



Association for Real Change (NI)

Response to the HSCB Equality Action Plan

**November 2015**

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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.

#### i) Accessibility of Communications and Information / Communicating Better

The actions relate mainly to the production of hard copy materials and whilst these are critical, **ARC would also advocate the need to make the HSCB website accessible, ensuring user friendly navigation which is easy to read.** This is acknowledged within the Disability Action Plan but should be cross-referenced to ensure it does not fall outside of the remit of equality.

**Furthermore any information specifically relevant to people with a learning disability should include easy read versions.** The web page providing information to service users on ‘Self-Directed Support’ is a good example whereby this is at risk of discriminating against the very audience it intends to reach.

With regards to produced materials, careful consideration should be given to an **appropriate distribution plan to reach intended audiences**, for example, local libraries and GP Surgeries for people who don’t have access to the Internet.

#### ii) Awareness raising, training and capacity

ARC welcomes a staff survey to assess impact of training however advocates this should be **baselined in 2016** to identify what level of awareness staff currently have, what training they have received to date, and then identify where the skills and learning gaps are so that any provision of training can be targeted to address specific gaps.

**ARC also promotes the opportunity of using this baseline to review annually thereafter.**

#### iii) Making Complaints Accessible

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.

ARC NI promotes the opportunity of listening to complaints and compliments and whatever facilities are made available for complaints should also be in place for compliments.

#### iv) Improving Data Quality / Improving Patients, Service Users & Carers Experiences

Accurately assessing the health and social care needs of local communities is dependent upon having accurate and detailed knowledge of local demographics and a good understanding of emerging need. Many differing figures are quoted for the population of children and adults with a learning disability in Northern Ireland. Through ARC's engagement in the *Learning Disability Health Care & Improvement Steering Group*, we are aware of work ongoing to meet the KPI's as set in response to the *Learning Disability Service Framework*, but there are challenges. **Accurate information on this population can only be obtained if the five Health & Social Care Trusts implement the same data recording system** to ensure that there is reliable consistently collated data.

When an individual is identified within the system, a holistic understanding of the needs of that individual is required and this is where multi-disciplinary perspectives are critical. In line with TYC, a person-centred reporting system utilised across disciplines and organisations would assist in the forward planning and commissioning of provision in accordance with 'known' individual. This would also facilitate the re-assessment of need, in light of the fact that a person's situation and needs evolve and change. ARC is aware of one HSCT piloting the Health Equalities Framework (HEF) tool. This tool measures the extent to which services minimise peoples' exposure to the known determinants of health inequality. The HEF tool can be used to establish a clear consensus around service priorities using indicators that focus on social, biological, behavioural, communication and service related factors. Data can be aggregated across services, professionals and teams to analyse variations in service outcomes.

#### v) Improving access to autism services for adults

**ARC NI welcomes the establishment of a multi-agency group and notes it should also include parent/carer and user involvement.** Representation needs to be diverse to ensure all aspects of life are included and feel the capturing of data as described above would also facilitate the planning of provision based on evidence of need.

vi) Improving access to mental health services

ARC NI welcomes the enhanced service in the Northern area but would **advocate the need for regional access to this across Emergency Departments**, if this is proven as successful intervention. Furthermore where an individual with a learning disability accesses the service **ARC NI would advocate the dual role and expertise required to include 'Learning Disability' Nurses.**

vii) Delivering Better Outcomes / Improving outcomes for Service Users & Carers

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.**



## TILII ADVOCACY GROUP RESPONSE TO THE EQUALITY 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. 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. TILII felt being treated equally and fairly was really important



### i) Accessibility of communications and information/ Communicating better

TILII said it is really important that all information is in an easier format and suggested easy read, DVD's, audio CD's as examples, so that people can listen and see a real person explaining the information if they need to. TILII also felt information both in hard copy and on websites should be in 'pure plain English'.



### 2) Making complaints accessible

TILII members liked the idea that it was going to be made easier for people to complain if they have a problem with their care and have already seen evidence of this (they have been asked to give feedback on a document provided by the Belfast Health and Social Care Trust called "Tell us what you think of our services" which is an easy read document on how to complain if you are not happy with the service you are getting). They also suggested a helpline or a way of being able to complain to someone face to face as some people find it easier to tell someone if they are having a problem with their care.





### 3) Improving access to autism services for adults

TILII members felt this was a great idea because a lot of people who have a learning disability have a diagnosis of autism, including quite a lot in the TILII groups. They felt that people recognised disabilities they could see but autism was a more invisible disability so people did not understand. They said it was really important to make sure that service users with autism and their carers were involved in this to make sure the support being developed was based on the needs of people with autism.

### 4) Delivering Better Outcomes

TILII members said "it would be dead on, if they were offered more choice and a better life".



However, this raised an immediate problem because only three people over the five groups had heard of Self-Directed Support and only one of those had any idea what SDS actually was. TILII feels this needs to be addressed to raise awareness among people with a disability of what SDS actually is, how it works and how it could improve the quality of their life.

### 5) Improving Patients, Service Users & Carers Experiences

TILII members thought it was a really good idea to develop a data base which will include a way to find out information on service users and carers. This should make sure that accessibility issues or communication requirements are identified and would allow them to be provided straight away, making it much easier for them and their carers. TILII felt it would be less stressful for people if physical or communication barriers were identified and supported at the start.



for reading our response