An All Age Disability Service for Kirklees

Clare Costello
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Healthwatch Kirklees
Unit 11/12 Empire House
Wakefield Old Road
Dewsbury
WF12 8DJ
Tel: 01924 450379
Email: info@healthwatchkirklees.co.uk
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Executive Summary

Kirklees Council are considering developing an All Age Disability Service (a working title). The aim would be to reshape teams that currently work with children and adults with a disability to become an all age disability service – one that maximises the independence of children and young people in preparation for adult life and enables a seamless experience for disabled users in Kirklees.

Healthwatch Kirklees have discussed this idea with people with a disability and their parents/carers and the following themes emerged:

- People feel almost all the care, support and services mentioned in the engagement process are important to them.

- Some people feel that having an integrated, All Age Disability Service in Kirklees will be a positive step which should alleviate difficulties at times such as transition from children’s to adult’s disability services.

- There is some concern about the idea of having an All Age Disability Service; some people feel the integration of services is a cost cutting exercise and are fearful of either adult’s services or children and young people’s services losing funding

- People want to have a very clear idea of how an All Age Disability Service would impact them - what will change, what will stay the same, what will there be less/more of?

- Many people value the support they access at community-based settings, but some spoke more negatively about the help and advice they have received from statutory organisations.

- People would like good quality support which is accessible to all and is flexible and responsive to the needs of people with a disability and their parents/carers.
1. Introduction

Kirklees Council are changing the way they work and over the next 3 years they describe becoming a New Council which will focus on people’s health and wellbeing, economic resilience and strengthening early intervention and prevention. With this approach, the council aims to support families sooner, prevent problems arising and reduce the demand for more costly support at a later date.

The council’s intention is to:

- Support communities to do more for themselves
- Keep vulnerable people safe and in control of their lives
- Focus on the things only the council can do.

As part of the council’s changes, they are looking at their approach to supporting people with disabilities - both children/young people and adults.

At the moment the council has separate disability services for children/young people and adults. They are now exploring the opportunity of creating an integrated disability service which will bring those services together to form an ‘All Age Disability Service’ (working title). The council envisage that having such a service will bring consistency, clarity and ultimately better quality services and support for people with a disability living in Kirklees.

The idea of an All Age Disability Service is about more than the savings which the council needs to make, they believe it’s about doing things radically different to ensure that people who need help and support get the best quality care, information and advice available not only from the council but the partners they work with both in the public, independent sector and the community.

The council envisage that An All Age Disability Service would fit with their programme of Early Intervention and Prevention (EIP) which is about reducing demand, preventing family breakdown and maximising independence. The aim of EIP is to:

- address problems at the earliest opportunity before they escalate
- work in partnership to improve outcomes for everyone, and
- help more people in the most appropriate way with the limited amount of money we have available to us.
Kirklees Council’s ideas for an All Age Disability Service mirrors lots of thinking which is being done up and down the country - it builds upon innovations which have already been made by some and they endeavour to make the most of the opportunities already out there. Staffordshire County Council, Coventry City Council, Wolverhampton City Council, Manchester City Council, Doncaster Metropolitan Borough Council and Gloucestershire County Council. The councils mentioned are at varying stages of their journey in the direction of having an All Age Disability Service, for example Staffordshire County Council have created their ‘Living My Life, My Way’ commissioning strategy which outlines their vision, ambitions and commissioning priorities for disabled people. Coventry City Council already have their All Age Disability Service up and running. Kirklees Council are looking at developing a similar service to those which exist in other areas.

2. Why are we focussing on this?

In November 2015, Kirklees Council asked Healthwatch Kirklees to undertake a piece of engagement in relation to an All Age Disability Service - to speak to people with a disability and their carers with the aim of gathering feedback on what people think to this idea; asking what is important to people, what works well and what needs to be improved.

Healthwatch Kirklees have a statutory role to ensure people are involved and have their opinions represented when service redesign is being considered.

3. What we did to gather opinion

Pre-engagement

Some pre-engagement documents have been reviewed, themed and taken into consideration as part of this engagement. The documents which have been looked at are:

- General Inclusive Sport and Physical Activity Consultation - West Yorkshire Sport November/December 2013
- Carers Consultation Feedback - Kirklees Council October-December 2013
- Healthwatch Kirklees’ ‘Welcome to My World: Issues affecting people in Kirklees who are Deaf and hard of hearing as they interact with health services’ report - February 2014
- Engagement with Parents of Children with Addition Needs (PCAN) September 2015
- Kirklees Council’s Budget Consultation - 26 October - 6 December 2015
The themes from this pre-engagement are shown in Appendix 1 and, where relevant, these are referred to in the findings below.

**Healthwatch Kirklees engagement**

In order to find out what people think about the idea of having an All Age Disability Service in Kirklees, Healthwatch Kirklees sought feedback in a variety of ways from people with a range of disabilities and their carers during November and December 2015.

The approaches used were:

- An [online survey](#) which asked how important various things are to people in relation to the 8 principles which the council have identified as important to underpin the formation of an All Age Disability Service:
  - Ensuring the best possible start in life for people with a disability.
  - Having services and communities which are as inclusive as possible.
  - Developing and maintaining people’s independence.
  - Enabling everyone to making a contribution to society, where this is possible.
  - Giving people choice and control over their care and support.
  - Enabling people to be as healthy as possible.
  - Planning for the future, including smooth and seamless transition between services.
  - Having a ‘whole family’, lifelong approach to care and support.

  The survey link was distributed widely across Kirklees (Appendix 2). Paper copies were made available and an easy read survey was available on request.

- Opportunity to attend a workshop where group discussion and activities would generate feedback from people with a disability and their carers. Information about the workshops was circulated widely and Kirklees Sensory Service also created a BSL video to promote the workshops to the Deaf community.

- Staff from Healthwatch Kirklees offered to go along to any disability groups or to meet individually with people with a disability and carers during November and December.

- Reflecting on the pre-engagement work done by Kirklees Council staff and other organisations.

Healthwatch Kirklees understand that the council will engage separately with staff to gather their thoughts on an All Age Disability Service for Kirklees, although the
council have already agreed some underpinning principles with the programme team and partners.

Following on from this engagement, the council will consider the best way to consult with people about future plans for disability services in Kirklees.

4. Results

The findings outlined below have been taken from:

- 135 online survey responses
- 19 easy read survey responses
- 4 group discussions at Milen Care in Batley (2 with men’s groups and 2 with women’s groups - total of 64 people engaged.
- 1 group discussion at Pakistani Association in Huddersfield - total of 9 people engaged.
- 1 group discussion at an exercise group in Huddersfield for people who are blind or visually impaired - total of 8 people engaged.
- 2 groups for Parents of Children with Additional Needs (PCAN) - most people just completed the surveys but additional feedback was given from 4 people.
- 1 person from Howland Centre gave feedback in a 1:1 meeting.
- Reviewing the pre-engagement work completed by the council and other organisations with both staff and service users.

A summary of the demographics from the online survey are shown below. A full breakdown of demographics are shown in Appendix 3.

- There were almost the same number of responses from males as from females.
- There were more responses from South Kirklees than from North Kirklees
- Most responses were from (or about) people with a disability aged 17 years or younger (24%)
- Most responses were from a white ethnic group (83%)
- Most people who responded had a learning disability (61%), communication disability (43%), mobility disability (36%) or physical disability (35%)

The planned workshops didn’t take place as there were not enough people who expressed an interest in attending, despite the events being widely promoted across Kirklees. This could have been due to a number of reasons including the time of year (December), organising care or travel arrangements, and perhaps people who completed the survey online didn’t feel the need to attend a workshop.
The findings are presented according to the 8 headings used in the survey, although not all comments were taken from survey responses; where comments are from group discussion this is indicated.

The overwhelming response to the survey questions is that all support and services are important to people - the difference between the most and least important themes or services was very small for most questions. However, the wealth of varied and detailed comments received adds context and clarity to the responses.
We asked 3 specific questions of children and young people with a disability and parents/carers of children and young people with a disability. 58 people (44%) responded to these questions which relate to the services, support and care needed to ensure the best possible start in life.

Ensuring the best possible start in life for people with a disability and their parents/carers
The most important things for people are:

- Issues being responded to early
- Information and support following diagnosis
- Having easy access to information and advice

The things which some people didn’t know about or felt were not relevant to them were the statements around childcare.

The most important things for people are:

- Young people’s activity services - support during school holidays
- Young people’s activity services - support on a weekend
- Care and support provided in the family home

Some people commented on how difficult they have found it to get their child diagnosed; very long waiting times, lack of support whilst waiting for an assessment or diagnosis and then little support once a diagnosis has been made were all things mentioned by parents and carers of children with a disability.
Feedback given from those attending a PCAN support group (pre-engagement, appendix 1) suggested that some parents felt their concerns about their child's health, development or behaviour were not taken seriously and that waiting times for assessment were far too long.

*My child has been waiting for a diagnosis now for over 2 years but in the meantime support has been minimal...*

*I have had no support in waiting for or getting a diagnosis*

*Waiting for assessment is very difficult. They put me on a parenting programme, increased my medication and didn’t believe me when I said my child had problems. Lots of parents end up getting depression because it’s such a difficult process*

*After diagnosis, I just got a big form to read through and make sense of it myself.*

*Most of them [support and services] don’t exist at the moment*

*We were only able to get a diagnosis within a reasonable timescale by paying £2500 for a private assessment and diagnosis. The CAMHS waiting list was so long we were told it would be 2 years before the process began and probably 3 years until we got a diagnosis. This is DISGUSTING we were all struggling as a family and needed access to support which just wasn’t available. I also feel that once a child is diagnosed there should be 6-monthly reviews with a paediatric psychologist/nurse to discuss how things are going and to offer advice going forward. Presently, our children get diagnosed and we get no support at all from the NHS. We get peer support from support groups but that is it.*

*Difficult to access without a fight. Nothing to support post-diagnosis of autism, completely alone*

*We got a diagnosis with no follow up help/advice. We had to research everything off our own back - nothing GP or social care led. Nothing but bad memories come to mind about the whole process of being diagnosed. When professionals are involved it would have been far easier if they had details of diagnosis prior to appointments/meetings, rather than me as the parent having to go over and over the same history with each professional*
Parents of children and young people with a disability emphasised how important support groups are to them.

In the pre-engagement with parents attending a PCAN support group, people commented on the positive nature of the support they received from school, health professionals, outreach services and community-based services (appendix 1).

*Support groups have been invaluable for me as a parent and unfortunately have been the only way I’ve had access to information and advice*

*I find support groups invaluable for sharing information and strategies. I find that in school there is a lack of understanding from teachers about how the disability affects my child*

*PCAN/Sprout*- lifelines!
* a gardening club for children and young people with additional needs

*My son goes to a social group on a Saturday which is very valuable. It is about the only thing he wants to leave the house for and gives me the opportunity to speak to other parents in similar situations*

Some parents report having very little support and some say they have been unable to access support because their child doesn’t meet certain criteria, or doesn’t have a ‘severe’ disability and they describe the impact this has had on their lives.

Pre-engagement with parents who attend a PCAN support group also highlighted a lack of information and a feeling of not knowing who to go to for advice and support (appendix 1).

*I have not received any of the above mentioned support. If it is available then I would like to be able to access it.*

*Respite is very important but never had it. Would all be very important but none exist.*

*At the moment your child needs to be extremely disabled to get anything. If they are only moderate or slightly then the services just say she doesn’t meet the criteria, go away*

*There is a large gap in accessing support for children with mild to moderate difficulties - the focus seems to be on the severe disabilities - others often don’t fit the criteria for support and this can lead to the parent and child in crisis*
Support for the family is vital. My daughter has a role in caring for her disabled brother and she receives very little support. She was turned down from ‘young carers’ and yet she needs support to help her understand her brother’s behaviour - to be with other siblings going through a similar experience.

We get our support from groups which are run by charities, I have not found any support offered by the council.

You [Kirklees Council] are failing to fund vital places of support like Sprout. If Sprout goes I will have nothing to help get through the weekend. It’s disgusting that you are turning your back on Sprout when it helps so many families and has stopped my child being put into care. Kirklees provides nothing for my child with an autism diagnosis.

We really need activities in the rural areas of Huddersfield - both on weekends and during the school holidays....to include kids with milder needs too, who may not be obviously disabled.

This survey is presented in a way which suggests services and support are available to parents but this is just not the case. It’s insulting to be asked how important these things are to us when we don’t get any of this support (PCAN group)
People were asked about the type of support they would like to see in Kirklees:

Parents and carers came up with the following ideas for new approaches, facilities and support they would like to see in Kirklees:

A purpose built disability information centre and training for staff under one roof would be wonderful

Parents and consultants should be made aware of NHS funding and other funding streams. Often the consultant or GP cannot fully help a carer because they are not informed of current changes or opportunities of help that the patient and carer could access

More support for parents with learning difficulties who can’t research or understand their child’s conditions

More support for families and siblings

I think the support provided by the Surestart centres need to be a lot more specialised. It is demeaning to be sent on a very basic ‘household’ skills course
or parenting course when what the parent needs is information on ASD. At times I have felt like I have done something wrong as a parent when actually I am doing incredibly well under difficult circumstances

Emergency support in times of crisis for parents and siblings

There needs to be more training courses for parents for how best to deal with their children’s special needs

Sibling support and family support. Counselling for family and activities bringing families together like SPROUT. We need more behaviour support, resilience training for parents. More support for siblings in school and out of school as their needs not always met

Tourette’s support groups

More availability of respite. More availability of holiday clubs

Help from social services as there are no clear ways of accessing the support you may need. We have relied on our own family for this as we don’t know how to access respite

Pre-engagement with a PCAN support group (appendix 1) found that parents would welcome a single point of contact to help navigate, inform and advise. A comment was received in this engagement to suggest a single point of contact would be useful to people.

A single point of contact would help. Not different people in education, social services, NHS or day placement, eg an allocated liaison worker
Having services and communities which are as inclusive as possible

All people with a disability should have opportunity to be fully included in all parts of the community. This should be the case however old you are, and whatever your disability might be. Thinking about your own experience, please rate how important each care/support service is to you or the person you care for:

Where inclusivity is concerned, a large majority of people felt all the statements were either ‘very important’ or ‘important’.

People want information to be accessible, whether that’s having information readily available in places where people regularly go for support or having information in a format or language which is understandable to them. People who don’t speak English or don’t have English as their first language clearly find this to be a barrier when accessing services and support.

*Easy to read info - I can’t read so important*

*Large print and braille not immediately available*

*The height of signage plus the distance away can make them painful and hard to read at times*

*Lots of services are moving from Batley to Dewsbury and then from Dewsbury to Huddersfield. We need more services closer to home*
Important for people in wheelchairs to get in to buildings

Would love local services to embrace social media more

Being allowed and able to go to “normal” people’s groups

Everywhere being accessible, ie ramps that can be pulled out

Online support is of no use to us. Everything is being moved over to online service but that is no good to us (Milen Care – women’s group)

Someone from Gateway to Care should come to places like Pakistani Association to explain what they do, what’s available. They should publicise their services more (Pakistani Association, Huddersfield)

I wouldn’t use Gateway to care due to language barrier, no transport, not seen as a local service (Milen Care – men’s group)

Gateway to Care is no good to us. You cannot get through on the phone and when you do they don’t have anyone that can speak our language (Milen – women’s group)

Language and transport is a barrier to accessing services and feeling inclusive (Milen – women’s group)

Important to have access to self-care advice and information - but it should be accessible to people like us who don’t communicate in English (Milen - women's group)

Carers who don’t speak English don’t feel comfortable going to the main groups as they don’t feel like they fit in or feel comfortable in groups (Milen - women’s group)

Accessible buildings are very important. Services need to be central, in town so that people can get to them without crossing busy road (Blind and Low Vision group)

Many elderly, disabled people are deaf or hard of hearing and struggle with any phone conversations (Milen - men’s group)

People talked about how they wanted others to have a better awareness of disability to help alleviate misconceptions and improve understanding of some of the issues
faced by people with a disability. Some people described how they have experienced discrimination or bullying because they have a disability.

Lack of understanding was also a theme in the ‘welcome to my world: issues affecting people in Kirklees who are Deaf or hard of hearing’ report (pre-engagement, appendix 1) where people described experiencing lack of patience, rudeness and poor customer service from receptionists.

*Perceptions of people with autism are improving. Perhaps better education about disabilities should start in schools at a young age*

*People in the community are uninformed about disability. If the disability is obvious (e.g., Down’s syndrome or use a wheelchair) there is usually support. However, if someone has a ‘hidden’ disability such as autism there is little awareness or support*

*Inclusion is extremely, extremely important because having more inclusive communities in Kirklees become as a result of disabled people integrating more by participating in activities that people without disabilities participate in will reduce isolation and loneliness of disabled people. Integration will allow both disabled and non-disabled people to develop friendships*

*My child has been a target of hate crime in my community. My child is bullied for being autistic whilst in school. Families with hidden disabilities are failed by Kirklees*

*Used to live in a home and got bullied... I’m happy where I am now*
Developing and maintaining people’s independence

People with a disability should be supported to live independently with their family and friends, where possible. Thinking about your own experience, please rate how important each care/support service is to you or the person you care for:

All the statements around maintaining or developing independence were ‘very important’ or ‘important’ to people. The thing which people either didn’t know about or didn’t feel was relevant to them was ‘access to assisted living devices’.

One person described how they felt unsupported since becoming registered blind:

*Feel let down on so many of these points. I was registered blind at 31. Luckily I am a pro-active person because I have been left to get on with it. Visual impairment affects every aspect of my life yet the only assistive aid I received was a guide cane. I have to buy others myself but these are always a lot more expensive than normal versions. I have also had to teach myself Braille and how to use assistive technology. Local blind centre in Batley does not cater for people of working age*
Having accessible transport is important to people so that they can remain independent. However, some people with a disability said that public transport services are often difficult to use and this presents an inequality of service for this group of people.

[I would like] disabled taxis available on a Sunday and Information on the criteria for the access bus. Don’t agree with how wheelchair taxis charge more for same journey as someone not using wheelchair taxi

There are not enough bus services in Kirklees. Transport is no longer accessible. I have to walk half a mile to get to the bus stop

Without accessible transport, many opportunities can’t be accessed

My nearest bus stop is half a mile away. As a disabled person I cannot walk that far

Being able to have 1/3 off all travel rather than free so I can pay too

Some buses are not accessible (Blind and Low Vision Group)

Some people have to pay for a bus into town and then catch another bus out of town so that they can get to the services they need....sometimes have to allow 1 hour travel time to get there (Blind and Low Vision Group)

Nobody uses access bus - didn’t know about it (Pakistani Association)

Use access bus to get to places. If it didn’t exist I would have to rely on my mum as I can’t drive and can’t manage to use buses or taxis. I have to work round the times that the access bus can pick up or drop off (Howland Centre)

People described the adaptations which they rely on for daily living and some people detail the difficulties they have experienced in accessing the equipment they need.

It has taken 3 years to get a downstairs toilet and adaptations for a lift

I am disabled due to deafness/hearing loss and am dependent on certain devices to help with living independently, eg a special highly amplified telephone; a smoke alarm with separate flashing light device and vibrating pad for under pillow to alert me in case of smoke/fire in house

Very hard to get adaptations, always told there are no resources, no funds available (Pakistani Association)
Some people report feeling let down by professionals not having enough knowledge about what’s available, unavailability of groups and facing a struggle to get information about what’s available to people with a disability.

Children and young people have to make do with social workers with little or no knowledge of what support mechanisms are available to support daily living and independence in the home or out in the community

There are not enough social groups in the community. There is no person centred planning

I do not see how help from the community would come about. It would be nice but it’s unreal

My child has not received any of the above support. He does not have access to any social services support. He is wasting his life away. There is no planning for my child’s need, I don’t even know what support my child needs or what he is entitled too. My son has no opportunities to follow his goals. He wants to play football but nobody can tell me where I can send him to play with the right support

One person was resigned to the fact that they would never be independent because of their disability.

My learning disability is such that I will never be independent. What is more important to me is having a small network of carers to spend time with me. Longer term I will need a comfortable, secure place to live as my parents will not be able to care for me at home indefinitely

In the council’s budget consultation (pre-engagement, Appendix 1) people want to see the council maximising disabled people’s independence by helping them do more for themselves. Some people within this engagement expressed concern about not feeling ready to take steps towards independence.

I don’t want people to push or pressure me to be more independent because I don’t like it. I’m OK as I am. I will ask if I want to be more independent

Not sure why the council think that everyone wants to live in supported accommodation. Lots of families I know would much prefer their son or daughter to live in a residential small home (4/5 people) just as a family would
Enabling everyone to making a contribution to society, where this is possible

The most important things for people in terms of making a contribution are:

- Opportunity to have your voice heard
- Support with employment
- Support to attend an education setting

Some people talked positively about the groups they go to, the volunteering and employment opportunities they are involved with, and the way they feel their voice is heard. Most people emphasised that effective support is essential to enable them to make a contribution in these ways.

Without the support of the REAL employment service [Realistic Employment for Adults with Learning Disabilities] and I would feel vulnerable and that no-one would understand what I needed. REAL have helped with my confidence and
have organised many activities for me to do to help me feel included and have something meaningful to do and given me the opportunity to build my skills while I look for work

At present I can still be involved with volunteering but the need to pace myself is not always understood by others

Keep important support services available including employment support services….I have a learning disability and without REAL employment my life would have been different. They have helped me with training, development, skills and my general wellbeing. Without this service I would have done nothing. Support to help disabled people in employment is the responsibility of their employers. If disabled people want support with applying for jobs or upskilling, they should receive it the same way as everybody else

People who live rurally or can’t afford transport need help to participate and attend. Befriending is a great idea and will help families

I go to Ponderosa 3 days a week, doing gardening activities. This helps to keep my hands mobile and I meet with friends. I go to Howland Centre once a week and do art activities. Then I work, supported by REAL employment. These are the services that are important to me. I would love to go to college but I had a nasty experience there. If I don’t like a service I would tell them. When I had a problem at college I felt they listened to me when I told them about it (Howland Centre)

People would be happy to make a contribution by working or volunteering, if their health was OK. Lots of people help in mosque. People here appreciate the opportunity to give their feedback on different services (Milen Care - men’s group)

Any additional support with life and social skills, clubs to help form friendships. Groups like this in Huddersfield give opportunity to meet friends, socialise and opportunity to exercise (Blind and Low Vision Group)

Other people described feeling let down by a lack of support or the way that they feel their disability means they are unable to work, volunteer or make any sort of contribution.

The support from Kirklees up to my child leaving junior school was fantastic….good few years at special school until college was a place to go. She didn’t really learn anything and then felt even more let down when thrown into the outside world. Job prospects are slim and volunteering not always suitable.
After all the hard work people put into supporting my daughter, her skills and abilities are not being used. All she wants to do is what her peers do - go to uni, work, leave home, get married.

I have no speech and severe learning difficulties. I will never be able to work or volunteer. The concept of “making a contribution” unfortunately means nothing to me.

My son has no access to support with education, support to attend educational settings, support to have voice heard. None of the above is available.

Currently I am not allowed to make a contribution because I need “Easy Read” and people assume that if you need “Easy Read” you are a drain on society and cannot contribute anything.

I want a personal assistant to support me to work/volunteer because I want to be a part of society and pay my own way and not get everything free.

Some organisations put barriers in the way so that people with visual impairments cannot become employed or volunteer. Organisations need to be encouraged to think outside the box and find alternative roles for visually impaired people.

[Need] opportunities for young disabled people to live and work in their communities in as independent a way as possible and educational opportunities for them to learn the life skills necessary are therefore essential.

We need support to have a voice. It’s difficult when you are not fluent in English (Pakistani Association).

I fear my children will grow up with minimal support when finding a job, making friends and having their voice heard.
Giving people choice and control over their care and support

People with a disability and their families should be involved in decisions about how their needs are met and the care that they receive.

Thinking about your own experience, please rate how important each care/support service is to you or the person you care for:

All the options to this question have been rated ‘very important’ or important’ by people responding, with people rating ‘being able to choose which staff will support you’ as slightly less important to them.

Being fully involved in decisions about care and support is clearly very important to people. They want to feel in control and empowered to make choices about important issues which will affect their life, or the life of the person they care for. Some people feel they have been excluded from discussions with professionals.

Should be your choice, your decision. Don’t want to be made to go somewhere if I don’t get on with staff

Full involvement in all care is vital for person-centred planning

Actually being allowed choice. Actually being allowed control. I am fed up of being given money to spend on my care then being given a legal document in
complex language. So I end up with loads of money as I was not helped to know my choices. Then other people decide for me when I was never given a chance.

Everyone with a disability should be able to reach their full potential and live as full a life as possible. The service should focus on what they CAN do, rather than what they can’t, and they should have as full a say as possible in what the system provides them with.

I would like to be there when they interview new members of staff. I would like to help and choose the staff who are working with me.

After asking for support with my son, an assessment was completed with what the assessor thought the needs were (sitting service) rather than what I knew the family needed (taking our son out and giving the family a break).

I don’t feel involved in decisions sometimes. Discussions are focused on medical issues. GP’s often don’t know enough about the support that’s available to people in the community, so they’re unable to make informed decisions about care packages (Blind & Low Vision Group).

I feel all my needs and wishes are taken into consideration when planning my care. Some people talk over me though, especially at home when people come to see me. They talk to my parents rather than to me and I have to say “excuse me, I’m here” (Howlands Centre).
Enabling people to be as healthy as possible

People feel most services which support people to stay healthy are ‘important’ or ‘very important’. The most important things are:

- Access to a GP
- Access to a dentist
- Access to specialist health services

Comments were made about some of the issues and barriers people face when attempting to access health-related services.

*Often elderly people would love to have access to more sport services but are too embarrassed to say that they need a carer to help with dressing or undressing. More elderly people would access sport if they had simple help like this*

*GP’s should highlight all carers young and old who attend their practice*

*There is a problem with finding an NHS dentist in Kirklees*
I have not had any support for access to specialist services

GP doesn’t do anything to make it easier. No flexibility. No continuity of GPs - always different....son needs to be familiarised

The dentist at Princess Royal is excellent. We need help with taking out son to the GP as many times the GP cannot get near to our son to examine him

As a child I had lots of support, co-ordinated through school (Castle Hil special school). As an adult, there is nothing done automatically. Everything seems to take an age, eg getting a new pair of shoes (necessary because I have abnormal feet) took over 6 months. I used to receive specialist dental care as I have abnormal gums and teeth - again, this has stopped

I have a rare condition so generalised services often cannot offer support beyond my own knowledge of the condition. It would be great if there was someone somewhere who supported the less regular LTC’s of asthma, diabetes, cardiac issues etc

Annual health checks and health trainers should not be imposed on people, but they should be available to whom so ever shall want them. It is important that people can care for themselves, but it is also important that they are able to access help from others if the help of others. Self-care should not be used as a way of replacing effective care methods that involve other people. Fitness group and health training providers should not receive funding from Kirklees Council if they will not employ people to support disabled people who wish to access them

My daughter’s GP was very unsupportive and we had to fight for everything. He clearly had no knowledge of her condition and as he was unable to refer her to a specialist service it was very difficult. He clearly thought it was all in her mind

The dentist is always full and to get a GP appointment is impossible (Milen Care - Women)

Self-care information should be in community centres, not online (Milen Care - Women)

Accessing GP’s can be a problem. Difficult to get appointments, have to wait 1 week sometimes. My GP says I’ve got to allow 3 days for a prescription; in the meantime I have to buy the medication from the pharmacy because I couldn’t get the prescription from the GP when I needed it (Milen Care - Men)
Some people said they were happy with the support they receive which helps them to stay healthy.

Through Real employment I was supported to join a group of people to go along to disability sports, I now attend every week to keep me fit

This does work, I am happy to say. Thank you to all involved

Current dentist, GP and hospital services for people with special needs are very good - nothing should be done to reduce the current service
Planning for the future, including smooth and seamless transition between services

It appears that having the right support when planning for the future is important for people at every stage mentioned in the survey. People feel the 3 most important times to receive support are:

- When changing schools or other educational setting
- When changes to family or carer circumstances mean being cared for by someone new
- When changing from specialist support in children and young people’s services to adult services

The thing which most people feel is either not relevant to them or they don’t know about is how important it is to have support when moving home, both within and outside of Kirklees.
People expressed concern about what might happen to them or the person they care for once their long term care arrangements have to change, and some described how they would want to make plans for this:

There will come a time when us parents can’t support our son. It’s quite frightening. Don’t know what will happen. He hasn’t got EHC plan yet. He’s in 3rd year at college but I’m not sure how long he can continue going to college for

I worry massively about how my children will cope as adults and who they would be cared by if anything was to happen to me

The most worrying thing for most parents is ensuring that their children will continue to have happy, productive lives when they grow up

I want some information when I’m ready to move out, about different places that I could live. And maybe to look around the different places. I live with family now

If only I could live independently…I know I’ll have to one day, I will have to move out. Mum and dad aren’t getting any younger. We have been thinking of perhaps getting a group of me and 5 friends and renting a house. (Howlands Centre)

People shared mostly negative experiences and concerns regarding transition between different services:

Changing schools is extremely difficult, we have wanted to change schools for over a year now but are being ignored

My daughter has learning difficulties and turns 18 in 2 months. She doesn’t understand why her respite play scheme out of school clubs finishes. How do you explain to an autistic person that you are now an adult

People want to have a seamless approach when planning for the future, eg moving home. They are concerned that relevant information might not be passed on to staff/organisations involved (Milen Care, men's group)

Support was lacking at transition to adult services and should be ongoing

I have already made the transition from school to day centres. The next big move will be when my parents can no longer care for me at home. So far there
has been very little support, because there is no money to support families like mine. My parents are seen to “cope”. I have been given an extra 6 days respite per year, bringing the total to 30. This is very welcome, but my parents foresee a big challenge in getting social services to support my move to residential care.

Moving from childhood to adulthood was the most scary and difficult transition. Hope this makes it easier in the future.

There should be more support and guidance in the transition from child to adult services with respect to ongoing health and wellbeing.

No support from age 16-18...He didn’t want to leave school and it was a very difficult time, a difficult process which meant lots of issues came out for him.

My son became an adult in terms of education, his benefits and health but not in terms of social services where the age is 18. Why?????

One person commented that their experience of transition had been a positive one:

The transition from mainstream to specialist provision was handled sensitively and smoothly for our son.
Having a ‘whole family’, lifelong approach to care and support

Families and carers often play a very important role in supporting people with a disability. It's important that carers and families can access help and support to help them look after their loved ones.

Thinking about your own experience, please rate how important each care/support service is to you or the person you care for:

The responses to this question suggest that support, respite and training for carers and families are all ‘very important’ or ‘important’ to people. Respite for carers/families was rated as slightly less important or people didn’t know about this/it wasn’t relevant to them.

Some people are concerned about the lack of support for siblings of children who have a disability.

There’s nothing for siblings of children with a disability. There’s nothing for young carers over the age of 8 but lots for carers of adults (PCAN group)

Could we set up a ‘SIBS’ group? The services provided to care for my son are excellent...and they do offer some respite to give us times as a family to draw breath, spend time with our daughter. However, I wish that these services were more flexible so that we could visit relatives (my mum and dad etc) more easily

Overwhelmingly, people wanted carers to be adequately supported in their caring role; having access to support groups and training and having respite which is flexible and responsive are all highlighted as being important.
Important for carers to have a break. Lots of carers are old. People go to Cherry Trees to give carers respite. Needs to be flexible support for carers, to respond to crisis. If people can get respite and stay over then it gives that person time away from their family too, chance to develop independence. Support for carers is very important, they need to have a break. Places like Waverley in Huddersfield really help (Pakistani Association).

It’s important that the needs and requirements of the carer are considered in any decisions…If the carer is unsupported themselves, this can have a knock on effect on the person that they are caring for. The carer has to be fit, well and content in their own pattern of life if they have any chance of looking after someone else in an effective and positive way. The carer’s wellbeing plays THE key factor when they are involved in looking after someone else’s life.

People here want to see carers have respite but they are unaware of carers accessing support groups (Milen Care - men’s group).

Often carers can feel lonely and isolated and it is important that they receive relevant information at the time of need, not by chance.

My daughter receives money to enable her to go to Waves in Slaithwaite and has a personal assistant so I can go to work.

Carers often spend their own care time meeting social workers etc in order to get the best for the person that they support. Please be considerate of the commitment and the time this takes and do not push too much responsibility onto the carer. Often they feel that their home isn’t their own and strain can be put on marriage and when we became carers we didn’t want to sign up to be the hirer and firer of staff etc.

What carers support?! I’m on my own here and once my mother has passed, I will be moving to central Europe as it scares me to think I will grow old in Kirklees.

Relatives of carers for the disabled should be encouraged to provide respite support so it is kept within the family rather than institutionalised.

My interests as a parent are non-existent. There is no time or support to pursue my own interests.

Respite is difficult due to lack of trained carers. Training for us as carers/family has been non-existent. We’ve had to train ourselves. Support groups have been the most helpful in this whole journey.
One comment suggested that carers get too much support:

*Kirklees Council spend too much on carers and not enough on actual disabled person. Tonnes of carers groups for only carers! Uneven balance!*

**Findings from easy read surveys**

There were very few responses to suggest people felt any of the things shown on the survey were unimportant, other than the section regarding ‘being able to make a contribution’. Almost half of all respondents said support with employment, volunteering or to attend an education setting was not important to them; all of the respondents said that having their voice heard was important.

Comments from the easy read surveys have been included in the main findings above.

**Other comments from all feedback obtained**

Some comments suggested people felt that positive changes and improvements would come from having integrated disability services for children, young people and adults, particularly where transition is concerned.

*Yes - more joined up thinking, smoother transitions from child to adult services*

*No transitions*

*No chance of being lost in the system*

*Working with same person*

*Overall brilliant idea, looking forward to it happening*

*I would be very happy if you gave parents the chance to be part of a forum in shaping the future of the All Age Disability Service in Kirklees - maybe if you advertised this to parents too, you could get some on board*

*It will make it much easier as children leave school and respite, to move on*

*In theory it should run more smoothly and there will be continued support with one service*

*Better transition on leaving school*

*The idea that there is an all age service is fantastic as the need to move from a care team which works, at times of life transitions, adds stress to both the*
individual, their family and carers. It also often wastes valuable previous input in terms of health and self care

Some people expressed concerns about what an All Age Disability Service might mean:

That the focus would be all on carer; disabled person forgotten

Disabled person not allowed a voice. Carer more important than disabled person. This is bad! Disabled people are getting forgotten!!

If adults and children’s services are joined together, how do we know which services will be affected? Either the children will miss out on vital support or the adults will (Milen Care - women’s group)

There needs to be a clear understanding of the different needs of different groups of people that you’re integrating services for

Concerned that people will lose specialised services. Elderly are not seen as a priority and more investment might go to children’s services and get taken away from services for older people. They need to realise that one service doesn’t fit all. You can’t make one big service to meet the needs of everyone (Pakistani Association)

Innovation does not always mean we are moving ahead. So don’t change things which patient/carers are happy with, ie don’t change for the sake of changing. Sometimes change in itself can cause distress to older people

I don’t know what is envisaged but fear that this change will be used to cover up the current inefficiency of the services and delay improvements as “we are going to make a major change and put all our energies into that”. Current services would be fine if services follow all the wonderful visions, objectives and procedures that currently exist and keep being re-invented. Policy makers and senior managers need to put their attentions to what goes on at the sharp end and not just keep re-inventing the wheel. I fear that whatever shape the new services take we will be in the same position if we keep concentrating on the top level and not what happens in practice

I do believe the council is too involved in many areas as people like it that way and have got used to it but with things having to change, my preference would still be able to access a skeleton service from the Local Authority than rely on community assistance which may be non-existent
There was concern from some people that if the council decide to create an All Age Disability Service then the decision to do so will be very much influenced by the financial pressures faced by the council. People don’t want to lose services as a result of the integration of disability services:

*It’s just another cost-cutting exercise (PCAN group)*

*They can join the services as long as no cuts to budgets are made. We don’t want any services to be cut (Milen Care - women’s group)*

*You joining services together will end up with children’s funding being even less. Disgusting to save money in disguise!*

*An All Age Disability Service sounds good in theory. However, in practise my concern is that it is merely a cost-cutting exercise*

*Concern would be cost-cutting exercise and would lose what little we get now.*

*Interested in idea of integrated approach but not to detriment of children’s services which are poor, particularly mental health and disability services. Open to explore possibilities*

*You don’t have enough funding to support children properly, adults get even less, so combining the two will mean children suffer. You save millions by using parents who struggle and often have their lives ruined by lack of support and money to have time to get out of the house. Further cuts will make those most vulnerable suffer*

*Adequate funding needs to be provided so that the quality of service in education and health improve and ease/lower the stress for parents and children*

*This is just a cost-saving exercise! Not focussed on what is best for the client*

*Do not allow Kirklees Council to shut or restrict respite care at Cherry Trees*

There were some comments which suggested that people had misunderstood what an All Age Disability Service might mean as they expressed concerns about children and adults services being delivered at the same time, from the same location, with children and adults having to share the same space when accessing services. During the formal consultation it will be essential to communicate exactly what having an All Age Disability Service will mean to people with a disability and their parents/carers.
Adults with disabilities could easily be frustrated by children even if they have the same disability as them and vice versa

If a service is merged it’s important adults and children still have their own space otherwise it’s just throwing them altogether for the sake of convenience

5. Limitations of the study

This engagement focussed on asking people about the support and services which are important to them. However, we were also asking people what they thought about the idea of having an All Age Disability Service in Kirklees. We could only talk in very general terms about what this change might mean to people; without having a plan of which services might be affected and how an All Age Disability Service might impact the support and care people receive, it proved quite difficult to gather opinion on this as people want to know how any changes might affect them, or the person they care about. It is hoped that any subsequent formal consultation process will present specific proposals to people which will help people to understand the impact the changes might have.

The online survey asked people to rate how important different support and services are to people and the overwhelming response to the questions was that all things, in all categories, are important or very important to people. In retrospect, it may have been more meaningful to ask what works well for people with a disability in Kirklees and what might need to be improved. However, because people were given opportunity to add comments in text boxes, this has helped to clarify opinion and has meant that people have been able to openly express how they feel about some of the services and support in Kirklees and how they might like things to change or improve.

The Council asked Healthwatch Kirklees to engage with anyone with a disability or their parents/carers, but additionally to focus on gathering feedback from black and minority ethnic (BME) individuals and those who are Deaf or hard of hearing. We had limited response from individuals who are Deaf or hard of hearing, despite trying hard to engage with this group through organisations we have worked with in the past. The Sensory Service created a BSL video to help communicate our message but there was little or no response to this. We were made aware that the online survey was far too complex for many people who are Deaf so we promoted the easy read version and the option for people to e-mail with answers to 3 questions: which services do you currently access and why are they important to you? Which services and support work well in Kirklees and what do you think needs to improve? We didn’t receive any response to this.
Appendix 1

Summary of Pre-engagement
2013-2015

General Inclusive Sport and Physical Activity Consultation - West Yorkshire Sport
November/December 2013

To identify need for inclusive sport provision for people with a disability.

The consultation was Kirklees wide and there were 65 responses.

The findings were:

The main factors which affected provision and participation were:

- Age restrictions
- Funding stopped
- Appropriateness of the session
- Date and time of the session
- Transport to get to and from activities
- Accessibility
- Extra support not always guaranteed

Following this consultation there were suggested actions for providers of sport and physical activities:

- To look at what should be considered to provide an ‘ideal’ activity session.
- Advice given on how to overcome barriers to participation (as shown above)
- To improve marketing to increase awareness of activity sessions.
Carers were asked about the kind of things that help to give them a break from their caring role and what they think are the most important features of a Carers Break Service.

The results were split down by care categories, making it possible to identify the results for carers of people with learning disabilities and carers of people with physical disabilities, sensory impairments and/or long term conditions.

Carers were asked to rate in order of importance the same six key features of a Carers Break Service and the results were as follows:

### Carers of people with learning disabilities

<table>
<thead>
<tr>
<th>Key feature</th>
<th>Importance</th>
</tr>
</thead>
<tbody>
<tr>
<td>Flexible breaks: save up and take longer breaks</td>
<td>1</td>
</tr>
<tr>
<td>Regular set breaks</td>
<td>2</td>
</tr>
<tr>
<td>Easy to access</td>
<td>3</td>
</tr>
<tr>
<td>Breaks allocated according to need: waiting times</td>
<td>4</td>
</tr>
<tr>
<td>Flexible breaks: book them when you need them including at short notice</td>
<td>4</td>
</tr>
<tr>
<td>Breaks allocated according to need: amount of breaks</td>
<td>6</td>
</tr>
</tbody>
</table>

### Carers of people with physical disabilities, sensory impairments and/or long-term conditions

<table>
<thead>
<tr>
<th>Key feature</th>
<th>Importance</th>
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</thead>
<tbody>
<tr>
<td>Regular set breaks</td>
<td>1</td>
</tr>
<tr>
<td>Flexible breaks: book them when you need them including at short notice</td>
<td>2</td>
</tr>
<tr>
<td>Flexible breaks: save up and take longer breaks</td>
<td>3</td>
</tr>
<tr>
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</tr>
<tr>
<td>Easy to access</td>
<td>3</td>
</tr>
<tr>
<td>Breaks allocated according to need: waiting times</td>
<td>5</td>
</tr>
<tr>
<td>Breaks allocated according to need: amount of breaks</td>
<td>6</td>
</tr>
</tbody>
</table>
Healthwatch held focus groups with 50 people during November 2013 and over 410 people completed an on-line or freepost survey.

Findings:

- There are significant communications issues at key stages in the patient journey for people who are Deaf or hard of hearing. The most significant theme which ran throughout the survey work and focus groups was the lack of deaf awareness of people at the GP surgery, hospital or other providers of NHS services.
- The dependency on landline telephone usage, rather than SMS texting, emailing or on-line facilities presents a real challenge for people, particularly younger patients and those with more profound hearing loss. It is important for GP surgeries and hospitals to offer and promote a range of contact methods to patients, to enable them to use their preferred method of communications.
- Many of the examples of poor communications, at this stage in the patient journey, appear to come from a lack of understanding and deaf awareness from reception staff, both in person and on the phone. A number of respondents mentioned the lack of patience of reception staff in dealing with them, which can sometimes give rise to rudeness and poor customer service.
- The way people with a hearing impairment are treated when they book in and are waiting to be called into their appointment is an indicator of the level of deaf awareness in the GP practice or hospital. It is a potentially stressful situation for patients and whilst there is much evidence of good practice across Kirklees, improvements could be made.
- Patients’ records should clearly indicate their communications needs and staff should be shown how to attract the attention of patients without calling their name.
- Feedback suggests HRI Audiology clinic should be demonstrating better practice in deaf awareness.
Recommendations:

<table>
<thead>
<tr>
<th>Recommendations</th>
<th>Applies to</th>
</tr>
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<tbody>
<tr>
<td>• Introduction of mobile phone system for SMS texting/email or introduction of internet appointment booking. These should be advertised to all patients so they know that these alternatives exist</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• Deaf awareness training to be developed and rolled out for provider staff (roles and responsibilities including handling phone calls, personal visitors and booking of BSL interpreters)</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• Patient records / computer systems to flag up communication support needs and information used in all direct dealings with that patient</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• Patients to have confirmation of BSL interpreter bookings and names</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• Use of on-line BSL translation services (e.g. SignTranslate) for emergency use in GP practices or hospitals. Low cost system uses a simple webcam to link to qualified BSL interpreters</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• Visual display screens (operating in real time) to call patients in or for people to be approached and personally escorted into appointments</td>
<td>• GP’s and Hospital Trusts</td>
</tr>
<tr>
<td>• GP’s to complete Choose and Book with appropriate communications needs / notify BSL interpreter required at hospital appointment</td>
<td>• GP’s and Hospital Trusts</td>
</tr>
<tr>
<td>• People to know their rights / policies and practices when it comes to communications support through an awareness raising campaign</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• Recruitment of a Deaf/hard of hearing support person at the hospitals - to help patients and liaise with BSL interpreters</td>
<td>• Hospital Trusts</td>
</tr>
<tr>
<td>• Induction loops should be introduced into waiting rooms or consulting rooms that don’t currently have them. These systems should be tested regularly and staff trained on how to use / test them</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• NHS 111 service to make suitable adaptations to the service to ensure it is fully accessible (text or video conference)</td>
<td>• NHS 111</td>
</tr>
<tr>
<td>• Awareness raising campaign to be rolled out on 999 emergency service registration system</td>
<td>• NHS providers</td>
</tr>
<tr>
<td>• Localised hearing aid after care service to be funded</td>
<td>• Health &amp; Wellbeing Board</td>
</tr>
<tr>
<td>• CHSWG to report into an appropriate body within the CCG’s or the council’s Physical &amp; Sensory Impairment Partnership Group</td>
<td>• All NHS and Social Care Commissioners</td>
</tr>
</tbody>
</table>
• Gain assurance from providers through the Quality Board mechanisms that they have implemented the recommendations of this report within 12 months

• All NHS and Social Care Commissioners

• Strengthen the quality schedules of NHS contracts to include the recommendations of this report

• All NHS and Social Care Commissioners

Changes which have been made since this work was completed:

• August 2014 - Received formal response to the recommendations from Locala that details initiatives such as staff training and induction loops.

• November 2014 - At Deaf and Hard of Hearing Group meeting Mid Yorkshire Trust Head of Audiology outlined some of the work that they do to meet the needs of individuals with hearing impairments.

• February 2015 - Action on Hearing Loss has been commissioned to deliver a hearing aid aftercare service (Hear to Help), which will provide drop ins for people to get support with using their aids and with any maintenance issues.
On 29 September 2015, Parents of Children with Additional Needs (PCAN) held their annual conference. The Chair of PCAN designed a questionnaire which asked parents/carers about their experience of using services for children with a disability. 17 questionnaires were completed and the main themes are shown below.

- Parents/carers are sometimes frustrated by the lack of information available to them, often leaving them feeling like they’re on their own, not knowing who to go to for advice and support.

  “Land of unknown. Don’t know where to go”
  “Lost, no help with which way to go”
  “Felt totally alone and isolated, didn’t know what to expect”

- Some parents/carers feel that when they had concerns about their child’s health, development or behaviour their concerns were not taken seriously.

  “No one seemed to take as genuine concerns. Felt got a diagnosis only because both have experiences of working with children. Had concerns early on and talked to a lot of people. Very regular - only taken seriously when behaviour issues at school”
  “At beginning went to Psychological Services to explain concerns and feel fobbed off... went to right persons and got wrong response - years of problems.... The initial contact is crucial....concern that issues only taken seriously when things go wrong”

- Parents/carers have been left for long periods of time without a diagnosis because of lengthy waiting times for CAMHS services.

  “Age 4 statement, age 7 then statement at 11, pending EHC progress. Still no diagnosis, now 15, on waiting list for ASD assessment”

- Some parent/carers identified a lack of empathy from staff within disability services.

  “Some staff desensitised - see it every day - lack empathy”

- Parents/carers commented on the positive nature of the support their child received from school, health professionals, outreach services and community-based services.

  “Ellerslie - brilliant at teaching me and my son”
“Children’s Centre, Dewsbury hospital. Play sessions (1:1) teaching you how to play with your child. Children’s day nursery ‘bought in’ - had walker - nursery and home. Home visit - Portage really good”

“Communication is brilliant with school. Teachers are more communicative - week end feedback. Fab at school and not as good out”

“Autism outreach worker - saved sanity. Teach for deaf - fantastic support”

“Joining PCAN best thing to give me peace of mind and realise not alone”

- Parents would like a single point of contact; a worker who can help parents/carers to navigate through the systems operated by different organisations and who can inform/advise.
In December 2015 Kirklees Council concluded their six week public consultation on your council’s budget for 2016-17. This happened by asking the public to ‘weigh up’ a series of statements, asking them to choose the ones that come closest to their own opinions. They also asked the public to name the single most important thing they think the council does. Some of the statements are particularly relevant to disability services.

In summary:

- 1410 people took part in the consultation
- 90% of responses were from residents of Kirklees

The most popular of the 12 options were:

- Parents have a clear responsibility for getting their children to school safely
- I think the council should help to maximise disabled people’s independence by helping them do more for themselves
- I think that the council should use modern technology to deliver services and reduce costs wherever possible

The least popular of the 12 options were:

- The council should provide services that enable children to get to school safely
- I think it’s important to meet the needs of disabled people by doing things for them
- Modern technology doesn’t really suit me - I need to have other options available to me

When asked what the most important thing the council does is, the most popular theme was supporting vulnerable people
Appendix 2

Distribution list used by Healthwatch Kirklees to disseminate information about the online survey, easy read survey, workshops and opportunity to meet with Healthwatch Kirklees in a group or 1:1. The reach was far more extensive than this as the same information was shared via Kirklees Council staff involved in supporting this work.

Mencap in Kirklees
Bridgewood Trust
All Special Schools in Kirklees
Parents of Children with Additional Needs (PCAN)
Cloverleaf & Kirklees Involvement Network
Carer’s Count
Kirklees Blind and Low Vision Group
Action on Hearing Loss
Huddersfield Deaf Centre
Milen Day Centre
Crossroads Care in Mid Yorkshire
Kirklees Active Leisure (disability groups)
Huddersfield Down Syndrome Support Group
Autism support groups
Sensory World Play Centre
Options Centre
Kirklees Voice and Influence Team
West Yorkshire Disability Sports
Howlands Centre
Remploy
Sensory Services
Huddersfield Pakistani Association
GP’s
Clinical Commissioning Groups
Integrated Youth Support Services
Ravensthorpe Disability Group
Volunteering Kirklees newsletter

The survey was promoted widely on social media and on the Healthwatch Kirklees website.
Appendix 3

Demographics from online survey only

Are you responding to this survey as: (select all that apply)

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>A young carer (8-18 years old)</td>
<td>0.0%</td>
<td>0</td>
</tr>
<tr>
<td>A parent/carer of a disabled child or young person</td>
<td>39.8%</td>
<td>35</td>
</tr>
<tr>
<td>A parent/carer of an adult</td>
<td>14.8%</td>
<td>13</td>
</tr>
<tr>
<td>A disabled person</td>
<td>36.4%</td>
<td>32</td>
</tr>
<tr>
<td>A Kirklees resident</td>
<td>43.2%</td>
<td>38</td>
</tr>
<tr>
<td>A Kirklees council employee</td>
<td>10.2%</td>
<td>9</td>
</tr>
</tbody>
</table>

answered question 88
skipped question 46

What is the first part of your/their postcode?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>WF12</td>
<td>5.7%</td>
<td>5</td>
</tr>
<tr>
<td>WF13</td>
<td>10.2%</td>
<td>9</td>
</tr>
<tr>
<td>WF14</td>
<td>2.3%</td>
<td>2</td>
</tr>
<tr>
<td>WF15</td>
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<tr>
<td>HD1</td>
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<tr>
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<td>11.4%</td>
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<td>HD3</td>
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<tr>
<td>HD4</td>
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<tr>
<td>HD5</td>
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<td>HD7</td>
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<td>HD8</td>
<td>5.7%</td>
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</tr>
<tr>
<td>HD9</td>
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</tr>
<tr>
<td>Other (please specify)</td>
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answered question 88
skipped question 46

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<th>Categories</th>
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<tbody>
<tr>
<td>1</td>
<td>Dec 18, 2015 10:31 AM</td>
<td>wf5</td>
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<td>2</td>
<td>Nov 20, 2015 11:51 AM</td>
<td>hd2</td>
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<td>3</td>
<td>Nov 18, 2015 3:53 PM</td>
<td>YO13</td>
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### Are you/they male or female?

<table>
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<tr>
<th>Answer Options</th>
<th>Response Percent</th>
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</tr>
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<tbody>
<tr>
<td>Male</td>
<td>48.8%</td>
<td>42</td>
</tr>
<tr>
<td>Female</td>
<td>46.5%</td>
<td>40</td>
</tr>
<tr>
<td>Prefer not to say</td>
<td>4.7%</td>
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answered question 86
skipped question 48

### What age group are you/they in:

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
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</thead>
<tbody>
<tr>
<td>17 or younger</td>
<td>24.1%</td>
<td>21</td>
</tr>
<tr>
<td>18-20</td>
<td>3.4%</td>
<td>3</td>
</tr>
<tr>
<td>21-29</td>
<td>16.1%</td>
<td>14</td>
</tr>
<tr>
<td>30-39</td>
<td>17.2%</td>
<td>15</td>
</tr>
<tr>
<td>40-49</td>
<td>14.9%</td>
<td>13</td>
</tr>
<tr>
<td>50-59</td>
<td>9.2%</td>
<td>8</td>
</tr>
<tr>
<td>60-69</td>
<td>8.0%</td>
<td>7</td>
</tr>
<tr>
<td>70-79</td>
<td>1.1%</td>
<td>1</td>
</tr>
<tr>
<td>80 or over</td>
<td>1.1%</td>
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</tr>
<tr>
<td>Prefer not to say</td>
<td>4.6%</td>
<td>4</td>
</tr>
</tbody>
</table>

answered question 87
skipped question 47

### What is your/their ethnic group?

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>82.8%</td>
<td>72</td>
</tr>
<tr>
<td>Mixed/multiple ethnic groups</td>
<td>3.4%</td>
<td>3</td>
</tr>
<tr>
<td>Asian/Asian British</td>
<td>9.2%</td>
<td>8</td>
</tr>
<tr>
<td>Black / African / Caribbean / Black British</td>
<td>3.4%</td>
<td>3</td>
</tr>
<tr>
<td>Any other ethnic group, please describe</td>
<td>1.1%</td>
<td>1</td>
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</table>

answered question 87
skipped question 47

### How does your/their disability affect you/them? (please select all that apply)

<table>
<thead>
<tr>
<th>Answer Options</th>
<th>Response Percent</th>
<th>Response Count</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication</td>
<td>42.9%</td>
<td>33</td>
</tr>
<tr>
<td>Mobility</td>
<td>36.4%</td>
<td>28</td>
</tr>
<tr>
<td>Hearing</td>
<td>9.1%</td>
<td>7</td>
</tr>
<tr>
<td>Physical</td>
<td>35.1%</td>
<td>27</td>
</tr>
<tr>
<td>Learning</td>
<td>61.0%</td>
<td>47</td>
</tr>
<tr>
<td>Visual</td>
<td>20.8%</td>
<td>16</td>
</tr>
<tr>
<td>Mental health</td>
<td>33.8%</td>
<td>26</td>
</tr>
<tr>
<td>Other (please specify)</td>
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answered question 77
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<tr>
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<td>Dec 22, 2015 11:16 AM</td>
<td>self harm/behaviour</td>
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</tr>
<tr>
<td>2</td>
<td>Dec 22, 2015 11:04 AM</td>
<td>anger issues</td>
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</tr>
<tr>
<td>3</td>
<td>Dec 20, 2015 8:28 PM</td>
<td>My disability is visual but this affects my communication too as I miss body language etc, risk of tripping or falling also affects mobility</td>
<td>arthritis</td>
</tr>
<tr>
<td>4</td>
<td>Dec 18, 2015 10:18 AM</td>
<td></td>
<td>high levels of anxiety and disorganisation</td>
</tr>
<tr>
<td>5</td>
<td>Dec 7, 2015 2:59 PM</td>
<td>social - my son has dyspraxia and ASD (Aspergers) and is awaiting to see CAMHS</td>
<td>arthritis</td>
</tr>
<tr>
<td>6</td>
<td>Dec 7, 2015 1:58 PM</td>
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<td>high levels of anxiety and disorganisation</td>
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<tr>
<td>7</td>
<td>Dec 7, 2015 1:34 PM</td>
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<td>sensory/self-regulation</td>
</tr>
<tr>
<td>8</td>
<td>Dec 4, 2015 10:45 AM</td>
<td></td>
<td>Behaviour I'll health for carer</td>
</tr>
<tr>
<td>9</td>
<td>Dec 3, 2015 10:19 AM</td>
<td></td>
<td>Global developmental delay</td>
</tr>
<tr>
<td>10</td>
<td>Dec 2, 2015 11:12 AM</td>
<td></td>
<td>difficulty with all activities of daily living</td>
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<tr>
<td>11</td>
<td>Nov 26, 2015 12:00 PM</td>
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<td>STRESS!! Not enough hours in the day!!</td>
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<td>13</td>
<td>Nov 20, 2015 3:36 PM</td>
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<td>Nov 19, 2015 9:00 AM</td>
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<td>social</td>
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<td>15</td>
<td>Nov 18, 2015 8:05 PM</td>
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<td>Isolation and lack of friends</td>
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<tr>
<td>16</td>
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<td>Social skills</td>
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Demographics from easy read survey only

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<td>Female</td>
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<table>
<thead>
<tr>
<th>Age</th>
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<tr>
<td>17 or younger</td>
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<td>18-40</td>
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<td>61-80</td>
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<td>81 or older</td>
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<td>Don’t want to say</td>
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<table>
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<td>Huddersfield</td>
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<table>
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<td>Hearing</td>
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<tr>
<td>Learning</td>
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<td>Mental health</td>
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<tr>
<td>Mobility</td>
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<tr>
<td>Physical</td>
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</tr>
<tr>
<td>Visual</td>
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<td>Other</td>
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