Suffolk Coastal Disability Forum

Minutes of the Meeting (via Zoom) on Tuesday, 15th April, 2025 at 2pm

Abbreviations used:

DAS	Disability Advice Service East Suffolk	DfT	Department for Transport
DWP	Department for Work & Pensions	ESC	East Suffolk Council
HWS	Healthwatch Suffolk	IDAB	Ipswich Disabled Advice Bureau
PC	Parish Council	SCDF	Suffolk Coastal Disability Forum
TC	Town Council	WDF	Waveney Disability Forum

Present:

Disability Forum for Suffolk [SCDF Chair] SCDF Secretary		
ESC Communities Officer for Kesgrave, Martlesham & villages		
Disability Employment Adviser - DWP		
SCC Integrated Transport Manager		
Community Development Officer, PAPYRUS Prevention		
of Young Suicide		
Staff Manager - Ipswich Depot, First Bus		
Melton PC		
Volunteer with various organisations		
Councillor, Aldeburgh TC		
Vice-Chair, Suffolk Sight		
Office Administrator, Leiston TC		
Project Officer, Community Action Suffolk		
Disability Employment Adviser, DWP		
Councillor, Westerfield PC		
WDF Vice-Chair		
Manager, DAS		
Councillor - ESC & Martlesham PC		
Chair, DAS		
Community Engagement & Partnership Manager, HWS		

Guests:

Trudie Harkin	Co-production Co-ordinator, HWS
Janet Perry	Cultural Development Lead, ESC

Apologies:

Simon Daws Rob Dunger Margaret Oldham SCDF Vice-Chair Suffolk Sound WDF Chair

1. Welcome

Linda welcomed everyone to the meeting and introductions were made.

2. Apologies

The above apologies were received and noted.

3. Culture and Visitor Strategy in East Suffolk

3.1 Janet Perry, ESC Cultural Development Lead, was welcomed to the meeting. She gave a short summary of the culture & visitor strategy and explained that her role was to oversee this strategy across the whole East Suffolk district.

3.2 ESC's cultural strategy was created in 2023 and planned to run through to 2028 - a strategic vision to enhance lives through culture.

- 3.3 The three main objectives of the strategy are:
 - East Suffolk's cultural and creative economy will thrive, realising its potential and providing benefits for itself and for other sectors.
 - Young people will have opportunities to cultivate creative careers, with clear pathways for skills, talent and career development.
 - Communities will have access to cultural participation opportunities inspired by the landscape, which benefit health & wellbeing.
- 3.4 Janet's role is to make this 3-point strategy work by:
 - Supporting businesses, social enterprises, charities, freelancers, town and parish councils plus anyone else involved in the creative sector or with visitor attractions.
 - Supporting young people to cultivate creative careers and to take part in creative activities.
 - Enabling everyone to take part in cultural participation opportunities to benefit health via creative health programmes.

3.5 Heritage Open Days are encouraged and a small grant is available for any groups wanting to run these activities. There is an ongoing national campaign & people can access heritage venues, walks and talks and everything is free.

This aligns with the third strategy objective to try and increase participation by removing barriers like cost.

3.6 A cultural connections volunteering project is increasing the number of volunteers in the cultural sector and also making it easier for people to get involved.

3.7 Young people are encouraged to think about careers involving events and festivals; there is a grants programme concerning events and festivals.

3.8 A new network has been created. Janet said that anyone who is in the creative sector, whether freelancing or employed, is welcome to join the network to communicate about events, network events and funding; it is really important to support people that are delivering these activities.

3.9 A venue that ESC owns is the Martello Tower in Felixstowe and a VE Day event is being run at the tower on the 10th May.

3.10 ESC is sponsoring some of the 'decorated hares' (sculptures) that are coming to Ipswich, Woodbridge and Felixstowe this summer.

3.11 There are barriers to participation in cultural events: non-accessible cultural venues; financial costs; lack of knowledge of which events are on offer; lack of confidence or support; poor public transport; cultural programming not meeting needs and not least, health & social isolation. Low diversity with the workforce makes it difficult to be successful in the creative sector.

3.12 A town development programme has been running for a couple of years: helping towns be more inclusive with issues such as dementia awareness training, neurodiversity, disability, signage and digital assets for communities and businesses offering feasibility support & training.

3.13 A Sizewell C Tourism Mitigation Programme features accessibility mapping (e.g. locations of changing places facilities) and physical adaptions to public spaces (e.g. dropped kerbs). This the starting point for Sizewell C to know what the visitor experience is like.

3.14 Summing up, ESC should be:

- Enabling an increase in cultural participation, even though it does not run many projects or its own venues.
- Working with this Forum.
- Championing accessibility and inclusion, especially in creative projects that are community-funded and should be co-developing and co-designing programmes of cultural activities alongside people with disabilities.
- Listening to feedback via the Forum of personal experiences in order to improve engagement and remove barriers.

- Listening to creatives within the sector.
- 3.15 A comment and reply session followed:
 - Scilla said that she was passionate about the creative industry and had a wealth of experience in this field. She would be happy to volunteer to be involved. Janet welcomed this approach and would like to receive some insight from Scilla.
 - Trudie said that we should be changing the culture and ensuring that coproduction is key, ensuring that the voices of the target audience is part of the decision-making process. Janet replied that it would be great if Trudie was able to run a session for creative organisations with the principles of co-production as a starting point.

3.16 As there were no further questions, Linda thanked Janet for her presentation - Janet replied that she would like to come to future meetings to tell the Forum about further cultural projects. The presentation slides will be distributed with the minutes.

4. Healthwatch Suffolk Ambassadors

4.1 Trudie Harkin, Co-production Co-ordinator for HWS was welcomed to the meeting. She gave a short summary of the different teams that exist within HWS and said that she was part of the co-production team which also has a team of ambassadors.

4.2 The Co-production team work to come up with solutions to a broad sweep of problems in health and social care, hoping to influence what is going on in the wider world.

4.3 Organisations such as the NHS, Adult Social Care, Medequip, E-Med and the Papworth Trust had approached HWS for support in in delivering a co-production ethos within their organisations.

4.4 HWS hold face-to-face workshops with these organisations, inviting people from within the organisation, people they work with, and their stakeholders. By the end of the workshop, it is hoped that participants understand what co-production is all about.

4.5 One of the key elements that HWS offers is access to our ambassadors. HWS ambassadors are volunteers who have different lived experiences. For example, Simon D recently joined as an ambassador for visually impaired people and recently came along to a meeting with Ollie, his guide dog. 4.6 HWS has volunteers from various backgrounds, for example: business, retired or have young families. Others have knowledge of special educational needs or the benefit system or mental health. All come with different passions and skill sets.

4.7 HWS invites a couple of these ambassadors to help deliver these workshops. Attendees listen to what these ambassadors have to suggest. If an organisation is designing something new then they may ask for the opinions and advice from our ambassadors.

4.8 For example, West Suffolk Alliance designed a health app for a women's health project. They noted that the project was much better after input from our ambassadors and various charities and voluntary organisations.

4.9 HWS is looking to increase the number of ambassadors. A flyer has been giving a brief summary of what HWS does and the QR code can be scanned to get in touch. The flyer will be distributed to members when HWS have agreed the exact format of the flyer.

4.10 HWS has two type of volunteers; one type who might claim for expenses, e.g travel costs; another type has a casual worker agreement for volunteers who wish to claim some recompense for their time. Both types of volunteer want to be involved and have a voice.

4.11 Trudie was happy to share her e-mail address with potential volunteers and would normally respond by arranging a meeting or a visit to talk face-to-face. <u>trudie.harkin@healthwatchsuffolk.co.uk</u>

- 4.12 A question and answer session followed:
 - Linda said that she had worked with Trudie's predecessor on a project concerning pharmacies. However, she had not become an ambassador. She had found the application process to become an ambassador somewhat bureaucratic, rather than just asking 'are you available?' or 'can you help with this project?' Trudie replied that there is a formal application process with an application form which she could help complete; 2 referees are needed but the reference form needed little time for the referee to complete. There is a handbook about co-production which requires initial reading
 - Volunteers are asked to express interest in one or more topics. Projects are then matched with suitable volunteers and she tries to ensure that accessibility is not a barrier to attending an in-person workshop and that travel costs are reimbursed.

4.13 The HWS website has a section dedicated to co-production. There is no obligation to become an ambassador; for example, their research team might be looking for someone with experience of a certain subject and they reach out to particular groups whose members have particular skills and/or knowledge. Trudie said that she saw our Forum as a good group to engage with in this respect.

4.14 There were no further questions and Trudie was thanked for her presentation.

5. Minutes from the Meeting held on 21st January 2025

The minutes were agreed.

6. Matters Arising not elsewhere on the Agenda

6.1 Item 4 Jenny Riddell-Carpenter MP: After an approach from Jenny Riddell-Carpenter, who is our MP, to know more about the Forum, Linda and Paul met Jenny via Teams.

It was agreed that Jenny would provide the Forum with a six-monthly update on what would be of interest and importance to the Forum; in turn the Forum would provide Jenny with a brief update also at regular intervals. However, if an issue arose that was of concern to members, this could be raised by the Forum at any time.

6.2 Item 7.1 Beach Wheelchair at Felixstowe: Pati reported that she had been in contact with the ESC department responsible for the beach wheelchair. They said that they were making plans for the coming summer and would be probably providing an update by next month after overcoming issues regarding beach wheelchair storage, maintenance and associated infrastructure. Pati would continue to follow up this matter.

Members were asked if any of them had any experience of using the beach wheelchair at Aldeburgh or Lowestoft. Marianne said that the beach wheelchair at Aldeburgh had been "lost" and had been told that it would not be replaced. Pati had asked the WDF for feedback on the beach wheelchair at Lowestoft but had not had a reply, but she would send a reminder.

Linda said that there appeared to be no progress on the boardwalk at Felixstowe. Pati said that she would follow this up.

6.3 Item 7.2 Bus Services: Regarding the poor bus services to the Grove Medical Centre in Felixstowe, Simon B said that this service is one that that SCC will be looking to fund when new money comes from the DfT in June. SCC has been talking to First Bus about options to run more trips past the Grove Centre. A decision is needed from First Bus to run a modified route on either the Felixstowe - Ipswich or the Felixstowe - Woodbridge route as an adjunct to the existing contract.

SCC had been talking to First Bus about the 64 bus route missing out Old Martlesham for at least two years and First Bus had said that when they next change their timetables, this route reversion would be included. It is not known how long this might take. Nigel said that he would be pushing the First Bus Commercial Team in the right direction.

6.4 Item 8.3 Ipswich Hospital Issues: Following members' impatience at the January meeting about the lack of progress being made, the Planning Group had progressed the issues again with Steve Bruce, Patient Experience Lead, at the Ipswich Hospital. He was doing his best to find answers from the various departments.

Responses have been received as follows:

Q: Have the number of Blue Badge parking spaces increased or decreased since the building works have been ongoing?

A: The number is just about the same as before.

NB: The Planning Group has commented that 6% of the parking spaces in a car park should be marked for blue badge holders, i.e. 111 spaces. There are currently 72.

[Secretary's note - see the DfT document "Inclusive Mobility" for recommendations on the number of Blue Badge parking spaces in publiclyaccessed car parks]

Q: Does the Hospital have a plan showing the location of Blue Badge parking spaces?

A: A very detailed map of the hospital site has been provided.

NB: The supplied plan was very complicated and difficult to understand. The Planning Group has asked if a more simple plan can be provided.

Q: Is the use of Blue Badge parking spaces enforced?

A: Yes - by parking attendants.

NB: The Planning Group has asked if there is any data to demonstrate this enforcement, for example, the numbers of cars removed from Blue Badge spaces etc.

Q: Why are Blue Badge parking spaces the first to be occupied by builder's temporary (or semi-permanent) equipment or construction material compounds, thus reducing the 72 supposed Blue Badge spaces? A: The hospital tries not to do that.

Q: Why are the buses entering the Hospital grounds for drop-offs still limited to mainly Ipswich Buses despite the enlarged size of the bus loop? A: Further time is required to think about this topic.

Q: Why do buses from everywhere north of Ipswich Hospital drop off in Woodbridge Road which is a long way for disabled people to get to the Hospital Main Entrance or the Outpatients' Entrance? NB: Simon B said that plans for the Martlesham Park & Ride service to use the hospital bus loop were on a list of proposed changes for when the new DfT money arrives at SCC in June.

Q: Why is some of the signage in the Hospital inadequate?

Q: Why when lifts are out of action is there no signage about the disruption until the inactive lift is reached, which means a long detour to find a working lift? How about some diversion signs along the way and a bit more customer service?

Q: Why are patients with impaired vision still not sent appointment letters in a format they can access?

Q: What is happening with the Patient Portal which informs patients about new appointments?

A: The existing Patient Portal is being replaced by MyChart, which patients cannot sign up to yet. In the meantime new signups are not available for the existing Patient Portal.

NB: Secretary's post-meeting note: MyChart is a software product from an American company, Epic. It enables patients to access upcoming and previous appointments, test results, medical records and other information via an app. The system is up and running at Guy's, St. Thomas's and Great Ormond Street Hospitals amongst others.]

Steve Bruce is continuing to work on the issues raised.

7. Issues, Concerns and News from Members

7.1 Disability Information Day 2025: The SCDF Planning Group members are working with Steve Race & Graham Walker of DAS on the next Disability Information Day. It will be held on Wednesday, 17th September, 2025 at the Woodbridge Community Hall from 9 am until noon.

Pati said that we are working through the specifics in order to ask for expressions of interest from prospective stallholders. Invitations to the event will be sent to the SCDF membership and beyond as planning progresses.

7.2 Update on IDAB: Graham said that IDAB in Ipswich had definitely closed. DAS are working with various parties to try and offer outreach facilities in Ipswich. Steve and his team were taking an increasing number of calls from the IP1 - IP4 postcodes that IDAB used to serve. DAS is trying to help where it can and has been operating in the Steam House Café for a while. Trying to cover the work of IDAB is quite significant, but various organisations including Ipswich Borough Council are coming forward with funding to help DAS in their efforts.

7.3 DAS 40th Anniversary: Graham said that it's DAS's 40th year but that no-one can remember the exact date that DAS was established. The process of tracing trustees and staff who were with DAS then has started. If anybody knows of people who were involved with DAS over the years, Graham would be pleased to hear from them.

DAS is organising events to celebrate the anniversary. The first event is a Charity Dance and Buffet at Woodbridge Football Club on 9th May, tickets are $\pounds 15$ including the buffet; for more details contact DAS. A series of presentations about the work of DAS is planned for the 12th of September; time and venue to be decided.

Linda said that SCDF and DAS were planning to link the Disability Information Day with the 40th anniversary.

7.4 Accessible Toilets at the James Paget Hospital: Andrew reported that wheelchair accessible toilets on hospital wards were too small and that he hopes that when the new hospital is built these toilets would be made larger. Linda said that she hoped that Andrew and WDF would be able to see the plans and make their views known. Edward said that as a member of the Health Overview and Scrutiny Committee for Norfolk and Waveney, he would feed back the issue as a concern. Linda said that it would be hoped that there would be changing places facilities incorporated into the new design.

7.5 Suffolk Sight Equipment & Information Day: Steve H drew our attention to the annual Equipment & Information Day that Suffolk Sight would be holding on June 11th at the Edmunds Room in St Edmundsbury Cathedral in Bury St Edmunds. Various equipment suppliers, plus information and service providers for visually-impaired people were already booked. Please see the Suffolk Sight website for flyers and more information.

7.5 REMAP: Paul reported that Peter Webb, the Chairman of the Suffolk East branch of REMAP, had contacted him. This charity makes customised equipment for disabled people for free. They are rather busy at present so are not really looking for more work but are keen to reach out to anyone who could benefit from having equipment designed and made to meet their specific needs. Contact details: 01394 386452 or www.remap.org.uk

7.7 Access to Work Scheme: Some concerns had been noted about the Access to Work Scheme. Michelle commented that from a DWP point of view they were trying to clear the backlog of applications to the scheme and that people starting a new job would be given priority. She said that if anyone has seen the Green Paper, there was still time to comment on the proposals. The proposed changes include an overhaul of the Access to Work Scheme, which is recognised as currently not fit for purpose.

Link to the Green Paper (closing date for comments is 30th June, 2025: <u>https://www.gov.uk/government/consultations/pathways-to-work-reforming-benefits-and-support-to-get-britain-working-green-paper</u>

Paul said that within the consultation process there is no provision to comment on changes to PIP or ESA, despite the major changes to PIP proposed. The Forum had expressed concerns about PIP in early March to Jenny Riddell-Carpenter, but had received nothing from her, except an automated reply to our e-mail.

Linda said that the Forum should remind Jenny of the importance of PIP payments to disabled people.

Action: Planning Group

8. Update from HealthWatch Suffolk:

8.1 Sally Watson, Community, Engagement and Partnership Manager at HWS, was welcomed to the meeting. Sally said that she had supplied notes to the SCDF Secretary. These notes are detailed here:

"Healthwatch Suffolk is in its 13th year. Healthwatches are statutory beings brought in because of the care Act 2012. There are 152 Healthwatches across England, of which Suffolk are one of the largest. Our aim is to seek feedback from people about their experiences of NHS health and social care services. To shape and influence care and services. Our CEO and Independent Chair attend many meetings to discuss the findings including Integrated Care Boards, the Suffolk Health and Overview Scrutiny Committee, various hospital trusts, (ESNFT, WSHFT, NSFT), Suffolk County Council Public Health, and the Health and Wellbeing Board.

We have 4 main functions/teams: Co-production led by Trudie Harkin, information and Communications, led by Michael Ogden, Research and Analysis also led by Michael and the Engagement and Communities team led by myself.

A lot of Michael's work is commissioned, surveys are sent out and results analysed and reported. Trudie's work is mainly commissioned (as Trudie alluded to earlier in the meeting) and my team's work is core funded. Engagement Officers can be found at various clubs and organisations, in GP surgery's hospitals and at events. People are encouraged to share their feedback either at the time or later through the website. On the website you will find the feedback centre comments and can select a particular service/surgery to see how people have commented on it and it will show a star rating. All our projects and insights can be found on the website <u>https://healthwatchsuffolk.co.uk</u>

Recent projects at HWS:

Virtual wards are a recent development in the NHS, and therefore it has been important to ask people about their experiences to shape and influence standards of services in the future.

The service allows patients to get the care they need at home, safely and conveniently, rather than being in hospital.

Once referred, patients and families receive monitoring technology that measures vital signs (such as blood pressure, heart rate and oxygen levels) at home.

People receive care from the hospital team through home visits and remote monitoring. Families can message, phone or have online meetings with clinicians at any time. HWS did some research with families who had cared for someone on a Virtual Ward. Over 40 people took part and voiced the benefits and advantages as well as the challenges. One of the biggest challenges was people not knowing what virtual wards are, another is the needs of the carers wasn't initially taken into account.

Following the research the virtual team ward have now put together an Action Plan that they're working towards. https://healthwatchsuffolk.co.uk/virtualwards/summary

The Spinal Care and Support: Project is in its closing stages & will be

published this month

Next Core Project at HWS:

Our core project starting early summer will be part of our organisation called 'Your Care Your Way' focussing on Visual Impairment.

This will follow our successful D-Deaf project a couple of years ago. Simon Daws who has signed up as a new Ambassador will be heavily involved.

Current / future work:

• My Health Our Future 9: Schools adding another survey this year called My Health Our Future Family. Very good response so far from parents telling us about the issues they face having teenage children.

• Learning Disability (Social Care Project): We have ongoing engagement with system partners to determine the potential for lead on lived insights.

• Admissions Prevention project later this year.

Engagement Officers current biggest complaints:

• Dentistry access continues to be a big concern for many patients. Lack of NHS access in Bury St Edmunds and Leiston areas.

• Access to medication continues to be raised. Patients have reported missing medications when picking up prescriptions. Items are regularly missing and then difficult to find. This causes stress and inconvenience.

Good news for Pharmacies:

A deal was reached to provide extra funding for pharmacies (April 9, 2025)

In March 2025, the Department of Health and Social Care reached an agreement with Community Pharmacy England to provide an additional £617 million for pharmacy services over two years.

What's included in the deal?:

Overall, the new pharmacy contract will mean NHS pharmacies in England will receive £3.073 billion funding for core work such as dispensing prescriptions, in 2025-26.

A further £215 million will be made available to continue the Pharmacy First programme – as an alternative to GP appointments for patients to be seen for certain conditions – as well as funding blood pressure checks and other extra services."

8.2 Linda asked there were any questions or comments about Sally's report:

- Sally said that HWS would like to be involved with Suffolk Sight's Equipment & Information Day in Bury St Edmunds. Steve H replied that he would pass Sally's details to Wendy at Suffolk Sight who was organising the event. He said that Suffolk Sight were currently providing services to around 2,500 people across Suffolk and that the organisation would love to be involved in the HWS project about visually impaired people and he was sure that Suffolk Sight would get lots of people engaged both from a user perspective and from an organisational perspective.
- Linda asked if the extra money going to local pharmacies would prevent them closing thus depriving villages of a local source of prescriptive drugs and other services. Sally replied that a recent report had noted that over 50% of pharmacies are running at a loss and that the UK seemed to pay more for drugs than other countries.

8.3 Sally was thanked for her comprehensive update. She said that she would be back at the July meeting.

9. Information Round / Any Other Business:

9.1 Felixstowe Seafront Development Strategy: The Planning Group would be attending a consultation meeting with Rebecca Styles, ESC Programme Manager for this project, in June 2025.

10. Topics for Meetings

10.1 It was noted that Suffolk Wildlife Trust seemed reluctant to engage with the Forum by not offering to provide a speaker for a future SCDF meeting after a request.

10.2 Paul asked if Steve Bruce could be invited to the next meeting to answer members' questions, but Linda explained that as so many hospital departments were involved, we would have to ask several department heads to attend and that this was not practicable. Other members also reported into insurmountable 'roadblocks' when trying to solve patients' problems.

It was decided that, for the moment we should leave Steve Bruce to explore explanations / solutions to our many problems with Ipswich Hospital.

10.3 Roberta from Papyrus said that she would like a slot on the agenda to tell members about the work of this organisation.

10.4 Sizewell C and its potential for the area was also thought to be a useful topic.

Action: Planning Group

11. Date of Next Meeting

The next meeting of the SCDF would be on Tuesday, 15th July 2025, from 2pm to 4pm, via Zoom. The link for the meeting would be sent out in due course.