



Association for Real Change (NI)

Response to the HSCB Disability Action Plan

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Association for Real Change, Northern Ireland (ARC NI) is an umbrella body, representing 36 providers of learning disability services. Members include statutory, voluntary and private organisations, all of whom are commissioned to provide a range of services to the learning disability population.

ARC NI facilitates a number of Advocacy groups called “Telling it Like it is’ (TILII), consisting of men and women with a learning disability. Three groups are based in the community and two are hospital based.

Our response therefore primarily focuses on how proposed action relates to people with a learning disability.

In principle the four key areas as outlined within the Action Plan make sense and continue to be relevant, however require further outcomes being achieved.

1. Communication

ARC NI welcomes the HSCB developing their website to make it assessable, including meeting at least an AA standard. This goes some way towards meeting diverse audience need that said more work is required. For example the **page on Self-Directed Support has no easy read materials, is not obvious to find and has very limited information** e.g. links to HSCT websites with more detailed information on who to speak to in your area if you wish to progress. Whilst ARC NI welcomes the proposed development of an Accessible Formats Policy it will require **all staff responsible for creating materials to fully understand their role in applying the use of plain simple language** with images, or having a resource to ensure adequate translation of documents into said formats.

ARC NI also welcomes the improved site being compatible with assistive technology and that user feedback will be sought. It may however be helpful to monitor footfall and after a year of the website being improved, have an **online survey for web visitors to complete seeking details on who they are, what they were looking for and did they find it.**

2) Awareness Raising and Training

ARC NI welcomes HSCB recognising the importance of encouraging staff to declare if they have a disability so long as they are reassured this will have a positive affect on their employment. It is also crucial that parents and carers do get the flexibility they need in their work life to care for their loved ones.

ARC NI also welcomes the HSCB raising awareness of specific barriers faced by people with disabilities, however as part of this awareness raising it will be as critical to educate people on how these can be reduced or negated. **ARC NI would welcome HSCB identifying if they can measure the reduction in these barriers as a result of the awareness raising.**

ARC NI welcomes collaborative work with service users to design, deliver and evaluate staff training. It is also important to make sure that the training is delivered proactively and explicitly promotes positive attitudes to disabled people, alongside an understanding that it is barriers of attitude, environment and organisation, which can discriminate or disadvantage people with disabilities. This is 'disability equality training' which as well providing disability awareness training, also focuses on ensuring that non-disabled people are aware of how disabled people lead their lives.

TILII, an advocacy group of individuals with learning disabilities, deliver staff training for HSCTs and **ARC NI would strongly urge consideration being given to utilising TILII's experience and knowledge by HSCB.**

3. Getting People Involved in our Work, Participation and Engagement

ARC NI strongly welcomes the continued embedding of PPI as this continues to challenge with much resistance being noted, including frequent suggestions of the inappropriateness of engaging a person with a learning disability in meetings. **ARC NI advocates the need for HSCB staff to be in receipt of training on meaningful inclusion and engagement methods** which would remind of the importance for the use of simple language at meetings, ensuring the role of advocates (if present) have time to further check in and explain any issues that continue to confuse to encourage active participation, as opposed to accommodating the continued thought that users and carers contributions are tokenistic or unhelpful.

ARC NI welcomes the facilitation of a specific focus group for people with a disability and assumes that **people with a learning disability will be a targeted priority for inclusion**, in recognition of their additional communication needs. To ensure a fair and honest response, ARC NI would propose these focus groups should be as a minimum **co-facilitated by representatives other than HSCB and who possess particular areas of expertise in relation to the target audiences.**

As part of any engagement process, ARC NI also assumes the continued communication with group participants will occur, informing them of any changes.

ARC NI would advocate multiple methods required to enable communication of complaints and it may be worthwhile exploring, for example, having face to face complaints procedures for people who are unable to complain in writing, or find it intimidating to do so. These could be included as part of the 'one stop shop' referred to the 'Improving access to autism services for adults' section further on in the consultation.

Self Directed Support is an initiative that empowers individual choice however ARC NI holds multiple concerns relating to the current implementation and roll out of this programme. Leaders within the learning disability sector have many unanswered questions as submitted by ARC NI to the HSCB and Health & Social Care Trusts are unable to confirm levels of funding available for SDS. ARC NI is already aware of variance in rates being applied by HSCTs and this is significantly concerning against a backdrop of efficiency savings.

Many parents/carers and users have little understanding of what SDS actually is and many providers have little awareness, not least understanding of implementing the ASCOT as an outcome measurement framework. This latter point is linked to current work being undertaken by the HSCB, scoping an outcome measurement tool appropriate to meet multiple KPIs to capture qualitative stories from parent/carer and users' perspectives.

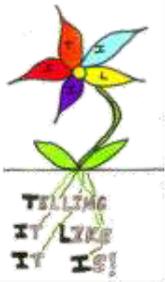
This results in ARC NI having grave concerns of the reality of meeting the 30% uptake target by 2017 and strongly advocates the need for the **HSCB to produce coherent SDS guidance that explicitly outlines regional consistency.**

Furthermore ARC NI would **advocate the need for providers, parents/carers and users being involved in the scoping of suitable tools which can assist in the gathering of outcome measures.**

Involving people in their own care through a new pain management pilot in Belfast local commissioning group area should be seen as a positive move forward, as people with a learning disability are often left on the peripheral. People with learning disabilities are living longer and continue to face many health inequalities. TILII members commented that often no one explains to them about their health or why they are taking medication and this would help relieve some of their anxiety when they are visiting their GP or hospital. **ARC NI would advocate utilising the skills and expertise of Learning Disability Nurses to enable this.**

4. Recruitment and Retention

ARC NI welcomes the creation and promotion of meaningful placements opportunities for people with a learning disability and **offers its support in the development of practical guidance.**



TILII ADVOCACY GROUP RESPONSE TO THE DISABILITY ACTION PLAN



ARC NI facilitates an Advocacy Groups of Men and Women with a learning disability to speak out on issues that are important to them. The groups are called 'Telling it like it is' (TILII) they consist of three community groups and two patients councils form a hospital.



TILII were pleased to be asked to give feedback on this consultation because they felt that they were the people who should have a voice as they were the people living their life everyday with a learning disability



The majority of the TILII members said that there are still a lot of people in the community who judge them on their disability instead of 'seeing the person'. They feel that there is still a barrier to them taking part in certain activities in their local community, and to them seeking employment. Some members were actually reluctant to go out by themselves as some of them had been targeted and made fun off.



This seems to be backed up by a survey completed through the NI Equality Commission in 2013;

Rise in prejudice found that attitudes towards people with a disability have deteriorated, including people with mental health issues.



In terms of those affected by prejudice, the survey found that one in three people in Northern Ireland, feels unfairly treated or harassed. Chief Commissioner Michael Wardlow said: "This is a worrying insight into the population's psyche and proves that much work remains to be done to break down barriers in our mind sets to create a fairer and more equal society for

everyone in Northern Ireland." (<http://www.bbc.co.uk/news/uk-northern-ireland-18414195>)

TILII members hoped people would change and become more understanding and take the time to find out what they were really like. One member said, "Listen to me and give me a chance to prove that I can and do valuable activities, like training staff and helping to make easy read documents".

1. Communication

The TILII members are pleased that the website is going to be made assessable with assistive technology that helps people who are blind or have other impairments, but they also explained that it was important that the information was in pure plain English. TILII also felt easy read should be available on the website so that people who cannot read have images and pictures to help them understand.



TILII is offering to be one of the service user groups asked to test it, to see if it was easy to use and to make sure people could understand especially if they could not read.

2) Awareness Raising and Training

TILII members said that it was important that staff who had disabilities were confident to share this information and that it would not affect their work and that they would be offered support. Five of the TILII members commented how hard it had been for their parents to work and provide them with the support they needed. It would have been helpful if employers had been more understanding to help their parents fit work and care into their everyday life. For some of the members this has eased because as they have got older they have moved into supported living but they worry about it happening to other families.



TILII members offer training to staff on Disability Awareness. They explain what it is like living with a learning disability as well as how people with a learning disability need to be treated as individuals and how they can be supported to lead a full life. They said it was important that people with a

learning disability provided Disability Awareness Training so it was real life experiences that staff were learning from. **TILII wish to offer their expertise to train HSCB staff.**

They thought that having Equality Champions was also a good idea but could they be people with a disability so they had experience of the problems people with a learning disability face

3. Getting People Involved in our Work, Participation and Engagement



The TILII group felt it was really important that people were listening to them about the care and support they receive. They really like the idea of an easy read form that allowed them to report on the services provided by the Trust. The TILII groups have already started to give feedback on "Tell Us What You Think of Our Services" (an easy read document from the Belfast Trust), which allows people to complain about poor quality care, highlight good quality care and has a comment or idea box to suggest improvements. **The TILII members felt this would be good across all trusts and health related services.**

4. Recruitment and Retention



TILII members felt that this was a great idea and hoped the right support plans would be put in place to help disabled people, including people with a learning disability to find work and to stay in employment. This would not only make them feel more valued but would help to give the public a more positive image of them because they were working and earning their own money. They said support for some people might have to stay in place for all of their working life so this needs to be planned for right from the beginning

TILII members said that it was important that people new that they had hopes and dreams just like everyone else and though they may need support they could still achieve great things and having a chance to have a real job would be brilliant



For reading our response.