

**Joint Response – SDEF, ILiS and Inclusion Scotland**

**The Scottish Disability Equality Forum (SDEF)** works for social inclusion in Scotland through the removal of barriers and the promotion of equal access for people affected by disability.



It is a membership organisation, representing individuals with any type of impairment, disability organisations and groups who share our values. It aims to ensure the voices of people affected by disability are heard and heeded. SDEF promotes access in its widest sense, including access to the built and natural environment and access to the same opportunities as are enjoyed by other people in our community.



**Independent living in Scotland**

The ILiS project is funded by the Scottish Government and hosted by Inclusion Scotland. It aims to grow and strengthen the Independent Living Movement in Scotland and to support disabled people to have voices heard. Independent Living means “disabled people of all ages having the same freedom, choice, dignity and control as other citizens at home, at work, and in the community. It does not mean living by yourself, or fending for yourself. It means rights to practical assistance and support to participate in society and live an ordinary life”. With such support, disabled people can exercise their rights and duties of citizenship via their full and equal participation in the civic and economic life of Scotland.

The principles of independent living, **freedom, choice, dignity and control**, do not only relate to specific services and provisions for disabled people, but to the whole of disabled people’s interactions with society; its organisations, facilities and structures; and every aspect of their quality and equality of life<sup>1</sup>: These principles are underpinned by the following basic rights.

- Full access to our environment
- Fully accessible transport
- Technical aids and equipment
- Accessible and adapted housing
- Personal assistance
- Inclusive education and training

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<sup>1</sup> ILiS; “The Essential Guide to Independent Living”, 2009

- An income, including income within the state-benefit system for those unable to work
- Equal opportunities for employment
- Accessible and readily available information
- Advocacy and working towards self-advocacy
- Counselling, including peer counselling
- Accessible and inclusive healthcare provision
- Communication and appropriate support for communication
- Civic participation

## **Inclusion**

### **Scotland**

**Inclusion Scotland** is a network of disabled people's organisations, individual disabled people and other organisations that support the principles of the Social Model of Disability. Our main aim is to draw attention to the physical, social, economic, cultural and attitudinal barriers that affect disabled people's everyday lives and exclude us from participating in the mainstream of society. Our role is to enable meaningful communication and consultation between disabled people in Scotland and policy makers at local and national government levels. We want to reverse, through civil dialogue, partnerships, capacity building, education, persuasion, training and advocacy, the current social exclusion experienced by disabled people.

## **Patient Rights and Responsibilities - Response**

### **What rights or responsibilities could be added to?**

#### **1.1 Renewal of aids and adaptations**

1.2 The majority of members who responded felt that the most important rights and responsibilities had been covered and that there was a fair balance of both overall. However, it was suggested by a few members that the length of time between the renewal or replacement of aids and adaptations was a concern and should be reviewed with respect to the Charter.

1.3 Whilst it is recognised that medical assessment will often be necessary prior to renewal/replacement of equipment, there is no legal time within which disability equipment to support disabled people must be provided and delays can therefore be excessive. This delay can leave disabled people without the support they need to live independently. Particularly in the case of children, where disruption of social and educational development may be a further factor, or of working adults where their employment could depend on it, it should be possible to create a timeframe for equipment replacement.

1.4 As with the 12 week treatment time guarantee, we would like to see patients have the right to a guaranteed timeframe within which the renewal/replacement of aids & adaptations will be provided.

## **2. Respected regular medication times**

2.1 A further member proposed that the Charter include:-

“The right to have your medication at the same time you would take it at home eg every 4 hours instead of 6 hours as NHS do”.

2.2 This is often a cause of stress for patients in hospitals when medication is not given at the correct time of day. One example was provided of an elderly patient who, having been informed that her epilepsy medication would be administered at a different time of day, suffered an epileptic episode. The patient’s daughter was convinced that this occurred as a result of the stress her mother experienced.

2.3 We would like to add to the Charter, the patient’s right to have their regular medication times respected, where medically appropriate or possible. **This could be included within the “Right to receive services which take your needs in account” section.**

## **3. Removal of anticipated and preventable stressors**

3.1 Reasonable preventative steps should be taken to minimize any potential stressors or trigger that may unduly cause distress to a person. These could include a quiet waiting area for a person with a learning disability who exhibits challenging behaviour under stress, or a short waiting time for a child with ADHD. It could also include the ability for someone who regularly receives care and support at home, and for whom this support is particularly specific, e.g. involves an appropriate way to move and assist, to get such non-medical support, whilst in hospital, from their usual providers or PA’s

## **4. The Right to be Involved in the planning, design and provision of services in your area.**

4.1 Patients must expect their communication support needs to be adequately met to enable full involvement with planning and decision-making processes. Some disabled people will need support to participate and be involved. It is important that this is acknowledged and that they supported adequately and appropriately to do so. You may like to look at the ILiS online guide to coproduction and also their factsheet on involvement, which both offer guidance on working with disabled people on policy and practice. You can access these at [www.ilis.co.uk](http://www.ilis.co.uk).

4.2 We feel that the Charter should include the right of a patient, or someone acting on the patient's behalf, to request that anticipated and preventable stressors be removed where possible. **This could be included within the "Right to receive services which take your needs in account" section.**

## **5. What would make it better?**

5.1 Members suggested that improved communication between departments in hospitals, and between health boards, would minimise the majority of common preventable incidents where a lack of communication causes patients delay, confusion or distress. Although this is part of a far greater issue which spans the working infrastructure and communication pathways between health care bodies, it would be good to see a commitment within the Charter to improve communication with a view to improving patient care.

### **The Right to Dignity and Respect from Nursing Staff**

5.2 The right to dignity and respect from nursing staff has also been raised as an issue which can be difficult to address unless a patient is willing to raise a complaint. For example, in previous written evidence to the Scottish Government during the drafting of the Patients Rights (Scotland) Bill, Inclusion Scotland raised the issue of discriminatory attitudes and behavior amongst NHS which robs disabled people of respect and autonomy (e.g. by directing questions on their conditions and treatment towards relatives, carers personal assistants and others rather than towards the disabled person). Inclusion in the Charter of respect for "inherent dignity, individual autonomy, including to the freedom to make one's choices, and independent of persons", as laid out article 3(a) of the UNCRDP, which the Scottish Government has a progressive duty to meet, might help to address this pervading issue,

5.3 Members raised their concerns that patients may be less likely to complain about this kind of behaviour whilst under the care and supervision of the nursing staff they are unhappy with. Whilst the complaints process is contained within the parameters of the Charter, patients may benefit from being offered a clear and immediate path to voice informal concerns at the point of their admission.

5.4 One member raised the pertinent question

"If I am unhappy about a member of staff, who do I ask to find out who I should speak to? So many nurses in and out of my room, it's confusing. I don't want to have to ask the very person I'm unhappy with"

5.5 We would like to see the provision of a clear and visible nursing staff line management structure added to the Charter to enable patients to discreetly voice their concerns to the appropriate person.

5.6 Such attitudes might also be addressed if more attention were paid to a fuller range of rights within the UN disability convention (or referral to it as a whole), as well as disability equality training for all NHS front-line workers provided by experienced disabled trainers. The SHRC's training on applying a Human Rights Based Approach, which was developed as part of their Care about Rights project, could also be usefully included such training.

## **6. Improved communication of a patient's needs at the time of admission**

6.1 There are still NHS environments where treatment is delayed due to access difficulties or communication support needs not being met. Improved communication regarding support needs and potential access difficulties at the time of admission (or prior to admission in the case of planned admissions) would help to reduce the number of patients who are unable to get treatment as and when they should.

## **7. Do you think the information in the Charter is written in a way that is easy to understand?**

7.1 Of those members who responded, 83.3% felt that the information was well laid out, and used simple wording.

## **8. Does the format of the Charter make it easy to find the information you need?**

8.1 We found that 71.4% of members felt that the information they needed was easy to find.

## **9. What would make it better?**

9.1 Some members felt that simpler language could be used, with shorter sentences. It was felt that in some cases, jargon was being used instead of straightforward everyday English.

9.2 One member expressed their opinion that the sections within the Charter could benefit from a further summary at the beginning of each section. This was on account of the large amount of information provided within each section.

9.3 Whilst the information itself is simple to understand, we agree with our members that in some sections, the amount of information may be regarded as overwhelming. Further subsections might be of benefit to further improve the readability of the Charter.

## **10. Do you have any comments on the design of the Charter?**

10.1 There were no suggestions with regard to the design of the Charter, other than one member highlighting that no one design will ever fit everyone's needs.

10.2 We were generally pleased to see that Access, followed by Communication and Participation, were flagged at the top of the charter. Although this does not place them in a hierarchical position in regard to the other themes, and that they are all equally of value, these tend to be prevalent barriers to disabled people receiving the same equality of outcomes as non-disabled people. We are therefore pleased that they have been given this attention in the charter.

10.3 Improved access to the information through a comprehensive range of inclusive formats was considered more important than the design of the Charter, as availability of accessible formats of the current Charter were not readily available where one might expect, eg., Scottish Government website, etc. Addressing these issues for disabled people will improve access to all health service users. They will also have an impact on other areas, for example, if a blind person receives a letter in a format they can access, they will have no complaints that their privacy has been breached because they had to approach someone else to assist them in reading a letter concerning confidential information.

<p>10.4 The charter should be produced in accessible formats not only 'on request' but as standard, such as in BSL and easy read, so that there is no delay and therefore no inequality for disabled people in accessing these documents in formats they need to be able to understand it.</p>
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## **11. Do you have any comments on the balance of rights and responsibilities set out in the Charter?**

11.1 We found the responses on this question to be as concerned with responsibilities of patients as with their rights. There was unanimous agreement amongst those who responded, that a harder line should be brought down upon patients who were abusive towards staff. However, staff attitude was also recognised as key to good relations.

11.2 "As I said before, its success or failure will be dependent upon the attitude of the staff. I also think it is very important that the responsibility of the patient is clearly outlined too".

**12, Do you feel that the exclusions to the 12 week treatment time guarantee are fair and logical? Should surgical procedures for Scoliosis patients be excluded from the treatment time guarantee?**

12.1 Members generally felt that there should be no reason to exclude certain treatments from the 12 week treatment time guarantee.

12.2 With regard to Scoliosis patients specifically, most of whom are usually children and require early attention for a good prognosis, the majority of members who responded felt that more should be done to reduce the waiting time for treatment.

12.3 As it is possible to seek medical treatment in another EU country under EU law, we would be interested to know what specialist staffing resources exist and whether efforts have been made to reduce waiting times for scoliosis patients using these resources.

**Mental Health Treatment**

12.4 We continue to be extremely concerned that mental health treatment is excluded from the 12 week treatment time and instead follows an 18 week referral timescale. If there is early access to adequate mental health services there will be fewer crisis admissions. Rationing care for people with conditions such as depression, anxiety, schizophrenia, bi-polar disorder until a crisis occurs is likely to intensify longer term psychological damage by leaving serious conditions unaddressed and untreated.

12.5 The mental health of Scotland's population is already extremely poor compared to other developed nations. With an estimated one in five Scots seeking some form of mental health treatment last year, only the United States has a higher incidence of mental health issues (Source: World Health Organisation). Scotland also has woefully high suicide rates particularly amongst young men.

12.6 There is a strong relationship between poor mental health and the incidence of (and ability to recover from) conditions such as heart disease, stroke and cancer. We believe that the current poor provision of mental health services partially explains Scotland's poor life expectancy, particularly amongst those suffering stress from poverty and deprivation – where people with physical, sensory and learning impairments are over-represented due to society's discrimination. Similar guarantees for waiting times for mental health issues must be established for the present undervalued, under resourced Scottish mental health services as those applying to physical health services. Otherwise, those with mental health issues will continue to be treated less favourably. As with meeting the 12 week treatment guarantee for scoliosis, such guarantees will mean investment in extra staffing requirements.

Many thanks from SDEF, ILiS and Inclusion Scotland for the opportunity to respond.

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