

# Workforce development for people with intellectual disabilities: the perspective from people with intellectual disabilities

Prepared for Health Education England  
working across Kent, Surrey and Sussex

September 2016



What does good support mean to us?

- Trust
- Making me feel comfortable
- Asking questions sensitively not prying or judging
- Choice and Control
- Encouraging but not Making you do things
- Staff checking that they're giving support that's right for you
- Being part of the Community



What does good support mean to us?

- Recognises you as a person and not just your disability
- Tailored support - support that you need - Flexible.
- Consistent support - someone you know and trust
- Remaining confidential - "don't talk about me in front of others"
- Support to become independent not just doing things for you
- Good communication is the basis of good support
- Good humour - "having a laugh with carers, not too serious"

How does good Support make us feel?

- In Control
- Safe
- Ecstatic
- Amazing
- On top of the World
- Involved in decisions
- Encouraged to do things you're not used to
- Able to take risks and try new things.



## Workforce development for people with intellectual disabilities: the perspective from people with intellectual disabilities



### BACKGROUND AND AIM OF THE CONSULTATION

Health Education England working across Kent, Surrey and Sussex (HEE KSS) have been developing a project over the last few years with the single aim to create a sustainable and secure workforce supply, for people that have intellectual disabilities who require support from and/ or access to services across Kent, Surrey and Sussex. Their report, 'Workforce Development for People with Intellectual Disabilities', was published in March 2015.

Following on from this, HEE KSS commissioned the Foundation for People with Learning Disabilities to produce a report that would detail the opinions and perspectives of individuals who have a learning disability from across Kent, Surrey and Sussex, asking them what they would like their workforce to know. The project ran from April to August 2016. The Foundation for People with Learning Disabilities is a national charity that promotes the rights, quality of life and opportunities of people with learning disabilities and their families.

### AIM OF THE REPORT

The aim of the report is to convey to HEE KSS an in-depth review of opinions and perspectives of individuals who have a learning disability<sup>1</sup> from across Kent, Surrey and Sussex, asking them what they would like their workforce to know. In order to reach those with more complex needs the report will also include the views of a small number of families.

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<sup>1</sup> In this document, we have used the term 'learning disability' because the people we consulted with preferred the term to 'intellectual disability'

## THE CONSULTATION PROCESS

### 1) The consultation groups

During the course of the project we visited seven groups across all three counties. In total we spoke to 70 people. The groups of people we spoke to are described below:

#### **Home Farm Trust, Edenbridge, Kent**

The Home Farm Trust runs supported living, registered care, domiciliary and day opportunities for people with a range of needs in the north and west Kent area. A focus group was run with seven participants, whose cognitive needs and ages varied considerably. Most people were supported within their home services but two attended day activities at the base.

#### **Skillnet Group, Dover, Kent**

The Skillnet Group supports people with learning disabilities to speak up, make choices and become powerful and influential. Seven people attended the focus group held in Dover, all of which had mild to moderate learning needs and were aged between 16 and 44 years.

#### **Consensus, Tandridge, Surrey**

Tandridge Hill Farm, part of the Consensus group supports adults on a day basis, at a 70 acre working farm. We held three focus groups with 19 people in total, most of whom were aged from 35 years onwards and again had a wide range of cognitive needs.

#### **Woodlands Meed School, Burgess Hill, West Sussex**

Woodlands Meed is a special school for 2-19 year old children and young people with a wide range of special needs. Most of the pupils come from the Mid Sussex area. We spoke to 19 learners in total, all of whom were able to follow instructions and communicate verbally. Their ages ranged from 15 to 19 years.

#### **Stay up late, Brighton, East Sussex**

Stay up late is a charity that was set up to ensure that person-centred planning for people with learning disabilities and autism truly reflects what an individual wants to do in their life. They particularly were concerned that people aren't able to stay up late and do the things that so many people, who don't need support, take for granted. We met seven members of their advisory group, all of whom had moderate to mild learning needs.

#### **Involvement Matters Team, East Sussex Partnership Board**

This group meets regularly as part of the East Sussex Partnership Board. Seven people were present, six were members of the group and, as others could not make it, an expert by experience also attended. As it happened, this person was also a member of the Stay Up Late advisory group, so he has only been accounted for once in the analysis.

## **West Sussex Parent Carer Forum**

The forum helps parent carers of children and young people aged 0-25 with additional needs and disabilities to improve and make positive changes to the lives of their families and others. They provide information, support and training to enable them to take part in helping to shape local services and make a difference in West Sussex. We thought it was important to gather the views of parents who have a vested interest in the future workforce and spoke to three members.

We also interviewed another two parents whose sons had complex needs and were unable to talk about their requirements of the workforce themselves.

## **2) The questionnaire**

In order to facilitate discussion during the focus groups, we co-produced a questionnaire with two consultants and easy read materials. The questionnaire included equalities monitoring sections to capture demographic data and to ensure we had spoken to a good cross section of people within a range of ages, ethnic backgrounds along with information on their living situations and current support received.

The next section of the questionnaire addresses the knowledge required from the workforce. The term 'knowledge' is a rather abstract concept, so in order to make this more concrete for people with learning disabilities, we developed a section with a focus on skills and qualities. We felt it was important to separate skills from qualities as they have very different definitions.

A **skill** is defined as 'an ability to do an activity or job well, especially because you have practised it'.

A **quality** is defined by the Cambridge English dictionary as 'a characteristic or feature of someone or something'.

Our consultants worked with us on producing a list of the skills and qualities they felt were important to them and other people with learning disabilities to lead a good life. The list is not exhaustive, and we did add a further skill and quality to a later version of the questionnaire, but we felt providing such a list gave structure to help people think about what is important to them. People were also asked what we had missed to ensure other skills and qualities of the workforce were included.

The questionnaires were piloted on two separate occasions, and were also disseminated to others who had not taken part in the focus groups. Please see Appendix 1 for a copy of the questionnaire.

### 3) Structure of focus groups

All the focus groups had a similar structure, however due to time constraints and the abilities of the participants, there was variation in each session. The groups lasted from 50 minutes to two and a half hours. We are very grateful to the organisations who agreed to take part and their coordinators who made it all happen.



The core components of the focus groups were:

- A discussion of what bad and good support looks like. We used a photograph depicting bad support to show people a concrete example, and in some groups we did a role play of the photograph to make it more realistic.
- Exploration of the skills and qualities required of the workforce.
- We developed several different ways to ask the same questions in order to allow flexibility in line with the needs of the audience we were to meet. In some instances we showed a variety of images of the workforce who may be in contact with people with learning disabilities (e.g. GP, health practitioner, support worker, job centre staff). We used a variety of tools to explore the kinds of skills and qualities people thought were important (based on what was in the questionnaire). They included making up sets of the images into cards, so the card game pairs was played in small groups, which allowed for discussion about each skill or quality on the chosen cards. With some groups we asked people to vote for their top two or three most important qualities or skills. If time was short, we did not play pairs but produced A4 sheets of the skills and qualities and asked participants to tick those important to them, and again, select the most important two or three.
- Completing the questionnaire, although it was not possible to do in every group.

## FINDINGS

### 1) Demographic information gathered from the focus groups and questionnaires

We spoke to 65 people with learning disabilities and five parents (who completed the questionnaires on behalf of their sons/daughters), and received 61 completed questionnaires. Many questionnaires were completed during the focus groups. During some groups we did not find it possible to support completion of the forms but we collected their information as a group. Other questionnaires were disseminated via the organisations we worked with and at the HEE KSS Community of Practice launch event on June 15<sup>th</sup>, where the project team presented early findings. We received a further five questionnaires through this method. A total of 75 people took part in this consultation.

Over half of the respondents or participants were from Sussex (40), as compared with Kent (18) and Surrey (17). One of the key reasons for this is that the school we visited in Sussex arranged for us to speak to two groups of pupils, making a total of 19 from Woodlands Meed School. The pilot of the questionnaire took place in Kent and those questionnaires were not counted in the final analysis as changes had to be made following the consultation.

### 2) Age, gender and sexual orientation

All participants were asked to declare their gender (44 male), (31 female) which they did very easily, along with their age. The ages ranged from 12 (we interviewed a few parents of school aged children) to over 65 years. The biggest age range was 12-24 year, largely due to our work at Woodlands Meed School. The parents who took part completed the questionnaires on behalf of their son/daughter. Initially, we did not ask people to disclose their sexual orientation, however, HEE KSS asked us to include this at a later stage so a separate form to identify sexual orientation was issued to the last two focus groups. A number of participants struggled with this request. It proved hard for people to understand, with some males reporting they were lesbian and then with discussion changed to heterosexual. Also we were not sure if they understood the term bisexual as some interpreted this as being friends with men and women rather than sexual orientation.



### 3) Ethnic origin

The demography of the three areas of consultation, according to the local census information is predominantly white/British and although we asked the organisations that helped to find participants to this consultation, they struggled to find a big mix of different cultures. 89.5% of the participants were of White/White British background, with 4% being of Black/African/Caribbean/Black British, 1.5% of Asian/Asian British and 4% being of mixed/multiple ethnic groups. This echoes the Census data recorded in 2011 for the South East region of the UK. This data indicates that 90.7% of the South East population is made up of White/White British, followed by 1.6% of Black/African/Caribbean/Black British, 5.2% being Asian/Asian British, 1.9% being of mixed/multiple ethnic groups and 0.6% of other ethnic groups.

### 4) Support and living arrangements

It was not possible to gain information on the status of all people consulted, however it appeared that the participants primarily lived with their family (48%), or with others (33%). Two young people were reported to be looked after children. Only 14% of the people taking part lived alone, some of whom received very intensive levels of support, whilst others lived fairly independently. Just under half of the people had support during the day and night (48%), but for many that was because they lived with their family. A small number (11%) received no support, whilst 14% of people were unsure of the support they received.

When asked what type of support people received, 72% said they had support from their family, followed by a social worker or care manager (64%) and over half (53%) received support to access leisure activities. The lowest scoring form of support was from the Community Learning Disability Team, at 19%. 28% of those receiving support were involved in the recruitment of their staff. 35% of the participants reported they had a person centred plan.

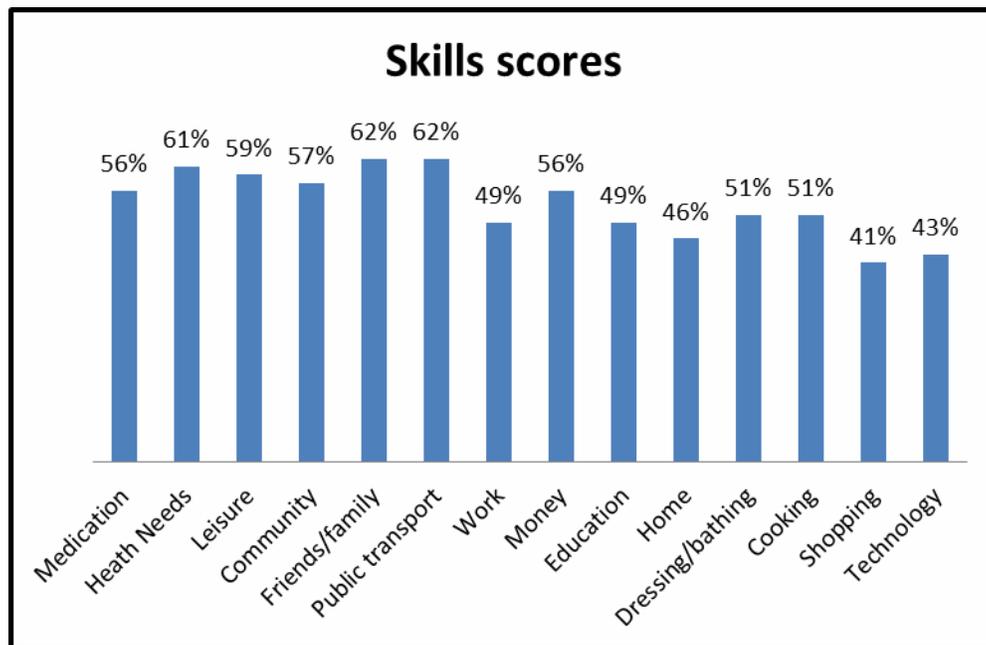


## 5) Health checks/health action plans

Around 45% of the participants reported to have had an annual health check, and 47% had a health action plan, however a number of people were unclear as to whether they had a health action plan, or if they received a formal health check. This number may be low due to the high number of school pupils taking part - the school was unaware if the health checks being available to people aged 14 plus had been rolled out in mid Sussex yet.

## 6) Analysis of the workforce skills

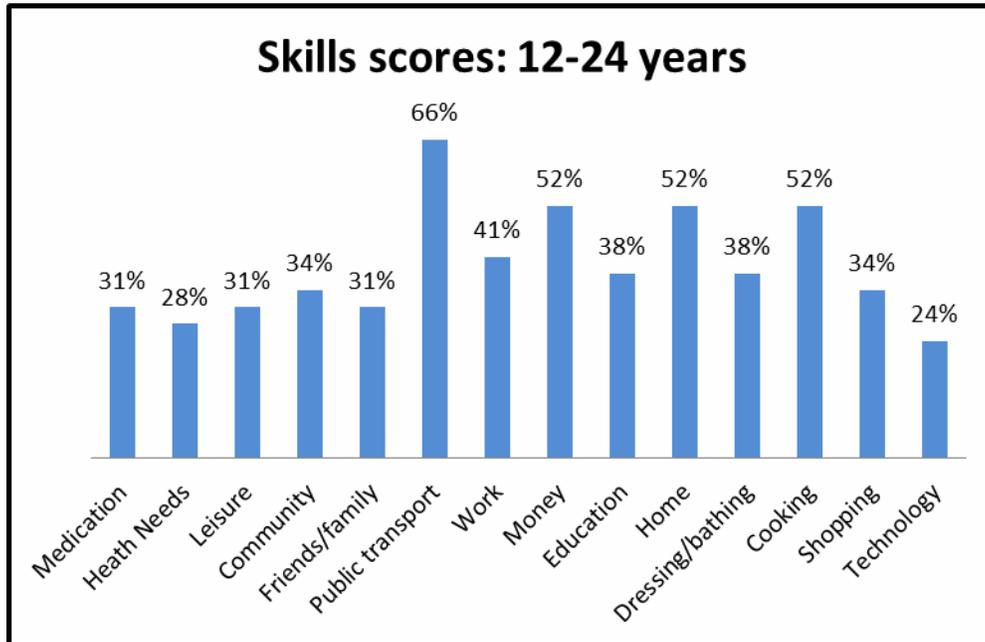
Data from the completed 61 questionnaires along with the data gathered during the focus groups was analysed. The following chart shows the results from all the age groups.



The highest scoring skills are: keeping in touch with friends and family and learning to use public transport, followed by having the skills and knowledge to support people's health needs. Other skills that are seen to be important are encouraging people to access their community and leisure facilities, knowledge about medication and managing money and learning to budget.

As the consultation spanned a large age group we thought it was important to analyse this data further by age group. They are shown below.

## Analysis of Workforce Skills – Results for 12-24 years



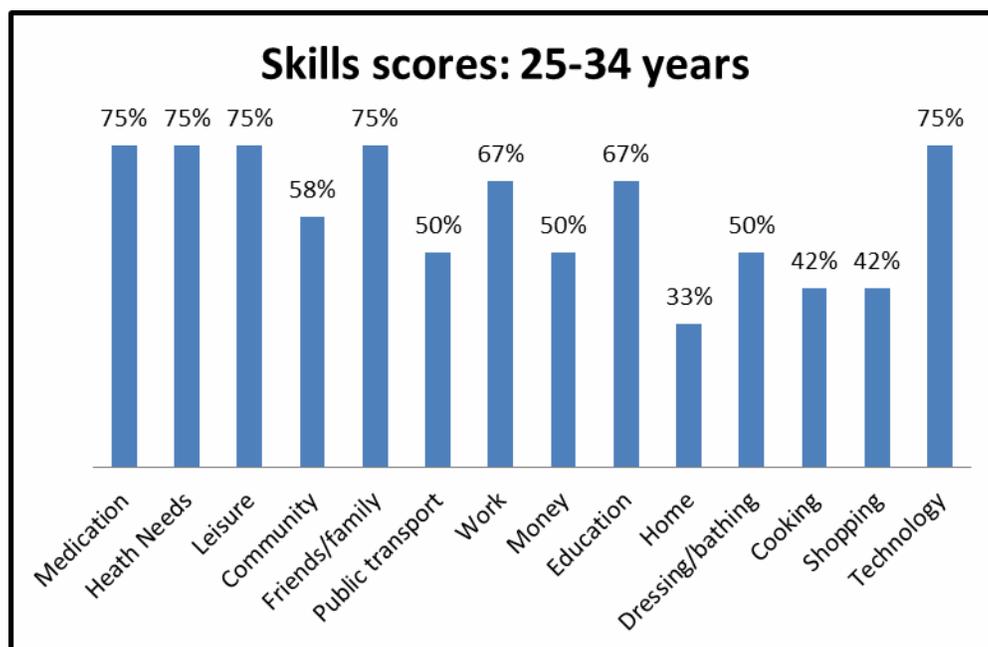
The findings from this age group demonstrate the need to be independent. It is clear that young people are keen to learn skills that will help them lead a full and active life. *One teenager told us:*

*“I want to learn to drive as then I can be more independent.”*



The highest scoring skill is to learn to use public transport, followed by managing money, finding the right home and learning to cook. Interestingly, keeping in touch with friends and family and looking after health needs do not score high for this group, possibly because most of them still live at home and their health needs are still being addressed by their family.

## Analysis of Workforce Skills – Results for 25-34 years



In this age group, health needs, along with accessing leisure activities and learning to use technology, are the most important skills required from the workforce. These are followed by finding a job and education. Some of the people we met in this age group had found paid work and were aware of the help required to achieve this.

One person told us how important his visits to the psychiatrist were, and how he appreciated the time alone to talk but the need for staff to attend some of the session in order to support him in his daily life:

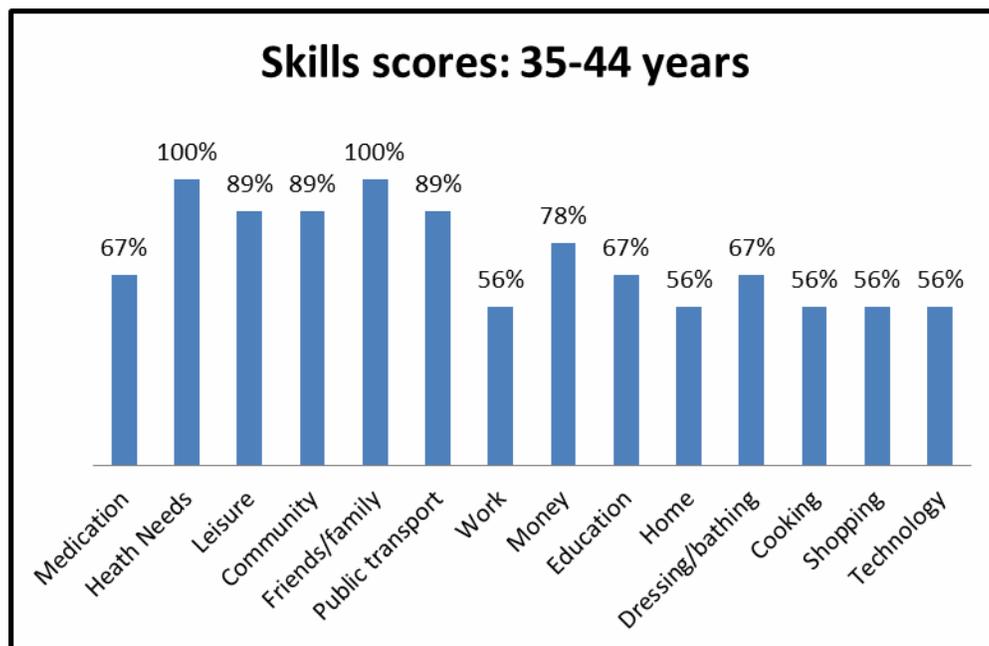
*"I go to see the psychiatrist and I talk to her about things by myself – the staff put words into your mouth and they are not your words. After I talk to the doctor the staff come in – I have a short-term memory problem so staff need to know how to support me in between visits."*

Another person described the importance of being treated by experts in whatever he was being treated for:

*"I need help with many things and need to see different doctors who are expert in what they are helping me with. Should have the best shouldn't I?"*

Another person spoke about his desire to work full-time in retail. He had found paid work through a supported employment agency but had been made redundant. He was aware that he may need to go back to college to learn something new as he felt the retail profession was in decline.

## Analysis of Workforce Skills – Results for 35-44 years



The number of people in this group is smaller (9) therefore there is less variation in the scores. However, health needs and keeping in touch with family and friends are important to everyone in this group. Being able to be part of the local community is also as important as is using public transport., Accessing leisure opportunities also scored well. Below is a quote from a person who explained why using her local community was important:

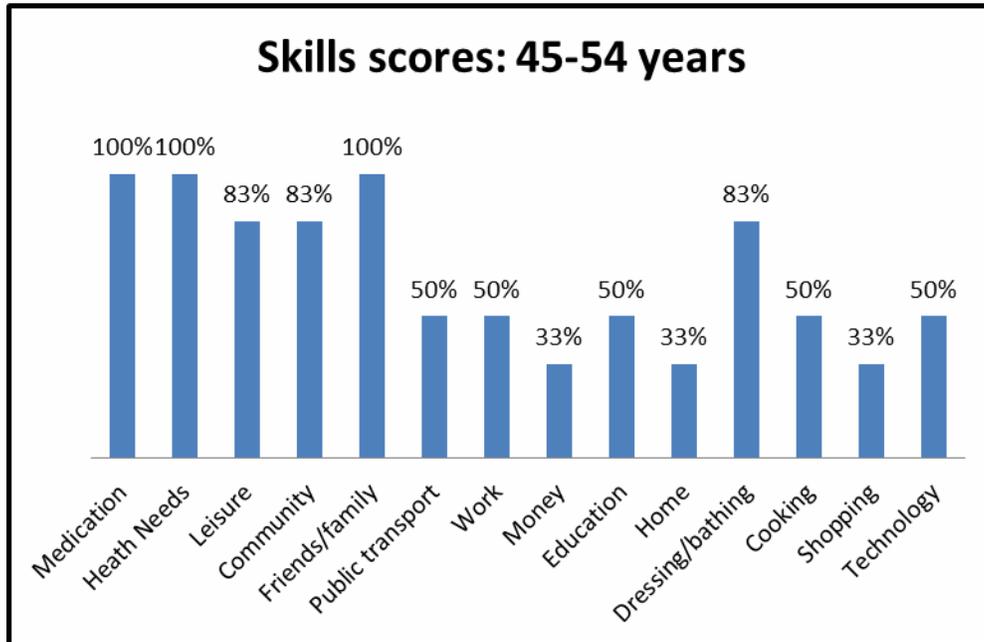
*“I want support to go to Slimming World. It’s in the sports centre”.*

The findings differ as people get older and their needs change, maybe because independence and work have not become a reality for them and they start to become more isolated as they are out of education. They reinforced the need to have friends and be part of the community and the importance of independence to be able to do more things that help reduce isolation. One person commented:

*“I want to do more things, go shopping with friends.”*



## Analysis of Workforce Skills – Results for 45-54 years

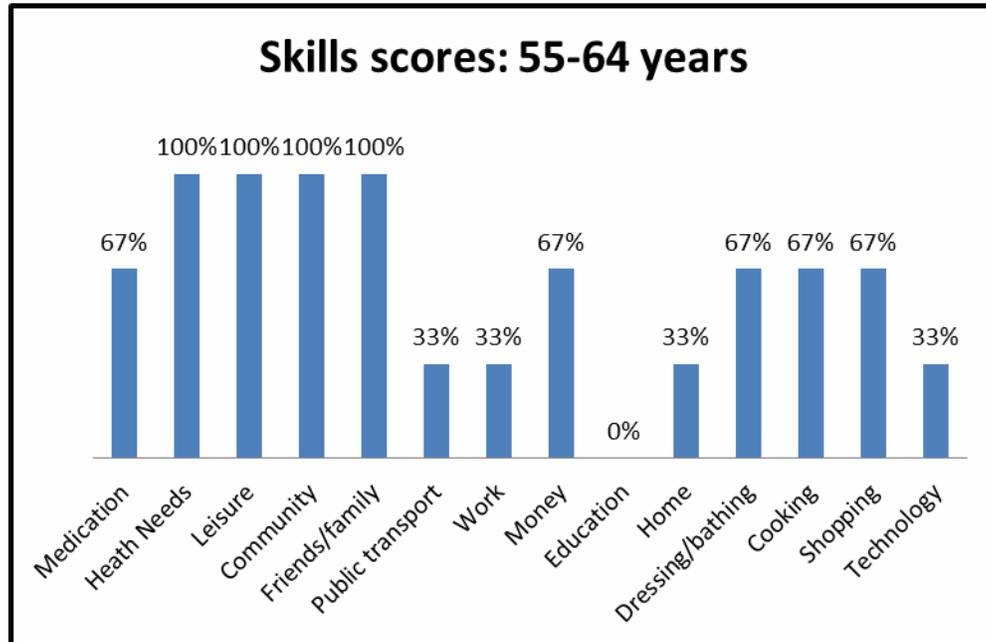


In the 45-54 years group, and sample size is smaller still (6) but there are clear indicators around health, keeping in touch with friends and family, followed by accessing the community and leisure opportunities and help with dressing/bathing. The wish for employment is diminishing in this age group as the reality of obtaining it is becoming less real for them. A number of people we spoke to did voluntary work. One person told us:

*"I'd like a job but do a lot in the charity shop."*



## Analysis of Workforce Skills – Results for 12-24 years



This chart has some similarities to the previous age group (the sample size is 3), with health, accessing the community, keeping in touch with family and friends scoring high, along with more practical day-to-day skills (washing, cooking, shopping and managing money). There is less interest in finding a job, the right home, education or using public transport in this age range.

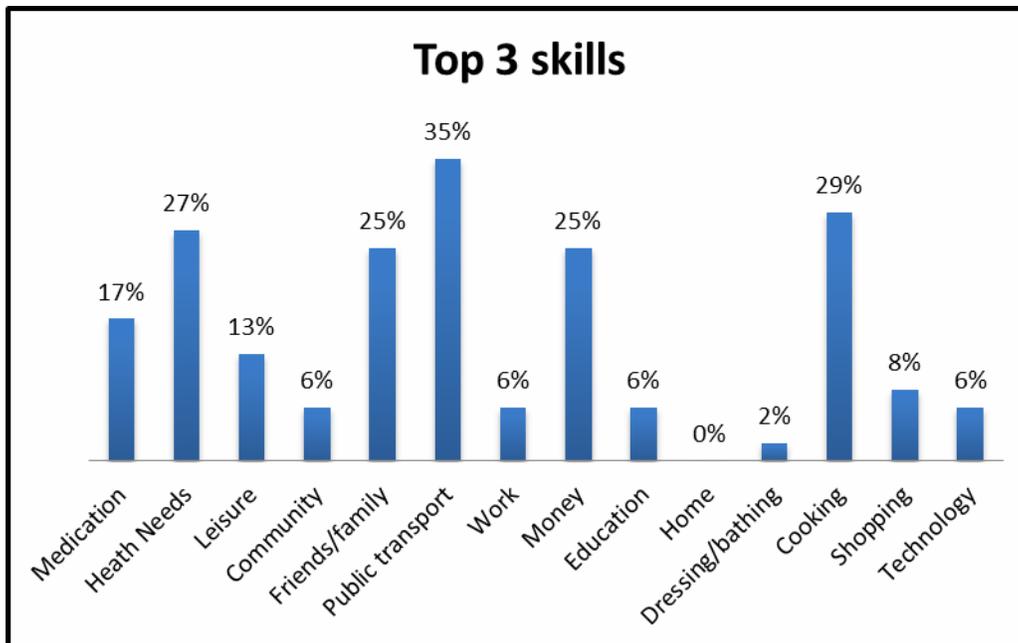
## Analysis of Workforce Skills – Results for 65 years and over

The findings from the 65 years and over group was only made up of two people, therefore it is unsuitable to make recommendations.



## Top three skills

After asking people to complete the skills section alone, we also asked some groups to come up with their top three choices. The results are in the next chart.



There is some consistency between this chart and the total scores chart. Two of the highest scores are the same as the total score chart (public transport and health needs), however, learning to cook was the second highest score in the group discussion (possibly due to the school taking part in this exercise). Keeping in touch with friends and family remains prominent, along with managing money.

## Other skills not covered in the questionnaire

It was impossible to cover everything in the questionnaire, so time was given during the focus groups or interviews to explore what other skills are required to build a knowledgeable workforce. These are described below:

- **Communication**

The workforce need to have a range of communication skills in order to support people, including the use of more technological approaches (use of iPad and the various apps to support communication development) and simply giving people time to express their needs. When 'communication skills' was added to a later version of the questionnaire and to the visual images used in the focus groups, it was seen to be highly important by many of the participants. The quote below is from a person who can understand verbal requests providing people slow down when speaking and give him visual cues:

*“He says things to me in stages – not all at once. The old staff didn’t say things in stages. The new staff do and have a board to write things on and put pictures on.”*

A parent spoke about the link between behaviour and communication:

*“The workforce supporting my son need to understand that all behaviour has a function and is a form of communication. Communication skills are very important – being able to understand my son’s signing, understanding and reading him in each situation so they can prevent and diffuse difficult situations.”*

As well as being able to communicate effectively with people with learning disabilities, it was also important to be able to communicate with the family and others supporting the person. One parent commented:

*“Communication is a huge issue – to be able to communicate with people with learning disabilities, family and carers, and share their knowledge across the team supporting the person.”*

- **Understanding behaviour and mental health**

Another area of knowledge required by the workforce is understanding the behavior and mental health needs of people with learning disabilities. This was highlighted by a few of the parents we spoke to, who intuitively know when their son or daughter has a bad day or when they are likely to become upset. Below are quotes from parents we interviewed:

*“Knowing how to plan the day – to have enough information to reduce anxiety but not too much planning to overburden her. The workforce needs to have an understanding of the motivation of the people they are supporting. For example, if we go on a family outing I need to plan in a few positives onto the day to keep her motivated. Motivation is essential in order to make sure they are doing positive things.”*

*“Have an understanding of behaviour – know their body language, not just look and listen to what he says. The workforce needs to be able to anticipate the trigger points and be good at shielding. People need emotional intelligence to be able to anticipate and avoid trigger situations and also do a continuous risk assessment.”*

There is also a need for bereavement counselling, as highlighted by one of the postal questionnaires. The person was unable to access counselling by a professional with experience in working with learning disabilities in their local area.

- **Delivering news after diagnosis**

Although this was not raised by people with learning disabilities, the skill in delivering a diagnosis has a life-long effect on the family and their community, which can ultimately affect the life-long aspirations we have for people with learning disabilities. The parents group we spoke to in West Sussex said many parents still need time to discuss how the diagnosis of their son/daughter affects them. They said:

*“We still hear stories that having a disabled child is the end of the world. It isn’t. Having a diagnosis explained in a negative way sets you apart from your community. There are more negative stories around diagnosis than positive. 10 years on we still remember the*

*diagnosis. The workforce needs training across the whole life course – so that those working with babies or young children have knowledge of adults with learning disabilities too. This can help to relay that the diagnosis is not the end of the world. The workforce should include those health clinicians, education and social care practitioner.”*

- **Positive risk taking**

Both people with learning disabilities and parents spoke about the need to be able to learn new skills and try them out. One person described how he used public transport on his own before he moved to his present home. Now he does not have a Freedom Pass and has not been trained to use public transport in this area. He said:

*“Since I moved into this house I’ve never had a bus pass – the last time was in 1998. I used to catch the bus. I only go out with staff – I’m not allowed to go out on my own. I used to go out on buses when I lived in Farnborough.”*

The same person faced limitations in keeping in contact with friends too. He would like to meet up with a friend but because they live in houses run by different organisations, it was not possible for staff to arrange this.

Having more responsibility over money was a recurrent theme throughout this consultation, and whilst some people had access to money through a bank card, others had no control over their money. One person said:

*“I want to look after my own money. The staff takes it off me – and say “put it in your tin.”*

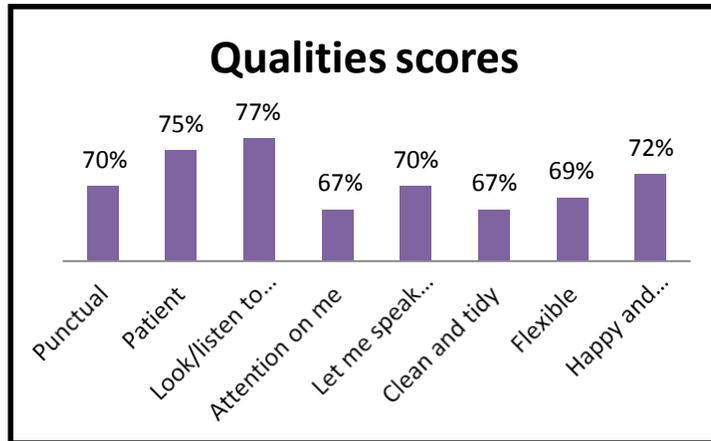
One parent described positive risk taking succinctly as:

*“A can do attitude and a positive approach to risk taking. They need to work as a team – my son behaves differently with different people so they need to share these things, and to be consistent in the way they support him.”*



## 7) Analysis of the workforce qualities

### Overall results

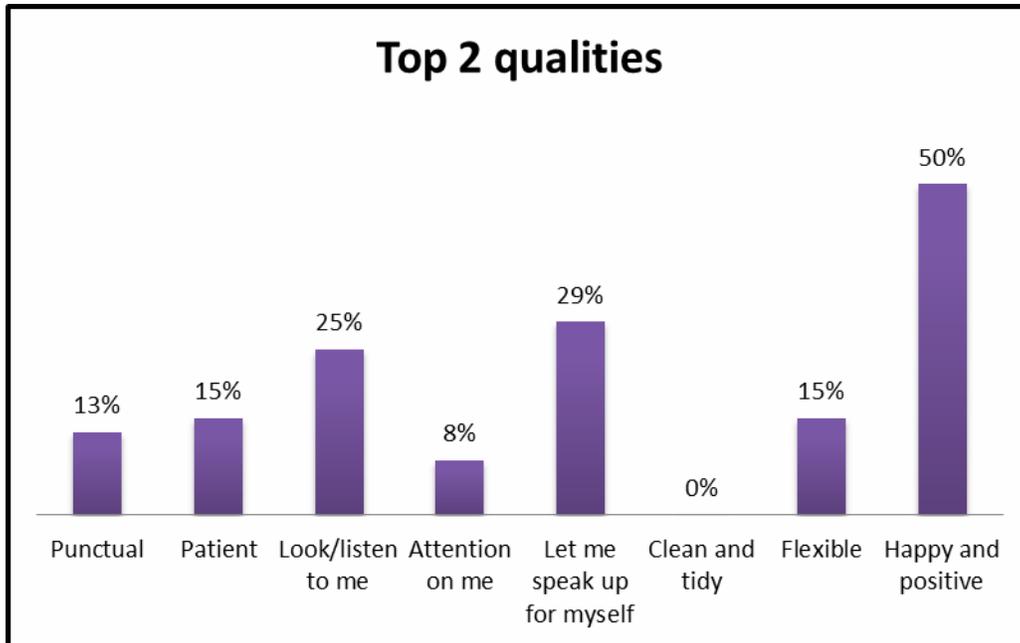


The chart above demonstrates that the most important qualities required from the workforce are: to be listened to, be patient, have a happy and positive attitude, be given a voice and be reliable (punctual). The people we met in the focus groups believed that having the support from someone with those qualities made a huge difference to their lives. They felt that these qualities should be inherent in everyone supporting a person with a learning disability - from a medical consultant or GP through to job coaches and personal assistants. With questions about qualities, there was less variation in the scores between different age groups, so we have only presented the overall results above. However we did collate the participants' top two most important qualities.



## Top two qualities

The results for the participants' top two qualities are shown in the chart below.



The chart demonstrates that having a happy and positive attitude is the most important quality by far, followed by letting people speak up for themselves and listening to them. Some participants did say that this would translate in someone who can encourage them to have an independent life and to be supported to make decisions.

## Other qualities not covered in the questionnaire

### ▪ **Keeping promises**

Again, as in the skills section, after running a few focus groups it was clear that people had often been let down by those supporting them, so the quality 'to keep promises' was added to a later questionnaire. This is not accounted for in the chart above but after describing it to later groups it was seen as an important quality. For example, one lady we spoke to was keen to try a new beauty salon for a manicure, and had made an appointment to coincide with the day she had support. The support worker was sick and the message did not reach the agency in time for another person to support her, therefore she cancelled the appointment as she was too nervous to go by herself. Episodes like this can knock people's self-confidence as well as their confidence in others.

### ▪ **Encouraging independence**

During the focus groups people told us how they wanted to learn new skills to be more independent, rather than be dependent on others. One parent said:

*“Our kids need to be as able as possible. Their carers need to enable them to do as much as possible for themselves. Don’t disable them – am I helping people in the long term if I put their shoes on for them? I don’t want my daughter to be a passive recipient. Give her time and explain to her that she can do it.”*

Intuition was also described by a parent who said it was a balancing act to know when a person can try something themselves and when to intervene:

*“The person needs to be savvy enough to know how to encourage people with learning disabilities to do things for themselves and to encourage them to help others.”*

In order to learn new skills, the workforce should also be aware that those people they are supporting may have never had opportunities to learn such skills before and could be nervous. One young person said she needs:

*Someone who can boost my confidence.*

#### ▪ **Attitudes**

We heard a few stories of when people didn’t feel respected. People described a positive attitude as:

*Recognises you as a person and not just your disability.*

One parent described her experience when she took her son to a medical appointment:

*“When my son saw a medical consultant after losing substantial weight, the doctor said ‘these people have a poor diet’ in front of me, his mother. It goes back to negative attitudes again.”*

The same parent believed that the workforce should:

*“... hold the core value of ‘he is a human being – the same as me; he’s a person – not a job’.”*

#### ▪ **Emotional intelligence**

This quality was raised by the parents, most of whom had children with complex needs, who often demonstrate their communication needs through their behaviour. These parents have had the benefit of living with their son/daughter for many years; they can intuitively tell when they are about to get upset and have the skills to defuse it. They believe understanding behaviour and the individual is essential in reducing untoward incidents. Some of their key messages for the workforce are below:

*Be a can-do person and think ahead quickly and respond to situations that can arise and diffuse situations and re-direct. They need to think three steps ahead – they need to know when to intervene at the right point – not too early.*

*Learning the unwritten rules – for example puberty can throw all sorts of inappropriate comments. My daughter needs to be taught it’s inappropriate to talk about periods in a room full of strangers. Also, teaching her how to understand the behaviour of others. Instagram is a minefield for a teenager with a learning disability when it*

comes to language and rating one another. I need to be one step ahead to prevent her from misinterpreting situations.

- **Humour**

It emerged through the discussions that humour was important in the relationship with support staff. One person described how her supporter used humour to help learn a new task as it kept her motivated. Parents also highlighted that having a sense of humour helped them in their caring role and in their relationship with their children. One parent, whose son can demonstrate behaviour seen as challenging stated that the workforce:

*“... need to have a sense of humour, particularly to deal with certain situations when out with the general public – people need to be thick skinned and be ok to be the centre of attention if they go somewhere and an incident occurs.”*

## DISCUSSION



In this section we bring together some of the key messages and themes from the consultation process.

### 1) Overall key messages

#### **Striving for independence**

Both people with learning disabilities and the parents we spoke to were very keen for people to learn a range of practical skills to lead as independent a life as possible. Some of the skills varied according to their age group and impairment, so the workforce needs to be aware of these so they can tailor the support they offer. Learning to cook, to use public transport and to have more control over finances were consistently spoken about, especially amongst those aged 44 years and younger, reflecting the goals of any other younger person in society. The younger age groups also had aspirations to find employment, which was why they wanted to learn to use public transport and be able to budget and look after their money.

For those aged over 45, some of the practical skills they required help with were dressing and bathing and help with technology. Some of the younger people we met were proficient in using social media and those who weren't were aware that using Facebook and Instagram are good ways to keep in touch with friends.

People spoke about the need for positive risk taking in order to learn such skills, and a few described how they have lost some skills due to the risk averse culture of the home they lived in. The parents we spoke to felt it was detrimental to their son/daughter's independence if they were supported by people who lack the knowledge in how to encourage and motivate people to maintain or learn skills.

## Health

Regarding health, those people using medication or with known health problems felt it was very important to be supported by knowledgeable staff and practitioners. They wanted professionals to be experts in their area. Some of the people we spoke to were able to self-administer medication but valued having support from an expert to keep them healthy.

A number of people from the focus groups were unaware of the role of the community team for people with learning disabilities (CTLD) and one parent had great difficulty in engaging with her local team, despite her son having complex needs. She stated:

*“The CTLD is a huge resource but now providers are providing their own staff. I’ve had no involvement from the local CTLD, despite my son having very complex needs. There is a huge gap in getting Occupational Therapy, Physiotherapy and the provider has to offer it all. I would like Speech and Language Therapy (SALT) for my son but they say ‘what can we do?’ I’d like the speech and language therapy team to support his support team to help him and implement the five good communication standards.”<sup>2</sup>*

## Maintaining relationships

Maintaining relationships with friends and family is at the heart of what makes a good life. Many people with learning disabilities require support to maintain contact with friends and family, because of communication difficulties and because they may not live close to their family anymore. This is particularly pertinent to people living away from the family home who have moved to a new area, or if their family or friends have moved away. Maintaining close contact with their families keeps people safe. We know from the Winterbourne assessment and treatment unit that many of the victims lived miles away from their families, and those that did visit were kept away from the communal living areas.

Being supported by staff to keep in contact with friends and family was extremely important to everyone we spoke to – it was the highest scoring skill along with using

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<sup>2</sup> Please see Appendix 2 for the Five Good Communication Standards (2013. The Royal College of Speech and Language Therapists).

public transport. Everyone aged 35 years and above said they needed help with this, yet it wasn't seen as important to the younger participants. A possible reason for this is that most of the younger people are living in the family home so have immediate access to their family and some friends. From our discussions, we also learned that lots of young people have the technology skills to use online forums such as Facebook or Instagram as a way to keep in touch with friends and family. Those who were older and had not been taught to use computers and technology at school were unable to keep in contact with their families in this way.

### **Accessing the community**

Whilst some of the people we met were able to access leisure and community facilities on their own, many required support to do so. Sadly, a few people, as described earlier, had little choice or control around what they pursued in their leisure time. People who use their community on a regular basis tend to make more friends, become known and feel safer as a result. Being able to access the leisure activities of one's choice can be highlighted through the person centred planning process, particularly for people who find it difficult to verbalise their interests. However, only 35% reported to have a person centred plan. For people who have very little or no support at all, having the confidence to try new activities is daunting to do on one's own. Sometimes people just require a very small amount of support before they can take the lead themselves.

When we think about citizenship, we often think about feeling part of our local community, having a role to play, and giving to others. A number of the participants had found some voluntary roles which made them feel proud of their achievements. Some worked in charity shops, some were members of the local learning disability board and others were involved in training social workers and nursing students.

## **2) Words from the IMP group**

The last focus group was held with the IMP group in East Sussex. By then we had a fairly clear picture of what people with learning disabilities wanted from the workforce, but by the end of the visit, it was fascinating to have the previous findings validated by this group. Prior to our visit, they had undertaken work addressing what good support meant to them. Their findings echoed the qualities listed in the questionnaire, along with other qualities we heard people talk about during our discussions. Their work so accurately reflected what we had heard during the past few months that we felt it was important to end the discussion with their words.



They described good support as:

- *Trust*
- *Making me feel comfortable*
- *Asking questions sensitively and not prying or judging*
- *Choice and control*
- *Encouraging but not making you do things*
- *Staff checking that they are giving support that's right for you*
- *Being part of the community*
- *Recognising you as a person and not just your disability*
- *Tailored support that is flexible*
- *Consistent support – someone you know and trust*
- *Remaining confidential*
- *Support to become independent, not just doing things for you*
- *Good communication*
- *Good humour – having a laugh with carers, not being too serious.*
- They also described how good support made them feel:
- *In control*
- *Safe*
- *Ecstatic*
- *Amazing*
- *On top of the world*
- *Involved in decisions*
- *Encouraged to do things you're not used to*
- *Able to take risks and try and new things.*

### 3) Validating our findings

In June we attended the Kent, Surrey and Sussex Learning Disability Community of Practice Conference, launched and supported by Health Education England working across Kent, Surrey and Sussex. We used it as an opportunity to validate our findings with the participants attending our workshops. We asked the participants to put themselves in the shoes of a person who required support on a regular basis, and to think about the skills and qualities required of such support (the questionnaire had not been shown prior to the exercise.)

Having held two workshops the findings from both groups were similar to the findings from the first three focus groups. That is, there was a need to learn practical skills such as to cook to be as independent as possible, to communicate clearly and listen as well as having a positive approach to risk taking. The majority of the discussion was based on the core qualities of people, namely to be patient, have a positive attitude, be honest and respectful, be flexible, motivated and have a sense of humour.

## CONCLUSION

The consultation was an extremely interesting process, as over time it gave us a very clear picture of what people wanted from the workforce. People value a workforce who hold positive attitudes about people with learning disabilities as being equals, and who bring specialist skills that can help people with learning disabilities remain healthy, keep connected with their family and local community. They also value having a workforce that encouraged the learning of new skills that will enhance their independence and help them have a good life.

At the heart of good support, people with learning disabilities need the workforce to be patient and kind, have a positive demeanour and ensure the people they support are given a voice. They also value reliability and for promises not to be broken. The workforce need to be experts in their area of speciality, which should include understanding health needs (both physical and mental), making connections with family and the local area and encouraging people to be more independent - whether it is through learning to use public transport, to cook a meal, to handle money or to find a job. People had high aspirations and the workforce needs to address this.

Our recommendation is that all curricula for the workforce have values (based on the social model of disability) input delivered by people with learning disabilities to make this possible.



Appendix 1.

# Questionnaire

	<p><b>Please answer the questions below.</b></p> 
<p><b>About yourself</b></p>	
	<p><b>1. Are you male or female?</b></p>
 <input type="checkbox"/> Male	 <input type="checkbox"/> Female
	<p><b>2. Where do you live?</b></p>
	
<input type="checkbox"/> Kent	<input type="checkbox"/> Surrey <input type="checkbox"/> Sussex



### 3. What is your background – are you?

- |                                |                                  |                          |
|--------------------------------|----------------------------------|--------------------------|
| <input type="checkbox"/> Black | <input type="checkbox"/> Chinese | <input type="checkbox"/> |
| Mixed                          |                                  |                          |
| <input type="checkbox"/> White | <input type="checkbox"/> Asian   |                          |
| <input type="checkbox"/> Other |                                  |                          |



### 4. How old are you?

- |   |   |
|---|---|
| <input type="checkbox"/> 16-24 years old old  | <input type="checkbox"/> 45-54 years          |
| <input type="checkbox"/> 25-34 years old old  | <input type="checkbox"/> 55-64 years          |
| <input type="checkbox"/> 35-44 years old over | <input type="checkbox"/> 65 years old or over |

### About your home



### 5. Do you live:



on your own



with others



with family

## 6. Do you get support:



Day only



Day and night

X No support

## About your health

### 7. Do you have a health check once a year?



Yes



No



## 8. Do you have a health action plan?

 Yes   Unsure   No



## 9. If you have a health action plan, who developed it with you?



Family



Support worker



Support worker / Personal assistant



GP / healthcare team



Community Learning Disability Team

Other – please specify:

## About the support you have in place



10. Do you have a person-centred plan?



Yes



Unsure



No



11. Do you have a direct payment? A direct payment is money from the council to help you choose your support.



Yes



Unsure



No



12. Do you have a personal health budget? This is money from the health service to choose support for your health needs.

 Yes      Unsure      No



**13. Do you have a personal assistant?**

 Yes      Unsure      No



**14. If you have a personal assistant, how often do you see them a week?**

5-7 days     3-4 days     1-2 days



**15. Do you hire your own staff or are they from an agency?**

 Yes      Unsure      No



**16. Were you involved in interviewing and choosing staff that**

**support you?**

 Yes

 No



**17. Please tick if you get support from the following:**



Social worker or care manager



Member/s of the community learning disability team



Health care worker e.g. district nurse



Family



Leisure activities



Personal assistant  
or support worker in  
your home



Self-advocacy  
group



Friends and  
neighbours

Do you get any other type of support?

E.G. at work?

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## About the people who support you



**18. What skills do people supporting you need to have?**

Know about the side effects of my tablets and medicine



Yes



No

Know about health needs



Yes



No

Supporting me to take part in leisure and activities I like



Yes



No

Understand how to help me take part in my community



Yes



No

Understand the importance of keeping in touch with friends and family



Yes



No

Getting around – using public transport



Yes



No

Finding me a job



Yes



No

Money and budgeting



Yes



No

Supporting me with my education and learning



Yes



No

Support to find me the right home



Yes



No

Dressing, bathing / showering



Yes



No

Helping me to make snacks and meals



Yes



No

Shopping



Yes



No

Teaching me to use technology e.g. mobile phone, computer



Yes



No

Anything else you need help with?

.....

.....

.....

.....

.....

.....

.....

.....

	<h3>19. What qualities do people supporting you need to have?</h3>
<p>Turn up on time</p> 	<p><input type="checkbox"/>  Yes</p> <p><input type="checkbox"/>  No</p>
<p>Be patient with me</p> 	<p><input type="checkbox"/>  Yes</p> <p><input type="checkbox"/>  No</p>
<p>Look at me and listen to me</p> 	<p><input type="checkbox"/>  Yes</p> <p><input type="checkbox"/>  No</p>
<p>Keep their attention on me and not on other things e.g. on their mobile phone</p> 	<p><input type="checkbox"/>  Yes</p> <p><input type="checkbox"/>  No</p>

Let me speak up for myself



Yes



No

Be clean and tidy



Yes



No

Be flexible – if I change my plans it is ok



Yes



No

Have a happy and positive attitude



Yes



No

Anything else you would like to tell us about the kind of support you need?

.....  
.....  
.....

**Thank you very much**

**Appendix 2.** The five good communication standards by the Royal College of Speech and Language Therapists, 2013:

*Standard 1:* There is a detailed description of how best to communicate with individuals.

*Standard 2:* Services demonstrate how they support individuals with communication needs to be involved with decisions about their care and their services.

*Standard 3:* Staff value and use competently the best approaches to communication with each individual they support.

*Standard 4:* Services create opportunities, relationships and environments that make individuals want to communicate.

*Standard 5:* Individuals are supported to understand and express their needs in relation to their health and wellbeing.

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