

# BBS Independent Living Survey

## Appendix

*Appendix contains comments made by respondents in the BBS Independent Living Survey.*

<a href="#"><u>APPENDIX A.....</u></a>	<a href="#"><u>2</u></a>
<i>Care Support .....</i>	<i>2</i>
<a href="#"><u>APPENDIX B.....</u></a>	<a href="#"><u>2</u></a>
<i>Housing needs and adaptations .....</i>	<i>2</i>
<a href="#"><u>APPENDIX C.....</u></a>	<a href="#"><u>3</u></a>
<i>Wheelchair and Equipment .....</i>	<i>3</i>
<a href="#"><u>APPENDIX D.....</u></a>	<a href="#"><u>4</u></a>
<i>Travel.....</i>	<i>4</i>
<a href="#"><u>APPENDIX E.....</u></a>	<a href="#"><u>5</u></a>
<i>Socialising and Relationships.....</i>	<i>5</i>
<a href="#"><u>APPENDIX F.....</u></a>	<a href="#"><u>5</u></a>
<i>Work and Careers.....</i>	<i>5</i>
<a href="#"><u>APPENDIX G.....</u></a>	<a href="#"><u>6</u></a>
<i>Topics BBS should prioritse .....</i>	<i>6</i>

## Appendix A: Care Support

*“My husband is my official carer and I feel that Carer’s allowance doesn’t compensate him for all the work he does helping me.”*

*“I only personally need care if I have fractured rather than day to day. When I moved to university I fractured and needed care urgently to allow me to stay at university, which was hard. Now I have direct payments from my local authority in place should I need them and then I just repay what I don’t use.”*

*“I pay for psychotherapy for both children, who suffer in different ways related to their OI. The complex psychological trauma of repeated unpredictable episodes of severe pain, and physical disability which leads to a stepwise reduction in what you are able to do, is poorly recognised. And then there is my own anxiety and guilt as an affected parent.”*

*“I don’t have regular carers, only have carers (family) when I fracture. I have an assistant dog that is self trained by me for what I need. He’s trained to alert to front door being knocked, the alarms activated on my ventilator and oxygen generator, locate keys, fetch Morphine, help me with putting and taking things out the washing machine.”*

## Appendix B: Housing Needs and Adaptations

*“Never thought to ask for help as I was convinced I would not get any”*

*“There are a lot of hoops you have to jump through to get the adaptations you need. It can take up to a year to have things sorted, which is why I chose to self-fund.”*

*“I looked into funding for more adaptations (my house needs work done to be fit for a wheelchair indoors, ie new kitchen) but my husband and I have too many savings to qualify. I understand why grants are means tested but it feels very demeaning sharing your financial details with a stranger.”*

*“I have always been rejected for any application as I have a mild form and work full time. However I feel this is harsh because on the 40+ occasions I have had a fracture I would have benefited from a ramp for my wheelchair when I fractured my hip for example. But because this was temporary and not full time I got no support.”*

*“There is plenty of funding and grants available across the country to support you to get the adapted equipment or physical adaptations to be made to where you live. Check out local disability independent living organisations and with BBS to see what is available to ensure you get what you need especially if your landlord or local authority are not particularly forthcoming.”*

## Appendix C: Wheelchair and Equipment Requirements

*"I've been trying to get a new powered chair through wheelchair services with no success whatsoever. They seem largely incapable of being able to accommodate the needs of someone smaller and different in size and shape than the 'normal' wheelchair user."*

*"My biggest problem was the wheelchair OT said I should have an electric wheelchair but because we do not have a through floor lift wheelchair services couldn't offer me one. They offered me a standard wheelchair but it would have been too heavy and bulky for me to propel. They would not provide a light weight one so I bought a Quickie Helium myself as I needed something lightweight and easy to manoeuvre."*

*"It's very difficult to get the right equipment from NHS. Recently been told if I want a new walking frame I can only have one that is held in their storage room. Currently can't get local NHS to assess my need for a new walking frame. Have been told to purchase one myself without any advice as to where or what type."*

*"The person interviewing me had no idea or interest in OI despite my back being in a state that puts people in wheelchairs (I'm not at that point yet) I'm fit and able apparently. Being disabled and able to work seems to work against getting any pip."*

*"Sadly due to lack of staff and underfunding my local NHS wheelchair services dept is extremely slow. I swapped my manual for an electric chair (after years of assessment) but the chair that arrived wasn't the one I had tried out in my home and it wouldn't go over the door threshold or fit in the bathroom. Therefore I had no choice but to swap back for a manual. Efforts to find a suitable electric wheelchair have been put off due to Covid."*

*"When I got my power wheelchair it was through access to work and it was just before the cuts to the schemes so it was pretty straight forward. However now I believe it's a lot harder and I'm not looking forward to needing to reapply. My experience was the nhs voucher scheme was pretty painless. I told them exactly what I needed and how much I could afford to put towards it and I was lucky that they agreed to a voucher for the rest - which was pretty sizeable."*

## Appendix D: Travel and Transport

### Walking

*"Pavements are so canted it's impossible to wheel, especially with few drop curves and problems with them being dug up by cable companies who do a bad patch job".*

### Public Transport

*"I will only occasionally, reluctantly go somewhere I can't take my car. Public transport is a nightmare. Taxis are unreliable and unsafe (I've had drivers admit they cancel "wheelchair jobs"), it's too cold and hard to get to bus stops, trains are also unreliable (assistance) and it's all just very very stressful and not worth it."*

*"If I didn't have my car (that is heavily adapted) I wouldn't go out much. I don't feel safe on any modes of transport. Taxis are unreliable and I feel very vulnerable with drivers who make it obvious they don't like "wheelchair jobs".*

*"Sometimes, assistance on trains doesn't arrive - even when pre-booked. Bus drivers from some companies can be reluctant to assist (I.e. put the ramp down) to enable you to board."*

### Flying

*"The stress of having equipment damaged ie wheelchair and being left stranded. Constant checking things for meeting on arrival and departure."*

*"I am not sure what the rules and regulations are about carrying oxygen cylinders, liquid painkillers and a ventilator on board a plane."*

*"It's far easier to travel by plane than it is for me to get on a bus."*

*"The cost of travel insurance for me is always very high and sometimes I chose my holiday location based on the quality of healthcare in that country. I also think the OI passport in numerous languages is great."*

*"If I travel by plane, I only ever go with my manual wheelchair which reduces my independence significantly. Also, a lot of airlines have let me down when bringing the wheelchair to the gate upon arrival. I will never travel by plane without my family".*

## Appendix E: Socialising and Relationships

*"I lack confidence to do anything socially - I tend to do things on my own, which can make me feel quite isolated & lonely."*

*"I love swimming but I need a friend to help me poolside to the pool lift thing and that's not always possible".*

*"I find relying on friends can be limiting, but I have looked into other options but help is only provided for `personal care`".*

*"Fatigue is the main issue but it's very hard to get this recognised, having medical professionals recognise that OI causes fatigue would be the first step".*

*"Hearing loss makes relationships challenging but I try to manage. Explaining the bone condition is more challenging and having to opt out of particular social events like ice skating, skiing, is always a bit depressing!"*

*"Anxiety re. access, the effects of such outings on fatigue and pain afterwards. The general hubbub caused when asking for assistance or access help can be embarrassing".*

*"My ability to form and maintain relationships are hindered and effected by my OI. Often due to fatigue and low energy am unable to join post-work social events or evening functions with friends often leaving weekends as the only time for this to occur."*

*"Difficult to identify places that are fully accessible and okay for me to access with friends and can be difficult to get that information from venues and often requires a lot of time and effort".*

## Appendix F: Work and Careers

*"I have used access to work in the past to fund travel to work when I didn't have a car and also to help assess my needs in the workplace. I thought they were brilliant."*

*"Access to work paid for my powered wheelchair rise and fall. Very good manager but still feels awkward to discuss access to work and work place adjustments."*

*"The earlier you apply to access to work the better for you and your employer. If you have reports from previous assessments or supporting evidence from University DSA useful to have to hand to share with assessors. Even if Access to Work not an option or not a route you want to go down, your employer has duty to provide adjustments you need to carry out your role. If you feel this is not being met, discuss with line manager, HR or trade union reps as appropriate and bring to attention of local disability network in office/organisation if there is one".*

*"I have never worked a paid job. Even though I wanted to when younger. The 'benefits' trap made it impossible. I would have lost more income than I would have gained and not been able to afford to rent my flat. Later in life when I was more financially secure my ability declined and I'd also no work experience by then."*

*"Yes, definitely OI has a huge impact on my career choices. Firstly, you cannot do some things that are expected of you. For example, traveling is difficult because you need assistance. Secondly, going to meetings and/or conferences is difficult because you need someone to take you. So it can be very difficult for OI people to find jobs that fit their needs."*

## Appendix G: Topics BBS should prioritise

Below is a list of suggested topics individuals requested the BBS should prioritise. Links have been inserted where there are current resources available.

[Becoming older with OI](#). Coordinating health care and being viewed holistically.

*Honestly just more networking for BBS adults. Looking from the outside in, everything feels very medical / medical-model based and its for many the last thing we want as people.*

*Physiotherapist support, Medication guidance e.g vitamins and collagen supplements, [Hearing support/ dental support](#)*

[Pregnancy and OI](#)

*Advice around family life - eg [genetic counselling](#).*

*Advice for things like the smear test which is more difficult for women with OI who are smaller than average.*

[Money/Financial Management](#), Living with others

*It would be good to see a BBS guide on how to go about [apply for funding](#) for carers, how the system works, what you have to do as an employer of carers etc.*

*Helping those with mild OI to unlock social support and benefits as I feel working full time is difficult and worry*

[Mental health support/advice](#).

*Emotional one to one support. Just a courtesy call now and again enquiring how people are getting on. Not every one likes to shout it out or blog about it. Some of us just don't have the energy,*

[Lobbying the government](#).

*It would be good if BBS could do something for younger members to show them some of the careers older members are doing. There are some amazing people with OI artists actors engineers IT film making DJs the list goes on. Young members need to be inspired and I think BBS has some [amazing members](#) with amazing careers and we should be doing more to inspire the next generation.*

*My adult daughter who has OI had a life-changing injury at work due to her employers' slowness in making "reasonable adjustments " for her physical disability and associated mental health disorder. It would have been helpful if a BBS expert in employment law and making reasonable had been available to support her in her interactions with the employers' Occupational Health service, before the accident happened. The Trade Union did try but lacked expertise.*