youth panel, or youth champion representation at Board level, are needed if young people are to be effectively engaged and are to be able to share their views about the services they may have used.

8.6 Recommendations

The following recommendations draw on the many ideas and suggestions made by the young people consulted in this investigation and also the stakeholders who were interviewed; they are supported by some of the key messages from the national policy and guidance and other research concerning complaints procedures.

Recommendation 1: Ensure adherence to NHS statutory responsibilities

Regulations apply to the NHS and local authorities with regard to complaints procedures.¹⁵ From this investigation, it appears that in many services, there is poor adherence to these requirements as they apply to children and young people.

- The Department of Health (DH) should issue guidance to the NHS and local authorities on adherence to the 2009 regulations concerning complaints and take steps to improve record keeping and analysis of complaints, including the collection of national level data broken down by age.
- The Health Service and Parliamentary Ombudsman (HSPO) should raise awareness of children and young people's rights to complain about NHS services.
- DH should ensure that Healthwatch plays a lead role in the monitoring, reviewing and promoting of child and young person friendly complaint processes. Healthwatch should also have a clear remit to publish feedback about the handling of complaints.

Recommendation 2: Provide comprehensive support for children and young people who wish to make a complaint

This investigation has highlighted that there is a widespread lack of appropriate information for children and young people about both their rights to complain about health services but also, about the process they should follow. Their access to support from advocates is also highly variable.

- Local NHS providers need to ensure that user friendly information is displayed in services outlining the existence and purpose of NHS complaint processes and how to access them. Posters and other ways of displaying this information in ways that are appropriate and accessible to children and young people should be developed.
- Advocacy services, in particular that are independent from the NHS, should be more widely provided and children and young people's access to them promoted.
- Services should provide a step-by-step guide of how to access complaints mechanisms and a comprehensive description of the process, timescales and possible outcomes.

¹⁵ Local Authority Social Services and National Health Services Complaints (England) Regulations 2009

Recommendation 3: Make the complaints process more ‘young person friendly’

Findings from the investigation have highlighted that the process for making a complaint must be made simpler, with a shorter timescale and should offer a variety of mechanisms that are acceptable to children and young people.

- Local NHS providers need to ensure that the process for making a complaint is simpler, less reliant on writing things down and where use of the internet and other technology favoured by children and young people is promoted.
- Services should develop complaints processes based on as short a timescale as is practical. A professional with experience of working with children and young people should act as the nominated point of contact for any child, young person, parent or carer, who wishes to complain, to prevent them getting ‘lost in the system.’
- Free help lines (in place in some adult NHS Mental Health Trusts) should be widely available with the staff running these services trained in engaging with children and young people.
- All young people should have their complaint acknowledged as soon as possible; they should be given a case reference number to validate that their complaint has been received and that their complaint can be tracked.

Recommendation 4: Take the necessary steps to address staff attitudes and change NHS organisational culture

It is apparent that a major barrier to children and young people being able to complain about NHS services is staff confidence to receive complaints, underpinned by an organisational culture that is largely defensive and which does not see complaints as in any way a learning opportunity.

- All staff working in the NHS should receive training in complaints policy and procedures and in how to handle complaints made by children and young people; this should be part of the induction, ongoing CPD and supervision of all staff.
- Providing feedback to service users, including compliments, comments and complaints,¹⁶ should be a routine feature of all services and senior managers should support staff in this.
- Commissioners should set out in their service level agreements and contractual arrangements with NHS providers requirements for all staff to receive training in handling complaints made by children and young people, or parents and carers on their behalf.
- Action is needed at the senior levels of the NHS to promote a more supportive management culture and greater clarity as to what can reasonably be expected to be delivered to patients. Staff attitudes are the most important barrier to positive approaches to complaints but underlying these is the fear of blame from management, professional bodies or as a result of legal proceedings. In a more litigious environment, these are rational and reasonable fears and a changed management culture will be an essential component in addressing this issue.

¹⁶ CCC – an effective system the research team encountered at the Discovery Workshop in Liverpool.

Recommendation 5: Embed the involvement of children and young people in NHS services, at all levels

Throughout the fieldwork for this investigation, young people demonstrated with a great deal of maturity, their understanding of and insights into the services they use. Time and again, they talked of not being listened to. They asked for systems that simply and effectively ask for and act upon service user feedback. In many cases there would not have been grounds for complaint had effective mechanisms been place for children and young people to give timely feedback.

- Children and young people need to be central to the role and remit of Healthwatch arrangements and this should be laid out in the DH regulations that govern Healthwatch, both nationally and at the local level.
- Healthwatch needs to engage with children and young people and to support their involvement in local health and wellbeing boards.

ANNEX I: SATISFACTION WITH HEALTH SERVICES AND COMPLAINTS SYSTEMS – SELECTED RESEARCH FINDINGS

i. Studies about service satisfaction and complaints – all ages

There have been a number of studies looking at satisfaction levels with services and complaints systems and many recurring themes. Many mainly look at all age groups and some explore the additional and particular issues for young people.

A recent listing of the top ten complaints about the NHS and health care from the Patients Association Helpline were as follows: GP diagnosis, being struck off the GP list, rude clinicians, waiting times, problems over referral to a specialist, adult social care, medical records and hospital care. A report by the Patients Association in 2005, *Survey of the UK public: patients' rights*, found that a majority of the general public believe that the NHS gives them many more rights as patients than was actually the case.

This gap between expectations about rights and the reality, either brought about because rights are not legally enforceable, or because of resource constraints, or geography may, of course, give rise to some of the dissatisfaction patients experience, whether or not they complain. A 2008 National Audit Office report¹⁷ commented that whilst in one survey about 14% were dissatisfied with care, only 5% of those had complained about the NHS, whereas a third complained about adult social care. Patients and carers reported that making a complaint was difficult and over two thirds were not offered help or support to do this.

A slightly earlier report by the National Audit Office,¹⁸ looking at health care service use by 16 to 24 year olds, found that 17% had had no contact in the previous three years compared with only 7% of those aged over 65 had no contact. Of the total patients in contact with health care, 13% were dissatisfied, 35% with their General Practitioner service.

Reasons for not complaining about health service provision

In a 2008 study by the Health Professions Council (HPC),¹⁹ a number of barriers to complaining were identified, some that related to patient or carer characteristics and others to the nature of the service or the seriousness of the problem. A number of psychological barriers to complaining were identified, for example, reluctance to be seen as ungrateful, awkward or moaners, fear of a complaint impacting negatively on any future treatment that is required and scepticism that the complaint will make any difference. The study found that the majority of people were dissatisfied with the complaints process and also that inadequate records were kept of complaints.

¹⁷ National Audit Office (2008) *Feeding back? Learning from complaints handling in health and social care*

¹⁸ National Audit office (2007) *Care Services Study*

¹⁹ HPC (2008) *Scoping report on existing research on complaints mechanisms*

In 2009, the Department of Health published a document *Listening, responding, improving: a guide*. It quoted report findings of considerable dissatisfaction with the response to complaints, and failure to learn lessons, with patients feeling there was no point in making complaints.

Patients reported that the system was too inflexible, did not meet the needs of the complainant, and was too complex and lengthy. Complaints also focused around problems of staff communication and attitudes; problems with record keeping, privacy, respecting dignity and the way complaints were handled.

In another study of those who did not want to submit a formal complaint about the unsatisfactory nature of their service, the main reason for not doing so was a belief that nothing would be done about it if they did (32%) - with 16 to 24 years olds being the *least* likely to cite this reason. However, the second most common reason for not submitting a formal complaint was feeling that the complaint was not serious enough to warrant it, and 16 to 24 years olds were the *most* likely to see this as a reason for not complaining (24%). Carers were found to be more likely than patients to complain, and to do so formally.²⁰

Complainant characteristics

If the position for all age groups regarding complaints systems highlights a low take up of complaint systems, this is even more the case for younger age groups and this in part relates to a disinclination to complain, but also a disinclination to use many services in the first place.

The HPC found that women were slightly more likely to make complaints on behalf of others than men, perhaps reflecting their greater involvement in caring. People from minority ethnic backgrounds were thought to experience on the whole more difficulties in accessing services or redress mechanisms. Older age groups are thought to be more likely to complain, perhaps reflecting their greater use of health services. Generally people with a higher educational background are more likely to complain. People who are very ill, or who have very busy carers are less likely to complain. It is often people with more robust support networks on whose behalf the complaint may be made.

Good practice

The HPC report mentioned characteristics of *good practice* as follows:

- That there should be clear information about the purpose of a complaints procedures
- That a procedure should offer alternatives to written complaints
- That support and advocacy for complainants should be provided
- There should be information on how complaints were handled
- There should be information about the results of complaints.

²⁰ National Audit Office (2007) *Op Cit*

The Health Service Ombudsman 2009 outlined six *principles of good complaint handling*, as follows: getting it right; being customer focused; being open and accountable; acting fairly and proportionately; putting things right and seeking continuous improvement.

Handling and using complaints

Although the following two studies were undertaken before the new systems for the NHS were introduced, it seems that many of the problems identified persist. In 2007 the Healthcare Commissioner had found that few Trusts captured and analysed complaints in a systematic way that might be used to further service improvement. Another finding was that a third of Trusts dealt with complaints without knowing what the complainant's expectations were, and yet a fifth wanted apology or recognition.

Another inherent feature of many complaints mechanisms is that of conflicting roles, and a study in 2008 explored role conflict amongst health care complaints managers.²¹ This study was conducted between 1999 and 2002 in London and the South East Region. It found that complaints managers operated in an environment that was rather defensive to complainants and yet they have a duty to handle complaints impartially. It also suggested that if the party resolving a case is also the party being complained about, the odds of the complainant achieving success are small, and that an essential part of arbitration and adjudication is an *independent third party* to hear the dispute. Thus in-house complaints systems are in practice unlikely to be impartial and meet complainant expectations.

The findings of the study suggested that complaints systems better meet complainant needs where complaints managers are *senior* in an organisation in order to deal with complaints about *higher status* staff and the same would also apply in primary care if the practice manager was a complaints manager and a GP was the person complained about.

The following points were also made:

- Complaints managers often wanted staff to apologise, however, there was reluctance to include this in correspondence.
- Senior staff often rejected requests for an external independent investigator.
- Often there were conflicting accounts and no independent information available - the study found that about two-thirds of complaints managers considered they were not getting the full picture, but about a third tended to side with staff.

ii. Attitudes of young people to services and complaints

A number of studies have explored all age patients and young people's attitudes to health care and particularly primary care. There has been a focus on the relatively lower use of health care by young people, the reasons for this, the impact on their wellbeing, and factors that might contribute to low use and also factors contributing to improved use.

²¹ Xanthos, C. (2008) Conflicting obligations: Role Conflict Among Health Care Managers. *Qualitative Social Research* Vol 9, no 1.

Many of the features that all ages complain about also apply to young people but there are additional sensitivities for them. If young people do not use services to an appropriate degree, there are likely to be very low numbers of complaints but this will not reflect service satisfaction or optimal service uptake for good health or wellbeing outcomes.

Accessing primary care and satisfaction levels

A study of the patient experience of accessing primary care, for all ages, published in 2010 looked at various measures of accessing care. These included: getting through on the telephone; getting an early appointment; getting an appointment with a particular doctor; surgery opening hours.²² The findings suggested that young people, people from black and minority ethnic backgrounds, especially Asians, those working full-time who had difficulty getting time off work, and those with a long commuting journey, were the least satisfied patients.

The study also reported that patients in small practices reported greater satisfaction, which, given the move to a larger group practices, may be problematic. People in more socio-economically disadvantaged areas were less satisfied, and nationally, those living in the North East were most satisfied with their GP, and those in London, least satisfied.

Positive reports were also associated with higher numbers of GPs per patient, which is perhaps not surprising given that it was presumably easier in those practices to secure access to particular doctors and get earlier appointments. Higher satisfaction rates were also associated with higher scores on the GPs Quality and Outcomes Framework (QOF).

The World Health Organisation has emphasised the need for youth friendly health services and in more established economies cites psycho-social problems, for example mental health problems, difficulties with substance use, reproductive health and advice about sexual activity as being some of the predominant issues facing young people. However, studies in many countries have found that the reality of encouraging young people to use primary care services departs somewhat from the ideal.

A study in Australia in 2006²³ reported, as other studies have tended to, the following:

- Young people are more likely to use informal networks as sources of help
- Boys are less likely than girls to seek professional help
- Some types of problem are more likely to prompt help seeking than others, and that often for personal and emotional difficulties young people turn to friends and family.

It quoted an American study that found a third of adolescents with serious suicidal ideation, depression or substance misuse, thought they should be able to handle this themselves, and the worse the problems became the less likely they were to seek help.

²² Kontopantelis, E; Roland, M. & Reeves, D. (2010) Patient experience of access to primary care: identification of predictors in a national patient survey. *BMC Family Practice* 11.61

²³ Australian Psychological Society (2006) *Supporting young people seeking professional help with mental health problems*

Thus it is very important that services are made as easy for young people to use as possible, given their often inherent resistance to seeking help.

The study also stressed the need for schools to have a major role in signposting, and with primary health care networks generally, including youth workers, being crucial to establish a range of youth friendly services, because if a first encounter is difficult to achieve, or the experience is poor, young people simply fail to return.

Some of the studies examining the pathway for young people moving from child and adolescent mental health services (CAMHS) to adult mental health services (AMHS) are also illuminating about the difficulties this age group have in accessing services. A study by Munoz-Solomondo and colleagues²⁴ discussed the decrease in use by young people as they move between the ages for children's and adult services. This may reflect a number of factors to do with preferences of young people as they move from dependence and the transition to independence, but also differences in the models of services with which they are faced. Also on the whole, thresholds for adult services are higher and accessing services is harder as children move from mid-adolescence into late-adolescence and adulthood.

Perceptions and presentations by young people at primary care

Various studies have explored young people's presentation to primary care, factors that seemed to improve service uptake and perceptions of their experience.

An Australian study in 2007²⁵ found that most young people visited their GP once a year, mainly for physical problems and that about 10% of primary care encounters were with young people. The majority of respondents to their survey were either studying or working, and only 8.4% were not involved in either activity. Half of the young people surveyed did not use their regular GP. Only 10% presented with a psychological problem but about 24% thought they had a mental illness. Although the majority presented with a physical complaint, 69% did not perceive that they had a physical illness and in fact most (59%) considered they had neither mental nor physical illness. However, nearly half of the participants declared they had some level of fear in relation to a health problem, with nearly 20% reporting fear of having a life threatening or serious illness or concerns about committing suicide or self-harm.

There was a gap between young people's perceptions of illness and their presentations to family doctors. These findings have important implications for clinical practice and medical training, the potential role of doctors in assessing young people's fears, expectations, and perceptions, and tailoring help accordingly.

²⁴ Munoz-Solomondo, A; Townley, M. and Williams, R. (2010) Improving transitions for young people who move from CAMHS to AMHS: lessons from research and young people and practitioner's experience. *Current Opinion in Psychiatry* vol 23, pp. 311-317

²⁵ Haller, D; Sanci, L; Patton, G. & Sawyer, S. (2007) Towards Youth Friendly Services: A Survey of Young People in Primary Care. *Journal of International Medicine* 22(6), pp. 775-781

In a study of young people and general practice conducted in Norway,²⁶ a measure of higher consultation rates was taken as an indicator of a youth friendly practice, because of previous studies in a number of countries which have observed the reluctance of young people to present to health care agencies with their real health concerns, and the importance of this for later life health.

The study found that the practices with higher consultation rates by young people were practices that tended to have a younger GP, good accessibility in terms of appointments, a less pressurised workload for GPs and GPs ability and willingness to deal with psychological problems.

In a study of children and young people's experiences of the NHS in England between 2001 and 2011,²⁷ the majority of 16 to 24 year olds reported satisfaction, but these were lower rates than for older people. 83% of 18 to 24 year olds were satisfied with primary care compared with 90% of older adults. 80.7% of 16 to 24 years olds were satisfied with A&E compared with 89.2% of older adults and 86.5% of 16 to 24 year olds were satisfied with in-patient care compared with 92.7% of older adults. Young people reported a poorer experience of their perception of involvement in their care, having confidence and trust in their doctor or being treated with respect and dignity.

Similar findings were reported in another recent study which examined the views of children and young people (up to the age of 24), of health professions in England.²⁸ This found that young people valued the following:

- Familiarity and continuity. They wanted to know the person, and if not, they felt it was pointless saying anything to them.
- They wanted the health professional to be informed and competent about the condition they presented with.
- They wanted accessible information, and as an example of inaccessible information, noted that most 10 to 18 year olds had not heard of PALS (Heaton et al, 2001), and even with the school counselling service, 79% said they knew of the service but had limited understanding of how to make an appointment.

A study of how adolescents communicate with health professionals, including GPs, by Harvey and colleagues,²⁹ highlights similar themes. The researchers noted that the poor understanding of confidentiality issues and consequent fear of potential breaches in confidence that many young people have, combined with the brevity of appointments with doctors, leads to unsatisfactory delivery of care. Young people reported feeling marginalised,

²⁶ Øystein, H; Haug, K. & Gjesdal, S (2010) Young people and their GP: a register-based study of 1, 717 Norwegian GPs. *Family Practice* 27, pp.3-8

²⁷ Hargreaves, D. and Viner, R. (2011) Children and young people's experience of the NHS in England: A review of national surveys 2001 to 2011. *Archive of Disease in Childhood* 10.1136/2011.300.603.

²⁸ Robinson, S. (2010) Children and young people's views of health professionals in England. *Journal of Child Health Care* vol 14(4), pp. 310-316

²⁹ Harvey, K; Churchill, D; Crawford, P; Brown, B; Mullany, L; Macfarlane, A. & McPherson, A. (2008) Health communication and adolescents: what do their emails tell us? *Family Practice* 25, pp. 304-311

unable to participate fully in a discussion with the doctor and that whilst they may want to discuss health concerns, they are only likely to do so when they feel comfortable.

The study explored the use of online communication and discovered that young people were much more inclined to use this form of communication to express their health worries, especially if the issues were sensitive. The researchers concluded that by “utilising their preferred medium of communication, online health advice may promote better engagement with this population.”

Such avenues of communication may be highly valuable for encouraging and supporting young people to express satisfaction or, in the case of how to make health complaints processes more accessible to children and young people, may have the potential to improve young people’s use of these processes when services fail to address their needs.

The findings of a consultation with young people aged 16-25 years about their experiences and views of GP services in relation to emotional and mental health also raises pertinent issues about how able or otherwise young people are to talk with their GP. Undertaken by the *Right Here* project in Brighton and Hove in 2008-2009, as a part of the setting up of the Right Here project, over 50 users of Mind in Brighton and the Hove & Sussex YMCA were consulted. They highlighted the need for doctors to speak in a way that young people can understand; that it is crucial that doctors do not give ‘quick fix reasons’ but rather, are supportive, understanding and try to really understand the young person’s problem and that ‘young person friendly GPs’ should visit places like hostels and other local services used by young people. The quote below provides a good illustration of what those consulted highlighted:

‘Some doctors don’t listen to us; they need to understand and support us. When we are unhappy our doctors are often the first professional we visit to tell them about our distress. Sometimes they are dismissive and we don’t feel listened to. We want GPs to have better training in mental health and in talking to young people about their problems.’

The 2008-9 consultation led in to some further work by Right Here in 2011; the findings of this more recent consultation are summarised in Annex II.

Young people’s satisfaction levels with complaints mechanisms

A 2005 study about advocacy provision in Wales³⁰ provides useful information about how satisfied young people are with local authority complaints procedures. This reported the following:

- About half of the young people in the study were very satisfied or satisfied with the complaints mechanisms available to them.
- A fifth were neither satisfied nor dissatisfied.
- A third were dissatisfied or very dissatisfied.

³⁰ Social Inclusion Unit at the University of Wales and the Department of Child Health Wales College of medicine (2005) *A study of advocacy services for children and young people in Wales.*

- About three quarters of the young people interviewed thought it had been worthwhile making a complaint to the local authority, but the others had mixed feelings or thought it had not been a worthwhile experience.
- About half thought making a complaint had improved their situation, a third considered things were about the same after they had made their complaint, and about a sixth felt that using the complaints procedure had made their situation worse.

The majority of young people thought it was hard for them to raise their concerns and make a complaint, and it was particularly hard to start the process.

Others suggested that not being listened to, being moved around, and the length of time the complaints process takes, all serve to deter young people from complaining. Crucially, a quarter of young people suggested that fear of repercussions could make it hard for young people to raise complaints.

Their suggestions about how their experience of making a complaint could be improved included the following:

- Involving key adults, e.g., social care staff, working with young people to take a more proactive support role
- Raising awareness through young people friendly information
- Better access to independent support
- Speeding up the length of time to get a decision.

They also thought that a commitment to education, information and support, and an effective and positive approach to listening to and resolving complaints, needed to be put in place if children and young people are to be encouraged rather than put off by the complaints process.

ANNEX II: FINDINGS FROM RECENT CONSULTATIONS WITH CHILDREN AND YOUNG ABOUT PRIMARY HEALTH CARE AND ADVOCACY PROVISION

i. Local involvement networks (LINKs)

In 2010 the National Children's Bureau was funded by the Department of Health to improve the involvement of young people with local LINKs. ³¹ It found that some local LINKs had involved young people in consultation, but fewer in decision-making. However, their involvement had led to an increased awareness by health and social care providers of the issues important to young people.

Some concern was expressed in this report about the run down of the LINKS system and the transition of some local LINKS into the new local Healthwatch.

ii. Advocacy

Legislation and policy has gradually led to improved access to advocacy services for children and young people wishing to complain about services. However, broadly, there is entitlement for only certain groups of young people, advocacy services are unevenly spread throughout the country and access is often reduced because of the lack of free phone systems.

A study by VOICE ³² for the Office of the Children's Commissioner found that because of the nature of the short term contractual relationships between local authorities and independent advocacy providers, there was often a lack of stability in services for users. It also found that there are very few large scale studies of advocacy, that monitoring and evaluation was not standardised and therefore it was difficult to compare the relative merits of in-house and external advocacy services and how advocacy impacts on outcomes for children and young people. It concluded that there was significant qualitative evidence for the benefits of advocacy but that the added value and cost effectiveness of advocacy long term had not been effectively evidenced.

In 2005 a study of independent advocacy services for children and young people making complaints about health and local authority services, was conducted in Wales. ³³ Although the provision in Wales has increased since then, many of its findings are still pertinent for the provision of advocacy services generally. The study considered that there was a strong case be made for independent advocacy especially for vulnerable groups of children, e.g., those looked after or disabled.

³¹ *LINKs involvement of children and young people*, National Children's Bureau 2011.

³² *Where is my advocate? A scoping report on advocacy services for children and young people in England*. 2011

³³ Social Inclusion Research Unit, University of Wales (2005) *Op Cit*

Key findings included that only a small number of complaints were made by young people and the reasons for the complaints were largely related to quality of care, to medications and diagnosis, availability of care, waiting times and communication, such as attitude issues. The study noted that the majority of the Trusts and Health Boards at that time reported no additional mechanisms for children and young people with specific difficulties to access complaints services, such as those with hearing impairment or learning disability.

With regard to complaints by young people about local authority services, many young people apparently knew they could complain, but did not know how to, and therefore they also needed to know about an advocacy or similar sort of support service. Independence was valued, and young people preferred it if the complaints officers were proactive and directly involved and that this led to more timely resolution of complaints.

An important conclusion of the study was that a complaints process alone is insufficient to give children and young people effective involvement, and it noted that many services were considering new methods of involving young people more actively in services, for example a children's panel, youth forums, youth champion representation at Board level, and local forums working with hard to reach young people.

iii. Consultation in January 2012 with young people by a local Healthwatch concerning sexual and mental health services

Shadow Healthwatch Croydon consulted with young people in early 2012 about their use of local services. Some of the issues which emerged with regard to sexual health services included:

- The need for services to be 100% confidential, unless a young person wanted information to be shared.
- That young people are deterred from using the service because of feelings of embarrassment, feelings of being judged and poor service opening times.
- The need for venues that are exclusive to young people, or which at least offer young people only opening times/sessions, with opening times which are outside school or college hours.
- More informal and less austere venues, with friendly approachable staff skilled in listening to young people, would make it more likely that young people would use the service.

With regard to mental health services, the young people who were consulted suggested that further work is needed to educate young people about mental health and that health information needs to be more accessible and engaging to young people.

They also noted that leaflets and flyers were not effective ways for raising awareness or sharing information and that services need to utilize new technology more effectively – e.g. using YouTube, BBM (Blackberry Broadcast Messages) and social media (Facebook and

Twitter). The same may be true for how information about complaints processes needs to be disseminated.

iv. Consultation in 2010-2011 with young people about their views and experiences of GP services

A study of young people's experience of primary care, specifically their views and experiences of GP services, was conducted in 2010-2011 by the UK Youth Parliament (UKYP) for the Office of the Children's Commissioner. In total, 898 children and young people were consulted, 780 via an online survey that ran between November 2010-January 2011 and 116 via focus groups that were held between February-April 2011.

Of the experiences of their last contact with a GP, 65% of those consulted thought it was good or excellent, 27% average and 8% poor. If they were unhappy, most young people did not tell anyone, or if they did, it tended to be a parent or a friend. Of the 385 who reported that they had been unhappy, only 46 (4%) had told anyone and reasons given for not telling anyone if they were not happy with the service they had received included:

- Did not think anything would be done
- Did not want to cause trouble
- Worried about what the reaction to the complaint would be
- Didn't know who to tell
- Didn't know how to complain
- Embarrassment.

Various comments were also noted to the effect that the young people did not feel they were taken seriously because of their age; if they raised concerns, they often were made to feel stupid and that they were wasting the GP's time.

Their definition of a good GP was as follows:

- Someone who is friendly and approachable – 65.3%
- Someone who showed respect and sensitivity – 53.3%
- Someone who sorts a problem – 50.2%
- Makes people feel comfortable – 34%
- Is understandable – 30%
- Observes confidentiality – 25.6%
- Understands young people – 16.1%

In terms of what young people felt they would consult a GP about, 62% said they would consult a GP about any problem. However, 38% said they would not consult their GP about sexual health issues and contraception, STIs, pregnancy, personal/private parts, adolescent concerns, mental health, self-harm, eating disorders and weight.

They stressed they liked seeing the same GP and valued continuity. They disliked waiting for appointments and the waiting room environment. They were particularly sensitive to the perceived friendliness and lack of intrusiveness of reception staff, who could be very important as a barrier or encouragement to consulting a GP. They stressed the importance of confidentiality, particularly if they share the GP with their parents and of feeling respected and not patronised.. They also mentioned they did not like being “fobbed off” with leaflets, pills or high flown jargon.

v. Consultation in Brighton and Hove in 2011 about young people’s experience of visiting their GP

172 young people aged 16-25 were consulted via questionnaires, focus groups and interviews during October-December 2011. In the focus groups, young people were asked to think about what made a good or a bad GP practice. Their responses are summarised below.

Table 6: What makes a good or a bad GP practice?

GOOD	BAD
Offers other options rather than just giving medicine	Not very friendly receptionist
Treats young people with respect	Waiting ages in waiting room
Offers a step by step solution	Not enough time with the doctor
Sympathetic	Not getting the same doctor each time
Friendly, makes you feel at ease	Not understanding
Active listening from staff	Unsympathetic
Staff well-informed about other services	Talking down to you
Being able to see the same GP	Making you feel stupid
Fit around the student timetable	Not treating the young person like an adult

In the focus groups and interviews, a wide range of themes was raised. These included:

- GP appointment systems are complicated and take too long.
- Opening hours are often incompatible with school/college commitments.

- Young people would like to be able to request the same doctor/a doctor of a specific gender.
- Busy waiting rooms, with chairs close together, can feel very intimidating.
- GPs are too quick to prescribe medication.
- Referrals to other services can take a long time.
- Young people feel stereotyped and do not feel as respected as other patients in older age groups; they can be made to feel that difficulties with their mental or emotional health are just a 'phase' or an 'adolescent thing.'
- GPs can be patronizing and judgmental, with young people highlighting "an inequality of status with the doctor who was seen as an authority figure who communicated briskly."
- Concerns about confidentiality and in particular, worries about GPs sharing information with the young person's parents/family.

As part of the project, some 6th form students were surveyed and were asked if they knew what was confidential when they went to their GP – 59% answered yes, however, 41% answered no.

Another question asked young people if they felt comfortable talking to their GP about mental health and emotional issues: 52% said yes, 36% said no and 12% were not sure. Reasons for saying no or being unsure included GPs judging the young person and not taking them seriously; that it was hard to talk to a stranger/someone much older; that the GP wouldn't listen and the appointments are too rushed; not trusting them.

Table 7: Young people's suggestions for improving GP services

- More use of online facilities and take away information (e.g. of instructions for treatment)
- Greater involvement of young people in planning the delivery of services, including 'young experts' who could be recruited to lead on consultations with young people
- Feedback after appointments
- Young people's input in to staff training
- Clearer information about referrals to other services (especially CAMHS)
- GP services to be young person centred in design, with staff who relate to young people
- Young people informed about their healthcare rights, especially around issues of confidentiality
- Choice of where to register and an easy registration process

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