

Disability Focus

held on the 25th October, 2016
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@avenuesgroup.org.uk**



Disability Forum
for
Suffolk

Disability Focus
Planning Group



Thank you to the following organisations for supporting Disability Focus:

Avenues East

Babergh District Council

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Disability Forum for Suffolk

Forest Heath District Council

Gt Yarmouth & Waveney Clinical Commissioning Group

Ipswich & East Suffolk Clinical Commissioning Group

Ipswich Borough Council

Ipswich Hospital NHS Trust

Mid Suffolk District Council

Norfolk & Suffolk NHS Foundation Trust

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Suffolk Coastal District Council

Suffolk Community Healthcare

Suffolk Police

Waveney District Council

West Suffolk Clinical Commissioning Group

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Disability Focus Planning Group

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Ipswich Borough Council

Ipswich Hospital NHS Trust

Suffolk Police

West Suffolk Clinical Commissioning Group

West Suffolk Councils

Easy Read Versions of Booking Forms and Agendas

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Foreword

I would like to thank everyone involved in making Disability Focus happen this year. I am fully aware of how much preparation and organisation it takes to put an event together.



I wish to personally thank everyone for attending this successful event, and in particular those of you that came to share your experiences and ideas. These will be used to improve services in the future. It is fundamental that users of services provided by public bodies are involved in a forum to raise issues, and be part of the solution.

I wish to thank the organisations that contributed to the cost of organising and running the day, and for those who attended and committed to improving the services they represented.

Any suggestions and action points made on the day will be followed up, and we will act on the comments made about improving the event for the following year.

Chief Superintendent David Skevington, Suffolk Police



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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 2016, 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 report includes an indication through the 'What do you think' questionnaire of what people in Suffolk think about their big issues – getting the right information, having enough money to live on, being able to get to where they need to go and keeping safe both by day and at night. Whilst the results on the whole indicate continuing year on year improvement, comments made by attendees indicate that there are still many 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.

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

- Living your life as you want to
- Getting information you can use
- Using services provided by agencies
- Keeping well at home
- Being in hospital
- Having a house to live in
- Support to live in your home
- Getting a job and keeping it
- Being safe where you live and where you spend your time
- 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 and these 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 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.

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:

- Great networking/information sharing;
- Very enlightening having people with a disability to give insight into difficulties they face;
- It was useful to meet people from a variety of agencies;
- I'm interested to see it (the feedback from the Discussion Groups) collated and shared;
- Very interesting to get such a wide range of views and experiences;
- A positive day and I look forward to seeing how the actions are taken forward;
- Informative, useful and good to hear about issues first hand;
- I enjoyed every part of the day and will be returning;
- Very informative and very useful, great integration of service users and providers;
- Positive networking with other agencies.



Introduction

The annual Disability Involvement Days began in 2011 and have now been rebranded as Disability Focus. The 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 2016. 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. Steve James, Chief Executive of the Avenues Group, gave his time and expertise to chair the proceedings, along with Chief Superintendent David Skevington, Suffolk Police, 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 the 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 giving their support to make this event happen for disabled people. It demonstrates an excellent team effort despite the lack of resources.

Over 130 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 were expected to take away action points where their organisations could 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

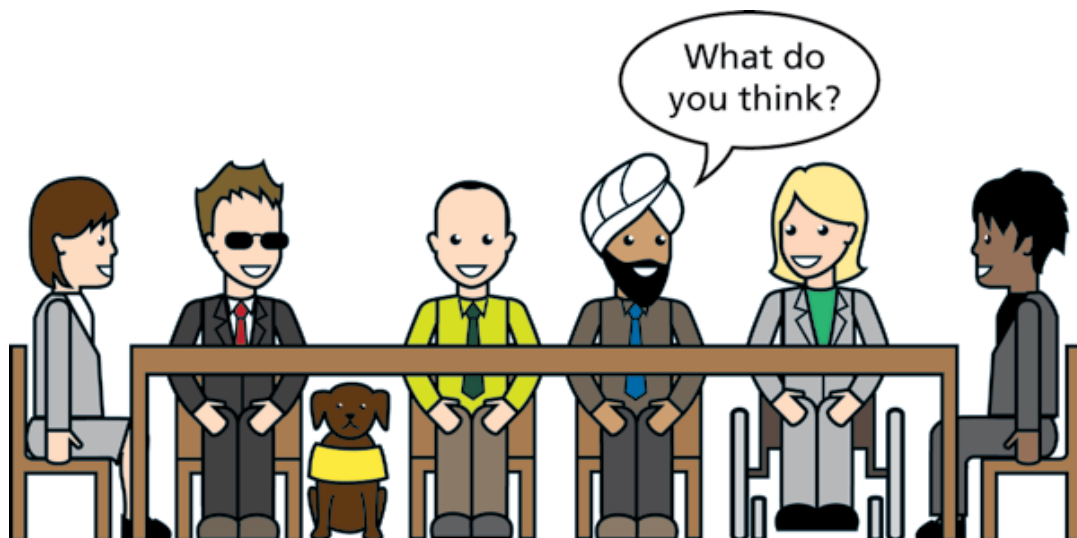
What do you think?

Introduction:

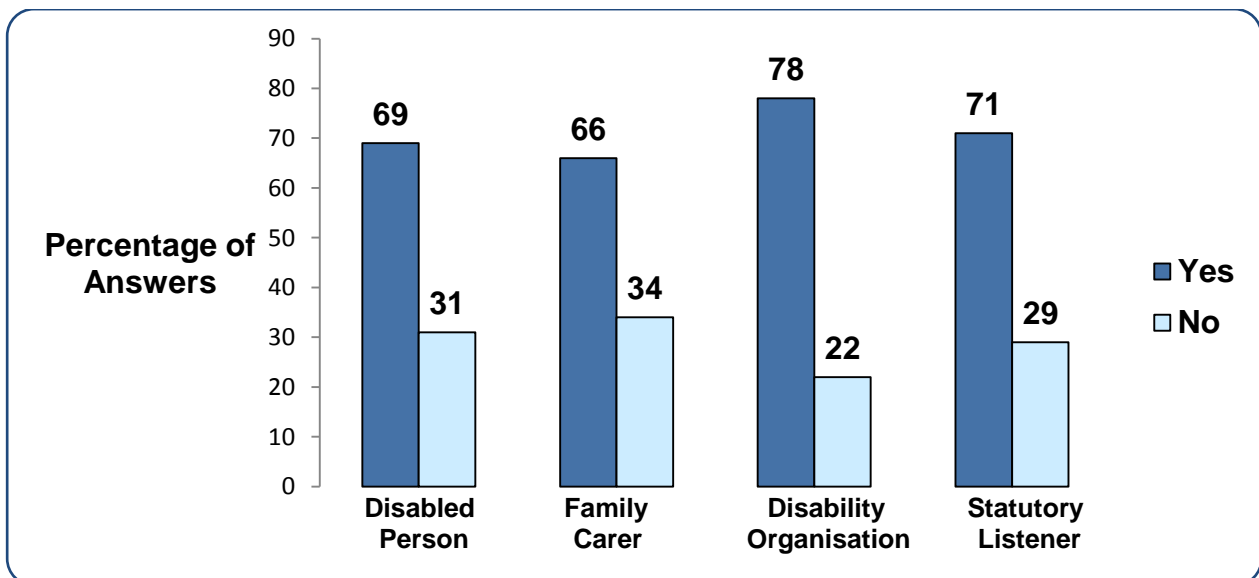
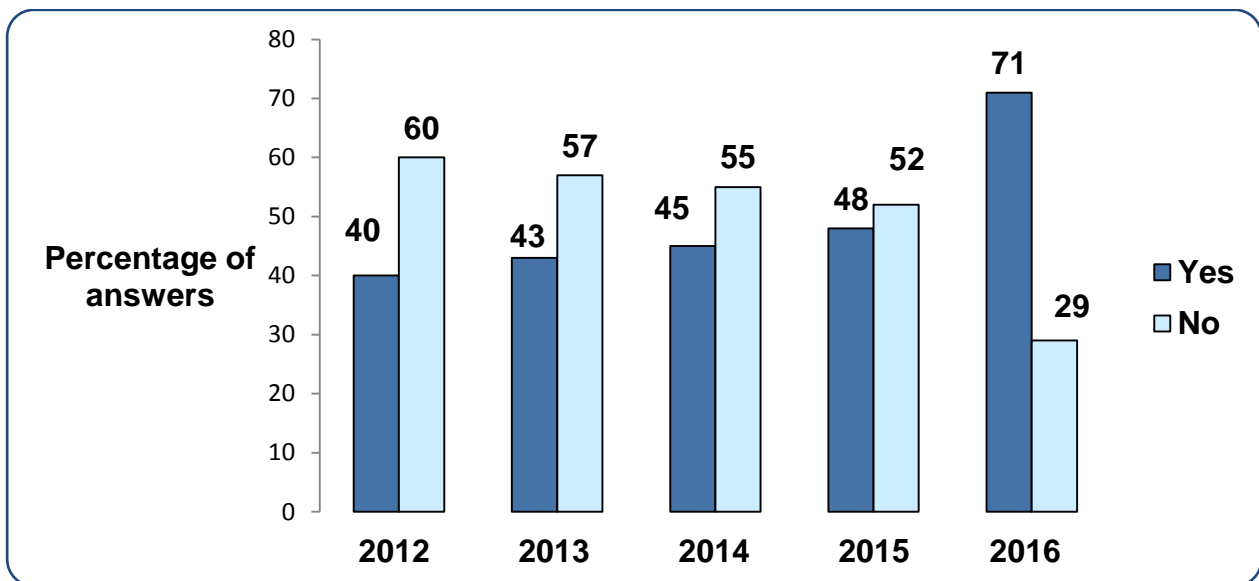
Delegates were asked the same simple questions as had been asked in previous years in order to facilitate comparisons. These questions are designed to gather a general overview of how disabled people, their family carers, and their representatives feel about some of their key issues and are not meant 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. 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 2016 Discussion Groups.

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 and 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:

- I sometimes find it a struggle to get information;
- I live in a care home so my needs are met by staff and family members;
- Yes, but only in some areas;
- I often have to search to find information;
- Sometimes I can find information but not always;
- It is a time consuming exercise to find the right information;
- Information is never or rarely in large print;
- If I need information, I can usually find out by asking;
- Yes in most circumstances, using Infolink or speaking to link/support workers. Information is sometimes well-hidden;
- Living rurally, I am not always informed of new activities/organisations;
- Staff at Genesis explain to me what I need;

- Yes, because I am closely involved with DIAL in Lowestoft and many Organisations.

Family carers said:

- Yes, but I have to search to find it;
- I am too busy, there is too much information and too many changes;
- Mostly I do by searching for it but I don't know what I don't know;
- I find out more by attending days like this;
- I had not heard of Disability Focus before now;
- We are in contact with a lot of organisations.

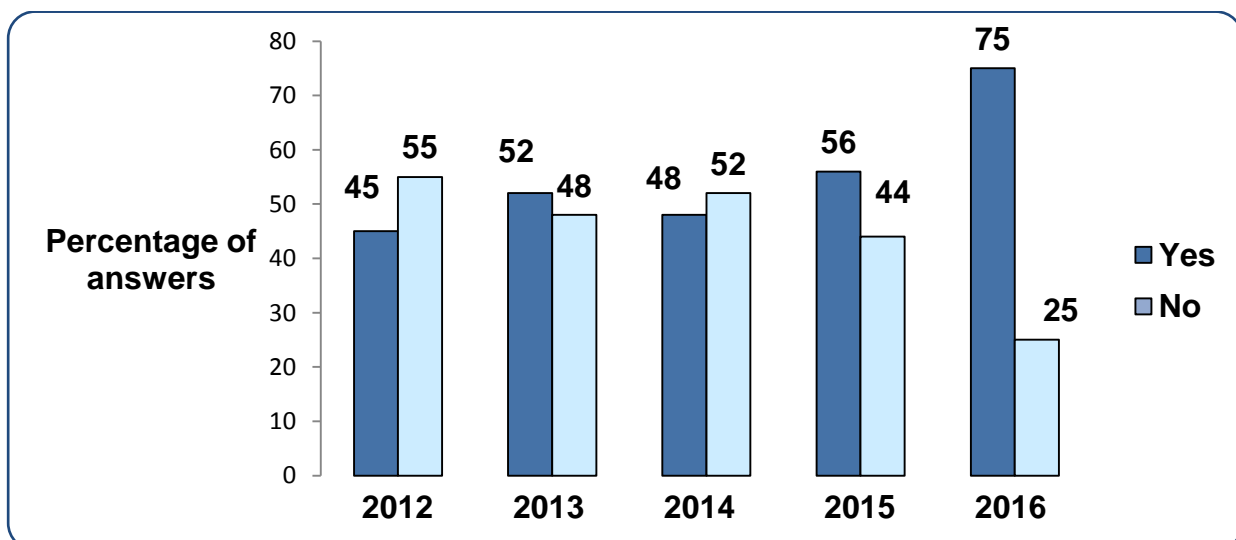
Representatives of Disability Organisations said:

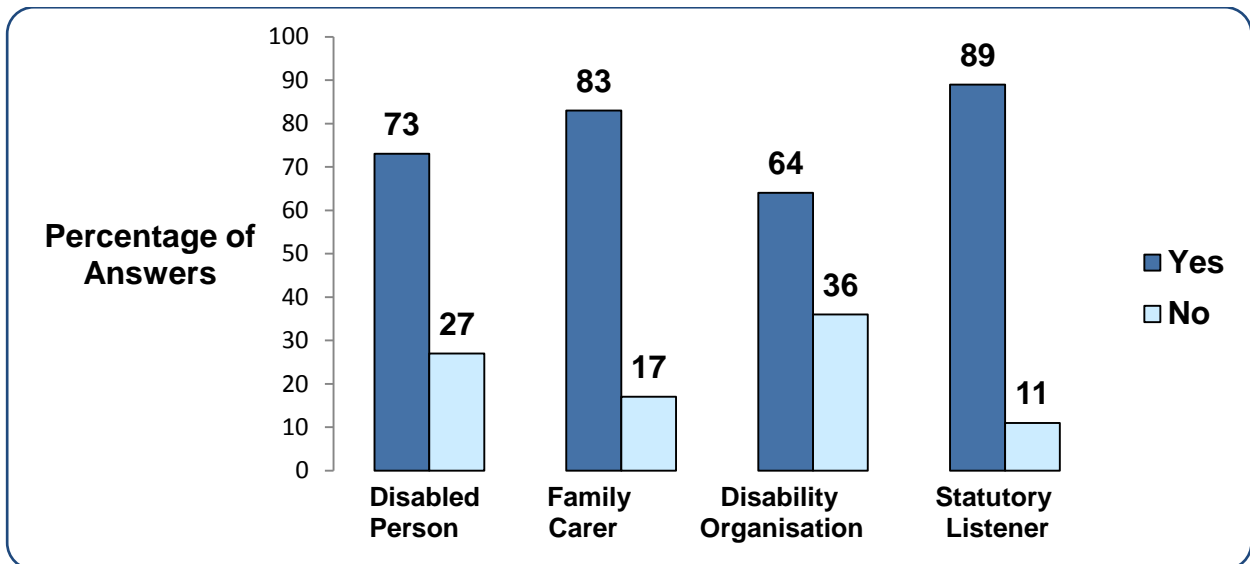
- Manager provides instructions;
- I have a selection of resources – agendas, reports, etc.;
- By attending the Mid Suffolk Disability Forum and these events and talking to people from local organisations offering learning facilities. I belong to 2 Boards of Trustees;
- I get information mostly from DIAL or the Waveney Disability Forum;
- I do because this is my job. However disabled people who contact our organisation do not have the information or advice that they need;
- I do because I can access information when I need it through various channels;
- Yes, through the job I do and the Forums I am involved in;
- The Parkinson's Nurse service is a vital resource yet people don't have access to it sometimes due to lack of community access to the service (it is hospital based). It is an important means of access to condition specific information;
- Information is available on certain topics, but it depends;
- I think you can always get more information;
- Not all information is available in the correct format / media;
- Sometimes we do not integrate our information across partners – so either duplicate or do not provide anything! We need to share more;
- It varies, some organisations are better than others;
- Information is given to me by consultants, doctors and nurses;
- I use the internet;
- There should be more uniformed passing in of information about agencies to support people with disabilities;
- Yes because I use the internet but some community information can be harder to find;
- IAG (Next Step Services) are weak, it is only a 15 minute interview with poor advice;
- I can use the internet and have a computer;
- Yes, because I ask, research and listen;
- No, because I have to search for it.

Listeners from Statutory Organisations said:

- I am able to access various avenues of information;
- No, information is limited in lots of areas;
- I don't always know the information is there – there are too many places to look;
- I am well informed with training and departments where I work are helpful;
- Yes, when I search for it. I do know where to search though.
- I query whether there is enough information available to those who need it in an easy read format;
- It is hard to know where to find it initially and then it can sometimes get too much;
- No, it is dependent upon access to the internet;
- As an organisation we try very hard to engage with service users. However, we still find that organisations do not know we exist and how to access our service (Community Dental Service);
- Yes, using the internet and talking to people usually means you can find out most of what you need;
- I am able to access information through contacts and other partner organisations;
- I am able to gain access to good information;
- I haven't got the time or mental capacity to take it all in;
- There is not enough easy read information and information is not provided in accessible formats.

'Do you get the money you need to live your life?'





Disabled people said:

- No, on state benefits. Income may improve in future;
- I live in a care home;
- I have very simple needs;
- I personally can cope but there are many in the Parkinsons Group who struggle to live e.g. younger onset people who have been refused PIP and had DLA cancelled;
- It is difficult to meet rising costs of living;
- Just about. It doesn't pay to save because it means you need to use money very carefully;
- I go to work;
- No, not in all circumstances;
- Only just. Budget is very tight and not always informed of new or changed benefit criteria entitlement;
- I live off my pension;
- I can buy the things I need;
- Disability benefits have been frozen and are not enough.

Family carers said:

- Yes but only because of the advice of the CAB;
- Personal planning;
- I've only just filled in the forms;
- I have my own savings;
- We can manage with what we get.

Representatives of Disability Organisations said:

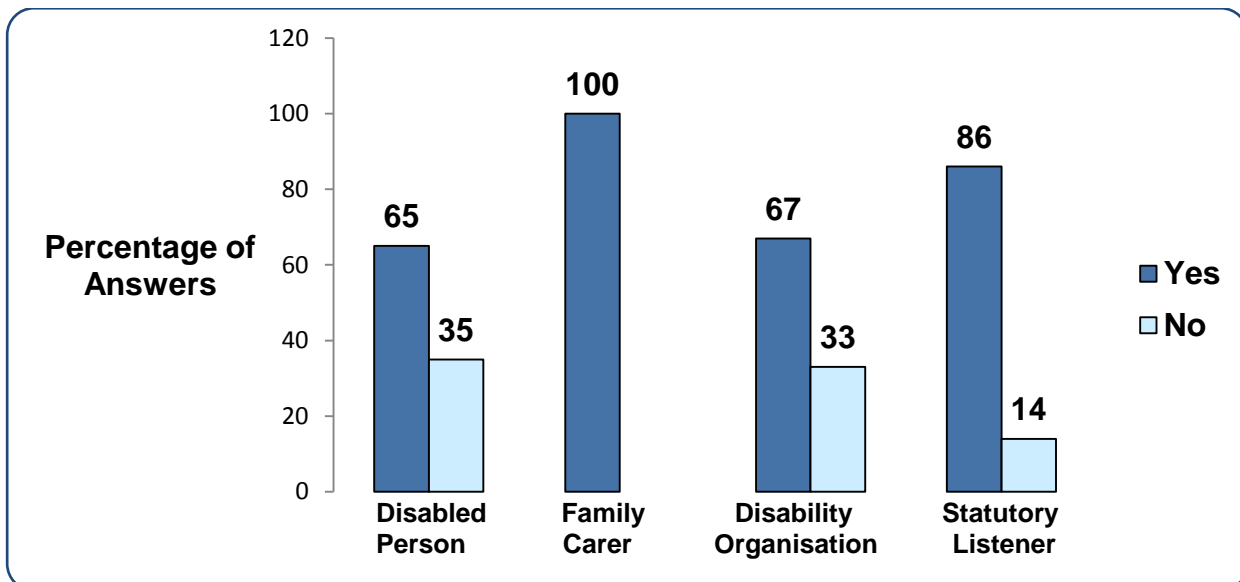
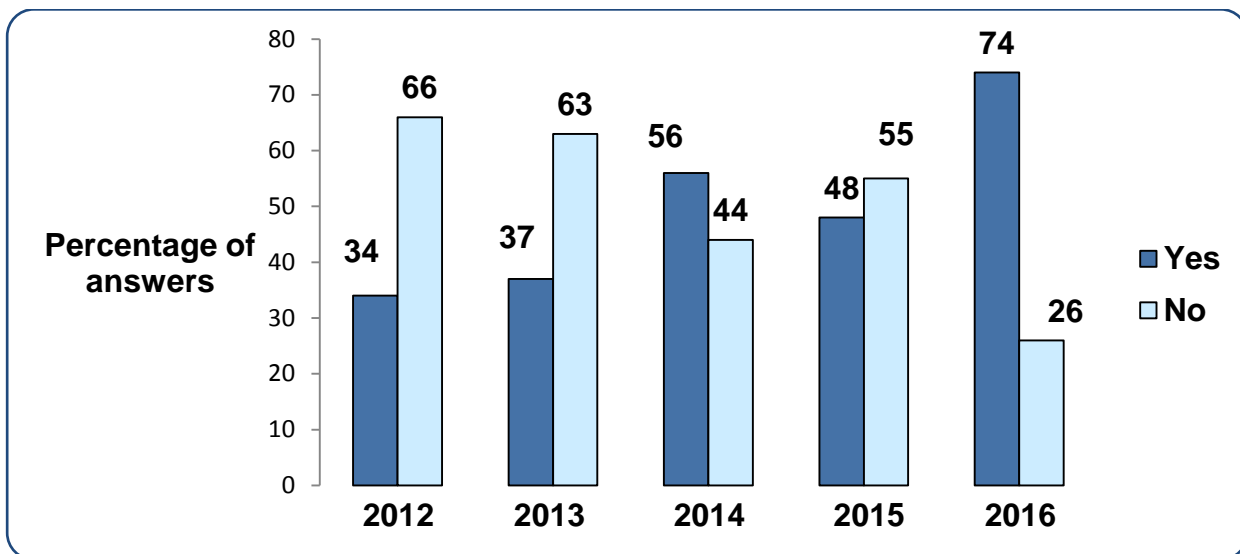
- No, a low pay sector. I cannot afford to rent a place of my own;
- My pay is very low and I just about scrape by;
- Facilities are good;

- I am fortunate not to be disabled;
- Yes, although Brexit may have something to say about the money I currently have to live on;
- Yes, because I work;
- Yes, because I am employed but I am aware through my work that many disabled people in Suffolk are living in poverty;
- Some do, for others assessment of disability is too simplistic to allow for the complexities of their condition;
- It depends on circumstances;
- Not always personalised;
- Often personal allowances are not available to a wide enough sector of the disabled community;
- Resources are continually being stretched. Again, we need more integrated approaches to use money wisely;
- It varies – some people we support have all the benefits they are eligible for, whilst others with the same needs do not. The system depends on (or seems to at least) the individual views of assessors and decision makers;
- I am on a pension;
- I have a job;
- I'm in full time work;
- Where are the jobs? Benefits are okay but there's an income ceiling;
- I work to earn enough money;
- No, not everyone has, although they may have similar disabilities. You need to know the words to use;

Listeners from Statutory Organisations said:

- I work full time;
- It depends on 'gatekeepers';
- I make sacrifices to survive;
- We both work very hard;
- Changes, or possible changes, in personal payments is very stressful. I need help to complete forms;
- My husband and I are in employment;
- I am able to work;
- No, because I have chosen to rely on my councillor allowances which doesn't give me enough to enjoy all the concerts and foreign holidays I would like;
- I would say the majority of the people I work with do not have enough money for the care they need.

‘Can you get to where you want to go easily?’



Disabled people said:

- I have a national bus pass. The 23.00 restriction needs to be amended to midnight;
- I can still drive;
- Many cannot because they do not drive and there are few rural bus services;
- Only because I have a car;
- I am concerned about future transport as my husband is 83 and finds driving tiring;

- I use public transport but I can be left waiting due to them being late. I do not know what is happening or when the bus is going to turn up. There should be more information at bus stops;
- I have difficulties in using public transport as I am a wheelchair user and rely on my family carer to drive me;
- Only because my husband uses our own car to drive me;
- If my support worker drives me I can manage but if I had to rely on public transport the answer would be 'No';
- No, transport is an issue for me;
- I live in a very rural location with no bus routes and very limited alternatives which can be very expensive. I am aware of transport options for disabled people but trips cannot be spontaneous;
- There isn't always wheelchair access to vehicles;
- My wife drives me;
- I can use buses and staff have cars;
- I am lucky. I have a Motability car and can drive myself with hand controls.

Family carers said:

- Yes, but only because the person I care for has a car;
- Yes, but there is still a lot more to do;
- I am mobile and I drive;
- I have to use a car. It is difficult to get transport out our way and at the time it is needed;
- We have a Motability car;
- We have a wheelchair and a Motability car.

Representatives of Disability Organisations said:

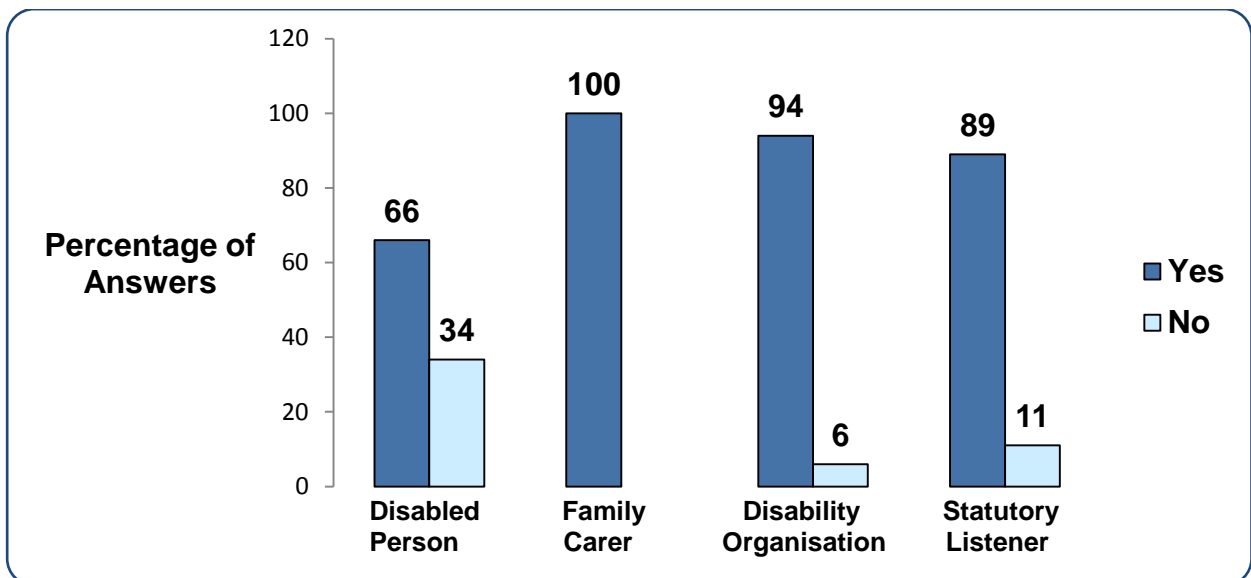
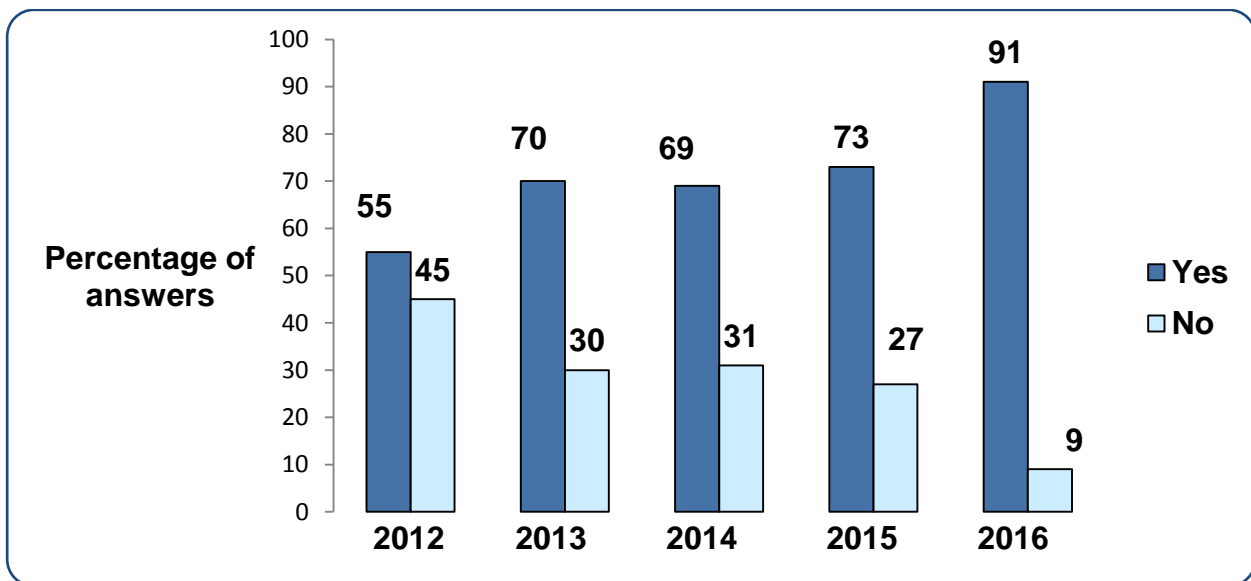
- My transport is provided;
- Public transport is generally provided;
- Yes, am alert and self-sufficient;
- I use my car;
- Yes, because I drive X 3;
- No, train services are a problem for those who find stairs difficult;
- The bus works well for me;
- Poor frequency of rural bus services;
- We are usually told there are transport issues;
- No, if you are not local it is difficult;
- No, public transport cuts to rural environments restricts choice;
- Need more information for people to know all that is available to them;
- In towns the service is good but we support many individuals in the rural community who struggle to rely on public transport which is lacking or completely non-existent;
- I can drive and I have a senior railcard;

- I have a car;
- I am able to drive and move freely;
- I'm lucky that I don't have to rely on public transport as I know that is more problematical in rural Suffolk;
- Yes, because I walk/drive/am confident and able to use public transport;
- Not everyone has the same access to all.

Listeners from Statutory Organisations said:

- I think, although there are still issues, public transport is starting to improve. However, some people I work with struggle to get to hospital or doctor's appointments;
- I can drive and access public transport;
- I have no disability restriction;
- It depends on where you live and where you want to go;
- I drive to where I need but I'm aware transport can be a struggle for many;
- No, there are traffic concerns around town;
- If I didn't drive, then 'No' as I live in a village and buses are not regular and they are limited to where they go;
- I have personal transport, however, if I didn't have the ability to drive, travel via public transport to the GP would be impossible from where I live;
- We need more community transport, share a lift schemes, etc., and at local level help from befriending or neighbours;
- No, restricted public transport in rural areas especially;
- Yes, because I have access to a car and can drive. Public transport is okay between major centres but poor otherwise;
- I have my own transport;
- I am able to travel independently and have access to a car;

‘Do you feel safe when you go out?’



Disabled people said:

- I am nearly always with my husband;
- I am always with carer or staff;
- Yes but I need to be aware of others;
- It is very rare that I go out alone;
- No, I would feel more confident with a befriender;
- No, not at night, because I have very little sight and can't see who is around me;
- Sometimes, if I've learnt the route;
- I am not usually alone;
- Sometimes because of people asking for money;
- I always go out with staff / support worker or family members.

Family carers said:

- We feel we live in a safe area (little major crime);
- Yes, I am happy apart from evenings;
- Yes, I am able bodied.

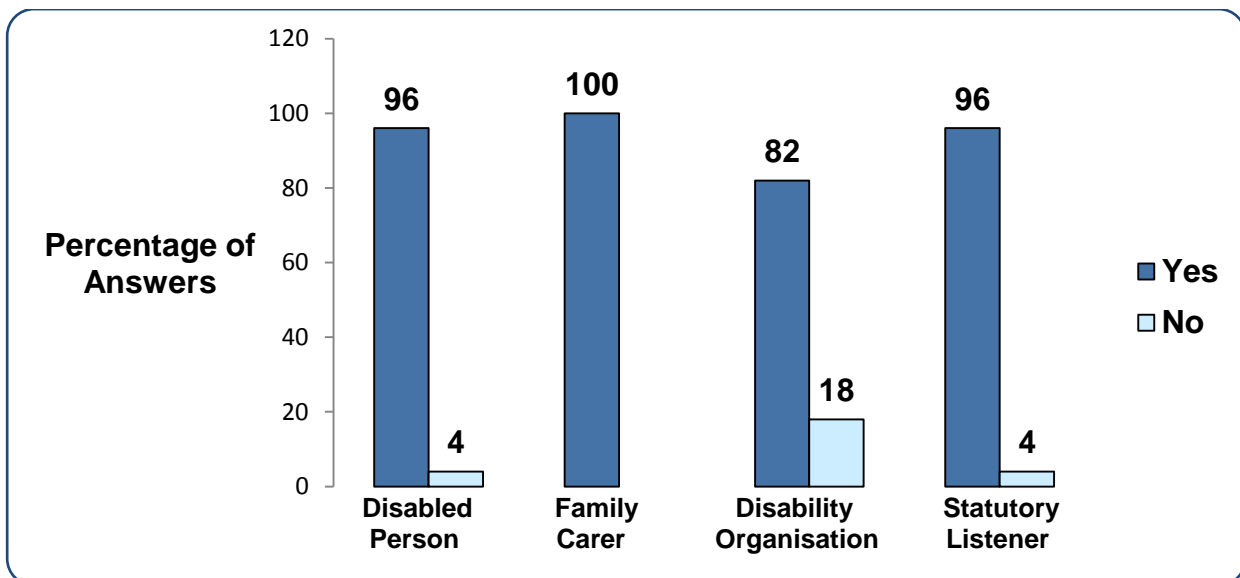
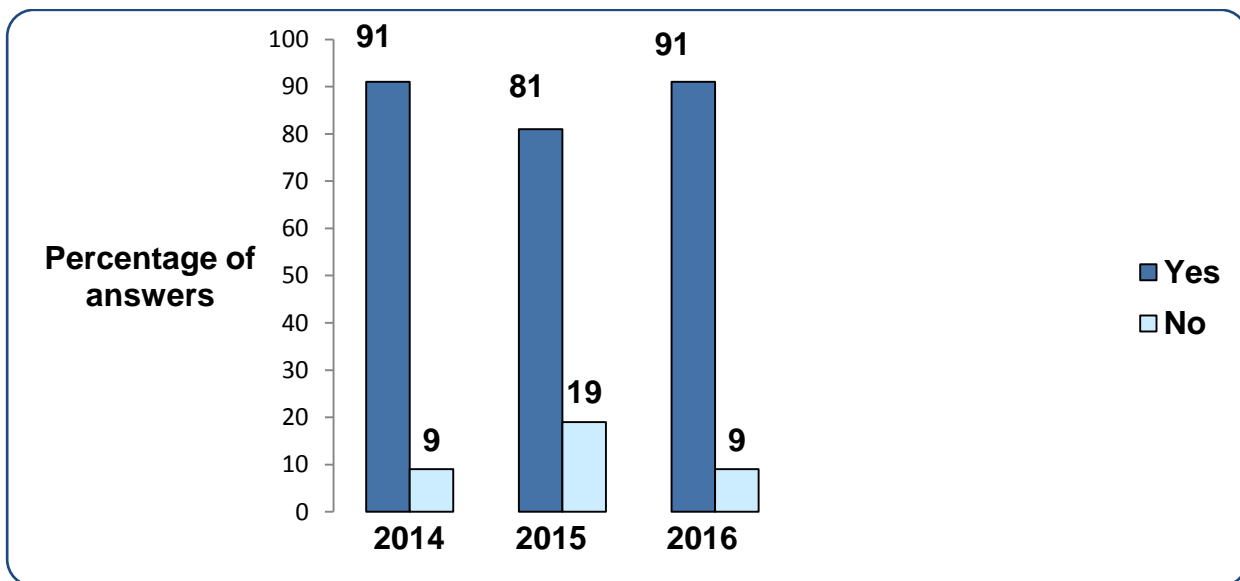
Representatives of Disability Groups said:

- I am unsure;
- I do mostly but not always. Not alone at night;
- Sometimes, it depends where I am;
- No, because I live on London Road;
- I am confident that I am able to feel safe whenever needed;
- I live in a safe area;
- I think the people we support mostly feel safe. We support the 'keep safe' initiative, provide travel training ensuring the individual can be as safe as reasonably practicable;
- People with mental health problems need to be given more 'support worker' type services to help with day to day and social activities as they may become isolated;
- No because of street hazards, banners, A boards, etc.;
- Individuals are more wary of possible changes;
- Usually no, especially long journeys;
- I don't know;
- Yes, depending on the time of day;
- Yes, most of the time. I do not go out walking independently at night;
- I live in a relatively low crime area;
- I do not walk far but do feel safe;
- I am able and independent;
- I use door to door transport.

Listeners from Statutory Organisations said:

- I have confidence in our community and that we and the police take action;
- I always feel safe during the day;
- I am usually okay;
- Where I live, there is no street lighting as it is out of town and I do feel wary about going out in the dark;
- During the day, I do, but not in the evening;
- I go out mainly during the day;
- It depends where it is;
- It depends on where you are going;
- In general, this is positive but I am currently supporting someone who is scared to leave home due to bullying by neighbours.

‘Do you feel safe when you go out during the day?’



Disabled people said:

- I am nearly always with my husband and I feel Lowestoft is quite safe;
- Yes, with help from friends and staff;
- It is very rare that I go out alone;
- Most of the time, I do;
- Yes, except for cars, signs, etc. on pavements getting in the way and causing danger;
- I carry a personal alarm;
- I always go out with staff / support worker or family members.

Family carers said:

- Yes, it is a good neighbourhood;

- Yes, I go to local areas, I don't go into Ipswich. Woodbridge area is safe;
- I am able bodied;

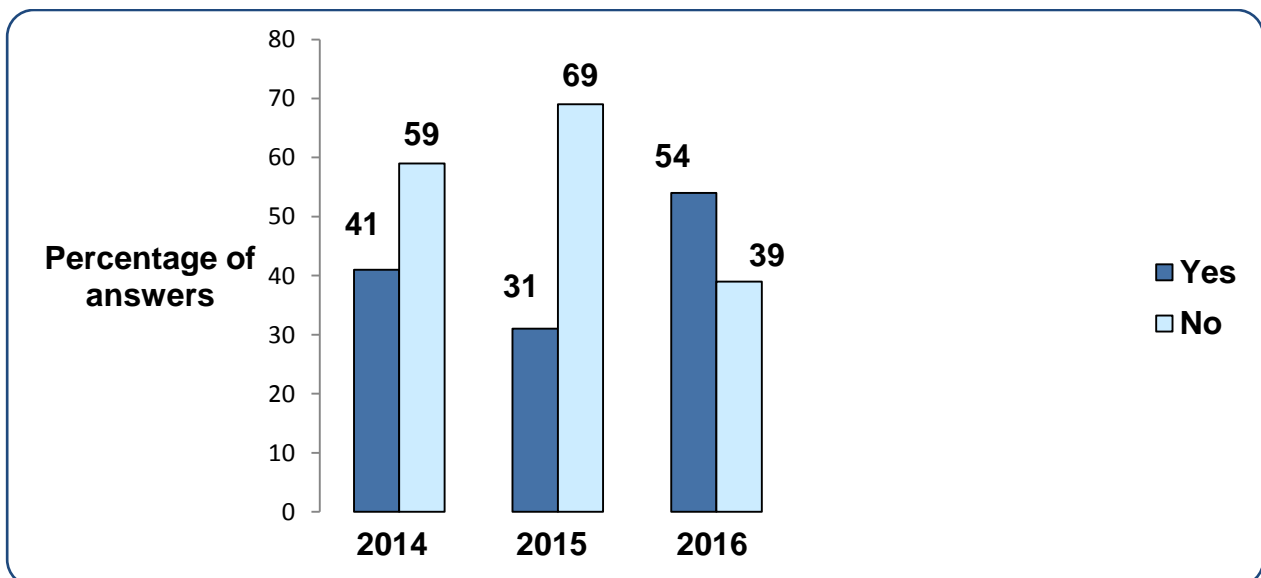
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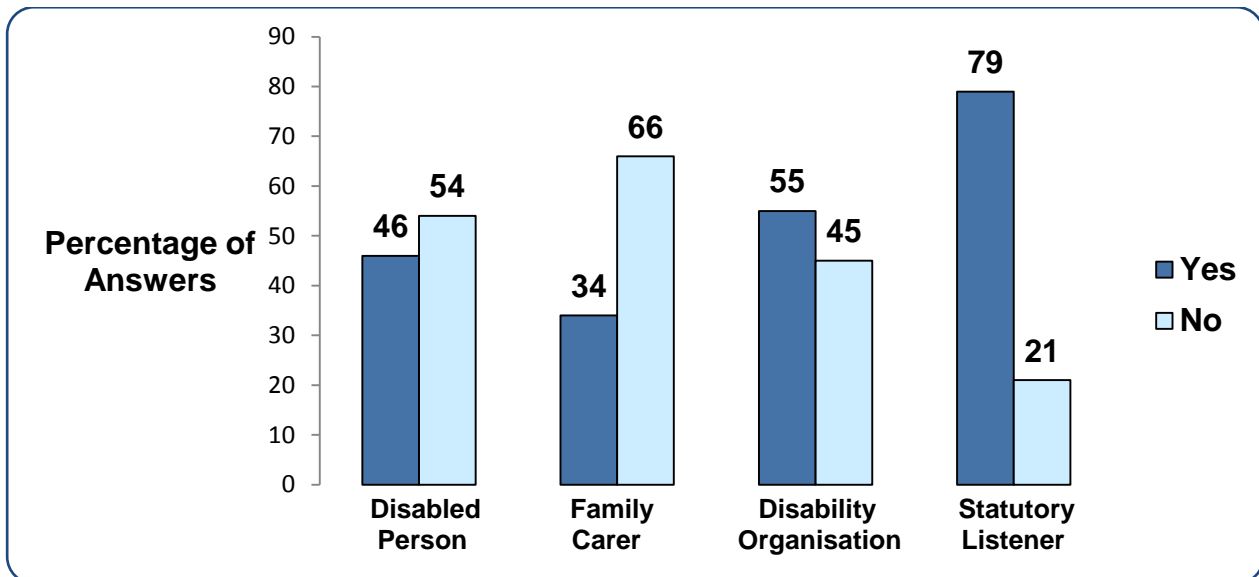
- A lot of people have lots of information with them when generally going out;
- It depends on destination;
- I don't know;
- Yes, due to the area I live;
- I feel safe but do have concerns about my empty property during the day;
- I live in a relatively low crime area;
- I use my car;
- Certainly;
- I use door to door transport;
- I am unsure;
- I live in a safe area;
- The people we support mostly feel safe;
- Street hazards such as banners / A boards etc.;

Listeners from Statutory Organisations said:

- I always feel safe during the day;
- If there are more people about it eases concerns;
- It depends on where you are going;

'Do you feel safe when you go out at night?'





Disabled people said:

- I would not go out on my own;
- No, I stay indoors;
- I am worried that something might happen to me;
- No, I am scared;
- It is very rare that I go out alone;
- Yes if I am with family;
- I would feel more confident with a befriender;
- I do most of the time;
- I need someone with me. I can't see the difficulties in my way;
- No, I have concerns who may be about. I only go with a friend / person I can trust;
- I don't go out at night. My husband does not drive at night;
- No, I don't go out;
- Sometimes;
- I always go out with staff / support worker or family members.

Family carers said:

- We go in the car;
- No, we rarely go out at night;
- We put up with it as we live in a 'no street lights' village. If it is wet or windy I think twice about going out;
- No, there are many dark areas, a lack of policemen 'on the beat' and an acceptance of anti-social behaviour;
- I don't go out because of not feeling safe.

Representatives of Disability Organisations said:

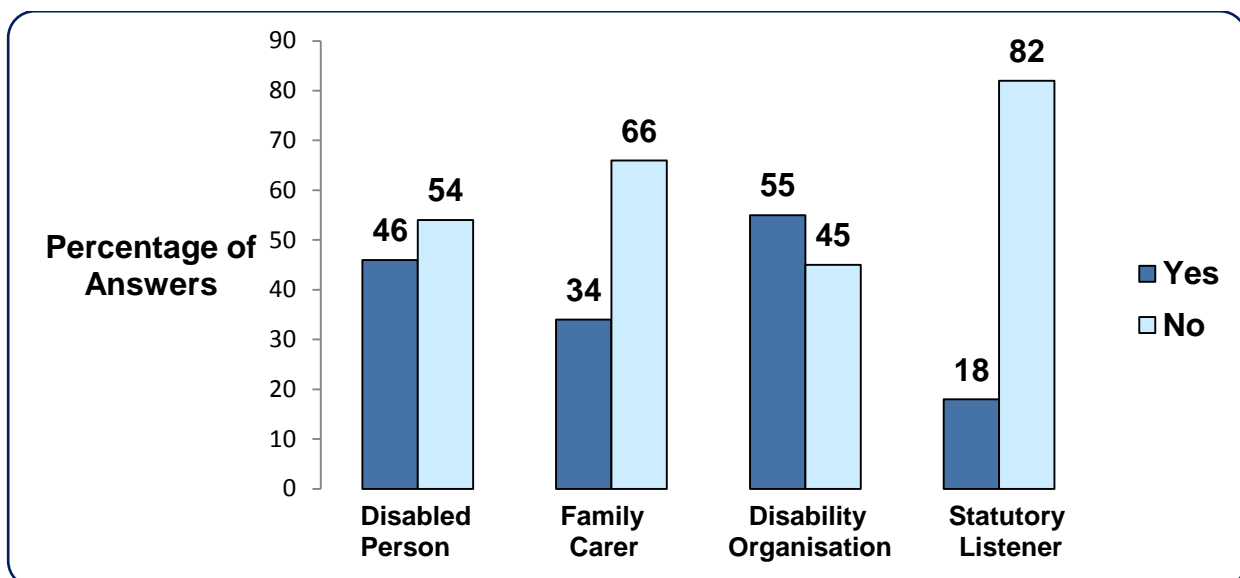
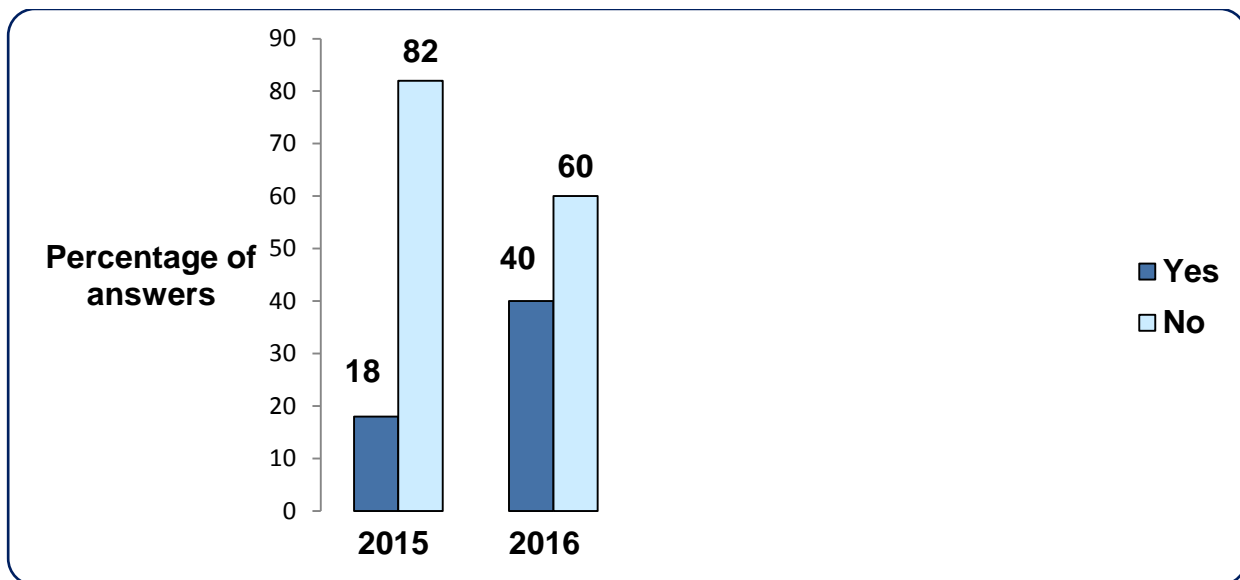
- I tend not to go out;
- I don't know;

- Unfamiliar people;
- Yes, depending on location and time;
- The only time I would not feel safe is if I was walking through a town on my own but this doesn't happen very often;
- Yes, but only in groups;
- Only if I am with someone / group;
- I live in a relatively low crime area;
- Yes, I usually use my car;
- I use door to door transport;
- I am unsure;
- No, not when I am alone;
- No, very little community policing;
- No, Ipswich can feel very intimidating at night depending on the area;
- There are some areas I would avoid walking in after dark;
- I am usually with others;
- I live in a safe area;
- Not many of the individuals we support would go out at night alone;
- Community transport services are needed at night as well as day. If people want to go to the pub, meals, gigs, theatre, this needs to be supported by good safe transport. It is part of people's care /life support;
- Street hazards such as banners / A boards.

Listeners from Statutory Organisations said:

- If I'm out at night I think carefully about where I'm going and who I'm with;
- I do feel safe within a group but wary to be out alone at night;
- Yes, but I don't go out so much at night time;
- Many older people do not like going out at night which means they can't attend activities and join in;
- Where I live, there is no street lighting as it is out of town and I do feel wary about going out in the dark;
- No, there are not enough police around visually;
- Less lighting causes security concerns;
- No, it depends where I am;
- It depends on where you are going;
- Mostly;
- I don't put myself in vulnerable situations;
- Mostly I have confidence in our community and that we and the police take action.

‘Apart from this event, do you think that the needs of disabled people are well represented throughout Suffolk?’



Disabled people said:

- Yes, at the Disability Forums throughout Suffolk;
- Yes, the Stroke Association is very good, and the Cheerful Friday Stroke Club;
- Generally things have improved. Services and information seems to be available – the problem seems to be access to a first ‘link point’;
- No, not consistently;
- Yes, due to more events like this and technology;
- The local authorities etc. don’t come to meetings to find out how things really are;
- There are not enough events like this;

- There should be more services. Shops don't have good disabled facilities. There should be better access to transport;
- Not always;
- I am only aware of this event;
- Sometimes there needs to be more awareness and training;
- Many in rural areas are without any help;
- I am slowly getting worse (dementia). I need something to do with my time. I need to learn to do something;
- It's sometimes difficult to find the help we need;
- No, there is stigma attached to people with mental health issues from the general public;
- Co-production with disabled people as equal partners is not something that Suffolk is good at. It is not about others talking on our behalf but being included as an equal partner.

Family carers said:

- There are a lot of organisations about to get any help that is needed;
- We have a good stroke club in Newmarket. We go to Family Carers meetings in Mildenhall;
- No, we need more days like this;
- Although there is good representation I am not sure it is correctly received or acted upon;
- No, we need more money rather than cuts;
- No, I only know of this event.

Representatives of Disability Organisations said:

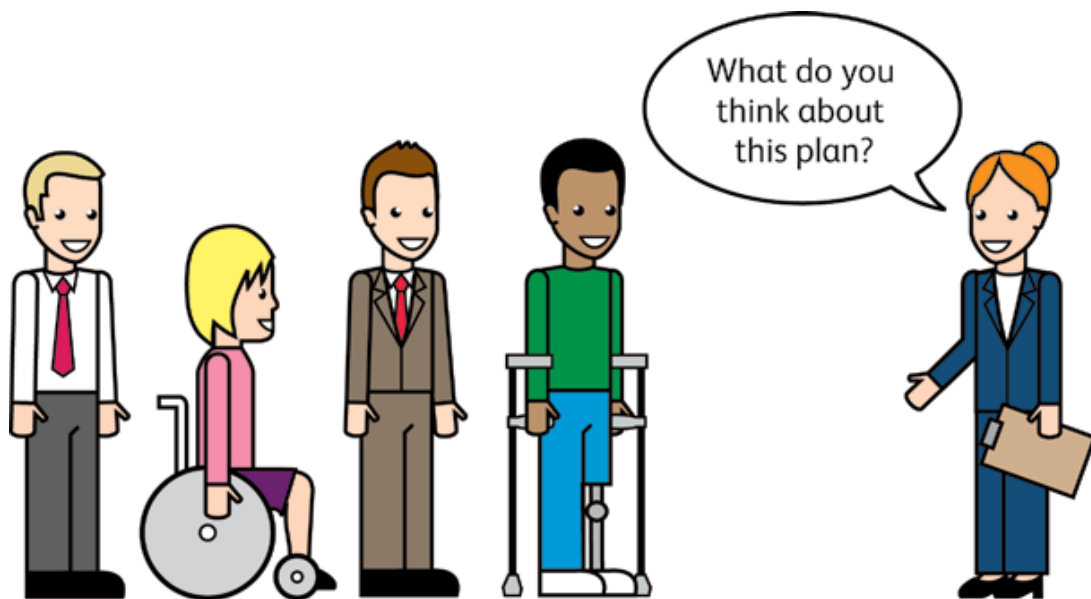
- No, health is a real issue;
- Definitely no;
- There's room for improvement. There are models of good practice that could be followed;
- Leading Lives gets me heard;
- There are good resources;
- There are many organisations that provide a variety of services;
- Through my job, I feel they are – from the knowledge that I have;
- Overall yes, but more can always be done to reach more people needing help and support;
- Yes, through events, social media and awareness;
- There could be some improvements to certain services;
- Yes but there is always more to learn;
- There are a number of organisations of different types operating;
- Yes, however organisations should be networked better to ensure people don't fall through the cracks;
- No, although disabled people are represented, there is not enough information or how to get hold of it;

- No, rurality / transport / varying needs and support offered across the county / funding needs – to name a few;
- I don't think I can comment as I am not local;
- Not always;
- I'm not sure – not being disabled means I may not need to find any information needed;
- I don't know X 2;
- No, there is a lot of misunderstanding about disabled communities;
- No, there is an inadequate funding model for service providers;
- From a community support point of view, there seems to be many organisations throughout Suffolk that represent disabled people;
- There are lots of organisations in Suffolk. Are there enough in my area (Waveney)? Sometimes all the services do not reach us and are Ipswich / Bury focused;
- No, greater availability and access to information would be good.

Listeners from Statutory Organisations said:

- I think more can be done to engage with and understand the needs of disabled people. We need to understand how policy decisions and how services are run impact on local people from all groups;
- To some extent. At Ipswich Borough Council we hold an Equalities Panel meeting quarterly at which we invite representatives of different organisations to discuss and influence proposed new policies / changes to procedures etc. There is not enough dialogue with those with disabilities – therefore information is second hand;
- It is varied – only in some sectors;
- No, I feel that mental health is very much the poor relation;
- It would be nice to be able to liaise with and work with a broader spectrum of disabled people;
- No, but not every disabled person wants to engage in this way. I do feel however that disability is protected better than any other 'protected characteristic' under the Equality Act;
- There should be more events to help represent disabled needs;
- I feel there is space for more publicised and accessible forums;
- No, we can all do more to make people's lives easier;
- It depends upon the disability / age / sex / race / religion;
- Mostly but needs to be addressed;
- Yes, through the Suffolk Disability & Health Action Group;
- Yes, but there is always room for improvement;
- Yes, the various Forums around the county for people with disabilities provide a vehicle for feedback;

- No, events like this are very positive, however the needs of disabled people are represented in the groups that are created to do so but not understood well in healthcare in Suffolk;
- Not sure – a reason for attending Forums like this is to ensure organisation doesn't act complacently;
- It depends on situation;
- No, people don't have the imagination to consider what life is like for disabled people or the patience to make adjustments;
- As I am not a service user, it is difficult to say;
- Services need to be promoted more in public services so more can attend and engage;
- It could be better – more joined up approach needed;
- Represented but not publicised;
- No, I don't think disabled people are well represented across the county consistently or fairly;
- No, not known by those not directly involved. Could do with more awareness for the general population.



Issues and Concerns from the 2016 Discussion Groups

Living your life as you want to

- There was positive feedback about the falls service - the Lowestoft out of hospital team is effective;
- No barriers are perceived if you have transport;
- I would prefer to get out more – there should be more accessible transport for wheelchair users;
- There should be more information on what is available;
- I have difficulty in getting on a bus as a wheelchair user;
- I am unable to get on a bus so have to use taxis (I have vouchers to help pay for these);
- I am generally living life happily;
- I am not concerned about going out, just the effort involved. I need someone to go out with;
- The cost of getting out can be prohibitive;
- There is no support from Suffolk County Council for the 'Shopmobility' system, providing mobility scooters. That is a barrier;
- There should be better and cheaper transport, having to use taxis (especially if you are a wheelchair user) is expensive, e.g. £60 Lowestoft to Norwich;
- Bus services are not accessible. There is only one place in a bus for a wheelchair user and this can be a real barrier. Bus drivers are not proactive in terms of getting the ramp out, depart before passengers are ready so the wheelchair user is not secure, buses move before passengers are settled in their seat;
- Getting to bus stops can be difficult;
- Steps to the bus cause barriers in getting on;
- Suffolk is a nice place to live. It is helpful and friendly but not all service providers are;
- The location of wheelchair spaces in public buildings in separate places can cause issues;
- I am dependent on a car for travel;
- In Ipswich, blue badge holders can only use their badge in the marked spaces. In Suffolk Coastal, a blue badge holder can use their badge in any space and can get double parking time for their money;
- In Lowestoft, it can be difficult to move around with a wheelchair in smaller areas. Awareness of accessibility needs to be improved;
- Pavements in Ipswich cause issues for wheelchair users, especially the gullies where the crossing places are not opposite each other;
- Taxis parking in bays for disabled people are a problem;
- The location of 'A' Boards causes difficulties;

- Parking in Ipswich is too limited, and at either end of the town causing issues with visiting shops in the middle of town;
- Costs of parking near public venues can be high;
- Parking issues impact on all people using the town and have a greater impact on those with a disability;
- Paths in Lowestoft can be uneven and narrow and this also occurs in other towns such as Woodbridge. The quality of repairs can be poor;
- There are some good examples such as Eastbourne and also Sam's Café in Lowestoft;
- There is inconsistency with regard to the awareness of the needs of disabled people. On the whole, I feel that Suffolk is generally okay regarding awareness;
- If we can find the 'right' person, we can solve issues but we have to search ourselves;
- In Ipswich, the CAB building is difficult to access, and people are unable to park, compared to Felixstowe where it is easy to park and access the building.

Getting information you can use

- Today's paperless society being adopted by statutory organisations and utility groups depends on people having computer skills – this does not work for many disabled people especially those who are partially sighted;
- People often do not have the money to get the computer equipment they need to access the internet;
- Leaflets are often printed in a type that is too small – sometimes stating that a large print version is available which is usually on the back of the leaflet – by the time the request is lodged for a large print version it is often too late – the need for the information has happened. This is very frustrating;
- To overcome this, it would be useful to have technical support and an immediate option to have documents in large print but on manageable size paper;
- It would be helpful if the statement advertising that leaflets are available in alternative formats was on the front of the leaflet and not in small print on the back;
- Many older people have the feeling of exclusion from constantly being told that the information they need is on line;
- With regard to Universal Credit, the main problem is that this is an 'online' process;
- Application forms are generally too complicated;
- Infolink needs to be more 'user friendly' with a direct route to the information needed – too much information and graphics only add to the confusion;

- Websites are often too complicated to use easily and not always kept up to date;
- It was stressed that everyone is different and therefore capacity and ability to understand varies. More consideration is needed to ensure information is accessible to everyone;
- People giving information at events need to speak slowly and clearly;
- Customer First is considered to be a useful contact point for people needing information regarding disability issues, there are different ways of making contact such as telephoning, sending a text or an email;
- It was a concern to note that if people completing forms for exemption of charges for Community Dental Services fill them in incorrectly they are fined;
- It ought to be possible to share data to help prevent errors in providing information;
- Information is not held all in one place and it requires time and effort to search for it;
- It is important that information is accessible to everyone, and that means providing interpreters and using plain English;
- Using services such as the NHS 111 service or telephone based helplines continues to be a problem for people with communication problems, especially if the person does not have access to a text phone, uses a language other than English, or has other difficulties such as little speech;
- It would be good to have one point of contact instead of being passed from 'pillar to post' in the search for information;
- Being referred to a local Disability Advice Service would be a solution where a disabled person could access information on a range of issues and services in one place. It would save time and prevent stress for the disabled person. This works very well in the Waveney area. However, Suffolk County Council should improve the funding arrangements for these services;
- The work to develop the Health Passport 'This is Me' document for all disabled people is a positive way forward and this will give health professionals a better understanding of their disabled patients. It was thought that a 'living will' could be part of this document.
- It was not easy to access Infolink if a person was partially sighted or had other difficulties in using an online service;
- Information was not always readily available in other languages or in easy read;
- An on-line directory for information about who to go to when I have a problem would be helpful;
- Technology continues to change and it will become easier for people to use in time;
- I would like to be able to actually ask a person;

- I can go to my local library as a starting point for information, provided the library is fully accessible;
- Once I have found the information and discovered the application form, then the forms are too complicated and are a barrier to applying for the services or benefits that I need;
- You can be overloaded with information.

Using services provided by agencies

- There are a number of issues regarding direct payments:
 - The contribution charge by the disabled person to the budget regardless of their balance is inflexible and can cause problems. It reduces a person's personal finances even if the budget is in surplus;
 - It can be difficult to source the support that meets the criteria for expenditure so it makes the budget difficult to spend for some people;
 - Using an agency or a broker for personal assistants can mean less control over who disabled people employ and who supports them;
- In terms of work:
 - The 'Access to Work' scheme is not well adapted to part time jobs which can be an important step into work;
 - Employers can struggle to make adaptations;
 - The culture of Jobcentre Plus can be inflexible, there can be pressure to move from ESA (Employment and Support Allowance) to JSA (Jobseeker's Allowance);
 - Vulnerable people can get very worried by the pressure put upon them by some of the questions asked by Jobcentre Plus and the way in which they are asked;
 - A Jobcentre had been alerted to the fact that a person had specific needs and a supporter had been arranged to be with that person for a telephone interview, only for the Jobcentre to call before the allotted time, put huge pressure on the person, get inappropriate answers that they stopped benefit payments;
 - This was further exacerbated by comments that a report had now been made so the person would need to make an appeal before payment could be reinstated. There was no thought as to how the person would survive financially in the meantime;
 - More training of Jobcentre staff was obviously needed so that they understand better the requirements of people who have disabilities or special needs;
 - I think there is a culture of identifying fraud by benefit providers as opposed to a culture of providing help and support. Therefore a fundamental change to attitudes is necessary for any training to be effective.

- There is limited opportunity for the provision of respite care, particularly in providing services that cater for more than one need;
- Telephoning for assistance or advice can be a challenge and a barrier. People spend lots of time on hold, they are passed around from organisation to organisation or department to department, and they have to explain what they need repeatedly. Automated systems are confusing to people;
- Services seem to be centralising but the transport options to access them are reducing;
- There is a difficulty in getting transport to match appointment times and people have to give a lot of notice to get transport;
- It is hard to access information if a person cannot do this on line;
- There is a lack of parking for blue badge holders at the hospital;
- Communication between different groups seems limited.

Keeping well at home

- First responders are very helpful;
- Health Passports or 'This is me' documents could be expanded to be used by all people with specific needs not just those with learning disabilities especially by those with dementia or memory problems;

Action Point: To continue working on the proposal to extend the use of the Health Passport, already used by people with learning disabilities in the Ipswich and West Suffolk hospitals, to any disabled person who has contact with health and care professionals.

Outcome: The Health Passport will be adapted for use by any disabled person and recognised by health and care professionals.

Made by: Suffolk Disability & Health Action Group

- It is important to be able to stay at home and keep independent. What help is there to avoid going into an institution?
- The barrier to staying at home is the cost of care. It is not just about care but also about cleaning;
- Psychologically I feel safer at home. If anyone sees a problem they will alert attention;
- There should be closer working together of local services. Are things too fragmented at the moment?
- There are solutions in progress such as the digital roadmap;
- GPs and nurses need to explain why they ask patients' questions to reduce time wasting;

- If you sign a form for self-medication, it is ignored;
- Flu jabs are well publicised and offered at pharmacies and GP surgeries;
- We need a more pro-active holistic approach;
- People need to be educated with regard to diet and nutrition. This will save on prescription costs further down the line;
- Phoning for advice would be helpful if I knew who to ring;
- With any diagnosis there should automatically be information about diet, self-help groups and useful contacts;
- There should be more awareness of people's needs;
- As well as Health Passports and Care Plans there could be Carers Passports;
- All these types of documents need to be standardised across the country;
- Transport is difficult. People rely on family members as public transport does not work for them;
- Receptionists can be faceless and uncaring;
- There can be too many options presented to patients at hospitals and GP surgeries which can be confusing and difficult to remember;
- Barriers to keeping well at home are accessing information and transport;
- It is essential to have the equipment you need such as safety aids, handrails and a walk in shower;
- It is important to be assessed properly;
- GPs and Social Services should provide the information you need to live at home;
- I found out about the Occupational Therapist after my stroke by finding leaflet on the hospital ward;
- It is possible now to self-refer to more services;
- I have my medication prescribed into a dosset box;
- There is not enough joined up working despite new initiatives such as the Connect East and Connect Sudbury projects, to take forward integrated care;
- There are problems in getting GP appointments. More surgeries now send text reminders to patients to cut down on non-attendance at appointments;
- Mid Suffolk Axis provides support for disabled people living at home by organising outings and hobby days and also direct telephone contact with those who attend;
- People look for information on care at home from their carer or they may approach the CAB or the Clinical Commissioning Group;
- Most people at this event know how and where to access information. The problem is the wider public who don't come to events or belong to groups;
- We have an ageing population. Hopefully this is being addressed.

Being in hospital

- It is a priority to avoid if possible the need to be in hospital, we need to promote the well-being of people and provide the right care and support;
- In Waveney, there are 'Out of Hospital' teams that provide 24/7 care either at home or in designated nursing homes instead of straight to hospital;
- There is a void between NHS and Adult Social Care – Integrate!
- People could be discharged to Assessment Wards to aid getting home;
- Health Passports are good;
- There should be basic communication whether a person has learning disabilities, sight impairment, or is older. People need extra attention to get the correct information;
- The problems in getting to hospital leads to increased use of Accident & Emergency Departments. Lack of access to GPs and lack of basic first aid care and knowledge also leads to increased use;
- There is a lack of disability awareness in GPs and hospitals (there is a tendency to get used to regular patients but not aware of others);
- Change must be properly managed and funded;
- Best practice must be shared across all areas;
- There should be effective advocacy particularly for people with mental health or capacity issues;
- There is a lack of advocacy for people with sensory disabilities. People would like a point of contact (someone to go to);
- People are scared so someone to go to is very important;
- A specialist nurse is needed to deaf and blind patients;
- Forms may be filled out to say someone is registered blind but it goes no further so extra help is not offered;
- More disability awareness training is needed in hospitals;
- Patients need to be listened to more by staff which would help them be more disability aware;
- Nurses sometimes do things to patients such as making them sit up without talking and listening to them. There is an assumption that the patient is 'stupid';
- Hospital policies vary;
- Communication needs to improve and is key;
- The hospital needs to engage more with care providers;
- People with learning disabilities should be involved in staff training;
- People with disabilities should be involved in staff induction training;
- Disability awareness training should be compulsory;
- Disabled people need to complain when their care or treatment in hospital is difficult for them;
- There are not enough staff to help patients eat at mealtimes;

- A small outlay on training would reap dividends in improving the care of disabled patients;
- Hospitals are more reactive than proactive;
- The transition from paediatrics to adult services needs looking at;
- There are difficulties providing adequate support for disabled people in hospital;
- Do providers know exactly what they are commissioned to do?
- More consistency is needed across all hospital wards.

Action Point: To raise with the Ipswich Hospital the need for disability awareness training for all staff.

Outcome: To improve the experiences of disabled people in hospital.

Made by: Gill Orves, Chair, Ipswich Hospital User Group



Having a house to live in

- It is difficult to access appropriate housing in the right area where there are public transport links and amenities;
- The web-based system of bidding for housing is frustrating for people with visual impairments;
- There is a lack of flexibility around the size of property for people with occasional need for support overnight;
- There is a lack of suitable housing in Stowmarket / Needham Market;
- There are additional barriers to accessing housing for those with health needs;
- A person has to have lived in a property for 5 years before they are able to apply for a disabled facilities grant;
- The Sheltered Housing review needs to take account of the need for supported housing by people under 55 years of age with disabilities;
- Additional support is needed in making appeals where the alterations policy does not reflect the need for individuals with multiple difficulties, for example, people with mobility difficulties, visual impairment or mental health issues;
- Automated telephone systems are difficult for people with additional needs to navigate;
- They require support to operate and this reduces independence;
- The same difficulties are experienced in navigating websites;
- A single point of contact for people with additional needs would help, for example, a dedicated housing officer;
- Letters need to be understood by those people who may not be able to read or have low level of literacy. Letters should be available in easy read for people who require that format (Accessible Information Act);
- A key contact system is needed for some people – the list of contacts should be kept in a pre-determined place;
- Support workers should attend sign-ups or follow-up visits in order to ensure that the particular needs of individual people are understood so the service can be tailored to meet those needs and promote independence;
- The system for applying for housing is difficult and complicated for people to manage;
- Support agency drop-in sessions are being used to assist with applications/ We need to bear in mind the development of public access points / strategy;
- The 'bedroom' tax works in theory but not in practice as there is insufficient housing of the right type or size in the right locations. It is being used to reduce expenditure at the expense of vulnerable people;
- The local MP in East Suffolk is not responsive to this concern;

- Housing associations as housing providers are not as effective as local councils;
- The financial situation of housing associations is perceived to be difficult;
- The remuneration of Chief Executives is thought to be excessive;
- Organisations are over-zealous with health and safety considerations such as the prohibition of garden ornaments;
- Flagship Housing is the main provider in the east of the county but not perceived as a good landlord;
- Tenants pay for maintenance of gardens but the service is not provided;
- There is concern that social housing properties are being occupied by those on high incomes;
- This will be affected by pay to stay (Housing and Planning Act). An initial assessment is undertaken but financial circumstances can change – fixed term tenancies will fix this and a review of circumstances every 5 years;
- Better use should be made of empty homes and buildings;
- Incentives for people to down-size should be balanced against the desire for people to stay in their own homes;
- Elderly people do not want to move in sheltered housing. Developers build the most profitable housing and not what is needed. Cheap land is no longer available for housing associations on rural exception sites;
- Sustainable Homes Standard – Life Time Homes requirement has been cancelled by the Government. This affects disabled people disproportionately;
- Shared ownership schemes are good. Living where you want to live has a positive impact on health and well-being;
- There is a need to consider parking requirements.

Support to live in your home

- Care can be compromised by carers who give ‘tales of woe’ as people then feel obliged to demand less;
- Some items exist that could make life easier, for example a travel kettle is lighter than an ordinary kettle;
- The knowledge of how to find services needs to be improved. Maybe there could be a simple telephone service (like 999 or 111) to act as a central point of contact;
- In Suffolk, carers are more difficult to find. In Norfolk, carers are paid about £2 an hour more;
- Is the new ‘Support to live at home contract’ being reviewed after implementation;
- People do not always claim the financial savings they are entitled to as they either do not know what they are entitled to or do not want personal items marked as being from an agency, or due to pride;

- People are sometimes let down by support in the home. Carers will not always travel the distances to jobs;
- I need to use private care because I am not eligible for NHS care;
- The contribution I pay after social services assessment is very high;
- NHS Continuing Health Care is not means tested but the criteria for this is very high;
- It depends on who your social worker is as to the level of care you get;
- People should go to Care Quality Commission assessed providers. Individual providers may not provide a replacement if your carer is off ill;
- We want to keep people at home and keep their family carers fit and healthy;
- The lack of respite care is a big issue for family carers;
- Respite care is difficult to get and is extremely expensive;
- The social care respite care prescription is looking after the disabled person when their carer is in hospital having a procedure;
- We don't always know who to contact to get the right help;
- Is there a central resource of information? Is this GPs?
- The voluntary sector has good links and knows who you should go to;
- Suffolk County Council provides support to live at home; It is not some place where people need care but no one wants to travel there;
- If a couple own their home and one needs care, the remaining partner can stay in the house;
- Not everyone is eligible for carer's allowance. Carers over the age of 65 do not get carers allowance and the cared for person gets attendance allowance;
- The new contract means there is an agency that can look after your caring needs;
- The number of different carers going into a person's home can be difficult especially if the person has personal care. It would be nice to get to know them;
- There are no fixed rules regarding female carers looking after men or male carers looking after women. It is down to preference;
- Data should be used to show any improvements in services;
- Support at home can cover adaptations. It was a problem when Suffolk County Council closed the Independent Living Centres in Bury St Edmunds, Ipswich and Lowestoft. These were closed without consultation and now occupational therapists have to work out of their cars. You have to buy equipment yourself. With an ageing population, these centres are needed more;
- The development of assistive technology may be helpful;
- There are more issues and less funding, despite the ageing population;
- Rural transport is an issue;
- I want to feel safe at night;
- There should be more events;

- Benefits are being frozen and are not adequate;
- There should be more bespoke clubs for disabled people.

Getting a job and keeping it

- Central Government strategy is wrong with regard to employment for disabled people;
- The support services available via the statutory sector do not help most disabled people find a job;
- Benefits have to be changed when disabled people work, risking such benefits as Personal Independence Payments and Disability Living Allowance;
- Benefits need to be more accessible and easier to get if needed;
- Disabled people need to be careful of the types of words they use in assessments as they may put their benefits at risk;
- The models of support available for people with disabilities are mainly for people with learning disabilities;
- Employers do not understand that skills take longer to learn for some disabled people;
- Disabled people need to be encouraged to speak up for themselves via courses, to get them to believe in themselves, and getting experience in employment;
- Disabled people do not know what skills and experience they have or need or where to go;
- Disabled people have been conditioned to think they 'can't' but they can go into main stream employment if they want to;
- You are your own person – disabled people need to go for it;
- Qualifications may not be possible due to disability;
- Less and less disabled people are going for jobs and getting jobs which takes the problem of employing disabled people away. That is not the answer;
- There is lots of form filling and ticking boxes;
- Disabled people may need an assistant to help them;
- As the culture is so target driven these days, disabled people get left on the side-lines;
- Employers may give token funding only to a disabled employee but it is not much;
- Employers need to take more responsibility for improving the confidence of disabled employees;
- The confidence of disabled employees depends on their disability and background;
- Appointments are only 20 minutes. You cannot do a lot in 20 minutes. Problems arise when going to group sessions;

- Employment is lacking and support is hidden. There should be more links between employers and disability groups;
- Nothing prepares people for work;
- Employers want people to be able to multi-task but this is not always possible for disabled employees who cannot cope with too many tasks;
- We are business orientated in the UK;
- The biggest issue is getting disabled people through the door;
- We need to raise the awareness of employers especially big companies;
- It might be possible to use the Chambers of Commerce to raise awareness;
- There are additional costs of going out to work;
- Individuals could benefit from having access to mentors;
- Human Resources Departments could work with organisations such as ACE Anglia Ltd;
- There is a need for awareness training at an early stage for example in schools;
- Could there be a way of ensuring access for disabled people to apprenticeships at statutory organisations;
- The interviewing culture (how you look, how you speak) is a problem and employers need to see past this;
- There are issues and concerns regarding health and safety in employment and a number of preconceptions in respect of the employment of disabled people;
- The complexity of the benefits system is a problem – part time work does not make financial sense;
- There should automatically be information about how to get to and from work;
- Disabled people face a number of barriers:
 - Transport;
 - Lack of understanding of employers;
 - Employers are not disability aware;
 - Thought of as just needing something to do;
 - Stigma of having a disability;
 - Lack of support;
 - Complex benefit system;
 - Being able to work to the pace required.

Being safe where you live and where you spend your time

- People should ask to see Identification Cards;
- Cyclists on pavements cause problems for people with disabilities;
- The 'Stay Safe' scheme provides a safe place to report any issues;
- There is a text number for people who are hard of hearing to use to report crime or problems;

- Reports can be made to the police via the Suffolk Police website as well as the usual telephone numbers 101 or 999. This needs to be promoted more as not everyone is aware.

Action Point: To look at the Suffolk Police website / all media sources to ensure ease of use and their suitability for all users.

Outcome: The website and media sources are fully accessible to everyone.

Made by: Chief Superintendent David Skevington, Suffolk Police

- There are issues with anti-social behaviour from young people;
- A device is needed to alert home owners that they have not shut the door properly;
- Advice is needed regarding coping with cold calling, both to the door and by telephone calls;
- Advice is needed for scam e-mails to prevent fraud. It would be helpful to know who to send these on to;
- The hate crime document is in easy read;
- It would be helpful to know where the third party reporting centres are, perhaps by using a logo;
- Stay Safe areas are similar to Neighbourhood Watch;
- Police Connect is a messaging service that connects people to the very latest policing news where they live, via email, text or telephone. It is easy to register on line. However there should be more effort made to ensure this service is accessible to people who need easy-read;
- There are a number of apps that can be used to obtain policing updates;
- It is important to get the message across that people can telephone 101 for non –emergencies;
- There were comments about the abuse of parking spaces for blue badge holders, vehicles being parked on or partly on pavements, and the dangers of traffic using pedestrianised areas. These were thought to be district council issues as opposed to Suffolk Police.

Action Point: To research statistics on the incidence of the abuse of parking spaces for blue badge holders and parking on pavements.

Outcome: More understanding of the difficulties caused to disabled people.

Made by: Chief Superintendent David Skevington, Suffolk Police

Using public spaces and places

- There are a number of issues with access such as getting into religious buildings, towns, uneven pavements and the location of 'A' Boards;
- Some places say they are 'disabled friendly' but when you arrive you might find only one area that is accessible;
- Shingle is used in a lot of places which is an impossible surface for wheelchair users;
- When planning a trip out, it is better if places are honest about what is accessible so that expectations are not raised;

Action Point: To issue advice about how to communicate with and help disabled people through training involving disabled people.

Outcome: Provision of an external newsletter.

Made by: Ipswich Borough Council

- Buses could have information available with details of how to help disabled people;
- There are issues about how people with mental health issues or learning disabilities are treated in public places. There needs to be an understanding that some people have difficulties with communication in noisy/public spaces. They need space and time to get their message across;
- Sometimes, disabled people are not taken seriously as customers. A difficulty with communication does not mean a lack of intelligence;
- It is not helpful to label people as disabled. People see the disability before they see the person;
- We need to start education young people at school so that they are brought up with an awareness and an understanding;
- Supermarkets and shops produce and put up signs near entrances to buildings which makes it really hard to access them. It is easy to work out when the Fire Service has been round to check fire exits as then they are clear. The way shops are set out internally makes it difficult to get around them.

Action Point: To check the whereabouts of the Ipswich Access Guide to help disabled people use Ipswich town centre.

Made by: Ipswich Borough Council

- When telephoning call centres, the option to enable disabled people to get assistance should be first because they cannot always take in a huge amount of information and can become confused.

Action Point: All statutory organisations in Suffolk should consider whether their telephone systems are easy for people to use or whether they are confusing to people with a range of disabilities.

All Statutory Organisations in Suffolk

- Consultation events are very important. We need to be able to say what we think;
- A lot of agencies and companies encourage you to do things on line. Even if you have access to the internet, you might not understand how to use it;
- Getting money into car park machines can be an issue but changes are being made to make this easier;
- Drivers do not tend to help disabled people access vehicles and do not wait until they have put on their seat belts before driving off;
- Some shops have lifts that are difficult to access and that do not appear to be well maintained. There should be some safety controls;
- The access needs of wheelchair users is not considered in shop layouts or in many changing rooms;
- If you pre-book assistance, the companies providing rail services can be very helpful.

Getting to where you want to go

What's going well:

- Buses are better than they were;
- Trains can be good – in terms of being able to plan your journey and getting support to get on trains (but only if you book in advance);
- Good Neighbour Schemes are in place in some areas across Suffolk;
- Connecting Communities/ Community Car services are available;
- Travel Training Team Suffolk County Council – This is free for families with children in education, currently £25 per hour for adults. The Visual Impairment team offers this too for those who are eligible;
- BSVEC run Connecting Communities services, they pay drivers and then invoice customers monthly for using the Community Car service. They are currently considering a buddy system in cars to include a befriending system;
- Mid Suffolk Axis in Stowmarket provides transport for members.

Identified Issues:

Expense

- One member of the Parkinsons Group in Eye pays £25 to attend a meeting, using a taxi as there are no buses;
- Cost for adults on travel training scheme;
- Some taxi services charge extra to take wheelchair users and can refuse to take people if their equipment will not fit in the car.

Information

- How is information about travel services accessed if a person has no internet? Is the information all in one place?
- Information on travel used to be in Parish Council newsletters, but this appears to have stopped.

Accessibility/Flexibility

- Bus services in rural areas are limited, often only one in morning with return in evening;
- The Parkinsons Specialist Nurses (in East of County) do not offer outreach appointments, patients cannot always access the nurse easily;
- Buses and transport are available during the day, but not available in evening or later at night for socialising. This takes independence away from younger people;
- Spontaneous trips are almost impossible for anyone without their own transport;
- Not all trains have wheelchair access, disabled passengers need to book in advance and staff do not always turn up as requested;
- Buses have wheelchair accessibility for one wheelchair user, but if a bus arrives and there are already passengers with buggies or other wheelchair users, then the wheelchair user will have to get the following bus which could be a long wait if there is indeed a following bus. Also, some people are unwilling to give up their seats (pull down seats) or make the wheelchair space available;
- Train platforms – if there is not access to the platforms on both sides of the railway line, it can be difficult; Wheelchair accessible taxis are always in use for transporting school children at key times of the day;

Potential Solutions/Ideas:

- If specialist nurses cannot deliver outreach service, would it be possible to offer appointments through Skype – ‘Tele-medicine’ which is used in Coastal areas to help people with mental health issues or learning disabilities;

- The Suffolk On Board Website offers information on travel options and there are customer service advisors to answer calls if needed;
- Could community transport services allow for more spontaneity? Connecting Communities services currently require 48 hours notice to ensure drivers can be available;
- Could Suffolk County Council look at whether the Connecting Communities services do meet the need of service users? There was a consultation ahead of the new contracts being introduced but these were not co-produced or designed with disabled people;
- Lift sharing schemes – what is out there already? How could this be used effectively? Suffolk Car Share – is this only for home to work? Can this be set up in Suffolk and linked into other transport services. How can people be encouraged to use it? (Drivers should ensure that they have business insurance to allow for carrying passengers in this capacity);
- Can Taxi drivers be informed/trained to better support passengers with disabilities.

Action Point: To contact Parish Councils to see what information they have on travel and what is shared in Parish newsletters.

Outcome: More information is available to people in Suffolk.

Made by: David Finn, Manager, BSEVC (Bury St Edmunds Volunteer Centre)

Action Point: To find out whether lift share can be used in a wider capacity as indicated on the website.

Outcome: More detailed information is available on this scheme.

Made by: Julie Mitchell, Transport, Suffolk County Council

Action Point: To continue to research the current transport services available, who knows about them, how they are advertised and who would use them.

Outcome: More information is available to people in Suffolk.

Made by: David Finn, Manager, BSEVC (Bury St Edmunds Volunteer Centre)

Action Point: To follow up on training opportunities for Taxi operators and their drivers with Forest Heath and St Edmundsbury Borough Council

Outcome: Improved taxi services in the west of the county.

Made by: Lauren White-Miller, Families and Communities Officer, West Suffolk Councils

Action Point: To identify the guidelines for wheelchair users when travelling by train.

Outcome: More information is available to people in Suffolk.

Made by: Lauren White-Miller, Families and Communities Officer, West Suffolk Councils



Getting your voice heard

- Does everyone know that Suffolk Infolink exists? They are looking to combine with Norfolk Infolink and also with Cambridgeshire to help people who live close to county borders. More publicity is required, for instance, in hospitals and GP surgeries;
- You can talk about your difficulties and there are Forums but the difficulties are in getting the decision makers and people who can change things to do anything;
- People go to:
 - the local library to get information;
 - their carer;
 - their local Member of Parliament when help is needed. Sometimes the MP is effective;
 - their local Disability Forum;
 - their local Disability Advice Service which can help with benefit claims (but funding for these services is drying up).
- It would appear that lots of small organisations who are struggling for funding have little voice;
- MPs need to think they will gain votes and then they make take more notice;
- There is a lack of political will to do anything;
- It is difficult to have one organisation representing all disabilities but it has advantages for pulling in funding and creating a bigger voice with a bigger campaigning weight;
- There are lots of places you can get information but very few to get action;
- There are places where you can make your voice heard, such as the Suffolk Coastal Disability Forum which invites disabled people to meetings and organise action days;
- There are still attitudinal barriers which require more education, understanding and compassion to ensure that disabled people are treated like everyone else;
- There is no reason why Disability Forums cannot approach Secondary Schools to do some work about disability and help change bad attitudes. Disability can happen to anyone;
- Working with schools would raise the profile of disability and get publicity;
- Contacting the Chairs of Governors would start this off;
- There will be a person at the school who is responsible for humanities;
- People talk over the person in the wheelchair regardless of who they are as the Mayor found out in Felixstowe earlier this year;
- People are not necessarily nasty, they are often ignorant, they often do not know what to do;
- Are there lessons to be learned from the Cancer Campaign? 25 years ago people did not talk about cancer but now feel they can. What brought

about this change and how can raising awareness of disability have a bigger impact;

- It is difficult for disabled people to take action because there is a fear that, if you complain, you may lose the services you do have;
- How can we work together better? Could Infolink be used as a way of contacting people?
- Are there any celebrities with disabilities who can promote disability awareness and get the interest of people with power?

Key Points:

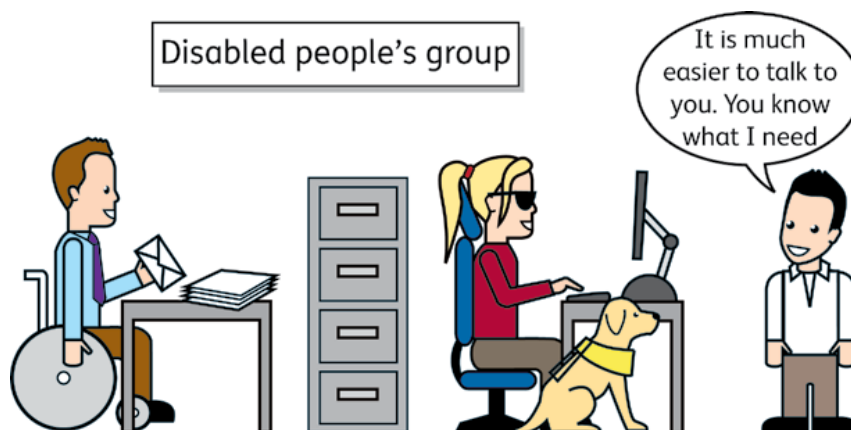
- Education is key. It was suggested that the Disability Forum for Suffolk could write to all Chairs of Governors in all Suffolk Schools to offer visiting during a PSHE lesson to talk about disability, preferably someone with a disability who is able to share their story;

Action Point: To consider contacting secondary schools in Suffolk to offer to provide talks on disability. identify the guidelines for wheelchair users when travelling by train.

Outcome: Disability awareness is promoted to students.

Made by: Disability Forum for Suffolk

- Ideally 'someone' needs to be the overarching organisation to represent people with disabilities. It was suggested that Infolink could be a central point as it has details of most groups. In terms of influence and power, people with disabilities have the influence but they need to harness the power of those people with the power to make changes happen;
- Most people with a disability are only able to make themselves heard to their carer/relative or the local organisations they use.



Appendix 1 – Delegates

Gemma Adams	Realise Futures
Margaret Anderson	BSVEC
Kelvin Armstrong	
Pam Armstrong	
Christine Barrett	
Jackie Bowen-Price	Mid Suffolk Axis
Liam Carr	Activities Unlimited
Olaf Castle	Leading Lives
Sue Chilvers	Mid Suffolk Axis
Jill Cocksedge	Realise Futures
Mark Conquer	ACE (Anglia) Ltd
Gary Crockett	Warm Homes, Healthy People
Sarah Jane Croft	Genesis Orwell Mencap
Frances Davies	West Suffolk Association for the Blind
Sally Dean	Leading Lives
James Dickson	Genesis Orwell Mencap
Geof Dix	Suffolk Coalition of Disabled People
Amanda Eaves	West Suffolk Association for the Blind
David Finn	BSEVC
Julie Frost	Mid Suffolk Axis
Mandy Garwood	Genesis Orwell Mencap
Yvonne Gostling	Parkinson's UK Ipswich & East Suffolk
Elaine Grace	East of England Homecare
Marie Grace	East of England Homecare
Carol Hales	Disability Forum for Suffolk
Michael Hales	Disability Forum for Suffolk
Jan Hardcastle	Mid Suffolk Axis
Jemma Hardy	ACE (Anglia) Ltd
Kecia Harris	Parkinson's UK
Andrew Henning	Genesis Orwell Mencap
Paul Hitchings	Leading Lives
Laura Holland	Avenues East
Tessa Holmes	Mid Suffolk Axis
Timothy Hunter	
Sandra Johnson	Mid Suffolk Axis
Brenda Joyce	Suffolk Coalition of Disabled People
Angela Keighley	ACE (Anglia) Ltd
Chis Kennard	Mid Suffolk Axis
Rebecca Last	Mid Suffolk Axis
Julie Longhurst	Genesis Orwell Mencap
Liz Mark	Suffolk Coastal Disability Forum
Chrystal Mason	Genesis Orwell Mencap

Karen McCormack	One Life Suffolk
Jane McNabb	Connect Group, Diocese of St Edmundsbury & Ipswich
Jonathan McNabb	Connect Group, Diocese of St Edmundsbury & Ipswich
Maureen Mee	Suffolk Coastal Disability Forum
Chrissie Moore	DanceEast
Micaela Nunes	Spinal Homecare
Les Oldham	Lowestoft Shopmobility
Margaret Oldham	DIAL Lowestoft & Waveney / Waveney Disability Forum
Kerry Overton	Healthwatch Suffolk
Catherine Plackett	Avenues East
Becky Penso	Parkinson's UK Ipswich & East Suffolk
Allen Pettitt	DIAL Lowestoft & Waveney
Paul Pilbury	
Janet Pittock	Mid Suffolk Axis
Andrew Provan	Waveney Disability Forum
Anne Sadler	Suffolk Family Carers
Michael Seeley	Mid Suffolk Axis
Gurmeet Singh	Genesis Orwell Mencap
Chris Southwell	Activities Unlimited
Geoff Stammers	Mid Suffolk Axis
Lily Stenhouse	Genesis Orwell Mencap
Maria Storesund	Living Paintings
Doug Swayze	Mid Suffolk Axis / Disability Forum for Suffolk
Sue Swayze	Mid Suffolk Axis / Disability Forum for Suffolk
Dave Taylor	Avenues East
Sue Vincent	Alzheimers Society
Carole Woodhead	Mid Suffolk Axis
Elizabeth Wright	Realise Futures

Appendix 2 – Listeners

Ben Ankers	Suffolk Infolink
Gillian Benjamin	Waveney & Suffolk Coastal District Councils
Ronald Benjamin	Norfolk & Suffolk NHS Foundation Trust
Roger Blake	Norfolk & Suffolk NHS Foundation Trust
Wendy Canham	West Suffolk Councils
Sallyanna Chatten-Berry	Suffolk Police
John Cherrie	Bartrams Healthcare
Annette Cotton	Connecting Communities, Suffolk County Council
Emma Currie	Suffolk Infolink
Claire Davies	Community Dental Services
Simon Dyer	Ipswich Borough Council
Emily Earl	West Suffolk Councils
Cllr Julie Flatman	Mid Suffolk District Council
Anthony Green	West Suffolk Hospital NHS Foundation Trust
Linda Griffiths	Suffolk Community Healthcare
Peter Haylett	Norfolk & Suffolk NHS Foundation Trust
Steve James	Avenues East
Margaret Johnson	Jobcentre Plus
Louise Jordan-Hall	Gt Yarmouth & Waveney Clinical Commissioning Group
Cllr Sandy Martin	Suffolk County Council
Julie Mitchell	Connecting Communities, Suffolk County Council
Luke Partridge	Bartrams Healthcare
Laura Rawlings	Community Equipment Service
Theresa Salmon	Travel Training Team, Suffolk County Council
Ben Singleton	Suffolk Infolink
David Skevington	Chief Superintendent, Suffolk Police
Marie Smith	Suffolk Police
Neil Stain	Hate Crime Co-ordinator, Suffolk Police
Lucy Stafford	Jobcentre Plus
Zach Tebbutt	Ipswich Borough Council
Richard Wall	Ipswich Hospital User Group
Stephanie Wells	Norfolk & Suffolk NHS Foundation Trust
Brenda Wykes	Community Dental Services

Appendix 3 – Facilitators/Note-Takers

*Nigel Brett	Babergh & Mid Suffolk District Councils
*Steve Bruce	Ipswich Hospital NHS Trust
*Lois Bull	Ipswich & East Suffolk Clinical Commissioning Group
*Laura Bullard	Babergh & Mid Suffolk District Councils
*Michelle Coulson	Ipswich Borough Council
*Alice Firbank	Ipswich Borough Council
John Grayling	Babergh & Mid Suffolk District Councils
Trish Hayward	Avenues East
Steve Hodgkiss	Disability Forum for Suffolk
Rachel Hodson-Gibbons	Babergh & Mid Suffolk District Councils
Linda Hoggarth	Disability Forum for Suffolk/Mid Suffolk Disability Forum
*Cllr Diana Kearsley	Mid Suffolk District Council
Simon Lanning	Ipswich Borough Council
Vicky May	Suffolk Police
Ellie McCarthy	West Suffolk Councils
*Gillian Orves	Ipswich Hospital User Group
*Shub Singh	Suffolk Police
Susan Vaughan-Williams	Avenues East
Graham Walker	Avenues East
Eleanor Ward	Ipswich & East Suffolk Clinical Commissioning Group
*Lauren White-Miller	West Suffolk Councils
Sue Wilson	Babergh & Mid Suffolk District Councils
Maureen Wood	BSL Interpreter

* **Also attended as a Listener**

Registration

Jane Bower	Babergh & Mid Suffolk District Councils
Carol Hales	Disability Forum for Suffolk
Michael Hales	Disability Forum for Suffolk
Trish Hayward	Avenues East
Catherine Parry	Avenues East

Appendix 4 – Market Stalls

Activities Unlimited
Alzheimer's Society
Avenues East
BSEVC (Bury St Edmunds Volunteer Centre)
Community Dental Services CiC
DanceEast
Disability Forum for Suffolk
East of England Homecare
East Suffolk Association for the Blind
Genesis Orwell Mencap
Healthwatch Suffolk
Ipswich & East Suffolk Clinical Commissioning Group
Ipswich Hospital NHS Trust
Mid Suffolk Axis
Norfolk & Suffolk NHS Foundation Trust
One Life Suffolk
Parkinson's UK Ipswich and East Suffolk
Passenger Transport, Suffolk County Council
Realise Futures
Suffolk Coalition of Disabled People
Suffolk Coastal Disability Forum
Suffolk Family Carers
Suffolk Independent Living
Suffolk Infolink / Customer First
Suffolk Police
Warm Homes healthy people
West Suffolk Association for the Blind





**Disability Forum
for Suffolk**



NHS
*Ipswich and East Suffolk
Clinical Commissioning Group*
NHS
*West Suffolk
Clinical Commissioning Group*



NHS
*Great Yarmouth and Waveney
Clinical Commissioning Group*

Forest Heath & St Edmundsbury councils

West Suffolk
working together

HealthEast

West Suffolk **NHS**
NHS Foundation Trust



The Ipswich Hospital **NHS**
NHS Trust

in partnership

Norfolk and Suffolk **NHS**
NHS Foundation Trust



Suffolk
Community
Healthcare



A service delivered by a partnership of:
The Ipswich Hospital NHS Trust
Norfolk Community Health and Care NHS Trust
West Suffolk NHS Foundation Trust



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