

GOOD LIVES ALLIANCE REPORT

MY LIFE MY CHOICES

MARCH 2023

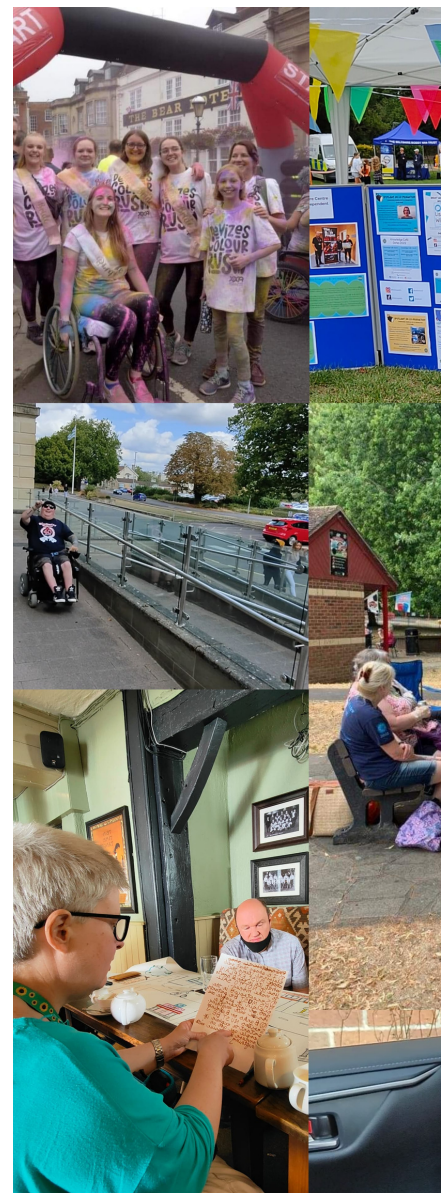


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This report was facilitated and produced by the Wiltshire CIL User Engagement Team, under a contract with Wiltshire Council, to provide a Wiltshire Engagement Service.

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 disabled people.



MY LIFE CHOICES KEY MESSAGES:

CHOICE

HAVING TIME TO DO THE THINGS
I WANT – PERSON CENTRED

CONTROL

HAVING CONTROL OVER MY
EVERYDAY LIFE AND HOW I
LIVE IT

RISK

BEING INDEPENDENT - I WANT TO
TAKE POSITIVE RISKS

FAMILY, FRIENDS, AND PETS
INVOLVEMENT IS KEY TO MY
DAY TO DAY LIFE
– RELATIONAL CONTACT

COMMUNITY

PEOPLE BEING KIND & NICE -
POSITIVE COMMUNITY
ATTITUDES

GOING OUT IN THE COMMUNITY
AND HAVING REAL
CONNECTIONS WITH PEOPLE

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Key Messages

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INTRODUCTION: GOOD LIFE

In groups, in the community and in one-to-one conversations Wiltshire CIL have asked in excess of 2000 people three questions:

What does a good life look like to you?

What have you got to achieve that life?

What do you now need to live that life?

You said:

WE WANT WHAT YOU WANT!

EVERYONE WANTS THE SAME THINGS TO LIVE WELL – A HOME, EQUAL AND MEANINGFUL RELATIONSHIPS, TO BE VALUED AND HAVE PURPOSE AND TO BE HOPEFUL ABOUT THE FUTURE

In this report we analysis the key messages:

- ▶ Homes not institutions
- ▶ Relationships really matter
- ▶ Real connections in real communities
- ▶ A meaningful life
- ▶ The right support

We will be drawing on and synthesising previous engagement with thousands of people with lived experience in Wiltshire, whilst also looking at how this now becomes a reality for people, focusing on the choice and control people need to live a good independent life.

WHAT WE DID

We contacted residential settings within Wiltshire and invited residents, to small group meetings within their space to talk about what matters to them; What is important for their 'Good Life'. The sessions were for anyone with Autism, Learning Disabilities and/or Mental Health issues.

The sessions were informal and relaxed and organised in their space, to support any issues around access and/or support that may be required.

At the start of each session - we initiated the conversation to focus on the 3 good life questions.



Our discussions then focussed on **CHOICE & CONTROL** - as we want to understand what choices and control people have about how they live their life and how involved were they in the daily management of their lives.

People with lived experiences should have the same rights and choices as everyone else, in order to live their good life.

CHOICE & CONTROL



WHAT WE FOUND:

People enjoyed having choice and control over a variety of things in and around their homes, including:

When to get up/When to go to bed, when I want

Having my own Bungalow

Making my own meals

Choosing my own meals/When to eat

Having a good cup of tea!

Living near family

At each group, people felt that it was important to have choices and that they managed those choices themselves, in the things that they wanted to do and take positive risks. Things such as choosing when and what to eat at dinner, when to go out or when to go to bed are all important.

Choice and control around managing our own day to day activities adds to feelings of fulfilment, feeling heard and appreciated and that those involved with your day to day needs, are not just 'supporting you', but are involved with understanding what is important to you enabling a persons own views and choices to be taken into account.



RELATIONSHIPS REALLY MATTER

“
‘Get by with a little help
from my friends.... my
neighbours, my pets,
the local supermarket,
the lad at the bus stop,
my hairdresser, my
grandchildren, my
daughter, the local
pub.....’

The Beatles 1967 (with additions)

”

At the heart of a good life are meaningful relationships! A wide variety of different types of relationships feature in everybody's lives from friendships to professional ones. This is exactly the same for disabled people.

We all have professional transactional relationships in our lives with doctors, dentists, a cleaner for example, but a disabled person's life should not be defined by these relationships. We are too quick to see disabled people's lives only through the lens of their transactional relationships and place too much importance on these people in their lives.

Whilst the transactional relationships are probably disproportionately important to disabled people and are needed for them to live their life well, the relationships that really matter are the reciprocal ones with the people that we trust and love. Relationships work best when people value each other as equals.

The importance of relationships are reflected through people's hopes and aspirations, in addition to friendships, disabled people want to have close and intimate relationships, to get married and to have children.

It is, however, important to remember that just like everybody else each disabled person is different and some don't have or don't want to have many relationships with other people.

Transactional relationships give people treatment, advice, input on their statutory needs. They often provide factual information - eg a Dietician - will advise about what foods to avoid if your blood sugars are high, but, they will not offer the time to help people make their own choices, take positive risk and understand how they can manage this. These relationships are "Informative".

In contrast, with meaningful/relational connections, people felt again that these relationships were developed, or continued with their own choices. They felt it was important for them to be in control of and to manage how and when these happen.

These relationships support and foster the feeling of connection, warmth, enjoyment, being involved, choice, control and risk.



Transactional relationships are a requirement in all our lives but are needed in tandem with meaningful and relational connections and relationships

Meaningful relationships can have their challenges, taking on others views and understanding them - creating space to allow for difficult conversations and making compromises, especially with loved ones. Or sharing a physical space with someone, who may have different views. However, overall, people felt that these were the connections that were most positive and meaningful in their lives.

REAL CONNECTIONS IN REAL COMMUNITIES

The community is predominantly defined by the people who live in it and as somewhere to make connections and maintain and grow relationships. Community is not necessarily the place, its the people.

People strongly valued being able to be part of their community and reap many benefits from doing so including:

- Developing relationships/connections with people - social connections
- An increase in mental and emotional wellbeing
- Better self-esteem
- Direction and purpose

Being meaningfully connected to a community is essential to a person's well being. We need to enable, encourage and facilitate those everyday interactions in the community such as a hello when walking the dog, a chat with the barista in the coffee shop, the neighbour who puts your bin out.

In order for communities to work for people they need to be fully accessible and safe for people who face physical and psychological barriers. If support is needed to help a person to be part of their community then this support needs to be delivered in a relational way, and led by the person being supported.

There needs to be purpose and value to peoples' experiences of community and for the relationship with the community to be reciprocal.

"Wednesday when the bin men come I put about 5 people's bins in, people are very grateful for this, my neighbour always gives me cheese at Christmas, and that very nice lass who is new to the area she has given me some biscuits, her children always say hello, I have seen a lot of people come and go and I always try to make new people welcome, I like to be able to help. In the morning if my curtains are closed my neighbour will come and knock on the door and the other day I fell asleep in my chair and missed going up the shop so the lady at the shop sent someone down to check on me"

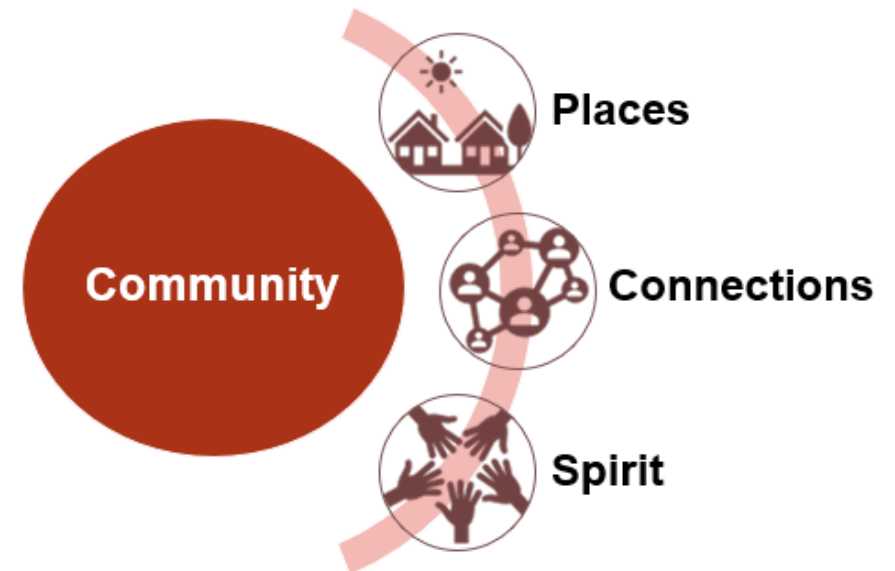
WHAT WE FOUND:

People talked about the different, important community links that matter to them. We see that individual and/or group links are important, such as seeing a family member or accessing a club nearby or going to the pub or local weekly disco.

These connections gave people positive feelings of being part of something, near/close to them, that involved either people they may reside with or near too, and/or family members - who would potentially take part in the activity with them, or possibly support with them accessing the event.

It is important to have choice and control over making and sustaining those real links in real communities as this promotes and grows independence and connection. There are many limitations placed on how and when people can make connections in their communities often caused by support service capacity or risk assessments that limit choice, control and impulsivity. Often people weren't able to go out to a gig because it finishes too late for shift times finishing or to choose to have a tattoo for example because the risk assessment says no! or, would have saved up support hours so that they could go to the seaside for the day.

Real connections are a two way connection, where people have connections that really matter, Have purpose and enjoyment, support with positive mental health, for the whole community and are inclusive.

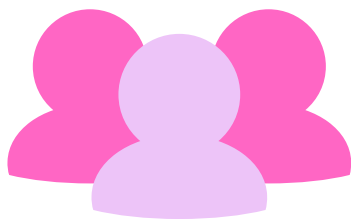


A MEANINGFUL LIFE

“**Meaning in life is a feeling that one’s life is significant, purposeful, and coherent; in other words, having a direction that makes sense and has a feeling of worth**”²

People want a sense a purpose in their day to day lives and to be aspirational and ambitious about their future. Purpose and meaning come in many different formats ranging from work or volunteering to hobbies and interests.

Foe example working/volunteering it provides structure to the day, a routine and something to do. By participating in work people feel useful.



75.5% of the population is in employment³



4.8% of people with a learning disability are in employment⁴

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.

Everyone has dreams, ambitions and something that they wold like to try. Having hope for the future and something to plan for, work towards and look forward to whether it be buying a home or going swimming.

Opportunities to socialise are also important, people value social clubs, going to the pub, the theatre, and music festivals for example.

People want to participate in the things that they enjoy with people with similar interests in their local community.

One of my passions in life is water skiing - I absolutely love doing this as its something I can do without relying on family to help me, it gives me independence away from them
Abbie ~ Voices of Disability

WHAT WE FOUND:

Further to the information in the sessions, some people felt that access to work, either paid or voluntary, hobbies and planning events supported them with being happy and involved in their community.

"I enjoy going out to do the gardens - I'm good at it and they like me coming - I'm going to do more again!"

Chris

"We used to do courses, they were good - but we don't do them anymore, I'd like to do those again!"-

Nigel



"I enjoy planning and doing the gardens" Bradley

"I go to Slimming World, I meet people and we look at meals. I've lost weight, I'm going tonight, it's good!"

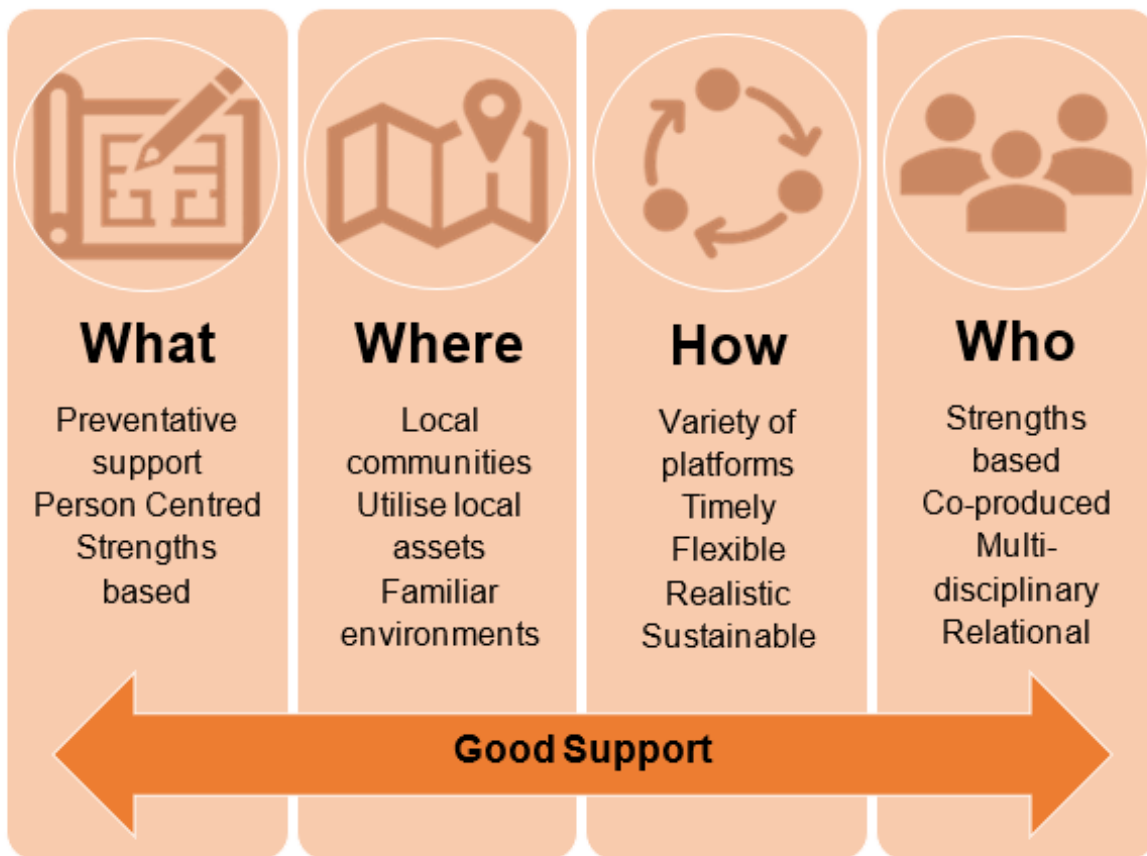
Natalie

"I love going to the Saturday night disco's" John

Having a meaningful life, and choice and control over what people wish to do, and when they can do it, can improve mental health, improve feelings of being worthwhile, reduce anxiety. Studies have also found, that this has a positive impact on emotions, people feeling more satisfied and it improves their self-esteem and confidence.

THE RIGHT SUPPORT

People may well need support, but they want and need the right support that enables them to live their life, support that is enabling and meaningful to their lives. People do not want to be passive recipients of transactional care delivery.



It is important to recognise and remember that independent living does not mean living without support. The support is the conduit used to live a good life, the support does not define a person and should not limit or suppress someone's capabilities and aspirations.

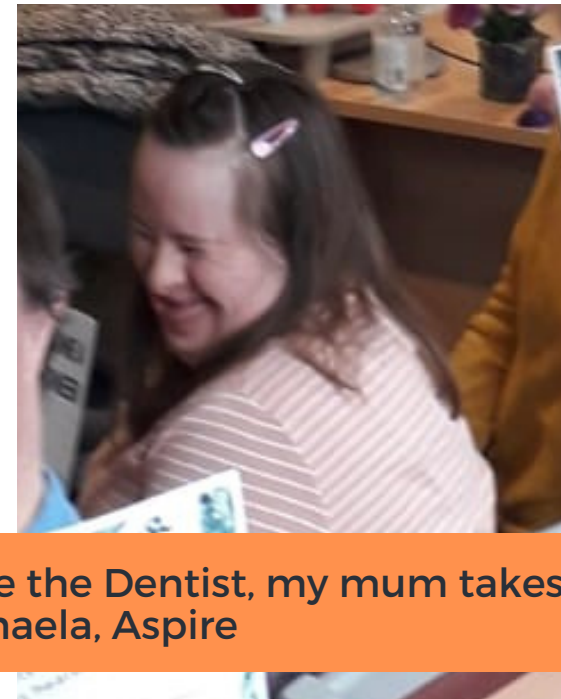
Good support should be person centred and holistic. Conversations need to be strengths based. Strengths-based practice is holistic and multidisciplinary and works with the individual to promote their wellbeing.

Support works best when provided by people that are liked, known and trusted. Support should be led by the people receiving it, enabling them to build on their strengths. Support should be about relationship building, with family friends and the local community.

The right support at the right time can stop people finding themselves in a crisis or unable to cope.

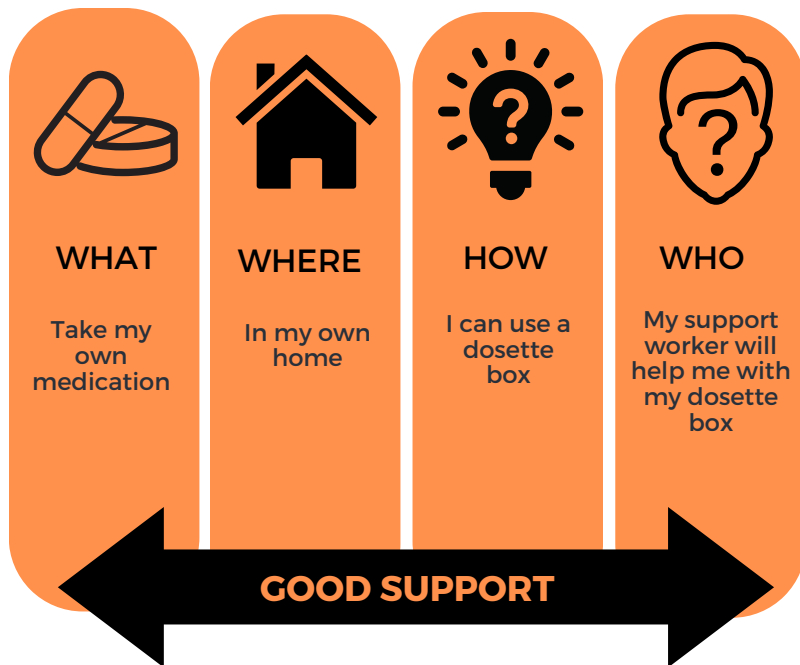
WHAT WE FOUND:

Michaela is a striking example of continued relational support, engaging with Michaela to achieve a positive transactional relationship, in a strength based way.



**“I use the Dentist, my mum takes me”
Michaela, Aspire**

Michaela has CHOICE & CONTROL. Her health care is important and crucially it's key that she accesses this in the way that best supports her.



Why is Choice & Control and taking positive risks, so paramount?

Positive risk-taking is an approach which focuses on what people CAN do, not just how they're limited.

Taking time to plan an activity with the important people in their lives and assess the risks and what-ifs can be a great way to enable people keep or regain their confidence and improve independence.

Positive risks, along with choice and control, leads to increased independence. The relationship of positive risks come between all parties; the person, the family and the staff - with the person being at the centre.

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* ⁵

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.



CONCLUSIONS

Disabled people want a positive rewarding good life, with access to their community, friends and to make important choices for themselves.

They do not want a prescribed life, but have opportunities created with them, which are personalised, to enable them to have a life of their choosing and for their good life to be achieved.

The Care Act 2014; it requires that people have "more control over how their care and support is organised" and should:

- promote people's wellbeing
- promote diversity and quality in provision of services

Wellbeing and Diversity go hand in hand with Choice & Control.

In a National Institute of Care Excellence report 2018⁶, regarding People's experience in adult social care services, two overarching principles were given:

- 1. Recognise that each person who uses services is an individual**
- 2. Use each person's self-defined strengths, preferences, aspirations and needs as the basis on which to provide care and support to live an independent life.**

Disabled people should be supported to maintain and develop their independence. This means finding out what people want from their life, and providing the support and assistance they need to achieve it.

Our feedback of our Wiltshire residents concluded the same - Choice and Control along with a high level of personalised care was vital in ensuring that people lead meaningful, valued and enjoyable good lives.

Wiltshire people, want a Good life that matters to them and involves the people that they have meaningful relationships with, in a positive community, having purpose and meaning to their life.



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