Action for Children and Herefordshire and Worcestershire ICB

(Integrated Care Board)

Health Participation Project, final report

Herefordshire
and Worcestershire
Integrated Care System

1015

people

Contributed to this report

82

Face to face and

20 virtual sessions

507 Surveys completed

By children, young people, parents, carers and professionals

619

Opportunities to engage via surveys, focus groups, workshops, events, sessions or interviews

Contents

Introduction

This enquiry, commissioned by Herefordshire and Worcestershire Integrated Care Board (ICB) formerly Herefordshire and Worcestershire Clinical Commissioning Group (CCG) took place between 2021 – 2023.

The ICB wanted to find out how children, young people and their families engage in conversation about their health and wellbeing, what mechanisms are in place currently and how these are utilised to influence thinking and decisions within commissioning and practice. They wanted to identify the good practice, challenges and gaps in participation along with the preferences that children, young people and families have in the ways they would like to engage.

The enquiry looked further afield for examples of good practice and engaged with local providers of health, education and youth and leisure services to find out how young people are participating and engaging now and how they would like to participate in the future.

A variety of methods were used to engage participants to ensure as many voices as possible were heard. The enquiry had a strong ethos of accessibility and inclusivity hence all publicity was produced in alternative formats, communication styles were adapted to participants needs, activities were differentiated to suit individual participants level of ability to contribute and all social media posts had alt text descriptions and plain text alongside the original call outs.

The enquiry team consisted of a Project Lead and Community Development workers who were guided and supported by other teams at Action for Children and a steering group of key stakeholders, formed at the inception of the project.

This final report and executive summaries will be shared at events in both counties, via the enquiry's landing page: [My Health, My Say | Action For Children]

and the ICB at: [Home :: Herefordshire and Worcestershire Integrated Care System (hwics.org.uk)]

Executive Summary

This report, commissioned by Herefordshire and Worcestershire Integrated Care Board (ICB) details the project “My Health, My Say” that took place between 2021 – 2023. The project set out to find how children, young people and their families engage in conversations about their health and wellbeing.

1015 residents of Herefordshire and Worcestershire contributed to the project via surveys, focus groups, workshops and 1-1 interviews. Innovative ways of engagement were employed such as “Jellybean Challenge” and participants contributed with written, signed and spoken word, drawings and votes.

The three main themes for enquiry were **Health and Wellbeing, Education and Life Choices** and **Community and Wider Connections.**

85% of parents and carers said that their recent experience of health appointments for their child/children had been “always good” or “Mostly good”.

86% of parents and carers whose child had an EHCP said that they were “Never” or “Not very often” consulted when it was being drafted.

35% of young people like to go to a youth club or group in their spare time.

The project found that:

- Once participants have a health appointment they are satisfied with the service
- Waiting times, especially for parents and carers of children with SEND and navigating complex systems made them feel less satisfied.
- Mainstream education is failing many children with EHCPs and the process of drafting a plan is difficult to navigate and often completed way beyond government timescales.
- Children and young people want to go to activities that they create, in their own area that are low or no cost.
- The best way to engage with young people is via existing groups.

The project recommends that the ICB:

- Create a dynamic participation team that builds relationships with existing groups in the community and takes consultations out to them.
- Create an online portal where parents and carers can make appointments and, specifically for parents and carers of children and young people with SEND, keep track of reports and the progress of their child’s EFCP.
- Create spaces that are multi-functional where children and young people can meet with their friends and choose and co-produce the activities they want to do
- Advertise more widely, for example through school newsletters, local services and events. Consider additional formats as well as online

With special thanks to AYOS (Active Youth Outreach Service), Malvern Cube, Starting Well Partnership, South Worcestershire, Bromsgrove Youth Hub, Worcestershire Acute Hospitals NHS Trust and Wye Valley NHS Trust

The Project

Background:

The project was initiated in the summer of 2021 when Herefordshire and Worcestershire ICB (Integrated Care Board, formerly CCG clinical commissioning group) commissioned Action for children to undertake a bespoke piece of work about listening to children, young people and their families and how they engage in conversations regarding their wellbeing and health needs. The project was originally named “Herefordshire and Worcestershire Health Participation Project”, which, following consultation with young people was changed to “My Health, My Say”. (Appendix A)

Purpose:

- To identify the present functions that are in place for children to participate in relation to their health needs, in order to influence thinking and decisions within commissioning and practice.
- To identify the good practice, challenges and gaps in participation along with the methods that children and families would like to use to engage in participation.
- To develop possible new ways of working to ensure children’s voices are sought, heard and then influence.

Key Stakeholders:

Members of the steering group,

Children and young people (0 – 19 and up to 25 with SEND) and their families across Herefordshire and Worcestershire

Decision makers across Herefordshire and Worcestershire

Governance:

A steering group formed of key stakeholders from both counties that represent health, community and education services was assembled and met at least bi monthly or as and when required throughout the project until June 2023.

Timeline:

Project Overview - Timescales

Year/month	September 2021 – January 2022	February 2022 – April 2022	May 2022 – July 2023	June 2023 – October 2023
Project delivery	Phase one	Phase two	Phase three	Phase four
Focus	Thinking Design and development	Testing Getting ready	Implementation Action and engagement	Reviews Evaluate and Disseminate

The project was divided into four distinct phases but with some flexibility built in to mitigate challenges around recruitment and responsivity to emerging data.

Phase one was the “scoping” phase, involving the background research necessary to ascertain the existing characteristics of both counties and which services and mechanisms were already in place for children, young people and their families. A stake holder mapping exercise, undertaken in collaboration with Action for Children's Growth and Service Design team (Appendix B) and a workshop, again in collaboration with this team, brought together members of the steering group and youth/leisure professionals.

This was followed by research into examples of existing good practice, details of this can be found in the section of this report, "Best Practice from Further Afield". Phase two consisted of devising and consulting on the project's publicity materials, preparing a "landing page", preparing participant information sheets, writing and consulting on surveys and planning the fieldwork delivery.

Phase three, consisted of the fieldwork where data was collected via various methods, a detailed description of this can be found in "Fieldwork and Findings". Finally, the fourth phase of the project involved analysing the data, feeding back to stakeholders, and sharing the findings via this report and executive summaries which will include a version for children and young people.

Opportunities and challenges:

It is often difficult to predict how a project of this type is going to progress and whether participants will be willing to engage, do they see the value in participating? Representatives from parent and carer groups told us early on that their members were feeling "all surveyed out" as there had been a number of recent consultations.

However, our experience showed us that both parents/carers and children and young people were more than willing to participate with over a thousand people actively engaging with the project. Some participants took part in surveys only, some in workshops, focus groups and 1-1 interviews only and some participants took part in more than one of these.

We found the Youth and Leisure sector particularly willing to engage with the project and we formed excellent working relationships with several, most notably, AYOS (Active Youth Outreach Service – Wyre Forest), Freedom Leisure (Worcestershire), Malvern Cube (Worcestershire) and Worcester Play Council. Groups for parents and carers were also welcoming to our approaches and included us in several of their events, inviting us to have a stand where we could promote the project and engage with participants directly.

There were some challenges engaging health professionals in this piece of work however as we have already acknowledged the timing of this project was post COVID when we know health care services were under pressure.

Similarly, there were also challenges engaging with the formal youth forums such as those for the Acute Hospitals Trust, NHS Herefordshire and Worcestershire Health and Care Trust, Worcester Youth Cabinet, Active Herefordshire and Worcestershire Youth Engagement and Herefordshire Children and Young people's partnership.

Current Provision

When looking at current provision we used the three general themes for enquiry to inform our research

- **Health and Wellbeing**
- **Education and Life Choices**
- **Community and Wider Connections.**

Directories of services were collated for health and youth services. Social media sites were searched for informal groups of parents and carers of children who had special educational needs or disabilities (SEND). Sites produced by both city and local councils were searched and both Healthwatch Herefordshire and Healthwatch Worcestershire were used throughout the project as sources of information, news and upcoming events.

Context

It is important to acknowledge that the project started when the country was only just tentatively moving out of restrictions imposed by the UK government since the outbreak of the COVID19 pandemic in the early part of 2020. Indeed in September 2021, with absence rates at school being 2.5% due to COVID infections levels[i] some schools re introduced "bubbles" and face masks for pupils due to the rise in cases. In November the UK Health Security Agency confirms the highest rates of COVID infections were amongst children aged 5 - 9.[ii]as the "Omicron" variant becomes prevalent.

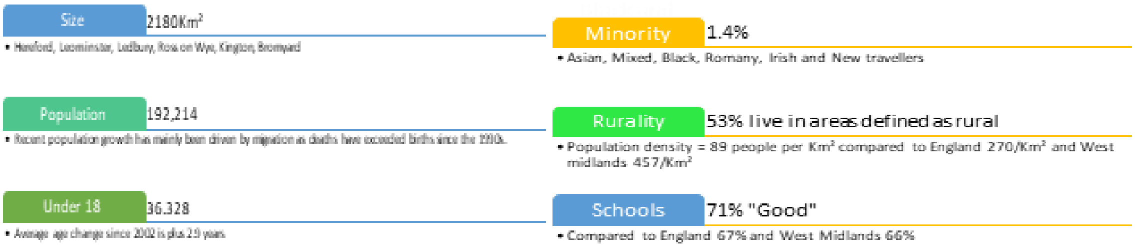
Many children, young people and families had "learned" how to manage without services that had been suspended or changed during the pandemic, Many people had become more resourceful at finding activities that could be done at home, alone or online and agencies, working with families, reported that they were having to work hard to re build trust and tempt families back to their services.

Because of the significant impact on health services during this time many participants also wanted to speak about or relate their experiences to the pandemic and may have "forgotten" what services were like pre pandemic.

The Counties

The project area covered two neighbouring, but diverse, counties therefore it is important to understand the similarities and differences between these.

Herefordshire



Size 2180Km^2
- Hereford, Leominster, Ledbury, Ross on Wye, Kington, Bromyard

Population 192,214
- Recent population growth has mainly been driven by migration as deaths have exceeded births since the 1990s.

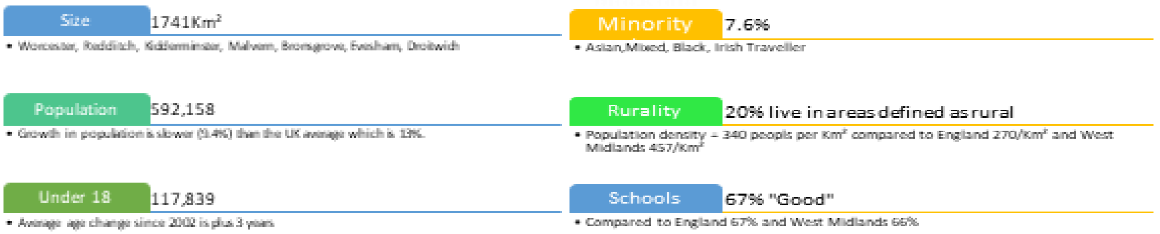
Under 18 36.328
- Average age change since 2002 is plus 2.9 years.

Minority 1.4%
- Asian, Mixed, Black, Romany, Irish and New travellers

Rurality 53% live in areas defined as rural
- Population density = 89 people per Km^2 compared to England 270/Km^2 and West midlands 457/Km^2

Schools 71% "Good"
- Compared to England 67% and West Midlands 66%

Worcestershire



Size 1741Km²
- Worcester, Redditch, Kidderminster, Malvern, Bromsgrove, Evesham, Droitwich

Population 592,158
- Growth in population is slower (9.4%) than the UK average which is 13%.

Under 18 117,839
- Average age change since 2002 is plus 3 years

Minority 7.6%
- Asian,Mixed, Black, Irish Traveller

Rurality 20% live in areas defined as rural
- Population density – 340 people per Km² compared to England 270/Km² and West Midlands 457/Km²

Schools 67% "Good"
- Compared to England 67% and West Midlands 66%

Herefordshire is one of England's most rural areas, with >190,000 residents scattered across 842 sq. miles. The county benefits from a natural environment versus challenges of service delivery; ‘urban flight’ and its boost to economy versus affordability. There is a lower proportion (16%) of children in Herefordshire compared with nationally (19%) and numbers have fallen over the last decade.

Worcestershire is, in general, not a deprived county. There are however 10% of people that live in the most deprived quintile. Proportions living in the 30% most deprived areas are particularly high in Redditch at almost 40%, and Wyre Forest at 35%. Almost three-quarters of the population live in urban areas, but the county has sizeable rural areas, with over a third of the population in the districts of Malvern Hills and Wychavon living in the most rural areas.

Health and Wellbeing

How services are organised across the counties:

- 4 NHS Trusts (inc WMAS)
- 2 Upper tier local authorities
- 6 District councils (Worcestershire)
- 15 Primary Care Networks
- 79 GP Practices
- 122 Community Pharmacies
- 96 Dentists
- 64 Optometrists
- 5 Hospices
- 1,000’s of VCSE bodies
- 1 Police Service
- 1 Fire and Rescue Service
- 1 Integrated Care Board

Health challenges in **Herefordshire** are:

- Child and adult obesity
- Poor oral health in children
- Proportion of pregnant women who smoke
- Infant mortality
- Looked after children who have emotional wellbeing issues that are a cause of concern
- Number of pupils (primary and secondary) with social, emotional and mental health needs

Health challenges in **Worcestershire** are:

- Inequalities in mental health and wellbeing, and lifestyle risk factors
- Excess weight in adults and children
- Challenges within the health and care system (including. waiting lists, emergency department pressures)
- Need deriving from Special Educational Needs & Disabilities (SEND)
- Maternity and early years related including smoking pregnancy, breastfeeding initiation, infant mortality and school readiness

Through the autumn of 2022 the Herefordshire and Worcestershire Integrated Care Partnership Assembly engaged with partners to understand their views on the opportunities and areas of focus for working together to address the needs of local people. The Integrated Care Strategy 2023-2033 [iii] includes a vision, mission and eight commitments describe what they want for local people, and how they are going to work together to take action and build on existing strategies and plans that enable improvement in health and healthcare outcomes for all.

Although services are organised across both counties we noticed small differences in strategy priorities and our conversations with participants highlighted differences too, particularly in the emergency departments. Access to dental care was a concern for participants in both counties.

Access to CAMHS ASD and ADHD assessments were universally criticised by participants. Although parents and carers in Herefordshire had a perception that their services were poorer, in reality, for example, CAMHS appointments in Herefordshire were performing better at 69% seen within 10 weeks as opposed to 48% for Worcestershire (Appendix C Children's Dashboard 2022-2023).

Education and Life Choices

	School population	**SEN support**	**EHC plan**	**Care experienced**	**Young carer**
Herefordshire	25,128	3,673 (0.26%)	1,055 (0.24%)	115 (0.02%)	2,250 (Approx)
Worcestershire	88,851	11,824 (0.86%)	4182 (0.97%)	468 (0.11%)	7,980 (approx.)
England	8.9m	1.37m (15.39%)	430,700 (4.83%)	400,000 (4.49%)	800,000 (UK8.98%)

Both counties had received "Inadequate" OFSTED/CQC reports within the previous five years for both Children's Services and Local area SEND inspections.

Worcestershire:

In November 2021 had made sufficient progress in eight of the 12 significant areas of weakness regarding SEND improvements. Early in 2023 Worcestershire introduced a "portal" enabling parents and carers to track the progress of their child's EHCP.

in July 2023 Worcestershire Children's services were awarded "Good".

Herefordshire:

As of June 2023 Herefordshire Children's services are still judged inadequate and receiving monitoring visits, there has not been a SEND specific inspection since 2016.

Herefordshire have produced a 2023-2026 SEND strategy that sets out their priorities for children and young people:

- your needs are identified and assessed in a timely and effective way;
- you and your family's voices are heard, and this makes a difference;
- you receive the right help at the right time;
- you are well prepared for your next steps in life; and,
- you feel valued, visible and included.

Worcestershire's draft proposal (2023 – 2026) is due to be presented to the cabinet at the end of September 2023.

Their priorities are:

- identification and assessment of SEND is timely and effective
- there is sufficient and effective SEND provision
- there is awareness and understanding of SEND within local communities
- outcomes for young people with SEND are improved as a result of effective planning, preparation for adulthood and better coordination of service delivery to ensure positive transitions as they progress through their education
- CYP with autism achieve positive outcomes and the support required to enable this is in place
- emotional health and wellbeing is actively promoted for CYP with SEND and their families and effective targeted and specialist support is available for those CYP at risk of, or experiencing difficulties

Whereas nationally the number of EHCPs issued within 20 weeks (2022 figures) is 49.1% the counties averaged 30%. (Appendix D) This was supported by what parents and carers told us about delays in the initial process and ongoing support.

The local SENDIASS service spans both counties and offers online workshops and courses for parents and professionals such as "What does a good EHCP look like?" and promotes SEND friendly events and information on its Facebook page. Recently the service in Herefordshire has been reduced to three days a week. (August 2023)

Community and Wider Connections

In Worcestershire we found many active clubs that covered a wide choice of sports and leisure activities and reasonable provision for children and young people with SEND on the council site, although it is difficult to find as it appears under "Short Breaks". The here2help page has been re branded as "Community Services Directory" and, again is quite tricky to find. Many parents and carers told us that, especially if they didn't use social media, it was difficult to find out about events and activities for their child/children.

“Having only moved to the area in the last one to one and a half years it's been difficult to find information on what is available without having to do extensive looking online.”

Parent/carer in Worcestershire

In Herefordshire the picture is very different with little or no low or no cost activities, which we experienced whilst looking for events to attend during the fieldwork phase. We heard from parents and carers about how the combined cost of travelling and the cost of the activities themselves make them unaffordable.

“Many of the activities involve signing up for a whole term of half term, we can’t afford this up front and then if your child is ill or anxious you’re paying for activities they don’t attend.”

Parent/carer in Herefordshire

The council’s “Talk Community” pages are the main source of information for events and groups, however in practice a lot of this is out of date and groups that do not run in school holidays still have their session advertised as “Every Wednesday” for example. A search on these pages finds Aspire Youth Club with a cost of £12.50 per session and Marches Family Network that do not currently have an operational youth group. HVOSS’s (Herefordshire Voluntary Support Services Support Organisation) report “Different places for Different People” highlights gaps in the service[iv].

Parent and carer groups

Herefordshire - Parent Carer Voice Herefordshire is led by a steering group of parents who are working alongside the local authority to provide advice and information, hold “coffee and chat” sessions around the county and facilitate a termly SEND summit. They have worked closely with the local authority and the Integrated Care System (ICS) to co produce the county’s SEND local offer page.

There is also a facebook group called “Herefordshire Parents of Special Needs Children and Adults”, “Look” for parents and carers of visually impaired children, “ECHO” for older young people with learning disabilities and the local authority site has links to national charities such as National Autistic society and SCOPE.

Worcestershire - Families in Partnership is Worcestershire's parent carer forum. They are an independent group of parent carers who work alongside Worcestershire County Council and other partner agencies to help shape services for children with special educational needs and disabilities in the county. Their aim is “To make sure that parent’s voices are heard when it comes to planning and decision making about services for our SEND children and young people in Worcestershire. By creating a safe and protective environment for Parent Carers to share their experiences, the forum can help to enable change or improvements when needed and promote those services when they are working well through positive dialogue and co-production.”.

Action for Children runs two groups that support specific parents’ needs SWANS (South Worcestershire Additional Needs) for parents/carers of children and young people with SEND and “Safe Space” a support group for parents and carers of trans and gender-questioning young people.

There is a facebook group with over 1,000 members called “SEND National Crisis Worcestershire”, Hansel and Gretel support group operates in Wyre Forest, Worcestershire Parents and Carers Community, Worcestershire Home Educators Network and many condition specific groups or national charities all listed on the county’s site.

At the Worcestershire SEND summit in March 2023 and the Children's Neurodiverse Care Pathways workshop in July 2023 several parents and carers stated that they felt the groups affiliated to the local authority and did not accurately reflect parents and carers views, for example:

"I am suspicious of the local authority affiliated groups, they've never represented mine or the views of most of the parent/carers that I talk to, I mean, who are they representing?"

Parent/carer in Worcestershire

Best Practice from Further Afield

When looking at best practice in participation and co production we considered:

- Local authorities
- National charities
- NHS
- Organisations that support children and young people with SEND

Not only did we look at these to help to inform our recommendations but to ensure our project design and fieldwork was inclusive and accessible for as many participants as possible. We used stage one, the first two elements of the Lundy checklist within our fieldwork.[v]

Local Authorities

Research established that **Lincolnshire County Council** has a highly respected advocacy group for children and young people with SEND "Lincolnshire Young Voices". Established in 2017, it was the result of a local partnership pilot programme offering young people with SEND the opportunity to share their experiences with Lincolnshire County Council. Emma Cross, Co- Chair of Lincolnshire Young Voices said:

> *"We knew GPs and other professionals wanted more training on working with those with SEND. And we knew we were the perfect people to help because we have lived experience of disabilities and additional needs and a passion to inspire change for people in our position and those around them."*

Their training "A Rough Guide to Not Putting your Foot in it" video[vi] has won a national award from NASEN (National Association for Special Educational Needs).

Derby City Council, **Derbyshire Council** and **NHS Derbyshire ICB** (Formerly CCG) worked with a social enterprise group "Leaders Unlocked" to produce "MH:2K Derby and Derbyshire, A Youth-led Approach to Exploring Mental Health" in 2020. The MH:2K approach had previously been run successfully in **Oldham, Birmingham, Central Lancashire, Nottingham and Nottinghamshire and North Tyneside.**[vii]

"Southampton Speak Up". **Southampton City Council's** Children and Young People's participation strategy is a bright, accessible, two-page document that explains participation to young people.[viii]

Charnwood Borough Council In Leicestershire has produced a "Children and Young People Participation Toolkit" that includes the classic "Participation Ladder" as described by Roger Hart[ix] and a useful reminder of what participation truly is:

- Informing those affected (inform);
- Informing those making the decision (consult);
- Change the decision (involve);

- Jointly make the decision (partnership / collaboration);
- Enable others to make decisions and/or take action (empower).

An innovative approach by **Croydon Council and YPHealth London** (no longer in operation) co-produced a “Prescription Pad” of how GPs could work better with young people and what services they would like to see, locally. (Appendix E)

National charities

In 2023 **Action for Children** announced its new participation strategy for children and young people. “Nothing about me, without me”. The strategy is a central part of the charity’s on-going commitment to the participation of children and young people in the decisions that affect their lives.[x] In addition “The Right Choice” is a comprehensive guide to involving children and young people in recruitment.[xi]

“Making Participation work”, a joint project between the **Council for Disabled Children** and **Kids**, funded by the Department for Education have produced a range of factsheets with insights and tips to facilitate participation.

National Youth Agency’s “Hear by Right” is an organisational development tool built on a framework of seven standards with 20 indicators that describe best practice supporting organisations to plan, develop and evaluate their participation strategy. It also offers the “Hear by Right” framework as a free self-assessment resource with the option for a formal assessment to gain a national NYA award.[xii]

NHS

NHS England’s “The 15 steps Challenge”[xiii] is a useful toolkit written for adults but for use with children and young people. It helps services to listen to service users and see the service through the eyes of the patient.

The **Royal College of Pediatrics and Child Health** has a useful resource called “Recipes for Engagement” which describes activities to facilitate with young people, there are recommendations alongside each engagement “recipe” for uses and the type of group they might work well with.[xiv]

NICE (National Institute for Health and Care Excellence have a useful visual reference of “My Healthcare Experience” Checklist[xv], which forms part of their guidance “Babies, children and young people’s experience of healthcare.” (NICE guidance NG204 August 2021)

East Kent Hospitals University NHS Foundations Trust has an example of a healthcare passport which could be adapted for use with young people[xvi]

SEND support organisations

Council for Disabled Children has a wealth of resources on their site including a checklist for OFSTED/CQC SEND inspections, Outcomes based SEND data dashboard with SEND outcome indicator dataset template. They have nine participation factsheets as mentioned above as well as information on current projects, blogs and case studies.

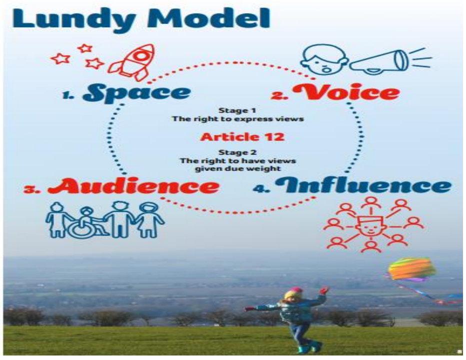
Contact has recorded online learning, co production and forum resources and case studies.[xvii]

Other useful resources are in our “Recommendations” section.

The Research

Methodology and research design

The overarching ethos (methodology) for the project was drawn from the Lundy Model of Participation and articles from the UN Convention on the Rights of the Child.[xviii]



Guided by these principles from the beginning, the project set out to be as accessible and inclusive as possible, to this end an inclusive methodology was chosen. This entailed a flexible design including consultation with young people about methods of engagement best suited to their needs.

Using information gathered from the scoping and mapping exercises at the beginning of the project a programme of visits was planned and undertaken. This included large scale family-oriented events as well as scheduled sessions at Children's Centres, Family Hubs and youth and leisure groups. In addition, events aimed at parents/carers of children with SEND and a large "Life Beyond School" event for young people with SEND were attended. Methods to collect data were tailored to each type of event to promote and maximise participation.

The hard copy publicity materials produced included an easy read version (Appendix F) and two designs co-produced with input from the steering group and young people. (Appendix G)

Evidence of average adult literacy levels (UK) from the National Literacy Trust[xix] were used to inform the wording for publicity materials and questions in surveys. Social media posts all included alt text descriptions (which describes the appearance or function of an image) and the message depicted was also described in plain text. When needed, Makaton (basic sign language) was used as a communication tool with participants.

A flexible design enabled the project to adapt and react to the journey of data gathering, for example when virtual focus group sessions were not well attended parents/carers were contacted with a proposal for a 1-1 interview which elicited a more positive response. Additionally, when gaps were identified in the gathering of data regarding parents/carers/young people's experience of health services three new surveys were created for use in the counties emergency departments.

For adult participants an invitation to leave an email contact was offered at survey or first contact and then followed up with further invitations as the data gathering continued. Two participant information sheets were prepared, one for parents/carers and one for children and young people.

All publicity, information sheets and surveys included a link to Action for Children's privacy policy[xx] with Action for Children's safeguarding policy and procedures followed throughout the project. At all stages participants were asked if they wanted to continue to participate and the procedure for withdrawing their consent explained.

Methods

It is appropriate for research where several, complementary enquiries are being made at the same time to have a mixed methods approach. Additionally, it is a means by which both quantitative and qualitative data can be collected – the quantitative data evidences the overall view of participants and is then confirmed, enhanced and complemented by the rich narrative “deep dive” of the qualitative narrative.[xxi]

Surveys:

Summary of surveys (Appendix H)

Surveys were written with input from the steering group, other professionals who engage with children and young people and with reference to the document “Themes in Detail” (Appendix J). Surveys were sent via email, starting in May 2022, to targeted groups. The first tranche being youth/leisure groups and parent/carer groups, and then subsequently schools and health professionals.

To maximise potential opportunities to engage each email contained; direct links to appropriate surveys, information about the project, project publicity, link to the landing page and a follow up email was then sent four weeks later re circulating the survey link and a further invitation to engage.

In January 2023 an invitation to engage with My Health, My Say was sent to special schools across both counties inviting their school council to take part in a specific “survey style” activity for the project

In August 2022 social media posts were created (Appendix K) and sent out periodically until May 2023. These contained the links to surveys and the hashtag #myhealthmysayafc making the project more visible.

The vast majority of surveys (460/507) were presented face to face at large events or at scheduled sessions at Family Hubs and Children’s Centres. This gave the project team an opportunity to build rapport with potential participants before the invitation to engage was offered. The numbers of surveys completed via this method suggest that this was an effective means of engagement. Participants were given the option to access the survey primarily via a QR code and for those that were unable or unwilling to access the survey this way an offer to complete the survey verbally with a member of the team was always extended.

Focus Groups/Virtual Focus Groups:

18 were convened between November 2022 and March 2023, 80% were virtual and the remainder face to face. They were advertised on Herefordshire’s Talk Community pages, social media and in the venues where they were taking place. Individual invitation emails were sent to participants that had expressed an interest in taking part further in the study. However, none of these were well attended, with a total of 5 participants and the decision was made to discontinue this type of engagement.

Workshops:

Predominantly these were offered to youth groups with one being facilitated for professionals. Initial consultation was made with each youth group to ascertain the most effective way of engagement and to determine the necessity for differentiation of activities according to the level of need of the participants. Where possible children and young people that attend the group were also consulted about their preference for activity. These provided excellent opportunities to gather rich qualitative data from children and young people and opportunities to collaborate with other experienced professionals such as Bromsgrove Youth Hub, Active Youth Outreach Service and Trancakes.

1-1 interviews:

These were facilitated face to face or virtually and presented an opportunity for a “deep dive” into individuals’ own stories. The majority of these were with parents/carers of children with SEND some of whom are not attending school. It is acknowledged that for these participants their story may give rise to some strong opinions about local services and that this is the motivation to access an interview. Two interviews were conducted with professionals working with young people from groups that had accessed workshops.

These four methods ensured the project enabled the widest number of participants to contribute.

Fieldwork and Findings

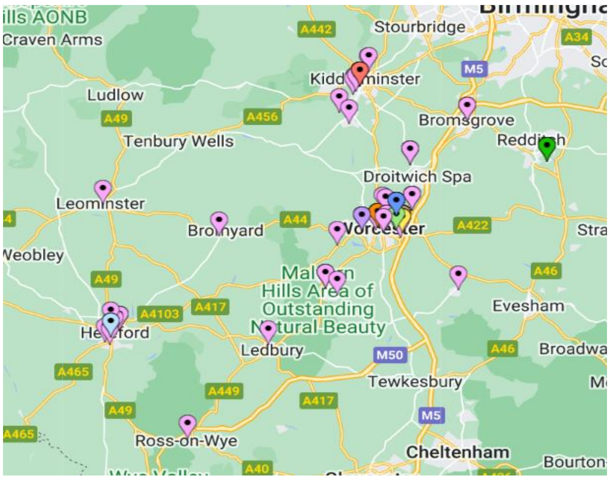
Fieldwork:

The fieldwork commenced in June 2022 and ended in August 2023, in total over a thousand (1015) people actively engaged in the project, 534 women, 99 men, 344 children and young people and 38 professionals. The aim was to gather a large amount of broad-based data at the beginning of the project, to then analyse this looking for emerging themes and then to reflect these themes in focus groups, workshops and 1-1 interviews as the project commenced.

Summary of number of events attended and sessions facilitated by county

Type of contact	Herefordshire	Worcestershire	Cross county
Family Hub/Children's Centre	6	10	0
Youth groups – sports, leisure, social	0	25	0
Large family events	2	5	0
Focus groups	0	3	15
Sessions for parents and carers (SEND)	3	4	**1**
Interviews	2	4	2
Emergency department	2	18	**0**
Totals	**15**	**69**	**18**

Map showing the geographical spread of face-to-face sessions during fieldwork



It was important to reach as wide a geographical area as possible, in total 82 sessions were attended across both counties. Location and postcodes were gathered for the majority of participants and a detailed breakdown can be seen in Appendix L.

Family Hubs/Children's centres:

Sessions were chosen with regard to the project's target groups and the JSNAs for both counties.[xxii] These sessions generally had 3 – 8 parents/carers in attendance. There is anecdotal evidence and some research to suggest that people, especially those with disabilities, have been more reluctant to engage in out of home activities since the pandemic[xxiii] Although this has now largely abated at the beginning of the fieldwork phase this was still a significant consideration and could have accounted for the low number of attendees.

Youth groups, sports/leisure and social:

These were sourced using internet searches and the "Local directory" compiled during the scoping phase. Several groups' Facebook pages were joined as an aid to sourcing upcoming events and key dates via social listening. This sector was particularly keen to engage and arranging and facilitating workshops or attending groups in Worcestershire were swiftly and successfully completed. We experienced more challenges in finding similar groups to engage with in Herefordshire. A spokesperson from The Marches Family Network (based in Herefordshire) stated that they were the only provider of sports/leisure/social groups for SEND in the county, at the time of enquiry they did not have an active youth club.

Large family events:

Were an excellent source of data with participants very willing to engage with the project via surveys. Activities for children to take part in ,whilst parents and carers completed surveys, were taken and resources such as flags, stickers or stress balls given as a "Thank you".

Focus groups:

Either face to face or virtual had very low or no attendance and these were not pursued after 3 face to face and 15 virtual sessions were facilitated in the period between November 2022 and March 2023.

Sessions for parents/carers of CYP with SEND:

Facilitated by local parent/carer groups these were attended regularly throughout the fieldwork phase and facilitated face to face engagement with the project. These provided opportunities to discuss individuals' stories and to invite them to take part further.

One to one interviews:

Provided an opportunity for participants to tell their own story or for a deeper discussion with a professional.

Emergency department:

These visits addressed a gap in the health sector data gathering and were an opportunity to gather quotes from users of a universal primary care service as well as survey responses.

Findings:

This section details the findings of the fieldwork phase. Survey questions, prompts for discussion, workshop planning and snap surveys were designed with reference to general themes, (table below) which were adapted during the project, and themes in detail. (Appendix H)

Health and Wellbeing	Education and Life Choices	Community and Wider Connections
Information Environment Appointments Feedback	School in general SEND EHCPs Aspirations/life choices	Availability and choice Accessibility and inclusivity Feedback

Theme One - Health and Wellbeing

Within this theme we aimed to find out how children, young people and their families access their health and wellbeing services, how do they find out about what is available, how easy is it to find information about health, how accessible and inclusive services are, what is their experience of services like and what are the opportunities to feed back.

Information – where and how do you find it?

Participants were asked where they go to for information about their health and wellbeing. Primarily Parents/carers said that they look online **35%, 5/17,** followed by talking to their GP **21%, 3/17** with speaking to another professional and family or friends both accounting for **14%, 2/17**. Whereas **75%, 3/4** of children and young people told us that their friends and online were where they looked for information.

> *“My friend is the most important thing in my life so I trust her and what* ***she*** *tells me.”*

Young person in Worcestershire

This was confirmed by a professional working with young people:

> *“I think interestingly I'm not sure how effective online health support is, even though young people use online a lot, but I don't think they'll go to any particular trusted sites. They get more information from friends, which isn't always beneficial.”*

Professional working with “Trancakes” a group for transgender young people and those exploring their gender identity

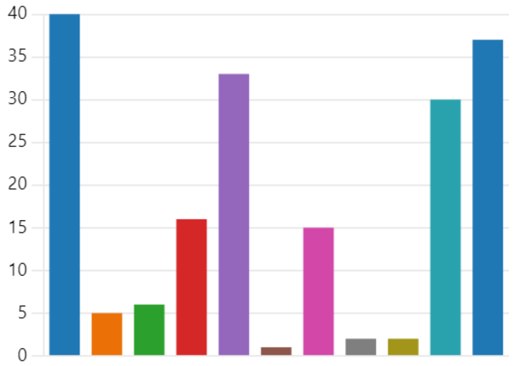
Many young people mentioned that they found the amount of information online overwhelming and that this made it difficult to find what they were looking for or they found several different answers to one question.

Parent’s/carers at the emergency departments were asked two questions about where they had looked for information before attending the department, the first concerned informal sources and the second formal sources of information.

Pie chart to show informal sources of information

Family or friends	29%
Handi Pediatric app	5%
Google or another search engine	15%
Other	8%
None	42%

Histogram to show formal sources of information



GP	21%
Out of hours GP	3%
Pharmacy	3%
NHS 111 online	8%
NHS 111 by telephone	18%
Health Visitor	0.5%
Minor Injuries Unit (MIU)	8%
An app or GP service that I pay for	1%
Dentist	1%
Other	16%
None	20%

Parent and carers explained how they searched:

> *"I only access information from proper health care sources e.g. GP, health visitor, nurse website."* Parent/carer

> *"I keep searching until I find something I can understand. Or I cross reference websites to get a fuller picture."*
> Parent/carer

Information – how inclusive is it?

Several parents/carers and one professional at the SEND conference In Worcester (March 2023) stated that the Worcestershire SEND local offer page was not accessible to screen readers and that the link to sign up for the disability register was not working. During the project Herefordshire have co-produced their Local offer page with input from parents/carers from Parent/carer voice Herefordshire.

The emergency department follow up survey asked parents/carers three questions about information and inclusivity during their recent visit.

1. Staff explained my child's condition and treatment in a way I could understand.
   Always = **62.5%, 5/8**
2. Staff spoke to me/my child in a way that respected my/their cultural heritage.

   Always = **87.5%, 6/8**
3. Staff spoke to me/my child in a way that respected our chosen religion.

   Always = **50%, 4/8**

When we asked young people if the information they were given at appointments was easily understood they told us that face-to-face explanation with written (available in different formats) information to take home was their preferred option (69%). Young people also stated that they wanted tailored information for themselves and their parents/carers (57%).

Information – how useful/understandable is it?

We asked participants “When/if you find information about your child’s/your health and wellbeing do you find it useful?”

Parents and carers

Yes	(71%)	10/17
No	(29%)	4/17

Children and young people

Yes	(67%)	2/3
No	(33%)	1/3

Information – opportunities to feed back:

The emergency department survey asked parents/carers to rank their top five desirable characteristic of the pediatric waiting area, “It is easy to see how to give feedback about my visit.” ranked low being 14th out of 16 choices. In a similar survey about environments, parents/carers were asked to rank their top five desirable characteristics in a general clinic/outpatient waiting area. “There are opportunities for me to give feedback about the waiting area.” had zero rankings.

During May and June 2023 we asked participants how they like to give feedback in general about services **28/75** of parents/carers said they like to do so face to face. However many of them mentioned that to get the best feedback a mixed approach is best so that as many views as possible are heard. Children and young people preferred to give feedback in a creative way with many participants saying they would like to draw a picture, write a poem or rap and several mentioned using signs and symbols to communicate.

Appointments – ease of making and changing:

In a survey specifically asking about appointments participants were asked how they liked to make appointments, responses were split equally between online and by telephone. **50%, 4/8** of participants wanted to receive information about their appointment by text, **38%, 3/8** by email and **13%, 1/8** by letter.

Children and young people **67%, 2/3** said that they found making appointments “Not easy” with some mentioning that it was difficult to change appointments to fit in with their school or college times. We asked parent/carers in an in-depth survey:

How easy is it to make and change appointments?

Appointments – availability and accessibility:

During the fieldwork we heard from participants of all ages speaking about their frustration whilst waiting for an appointment or even getting an appointment, particularly for CAMHS, GPs and dentists. Several parent/carers that attended SEND events in Herefordshire said that the only dental appointments they could get for their children were emergency ones.

When asked about face to face versus virtual appointment the majority of parents/carers preferred face to face **71%, 10/14, 29%, 4/14** “didn’t mind” but zero ***preferred*** virtual. Results for children and young people were similar with **67%, 2/3** preferring face to face, **33%, 1/3** “didn’t mind” but zero ***preferring*** virtual appointments. One participant said that having virtual appointments whilst they were at home or school felt intrusive and may breach their confidentiality. Some young people mentioned that being able to travel to appointments independently was important to them and for some, that lived in rural areas this was not possible.

An experienced youth leader told us:

> *“A lot of our young people say they don’t like going to their GP, especially if it’s about a sensitive subject, or something they don’t want their parents to know about. They see the GP as a family doctor and have the perception, even if it’s incorrect, that the GP will not keep things confidential. We also have a lot of young people that don’t have access to the school nurse service, so again, this can be a problem tor them accessing, say, sexual health services in out rural location.”*
>
> *Youth leader in Worcestershire*

For clinic or outpatient appointments **75%, 6/8** of parents/carers felt that the acceptable waiting time for an appointment would be less than 3 months, whereas **13%, 1/6** of parents/carers cited 3 – 6 months or more than 6 months equally.

Appointment – opportunities for feedback, type of feedback

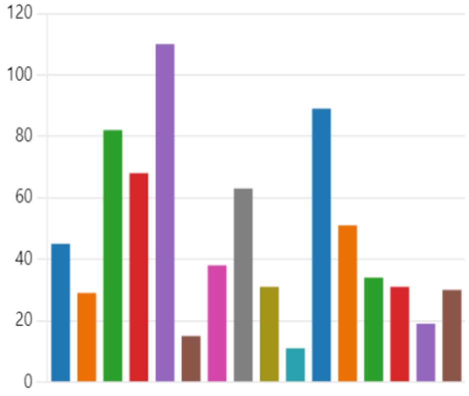
Parents/carers were asked whether they were able to give feedback after their child’s clinic or outpatient appointment, only **1%, 1/14** said yes, **36%, 5/14** didn’t know and **57%, 8/14** said no. Similarly **67%, 2/3** of young people said that they were unable to give feedback following their appointment.

The majority of participants said that they would either like to give feedback face to face or via an individual email or text although more young people cited face to face than adults. Some stated that surveys do not always allow them to communicate all of their feedback as the questions are closed.

Environment:

Parents and carers told us emphatically that the first thing they notice about the environment for a clinic or outpatient appointment is whether they feel it is safe for them and their child. This was reflected in the emergency department surveys where participants were asked to rank their top five from 16 characteristics of waiting areas.

Histogram to show rankings of environmental characteristics



Free Wi-Fi	45
There is lots of information to read	29
There are suitable toilets/changing areas	82
There are toys for my child/children to play with	68
There is a separate waiting area for children	110
There are refreshments to buy	38
There are pictures that look like me and my family on display	15
There is free drinking water available	63
My child/children cannot easily access the outside	31
There are photographs on display of the staff that work here	11
The staff are friendly	89
Staff speak to both me and my child	51
There is somewhere quiet to go if my child is distressed	34
The waiting times are on display and are correct	31
It is easy to see how to give feedback about my visit	19
My partner can wait with me me	30

Accessing information whilst waiting did not rank highly in any of the surveys however in a specific survey about environments parents/carers in a ranking question expressed a preference for:

1. Leaflets that they could take away and read at home later
2. Information that is suitable for children
3. Attractive pictures as well as written information

Participants did want to tell us how important the staff were in their overall experience of health and wellbeing environments, in a specific survey about environments we asked parents/carers to rank their top five of 14 characteristics whilst waiting for an appointment, "The reception staff are friendly and approachable." ranked highest and in the emergency department survey "The staff are friendly" ranked as the 2nd most important aspect of the environment for parents and carers.

Overall experience

Findings indicate that overall most parents/carers and children and young people have had a positive experience of health and wellbeing appointments/interactions in Herefordshire and Worcestershire. We asked parent/carers:

"What has your experience of health and wellbeing appointments for your child been like?"

Always good	Mostly good	Mostly bad	Always bad
20%	61.5%	16%	2.5%

Children and young people were asked several questions that sought their experiences of health and wellbeing interactions:

"If you feel nervous about an appointment, how do the staff make you feel better?"

"Some nurses are reassuring others not so much. Some consultants are a bit gruff. Being friendly and not aloof or gruff usually helps. I.e. being human."

Young person

"What advice would you give to staff to make you feel less nervous about appointments?"

"Asses the person your (you're) seeing by talking to them, ask them if they'd like to be spoken to, if they want to be left alone until necessary, make their personal well-being a priority as well."

Young person

"How could staff be more welcoming?"

"Smile. Cheerfulness and a smile go a long way."

Young person

The "three Questions" survey in May and June 2023 asked parents/carers which services work well and which services do not work well:

"Works well - continuity of care, antenatal care. I had a different midwife for every appointment with my first child so was very impressed with the continuity model that I had for my 2nd child. (Wr4 ruby team midwives) My doctors surgery has so far been fine getting appointments for the children."

Parent/carer in Worcestershire

"Waiting lists to be seen by community paediatrician and ENT consultants are appalling. Speech and language provision for children with hearing loss and access to specialist education/schools is nonexistent. The child development centre itself is the most unwelcoming, outdated facility I've ever been to with my children. However, the specialist communication groups are brilliant and the staff working in this group are experienced and caring."

Parent/carer in Herefordshire

Participants at a group that supports LGBTQ+ young people in Worcestershire were asked to think of the best and worst of their experiences of healthcare.

Best of health services	Worst of health services
Good beds – Sorta comfy Plenty of chemists Local GP is not bad for appointments Free anti-depressants They are quick for GP's Staff at hospital do practical activities – are very nice Nice doctors My GP = good Doctor was lesbian – nice conversation during asthma attack Good KMIU local	Doctors impossible to get an appointment Not enough appointments – hard to get Long time waiting Out of hours prescriptions – travelling 40mins for medicine Trying to get an appointment – have to call at 8:30 but if you work you can't! They need to step up and help people and stop being 'idiots' Talking to neurodivergent people, like they are incompetent Being able to get a doctors appointment The mental health services are in shambles Urgent care/out of hours GP are 20 miles away CAMHS GIDS = terrible (Gender Dysphoria)

Theme Two – Education and Life Choices

In this section we planned to find out how all children experienced education however the focus changed to children with special educational needs and disabilities (SEND) as an initial contact to all schools via e-bulletins didn't elicit any response. Challenges were then experienced with the level of engagement that schools were able to offer therefore we spoke to children and young people about school through other channels and sought the views of parents/carers too via our surveys.

School in general:

In our initial short survey we asked parents/carers In which of the following area they had concerns about their child? (Multiple answers possible)

1. Health and wellbeing = **51.5%, 49/95**
2. Education and life choices = **65.2% 62/95**
3. Opportunities for activities = **48.4%, 46/95**

We went on to ask them what was their **main** concern:

1. Health and wellbeing = **31.5%, 30/81**
2. Education and life choices = **34.7%, 33/81**
3. Opportunities for activities = **18.9%, 18/81**

We asked young people, some with SEND, at a social/leisure group to think of some things that are good, some bad and some things to improve about school.

Good	Bad	Improvements
Field trips They teach us Caring Kind Seeing mates x 2 Help you learn Do lots of events	Being partnered with a new person Too loud Half a headteacher Racist teachers Our teachers are disappearing Too much homework x 3 Too many sheets for work Not always there for students Stressful x 2 School is too small It starts too early Mental health * 3 classes * Unequal treatment Students vaping/smoking outside school	Better routes for school buses Better teachers x 2 Non racist teachers More free school meals More verbal work, less written work Better bathroom doors Need to let us go to the toilet x 2 More fun lessons Treat people better Encourage more out of zone a bit More clubs Stop forcing performances Let us sleep in school Stop assemblies – makes my legs hurt No judgement Use phones at break No bullying No school in really hot weather or really cold weather

**Young person's own words*

SEND:

In a detailed survey parents and carers of children and young people with SEND were asked **"During class activities does your child's school act in an inclusive way for your child?"**

Yes **50% 7/14** No **43% 6/14** Not Sure **7% 1/14**

We then asked **“What could school do to make your child feel more included?”**

> *“Be proactive against bullying, use reasonable adjustments to accommodate needs rather than excluding or punishing the child, share the child’s needs/ disability/ support plan with all relevant staff. Be honest to the child and parent if they can’t meet their needs rather than lying and covering up what they should be doing in law.”*
>
> *Parent/carer in Worcestershire*

Finally, **“What could school do to make your child feel more included outside of class time?”**

> *“They have worked hard at break times to support my son's restricted diet and now include him in main school mealtimes - so he can experiment with eating a school dinner but, ultimately, eat his packed lunch.”*
>
> *Parent/carer in Worcestershire*

> *“Have alert staff that are monitoring behaviour of others, stop and punish those that are bullying rather than ignoring it. Have a safe place where students can go.”*
>
> *Parent/carer in Worcestershire*

Children and young people told us about whether they felt included in class:

> *“I struggle to concentrate and get into trouble so I don’t feel the same as everyone else.”*
>
> *Young person in Worcestershire attending HAF session*

EHCPs:

We asked parents and carers that had a child with an EHCP a series of questions:

“How often were you consulted when the EHCP was being drafted?”

“Do you feel as though your views are included in the EHCP?”

Yes = **57%, 4/7**   No = **43%, 3/7**

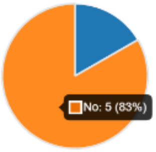
“Is your EHCP a true picture of your child?”

Yes = **14%, 1/7**   No = **86%, 6/7**

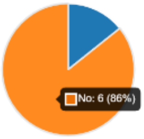
> *“No because the plan currently paints a picture of him years ago and needs to be updated to reflect how he has progressed.”*
>
> Parent/carer in Worcestershire

Would you describe
The EHCP aspirational
for your child?
No = 67%
Yes = 33%

Are the timescales
of the EHCP
being met?
No = 83%
Yes = 17%



Were the contributions
from professionals
good quality?
No = 86%
Yes = 14%



Finally we asked parents and carers about their overall experience of the EHCP process:

“A fight that I didn't achieve alone. I constantly rang SENDIASS who never got back to me (last summer). Mediator was in with LEA so not helpful, Ed Psych wrote incorrect report paid for outside of Worcestershire.”

Parent/carer in Worcestershire

Concerning EHCPs, one young person said that they were consulted “often” and one person said “never”, however neither felt that their views were made an important part of the plan. Neither of these young people thought that they understood their EHCP or that it was a true picture of who they are.

“It was written when I was younger and I have changed.”

Young person in Worcestershire

Aspirations/life choices:

Parents and carers of children and young people with SEND were asked whether **“Careers advice and guidance on life choices discussed at school are suitable and aspirational”**

Suitable = Yes **50%, 6/12**

No **50%, 6/12**

Aspirational = Yes **46%, 6/13**

No **54%, 7/**

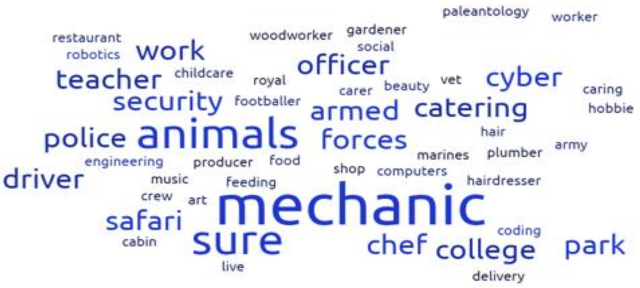
One participants said:

“Staff have little interest in building aspirations as they stick to what they have to teach in set time. No celebration of child's achievements are made - that's up to the parent like trying to encourage them to keep going into this environment in school.”

Parent/carer in Worcestershire

We attended a “Life Beyond School” event for young people with SEND in Yrs 10-13, 104 young people visited our stand and 95 of them answered our questions. We asked them questions about school and their aspirations.

What job do you want to do when you finish school?

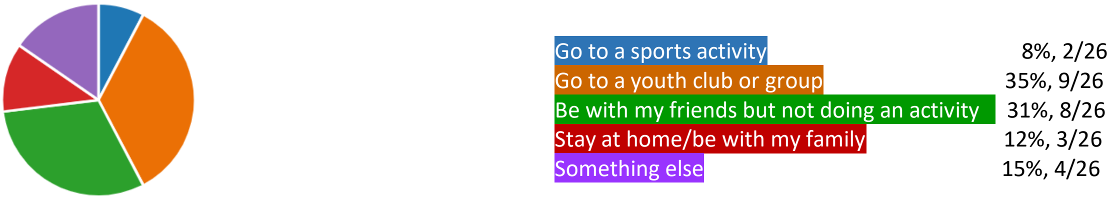


Theme three – Community and Wider Connections

Getting out, taking part in activities, being with friends, all aspects that contribute to wellbeing. We wanted to find out how do the children and young people of Herefordshire and Worcestershire spend their spare time? How do they find out about activities, what choice is there and how accessible and inclusive are they?

Choice and barriers:

We asked children and young people **"When I'm not at school I like to"**



(The four participants that stated "other" mentioned home based activities.)

When we asked young people if there was anything that stopped them from doing activities out of school they told us: (multiple answers possible, top five scoring)

1. They cost too much money **51%, 14/27**
2. There aren't any activities I would like to do **22.9%, 7/27**
3. I am doing all the activities that I want to do **22.9%, 7/27**
4. I prefer to be at home/be with my family **22.9%, 7/27**
5. I can't travel to the activities **22.2%, 6/27**

Parents and carers were asked questions about community and wider connections via the short parent/carer survey, the detailed parent/carer survey and in the "Three Questions" survey. They told us the barriers to accessing activities were: (multiple answers possible, top three scoring)

1. They cost too much **27%, 29/95**
2. There are no suitable activities **25.5%, 20/95**
3. Travelling to the activities is difficult **8%, 9/95**

In addition to requesting “More activities” parents and carers in the “Three Questions” survey spoke frequently about affordability, variety and their difficulty in finding out what was available. Both parents and carers and young people said that they found out about most activities via friends or “Word of mouth”.

Two parents and one professional spoke about the value of nonstandard activities such as car and motorbike interest and maintenance clubs, mental health “Thrive” groups. The report from Herefordshire Voluntary Organisations Support Service (HVOSS) “Different Places for Different People” highlights this and points towards the value of having a youth “Space” where young people can create the group that they want.

In a 1-1 interview with a youth professional they spoke at length how their staff are always listening – gathering informal feedback as well as their more formal route of surveys. They explained that the reason their group is successful is because it is not static, activities reflect the interests of their current users and that they adapt and change on a regular basis. Following the opening up of services after lockdown they had 10 attendees at their youth café now, that number is over 60 and they are considering opening the café on an additional evening.

We asked parents and carers what’s missing?

“There are activities for extrovert outdoorsy kids and for severely impaired kids. But for introvert or social anxious but intelligent kids it's hard to find something they'll go to.”

Parent/carer in Worcestershire

Inclusivity and accessibility:

When we asked about inclusivity and accessibility parents and carers told us:

“Recent swimming lessons ended in a bad experience - I ended the lessons because the swimming teacher did not understand my son's need to move. She was putting him on time out for not sitting still for long periods of time waiting for his go (this was outside the water so he was also cold).”

Parent/carer in Worcestershire

A professional working in a group supporting LGBTQ+ children and young people spoke about those living in rural areas:

“I think they struggle to do that (after school clubs) because even if it's in school, if it's after school, the buses go at particular times, so they can't then get involved in that and some of them live right out in the sticks. So unless you've got a parent, maybe taking you somewhere, I think that's really tricky.”

Community:

We asked young people what one thing they would change in their area to make it better:

“Better everything really but mostly not be so old - modernise it (Ledbury & Hereford).”
Young person in Herefordshire

“More things to do so we can walk and not get on a bus which is very busy and crowded.”
Young person

Out of 37 responses four young people expressed their concern about fast and noisy traffic and one young person with SEND said:

“My long journey to school it makes me feel tired and then I get told off in first lesson for yawning.

Analysis and Conclusions

Health and wellbeing

Who did we speak to?	What did we ask them about?	How did we ask them?
• Children and young people • Children and young people with SEND • Parents and carers • Parents and carers of children and young people with SEND • Professionals	• Accessibility • Appointments • Environment • Feedback • Inclusion • Information • Services	• Focus groups: face to face or online • individual interviews • surveys • workshops

Headlines

When asked about their overall experience **85%, 79/95** said that it was “Always good” or “Mostly good”.

65%, 9/14 of parents and carers said it was “Not easy” or “Very difficult” to make appointments. This figure was **67%, 2/3** for children and young people

When looking for health and wellbeing information **75%, 3/4** of children and young people use informal sources whilst for parents and carers the figure is **49%, 7/15**

Before attending the emergency department **63.5%, 99/156** of parents and carers consulted another healthcare professional.

Analysis:

Information:

Most people want a central source of general health and wellbeing information. They want specific information to be tailored to their needs, to be verbal initially, backed up by written information. Children and young people want the information they receive from healthcare professionals to be tailored to them but they are happy for their parent/carer to receive their own version of the information too.

All participants were happy with the amount of information they receive from healthcare professionals.

Inclusivity and accessibility:

The majority of services are accessible and inclusive and environments are welcoming with friendly staff. However many young people want to be able to access services independently and perceptions of confidentiality and ability to travel prevents them from doing this.

Appointments:

When residents of Herefordshire and Worcestershire receive primary health services they are happy with them, however the waiting times for services are overwhelmingly criticised and cause distress.

However for secondary care services it appeared that the frustration of waiting for an appointment or being able to get to see the healthcare professional that they wanted sometimes, made parents and carers more dissatisfied with the service that they then received.

Parents and carers of children and young people with SEND:

Parents and carers of children waiting for a diagnosis that may include special educational needs (SEN) or disability find waiting times for assessments far too long and feel that their children do not receive appropriate support in the meantime. Parents and carers of children with disabilities or special educational needs were more likely to have difficulties with secondary care services, sometimes because of the number of appointments that their child needed to attend.

Parents and carers of children and young people with SEND also called for one system to be in use across all primary and secondary healthcare that describes, for example, their communication style, their preferred environment and the way they may present at appointments, as they and their children had encountered difficulties when healthcare professionals had not been aware of their child's condition, for example when attending the emergency department.

Feedback:

Giving feedback was not a priority for most people but sharing it immediately and using different techniques were the most important considerations. Current feedback mechanisms were not seen as engaging or effective.

Patients would like to give feedback, predominantly verbally, but were not aware if they were able to or how to following an appointment. For example the level of language on the 'friends and family paper' based feedback form for children and young people is suitable for literacy level 3 (9 – 11 years)[xxiv] but has monkeys illustrating the text, possibly meaning it is targeted at a younger audience. Participants said that they would be more likely to feed back if there were quick and simple ways to do so, for example by text or via a feedback tablet within the department/clinic they are attending,

Conclusions:

1.Parents, carers, children and young people want it to be easier to make appointments

2.Parents and carers want waiting times to access secondary care services to be reduced

3.Parents and carers of children with SEND want it to be made easier to manage many different appointments

4.Parents and carers of children with SEND want it to be made easier to keep track of the many different services that their child needs, their assessments and timescales in relation to their child's EHCP

5.Participants wanted consistency in information, advice and that different services are aware of their child’s condition before they attend

6.Patients want to give immediate feedback in simple formats

> *“I want to tell them the nurses was good, I doing a happy face, I want to draw me with my bad leg and doctor and mummy. Where do I post it in?”*
>
> Child asking for help to fill in Child and Young Person Friends and Family form at WRH

> *“ I just think if there was one system so that everything to do with that child, whether it's speech and language reports…EP reports, should be on one system and Worcestershire children’s first can access that and pull off everything.”*
>
> Parent/carer that attends SWANS group

Education and Life Choices

Who did we speak to?

- Children and young people
- Children and young people with SEND
- Parents and carers
- Parents and carers of children and young people with SEND
- Children and young people attending a special school

What did we ask them about?

- Are schools offering a good service?
- How is your SEND child doing in maintream school?
- EHCPs
- Aspirations for SEND children

How did we ask them?

- Focus groups: face to face or online
- individual interviews
- surveys
- workshops

Headlines:

65.2%,62/95 stated that education and life choices were a concern for their child and **40.7%, 33/81** said it was their main concern

Young people with SEND told us the best things about school were their lessons and friends.

50%,7/14 of parents/carers thought that class activities at their child’s school were inclusive.

86%, 6/7 of parents and carers said that they were never or not very often consulted whilst their child’s EHCP was being drafted

Analysis:

Are schools offering a good service:

Parents and carers of children without SEN or disability were happy with the service that school offered, saying that they had got the school of their choice and that their children enjoyed going there. However when we spoke to our targeted group of parents and carers that have a child with a disability or SEN we found that, almost exclusively parents and carers were unhappy about either the process for getting an EHCP or whether it was being implemented.

SEND children in mainstream schools:

During our 1-1 interviews parents and carers were invited to tell their story, frequently they spoke passionately about their journey with their child and some parents and carers had distressing stories to tell. Many of these parents/carers had made the decision to take their child out of school settings.

EHCPs/aspirations for SEND children:

Two thirds of parents and carers that spoke to us about their child's EHCP said that it was not aspirational for their child. Six out of seven said that the contributions from professionals were not of a good quality and five out of six said the timescales were not being met. We did not find any parents or carers that were entirely happy with all aspects of their child's EHCP.

Children and young people said that their plan was not a true picture of them and that they wanted it to be updated more frequently as they grow and change. Children and young people had ideas and aspirations about life after school and were clear about how they needed to achieve these.

Conclusions:

1.Many parents and carers have had a negative experience of the EHCP process and want to be more involved at every stage

2.Parents and carers want timescales to be met, reviews conducted on time and for it to reflect their child more accurately as they grow

3.Children and young people want their EHCP to be a more accurate reflection of them and for it to be updated as they grow

4.Parents and carers want clarity on whether their child's school is adhering to the EHCP

5.Parents and carers want everyone to share achievable and ambitious aspirations for their child

> *"CDC works well- audiologists and team are lovely and caring. Getting support with education and getting an EHCP seems to be more of a battle than supporting!"*
> Parent/carer in Herefordshire

> *"I (Want to be) an architect, I need good grades and to go to university. (Who will support you?) My parents and my teachers are there for me."*
> *YP at "Life Beyond School" event Worcestershire*

Community and Wider Connections

Who did we speak to?

- Children and young people
- Children and young people with SEND
- Parents and carers
- Parents and carers of children and young people with SEND
- Professionals

What did we ask them about?

- Which services are available in your area?
- Which services would you like to see?
- What are the barriers to accessing services?
- How inclusive are they?
- What's the best thing about living here?

How did we ask them?

- Focus groups: face to face or online
- individual interviews
- surveys
- workshops

Headlines:

35%, 9/26 of young people like to go to a youth club or group in their spare time

Cost, **51%, 14/26** was the main barrier to young people accessing activities and **22%,6/26** found travelling to the activities difficult

Nearly **23%,7/26** of children and young people said that they were accessing all the activities they wanted to

Only **8%,2/26** of young people wanted to go to a sports activity

Analysis:

Availability, choice and barriers:

There was a distinct difference in both parents and carers and children's and young people's views of activities dependent on their location. Families within the major population centres of Hereford, Worcester and Bromsgrove said there was a wide choice of activities with many of them being free, especially during school holidays. In more rural areas families may have the option of one or two sporting activities, such as football or swimming operating nearby but would need to travel to access varied leisure activities such as Lego clubs or acting.

A third of young people wanted to be with their friends but not taking part in a specific activity. This was reflected in the popularity of clubs such as Malvern Cube and Perdiswell Young People's Leisure Club where a variety of activities are on offer and children and young people are consulted regularly about what they would like to do. This youth leader spoke about how youth work has evolved:

> *"…one of our trustees, she was a youth worker back in the 70s, 80s and I think that it was a lot more young person led in the sense that they would just rock up, parents wouldn't necessarily know where they were or being too bothered but I think it's a different generation now and parents on the whole absolutely do want to know that they're sending their young people to, you know, to somewhere safe."*

Accessibility and inclusivity:

The same leader spoke about the importance of a diverse staff team:

> *And we've got, as you probably notice, an eclectic bunch of youth workers. I like to think we've almost got a youth worker for every type of young person so that they're reflecting the young people we're working with. So of our 64 attendees last week half of them were in receipt of free school meals or were from the refugee community or were from areas clusters within the 10% of most deprived areas within the whole country. You know, there was some really sort of like challenging young people in that mix with special educational needs, those that have been excluded from school.*

We saw that all of the clubs we visited are inclusive, offering a variety or differentiation in activities to enable everyone to take part. We heard from a few parents and carers about bad experiences they had had for example a sports coach that would not accept a child's asthma inhaler being available and a swimming coach that could not accommodate the need for constant movement from a child that has been diagnosed with ADHD.

Conclusions:

1.Children and young people want to be with their friends and be able to choose the activities that they do

2.Parents and carers want widely advertised, low or no cost activities for their child in a safe environment

3.Parents/carers and children/young people want alternative activities to choose from rather than just sports

4.The majority of parents/carers and young people think that Herefordshire and Worcestershire are good places to live

"Days like this where I can do activities with my family and there's something for me and my brothers and sisters."
Young person at Ronkswood Community centre fun day

"A gaming club, I do gaming at college and I am developing a game based on Greek mythology."
"A car maintenance club."
"A sports club, rugby and get really muddy."
"A book club, something quiet, not sports."
"I like doing crafts and art things, I volunteer to help at art club. Or a music club"
Young people with SEND at Perdiswell Young People's Centre

Gathering feedback:

A consistent and overarching theme throughout this enquiry has been about gathering feedback, the "Who, what, where, when, why, how?" of data collection. All of our surveys, focus groups, workshops and 1-1 interviews included questions on this subject.

We looked at how feedback is currently gathered and how organisations such as national charities, local authorities and local youth groups gathered theirs. One youth leader told us:

> "Before I joined, we used to have a dedicated youth forum that met I think it was fortnightly, but numbers were very, very low and it was pretty much the same two or three young people from my sort of understanding of what happened I think if you're trying to force young people to sit down and share their ideas, it's not necessarily always the best way at all. You either hear what they think you want to hear or they just garble out something quick so they can get back to doing something that they want to actually do."

They went on to speak about how their staff are always listening, gathering feedback and ideas from the young people as they work with them. After the sessions they discuss any suggestions for activities, changes that could be made or how the young people are feeling about the group at a review. They said that they think this is one of the main reasons their youth group is so successful.

Conclusions:

1. Gathering feedback, consultation, participation and engagement need to be dynamic and ongoing – not a "one off" exercise
2. The building of relationships with and use of existing services are key to ensuring the maximum number of voices are heard
3. Children and young people need innovative, fun and appropriate activities alongside any consultation or feedback enquiry to maintain their enthusiasm and attention

Recommendations

Participation and engagement:

- Create a dynamic participation team that builds relationships with existing groups in the community and takes consultations out to them.
- This would encourage a wider and more diverse range of voices to be heard and promote the building of links to underrepresented communities.
- Allows flex of the resource to work across different parts of the ICB

Health and Wellbeing:

- Create an online portal where parents and carers can make appointments and, specifically for parents and carers of children and young people with SEND, keep track of reports and the progress of their child's EHCP.
- Consider creating "hubs" that can be a single point of access for children, young people and adults that may be diagnosed with a condition of neurodiversity. These could have a central phone contact for referrals, be used for assessments, appointments, ongoing support and information for patients.
- A "passport" or "all about me" system for children and young people with SEND so that clinicians are able to meet their needs and know how they may present in advance.
- Provide and promote the opportunity, especially for children and young people, to give immediate feedback in innovative ways. For example drawing or feedback tablet

Education and Life Choices

Findings in this sections align with the difficulties that parents and carers expressed in regard to EHCPs and are already being addressed via the OFSTED/CQC SEND inspection process and national strategic reforms.

Community and Wider Connections:

- Create spaces that are multi functional where children and young people can meet with their friends and choose and co produce the activities they want to do
- Advertise more widely, for example through school newsletters, local services and events. Consider additional formats as well as online
- At midwife/health visitor new baby appointments/visits consider asking a question about whether parents have access to online services and offer information about services accordingly

Other useful resources

- Team EPIC – Working with a group of young people with PMLD and complex communication needs to create a conference presentation about "top tips" for participation Ref xii

- Advocacy for children and young people with disabilities and emotional needs – young people's advice about hearing their voice Special Measures Project (corc.uk.net)
- Make Your Mark – UK youth parliament annual survey British Youth Council | Make Your Mark - UK Youth Parliament (byc.org.uk)

Newsletter subscriptions

Anna Freud Centre - Anna Freud National Centre for Children and Families (list-manage.com)

Contact - Sign up to parent carer participation updates | Contact

Council for Disabled Children - Council For Disabled Children (list-manage.com)

Mind of My Own - Home - Mind Of My Own Mind Of My Own

Nasen - Member Newsletter | Nasen

National Centre for Family Hubs - National Centre for Family Hubs

SEE Change Happen - Inclusion Bites Read - SEE Change Happen: The Inclusive Culture Experts

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[xxiii] Home - Centre for Cultural Value last accessed Dec 2022

[xxiv] What do adult literacy levels mean? | National Literacy Trust last accessed July 2023

Appendices

A Feedback from YP

B Stakeholder Mapping Exercise

C Children’s Dashboard 2022/23 December 2022

D Children’s Dashboard 2022/23 December 2022

E Croydon Prescription Pad (excerpt)

F My Health, My Say easy read leaflet (excerpt)

G My Health, My Say leaflets

H Summary of Surveys

J Themes in detail

K Social Media Posts (example)

L Participants by County