Downtown Women's Building
109-113 Royal Avenue
Belfast
BT1 1FF
T: 028 9023 6923
W: www.wsn.org.uk

A Response to: Transforming Your Care

This response is informed by feedback provided by meetings held with key staff members at Peninsula Healthy Living Centre, located on the Ards Peninsula, and by three focus group discussions organised by the WSN Outreach team, where women from disadvantaged areas deliberated on the proposed changes to the current health system in Northern Ireland. Topics specifically discussed were as follows: Integrated Care Partnerships; Technology; Carers; Maternity Services; Mental Health; Increasing Links with the Republic of Ireland and Great Britain. The first focus group was held in the Falls Women's Centre, where 8 women attended. The second was hosted in Greenway Women's Centre and was attended by 13 women. The final focus group was in The Women's Centre Derry and there were 9 women present. Furthermore, we have also liaised with organisations like Age NI and Carers NI in relation to aspects of this consultation document, thereby acknowledging their specific expertise in certain areas and gaining deeper insight into issues that might have detrimental effects on women from deprived areas.

Issued by: Department of Health, Social Sciences and Public Safety

January 2013

1. Introduction

1.1 The Women's Support Network (WSN) welcomes the opportunity to respond to this consultation.

1.2 The Women's Support Network (WSN), established in 1989, is a regional organisation which works across all areas of Northern Ireland. It includes in its membership community-based women's centres, groups and organisations with a concentration in disadvantaged areas. WSN is a charitable and feminist organisation, which adopts a community development approach. We provide a range of support and services to 63 community-based women's centres, projects and infrastructure groups, and 26 associate members drawn from across the community and voluntary sector, who support women, families and communities. (See appendix 1)

1.3 Our members provide a wide range of women-centred front-line services across Northern Ireland, including:

- Specialist Advice
- Childcare and Family Support
- Counselling, Support and Advocacy
- Complementary Therapies
- Training & Education
- Health & Wellbeing Programmes
- Personal Development & Employment Support
- Volunteering, Leadership & Empowerment

1.4 WSN aims to achieve social, political and economic justice through the promotion of the autonomous organisation of women. The Network aims to strengthen the collective voice of women's groups and to promote and develop networking opportunities, in order to enable collective action and to impact upon policy and decision-making processes. WSN provides an accessible, feminist, relevant and high quality support service and resource for its member groups. The Network is also an important information resource on issues relevant to community- based women's organisations and for other infrastructure groups, nationally and internationally.

1.5 Over the past 30+ years, the community-based women's sector has developed a range of front-line services such as childcare, support, advice, education and training in response to the needs they identified at a grass-roots level. Women's groups continue to meet the particular needs of women and their children living

in areas considered to be some of those most affected by the conflict, and recognised as among the most disadvantaged areas across Northern Ireland today.

1.6 Network members are actively engaged with their local communities, cross-community initiatives and regional structures throughout Northern Ireland.

2. Comments

2.1 The Women's Support Network (WSN) - as an organisation representing women's centres, projects and infrastructure groups drawn from across the Northern Irish community - welcomes the opportunity to respond to the Health and Social Care Board's consultation 'Transforming your Care: Vision to Action'. In so doing, the WSN strongly recommends that the DHSSPS properly consider the potentially pejorative outcomes of TYC, as the proposals therein, if realised, are likely to be responsible for one of the biggest transformations in the history of the Northern Irish health and social care system.

2.2 At the outset, we commend the Health and Social Care Board's commitment to ensuring that every decision taken, with regard to changes in the health system, will be done based on what is best for the patient or user. We acknowledge and appreciate the Minister's determination to provide 'quality of care for patients, clients and service users, improve outcomes and enhance the patient's experience so that people are treated in the right place, at the right time and by the right people'. That said, it must be noted that, although many people agreed with the overarching idea of 'home as the hub of care', numerous concerns were voiced about the quality, planning and delivery of community-based services. There was further dismay, expressed by our participants of the focus group, at the possibility that these proposals could be implemented despite the obvious long-term problem with infrastructure resource provision in Northern Ireland. Technology, road networks, public & community transport, building & planning and the ever-dwindling budget are all issues which could potentially impact on the TYC proposals, or vice versa. Essentially, in this response, the WSN seeks to highlight the substantial number of concerns voiced by our member groups, relating to the many different elements addressed in the consultation (Integrated Care Partnerships, technology, maternity services, increasing links with Ireland and GB, mental health and the role of carers) and asks that they will be given appropriate time and consideration so that the best decision for the population of Northern Ireland can be reached.

3. Specific Comments

3.1 Integrated Care Partnerships

3.1.1 The WSN applauds the proposal to increase the role of GPs in primary care. The consensus of the focus groups was that increased access to a varying number of services at local GP surgeries could be very positive, especially if individuals are living in remote areas or are hindered as a result of a disability and thus less able to travel long distances. Other potential advantages of ICPS were also identified: reduction in visits to hospital; shorter stays if admittance is deemed necessary; quicker access to diagnostic testing if it is removed from hospital setting and a more collaborative and comprehensive system put in place through the introduction of electronically shared information across healthcare professionals.

3.1.2 Despite these potentially positive outcomes being acknowledged by the focus group, there was a certain level of disquiet among the participants. There was a clear call for government to provide much greater clarity on the role of GPs in relation to the health trusts, other health and social care professionals, independent providers, primary care partnerships and the local commissioning groups. In attempting to provide for the most effective form of local commissioning, it is imperative that clear guidelines be issued in relation to how this structure should operate and that, consequently, control of provision is truly allocated to local level.

3.1.3 According to Armitage et al (2009), there is a limited number of recognised measurement tools to assess and properly critique the integration process and little research has been done with regard to the outcome of integration on society and its healthcare as a whole. Furthermore, the majority of the studies which have been conducted focus on perceived benefits or desired outcomes, similar to what the Transforming Your Care document is currently doing, rather than on confirmed and determinable outcomes. Moreover, studies which do report real benefits often yield conflicting results. The European PROCARE study (Billings & Leichsenring, 2005), for example, reported both positive and negative results in relations to ICPs. Among the results recorded were: reduced cost; improved financial performance; reduced admissions; but also difficulties retaining staff; reduction in quality; and increasing workloads.

3.1.4 In order to ensure an effective integrated care system, WSN, in keeping with the findings of Stuart & Weinrich, 2001) recommends that the HSCB give the following factors due regard: shared values; co-ordination of services; better communication across health and social organisations; sense of continuity and consistent rules and policies at organisational level.

3.1.5 It is clear from the evidence that, in many cases, integration is disjointed and often limited (Van Rakk et al, 2003). Interestingly, the PROCARE project stated that getting doctors involved was the main barrier and thus, this is an aspect that has to be given due regard and be addressed appropriately. Wistow and Hardy too acknowledged that professional barriers were the hardest to overcome (1991). The proposal suggests that ICPs would provide a collaborative network for local health and social care professionals working as part of a multi-disciplinary team to come together and work in a more integrated way. However, evidence also shows that the perceived lower status of social care staff compared to healthcare staff created significant barriers in developing integrated systems (Coxon, 2005). The human element involved in the development of ICPs and the complex nature of human relations cannot be underestimated or in anyway disregarded. Proper provision and instruction must be set out to ensure that no division is created between social care and healthcare staff.

3.1.6 There were also fears expressed by many of our membership in relation to the integration of information and the likelihood that it could cause very real difficulties, because of the existence of separate and incompatible IT systems, as well as a hesitation in sharing data with other organisations. Other potential obstacles that need to be addressed are problems, or perceived problems, with regard to data accuracy or timeliness and problems arising when attempting to aggregate different versions of the same data (Woodward et al, 2007). The best approach is to consider whether or not new legislation is needed to better dictate the sharing of information and avoid delays and technical problems.

3.1.7 A perceived problem which arose repeatedly in the focus groups' discussions relates to training. Howarth, Holland & Grant (2006) suggest that staff face a number of challenges when adapting to new roles as they begin to deliver an integrated service. There is, inevitably, a certain level of uncertainty about a staff member's new role in an integrated team set-up and very little understanding about other roles involved; this ultimately means there is a difficulty in deciphering different job roles

and deciding who is responsible for that particular role. Thus, staff training has to be a fundamental part of the set-up of ICPs.

3.1.8 Essentially, the Executive must clearly state that standards of care will not be compromised if Integrated Care Partnerships are established. It was clear, from the points raised at the focus groups, that people want reassurance that they will have the same access and level of care as formerly, if ICPS are to be introduced in the future.

3.2 Technology

3.2.1 Access to services was a central theme of all focus groups. The varying and multifaceted Patient and Client Council reports, too, suggest that access is an important issue for most people (June, 2012). There was a clear consensus at the focus group discussions, that the same standard of service is not available to everyone because of issues of transport and location of hospitals. From this standpoint, tele-monitoring could be a very positive development, especially for those located in more rural and less accessible areas. Similarly, virtual ward rounds may mean that more patients across a wider geographical area can be assessed quickly and efficiently by a specialist, resulting in a reduction in waiting-lists and referral time.

3.2.2 However, the introduction of tele-medicine or at least some form of tele-monitoring, will, for many people, be quite a frightening prospect. This particularly applies to the older generation, the disabled and those not so *au fait* with the workings of modern technology. In fact the reality of this digital divide was clearly acknowledged in the Government's consultation document 'Bridging the Digital Divide in Northern Ireland (2002) where it was stated specific groupings within society felt particularly disconnected from the 'information society'. This included 91% of those aged 65 and over, 70% of people with disabilities and 64% of those in the lower socio-economic groups. The consultation document makes a number of references to the important role which tele-monitoring will play in the health system. It states that a person may have new technology in the home to monitor and test his/her condition, thereby enabling clinicians to receive information about the illness on a real-time or regular basis. However, WSN suggests that there has been insufficient information provided concerning this new approach of using technology at home and in the hospital. More detail is required in several areas:

- The laws, rules and ethics and how they should be applied before tele-monitoring can be used regularly in various capacities;

- How services and the relevant professionals will be remunerated as tele-monitoring becomes a more regular practice;
- The extent to which organisational and bureaucratic difficulties impede the process;
- How to monitor the quality of health information and support being provided;
- Who will be held responsible should incorrect information be transferred or there be insufficient monitoring of patients.

3.2.3 Though the focus group acknowledged that the notion of tele-monitoring could be very positive in that, if functioning properly, it might enable quicker checking and earlier intervention for people living with a long-term illness, there was also real concern about the idea of 'self-management' of conditions. The difficulty for an individual with more than one condition gave rise to anxiety – as in the case, for example, of someone with rheumatoid arthritis and diabetes, who might find it difficult to administer insulin injections. This could mean that the responsibility would fall to the carers, creating an additional burden.

3.2.4 The WSN is also concerned about the issue of finance and resources. Tele-monitoring requires the installation and use of expensive equipment. Furthermore, the availability of a person to take responsibility for co-ordination of tele-medicine applications and their continuous assessment is essential. To ensure that a coherent administrative and technical perspective would emerge, it would also be necessary to employ an individual with sufficient status to liaise between the many people involved. Further clarification is needed, especially in the midst of a continuing recession and an increasingly rigid budget, in terms of how it is intended to finance resources and provide reassurance that the level of service, as a result of the tightening of government purse strings, would not be in any way compromised. Furthermore, some participants pointed out that a lot of money had already been spent within the NHS, on technology that neither fulfilled its function (e.g. national patient database) nor had the people with the necessary skills required to operate it successfully. Thus, any financing of future technology would need to be monitored and evaluated to ensure its efficacy, need and success. It is clear that if the proposals outlined in TYC are to be realised, additional money will have to be invested, in order to acquire the technological equipment and provide the training necessary to put it to efficient use. Thus, the anticipated but unconfirmed benefits and outcomes would have to justify this outlay. The WSN suggests that a larger pilot study may be beneficial.

3.2.5 Health Care Professionals, whose active involvement in tele-medicine services will be important in order to generate enthusiasm and support and ultimately to ensure the success of such a system, will first need to be convinced about its usefulness and feasibility.

3.2.6 As an organisation dedicated to lobbying on behalf of socially and economically disadvantaged women across Northern Ireland, the WSN is anxious that women, both young and old, get the level of health-care which they require. Thus, the possibility that the use of new technology - like tele-monitoring - may undermine the traditional doctor-patient relationship is a very real worry, given that the medical interview between patient and doctor is the major medium of health care. According to Lazare et Al, there are specifically three functions of the interview: gathering information; developing and maintaining a therapeutic relationship and communicating information. These three functions inextricably interact: a patient who does not trust or like the doctor will not disclose complete information effectively (Gould & Lipkin, 1999). A patient who is anxious will not comprehend information clearly as he/she is unable to take in everything at once. The truth is that, quite simply, tele-monitoring takes the personal element out of medicine. This is something which could have a very negative impact on patients, especially the old or vulnerable, who experience an increased reliance on the physician's competence, skills, empathy and good-will. The WSN would stress that health-care administrators, whose aim is to nurse the sick, should not understate the need for competence, compassion, and individualisation of care. This was something clearly emphasised by the focus group. In fact, a doctor-patient relationship that is founded on respect, compassion, trust and care can actually promote the healing process (Hopkins, J, 2003). Clearly, the HSCB need to carefully evaluate the outcomes most likely to occur from the introduction of technology, namely, the undermining of the traditional patient-doctor relationship and the destruction of the important elements of trust and faith in the health system.

3.2.7 Thus, in light of all of these possible implications, WSN suggests the need for future studies focused on building evidence related to the clinical effects of tele-monitoring: its cost effectiveness, its impacts on services utilization and its acceptance by health-care providers, as well as the level of potential damage to the patient doctor-relationship which might result from its introduction across the North.

3.3 Carers

3.3.1 Carers play a very important role in today's society and they need to be given the appropriate recognition and support. Accordingly, as a starting point, the WSN considers it a positive outcome to have them acknowledged and their work appreciated in TYC. Currently, there are approximately 207,373 carers in the North of Ireland. It is estimated that 64% of carers are women compared to 39% men. The level of care and help which carers provide is hard to quantify, but it is known that carers save the Northern Irish economy over £4.4 billion a year. It is true that the vital role of Northern Ireland carers has to some extent been recognized: @People First: Community Care for Northern Ireland in the 1990s (DHSS,1990); Valuing Carers in which The Carers' Strategy for NI was also proposed - Proposals or a Strategy for Carers in NI (DHSSPS, 2002b); Caring for Carers: Recognising, Valuing and Supporting the Caring Role (DHSSPS), which recognizes that carers have a right to a life outside of caring - the Strategy itself was launched in 2006. It is true that these have been steps forward, but despite these policy developments and the promises in this consultation of better respite and more support for carers, the reality is that people providing high levels of care are twice as likely to be permanently sick or disabled than the average person. In fact, sometimes, the pressure of caring for someone who has a chronic illness or is elderly, can lead to stress and a condition called 'carer burnout'. The WSN is understandably concerned that the TYC desire to shift caring responsibilities to the home will place an additional and unacceptable burden onto carers.

3.3.2 Central to discussion was the need for precise information. The focus groups called for more clarity in terms of how respite care and care breaks would be provided, more information and support when it comes to assessment and more detail regarding how respite breaks would be financed. The WSN both emphasizes this very real concern on the behalf of the focus group and fully endorses the difficulties that Carers NI have already voiced. According to the survey produced by the department of Health, Social Services and Public safety (survey of carers of older people in Northern Ireland, 2006) only 43% of the respondents knew that they could have a separate assessment of their needs as a carer and only 39% had been offered such an assessment. The WSN calls on the government to provide more concrete detail in this area: how they propose to provide these services for carers and how they will make them more accessible, thus ensuring that carers will be more inclined to take advantage of a much-needed break. It is necessary to produce solid information, a clear action plan and concrete detail as to how it is to be successfully financed to cover all those involved in providing care.

3.3.3 Another knock-on effect implicit in TYC's implementation is the potential problem of inevitable time off work required to care for a family member. In the current recession and given the high level of unemployment, getting time off work to deal with personal problems becomes increasingly difficult. Thus, if caring for a sick or disabled child, husband or parent becomes necessary, this creates a serious issue for women in employment. This time-burden on women, as primary care-givers, means that faced with the predicament of having to provide care, women potentially jeopardise their involvement in the formal employment sector. WSN is also concerned that the stress attached to the worry of losing a job puts a woman's mental health at risk. New statistics confirm that mental illness and depression in women are mostly commonly triggered by stress and anxiety, fuelled by a broad range of pressures normally relating to family and the struggle to look after young children[1]. The anxiety arising from job loss and potential financial difficulty is made worse by the by the stress and upset caused by the inevitable emotion felt when caring for a family member. Research by Prigerson and other experts shows that caregivers caring for family, experience increased risk of major depressive disorder, anxiety, reduced quality of life and chronic stress which can lead to other health problems. The government must take real cognisance of the many risks to the health and well-being of the carer, and make a commitment to support carers and improve their lifestyle by providing easily accessible and quality respite breaks. Lucas Love Healthcare is the first nursing agency in Northern Ireland, which guarantees care assistants the £7.20 an hour rate, plus paid holidays, lifting the worker's salary to £1.01 per hour over the minimum wage. Lucas Love recognises the vital role carers play in improving vulnerable and sick people's lives. Though many people take on the role of caring very much in an informal and therefore unpaid capacity, the government must consider the need for the introduction of a 'living wage' for family members who, by taking on the role of caring for family members or loved ones informally, are forced to give up work or unable to seek work outside the home, if major areas of stress are not to be allowed to develop.

3.3.4 Hugely important too, and something which was voiced repeatedly at the focus group discussion, is the need for carers to be equipped with more skills and resources to be better able to handle the situation in which they find themselves.

[1] Belfast charity New Life Counselling. The charity, which offers free counselling across Northern Ireland, experienced a 23% rise in the number of women accessing their service from 2010 to 2011.

3.4 Maternity

3.4.1 The consultation proposes the development of a midwifery-led unit at the Mater, Downe and Lagan Valley hospitals. Though the WSN agrees, in principle, that there is a need to expand the role of midwives and wishes to reiterate the concern felt at the current lack of midwives, as highlighted in our response to the recent consultation on maternity services in Northern Ireland, we are dismayed at the absence of essential information detailing how the funding for antenatal care will be structured to encourage and ultimately ensure the growth of the midwifery sector. Clearer insight of a more concrete nature vis-à-vis the financial implications of such a proposal is vital: broadening the resources of midwives and extending midwifery education and training, which is implicit in such a proposal, will require considerable investment.

3.4.2 We would like to emphasis the anxiety felt by many of our membership at the suggestion that there would be no consultant-led obstetric unit on site at the aforementioned hospitals. With the introduction of more midwifery units must come a commitment from the government, that any women treated in such a unit will have access to appropriate equipment and scans and that there exists a clear action plan for any referrals to a consultant which are deemed necessary.

3.4.3 It is important to recognise that pregnancy complications can range from routine problems to serious, even potentially fatal conditions. There exists a multifarious number of possible complications:

- Bleeding;
- Chronic vomiting;
- Depression;
- Ectopic pregnancy ;
- Miscarriage;
- Placental abruption;
- Placenta previa;
- Pre-eclampsia;
- Pregnancy-induced hypertension;
- Preterm labour.

This list is far from exhaustive but indicates the wide range of potential dangers that can arise and can threaten the health of a woman during pregnancy. Thus, women with more complex obstetric conditions need to have reassurance that there will be proper care provided by an easily accessible consultant-led obstetric unit on site, and that no problems will arise in relation to speed or efficacy of necessary medical

intervention. In fact, approximately 15% of all pregnant women develop a potentially life-threatening complication that calls for skilled care and many will require a major obstetrical intervention to survive. It is clear that many of the procedures require specialised equipment and the expertise of specifically specially trained doctors. (The integrated management of pregnancy and childbirth (IMPAC): a guide for midwives and doctors, 2000 Reproductive Health and Research World Health Organisation). Therefore, though it is of paramount importance to augment the number of community midwives, it is just as crucial to also increase the number of consultants and contain the desire to reduce facilities to such a level as might endanger the lives of pregnant women in Northern Ireland.

3.4.4 The consultation makes reference to the importance of promoting ante-natal education and early parenting to encourage good parent/child relationships in the early years. Our focus groups were in strong agreement with this suggestion and WSN recommends that further investment in community services should help reduce the burden on hospitals with regard to parenting craft classes. A woman, once registered with a maternity hospital, is obliged to undertake a number of parent preparation classes. However, currently these classes are already oversubscribed and thus an alternative option needs to be considered. It would be appropriate and more financially sound to transfer some of these classes to the women's centres that already provide a high level of support to women in a broad range of areas. The location of many of these women's centres, in areas of deprivation and poverty, means that many women, even those most likely to be isolated and overlooked will be accommodated.

3.4.5 The potential of these women's centres to provide support and education in the community should not be overlooked. Many of these women's centres and community centres are accessed by the local people and bring added benefits and resources like adult education, childcare facilities, personal development courses and advice services.

3.4.6 One of the key proposals in the section on maternity is to 'reduce the length of time mothers stay in hospital, where appropriate'. The WSN seeks a clear explanation of what exactly is included under the phrase 'where appropriate' and suggests that theHSCB take into account factors that can influence the need to spend more time in the hospital:

- Having a baby for the first time
- Insufficient education on baby-care
- Giving birth during non-routine hospital hours
- Having a chronic condition or complicated birth

- Less or inadequate prenatal care
- Certain ethnicities

According to Berstein et al, mothers, paediatricians, and obstetricians must make decisions about post-partum discharge jointly, as perceptions about being ready often differ. Sensitivity toward specific maternal vulnerabilities and an emphasis on perinatal education to insure individualized discharge plans may increase readiness and determine optimal timing for discharge and follow-up care. Furthermore, though many of our participants in the focus group felt that pre- and post-natal care being predominately available in the community sector might be an outcome, all were unanimous in thinking that options surrounding birth and care should not be prescriptive. A new mother's preference, coupled with consideration being given to the 'safest and best health outcome', should inform the decision taken.

3.5 Increasing Links with Republic of Ireland & GB

3.5.1 Staff at the Healthy Living Centre did highlight one potential positive of increasing linkages to services on the island of Ireland and in the UK, namely, that it would probably increase the capacity for service provision and thus it would be envisaged that waiting times would be reduced for elective surgery, primary care services and investigations.

3.5.2 However, unanimous concern over the possibility that services might be unavailable or inaccessible locally, especially in emergency situations, was expressed by the participants of our focus groups. The WSN, while welcoming the reassurances that a high standard of healthcare will be ensured, irrespective of the chosen outcome, believes that there are many issues not sufficiently addressed in relation to the effects, which this decision to have increased links with GB or the Republic of Ireland, might have on women in Northern Ireland. If the South or GB is considered to be the most viable option for supplying healthcare in certain circumstances, because services have been removed from Northern Ireland, this is likely to cause many potential problems in relation to travel and expense. (Please see our response to the Consultation for the Future Commissioning of Paediatric Cardiac Surgery and Interventional Cardiology for the Population of Northern Ireland). In Western culture the role of providing care for children has traditionally been assigned almost exclusively to the mother (Hock & Schirtzinger, 1992). Thus, as women provide the majority of informal care to spouses,

parents, parents-in-law, children, friends and neighbours[2], the lack of clarity and necessary detail in parts of this consultation will negatively impact on women.

3.5.2 The WSN calls for clarity on the following issues:

- Whether a specific mode of transport has been recommended in terms of travel to the South and GB;
- Whether the HSC or the NHS will cover the costs of travel;
- Whether proper accommodation will be organised;
- Whether there will be suitable accommodation located in proximity to the hospital if travel is required;
- Whether these accommodation costs will be covered;
- Whether families from deprived areas, unable to afford the cost of eating out and paying additional costs associated with travel for treatment, will be negatively affected;
- Whether the financial burdens, which travelling outside the province for such medical treatment for their children, would put on single mothers and those women not in employment, have been taken into consideration.

3.5.3 More information is also needed, detailing specifically the approach to be taken if a sick child in need of treatment, has siblings who need to be catered for, should a parent or guardian need to travel with the unwell child for the necessary healthcare. A report by the Women's Centres Regional Partnership (WCRP) identified lack of appropriate childcare as the single biggest barrier to women's participation in education, training and work, as well as public and political life (Navaie- Waliser et al, 2002). The WSN suggests that a lack of appropriate childcare is also a potential barrier to allowing women to travel with their children for Cardiac surgery. The report made a number of recommendations, including the development of an integrated childcare strategy for Northern Ireland and increased provision of local, high quality, affordable and flexible childcare. The WSN also believes it is necessary to consider the need for appropriate childcare and support if a parent or guardian, who has more than one child, is required to travel with a sick child to receive the necessary treatment. Clearly, the need for some agreement vis-a-vis childcare is intensified in cases involving a lone parent and/or a family containing more than one child.

3.6 Mental Health

3.6.1 The WSN and its focus groups support Transforming Your Care's desire to promote awareness of mental health issues and reduce the well-established stigma associated with mental ill-health. However, a number of worries were highlighted by the focus group.

3.6.2 According to statistics, 1 in 4 people will experience some kind of mental health problem in the course of a year. What is interesting and very important when it comes to addressing the need for proper support for carers – already mentioned in this document - in the future health system of Northern Ireland, is the fact that mixed anxiety and depression are the most common mental disorders. Furthermore, women are twice as likely to experience anxiety as men. Of people with phobias or OCD, about 60% are female. Research conducted by the Princess Trust (2002) indicated that the physical and mental health of 41% of carers has been affected as a result of caring for someone with a mental illness. Among carers who look after mental health patients, depression, worry and sleeplessness are frequently reported as outcomes. This is a real cause for alarm and must be given due regard, since, as already seen, women are more likely to be carers than men and recent statistics suggest that mental health problems are on the rise for women in Northern Ireland. In attempting to de-stigmatise mental illness and provide more care for people who suffer from it, it is imperative that we do not create a situation that will actually encourage the likelihood of an augmentation of mental health problems because of the ever increasing burden put on carers.

3.6.3 Research also suggests there is a connection between the conflict in Northern Ireland and the risk of mental ill-health (O'Reilly & Stevenson, 2003). The greater the extent to which someone's area or life is affected by the conflict, the greater the likelihood that that person will have poorer mental health. A History of Falls Women's Centre (1982-2008) also noted that due to the political situation during the 'Troubles' women, for example, in West Belfast, were under tremendous pressure, with "many women having sole responsibility for their families as men were in gaol." The notion that women could again be taking on the primary caring role in a family, especially if a member of the family is suffering from a mental illness, suggests thus that mental illness in women is likely to increase. WSN would therefore urge the Health Board to acknowledge that the area of mental health among women in Northern Ireland is a very serious issue and that in light of the North being a special case, there must be a commitment made to ensure the establishment of long-term measures to alleviate those areas of distress most likely to give rise to increased levels of mental ill-health.

3.6.3 All three focus groups called more information and transparency as to what format exactly the 'joined-up approach' of health professionals will take and how this will be resourced. There is alarm at the prospect that the proposals will result in a shift in services, whereby areas currently being resourced may lose out.

3.6.4 There was agreement in all the focus groups that Women's Centres, and indeed other voluntary and community organisations, can be resourced to provide services in the community for mental health issues and should be factored into any future plans resulting from the proposals.

3.6.5 Currently, there is no proper provision for young people in relation to this area. There is a clear gap between paediatric care and adult care, but, in fact, 40% of young people (under 16) today are being treated in wards assigned to adults, something which our member groups feel to be inappropriate and undesirable. Recent figures indicate the increasing strain on mental health services in the Republic, where over 2,000 children and adolescents are on waiting lists for appointments. Moreover, they point to the reality that cuts can lead to very real vulnerabilities and that denying resources inevitably leads to late interventions. In light of these findings, it is important that the Executive and HSCB make sure that any decisions taken will be centred around people most in need of the services.

4. Conclusions

4.1 It is clear from the continuous feedback from our member groups and from the different focus group discussions which the WSN organised, that people recognise that the existing model of health and social care is no longer addressing the needs of society and cannot be maintained. It was noted that the individuals attending these discussions had no difficulty with the suggestion of change with regard to health in Northern Ireland, most feeling it was inevitable in the current climate.

4.2 The principles for change that underpin Transforming Your Care are largely *ad idem* with those of the general public. Both acknowledge the need to place the patient at the centre of any new model of care.

4.3 The main theme running through Transforming Your Care is that care, where possible, should be provided as close to home as is viable and that there should be a shift away from hospital resources to the community and that the home should be the hub of care. This suggestion, at the outset, was not negatively received as many present at the focus group discussions aired their desire to be more involved with the monitoring of their own care in a community setting. However, what was clearly highlighted by the three focus groups is that many people do not have confidence in community-based services. Many issues were raised concerning the quality of services provided in the community and the fear of inconsistent and badly organised delivery of the service. The establishment of ICPs would seek to address this concern. However, further worries about disjointed partnerships and problems with integrating technology need to be addressed and proper research commissioned into the likely outcomes on society if ICPs were to be introduced.

4.4 Proper resources and time must be made available to investigate and ensure that these proposals will not create new, worse, unforeseen outcomes for the people of Northern Ireland. Currently, as was clear from the focus groups, people prioritise access to quality hospital services, especially in cases they deem to be an emergency. Thus, the proposed reduction from ten to possibly five major acute hospitals will concern people across Northern Ireland. Furthermore, the majority of radiology imaging is currently performed in these acute hospitals and it is necessary to consider the future use of the equipment that exists in these hospitals. The objective of these proposed changes to the health system is to save money and make better use of resources. Thus, it would seem to be, at the very least, ill-advised to make useful and no doubt expensive equipment redundant in an attempt to cut budgets.

4.5 If the way forward for Northern Ireland is about structural change, then the Executive and the HSCB most also acknowledge the need for the NHS to undergo a culture change. Extensive research conducted by Age Concern NI demonstrated that many patients have experienced age discrimination in health and social care services. Thus, it is also clear that essential to the success of 'Transforming Your Care' is the continuous promotion of age-friendly health and care services. Currently, people of more advanced years account for 70% of bed-days in NHS hospitals and 60% of admissions. Therefore, it is imperative that hospital wards and services be age conscious. Ensuring that health and social care services are designed around older people's needs and people with disabilities, will, in fact, have positive outcomes for all services users. Bernard Isaacs, founding Director of the Birmingham Centre for Applied Gerontology, put it rather succinctly when he declared "design for the young and you exclude the old; design for the old and include the young." Essentially the WSN fully endorses Age Ni's vision of a 'quality integrated social care that recognises the rights, aspirations and diversity of us all, and is based on the right to live with dignity independence, security and choice.'

4.6 The WSN is also concerned with what appears to be a shift towards a totally privatised residential care sector. The proposal seeks to close at least 50% of statutory residential homes, but that does not necessarily mean a reduction in the number of private residential homes. That sector is currently well regulated from the point of view of standards in residential homes, but there is no financial regulation around the robustness of the businesses that are responsible for those homes. This potentially means that older people may find themselves unable to pay the high fees of a privately run residential home. 'Older people should be provided with a range of choices which both address their needs and are seen by them as desirable options for their future care' (Care at Home PCC 2012:62).

4.7 The WSN acknowledges the HSCB's efforts in producing a comprehensive consultation document, which seeks to summarise the key proposals for change to be considered in the context of Health and Social Care in Northern Ireland. The Network applauds the clear commitment to have safe, resilient, high quality and sustainable health and social care services for future generations, while, at the same time, harbouring real reservations as to how these aspirations are to be funded. Moreover, we have highlighted a number of fundamental concerns aired by the most vulnerable in society, concerns which, we feel, must have a central place in any proposed new system. We have made a few suggestions as to how the proposals might possibly be improved, which are surely worthy of consideration. We have asked a number of key

questions which must be answered. We are in no doubt as to the immensity of the task being proposed in TYC, as also of its far-reaching implications. It is for this reason that we continue to emphasise the need for consultation with all the groups involved, especially the most vulnerable, as well as the need for honesty, transparency and, most of all, good listening.

4.8 We would further like to emphasise that this consultation is not standalone or independent of other government decisions and in fact relates closely to many of the recently proposed and already agreed changes to Northern Irish society. In essence, this document has come at a time of huge transition in Northern Ireland. Thus, the Executive must be continuously aware of the need to improve and augment cross-departmental relations so that every document produced by the government for consultation, takes due cognisance of any other proposed decisions made by other departments, which will likely to impact on the consultation produced.

4.9 The WSN in order to feedback to its membership and answer any queries arising require information with regard to the process implemented by the HSCB after responses to consultation documents have been written and submitted in terms of what method is used to sort and best understand the views of the public.

Would you please provide information on the following:

When will your analysis of the responses submitted be complete;

What is the name and contact details of the person undertaking this work;

When will the responses be published;

5.0 We look forward to the feedback. In the meantime, if you have any queries please feel free to get in touch.

Bibliography

Armitage, G.D Suter, E, Oelke, N.D Adair, C.E (2009) Health Systems Integration: State Of The Evidence', *International Journal of Integrated Care*, 9 (Apr-Jun) .

Bernstein HH, Spino C, Finch S, (2007) *'Decision-Making For Postpartum Discharge Of 4300 Mothers And Their Healthy Infants: The Life Around Newborn Discharge study', Paediatrics* 2007 Aug; 120(2) :391-400.

Billings, J. And Leichsenring, K (eds) (2005) *Integrating Health and Social Care Services For Older Persons : Evidence From Nine European Countries*, Ashgate, Aldershot.

Coxon, K. Clausen, T. Argoud, D (2005) 'Inter-Professional Working And Integrated Care Organisations' in Billings, J. And Leichsenring, K. (eds) (2005) *Integrating Health And Social Care Services For Older Persons: Evidence From Nine European Countries*, Aashgate Aldershot.

Gould, S. D & Lipkin N, (1999) 'Doctor-Patient Relationship: Challenges, Opportunities And Strategies', *J Gen Intern Med.* 1999 January; 14(S1): S26–S33.

Hock, E. & Schirtzinger, M. B. (1992). Maternal Separation Anxiety: Its Developmental Course And Relation To Maternal Mental Health, *Child Development*, 63, 93-102.

Hopkins, J, (2003) 'Defining The Patient-Physician Relationship For The 21st Century', *3rd Annual Disease Management Outcomes Summit.*

Howarth, M, Holland, K, & Grant M.J (2006) 'Education Needs For Integrated Care: A Literature Review' , *Journal of Advanced Nursing*, 56 (2), 144-156.

Lazare A, Putnam SM, Lipkin M, Jr. 'Three Functions Of The Interview' In *The Medical Interview: Clinical Care, Education, and Research.* Lipkin M Jr., Putnam SM, Lazare A, editors. New York, NY: Springer-Verlag; 1995. pp. 3–19

Navaie-Waliser, M. Feldman, P. H. Gould, D. A., Levine, C. L. Kuerbis A. N. & Donelan, K. (2002) 'When The Caregiver Needs Care: The Plight Of Vulnerable Caregivers', *American Journal of Public Health*, *92*(3),409–413.

O'Reilly, D & Stevenson, M, (2003) 'Mental Health In Northern Ireland: Have 'The Troubles' Made It Worse?', *Journal of Epidemiology and Community Health* Vol. 57, pp. 488-492.

Patient and Client Report: *Care at Home* June 2012.

Patient and Client Report: *The People's Priorities* November 2010.

Stuart, M & Weinrich, M. (2001) 'Home and Community-Based Long-Term Care: Lessons from Denmark', *The Gerontologist*, 41(4), 474-480.

Van Raak, A. Mur-Veeman, I, Hardy, B, Steenbergen, M & Paulus A (eds) (2003) *Integrated Care In Europe: Description And Comparison Of Integrated Care In Six EU Countries*, Elsevier Gezondheidszorg, Maarssenm, NL.

Wistow, G & Hardy, B (1991) 'Joint Management In Community Care', *Journal of Management in Medicine*, (594), 40-48.

Woodward, F et al. (2007) *How To Achieve Effective Clinical Engagement And Leadership When Working Across Organisational Boundaries: Practical Recommendations*. London : Modernisation Initiative.

Woman's Centres Regional Partnership, 2009 'Women Living In Disadvantaged Communities: Barriers To Participation'.

World Health Organisation (2000) 'The Integrated Management Of Pregnancy And Child-Birth (IMPAC): A Guide For Midwives And Doctors', *Reproductive Health and Research*.

For further information, contact:

Rioghnach Murphy - Policy and Research Co-ordinator

Tel: 028 90236923

Email: policy@wsn.org.uk

Appendix 1

MEMBERSHIP 2012

	Member Group
1	All Ireland Mothers' Union
2	An Munia Tober (Travellers)
3	Antrim & Ballymena Women's Aid
4	Ardmonagh Women's Group
5	Ardoyne Women's Group
6	ATLAS Women's Centre
7	Al Nisa Women's Group
8	Ballybeen Women's Centre
9	Ballymurphy Women's Group
10	Belfast & Lisburn Women's Aid
11	Belvoir Women's Improvement Group
12	Carrickfergus Women's Forum
13	Carew II
14	Causeway Women's Aid
15	Chrysalis Women's Centre
16	Clan Mor Women's Group (Sure Start)
17	Derry Well Woman
18	Derry Women's Centre
19	Falls Women's Centre
20	First Steps Women's Group
21	Footprints Women's Centre
22	Foyle Women's Aid
23	Foyle Women's Information Network
24	Granaghant District Women's Group
25	Greenway Women's Centre
26	Kilcooley Women's Centre
27	Lesbian Advocacy Services Initiative
28	Lesbian Line
29	Lenadoon Women's Group
30	Ligoniel Family Centre
31	Link Women's Group
32	Manor Women's Group
33	Markets Women's Group
34	NI Women's Aid Federation
35	NI Women's European Platform
36	Fermanagh Women's Network
37	Newry & Mourne Women
38	Newtownabbey Women's Group
39	Older Women's Network NI
40	Omagh Women's Aid
41	Rape Crisis Centre
42	Rasharkin Women's Group
43	Shankill Women's Centre
44	Strabane & Lifford Women's Centre
45	Strathfoyle Women's Centre

46	The Learning Lodge
47	Voices Women's Group
48	Waterside Women's Centre
49	Windsor Women's Centre
50	Women Connect Project
51	Women into Politics
52	Women's Information Group
53	Women's News
54	Women's TEC
55	Women 2 Gather
56	Women's Resource & Development Agency
57	WISPA (Women in Sport & Physical Activity)
58	Ardcarn Women's Group
59	OIYIN Women's Group
60	Mossley Women's Institute
61	Mount Vernon Women's Group
62	Coole New Opportunities
63	North Belfast Women's Initiative & Support Project
	Associate Members
1.	Ballymena Community Forum
2.	CINI
3.	Community Relations Forum
4.	East Belfast Community Partnership
5.	Employers for Childcare
6.	HIV Centre (Women's Support Group)
7.	Mencap
8.	National Women's Council of Ireland
9.	Playboard
10.	RNIB (Women's Group)
11.	Good Morning Newtownabbey
12.	Monkstown Community Association
13.	WAVE Trauma Centre
14.	WEA
15.	Parents Advice Centre
16.	Templemore Community Action Group
17.	Gingerbread
18.	Larne Community Development Project
19.	Community First Coaching
20.	Changing Faces
21.	Sands NI
22.	Women's Project Ashton Centre
23.	Women on Track
24.	Matt Talbot Women's Group
25.	Ulster People's College
26.	Council for the Homeless NI