

The life you want to lead

Adult social care in West Sussex (2022-25)

Introduction

The voices of people who access care and support should be at the forefront of conversations about the future of social care in West Sussex. Together with their carers and the organisations who support them, their experience and knowledge should shape what we do and how we do it, developing a collective vision for where we are trying to get to.

This is why we have developed the priorities outlined below based on what people have told us is important to them. Specifically, what their vision of a good life is and what needs to change to realise this vision.

We have developed this through eight co-design workshops with voluntary sector partners and service providers, and two workshops with West Sussex County Council (WSCC) staff. We have talked to people who access services and their carers through 15 group discussions and six 1-1 interviews. We also received 1079 survey responses from local people who access services, their carers, WSCC staff and community organisations. People with existing care needs across a wide range of conditions and stages in their journey, people who pay for their own care and people without any current care needs were all involved. We also looked at the latest data available to enhance our understanding of what people were telling us.

Five key priorities emerged from these discussions and responses to the survey.

- Relationships and connections
- Empowerment
- Home
- Addressing gaps
- Inclusion and tackling inequalities

National Context

Councils across the country are exploring ways that they can continue to improve access and support. A key focus is putting people at the forefront of decisions around care, with a drive towards person-centred care and strengths-based practice. They are working to promote inclusion and understanding of diversity, so that everyone has equal access to care; and are moving towards integrating health and social care. They are looking at how they use resources in the most effective way; how assisted technology can help achieve outcomes; and plans for workforce development. This is all underpinned by an understanding that communities have their own strengths and capacity and a drive to prevent, reduce and delay needs from arising, building an evidence base of what works, and learning from each other how preventative services can be scaled quickly. Councils directly provide and commission services, but they also have other roles such as encouraging, facilitating, and convening partners to come together, all of which is being used to help improve the lives of people who access support.

This is against a backdrop of significant funding challenges. We will have to do things differently to ensure we are making the best use of resources. More people need support and costs are going up. £16.5bn¹ is spent by Local Authorities across the country and all are seeing increasing demand and costs. The number of adults requiring care aged 18-64 is forecast to increase by 29% in 2038 compared with 2018. For people aged over 65 it is even higher at a 57% increase. The cost of care is also increasing, with a projected 90% increase in costs of care for adults aged 18 to 64 by 2038 compared with 2018 and a 106% increase for over 65s. While there has been some positive news from national government around funding, this is unlikely to be sufficient to bridge the gap between demand and money available.

There are also many changes around social care coming from central government following the social care white paper² and the Health and Social Care Bill³. We will need to respond to these changes in a way which is grounded in what is important to people in West Sussex. This strategy will provide us with this grounding.

Local Context

Our Council Plan (2021-2025)⁴ sets out four key priorities for WSCC, underpinned by a cross-cutting focus on climate change.

1. Keeping people safe from vulnerable situations.
2. A sustainable and prosperous economy.
3. Helping people and communities fulfil their potential.
4. Making best use of resources.

This strategy sets out how WSCC will deliver adult social care to meet each of these priorities. It sets out what people want to keep them safe from vulnerable situations; the importance of the local economy in delivering adult social care to local people; the important role of communities including the voluntary and community sector in supporting people with care needs; and finally, the fact that adult social care services must be delivered with best value, collaborating with partners to combine resources to support local people with care needs. The cross-cutting theme of climate change underpins this strategy, with a focus on future service delivery meeting the Climate Change Strategy (2020-2030)⁵.

Our Council Plan (2021-25) also commits the county council to ensuring that across all areas of our work, we will:

- put residents and communities at the heart of everything we do.
- create strong and visible leadership.
- work closely with communities and partners.
- invest in and value the staff that work for WSCC.
- make the way we work as a county council as straightforward as possible for the communities we serve.

This commitment directly shaped the way in which we developed the priorities and the 'we will' statements in this strategy, many of which will only be delivered by collaborating with partners, people who access services and their carers. This is a truly shared endeavour in equal partnerships. This means

ensuring everyone's voice is heard when designing services for the future – those who access services now and those who may access them in the future. We have set out the priorities and the high level 'we will' statements, but we will be working with people to work out how we deliver these aspirations. We will be co-producing solutions. Having developed the priorities with local people and partners, this puts us in a strong position to work together to enable more people to realise their vision of a good life.

Our Council Plan also sets out WSCC's approach to keeping people safe from vulnerable situations. While safeguarding is not pulled out as a separate priority here, it underpins everything we do. The priorities below contribute to the Our Council Plan commitments to helping people and communities fulfil their potential and making best use of resources.

West Sussex has an adult population of 699,330. The county has a higher population aged 50 years and 65+ than national averages. Females outnumber males and are more likely to live longer in poorer health. Approximately 7% of the population would identify as Black or Asian.

West Sussex Adults' Services supports 1.2% of the adult population with social care needs, of which the majority (59%) are older people, with many more people paying for their own care. The number of people the county council supports is set to grow over the next five years by a further 500+ people.

While the population is ageing, most of the projected rise in demand comes from working age adults (18-64), with two thirds of this group related to mental health problems and the remaining third being autistic adults and adults with learning disabilities.

The county council spends approximately 34% of its total budget on adult and health services. We know WSCC, like other councils across the country, are facing financial challenges. It is therefore critical that we make the best use of the resources to go as far as we can possibly go to achieve the ambitions set out below. This means that we need to focus on delivering services differently to prevent, delay and reduce needs for escalating; as well as delivering and commissioning services which people need in the most cost-effective way.

The priorities set the foundations for decision making for the adult social care within the county council until 2025. It will act as a guide for prioritising areas for improvement and how we spend money. It aligns with other strategies such as the Carers Strategy and programmes, such as the Changing Futures Programme, and will inform future iterations of joint health and social care priorities in West Sussex.

Priority 1 - Building relationships and connections

People are the most important asset that we have in West Sussex. It is the relationships between family and friends, between the cared for and the carer, within communities, and between businesses, employees, and customers that has the biggest impact on people's lives.

Three key relationships came out as important.

- Close personal relationships with family and friends.
- Relationships between people and paid support.
- Community connections.

Families and close support networks

We will:

- Take a whole family approach when planning and delivering care in all circumstances where it is right for the individual and family.
- Deliver the Carers Strategy.
- Collaborate with partners, in particular community groups, to tackle social isolation.

Families and close support networks, including family and friends (unpaid) carers, are the bedrock of social care. It is estimated that unpaid carers save the West Sussex £19 million per annum⁶.

'I'm close to all my daughters and grandchildren which are a great help to me both physically and mentally.' (Survey response)

Close personal relationships with partners, children, parents, siblings and close friendship networks are core to people's wellbeing. While these relationships develop and evolve for everyone, we heard that having a social care need can add complexity. This is especially true when a person takes on an unpaid carer's role. It is important to people that they can maintain relationships.

It is important to think about the whole family/household around people. Not only in terms of how the wider family supports the individual, but also for the family members own well-being. Unpaid carers say that they experience stress and struggle to manage their own physical and mental wellbeing alongside their caring role. This is supported by research which shows unpaid carers are more likely to suffer from poorer health and well-being. For example, we heard about the importance of keeping young carers informed about the support their parents are receiving so they can go to school without worrying about their Mum or Dad.

While anyone can experience loneliness, people who are living on their own, homeless and rough sleeping, housebound or without close family and friends nearby are more likely to experience loneliness. We also heard that relationships can breakdown after diagnosis, for example due to sight loss. Social isolation has a significant impact on people's quality of life and is linked to a greater risk of dying⁷. They will also need to rely more on their community or organisations for support.

'I am housebound and very rarely can get out or meet people / have people to my home. This is very isolating.

Covid has made it much worse. I have seen friends and family just twice in the last two years. The rest of the time I've been alone.' (Survey response)

Help and Support

We will:

- Put relationships at the forefront of our approach to improving services, including work to improve practice, systems, processes and commissioning.
- Develop inclusive services which don't put people into boxes, where specialist knowledge is integrated and shared.
- Focus on joining up services in a person-centred way between county council teams, other statutory partners and Voluntary and Community Sector at an operational as well as strategic level. Including professional development, trusted referrals, data sharing and the role of partnership agreements.
- Provide information on minimum standards people, including people who pay for their own care, can expect from care and where they can go if they have a problem with the care they received.

When people talked about help, they focused on how it felt and the relationships that were developed.

It is important for people to feel listened to and supported in a non-judgemental way. They want people who provide support to really understand the challenges they are facing, but not to define them by their condition or situation.

This was especially true for people who had more than one condition who told us they feel like they were being labelled as 'complex' when they fit into more than one box. More people will be impacted by this in coming years if not addressed, as the number of people with more than one condition (co-occurring conditions) is set to increase. In 2018 there was estimated to be over 200,000 people of all ages living in West Sussex with two or more chronic conditions, the largest prevalence being in older people, affecting

Sarah was frustrated that she had been assigned a mental health social worker when the personal budget she received was primarily for her physical needs. 'The conversations [with the social workers] always focuses on mental health, when is irrelevant to what I am asking for help with.' (Autism Focus Group)

over 100,000 residents aged 65 years and older. Of which, 80,000 older people had three or more chronic conditions. Conditions can be physical or mental, and include diabetes, hearing and sight loss, asthma, eating disorders, anxiety, and dementia. As the population ages, this number is predicted to increase.

People want support organisations to proactively reach out to them. This includes helping them to prevent needs from starting such as supporting them to stay healthy (physically and mentally) and support to regain skills and reduce needs wherever possible.

They want services to be accessible in a variety of different ways and, critically, to be joined up so they don't have to repeat their story multiple times or being 'passed around' different teams. We often talk about this as person centred care. For people with lifelong conditions, they do not want to have to continuously explain and demonstrate that they still have a disability.

This would then flow into clear communication about how they can work together to move forward and transparency on decisions made.

The focus on relationships doesn't necessarily mean more interactions. It is about the quality of the interactions. Therefore, it is imperative for every team in every organisation to understand this, from back-office functions to those giving direct personal care.

People also want to know that if there is a problem with care, that there is somewhere they can go for support and that clear controls are in place to ensure care paid for is delivered. That the issue will be addressed in a timely and appropriate way, with clear processes.

Wider social networks

We will:

- Enhance opportunities for people to participate in and benefit from peer support.
- Improve information about what community groups are available.
- Encourage and work with communities and businesses to be more inclusive.
- Collaborate to understand if there are gaps in specific geographical locations and improve the offer across the county.
- Explore opportunities to enhance access to community-based transport solutions and work with public transport providers to promote accessibility, recognising that the county council can only fund transport in very limited circumstances.
- Work with voluntary and community sector infrastructure organisations to consider how more people who access social care can be supported to volunteer.

Having a social life is important to people. They want to be able to talk to and connect with people beyond the people they live with and their family. Having the skills and opportunities to make friends and maintain these friendships improves people's quality of life and overall well-being.

'I have a lot of connections and links so I have a lot of support if I need it and people to talk to, spend time with, share my life with - which enriches my life.' (Survey response)

Connection with people with similar experiences is important to people. It enables them to connect with others who truly understand what they are going through and learn from each other. These groups can be a 'lifeline' for each other. For example, we heard that dedicated groups and activities for people who are Deaf, or with hearing loss, are less intimidating for people to share their experiences and is a space where their experiences would be understood. How people find out about these groups is important to understand. People may also need time, support and encouragement to get involved. For example, we heard that people with an acquired brain injury can suffer from low self-esteem and anxiety, so it can take them some time before they feel able to join a group or activity. There was a feeling that there was untapped potential to make the most of peer support.

Often people also want to connect to the wider community. This might be people in the local area or people with similar interests, hobbies or volunteering. For example, we heard that getting involved in the wider community is a critical step on the journey of recovering from a mental health problem. The seven Community Hubs in West Sussex, working extensively with a diverse range of voluntary, community and social enterprise organisations, will play an important role over the next few years to support people who access services to get connected with their wider community.

There is a wide range of needs in terms of being able to access groups and activities. Some people are able to attend activities on their own, whereas others may need different types of support to get there and/or to be able to build friendships while they are there.

To access wider opportunities in the community people needed.

- Information about what is available – people need to know what groups are available and how to access them. Online information will play a clear role, but there should be a way to find out this information if people are not online.
- Inclusive groups and businesses - for some people, the only barrier to them taking part is confidence that they will be accepted by the group. Community groups and businesses need to be open to people with different life experiences and needs. This is not to say that all groups need to understand every condition that people may have, but they need to have an openness and willingness to learn how to make their groups inclusive.

- To be able to physically get to the groups and activities – people need affordable transport, good route networks and accessible public transport. This includes both the practical elements (such as trains which can accommodate mobility scooters and use of audio announcements) and transport staff with knowledge, understanding and a willingness to support people with different needs. For those getting to places on foot or in a wheelchair, accessibility of footpaths and lighting are important. Some people will need support to build skills so they can travel on their own. Innovative approaches are being developed to address these needs, including the Travel Buddy Service which will be piloted for people with dementia in 2022.
- Support – when people can access opportunities in their communities on their own, they have more freedom to do what they want, when they want it. Like support with travel, some people may need help to develop the skills and confidence to get to this point. There are also people who may continue to need support to participate in the community. Funded care packages and having sufficient care workers are important in these circumstances (see staff shortages below). However, we need to also think creatively about how people can access their communities, so they have more flexibility and autonomy. For example, this could include exploring how much help and support the community themselves are willing and able to provide.
- Some people will require more support to get around and may need support to access the groups for a variety of reasons. It's important to understand what help and support the community themselves are willing to provide. The shortage in care workers (as outlined below) and financial limitation within care packages can make this challenging.

Having meaningful and varied activities to do is fundamental to wellbeing. It promotes people's physical and mental well-being, but also their sense of purpose and can provide an opportunity for them to give back. For some, it also provides a much-needed routine. While there was a split in terms of what people told us this should look like, all agreed that having an opportunity to meet other people and having time away from the place where they live, is really important. In West Sussex, innovative models which blend access to care with interests and hobbies, such as Shared Lives Carers⁸, can play a role in helping people connect with others. Accessing community groups and activities is also an essential part of having varied and meaningful activities.

There are many ways people can give. People told us about helping their friends, family, neighbours, religious and community groups. About fundraising, donating money and physical items to charities. There was a clear appetite for more opportunities for people to give, in particular opportunities to volunteer. Volunteering should be valued as an end in itself. It helps people build confidence and self-worth and provides an opportunity to connect with others. The infrastructure needs to be in place to support volunteers to find suitable placements.

Priority 2 – Empowerment

People want to be equal partners, and in some case be in the lead on making decisions about what happens in their lives. We need to empower them to achieve this. The discussions identified four key areas:

- Putting people at the centre of care – choice, control and flexibility.
- Information advice and guidance.
- Paid work.
- Decision making power of frontline staff and role of positive risk taking.

Putting people at the centre of care – choice, control and flexibility

We will:

- Recognise and build people’s strengths, empowering people to co-produce their care and support packages.
- Think about the complete vision for a good life when planning care.
- Look to best practice and collaborate with partners to make direct payments more flexible and easier for people to use, so more people can use them and realise the full benefits it can bring.
- Explore alternative creative approaches to managing personal budgets, including the opportunity to pool budgets and the role an Individual Service Fund might be able to play.

Over the years, people and their carers often develop significant knowledge and understanding about what helps them, the people they care for and people in similar situations. Fundamentally linked to relationships, good help recognises this expertise, with help that is flexible enough to be able to respond to what people are saying they need.

When people become eligible for social care, they are given a personal budget. This is the amount of money the county council will pay towards any social care and support they need. People can choose to have this money paid directly into a bank account so they, or their carer, can manage it to achieve the outcomes agreed in their care plan. It can be a good way to increase choice and control and research has shown it can lead to better outcomes for the same or less money.

‘I love being independent and making decisions about my life and how I choose to live it.’ (Survey response)

At present, 17.5% of people or their carers manage care through direct payments. Overall, people welcome this opportunity but felt there needed to be more flexibility on what they could spend the money on. For example, we heard from people who had identified a service which would support them to achieve their agreed outcomes for less money than alternatives but were told this was not something which adult social care funds. They also wanted less bureaucracy overall and more support with the reality of employing people.

People also expressed an interest in being able to be more creative with their personal budgets, such as pooling personal budgets together to benefit from economies of scale and enable them to get more for their money. Other areas are also exploring Individual Service Fund, which is where a person can choose an organisation to manage the funding in conversation with them.

Care plans also need to be flexible as needs change. For example, people with acquired brain injury talked about how the impact can be changeable from day to day. Blind and partially sighted people told us about seasonal impact, with darker winter evenings making it more difficult for them to get out and about without support.

It is also important to think about the whole of the person's vision for a good life. For example, we heard that autistic adults and adults with learning disabilities want to develop and need support to understand how to do this in a safe way. However, this is not something which is often talked about with them. Sometimes trade-offs between the different elements of a good life will need to be made, but this should be carefully considered. For example, decisions around where someone lives can have a direct impact on relationships and freedom.

Information, advice and guidance

We will:

- work with partners to review our collective approach to providing information, advice and guidance.

The need for good information, advice and guidance cuts across many components of a good life. Some of which we have already touched on, such as the need for information on what community groups are available.

Having easily accessible and tailored information, advice and guidance on what help is available, who can access it and how to access it, is important. This is especially important once people first have identified social care needs or when going through a transition in life. People told us they often don't know what is available and, in many cases, don't know what they can ask for in these stages. This information, advice and guidance is important for people receiving social care via the county council and for people who pay for their own care. One of the main sources of information for many people we spoke to was other people who are facing similar situations. It is important to note that often the information is there, but it is the ease of navigation, accessibility and how it reaches families which needs to be improved.

'Just don't know what exists...Takes so much time to find things...Local support groups are often the key source for reliable information.
(Parent Carers Focus Group)

Paid work

We will:

- Improve the county council's own recruitment processes to employ more people who access social care and work with other statutory partners to do the same.
- Collaborate with employment support partners to encourage more employers to provide a wider variety of suitable job opportunities.
- Raise the aspirations of individuals, parents and organisations who support them to see that paid employment is a viable route for people who access support
- Explore opportunities to work more closely between education providers, supported employer providers and employers to create better pathways into work for young people.

Work is not only about providing an income; having a job enables independence and builds confidence. It gives an opportunity for people to contribute, have a purpose, and make connections with other people. While work may not be appropriate for everyone and some do not currently see it as a possibility, there was a clear appetite from many people we spoke to about getting into, staying and progressing in work. This also applies to carers. For example, we heard from working age carers who had given up their jobs to care for their family member and then struggled to get back into work.

Malcolm has learning disability and worked for a high street chain store for 13 years before he retired. He still has friends who work there that he sees. (Learning Disabilities Focus Group)

It is not only the individual person that can benefit. There are several benefits to the employers. For example, research shows⁹ that employees with a disability work harder, are more productive, more loyal and show lower absenteeism rates. It can also create a more positive environment for other employees and customers alike. Social enterprises in particular have recognised these benefits.

West Sussex has supported employment in place which helps people get into and maintain employment and helps employers find the right employees for their companies. However, while the county has an above average employment rate, data suggests that employment levels for some groups of people are below already low national averages. Nationally only 6.6% of adults with a learning disability are in paid work. In West Sussex this figure drops to 2.1%. While West Sussex is doing better than national averages (9%), only 12% of people in contact with secondary mental health services are in paid employment.

Decision making power of frontline staff and role of positive risk taking

We will:

- Grow a culture of positive risk taking within WSCC Adults' Services.
- Review processes and systems to empower staff to be able to make decisions more quickly where appropriate.

People want timely support. In conversation with the individual and carer, the people who are working directly with them are best placed to understand what support is appropriate. However, they have reported that they need to 'jump through hoops' or wait for weeks before a specific meeting takes place before they are able to get approval.

'Enabling people to have meaningful lives based on who they are and what they want. Having control and making choices independently is fundamental, including taking risks.'
(Survey response)

Positive risk taking is core to the idea of freedom. Taking managed risks is part of leading a fulfilling life. It is not only the individual who needs to be willing to consider and make different choices. It is their carers, support networks and, critically, the professionals involved in their care.

For professionals to be comfortable to support positive risk taking there needs to be a safe culture, where managers encourage staff to empower people to take positive risks, recognising that sometimes things will go wrong. Policies and procedures need to support this, promoting innovation and creativity to find solutions for people.

Priority 3 – Home

Home is about where people live. For homeless people, rough sleepers and people living in insecure accommodation, simply having a roof over their head where they feel they can stay and be safe is critical. For those who have somewhere to live, accessibility and suitability of their home for their care needs is essential. It needs to be a safe, warm environment, where they can move around comfortably and have access to the things which they need.

A home is not only about its physical aspects. When people talked to us about where they live it was about feelings and connection to people and place as much, if not more, than the physical aspects of their home. People talked about continuing to live with their life partner, being near their children, being able to keep their pet, knowing their neighbours and local shopkeepers, and being involved in local community groups. This was balanced with having their own personal space too. They also talked about control, not only in terms of where they live, but who they live with.

There are three broad areas:

- Living in their own home.
- Living with others.
- Moving out of the family home.

Living in their own home

We will:

- Support more people to stay in their own homes, building on work with partners to improve support when people leave hospital and timely access to adaptations, equipment and technology.
- Explore community solutions to support people to maintain their homes.
- Work with district and borough partners to ensure homes are built for an aging population and for those who access care and support.

Most people looking towards older age or who had increasing social care needs told us they want to be able to remain in their own home. They want to do this with quality, reliable support so they can continue to live well and retain control within their home.

Work to help people when they leave hospital and timely access to adaptations, equipment and technology results in people being able to remain at home for longer, reducing the need for long-term care or residential support. Wider work that the county council and its partners do across several areas also supports this. For example, making homes more energy efficient and the Safe and Well visits carried out by the Fire and Rescue Service.

This not only applies to older people. We heard from a range of people who were currently living in shared accommodation or were currently homeless about the importance of having their own private space to live independently.

In West Sussex, the majority (64%) of the people the county council supports live in their own homes (either rented or owned). There are still relatively high numbers of people living in residential care, demonstrating that we can do more to help people live in their own homes.

There was also a significant interest from older people for support with maintaining their homes, such as cleaning, gardening, decluttering and general home maintenance. Over the long term, it will also be important that the county council works with district and borough councils to ensure there are more homes that are suitable for an aging population, such as bathrooms on the same floor as living space and bedrooms.

'I have 1:1 24 hour care in my own home because of my complex needs...This enables me to live in my own home, be as independent as possible and for the first time in my adult life (I'm 48) I am able to choose how I spend my day, what I eat/when I eat, I have my own bathroom, kitchen and outside area. I was really unhappy living in residential care...I am doing really well now. Me and my family are so grateful for all this support which has been life changing for me.'

(Survey response)

Living with others (alternative housing options)

We will:

- Expand alternative accommodation models and promote them as viable options for people.
- Work with traditional residential care settings to more closely align with what people have told us is important.

Not everyone with social care needs lives on their own or with their families. 36% of adults with social care needs in West Sussex live in a variety of different care settings, from traditional residential care homes, to extra-care and supported living.

Extra-care and supported living can be a very positive experience for people. It enables people to feel safe, secure and to connect with people, addressing social isolation.

For this to be a positive experience, people told us they wanted:

- Choice over who they live with, in particular people wanted to live with people who were a similar age who they could 'get on with'. This was especially important when sharing kitchen and living spaces.
- Their own private living space.
- Control over what they do and when they do it, meals and access to family and friends being highlighted most often.
- To be close to their family and friends so connections can be maintained.

Bill and Noeleen are in their 80s and moved into extra care housing four years ago. Bill said they 'moved in just at the right time' as he suffered a stroke shortly after moving in. 'Everything is purpose built for us. There are lifts to all the floors and handrails everywhere.' They also talked about the sense of community. 'Before, our neighbours would be out at work all day and then busy in the evenings...now there is always someone to talk to.'

(Older People Focus Group)

- Appropriate support.

Essentially, they want it to feel like their home as much as possible.

There are already models of care in West Sussex which demonstrate these qualities, such as Shared Lives and extra-care housing. These models will be expanded and promoted as viable options for people. We will also work to ensure traditional models of care more closely align to what people have told us is important.

Moving out of the family home

We will:

- Support young adults to move out of family home in a planned way.

For young adults, moving out of home is an important milestone on the transition to adulthood. People with social care needs, such as autism, learning disability or a physical disability, are no different. For some young people this will mean a fully independent place and for others this will be living with other people. In addition to the points above on what is important when living with other people, for young adults transitioning out of the family home, the young person and parent need to be involved in the conversation. Both need to feel confident that the young person will be able to live well.

Chris is the Dad of an autistic young adult talked about how well his daughter was doing following a serious breakdown. She is thriving in her cleaning job and 'desperately wants to move out so she can have her independence.' Her Dad is fully supportive, but also worries about how she would be supported if she has another breakdown. (1-1 interview)

Priority 4 – Addressing Gaps

During the discussions there were four key areas which were identified which felt like key gaps to be addressed:

- Shortage in care workers.
- Potential gaps in understanding and support for specific groups.
- Moving from children to adult services (transitions).
- Paying for care.

Shortage in care workers

We will:

- Work collaboratively to explore potential local solutions to carer shortages, drawing on lessons from elsewhere.
- Continue to work at a regional and nationally to promote the positive value of working in social care and to attract, retain and develop care workers in West Sussex.

Nationally there are 1.67 million jobs in adult social care, but there is a significant shortage of care workers nationally. 8.2% of roles were vacant in August 2021 and there was a 34.4% turnover in staff in 2021/21¹⁰.

These shortages can be seen in West Sussex. There are also shortages across roles in adult social care, but the care worker shortage is the one which people we spoke to felt most acutely.

This is having a direct impact on people and is leading to gaps in support, especially for the things that are considered 'extra' to people's basic care needs. We heard this was having an impact across a wide range of people with differing needs.

Lisa is a transgender woman with learning and physical disabilities. She goes to a transgender support group in Brighton but needs carers to help her get there. When there is a shortage of carers she is unable to go. (Learning disabilities focus group)

There is no easy solution to this, but there are examples of other areas where local actions are going some way to address the care worker shortages such as enhancing the role of micro-enterprises and promoting self-employed Personal Assistants. We need to explore what these local solutions can be for West Sussex.

Potential gaps in understanding and support

We will:

- Explore and address the potential gaps for autistic adults and people with acquired brain injury.

There were two key groups where it was felt that there were gaps in understanding and support.

- Autistic young adults – nationally there has been an exponential growth in autism diagnosis over the last 20 years, with the most significant growth seen in adults¹¹. People told us that there was unmet need among this group as their needs are often not fully understood or recognised, with labels such as ‘high-functioning’ hiding the struggles faced by autistic people. The labels also miss the fact that the level of support required can change over time. For example, someone who was verbal can become non-verbal when they are overloaded.
- Acquired brain injury (ABI) – While there is limited data available, research from 2017 suggested a 10% growth in ABI since 2005 in the UK¹². The gap identified with people with ABI and their carers was around understanding of impact of brain injury. This can be wide ranging from movement, sensory impairment, communication through to emotional difficulties. The way services communicate and the access routes into the services can be problematic.

‘You can’t express yourself because of the loss of short-term memory recall and you are in your own ‘bubble’. (Acquired Brain Injury focus group)

Moving from children to adult services – Transitions

We will:

- Work collaboratively between children’s and adult social care services to review how we support young people in their transition into adulthood, to ensure they continue to feel supported.

The transition between children’s and adult social care services was highlighted as a key challenge.

People talked about ‘falling off a cliff’ after their support via the county council’s children’s services comes to an end. For some, the difference in eligibility between children and adult social care services meant that they were no longer eligible for support. It’s important that they are aware of this as early as possible so they can prepare and be signposted to other places where they may be able to get support. For those still eligible for support, they talked about a stark difference in the overall approach and level of flexibility available when they reached adults services. The key elements which people felt would make for a successful transition included:

A parent carer to adult children with learning disabilities talked about the significant funding spent on their education. ‘This isn’t a good return [on investment] if there is no life and they are just going to sit in their bedroom after education finishes.’ (Parent Carer Focus Group)

- Conversations to start as early as possible.
- Good information which sets out clearly what will happen by when.
- Linking educational opportunities between 18-25 with future work prospects, with clear next steps after leaving specialist education settings.
- Continued focus on life skills for independence.
- Plan for living outside family home (see priority 3 above).
- Parents still in involved in the conversation, where the young person is happy with this.

Paying for Care

We will:

- Review the county council's approach to charging, fees, and contributions for adult social care services, ensuring it is in line with national guidance and is appropriate for people in West Sussex.
- Monitor the number of people turning down care or withdrawing from care to better understand their reasons and the impact.
- Continue to work with regional and national partners to push for fair funding for adult social care.
- Work with partners to support people to apply for the benefits which they are entitled to.

As outlined above, there are widely recognised national challenges for social care funding which are having a direct impact on people in West Sussex. The reality is that publicly funded social care is only available to people with the highest needs and lowest assets¹³. This means that most people living in West Sussex who require care will have to pay for at least part of their care¹⁴. People are angry about this and many are worried about what this means for their future, in particular their retirement.

We are not going to be able to solve this national issue here and the county council will still need to follow national guidelines, but there are clear areas for improvement in West Sussex:

- Early information - provide people with more information to enable them to plan for their future before they have an identified care need.
- Enhance transparency - improve transparency about when people will get support with the cost of care and the individual contributions people will have to make. Wherever possible, people should know how much it is going to cost before they receive the care.
- Fair charging – charging which takes into consideration the high cost of living in West Sussex and the personal circumstance of the individuals, such as their level of personal debt.
- Access to the finance team to resolve issues – improving access to the finance team to resolve queries as early as possible.

'Government [needs] to make it absolutely clear - what the individual must pay for and what we can expect from the state. This is the only way that any of us (people with normal levels of income) can plan for our futures.' (Survey response)

We also heard of cases where people have pulled out of council funded care. There are often multiple and complex reasons for this, but we are aware that one of the issues is around costs.

This linked to wider concern around poverty in West Sussex. Overall, West Sussex is considered an affluent county, however the division of wealth is not equal, and just as some areas feature in the most affluent in the country, some feature in the most deprived. The West Sussex Joint Strategic Needs Assessment 2019 placed 70,000 people living in poverty in the county, of which 53,000 were adults¹⁵.

National poverty research¹⁶ shows that half (50%) of all people in poverty live in a family that includes a disabled person. 9.7% of carers in West Sussex reported that their carer responsibilities had caused them a lot of financial difficulties¹⁷. Therefore, it is critical that people are supported to access the financial support they are entitled to.

Priority 5 – Inclusion and tackling inequalities

Through all the conversation to develop this strategy there was a clear message that people wanted to be valued and included, whether that was within their own families and friendship groups or in the wider community. It was also clear that not everyone had the same access to information, services and support. Specific groups find it more difficult to get their needs recognised and get the support they need. Others are being left behind and missing out on opportunities presented by the evolution digital age.

There are three key areas to consider:

- Inclusion for people facing multiple disadvantage.
- Diversity.
- Digital inclusion and technology.

Inclusion for people facing multiple disadvantage

We will:

- Continue to collaborate with partners to deliver the Changing Futures Programme and the joint Mental Health and Housing Strategy.
- Involve people who have experienced multiple disadvantage in designing and commissioning services.
- Collaborate to identify ways to prevent people from facing multiple disadvantage.
- Collaborate to explore alternative housing arrangements for people facing multiple disadvantage who need personal care.

There is a cohort of people who face multiple disadvantage across West Sussex. While everyone's situation is unique, we know that they have often experienced traumatic events in their lives; face continuous or repeated periods of homelessness, rough sleeping or housing vulnerabilities; and have high prevalence of mental health problems and substance misuse, cognitive impairment, criminal justice involvement and physical health issues. Many are also experiencing or fleeing domestic abuse. Based on their experiences, they also often have low or no trust in people or the system of statutory agencies that are in place to support them but are perceived as failing them.

The West Sussex Single Homeless and Rough Sleepers (SHARS) Annual Report captured 2720 client audits, covering 1186 individual people. The audit showed that 71% have a known mental health problem. 61% have a substance misuse problem. 40% are in poor physical health and 6% are fleeing domestic violence.

The data focuses on single homeless people and rough sleepers and does not capture people currently in their own housing or accommodation, so the number of people who are facing multiple disadvantage is likely to be higher.

The multiple disadvantage experience can drastically reduce life expectancy and quality of life, as well requiring the intervention of more acute services if not tackled at an early stage.

Successful interventions for this group need to be:

- Joined-up – people need support from several services and organisations. This needs to be centred around the needs of the individual so they don't have to repeat their story multiple times or to try to navigate a complex system.
- Suitable to the realities of their lives – we heard about people not being able to access services because of the requirements or thresholds which are put in place. The clearest example being around mental health and substance misuse services. With mental health services unable to support until the drug or alcohol issue is resolved and drug and alcohol services are unable to support until mental health is stabilised. Services need to understand the realities of people's lives and have access requirements which recognise this.
- Patient – for some people facing multiple disadvantage, it can take them a long time to be able to trust the people and organisations which are trying to support them.
- Timely – it can take a lot for people to reach out for support, so when they do it's important to respond as quickly as possible.

Andrew has been homeless since 2004. He has had some short periods in hostels and supported accommodation and he talked about how 'it was nice a first because you are off the streets, but it never lasts'. Living with other people just doesn't work for him. He needs his own space. (1-1 interview)

The county council and voluntary and community sector organisations are seeing an increase number of people facing multiple disadvantage needing personal care as they age. They often reach need this care at a much younger age. For example, substance misuse can lead to alcohol related dementia or brain damage in their mid to late 40's. However, mainstream care within group settings (such as extra-care or residential care) are not always suitable for them or for the other residents living there. Alternative models are required.

There is significant work already taking place to help people facing multiple disadvantage through the Changing Futures Programme¹⁸ and the Sussex Mental Health and Housing Strategy¹⁹. It will be important to build on this.

Diversity

We will:

- Improve our understanding of the communities in West Sussex, including better data about who is and isn't accessing services.
- Reach out to communities to understand how to improve access and create more inclusive services.
- Focus on recruiting a diverse workforce which reflects our communities.
- Improve training and development so people providing care understand how to support people from a variety of backgrounds.

People from different cultural backgrounds, ethnicities, races, sexual orientation and identity, and disabilities have different experiences of accessing and receiving care. This can impact on if, when, and how they access support, and how they might receive that support.

We heard that people that are unable to find carers who understood their needs. For example, one person being unable to find a carer who could help them put on a sari and another person who struggle to find carers who understands how to care for natural afro-textured hair. Misunderstanding between carers and the people they care for due to language barriers. People not recognising that they are unpaid carers as this is simply looking after a family member and is expected, and therefore not getting support. We heard about missed opportunities to promote the health of adults when they are seen by health professionals and when living in supported accommodation. We also heard about the importance of removing discrimination of same sex relationships within care settings and in care within people's homes.

It is not only their personal care experience which is impacted. Research nationally consistently shows that people from minority groups face poorer outcomes in terms of their physical health, mental health and quality of life. For example:

- The median age of death for a person with a learning disability is 59, compared to 83 and 86 for males and females in England without a learning disability respectively²⁰.
- Black men are four times more likely to be detained under the Mental Health Act²¹.
- Blood pressure, diabetes, stroke, and heart disease are more common amongst Asian and Black Caribbean communities, which are all risk factors for dementia²².
- The LGBTQ+ community rate quality of life, life satisfaction, happiness, and perception that things they do in life are worthwhile, lower than members of the heterosexual community²³.
- Life expectancy for Gypsies and Travellers' is 10 years lower than the national average²⁴.

These health inequalities are not inevitable. They are largely preventable.

There are pockets of good practice in West Sussex. For example, the Dementia Strategy identified some ethnic minority communities which are at higher risk of dementia, lower levels of awareness and social stigma around the condition. Therefore, a Bilingual Wellbeing Co-ordinator will work with South Asian communities to raise awareness; connect individuals and their families with support early; and help reduce stigma attached to diagnosis.

'I would like to see more people and in particular carers being aware of how the use of free images and symbols with communication charts and flash cards, alongside other forms of communication can help understanding and are very necessary where English is not a first language.' (Survey response)

The causes of these inequalities are complex, with wider determinants of health such as poverty playing an important role. We cannot tackle all the causes here, but there are concrete actions we can take, in particular around access to care services. The data suggests unequal access to adult social care for specific communities in West Sussex. For example, data suggests that while the Asian population is 3.7% of the total population, they only account for around 1.5% of people accessing social care. Similar patterns can be seen for people who identify as mixed race, 'other' and Gypsy, Roma and Traveller.

Digital inclusion and technology

We will:

- Work with partners to promote digital inclusion.
- Explore opportunities to enable people, carers and the social care workforce to understand and benefits of assisted technology.

The pandemic has accelerated the trend towards more services being online, from GP appointments through to the growth in online grocery shopping. This has been a positive for many. For example, a Deaf and hearing loss group of people told us that having appointments and meetings online improved their access, as it was easier to get interpreters as they didn't need to travel, and they could use live caption (where the words being spoken are written on the screen in real time). We also heard from others that it has enabled them to keep in closer contact with family and friends living far away.

However, this has not worked for everyone. The reasons for this are very individual, but there are common themes. While access to computers, smart phones and having internet access are important, they are not the only barriers to people benefiting from and being able to participate online. People need to see the value of going online and have the confidence and skills to do so. They also want to have confidence in online services, with privacy and safety being key areas of concern. This is where assisted digital access may be appropriate, to help people gain knowledge and skills and help provide advice on how to stay safe while online, for example helping them reduce to risk of online scams. There may be others where digital is more difficult due to their condition, such as sight loss, and therefore it is important that alternative methods of communications and support are still available.

'We have worked all our lives. I was a company director and Mrs. W was a teacher. What I struggle with is knowing what I can claim and how I can do it. I have just found out that the attendance allowance Mrs. W gets is the lower rate, I've been told to apply online for the higher rate, but I don't have a computer.' (1-1 interview).

Where people want to get online, people told us it was also important that their support plans reflected the need to be digitally connected.

Beyond access to the internet, there has been, and continues to be significant advances in the use of technology to improve people's lives. This applies to individual support for people to remain in their own homes, reduce risk of falls across all settings and much more. There are also developments which will support care organisations themselves to improve services. This did not come out as a clear theme in the discussion, which would indicate that there is a clear gap in people and organisations understanding of the potential of technology to improve lives.

Finally, an underpinning theme in the county council's 'Our Council Plan 2021-25' is tackling climate change and this is supported by the county council's Climate Change Strategy (2020-2030). Greater digital inclusion creates an opportunity for people to stay connected to each other while reducing the need to travel as frequently, thus having a positive impact on reducing carbon emissions for the county.

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