Disability Focus

Held on the 23rd October, 2018
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

Disability Forum for Suffolk

Disability Focus Planning Group
Thank you to the following organisations for supporting Disability Focus:

Avenues East  
Babergh District Council  
Councillors Locality Funding, Suffolk County Council  
Disability Forum for Suffolk  
East Suffolk & North Essex NHS Foundation Trust  
Forest Heath District Council  
Gt Yarmouth & Waveney Clinical Commissioning Group  
Healthwatch Suffolk  
Ipswich & East Suffolk Clinical Commissioning Group  
Ipswich Borough Council  
Mid Suffolk District Council  
Norfolk & Suffolk NHS Foundation Trust  
St Edmundsbury Borough Council  
Suffolk Coastal District Council  
Suffolk Constabulary  
Waveney District Council  
West Suffolk Clinical Commissioning Group  
West Suffolk NHS Foundation Trust  

Acknowledgements  

Disability Focus Planning Group  
Avenues East  
Babergh & Mid Suffolk District Councils  
Disability Forum for Suffolk  
East Suffolk & North Essex NHS Foundation Trust  
Ipswich and East Suffolk Clinical Commissioning Group  
Suffolk Constabulary  
West Suffolk Councils
Contents

Page 4 Executive Summary

Page 6 Introduction

Page 7 What do you think?

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

Page 28 Issues and Concerns from the 2018 Discussion Groups

28 General Comments
29 Being a full part of our community
32 Getting information you can use
36 Getting the benefits you are entitled to
37 Using hospital services
39 Using health care services (not in hospital)
41 Having a house to live in and support to live there
42 Getting a job and keeping it
44 Being safe where you live and where you spend your time
45 Being treated badly because of your disability (Hate Crime)
47 Getting to where you want to go
50 Support for family carers

Page 52 Appendix 1 – Delegates

Page 54 Appendix 2 – Listeners

Page 55 Appendix 3 – Facilitators

Page 56 Appendix 4 – Market Stalls
Executive Summary

This report details the concerns and issues raised by disabled people, their family carers and representatives of their organisations at Disability Focus 2018, 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 to make known and hopefully more widely visible the problems these groups of people face. This event has now been held for seven years and feedback from delegates shows that it still remains one of the very few opportunities for disabled people and their carers’ in Suffolk to have their say!

This report provides an indication through the responses to the ‘What do you think’ questionnaire of what people in Suffolk think about their big issues (listed below). Whilst overall, respondents with a disability do express that they find Suffolk a relatively safe place to live, the challenges of living in a rural county with somewhat limited access to public transport and information continues to create barriers and adversely impacts on their lives. In several key areas there continues to be a marked negative perception e.g. the feeling of personal safety (especially at night) and having an opportunity to directly express their views or have their views represented, in both areas a continued downward shift of opinion has been seen with family carers being especially critical of the latter.

Comments made by attendees clearly indicate that in many areas of daily lives there are still considerable barriers to the effective inclusion of disabled people in our communities, for example, use of the internet as a sole channel for dissemination of information. There are many specific examples of such barriers within the body 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 hospital services
• Using health care services (not 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)
• Getting to where you want to go
• Support for family carers

These topics again this year provided lively debate and details 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 so occur throughout the report.

It is worth highlighting that there is a small but noticeable positive trend in several areas with respondent groups feeling slightly more positive in some areas when viewed over the seven years this event has been running. However, the results again this year do indicate there is still much to be done to really understand and take into account the issues and concerns of disabled people and their carers across all areas.

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:

• Really good day (as always). Good networking.
• First time I have attended, thoroughly good.
• Really good, needs to be more events like it.
• Interesting and an eye opener.
• Good to express your experience, share with service providers and users how services work and, if not, why they are not working.
• Excellent conversations with a wide range of individuals and organisations.
• I liked hearing others.
• It was good to have full discussions with other people and groups about problems and issues that they have and any possible solutions.
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 2018. 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 Cllr Robin Millar, Portfolio Holder for Families and Communities, Forest Heath District Council, 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.

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
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 both as an on-line survey and 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 2018 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.
Breakdown of those completing the questionnaire:

- 43% Disabled People
- 26% Family Carers
- 17% Representatives of Disability Organisations
- 14% Statutory Listeners or Others

Do you get the information you need?'

- Yes
- No

<table>
<thead>
<tr>
<th>Year</th>
<th>Percentage of Answers</th>
</tr>
</thead>
<tbody>
<tr>
<td>2013</td>
<td>43%</td>
</tr>
<tr>
<td>2014</td>
<td>57%</td>
</tr>
<tr>
<td>2015</td>
<td>55%</td>
</tr>
<tr>
<td>2016</td>
<td>52%</td>
</tr>
<tr>
<td>2017</td>
<td>29%</td>
</tr>
<tr>
<td>2018</td>
<td>44%</td>
</tr>
<tr>
<td>2018</td>
<td>33%</td>
</tr>
</tbody>
</table>
Disabled people said:

- I think I have good opportunities to discover the information I need but sometimes I have to really search to find it;
- The printed word is too small and difficult to access. I do not have a talking computer;
- I can access the internet but it isn’t easy for everyone;
- It is difficult to find out information. I wanted training but Sensing Change wouldn’t provide ‘white stick’ training;
- I don’t have much information and I don’t have contact with occupational therapists. I can’t use the internet;
- I look it up on Google;
- I use the internet and the community groups I am involved with (though ‘information’ is a very broad issue);
- I can usually find information from the internet and by talking to friends;
- There is a mental health stigma. The internet is not always an option;
- Rights are not fully made clear at the point of any changes to situations, particularly in relation to Deprivation of Liberty Safeguards (DoLS);
- I find it for myself and people as part of my job;
- The onus is on the individual to look;
- Yes, through DIAL, magazines and the internet;
- As a trustee of DIAL, I am able to access various information;
- Yes, with help from my support worker;
- Yes, because I have a good understanding of what is available and I have connections to be able to find out more if I have to;
- Living rurally, information is not always available;
- Sometimes I have difficulty in getting information;
- No, not now I’m an adult;
I have to look for it and it is not always easy to find. I worry about people who may struggle without support;
- You tell me, I don’t know where to go to find out;
- No idea, never even heard of Disability Focus;
- I don’t believe that there is sufficient information out there for disabled people. For example, I did not know I could get a medical exemption for prescriptions or assistance from Access to Work until a friend told me;
- I do not know who or where to ask;
- I can access information;
- Yes, through Suffolk Axis.

**Family carers said:**

- I am reasonably literate and have access to the internet;
- I have access to the internet and local services;
- My son has a rare condition. To help him, I educated myself. I look for information and attend meetings / courses or training;
- I’m networked computer savvy;
- Not all information is accessible. It is not obvious where to find certain pieces of information on benefits, entitlements, groups, etc.;
- I am proactive in seeking out information and have a few key professionals who are very supportive;
- No, because information is not always accessible;
- Not sure where to go for the information I need;
- Information is not always accessible for all. You have to have the ability to find it for yourself;
- No, I cannot access the internet.

**Representatives of Disability Organisations said:**

- Yes, because I can seek out the information I need as I do not have a disability;
- Yes, online and Citizens Advice Bureau;
- I can access information and enjoy my work in supported housing. I am an Equality and Diversity Champion for age and disability;
- I will search until I find the information required;
- I have access to the internet, links with statutory organisations and training. I know where to look;
- Letters aren’t sent out in accessible form even though they should be. Websites aren’t accessible for visually impaired people. There is no telephone back up option – this is being withdrawn by a lot of councils and businesses;
- Yes, because I choose and am able to research;
- No, not enough sharing of information and confusing access;
- Yes, through reading, computer, e-mail, and local contacts;
I feel there should be more events to provide information for disabled people. If there are some, they are not very well publicised;

I am able to find out information;

I am lucky enough to work for Suffolk Family Carers and also have no disability;

A lot of the community feel that there are barriers to accessing information.

**Listeners from Statutory Organisations said:**

- I am a disability employment adviser and as part of my job I find out about what support and information is available and pass this on to customers and others;
- I am able to access the internet and able to ask;
- I have the access and ability to digitally research and the professional knowledge of who does what – more than the general public;
- Yes, but not always, some information takes more effort to find;
- Yes, good communication with services and I know where to access support;
- I have access to the internet and the ability to find stuff out when needed;
- I have been involved in producing/sourcing easy read information;
- I usually can. Sometimes it’s a bit of a chase to find out information or who to contact;
- Yes, no issues;
- Yes, I have good links with the Department of Work and Pensions;
- I can dig around to find it;
- I know where to access the information I need;
- Yes, awareness through my work and who to go to for information;
- Yes, because I can ask, read, see and hear.
‘Do you get the money you need to live your life?’

Disabled people said:

- I get expert help with my benefits;
- Yes, due to working but it can be hard as I myself have medical conditions which can make it difficult to work;
- Yes, provided I remain living with my partner;
- I am self-supporting but I have to pay out a lot to go to groups and then they do not seem to do anything;
- I get expert help and support with my benefits;
- No, because we don’t know where to get the information from;
- I need a power wheelchair as ordered by the Pain Clinic at the James Paget Hospital but no one will fund it;
- I work full time X 3;
- I can’t always do what I want but can do what I need. People are not given information to access extra funds needed;
- I have a disability but can’t get anything for it. I’m hearing impaired and have been most of my life but we can’t get anything such as PIP as I’m able to work;
- My PIP is the amount I require, though this cannot be said by many other disabled people because the system is broken;
- I am fortunate to have held a job that pays an adequate pension;
- No, pension and disability benefits are not enough;
- I could always do with more;
- Yes, with help from my support worker;
- It does not cover all my bills and needs;
- Only just. Sometimes I find myself short for one week in particular when no benefits are paid in;
- Sometimes I have trouble with call centre staff;
- I have a good pension;
- My sister helps and there seems to be enough.

**Family carers said:**

- Yes, via employment;
- Yes, but feel my son has lost money due to government changes;
- I’m luckily employed. PIP payments for stepdaughter help;
- No, my pension is not enough;
- I fill in the lengthy DLA form on behalf of my daughter and follow up leads for funding I am given;
- Yes, because I know how and where to access for my son. Others however don’t;
- As a carer, we get taxed on so little money. Why do we get taxed on caring for the people we love.
- Just about managing!

**Representatives of Disability Organisations said:**

- My husband and I both work;
- I am fortunate to work full time and enjoy my job;
- I am in a position to work and live with the money I receive from my employer;
- No, because of PIP and all of the ongoing problems that brings;
- I work full time;
- No, need more for adjustments criteria;
- Yes, retired teacher on a pension. I don’t choose expensive holidays;
- I work for a charity;
• Yes, because I am able to work;
• I am lucky enough to be able to work and earn money to support my lifestyle.

Listeners from Statutory Organisations said:
• I am in full time employment. Money budgeting;
• I have good education qualifications and able to work;
• I have a full time job which covers living costs and a bit extra;
• No, because of the cost of living and housing;
• I work for the money;
• I am employed full time;
• I’m a retired teacher and lucky enough to have a decent pension;
• Luckily I am employed and have enough to provide for myself and family;
• My partner and myself work;
• I have a good job and will shortly get a pension as well;
• I work full time and receive no benefits or help;
• Yes, but I could always do with more;
• Yes, because I can work;
• I work full time;
• I am employed and paid well.
‘Can you get to where you want to go easily?’

Disabled people said:

- It is difficult to read timetables. I’m in a rural area with infrequent buses;
- I need help as bus doesn’t go all way;
- Yes, provided my partner remains fit to drive;
- My basic thing is relaying on carers or family. It is a worry;
- Public transport is unreliable;
- My disability does not affect this;
- I have a car and can drive. My disability does not affect this;
- No, very few taxis take wheelchairs;
- No, it is good in Lowestoft (except the beach) but not in most other towns;
I have my own transport;
I own a disability vehicle;
No, no wheelchair;
I can but people with disabilities especially those in rural areas are not able to get out and about. They are unable to get the care and support they need in these areas and the services are few and not accessible;
I rely on buses and my parents to get me to places while I wait for my car to be fully adapted to my needs. Travelling by train is far too stressful as it is so unreliable for disabled passengers who require ramps to get on board;
Yes, with my support workers;
Some shops do not facilitate wheelchair access. The local authority has not provided beach access after years of campaigning;
Living rurally, there is no accessible public transport and other services are unreliable or inaccessible for a ‘spontaneous’ trip;
Parking is terrible in Mildenhall. It isn’t monitored at all. I’ve had arguments that have sometimes turned into aggressive behaviour asking people to move out of the spaces (for blue badge holders)! And two of the spaces end up with three non-disabled people parked in them. It’s terrible!
I rely on driving as I cannot use public transport due to balance problems. However, I find the parking facilities in Ipswich town centre, particularly disabled parking, very poor and therefore have to spend a lot of money on taxi fares;
I still have a driving licence but have off-days when I can’t drive and am not able to walk to a bus stop;
This so much depends on accessible travel information, familiarity of route and destination;
I have a vehicle and support;
I have a disability car;
Yes, because I drive but if I didn’t it would be very difficult;
I rely totally on my husband for transport;
I live locally;
At the moment, I can still drive;
I have a car;
I get family help.

Family carers said:
Yes, I use buses, taxis, the train and National Express coaches;
I drive so can access easily;
Transport is a struggle in a rural community. Community transport is not available out of hours;
Homes struggle to encourage visits out, particularly for residents with mobility problems;
- In a lot of towns, it is not easy;
- Yes, because I can drive;
- Yes, because I can drive and I enable my son to access as much as he is able;
- No, I need a wheelchair accessible vehicle;
- I own a vehicle;

**Representatives of Disability Organisations** said:
- I can drive (X 2);
- I have a car and am independent;
- Yes, via walking or car;
- Yes, as I have a car but not if I had to rely on public transport or have to fund taxis;
- No, buses don't always stop. Once on the bus, drivers don't always tell you when they are at your stop. Shared spaces are not accessible and are unsafe and confusing;
- Parking is an issue – long trips are not easy. Difficult to work;
- I can drive, walk, find out information and am in reasonable health;
- As an able bodied person, I am able to go anywhere – less sure for less able bodied people;
- No disability, able to drive or walk without issue;
- Buses should have appropriate visual signage. All transport including trains should be more visual and less aural.

**Listeners from Statutory Organisations** said:
- I am a car owner and able to drive;
- I am a driver and can afford a car;
- I use my car or walk as appropriate;
- I can drive and walk to where I want to go;
- I can use most forms of transport;
- I have a car (X 3);
- I have a car. I can get to bus stops. I don’t have to think about how I’ll get to places;
- I am an able person;
- I have a car which I use often, plus I live on a main bus route;
- I drive or I can get a bus or walk.
‘Do you feel safe when you go out?’

Disabled people said:

- Yes, generally;
- I feel safe (ish) but apprehensive about other people and trip hazards;
- I keep out of trouble;
- I am always with someone;
- Due to my medical conditions, I never go out alone;
- I have been targeted by drunk people in town and on the train on occasions;
- Yes, when I’m with my support worker;
- Yes, due to use of disability vehicle to take me where I want to go;
- It depends where I am;
- I am usually with my husband;
- I carry a walking stick;
- My disability does not affect this;
- I am anxious about what will happen to me;
- I’ve been more concerned about the recent attacks;
- Pavements are not always good so that is a concern;
- As a woman, I will avoid certain areas and do not go out late on my own but otherwise I am fine with most places.

**Family carers said:**

- I am confident to communicate on my daughter’s behalf though I worry for her as she is vulnerable;
- Yes, but I wouldn’t for my son as he’s extremely vulnerable and needs me to help keep him safe;
- I am more concerned for my 18 year old. I don’t always feel safe for him. As for me, if I know where I’m going, I am confident.

**Representatives of Disability Groups said:**

- I do sometimes;
- It depends where I am going;
- No, I trip and fall on my own;
- I am confident and mobile;
- Yes, I feel safe;
- I think I am lucky to live in a nice area and feel safe.

**Listeners from Statutory Organisations said:**

- Yes, if I am sure of where I am or are going;
- Yes, although I keep away from areas I feel would be unsafe, especially at night;
- I live in a nice rural area with low crime;
- I am ambivalent, pending on place and environment;
- I avoid places that could be risky;
- I live in a nice area;
- Mostly;
- Yes, because as a driver, I have more control;
- Yes, I take precautions.
‘Do you feel safe when you go out during the day?’

Disabled people said:

- I keep out of trouble;
- I am always with someone;
- Yes, when I’m with my support worker;
- It depends where I am;
- I have learnt routes for known places. New places are more difficult;
- The world is changing for the worst;
- Some days it is hard as I find some days better than others;
- Yes, because I feel comfortable in my community;
I am comfortable going to places I have been to before – new places are a different story because there is always a chance the access is inadequate;
- Yes, because I have carers with me;
- Uneven pavements and kerbs affect my balance and walking so I rely on a friend or family member to walk with me to support me;
- As it is light, there are people about.

**Family carers said:**
- Yes, I do but I’m very confident;
- I live in a village where I feel secure;
- I go where I need to go taking safe routes.

**Representatives of Disability Organisations said:**
- I have no issues in daylight hours;
- I trip and fall on my own;
- Yes, I feel safe;
- Yes, I can see, I have good mobility and can use a mobile phone.

**Listeners from Statutory Organisations said:**
- Yes, mostly;
- Not always, I feel vulnerable where streets are not lit or in places I don’t know well.
- Yes, good awareness of my environment;
- I know areas to avoid if possible.
idal people said:

- No, not at night, I would not go out alone;
- No, because of recent violence in previous nightclubs;
- I don’t go out at night;
- No, as I am afraid of what might happen to me;
- Yes, because I go out with friends;
- Sight problems are worse at night. I need to have a companion;
- I feel vulnerable in the dark, particularly when I’m on my own. There are too many homeless people around town (which is an issue all in itself) who have been known to ask for money in small groups. Though it’s easy
to understand why they do it, this can be very intimidating. Should the worst happen, I’m not sure I would be able to defend myself;

- Lack of street lighting, the lights going off at a certain time, etc., means that I cannot see bumps, etc., in the pavements and roads;
- I don’t go out on my own at night because my night vision is poor but feel safe when with a companion;
- Yes, because I have carers with me;
- No, I am anxious about what will happen to me;
- I carry a walking stick and a light;
- Yes, but I rarely go out at night;
- No, I need someone with me;
- No, because of crime;
- I do not go out often at night;
- I don’t go out at night;
- It depends where I am.

Family carers said:

- Yes, if I go out with friends, I use a taxi to get home safely. In the local area, I am comfortable with where I’m going;
- I do not feel safe on my own so do not go out at night;
- Yes, usually in my car;
- Not always;
- I don’t go out;
- I avoid certain areas as a precaution.

Representatives of Disability Organisations said:

- As a woman, if it is dark then I do feel on edge and try not to walk around alone;
- I feel that with the policing budgets being cut there are not enough resources to patrol and police as they should;
- Yes, but not very late at night by myself;
- Mostly. Sometimes it is too dark when the lights are turned off at midnight on my estate (Moreton Hall, Bury St Edmunds).

Listeners from Statutory Organisations said:

- I know the areas to avoid;
- No, not alone in areas I wouldn’t know;
- Most of the time, pending on environment;
- No, having previously been a victim of crime. I rarely go out alone at night;
- Yes, but it would depend where I was – not in central Ipswich;
- Not always. I feel vulnerable where streets are not lit or in places I don’t know well.
‘Apart from this event, do you think that the needs of disabled people are well represented throughout Suffolk?’

**Disabled people said:**

- Organisations do not work together enough to pool information and good practice to upskill each other and support people’s needs;
- Some areas are well represented but all disabilities are not so more work needs to be done in certain areas;
- Disabled people are seldom included;
- No, not throughout all of Suffolk;
- No, it takes too long for things to happen and be resolved most of the time as too many people have fingers in the pie;

---

**Graphs:**

- **Percentage of Answers:**
  - 2015: Yes 18%, No 82%
  - 2016: Yes 40%, No 60%
  - 2017: Yes 29%, No 71%
  - 2018: Yes 27%, No 73%

- **Percentage of Answers:**
  - 2017: Yes 29%, No 71%
  - 2018: Yes 32%, No 68%
  - 2017: Yes 100%, No 0%
  - 2018: Yes 7%, No 93%
  - 2017: Yes 50%, No 50%
  - 2018: Yes 38%, No 62%
  - 2017: Yes 21%, No 79%
  - 2018: Yes 25%, No 75%
- No, need more places to meet in the smaller towns and villages;
- I have no contact from services;
- I regularly attend a day care facility;
- I feel well supported;
- Sometimes, but not always;
- Not always easy for access and not always enough thought going into what our needs are or the time it takes us to get out of timed car parks like the West Suffolk Hospital. For example, the time to go from the hospital to the car park and load up my mobility scooter before I am ready to leave the car park;
- Not sure but I’m currently in accommodation that isn’t suitable for my needs and all I’ve been told to do is re-register us for bidding again. I expected a bit more support and help, 56 days later and we still can’t bid;
- There are lots of sources but not everyone manages to access them;
- Yes, ACE meetings;
- Mostly and improvements are always being made but sometimes there are frustrating areas not so well covered;
- Yes, information is provided;
- Generally information is available through various organisations;
- Yes, there is a lot but it needs mapping and it is not easy to access;
- Only because I am new to this event and so am not aware of many of the things mentioned;
- Physical disability – yes, mental health disability – no;
- People with mild disabilities don’t get properly represented;
- Yes, but only if you know where to look;
- There are several disability organisations in Suffolk. But I feel like, if you need information, you have to try hard to find it from the relevant organisation;
- The Disability Forums are a good source but it is difficult to go to places;
- No, there is nothing to empower young people;
- NO! Young people fall through the net.

Family carers said:

- Generally yes but in smaller districts (villages) the awareness seems less;
- Yes, although it could be better;
- I think they are to some extent but I do worry that it is a tick box exercise and the most vulnerable and isolated do not get their voice heard;
- No, their needs are largely ignored especially by senior officers in statutory organisations;
- No, need to be listened to more and have a voice – co-production, all working together;
- Not sure, it is not always visible to the non-disabled community;
- No, it could always be better through Disability Forums and representative organisations. The voice could be louder and stronger;
- No, lots of people fall through the net with a lack of support;
- There are plenty of events and information about, yet there’s still far too many disabled people and carers not getting diagnosis, funding, help and support, or directed to services (or the right services).

**Representatives of Disability Organisations said:**

- I hope so. The organisation I work at values our customers’ diversity. We have an Equality and Diversity Forum and take equality and diversity seriously;
- There are plenty of support groups coming together;
- There are lots of charitable organisations and statutory bodies to help people with disabilities in Suffolk;
- No – regarding my community. More can be done to consult and build trust within the deaf community;
- There doesn’t seem to be many information events for disabled people to gather information on services and facilities available for them especially if they are newly diagnosed or disabled;
- Not enough sharing of information;
- It is mixed – some areas are represented more than others;
- A lot of organisations are there but aren’t known about. Help is available but you have to look for it. A lot is there if under 18 or over 70 but hard and lacking for people of working age;
- I set up my Progression Sessions to held tackle the under-representation of disabled people. Nevertheless there is still a feeling that there are many out there crying out for support they think they can’t access;
- Don’t know, what use is representation without action;
- There are many groups that support disabled people but funding issues are a major problem;
- It is better than it was.

**Listeners from Statutory Organisations said:**

- No, limited forums providing access;
- There are charity organisations throughout Suffolk;
- No, needs vary, not everything is inclusive yet;
- I reckon there are lots of organisations but is there ‘joined up’ thinking? I know of a recent situation: the mother of a adult with learning disabilities was not treated well by her GP at the time of his early death but the mother did not realise she could complain;
- Could be much better if information is shared;
- Events like this clearly help. I would hope they are well represented;
- Somewhat – I’m aware of various community groups run by local councils and voluntary organisations but I worry that Government cuts will impact on vital services such as cuts to bus services and changes to benefits;
- There is a strong voice for disabled people which is welcome. It would be good to broaden the conversation to strengths, enablement and contribution;
- The needs of disabled people are not always considered in the development of services;
- No, not always;
- Improvements can always be made;
- We have really good active Disability Forums;
- Requires ongoing awareness always;
- I think there are a number of organisations in the area but the main issue is lack of money/funding;
- I can only comment for the area I live in which is Waveney. Opportunities are there for people to raise concerns and share issues with service providers.
Issues and Concerns from the 2018 Discussion Groups

General Comments

- What is a disabled person?
- The individual decides;
- I don’t want to be defined by a label as a disabled person.
- I don’t see disability as a bad thing;
- What about self-diagnosis?
- Is it more difficult for people with a hidden disability?
- The disability doesn’t disable me but the environment does;
- Young disabled people are not being educated or supported to get the information they need.
Being a full part of our community

What does being part of the community mean to you?

- Being involved;
- Getting to where you want to go and doing what you enjoy;
- Being able to get to what you want to do without barriers e.g. lack of buses;
- Accessing what you need;
- Having the means to be able to contribute to community and having support available;
- A community that allows you to be you;
- Having the same opportunities;
- Being noticed and acknowledged in the community;
- Safety;
- Access;
- Being valued;
- Having good networks;
- Having the ability to influence and change;
- Being supported and being supportive/

What are the barriers?

- Transport issues;
- Accessibility of buildings;
- Communication around what is on offer;
- Lack of interest in community groups;
- Lack of choice of where you want to live e.g. being placed so nowhere for social housing;
- Expectations of the community – certain village communities may want you to fit into certain roles or have certain agendas whereas a town has wider options;
- Community centres / hubs reducing;
- Bin collection days are not safe for people with sight problems as the bins are left obstructing the pavement by the bin operatives;
- The development in on Ipswich Cornhill is a trip hazard and access across the cobbled paving is uncomfortable for wheelchair users (it is understood that additional grouting is to go between the paving slabs).

What needs to be in place for a community to let you be you?

- Community buildings;
- Connections and networks;
- Face to face community but for some it could be online;
- Good accessibility and transport;
Is this happening?

- More could be done to encourage more people with disabilities to get involved in forums and groups;
- Making sure there are online resources if people can’t physically access groups, using social media / forums.
- In the East, they can offer supporting coffee and cake groups;
- There are informal meetings and events once a year in Waveney to encourage people to come rather than attend a standard meeting;
- The Gt Yarmouth & Waveney Clinical Commissioning Group is on Facebook in order to share news;

Issues

- Young people are not taking an interest in community but the sense of community has evolved and changed over time;
- However, there are lots of community groups out there that young people are engaged with;
- General lack of interest in community groups;
- East Suffolk is small with not very well connected places. It is limited due to narrow roads and no pavements. It makes travelling difficult if you can’t drive;
- Transport;
- Closure of Post Offices and Banks. These were once part of the community as people used them to make social connections and part of their routine;
- Broadband in rural areas – poor connection and mobile phone signal across rural areas in East Suffolk e.g. Framlingham;
- Affordability of technology;
- Some people don’t get involved and attend community groups where they can get information and support. This can be due to lack of confidence. These people need someone to attend with them e.g. those affected by social anxiety, those already feeling isolated and those on the autistic spectrum. There is a need to look at ways of improving confidence;
- Courses not accessible in some rural areas;
- Social media can be used as a negative platform, although it can create communities;
- Not enough knowledge about what is out there and not sharing information. Need to work more with other local organisations rather than working against each other;
- Could more be done to let users of services know about groups via community boards in local shops and social media posts;
- It is always going to be a struggle to reach everyone. Need to ensure users of services are involved in project design;
Communication is a barrier – Suffolk Infolink is out of date;  
Making sure online forums are available and make sure more than one format is available to ensure accessibility e.g. larger text. People have to find out for themselves but there are some that are not in a position to do so e.g. those with dementia or those who don’t want to know;  
Those with depression can struggle to access information themselves – need to ensure we engage with these people too;  
Transport is an issue regionally;  
Isolation of those who have English as a second language in Lowestoft. However some BME Groups in Great Yarmouth have existing groups for support. The issue is that some don’t engage.  
Those with a visual impairment are not always heard and not taken into consideration especially because of accessibility;  
More powerful messaging to remind people that not every disability is visible.

Good Practice / Opportunities

Meet up Mondays arranges transport to improve accessibility. This has been successful and lots of people were interested but initially it was hard work to get people together;  
The Coffee Caravan in East Suffolk;  
Coaches can be very accommodating with pick up points in villages.  
The internet can be a way of connecting but it doesn’t replace face to face contact;  
Facebook support groups can be very positive and a good way to solve problems e.g. with Universal Credit;  
It is valuable to signpost and attend lots of events, and encourage people to attend as it maintains services;  
The Church – looking outwards in the community;  
Encourage through education for those who lack confidence e.g. stress management and improving confidence courses;  
Haverhill Life Link - positive through social prescribing. There is also a scheme in Lowestoft;  
Working with schools to help those suffering with isolation. Schools provide entertainment.  
There are schemes in East Suffolk providing transport, tea and cake, and in Beccles;  
Providing transport means people can go to groups with others which helps those with low confidence;  
Morrisons enable autistic people to go shopping but only at certain times;  
Greater Anglia has a card scheme to say that if a person has an invisible disability then they need a seat;
- But subtle schemes are needed so that people don’t have to make a big deal out of having a disability;
- Suffolk County Council has a campaign to have posters on toilet doors as students are less likely to take down details in corridors or busy spaces;
- It is about having messages in public, safe areas;
- A dementia friendly community could work for those with all disabilities;
- Flyer designed to bring community together and encourage people to talk and have volunteers e.g. chatty cafés and Meet Up Mondays. You can put a sign on a table to say if you would like to talk to someone;
- Good Neighbourhood Schemes;
- Hospital Car Sharing Scheme.

**Getting information you can use**

**Disability Advice**

- Adequate funding is required for Disability Advice Services throughout Suffolk. This is currently not the case, grants have not been awarded and Suffolk County Council is talking about forcing Disability Advice Services to tender to provide the service, now being reviewed. Disability Advice Services cannot help if they do not have the resources;
- The Citizens Advice Bureau is often the route for funding for Government initiatives, e.g. digital access to Universal Credit, yet for disabled people the CAB is often not best placed to assist;
- Sponsors often restrict funding to a region or a locality rather than aligned to a service;
- How do users find access to information;
- Information on the internet is not easy to find, often not current or accurate. Live chat can help but it depends on who you speak to as often they have a script or prescribed format;
- What happens if you have no internet access? The skill needed, training and access can be expensive;
- Click through or menu select options are too long – it is hard to remember more than four options;
The telephone is better though not much use if the call handler has a script and cannot go off this to assist the caller. The same observation relates to face to face interviews;

Options on telephone services must be a maximum of four choices as otherwise the caller gets lost. Many public sector organisations do not follow this good practice;

Having someone at the end of the phone would be useful – we are losing this life line;

A Disability Handbook exists and is available from the Library. It is kept up to date;

It is hard to get users to ‘live’ events. Access by public transport is often hard or parking poor;

Finding out can be assisted by workshops or exhibitions but disabled people often find difficulty in accessing these;

The main issue is that there is no easy route to know what you need to know. Very limited information is given, you must go and find out for yourself. Information is often discovered by chance;

Finding out what you need to know is tiring and requires tenacity, carers are often not able to provide the time and energy to follow through;

Information needs to be where people are – funding can restrict access as the information will reflect funding sources, especially where the organisations providing funding have a local focus. Many people do not have access to the required information until they are in crisis. They need information on how to keep well in the community rather than have a crisis focus. Mobile provision of information in the community is required. The previous link via mobile libraries is now being lost.

Hospital

Appointment letters are still an issue for people with visual impairment.

Hospital letters are not helpful to people with visual impairment due to the small font used;

Whilst there are some improvements, letters are often in very small print and are never tailored to a person’s requirements unless specifically asked for and then this takes a long time;

You cannot change appointments if over six weeks in advance. It is easy to end up getting referred back to your GP;

Hospital services are picking up on the impact or consequences of lack of care provision in the community;

Hospitals are treating illnesses resulting from symptoms created by lack of care;
People are released back into the environment that exacerbated their symptoms – often driven by a lack of information about social care;
This can lead to homelessness;
The John Le Vay Cancer Centre, Ipswich Hospital, and the Louise Hamilton Centre, James Paget Hospital, in conjunction with Macmillan, provide good sources of information and support to people with cancer;
It is difficult to obtain easy read products.

Reliance on Computer Access to obtain Information

- Training to access computers is hard to find and costly;
- There is an assumption with organisations that online information is the solution for everyone;
- There is a fear of information overload as web based information is duplicated and people are bombarded with ‘stuff’;
- The assumption that the internet is best leaves those groups that cannot access the internet isolated;
- We could use the information technology more effectively;
- Websites are not always accessible to everyone.

Who is responsible for informing people?

- It depends on what the information is for but how does the user often know?
- Systems are not joined up and it is hard to get needs met from a single point;
- An issue which frequently arises is the lack of a joined up approach across different social and health services. People have to provide their same information over again and again.
- Assessments are too complicated and seen as a barrier to success, set up to save costs.

Examples of Good Practice

- Suffolk Family Carers uses information advisors to signpost applicants to the correct place;
- They use a warm handover service which joins up 12 other organisations – online and contact other member organisations who have 5 days to respond to the applicant. One form is completed with information for the applicant and then passed across to other organisations. This is available from the Suffolk Information Partnership. It was considered that this should be public facing;
- The signpost is completed by the service provider on the website ‘Suffolk Infolink’ for the applicant;
- Suffolk Infolink is:
  - An online directory under Adult and Childrens’ Services, Suffolk County Council;
It is managed and promoted by Kate Turner, Suffolk County Council;
People do not know about this service;
It has a search facility to locate regional services;
It has links to other services’ websites;
The challenge is to put this where people are and keep it regularly updated.

Social Prescribing:
The aim is to reach people in the community to keep them well;
Suffolk Family Carers has a twice weekly mobile service to share and communicate on the Shotley peninsula, which is great for residents who have access to little else, especially young people with mental health issues who are ‘trapped’ in the area;
Leiston also has social prescribing via the GP surgery which is looking to treat loneliness.

‘Ask Google’ is often used by people searching for information;
Hospitals are part of the Learning Disabilities Mortality Review Programme aimed at improving the standard and quality of care for people with learning disabilities;
The Mental Capacity Act is designed to protect and empower people who may lack the mental capacity to make their own decisions about their care and treatment. There is a need to support people in this process;

Barriers
The costs of attending groups and activities for people who self fund their support drives people away;
The delivery of care services is often linked to local budgets as set by donation criteria;
Delivery of service is a Catch 22 – no service – no demonstrated use – no funding – no service;
Information is often out of date, particularly printed material;
It is hard to get the right (current, accurate or appropriate) information from websites and to know that it is indeed right;
Government information is often not provided in plain English. Web sites can have several links from one section to another and this is confusing;
Forms and processes to obtain assistance are often long and complicated and become a barrier.
Getting the benefits you are entitled to

- There is no single point you can obtain a summary of information available – the Disability Rights Handbook issued by Disability Alliance was raised as one point of contact;
- Suffolk County Council used to recommend services to assist people but have now stopped this. It is thought the Council is going to introduce an accreditation scheme but it was felt that this was not a helpful approach;
- Disability Advice Services run out-reach services in Suffolk Coastal and offer support regarding completing benefit forms, appeals, housing, etc.;
- Customer Services, Babergh and Mid Suffolk District Councils are currently running pilot schemes for pop-up services in Shotley and Hadleigh;
- A suggestion that has worked in Forest Heath was partnership funding with Citizens Advice for support to Universal Credit claimants. The funding was split between ‘walk-in' customers and support before they reach crisis point e.g. food parcels and support with rent arrears;
- The application process for a Personal Independent Payment (PIP) is difficult with long winded forms that are very detailed;
- At a PIP appointment, the person is not trained in area in relation to application;
- The appeals process is also difficult;
- Assessments are not fit for purpose – the questions either have a ‘yes' or ‘no' and the response of ‘but' is ignored;
- The PIP initial application is seen as a tick box exercise;
- A customer has to ask for a re-consideration for the case to be looked at closer;
- The appeal process is filling in a form;
- The language used is not always appropriate. Key words are an advantage to get the bigger picture;
- JobCentres, Mental Health Teams, and GPs will refer customers to Disability Advice Services for help to complete PIP forms;
- This process for referrals is working for Disability Advice Services but also referring beyond those services e.g. housing;
- The Local Authority Access Point, the Job Centre and the Citizens Advice Bureau are all within a small distance in Stowmarket;
- People with more complex needs will need further support. The Local Authority at the moment does not do follow up calls to customers who have visited the Public Access Teams;
- As more Universal Claimants access customer services, more support is needed to support claimants and resources are limited. The Department
of Work and Pensions is working in partnership with Citizens Advice Bureaux from April, 2019. Will that partnership cover this support?

- Universal Credit is working for most people. The advice is to stay on a legacy benefit rather than transfer to Universal Credit;
- More support is needed to help people transferring to Universal Credit. There should be more one-to-one organisations to support people as needed;
- Whether customers are vulnerable or not, support is needed because of the complex process of Universal Credit;
- People’s awareness of what benefits they can claim needs to be improved. For example: How do they claim? What can they claim?
- At the start of the process, who is responsible to offer support;
- Where do I go to find out what I am entitled to?
- Where do I go when I am discharged from hospital? What services can be accessed?
- There could be access to an ‘InfoPoint’ on line for people with access to a computer;
- GPs could work with local organisations to support patients regarding what benefits they are entitled to:
- Hospital services can offer this as well.

**Action Point:** Implement support via organisations like DIAL, Suffolk Axis, Disabled Advice Bureau, etc. for patients leaving hospital;

**For action by:** West Suffolk NHS Foundation Trust and the East Suffolk & North Essex NHS Foundation Trust to note

**Using hospital services**

- There are two user groups at the Ipswich Hospital, one for people with learning disabilities and one for parents and carers of people with learning disabilities;
- Do patients with mental health issues presume that most short term visits to hospital get reported to mental health services;
- Wards for people with dementia have improved at the Ipswich Hospital;
- Being on a ward with many patients with dementia was quite frightening;
- General waiting times have improved;
- Appointments that are delayed or are cancelled can be a problem;
- The label of ‘borderline personality disorder’ does not help in getting services or a solution;
- The is a need for user feedback group or a forum for co-production of services;
- Signposting to available services needs to be improved (via GP or other Care Navigator);
- For most people, the first point of contact will be their GP but does it need to be if there is joint signposting?
- There needs to be a priority of esteem for people having to access hospital services for ‘invisible’ problems as for those with visible physical problems. There is a perception of discrimination against people with mental health issues. This could be a question of training for people involved in hospital triage;
- Hospitals work very differently in different places. Parents may be entitled to assistance. Ask Social Services about services. Have a parent information service;
- Going to hospital in London creates transport issues but these are not insurmountable. You don’t have to drive into London and incur congestion charges;
- There is information on display in hospitals but people don’t read it;
- Support groups are worth contacting and asking questions;
- How do I find out what is available as a carer?
  - Volunteer signposting;
  - Nurse at appointments;
  - Inpatients can speak to healthcare support workers;
  - Hub for carers/parents;
  - Customer First in Suffolk.
- There is an Accessible Information Standard – information needs to be in a form that individuals can understand;
- The biggest barrier is the levels of staffing in a hospital setting;
- Should we have equity or equality?
- GDPR can create problems in getting information to use and getting it out to people;
- Disabled people are led to believe that they are expensive and made to feel guilty. This needs to be discussed at the Ipswich Hospital User Group;
- Transition from child to adult services – Children’s and Adult Services do not communicate adequately. The transition is too brutal;
- There is no diagnostic service for adults with learning disabilities. The Clinical Commissioning Groups need to pick this up;
- Physiotherapy services are too remote;
- Services in the community for people with learning disabilities appear poor and need quantifying and improving.
Using health care services (not in hospital)

- The GP is the gateway to other services;
- It is difficult to access appointments weeks ahead. I can’t book double appointments on line and am asked to phone on the day which discriminates as transport has to be arranged;
- I miss a personal relationship with a known GP who knows my complex history. I have to explain all over again;
- GPs can have predetermined ideas that new issues are part of an existing condition. They don’t listen and the patient doesn’t feel valued;
- Health carers don’t appreciate how difficult it is to control weight when immobile. It is too easy to blame weight gain for issues;
- There is dissatisfaction with the wheelchair service:
  - Motorised wheelchairs are not available for indoor use when requested and expensive to purchase privately;
  - Two were not allowed to have electric wheelchairs for external use (it was explained that these are not appropriate for people with visual impairment). However such wheelchairs can be purchased privately;
  - There was no follow up when issued wheelchair to check it was suitable after a period of time. People were not aware they can phone and request reassessment. (This information is provided at time of issue but not recalled.)
- My mobile hoist is no longer appropriate but I was not aware I could phone for Occupational Therapy reassessment;
- I am carer to my daughter who now lives in the community. There are lots of different services and help available but it is not always ‘joined up’;
- It is more difficult when caring for an adult;
- When ‘in crisis’, who can help immediately before a referral date is received?
- There is a lack of information and knowing where to look – signposting is really important;
- Vital information is not always passed on to a new provider. The result of this maybe that the health of the person concerned deteriorates;
- Communication is key – but you have to ask the right questions;
- If a person has more than one health issue, they may get treated for their mental health but the underlying reason is autism;
- It is hard to prove mental capacity;
- Mental Health practitioners and social workers are not working together;
- Visits by Leading Lives are appreciated;
- Department of Work & Pensions workers can only direct people to their GP. They have no other powers to refer to other organisations. The
appointments may take up to three hours. People may threaten to take their own lives. Staff are having to deal with stressful situations on a daily basis;

- People with learning disabilities know they can visit the Job Centre as it is a familiar environment. They may not have an allocated support worker and have ‘dropped off the system’. Staff at the Department of Work & Pensions would be willing to signpost if given the information;
- A person who had had a stroke was not given any information when discharged from hospital. Help was provided by the Stroke Association which was gained independently. There was only six weeks of speech therapy with no follow up health care. There was no link between the hospital and social care;
- GPs do not like promoting particular counselling organisations. They advise that there are a choice or options for a patient to resource themselves;
- People find themselves dependent on charities to provide help but these groups are not joined up and run by volunteers;
- Over referral to charities can swamp staff – they are unable to help everyone;
- Relatives should be listened to as they have the ‘expert’ knowledge of a patient. They are frightened that if they make a fuss the patient will lose services e.g. supported living or moved to another provider;
- People are afraid to ask for help. They spend their own money to adapt their home;
- When a GP surgery closes, it causes difficulties having to travel to another part of the town for their appointments;
- It is too complicated to apply for a grant for a wet room so I am managing without. Where do you get support?
- Sensing Change would not provide me with white stick training as I have mental health problems;
- Social Prescribing by GP surgeries is now being rolled out. People are signposted to other organisations.

**Action Point:** To take forward the need for people to have easier access to appointments, to have the ability to have double appointments, to have easier access to online services, shorter waiting times and a dedicated GP and to ensure that family carers are kept in touch with services

**Outcome:** Better more customer friendly services

**Made by:** Suffolk Disability & Health Action Group to take forward
Having a house to live in and support to live there

- Councils and Housing Associations are keen to develop new homes for people with special needs, they admit they could do better when planning for the needs of individual people;
- Councils have less money to spend on providing services;
- There is insufficient adapted housing available where people want to live;
- The application process and banding limits the options because of the shortage of suitable housing;
- Choice based letting schemes are difficult to understand;
- People ready to move into settled homes have to wait a long time;
- Care services need to be available;
- There must be activities available close by;
- Care services and activities should be arranged before a person is moved into their home;

**Action Point:** To ensure that a person in supported housing has holistic care packages and activities in place. To consult with health workers and agencies already involved with a person before a property is allocated

**Outcome:** Better consultation on commissioning and developing new homes which cater for people with special needs

**Made by:** David Clarke, Babergh & Mid Suffolk District Councils in partnership with other social landlords in Suffolk

- Having access to good services is important, people need to be close to their support networks;
- Councils need to address housing needs more quickly and they also need to work better with local support services;
- Councils need to build better relationships with support staff;
- We need to do much more for young people – homes are too expensive;

**Action Point:** For District Councils/Gateway to Homechoice to be aware of the list of young people held by Suffolk County Council who may require supported housing (Housing Needs Awareness)

**Outcome:** To ensure information is available when considering housing need

**Made by:** David Clarke, Babergh & Mid Suffolk District Councils in partnership with Suffolk County Council and other social landlords in Suffolk
- It is not always easy to understand where to go for help;
- Places in supported housing are difficult to access, we don’t always know what’s available;
- More housing is needed for people with carers;
- A new build housing association bungalow had high threshold to the doors. This was a design fault and snagging was important to get a quick resolution. This issue prevented independent access to the bungalow for months;
- Another adapted property had light switches at an unsuitable height. The design and consultation with disabled people is vital;
- Local Authorities should obtain a list of young people who wish to live independently and their forward plan.

**Getting a job and keeping it**

- Employers have no clue how to make their recruitment processes accessible;
- It is scary for employers. They cannot possibly understand every condition;
- Employers don’t understand the ‘Access to Work’ scheme;
- They believe they cannot afford to take on disabled employees and therefore they don’t want to;
- Employers can be narrow minded;
- Employers miss out on talent;
- If you google images of disabled workers, you see pictures of people using wheelchairs which makes employers think all disabled workers are wheelchair users;
- Is ‘disability confident’ accessible?
- We are not ‘disability confident’ as a country;
- Employers could be disabled – we assume that they are not;
- Easy read information is provided as an afterthought;
- The RNIB never uses powerpoint;
- Employers have to think of the whole organisation when employing someone with a disability;
- We ask people to ‘declare’ whether they have a disability. This has negative connotations;
- Make sure people are aware of what is available to support them e.g. technology. This would help them;
- Information about ‘Access to Work’ needs to be widely available. This would mean more people with disabilities would be in employment;
Would you put your disability on your CV? No, once you have an interview is the time to say you have a disability;
You need to know how to solve any issues i.e. know about ‘Access to Work’;
If someone says they have a disability, some organisations will guarantee an interview but this is not the case for most private employers;
There is a need to break down the stigma. Employers are already employing people with disabilities who have developed disability whilst at work;
If adjustments can be put in place, then they should be;
Blind people who go into JobCentres are told that they cannot work;
JobCentres do a lot of retention work but they are only ever consultants for retention;
RNIB go into workplaces to support and explain about ‘Access to Work’;
Mencap are very good at going in and training employers;
I can be awesome if you support me;
People on the autistic spectrum find employment difficult – there is not enough support;
Some firms such as Birds Eye only recruit by on-line application forms – they are now looking at this process;
Local Authorities don’t have employment advisers – it would help if they did;
JobCentres have Community Partners upskilling staff to understand disabilities;
There are areas of good practice and horrendous practice – the language used by professionals makes you bristle. People are able and skilled;
A label can be a blessing and a curse;
Anxiety can be hid behind a mask;
Interviews with Disability Employment Advisers for those who are deaf can sometimes have negative connotations. That is why JobCentres have Community Partners;
Small employers just haven’t got the capacity to have the time, energy and the will to make adjustments;
Evenbreak is a recruitment agency for disabled people. It is very interesting;
Standing chairs and desks are helpful. Standing to work should be seen as a ‘norm’.
Being safe where you live and where you spend your time

- It is very important to feel safe. Visits from the police tend to be invisible;
- Consideration needs to be given to people whose first language is not English, particularly for long letters;
- The ‘News’ increases fear and further builds isolation;
- There is an integration project in Waveney to build relationships between schools and the older generation. This addresses the shifting of perceptions so that older people are respected and their fear of young people is removed;
- The inclusion of people with learning disabilities and physical disabilities including those with neurological difficulties, autism and mental health is important;
- There is a large gap in provision which impacts on communities;
- Awareness of disabilities is key and it is important that representatives have an understanding of disabilities;
- Small communities where people are more likely to know each other can have a massive impact on individuals;
- Challenging behaviour can be seen as a problem. Having a ‘health passport’ to explain a person’s disabilities and the adjustments they need would be useful;
- Lots of ‘new’ changes affect people and the atmosphere in which they find themselves. This can lead to self-harming;
- Social isolation is an issue. Suicide is happening!
- The range of disabilities needs to be understood and people should not be put in an unsuitable atmosphere;
- Labels help understanding but people do not want to be labelled.
- Autism and learning disabilities do not always go hand in hand;
- There is a range of levels within autism;
- People with autism may need emergency adjustments such as:
  - Calm welcome;
  - Communication and understanding;
  - Alert system – so that people can understand the range of disabilities and the impact of the atmosphere;
  - Quiet room – managing the atmosphere;
  - Support for the individual;
  - Training/awareness/understanding – is this mandatory? (Professionals need training and knowledge about dealing with individuals);
  - Feeling safe as it is a scary atmosphere.
- There is supposed to be a 10 year plan. Where is this?
- Priorities of people with chronic illness or disabilities can vary with the situation and impact;
- Things that can help are visual information or times to shop for people with autism that are safe;
- It is a challenge to personalise safeguarding. How can this be done?
- In terms of handling inappropriate touching, it is necessary to balance rights, stigma and conciliation versus people feeling safe and secure;
- There is no support or options available for people with high functioning autism;
- People are left on their own too much;
- Activities need to be available at half term in order that people feel included. Resources need to be available so services do not stop;
- There needs to be cover of activities for a range of organisations. Organisations need to be accountable and have ownership of the ‘big picture’;
- Local Authorities should listen to the needs and do simple things such as communication changes;
- It is important to understand when people feel they are not ‘safe’;
- Community Support Officers should be able to support people with differing needs;
- The empowerment of people is necessary;
- Recognising the individual and ensuring social involvement is key.

**Being treated badly because of your disability (Hate Crime)**

- The description of hate crime and incidents are considered to be motivated against people with protected characteristics;
- It is for the ‘victim’ to perceive that they have been affected by a hate crime or incident;
- The Police role is to respond to a reported incident;
- An understanding of disabilities is crucial to realise whether a hate crime has been committed;
- There are a range of incidents that can be considered as hate crime, including:
  - Being spat at;
  - Stabbed;
  - Assault;
  - Offensive language;
  - Abusive language.
- A better understanding of disabled people and raising awareness of disability would help;
• Disabled people could benefit from information on safe locations, safe places to go, and people who would help them;
• It is part of social inclusion to provide safe places where people with disabilities are accepted and can enjoy being out and about;
• Disabled people need to be educated to understand that such behaviour is against the law and to understand the impact of the crime/incident on their well-being;
• Disabled people can be very vulnerable and drawn into things like County Lines or be affected by Mate Crime;
• It is not always easy for them to report hate crime, they fear a lack of action to deal with the perpetrator, they fear reprisals, they become used to the abuse; there is no support for the victim, it is seen as a minor crime and the victim becomes isolated;
• Evidence of an incident should be reported to the Police who respond within their available resources;
• There has to be appropriate support for a person’s disability;
• People need to know what they should report to the Police;
• Licensees and Shop Owners need to have an understanding and awareness of disabilities;
• There should be representation at all levels;
• The law should be enforced and cause and effect recorded;
• People need to have confidence in the Police – so that they can respond to questions about having a disability and was the crime or incident a hate crime;
• There needs to be support and opportunities to test out the legislation;
• Crimes go unreported because people do not class themselves as having a disability;
• There can be an unfair assessment of actions;
• People need to know how to make complaints to the Police;
• It is thought that Police do not always record incidents as a hate crime;
• Officers need sufficient training;
• There is not a separate unit to support victims and the impact of the victim statement is not always taken fully into consideration;
• Are there trained disability liaison officers?
• Do people understand fully what a hate crime is?
• More needs to be done.
Getting to where you want to go

- In a rural community, there is often no public transport available;
- So people have to rely on family and friends, taxis, voluntary services or community transport;
- Community transport requires 48 hours advance notice for a journey;
- The County has a duty to consider providing services where operators do not provide a service. However, the Council no longer has the resources for this that it used to;
- Some car parks charge blue badge holders but at discount rates;
- Conditions for disabled people have greatly improved;
- People need to adjust their expectations on what is practically possible;
- Most transport services are better than they used to be.

Trains

- Greater Anglia will have new trains in place in the Autumn of 2019. Their entire fleet will be replaced. A group of disabled people has been involved in assessing the accessibility of the trains;
- More than 80% of the issues raised have been resolved. This includes wheelchair access; accessible toilets; colour contrasting; and floor level emergency buttons;
- Greater Anglia has tried to enable level loading but there is a 50mm difference between the carriage and the platform;
- Greater Anglia is doing its utmost and are still working on the provision of access ramps;
- There is no current intention to remove conductors from trains and they will assist people at unmanned stations.

Buses / Coaches

- Is there a law that requires drivers to put their steps down?
- Buses have both ramps and a facility to lower the bus;
- People should complain to the bus operator as all passengers have the same rights regardless of time constraints;
- Audible information at bus stops is being brought in;
- How are coach regulations different from buses?
- Most coaches have lifts;
- Operators should not discriminate against passengers with disabilities;
- People need to contact the operator beforehand to notify them that a disabled passenger needs assistance;
- There are now ‘talking buses’ for Ipswich Park and Ride;
The Secretary of State is able to make a law to introduce ‘talking buses’ widely. This has not yet been done so there is no regulatory requirement;
- There is an App which can be used so that a passenger knows when their stop is next;
- However, many people are reluctant to use technology;
- There is insufficient training for bus drivers to provide assistance to people with learning disabilities;
- I was refused the use of my discretionary pass on the scheduled 9.33am bus as the bus came before 9.30am;
- Buses move off before passengers sit down;
- Drivers have a Certificate of Professional Competency which requires them to have 7 hours of training per year. There are no compulsory courses that drivers must undertake;
- Rural routes tend to be better as the drivers are more likely to know their passengers;
- Galloways do disability training for their drivers;
- There are issues with delays which cause anxiety;
- Drivers are sometimes rude; Passengers should keep their ticket in these instances as they identify the driver to the operator;
- Spaces for wheelchair users are often used by parents with pushchairs, this is not the case in London;
- This raises the question as to who has priority – disabled people, elderly people and people with babies;
- Who licences bus companies? There are seven transport authorities who have control. It is very easy to set up a company;
- Complaints can reach the Traffic Commissioner who can remove bus licences;
- Bus companies often provide cards (online) which people can use to inform the bus driver what their disability is.

**Concessionary Fares**

- The responsibility for concessionary fares was returned to the County, before then, concessionary fares were 24/7;
- There is still an issue with concessionary fares not being able to be used before 9.30am;
- This causes problems for people with jobs or who have appointments to get to;
- By law, concessionary fares are not able to be used before 9.30am;
- District and Borough Councils used to contribute funds to the scheme to allow bus passes to be used earlier than 9.30am;
- The County Council does not have the funds to do that;
- It was thought that if people were employed they could fund their morning journey;
- Or, if people worked for organisations like Leading Lives, could they work different hours;
- Disabled people need to be pro-active. They need to realise that there are financial pressures.
- Travel vouchers are still available but the disabled person must choose between vouchers and a bus pass.

**Uber / Minicabs / Taxis**

- It is illegal to refuse to take guide dogs and wheelchairs;
- The government has ‘red lighted’ enforcement;
- If a taxi driver refuses to pick up a wheelchair user at a rank, a written complaint is required;
- Councils are working on prosecutions to ensure the message is put across.

**Finally**

- Following last year’s Disability Focus, the Council and the Disability Forum for Suffolk are working together to organise a conference with bus operators. This will include a presentation to share the experiences of disabled passengers

**Action Point:** To work together to put on a Conference for bus operators and others

**Outcome:** To provide information to Bus Operators and increase their understanding of the issues and experiences of disabled passengers

**Timescale:** 6 months

**Made by:** Phil Magill, Operations Manager, Passenger Transport, Suffolk County Council and Linda Hoggarth, Chair, Disability Forum for Suffolk
Support for Family Carers

- Information sharing is poor;
- There is a range of help available but people who need help are not always aware;
- It is important to keep in regular contact, for example someone who has registered as a family carer but contact has stopped;
- There is a lack of support groups for carers. There are 4 left but originally there were 7. This is due to financial constraints;
- Respite care for children and young adults is available but families are not aware;
- It is disjointed as young people with the same diagnosis are not able to access the same help;
- Giving options (signposting) on other help is available;
- Social media feeds are linked with other providers;
- We should have been given a ‘help’ package when discharged from hospital after a stroke. There was no signposting or help to find services given;
- Better engagement is needed between hospital services and patients;

**Action Point:** To ensure that family carers are kept in touch with services

**Outcome:** Better informed family carers

**Timescale:** 2 months

**Made by:** David Grimmer, Suffolk Family Carers

- It is important to share views on negative experiences. Training can then be provided;
- Suffolk Family Carers are currently training staff on Shotley Ward at the Ipswich Hospital;
- GPs have limited knowledge of the family carers within their practices;
- Information should be in the GP surgery, the pharmacy and schools;
- GPs are not always aware of patients’ caring responsibilities;
- We should promote Family Carers across Suffolk like flu jabs;
- There should be the provision of a fact sheet for each locality which could be available via Suffolk InfoLink;
- Disabled people are worried about what might happen if their family carer is taken ill especially if they have no friends or family who could help.
**Action Point:** To raise the issue of emergency care planning when a person has no friends or family to help with Suffolk Family Carers and the Suffolk Parent Carer Network

**Outcome:** To provide a solution to reassure disabled people

**Timescale:** 6 months

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

---

**Action Point:** To liaise with Suffolk Family Carers and the Suffolk Parent Carer Network to arrange training to enable Council staff to signpost services or provide information on the help available

**Outcome:** To provide information to family carers on the help and support that is available

**Timescale:** Initial meeting within 1 month

**Made by:** David Clarke, Babergh & Mid Suffolk District Councils in partnership with Suffolk Family Carers and the Suffolk Parent Carer Network
## Appendix 1 – Delegates

<table>
<thead>
<tr>
<th>Delegate</th>
<th>Organisation</th>
</tr>
</thead>
<tbody>
<tr>
<td>Jackie Bowen-Price</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Sue Chilvers</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Heidi Cobb</td>
<td>Ipswich Shopmobility</td>
</tr>
<tr>
<td>Sharon Dunlop</td>
<td>Habinteg Housing Association</td>
</tr>
<tr>
<td>Amanda Eaves</td>
<td>West Suffolk Sight</td>
</tr>
<tr>
<td>Laura Feveyear</td>
<td>Havebury Housing Partnership</td>
</tr>
<tr>
<td>Julie Frost</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Tracey Fryatt</td>
<td></td>
</tr>
<tr>
<td>Teresa Goldson</td>
<td>DIAL Lowestoft &amp; Waveney</td>
</tr>
<tr>
<td>Elaine Grace</td>
<td>Purely Care</td>
</tr>
<tr>
<td>Maria Grace</td>
<td>East of England Homecare</td>
</tr>
<tr>
<td>Carol Hales</td>
<td>Disability Forum for Suffolk</td>
</tr>
<tr>
<td>Michael Hales</td>
<td>Disability Forum for Suffolk</td>
</tr>
<tr>
<td>Sharon Hobbs</td>
<td>Suffolk Parent Carer Network</td>
</tr>
<tr>
<td>Melanie Hollis</td>
<td>Colchester &amp; Ipswich Museums</td>
</tr>
<tr>
<td>Suzanne Horrex</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Timothy Hunter</td>
<td></td>
</tr>
<tr>
<td>Rosa Iddon</td>
<td>Leading Lives</td>
</tr>
<tr>
<td>Donna Keenan</td>
<td>Disability Advice Service East Suffolk</td>
</tr>
<tr>
<td>Tomas Kores</td>
<td>Richmond Fellowship</td>
</tr>
<tr>
<td>Steven Largent</td>
<td>Mid Suffolk Disability Forum</td>
</tr>
<tr>
<td>Beccy Last</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Shirley Layne</td>
<td></td>
</tr>
<tr>
<td>Ashley Maw</td>
<td>Leading Lives</td>
</tr>
<tr>
<td>Jo Mays</td>
<td></td>
</tr>
<tr>
<td>Margaret Morris</td>
<td>Suffolk Coastal Disability Forum</td>
</tr>
<tr>
<td>David Mottram</td>
<td>Affinity Trust</td>
</tr>
<tr>
<td>Gill Mossop</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Lewis Old</td>
<td>Realise Futures</td>
</tr>
<tr>
<td>Leslie Oldham</td>
<td>Waveney Disability Forum / DIAL Lowestoft &amp; Waveney</td>
</tr>
<tr>
<td>Margaret Oldham</td>
<td>Waveney Disability Forum / DIAL Lowestoft &amp; Waveney</td>
</tr>
<tr>
<td>Glenn Oxford</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Ben Parker</td>
<td>Realise Futures</td>
</tr>
<tr>
<td>Allen Pettitt</td>
<td>Waveney Disability Forum / DIAL Lowestoft &amp; Waveney</td>
</tr>
<tr>
<td>Helen Prior-Townsend</td>
<td>Suffolk Family Carers</td>
</tr>
<tr>
<td>Andrew Provan</td>
<td>Waveney Disability Forum</td>
</tr>
<tr>
<td>David</td>
<td></td>
</tr>
<tr>
<td>Courtney Reeve</td>
<td>Forest Heath Disability Forum</td>
</tr>
<tr>
<td>Michael Seeley</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Janice Skilling</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Name</td>
<td>Organization</td>
</tr>
<tr>
<td>------------------</td>
<td>---------------------------------------------------</td>
</tr>
<tr>
<td>Sue Spencer</td>
<td>Disability Advice Service East Suffolk</td>
</tr>
<tr>
<td>Geoff Stammers</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Doug Swayze</td>
<td>Mid Suffolk Disability Forum / Suffolk Axis</td>
</tr>
<tr>
<td>Sue Swayze</td>
<td>Mid Suffolk Disability Forum / Suffolk Axis</td>
</tr>
<tr>
<td>Beki Tolliday</td>
<td>Mid Suffolk Disability Forum / Suffolk Axis</td>
</tr>
<tr>
<td>Cathy Walsh</td>
<td>Royal National Institute for Blind People</td>
</tr>
<tr>
<td>Wendy Warren</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Jim Watt</td>
<td>Forest Heath Disability Forum</td>
</tr>
<tr>
<td>Rebecca Webb-Heath</td>
<td>Realise Futures</td>
</tr>
<tr>
<td>Monica Wilkins</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Matt Wilson</td>
<td>Richmond Fellowship</td>
</tr>
<tr>
<td>Carole Woodhead</td>
<td>Suffolk Axis</td>
</tr>
<tr>
<td>Louise Woods</td>
<td>Realise Futures</td>
</tr>
<tr>
<td>Joe Woodvine</td>
<td>Medequip</td>
</tr>
</tbody>
</table>
Appendix 2 – Listeners

Alison Baker  
Department of Work & Pensions

Michael Bellward  
JobCentre Plus / Department of Work & Pensions

Gillian Benjamin  
Suffolk Coastal & Waveney District Councils

Cllr Glen Chisholm  
Ipswich Borough Council

Anthony Green  
West Suffolk Hospital NHS Foundation Trusts

Stuart Halsey  
Suffolk Coastal & Waveney District Councils

Sharon Hobson  
Norfolk & Suffolk NHS Foundation Trust

Gill Jones  
Healthwatch Suffolk

Jo Land  
Group Deputy Chief Executive, Avenues Group

Irene Macdonald  
Lay Member for Patient & Public Involvement, Ipswich & East Suffolk Clinical Commissioning Group

Cllr Robin Millar  
Forest Heath District Council

Gareth Moir  
Suffolk County Council Localities & Partnership Team, Directorate Health, Wellbeing & Children’s Services

Jerry Newman  
Norfolk & Suffolk NHS Foundation Trust

Vicky Perry  
Ipswich Borough Council

Laura Rawlings  
West Suffolk Hospital NHS Foundation Trust

Nikki Reeve  
West Suffolk Hospital NHS Foundation Trust

Cllr Christine Shaw  
Ipswich Borough Council

Jake Titterington  
East Suffolk Councils

Alex Winterbone  
Wheelchair Services

Alison Wright  
JobCentre Plus / Department of Work & Pensions

Brenda Wykes  
Community Dental Services
Appendix 3 – Facilitators/Note-Takers

Christine Ambrose  Babergh & Mid Suffolk District Councils
*Jess Barber  West Suffolk Councils
*Roger Blake  East Suffolk & North Essex NHS Foundation Trust
*David Clarke  Babergh & Mid Suffolk District Councils
*Cheryl Claydon  Suffolk Constabulary
Helen Clegg  Avenues Trust
*Marielena Giner  Ipswich & East Suffolk Clinical Commissioning Group
Rebecca Goodsell  Babergh & Mid Suffolk District Councils
*John Grayling  Babergh & Mid Suffolk District Councils
*David Grimmer  Suffolk Family Carers
Julie Harvard  Babergh & Mid Suffolk District Councils
*Steve Hodgkiss  Disability Forum for Suffolk / East Suffolk Association for the Blind
Rachel Hodson-Gibbons  Babergh & Mid Suffolk District Councils
*Linda Hoggarth  Disability Forum for Suffolk / Suffolk Disability & Health Action Group
Paul Jarvis  Babergh & Mid Suffolk District Councils
*Robert Kemp  Passenger Transport, Suffolk County Council
*Ronnie Knight  JobCentre Plus / Department of Work & Pensions
*Phil Magill  Passenger Transport, Suffolk County Council
*Lisa Overton  Ipswich Borough Council
Kate Parnum  Babergh & Mid Suffolk District Councils
*Paul Retter  Ipswich Borough Council
Claire White  Babergh & Mid Suffolk District Councils
*Lauren White-Miller  West Suffolk Councils
Kristina Wilkinson  West Suffolk Councils
Caroline Smith  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
Louisa Stewart  Avenues East

Administration

Trish Hayward  Avenues East
Catherine Parry  Avenues East
Appendix 4 – Market Stalls

Community Dental Service
Department of Work and Pensions
Disability Advice Service East Suffolk
Disability Forum for Suffolk
East of England Homecare
East Suffolk Association for the Blind
Forest Heath Disability Forum
Ipswich Shopmobility
Leading Lives
Medequip
Mid Suffolk Disability Forum
Norfolk & Suffolk NHS Foundation Trust
Realise Futures
Richmond Fellowship
Suffolk Coastal Disability Forum
Suffolk Disability & Health Action Group
Suffolk Family Carers
Suffolk Parent Carer Network
West Suffolk Sight