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INVITATION TO MAKE WRITTEN SUBMISSION

Dear Ms Fallon,

Thank you for your invitation to make a submission to the Special Committee on Covid-19 Response.

Please find attached our submission which is informed by our interactions with care setting staff prior to the Covid-19 crisis and response.

Please do not hesitate to contact me for further information should it be required.

I wish the Special Committee constructive reflection.

Kind regards,

Mary Harkin
Policy, Research and Evaluation Manager
Age & Opportunity



SUBMISSION TO THE SPECIAL COMMITTEE ON COVID-19 RESPONSE

25 JUNE 2020

Ireland will be a society for all ages that celebrates and prepares properly for individual and population ageing. It will enable and support all ages and older people to enjoy physical and mental health and wellbeing to their full potential. It will promote and respect older people's engagement in economic, social, cultural, community and family life, and foster better solidarity between generations. It will be a society in which the equality, independence, participation, care, self-fulfilment and dignity of older people are pursued at all times.¹

1. EXECUTIVE SUMMARY

1.1 This submission to the Special Committee on Covid-19 Response draws on Age & Opportunity's experience and insights in challenging ageism and promoting the participation by all older people in society over the last 30 years.

1.2 We offer our views on ageist language and representation of those living in care settings which has been exacerbated during the pandemic.

1.2 We outline that our insights about care settings are related to the provision of capacity building education and training opportunities for care staff, volunteers and visiting professionals to promote greater participation in meaningful activities by residents in care settings.

1.3 We explain and outline the importance of quality of life domains for those living in care settings.

1.4 We argue for the right of all residents in care settings to participate in meaningful activities

1.4 We make the case for upskilling care staff to facilitate participation in meaningful activities and point to the lack of a continuing professional development framework for care assistants

1.5 Finally we include, as requested, a summary of the recommendations we offer for your consideration.

¹ National Positive Ageing Strategy 2013

2. INTRODUCTION

2.1 We are Age & Opportunity, the national organisation that provides a range of opportunities for older people who want to get more involved in arts and culture, sport and physical activity, civic engagement and personal development.

2.2 Our aim is to inspire people aged 50+ to live a dynamic life in which they are more active, more visible, more creative and more connected.

2.3 One of our key priorities is to truly understand what ageing in Ireland means for people today by increasing the dialogue we have with them – conducting regular research through focus groups and workshops and by generating more opportunities for their feedback across all of our programmes.

2.4 We work with local communities and organisations across the country to run a range of programmes and activities in three key areas:

- Age & Opportunity Arts provides opportunities for us to engage more in arts and cultural events and initiatives.
- Age & Opportunity Active is designed to get us more active and participate in recreational sport and physical activity.
- Age & Opportunity Engage offers a range of workshops and learning initiatives for our own personal development as well as opportunities for us to play an active role in our community.

2.5 Vision

An Ireland where all older people are more active, more visible, more creative, more connected, more often.

2.6 Mission

The best possible quality of life for people aged 50 to 100+.

2.7 Values

At Age & Opportunity we are bound by a set of five core values which shape the way we behave and everything we do and are:

- Older People First: The views, opinions and experience of diverse older people inform all that we do.
- Equality & Inclusivity: We work to ensure equality of participation for all older people, irrespective of background, culture, identity, setting or location.

- Inspiring: We celebrate and showcase stories of ageing.
- Pioneering: We explore and push out boundaries relating to opportunities for activity, creativity and visibility.
- Excellence: We strive to create an ethos of excellence with strong governance and clear transparency.

3. EXPERIENCE AND INSIGHT

3.1 Age & Opportunity are responding to this request on the basis of our engagement with care staff prior to COVID-19 through the following education, training and Residency initiatives.

- CarePALs: Trains those working or volunteering in care settings to lead suitable physical activities with people in their care.
- Creative Exchanges: QQI Level 6 Training Course which trains participants to plan and facilitate arts activities for older people in care settings.
- Artist(s) in Residence in a Care Setting: This opportunity creates access to the arts for older people in care settings and supports the work of care settings.
- Azure: Explores how people with dementia-related conditions such as Alzheimer's, and the people who care for them, can have a deeper involvement in cultural institutions and can participate in cultural activities.
- AgeWise Workshops: Professionally facilitated workshops for employers and staff who are providing services to older people. These workshops are designed to create awareness of attitudes to ageing and older people.

3.2 As we are not a medical agency nor a care provider and as we have had limited contact with care settings during COVID-19 our submission draws on prior experience and learning we believe could inform future direction.

4. FACTUAL INFORMATION

4.1 AGEIST LANGUAGE AND REPRESENTATION

4.1.1 During the COVID-19 Pandemic, older persons were talked about more than ever in the Oireachtas, in the media and in real life. We would like to draw the Committee's attention to the importance of using language that is precise, accurate and value free in private and public conversations with and about older persons is more important than ever. Ageist terms should be as unacceptable as sexist or racist ones.

4.1.2 Older persons is the most appropriate term to use. The 'er' qualifier makes it more acceptable and inclusive than just old. It indicates that age is relative - everyone is older or younger than someone else. It recognises a continuum of ageing, all older people are not the same age. Above all, it is the term that older people prefer. This is reflected in terms such as the United Nations Principles for Older Persons and the International Day of Older Persons.

4.1.3 The elderly is one of the worst ways to describe older persons. It lacks an equal and opposite term and is problematic because of its association with dependency and frailty. In 1995, the UN Committee on Economic, Social, and Cultural Rights of Older Persons rejected the term elderly in preference for 'older persons'.

4.1.4 Geriatric is a medical term and should only be used in medical contexts, we would never refer to children as pediatrics. Likewise, just as we don't refer to people under 50 as junior citizens there is no need to refer to people of any age as senior citizens. Pensioner or OAP implies financial dependency and renders invisible the very many older people who are in paid or unpaid work.

4.1.5 We do change as we get older. Functional abilities change over time. Older persons do become ill, do live with disabilities and many health issues do become more prevalent with age. When dealing with any disability or health issue - at any age - person-first language should always be used. Someone lives with dementia rather than exists as a dementia sufferer. People are users of wheelchairs rather than wheelchair bound and have had strokes rather than are stroke victims.

4.1.6 Portrayals of older persons can also be stereotypical leading to ageist attitudes and behaviours. Many of the images used to represent older people in care settings during the COVID 19 crisis have been negative stock images - wrinkly hands, slippers, walking frames. "If you use body part media to signify older people you effectively portray them as an object of pity. People that are old [especially those in care settings] are already far away from mainstream consciousness and if you then see them presented as a pair of wooly slippers you're less likely to respect their rights and treat them as an equal. They're less likely to have control over their care and their environment if they are seen as victims"¹. On the other hand,

portrayals (often in advertising) of older people as happy and affluent, active and leisure oriented can be positive but often exaggerated and unrealistic. These representations do not reflect the diversity of older persons and the experiences of ageing.

4.1.7 Referring to the provision of care as an industry is also damaging to those who live in care settings as it reduces them to dehumanised economic units without individual needs and desires.

4.1.8 Recommendation: Measures taken to ensure that all ministers and public servants, including those in public sector media organisations use appropriate language and imagery when referring to all older people including those who live in care settings.

4.2 QUALITY OF LIFE IN CARE

4.2.1 A range of studies have been done into what constitutes quality of life for older people who live in care settings. These include one study carried out by Age & Opportunity.² While there can be differences of emphasis, Ann Leahy³ in her 2013 contribution to the evaluation of Age & Opportunity's Creative Exchanges initiative outlines that studies carried out in Ireland, the UK and the US show a good deal of consistency as to what the key issues for this group of older people are: autonomy, individuality, relationships and activities.

4.2.2 Leahy explains that other large studies in Ireland and the UK characterise the key quality of life domains in long-term care similarly, calling them: ethos of care/care environment (linked to autonomy), sense of self and identity, relationships and activities and explains these terms as follows:

- Ethos of Care/Care Environment (linked to autonomy)

This is closely related to the exercise of autonomy and includes being able to exercise some choice around routines like time of waking or sleeping or mealtimes. For some residents routines dominated, and they felt just one of a number.

- Sense of Self and Identity

This domain involves maintaining a sense of self, through personal appearance and possessions, religion or spirituality and preferences for personal space. Acknowledging residents' skills and contributions enhanced self-esteem and sense of self, which was also influenced by meanings made by participants of their own and others' frailties. Finding ways of asserting themselves

² Age & Opportunity, 2003. Home from Home? The views of Residents on Social Gain and Quality of Life: A Study in Three Care Centres for Older People.

³ Leahy, Ann 2013: Quality of Life (Creative Exchanges)

was a way to counter or compensate for frailty. Domains overlap: having some control over activities of daily living helps maintain a sense of self.

- Connectedness/Social Relationships

Relationships mattered – with other residents, with families and communities and with staff. Relationships were facilitated by getting people with similar interests together. Communication was an issue that was essential to forming and maintaining relationships, to maintaining sense of self, participating in activities, and making meaning of experience, and non-verbal, emotional expression was considered valuable along with verbal-expression

- Activities

Activities facilitated relationships and helped confer a sense of achievement and maintain a sense of self. Some activities are more valued than others, generally characterised as ‘meaningful’. Key to this is

- taking account of individual interests,
- small group activities were most appreciated,
- integration into everyday life.

This means that staff need to take time establishing what is considered valuable by individual residents; without ‘meaningful activity’ residents were frustrated.

4.2.3 While we have not yet carried out research on the impact of COVID-19 on quality of life it is certain that, with care settings closed to family and friends, the quality of live domain of Connectedness and Social relationships will have been affected. It is likely that in many settings, with staff shortages widely reported, Activities and Autonomy were also compromised with subsequent deterioration in quality of life for residents.

4.2.4 Recommendations: That research is conducted into the impact of COVID-19 on quality of life in care settings; that innovative solutions are sought to ensure that care settings are not required to cut off all but virtual contact with family and friends; that staff are trained and resourced to facilitate meaningful activities and that these activities are prioritised as an essential component of quality of life in care.

4.3 MEANINGFUL ACTIVITY IN CARE

4.3.1 As an organisation promoting participation of older people in the arts for over 30 years we have seen first hand many times how transformative such participation can be. We consider that participation in the arts is a human right that should be extended to all including those living in care.

4.3.2 “In the moment feedback includes that of pure joy and escape and an enthusiasm to try something new among those for whom a strict routine is the norm. Staff report seeing older people tap into a creative side, including and especially those who may be hard to reach and have not engaged with other activities at the setting. On reflection staff report seeing people differently as their personhood is expressed more clearly through engagement with the arts. They also report seeing their role differently and finding ways in which they can change how they engage with older people.”⁴

This quote is from the independent evaluation of Age & Opportunity’s Artist in a Care Residency Initiative which details overwhelmingly positive outcomes for the residents, staff, care settings and artists who took part in this initiative in six care settings during 2019.

4.3.3 Our Creative Exchanges initiative (formerly Arts in Care) similarly reports positive outcomes for staff and residents of care settings. “Clearly it is difficult, if not impossible, to place a value on many things that impact peoples’ lives and sense of well-being. Take, for example, the feedback from one doctor to a participant of the Dublin Creative Exchanges Programme. “I don’t know what you are doing but I am definitely prescribing less.” The value here goes far beyond the monetary savings as a result of fewer drugs being administered. This is a perfect example of where other indicators are needed in the pursuit of more rigorous and transparent valuation”.⁵

4.3.4 Bairbre-Ann Harkin, Art and Ageing Fellow at IMMA describes the transformative effect that engaging in the arts through our Azure initiative can have . “Azure is about trying to create moments where, at least during the programme, people stop being ‘the person with dementia and their carer’ and, in some ways, go back to being husband and wife, mother and son, father and daughter, sister and brother. Programmes like this allow for that moment, and that is a real privilege to see.”

4.3.5 Residents of Care Settings also have a right to be as physically active as possible and to enjoy the well documented evidence based attendant health benefits that physical activity can promote. The current COVID-19 pandemic is an enormous challenge for care home staff to manage. Helping residents to be active and enjoy social interaction whilst social distancing is important to avoid deconditioning. This is where residents lose functional capabilities like getting dressed, sitting into a chair or being able to walk to the toilet.

4.3.6 CarePALs is a person centred health promoting intervention developed in 2014 by Age & Opportunity's Active programme as a direct response to demand from those working in care

⁴ Ward, Aideen 2019: Age & Opportunity Artist in a Care Residency Initiative: Evaluation Report

⁵ McCoy, Jackie (2014) Age & Opportunity Creative Exchanges Evidence Based Evaluation, University of Ulster

settings for whom there was no similar opportunity to gain the knowledge and skills needed to promote appropriate physical activity in fun group settings.

4.3.7 CarePALs is focused on keeping older people as healthy as possible for as long as possible. But it is not just aimed at transforming the lives of older people. It incorporates an ethos developed by Age & Opportunity over 30 years that seeks to promote affirmative concepts of ageing and to bring everybody on their own journey regarding their own ageing. We believe that this can have a transformative effect on the attitudes and actions of those caring for older people as well as older people themselves and act as a catalyst for a fundamental shift in thinking by all those who live and work in care settings.

4.3.8 This ethos also supports the aspiration outlined in the National Quality Standards for Residential Care Settings for Older People to bring about a transformation from institutional to more person centred models of care. On a practical level it helps to meet Standard 18 by facilitating greater opportunities for participation in leisure activities that suit their needs, preferences and capacities.

4.3.9 Recommendation: Recognise that participation in meaningful activities is a right, that such participation can be transformative socially, mentally and physically, and to extend and enhance opportunities for participation in meaningful activities to all care settings.

4.4. CARE STAFF

4.4.1 As providers of education and training opportunities for those who work in care settings we have been struck by the fact that while other medical professions working in care, nurses, physiotherapists etc. operate within mandatory continuing professional development contexts and are therefore resourced and facilitated to access training, an equivalent system does not seem to be in place for care assistants beyond basic health and safety requirements. This reflects the lack of value placed on the role of care assistants and, indeed, those for whom they care.

4.4.2 During COVID-19 residents of care settings effectively cut off from the outside world have been utterly dependent on care staff for all of their social, mental and physical wellbeing. Staff with the skills and resources to provide meaningful opportunities for engagement in the arts, physical activity, lifelong learning and other means of self-fulfillment and actualisation will have met these needs more effectively.

4.4.3 Furthermore, initiatives to upskill care staff can contribute positively to the requirement set out by HIQA that staff are encouraged and valued by their organisations and by society for their contribution to the wellbeing of older people living in residential care settings in Ireland.

4.4.4 Recommendation: More training opportunities are provided for care staff in a structured continuing professional development framework in order that a better quality of life is afforded to those living in care.

5. SUMMARY OF RECOMMENDATIONS

- 5.1 Measures are taken to ensure that all ministers and public servants, including those in public sector media organisations use appropriate language and imagery when referring to all older people including those who live in care settings
- 5.2 Recognise that participation in meaningful activities is a right, that such participation can be transformative, and extend and enhance opportunities for participation in meaningful activities to all care settings
- 5.3 That research is conducted into the impact of COVID-19 on quality of life in care settings
- 5.4 That innovative solutions are sought to ensure that care settings are not required to cut off all but virtual contact with family and friends during this or future pandemics
- 5.5 That staff are trained and resourced to facilitate meaningful activities and that these activities are prioritised as an essential component of quality of life in care.
- 5.6 More training opportunities are provided for care staff in a structured continuing professional development framework in order that a better quality of life is afforded to those living in care.
- 5.7 Age & Opportunity are a member of the Alliance of Age Sector NGOs and, in addition to the recommendations we have made based on our own limited experience of care settings, we are aware of and support the wide ranging recommendations that our fellow organisations are making to this committee also.

END