## What Does Positive Ageing Mean to Older People?

A summary of feedback from Older & Bolder's consultation meetings with older people









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## **Contents**

Acknowledgements	2
Introduction	3
Presentation of Feedback	7
Independence	8
Participation	12
Care	18
Self Fulfilment	25
Dignity	30
Concluding Remarks	33
Appendix One	34

## Acknowledgements

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We would like to thank Maureen Bassett who prepared a resource document summarising the contents of eight reports and distilling key themes to emerge from the consultation process. This summary of feedback from the consultation meetings is based on her report.

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## Introduction



## 1. Older & Bolder

Older & Bolder has been formed to champion the rights of older people in Ireland and to combat ageism. It is an alliance of seven non-governmental organisations in the age sector in Ireland. The members are:

- ⇒ Active Retirement Ireland
- ⇒ Age & Opportunity
- ⇒ Alzheimer Society of Ireland
- ⇒ Carers Association
- ⇒ Irish Hospice Foundation
- ⇒ Irish Senior Citizens Parliament
- ⇒ Senior Help Line

## 2. Consultation Meetings

Between November 2008 and June 2009, Older & Bolder conducted eight consultation meetings with older people. The meetings took place in Cork, Dublin, Limerick, Sligo, Tralee, Trim, Tullamore and Wexford and were attended by six hundred and sixty older people in all. They were organised with the assistance of member organisations of our alliance and of local individuals and groups who wanted older people to have an opportunity to come together, and to make their voices heard on issues of significance to them.

The approach to the conduct of the meetings evolved over time but the focus throughout was on facilitating participation, on eliciting older people's understandings of the concept of positive ageing and on enabling collective identification of key issues and priorities (See Appendix One for a sample programme for the meetings and sample notes for participants and facilitators).

### 3. Aims of The Meetings

The aims of the meetings were:

- ⇒ To introduce older people to Older & Bolder;
- ➡ To ensure that Older & Bolder's campaigns are directly informed by the needs and preferences of older people;
- To hear from older people what "positive ageing" means to them and what is needed to support positive ageing in Irish society;
- To inform older people about the National Positive Ageing Strategy (NPAS) and to encourage them to make their views known to the policy makers who are developing the strategy.

## 4. Positive Ageing

The development of the NPAS is a commitment in the June 2007 Programme for Government. In meeting with older people, Older & Bolder has explained the NPAS as:

"A long-term plan for making Ireland a better place in which to grow older. This blueprint will involve all levels of government from Ministers to city and county councils. It will cover policies, services and practices in areas such as health care, housing, transport, income, employment and independent living. The National Positive Ageing Strategy will also influence the activities of organisations in the private and voluntary sectors."

Older & Bolder has consistently taken the view that, if policy-makers are to develop an effective positive ageing strategy, they need to know:

- ⇒ What positive ageing means to older people; and
- What older people identify as the supports that enable positive ageing in society.

With this in mind, the alliance has campaigned for a meaningful consultation process with older people on the NPAS. In June 2009, the Minister for Older People and Health Promotion, Áine Brady TD, announced a public consultation on the NPAS with a four month window (to September 2009) for individuals and groups to make written submissions. Regional consultation meetings were also promised though details are not available at the time of writing.

## 5. Changing Circumstances for Older People

When Older & Bolder's consultation meetings began in November 2008, older people were protesting the loss of a universal entitlement to a Medical Card for the over-70s.

Since then, they have lost the Christmas Bonus; experienced the temporary suspension of the Community Support Scheme for Older People which provides personal and home security devices; and older people have faced cutbacks in frontline health and social care services.

The McCarthy report was published in July 2009 with recommendations that include cuts to State pensions, closure of the Rural Transport Initiative, increases in co-payment by older people and their families for nursing home care under the Fair Deal Scheme and cuts to cultural, arts and sporting programmes which actively target and support older people's participation in society.

Circumstances for older people have deteriorated since the consultation process was initiated in terms of access to entitlements and basic services and a sense of security about their future. The implications of some of these changes for older people, for the NPAS and for the ideal of Ireland as a better place in which to grow older become clearer when one reads the feedback set out in section two of the report.

### 6. Audience for This Report

The primary audience for this report is older people, notably those who participated in Older & Bolder's consultation meetings. <sup>1</sup> We hope that it will act as a resource for those who want:

- ⇒ To participate in the public consultation on the NPAS; and
- ➡ To make their voices heard regarding threats to services and supports that enable positive ageing in our society.

Some ways of doing this include:

- Sending a written submission to the Minister for Older People and Health Promotion;
- ⇒ Participating in public meetings on the NPAS;
- ➡ Lobbying politicians;
- → Participating in local radio programmes;
- ⇒ Writing letters to local and national newspapers.

### 7. Feedback From Consultation

Though the locations for the eight meetings were varied and the groups of older people attending were diverse in age, background, experience, there was a striking commonality and consistency in the issues articulated. It is important to note that the messages presented reflect those identified through the consultation process and are not exhaustive of all possible messages which may need to inform the NPAS.

It is also important to note that the consultation meetings canvassed the views of older people who were active and able to access public meetings. The views of key groups of older people - e.g. those who are housebound, living in nursing homes, socially isolated - also need to be included and considered in the development of the NPAS.

An interim summary of feedback from the consultation meetings was circulated as a Word document in September 2009

# Presentation of Feedback

## 8. UN Principles on Ageing

Older & Bolder has previously recommended that the United Nations Principles on Ageing – Independence, Participation, Care, Self-fulfilment and Dignity – should underpin the NPAS. The Minister has also affirmed a commitment to applying the UN Principles in the development of the Strategy. The UN Principles have been used here to structure the presentation of feedback from the consultation meetings.

These principles are interwoven and interdependent, as are the means to ensure their realisation. For example, the majority of participants identified 'support to remain in own home' as fundamental to realising the principle of independence, while the range of services and supports identified to facilitate this also fits under the 'care' principle. Other themes/issues identified by participants which cross cut the UN principles include rights and entitlements incorporating access to an adequate income, a full range of quality accessible services and accessible information and transport.

## Independence



## 9. Introduction

The desire and ability to continue to live an active, independent and engaged life was emphasised as core to what the majority of older people want under this principle but also across all principles. The majority associated this with being able to live in their own homes as well as to participate in all aspects of life and society. The consultations highlighted a number of core associated themes under this principle including:

- ⇒ Definitions of independence;
- ⇒ Access to quality services based on entitlement and rights; and
- ⇒ Access to an adequate income.

These are dealt with in more detail below. Where it fits, feedback is presented in terms of core messages, issues and proposed actions.

## 9.1 Understandings of Independence

A fundamental issue that emerged in relation to independence concerned its definition. Different understandings of independence are clearly held across different groups of older people. For example, there are different stages in the ageing process, different capacities, differences based on geographic location, and so forth. 'Independence' for one group such as 'active older people' could be very different for those in residential care. All these differences need to be reflected in policy-making and the understanding of independence amongst groups in residential care needs to be checked directly with them. There was a recognition of the challenges of doing this especially with older people with dementia but this should not deter efforts as mechanisms can be developed.

### 9.2 Services

'Provide independent living options to people in their own homes through care and community services' (Dublin Consultation Report, P9 2009)

'It's often hard to access the service you need, but this varies from one (local) area to another' (Tralee Consultation Report: P14, 2008)

'More joined up and person centred health and social care services are needed' (Trim Consultation Report: P12, 2008).

#### 9.2.1 Core Messages

The ability to live an independent life was linked by participants to access to a wide range of quality services. The range of services most referred to and considered core included: housing (including supports and a range of housing options); health; education; leisure; transport and information. An important theme relating to service delivery was the need for a 'more joined up approach.' This was re-iterated in other contexts also.

#### 9.2.2. Issues

Appreciation was expressed for services where they existed, but concern was also expressed, across all the consultations, about availability of core services. Specific issues that arose:

- ⇒ Inadequacy of funding and coverage;
- ⇒ Inconsistencies in availability and accessibility;
- ⇒ Quality and unpredictability e.g. threatened/actual cutbacks;
- More services needed on an outreach basis thus bringing services to older people as locally as possible;
- ⇒ Difficulties of dealing with multiple agencies.

#### 9.2.3 Some Proposed Actions

There was a recognition that some improvements need not cost a great deal but need a shift in understanding towards a society that is 'age friendly.' Some suggestions:

- ⇒ Need for greater use of publically funded /owned facilities in the interests of older people e.g. schools (after hours);
- Improved street lighting, timing of pedestrian lights, reduction in height of paths. (It was pointed out that improvements such as these are also relevant to other groups e.g. people with disabilities, parents pushing children's buggies);
- ⇒ Different agencies need to share information and work together.

## **9.3 Entitlements and Rights**

'...older people are entitled to quality services, including health and education and information on their rights' (Tullamore Consultation Report: P2, 2009)

#### 9.3.1 Core Messages

The need for a strong basis of entitlement and rights was a related and recurring message associated with services. This was also seen as essential to the support of positive ageing and the realisation of the UN principles generally.

#### 9.3.2 Issues

The current system was felt to be too dependent on eligibility criteria that were often complex, hard to understand and inconsistently applied. This approach often results, it was said, in older people being made to feel 'dependent', a 'burden', treated with 'condescension' or as if they are 'begging' rather than entitled by right of citizenship to supports and services; this was phrased in some cases as giving rise to 'embarrassment' in claiming entitlements. Many acknowledged the positive role of the Citizen Information Centres. Specific issues:

- Strong basis of entitlement that is respectful of older people as citizens with rights;
- ⇒ Need for accessible information that clarifies eligibility;
- Information also needed on what activities are available to older people and on relevant developments and policies;
- Difficulties experienced in trying to ascertain which public body or agency is responsible for a service;
- Difficulties experienced due to the use of automated telephone answering systems by Government Departments and national and local public agencies;
- Access to and competency with the internet is often assumed, whereas older people often have no such access.

#### 9.3.3 Some Proposed Actions

As with other proposals it was highlighted that information on entitlements, services and activities was also important for other groups including 'non-Irish nationals'. Some suggestions:

- A comprehensive accessible information system involving a 'one stop shop approach' with face to face contact being an option where appropriate;
- Citizens Information Centres need to promote themselves more and also offer an outreach service, where this does not already exist;
- ⇒ Use other methods of providing accessible information including leaflets mailed to people's homes and the use of local radio.

## 9.4 Adequacy of Income

'Ageing should be a happy time. With financial cutbacks and loss in schemes and pensions it means that a security has been taken away' (Wexford Consultation Report: P1, 2009).

'Various groups highlighted the inequalities experienced by women who gave up working (or were forced to) to look after families and who now qualify for a lower state pension' (Trim Consultation Report: P6, 2008).

#### 9.4.1 Core Messages

Ensuring an adequate income for all older people was stressed by most and this was strongly linked to the possibility of leading an independent life; the observation that 'money matters' captured this reality in one consultation.

#### 9.4.2 Issues

Particular challenges exist for those solely dependent on the State Pension, and for women, and these groups were identified as deserving particular attention. A number raised the question as to whether 'politicians could live on this' and many were particularly upset by the removal of the 'Christmas bonus' conjuring up images in many minds of 'Scrooge'. Specific issues:

- ➡ Women who left the workforce (sometimes because of the marriage bar) to rear children were now penalised;
- ⇒ Uncertainty is caused by the falling value of occupational pensions;
- ➡ The recent levy on part-time workers which, it was felt, would impact negatively on the income of older people who fell into this category and the possible introduction of a property tax;
- ⇒ Specific concerns regarding the cost of heating and 'fuel poverty';
- ⇒ Need to extend the fuel /heating allowance beyond the winter months.

'I am a widow living on my own. When my husband died, I lost most of my income his O.A.P. and a work related pension. I still have the same expenses on one third of the money' (Cork Consultation Report: P3, 2009).

## **Participation**



## **10.1 Introduction to Participation**

The current participation of older people in Irish Society needs to be recognised and valued and participants (in the consultation meetings) wanted to be supported to participate more fully, including in the social, cultural, political and economic aspects of society. Supports provided must take account of the differences which exist amongst older people as highlighted earlier (see Independence, above). This support should come from a number of sources including family and neighbours, other older people, young people through the development of 'intergenerational solidarity', voluntary and community organisations and local and national government.

A number of strong related themes emerged including: participation in social, cultural and leisure activities; participation in education and life-long learning (covered further on under principle of self-fulfilment): participation as active citizens, both as volunteers and by having 'a voice' on issues that affect them and Irish society generally; and participation in the paid work force. Other core themes related to facilitation of participation included:

- ⇒ Access to affordable and appropriate transport;
- ⇒ Information (referred to earlier under 'Independence');
- ⇒ A physically accessible and secure built environment;
- ⇒ Affordability (dealt with here but also further on under 'Care').

## **10.2 Social, Cultural and Leisure Activities**

'I now have time for participation in other interests and organisations ... we have many classes i.e. computers, bridge, French, PE, also we have many days out and functions which we all enjoy very much' (Limerick Consultation Report: P7, 2009).

'Huge potential [in Sporting Chance initiative] for people with disabilities, including mental health problems, visual impairment, deafness and all older people' (Tralee Report: P 8, 2008).

#### 10.2.1 Core Messages

It was strongly put that participating in physical, social and cultural activities is required to ensure that older people remain healthy and active members of society, capable of making an ongoing contribution to the life of communities. People require access to a wide range of opportunities and supports in order to do this. As with earlier discussions, it was observed that initiatives and approaches which promote participation for older people can benefit a wide spectrum of groups, including those with disabilities.

Many participants highlighted that a real sign of 'positive ageing' for them was the time to participate in things they may not have been involved in before.

#### 10.2. 2 Issues

Specific examples were cited of good practice and programmes that currently offer opportunities for participation. In a number of locations there was a particular stress on the importance of physical activities. One programme referred to in this regard was 'Sporting Chance'; another was the 'Go for Life' Programme (National Programme for Sport and Physical Activity developed specifically for older people and run by Age & Opportunity in collaboration with the Irish Sports Council and Local Sports Partnerships). Some issues:

- Concerns that good practice programmes do not exist in all areas and that they are contingent on uncertain funding from local and central government;
- Particular actions and supports also needed for those less active or mobile, housebound or in residential care settings, including those with dementia.

#### 10.2.3 Some Proposed Actions

Some suggested actions:

- Ongoing financial support by local and national government agencies essential for Active Retirement Groups and for initiatives and programmes;
- ⇒ Provision of more community/day centres;
- Access to existing community facilities such as GAA facilities and schools (it was added that, to facilitate the latter, 'red tape' and issues regarding insurance need to be sorted out).

### **10.3 TRANSPORT**

'Others who don't drive and have no access to public transport or the Flexi Bus lose their independence as they need friends and family to provide them with lifts' (Trim Consultation Report: P11, 2008).

#### 10.3.1 Core Messages

Provision of a comprehensive, accessible (to all) and affordable transport system was identified as key in accessing activities and services, and vital to everyday activities such as attending medical appointments, collecting pensions, shopping and visiting family and friends. Transport had particular resonance in rural areas but issues were also highlighted in relation to towns and cities. A strong message in a rural context was the need to further develop and support the Rural Transport Initiative. The importance of transport in maintaining independence was emphasised.

#### 10.3.2 Issues

Some issues:

- ⇒ While free travel was much appreciated and used, this was felt to be of little value for people living in areas where appropriate and time relevant public transport did not exist;
- ➡ Local transport initiatives often run by voluntary/ community organisations were also appreciated but were not available in all areas;
- ⇒ Overall it was felt that there was an 'ad hoc' approach to transport policy as it affected older people and rural dwellers in particular.

#### 10.3.3 Some Proposed Actions

A number of suggestions were made, including

- The comprehensive development and implementation of a rural transport scheme, managed and run by locally based community groups, which pays attention to travel times relevant to older people;
- ⇒ Improved physical accessibility of buses;
- Provision of support for people with limited mobility e.g. the use of personal assistants;
- A transport scheme should not rely completely on buses but could also include other options such as car sharing;
- ⇒ Use of School buses;
- ⇒ Provision of seats in train stations, bus shelters;
- → Provision of taxi vouchers;
- Provision of parking for older people with mobility problems, but not necessarily in a wheelchair;
- ⇒ More wheelchair accessible spaces;
- ⇒ Review of parking costs, particularly in hospitals;
- Sost issue associated with car insurance and the need for GP to renew driving licence at age 70.

## **10.4 Built Environment**

'Positive ageing is to continue to live life feeling valued and respected by society. There is a national tendency to regard older people as being incapable of making a positive contribution to the affairs of the Nation, the city, or the local community. The notion that all old people are on trolleys in hospitals is often emphasised by the media' (Cork Consultation: P2, 2009).

#### 10.4.1 Core Messages

The need for a supportive, secure and accessible built environment to support participation was stressed. It was highlighted that attention to this can also benefit other groups in society such as those with disability and women.

#### 10.4.2 Some Proposed Actions

Some suggestions:

- ⇒ Improvement of street lighting;
- ⇒ Retention of Garda stations and more Gardaí on the streets;
- ⇒ Attention to height of footpaths;
- ⇒ Ensure accessibility of buildings.

#### **10.5 ACTIVE CITIZENS**

As already highlighted, a strong message throughout the consultation process was the desire by older people to be recognised and valued for their past and current contributions as active citizens; and to be supported to continue to make such contributions while, at the same time, recognising other demands on older people's time such as family/carer responsibilities and the need for time for themselves. Older people can and do make significant contributions to the support of other older people in the community as well as to community and national life generally.

#### 10.5.1 Issues

Some issues:

- A strong belief in the right to be consulted in the formation of public policy, as well as on the implementation and review of services;
- Policies and services would then 'respond to the needs and lived experience of older people' in their diversity;
- ⇒ Participation is linked to rights as 'equal citizens'.

#### 10.5.2 Some Proposed Actions

Some suggested actions:

- ⇒ Facilitate consultation as a right;
- ⇒ Promote recognition of contributions;
- Provide supports, where necessary, that facilitate contributions to society, i.e. through training, out of pocket expenses, transport etc.

## **10.6 Participation in Paid Workforce**

#### 10.6.1 Core Messages

Many participants emphasised that mandatory retiring ages should be reviewed but that the concept of choice should be included in any proposed changes. Many people would prefer a more gradual approach to retirement in the form of reduced number of days /hours.

#### 10.6.2 Issues

Some issues:

- Application of the recent income levies was impacting unfairly on older people doing part time work;
- Discrimination encountered by older workers in getting promotion, accessing training /re-training and jobs if made redundant;
- ⇒ The value of pre retirement courses in preparing people for retirement.

### "The younger ones ask me why I'm still there, working, but I want to work. My age doesn't mean I don't want to work."

## **10.7 Social Engagement**

#### 10.7.1 Core Messages

It was stressed that, at a very fundamental level, all people including older people need to have social contact and be part of social networks. This was talked about in terms of 'being connected', 'having a sense of belonging' and 'being involved'. Attention needs to be paid in particular to those that live alone, are housebound or in residential care, including those with dementia. Men were mentioned in particular. It was felt that their isolation has increased particularly in rural areas with the change in laws and attitudes to drinking and driving.

#### 10.7.2 Issues

Some issues:

- Concern that many older men are less likely to join groups and that specific attention and proactive efforts need to be made to promote their engagement;
- Alternatives are needed including other types of activities which take account of gender specific interests as well as rural transport that can facilitate access to and from public houses.

#### 10.7.3 Some Proposed Actions

Some straightforward actions proposed:

- A 'phone a friend' approach (already in operation in a number of areas) and visiting house bound neighbours;
- ⇒ Intergenerational initiatives such as those which involve Transition Year students visiting/interacting with older people, in a planned and supported way, play a useful role.

## Care



## **11.1 Introduction To Care**

In terms of the overall consultations, the messages and themes that emerged under this heading were the most emphasised and were considered to be of central importance to the achievement of positive ageing. The themes that emerged related to the need for a range of housing /accommodation/living options together with a wide range of associated supports, and access to quality affordable, holistic health care as of right.

## **11.2 Housing and Supported Living**

'We need facilities to stay in the home. We want to be able to live independently but we need services for that – for example, home help services. Home help services are needed seven days a week' (Cork Consultation: P10, 2009).

**'Emotional, financial and other supports for carers who feel very much on their own'** (Dublin Consultation Report, P 7 2009).

#### 11.2.1 Core Message

There is a need for a housing strategy for older people which would include a range of housing/living options to meet the diversity of needs among older people. The provision of supports should be central to this. Overall, this was seen as part of a 'continuum of care' which would support living at home as the ideal, but also provide supported living arrangements within community settings and again, if necessary, allow for transfer to fully residential settings.

All parts of the continuum need to take account both of those with high dependency needs and of their carers. It was emphasised that many older people will never need to move from home, particularly if the necessary supports are provided.

#### 11.2.2 Issues

The issues of concern already outlined under 3.2.2 (Services) and 3.2.3 (Entitlements) are relevant here also. Some additional issues:

- It was stressed that accessing appropriate housing/nursing home options (as well as health and social supports) should be based on assessment of need and not ability to pay;
- A major issue of concern was the proposed 'Fair Deal' scheme, which many felt was unclear in terms of how it would operate.
- Many indicated that it was causing concern amongst some older people regarding the potential loss of the family home. It was stressed that it needed to be 'decoded', explained in clear and concrete terms and that it should be fair in practice.
- At one consultation some participants wanted the Fair Deal abandoned and recommended that the cost of long stay care for all should be funded from 'a social insurance scheme as in some Western European Countries';
- Elder abuse was an issue in terms of nursing homes and also in other institutional settings e.g. acute hospitals and it was suggested that the most vulnerable older people need advocates to speak on their behalf. It was suggested that the 'active old' could play an important role as advocates;
- It was suggested that an in-depth review of elder abuse was required on the lines of the recent child abuse enquiry and report;
- Also it was stressed that many older people are themselves carers to a family member and need more supports and services to continue carrying out this role;
- The vital role of community and voluntary organisations which provide many community based services e.g. The Alzheimer Society of Ireland, 'Meals on Wheels', Carers Association and community development organisations was emphasised.

## 11.2 Housing and Supported Living (continued)

#### 11.2.3 Proposed Actions

These fell broadly under three categories: support to remain in own home; more supported group/community housing; well run and regulated nursing homes.

Support to Remain In Own Home

- Supports to enable older people to continue to live in their own homes should include adequate budget lines<sup>2</sup> and individual grants for home modifications, improved home care packages, extended hours for home carers (instead of current reductions) as well as extended tasks which they are allowed to perform;
- More training, vetting and monitoring of home care staff as well as increased understanding on the part of managers of the needs and demands of caring for older people with dementia;
- ⇒ More home visits by relevant professionals e.g. GP's and PHN's;
- A more proactive approach needed for those living alone and for older people from the most marginalised groups including those with dementia.
- Family members should get more support as carers e.g. increased respite opportunities, and that very particular services and supports were required for those caring for someone with dementia;
- Continued government funding and support needed for voluntary organisations; it was also highlighted that 'community run services' should not be seen by government as a cheap option and that funding levels should be sufficient to ensure high quality;
- The need for 'reliable and affordable home repair services', possibly offered by voluntary /community organisations;
- More security and safety was emphasised through the provision of both personal and house alarms, and review and development of 'neighbourhood watch' and the 'community alert' schemes.

More Supported Group/Community Housing

- A need for more supported group/community housing which uses 'a household model approach' integrated into the community and not segregated or isolated from it;
- Relevant services e.g. medical, community and social, should also be integrated;
- Particular care and supports were needed for those being transferred out of psychiatric institutions into community care settings;
- ➡ Greater regulation and monitoring of developments funded under Section 23 - an example was given of a private development which had

<sup>2</sup> It was noted in one area that, in the month of May, the budget for home modifications had already run out.

## 11.2 Housing and Supported Living (continued)

received public funding under Section 23 and which was not providing the services promised.

Well Run and Regulated Nursing/Long Stay Homes

- Need for better developed and regulated long stay facilities for those who could no longer be accommodated in the other living options outlined above;
- These should provide stimulating activities for all residents including those with dementia;
- Proposals for specific units for those with dementia, again run on a 'household model'.

'For me, positive ageing is looking forward to growing old, not afraid, equal, enabled, included, remain in my own community, valued, connected, respected. (It is) an alternative model of long-term care, step down and step up facilities, independent and supported housing, joined up health care with availability of alternative therapies... Three key issues to be addressed in a national plan for older people are attitudes and values, supports, services.'

## **11.3 Health and Related Services**

'Whole area provision of adequate services for all older people, including those who do not qualify for medical cards, home helps, GPs, hospitals, as a right' (Dublin Report: P10, 2009).

#### 11.3.1 Core Message

A strong message emerged that access to quality, accessible, integrated health care services, based on need, is viewed by participants as a fundamental and basic right. There was anxiety and concern regarding access to affordable quality health care services and there was discussion and concern about the abolition of the automatic entitlement to the over 70s medical card.

#### 11.3.2 Issues

A range of issues were discussed. The themes that emerged included access to and affordability of medical services, access to and treatment in acute hospitals generally, hospital closures and relocation of services, nature of some GP services/approaches, and inconsistent and discriminatory practices. The main focus in the discussions was on improving the quality of health and life generally but issues were also raised regarding the right to services and supports to ensure that older people could die with dignity. These issues are outlined below under these headings

Access and Affordability

- ⇒ The removal of the right to a medical card for over 70's adds to existing anxiety about access to health care and the two tiered medical system;
- Many felt that all people over 70 (in some cases it was stated that this should be at age 65) regardless of means should have a right to a medical card. Some agreed with means testing but only if the threshold is high;
- ⇒ The two tiered system operating in Ireland was considered unjust, with those in the public system having to wait long periods for treatment;
- The Treatment Purchase Fund was seen as a valuable development but it was felt that GPs should promote it more and that more information is needed about how it operates;
- Whilst the medial card was seen as essential in accessing medical services, it was highlighted that it did not cover all services e.g. physiotherapy and some dental treatments.

Treatment in Acute Hospitals

- Whilst many had positive experiences of hospitals there was a concern about the quality of care for some older people;
- Attending A &E and the prospect of long periods on a trolley for oneself or a loved one was of grave concern;
- ⇒ The issue of hospital infections was also highlighted;
- Specific gaps in hospital based services were mentioned e.g. insufficient stroke units;

### 11.3 Health and Related Services (continued)

- Proposed that short term support should be provided to older people following falls and hip replacements;
- The prospect of cutbacks in health services generally was of grave concern.

Hospital Closures and Relocation of Services

- The proposed closure of local hospitals and services was raised in some locations with one participant stating that the whole concept of 'centres of excellence' needs to be more fully explained, including how it will improve access and outcomes;
- Many expressed concern about the long journeys that will be involved when the closures happen;
- It was proposed that consultants should hold clinics in local areas and so necessitate one person travelling rather than many older people travelling to see one consultant.
- **GP** Services
- Though many participants were happy with GP services, others felt that their GPs 'talked down to them', dismissed all medical complaints as age-related and to 'be put up with', or did not always make sufficient time for them;
- In some areas it was identified that improved 'out of hours' doctor services were required.

Inconsistencies and Discrimination

- Inconsistencies were identified in terms of access to services (i.e. certain medical conditions involve access to free services whilst others do not e.g. people suffering from a chronic illness such as asthma or dementia do not automatically qualify for a medical card);
- Direct and indirect discriminations were also identified (e.g. upper age limits for cancer screening services (direct discrimination).
- The view that people in older age categories such as 75+ were discriminated against in relation to health and related services with priority given to younger people (indirect discrimination);
- ⇒ Many expressed concern about the care of older people with dementia.

Dying with Dignity

- ⇒ The right to services and supports to ensure that older people could die with dignity such as access to palliative care services was a concern;
- A number of participants had positive experiences of hospice care for family members but were concerned as to whether there were sufficient places available;

## 11.3 Health and Related Services (continued)

'We need one point of contact, ⇒
it's not helpful being passed
from one person to the next'
(Tullamore Report: P4, 2009).

Patient choice regarding what treatments and procedures to have in the final stages of life was raised.

#### 11.3.3 Proposed Actions

Some proposed actions:

- Standards of care for older people in acute hospitals need to be set, implemented and reviewed - principle of dignity should underlie these standards;
- Need for holistic and integrated approaches as well as preventative ones; need for attention to specific groups, attention to physical and mental health, and support for dying with dignity;
- Many called for a more integrated approach in the provision of services with relevant services being available in one centre; these should include GPs, PHNs chiropodists and so forth. It was also suggested that centres could carry out routine tests;
- Particular attention should be paid to men's underuse of health services and initiatives put in place to address this;
- ⇒ Make dementia 'a national health priority' and improve legislation to safeguard the interests of older people with dementia;
- ➡ Funding for hospice and palliative care services essential as well as access to them when necessary;
- Introduction of legally binding 'advance care directives' proposed by one participant; work in progress in this area by Law Reform Commission was noted;
- ⇒ Extra supports were needed for bereaved older people.

## Self Fulfilment



## **12.1 Introduction to Self Fulfilment**

Many of the issues and themes that arise here are already outlined under the participation principle, in particular, and they also cross over with the 'independence' and 'care' principles. The impact of care structures and approaches on the possibilities for self-fulfilment was raised many times with the need expressed for care choices and for access to meaningful activities for all, including those living in care and those with dementia. Many elements relating to self fulfilment were raised in the consultations. Elements of self-fulfilment referred to include many times in the consultations include positive relationships, social engagement, health and wellbeing, time for one's own enjoyment and development and the possibility to make a contribution. The themes which are considered here relating to this principle focus mainly on potential and contribution, education and ageism, and positive ageing.

## **12.2 Potential and Contribution**

'Being an avid reader, I love the time I now have to read away and not have to feel guilty about anything. I have a lot of new friends I have met through membership in organisations. It's also great to have the time and health to contribute when I can to fill the gaps to help out in any way I can for any one in need. I enjoy the weekly meetings of ARA and attend as often as I can. I also find working in Senior Help Line very rewarding and can relate to the callers. I came to appreciate how time is precious and a smile goes a long way!'

(Limerick Report: P7, 2009)

#### 12.2.1 Core Message

The need to recognise and support the rich potential and contribution of older people was a core message in relation to forwarding the principle of self fulfilment. Making a contribution was raised by most participants as vital to self fulfilment, personal identity and worth. Many people refer to a renewed realisation of their own potential, based on their knowledge, skills and experience as well as the possibility for ongoing learning and development.

#### 12.2.2 Proposed Actions

Supports to maximise the capacity to develop and contribute have already been outlined under participation above. Some additional suggested actions:

- Make possibilities for self fulfilment available to all older people and not just the 'actively old', including members of the most marginalised groups and specifically to older people in residential care and those suffering from dementia;
- Encouragement and opportunities for learning are considered necessary to facilitate contribution to society, as well as transport, training and out of pocket expenses.

## **12.3 Life Long Learning**

"...More services and help for adult education and more encouragement for older people to participate in the education system as learners or teachers' (Sligo Consultation Report 2009)

#### 12.3.1 Core Message

All consultations emphasised the need for opportunities for ongoing development and learning, with these being understood as possible in all sorts of settings including active age groups, specific programmes and initiatives (e.g. Sporting Chance) engagement in community /voluntary activity as volunteers, and also through specific training and education courses.

#### 12.3.2 Issues

Some issues:

- Barriers to accessing learning and development opportunities identified included cost, transport, inaccessible buildings, lack of accessible information, care responsibilities;
- Support is needed to overcome fears about taking up learning opportunities;
- Concern was expressed about the 'endemic uncertainties of funding 'of programmes and initiatives overall.

#### 12.3.3 Proposed Actions

Some proposed actions:

- Participants' interests were wide-ranging but specific mention was made of positive ageing courses (some had attended these and found them very valuable);
- Other suggested courses included pre –retirement courses, computer training and literacy;
- Programmes where younger people taught older people such skills, were felt to be very positive and it was highlighted that these could help build intergenerational solidarity;
- ⇒ Engaging older people as learners and teachers was also emphasised.

## **12.4 Positive Ageing and Ageism**

'It is clear from the response that a lot of older people were clear on what to do to achieve positive ageing. The dichotomy seemed to fall between what older people could do as individuals to ensure they aged positively, and the concerns emerging from this that older people needed appropriate supports in society to enable them to age positively'. (Wexford Report: P1, 2009).

'Experience of ageism can be difficult for women to pinpoint as they can be discriminated against or patronised as women first and foremost'

**'Traveller women hit ageism early, there is an assumption that you disappear from life after 60 even if you're alive!** (Trim Consultation Report: P4, 2008).

#### 12.4.1 Core Message

The core message here was a complex one with many of the consultations highlighting that whilst aspects of 'positive ageing' are within the grasp of some older people themselves, particularly in terms of adopting a positive frame of mind, getting involved and taking up opportunities that exist (e.g. active age groups), many factors lie in the wider society and in the sphere of national and local government. The issue of supports to promote positive ageing arose here (but has already been considered above) as did the issue of ageist barriers to full participation.

#### 12.4.2 Issues

A key factor identified by many participants as supporting or hindering self fulfilment for older people were current understandings and attitudes to ageing. Some issues:

- Many felt that ageism needs to be addressed and that it is necessary to change attitudes. The potential audiences here included older people themselves, young people, and very importantly professionals, national and local government officials and agents, politicians and the media;
- Unhelpful media attitudes that contribute to an ageist culture, included attention on older people as a burden (i.e. strain on resources; 'bed blockers'), portrayal as either frail and vulnerable or obsessed with staying young looking (the latter particularly associated with advertising and impacting negatively on older women);
- Some participants expressed shock at encountering resentment from younger people about 'proposed increases in health insurance charges';
- Ageist attitudes to older people then translate to behaviours with many citing examples of professionals and public servants talking 'down to' or 'over' older people, with this intensifying as people move through phases of aging with the 'oldest old' being particularly vulnerable;
- Ageism was not only to do with attitudes and behaviour but to systemic/ structural discrimination such as age limits to certain cancer screening services;
- Intergenerational initiatives can break down stereotypes on both sides and help allay fears that some older people have of young people, particularly when they encounter them together in groups;
- Pre-existing patronising attitudes to women can be compounded by ageism and this was seen to intensify for women from the Traveller community.

## 12.4 Positive Ageing and Ageism (continued)

'There should be a 'charter' of principles or set of agreements for staff who deal with older people, and inservice training days should be provided for staff of day centres and others' (Tralee Report P8, 2008).

#### 12.4.3 Proposed Actions

Some suggested actions:

- Systemic discrimination such as age limits to certain cancer screening services need to be addressed;
- In-service attitudes training for care staff such as those in Care Centres and a charter of rights for older people receiving care;
- Programmes to develop greater intergenerational solidarity where both older people and younger people benefit through, for example, older people going into schools in structured programmes, (e.g. a storytelling programme, Fadó Fadó; or Transition Year programmes where students visit older people who live alone or in nursing homes, students training older people in new technologies and computer skills and also events where young and old come together);

"For me, positive ageing is being treated with respect regardless of your age, seeing more positive images of old people in the media and fewer negative ones, being able to enjoy being your age and doing things at your own pace. The desire to have a laugh doesn't diminish with age!"

## Dignity



## **13.1 Introduction to Dignity**

The need to be respected and valued was seen as fundamental to realizing the principle of dignity, and this was linked to the need to be treated equally with others in Irish society and to have a sense of rights and entitlement as citizens. For many, these issues are aligned with citizenship and also with recognition of the contribution older people have made to Irish society throughout their lives. Most participants stressed the importance of being treated with dignity in all settings but there were particular concerns about this in acute hospital contexts and for the most vulnerable in residential care settings. Another associated theme is the right to be heard by society generally but also by government. There is considerable overlap between this principle and the other UN Principles and many of the issues that arose here have already been considered under the Independence, Care and Participation principles, above. In this section we will set out the issues that arose under the heading of policy formation, implementation and review. 'There is a need for rights based legislation that guarantees older people a proper income and proper services' (Cork Consultation Report: P14, 2009).

'Listen to older people. In rolling out strategies, do not make assumptions about what we need' (Dublin Report: P9, 2009).

'Participants felt there was no point in a Strategy that doesn't reflect what older people want and include things that are important to them. Equality for all older people should be a right. The voices of those in nursing homes, those who are living at home but in very bad health and those who are living alone and isolated, say in rural communities, need to be heard' (Limerick Report: P14, 2009).

#### 13.2 Policy Formation, Implementation and Review

The core message from the consultation was that the National Positive Ageing Strategy (NPAS) must be based on the expressed needs and input of older people. Most participants supported the development of the NPAS and participants in all locations were very positive about the role of Older & Bolder in hosting this round of consultations. It was also stressed that the NPAS needed to be adequately resourced and fully implemented and reviewed. Its development and implementation called for real cross departmental co-operation and commitment. The issue of difficulties in current policy implementation was raised again here, including people experiencing a loss of dignity due to a lack of a 'joined up approach' to services.

#### 13.3 Issues

- Concerns were expressed as to whether the proposed official consultation would include the most marginalised including those in residential care and those with cognitive impairments;
- ⇒ Some doubts as to whether full implementation would happen;
- A high level of disillusionment on the part of many participants with government, in light of recent cuts, proposed cuts and the handling of the economic crisis;
- Some felt that older people had missed out on the 'Celtic Tiger' but now were being made pay for the 'wrongs of bankers';
- Many felt that older people were not being prioritised and that social justice and equality were not guiding values in the decisions being made;
- Difficulties experienced in current policy implementation including the need for a more 'joined up approach';
- ⇒ Local Authorities considered to have a particular role to play in ensuring access to quality supports and services. In some cases it was felt that they fell short on this.
- The potential for a positive role was highlighted (e.g. an approach in Dún Laoghaire/Rathdown. In this Local Authority area a network of older people supported by officers of the County Council is proving effective 'as a channel for older people');
- A strong case was made for positive ageing policies on the grounds of older people's rights as citizens, but it was also highlighted that such policies are cost effective as they support older people to stay healthy and active longer, living at home and contributing to communities, with less need for health services and associated higher costs;

**'Important for the government to remember that older people are a large portion of the electorate'** (Wexford Consultation Report: P5, 2009).

- An expressed need for more emphasis on elder abuse wherever it occurred and questions arose as to whether Government was doing enough to tackle it;
- ⇒ Older people were prepared to stand up for their rights, to campaign and protest when necessary and to use their vote.

#### **13.4 Proposed Actions**

- ⇒ More inter-agency working needed at local level and more cost effective use of existing resources;
- ➡ Consistency needed regarding eligibility criteria for entitlements and also in what services and supports were provided;
- A need for advocacy services particularly for the most vulnerable and for a mechanism for older people to have grievances heard;
- ⇒ The role of Local Authorities and public bodies generally needs to be improved and strengthened in relation to their delivery of services and supports to older people. It was suggested that one way to do this was to make the UN Principles 'real'.

'[The UN Principles]... need to be adopted by every Town Council, Local Authority and public body' (Tullamore Consultation

Report: P7, 2009).

## **Concluding Remarks**

The feedback of older people during the consultation process highlights a number of points.

- 1. Mutually supportive relationships with peers, families, friends, neighbours and others are highly valued by older people, as are opportunities for contribution to families and communities and for involvement in meaningful activities in communities and society. These are the priceless and critical ingredients in positive ageing.
- 2. When necessary supports and services are available to older people i.e. State pension, rural transport, access to primary care, Home Help and household adaptations, opportunities for participation in local groups and networks, those supports and services make a tangible difference to quality of life and facilitate positive ageing. They are the building blocks of an effective National Positive Ageing Strategy.
- 3. It was evident as the consultation process continued that older people were experiencing a growing sense of insecurity and concern about the future as new threats to services and supports were mooted.
- 4. Failures of policy implementation and gaps in services to older people predate the current recession and were evident during the years of economic surplus. These deficits are likely to outlast any resolution of the budgetary crisis unless root causes are tackled.
- 5. The challenges facing the policy-makers developing the NPAS include :
  - Threats to existing services and supports that are fundamental to positive ageing ;
  - → Ageism;
  - The establishment of effective mechanisms for ongoing consultation with, and participation by, older people in the process of shaping a national strategy that will directly affect their lives;
  - Development of effective mechanisms for cross sectoral working, nationally, locally and between national and local levels;
  - The need to plan for the implementation and financing of systems of social care and protection based on principles of risk pooling and social solidarity that will meet the needs of all citizens, including older people.

## **Appendix One**

### SAMPLE MATERIALS FROM OLDER & BOLDER MEETINGS WITH OLDER PEOPLE TULLAMORE, WEDNESDAY 27 MAY 2009

## 1 Programme

10.30 am	Registration and Tea/Coffee
11.00 am	Welcome and Introduction to Meeting
11.05 am	Feedback from Older and Bolder on success of earlier campaign: Where things stand
11.15 am	"O&B on the Doorstep" campaign
11.30 am	Small group discussions
12.15 pm	Feedback Session
12.55 pm	Lunch
2.00 pm	Introduction to Panel Session with politicians
2.05 pm	Summary of themes from this morning and O&B meetings
2.15 pm	Panel Session
3 .00pm	Wrap-up and thanks; departure of politicians
3.05 pm	Where do we go from here?
3.20 p.m.	Open Forum: What actions can participants take following our meeting today?
3.55 pm	Wrap-up and Thanks
4.00 pm	Close

## 2 What Does 'Positive Ageing' Mean to You?

Dear Participant,

Please take a few minutes to think about the term "positive ageing". What does "positive ageing" mean for you as an individual?

We are asking you to jot down your views on "positive ageing" on this sheet of paper. There is no right or wrong answer and a rough note will do fine.

Older & Bolder is gathering ideas about "positive ageing" from meetings with older people around the country. We hope to compile a report to share feedback with participants in the meetings and with everyone who is interested in older people's issues.

There is no need to sign your name on the sheet of paper. If you have any questions about this request, there will be a facilitator at your table and you can ask him/her about it. You can hand your sheet of paper to your facilitator or to members of the Older & Bolder team.

Thank you for your help.

For me, positive ageing is

## **3 Notes for Facilitators**

#### Facilitators are responsible for:

- Ensuring participants have a chance to introduce themselves at the start of the session
- Guiding the discussion and ensuring that everyone has an opportunity to contribute
- Agreeing a rapporteur to give feedback from the small group to the meeting
- ⇒ Minding the time
- Taking written notes of the small group discussions for feedback to Older & Bolder
- Agreeing with the group the three key issues that participants want addressed in a national plan for older people (i.e. National Positive Ageing Strategy)

#### Small Group Discussion: 11.30 – 12.15 p.m.

Forty five minutes has been allocated for the small group discussion session. The questions you are asked to raise are as follows:

- 1. As an introduction to the discussion, ask each participant to share one comment on what 'positive ageing' means to them. (Participants have also been given sheets of paper and asked to jot down their views on what 'positive ageing' means to them. If sheets are available, collect and give to Mary).
- 2. What is needed to enable positive ageing for people in Irish society e.g. services, supports, attitudes, values, anything else that participants want to identify as necessary? (Encourage participants to be specific in their comments).
- 3. What are the three key issues that you want addressed in a national plan for older people?

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