



Disabled Members Council



# Hidden Disabilities

# Preliminary report

## Compiled by Stephen Brookes Rachel Broady and Lena Calvert (NUJ Equalities Officer)

As part of the work of the NUJ Disabled Members Council, it was decided that we look at how hidden disabilities and how their presentation (or not) by our colleagues in press and PR can affect people. At the very least we feel that hidden disabilities are frequently overlooked or at the very worst demeaned.

In his early days in show business, actor and comedian Kenneth Williams wrote to a close friend about a mutual colleague in the theatre who had to withdraw from a play because of a growth which turned into a permanent throat disorder.

'Such a bore that kind of thing' said Williams 'not even what you can call an interesting complaint. I mean you can't even show it to anyone can you!'

Later in life before his own untimely death he found his own various hidden illnesses were more than boring, rather they were frustrating as 'the pain is agony. Can't stand. Oh these are awful days to live through, and the idea of going to do publicity photo's. What a joke to think I was smiling and smirking into the camera for these photo's, with the inside crying out 'Die'-forget it with the ever present pain'.

And as we can see from Kenneth Williams observations one of the major problems faced by people who have hidden disabilities is that often other people don't see the disability and often don't believe them. Frequently we are told that we don't seem disabled. For many people they feel that the foremost discrimination anyone faces is to be disbelieved. Hidden disabilities can also cause difficulties because of the attitude of others due to fear or ignorance as people fear what they do not know or understand or what they can not see.

It is something of a surprise to accept that the majority of the so called visible disabled people have 'hidden disabilities'. Colleagues whose impairment is immediately apparent are in the minority, but each and everyone who has a long term 'hidden disability' does also fall within the remit of legal support of the Disability Discrimination Act of 1995.

As suggested 'Hidden disability' is sometimes demeaningly used as a catch-all phrase that simply means that a person's impairment or condition is not obviously apparent or visible. So it is quite possible that you have friends in your work or life group who are disabled but who you may not immediately recognise as such. Your organisations HR or disability officer may have informed you or trained about the needs of people with hidden disabilities but you may only discover that they have a hidden disability once you get to know them better. This could be because they may have decided not to disclose their disability to you or to the institution, possibly for fear of discrimination. Or they may not consider that their impairment or condition is a disability and so may not have been in contact with any available disability service. For example many people feel dyslexia is about learning differences rather than being a hidden disability.

Hidden disabilities can include some people with dexterity difficulties such as repetitive strain injury. It may also include those who are hard of hearing or have mental health difficulties. However, it is probably more commonly used (particularly in media terms) in relation to people who have disabling medical conditions of one sort or another. However the list of medical conditions that may be regarded as hidden disabilities is very long and the effects of these different conditions are varied. It can include people with epilepsy, diabetes, sickle cell

condition, chronic fatigue syndrome or ME, cystic fibrosis, cancer, HIV and AIDS, and heart, liver or kidney problems. The conditions may be short term or long term stable or progressive constant or unpredictable and fluctuating controlled by medication or another treatment, or untreatable.

Disabling medical conditions can often have a considerable impact on a person's everyday life, which can have an adverse knock-on effect on working life. They may cause fatigue or pain and this may be continual or intermittent. They can cause sleep problems, seizures, incontinence or dizziness. The impact of hidden disabilities on daily life and study can be considerable: they often interfere with concentration and stamina, as can the medications that are used to treat them. Rather like long term disabled people, those with hidden disabilities may be well and coping one week and absent from your vision the next, and they can have difficulties meeting deadlines or participating in group work. It may not be possible for them to arrange medical appointments or regular treatments that do not clash with day to day life.

Because of the variation in symptoms it is not possible to generalise about how hidden disabilities may affect work. Some people who get to know you may just want you to be aware in case they have difficulties or a medical emergency, such as fainting or a seizure. You should be aware of what to do in case of medical emergencies. Some people may wish their colleagues to know about their medical condition and may be willing to discuss it openly. Others may want their privacy protected and may want discretion and confidentiality.

These are two examples of people who have hidden disabling medical conditions, with suggestions of ways in which they can be provided support.

A person with sickle cell condition is well most of the time, but during periods of illness (known as crises) has severe joint pains and has to rest at home. Support arrangements may include electronic work at home so that they can keep up keeping in touch by e-mail on assignment deadlines. Environmental conditions such as cold and damp may precipitate crises and so they may ask not to sit close to a window, or they may not be able to attend when the weather is cold and wet joint pain means that they will need a comfortable and back-supporting chair to sit on while in work.

A person with renal failure may need to undergo dialysis in hospital during the night, or may need time made available for short periods of dialysis. They may experience periods of great fatigue and may not be able to attend for a full day. They may not be able to work for long periods and will need to conserve their energies.

People with hidden disabilities and disabling medical conditions can apply for home working support. If they experience fatigue and pain, having access to their own computer so that they can work at home at their own pace is often of great benefit. The key to providing support for people with medical conditions is flexibility and responsiveness. In a large group it can be easy to forget that some people have hidden disabilities and that they need certain arrangements to be made to ensure access to the working environment. People may be very reluctant to keep reminding you, so make sure that you remember what is required and have a system for putting it in place.

Given the importance of the issues stated so far, and following some personal experiences of council members the DMC felt that they needed to know more about the issues of hidden disabilities, so in 2008 we sent the set of 4 simple questions to various colleagues and contacts asking their views about hidden disabilities, and received some deeply disturbing responses. The responses were based on individual attitudes, and so we share the questions with you before looking at the responses.

## THE QUESTIONNAIRE:

- 1) What do you believe are hidden disabilities?
- 2) Do you feel that the general public ignores the problem of hidden disabilities? If yes, do you feel that this is through fear or ignorance?
- 3) Do you feel that hidden disabilities are overlooked in the media and PR? If yes, how do you think that the media could do more to support issues of hidden disabilities?
- 4) Do you feel that the government and the disability sector (including charities) do enough to support people with hidden disabilities? If not, then what do you feel could be done to improve matters?

## THE RESPONSES, from numerous contacts in order of question:

### 1 *What do you believe are hidden disabilities?*

It is not unexpected that each respondent considered their own condition as hidden – Heart, deafness, mental health, bladder and bowel ('age related') disabilities.

The best answer was one which stated those above, but then added speech defects, some types of stroke, arthritis, thyroid problems where obesity is a medical condition, and importantly, illiteracy!

>Epilepsy, ME, MS, FMS, cancer, heart disease, mental impairment, diabetes; those conditions not visually obvious to others.

>A hidden disability is a disability that is not visible. It can take many forms. It can be an illness such as cancer or a respiratory illness which can prevent a person from walking far or carrying heavy objects. Hearing loss can also be hidden. It can be a disabling illness such as FMS, ME, MS or epilepsy to name but a few.

>Too numerous to specify but if the person involved doesn't want to tell anyone about them they will remain hidden unless they manifest themselves e.g. epilepsy where, I suspect, there is still some stigma. In the case of epilepsy it is really important for managers to know if a member of staff is affected so that they can inform themselves of what action to take if that person had an episode.  
Many people with some form of disability don't regard themselves as disabled and therefore don't declare it. As a manager, if you don't know about it you can't do anything.

>Any type of disability that may not be evident from someone's appearance, demeanour or social interaction. For example, depression, heart problems, diabetes, some hearing loss where corrected by hearing aids; cancer etc.

>I believe hidden disabilities to mean those disabilities which are not immediately perceptible to the naked eye or from immediately talking to someone. For example if someone has MS, or is visually or aurally impaired it can be immediately apparent.

>Disabilities that are not obvious i.e. mental or medical conditions that are not apparent. Also physical conditions where it is not immediately obvious due to the lack of equipment hearing aids walking aids etc.

>It is a disability that is not readily apparent. For example I suffer from itchyosis, and as it is a skin problem, it is obvious when it is causing any problems regarding my work ability. Alternatively, with my high blood pressure, it was not something I was aware of immediately, until I had problems with headaches. Now with the medication I am taking, there are no day to day problems. The hidden disability that affects me most is chronic fatigue, the day to day tiredness is not something that is noticeable to others and it is not until I pass out, which I have done on some occasions, is that there is anything done about it.

>I believe that hidden disabilities are things that people can't see or have never heard of before and therefore find it hard to relate to someone.

>Long term physical and mental health illnesses that sufferers have to learn to contend with on a daily basis. Although those with illness that are not visible can look really fit and well, they have to deal 24/7 with the illness that they have.

>Any long term impairment that is not visible i.e. - heart conditions, epilepsy, dyspraxia, mental health issues, autism, aspergers etc

>ME, Parkinson's (early stages), Bowel disorders, MS, Arthritis, Epilepsy, Mental conditions including Depression and Deafness.

>Mental health problems, health issues like HIV, CFS,

>Any disability that isn't readily obvious. These can be either mental or physical disabilities. On the whole they are mainly mental.

>Any physical or mental disability that cannot be seen or where stereotypes exist to force generalisations

>This is anything which is not outwardly visible. For example, mental health conditions or depressive disorders. It also includes physical conditions such as arthritis, heart problems, hearing difficulties, epilepsy, diabetes etc. Very often, the symptoms of a disability are controlled by very aggressive medication.

>Anything that is not obvious due to equipment use such as:

- Mental health problems
- Sensory disabilities
- Medical conditions such as arthritis, diabetes, MND, HIV, Aids, MS etc.
- Assumptions of what you can and can't do e.g. if you are in a wheelchair assume you are paralysed and unable to walk short distances or stand up. If you can walk a short distance and use a wheelchair accused of cheating!
- If you wear a hearing aid assume you can't hear anything and talk to you in a loud speech with contorted face. Deaf people have similar problems- impossible to lip read.
- If you are blind you don't know where you are going and people ask your guide dog for directions!!! Yes it happens!!!

## **2 Do you feel that the general public ignores the problem of hidden disabilities?**

Here, responses varied a bit, some angry some resigned. But key comments were

>Yes, but I don't think it is intentional, it's more ignorance and fear and for many people, also the 'busy life' gets in the way of 'seeing any other than the most obvious problems'. It is a combination of ignorance and awareness which is caused by almost overstating the stereotype of disability. TV and mainly soaps sometimes show the usual disabilities, but there are very few shows which portray hidden disabilities as these are not very easy to show (waterworks issues and learning difficulties are usually shown as figures of fun!).

>I feel the general public do ignore hidden disabilities - if it cannot be seen then it does not exist! I think this is down to ignorance.

>I don't think hidden disabilities are necessarily something they think about rather than positively ignore. But it's Ignorance mostly.

>I've both visible (walking difficulties) and invisible (chronic pain) disabilities. I find that in my case they do lead to different forms of discrimination, but the specifics mean that may not carry across to everyone. The visible disability occasionally leads to abuse in the street, the invisible one doesn't because people can't see it (OTOH it might lead to problems if I didn't have the crutches to show that I'm using disabled seats for a reason). The invisible one has lead to discrimination at work because people are reluctant to acknowledge its effects. 'Pain is affecting your work, but we've already given you a chair for that.' Management are good with tangible things like needing a chair or a disabled parking space next to the building, intangibles like continuous pain affecting your work rate are more of a problem because they might need to think about something and there might not be a solution they like. That said my first line supervisors have been universally excellent, it's second line and above that are complete idiots, the difference is probably down to first line supervisors needing to deal with you day to day and getting a better understanding that way.

>Ignorance and the way the individual carries their disability as they don't necessarily broadcast the fact that they are disabled.

>Hidden disabilities may be those that are not always physical. Hidden disabilities may be physical, emotional or mental. 'Hidden' may be a physical disability that is not perceived as maybe important (you do not have to be in a wheelchair to have a blue badge).

>I have lost friends since falling ill and when I fit or have my dyskinetic episodes, and I feel the general public have reacted very badly to me.

>I feel that like a number of things these days, if it does not affect you, you tend not to take any notice of it. Whether it is through fear or ignorance, it depends on what the disability is. For example, with mental health problems, it may be due to fear of the subject. With something else, such as heart problems, it may be that there is the feeling that with the progress of medical science these days, that there is no need to be aware of any problems. Or for something, such as ME, there have been over the years, conflicting reports in the media, so that the general public are not sure whether to treat as a medical problem or not.

>I think people choose to ignore what they cannot see or understand, and people who are lucky enough to be in good health find it hard to relate to people who are not. I think the public reaction is often because people don't have the time to listen or simply cannot understand how things affect people. Again I think there is a lot of 'disbelief' and some people simply think you are either moaning over nothing or looking for sympathy.

>I do believe people choose to ignore the problem. I feel it is a bit of both fear and ignorance as they aren't sure how to react and the general public believe that we disabled people are costing too much money and feel we are unable to lead a normal life, which isn't true.

>I feel that unless anyone has direct experience of having to cope with a long term, often progressive condition, they fail to understand the mental impact of having such a condition – nobody asks to have a health problem and I feel that society in general should be far more supportive and understanding of the need for those with health issues still to be able to achieve the same ambitions as those without health issues. I feel it's a case of 'as long as it doesn't affect me, then it doesn't really concern me'. Having had long term health issues since childhood this had a severe impact on my education and confidence as a child. Having returned to work after having children in my late 40's together with health issues, I have found it impossible to progress and improve my situation for myself and my family, which as a single parent has left me in something of a poverty trap in my late 50s.

>Yes to some extent, I don't think the understanding of obvious disability is very good so we have little hope of getting people to understand hidden disability better. Ignorance is a major part as in a lot of training sessions I've delivered, it is almost a given that someone will say that they never think about disability until it affects them or their family. A selfish view I think, but a common one.

>I doubt they're even aware of them or have ever thought about them. I think it is ignorance. Most individuals do not even understand what is defined as a disability under the DDA. People often don't understand the reality of living with certain conditions unless they have experienced it first hand or in somebody close to them.

>There is an assumption that if they can't see it or it isn't obvious then it doesn't exist. They accuse disabled people of cheating. If you are doing a job well and are articulate, they assume there are no other obstacles to deal with due to disability. They assume what you can and can't do by how you appear to them. Hotels and services are putting in ramps that are too steep and dangerous, no loops, or providing them incorrectly, inaccessible toilets, door handles etc- because assume they know what we want rather than asking or checking Doc M, often failing to provide alternative formats or interpreters because of the cost. Putting disabled people at a disadvantage. Much reaction is through both fear and ignorance, but also malice. Many comments are made based on negative assumptions. For example don't need a disabled space because they can walk, shouldn't have expensive or nice cars because disabled, should put up with what reasonable adjustments we have given them rather than what they need, should be seen and not heard. All above have been levelled at me as a disabled person.

>I find the hardest thing about having a hidden disability is when I have to inform people of it because I know as soon as I have informed them their attitudes will change towards me. For example when I apply for jobs and I am just another worker until they are informed of my epilepsy, then everything changes and I am like an outcast who needs to be treated differently than everyone else (she has a disability so treat her with care). Or when I meet new people and some people have been really good about my epilepsy but others were great with me until I mentioned it, then didn't want to know me any more. It makes it quite nerve racking informing people because you don't know what the consequences will be. With a visible disability you have no choice because people can

clearly see your disabilities so I guess we both face the same prejudices, but some of the fears and experiences will be different.

**3 Do you feel that the media overlook hidden disabilities, and if so what may be done.**

This answer brought out some real vitriol. But in summary the specific answers were

>The media should be educated into promoting issues of hidden disabilities more wisely. The various newspapers and magazine staff should get more training and awareness in community issues and not just reporting sensational news about Big Brother!

Adverts on TV could be a platform for overcoming, or understanding hidden disabilities. There are increasing 'personal matters' being advertised, such as hygiene, so why not educate and well as sell.

>The only portrayal of hidden disabilities tends to be of mental health issues when there has been a serious crime or attack.

>Promote awareness of hidden disabilities, how they affect people and the impact it can make on their lives, more information on awareness days, e.g. fibromyalgia day in May, there are awareness days for many disabilities, hidden or otherwise. More information about support groups in local areas.

>I feel that whenever the opportunity arose i.e. promoting the positive side of disability then hidden disabilities should be highlighted. It is easier for people to understand that someone who is blind (such as myself) or someone in a wheelchair may have difficulties in their everyday life but for someone with a hidden disability everyday life can be very difficult. There are documentaries on a variety of disabilities and I think more emphasis could be put on hidden disabilities and how people are affected by them.

>The media should run more articles and documentaries on hidden disabilities and through general programming involving characters with such hidden disabilities.

>In my opinion the media spend very little time getting their facts right, and would not devote the time to even begin to understand a hidden disability, let alone be able to write about it. Maybe if they were to attend conferences or listened to what people with disabilities say and the sort of things they come up against, it would maybe make it a bit easier to understand.

>There is not awareness of knowledge of disabilities as a whole in society although through media- this is slowly changing through documentaries /media coverage. However, although coverage may be the case; who actually would understand hidden disabilities? Possible fear and ignorance is the reason for general public ignoring the problem. An example may be mental health- this is something that is stigmatised and awareness may be limited by the general public. The media are doing 'their bit' but is it coming from the correct sources? Take soap operas, for example, they may feature a person with a disability without getting the full, 'real' picture. Through working with media, charities & companies awareness may be increased. Another quick point- there are those that are taking advantage of disabled rights/acts- such as those using blue badges and have no disability at all.

>This seems to depend on the disability. If some research is announced that would either improve or eliminate a problem, such as the recent treatment of a certain type of

blindness, then it gets quite a good exposure in the media. Likewise when a problem with health care arises, such as the recent reports of compensation for military personnel, again there is widespread coverage. It appears that if there is nothing 'news-worthy', then it never gets highlighted by the press, e.g. I can not remember when I last saw an article on deafness.

>I do feel that the media is definitely starting to discuss disability issues but as for PR I believe they choose to ignore it, having done a degree in PR and applied to PR agencies and when I have confronted them about my disability they make an excuses as to why they didn't want to offer me the job, I feel that they see disability as a hindrance to the work place and that having a disabled person in the world of PR wouldn't be a good image. I feel the media should interact hidden disabilities' with more every day life issues that hidden disabilities' come across.

>I feel that there should be much more awareness and information available to managers and businesses to give those with long term disabilities more dignity and support - those who choose to work rather than claim long term sickness benefits would seem to be severely penalised for their attempts to do the right thing and to do their bit for society.

>Mental health isn't given real cover largely because it's portrayed negatively. I think there is a lot of sympathy for people with certain types of conditions like cancer, but not so for other things. The level of public discourse in the media on disability really needs a shake up, so we would have to start with the more obvious stuff I think. Perhaps promote role models and have more articles on hidden disabilities.

>The media concentrate on blindness and conditions that are evident and they could help by running awareness campaigns and articles that highlight/explain the types of hidden disabilities.

>Yes, I think this is true. They don't necessarily make for a good story and living with a disability is not very glamorous. Highlight high profile personalities with hidden disabilities. Also, give wider PR support to charity events in relation to disability issues.

>I remember a woman in a wheelchair in X factor having negative press because she could stand up-she was being accused of not being disabled! Very often, the views of people with hidden disabilities are not sought because they are assumed on face value not to be disabled! I receive comments and am interrogated all the time about my disability because I use a wheelchair. 'What's wrong with you then?' 'Why are you in that?' Other colleagues who have mental health disabilities when they are with me are not questioned at all; it is assumed they haven't got a disability. A good start would be acknowledging hidden disabilities exist and writing about providing alternative formats, interpreters, information on hidden disabilities, featuring people with disability in a 'non disabled' way i.e. seeking their views, celebrating achievements if not solely to do with disability, providing useful information, treating as equal.

#### **4 Do the government and charities do enough to support people with hidden disabilities, and if not what could be done.**

The answers varied here quite considerably.

>I am not sure what kind of support is ever offered where there are hidden disabilities. Media companies don't give big coverage of the issues so any support agencies tend to be off the radar for most people. The types of hidden disabilities do have there own networks bit they don't seem to get to the general public.

This is a bit of a sweeping statement question, but I think that much more could be done to promote interests of types of hidden disabilities such as IBS, or Prostate issues.

>Awareness raising, good quality materials and information, leaflets tend to be very generic and vague, more support groups in local communities accessible to people who need to attend, no presumption that having a disability means no cant work and therefore running support groups in daytimes when people are at work and unable to attend.

>You have got various charities relating to disability but I feel those relating to hidden disabilities do not promote themselves. Public events could be arranged and advertised explaining what a hidden disability is. The Government could promote hidden disabilities through documentaries etc.

>We need awareness campaigns, having more support groups for helping those of us with hidden disabilities cope with reactions. There is a lack of government recognition that our life is impaired and lack of awareness amongst health professionals and employers for making or assessing reasonable adjustments under DDA.

>From the charities side, I presume it would also depend on the media/PR, which depending on how well they were getting their message across to the public, would in turn effect their funding, which in turn affects the ability to support people with hidden disabilities. On the Government side, it sometimes feels that they are doing the opposite of supporting people with hidden disabilities. For example, working for PR in the civil service, the targets for reducing sick leave are about 7 days per year; that when age discrimination was used as the excuse for reducing the time off sick from 21 days [for those over 45] to 10 days before official warnings on sickness absence; the sex discrimination was used as the excuse for moving the retirement age from 60 to 65. Then you read reports that they want doctors to give "well notes" instead of sick notes. As it appears that there has been pressure put on doctors to cut the numbers of sick notes issued, it appears that I have been urged to return to work after shorter periods as the years have gone by. [E.g. for the same problem, in the early 1980's, I got six months off work, whereas last year, it was 7 weeks. The six months may have been generous, but the 7 weeks was I felt too soon to return.

>I am beginning to realise that there are people out there with knowledge about ways in which people with disabilities can get help, either legally or financially, but how they reach people is difficult. I have had Rheumatoid Arthritis for over 20 years now, and until I recently attended your DSN Conference in London was unaware of what help was available. There seem to be a lot of grey areas and most people that you meet or work with on a day to day basis are not aware of where to get specific information, or how to get help. Unless the person with the disability looks into things for themselves which can very time consuming and not always sufficient, people are left to fend for themselves. There doesn't seem to be any way of "advertising" the help that is out there. Maybe advertising help and advice places in the media, press or TV. There are plenty of adverts that are looking to sell things for people who want to give up smoking for instance, or similar things, so why not advertise places where disabled people can turn to for advice and support?

>If you stand and scour through all the various magazines you find there is something for everybody, and there are magazines for just about every hobby you can think of. Things like cookery, DIY, how to decorate your home; bring up your children and umpteen other things. What if someone was to put together a magazine about Disability, not just the one 'Disability Now' which often misses the point about real hidden disabilities. We need

a magazine where you could read true life stories from people living with disabilities, how they cope, what things they do to help them deal with problems, and lists of companies to contact for further information. It could even have a 'doctors' column where people could write in for advice. I'm sure there are lots of people out there who would find this most useful and it would be a way of reaching all those people out there like me, who are unaware of how they can get help, or that may want to reach other people dealing with similar problems.

>I feel that an awful lot more could be done to help those with health issues. As someone who is prone to periods of severe chest infections, I now find that I am under pressure to keep to somewhat low sick absences – despite letters from my GP and consultant confirming that I have an ongoing condition. I feel that there is not enough consideration given to the problems faced by those with long term health problems and that the added stress in the workplace can often make conditions much worse – improved communication and understanding for those who are not deliberately taking time off for the sake of it would enable those with health issues to feel much more valued for the efforts they make to maintain a normal lifestyle.

>The government and charities could help more by education and awareness campaigns so that people are more aware of hidden disabilities and the effects that they have, both on the individual, their family and friends. Also there should be provision of Help Numbers and Advice Sections at the relevant HMG departments and charities.

>I think charities do a lot of good work to support people, given the constraints of funding. However, I think the government has a lot to answer for in ensuring the some people with hidden disabilities get the right medical treatment where appropriate. There are lots of people living on disability allowances who could be helped back to work and live a better quality of life if they were allowed to receive the appropriate drugs to manage their condition. It's a case of the post code lottery and to some extent those that shout loudest and are prepared to fight, often get them, but this should not be the case. Also, I feel that the government needs to look at education in schools so that children grow up from an early age with a better understanding of all types of disability issues.

>Having worked for a variety of Charities such as Scope on their marketing Panel and "Time to Get Equal Campaign" as well as Blind in Business, and Action for Blind I feel the charity and the disability sector are trying their hardest for the media and PR and people in society to make people aware what are hidden disabilities' and there are more to what you can just see visually, I just feel people choose to ignore it. There should be proper policies that try to take into account people with all disabilities, not just the obvious ones.

>Too many charities and government concentrate on the medical model- what if you have more than one disability, what support is there holistically? I am sick of going to specialist charities and people saying they don't want to end up as 'bad' as me- meaning as severely disabled. It really knocks my confidence and causes depression. How is this helping at all? Why are more disabled people not involved in charities helping each other with their experience? A lot is done for carers and very little for disabled people themselves. It is as if we don't exist, don't have an opinion or say in our care and support. The answer is to involve disabled people more in policy and processes. Ask disabled people what they would like to support them. Encourage positive attitudes towards disabled people. Manage better people (including disabled people) on their soap box about themselves not looking at the greater good for everyone needing a service.

Often appalling things have been done because someone has shouted the loudest for their self interest- often those who shout loudest are not disabled at all!

Who is listening to what we say? How are we being heard? Carers and non disabled people think they know what we want- in most cases they don't! They are often looking at what makes their life easier rather than the disabled person. Look at the appalling lack of, and type of, respite provision on offer that disabled people are forced into.

I'd like to see more charities based on the social model i.e. for all disabled people, or broad categories of disabilities rather than just medical conditions. Run by disabled people for disabled people. I'd like to see less assumption that we all need the same things; mental health needs., learning disability, physical disability, sensory disability all have differing needs and are not mutually compatible. There are unique situations needing support when you experience more than one disability across the hidden disabilities.

Some respondents didn't answer the questions but sent in statements relating to their own issues and these are included as they contain some serious points we need to bear in mind.

>I have an Invisible Disability where I suffer from chronic pain most of the time... I have Endometriosis and I have almost lost my life from this disease.

But what really annoys me is when I get out of the passenger seat of the car when we park in a disabled parking bay and get bombarded with dirty looks, tuts and have even been told "These spaces are for disabled people only!"

I am not always in a wheelchair and have good days, bad and ever worse days where I don't go out for days on end!

But do all people assume just because you can't see it, it doesn't exist?

Sorry for the \*rant\* I just wanted you to know my thoughts on this subject.

>Hidden disabilities may be those that are not always physical. Hidden disabilities may be physical, emotional or mental. 'Hidden' may be a physical disability that is not perceived as maybe important (you do not have to be in a wheelchair to have a blue badge). There is not awareness of knowledge of disabilities as a whole in society although through media- this is slowly changing through documentaries /media coverage. However, although coverage may be the case; who actually would understand hidden disabilities? Possible fear and ignorance is the reason for general public ignoring the problem. An example may be mental health- this is something that is stigmatised and awareness may be limited by the general public. The media are doing 'their bit' but is it coming from the correct sources? Take soap operas, for example, they may feature a person with a disability without getting the full, 'real' picture. Through working with media, charities & companies awareness may be increased. Another quick point- there are those that are taking advantage of disabled rights/acts- such as those using blue badges and have no disability at all.

>I recently attended a disability conference in London and was grateful for the opportunity to meet people to whom a 'disability' is something they live and cope with and not simple a word with no meaning.

I have Rheumatoid Arthritis, and have other illnesses that run alongside it but that are largely due to the RA itself or have developed as a result of the RA. The problem I have is that if anyone were to look at me when I was in work, I appear to be fit and well, and nobody can really tell whether or not I am suffering in silence. I am not a person who complains constantly about my symptoms, or that really wants other people to know how bad it is sometimes, I tend to "grin and bear it" and bear it' and have difficulty in explaining how it really affects me without it sounding totally stupid and unbelievable to anyone who doesn't understand. Even my close family are not fully aware of all the problems this causes me, and most of the time I carry the burden on my own.

I work for CPS PR office in Merseyside in the Area Secretariat and can more than cope with my job, in fact I like the variety and being able to get up and walk around if ever I need to rather than sit for long periods of time when I become rather stiff and uncomfortable. Due to a lot of restructure within our office I have had several line managers and none of them have ever really been able to understand my RA or how it affects me. Whenever I have been off sick they never know how to record my sickness because they cannot understand that even what appear to be simple things like a migraine, sickness or back pain can be related to RA, along with umpteen other things.

I have reduced my hours at work slightly to 35 hours a week instead of 37 as a result of an ATOS report that suggested a later start in the morning would benefit me as this is the worst time for me. I also had my sickness trigger point extended last year from 10 days to 15, but have just received a notice of first formal meeting because I have gone over my trigger point by half a day.

I was looking on the intranet the other day at the criteria for special leave, because I have recently been undergoing tests at the hospital and have now found I have angina, and am due to have an angiogram in June as they think I have a problem with one of my heart valves. When looking at the PMM Guidelines I came across Disability Special Leave which seems to take into account "illness -related" sickness, and that this should be recorded separately from normal sick leave but I don't know how this works. I have mentioned it to my line manager but she is also unaware of what this really covers or whether or not I should be eligible for this. I have a meeting tomorrow morning (Wed 7th May) at 10am with my line manager and my Union Rep about my sickness, and this will be the first formal meeting under the new procedures.

I have been looking at your email about "hidden disabilities" and can really relate to the comments you make about "hidden disabilities" not being believed or understood, and even worse being demeaned. I know Rheumatoid Arthritis is one of many hidden disabilities and would think anything that isn't immediately visible to other people, particularly things like M.E., HIV or Aids, to name just a few.

There is some hope for recognition in political circles following LibDem Euro-MP Liz Lynne calling for greater awareness for the millions of people in the UK with hidden disabilities, who suffer from conditions which are not immediately obvious to others. She feels that hidden disabilities include mental ill health (which affects 1 in 4 people in their lifetime), asthma (over 3 million UK sufferers) and dyslexia (up to 1 in 10 people) and many other conditions. In her statement she says 'It is estimated that 70% of people with a disability in the UK have a hidden disability. Lynne, who is Vice President of the European Parliament's Disability Intergroup and has campaigned for years on disability issues, said:

"People with recognised hidden disabilities are legally protected under the Disability Discrimination Act but too often others don't believe they are disabled because there is no condition to be seen at first glance.

"Fear of stigma and discrimination also leads many with hidden disabilities to hide or ignore their condition and this is a great shame because they miss out on the help available to them from the Government and charities.

"Whether someone has from a hidden disability or not, everyone needs to be aware of what they entail. Through more understanding and awareness, people will hopefully feel freer to discuss hidden disabilities and if necessary ask for the information and resources out there."

It may be that the advantage of having a hidden disability is that one has at least a degree of choice in whether or not to disclose it to others and when to do so. The disadvantage being that when one does make that choice to disclose it the will tend to be more difficulty having that disability accepted as being "real", because of the prevalence of what could be called "The doubting Thomas" syndrome applies here (If I can't see it, it isn't there or can't exist at all.)

The reverse tends to apply to those with a "visible" disability, in that the disadvantage is that

one generally has little or no choice at all in whether or not or even when to disclose, as the disability is self-disclosing.

The advantage from this, of course, is that gaining acceptance and belief in the existence of disability tends to be far easier.

Many of us, of course, have both hidden and visible disabilities at one and the same time and so experience both all the advantages and all the disadvantages of both.

What unites us all though I think is that having disclosed and having been believed (and sometimes even when we have not) there will almost always be a noticeable change in the way we are perceived by others. and often sadly this will be in a negative way.

The difference in perception will not always be a negative though, not least at times when we actually need the world to acknowledge and accept our differences. When such acceptance then leads to suitable adjustments being made to ensure our full inclusion as equals it, of course, becomes far more of a positive.

### **So, is there anything to declare?**

Lena Calvert, as NUJ Equality Officer feels that it's entirely understandable that members with hidden disabilities may be extremely worried about declaring their condition to their management.

Her conclusion is that attitudes still tend to reflect a lack of understanding and those toying with the idea of declaring their disability may themselves feel that it is like admitting to some kind of "weakness". They worry that their management and colleagues alike will see them in a different light and this will have an adverse effect on their career.

But there are very good reasons why it makes sense for people with hidden disabilities to "come out". Apart from the more accurate reflection of society as a whole (around 20 per cent of the UK's population is disabled), the individual will gain a degree of protection from the Disability Discrimination Act (DDA).

This protection may not be uppermost in a member's mind whilst they are able to control their condition and there is no worsening of the symptoms. But this may not always be the case and a member with a hidden disability may find that overtime, they are beginning to take slightly more sick leave or needing to arrange more medical appointment leave.

Many employers operate sickness absence monitoring policies. These usually require employees who record a certain number of sickness absences within a set period to attend a monitoring interview. As a result disabled employees may be required to attend more absence-monitoring interviews than their non-disabled colleagues. This can lead to disciplinary procedures being implemented and, in the worst-case scenario, dismissal on capability grounds.

It is extremely difficult to argue that an employer *should* have known that their staff member was disabled once disciplinary procedures have commenced and invoke a discrimination claim under the DDA. Far better that management are made aware, formally, of the employee's condition before this situation arises.

Apart from giving a disabled person protection against discrimination, the DDA also suggests that organisations consider making a provision for Disability Leave. This is viewed under the legislation as a reasonable adjustment for a disabled employee.

Disability Leave would normally consist of a jointly agreed estimated annual number of days required for disability-related absences. Thereafter any absences relating to disability, such as a meeting with a consultant, for example, is not registered as sick leave but as Disability

Leave. Normally an agreement will be reviewed after a year. The disabled employee would continue to record sickness absences for non-impairment related reasons in the same way as non-disabled employees.

Even if a Disability Leave agreement is not formally agreed, it may be possible to challenge disciplinary procedures being taken against a disabled employee on sick leave or capability grounds – but only if they can prove that the organisation has been informed that they are disabled. There is provision in the DDA that in some cases, it can be argued that an organisation *should* have known that their employee was disabled but this is extremely difficult to argue and to win, if required, at tribunal level. If an employee has declared a disability which is covered by the DDA, it may be possible to argue that some of their sick leave is actually disability leave and therefore it is a reasonable adjustment for the organisation to disregard these when monitoring sickness absences.

The DDA is not a magic wand and it is important that we do not get carried away with the idea of disabled employees having a permanent “get out of jail” card. As we know, many employers will go ahead with disciplinary procedures and try to get rid of their disabled employee at any cost, especially if they are of the mistaken belief that disabled employees are likely to be less productive. However, the more enlightened employer may be willing to entertain a Disability Leave agreement and the employer who doesn't want a fight may be put off sacking an employee or giving them a hard time about their leave.

Further information on disability leave and a model disability leave agreement can be found on the equality pages on the NUJ website – [www.nuj.org.uk](http://www.nuj.org.uk). This information is also available in a printed format in the union's Disability Handbook, copies of which are available from the NUJ.

So, finally it is important that disabled people make employers and colleagues aware of the impact of hidden disabilities, and all organisations should make sure that training for acceptance of hidden disabilities is built into their process.

This must comprise a minimum level of each of the following:-

Understanding and awareness

Statistics and trends

Depictions of disability

Communicating with disabled people, whether employers or employees

Models of disability

What are hidden disabilities?

Experiences of disability

Describing disability

How much support should you provide?