

RE: Submission to Health and Social Care Board on Transforming Your Care Proposals

15 January 2013

1. Origin and Ethos of the Forum

The Northwest Forum **OF** People with Disabilities is an independent human and civil rights organisation 100% managed by People with Disabilities. Founded and established in 1995, we are dedicated to ensuring the voice of our membership and disabled people more generally is represented in the public and social arena in all matters which impact on the lives. We are a pan-disability rights based organisation representing people with sensory, physical, hidden, learning disabilities as well as people with mental health issues.

Disabled people are first and foremost human beings entitled to fundamental human rights regardless of gender, creed, political opinion, sexuality, age, social background or economic status. We do not have 'special needs' or seek any 'special' consideration beyond recognition of the fact that we are entitled to be treated as human beings – citizens; equal to all others within society in all matters of governance, self determination, including the right to live independently within the community and enjoy a good quality of life.

We recognise the opportunity for economic, social and cultural interaction to contribute to the community and society on an

equal par with others requires society to address the historical violation of our human and civil rights, by removing attitudinal discrimination and providing full access to all information, goods and services without recourse to the justification of ‘limited existing resources’ or continued prejudice to maintain the status quo.

Our mission is to work to bring about social change through working in partnership with our allies in the community and voluntary sector and statutory agencies to bring about recognition of and advance our human rights as citizens within Northern Irish society and beyond.

Our vision is of a society in which equality and diversity are respected, valued and embraced, that is free from, discrimination and social exclusion, and where human rights are guaranteed and fulfilled, where we are not viewed as objects of ‘charity’ and ‘pity’ but as people fully included in all aspects of life, to the community and society in which we fully contribute to its development.

2. Introduction – Opening Commentary

The Forum welcomes the initiative to reform the way in which health and social care is provided to the general population in Northern Ireland. We believe this presents a great opportunity to ensure that we build a health system, which has human rights and equality at its core, in particular the need to ensure that those most effected by these proposals are included in the decision making processes in its future development, especially older/disabled people who have historically been excluded from decision making process in respect of health and social well

being as a result of the prevalence of the medical model interpretation of disability issues within the health service and wider society.

3.Participation in Decision Making

Provision of choice and decision making within the confines of personal health and social care, already well practiced and understood doctrine in such areas the Independent Living Fund and the operation of direct payments is welcome, but does not go far enough to ensure that we are properly represented in decision-making processes at all levels within the health and social services paradigm including at the highest level. At the 'macro' level of decision making disabled people and other traditionally marginalised groups are to a greater extent absent within health and social care structures that influence and shape the design, delivery and investment in services.

Along with older people despite being the primary users of health and social care services we are virtually ignored in any meaningful decision-making processes concerning our health and social care. Within the broad range of the proposals the equality screening template in the consultation paper acknowledges that no new public life opportunities have been created for disabled people with reference to the Department obligations under the 'disability duties'.

The human rights assessment of the proposals within the consultation paper does not take into account the department obligations under the UN Convention on the rights of Persons with Disabilities in particular article 4.3 and article 29 of the Convention, which requires the department to effectively

involve and engage us in decision-making processes beyond traditional consultation methodologies where our views can all too easily be ignored, or from a public relations standpoint taken account of, but not reflected in any final decisions or outcomes.

An independent evaluation of the public sector disability duties concluded that public authorities were not taking their obligations to encourage the participation of disabled people in public life seriously, we are of the view that this document is a clear endorsement of that particular finding and general conclusion and the Department must do more to address this. As the title of the consultation paper suggests this is an opportunity to transform our care not reinstate old and bad practices of excluding disabled people from decision-making processes which affect their daily lives. (Research on Evaluation of the Disability Duties 2009 is available on the Equality Commission for Northern Ireland website: www.equalityni.org)

4. Equality and Human Rights Context: equal access to the right to health

With respect to the range of equality and human rights issues highlighted in the consultation paper we have a number of issues we would like the Department to consider:

- Their consultation paper does not make clear to what extent there is positive and negative or adverse impacts arising from the proposals.
- No reference is made to the UN Convention on the rights of Persons with Disabilities, further consideration should be given to the assessment of the proposals against this

Convention specifically Articles 5, 6, 7, 9, 19, 25, 28, and 29.

- We seek an assurance from the department that the quality and human rights will be a central consideration in any final decision regarding these proposals as opposed to primary consideration of value for money as the overriding factor.
- Measures that have already been screened should be included in for ease of reference.

5. Monitoring and Accountability

In the screening document, it was pointed out that Board intends to meet with the Northern Ireland Human Rights Commission on an “on-going basis ... to discuss and better understand how we can monitor and assess human rights impacts of changes in health and social care provision as a result of TYC”. The Forum welcomes this approach and urges the Board not only meet with the NIHRC in relation to this as soon as possible, but also the Equality Commission for Northern Ireland with respect to review and enforcement powers concerning Section 75 and the public sector disability duties. We would take this opportunity to remind the Department that both Commissions form the Independent Mechanism with responsibility for monitoring the State’s implementation of the UN Convention on the Rights of persons with Disabilities, and the department should engage with both in any equality and human rights considerations in relation to any monitoring exercise which needs to be transparent and accountable to service users.

6. Specific issues and Concerns with the TYC Proposals Summarised

- Proposals need to take account of Bamford Review of Mental Health and Learning Disability Services and the historic under investment in this area. Transitional funding to Community settings from residential settings should not take away from investment in this area.
- TYC proposals offer an opportunity for health and social care services to be delivered in an age-appropriate way taking into account the forthcoming is age discrimination legislation. Children with disabilities often fall between two services disability and children services often receiving health and social care under the auspices of adult services rather than a more appropriate children context.
- Children and young people are often ignored when it comes to the delivery of the health and social care; the TYC proposals, must ensure that the views and sorts of children and young people are included in any final decisions relating to the TYC proposals and in the decision-making processes regarding the health and social care generally particularly disabled children who often even more isolated and excluded in that regard.
- The Forum is concerned that the public private partnership investment model in all proposed in the consultation will not deliver equitable outcomes, with a greater emphasis being placed on value for money rather than quality of outcome and equality considerations in the protection of key services and health and social care staff employment and working conditions.
- We welcome consideration being given to the social enterprise model such measures in the past have assisted grass root community projects such as the Shop-mobility and Door 2 Door accessible transport services here in the

north-west.

- Location of acute services and mental health service provision must take into account rural equality proofing and consider issues such as a balance of provision between east and west of the Province. Such an exercise should also consider the availability of transport provision and transport infrastructure, ensuring that the consultation paper lives up to its promise that people will be able to access local services as when they need them.

7. Conclusion

The Northwest Forum of people with disabilities hope that the Department will take its concerns and issues regarding the TYC proposals seriously and that they will be meaningfully reflected in any final decisions. In particular we would welcome a seat at the decision-making table regarding the future implementation of the TYC proposals following the conclusion of this consultation process in line with our ethos and aspiration as an organisation. We would welcome the opportunity to continue to work with and engage with the Department on matters concerning people with disabilities relating to the future of health and social care but that is a choice not entirely within our gift. If our views are fully reflected in the Departments thinking and consideration, that may change.