

It's My Life

understanding people's views
and ideas about how they
want to live their lives, what
is important to people and
what they need in order to
live their good lives

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This report was facilitated and produced by the Wiltshire CIL User Engagement Team, under a contract with Wiltshire Council, to provide a User Engagement Service.

The User Engagement Team works alongside people with lived experience of health and social care services to support, encourage and facilitate them to have their say, ensuring that their voices are heard and that they are able to contribute and influence how services are shaped and developed in Wiltshire.

The User Engagement Team uses creative and interactive ways of engaging with people, co-producing each piece of work uniquely, to value the authentic voice of all service users.

It's My Life Key Messages

People with learning disability and/or autism want what everyone wants to live well: a home, equal relationships, to work and have purpose, to have dreams and aspirations. Making this a reality for everyone is a priority for now

Housing needs to be de-institutionalised: people want to live in homes not houses, where they have choice and control over all aspects of their daily life

Independent living does not mean living without support. Relational support provided by people that are liked, known, and trusted can work with the person to enable them to keep safe, learn new tasks and take care of themselves

'Written off for being different' is not an acceptable experience for people living in Wiltshire today. We now need to act and ensure that every Wiltshire resident and every professional involved in the health and social care system play their part to ensure that disabled people get to live the lives they deserve

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1 Introduction

Between May and December 2021 Wiltshire Council conducted six online workshops with providers of adult social care in Wiltshire. The providers that attended the workshops were all part of the Wiltshire Good Lives Alliance (providers that Wiltshire Council has checked to make sure that they can provide good quality services).

The workshops focused on various themes which are aligned to Wiltshire's vision that services should support people to achieve their goals, to be understood and have their communication needs met, to learn skills which enable them to take an active part in society, to be economically independent and to be enabled to take positive risks.

To compliment and run alongside the provider workshops Wiltshire CIL ran a series of mini Knowledge Cafés over the same time period to gather the views and ideas of people with a learning disability and/or autism.

The Knowledge Cafés looked at the following topics –

- ▶ My good life
- ▶ Good support
- ▶ My community
- ▶ Work and employment
- ▶ Living my life
- ▶ Health

This work was carried out at the request of Wiltshire Council to support them with creating a robust care market in Wiltshire which meets the full range of needs of Wiltshire's residents in a strengths-based way

Aim – the purpose of this piece of work is to understand people's views and ideas about how they want to live their lives, what is important to people and what they need in order to live their good lives.

2 What we did

Between May and December 2021 six themed knowledge cafés were held, with two taking place for each theme: one in Devizes and one in Warminster.

Knowledge cafés are fun, interactive events using work sheets, colourful pens, stickers, post-its, sweets, fruit etc. creating a relaxed informal environment where people feel comfortable to have open and honest conversations about their views and experiences.



Posters were made for each of the Knowledge Cafés and were publicised through Wiltshire CIL's contacts, on Wiltshire CIL's social media platforms and through the Good Lives Alliance membership.

A total of 95 people attended the Knowledge Cafés over the 6-month period that they were held.

A series of questions were developed and asked at each Knowledge Café that were specific to the theme that generated lively discussions. In this report we analyse the feedback gathered from all of the Knowledge Cafés.

3 My Good Life

The first Knowledge Café looked at people's good life so that we could get an understanding of what a good life looks like for people, who they are and what is important to them.



Purpose and Autonomy

Crucial to people having and living their good life is having a sense of purpose to their days. People want and need things to do whether it be being active, **going for walks**, **going on days out** or **gardening**. Or, enjoying hobbies such as **stamp collecting**, seeing the world and going on **holiday**, **watching TV** or **shopping**. Opportunities to socialise were also important, people valued **social clubs**, going to the **pub**, the **theatre**, and **music festivals**.

Positive Relationships

Relationships are fundamental to people's good lives, highlighted were relationships with **family**, **girlfriends**, **partners** and **neighbours (to get on with)**. Having positive relationships where you **feel valued** and **accepted** are important. People described how they **don't want people to write you off for being different**.

Getting the Basics Right

The basic minimums that we should all expect were highlighted as key factors that contributed towards having a good life.

The opportunity to **live where I want to live**, to **live in a bungalow** or **live in a house** – having choice and control over where you choose to reside is important. **Good health** was highlighted as a contributing factor towards having a good life.

Accessibility also plays a key factor in people's ability to live their good life especially **having accessible places to go**. Having the **freedom of a car** was also beneficial.

The basics that many take for granted such as choosing where you live, having a job and being able to access your community for example are things that most people don't consider necessary to mention as they are just part of their everyday life. However, the fact that these basics are mentioned by people with a learning disability and/or autism highlights that they do not get to experience these things as standard and part of their everyday life; they often have to fight for the basics to be acknowledged.

Throughout this report we look at the importance of getting the basics right and how crucial this is to the quality of people's lives and their ability to live their good life.

Alongside looking at people's good life we also wanted to understand what people's hopes and aspirations for the future are and what people had to achieve this.

Hopes and aspirations for the future centred around four main themes:

- ▶ Home
- ▶ Work/Learning
- ▶ Relationships
- ▶ Experiences



Home

Choice and control over where people lived featured in peoples hopes and aspirations for the future. One person described how they **wanted to have a flat with a garden** whereas, another simply just wanted **to move out**. Someone else wanted the opportunity to be able to **sort and tidy their house**.

Work/Learning

There is an ardent desire amongst people to want to **improve their (my) education**. Some people want to learn specific skills such as **computers**. The motivation for people to improve their education centred around the aspiration to work - **to help me find work** and to be in **paid work - a full time job**.

Relationships

As we have already seen, positive relationships are fundamental to people's good lives, and this is reflected through peoples hopes and aspirations. People want to **get married** and to **meet people in person**, **they don't want to be excluded**.

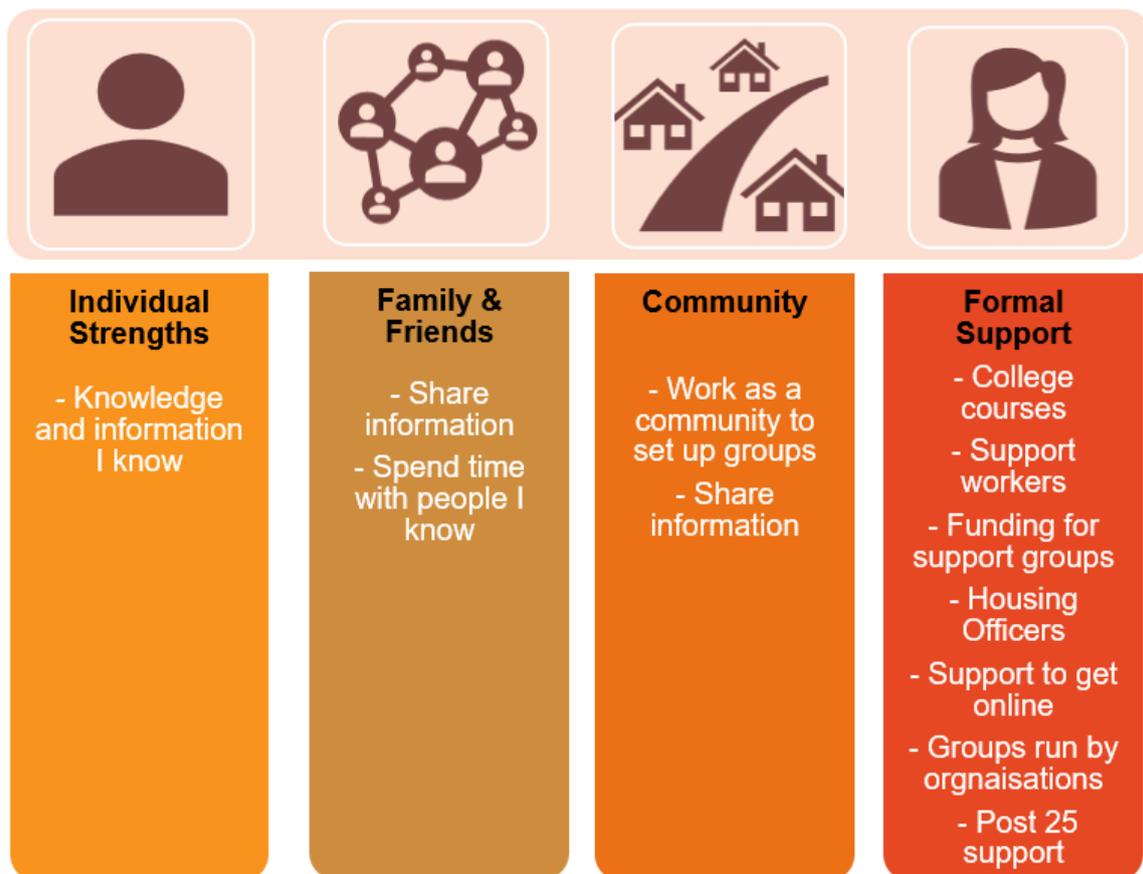
Experiences

People have hopes and dreams to experience new and exciting things such as **sky diving to raise money for charity**, to go **on holiday to**

France, to win the lottery. For some people Covid had impacted on their hopes and aspirations and following prolonged periods of isolation and lockdowns people’s hopes were around wanting **Covid to go – to get back to bingo and social clubs, to get out more and to carry on with their hobbies.**

People do not have unrealistic hopes and aspirations for their futures they have everyday dreams that we can all relate to.

We then looked at what people needed, what resources they had and could call on from other sources in order to achieve their hopes and aspirations. There was a disproportionate need or requirement of formal support to be able to realise their dreams.



The realisation of hopes and aspirations becomes more difficult for people with a learning disability and/or autism as their lives are often lived in a ‘service world’ that is led by staffing, budgetary and risk assessment constraints.

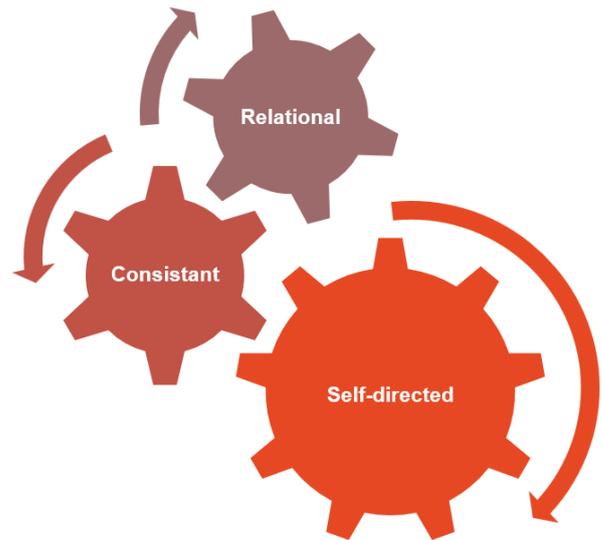
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Good Support

In this Chapter we look at what good support looks like and means to people.

Good support needs to be:

- ▶ Relational
- ▶ Consistent
- ▶ Self-directed



Relational

People want to be supported by people who are **friendly**, people who they can **build a good relationship with**. It is important that support is provided by **people that know me** and they recognised that **new staff need extra time to get to know me**.

People found it very difficult to be supported remotely and wanted to **talk to a person and not a machine**. Value was also placed on support from people **who would stand up for you if you are being bullied when out and about - 90% of good support is because of good people**.

Good quality, accessible support where you can **ask people for help** was valued. The merit in having a **good social worker** was recognised as was society being educated about disability and equality; an example given suggested that **public transport staff and customers need to be more aware of different people's needs**.

Only having one social worker instead of meeting new ones all of the time and having to go over everything again.

Good, effective support is provided by a variety of people/sources including **family, friends, the community and professionals**.

Consistency

There were many examples of inconsistent support and why it is detrimental. Experiences such as having **lots of agency workers in the past year which has been really difficult, in particular during a recent bereavement.** People described how they **could not cope with agency care and inconsistent carers.** Covid has impacted on some peoples support and causes uncertainty over who can provide the support and **knowing who can step in if staff get pinged - this is worrying for people.**

Good support can also be impacted upon by time limitations and constraints, you **don't always know how much staff time is available for plans until the day.** This makes it difficult for people to be able to plan what they are doing.

Limitations were experienced by people when looking at what support they valued as they felt that they needed more **support groups for adults as most groups are for children;** it was felt that **transition is good but there is not enough to do for 18+.**

There were strong feelings about financial accessibility of support and that social care support should be **non-means tested** and that **it should be free for all people to get help to access the community.**

Self-directed

The best support put the person front and centre, it was **person centred** and **inclusive.** It was suggested that it would be hugely beneficial to **match people with support based on interests.** Being able to choose and direct what you did when being supported was important, one person described how being supported to **meet people in the community and friends and family is important to me.**

Support that is person centred enables people to lead a fulfilling life. For some this was around having **emotional support - I need this as there have been difficult times,** for others it was **1-1 support** or **support for me to be able to help my family (I care for family)** or **medical support.**

Voices into Action!

The importance of people being able to live independent lives where their support is directed by them can be seen in national campaigns such as *Stay Up Late* <https://stayuplate.org/>¹



Stay Up Late was set up to ensure that person centred planning for people with learning disabilities and autism meant that it truly reflected what an individual wanted to do in their life.

In particular they were concerned that people with learning disabilities, and autism, weren't able to Stay Up Late and do the things so many people, who don't need support, take for granted.

The support people valued was unique to them and their good life. It enables them to do the everyday things that are important to us all such as cooking - **support for recipes if they more complicated, support with things going on in the community, going to the park, filing in forms, support with spelling and grammar or music and technology.**

Value was placed on support that enabled people to learn, develop and become more independent. People want to learn new skills - **to be able to do courses at college for learning disabilities, I want to do reading, writing and computers but there doesn't seem to be anything.** Learning for career purposes such as **how to be a police officer** was suggested or for personal development so they could become **kinder and more enthusiastic.**

Support to increase people's independence and autonomy was valued by many especially around independent travel – **planning a journey and travel training for new places to build confidence both on foot and on public transport.**

The recipe for achieving good support requires support providers having a mixture of knowledge, skills and qualities.

Skills such as **listening, sign language** or the ability to translate/change the **wording so that I can understand** are valuable.

Support providers should be **welcoming, tolerant, flexible, patient** – **I can't get my words out always, so people need to be patient and not jump in.** Support providers **doing what they say they will do** is also important.

Knowledge is very important, especially of the person being supported. It is essential that they **understand you properly - understand your background and where you are coming from.** To achieve this, it was also recognised that **the person being supported needs to explain how the condition/s affects you - be open and honest.** The support provider should always **ask what I, the person being supported want.**



5 Community

Next, we look at the role of communities. We focus on what communities mean to people and the benefits people get from being part of their community. We will discuss how communities work for people and to what degree people feel part of their community, finally we will look at how communities could be improved for people.

Community means lots of different things to people and is centred around places, connections and community spirit.



Places

When people think about what their community means to them, they identify with physical places in the community. Places such as **the pub, sports centres, creche, bingo, sports groups/clubs, community hubs, church and the railway.**

People access the places in their community that are central to living their life and that benefit them, such as, the places that provide them with entertainment like **bingo, the theatre or cinemas**; places that provide education such as **museums and libraries**; places that meet

cultural and religious needs like **churches**; places that promote wellness and health such as **leisure centres, Zumba, dance or relaxation**.

Benefit is gained from accessing places in the local community, they have **fun, visit new places** and **it gets them out of the home**.

Voices into Action!

During the course of discussion about the community one group talked about difficulties in getting sunflower lanyards locally. One person had ordered one online, but it was never sent.



The group agreed that the Civic Centre would be a good place to get them as it is not as loud and busy as a supermarket and the staff are very helpful.

Together they drafted a letter to take to the Civic Centre to hand over in person to ask them if they could be a local distributor of sunflower lanyards.

How people get to places and access them is also important. Many people rely on local infrastructure networks to be part of their communities, they need **public transport** to be able to part of their community.

It was also highlighted that people's ability to **go to places independently, practicing new routes and places** was important and follows on from the need to have good support that facilitates learning and independence.

Connections

Connections with people play an important role in how much people feel that they belong to their community. Connections come in many different guises. There are the relationships that people have with **neighbours, family, with friends through WhatsApp and Facebook and social media**.

There are the social groups and clubs such as **Monday Club, WAVE, Golden Oldies** the **WI** or **camera club** which are a huge catalyst to people making connections within their community.

People have connections with those that they work with when **working in charity shops and doing charitable work**. Volunteering at the **Christmas bazaar**, the **theatre** and the **park café** all sited as ways to **meet different people**. There are the connections that people have with the local emergency services such as the **police, fire** and **healthcare**.

Community connections bridge isolation gaps and loneliness giving people **something and someone to talk to/about**. It helps **build confidence around people** and facilitates **meeting other people not in your home**.

Spirit

A sense of belonging to a community and feeling part of 'community spirit' is important. The covid-19 pandemic highlighted the importance of communities for so many people and the overwhelming display of community spirit that was displayed in the setting up of local support groups that showed the kindness within our communities. This was seen in the **clapping for paramedics** and the joint collective effort to **wear masks and using sanitiser in public places**.

Outside of covid-19 people also feel the value in kind communities and doing things for the benefit of others:

Communal garden - where we live that I do some things in. The new chap downstairs has got some plants so it might become a thing a few people do

On the flipside however, not everyone experienced this as some felt that **like in the war where people used to look out for each other – this doesn't happen anymore**.

There are very mixed feelings about whether people feel that their community works for them and whether they feel part of their local community.

On the whole most people felt like their community was working for them; they **felt safe living there**, they had good connections with their **neighbours**, there were people who were **kind and would look after me and calm me down when I have panic attack**. There was a feeling that **we need to remember to embrace and appreciate what we do have in my community**.

In Boots they know me so can just go up to the counter and ask for what I want. I am getting to know their names too.

The connections that people have make them feel like they are part of the community, whether this be with **neighbours**, local shop keepers or at work where people **feel part of the team**.

For those who felt that their community did not work for them this was due to them feeling that there was **not enough to do here so go to other towns where there is more to do**.

There were also lasting consequences of people's experiences during covid-19 and lockdowns, one person described how **since pandemic feel petrified about leaving the home** another saying that they are **not used to large groups anymore I got used to us staying at home and watching TV**. These fears and concerns added to people's feelings of not belonging to or relating to their community.

There were several suggestions made about how Improvements could be made to the community so that it was a nicer place to live and became more viable for people.

Suggestions included improving the high street – having **stores and markets on the streets, filling spaces of the shops we lost during the pandemic**.

It was felt that communities could be kinder, that people could be **more friendly to each other** and that the **council could be more welcoming**.

Having **more support** to access the community would mean that people had more of a sense of belonging to their community and **reduce the strain on families**. **More social opportunities** for people to engage with was also suggested.

Accommodation was also touched on, **having more affordable social housing, quiet neighbours and good quality landlords who listen to you** are all improvements that people would benefit from.

There were some general attitudes in communities that could be improved and would lift the spirit of community such as people **not dropping their litter and looking after the environment better, reducing bullying and controlling people** and generally **more positivity**.

There were some ideas suggested about improving community spirit like having **more community events** and/or **street parties**.

The most improvement of all would be around accessibility and equality:

Make all events inclusive to everyone, accessible, and affordable so that everyone has equal opportunity regardless of who they are.

6 Work and Employment

Work and employment are part of everyday life for millions of people in the United Kingdom where 75.3%² of the population is in employment. In comparison however, only 5.1%³ of people with a learning disability are in employment.

The discussions at the knowledge cafés looked at why work and the opportunity to work is important for disabled people, three themes emerged:

- ▶ Purpose
- ▶ Reward
- ▶ Development



Working gave people a huge sense of **purpose** and meaning to their lives. It gave people **structure to their day, a routine, something to do.**

By participating in work people felt that they were **being useful.** It also gave people a reason to **get out and about,** with one person describing how participating in work has **changed my life.**

People placed importance and value on work and viewed it as an **occupation – something that a person does or has done.** There was a desire to **find a good job – paid employment** and people felt **grateful to have a chance to work.**

Those that did some form of work (paid or voluntary) described how they **love work and would like more work** and how they really enjoyed **being part of a team.**

Some of the knowledge café participants had experience of **being an employer and employing Personal Assistants** but found it difficult as a disabled person to get paid employment themselves.



Work is generally viewed as a catalyst to gaining reward especially monetary; it was recognised that paid work = **money**.

Whilst money is important the other rewards that work gives people were more significant. **Helping other people, giving back to others and working in a team, helping each other**, were all highlighted as gains that people got from working. The feeling of **helping the community** was also highlighted.

People were also rewarded by the relationships and connections that they built at work with their colleagues and/or customers – **where I work feels like a family to me**.



Alongside working giving people purpose and reward it also enabled people to grow and develop as an individual learning a plethora of transferable skills.

The **trust** and **respect** that was placed in people at work boosted confidence and self-esteem as did **being accepted** by colleagues. People learnt **responsibility** when working, in particular around time keeping – **getting there on time** and **letting them know if you are running late**. **Keeping safe and looking after yourself** were also important.

Confidence grew through **coping with changes, making friends** at work and **going out after work** with colleagues. People felt able to **ask for help** when needed, having a **buddy to work with** and **job coaches** helped.

Taking instruction and **listening to your boss/line manager at work** was an important skill to develop. People recognised the importance of **learning company rules and policy** and being a representative of their employer.

Many of the knowledge café participants took part in either paid or voluntary work and spent some time looking at paid work V voluntary work.

Paid Work

Some of the main advantages of having paid work is earning **money** which then can enable you to **give money to charity**. Paid work gives people **security for life** as they can **build up a pension**, they can **progress further** in their career and **feel secure in what you do**.

The benefits that you receive with paid work such as **annual leave** and **sick leave** are a big advantage of having paid work over voluntary work. Paid work also supports people to **gain confidence in yourself**.

Voluntary Work

Peoples' experiences of doing voluntary work showed that **employers can be more understanding about health and disability, more flexible** and can be **more empathetic when things go wrong** than employers you do paid work for. It was felt that if you **have an off day, you can't get the sack** and there are **less implications if you can't go into work**.

Volunteering opened lots of opportunities for people where they could **try out a role**, they **learnt new skills**, they could **gain experience**. Volunteering was also viewed as a steppingstone as you **may end up getting a paid job**. Volunteering also **affects your benefits less**.

As there are **lower expectations** of people doing voluntary work it **takes away the pressure**. The experience of working is better as it is **more relaxing, and it doesn't matter if you take longer to do things**.

People found volunteering rewarding as they were able to **help the community**. It presented them with opportunities to **get out and about, talk to people and get to know people**, as well as make new friends and have a social life. Volunteering can also give you a **sense of achievement if it is something you've wanted to do for a while**.

Barriers to Employment

There is little incentive for people with disabilities to take up employment as there are so many barriers preventing them from doing so.



Attitudes

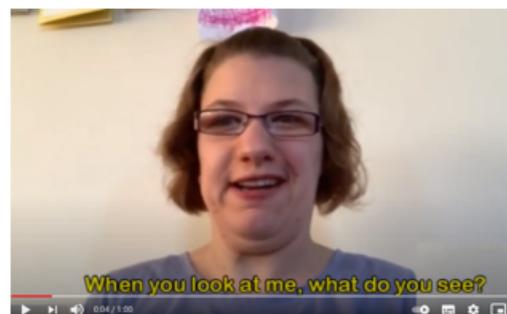
The attitudes within the work environment from the employer and the workforce can be a huge barrier to disabled people being employed.

Discrimination from colleagues - builds up and gets to the point where you feel like you will explode can be incredibly difficult to handle as can **sexist jokes in the workplace** or people making **sarky comments about how you look** or being **rude**.

There is a lack of understanding that people may have **hidden disabilities**. It should also be **taken into consideration that it might take me longer to do a job**. Some found that employers **expectations can be high**, there is **more pressure** doing paid work and **if you work a few hours, you can be pressurised to do more leading to stress**.

Voices into Action!

The **#SeeMySkills⁴** campaign has been coproduced with people with a learning disability who wanted to raise awareness amongst employers that they should see their skills first before their disability.



A video was created to highlight their message -

<https://www.youtube.com/watch?v=wyvDW8aFWP0>

There are some very simply solutions that can be adopted by employers so that they can become inclusive employers including educating their workforce and supporting their disabled employees. The ***Tips for Becoming an Inclusive Employer***⁵ guide created by disabled people in Wiltshire has lots of really useful information and idea for employers.

Due to the barriers that many disabled people face some at the knowledge cafés see becoming **self-employed/being my own boss** as the best way forward for them.



They also wanted to reiterate that **just simply listening to people and understanding them removes many barriers!**

Work Environment

The working environment can pose many challenges to disabled people. This can be physically due to poor or no **wheelchair access and not being able to get places.**

Covid-19 has also introduced barriers and has **made work hard for some people.** The recent move to hybrid working can make it easier for some people to work but for others **working from home can be a real barrier.**

It was recognised that embracing technology to assist people in the workplace such as using **Alexa and mobile phones** to assist in doing the job was beneficial.

Suggestions were also made to improve the accessibility of workplaces by investing in **talking toilets and installing handrails etc.**

Financial

Whilst paid work presents many advantages to people it also can cause concerns for many disabled people especially around the implications of earning money. People worried that **benefits may be taken away** or it will **affect your benefits** therefore creating a barrier to employment.

Employability Skills

Many challenges are faced by disabled people when trying to get paid work.

People experienced difficulties and challenges with the skills needed to find and get a job. **Applying for jobs can be stressful – so much paperwork**, the interview process is difficult especially as the **questions can be confusing**. People found it **harder to get work or keep work without a job coach**.

The **Top Tips for Finding Work**⁶ guide written by and for disabled people in Wiltshire has lots of useful practical advice and information.

Possessing the social skills needed to successfully navigate the workplace can also be challenging for some. Lack of **confidence, nerves** and how to **manage situations like disagreements** can be difficult. **Asking for help can be difficult** and people may not always feel **able to ask for help** or for example **let your employer know if you are unwell**.

The knowledge café participants had some useful and motivational tips for each other to overcome some of these barriers such as – **learning about the company before you start, not giving up on yourself if things go wrong** and **going in with an open mind and try things!**

Top Tips for Finding Work

Written by disabled people, for disabled people.

Disabled people are **30%** less likely to be employed than non-disabled people.

Only **6%** of adults with a learning disability are in paid employment.

It's time to change this in Wiltshire...

This guide has been created as part of a ListenUP Wiltshire Campaign.

With support from Wiltshire Centre for Independent Living.

WILTS CIL ListenUp Wiltshire

7 Living My Life

In this chapter we discussed what people need in order to live their lives in the way that they want to. We look at what independence means to people and how important choice and control is for them.

Crucial to being able to live their lives it was identified that people needed:

- ▶ Purpose/autonomy
- ▶ Connection
- ▶ Money
- ▶ Support



Purpose/Autonomy

As we have already seen throughout this report having purpose and autonomy is a reoccurring theme. It comes in many guises from having a **job** and being **part of a team** to doing activities such as **dancing**, **having a social life**, **gateway club** and being able to experience **new opportunities**.

Learning/**education** continues to play a huge part in what people need to live their lives. Being able to do **college courses to learn new skills** meant that people were **able to keep their independence**.

Connections

Having connections contributed to how people wanted to live their lives. Important are connections and relationships with **friends, neighbours, family – mum, dad, nephews, nieces** and **girlfriends**.

People wanted to be able to have those ‘traditional’ connections and relationships where they can **get married** and **have a family** of their own.

Money

It was recognised by everyone who took part in the knowledge cafés that money is an important factor to life and people’s ability to live the life they choose. They all experienced difficulties with **money**, needing **more of it** and having frequent issues with **Universal Credit**.

Support

Many people highlighted that they needed a degree of **support** to enable them to live their lives. Having choice and control over that support was crucial – **my own carers in my own home**.

The type of support people wanted was to enable them to develop their skills in areas such as **cooking, computers, filing in forms**.

Support wasn’t always needed by ‘people’. Having a **bus pass** was a valuable form of support. For others technology was a huge asset

Alexa helps me to live my life - music, check spelling, the news and weather, 2-minute timer to brush my teeth, medication etc.
Technology really helps

We looked at what independence means to people and what they want to have choice and control over in their lives.

With independence also comes **responsibility** and people wanted to be responsible for **cleaning the house, paying the rent**. People want to be able to **live their lives to the full**.

Having choices was described as being given **freedom** and **it means everything - living your life is about doing the things you want to do**. It was highlighted how important it was to **let me make choices and take risks, I don't want to be told what to do**.

Control

Independence means having **control** over your life, all aspects of your life. The things that were mentioned at the knowledge cafés that people wanted to have control over were the everyday mundane things that we all take for granted.

The lack of control that people currently experience over where they live was highlighted, people wanted to **move out from my parents to be in my own home** and **make decisions about their life, I don't want my parents to control my life**.

I want to live independently in my own home with my own support not in a bad home, it is suffocating, I want my own privacy, people get on my nerves, I need personal space.

It was not only where someone lives that they wanted to have control over but also **who they live with** and how they live their life in their home. People wanted control over **decorating my own room, having my own things in my room like pictures and knickknacks, putting up their new furniture, having my own furniture** and to be able to **do their own washing and ironing**.

People want control over **when I get up and when I go to bed, there are limits at home!** They also didn't want to be **pushed around by other residents**.

Having control over what you do each day is also important, people **don't want to be told what to do**, they want to **go out on their own on public transport**, they want to **decide what they do each day**.

It was also very important for people to have control over their relationships, such as **when I can see my girlfriend** for example. Some also indicated that they did not have control over how they lived their lives, they didn't want to have to **ask permission to go out with people**. They wanted to be able to **do what they want and go where they want**.

Having control of and being able to manage your own **health** was also highlighted. One person described how they wanted to manage their **diabetes** and that they **use an app to help control my diabetes**.

The fact that people felt the need to highlight these areas indicates how little control people with a learning disability and/or autism feel that they have over their lives and that they need to ask to have control, to be given choice and to be granted the permission to live their lives how they want to.

I want control over cooking my own meals, control over choosing my key worker, control over what support I have, control over my own choice of furniture and plants in my own bedroom.

Whose Social Care is it Anyway Inquiry

The powerful thing about this inquiry is that it has been led by us, people who draw on social care to lead our lives or who support loved ones to do so. We got tired of being left out of the discussions about reform or being the 'tick box service-user' so we took matters into our own hands and started the Whose Social Care is it Anyway? Inquiry.

**WE ALL WANT TO LIVE
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HOME WITH THE PEOPLE
AND THINGS THAT WE
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WHERE WE LOOK OUT
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DOING THINGS THAT
MATTER TO US.**

**THAT'S THE SOCIAL
CARE FUTURE WE SEEK.**

#socialcarefuture

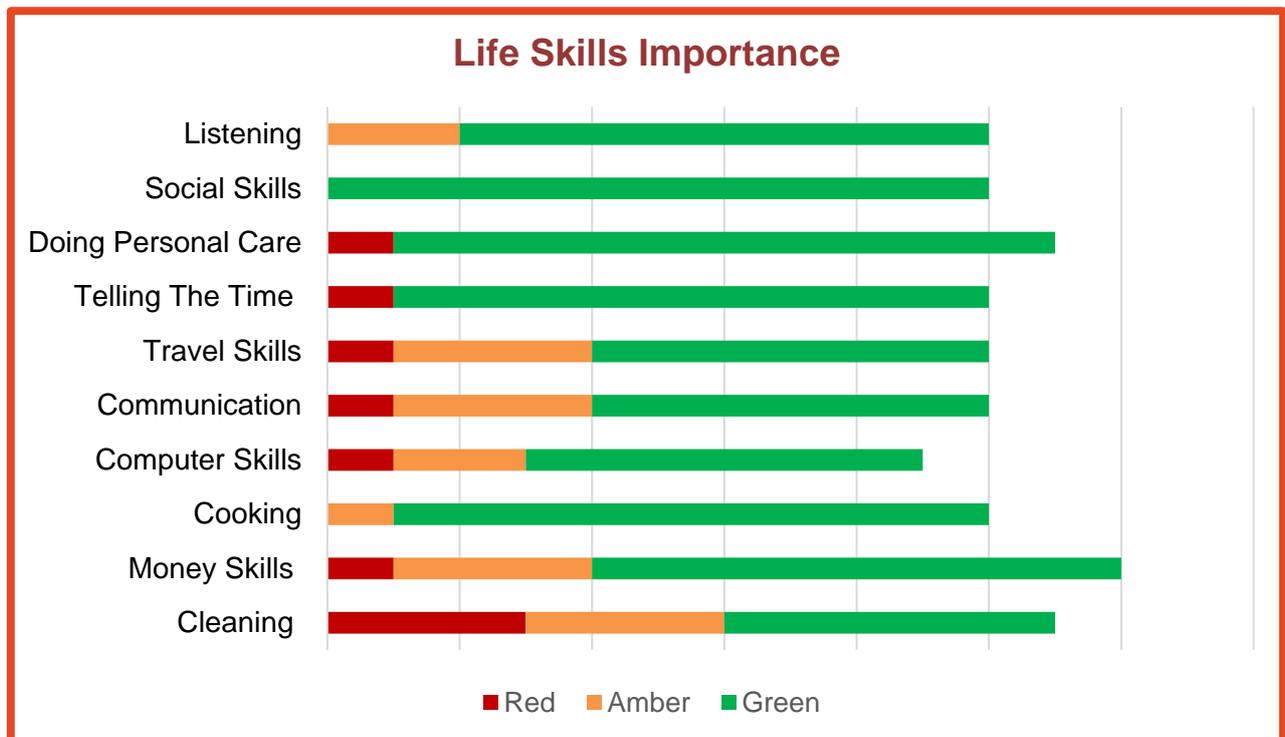
In May 2021 the 'Whose Social Care is it Anyway?' Inquiry group issued their 5 key changes that are needed to bring about their vision:

1. Communities where everyone belongs
2. Living in the place we call home
3. Leading the lives we want to live
4. More resources, better used
5. Sharing power as equals

Read the **Whose Social Care is it Anyway? Report⁷**

Life Skills

We spent some time looking at life skills and which one's people feel are important to them. At the knowledge café we asked people to rank how important a life skill was to them using the traffic light system of green being important, amber some what and red not important.



Significant importance was placed on all of the life skills detailed above; **social skills** were of particular significance which included for some **being able to help others**. This sat alongside **listening** and **communication** being important especially around being able to **talk on the phone** and **knowing how to say things**. Good **communication** skills could also help if you needed to **contact the emergency services**.

Cooking featured highly on the list of life skills that are important – **cooking, is important but it's not easy to do, I wish there were more opportunities to learn to cook**.

Money skills was of significant importance to most people, people wanted to **know the value of coins, counting change, reading receipts, cash machines, paying bills and understanding bills**.

General living skills including **personal care, telling the time and cleaning** all had a level of importance placed on them as did **travel skills**. People also wanted to learn things such as the **bin day and recycling day**.

Computer skills generated quite a bit of discussion as although many wanted to learn computer skills to do things like **online shopping** there was apprehension. Some were concerned because of **scams and pressing the wrong buttons, I need advice on keeping my personal info safe. Personal safety** was also a concern – **who/what to tell information to and how much I should tell**.

The skills highlighted are all ones that promote and facilitate people living an independent life giving them the choice and control on how they wish to live their life.

8 Health

In this chapter we focus on health – what being healthy means and how people would like to be supported with their health and to make decisions about their health.

When we looked at what being healthy means to people, four key themes emerged –

- ▶ Active
- ▶ Lifestyle
- ▶ Connect
- ▶ Wellbeing



Active

When discussing what being healthy means to people being active featured most prominently.

Participating in physical activity such as **Judo, Zumba, swimming, cricket** or **dancing** were all ways that people kept active. It was also recognised that being 'active' didn't necessarily mean that you had to participate in strenuous activity. **Walking my dog** or just **being outside**

achieved the same goals in contributing towards being healthy. Gentle exercises such as **yoga** also **helped with breathing and anxiety**.

Peoples' motivation for being active was **looking after my weight and conditions** and **helping physical and mental health**.

Lifestyle

Alongside being active your lifestyle also contributed towards what people felt being healthy was.

It was important for people to have a good diet and to eat well; eating **veg, carrots and fruit** were all mentioned as was having **three meals a day and a balanced diet**. Whilst some enjoyed **making healthy smoothies** others needed **my caffeine** and a **double scoop of coffee!**

Eating healthily was important because it helps to get your **vitamins and minerals** as well as **looking after your weight and conditions**.

If I wasn't healthy, I couldn't go out and enjoy myself this is why it's important to stay healthy

Having a **good amount of sleep** and **peaceful sleep** is also an important contributing factor towards being healthy. People tried to **stick to a sleep routine** but could find that **when something worries me, I don't sleep very well**.

Connect

Having connections and relationships with people played a huge role in being healthy for people. Having interactions with **family, meeting up with friends**, and **talking to other people** all helped people's **mental health**. Some also **found dogs very therapeutic**.

Social activities such as the **Camerados Living Room** in Devizes or **going to a coffee shop** were all important.

Wellbeing

Your **mental and emotional wellbeing** influence your feelings of being healthy. There were many different techniques used to promote positive wellbeing such as **music, aromatherapy, meditation** and **essential oils**.

Listen to a favourite song that brings back happy memories and lifts your mood

People also talked about using their **senses to help ground** them and to help them **not get too anxious**.

Keeping the brain active also helped - **fine motor skills like going on a computer, knitting and art helps my mental health and keeps my brain active**.

In addition to being active, your lifestyle, wellbeing and connections medication was needed by some to promote them being healthy especially around **managing diabetes**, having **vaccinations** and taking **vitamin supplements**.

When discussing how people wanted to be supported with making decisions about their health and being healthy the discussions mainly centred around have practical support and who they would like this support from.

Many relied on the people that know them best such as **family and friends** for guidance and support. Or their support workers – **I will ask my support worker whether they think I should go to the doctors; it stops me going to the doctors for issues like a cold when I don't need to see a doctor**.

Some people needed support to keep active and may **need lifts to get to places to do exercise**, others needed **meals on wheels** to help with having a good diet. Some have **health coaches** who talk to them about being healthy.

People were keen to make their own decisions about their health especially **now that I am an adult, I should be able to make my own decisions, it should be up to us to decide what we eat, drink and whatever we want to do**.

It was frequently identified that people needed support to **attend appointments**, there was a lot of concern, anxiety and fear around going to medical appointments or staying in hospital.

I need someone to support me to go get a smear test because I'm scared, I need to pluck up the courage to go to the surgery. I am nervous, I had a bad experience last time I went as the staff were so rude I am scared to go again I wish someone would go with me

There were some suggestions made around using **health passports** so that you can **tell professionals what you do and don't want**. Health passports would also help when communicating with the doctor, **I need to be given time to talk because it takes me longer to get my words out**.

Some people had had great experiences with their GP practices where their **GP asks how they can support me, they say that I am in the driving seat, and I am in control – this empowers me**. It was however also felt that a lot of work needed to be done around **challenging people's perceptions of disabilities in particular learning disabilities**.

Support from friends who had been through similar situations were really empowering and beneficial to many, such as being part of **peer groups and chat rooms with people who have the same condition as me**.

Being informed was an enormously powerful way in which people felt that they were in control of managing their own health, some would use **Alexa** and **google** to find information on health as their previous sources of information no longer existed.

Years ago, they used to have leaflet and booklets about health, now they put it all online, but I wish they had more paper-based information- have these in doctors, surgeries, dentists, opticians and libraries.

A nurse used to be at the library, and I was able to talk about any of my issues and worries, it helped me know whether I should go to the doctor or not. I think the nurse was paid by a charity, they don't come anymore and that's shame because we missed a great resource.



Conclusion and Recommendations

People with learning disability ‘*experience some of the worst of what society has to offer: low incomes, no work, poor housing, social isolation and loneliness, bullying and abuse*’⁸. Professor Sir Michael Marmot, 2018

This report outlines what people with learning disability and/ or autism want to live a good life of their choosing. It is simple in its message of what constitutes a ‘good life’:

- ▶ A home where people can live how they wish
- ▶ Choices and control in all aspects of daily living
- ▶ Relationships that matter and which are based on people being equal partners
- ▶ Person centred/ person led support that enables people to live full and independent lives
- ▶ A sense of purpose in life achieved through work and being part of a community
- ▶ Things to hope for, dream about and plan for, things to be joyful and excited about

No one can argue with this, and it is something that those without disability take for granted. However, the fact remains that for many Wiltshire residents who have a disability these fundamentals for a good life are out of reach. We know and have known for many years that all disabled people already experience inequality at some level and it is well reported that being disabled increases the likelihood of disadvantage in social activities, income, housing, employment and health. We also know that people with learning disability and /or autism are particularly disadvantaged. For example, people with a learning disability die up to 20 years prematurely⁹.

What needs to change in order to afford all Wiltshire residents with the same life chances? This report shows there are two elements: changes that happen on an individual basis and changes that need to take place on a wider societal basis.

The two words that most represent what individuals need to live well are: choice and control. This report shows that people lacked choice and control in key areas of their lives, and this limited their ability to live well.

Group homes, in particular, can impact significantly on people's ability to make even basic life choices from what they ate to who they saw to when they went to bed.

Good, person-centred support can enhance all aspects of people's lives by ensuring they do have choice and control. Support works best when it is relational: provided consistently by people who are known, liked and trusted. Having a good foundation of support enables people to flourish. They can continue to learn and work and live independently whilst also having the support to stay safe and look after themselves. With this in place people can do all the things that enable them to live their 'good life'.

The social model of disability is over 40 years old¹⁰: it states that people are disabled by barriers in society, not by their impairment or difference. Barriers can be physical, like buildings not having accessible toilets. Or they can be caused by people's attitudes to difference, like assuming disabled people can't do certain things.

This report contains many examples of the barrier's participants had to face in their daily lives: having to leave jobs as employers and work mates lack understanding, feeling fearful of going to health appointments because of staff attitudes, and the feeling of being 'written off for being different'. There is a lot that disabled people are doing to address these barriers and there are some great examples in this report such as the 'see my skills' campaign, and where people with learning disabilities make valuable contribution to creating kind and respectful communities, through volunteering and co-creating community spaces like gardens.

However, it is not disabled people's responsibility to make society accessible. We know what people want and need to live a good life, it is up to all of us as residents of Wiltshire and particularly professionals involved in health and social care to be allies, and work to make this vision into a reality.

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