

LIFE IN SOMERSET FOR PEOPLE WITH LEARNING DISABILITIES AND AUTISM CONSULTATION

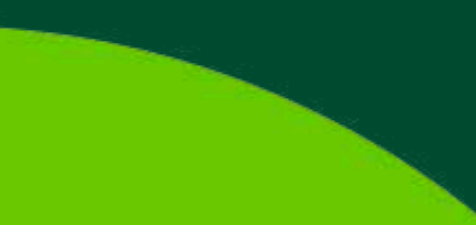




This research report was commissioned by Somerset Community Foundation. It aims to bring together data and local insights to help us decide how best to use some of our funding.

Specifically, this report tells us how our funding could support adults with learning disabilities and autism to live fulfilling lives in their own communities. Our aim when we commissioned this research was to build our understanding of what works well, what needs attention, and how positive changes can be sustained within communities.

This report is copyright free and we hope it will also serve as a valuable resource for others.



AUGUST
2021

Life in Somerset for people with Learning Disabilities and/or Autism consultation

Prepared by: Somerset Parent Carer Forum CIC
and
Autism Somerset CIC



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EXECUTIVE SUMMARY

The partnership between Dimensions and Somerset County Council was ambitious and through the social enterprise, Discovery, they looked at new ways to provide care to the residents of Somerset. As is the case in most areas, in the last 18 months care provision within Somerset has experienced significant challenges due to the impact of the covid pandemic.

National and local trends show that the demand for care will continue to grow over the coming years. It will be hard for local services to plan to meet the demand as the pandemic has brought challenges we have not faced before, and the Joint Strategic Needs Assessment is not robust in its data around Autism therefore the area cannot be confident in its predictions of need. With the development and implementation of the Integrated Care System (ICS), the merger of Somerset Foundation Trust and Yeovil District Hospital NHS Trust and the implementation of One Somerset, it will be essential that a robust strategic plan to meet the needs of individuals with a diagnosis of learning disabilities and/or autism, which places them at the heart, is in place.

Local individuals with a diagnosis of learning disabilities and/or autism are reporting that the feelings of isolation that were present before the pandemic are now stronger, they feel that they often do not have a voice and are experiencing challenges around elements of their care and support. Lack of information about the offer locally is a vital area to address as this is hindering an effective gap analysis and many are missing out on opportunities to access the community because they do not know what is there.



EXECUTIVE SUMMARY CONT...

There are some positive elements highlighted within this report including the use of micro providers which allows greater flexibility. Value has been placed on the accessible information being provided over the last 18 months, which has supported individuals with a diagnosis of learning disabilities and/or autism to understand the changing covid requirements. Learning from this can be taken forward and will help support the area to tackle some of the challenges that the report highlights.

The community fund from Discovery has clear aims and the consultation shows that delivery of these aims, and the fund can play an essential role in supporting with recovery after the pandemic. For the fund to succeed in making the most impact it is essential that individuals with a diagnosis of learning disabilities and/or autism are central to the process and involved within the decision making.

This report includes the detailed findings of the consultation and recommendations based on the views of our local community of adults with learning disabilities and/or autism and those that support them.

KEY FINDINGS


The consultation highlights the heavy reliance on families (parents, siblings, spouses, and children) to provide support for the needs of individuals with a diagnosis of learning disabilities and/or autism. This ranged from support for communication needs, financial support through to care needs on a daily basis. Families often act as coordinators of care.

Choice and control were not consistently given to individuals with a diagnosis of learning disabilities and/or autism. Only 30% were able to choose when they went out and 22% reported not always having control on what they did in their free time. We heard the terms 'done to', 'decided for me' or 'gate keeping' within the consultation. Individuals with a diagnosis of learning disabilities and/or autism reported they didn't feel valued and felt underestimated as people only focused on their needs and not their strengths.

There was a feeling of not being listened to and disempowerment coming through from responses. This was evidenced during the consultation as we came across multiple situations where we were told that the individual with a diagnosis of learning disabilities and/or autism wouldn't be able to or want to get involved.

There is a lack of support for individuals with a diagnosis of learning disabilities and/or autism to be able to discuss and understand their disability, beliefs, gender, and sexuality. Access to support to look after their sexual health was very low at 28%.

Throughout the consultation responses, there were requests to have information or support to be more independent. Information which is clear and accessible is a major issue across individuals with a diagnosis of learning disabilities and/or autism and those that support and care for them. We heard that mechanisms which had been put into place to fulfil this function, were at best not consistent (Somerset Direct) through to being not fit for purpose (Community Connect website).



Only 30% of people said they were able to choose when they went out



KEY FINDINGS CONT...

52% OF RESPONDENTS REPORTED THEY FELT THEY COULD WORK AT LEAST SOME OF THE TIME BUT ONLY 13% WERE IN PAID EMPLOYMENT

A lack of information and support to get into work/volunteering was highlighted as a barrier, compounded by a lack of opportunities. Placements were also heavily focused on need, and this resulted in people being placed to do roles they didn't enjoy.

Anxiety and mental health needs featured in discussions for many individuals with a diagnosis of learning disabilities and/or autism. It was felt that having a learning disability and/or autism were seen by mental health teams as a reason they did not need support. Organisations are seeing this since restrictions have eased with a reluctance to come back into society and it was felt support is needed to tackle this.

There is a significant lack of things to do and places to go. We heard that there was a desire to have safe places and activities where individuals with a diagnosis of learning disabilities and/or autism could go. We have seen many groups close during the pandemic and these have not reopened. There needs to be better information about what is available as services told us they didn't know where to sign post people.

Assessment processes were felt to be challenging with high thresholds and delays in funding/support while appeal processes took place. Information was not always clear and accessible. The Department for Work and Pensions was seen to be a challenging department to work with and it was felt they didn't understand needs or make adjustment well.

A background image showing a man in a checkered shirt holding a cup, with a woman's face partially visible in the background. The image is overlaid with a semi-transparent blue filter.

RECOMMENDATIONS

The following recommendations have been formed on the experiences shared by Somerset residents who have a diagnosis of learning disabilities and/or autism and the people and organisations that support them.

We have included recommendations which could easily be established without costing large amounts, but based on the conversation we had during the consultation, will make the lives of individuals with a diagnosis of learning disabilities and/or autism better.

Some recommendations can be facilitated through Discovery's Community Fund, others however, require systemwide responses and we have separated these accordingly.

Recommendation 1 -Make the voice of individuals with a diagnosis of learning disabilities and/or autism central to the funding process and evidence that they are valued

Recommendation one can be achieved by adoption of a model often used in participation-based organisations such as Healthwatch, Maternity Voices and Parent Carer Forums is that a significant percentage/all the people central to the decision-making process, including funding decisions, have lived experience. Currently, Discovery's board adopts this model, and our first recommendation is to strengthen this approach through the application process, the funding allocation, and the impact monitoring.

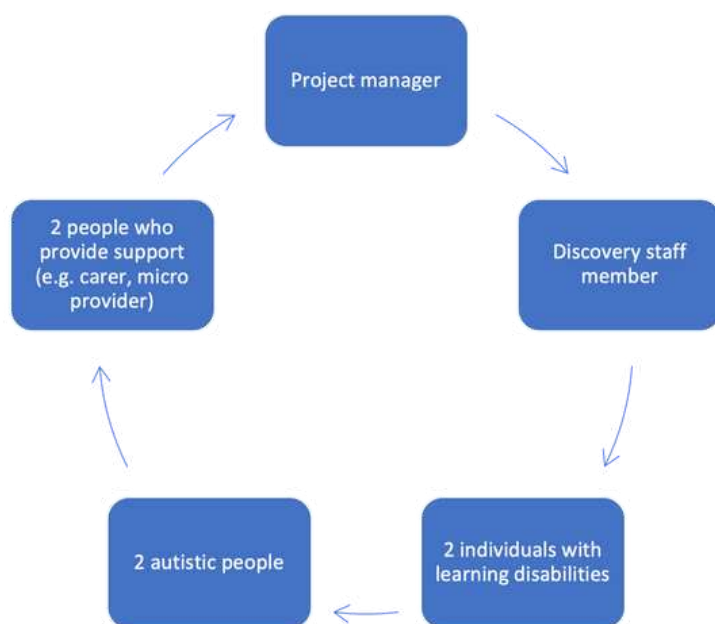
Applications - All grant applicants should be required to evidence how they have worked with adults with learning disabilities and/or autistic people in the development of their application. When adults with learning disabilities and/or autistic people are delivering part of the project it should be clear how they will be rewarded. The organisation will have also undertaken the self-evaluation (please see recommendation 2 for more details).

The funding allocation process - To ensure users are at the heart of the process, Discovery will establish a subcommittee who oversee the Discovery Community Fund management.

Ensuring these are paid roles would further demonstrate Discovery's commitment to valuing individuals with a diagnosis of learning disabilities and/or autism, thereby leading by example and role modelling expected behaviour.

The committee would:

- review all applications and recommend how the funding is spent.
- review, mentor and support the projects
- meet monthly to discuss each projects progress
- meet with Discovery board to discuss the projects
- support an annual event to share learning



Impact monitoring – The fund should provide organisations it funds with a framework/measuring tool to:

- measure the social impact of the project
- demonstrate the reflection of the voice of adults with learning disabilities and/ or autistic people throughout the project
- measure key performance indicators of the core outcomes/goals
- record learning from the project
- show unplanned benefits or impact

Examples of frameworks include HACT who provide tools to measure social impact of housing initiatives (HACT 2021) and evidence-based tools for measuring and supporting change when working with people such as the Outcomes Star (Triangle 2021).

Each year the committee should host an event, which brings together organisations who have benefited from the funding, to share good practice and find practical solutions to issues they have come across.

Recommendation 2 -Ensuring individuals with a diagnosis of learning disabilities and/or autism central feel valued and included

Things have changed drastically over the last 18 months and as a community we are only starting to understand what this means for life moving forward.

We recommend a small amount of the funding is used to engage an organisation to run 4 events annually which would bring together individuals with a diagnosis of learning disabilities and/or autism, those who care for them, and providers.

We would like to see providers of activities for children's social care included in the events, as references were made during the consultation to something similar to this provision being wanted by adults.

The sessions should be a blend of face to face and online as the consultation showed that different options were preferred by different people.

They need to be fully accessible and provide those attending the space to engage in a way that suits their needs.

These sessions would enable the conversations in the consultation to be built upon and for these groups to collectively explore in detail what could be provided based on the actual needs of the community.





Recommendation 3 -Ensuring individuals with a diagnosis of learning disabilities and/or autism central feel included in their community

The Community Fund has previously supported groups and organisations to be able to establish activities for individuals with a diagnosis of learning disabilities and/or autism. The impact of Covid has seen a reduction in activities and leaves a significant gap, so we need to regenerate this area. Therefore, one of the funds priorities should be to extend the range of community-based activities available to individuals with a diagnosis of learning disabilities and/or autism by:

- 1.funding existing social groups, helping them to grow and try new things e.g., a young people's group to offer a transition group and/or young adults' group
- 2.help new groups get started e.g. how to advertise, things they need to have in place and finding venues
- 3.help mainstream clubs and activities to include individuals with a diagnosis of learning disabilities and/or autism e.g. work with libraries to offer Book Clubs or art studios to offer classes for adults with learning disabilities and/ or autistic people
- 4.fund groups that address anxiety due to the covid pandemic at least for the next 18 months to have a higher ratio of staff. These should be time specific pieces of work which enable individual and small group work to take place to rebuild confidence.
- 5.fund projects which make community spaces more accessible e.g., improving access, improved lighting and changing places

We feel it would be beneficial for part of the funding to be dedicated to working with groups to get up and running, support them to overcome the barriers they are facing due to covid rules, and/or help them to review how they can adapt their practice to be inclusive of individual needs. This could also include design a plan for them to become sustainable through full or partial self-funding and to access other national funding schemes. This could be achieved through a dedicated member of staff being employed by Discovery or by funding a consortium of existing organisations to provide a package of support drawing on their own area of expertise.

Recommendation 4 -Help individuals with a diagnosis of learning disabilities and/or autism feel safe in the community

A recurring theme within the consultation was not having things to do and safe places to go. Building on programmes such as dementia friendly communities , safe spaces scheme, Hidden disabilities and Ollie the Flamingo we would like to see the fund establishing a programme which enables individuals with a diagnosis of learning disabilities and/or autism to easily identify places they could safely use.

This could be managed in-house, through out-sourcing to an existing group or a new social enterprise could be established to set up and manage the scheme. The programme would have a panel which included people with lived experience (similar to the community fund panel recommendations) who would award the bronze, silver or gold quality certificate. The panel would also review the awards every 2 years to ensure the organisation still qualified e.g., there was evidence that new staff members had been trained.

Through a quality standard model, organisations would be identified as having the knowledge to support individuals with learning disabilities or autistic people. The quality standard would be based on a framework which would include a bronze, silver, and gold award.

The quality standards system would have clear guidance on core levels of knowledge, and actions undertaken to demonstrate and reflect to adults with learning disabilities and/ or autistic people and families training has been undertaken/ and recommendations have been implemented.

Bronze – All staff will have undertaken the 2 training modules - What you need to know & what you can do (free courses, designed with adults with learning disabilities and/ or autistic people)

Silver – The organisation will have undertaken a self-evaluation and submit to along with an action plan to address findings. Once 75% of the action plan is completed, they would be awarded the silver.

Gold – The organisation will have completed 100% of the plan, based on their self-evaluation. Discovery or a company appointed by them will conduct a review of their plan and make any further recommendations. Once completed they will be awarded the gold.

Discovery can hold a record of organisations and groups who have successfully achieved the awards on their website for people to easily find one near them.

Recommendation 5 – Enable and empower individuals with a diagnosis of learning disabilities and/or autism to have their voice heard

Through the consultation, including the mapping work, we identified that Somerset has various organisations/groups who are currently doing elements of this work. Reflecting on the whole system we feel there is enough knowledge and skills to bring achieve this through a consortium model. Although we could not find any examples of this in practice at a local level, we have the example of the national consortium between Council for Disabled Children, Contact, and Kids who provide advocacy and participation services. We recommend establishing a consortium of social enterprises and organisations who provide:

- Advocacy, specifically tailored for learning disabilities and/ or autistic people building on learning from Swindon Advocacy Movement
- Workshops and skills groups to support individuals to be confident to speak up
- Training to upskill individuals/groups/organisations to enable them to effectively engage with and listen to people with learning disabilities and/or autistic people.
- Safe spaces to discuss key topics such as sexuality and gender
- Specialist knowledge in learning disabilities and/or autism

Combining the skills across the following organisations/groups, Discovery could establish a strong consortium who they could lead to work together to strengthen the voice of people with learning disabilities and/or autistic people aged from 14.

1. Swan Advocacy
2. Our Voice
3. Autism Somerset
4. AuSomer
5. Somerset Disability Engagement Service
6. Somerset Parent Carer Forum
7. Healthwatch
8. Somerset's special schools and post 16 provision.
9. SENDIAS
10. 2BU

It would be an essential part of this consortium that they provide legacy resources which could continue to be used and shared across they area to help anyone adapt practice.

Recommendation 6 – Improved support for independent living for individuals with a diagnosis of learning disabilities and/or autism

The consultation evidenced that individuals with learning disabilities and/or autism are unable to have the living arrangements they want due to insufficient information and advice to make the necessary arrangements. Therefore, the Discovery community fund could be used to support a startup or expansion to an existing service to address this gap by:

- Create a visual flow diagram to show a pathway of living independently choices for adults with learning disabilities and/or autism
- Create detailed information on options, the pros and cons
- Create a How To guide to access each option
- Provide support to access and complete each step through a mentoring system
- Help individuals to look at where they are now and where they want to get to and how they can do it e.g., living with family to living on own or with friends
- Signpost to local support and services



This fund should have the capacity to set up training on topics in specific areas for adults with learning disabilities and/ or autistic people being responsive to need. For example, if 5 people in Frome are identified as needing information on living independently, they could run a workshop/course or work 1-1 to signpost to a bespoke program of opportunities.

The service would need to provide specific targeted support but include the option to go back and check in if help is needed further down the line. This could be achieved through Pop-up information and signposting hubs (in libraries, DWP, GP surgeries, CAB's, talking cafes etc.).



Recommendation 7 – Support individuals with a diagnosis of learning disabilities and/or autism to learn and develop new skills

Through the consultation were heard that people were not always able to learn the skills they needed to be independent within three main areas, practical skills like cooking and cleaning, managing money and using technology. We have identified 3 possible ways to address this through the Discovery Community Fund.

1. Establish or extend an existing community organisation to work with new housing developments, district council's and the county council to identify buildings that can be used as hubs to practice life skills from making beds, cleaning, cooking, and decorating. The hubs should also act as a resource center for information and support with the delivery of other recommendations for example being identified as safe space people can go to.
2. Identify a list of providers who can work with groups listed in recommendation 3 to provide skill sessions on using technology and managing finance including budgeting. This should include the option of health checks on family budgets and link with debt management schemes already in existence through organisations like Citizens Advice.
3. Fund existing schemes to extend their offer which promotes life skills as these often are one off session which do not allow the skills to be practiced on multiple occasions. For example, Magdalen Farm have run session for adults with learning disabilities to learn to cook and clean. These hands-on practical sessions need to be extended to run over a period of several weeks to embed the new skills.

SYSTEM WIDE RECOMMENDATIONS OUTSIDE THE SCOPE OF THE CONSULTATION

Recommendation 1 - Improve access to information

We recommend the inclusion of individuals with a diagnosis of learning disabilities and/or autism as part of the 'Help You to Help Yourself' project currently being run by Somerset County Council and Somerset Clinical Commissioning group to improve information systems.

Previous systems have not been effective because they have been designed based on what we think is needed rather than asking all users what they need. This needs to be a continual process which includes reviewing as information can quickly go out of date.

For example, information on managing your finance should include more practical help on budgeting, funding available and paying bills. This could be created in a similar way to Life hacks for mental health a Life Hacks for everyday living.

Recommendation 2 - Promote a whole family approach to independence

As part of a Carers Assessment or Early Help assessment a plan is in place to support carers once the cared for person is more independent.

Examples ideas are, Pop up information and signposting hubs for Carers: providing practical help and signposting to write a CV, financial information, support to learn a new skill, or courses to help manage their anxieties and worries about the changes.

These need to be facilitated when respite is available to enable carers to take up these opportunities.

SYSTEM WIDE RECOMMENDATIONS CONT.....

Recommendation 3 - Help to look after sexual health

We recommend a review of services that provide support for looking after your sexual health through the lens of individuals with learning disabilities and/or autism. This needs to start with school education programmes and continue through to services such as swish.

The consultation highlighted how a large proportion of care and support was undertaken by family members. Adults with learning disabilities told us that they are seen as younger than they are and often there is a belief they are not sexually active.

We recommend the review includes how these services are accessed as most people would not want to ask a family member to help with this area of their life.

Recommendation 4 – Supporting access to work

Improved information needs to be available about how to get into work, as we heard that people often don't know where to start.

The Disability Teams who can support with access to work are not well known and this resource needs greater promotion.

The creation of online courses for people wanting to get into work, and to support Employers to make adaptations, would be a good starting point. These need to include local examples of how this has been achieved.

An example of one such guide is the guide 'What to do when interviewing an autistic person for a job' created by the University of Bath (Maris 2021).

BACKGROUND

A learning disability is a reduced intellectual ability and difficulty with everyday activities – for example household tasks, socialising or managing money – which affects someone for their whole life.

People with a learning disability tend to take longer to learn and may need support to develop new skills, understand complicated information and interact with other people (Mencap 2021)

It is estimated that 3,100 people in Somerset had learning disabilities in 2019/20. This figure had risen from 2,600 in 2016/17. The proportion of the population with learning difficulties in Somerset in 2019/20 was 0.5%, aligning with the South West region and England (Somerset County Council 2021).

Autism is a lifelong developmental disability which affects how people communicate and interact with the world. Autism is a spectrum condition and affects people in different ways. Like all people, autistic people have their own strengths and weaknesses.

2019-20 figures from NHS digital, identified 782 people as autistic in Somerset. During the same period 2096 people registered at a GP surgery were recorded autistic. However, based on national prevalence figures of 1%, we would expect for this number to be around 5,600 (Somerset County Council 2021).

Discovery is a social enterprise formed in 2017 as part of the partnership between Dimensions and Somerset County Council. They support people with learning disabilities, autism, challenging behaviour, and complex needs throughout Somerset.

**Discovery's five
core values are:**

**Partnership
Courage
Integrity
Ambition
Respect**



Discovery's five core values that influence their service delivery are:

- Partnership- working in partnership with others to achieve more for people.
- Courage - guided by the courage of our convictions to make a difference. They are committed to developing and maintaining an open and inclusive culture which values and respects difference to enable us to reach shared goals.
- Integrity- We act with integrity to ensure what we do is grounded in what we believe.
- Ambition - They are ambitious about helping people reach their potential.
- Respect – The people they support will be treated with fairness and respect.

More than half of any surplus made is reinvested into improving services for people with learning disabilities and/or autism in Somerset through the Discovery Community Fund. To ensure the fund is meeting the needs of the community, Discovery commissioned an accessible consultation through Somerset Community Foundation in May 2021. Somerset Parent Carer Forum CIC and Autism Somerset CIC were appointed to deliver the consultation (see organisational profiles in Appendix A).

SCOPE

The consultation for use of the Discovery Community Fund had to be accessible and adapted to the needs of adults with learning disabilities and/or autism as well as their families, friends and carers across Somerset.

- The aim was to engage these groups in a way that allowed them to get their voices heard and then draw together these voices to help understand:
 - how people feel about their lives today
 - what is working well
 - what changes are needed
 - why they are needed
 - what might be the unintended consequences of making a change

METHODOLOGY

The consultation was underpinned by Somerset Parent Carer Forum's and Autism Somerset's ethos that everyone should have a voice and be supported to engage in a way that works for them. To enable this to take place the consultation had to be widely accessible. To enable delivery of the consultation we split it into the following four phases:

1. Pre-delivery
2. Discovery and design
3. Delivery
4. Evaluation and reporting

PRE-DELIVERY

As part of the pre-delivery phase, we undertook a review of the following documents to help shape our thinking of areas that need to be explored:

- Survey results and feedback collected over the previous 18 months
- Somerset's JSNA
- The Learning Disabilities Mortality Review Annual report 2020
- Strategic systemic review of learning disabilities and autism for people aged 14 + in Somerset-Unpublished
- Enter and View report: Able2achieve
- Accessing health and social care during Covid 19- A Somerset perspective
- Care Homes during covid- care staff perspective.

An exercise to map key stakeholders, including organisations who we would approach to support the individuals they worked with to engage with the consultation, was undertaken (see appendix B).

DISCOVERY AND DESIGN

The establishment of a reference group of experts by experience to help us shape the consultation was one of the most important parts of the process. This included:

- Young adult with learning disabilities
- AuSomer: Somerset based unregistered charity representing autistic adults
- Young person with autism
- Parent Carer of young person with learning disabilities, recognised for work on national policies
- Local Micro provider with additional experience around using technology to support people with learning disabilities

The group worked together refining the consultation questions and formats to ensure it covered the important subject we had identified and was accessible. Based on lived experience and research the following areas were included:

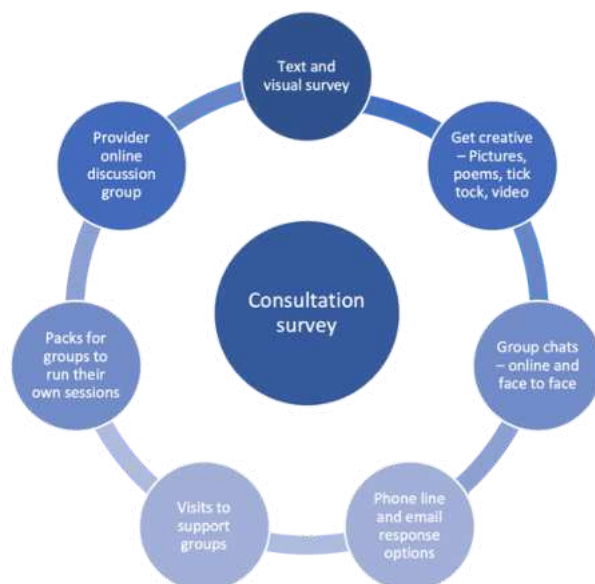
- Communication
- Work
- Finance
- Housing
- Support
- Accessing the community/free time
- Health
- Impact of covid
- Use of technology



Through the consultation, the group wanted to know more about what it is like to live in Somerset if you have learning disabilities and/or are an autistic person. We decided having the consultation open to anyone aged 14 and over, would enable us to identify any potential gaps coming through the system which may need to be supported in future years.

DELIVERY PHASE

The consultation launched on 7th June and ran for 6.5 weeks until the 23rd of July. We established a website area as the central place to hold all information relating to how people could get involved. The advisory group recommendation was to have 2 forms of the survey, a text only version and a version with graphics (see appendix C).



The survey was uploaded onto an online platform and paper copies were distributed. This was supported by a full range of alternative ways to get involved. The consultation was promoted across our networks and to all identified stakeholders (Appendix B & D). This included social media platforms, newsletters, live Talking Café session and radio. Emails were sent to over 600 organisations and groups including all 515 micro providers to raise awareness of the consultation.

EVALUATION AND REPORTING

Quantitative data -140 responses were collected either online or via hard copies. A data analysis of the results was undertaken, and themes were identified across the data sets.

Qualitative data was collected through the discussion groups, emails, individual phone calls and the surveys. A thematic review of these has been undertaken and fed into the report.

Reporting will take place over August and September through the following mechanisms:

- Formal report will be shared with Discovery, Somerset County Council, and the advisory group.
- A supporting slide pack has been prepared for various boards.
- Presentation to September's Learning Disabilities and Autism board (CCG)
- Infographics
- Website pages
- Results to be shared with Greatest Hits radio and Talking Cafe



CHALLENGES AND BARRIERS

Through the course of the consultation, we experienced challenges and barriers to ensuring we captured a wide range of voices. Some of these were expected, such as people's capacity to engage due to covid and what is often referred to as zoom fatigue.

During the mapping of stakeholders, we discovered there had been a significant change to the group. We estimate that about 15% to 20% of the groups we contacted were either dormant because of covid or had ceased.

We were surprised to find that some organisations acted as gatekeepers. There were a variety of reason and often the unsettling impact of covid was a factor which impacted on their willing to engage the individuals they worked we.

We also experienced what felt like groups and organisations underestimating the ability of people to get involved. Initially we were surprised by this but as the consultation progressed this was reinforced by the responses we were getting. There was a lack of confidence in gaining the voice of this group emerging and this has led us to make the recommendations to support these skills across the Somerset system.



DETAILED FINDINGS

The following findings have been drawn from the feedback received by:

- individuals who have learning disabilities
- individuals who have learning disabilities and autism
- autistic people,
- unpaid carers
- paid carers
- micro providers
- organisations supporting individuals who have learning disabilities and autism
- adult social care staff

See appendix E for a detailed breakdown.

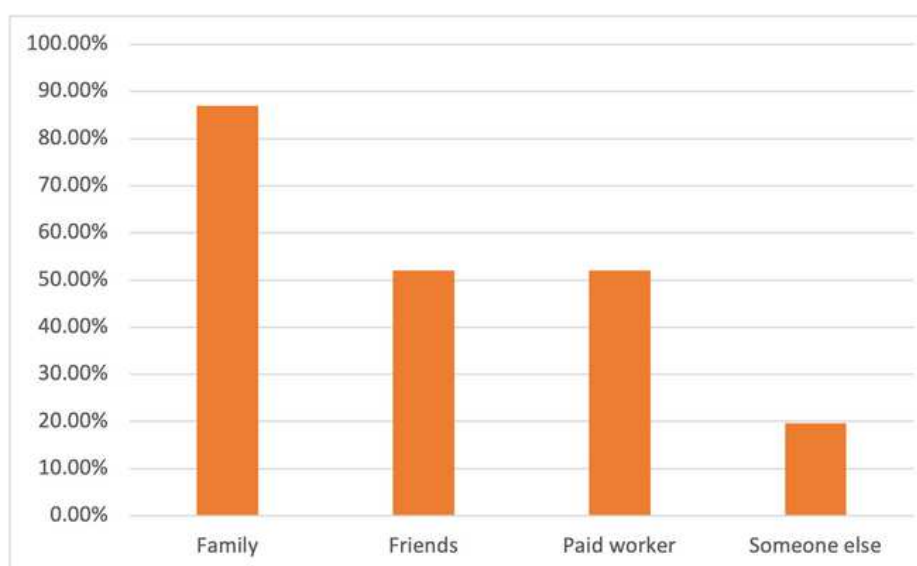
COMMUNICATION

Within this section we focused on two key areas:

1. having someone to talk to about accessing support
2. the ability to feel comfortable to talk about your views.

The majority of respondents (87%) identified a family member as the person they would go to when they needed something. Younger respondents also identified education staff as people they would talk to.

"I don't have any help. It's too expensive and difficult to tell strangers/agency staff and time consuming and they charge £20 per hour"



87% of respondents identified their family members as a key person they would talk to if they needed something.

Other key people were staff in education including teachers and learning support assistants.

Barriers to communication that were identified, included things only being accessible online when you need face to face communication or support.

Forms were seen as a barrier for many to be able to communicate their needs and concerns were raised around the processes involved in the assessment processes.

The Department for Work and Pensions was identified as being a particularly challenging service to communicate with. Carers and spouses resonated with this view, and often felt they were the coordinators of support and had to speak on behalf of the individual they cared for.

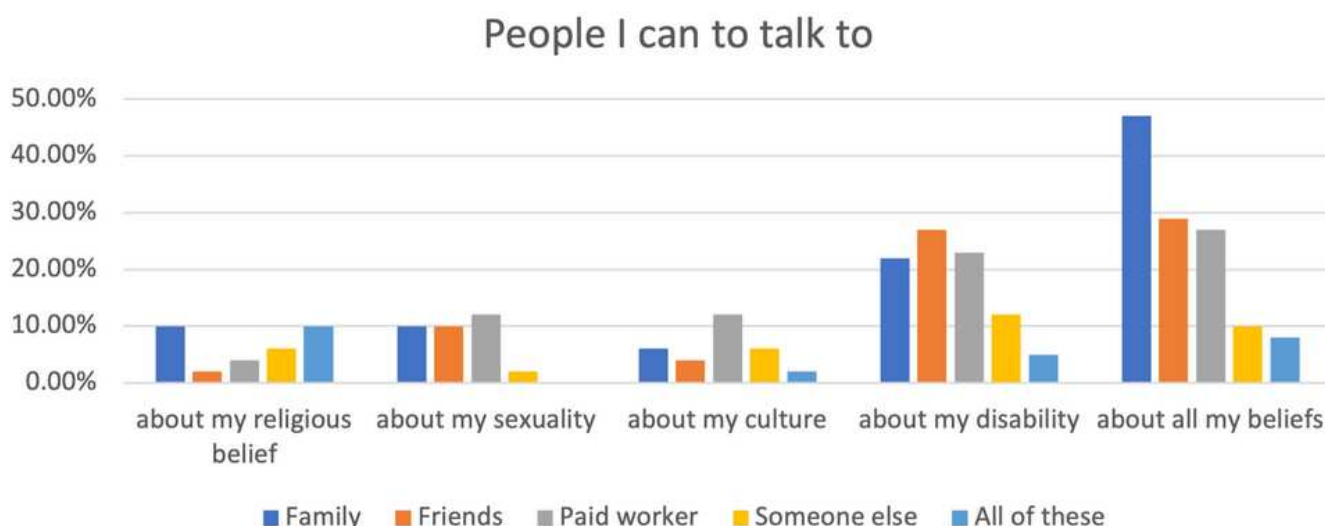
COMMUNICATION CONT....

"Explain things to me. Make an attempt to explain things to me in a way I can understand. Don't just 'not bother' because it's inconvenient to you to have to explain things to me".

We heard how difficult it can be for people with learning disabilities and autism to communicate their needs and this results in them not feeling fully involved in the decision-making process. Only 4% of the survey respondents had been supported by an advocacy service, although some reported attending groups like Our Voice, which is designed to support people with learning disabilities to have a voice. The feeling of "being done to" was strongly expressed by several individuals and those that support them.

In the United Kingdom it is a right for people to be able to talk about their beliefs and values, however less than half of the Somerset residents that took part reported that they felt they could do this. Group discussions and individual comments highlighted the lack of support and organisations to talk to about gender/sexuality.

As part of this the impact on people's mental health and wellbeing was highlighted, with a view being held, that this increased anxiety and depression. We frequently heard that having a diagnosis of a learning disability and/or autism was preventing them from receiving help from mental health services when this happened.

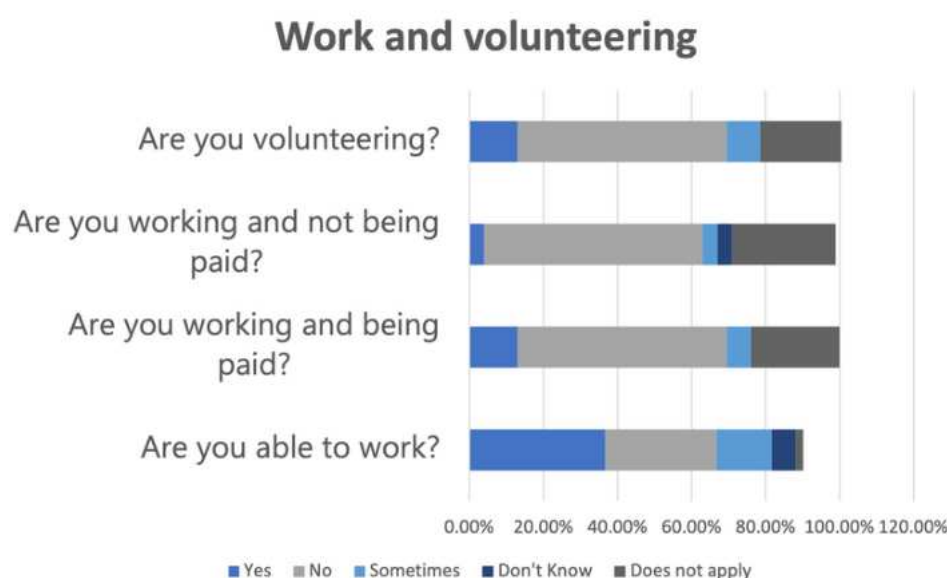


COMMUNICATION CONT....

“There are high levels of anxiety and depression and there is nowhere for them to go. When they seek help they are shunned because they have a diagnosis and sent packing” – Support worker

A key theme that reoccurred throughout the discussions was lack of information, both for the individual looking for themselves and those trying to sign post. Somerset Direct (now known as the contact centre) was reported to be ineffective by several participants and local websites such as Somerset Community Connect were confusing and difficult to navigate.

WORK AND VOLUNTEERING



52% of respondents reported they felt they could work at least some of the time however the amount reporting being in work (paid and unpaid) accounted for only 27.5%

We heard the difference that it can make having supportive and understanding employers. This included the ability to take extra breaks and adapt work to meet needs. Other areas highlighted in work that were positive included:

- teamwork
- building confidence
- having flexibility
- supportive employers who understand needs
- being allowed to take breaks when needed
- enjoying the work
- schools providing work experience
- not having to talk to people
- working online
- volunteering worked well with the individuals needs

WORK AND VOLUNTEERING

"I don't know anywhere where my physical disability, communication needs (I use AAC) and social communication difficulties would mean I could work"

The lack of placements was cited as a barrier to working, and it was felt this has been made worse by the covid pandemic as some volunteer opportunities have stopped, and work has gone online. The limited opportunities to volunteer or work led to situations where people were engaging in work they didn't enjoy.

We also heard of several cases where volunteering, or work, has decreased due to the lack of support, funding withdrawal being cited as a common issue.

Equality within the process to get work was raised. We heard that people would like to work but just don't know how, or where, to go for information. It was felt that the interview process was not accessible for many, and this disadvantaged them.

Members of the autistic community talked about applying for jobs that they could manage with their anxiety but being rejected as they were overqualified.

One person explained they felt there was "prejudice against people with learning disabilities. Better education for people with learning disabilities is needed: many people can't read because they haven't had appropriate education. When they are older people assume they can't read (or can't do other things) because they have a learning disability - actually that is often not the reason. Not every difficulty/problem I have comes from my learning disability - but everyone assumes that's the reason I can/can't do certain things". It was felt by participants in the group discussions that placements are made based heavily on a needs basis and didn't work to individuals' strengths and interests.

This connected with the reoccurring theme of being underestimated and not feeling valued. We heard that individuals with learning disabilities and/or autism often worked with very little or no financial benefit. The main responses to what could be better about work was "I got paid" and "being paid what I am worth".

"I need to be able to do the things I'm good at, that I enjoy and not pretend to enjoy serving people"

CASE STUDY ONE

We heard from one carer how the adult they supported worked in a café regularly each week. He enjoyed attending the café and getting to meet and talk to people. The family thought elements of the support were good, he was safe and happy but had concerns around the financial arrangements.

The organisation received financial recompense from paying customers but there was no financial or other form of reward for the individuals working there. It also became evident that the family were having to pay the café for their son to attend.

There was a lot of discussion in the group about this situation. While everyone could understand the financial costs of running the scheme and that it might be challenging to pay the individual, they strongly felt there should be some benefit.

The main conclusions from the discussion included:

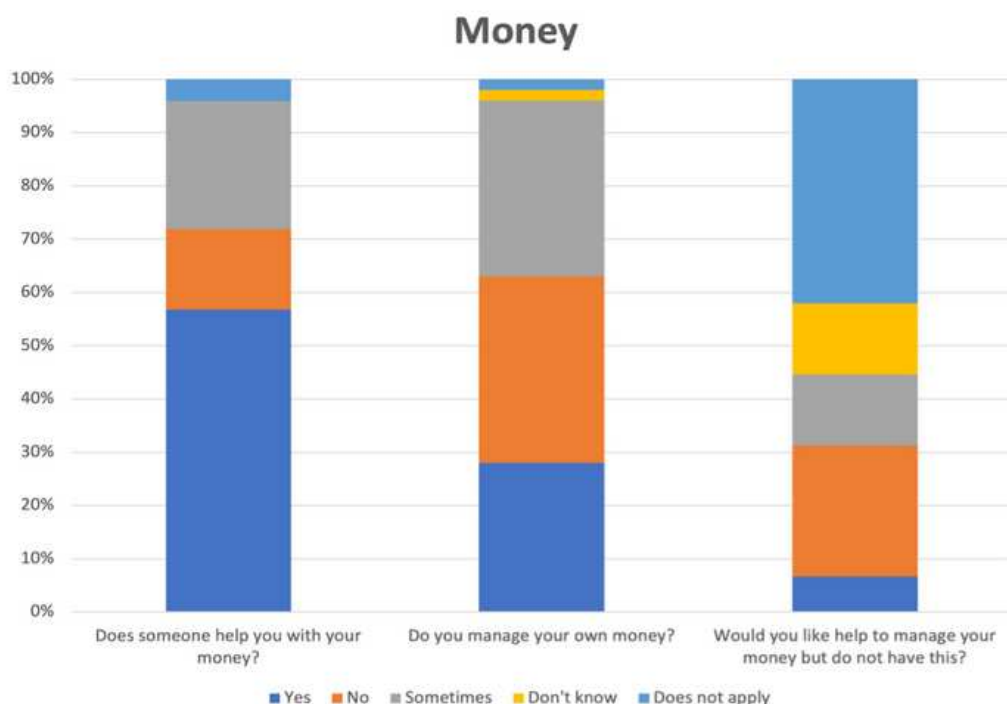
1. this was unpaid work not volunteering
2. unpaid work and volunteering should support the development of skills to help gain paid employment
3. unpaid work and volunteering should be reviewed to ensure the person is not being taken advantage of
4. it is morally wrong to be charging the family for the individual to work



FINANCE

81% of respondents said they have some help to manage their finance. Most of the support is from family members, with some getting help with day-to-day purchases from support workers.

19.5% also reported that they would like support but do not have access to it. Accessible information about finance and benefits was lacking for a lot of individuals, this includes basics like how to get a bank account. A large volume of concern was expressed about managing money and budgeting, several people expressed that money was tight, benefits were very low and there was concern about running out of funds. Carers and support workers expressed concern over the level of funding which was being used on care by individuals. This was especially the case for those that just missed the criteria. We heard about individuals that can no longer afford to pay for care and therefore no longer have any care in place.



"School should teach us how to live and use money correctly not how to measure the inside of a triangle."

FINANCE CONT....

“These assessments need to merge into one and money needs to stay constant. I have temporarily lost my PIP because I'm being assessed, and it was awarded by a court tribunal last time”.

Respondents felt there is a lack of understanding about the mental capacity act across the whole system. Comments indicated that appointees were not always aware of what they are required to do and survey comments included references to gatekeeping and being denied access to money.

The benefits system is hard to navigate, assessments need to be streamlined and quicker. We heard about the knock-on impact of benefit issues and gaps in access to money while these issues were being addressed. Many felt that the Department for work and pensions were not helpful and did not understand

We also heard about the difficulties that were face by individuals with physical needs Although able to manage money and budgeting the transactional part of purchases needed to be managed by family, the respite home or direct payment workers. No one was able to find a way they could physically pay for things with a card. Banks need to cater for people with physical disabilities who use AAC and who need PAs to help them with a payment card.

Practical suggestions about how things could be improved included:

- combining assessments
- access to easy read information
- training for staff on working with people with learning disabilities
- guidance on managing money
- Household budget MOT's



CASE STUDY TWO

X related the experience of claiming Personal Independence Payments (PIP). Right back from the time of being at school discussions had taken place that X may have autism and a learning disability. This was further explored when X returned to education as an adult and subsequently X was diagnosed with autism, dyslexia and other learning needs.

X's health has got worse over the years and now X requires help to complete day to days task. It was suggested by the GP and others that X should apply for PIP. An application was made, and X received a call from the Department for Work and Pensions which later turned out to be an assessment over the phone.

X received the decision that awarded 0 points and everyone working with X was confused how this was the case. X appealed for more time to submit further evidence due to extreme family circumstances and this was granted. With help X submitted evidence of need and clarified the misunderstanding that had taken place e.g., X had responded that X liked to spend time in the garden, and this was recorded as being able to undertake heavy manual work – not potter around and water pots on good days. Within a few days the DWP responded and upheld their decision.

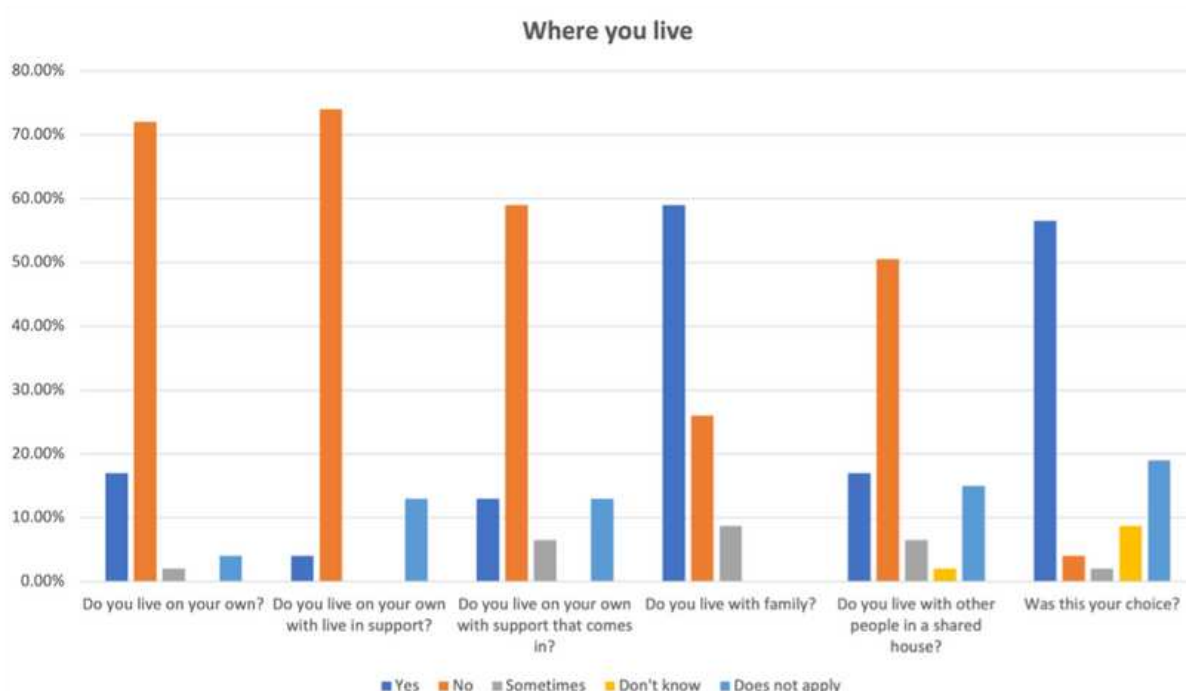
With help from Citizens Advice X logged a case at tribunal and upon the case being heard an award was made in recognition of X care needs. This was backdated for over a year. During the year X had to do without the care that X needed while the process went through. In addition, the stress caused X to be hospitalized and has left ongoing additional health needs.



HOUSING AND INDEPENDENT LIVING

68% of respondents currently live with their family either some or all the time, while 30% reported living on their own or with others with support. We heard some positive examples of how people have wanted to live on their own and how they have been supported to get a flat in a shared building. We also heard how shared accommodation, including sharing of roles such as cooking, and cleaning was working well for some.

Care staff told us it is essential that people with learning disabilities and autistic people are able to stay in the same community. If they are rehoused it takes a long time for them to get to know people around them. During the provider group it was reported that they felt things had started to improve and that housing generally understand the importance of an autistic person or a person with learning disabilities being able to stay in the same community if being rehoused.



"ALTHOUGH I HAVE A FLAT TO MYSELF THERE ARE OTHER PEOPLE IN FLATS AND THE MAIN HOUSE IN THE GROUNDS. I REALLY LIKE THE MIX OF INDEPENDENCE AND COMPANY NEARBY. THE ONLY DOWNSIDE IS THAT EVERYONE ELSE IS MUCH OLDER THAN MEANS I ONLY GET TO SEE PEOPLE MY OWN AGE WHEN I GO OUT E.G. TO COLLEGE"

HOUSING AND INDEPENDENT LIVING CONT....

58.5% said where they lived was their choice, but comments revealed that this was often because it was easier than trying to get the right support in place to live independently. Barriers included:

- Difficulties in expressing their feelings about housing needs to decision makers.
- Lack of consistency in paid support staff.
- It was better to stay with family due to not knowing staff even though not ideal.
- Unable to manage on own so had to stay with family.
- Not knowing how to go about living with friends or on their own.
- Cost of living on own was too high.
- Financial impact on the wider family.
- It was reported that supported independent living in Sedgemoor now only for over 65's

There was evidence that housing arrangements were having an impact on wellbeing. The location of the housing was an issue and we heard that people were unable to get out and about due to lack of transport options, which impacted on the ability to spend time with friends. We also had responses which indicated that a least one person had recently had to sell their house to pay for care, and another felt they had been lucky as a successful legal case was allowing them to pay for their care.

With a large proportion of people living with family we wanted to understand the impact of this. One adult told us “I would like to move out of my family home because it is bad for my mental health, but I don't feel I have the support I'd need to do that as I can't manage everything on my own (mainly phone calls, appointments, etc.)”.

We heard how carers have often given up work to be able to manage the full-time caring role. The costs of caring have been identified by national research as being between an additional £581 to £1000 to have the same standard of living as a family with a non-disabled child (Scope, Uk 2021).

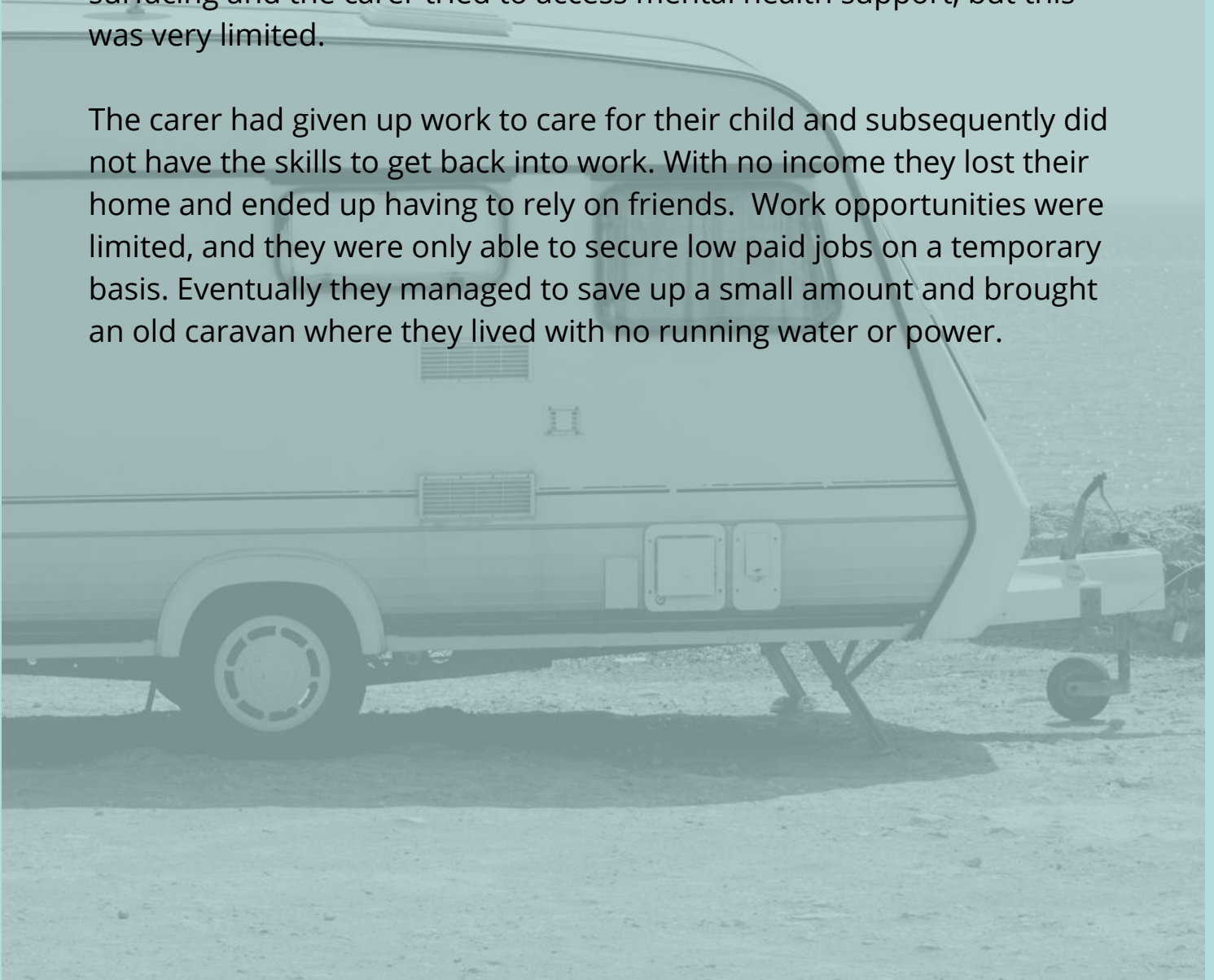
The financial contribution from benefits often becomes essential to maintaining the household budget during the time the child is growing up. Once the child reaches adulthood there can be concerns about the impact financially of them leaving home, and often carers feel they have lost the skills needed to work, cannot have the time to retrain, or are too exhausted from caring.

CASE STUDY THREE

One of the professionals related the experience of a young person with disabilities moving into independent accommodation with carer support. The young person had adapted and after a transition period had settled into their new life.

However, the impact on the carer was not positive. Initially the young person was overwhelmed, and this led to a period where the carer had very little contact. Going from being a full-time carer to having limited interactions was emotionally hard. This led to mental health needs surfacing and the carer tried to access mental health support, but this was very limited.

The carer had given up work to care for their child and subsequently did not have the skills to get back into work. With no income they lost their home and ended up having to rely on friends. Work opportunities were limited, and they were only able to secure low paid jobs on a temporary basis. Eventually they managed to save up a small amount and brought an old caravan where they lived with no running water or power.



ACCESS TO SUPPORT

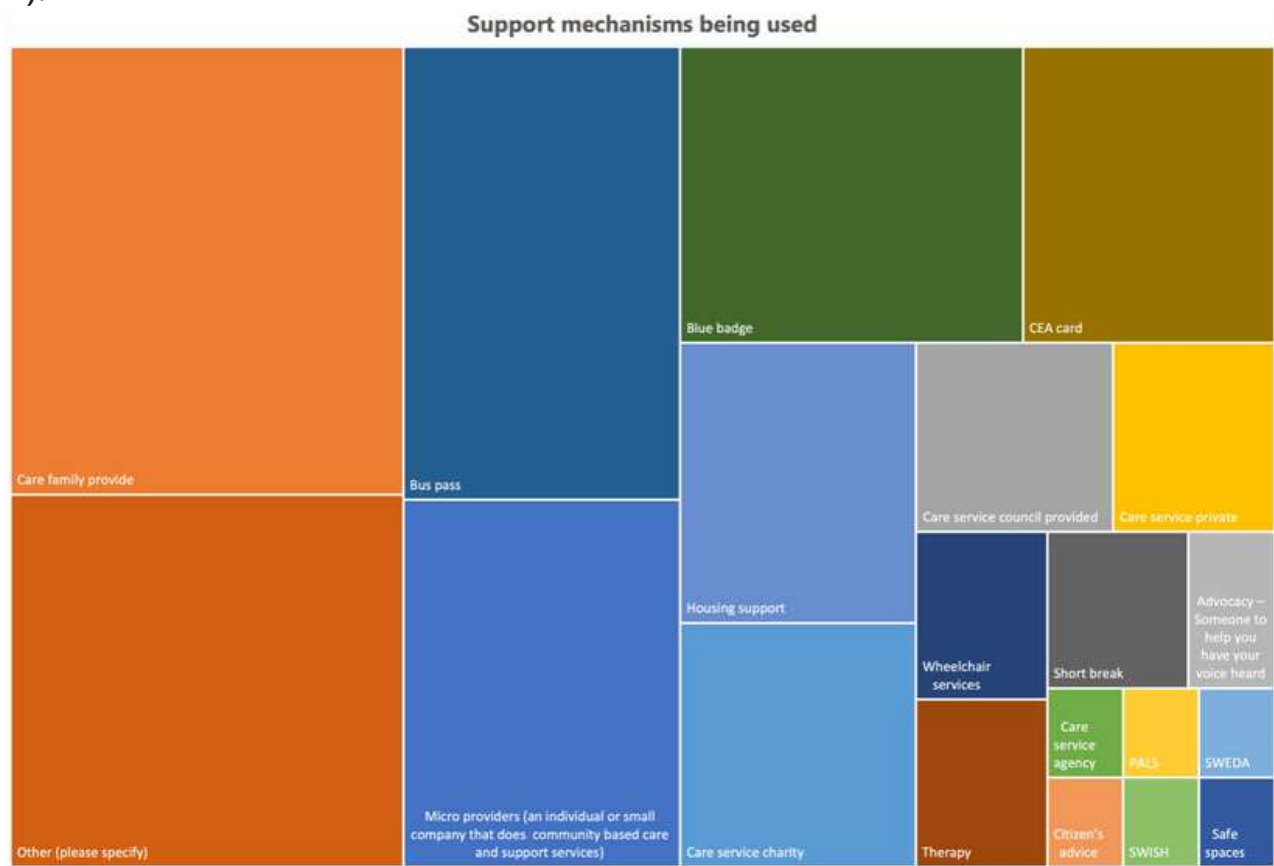
In 52% of survey responses care is being provided by the family, this aligns with feedback via the other consultation response options. Care arrangements outside of the family was a mixture of:

- 30% micro providers
- 17% charity care services
- 11% council provided care services
- 9% private care services

Living in a rural county transport can be challenging for many and as mentioned previously it can have a large impact when mixed with housing arrangements. The South West has a slightly higher number of blue badges, at 2% of the population compared to nationally 1.7% (gov.uk 2021).

30% of respondents had a blue badge under the scheme and several were in the process of applying, support workers helping with the process. We heard that it is not always straight forward and further assessments are sometime required.

This is in line with the national data, which indicates the South West is likely to request further assessment in 65%, slightly higher than the average for England at 58%. 37% of respondents had a bus pass to help them with getting around.



ACCESS TO SUPPORT CONT....

Organisations identified as providing support included Discovery, Our Voice and Open Story tellers. We heard the quality and consistency of support was often dependent on individuals rather than services. Over the last few years Somerset has invested significant funding into village agents, and have established community connectors, but throughout the consultation no one identified these as a support mechanism they have used.

Repeatedly the phrase “there just are not any services for us” was used.

The lack of information about what is available was a common theme that came up throughout the consultation, with people saying they didn’t know what services did and that they could use them. Somerset Direct was mentioned as not always being helpful and the community connect website was deemed to be unfit for purpose by many users, including providers who were unable to put their records onto it and often just gave up. Micro-providers have said they don’t want to use the site as it looks unprofessional and is not managed well so is often out of date.

Reports into the national trends in social care stated that “demand was increasing but receipt of long-term care was falling.

Between 2015/16 and 2019/20, 120,000 more people requested social care support but around 14,000 fewer people received either long- or short-term support” (Bottery and Ward, 2021). Means testing is getting harder due to thresholds not rising in line with inflation. Therefore, it was not a surprise that barriers to support fell into 2 main categories, 1- unable to meet the criteria and 2- funding issues.

“Support seems to only be available for people who are very “low functioning” or whose families advocate for them, but not all families care or want to help and not everybody can advocate for themselves even if they appear functional to others”
– survey response

ACCESS TO SUPPORT CONT....

Concerns were raised around the use of IQ testing and that often people they meet had just missed the IQ threshold but still required support with daily tasks. If they don't meet the criteria, then they had to fund care themselves and this risks inequality across the area.

Carers of young adults stated that if a young person is doing well e.g., in college then often the support is withdrawn and then they struggle, feels like they are set up to fail. There was also several example of how an autistic person can be academically able but unable to manage day to day tasks.

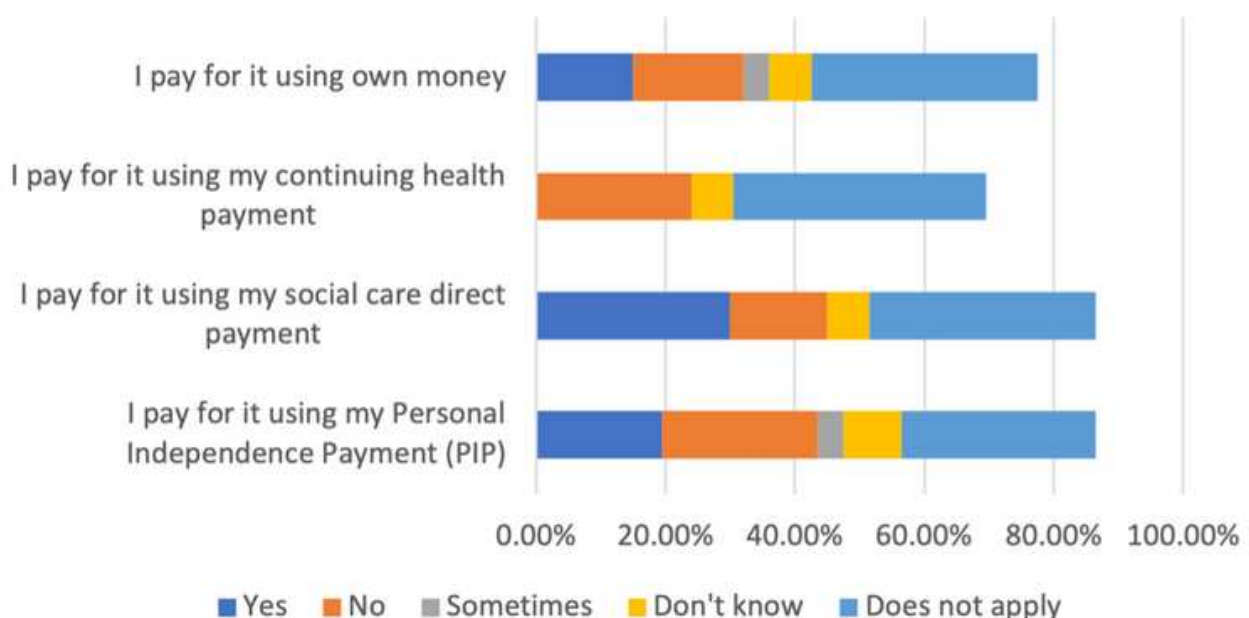
Financial support was seen as poor in Somerset. 43% of individuals reported using their own money or benefits to pay for care compared to 30% using social care funding and 0% using health funding.

We heard a lot about how care was being funded by family members or the individuals were using all of their money to cover basic care needs.

Support that was identified as needed locally included:

- More things to do
- Increased amount of support
- Support for days when not in college, volunteering etc
- Someone to talk to about anxieties
- Support with travel
- Someone to help me go out with friends
- Streamline processes which are easier especially direct payments
- Micro providers to start working with people at an earlier age

paying for support



A background image showing a group of people's hands and faces in a circle, looking down at the center. The image is faded and serves as a backdrop for the text.

CASE STUDY FOUR

A local micro provider supporting a 30-year-old lady with learning disabilities and autism reported how the group she had been attending regularly had said she could no longer attend due to age. The lady received a care package and her family had been topping this up to enable her to have the care she needed.

Due to the group no longer being available, the social worker visited to review the package and help with finding an alternative. After 2 visits the social worker 'gave up' and the care package eventually ceased.

The lady with learning disabilities and autism no longer has support and is not attending anything which allows her to mix with others.

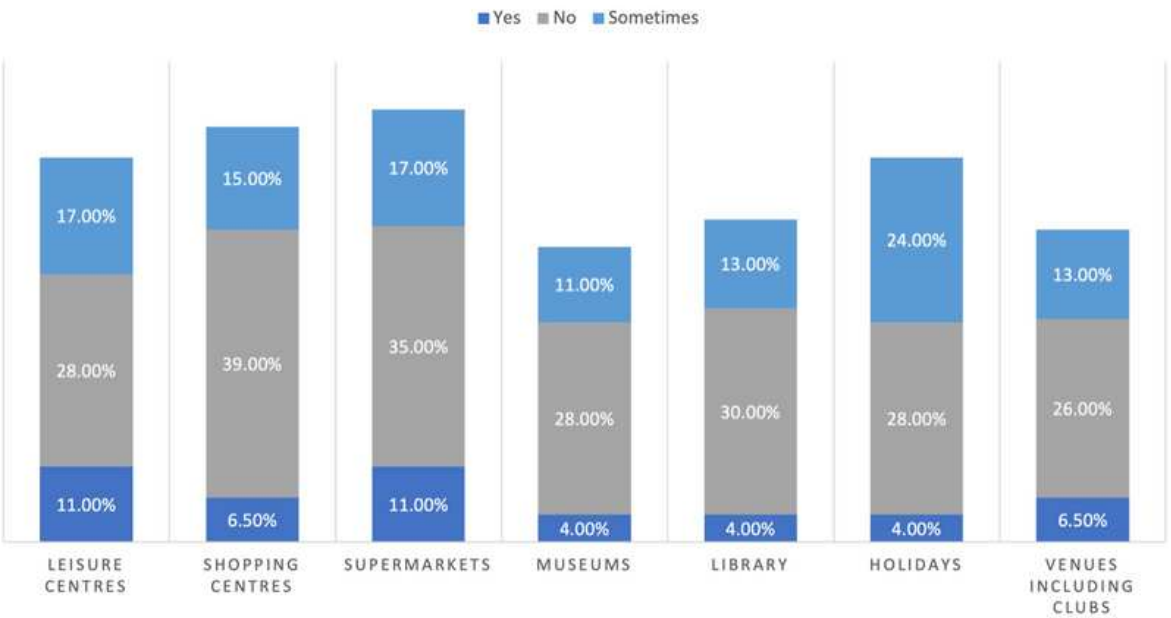
ACCESS TO COMMUNITY AND FREE TIME

As part of the consultation, we wanted to understand if people with learning disabilities and autistic people felt included. Research has repeatedly shown that wellbeing and resilience depends a lot on being involved with other people, the local community and ordinary life; in other words, connected (SCIE 2021).

We heard from many respondents that they felt isolated, and they felt they were spending too much time alone. Similarly, carers reported feeling isolated, this included spouses who often did not identify as a carer. Very few people were aware of provision in the community that made adjustments for their needs. The main things that people were aware of were quiet hours at supermarkets and some leisure activities allowing carers in for free.

Timing of accessible sessions are not always at a suitable time for people, and it felt like a done to model, as times were picked without speaking to those it was meant to help. One respondent made the point that quiet hours are “normally very early before 10am. So not always accessible for those that needed it. It takes some of us longer to get up and wake up enough to go out due to medications etc.”

There was a large variance in provision across Somerset, for example Yeovil leisure centres were reported as being supportive and allowing carers in for free, but Mendip charged double as they argued they would be losing money by having a carer take up a paying space.



ACCESS TO COMMUNITY AND FREE TIME CONT....

A major issue which was raised was around the access to changing places. Often the distance between them is long. We heard about families, who went to areas like Minehead, having to travel back to their home to provide care, as that was the nearest place.

The lack of information about what was available to do was raised repeatedly during the consultation. Everyone whether a paid, unpaid carers, individual with learning disabilities or an autistic person all agreed there is lack of things to do.

Although it was acknowledged that it was challenging before the pandemic, it appears to have got worse. The micro providers we spoke to said they would love more clubs to be available so they can take their clients to them, often they said they end up in a café as there was nothing else to do.

When asked what would be useful, we heard they wanted access to a space they can just drop into when they don't want to be alone or feel anxious. We were told by several people "I don't think there are any safe spaces in our local community where I could go".

"People can be afraid/prejudiced/patronising/abusive when people with LD access groups or other leisure activities that are open to the general public. It's horrible but it's true. We should be able to access choirs/ painting classes/ yoga groups/ etc that are open to the general public (not merely the narrow range of clubs set up specifically for people with LD). Segregation is bad".

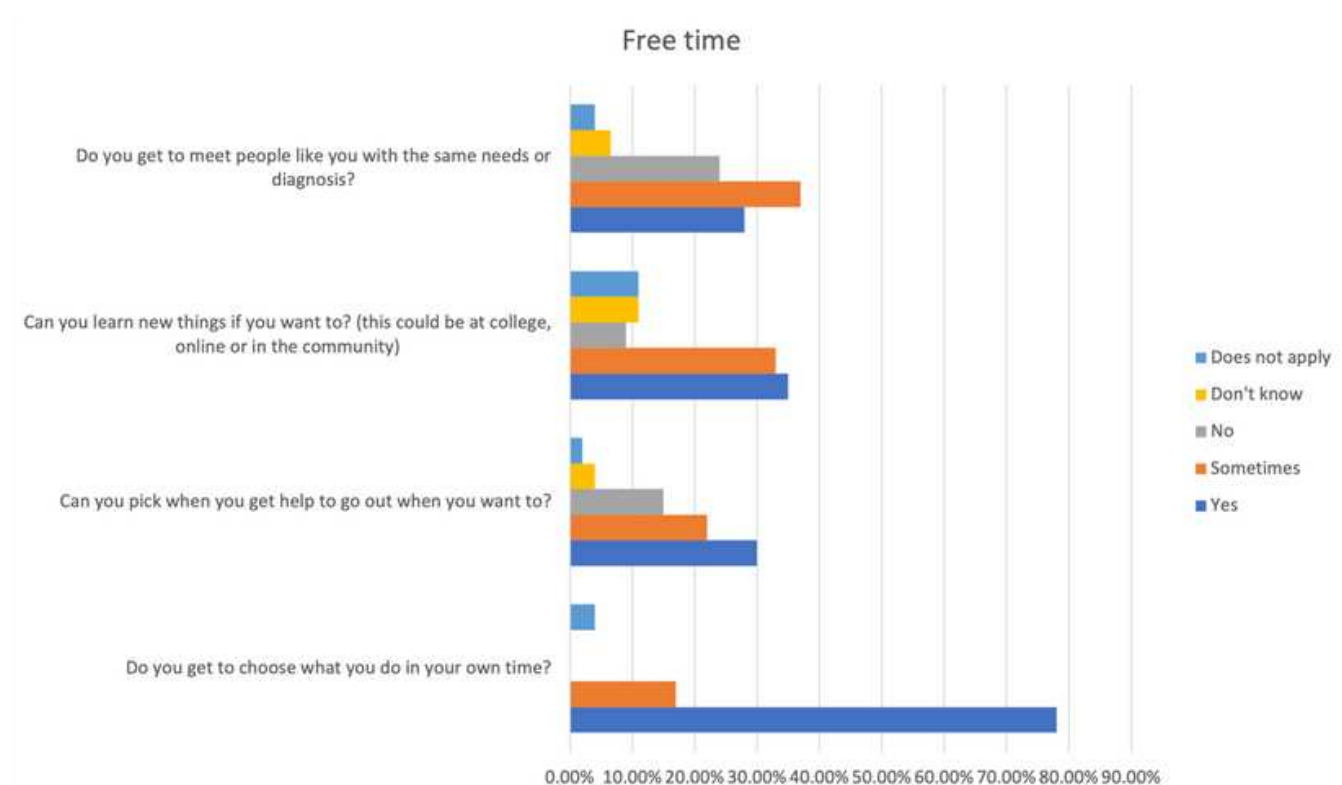
There was discussion, through the groups and in the survey, about what is open to young people verses adults. Examples were given of inclusive sessions run by organisations, like Nova sports and SASP, and there was a desire for this type of activity to be opened up to adults with learning disabilities



ACCESS TO COMMUNITY AND FREE TIME CONT....

Only 35% of respondents said they were able to choose when they received support to go out. Barriers to be able to do this mainly centered around the requirements of the company providing care or the ability to get transport.

For example, we heard that young adults were going home at 8pm so the carer could get them ready for bed. At the provider session we talked about organisations in urban areas, such as the Stay Up Late organisation, and how micro providers could be used to support this as they often are more flexible around working hours.



There was also an element of protection, which was impacting on what people with learning disabilities and autistic people can do. The provider session discussed that they see a belief that they should be completely protected from any level of risk. The lack of sexual health support could also be evidence of a protective bubble being placed around this group. While we wouldn't want to expose anyone to harm, there is the reality that most people make bad choices, and we learn from them.

One young adult, in the 18-24, age group stated a barrier to them being able to spend time with their friends is they "work and their friends' parents won't let them, even though they are adults".

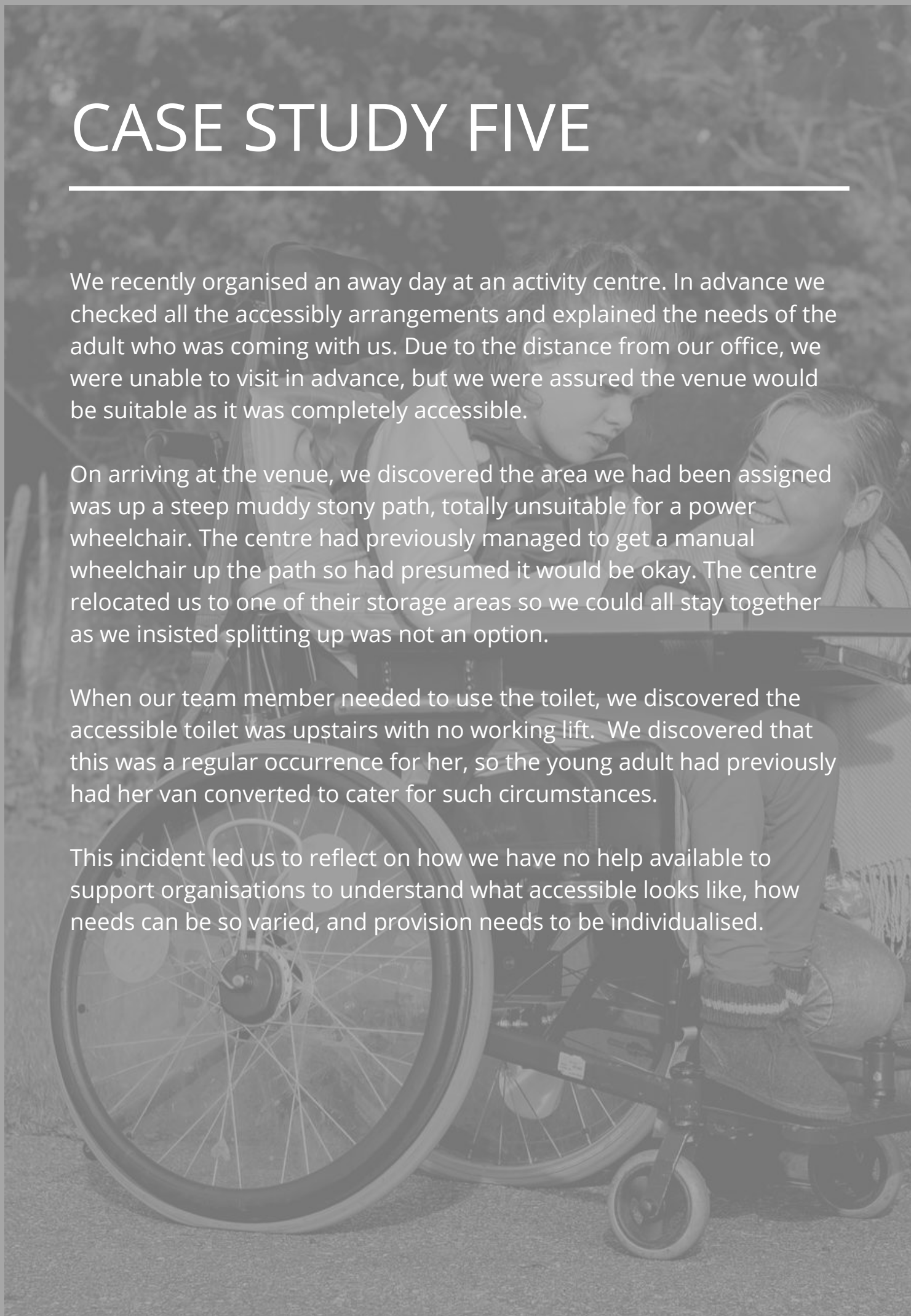
CASE STUDY FIVE

We recently organised an away day at an activity centre. In advance we checked all the accessibility arrangements and explained the needs of the adult who was coming with us. Due to the distance from our office, we were unable to visit in advance, but we were assured the venue would be suitable as it was completely accessible.

On arriving at the venue, we discovered the area we had been assigned was up a steep muddy stony path, totally unsuitable for a power wheelchair. The centre had previously managed to get a manual wheelchair up the path so had presumed it would be okay. The centre relocated us to one of their storage areas so we could all stay together as we insisted splitting up was not an option.

When our team member needed to use the toilet, we discovered the accessible toilet was upstairs with no working lift. We discovered that this was a regular occurrence for her, so the young adult had previously had her van converted to cater for such circumstances.

This incident led us to reflect on how we have no help available to support organisations to understand what accessible looks like, how needs can be so varied, and provision needs to be individualised.



SUPPORT TO BE HEALTHY

“People with a learning disability are more likely to have physical health problems, such as obesity and diabetes. Certain kinds of learning disability, such as Down’s syndrome, can make people more vulnerable to respiratory infections, which can increase their risk of dying from COVID-19” (LGA 2021). During the last 18 months access to health services has often had to be remote via online platforms, despite this 74% of respondents felt they were supported to look after their health needs all or some of the time. Highest levels of support came from family, doctor and optician.



General Practitioners (GP'S) were seen as being good and supportive, with regular health checks helping to manage diet and weight, being seen as useful. It worked especially well when you are able to see the same person.

Some people liked the ability to manage prescriptions online, and having them sent to the house was working well, because they didn't need to physically go to the surgery.

Only 28% of those taking the survey felt they had support to look after their sexual health needs, this was very low compared to all other areas. We heard that this may stem from a misunderstanding that people with learning disabilities do not have sex. Young adults with learning disabilities told us that often they are spoken to like young children and are seen as much younger than they are.

SUPPORT TO BE HEALTHY CONT....

"I get plenty of support for my health from my family and if I need help from doctor/ dentist then I can get that although the dentist has to be a private dentist as the special needs one moved 15 miles away and I need to be local"

Although 79% of respondents stated they help to manage their wellbeing, access to specialist mental health support was seen as difficult to get. Responses from several people indicated they felt they would benefit from a counselling service and services to understand mental health needs. AuSomer stated that "levels of autistic people reporting anxiety and depression are at high levels. Mental health services won't help due to the diagnosis of autism, and there is no support or help to live with these issues".

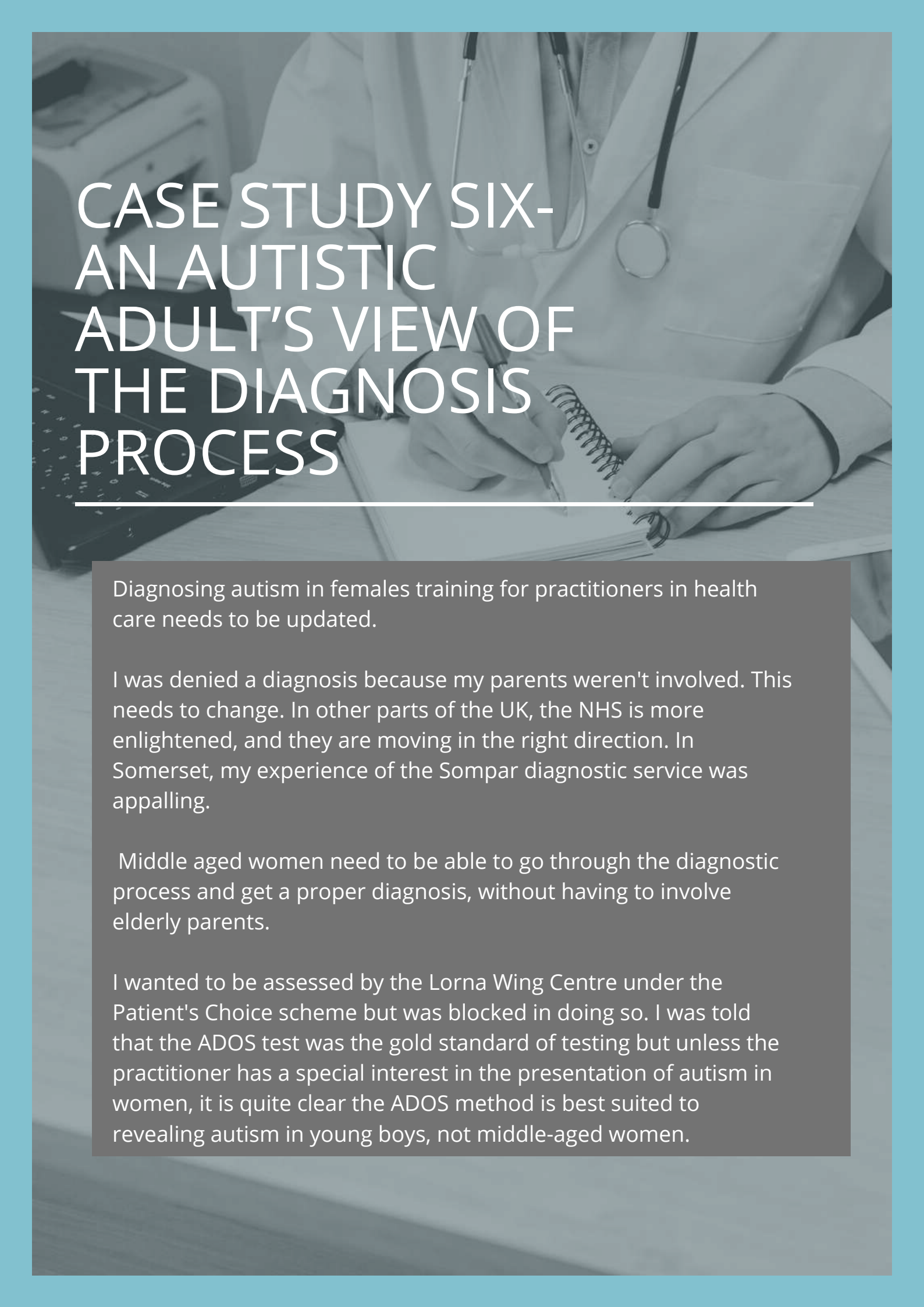
Carers and care workers also reported that support from the mental health team was not happening, stating the "mental health team is no good".

An increase of training and awareness raising for everyone in mental health, and condition specific training such as autism and ADHD, was seen as vital if improvements are going to be met. There was specific reference to cases of bullying from government departments and local authority staff, which it was felt had resulted from a lack of understanding.

"For training to be effective training needs to be delivered by people with lived experience, not people who know about Autism from a book."

AuSomer representative



A grayscale photograph of a medical professional, likely a doctor, wearing a white lab coat and a stethoscope. They are seated at a desk, writing in a spiral-bound notebook with a pen. A calculator is visible on the desk to the left. The image is overlaid with a semi-transparent dark gray box containing white text.

CASE STUDY SIX- AN AUTISTIC ADULT'S VIEW OF THE DIAGNOSIS PROCESS

Diagnosing autism in females training for practitioners in health care needs to be updated.

I was denied a diagnosis because my parents weren't involved. This needs to change. In other parts of the UK, the NHS is more enlightened, and they are moving in the right direction. In Somerset, my experience of the Sompar diagnostic service was appalling.

Middle aged women need to be able to go through the diagnostic process and get a proper diagnosis, without having to involve elderly parents.

I wanted to be assessed by the Lorna Wing Centre under the Patient's Choice scheme but was blocked in doing so. I was told that the ADOS test was the gold standard of testing but unless the practitioner has a special interest in the presentation of autism in women, it is quite clear the ADOS method is best suited to revealing autism in young boys, not middle-aged women.

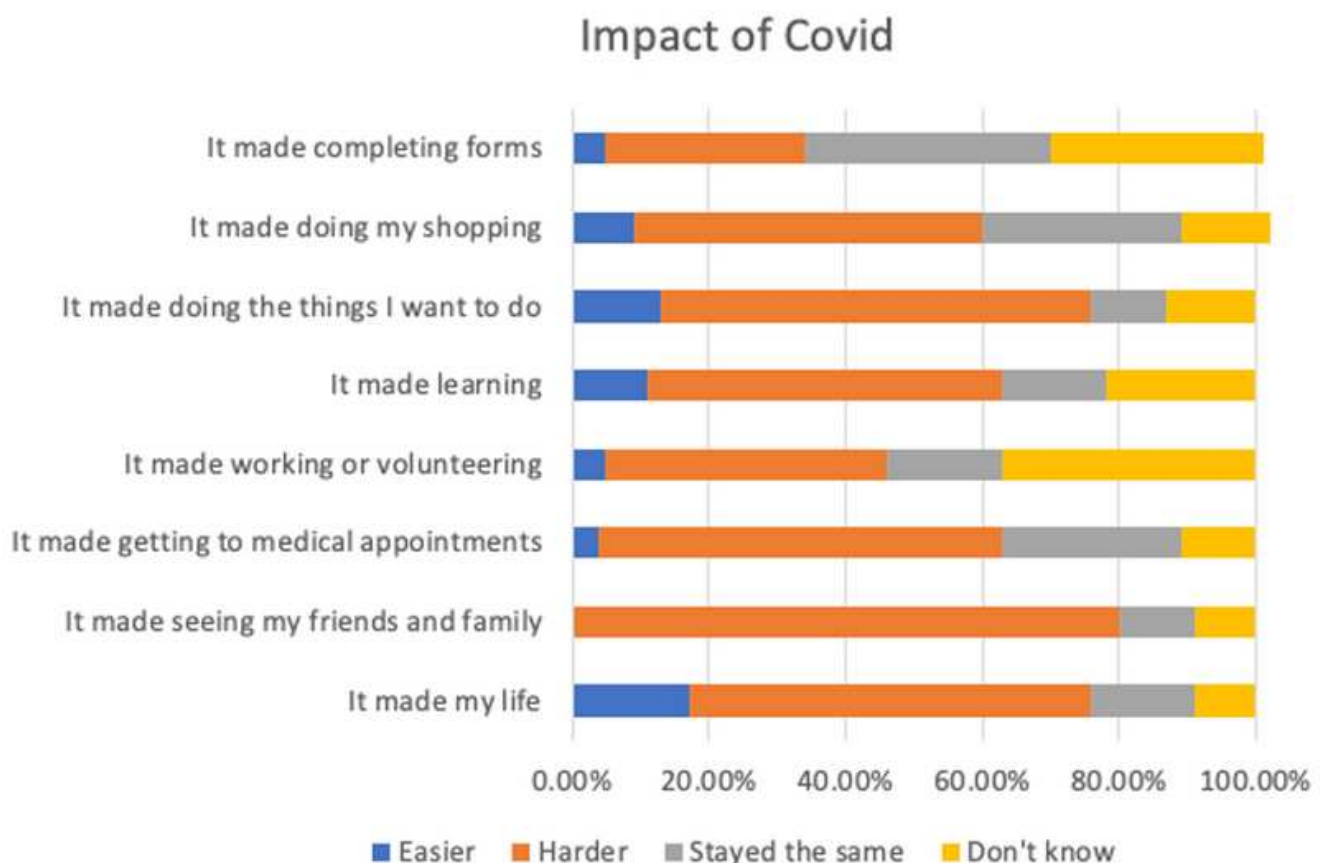
IMPACT OF THE COVID PANDEMIC

Life has changed for everyone during the covid pandemic, but even more so for people with learning disabilities. The loss of routine, activities, and contact with family and carers was often confusing and distressing.

People told us that the changes to normal activities caused upset and anxiety for them. Groups tried to minimise this and made changes to normal provision, such as from outdoor activities to small groups craft session, to keep something available.

While some individuals have found that it was easier as they have not had to interact with people, most people are reporting that things are harder.

Those with a caring role told us that they had to pick up a large volume of the care during the pandemic, and often felt isolated and abandoned. Similarly, those being cared for felt forgotten. This has led to significant anxiety and reinforced the feelings of isolation.



IMPACT OF THE COVID PANDEMIC

CONT...



Many organisations told us how they had to shut over covid, as the requirements made it not viable to continue. For smaller voluntary run groups, the risk assessments and additional covid measure were really hard to implement and these closed. As part of the stakeholder mapping, we found that around 15% of organisations were not open or planning to reopen and this is impacting further on having things to do during free time.


Organisations that have reopened are reporting declined numbers, with the underlying cause being the level of anxiety about coming back out and returning to a level of normality. At the provider session we discuss how this will need to be supported and the challenge this will create with funding. For groups to do this there will need to be a higher ratio of staff and/or smaller groups.

Historically it has always been challenging to get funding for activities that support small groups, and this is a potential barrier which will prevent activities running as groups will need to remain small to help people manage their anxiety.

Throughout the consultation access to information has been highlighted as a weakness, however, we were told there has been lots of good easy read information to explain what COVID is, and all the rules what you can and can't do etc. We need to review this and how we can use these approaches more widely to improve access to information across the system.

"It was shocking that vital services were deemed non-essential and simply not provided for so long - we felt pretty much abandoned."

CASE STUDY SEVEN



We spoke to an organisation who had made the decision to close for a significant period due to the covid pandemic. Although they had been able to use the furlough scheme, they had lost money and when they reopened had to do so with a significant reduction in staffing. We discussed the frustration of planning to reopening and then having to change plans at the last minute due to national changes.

People are nervous to come back out, but things are starting to pick up. While it's not as busy there is additional work including significant cleaning down required between users and this reduces the amount of people they can have in and therefore money coming into the business.

We discussed clubs and activities which has previously been run and how these had needed to stop as funders were expecting high take up between 30-40 when the level of needs realistically meant it was only safe to have 10.

USING TECHNOLOGY

During the last 18 months the use of technology has become the default model for lots of services. Internet access has become essential to be able to access health appointments, work, learn and to access basics like food.

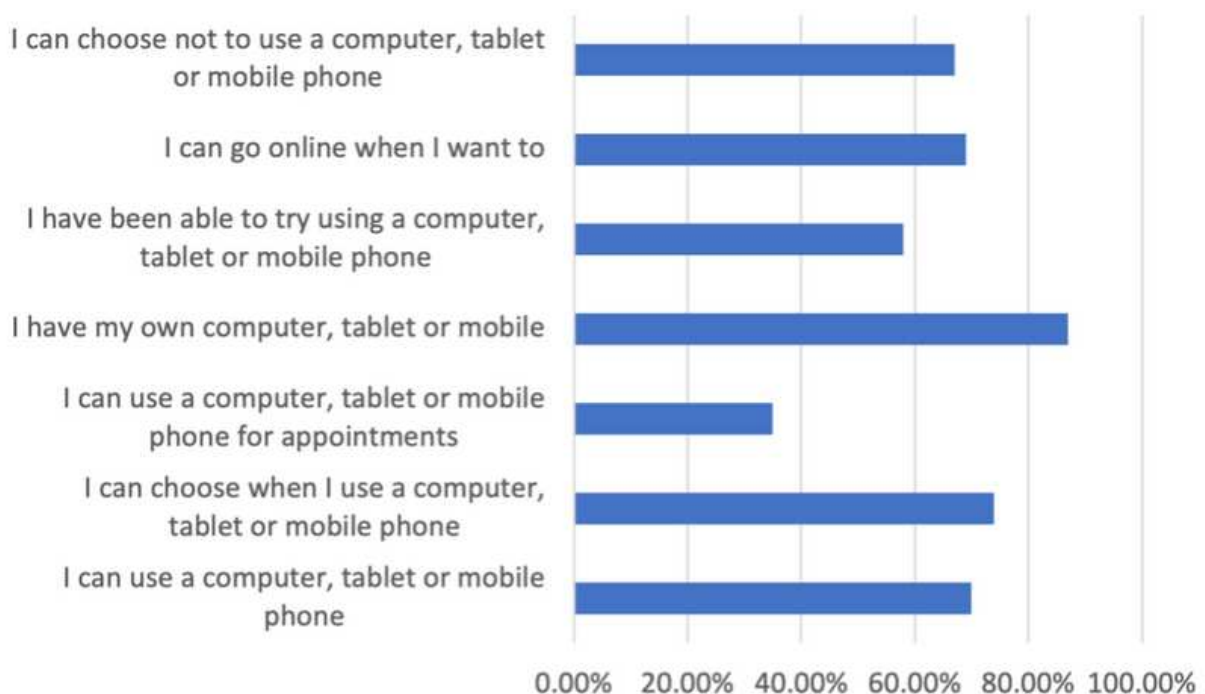
The consultation has shown that due to lack of access to work, the need to pay for care needs and benefits not matching the rate of inflation many are reporting that they are struggling financially.

Researchers at Cambridge University state that “the likelihood of having access to the internet from home increases along with income, such that only 51% of households earning between £6000-10,000 had home internet access compared with 99% of households with an income of over £40,001. The link between poverty and digital exclusion is clear: if you are poor, you have less chance of being online (Holmes and Burgess 2021).

“It is essential for me to have face to face or in person support as the reliance of meeting people online for the last year has affected my mental health negatively and I don't find it very useful.”

Only 35% of respondents reported being able to use a computer, tablet or mobile for appointments and 31% were not able to go online when they wanted or needed to. Being able to access the information online was also a barrier for many and they needed help to understand it. We heard that often access to services was limited to one form of contact and this did not work for everyone.

For example, online or phone access was often seen as overwhelming and a barrier with people wanted to be able to text or email. Lots of people told us they had to use a phone, and this made it impossible to look at lots of information or to complete forms. Individuals who are confident in using technology reported finding platforms like teams or zoom overwhelming especially if there were multiple people involved.



CASE STUDY EIGHT

As part of the consultation were heard from individuals who it might be presumed would not struggle with technology and appear to be able to use this confidently. Their insights on how our reliance on technology for many things impacts them are captured below:

"I have a tablet for AAC mounted to my chair, but my physical access needs mean I have not really been helped to learn to access the internet, use a computer functionally, the computer is central to my life and is my main way to access the world but there is a long way for me to go to be able to use it for so many things"

"I love technology. The last year has made technology even more important in all our lives. However, I find zoom meetings, or Team meetings extremely difficult and tiresome in a group. They are extremely stressful for me. One to one is ok."

"It is essential for me to have face to face or in person support as the reliance of meeting people online for the last year has affected my mental health negatively and I don't find it very useful."



CONCLUSION

The review of the local provision for individuals with a diagnosis of learning disabilities and/or autism, will help to shape the community fund to ensure it reflects the local needs.

We know the demand for care will continue to grow over the coming years and it will be essential that a robust strategic plan to meet the needs of individuals with a diagnosis of learning disabilities and/or autism, which places them at the heart, is implemented.

The report has highlighted areas of provision which need to be improved for individuals with a diagnosis of learning disabilities and/or autism. While some of these are outside of the remit of the Community grant funding, there are many things which the grant can support which will impact positively on the quality of life of this group.

Throughout the consultation we have heard clear messages about what our community needs. The key to the success of the funding is contingent on listening to and involving individuals with a diagnosis of learning disabilities and/or autism.



SOMERSET PARENT CARER FORUM CIC

Somerset Parent Carer Forum C.I.C
www.somersetparentcarerforum.org.uk

Company No: 10227489

Unit 2, 32 Goldcroft, Yeovil. BA21 4DH
Email:admin@somersetparentcarerforum.org.uk

Tel: 01458 259384

Somerset Parent Carer Forum C.I.C is an independent not for profit Community Interest Company formed by parent carers in 2016. The directors of the forum are all parent carers themselves and we are advised by a steering group who is made of up parent carers in Somerset.

The forum feels passionately about ensuring all our children and young people have the best chance in life and receive the correct support and services in order to achieve their full potential. Our company strongly believes that it is only by listening to those that use services can we improve their experience and ensure they are getting the best opportunities in life.

Our three main aims are to:

Enable families to have a voice - we support the development of participation, a process in which service users work together with professionals to make improvements to local services. We act as a conduit for a wide variety of local professionals to work with children and young people with special educational needs and disabilities. We organise consultations, surveys, focus groups and events for people to come together and share their experiences.



SOMERSET PARENT CARER FORUM CIC

Enable families to have the information they need - Through our support groups, events, and telephone line we support our community in accessing the information they need. Our website has information on local issues such as education, health and benefits and family life.

Enable families to support each other - We organise local groups and workshops to bring parents carers together for practical and emotional support. We organise coffee mornings so parents can make new friends and socialise.





AUTISM COMMUNITY NETWORK C.I.C T/A AUTISM SOMERSET

www.autismsomerset.org

Company No: 7894336

Brentholme, Burton Row, Brent Knoll Somerset TA9 4BX

Email: allison.ward@autismsomerset.org

Tel: 07585906166

Our Aims, Founder & Directors

Our Founder Campbell Main set up Autism Community Network CIC 30th December 2011 <https://beta.companieshouse.gov.uk/company/07894336>. Trading as Autism Somerset the original website began life in response to the NICE

Guidelines <https://www.nice.org.uk/guidance/cg142> the Autism Act <http://www.legislation.gov.uk/ukpga/2009/15/contents>.

Autism Somerset's activities benefit individuals, their families and carers who are affected by the autism spectrum and comorbidities including Education, Health & Social Care agencies charged with supporting individuals, families and Carers.

We offer training and consultancy to Public and Private providers of that support., families, individuals, communities, schools and employers.



AUTISM COMMUNITY NETWORK C.I.C T/A AUTISM SOMERSET

Our aim is to build a '**community membership**' for those who come into contact with autism sharing a common interest in the wellbeing of those affected. We do this by enhancing awareness and understanding of the condition and its comorbidities. As part of our autism communication strategy, we offer a calendar of training, events and 1-1 coaching.

- Training and events are designed to facilitate opportunities for continuing professional and personal development for individuals, families and professionals alike.
- Our objective is to work collaboratively with agencies to inform, advocate and raise autism awareness while asking what is needed so we can signpost effectively.
- Our training courses are directed at raising autism awareness for parents, carers and professionals with workshops to improve emotional wellbeing, resilience, employability and mental health.
- In response to high anxiety in Autism we have developed a 12 Step Anxiety Program which leads to a continuing peer-support group.

On the 1st January 2016 Allison Ward, parent, trainer, and coach joined the team, sadly due to ill health Campbell resigned but continued to advise and advocate. On the 30th December 2018 Stephen Bradshaw joined us, with a successful career setting up and running special schools and residential care for both children and adults.

Our Newsletter reaches over 3000 readers, and we maintain a social media presence.

Appendix B – Stakeholder list/directory

Organisation	What the organisation does	Contact details
Discovery Day Services	<p>Discovery provides a range of activities for adults with learning disabilities and/or autism.</p> <p>They work together to provide activities that promote greater independence, confidence, self-esteem, choice and inclusion.</p> <p>People they support can access a range of activities including gardening, sports, games, cooking, arts and crafts, storytelling and going into town. Whatever the people they support want to do, they will do their best to make it happen.</p> <p>Whether someone needs only a few hours each week, or an intensive period to work towards a specific goal, their experienced staff members will support them to achieve their aims. And as the people they support develop their skills, they adapt their services to meet their clients' changing ambitions.</p>	<p>https://discovery-uk.org/contact/</p> <p>The Exchange Express Park Bridgwater Somerset TA6 4RR 0300 303 9013</p>
The POD POD Plus	<p>Pod Plus is a social club that meets every Monday night except for Bank Holidays at the RISE, Frome, BA11 3BY.</p> <p>The Young Adults who attend Pod PLUS have additional needs and are aged 18-30 years. The ratio of staff to members is 1:5, however there are members who attend with their own Personal Assistants.</p> <p>Activities are led by the members with a firm favourite being Casino nights & Zumba! Other activities have included cooking and arts and crafts as well as meals out and a horrible history tour of Frome. The group are always looking for ways they can engage in community activities.</p>	<p>RISE, Whittox Lane Frome, Somerset. BA11 3BY</p> <p>Nicki Tel: 07592 501022 (Pod Plus Lead Worker & Administrator)</p>

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<p>Blossom in Somerset</p>	<p>Blossom in Somerset provides opportunities for adults with learning disabilities to meet people and participate in new and fun activities in a safe and welcoming atmosphere.</p> <p>Blossom in Somerset offers a varied and exciting timetable of both stimulating and relaxing activities which are client led and suitable for the majority of disabilities. The activities are designed to improve social and communication skills and promote self-confidence.</p>	<p>Community Hall at the Baptist Church, St Mary Street, Bridgwater, TA6 3EQ</p> <p>Jo Huxtable – 07516 491797 Tracy Rolph - 07761 501322 Or email us – info@blossominsomerset.co.uk</p>
<p>Open Story Tellers</p>	<p>Open Story Tellers is a community arts charity supporting people with learning disabilities and autism. They help people to find their voice and use it, because stories are what make us human.</p>	<p>Open Story Tellers - RISE, Whittox Lane, Frome, Somerset, BA11 3BY.</p> <p>info@openstorytellers.org.uk 01373 454099</p>
<p>Compass disability service</p>	<p>Compass Disability Services is a customer led organisation and our Board of Trustees, who are elected by our customers, is comprised of at least 80% disabled people. We have adopted the <u>Social Model of Disability</u> as a way of working to remove barriers which exclude disabled people from equality of opportunity.</p> <p>Our Values and Beliefs</p> <ul style="list-style-type: none"> • We promote independence, choice and control • We support equality of opportunity for all people • We operate within and promote the Social Model of Disability • We aim to empower and enable disabled people • We promote equal access and inclusion to all services and facilities • We adopt a partnership working approach • We are a non-campaigning organisation 	<p>Units 11 - 12, Belvedere Trading Estate, Taunton, TA1 1BH. 01823 282823 info@compassdisability.org.uk</p>

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REACH alternative education	<p>REACH offers a variety of professional services to schools and services in the South West.</p> <p>They can provide a range of Youth Work staff to offer support, interventions and general services to students and young people. This can be in both one to one and group settings. Individual staff, or part / full teams can be commissioned on an hourly, daily or package price.</p> <p>Roles offered include:</p> <ul style="list-style-type: none"> • Alternative education provision • Youth work • Bespoke project work in or out of school <p>They offer flexible packages with no long referral processes or waiting times. All work is documented and a range of <u>testimonials</u> from a variety of agencies can be supplied upon request.</p> <p>Read more about REACH's <u>Alternative Education</u>.</p>	<p>07966 281959 info@reachyouth.co.uk PO Box 37 Martock, Somerset, TA12 6WN</p>
You first support services	<p>Offer individualised supported living services for individuals with learning disabilities in Somerset.</p> <p>THEY OFFER HELP WITH:</p> <ul style="list-style-type: none"> • Feeling good and positive about yourself • Learning new skills • Keeping your home clean • Going to clubs, groups, events and visiting family and friends • Supporting you with activities and hobbies you enjoy • Keeping you safe, during the day and at night • Taking your medication 	<p>You First Support Services The Salt Store The Great Bow Wharf Bow Street Langport Somerset TA10 9PN Telephone 0300 111 9999</p>

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	<ul style="list-style-type: none">• Deciding what to eat, shopping and then cooking your meals• Supporting you with eating your meals• Helping you make and get to appointments• Getting up and going to bed• Dressing and undressing• Washing and bathing• Using the toilet• Getting around your house and getting out and about• Support if you need to go into hospital and recover afterwards• Help and support to get well• Collecting your medication• 24-hour support• Managing your money and paying bills• Help at college or going to work• Practising your faith or religion• Going to the doctor and dentists• Looking at your housing options, support options and advocacy• Making choices about how you want to live your life• Looking for work• Maintaining your home• Living within your tenancy agreement• Supporting your goals, aspirations, and ambitions	<p>Email: admin@youfirstsupportservices.org.uk</p> <p>www.youfirstsupportservices.org.uk</p>
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Reach Respite Community organisation	Reach Respite is a unique day care service for adults with additional needs. The service they offer ranges from emergency day care respite to prebooked sessions	Email: reachrespite@gmail.com www.reachrespite.co.uk Call: 07850 096528
Enable support services	Based in Yeovil, Somerset they support people across Somerset. Their services are commissioned by Somerset County Council and Somerset Foundation NHS Trust and they work hard to provide the highest quality support. They work with a diverse range of people, including people with mental health needs, Asperger's Syndrome, Acquired Brain Injury and Learning Disability.	Call: 07487 581777 Email: info@enableandsupport.co.uk

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<p>Community Team for Adults with Learning Disabilities Bridgwater, Minehead, Sedgemoor and West Somerset</p>	<p>They assess a person's requirements and provide statutory care and support as needed for adults over 18. Their aim is to promote a person's wellbeing, independence, choice and control, with the support of a transitions worker for under 18s.</p> <p>They safeguard vulnerable adults who are experiencing abuse or neglect.</p> <p>They can provide a range of specialist health care support including psychiatry, psychology, speech, and language therapy, learning disability specialist nursing and occupational therapy to support people with a learning disability.</p> <p>They support a person who may be caring for someone and is not being paid to do so.</p> <p>They assist people through the provision of equipment, telecare, and housing adaptations. Depending on a person's needs, we also arrange the provision of appropriate accommodation, for example, independent flats, supported living and residential care.</p>	<p>Call:01278 454300</p> <p>Adults@somerset.gov.uk</p> <p>Parkway, Bridgwater, TA6 4RL</p>
<p>People First Peer support group for people with a learning disability – Yeovil.</p>	<p>A support group for adults with learning disabilities to;</p> <ul style="list-style-type: none"> • Have a voice about things that matter • Meet new friends and have fun • Get information and support • Gain new skills and confidence <p>They meet on a monthly basis on Thursdays from 1pm to 2.30pm in Yeovil Library.</p>	<p>office@peoplefirstdorset.org.uk</p> <p>01305 257600</p> <p>(3) Yeovil Peer Support Group Facebook</p>

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Dance class for people with learning disabilities in Ilminster	Inclusive dance classes for people with Learning Disabilities and their carers or support workers. £3 per session (free for carers).	Contact: Mathew England 01460 250915
Magdalen Farm	Magdalen is a 132-acre organic working farm on the banks of the River Axe where Dorset, Somerset and Devon meet. They offer flexible accommodation for small and large groups in their residential centre and traditional farmhouse. Good food is a big deal there - Their visitors can enjoy delicious home-cooked food from the farm's own kitchen and gardens.	01460 30144 info@magdalenfarm.org.uk
The Hub – Yeovil	The name says it all. The Hub. A place where people, ideas and practical solutions come together. A place where those with learning difficulties and autism get to meet, master new skills and move forwards. A place with a clear-sighted mission: To provide support and training to empower the lives of people with learning disabilities and autism, helping each individual achieve their own personal independence, support their community and work together, beyond disability.	hello@thehubyeovil.co.uk 01935 429277 https://www.thehubyeovil.co.uk The Hub Yeovil 13 Buckland Road Pen Mill Trading Estate Yeovil Somerset BA21 5EA

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Able 2 Achieve	able2achieve supports individuals with learning disabilities, mental health, and other associated disabilities. we support individuals in a variety of different ways from everyday living skills to attending social events such as concerts.	01935 429430 info@able2achieve.org.uk able2achieve Limited, 23-25 Princes Street, Yeovil BA20 1EN Registered in England and Wales 07111584 T: 01935 429430 E: info@able2achieve.org.uk
AuSomer	For Autistic Adults around Somerset, they will be having a variety of meet ups, from simply having a coffee and chat together to perhaps a more structured workshop where one of our members with a particular skill, might be keen to share this with others - they can support where necessary with either the equipment for a workshop or support to deliver it	office@ausomer.org.uk 0300 102 0412
EAQ Manor Farm	EAQ Manor Farm is an outdoor and equine-assisted learning centre set in 12 acres of beautiful Somerset countryside. They welcome those of all ages seeking acceptance, connection and nurture, personal growth and recovery. Children, young people and adults who are overcoming isolation, exclusion and social and emotional difficulties or who just love being outdoors amongst friendly people and animals find the space and opportunity here to grow their confidence and skills. They offer a range of programmes which can be tailored to suit individual needs.	EAQ MANOR FARM CIC Stocklinch Ilminster Somerset TA19 9JG 01460 394375

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Conquest Centre	<p>Over the last few years, Conquest Centre has evolved from a traditional Disabled Riding Centre to become a comprehensive and progressive Therapy Centre providing invaluable support to people of all ages and abilities in the local community.</p> <p>Their specialism is still working with a herd of exceptional therapy horses, but to provide, with greater flexibility, in their work they have added a selection of smaller animals to their 'menagerie' (for example: donkeys, goats, chickens, turkeys and guinea pigs) so they are able to offer broader scope in their range of therapies to help more people.</p>	<p>Conquest Centre Conquest Farm Norton Fitzwarren Somerset TA2 6PN 01823 433 614 info@conquestcentre.org.uk</p>
Focus Social club	<p>They are a social club for anyone with a learning disability in Somerset. They also act as a support group to families and carers for people with learning disabilities. Focus Club aims to create a social space for people with learning disabilities.</p> <p>Provider of support and care for anyone with a learning disability and the elderly in Somerset.</p>	<p>07718 084843 focuscare@hotmail.com</p>
Mencap	<p>The services they provide range from round-the-clock care to helping someone join in with local leisure activities, providing advice and information on things like employment and education, helping someone to live independently for the first time, and even things like reporting a crime to the police.</p> <p>In a nutshell, they try to help in any area of a person's life where they need support.</p>	<p>08088081111</p>
Our Voice Somerset – Street	<p>A peer support group for adults with learning disabilities to;</p> <ul style="list-style-type: none"> • Have a voice about things that matter • Meet new friends and have fun 	<p>Crispin Community Centre, 4 Leigh Road, BA16 0HA, Street, Somerset office@peoplefirstdorset.org.uk</p>

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	<ul style="list-style-type: none"> • Get information and support • Gain new skills and confidence <p>First Thursday of the month from 12pm to 1.30pm</p>	<u>01305 257600</u>
Burcott riding for the disabled	Riding can provide so many therapeutic benefits. There is the physical; the warmth and movement experienced from sitting on a horse and a rider uses many different muscle groups without even realising it. There is the freedom it gives and the feeling of achievement. It boosts confidence and helps to develop social skills. There is the social interaction between the riders themselves, the riders and the volunteers and of course and perhaps most importantly between the riders and their horses and ponies. They aim to make our sessions fun, enjoyable and a rewarding experience.	<p>Burcott Lane Wells Somerset BA5 1NQ 01458 272726 mickh.julieb@btinternet.com</p>
Strawberry Club, Street – Social group for adults with learning difficulties	They welcome any adults with learning difficulties. Craft and other activities are available as well as refreshments.	<p>Strawberry Club meet at The Salvation Army, Goswell Road, Street, BA16 0JG</p> <p>street@salvationarmy.org.uk 01458 448963 / 01458 445232 https://www.salvationarmy.org.uk/street</p>
The Orchard Vale Community Gardening Project – Wells	This project aims to benefit people with learning disabilities and people who are isolated, elderly or vulnerable in the community. A gardening service, led by adults with learning disabilities will be available to people in the community who are unable to care for their gardens themselves.	<p><u>The Garden House, Wells BA5 1AR</u></p> <p>info@orchardvaletrust.org.uk <u>01749 671706</u></p>

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	<p>The activities include: garden assessments – garden maintenance – garden waste disposal and some planting. Call the number below, leave your contact name and number and the jobs you would like done and the gardening team they will call you back.</p>	https://www.orchardvaletrust.org.uk
<p>Community Team for Adults with Learning Disabilities Frome, Glastonbury, and Mendip</p>	<p>They assess a persons requirements and provide statutory care and support as needed for adults over 18. They aim is to promote a persons wellbeing, independence, choice and control, with the support of a transitions worker for under 18s.</p> <p>They safeguard vulnerable adults who are experiencing abuse or neglect.</p> <p>They can provide a range of specialist health care support including psychiatry, psychology, speech and language therapy, learning disability specialist nursing and occupational therapy to support people with a learning disability.</p> <p>They assist people through the provision of equipment, telecare and housing adaptations. Depending on a persons needs, we also arrange the provision of appropriate accommodation, for example, independent flats, supported living and residential care.</p> <p>They support a person who may be caring for someone and is not being paid to do so.</p>	<p>Christchurch Street West, Frome BA11 1EF</p> <p>Adults@somerset.gov.uk</p>
<p>Somerset Tennis</p>	<p>Learning Disabilities Tennis</p> <p>learning disability (LD) tennis at a recreational level, they are including learning difficulties as well. This includes Down's Syndrome, Asperger's Syndrome, Autistic Spectrum Disorder (ASD) and Attention Deficit Hyperactivity Disorder (ADHD). However, in LD specific competitions and</p>	<p>c/o The West Hants Club</p> <p>Roslin Road South</p> <p>Bournemouth</p> <p>Dorset BH3 7EF</p> <p>Tel : 01202 519694 / 07392 551493</p>

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	<p>tournaments criteria for entry is connected to the person's IQ (under 75) and are only open to those who are eligible.</p> <p>Opportunities in Somerset</p> <p>The Learning Disability sessions normally take place at Taunton Tennis Centre on Wednesdays from 11am - 12noon.</p>	<p>email:</p> <p>annie.smith@somersetlta.co.uk</p>
BANDS CIC	<p>BANDs run social opportunities meetings for over 16s who identify on the autism, Asperger syndrome and similar spectrums, including (but not limited to) AD(H)D, Non-Verbal Learning Disorder, dyslexia, dyspraxia, social anxiety, dyscalculia, Bipolar, Borderline Personality disorder, Emotionally Unstable Personality Disorder, OCD and schizophrenia. Participants may attend the group regardless of a diagnosis. Anyone who identifies as having something similar to these conditions will be considered for inclusion on a case-by-case basis. BANDs aims to provide a safe and welcoming environment for people, especially those without social opportunities which encourage peer-to-peer networking and developing and maintaining shared interests (Mazurek, 2013). The groups include a cinema group, café group and pub group (including the Christmas meal). The CEO is on hand to clarify and implement the guidelines of the groups (NAS, 2003). BANDs encourages anyone regardless of location to attend. To encourage independent travel by potential members (Walton and Ingersoll, 2013) on public transport, videos including directions can be sent to you on request. We can also help with public transport route planning on request.</p>	<p>Email us at:</p> <p>bathfiltonbands@gmail.com</p> <p>Telephone or text us on:</p> <p>0795345591</p>

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	Attendees to the groups have to pay for any activities they participate in: the drinks, snacks, meals, cinema tickets, venue hire, transport to and from the groups.	
Orchard Vale Trust – for adults with learning difficulties.	Orchard Vale Trust is a local charity offering residential, day and community services to adults with learning disabilities. Orchard Vale Trust offer opportunities that enable people to develop social, communication and independent living skills, so that they are able to feel more connected and engaged within their local communities. The opportunities are offered in various locations within the Mendip area.	info@orchardvaletrust.org.uk 01749 671706 07340 495520 https://www.orchardvaletrust.org.uk
Heads-up Wells	Provides a therapeutic environment and a range of services, support and guidance for adults of all ages recovering from or living with mental health needs and other difficulties. Programme of workshops and activities available. They currently offer the following workshops: Pottery Woodcraft Arts and Crafts Creative Social Group Gardening Health and Wellbeing	Heads Up, Upper Breach, South Horrington, Wells, BA5 3QG www.headsupsomerset.org.uk Telephone: 01749 670667
West Somerset Asperger's/Autism Support Group	Type of service: Social groups West Somerset Asperger's/Autism Support Group meets in a local cafe for a drink and chat, support and information. Other things can be arranged as required.	Peter and Cathryn Wilson - Coordinators 01643 702202

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	<p>Eligibility:</p> <p>Age: For people of any age</p> <p>Aimed at: Adults, Adult sibling, Parent/carer of an adult, Partner</p> <p>Gender: All genders</p>	pcwilson@talktalk.net
Ups and Downs	With dedicated teams based in Somerset and Bristol, their membership and reach covers the majority of the South West; from Devon to Bristol, including Dorset, Somerset, North Somerset, and Wiltshire. Whether you're a new parent, family member, professional involved with a child who has Down Syndrome or someone who has an interest, you will be able to find the support and information you seek from Ups and Downs Southwest.	<p>01278 691100</p> <p>info@upsanddowns.net</p> <p>Ups and Downs Southwest</p> <p>The Old School,</p> <p>School Road</p> <p>Westonzoyland</p> <p>Somerset</p> <p>TA7 OLN</p>
Active Living Network 50+ Group Various places	The Active Living Network in Somerset has groups throughout the county for people aged 50 and over and welcomes both carers and the people they care for.	<p>www.somersetactiveliving.org.uk</p> <p>carers@somersettrcc.org.uk</p>
Lufton college	Special education setting	<p>Lufton,</p> <p>Yeovil,</p> <p>BA22 8ST,</p> <p>Somerset</p> <p>www.cambiangroup.com/lufton-college</p>

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3 dimensions	Special education setting	<p>3 Dimensions Care Chardleigh House Chardleigh Green CHARD TA20 3AJ</p> <p>Phone: +44 01460 68055</p> <p>generalenquiries@3dimensionscare.co.uk</p>
Cambien Somerset School	Special education setting	<p>Creech Court, Mill Lane, Creech St. Michael, Taunton, TA3 5PX, Somerset education@cambiagroup.com</p>
Foxes academy	Special education setting	<p>Selbourne Place, Minehead, TA24 5TY, Somerset Fox-Admin@the-aurora-group.com</p>
Farleigh further education college	Special education setting	<p>North Parade, Frome, BA11 2AB, Somerset 01373 456 470 farleighfecollege@priorygroup.com</p>

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Inaura School	Special education school	Moorview House, Burrowbridge, Bridgwater, TA7 0RB, Somerset 01823 690211 Email: office@inauraschool.org
Newbury manor school	Special education school	Newbury, Mells, Nr. Frome, BA11 3RG, Somerset 01373 814 984 newburymanor@priorygroup.com
North hill house	Special education school	Fromefield, Frome, BA11 2HB, Somerset 01373 466222 Email: northhillhouse@priorygroup.com

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Somerset progressive school	Special school	Bath House Farm, West Hatch, Taunton, TA3 5RH, Somerset 01823 481902
Sedgemoor manor school	Special education school	Highbridge, TA9 4NP, Somerset <u>01278 641 426</u> <u>sedgemoormanorschool@priorygroup.com</u>
Silver Bridge	Silver Bridge is a day school in Taunton, Somerset covering Primary, Secondary and Post-16. It offers education for children and young people with SEMH and associated conditions.	Silver Bridge School, 54 Silver Street, Taunton, Somerset TA1 3DL email: <u>referral@silverbridgeschool.co.uk</u> call: 01823 795800 www.silverbridgeschool.co.uk
Mark college	Special education	markcollege@priorygroup.com
The Lodge	Care home for ASD	Portway, Langport TA10 0NQ

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Daneswood Care Home for Adults with Learning Disabilities	Care home for LD	Cuck Hill, Shiphams, Winscombe BS25 1RD
Longrun House	Care home for LD and ASD	Longrun Lane, Bishops Hull, Taunton TA1 5AY
Voyage Care Huish House, Chard Manor, Ashleigh House, Blackberry Hill, Bridge House, The Bungalow, The Minster, Westleigh House, Wellington Road. Care homes for adults with Learning Disabilities	Voyage Care is a sector leading provider, with over 30 years' experience of specialist care and support. They support over 3,500 people with learning disabilities, autism, brain injuries and other complex needs across the UK.	referrals@voyagecare.com
Wilton House	Care home for ASD/LD	Upper High Street, Taunton TA1 3PX
The Dairy House	Care home for ASD/LD	Bishops Hull, Taunton TA1 5AY
Autism Wessex – Barn Close/Middle Path	Care home for ASD	32 Barn Close, Crewkerne TA18 8BL 58 Middle Path, Crewkerne TA18 8BG

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Catherine House	Care home for ASD/LD	131 Hamilton Road, Taunton TA1 2EP
Cherry Trees	Care home for ASD/LD	28 Berrow Road, Burnham-on-Sea TA8 2EX
Park View	Care home for ASD/LD	Burnham Service, 1 Westfield Road, Burnham-on-Sea TA8 2AW
Stafford Lodge	Care home for ASD/LD	87 Berrow Road, Burnham-on-Sea TA8 2PF
Stanway close and Greenway road	Care Home	18 Stanway Close and Greenway Roa, Taunton TA2 6NJ
Wembdon Rise Home	Care Home	4 Wembdon Rise, Bridgwater TA6 7QU
Lakeside House	Care Home	Somerset Court, Harp Road, Brent Knoll, Highbridge TA9 4HQ
Holly Tree Cottage	Care Home	243 Berrow Road, Burnham-on-Sea TA8 2JQ
Laural House	Care Home	3 Buckland Road, Taunton TA2 8EW
Elmsmead	Care Home	82 South Road, Taunton TA1 3EA
All Seasons	Care Home	Springside, 71 Halcombe, Chard TA20 2DU
Barley House	Care Home	49 Buckland Road, Taunton TA2 8EW
Apple Tree House	Care Home	243a Berrow Road, Berrow, Burnham-on-Sea TA8 2JQ
SeeAbility Fiennes House	Care Home	Drakes Park North, Wellington TA21 8SZ

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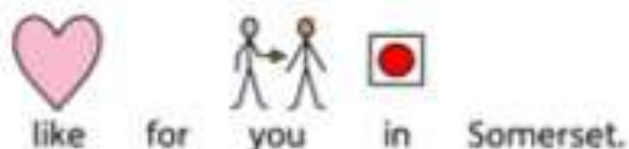
The Wheelhouse	Care Home	Linden Hill, Wellington TA21 0DW
Porlock House/ Blackdown House/ Knoll House/ Greatwood House/ Cotswold House	Care Home	Somerset Court, Harp Road, Brent Knoll, Highbridge TA9 4HQ
The Lodge	Care Home	18 Huntspill Road, Highbridge TA9 3DQ
Rosewood Lodge & Brook House	Care Home	11/13 Friarn Street, Bridgwater TA6 3LH
The Knowls	Care Home	86 Trull Road, Taunton TA1 4QW
Church Road	Care Home	Wembdon, Bridgwater TA6 7RQ
Bridgwater Court	Care Home	42 Market Street, Bridgwater TA6 3EP
Micro providers	Micro-providers offer care and support in really flexible ways at times that suit the individual. The micro-provider list is open to those who have signed up and are committed to the Doing it Right Quality Standards . They also have undertaken a best practice workshop and provided Somerset County Council with evidence of : <ul style="list-style-type: none"> • Enhanced DBS check (within 3 years) • Public Liability Insurance • Complaints Procedure • Terms of service • Template support plan. 	https://drive.google.com/file/d/0B4G_vxabtN4FakllZm1Ocm1Najg/view?resourcekey=0-FwgV0tumalkg11kboVo31g

Appendix C - Visual survey

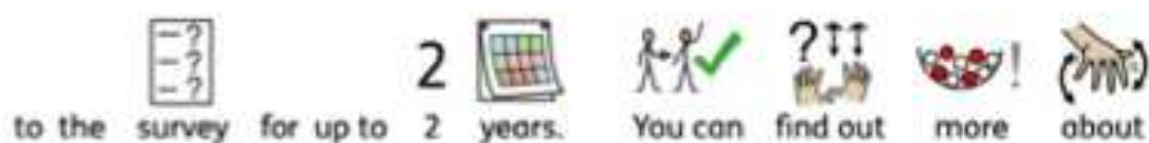


Life in Somerset for people with Learning Disabilities and/or autism (with pictures)

This survey is being run by Somerset Parent Carer Forum C.I.C and Autism Somerset C.I.C in association with Discovery and Somerset Community Foundation.



Appendix C - Visual survey

















Appendix C - Visual survey

 We  think  the survey  will  take  you  20 minutes  to
 complete.  If  you  need  help  to do  the survey  or  would like
 a paper  copy,  please  contact us  on  01458 259384  or email

getinvolved@somersetparentcarerforum.org.uk.

 If  you  are  worried  about  something,  please  talk to  someone
 you  trust  and  they  can  speak  to  us.

 You  do not have  to  do  the  whole  survey  you can  stop  and
 come back  to  do  more.

Appendix C - Visual survey



* 1. I am

- ☐ a person with Learning Disabilities
- ☐ an autistic person with Learning Disabilities
- ☐ an autistic person
- ☐ completing on behalf of a person with Learning Disabilities
- ☐ Other (please specify)
- ☐ completing on behalf of an autistic person
- ☐ completing on behalf of an autistic person with Learning Disabilities
- ☐ neurodiverse
- ☐ completing on behalf of a neurodiverse person



Life in Somerset for people with Learning Disabilities and/or autism (with pictures)

* 2. Please tell us how old you are

* 3. Please answer all questions based on the person you are completing the form on behalf of. How old are they?

Appendix C - Visual survey

* 4. I identify as

- ☐ female
- ☐ male
- ☐ transgender
- ☐ gender fluid
- ☐ non binary
- ☐ prefer not to say

* 5. Do you consider yourself to be from a black or minority ethnic background?

- ☐ Yes
- ☐ No
- ☐ Prefer not to say








* 6. When you need something do you talk to your (please tick all that apply)



☐ If you ticked someone else, please tell us who.

Appendix C - Visual survey

* 7. I feel I can talk to (please tick all that apply)

	about my religious beliefs	about my sexuality	about my culture	about my disability	about all my beliefs
 Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Paid worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 someone else	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 All people	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Is there anything you want us to know about this?

    + 
This section is about work and money.

Appendix C - Visual survey

* 8. These questions are about work and volunteering



Yes



No



Sometimes



Don't
Know



Does
not apply

Are you able to
work?

☐☐☐☐☐

Are you
working and
being paid?

☐☐☐☐☐

Are you working
and not being
paid?

☐☐☐☐☐

Are you
volunteering?

☐☐☐☐☐

* 9. Thinking about work or volunteering



What
is working well
for you?



What
could be better?



Does
anything need to
change?

Appendix C - Visual survey

* 10. These questions are about money



Yes



No



Sometimes



Don't
know



Does
not apply

Does someone
help you with
your money?

☐☐☐☐☐

Do you manage
your own
money?

☐☐☐☐☐

Would you like
help to manage
your money but
do not have
this?

☐☐☐☐☐

Is there anything you want us to know about this?

* 11. Thinking about access to money



What
is working well
for you?



What
could be better?



Does
anything need to
change?



This



section

is



about



where



you



live.

Appendix C - Visual survey

* 12. These questions are about where you live



Do you live on your own?



Do you live on your own with live in support?



Do you live on your own with support that comes in?



Do you live with family?



Do you live with other people in a shared house?



Was this your choice?



Is there anything you want us to know about this?



This



section

is



about

the



support



you



get.

Appendix C - Visual survey






* 13. What support and help are you getting? (tick all that apply)

- | | |
|---|---|
| <input type="checkbox"/> Micro providers (an individual or small company that does community based care and support services) | <input type="checkbox"/> Blue badge |
| <input type="checkbox"/> Care family provide | <input type="checkbox"/> Housing support |
| <input type="checkbox"/> Care service council provided | <input type="checkbox"/> Citizen's advice |
| <input type="checkbox"/> Care service private | <input type="checkbox"/> Advocacy - Someone to help you have your voice heard |
| <input type="checkbox"/> Care service charity | <input type="checkbox"/> Village agents |
| <input type="checkbox"/> Care service agency | <input type="checkbox"/> Community connectors |
| <input type="checkbox"/> Wheelchair services | <input type="checkbox"/> PALS |
| <input type="checkbox"/> Therapy | <input type="checkbox"/> Healthwatch |
| <input type="checkbox"/> Short break | <input type="checkbox"/> SWEDA |
| <input type="checkbox"/> CEA card | <input type="checkbox"/> SWISH |
| <input type="checkbox"/> Bus pass | <input type="checkbox"/> Safe spaces |
| <input type="checkbox"/> Other (please specify) | |

* 14. Is there any support you would like or need that you are not getting?






Appendix C - Visual survey

*** 15. Do these services make special provision for your needs (for example quiet hour, sensory room, changing places)**

	 Yes	 No	 Sometimes	 Don't know	 Does not apply
Leisure centres	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Shopping centres	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Supermarkets	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Museums	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Library	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Holidays	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
Venues including clubs	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Please tell us about anyone who does this well

*** 16. These questions are about how the support you get is paid for**

	 Yes	 No	 Sometimes	 Don't know	 Does not apply
I pay for it using my Personal Independence Payment (PIP)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I pay for it using my social care direct payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I pay for it using my continuing health payment	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
I pay for it using own money	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

If someone manages this for you please tell us who

Appendix C - Visual survey

* 17. Thinking about access to support



What
is working well
for you?



What
could be better?



Does
anything need to
change?



This



section

is



about



things



you



might



want to



do



in



your



free time.

Appendix C - Visual survey

* 18. These questions are about your free time.



Yes



Sometimes



No



Don't
know



Does
not apply

Do you get to
choose what you
do in your own
time?



Can you pick
when you get
help to go out
when you want
to?



Can you learn
new things if
you want to?
(this could be at
college, online
or in the
community)



Do you get to
meet people like
you with the
same needs or
diagnosis?



Is there anything else you want us to know?

Appendix C - Visual survey

* 19. Thinking about how you use your free time



What
is working well
for you?



What
could be better?



Does
anything need to
change?



This



section

is



about



looking after



your



health.

Appendix C - Visual survey

* 20. I am



Yes



Sometimes



No



Don't know



Does not apply

helped to look after my health

☐☐☐☐☐

helped to look after my sexual health

☐☐☐☐☐

helped to look after my wellbeing (mental health)

☐☐☐☐☐

helped to make sure I eat well

☐☐☐☐☐

helped to make sure I get the rest I need

☐☐☐☐☐

helped to make sure I get exercise I need

☐☐☐☐☐

helped to understand my needs/diagnosis

☐☐☐☐☐

Is there anything else you want us to know?

* 21. This person helps me look after my health.



Yes



Sometimes



No



Don't know



Does not apply
















doctor

☐☐☐☐☐





















dentist

☐☐☐☐☐

Appendix C - Visual survey

	 Yes	 Sometimes	 No	 Don't know	 Does not apply
 therapist	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 dietician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Optician	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Special Clinic	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Hospital Staff	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Family	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Friends	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
 Paid worker	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Appendix C - Visual survey

								
Yes	Sometimes	No	Don't know	Does not apply				
<div> someone else</div> <div><input type="radio"/></div> <div><input type="radio"/></div> <div><input type="radio"/></div> <div><input type="radio"/></div> <div><input type="radio"/></div>								
<p>* 22. Thinking about the support you get for your health</p>								
	<p>What is working well for you?</p> <div></div>							
	<p>What could be better?</p> <div></div>							
	<p>Does anything need to change?</p> <div></div>							
								
Over	the	last year	things	have been	different.	We	want	to
								
know	what	it was	like	for	you.			

Appendix C - Visual survey

* 23. Please tell us how true these statements are for you about covid:



easier



Harder



no



change



Don't know

It made my life



It made seeing
my friends and
family



It made getting
to medical
appointments



It made working
or volunteering



It made
learning



It made doing
the things I
want to do



It made doing
my shopping



It made
completing
forms



Is there anything else you want us to know?

Appendix C - Visual survey

* 24. Lots of things need a computer to do. Please tell us how true these statements are for you:



I can use a computer, tablet or mobile phone



I can choose when I use a computer, tablet or mobile phone



I can use a computer, tablet or mobile phone for appointments



I have my own computer, tablet or mobile



I have been able to try using a computer, tablet or mobile phone



I can go online when I want to



I can choose not to use a computer, tablet or mobile phone



Is there anything else you want us to know about this?

Appendix C - Visual survey

?        to know?

Is there anything else you would like us to know?

*** 25. Please tell us here**

Appendix D- Promotion

Somerset Parent Carer Forum CIC

Date	Platform	Reach
Period of the consultation	SPCF website area	592
17 th June 2021	SEND news	3700
28 th June 2021	SPCF newsletter	1267 click rate 44%
7 th July 2021	Text message service SPCF	120
26 th June 2021	SPCF Get involved contact list	294
09 th June 2021	SPCF social media	1575
22 nd June 2021	SPCF social media	520
23 rd June 2021	SPCF social media	156
24 th June 2021	SPCF social media	292
26 th June 2021	SPCF social media	895
29 th June 2021	SPCF social media	145
6 th July 2021	SPCF social media	1582
6 th July 2021	Talking Café	
6 th July 2021	Greatest hits Radio	
12 th July 2021	SPCF social media	208
13 th July 2021	SPCF social media	273
14 th July 2021	SPCF social media	117
15 th July 2021	SPCF social media	190
	Somerset's Local Offer Facebook page	1646
19 th July 2021	SPCF social media	183

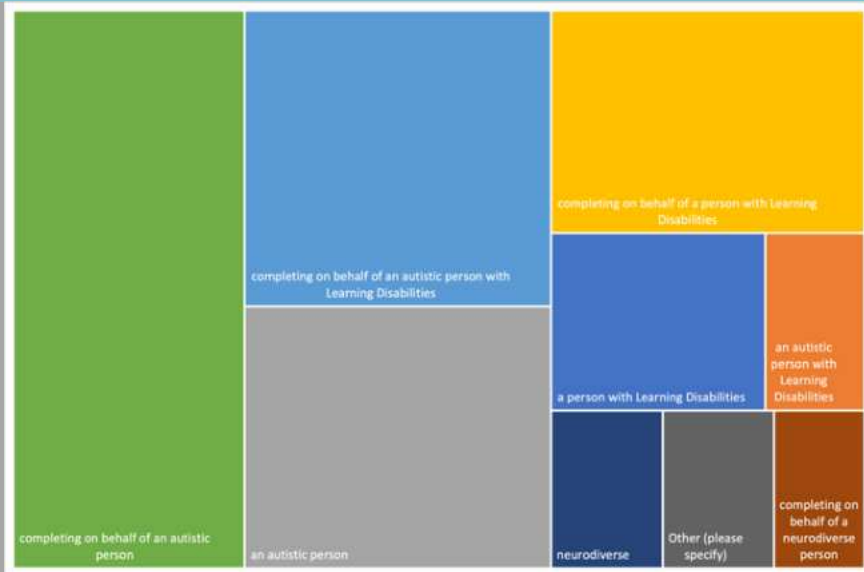
Autism Somerset CIC

Autism Somerset promoted the survey through its networks. The survey and wider consultation were shared through the newsletter and social media. The survey was also shared through the village agents and they arranged a live session on the talking cafe.

APPENDIX E- PARTICIPANTS

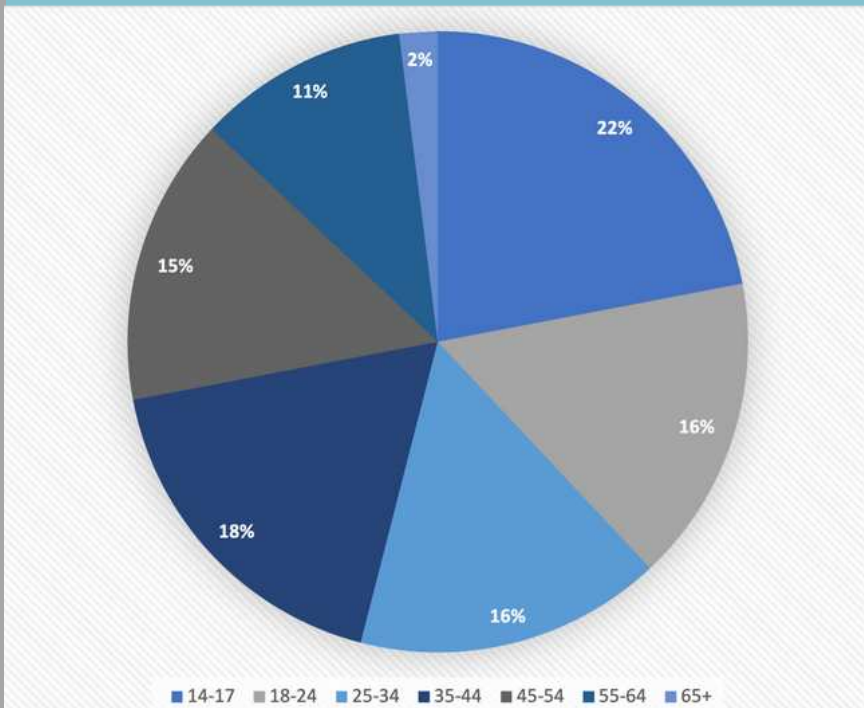
IDENTIFIED AREA OF NEED

22.7% of respondents identified as or were completing on behalf of someone with learning difficulties, 44.1 % of respondents identified as or were completing on behalf of an autistic person, 22.8% of respondents identified as or were completing on behalf of someone with learning difficulties and autism, 6.7% of respondents identified as or were completing on behalf of someone identifying as neurodiverse and 3.7 identified as other.



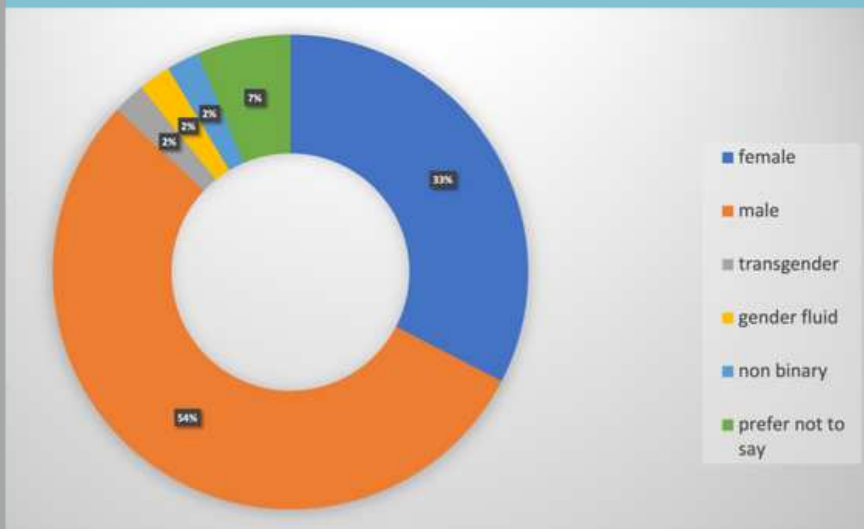
AGE RANGE

50% of respondents were between the ages of 25-44, 28% were 45 and over, with the remaining 22% being under the age of 18.



IDENTIFICATION OF RESPONDENTS

A higher proportion of respondents identified as male 54.4%. and 95.6% of respondents did not consider themselves to be from a black or minority ethnic background.



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LIFE IN SOMERSET FOR PEOPLE WITH LEARNING DISABILITIES AND/OR AUTISM CONSULTATION

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