WHAT WORKS:

CHILDREN'S HEARING SERVICES WORKING GROUPS

A guide for commissioners, and health and local authority providers who support children and young people with hearing loss

NHS England and NHS Improvement

Document Title

What works: Children's Services Working Groups

A guide for commissioners, and health and local authority providers who support children and young people with hearing loss

Publication number: 000876

Version number: 1

First published: October 2019

Updated: not applicable

Initial work prepared by: Vicki Kirwin, Development Manager (Audiology & Health), National Deaf Children's Society, Carla Rose-Hardman, Family Programme and Involvement Manager, National Deaf Children's Society, Lucy Read, Head of Children and Young People Participation, National Deaf Children's Society.

Classification: OFFICIAL

This information can be made available in alternative formats, such as easy read or large print, and may be available in alternative languages, upon request. Please contact 0300 311 22 33 or email england.contactus@nhs.net stating that this document is owned by Office of Chief Scientific Officer, Medical Directorate.

Equality and Health Inequalities Statement

Promoting equality and addressing health inequalities are at the heart of NHS England's values. Throughout the development of the policies and processes cited in this document, we have:

- Given due regard to the need to eliminate discrimination, harassment and victimisation, to advance equality of opportunity, and to foster good relations between people who share a relevant protected characteristic (as cited under the Equality Act 2010) and those who do not share it; and
- Given regard to the need to reduce inequalities between patients in access to, and outcomes from healthcare services and to ensure services are provided in an integrated way where this might reduce health inequalities.

Contents

1 Executive summary

Children’s Hearing Services Working Groups (CHSWG)

The ‘What Works’ guides have all been produced in partnership between NHS England, Government Departments, and hearing loss charities. These guides provide practical advice to organisations, commissioners and providers on how they can ensure individuals with hearing loss receive the support they need throughout the system, so that they can lead successful, fulfilling and independent lives.

The Action Plan on Hearing Loss emphasises a whole system approach to the delivery of integrated public services, work collaboratively, and focuses upon the individual needs of the person with hearing loss[1]. This is mirrored by NHS England’s Long Term Plan[2] which emphasises the need to give children the best start in life, address health inequalities and deliver integrated care.

This document What Works: Children’s Hearing Services Working Groups (CHSWGs) updates earlier guidance produced by the NHS Newborn Hearing Screening Programme in England (2010)

This document looks:

- The importance of joint working across education, health and social care to improve outcomes for children with special educational needs and disabilities[3]
- The purpose of the CHSWG
- Membership
- Responsibilities
- Accountability and reporting
- Good practice in parent, carer and service user participation in CHSWGs.

It also provides case studies and templates which can be adapted for local use.

> **“A strong CHSWG makes a huge difference to the support available for deaf children.”**
>
> **Parent of deaf child**

> **“ I feedback about local services via the CHSWG and feel that changes have happened as a direct result of my work with the group.”**
>
> **Parent of deaf child**

---

[1] The Action Plan on Hearing Loss, NHS England and Department of Health, 2015
[2] NHS England (2019) The Long Term Plan
[3] Special educational needs and disability code of practice: 0 to 25 years; Statutory guidance for organisations which work with and support children and young people who have special educational needs or disabilities, DfE and DH (January 2015)

2 Foreword

By Professor Dame Sue Hill OBE, Chief Scientific Officer for England

Hearing loss continues to be a growing challenge in England with over nine million people affected by it. The scale of the challenge requires concerted effort and action from a wide range of stakeholders across the public, private, professional and voluntary sectors.

Significant progress has been made since the publication of the Action Plan on Hearing Loss in 2015 which brought together a wide range of organisations from all sectors committed to improving services for children and adults with hearing loss.

Following the publication of the Action Plan, I was very pleased to launch the National Commissioning Framework for Hearing Loss services, which delivered one of the key recommendations of the Action Plan and provided a practical guide to support commissioners making day to day decisions with patients affected by hearing loss. The framework represented a dedicated partnership with stakeholders and set out a series of recommendations on how services for people living with hearing loss could be improved.

I am delighted that the true partnership and ongoing commitment by our stakeholder organisations within the hearing loss community continues and that we have worked together again this year to deliver more of the recommendations in the Action Plan.

A series of “What Works” guides has been produced in partnership by NHS England, the Department of Work and Pensions, the Department for Education and hearing loss charities covering the life course as individuals with hearing loss transition from childhood to adulthood, join the workforce and age healthily. The aim of these guides is to help a whole system approach to the delivery of public services. They help organisations to support individuals with hearing loss, as they navigate the system throughout their life course, so they have a positive experience and can lead successful, fulfilling and independent lives.

This guide is specifically aimed at local authorities, NHS commissioners and providers working with children and young people with a hearing loss to support them and their families in maintaining their health, wellbeing and independence.

We are very grateful to all those who have given so much of their time to produce this series of guides, in particular Action on Hearing Loss, the National Deaf Children’s Society, the National Community Hearing Association, the Ear Foundation, Deaf health charity SignHealth and the Hearing Loss and Deafness Alliance.

3 Introduction

The Action Plan on Hearing Loss emphasises a whole system approach to the delivery of integrated services, working collaboratively, and focusing upon the individual needs of the person with hearing loss[1]. NHS England's Long Term Plan also emphasises the need to give children the best start in life, address health inequalities and deliver integrated care[2]. Working together across education, health and social care to improve outcomes for children with special educational needs and disabilities and improve the services they receive is central to the SEND Code of Practice (2015)[3].

By bringing together multi-disciplinary and multi-agency professionals, with their commissioners, working across STP[4] footprints, Children's Hearing Services Working Groups (CHSWGs – pronounced "chizzywigs") can play a key role by helping to ensure:

- Service quality
- That children, young people and their families' voices are heard and acted upon in service development
- That children's and young people's hearing services are high on the agenda of those responsible for planning and resourcing services at a strategic level
- Accountability

> **"In my experience, virtually every one of the service professionals and voluntary sector officers I have encountered in my 8 years on the CHSWG has been dedicated, qualified and keen to do the best job they could. Everyone really is on the same page, and the CHSWG helps them work together as a team more effectively. I have felt privileged to know these professionals, and to see the excellent work they are always trying to do. They have been unfailingly patient and supportive, explaining their acronyms and shorthand and always respecting my views as a parent."**
>
> **Ellen Purton, Parent Representative, Richmond CHSWG**

CHSWGs are not a new concept, recommended (as Audiology Working Groups) in Hall's *Health for all children*[5,6] and NDCS Quality Standards[7] since 1996. Since

---

[4] Sustainability and Transformation Partnership - where NHS organisations and local authorities have drawn up proposals to improve health and care in the areas they serve.

[5] Health for all children, David Hall, Oxford OUP (1996, 3rd edition)

[6] Health for all children, David Hall & David Elliman, Oxford OUP (2006, Revised 4th edition)

[7] Quality Standards in Paediatric Audiology, NDCS (Vol II 1996 & Vol IV 2000)

CHSWGs were first recommended a number of different models of organisational and accountability structures have developed. There is no clear evidence that one is superior to another. This document does not attempt to be prescriptive in terms of what a good CHSWG looks like. Instead, it aims to develop earlier guidance whilst highlighting the current policy and legislative context, providing resources on parent participation, and examples of good practice. This document supersedes previous guidance produced by the Newborn Hearing Screening Programme[8].

---

[8] NHSP Children's Hearing Services Working Group (CHSWG) Guidance, v 1.1 July 2010

4 Purpose of CHSWGs

‘Children’s hearing services’ is used to describe the entire network of hearing services from screening, diagnosis, to management and support of any hearing difficulties provided by the NHS, specialist education and social care support services provided by Local Authorities, and other support services offered by the voluntary sector.

The CHSWG is a multi-disciplinary and multi-agency group comprising – along with parents and young service users - representatives from these services who share a vision and goal of achieving the best outcomes for the deaf children, young people and families who use their services.

The CHSWG has a key role in coordinating and integrating the planning, commissioning, development of interagency protocols, service delivery, provision of information, and assuring the quality of children’s hearing services. This closer cooperation and coordination between agencies can also improve safeguarding of deaf children who are recognised to have additional vulnerabilities as disabled children[9]. It should offer advice, guidance and where necessary exert influence to ensure high quality services are available.

The reduction of inequalities in access and outcomes should be central to the development of Children’s Hearing Services. Local commissioners should make explicit in their plans how they have taken into account the duties placed on them under the Equality Act 2010, and their duties with regard to reducing health inequalities as set out in the Health and Social Care Act 2012. Service design and communications should be appropriate and accessible to meet the needs of diverse communities.

Benefits of multi-agency working for professionals have been identified as including[10]:

- Increased knowledge and understanding of other agencies
- Improved relationships and communication between agencies
- Learning from each other and about each other’s roles
- Joint problem solving
- Opportunities created to monitor and evaluate services and offer support in a coordinated and consistent way.

---

[9] Deaf children are legally defined as ‘disabled’ under the Children Act 1989 (Section 17) https://www.legislation.gov.uk/ukpga/1989/41/contents and the Equality Act 2014 https://www.legislation.gov.uk/ukpga/2010/15/contents

[10] Atkinson, M., Jones, M., & Lamont, E. Multi-agency working and its implications for practice: A review of the literature. CfBT Education Trust 2007)

Case Study:
Bolton CHSWG

The membership of Bolton CHSWG has grown over the past two years to include a very wide range of disciplines and has become a strong, productive group. There are now some very close links between professionals and multi-agency working has become embedded throughout the professionals within Bolton. There is always someone who knows how to find an answer to a query.

The CHSWG meetings provide an opportunity for all agencies and parents to gain an understanding of other disciplines, the work they are doing and the problems they are facing. Previously the group has written a letter of support to social care to emphasise how good the services in Bolton are for deaf children and there has been work undertaken in the Foundation Trust regarding BSL interpreters specifically for children and sign supported English. At one meeting it was found that both the local deaf society and Bolton deaf club both had separate plans to form a youth group for 14 to 18 year olds.

A sub group was developed from the CHSWG who look at transition services and supporting young people age 14 plus, a difficult to reach group. There is a youth group being started in October half term at Bolton deaf club for this age group with about 8 young people showing an interest in attending. It is hoped they will take the lead on the running and organisation of the group with support from a youth worker. This was identified as a gap within Bolton with the local deaf society being for younger children and the Deaf club for over 18s.

Three areas have been identified as important in developing effective multi-agency processes[10]:

- Ensuring effective communication and information sharing (e.g. by having transparent lines of communication, creating opportunities for discussion)
- Developing a shared purpose (e.g. by agreeing joint aims, conducting a needs analysis) and effective planning and organisation (e.g. by developing shared protocols, having a clearly defined structure)
- Effective governance and management arrangements (e.g. by developing appropriate accountability systems and having a transparent decision-making process)

It is important that the CHSWG operates with the cooperation and authorisation of senior management across agencies, which recognises the group's aims and provides support in terms of resources and promotion of services.

> **“I feel CHSWG is the main vehicle to change and improvements to services for my deaf child. It is positive that we are consulted on any changes, and I feel it is the one way we can make a difference.”**
>
> **Parent of deaf child**

To prevent token ‘multi-agency partnerships’ and ‘parent participation’ all expenses and resources for the meetings should be jointly funded from respective services’ budgets. It should be possible to fund communication support (if needed for a deaf parent representative) and reimburse travel costs. Consideration should be given to provide or reimburse parents for childcare where this is beneficial and appropriate.

See appendix A for example Terms of Reference and aims.

5 Membership

Besides parents and young people who are service users, membership should include representatives from all statutory sector and voluntary organisations who have a significant interest in local children’s hearing services.

Each member of the CHSWG will have an interest in funding, delivering, developing, overseeing quality of services, or as a service user, and will have expertise in one or more of these areas.
The following list is not exhaustive but depending on local circumstances it might be appropriate for the CHSWG to include representatives from:

- Newborn hearing screening team leader and/or local manager
- Paediatric audiology lead (and/or head of audiology)
- Audiovestibular physician
- Local cochlear implant team coordinator or representative
- Paediatrician
- Ear, Nose, and Throat consultant with responsibility for deaf children
- Speech and language therapist
- Health visitor
- Deaf CAMHS
- Family Support Worker
- Head teacher of local school with Hearing Impaired Unit
- Representative of Further Education/ services supporting young people post-16 years
- NHS directorate / divisional manager / business manager
- Head of sensory support services / lead Teacher of the Deaf
- Social services
- Parents / young people who are current service users
- Voluntary sector representatives serving diverse population groups delivering local services, who have an interest in supporting local families, or in ensuring the quality of services locally

- Clinical Commissioning Group (e.g. children's services director / children's commissioning lead)

Case Study: Richmond CHSWG

Having parent involvement is absolutely vital on a CHSWG, for two reasons: The first is that only the parents see the big picture of caring for a deaf child, and only the parents see the whole child. Parents can tell you what works and what doesn't.

The second reason is that all of the paid professionals report to us, the local citizens. We are not just the clients, we are the owners of the service. The various organisations and departments do not answer to one another, so one professional can't push another one to do things differently. But they all answer to taxpayers and service users. So as a parent and a resident I can make suggestions, or even demands if I feel they are justified, that would be seen as unwelcome interference by another professional. This is why the head of audiology wanted me to take the chair - as a service user and a citizen I have standing to defend the interests of deaf children at all times without concerning myself with what effect my views might have on my career or my professional relationships."

Ellen Purton, Parent Representative, Richmond CHSWG

All members should be clear about who they are representing – are they representing themselves, or basing opinions on their own experience; representing their service, or a group?

If parent representatives are representing the experience of families in the area it needs to be clear how they are canvassing opinion from, and feeding back to, other families. It is important that parents seek to include the views of a wide range of parents to feed back to the group, and utilise a range of methods in order to do so effectively. Examples from current CHSWG parent representatives are included in appendix B.

Guests may be invited to meetings when their specialist knowledge is required or for information sharing or training purposes. Inviting commissioners, SEN strategic leads and NHS Trust operational directors can support strategic engagement when needed. Those who are not required to attend on a regular basis may like to be copied into minutes and kept abreast of CHSWG discussions.

Roles within the CHSWG

Chair

The Chair of the CHSWG can be any member of the group and will normally be elected by the group members. A term of office needs to be agreed, with many

CHSWGs regularly changing the person in this post, or having a rota for who takes it on. A Vice Chair, if elected, will deputise for the Chair when necessary.

The Chair is responsible for collating the agenda for meetings, as well as chairing the actual meetings. Agendas should be circulated at least one week in advance of the meeting. All apologies should be forwarded to the Chair or Secretary prior to the meeting. In addition to this the Chair has a duty to report directly to the host organisations and wider stakeholders.

> **"We have a 2 year chair period and try to alternate between a professional / parent chair - so the current vice chair is a parent, and hopefully her vice-chair (once she takes over as chair) will be a professional."**
>
> **Adam Walker, Trafford CHSWG**

Secretary
CHSWGs work well with designated administrative support. Where this is not possible it may be necessary to share this role amongst group members on a rotational basis.

Sharing or rotating roles within the CHSWG, not only of who is chair and secretary, but also who provides the venue for meetings and refreshments, can encourage a real teamwork approach.

6 CHWSG Responsibilities

The CHSWG should:

- Record and circulate minutes of meetings to all members and interested stakeholders
- Support implementation of the actions within the Action Plan on Hearing Loss by feeding into local Health and Wellbeing Boards and Local Authorities when developing health needs assessments, Joint Strategic Needs Assessments (JSNAs), and Joint Health and Wellbeing Strategies (JHWSs)[1]. There may be other local groups where CHSWG guidance is necessary, such as Children's Disability Boards or SEND Forums
- Support implementation of the actions within the Action Plan on Hearing Loss by ensuring hearing is included within the local offer for children with SENs and safeguarding arrangements[1]
- Develop strategic partnerships for the management of services
- Ensure that the views of service users are regularly and effectively captured and acted on
- Share national strategies and targets that may determine the direction of local services

> **"As a parent you are passionate and care, so when there were cuts threatened to Teacher of the Deaf services we were able to get involved and prevent that happening."**
>
> **Emma Newton, Parent Representative, Tameside**

- Agree the framework for quality standards and targets for national and local performance management.
- Ensure publication of information on local services' performance and outcomes so that service users, the wider public, and local strategic bodies can review the effectiveness of local provision
- Monitor the quality of delivery of services for children, young people and their families via progress against quality standards, such as IQIPS[11], Quality Standards in Transition[12], Quality Standards: Early years support for children with a hearing loss, aged 0 to 5 (England)[13], and Quality Standards for Sensory Support Services [14]
- Monitor, discuss and evaluate data on deaf children in the area and their outcomes, using tools such as the CRIDE reports and the NatSIP outcomes benchmarking project in England, to assess how the local area compares against other areas. Where there are gaps in the availability or reliability of data, the CHSWG should consider what steps can be taken to address this.

> **"Parents have been able to respond quickly to issues.**
>
> **When there was a staff crisis in audiology the CHSWG was able, with parents on board, to have a short campaign to ensure staff were replaced. I was also able to respond on behalf of parents to a big change to the hearing support service recently through CHSWG – otherwise parents might not have been consulted on this change."**
>
> **Suzi Watson, Parent Representative, Hertfordshire CHSWG**

- Review the findings of any relevant reviews or inspection reports, such as the Ofsted/Care Quality Commission inspections of local area SEND provision (England), and consider implications for children's hearing services.
- Develop, monitor and update improvement plans for services

---

[11] Improving Quality in Physiological Services https://www.ukas.com/services/accreditation-services/physiological-services-accreditation-iqips/

[12] Quality Standards*:* Transition from paediatric to adult audiology services, NDCS 2011 https://www.ndcs.org.uk/media/4481/qs_transition_from_paediatric_to_adult_audiology_2011.pdf

[13] Quality Standards: Early years support for children with a hearing loss, aged 0 to 5 (England), NDCS 2016 https://www.ndcs.org.uk/documents-and-resources/quality-standards-early-years-support-for-children-with-a-hearing-loss-0-to-5-england/

[14] Quality Standards for Sensory Support Services, NatSIP & DfE, 2016 https://www.natsip.org.uk/doc-library-login/quality-improvement-for-services/quality-standards-for-sensory-support-services/1044-quality-standards-for-sensory-support-services

- Review the management of critical incidents, agreeing the major lessons that need consideration and actions that should be implemented
- Review policies, guidance and training relevant children's hearing services teams
- Work with commissioners in completing an Equality and Health Inequalities Impact Assessment for developing new services or services that are under review
- Identify gaps in, or duplication of, services and areas where investment is required
- Influence resourcing so that it responds to the evolving needs of service users
- Ensure that information about the work of the CHSWG is available to service providers and users
- Make recommendations which inform and influence strategic and operational decisions, such as directorate or divisional plans
- Communicate the achievements and unresolved issues of children's hearing services to strategic planners and key stakeholders for resolution.

Additional responsibilities may be appropriate depending on local circumstances.

7 Accountability and reporting

Each professional member of the CHSWG is working within accountability structures of their professional organisation (such as the Health and Care Professions Council) and/or their employing organisation (such as an NHS Trust or charity). Achieving effective accountability in partnership arrangements such as CHSWGs may appear difficult because of the complexity of different management and governance arrangements across organisations.

Warwickshire CHSWG publish their membership, all agendas and minutes of previous meetings, and dates of future meetings on their website:

http://www.warks-chswg.org.uk/Home.html

> **"I raised two issues regarding my council's services for deaf children at the last meeting and the chair actually commented that it was good for someone to challenge."**
>
> **Parent of deaf child**

Children's hearing services are all provided with public funds. This means that they are accountable to their service users and the wider public. Accountability can be achieved by:

- the involvement of service users in the CHSWG
- the publication of CHSWG minutes/agendas
- the publication of information on local services' performance and outcomes

In this way service users, the wider public, and local strategic bodies can all review the effectiveness of both the CHSWG and local provision. A simple way of providing information on service performance/outcomes is via an annual report - see appendix E.

Health and Wellbeing Boards

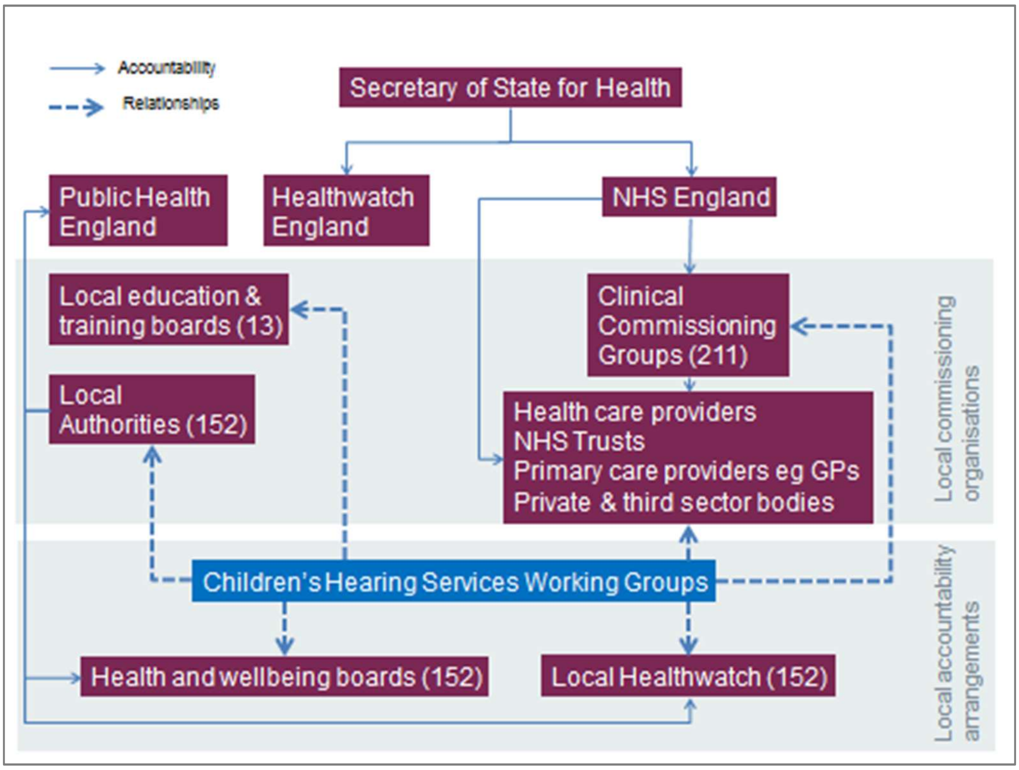
Health and wellbeing boards were established under the Health and Social Care Act 2012 to act as a forum in which leaders from the local health and care system could work together to improve the health and wellbeing of their local population.

These boards are a formal committee of the local authority charged with promoting greater integration and partnership between bodies from the NHS, public health and local government. They have a statutory duty, along with clinical commissioning groups (CCGs), to produce a joint strategic needs assessment and a joint health and wellbeing strategy for their local population.

They have limited formal powers and do not directly commission services. Although the boards are a partnership forum rather than an executive decision-making body, there is general agreement about their value in bringing together major local partners around the table.

CHSWGs will therefore want to build relationships with their local Health and Wellbeing Board in order to inform priorities and strategic plans. To ensure good linked up working, CHSWGs may also wish to engage with their local Sustainability and Transformation Partnership (STP) or equivalent (e.g. Local Care organisation (LCO) in Greater Manchester area).

The diagram below shows the position and relationships of CHSWGs within the health and social care system in England.



8 Involving deaf young people and their families

Children and young people have the right to be meaningfully involved in all decisions that affect them[15] and government policy emphasises the importance of listening to them and their parents, as well as their involvement in shaping the services they receive and ensuring they can access the information they need.

Deaf young people and their families are the experts and are therefore often best placed to tell you what they need and how you can meet their needs.

> **"Parent representation and communication and feedback from deaf children and young people and their families was, and remains, a key consideration.**
>
> **At Bromley, CHSWG minutes were not published and there was little publicity for the group. We explored methods of improving this for some time but nothing came to fruition when, with a degree of exasperation, I decided to create a dedicated website myself**
>
> **This ensures that all relevant material is stored in one place and is an easy point of reference for families and services. There are also links to social media and to allow feedback via surveys etc."**
>
> **Graham Manfield, Parent Representative, Bromley CHSWG**

Services designed and developed with the feedback and involvement of young people and their families are more likely to be relevant to those individuals. Health, education and social care services have a responsibility to ensure that adequate resources are available to support young people's participation in service development activity such as communication support costs and reimbursement for their time and travel expenses.

> "Participation is not about one-off projects. Rather it represents a philosophy of service user involvement which should pervade every aspect of service design and development."
> (Royal College of Paediatrics and Child Health, 2010)[16]

Parent Carer Forums are representative groups of parents and carers of children and young people with disabilities who work alongside local authorities, education, health

---

[15] The United Nations Convention on the Rights of the Child (1989) www.unicef.org/crc/

[16] Royal College of Paediatrics and Child Health (2010) Not Just a Phase: A guide to the participation of children and young people in health services

and other service providers to ensure the services they plan, commission, deliver and monitor meet the needs of children and families.[3] Where these exist the CHSWG should communicate with the local Parent Carer Forum to encourage engagement with and share information to support the process of getting more families with deaf children engaged with any consultations or reviews across services generally rather than hearing specific etc.

There are different ways and levels of consulting with young people and their families and involving them in evaluating and developing services. Engagement must be:

- planned and resourced thoroughly
- ongoing and young person-centred
- relevant to young people and their families
- done in a meaningful, flexible and accessible way to individual deaf young people, for example by using appropriate communication support such as qualified BSL interpreters, using media that is widely used by deaf young people, etc.
- clear about how the outcomes will be reviewed and acted upon.

For guidance on getting parents involved in your CHSWG see appendix B.

For guidance on young people's participation see appendix C.

9 Questions for the CHSWG to consider

- What are the priorities that we should focus on for the next 12 months?
- What is it that we want to achieve as a group? How are we going to measure success?
- To what extent are local hearing services for children and young people
    - Effective?
    - Family friendly?
    - Integrated?
- Are there any issues concerning the quality of local children's hearing services and the support provided that we are concerned about?
- What issues do we want to bring to the attention of the Health & Wellbeing Board and STP?
- What information/data do we need?
- What are the lessons to be learned from any recent critical incidents?
- What service achievements do we have to celebrate and communicate?
- How are we going to publicise the work of the CHSWG so as to encourage more people to get involved?
- How can we better engage with those service users who cannot attend CHSWG meetings?

10 Questions for Health and Wellbeing Boards to consider in relation to children's and young people's hearing services

- Are inequalities in access to local children's hearing services being addressed?
- How well are local children's hearing services meeting the needs of our diverse communities particularly by reference to our different ethnic and faith communities?
- What measurements are used to demonstrate that health and wellbeing is improving and that health inequalities are reducing?
- Do children, young people and their families experience seamless and continuous care?
- Are the measures of success that the Board uses generated by the people who actually use the services?
- In relation to children's and young people's hearing services, is it clear how commissioning plans will address the Joint Strategic Needs Assessment and achieve the outcomes of the joint health and wellbeing strategy?
- How does the Board engage with the CHSWG? How often?
- Are initiatives, projects and partnerships evaluated on their effectiveness and efficacy? What action is taken when indicators show initiatives/projects or partnerships are not working?

Appendix A: Example Terms of Reference

xxxx Children's Hearing Services Working Group
Terms of Reference

1 Purpose

1.1 The Children's Hearing Services Working Group (CHSWG) is a multi-disciplinary and multi-agency group with representatives from services who share a vision and goals of achieving the best outcomes for deaf children, young people and the families who use their services. The CHSWG has a key role in coordinating and integrating the planning, commissioning, delivery, and assuring the quality of children’s hearing services.

1.2 The CHSWG operates with the cooperation and authorisation of service providers, which recognises the group’s aims and provides support in terms of resources and promotion of services.

2 Vision and Aims

Vision

2.1 The delivery of good quality services that are integrated, work collaboratively, and focus upon the individual needs of the child or young person with hearing loss and their families.

Aims

2.2 The CHSWG aims are to:

- provide a forum for information sharing between all members
- provide an opportunity for issues of local and national importance in relation to services for children in a wider context to be considered by parents and professionals.
- provide a forum through which parents can have a voice in the planning and review of services
- make recommendations which inform and influence operational decisions
- provide advice, guidance and recommendations to commissioners and other decision makers with responsibility for planning and resourcing services at a strategic level
- develop strategic partnerships across services
- communicate the achievements and unresolved issues of services to strategic planners and key stakeholders for resolution
- ensure that good quality information about the work of the CHSWG is readily available to service providers and users

3 Policy and Guidance

3.1 The CHSWG will consider the local and national context, including relevant drivers and targets, and:

- support the development of new policies to meet the needs of children with hearing difficulties and their families
- discuss and agreeing the content of all local policies and guidance for services
- review existing policies on a regular basis to ensure they remain relevant and up-to-date

4 Training Review

4.1 The CHSWG will review any relevant training needs across agencies and make recommendations where gaps or areas for improvements are identified. In particular this might focus on cross-agency themes such as deaf awareness, young people's participation in appointments or service development initiatives etc, where learning may come from other members of the CHSWG or where joint training might be appropriate.

5 Quality Assurance

5.1 The CHSWG will:

- agree a framework for quality standards and targets for performance management of services, including measurable outcomes
- oversee the implementation of any national and/or locally agreed quality standards and good practice
- monitor and review the performance of local services
- report any issues concerning the quality of local children's hearing services and support provided
- reviewing the management of, and learning from, critical incidents and agree recommendations for improvement

6 Service User Satisfaction

The CHSWG will ensure that the views of children, young people and their families who use hearing services are regularly and effectively captured and acted on.

7 Minutes and Annual Report

7.1 The CHSWG will produce minutes of meetings. These will be agreed by the Chair and distributed to group members within one month. The minutes will also be available publicly via ….. (request to Chair, website etc)

7.2 The CHSWG will review the achievements and effectiveness of the group annually to ensure it is meeting the vision and aims.

7.3 The CHSWG will produce an annual report and information on local services' performance and outcomes so that service users, the wider public, senior management and local strategic bodies can all review the effectiveness of both the CHSWG and local provision.

8 Meetings

8.1 The CHSWG will meet at least three times each year; members unable to attend should be represented whenever possible. The Chair will be responsible for collating the agenda which will be circulated at least one week in advance of the meeting. Any departmental updates, apologies for absence and details of nominated representatives should be forwarded to the Chair /Secretary prior to the meeting.

8.2 Dates will be set 12 months in advance.

8.3 Agenda items will reflect agreed group priorities and concerns; sub groups may be formed to take forward specific areas of work.

8.4 Guests may be invited to meetings when their specialist knowledge is required or for information sharing or training purposes.

9 Confidentiality

9.1 All persons present at CHSWG meetings must be aware of and respect that there may be a need for confidentiality in relation to some of the issues discussed. In the event that a matter requiring confidentiality is raised, a note to that effect only will be recorded in the minutes

10 Committee Roles and responsibilities

10.1 The Chair and Vice Chair of the CHSWG can be any member of the Group and will be elected annually by group members.

10.2 The Secretary will be responsible for arranging meetings and taking minutes. This role may be shared amongst the group and reviewed annually.

11 Membership

11.1 Membership will be invited from all organisations providing services for deaf children and young people and their families across education, health and social care, including the voluntary sector and representation from service users including parents and carers.

11.2 **Education**
List local members…

11.3 **Health**
List local members….

11.4 **Social Care**
List local members….

11.5 **Family/Carers/Voluntary/Third Sector**
List local members…

We have widened membership to include more services, and pushed the services to integrate, to talk to each other, and to have high aspirations for our deaf children. We have gone from tinkering with the details to trying to plan whole new initiatives, and we have started reviewing more data amongst ourselves to try to create cross-service accountability."

Ellen Purton, Parent Representative, Richmond CHSWG

Date Approved: ___________________________

For Review:______________________________

Appendix B: Guidance on getting parents involved in your CHSWG

Introduction

Ensuring that parents of deaf children and young people are fully involved and engaged in CHSWG groups can be challenging. However, regular attendance at meetings from parents can provide many benefits. A parent can really articulate the needs of a deaf child by bringing first hand experience of the challenges that deafness can bring. Their contribution and experience can further enhance the practical knowledge that professionals share at meetings.

Parents who engage with CHSWG groups can become an integral voice in improving standards and effectiveness. Some parents go on to become chair of their local CHSWG.

Case Study:
Chair, Richmond CHSWG

I was recruited by our head of Paediatric Audiology, who was chairing the CHSWG at the time. My son had been diagnosed by her a couple of years earlier. There was one other parent attending occasionally at that time. The same head of Paediatric Audiology asked me to take the chair of the meeting about three years ago. At first I was too intimidated by the suggestion, as I still found the system of care bewildering. But eventually I felt like I was beginning to grasp how things worked, and then I felt ready to take on the challenge. All of the other members of the group were very supportive and helpful. I was very nervous for my first meeting or two, but I was also very keen to have a say in how services are delivered in my borough, and I felt like I had to give it my best effort in order to try to get some of my ideas pushed forward.

One of the main problems we had at that time was a lack of participation by some professional sectors, who were less enthusiastic about giving time to the CHSWG, so I would say that was the only resistance I found when I became the chair. But with a lot of patient prodding we have succeeded in gaining some members from those sectors, and I think their view is more positive now.

This guide sets out some helpful tips for encouraging parents to get involved with your group, and how to ensure continued commitment so that meetings are effective and actions that come out of them are followed up.

This guide is not exhaustive and your group may have plenty of other ideas and experience of recruiting and retaining parent representatives, which we would really appreciate you sharing with us.

Please note: Within this appendix we use the term ‘parents’ to refer to both parents and carers.

Top tips

Recruiting parent representatives

Many parents are recruited via a direct approach from a professional they have contact with, or an approach to a group of parents linked to a school or nursery. Others are recruited via other parents already involved.

Make sure that you provide contact details for the group so that professionals or families can find out when meetings are and what happens at them. Consider where to distribute this information and make an effort to advertise the group more widely through channels that parents and carers will see. Use the local audiology service or Local Offer website, local Deaf Children's Society groups, and produce flyers and leaflets in health and education settings and for local Teachers of the Deaf.

"Parents tend to get given the information about CHSWG quite soon after diagnosis and this is not the right time, they have bigger things to worry about."

Leah Herbert, Parent Representative, Staffordshire CHSWG

"Parents are told about the CHSWG verbally at the point of hearing loss diagnosis / hearing aid fitting, or we have information in a hearing aid leaflet that we give out at fitting. I think we could probably engage with more parents so we could do better but that applies to multiple aspects of life and not just CHSWG!!"

Adam Walker, Trafford CHSWG

Location

Make sure you hold meetings in locations that are parent-friendly and accessible, particularly for those who do not have a car. If in doubt, ask your local school, children's centre or community centre for advice on which venue(s) may be suitable for parents to get to within their community. Consider venues that may be familiar to parents and therefore seem less daunting.

"Genie Networks kindly provide a room free of charge"

Adam Walker, Trafford CHSWG

(Genie Networks is a local charity supporting deaf people and their families. Genie Family Centre http://www.genienetworks.org.uk)

Timing of meetings

If possible, plan your meetings at times that are suitable for parents. Around 9.30am to 10am after school drop-off would mean a parent could go straight to the meeting, rather than having to go home and wait around for a meeting later on that day. Early afternoon meetings that finish before school pick-up (by 2.30/3pm) could be another option. Evenings could also be considered, but it may be difficult to get agreement from professionals to attend meetings during their personal time.

“The group meets during the day on a weekday, the times and days are varied but times allow parents to drop children off at school or finish in time to pick them up.”

Gill Edginton, Bolton CHSWG

Have clear terms of reference and glossaries

Make sure that your group’s terms of reference are in plain language that can be understood by all. Avoid jargon and set out clear expectations, so that parents and carers know what it is they are signing up to. Producing a glossary that can be distributed in advance can help to ease a parent’s anxiety as to whether they will understand what professionals are talking about. (See Appendix A and Appendix D.)

“CHSWGs need to break down the jargon and make what they do relatable to parents.”

Joanne Hind, Parent Representative, Great Yarmouth CHSWG

Make your group accessible

All expenses and resources for the meetings could be jointly funded from the respective services’ budgets. It should be possible to reimburse travel costs, and consider whether it is appropriate to provide or reimburse parents for childcare.

Great Yarmouth CHSWG meetings are held in school time. The parking is paid for. A small amount of funding became available one year which was divided equally between the parents to cover travel expenses.

East Cheshire Deaf Children’s Society have two representatives on their local Cheshire CHSWG. Travel costs are reimbursed for parents.
http://www.ecdcs.co.uk/index.php/family-friendly-audiology

Norfolk and Norwich CHSWG reimburse both travel and childcare costs for their parent representatives.
http://www.nnuh.nhs.uk/departments/audiology/paediatric-audiology/

Have information about other ways that parents can get involved in your group without having to attend a meeting. Some groups set up places in the community where parents can drop in to give feedback or provide the option to email or make a phone call.

Are parents comfortable that they have the skills to effectively take part in meetings? Is it possible to provide support for them from a member of the group or maybe recommend some training, e.g. NDCS Parents as Partners workshops?

Acknowledge contributions
If parents and carers see the impact of their comments they may be more encouraged to attend meetings as they will see that their contribution is valued. You could email parents with feedback, have a newsletter with a section on parental contribution, or make contact by phone or mail to acknowledge their input and what has happened as a result.

Case Studies & examples

- **Salisbury CHSWG has a central email: CHSWG@salisbury.nhs.uk**

- **"Trafford Deaf Children's Society (DCS) will usually act as a medium for parental concerns/ questions. For example when deaf friendly swimming was set up , there some issues that were raised through the Trafford DCS and representatives from the CHSWG met with Trafford Leisure to attempt to resolve." Adam Walker, Trafford CHSWG**

- **"the local [DCS] group have supported the CHSWG work I do. They helped me facilitate focus groups for a parent consultation and to get in touch with parents. Local CHIPS groups, and Facebook groups I have set up to support feedback to CHSWG have also been a big help, as well the local parent carer forum." Suzi Watson, Hertfordshire CHSWG**

- **Bristol Area CHSWG produce a flyer that encourages parents provide feedback anonymously via "Give us your feedback" process, using feedback boxes at the service centre, via the group Chair, or via the Parent Representative. See example information for parents and families below or download http://www.fcdc.org.uk/usermedia/chswgfinfo.pdf**

- **In Northampton the Local Authority Parent Involvement Facilitator invites parents to complete a consent form if they would like to be included on the CHSWG mailing list or join the Parent Group that informs feedback from the CHSWG Parent Representative. Download http://repository247.org/resources/uploads/Northants_PFG/files/Consent_Form.pdf**

- **"I have been able to communicate to other parents any changes that are happening and also to pass on feedback from parents to the group. I gave a talk about my experience as a mother of a deaf child to trainee teachers of the deaf. I also attended a training session and talked about my experiences for the new Newborn Hearing Test Screeners when the service moved in-house. I was present at the opening of the new facilities and ended up giving a radio interview explaining what the audiology department and staff have done for my family." Joanne Hind, Parent Representative, Great Yarmouth CHSWG**

Have a relevant agenda

The group should be strategic and should make a difference, but if the content is focused, say, on operational service issues, parents will not think that the meetings are relevant to them. Consider having two parts to the agenda so parents are free to attend just the part that is relevant to them.

> **"…if there was something specific related to families that the CHSWG was working on (e.g. a new service or service improvement) then parents could be asked to attend for their input on that item. The parents would then see why the CHSWG was relevant to them and that they might get some benefit from it. There have been many meetings where I've felt that my presence is not needed. However, I remember something from the training *(Joanne attended the NDCS training for parent representatives)* that just my presence may make the attendees think differently! I have also got something out of being on the CHSWG. If I have any issues, I can take them directly to the group. I hear about the latest technology and am aware if any of the changes taking place affect my child."**
>
> **Joanne Hind, Parent Representative, Great Yarmouth CHSWG**

Plan meetings in advance

Ensure that dates and locations of meetings are agreed well in advance, but with a timely reminder ahead of the meeting date, so that parents can plan ahead and arrange childcare where appropriate. Ensure an agenda is provided in advance.

Take minutes

Send out minutes within an agreed time frame, setting out brief, clear action points, showing who is responsible for them and when they should be completed. Be realistic when expecting parents to take on tasks as they may have many other responsibilities.

> **"At CHSWG meetings I am able to share information about future local DCS events and activities so they can hopefully encourage parents to attend. If parents contact the local DCS with concerns about local services I can raise these issues at the CHSWG. In truth I'm not sure local parents are aware of CHSWG - or if they are, they are not sure what it does. I would imagine a lot of parents don't know I am a parent rep even though my name is on the leaflet."**
>
> **Leah Herbert, Parent Representative, Staffordshire CHSWG**

Get local input

Use local contacts to recruit members – link with nurseries, schools, deaf clubs, local Deaf Children's Society groups and other charities working with deaf children. Produce a leaflet which sets out what CHSWGs do in parent-friendly language and easy-read format. A group of parents who see one another in informal settings may be willing to elect a representative to attend CHSWG and offer an alternative if one is unable to make a meeting.

Remember the value of parents

Parents should be recruited as equal partners in the group where all members have mutual respect for individual roles and the contributions each can make whether that is from professional or user perspectives. Remember the value of parents' first hand experience of the services you are representing. Their user experience and interpretation of what you do helps you to know how you are doing in your job of improving outcomes and services for deaf children.

> **"We are treated like we have a valued opinion, and enjoy going to keep up to date with any developments."**
>
> **Parent of deaf child**

Parent representatives must not feel that by being a member of the CHSWG the service they receive will in any way negatively impact on the service their child receives.

Expectations of parents and carers

Make it clear to parents what is expected of them within their role. Ensure they know that they are there to represent families with deaf children within their community rather than just represent their own family.

Find tactful ways of ensuring that parents' personal comments are taken on board, but that the wider community of families with deaf children is also considered. Try and acknowledge their personal circumstances whilst asking how other families have also been affected.

Confidentiality

Parents, particularly new members, must understand that there is a standard of confidentiality within the group. Make sure they are aware of what information from meetings can be shared with other local parents and what is confidential to the group.

Ground Rules

These are important as a point of reference if a difficult situation arises. Some ground rules to consider include:

- CHSWG is not a forum to pursue individual complaints
- Confidentiality
- Treat everyone's ideas with respect
- While disagreeing or debating, focus comments on the facts and not on personalities

- No phone calls – emergency interruptions only
- All meetings will begin and end on time; no meeting will last longer than xx hours

Impact

Ensure that you have a structured way of showing the impact of your group. Monitoring the outcomes from each of your action points, showing a clear starting and end point will evidence the time and work everyone contributes. Not only does this encourage membership but shows the members that it is worthwhile attending and that giving their time and effort to do so can really make a difference for deaf children.

> **"I would say 6-7 parent reps are regulars and there is another handful that dip in and out. Anybody can raise anything that is in the best interests of deaf children as a whole - we discourage anything that is specific to individual cases."**
>
> **Adam Walker, Trafford CHSWG**

Letter to parents (based on an example shared by Portsmouth CHSWG)

Children's Hearing Service Working Group – CHSWG

Dear Parents,

We are looking for a parent, or a group of parents, who would like to become a parent representative to voice the opinions of what families with deaf children need and want from their services. You may also be the carer of a deaf child who would like to support us.

The CHSWG is a working group that includes health, education and **parent representatives** that aims to have a full picture of the overall service from all sources and constantly strive to improve on the current service. This is an informal meeting held ** times a year. The meetings run between 10 -12.30 and is held in the ***********.

What would it involve: As a parent representative we would like you to gather feedback from parents, who have children with a hearing loss. Parents could pass their comments to you via phone, social media, or email or face-to-face, if you attend a nursery with other parents i.e. The ******** nursery.

At the meetings we do not discuss individual children but do raise any concerns and put forward any suggestions on how to improve the service. As a service user your families experience, and that of other local families is therefore key to doing that.

Who will attend the meeting: Many people who you have met already. Those who usually attend are: ****** - representatives from audiology and the Ear, Nose and Throat department, Teachers of the Deaf, social workers for the deaf, speech and language therapists, voluntary organisations, local co-coordinators from the newborn hearing screening programme and some representatives from management and finance. All the professionals attending really welcome the feedback and views of parents of the deaf children they support.

It is a fantastic time to be a representative, you won't be on your own with support offered by the local co-ordinator. Or the co-ordinator can arrange to talk to you ahead of the meeting so that you know the sorts of things that go on and what we need parent's contributions about.

If you are interested in this role please contact me as soon as possible as we would really value your support.

Thank you

For example information for parents and families, see Bristol CHSWG, downloadable from:
http://www.fcdc.org.uk/usermedia/chswgfinfo.pdf

and Wolverhampton CHSWG, downloadable from:
https://www.royalwolverhampton.nhs.uk/EasySiteWeb/GatewayLink.aspx?alId=2765

Further resources

Contact a Family and Council for Disabled Children have published two excellent guides on parent participation – one for parents and one for professionals:

- Parent participation: parents' guide, 2005:

  https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/parent_participation_parents.pdf

- Parent participation: professionals' guide, 2004:

  https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/parent_participation_proffs.pdf

The National Network of Parent Carer Forums (NNPCF) was launched in 2011 and is funded by central government. The NNPCF membership is made up of Parent Carer Forums of which there is one in almost every local authority area in England.
http://www.nnpcf.org.uk

Appendix C: Guidance on young people's participation

Introduction

The involvement of service users in decision making has been a key theme across recent legislation and policy. Young people have a right to be involved in decisions that affect them, and the right of young people to individual and collective participation is emphasised in several documents. [17]

Therefore as well as including parents, you may wish to consider having input during all or part of a CHSWG meeting from a deaf young person, for example someone attending college part-time and able to attend without missing school. They may be able to articulate their user experience and the needs of children and young people in a way their parents can't. Whilst it may be difficult to engage young people in formal adult meetings regularly, it is important that the views of young people who use the service are gathered and used to inform service development.

Service providers need to plan to deliver involvement exercises periodically using a range of engagement mechanisms. CHSWGs are ideal forums to input into the planning, costing and provision of appropriate training for staff and resources in order to meaningfully involve children and young people on a continuous basis in alternative ways.

Benefits to the young person from being involved:

- Increases knowledge and understanding of services available
- Increases accessibility, relevance and quality of support and service
- Increases self-esteem and self-worth
- Improves decision-making and communication skills
- Builds peer support

Benefits to services and to wider society:

---

[17] Part 3 of the Children and Families Act of 2014 identifies general principles for Children and young people in England with special educational needs or disabilities. Section 19 of the Act clearly sets out in the principles of participation as a right for children. This means that children, young people and their families should be involved in decision making at every level of the system. Section 19 links these rights to Local Authority functions. As such we've asked the question whether children's audiology services would be included and have been advised by a legal expert in this area that they would because the service is included as part of both the Local Offer and child's Education, Health and Care Plan.

Health and Social Care Act of 2012. This Act introduced significant amendments to the NHS Act 2006. It contains two new legal duties requiring Clinical Commissioning Groups (CCGs) and commissioners in NHS England to enable patients and carers to participate in planning, managing and making decisions about their care and treatment, and to ensure the effective participation of the public in the commissioning process itself, so that services provided reflect the needs of local people.

- Supports services in meeting their obligations under government policy and legislation that says children and young people have rights to have a say in decisions which affect their care and to participate in service development. [18]
- Improves knowledge and understanding of issues that affect deaf young people
- Ensures policy, services and support is reflective, accurately meeting their needs
- Increases the quality of service and support
- Increases user engagement.

This guide sets out some helpful tips for consulting with deaf children and young people. This guide is not exhaustive and your group may have other ideas and experience of getting the views of deaf young people about your services - in which case NDCS would appreciate you sharing them.

---

[18] UN Convention of the Right of the Child, Children & Families Act 2014, and the NHS Constitution (2015).

The rights of children and young people to participate in decision making about their lives is enshrined in Article 12 of the UN Convention on the Rights of the Child. It says that when adults are making decisions which affect them, they have the right to say what they think should happen and have their opinions taken into account. This right applies to all children and young people with the principles of participation. Article 23 of the convention recognises the rights of disabled children to a full life and special care.

Top Tips: Consulting with deaf children and young people

Involve deaf young people at every stage of the process

It's important that deaf children and young people fully understand why they are being asked to share their views, what the consultation will involve, and what will happen as a result. Make sure they know the following:

- Why are they being asked to get involved?
- How will their views will be used and shared?
- What happens next: How have their views impacted on changes and development?

1. Work out what the best approach is

There is no perfect way to go about involving deaf children and young people in consultation. But don't panic! Evidence suggests that reliance on questionnaires alone is not sufficient, but a combination of approaches will increase the chances of meaningful, effective, representative and accessible engagement.

It's helpful to ask yourself some questions, to determine what type of consultation is the most appropriate:

Do you need to engage large numbers or need to consult very quickly?

- Creating an online survey or poll. Using online engagement will help with gaining the views of more young people, as will working with other organisations or professionals to increase the number of young people you are reaching. Some online survey tools allow the uploading of video using BSL to improve reach to all groups.

Do you need to explain what you're consulting on in great detail/quite carefully (is it complicated)?

- If the topic is complicated (and needs unpicking), face-to-face focus groups and interactive sessions outside of school time work really well.

2. Make it accessible

It's really important to make sure that all information and activities are accessible (that they make sense, are interesting etc.). This can be done by:

- Breaking down information into small, easy-to-understand chunks
- Ensuring activities are age-appropriate
- Using young people's own experiences as a basis for understanding the issues
- Making the information relevant to young people's lives.

Further resources

The Participation Toolkit (Scottish Health Council, 2010)

Not Just a Phase; A Guide to the Participation of Children and Young People in Health Services **(Royal College of Paediatrics and Child Health, 2010)**

'You're Welcome': quality criteria for young people friendly health services **(Department of Health, 2011)**

Understanding what matters A guide to using patient feedback to transform services **(Department of Health, 2009)**

"Participation in the Children and Families Act 2014" Council for disabled children https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/MIH_Participation.pdf

Council for Disabled Children (2010) *Children's Right to Communicate Their Views and Be Listened To* *https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/mryr1.upload.pdf*

How to involve children and young people in formal meetings, Council for Disabled Children, https://councilfordisabledchildren.org.uk/sites/default/files/field/attachemnt/Participation%20Factsheet%205%20Final.pdf

How to involve children and young people in commissioning Participation Works, 2012 https://search3.openobjects.com/mediamanager/manchester/fsd/files/commissioningypguide.pdf

The NHS Youth Forum has a series of posters/leaflets on young people's rights when using NHS services (2015)

The NHS bitesize guides provide guidance on patient and public participation: https://www.england.nhs.uk/publication/bite-size-guides-to-participation/

Get your rights **–** an interactive website designed in partnership with children and young people to explain their rights when using the NHS. It includes videos from young people telling their stories about how the rights have made a difference to them, and messages from professionals explaining why they value young people's rights. The website is based on research that found that children and young people did not know about the NHS Constitution and did not understand that they had rights and that this was having a negative impact on their experience of using the NHS (Council for Disabled Children and National Children's Bureau, 2015)

Your Rights, Your Future - is a resource developed in partnership with disabled young people. It provides training and interactive activities to help young people understand the Children's and Families Act 2014 and what is means to them (Council for Disabled Children, 2015)

If you're interested in producing information for children yourself then read Guide to Producing Health Information for Children and Young People (PIF, 2014)

For advice on making your information resources accessible to deaf children and young people download this NDCS guide How you can make your resources accessible to deaf children and young people (2013)

Appendix D: Glossary for CHSWG members

Add any local abbreviations, for example: local services, voluntary groups etc.
e.g. CYPAC Children & Young People's Audiology Centre

ANSD	Auditory Neuropathy Spectrum Disorder ANSD is a type of hearing impairment caused by sounds not travelling to the brain effectively (more information).
APD	Auditory Processing Disorder An auditory processing disorder is a hearing or listening problem caused by the brain not processing sounds in the normal way (more information).
BSL	British Sign Language BSL is a visual language using hand shapes, facial expressions, gestures and body language to communicate (more information).
CAF	Common Assessment Framework The CAF is a process whereby practitioners can identify a child's or young person's needs early, assess those needs holistically, deliver coordinated services and review progress (more information).
CAMHS	Child and Adolescent Mental Health Services NHS provided services for children in respect of mental health. Services are multidisciplinary in nature and the staff come from a range of professional backgrounds (more information).
CCG	Clinical Commissioning Group A CCG plans and purchases, or commissions, NHS services to improve the health of people.
CHSWG	Children's Hearing Services Working Group CHSWG is a multi-disciplinary group, involving professionals and local service users, including parents. The group has a key role in coordinating and integrating the planning, commissioning and delivery of education, health and social care strategies and services for deaf children and young people and their families.
CI	Cochlear Implant (more information).
CQC	Care Quality Commission Independent regulator of all health and social care services in England (more information).
CRIDE	Consortium for Research in Deaf Education. NDCS and CRIDE publish annual reports based on data provided by education services, such as numbers of deaf children and Teachers of the Deaf etc (more information).
EHCP	Education, Health and Care Plan EHCPs, introduced from September 2014, set out the special educational needs of children and how they should be met (more information).
IQIPS	Improving Quality in Physiological Services Accreditation scheme for diagnostic services across the NHS and independent sector, including audiology. IQIPS is designed to help healthcare organisations ensure that patients receive consistently

	high quality services, tests, examinations and procedures delivered by competent staff working in safe environments (more information).
KPI	Key Performance Indicator There are two Newborn Hearing Screening Programme (NHSP) key performance indicators; the focus of the first is coverage – screening offered, started and completed - and the second considers the timely referral for assessment following the screen (more information).
LA	Local authority
NatSiP	National Sensory Impairment Partnership NatSIP works to improve educational outcomes for children and young people with sensory impairment (more information).
NDCS	National Deaf Children's Society The NDCS is the leading charity dedicated to creating a world without barriers for deaf children and young people (more information).
NHSP	Newborn Hearing Screening Programme The NHS Newborn Hearing Screening Programme aims to identify moderate, severe and profound deafness in newborn babies (more information).
NICE	National Institute for Health and Care Excellence NICE provides national guidance and advice to improve health and social care (more information).
OFSTED	Office for Standards in Education, Children's Services, and Skills. Ofsted inspect and regulate services that care for children and young people, and services providing education and skills for learners of all ages (more information).
SEN / SEND	Special Educational Needs / Special Educational Needs and Disability (more information).
SLT	Speech and Language Therapy/Therapist A SLT offers assessment, treatment and advice to people of all ages, who have communication difficulties (more information).
SSS	Sensory Support Service. The sensory support service enables pupils with sensory impairment to have the best possible access to the curriculum and the life of their school, whilst meeting needs which are specific to their sensory impairment.
STP	Sustainability and Transformation Partnership (or Plan). Sustainability and Transformation Plans are five year plans covering all aspects of NHS spending in England. Forty-four areas (the Partnerships) have been identified as the geographical 'footprints' on which the plans are based, with an average population size of 1.2 million people (the smallest covers a population of 300,000 and the largest 2.8 million). A named individual has led the development of each STP. Most STP leaders come from CCGs and NHS trusts, but a small number come from local government.
ToD	Teacher of the Deaf A qualified teacher, who is also qualified to teach deaf children. They provide support to deaf children, their parents and family, and to other professionals who are involved with a child's education.

Appendix E: Example Annual Reports

There is no set format for CHSWG annual reports. The following links (or an internet search) may provide some inspiration:

Richmond CHSWG Annual Report for 2016 - Rackcdn.com

(CHSWG) Annual Report 2016-17 - Chime Social Enterprise

Below is a checklist of items that might be included. The table details the relevant quality indicators e.g. demographics, local service provision, service/user outcomes, together with the relevant national targets and references where these are available. Be realistic – CHSWGs are not expected to be able to report on all these indicators. Instead, annual reports should focus on the key local priorities.

CHSWG name:

Reporting year (e.g. April 2019 – March 2020):

Contact name and email:

Website:

Executive Summary: Free text, to include

- Reporting of outcomes for the year
- CHSWG plans/priorities for coming year
- Any further information
- Any acknowledgements

	Local data	***National target (where available)***	***Free text box for further narrative if required***
Service information:			
Locations where audiology services are provided:			
Audiology service commissioned by:			
Education services based at:			

Demographics:			
Population			
Birth rate			

Number of PCHI on caseload			
Number of children with glue ear supported annually			
Number of children with glue ear using hearing aids on caseload			
Number of babies identified with PCHI following NHSP this year			
Number of children identified with PCHI this year (not including those identified following NHSP)			
Number of children (0-2 years) referred for cochlear implant assessment this year			
Number of children (2+ years) referred for cochlear implant assessment this year			
% Population BAME			
% DNA rate audiology			

Service data:			
Referral to assessment time: Parents of babies that refer from the newborn hearing screen and wish to continue offered an appointment that is within 4 weeks of screen completion.[19]		100%[20]	
Referral to assessment time: Parents whose baby required targeted follow up offered an assessment before the baby is 9 months of age.[21]		100%[18]	

---

[19] NHS Newborn Hearing Screening Programme Standards 2016 to 2017 https://www.gov.uk/government/publications/newborn-hearing-screening-programme-quality-standards

[20] Quality Requirements, Template Service Specification (Hearing Services for Children), NHS Standard Contract 2016/17 https://www.england.nhs.uk/wp-content/uploads/2016/07/P37-CYP-Service-Specification-Template.pdf

[21] Quality Standards in the NHS Newborn Hearing Screening Programme (2010) - for the child's pathway from the point of referral from screening to paediatric audiology, medical and early intervention services. Standards for newborn hearing screening now superseded by Public Health England Programme Standards – both available https://www.gov.uk/government/publications/newborn-hearing-screening-programme-quality-standards

Referral to assessment time: Children referred for assessment post-newborn hearing screen offered an assessment within 6 weeks[22]		100%[18]	
Assessment: Developmentally appropriate hearing assessments are undertaken.[19] A comprehensive range of electrophysiological and behavioural assessments are offered and performed by competent staff.[19]		100%[18]	
Permanent childhood hearing impairment (PCHI) confirmation: Permanent childhood hearing impairment (PCHI) confirmed and entered into SMaRT4Hearing		80% of babies referred from newborn screening confirmed by 6 months of age, and 98% by 12 months of age[19]	
Habilitation support: Time taken to notify education services of children on confirmation of PCHI		Education services notified within 1 working day of confirmation of PCHI[19]	
Time taken for education services to offer a visit on identification of PCHI		Education services offer a visit within 2 working days (year round) of identification of PCHI[19]	
Assessment to fitting time: Average waiting time new hearing aid fittings following NHSP		Hearing aids should be fitted within 4 weeks of diagnosis[23,18]	
Assessment to fitting time: Average waiting time new hearing aid fittings (referred age 6 months+)		Hearing aids should be fitted within 4 weeks of diagnosis[18,19]	
Fitting of hearing aids: The selection, fitting and verification of hearing aids should follow accepted best practice		100%[18]	

---

[22] 6 week diagnostic target within 18-week pathway

[23] Transforming Services for Children with Hearing Difficulty and their Families: A Good Practice Guide, DH 2008

guidelines[19,] including RECD and REM (exceptions reported in IMP) E.g. MCHAS, British Society of Audiology			
Follow up care: Average waiting time hearing aid repairs Average waiting time for impressions Average waiting time for new moulds to be fitted (at home or in clinic)		90% same day access to a repair service, and a quick turn around postal service (3 working days) for replacement batteries. Moulds are returned or replaced within 5 working days[18,19]	
Multi-disciplinary team: An integrated care pathway, which facilitates joined-up multi-agency working to ensure all aspects of the child's development, safeguarding, and hearing aid use in the real world are appropriately assessed, monitored and supported as needed. E.g. medical support for developmental assessment and aetiological investigations, Teacher of the Deaf, speech and language therapist etc.		Referral for aetiological investigations and paediatric assessment – 100% offered referral to appropriate medical consultant at an appropriate time[18,19] Education services notified within 1 working day of confirmation of PCHI[18,19]	

Service user outcomes and experience of services:			
Children and young people have Individual Management Plans (IMP): All children and young people with a permanent (or longstanding) hearing loss have an Individual Management Plan (IMP) that includes goals and intervention, and is produced and agreed jointly with them and their family		100% of children and young people have a plan within 3 months of diagnosis[18,19]	
Children and young people achieve their personal listening goals in hearing and listening development:		90% of children and young people achieving their personal goals as identified in their IMP[18]	

Children and young people making expected progress in hearing and listening development as a result of the intervention, as identified goals in their IMP.			
Children or young people and families receive choice of intervention: Percentage of children, young people, and their families reporting being satisfied with their choice of intervention		90% of children, young people, and their families express satisfaction in their choice of intervention[18]	
Children or young people and their families receive clear and age-appropriate information: Families are given clear information to facilitate attendance and reduce anxiety.[19] Children and young people's views are sought and listened to in respect of amplification options and their impact, and information about their hearing loss is provided to them at age-appropriate levels19[19,24]		90% of children, young people, and their families express satisfaction with the quality of information provided[18]	
Regular reviews: Children and young people receive regular appointments (as identified in their IMP) to monitor progress against goals, interventions used, and review support needed and priorities. IMP is updated to reflect changes.		100%[18]	
% of children with PCHI who have language and communication skills within the typical range at Early Year Foundation Stage			
% of children with PCHI who have language and communication skills within the typical range at End of Year 2			
% of children with PCHI who have language and communication			

---

[24] Children and Families Act, SEND Code of Practice, 2015

skills within the typical range at End of Year 6			
Education, health and care plans (EHCP): Services must actively engage with the planning process for any child or young person who goes through assessment for, or review of, their EHCP to ensure their hearing and listening needs are appropriately addressed within the plan.[3]		100%[18]	
Information sharing: Records and associated letters/reports are completed and sent to the family, and GP/other professionals involved in the child's care (with family's consent) within 5 working days of hearing assessment/ fitting/ review		95%[18]	
Percentage of children, young people, and their families reporting being satisfied with the information provided, explanations of their/their child's deafness, their choice of intervention, transition (where appropriate) and overall satisfaction with service.		90%[18]	
Young people transitioned to adult audiology following a period of preparation: Percentage of young people and their families who report satisfaction with the preparation period prior to transition		90% of young people and their families express satisfaction with the timing of transition, and the preparation offered prior to transitioning to adult audiology services[18]	

Service development			
Service improvement: Service user questionnaires and peer satisfaction surveys to capture areas for improvements. 100% of recommendations made and agreed with Commissioners are addressed		100%[18]	

Reducing inequalities: Family questionnaire demonstrates a high satisfaction rate from all protected characteristic groups (PCGs)		95%[18]	
Reducing barriers: An integrated care pathway, which facilitates signposting and referral to wider support services E.g. Specialist education hearing support services, speech and language therapy, social care services, National Deaf Children's Society, local deaf children's support groups, etc.		100%[18]	

Quality assurance:			
Audits carried out this year			
Audits in progress			
Progress against IQIPS[11]			
Part of ABR Peer Review Network			
Progress against Quality Standards for Sensory Support Services [14]			
Quality Standards: Early years support for children with a hearing loss, aged 0 to 5 (England) [13]			

Guidance on making documents accessible is available here: https://www.england.nhs.uk/ourwork/accessibleinfo/ .