Disability Focus

held on the 24th October, 2017
at One, Scrivener Drive, Ipswich, Suffolk

As far as possible this report has been written in Plain English

If you require this report in a different format, please contact Avenues East on 01473 836777 or Email: enquiries@avenues group.org.uk
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- Avenues East
- Babergh District Council
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- Forest Heath District Council
- Gt Yarmouth & Waveney Clinical Commissioning Group
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- Ipswich Hospital NHS Trust
- Mid Suffolk District Council
- Norfolk & Suffolk NHS Foundation Trust
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- Suffolk Coastal District Council
- Suffolk Constabulary
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- West Suffolk Clinical Commissioning Group
- West Suffolk Councils

Easy Read Versions of Booking Forms and Agendas

- Genesis Orwell Mencap
Foreword

I was so very pleased to be invited to speak at your conference and even more pleased to spend the day with you.

Thank you to everyone involved in making Disability Focus happen as it takes an immense amount of organisation and hard work to make such an event so successful.

And I would like to thank all of you for attending. It is the attendees who make events like this so worthwhile. Hearing of experiences and ideas from service users along with providers of services from across the sectors is so valuable. It promotes understanding, a shared understanding. It captures the essence of partnership where the care recipient is the expert on what they need and want and this is blended with the knowledge and expertise of service providers. The result should be an individualised service which seeks to maximise potential at all times.

This kind of partnership working is what so many of us are working towards. Certainly the Ipswich and East Suffolk Clinical Commissioning has committed to developing partnership working and there are signs that this approach is beginning to gain support. A number of pieces of work undertaken by the Clinical Commissioning Group are now going forward in partnership with service users.

Thank you to the organisations who contributed to the cost of organising and running the day, to the facilitators and note takers, to everyone for their commitment to working together to improve local services.

Suggestions and actions made on the day will be followed up – a grand action plan. And feedback regarding how to improve the event moving forward will be taken into account by the organisers.

Pauline Quinn

Lay Member for Patient and Public Involvement
Ipswich and East Suffolk Clinical Commissioning Group
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Executive Summary

This report details the concerns and issues raised by disabled people, their family carers and representatives of their organisations at Disability Focus 2017, a one day event organised by the Disability Focus Planning Group, the Disability Forum for Suffolk and Avenues East. It is a partnership event designed to bring together disabled people, their family carers, representatives of disability organisations and representatives of statutory organisations in Suffolk. This event has now been held for five years and feedback would support that it still remains one of the very few opportunities for disabled people and their carers in Suffolk to have a say!

This report includes an indication through the ‘What do you think’ questionnaire of what people in Suffolk think about their big issues (listed below). Whilst the results for previous years had shown some year on year improvement, this year in several key areas there has been a significant negative shift in perception e.g. the ready availability of transport and feelings of personal safety (especially at night) where a real shift of opinion has been seen, in both examples only a quarter of people polled are happy with the current situation. Comments made by attendees clearly indicate that in some areas of daily lives there are still considerable barriers to the effective inclusion of disabled people in our communities. There are many specific examples of such barriers within the detail of this report under the headings listed below:

- Do you get the information you need?
- Do you get the money you need to live your life?
- Can you get to where you want to go easily?
- Do you feel safe when you go out?
- Do you feel safe when you go out during the day?
- Do you feel safe when you go out at night?
- Apart from this event, do you think that the needs of disabled people are well represented throughout Suffolk?

The report also includes the output from a number of round table debates. Attendees were able to choose from a list of topics circulated in advance of the event. Output from these discussions is covered in the report under the major headings listed below:

- Being a full part of our community
- Getting information you can use
- Getting the benefits you are entitled to
- Using health care services at home or in hospital
- Having a house to live in and support to live there
- Getting a job and keeping it
- Being safe where you live and where you spend your time
- Being treated badly because of your disability (Hate Crime)
- Using public spaces and places
- Getting to where you want to go
- Getting your voice heard

These topics provided lively debate and detail on the specific issues including verbatim comments from those attending are contained within the body of the report. Many of the issues and concerns overlap but have been left in the discussion group in which they were raised. Therefore, it is strongly recommended that people take the time to read the whole report rather than pick out particular headings, for example, transport issues affect many other areas of concern.

However, it is worth highlighting that in general there has been very little change in the perception of disabled people and their carers across these questions in the five years of undertaking this exercise. Listening is sometimes not enough, change has to occur.

Overall feedback on the event was extremely positive again this year with many people expressing that this was still one of the few opportunities they had to raise, and have addressed, their concerns and issues directly with service providers and commissioners, who in turn valued the opportunity for direct user contact and feedback. Specific comments included:

- Decision makers need to attend events like this;
- Organisations only pretend to listen to disabled people;
- It was good, I did get to say what I wanted to;
- A very engaging series of discussions with groups including representatives from statutory services, organisations and those with disabilities, their families and carers;
- An excellent opportunity to hear the views and experiences of people living with disabilities;
- People need to be involved in an ongoing way.
Introduction

Disability Involvement Days began in 2011 and are now widely known as Disability Focus. This annual event is firmly established as a much appreciated opportunity for disabled people and their organisations in Suffolk and, therefore, the Disability Focus Planning Group decided to organise an event in 2017. Once again, the Planning Group worked with the Disability Forum for Suffolk and Avenues East to ensure the full involvement of disabled people and their organisations in putting the day together in the spirit of co-production. Jo Land, Deputy Group Chief Executive of the Avenues Group, gave her time and expertise to chair the proceedings, along with Pauline Quinn, Lay Member for Patient & Public Involvement, Ipswich & East Suffolk Clinical Commissioning Group, who kindly gave the introductory remarks.

The principal objective of Disability Focus is to enable disabled people to raise their concerns and issues and make their voices heard, and for those in statutory organisations to listen to those voices and take note of those concerns and issues. It is very pleasing that representatives from all the statutory organisations in Suffolk were able to support this event.

The organisation of this day remains a challenge for the small number of members of the Disability Focus Planning Group and our thanks are recorded to each of them for ensuring this event happens for disabled people. It demonstrates an excellent team effort despite the lack of resources.

Well over 100 people attended including disabled people, their family carers, representatives of disability organisations and statutory organisations.

The main purpose of Disability Focus is to facilitate discussions on the topics that are important to disabled people, such as where they live, how they get to where they want to go, how they find the information they need, and how to access the services that help them live their lives. In order for the event to be effective and make a difference, listeners take away action points where their organisations can make changes.

In addition to noting the issues and concerns raised and the actions to be followed up, this report also includes the results from the ‘What do you think’ questionnaire with comparisons to the responses from previous years.

The evaluation indicates clearly that this event continues to provide a very useful and valuable insight into the concerns of disabled people in Suffolk, and is a welcome opportunity to come together to discuss a wide range of topics.

Linda Hoggarth MBE, Chair, Disability Forum for Suffolk, and Chair, Disability Focus Planning Group
What do you think?

Introduction:

Delegates were asked the same simple questions as had been asked in previous years in order to facilitate comparisons. These questions are designed to gather a general overview of how disabled people, their family carers, and representatives of disability and statutory organisations feel about some of the key issues and are not meant to be taken as significant research, hence the simplicity of the wording. This exercise was carried out as a paper based questionnaire and delegates were also invited to make additional comments if they so wished. Those comments are included here in full and many useful points have been made. These should be read in conjunction with the feedback from the 2017 Discussion Groups.

Again this year, the results have also been broken down into four categories – disabled people, family carers, representatives of disability organisations and listeners from statutory organisations. However, some delegates clearly fit into more than one category, for example, a disabled person could also be a family carer or a representative of a disability organisation.

It should be noted that the attendance and voting participation at each year’s event is different and hence the results should be taken in the spirit of identifying trends in terms of satisfaction, year on year improvement or otherwise.
‘Do you get the information you need?’

Disabled people said:

- Information is mostly readily available;
- I generally get the information I need;
- Things are not explained clearly and properly;
- Services are disjointed – no communication – no ownership or accepting responsibility – inaccessible;
- There are different standards of information available;
- No one explains things to me. I don’t know where to go. Things aren’t in easy read. I don’t understand long words;
- Everything is on-line and that is a problem;
- I asked for an appointment letter in an accessible format – Ipswich Hospital said they had no facilities to do that. In comparison, my Personal
Independent Payment application was sent through in audio so I had the power to deal with this myself;
- There is no sign posting, nothing straight away, but service support groups are good;
- I find information through various organisations and friends;
- I have to pursue it to get the information as sometimes it is not forthcoming;
- I am quite independent so I can create issues when needed;
- There’s a communication breakdown;
- I have problems with the dementia caring system;
- Red tape, too complicated and live in rural area;
- Yes, but I had to search for it;
- It can come if you know;
- They don’t give me information;
- The Vision 2020 Strategy is a positive example. 2 months prior to the event we were asked what format information was needed (this included equipment). Improvements would be requesting what information individuals need for events like this;
- I get information on the internet because it is easier for me to look it up;
- Yes, as a trustee of a disability organisation;
- I cannot use a computer;
- Usually but it often takes a long while to find it.

Family carers said:
- I am too busy caring to hunt for information;
- I have family around me;
- Yes but I have to search for it;
- It is difficult to find information. It is not offered by various organisations. I have to find time to look around. We need a one stop place;
- I can access the internet but not everyone can.

Representatives of Disability Organisations said:
- Yes, however, we have found that members of the public struggle to do so. It can be difficult to access information if you don’t know the right people;
- We try very hard to circulate details, being a charity, advertising on a large scale is hard to find. We cover Ipswich and all Mid Suffolk so loads of homes to cover;
- I attend VASP meetings and receive e-mails from partners;
- It could be important that you might need information;
- I get lots of information through the post which is very helpful to me;
- Information can be contradictory and confusing;
- Inaccessible information and misinformed;
As a service provider, we find out information from our tenants by forums and tenant contact. Service users need to know where to get information and continued support;
- Required formats are not always available;
- Mostly, yes;
- Sometimes;
- Yes, but not always from Suffolk County Council and local authorities;
- No, because information is not delivered in a co-ordinated way;
- I subscribe to a number of information services and access most things on line. Our service users struggle to get their information in an accessible format and are often not web users;
- No, not consistent and the format is not as needed;
- There is not enough clear and accessible information;
- I have access to the internet and I am able to get out and about;
- Yes, because I am aware of all local services;
- I get information from work and from the doctor’s, etc;
- No, no one wanted to know.

Listeners from Statutory Organisations said:
- No, there is no one-stop shop;
- No, I believe there is a lot of crime/incidents that still go unreported;
- Good service advertisement;
- Yes, through service advertisements and engagements;
- It is very difficult to get first-hand experience of changes affecting disability groups so that I can lobby for them;
- Misinformed with information: Where do you get the information from? Where is the information in order to get it and is it what people want and need? It is not always readable – too much jargon. It is not always available in the right format. Some need support workers as information is not easy to read and understand. Services don’t always explain everything, for example, around tenancy and there is no follow up information when moving into a new tenancy;
- I need to find out information to help others;
- Information is not always shared or cascaded;
- Generally yes although sometimes data protection can be an obstacle;
- I have resources available to my organisation;
- Yes, from mailing lists of various groups and work colleagues;
- Yes, but only because I work within local government and with service providers;
- It is sometimes not easy;
- Yes, because I have access to professionals and I know who to ask;
- I am aware that certain groups don’t get the information they need;
- Yes, via the internet and networking;
I have access to the internet and contacts in my job – lots of information via social media;
I can easily access the internet and communicate with others. I readily access information;
As a professional, I know where to get the information I need;
No, it is not easily available;
I get information needed through other professionals.

‘Do you get the money you need to live your life?’

Disabled people said:
- My daughter or husband sorts it;
- Not enough but I do get by;
- I am not receiving enough benefit to cover my outgoings and living. I don’t know exactly what I am entitled to;
- No, it affects my quality of life. Private rental is not covered in its entirety by housing benefit;
- I have help from social services with managing my money;
- The future of the benefits system is worrying;
- I was medically pensioned off. I feel sorry for people on Universal Credit having to through that process;
- I only get Disabled Living Allowance which is not enough to cover taxi fares and my expenses relating to my disability;
- My Personal Independent Payment appeal is outstanding;
- Yes, because of the investments that were made whilst I was in employment;
- Yes, I’m independent;
- Yes, because I’ve got a job;
- No, our pensions are small;
- No, my pension is low;
- I spend money on what I want;
- No, because of the eligibility for direct payments. Assistive technology is expensive. The cost is not reflected based on funds received;
- Yes, because I have everything I need plus more;
- The cost of living is now increasing which will undoubtedly reduce our spending power;
- Living on disability benefits is a challenge.

Family carers said:

- There are many extra costs associated with disability;
- I have savings and a pension;
- Most people who have enough have saved it themselves. The benefits system is complex.

Representatives of Disability Organisations said:

- Some people struggle with paying for travel and we do have a small fund to help those in most need with costs;
- Yes, due to having a full time job;
- The Personal Independence Payment assessments for service users living in 24 hour supported housing are not necessary and causes them in some cases to become ill;
- It’s good to know where to go and get the information;
- Disabled individuals are often unaware of their entitlement in regard to benefits;
- Some service users struggle to get by. They do not always receive the benefits they may be entitled to;
- It depends on the person and their circumstances;
- Yes, I am in employment as an apprentice;
- No, because it costs me more to travel and my equipment costs are high. I can't work full time because of my disability;
- Yes, because my husband and I are both able to work;
- Yes, both myself and my partner work;
- Yes, because I am working;
- Eventually.

**Listeners from Statutory Organisations said:**

- I am paid a salary;
- Yes, but benefit assessments have become harder;
- I live with family plus working pay;
- Are disabled people able to get employment if they want? It's not clear whether people get the opportunity and whether the benefits system works in these situations. I am not sure claim forms account for individual circumstances;
- I have a job;
- Both myself and my partner are employed;
- I have salaried work;
- I work part time;
- Yes, because I work full time;
- Yes, because I am able to work;
- Whilst I do, I think many other people struggle with money;
- I'm in paid employment;
- I work full time and manage my own finances and have my own bank account so have access to my own money;
- I see some service users who are able to claim the correct benefits and some who are not;
- Wages are low in Suffolk and living costs are high in rural areas. Travel costs a lot;
- No, because of the public sector pay cap;
- I am employed.
‘Can you get to where you want to go easily?’

Disabled people said:

- Yes mostly because I am taken out by my husband;
- Yes, because I have my own vehicle;
- I feel okay on trains but not so with buses e.g. buses turning up on time;
- No, because I can’t drive and public transport is unreliable with times;
- There is a lack of accessible transport;
- I can drive but not walk far – accessible parking is limited;
- Transport isn’t accessible. I have to find ramps / slopes;
- No, I like support as I don’t like to go out on my own;
- I live in a small village and public transport is not always available;
- No, because my transport has to be wheelchair accessible;
- No, because it depends on someone to take me;
- Buses won’t stop for me at bus stops;
- Lack of transport accessible to me and lack of Personal Assistant support;
- Lack of transport e.g. bus services:
- Accessibility within Suffolk is controversial at times;
- My partner and I use the bus but we live in a village and the buses don’t come very often and the timetable often changes. If we can’t use the bus, we rely on taxis which are expensive;
- Lack of frequency of buses;
- I can still drive;
- Yes, because my wife drives;
- I am not able to use public transport;
- I have to flag down a bus;
- It is hard for me;
- There is a lack of public transport. Buses don’t run in the evenings. There are no ‘talking’ buses. Taxi drivers can refuse to transport guide dogs;
- Yes, in my disability car;
- I have a mobility vehicle;
- I cannot go out alone;
- It is difficult to access taxis or bus services with wheelchair access.

Family carers said:

- It is hard now my husband uses a wheelchair;
- I am elderly and rely on family and buses. It is tough to get to appointments at the hospital or to the doctor’s;
- My personal circumstances prevent my ability to get out and about;
- No because of the cost of rural living and because of visual impairment and autism;
- I am a carer and currently able to drive. If that were not the case, transport in rural Suffolk would be an issue.

Representatives of Disability Organisations said:

- There is a lack of accessible transport. We are applying for an ‘Access for All’ grant;
- Our minibuses are accessible by ramps. We provide 3 wheelchair accessible minibuses travelling within the confines of Mid Suffolk for anyone unable to access public transport. We run one minibus on the same terms in central Ipswich. We also have a community car service which includes a wheelchair friendly vehicle. This service is predominantly used to take people to day centres, hospitals, clinical appointments and visiting relatives. The drivers will wait whilst people attend clinical appointments. The cars will travel out of Mid Suffolk and Ipswich;
- While working with the Waveney Disability Forum, I have become aware that many people struggle;
No, because of cuts of public services in our area;
I need support to go to these places;
Yes, I use bus transport;
With support, yes, I can;
Yes, I can access public transport;
Yes, I access the community with provided transport;
There are many issues surrounding transport – accessibility and unreliability;
There is a lack of accessible transport and a lack of funding;
Some service users find there is not enough accessible transport;
Public transport is not readily available in the rural areas;
Roads are poor. There is a lack of transport options. Costs are an issue. Timings are not right;
I can travel by car;
Our service users often rely on public transport and West Suffolk does not currently offer ‘talking’ buses or ‘talking’ bus stops. The rural nature of the county also doesn’t help;
My bus service (Claydon) is poor, not just the time-tables. Buses do not run to the time-tables. I have to signal to get the bus to stop – this is not easy because I am blind. Drivers need more training;
Yes, because I am fortunate in that I can drive and have my own car;
I drive my own car;
Yes, because I drive;
I have a mobility car.

Listeners from Statutory Organisations said:
I have access to a vehicle;
Yes, except for more rural areas;
Yes, I rely on family and public transport until I get my own form of transport;
My understanding is that, in particular, transport is a significant factor for disabled people;
I drive;
Yes, because I have a car, but I wouldn’t fancy taking on public transport;
Yes, because I am a car owner;
I drive and have a car;
I have a car but know transport is a concern for people with have a disability, mainly due to costs;
Yes, I have a car;
Yes, because I can drive;
Whilst I do, I appreciate many people rely on public transport;
Yes, because I am able-bodied;
I drive and can easily access public transport;
- Yes, I have no physical disabilities which limit me from going where I want to go. Although, I don’t drive, I feel confident and comfortable using public transport with ease;
- The rural nature of Suffolk makes travelling very difficult for some service users. Cuts within the local authority mean support with transport costs is almost impossible to obtain for some service users;
- I live in a rural area and public transport is terrible;
- I drive or walk.

‘Do you feel safe when you go out?’

Disabled people said:
- I do not go out alone;
- Local violence in towns is increasing;
Yes, because of my support worker;
Sometimes, it depends on where I am going or when. I change plans or take no direct routes to feel safe. It is an unnerving feeling around poor reputation or gang cultures. I don’t feel safe in Shared Spaces;
Yes, all the time;
Yes, because I always have someone with me;
I live in a rural area;
I don’t often go out;
No, due to my eyesight problem;
No, because of paranoia and anxiety;
I use a crutch and feel vulnerable;
No, I have post-traumatic stress disorder and can’t see properly;
Yes, but I must be very aware of where I am. It takes a great deal of concentration;
I feel very vulnerable due to visual impairment;
When I have support, I’m okay;
Sometimes it is okay;
My area feels unsafe;
I haven’t the sense to consider otherwise;
Other people who have disabilities and problems sometimes trick on me;
It depends where I am;
Yes, because I have my 1 to 1 with me at all times;
No, not so much when I am alone;
No, because of falling over.

Family carers said:

Yes, usually;
No, autism and visual impairment create problems;
We only go out during the day;
I don’t go out much.

Representatives of Disability Groups said:

Our drivers will see their passengers from their door, to the vehicle and back to their door. They will not enter the passenger’s property. They wear badges and have all been DBS checked. The passenger will be given the name of the driver picking them up. If the passenger usually has a carer, we will make sure they are at home before leaving the passenger at their door. We have contact numbers for all passengers and also emergency contact numbers of their nearest relative or friend; Both our office and the drivers have these details;
I was taught road sense and I drive;
I go out with my partner and am aware of dangers;
I live in Stowmarket which is a safe town to live;
- No, because people don't understand certain disabilities and learning difficulties;
- Yes, with exceptions. Changes to situations can cause problems;
- Our service users often comment that they feel vulnerable because of their sight loss;
- No, because of my anxiety and the rise of hate crime and crime, full stop;
- Yes, although some places feel less safe because of poor lighting especially rural areas;
- Yes, I feel safe all the time but cautious when visiting new places;
- No, the environment is not visually impaired friendly;
- No, because of judgement from others and bullying, and the ease of getting around – will places accommodate needs and be understanding;
- Yes, as I am always supported by group staff or family;
- Yes, when with my support staff but I don’t feel safe without anyone with me;
- I have support from support workers;
- Yes, I can have support if needed;
- Yes, but not so much during evenings.

Listeners from Statutory Organisations said:

- Yes, but it depends where I am, but most of the time I feel safe;
- Yes, rural area and nice people;
- I feel that Suffolk is, on the whole, a safe place to live for service users. However, this is based on my own experience as a professional;
- Yes, there is no reason why I wouldn’t be;
- I live in a safe neighbourhood and can contact someone if I need help;
- I am able to judge and assess the environment;
- I would like to say I do mostly feel safe. However, there is a risk of having to be more cautious due to division in society;
- No, not always, it depends on where I am going;
- Yes, but this can depend where I am;
- I do not know for certain, but given today’s increase in hate crime and an unsympathetic government I suspect many will feel unsafe;
- Yes, when I amongst other members of the public and services in my area;
- I am comfortable in the area;
- Yes, because I am aware of personal safety recommendations and act accordingly;
- No, because of an uplift in violent crime where I live.
‘Do you feel safe when you go out during the day?’

Disabled people said:

- I usually travel from A to B by car;
- Yes, because I am never alone;
- Yes, but there are some areas I will avoid such as shared areas with traffic due to high levels of traffic;
- All the time;
- Yes, because I can see better;
- Yes, during the day;
- No, due to paranoia and anxiety;
- I feel very vulnerable due to visual impairment;
- I need support;
I just depend on the people around me;
Yes, with support;
Yes, except for when I feel too ill;
Yes, I’m big and ugly enough to be safe;
I feel more safer because I can see during the day but I still have some people who pick on me;
Yes, I have had experiences but mostly okay;
No, not when I am alone.

Family carers said:
Yes, because there are more people about to assist if required;
Yes, the town is safe and the bus is safe.

Representatives of Disability Organisations said:
Our service users feel vulnerable because of their sight problems;
Shared space is not a good idea;
Yes, when attending groups;
Yes, because in the daylight I can see a lot more and feel a lot safer;
I’m always with someone;
I have support from support workers;
Yes, because there are people around me.

Listeners from Statutory Organisations said:
Yes, it depends where I am;
I have no physical limitations and can communicate with others e.g. if I was lost;
Yes, most of the time;
Yes, because I am amongst many other members of the public.

‘Do you feel safe when you go out at night?’
Disabled people said:

- I feel safe if I am with someone, but not on my own;
- No, less safe at night;
- Yes, because I’m never alone;
- No, because of my vision;
- It is dangerous at night;
- No, because of the cars and volume of people;
- No, not if driving away from villages and the pavements need mending as there are no street lights so they are unsafe at night;
- Generally yes, I live in a 'good' area;
- I don’t feel safe at night. There have been some violent crimes and burglaries where I live;
- No, because of dangerous, hazardous pavements;
- I feel very vulnerable due to visual impairment;
- I don’t go out at night;
- Sometimes, because it can be dark and can be very unsafe in some areas;
- I feel unsafe on my own;
- It depends where I am;
- At night, there’s not enough lighting and there are not many nice people about nowadays;
- Sometimes, apart from walking to and from the pub;
- No, I get lost more often.

Family carers said:

- No, there are too many news reports of anti-social behaviour, drug taking, etc.;
- Being visually impaired creates problems;
- Yes, depending on location;
- I never go out alone at night;
- I don’t go out at night.

**Representatives of Disability Organisations said:**
- I don’t go out at night;
- Yes, because I am with friends or partner;
- I try to avoid walking through the town centre after the shops have closed;
- I feel vulnerable and I don’t usually have the energy;
- Yes, mostly;
- If supported, yes, but I very rarely go out;
- It’s scary because of the lack of lighting. I only go out when with someone else;
- I don’t go out at night;
- Yes, because I get some support from support workers;
- Some service users will not go out in the dark and staff are not always available after 8pm;
- There’s a lack of street lighting and there are no Police Community Support Officers after 6pm.

**Listeners from Statutory Organisations said:**
- Driving yes, but I wouldn’t walk on my own;
- As a professional I feel safe but I can understand why service users would not feel safe;
- Nothing limits me physically or mentally so I rarely feel vulnerable when out on my own after dark;
- I prefer to go out with someone. Sometimes, as a young woman, I feel vulnerable;
- No, not on my own;
- I usually drive and I live in a safe area with very little crime;
- No, not when I am alone and feel vulnerable.
‘Apart from this event, do you think that the needs of disabled people are well represented throughout Suffolk?’

Disabled people said:

- Organisations only pretend to listen to disabled people;
- As my speech is unclear, no one listens to me;
- Involvement of disabled people could be improved if we could encourage younger persons to participate;
- Disabled people need to know they are supported;
- Yes, but good representation and communication is key. Not everyone knows what they are entitled to;
- I support people as a job;
- There’s no one here from a dementia organisation;
- No, because of lack of funding;
• Some needs are well represented but not all. There is lots going on, Suffolk People First events and the Learning Disability Strategy being two good examples;
• Hate crimes are reported more throughout the UK but more can be done to create safer environments such as community cohesion;
• The biggest problem for any disabled person is transport. Suffolk is the worst county in England for transport (bus availability);
• There are several groups and organisations;
• Mental health problems (of others) can impact on own mental health;
• Things are a whole lot better but there is still room for organisations to take more note of disabled people. They give us what they think we need rather than what we want. Partnership working is given lip service;
• No, there are improvements but it is an uphill struggle;
• There are not enough events or organisations that can represent;
• We need more people to represent disabled people;
• Improvements are being made. Whilst many groups are out there, access can be difficult. Whilst groups like this are improving matters, getting others to listen can be a struggle;
• I don’t think my disability is recognised enough;
• No, not always well catered for as we do not know what is available unless we come to an event like this;
• Yes, through Disability Forums.

Family carers said:
• It varies depending on the disability;
• No, it could be improved;
• A lot more can be done especially by organisations pulling together to distribute information about available services;
• No, I just don’t know how others feel;
• No, no one really listens.

Representatives of Disability Organisations said:
• No, all workers in our sector are over-subscribed and overworked;
• There is lots of information on websites;
• An annual event with a handful of service users is not really enough;
• No, opportunities are not well known. Need to be in the system. Lots of people don’t know about events;
• More Planning Groups are coming to us to ask for our input;
• No, the councils don’t necessarily understand;
• Yes, but we need to be tougher in our approach;
• Yes, thanks to groups like the Suffolk Coalition;
• No, there is a lack of awareness, not enough employment opportunities. Need to be more involved;
• In some ways, yes. Could be improved;
- Disabled people’s needs are given less priority than they should be;
- Yes, many places are becoming wheelchair friendly and accommodating people’s needs;
- There is a lack of groups/support and general awareness;
- Yes, there are plenty of events we attend, related to disability awareness. We get lots of information and Suffolk is represented well in the community;
- Events could be something that help other people;
- There are many organisations that service users can be signposted to. Staff have access to these;
- There needs to be more public knowledge/advertising for the services and groups available.

**Listeners from Statutory Organisations said:**

- It’s getting better;
- No, there are barriers to accessing services. There’s a lack of accessible information, poor understanding of reasonable adjustments, poor understanding of mental capacity, and poor understanding of the needs of people with learning disabilities;
- No, terrible public transport, shocking access to services, often can’t get to appointments at hospital, etc.;
- From my limited time at Suffolk County Council, I have not witnessed any service user involvement in service restructure. I have only been with the organisation for a short time so there may be involvement I haven’t witnessed;
- Discussions such as these should occur on an everyday basis, not annually. Disabled people should be able to influence provision/services at any time;
- There are a range of support organisations but funding is always an issue;
- This event can be seen as a tick box exercise if meaningful partnership work is not achieved throughout Suffolk. This means creating innovative ideas to support disabled people from a wide range of backgrounds involved in having their say and work collaboratively with organisations to improve how we deliver services;
- I feel that there is still work to be done but I know that disability issues are considered in all project planning;
- It is difficult for people in rural areas to access services;
- There are Disability Forums across Suffolk which give people the opportunity to discuss ideas / concerns. These can link with local service providers;
- I feel that information is available to those that know about it but can sometimes be hard to find;
Accessibility to services and information is limited, society is geared towards people without a disability across the board. People with a disability have little or no voice in shaping services;
- It is getting better but still needs improvement;
- Many with rural needs are left feeling isolated;
- It is patchy. Sometimes people don’t think about consulting or involving;
- There are plenty of organisations and funding for support;
- There are Community Hubs / Social Groups and events such as this bringing people together;
- It’s something that I feel, as a county councillor, needs greater effort.
Issues and Concerns from the 2017 Discussion Groups

Being a full part of our community

What does being part of the community mean?

- People do not like the term ‘service user’ because it feels derogatory and belittling.
- We are disabled people or people with a disability, although both terms are patronising and do not recognise what people can do rather than what they are not able to do;
- The use of language can be a problem;
- People would like choices. It is okay if you live where there are choices;
- I want to be able to be allowed to make my own choices and my own decisions;
- There is a lack of freedom of movement – difficulties with transport to get to where you want to go;
- The support of a suitable person or service needs to be available when you want or need to go out;
- There is a need to be able to be alone and have some personal space;
- People need the chance to be independent and the chance to learn;
- There is a need for personal accommodation; There is a feeling of not leaving home if that is attached to or in the family home;
- There is a feeling of satisfaction when you are left to live as you would like to live;
- It is important to have pride over where you live;
- Networking is important so you know where to go for help;
- Community Centre Hubs are good but only if they are accessible;
- Buildings used for public meetings need to be accessible to all people and have facilities such as hearing loops;
- Feeling a valued part of the community is very important – not just a tick box exercise;
- Communication is vital. Information via websites is not always the best way forward.
- Not everyone has internet access and it costs too much or the connections are poor. Therefore, people are isolated from the community;
- Suffolk County Council removed the hard copies of bus timetables to save money but not everyone can access the bus timetables on line.
What would success feel like? How would it feel to be fully part of the community?

- Villages do not have much for young people to do, it is mostly for older people;
- Most activities, social opportunities and services, are concentrated around Ipswich and Bury St Edmunds;
- There is a lack of public transport to get to places to do the things you want to do;
- That cuts down what you can take part in;
- You need easy access to all the parts of your life and able to access transport to do that;
- People want to be with the people of similar age and interests. How do you enable that in a rural community;
- The biggest barrier is public transport. If you cannot drive you have to rely on others or have to spend a lot of money to get to places;
- Some people use Community Transport but normally you have to give advance notice of your journey;
- The lack of transport restricts where you can live;
- It helps if you can get to places on your own;
- All buildings should be fully accessible. Suffolk Coastal District Council has relocated to East Suffolk House and their large public meeting room is on the first floor. The lift is not fire proofed and the safe evacuation of people with mobility impairments in an emergency would be difficult.

Do you feel having a job helps you feel more part of the community than if you do not?

- We all feel that being a part of any community is made easier and more fulfilling if we have gainful employment;
- We do want to have a job and not be reliant upon the welfare state then our self-worth and standing within the community would be greater.
- It gives you a purpose in life to have a job rather than be on benefits;
- It is great to have your own money and you can do more;
- It broadens your social circle;
- It stimulates your mind and broadens your outlook;
- You can provide for your family and give them a good life with chances;
- There are barriers to work. Employers need to look at what people can do and what they can offer rather than stereotype people;
- It is not very easy to get access to training;
- It is not even easy to get work experience because employers say they do not have time to provide it;
• Employers need to be less negative about employing people with learning disabilities;
• People feel they are being discriminated against because of their disability;
• Work experience is good if you can get it as it may help get a job in the end;
• People need good support to help with forms and applications;
• People may need support to do the work and therefore employers need to be able to understand and be prepared to make adjustments (in commercial firms this is difficult to see happening);
• Firms do not reply when asked what their policies are regarding employing disabled people;
• It might be helpful if there were mentoring groups to help other people to get work;
• One person was told that they needed an NVQ Level 3 at least to get any sort of job;
• Work and employment is a key part in marking someone feel part of their community;
• People need someone to give them the opportunity to work and this builds confidence in the long term.

Is our voice loud enough? Is there enough pushing of the issues for anyone to take any notice? What about the benefits to society? What is accessible?

• Lots of things still have a long way to go;
• Everything should be in easy read language;
• We need access to jobs, services, and social activities;
• We need access to transport;
• We need training and work;
• All these help and the lack of them hinders people from taking their full part in the community.
• The whole process of voting in elections is not disability friendly. People who want a postal vote cannot get information and forms in large print unless they travel to a Polling Station. This is not ideal;
• Deaf people do not always vote because of a lack of information available via an interpreter. Could sessions with candidates and an interpreter be arranged for people attending groups for deaf people?
• A Boards in Town Centres keeps people away from shops and cafés. Enforcement is needed to ensure that these do not become barriers to access;
Dementia friendly communities are a positive way forward but more awareness is necessary so people understand what this means and how it can be done;
Shops should have clear signs showing the assistance they provide to disabled people;
Having people with disabilities on television and on advertisements makes others (especially young people) see disability as ‘the norm’;
Being happy is very important;
Social isolation of disabled people is all too common. Clubs, groups and classes can all help;
Having good neighbours builds a sense of community – knowing that there is help available; I live on my own anyway. My way of being in the community is being involved in Community Church and being part of a local group which is round the corner;
People being part of the community need more access to local services which in most cases they cannot have.

Getting information you can use

Schools are not always the best communicators – they need to listen to parents and medical consultants;
Local authorities and other organisations’ websites are confusing and not straightforward;
With all the changes of local authorities, how do we know where to find people;
Do local authorities have a number so that people with hearing impairments can text?
Other disabled people who use services are some of, if not, the best people to go to for advice;
The internet is a good resource. However, some people cannot or do not wish to use the internet;
Social media is brilliant but do not presume that everyone uses it;
Make sure that paper copies are available, also a point of contact or someone to speak to;
Do not tunnel vision technology, there is often no equal access for those unable to fill in forms on line;
If you want something, you have to apply for everything because no one tells you what you are actually eligible for;
The NHS is not currently providing accessible information – Ipswich Hospital is working on it;
Information needs to be accessible;
People with hearing impairments have difficulties with booking appointments and are unsure as to their rights to have an interpreter;
Family carers are not always able to cope so require assistance in accessing services and information;
Data bases must be kept up to date;
It feels like a constant battle to get information;
Families with young disabled people are not able to attend meetings often due to timing issues (mostly evenings);
Young disabled people are not very involved. However maybe or possibly because they are not at that stage of their life’s journey;
Everyone has the responsibility to signpost people to information;
Often communications are only occurring with new service users, organisations are not going back providing new information to previous or long term service users;
More voice assisted technology needs to be available;
Providers need to make sure the information they provide is accurate;
Too many service providers are using jargon or acronyms without any explanation;
Some telephone service providers speak too fast and do not speak clearly;
Staff in organisations seem to always be moving on and then it is difficult to find out who has taken over;
Leaflet design needs more attention, the font needs to be larger, the colour contrast needs to be clear and the words should not be superimposed on a picture;
It is difficult to contact Universal Credit;
Does the government still make information videos in British Sign Language?

Action Point: To find out if the government still provides information videos that provide information in BSL and other accessible formats.

Outcome: To allow people access to information.

Timescale: 2 months

Made by: Lauren White-Miller, West Suffolk Councils

We need to look at forms to make them clearer to fill out or have services accessible to those with all needs that will assist in filling in the forms;
Political correctness occasionally seems to get in the way of communicating;
Can we know the reasons why we are being denied contact details? We need to talk to specific people not just whoever happens to be there;
Accessible information systems – it is challenging to have a standard for all computer systems. This goes to the bottom of an organisation’s list of priorities as it is only used by 0.06% of the population;

The materials used cannot assume everyone has had the same education – simple language and no jargon is essential. It is difficult to have a ‘standard’ and it is difficult to personalise accessible information. The ‘one size fits all’ approach is not realistic;

Some service users do not understand what ‘alternative format’ means and thus do not realise that they can get information in large print;

Talking text works well;

Suffolk Infolink is not very accessible, it is not promoted enough and does not include events. Partners need to take more of a responsibility to share messages and communicate;

In cities there are ‘talking buses and lamp-posts’. There should be more focus on this kind of development in our area;

Using images in the provision of accessible information does not always help as people interpret images differently;

A uniform picture bank for all Suffolk organisations to use for their easy read documents would promote accessibility;

There should be more public awareness of accessible information standards. How do we raise the awareness of people’s rights?

Organisations can produce easy read documents themselves and training can be provided by ACE (Anglia) Ltd.;

It is difficult to get information if you do not have the internet;

The ‘hold’ music on telephone helplines aggravates conditions such as tinnitus;

Telephone helplines are complicated. There should be an option to bypass the automated system for disabled and elderly people.

Getting the benefits you are entitled to

Assumptions are being made at Personal Independent Payments (PIP) and Employment Support Allowance (ESA) assessments and this is resulting in people not being awarded benefit, feeling anxious and demoralised;

Assessors are not asking supplementary questions to ‘dig’ for additional information;

Assessors are inconsistent about whether they will take into account the views of someone supporting the claimant;

Assessors are just trained to complete forms;
• Claimants should be made aware of the scoring of benefit claims;

**Action Point:** To share the scoring criteria for PIP and ESA claims (via current distribution lists and Disability Forums).

**Outcome:** To make claims easier.

**Timescale:** 3 months

**Made by:** Ros Ross, Avenues East

• The system is very off putting and claimants do not feel able to navigate it confidently;
• There is an inconsistent approach from GPs with regard to charging for support with assessments for PIP and ESA. Charges can be between £15 and £85.
• It is possible that individuals and organisations are being charged differently;

**Action Point:** To follow up with GP Practices about the range in charges for assisting with benefit applications by providing information.

**Outcome:** To provide clarity for patients and claimants.

**Timescale:** Ongoing.

**Made by:** Katie Sargeant, West Suffolk Clinical Commissioning Group

• GPs do not understand the system and therefore this leads to poor quality assessments;
• If benefit claimants are not in receipt of services, it is difficult to access information and support from organisations;
• The claim process impacts on the physical and emotional wellbeing of claimants and their families;
• People with hidden disabilities such as dementia, Alzheimer’s Disease, Asperger’s Syndrome or autism find the system discriminatory;
• What about Universal Credit?
• Confusion about when Universal Credit is being rolled out in each area;
• Benefit arrears cause anxiety and stress and potentially claimants to lose their homes;
• Staff working in the benefit system in local government are struggling to understand and keep up with the Universal Credit changes;
• Pension credit has a lengthy claim process. Some people are being told on the telephone if they are or are not eligible to make a claim;
• There is a lack of understanding about benefit entitlements;
 Queries about benefit claims are made to 0300 telephone numbers which are not free to mobile telephone users and are charged at local rate to landlines;

Suffolk Coastal are relaunching the 'Coffee Caravan' to help make information about benefits more accessible;

PIP assessments are daunting and intimidating for the claimant;

The Bury St Edmunds Assessment Centre is not accessible to wheelchair users;

Assessments are cancelled or times being rearranged without the claimant being made aware. Claimants are travelling long journeys on public transport only to discover that they have had their appointment rearranged;

The Disabled Advice Bureau in Ipswich has an inaccessible building;

There are so many different names of organisations that offer support to claim benefits that they are difficult to find.

The poor access arrangements in buildings has meant claimants cannot get in to attend their appointment and this goes down as a 'no show';

There is a public misconception around eligibility for overseas citizens;

Non UK residents are frightened to access the benefit system due to fear of receiving a letter advising they may have to leave the country;

There is lots of uncertainty around the long term nature of Employment Support Allowance and Personal Independence Payment claims;

There are difficulties for those with autism, mental health issues, and other such conditions to receive an award of PIP;

Claimants feel that short term awards are like 'a knife hanging over them';

Some people are going to find themselves over £30 worse off once Universal Credit comes into play;

The local (Mid Suffolk) benefit officers have suggested that the discretionary fund may not be available to those with private rental arrangements;

The private rental system discriminates against those in receipt of benefits;

Many people on benefits do not claim their full entitlement due to the stress and anxiety involved;

The benefit system does not take into account the fluctuating nature of some illnesses and disabilities. Not all disabilities are visible;

Claiming benefits has a detrimental impact on the mental health of the individuals claiming and the families involved.
Using health care services at home or in hospital

- Mental health services have ‘got really bad’;
- It is more helpful for staff to pay home visits, as they can then get a better overview of the issues patients with mental health problems face;
- The secondary mental health services are not working;
- Wellbeing services are okay, but could be tweaked;
- The Police, Health and Service Users need to develop joint training in managing hot spots in mental health services;
- Patients with mental health issues are generally reluctant to complain about mistreatment by staff for fear of repercussions;

**Action Point:** To speak to the Head of Complaints at the Norfolk & Suffolk Foundation Trust regarding anonymous complaints and why patients feel they cannot complain.

**Outcome:** To remove the feeling of discrimination when making complaints.

**Timescale:** 6 months

**Made by:** Ravi Seenan, Head of Equalities and Engagement, Norfolk & Suffolk Foundation Trust, in conjunction with patients as appropriate.

- There is no point talking about innovation if the financial support is not available to improve services;
- I had a really positive person centred experience at the Ipswich Hospital in the dermatology and neurology departments;
- It is difficult on assessment wards to get specialist consultants to see patients especially at weekends;
- It can also be difficult to get specialists to see patients with a disability at weekends when they are inpatients;
- Staff have a high case load;
- Discharge to Assess – there is not enough support in the community to provide care for patients;
- Patients need to take responsibility for attending appointments;
- Updates of clinic waiting times are helpful;

**Action Point:** To investigate why some clinics run with no waiting times.

**Outcome:** To identify good points that can be mirrored in other clinics increasing patient satisfaction and reducing waiting times.

**Timescale:** 4 months.

**Made by:** Steve Bruce, Patient Experience Insight and Improvement Officer, Ipswich Hospital NHS Trust
- Communication is key in hospitals;
- NHS accessibility standards state that patients should be asked the type and size of font they prefer/require on appointment letters. This does not always happen;
- There is a severe lack of beds for respite care;
- Some staff do not know how to apply for extra care, such as beds in the community for respite care (private homes paid to take patients in);
- I have always had fabulous treatment from the Ipswich Hospital;
- There are issues with Universal Credit and Personal Independent Payments;
- The Learning Disability Action Group at the Ipswich Hospital have drawn pictures to show to patients and prospective patients what it is like to visit different areas of the hospital.
- Photos of things like pacemakers are used to show for information to patients with learning disabilities;
- It is very difficult to get through to the GP surgery by telephone. It is even harder if you have mental health issues;
- There is a severe lack of transport to get patients from home to GP surgeries;
- The reduction in community transport is causing issues;
- There are problems in rural locations of getting transport to GP surgeries or hospitals;
- There are difficulties accessing GPs especially in rural locations;
- Patients would like consistency in seeing the same GP;
- Education for GP receptionists could be improved;
- GP staff need knowledge of GP Plus and Out of Ours services and should pass this knowledge on to patients when appropriate.

**Having a house to live in and support to live there**

- Orwell Housing supported me very well and looked out for me;
- Bad support workers took my money;
- The gate was locked so I could not get out. The gate was put up by the owner of the property. This was a risk to my safety;
- A safeguarding meeting was held;
- You need the right person to help you live independently and help sort out your bills;
- I did not read the letters so I went into arrears and had a nervous breakdown;
- People do not speak to me but speak to my support worker;
- There needs to be an adaptation programme, the pull cord was nowhere near the toilet;
- CCTVs are only allowed to record around the home;
- The tenancy was difficult to understand but my support worker helped;
- Adult & Community Services pays the rent but the money is always delayed by a week so I am always in arrears;
- Services need to approach the tenant, not their support worker;
- I am interested in training staff around what disabled individuals may need;
- The Gateway to Homechoice system did not work for me. The formats the councils use is not flexible;
- I am a private tenant and the landlord is not available;
- I have a monthly rolling contract;
- I had no hot water and the boiler was not working;
- I had somewhere to live but no council house;
- In Forest Heath, you have to be out on the streets for six weeks before there is any housing;
- It can be difficult to find a house accepting guide dogs – they are working dogs not pets;
- I went to 22 properties where dogs were not allowed;
- Private rentals often say ‘no pets’;
- Councils want to see people homeless before you can be given a home;
- The advice from the Council was to stay in the house until the bailiffs evict you;
- It was hard trying to find people to help;
- I kept bumping and hurting myself and ended up in tears;
- You can be put in a top floor flat if you have a visual impairment or amongst drug addicts. You feel worthless;
- A tenancy agreement can mean you cannot have people stay over for a visit. It would be a breach of the agreement;
- Getting a house is difficult – people can only bid for accommodation in the area in which they live or they need to have family connections with an area;
- Some people need to move on from their housing and are ready to do but there is nowhere to move on to. It is hard;
- This is not good for their mental health;
- Private landlords will not take people on benefits;
- My Housing Benefit is not covering half the cost of the rent;
- I tried the Citizens Advice Bureau but was not satisfied with their response;
- Remap are able to provide bespoke equipment;
Social housing or private housing will not allow equipment to be fixed;
I would like to support others through charity work;
I was offered an apartment on the first floor in a different county;
Things that can be done:
- Talk to Suffolk County Council about safeguarding issues;
- Talk to your District Councillor;
- Present yourself as homeless to the Local Authority as they have a legal duty to support you;
It is scary to be moved out of your safety network;
There is a lack of temporary accommodation in Mid Suffolk;
I was scared to have environmental services come to my home and perhaps ruin my chances of keeping my home;
If a service user has mental health issues and is being treated, do they lose their home?
Orbit has short term tenancy of two years for people with mental health needs. Then people are moved to Gateway to Homechoice and supported for up to six months by Orbit;
We need guidelines on tenant’s rights;
When a parent dies, succession tenancy may be an issue and this leads to an unsure future;
There may be 5 yearly reviews of tenancy but this is not yet implemented;
It is good to have independence;
If it is a private tenancy, what would the process be?
If you have never been in a situation for housing, where do you start?
How do people with a disability get housing and get out of residential care?

**Getting a job and keeping it**

The clear and apparent problem is how to bring together disabled people who have difficulties in getting support and information with those people who know about what is available.

**Issues**

- Training/skills of Jobcentre Plus staff is mixed at best and from a user perspective often poor. Information about opportunities and services available are not consistently passed on;
- CV writing skills needed – access to training;
- Interview skills needed – access to training;
- IT training needed particularly for ‘older’ disabled people who want to find work either for the first time or re-entering after a prolonged absence;
• Getting to work can be a serious issue particularly in a rural area when you are not able to drive;
• Flexibility of work around fluctuating health problems is a problem. Employers are generally not tolerant of someone who cannot consistently attend work for fixed hours;
• Support in the early days of getting a job is needed for some when people are not used to work. Simple things like making sure of getting there on time;
• Voluntary work is used as/ considered to be a replacement for paid work for disabled people;
• The voluntary sector is having to fill a very large gap left by the public sector;
• The location of available work can be a problem – transport or relocating;
• Social housing is a constraint to mobility in looking for work;
• The impact on benefits by taking paid employment is a significant disincentive. This has not/ will not change with the new benefit system. If someone tries to work and this goes wrong, a job fails or ends (short contract) it is very difficult to return to previous benefits. People can end up on Job Seekers Allowance when they were previously on Employment Support Allowance;
• Providers of support services are constantly changing, largely due to the fact that they are 3rd sector and funded only in the short term, so that it is difficult to keep track of who does what even for the professionals working to support disabled people. An example of this is ‘Work Choice’ (referrals are meant to be made through Jobcentre Plus) which was only funded for six months and is coming to an end;
• Not enough is done at school to prepare disabled people about what happens next;
• The £20 limit on paid work before benefits are affected is too low;
• People are concerned that employers interview disabled people top tick a box and really have no intention of actually employing someone with a disability;
• Challenging employer discrimination is very hard;
• Employers do not have an understanding of what disabled people can contribute;
• There needs to be more support not only from employers but also from the Department of Work and Pensions. Experience is better than qualification in certain areas.
What is available

- Minding the Gap – providing a range of activities for 15 to 24 year olds to gain skills for work. [www.mindingthegap.org.uk](http://www.mindingthegap.org.uk)
- Opportunity Suffolk – opportunities into employment for anyone aged 24 or over, who lives in Suffolk and has not worked in the last two years, [http://www.tchc.net/services/building-better-opportunities/opportunity-suffolk](http://www.tchc.net/services/building-better-opportunities/opportunity-suffolk)
- MyGo - Job Vacancies, Career Coaching and Employability Training for 16-24s in Suffolk, [https://www.its-mygo.co.uk/](https://www.its-mygo.co.uk/)
- Work Choice - Helping you get and keep a job if you’re disabled and find it hard to work. [https://www.gov.uk/work-choice](https://www.gov.uk/work-choice)

What might make a positive difference

- Disability awareness training for employers;
- An information directory about available services;
- Raising the restriction on how much can be earned by disabled people before benefits are affected;
- Consistency/ longevity of support service provision;
- Better preparation for work at school.

Being safe where you live and where you spend your time

- I feel safe in Woodbridge and Melton;
- I don’t feel so safe in parts of Ipswich;
- There are concerns about:
  - Door to door fraud;
  - Online fraud;
  - Bogus callers;
- Elderly and vulnerable people can be embarrassed to report incidents;
- In Lowestoft, the street lights are turned off at midnight. There is a spate of cars being vandalised;
- The lack of PCSOs after 6pm is a problem;
- More CCTV coverage would be good;
- Felixstowe feels safe;
- Groups of youths cause fear and concern, when hanging around places such as leisure centres, and bus stops;
- Councils should be asked about street lights. Perhaps there could be motion sensors if they cannot be left on all night.
We talked about the importance of understanding Hate Crime, particularly when relating to the disability strand of this group;

When calling 101, control room operators were not all aware of the Constabulary’s Hate Crime Co-ordinator role. The Constabulary’s Hate Crime Co-ordinator role is quite a relatively new role which has been created as a result of Suffolk Constabulary’s restructure last year, and ongoing awareness raising of the Community Safety department’s newer roles is something that is ongoing;

The Hate Crime co-ordinator role is a strategic level role, and is different to the roles that were part of the now dissolved joint Hate Crime Service for Suffolk. This is currently awaiting funding decisions to be made so that a new joint Hate Crime hub can be commissioned with partner organisations;

We discussed the definition of Hate Crime and agreed that it is a complex subject area. Some of us knew that a Hate Crime can be either violent, or non-violent, others felt that more clarity of the definition is required in the public consciousness.

How is the recording of a Hate Crime decided? Hate Crime recording is led by the victim’s perception, for example, “I think that I was targeted because of my disability”. This raised concerns that a ‘perpetrator’ could be wrongfully accused by the victim of committing a Hate Crime, due to a misunderstanding, or a lack of understanding of hate crime, and this would have potentially have big ramifications for the alleged perpetrator when progressed via a criminal charge;

Would (wrongly) being accused of a hate crime show up on a DBS check? It would not, but it would likely show up on an advanced DBS check, but this procedure is decided centrally by the Home Office;

What is being done to promote community cohesion and the reporting of Hate Crime. Suffolk Constabulary has Police Community Support Officers who are trained and supported to fulfil a specialised ‘Vulnerable Communities’ link role in each area of the county, which includes a large focus on going out into the community and communicating these important messages effectively at an ‘on-the-ground’ community level. There is awareness raising and information cascading work ongoing with several Voluntary and Community Sector partners as well as other public service organisations;

Disabilities can prevent some victims coming forward, due to communication or capacity issues, or feelings of embarrassment. Suffolk Police and other partner agencies throughout the county promote and encourage everyone reporting Hate Crimes. Hate Crimes can also be reported by witnesses, independently, or on behalf of the victim. We discussed reporting methods for Suffolk. These include: the Police
website reporting tool, Police 101 (non-emergency) and 999 (emergency) telephone numbers, Crimestoppers (can be reported anonymously), and the TrueVision website (report-it.org.uk);

- Concerns were raised that the TrueVision website may not link in to Suffolk Constabulary and is not a viable reporting tool for Suffolk. It was clarified that the ‘Stop Hate UK’ service is not currently tied in to Suffolk, but the TrueVision website is a national service and passes reports on to all national Constabularies;

- ACE (Anglia) Ltd Anglia are currently producing Hate Crime communications for people with different communication needs;

- Many of us said there was a general feeling of not being safe in Ipswich and Bury due to high profile crime in the news, particularly not feeling safe at night. Some of us still use the Stay Safe Card Scheme alongside information on how to stay safe in the community. Stickers in public buildings such as shops can still be seen in some towns and this helps us to feel safer;

- We felt that we would feel safer if groups of people loitering in public were removed. It was stated that groups gathering in the street and public places is not illegal unless it is blocking a public walkway;

- The ‘sense of community’ is not there anymore. More interaction amongst the community and amongst neighbours and neighbourhoods would make people feel safer;

- Members of disability communities would be stuck without ‘community friends’ supporting them day-to-day;

- One of us raised an issue with receiving help from strangers following a traumatic situation, even if that is police officers or other emergency services;

- This is going to be an issue that ranges from individual to individual and the emergency services are some of the most suitable people to assist following a traumatic situation;

- It is important to encourage the reporting of issues so that they can begin to get resolved;

- Seeing drink and drug users in the streets can cause passers-by to feel unsafe. It is important to make agencies such as local councils and police aware. Things like legal smoking behaviours in public are common courtesy issues, but illegal substance misuse and anti-social behaviour can be tackled if reported;

- What is the process after a Hate Crime has been dealt with? What support is there to deal with the lasting impact on victims?
The support agency that is currently commissioned is ‘Victim Support’, the new Hate Crime service will include enhanced support for victims of Hate Crime;
Victim Support will not offer additional support if the victim has a social worker in place;

**Action Point:** To clarify whether Victim Support does not provide additional support to victims who have social workers.

**Outcome:** To provide clarity for victims of hate crime.

**Made by:** Neil Stain, Hate Crime Co-ordinator, Suffolk Constabulary

- ACE (Anglia) Ltd has previously featured in articles for Suffolk Constabulary’s internal staff magazine ‘Constables County’ regarding Hate Crime and sharing experiences of Hate Crime;
- Can I report historical Hate Crimes? Yes, it is the same process as reporting a current Hate Crime, but if it is historical, there may not be the same access to evidence, for example, CCTV recordings;
- I have not reported Hate Crimes to the Police because I feel that the police are too busy, with them not having enough staff unfortunately. Advice was given to report all crimes to the police and that the police are there to help;
- We discussed the thresholds between and the definitions of Hate Crime and Hate Incident;
- We summarised Hate Crime as follows: “A Hate Crime is committed against somebody because of who they are or what they believe in”.

### Using public spaces and places

- Suffolk libraries are more of a community space rather than just a library. They are generally welcoming and accessible to all;
- The implementation of Universal Credit might need a dedicated computer. How will people apply if they do not have a computer?
- From a service user perspective, accessing information can be difficult. There can be problems with the internet and it is difficult to spot ‘scams’;
- There are insufficient resources for disabled people, everything seems to be on line and it is not always easy to understand;
- There is an assumption that the information is ‘out there’ and is understood but not all of it is easy read. Very few people use braille and it seems like a tick box exercise when information is said to be available in braille;
- Social Services is less likely to refer to specific support organisations. Why is this? Is it policy or cuts in funding? More organisations need to
know about Suffolk Infolink as it is creating duplication. It is not publicised enough;

**Action Point:** To make a link between Suffolk Libraries and Suffolk Infolink.  
**Outcome:** To raise awareness of Suffolk Infolink as a resource.  
**Timescale:** 1 month to put proposal forward.  
6 months to implement a strategy.  
**Made by:** Kate Yates, West Suffolk Association for the Blind and Suffolk Libraries

- Some shops are more accessible than others;  
- Some shops do not have automatic doors;  
- Listed buildings are difficult to adapt to make them more accessible;  
- A Boards and displays on pavements limit access;  
- Mid Suffolk Disability Forum recently completed a survey about accessibility in Stowmarket. A number of recommendations were made but it is always difficult to work out which organisation (County, District or Town) is responsible for issues identified;  
- Ipswich is using churches as community spaces;  
- There are not enough hoists in accessible toilets in Ipswich, particularly taking account of the closure of public toilets;  
- There is a need to ensure information is available to let people know which places are accessible rather than no information at all.  
- Websites such as [www.accessiblecountryside.org](http://www.accessiblecountryside.org) are useful. It would be helpful for Councils’ Marketing and Communications Teams to promote this to show accessible countryside routes, parks and beaches;  
- There is an issue with the availability of spaces on buses to enable wheelchair users to travel;  
- I am concerned about the Bus Station in Bury St Edmunds. The information access points are no longer there and there is no audio information. There used to be staff that I could speak to for information. It is difficult for blind people. Are there any plans in place to rectify this?  
- There are only 12 accessible taxis in Ipswich. A list does exist of taxi operators who provide accessible transport but this has not been promoted enough;  
- At Ipswich Railway Station, the taxi stand is too narrow due to tree planting and the pavement;
• Woodbridge plans to remove the parking for blue badge holders in the Thoroughfare. It is a good idea as the parking is actually in the way of wheelchair users trying to access the shops;
• There are concerns over the plans for the Cornhill in Ipswich particularly during the development phase. I am awaiting answers to questions raised and wish to be kept informed;

**Action Point:** To see whether Ipswich Borough Council can facilitate an event for disabled people to know more about the Cornhill development.

**Outcome:** To ensure that disabled people are kept best informed about any disruptions/obstacles during the development phase.

**Timescale:** 6 months.

**Made by:** Alice Firbank, Community Engagement Officer, Ipswich Borough Council, in partnership with Simon Daws, Guide Dogs

• Councils need to look at transport operators as bus services are very limited making access to more rural areas difficult;
• There should be a pedestrian crossing in Old Martlesham between the bus stops;
• Crossing roads is always difficult;
• There should be audio announcements on public transport.

**Action Point:** To investigate the implementation of the Transport Bill regarding audio description on Ipswich Buses.

**Outcome:** To seek information.

**Timescale:** 1 month

**Made by:** Alice Firbank, Community Engagement Officer, Ipswich Borough Council

**Action Point:** To link issues raised from the learning disability community when accessing public transport.

**Outcome:** This action will be taken to the next ‘Travel and Transport’ Group at Suffolk County Council.

**Timescale:** To be confirmed but likely to be around the 17th December.

**Made by:** Max Clark, ACE (Anglia) Ltd

**Working in Partnership** with Suffolk County Council, Essex County Council, Learning Disability Strategy and Partnership, and ACE (Anglia) Ltd.
Getting to where you want to go

Barriers

- There is a lack of public transport. Suffolk has the worst transport system nationally (apart from one other) and has the largest number of people with disabilities;
- People have to rely on friends for lifts;
- Buses have been cancelled in rural areas because they do not have enough people to warrant the service. This results in people being more isolated and not been able to make appointments;
- There are no audio announcements on bus services so how do we know which bus we are getting on if we are visually impaired? We feel vulnerable. We need ‘talking’ buses;
- Buses should make stop announcements so people know where they are;
- Bus drivers drive past when you are waiting at the bus stop. If you are visually impaired how are you meant to signal the bus to stop if you cannot see it? This happens to me time and time again. I have complained but it still happens. The bus driver is responsible for stopping;
- For people who cannot see or read, signs and timetables are not accessible. This is discrimination. If you are in London, audio announcements work well;
- Visually impaired people cannot read timetables. The First Bus app was changed and is unfriendly, does not work and gives completely visual information which is useless;
- Bus stops often have the wrong information and need to be regularly updated;
- The council’s subsidy needs to increase. If you live in a rural area the services are limited and even these are unreliable. For example, there are two morning buses from Claydon to Ipswich, one at 7.50am and one at 9.25am with nothing in between;
- There are no buses in my area after 6pm;
- The future of Bury St Edmunds Bus Station is of concern;
- The law is not clear whether people with pushchairs should fold these up to enable wheelchair users to use the space on buses. Drivers need to be empowered to ask passengers to fold up pushchairs;
- Not everybody has someone to help them;
- Taxi fares should be the same for wheelchair users. It is illegal to charge a wheelchair user more for a taxi journey than a person without a disability would be charged;
- Concessionary bus passes cannot be used before 9.30am and this is a problem for many disabled people trying to get to work or college;
- In Suffolk, companion bus passes are not available for people whose disability means that they are unable to travel on the bus on their own;
- Not everyone knows that disabled people unable to use bus services can apply for £100 of concessionary travel vouchers to help pay for taxis;
- Travelling by taxi is not cheap and it does not take many journeys to use up the £100 per year;
- If money is an issue, people with disabilities could be charged half fare rather than have their transport options reduced;
- Getting out and about is difficult for disabled people who have to rely on the availability of support workers who only work certain hours. Some will make allowances but it does impact on arrangements and socialising;
- Community transport gets very booked up so sometimes it is not possible to travel;
- Getting to hospitals is difficult especially with more appointments being given for early mornings, weekends and evenings;
- Non-emergency hospital transport has criteria you have to meet in order to be eligible. Even if you do meet the criteria, you may not take someone with you. It is not a customer friendly process to try to book transport;
- Some people are being refused access to public transport if they have guide dogs;
- Out of 500 Ipswich licensed taxis, only a few of these have wheelchair access. Ipswich Borough Council does not think this is discrimination;
- Taxis for travelling to work can be difficult as school runs take priority at peak times;
- People can be hostile to each other on public transport – sometimes there is a conflict when disabled people do not want to be on the same vehicle because of their behavioural difficulties;
- There have been attacks on guide dogs when they are working with their owners;
- Some drivers are allergic to dogs and therefore guide dog users are refused access on coaches, buses and taxis;
- The larger airlines can provide wheelchair access but coaches do not and this is unfair;
- Many wheelchair users have lost confidence in travelling by public transport because of worrying or poor experiences;
- Disability awareness training is patchy and sometimes new drivers do not receive timely training;
- Even on trains, the wheelchair areas are sometimes filled with luggage or pushchairs. It is best to ask for assistance;
• Ticket machines at unmanned stations are a worry. How do visually impaired people book their tickets?
• Trains from Ipswich to Cambridge do not run regularly;
• There is no one present at Newmarket Railway Station to help with people with wheelchairs or other disabilities;
• There is no lift at Stowmarket Railway Station so it is not possible to cross the railway line;
• Needham Market Railway Station has no access for disabled people to the Ipswich bound platform;
• Everything has to be planned and always having to book in advance is seen as a necessity;
• Disabled people worry that lifts or equipment might not work so that they become stranded;
• Blind people cannot relax as they always have to listen and concentrate in order to understand their journey;
• Potholes and speed bumps are a hazard for wheelchair users;
• Narrow pavements cause difficulties especially if you have a big wheelchair and you are scared of falling off the kerb and into the road;
• Other hazards are cars parking on pavements, overgrown hedges, overhanging branches, scaffolding, cutaway driveways, sloping pavements, and obstructions caused by wheelie bins and A Boards being left on the pavements;
• In Martlesham, there are concerns about the safety of disabled pedestrians using Beardmore Retail Park with the expected additional traffic from 2000 new homes being built in Adastral Park;

**Action Point:** To lobby for improvements for pedestrians at the Beardmore Retail Park in Martlesham.

**Outcome:** To have pedestrian crossings installed.

**Made by:** Simon Daws, Suffolk Guide Dogs Forum and the Suffolk Coastal Disability Forum

• Shared space schemes are dangerous and scary for visually impaired people;
• Mobility scooters can be driven very fast and be dangerous to pedestrians. Not all mobility scooters are insured;
• There are no regulations and anyone can go and buy a mobility scooter even if they are visually impaired;
• Rural communities are under-served. It is difficult to travel to larger towns if you cannot drive.
Good Points

- Trains provide a good service with assistance for disabled passengers at railway stations;
- Some bus drivers get out and help with access – this should be part of driver training;
- There are ‘Good Neighbour Schemes’ in some villages that are able to assist people with transport needs and it is hoped that there will be more of these.

Suggestions

- Council transport officers should spend a day in our shoes, both as wheelchair users or visually impaired to make a journey and experience the difficulties we face. We could set up a ‘Make a journey’ project.

**Action Point:** To consider setting up a ‘Make a Journey’ project.

**Outcome:** To improve the understanding of officers regarding the difficulties faced by disabled people when using public transport.

**Timescale:** 6 months

**Made by:** Linda Hoggarth, Chair, Disability Forum for Suffolk

- We need to meet with bus operators in Suffolk to talk about our issues.

**Action Point:** To contact bus operators in Suffolk to seek a meeting to discuss issues affecting disabled people.

**Outcome:** To improve the experiences of disabled passengers.

**Made by:** Linda Hoggarth, Chair, Disability Forum for Suffolk

- We need to raise our difficulties with public transport with Suffolk County Council.

**Action Point:** To raise the issues outlined with Passenger Transport, Suffolk County Council.

**Outcome:** To provide responses to the issues raised and information for disabled people.

**Made by:** Linda Hoggarth, Chair, Disability Forum for Suffolk
Getting your voice heard

- Decision makers need to attend events like this;
- People need to be involved in an ongoing way;
- More use can be made of social media – why not stream this event;
- Should events for disabled people be theme based?
- Should they involve family?
- Should events be more exciting to encourage more people to attend?
- There are many organisations and statutory agencies here but where are all the disabled people?
Appendix 1 – Delegates

<table>
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<tr>
<th>Name</th>
<th>Organization</th>
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<tr>
<td>Joanne Bailey</td>
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<td>Roxy Begum</td>
<td>ACE (Anglia) Ltd</td>
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<td>Kathy Bole</td>
<td>Suffolk Coalition of Disabled People</td>
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<td>Karl Butler</td>
<td>ACE (Anglia) Ltd</td>
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<td>Terence Carter</td>
<td>Mid Suffolk Disability Forum</td>
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<td>Paul Chambers</td>
<td>Genesis Orwell Mencap</td>
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<td>Max Clark</td>
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<td>Mark Conquer</td>
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<td>Sarah Jane Croft</td>
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<td>Ian Dunstan</td>
<td>ACE (Anglia) Ltd</td>
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<td>James Dickson</td>
<td>Genesis Orwell Mencap</td>
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<td>Amanda Eaves</td>
<td>West Suffolk Association for the Blind</td>
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<td>Yvonne Edge</td>
<td>Community Action Suffolk</td>
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<td>Adesola Farinmade</td>
<td>Suffolk Well-Being</td>
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<td>Laura Feveyear</td>
<td>Havebury Housing Partnership</td>
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<td>David Finn</td>
<td>BSEVC</td>
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<td>Matthew Foulger</td>
<td>Avenues East</td>
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<td>Emma Free</td>
<td>Guide Dogs – Suffolk Guide Dog Forum</td>
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<td>Tracey Fryatt</td>
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<td>Carly Gould</td>
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<td>Elaine Grace</td>
<td>East of England Homecare</td>
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<td>Carol Hales</td>
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<td>Michael Hales</td>
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<td>Peter Hulbert</td>
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<td>Timothy Hunter</td>
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<td>Janet Jones</td>
<td>The Richmond Fellowship</td>
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<td>Angela Keighley</td>
<td>ACE (Anglia) Ltd</td>
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<td>Steven Largent</td>
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<td>Julie Longhurst</td>
<td>Genesis Orwell Mencap</td>
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<td>Damian McCarthy</td>
<td>Leading Lives</td>
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<td>Rowena Marjoram</td>
<td>Realise Futures</td>
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<td>George Mark</td>
<td>Suffolk Coastal Disability Forum</td>
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<td>Liz Mark</td>
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<td>Sarah Mayes</td>
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<td>Joel Mayo</td>
<td>ACE (Anglia) Ltd</td>
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<tr>
<td>Maureen Mee</td>
<td>Suffolk Coastal Disability Forum</td>
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</tbody>
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Joanne Patrick
Steph Peck
Allen Pettitt

DIAL Lowestoft & Waveney/Waveney Disability Forum

Kelly Priestnall
Emma Pritchard

SENDIASS (Special Educational Needs and Disabilities Information Advice and Support Service)

Andrew Provan
James Scott

Waveney Disability Forum
Twenty-Four Hour Parky People (24HPP The Parkinson’s Social Group)

Lily Stenhouse
Isabell Stribling
Pat Summers
Doug Swayze
Quentin Thurtle
Cathy Walsh
Matthew Wilson
Chloe Winlow
Anyawooddissee
Hilda
Louise Woods
Kate Yates

ACE (Anglia) Ltd
ACE (Anglia) Ltd
Realise Futures
West Suffolk Voluntary Organisation for the Blind / Suffolk Libraries
Appendix 2 – Listeners

Roger Blake       Ipswich Hospital NHS Trust
Kay Bonning-Schmitt Waveney District Council
Stephanie Chamberlen   Norfolk & Suffolk NHS Foundation Trust
PCSO Stephen Cooper Suffolk Constabulary
Claire Davies       Community Dental Service
Clrr Sandra Gage    Suffolk County Council
Carolyn Gidney-Kelly Suffolk County Council
Anthony Green       West Suffolk Hospital NHS Foundation Trust
Siobbhan Hemmett   Suffolk Constabulary
Julie Irving        Ipswich & East Suffolk Clinical Commissioning Group
Jo Land             Group Deputy Chief Executive, Avenues Group
Gareth Moir         Suffolk County Council Localities & Partnership Team, Directorate Health, Wellbeing & Children’s Services
Karen Murton       Suffolk Constabulary
Terry Newman        Norfolk & Suffolk NHS Foundation Trust
Pauline Quinn       Lay Member for Patient & Public Involvement, Ipswich & East Suffolk Clinical Commissioning Group
Ravi Seenan        Norfolk & Suffolk NHS Foundation Trust
PCSO Ginny Shoesmith Suffolk Constabulary
PCSO Marie Smith    Suffolk Constabulary
Phoebe Vokes       Suffolk Coastal & Waveney District Councils
Jim Watt            Forest Heath District Council
Brenda Wykes       Community Dental Services
Appendix 3 – Facilitators/Note-Takers

*Jess Barber  
West Suffolk Councils

*Gillian Benjamin  
Suffolk Coastal & Waveney District Councils

*Steve Bruce  
Ipswich Hospital NHS Trust

*PCSO Sallyanna Chatten-Berry  
Suffolk Constabulary

*PCSO Michelle Crompton  
Suffolk Constabulary

*Teresa Farley  
West Suffolk Clinical Commissioning Group

*Alice Firbank  
Ipswich Borough Council

*Marielena Giner  
Ipswich & East Suffolk Clinical Commissioning Group

*John Grayling  
Babergh & Mid Suffolk District Councils

*Stuart Halsey  
Suffolk Coastal & Waveney District Councils

Sophie Hawkins  
Suffolk Coalition of Disabled People

Steve Hodgkiss  
Disability Forum for Suffolk/East Suffolk Association for the Blind

Linda Hoggarth  
Disability Forum for Suffolk/Mid Suffolk Disability Forum

Brenda Joyce  
Suffolk Coalition of Disabled People

*Gillian Orves  
Ipswich Hospital User Group

Ros Ross  
Avenues East

*Katie Sargeant  
West Suffolk Clinical Commissioning Group

*Shub Singh  
Suffolk Constabulary

*Aruna Sharma-Balls  
Babergh & Mid Suffolk District Councils

*Neil Stain  
Suffolk Constabulary

*Lauren White-Miller  
West Suffolk Councils

*Kristina Wilkinson  
West Suffolk Councils

Maureen Wood  
BSL Interpreter

* Also attended as a Listener

Registration

Tracey Fryatt  
Disability Forum for Suffolk

Carol Hales  
Disability Forum for Suffolk

Michael Hales  
Disability Forum for Suffolk

Administration

Trish Hayward  
Avenues East

Catherine Parry  
Avenues East
Appendix 4 – Market Stalls

Avenues East
BSEVC (Bury St Edmunds Volunteer Centre)
Community Action Suffolk
Community Dental Service
Disability Forum for Suffolk
East of England Homecare
East Suffolk Association for the Blind
Forest Heath Disability Forum
Genesis Orwell Mencap
Healthwatch Suffolk
Ipswich & East Suffolk Clinical Commissioning Group
Ipswich Hospital NHS Trust
Leading Lives
Mid Suffolk Disability Forum
Norfolk & Suffolk NHS Foundation Trust
Primary Care Learning Disability Liaison Nurses
Realise Futures
REMAP
Suffolk Axis
Suffolk Coastal Disability Forum
Suffolk Coalition of Disabled People
Suffolk Constabulary
Suffolk Disability & Health Action Group
Suffolk Learning Disability Partnership
The Richmond Fellowship
Warm Homes Healthy People
West Suffolk Association for the Blind
West Suffolk Clinical Commissioning Group