

## A Response to: Who Cares: The Future of Adult Care and Support in Northern Ireland

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

March 2013

## 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 that 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, 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, and education & training services 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 most affected by the conflict, and recognised as some of 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 Department of Health, Social Services and Public Safety's consultation 'Who Cares: The Future of Adult Care and Support in Northern Ireland'. In so doing, the WSN strongly recommends that the DHSSPS properly consider the potentially pejorative outcomes of Who Cares, as any proposal to change the current health system, if realised, is likely to greatly impact on Northern Irish society. Thus, it is vital that 'Who Cares' be given the proper consideration in the event of any proposal that the provision of social care be substantially overhauled, as it is important not to miss an opportunity to develop a broader preventative agenda for older people that is underpinned by the principles of dignity and equality.

2.2. At the outset, we commend the Health and Social Care Board's commitment to ensuring that core principles like dignity, respect, quality, equity, equality human rights and diversity will underpin our future system and form the basis of what the population of Northern Ireland has a right to expect from care and support at all stages of our adult life. We acknowledge and appreciate the Minister's determination to ensure that care and support be personalised to individual need and that the right support will be provided at the right time in the right location with a focus on early intervention to protect dignity and independence.

2.3 We are glad to see proper recognition given to the important work done by the voluntary sector in offering non-profit making services which promote community participation and mutual support. In fact, the work done by the Women's Centres in this regard should not be underestimated. Many preventative and complimentary services are provided by the voluntary and community sector organisations, whose funding is often precarious and unsustainable. Thus, any decrease in funding to voluntary organisations, that provide these services, will likely lead to the removal of very valuable support services, designed for older people, who as yet may not be eligible for publicly funded home care services, which are normally solely offered to those with critical or substantial needs.

2.4 The WSN and its membership appreciate the need to update and review the current health system in light of the ever changing nature of law and society. We fully recognise that Northern Ireland has an ageing population. Furthermore, it is clear that today people live longer and thus, the ratio of older people to younger people is continuing to increase at a fast rate. However, the WSN, would like to point out that any decision made to change the healthcare system with regard to adult care has the potential to negatively impact on older women as they live longer than men and as your document highlights, by 2025, the number of people aged 85 and over will increase by 25,000 (83%), of whom 62% will be women. Therefore, it is crucial

that any proposal made, be carefully considered, to ensure that the level of care for older people, especially women, will not be compromised or reduced.

2.5 One of the key aspects of this discussion document is the need to incorporate and encourage preventative measures. We greatly welcome this emphasis on prevention rather than cure, and we call for the Department to provide proper strategic policy direction in this area. We believe that without this very necessary direction, prevention will remain limited and largely theoretical.

2.6 The WSN is delighted with the promise to work across Government and sectors and welcomes the Department's acknowledgement of the fact that care and support is a 'collective responsibility across government' and that a more joined up approach is appropriate in identifying and planning better support . For many years, the WSN has repeatedly called for a more systematic, integrated approach to cross-departmental working. We have continuously stressed the fact that integrated working at government level enables an alignment of goals, maximisation of resources and more efficient delivery of services.

2.7 The WSN is happy with the commitment in the *Programme for Government, 2011-2015* to extend age discrimination legislation vis-a-vis the provision of goods, facilities and services. In line with UK legislation, we recommend that this also covers health and social care and forbids age discrimination by public bodies when exercising public functions. The introduction of age discrimination legislation in health and social care would mean that a service provider or practitioner (such as a health and social care trust or an individual practitioner) will have to justify aged-based decisions.

2.8 The WSN is dismayed and concerned at the apparent divorce of the review of adult social care from the Compton Review (*Transforming Your*

Care). It is of fundamental importance to recognise that any decision as to how services will be delivered in the future under *Transforming Your Care* will be intrinsically linked to any review of the future of adult social care. We were also disappointed that the document lacked insight into the Department's thoughts on how to fund adult social care, especially in light of the Dilnot Commission's report.

### **3. Specific Comments**

#### **3.1 Direct Payment**

3.1.1 The WSN welcomes the suggestion that people who need care and support should have control over how their assessed care and support needs should be catered for. Individuals, more often than not, are best placed to know the types of support that are most appropriate for their specific demands. We agree that there is a real need to mould and design the services to meet an individual's need, preferences and wishes, rather than assuming that everyone will fit into a pre-determined standard service. Consultation with the public and key stakeholders will enable a process of working together to choose an appropriate care plan, which will ensure the best outcomes for everyone concerned.

3.1.2 Though the WSN is delighted at the prospect of every individual having more say vis-a-vis support and care and fully understand that Direct Payments are proposed as one of the means of ensuring people have control over their care and support needs, we would like to highlight the fact that our membership is concerned that a current lack of proper information at a very basic level, indicates the existence of barriers to meaningful control by individuals. For example, a majority of carers, mainly, female, still do not comprehend that they are entitled to see a copy of their patient/loved one's care plan. Furthermore, there is the problem of cost inflation. Market

systems can be financially inhibitive to run and coupled with administrative costs can be very expensive. A major outcome of Direct Payments will be a reduction in budgets putting existing services at risk; this will likely result in reductions in capacity.

3.1.3 Another potential difficulty with using a system of Direct Payments is that social services departments could lose their skills, experience and economies of scale, leaving fewer, more expensive services for those too vulnerable, like older women living on their own, to cope with the responsibility of Direct Payments. The adoption of such a system will also have the potential to encourage the emergence of an unskilled, unregulated workforce of Personal Assistants directly employed by patients.

3.1.4 In principle, Direct Payments are a step in the right direction. However, there are practical obstacles; the WSN is delighted that this document recognises the reality that for a substantial part of the population, Direct Payments can be daunting. For many people, there has been ongoing difficulty in relation to getting the Health and Social Care Trust to agree to Direct Payments. There is also potential for possible impediments in relation to the actual management of Direct Payments and in relation to finding appropriate care and support in the first instance. We commend the fact that piloting is underway across Northern Ireland on the wider concept of Self-Directed Support.

3.1.5 The WSN strongly urges that the HSC construct a simple and transparent means of obtaining Direct Payments while ensuring that services provided by the social services department are not undermined or reduced and continue, through the system of piloting, to support people to identify services to meet need and manage the budget.

## 3.2 Areas of Reform

Although many people agree, as highlighted by the responses to Transforming your Care and the Patient Client Council Report, with the overarching idea of 'home as the hub of care', and the role of the community in healthcare, numerous concerns have been voiced about the quality, planning and delivery of community-based services. We are dismayed at the prospect that proposals will be made to change the current healthcare system with regard to adult care, 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 Who Cares proposals, or vice versa.

### *3.2.1 Transport*

The WSN is glad that this document recognises the reality that transport services are vital in promoting accessibility and reducing isolation and thus subsequent hardship and we are relieved that the Department consider this a necessary area for reform. Women, living in rural areas, face the reality that public transport is inaccessible and unaffordable. Too often, transport is offered at peak times but services outside these times, ones most likely to facilitate the unemployed, women working in the home and the older population, are non-existent. Quite often too, bus journeys, especially in rural areas, take longer than the same distance in a car.

### *3.2.2 Support For Carers*

As previously highlighted in our response to 'Transforming your Care', carers play a very important role in today's society and they need to be given the appropriate recognition and support and thus, the WSN agrees that this is also an area in need of reform. As starting point, the WSN considers it a positive outcome to have them acknowledged in this consultation. 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 these have been steps forward, but despite some policy developments and the recognition in this document of the necessity of ensuring that

the needs of the carers are properly understood and that service providers respond with flexibility, offering carers real and appropriate choice as to how their needs are met, 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, as was hitherto mentioned in TYC, that the desire to shift caring responsibilities to the home will place an additional and unacceptable burden onto carers.

This is certainly an area in need of reform and our membership would like clarification with regard to how respite care and care breaks will be provided, more information with regard to assessment and more detail regarding how respite breaks will be financed. 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.

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. There is also a very real need for carers to be equipped with more skills and resources to be better able to handle the situation in which they find themselves.

We would also say that the consultation makes an assumption that families are willing and able to take on the caring role, which is not always the case. Additionally, we believe that carers have the right to a life of their own outside of caring.

### **3.3. Part Four: Role of Government and Individual**

3.3.1 The WSN believes that a certain level of accountability, responsibility, self-care or personal control should be encouraged by the State. It is clear that new technology developments are allowing the public much greater access and an easier way to track health information and this is something that the Government should continuously emphasise. Currently, one in five mobile phones contain an accelerometer which means that it can be used as a pedometer. Nokia too are experimenting with adding biosensors which will be capable of measuring blood oxygen, glucose, heart and breathing rates. And there is a free 'drink tracker' app to monitor your alcohol intake available free on the NHS Choices website. Furthermore, the Public Health Agency have run and continue to roll out campaigns in attempt to make people aware of growing epidemics like obesity that increase heart disease, diabetes and will ultimately lead to death. However, the challenge for government is how to prevent those with busy lifestyles, special needs, disability or frailty from being disregarded or forgotten as this new age of technological health promotion dawns. It is important to remember the fact that 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. Thus, the WSN would argue that it is necessary for the government to make every attempt to support the older generation in accessing information and support.

3.3.2 The WSN would like to stress the fact that the Government needs to continue to contribute to the care and support system through funding support services determining which support services require a contribution

from people who use services and through very necessary benefits such as Attendance Allowance and Disability Living Allowance. Any decision to reform

support and care for older people in Northern Ireland can only be taken when due consideration has been given to the potentially crippling impact that the Welfare Reform Bill will have on society. The WSN is concerned about the removal for example of the Severe Disability Premium. It has been noted by the Department of Social Development that if a Severe Disability Premium were to be introduced under Universal Credit it would cost approximately £52.6m per annum. The Government has a duty to provide proper care and support to those most vulnerable and isolated in society.

3.3.3 The WSN understands that the Government's view is that the cost of residential and nursing home care is predicted upon the principle that those who can afford to pay the cost of their own should, and that those that can should pay a means-tested contribution. We would, however, remind the Government that the WSN represents women from deprived backgrounds who are unlikely to have the means necessary, because they are not in receipt of a pension or have no savings, to pay for residential care but who may, however, own the house they currently inhabit and thus, are in need of help from the Government. We would like to draw one specific phenomenon to the attention of the Executive: the asset rich but income poor. This is the term used for a situation where the home of an individual, who more often than not is old, is valuable, with little or no debt secured on it; but their income is so small that they are entitled to Pension Credit, for example. Furthermore, many of those who own a house but have a limited income or no income at all, desire to keep the house as opposed to selling, in order to provide for children or dependents. Dilnot, in his independent review of the funding of care and support, stated that housing wealth has a part to play in the funding of people's social care and that equity release can help people to access that wealth. Certainly, a convenient argument is to propose that older people should provide for themselves, through spend down of assets and insurance schemes. Therefore, despite huge increases in general standards of

living, many are forced or will be forced to sell their family homes and spend most of the proceeds in fees before they can receive state-funded residential

and social care. Thus, the WSN suggests that the Executive, when financially assessing an income to determine a person's ability to pay for care should exempt the owner-occupied home from the means test.

3.3.4 The WSN would argue that any cap and/or means test should be set at appropriate and fair levels, which will offer optimum protection to people on low and middle incomes while remaining affordable for the public purse. A high level cap would fail to provide people with an adequate level of protection from catastrophic costs. This would in turn risk undermining the wider impact of the system by reducing people's incentive to plan ahead and invest in preventative services.

3.3.5 Older people in general express a strong desire to remain in their present home (Tinker 1995). This allows suggestions, with regard to the possibility of mobilising old people's housing wealth through some form of equity release scheme, to be aired. Though the WSN does not agree with the principle of equity release, as a potential way of dealing with adult care, we would suggest that advice is absolutely crucial when it comes to utilising equity release correctly and having it there as a potential solution in the first place. For too long, many of those involved in providing any form of retirement planning advice have avoided the notion of equity release, and one might suggest that the relatively low take-up of equity release is in part due to a lack of engagement by some in the advice profession. The WSN would like to remind the Executive of the importance of independent advice services, like that offered at Falls Women's Centre who, provide women who seek advice, a sensitive safe and secure environment. The Centre offers a unique holistic advice provision service, which covers issues such as health, financial difficulties caring responsibilities, and educational needs.

## 4. Conclusion

4.1 While greater diversity in the care market is welcome, it is important that rigorous checks and balances are in place to ensure that all those involved in provision of care have the interests of the service users as a priority. Any reforms to the sector need to ensure that there is adequate protection for people in care, especially those from deprived backgrounds. Furthermore, with the continuing increases in the number of providers expected, as the population increases, it is imperative that there is proper oversight structures put in place to ensure the protection of service users.

4.2 It is important that the reform of social care for adults proposes changes that are both radical and realistic and that any options suggested will be capable of delivering the change that is needed. At the heart of the proposals should be a recognition of the need for a system that enhances wellbeing and independence, so that older people can continue to engage socially and maintain their self-esteem, dignity and purpose.

4.3 There is much confusion, currently, concerning the question as to why people pay National Insurance Contributions, which are quite substantial and span over a long period, maybe 30 years +, if aspects, like older age care, are not covered. The WSN would request that the Government make every effort to clarify the general confusion.

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## MEMBERSHIP 2012

|    | <u>Member Group</u>                  |
|----|--------------------------------------|
| 1  | All Ireland Mother's 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 | Ligoneil 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           |

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|-----|---|
| 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 Womens Initiative & Support Project |
|     | <u><a href="#">Associate Members</a></u>          |
| 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                       |