



# On The Buses (Hidden Disabilities)

March 2022

# Content...



Introduction P3

Methodology P5

Observations and Analysis P6

Passenger Survey Analysis P8

Summary of Passenger Survey P12

Bus Driver Survey Analysis P13

Summary of Bus Driver Survey P16

Community Survey Analysis P17

Summary of Community Survey P27

Conclusion P29

Recommendations P30

With thanks P32

About Young Healthwatch P33

Appendices P34

# Introduction

Some members of Young Healthwatch have a hidden disability and have previously been subjected to discrimination whilst sitting in the priority seats on public transport. This has often made the young people feel uncomfortable, intimidated and insulted.

Young Healthwatch Central Bedfordshire (YHW) therefore decided to undertake a project to determine how aware people are of hidden disabilities, by observing passengers using public transport, to notice whether they showed signs of discrimination against people who had a disability. For the purposes of this project, the young people concentrated on passengers travelling by bus.

The aim of the project was to raise more awareness of hidden disabilities, across all ages, and to combat discrimination experienced by people with a hidden disability sitting in the priority seats on buses, and to address inequalities.

A hidden disability is a disability that does not have any physical signs so we cannot always tell if someone has one. According to the charity 'Enhance the UK', they say – *'As the name suggests a hidden disability isn't obvious or visible.'*<sup>1</sup>

According to the website 'Progress Lifeline', examples of hidden disabilities include<sup>2</sup>:

- ◆ Autism
- ◆ Brain injuries
- ◆ Crohn's Disease
- ◆ Chronic pain
- ◆ Cystic Fibrosis
- ◆ Depression, ADHD, Bipolar Disorder, Schizophrenia, and other mental health conditions
- ◆ Diabetes
- ◆ Epilepsy
- ◆ Learning difficulties, including dyslexia, dyspraxia, dysgraphia, and language processing disorder
- ◆ Lupus
- ◆ Rheumatoid Arthritis
- ◆ Visual and auditory disabilities. These could be considered invisible if the person with the disability didn't wear support aids such as glasses or hearing aids

The project, and the recommendations in this report, aim to strengthen the resilience in young people with hidden disabilities, when using public transport, and to increase their confidence knowing that they are being supported by the bus company and the wider community.

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<sup>1</sup> What Is A Hidden Disability? – Disability Awareness Training, 'Enhance the UK' registered charity

<sup>2</sup> 'Living with Hidden Disabilities' on the website 'Progress Lifeline', [www.progresslifeline.org.uk/news/living-with-hidden-disabilities](http://www.progresslifeline.org.uk/news/living-with-hidden-disabilities), 2nd December 2021





By raising awareness of this issue, and seeing posters on the buses, this will ultimately increase a young person's feeling of safety and in turn, encourage young people to use public transport more regularly, and benefit from a more positive experience as a young disabled passenger.

To take this project forward, Young Healthwatch<sup>2</sup> volunteers applied for a grant through Central Bedfordshire Council's 'Ward Councillor Grant Scheme'.

They secured the support of Councillor Neil Bunyan, Councillor Charles Gomm and Councillor Gareth Mackey. Healthwatch Central Bedfordshire also match funded the grant monies to undertake this project. The funding enabled the volunteers to buy tickets to travel on the buses, to develop the final report and posters, creating awareness and education.





# Methodology

Young Healthwatch volunteers approached local bus companies; Grant Palmer, Arriva, Stagecoach and Uno, to support the project, and they kindly gave permission to conduct this research on their buses using various routes.



Young Healthwatch volunteers were always accompanied on each trip by either an adult volunteer or Healthwatch Central Bedfordshire's (HWCB's) Youth Engagement Officer.

The 'On the Buses' project began on 18th August 2021, when the first journey took place. Five young volunteers, and one adult volunteer, participated in several journeys using the Grant Palmer bus company.

For the second series of journeys three volunteers took part along with HWCB's Youth Engagement and Volunteer Officer. This took place on 9th October 2021 using Stagecoach and Arriva bus companies.

The third series of journeys took place on 27th October 2021 using two volunteers and one adult volunteer using Uno bus company.

During each journey a Young Healthwatch volunteer, who had a hidden disability, sat in a designated disabled seat, whilst the other volunteers observed other passengers on the bus to see if any discrimination was directed towards them.

During the bus ride the remaining volunteers asked passengers if they would like to complete a questionnaire relating to treatment of people with hidden disabilities on public transport. Young Healthwatch volunteers also asked questions of the bus drivers via a short survey.

The same method was used on each journey for the other bus companies; Arriva, Stagecoach and Uno.

To support their project, the young volunteers also created a survey which was sent to various members of the local community, and in particular, members of organisations who focused on supporting hidden disabilities.

A copy of the survey questions for both passengers and the bus drivers can be found at Appendix A and B, and a copy of the community survey can be found at Appendix C.



# Observations and Analysis

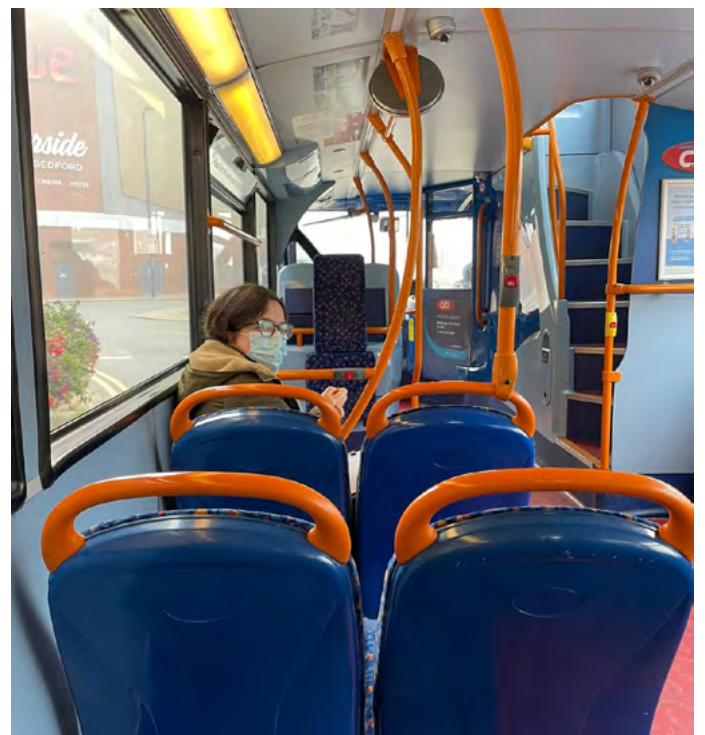
During the first bus journeys on 18th August 2021, the young volunteers who were observing the passengers, found that discrimination, aimed at the young person sitting in the disabled seat, was quite pronounced in that many passengers were staring very openly at the young volunteer.



On one occasion, a member of the public, about to board the bus, complained to the bus driver about a young person being in the disabled seat, asking the bus driver if the young person would be getting off the bus. The bus driver replied by saying 'no' and went on to explain why the young volunteers were travelling on the bus that day. The passenger, clearly

not happy with this response, proceeded to get on the bus and then asked the Young Healthwatch volunteer to move to a different disabled seat as she wanted to put her child's pushchair in the space where a wheelchair would normally be positioned.

For the second bus journeys (9th October 2021), the young volunteers observed a range of behaviours. The young volunteer, again sitting in the disabled seat, was subjected to continual staring from a wide selection of people (younger and older). Also, a lady with a trolley was sitting in a seat reserved for disabled people, taking up two spaces with her trolley. It is unknown whether she had a disability, and other passengers may have been afraid of recriminations if they had asked her to move the trolley.





For the final bus journeys (27th October 2021), the young volunteers observed a wider range of behaviours. They did not witness the same level of 'stares' from other passengers but as previously noted, there was someone sitting in a seat reserved for disabled passengers with a trolley. Once again they were not asked to move by any other passengers, quite possibly for the same reason as previously described.



On this particular date however, the young volunteers and the adult volunteer noticed that the bus driver was driving very erratically at speed, which would have had an adverse effect on any passengers who may have had a disability (especially hidden ones).

The volunteers at times felt quite unsafe whilst on the bus, and some experienced physical pain because of reckless driving. The driver appeared quite unaware of the effect his driving would have on his passengers and clearly did not take into consideration any hidden disabilities his passengers may have had.



Young Healthwatch volunteers did raise this issue with the bus company who said they would investigate further.

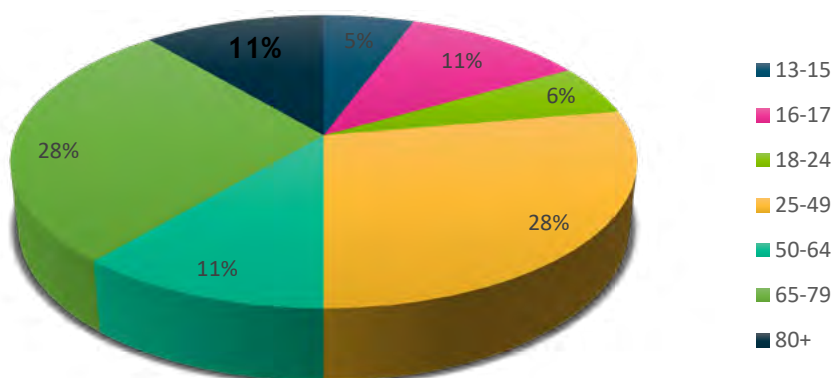
On a more positive note, during this particular journey, one passenger, offered their seat to a Young Healthwatch volunteer so they could sit down, as there was no designated seating area for people with disabilities, only a space for the elderly and wheelchairs, see photo below:



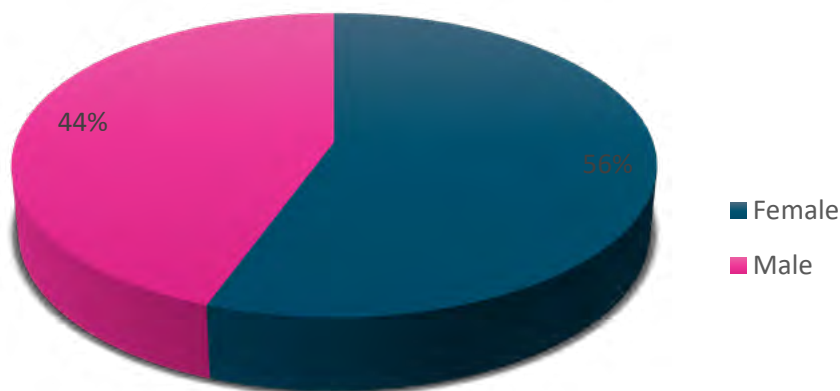
# Passenger Survey Analysis

During each journey taken on the buses, passengers were asked to take part in a short survey, relating to treatment of people with hidden disabilities on public transport, the results of which are shown below:

**Question one** asked the age of the respondents to the survey which produced a very mixed range of ages. A very small minority (5%) said they were 13-15 years, 11% said they were 16-17, 6% said they were 18-24, 28% said they were 25-49 years, 11% said they were 50-64 years, 28% said they were 65-79 and 11% said they were more than 80 years old. Nobody felt uncomfortable sharing their age.



**Question two** asked how best the respondents would describe their gender and 56% said female and 44% male.

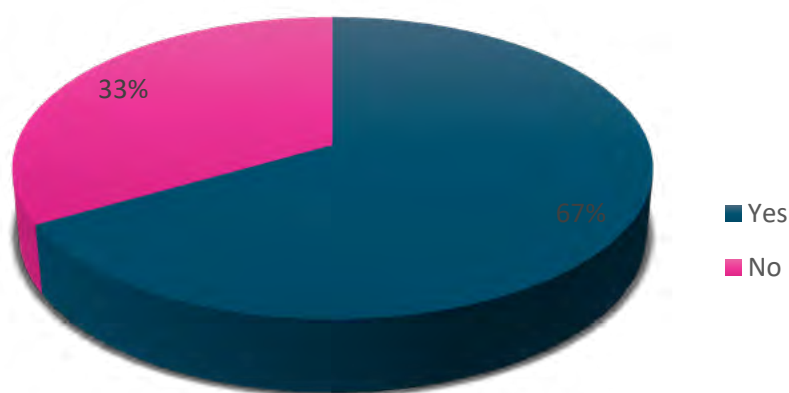




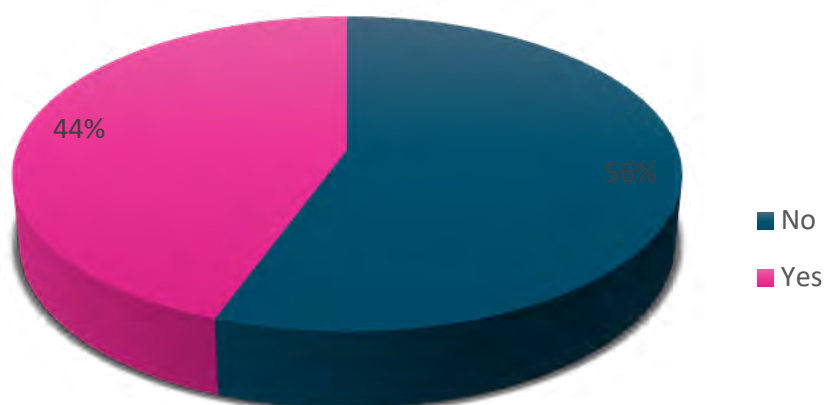
Question three asked if the people taking the survey knew what a hidden disability was. Almost two thirds of people stated they knew what a hidden disability was (67%), although the remaining 33% did not.

Respondents were also asked to name some hidden disabilities, and those given included:

- ◆ A learning disorder (the most common being autism)
- ◆ ADHD, autism, mental health, MS
- ◆ Depression, anxiety
- ◆ Dyslexia, Dyspraxia, schizophrenia, ASD, ADHD, OCD.
- ◆ Learning disabilities and hearing difficulties
- ◆ Blindness

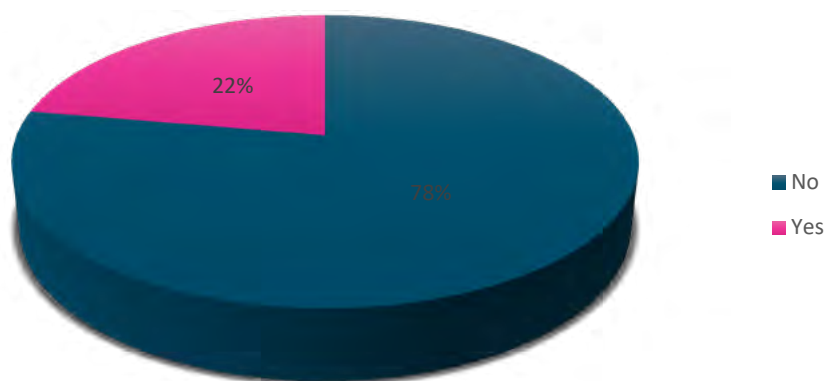


Question four asked the passengers on the bus if they thought anyone riding on the bus that day had a hidden disability. The majority (56%) did not think there was anyone with a hidden disability on the bus, while 44% thought there was, although no-one wished to elaborate on their answer.

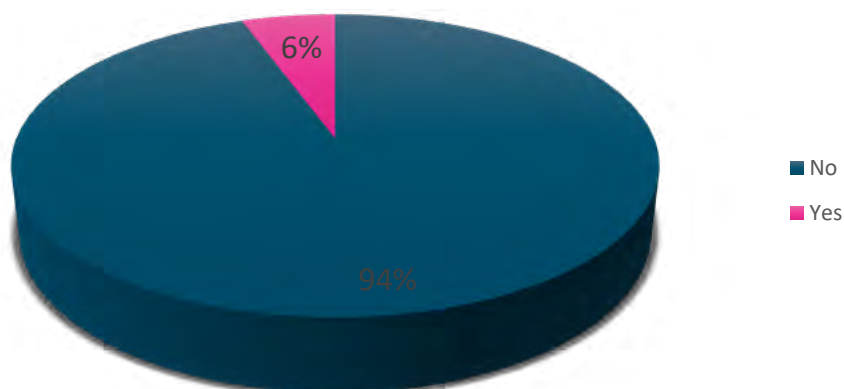




**Question five** asked have you ever witnessed discrimination against anyone with a hidden disability? A fairly large majority (78%) responded by saying No, and 22% said Yes. If the answer given was 'yes' respondents were asked 'how it was dealt with'.

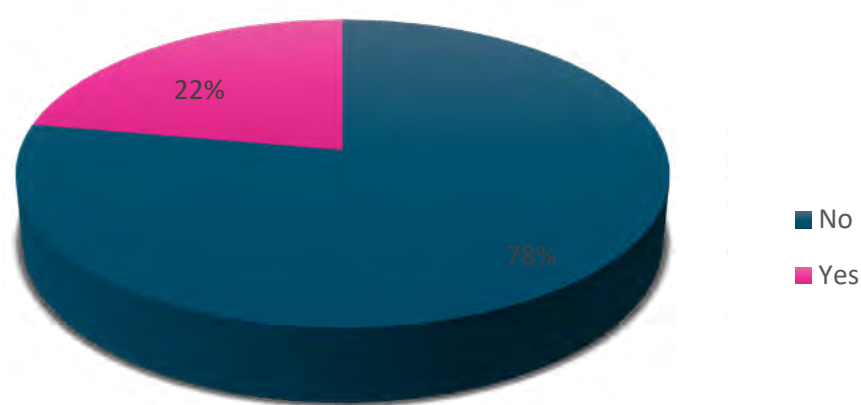


**Question six** asked passengers if they had ever unintentionally discriminated against someone with a hidden disability. Unsurprisingly, only a few admitted they had (6%), the remaining 94% claimed they had not.



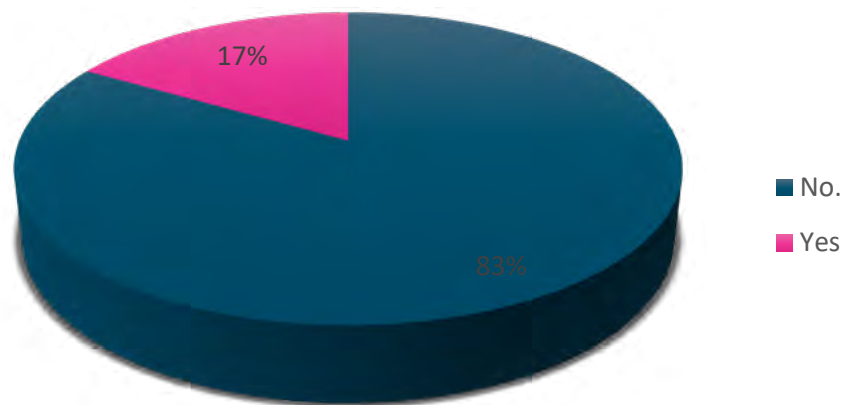
Question seven asked passengers had their experiences with hidden disabilities changed over the pandemic. A large majority (78%) said they had not, and 22% said their experiences had changed. Some supporting comments included:

- ◆ I think it has stayed the same if not got worse over the pandemic
- ◆ More mental health variation



Question eight asked if respondents had had any positive experiences with hidden disabilities. Many people said they had not (83%) and 17% said they had. When asked to elaborate comments included:

- ◆ Not sure
- ◆ Most people give up seats







# Summary of Passenger Survey

Young Healthwatch findings suggest the majority of people using the buses, who completed the passenger survey, are between the ages of 25–49 and 65–70, (both at 28%). The survey respondents were a fairly even mix of both male and female.

The majority of those who answered the survey said they did know what a hidden disability was, and they gave some examples, although 33% did not. However, even though a young Healthwatch volunteer with a hidden disability was sitting in the disabled seat during the bus journey when the survey was completed, a fairly large percentage of people (56%) thought there was not anyone on the bus with a hidden disability, with most people saying that *'It's possible but I wouldn't know unless you asked them'*.

A very small minority of passengers, who answered the survey, said they had witnessed discrimination against somebody with a hidden disability whilst travelling on public transport. When asked how the discrimination had been dealt with one passenger said, *'It wasn't dealt with, the driver didn't do anything'* and another said *'it should be dealt with in schools'*, but it was not clear exactly what was meant by this.

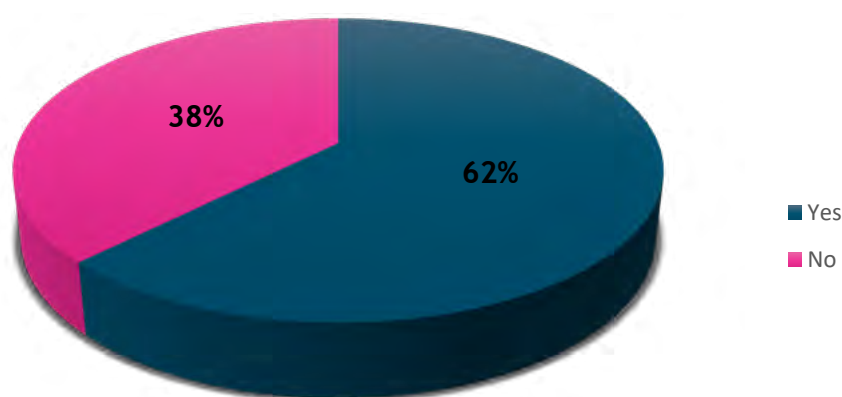
Unsurprisingly when asking passengers if they had unintentionally discriminated against someone with a hidden disability, an overwhelming majority answered 'no' to this question with a very small amount who answered 'yes' (6%). No passengers were prepared to elaborate on their answer.

Interestingly, many people felt discrimination against those with a hidden disability had not changed over the pandemic, and only a few people (17%) said they had had positive experiences of discrimination against hidden disabilities on buses, although the majority of people surveyed said they had a negative experience, one passenger said *'most people stare and are quite rude if someone sits in the priority seat when they don't look disabled'*. However, it was difficult to determine a true comparison answer for some of the questions, as many people were unable to use public transport during the pandemic, so could only comment and compare their experience pre-pandemic and how it is now.

# Bus Driver Survey Analysis

At the end of each journey taken on the buses, Young Healthwatch volunteers asked the drivers to take part in a short survey, relating to their observations of how people with hidden disabilities are treated on public transport, the results of which are shown below:

**Question one** asked how the bus drivers felt about people sitting on disabled seats who were not visibly disabled, and whether they had witnessed this themselves. A fairly large majority of bus drivers (62%) said they had witnessed this, with 38% who said they had not.



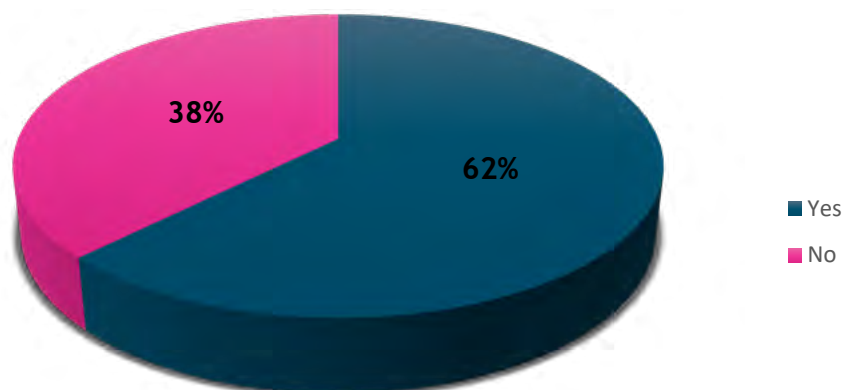
Additional comments in relation to this question were as follows:

- ◆ 'Unfair but hard to know what to do'
- ◆ 'I have challenged some passengers if someone boards who may need the priority seat'
- ◆ 'Try and help'

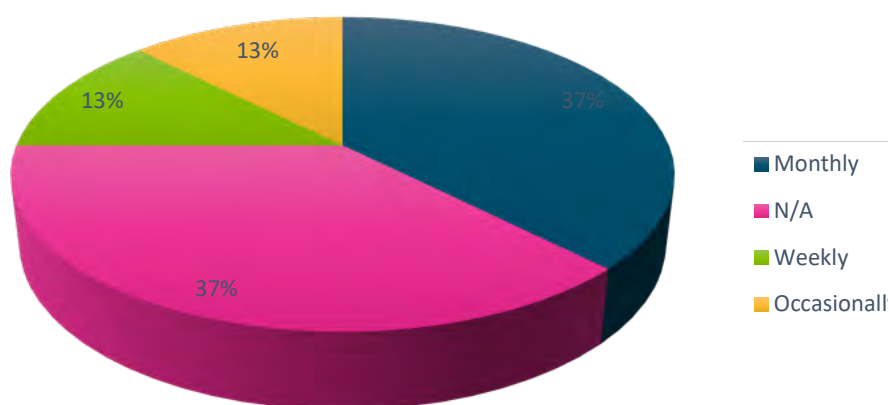
**Question two** asked if the drivers believed they had a bias, based on their previous answer. The answer was 100% 'no'.



**Question three** asked if the bus drivers had ever witnessed discrimination from passengers on their bus, and if so how frequently. 62% said they had, and 38% said they had not.



The second part to this question asked how frequently had they witnessed discrimination. With regards to how frequently they had witnessed discrimination on their bus, 37% of bus drivers said, 'on a monthly basis', others were fairly evenly split between 'occasionally' or 'weekly', (13% each). A further 37% said this question was not applicable to them as they had answered 'no' to the first part of question two, which referred to whether they had witnessed discrimination on their bus.



**Question four** asked the drivers if they felt more support or training relating to hidden disabilities was required. Comments included:

- ◆ 'A refresher course would be useful, but some training has been provided'
- ◆ 'No'
- ◆ 'Yes'
- ◆ 'Most passengers are generally sympathetic to each other'
- ◆ 'On CPC course'



**Question five** asked if the drivers' experience of hidden disabilities had changed in the pandemic, comments included the following:

- ◆ 'Yes, people seem to be more aware of each other and looking out for others'
- ◆ 'People seem more aware of those who need help'
- ◆ 'No'
- ◆ 'Passengers seem to be kinder to each other now'
- ◆ 'Yes'
- ◆ 'Not sure'



**Question six** asked if the drivers had any positive experiences of hidden disabilities witnessed on their bus. Comments included the following:

- ◆ 'No'
- ◆ 'Try and help where I can'
- ◆ 'Little things - people helping another with shopping'

# Summary of Bus Driver Survey

The majority of bus drivers spoken to had witnessed people sitting on seats who were not visually disabled, but almost a third of those who completed the survey had not. Of those who had witnessed this, many drivers said although it was unfair, this was *'hard to police'*. Others indicated they had challenged passengers sitting in a disabled seat if another passenger had boarded the bus with a clear disability, and one driver said they *'have no problem with it as long as there is no one with a greater need standing'*.

Of the bus drivers who had witnessed discrimination on their bus, the majority said it happened on a monthly basis, with a smaller percentage who said 'weekly' or 'occasionally'.

There was a mixed response when asked if they felt more training was required with regard to hidden disabilities. Some drivers did not feel more training was required, whilst others would welcome the training, or a refresher course, at the very least.

When drivers were asked if the behaviors of the passengers had changed at all during the pandemic, towards other passengers with hidden disabilities, some said 'no', while others seemed to believe it had changed for the better, adding that, generally, passengers are more empathetic to other passengers on their trip.

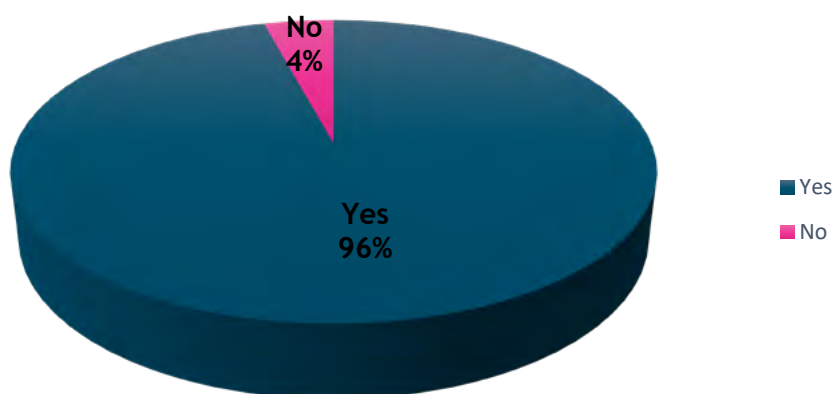
Finally, drivers did recall some positive experiences on their bus trips which included many passengers supporting one another. One driver said, *'Someone asked another passenger if they would like a disposable face mask as they weren't wearing one and offered a disposable one'*.



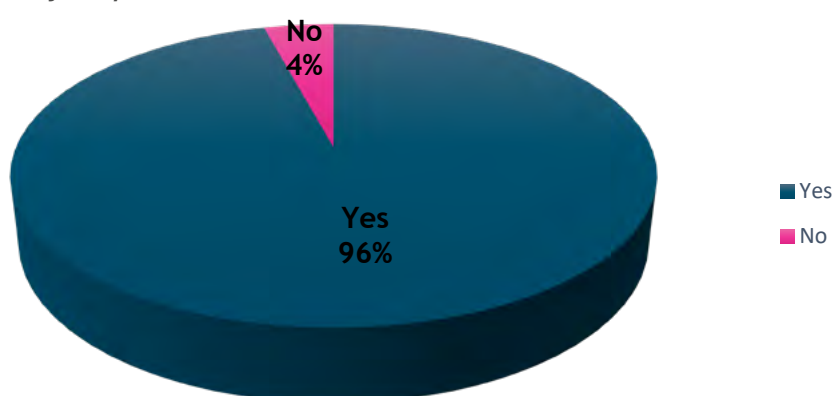
# Community Survey Analysis

To support their project, the young volunteers also created a survey which was sent to various members of the local community, and in particular, members of organisations who focused on supporting hidden disabilities. The results of this survey are shown below:

**Question one** asked if the respondents had a hidden disability and interestingly, a very big majority of those who completed the survey said they did – 96%. A small minority said they did not (4%).



**Question two** asked if the respondents had ever been on public transport and again the vast majority had at 96%, with 4% who had not.



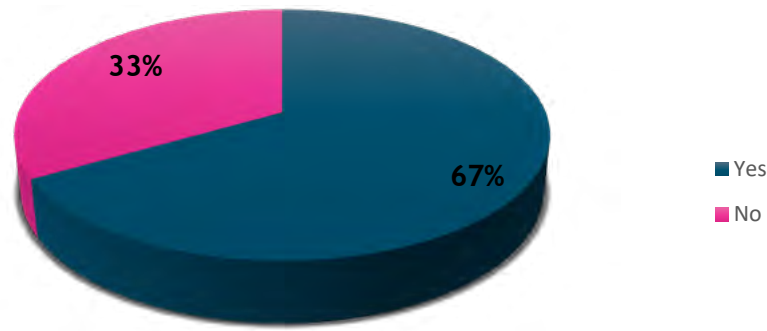
Additional comments given in answer to the above question were as follows:

- ◆ 'Very rarely. I often feel cramped, and it seems unhygienic particularly with current affairs'
- ◆ 'Not since I could drive (33 years), driving is so much easier to control'.
- ◆ 'I've taken the occasional train but definitely not buses'
- ◆ 'Yes I have but not had such a great experience, so choose to avoid it'





**Question three** asked if the respondents were hesitant to use public transport. Almost a third of respondents (67%) said they were, and 33% said they were not.



There was a wealth of additional comments in support of the answers given to this question, which included the following:

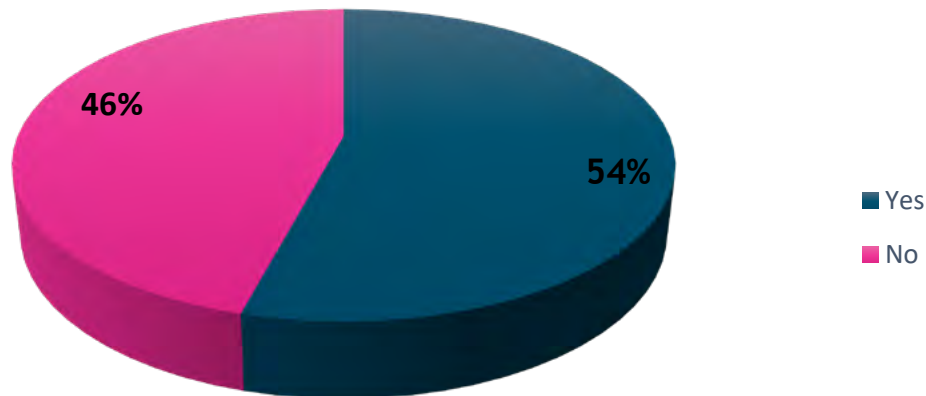
- ◆ *'Most of the time, the bus I get on is a double-decker with the bottom section full, due to my disability I struggle with stairs (especially steep and spiral staircases). When the bus starts moving, I cannot walk up the stairs and I often get weird looks or asked why I'm not going up'.*
- ◆ *'I have had negative comments from males'*
- ◆ *'Because of discrimination of my children who both have hidden disabilities'*
- ◆ *'Apart from the current pandemic I feel that using public transport is exhausting and I much prefer to know I can go home whenever I want, so I drive'.*
- ◆ *'Due to people staring, discrimination, there not being any available space due to people not folding their buggy's or people not moving'*
- ◆ *'Am in a wheelchair so feel embarrassed when the bus needs to be lowered and everyone stares at you'*

- ◆ *'Worried about accessibility. I can't stand on the bus if there are no seats and am not steady enough to walk down the bus when it's moving, so need to sit at the front'.*
- ◆ *'Because I struggle to stand for a long time and have poor balance'*
- ◆ *'On underground trains, the seats for disabled people are regularly occupied, even when other seats are not. I have, with EDS, poor balance. This means that getting to those middle seats – and out again – is difficult. I have landed in people's laps, before now'.*
- ◆ *'Anxiety'*
- ◆ *'It is too crowded, painful, difficult to get a seat and often unreliable'*





**Question four** asked if anyone had ever experienced discrimination, or witnessed discrimination, of someone with a hidden disability, while on public transport because they sat in disabled seating. Just over half of those who answered this question (54%) said they had experienced discrimination, and 46% said they had not.



Once again, many additional comments were given in response to this question which included the following:

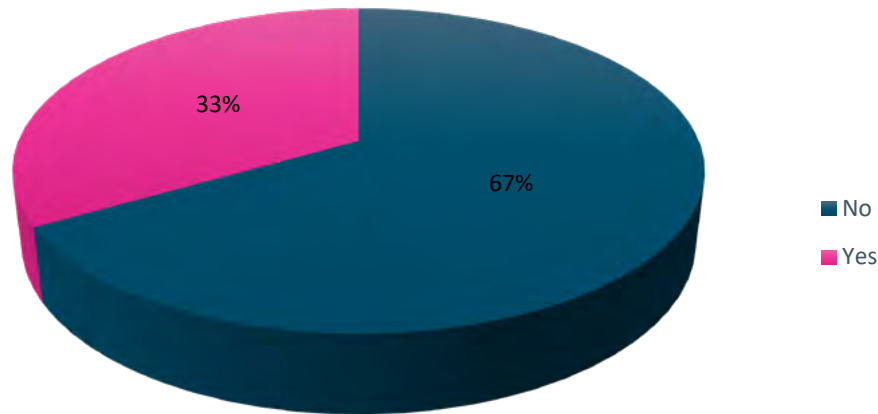
- ◆ *'This was before my diagnosis. I had been around the Harry Potter Studios with my crutches, and I was getting on the bus back to Watford Station. I naturally sat at the front of the bus when my mum who was with me went to the back, and we agreed a meeting point. A lady got on the bus after all the seats were filled (she was about the same age as my mum - early 40s) and started yelling at me to stand up and let her have my seat. The gentleman who sat next to me came to my defence immediately saying that I was injured, and it wouldn't be safe for me to stand. This is the bit that annoyed me with this, the lady said, "she's too young to be reliant on crutches". I was 18, I dislocated my knee about 4 weeks prior to this and with all the walking I wanted to have my crutches with me. Just because it didn't look like there was anything wrong she assumed I was faking it. I have witnessed wheelchair users get turned away from buses because a parent didn't want to fold the pram down. I've witnessed wheelchair users be left behind when waiting on a train because no one turned up to assist even though they booked assistance'.*



- ◆ *'Had an argument with a lady on the bus about my disability'*
- ◆ *'I have had comments from older people saying I shouldn't be sitting there'*
- ◆ *'I'm sure it happens, I just don't often use buses'*
- ◆ *'Constant stares when someone believes you don't have a right to sit in the disabled seating'*
- ◆ *'One time on a train I had pre booked disabled seats and this man took my seat! I asked him nicely to move but he refused. I said are you going to take my seat that I've pre booked so I can't sit with my disabled children? He claimed he had booked it, but he hadn't! I screamed at him and told him I'll sit on him if he didn't move! The whole carriage was watching! Not one man stepped in to help! That I found shocking! I said I'll go and find the guard and he will move you then! Two youngish girls shouted, "you go girl". I tried to find him but couldn't, but a lovely lady had gone further up the carriages to get the guard. Needless to say, I proved the seats were mine and he couldn't! So, the guard moved him but I was so angry. It definitely put me off using public transport. The elderly stare at us and mutter under their breath whenever we are in the disabled seats.'*
- ◆ *'Being shouted at by older people because I'm sat in a disabled seat and I'm 'too young' to need it'*
- ◆ *'I have been challenged by and received abuse from members of the public when doing this'*
- ◆ *'I have experienced resentment because I can't stand on occasion'*
- ◆ *'I have basically been told on a number of occasions that I don't look disabled'*
- ◆ *'The taxi driver didn't understand why I needed to sit in the front of the taxi so was unkind and lacked understanding'*
- ◆ *'My best friend has been tutted and stared at for sitting in the disabled seats'*
- ◆ *'I have no option other than to use public transport when attending hospital appointments in London and this is when I experience the most problems with Joe Public just not getting it or wanting to try to understand, despite wearing the TFL 'I need a seat' badge. Looking a lot younger than my age due to my disability, doesn't help my cause either.'*
- ◆ *'Obviously struggling to stand but had verbal abuse from strangers for using the priority seat. Other times have had to stand and struggled but accused of faking it or attention seeking. Once had to ask someone to make space but they refused to move their bag and told me I was young and able to stand.'*



**Question five** asked people if they have ever had a positive experience, (if they have a hidden disability), when using public transport. Nearly a third of respondents said they had (67%) although 33% said they had not.

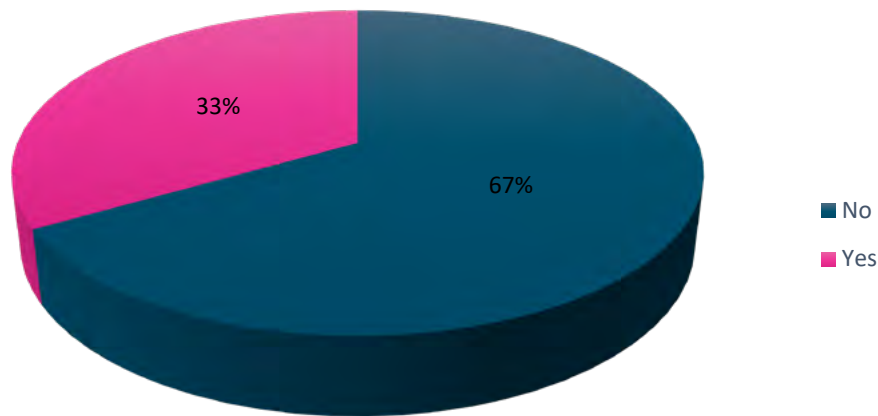


Additional comments included in the answer to this question were as follows:

- ◆ *'I was getting on the bus after a day out in town with friends, I live in a different area, so I was alone on the bus. I had a limp on my left leg at this point and someone sat at the front of the bus moved (without me asking) to let me sit there.'*
- ◆ *'When wearing the sunflower lanyard<sup>3</sup> someone asked if I would like them to move away'*
- ◆ *'Once you explain about your disability if people ask you to move, they understand (but on very few occasions this happens)'*
- ◆ *'I've had two people chat to me on the bus to calm me down as they could see I was panicky'*
- ◆ *'I've had some taxi drivers who have been ever so helpful and kind'*
- ◆ *'I carry a small cushion, with a knitted strap on it, over my shoulder, to make seats comfortable. Since I began doing this, it had the welcome and unexpected side-effect that people offer me a seat, on public transport, pretty regularly.'*

<sup>3</sup> As defined by the 'Hidden Disability Store' a lanyard is because, "without a visual cue, it can be difficult for others to identify, acknowledge, or understand the daily barriers faced by people living with an invisible disability. We wanted a discreet sign which was still clearly visible from a distance as well as being distinctive, joyful, and dynamic. We chose a sunflower as it suggests happiness, positivity, strength as well as growth and confidence and is a universally known." [www.hiddendisabilitiesstore.com](http://www.hiddendisabilitiesstore.com), 2021

**Question six** asked people if they had ever experienced any changes in how they were treated (if they have a hidden disability) on public transport due to Covid-19. Nearly a third of respondents (67%) said they had not and 33% said they had.

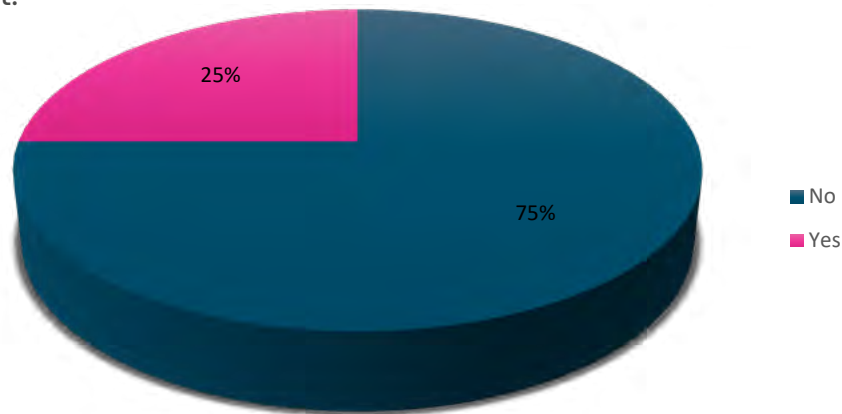


Additional comments to support their answers included the following:

- ◆ *'Again, limping on my left leg, I got on a bus to go back home from the hospital and the only downstairs seat was near the back of the bus, I limped down with all the other passengers avoiding looking at me. Thankfully the driver waited for me to sit down before driving off'.*
- ◆ *'I haven't travelled on the bus since Covid'*
- ◆ *'As travel with mum, we had a lady I sat near her and she got up and moved'*
- ◆ *'Lots more seats have tape on them so you can't sit down. There have been teenagers with micro scooters sitting in the disabled seats as there is more room'.*
- ◆ *'In general, the lanyards seem to have less meaning not only on public transport'*
- ◆ *'People are trying not to sit next to others it's almost like no one is now bothered about the disabled seats it's more of being aware of social distancing'*
- ◆ *'Not been on since the pandemic started'*
- ◆ *'I haven't used public transport much since the pandemic started'*
- ◆ *'Can't sit in the front of a taxi due to Covid'*
- ◆ *'The app that my bus service use now tells you how many seats are free on the next bus in real time'*
- ◆ *'I haven't been on a bus after covid'*
- ◆ *'When it wasn't so crowded it was easier to get a seat but now it is crowded; again, it's harder and people on the whole seem less kind'.*



**Question seven** asked people if they had ever worn the sunflower lanyards and if so, did they find they reduced discrimination whilst sitting in disabled seats. A fairly large majority (75%) of respondents said they had worn the sunflower lanyards and 25% said they had not.



More detailed answers were included in the comments below:

- ◆ *'Yes and No, pre covid it helped, some people knew of the scheme from airports and would either avoid the front seats of a bus or move without questions'*
- ◆ *'Since covid everyone assumes it means that I'm exempt from face coverings, even though I wear a mask when social distancing is not possible (so on a bus or in shops)'*
- ◆ *'N/A I've been physically unable to get to the supermarket, so I haven't used the lanyards.'*
- ◆ *'People have misunderstood the badge as 'mask exempt' '*
- ◆ *'Previously they had a lot of meaning but now they are used as mask exemption and are basically useless'*
- ◆ *'I believe they do but I do feel that they reduce discrimination when in those seats but people now think they mean mask exempt, so I also wear a badge that says "my disability is not always visible" as well'.*
- ◆ *'I haven't but I would. I have a badge from Greater Manchester transport saying please give me a seat, but I don't think I'd wear it because it doesn't explain why. The sunflower lanyard is more recognisable'*
- ◆ *'I did not know about them, until today. What a good idea!'*
- ◆ *'Unsure about whether they help or not now; I also wonder whether now they are being used for mask exemption by many whether it has confused the message for people. There is still a general lack of awareness overall'*

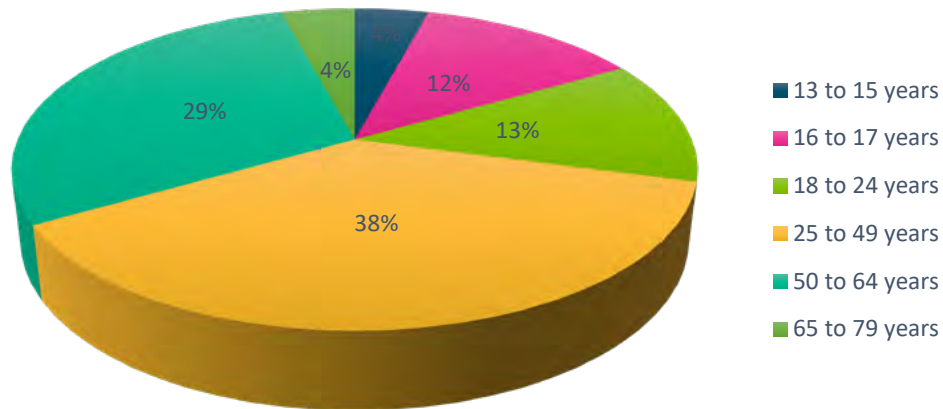
**Question eight** asked people if there were any further comments they wanted to add which they feel would improve the experience of someone with a hidden disability while using the disabled seats on public transport. Comments included the following:

- ◆ *I think there needs to be a new lanyard so the assumption of exemption from face coverings is not made and so in younger generations they understand the difference in years to come.*
- ◆ *I do think owning a badge or some way of identifying/proving we are disabled even though it doesn't look it that is held in high esteem would help. Signs saying some peoples' disabilities are invisible I don't think helps massively, it's nice to see but I don't know how much people without disabilities absorb/apply this.*
- ◆ *Maybe having a sign with the sunflower on transport with why people wear it and staff helping on train if see one with lanyard.*
- ◆ *One day we might need a seat with more room. We can feel more faint/tachycardic when we are menstruating.*
- ◆ *Again, just make the lanyards mean something again.*
- ◆ *Teach about them more in schools.*
- ◆ *I would love a solution, but I do think not everyone knows what a sunflower lanyard is. Maybe a card you hold up to someone? I don't think there's an easy solution and a lot of people get severely distressed with confrontation.*
- ◆ *I'd recommend an identity card scheme, with the idea that people can't take advantage (at least not easily) – because some people will, and it always means people with real problems are treated badly. However, this would need to include confirming symptoms before formal diagnosis in some way.*
- ◆ *People should be less quick to judge and education about disability needs to be in all school's curriculum.*
- ◆ *They could, like me, carry a small cushion with a wipeable cover, which makes hard, flat seats, more comfortable. As written earlier, passengers notice and then offer their seat.*
- ◆ *More signage, more campaigns to raise awareness. Increased support from providers and staff.*

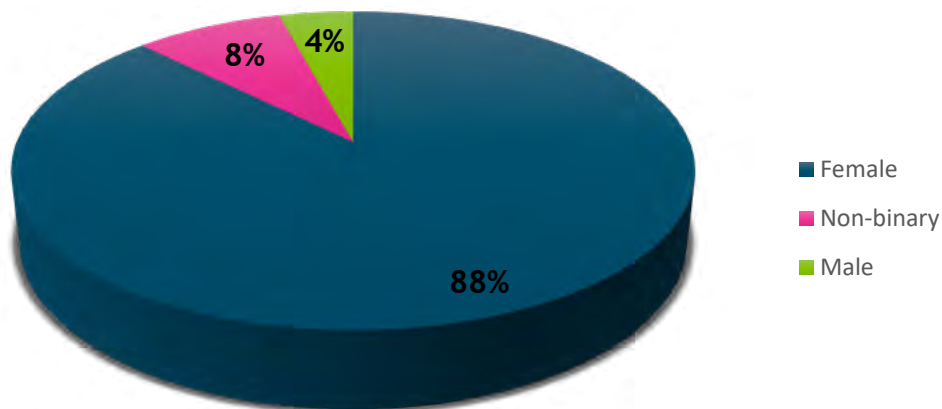




**Question nine** asked respondents to indicate their age range. The results showed that the majority (38%) were 25-49 years old, 29% were 50-64 years old, 13% were 18-24 years old, 12% were 16-17 years old, and the remaining age groups – 13-15 and 65-79 years old were given as 4%.



**Question ten** asked people how they would describe their gender. 88% of respondents were female, 8% non-binary and 4% male.



**Question eleven** asked which location the respondents were from, and this produced a range of different areas, some of which were quite local to Central Bedfordshire, e.g., Dunstable, Sandy, Marston Moretaine, however many were from across the UK as far away as Rochdale, Norwich, and Devon.



# Summary of Community Survey

The majority of people who responded to the community survey were located across the country and were mainly women. The highest age range was between 25–49 years old (38% of respondents) closely followed by 50–64 years old at 29%.

The overwhelming majority of respondents said they did have a hidden disability (96%) and most of those had used public transport.

However, nearly a third of respondents to the survey admitted they were hesitant about using public transport, because of their disability, and many additional comments were received in answer to this question. Many people mentioned *'crowding'* and *'lack of seating'* and being forced to use the stairs which they struggle with. Others mentioned they were concerned, when boarding a bus for example, if no seating was available, they knew they would be unable to stand for any length of time. One person said, *'I have extreme anxiety when it comes to any form of public transport, due to the fact that I have to sit down on a bus and that I don't physically look disabled, I often get looks or even people saying things which make me feel incredibly uncomfortable.'*

Just over half of respondents said they had experienced discrimination, or witnessed discrimination, of someone with a hidden disability while on public transport because they sat in disabled seating, with just under half who had not. Once again there were many additional comments in response to this question with many people who have a hidden disability feeling unfairly treated on public transport. One person said, *'I've mainly had dirty looks and I've never felt brave enough to ask someone to give up their seat for me when I need it because I don't look disabled and I'm worried about the conflict that could occur if I were to ask.'* Another said, *'I have basically been told on a number of occasions that I don't look disabled'*. One person mentioned an experience in which they were in danger of being physically assaulted.

However, many of the respondents who had a hidden disability had experienced a positive experience when using public transport. A few mentioned being offered a seat by other passengers, especially if it was clear they were struggling, and others mentioned if they had explained they are disabled, people will give up their seat for them. Comments in this section included, *'When it's been clear I am struggling, I have sometimes been offered a seat by someone or they have offered their arm to help me'* and *'Once a nurse on her way to a trade union conference gave me a seat because she could see it was painful for me to stand.'*



Most respondents felt **they had** experienced changes in how they were treated on public transport due to the pandemic. Comments included, *'In general, the lanyards seem to have less meaning not only on public transport'* and *'covering the face increases my pain fourfold so I am exempt from it, I get hostility if I use the exemption not to cover my face.'* Others mentioned more of the seats having tape across them, so they were unable to sit down, and many others said they had not used public transport since the pandemic.

Over a third of respondents had worn the sunflower lanyards, and were asked if they felt they reduced discrimination (if sitting in a disabled seat). Almost all of those who commented on this question said that the lanyards are now misinterpreted by many people; they feel the wearers are just exempt from wearing a mask – not that they are disabled. One person said they would like to see a different design on the lanyards for people with a physical disability, as follows, *'I don't feel comfortable wearing one as I don't want people thinking I'm autistic/mentally disabled. I wish there was a different design which meant the disability was a physical one. As people don't see a crutch, wheelchair, they assume my disabilities are mental.'*

Finally, people were asked if they had any further comments to add which they felt would improve the experience of someone with a hidden disability while using the disabled seats on public transport. This produced a wealth of comments which were all mainly related to raising more awareness of hidden disabilities, comments included, *'more advertising campaigns about hidden disabilities and varied symptoms ....'* and *'there could be a poster saying not all disabilities are visible, like it does at some disabled toilets, but this could be taken advantage of by people who don't need it, but you wouldn't know. At least if you have to apply for a sunflower lanyard then people with them are likely to really be in need'.* Others indicated they are very keen for a solution to be found and felt that to avoid overcrowding on public transport it needed – *'A reliable service with more carriages or more regular buses to help with overcrowding; it's terrible in the North-West.'*



# Conclusion

In conclusion, from all the feedback gathered from across many different locations, and observations made on bus journeys across Central Bedfordshire as part of this project, it is clear there is a lack of knowledge and awareness of hidden disabilities in the general community.

The results from the bus journeys taken would strongly indicate that discrimination exists against young people with a hidden disability, sitting in a disabled seat, which clearly makes the young person feel uncomfortable and anxious about using public transport.

In addition, the interviews with passengers on the bus journeys showed that 78% of people believed they had never seen someone with a hidden disability be discriminated against, however 33% failed to recognise what a hidden disability was. This would point to a distinct lack of information about hidden disabilities, often leading to discrimination which is then swept under the carpet.

With around 67% of disabled people reporting that they feel hesitant about using public transport, usually due to the fear of discrimination, it is noticeable that a lack of knowledge on this subject can directly and indirectly cause psychological harm to those with hidden disabilities, and it is imperative that people are educated on this topic in order to prevent this.

Another key underlying issue is that current disability awareness tactics are failing, for example, many people do not recognise what a sunflower lanyard is for, or respect the meaning behind it. Furthermore, as a result of more people wearing the sunflower lanyard during the pandemic, to indicate they were exempt from wearing a face mask, many people now simply assume that is what the lanyard represents and not what it was originally meant for; to raise awareness of a hidden disability.

The Government and public services are not doing enough to help or support those with hidden disabilities on public transportation, and there is not enough emphasis on public knowledge of how to recognise hidden disabilities and cater to them.

The survey sent out to the community was conducted across a range of different locations and shows that this problem is not specific to one location and occurs nationally. Plans to reduce the lack of awareness of hidden disabilities across the entire country are therefore highlighted in the recommendations below.

# Recommendations

Although the feedback gathered is a relatively small snapshot analysis designed to determine whether it is safe to travel against when using disabled seats on public transport, there is clear evidence to show that it is safe to be travelling on public transport.

To help improve awareness, Young Healthwatch volunteers would recommend the following:

1

**All bus companies to ensure people are more aware about hidden disabilities by displaying posters which explain that not every disability is visible.**

2

**For bus drivers to receive additional training (or refresher training) about hidden disabilities and how this can affect a passengers journey when travelling on their bus.**

3

**For bus drivers to look out for and be more aware of the discrimination people with a hidden disability may be subject to when travelling on their bus.**



ine how aware people are of hidden disabilities, and whether people are discriminated  
there is a distinct lack of knowledge and awareness of hidden disabilities when

4

**For the bus companies to set up a clear reporting line so bus drivers can easily report incidences of discrimination on their bus which will allow the bus companies to be more aware of the scale of the problem so they can act to prevent/reduce it.**

5

**For Central Government to improve education and awareness about the Sunflower Lanyard; who it is for and what it means. Whether this be to members of the public on the bus, the bus companies in general or via social media channels to reach a wider audience.**

6

**Each local authority to create a marketing campaign, involving local voluntary, community and social groups, to help educate all local residents about hidden disabilities when travelling on public transport.**



◆ Arriva



◆ Central Bedfordshire Council



◆ Grant Palmer



◆ Stagecoach



◆ Uno



◆ Young Healthwatch Central Bedfordshire volunteers





Young Healthwatch Central Bedfordshire exists to make health and social care services work for the people that use them, especially young people.

Our role is to ensure that local decision makers and health and care services put the experiences of young people at the heart of their work.

We believe no one should be afraid to speak up .... because our opinion is as good as anyone else's.

Our volunteers have received appropriate 'Enter & View' training and are keen to put their learning into practice by visiting health and social care services such as hospital wards, surgeries and care homes. The young people will then be able to report their findings from their unique perspective. If you would like a group of young Healthwatch volunteers to visit your service please contact [eleanor.ryles@healthwatchcentralbedfordshire.org.uk](mailto:eleanor.ryles@healthwatchcentralbedfordshire.org.uk).

There is a lot more information on the Young Healthwatch website, <https://healthwatch-centralbedfordshire.org.uk/young-healthwatch>, including the great achievement of one of our volunteers who has secured a fantastic apprenticeship with Cancer Research UK.

If you are under 25, why not consider becoming a member of Young Healthwatch Central Bedfordshire? Get in touch for more information, email [eleanor.ryles@healthwatchcentralbedfordshire.org.uk](mailto:eleanor.ryles@healthwatchcentralbedfordshire.org.uk) or call **0300 303 8554**.





# Appendices

## Appendix A

### Questions to members of the public taking the bus trips

- Q1: What is your age?
- Q2: What is your gender?
- Q3: Do you know what a hidden disability is?
- Q4: Do you think anyone on this bus has a hidden disability?
- Q5: Have you ever witnessed discrimination against anyone with a hidden disability?
- Q6: Have you ever unintentionally discriminated against someone with a hidden disability?
- Q7: Have your experiences with hidden disabilities changed over the pandemic?
- Q8: Have you had any positive experiences with hidden disabilities?

## Appendix B

### Questions given to the Bus Drivers

- Q1: How do you feel about people sitting in the disabled seats who aren't visibly disabled?
  - a) Have you seen it before?
  - b) How do you feel about it?
- Q2: Do you believe you have bias based on your previous answer?
- Q3: Have you ever witnessed discrimination, and if so, how frequently?
  - a) Yes or no?
  - b) How frequently? Daily, weekly, monthly, other?
- Q4: Do you feel you need more support or training on hidden disabilities?
- Q5: Do you think your experiences of hidden disabilities has changed in the pandemic?
- Q6: Do you have any positive experiences of hidden disabilities on the buses?

# Appendix C

## Questions to members of the community outside of the bus trips

This survey was typed up on SmartSurvey and sent out via the volunteers and their contacts, as well as through Young Healthwatch and their stakeholder groups.

- Q1. Do you have a hidden disability?
- Q2. Have you ever been on public transport?
- Q3. Are you hesitant to use public transport?
- Q4. Have you ever experienced discrimination, or witnessed discrimination, of someone with a hidden disability while on public transport because you/they sat in disabled seating?
- Q5. Have you ever had a positive experience because of your hidden disability, while using public transport?
- Q6. Have you experienced any changes in treatment on public transport due to Covid-19?
- Q7. Have you ever worn the sunflower lanyards and if so do you find they reduce discrimination while you sit in disabled seats?
- Q8. Do you have any further comments or any recommendations, to improve the experience of someone with a hidden disability while using the disabled seats on public transport?
- Q9. Please can you confirm your age range?
- Q10. How would you describe your gender?
- Q11. Please can you confirm the town you are from?





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