THE FUTURE OF MENTAL HEALTH SUPPORT

Representing and understanding the views of people with lived experience of mental health to create, shape and influence a new vision for Mental Health support for the future in Bath & North East Somerset, Swindon and Wiltshire
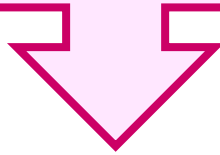
SEPTEMBER 2021

WiltsCIL

healthwatch Wiltshire

Wiltshire Parent Carer Council
Improving Services for Disabled Children & Young People 0-25 yrs

Key messages

People want:
- a sense of purpose in their day to day lives and to be aspirational and ambitious about their futures
- equal and rewarding relationships, where they are valued and value others

People are resourceful: willing and able to find ways to support themselves and others to live well, using their networks that they have in their community
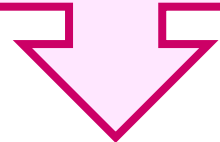
Professional support will work best:
- if it is quick, agile and local; working with the person to prevent escalation of issues.
- If it is delivered in a relational way, prioritising listening. Respecting all that people do for themselves and all that people know about themselves.
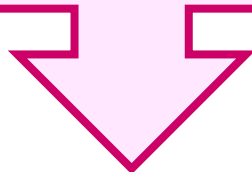
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Key messages

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1 Introduction

Who we are

Wiltshire Centre for Independent Living (WCIL) is an organisation led by disabled people which promotes choice and control for independent living. We provide a range of services to support disabled people who live or work in the county. 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. We use creative and interactive ways of engaging with people, co-producing each piece of work uniquely, to value the authentic voice of all service users.

Wiltshire Parent Carer Council (WPCC) is an independent organisation which is managed and run by parent carers, for parent carers. We provide a specialist consultation and participation service that enables parents and carers to voice their opinions about the services and support that their families receive.

Healthwatch Wiltshire is the independent champion for people using health and care services in Wiltshire. We listen to what people like about services and what they think could be improved and share their views with those who have the power to make change happen.

Mental Health Service Framework

A national Community Mental Health Services Framework has recently been published which outlines changes to adult community mental health services. It looks at how support for people in the future can be delivered more locally, so that they can get the support that they need to live well[1].

In May 2021, Wiltshire Centre for Independent Living (WCIL), Wiltshire Parent Carer Council (WPCC) and Healthwatch Wiltshire were asked by Bath and North East Somerset, Swindon, and Wiltshire Clinical Commissioning Group (BSW CCG) to facilitate a series of online workshops for people with lived experience of mental health support to hear what good support looks like for them.

The feedback shared in this report supports previous engagement undertaken by BSW CCG to hear people's views and experiences of community mental health support and this will be collated to help shape and develop the new service.

2 What we did

In May 2021 BSW CCG, Wiltshire Centre for Independent Living, Wiltshire Parent Carer Council and Healthwatch Wiltshire worked together to plan the online workshops. It was agreed that there would be five in total, three for the Wiltshire locality, one in BaNES and one in Swindon. The areas for discussion would focus on three main themes:

- What does a good life look like for you?
- What do you need to live a healthy life in your community?
- What does good community mental health support look like for you?

The workshops were held in June and July 2021, and we heard the views of 32 people across BSW. For those who could not join us for the workshops we offered one to one online meetings or telephone interviews to capture their thoughts. We also received feedback via email.

- 6 people attended the BaNES workshop
- 7 people attended the Swindon workshop
- 11 people attended the Wiltshire workshops
- 7 people shared their views in one to one interviews via Zoom
- 1 person shared their views via email

3 **Good Life**

At each workshop we started by discussing what people's good life looked like for them so that we could get an understanding of who they are and what is important to them.

A variety of words and phrases were used to describe what a good life looked like for people with 80 answers being given and 49 different words and phrases used.
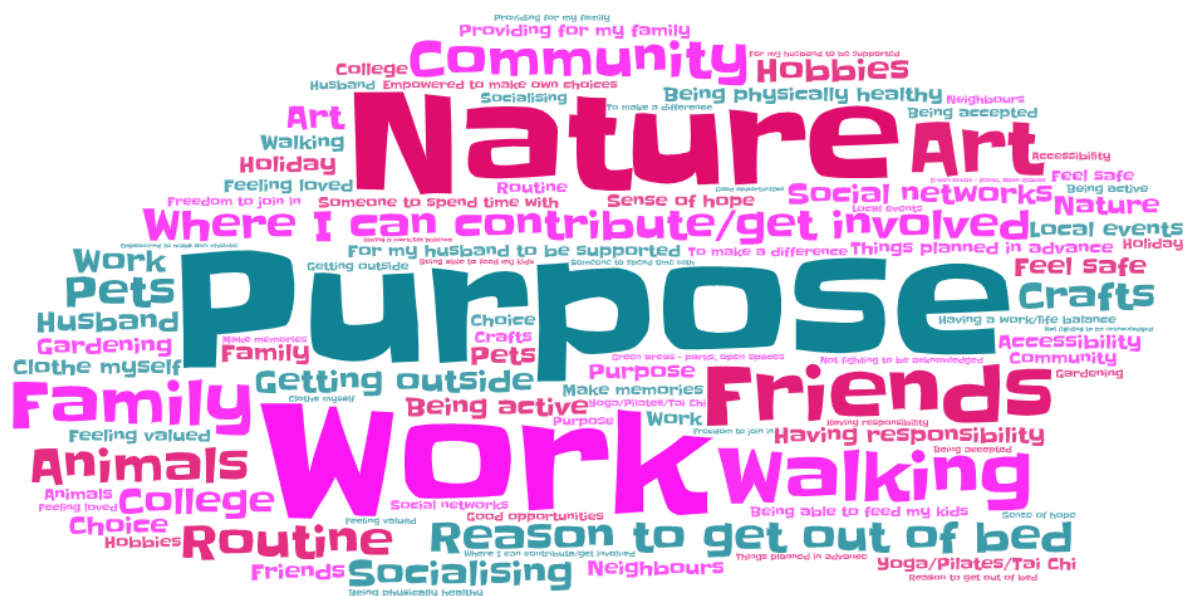
*Text size is linked to the numbers who made comment

Below is a summary of main themes.

Purpose and Autonomy

For most people having **purpose**, a **reason to get up out of bed** is crucial to them having a good life. People want to have active roles in society, they do not want to be passive recipients and be done on to. Having purpose comes in many guises for some it was having a vocation in life - being **able to contribute/get involved, to make a difference, work** or going to **college** gave people purpose.

Having a sense of purpose, a reason for being contributed to people having a good life – **having responsibility**, **providing for my family** or **being able to feed my kids** gave people meaning.

> **Purpose... I want to 'do my bit' I have joined a local enviro group and love it. But am limited to laptop stuff unless I have support, my DP doesn't cover enough hours. The same with attending events, socials and WCIL stuff... I have to sit at home and watch when I want to join in… sometimes due to health but often due to not having someone to support me, or an accessible loo, or a quiet space due to sensory overload.**

<p align="right">Extract from a focus group participant</p>

Independence and control played a significant role in people having a good life. **Being empowered to make your own choices**, having the **freedom to join in**, **routine** and **good opportunities** all contributed.

The feelings that people experienced from having purpose and autonomy also made their lives good as they then felt **valued, loved,** did not have to **fight to feel acknowledged** and felt that they were **being accepted.**

<u>**Aspirations**</u>

Having aspirations, something to look forward to and things to do and occupy time are important when people consider what makes their good life. **Being active** and participating in things such as **Yoga, Pilates, Tai Chi** and **walking** were highlighted.

Being creative such as **art, crafts** and **gardening** were enjoyed by people and made their lives good. Of particular benefit to people was **nature** and **getting outside,** of particular note were people being able to access **green areas** – **parks and open spaces.**

> **My happy places are outside among nature with my husband as my husband, so we need my PA to support me.**

<p align="right">Extract from a focus group participant</p>

Having the opportunity to participate in things was important and people recognised that it helped if **things were planned in advance** and if **events were local.** People enjoyed making **memories,** enjoyed being able to have holidays – for some however, this is a wish rather than a reality, as people struggled to **afford the extra costs of accessible accommodation.**

Positive Relationships

Relationships are of great importance and significance to everybody and contribute towards what a good life looks like for many. Relationships need to be positive and mutually beneficial, people have **friends, family, husbands, neighbours, pets** – these relationships are important, meaningful, and equal.

People enjoyed and benefited from having **someone to spend time** with and **socialising** and **social networks.**

> I want to be a wife, daughter, cousin ... not 'cared for'
> I want basic facilities... not having to ask for a ramp to go into somewhere or a door to be unlocked.
> toilets...
> Help when I need it so that I can do things with support rather than have them done for or to me.
> Nature, green space, and animals.
> Less care and benefits paperwork... it's a full-time job...
> Not having to justify every choice, decision, purchase
> To be part of a community
> To not be talked down too... I have a brain; I am educated it just doesn't always work as it once did and needs recovery time

Extract from a focus group participant

Getting the Basics Right

The necessities in life that we all expect and hope for were also mentioned such as **feeling safe, hope**, being able to **clothe myself, being physically healthy.**

The need for society to **be accessible** and for there to be a local **community** were both highlighted as factors that would contribute towards having a good life, but people often experience their **community as being inaccessible**.

4 What do you need to live a healthy life in your community?

At the workshops we talked about what people need to live a healthy life in their community, several themes emerged:

Vocation

Knowledge

Accessibility

Healthy Life in My Community

Attitudes/ Values

Connections

Support
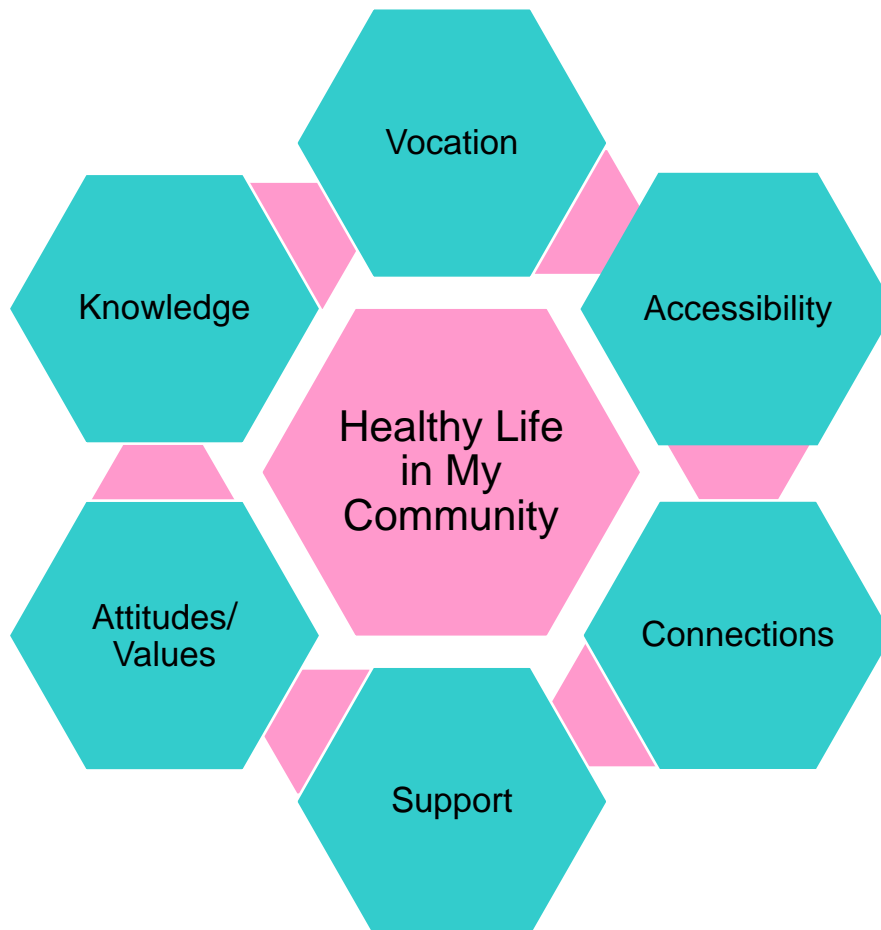
Vocation

The most essential thing that people felt that they needed to live a healthy life in their community was to a vocation, to **have things to do**, for there to be a **purpose** and meaning to their day-to-day life, this resonates what people say makes their life good.

In particular people wanted and needed to be able to **work** or to have **opportunities to volunteer;** but for work to not only be voluntary but also **paid** and meaningful.

> **Going from being a volunteer to working for the organisation – not just working for financial reasons (stressful) but because you are passionate about the work that you do (enriching).**
>
> *Extract from a focus group participant*

There is drive, ambition and desire to work. People described how they were asked **'do you really want to work?'** – the overwhelming message being yes, I want **to be able to do my career.** When asked what they would like to achieve this summer, the response was - **just get a job, give me something to do. Work is hugely important.** Education was also very important; people wanted to **study** and to **learn life skills**

Alongside having a vocation people also wanted to **keep busy**, to have **purposeful activities.** Creative activities were frequently mentioned such as **art, singing, mindfulness, cooking** and **music**. As well as the need to be more physically active doing things such as **crazy golf**, **walking netball** or **football.**

> **It's not what services can do, due to lockdown, its more socialising – I've asked everyone on my course, it's about socialising. I came up with 'Youth Hub'.**
>
> *Extract from a focus group participant*

Being outdoors in **nature**, with **animals**, at the **allotment** or in the **garden** contributed towards living a healthy life. Many highlighted how they needed walks for example to be **accessible** to them, people needed **improved country walks**. A recent response to this has been the **Wheeling 'round Wiltshire**[2] magazine which is a guide of accessible walks reviewed by and for local disabled people in Wiltshire.

There was recognition that in order for 'activities' to be able to contribute towards you living a healthy life in the community that they must be **fun**, **affordable** and **flexible.** Having things to do gave people **something to look forward to** and they enjoyed having **shared interest** with people**.**

Having activities that are **open to everyone** also reduced **stigma as that way you don't stand out**.

Connections

Connections with people were crucial to building and leading healthy lives in the community. People found that **peer support helped to form social networks** in the community.

> **Case Study**
> **Wendy made the ambitious decision to join the Community Connector on a day out with others to a local Community Farm. For the first time in several months Wendy was outside connecting with others. She brought a lot to the group that day and it was a big turning point in Wendy's ability to believe that she can make (and have) good relationships with others**
>
> Community Connector Case Study (WCIL)

Building and having relationships with other people has reciprocal benefits; people had **someone to talk to,** someone who **listened,** someone to offer **reassurance,** someone who **knew them. Friendship groups** formed offering people a way to **connect and decompress,** a way of feeling as if they could **reintegrate back into the outside world.**

> **Case Study**
> **I met someone else going through exactly the same situation as me on the day that they were releasing me. It was a chance to talk to someone in my situation. I don't even know his name, but he was a lot older than me. It was nice eventually to manage to meet someone in the same situation**
>
> Bluebell Place of Safety Report (Healthwatch)[3]

People really reflected on the importance of relationships and connections, describing how **some GP's only offer medication when meeting other people may be far more beneficial.**

> **I do not want a prescription, I want a connection**
>
> Extract from a focus group participant

Support

Many people talked about how having access to support enabled them to live a healthy life in their community. The area where most people felt like they needed support was with **transport** for various reasons

including **cost**, **accessibility**, **rurality,** and **anxiety;** generally observing that **better infrastructure** is needed.

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Case Study
Troy was anxious about leaving his home, being in crowded places and using public transport.
The Connector and Tory used the bus to go into town, no small task for Troy, but he showed such courage and determination throughout. The Connector could be alongside him and suggest techniques for managing anxiety, which enabled him to complete a task that he had avoided for years!

Community Connector case Study (WCIL)

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Other areas of support that were highlighted included **emotional support**, **practical support** for things such as **shopping,** and **counselling.**

<u>Attitudes and individual strengths</u>
The attitudes and values held by communities that people experienced contributed to what people needed to live a healthy life in their community. **People who get it** and understand make it easier for people to be **happy to be themselves whatever the circumstances.**

People **listening properly** meant that you **only had to tell your story once** and reduced the feeling that you **have to jump through hoops to prove you have tried things**.

There was recognition amongst the focus group participants that they had lots of individual strengths that enabled them to live healthy lives in their communities.

> **I do mindfulness it's a great help as well as keeping a daily diary.**
>
> Extract from a focus group participant

Some found **routine** beneficial, having **breathing space** as well as **stability.** Being given **responsibility to organise their own activities/groups** was highlighted as important for young people.

> **Case Study**
> **Jessie said to me once that she still didn't think that she had been a mum but then she corrected herself, she said actually I have been doing some things without realising. Jessie started to understand that she was responsible for her happiness and taking control.**
> **Jessie made a brave decision to change her life, in her opinion for the better and she did all of this whilst I was on annual leave. Jessie had the belief in herself and took the steps she needed to take control of her life. When I came back from leave, it was like Jessie was a completely different person. She told me she was proud of herself for what she had done.**
>
> Community Connector case Study (WCIL)

Knowledge

Being equipped with knowledge empowered people to live healthy lives in their community. Knowledge and information about **what is out there** and **what is going** on in peoples' communities was of particular pertinence.

> **Need for information about what is available is important as you don't know what you don't know so don't ask for it**
>
> Extract from a focus group participant

Websites such as **www.wiltshiretogether.org.uk** were suggested as platforms for finding out what is happening in communities, but people were not familiar with it. There was also the recognition that information needed to be **concise** and **good communication** was essential.
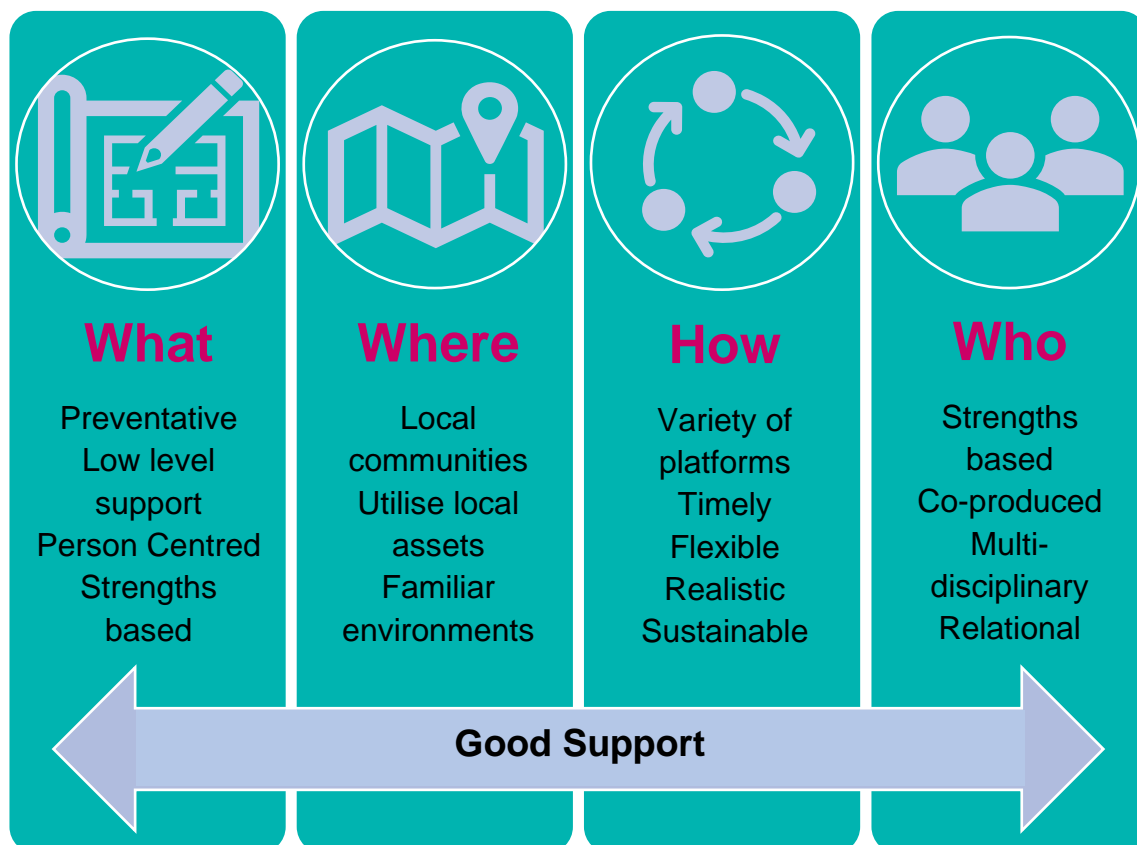
Accessibility

The community being accessible impacts on how well people are able to live healthy lives. People also noted that availability of accessible toilets had an impact.

> **Access is improving but has a long way to go especially in the immediate vicinity... the tears and sadness and anger as not being able to walk round the block as my wheelchair slips on mossy paths, drop curbs that aren't, cambers do nothing for experiencing freedom.**
>
> Extract from a focus group participant

5 What Does Good Community Mental Health Support Look Like?

We will now analysis what people felt good community mental health support should look like; concentrating on what support should be provided, where, how and by who.

What	Where	How	Who
Preventative Low level support Person Centred Strengths based	Local communities Utilise local assets Familiar environments	Variety of platforms Timely Flexible Realistic Sustainable	Strengths based Co-produced Multi-disciplinary Relational

Good Support

What

There is a very clear message that good mental health support should at its core be **preventative**. It was highlighted repeatedly that what people needed and felt was the most effective way of supporting them was to provide **low level support before things escalate** and develop into a crisis. But, that **crisis support (when needed) should provide/offer real help.**

> **Good mental health support is about prevention…prevention is better than a cure, it's about understanding a table (professional plan) isn't the answer, let's work on the causes.**

Extract from a focus group participant

Young people especially observed how **early intervention for those at risk and not waiting for crisis to be the intervention point**[4] was crucial for them.

Having **low level support** for people who **don't meet thresholds** for higher levels of intervention was also crucial. People described how difficult it is to access support, they were either **not ill enough, too ill, or just the right amount of ill.**

> **Services that are accessible whatever level of mental health issue you have, preventing escalation. Not only focusing on people who are unwell, offer support before then to avoid a crisis.**

Extract from a focus group participant

Good mental health support should be **person centred** and **holistic.** Conversations need to be strengths based and built on the principles of Asset Based Community Development (ABCD)[5]. Strengths-based practice is holistic and multidisciplinary and works with the individual to promote their wellbeing.

A range of different types of mental health support should be available for people, with acknowledgement that one size does not fit all. **Non-medical options** need to be available, suggestions included **listening cafes, support cafes/walks,** being able to **watch football** or **knitting groups, art and music therapy.**

Much of the support that people feel will benefit them does not require 'professional' involvement. It should all be self-organising and people need to be given the autonomy to be able to get on and do it. A listening café does not need to be organised and planned by a professional, it needs to be developed and led by people in the community with lived experience who decide to meet at the café on the high street on Monday at 1pm; it will then grow and develop.

The public living room in Devizes set up by one of the WCIL Community Connectors is an example of how non-clinical initiatives that use the ABCD principles make a difference to people's wellbeing and mental health.

Devizes Living Room

Built on the simple formula of kindness and looking after each other, the Public Living Room brings people together. Camarados[6] is a movement based on the "simple belief that having people and purpose in your life is the most important thing" for a happy life.

Every Friday afternoon the Living Room is set up, chairs put out, games on the side, the radio on, ready to welcome anyone who wishes to come along and have a natter. People are encouraged to bring along something to share; their knitting, a book, photos, cake – lots of! The idea is that everyone has gifts they can share with others.

The atmosphere is light and comfortable, just as any Living Room should be. A place where people can talk, friendships can be made, and communities can strengthen.

Lots of kind things are already happening, phone numbers have been swapped, lifts given to help others, people saying hello to each other in the street, whilst others have met up and gone swimming together or given a 'hello' text to ask how someone is.

Community Connector Case Study (WCIL)

Young people and parent/carers highlighted how there is relatively little support for young people after the age of 25 in comparison with what is available and on offer for young people up until this age. Healthwatch

Wiltshire's Mental Health Survey[7] found that **by concentrating on the younger 'end', we might reduce/alleviate the problems for the future.**

Families also felt that they need to have access to support as well as the person who they are supporting.

> **My son has had twenty years of psychotic episodes and the impact it has on families when acute is enormous – there is very little support.**
> Extract from a focus group participant

Central to all good mental health support is **listening**. People want to be heard and listened to, having to **tell your 'story'** time and time again is exhausting for people. People want to be **really listened** to. It was stressed that professionals also need to **listen properly to relatives, carers, friends – we know the person**.

Where
The rural geographical nature of the area ran through all of the discussions about where mental health should be provided. The conclusion being that good mental health support services should be provided in **local communities**.

It was felt that **isolation** needs to be really understood as there are many **rural or small communities** within the BSW CCG footprint and that the isolation had been **compounded further by Covid and lockdown**.

It was frequently suggested that when designing and delivering good mental health support that the physical assets that are available in local areas should be utilised. These assets are also in a **familiar environment** for people.

> **Parish Councils know their local resources – mental health teams could link in with them. Do the mental health team connect with Parish Councils? Liaise with them as they have spaces that can be used – church/village halls…. There is a community centre, and it is not being used apart from as a clothes bank.**
> Extract from a focus group participant

The value of support groups in the local community was also raised by Healthwatch Wiltshire in a previous report[7] but it was felt that there was not enough available, or it was not known about.

How

How mental health support is delivered determines how good and effective people feel it is. It is clear that there needs to be a variety of platforms for people to choose from so that they can access support in a way that suits them.

Having a central **information hub/one stop shop** that people could access to look up information, advice and support independently was an idea suggested by many.

People want to be able to access support through a variety of mediums including **physically meeting** people, through **drop ins** and virtually via **social media, Facebook groups, WhatsApp, virtual groups, Zoom** and on the **telephone** and through **websites.**

There was also recognition that as people are supported, how they receive that support should be fluid and change depending on circumstances.

> **Mixture of face to face and virtual services can be offered, tailor made packages depending on the needs of the individual, changing as needs change e.g., assessments face to face in early support giving followed by virtual sessions to maintain, prevent deterioration.**
>
> Extract from a focus group participant

All support should be provided in a timely manner, people are frustrated with **long waiting lists**, **not being acknowledged**, **phones not being answered.** Support needs to be r**esponsive**, **flexible** and **recognise fluctuations in (peoples) needs**.

Only being able to access support between the hours of 9-5 causes difficulties especially for **people who work**, **there is nothing at the weekends or in the evenings.** People require access to support **24/7** when they **need it most**.

> **Good mental health support for me would be having a way to access help when I need it, not with a year's wait, to have someone at the end of the phone who has my file, knows my info, and can offer realistic options, that can support my husband and then make a house call if needed. It needs to be fast not dragged out going over the same stuff and jumping the same hoops just wears me down…**
>
> Extract from a focus group participant

People find short, time limited support and interventions not conducive to supporting their long-term mental wellbeing, courses are **only offered for 6 weeks.**

There were however concerns about the **longevity of support** and the lack of funding and investment in communities. Some questioned **sustainability as any initial funding is unlikely to be continued indefinitely**.

Who

When considering who should provide mental health support there was a call for much of it to be developed and delivered by people with lived experience of mental health not by professionals. The ideas of **buddy's** and **champions** were suggested frequently. It was discussed how people with their **own mental health needs can and want to offer support to their community**.

> **In addition to obtaining support, a mixture of giving and receiving support is beneficial – getting something for yourself and giving to others.**
>
> Extract from a focus group participant

Opportunities for individuals to **get involved**, **volunteer** and **support others in their local communities** does not necessarily need to be extensively led, organised and co-ordinated by 'professionals'.

Young people talked about wanting to be **given the responsibility to organise their own activities/groups (with guidance but be led by the young people themselves).** Adopting a strength based approach to supporting people will recognise and use **people's strengths** to organise in their communities.

Coproducing support with people with lived experience will add value and validity to the support being provided.

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Case Study

Ronnie has an interest in the outdoors and previously shared an allotment. Ronnie has formed a friendship with another gentleman who he now shares an allotment with. This friend also enjoys sessions at the Barford Wood Workshop, ran by Alabaré; Ronnie has shown an interest in also attending the session or the gardening one and is waiting for the Covid restrictions to lift so that he can join up.

Community Connector case Study (WCIL)

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There is a need for mental health **teams to be multi-disciplinary** for it to be acknowledged that people can and do have other needs in addition to their mental health needs.

> **I was moved to a mental health team a few years ago and the experience was awful. My hours were cut, I was told I would be trained to 'do stuff' despite my health limiting me. After numerous complaints I was put back with the physical disabilities team, but they don't allow support for mental health needs – its insane the two aren't linked.**
>
> Extract from a focus group participant

Professionals providing mental health support also need to hold the skills, standards and values that those who utilise their support feel are essential to supporting them. Professionals need to be **polite**, **reliable**, **consistent**, **good at listening**. A **mutual level of trust** should be developed, **expectations** should be set/managed and the professional should do what they said they are going to – **don't say you will ring then don't,** people want **to not be let down.**

The skills that professionals need are the skills that anyone needs in order to form good relationships and are based on relational ways of working. This method of working with people is at the core of how the Wiltshire CIL Community Connectors work and can be seen in their training manual[8].

Highlighted was also the need for education and for those professionals external to mental health support and services to have a level of training and knowledge about mental health. Some experienced **no understanding from the DWP around mental health** and noted that **Jobcentres needed more awareness and training on mental health.**

6 Conclusions & Recommendations

It is clear from what we have heard that people want to live their lives, go to work, and do the things that they enjoy, with support as and when needed.

There is a focus on prevention and early support, people want to get support early and not be left to reach crisis point.

People don't want interventions from professionals and would prefer peer-led support groups. They want opportunities to get involved, volunteer and organise their own activities and events.

People want to be listened to, not have to repeat their story and to be involved in the design and delivery of the support that is available to them.

People want support to be available locally, and in a timely and flexible manner. They want support to be accessible – not just 9-5 weekdays, and to be available in a variety of different mediums for example online and face to face, group and individually.

People want to be valued and active members of their community, and don't just want to attend groups and sessions specifically designed for people with mental health needs.

Based on what we have heard we make the following recommendations:

▶ More emphasis should be given to early support and prevention
▶ There should be more support available locally and in the community. This should be flexible and accessible
▶ People should be supported and empowered to set up their own support groups, activities and events
▶ Support should be co-designed and co-produced with people with lived experience of mental health.

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Additional contributions from:

WCIL Community Connector Service: https://www.wiltshirecil.org.uk/community-connecting/
Wiltshire Mental Health Forum